‘Examining the characteristics of multimorbidity as a uniquely disparate population group in Health Care’.

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Abstract

Multimorbidity is a prevalent concern that burdens not only the individual but healthcare system delivery. This thesis identifies the characteristics of people with multimorbidity, through an exploration of vulnerability and disparity in relation to determinants of health in a population group with chronic kidney disease known to be multimorbid. The position of this thesis is known factors of disparity are equalised by the presence of multimorbidity where a discrete point of change is identified. This work is underpinned by critical discourse analysis through a lens in blending critical social theory methodologies. Key concepts include vulnerability, inequity, identity, power, and social networks where the work of Foucault, extended by Fairclough, provide the framework to examine these concepts further using games of truth, eventalisation, technologies of self and resistance.

This study is embedded in the New Zealand healthcare context and takes a multimethod case study approach with a strong qualitative position through examination of a regional specialist service. Community, clinical care, and Indigenous Peoples needs are strong drivers.

Findings describe a continuum of vulnerability, where determinants and healthcare are influencing disparate factors. Two or more comorbid conditions demonstrated statistical significance in identifying a discrete point in which known factors of disparity are outweighed by the presence of multimorbidity increasing the risk and need for elevation of care. People with Chronic Kidney Disease multimorbidity are exposed to multiple truths in their pursuit of care in a health system struggling to meet government aspirations for care and become voiceless and hidden in the noise of the system.

This thesis proposes a novel way in interpreting Foucault's concepts of power and social capillary networks where discursive shifts, fissure points and a change in identity and the technology of self is explored in a new suggestion of a Reset and Translational Change process. Findings also suggest an extension in interpretation of person-centred care to person-centric care and the need to realign care models in the modern context of multimorbidity. It offers caution in the use of Quality-of-Life surveys, commonly used to understand care perspectives and effectiveness of treatment regimes. Importantly this

thesis provides a ‘voice’ for people who walk a ‘trail of tears’ in their attempt to find a way through each day who deserve and need health care providers to walk with them differently.

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The work of this thesis truly belongs to the brave people who were willing to share their incredible stories, and their tears, with me in the hope that this work will contribute a difference to how life is lived once you have developed chronic conditions. They want us as health professionals to know more, find a way to help and understand their world. They are the voice of within this Thesis and I dedicate this work to them. Thank you for allowing me to share your world for a little while.

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I recently explained to a group of next generation nurses, that you will come across nurses in your career who will become your nursing hero, person to look up to and model your style of care from. **Clare Harvey**, this is you for me. You have become my nursing idol, and I am in awe of what you do, your generosity in time and willingness to help me grow, just when I thought my learning was done. I am most grateful for your friendship. What you have taught me about how to care for people is immeasurable. I accept the challenge to do my best to nurture and grow the next generation of nurses around us, in the way that you have shown me how.

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Glossary

BSC	Body Systems Count
CDA	Critical Discourse Analysis
CQUniversity	Central Queensland University [CQU]
CST	Critical Social Theory
CKD	Chronic Kidney Disease
CKDMM	Chronic Kidney Disease Multimorbidity
ESKD	End Stage Kidney Disease
FTA	Failure to Attend
GP	General Practitioner
HB	Hawkes Bay
HBDHB	Hawkes Bay District Health Board
LOS	Length of Stay
MM	Multimorbidity
NN	Nurse Navigator
NP	Nurse Practitioner
NZDep	New Zealand Index of Deprivation
NZ	New Zealand
QoL	Quality of Life
RQ	Research Question
SDH	Social Determinants of Health
SEIFA	Socioeconomic Indexes for Area
WHO	World Health Organisation

Te Reo Kupu

Aho	String or thread
Awhi Rito	Parents
Harakeke	Flax plant
Hinengaro	Mind, though, intellect, consciousness, awareness
Hui	Assembly, gathering or meeting
Kaitakawaenga	Māori support person
Kaupapa	Principle, policy, ideas and values
Korero	Conversation
Matauranga Māori	Knowledge system that encompasses Māori understanding of the world
Meke Meter	Indigenous quality of life assessment tool
Rito	Child
Rongoa	Traditional healing methods
Tangi	Funeral
Te Ao Māori	Māori World View
Te Whatu Ora	Weaving of wellness
Tiriti o Waitangi	The Treaty Of Waitangi – Written agreement between the Crown and Māori
Tupuna	Grandparents
Whānau	Family
Whare Tapa Wha	Māori Healthcare Model
Wharenui	House
Whatu	weaving process
Whenua	Land

Preface

I have been a practicing Registered Nurse for 37 years and in the last 27 years, I have worked with a branch of healthcare known as nephrology. For the last eleven years, I have been practising as a registered Nurse Practitioner (NP). My role in the nephrology team was to see patients, and to implement treatment plans. I also work in a primary care practice where I manage the long-term conditions for the enrolled population. Both positions have exposed me to multimorbidity and the social determinants of health and how these impact on health and wellbeing. I am an insider within this study, as I work alongside these people every day and have an intimate view of their struggle. But I am also an outsider as I do not 'live' their lives and cannot begin to understand what daily life may take to live, while they grapple with a fragmented health system that struggles to see beyond a single disease focus. This study is important, because it is the voice of those living with multimorbidity (MM) who can best shed a light on their reality, something that will assist health professionals in understanding what the whole person needs in care, not just the condition or the treatment. It will help us to understand how we need to situate the health system around these people, as well as to provide this vulnerable group, a voice.

The people I work with in chronic kidney disease (CKD) and end stage kidney disease (ESKD) are the epitome of multimorbidity at its worst. I work with them daily, yet I still wonder if I knew everything I needed to know about them in order to care for them holistically. I refer to these patients under a collective umbrella as chronic kidney disease multimorbidity (CKDMM). All people with advancing CKD and ESKD develop multiple medical conditions whereby all body systems eventually become involved as disease states advance. I have also observed in those I have cared for who present with multimorbidity, that regardless of their economic situation, education level, ethnicity or culture, their need for and contact with the health system is high. I believe this creates a unique health disparity.

Since undertaking this research, I have had to examine how I acquire knowledge, what 'speaks to me', where my worldview interacts with my patients' and if I fully understand their worldview. From an ontological perspective my worldview sits most comfortably with a postmodernist perspective. I believe reality is based on the perspective of the person, which alters depending on their beliefs and culture and is shaped by their environment and experiences.   Therefore, reality changes throughout life, as a person develops, experiences, and learns. Because of this I am interested in people and their lived experiences, stories, and thoughts. Each person's reality is their truth; you cannot live life the way you want to if you are sick, hospitalised or your symptoms are so bad you cannot work.

The different parts of the health system also have their own truths, workforce constraints, economic deficits and space limitations. The health professional may want to offer care in a certain way but, due to these constraints, is not able to.   The system has not kept up to date with the changing needs of the patient. The person with multimorbidity has a multitude of touch points with the health system and health professionals, who all hold their own truth. They are exposed to everyone else's different, and at times, opposing truths. This creates the 'games of truth' in which the patient becomes lost. Whose truth do I, as a health professional and researcher, listen to and follow? Multimorbidity creates vulnerability and the opposing truths combined with fragmented care increases this vulnerability. When multimorbidity exists creating a unique disparity, the 'games of truth' become more complex. Therefore, the idea of the creation of a unique disparity and exposure to complex 'games of truth', underpin this body of research.

I am also inquisitive and sceptical, and like to explore all facets of a problem from different angles.   I am a woman and a nurse; both constructs have shaped my worldview. Nurses worldwide are predominantly women. I believe nurse researchers also lean toward inquiry that focuses on people's reality and their voices. Nurses work in a wellness paradigm which is relational, and so we are keen to assist people to get better, or to help them to be comfortable in dying. It was Jean Watson who said that caring is important for healing, and therefore a caring relationship with patients is central to nursing practice. Studies show that when Watson's caring theory is used, patient outcomes and satisfaction improves (Perkins, 2021). I have spent my career caring for people who have increasing burdens of chronic conditions and have seen the ways long-term condition management has emerged in healthcare over the last 30 years. I like to listen to patients and have seen firsthand how disease progression impacts them and their environment, especially when determinants of health lead to inequities, social injustice, and power imbalances. My role, therefore, as researcher, is to seek out the relational and holistic aspects of care through stories told by patients. By critically examining how language and power intersect in the narratives of patients with chronic conditions, we can better understand the implications of care where nursing practice, patient advocacy, economic indicators and medical management intersect. It will help to build a rich understanding of the renal patient journey beyond current budget-focused activities such as measures of nursing hours per patient day, emergency department admissions and inpatient occasions of service.

Underpinning this study was the Nurse Navigator project that was undertaken in Queensland (Harvey et al., 2021a). Professor Harvey and I were the brainchildren of this project and, as a subsequent researcher on it, I needed to reflect on the importance of understanding social, economic, service and patient data to show the value of comprehensive care, and the individual nature of healthcare that was required to support patients with complex needs. I have built on these learnings in this thesis.

During my doctoral studies, I continued to work full time as a Nurse Practitioner in CKD/ESKD. My work in this space was to follow up patients who are in end stage renal failure and are post-transplant patients. I run clinics where I check in with them regularly and ‘navigate’ their care, review their diagnostics and their medications. In this role I see the reality of fragmented care across condition-specific silos of medical specialist care. Much of my work is ‘fixing issues’ related to fragmented care such as having to reconcile duplicate medication, make and follow up on appointments and referrals to other services.

About halfway through my studies, I had the opportunity to assist with a novel rehabilitation programme in which I planned and initiated care for one of my young post-transplant patients that developed from the learnings I was gaining in this research. Expected (by the system without consultation with the person), to be reliant on public health supports for the rest of his life, this young man refused to accept that fate, and when he became frustrated because everything he wanted to do, was not available for people on the public health benefit, he sought my help. I undertook to map out a rehabilitation plan with him that suited his needs. I applied for and received a Health

Research Council Activation grant to enable this novel work to be implemented and evaluated. My principal supervisor, Professor Harvey assisted me with this project. It was successfully completed with excellent results, and something that really resonated with me, was that with the right team we could do so much more to help our rehabilitating transplant patients. Not only did we see very real wellness results, to the point where this person's inpatient hospital utilisation was reduced to zero and his quality of life increased significantly. Whilst individualised rehabilitation plans are seen as costly, the cost benefit across time with this young man cannot be denied.

This project was integrated into the thesis research, even though it was not initially planned. This is because, when I came to the analysis of data gathered to that point, I had a 'light bulb moment' in that I realised that the work I did with this young man exactly illustrated the value of acknowledging the capacity of the patient to reset their lives. It highlighted the fact that these high-needs CKD patients are hiding in plain sight; lost in a complex and fragmented system. The rhetoric of care provided to a person's needs in complex care is very far from the truth. In view of these 'awakenings' I included the project in with the research discussion (see chapter six).

The use of first person in this thesis

This thesis uses critical discourse analysis and is underpinned by Foucauldian theory. Using the first-person perspective allows the researcher to situate themselves within the research, acknowledging their role as a researcher who is embedded in the discourses. It enriches awareness of the power relations shaping interpretation and the production of knowledge. Reflexivity allows researchers to critically engage with their own positionality, biases, and the socio-historical contexts that inform their interpretations. As Bright et al. (2024) noted, intellectual preparation is not only "an intellectual one, but an existential one that transforms the researcher's very being" (p.418).

Thesis Outline

This research explores the lived experience of people with multiple chronic conditions that coexist and asks what it takes for them to navigate, not only their daily life, but also their engagement with the health system. It is an attempt to understand patients' needs and to inform how we, as health professionals, may need to positional our care differently to enable a 'good' life' for those in our care. It uses a Case Study approach of a Secondary Care Renal Service in New Zealand to profile a population group with chronic kidney disease (CKD) who are known to live with disease processes that effect every body system. My focus for this work is people with chronic kidney disease with multimorbidity (CKDMM). From a philosophical perspective, I have positioned the research to represent a cross over of a traditional philosophical study, grounded strongly in clinical practice. Given the interpretative and sensitive nature of this body of work, the structure of the thesis and chapter titles deviate somewhat from the traditional scientific positivist notation. This work is personal, and some chapters are intentionally descriptive to covey the essence of the participants' stories.

Three research questions are posed to unearth and explore the 'games of truth' in health care for people with CKDMM using the concept of voices that represent social ordering in healthcare. The structure is divided into three sections: the beginning, the findings and then discussion to extract meaning and, importantly, to increase our knowledge to inform our healthcare practice.

SECTION ONE: Positioning the Research

This section describes the conception of this study and my focus in clinical practice to help explain why it is important to improve our understanding of how we position care for people living with a multitude of chronic conditions. The literature is explored to understand core concepts surrounding people living with CKD, the development of MM, and the vulnerability that is created by disease and illness that suggests MM is a unique healthcare disparity. This section then describes the philosophical stance of the study and the methodology chosen as being the most appropriate approach to help answer the research questions.

Chapter One introduces the focus for this thesis and describes the background that led to the development of this thesis and my background and history of working with a MM population. Three research questions are outlined showing the overall focus of the research being the concept of ‘voices’ and ‘games of truth’.

Chapter Two reviews the body of knowledge through a review of literature where the focus is on vulnerability within MM, what contributes to this and how it possibly creates a unique disparity. These two concepts are important to understand as vulnerability in healthcare drives both our health care needs and the risks to living life the ways we chose to.

Chapter Three describes the methodological approach used to frame how this study was undertaken and the theoretical perspective as seen through a critical social lens using critical theorists Michel Foucault and Norman Fairclough. It details the aspects of Michel Foucault’s and Norman Fairclough’s theories that are applied to this thesis and how they help to shape the constructs under examination.

SECTION TWO: Findings

Section Two presents the findings. These are outlined in chapters four, five and six, and profile the CKDMM population under examination as representatives of multimorbidity (MM). Characteristics of this population are described throughout the findings and analysis of the collated data, whereby each chapter represents a social order presented through macro, meso and micro levelling. The concept of ‘voice’ is aligned with the social order it represents, providing the title for each chapter, which are positioned to answer the three research questions. The focus is on the ‘games of truth’ (explored further in chapter three) and examines how these are discursively constructed when seeking healthcare in a secondary care level healthcare service, such as the renal service in New Zealand.

Chapter Four: ‘Establishing Systems Voices’, represents the macro level of analysis and answers research question one, “What are 'games of truth' in the healthcare system of patients within a regional secondary care renal service and how are they discursively constructed?”. This is achieved through the examination of retrospective hospitalisation data as representative of the level of need for care profiled through three aspects:

outpatient utilisation, Emergency Department presentation and admission data. High level government policies, media/social media accounts are included to understand what the macro and meso systems promises are in care provision against the reality of care as experienced by patients with CKDMM. The exploration of opposing truths establishes the 'games of truth' experienced in healthcare.

Chapter Five: 'Establishing Own Voices' answers research question two, "How do patients with chronic illnesses construct and negotiate 'games of truth' about their condition and treatment through their narrative accounts, and how do these constructions reflect and potentially challenge dominant medical discourses?".

This examines how patients navigate the games of truth in healthcare and includes a profile of the interviewed participants' demographic information. It represents the collective voices of patients at a meso level and aims to capture the experiences of patients with CKD through thematic analysis of the interviewed participants as representative of the wider renal cohort. Quality-of-Life survey data is included as part of the perspective of the lived experience. It then describes a new understanding of identity change experienced by people with CKDMM as they journey through the development of MM using the concept of Eventalisation based off Michel Foucault's work. This new understanding is described as the 'Reset and Translational Change Process'.

Chapter Six: 'Establishing My Voice' -act of resistance completes the analysis section and answers research question three, 'How does an individual with multiple chronic conditions construct and deploy technologies of the self through processes of Eventalisation, and in what ways do these reshape health trajectory and subjectivity?' It profiles a single case study within the overarching Renal Service case study methodology. It provides a real-life example at a micro level through one patient's voice and his lived experience of care structured differently using the new concept of the Reset and Translational Change and how this transformed his lived experience.

SECTION THREE: Bringing it all together

Section Three completes this thesis with the discussion, drawing the three findings chapters together with the literature review to establish the meaning of this work in relation to how life is lived through CKDMM. It explores what needs to change in our models of healthcare, the language we use and what future work in this area may look like.

Chapter Seven is the discussion chapter with a focus of 'what does all of this mean and where to from here'. It details how the research questions are answered and discusses the impact of the findings and analysis and what these may mean in the delivery of care to people who live with CKDMM. It then moves on to implications and discusses the opportunities for advancing the learnings from this research.

Chapter Eight describes the limitations of this research, acknowledging what needs caution in interpretation, what was not able to be achieved and why, as well as the strengths of the work.

Chapter Nine is the final chapter and concludes the thesis. It details what has been learnt and suggests where to next. It also highlights how work in this area of healthcare that is this the focus of this thesis is urgently needed.

The next chapter starts Section One and positions the research, guiding concepts and how the research questions were developed.

SECTION ONE: Positioning the Research

Chapter One: Introduction

Health services are grappling with the enormity of providing care in an environment where the recognition and growth of chronic disease and its management have eclipsed any other single factor facing health providers today (Smith et al., 2012; Stokes et al., 2017; World Health Organisation, 2023). It is well recognised by leading international health agencies that chronic diseases are responsible for the increasing health dollar spend, hospitalisation, poor mortality, and morbidity statistics especially in low and middle-income countries (World Health Organisation, 2013).

As the need to manage chronic conditions such as chronic kidney disease (CKD), becomes more apparent, our models of care have not changed. Commonly health services still have an acute care and single disease focus when planning care and resources (Smith et al., 2012; Stokes et al., 2017; Holman, 2020). There is a significant body of work now that focuses on chronic care and the need for models of care to change to refocus on managing chronic conditions especially in the presence of Multimorbidity (MM). In the New Zealand context, there are pockets of work with a focus on recognising the need to change models of care for people with multiple chronic conditions, but this work tends to be isolated without a national consensus on effective models, resulting in risk of reduced access to appropriate care for those who most need it (Askerud et al., 2020).

Within primary care, nurses are still engaging in care provision that is determined by frameworks that emphases single disease approach, such as cardiovascular risk assessment programs or ‘Diabetes Annual Review’ programs. Our hospital wards are similarly located by disease focus such as cardiac or respiratory wards. The reality is they are often dealing with people who have multiple chronic conditions competing for attention at the same time. This single disease focus has created fragmented care for people with multiple chronic conditions compounded by access barriers, lack of clinical guidelines and disorganised systems (Stokes et al., 2017; Holman, 2020). Holman (2020, pg. 167) describes this as an ‘emerging health care crisis’, where manipulation of systems has occurred through different influences and interests e.g. drug companies and profit margins, health insurances, social benefits aligning with government policies with a need to contain costs. People, simply by the nature of being human, are vulnerable (Sveinsdottier & Rehnsfeldt, 2005). But 'vulnerability' has become the basis of health care access to reduce inequity of care, where programs are developed to focus on specific vulnerabilities, but this approach means there is now the risk of creating inequity for others who do not fit these programs (Stokes et al., 2017; Clark & Petro, 2018).

This thesis aims to raise the awareness of the real vulnerability of the renal patients. I do this by exploring the complexity of care and what living with Chronic Kidney Disease (CKD), End Stage Kidney Disease (ESKD) with multimorbidity is like for the patient who has to manage these clinical, economic, social, family and illness issues in a siloed health system where they encounter many different health professionals who all have their say in how their care is positioned. Understanding how the patient can be lost to the many voices they have to navigate compounded by progressive and multiplying disease states.

The problem of multi-morbidity in chronic kidney disease

"In the United States, neoliberal policies and practices erode programs that offer a measure of dignity to disadvantaged individuals while discouraging their participation in collective life" (Charmaz, 2020, p. 23). New Zealand aligns with neoliberal ideology, with its main strategies being privatisation and competitive markets, reduced public expenditure on social services, and economic deregulation (Barnett and Bagshaw, 2020). It was no surprise then, that as a Nurse Practitioner in renal services in New Zealand, I questioned the social and economic impact that end stage kidney disease (ESKD) was having on the patients that I see in my clinic. In my view, and from my perspective as a Nurse Practitioner, I see ESKD more than a clinical condition. It affects the very fabric of a person's life and that of those closest to them. I started questioning what vulnerability and multimorbidity (MM) really meant to those patients. MM is identified as having two or more chronic conditions simultaneously (Boehmer et al., 2018). Hawthorne et al. (2023) also describe complex multimorbidity where four or more coexisting chronic conditions are present. People with advancing chronic kidney disease (CKD) are some of the most vulnerable patients in the health system because they frequently have more than four chronic conditions in tandem with their renal failure, now referred to as the clustering of multiple conditions (Fraser et al., 2015; Schlieper et al., 2015; Francis et al., 2024; Karam et al., 2023; Hawthorne et al., 2023). The importance of clustering of disease patterns helps to target management strategies that don't treat disease as a single entity when they rarely exist that way (González-Chica et al., 2017; Whitty et al., 2020). Despite this knowledge there has been little research to date on clustering patterns around CKD and tends to deal only with well advanced states (Hawthorne et al., 2023).

Illness trajectory with progressive CKD typically ends in death, regardless of intervention. That journey is not just clinical either. Their world is turned upside down socially, economically, and personally, as they face consistent degradation in their ability to remain productive in today's materially driven society. CKD progressing to End Stage Kidney Disease (ESKD) means being tied to a machine two or three times a week, at the very least, for the rest of an individual's life, tied to multiple medical specialists, each caring for one of the inevitable several, failed organs, for the rest of their life. That is because 'multimorbid' in a renal patient's world means at the very least, failed kidneys, failed pancreas, failed cardiac system and often a concomitant failed respiratory system. Yes, they might be lucky enough to receive the gift of a kidney from either a 'live' or 'dead' kidney donor, but whether they do or do not, they are linked into the illness cycle forever. As a 'transplant' patient, the individual is tied to multiple medical specialists across multiple organs because of the effects of the anti-rejection drugs they rely on to keep their body from rejecting the 'new' kidney, for the rest of their life. Despite being the 'high-end' users and the most expensive of all chronic conditions to fund in a health system, they are also the most neglected, the most vulnerable to reduced wellbeing, the most at risk of financial insecurity, and reduced quality of life affecting everyone, regardless of socio-economic status. Those people relying on the public system for all their care face a constant waiting game of appointments that must be accepted regardless of work and life commitments, and those on the higher end who can afford to pay for health care, spend a life's savings on treatment (Luyckx et al., 2018; de Sousa et al., 2022).

End-stage kidney disease (ESKD), is the final stage of chronic kidney disease (CKD), characterised by a significant decline in kidney function, typically defined as a glomerular filtration rate (GFR) of less than 15 mL/min. At this stage, patients require renal replacement therapy, which includes dialysis or kidney transplantation, to sustain life. There are no established prevalence rates for CKD within the NZ context, but the estimated prevalence based in regional data suggests around 350,000 – 500,000 people have a level of CKD with one in ten estimated to have undiagnosed disease where approximately just under 1000 adults being newly diagnosed with ESKD each year (Best Practice Advocacy Centre, 2022; Kidney Health New Zealand, n.d.). The global prevalence of CKD is estimated at 13.4%, with millions of individuals progressing to ESKD, thereby imposing a substantial burden on healthcare systems worldwide. The progression to ESKD is often associated with various comorbidities. Factors associated with progression to EDKD are well documented, and these include low socioeconomic status, poor education and poor health literacy.

Commonly, the literature refers to ESKD alongside deprivation, linking it to health disparities, marginalisation and poor access to care. (Burgos-Calderón et al., 2021). Whilst the common research focus is on ESKD in lower socioeconomic levels, there is also a strong relationship between Type 2 diabetes and ESKD, associated with poor diet, poor lifestyle choices and genetic predispositions (Norton et al., 2016; Morton et al., 2020). The progression to ESKD therefore, in my view is influenced by, but also influences, social determinants of health (SDH), and although there is little in the literature to argue this point, Snow et al. (2022) advise that the approach to ESKD should combine individual and community factors when planning services for ESKD. In New Zealand, the life expectancy of patients on dialysis is six years (relying on a machine 3 times per week), and with deceased or live donor transplants, it is up to 20 years (Hogan, 2021).

The average cost of dialysis in New Zealand is NZ$115,000, with Māori and Pacific Islanders representing 60% of the population requiring dialysis (Hogan, 2021). Very few people, regardless of station in life, are able to have a home dialysis arrangement, relying on publicly funded machines in New Zealand. There is the real risk of inadequate public funding for dialysis services in the future with the threat of rationing services raising the question of who then will be eligible (Kidney Health New Zealand, 2023). This equality and equity phenomenon was really brought home to me when arriving at work one morning I observed the cars parked in front of our Renal Unit. There was a rusted old ute and on either side was a brand new, top of the range Land Rover and Maserati, with a Kingswood family wagon beside that. My first thought was that at the end of the day no-one, regardless of their background, wealth, status or education, is protected from the severe consequences of kidney disease. The need for life preserving care and the significant and negative impact that kidney disease has on the life of a person, is a sobering leveller. Here the poor, wealthy, uneducated and well educated, regardless of whether an individual is living in the top street address, or the from the poorest area of town, the impact of chronic kidney disease and of multimorbidity itself does not discriminate. They are a collective of deprived people, (many of whom were already deprived before they started this journey), who rely on a machine to keep them alive. These people are more than the sum of a recognised status that counts social determinants of health (SDH) and co-morbid conditions as the key factors that determine deprivation with poor health outcomes. Additionally, the family increasingly suffers as family members have to work harder and become carers.

It is clear from the international literature that SDH has a negative impact on a person's health and wellness and is known to be a significant driver to the outcomes of ESKD. (Chelak & Chakole, 2023) However, from my own experience, I believe that there is also a threshold at which those determinants no longer take precedence, because, rich and poor, educated and uneducated, the progressive, ill health journey is the same. Every day, I see the loss and despair in my patient's eyes; I hear their struggles to survive, against odds that seemingly are not just generated by SDH or multimorbid related reasons. These patients are linked into numerous care providers and care systems, yet I see them return to my clinic time and time again with medical issues not addressed. In this situation, patients become labelled as, 'high end users' of care or referred to as 'frequent attenders' (of emergency department), 'non-compliant' (with treatment), and 'did not attends' (clinic appointments) (Li et al., 2022; Nielson et al., 2018). Yet, as seen in a recent project supporting people with long term care needs, those disengagement events, are because of real and valid reasons, which are dismissed by the health system in favour of an implicitly applied 'three strikes and you are out' policy, thus problematising the person in not managing their health effectively (Byrne et al., 2021a).

Instead, the focus is on service efficiency where the dollars saved are the most important element of any episode of care. In this constrained environment each appointment not attended or any 'unnecessary' admission to an emergency department is a cost to the organisation, ‘unnecessary’ implying in many cases, that the patient has not been compliant with medication or has not attended clinical appointments (Bryne et al., 2021b). They are a statistic that the financial officer of the hospital sees as ‘outliers’ that are expensive. Foucault’s idea of problematisation refers to the relationship between truth, power and the self, where that which is accepted as true is driven by the discourses of those who have control over knowledge and how that knowledge is accepted into everyday discourses (Koopman, 2014; Frederiksen et al., 2015). Thus, in the case of patients with ESKD, they are expensive to the health system, a drain on the social system, and they become an economic burden, they are the problem, not the system. In focusing on the system, patients are objectified.

The healthcare system's emphasis on efficiency leads to a lack of understanding regarding the actual burden of chronic conditions on patients (Knauert et al., 2015; de Vries et al., 2021; Thomas et al., 2022). Francis et al. (2024) identified that ESKD is ‘notably absent’ from the list of non-communicable diseases that are being targeted in the achievement of the reduction of poverty and inequality listed as one of the Sustainable Development Goals (SDG). Goodyear-Smith and Ashton (2019) described the universalism of the health system in NZ during the 1990’s health restructure, in the country’s attempt to treat all as equal for equal outcomes, has focused on individualised care at the expense of public and community wide health promotion, disease prevention and access to care which has added to the burgeoning epidemic of chronic disease prevalence.

All the people I care for have at least three concurrent medical conditions, with many of whom have in excess of seven conditions that include multiple body systems and effects. Most of these people are on an average of five medications but many take ten, with one patient I care being on twenty-one different prescribed medications and supplements to stay as well as he can. They are involved with multiple health specialists, and it is not uncommon to have appointments with seven different specialists at the same time, with touch points into nearly every area of healthcare. Patients receive conflicting directives and poor communication where services are not connected and do not speak to each other, meaning their story must be retold at each new appointment. When multimorbidity is present, the effect and impact on everyday life is far reaching. Multimorbidity impacts and influences the state of SDH in profound ways.

A View of Vulnerability

The concept of vulnerability in health care is not a new one and has been explored in many ways as we seek to understand what is and what causes vulnerability. Vulnerability is often defined in relation to the risk of harm to individuals, however it is often stereotyped based on functional deficits (Sveinsdóttir & Rehnsfeldt, 2005). Although definitions of vulnerability relate to the risk of being attacked or harmed, there are many variations to this in health care, so that there is inconsistency in the use of this definition. Health vulnerability refers to the susceptibility of certain populations to poor health outcomes due to various social, economic, and environmental factors. The World Health Organization defines health vulnerability as the circumstances in which individuals are born, grow, work, live, and age, which can impact their overall health (Marmot & Wilkinson, 2005). This concept is closely related to social determinants of health, which are the non-medical factors influencing health outcomes (Marmot & Wilkinson, 2005; Marmot et al., 2008).

From a health equity perspective, vulnerability highlights the importance of addressing disparities and inequities in access to healthcare and social determinants that contribute to poor health outcomes. The United Nations also recognizes health vulnerability as a critical issue that requires attention to ensure the highest possible standard of health for all individuals (Wakefield et al., 2021). Information is missing on the specific definition of health vulnerability by the United Nations and public health literature on this topic. Health vulnerability is often operationalized as the presence of risk factors that increase the likelihood of adverse health outcomes, including chronic diseases, environmental exposures, and socioeconomic status (Chelak & Chakole, 2023). Health vulnerability is understood because of social determinants, such as education, employment, and housing, which influence individuals' ability to maintain good health and access healthcare services. It is important to reflect here that it is a multisector approach with commitment and responsibility accepted by all (Gomez et al., 2021). From a health equity perspective, vulnerability is linked to disparities in health outcomes and access to care, focusing on identifying and addressing the root causes of these disparities to promote equitable health for all (Hacker et al., 2024).

There is a risk in over defining who is vulnerable, as resources and strategies to improve access to care are then targeted creating an inequity for those who do not fit this definition (Clark & Preto, 2018). In the explored definitions there is a focus of vulnerability through SDH which then determines health vulnerability. The underlying assumption in these definitions is that vulnerability is PREVENTABLE. The goal is to keep more people productive, a very neoliberal view. Neoliberal ideology in health care frames chronic illness as a personal failing rather than a systemic issue, because neoliberalism argues that for a person to be valued, they must be productive, production meaning contributing to industrial endeavours that benefit society, there is no room for illness (Wilson, 2018). According to Charmaz (2020), "bodies exist within social structures and are imbued with meaning through sensory experience, language, relationships, and interactions" (p. 22). As such, individuals are held accountable for their health outcomes in a context where social safety nets are limited, and governmental accountability is small. The potential to marginalises and silence those who have crossed the threshold of wellness and are living with multi-morbid conditions (illness) is clear, and it fails to acknowledge the burden that living with multi-morbidity has on the person, family and community, meaning vulnerability is compounded (Charmaz, 2020).

Charmaz's view on bodies existing and conforming to social structures is important in the case of people living with chronic conditions. The more complex a case is, the more services are involved, and the more fragmented care is demonstrated. The emphasis on efficiency and cost-effectiveness in neoliberal healthcare systems often results in a bureaucratic environment that prioritises organisational goals over patient experiences (Willis et al., 2017). Yet, how life is lived for each person is different, so a single definition of vulnerability cannot exist, nor can person centred care be achieved in a system that focuses on organisational efficiency (Sobolewska et al., 2020). However, in the health system that is simply what we as health professionals try to do. This is prompted by the need to make health system design easier to manage and to simplify stratification of approaches to target interventions and policies that attempt to reduce the influence of vulnerability on health outcomes. Yet people cannot be contained. Each person responds differently to life, to illness, and to wellness (Hudson et al., 2020). The impact of vulnerability and its association with inequity in health care has been under examination for several decades (Whitehead& Dahlgren, 2006; Allotey et al., 2012; Richard et al., 2016; Chung, 2021). Yet we are no closer to understanding how to address this impact when what we know of vulnerability is still evolving. What is understood is that the inability to access health care when needed impacts significantly on our vulnerable populations, those with the most complex healthcare need. This translates into poor health outcomes and increased cost creating inequity not only in access but in healthcare itself (Richard et al., 2016). Therefore, as MM creates complexity, it must also create vulnerability. Understanding vulnerability, inequity in access and health outcomes, and how these impact on patients with MM are essential themes for this study.

There is a plethora of literature that links chronic illness and multimorbidity to deprivation and health vulnerability (Avendano et al., 2009; Davis et al., 2017; Hill et al., 2017; Johnson-Lawrence et al., 2017; Laditka & Laditka, 2006; Lebrun & Laveist, 2013; Markwick et al., 2014; Stanley et al., 2018; Thavorn et al., 2017). Frequently, marginalised ethnic, cultural or migrant groups in many parts of the world, are over-represented in hospital admissions related to chronic and complex conditions and are often the focus of health care policies that actively implements strategies to support this cohort (Laditka, & Laditka, 2006; Stanley et al., 2018). In some cases, this has led to the necessary co-ordination of health care services for people living with chronic conditions and the specific targeting of ethnic and marginalised populations in any new or revised model of care. It is also known that deprivation is a risk factor for increased morbidity and mortality in chronic illness (World Health Organization, 2011).

What is not clear however, is the level of vulnerability experienced by people living with chronic conditions, regardless of socio-economic, cultural or ethnic categorisation. People living in wealthier metropolitan areas for example, are thought to be socioeconomically better off with higher education status and fewer barriers to accessing primary health care (Ellison-Loschmann & Pearce, 2006). Yet work undertaken by Harvey et al. (2015), showed a trend that these people may be as vulnerable as those identified as belonging to at-risk population groups, especially when they have two or more chronic conditions at the same time.

In New Zealand, the most vulnerable population are considered by ethnic groups, that being Māori and Pasifika who commonly (by not exclusively), live in the most deprived regions (identified by postal addresses of NZ). To improve access for this population and reduce the disparity gap, extra funding is available for low rated decile areas, thought to have higher level of deprivation. This resource is available to primary care practices that have high enrolment numbers of Māori and Pasifika in low decile rated areas. However, a recent study by Sheridan et al. (2023) highlights how this approach has not addressed the access issue or improved health outcomes for vulnerable populations in NZ such as Māori and Pasifika. A high percentage of Māori are enrolled in traditional practices exempt from ethnic based and decile linked funding models, meaning those who reside in higher decile rated areas of NZ are unable to access this initiative.

Census based indices have been used as a framework to help understand needs-based health resource allocation for areas of deprivation. The New Zealand Index of Deprivation (NZDep) are a decile rating system that represents the impact of the combination of the individual, household and community factors that influence the health of a population (Atkinson, et al., 2014; Exeter et al., 2017; Hill et al., 2017). These tools classify areas of deprivation by area of population into deciles and quintiles. Deciles are used to measure small areas of population while quintiles represent combined decile areas that are collapsed for cartographic purposes (White et al., 2008). Decile 1 represents lowest percentage of social deprivation and Decile 10 representing the highest percentage of deprivation. Quintiles are used in a similar way where Quintile 5 presents areas of increased deprivation. Government attempts to improve this situation have not worked. Addressing health concerns for those with the highest health vulnerability and disadvantage, is a complex situation not answered by a simple approach.

As a background to my doctoral study, I reviewed data for the admissions to Hawke's Bay Regional Hospital in 2017 for patients with at least one of the following conditions, diabetes, cardiac, respiratory and renal failure. It showed there is an increased readmission to hospital rate at seven days and twenty-eight-days post discharge for people living in the lower socioeconomic deprivation areas of Hawke's Bay as represented by decile rating eight to ten. This was especially true for Māori and Pasifika populations. The data indicated a spike in readmissions for people with two or more of the chronic conditions of focus. This was also associated with another spike in readmissions for people living in decile four areas who are not known to face the same levels of disparity as those living in deciles eight to ten. This crude analysis of the data suggests that there is a point at which the health burden of multi-morbidity has an important impact on health outcomes regardless of SDH. This may seem logical yet the role that multimorbidity has in the determination of vulnerability regardless of SDH and therefore equitable access to care and services is hidden in plain sight.

Rupture of the Rhetoric

Over many years I have understood that people with multiple long-term conditions have certain characteristics in common. These include complexity of care needs, multiple health providers, many contacts with the health system in a variety of ways, financial struggles, dependence on others for help, the need for increased education and support around their conditions, social isolation, and the need for time for education, to hear their story and to address the multiple conditions and problems they present with. Therefore, as multimorbidity creates complexity, it must also create or be productive of vulnerability. Giving voice to those who live daily in this world and who are otherwise marginalised and silenced is the first step to re-conceptualising vulnerability through their eyes. The challenge, therefore, is to examine the nexus between the dimensions of lived experience across social, personal and multi-morbid disease and explore the conditions that produce and construct subjects as vulnerable. Walton and Lazzaro-Salazar (2015) describe the absence of a nexus between health care services and the needs of patients with chronic conditions in New Zealand as "othering", (p.462), where those with an illness are different from the "normal" population. The authors highlight how health policy not only discards the patient but also describes them as a burden to their family, to the health service and to the community at large.

To illustrate this, I share the story of Mr CKD who I care for with kidney disease as one of his health problems. His care is managed under several medical specialists within the hospital service, one of them being the renal service. He self identifies under the umbrella of Pasifika. When I met him, he was 55 years old with a wife and five children all of school age. His English is poor, and he is in seasonal employment as many are in my region. He has several months of the year where he needs to earn as much money for the whānau[1] unit as he can. He is in rented accommodation that has broken windows, black mould on the walls, and no heating. He has a ‘funny’ rash of which three of the children also have a ‘funny’ rash. He has seen four different doctors in the last six months for his rash and had six different treatment regimens of which none of them have worked. He has crashed his car driving to work, five times in the last month because his eyesight has deteriorated. He has told no one of this because he needs a job for his whānau, and the doctors might motivate to take his licence off him. How would he get to work? He has had to take many sick days because his gout is bad. He has not had any of his medications that he needs for high blood pressure, cholesterol and poor kidney function, because he cannot afford to pick these up from the pharmacy. He has pre-diabetes, gout, previously undiagnosed sleep apnoea, an undiagnosed eye condition where he is going blind, hypertension, hyperlipidaemia, and a skin rash of unknown cause. In these visits to the general practitioner (GP)[2] no one has asked him about his other chronic condition-related medications because the focus is on his rash, one condition per the 15-minute appointment window that has become the rhetoric in primary care appointments. He cannot make an appointment with any of the specialty physicians, because a rash is in the domain of a primary care general practitioner. In desperation he has seen multiple general practitioners in the hopes of a positive outcome to his rash. His last resort is to attend the renal clinical in the hopes that I, the Nurse Practitioner may be able to help him. In talking with this man, he was on a referral waiting list to be reviewed by a social worker. Not once was the rash examined for links to poor living conditions, food insecurity or exacerbation of medication sensitivity, or an existing condition. This is not an uncommon story either.

Many of the patients I see in my ESKD clinic come to me seeking help because they are unable to see any of their many medical specialists, are on waiting lists for referrals for social reviews and struggle to get general practitioner appointments. Yet our policies for chronic conditions speak of person centred care, health promotion and disease prevention. Neither equity nor equality is addressed, nor the patient needs (Sheridan et

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[1] In Māori, the term whānau is family.

[2] In New Zealand, the general practitioner is the same as a family doctor.

al., 2011; Walton & Lazzaro-Salazar, 2015). It is well documented that this siloed health system does not accommodate 'life events' and is not flexible enough to negotiate appointments around work or family commitments for people living with multiple long-term conditions (Holman, 2020; Mold, 2017). In this system Mr CKD is considered a 'Failed to Attend' patient in the health system because he has missed scheduled appointments because of his need to work and not lose his job. He is considered 'non-compliant' by the 'system' because he doesn't take his medications as prescribed. Mr CKD's examples disparity buried within "system rigidity and a compounding jeopardy" (Sheridan et al., 2015). The compounding jeopardy refers to the patient who cannot comply with the hospital processes, therefore does not get the care they need, which means they are additionally disadvantaged above that of the condition and associated social issues arising from SDH and MM.

The system expects that people like Mr CKD, will prioritise the demands of the hospital system in providing care, over his family and his job; there is no negotiation (Sheridan et al., 2015; Bryne et al., 2021). Thus, the power differential is favoured to the system, where the patient voice is lost, amidst the predominating narrative of finite hospital resources, and a lack of innovation of services to accommodate an increasing demand from people living with multimorbidity (Bourgois et al., 2017; Holman. 2020).

Holman (2020) highlights the fact that there has been little change to health services for decades, because of the focus is on cost containment and efficiency introduced through the ideology of New Public Management (NPM). NPM is the neoliberal answer to control budget, introduced in the 1980s to reduce waste in government services, using the Toyota factory model of lean thinking. This was quickly adopted by public health services heralding in a quazi-business design to control expenditure (Kollberg et al., 2006; Radnor et al., 2012). Initiatives such as the 'productive ward', the nursing process, and integrated care designs, was hailed as the answer to providing good care, but in fact, has not changed the way care is delivered (Waring et al., 2010; White et al., 2017). Based upon units of service, the system has failed to address the elephant in the room, and that is the increase in multimorbidity which requires multiple units of service, not as an episode of care, but as ongoing care that follows the patient to their inevitable death (Bourgois et al., 2017; Mold, 2017; Holman, 2020). The quest to improve hospital efficiencies, means that there is no room for negotiation around best times for patients to see doctors, and even less where there are several medical departments that appointments are made with, none of whom are talking to each other, let alone the patient (Willis et al., 2017; Byrne et al., 2021).

Vulnerability and MM are also linked to Patient Centered Care (PCC). The term Patient Centered Care has taken on prominence in health care since first appearing in the literature as ‘person centeredness’ in 1969, by Balint (1969). McWhinney (1986) later described the concept within clinical assessments and stated the doctor needed to “try to enter the patient’s world, to see the illness through the patient’s eyes.” (p. 876). However, the concept has taken on different meanings, with a common focus in descriptions on ‘shared decision making’ that has evolved in literature reviews (Williams et al., 2017; Langberg et al., 2019, Bryne et al., 2020). PCC is now a fundamental principle in health care strategy and care delivery programs and is often heralded as placing patients at the heart of care decisions and improving outcomes, yet its definition remains inconsistently applied or used. (Langberg et al., 2019; Bryne et al., 2020).

A recent paper by Judge et al. (2022) however has challenged the assumptions that underly the concept of “centeredness’. When these challenges are applied to the case of Mr CKD the reality of the limitations and ruptures to this idealized approach become plain to see. Despite multiple healthcare interactions, Mr CKD's complex health needs remain largely unaddressed, challenging the assumption that PCC inherently leads to more comprehensive and effective care. The fragmented nature of his care - with multiple doctors focusing on a single symptom without considering his overall health status - reveals how the rhetoric of patient-centeredness can falter in the face of systemic constraints and ingrained practices. Moreover, the failure to address Mr CKD's social determinants of health, such as his poor living conditions and financial struggles, exposes the narrow focus of many PCC approaches that neglect the broader context of patients' lives. Furthermore, Mr CKD's story challenges the assumption that PCC naturally empowers patients and democratizes care. His limited English proficiency, cultural background, and socioeconomic status create significant barriers to meaningful participation in his care, contradicting the notion that simply declaring care as "patient-centered" is sufficient to overcome power imbalances and structural inequities. The fact that Mr CKD feels unable to disclose crucial information about his deteriorating eyesight for fear of losing his job highlights how PCC, in its current form, can fail to create a truly safe and open environment for patients.

The rupture in rhetoric can be seem in the current emphasis of SDH as a primary determinant of vulnerability and the ideology of centredness. This challenges us to revisit our assumptions of the care that is provided to our most vulnerable and see beyond the status quo. Patients such as Mr CKD require the most care yet receive the least care or care in a way that is not overly meaningful to them. Their voice is silenced, they are invisible and lost within a system that cannot accommodate the personal, social and the economic complexity that multimorbidity exacerbates. There is a risk that the marginalisation of multimorbidity in the construction of our understanding of vulnerability productive of another, yet to be acknowledged, form of inequality.

Power, knowledge, self and truth

The theoretical approach and concepts of Michel Foucault, a French 20th century philosopher, provides a critical lens through which to examine the complex interplay of power, identity, and social structures in healthcare. The case of Mr. CKD illustrates how institutional power can marginalise patients, how personal, social and cultural identities intersect with healthcare experiences, and how systemic rigidities can create barriers and even penalise. The goal of Foucauldian insights, is not to reveal a true meaning in terms of what is said or not said but intervene in the relations of what can be known, said, or practiced" (Arribas-Ayllon & Walkerdine, 2008, p. 120). Foucault did not speak of truth as we might, but spoke of 'regimes of truth', supported by discourse, that are made true through 'discursive practices and formations'. His point was that regimes of truth are infused with relations of power and, thus, ways-of-seeing that impact on the object of inquiry, which, in this example, are people such as Mr CKD. Foucault's description of his concepts as a "toolbox" (O'farrell, 2005, pp 50), reflects his intention for them to be used as a lens for analysis and critique, rather than as rigid theoretical framework. His 'toolbox' metaphor emphasizes the flexibility and applicability of his ideas across various contexts and disciplines.

In this study I draw on some of these concepts including specifically the problematisation of vulnerability, technologies of power, self, Eventalisation, and resistance to explore the lived experience of patients living with multimorbidity. In exploring these concepts, I use Foucault's concept of the 'games of truth' to position the research questions that guide the thesis analysis. The purpose is to deconstruct the way power dynamics present and how they exist, to then understand the construction of truth for people with CKDMM. This helps us to understand the reality faced by patients when they engage with the health system over long period of time, in the way that this patient group does. Furthermore, it is important to remember that Foucault offers a very different definition of discourse than that ordinarily used by linguists, in the sense that it is as much about ways of thinking and practices as it is about language (Hall, 1997).

Foucault, however, was well known for his reluctance to delineate a definitive analytical method of discursive analysis (Phelan, 2010; Hansen & Triantafillou, 2022). For this reason, I will use Fairclough's concept of 'Social Orders' (Fairclough, 2013) as a framework to position the critical discourse analysis and identify threads of connection from the individual at a micro level where life is lived, the meso level where discourse is structured within institutions to the macro which explores how discourse shapes and is shaped by broader social and cultural structures. This study is embedded in a social context, describing how life changes and, with it, how identity changes for people living with MM. Fairclough's critical discourse analysis provides a flexible methodology, where a multi methods approach is used as part of the 'toolbox' of data used to unpack the discourse within social structures, to examine the relationships of power, knowledge self and truth that give voice to lived experience.

Research Question & Aims

As mentioned earlier the challenge in this thesis, is to examine the nexus between the dimensions of lived experience across multi-morbidity, the social and health system/environments and explore the conditions that produce and construct subjects as vulnerable. Therefore, the purpose is to analyse the discourse across social orders of a cohort of patients accessing the renal service of Hawke's Bay in New Zealand using a Case Study approach. The aim is to analyse the games of truth that construct vulnerability through multimorbidity. This is achieved by Fairclough's framework using multi-societal perspectives of the patient in the healthcare system by employing 'voices' to represent this; *Health System voice* (posed by research question one), *voices of the patients* (through research question two), and a *patient voice* through a case study (aligned to the methodological case study approach used in this thesis) of a single patient representative of the wider cohort (in research question three). The research questions are therefore three-fold.

1. What are 'games of truth' in the healthcare system of patients within a regional secondary care renal service and how are they discursively constructed?
2. How do patients with chronic illnesses construct and negotiate 'games of truth' about their condition and treatment through their narrative accounts, and how do these constructions reflect and potentially challenge dominant medical discourses?
3. How does an individual with multiple chronic conditions construct and deploy technologies of the self through processes of Eventalisation, and in what ways do these reshape health trajectory and subjectivity?

Chapter One reviewed the background to this study, the Patients it profiles and how the research questions developed out of the principles of the guiding philosophers, Michel Foucault and Norman Fairclough. As part of Section One, the next chapter describes the Literature Review and how the two core concepts of Multimorbidity and Vulnerability link the literature to this body of work and provide a way forward.

Chapter Two: Tapestry Of Knowledge

Literature Review

Introduction

This study is positioned around CKDMM, where vulnerability is seen as a dominant feature due to multimorbidities, forcing patients to be more involved with the health system at a higher level. This then exposes them to a more complex 'games of truth' and power dynamics (described in detail in chapter three). Three research questions, framed by Fairclough's social ordering guide how the games of truth are exposed and explored and what this then means to the people who must navigate their health needs within a healthcare system that is struggling. Vulnerability and multimorbidity form the basis of the Literature Review.

The review of the literature was undertaken in 2019 at the start of this study. Acknowledging that new information would have come through since then, any new and relevant literature is included in the discussion sections of this thesis. The review follows a more traditional literature review format rather than a systematic approach (Grant & Booth, 2009). This is a broad topic and required a format that would allow for a broad overview of this topic. Information is collected without a systematic or prescribed process where findings are positioned as subjective summaries (Grant & Booth, 2009). This allows for a variety of literature types to be incorporated in the review. This is useful when the topic is broad, such as multimorbidity, where Greenhalgh et al. (2018) describe how narrative reviews (also called traditional reviews) are useful to provide a deepening understanding of a subject. They argue that complex situations (such as the complexity of living with multimorbidity), "requires a broad range of knowledge sources and strategies for knowing and undertake multilevel interpretation using creativity and judgement" (p.2). However, in this review, primary literature from original studies were used as part of the search method and grey literature has been referred to in discussion.

This review establishes that there is a significant gap in understanding multimorbidity as an influencing factor of vulnerability and the disparity that created.

Vulnerability is a key influence in health care utilisation, as is multimorbidity. Both concepts have been areas of inquiry within health care fields in the last 20 years. Observation in clinical practice recognises intricacies in association between vulnerability and multimorbidity, yet the literature seems vague on how these concepts are associated and interwoven. Comorbidity was defined in 1970 as a combination of diseases coexisting in the one person but still had an emphasis on a single disease state with an additional comorbid disease (Feinstein, 1970). Multimorbidity was first defined in the literature in the early 1990s, with its current definition as co-occurrence of diseases in a person, indicating a shift in mind set from a single index disease (Batstra et al., 2002; Northwood et al., 2018). There are interchangeable terms used for multimorbidity such as chronic and long-term conditions.

There was a large volume of literature on the concept of 'vulnerable populations' in health. People are made vulnerable in several ways. There are commonalities in health, social and environmental characteristics amongst these populations that increase their risk for poor health outcomes (Frohlich & Potvin, 2008; Lewis et al., 2012). Frohlick and Potvin (2008) describe populations known to be vulnerable as those of Indigenous decent, who come from poorer socioeconomic suburbs with low income and education levels. As a result of this vulnerability, Indigenous populations experience a disparity in health outcomes over non-Indigenous populations (King & Gracey, 2009 as cited in Gibson et al., 2015). Lewis et al (2012) expand vulnerability where socially disadvantaged and those with high clinical care needs are increasingly vulnerable where SDH are strong drivers. In both New Zealand and Australia, this is true for Aboriginal, Torres Strait, Māori and Pasifika people who are known to experience social disadvantage, inequities in access to health care and prevalence of chronic disease and higher mortality rate at a younger age than non-Indigenous People (NQPHN, 2016; Oetzel et al., 2017; Reilly et al., 2016; Talemaitoga, 2010). This thesis study is situated within a health care system where Indigenous People are overrepresented and have worse health statistics in nearly all areas of health care measure (Towns et al., 2004; Barton, 2018; Yu et al., 2021).

As previously identified, social determinants of health (SDH) have a significant influence therefore, SDH and Indigenous health must also form part of any health review in NZ if strategies to improve these outcomes are to be realised. These variables, as part of vulnerability, form the focus of this literature review to improve our understanding of vulnerability in healthcare and to see if there is any suggestion in the literature that multimorbidity may exert a unique influence on disparity over and above what is already known. Understanding vulnerability helped to shape the research questions to deconstruct the 'games of truth' when people with multimorbidity are exposed to the health system.

This literature review searched primary studies as a reflection of the literature and is structured to understand the definitions of vulnerability and multimorbidity, how the determinants of vulnerability are expressed in relation to multimorbidity, and if multimorbidity creates vulnerability. The final exploration focused on whether there is any suggestion in the literature that multimorbidity is or may create a unique disparity.

Literature Review Search Question

The Hawkes Bay (HB) data generated from an audit in 2017, suggests that multimorbidity creates an additional element to what makes patients vulnerable and at risk of not coping with their disease as represented by hospital admission. For this review, and as a starting point, multimorbidity is defined as two or more complex chronic conditions (Davis et al., 2017). It is proposed in this thesis, that social disparities, created by socioeconomic factors and ethnicity are equalised by a patient's multimorbidities. People with multimorbidities can then be considered a specifically vulnerable population group of their own, where a unique disparity is created. This is a new suggestion that warrants further exploration to see if it is perhaps ethnicity, environment and SDH that creates disparity in this group or the presence of multimorbidity that makes this population group especially vulnerable. My working statement for this literature review was 'people with multimorbidity are a uniquely disparate population, in addition to other previously known social disparities'. The basis of the search strategy focused on the definition of multimorbidity and vulnerability and how the two concepts may be associated. This resulted in using three focused questions that were developed to provide a logical sequence of inquiry where each question builds on the previous question. Three questions that guided this review were, '*how is multimorbidity and vulnerability within Long Term Conditions described in the literature*', and by understanding how these concepts are defined, '*what information is there in the literature that suggest multimorbidity creates vulnerability*', and '*are people with multimorbidity a unique disparate group*'?

Search Method

The search strategy involved a search of the computerised databases through CQUniversity Library Databases related to Health Sciences. These included CINAHL, Emerald, Family Health, Nursing and Allied Health, Scopus, and Sociology Source Ultimate. Other search criteria included English language, full text with Open Access and only those reporting on countries that have a similar health system to Australian and New Zealand with Indigenous populations. These included USA, Australia, New Zealand, United Kingdom, and Canada. These focused population groups would help to situate this review with an indigenous consideration for Australia and New Zealand where Indigenous People are prominent within these health systems. These countries are also multicultural with similar presenting health systems though not organised in the same way. I also only considered articles from the year 2000 to 2019, to ensure currency and those studies that are considered primary studies. The results of the search strategy can be found in Appendix One.

In reviewing articles, I wanted to identify those that looked at multimorbidity and synonyms, as a disparity. Though search terms resulted in very high numbers of articles in some databases related to multimorbidity or ethnicity, the majority of these discussed multimorbidity in the context of clinical case studies for disease specific management strategies, rather than the unique challenge of multimorbidity. There were very few articles on multimorbidity and indigenous considerations in the Australian and New Zealand context. Many articles were based in countries outside of my search criteria and in low-income countries. For data bases that indicated many thousands of articles I reviewed the first 20 articles and within this, if there were no clearly relevant articles to my questions, I then moved onto a new database.

I identified 16 articles from primary studies that were related to my search question, though only one discussed the possibility of multimorbidity as a disparate group. Three articles from the original search based in the New Zealand and Australian context where discarded. Though they discussed multimorbidity and disparity, after a more in-depth review, the context of the study was positioned more as discussion articles and did not feature as original research, therefore 13 articles were taken forward. A table of the identified studies that met search criteria is found in Appendix One and is structured by author(s), study focus, study population, study outcomes and relevance to disparity.

Findings

The findings section is framed by the three research questions developed for this literature review.

How is multimorbidity and vulnerability within Long Term Conditions described in the literature?

One of the issues facing health care today is the inability to consistently define what is multimorbidity, where interchangeable terms are also used; comorbidity, multimorbidity, multiple long-term conditions, complex care, high health care needs, burden of disease and frailty (Harvey et al., 2019; McPhail, 2016; Valderas, 2009). This review indicates multimorbidity has also been defined as more than one chronic condition existing in a person associated with higher rates of death, health service utilisation and lower quality of life (Davis et al., 2017; Goins & Pilkerton, 2010; Stanley et al., 2018; Stokes et al., 2017; Thavorn et al., 2017). Increasingly, people are presenting for care with one to four co-morbid conditions making them multimorbid (Boyd & Fortin, 2010).

There was no specific set of chronic conditions used that define multimorbidity. The top ranking chronic conditions identified by several authors from this review, as well as in the grey literature, are diabetes, cardiovascular and respiratory related conditions, with cancer next and some studies acknowledge mental health (Boyd & Fortin, 2010; National Advisory Committee., 2007; Jackson et al., 2017; Kastner et al., 2018; Laditka & Laditka, 2006; NQPHN, 2016; Stanley et al., 2018) . Understanding the presence of multimorbid conditions is important in establishing the health needs of a population, the health care services they may require as a result of increased disease progression and the association of increased risk of adverse health events. All studies exploring multimorbidity acknowledge the complexity over caring for people with single disease states. Thavorn et al (2017) stated in their study that there is a requirement for complex care to match complex needs.

In relation to vulnerability, many of the articles discussed or used the term ‘vulnerable population’ to describe the focus participants of the reported study. Some authors also used the term ‘marginalised population’ as an interchangeable term for vulnerable populations (Thavorn et al., 2017).

There are many different definitions within the literature. Grabovschi et al. (2013) reviewed the literature to understand the concept of vulnerability. Their working definition included those who were at increased risk of disparity in relation to health and receiving healthcare. These were based on individual factors such as gender and race with genetic disposition to disease, acquired vulnerability as a result of trauma or lifestyle choices and environmental vulnerability relating to physical and socioeconomic factors such as environmental hazards, income, and the political agenda of the country. They reviewed 23 publications, of which half defined vulnerability as existing in segments of the population but did not describe specific characteristics. The other half described vulnerability as multifactorial. These included factors such as older age, specific ethnicity, lower education level, low socioeconomic neighbourhoods, lack of health insurance, poverty, and inability to access care.

Several other authors referred to characteristics of a vulnerable population but did not specifically describe them as ‘vulnerable’. They included ethnic minority referred to as Black Canadian, African American, Hispanic, Pacific Island and Indigenous Peoples including Canadian Indian, Native American, Aboriginal and Māori. These populations were described as having an association with low education levels, poor income status and living in socially deprived areas (Davis et al., 2017; Hill et al., 2017; Jackson et al., 2017; Johnson-Lawrence et al., 2017; Markwick et al., 2014; Stanley et al., 2018; Thavorn et al., 2017).

Johnson-Lawrence et al. (2017) describe a vulnerable population as being younger people with multimorbidity who have life events associated with significant change and psychological stress that poses a vulnerability. This can predispose a young person to developing a chronic disease or make managing chronic disease very challenging. This is then linked to populations at risk defined by socioeconomic factors including race and ethnicity, housing, income, and age.

Review of the relevant articles provide a series of definitions for both multimorbidity and vulnerability and that the understanding of this is complex with strong associations to SDH[3] (SDH), where ethnicity and poverty in particular are prominent drivers. These factors formed dimensions of vulnerability. There currently is no one definition used within either concept that is uniformly applied. There is also no definition identified that specifically states both concepts within the one definition, where the relationship to these concepts is through associations.

What information is this there in the literature that suggest multimorbidity creates vulnerability?

The literature was positioned around dimensions of vulnerability as identified when attempting to establish a definition. These dimensions included ethnicity, age, gender and social disparity, as portrayed by SDH, and the relationship to vulnerability and multimorbidity. Several authors report a strong relationship between race and ethnicity and a chronic condition (Avendano et al., 2009; Davis et al., 2017; Grabovschi et al., 2013; Hill et al., 2017; Johnson-Lawrence et al., 2017; Laditka & Laditka, 2006; Lebrun & Laveist, 2013; Markwick et al., 2014; Stanley et al., 2018; Thavorn et al., 2017). These reports suggest that chronic conditions are more prevalent in the Indigenous populations of Australian, Canada, and New Zealand, and in the USA Native American and Non-Hispanic Black people. Chronicity was also often associated with increasing age. Older age featured in several studies with higher risk for health status deterioration, difficult or less frequent access to health care services and increased rates of hospitalisation especially in the over 65year group (Grabovschi et al., 2013; Stanley et al., 2018; Thavorn et al., 2017). It was unclear, however, whether it was ethnicity alone, or a combination of ethnicity and age, that created disparity. These specific population groups are often referred to as ethnic minorities in comparison to dominant white people of European descent.

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[3] SDH are described as the environmental, socioeconomic and demographic conditions in which people are born, grow, live, and age. These include "income, education, occupation, social class, gender, race/ethnicity" (World Health Organization, 2010, p. 10)

However, the literature is overwhelmingly situated in the USA context. Studies on Indigenous People of Australia and New Zealand in relation to multimorbidity are difficult to find. This suggests there is a lack of research in understanding how these populations cope with multimorbidity and what the particular needs of these people are.

Most studies tended to relate to a single chronic condition state such as diabetes. Stanley et al. (2018) compared the prevalence of multimorbidity in the New Zealand population and found a higher prevalence amongst Māori at a younger age than other populations, with increased rates of hospitalisation in the elderly. Markwick et al. (2013) studied multimorbidity in the Aboriginal population of Victoria, Australia and noted that disparity was strongly related to determinants of health, impacted by the tranisent nature of Aboriginal people and their lack of trust in seeking services from mainstream providers who where seen not to offer them the same quality of care as to white Australians. Hill et al. (2017) conducted an observational study on Type 1 diabetes and progression to end stage kideny disease in socially deprived ethnic minority groups of Australia and New Zealand. They found an inverse relationship between low socioeconomic status and prevalence of these diseases but, interestingly, this has not changed over the last 20 years despite health care reform. There was a clear disparity between Indigenous People and those of European descent.

One study, however, reported a reverse disparity. The study conducted by Lebrun and Laveist (2013), who compared specific health indicators of those considered 'Black and White' Canadians (p.143), found a reverse disparity seen amongst common health indicators such as smoking, cardiac disease and cancer. Black Canadians were seen to have 'lower odds' for these measures than White Canadians which they acknowledge has not been suggested in other studies. Data was collected via a National Health Survey that was dependant on self-reporting of disease. The authors also propose reasons as to why Black people may have been overly positive of their health status including acquiescence bias and that Black people may under report disease so as not to be seen to be oppressed.

The literature provides some evidence that this disparity lessens with increasing co-morbid conditions in the individual, regardless of socioeconomic variables. Davis et al (2017) studied the prevalence of cause of death from a single and multimorbid state in the

USA among older adults. There was a notable difference in disease dyad and triad patterns related to ethnicity but found a decreasing prevalence of racial disparity with increasing multimorbidity. Their study had limitations where they acknowledge that there is an issue with classifying a single chronic disease due to the high probability of undiagnosed disease. This could affect the ability to track additional chronic conditions in an individual and may have affected their results. Most studies, however, report the link between chronic diseases as being more prevalent in minority racial groups but are not specific about the association with increasing prevalence of multiple conditions except to report that it is present.

Social disparity has a direct relationship with factors that are collectively known as the SDH.

> The World Health Organisation (WHO) provide a simple definition of the SDH:
> The SDH are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power, and resources at global, national and local levels. The SDH are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries (World Health Organisation, n.d).

All articles reviewed associated SDH with ethnicity, and poor health outcomes. The most common determinants included socioeconomic factors such as highest education level achieved, wealth and income, employment, and health insurance with sociodemographic factors such as area of residence, age, race, ethnicity, and language. Most authors apart from Lebrun and Laveist (2013), report this relationship as inversely proportional. Low socioeconomic and demographic status was associated with higher prevalence of multimorbidity. This translated to poor access to health services and poor health outcomes as a result. Hospitalisation and use of pharmaceuticals were higher, as was the risk of an adverse event (Grabovschi et al., 2013; Stanley et al., 2018; Thavorn et al., 2017). Grabovschi et al. (2013) describe the coexistence of these factors as well as incarceration, widow ship and homelessness as the multiplicity of vulnerability which increased the need for health care and decreased the accessibility of services that resulted in poor quality of care. They describe an inverse relationship where the increasing factors of vulnerability, relates to higher healthcare need and lower accessibility and quality of care. They have described this in a "dynamic multi-vulnerability model of health care disparities" (p. 2). Thavorn et al. (2017) described how higher health needs in the older person with multimorbidity increased health care costs significantly, whereas Stokes et al (2017) discussed the barriers that prevented efficient management of multimorbid conditions in New Zealand. These included demands on primary care appointments, with insufficient time to address more than one issue, symptom, or condition within these appointments, meaning many issues went unaddressed. They suggest there is an issue with the current capitation financial structure, within New Zealand, with co-payments and inadequacies of Care Plus[4] programs that were designed to support chronic conditions management in primary care, but patients with multimorbidity who most needed Care Plus funding, are not always able to access this.

Three articles also addressed the specific need for the redesign of the health care system to manage multimorbidity and to move away from the single disease focused system currently in use (Northwood et al., 2018; Stanley et al., 2018; Stokes et al., 2017). Northwood er al. (2018) examined how SDH in relation to older adults were positioned in relation to multimorbidity. They found that the literature paid significant attention to gender, age and education but found ethnicity and socioeconomic status, social class and political context received little consideration.

Certainly, the literature draws significant association to the dimensions of vulnerability of which multimorbidity forms part of this. However, the literature is scarce in understanding how and to what extent multimorbidity influences vulnerability specifically. The association is recognised within the risk of health care utilisation and increased hospitalisation where poverty and age are linked. This area as a whole is largely unexamined.

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[4] Care Plus is a subsided primary care capitation-based funding program, for the coordination of chronic conditions management, aimed at reducing inequities through a criteria-based access model introduced into the NZ healthcare system in 2004 (Stokes et al., 2017).

Are people with multimorbidity a unique disparate group? A suggested gap in the literature.

In attempting to answer the question 'does multimorbidity create vulnerability?', certainly from undertaking this review, it was difficult to identify original research that questioned whether multimorbidity is a discrete vulnerability, or how this might be identified. Many articles discuss multimorbidity as an association to vulnerability but not as a discrete factor. Stokes et al. (2017) conducted a study with primary care physicians in NZ and describe the challenge of looking after people with multimorbidity but associate this to constraints in providing care in the NZ healthcare system rather than the effect and influence on vulnerability. One study by Davis et al. (2017) acknowledged a suggestion within their findings that the inverse relationship between chronic conditions and SDH lessened as morbidity increased but did not go as far as to state it was a unique or discrete factor. Lebrun and Laveist (2013), in their study suggested race disparity may lessen with increasing morbidity but do not define this as more important than other factors of disparity. No primary studies were found that describe or discuss the relationship of multimorbidity to vulnerability or disparity as independent or unique without the presence of other known factors. This may be because multimorbidity alone has not been the focus in understanding vulnerability in primary studies to date, due to the co-existence and influencing nature of the other known factors of vulnerability.

Discussion

In this review, multimorbidity is described in the literature most commonly as the coexistence of two or chronic or long-term health conditions. Whereas vulnerability is defined either by individual factors related to SDH such as ethnicity, age, poverty, education level or as a combination of these factors. There is suggestion that social and clinical need and in combination created complexity and increases vulnerability in association with health care. Outside of primary studies there has been attempts to definition vulnerability as a driver of healthcare needs. Ruof (2004) reviewed literature on what and who vulnerable populations are in healthcare and research and found that though vulnerable populations are referenced and used within guidelines that enhance special protections for the vulnerable, the concept and criteria for this remains vague. This inability to define who are vulnerable or what vulnerability is has implications in its use as part of funding decisions and resource allocation in healthcare. Ruof (2004) also found that many authors offer caution over labelling what is and who are vulnerable, as this then allocates people to categories and may form a sense of injustice in doing so. There is acknowledgement by several authors of the importance to continue to define vulnerability though it has "it's distractors…it captures significant aspects of marginalised groups" (Ruof, 2004, p. 2). Hutchins et al. (2009) reviewed the definition from the perspectives of social science in the policy and practice of public health science, based on public health needs during a pandemic. These included populations that face the potential for loss from a socioeconomic and demographic view.

Disease elimination was also used as a context for vulnerability that included risk of infection, hospitalisation, severe disease, and death, with poor access to health care. Hutchins et al. (2009) also reported that, in terms of public health within the USA, the Pandemic and All Hazards Preparedness Act of 2006 describe vulnerable populations as those with special needs; pregnant women, children and elderly. They further explored the definition of at risk with special needs identified under the broad context of needs relating to communication, transportation, medical care, supervision, and independence.

Lewis et al. (2012) describes two specific groups for consideration of being defined as a vulnerable population. These are those who are at 'clinical risk' of a medical or health condition and the second group as the 'socially disadvantaged'. These groups are defined by characteristics where social, economic, and geographic elements include income, race, and social isolation. Lewis et al. (2012) considers those who are both clinically at risk and socially disadvantaged as being a highly vulnerable group. They profile complex chronic disease and multiple chronic conditions as part of this vulnerable population but do not specify if having this alone, outside of other risk factors in their criteria, make them a uniquely vulnerable group.

What this review has identified is the lack of consistent definition for understanding multimorbidity and has highlighted the variety of ways vulnerability in healthcare is measured and viewed. A link exists between vulnerability and disparity as does an association between multimorbidity and vulnerability. The review articles all discuss dimensions of vulnerability that create disparity especially when in combination with certain influences of SDH such as poverty, ethnicity and age featuring more prominently. One study by Lebrun & Laveist (2013) suggested that a reverse disparity based on ethnicity may exist, but this is not supported by other studies that overwhelming suggest ethnicity is important in understanding vulnerability.

There were no distinct articles found that discuss multimorbidity as an independent factor or more strongly associated to vulnerability over other factors. However, one study by Davis et al. (2017) offers a suggestion that multimorbidity in itself forms an influence that may start to equalise across these other known factors. A NZ study associated multimorbidity specifically to disparity in providing care in the context of system constraints but not in how care is needed. Understanding this is important, as much of the literature on vulnerability suggests dedicated health resources and design are needed and based on vulnerable factors or at least requires a specific focus within health care delivery to address those who are vulnerable as special population groups. Lewis et al. (2012) suggest that clinical need combined with social need create high levels of vulnerability where health resource should be targeted.

This PhD study is focused on understanding and recognising people with coexistence of multiple chronic conditions as a special population group that have a unique influence for individuals around complexity of care. By Lewis et al. (2012) definition this would suggest specific and targeted care and management plans through dedicated guidelines and resource funding to establish specific programs for people with multimorbidity. This would be required regardless of other factors of disparity. Currently in NZ health care funding recognises ethnicity most prominently Māori as an Indigenous People, and socioeconomic status as two of the strongest influences of increased health care support (Towns et al., 2004; Barton, 2018; Gray & Hunter, 2019). This paper suggests multimorbidity needs to be factored as a significant influence on the need for health care support as prominently as ethnicity and poverty with be a dedicated focus if we want to improve equality and equity of care for this 'special' population group who are over presented in all of these other known disparate factors. Understanding of multimorbidity is limited and how it truly impacts as a vulnerability is unclear. This forms a significant gap where this area of inquiry helps to provide some insight into this issue.

Summary

This Literature Review was undertaken to explore the concepts of vulnerability in multimorbidity and whether or not it creates a unique disparity as a vulnerability. These are important factors in how the patient is positioned in the 'game of truth' within healthcare. In an attempt to answer this a review of how the literature defines multimorbidity and vulnerability in health care was undertaken. As a result, 13 articles matched the search criteria. There is a lack of consistency in how we understand these concepts. Many factors of vulnerability are identified and described in how they increased risk for health care utilisation where multimorbidity is recognised as in association with other factors. Information specifically on multimorbidity as a disparity, or as causing a unique vulnerability, was difficult to find. Multimorbidity is well recognised within the literature and is often referred to in association with age, gender, ethnicity, and culture with SDH that include socioeconomic and demographic factors. The coexistence of these factors has been described as multiplicity of vulnerability where clinical and social variables impact on risk. The more coexisting factors that are present for an individual, the more vulnerable they are to progression of disease, hospitalisation, and disparity. Disparity was often associated with ethnicity where studies compared people defined as either Non-White or White within a population. Most of these studies were based in the international context where this form of identity is more widely used. Currently in NZ health care funding recognises ethnicity most prominently Māori as an Indigenous People, and socioeconomic status as the basis of increased health care support. Education levels, poverty and social environments were also prominently featured as part of disparate variables.

What was difficult to determine from the literature is whether these variables created disparity because of their coexistence or whether they create disparity in discrete forms. One study reported findings that start to suggest coexistence of chronic conditions and presence of multimorbidity appears to become an equaliser across gender, ethnicity, socioeconomic and sociodemographic factors, creating a discrete disparity. What we observe in practice in a causal or casual way, warrants examination as the current body of literature does not suggest this has been well recognised, or that the association with multimorbidity have been fully explained to date. This may be because multimorbidity is an evolving issue that is becoming more prominent as each decade passes. Multimorbidity is changing the needs of patients and how the health system responds, influencing the way the 'games of truth' are constructed. This thesis is situated within this gap and seeks to provide some form of answer, or at least to contribute to further understanding through a differently focused lens with a population group known to be multimorbid.

The following chapter completes Section One and positions the research within a philosophical paradigm. It describes the perspective that best aligns to this study through the guiding theorists of Foucault and Fairclough and explains how they have shaped the way the study has unfolded. The data collection and analysis methods are described, as well as how the analysis is structured, and how the research was conducted within the principles of good ethical research. The timeline of the study is also outlined.

Chapter Three

Research Framework

Introduction

In this chapter, the theoretical perspectives and approach to my research is discussed. To put the study into context, I have explored what factors influence or define patients with CKD in relation to vulnerability, multimorbidity and to understand the ‘games of truth’ in healthcare. Three research questions were posed to represent three social orders. From my ontological position, the voices of patients are often drowned out by the operational and budgetary concerns of the health system on which they depend for survival. This creates a paradox: a population with significant health needs reliant on a system that views their care as an expensive outlier, constantly seeking cost reductions (Harvey et al., 2016). In my own practice, I observe patients falling through gaps in care, a phenomenon Leiser et al. (2017) describe as structural vulnerability, where patients are compelled to comply with an inflexible system. Sheridan et al. (2015) further describe this as "compounding jeopardy," where patients feel disempowered in their interactions with healthcare providers. The increasing standardisation of care processes aims to reduce costs while maintaining quality care.

The subsequent implementation of clinical guidelines and management protocols has diminished the critical thinking essential to comprehensive patient assessment, leading to fragmented and impersonal care and medically siloed treatment. This tension between financial and clinical priorities creates challenges that clinicians often address through "workarounds" to bypass systemic barriers (Slemon, 2018). Foucault’s concept of “ordering systems” is relevant here, as he argues that such frameworks impose categorisations that claim universal validity, reinforcing power imbalances between those who design these "truths" and those tasked with implementing them. These truths, while appearing authoritative, may be misaligned with the complexities of real-world practice (Foucault, 1966).

The patient, the power and the care – seeking truth

For Foucault, power is everywhere, and no-one owns it. It is also relational and productive as it shapes and reshapes knowledge, norms, and social realities. Institutions and systems of power produce and disseminate knowledge, and, conversely, knowledge reinforces and justifies existing power structures. This connection between power and knowledge is evident in what Foucault termed the "power/knowledge" nexus which is perpetuated through discourse. Power becomes dynamic, relational, and embedded in the fabric of society. For people living with CKDMM, the relationship with the health system is undeniable and inescapable. Yet, their care cannot be individual because neoliberal policies shape the choices, interactions, and actions available to individuals, often leading to increased marginalisation (Charmaz, 2019). The power is not with the patient, it is with the system, enacted through its health care team. Patients with chronic conditions must negotiate multiple access points in the health care system to receive care across siloes of medical specialty areas and departments, each following discipline specific, evidence-based protocols. Power and the social fabric are inherent within each area of care, sustained and expressed by the health professionals who embrace their roles and responsibilities within that framework.

Whilst this system largely works for simple case presentations, it unravels with complex cases, such as those patients with advanced CKD and ESKD because of duplication, conflicting messages and treatments from each of the health siloes involved in a patient's care. At the end of this cascade of health access points is the patient, trying to make sense of the messages and directives given to them. As Charmaz (2020) noted, "people with chronic illness cannot assume their bodies will function smoothly" (p.36) and because of that, their lives, by nature are uncertain and erratic. Instead of being given good support and guidance, patients are dealing with contradictory treatments within which they become "objects" that result from "dehumanizing processes of objectification and dismissal" (p.38), witnessed by the labelling that occurs when patients are unable to meet the expectations of the system; 'frequent fliers' (frequent inpatient admissions; 'non-compliant' (not following treatment); and 'DNAs' (did not attend outpatient appointment), the blame being apportioned to the patient regardless of reasons underpinning such labels even when the patient is not at fault. I discuss this further in chapter four. Compounding this social dismissal is the never-ending stream of outpatient appointments and referral waiting lists.

An example of these compounding factors in my own work was a patient in my clinic being prescribed five different medications with a diuretic effect from three different specialists, each applying their own specialty focus, but the end result is compounding diuresis where the patient presented with dehydration. Who led care in this case and by whose truth was this patient to follow? Each health professional and speciality saw themselves as the leader of his care and the patient was simply following a multitude of instructions but instead, a compounding jeopardy was created. It's not uncommon to have a patient waiting for a referral from an acute service's social worker to a community social worker, another waiting weeks to see their general practitioner because they (the renal patients) have been told not to come to secondary services as their first port of call. Power is held with the health service, not the patient.

For Foucault, knowledge is not just about discovering objective truths, but it is created and used to shape how people think, behave, and organise their lives. Knowledge and power are co-constitutive, and knowledge produces power, and power determines what counts as legitimate knowledge. Neoliberal policies reflect this power in health care through biopolitical control, prioritising economic productivity over individual well-being. Chronic illness and disability are framed as burdens to the system, leading to exclusionary practices. As Charmaz (2020) notes, "social scientists miss making crucial connections between subjective experience and social structure", (p. 39). Thus, underpinning this study with the work of Foucault is important. By drawing on different lenses that associate with the care of CKDMM patients, I can explore the perceptions of the patients as to how they view their care but also examine descriptive information that hospitals rely on to understand their patient and financial profile.

Critical Social Theory and Foucault

Critical Social Theory (CST) is concerned with power structures and the 'emancipation' of people, from within the environment of oppression (Dant, 2003). Its philosophical underpinnings are rooted in a combination of objectivist ontology and subjectivist epistemology, allowing it to bridge various paradigmatic boundaries, including positivist and interpretive perspectives. This duality enables CST to incorporate both empirical knowledge and hermeneutic understanding, fostering a comprehensive analysis of social phenomena. CST is the commitment to social transformation and emancipation. Scholars like Max Horkheimer have emphasised that critical theory is fundamentally concerned with the exposure of social injustices, advocating for a critical examination of societal norms and values. CST draws from various theoretical traditions, including Marxism, feminism, and postcolonial theory, which provide critical lenses through which to analyse social relations and power dynamics. For instance, intersectionality and critical race theories highlight the complexities of identity and the ways in which systemic inequalities intersect (McGibbon & Lukeman, 2019). CST advocates for methodologies that prioritise reflexivity and critical engagement.

The approach is commonly used where an inquiry seeks to understand the position of vulnerable populations, social justice, and power influences. Leonardo (2004) describes how critical social theory has been used in the educational sector in pursuit of quality education to create 'emancipatory functional knowledge' and promote criticism and the student's ability to recognise and analyse the institutional and conceptual dilemmas (p. 11). Power evolves from knowledge, and through understanding how people are positioned within power structures, strategies can be developed to bring about change. This is often explored through understanding the real experience of patients as a way of examining the social conditions within a structure (Haydon et al., 2018).

Critical Social Theory provides a framework for positioning this study within a Constructivist and Interpretive theoretical perspective and the utilisation of Critical Discourse Analysis through the orders of discourse, with a focus through Interpretive Sociology Theory to gain the 'lived experience'. Critical Discourse Analysis provides a structure that reflects the interacting and social variables that exists from a micro to macro level to optimise the analysis of chronic care needs. Drawing on Foucault's views, power operates relationally through discourse, influencing what is considered knowledge and whose voices are legitimised. Research from this paradigm often employs qualitative methods such as discourse analysis (examining both text and action), interviews, and storytelling. These approaches allow participants to articulate their lived realities and challenge dominant narratives (Frechette et al., 2020). While interpretivism focuses on understanding social phenomena within cultural contexts, the critical paradigm interrogates how systems of power and ideology structure these realities. By analysing how knowledge is produced and maintained, the critical paradigm reveals opportunities for transformation in social structures and relationships. Researchers have often referred to both Critical Social theory and Interpretive Sociology theory as being of opposing views (Dent et al., 2013). Critical approaches aim to understand the domains of power, knowledge, and ideology within social practices. Where Interpretive studies explore the intricacies of the construction of social realities and social practices. They are concerned with people and realities and how societal influences impact on these realities (Pozzebon, 2004).

Foucault and Fairclough: Underpinning Discourse analysis

The objectives of this thesis are to examine the nexus between the dimensions of lived experience across multi-morbidity, the social and health system, and environments, and explore the conditions that produce and construct patients as vulnerable. I want to identify the issues that perpetuate and/or exacerbate depravity and vulnerability within a group known to be extremely disadvantaged because of the severity and complexity of their illness and its inevitable deterioration even with highly medicalised intervention. The research questions posed in this thesis are three-fold (Research Questions and Aims, chapter one) and employ several key theoretic concepts from Michel Foucault's work. These include primarily his concepts of "Games of Truth," "Power/Knowledge," "Discourse," "Governmentality," "Subjectification", "Resistance", "Technologies of the Self," and "Eventalisation." These concepts and theories are explored within this chapter and the interplay of Foucault's concept of Discourse alongside Norman Fairclough's Critical Discourse Analysis (CDA) discussed as a methodological approach at the end of the chapter.

Foucault's work is influential in understanding the power relationships, identity, the role of society, and the essence of knowledge. He spent much of his career exploring relationships between scientific disciplines and social practices and is considered one of the leading theorists in this area (Fraser, 1981; Foucault & Rabinow, 1984; Foucault, 1998; Powers, 2007). As part of the critical theory movement, Foucault's work is considered one of the most important influencers of post-structuralism (McCarthy 1990; Fendler, 2014; Sotiropoulos, 2021). McCarthy (1990, p.4237) describe his "intellectual coming of age" during post-World War 11 France. This was an era in critical theory where Marxism philosophy flourished and was centered around the examination of economic basis, ideological structure, and society and in particular socialism. The leading theorists in this work were known as the Frankfurt School. Early theorists of the Frankfurt School in the 20th Century included Horkheimer, Adorno, Marcuse, Benjamin, Pollock, Lowenthal, Fromm and now third generation theorists such as Habermas who, like Foucault and Marxism, worked in critical theories concerned with power, culture, society and knowledge, though they differ significantly in interpretation (Macarthy, 1990; Corradetti, 2012). Fendler (2012) in her exploration of Foucault's work, defines a Foucauldian difference to other critical theorists in that he does not seek "to provide answers to societal or political problems but to ask questions about how we think" (p. 8). His work has a strong influence in several fields such as scientific inquiry as well as sociology though he did not consider himself a theorist as such:

> Although it has been claimed that his work can reside within the domain of social constructionism, structuralism, post-structuralism and post-modernism, (Foucault, 2002), himself dismissed any claim to philosophical genres (Phelan, 2010, pp. 894).

Foucault described his approach as analytical tools rather than a prescribed methodology. He did not want to add to 'the regimes of truth' and was concerned with avoiding ''developing yet another scientific theory" (Hansen & Triantafillou, 2022, pp. 560). A Foucauldian approach considers reality as constructed through discoursing the 'everyday experiences', where society is in constant change influenced by what is said and done and represented through language, actions, and events. He was interested in examination of the 'meaning' behind such things and the complexities of power and knowledge where power is enmeshed in knowledge and vice versa (Hall, 1997, Gutting 2005, Phelan, 2010, Hansen & Triantafillou, 2022). He developed a novel concept of power, not as a linear, top-down concept, but something that surrounds and is circulated through networks of practices (Hall, 1997). This influenced how we think about power, its meaning, affect, who and where it is held and what the consequences of power relationships are. Power must then be intricately tied to discourse.

He was known to be a ‘provocateur’, interested in the discourse of problematisation and its historical context. He encourages the challenge of prevailing assumptions, and to question, deconstructing issues to understand invisible influences, enticing a new view of our world. Foucault's work provides a critical lens through which the interplay of power, knowledge, and truth can be examined. In the healthcare context, Foucault's concept of the power/knowledge nexus is particularly relevant. This concept suggests that knowledge and power are interdependent, with power producing and disseminating knowledge, which in turn reinforces and justifies existing power structures. Much of his work is based around the understanding of knowledge, truth, and the study of power, how it is exercised and its nature, the analysis of power relations and its historical context relative to subjects (people). He describes subjects and subjectification, which was his main purpose in study and not power itself. His main goal was to understand the ‘what,’ ‘why’ and ‘how’ of power relations (Foucault, 1982). Furthermore, as Foucault reminds us in "The History of Sexuality" (1978, p. 95), "Where there is power, there is resistance," suggesting that within these complex power dynamics lie opportunities for transformation and change in healthcare practices and policies.

Next, I explore some of his core concepts and their relevance to the thesis research questions in more depth.

Games of truth and it’s power rationalities

Foucault's concept of "Games of Truth" refers to the mechanisms and processes through which truth is constructed, contested, and maintained within societies. Unlike traditional notions of truth as an objective reality, Foucault posits that truth is a product of power relations and discursive practices. In the context of healthcare, "Games of Truth" are particularly relevant as they illuminate how different stakeholders—such as medical institutions, media, and patients—participate in shaping what is considered true about healthcare quality, patient experiences, and treatment outcomes. Foucault relates truths to 'systems of power' that incorporate regimes that produce, and enact the means of power (i.e., structures of influence that stipulate order and functioning such as societies and government) where he refers to this as the 'regime of truth'. Truth is not power as such but the means to produce, distribute and maintain power. (Foucault, 1995; Lorenzini, 2015). In "The History of Sexuality" (1978), Foucault argues that truth is not an objective reality but a product of power relations and discursive practices. Discursive practices are then considered agents of power (Gutting, 2005). In healthcare, these games are evident in the interplay between patient hospital utilization statistics and media narratives.

Foucault rejected the tradition of power but believed power was multifaceted and describes "a 'technological' vision in which he analysed the 'techniques' of multiple, decentralised power in a society described as an 'archipelago of different powers" (Pavon-Cuellar, 2022, p.338). Foucault describes power as often seen in a negative, repressive, or diminishing sense but can also be positive where it is productive and enhancing. For Foucault, as described earlier, power is everywhere, and no-one owns it. It is also relational and productive as it shapes and reshapes knowledge, norms, social realities and existing in all social interactions and institutions but not owned by any individual or group. In Foucault's view, knowledge is not merely a tool for understanding the world but is intrinsically linked to power dynamics (Foucault, 2007). Institutions and systems of power produce and disseminate knowledge, and, conversely, knowledge reinforces and justifies existing power structures. This connection between power and knowledge is evident in what Foucault termed the "power/knowledge" nexus which is perpetuated through discourse.

Foucault argued that it is the power/knowledge relations that are important, rather than the subject itself. Thus, it is the power-knowledge struggles and processes that determines how knowledge is accepted in society (Nola, 1998). For people living with advancing CKD, the relationship with the health system is essential, yet the power and the knowledge is not with them, it is with the many members of the health care team involved in directing their care. They have multiple entry points between multiple (single organ) specialists, hospital admissions, dialysis, outpatient clinics and allied health support (e.g. dieticians, x-ray, laboratory testing), each one of these areas following a protocol of 'evidenced-based care' focusing on their specialty area, the power and the social fabric being that each of those areas of care are accepting of their role and their protocol to manage care correctly. This acceptance of a systemised process unravels, when each one has different protocols for different systems competing, so that in the end, the patient is not sure which directive they must follow. Statistics, often perceived as an objective measure, are embedded within institutional power structures that determine their collection, interpretation, and presentation. Media narratives further shape public perception by framing these statistics in ways that influence health policy and public opinion. This dynamic illustrates how truth about healthcare quality is not simply discovered but actively constructed through various institutional and social processes. Understanding these games reveals the contingent nature of healthcare truths and the power dynamics that shape them. This exemplifies Foucault's "Power/Knowledge" concept, where knowledge is not neutral but is produced and disseminated through power relations. As Foucault states in "Power/Knowledge: Selected Interviews and Other Writings" (1980a, p. 52), "We should admit that power produces knowledge... That power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations."

Power/knowledge relations can also be seen in Foucault's concept of "subjectification" which refers to the process by which individuals are constituted as subjects, shaped by power relations and discursive practices. In "The Subject and Power" (1982), Foucault argues that power operates not just through overt domination but through the creation of subjects who internalize certain norms and self-regulate their behaviour. Patients with chronic conditions are often subjectified through medical discourses that define their identities and experiences. In the healthcare setting, patients may be subjected to various forms of categorization, normalization, and disciplinary techniques that construct them as particular types of subjects (e.g., "the compliant patient," "the non-adherent patient"). These processes can have significant implications for how patients experience and navigate the healthcare system. Additionally, the concept of "Eventalisation" can shed light on the "Games of Truth" as it refers to the process of uncovering the contingent and historical conditions that have led to the emergence of a particular truth or phenomenon. Foucault introduces this concept in "Questions of Method" (1991), arguing for a critical approach that questions the apparent self-evidence of practices and discourses. In healthcare, this concept is relevant for understanding how medical practices and discourses are constructed and maintained. In the context of healthcare research, this concept can therefore be used to examine how certain healthcare truths or practices have come to be accepted as "natural" or "inevitable," when in fact they are the product of complex power dynamics and discursive struggles.

Biopolitics, governmentality and technologies of self

Foucault (1982a) describes three modes of objectification: dividing practices, scientific classification, and subjectification. These modes describe ways in which humans as individuals and groups hold knowledge, are categorised, controlled, disciplined, and monitored or surveyed within formal structures such as institutions and organisations where these systems of power shape our identities and experience, that determine our behaviours. He coined the terms ‘Biopower’ and ‘Governmentality’ to describe the management of societies and how control is exercised through the institutional power of governing bodies and regimes of authority expressed through societal practices, rules, boundaries, policies, and social orders (Lynch, 2016).

Biopolitics and governmentality play significant roles in the context of multimorbidity care within neoliberal healthcare systems. Biopolitics refers to the ways in which governments regulate populations through policies that impact health and well-being, often prioritizing economic efficiency over individual care needs. In neoliberal frameworks, health is often commodified, leading to a focus on managing diseases rather than addressing the holistic needs of individuals with multiple chronic conditions (Dixon et al., 2023). Foucault's concept of "Governmentality" refers to the way governments try to produce citizens best suited to fulfil government policies and is the “ensemble formed by the institutions, procedure, analyses and reflections, calculations, and tactics that allow the exercise of this very specific albeit very complex power “(Foucault, 2007, p108). Governmentality describes how power is exercised through the governance of individuals' health behaviours and choices. This can result in the responsibility for health being shifted onto individuals such the case of the self-management movement, and communities often from a volunteer basis, rather than being addressed through systemic changes in healthcare delivery. Consequently, the integration of care for multimorbidity is often limited, as existing frameworks may perpetuate inequalities and fail to disrupt the underlying neoliberal policies that shape health systems

In his seminal 1978 work 'The History of Sexuality, Vol. 1' (1978), Foucault introduced the concepts of biopolitics and biopower. Foucault discusses how modern power operates not just on individual bodies, but on entire populations, regulating and managing life itself through various techniques and knowledge systems. Biopolitics, therefore refers to the mechanisms and techniques through which states regulate and control populations by focusing on the biological and social aspects of life. Political power is concerned with controlling individuals, and operates through institutions and practices, such as health care, to collectively shape and manage the health, reproduction, labour, and behaviour of populations. Governmentality refers to the rationalities and techniques employed by governments to govern populations. Biopolitics and governmentality intersect to create a regime of power that not only controls individuals but also shapes the very conditions of existence for entire populations. Interweaving within biopolitics is the concept of works 'technologies of the self.' Introduced in his later works "Technologies of the Self," offers a counterpoint to subjectivity, highlighting how individuals actively shape their own subjectivity through various practices and techniques. In "Technologies of the Self: A Seminar with Michel Foucault" (Martin and Waring,2018), he explores how individuals "effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves" (p. 18). Patients construct and deploy these technologies to manage their health, asserting their agency within the healthcare system. This is a dynamic that illustrates the interplay between institutional power and individual agency in shaping patient experiences and identities.

In the contemporary neoliberal healthcare landscape, self-management is often encouraged as a means of reducing healthcare costs and hospital utilization. Patients are expected to take an active role in managing their own health, engaging in behaviours such as medication adherence, lifestyle modifications, and monitoring of symptoms. However, Foucault cautions that these technologies of the self are not neutral; they are shaped by the power relations and discursive practices within the healthcare system. Patients may internalize the norms and ideals promoted by healthcare institutions, leading them to engage in self-surveillance and self-regulation to conform to these expectations. This can create a disconnect between the rhetoric of self-management and the actual lived experiences of patients, as they may struggle to meet the demands of the system while also navigating their own complex health needs and social circumstances. By examining the technologies of the self, insights into how power and knowledge are operationalized at the individual level can be formed and can inform relational approaches to patient-centered care, where the voices and experiences of patients are more realistically centered in the construction of healthcare truths and practices. In the contemporary neoliberal world of health care, self-management, in most cases falls short of the system's utopia because of the disconnect between policy rhetoric of self-management and its operational implementation (Brijnath & Anonaides, 2016).

Eventalisation

Foucault's work was directed toward power bases and the political effects on the social body. He uses the terms event and Eventalisation. Foucault describes the concept of 'event' as being more than an occurrence of a noteworthy activity, action or happening, but infers all of the socially important 'diverse shifts' that bring this event into being (Gilson, 2014). Traditionally an event is thought of as a singular causal happening, whereas Foucault describes a shift from 'causality' as a straightforward cause and effect relationship to 'causality' as a set of complex relations and cannot 'be detached from the conditions that give rise to it' (p,146). He describes three dimensions to an event, a metaphysical surface, its logical dimensions and the infinite point of the present, inspired by Deleuze's theory on event formation (Deleuze, 1990), where events can be a cause and/or effect (Gilson, 2014). Foucault uses Eventalisation to refer to the 'procedure of casual multiplication', the analytical process of critically examining historical events not as seemingly ordinary occurrences but made up of multiple factors that contribute to them. He encourages us to discourse commonly held assumptions and uncover the power dynamics, to challenge the traditional view, understand its history and the construction of and contributed to the assumption. In doing so we may see the possibility that exists for change rather than accept that the current state is the only one that can exist (Kusch & Kusch, 1991; Foucault, 1996; Gilson. 2014).

I have lent on the understanding and use of the term Eventalisation in this study to support the description of the Reset and Translational Change Process (chapter five). This process describes the many types of events that precipitate change for the person with CKDMM where multiple factors contribute to the complexity of change. These are constructed by elements that are not only physiological, through the effect of diagnoses and symptom burden, but socially derived through relationships and economically, that all contribute to the dynamic factors driving change and the resulting impacts of that transformation. Eventalisation developed as a core concept in understanding the change process described in chapter five.

Resistance

Foucault describes a form of power through resistance and that where there is power there must be resistance. In comparison to the exploration of Foucault's views on power, there is little examination of his concept of resistance, and what has been examined has differing interpretations and constructions (Heller 1996; Flohr, 2016). Heller (1996) explores how Foucault describes power and resistance through ontologically correlative terms where resistance has the same capacity to create social change as power. This interpretation aligns in how resistance has unfolded in this thesis where resistance is presented on a continuum of power.

I present a process of transformational change influenced by diagnosis, social events and interactions with the health system impacting a person's identity (chapter five). Being perceived as ill, in how you may view yourself, how society and the health system view you changes how you know and identify yourself losing a sense of control and power over your life. Participants describe how they take control or power back seen as acts of resistance. Sites of resistance can be seen in the actions, thoughts, and behaviours (acts of resistance) described in the narrative findings in this thesis, despite the participants stories of loss of control in their lives through the trajectory of disease and power structures exerted within the healthcare system. Power sits within the acts of resistance and becomes the energy of change. In this way it can be described as an agent of change, where the act of discoursing is powerful and promotes transformational change. Power then takes on a more productive role that opposes its negative connotation. Foucault found power to be present in all levels of the societal body and therefore cannot be held by any one person at any level:

> Power traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression (Foucault, 1980, p. 119).

Brink et al. (2023) describe how resistance is a lens to understand adaption, and in this sense, adaption represents transformational change. The vulnerable are often described in the literature as powerless (Barnett, 2020) but a Foucauldian understanding of power believes that it is not only repressive, through discourse, it can be productive where the powerless become powerful. For the participants of this study who initially appear repressed and experience a loss of identity throughout their health journey, if provided the right environment and support systems where policy and practices align, resistance is fostered, they can re-establish themselves and transform their experiences, regaining a sense of power developing the productive self once again (technology of self). Power does not belong to one group or housed within a structure or hierarchy, it cannot be owned or employed but is an agent of opportunity. Heller (1996) in his study of Foucauldian power relations, views power as a facility rather than a thing (p. 84). This aligns with Foucault's view that power cannot be 'owned' and is everywhere:

> (power) is not an institution, and not a structure; neither is it a certain strength we are endowed with ... that power is never localized here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised through netlike organisations (Foucault, 1980, sited in Heller, 1996, p. 84).

What emerged in this thesis was the concept of empowering through these netlike organisations, creating pathways of resistance. As a key concept, resistance and how the health care team can promote this as a contribution to the capillary like social networks (netlike organisations) that surrounds the renal patient, is explored in chapter five and demonstrated through Jody's story of transformational change in chapter six.

Social Ordering and Fairclough

Fairclough is a prominent linguist, who developed the CDA methodology as an extension of Foucault's (1984) work on discourse that is inherent in how society is shaped and the constitution of that society. It involves the understanding of the power relationships between groups and individuals and social constructs (Waller, 2006). Fairclough (2003) was concerned with the relationships between the linguistic properties of text, where he describes text as 'any instance of language in use' (Fairclough, 2003), and the discursive production and interpretation of that text and how these processes related to, and impacted on, social conditioning. Discourse includes social practices or 'moments' of social life. They are represented in two ways: as discursive practices and socio-cultural practices. Discursive practices are actions, interactions, values and desires, beliefs and attitudes, material practices and includes institutional practices (Chouliaraki and Fairclough, 1999). Socio-cultural practices are practices that relate to the wider socio-cultural-political environment or practices that shape institutional structures, systems, and processes (Fairclough, 2003). Social practices influence each other and are represented in three ways: ways of acting (genres), ways or representing (discourse) and ways of being or one's identity (style) (Waller, 2006).

CDA is carried out through three stages that create the dimensions of the analytic process: Descriptive (text analysis), Interpretive (processing analysis) and Explanation (social analysis). These stages are framed through three levels of social cultural practices: personal level, institutional level, and societal level (Fairclough 1995). This framework represents the Orders of Discourse where all elements create reciprocal influence and must consider the multifactorial impacts of these influences for analysis to be meaningful. I have used this framework to analyse the data collected through various methods that will allow interpretation across paradigms utilised for this study. Analysis is structured through Orders of Discourse that allow examination at an individual (micro level), societal (meso) and government (macro) level.

CDA examines the relationship between language, power, and social structures, emphasizing how discourse—understood as both action and text—shapes individual and social realities, ideologies, and power dynamics. Discourse and practices are continuously shaped and reshaped by the interconnected systems of society, institutions, and the regulations imposed by those in power. The way people speak, and act is influenced by societal norms and government strategies. Discourse not only manifests in language but also represents the site of power struggles, often subtle, which Fairclough calls the "power behind the discourse." This means that whenever people engage in communication—whether speaking, listening, reading, or writing—they do so in ways shaped by social forces, which in turn have social consequences. Language operates within social contexts, not merely reflecting social processes and practices but actively participating in them. Power is inherent in all forms of text, language, and action, and the social relationships influenced by discourse help to construct social identities.

Social orders, according to Fairclough, refer to the structured networks of social practices that make up a society or an institution. These practices include ways of acting and interacting, ways of representing the world, and ways of being (identities). Social orders are the organisation of social life, including power relations, roles, and hierarchies within a society or institution. Orders of discourse are the linguistic aspect of social orders. They are the semiotic dimension, focusing on how language and other forms of communication are structured within a society or institution. Key components of orders of discourse include ways of acting and interacting through language, discourses which are ways of representing aspects of the world (e.g., political discourses, medical discourses), and ways of being or identities as they are expressed through language.

Social orders shape and are shaped by orders of discourse. Changes in social orders can lead to changes in orders of discourse, and vice versa. Analysis of orders of discourse can reveal insights about social orders and power relations. Fairclough's approach argues that language use is not neutral but is deeply embedded in social practices and power structures. By analysing orders of discourse, we can uncover how language both reflects and contributes to maintaining or challenging social orders. Understanding these concepts helps in critically analysing how language use in specific contexts relates to broader social structures and power dynamics. By examining the language used in texts and interactions underlying social structures, power relations, and ideologies can be analysed. This involves identifying and interpreting the discourses, and styles within the orders of discourse, and understanding how they relate to the broader social orders. The analysis is both qualitative and interpretive, focusing on how language reflects and shapes social realities (Fairclough, 2001; 2013; Fairclough & Fairclough, 2015).

The work of Foucault and Fairclough offer powerful tools to raise to awareness, how power is embedded and exercised in the health care system, shaping the ways patients must navigate care. Foucault's concepts of power/knowledge and disciplinary structures help us to understand how authority is vested in professional roles, clinical protocols, and institutional routines, which collectively define what is considered valid knowledge and appropriate care, often excluding the patient's voice. CDA assists in identifying how language and discourse within each specialty and department reproduce hierarchical relationships and reinforce fragmented, siloed practices. Together, these approaches uncover how patients, especially those with complex conditions like advanced CKD and ESKD, are positioned within a system that demands negotiation across multiple discursive and institutional boundaries, highlighting the systemic barriers that undermine continuity and coherence in care and the broader socio-political structures that sustain them.

The study context

The context of this study is one regional health centre in New Zealand, and the population are the individuals who are linked into the renal services and who have CKD/ESKD. This study not only has a theoretical framework, but also, an underpinning clinical guidance as well. This allows the study to examine the 'touch points' that individuals have with the healthcare system. Government policies that guide care delivery and stipulate funding rules will therefore be used in analysis as they ultimately affect the everyday healthcare access and decision-making for these patients. I have used blended theories, grounded in critical social theory with interpretative theory to position this study. I have then used a case study approach of a regional hospital level speciality service where the enrolled patients are known to be multimorbid. A clinically focused healthcare model also referred to because they represent clinical frameworks that guide care. This is the Kaiser Permanente Model of Care for Chronic Condition management. The Kaiser Permanente Model sets out an integrated care model for health services to follow (Bellows et al., 2014). Whilst this model is systems focused, with an aim to provide chronic care within existing resources, it does recognise that patient needs are best understood in the context of their personal lives within the environment in which they live (Kanter & Courneya, 2017). Methods of data collection are therefore tailored around both the patient and the service. The patients' voice and their experiences are what is important here, where hospital utilisation and impacts add to complexity to daily life. To make this study credible, I cannot interview patients only, I must add descriptive statistical information which can support the patient voice in the language that health systems understand. That, in itself, lends itself to a Foucauldian lens, because already, the power differential between the health system and the patient is evident. Foucault famously said that he is not a profit, he merely adds a window where there was once a wall.

The key themes discussed in the literature review provide the background focus for the methodology to ensure each step links back to the research questions and aims of the study. The literature suggests a link between multimorbidity and vulnerability and that SDH are important variables, when combined create a concept of multiplicity of vulnerability with an evolving idea that this may be a unique disparity. The presence of these cofactors increases risk associated with not managing and coping with daily life, as represented by deteriorating physical, emotional, and mental health. Ethnicity, culture, and gender are known factors associated with disparity and often coupled with low education and poor social environments. These factors are synonymous with creating inequity in the respect of difficult access into the health system, differing outcomes in disease progression, with morbidity and mortality associated with disease clusters, often overrepresented in these populations. These factors contribute to the 'games of truth' associated with patient experiences, when seeking healthcare where this is often 'hidden in plain sight'. Unravelling these games and understand the interplay of historical social context, behaviour and the challenges faced by patients requires a complex set of measures.

A case study of a single centre is used to combine different methodological approaches necessary to examine the different type of data that captures the discursive nature of this phenomenon. This chapter positions the study and explores the theoretical framework used. It is structured by first describing the research aim and what the research can contribute, supported by the anticipated outcomes from the study. Then focuses on the theoretical framework through a blended critical social and interpretive lens, using critical discourse analysis from the perspective of Foucault and Fairclough. Their work is embedded in understanding power and identify through impacts within social orders from the perspective of the patient (micro-order) through our health systems (meso order) to governmentality (macro order).

My approach to the data collection is undertaken in three stages:

Stage One utilises a yarning methodology through conversational interviews of patients who are receiving treatment at the hospital for ESKD. This group is diverse, from individuals newly diagnosed with ESKD to those who are a path to palliative care. Thematic analysis is used to bring meaning to patient descriptions of the journey they have travelled so far.

Stage Two utilises the same interviewed participants where they have completed two different Quality of Life surveys after being interviewed. Descriptive statistics was used to unpack the findings from surveys.

Stage Three completes data collection through reviewing retrospective hospitalisation data across a 12 month period for the enrolled population of the service utilising descriptive statistical methods to break down this data for meaning. Reporting of analysis for each stage is represented within individual chapters in this three-stage approach continuing the structure from data collection.

I have used a concept map to provide an outline for how the different elements of the research design would link to create a logical flow of methodological steps (Figure 1). Novak and Gowin (1984) describe how "A concept map is a schematic device for representing a set of concept meanings embedded in a framework of propositions" (p.15). This translates well into a useful tool when constructing a research framework to help visualise how the different parts of the research process integrate in a hierarchical fashion and to show how each part supports the framework. This is especially useful in qualitative studies with complex inquiries (Daley, 2004, 2010), of which this study is one. Its complexity is due to the type of inquiry and its reference to a clinical framework utilized to understand the influence of biopolitical power. To describe the methodology, I have used the diagram of each step of the concept map to identify the separate components of the framework where the research position, theoretical perspective, theoretical framework, approach, methods, and analysis are detailed.

The Concept Map

Research aim: The study adopts a multi methodology through a staged approach to map the different truths and power dynamics experienced by a person with CKDMM as they engage with the health system, and how this influences vulnerability and what it means from the viewpoint of disparity and inequity when managing care.

Theoretical perspective: Critical Social Theory

Theoretical framework: Interpretive Sociology Theory – 'Lived Experience'

Approach: Critical Discourse Analysis – Foucault and Fairclough

Context: One regional centre in New Zealand – Hawkes Bay Renal Service

Population: Patients accessing the renal service for CKD/ESKD

Methods: Interviews

Quality of Life survey

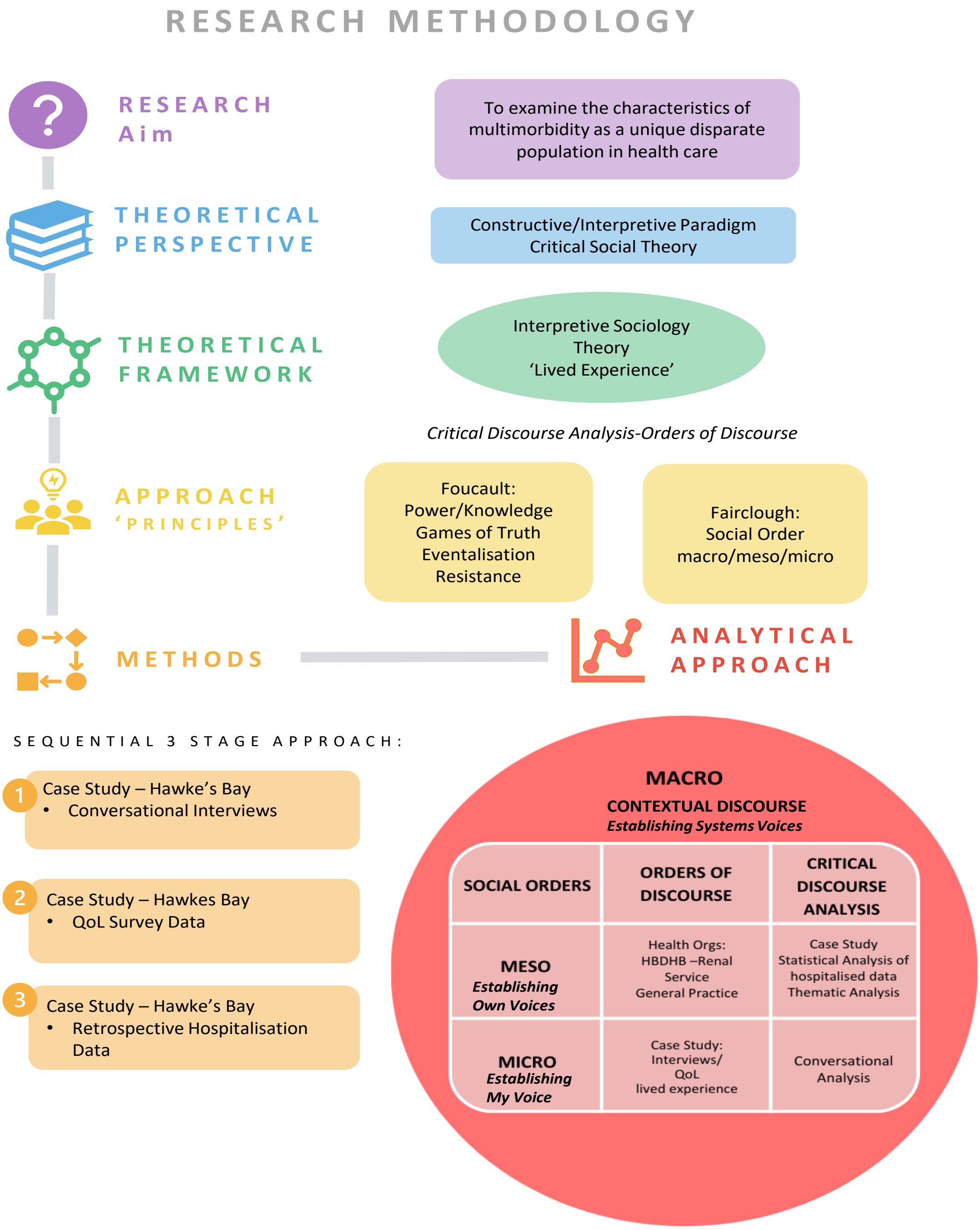
Hospital utilisation data for the renal service

Conceptualising the patient's truth through one patient's journey to health

Analysis: Fairclough's social orders of discourse

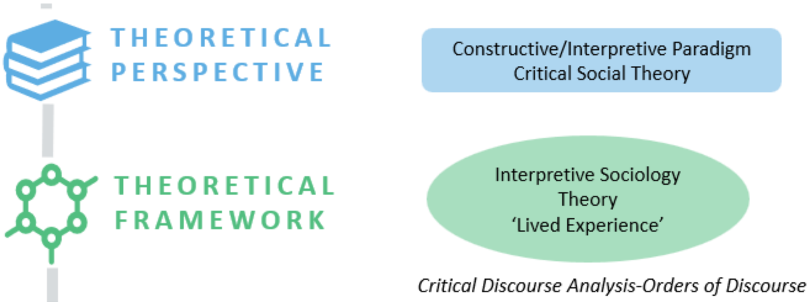
Figure 1

Concept Map of the Research Design



Additional Note: In working through the analysis of data, I amended the analysis structure to include a single patient profile as a mini case study that enabled the focus on micro social order impacts titled 'Establishing My Voice – Acts Of Resistance.' See page 84.

Theoretical Perspective and Framework



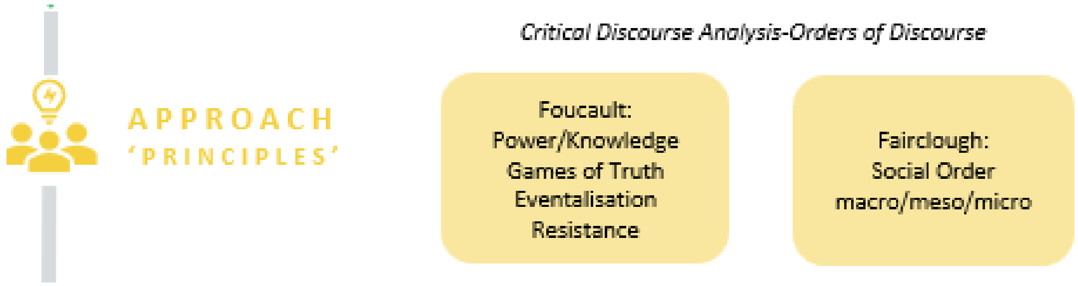
In my approach to conducting this research, I needed to understand the research process itself. The purpose of research is twofold; to fill a knowledge gap or to solve a problem. The reason for research will determine how it will be positioned within the research paradigm. Is there a single reality, and clear relationships between variables, that leads to a deductive approach? Or is the research driven by how and why, with multiple realities, requiring an inductive interpretive approach that requires validation (Patel. S, 2015). Understanding these steps determined the ontological and epistemological stance for this study. Ontology is concerned with the study and acquisition of knowledge. It is a philosophy of the concepts of existence, being, becoming and reality (Crotty, 1998). Epistemology is how this knowledge is gained. It is a belief that knowledge exists, and it is the researcher's role to discover it. Knowledge is developed by people based on perceptions and experiences. It is what a person states it is, and it is concerned with how we know things (Cohen et al., 2007). This study is positioned within the reality of people who have multiple chronic conditions simultaneously through the lens of CKD. Knowledge is of their lived experience and how health care is presented and facilitated for them. They represent multimorbidity.

Examining reality through discourse

To really understand the role of power and knowledge and how it constructs or deconstructs the renal patient seeking out care, Foucault's concept of the power-knowledge nexus provides an insightful framework for unpacking the power dynamics that drive care for individuals with CKDMM, especially within the context of neoliberal healthcare systems, which New Zealand falls under. Guided by commercialisation of health care, the World Bank advocated for reductions in public spending in favour of privatisation. Under this governance, care is focused on cost-cutting and efficiency, with standardised care models that do not adequately address the complex and individualised needs of patients with chronic conditions. Efficiency is prioritised over person-centred care (Nagal et al., 1997; Saunders, 2023). This links to Foucault's biopower and governmentality which regulates populations. As noted in chapter one, renal care is intensive and expensive. Foucault's ideas suggest that the categorisation of multimorbidity as a burden or a set of diseases can reinforce existing power structures, making it difficult for patients to advocate for integrated and person-centered care. The neoliberal emphasis on self-management and individual accountability may further disempower patients, as they are expected to navigate their health challenges largely on their own (Dixon et al., 2023).

Understanding how the patient can be lost to the many voices they have to navigate compounded by progressive and multiplying disease states, means that the patients' voice and their experiences are what is important here. To collect information on this, Fairclough's approach to critical discourse analysis was chosen. This approach aligns well with the Foucauldian perspective and can offer valuable insights into the power dynamics at play in healthcare systems. This multi-level analysis offers examination of how broader societal discourses and power structures (macro-level) influence institutional practices (meso-level), which in turn shape individual experiences and interactions (micro-level). It would also help us identify how discourses at the micro-level might resist or transform practices and structures at higher levels.

Approach: Critical Discourse Analysis



The population in this study, is known to be vulnerable and impacted negatively by SDH, politics and healthcare governance decisions creating power struggles. CDA is used to understand the truths that exist and how these feed into the 'games of truth' to then understand how this influences the patient journey as they navigate their healthcare needs. Having chronic health conditions changes the way you perceive yourself and your position in society. You may have had to give up employment and are financially dependent on a social support system. How society then sees you, can change, how the health systems view you, can change. Therefore, the power influences are not only through an individual's perception but through society norms as well. CDA and Orders of Discourse is a methodology that relates to this population group. It is an extension of Critical Theory that aims to understand structural relationships of dominance, discrimination, power, and control manifested through language. It is an approach to investigate inequities, marginalisation, and social injustice as it is expressed and legitimised (Waller, 2006). Choulairaki and Fairclough (1999) explain how CDA can be used to bring about transformation in the lives of the disempowered and less privileged.

It is necessary to understand social reality and social practices that occur within and between the micro, meso and macro levels. Examples of how this may be structured can be seen in individual, societal or regional health system level to governmental mandates and practices. Analysis must consider all three levels and appreciate that influence and impact, oscillate within and between these levels. This methodology is guided by two prominent CDA theorists, Michel Foucault and Norman Fairclough. Fairclough's model of CDA (1995) provided the framework to guide the analysis for this work.

Discourse and practices are constantly shaped and reshaped by the interwoven systems of society, institutions, and the regulations enacted by those in positions of power. The ways in which people speak, and act are influenced by societal norms, institutional structures, and government strategies. Discourse extends beyond language, it is also a site of power struggles, often subtle and implicit, which Fairclough describes as the "power behind the discourse." This means that every act of communication—whether speaking, listening, reading, or writing, is shaped by underlying social forces, which in turn have tangible social consequences. Language not only reflects social processes and practices but also actively contributes to shaping them. Power is embedded in all forms of language, text, and action, and discourse plays a critical role in constructing social identities and relationships.

Fairclough's Critical Discourse Analysis (CDA) enables researchers to examine how power operates within society across three levels: micro, meso, and macro, thus aligning with the nested systems framework described by Woolcott et al. (2019). In this study, the experiences of people living with chronic conditions are analysed through these three levels of social order. I use the concept of voices to represent the discursive dynamics within the healthcare system. Multiple voices shape the journey of a person with CKDMM; however, this study is centred on the often-silenced or lost voice of the patient. The findings will help to highlight how dominant voices tied to institutional discourse tend to overshadow the patient's perspective. From a social orders perspective, the macro level encompasses hospital governance and government policy, the meso level reflects collective patient experiences and shared narratives, and the micro level represents the individual patient's personal journey and moments of transformational change.

The Methods used in this research are now described.

Macro level – this explores the biopolitical environment and the influence of governmentality within the current healthcare structure and establishes the voice of the system. Hospital data includes frequency of attendance, emergency admissions, length of stay and outpatient attendance. These measures are routinely used in assessing the 'non-compliance' of a patient, the idea being to keep them out of hospital and being cared for in the community. This method explores institutional policies, guidelines, and communication which reflect the broader discourses and ideologies within the hospital system.

Meso level – This level draws on interviews with participants whose voices are representative of the broader cohort within the renal service, alongside analysis of wellness measures and quality of life survey data. Together, these sources provide insight into the subjective experiences and perceptions of patients. This level reveals how social orders and power dynamics are enacted in everyday interactions and how they influence the lived experience of care. It also examines how patients engage in technologies of the self, strategies of self-regulation and adaptation, as they navigate the health system and seek to have their needs recognised and met.

Micro level – this profiles a single patient voice from the larger cohort that demonstrates how Eventalisation, technology of self and resistance is experienced through a new process of transformational change derived from the understandings gained from analysis, allowing him to reposition himself and regain his individual personal power.

Fairclough's situational context approach is useful in the analysis for such information. It helps to draw connections between individual experiences, institutional practices, and broader societal factors, offering a rich and nuanced understanding of the complex dynamics at play in a neoliberal hospital system. It allows for the analysis of individual experiences in relation to how they are shaped by institutional practices and broader societal factors. How power is exercised at various levels and how it affects people with chronic conditions assist in uncovering how power manifests in language and practices across all levels and helps to understand the interconnections between the levels and how they are influences across and between the levels of social order. The following questions guide analysis (Fairclough, 2001):

1) What's going on? (content)
2) Who's involved? (subject)
3) In what relations? (relational)
4) What's the role of language in what's going on? (connections)

Integrating a Foucauldian lens

The integration of Michel Foucault's ideas with Norman Fairclough's Critical Discourse Analysis (CDA) offers a powerful framework for examining the complex interplay of language, power, and social practices. Foucault was known for his reluctance to prescribe a specific methodology for applying his concepts. But, on more than one occasion, described his work as a "toolbox" of ideas and as flexible and adaptable thereby encouraging the use of his ideas as analytical tools rather than rigid theoretical constructs.

> I would like my books to be a kind of tool-box which others can rummage through to find a tool which they can use however they wish in their own area... I would like the little volume that I want to write on disciplinary systems to be useful to an educator, a warden, a magistrate, a conscientious objector. I don't write for an audience, I write for users, not readers (O'farrell, 2005, pp 50)

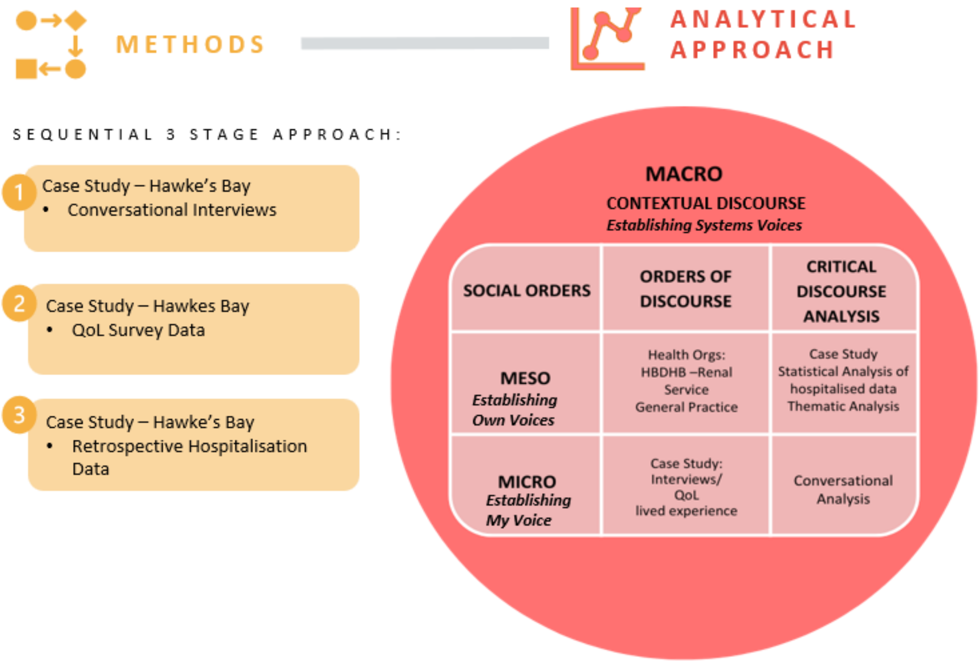
The integration of Foucault's theoretical insights with Fairclough's CDA offers a flexible and powerful approach for examining discourse in healthcare and other social contexts. This combination allows researchers to draw on Foucault's conceptualisation of discourse, power, and social structures, while applying Fairclough's more structured methodological framework to operationalise these ideas in empirical analysis. Fairclough's concept of social orders is particularly valuable, providing a lens through which CDA can be applied across micro, meso, and macro levels of social interaction. This multi-level framework aligns well with Foucault's emphasis on the interconnection between discourse and the institutional mechanisms through which power operates. It enables the analysis of healthcare discourse at multiple levels, from individual patient-provider encounters to the broader societal and policy narratives surrounding health and illness.

This integration offers several advantages because it bridges abstract theoretical concepts with concrete analytical practice, and it provides a critical perspective to expose and challenge the power relations embedded in discourse, revealing how dominant narratives can perpetuate structural inequities and marginalise particular groups.

This analytical approach is clearly demonstrated in the case of ‘Mr CKD,’ described in Chapter One, whose experience involved multiple health service encounters driven by unmet needs, leading to labelling as ‘non-compliant,’ fragmented care planning, and disjointed communication with healthcare providers. Through Foucault’s concept of Games of Truth, the study seeks to understand how participants’ truths are constructed, legitimised, and maintained—while identifying where moments of resistance emerge in relation to the governing power structures of the health system. This perspective highlights how discourse and power relations shape individuals’ sense of self and influence their identities as people living with complex, multimorbid CKD navigate their illness trajectories.

Foucault offers a conceptual foundation to explore how governmentality operates through both institutional systems and interpersonal interactions, while Fairclough’s CDA provides the analytical tools to examine how these power dynamics are enacted across the social orders, shaped by the orders of discourse. This approach situates the analysis within its social and institutional context, where the primary actors include the health system, guided by government policy, health professionals who exert power through local practice, and the patient with advancing CKD to ESKD, who remains dependent on care within a system that often renders their voice inaudible. The blending of Foucault and Fairclough’s frameworks provides a powerful lens through which to explore the complexity of this landscape—revealing how patient voices are frequently lost amid the noise of the system yet also showing where those voices might begin to be reclaimed.

Method and Analysis:



SOCIAL ORDERS	ORDERS OF DISCOURSE	CRITICAL DISCOURSE ANALYSIS
MESO ***Establishing Own Voices***	Health Orgs: HBDHB –Renal Service General Practice	Case Study Statistical Analysis of hospitalised data Thematic Analysis
MICRO ***Establishing My Voice***	Case Study: Interviews/ QoL lived experience	Conversational Analysis

A triadic multimethod analysis

This section details the structure for data collection and analysis using a three staged approach. The data is represented through a case study of the renal service, where justification in using this approach is explored first, followed by the methods of data collection and analysis. This chapter is completed with discussion around the population cohort and the consideration of ethical impact.

The Case Study Approach

This study adopts an embedded single-case study design, with the central case bounded by the experience of individuals living with complex multimorbid chronic kidney disease (CKDMM) within the New Zealand healthcare system. Multiple units of analysis are examined across macro, meso, and micro levels, allowing a rich and layered exploration of the discursive practices and power dynamics that shape care experiences and patient identity. Anchored in Foucauldian theory and CDA, the case study design provides a flexible yet structured approach to analyse how social orders and orders of discourse manifest across institutional systems, collective narratives, and individual stories.

The ‘case’ under examination is profiled through a secondary care hospital level cohort of patients enrolled in the Renal Service of Hawkes Bay, New Zealand. A case study is a research methodology that allows an in-depth exploration of real-life issues in real life settings within a bounded context (Alpi & Evans, 2019). The bounded context in this case study is the HB population who have CKDMM and are receiving care from a renal service in a regional area of New Zealand. By using this population group, the intention is to identify elements that signal people living with multimorbidity are vulnerable and to understand if people with MM can be considered a uniquely disparate population group. Case studies allow researchers to explore the discursive construction of subjectivity, and social organisation and how these are legitimised and accepted (Jansson, 2014). Case study methodology allows for data to be gathered in a variety of ways that helped to broaden findings and enable validation of data through triangulation across a diverse of data collection points. According to Yin (2009) and Crowe et al. (2011), case studies are particularly useful when there is a need to understand causal links and pathways where several variables exist.

The use of a case study is not universally defined by researchers. As a result, confusion surrounds what constitutes a case study and how it is employed. Yazan (2015) reviewed and compared the approaches of three prominent methodologists in case study methodology to gain clarity for his own work as an emerging researcher. He describes Yin (2009), Stake (1995) and Merriam (1998) as prominent fundamentalists who each have differing views on the definition, design and implementation of case study research but agree that data collection must come from multiple sources to capture ‘the case’ (Yazan, 2015). Stake (1995) and Merriam (1998) maintain a constructivism epistemological viewpoint grounded in qualitative research design where reality is constructed by the individual’s interaction with her or his world. This allows for multiple interpretations but with distinct boundaries guided by the research purpose.

Stake also defines case studies as coming from a social constructivism epistemology, describing a case as a single entity that is either ‘instrumental’, where the issue is dominant, or ‘intrinsic’. Merriam positions case study within a bounded phenomenon that could be a person, group, or policy, with the flexibility of a wider use of cases. Both advocate qualitative research methods. Yin (2005), by comparison, follows a positivist epistemological view, in which knowledge is accepted as established facts to be verified by real life experiences. He does not draw a distinction between qualitative or quantitative approaches but advocates the use of triangulation, with evidence drawn from multiple variables rather than discrete data points and describes this as a multiple embedded design (Yazan, 2015). The epistemological view underpinning my research tends more toward Stake's (1995) constructivism approach using the service as a single case study using multiple instruments embedded in the design where the dominant issue is multimorbidity.

In this study, triangulation of both qualitative and quantitative data was used. The case under study is a health care service that is bound by the experiences of patients with multiple morbidities, with ESKD as the commonality among the HB patient participants. As I was working through the analysis from a social orders perspective, I included a mini case study of a young man from the renal service patient cohort to profile the impact of multimorbidity and systems influence from a social orders perspective, how the games of truth impact at a micro level and how models of care can help shape how life is lived. This is captured under the focus of conceptualising the patient's truth through one patient's journey to health. The project of this case came about as part of learnings from the study and occurred at the same time as the body of data was collected.

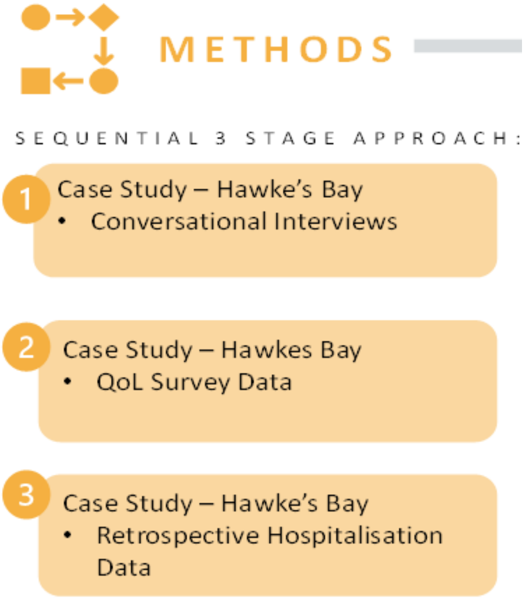
Methods

Wisdom and Creswell (2013) describe how using different techniques in gathering data provides a comprehensive synergistic approach that produces rich data. It is particularly useful for understanding complex interventions or where one methodology can be used to validate another, for example, qualitative data that reflects a participant's view can validate quantitative findings. Single method approaches have their disadvantages. Qualitative methods have been criticised for lacking objectivity and generalisability, whereas quantitative methods have been criticised for lacking the participant's voice and real world view (Creswell & Plano Clark, 2007). Creswell and Plano Clark (2007) explain that combining both methods in the one study addresses these issues and has the advantage of utilising the strengths of both approaches. Bazeley (2023) identified that when multi methods are used, each component and dataset can stand alone and make an independent contribution to how the research questions are answered but importantly complement each other in doing so. Obtaining data through multi methods is also known as triangulation of data, multiple sources of data that can be used to cross check (Pinto, 2012). This is where the findings of one method are checked against the findings of another. The advantages gained by this approach are described by Hastings (2012) as being essential in establishing collaborating evidence from multiple sources and contexts that enriches understanding of the research question. The difference in using a multi method over a mixed method is in how the data is integrated. Multi method gathers data independently of each data set and presents them in that fashion (Baseley, 2009). Therefore, the analysis section of this Thesis has been presented within distinct chapters representing the data gathered and presented in the discussion chapter as a blending of interpretations where the findings support the purpose to do so.

The collection of quantitative data helped to identify the impacts of illness created by multimorbidity and the need for elevated levels of care through hospital contact and identified the causal link with interacting variables. But only using quantitative means would provide only a one-dimensional answer and would not help to understand the experiences of patients and what it means to them. Talking to the participants, enabled their experiences to be better understood in their own words. Qualitative data helped explore the relationships that existed between variables (Pinto, 2012).

Researchers caution that there are challenges in using a multi or mixed method approach to research. It requires a multidisciplinary team to gather data, the process is time consuming as well as producing complexity in evaluation (Wisdom & Creswell, 2013). This caution is shared by McKim (2017) who states that mixed method (similarly, multi method) approaches require additional time, funding, and resources. The researcher needs to understand both qualitative and quantitative methodologies. It is therefore important to understand the value of this approach to the study and to ensure the perceived benefit outweighs what single approaches can achieve. This study involves vulnerable people who experienced difficulties that create emotion and had the potential to impact objectivity. These vulnerable populations are also multi-cultural therefore it is equally important the participants' perspective was profiled to understand what the effects of multimorbidity are from a cultural point of view. Due to cultural differences, there is a risk that meanings could be misunderstood. Quantitative methods provided additional comprehension in support of the interpretation of the qualitative data, bringing a structured and controlled perspective that helped increase the reliability of results, improve generalisation of findings, and enhanced credibility of the study.

Staged Approach to Data Collection



Data was collected in a sequential, three-stage approach within a Case Study perspective. Data were derived from three main sources where the data was obtained from the HBDHB Renal Service in Hawke's Bay, New Zealand. This PhD study was included as a sub study of the primary research in the Queensland Nurse Navigator Program had previously been collected as part of a bigger research project. It was initially thought that the smaller Case Study population of New Zealand may not be big enough to provide convincing data and would be strengthened by utilising the data set of a bigger trans-Tasman project. This had ethics approval to do so. Following data collection, and utilising the CDA process, it was found that the HB Case Study data was incredibly rich and was able to stand alone. Therefore, the NN Program data was able to be used to support the findings of the HB Case study data rather than as comparison.

Employing a staged approach helped to define the collection of data from different sources. A variety of techniques was used to obtain data at each stage.

Stage One

Data collection for this study occurred over a three-year period, with retrospective hospitalisation data gathered between 2019 and 2020, and interviews conducted in 2022. The onset of the COVID-19 pandemic in New Zealand in February 2020 coincided with the early stages of this PhD study and significantly impacted participant recruitment for interviews. A nationwide lockdown was implemented, resulting in substantial changes to healthcare delivery, including the adoption of minimal physical contact protocols across services. The Hawke's Bay Renal Service adhered to these measures, further delaying in-person data collection. By May 2022, following the most severe waves of the pandemic, national restrictions began to ease and face-to-face engagement with patients resumed.

Mapping the Characteristics of the Population Group - Micro and Meso Level

Mapping the characteristics of the population group at both the micro and meso levels is a critical step in understanding how broader social determinants of health (SDH) contribute to the vulnerability, health engagement, and identity formation of individuals living with chronic kidney disease and multimorbidity (CKDMM). These mapped characteristics provide a foundation for situating participants within their social, geographical, and economic contexts, offering insights into how structural inequities and individual experiences intersect in shaping healthcare journeys.

At the micro level, attention is directed toward the individual profile of a key participant, whose experiences are analysed in detail to demonstrate how health system engagement, resistance, and transformation unfold through discourse. This level provides insight into personal narratives, revealing how positionality and technologies of self are enacted in response to systemic conditions.

At the meso level, the characteristics of the broader cohort group were mapped to identify common patterns and positional factors that influence healthcare interactions. Key demographic variables such as ethnicity, age, gender, employment status, and area-level deprivation (using decile and quintile codes of residence) were analysed to build a collective profile of the group. These characteristics, explored further in chapter five, reflect important elements of social ordering and collective knowledge, contributing to an understanding of how structural disadvantage operates within the healthcare system. As noted by Alcoff (1988), positionality helps to construct social realities and identities, while Takacs (2003) highlights the value of lived experience in shaping collective knowledge.

Incorporating wellness measures and quality of life survey data further supports this meso-level understanding, capturing participants' self-perceived wellbeing alongside their demographic and social contexts. These elements help tell the story of the cohort as a whole, contextualising the discursive environments in which healthcare is navigated and experienced.

Mapping the characteristics of the larger cohort population helps to tell the story of this group. It situates the social context in which participants' narratives and interactions take place. Mapping the cohort's characteristics is a necessary first step to identifying the structural and discursive conditions that influence power dynamics, access to care, and identity formation. SDH contribute to vulnerability as identified in the literature review. Therefore, understanding the characteristics that form part of the SDH of the group, constructs their social realities and therefore contribute to their social identities through geographical, demographic, and social economic knowledge that informs their positionality (Alcoff, 1988). These characteristics help shape knowledge of how the participants engage in the world, in this case health care. Takacs (2003) describes the importance of individuals' knowledge through life experience as contributing to collective knowledge. Therefore, a profile of the cohort group adds to the collective knowledge of characteristics of multimorbidity. The characteristics that were mapped in this study included ethnicity, age, gender, and decile (and quintile) code of residence mapped in chapter five.

Background characteristics were also mapped for the interviewed participants that included employment status as well. This profile supports the later critical analysis by helping to contextualise the voices that emerge in the micro and meso levels of this study, anchoring them within the broader macro-level structures of power, discourse, and institutional practice.

Conversational Interviews Dataset – Meso Level

Conversational interview data came from 18 participants enrolled within the HB Renal Service. To assist the conversational way of interviewing, a Yarning methodology was used (Geia, et al., 2013), through the concept of 'Hui', to gain a perspective of their experiences. Within qualitative research, different types of interviewing methodologies are used dependant on the purpose and type of inquiry, research question, and the who the participants are being interviewed. Examples of types of interviewing techniques include, semi structured interviews where lead in questions are used and allows the participant to explore in their own way and is considered more flexible; structured interviews that explore information in a more prescriptive way and does not allow for flexibility, focus group interviews that generate a group discussion and sharing of information, ideas, experiences; in-depth interviews that tend to focus on a specific theme where detailed experiences are encouraged; ethnographic interviews where the participants natural environment is a key component and the interviewee decides what it is they will share (Westby et al., 2003; Brounéus, 2011; Adhabi & Anozie, 2017). Yarning methodologies differ in that it is a specific cultural way of exploring a lived experience. Leeson et al. (2016) describe 'Yarning' as a culturally respectful data collection tool to gain the lived experience used with Aboriginal and Torres Strait Islander peoples and is essentially a way to 'tell a story'. It can be defined as a cultural conversation where relationships to each other and identity to country and culture are important connections. Lesson et al. describes how Yarning creates a 'telling space', that is a safe place to impart traditional cultural knowledge, where the person telling the story retains ownership and are seen as the authority of that knowledge.

The researcher's role is then of 'learner', through listening to their stories and memories. This approach has been particularly supportive of conducting health research within communities where storytelling in the indigenous way, creates respectful relationships and collaboration, allowing people to tell their story in their own time and in their own way, to ensure better outcomes for Indigenous People (Geia et al., 2013; Walker et al., 2014; Leeson et al., 2016). This closely aligns to the traditional Māori way of passing on history and meaning, where 'Hui' is a way of bringing people together to share that space, applying traditional principles of "greeting, introducing, starting a relationship and closure of an encounter" (Lacey et al., 2011, p.73). The use of Hui is an important aspect of communication within Māori culture and a culturally appropriate way to engage with Māori (O'Sullivan & Mills, 2009). This method has been successfully used in the education of healthcare students, to help students develop the concept of trust in a culturally safe way (Lacey et al., 2011; Minton et al., 2022). In keeping with a Kaupapa perspective, the research assistant that conducted the participant interviews for this study, identifies as Māori and in this way enabled conversation, where the concept of 'with Māori and by Māori' was upheld.

One of the key drivers for this research was to understand the 'lived experience' that would contribute primary knowledge to identify the characteristics of Multimorbidity. This study is grounded in an Interpretive, Critical Social theoretical perspective. Understanding social constructs and what influences these, are key components in understanding power relationships, who it effects most and what contributes to inequity. Incorporating the experiences of others has other benefits where it helps to develop depth of knowledge on a topic. Beames et al. (2021), explored integrating the lived experience into scientific data synthesis studies, and concluded in how it adds a richness of knowledge, improving treatment plans that align with the people who can benefit most. This richness shapes inquiry and lends a level of endorsement by the people who matter most.

Narrative inquiry is also key to research with and for Indigenous People who make up a significant part of the cohort in this study. The ability to tell their own stories, to participate and to describe what has happened to them, in their way through their own voice's aids in "unburdening themselves of deeply embedded historic trauma and loss" (Wesley-Esquimaux, 2010, p. 53). Wesley-Esquimaux (2010) also describes this as undertaking in a cultural respect, the employment of a Māori approach to research referred to as 'Kaupapa Korero', (where Kaupapa means Māori world view and Korero means conversations), is a way of honouring the oral traditional approach of Māori as an Indigenous People, used as a way of passing on knowledge and honouring customary practices (Ware, et al., 2017). Main themes in this study describe the trauma and loss, not only for the Indigenous People who have experienced this but all of the participants who have engaged in this study. Multimorbidity in some respect is about trauma and loss and the best way to understand how these issues effect the participants who are representative of people with multimorbidity, is to ask them. Therefore, interviews are used here as the guiding method for gathering data to understand these perspectives.

Patients who were enrolled within the Renal Service Case Study Cohort were invited to participate, resulting in eighteen participants volunteering to be interviewed who became the 'voice' of this study. The interviewed participants were also represented in the larger cohort group. The study data was collected over a period of three years where retrospective hospitalisation data was collected in 2019-2020, and interviews occurred in 2022. The arrival of the COVID pandemic in NZ, in February 2020, caused a delay in the ability to recruit participants for interview. The country in its entirety went into a national lockdown altering how healthcare was delivered. Health services employed physical contact avoidance with patients as much as possible, of which the HB Renal Service also followed this. By May 2022, NZ was through the worse of the first and second waves of COVID and covid rules began to change, including physical interaction with patients. At this point in time, patients in the HB group of the research were invited to participate in a conversational interview in keeping with the Kaupapa Māori and Yarning methodology (Geia et al., 2013; Jackson, 2015). Interview data was obtained from participants who were invited using the Participant Information and Consent form (Appendix Four). At the time all interviewees were enrolled in the Regional Renal Service and knew of the study from the advertisement flyer in the clinic waiting room.

The interviews were conducted by a colleague of mine that was independent of the research but who also works with comorbid populations and understands the patient population. I elected to not conduct the interviews myself after receiving feedback from the Central Queensland University Ethics Committee and the NZ Health and Disability Ethics Committee, around the potential for bias and an imbalance in power relationships, having provided care to the renal population group for 25 years and therefore I was likely to have a long term relationship with many potential participants. I decided it would be beneficial to the research to remove the possibility this may occur and asked a colleague who identifies as Māori and is conversant in chronic care management, to conduct the interviews for me. My colleague also had research interviewing experience and was knowledgeable around the interviewing process. The interviewer also identifies as Māori.

I believed this would then be respectful to a Kaupapa Māori approach to research in meeting the goal of research with Māori people that is for Māori, with Māori and by Māori. The service I work in has a high percentage of Māori patients and I anticipated many of the participants may identify as Māori. This did occur, where 10 of the 18 interviewed participants identify as Māori also.

I developed semi structured and open-ended questions to help enable the conversation (Appendix Four). This also provided the interviewer with an indication of areas that I was interested in exploring further as these topics came up in conversation. As part of preparation for the interviews, the interviewer met with me and was provided with an outline of the aims of the research and research questions to become familiar with the semi-structured interview questions. Some direction was provided around potential discussion points that would be of interest to explore further. These related to what it was like living with multiple medical conditions and vulnerabilities that emerged from the Literature Review. These included SDH (employment, finances, schooling, living situations etc) culture, community, and whānau relationships, relationships and experiences of the health teams they have interacted with, as well as feelings evoked by health, happiness, sadness, depression and frustrations. Interviewees were also asked what actions by the health teams made daily living better or worse and or what could health professionals do differently. The interviewee was then able to take the discussion where they wished and in doing so talked about experiences that were important to them in relation to the questions. Interviews took place in a setting chosen by the participants in either their own homes or within a quiet room linked to the renal service clinic facility, with one interview conducted by Zoom as the participant's choice. Interviews were between 57mins to 147mins long. There was no time limit on any questions or length of interviews and interviewees were encouraged to talk freely in keeping with the Yarning and Conversational methodologies.

Stage Two: Quality of Life and Wellbeing Surveys – Micro and Meso Level

Data derived from wellbeing surveys utilised the Meke Meter (Forrest et al., 2016) and Flanagan's Quality of Life (QoL) survey (Burckhardt & Anderson, 2003). This data was collected during 2022, and participants were asked to complete these surveys following their interview. There is significant research on the quality of life for people who have Chronic Conditions. Themes from the interviews suggest that the more conditions you have, the more challenging life becomes, and the more difficult it is to balance disease progression, symptom control and to pursue the goals a person may have in life. However, it is the development of complexity in a patient's everyday experiences that is the true challenge. As described in the participants interviews, living with multimorbidity creates that challenge. How a person views their day, and their life is a very subjective measure and is meaningful in the context of a person's experiences. This individual knowledge adds meaning to the collective results. Two Quality of Life (QoL) surveys, the Meke Meter and the Flanagan's Quality of Life Scale, were used to gain an impression of how QoL is viewed and what aspects are rated highly or poorly, by the participants. This provides meaningful data around what is working well for them in relation to the healthcare environment and societal systems, but importantly, what is not working well for them, suggesting gaps exist.

Quality of Life surveys (QoL) offer a glimpse into a person's 'everyday'. They help us understand what is meaningful and can offer a way to identify where change may need to occur to improve how life is lived. As modern-day medicine has found ways to treat different diseases and conditions, life expectancy has improved where people are living longer with chronic conditions. But this is not the case for people who have developed multimorbidity. There is a negative association between life expectancy with each comorbid condition a person develops (DuGoff et al., 2014; Laditka & Laditka, 2016).

The use of validated QoL surveys within the health field have become a popular way to measure the effectiveness of health care plans through how life is experienced. Haraldstad et al (2019) conducted a systematic review of QoL research in the medical and health environments that included 163 studies on the measurement of QoL, in both generic and condition specific studies. They found that QoL surveys hold prognostic importance that help identify problems, gain an understanding of the effectiveness of treatment, and inform broader management plans. Doward et al (2004) discusses the elements that support a useful QoL survey used within clinical research. These elements include theoretical validity; are replicable and reliable; have internal consistency where what is measured has inter-relatability within the construct they are applied; have relevance to the person/people it is being applied to; responsive in that it is able to detect real change over time; practical, easy to answer and administer, and be culturally sensitive or able to be adapted within a cultural context. Both the Flannagan's QoL Scale (Burckhardt & Anderson, 2003) and Meke Meter (Forrest et al., 2016) have been validated and applied within different contexts of health. They were the survey tools that were best available to provide an understanding of how participants would rate everyday life. The Meke Meter in particular, was validated within a Māori specific culture and made adaptable when applied to the Torres Strait community as part of the Nurse Navigator program evaluation in Queensland (Harvey et al., 2021a). The use of the Meke Meter was important to include in this study, as part of acknowledgement to Kaupapa Māori perspectives using a tool developed by and specifically for, Māori.

Significant keywords within this case study include well-being, mental health, and socioemotional connections. These keywords and concepts are present within the major themes of this study suggesting they are important to the participants and hold value as part of their QoL. The definition of 'wellbeing' is an encompassing term that best aligns with this thesis topic. It has been described by the Mental Health Foundation of NZ as having an holistic approach that also includes environment, support and the resources a person has that enables them to live the life they feel is worthwhile, "we have the tools, support and the environment we need to be who we are and to build and sustain lives worth living" (Mental Health Foundation of New Zealand, 2023, *what is wellbeing*). The WHO (2001) include wellbeing in their definition of mental health, "Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community" (p. 1). Socioemotional connection relates to our sense of self and our perception of others' reactions to us, including dimensions such as identity, sense of belonging and emotions associated with interactions, such as trust, fear, and respect (Delahunty et al., 2014). Collectively these concepts are represented under the umbrella term of 'wellbeing'.

It is important to note here that Indigenous People do not necessarily subscribe to the concept of 'mental health', as being a separate entity from the rest of their existence. Sutherland and Adams (2019) in their exploration of social and emotional wellbeing from an Indigenous perspective, describe how Indigenous Canadians, Aborigine and Māori cultures do not use the term 'mental', but rather use wellbeing in a holistic way, that includes balance in socio emotional, physical, mental and environmental aspects as making up 'wellbeing'. They refer to the concept of 'mental health' as a Eurocentric term, not used by Indigenous People. In this perspective one key concept does not exist without the others. In this thesis the QoL surveys are used to understand the broader concept of wellbeing as defined here. The participants' level of wellbeing was analysed using the statistical scores from the Flanagan's and Meke Meter QoL datasets. Participants were asked to complete both surveys at the same time as, and following their interview. This was important to ensure how they were feeling on that day was applied to both surveys and within that moment in time.

Stage Three: Retrospective Hospitalisation Data –Macro Level

De-identified retrospective hospitalisation data was obtained for all people enrolled in the HB Renal Service, over one year from January 2019 to January 2020. This time period was selected to avoid the COVID years of 2020 to 2023, where admission data would be skewed due to the COVID rules during this period. Data measures included Emergency Department (ED) visits with allocated Triage codes, hospital admissions bed days, classification of body systems involvement of admitted patients as a measure of the number Chronic Conditions per person; discharge data from ED and hospital stay; and demographic data in including ethnicity, age, and domicile residence by decile code.

This thesis is embedded in multimorbidity as a broader topic within the field of health care. As explored earlier, there is a growing trend of people presenting with an increasing number of comorbidities once they develop a chronic condition. There is also a recognised pattern of combined conditions derived from a similar aetiology, where they are seen to cluster together adding to the multimorbidity count i.e. diabetes, hypertension and heart disease (Academy of Medical Science, 2018; Robertson et al., 2022). This study seeks to understand more about this population group and to identify if they can be considered a unique disparate group. Part of understanding this, lies in the need for elevated levels of care for these people such as hospital service utilisation. There is evidence that as the number of comorbid conditions increase, so does their usage of acute care services such as Emergency Department presentations and hospital admissions (Gruneir et al., 2016; McPhail, 2016; Academy of Medical Sciences, 2018).

In reviewing multimorbidity, this is important to understand as it provides evidence of prevalence and incidence, as well as trends and patterns of disease states but healthcare utilisation and optimisation of care. It can be suggested that increased presentations to hospital imply deterioration in disease states, increased symptom burden and potential missed opportunities for care at a primary and community care level. Witham et al (2023) in their review of the care of people in hospital with multimorbidity suggest this group "constitute a distinct and select subgroup of people…. they are by definition, unwell enough to require hospital admission" (p.765).

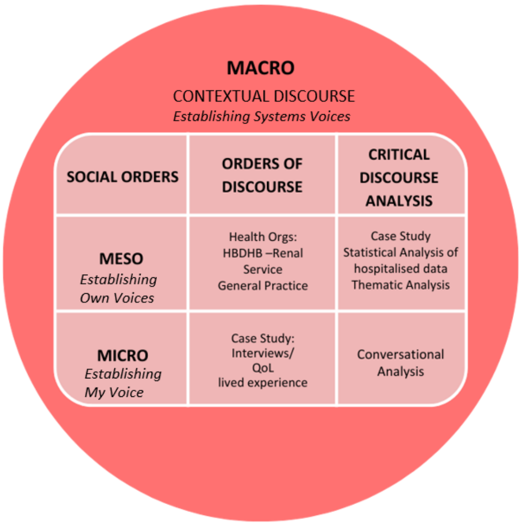
There is increased emphasis by healthcare systems internationally, on hospital avoidance to contain healthcare costs (Harvey et al., 2017; Harvey et al., 2019). This is true of the NZ healthcare system also where funding and care access is focused on avoidable hospitalisations (Ministry of Health, 2020; McGeoch et al., 2019; Vaithianathan et al., 2012). Understanding the impact multimorbidity has on hospital utilisation rates also helps us to understand what might contribute to risk, such as are the demographic, ethnic and or age disparities that contribute to risk in this group. This data also helps us to understand what may be needed within the healthcare system to achieve effective care and contribute to system design and policy development for this population group. Ultimately this data set contributes to what is known about the characteristics of multimorbidity through the lens of CKDMM.

The retrospective hospitalisation data collected for this thesis extends the description of the renal cohort group as presented in chapter four and provides a breakdown of the data in what was found to be meaningful in respect of contributing to risk for deterioration and hospitalisation. A description of the data explores ED presentations, triage codes (score that indicates priority for review), discharge from ED separate from those who are admitted and the impact on admission as measured by number of days in hospital and length of stay. The data was collected with the help of the Business Analysts employed by the regional secondary care health provider, at the time known as Hawkes Bay District Health Board. Since starting this study, the NZ health system has restructured and the secondary care sector is now known as Te Whatu Ora, with the Hawke's Bay region health system now being part of the national system, known as Te Whatu Ora Te Matau a Maui. The data collection was enabled as part of the regional localities, ethics approval process. It was retrieved from the hospital level patient management system. Patients were identified by a NZ unique patient identifier number, known as the National Health Index number (NHI) that is person specific and allocated to every person who presents for care in the NZ health system, or allocated at birth (Te Whatu Ora, 2023). The NHI number also needed to correlate with enrolment with the Renal Service. A person's NHI number enables tracking through different processes used with in the NZ health system wherever care is encountered. Hospital systems in NZ use the International Classification of Diseases - 10th Revision (ICD-10) to capture and code disease presentations (International Statistical Classification of Diseases and Related Health Problems, 2016). This is an internationally applied coding system managed by the World Health Organisation, that provides a uniform approach to tracking disease and was originally designed to understand causes of mortality and now also tracks morbidity (Hirsch et al., 2016).

In capturing multimorbidity as a measure of chronic diseases, the hospitalisation data represented in this study is based on a body system count rather than individual chronic conditions. Within hospital systems, ICD-10 categorises chronic disease or conditions through chapters and by effects on body systems rather than distinct disease or conditions (Harrison et al., 2014). Therefore, the data presented here includes a count of one to four or more, body systems involvement as a proxy for chronic conditions, identified by codes at the time of discharge or death. ED presentations are identified differently, using NHI presentation and Triage Code as an identification system for priority need of care (explained in detail in chapter nine). If admitted to hospital from ED, this then changes to a diagnostic code within the chapter axes for body systems count. There are inconsistencies in the way chronic conditions are recognised and measured within the health care system, mostly because of the way different parts of the system collect data. This adds to the complexity and perhaps disparity of understanding the true presentation of chronic disease. This complexity extends to published literature where Harrisons et al. (2014) describe how this creates difficulty in defining chronic conditions and then multimorbidity, where there is a lack of consistent definition. In their review of this topic, there is a suggestion that body systems impact as a measure, may be a more consistent way to understand effects of physiological consequences. This then can also be related to symptom burden and quality of life measures which is important in understanding how life is lived. This was also found to be the case in the study by Roe et al. (1998) in their investigation of predicting Length of Stay in hospitalised patients where they used a definition of Body Burden of Disease (BBD) defined as the number of body systems affected by disease, was more predictive of need than severity of comorbidity. Using this definition in this way of accounting for burden to be less inconsistent than using disease counts.

As the basis of measurement, the purpose of the data was to understand if there is any association between known factors of disparity and levels of care need as expressed through urgency for treatment and utilisation of hospital level care. Disparate factors included ethnicity, age, gender, and quintile rating (as a representation of socioeconomic status). Levels of care need is also associated with complexity of care. Within the model used to understand this data, complexity of care is represented by Body Systems Count (BSC) and Length of Stay in hospital (LOS) as a presentation of days in hospital. The need to spend more days in hospital and an increasing number of body systems involved suggests complexity in care and higher impacts of the effects of chronic conditions.

Analysis



The analysis section steps through how the different data elements were examined through a discursive lens and then brought together in order to find meaning within the data. Each dataset, i.e. conversational interviews, retrospective hospital data, wellness scores, policy/strategy documents, even media portrayals, offers a different entry point into the discursive construction of social orders at different levels:

- QoL/Wellness scores bridge micro and meso levels
- Hospital data reveals how macro discourses manifest materially in care patterns
- Interviews show how discourse lives in individuals
- Media/government policy illustrate how dominant narratives are constructed and circulated at macro level.

Table 1 provides an overview of the social order the data identifies and how the discourse within that data set was approached, providing a focus on the analytic element under examination.

This study draws on Fairclough's concept of social orders and social orders of discourse to structure the analysis across micro, meso, and macro levels of the healthcare system. Each level represents a distinct but interconnected dimension of how discourse shapes, and is shaped by, power relations within healthcare. At the micro level, individual interviews and wellness and quality of life measures reflect personal experiences and identity construction, capturing how patients internalise or resist dominant discourses such as compliance or self-management. The meso level focuses on institutional interactions and practices, drawing from aggregated interview data and cohort wellness patterns to illuminate how discourse operates collectively within healthcare teams and service delivery. At the macro level, hospital utilisation data, policy documents, and media discourse are examined to uncover systemic ideologies, such as governmentality, neoliberalism, and biopolitical control, which shape institutional expectations and patient positioning. This multi-level framework enables a layered analysis that connects individual experience with institutional practice and broader societal discourse, revealing how power is enacted, maintained, and occasionally resisted across the health system.

Table 1

Social Order and Discourse Data

Social order	Discourse data	Social order/discourse	Analysis focus
Micro Individual Experience and Identity (Social Order of Self)	Patient interviews, narratives of illness experience, wellness and QoL measures at individual level.	How individual patients talk about their illness, express self-perception, identity, resistance, and agency (e.g. Mr CKDs story	Technologies of the self, subject positions, internalised discourses (e.g., being "non-compliant", "burden", or "good patient").
Meso Institutional Practice and Interaction	Aggregated participant interviews, clinician discourse, collective QoL and wellness patterns.	Institutional routines, local practice norms, the "voice" of the service or ward culture, shared patient-provider dynamics.	How discourses of compliance, care navigation, patient responsibility, and efficiency shape everyday care and interaction patterns.
Macro Systemic Structures and Ideologies	Hospitalisation data (attendance, ED use, admissions), policy documents, media discourse, government health strategy.	National health discourses (e.g., 'self-management', 'cost-saving', 'risk stratification'), structural inequities, neoliberal policy logics.	Governmentality, biopolitics, structural labelling, discourse of burden, media shaping public perception of chronic illness and care.

Once data were collected, the process for analysis was undertaken utilising Fairclough's CDA framework. The structure for the analysis was developed through grouping the data collected, into three levels of Social Order according to Fairclough's levels of social order (Fairclough, 2001). Fairclough argues that there is a dialectical relationship between language, power, and social structures. Discourse is not just a reflection of social reality but actively contributes to the construction and reproduction of social orders. By analysing discourse within its social and historical context, the underlying power relations and ideologies that shape and are shaped by discourse can be uncovered. Orders of discourse, refer to the specific discursive practices and patterns that exist within a social order. Fairclough suggests that different social orders can have different orders of discourse, each with its own dominant ways of making meaning and marginal or alternative discourses. These orders of discourse are not fixed but can change over time as power relations and social structures evolve (Fee, 1993). The division between macro, meso, and micro levels is a widely used conceptual framework to analyse and understand different levels of social phenomena and interactions._ As an example, the Social Order at a macro level represents the Government agency such as the Ministry of Health for New Zealand. This provides the overall context for situating the health service and patients requiring care within this structure in New Zealand. The Social Order of Discourse then relates to a contextual discourse where meso and micro effects are strongly influenced by government policies that guide the governance for Long Term Condition management. The process for this structure is represented by the following which mimics the sequential stage of data collection explaining the method of analysis that related to that data situated within the socio-cultural order according to Fairclough.

Due to the multi method nature of this study, data analysis needs to reflect the different methodological approaches. Yarning and storytelling methods was used to gather information from conversational interviews and analysed using thematic coding. QoL survey data was analysed through using Likert scales, ordinal statistical analysis and description. Quantitative data collected has been analysed using statistical analysis with descriptive and inferential statistics. This study is strongly qualitative in nature where thematic analysis guides the findings section with supportive data findings derived from quantitative methods.

The descriptions of the analytic technique used for each data set is described here and follows the way the findings and analysis chapters have been set out. The concept of the ‘games of truth’ that thread through the three research questions is used to structure the findings to understanding the dominant voice at each social order and, ultimately, where the patient voice is heard or not heard.

Establishing the System voice is profiled first. The characteristics of the wider cohort are described that then reviews the retrospective hospitalisation data with a break-down of guiding government policies as well as the media's voice. Here it explores the truth of system and what influences this.

Establishing Own Voice is the next analysis chapter and represents the meso order. It identifies the voice of the patients where conversational interview data is described. This chapter profiles the interviewed participants. Interviewed participants then completed QoL surveys, where this data set is analysed aligned to the interviewed data set. Thematic analysis is used to unpack the interview data and likert scores provide a means of reviewing the QoL data.

Establishing My Voice - Act of Resistance **-** My voice represents the micro level of order and profiles one young man from the larger cohort group as a smaller case study within the larger case study approach. This level of analysis identifies the effect of CKDMM, an individual's loss and how that loss can be transformed by changing how we position our model of care. Staging is used to represent the order and the way data was collected, whereas analysis is structured by social order description and how the data was collated.

Stage One: Mapping the Characteristics of the Population Group - Micro and Meso Level

To analyse the narrative data, a layered approach was employed that integrates narrative analysis with Fairclough's Critical Discourse Analysis (CDA) and Foucault's conceptual framework. This allowed for a deep exploration of both the content and form of participant stories while maintaining a critical lens on how language constructs power, identity, and social positioning. The narrative data from the conversational interviews with participants is the largest source of data and forms the lens through which to analyse the data.

The first stage involved thematic narrative analysis, identifying key patterns and storylines in participants' accounts of navigating the health system, such as moments of disconnection, resistance, compliance, and voice loss. Structural and performative elements of the narratives were also examined to understand how participants positioned themselves and others within their stories, including the roles they assumed (e.g., compliant patient, disempowered recipient, active resistor). These narratives were then examined using Fairclough's three-dimensional model to explore how individual expressions reflect broader discursive and institutional practices and social structures, i.e. how narratives are produced and circulated, and social practice analysis within the wider sociopolitical ideologies influencing healthcare interactions. Foucault's concept of eventalisation was then used to identify moments within the narratives where shifts in power, subjectivity, or resistance emerged, highlighting the dynamic discursive connections between structure and agency. This combined method helps to reveal how power operates through discourse at the micro, meso, and macro levels, and how patients with CKDMM negotiate their identities within a complex and often fragmented system of care. Table 2 demonstrates the elements involved in the analysis of the narrative data and the focus of each method used to examine the data and what that outcome measure was.

Alongside narrative interview data, descriptive hospitalisation data (including frequency of admissions, length of stay, emergency presentations, and outpatient attendance) and self-reported wellness and Quality of Life (QoL) measures were incorporated to contextualise and deepen the analysis. These datasets do not stand in isolation but were used to complement the narrative findings and highlight areas of alignment or dissonance between patients' lived experiences and the health system's operational responses. The descriptive data were mapped to help construct the situational context and social orders of discourse, revealing how system-level practices reflect broader institutional ideologies and contribute to the construction of patient subjectivities. The triangulation of qualitative narrative, hospital-level data, and wellness measures enhances the robustness of the analysis and allowed for a more comprehensive understanding of the interaction between personal experience, social discourse, and structural determinants of health.

Table 2

Narrative Data

Method	Focus	Outcome
Thematic Narrative	Content & meaning	What is being said
Structural/ Performative	Narrative form & role	How it is said, identity roles
CDA of Narrative	Power & discourse	Whose truth, whose power
Eventalisation	Foucauldian moments	Resistance, change, identity shifts

The characteristics data of the population under examination included ethnicity, age, gender, and decile code of residence to provide a demographic summary of people enrolled in the service and the interviewed participants. Descriptive statistics are used to describe the characteristics of this cohort to identify patterns of meaning and represented in graph form. For this study the nominal measures involving frequency and percentages would be the most useful form of measure. This allowed coding of data to occur where meaning can be derived (Tsin-yee Leung & Tan-lei Shek, 2018).

Conversational Interviews Dataset – Meso/Micro Level

Thematic analysis was used to collate the narrative from the HB patient interviews, looking for themes and patterns that identify how disparity created by multimorbidity was verbalised. Also, whether there were any specific indicators that identify disparity and coping, and when these elements emerged in their health care journey. The six-step thematic technique developed by Braun & Clarke (2006) was utilised to capture and further interrogate the data that was then characterised into themes. This framework encourages a method for familiarisation with the data, generating codes, identifying themes, reviewing these themes, redefining, and naming the theme. Themes were identified using an inductive approach, by listening to the interviews and highlighting any passage, or phrase that appeared meaningful. Meaning was attributed to phrases that described interviewees thoughts, feelings, experiences, relating to SDH, cultural experiences, and experiences with health professionals. Interview recordings were captured on a dictaphone and uploaded to a transcription software tool, Otter.ai which is a speech to text transcription application (Corrente and Bourgeault, 2022). This allowed for line-by-line interrogation for key words and phrases and to ensure the transcript was accurate. If a sentence was unclear in meaning, the audio could then be referred back in an efficient way to bring about clarity. Colour coding of key words was used to help identify connections that were then able to be progressed into a theme. As the interview data was interrogated, this enhanced the visualisation of themes.

The interviews identified multiple themes with layers of subthemes. To make sense of these and identify groupings, I utilised a mind map approach (Wheeldon & Faubert, 2009) where the technique is also often described as a concept map or thematic map (as used by Braun and Clarke, 2006). This is a way of displaying themes in a graphic representation. Wheeldon and Faubert (2009) describe this as a 'participant-centric means to ground data within theory' (p. 1).

How this occurred is explored further in chapter Five.

Stage Two: Quality of Life and Wellbeing Surveys – Meso/Micro Level

All interviewed participants were also asked to complete two Quality of Life (QOL) and wellbeing surveys. Participants' levels of wellbeing were analysed against this information using the statistical wellbeing scores of the Meke Meter and Flanagan's QoL dataset (Burckhardt & Anderson, 2003; Forrest et al., 2016). The Flanagan's QoL scale has been used to assess the quality of life in quantitative terms for people with chronic illness by many researchers since its development in the 1970's (Table 3). Burchardt and Anderson (2003) found it a valid tool for use in chronic illness across a diverse cultural population. It assesses 6 main domains of well-being that includes financial security and physical health, personal relationships, ability to take part in social and community life, personal integrity development and satisfaction and self-management ability and self-reliance.

Table 3

Flannagan's QoL. Scale

Higher-order domain	Lower-level Domain	Defining Features	Question
Physical and Material Wellbeing	Material wellbeing and financial security	Having good food, home, possessions, comforts, and expectations of these for the future.	1
	Health and personal safety	Freedom from sickness, physical and mental fitness, avoiding accidents and health hazards. Availability of effective health treatment.	2
Relations with Other People	Relations with parents, siblings, or other relatives	The presence of relatives with whom one feels belonging. Enjoying spending time with and visiting such relations.	3
	Relations with spouse/partner	Being married/having a loving companion, sexual satisfaction, effective communication, and devotion.	4
	Having and raising children	Becoming a parent, watching children develop, and enjoying spending time with one's children.	5
	Relations with friends	Having close friends with whom one shares activities, interests and views. Friendships are characterized by trust, support, love, and acceptance.	6

Higher-order domain	**Lower-level Domain**	**Defining Features**	**Question**
Social, Community, and Civic Activities	Activities related to helping or encouraging other people	Efforts as an individual or as a member of a group (e.g., a church) to help others beyond one's network of friends/relatives.	7
	Activities related to local and national governments	Voting, staying informed through the media, having political, social and religious freedoms.	8
Personal Development and Fulfilment	Intellectual development	Education access, ongoing mental stimulation/challenges, opportunities to improve problem-solving ability, comprehension, etc., in or outside of school.	9
	Personal understanding and planning	The presence of guiding principles in one's life. Developing maturity, personal growth, agency over decisions and one's life-course (sometimes involving religious or spiritual experiences).	10
	Occupational role	Interesting, worthwhile work at home or in one's formal job. Being recognized for accomplishments and feeling competent at one's tasks.	11
	Creativity and personal expression	Expressing oneself or applying one's imagination via artistic pursuits, such as writing, drama, music, etc.	12

Higher-order domain	Lower-level Domain	Defining Features	Question
Recreation	Socializing	Meeting new people, participating in social group activities, hosting/attending events.	13
	Passive and observational recreational activities	Appreciating passive or relaxed recreational activities, such as reading, media, or sports events.	14
	Active and participatory recreational activities	Enjoying active recreational activities, such as travel, sports, nature activities, games, artistic activities, etc.	15
Independence	Independence, doing for yourself	Remaining independent and being able to care for oneself, which is particularly relevant among populations with chronic illness	16

Celestine, N. (2019) 5 quality of life questionnaires and assessments. Body & Brain. Positive Psychology.
Key to Scoring, 7 point scale: 1- Terrible, 2 -Unhappy, 3 -Mostly Dissatisfied, 4 -Mixed, 5 -Mostly Satisfied, 6 -Pleased, 7 -Delighted

The Meke meter is a unique tool developed and validated in New Zealand for Māori that provides a self-reported measure of wellness. It is culturally aware, easy to use and interpret (Forrest, 2016). Both surveys employ a Likert scale measure to answer survey questions. Ordinal statistics has been used to analyse the Likert scale answers for each participant and plotted on graphs to indicate clustering of results across surveys using a simple excel program. This method is useful for measures with a hierarchical value i.e. good to bad or 1-5, without specific interpretation of a value but indicates a value that is greater or less than another data point and is a way to create order within the data. Categorising the data then enables interpretation (Ingram & Ternes, 2018). Though both surveys do not interrogate in the same manner, they interrogate similar categories and therefore can be compared in description. Reference is made to the similarity of results in chapter five, where the QoL information is detailed.

Both surveys use a Likert type scale in scoring. Flannagan's QoL survey covers eight life 'Domains' including material and physical wellbeing, relationships, social and civic activities, personal growth and satisfaction, recreational activities, and sense of independence (Table 3). These are then further broken down by 16 lower level or sub domains. These domains are captured through answering 16 questions with a scale of 1 (terrible) to 7 (delightful).

The Meke Meter (Table 4) reviews three main categories or domains that cover mental, social, and physical wellbeing through 15 subcategories that explore happiness, confidence, spirituality, relationships, and social connections, and physical.
health activities such as exercise and sleep. A scale of 1 (Bad) to 10 (Good) is used with 5 as a midpoint.

Table 4

Meke Meter Domains

Domains	**Key Indicators**
Mental (Hinengaro) - M	Relaxation, happiness, motivation, self-esteem, spirituality
Social (Te Oranga & Whānau Ora) - S	Recreation & sport, work/study, cultural identity, finances, friends and family
Physical (Tinana) - P	Fitness, sleep, general health, diet, addiction free

(Forrest, R., Taylor, L.-A., Roberts, J., Pearson, M., Foxall, D., & Scott-Chapman, S. (2016). Patu™: Fighting fit, fighting fat! The Hinu Wero approach. *AlterNative: An International Journal of Indigenous Peoples*, *12*(3), 282-297. https://doi.org/10.20507/AlterNative.2016.12.3.6

Key to Scoring, 10-point scale: 1- Bad, 5 -OK, 10 -Good

Stage Three: Retrospective Hospitalisation Data – Meso/Macro Level

Stage three of this research was concerned with obtaining and mapping the characteristics of the Cohort Group through retrospective hospitalisation data. This utilised quantitative methods. The raw data was obtained through the Information Services Data Analysts for HBDHB under the Localities ethics approval. The information time periods were January 2019 – January 2020. This time period was selected as the years from February 2020 to mid-2022 are what has been coined the 'COVID years.' Hospital presentations and admissions during these years operated under pandemic influence where presentations and admission are known to not follow typical patterns. Hospital avoidance was sanctioned unless life threatening or COVID related and alternative forms of system management and provision of treatment in health care were prevalent. This would skew the 'normal' patterns of utilisation, where COVID as part of presentation and admission nationally and internationally, was prevalent in the Chronic Conditions population and resulted in higher numbers of life-threatening presentations as well as hospital avoidance (Cassell et al., 2022; Rozenfeld et al 2021; Jefferies et al., 2020).

This dataset collected information against patient profiles and captures ethnicity, age, location quintile information represented by Quintile Code and chronicity represented by body systems involvement count on discharge. The HBHDB data systems collect body systems involved on discharge as a measure of chronic conditions. When reviewing this information, a parallel can be drawn to type of chronic conditions. For example, cardiovascular system events are linked to myocardial infarction (MI), heart failure (HF), cardiac arrythmia etc.; where Respiratory system events are linked to chronic obstructive pulmonary disease (COPD), asthma and respiratory failure etc. Information drawn from this dataset was de-identified.

Data was also collected to follow trends of hospital service utilisation as a measure of the need for elevated levels of care. This was obtained through emergency department presentations, allocation of triage code at presentation to indicate level of need for care and life-threatening nature of presentation, admission, number of inpatient bed-days, outpatient appointments and discharge. Mapping this data over the 12-month period allowed for the development of a profile of the case study population in HB.

The analysis for the hospitalisation data used Descriptive and Inferential statistical methods to map the data for meaning. Inferential statistics facilitates the exploration of meaning between variables where relationship differences and impacts can be determined This method of analysis also allows results to be generalised to a larger population (Bettany-Saltikov & Whittaker, 2014). Data was analysed using SPSS version 29 (IBM SPSS Statistics). The approach to analysis is as follows. Continuous variables are summarised using means with standard deviations or medians with interquartile ranges and categorical variables using frequencies and percentages. Univariate analysis using the following non-parametric statistical tests: the MannWhitney test where only two groups exist, Kruskall-Wallis test where more than two groups exist, and Spearman's rank correlation coefficient where the data was continuous. A p-value ≤ 0.05 was considered to be significant. A Chi-squared test for homogeneity is used to determine whether there was a statistically significant difference in the probabilities between two independent groups in terms of a multinomial dependent variables. Statistically significant differences in probabilities, will be investigated further using a post hoc analysis. A generalized linear regression model of the binomial family with a log link and robust variance estimation is used to estimate risk ratios of selected predictive patient variables with the number of days hospitalised. Analysis models are represented in Appendix Five.

Collation of Analysis – Micro, Meso and Macro Level.

Following the descriptions of the different data sets and their respective meanings, the findings were then collated, expanded and discussed in the discussion chapter (chapter seven). Taking a social orders approach is necessary here to unpack the complexity of the intersecting influences across a societal platform, in this case healthcare, and to understand the power differentials within and between levels. Decisions, and aspirations at a government macro level around the health of the nation impacts on how organisations at a meso level carry out policy which in turn affects the very people who need to benefit (micro level). The macro level represented by government policies and goals, was considered as part of contextual discourse in relation to how the participant perspective presented, and the patterns of need for elevated levels of care, mapped in the retrospective hospitalisation data. This provided a real-world view to understand how macro level decisions impact on meso and micro level orders and to identify the power differentials between these levels. Contextual discourse analysis was considered during all phases of analysis. Figure 2 is a pictorial of a NZ Harakeke plant (Flax plant) weaving to demonstrate how Critical Discourse Analysis enables understanding these influences and how the different elements of inquiry have been woven across societal orders and healthcare goals indicating lines of influence and should weave and intersect creating a whole. In this example from the findings of this study, the NZ government policy of 'care closer to home' informs a model of practice with a goal of care to increase healthcare access and keep people at home self-managing in their own environment. Care is situated around the person or patient (person centered care), where health systems across sectors are cohesive and work together to enable the patient to be where they want to be, at home (Ministry of Health, 2023b). But the data from this study suggests that for the renal service cohort and interviewed participants, there is a disconnect between levels and misaligned realities creating holes in the weave. There are differing truths situated within the different social orders. Government level goals have not been well enabled at the meso level, creating fragmented care pathways because of a siloed approach to how services are funded and resourced. Organisations now have an inability to meet high level goals, creating issues around access to appropriate healthcare and hardship for the patient. Along the way the patient voice is lost. The participants describe a sense of being forgotten. In this research our patients have told us that, and the literature collaborates this. Critical Discourse Analysis allowed for the correlation of quantitative data interrogated against the findings of thematical analysis, where a robust picture of disparity including ethnicity, chronicity and geographical isolation could be formed.

What transpired was an understanding of how health events combined with social needs, and fragmented systems, built a picture of change that altered how participants lived their lives, were identity and a lost sense of belonging were key factors. The mapping and meaning of findings were then able to be applied to answer the research questions and is discussed further in chapter seven.

Figure 2

Social Orders of Discourse

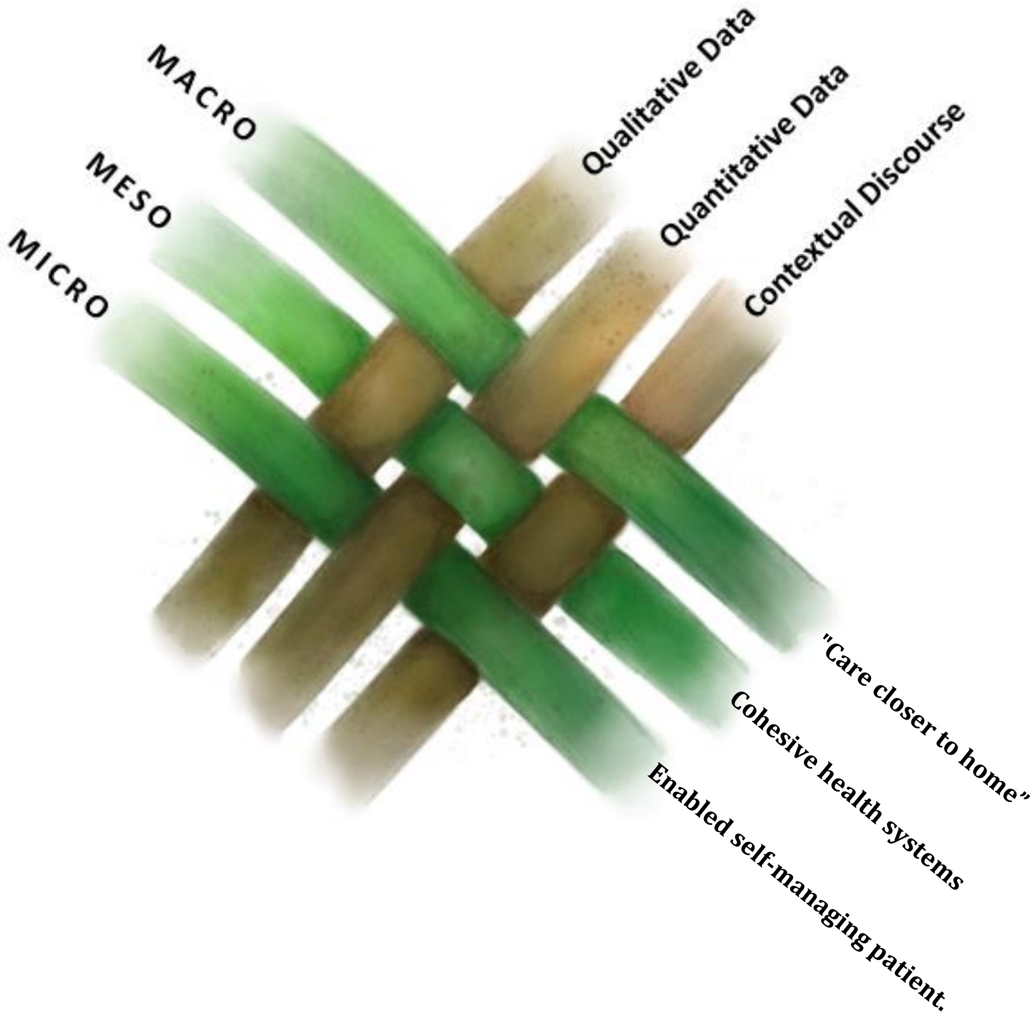


Table 5 represents a summary of the data collection points and analytical technique used for the type data. Prior to the Pandemic event of Covid-19, this research was designed to occur from 2019 to 2021 with completion at the end of 2022. Timelines needed to be adjusted resulting in little progress over 2020-2021 due to the inability to work directly with patients through face to face contact. Government mandates in NZ meant the way frontline healthcare changed reducing face to face contact. I felt that personalised face to face meetings were an important component to conducting interviews as participants were sharing deeply personal and potentially emotional experiences. A decision was made to defer interviewing until this could occur. What was unpredictable at the time was how long the pandemic would last and initially this was thought to be only a matter of a month. In the end it took nearly two years for the Pandemic to subside to a point were certainty around resuming normal care delivery occurred.

Population Groups

There was one main cohort group used for this study identified as those people enrolled in the HB Renal Service from 2019-2022. Within the Case Study cohort, participants who were interviewed, formed a subgroup and were the same group that completed QoL surveys.

Stage One

Participants who were interviewed as part of Stage One cohort (n=18)

Stage Two

Participants who were interviewed also completed QoL surveys (n=18)

Stage Three

HB Renal Service enrolled population from January 2019 to January 2020 (n= 647).

The HB patient cohort provided the focus group for this study. The HBDHB covers a geographical area of 14200 square kilometres and provides health care to approximately 165,000 people. It is a large rural population within areas with high levels of disparity, inequality, and isolation. The region has a higher than national average in population for Māori and Pacific Islanders living in deprivation with poor access to health care (McElnay, 2014).

Table 5

Summary Data Collection and Analytical Technique

Stage	Time Frame	Participants	Data Collection Method	Data Points	Analysis
One	Across one year - 2022	HB Renal Service Patients n=18	Conversational Interviews	Participant Interviews	Qualitative - Thematic Analysis data
Two	Across one year - 2022	HB Renal Service Patients n=18	QoL and Wellness Surveys	Meke Meter Flanagan's QoL	Quantitative – Likert scores and Descriptive and Inferential Statistics
Three	2019, Jan-2020 - Jan	Case Study – Hawkes Renal Service enrolled population n= 647	Survey of de identified Hospital data	Ethnicity, gender, age Quintile by postal address Emergency Department visits/ triage scores/admit/discharge Admission- Number of Bed days Appointments Body systems count	Quantitative – Descriptive and Inferential Statistics Review of all data to identify early warning signs of deterioration in multimorbidity and need for elevated levels of care.

The HB Renal Service offers care to people who meet Secondary Care renal service care criteria. The makeup of this population cohort includes those different stages of chronic kidney disease as classified following the KDOQI classification system (Levey et al., 2002). The top five chronic conditions are cardiovascular disease, diabetes, chronic obstructive respiratory disease, ESKD and chronic liver failure (McElnay, 2014). This study cohort are known to be multimorbid by definition and are representative of these chronic conditions as being the predominant comorbid conditions seen within my practice setting. The participants who were interviewed were all in ESKD, with six participants having received a kidney transplant and the other participants (n=12) receiving dialysis services.

Within the HB Case Study patient population group, there was a focus on recruiting patients in the main ethnic groups as represented by Indigenous and non-Indigenous ethnicities. The study randomly selected and interviewed eighteen people. While the original target was twenty, interviews continued until data saturation appeared to be reached at n=7. By this time eighteen interviews had been undertaken, and it was felt there was no need to recruit any further participants. Analysis of findings aimed to compare what they said, what and how themes emerged and if there were any differences in culture and ethnicity in relation to multimorbidity. This is discussed further in chapter five, under Characteristics of the Cohort Group. Table 5 summarises the sequence of data collection by stage, time frame, number of participants involved, description of the data and the analytic method employed in each stage.

Ethical Considerations

There were several ethical considerations necessary to accommodate in this study. In terms of the requirements for review by an appropriate ethics committee, these included research involving vulnerable people and cultural support, insider research, potential to evoke emotional responses for participants and interviewer, and data storage.

Ethics Committees

This study originally received ethics approval from the following bodies: New Zealand Health and Disability Ethics Committee, Queensland Health and Central

Queensland University Ethics Committee, and the HBDHB Localities and Māori Health Unit. At the conception of this study, I was embedded within the larger Nurse Navigator study undertaken in Queensland Australia. Australian Ethics had already been gained for the Nurse Navigator program in Queensland (HREC/18/QTTD/8 - "The Evaluation of the effectiveness and sustainability of Nurse Navigator/Health Navigator Model: A Trans-Tasman Study". An amendment enabled the NZ focus of the study to be incorporated as a related sub-study. As this thesis study unfolded it became obvious, I would not need to include data from the larger study, requiring New Zealand national, localities and cultural ethics approval only.

- HREC/18/QTDD/8 Qld Health, and 0020740 HREC CQUniversity – Appendix Two
- HDEC- Ethics ref: 20/CEN/214 – Appendix Two
- Localities Ethics – HBDHB and Māori Health Unit – See Appendix Two for approval letters

Vulnerable People and Cultural Support

This study involves vulnerable people. Vulnerable populations within the context of this study include Indigenous People, Māori, and marginalised populations such as Pasifika people and people who come from low socioeconomic environments who may have low literacy levels. The Te Ara Tika Guidelines for Māori research ethics was employed that details a framework for researchers and ethics committee members, used as a guideline for working with Māori for the purposes of research (Hudson et al., 2010). These guidelines incorporate and acknowledge the principles of the Treaty of Waitangi to ensure Māori culture is preserved and protected. Approval of the Māori Health Unit of the HBDHB was sought. The support of a Kaitakawaenga (Māori support person) was offered throughout the course of the research to all Māori participants and others who wished for this support. Support of the Māori Health Unit was sought to ensure the research that involved Māori was appropriate and to establish that the intent of the study, was to improve healthcare for Māori people of New Zealand. This was recognised as part of localities ethics approval. It is an important part of participation and partnership principles of the 'The Treaty of Waitangi/Tiriti o Waitangi' (Treaty of Waitangi [English version], 1840) the guiding document for NZ in recognition of Māori as the Indigenous population of NZ, that any information gained from Māori is shared with Māori (O'Sullivan & Mills, 2009).

As part of the dissemination of results, these were made available to the participants and Māori Health representatives such as the Māori Relationship Board, HBDHB at the end of the research. Cultural support was also required to facilitate Hui and the Yarning methodology as the researcher is a non-Indigenous person and does not have experience in facilitating story telling with Indigenous groups. A research assistant who identifies as Māori and is a Registered Nurse with research interviewing experience, who is also conversant in Chronic Disease Management, was engaged to conduct the interviews. This facilitated the concept of 'for Māori, by Māori and with Māori', as well as allowing me as an 'insider', to step back from interviewing the participants to help manage the potential risk of bias and influence as I have known and cared for the participants in the Renal Service of Hawke's Bay for many years.

Insider Research

Insider research is considered when the researcher either comes from within the research group population or is conducting research on a population with whom the researcher has had a close association over several years (Unluer, 2012). Saidin (2016) explored insider research and highlighted how 'insiders' have a passion for their research and can undertake this despite all of the challenges this approach may have. I place myself as an 'insider' to this research and have a passion to know more. I have worked with this population group for many years and have witnessed their daily struggles. Bonner and Tolhurst, (2002) describe several advantages for nurse researchers as insiders, with the main advantage being a greater understanding of the issues and cultural experiences the population under examination faces. But also, as an insider has a good understanding of the political environment in which the study is being conducted. This includes the organisation structure and 'daily workings' but also the higher or more macro level environment such as government agency policies and proceedings that may influence environments at local meso levels and miro individual levels. As I have worked in healthcare for over three decades, I have intimate knowledge of the healthcare structure of NZ and the many changes that have come about over that time.

One of the issues I had as the researcher, was pre-existing relationships with the participants, a professional healthcare provider, and because of this I had the potential to lose objectivity (Bonner & Tolhurst, 2002; Unluer, 2012; Saidin, 2016; Toy-Cronin, 2018). This could not only create a power imbalance with the participants, resulting in their wanting to help me because I have helped them in the past, thereby creating a sense of obligation to participate. Toy-Cronin (2018) in her experience as an insider researcher, describes how the researcher must employ strategies to mitigate these issues, and that despite these strategies the researcher will still have intimate knowledge of the topic area which creates advantage. She also discusses the viewpoint of an 'insider-outsider' to the research. As I have not lived the experience of the participants in the way they have, I can be considered an outsider also.

However, the main mitigating strategy I employed was to not undertake the participant interviews myself and instead I employed a colleague who had knowledge in this area as well as an aligned culture identity. My insider view was acknowledged as a concern within the HDEC committee when my application was reviewed, and this mitigation strategy was seen as supportive. In reality, I found that listening to the interviews with my patients as they were transcribed, to be an emotional process that was difficult to put aside, and their voices would stay with me for several days. I believe I would have struggled with face-to-face interviews and in doing so, may have lost objectivity.

Evoking Emotion

Conversational interviewing involves asking participants to share their experiences and stories. This study has acknowledged that life for people with multimorbidity and chronic conditions, is known to be difficult and at times hard. It was possible that in sharing stories, participants may experience emotions in recalling difficult times, hardship, loss, and change. As described in chapter five, this was an emotional experience for most of the participants, the nurse interviewer and myself when listening to their stories and the emotions expressed. The Renal Service of Hawkes Bay employs a Psychologist and Social Worker with counselling experience. Both employed positions, agreed to be available for support as well as the Māori Health Unit representatives. All participants and the nurse interviewer were offered these services and follow up if they felt this was required. To my knowledge this has not been taken up by any participants to date. The nurse interviewer and I took the opportunity to discuss the interview process together many times over the course of the interviews, and in that way offered support to each other. I also debriefed this with my principal and associate supervisors at scheduled meetings. In encountering participants during routine clinic reviews, after the interviews, many have indicated their relief in having the opportunity to have engaged in this study that provided them with a safe space to express how they were feeling as many had not done this before and valued the opportunity to do so. Some participants also stated in the interview when offered psychology support that they felt better speaking with one of the nurses as they knew them and knew what they had been through. This participant quote is an example of that:

> *No, not really [to the nurse interviewer when asked about the opportunity to see a Counsellor or Psychologist], because I'm not really...well...oh, you know, I could talk to you, [nurse interviewer], you know, quite straightforwardly and everything, honestly and everything, but when I'm with someone like a psychiatrist or something like that, I seem to think a bit too much and then start, well, start not making sense, if that makes sense? Because I'm starting to think a bit too much about what that guy thinks?... But just some of the things that... the hard truths…. is a bit more...not what I want to hear [indicating someone he does not know], than from somebody that I do know, that knows me, that knows where I've been, that knows who I am, and knows what I...you know, all of that. I don't know [nurse interviewer], about the psychology side of things.* (Participant C: 32.17min).

Data Storage

Raw data has been kept by the principal researcher in accordance with New Zealand Privacy Act (2020) and Massey University policy Guide: Code of Responsible Research Conduct (2015). All information collected from the study has been stored in triplicate:

- Securely on a dedicated personal computer system that is password protected.
- Backup copies are also stored on a Cloud password protected facility, One Drive.
- Temporary storage on encrypted password protected USB.

The following chapters detail the findings, analysis, and discussion.

Summary

Section One is concluded by chapter three and the presentation of the research design and framework. It described how Foucault and Fairclough have influenced this work, the method of data collection and how it was analysed. The following three chapters now position the analysis of the data collected and is structured by the three research questions using a social ordering approach, where each chapter identifies and answers the related research question. Chapter Four describes the macro level order through hospitalisation data and the wider contextual environment at a national health system and Government level.

Section Two: Voices Across Social Orders

Chapter Four

Establishing System Voices

One of the focuses of this thesis is to understand how the renal patient experiences the healthcare system in NZ. As their health journey progresses, we understand that there is hardly a part of the health system they do not interact with.   With reference to Fairclough's social orders, the NZ health system can be seen as representing 'the truth' for health care delivery. It makes the policies and the regulations that govern the health services. Because of its direct influence on health services, the Government is highly influential at both the macro and the meso system of health care delivery. Before 2022, health delivery was divided into regional health units, initially called district health boards, which then became Te Whatu Ora Health New Zealand regional centred of health. Te Whatu Ora simply means the "weaving of wellness" in the Māori language. Changing the title of the health services from 'district health boards' to jurisdictions within a 'place of wellness', whilst not generally noticed as a shift in the way services were managed, does, in fact, shift the intent of the health system from a traditional medical model to a more primary health focused model, because, "in the weaving tradition, the whatu is the weaving process that brings together the aho (horizontal thread) and whenu (vertical thread)" (Te Whatu Ora - Health New Zealand [TWO-HNZ], 2024a). The changing of the name was "gifted" by the expert advisory group set up at that time, 'pou tikanga Rahui Papa'. At the same time, Te Aka Whai Ora (Māori Health Authority) was established, giving New Zealand bipartite health system, one for Māori and one for 'other' population groups, and "while distinctly different to each other, share a close relationship founded in the ancient legend of Tāwhaki" (TWO-HNZ, 2024a). This change is not merely semantic but rather, it represents a reconfiguration of power relations within the health system, aligning with Foucault's assertion that discourse shapes our understanding of truth and power (Durie, 2023; Massari, 2021). The partnership between the Māori Health Authority and Health NZ was aimed at investing services grounded in te ao Māori and ensure the wider health system recognises and is more responsive to Māori needs, alongside that of the wider population (Reweti, 2023).

Whilst these changes have been viewed as maintaining the status quo, they have only been in place since July 2022, so have had little time to establish at the next level of government, nor has it had time to disseminate to actual health interventions. Yet, in 2023, the structure was dismantled and the health system placed under direct central governance. The retraction of the Māori Health Authority can be interpreted as a move towards a more homogenised health discourse that prioritises efficiency and standardisation over culturally specific health practices. This reflects neoliberal values that emphasise individual responsibility and market-driven solutions, which can undermine collective approaches to health that are essential for addressing systemic inequities. As Reidy et al. (2023) noted, "health inequities result in part, from market conditions, and profoundly damage both health and the economy hence the importance of social and economic policies to reduce inequity in outcomes between and within population groups" (p. 74).

At the end of this political wrangling at a macro level of the health system structure, are health professionals attempting to please two masters – the health system as their employer and regulatory body, and the patient who just wants to be treated and cared for. Patients with chronic and complex conditions at the micro level, are trying to manage their illness and their life. The complex relationship between institutional knowledge, professional practice, and patient experience within healthcare systems creates distinct 'games of truth' that shape how care is conceived, delivered, and experienced. Yet, even at the meso level of health care, the patient is invisible in the way that hospital utilisation is tracked, recorded and reported. Hospital utilisation measures 'hospital avoidance' which refer to interventions, strategies, and indicators aimed at preventing 'unnecessary' hospital admissions. These measures are collected to evaluate the effectiveness of health systems, identify areas for improvement while reducing healthcare costs. Although hospital avoidance measures are critical for enhancing healthcare quality, reducing costs, and addressing health disparities, there is no patient voice represented, merely a focus on how to contain an ever-decreasing budget against ever increasing demand. Foucault's notion of "games of truth" can be applied here to analyse how knowledge about patient preferences is constructed and utilised within healthcare settings.

Hospital data can be thought of as the Health System's voice through which decisions are made about what services to provide, and what conditions are prioritised in terms of funding arrangements. For complex patients such as renal patients, 'hospital avoidance' is a conundrum. They are after all, high-end users of health care. The question remains, is the voice of the patient as a 'high end' user heard or not? During the data collection period of this thesis, a significant administrative event occurred where it was recognised by the Renal Service that significantly high numbers of patients (>300) that had been lost to the service due to a data entry error sustained over a 12-month period. This is discussed in detail later in this chapter. Information lost means that budgets are retracted, and care is reviewed against these figures. Losing data means losing funding and cutting services. This event drew extensive media attention at that time but also contributes to the 'games of truth' that seems to be surrounding the care of a renal patient. If Foucault's concept of 'games of truth', refers to the ways in which power and knowledge interact to shape what is considered true or valid within a given discourse, how then is the renal patient represented? In this context, the health system's voice reflects the institutional narratives that prioritise certain needs and experiences over others, particularly in light of the significant administrative error that resulted in over 300 renal patients being lost to the service.

This incident not only highlights systemic failures but also raises questions about whose voices are amplified within the health discourse and how these voices influence the perception of care needs. The recognition of the administrative error and its media attention can be seen as a moment where the voices of these patients are momentarily elevated, challenging the dominant narratives that often overlook their needs. This chapter explores how truth claims about renal care are established, maintained, and contested through institutional structures and practices and seek to address the first thesis research question "What are 'games of truth' in the healthcare system of patients within a regional secondary care renal service and how are they discursively constructed?"

Exploration of Elevated Levels of Care for the Renal Service Cohort

The literature on individuals with CKD and multimorbidity frequently highlights the heightened risk of hospitalisation, which contributes to their overall vulnerability. As discussed in the thesis Introduction (Chapter One), the dominant discourse within the current health system emphasises prioritising those most at risk of social inequities, primarily through the lens of social determinants of health such as ethnicity and socioeconomic deprivation.

To investigate how these factors manifest within the enrolled cohort of the HB Renal Service, this section examines the need for elevated levels of care and the influence of multimorbidity on healthcare utilisation. Using de-identified retrospective hospitalisation data, the analysis explores the relationship between multimorbidity and patient characteristics like ethnicity and deprivation, particularly in their impact on hospital service utilization. This includes the progression from outpatient clinic attendance to emergency department (ED) presentations, hospital admissions, and total days hospitalized.

The analysis focuses on understanding how known disparities and multimorbidity affect care levels, especially the urgency of treatment in the ED and overall use of hospital services. Data from the study period tracks the transition from outpatient care to ED visits and subsequent hospital admissions—either from the ED or directly from general practice—reflecting the inevitable decline in health associated with these conditions. Twelve months' worth of data from January 2019 – January 2020 was obtained as recorded in the Regional Hospital's patient management system. This period was selected to avoid the COVID years of February 2020 to 2023, where admission data would likely be skewed from normal patterns due to the rate of hospitalisations complicated by the admission with COVID and the precautionary measures taken for people with certain chronic conditions such as admission threshold criteria. A descriptive analysis of the findings is provided in this section to allow for the interrogation of discursive formations that emerge from the data rather than the focus being on the technical details of analysis (Appendix Five) that dominate and are characteristic of positivism.

Hospitalisation utilisation is also mapped against a well-known population healthcare stratification tool, the Kaiser Permanente Pyramid of care need, to understand how this cohort of patients is represented along a chronic conditions' continuum. This tool is commonly used by health organisations to estimate economic and workforce development needs for a given population and is promoted by WHO as integrated model of care in chronic care management.

An overview of the geographical region within NZ is detailed to provide background for positioning the findings of the cohort and sub cohort groups.

Hawke's Bay Region

Hawke's Bay (HB) Region has a diverse population of 187,500 people spanning 14,200km with 350km of coastline with northern and western borders of mountain ranges, including seven prominent rivers (Hawke's Bay Regional Council, n.d; Hawke's Bay Regional Skills Leadership Group [HBRSLG], 2023). There are five main centres with two of these as metropolitan cities and three rural townships. There are also many smaller scattered settlements within the region. Hawke's Bay is considered a rural regional centre within NZ. From the latest census information available in 2018 (Stats Tatauranga Aotearoa NZ, 2018), HB has higher than the national average of indigenous population of 27% who identify as Māori, with mean age of 25 years old (national average 16.5%). Pacific peoples make up 5.6% of the population with the national average of 8.6%. People of European decent make up 75% of the population. HB has 40.3% of its population over the age of 45, and the highest older age representation is in the 55- to 59-year-old age band. 59.7% are under 45 years of age with the highest percentage of younger people between five- and nine-year-old age band (Stats Tatauranga Aotearoa NZ, 2018). There is an even spread of non-Māori population across the ten decile rated areas. But there is a two-fold increase in the number of Māori (approximately 50%) who live in the most deprived areas with a decile rating of nine to ten (Marsters et al., 2012).

The HB region has a dominant labouring workforce with main industries including horticulture, meat processing, building and construction (HBRSLG, 2023). Much of the horticultural work is seasonal with a transient population surge at different times of the year, reliant on a migrant workforce. Mean household earnings are $94 000 vs the national average of $106 000. There are 14,500 (7.7%) people of working age on a government social support benefit (HBRSLG, 2023). A report into the state of health of

HB in 2012 describes the highest avoidable cause of mortality is attributed to ischemic heart disease across all ethnicities. While Māori also have higher mortality through lung cancer, COPD, and diabetes. Non-Māori secondary cause of death is stroke, COPD and colorectal cancer. The most common hospitalisations are due to 'respiratory infections, dental infections, angina and ear-nose-throat conditions' (Marsters et al., 2012, p. 22).

About the Renal Cohort Hospital Service Utilisation

The need for elevated levels of care represented by hospital service utilisation through acute care presentations to ED and admission to hospital, suggest need above that of a specialist outpatient appointment and is used as a proxy in this study for elevated levels of care. In relation to this data each presentation to outpatient services, ED and or admission relates to an 'episode of care'. Rosen and Mayer-Oakes (1999) describe how an 'episode of care' has several meanings based on the perspective of the user i.e. patient, provider or payer, and is usually for a defined period with a start and finish or date of resolution. However, the context of the care provision determines the episode of care. In the sense of healthcare and the definition used for this thesis, an episode of care incorporates all health care contact and activities related to that presentation, clinical condition or procedure (Rosen & Mayer-Oakes, 1999).

The renal service cohort group represents the enrolled population in Outpatient Services offered by the secondary care Renal Service from January 2019 to January 2020. This population group all have a degree of CKD as a primary diagnosis for purposes of enrolment in the service, with comorbid conditions as secondary diagnoses. All patients receive outpatient services that range from clinical reviews for primary and secondary CKD conditions, and ESKD with participation in Renal Replacement Therapies such as Peritoneal Dialysis, Haemodialysis and Post Transplantation Care. There is a diversity in the length of time patients have been enrolled in the service. Longevity of care is a significant attribute of the service. Many of the cohort have been with the service since they were young adults, where care has spanned 20-30 years. Some of the cohort are new to the service within the analysed time frame and may have only been enrolled for a few months. Associated with this is a range of people with different degrees of comorbidity. A few may have only one chronic condition, that of CKD, but the majority have several comorbidities. The youngest I have cared for in my time with the renal service is 17 years old (yo) and the oldest has been their 90's.

Table 6 provides the breakdown of the renal cohort characteristics from the retrospective hospitalisation data. The cohort are divided into subgroups, with Out Patient Services (OPS)(Group One) and represents the total number of patients who were enrolled in Out Patient Services; Group Two are those who were enrolled in OPS and had an ED presentation (EDpresent) (Group Two) but not admitted, and Group Three are those who were enrolled in OPS, had at least one EDpresent and were also admitted (Admitgp) (Group Three) for an overnight stay. Each subgroup indicates the level of care need with the highest care need indicated by representation in all three subgroups. Data was captured across ethnicity (Ethnic), gender (Gender), four age group bands; 15-24 yo, 25-44 yo, 45-64yo, 65+ yo (Age), and socioeconomic measure (Quintile) where Quintile 1 is the least deprivation areas and 5 the highest deprivation areas as determined by domicile residence.

The data is reported against a count of the total number of patients (n=), with a corresponding percentage of the cohort group in that category. There were 355 patients of the total cohort (n=647) who are represented as having an OPS (Group One) need only, 91 had both an OPS and EDpresent (Group Two), while 201 were represented in all three categories with Admitgp (Group Three). This suggests that 14 % of the cohort were seen in ED and able to go home but 49.5% of the renal service cohort required admission. Overall, 63.5% of the renal service cohort utilised hospital services over and above the need for OPS contact, suggesting a significant number of the cohort use and or need higher levels of elevated care. This data does not identify the reasons for additional contact with hospital services but suggests this cohort are sick requiring more than self-care or self-management to be well.

Māori are the dominant single ethnic group with 30.3%, and Pacifika of 5.9%. This is very similar to the number presented in the overall HB Region statistics of 27% and 5.6% respectively. 'Other' represents all other ethnic groups including NZ European decent and Asian ethnicities. Māori and Pacifika people featured more prominently in the use of elevated levels of care represented by OPS, EDpresent and Admitgp (Group Three). This number increased to 41.3 % for Māori who required admission. This suggests they are sicker when they presented to ED. Pacifika had increased percentages in the OPS and ED presentation category, but were able to be discharged home from ED. This suggests Pacifika are using ED services as a proxy for primary and community care.

Of the 647 patients, 55% (n=355) were outpatients only, 14% (n=91) were outpatients that had attended the emergency department and 31% (n=201) were outpatients that had attended the emergency department on one or more than one occasion and had been admitted to hospital on one or more than one occasion. These three subgroups represent elevated levels of need of an 'episode of care'. Patients in group 3 have the highest level of clinical need. The renal service is unique in respect of the length of time people are cared for by the service. There is a variance in respect to the length of time enrolled in the service and complexity of conditions for patients, that may have an influence on service utilisation and need for elevated levels of care. Generally, the longer a person has been enrolled with the service, where progression of conditions has occurred, relates to increased contact, active involvement and need for care.

In summary the renal cohort group had a significantly higher need for elevated levels of care through total hospital services utilisation. Māori as a single ethnic group are over-represented in all categories and are presenting more unwell requiring admission. There is a suggestion that some groups are using ED as a primary and community care alternative represented by increased rate within the Pacifika and 25-44 yo age group bands compared to the OPS or Admitgp bands. There is a higher risk for needing admission if a patient is a Māori male, 65+ yo and lives in a Quintile 5 location. There is a higher risk for using ED services if a patient is other than Māori or Pacifika, male, and in the 45 to 64 yo age group band. While a patient who is 'other', male, 65+ yo and living in a area of deprivation is more likely to need only an OPS. However, the difference in percentages across all categories and within categories is relatively small. A larger sample size would need to be interrogated to be able to generalise these findings in suggestion of people with multimorbidity.

Table 6

Renal Service Cohort Group Characteristics

	Cohort Subgroups						Total	
	OP (Group 1)		OP+ED (Group 2)		OPS+ED+Admit (Group 3)			
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Ethnicity								
Maori	83	23.4%	30	33.0%	83	41.3%	196	30.3%
Other	252	71.2%	50	54.9%	110	54.7%	412	63.8%
Pacific	19	5.4%	11	12.1%	8	4.0%	38	5.9%
Gender								
Female	151	42.5%	41	45.1%	85	42.3%	277	42.8%
Male	204	57.5%	50	54.9%	116	57.7%	370	57.2%
Age								
15-24	6	1.7%	2	2.2%	5	2.5%	13	2.0%
25-44	46	13.0%	24	26.4%	32	15.9%	102	15.8%
45-64	150	42.3%	36	39.6%	71	35.3%	257	39.7%
65+	153	43.1%	29	31.9%	93	46.3%	275	42.5%
NzDecile								
1	28	7.9%	7	7.7%	8	4.0%	43	6.6%
2	83	23.4%	18	19.8%	24	11.9%	125	19.3%
3	53	14.9%	10	11.0%	28	13.9%	91	14.1%
4	60	16.9%	18	19.8%	41	20.4%	119	18.4%
5	131	36.9%	38	41.8%	100	49.8%	269	41.6%
Total	355	100.0%	91	100.0%	201	100.0%	647	100.0%

Further to this, data capture also included the allocated ED Triage codes, hospital admissions bed days, classification of body systems involvement of admitted patients as a measure of the number of chronic conditions per person, discharge data from ED and hospital stay, as well as demographic data, ethnicity, age, and domicile residence by quintile code. Disparate factors included ethnicity, age, gender, and quintile rating (as a representation of socioeconomic status). Levels of care need, also has an association with complexity of care. To understand this data, complexity of care is represented by Body Systems Count (BSC) as a measure for chronic conditions and Length of Stay in hospital (LOS) as a representation of total days in hospital during the data capture period. The need to spend more days in hospital and an increasing number of body systems involved, suggests complexity in care and higher impacts of effects of chronic conditions.

Triage categories are used to identify emergent or immediately life-threatening need for care as indicated by Triage one and two (time critical), Urgent care (potentially life-threatening with adverse outcomes from delay) indicated by Triage 3 and non-urgent care (potentially serious or complex) indicated by Triage 4, with Routine care (less urgent or administrative issues) indicated by Triage 5 (Australasian College for Emergency Medicine, 2016). Due to the low number of presentations in Triage 1 and to enable the model to work, Triage 1 and 2 have been combined and is presented by Triage 2. The data looks at whether there are differences between the proportion of visits within each triage category presenting to the ED in renal patients with higher care needs (i.e., one or previous hospital admissions) and renal patients presenting to the ED with no history of hospitalisation (hospitalisation infers admission). Renal patients who do not have a history of hospital admission (as a proxy of level of care) could potentially be accessing primary care first and if presenting to the ED would either not differ from expected values or present with more urgent care requirements as indicated by triage codes (<3).

An admission to hospital indicates a higher level of need for care. A distinction is made between Total Number of Hospital Days and Length of Stay (LoS) in days. The "Total Number of Hospital Days" refers to the cumulative number of days that patients spend in the hospital over a specific period. It represents the sum of all individual lengths of stay for each patient during that period. For example, if Patient A stays in the hospital for 3 days and Patient B stays for 5 days, the total number of hospital days would be 8. As a point of difference, the "Length of Stay" refers to the duration of an individual patient's hospitalization, measured in days. It represents the specific period from admission to discharge for each patient. For example, if Patient A stays in the hospital for three days on only one admission but Patient B stays for three days on one admission but then later has another admission and stays for six days, the length of stay for Patient A would be three days, and for Patient B, it would be three plus six is nine days. It's important to understand that the total number of hospital days captured during the data collection period reflects the overall utilization of hospital resources by considering the cumulative days of each patients' hospitalizations and is therefore provides an overview of utilisation. On the other hand, the length of stay focuses on the duration of each individual patient's hospitalization and provides an estimate of the utilisation per hospitalisation. Here, Patient A has three days stay with one admission the length of stay is three days per admission whereas, Patient B has a total of nine days over two admissions the average length of stay per admission is four and a half days. Both metrics provide valuable insights into hospital utilization patterns and can be used to assess resource allocation, efficiency, and patient outcomes (Stone et al., 2022).

In obtaining data for the purpose of this study, involvement of multi body systems count (BSC) was used as a proxy to represent multimorbidity in renal patients. The different parts of our Health System in NZ does not count data in a consistent way, a further example of how the National Renal Network principle of data driven evidence is challenging to achieve. The system simply does not allow for it. It's acknowledged that this proxy metric does not capture the many different types of long term or chronic conditions that people may have or present with but does signal the degree of multiple system dysfunction and the increasing utilisation of healthcare services and burden of the way life can be lived. Primary care systems collect different data to secondary care systems. Presentations to ED collect data in a different way to those captured through ICD10 diagnostic coding used on discharge from admission. Due to the smaller sample size of the renal cohort (impacted also by lost data) some categories had insufficient numbers (less than five patients) and needed to be collated to form categories of patients within specific characteristic bands into large enough groups to be included into statistical models. A larger sample size would provide more information into the effect of potential interactions in terms of ethnicity and quintile for example, and more sensitivity in the analysis of the predictors and the total number of days in hospital. This effected the ability for further refinement and to drill down on some categories. Three NHI numbers were discarded as extreme outliers, as inclusion would have skewed the data. As a result, the findings here may not be able to be generalised to a larger population or to truly represent multimorbidity. However, the data is an accurate record of the 647 individual NHI's representing the patients of the renal service. The models used were robust and replicable. The data reflects hospital utilisation rates for this known multimorbid population. The interpretation of the data was carried out in consultation in a with the statistical analyst and supervisors, to ensure I had not misinterpreted numbers.

Is it time to realign the Level of Care Need?

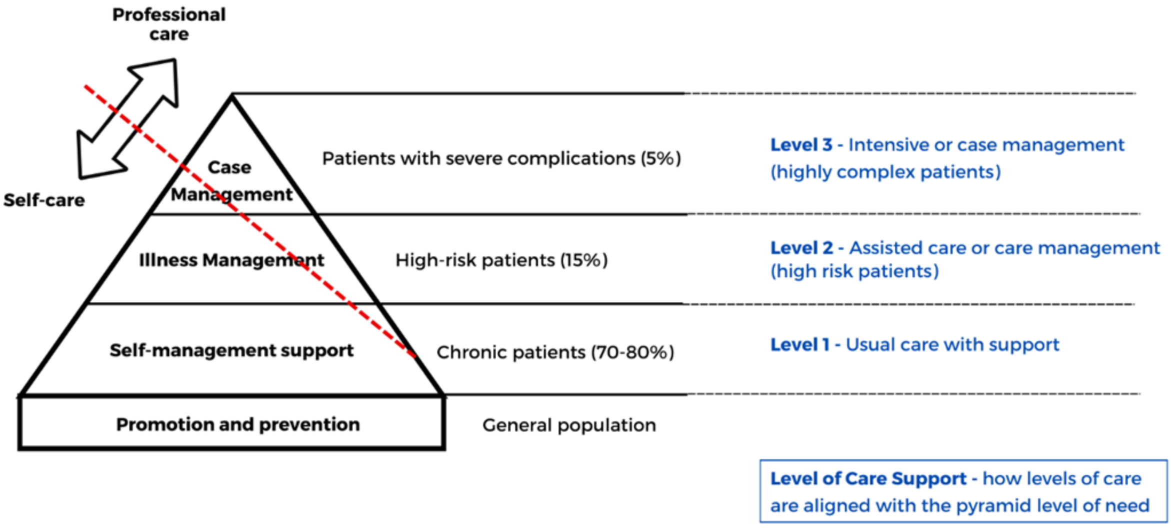
As part of examining hospitalisation data and what this means in levels of care, I mapped the data against a commonly used clinical framework in healthcare that is based on a population health model, Kaiser Permanente Pyramid of Care.

The Kaiser Permanente Model of care was first launched in the United States in 1941 by Henry Kaiser (Shipbuilder) and Doctor Sidney Garfield (Physician) to provide a healthcare model to the shipyard employees (Pines et al., 2015). It grew out of a need to contain acute care costs and keep employees out of the more expensive hospital system. Post World War 11, the model was developed into the 'Permanente Health Plan' and became accessible to the general public. It has remained relatively unchanged since its launch. The Kaiser Permanente Model of chronic care is known as a population based integrated chronic care model that stratifies care based on need (World Health Organisation, 2016). Patients are assessed and assigned to a level of care as represented by four levels within the Kaiser Pyramid. The foundation level is structured around health promotion and preventative care, and as diseases develop and chronic conditions are established, care is elevated from self-management to illness, with the most complex care needs met through a case management model (see Figure 3). Care is offered through multispecialty, team-based care that combines a primary and secondary care approach where generalist care is offered alongside specialist care (World Health Organisation, 2016). It encourages whole systems care where self-management and health education enables the patient to be central in health related decision making (Tsai et al., 2016). It is recognised by WHO as one of the leading models of care integration with a particular focus on complex chronic care management. Participants were mapped into each level of the pyramid (World Health Organisation, 2016) and key characteristics at each level were able to be identified.

The Kaiser Permanente model provided guidance in considering severity of illness against hospital avoidance and patient views on their illness. These three parameters were important to gain an understanding of the relationship complexity and deprivation. In the 2017 review of the renal patient data, it became clear that the renal patient group could be ranked in the top five percent of cases on the Kaiser Pyramid, already suggesting that these patients would do well to be case managed. Under the current health system of New Zealand, this is not the case. These patients are termed 'complex' but are not afforded any extra support. The use of the Kaiser Permanente pyramid, alongside the evaluation of patient views, hospital avoidance parameters and illness severity, it was anticipated that the threshold at which patients became a unique disparate group could be identified.

Figure 3

Kaiser Permanente Model with aligned levels of care

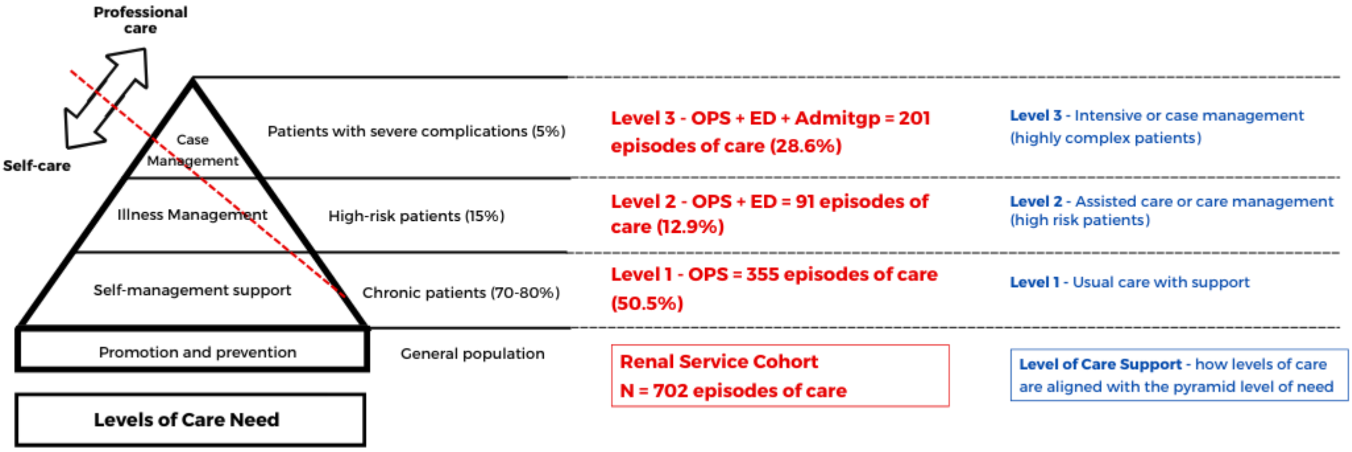


Kaiser Permanente Model with aligned levels of care (Extended Kaiser Permanente Pyramid, World Health Organisation, 2016, p.15)

Of the 647 enrolled renal service patients, who had 702 episodes of care, 63.5% have required elevated levels of hospital care beyond outpatient clinic appointments. Using the KP pyramid I mapped the renal service population as represented by the hospitalisation data against the Kaiser care pyramid tiers (Figure 4). Where the top tier (level 3 care support) represents the highest level of care needed indicated by the number of episodes of care involving all three categories, OPS (Group 1) + EDpresent (Group 2) + Admitgp (Group 3). The second tier represents Level 2 care needs, OPS + EDpresent, (Group 1 and 2) with the Level 1 tier of care support represented by OPS (group 1) only, not requiring elevated acute care through ED or Admission. The data suggests the need for top tier and case management support, is much higher in this population than the original pyramid model suggests should be needed (28.6% vs 5% in the original model). The model of care is still actively used within health care circles today, to guide management structures in appropriating care for identified populations. The data presented here suggests the model underestimates care at certain levels or at least for certain populations and especially when care is situated around people who have renal multimorbidity and more than one body system involved.

Figure 4

Current Care Pyramid



The implications of this misalignment extend far beyond theoretical concerns. When planning models systematically underestimate the proportion of patients requiring high-level care support, they create structural vulnerabilities within healthcare systems. Resources are allocated based on flawed assumptions, potentially leaving services chronically underprepared to meet actual patient needs. This situation is particularly concerning for renal patients with multiple body systems involved, whose complex care needs may be systematically underestimated by current planning frameworks.

The continued use of the Kaiser Permanente model within health care circles today despite evidence of its limitations reveals a deeper issue within healthcare planning systems. It suggests that established frameworks can persist even when they fail to accurately represent patient needs, creating a form of institutional truth that resists evidence-based challenge. This resistance to change may reflect broader systemic issues in how healthcare systems adapt to emerging evidence about patient care needs.

The data presents a compelling case for reconsidering how healthcare systems assess and plan for care needs, particularly for populations with complex conditions and multimorbidity. The significant disparity between predicted and actual high-level care requirements suggests that current planning frameworks may be contributing to systematic under-resourcing of healthcare services for complex patients. This understanding demands a fundamental reassessment of how healthcare systems plan for and allocate resources to meet patient needs when multimorbidity is present.

Examination of Triage Categories and Levels of Need for Care

The analysis in this section looks at whether there are differences between the proportion of visits within each month period and triage category presenting to the ED between patients in Groups 2 and 3. Renal patients who do not have a history of hospital admission (as a proxy of level of care) could potentially be accessing primary care first and if presenting to the ED would either not differ from expected values or present with more urgent care requirements as indicated by being assigned triage codes 1-3. In comparison it would be reasonable to expect patients in Group 3 to present to the ED with more urgency. The goal of this analysis therefore was to determine if there is a significant difference between cohort groups 2 and 3 in the expected and observed distribution of patients across triage codes (Triage 2, Triage 3, Triage 4, and Triage 5) in their presentation to the emergency department.

Overall, there were 702 (N = 702) episodes of care for groups 2 and 3 (n=292 i.e. 91 + 201) with 143 visits were recorded in Group 2 and 559 visits for the group 3. Table 7 shows the breakdown of the visits for those in the cohort subgroups and the count of triage codes of the ED visits. The median duration of the ED visit recorded was 205 minutes for group 2 (IQR 144 – 335, range 1614) and group 3 was 300 minutes (IQR 183 – 429, range 1613).

A chi-square test of homogeneity with post hoc analysis (Appendix Five) examined the difference in the proportions of triage codes observed and expected between Groups 2 and 3. The results demonstrated noticeable differences in how these two groups were assigned these urgency levels:

- Patients in the Group 2 were twice as likely to be given a Triage 4 code, which indicates a less urgent situation, compared to those in group 3.
- Patients in Group 3 were three times more likely to be given a Triage 2 code, indicating a much more urgent situation, compared to those in Group 2.
- There were no significant differences in the assignment of Triage 3 or Triage 5 codes between the two groups.

Table 7

*Levels of Care Triage Code * cohort group Crosstabulation*

	Cohort Group					
	Edpresent: Group 2		**Admitgp: Group 3**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
Triage Code						
Triage <2	12	8.40%	122	21.80%	134	19.10%
Triage 3	53	37.10%	261	46.70%	314	44.70%
Triage 4	66	46.20%	155	27.70%	221	31.50%
Triage 5	12	8.40%	21	3.80%	33	4.70%
Total	143	100.00%	559	100.00%	702	100.00%

These findings indicate that the emergency department may be being used by patients who have no previous history of hospital admission as an alternative for treatment in primary care (Group 2). In this group, the proportion of visits triaged as codes 4 and 5 made up 56.4% of presentations and the proportion of visits triaged as code 4 was significantly higher compared to the visits recorded for the patients who had a least one hospital admission (group 3). The odds of a patient visit to the ED in group 2 being coded as triage 4 is two times higher. Whereas, in those who have had a least one hospital admission (group 3) are three times more likely to be triage 2 or lower in the ED and are therefore more complex requiring higher level of care. While those who have no record of hospital admission are presenting to the ED with some risk identified as triage 4, the higher proportion in this category raises the question of whether primary care is being bypassed.

In review of the literature around ED utilisation, there are several proposed reasons as to why patients may choose ED over their primary care or community practice teams. This thesis does not offer an examination of these reasons but to offer suggestions that may help to gain an understanding of practices of multimorbid population groups:

Access barriers to primary care: Studies have shown that a significant proportion of patients cite access barriers to primary care as their reason for using the emergency department (Grumbach et al., 1993, Keho et al., 2023). Patients with a regular source of care tend to use the emergency department more appropriately than those without (Grumbach et al., 1993). This suggests that patients may turn to the emergency department when they face difficulties in accessing primary care services.

Willingness to trade emergency department visits for primary care appointments: Research has found that a considerable number of patients waiting for emergency department care express a willingness to trade their visit for an appointment with a physician within a few days (Grumbach et al., 1993; Rubin et al., 2006; Henninger et al., 2019). This indicates that patients recognize the potential benefits of receiving care in a primary care setting rather than the emergency department.

Lack of alternative sources of care: Patients may rely on the emergency department because they lack alternative sources of care (Grumbach et al., 1993). This is particularly relevant for individuals who do not have access to a primary care provider or face challenges in accessing primary care services (Moineddin et al., 2011). The convenience and ease of access to emergency services, relative to primary care services, may contribute to patients choosing the emergency department as their source of care (Moineddin et al., 2011).

Overutilization of emergency department for non-urgent conditions: Studies have shown that a significant proportion of emergency department visits are for non-urgent conditions that could be treated through non-emergency, primary care sites (Rust et al., 2008; Farion et al., 2015; Sieck et al., 2016; Kohe MacLeaod et al., 2023). This suggests that patients may be using the emergency department as a substitute for primary care for conditions that do not require immediate attention.

Inadequate availability of primary care outside office hours: The short supply of primary care outside office hours may contribute to patients seeking care in the emergency department instead (Sieck et al., 2016; Ellbrant et al., 2017). The availability of primary care, particularly outside office hours, plays a crucial role in reducing emergency department visits for low-acuity problems (Farion et al., 2015; Kang et al., 2020).

High utilization of emergency department by certain populations: Studies have found that certain sub-groups of patients, such as adolescents and individuals with inadequate health insurance or financial means to pay for primary care visits, rely heavily on the emergency department for their healthcare needs (Ziv et al., 1998, Henson et al., 2016; Kohe et al., 2023). There is a suggestion also that learnt behaviour and prior ED use may also contribute to high utilisation (Kang et al., 2020). This suggests that these populations may view the emergency department as a more accessible option compared to primary care.

The goal in reviewing Triage data for this cohort was to understand levels of care need as part of hospital service utilisation. The data suggests that this cohort of patients have increased levels of care need. They present sicker needing hospitalised care. The evidence suggests also that the emergency department is potentially being used by some patients as an alternative for treatment in primary care. Access barriers, willingness to trade emergency department visits for primary care appointments, lack of alternative sources of care, overutilization of emergency department for non-urgent conditions, inadequate availability of primary care outside office hours, and high utilization by certain populations all contribute to patients seeking care in the emergency department instead of primary care settings. Utilisation of ED and the need for admission signals access barriers, in the form of unavailable alternative to care, elevated need for care a renal patient does present outside of a normal clinic visit, potentially cost barriers and patient choice.

The next section extends the health system's voice through impact on the system through admission data following ED visit outcomes.

Examination of Patient Characteristics, Multimorbidity and Hospital Days of Stay and impact on care

One of the objectives in this thesis is to understand the characteristics of multimorbidity through CKDMM, it's influence on level of service utilisation relative to other variables such as deprivation. While this is a complex question the hospitalisation data does have its own voice and while limited and constrained within the boundaries of crude metrics it can provide some insight into service utilisation. This section seeks to explore which patient variables including body system counts (as a proxy for chronic conditions) influence the total days hospitalised. In this analysis, two or more body system recorded on admission is used to represent multimorbidity.

An admission to hospital indicates a higher level of need for care. The results are presented as a statistical analysis of patient variables influencing total length of stay which is defined as the total number of days hospitalised using a negative binomial regression model with robust estimations (see Appendix Five). The model accounts for potential overdispersion commonly encountered in count data. The research focuses on the effects of commonly accepted SDH that create disparities that are known to exist and impact on care including ethnicity, age category, gender and socioeconomic quintile, against body systems count on the total number of days hospitalised per patient in the renal cohort. The goal is to investigate the impact that the independent effects of patient variables have on the length of stay. These variables included ethnicity (Ethnic), Age as (Age), Gender (Gender), Socioeconomic Status (NzQuintile), and body systems count (BSC) as a proxy for morbidity count.

The key findings regarding patient variables influencing total days hospitalized in the form of Incident Rate Ratios (IRR) show that comorbidity by BSC and then are the strongest correlated factors (See Appendix Five). Number of BSC involved was also impactful where patients with four or more systems involvement were hospitalised at eight and half times more days than those with three body systems, who experienced four times more days and with two body systems were three times as many days than when one body system was involved (IRR=8.615, 3.984, 3.249 respectively). Age showed an influential bearing where patients >45-64 and 65 + were admitted to hospital with double the number of days in hospital as those in the <24-44 age groups (IRR = 2.006, IRR=2.054).

Other factors of SDH that included ethnicity, gender, socioeconomic status by quintile when compared with the interaction between age and gender, were not predictors of elevated levels of care associated with increased length of stay in hospital. Māori and Pasifika had less days in hospital (9.27 days) than NZ Europeans and other ethnicities combined (9.80 days) but did not reach statistical significance. Females were hospitalised for longer (10.43 days) than males (8.71days) and quintiles 4 (9.49 days) and 5 (10.77 days) from low socioeconomic status areas, had higher rates than quintile 1 with a higher socioeconomic status, where quintiles 2 and 3 (medium to high socioeconomic status) had the least days but again did not reach statistical significance (see Appendix Five for full model representation).

The estimated marginal means provides an average of the number of days hospitalised for each level of the predictor variables while holding all other variables in the model constant. The overall estimated mean for the total number of days spent in hospital over the data capture period was 9.53 days (se .929, 95% CI 7.88 - 11.54). I was not able to find any studies looking at LOS for patients with CKD in NZ or internationally but Wright et al. (2002) in their study suggest that patients with heart failure had a mean average of LOS in hospital of 6 days where the presence of renal impairment was impactful on LOS. This thesis study suggests that CKD patients have an even longer than average LOS with the mean at 9.53 days where increasing BSCs extended this further.

While there are limitations to this data the analysis highlights that body system counts (BSC) significantly impact the length of hospital stay, surpassing the influence of other factors such as ethnicity and socioeconomic status. Notably, patients with four body systems recorded on admission spent an average of 25 days in the hospital, compared to just 3 days for those with only one body system. This is signalling that indeed the number of chronic conditions by BSC may represent a unique point of disparity in relation to the level of healthcare need and impact in comparison to other SDH. Age also plays a role, with individuals over 65 years old experiencing an average hospital stay of 12.5 days. Although age shows a significant effect, particularly with a two-fold increase in length of stay compared to the 25-44 age group, it is not as influential as the number of body systems affected.

In summary, this data highlights the increasing complexity of care required by renal patients with multiple comorbidities in this small regional centre. When their health deteriorates, they commonly present for higher levels of care through the emergency department (ED), despite their presentation being able to be managed at primary care level or not. Presentation leads to higher admission rates and extended hospital stays, irrespective of age. The more hospitalisations that occur and the longer the length of stay increases the burden of care. The financial burden of dialysis is well recognized, but as Manns et al. (2019) demonstrate, costs to the healthcare system double at all stages of chronic kidney disease (CKD). These costs persist into ESKD, whether the patient is on dialysis or has undergone transplantation. But what is the alternative? Do we treat these patients to sustain life, or do we withhold care, knowing that the outcome—whether in days or years—is ultimately death, all while consuming healthcare resources? The games of truth exist with a neoliberal push for cost containment and expenditure rationalization at the government level that raises a critical question: at what cost? For renal patients, such policies are not just inadequate; they are fundamentally misaligned with the reality of their medical needs. This data strongly suggests that the usual directives—encouraging patients to seek care at the "appropriate level"—do not hold for those with renal disease. When these patients present with an escalated need for care, hospital admission is not just likely; it is often essential. Attempts to enforce cost-saving measures in this context risk prioritizing financial efficiency over patient survival.

A critical examination of the systems and the lost voices

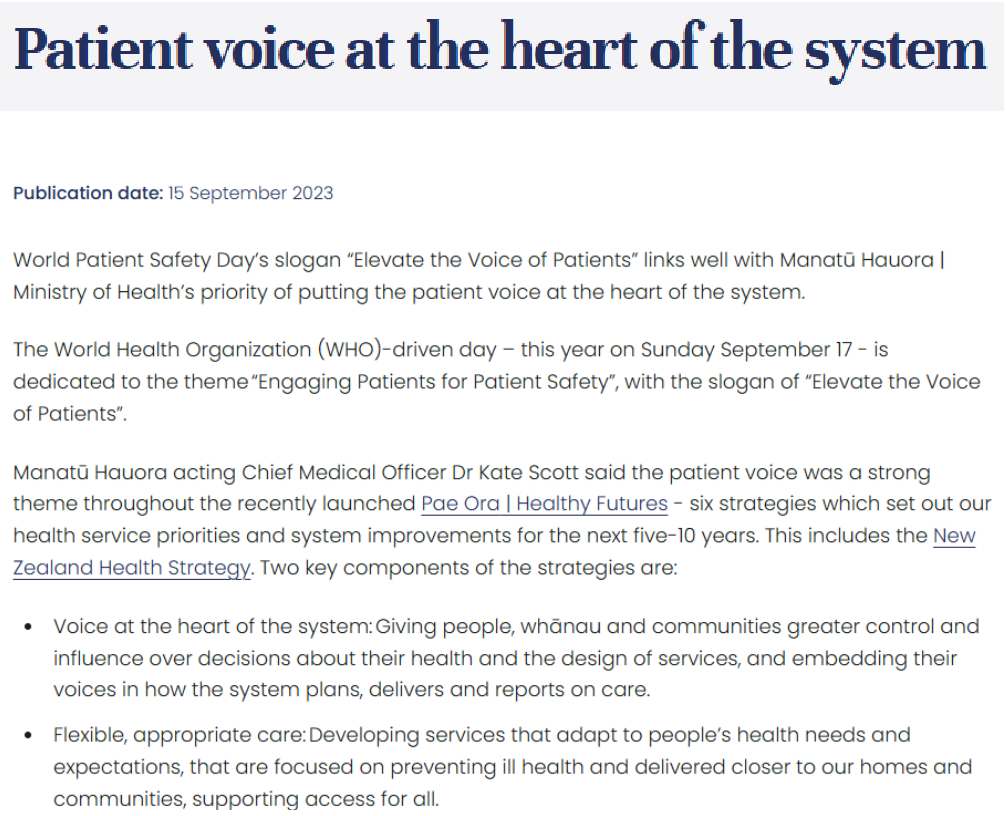
Based on the findings from the descriptive data in the previous section, is the realisation that a renal patient's voice is far from being heard. They are expensive, high-end uses of the public health services, and they always will be (Manns et al., 2019). In the face of clear messages that care must be tailored to a patient's needs, it is a paradox that the data that helps to inform funding, is ignoring this mandate, making the idea of weaving wellness into the health system null and void, certainly for the renal patient at least. After all, the highest users of the renal service are Māori.

Earlier in the chapter, the current instability of the national health system was described. The tension between acknowledging the needs of Māori driven health care and neoliberal intent was clearly emerging. The Treaty of Waitangi, which establishes a partnership between Māori and the Crown, mandates that Māori have equitable access to health services and that their cultural values are respected within the healthcare system.

Yet the neoliberal framework that New Zealand works within prioritises efficiency and cost-effectiveness over the holistic and culturally responsive care that Māori communities expect. This neoliberal approach was heralded in by a labour government in 1984, arguing that the 'crisis of the welfare state' needed to be urgently addressed (McMaster, 2013, p. 523) and which was a departure from the usual social democracy that labour traditionally supported (McMaster, 2013). As Roper (2024) notes, economic crises provide governments with "a convenient rationale for austerity measures, rolling-back of welfare policies, privatisation, attacks on unionised public servants, and the like" (p.44). Even as the health system of New Zealand has changed direction three times in as many years, one must surely acknowledge that a more wellness focused system is needed. In fact, as part of a globally driven goal to improve how the patient is heard within the health system, the World Health Organization promoted "Engaging Patients for Patient Safety", with the slogan of "Elevate the Voice of Patients". The NZ Ministry of Health (Ministry of Health, 2023b) quickly picked this up with a message on their website, demonstrated in Figure 5.

Figure 5

Statement by The NZ Ministry of Health



Patient voice at the heart of the system

Publication date: 15 September 2023

World Patient Safety Day's slogan "Elevate the Voice of Patients" links well with Manatū Hauora | Ministry of Health's priority of putting the patient voice at the heart of the system.

The World Health Organization (WHO)-driven day – this year on Sunday September 17 - is dedicated to the theme "Engaging Patients for Patient Safety", with the slogan of "Elevate the Voice of Patients".

Manatū Hauora acting Chief Medical Officer Dr Kate Scott said the patient voice was a strong theme throughout the recently launched Pae Ora | Healthy Futures - six strategies which set out our health service priorities and system improvements for the next five-10 years. This includes the New Zealand Health Strategy. Two key components of the strategies are:

- Voice at the heart of the system: Giving people, whānau and communities greater control and influence over decisions about their health and the design of services, and embedding their voices in how the system plans, delivers and reports on care.
- Flexible, appropriate care: Developing services that adapt to people's health needs and expectations, that are focused on preventing ill health and delivered closer to our homes and communities, supporting access for all.

The New Zealand Health Strategy, released in 2023 said this (Figure 6):

Figure 6

The New Zealand Health Strategy

The New Zealand Health Strategy vision and goals

The New Zealand Health Strategy will help achieve a shift in thinking, so that health is viewed as an outcome, and an enabler of wellbeing.

The New Zealand Health Strategy's vision of pae ora is underpinned by **two long-term goals.** These are:

- **to achieve health equity** for our diverse communities, and especially for Māori, Pacific, disabled and other groups who currently have poorer outcomes
- **to improve health outcomes** for all New Zealanders.

https://www.health.govt.nz/strategies-initiatives/health-strategies/new-zealand-health-strategy

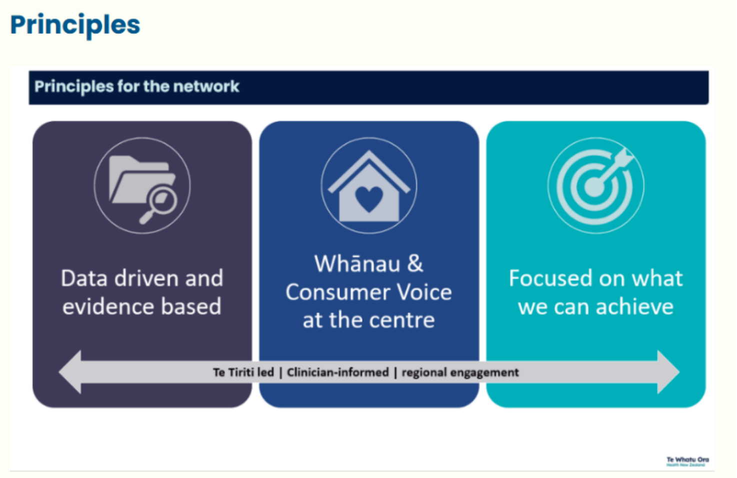
The Strategy continues by saying that these goals will be achieved by "Giving people, whānau and communities greater control and influence over decisions about their health and the design of services, and embedding their voices in how the system plans, delivers and reports on care", through the provision of "flexible, appropriate care" and developing "partnerships for health and wellbeing" (Ministry of Health, 2023a)

In keeping with the inclusion of the consumer (patient and family) voice the principal goal within the newly established National Renal Network revolves around the patient (TWO-HNZ, 2024b). This Network is a government appointed office of professional health experts specialised in renal care who are charged with improving how renal care is delivered in NZ (Figure 7).

Despite the government rhetoric supporting patient/public voices, the media has provided an alternate view of the reality, with articles highlighting the data error in Hawke's Bay, "losing 300 patients". The fact is, in addition to the risk to funding losses with incorrect data, the issue is closer to home. The lost patients in the system meant that recall for appointments was not followed through, meaning potential risk to clinical deterioration. Whilst the issue made the news, there was no response elicited from renal patients or their family. Instead, the Acting Chief Medical Officer "undeservedly apologised to those people [affected]" (RNZ, 2020, January 24th).

Figure 7

Principles of the National Renal Network. Te Whatu Ora New Zealand Health



Principles

Principles for the network

Data driven and evidence based

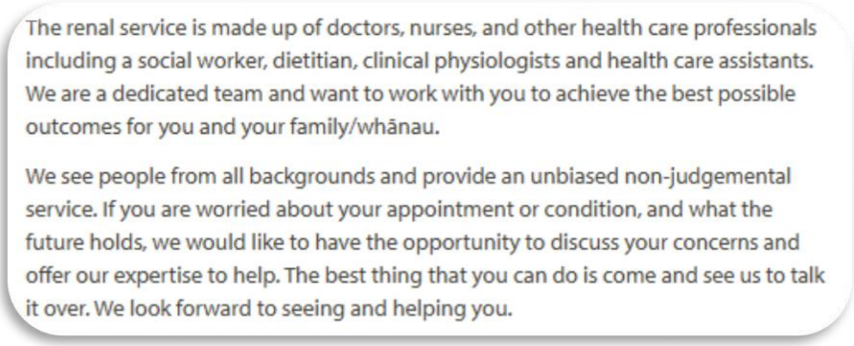
Whānau & Consumer Voice at the centre

Focused on what we can achieve

Te Tiriti led | Clinician-informed | regional engagement

Health New Zealand. (nd). Renal National Clinical Network.
https://www.tewhatuora.govt.nz/corporate-information/our-health-system/strategic-initiatives-in-health-research-and-innovation/national-clinical-networks/renal-national-clinical-network#

The only patient/public pushback was seen on the Hawkes Bay District Health Board's Facebook despite the Hawke's Bay Renal service's website stating that:



The renal service is made up of doctors, nurses, and other health care professionals including a social worker, dietitian, clinical physiologists and health care assistants. We are a dedicated team and want to work with you to achieve the best possible outcomes for you and your family/whānau.

We see people from all backgrounds and provide an unbiased non-judgemental service. If you are worried about your appointment or condition, and what the future holds, we would like to have the opportunity to discuss your concerns and offer our expertise to help. The best thing that you can do is come and see us to talk it over. We look forward to seeing and helping you.

(Te Whatu Ora Hawkes Bay, nd).

The National Renal Network promises data driven results, but it is difficult to be data driven when the data is incorrect. Users of the system have lost faith in the system's ability to see them. When events such as 'the lost patients of Hawkes Bay Renal Service, happen these become empty promises where it could be interpreted as "though we invite you in, we may not be able to keep you". Through events such as this everyone loses faith they can be cared for, the patient, whānau, staff and referring health professionals. This type of problematic messaging is then backed by the third principal that states "Focus on what we can achieve" which could be interpreted as "we do only what we can achieve". This suggests that even the system does not have faith in their ability to optimise outcomes or achieve what you need, when you need it. In some respects, this could be seen as enforcing healthcare's rhetoric of Self-Management that has become the main stay behind chronic conditions care, care for yourself in the best way you can as 'we' cannot do it for you.

The National Health body, Te Whatu Ora, continues the games of truth through messaging translated down the healthcare societal chain to a local regional level. At the meso level, the Renal Services front facing message for the renal population of Hawkes Bay on the Te Whatu Ora Te Matau a Māui (Te Whatu Ora Hawkes Bay) promises to work with you (the patient) and your whānau to achieve the best possible outcome. This supports the 'Network' goal of 'Whānau and Consumer Voice at the Centre'.

As much as the government make certain healthcare promises in the form of principles this is not the reality of the renal population. The system is constrained by the burgeoning cost of healthcare in its ability to see these goals through. In this, the patient is lost, literally lost! This is demonstrated by a significant event that was recognised in January 2020 where over 300 patients were found to be lost to the system. There were 647 (n=647) patients enrolled in the service identified by NHI (hospital) number for the twelve-month period of data collection. I was surprised by the number as anecdotally through my knowledge of the service, I had expected to see a figure of around 800-850 enrolled patients over this time-period. This discrepancy made me go back and look at the events that occurred during that period attributed to a systems data error event that involved the renal service enrolled patients over late 2018 to Jan 2020. I discovered this error early January 2020 and ended up leading the resolution management at a service level for the organisation. This involved approximately 300 patients identified by NHI who had follow up appointments and timeframes affected were data was not entered correctly and NHI numbers were lost to follow up. The error extended across the twelve-month period between the end of 2018-Jan 2020. As a result, many NHI's (patients) appeared to have been discharged from the service incorrectly in late 2018. There was also an additional 24 NHI numbers registered with the service in this data query that did not have information on service utilisation and therefore were not able to be included in the count. The 'lost patients' was a significant event that carried a high clinical risk and was consequently reported by media and news stations throughout New Zealand;

RNZ
https://www.rnz.co.nz › news › top › data-error-leaves-3...

Data error leaves 300 renal patients with missed follow-ups

24 Jan 2020 — Three hundred renal **patients** have been caught up in a data blunder at Hawke's Bay district health board.

Missing: ~~Lost~~ | Show results with: Lost

(RNZ, Accessed 1.10.24. https://www.rnz.co.nz, Accessed 1.10.24)

1News
https://www.1news.co.nz › 2020/01/24 › hawkes-bay-dh...

Hawke's Bay DHB scrambling to check up on 300 patients ...

24 Jan 2020 — More than 300 **renal** patients in **Hawke's Bay** have had to be recalled for appointments and one patient may have been affected due to a "**data** ...

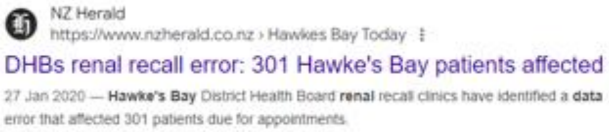
(1News, Accessed 1.10.24. http://www.1news.co.nz,)

Facebook · 1News
120+ reactions · 4 years ago

Hawke's Bay Hospital scrambling to check up on 300 patients

EXCLUSIVE: **Hawke's Bay** DHB is scrambling to check up on 300 pat caught up in a **data** blunder. People with potential **kidney** problems ...

(1News, Facebook, Access 1.10.24. https://www.facebook.com/watch/?v=2504946903107196)



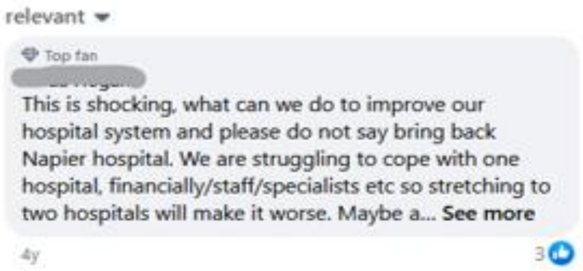
NZ Herald
https://www.nzherald.co.nz › Hawkes Bay Today

DHBs renal recall error: 301 Hawke's Bay patients affected

27 Jan 2020 — **Hawke's Bay** District Health Board **renal** recall clinics have identified a **data** error that affected 301 patients due for appointments.

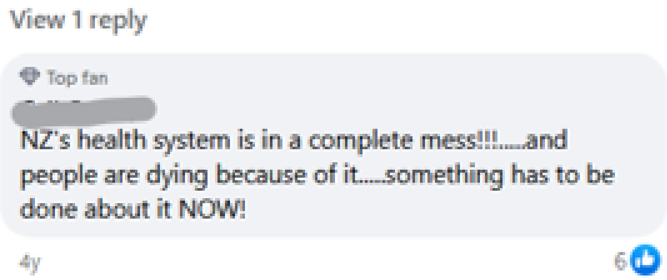
(NZ Herald. Accessed 1.10.24. https://www.nzhearld.co.nz)

On social media the news reports generated considerable public attention and backlash;



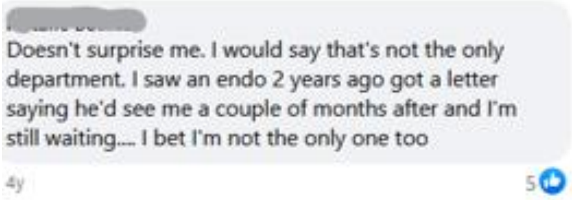
[redacted]

This is shocking, what can we do to improve our hospital system and please do not say bring back Napier hospital. We are struggling to cope with one hospital, financially/staff/specialists etc so stretching to two hospitals will make it worse. Maybe a... **See more**



[redacted]

NZ's health system is in a complete mess!!!.....and people are dying because of it.....something has to be done about it NOW!



[redacted]

Doesn't surprise me. I would say that's not the only department. I saw an endo 2 years ago got a letter saying he'd see me a couple of months after and I'm still waiting.... I bet I'm not the only one too

(Facebook. https://www.facebook.com/watch/?v=2504946903107196. Accessed 1.10.24)

A critical examination of four media articles and public social media response contained in this table reveals multiple competing narratives. The institutional voice, represented by the DHB's (now known as Te Whatu Ora Hawkes Bay) official communications, framed the incident as a "data issue," using language that acknowledges responsibility while maintaining organizational control. The Acting Chief Medical Officer at that time’s statement to media is typical of how institutions manage public communication during the crises and attempt to rebuild trust and reassure "the DHB unreservedly apologised to those people" and that "All patients have, and are still, being personally phoned to advise of the error, apologise and arrange an appointment as soon as possible". However, the resistance to the expected rhetoric is clear in the expressions of mistrust and frustration in the system as indicated by one commentator:

> typical alrite, an alwayz trying find excuses, my daughter being in out for the last year, her last 3 stay in's they didnt even pick it up, her kidney wasnt good, 👍🏿 to the chinesse dr chee, well dr in my eyes, sad hastings hospital, playing with lives. (Facebook. https://www.facebook.com/watch/?v=2504946903107196. Accessed 1.10.24.)

Another states bluntly:

> NZ's health system is in a complete mess!!!.. and people are dying because of it …. something has to be done about it NOW!
> (Facebook. https://www.facebook.com/watch/?v=2504946903107196. Accessed 1.10.24.)

These and other public comments that represent the micro level patient voice, point to deeper systemic issues where the administrative error is viewed as symptoms of broader organizational problems related to resource allocation and management priorities. As one commenter notes:

> “Understaffed and over worked! They never have enough admin because they are always trying to save the budget! It starts at the top trying to stay in the black!"

The public discussion also generates proposals for structural solutions: "Yes HB

> needs 2 hospitals not 1. That way we can get more staff. There so overworked and underpaid." "Doesn't surprise me. I would say that's not the only department. I saw an endo 2 years ago got a letter saying he'd see me a couple of months after and I'm still waiting” (Facebook. https://www.facebook.com/watch/?v=2504946903107196. Accessed 1.10.24.)

The real-world impact of this administrative failure is acknowledged in the report that "the DHB has identified one patient whose condition may have deteriorated because of the delay." To which the public response was emotionally charged "Not Fricken any where good enough for any person to be in this situation my heart goes out to u."

Overall, the competing narratives - between technical error and systemic failure, institutional reassurance and public scepticism - demonstrate how different stakeholders understand and interpret healthcare system failures. Notable from all the media articles and social media comments is the silencing of the patients themselves. There was not one quote or comment from any one of the 300 affected. Not only does this highlight how easily the voice of our most vulnerable is lost within the system but also to the debates that rage on and how very easily their voice is silenced. This was the shameful reality for the 300 renal outpatients in the Hawkes Bay in late 2018 to Jan 2020.

Games of Truth: System and Public Perception

This chapter sort to understand the macro level experience of the renal patient population evidenced by use of the secondary care health system guided by Government level policies and promises, through a Social Order Lens.

Through Foucault’s construct of the ‘games of truth’, the patient has to navigate a myriad of truths in the pursuit of health care. Government led health policies enacted by the various agencies entrusted to deliver health care make promises on one hand but fail to support an environment that is conducive in ensuring this can occur. The media and social media also shape how we view this care and can act as a ‘watch dog’ but also silence those it seeks to defend. For the patient requiring care self-agency and access to health care and the assumptions that underly the determination of vulnerability also contributes to these myriads of truths. These are the themes that have emerged from discourses explored in this chapter and are now discussed in response to the thesis question posed in chapter one “What are 'games of truth' in the healthcare system of patients within a regional secondary care renal service and how are they discursively constructed? Highlighting the NZ ties to global neoliberal policy, one commenter on the Hawke’s Bay Facebook page said “About time our government stopped paying 15 billion dollars to the UN every year and spent it at home instead.”

Institutional Goals and Operational Failures

The complex relationship between institutional goals and operational failures within regional secondary care renal services reveals critical tensions in how healthcare truth is constructed and maintained. The data error affecting three hundred renal patients at Hawke's Bay DHB serves as a critical incident that exposes fundamental contradictions between institutional truth claims and operational realities within a modern health system, in this case renal care delivery.

Within the framework of healthcare delivery, the National Renal Network, established during the 2022 healthcare system restructuring, constructs its truth claims through expert authority and systematic organization. The network was charged with improving how renal care was delivered at a national level becoming the systems voice for the basis of renal care. These institutional truth claims manifest most prominently in the rhetoric of patient-centered care, evident in statements like:

> We are a dedicated team and want to work with you to achieve the best possible outcomes for you and your family/whānau. (Te Whatu Ora Hawkes Bay, nd).

Such rhetorical commitments to patient engagement align with global initiatives, including the World Health Organisation's promotion of "Engaging Patients for Patient Safety" and "Elevate the Voice of Patients." However, the operational reality reveals a significant gap between these aspirational truth claims and actual system performance. The systemic failures revealed through the loss of patients to administrative error represent a powerful counter-truth to institutional claims about system capability. The telling observation that "though we invite you in, we may not be able to keep you!" exposes a stark contradiction between institutional rhetoric and operational reality. This administrative failure, affecting patient recall appointments after initial specialist assessment, fundamentally challenges the truth claims about system competence and patient safety.

These contradictions extend deeper into the power relations between institutional authority and system accountability. While the National Renal Network maintains its position as the "systems voice for the basis of renal care," the actual loss of patients through administrative error highlights the limitations in how this authority translates into effective patient care. This disconnect exposes critical tensions between institutional power and operational capability, raising questions about the nature of healthcare truth itself. The erosion of patient trust through these system failures presents a fundamental challenge to institutional truth claims about healthcare quality. When patients become invisible to the system designed to care for them, it undermines not only individual experiences but also the broader truth claims about patient-centered care and system effectiveness. This invisibility creates a form of structural vulnerability that particularly affects patients with complex care needs and multimorbidity, revealing how institutional failures create new forms of healthcare inequality.

These tensions have deeper implications for healthcare delivery. The significant gap between rhetorical commitments and system capabilities suggests an urgent need for more robust mechanisms to maintain patient visibility, better alignment between institutional claims and operational capacity, and stronger frameworks for system accountability. Moreover, the integration of patient experience in system design emerges as a critical factor in bridging this gap between institutional truth claims and lived reality. This is further impacted by out of date funding models used to position care designed in an era where health systems were yet to experience the changing face of healthcare that multimorbidity brings. Adding to the games of truth where the potential failure of our care stratification models such as the Kaiser Permanente Care Pyramid may underestimate the level of care required by multimorbid renal patients and suggest that funding models are not accurate or appropriate for the changing needs the emerging multimorbid population seen in healthcare today.

The 'games of truth' within regional secondary care renal services thus reveal fundamental tensions between institutional goals and operational realities. The loss of patients exposes how institutional truth claims are fundamentally undermined by system inadequacies. This suggests that effective healthcare delivery requires not just better administrative systems, but a fundamental reconceptualization of how healthcare systems construct and maintain truth about patient care. Only through addressing this gap between institutional rhetoric and operational reality can healthcare systems create more effective and accountable services that truly serve patient needs.

Vulnerability, Multimorbidity and Care

The institutional structure of healthcare truth-telling, governed by national policies and directives, creates a framework that potentially obscures the independent impact of multimorbidity on patient outcomes. While the data presented in this chapter demonstrates that patients with multiple system involvement experience significantly longer hospital stays, this stark reality remains largely unappreciated in institutional discourse about healthcare vulnerability and access. As discussed in chapter one, current healthcare discourse privileges social determinants of health in understanding vulnerability and access to care. However, this emphasis may inadvertently mask how multimorbidity creates its own form of vulnerability that transcends socioeconomic status. Where, even specialized healthcare networks may not fully acknowledge the independent impact of multimorbidity on patient outcomes and care needs. Professional truth claims within the healthcare system often focus on single-condition management, which may underestimate how multiple conditions create compound vulnerabilities that exist independently of social determinants.

While a crude and blunt tool the hospitalisation data examined in this chapter does strongly suggest that multimorbidity's independent impact on health outcomes challenges current truth constructions about existing discourses of vulnerability for patient’s living with multimorbidity. This represents a significant 'game of truth' where hospital data evidence confronts established institutional understanding of how healthcare prioritisation of access and equity is universally applied to all patients regardless of their clinical status. The fact that this truth remains "hidden in plain sight" suggests a systematic blind spot in how healthcare systems construct and understand patient vulnerability. The power relations within healthcare systems tend to privilege single-condition expertise and social determinants of health creates a situation where the independent impact of multimorbidity on healthcare outcomes remains underrecognized despite clear evidence of its significance and despite its intuitive logic. The current structure of healthcare truth-telling may inadvertently perpetuate this blindness through fragmented care pathways and siloed expertise.

The burgeoning cost of health care has seen the advent of self-management to improve outcomes and improve how life is lived. Self-management has become a strategic tool as part of health care cost containment, promoting individual responsibility for their healthcare and outcomes, and is employed as part of hospital avoidance (Gauthier-Beaupre et al., 2023). What the hospitalisation data in the thesis also suggests is a disconnect between self-management and the actual lived experience wrapped in barriers of access, affordability, and confidence that care will be available. There is evidence of the need for step up care seen through ED presentations, triage codes, need for admission and length of stay. The reality of the renal patient with MM, self-management is an elusive concept. Despite this, Hospital data suggests patients assert their own agency irrespective of when and where they access care. The growing difficulty in acquiring a primary care appointment, that has time limited access, forces the patient to seek care where and when they can. This challenges the construct of Institutional power vs individual agency. Furthermore, the continued use of historical frameworks such as the Kaiser Permanente model can be challenged when used in assessing and planning for care needs, particularly for populations with complex conditions. But as shown in this chapter, may well be inadequate for capturing the complexity of patient care needs, potentially contributing to systematic service gaps.

Summary

The analysis of 'games of truth' within regional secondary care renal services reveals fundamental tensions between institutional frameworks and lived patient experiences. These tensions manifest most prominently in three critical areas: the disconnect between the Kaiser Permanente model's predictions and actual care needs, the invisibility of multimorbidity's impact regardless of social determinants of health, and the systemic loss of patients through administrative failures that highlight the irony of ‘patient-centered’ care. Moving beyond traditional frameworks to develop new models is required. These should reflect the complex realities of patient care needs and system capabilities that align institutional truth claims with operational realities while maintaining sight of the fundamental goal: providing effective, equitable care for all patients, regardless of the complexity of their care needs. Only through such realignment can healthcare systems hope to provide truly adequate and effective care for all patients.

This chapter identifies the various voices of the health system and how the perspectives of truth are influenced, why, by whom, and where health organisations are struggling to meet government level aspirations, leaving the patient lost in the system. Chapter five now positions the analysis of the data that represents the meso social order, importantly, the patients, through conversation interviews and the completion of QoL surveys by volunteer participants.

Chapter Five

Establishing Own Voices

In keeping with Fairclough's social orders and social orders of discourse, this chapter represents the 'voices of the patients', which is the meso level of social order. The accounts of the interviewed patient cohort are detailed, people who bravely volunteered to tell their stories in the hope they will be heard. In the previous chapter, we explored the invisibility of the patients overshadowed by the Health Systems voice where the broken rhetoric is exposed, promises made but unable to be kept due to structural issues that exist in attempting to care for our community. It represented the reality from within the hospital data system through numbers, news stories and media accounts, to describe to a certain extent, an aspect of what living with CKDMM is like.

Data is powerful and difficult to dispute making it the vehicle of choice for the positivist who seeks purity with simplicity. Data tells us one story but people who live and experience a different daily reality, have another story to tell that is complex and complicated. This chapter is presented in two subsections that draw on the themes from narrative accounts, and QoL survey results. For themes from interviews, I have included an overall messy map and then subgroup messy maps with each major theme to help demonstrate the complexity the renal patient experiences in their navigation of the health system. The participants were asked to complete QoL surveys (the Meke Meter and Flannagan's' QOL) at the time of interview to gain another perspective of daily living. These accounts together provide a rich narrative for analysis. Emerging from these two sources of narrative, was the juxtaposition of the patient, on the one hand portraying the struggle that their renal illness journey is but also highlighting the capacity to have hope. This chapter explores how the use of such surveys contributes further to the 'games of truth' and what's hiding in plain sight in respect of the health systems attempt to understand what makes life better and improve the way we care. This chapter is positioned to answer research question two: "How do patients with chronic illnesses construct and negotiate 'games of truth' about their condition and treatment through their narrative accounts, and how do these constructions reflect and potentially challenge dominant medical discourses?" This chapter shares incredible insights into the lived experience of these people and taught me so much more than what 37 years of observing peoples' lives, had.

Interviewed Participants - Sub Cohort of Renal Service Population

Eighteen people from the renal cohort accepted the invitation to be interviewed for this study and completed the QoL surveys. The intention was to have 20 interviews. However, data saturation occurred at interview seven, therefore no more interviews were sought beyond eighteen. In the additional eleven interviews after saturation was tentatively established, the only theme that was more prominent was that of 'faith', though this was identified in some of the early interviews as well.

Characteristics of the Interviewed Cohort

The participants (n=18) all came from the Hawkes Bay region and were of varying ages, gender, ethnicity, age, and decile rated locations. All participants had reached the stage of ESKD and were receiving renal replacement therapy with eight participants on dialysis and ten participants having received a kidney transplant. It is reasonable to assume that the reason all participants who volunteered for this study, relates to the fact that people with ESKD are the highest users of the renal service and therefore were regularly exposed to the recruitment method used to advertise this study, such as the flyers within the clinic environment. Once in ESKD, then utilisation of the outpatient service environment becomes significant with some participants who are on dialysis as part of renal replacement programs, being seen three to five times per week. In this section, the use of the word participants refers to the interviewed cohort.

The average age of the participants was 52.8 yo with the youngest at 29yo and the oldest of 69yo. Females were more represented than males with eleven women who had an average age of 50yo and the youngest age of 29yo, and seven men with an average age of 56yo and the youngest being of 41yo.

The most represented ethnicity identified was Māori, where ten participants noted this as there first identified ethnicity, and within this group, two participants recorded a second identified ethnicity of NZ European. The breakdown of ethnicity were Māori – 55.5%, Pacifika – 16.6%, NZ European – 22.2%, Asian/NZ European – 5.5%. Most participants lived in the lower decile rated areas of Hawkes Bay with fifteen living in the seven to ten decile and most deprived areas. Three participants are living in decile ten areas as the very most deprived areas of Hawkes Bay. Two participants lived in the more affluent areas (decile three) and one participant lived in the middle band of decile rated areas (decile five). Over half of the participants (n=8) were currently in paid employment. The participants who were employed, had also received a kidney transplant and were no longer dependant on dialysis services. Therefore, potentially had improved health status where their time was not dependant on being present for frequent dialysis allowing them the time to engage in employment. The majority of participants came from the two larger metropolitan areas of Napier city (n=7) and Hastings city (n=7), with the remaining four living in rural townships. Tables 9 and 10 provides breakdown statistics for this subgroup cohort.

As this chapter identifies, the larger cohort group are typical of what is known about people who develop CKD in the NZ context with multimorbidity represented here as systems involvement (Huira et al., 2020). Non-Māori represent most of the ethnic groups by identity in the overall renal cohort, but Māori are the largest single ethnic group in the interviewed cohort. They were also younger, live in lower areas of deprivation and more likely to be unemployed. These findings are similar to other reported studies in NZ (Sullivan et al., 2023; Ministry of Health, 2023; Dixon, 2015). Seven of the eight participants who were unemployed identified as Māori or Pacifika. The subgroup was aligned with the overall group, where Māori were the highest recorded single ethnicity. But in the participant group women were representative more than men and at a younger age. This has been noted in previous studies looking at chronic conditions, were gender assumed a significance and women developed comorbidity more prominently than men, likely due to women's longer life expectancy. This was seen to be more prominent in older age >65 years of age (Abad-Diez et al., 2014; Alimohammadian et al., 2017, Cassell et al., 2018). Cassel et al. (2018) found within their study of multimorbidity in England, that women develop primary morbidity at a younger age. However, the overall renal service cohort group did not find this.

Table 8

Interviewed Cohort Group Demographics

Demographic	**n=18**
First Ethnicity	
Māori	10
NZ European	4
Pasifika	3
Chinese	1
Second Ethnicity	
NZE	
Māori	4
NZ European	-
Pasifika	0
Chinese	1
Location	
Hastings	7
Napier	7
Wairoa	3
Waipukurau	1
Gender	
Female	11
Male	7
Decile Bands	
0-3	2
4-6	1
7-10	15
Employed	
Yes	10
No	8
Ave. age (years)	52.8

Table 9

Interviewed Participants Cohort Demographics

Coded	Ethnicity	Age (Yrs)	Gender	Employment	Decile
A	Māori	54	F	Y	8
B	NZ European	41	M	Y	8
C	Māori/NZ European	55	M	N	10
D	Māori	59	M	N	10
E	Cook Island	65	M	N	8
F	Māori	40	F	N	7
G	Māori/NZ European	55	F	Y	9
H	NZ European	63	M	N	5
I	Samoan	58	F	Y	8
J	Māori/NZ European	29	F	Y	8
K	Māori	69	F	N	10
L	Māori	49	M	Y	8
M	NZ European	37	F	Y	8
N	Tongan	62	M	N	10
O	Chinese/ NZ European	59	F	Y	3
P	Māori	56	F	Y	7
Q	Māori/NZ European	65	F	N	3
R	NZ European	32	F	Y	10

In NZ studies, ethnicity and socioeconomic factors have been found to be the main drivers of multimorbidity and need for healthcare (Ministry of Health, 2023; Aminisani et al., 2020; Gurney et al., 2020, Signal et al., 2017). Results from this Cohort (renal services) and sub cohort (participants) of this study support the findings of these NZ studies where being older in the 65+ age group, living in low deprivation rated areas and of Indigenous descent have a higher need and therefore risk for elevated hospital service utilisation.

Participant Interviews: brush strokes of life

Introduction

Understanding the lived experience of CKD with multimorbidity is the driving process for this study. Participants from the larger renal service cohort were invited to participate in a conversational style interview. Participants were also encouraged to have a whānau member present during interview if they wished to. Several of the participants invited their family to join. This is identified in the participant quotes cited here as a second or third speaker. Interviews were held between May 2022 and September 2022, conducted by a nurse research assistant who also identifies as Māori. There was no time limit applied to interviews where the shortest interview was 57mins and the longest was 147mins. Overall, there were five Major themes, 56 secondary themes and 62 tertiary themes (see Table 10). A mind map concept was utilised to analyse and unpack the conversations and developed the data into themes. Figure 8 is a visualisation of the map of the over-all themes. I have also included the mind map at the beginning of each new major theme and subtheme grouping. In describing these themes, certain groups also appeared, and I have clustered these together where this made sense to do so. As a result, the mind maps may vary slightly in the way the theme has developed.

The major themes derived from the participant interviews were characterised under five main headings: Mental Health; Loss and Hardship; Impact on Self and Whānau/Family; Healthcare Teams; and Support. Each major theme was then further categorized by secondary and tertiary themes. There were several overlaps between categories of subthemes that presented in slightly different ways therefore these have been included in each category they relate to. Table 10 identifies the major theme, related subtheme, and tertiary theme. The structure for the analysis and descriptions of the themes follows the identification of the theme group followed by descriptions of the subthemes. Participant quotes are used to illustrate and support the theme description and allows the participants voice to be demonstrated. In the writing of this thesis, American Psychology Association (APA) 7th edition has been followed as part of the requirements when completing a PhD with Massey University. However, I have deviated from the strictness of this format in inserting participant quotes. This was to allow the quote to be prominent and easily identified as the important text. APA 7th utilises a different formatting depending on the length of the quote. The quotes in this thesis are of varying lengths were strict format distracted from the sense of the quote. Therefore, all quotes are identified by the participant A, B or C etc and by the time script within the transcription for reference if needed.

Figure 8

Mind Map – Overall themes

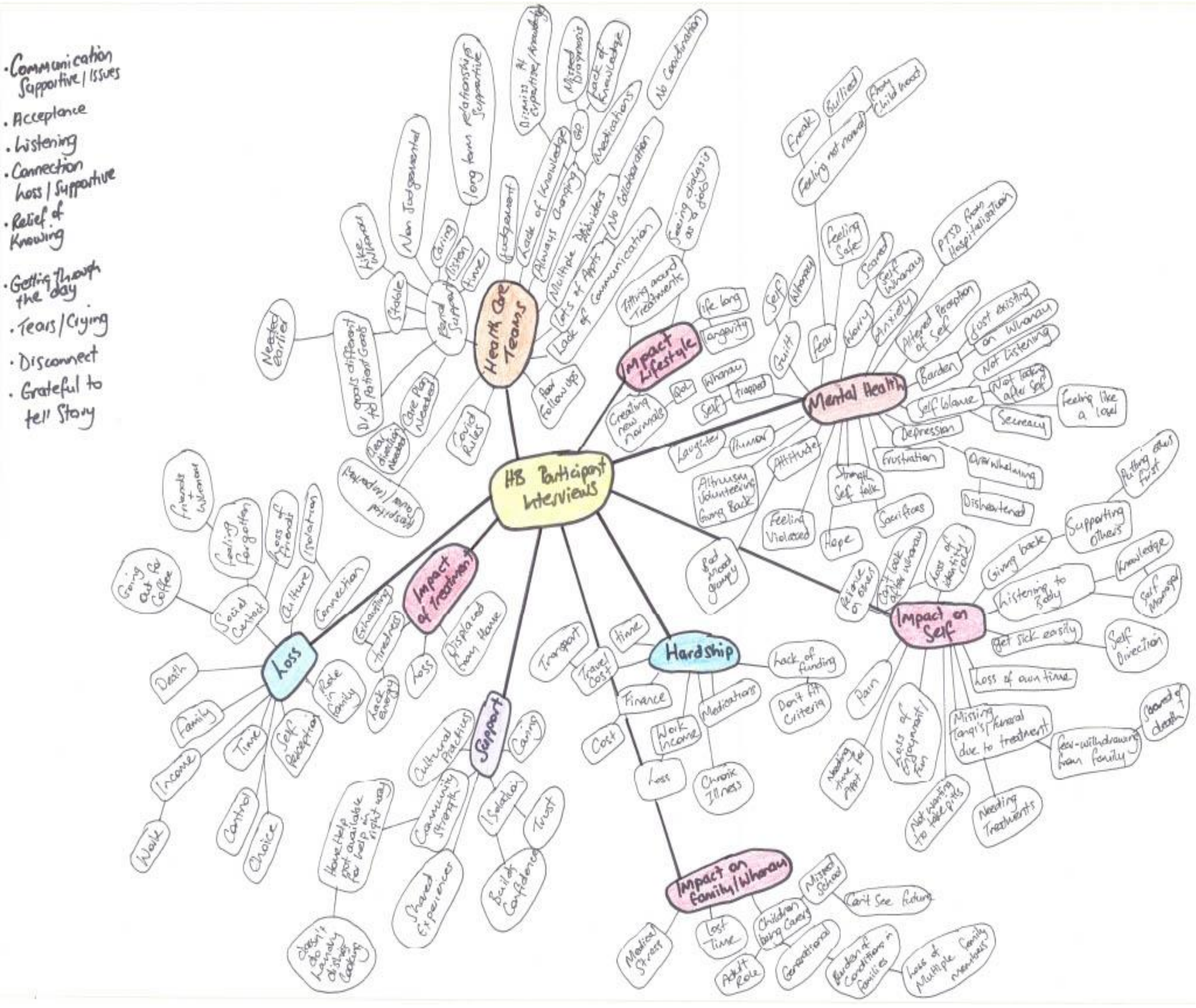


Table 10

Major Themes and Subthemes

Major Themes	Sub Themes	Tertiary Themes
Mental Health Impacts: emotional, psychological, social wellbeing	Group One: fear, worry, anxiety, burden, depression and altered perception of self. Group Two: trapped, guilt, frustration, lost sense of fun, enjoyment and loneliness. Group Three: self- blame, sacrifices and struggle. Group Four: attitude, humour, altruism, faith and hope	Unsafe, hospital procedures, PTSD from hospitalisations Not normal, freak, bullied, health, whānau, self Robbing Peter to pay Paul, Just existing, burden self and whānau, disheartened, overwhelmed, good days/bad days, struggle, moody, grumpy, lazy, long days, health professional's attitude, embarrassed, self-talk, volunteering, giving back, laughter, acceptance, faith, pray and meditation
Loss and Hardship	Loss of sense of Self Loss of culture Loss of Finances: self, whānau Loss of employment Cost Lack of funding to meet costs. Time Displaced from home	Loss of identity, connection, confidence, sense of safety Cost: treatments, prescriptions, travel, GP

Major Themes	Sub Themes	Tertiary Themes
Impact on self/Impact on Whānau and Families	Self: Pain, Disability, Loss of functionality, Loss of independence Living by hospital rules Frustration: Not being listened to Fear of dying Sense of burden on Whānau, Reliance on Whānau/family Whānau/ Families: Leaving dependants to attend medical treatments. Medical Stress Children as Carers Missing important Whānau events Burden, isolation, altered future plans. Fear of losing loved ones. Repeated Generational experiences of Chronic conditions	What impacts on self also impacts on Whānau
Healthcare Teams	Renal Service: Sense of Whānau, Support, Stability, Goals of Care, Navigators,	caring, listening, nonjudgmental time and contact consistency, relationships, personnel knowledge patient goals vs Dr goals, needed earlier, clear directions, care plans
	Other Health Services: Multiple providers, Attitude, Caring, Changing Providers, Covid Rules,	appointments, communication, coordination, collaboration, follow up, medical visits, violation differences, GP, medications, missed diagnoses, knowledge, judgement, isolation, perception
Support	Community, Cultural, Home, Travel, Whānau, Worship	Funding, caring, shared experiences, confidence, strength, and trust

Major Theme One: Mental Health – Impacts

From the Hawkes Bay patient interviews, one of the strongest major theme to emerge concerned Mental Health, which was characterised by 19 secondary, and 36 tertiary themes (Figure 9). These themes suggested an impact on emotional, psychological, or social wellbeing and were expressed as thoughts and actions or in many cases as emotion through crying and tears. My first sense of mental health impact on this patient group is one of struggle and sadness but also resilience and strength.

Within the Mental Health theme, there were four distinct groupings of subthemes. These presented in the following way: theme one subgroup as fear, worry, anxiety, burden, depression and altered perception of self; theme two subgroup were feeling trapped, guilt, frustration, lost sense of fun and loneliness; the third theme subgroup was self- blame, sacrifices and struggle; and the fourth theme subgroup related to coping mechanisms, and these presented as attitude, humour, altruism, and hope.

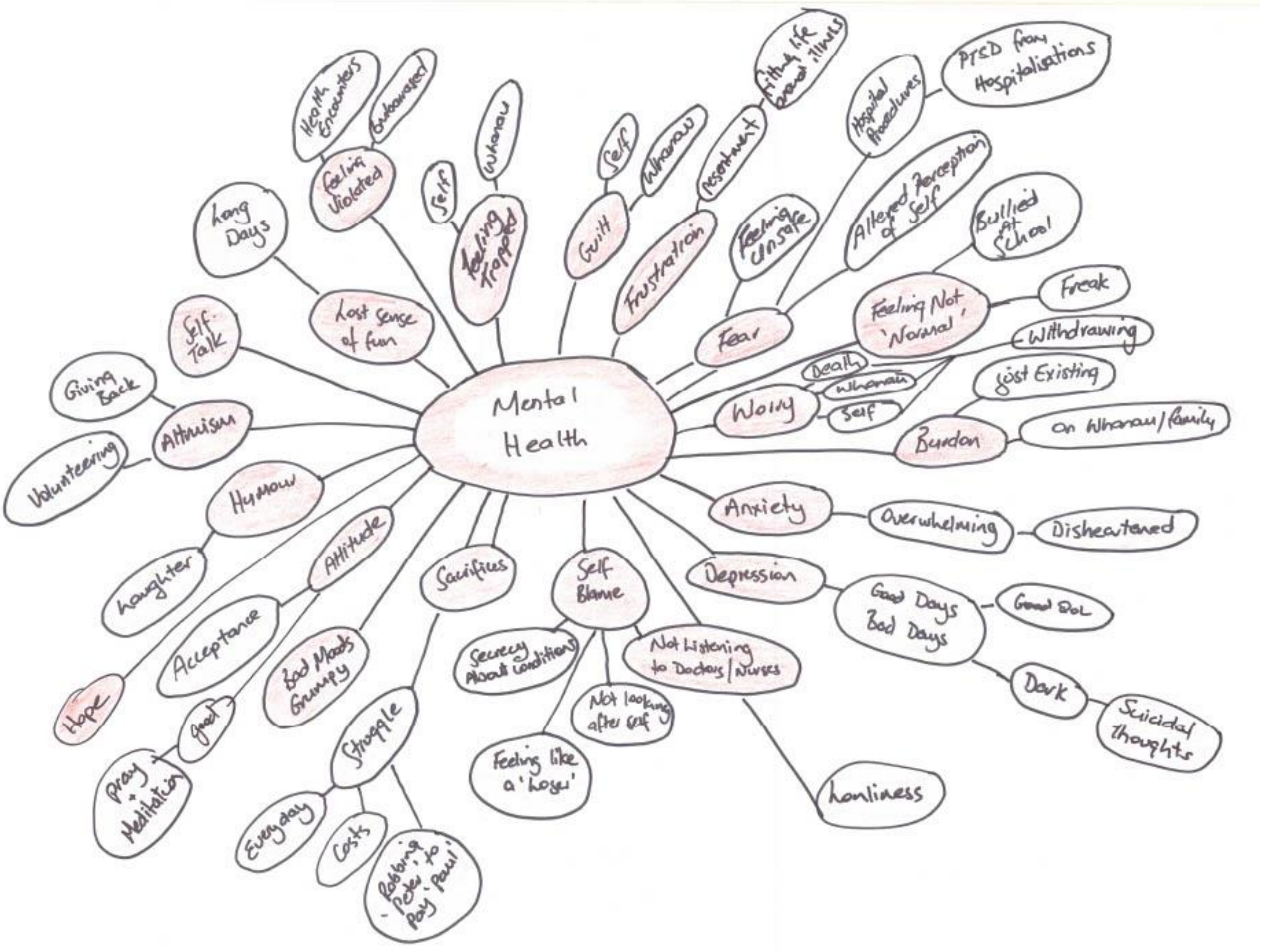
In identifying the theme, I have examined the characteristics of each grouping as described above, providing the context in which they presented. To emphasise the theme, I have included participant quotes that best describes the theme.

Theme Subgroup One: fear, worry, anxiety, burden, depression and altered perception of self

This grouping emerged when the interviewer directed the discussion to what has been the effect of having chronic health conditions. At first all participants attempted to phrase their experience as being 'ok'. This changed very quickly when participants started exploring how it felt when they were first diagnosed with chronic kidney disease. But many participants described that the reality of this was more prominent when the Renal Team started discussing the need for dialysis plans as the participants entered the phase of End Stage Kidney Disease. Fear presented as fear of dialysis, needles and wanting to stay alive. There was also fear from living alone of something going wrong and not being able to get help in time, as well as the fear of the 'unknown'.

Figure 9

Mental Health Mind Map



This quote represents a participant's thoughts when first viewing another patient on a dialysis machine:

> *It looked horrible (Long pause), But the patient was obviously comfortable. I suppose it's the fear of the unknown* (Participant K, 59.48sec).

Fear was also described when seeing other patients in the dialysis unit and witnessing the experiences of other patients, where many had experienced depression and amputations of legs and fingers. Though new to dialysis, Participant L knew some of the other patients from his working life and was fearful this would be his fate:

> *Yeah, well I've...yeah...I've seen some of the people, what it can do when they get depressed, and it's pretty sad… Um, and sometimes it's...a reflection of this place when I first got here...I was looking at some of the others.. I know (patient name) and all that, man. I worked with (name) years ago. (Another patient name), I worked with him at the meat works, you know, so I know a lot of these fullas……I was looking at everybody, and it's like looking at a mirror into the future.. Well, it didn't make me feel very good at all. That's, that's another...there was another moment where I thought...I just gotta get out, I've gotta do...I've gotta get better, I've gotta do what I can, you know, otherwise I'm gonna end up missing fingers, and missing toes, and legs and stuff...* (Participant L, 57:03min).

Participants also discussed the fear of getting sick and whether this might hasten the end. The end meant two things, the end of trying to stay off dialysis and a machine, and the end of life through death:

> *When it came to my turn to start needling, it took me probably close to an hour, an hour and a half to get the needle anywhere near my skin. I was just so petrified. I couldn't do it…….I did it. I had no choice, because there was no other option in my life, BUT to do it. I didn't want to die, I wanted to keep living. So, for me that was, that was it.* (Participant B, 26.37mins).

For some participants, they had experienced nearly dying several times in the health journey with chronic conditions, and developed an acceptance that this was a reality and that their death may not be far away. This participant felt lucky that he had lived despite these experiences, but feels he has run out of luck now and death may happen at any time:

> *That I'm still alive, because I've died several times. And it's on my file, um, in the past...not just that heart thing, there's been a few other times as well, where I've been lucky. You know, most of my friends say the nine lives thing...the cat with nine lives thing comes up all the time…..I mightn't have won heaps of money, but when it comes to life and death situations, I'm quite lucky...quite lucky. Yeah, I'm prepared, man. I.. like I, I believe I'm on borrowed time, because I've been so lucky, so yeah...* (Participant L, 9:17 min, 40:50min).

Worry and anxiety were closely related and presented in similar ways, concerned for self as well as for whānau/family members. For one participant it was the fear contributing to anxiety around the loss of ability to do simple tasks for herself due to the impact on functional mobility from pain caused by chronic conditions. She also carried several worries for her son who through her illness had become her carer. This impacted on his life as he lost school days, was inattentive at school due to constant worry for his Mum, and how she would cope without him:

> *That's, I think, what was hard, was every day at home, because it was just my life was just dialysis every single day……and so was his (indicating son - speaker 3). He was there helping to carry the big two litre bags. He was the one, because it was too hard for me. And he was even younger than he is now……. what's happened to me, is what's happened to my son as well. Whatever has affected me has affected my son… So, I felt that what was going on with me was affecting his personal life, and his school life.* (Participant F, Mother: 3.54min).

Worry extended to whānau members, where planning for the future became less of a priority in respect of current whānau concerns around surviving today. In the following quote the son expressed a concern for his future because of his worry for his mum:

> *It's been hard trying to think about, like Mum also said, about my future, when I'm trying to worry about my family's present*. (Participant F, third speaker, Son, 1.13.44 sec).

Worry created a sense of over protectiveness for some whānau members who had walked the journey with their loved one during life threatening events, this results in loss of independence for some participants who are trying not to burden their whānau:

> *I didn't appreciate how much I had frightened my Dad, because he saw me die nearly three times down in Wellington. And because he had lost my Mum, he didn't want to lose his daughter as well….he just had this overprotectiveness that was just absolutely just...yeah.. Suffocating. Yeah.* (Participant O, 15:49min).

Anxiety was also prominent for many participants. They discussed diagnosis as being overwhelming and too much to take in when sitting in a doctor's office. Most describe how unprepared they were for this type of discussion and at the time did not understand what it would mean to their lives. For those who had whānau members with the same condition and had passed away, diagnosis felt like a 'death sentence'. For one participant, he found he withdrew from his whānau who also withdraw from him, due to fear of his death:

> *They (daughters) got a bit defensive after a while with me, because they didn't want to get too close to me, just in case they lost me….. (daughters) ..we didn't want to get close to you because we were scared you were gonna die.* (Participant C, 11.16mins).

As a way of coping, one participant had disassociated herself from her kidneys, and saw her condition as her kidney being sick, separate from the rest of her, "*So, and to me, I'm not sick, my kidney is*" (Participant, 24.46min).

Anxiety was also discussed in terms of repeated hospitalisations and the potential for more 'trips to hospital'. Needing to travel long distances for medical treatment also caused anxiety when treatment may leave them feeling sick and unable to travel home or worry about driving home when feeling unwell. One participant describes this as having Past Traumatic Stress Disorder (PTSD) especially if she thinks about needing to be hospitalised:

> *I'm running on anxious energy a lot, and um, I am medicated for that. But some days it gets the better of me. And I think a lot of it probably is probably, like, post-traumatic stress from the hospitals. You know, there was a lot of yucky stuff at the beginning, and um, I think I've dealt with it all, but it does, it can be a trigger.* (Participant R, 40.04min).

Associated with worry, fear, and anxiety, was the sense of 'burden' that all participants felt. Burden presented as a burden on others and the burden of chronic conditions. Participants were worried about the burden they had placed on their whānau for needing to care for them and the restrictions their medical illnesses had placed on their lives. This sense of burden affected some participants to the point where they chose to go without essential medical treatments such as medications, if they felt they had already asked too much of their family that day:

> *I AM a burden! I'm a burden every day on my family. That's, that's the frustrating thing about it. I'm a burden on my family every day. Every day……I can't do it anymore, you know? ….Even when I drop a pill on the ground, I can't pick it up because of my fingers….So then my next step is to not put it on anybody……To go without these pills, and to go without that help, and to....HANDLE the pain...rather than BE a pain* (Participant C, 27.05 min).

One participant also spoke of the burden of chronic conditions and extra activities and responsibilities needed to look after themselves. There was a sense of enormous commitment to try and stay well and look after yourself:

> *To me living with a chronic health condition is one of the most difficult things you can do, because your, your time - that's the first thing - your time is is taken up, not only by dialysis, but by travelling. Now, um, for me, when I, when I, when I started...(crying)…….It's a disease I wouldn't wish on my worst enemy (sighs). Actually I wouldn't wish it on anybody, even if they were people I didn't like so much…..Just generally it's, it's one of the hardest things to live with, really…. you got to think about everybody…………Nutrition...you've gotta look after yourself at home. You kinda have limitations about things you can and can't do... You can't go around thinking you was the man you was ten years ago. Or even five years ago. Not even one year ago.* (Participant D, 0.30, 55-56.19mins).

Burden was something experienced by those trying to juggle the management of several different conditions at the same time. This resulted in a sense of struggle and effort:

> *So...diabetes. Renal. Ophthalmologist. Cardiac. Um, who else? Yeah, those are the main ones. I've had clinic with the dentist... Yeah, it's a big juggling act, you know, with my bloods and stuff like that. So I've had to balance...try and balance everything because one if one thing is up, then another thing is down. Another thing's down and another thing's up. You know, so...it's having to juggle all those things, and then with diabetes on top of it? Mmm, yeah..* (Participant P, 1:59, 9:32).

This was intensified if the participant was employed and trying to maintain the ability to work as well as manage health related care such as dialysis:

> *I guess it's the setting up of, you know, the hooking up, the being on it (reference to dialysis), and taking myself, coming off it and setting things up and getting things ready and stuff like that. Being limited to time that, you know, if I'm working the next day, for then I have to be on the machine at a certain time for it to finish a cycle in the morning, so I can get up early in the morning, you know, put things away and then have shower and get ready for work. So all those things.* (Participant P, 10:50min).

Despite the demands of treatment and employment responsibilities, participants were still able to consider themselves lucky compared to other people:

> *I don't like to, I would say moan about things, because I know these people worse than myself. Do you know what I mean? So, I just thank, just thank...I guess I'm just grateful that I'm here. Because things could be worse.* (Participant P, 13:50min).

Burden was also associated with an altered perception of self where participants saw themselves after diagnosis, as being different before. This led to expressions of self-doubt and depression, having dark days and suicidal thoughts. This was often related to not being able to provide for and look after, their families. This was most noted when the participants were unable to work or needed to give up employment. Words used by participants included, "feeling like a freak", "not normal", "useless" and a "loser:"

> *Yeah, I always was different, because of my condition. It was out of my control. I was actually a freak of nature (*Participant B, 5.02min*).*

> *Well, it robs you of your peace of mind, well, I think...because if you're working, like we have... we have we've been working for over 30 years, and, and then you get told that you can't even go to work anymore, that was... (choking up)...I can't look after them. Well, I don't feel whole (pauses)…. But I been working ever since I was fifteen, and (pauses) change like that saddens me, 'cos I can't work… I feel useless (mumbled)* (Participant D, 41.22min).

> *It just makes me feel like a loser.* (Participant C, 1.02.31sec).

For some participants, this was related to experiences as a child, being at school with a chronic condition and self-catheterising or with indwelling catheter bags. School was a time described as being in "hell" and "hell on earth" were bullying from others was a strong memory:

> *Primary school was probably the worst. It was hell. It was hell on earth. 'Cos you don't realise how cruel kids can actually be, especially to other children. So it's something I can't control. You know, I could never control it, because I never had control of my bladder, even as a baby, but I brushed it off, and just carried on. Did my own thing. High school wasn't too bad, because at Intermediate, I got my transplant.* (Participant B, 2:06min).

Some participants spoke of coping mechanism such as finding a way to feel normal by was to keeping their medical conditions a 'secret' from others,

> *It's, ah, I never used to talk about my health, my kidney. No one down there [hometown] knew I was crook (*Participant A: 1.09.17 sec*).*

> *It's that isolation...um. Noone wants to talk about, you know, renal. Um...I haven't met anyone that openly talks about their conditions, let alone mine* (Participant K, 57.49sec).

Dark days and suicidal thoughts were also evoked by daily struggles and a sense of worthlessness, not eased by having a sense that there will be a change in how life is lived:

> *I don't know, I've had my dark days. I've had some very, very dark days. I've thought of suicide multiple times. Because you just think, 'Is it ever going to end. Why me? Why did I choose this? What do I do in this life to deserve this?* (Participant B, 39.16min).

The following passages express the dark and sad days, not only for the patient but the effects on those closest to them as expressed by Participant F's son:

> *There's been a lot of times in my life where I've been really down and low, and I've wanted to give up, and I've just wanted to just leave this world behind, and just go.* (Participant F: third speaker, Son, 1.33.45sec.)

> *Yeah, you know, like, I'll walk around and sometimes I feel sorry for myself, and then when I stop and think about it, I'll go, 'Gee, how come you're feeling sorry for yourself?' And your kids are looking at you and they want to cry*. (Participant D, 58.00min).

Having to rely on whānau members for activities of daily living, promoted a sense of merely existing and not really living life. Feeling that they needed to be there for their whānau was often the only thought that kept some participants from ending their life:

> *Cooking and the cleaning and laundry and...and he's (indicating son) had to take on so much because I...I get short of breath. If I move around too much, I literally...there's been days where I walked to the kitchen and back, I had to sit down because I ran out of breath..... Standing up...anything standing up?....yeah…you know, become like these big gigantic..., 'that's your life now, dialysis three times a week, five hours', for so many years now. ….Just like my life sucks. Um, all I'm doing is existing* (Participant F, 27.38min)

> *(Crying) There's days sometimes I don't want to be here. But then then I can't leave him (indicating son). He's the only thing that pulls me through sometimes, And I just feel like what is the point of me? What is my purpose anymore? I'm just...HERE, and I'm not USEFUL in any way. That's what I feel like now. It can be really bad sometimes, because I don't feel like I have a purpose in life. I don't feel like I'm doing anything productive. I'm just here* (Participant F, 30.15min).

Theme Subgroup Two: trapped, guilt, frustration, lost sense of fun, enjoyment and loneliness

Themes in group two explore mental health through close associations with worry, anxiety and burden. Guilt, frustration, and loneliness were a feature for every participant. This was related to multiple factors, such as an inability to be independent, to get jobs done, inability to go to work, waiting for appointments and surgery, the amount of time treatment takes and being unable to do anything else at that time. Loneliness was discussed in relation to being isolated when on the dialysis machines and not seeing others for long stretches of time, as well as the inability to get out of the house due to painful conditions:

> *But it can be isolating when you're stuck in a little room by yourself at home. It can get lonely. And then someone will ring and talk and I'll talk and talk and talk like I've got no friends. Like, like no mates Nancy. So yeah, but yeah, it was hard.* (Participant A, 1:06:07min).

> *Ever since my leg playing up um. (pause) And there's nothing I can do really. I tried going for a walk but my leg won't go that far now. um maybe because I haven't been out for a long time and I'm just restricted on how far I can walk…my two brothers …that are looking after the family at home. Um, I see them probably maybe once every two months or three months or something. Not as much as what I used to.* (Participant E, 24:39min).

One participant described how friends and family were very supportive at first but as time went on, they slowly disappeared. Inability to visit others due to disability and mobility issues meant some participants did not see their family members as often as they used to and who were also often sick themselves:

> *Yeah. It is. I think also what's been hard is...the people in my life stopped being there when I got sick. And I found that really hard…. I have some really close friends. They were really concerned in the beginning, but after a time, they just sort of, I guess...a part of it, they don't know what to do themselves. In a way, I was hurt because...I don't see...my brothers don't come to visit me.* (Participant F, 21:1, 32:48min).

Another participant described how her family won't share their thoughts with her any more or the hardships they are experiencing, because she is seen as 'sick'. This makes her feel lonely and isolated from her them:

> *You can't, you know, I like a good discussion...that's not a good discussion topic … I suppose health issues, um...I listened to one of my schoolmates. My brother talks more to him about his health issues, than my brother speaking to me…. Um...it's a lonely journey when people don't understand...* (Participant K, 42:37s; 1:06:45min).

A lost sense of fun and enjoyment compounded loneliness, often as a result of fear of becoming sick, or immobility due to painful conditions and as a result of losing social contact with others. It was a loss of simple pleasures such as being able to go out for coffee, riding a bike, walk on the beach or simply get out of the house that were felt sharply. One participant described one of these simple pleasures as an indulgence. These losses highlighted significant moments of sadness for the participants during interviews:

> *Yeah, just a cup of coffee somewhere or, you know, sitting at the park for a while. (starts crying) I haven't even been to the park, or a beach, in a long time. Those kinds of things. Just really simple pleasures in life. I mean, it would make things so much better in just a day…… And that's just what I feel like my sickness has done. Cut me off from everyone.* (Participant F, 39.42 min)

> *I miss being able to just go down the road for coffee and, you know, just something to indulge in* (Participant G, 20.54min).

> *I think that's what it is. It's just feeling like I'm trapped here. Like, um, all those cool things, all the basic things I used to do before... I've missed them, and sometimes I'll literally be staring at a sunset because I miss*

> *going out and seeing things, or I'll be staring at a beach because I miss things like that.* (Participant F, 40.07mins).
> *But I am limited as to my actual hobbies, being able to engage in those now. I can't ride my bike anymore* (Participant Q, 0.16 secs).

Guilt was associated with burden, particularly when participants reflected on their relationships with their whānau. This was related to the help they required to complete activities of daily living:

> *But I've really leaned on him a lot throughout the past three or four years, and I know it's so hard for him some days, having to deal with the things that I need, and I feel so guilty and so bad. I don't want him to have this heavy burden on him sometimes.* (Participant F, 23.42 min).

Frustration was also strongly expressed and related to the inability to 'get things done', not being able to work, having to wait for medical treatments such as surgery, getting sick, prescriptions and appointments, and difficulty in negotiations with social services that provide government supported benefits:

> *Well, it can be, because it's frustrating, because, um...it can be overwhelming, because you know what you want to do, but you're limited to what you can do. Yeah, and that's the, you know, frustrating part of it. Yeah. And that can be emotional…..so...that was a big one. Not working. I've worked all my life. So that was a big one.* (Participant G, 5.05min).

> *I felt it a nuisance, because of the impact and the change on my lifestyle, and because I've always had a busy lifestyle, it was annoying. So, if I have a really busy day, I've got to get up like 2, 3, 4 in the morning to start my treatment to get it out of the way* (Participant A, 0.33sec).

> *For the last two years, there's been barriers with being able to progressively move forward [reference to waiting for surgery] and seeing someone…. It's SUPER frustrating, for me, I thought right… no more illnesses, but then along comes another symptom, or something else that's gone wrong…(*Participant A, 28.34smin).

Frustration also related to access to a health professional, such as trying to obtain a prescription from the GP:

> *About four times yesterday [number of phone calls), and I got - the first time I was fourth in the queue, and then I got to number one in the queue and then it said to ring back later… but I mean it took, what? You know, and this started early in the morning...took till half past five when we ended up down there at the pharmacy.* (Participant D, 27.08 min).

Theme Subgroup Three: self- blame, sacrifices and struggle

This subgroup of themes related to a more direct impact of chronic conditions on the participant. A sense of self blame was present for many participants. This mostly related to their perception of not listening to medical advice earlier in their journey, or from not having learnt from other family members who had also suffered from the same conditions, despite having grown up witnessing their journeys. They then interpreted this as not looking after themselves as they should have. They often expressed a need to help educate others or influence their own children's or siblings' behaviours, so they were more aware and did not make the same mistakes as they had.

> *When I was ten years old, I had to carry my mum to the toilet, and carry her around because she couldn't walk. That's how chronic her gout was. I had to do all that for her. When I was ten. So, I know how hard it was for her, and I know...I know I'm in this position with my gout because of my own young days. I didn't listen, I didn't take my pills when I was supposed to. And when I did take my pills, I abused, because you know, when you want, when you get sore and everything, you want to try and get rid of it straight away. So you, instead of taking one, I was taking two. Okay, so after 10 or 15 years of me taking these gout pills, my doctor told me to stop, because apparently it was killing off my kidneys. Hence the reason why I'm here…… And I do, you know, like, I tell people it was my own fault, really. I've had Nannies and Koro's that have had this gout for years, and they...and I saw all the pain and all the hard that they went through, and I still didn't click.* (Participant C, 5.35mins).

> *You know and I know that relatives with diabetes and that and I say to them, you know, you, I knew nothing about diabetes till I got here and seen some of our patients …..What I see with them, and I tell my relatives and that, nail it man. Get onto your health. Don't let it get any worse. Don't drink all that alcohol. Look after your body….And because I try and educate them, please don't go down this road with your diabetes. It can lead to this.* (Participant A, 1.09.17 sec).

Sacrifices and struggle were closely linked themes. Sacrifice was related to needing to alter their previous lifestyle due to changes in financial statis when participants had to give up work and go on a government supported benefit. Sacrifice was also associated with giving up family time when needing to be on a treatment modality such as dialysis. Five hours on a dialysis machine meant less time with family, where others described time off treatment as precious, in order to be able to see family.

One participant also talked about lost family holidays due to the commitments of dialysis and the inability to travel away, which meant the sacrifice was made by the family. One participant described sacrifice in terms of a robbed childhood due to the many medical commitments he had, where he also describes not being able to pursue higher education and felt he had sacrificed this to his illness. Most described the simple struggle of living with the everyday, struggling with household chores, shopping, finances, getting appointments with the doctor, needing to travel for elevated levels of medical care, not available in their hometown:

> *So, forty years of struggling. And I mean, unfortunately, it's just one of those things that when you live with an illness like this, you'll always struggle.* (Participant B, 8.05min).

> *Um, to me living with a chronic health condition is one of the most difficult things you can do, because your, your time - that's the first thing - your time is taken up, not only by dialysis, but by travelling. Now, um, for me, when I, when I, when I started... It was, um...emotional…I come from north Wairoa. Um, it's about, I dunno, about 280 - 300ks. (crying).* (Participant D, 0.33sec).

> *So I try not see my GP, because it's just costly. And the fact that I've got to put petrol in the car to go to Waipukurau, because I can't get a doctor here. There's no doctors up this way. They're not taking anyone at the moment, so that kind of makes it tricky… And the doctors up here, from what I've heard, aren't even seeing patients.* (Participant B, 11.02min).

Having to rely heavily on whānau to help as they were unable to be independent. But this became a struggle for whānau as well especially if they were unwell also:

> *Like, with the transport, for a long time there, I was having trouble getting to appointments because of Dad wasn't able to take me (who was sick), and so I wasn't going to them.* (Participant F, 17.00min).

Struggle was also experienced in feeling a loss of the expectations of a 'normal life':

> *Probably fitting in. Because I'm not normal. Because everyone else is normal. They get to live this normal life, and travel, and do everything... (tearful), and I've never been able to do anything like that. I've always wanted to, but never could, because of my condition.* (Participant B, 6.15).

Family sacrifice was also experienced by siblings when the family needed to move to a larger city to access treatment for the participant.

> *I mean, (sighs), it was hard, I suppose, for my parents and my brother, because I'm the youngest of three. My brother is six years older than me, my sister's four years older than me. I can imagine it wouldn't have been easy for them at all. My brother was starting high school when we left. So, it can't have been easy, even for him to move, to uproot and everything...even my sister...and leaving all their friends behind. Uproot and move.* (Participant B, 33.36 min).

For many of the participants, there was a struggle to balance their own needs against their family's need. This created a sense of burden and guilt if they then mismanaged the burden:

> *If I've got a busy morning, and the kids are all over the show, then my priority goes to them, and then I forget to take the pills. My lifesaving pills!* (Participant J, 33:43min).

Theme Subgroup Four: attitude, humour, altruism, faith and hope

The fourth subgroup of Mental Health themes related to coping mechanisms. These were strategies used by the participants to offset the more negative consequences of living with chronic illness. Participants describe these as a way to cope, block the bad stuff out and to give their life meaning. Some participants used a form of altruism, engaging in volunteer activity as they felt the need to give back as they had been helped by others, even if this may be detrimental to their own health at times:

> *I'm doing two jobs, plus my voluntary work at the op shop. Plus singing, plus cooking, plus baking, plus life! So it's still pretty full on….because I like to help everyone. Yeah, but I've still got to learn to start putting myself first…And I push myself to the limit. Yeah, and my husband tells me not to, because he says you'll become unwell. You know, your body won't be able to keep up and you'll become unwell.* (Participant A, 0.33, 6.29sec).

There was also a strong indication of wanting to help others who they could see were struggling with a similar experience. As they were able, participants engaged in volunteer work in the community, providing phone support to other patients and wanting to engage in peer support programs for other people facing a similar journey. Participants expressed how engaging in this way made them 'feel good', 'valued' and 'useful':

> *Yeah, yeah, And that's what it's all about. See my time as a worker might be over, but I'm still going on, I'm still carrying on in different ways. Yeah. So, like, when I do the community patrol, I'm doing that because I'm volunteering to do it, besides that, I'm, you know, I'm also donate to the rescue helicopter, the one in Wellington, yeah, so it's all these things that I like to do, to help other people.* (Participant E, 1.05.42min)

> *Yeah, yeah. So what I did was, I gave them [other patients] my phone number, anything that comes up, just let us know. I said I might be on dialysis, but I says, I can still write, Yeah, yeah, so I like to listen to what you got to say. So that was good. And I, I felt really good after that day. I thought jeez, I think I've done really well. Couldn't believe it. Yeah.* (Participant E:59.25min)

Having a good attitude, using humour to engage in 'fun' and laughing were ways of blocking the 'bad stuff':

> *Yeah, and also blocking out all the bad stuff. Just burying it deep inside. I try, it's, I have no choice. Bury it. Otherwise, you're just gonna keep dwelling on the bad things. And I try and look towards the future and the positives of living with an illness like this. Not many positives, but there are still positives. At least I'm still alive. That's my biggest positive.* (Participant B, 27.42).

> *I have a good supportive family. My children will only respond to how they see me react. The same with my family. So I am only...they are only mirroring what I am putting out and they mirror back to me... positivity. They're always encouraging. They're always supporting and they mirror back that positivity. And that's important.* (Participant A, 1.12.19 min).

Faith, prayer, and meditation was also a way to draw strength and maintain a positive attitude:

> *I was just deteriorating. And yeah, that's a massive lifestyle change. I just thank God I have my faith and I meditate, because I believe that's what helped, helps me get through. And I try and stay focused and positive….I*

> *like to thank God in the morning for waking me up. Yeah, and then do my meditation, because it helps set my mind for my busy days.* (Participant A, 1.10.03).

Having hope was also a strong motivator to cope with the every day. Hope provided a sense a change was possible. For many of these participants, hope came in the form of achieving a kidney transplant or surgery, where they felt this would give them back a normal life, relieve the struggle, hardship, and loneliness by being able to go back to work and engage in family activities:

> *But getting that hope back, from hearing from someone down at the bariatric team down there, or someone, gives you that little glimmer of hope. And hope is massive when you're stuck in my situation,… Yeah, definitely. I have still got that little pot of gold there at the end of the rainbow that I'm aiming for [transplant surgery].* (Participant A, 11.33).

Strength and hope were also obtained from supportive family, health professionals and employers. Participants describe patients within the dialysis unit as being like a family, where unity and the ability to cope came from the sharing of similar experiences:

> *Yeah, I mean, you've only got to sit in the waiting room in the mornings and listen to them [patients] talk to each other, it's like a family. They have a giggle, they have a laugh, and have their little moans, as we all do. 'Grr, the doctors have made us wait longer and longer', or 'Why does this keep changing? What is it?' But at the end of the day, we're still here, and supporting each other in a different way.* (Participant B,48.13min)

> *Yeah, no, we help each other [patients] out as much as we...you know, we all have our own little niggles and stuff, and we all tautoko (support) each other and, yeah...as we should. 'Cos like I always say, we're just like one big family in here. As I said to the lady just out there [in dialysis unit], that she just started, I said, 'Look.' She was a bit, you know. I said, 'Look, you just go in there, and these nurses will take care of you. And they're all lovely and kind, and we're all just like one big family.' And she felt at ease straightaway, you know?* (Participant C, 35.46min).

> *But also supporting other patients when they need it. Knowing what they're going through and saying, 'I've been there, I've done that, mate'. Just try to encourage them to keep going. That's the biggest part, is watching the next lot come through, and you're just going, 'oh man, I was that person not so long ago'. You know, just saying 'Hello', 'Morning', support them, 'How's things going?' Little things like that actually makes them feel welcome.* (Participant B, 46.42 min).

Several of the participants engaged in positive 'self talk' as a way of coping and preventing negative thoughts from influence their day:

> *And there is days behind closed doors that you do wake up and you do resent the machine, and you do get in a shit mood and...but...I have that little hour or so of meltdown, and then I think no, no, got to change the mindset. Get back on track, because it's not going to help me any.* (Participant A, 53.30min).

> *And that's the self talk I do. So I get sick and tired of doing it, talking to myself. I do a lot of weighing up.* (Participant K, 55:44sec)

> *But it's not letting the...don't let the illness rule you. You rule the illness. Don't let it beat you. Just pick yourself up and carry on. Get up off the ground, and fight harder, fight longer*. (Participant B, 8.05min).

Participants also had a strong sense of still being lucky despite descriptions of struggle and burden. They felt lucky they had family support, or a partner who worked and for one participant he saw himself as lucky because he was young compared to other dialysis patients whom he felt were worse off:

> *I'm just lucky that they love me, and that they can bear all my burdens.* (Participant C, 27:05min).

> *I'm quite lucky. I'm on the younger side of it when I did it. I'm not, fortunately, on the older side, like a lot of the patients are. So, I still have the youth.* (Participant B, 36:04).

> *So I'm really lucky to have that support. Really lucky, because my partner's at work. So, um, yeah, we're lucky with family support.* (Participant R, 4:52min).

Participants were able to still feel a sense of being lucky when they saw others whom they thought were worse off. This allowed them to cope with the need to wait themselves, for appointments and treatments:

> *But then, you know, I, there's just so many people out there that are way worse off. And I have that in my head all the time.* (Participant M, 15:52min).

> *Um...yeah, I suppose, but yeah. I just take what I can because there's other people that have to be on the waiting list as well. You know what I mean? So, I'll just take what I get, really.* (Participant P, 29:04min).

A sense of being lucky was a way to stay strong, to cope and be thankful they were still alive:

> *Yeah, well...I compare myself to people that are worse off, like on TV or something. And I think to myself, 'I'm lucky'. That's how I keep the mind going. I'm lucky, and they're the one's that aren't…. That I'm still alive, because I've died several times… I've been lucky.* (Participant L, 8:45min).

Mental Health had one of the strongest impacts on participants with the most number of subthemes. The sense of struggle, frustration and how life had altered since diagnoses, was a reoccurring description. Despite bad days and impacts on how life is now lived, participants still describe a sense of having good days also, where the need to give back and help others was demonstrated by many of the participants. This appeared to relate to a sense of resilience and value. A sense of family and the support of whānau were strong motivators in their need to keep going. Hope was also present and related to the hope that things may change and there was something better around the corner. Mental health descriptions were also closely linked and crossed over with Hardship and Loss.

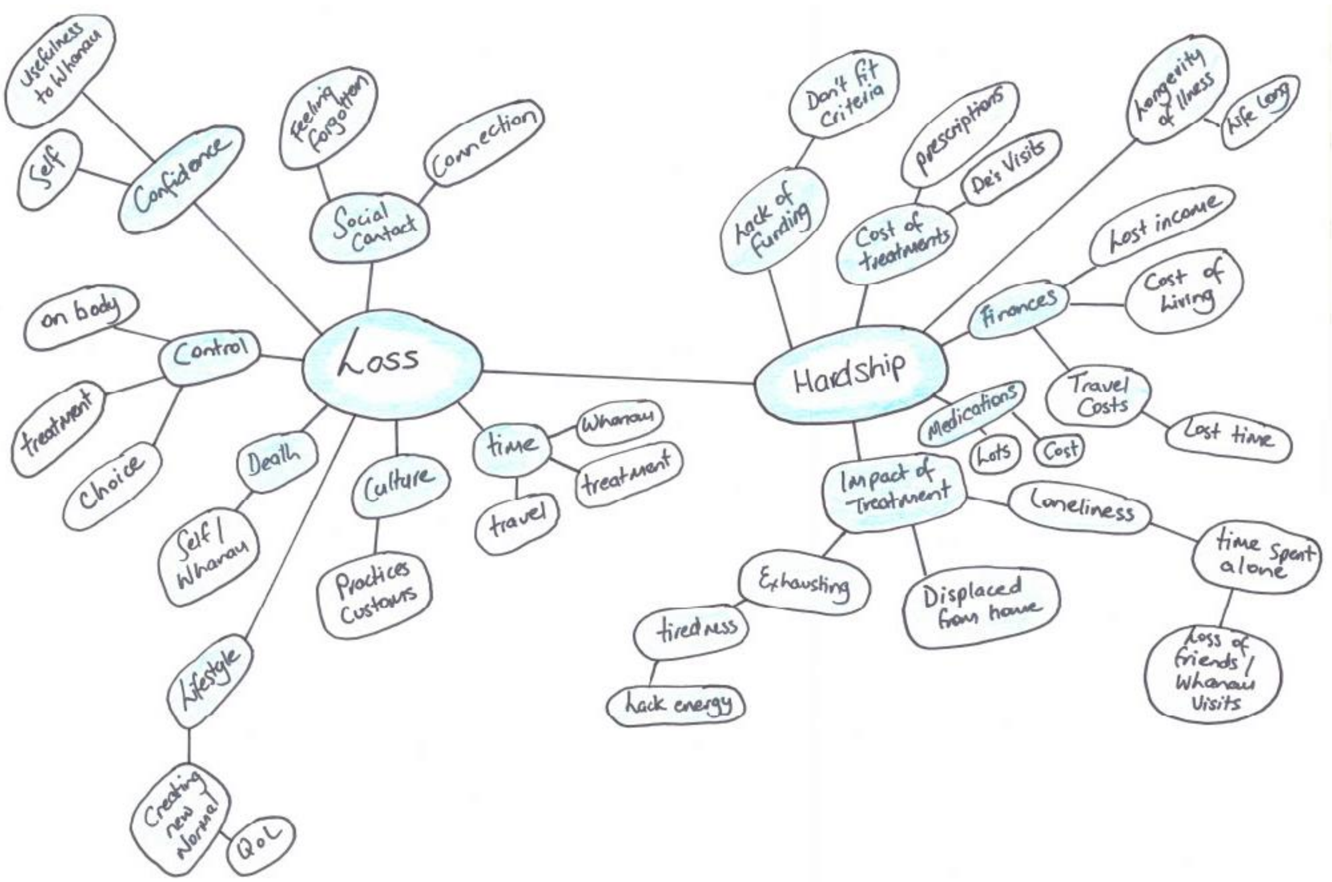
Major Theme Two: Loss and Hardship

Loss and hardship were major themes that were closely linked overlapping at times and seemed to be a logical grouping (Figure 10, demonstrating connected subgroups for Major Theme Two). Many of the hardships and loss experienced by the participants were represented by mental health experiences as described above. Hardship was created through loss of income and ability to finance daily living, as well as the cost of treatments, prescriptions, doctors' appointments and funding travel:

> *My doctor will send a script down, and it's got like five things, and I'm thinking 'no!' I mean, one that was like 50 bucks, and I was like, holy heck. But I needed it. So you rob Peter to pay Paul, and when Peter and Paul are broke, you're scrimping everywhere else*. (Participant A, 1.07.16sec).
>
> *There's not really anything good about it! I mean, I'm well now but, um, yeah, there's nothing that's overly great about living with these conditions. Um, medication? Actually just, you know, the panic when I'm going away for a weekend, and making sure I've got all my medication. I have gone away for a weekend and not had it. I had to go to after hours and paid $150 for an emergency script*. (Participant J, 30:32 min).

Figure 10

Loss and Hardship Mind Map



Hardship was also created by treatment regimes. This presented as fatigue and exhaustion during dialysis treatments, not only as a result of the hours involved but the toll on their bodies, needing to fit the time involved in around other important aspects of their lives such as whānau/family care:

> *But for me, the biggest barrier I have found is the timeframe of being on the machine. Because you can safely put aside six hours with our five hour treatment and then our priming and lining, and then the end cleanup. Um, I've now adjusted to it mentally. Um, so I just fit it in when and where it fits in…I'm doing two jobs, plus my voluntary work at the op shop. Plus singing, plus cooking, plus baking, plus life!* (Participant A, 0.33secs).

> *The main thing at the moment, is that I'm often quite tired and lethargic. Which makes it hard to commit to things like, I would love to go back to work, but at the stage, I wonder if I could do a full day work. But, so (Dr name) had written a letter saying that I should take the next two years off work.* (Participant R, 0.21sec)

Seeking life saving treatments such as dialysis and transplantation resulted in having to leave home where they felt safe, and being displaced from home though long distance travel. Treatment also meant long periods of time on their own, as described previously:

> *But it can be isolating when you're stuck in a little room by yourself at home. It can get lonely. And then someone will ring and talk and I'll talk and talk and talk like I've got no friends. Like, like no mates Nancy. So yeah, but yeah, it was hard.* (Participant A, 1.06.07sec).

Hardship was still present despite the government's attempts to help relieve that. National Travel Assistance (NTA) funding is available for travel but has strict criteria to meet, which many participants did not meet. Cost of living increases also meant that NTA funding was inadequate and only covered part of the costs:

> *But even the National Travel Association funding is a joke. What they give you is like….I don't understand how they work it - 20 cents a kilometre is not enough. You don't pay for the wear and tear on the vehicle. You don't pay for the tyres, you don't pay for the oil.* (Participant B, 22.48).

> *Well, we have had to pay every sort of like every, um, second trip. 'Cos what happens is, you get enough for two days [Reference to NTA funding], but you haven't got enough on the third day. And then you're getting it out of your pocket, just 'cos petrol's gone WAY up…it gets into the food budget, and* everything else, you know. (Participant D, 153.51min)

> *Yes, so, my medications are my main, main costs with my health, and travelling for appointments in Hawke's Bay, because I'm not able to get petrol vouchers or anything, um, because I don't have a community services card, so now when I come to Hastings, it's out of our pockets.* (Participant R, 2.56min)

Prescription charges apply until a certain threshold of medications had been met, and hospitalisation often meant more or new medications that needed to be funded:

> *Because when I go to the hospital, there's fifty dollars worth of pills I have to pick up*. (Participant B, 10.37min).

The biggest hardship was created by the inability to continue in paid employment and needing to seek support from social services in the way of a 'benefit'. This often meant the loss of a major income for the whānau or self:

> *You know when you go from over $1,000 a week, you know, eh, and still you're only getting $200 a week.. Yeah, all the outgoings are still the same…And that's why anything that involves our finances, and us spending it, is a bit of a haul for us. You know like, um, fifty bucks doesn't sound like much but, when you got nothing, that's a lot.* (Participant D, 37.24 min).

> *But the hardest part was signing up, um I've never ever (stressed this) been on the benefit, on the dole.* (Participant E, 6.26min).
> *Yeah. But with my situation, I was unable to get any financial support. So, um, at the moment, my partner has covered us with he's paying all bills, but realistically, we'd both be working. So there's been a big challenge for both of us - more for me, because I don't like being dependent. But I can't even get a Community Services Card.* (Participant R, 1.01 min).

Some participants found they did not meet government financial support criteria as their partner, wife or husband was working, whose income in many cases was just outside of criteria. This still resulted in family income being halved without a change in financially focused responsibilities.

Loss was experienced as loss of control, over their bodies, where and when treatment could occur, where they could go out and when. This was despite treatment modalities offered at home or within a medical centre such as the dialysis unit. In more rural areas, this meant needing to travel for treatment, up to three times per week for several hours at a time with a loss of four hours a day in travel. This was not only lost time but meant being unable to continue paid employment due to the time involved in travel, which then caused hardship due to loss of income:

> *You know how (patient name) used to go to work, while he was living... local. Well, he (pointing at participant) can't go to work because of that…. couldn't continue working because he has to be here three days a week [on dialysis].* (Participant D: third speaker, wife: 21.32min).

Loss was also noted through the breakdown in connections with others, social contact and feeling forgotten. As described under the mental health theme, this presented as a slow withdrawal of friends and less frequent whānau/family visits. As participants moved through their medical journey toward end stage disease and the need to start dialysis, they lost a sense of themselves, their identity as the head of the family or major earner, as well as their usefulness to their whānau when they could not help care for grandchildren, do house work or contribute to whānau activities:

> *And I want to I take my grandchildren in the weekends, but to be honest, I can only have the boys for maybe the day... Because that's all my energy can give them and I want to give them...something is better than nothing.* (Participant A, 30.55min).

> *Well, it robs you of your peace of mind, well, I think...because if you're working, like we have... we have we've been working for over 30 years, and, and then you get told that you can't even go to work anymore, that was... (choking up)...I can't look after them…I feel useless (mumbled).* (Participant D, 39.25min).

> *And I just feel like what is the point of me? What is my purpose anymore? I'm just...HERE, and I'm not USEFUL in any way. That's what I feel like now. It can be really bad sometimes, because I don't feel like I have a purpose in life. I don't feel like I'm doing anything productive. I'm just here.* (Participant F:30.15min).

As their own care needs escalated and they experienced longer periods of being sick, they lost confidence in their ability to cope outside of home and home became a place of safety. Loss was also experienced in a loss of whānau members who had passed away with similar illnesses and medical conditions. This loss also created a sense of fear through their own experience looking and feeling similar, meaning their own death may not be far away:

> *Well, cos I had three siblings die from this one disease, um..one, I was scared. And two, when I heard peritoneal in my sister and my brother, I said 'F***, I'm not going there', and that's why when I came here, I was just about dead. Because I was so scared…Well, my brother and my sister, they both died within a year.* (Participant D, 35.56min).

These combined loses and hardships meant participants had to find and accept a 'new normal'. Chronic Illness meant plans for the future they thought they would have, needed to change:

> *Um, so, my plan was to have like, six, seven kids, eight kids, maybe more. I just wanted - we were farming at the time - so, I wanted to farm and have kids. That was the plan. Yeah. So lots of unexpected changes….I think I probably feel bad frequently, um, but it's normal for me.* (Participant R, 10.07, 39.53min).

Through acceptance of a new normal, several participants felt they still had a good quality of life, where others felt life had changed too much and were struggling to find a sense of peace:

> *I still want to have a reasonably...I can say, as a dialysis patient, um...I have a pretty good life. It's a busy life, but it's a good quality of life.* (Participant A,2.19min).

> *I'm making the best of it. Yeah, you've got no other choice you know.* (Participant E, 17.36min).

> *Just like my life sucks. Um, all I'm doing is existing…(Crying) There's days sometimes I don't want to be here.* (Participant F, 27.22 min).

For some participants the loss of their culture was also felt, through their needing to seek medical treatments in a Westernised system. Care was not always offered in a way that recognised cultural practices. This contributed to a loss of identity and feeling safe:

> *Because I was gonna say, that I practice holistic. So it's always been important. The mind, health, soul, and plus, because Māori... those sorts of things in health are important to me. Maybe if someone were, you know, more understanding of those sorts of perspectives?* (Participant F, 50.28).

> *When I was in Wellington hospital unfortunately there was no one available to come [to do a Karakia prior to surgery] and (nurse) .. she said I'm very sorry that no one came to you. There was no… I don't know why the Māori isn't wasn't available.* (Participant Q, 1.09.07).

> *It's mainly for her, because she now has to sit in the car. Now, me and her both do tests (covid test), so this is, um, is something that I think is, is not fair. If she's doing the same test as me how come she can't come in with me. She is my support person. And my support person has to sit out there in the hot sun and wait for me….It's very scary for me.. What I struggle with...is not the fact that I'm doing dialysis. It's that I have to travel and leave my missus outside. That's what I struggle with.* (Participant D,4.17min).

Loss and hardship were closely aligned. Hardship was often felt though losses such as income, changing how life was lived in the midst of rising costs of living and impacted by system rules where participants were ineligible for financial aid. Hardship and loss also related to change in identity, physical limitations, loss of time to treatments and travel in accessing treatments. Changing relationships with family and friends were a point of sadness and loss. A lack of cultural understanding in, as well as absence of being able to participate in cultural practices that were important, added to a sense of loss. A sense of establishing a new normal was prominent amongst participants, and if they we able to achieve a level of acceptance of their changed situation, then participants were able to view their lives as still being of a good quality. For those where acceptance was difficult to achieve, then life appeared pointless.

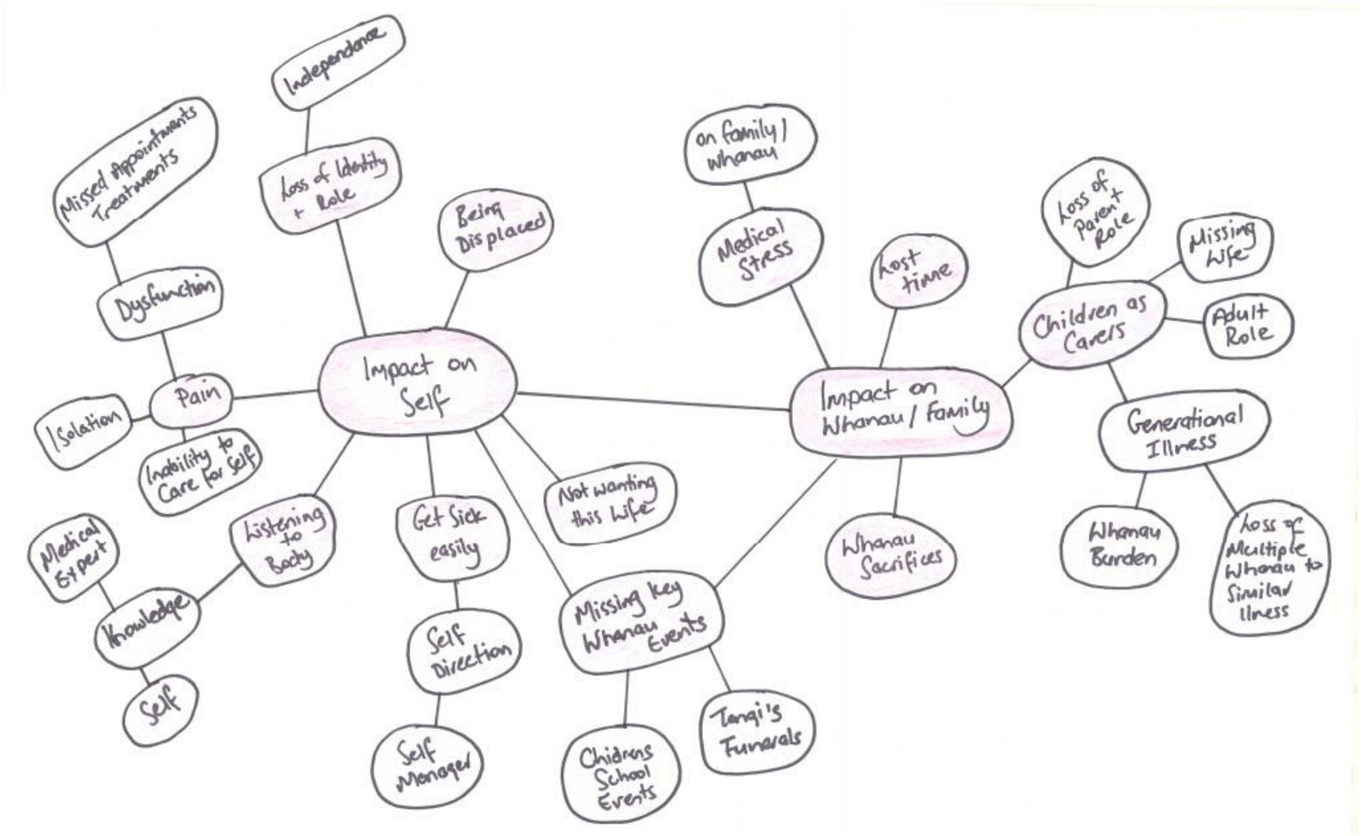
Major Theme Three: Impact on Self, Impact on Whānau/Family

Another major theme described by the participants was the impact of living with chronic conditions on participants themselves as well as on their whānau and families. Many of these impacts have a cross over with subthemes from mental health, hardship and loss (Figure 10). But there were also additional impacts on self that were identified when participants were asked how it was for them, living with a chronic health condition. These impacts focused on physical impacts such as pain, the inability to mobilise freely due to painful conditions, getting sick easily, needing to listen to their bodies, reliance on others to help with activities of daily living and loss of independence (Figure 11).

There were several subthemes that had an impact on self and at the same time, an impact on whānau members. These included needing to leave young, as well as adult, dependent children at home while seeking treatments in other locations, and missing important whānau events such as school events, tangis and funerals, due to treatment commitments.

Figure 11

Impact on Self and Whānau Mind Map



One of the most commonly expressed physical impacts was that of pain caused by a chronic condition, with arthritis and bone pain most often referred to. Some participants felt treatment options for pain were limited due to their renal failure and inability to take some of the most effective mild analgesics, and described needing to 'just bear it' and get through the day:

> *I prioritise my pains. It's funny in a body there are pains that are more painful than the pain before it.* (Participant A, 24.35min).

> *Lot of my pain, this time, has has come from my operations, through this process of this calciphylaxis experience that I'm going through now. Um, the pain side of things is, in the last maybe six months, has been extreme. So extreme that it's affected me, my family, everything that I do, and everything that I want to do. It stops me from doing a hell of a lot of things, because a lot of the time I can't concentrate because of the pain.* (Participant C, 1.46min).

Pain caused dysfunction, mostly in the form of mobility issues, where participants became reliant on others for help to complete household tasks, do their shopping or get to appointments:

> *And it doesn't help when I've got arthritis in my legs, which is a bit of a, bit of a thing.* (Participant E, 0.29 sec).

> *Yeah. Well, apparently, they said Lupus has arthritic sort of side effects. So that sucks… it affects my mobility, probably the worst. I mean, from someone who walked everywhere, to where I wanted to go, to not even being able to go to the shop, for example, or even, I can't walk to the doctor, which is just up the road around the corner there. It's that's bad.* (Participant F, 0.25sec, 15.18 min).

> *"Reduce the pain that I suffer in my legs, and my knees, my feet, my back. And I could be... I know I could be a lot more active than what I currently am."* (Participant A, 27.18).

Some participants described missing appointments if they did not have someone to take them, or if they felt they asked too much already that day. These created a sense of loss of independence. Getting to health appointments was impacted by slow and difficult mobility and often caused pain. Difficulty in obtaining NTA financial support in the form of travel vouchers was a factor, as participants are required to pick these up in person to sign for them as part of 'hospital rules' but have to obtain them from the second floor of the multi-story hospital block. Several participants found this to be too cumbersome and difficult to get to, due to pain, and chose to forgo these at times:

> *So, that's the only drawback there, where, if you get the petrol vouchers, you've still got to go to the hospital, and you've got to go up to the second floor to get it. And I thought, oh, no, I'm not, I'm not walking (exasperated laugh). And you know, you gotta go to the hospital, and then you got to walk up, to get up to that second floor um.* (Participant E, 19.56min)

Concerns and fear around getting sick easily, also saw participants stay at home rather than risk an additional illness, further increasing a sense of isolation. This was especially prevalent during the 'Covid years'. Some participants described 'listening to their bodies' and learning to react early when they felt they were becoming unwell, seeking medical attention as quickly as possible:

> *And I think that's attributed to the fact that I listen, and if there's anything that I notice out of sync with my body or my machine, I will contact the nurses straightaway.* (Participant A, 3.14min).
> *Yeah, well, you start to listen to your body.* (Participant B, 15.26 min).

One participant describes the Emergency Department and the hospital as important and his support, for when he is ill:

> *I was going into hospital every week with my puku, bleeding and everything. And then one of those times, well, they nearly lost me. I bled out. I bled out all the way from my house to the hospital, bleeding, bleeding, bleeding…every time I went into ED. Before I got in there, into the actual*

> *ED itself, I was frustrated...all of that. But once I got in there, I knew I was all good. Because I knew I was in the best place for where I need to be….it's just it's made me feel a lot better knowing that I've got nurses and doctors here every day, for me.* (Participant C, 18.02min).

Some participants felt they had come to know their bodies very well and felt frustrated when health professionals dismissed their concerns. One participant described being unwell or sick as a silent illness and became frustrated when others such as friends could not 'see' her illness therefore thought she was not sick but lazy. Several participants also described this as a reaction from health professionals when they were seeking care when feeling unwell and needing to convince a health professional of the need for more investigations:

> *People often say to me, 'Oh, you don't even look sick'. And I'm like, 'Well, what does sick look like?' You know, even when I go to the doctor, I've had doctors say to me, 'You don't even look unwell', and I'm like, 'Well, I am!'* (Participant R, 50.29 min).

> *You may be the specialist, but this is my body. I've lived with this condition now, that I've known, since I'm 14. I know when it's out of sync, I know.* (Participant A, 47.49min).

The most important concerns participants had, were impacts they felt they had on their whānau and families and the burden they were placing on them. One participant described how the family had experienced a lot of medical stress related to the number of different doctors and hospitalisations they had experienced. Talking about impacts on family was often when participants became emotional and began crying:

> *Yeah so, I've taken a lot out of my girls, because they've seen me in my pain, and it takes a lot of them to see, (choking up) for them to see their*

> *Dad in pain…the pain issue, for them, is probably more of an issue for them than it is for me, and just to see how they react to all of that, you know"…. I'm just lucky that they love me, and that they can bear all my burdens, and they all take it on the chin that I can't do it. I need help. Dad hates asking, but sometimes Dad needs help, and that's when they acknowledge, 'Yeah Dad.'* (Participant C, 9.08 min).

> *And there's been a lot of medical stress in our, in our little family, so, it's a lot when you think about it. (*Participant R, 41.42 min).

Participants felt guilty when they were unable to keep up with partners due to fatigue or symptoms they were experiencing, this made them feel as if their illness was also being lived by their partners:

> *So obviously, the energy levels, like I'm really struggling with that… it's the fatigue and just not feeling like you want to get up and go, you know, and that's probably quite hard. Um, especially being married as well, like, you know, my husband wants to go off and do this, that and the other all the time, and I just don't have the, the physical energy to do that…. you know, I can be quite moody and snappy, and he's had to take all that on, you know, that's nothing I can, like, it's just, I don't mean to be that person…. Um, so that's, that's the struggle and, and then work, you know, not not being able to feel like I contribute 100% because I'm not working…. Oh, you know, "I'm sorry, you've got to deal with this," he say's "Don't be ridiculous. Like, you're my wife, and it's fine. We're together, it's, it's not a thing." But you think that as a person, because it's your, your thing? It's your burden, you know, like, Yeah.* (Participant M, 0:23sec).

There were many cases of children becoming participants' carers and concern for the life they felt their children were missing because of this. This caused children to take on adult roles, where one son felt he had become the parent, and that he had 'lost his parent':

> *Daily chores, you know. The cooking and the cleaning and laundry and...and he's (indicating son) had to take on so much because I...I get short of breath….As a mother, really, how that...like my role, and how he's had to take over my role, almost.. And he's had to sort of take on adult roles that he shouldn't really have had to. He's had to become a caregiver, you know, at the age of thirteen.* (Participant F, 21.07 min).

This son found support from a friend as he was also caring for his Mum.

> *And like even when my friend (name) we made a pact together, because his mom, unfortunately she's passed now, but before she passed away, his mother was actually paralysed, so he was sort of going, we were both going through the same sort of thing of looking after our Mums, and we made up a pact together that when I go away I'll come over and check on your Mum and make sure she's okay, and then when you go away you'll come and check over on my Mum now and then and make sure she's okay.* (Participant F, Speaker three, son: 1.23.01 sec).

There was also a consistent theme of generational illness, where the same chronic conditions were present in parents, grandparents, aunties, and uncles. Some participants described being their own parents' 'carer' from a young age, in a way that their children were now helping them:

> *I'd come home from school one day and I said to my Dad, 'oh look, I think I've broken my toe'. He laughed straight away, because he knew...my*

> *nanny, my mum's mum, and my mum had kinda gout. I was in...when I was ten years old, I had to carry my mum to the toilet, and carry her around because she couldn't walk. That's how chronic her gout was. I had to do all that for her. When I was ten.* (Participant C, 5.35min).

> *Well the thing about Mum is that her mobility is no better than mine almost. It's sad, because we're actually really close but we're both like trapped in a situation where we can't really get to see each other easily….But yeah, it's just hard for both of us, because BOTH of us, it's like, 'Are you trying to copy me or something….Because my grandmother passed from kidney failure in the 1970s…And with her Mum, she did the same thing that my son is doing for me, she did the same thing for her Mum….Because my son was a very sick child' (laughs).* (Participant F, 43.29 min).

Participants also described being on dialysis with their parent or siblings and the sadness that caused but also the shared experiences that drew them closer together:

> *Dad was so supportive, because of...because he had been...he was going through it too. But I remember when I was first diagnosed, he was so upset and sad, because he didn't want me to do go through what he was going through* (Participant F, 10.09min)

But this also meant they lost multiple whānau members to similar illnesses; with fear their own children may end up in a similar situation:

> *And that's why I, why I get emotional (crying). I lost my oldest brother, then my oldest sister, and my youngest brother [with renal disease]… Well, cos I had three siblings die from this one disease, um..one, I was scared.* (Participant D, 7.48min, 34.56min).

Dialysis treatment and hospitalisations also meant time away from their whānau and partners. Family fun and holidays were sacrificed as the participant could not go as well due to treatment commitments, or frequent periods of being unwell:

> *We don't get to go away and have time out, or holidays, because I'm on dialysis.. And he [husband] doesn't take holidays for that reason….And he said to me.. Oh, honey, I wish you weren't on dialysis', so we could go, you know, and see his brother's out of the country. And we've both never been out of the country. So, yeah, in that regards it's hoha as…* (Participant A, 19.22 min).

Lost income meant reduced standard of living for the whole whānau, were luxuries and extras also disappeared. When participants became sick, this often caused fear for whānau members, as they may be put into a situation of needing to react quickly to save their loved ones life or get help. This placed a significant strain on relationships as well as the burden from fear of losing the participant:

> *And that's another he (husband)doesn't cope well, when when I faint or when I have a fall. Because he looks at his hands, tends to just be frozen with fear not knowing what to do….because he used to say to me, oh, there's always something wrong with you.* (Participant Q, 1.02.51).

The impact of chronic illness altered the every day for participants where they felt they had to find a new 'normal'. There was often sadness and emotion expressed when describing some of these impacts. The sense of impact on whānau and family members was also a significant concern and where tears and sadness was most prevalent. Reliance on others was a consistent description that included how reliant they had become on whānau and family members for support which was also similar for them in support to their own parents who experienced similar illnesses and conditions.

Major Theme Four: Healthcare Team and Support

Relationships and experiences between the healthcare team and participants was a significant major theme. The concept of support was closely related to the Healthcare Team and seemed to be a logical grouping (Figure 12). When looking at the subthemes for the Healthcare Team, these appeared to fall into two categories, Renal Service, and other Healthcare Services such as Specialist Services and Primary Care.

Renal Service as a major theme, had five secondary subthemes that included whānau with tertiary subthemes of patients and staff; support with tertiary themes of caring, listening, non-judgemental, time and contact; stability with tertiary themes of consistency, relationships, personal knowledge; goals of care with tertiary subthemes of patient goals vs doctors' goals; and Navigators with tertiary subthemes of needed earlier and, clear direction and care plans.

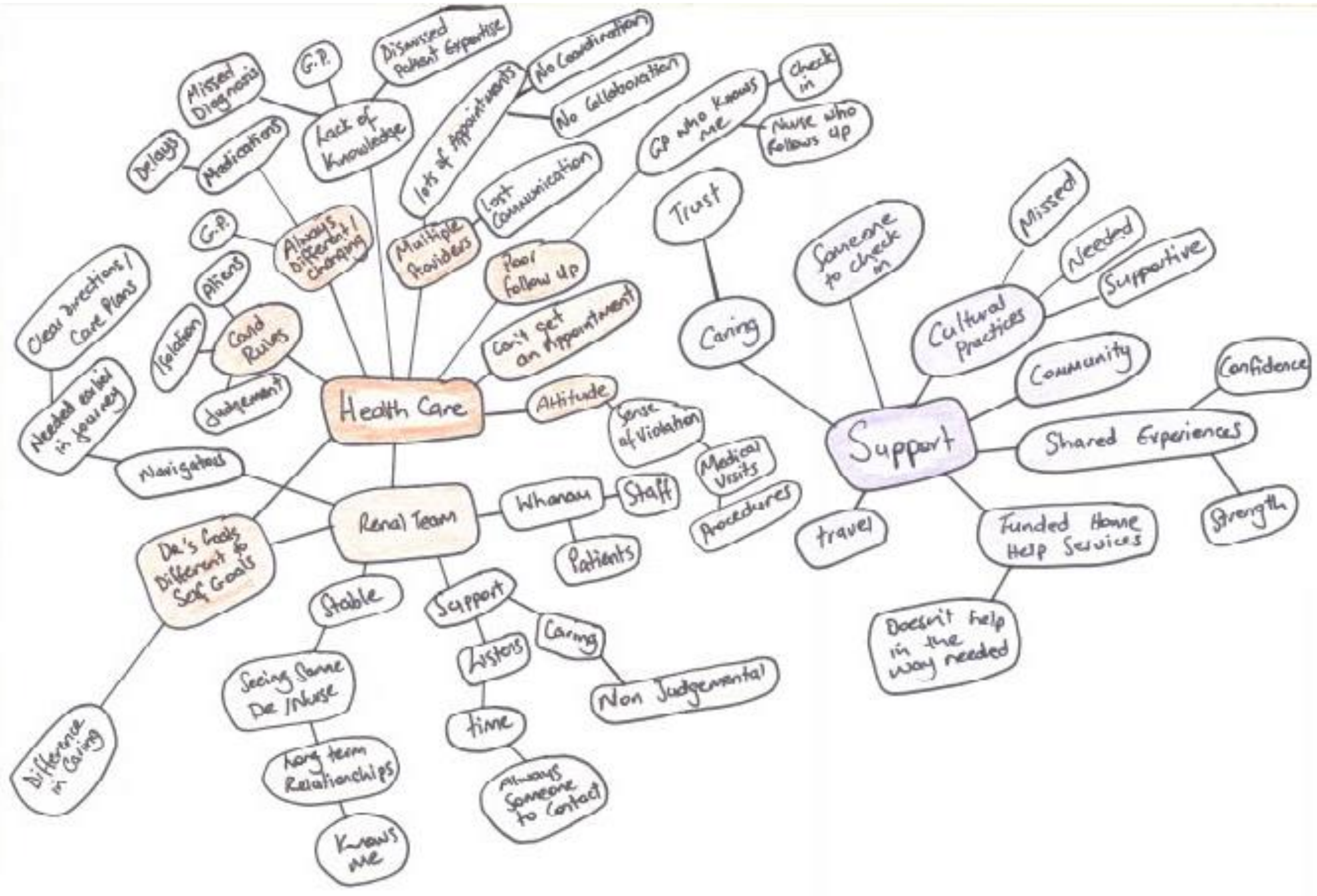
Other major subthemes collectively referred to experiences with other Specialist Services and Primary Care. There were six significant secondary level sub themes and a further 12 tertiary level themes. Significant subthemes were Multiple Providers with sub themes of appointments, communication, coordination, collaboration and follow up; Attitude with sub themes of medical visits and violation, caring with a tertiary level theme of differences; Changing Providers with subthemes of GP, medications, missed diagnoses, knowledge; with a final subtheme of Covid Rules with subthemes of judgement, isolation, and perception.

Subtheme: Renal Service

The Renal Service was identified by all participants as having a significant impact on how they now lived their lives. All the participants have reached 'End Stage' disease even though many of the participants had received a kidney transplant and now have improved level of renal function. While approaching End Stage, and once they have started dialysis or received a transplant, they have had close interactions with the staff within the service by the nature of the support they needed within this phase of disease trajectory.

Figure 12

Healthcare Team and Support Mind Map



Support as a prominent secondary theme was most often referred to by participants as feeling confident that there was always someone to contact if they were unwell or needed help. This aided in reducing the sense of being 'alone' when life was feeling difficult:

> *And in saying that, the doctors and the nurses have been helping me so much, it's just it's made me feel a lot better knowing that I've got nurses and doctors here every day, for me.* (Participant C, 0.19 sec)

> *Oh, yeah, um, just like, um, it was like, um, my medications had been updated with renal, but not with the hospital. And so they wouldn't prescribe me stuff (GP Practice). And just things like that. It's like, oh, my gosh, what do you do when you can't get what you need? So, I have been lucky, where I've rung renal, and they've got it sorted for me.* (Participant R:16.12min).

> *Um, My renal team. Yeah, they're amazing. And, like, (husband), and I discuss it a lot, like, super fortunate to have people on call, you know, and, and for lots of other things, not necessarily always kidney related, but just with medications, or, you know, if you go to the doctor for the normal GP for something else, and like, I always check in with the renals. And just see, like, if that's okay to take or, you know, so it is it is reassuring to know that you've, you can ring someone 24/7. Really. (*Participant M, 8:21min).

The participants had long standing relationships with the staff they more commonly dealt with daily. The staff turnover for the service is low, therefore the health professionals they were dealing with did not change often. This long term relationship built trust, reassurance and knowledge of their conditions for the participants:

> *Yeah, absolutely. Because I've had the same sort of team for most of my journey, so we've built quite a good relationship…been seeing each other more often…Because then I can sort of track where I'm at, and it's good peace of mind. And I find (Renal Doctor's name) will sit and talk me through everything. So I know exactly where I'm at with my health.* (Participant R, 9.15, 14.40 min).

Participants describe the health professionals as caring, non-judgemental and had time to listen. The perception that the doctors and nurses who work within the service 'care' was described with a feeling of being loved and cared for:

> *The care and the love and support they have for their patients. Honestly, I couldn't fault them in any physical way, at all. They just really do care.* (Participant B, 12.06min).

> *Yeah. Yeah. So I think, I think I've been well cared for. I do, I think I love the renal clinic here in (Region).* (Participant G, 54.13 min).

Checking in with participants also created a feeling of being cared about, not just cared for:

> *Because you guys always come to ask us how we are. All of yous, you know? This place is a very caring place, and I love the fact that you guys ask me how I am when you see me. You know, 'cos some days I might feel ratshit, some days I might feel good. Some days I might want to talk to one of yous, and some days I might just not even want to acknowledge you, you know what I mean?* (Participant C, 18.02 min).

The longstanding relationships with staff created a sense of stability when everything else in their lives felt like it was changing. The level of caring and support and willingness to listen builds a concept of health professionals being 'like whānau/family'. Longevity of relationships also meant staff have walked the journey with the participant over many years and knew intimately what they had been through and provided a sense of safety:

> *But I have a great team - all of you's, my nurses, they're not just - you guys aren't just my Renal team - you're my family.* (Participant A, 3.18min).

> *The fun you can also have with the nurses too. They're just as supportive. And they're like family. I mean, you know, you...I've watched multiple nurses, kids grow up from little kids to 20 plus now. And that's amazing. You don't get to do that very often. Not with many people. I mean, I even had a few nurses at my wedding. Because to me they were family, because they've supported me so much. It's over the years.* (Participant B, 48.13 min).

> *The nurses are really nice...(sighs). I'm, I'm a scared person anyway, but, um, if it wasn't for here, I'd probably just fade away, to be honest. Coming here, um, I feel safe.* (Participant D, 1.50min).

Ease and acceptance provided a safe environment for the participants to share information, feelings and struggles:

> *You know, I could talk to you, (speaker 1 name), you know, quite straightforwardly and everything, honestly and everything …I'm just not as confident talking to someone like that (Psychologist), because, yeah, I just don't know how they're gonna judge me. I would feel more free in talking to you, and the doctor's here, and the nurses here, than anybody else in this profession…from somebody that I do know, that knows me, that knows where I've been, that knows who I am, and knows what I... So, you know, we're communicating, which is the main thing to do, whether we are struggling, or not.* (Participant C, 32.17min).

The close relationship with the Renal Staff facilitated the acquisition of knowledge for the participants. This knowledge was valued and enabled improved self-management and determination. This presented as appreciation for knowledge of their conditions, medications and need for these as well as how to care for themselves. Participants felt more in control of what was happening to them with this knowledge, this also gave them confidence to advocate for themselves when seeing other health professionals:

> *And I LIKE that knowledge of knowing how, you know, you shouldn't have to test the water before you know it! (laughter). I like that knowledge of knowing what medication does what, and how it helps you.* (Participant G, 3.23 min).

> *Yeah, I think so. Because then I can sort of track where I'm at, and it's good peace of mind. And I find (Renal Doctor) will sit and talk me through everything. So I know exactly where I'm at with my health. And of course the other staff members, when I have a nurse, or, they're all really good, and patient with me, and make things nice and clear….Yeah. Well, I mean, I was clueless at the start of it, of the journey. But as we've gone along, I've learnt a lot, and I really learn about what's happening…um, I try and be as clued up as I can, because at the end of the day, you don't know who you're going to deal with when you go in to the doctor.* (Participant R, 14.40min).
>
> *Yeah. Because when they share that knowledge with me, then I know what I can do to either improve my wellbeing, or I know what I need to maybe stop doing.* (Participant O, 54:54min).

> *Yeah [being independent] but I prefer doing it at home". It's a, it's a better feeling when you're at home. Yeah, and um, they know, and I've got a chart here. So I write it down [medical data from the haemodialysis*

> *machine] on the chart as well. So, um, that's how I keep in touch with that… That's how they (nurses) monitor me as well.* (Participant E, 1.04.15hours).

Participant knowledge of their conditions and requirements enabled confidence and self-advocacy. Participant O described how she ensured she had the correct tests done when visiting the lab for surveillance monitoring of her condition:

> *Absolutely! And the data - so I go by the data - I'm not giving my blood for nothing! (laughter). Because I go to the lab, and I tell them, 'Well, we need a purple today, and a green, and a blue,' and they're going, 'Okay!' I say, 'There you go!' So if it's a new nurse, I'll just tell them exactly the tubes I want, and I say, 'Don't forget that cyclosporin!* (Participant O, 55:23).

Knowledge also enabled self-efficacy when dealing with health professionals. This participant felt she had to ensure that whichever health provider she dealt with, was up to date with her situation and she saw this as her responsibility to hold the tools to do this:

> *Well, it's about information sharing. So I think its - the way I see it - as a long term patient, it's your responsibility. Because, for example, you're not a crystal ball. If I didn't have the tools at hand, and be able to equip you with the information, should anything happen, you'd be able to step in straight away and say, 'Look, I know exactly what to do'* (Participant O, 59:15min).

Though the Renal Service was seen as very supportive and caring, one participant described how having this level of support earlier in her journey, which she did not, would have helped her to understand more and improve her ability to reach her own goals. These goals at times, were different to the health professionals' goals. She found the doctors and nurses concentrated on plans around her conditions, but her goal was orientated around gaining employment again. However once in end stage disease and on dialysis, the healthcare team introduced the idea of transplant which she wasn't aware she could be eligible for and she had lost several years of planning. Having a common care plan agreed by the health professional and herself, would help to obtain her goals where she would also have a clearer idea of what her health journey may look like. Having someone to reach out to and help navigate her dealings with health professionals and the health system would have helped her. She acknowledged the support she received now she was in end stage disease, was needed earlier on:

> *But it would have been nice to have it one to one where, 'Well, this is where I want to be...I want to be actively working again, I want to be actively...', um, maybe it was me, I didn't ask enough questions, 'I want to be...I want to be working. I'd like to have a transplant'. This is just me. 'How do I achieve that goal?', you know, and then just having the plan work towards that, instead of having the plan work towards my...(illnesses).. I know I had health issues, and I get that, but you don't really know what, what kind of progress you have to make on yourself to get to where you want to go? So, and they're trying to just build a plan around you, for the health issues you have right now. I get that, I get that. But yeah, it would have been nice...It feels like I've used up three years of my life, and I could have been HERE where I am now, back THERE three years ago.* (Participant G, 31.42 min)

> *But I think that um, not understanding some things as clearly as I thought I did, you know, the communication, it's, it's pretty good now (on dialysis), but I think at the beginning, yeah, it was trying to catch what they were saying. There's not a clear path about where you're going! It's just they're doing...they're talking to you or, you know, and they're expecting that you understand some of it, but you don't know…. Mmm, I*

> *think...you know how you set up a care plan for somebody? You know, you've got a client, and they tell you what they hope to be doing? And then you set up these little care plans? That would be nice. You know, I mean,…. And I don't know, I kind of thought it would have been nice if someone stepped in and said, 'Well, you go to A to B to C to D, you know, this is where you're going, to get where you want to go'.* (Participant G, 29.14 min)

> *I think, I think that would be great [having a navigator]. Well, I wanted someone to, um, steer my ship, because at that moment, I was in no condition to steer that, you know? If you can have someone who...and you know, and I feel comfortable and confident in myself, but it would...it would be nice to have someone there, that you can, you know, just bounce off, you know, outside of that clinical appointment, that you can just sit down one on one, and say, 'Well, these are my options. I've been thinking about this and this'.* (Participant G, 37.51 min).

The Renal Service as a subtheme of Healthcare Teams, held significance for participants related to the concepts of consistency, communication, knowledge and support. This was demonstrated through being present, willingness to listen, offering support that extended beyond treating disease states and holding the necessary knowledge to be able to truly help participants manage their conditions as well as their everyday activities. This implied a sense of being cares for, loved and supported. Longevity of relationships and consistency of contact with healthcare providers within the team were important for participants to feel 'known' and having the ability to help meet their needs quickly and easily.

Subtheme Two: Other Healthcare Services

The second subtheme around healthcare services revolved around care that was experienced and received outside of the Renal Service. Categories under this subtheme related to multiple providers and changing providers, attitude, caring and covid rules that changed the experiences of participants. Tertiary themes were then further identified as communication, collaboration, follow up, medical visits, personal sense of violation, medications, missed diagnoses, knowledge, judgement, isolation and perception.

Multiple providers and changing providers were identified as important by several of the participants. They spoke of having to tell their stories many times, which evoked feelings of mistrust and lack of confidence in the provider. Participants felt that being cared for by someone who knew them increased trust and confidence and assurance that their problem was being listened to and addressed:

> *Um, it would be really handy to just see everyone at the same time. Yeah, because I've got respiratory, gynaecologist, renal, yeah, all the teams, and they don't really seem to talk? So, (Dr name)'s good, because I, like I've said to her before, like, I've seen my gynaecologist, this is what she said, and so she looks into that and, and they kind of liaise, which has been really cool, especially with transplant workup. But, yeah...asthma...the doctors...I got diagnosed with asthma earlier this year by Respiratory, and my doctors didn't know, and so they couldn't give me asthma inhalers. And so I'm like, 'guys, like, you guys should be, you know...communication...or just send a letter? I don't know'. So things like that would be good if they changed a bit. So everyone's on the same page.* (Participant R, 36:45min)

When services worked together, participants found they were able to navigate for themselves more easily. Healthcare teams working and supportive of each other were seen as enabling, through improved communication and a clear idea of the healthcare plan:

> *Yeah, so I was really impressed with (Renal Services). Really impressed! Made the process so easy, and I think probably the biggest part of that was the communication. I just felt like, you know, Gastro - and between Gastro and Renal - everybody knew who I was, and what, what the issue was….I think the communication was a biggie here, and probably the biggest difference. It just made it a whole lot easier that I could walk into appointment - there was no mucking around with who I was, and what was happening, and they could just do the next steps, and things like that. So yeah, it was really good. Very impressed. Yeah.* (Participant J, 23:33min).

When this wasn't the case, different services tended to deflect any concerns thereby placing the responsibility for care onto other teams. As Participant J explained, the led to feeling blame was then projected onto them by the provider:

> *I was under Rheumatology and Gastro in Renal at (different geographical Region Service) and nobody communicated whatsoever. It was just blame them, blame them and blame them, and actually nobody communicated - blamed them and me in an appointment and, um, that was the end of it.* (Participant J, 23:33mins).

Constant change of providers at the primary care clinic resulted in frustration in having to recount their medical history and feel that their own experience isn't valued or listened to:

> *I find it really, really hard in (rural town) because we don't have set GPs. And I often go in and they have no idea about my medical history… that I'm constantly explaining, or, I've even had to, like, argue about a medication, because I'm like, 'No, I'm not taking that'. Like, I'm not taking it. So it's been, that's, that's a journey, not having a doctor all the time. We sort of just get who's here, and most of them are awesome. But there's been a couple of hiccups where I've been like, Oh, my God. So I have rung (renal Dr name) in panic mode. And like' help!* (Participant R, 15:17min).

Participants felt at times, that they had to become knowledgeable themselves as they could not count on the next doctor they saw. They developed their own expertise to help manage their health journey:

> *I was clueless at the start of it, of the journey. But as we've gone along, I've learnt a lot, and I really learn about what's happening. Or, if I'm on new medication, I generally argue with my doctor about that (laughs) before I take anything. But, um, I try and be as clued up as I can, because at the end of the day, you don't know how you're going to deal with when you go in to the doctor. So... And I often hear myself saying, I know my body. Yeah, I know what's happening.* (Participant R, 16:46min).

Due to having chronic conditions that elevated an understanding of how their body felt from day to day, enabled a participant to advocate for herself when she felt unwell. But this became frustrating when she felt health professionals were not listening or taking her concerns seriously, despite knowing something was not right. This lack of respect for her knowledge of herself resulted in needing to receive lifesaving care, where she felt this could have been avoiding if her self-knowledge was respected:

> *Just in the fact that I was actually having a major haemorrhage, and nobody knew, and nobody took it seriously. And I had told someone that something's, you know, I had told the midwife and that had also randomly come into my - I can't remember who it was - that something's wrong. And nobody actually took that very seriously. I mean, I ended up in ICU. And (husband's name) said when he came to see me, I couldn't talk, I wasn't waking up, and things like that, so...And baby was in SCBU at that point with breathing difficulties. And so, yeah, (husband's name) really struggled with that….. I was in hospital for over a week. And again, really just generally struggling. I struggled with, like, breathing. I struggled to walk.* (Participant J, 123:38 min).

Multiple providers also meant multiple and at times, conflicting messages for the participants. There was often a tension between what different providers were asking participants to do, creating confusion. As an example in this participant quote, the participant was left with a sense of needing to 'survive' the confusion:

> *Um, I had to watch the diet. And, um, yeah, I sort of got a bit confused at times, because the renal diet was different to the diabetic diet. So, um, yeah, I survived it though.* (Participant H, 2:08min).

Responsibility for treatment and lack of communication extended to other types of health care teams such as medical product companies who delivered essential dialysis supplies for home treatments. The onus is on the participant to remember to order enough supplies and on time to ensure a delivery. If this didn't occur, then it became the work of the participant to chase this up and make urgent arrangements for supplies:

> *Yeah, when you actually, when you actually sit down and give it a good think, or write it all down on the paper, and then I've got to do my order to (medical product company) - I've got to remember, for a start... Um, the*

> *last lot I did, because (medical product company) forgot my order. And I sent them off a courtesy message to say, 'Hey, team, I haven't yet received my order. It was due on the fourth, and I didn't receive it'. And this was like the seventh. 'Could you please get back to me what was going on?' They didn't. Then on the Monday, I followed it up again…. So I had to ring my nurse to shuttle me down some softpacks and filters, some lines, and some kidneys. Well, I had four boxes to pick up. And three of them were heavy, because those softpacks are like three and a half, four kilos, something like that. And there's three to a box. So that's like 10 or 12 kilos you're lifting when I shouldn't be lifting it. But if no one else is there, I will lift it because I have to do what needs to be done.* (Participant A, 42:25min).

Healthcare appointments were also seen as exhausting. This was compounded by a lack of coordination of appointments across services increasing the waiting times for participants in order to access care. This could take all day:

> *I might have had an early one with (NP name), and then I had another one, and then I had an x ray or some sort of scan, and that was mid afternoon. So I'd sort of hang around here most of the day.* (Participant H, 2:08min).

Accessing healthcare services meant more than just taking time off paid employment to attend an appointment. There were associated frustrations and difficulties such as inability to find a car park at the hospital, juggling children, work, and appointments. Time was valuable and participants described needing appointments to be efficient and necessary also, as they had many demands on their time. At times the value of the appointment was difficult to understand by the participant who felt there needed to be options in how the appointment was facilitated:

> *Appointments can be exhausting. So, I used to have, you know, two to three appointments in one week. And, you know, the access to the hospital's pretty terrible these days, with the car park if you're at the wrong time - things like that. So it can be really stressful, like getting there, finding up carpark, getting to your appointment. Also some appointments, um, I say, 'Well, that could have been a phone call,' you know, stuff like that, and saved me some time. I do like to go in though, and just - yeah, but just even with my kids - (child's name) was under CDU for a wee while with thyroid issues and, and yeah, it's like, the time, the appointment, and then they want to book a follow up appointment, because they didn't actually know what was going on in that appointment.* (Participant J, 28:1min).

Health provider attitude was also represented as both positive and helpful as well as negative, judgmental and in one participants case, through actions that were seen as violating:

> *But he (the doctor) expected me to strip off right then and there and the room in this coat cupboard, in this cupboard size room, just stripped everything off down to my underwear. And I thought, this is not, this does not feel right for me, I say to that … is there nowhere else I can go to a room to take my clothes off. And private. And then when when I'm done there, just lie down on the bed and wait…. He just went over the body, looking at the various parts while I'm standing. And while we were in there, somebody or somebody else, nothing to do with the (appointment) came in to use their computer. But she's talking she said Don't mind me. And she's looking at the screen, doing what she wishes to. And I thought this is just horrible. I felt terrible… to me I'm just a piece of skin. But I felt violated, really,.. ideally, I would have liked the curtained area room,*

> *because it's big enough that you can, you know, go behind the screen, take clothes off and a bed to lie on..* (Participant Q, 44:22min).

Respect was also felt when health professionals took the time to listen and explain where this was seen as a positive and helpful:

> *Yeah, I think so. Because then I can sort of track where I'm at, and it's good peace of mind. And I find (Dr name) will sit and talk me through everything. So I know exactly where I'm at with my health.* (Participant R, 14:40min).

Access to care changed when Covid 19 became a pandemic around the world at the end of 2019. Over the Covid years in NZ between February 2020 through to mid 2022, access to care and attitudes of healthcare staff toward patients created a stressful time for participants, who often felt pressured by health professionals when attempting to access care during this time. This resulted in missed care, lack of treatment and feelings of isolation:

> *So with the COVID business, I had gone up to the hospital...well, one particularly bad incident was, I got up to the hospital, because I could feel my lungs...I get infections in my chest….. So I made an appointment to see the doctor and book an X ray. And he just kept saying, 'oh, Covid this, Covid that. We need to take you to the COVID clinic, you can't come into the hospital'. And so I had to go through the back of the hospital into this room where there was like everyone dressed like aliens. And they were like, kind of mean, actually, about it…* (Participant R, 21:21min).

This participant felt undue pressure and judgement to complete Covid vaccinations despite having a bad experience with the first vaccination:

> *Yeah, I felt judged, like, 'oh you're making the wrong choice', and I'm like, 'well, it's my body', and it should be my choice. But actually, (Dr name) had said like, at the stage, just don't get the next one, um, because my reaction wasn't good. So I found that really hard. And they wouldn't let me in the hospital, so I didn't end up getting X rayed.* (Participant R, 32:47min).

Covid rules made some participants feel isolated and treated unjustly when they were in the hospital system, even if they didn't have a Covid infection:

> *Yeah, well, they treated me like I had COVID. Because when we got back, like the ambulance from the airport, um...Oh I can't even think of her name...the ER nurse came up to get me. She was just shaking, and saying, 'Oh, I might need to pull the sheet all the way over your head'. And the ambulance guy says, 'Well, to be honest, we practically do. You've got to have the sheet right up to your eyes.. And he said, if anyone's in the hallway, we gotta tell them to back off, and clear the hall.* (Participant H, 19:48).

As explored in earlier themes, one participant was unable to have his wife with him during treatment due to covid isolation rules. This caused him to be fearful and anxious, where he took longer to feel trust and confidence in the care he was receiving. One participant felt that it was important to acknowledge and reflect on what it was like to be a patient at the time of the 'pandemic', and what it would mean for their treatment:

> *Um, I think COVID's made me feel isolated. Alone. And that'll be important for talking about what really matters, and it means for like, my health issues*. (Participant K, 36:24min).

Faith, trust and knowledgeable practitioners featured for several of the participants. Some participants felt they had been misdiagnosed in the earlier phases of their health journey. This left the participant feeling let down and that an opportunity to correct, restore or prevent deterioration in disease states, was missed. This eroded trust and took time to rebuild in health professionals. Trust and emotions such as relief and reassurance were gained when participants were referred to specialist services. This related to knowledgeable practitioners but also to consistency in the health professional they were seeing and interacting with:

> *Because I was presenting to her (GP) with classic symptoms of renal failure, and she totally missed it totally wasn't on her horizon at all to test for that. It's pretty worrying…. And she totally missed the last time she did a kidney function test on me was in 2011. So from between 2011 and 2017, when I was diagnosed, my poor kidneys had been dwindling. They could have been giving medication and, you know, helped.* (Participant Q, 34:47min).

> *Eventually went to a different doctor, like a different GP, and I had high blood pressure, and yeah, all these kidney infections. And so they did all these tests. And that's when I found out so I think within the year, a year later, I was on dialysis, so...* (Participant M, 3:12min).

For some participants, finally gaining a diagnosis brought a sense of relief and hope, this was often not achieved until they saw a different health provider:

> *Well, now I know what's wrong with me. It was a bit of a relief, actually. Because I've waited I'd been so long, so many years, stuffing around trying to find a cause and no one was able to pinpoint it until that very time. So I was relief actually.* (Participant Q, 34:47min).

> *Yeah. I kind of, it was a bit of a relief, actually, to be fair, when I found out because I was so sick for a good 18 months and not really knowing what was wrong. And then when you had a diagnosis that was kind of like, oh okay.. Yeah, it explains it. So you weren't going crazy, you know, like, it was like, Okay, this is what's wrong, and let's go forward from there. So it kind of was a bit of a relief.* (Participant M, 4:09min).

Frustration was prominent when participants had multiple medical problems and experienced rushed medical appointments with doctors who did not know them. Knowledge of the participant from years of caring for them was valued and expediated care:

> *It's really frustrating more than anything, because they give you 15 minutes, and then they're like, 'We know, we're running out of time'. Like, you can't rush me like, I'm gonna tell you all the stuff. I need, like, a warning label or something. (laughs). But, um, it's hard, it's really hard because, especially when it's a stranger you've never met, you don't know them, and they don't know you, and, like, my old doctor that was there fulltime, I would just go and tell him the problem, and he was like, right, and he would get things sorted within minutes.* (Participant R, 23:47min).

Trust in health providers to keep them safe was also difficult for participants to achieve if they had experienced harm or felt at risk because the health provider appeared inexperienced or lacked skill:

> *And when they were taking the drains out, a tamponade, that was on my heart...one of the nurses accidentally pulled it and it ripped a hole in the sac where my heart is, and blood went in and my heart stopped. So they had to revive me, open me up again……..I had a feeling about that,*

> *though! That's the weird thing about it! And she looked at me....honest to God, she looked at me. And that's when I thought, 'F**k, she doesn't know what she's doing!' (laughs). But, you know, boom, lights out! But I remember that was my last thought...when I looked at her, and she was looking at me, and I thought, 'Ohhhh, faaarrrkk'.* (Participant L, 5:08, 36:06min).

> *Oh, absolutely. I had some advice from a doctor I'd never met last Saturday, and I you know, absolutely freaked out panicked because he just, he didn't know what was happening with me. You know, he didn't he wasn't a renal specialist. And he was saying, oh, you know, you're not very good. And this and that. And, and it was really frightening. And I rang straightaway, and they were like, no, no, no, you know, like, it's explained it all to me, but not everyone has that… And, yeah, they'll advise or reassure or. Yeah. And that's good.* (Participant M, 9:04min).

Trust was rebuilt when the health providers the participant interacted with on a regular basis, demonstrated confidence and skill:

> *Yeah, that's the calciphylaxis, but once again, I just...sit there and think...I'm not dead. I'm in a controlled area. If something really bad happens, they'll (renal staff) know what to do.* (Participant L, 35:432min).

The main concepts in the theme of Healthcare presented as two significant subthemes, The Renal Service and Other Healthcare Providers. As for the Renal Service, consistency in provider, personal knowledge, being treated respectfully and, feeling listened to, respected for their own developed expertise and knowledge that participants had were also important to feeling cared for, respected and valued. The main concepts that the subtheme of 'other healthcare providers' related to fragmentation of care, lack of coordination and communication, with the onus of treatment and organisation of this as the work of patients, as well as attitude where events such as Covid changed how participants as patients were treated. This also extended to a perception of lack of respect for them as a person and being treated as a condition.

Major Theme Five: Support

Closely related to the theme of Health Care is the theme of Support. Though represented within other themes, Mental Health and Healthcare Team also, it has other subtheme groupings, and therefore also stood out as a major theme. Subthemes included community, cultural, finances for travel and daily expenses, worship, and faith, as well as caring and shared experiences, with tertiary level themes of confidence, strength, and trust.

Community support was important for navigating difficult times when chronic conditions or treatment regimes removed someone from their 'normal' day making life difficult to live. This support enabled families to continue to function and for the participant to meet their other family responsibilities such as childcare and picking children up from school, or getting groceries and access to food etc. Having knowledge of your community

and what resources were available to help was also important and not always easy to understand for participants:

> *It was amazing, really, like, that's where we're lucky with our community. Everyone sticks together when the shit gets hard.* (Participant R, 21:17min).

> *Yeah, I think I would like more...and I might still have to do some research, and it's knowing your community...any support groups in the community.* (Participant K, 36:24min).

Having the understanding of people in the community such as employers or landlords, who then helped out and were considerate at difficult times, were seen as supportive and helped to bridge these difficult times without adding further stress:

> *Again, I was very lucky. I had a landlord who was a nurse, and when we told her they were very supportive too, and they actually came around and did a lot of work around the house for us, and stuff like that. So we were, we were very lucky to have had a lot of support around us.* (Participant J, 3.38sec).

> *We both (husband's name) and I - (husband's name) work is very supportive, and they understood, and he worked from home, that period of time as well.* (Participant J, 19:47min).

> *I worked for the Department of Social Welfare, as they were known back then. And I had really supportive – (Director's name) was the director back then - and the support from him was absolutely overwhelming. He allowed me to set myself up in the nurses bay I could dialyze. He allowed me to return to work part time, he allowed me to pretty much call the hours that I wanted to work….. 'Look, I can't come in today'. And it was like, 'Don't worry about it.' You weren't made to feel guilty whatsoever. You were just so supported.* (Participant O, 12:14, 13:00min).

Having employers support enabled an eventual return to work when the participant was able. This provided financial support and minimised the change in lifestyle and quality of living. This strengthened relationships with the employer and bought a sense of loyalty:

> *I was really lucky because again, they supported me - they still paid me a wage. And then they were - because I was at the Department of Social Welfare, they were able to arrange the relevant benefits. I was able to access like a sickness benefit. So they pretty much took care of me financially. They held my position for me, they put me on sick leave.* (Participant O, 13:28min)

Having supportive friends and whānau enabled the ability to engage in activities that were now difficult to do, but also relieved the isolation some participants felt and helped them to build trust within their environment again:

> *Then I've got a couple of friends, and we go out for cups of coffee, and that's good. So it's getting more out of myself, and yet I used to be a very social person. And it's that trust...trusting people again.* (Participant K, 36;24min).

Cultural practices were also important to participants. Access to traditional cultural methods of healing was important for feeling whole. Being able to have access to a healing method known as Rongoa and engaging in a culturally supportive way was necessary. For one participant who described how this helped her strengthen her tie to her cultural whānau roots, this included treatment methods she had been brought up with which brought her comfort, familiarity, and was seen as supportive:

> *I...we used to watch Mum...oh, the younger brother, he had asthma and eczema, and Mum would put cobwebs on him, and all these metal and different Rōngoa, and he's got the best skin out of all of us. So we saw her using treatments. When I was born I didn't walk until I was over three. She told me that she was gonna take me to the healing water, and I started walking. So she was a firm believer. And I know we used to go and see a*

> *Tōhunga often, and that's why I find karakia soothing.* (Participant K, 1:10:10sec).

> *Um, I've got a couple of friends...oh well, last year I did Te Reo Māori classes, and that was good. Yeah….. and karakia is good. It's my number one.* (Participant K, 36:24min, 1:14:51sec)

> *Use of traditional healing concepts also brought a sense of togetherness, harmony and 'oneness' for this participant, "And in my head and my heart, and probably my soul, I believe that pākeha and Māori are complete Rōngoa (joining hands),"* (Participant, K 1:10:10min).

Distress can be seen when the health system failed to meet the cultural needs of a participant, especially during significant life events such as receiving a kidney transplant. This participant expressed her distress and disappointment during the interview, when she recounted her experience of asking for a Karakia (prayer) prior to going into major surgery. Unfortunately, this was not facilitated for her and left her unfilled and added to her anxiety about going into theatre:

> *When I was in (Tertiary) hospital unfortunately there was no one available to come and (nurse) was quite ..she said I'm very sorry that no one came to you. There was no… I don't know why the Māori person isn't wasn't available (to provide a Karakia), but she said what would you like another (person)? I forget… anyone anyone could come I don't mind…would be nice to before I go (into surgery).* (Participant Q, 1:09min).

Struggle and competing commitments between health and cultural needs, were also seen when important cultural events occurred such as attending tangis, where it was difficult to accommodate dialysis while being with and for whānau. One participant shared how difficult it was to balance her health needs against her cultural needs. She had to take her dialysis equipment with her to enable her to be at her Aunty's tangi. Her whānau and community adapted a space to accommodate her machine. Her cultural need to be with whānau at this time took precedence over her health needs, but this then meant she struggled for the next few days due to missed dialysis sessions:

> *When I went to my, um, my Auntie's tangi, yeah, and um, yeah, I didn't hook up for... up on dialysis...for one night, you know? Well, yeah, I was right by the casket you see, so yeah, yeah. For me, I didn't think it was...I mean, they gave me a room, or they...they set up a room on the side there, oh, by the...in the church, because some of us stayed in the church area? Yeah. So they put me in there and just hooked up there. And could hook my machine up there. But I...because I was her last night, you know, I wanted to stay by her for the night. So, you know, just things like that..* (Participant P, 26:235min).

Another cross over theme explored under the theme Mental Health, was financial support, specifically the lack of it. As conditions and symptoms progressed and the ability to work became a struggle, participants would have to sacrifice taking the time to be sick or unwell, with the balance of working to maintain important finances for maintain current living conditions. Rigid funding support rules meant even a few dollars over the funding criteria removed funding support entitlements:

> *You'd have to go to work. Or have to give up your house. Yeah…. we were entitled to nothing. We tried. We tried, and even the caseworker (social support agency) was pretty upset about it, because obviously I have all the, you know, letters and that there to say how sick I was, and you know my history. And I think we were, I think (husband's name) earned, like, a grand over the cut off. So, you know, that's not going to make a difference.* (Participant J, 4.42, 5.17min).

Progression of chronic conditions and the development of other chronic conditions as a result of treatment, forced a change in functionality that meant working to earn money was difficult:

> *So I think a lot of the time, even when I was studying and things like that, we tried to get me some sort of health benefit, or something, so the pressure wasn't on me to work. But yeah, I didn't. I had to quit a job, because I started developing lupus, a drug-induced lupus. So I actually had to leave. Because it was so bad at night - I worked in a bar, and obviously, late nights, and I had to leave because I couldn't - 'cos that was when it was the most painful.* (Participant J, 5.;17min)

This resulted in participants needing extra support and help from whānau. Whānau then became major support systems in meeting everyday living costs:

> *My parents actually paid my bills. That's how we got through. My parents covered my rent and anything else that I needed.* (Participant J, 3.38min).

One participant described how whānau were her main support system, and that she felt she had an obligation to help them also, to remain positive to enable them to be positive where she found this mutual support to be a strength:

> *I have a good supportive family. My children will only respond to how they see me react. The same with my family. So I am only...they are only mirroring what I am putting out and they mirror back to me... positivity. They're always encouraging. They're always supporting and they mirror back that positivity. And that's important.* (Participant A, 1:12:19sec).

Support was also needed for the close Whānau of partners with chronic conditions and that their support needs may be different. Having separate support systems for partners was also seen as helpful:

> *We both kind of needed to go our separate ways for our own separate support. So (husband's name) needed to go to his Mum's house, you know, and things like that with things, and I, you know, I needed to go and see my family. And so it was, yeah, it was nice that we both had people that we could go to, and not rely on each other, or each other's families. So yeah, that was really good. Very lucky, anyway.* (Participant J, 53:26min).

Support extended beyond whānau and community where family pets became a significant part of support systems also:

> *Yeah, yeah. ten years since being diagnosed. He was like my little therapy dog. And he knew when I was sick, and he would just lie next to me. And he would, he would kind of I, even when I knew something was wrong, he'd kind of sit there and like, cry, like, you know, he's one...He was a great little therapy dog.* (Participant J, 14:19min).

Having supportive and understanding healthcare providers who knew the participants, what was important to the participant and being able to accommodate their needs was seen as supportive:

> *That's the biggest thing is just actually having that relationship with your patients, and knowing who they are, and maybe what they do for a job, and being able to work around that.* (Participant J, 26:49min).

Participants also described not knowing how to go about gaining support when needed and not knowing who to approach to assist with this. It was difficult and distracted from being able to focus on personal strategies to try and get well again.

Having a support person who they could turn to would have been helpful through anxious times:

> *But yeah, like the access to, you know, ensuring that they've got rides to hospital appointments, yeah, rides to their appointments, and maybe any other needs that they need to be met, like, at home, especially in this day and age, like with food or stuff like that, because, yeah, I mean, you're trying to look after yourself, and you've only got $5 for the remainder of the week, you know? And so maybe just, yeah, someone who could be there to help them with other services, whether it is, you know, (social funding support agency) or, you know, letting them know how to go through that process. Yeah. For some people, it's such a process, and some people will just choose not to do it, and suffer rather than...someone that can tell them, 'This is available, this is available, this is available. What can I organise for you….it's one thing to, you know, try and focus on yourself, but if you've got kids at home, and are struggling week by week financially, food, everything - just someone that can take that load off you so you can focus on getting a bit more rest, or not having to worry about feeding yourself or your family that night, and yeah, yeah, I think that would be really helpful?* (Participant J, 46:29).

Being able to share worry and anxiety when health events resulted in change and treatment options that were scary, with people who had gone through similar experiences, was also a key support mechanism and helped to relieve fear and anxiety. For participants being able to help and support others was rewarding and provided strength:

> *And she was really scared. And I talked to her - her son actually put a post up - and I said, 'Look, I have had a transplant, I'm happy to talk to your Mum'. And so we started to talk, and she asked all these questions. And she said, 'Thank you so much. You've really helped me'. And I thought, yeah, because I remember talking to someone that had had a transplant before I did, and they know. They've been through it. And so I think another option is to have a support network of people that have done it, to say, 'Oh, I've been through that, and this is how I felt', or, 'this is what happened'. I think that would really help and benefit…"So it was quite cool to have a perspective from someone that's got chronic health conditions, gone through the transplant and dialysis process, and come out the other side really well. So it's reassuring.* (Participant R, 48:46min).

For some participants, having the opportunity to talk to like minded people who had similar experiences would be helpful:

> *Yeah, I think, for me, maybe more so if there was some kind of like support through other people that would be keen to talk to like minded people like me, like say, as a patient. If there was, like a chat on a Facebook group, or, you know, have a like a meeting available, or once a fortnight, where, if you wanted to be open, and go and talk to these people. Like, it'd be quite nice if I sat there with someone else going through the same thing as me because, talking to a counsellor, or a renal nurse, that they don't know what you're going through, you know, they can empathise, but they can't, they don't know. But when you're talking to someone that knows… And, it was just nice to know someone else was going through what you're going through,. (*Participant M, 11:41min*).*

Worship, faith and God were also major sources of support for some participants. They described this in terms of a partnership with God. This helped them to have hope for a better day and achieve healing as well as faith that their struggle and difficult times were part of a bigger, ultimate plan for their lives:

> *I'm saying this because I always read my Bible. I believe in God as well, God's healing and things like that. But with God's healing, you have to do action as well, like seeing doctors, and...and comply, yeah, because it's all part of it. Yeah. You have faith and you have to do actions, you have to act on that. (*Participant I, 45.05min)

> *There was nothing that I wasn't doing to help keep my kidney function. I was just deteriorating. And yeah, that's a massive lifestyle change. I just thank God I have my faith and I meditate, because I believe that's what helped, helps me get through…when I know there's my ultimate plan. I say God's got a plan. We're working on it! Yes!* (Participant A, 1:10:30sec).

Faith also helped a participant to get out of bed every day, stay focused and to have hope that medical science will be able to provide a cure:

> *Yeah, of course! Is a good thing to go through this (referring to medical journey). We don't know, how far from, how long from here...we have a medical break on kidney things, and we have a lot of hope (laughs)Yeah. That's our faith. That's a big word that drive us...* (Participant N, 1:06:45sec).

Summary

Of all the major themes, mental health had the largest number of sub themes. Many participants found sharing these issues to be an emotional experience often associated with tears, crying or sadness. At times the interviewer was also tearful as the participants shared their sadness, frustrations, and struggle. Worry, anxiety, and fear, closely aligned with loneliness and loss often related to changed relationships with friends and whānau/family and an altered perception of self and what was normal. Self-blame for the 'illnesses' they had, was also prevalent and associated with self-recrimination for not listening or learning from the experiences of others in their younger years. Depression and 'bad days' were closely linked and experienced by many. But there was also a strong sense of resilience in the way participants coped with daily living, altered financial states, loss of income and employment, medical treatments, and dark days. Coping mechanisms were centred around self-talk to change negative to positive attitudes, finding enjoyment and fun and a strong sense of developing new whānau groups, from within the patient population with a kinship developed out of shared experiences, feelings and living medicalised journeys. Support from Whānau, family, pets and health professionals who knew them well, helped to gain a sense of 'managing' and that it would be 'ok'.

Many of the themes were interrelated with several cross overs that made it a challenge to categorise these into distinct groups. Therefore, within descriptions there is also cross over. One such example is 'hardship' where hardship was described as financial hardship meaning loss of income, and hardship in the sense of living with the effects of medical conditions that was difficult and 'hard'. In reading back on these themes, what struck me is the level of resilience the participants demonstrate every day in living. They described being sad and down one day but were able to find fulfillment in activities that bring them joy through shared experiences or the in having the ability to 'give back'. In hearing their stories told in their voices and in their way, it provided me with an understanding of the impact of multimorbidity on their lives, in a way 37 years of nursing and caring for people, had not taught me. I am grateful for having the opportunity to hear their stories and acknowledge their courage and heroism in doing so.

Participant Quality of Life survey results

Introduction

This subsection explores the everyday experiences of the case study interviewed participants, through two Quality of Life (QoL) surveys, the Meke Meter (Forrest et al., 2016) and Flanagan's Quality of Life (QoL) survey (Burckhardt & Anderson, 2003). The QoL data results are used to support the focus in the qualitative approach to this study. This data was collected during 2022, and participants were asked to complete these within a few days of completing their interview. Both surveys were completed at the same time to ensure consistency in responses for each participant. This was important as wellbeing surveys reflect a moment (or day) in time but are also a reflection of how life is currently, whereas the conversational interviews directed the participant to reflect on past experiences as well, that for some spanned a lifetime. After completing the development of themes from interviews, I found similar categories appeared in the QoL survey domains, and this felt to be a logical flow to presenting these results. An overview of results is presented first followed by exploration of categories. At times I have also inserted participant quotes where this supported the QoL finding. What became clear in examining the QoL survey results is that overall, they were describing a different experience or account from participant interviews.

QoL Survey Results

All 18 participants completed both surveys. Overall, the results of both surveys were more positively positioned with majority of scores within the top half of the Likert scales used.

The Meke Meter reviewed three main categories with a total of 15 subcategories on a scale of 1 (Bad) to 10 (Good). The average score across all key areas and participants was 6.9, meaning they felt 'OK' or 'good'. Similar results occurred in the Flannagan's QoL survey that included 16 questions with a scale of 1 (terrible) to 7 (delightful), where the average score across all participants and questions was 5.2, meaning most felt 'mostly satisfied' to 'delighted'.

Both of the QoL surveys explored areas of mental health or wellbeing and social interactions. There were mixed results from the two QoL survey questionnaires that related to the theme of Mental Health. Even though overall, the scores were inconsistent with how these themes were represented within the interviews, some areas were similar. Flanagan's survey questions 2, 3, 4, 5, 6,13 and 16 explore freedom from sickness, physical and mental wellbeing and free of health hazards and availability of effective health treatments, relationships with loved ones and others, socialising, and independence. Question two was the lowest scoring question in the survey and explored physical fitness and vigour. The average score for this question across all participants was low with a rating of 3.87. This relates to the scale of 'most dissatisfied' and is consistent with the overall expression of this theme group from interviews.

These results suggest that most participants did not feel physically fit and have the energy for what they may have wanted to achieve. In interviews they felt worried about disability and impending death. Most participants discussed lack of energy and the need to keep trying to carry on. Pain was a strong feature for many of the participants and is consistent with physical scores in the QoL surveys.

Flannagan's Questions 2, 3, 4, 5 and 6 explored relationships with loved ones, family, and friends. These scores respectively were in the mid to upper end of scale, at 5.5, 5.7, 5.8, 5.7, rating as 'mostly satisfied' to 'pleased'. This was surprising as participants often spoke of struggles and frustration in their everyday lives, the burden they felt on their whānau from their being sick and unable to help with family matters, loss of income and employment, feeling not normal or a freak, and times of dark days and times where depression often featured:

> *I don't know, I've had my dark days. I've had some very, very dark days. I've thought of suicide multiple times. Because you just think, 'Is it ever going to end. Why me? Why did I choose this? What do I do in this life to deserve this?'* (Participant B,39.16min).

Flannagan's Questions 16 explored independence and ability to care for oneself. In contrast the mean score for this question again is more positive at 5.78, 'mostly satisfied' to 'pleased'. There were four participants who scored this as 4-4.5, meaning they felt 'mixed' about how independent they felt. One participant described how he needed help to pick up anything he had dropped, and this caused him to feel frustrated and a burden. This frustration was common to many of the participants.

> *I AM a burden! I'm a burden every day on my family. That's, that's the frustrating thing about it. I'm a burden on my family every day. Every day……I can't do it anymore, you know? ….Even when I drop a pill on the ground, I can't pick it up because of my fingers….* (Participant C, 27.05 min).

The Meke Meter domains that support this subgroup were similar to the Flanagan's scores. The domain that relates the most to this subgroup is the domain that reflects elements of Mental wellbeing, the domains of happiness, motivation, and relaxation. Happiness had an average score of 8, relating more closely to a feeling of 'good'. Motivation scored 6.9, again at the higher end of the scale above 'ok', and relaxation scored 6.8, above 'ok' to 'good'. Spirituality also scored positively with an average score of 7.2. These scores were in the positive and upper end of the rating scale which again appears to conflict with the participants descriptions of their experiences and feelings especially when sadness or descriptions evoked silent tears.

However, the fourth subgroup of Mental Health themes described altruistic acts, volunteering and giving back to the community. This brought a sense of fulfillment, hope, and goodness where for some, faith and meditation were supportive activities. This related to Flanagan's questions 7, 10, 12 and 15. These questions explore community and civic activities, personal growth, personally agency, expressing oneself and enjoyment of recreational activities when able to achieve them. Scores were respectively 5.6, 5.7, 4.9 and 4.5, mixed to satisfied. In some questions, these scores are reflective of the struggle expressed by participants but those who described their involvement in these more altruistic activities, spoke positively and expressed the joy they experienced at these times. The Meke Meter scores in the social domain of sport and recreation, culture, finances, and family were again more positively presented. Recreation was in the lower end of the rating scale toward ‘bad ‘at 4.6 but culture and family scored highly at 8 with finances reflected positively at 6. Financial hardship was a frequent theme within the interviews, as well as missing out on family and Whānau time and activities, and the burden they felt on their families at times. The domain of relaxation, happiness and motivation are also indications that participants overall felt happy and fulfilled. These scored highly with average scores of 7, 8 and 6.9 respectively, and are supportive of the ‘feel good’ opportunity that altruistic acts appear to bring participants.

Hardship and loss were also a strongly expressed theme in the interviews that were explored in the QoL surveys. This theme had a significant cross over with Mental Wellbeing as well as Impact on Self and Whānau/Families. Hardship related to financial stress, loss of income, loss of identity. These presented when needing to give up work and transition to a social support benefit, loneliness through social isolation, physical inability to get to appointments, exhaustive travel to seek health care, and degree of sickness that also caused frustration when unable to easy obtain prescriptions and medications. This area relates to Flanagan’s higher domain of Material wellbeing, health and personal safety, Occupational role, Socialising, and Independence (Q1, 2, 11, 13 and 16).

Areas such as good food, housing, possessions, and comforts were explored as well as expectations for the future (Q1). Scores in this area were relatively high at an average of 5.3 but decreased when freedom from sickness and availability of health appointments were explored (Q2), with an average of 3.9 across participants, similarly to the interview findings. Two participants had particularly low scores at 1 and 2, with three participants scoring this as 3. Most participants scored around the midpoint of 4, and only one participant scoring a 6. Employment, worthwhile work and feeling competent (Q11) scored around the midpoint also with an average of 4.8, mixed to mostly satisfied. During interviews, many participants described low points in their life around needing to give up work and losing confidence in their place within the Whānau unit now they were not earning. They describe the hardship that loss of income brought to the Whānau, therefore I had expected this result to be lower. Socialising and community connections were explored in Q13, and again the average score was 4.8 suggesting most were mixed to mostly satisfied with their ability to do this. In describing the impacts of loneliness, many participants shed tears during the interviews, especially when talking about the loss of work mates, and inability to get out and go for a walk or have coffee that are now not achievable.

Independence was also a surprising result with an average score of 5.8 suggesting most felt 'satisfied' to 'pleased'. This related to the ability to care for oneself and was significantly affected when explored in interviews. Meke Meter results were similar in the respect that most participants scored these more positively across the social domains where work and study, and finances scored 6.4 and 6.7 respectively, indicating they felt better than 'Ok' to 'good'. Three out of eighteen participants scored this poorly at a 2 and 3, suggesting they were disappointed in their financial situation. Culture and family/friends scored more highly across most participants who felt 'good' about their ability to meet these needs with an average score of 8.3 and 8, with only one participant scoring this at 1 as 'terrible'.

The final major theme groupings were Healthcare Teams and Support. These themes were suggestive of how participants viewed support systems and what enabled good days and bad experiences. Good healthcare experiences and teams were seen as caring, listening, and non-judgemental but also being present with easy access to care and team members. Consistency was found in the Renal team where longevity of relationships enabled strong supportive systems. This was experienced differently for GPs and other health care teams, where relationships with constantly changing providers meant changing medications and care plans that increased fragmentation of care. Whānau were seen as the strongest and enabling support system but was also strained by illness and disability with increasing care needs.

The QoL surveys both explored these themes through different domains. The Flannagan's survey explored relationships with parents, partners, and siblings (Q3 and Q4) scoring similarly with 5.3 and 5.6 respectively, relating to 'mostly satisfied'. Relationships with children including the ability to care for children (Q5) scored 5.7 with three participants rating this as an NA (Not Applicable). Having close friends with shared interests and supportive, loving relationships that embodied acceptance is seen as important (Q6), again scored slightly above the midway point of 5.5 and 'mostly satisfied'.

The Meke Meter explored similar meaning in relationships through key indicators under the Social Domain where recreation, work/study and cultural identity was explored with friends and family support. Recreation and sport overall scored below 'ok' at 4.7 that relates to participants expressing sadness over the effects of increasing disability on relationships with others especially partners, friends, and family, as participants became more immobile and home bound. This recorded very similar scores to physical fitness (4.7). Relationship with family and friends overall scored reasonably well at 8.08, with six participants scoring this at a 10 being 'good'. This domain scored the second highest domain overall with Addiction Free scoring the highest at 9.2, where 13 participants scored this as a 10 and 'good'. Having a high number of participants considering themselves as addiction free suggests strong support mechanisms, without reliance on harmful 'vices' to get through the day. Many participants described pain as a constant feature, but QoL surveys suggest this is well managed or manageable.

Faith and cultural identity featured more specifically in the Meke Meter as this was designed by and for Māori and is an important aspect of Māori cultural beliefs. These were explored as part of the Mental Wellbeing domain under Spiritual which scored highly at 7.2 and Social Domain as Culture, scoring 8.3. Culture was a guiding framework that was needed by Participant K, who identifies as Māori and female, who included a note with the returned completed surveys to explain that she could not make sense of the surveys until she applied the following thoughts embodied within a Te Ao Māori perspective. Table 11 represents these as quoted in the note returned to me on a piece of paper. I have applied an English translation taken from a Māori Translation source, to understand their meaning and context. This exampled how the act of completing a survey cannot be done in isolation from how a person identifies where their 'truth' stems from and that, as part of a 'holistic' view, must be embedded in the context of identity and culture. The Te Ao words that embody her culture are words that symbolises the cultural framework for this participant, that needed to be understood to find meaning in the surveys. These can be thought of as her own self-identified themes. These words also reflect many of the perspectives of other participants as expressed in the interviews and were identified as themes and key findings.

Table 11

Te Ao Maori Perspective and translation

Te Ao Māori Perspective (Participant K)	Translation
Karakia	To recite ritual chants, say grace, pray, recite a prayer, chant.
Nga atua	The gods
Ancestors	Grandparents, whom you are descended
Kuia and Koroua	Kuia – elderly woman, grandmother, female elder, Koroua – to be old, elderly
Rongoa Māori	Natural remedy, traditional treatment, Māori medicine
The environment – taiao	World, Earth, natural world, environment, nature, country
The stories of Maui	Stories of the first people in Māori tradition (Royal, na).
Wai	Who, whom.
Tohunga	To be expert, proficient, adept.
Whakapapa	To recite genealogy in a single line of descent
Aroha	To love, feel pity, feel concern for, feel compassion, empathise
Manaakitanga	Hospitality, kindness, generosity, support – the process of showing respect.
Whānaungatanga	Relationship, kinship, sense of family connection, a relationship through shared experiences and working together which provides people with a sense of belonging
Pono	To be true, valid, honest, genuine, sincere

Translation and meaning (Moorefield, 2011).

> *As I was filling in your questionnaires, I was very aware my Te Ao Māori perspective kept popping up. I have jogged some of these thoughts down and as a consequence I feel more comforted or more whole.* (Participant K: personal correspondence; Table 11).

The importance of mental health, wellbeing and socioemotional connections are reflected throughout the interviews and QoL survey responses. These surveys reflect a moment in time and how the participants may have felt on the day of completion.. Though two different surveys were used, they examine similar domains of life and what are considered defining features. The average scores for both survey tools across all participants, domains, and key areas, represent slightly higher than the midway point with mostly satisfied as measured by the Flannagan's survey scale, and between 'OK and good' as represented by the Meke Meter. This suggests that life in general is positive and meeting most of the key elements identified by the survey authors as important in achieving a meaningful QoL. But there are key areas that can be improved. One of the key findings here for me is the scores of Participant D. I have applied the concept of insider research here to help explain the meaning I have drawn from this participant's scores, as I have observed the journey of this participant over the time he has been with the Renal Service where I practice. As a patient, this participant is relatively new to Dialysis Therapy. Engagement was difficult for him as he developed ESKD. He needed to travel several hours a day to access dialysis services, meaning he left his Whānau behind to do that. His support network was not overly developed but he had a very supportive wife who would travel with him:

> *"Um, to me living with a chronic health condition is one of the most difficult things you can do, because your, your time - that's the first thing - your time is is taken up, not only by dialysis, but by travelling. Now, um, for me, when I, when I, when I started...(crying)…. I come from (Town)…..Um, it's about, I dunno, about 280 - 300ks [traveling distance to Dialysis Unit]"* (Participant D, 0.33, 3.52mins)

At the time of the interviews and completing the surveys, his low scores reflect what life was like for him. Previously he had little engagement with health professionals until this was forced on him to be able to continue living. His General Practice is in a relatively remote town where retention of doctors has been a challenge for many years. They have experienced a rotation of Locum Doctors who only stay for months at a time. In his interview he describes his fear and worry of needing to attend a clinic several times a week to access dialysis services where the westernised and medicalised environment scares him. He has experienced loss of job and income, fragmentation of care, difficult access to care, displacement from home, multiple health providers, inability to have his wife with him during treatment due to COVID 19 hospital rules where she was not allowed to sit with him. She would wait five hours in a car outside the unit until he was finished, to then travel several hours home. His usual supports were not available to him:

> *It's mainly for her, because she now has to sit in the car. Now, me and her both do tests, so this is, um, is something that I think is, is not fair. If she's doing the same test as me, how come she can't come in with me. She is my support person. And my support person has to sit out there in the hot sun and wait for me…..What I struggle with...is not the fact that I'm doing dialysis. It's that I have to travel and leave my missus outside. That's what I struggle with… especially when I have to leave my son, because I worry about my son.* (Participant D, 4.17, 8.5, 22.0min).

But during his interview he is starting to acknowledge the new support system that is developing for him in respect of the other patients and staff he is now interacting with daily:

> *The nurses are really nice...(sighs). I'm, I'm a scared person anyway, but, um, if it wasn't for here, I'd probably just fade away, to be honest. Coming here, um, I feel safe ….and that's the reason why I slowly got better with my, my emotions. It's because I sat there and I talked to (name) and I*

> *talked to… [patients and staff].. all of them, really. Every one of them. A couple of the bros were hassling me about the fistula. It took me months to agree to that, It was fear, eh...* (Participant D, 1.50, 9.51min)

> *They've got so much experience and shared a lot of their time here, and said, you know, we'll give him a bit more encouragement to do these things and try it, and it gave him less (fear)...* (Participant D, Specker 3(wife): 10.42min).

> *Oh, I say too, I like, um, the nurses, I like, um, the bros that come in, you know, the ones I talk to all the time? Yeah. And the new ones...it's good to meet them too, cos you can start a different friendship. Like there's an Islander lady that's just started, and she knows my name, but I don't know her name (laughs). I always forget names!..... "I feel safe because I've got a...a team of nurses that can look after me….Cos we don't have that in (town)"* (Participant D, 48.13min).

Overall, his QoL survey scores are at the lower end of the scales suggesting struggle, hardship, and loss, for example Flannagans QoL result for Question 3, scored at the low end of the scale at 2, unhappy (Table 12) and his Meke Meter for his social domain scored poorly at 1 or bad (Table 13).

Table 12

Flanagan's QoL results Participant D

Higher-order domain	Lower-level Domain	Defining Features	Question	Score
Relations with Other People	Relations with parents, siblings, or other relatives	The presence of relatives with whom one feels belonging. Enjoying spending time with and visiting such relations.	3	2 (Unhappy)

Table 13

Meke Meter QoL results Participant D

Domains	Key Indicators	Score
Social (Te Oranga & Whānau Ora) - S	Recreation & sport, work/study, cultural identity, finances, friends and family	1 (Bad)

However, during the interview, Participant D describes how good the staff and patients are to him now he is getting used to the change. He has reached a point with acceptance of the change that has occurred for him, and he is starting to translate this to his new identity with a strengthening social network through not only whānau, but other patients and healthcare staff. The following quotes from his interview indicate the change that is happening for him:

> ***Changing Identity:***
>
> *Yeah. Change in your, your status as a worker...that's a big thing for me…My ability to work for my family. That's like, big as. You know, I, I cried for months, just thinking about the job.* (Participant D, 56.40min)

> ***New social network forming:***
>
> *Oh, I say too, I like, um, the nurses, I like, um, the bros that come in, you know, the ones I talk to all the time? Yeah. And the new ones...it's good to meet them too, cos you can start a different friendship. Like there's an Islander lady that's just started, and she knows my name, but I don't know her name (laughs). I always forget names!* (Participant D, 48.13min).

Covid rules have now changed, and his wife is able to attend the clinic with him. What will strengthen his social capillary network further, will be his ability to be home and stay home, have his primary care and renal team working together without constant change, and social support systems that address financial needs.

Discussion – unpacking the trail of tears

What stood out first and foremost, was the emotion that all the participants displayed. Every participant shed tears as some point of their interview, hence the flow of tears is the central theme throughout. Sometimes the tears were of anxiety, sometimes regret, relief, guilt, and sometimes simply being grateful for still being alive. Listening to the participants tell their story through interviews was difficult at times as participants described their lives and what they had experienced over the last few years. This was usually in the setting of declining health, and needing to seek medical help from health professionals, as well as the government social support systems.

The central theme of the interviews is the deep emotional impact of multimorbidity on patients in the Renal Service at Hawkes Bay. Key themes from patient interviews included the mental health struggles, loss of identity due to unemployment, financial strain, reliance on whānau, and physical pain. Medical treatments, frequent hospital visits, and medication costs significantly disrupted family life, leading to social isolation and cultural disconnection. What happens to them, happens to their Whānau. If they struggle, so does the Whānau Unit. Loss was profoundly felt with impact on employers, schools, church support groups and community resources but most commonly by the Whānau, lost time through supporting, loss of whānau trips, lost Whānau finances, where 'coffee' was seen as a luxury.

One participant described her whānau as being under 'medical stress' due to the number of hospitalisations, doctor's appointments, and visits to the pharmacy they needed to make. Confidence and self-esteem were lost in the effort to carry out normal everyday activities.

Sense of self and identify were lost in the enormity of change. Being forced into a westernised health clinic provoked a sense of culture distress and loss of familiarity in that space where hospital rules removed loving and supportive Whānau, coupled with long drive times to access care taking them away from what they know and who they are about.

"Suicide" was considered as a result of dark days. Patients often felt distrust towards healthcare services outside the Renal Service due to inconsistent care and misdiagnoses. However, strong bonds with the Renal Service staff and fellow patients provided comfort, trust, and a sense of community. Whānau was a source of strength as were other patients who were experiencing a similar thing.

Many participants describe activities of giving back, and a want to support others, to help them ease their fear. Many engaged in altruistic and volunteer work despite the difficulties they experienced in navigating their own days with illness and disability. For many participants, a sense of helping and giving back was fulfilling. A sense of having professionals who were knowledgeable was reassuring but many described being 'lost in the medical conversation' in their attempts to understand what was happening to them. Caring and supportive health professionals who took the time, created reassurance, comfort, faith and trust. Communication, contact, and consistency were important factors in helping to navigate the bad days.

What also developed as a strong take away from this work, is the need for health and social support services to collaborate and work together to align our efforts and strategies to ease the burden of illness. Despite how the participants describe a life of burden, depression and such profound change, there appeared to be a level of acceptance amongst the participants of where their daily lives were at and how they now lived, evidenced by most of the participants completing their interviews describing life as good.

The Disconnect between Themes and QoL – QoL in a Survey?

Overall, most of the participant interviews left me with a sense of sadness, loneliness, and frustration for the participants in how their lives had changed and the loss they had experienced. There appeared to be a trail of tears behind them as they recalled what their journeys had been like. Therefore, I was confused when I reviewed the QoL surveys. Each participant completed two different QoL surveys, the Flannagan's 16-point QoL survey and the Meke Meter (Appendix Three) designed for the New Zealand indigenous context. The survey results were more positive than the interviews led me to believe they would be. The Meke Meter reviewed three main categories with a total of 15 subcategories on a scale of 1 (Bad) to 10 (Good). The average score was 6.9, meaning they felt 'OK' or 'good'. Similar results occurred in the Flannagan's QoL survey that included 16 questions with a scale of 1 (terrible) to 7 (delightful), where the average score was 5.2, meaning most felt 'mostly satisfied' to 'delighted'. So, what was happening here, in what appears to be overwhelming sadness, struggle and loss with tears at times, participants still felt a sense of 'life was ok' or even 'good'. Why was this?

On reflection of the disconnect that seems to have occurred around the difference in results, it dawned on me that QoL surveys really measure a moment in time and how participants were feeling on the day they completed them. They were asked to complete these at the end of the interviews. Some participants took an extra couple of days to do this as they needed time to think about their responses. My reflection has led me to question the value of this tool especially in a very multimorbid population group such as people with CKD. How can the quality of life be measured and applied to a number when what they have experienced has been so complex with good days and bad? The use of QoL surveys have been a main stay in modern healthcare fields as a way of measuring success. They help us understand what is meaningful and can offer a way to identify where change may need to occur to improve how life is lived. As modern-day medicine has found ways to treat different diseases and conditions, life expectancy has improved where people are living longer with chronic conditions. But this is not the case for people who have developed CKD multimorbidity. There is a negative association between life expectancy with each comorbid condition a person develops (DuGoff et al., 2014; Laditka & Laditka, 2016).

The use of validated QoL surveys within the health field have become a popular way to measure the effectiveness of health care plans through how life is experienced. Haraldstad et al (2019) conducted a systematic review of QoL research in the medical and health environments that included 163 studies on the measurement of QoL, in both generic and condition specific studies. They found that QoL surveys hold prognostic importance that help identify problems, gain an understanding of the effectiveness of treatment, and inform broader management plans. But they offer caution as well, as interpretation alters when viewed through different lens. Doward et al (2004) discusses the elements that support a useful QoL survey used within clinical research. These elements include theoretical validity; are replicable and reliable; have internal consistency where what is measured has inter-relatability within the construct they are applied; have relevance to the person/people it is being applied to; responsive in that it is able to detect real change over time; practical, easy to answer and administer, and be culturally sensitive or able to be adapted within a cultural context.

Both the Flannagan's QoL Scale (Burckhardt & Anderson, 2003) and Meke Meter (Forrest et al., 2016) have been validated and applied within different contexts of health. But can we actually say they held relevance to the person they were applied to? They were the survey tools that were best available to provide an understanding of how participants would rate everyday life. The Meke Meter in particular, was validated within a Māori specific culture and made adaptable when applied to the Torres Strait community as part of the Nurse Navigator program evaluation in Queensland (Harvey et al., 2021a). The use of the Meke Meter was important to include in this study, as part of acknowledgement to Kaupapa Māori perspectives using a tool developed by and specifically for, Māori. But was I right in doing this, could it actually provide an insight in the way I was hoping it would?

Testa and Simonsons (1996) explored the use of QoL surveys. In their review they describe how their search on the use of QoL survey appeared in only 5 articles up to 1975, but by 1996 more than over 200,000 such articles existed. They reference how people with the same health status are likely to have very different qualities of life despite a survey measuring the same domains, where it is possible to have an infinite number of states of health.

In the last decade the ability to measure QoL has been explored by several authors (Post, 2014; Karimi & Brazier, 2016; Haraldstad et al., 2019; Ruggeri et al., 2020) where there is inconsistency in understanding terms and the application of this. QoL however has become a significant concept in health used to understand the effectiveness of treatment and to understand the range of problems patients may have. Haraldstad et al. (2019) described the complexity of this concept and how different disciplines interpret and define this in a variety of ways. From their systematic review of the topic in health, their study indicates that most QoL studies have conceptual and methodological challenges and in this offer caution in how we use and interpret results. The WHO (1947) first offered a definition in "state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity" and again in (1995) with an expanded understanding within their position paper; "An individual's perception of their position in life in the context of the culture in which they live and in relation to their goals, expectations, standards and concerns" (p.1).

But there are also problems in the application of these definitions. Post (2014) looked at how QoL concepts have evolved over time and describe how the WHO's definition also inferring wellbeing has added to the confusion in the conceptualisation of QoL and how this is categorised. As seen by one of the participants in this study, she could not make sense of the QoL surveys as they had no cultural context for her, until she attempted to understand what was being asked, by needing to think in a Te Ao Māori way where she had difficulty in interpretation. Though one of the surveys I used was developed for use by Māori, it demonstrates that even with a cultural lens applied, interpretation by the individual is varied. QoL surveys do not allow for cultural interpretation as such and are meaningless without the person's 'world' concept. They are open to interpretation.

Ruggeri et al. (2020) in their review of well-being under the umbrella of QoL, describe the need for multidimensional measures as using a single measure or instrument will fail to offer true insight in how people experience their lives. They have become a way to measure the success of a treatment or a program as organisation's attempt to justify the spend on expensive health technology or resources, hence the proliferation of their use over the last four decades. If we only assess and measure the 'moments' and place our prognostic importance on these results, significant impacts of illness are missed.

Health surveys such as the QoL and Meke Meter are not merely tools for data collection, they are embedded within a complex web of social relations that influence the way health information is produced, interpreted, and utilised. The discourse surrounding patient rights in health care illustrates how power dynamics can shape health. On the one hand the rights of patient are to privacy, yet the surveys ask patients to disclose elements of life that they may not normally share. This discursive practice reflects a broader tendency of health discourse to use the accepted perceptions and identities of chronic illness to assess patient satisfaction, meaning that the survey itself may be influenced by these power dynamics, leading to results that do not accurately reflect the true experiences of patients (Ravn et al., 2016). Here once again the games of truth play out in what we deem to be acceptable measures of how well the health service is doing and a very superficial view of the quality of how live is lived, allowing the true impact of CKDMM to remain as hidden moments.

They may also represent a power imbalance for the patients in their desire to please the health professionals who look after them in who they are reliant to help make a difference in their every day. As discussed in earlier sections of this thesis, Foucault describes power as a core element within all layers of society. Power and power influences are not more prominent then in a health environment. In the perspective of this study patients may feel they need to represent the health professional or health service positively to ensure they do not appear 'ungrateful'. I believe this has occurred in my study. I have cared for these people and for some, over two decades. They often express to me how grateful they are for what I do to help them. What I have taken from this study is a sense of caution in interpreting what the surveys are indicating and understand they cannot be a measure of success or of a QoL on their own.

However, the results from the survey used in interpretation with the interview data, helped me to understand that there is a difference in how life is lived at different stages of illness. A person who has been in a specialised health service for some time and worked through many changes in their lives, are likely to interpret where they are at differently to a patient who is experiencing significant change that has occurred quickly when suddenly told they have developed end stage disease kidney disease experiencing the multiple morbidity that brings. There is a process here that an individual must work through to understand this change and how they now identify with this change. The next section steps through my understanding of what may be happening here and why survey answers and recounts of life may appear different. The deep exploration of this has led me to the development of a reset process and how participants may have translated a new identify in working through a discussive shift through their need to understand the way life is now lived.

The Capillary Effect and Positive Reset and Translational Change Process

The discordance between what the participants tell us, through their descriptions of longevity of living with compounding conditions and illness to their snapshot of a day in QoL data. This may be partly explained using a Foucauldian inspired 'Capillary Effect' of discursive shifts, power, and regaining autonomy that demonstrate acts of resistance. This shift is part of a 'cyclic reset process and translational change' through recognition or formation of a new identity. One of the ways Foucault refers to power, is at a micro or individual level that involves modernised knowledge of power present in everyday practices where power circulates in a capillary way throughout a social body. Here power is not hierarchical but circulates through intimate channels "gaining access to individuals themselves, to their bodies, their gestures, and all their daily actions" (Foucault 1980, p.151) and describes these as capillary networks rather than arteries, a fine network that facilitates the flow of beliefs and actions that align to specific regimes of truth (Worthman & Troiano, 2016; Armstong, 2003). It is in working through the discursive shift and flow of beliefs and societal acceptance that identity can be reformed.

Keywords to help explain this process include reset process, discursive shift, fissure and fissure points, angiogenesis, capillary effect and capillary network, power, truth, autonomy, acceptance, identity, socioemotional connectedness, time, and translational change.

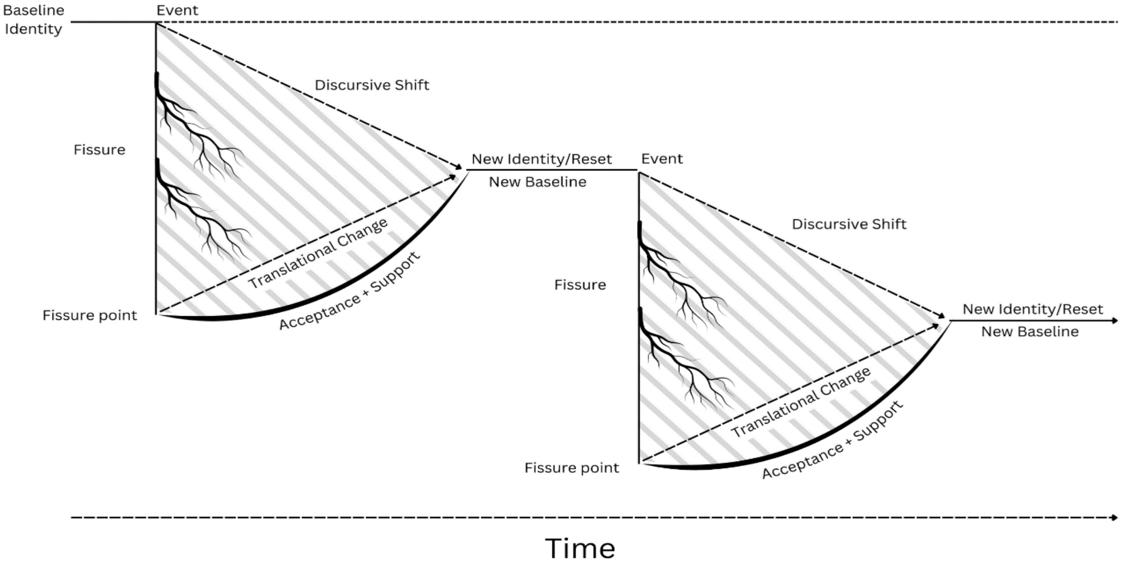
Here, I will provide an overview of the process followed by a more detailed breakdown of the different phases of this process.

For people with Chronic Conditions, daily living can be a constant change over time. This influences their capacity and capabilities for everyday living, where certain events can change who they are and how they see themselves. How someone works through this change and how they then understand themselves is dependent on several factors. From engaging in this work, examining the data, exploring themes from the patient interviews, and hearing their stories, I have been able to map this process. I have called this 'the reset and translational change process'. This is an ongoing or cyclic process, as change occurs. Figures 13 to 16, provide diagrammatic representation of this process.

The cyclic reset process starts with an event and can occur suddenly or builds over time. This event maybe be clinically focused such as a new diagnosis, functional disability caused by symptom burden, or a social event such as the loss of employment. These events promote a change in our social identity. This is how a person sees themselves and how they are perceived by others. This change creates a fissure or a cleaving away from 'normal'. The process of working through this change is referred to as a discursive shift. Within this shift, a network forms and creates a capillary effect. This network is derived from the concept of 'power', where the capillary network acts as a conduit for power. Power is (or provides) the ability to discourse Truth, where Truth represents the beliefs, customs, and values of an individual as well as society. An individual's 'truth' changes as these influences change (Foucault, 1998; Foucault & Rabinow, 1984). The purpose of the 'shift' is a remodelling toward acceptance of the new 'me'. There needs to be a translation of the past 'me' to the new 'me', informing the Truth through social identity. Discoursing truth is the process of creating what is true for ourselves. This is an evolving process, and it is when there is acceptance of this new change that stability for an individual, is found. The transition to acceptance is the fissure point and from here a new baseline can be achieved. This baseline exists until a new event forces a change, engaging a reset process once again (see Figure 13).

Figure 13

Reset and translational change process



The extent and outcome of the change is in part influenced by the capillary effect through the network and is key to the depth of the fissure and how quickly a fissure point can be reached. From my clinically focused lens, I relate the development of this capillary network and effect to be a similar process to angiogenesis and thus deriving a novel extension to the Foucauldian theorem. Angiogenesis is a physiological process the body employs in the development, repair and strengthening of the vasculature through a capillary network. This network forms a mesh of intercepting and dividing small blood vessels that, at the most definitive level within tissue, facilitates the delivery of nutrients and oxygen ultimately to the cell, to grow, repair and exist (Felmeden et al., 2003).

Like Foucault's theorising of the capillary network of power, this network has properties of permeability with diffusion of power through-out the network. Power within the vascular network is blood and nutrients and is required by the body to initiate movement and carryout physiological processes. It disperses 'power' and removes negative substances such as waste products, deoxygenated blood, and carbon dioxide. Power can ebb and flow, be taken on and given away, such as nutrients do in a blood vessel. Loss of too many nutrients and the tissue cannot thrive, and essential processes fail. Similarly, the loss of too much power by the individual means they lose a sense of themselves, their identity, autonomy and fail to thrive. Our social capillary-like network provides us with the power to discourse truth for ourselves (create, strengthen, and challenge truth) as well as help us to deal with stress (waste). This helps us to reconceptualise ourselves and our situation, or our truth. A lack of capillary network in the body and we ultimately lack endurance and movement. Similarly, deficit in our social capillary network results in an inability to endure stress and discourse truth.

The stability of our social network is dependent on the micro, meso and macro levels of societal practices and their influence within and between social orders, creating the environment that the person exists within. This is reinforced by Fraser (1981) who through a Foucauldian inspired lens describes the nature of power existing within a capillary network and therefore has a capillary effect "that operates at the lowest extremity of the social body in every day social practices" (p. 272). Again, identity is key here and how we are situated within that societal body. People understand their social existence through recognising themselves as 'similar or different' in comparison to others (Taylor, 2004). Taylor describes this as 'social imaginary", in other words how we are interpreted by others and how we fit together with each other. This then enables us to articulate our social identity within the societal orders we exist in, that include orders of a social, political, and economic nature and involves our ancestorial history, culture, and sense of belonging (Taylor, 2004; Krzyzanowski, 2020). These factors all contribute to our social network and therefore influence how our social capillary network develops.

In essence, the reset process is about power influences, social identity, and the productive self. Foucault describes modern power as operating within every day societal practices and at the individual level. Power is represented by action and beliefs referred to as 'truths.' He describes power as 'being everywhere' and 'comes from everywhere' and is in constant flux (Foucault, 1998). Foucault explains how discourse facilitates the flow and effect of the action or 'truth'. The 'act' being a diagnosis, illness that causes loss of functionality, physical state, or symptom burden. This causes a change, where a person is no longer able to carry out their 'normal' activities of living altering how they see themselves and how they are perceived by others, their social identity. Identity is shaped by diagnosis. Jutel (2016) describes the power of the diagnosis that can influence the social, cultural phenomenological position of that person in society, and how they then behave and others behaviour toward them reshaping their social role (p.3). You can enter a Doctor's office knowing who you are (referring to myself, Janine) but leave now knowing I am Janine the Diabetic. I am forever changed and how I see myself and the world now sees me is changed. Fleischman (1999) describes diagnoses as a 'symbolic act, where these words bring about profound change, in knowing who I am, my view of the future and relationships with those close to me. It divides a life into 'before and after', where the 'after' self now transfers into all future health encounters, the 'before' all but forgotten. The patient now needs to translate a new identity. Charmaz (1995) describes the effect chronic illness has on a person as an intrusion where "it undermines the unity between body and self and force's identity changes" (p.657). They then need to employ a process of 'adaption' to unify the body and self while navigating the loss of physicality, changed self-impression and worth. The recognition of this identity can also be related back to Foucault's interpretation of the 'gaze'. In his book *The Birth of a Clinic*, Foucault describes the concept of the 'medical gaze' where doctors learn to see a patient with a focus on what is known as normal and abnormal. The biomedical model employed by medicine, occurs at an organised level, incorporating the 'visible and invisible'. It was a way of knowing the patient and presenting signs and symptoms of illness. It involved a way of seeing, distinguishing, and characterising, recognising normal and abnormal, combining these elements that endowered the power of decision and intervention, in other words to be able to diagnose and treat (Foucault, 1963). In developing this gaze, the practitioner "reorganizes himself, changes himself, and begins to function in a new way" (Foucault, 1963, p.90). This concept of developed 'gaze' is applicable here, in the respect that the person with a chronic condition needs to reorganise their gaze and how they see themselves, understand a new state of being, to inform their new identity, adapt and find their new truth.

In early stages of a disease process where the impact on daily life is less intrusive, people can ignore or minimise what is happening and the effect of it until the change multiples, deepens, and impacts on all facets of life forcing a reality of loss (Charmaz, 1995). The change in identity this brings is not a new concept having been explored by many, but it is in the context of multiplying changes that MM brings, the social impact and consequences and, as Sheridan (2023) describes as the 'compounding jeopardy', that our understanding of how this truly alters a life, deserves attention. In developing my understanding of this process, I have attempted to understand this change and how it represents. I have applied the term Translational Change here. This is a process that involves a discursive shift whereby a person works through how they now see themselves and translating the new 'me' into their existence and social imagery. This is a continuous process whereby the 'gaze' evolves as acceptance of a new norm is reached. It is in the need to construct this new identity and work though a translational change process, that a sense of self is developed, with a more positive shift in autonomy.

Ainsworth and Hardy (2004) describe how they have reflected the process of CDA and formation of identity in their exploration of identity and the older worker. Using Discourse Analysis, identity is an ongoing process of construction, where social interactions and the reflection of thoughts and attitudes of others, as a shared social resource, continually shapes our identity. How we feel, react, and understand ourselves is shaped by those around us and the societal systems we exist in. Society places significance on contribution and production, and our perspective, is geared toward this. This becomes a strong influence on how we see ourselves, how we belong and are seen within our society and what our social identity is (Fleischman, 1999; Ainsworth & Hardy, 2004; Taylor, 2004: Hay, 2010; Jutel, 2016; Fadyl et al., 2020; Krzyzanowski, 2020). One such example of being productive and a contributor is through employment and earning your way. This is a driver in neoliberal thinking societies where if someone is not productive then they are not useful. This was a strong theme for the participants and one of the ways a discursive shift was most evident. This presented in the need to give up employment and how this forced a change in living status, household finances and how participants viewed themselves as being unproductive in the workplace, as well as in the whānau or family group. Their perception of the importance and place in the whānau group changed. This was compounded if functional disability was also present and the need to have family members help with everyday activities of living such as dressing; again, changed how they see themselves and resulted in a loss of autonomy or as a decision maker.

Events such as loss of employment, and the need to establish a new identity, align with Foucault's description of Eventalisation. Eventalisation is the action or truth that causes a change in 'normal' (Worthman & Troiano, 2016). In working through a discursive action and the acquisition of a new normal, a level of acceptance is achieved. A new identity is accepted, and the person stabilises the effect of change, remodelling to a new baseline of normal (Figure 14). A process of Adaption has occurred allowing for how life can be acceptable again (Charmaz, 1995). This relates to Foucault's reference to 'fissures' which he describes as opportunities of 'resistance'.

Fissures represent the discussive shift in this process where a person understands a change is happening and begin the work of identifying with a new me. It is within this process of acceptance that participants start to see themselves as being productive again within their new normal, creating a more positive effect on the discourse path. In this respect, resistance is a powerful tool of change. An environment that provides strong support systems helps to stabilise the fissure and establish a new baseline at an earlier stage, lessening the effect of change (Figure 14). Strategies that support acceptance and influence the point of resistance can be thought of as part of the capillary network of power (Figure 15). These influences are represented by the participants through socioemotional connections in how they describe the love and support of whānau, families, communities and the presence and consistency of health professional teams, through actions, and behaviours (Figure 15).

Figure 14

Reset and translational change process with a smaller discussive shift and strong capillary network

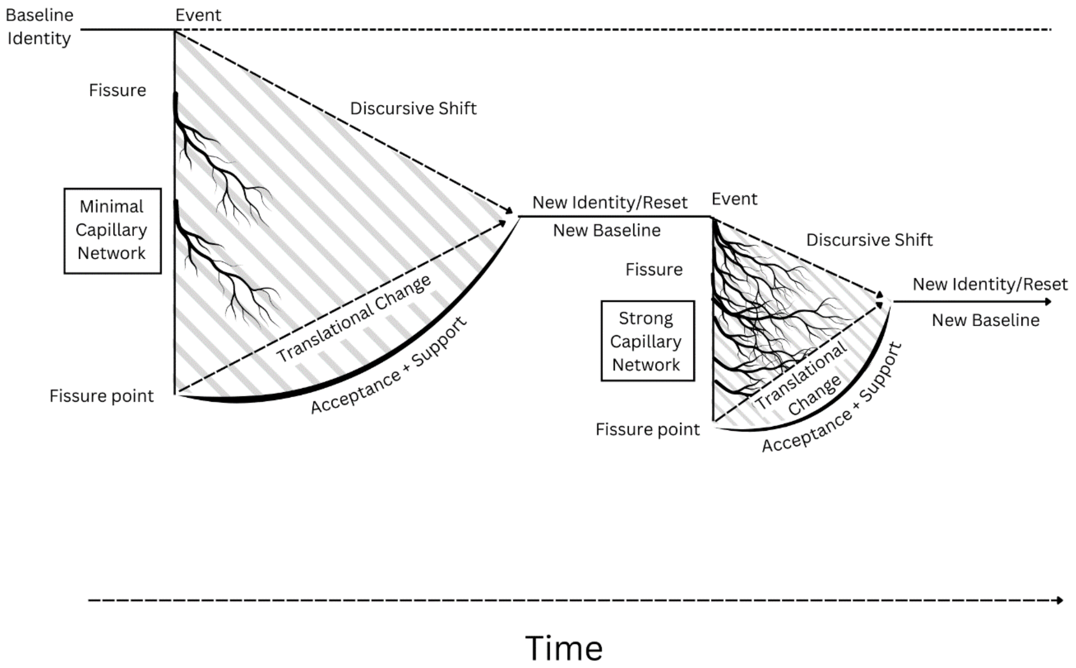
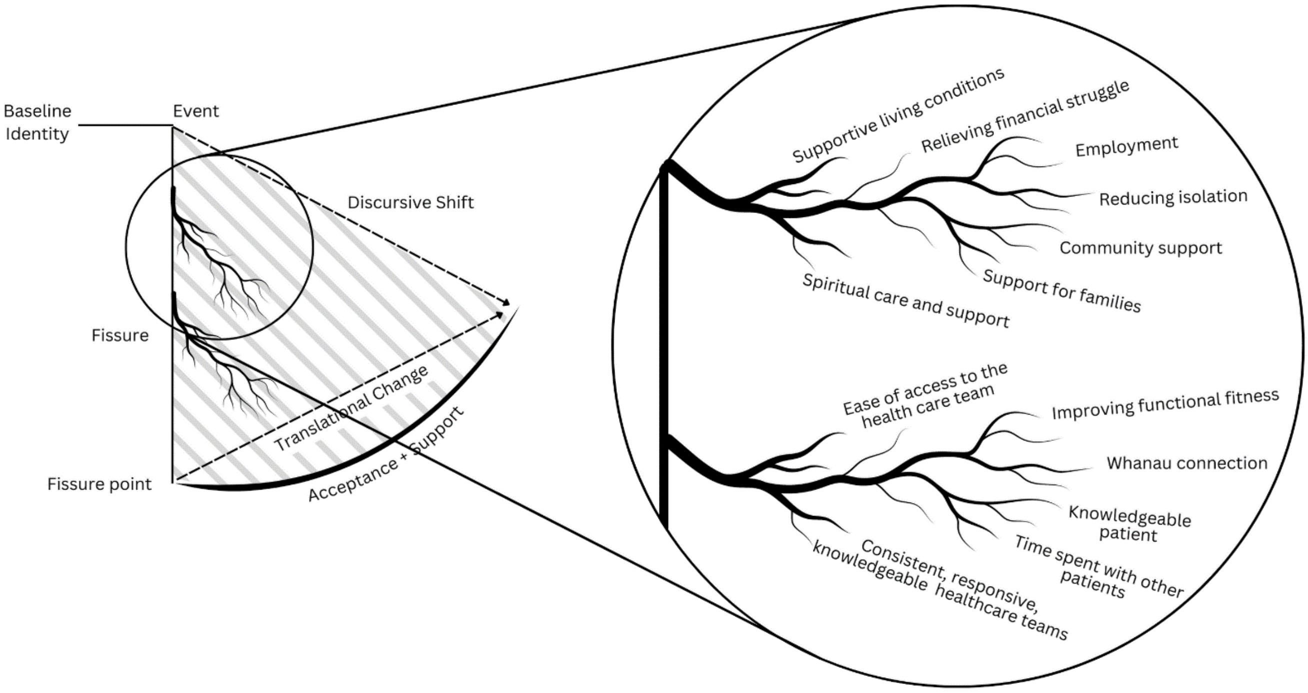


Figure 15

Reset and translational change process: supportive capillary network



The process of reset represents the development of the capillary network, and the strategies that have a productive or non-productive effect on the discursive path and final settling point (Figure 13). In relation to the participants and the development of CKD and multimorbidity, the process of reset is usually one of negative change from normal, with deterioration in their physical and mental state. This results in a decline with a cyclic process of discourse, formation of fissures and capillary networks, and remodelling until acceptance of new state of normal. It is the point of reset and formation of a new identity, that a person can see themselves as productive and contributing to society (forms of resistance) or non-productive and of little worth. When this is a positive process, participants describe life as still being good and worthwhile (hence the positive nature of the QoL scores for most participants) and is represented by their want to pursue altruistic activities, such as volunteering and wanting to support other people experiencing a similar process. When the participant struggles to achieve acceptance, they then see themselves as non-productive, where a participant is still grieving the life, they had and feel a burden on their whānau or of little worth now (seen in Participant D’s QoL scores).

From the patient interviews, capillary networks that help to create stability in the 'new normal' are whānau support, connectedness with whānau and community, a health team who are consistent, available, responsive and care. This involves communication, reducing isolation through contact, addressing socioeconomic concerns through alleviating struggle such as financial burden, and strengthening the whānau unit with support. Patient knowledge of their condition and management plan, through the facilitation of time, knowledgeable health professionals and support of expert patients also helps to build and strengthen the new capillary network, stabilising the fissure. Figure 13 is an example of what a supportive capillary network involves. This process of reset occurs irrespective of the known causes of disparity such as SDH (income, education level, housing, finances, employment) however the SDH can impact the severity of the decline or depth of a fissure and the extent of the supportive network to recover. Equally, the sudden alteration of our SDH such as loss of income, can often be the cause of initiating Eventalisation.

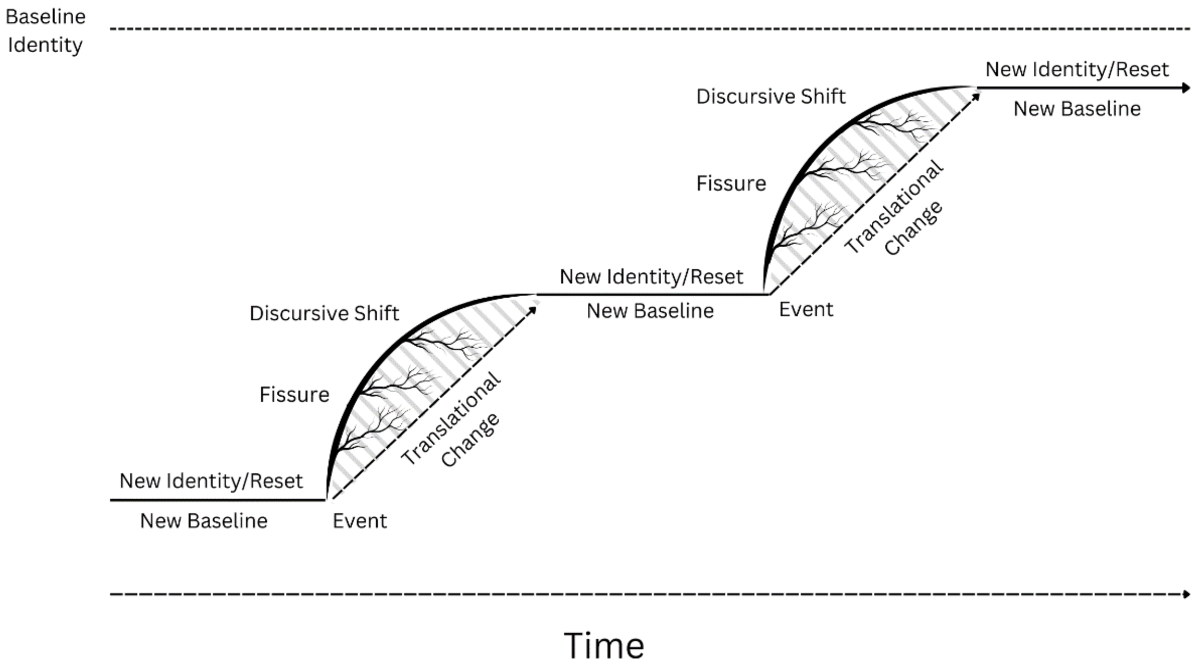
The path of multimorbidity is one of constant change, struggle and loss that requires focused and dedicated support. Conversely with the right support, environment and motivation, the discursive trajectory can be flipped, and a more positive reset point achieved, meaning the fissures are also positively reset, once again remodelling to a new baseline and a positive translation of change (Figure 16). How a positive translation of change can be represented is explored further through a case study of a young man with multimorbidity in Chapter Six.

Summary

Themes describe progressive deterioration of disease states, physical dysfunction, hospital rules, fragmented healthcare teams, loss of identity and hardship and struggle that have resulted in whānau, economic and identity changes that are for some incredibly hard to live with. Yet there is a resilience suggestive of self-determination where there are acts of resistance in accepting 'what is', that translates to achieving a sense of balance. The acts of altruism, positivity of the QoL surveys, the want to care for others going through the same thing, is resistance in action.

Figure 16

Reset and translation change process with strong support systems and positive trajectory.



Foucault reminds us of where there is power there is resistance that is powerful in its own right. But evidence also suggests is that certain elements help to influence a persons' act of resistance. Strengthened social networks through consistent support systems, the presence of Whānau, shared experiences with others, helpful health care teams that listen to needs, caring in timely ways, and stability of financial situations, helps to turn this trajectory around that ultimately strengthens the individual and makes a difference in their 'day' promoting their moments of resistance. Out of this understanding a new process can be applied,the Reset and Translational Change process that developed out of deep examination of what the participants describe has occurred as disease processes progressed impacting whānau relationships, employment, socioeconomic standing and ultimately how a person may view themselves. What also became apparent is that to measure the quality of one's life is a complex undertaking and requires a multidimensional approach. Taken in isolation may only offer benefit to the organisation or health professional applying this and may not actually service to benefit the people we are attempting to measure. Then allowing other important aspects of life and wellbeing to remain hidden that once again contributes to the games of truth that is becoming a significant influence in understanding how this population experience life.

I have chosen to include a poem that summarises the main findings in this Section, the author of the following poem is unknown, but it resonates with the narrative of participants who live life in the way that they do.

A trail of tears, a somber call.
Multimorbidity, a burden to bear,
A winding path of deep despair.

Each ailment weaves its tangled thread,
A symphony of sorrow, a tapestry spread.
Heart and lung, entwined in pain,
The body's harmony, a discordant refrain.

The mind, a battlefield of its own,
Depression's grip, a tempest thrown.
Anxiety, a relentless tide,
On this trail of tears, where spirits hide.

Through the valleys of fatigue, we crawl,
As pain and frailty slowly install.
The tears we shed, unspoken, deep,
On this trail, where sorrows seep.

Yet, in the midst of this shadowed plight,
Resilience blooms, a fragile light.
Connections forged in shared despair,
A trail of tears, but also care.

In unity, we find strength to face,
The trials that linger, the endless chase.
Multimorbidity, a burden shared,
A trail of tears, but love declared.

Chapter Five identified the voice of patients who describe the loss and struggle within a healthcare system that often appears to be fractured. Technologies of self are evident in patients through acts of resistance motivated by losses and hardship where it is important to find meaning in everyday struggles. There was a discord between what the patients were describing and how the QoL surveys presented, raising questions about how these surveys should be used and how they came to be used so widely in healthcare to understand patients' quality of life. Analysis of these findings has led to a new process development, The Reset and Translational Change Process, that may hold significant potential to inform new models of care that strengthen identity and promote the technology of self through resistance. The next chapter profiles a young patient with CKDMM as a single case study that represents the analysis at the micro level through My voice. It describes the effects of living with CKDMM and how identity and quality of life can be transformed when care is positioned differently.

Chapter Six: Establishing MY Voice - Act of Resistance

Case Study of Positive Reset and Translational Change Process

'A Healthy Lifestyle Program: Supporting lifestyle
change and vocational rehabilitation for a person living
with chronic and complex conditions.'

Introduction

During my data analysis, and whilst considering the Reset Process and Translational Change Process, I realised that I had a perfect opportunity to test this new process and understanding I was gaining in how to bring about transformation through strengthening social capillary networks, with impacts on identity and seeing yourself as productive again. This is an example of regaining personal power through resisting the social narrative often associated with people who cannot work due to complications of chronic conditions. This subsection profiles a mini case study of a young man who did exactly that. His fissure points were created by compounding jeopardy of illness and social events causing acts of Eventalisation; development of kidney failure, a loss and change within his support system and inability to work due to cumulative complications of illness. By working with this young man focusing on his self-directed goals in a different and somewhat nontraditional way, his social capillary network was strengthened and identify transformed enabling a sense of productive self and with that power.

I had a young man who, following his renal transplant, was seeking help to get back to work. Following some discussion with my supervisors, we agreed that a particular focus on this patient would add depth to the case study approach applied to this research. The patient was not one of the cohort of 18 who were interviewed for the research, but did attend the same Renal Clinic and therefore was part of the overall Case Study population.

This subsection provides an example of how the concept of the 'Reset and Translational Change Process' can be applied. It profiles one young man with multimorbidity developed through his teenage years, where he experienced many challenges and hurdles that come with progressive disease. I applied a case study approach to demonstrate how this new process can work in a positive way, enabling him to change his outcome and meet his life goals. Applying a person centric lens is essential in understanding what is needed to focus and strengthened a person's social capillary network, establish their truth and refocus their identity. This case demonstrates how healthcare providers need to work in a different way, collaboratively through a team approach, and in this way achieve true integrated care.

People with MM experience many changes over time. The prevalence of chronic conditions is more often reported within an aging population (Linden et al., 2022; van Oostrom et al., 2016; Pew Research Center, 2013, Schoen et al., 2008). However, there is growing evidence that suggests a burgeoning tidal wave of young people who are diagnosed in their youth and will carry the burden of chronic conditions across their lifespan. Sawyer et al (2007) describes the additional challenges of developing management plans with adolescents, that are acceptable to them at a time when they need to navigate this phase of their lives which often includes an increase in risk taking behaviour. This then impacts on how their lives are lived, what is achieved and the potential need for social support from a younger age.

This case study focused on a young Māori man diagnosed with a chronic condition at age 20, who then went on to develop multiple medical conditions. This man is a patient whom I cared for and enabled a supported program. The focus of this program was to develop his network of support, to improve his quality of life and to achieve two patient directed goals, which were to work out in the gym and to regain enough physical functionality to consider returning to paid employment. His journey through this program is an example of how the 'Reset and Translational Change Process' can shift a patient into a positive health trajectory. This means the direction of the discursive shift, and the building of a new baseline, is an upward trend when the right supportive capillary network is developed, changing a negative outcome to a positive outcome, that improves quality of life and patient satisfaction.

Throughout his illness from first diagnosis, developing End Stage Kidney Disease to Renal Transplant with complications in the first two years, he has experienced many Eventalisation episodes. These episodes had caused a downward spiral from his original baseline. His self-image and identity have been challenged by these events with deepening fissures and the need for increasingly bigger discursive shifts, to be able to find his new truth and stabilise. Most definitely how he saw himself and his place within his Whānau unit had changed. How his Whānau viewed him, also changed. He was seen as someone who needed their wrap around care and in doing so, he lost autonomy. His Whānau was a strength within his capillary network. However, he had a limited social capillary network, where his strength came from his Whānau unit and the interspersed contact with his health care team. He was generally isolated, and less communicative. He experienced episodes of depression, anxiety, and suicidal thoughts at times. Throughout this program as he gained physical strength, he also gained emotional and psychological strength. mental health, wellbeing and socioemotional connections were key concepts here. What this program of change for this young man demonstrates, is that if we as health-related professionals understand how to strengthen his support network by working across social sectors outside of health, with support systems that include educational, employment and community structures, we can help build a much stronger and enduring supportive capillary network. This can change the direction of the discursive shifts, establishing a more positive baseline.

The following provides an outline of how this program came about, what needed to occur to bring these teams together and why this was so successful. I have included quotes from the research participants to lend their 'voice' to this description. The evaluation of this program was enabled by successful application for an Activation Grant through the NZ Health Research Council (HRC), reference HRC Ref: 21/890, as well as a grant from a regional health sponsorship program, Royston Health Trust. Ethical approval was obtained through the NZ National Health and Disability Ethics Committee (HDEC Ref: 21/CEN/13) and Massey University clearance (SOA21/25). It was regarded as low risk and therefore only required Localities ethical approval (Institutional ethics committee approval), which was granted.

The program was guided by four evaluative research questions, designed to understand what characteristics of the program were effective, to explore the cost benefit of such a program and, if the program were to be replicated, where it may be able to be considered a strategy as part of everyday care delivery (Table 14).

The project was titled 'Supporting lifestyle change and vocational rehabilitation' and had a running title of 'ACTLIFE and the Jody Project.' The focus of this project was a young Māori man of 24 years of age (pseudonym Jody), with multimorbidity following ESKD with a period of dialysis and generalised physical deconditioning. He received a kidney transplant and over this first year after transplant, developed a series of complications from a complex medication regime that included new onset diabetes after transplant, significant weight gain >20kgs, hypercholesterolemia, hypertension and severe peripheral neuropathy causing functional disability. Each of these new diagnoses are events that form part of the concept of Eventalisation, and the engagement of the Reset and Translational Change process. He was unemployed and, on a government, supported Disability Allowance. As physiological functioning worsened, he became sedentary and spent most of his day sitting on the couch and 'gaming', often into the small hours of the morning. After two years of intensive treatments and clinical input, he achieved a certain amount of clinical stability. During a clinical consultation, where he had now achieved a level of stability without constant change I asked him, if he had two goals for himself what would they be. He replied that he wanted to enjoy working out in the gym again and to be able to get a job one day.

Table 14

Research Evaluation Questions

	Research Questions
1	Can the collaboration between local Renal Service and MSD create an opportunity for a patient with multiple chronic/long-term conditions to successfully return to work, in conjunction with an improved quality of life, health and wellbeing?
2	What is the cost-benefit for this individualised programme in relation to actual costs and future cost savings evidenced through reduced hospital and MSD utilisation?
3	Are there any patient, clinical and social pre-requisites that should be used to screen patients for such a programme?
4	Can this project be replicated and developed into a business-as-usual approach for selected patients to follow as a programme for returning to work improving their quality of life?

To achieve these goals, it was determined that Jody, due to his functional disability, would need a focused program of functional assessment and rehabilitation. I believed he would need a broader multidisciplinary team (MDT) to work together to help him rehabilitate. Firstly, we would need an understanding of what his physical capability actual was, to understand where his potential could be, as many things had changed for him. I developed a programme that I believed would support Jody with a broad team of community and health providers who were willing to come on board and trial the programme as a pilot. A research team was also developed to evaluate the programme with the view that it may be able to be expanded if successful. A systematic review was conducted and indicated there were no programs set up for rehabilitation for people with multiple chronic conditions to address preparation for return to employment, nor did they fully address the concept of wellbeing and quality of life. By supporting Jody's goals, the premise was that clinical and wellbeing goals would also be addressed.

The team working with Jody included a renal dietician to assist with weight loss and healthy eating education and a nurse practitioner (myself), who would guide clinical management through anticipated physiological changes. Both roles were employed by the local Renal Service. Also working with the team was a physiotherapist from a private provider to assess functionality and develop the physical rehabilitation program, and a strength and conditioning coach to guide exercise and strengthening, who was employed by a local sports and recreation community trust. The Trust also sponsored a full gym membership for Jody.

Both the physiotherapist and strength and conditioning coach, worked within a local community sports and recreation hub and provided a collaborative 'one stop shop' facility that also helped to reduce travel for appointments for Jody.   I approached the local branch of the national social support agency known for the purposes here as MSD (Ministry of Social Development), who provide Jody with a weekly financial support benefit, to help fund the programme as Jody would not have the funds to meet normal costs for this. They also were able to fund an employment advisor who would work with Jody to help understand what employment could look like, and to put in place a creative 'return-to-work' process that would include vocational profiling, community connections, job development and search and support once employment was gained.   Unfortunately, this part of the programme design was not implemented at the time of the project due to COVID disruptions.

I presented a rudimentary cost benefit analysis for the programme to the providers to gain their support. The main advantage presented was the argument that, if we were able to rehabilitate Jody back to paid work and off a social support benefit, there would be gains for Jody as well as financial gains for MSD through the reduction of social support costs.   Financially, this far outweighed the cost of the programme despite its resource intensiveness. MSD agreed to support the additional cost of the physiotherapy consultations, gym membership and travel to the gym. The Community Sports Park Trust sponsored the Coach's time and reduced the cost of the gym membership. Without this collaboration and sponsorship by the parties involved, I would have struggled to enable this program for Jody. Quotes from interviews with the participants and the team who cared for Jody are used throughout this chapter to provide support for descriptions and main points. The following quote demonstrates barriers often encountered by people with chronic conditions who may want to make a change. Cost is one such barrier:

> *But, there's a cost to programmes like this and I knew Jody and his family would not have the money to do that. And through our service in the secondary care system, I couldn't see that there was a clear funding pathway for him either. So with Jody's consent and on his behalf I pulled a team together, including a dietician and myself as a Nurse Practitioner, a sports and conditioning coach that works out of our local sports centre and a physio who's associated to that sports centre. And we put the bones of a programme together for a 12-month programme. And then I approached the Ministry of Social Development and wrote a proposal to them to kind of, ask them to help us support it really, to help support him. It's not something that Ministry, MSD have done before. So, I wrote a proposal that detailed what the programme would be, what we thought the benefits would be. And that we felt he had the ability, if we were able to take him through a rehab programme, to get to a point where we could seriously think about what a return-to-work programme might look like for him.* (Nurse Practitioner)

The programme required a certain level of commitment from the team members as well as from Jody and his Whānau. Jody's motivation was a core aspect to the success of this program. Jody initially had a first consultation with the clinical staff including physio therapist who identified areas of need and was then able to develop what was needed in the gym program. The strength and conditioning coach were then responsible for working with Jody one on one, three times per week. Connection with the coach was a key aspect for Jody. As the Strength and Conditioning Coach explained:

> *He might not have liked the kind of things, especially all of the horrible things I made him do to get his feet and ankles strong. But I knew that he had been to the gym before, he naturally moves well, he has a family that loves going to the gym, so how could I just relate back to that as much as possible? I know that little things, like where he was living, I was playing for a local rugby league team out there as well, so I talked to him about how my games had gone on the weekend. I remember him asking me first how the game went on the weekend which was awesome, because at the start he would never, ever [have] done that. Which I remember that being a key thing. I probably even wrote it down in my notes.* (Strength and Conditioning Coach).

Early in the program the strength and conditioning coach identified an issue with Jody's balance. Jody was them assessed further by the physio who suggested a podiatry assessment was needed, which was also available in the community hub. The Renal Service agreed to pay for this as this was a private provider and public funded podiatry assessments are extremely difficult to achieve. There was an advantage in engaging this provider as the team all work together out of the same community hub and existing relationships was seen as an advantage as well as expediated consultations. There was some evidence that Jody was developing a very early Charcot's foot. The rehab program was adjusted to incorporate specific foot exercises and strengthening as well a specific footwear for working out. This was expensive and out of range for Jody. MSD agreed to fund this to enable Jody to continue in the program. Under care as normal, this condition would not have been detected until in advanced stages.

Jody gained significant outcomes over the course of 12 months, which was extended to 18 months due to the Covid event in NZ requiring a period of country wide lock down where the program came to a halt. The team devised a way of connecting with Jody by zoom to help him continue to exercise at home as well as have consultations. The length of the program was important in ensuring gains where sustainable. The physiotherapist said:

> *I think 12 months was a good test because hiss and a roar, everybody loves to start with enthusiasm and goes well, and then you hit hiccups. And maybe you do make significant changes in the person's blood pressure, and maybe the medication isn't right and they feel a bit unwell with it until you get it back on track. And so I think to actually tease those things out over a long, long period of time gave us all confidence that it would last for a long time. Three to six months is potentially not long enough to create that level of independence, that level of confidence and that balance with their medical needs if you've got them suddenly active and losing weight and, you know, that's always changing things for them for medication.*
>
> *So to stabilise is probably the word I'm looking for, those things and allow them to be stable for long enough, yeah, certainly nine months minimum I think is needed. And ofcourse that depends on how long the chronic health problems have been going on, how well it's managed or not managed, and how many comorbidities you're dealing with. Just getting them motivated to come to the gym is actually not what it's about. It's about more than that. It's about creating lifestyle change and that has to be over a while. It has to be sustainable*. (Physiotherapist).

The MDT team met monthly throughout the program to check in on progress and adjust the program as needed. This communication was also key to the success of the program as changes were needed to be made as Jody gained strength, condition and made gains on biochemical/mechanical parameters such as HbA1c, weight and blood pressure. He needed medication adjustment as gains were made. He also made significant strength and fitness gains:

> *To discuss how everything was going from each of our different ends. We also put a lot of thought into who would action problems. Whether it was best for me to go about it or whether it was best for the physio or whether it was best for the dietician or the nurse practitioner herself*. (Strength and Conditioning Coach)

Operationalising the Reset Process

The reset for Jody occurred, not just in his physical health, but his nutritional health, his mental health and his sense of self-worth and a renewed identity.

Reset No 1: Physical strength and capacity

Throughout the program Jody experienced physical and mental health changes. Jody's physical capacity was one of the first changes to occur. Rose (his mother) noted that before the programme commenced, Jody was not able to stand for five minutes in the kitchen, but at the end of the programme, Jody was making a meal for the family. At the beginning of the programme, Jody could not walk very far, and his balance was poor. Throughout the programme the endurance calf raises, and one-legged balance exercises improved, as did Jody's floor to waist lifts. Jody was able to walk for longer periods and walk upstairs with more control and energy. By the end of the programme, Jody was standing for more than an hour and walking 4 km. Sam (Strength and Conditioning Coach)noted that towards the end of the programme, Jody had made such good progress that the six-minute walk test was a borderline run Sam noted that Jody's capacity to carry weight improved and after three months, Jody was able to carry 40 kg without a rest (2/5 difficulty). By 7 months he was able to carry 22 kg in each hand (2.5/5 difficulty), although his grip strength was noted as a limiting factor. By the end of the programme this had greatly improved.

Overall, the pilot programme had enabled very positive outcomes for Jody, physically, socially and psychologically. Of significance, Jody lost 20 kg in weight and went from being able to stand for only very short periods (due to a peripheral neuropathy and foot pain) to being able to walk significant distances. He said, "*I started to feel a lot better and a lot more healthier and I started walking around a lot more, feeling better in myself*" (Jody).

Jody also gained significant changes in mood and felt his life was worth living again whereas he had previously experienced very dark days since becoming unwell. Jody admitted that prior to his kidney transplant, *"when I was on regular dialysis, I was angry, didn't want to do anything, and wanted to commit suicide"* (Jody).

After the transplant, he began to have rehabilitation goals, but it was not until he started the pilot programme that he started to feel a lot better [in himself]. His mother added,

> *…yeah, he was quite angry back then and then when he joined up with the programme, we noticed a big change in his persona and even in the way that he carried himself. And his headspace was so much better. There's a lot more laughter going on in the house now, yeah* (Rose).

Reset No 2: Nutrition and whānau unity.

One of the early changes that occurred for Jody was around nutrition, how he ate and his engagement with meal preparation. Working regularly with the Dietitian and Sports and Conditioning Coach helped Jody to understand food beyond simply eating because he was hungry and the satisfying taste of food. Through the impact of exercise and needing to fuel his body differently, Jody learnt the need to have nutritional balance to fuel increased physical activity. The impact of this new knowledge extended to his whānau unit who also gained positive benefits through understanding of healthier eating, but it also resulted in a renewed whānau presence that brought a sense of unity. For example, the family came together to eat meals. Jody learned to cook good meals, and his family loved them. They all lost weight and gained inspiration and joy out of cooking and eating differently. What Jody was learning about food and nutrition from the dietician and the sports and conditioning coach, extended to his whānau unit. Meals became regulated for the whānau who were now preparing their own meals from fresh and nutritional sources as they learnt alongside Jody. Prior to the program Jody's mother explained they ate take-away food frequently, and that Jody often ate fried foods as "his go to when he was feeling low" (Nurse Practitioner's personal communication with Jody). Eating more regularly and having home prepared meals resulted in the whānau members experiencing weight loss:

> *What I saw is that there was a change in the family, it wasn't just Jody doing the project. It was about them supporting him and they were eating better which would improve their health. Improving their health too, I guess that improves the community.* (Dietician).

Reset No 3: Shift in personal agency.

Throughout the course of this program, one of the most significant changes that occurred was Jody's sense of agency. Personal agency is reflected in the way people make choices, act with intention, set goals or plans and follow them through (Thoits. 2006). Thoits (2006) studied stress responses and processes and how improved mental health and coping strategies were more likely to engage in agency. Improvement in agency then results in positive decision making and self-efficacy (confidence) through to the ability to change a lifestyle habit with sustainability that has links to health stability when chronic illness is present (Butterworth et al., 2007). For Jody this not only presented in self-confidence, but his self-presentation had a significant positive impact for his whānau.

The multidisciplinary team noted subtle changes in Jody's self-confidence throughout the year. For example, Sam, the Strength and Conditioning Coach, spoke of how in the beginning, Jody would come to the gym and not make eye contact with anyone and would not initiate conversation. However, as the months passed, Jody would come in smiling, making eye contact, and chatting to people during his session. Another secondary benefit was the change in Jody's confidence and overall change in positive outlook. As he gained strength and physicality, he also gained confidence and pride in himself for his achievements. This extended to the whānau unit where laughter became a feature at home again. He said,

> *I was angry, didn't want to do anything, and wanted to commit suicide". (Jody)*
>
> Jody's mother, Rose added, *"yeah, he was quite angry back then and then when he joined up with the programme, we noticed a big change in his persona and even in the way that he carried himself. And his headspace was so much better. There's a lot more laughter going on in the house now, yeah.* (Jody's Mum)

Being able to contribute to how his Whānau functioned as a unit was also a major gain for Jody. As Jody gained physical strength his reliance on pain medication reduced and he went from not being able to stand for 10minutes to being able to walk up to 4 km:

> *One of the ways we measured how successful we were being is that he was only able to walk on his feet for more than 10 minutes when we first started the programme. And then after about six months he came into clinic for one of our appointments and he told me that he stood at the bench last night and made a meal and he hadn't been able to do that before. And his mum, she'd just had tears in her eyes, you know, that he was able to [do that], he got such joy out of doing that. And making a meal for his family and, you know, he was just completely, he was absolutely beaming.* (Nurse Practitioner)

This improved sense of agency also translated to his clinical consultations in the Renal Service outpatient clinics. There was a change in Jody's behaviour which was similar to Sam's impression of Jody's disposition in the gym over time. Jody appeared more confident when attending clinic visits, often with smiles and laughter. There was a notable change in how he held himself, from a slumped and stooped gait with his head covered by his hoodie, to upright with his head up. He often became chatty, telling Jane (Nurse Practitioner) about a gain that had happened that month. The behaviour change that Jody experienced has been sustained since the program officially concluded, where Jody will now attend clinic appointments without the support of his mother who had always attended his medical appointments in the past.

Reset No 4: Long term impact – whole of life change.

Initially, Jody's goals were to get back to gym and to return to work. But biochemical and clinical improvements were also realised. These included improved HbA1c; lipid profile, reduced weight, improved neuropathic changes and improved creatinine levels. Jody's goal was to lose more than 10 kgs and although he picked up weight initially, which may have been an effect of building muscle mass after engaging in strength and conditioning, he was able to get back to almost his pre-transplant weight of 83.5 kg and BMI of 27.7kg/m2.

> *He [Jody] did need some more clinical oversight. Because as he was losing weight and physically was changing then we were able to start reducing some of his blood pressure medications and adjusting his diabetic medication. He needed that closer oversight to ensure that we were keeping up with the changes that he was making* (Sports and Conditioning Coach).

It has now been 18 months since the completion of this program for Jody and he has been able to sustain results and continue to improve others.

> *So to stabilise is probably the word I'm looking for, those things and allow them to be stable for long enough, yeah, certainly nine months minimum [length of the program] I think is needed. And of course that depends on how long the chronic health problems have been going on, how well it's managed or not managed, and how many comorbidities you're dealing with. Just getting them motivated to come to the gym is actually not what*

> *it's about. It's about more than that. It's about creating lifestyle change and that has to be over a while. It has to be sustainable* (Physiotherapist).

The impacts of lifestyle change have continued to benefit Jody. His latest diabetes marker and HbA1c are now in prediabetes range, he has reduced pain medication further and has interviewed for his first employed job and waiting for the outcome of this. The benefits for his whānau have also been sustained where they have gained confidence also in Jody's ability to cope. Jody's, mother explained that his twin brother has moved to a different city to pursue employment and his own life goals, now that he feels Jody is in a better place.

> *Mum seems less worried about [Jody] now. He's gaining so much, and she can see him now in a job, living more the way a young man in his twenties should be living life. His twin brother [who] was living at home with them…has moved to Wellington. I think part of that is he felt confident that his brother was going to be okay* (Nurse Practitioner).

Though Jody will always have chronic conditions, he has developed positive coping strategies through sustainable behaviour and capability changes, both emotional and physical, to now lessen the discursive shifts that may come with Eventalisation and the impacts of illness. Leaning back to Foucault, Jody actively shaped his own subjectivity supported by the health care team and funding agencies willing to work differently. This was a powerful process for Jody and his whānau whereby Jody learnt to assert his own agency, not through self-management as common rhetoric in health, but discursive action in partnership between Jody, his whānau, health care team and funding agencies. Though this act of resistance Jody has gained a new sense of power changing his reality and that of his whānau

Summary

Through a dedicated programme of work where goals incorporated a person centric approach based around what Jody wanted to achieve, this young man with multimorbidity, was able to successfully rehabilitate to a functional status again. This provided him with the ability to meet his self-determined goals of returning to working out in the gym in a positive way and to gain functionality that would enable him to look at successful employment. These can be seen as acts of resistance through his young man's desire for life to look and be lived differently. This required support and different way for the health professionals to partner with him differently bringing together a team that reinforced and expanded his social network.

When applying the reset and translational change process, there were four main reset phases for Jody during his rehabilitation. These occurred around his physical and emotional capacity, with improvement in his nutritional status where improved knowledge and behaviour also united his whānau unit, and his personal agency and confidence were impacted where Jody's mental health and confidence significantly improved. His final reset phase occurred around sustainability of results and behaviour, leading to a whole of life change for himself and as his whānau. Jody had experienced several Eventalisation through disease and treatment complications that created disability and psychological distress. This affected his identity in how he viewed himself and his position in his whānau unit. His fissures at times were deep, and his social capillary network was isolated, limited to mostly his whānau. He had considered taking his life as a way out of his situation.

A focused program was developed that included developing a broader and stronger social capillary network for Jody. This occurred through a multidisciplinary approach, using non-traditional collaboration of health, the fitness industry, and social support services, through a partnership with Jody and his whānau and enabling him to become stronger, more confident and an equal contributor within his whānau unit. This changed his discursive shift, and his trajectory became more positive, shifting his new baseline upward. This improved his self-imagery and identity, helped him to establish an improved truth, where he now can see him self-employed, creating a positive future. More importantly, these positive benefits have been sustained now for over eighteen months with cost benefit. The benefits of this program of work extended beyond Jody, to include his whānau unit and the community, providing him the means to become a stronger community member. Intersectoral collaboration, teamwork and identifying what his social capillary network needed to look like were key concepts for the success of this program.

This case study is an example of the need for change in how we view and work with people with multimorbidity at a meso level (as described by Fairclough when using Critical Discourse Analysis), with recommendations for macro level change and investment through State policies to enable this work to happen. I was asking the organisations who supported this program, to work with me in a non-traditional way. Within the current health system and local secondary care services, there also wasn't the structure in place to connect a program like this. There were no clear funding streams, and it relied on their willingness to work differently. This program was able to happen because of sponsorship from community organisations, and the willingness for a national social support organisation at a regional level, to fund a person outside of traditional funding models. It also took a creative approach to the team make up that included a Sports and Conditioning Coach, not commonly used in health professional teams, to engage in this program to achieve the sustainable results that this young man was able to obtain.

Despite the very successful outcomes for this young man, to date we have not been able to replicate this work for others due to a lack of funding and lack of mandate to work together from all levels of social order, micro (individual), meso (local health system), and macro (national guidance, mandate and funding).

Chapter Six concludes Section Two. It describes the data collection process and how the data were analysed to find meaning. It describes the various truths in the healthcare environment and how these influence the perspective of the truth holder, how care is delivered and received. Section Three brings the data together by discussing how the research questions were answered and what the findings mean. It suggests implications for practice and where future inquiry around this subject could be focused.

SECTION THREE: Bringing it All Together

Chapter Seven: Discussion

Introduction

The overall objective of this study was to examine the nexus between the experiences of people living with multi-morbidity and the social and health system/environments, to identify and examine the factors that produce and construct subjects as vulnerable. This was done by analysing the discourse across social orders, of a cohort of patients accessing the renal service of Hawke's Bay in New Zealand using Fairclough's critical discourse analysis of social orders and social orders of discourse (Fairclough, 2001). Also informing this work was Foucault's games of truth (Foucault, 1975, 1998). The objectives were to analyse the discursive discourses that serve to frame and construct vulnerability in relation to the care for patients with multimorbidity. Three research questions were posed to reflect the social ordering approach to analysis. Within this, the study examined how patients negotiate and/or contribute to the 'games of truth' and how these constructions reflect and potentially challenge dominant medical discourses.

Fairclough's social orders and social orders of discourse align with Foucault's framework by highlighting the intertwined nature of knowledge, power, and context. Social orders provide the broader structural conditions for discourse, while social orders of discourse determine the specific ways knowledge and meaning are produced, circulated, and contested within society. For Foucault, discursive practices are not just about language or communication; they are about the ways in which knowledge is produced, regulated, and transformed within specific historical and social contexts. Context for Foucault is inseparable from power relations. Discourses are practices that both reflect and reinforce power structures in society. The context in which a discourse takes place determines who has the authority to speak, what can be said, and what is considered true or valid. Power and knowledge are dialectical and serve to produce and sustain particular power relations. The study sought to examine these concepts, with reference to how vulnerable people living with CKDMM are, and how hidden their plight really is. Finally, the study wanted to know how individuals with multiple chronic conditions construct and deploy technologies of the self through processes of Eventalisation (Foucault, 1996; Gilson, 2014), and in what ways these reshape health trajectory and subjectivity.

The study used a multi method approach for the collection of data across a number of different patient and hospital measures, interviews and quality of life surveys. Although CDA does not use statistical data in analysis, the descriptive statistics drawn from a data set of the Hawkes Bay Renal service, provided a good service profile of these patients. This data 'spoke' to the service discourse that describes patients in language of occasions of service and unit costs of care. As a nurse practitioner working with these people the constant mantra from health service providers is that they (chronically ill patients) were 'non-compliant'; they often missed outpatient appointments; and they were high users of the public health dollar. Constant reference is made to how health services can streamline care (with budget measures). This is in stark contrast to the advertising services as individualised, patient centred, working with patients and families to provide the best and most appropriate care to individuals. Using interviews and quality of life surveys, accentuated the narrative that suggests patients are hidden behind a budget dominated discourse.

Games of Truth: Patients hidden in plain sight

This study was about gaining and growing knowledge of people who live with multimorbidity through the lens of CKD. Knowledge produces power but can also feed into what Foucault describes as 'games of truth'. As explored in chapter three, truth is not power itself but the means to produce, distribute and maintain power. (Foucault, 1995; Lorenzini, 2015). There are conflicting truths in seeking and experiencing health care in NZ. The health system has its truth, and the patient, a different truth. All are genuine. The health system is constrained by budget restrictions, workforce retention and need for resourcing, and the demand by the public to have available the latest and most modern technology that social media provides a window to.

A truth for people with CKD is that life is hard to life with MM and the profound changes this brings, through loss of economic stability, a loss of the productive self and identity changes that alter their perspective of who they are, from what they have been. They are more exposed to the tension that is created on opposing truths due to the increased exposure they have to the health system. Primary care has been reduced to a 10-15 min time allocation regardless of the complexity or multitude of health concerns you may have (Flaxman, 2015). Specialties siloed by single disease focused expertise and clinical guidelines extending to hospital wards structured by a body system disease state such as cardiology for example. The health system is struggling to understand how to fit the multimorbid person into its current structure that has no accommodation for the whole person.

Patient interviews describe being stuck in sectorised thinking where health systems don't communicate well or at all and care becomes fragmented (Rijken et al., 2017; Lau et al., 2024; Al-Chalabi et al., 2025). As McKeown (2023) noted, most health care systems want and encourage integrated care to manage patients whose care is multimorbid, however, "it is ethically and practically complex, involving trade-offs" because it "risks undermining the locus of responsibility for care decisions via confusion about who has ownership of specialist knowledge where domains overlap" (p.4). The result is continued siloed and fragmented care.

Despite the rhetoric of patient-centeredness, the patient remains absent in clinical decision-making. Through Foucault's "games of truth," this absence becomes more apparent. The discourse of integration constructs truth claims about what "good care" looks like, but these are shaped by institutional priorities rather than by the lived realities of patients. The power to define integration remains with policymakers and professionals, leaving patients as passive subjects of care rather than co-creators of it. Any participation in this process requires the patient to navigate complex medical and bureaucratic language, with any patient knowledge considered anecdotal rather than authoritative, reinforcing epistemic injustice where their perspectives are undervalued (de Boer, 2021).

Fragmentation challenges healing and patient autonomy. Hospitalised data in this study evidences the high need for elevated levels of care that hospital services provide but patients are told they need 'to see their primary care doctor', 'the hospital is full today', ‘don’t come if you don’t have to’, but the data supports a level of self-determination and power to understand what is needed and when it is needed. Though there were some presentations to ED that could potentially be seen in the community if there was the pathway and availability of the care in those sectors, but increasingly the opportunity for this level of care is constrained.   For some, many years in specialist care, reduced the confidence of the CKDMM patient to be cared for effectively in primary care, seeing patients reach out to the specialist team time and again for reassurance.

Care models have not kept up to date with changes to the health of the people with the emergence of MM in today’s healthcare. Mapping of the renal service data indicated that this population group needs elevated levels of support and care at much earlier stages of their disease trajectory than the models of care predict. Participants told us that and hospitalisation data supports this. They present sick and experience increased lengths of stay with increasing conditions or body system involvement they have. This is a truth, based on the data from this study.

QoL survey data measures a moment in time and is not congruent with the journey the participants have walked or their experience of the need for hospitalisation. Add the interviews to this, and there is a very different picture to be seen. A lifetime of struggle with good and bad times cannot be measured by a number, which raises the question of why do we use QoL in health care and who are they serving? As explored, they make the healthcare team feel better about the care they provide and assure the financier that money has been well spent. Molina-Mula (2021) looked at self-determination in decision making in clinical settings using a Foucauldian ethical framework and found that the quality of health decision making to engage self-determination remains elusive. This is despite the various communication tools, and tools employed to provide information/education or a sense of measure, the power of autonomy is still restrained by the choice presented by the health professional, influenced by their preferences. The use of the QoL surveys in this study is an example of this. The patient could only complete a score in the allocated domains, not determined by them. This did not necessarily hold relevance for them. One participant stated she could not make sense of them outside of her cultural context.   In the end, after adding the patient narrative to this dataset, all the QoL served was to add to the silencing of the patient voice.

By the end of this study I questioned whether the use of a QoL survey was valid, yet inclusion of these tools became valuable in understanding how the games of truth play out for patients and how they may hide what the reality of living with deteriorating multiple medical conditions really is. A number is easier to hear then tears of a hard journey. The QoL resonates with budgets too. Budgets cannot quantify feelings. Budgets are what drive health service delivery today. Numbers sell the need. A stark contrast to the rhetoric of a service's mission of people centred care and the journey of a patient with multimorbid conditions trying to make sense of a siloed health service. The games of truth are different for the service, for the financial officer, and for the patient. Who wins? From my study, the patient does not.

An approach taken in this thesis was to use CDA and a social ordering to understand the voices of the system, the people, the person. Patient voices were silenced when patient data was lost to the system, through administrative errors that saw >300 people lost to follow up in the renal service and 24 patients with evidence in the system but no data. You cannot be heard if you are not present. You cannot be present if you are not in the recall database. The media served also to silence the patient voice in their attempt to be heard. Lost patients made National headlines but resulted in the loss of faith that the patient could be protected and cared for. Another silencing, leaving patients in doubt. Government level promises of the care you would be provided, was drowned by the systems inability to have and use technology to support these promises. Clinical guidelines that inform and guide us in how to care for you cannot account for the level of care need or the multiple needs the multimorbid require to be addressed simultaneously. Triage systems are relied on to determine your priority for care or if you are likely to need hospital level care or not. These systems have been constructed to help the system to manage and to provide a safety net in part for accountability. Each part of the system exerting its own power in how you will be seen and where.

But patients in this study also evidenced self-determination, autonomy and their own agency. They repeatedly demonstrated resistance, which Foucault states, holds a form of its own power. They reached out to teams who could help them, bypassed primary care doctors that were not listening, presented to ED when they needed care regardless of if they met triage code criteria for urgent care or not. We heard in interviews where they strongly voiced what they needed and when they needed it, highlighting the need for healthcare teams to listen, care, be present and support their needs at earlier stages in their illness journey. Social support systems that helped them to manage in the everyday, when the sudden loss of income produced profound effects on the whānau unit.

The establishment of My voice in a case study evidenced how listening to the patient, designing care around their goals and wants in life, collaborative teams working across health, social support and employment sectors can turn life around, build resistance and make life meaningful and productive again. Not by focusing on individual disease states but a focus on the person. But this was a one-off, funded by an external funder (which is meant to support health care innovation), but which ended as the project ended. Even with a positive report, the patient voice went back into hiding, even though sustainable, long term cost savings were clear. The report is lost, even though it was funded by a national body; even though the health service read the report and said it was good.

A multimethod approach to gain knowledge in this study was used with the view that multi sources of data provides a more wholistic view. In the use of qualitative and or mix method approaches in Foucauldian based studies, Fadyl and Nicholl (2013) suggest a cautious approach in use of patient interviews that can be problematic in the ability to analyse meaning. Foucault positions discourse and knowledge to be historically situated where history becomes an important tool to understand the present (Foucault, 1970; 1995). Dreyfus and Rabinow (1983) used an applied term 'history of the present' where they use historical analysis of the sociopolitical issues faced in society to challenge the truths that shape our current realities. Fadyl and Nicholl also point out that the research interview is a form of discourse or an act of engaging in discourse and in this way the interviewer perpetuates the discourse. The voice that becomes text for analysis needs to be considered as to whether it meets that purpose for interviewing that then can become methodologically problematic. The themes derived are of the choice of the researcher evaluating them and what becomes meaningful to that person. They offer caution in that consideration should be given to the congruences between methods used. In this same vein it would be reasonable to also apply this caution in the context of using numerical data to support the research voice (participant's voice). The context in which both methods are applied and in what constitutes the discourse at that time changes, then is it reasonable to expect numerical data to have the ability to support the thoughts, view and history that makes up the discourse of the research voice or interviewee. The QoL data from the same participants applied at the same time as the interviews is an example of the caution in interpretation that needs to be applied. The two data sets were discordant in this study where the contexts differed. Interviewees recounted their history and the experience of that whereas QoL data was a snapshot of the moment in time and does not necessarily have a historical contribution to answers.

Production of Knowledge and the Games of Truth

Foucault describes the production of knowledge as derived when there is an imbalance in the power relations between different groups or institutions and states (Mills, 2003, p 69). As discussed in chapter three, there cannot be power without knowledge or knowledge without power. This study describes several different power imbalances that has led to the understanding of how people with CKD with MM live life within a health system promoted at government level to care for them.

Participant narratives describe many accounts of the loss of power and control over their own lives as multimorbidity took hold of their bodies, within a health system that has struggled to understand how to care for them. Loss of power was evidenced through accounts of loss of identity when diagnosed with a chronic condition that indicated life would need to be lived differently. How they perceived themselves changed and with that how society including their closest whānau now viewed them, changed. This was described in chapter five as social imagery. Long term employment, whānau events, children's school productions or achievements were difficult to now attend, also resulting in abandonment. Socioeconomic status changed seeing people on a support benefit for the first time in their lives where the society that we know, focused on a neoliberal truth that to be a good person in society, one must be productive, hardworking and contributing to the machinations of society. Without this station in life, a person no longer has the social rights and responsibilities in life, they are now a burden on society (Bacchi, 2016; Lerch et al., 2022). The problem here, is the person with multimorbid conditions, now needing help, who now must be managed. These events are coined under Foucault's term of Eventalisation.

Eventalisation involves questioning what seems self-evident or natural by showing that it has a history. It focuses on how power operates through institutions, discourses, and practices to constitute subjects, norms, and knowledge. It challenges the idea that history follows a smooth, inevitable trajectory. Instead, it highlights moments of rupture, contradiction, and contestation. The knowledge by the health system suggests the need to resource more care through increased contact, specialist support, visits to ED and hospitalisations. This knowledge is based on the taken-for-granted- processes that have always been what health services are; a place of bio medicalised consultations by specialist health professionals, who see patients in what is called 'occasions of service', the cost and time for which is dictated by a budget, the budget being based on an algorithm that accounts for the cost of that service.

Knowledge by the patient is of a changing life; a loss of social and economic identity by a body that has let them down. This changing life is more than the clinical occasion of service; it is about their past, their experiences, their culture, their circumstance, and the systems rigidity that prevents them from creating a new identity that is seen and heard as a person in need. This disruption of the discourse considers the power relations and epistemic struggles that influence which knowledge is legitimised or marginalised, which is the patient. Given the high percentage of the CKD patients who are Māori, the dominance of biomedical model has historically marginalised Māori health knowledge (mātauranga Māori), including rongoā (traditional healing), and the interviews in my study reflected this clearly. Their cultural and spiritual needs were clearly not addressed in clinical settings. Although my participants did not indicate total disengagement from mainstream healthcare, they did create their own networks, and this is addressed in the next section.

The games of truth extend into how we employ research to understand a phenomenon. Multi-methods were used to support data findings through qualitative and quantitative means, with the intention of providing rigor in findings. To an extent this occurred. Hospitalisation data supported what the participants were saying in interviews, the effects of illness are profound with the higher levels of needing hospital level care with triage codes that evidenced how sick they were when they presented. Days in hospital accumulated with the increase in body system counts. But trying to use numbers to support oral accounts is also problematic. QoL survey data was not congruent with the overall account of dark days and hard times with tears shed by every participant interviewed.

Population stratification models in our models of care cannot predict the actual level of need and care required. A number cannot measure the quality of someone's life leaving questions around the benefit or appropriateness of such a measure and promoting the perception that numbers being more meaningful than patient's voices. What does quantitative data tell us if this is not congruent with what a lived experience actually is. Foucault argues that 'the analysis of the dialect of certain groups in research is frequently people who are in less powerful positions' (Mills, 2003, p70). I believe this is true of research of the nature undertaken in this thesis. Chapter one and two and later in analysis, positions this population group as vulnerable and impacted negatively by the development of MM in a health system that is not designed for their needs, rendering them powerless within the system. Our goals of elevating the patient voice are aspirational. Studies such as this one, are needed, to promote what should be one of our guiding goals in healthcare, to improve how life is lived. We can have the best of clinical guidelines, medicines that promote longevity, health promotions that address the 'equity' gap but how is this measured and what is the most appropriate tool to do this?

Work is occurring to try and bridge the multimorbidity gap created by inadequate guidelines. Boudewijns et al. (2020) reinvented the ABC-tool to assess burden of chronic condition management and QoL. This was originally designed to be used for chronic obstructive pulmonary disease but is now being modified in an attempt to recognise the multi disease state people are now living with. There is tension between the specificity of a focused disease state survey versus a more generic oriented survey that may offer more domains around QoL but lacks the depth of burden. But to what kind of depth can a survey truly convey, perhaps serving only to silence those who matter most as an unintended but real consequence.

In my pursuit to understand what makes up a life of multimorbidity, my knowledge has changed regarding what it truly takes for a person with CKD with MM to navigate the myriads of truth games in healthcare and social support systems as well as recognising the opportunity to position care differently to lessen the effect of Eventalisation and foster healing.

Eventalisation – the power of the diagnosis

A diagnosis brings with it, a healthcare expectation that you will now become compliant with that diagnosis, follow medical orders and take prescribed medications, carry out lifestyle changes as you are told to. It is very common to hear people referred to in health circles as non-compliant, or did not follow orders. The more complex a patient becomes, the more we rate success on a patient's ability to conform. Hospital utilisation and budgets bear testimony to this. An example of this was Nurse Navigators in Queensland, who were introduced to the health system as an election promise, not because patients needed help, but to reduce the hospital utilisation, particularly by those 'non-compliant', 'frequent fliers' who filled up the ED Departments on a regular basis (Byrne et al., 2022; Harvey et al., 2021).

Jutel's (2016) has completed much of her work on the power of the diagnosis and comments on how a diagnosis brings with it relief and that it can give a person permission to step out of their traditional role. What the participants describe in this study suggest the diagnoses precipitates a change in who they are and how they function that deepens as diagnoses accumulates. Power sits with the diagnoser who 'transforms the patient into the diagnosis' (Jutel, 2016, p.4), shifting identity but it can also offer a name to what is ailing them that brings a sense of relief. Diagnostic relief was experienced by several of the interviewed participants, when they finally understood what was happening to them despite how life changing the diagnosis was. Many of my study's participants did not appreciate the meaning of this until disease states advanced and they were seen by the renal service where, time with a person offered the opportunity to understand more about their condition and how to manage it, an opportunity not often afforded in our current primary care setting where budgetary constraints and workforce shortages dominate. This suggests that diagnosis alone does not prepare someone for the reality of the change this may bring. Jutel also states that we must understand a patient's social world to understand and promote different outcomes which is in keeping with Foucault's description around the process of Eventalisation.

Eventalisation is more than the diagnoses, it represents change, physiologically and socioeconomically. Understanding the change that is occurring, what contributes to it and how it manifests through identity, our social roles and relationships, helps us to counter what is commonly a negative trajectory after diagnoses especially for the multimorbid. This was a dominant theme described by the participants and contributed to what they described as 'dark days'. Enhanced understanding of this concept offers an opportunity to reposition this change to explore and encourage a different outcome. As health professionals we are strong influencers of change. Jody's case is an example of that. What this study suggests is that people with CKDMM need contact, connection, time and repeated exposure to health professionals who are present, experienced, hold expertise and not constrained by budgetary forces. Our participants told us that they needed this attention and support much earlier in their disease trajectory and though helpful once they were ill enough to be seen by the renal service, in some respects this was too late. Through an improved understanding the consequences of Eventalisation, we can improve positioning of the health service and our efforts to provide care that is meaningful, but in reflection of the causal multiplicity of MM, requires collaboration across all social, education, and employment services to contribute to a meaningful life. The participants told us this, who are after all the experts in what it is they really need and when we as health professionals listen, change can truly be transformational, and we can then be seen to be meeting our global and governmental aspirations of **elevating the voice of the patient**.

The Great Reset and Capillary Fissures: Patients clawing back control

Foucault's concept of capillary power (or capillary fissures of power) refers to the way power operates in decentralised, everyday practices rather than only through top-down institutions. Power does not merely flow from the state or dominant structures but also moves through subtle, dispersed, and micro-level relations—such as medical routines, patient interactions, and social expectations. Foucault was interested in how individuals come to understand themselves in relation to the problems that are constructed around them, shaping their self-identity in ways that align with the problematisation imposed by the healthcare and social systems they live in.

Scott (1992) describes Foucault's ethos on how a person relates to themselves and the circulation of 'power' in and around us. "we belong to..we are..power" (p.105). We engage in self-governing practices that shape a person's identity influenced by their historical context, that may not conform to a traditional set of ethical practices such as what may be expected within an organisation or by health professionals. But importantly "one is always able to detach oneself from the *oneself* by virtue of the fragmented elements that constitute it" (p.104). But the participants of this study demonstrated how they exerted their own determination and resisted the convention assigned to them by diagnoses, loss and social standing bought about by illness. Examples of this is seen in the hospitalisation data and the participant interviews where they describe bypassing traditional pathways to access health i.e. primary care, and present directly to hospital for the care they perceive they needed. This was despite public messaging from hospital systems that is constantly directly people away from the hospital as they are full today. Many of the participants presentation to ED resulted in admission. The dominating power of the institution is then modified by the patient.

Foucault describes applying critical thought that results in 'attunement to fragmentation' (Scott, 1992) and interrupts other sources of power. When a patient engages in critical thinking, they then step away from what is controlling them making change possible. Fragmentation in its simplest term means a 'broken piece' of the whole (Pearl, 2018). As a person becomes ill with CKD and develops comorbid conditions, how they see themselves changes, a fragmentation occurs (I describe this as fissures). Attunement then relates to the aligning of the new 'me' in relation to what I was. Foucault describes this through a process of 'check ins' around oneself a form of critical thinking that has a power relationship. Pearl (2018) in her work on healing the fragmented self, relates fragmentation as more serious than disconnection, but as a broken relationship such as with self, that cannot simply be reconnected and healed. Healing requires a new process to enable reconnection to occur. If left unchecked fragmentation results in collective traumas with a repeated cycle of suffering and destruction (p.39). Attunement then becomes self-preservation to reconnect with oneself and in doing this, a person can claw back some control, redirect power. The Reset and Translational Change process as I describe it, can be thought of as a process of reconnection to self. Assisted in the right way, this can be an incredibly healing tool as seen by Jody in chapter six.

Capillary power helps us understand how discipline and control are embedded in routine healthcare practices, self-management expectations, and patient-provider relationships. When care is fragmented—due to siloed specialties, inconsistent follow-ups, or systemic barriers—patients are often left to reorganize themselves, seeking alternative pathways to manage their conditions. This self-reorganization fits within Foucault's capillary power because it demonstrates how power operates beyond formal institutions, filtering into the daily survival strategies of patients. With fragmented care, patients take on more responsibility in coordinating their treatments (e.g., navigating referrals, tracking medical records, self-adjusting medications). This shifts the burden from healthcare systems to individuals, aligning with neoliberal health discourses that promote self-management and personal responsibility (Tran et al., 2015; Spencer-Bonilla et al., 2017; Numerato et al., 2021) Fragmented care amplifies capillary power, making patients both governed and self-governing subjects within a dispersed healthcare network. Rather than being passive recipients of care, they actively navigate, negotiate, and sometimes resist the system—often in ways that reinforce or subvert medical authority.

When formal care structures fail, patients turn to peer networks, online forums, family caregivers, and alternative medicine to supplement gaps. These informal strategies create counterflows of knowledge, where patients resist, reinterpret, or bypass biomedical authority. There were examples of this throughout the participant interviews when they describe bypassing the GP and went straight to the renal services because of knowledge, familiarity, trust and ease of access. Participants describe becoming experts in their own care especially when rare conditions are involved. They gained reassurance and confidence from patient peers and support groups, who have lived what they are now experiencing, creating a safe space to share vulnerable experiences and gain validation of their feelings. This was often seen as more supportive than discussions with health professionals. Participants bypassed the fragmented and unorganised care structures around them. The more rural and distant from major health services a participant lived, the more self-reliant and resourceful they needed to be. Peer support groups reduce the confusion of fragmentation of services and have been found to have benefits derived from psychosocial support, providing insights and role modelling leading to behaviour change and improved coping strategies and most definitely have their place as patients grapple with the unknown and unfamiliar (Joo et al., 2022; Te Hiringa Mahara - Mental Health and Wellbeing Commission, 2023). This aligns with Foucault's concept of technologies of self where we engage in activities, thoughts and conduct in taking control and exerting our own agency to transform ways to cope (Martin et al., 2018).

Reorganising in the face of these challenges is aligned with self-management through self-determination and wanting life to look different. But there is a toll as patients are asked to do more and be responsible couched in the 'its good for you' mantra, making the health professionals feel good in supporting attributes of self-efficacy, improving health literacy and 'wellness' but from a system point of view reduces health care contact, cost and resource utilisation (Ahn et al., 2013). The concept of self-help and good health literacy is part of the integrated care strategy that encouraged patients to self-manage their conditions at home, made visible through the New Zealand Health Strategy (Ministry of Health, 2023). There is growing evidence that promotion of these concepts with seemingly helpful tools (self-management and health literacy) may not be so harmless or autonomy producing. Trappenbury et al. (2013) found evidence from three large trials of negative outcomes and increased mortality when self-management programs were promoted. This may be through the consistent loss of health professional contact and reliance on self-interpretation of levels of illness and timely employment of management strategies. Again, the patient becomes the problem, 'poor health literacy, did not attend, prioritised other activities over their healthcare (working, family commitments, affording groceries or clothing over healthcare spend).

Patient self-reorganisation is not just an individual act but becomes part of a broader power structure. It is the band aid over fragmentation of care. This links back to Eventalisation and the problematising of taken-for-granted practices such as self-management promotion. In our understanding we need to critically analyse why fragmented care exists. By eventalising fragmented care we would ask, why has care become so fragmented, who benefits from this fragmentation and how did we come to accept patient self-reorganisation as normal practice? The answers to this lie in historical, political and social contingencies.

Neoliberal thinking of the 21st century creating polices of economy, production and sacrifice of the weak, poor and costly for the benefit of the greater good. Medical and clinical practice has increasingly become specialised, as technology and public demand for freedom of choice with access to highly technical health care advances, in a westernised and commercialised world. But this demand creates cost in an environment where funding cuts occur daily as the world struggles to cope with the changing landscape of climate change, pandemics and burgeoning population growth. Competitive markets and underfunded public health systems promote privatisation, and rationalising of social services where inequities dominate and our determinants of health are privileged resulting in unequal deterioration of health status for the disabled, poor, immigrant and indigenous populations (Sakellariou & Rotarou, 2017; Barnett & Bagshaw, 2020). This is an environment where power of economy sits with pharmaceutical companies, health insurance moguls and bureaucrats.

Patient re-organisation concepts in the form of self-management have their origins in the 1960s and appeared in publication in the mid 1970’s (Lorig & Holman, 2003). There is a long history of the continued use in health promotion and patient education programs. Despite its longevity does it truly work and does the patient really benefit or can it be seen as a byproduct of health care failure and cash strapped programmes. Trappenbury et al. (2013) have questioned its validity suggesting there may be problems with the concept. Fragmentation is not a natural consequence of growth and demand but born of the privileged state. Self-reorganisation is often seen as a patient education tool or cost-effective strategy for hospital avoidance but can also be an empowering adaptive mechanism for resistance and self-transformation when supported in the right way.

In summary, self-reorganisation is a double-edged phenomenon, it can reinforce neoliberal health policies, but it can also be reclaimed as a form of self-determined transformation, particularly when supported through critical, relational, or decolonising approaches. Patients with chronic conditions are enrolled in structured self-management programs, reducing hospital visits and shifting burden onto individuals rather than addressing broader systemic issues. Yet, through resistance and self-transformation, the participants showed that by reorganising themselves within peer and social support strategies, using shared experiential knowledge, they in fact, pushed back on the shortfalls of the fragmented health system, pushing back against purely biomedical models, and advocating for social determinants of health interventions instead.

Increasing Understanding of Multiplicity of Vulnerability

The collective data from this study has drawn a map of vulnerability for those who live with multimorbidity. The term Multiplicity of Vulnerability was introduced in the Literature Review where Grabovschi et al. (2013) describe the coexistence of factors creating an inverse relationship that increased the need for health care and decreased the accessibility of services that resulted in poor quality of care.

The very raw accounts of what is has been like to live with CKD and emerging MM describes life that has changed beyond participants recognition especially as conditions advanced in ESKD. Participants describe waiting for their turn to have diabetes, gout or kidney disease as they observed similar illnesses in family members and were not surprised when they were diagnosed as such. Generational illness patterns were seen amongst Whānau and accepted as a way of life because parent, grandparents and great grandparents experienced life this way. Walker et al. (2017) described in her research, family members who were fearful due to witnessing generational whānau members on dialysis, as sickness and death were a part of their experiences. There was evidence of generational trauma within the participants whānau, as children not only witnessed the impact of illness, but became their parent's carers, as their parents had been for their grandparents. O'Neil et al. (2016) explored intergenerational trauma and discussed the effects on young minds where maladaptive coping mechanisms are seen that cumulate through exposure in future generations impacting on culture and society. Though their study was situated in the trauma of uprooted families, genocidal exposure and the psychosocial emotional effects of violence in their work with aboriginal communities, similar effects can be seen in the stories shared by the participants. Their descriptions describe traumatic observation of sick parents and the involvement of children who carry the burden as carers with repeatable losses of important support systems in parents and grandparents effected by illness.

Underwood et al. (2024) looked at health conditions in families in NZ and found one in four families were living with more than one person in the household with a chronic condition. This thesis study has also found children are affected across a lifespan when they live with parents who are ill. Several of the participants describe first becoming ill as a child and felt guilty about what they considered to be constraints on siblings when the family did not have freedom from illness to do 'normal' family outings. The family unit living with chronic illness is impacted not only through having to watch the demise of ill loved ones, but they also experience their own loss of economic productivity and earnings due to caring for their family members. Participants and their support people described the loss of quality family time, not having the luxury of going out for coffee due to being too sick or sore to go out today. Children who grow up caring for parents are afraid of what's happening to their family and are unable to improve their own health status or plan for their futures due to their involvement in the care of their parents. This was very prevalent in the interviews where one teenage son stated "how can I worry about my future when I am worried about my family's present". O'Neil (2016) in their review stated there is a lack of literature on this subject in NZ yet this is and will be a prominent impact on our society as the MM rates rise.

Not only was there a high demand on whānau units but where you live impacts on how and where you receive care and what care is available. This was noted in the participant interviews and hospitalisation data. The participants living in more rural centres within the HB region, describe difficulties in accessing care as well as consistency in care. GP retention in smaller regions is known to be difficult, with increased utilisation of Locums that change regularly. Participants describe how they tell their story repeatedly and were not respected for their 'expert patient' knowledge of themselves or their conditions. There were barriers in obtaining repeat prescriptions requiring them to reach out to the Renal Service several hundred kilometres away, to obtain prescriptions because they were known by them after many years of belonging to the service. Some GPs were reluctant because they did not know the participant (patient status). At times rural pharmacies ran out of medications and there was a delay in obtaining needed medication. This was compounded if it was a specialist medication that was not commonly used in the community. Participants also described lack of access to after-hours medical centres in their towns and needing to travel extended distances to access the nearest ED or medical help. Many participants describe not being able to afford medical costs coupled with travel to medical help especially when they had lost their employment status. Triage data suggested overuse of ED for presentations that could be managed prehospital, but as demonstrated in participant interviews, this level of care is not available when needed but also that in the majority of presentations to hospital, admission was required to achieve the right level of care. Hospital for these people cannot be avoided.

Several participants described how social support service benefits did not help to cover related care costs adequately and many fell through funding gaps because of partners who were earning, creating an expectation that they had to be looked after and could not be financially independent. This created strain in relationships and altered the whole house hold's economic positioning. Māori as a single ethnic group featured more prominently in hospital statistics, utilisation of hospital-based services and need for urgent or emergent care as indicated by triage codes. There was a suggestion also that Māori and Pasifika may have difficulty in accessing care in primary or community settings as indicated by the number of triage 4 and 5 presentations and those treated in ED and sent home without admission. These are not new findings as there are multiple publications available on the ethnic impact of healthcare access. Sheridan et al. (2023) recent paper in the NZ context, continues to evidence that lack of progress in this area.

This thesis study exemplifies how despite the multilevel discussions and inequity focused programs that are designed and funded in NZ across the last three decades (MOH, 2002; Hobbs et al., 2019; Te Whatu Ora, 2024c) we are not making any progress. Though the renal cohort differed in their age, ethnicity, socioeconomic status and living status by address, what did not differentiate the participants in this study, was the significant involvement and need for higher levels of support from hospital secondary care services due to advancement of chronic conditions. Known social disparities in combination with multimorbidity for the patient with CKD with advancing disease states increased the level of vulnerability they lived with.

Themes from participant interviews mapped against demographic data, indicated that effects of multimorbidity were experienced by all participants in similar ways regardless of economic, ethnic, educational, or cultural status. Hardship and loss, depression, dark days, and tears were expressed repeatedly by diverse participants. Loss of income and employment was a turning point that caused negative trajectories in how life was lived.

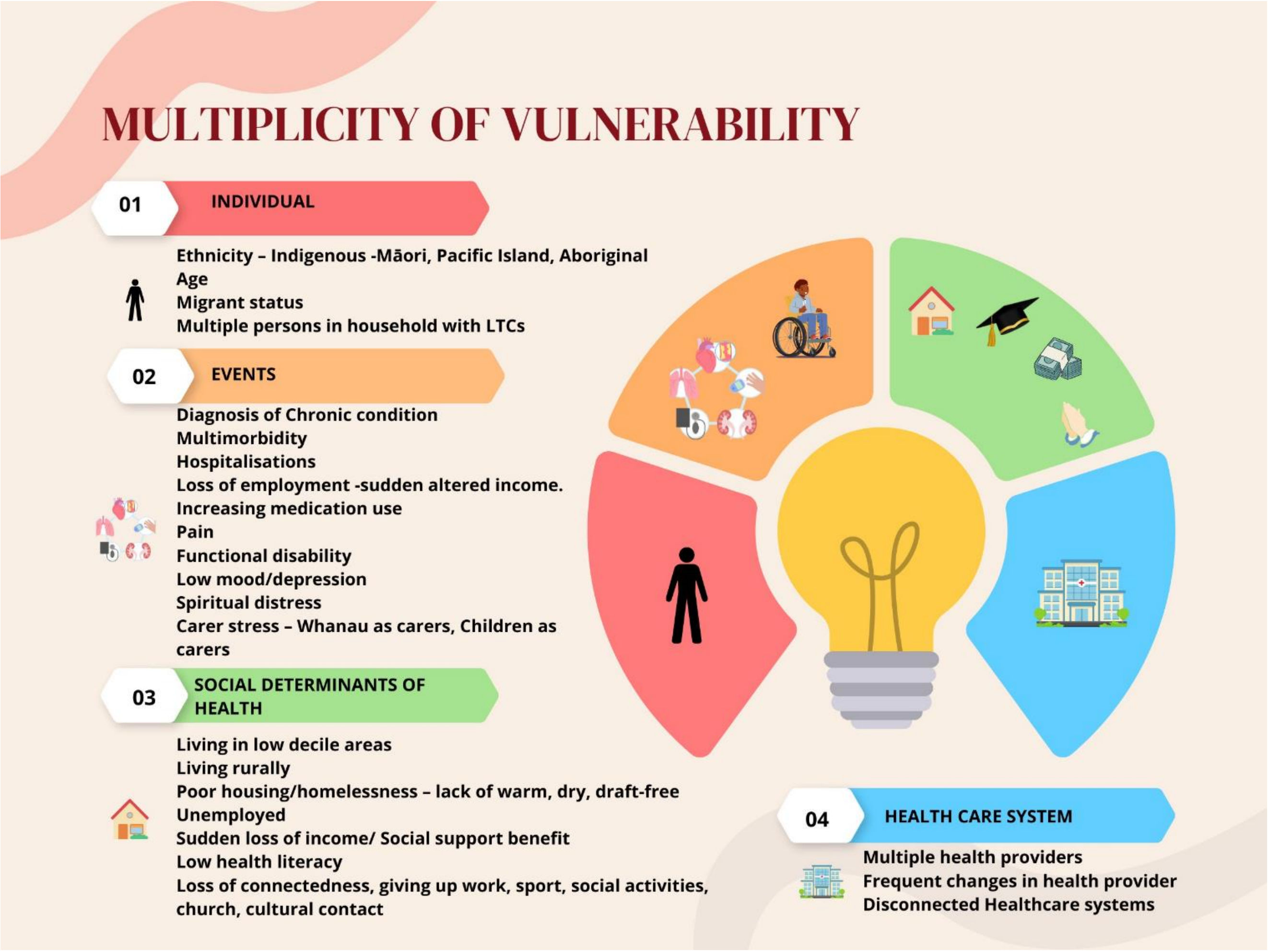
The support required by the Renal Service or GP practices was expressed by all participants. I was interested in seeing if there was a discrete point in which CKD with multimorbidity became a disparity. Hospitalisation data from this study, suggests multimorbidity may be equalised across some known factors of disparity. This was suggested by the level of use of hospital-based services coupled with demographic data that incorporated quintile rating (level of sociodemographic burden) indicated by postal addresses. Use of hospital services was experienced fairly equally across quintile groups. The data suggested a correlation between the number of body systems involved, as a measure of morbidity count, and hospital admissions when participants had two or more body systems affected. Length of stay increased from two days to nine days with two body systems to three body systems, which then saw a further two-fold increase in days in hospital with four body systems involvement. This also appeared to support the establishment of a discrete point in which multimorbidity equalised across SDH factors, where participants that had two or more body systems involvement, required elevated levels of care as measured by days in hospital.

When disparity against disease states is the focus, the use of body system counts over counting the number of chronic conditions a person has, is more useful in determining this discrete point of change. Inconsistencies amongst IT systems presented a challenging in attempting to categorise the number of chronic conditions participants had. Data that uses body system counts is easier for IT systems to capture, as there is an exhaustive list of chronic condition diagnoses under different body systems. People also live with many consequences of disease or body system disorders that are not recognised or acknowledged in the formal literature but include symptomology of a long-term nature. This also helps to move past the single disease mindset that health care tends to be structured by. Roe et al. (1998) and Harrison et al. (2014) have previously suggested this approach also, as a way of navigating the inconsistent way chronic conditions are captured in data and the literature.

Considering the extended understanding of what and how people with CKDMM are vulnerable, I have mapped this into four categories (Figure 17) that represent how vulnerability presented for the participants and from the data derived from the larger case study cohort. What is new here is the addition of how the healthcare system adds to vulnerability once MM develops and the need to interact with the health system in a more intimate way exposes these vulnerabilities.

Figure 17

Multiplicity of Vulnerability



MULTIPLICITY OF VULNERABILITY

01 INDIVIDUAL

Ethnicity – Indigenous -Māori, Pacific Island, Aboriginal
Age
Migrant status
Multiple persons in household with LTCs

02 EVENTS

Diagnosis of Chronic condition
Multimorbidity
Hospitalisations
Loss of employment -sudden altered income.
Increasing medication use
Pain
Functional disability
Low mood/depression
Spiritual distress
Carer stress – Whanau as carers, Children as carers

03 SOCIAL DETERMINANTS OF HEALTH

Living in low decile areas
Living rurally
Poor housing/homelessness – lack of warm, dry, draft-free
Unemployed
Sudden loss of income/ Social support benefit
Low health literacy
Loss of connectedness, giving up work, sport, social activities, church, cultural contact

04 HEALTH CARE SYSTEM

Multiple health providers
Frequent changes in health provider
Disconnected Healthcare systems

Rethinking coordination of care in multimorbidity

We need to rethink how we coordinate the care of people with MM, where the patient with CKD with MM epitomises the complexity of issues and confounding factors that complicates coordination from a patient and organisational systems point of view. Fragmentation and vulnerability are key issues driving the need for change. Doessing and Burau (2015) scoped the literature around care coordination in MM and found two main concepts, minimising the complexity through coordination, or embracing complexity, where both concepts involve moving away from single disease focused services and frameworks. Minimising complexity tends to involve the coordination of care and requires connection at service level with an Organisation focus on resources at the centre of change, versus embracing individual complexity and coordinating care around the patient centered need. Regardless of approach, challenges exist. Coordination, collaboration, cooperation and communication remain foundational components in any framework development. The need to build social networks at a professional level creates challenges around cohesion, ownership of the patient, the ad hoc nature of the multidisciplinary team that changes with individualised patient need, the availability of organisation resource and policy alignment, and developing a mindset change of volume of output to the value of quality in care (Doessing & Burau, 2015; Volland & Blokerger-Miller, 2015; Huges et al., 2022). But ultimately for any model to work it needs the buy-in and cooperation of the patient.

Regardless of challenges presented, Integration Care Models in multisector health care arrangements, such as that in NZ, must be context driven as tension exists between the aspiration for unity in such models and the complexity of application complicated by the need for policy alignment where creeping privatisation of primary care versus government 'public funded' models exists (Keene, 2023). There is evidence in this study in the gap that exists between Government aspirations and promises of meeting care needs, and the reality experienced by the patients and the care providers. We need to ensure our care models continue to evolve as care needs evolve, such the care model used in this study (the Kaiser Permanente Pyramid of Care) that in its inception made gains in how care was coordinated but now seven decades later, does not meet the needs of a multimorbid population group such as those with CKD. Navigated care models have been developed to bridge the gap between single disease frameworks and the burgeoning complexity of multimorbidity in rigid healthcare systems. The Queensland Navigated Care model discussed in this thesis as an aligned research project, is an example of the mutual benefits to both the system and the patient, when care is positioned with a patient centred approach in a holistic manner.

The following sections describe the changes that are required and what can be achieved through conceptualising care differently through navigation, collaboration and a true patient centric approach.

Realigned Kaiser Permanente Pyramid and Navigated Care

The Kaiser Pyramid model conceived post-World War 11 has remained relatively unchanged since its launch (Pines et al., 2015). Over the last three decades, chronic conditions have progressed, where multimorbidity now has a prevalence. What the findings of this study suggest is the pyramid in its original form, may no longer reflect the needs of the population especially as disease states advance. Case management is now required by more than the 'top 5%', and in this study, 28% were represented in the top tier. 41.5% needed hospital services above outpatient service contact in clinic. Burden of chronic disease states are occurring across a population age span at a younger and older age, exemplified by the participants of this study. Participants describe needing the elements of 'case management and more intensive support' expected in the top tier of the pyramid, at an earlier stage of disease progression. They felt they did not gain the level of understanding needed until they were engaged in elevated levels of the care structure such as the level of support experience through the Renal Service. This view has been supported by the triangulated data sets used in this study. Queensland Nurse Navigators were assigned complex needs patients who either had multiple hospital admissions or complexity care fragmentation requiring additional support. Unmanaged crises meant the Navigators needed to invest significant time to sort and stabilise patient situations to get back on track. In that evaluation, the researchers were able to identify the transitions of care and support needed by patients as they progressed from not coping to self-management with the navigator's individualised support and co-ordination (Harvey et al., 2021a; Figure 18). This work could align well with the development of indicators of reset and translational change, and capillary support.

This study identified themes similar to the regional context, such as care fragmentation, difficult access to care and missed opportunities for care. One of the significant differences in using the KP model of care, is the focus on clinical care needs driven by cost of disease management. Stille et al. (2018) used a risk stratification and tiering model to examine complex care needs of children and found that current risk models are clinically based without consideration of social needs and must expand to include SDH, behavioural health, and the perspectives of families. The participants of this study indicated whānau and the behaviour of their healthcare team were key to their capillary support systems as suggested in the Reset and Translational Change process. In assigning risk, all key elements of Multiplicity of Vulnerability need to also be factored. This then changes how we perceive risk and how we would allocate care resources. Perpetuating fragmentation and poor access to care has changed how we need to conceive care models.

Figure 18

Nurse navigator continuum of care

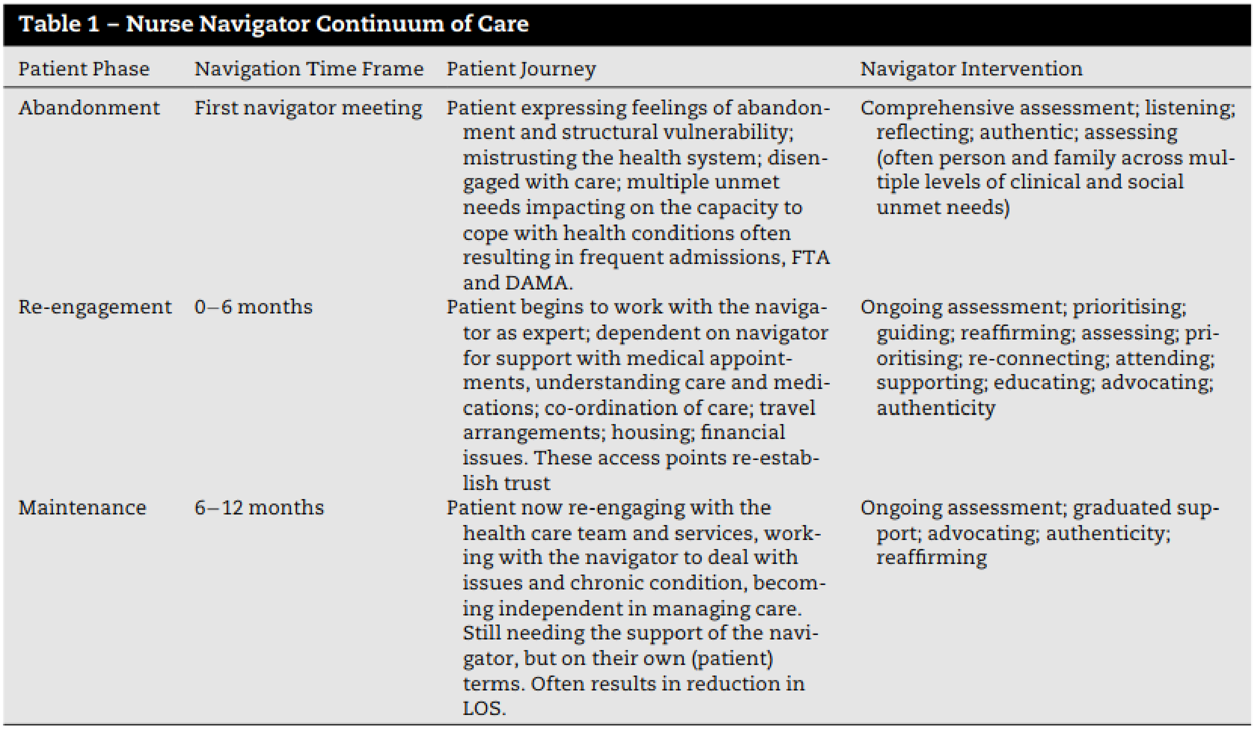


Table 1 – Nurse Navigator Continuum of Care

Patient Phase	Navigation Time Frame	Patient Journey	Navigator Intervention
Abandonment	First navigator meeting	Patient expressing feelings of abandonment and structural vulnerability; mistrusting the health system; disengaged with care; multiple unmet needs impacting on the capacity to cope with health conditions often resulting in frequent admissions, FTA and DAMA.	Comprehensive assessment; listening; reflecting; authentic; assessing (often person and family across multiple levels of clinical and social unmet needs)
Re-engagement	0–6 months	Patient begins to work with the navigator as expert; dependent on navigator for support with medical appointments, understanding care and medications; co-ordination of care; travel arrangements; housing; financial issues. These access points re-establish trust	Ongoing assessment; prioritising; guiding; reaffirming; assessing; prioritising; re-connecting; attending; supporting; educating; advocating; authenticity
Maintenance	6–12 months	Patient now re-engaging with the health care team and services, working with the navigator to deal with issues and chronic condition, becoming independent in managing care. Still needing the support of the navigator, but on their own (patient) terms. Often results in reduction in LOS.	Ongoing assessment; graduated support; advocating; authenticity; reaffirming

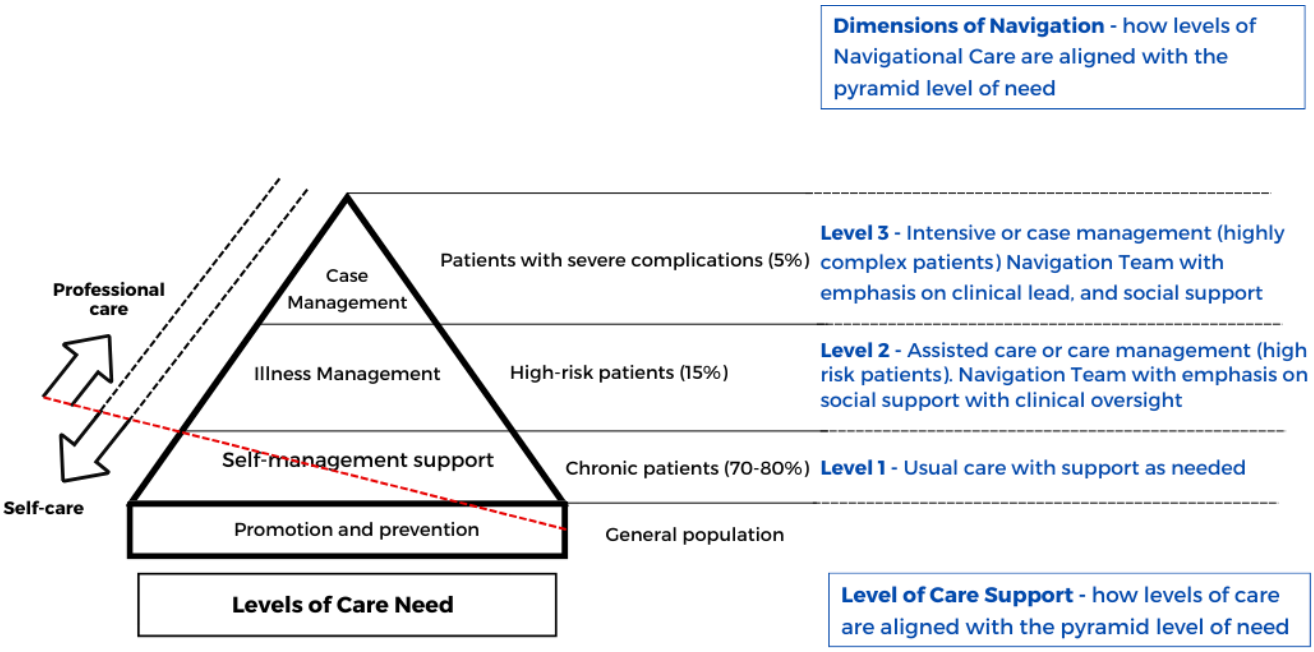
(Harvey et al., 2021b, p. 8)

Long wait times for GP and specialist care leads to deterioration in health and increasing reactionary care with primary level care sought through Emergency Departments. This has become a popular focus in grey literature and the media as frustration in our health system grows and GPs are reported as saying wait times are becoming 'dangerous' (Schibell & Wilson, 2022; Radio New Zealand [RNZ], 2022). These claims are supported by the number of hospital presentations, triage scores and direct discharge from ED seen within the retrospective hospitalisation data in this study, with prevalence in Pacifika and young people presenting. This is especially true for complex care patients who cannot wait four weeks to have their health problems addressed. Addressing these issues requires a dramatic change in care management.

Participants highlighted their need to have social and spiritual care support alongside their clinical care. Confusion with the loss of consistency in messaging occurs when a variety of health professionals become involved in care without dedicated support to coordinate efforts. Nurse Navigators in the Queensland program provided consistency and aided connection to the various parts of the health system. The Jody case study showed that a coordinated team with the right skill and provided in the right way based on his needs, led to significant and sustained health improvements as well as cost savings to the health system. He is now 'work fit' and in a position to embrace paid employment that will benefit his whole whānau reducing the burden of demand on health and social systems. The solution may lie in 'navigation teams' comprising health multidimensional professionals across social/employment/fitness sector support roles. Understanding dimensions of navigation against care demand is demonstrated in Figure 19 highlighting the KP pyramid, incorporated with levels of care need. Lower levels of care need may require more social navigation through the health system with integration of clinical oversight. As clinical care needs progress in complexity, the balance in clinical to social support may change where case management through intensive clinical support take precedence in alignment with social support resources. Care models must be able to flex and be individualised to be patient focused. The nature of navigation and what best works for the patient as well as the health system, requires deeper examination. A 'one size' solution does not work in today's healthcare environment. However, the solution needs to respond to patient indicated needs, truly placing the patient at the centre.

Figure 19

Dimensions of Navigation



Patient Care to Person Centered Care to Person Centric Care

Throughout the journey of this research, there has been a focus on Patient or Person Centered Care. Bryne et al. (2020) sought to define person centred care tracing its origins back to the 1950's. It remains universally undefined with issues in operationalising this into our healthcare settings. Their work titled "Whose centre is it anyway" seeks to understand the patients position in care. The terms patient centered care, person centred care and patient/person centric care are used interchangeable. Haakansson Eklund et al. (2019) synthesised reviews from 2000-2017 of the use of person vs patient centred care. They found a differences in the concept of goals. A person-centered view focuses on what a meaningful life is, versus a focus on a functional life with a patient centered view. There are similarities in the way the terms are used with person centered care broadening the concept to the whole person.

What was not defined in these reviews is who the decision maker actually was. Shared decision making, with partnership is discussed in much of the literature. Haakansson Eklaund et al. (2017) and Bryne et al. (2020) discuss this in terms of importance of the relationship that enables sharing information, and facilitating decision making between patient and health provider, but do not elaborate on how decisions are made and from whose perspective. The patient perspective is implied but not specified. Burgers et al. (2021, p. 4) reviewed earlier publications on patient centred care noting patient centred care was situated around “shared control of decision making”. But the emphasis implies the patient does not have control. Haaknasoson Eklund et al. (2017, p. 7) describes concepts of “empowerment, autonomy and involvement in treatment”. These descriptions have a paternalist view where health providers are focused on encouraging empowerment through building skills within the patient to enable them to be decision makers in their care, implying they are unable or ill equipped to do that now. Yet outside of the health care consultation, people make decisions for themselves in everyday life. There is a difference in the ‘ability’ to make decisions and to be ‘informed’ in being able to make decisions. This topic is complex, and I have applied a somewhat simplistic approach to the use of terminology in an effort to highlight the issue in establishing who person centered care is for and what it means.

In engaging in this study, I felt a shift in my perspective and started viewing health interactions differently attempting to view this from the patient’s perspective, looking out toward the health care system and felt the frustration and tears they have shed. This was a fundamental change. Numbers became less important and what really mattered was how life was lived. What I believe needs to happen extends beyond how life is lived to also incorporate functionality, where these terms and goals are blended. The terms person centered vs person centric takes on a different meaning. Person centered implies the person at the middle were as person centric implies coming from within the person.

Theorists Foucault and Fairclough have spent much of their published work in linguistics and theorise ‘power’ in words (Fairclough, 1995; Foucault, 1998). Therefore, the language we use, and the concept of power is important. Person centered care has an objective of wrapping care around the patient, placing the patient at the middle and the patient partnering with the health provider. But where the power sits within this model is still undefined. Many of the publications I have read imply the health professional still holds the concept of power in decision making though partnership is often described. Integrated care is a suggestive model of partnership between services and the patient, in a coordinated manner, but this coordinated manner has a primary focus of cost containment and does not work for people with multimorbidity in our current health system due to siloed and fragmentation of care teams (Francis et al., 2019; Hughes et al., 2022). The power still tends to sit with services and implies we allow the patient to partner with 'health providers' so that decision making is shared. Mold (2017) and Bourgois et al. (2017) describe how medically siloed care creates structural vulnerability where the person, even in a so-called person-centred model, has no control of their lives or illness.

Despite moving care toward the patient, best practice guidelines remain disease focused with goals to improve blood pressure numbers, diabetes number targets and improved pain scores etc. States of diabetes and heart disease for example, may be improved but does this improve the ability to 'live' from the patients' perspective. Alkhaibari et al. (2023) in their work in understanding patient centred care within a middle eastern context, also found confusion within the literature and what this means and note that studies to date do not include a cultural context which can change the meaning and application of this concept. Westernised terms may not resonate with different cultures as described earlier in chapter five, the concept of 'mental health' does not hold meaning for Indigenous People outside of the whole person and connection to whānau and land. What was found to be meaningful in this thesis study, were insights patients were able to make through connection and conversations with other patients, not on whether their fluid gains were better on dialysis or diabetes goals have been met, but on how to get through the treatment, prevent cramps etc, with a focus on coping and support of each other (patients).

In using the Reset and Translational Change process, capillary networks developed through needs identified by the patient. They told us what they needed, to go for coffee, be at whānau events, not be a burden on their families and to live differently. One of the key successes for the Jody case study, was the change in focus from improving diabetes, blood pressure and cholesterol, to his goals of being able to gain employment and feeling physically stronger by working out in a gym. However, in focusing on Jody's self-directed goals and through activities to meet Jody's goals, clinical targets improved where diabetes numbers returned to a non-diabetes state, blood pressure and cholesterol improved, and pain interventions reduced. Applying the concept of the Reset and Translational Change process, his achieved a positive trajectory. His capillary support system was developed and strengthened. The power in this situation was returned to *him* as the director of his own care and gains in *his* way. He needed navigation in how to bring a team together. Recognising Jody as the expert in his care, is where care becomes meaningful. The Queensland Nurse Navigator patient and nurse interviews became cathartic for the patients and provided an avenue to final be able to tell their story and be heard. Interviews invariable started with a description from the patient describing what had gone wrong, the system gaps they had fallen into and how they were not being listened to. Navigators helped first by listening, then by coordinating care and closing gaps. Their interactions were time limited for some, as once gaps were closed and the patient was stabilised again, their care input was completed with the patient then continuing on their journey enabled as the directors of their care needs (Harvey et al., 2021a). This approach was economically sound with proven savings to the health system through reduced hospitalisations and less demand on the need for elevated levels of care.

Health literacy is also a common term used in care of people with chronic conditions and again many publications discuss the need to educate and take into account a person's health literacy level. I pose that this places the onus on the patient to learn and improve, where perhaps the onus is on the health provider to 'walk in their (patient) shoes and look through their lens' to provide understanding from a patient's perspective. On many occasions I have encountered how patient understanding finally supported by how I phrase a problem or solution through the terms and the language I use, despite patients many previous encounters with health professionals on the same topic. It is not that a patient does not have that ability to understand or requires further education on the topic, but the way in which we couch a message. This is clearly identified in the work by Byrne et al. (2022) where they debunked the notion of health illiteracy. They found that the technologies of government ensure that people are made to be responsible for their own health. This shifts the emphasis from the health service to the patient to make care possible. In doing this they have problematised the patient. It is the patient who does not listen to the regime of care (not the instructions given to them by the health practitioner!), it is the patient who is non-compliant when they do not attend appointments (not the service listening to the fact that the patient cannot attend the appointment, often because of reasons such as lack of transport). The fact that the message from the service creates an environment of blame (three strikes and you are out if you miss appointments), the patient is the 'failure to attend'. Yet the data analysed by Bryne and colleagues, showed that the patient knew exactly what was wrong (not illiterate) and inevitably was not at fault, rather it was the messaging or the structural rigidity of the service that caused the issue. In my study, patients describe similar issues.

In taking a patient perspective, Person or Patient centric is perhaps a more apt term. This implies 'from within'. There is a lack of definition in the published literature that views this term situated from the patient perspective. In an attempt to understand the meaning, I also searched grey literature and found some reference to this. The Cambridge Dictionary describes the term in this way; "seen from the point of view of a particular type of person" (Cambridge University Press, n.a). Leescher (2012) indicated in a press release through digital health discussions and states that "patient centric healthcare differs in the information and interactions emanate from the patient" (Leescher, 2012, no p.). He goes onto say "patient centric movement requires a change in provider mental framework" and describes this as personalised medicalisation (no page). He also stresses that the current system that allows only 15-minute consults with up to four weeks wait for an appointment, is not patient focused care. This is supported by Askerud et al. (2020) and Mold (2017) suggesting integrated care with person centered focus cannot work in the current 15-minute episodic acute care frame. This developing structure of health care consultations is most definitely not patient centric. The participants stated they did not gain understanding of their conditions until they became engaged with the Renal Service. This is in part due to the increased level of support through contact as the secondary care system in NZ is not restricted by 15-minute consultations. I was unable to find peer reviewed primary literature on the concept and definition that describes patient centric care as determined by the patient. I believe they exist but due to the myriads of definitions applied to these terms, this was not easily identifiable.

There needs to be a paradigm shift in first the use of language to understand what terms we are using (Alkhaibari et al., 2023; Abdelhalim et al., 2019; Bryne et al., 2020;

Burgers et al., 2021; Rubashkin et al., 2018; Walsh et al., 2022), then to shift the power base from medicalisation back to the patient, with a distinction between medical care, power, and the person. Decades of Medicine holding the power base has not made significant gains evidenced by a growing pandemic of non-communicable disease burden on the world (Askerud et al., 2020), where the latest report from WHO (2023) describes a 90% increase in absolute numbers from deaths related to chronic conditions since 2019. A change in how we conceptualise care has to be part of the change that makes a difference.

Understanding afforded to me through the Reset and Translational Change development, along with the Jody Case Study, suggests a different way to conceptualise care, that focuses on patient directed needs and strengthening social capillary networks. There needs to be a blending of the patient centric model to set the direction, and the medicalised model in true partnership to help determine how to get there. The Reset and Translational Change process as a model recognises the flow of power in the capillary system as emanating from and surrounding the patient, through developing coping and supportive networks as defined by the patient. Patients are experts in their own care and are best positioned to understand what they need once they understand what has gone wrong. Participants in this study have told us that. Listening to what our patients are telling us is where meaningful partnerships begin.

Person Centric Care and Social Orders Alignment.

As patient/person centric care is truly understood and positioned by the health care provider, focus must then move to the environment that supports these goals. The concept of environment extends to not only incorporating a physical nature but includes broader concepts of the person, whānau, society, and governing environments where policy determines societal direction and influences how we are 'born, live, learn, work, play, pray and die' (our SDH). This is not a new concept and is largely understood in healthcare to influence the development of non-communicable and chronic disease states (Marmot& Wilkinson, 2005; Baum, 2008; WHO Commission on Social Determination of Health, 2008; Baum & Fisher, 2010; Brown et al., 2023). The WHO commissioned report in SDH in 2008, provided direction on a global level, to address these impacts through aligning governing and political agendas. In the current global environment of 2023/2024, the world is still reiterating the same message with a burgeoning pandemic in chronic conditions (Brown et al., 2023; WHO, 2023). COVID-19 pandemic was a world event that saw countries 'locked down' to minimise the spread of infection. However, a consequence in doing so, resulted in a pandemic of worsening chronic condition management through increased sedentary behaviour and obesity, inability to obtain fresh food and vegetables, lack of access to the doctor through healthcare facility closures or change in practice, and lack of transport (Fekadu et al., 2021).

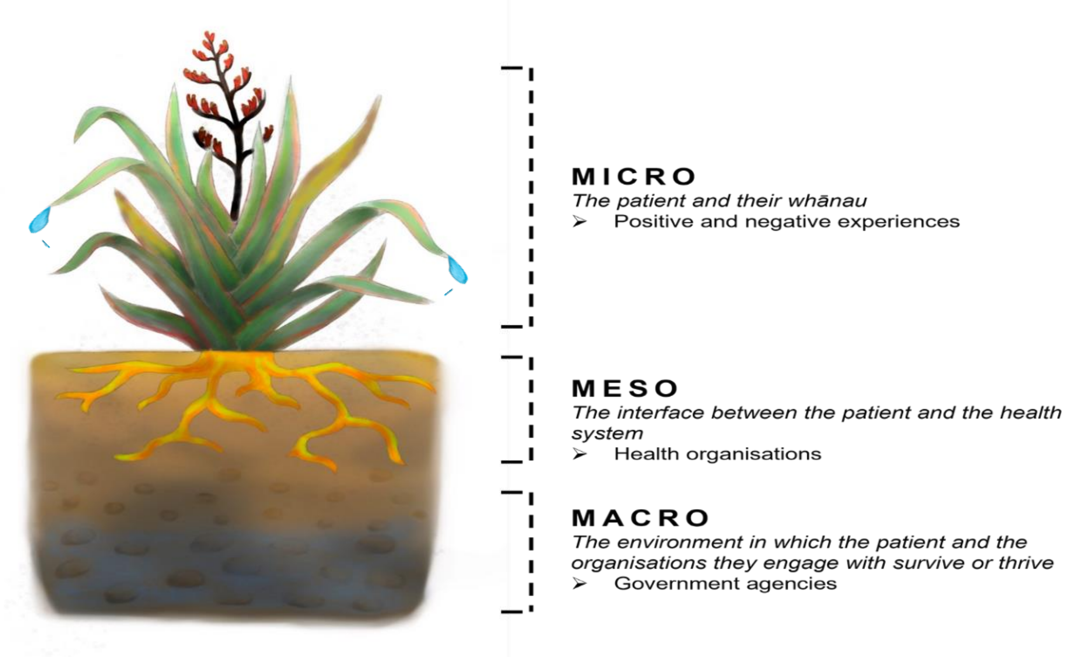
Solar and Irwin (2010) describe structural oppression in their report commissioned by WHO, on actions required to mitigate the rising tide of chronic disease. Policies that suppress the vulnerable and disadvantaged in our community, not by intention but as a consequence of decisions and actions, exert structural oppression. Young (2014, p. 5) explains this when there is "systemic constraints on groups" that occurs but not necessarily intended. This can be created in our communities when advantaged members exert a coercive power base as seen in public debates and decision making, where the dominant voices tend to be from the advantaged and suppresses the disadvantaged meaning their voice is lost. This is an unintended consequence but nevertheless, damaging. During the COVID pandemic, the NZ government decisions to lock down the community for the greater good, had unintended consequences. Indigenous health was disproportionately affected, deepening inequity where governmental decisions only considered the impact of health from a communicable perspective. The combination of chronic care and health with economic and social factors, had the highest impact of increased morbidity and mortality for Indigenous Peoples who are known to be already vulnerable (McLeod et al., 2020). In patient interviews within this body of work, distress was expressed by some of our Indigenous People who were not permitted to have whānau support them in the dialysis unit during 'COVID times', in an environment that was unfamiliar, induced fear and deepened thoughts of depression. This is an example of the effects of one social order on another with the unintended consequence on the individual. At government level (macro level), social isolation through lock down was mandated. Healthcare facilities (meso level) limited access to staff and patients only, affecting support systems for the patient (micro level). This was as a direct contradiction to previous established government policies of the right to support in health care interactions as defined by the 'Code of Rights, Right Eight' (Health and Disability Commissioner, Code of Health and Disability Services Consumers' Rights Regulations, 1996).

Brown et al. (2023) discussed structural oppression through interconnected systems where discrimination is seen across societal domains that include health, social support, and education. Bourgois et al. (2017) describes this as 'structural vulnerability', how health pathways and broader power relationships can exacerbate an individual's health concerns creating illness especially when the patient is exposed to high level decision making that does not include their holistic context. Understanding a broader social history is often treated as an optional extra (Bourgois et al., 2017, p. 1) or has a narrow focus around a determined set of social behaviours such as alcohol intake, smoking and sexual partner practices. Structural vulnerability was repeatedly described in participant interviews within this study. A representation of this was the subtheme 'Connection', where structural oppression or vulnerability featured. The participants described the impacts of loss of social connection when disease states progress, isolating them at home. Lost connection with the wider social groups and support services contributed to isolation. They also described inadequate financial support benefits when employment was lost due to symptom progression. Disconnect was also seen when their health care provider changed on every occasion they sought care, or they were unable to access care.

Through the concept of the Reset and Translational Change process, negative trajectories were seen when social capillary networks are minimised or non-existent but could be strengthened through whānau support and involved health care teams. The Jody case study is an example of how improved social connections at a meso level with intersectoral collaboration was fostered. This had a direct effect on the micro individual level and developed stronger social capillary networks that lessened 'Eventalisation' and influenced a positive trajectory. What is currently missing is the connection at a macro or governmental level for support and direction to ensure intersectoral connection occurs in a meaningful way and becomes part of collaborative partners in everyday care. As a way of demonstrating this concept I have used an analogy of the Harakeke Plant native to NZ, which forms part of Māori world view and is a representation of Whānau. Harakeke is a flax plant, with interconnecting fronds or leaves that appear to wrap around and support each other in three layers or levels. The levels are represented by Rito (child) at the centre, Awhi Rito (parents) in the middle layer and Tupuna (grandparents) as the outer and older layer (Watson, 2020, p.32). Watson (2020) explains through her research how the Pa Harakeke research model forms a framework for strengthening Whānau where protection, vulnerability and connection are key concepts that draw on ancestors as a source of strength. I have adapted this philosophy in staying committed to the meaning of strength, connection, and protection to demonstrate how social orders need to align for people with multimorbidity to grow and thrive. Figure 20 is a representation of the Harakeke plant and indicates the level of social orders. For the plant to thrive, all levels of order need to interconnect and align. The environment the plant grows in, needs to provide nutrients, sun, rain and be toxin free. The social orders are presented through the plant as the individual and the fronds as part of the capillary supportive network or interconnected elements such as Whānau. The roots form an interface between plant and the soil, similar to the health system and the individual where roots form part of the capillary network also. Soil represents the macro level and contains the nutrients to grow. Yellowing leaves are a sign of distress and lack of nutrients or support (Figure 20).

Figure 20

Harakeke Plant



Dripping water represents the tears participants have shed when describing instances where lack of support and changes have impacted negatively. Healthy green leaves imply balance and strength. When our social orders do not align, the patient is broken, isolated and fails to thrive and live life in the best way they can. Intergenerational trauma is precipitated to the next generation. The following participant quote summarises the effect of disease and symptom progression that forced a change in a core strength for a participant when he could no longer remain connected to his brothers (who were also affected by multimorbidity),

> *Well, I've only got um, my two brothers ... I see them probably maybe once every two months or three months or something. Not as much as what I used to (before I became sick [crying])* (Participant E: 47:25 sec).

The back story for this participant (personnel communication) involves progression of chronic disease to a point where he could no longer remain functional at work. He then experienced loss of employment, struggled to survive on a social benefit, became socially isolated through an inability to drive, and experienced significant pain causing disability forcing him to be housebound. This then led to a loss of contact with his whānau unit as they are working or were also sick. When breaking down the social orders and influences in this participant's case, one of the main concerns here and disconnect that is evident in NZ, is where current government health policy does not require the health system at all levels to align and interact with other sectors. When reviewing government policies to understand the links here, there is suggestion and intention for this to occur, but it is described in encouragement terms such as goals and integrative aspirations. The Ministry of Health's guiding document released in 2021 titled "*Strategic Intentions 2021 to 2025*" is an intention without directives (Ministry of Health, 2021). This document lists eight Government priorities for the health and disability sector but intersectoral collaboration is not included at this higher level. This again feeds into the games of truth at play in our health system. Such et al. (2022)

conducted a systematic review on government level policies for evidence of 'Health in All Policies' (HiAP) and how this has been approached across nine countries including NZ. Only one publication from Canada indicated a national level collaboration aligned with HiAP, but again this was embedded at a local level strengthening their findings of localised collaboration only. Collaborative partners in health were evident throughout many publications but infrequently addressed, social services, leisure and recreation, as well as immigration.

The current funding model of health in NZ in which this study was situated and still applies, has an aspiration of community led healthcare that has not been fully realised due to structural and institutional barriers experienced by the effect of changing funder priorities (NZ government) and budget pressures through competitive contract arrangements (Tenbensel et al., 2017). The family doctor practice in NZ has been impacted by acute care demands and challenging contractual arrangements with increased administration burden that have seen many family practices amalgamate into corporations to survive triggering the creep in privatisation that is now seen in primary care (Keene, 2023; Meier, 2023). Workforce gaps and deficiencies have further impacted the ability to recruit where there are increasing wait times to see a doctor or nurse due to staff shortages and the lack of planned care creating acute demand (Te Whatu Ora, 2023). This was seen in the hospitalisation data of this study where there were more presentations in Triage 4 categories and discharged home without admission, suggesting many of this cohort were using ED instead of primary or community care.

Part of the solution to these problems is sector collaboration in healthcare. If we do not have healthcare embedded in the depth and breadth of government, utilising frameworks such as HiAP, that mandate sectors to collaborate with the appropriate leadership and funding streams, equity and social justice will remain aspirational. During 'the COVID years' the NZ government proved this can be done. All sectors were required to comply with mandates and collectively and collaboratively, we (NZers) did this. This is the level of national support that is needed to enable healthcare to be collaborative in achieving integration.

The Final Connection

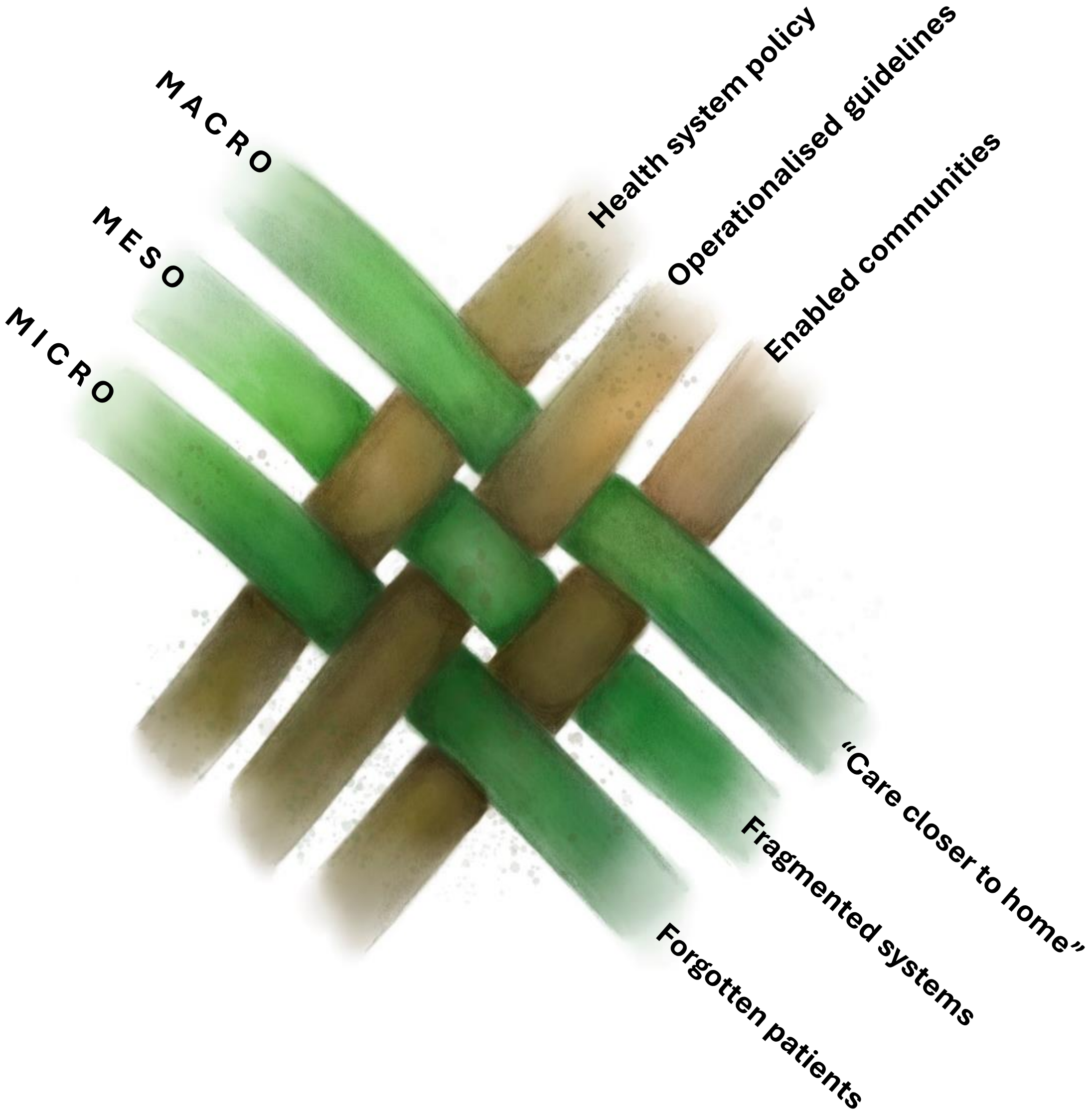
Basket weaving is the hallmark of Pacific culture. For me, this study has helped me to weave my own knowledge into understanding what it means to be sick and how disconnected to family, self and health care can have such a significant negative impact on patient outcomes. For person centric care to occur, all parts of the basket that is weaved together must be strong and must equally hold true to the continuity of the basket. This is what person-centric care is all about. It is not being left alone as a problem of care, nor is it wrap around care where self-sovereignty is lost. It is weaving together those elements of care (socio-economic, material, clinical) to support care in the best way possible. Harvey et al. (2021a) showed how nurse navigators providing person centric care, not only improved patient wellbeing and helped them to manage their illness but also saved the government money. In fact, they saved $110 million per annum (Australian dollar), demonstrating that self-care, person centric care and care co-ordination is not expensive as some research studies have indicated. Weaving the ‘basket of care’ works, if you have the right mix of material, without loose or missing threads.

Figure 21 highlights the weaving of the basket of care with a person centric lens striving for care closer to home. People want to be closer to or at home when they receive care, especially to be able to access whānau and community support. At a macro level, the NZ Ministry of Health has a high-level policy of providing care closer to home which aligns with a person centric goal (Ministry of Health, 2023b). For this to occur, health services at a meso level, who enact policy must have operationalised guidelines that support this goal. This means they must have resource funding and workforce capability to offer services that enable care at home or close to home (goal of within 50km of home). For care to be provided at home for the patient, resources enabled by services need to be able to reach home or in the case of whānau supported care, whānau need to be enabled to provide care at home, ie they have the physical and financial capability to do so. All levels need to align to enable this to be a person centric approach. Currently, as demonstrated by the participants in this study, many are unable to access care closer to home, with some people having to travel up to 300km to access life-saving care or needing to travel to a different city to access a primary care centre. Many have described cost of travel as barriers and the distress of being separated from support systems and whānau.

Until the basket and be weaved with strong aligned and supporting material, care will continue to be fragmented with a lost patient far from the centre of care decision provision.

Figure 21

Harakeke Plant – Connection



Summary

We need to do better. What remains hidden in plain sight needs to be unearthed, elevated and talked about. We need to reassess what hospital avoidance is about and who it serves, just as we need to rethink what benefit a QoL survey has for a person who can hardly know what the day will bring let alone understand what quality that day should have. How to measure the unmeasurable. Foucault discusses truths and what makes up a person's truth. But as highlighted here, there are multiple truths where these truths can at times be at complete odds. The health system has a truth, budget and work force constraints, the promise of providing what you need but the reality of not entirely having the means to do so. Our systems are lacking, we may lose you to the system. The patients, have a truth. Life living with multimorbidity is hard, can be sad with dark days and for ever changing. How you see yourself changes, how your whānau and the health system sees you, changes. This is compounded by multiple people in a household living the same truth precipitating generational illness patterns and trauma, the child becomes the carer. Here lie the' games of truth' where truth depends on the side of the fence you stand on. All of this remains hidden in plain sight.

While our programmes focus on hospital avoidance in an effort to contain costs and focus on what it can achieve. The voice of the patient is lost in a system of truths. But people are resilient and despite these truths, giving back, altruistic acts, a desire to be different and live life differently are acts of resistance, If we listen and position care differently, be patient centric, be directed by their goals, we can support a transformational change that translates a new 'me' where illness trajectories are altered and life is lived more positively, beginning a new truth. Then the games of truth might align where the patients voice is elevated and heard. Understanding that MM transcends other known disparate factors and is at the core of health care vulnerability. What we do as health professionals makes a difference through listening, supportive actions and being present, we can lessen the disparate gap supporting people to live life differently.

Chapter Seven detailed the analysis of the data from the three main data sources and identified how the three research questions were answered through these data. Games of truth influence the perspective of the patient, the health professional and the extent to which government level aspirations are not congruent with the patients' lived experience. Models of care need to evolve as the needs of the patient evolves as they live with multiple chronic conditions and try to make sense of their altered lives. The language we use is important and influences how we position care.

The following chapter identifies and acknowledges the limitations of the study and describes where caution is required in the interpretation of the findings of the study.

Chapter Eight

Limitations

The main aim of this study was to identify the characteristics of people with CKDMM through a focused cohort of people who are known to be multimorbid, and to explore how people live with multiple medical conditions. What it also provided was means to enable a 'voice' of the people living with CKDMM. In doing so though, the findings of this study are representative of this cohort, whose commonality is CKD. Therefore, caution needs to be applied in being able to state they are representative of people with multimorbidity. Yet, arguably, this study is supported by the larger Australian work of Harvey et al. (2021a). In understanding that, there are several limitations identified within this study. What this study does do, is to shine a light on the need to include cultural care into chronic care activity.

In analysing data from the participant interviews, data saturation in the respect of new themes occurred at interview seven of eighteen interviews, suggesting these themes were highly representative of the cohort with similar medical conditions and living environments. Similar themes were identified in the Queensland Nurse Navigator program in Australia, as well as themes of inequity, disparity and marginalisation explored in the Literature Review. This implies that the impact and effect is comparable between people of different ages, ethnicities and living circumstances, strengthening the generalisability of results to other multimorbid groups.

There were identified limitations to the interpretation of the retrospective hospitalisation data. It was a small cohort size of 647 people in a regional centre with a wide geographical spread. Healthcare resources may be limited compared to larger metropolitan centres meaning utilisation of hospital services and admission practices may differ to other centres. Due to the smaller sample size and limited numbers within each category of data, several categories needed to be collapsed for statistical models to run without error. This limited the ability to define the data further when exploring interacting variables that required larger numbers. This was an incomplete representation of the number of people cared for by the service due to organisational data system errors over 2019-2020 where some data was lost.

Body systems count was used as a proxy measure of chronic conditions as a result of the way information systems are set up to capture data. There is currently an inability within the NZ health information technology systems to measure data in a consistent way. This may affect understanding of the data across different systems and may not be as representative of chronic conditions. However as described in this thesis there is evidence in the literature that the use of body system effects is a more useful way to understand the whole body burden of disease. I have spent time reflecting on this in the chronic condition space. Though it does not help us to understand the enormity of different conditions that can be considered chronic, it perhaps does provide a better understanding of what drives health service utilisation at a higher level and what the main impacts when considering dysfunction and impacts. Is it important at all levels, to know that there are 50 different cardiac conditions (random selection of number for example purposes) counted as a chronic condition or that conditions counted as a cardiac body system impacts hospital utilisation and cause dysfunction? The very different presentations of cardiac dysfunction are hard to quantify in one place, where a body system impact is a simpler measure but equally as meaningful. There is more to understand about who and why people present to hospital systems in the way that they do. This is especially true for people with CKDMM.

LOS and days in hospital were used as a proxy to understand the need for elevated levels of care need. Cryer et al. (2010) found the use of LOS to be an unstable proxy for severity of non-fatal injury due to the many variables that influence LOS. This must also hold true for non-injury disease states. However, it can be postulated that the longer one needs to stay in hospital the more complex their overall need is. This is likely to be complex due to clinical, social and culture demands. This is still impactful on the person, the health system and society and warrants inclusion and further investigation to deepen our understanding of this population group.

A further limitation in this study is the use of socioeconomic status as a factor of disparity and using this factor as part of the data collected. In NZ, quintile and deciles ratings are used to indicate socioeconomic status in healthcare IT systems. These ratings assign a blanket score to demographic areas or suburbs. However, within a city or rural block, households of varying economic statuses may receive the same rating, leading to inequities. Individuals of lower socioeconomic status might miss out on funding support due to their area's overall rating rather than their personal economic situation. It also does not offer a true reflection of socioeconomic status when considering the SDH for an individual. Therefore, caution should also be applied when making generalised statements concerning SDH, use of cartographic applied socioeconomic ratings and association to chronic disease patterns. Brameld and Holman (2005) addressed this problem in their Australian study by using socioeconomic status collected at the level of Census data collection, achieving a more individualised discrete measure. The health IT systems in use for their area of study utilised a data linkage system that enabled more accurate data. There is ongoing acknowledgement within the literature regarding the issues with measuring socioeconomic status at a population level. Psaki et al. (2014) discusses the difficulties in using and comparing socioeconomic status as a measure across multi-country sites as there is no internationally accepted measure.

The development of the Reset and Translational Change process came out of the examination of the triangulation of data from this study but has also been informed by the experience gained from working with this population group over many years. It is possible that this understanding is isolated to this population group only and may not have applicability to other population groups. However, there is evidence in the literature of similar themes by Charmaz (1995) on identity, Jutel, (2016, 2024) on diagnoses and identity, and Polidano et al. (2020) on embracing a 'new normal'. Further examination of this process across other groups will help to understand its wider application.

Limitations in the use and interpretation of using QoL survey data also exist. In the writing of this thesis, prompted by the seemingly dichotomous position between participants stories and QoL survey answers, it became clear to me that there is a problem with using them as part of understanding a patient's perspective on care, treatment or how life is lived. As explored in this study, the use of QoL surveys has become a common tool in clinical care to understand effectiveness of treatment regimes, symptom burden and in some respect the experiences of people in healthcare. But I have questioned their use and ability to be to be reflective of the perspective of people with chronic conditions especially as multimorbidity grows. They measure a moment and have no historical context. They include predetermined areas of survey, not of the patient's choice and offer no ability to be critically reflective. Through a Foucauldian lens one would then ask who do they serve and what is the purpose or benefit? The main benefit in their use in this study is that they helped me analyse and question what was happening in relation to interview data resulting in the conception of the Reset and Translational Change Process. In their use and as part of cultural considerations I chose to use the Meke Meter. Its origins were for the Māori people of New Zealand. It has been validated for use with Māori but as Harvey et al. (2021) found, it was easily adapted for other cultural and Indigenous groups.

The inclusion of QoL surveys were also considered as part of using a mixed or multimethod approach to enable data triangulation with the aim of strengthening and adding to the robustness of findings. As discussed in chapter three, expert researchers suggest this improves generalisability. But reliability is dependent on the researcher's ability to interpret distinct sets of data bring them together and draw conclusions from this. Using a CDA methodology, a Foucauldian approach encourages discourse and taking a multiangled approach to understanding the deeper impacts and influences of a problem. Fairclough encourages the impact of social ordering within a similar lens. But Fadyl and Nicholl (2013) offered caution in Foucauldian discursive interpretation that is influenced by the interviewer/interpreter as part of the discourse. They also saw taking the participants 'voice' translated to text as problematic in interpretation. I questioned the ability to be able to find commonalities in quantitative numerical driven data and deeply emotive qualitative data, to enable such opposing data threads to be able to be drawn together and not lose the meaning of either data set. But the wider impact of multimorbidity especially for those with CKDMM would be underserved by one methodological approach alone. Each data set told a story of its own and together a broader perspective can be gained.

Using a CDA lens also enabled the recognition of the 'games of truth' in healthcare and understanding of how patient's concerns are hidden in plain sight but for the want of looking. But as a new researcher, entering this course of study, my perspective was truly narrow, and I had blinkers I didn't understand I was wearing. I was offered the opportunity to consider what methodology exists, the meaning and use of it and how we go about answering a question. My knowledge was enriched, my perspective broadened, my ability to question deepened, where I have come to understand is the purpose of engaging in a subject matter at a PhD level.

I have also had the opportunity to consider care models in engaging in this work. How best practice guidelines and protocols enable care but offers a one size fits all approach. This does not work when disease processes include multi body system involvement with conflicting siloed treatment plans. Models of care that drive best practice, need to continually evolve to be fit for purpose. Care models also drive clinical practice and decision making. Decision to admit to hospital or not comes down to the medical decision makers practice, intuition and localised protocols informed by education and experience. To admit or not is also influenced by current resource constraint. Are beds available or is there enough staff to look after them? This impacts the patterns of admission to hospital and length of stay. Local practice patterns are known to change by regional location and influence, government policy of the day, ethnic and social makeup of the region (Knickman & Foltz, 1984; Westert et al., 1993; Reid et al., 2022). These are variables that have not been accounted for in this study, therefore caution must be considered with any data interpretation using these parameters. In realigning and reimagining the Kaiser Permanente Care Pyramid of needs against care provision, acknowledgement is made in respect that this was based on the care needs as described by this cohort group. These needs have been similarly recognised in a different NZ study in a larger Auckland renal service (A. Salmond, personal communication, November 2022) where they are in the early stages of conducting a project on realigning wrap around professional care support, traditionally offered at the tip of the Kaiser pyramid, to lower levels of the pyramid population, in a similar way that I have described here. To my knowledge their work is not based on the Kaiser Pyramid of care rather than a recognised need that fits my interpretation. This work is coincidental and independent of each other but are of an aligned concept suggesting this is becoming a wider recognised issue. Once again this is with a dedicated and focused special population group, where I am suggesting this is applicable in any multimorbid population group that strategizes care risk across a population as the Kaiser Permanente Pyramid aims to do. This needs to be tested further and is proposed here to generate discussion around changing needs in the population.

As the principal researcher for this study, I also acknowledge my insider view as I have worked with this population group for more than two decades. It is possible that I have anticipated outcomes based on what I thought I knew of this population. This has been mitigated somewhat using data triangulation. This provided a cross check of key findings in three different ways, making the overall findings less likely to be influenced by a bias. Throughout the last year as themes emerged, I have informally checked my interpretation of the findings within my normal working environment, randomly with other patients as I have worked with them, as well as with individual participants. I also cross checked my interpretation with my colleague who conducted the interviews and heard the participants stories firsthand, who also provided me with a Māori cultural perspective from her viewpoint as she identifies as Māori. The case report as an example of a positive discursive shift in applying the Reset and Translational Change process, also helps to validate the application of this new development. This research project occurred alongside this thesis study but was informed by this thesis study. The patient and his Whānau were not part of the interviewed participant cohort for this study but are part of the larger Renal Service cohort as an enrolled patient of the service. As such, this patient's data was also captured within the quantitative retrospective hospitalisation data.

The limitations as described here suggest caution in translating results. These are mostly related to the size of the population group, regionalisation of a geographically spread but smaller population, with higher than the national average of people who identify as Māori. Mitigating factors though, suggest they can be generalised across larger multimorbid population groups and provides evidence to explore these findings further in future studies.

Limitations exist in all research. Complex data and/or inadequate data systems prevent a full and true picture to be easily understood. There is a need for a common language in healthcare that is understood by the patient, the health provider and the system. As we question the models of care we use in health, it is also right to question the research methods we use to examine and understand the care we provide. The following chapter concludes this study and outlines what has been learnt, how it adds to the body of knowledge and what the main ‘take away’ messages are. It describes what has impacted and influenced the way I now practice and how it has enabled me to care for people differently.

Chapter Nine

Conclusion

This thesis examined the factors shaping how life is lived with multimorbidity among individuals with chronic kidney disease and end-stage kidney disease, collectively referred to as chronic kidney disease with multimorbidity. The study was conducted as a single-site case study within a regional secondary care hospital in New Zealand, focusing on a Renal Service that provides outpatient clinics, dialysis services, and acute inpatient care. A critical discourse analysis, informed by the work of Foucault and Fairclough, provided the methodological framework. This approach enabled an exploration of how social orders and discursive practices shape healthcare delivery, particularly through the lens of Foucault's games of truth.

The analysis focused on how patients with complex renal disease navigate discursive care terrains and how they engage in technologies of the self to live meaningfully and authentically, even within the constraints of a complex and often fragmented healthcare system. It was their stories that told me what the characteristics of multimorbidity are. How life is lived is vivid in the themes that appeared and tears that were shed, in their journey to make sense of their lives in the face of multimorbidity. By far the strongest impact was one of mental health. This life is hard! The sense of loss and hardship was at times difficult to listen to let alone how difficult it must be to live it. How whānau were impacted, described through a sense of concentric circles, in that impacts are far reaching on whānau, work mates, and friends as well as the healthcare system. Generational patterns of illness that turned children into carers of parents were told with a sense of the inevitable, where descriptions indicated a loss of dreams of what life could be.

The analysis illustrates how such patients often become 'hidden in plain sight', unheard, unseen, and increasingly vulnerable within institutional settings that are not designed to respond holistically to multimorbidity that has clinically and socially complex health needs. Through a multi-layered analysis of retrospective hospital data (macro level), patient interviews (meso level), and an in-depth mini case study of a single patient's experience (micro level), the study exposes a fragmented system of care delivery that lacks a whole-of-systems approach. This fragmentation generates uncertainty, exacerbates hardship, and amplifies disparities for those navigating care with complex, kidney disease. The narratives shared by participants, presented through conversational, story-based interviews, formed the backbone of these findings. These stories illuminate the profound shifts experienced as disease burden accumulates, resulting in personal, whānau, and societal losses. Participants described a fundamental transformation in the way life is lived, as illness reshaped identity, relationships, and social participation. The findings also highlighted key discursive tensions within the healthcare system, which Foucault describes as games of truth. These games reveal how particular forms of knowledge and language shape who is seen, heard, and valued in care delivery.

The research draws attention to the multiplicity and vulnerability of patients within the health system and the significance of language in shaping care, from traditional notions of patient-centred care to a more appropriate understanding of patient-centric needs. These patterns reflect forms of governmentality, where policy structures shape care-seeking behaviours and reinforce inequalities. Yet, the study highlights the necessity of socially ordered, coordinated navigation of care, an approach that attends to both clinical and social realities. Empowering communities with accessible and culturally responsive care challenges the entrenched logics that sustain inequitable health systems. Participants' narratives reveal that meaningful reclamation of life becomes possible when care is reimagined and when systems move beyond rigid, top-down structures to become responsive, relational, and grounded in the lived realities of those they serve. In doing so, these shifts create fissures within dominant power structures, unsettling disciplinary mechanisms and opening space for community-driven, equity-centered approaches to health and well-being.

Viewing multimorbidity through the lens of body systems represents a significant discursive shift from the traditional classification of chronic conditions. Rather than naming discrete diseases, this systems-based approach highlights the cumulative functional impact on the body and the implications for how life is lived. It challenges prevailing regimes of truth that define illness primarily through diagnostic categories and instead positions functional impairment and systemic complexity as central markers of health need. This reframing not only influences how need is constructed but also how resources, attention, and care are distributed, an expression of Foucault's notion of truth production within institutional structures. The data also revealed how social positioning, particularly ethnicity and domicile, continues to shape access to and use of health services. Māori, as a single ethnic group, were overrepresented in both inpatient admissions and outpatient service use, consistent with broader health inequity trends in Aotearoa New Zealand. These patterns reflect deeply embedded social orders of discourse, where health inequities are both reproduced and legitimised through institutional arrangements and discursive practices.

At the same time, a critical gap in pre-hospital and community-level care was evident, particularly through high rates of emergency department use. Over half of emergency department presentations were triaged as low acuity, suggesting that many patients might have been better served through primary or community-based care. However, participant narratives shed light on the structural barriers that make these options inaccessible, with limited appointment availability, cost barriers, and a lack of continuity of care. These systemic conditions act as technologies of power, shaping the health-seeking behaviours of patients and reinforcing patterns of reliance on hospital-based services.

While this thesis did not seek to examine these dynamics in full detail, the findings resonate with broader critiques of governmentality, how the state, through funding structures, health policies, and access models, governs the conduct of individuals and populations. The emergency department becomes not just sites of care but instruments of biopolitical management, absorbing unmet needs from inadequately resourced sectors. In this way, care is fragmented, reactive, and misaligned with the lived realities of those most affected by multimorbidity.

The preference for the emergency department as a care entry point may also reflect a form of learned institutional behaviour, where patients navigate the system based on what is predictable, timely, and cost-neutral. The department is perceived as a 'one-stop shop,' offering diagnostic tests, imaging, and medications in a single encounter. Unlike primary care, where fragmentation, costs, and scheduling constraints can deter access, these choices are shaped by both discursive formations (what care is seen as legitimate or accessible) and material conditions (what care is actually available). Moreover, participants described trust in hospital systems, particularly in specialist teams, further reinforcing hospital settings as the central hub of care. The hospitalisation data supports this, showing that patients with multimorbidity who presented to the emergency department were more likely to be admitted, indicating legitimate need despite low-acuity triage codes. This further complicates the truth claims embedded in triage classifications, exposing the limits of institutional categorisation systems and reinforcing Foucault's notion that classification is a form of power, one that can both reveal and obscure patient need.

The findings of this study, framed through a critical Foucauldian lens, highlight the urgent need to rethink how healthcare systems conceptualise and respond to multimorbidity. As demonstrated, the current institutional logic, shaped by diagnostic classification systems, fragmented service delivery, and dominant discourses of clinical prioritization, fails to adequately meet the needs of people with complex, layered experiences of illness such as chronic kidney disease with complex multimorbidity. These systems are not neutral, rather, they reflect historically entrenched truths, organisational logics, and technologies of governance that reproduce inequities and obscure whole-person care needs. To move beyond the limitations of reactive, disease-centric models of care, this thesis now turns to consider the practical, structural, and policy-level implications of these findings. These implications call for a reimagining of care that centres relationality, accessibility, and integration across the continuum from primary to acute care, while also interrogating the very discourses that shape how care is defined, funded, and delivered.

Despite the systemic fragmentation and hardship described, what also emerged strongly was the human capacity for altruism and purpose. Many participants demonstrated a desire to give back through volunteering, mentoring others, or simply offering kindness to those patients who are new to dealing with challenges of disease progression. These acts of generosity and social connection stood in contrast to what traditional metrics, such as Quality of Life (QoL) surveys, often portrayed. At times, these tools felt misaligned with the depth of participants' experiences, prompting me to question their utility and whose truths they ultimately serve. This realisation became a pivotal point in my own learning, the recognition that higher study is not simply about acquiring knowledge, but about dismantling it, questioning assumptions, and reconstructing understanding from lived perspectives.

As health professionals, we hold immense influence in shaping how people live with illness, how they experience care, and even how they die. Active, consistent, and relational care teams can help buffer the burden of illness by strengthening the 'social capillary network', in which a web of trust, presence, and shared meaning is created not just through clinical knowledge, but through listening, learning, and seeing the world through our patients' eyes. It was through engaging with the works of Foucault, Fairclough, the use of critical discourse analysis that I came to appreciate how healthcare is not only delivered through systems and protocols, but through language, power, and social orders. Their theoretical lenses enabled me to unpack the complexity of lives lived and to recognise how macro-level structures influence micro-level experiences. This study has made it clear: health must be understood and resourced, not only within healthcare sectors, but across all domains of public life. Without such alignment across education, social services, and employment policy, systemic fissures will deepen and efforts toward health equity will continue to falter.

Final Reflection

Already I see my world differently. I now identify the social and policy 'red flags' with greater clarity. For example, observing politically dominated shifts in the World Health Organisation that are contributing to diminished trust in the guidance it has long provided with primary health care since the Alma Ata Declaration of 1978. I find myself questioning how such global dynamics may influence my work with the vulnerable populations I care for. My reflections now extend beyond clinical procedures to include the political motivations behind policy guidance and who controls knowledge, what purposes it serves, and how it connects to the lived experiences of those in care. After 37 years in clinical work, I had only ever seen myself as a clinician. Yet, through this thesis, I've discovered a passion for academia as a space where I can critically unpack the realities I have witnessed in practice and contribute to meaningful change. I have accepted a position within a university faculty, where I am privileged to carry forward the voices of the people I have cared for, educating future nurses on the meaning and value of 'caring.'

I am now engaged in discussions about post-doctoral work and international collaborations focused on developing navigational practices and reimagined care pathways, as explored in this thesis. My post-doctoral research will delve into early warning systems for chronic care, bringing together clinical, material, and social dimensions, and continuing to explore the Reset and Translational Change process in new contexts. This thesis is not an end, it is a beginning. I am deeply grateful to have heard the stories of those living with multimorbidity and to carry their experiences forward in my ongoing academic and professional journey. Despite the rapid advancements in technology, robotics delivering hospital meals or AI transforming informational systems, the human need for empathy, continuity, and relational care endures. People living with multimorbidity still face uncertainty, struggle, and isolation. But they also demonstrate immense strength and resilience. This work has transformed how I see care, how I practice it, and how I wish to contribute to reshaping its future.

As a symbolic reflection of what this thesis represents, my supervisors and I asked ChatGPT to write a poem about life with long-term conditions. The poem resonated deeply, capturing the heart of this work. It is offered here, alongside this thesis, as a dedication to those who live this reality daily

“Living with Long Term Conditions”

In a world of constant motion and fleeting grace,
There stand warriors of strength, a valiant embrace.
They bear the weight of long-term conditions they endure,
A journey through trials, both painful and obscure.

With unwavering courage, they face each new dawn,
Through the ebbs and flows of battles fought and won.
Their spirits resilient, though pain may persist,
They find beauty in life; amidst the trials they exist.

In the tapestry of time, their threads interweave,
A story of resilience that's hard to conceive.
Through valleys of darkness, they find a guiding light,
Embracing their struggles, they rise with all their might.

Each day is a canvas, where courage paints a scene,
Brushstrokes of hope and strength, vibrant and serene.
They cherish small moments, each victory they hold,
A testament of fortitude, fearless and bold.

With every step forward, they discover anew,
The power of love, kindness, and compassion so true.
In the warmth of support, their spirits find peace,
As they navigate this journey, seeking release.

They learn to savour life's precious, fleeting streams,
And cherish each moment, embracing their dreams.
For in living with long-term conditions, they find,
A deep appreciation for the heart and the mind.

So let us stand beside them, with open hearts,
Understanding their struggles, playing our parts.
For in unity and love, we can surely see,
The strength that they embody, the spirit so free.

Living with long-term conditions, a testament of grace,
Their unwavering spirit, a beacon to embrace.
May their stories inspire us to cherish and adore,
The precious gift of life, forevermore

(ChatGPT, formulated 6th of August 2023)

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Appendices

Appendix One: Database Search Results

Database	Key words/Phrases	Total Articles	Relevant Articles	Reason to discard
CINAHL	Chronic Conditions AND culture AND Vulnerable Populations Chronic Conditions OR Long Term Conditions OR Chronic Illness And Vulnerable Populations	2 37	2 3	Not specific for Culture or Ethnicity/ Not within specified countries
Emerald	Chronic Conditions and Vulnerable Populations Chronic Conditions and Marginalised Populations Multimorbidity AND Culture OR Ethnicity	0 0 0		
Family Health	Chronic Conditions AND Vulnerable Populations Multimorbidity AND Culture OR Ethnicity Multimorbidity AND Culture OR Ethnicity AND Vulnerable Populations	20 5234 (first 40 reviewed) 1005 (first 40 reviewed)	2000	Single Disease Focus/Related to Clinical Case Studies/ Not within specified countries
Nursing and Allied Health	Multimorbidity AND Culture AND Ethnicity Further refined to Multimorbidity and Culture Chronic Conditions (CC) as a Disparity	134,000 107,000 55,000	1 - There were not relevant articles to my question in the first 20 articles. One relevant article in the for 20 reviewed related to chronic conditions as a disparity One relevant article in the for 20 reviewed related to chronic conditions as a disparity	
Scopus	Multimorbidity AND Culture OR Ethnicity	36	4	Case Studies/ Not within specified countries
Sociology Source Ultimate	Chronic Conditions OR Chronic Disease AND Disparity	150	4	Single Disease Focus/ Not within specified countries
TOTAL		319	16	

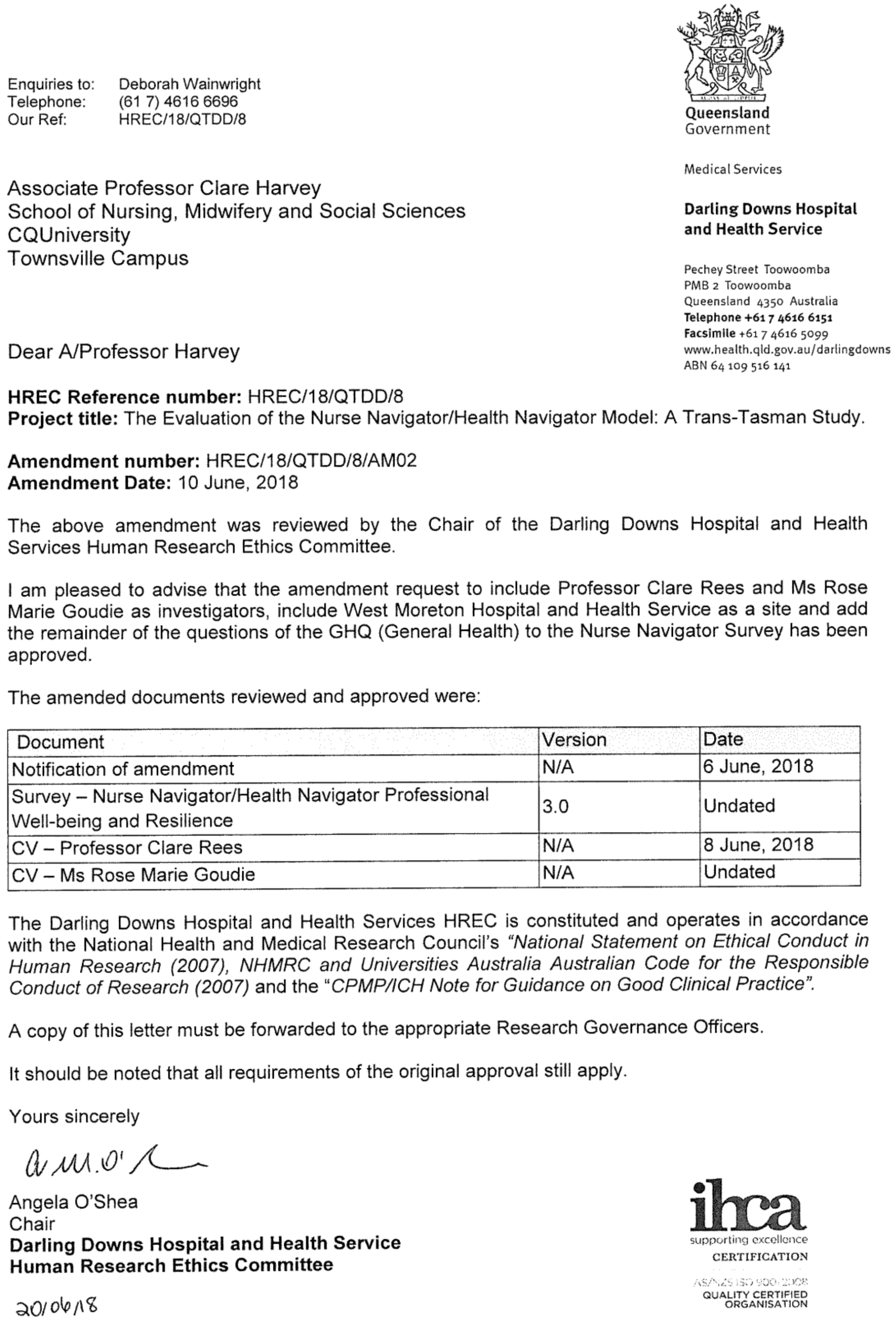
Appendix One: Publications Table

Article Reference	Study Focus	Study Population	Outcomes	Relevance to Disparity
Avendano, M., Mackenbach, J. P., Glymour, M. M., & Banks, J. (2009). Health Disadvantage in US and Adults Aged 50 to 74 years: A Comparison of the Health of Rich and Poor Americans With That of Europeans. *American journal of public health, 99*(3), 540-548. doi:10.2105/AJPH.2008.139469	Comparison of health outcomes for 6 chronic diseases between Americans, Europeans and English.	Phone interviews with 9940 participants aged 50 to 74 year. Data from the 2004 US Health and Retirement Survey (HRS); the 2004 Survey of Health, Ageing and Retirement in Europe (SHARE); and the 2004 English Longitudinal Study of Ageing (ELSA) was used to identify participants.	Americans are less healthy than European and English counterparts across all wealth levels. Health disparities related to wealth are less prominent in Europe compared to Americans. Poor Americans experience worse health disparity. For all populations lower wealth was associated with smoking, alcohol use and lack of physical exercise	Health disparity in America is inversely related to wealth. Americans are less healthy across major chronic conditions. Poorer people in all continents were associate with increased health risk behaviours.
Davis, J., Penha, J., Mbowe, O., & Taira, D. A. (2017). Prevalence of Single and Multiple Leading Causes of Death by Race/Ethnicity Among US Adults Aged 60 to 79 Years. *Preventing Chronic Disease, 14,* E101. doi:10.5888/pcd14.160241	Study racial/ethnic differences in prevalence of cardiac, diabetes, respiratory and cancer as cause of death in older adults	USA residents aged 60-79 years using the National Health Interview Survey for 2006 with 56, 290 participants identified.	Hispanic and Non-Hispanic Black people had higher prevalence of diabetes and cardiac with non-Hispanic white people with higher prevalence of respiratory and cancer. Ethnicity related multimorbidity in an individual varied less across ethnic groups. There was an inverse relationship between multimorbidity and education status.	Disparity linked to strong racial/ethnic differences noted for single disease conditions, but this was less prevalent in the multimorbidity
Grabovschi, C., Loignon, C., & Fortin, M. (2013). Mapping the concept of vulnerability related to health care disparities: a scoping review. *BMC Health Services Research, 13*, 94. doi:http://dx.doi.org/10.1186/1472-6963-13-94	Studied the relationship of health disparity with the multiple factors the create vulnerability through a scoping review of the literature related to phenomenon of 'inverse care law'	759 reference identified with 23 related to the review	Multiple vulnerability factors present for an individual increase health care needs and are associated to lower health care accessibility and quality. Top ranking factors included poverty, ethnic minority groups, old age, lack of insurance and chronic conditions. There is a lack of research on the relationship between multiple vulnerability factors and health disparity	People with multiple vulnerability factors are more likely to experience health disparity.
Hill, K., Ward, P., Grace, B. S., & Gleadle, J. (2017). Social disparities in the prevalence of diabetes in Australia and in the development of end stage renal disease due to diabetes for Aboriginal and Torres Strait Islanders in Australia and Māori and Pacific Islanders in New Zealand. *BMC Public Health, 17,* 1-8. doi:10.1186/s12889-017-4807-5	To study the prevalence of Type One Diabetes in Australia associated with socioeconomic status. To re-examine Type one related end stage kidney disease for the most social deprived vulnerable minority populations including Aboriginal, Torres Strait, Māori and Pacific Island.	Observational study from secondary analysis of existing data from 534 records from New Zealand data using an ecology design	There was a strong inverse relationship demonstrated between lower socio disadvantaged populations and prevalence of disease. Being in an ethnic minority population and from low socioeconomic areas is independently associated with poor outcomes. This has not changed over 20 years	Ethnicity and low socioeconomic status is strongly associated with disparity in the New Zealand and Australian populations.
Jackson, B. E., Oates, G. R., Singh, K. P., Shikany, J. M., Fouad, M. N., Partridge, E. E., & Bae, S. (2017). Disparities in chronic medical conditions in the Mid-South. *Ethnicity & Health, 22*(2), 196-208. doi:10.1080/13557858.2016.1232805	Studied differences in socio-demographic characteristics and health behaviours related to chronic medical conditions in the Mid-South region of the USA. and	Cross sectional analysis of data from 2013 Behavioural Risk Factor Surveillance System involving 4,303 respondents contacted by phone	Black people had the worse overall association of health conditions and low socioeconomic characteristics with poor outcomes	Strong association of ethnicity and socioeconomic status creating poor health outcomes creating disparity.

	identified subpopulations with increased burden of chronic disease.			
Johnson-Lawrence, V., Zajacova, A., & Sneed, R. (2017). Education, race/ethnicity, and multimorbidity among adults aged 30–64 in the National Health Interview Survey. *SSM - Population Health, 3*, 366-372. doi:https://doi.org/10.1016/j.ssmph.2017.03.007	To understand the relationship between education and race/ethnicity with mutimorbidity.	11,5094 participants. USA adults aged 30–64 using cross-sectional data from the 2002–2014 National Health Interview Surveys.	Non-Hispanic blacks had higher multimorbidity compared to Non-Hispanic Whites. Lower educational accomplishments were associated with increased odds of multimorbidity. This outcome persisted despite age, marriage status, gender and race	Disparity created by lower education levels associated with lower socioeconomic/demographic status may result in poorer health practices and development of chronic disease.
Laditka, J. N., & Laditka, S. B. (2006). Race, Ethnicity and Hospitalization for Six Chronic Ambulatory Care Sensitive Conditions in the USA. *Ethnicity & Health, 11*(3), 247-263. doi:10.1080/13557850600565640	To study the association between 6 prominent chronic diseases, preventable hospitalisation and impact of race and ethnicity	1,782,240 records from hospital discharge data from the 1997 Nationwide Inpatient Sample (NIS), from the Health Care Cost and Utilization Project (AHRQ 2002). States included Arizona, California, Colorado, Connecticut, Florida, Iowa, Maryland, Massachusetts, Missouri, New Jersey, New York, Pennsylvania, Utah and Wisconsin	African Americans and Hispanics compared to non-Hispanic white people had higher preventable hospitalisations for most conditions after control for disease prevalence, notable in preventable conditions such as asthma, hypertension and diabetes	Ethnicity creates a disparity for risk of hospitalisation relating to preventable causes.
Lebrun, L. A., & Laveist, T. A. (2013). Health Status among Black Canadians: Results from a National Survey. *Canadian Ethnic Studies, 45*(1/2), 143-155.	Comparison of Nationally represented health indicators between Canadian Black people and White people	Records from the Canadian Community Health Survey included 729 native-born Blacks and 280,672 native-born Whites aged 18 years and over with comparison of socio economic, health behaviours and outcome factors. Health indicators were self-reported.	They found the Black Native-born Canadians had lower odds for smoking, cardiac disease and cancer than their white counterparts with no statistically significant difference in other health indicators. These outcomes were at odds with other surveys from different regions in Canada. Self-reporting of health disease may have affected these results.	Reverse disparity was seen in this study which is at odds with other studies. There was no comparison drawn to other known causes of disparity. Self-reporting may not be a fair representation of disparity.
Markwick, A., Ansari, Z., Sullivan, M., Parsons, L., & McNeil, J. (2014). Inequalities in the social determinants of health of Aboriginal and Torres Strait Islander People: a cross-sectional population-based study in the Australian state of Victoria. *International Journal for Equity in Health, 13*(1), 91. doi:10.1186/s12939-014-0091-5	To identify the determinants of health for Aboriginal and Torres Strait populations of Victoria Australia in comparison to Non-Aboriginal	Data from Victorian Population Health Survey 2008 using Cross sectional computer assisted Telephone interviews with 34,168 random selected adults	There was a higher prevalence of social determinants associated with moving frequently, lower household incomes and employment rates with a poor impact on health status creating inequity. Racism was evident in lack of trust. Aboriginal who use mainstream health services are less likely to receive same quality of care as non-aboriginal	Disparity is created in this population by relationships effected by trust, ability to receive equal quality of care and social determinants that include stable homes, income and employment.
Northwood, M., Ploeg, J., Markle-Reid, M., & Sherifali, D. (2018). Integrative review of the social determinants of health in older adults with multimorbidity. *Journal of Advanced Nursing, 74*(1), 45-60. doi:10.1111/jan.13408	To review how social determinants of health has been conceptualised in relation to multimorbidity in older adults within the literature and implications for nursing practice	Search of electronic databases over a 15-year period identified 33 relevant articles	There is limited evidence of the consideration of the complex association of multimorbidity and the social determinants of health. Gender, education and health system design were prominent with little evidence around ethnicity, income and social standing. Multimorbidity seen as medical problem rather than social	There is a mismatch between the needs of the multimorbid older adult and health delivery creating disparity in this population through lack of understanding
Stanley, J., Semper, K., Millar, E., & Sarfati, D. (2018). Epidemiology of multimorbidity in New Zealand: A cross-sectional study using	Compare prevalence of Multimorbidity in New Zealand	All New Zealand adult population with NHI based on National Level health data from discharge summaries and pharmaceutical dispensing using 61 ICD-10 coded	Higher prevalence of multimorbidity in Māori and Pacific populations esp in younger patients with increased risk of subsequent hospitalisation in older patients. Some evidence	Inequity considerations for Multimorbid across ethnicity and socioeconomic factors. Māori and Pacific living in low socio demographic areas are more at risk of adverse events and

national-level hospital and pharmaceutical data. *BMJ Open, 8*(5). doi:10.1136/bmjopen-2018-021689	adult population and compare risk of health outcomes	diagnoses from the M3 multimorbidity index); and recent pharmaceutical dispensing records (30 conditions from the P3 multimorbidity index).	of prevalence of multimorbidity equalising across ethnicity and sociodemographic status with increasing age. Prevalence was higher across socioeconomic deprived areas with consistent pattern across age groups	hospitalisation. Multi morbidity needs consideration in healthcare design with a move away from single disease management
Stokes, T., Tumilty, E., Doolan-Noble, F., & Gauld, R. (2017). Multimorbidity, clinical decision making and health care delivery in New Zealand Primary care: a qualitative study. *BMC family practice, 18*(1), 51-51. doi:10.1186/s12875-017-0622-4	Exploration of GP, Practice Nurse and Nurse Practitioners experience of managing multi morbidity in New Zealand	Qualitative study – 16 semi structured interviews with GP, Practice Nurse and Nurse Practitioners in the Otago Region	Barriers in clinical decision making and health care delivery with guidelines that are single disease focused. Lack of time to deal with complexity of multimorbidity. Compromises on achieving best practice targets for disease management. Need to make Care Plus flexible and doesn't necessarily capture those who most need it with multiple conditions. Fragmentation of care in primary care and across secondary care sectors	Barriers experienced by primary care professionals increased disparity of multimorbid.
Thavorn, K., Maxwell, C. J., Gruneir, A., Bronskill, S. E., Bai, Y., Koné Pefoyo, A. J., . . . Wodchis, W. P. (2017). Effect of socio-demographic factors on the association between multimorbidity and healthcare costs: a population-based, retrospective cohort study. *BMJ Open, 7*(10). doi:http://dx.doi.org/10.1136/bmjopen-2017-017264	To estimate the cost of multimorbidity associated with sociodemographic factors in young and older Ontarians. (<65 years and <65years)	Population based retrospective cohort study of 6,639,089 residing in Ontario diagnosed with =/> one chronic condition	There was a higher cost related to over 65-year groups and women. There was an association between higher health care cost and multimorbidity with higher levels of marginalised populations that included areas of instability, dependency and ethnic concentration	Disparity can be seen as related to high health care costs in marginalised ethnic groups and older age effecting more woman.
Three articles from the original search based in the New Zealand and Australian context where discarded. Though they discussed multimorbidity and disparity, they were discussion articles only and did not feature original research. Therefore, I chose not to include them.				

Appendix Two: Queensland Ethics Approval - HREC/18/QTTD/8



Queensland
Government

Medical Services

**Darling Downs Hospital
and Health Service**

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ABN 64 109 516 141

Enquiries to: Deborah Wainwright
Telephone: (61 7) 4616 6696
Our Ref: HREC/18/QTDD/8

Associate Professor Clare Harvey
School of Nursing, Midwifery and Social Sciences
CQUniversity
Townsville Campus

Dear A/Professor Harvey

HREC Reference number: HREC/18/QTDD/8
Project title: The Evaluation of the Nurse Navigator/Health Navigator Model: A Trans-Tasman Study.

Amendment number: HREC/18/QTDD/8/AM02
Amendment Date: 10 June, 2018

The above amendment was reviewed by the Chair of the Darling Downs Hospital and Health Services Human Research Ethics Committee.

I am pleased to advise that the amendment request to include Professor Clare Rees and Ms Rose Marie Goudie as investigators, include West Moreton Hospital and Health Service as a site and add the remainder of the questions of the GHQ (General Health) to the Nurse Navigator Survey has been approved.

The amended documents reviewed and approved were:

Document	Version	Date
Notification of amendment	N/A	6 June, 2018
Survey – Nurse Navigator/Health Navigator Professional Well-being and Resilience	3.0	Undated
CV – Professor Clare Rees	N/A	8 June, 2018
CV – Ms Rose Marie Goudie	N/A	Undated

The Darling Downs Hospital and Health Services HREC is constituted and operates in accordance with the National Health and Medical Research Council's *"National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the "*CPMP/ICH Note for Guidance on Good Clinical Practice*".

A copy of this letter must be forwarded to the appropriate Research Governance Officers.

It should be noted that all requirements of the original approval still apply.

Yours sincerely

Angela O'Shea
Chair
Darling Downs Hospital and Health Service
Human Research Ethics Committee

20/06/18

Appendix Two: NZ Health and Disability Ethics

20/CEN/214

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington

6011

0800
4 ETHICS
hdecs@health.govt.nz

22 January 2021

Mrs Janine Palmer

[redacted]

[redacted]

Dear Mrs Palmer

Re:	**Ethics ref:**	**20/CEN/214**
	Study title:	Examining the characteristics of multimorbidity as a uniquely disparate population group in Health Care

I am pleased to advise that this application has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.

2. Before the study commences at *each given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your next progress report is due by 21 January 2022.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

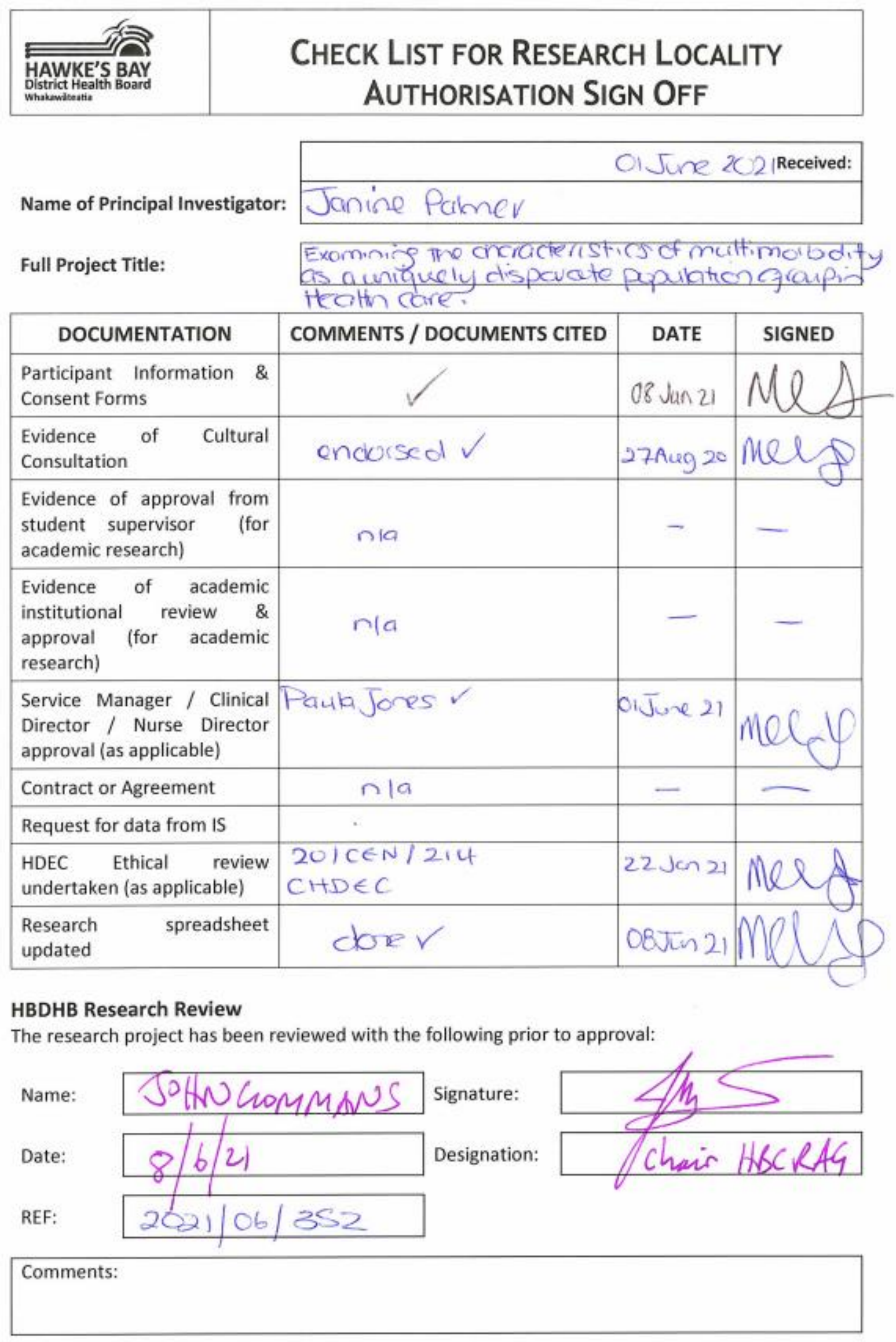
Mrs Helen Walker

Chairperson

Central Health and Disability Ethics Committee

Appendix Two: Localities Ethics

a) Examining the Characteristics of Multimorbidity as a unique disparity in healthcare



HAWKE'S BAY
District Health Board
Whakawāteatia

CHECK LIST FOR RESEARCH LOCALITY AUTHORISATION SIGN OFF

Received: 01 June 2021

Name of Principal Investigator: Janine Palmer

Full Project Title: Examining the characteristics of multimorbidity as a uniquely disparate population group in health care.

DOCUMENTATION	COMMENTS / DOCUMENTS CITED	DATE	SIGNED
Participant Information & Consent Forms	✓	08 Jun 21	
Evidence of Cultural Consultation	endorsed ✓	27 Aug 20	
Evidence of approval from student supervisor (for academic research)	n/a	–	–
Evidence of academic institutional review & approval (for academic research)	n/a	–	–
Service Manager / Clinical Director / Nurse Director approval (as applicable)	Paula Jones ✓	01 June 21	
Contract or Agreement	n/a	–	–
Request for data from IS			
HDEC Ethical review undertaken (as applicable)	20/CEN/214 CHDEC	22 Jan 21	
Research spreadsheet updated	done ✓	08 Jun 21	

HBDHB Research Review

The research project has been reviewed with the following prior to approval:

Name: JOHN COMMANS

Signature:

Date: 8/6/21

Designation: Chair HBCRAG

REF: 2021/06/352

Comments:

b) ACTLIFE

HAWKE'S BAY
District Health Board
Whakawāteatia

CHECK LIST FOR RESEARCH LOCALITY AUTHORISATION SIGN OFF

Received: 01 June 2021

Name of Principal Investigator: Janine Palmer

Full Project Title: Case Study of a Healthy Lifestyle Programme. Supporting lifestyle change & vocational rehab for a young man living c̄ chronic & complex conditions

DOCUMENTATION	COMMENTS / DOCUMENTS CITED	DATE	SIGNED
Participant Information & Consent Forms	n/a	—	—
Evidence of Cultural Consultation	✓ gained endorsement.	07 Apr 21	Mel
Evidence of approval from student supervisor (for academic research)	n/a	—	—
Evidence of academic institutional review & approval (for academic research)	n/a	—	—
Service Manager / Clinical Director / Nurse Director approval (as applicable)	Paula Jones ✓	01 Jun 21	Mel
Contract or Agreement	n/a	—	—
Request for data from IS	not required	—	—
HDEC Ethical review undertaken (as applicable)	HDEC letter ethics not required	14 Jun 21	Mel
Research spreadsheet updated	done ✓	08 Jun 21	Mel

HBDHB Research Review

The research project has been reviewed with the following prior to approval:

Name: John LOMMANS
Signature:
Date: 8/6/21
Designation: Chair HBCRAG
REF: 2021/06/352

Comments:

Appendix Three: QoL - Flannagan's QoL Survey

INSTRUCTIONS FOR SCORING THE QUALITY OF LIFE SCALE

This form of the Quality of **Life Scale (QOLS) has** 16 items rather than the 15 found in the original Flanagan version. Item #16, "Independence, doing for yourself" was added after a qualitative study indicated that the instrument had content validity in chronic illness groups but that it needed an item that reflected the importance to these people of remaining independent and able to care for themselves.

The instrument is scored by summing the items to make a total score. Subjects should be encouraged to fill out every item even if they are not currently engaged in it. (e.g. they can be satisfied even if they do not currently participate in organizations. Or they can be satisfied about not having children.) Missing data can be treated by entering the mean score for the item.

If you wish to compare scores in your groups with any scores that have been published, please be aware that most of the Burckhardt references published so far use the 15 item scale. More recent and forthcoming publications all use the 16 item scale. So be sure to check the methods section of the reference before comparing your means to published ones.

If you have further questions, please write to me or call.

Carol S. Burakhardt, PhD, RN
Professor of Mental Health Nursing
School of Nursing - SNMH
Oregon Health Sciences University
3181 SW Sam Jackson Park Road
Portland, OR 97201-3098

phone - (503) 494-3895
FAX - (503) 494-3691
e-mail - burckhac@ohsu.edu

References

Burckhardt CS, Woods SL, Schultz AA, Ziebarth DM (1989). Quality of life of adults with chronic illness: A psychometric study. Research in Nursina and Health, 12, 347-354.

Burckhardt, CS, Clark SR, Bennett RM (1993). Fibromyalgia and quality of life: A comparative analysis. Journal of Rheumatology, 20, 475-479.

Flanagan JC (1978). A research approach to improving our quality of life. American Psychologist, 33, 138-147.

Flanagan JC (1982). Measurement of quality of life: Current state of the art. Archives of Physical Medicine and Rehabilitation, 63, 56-59.

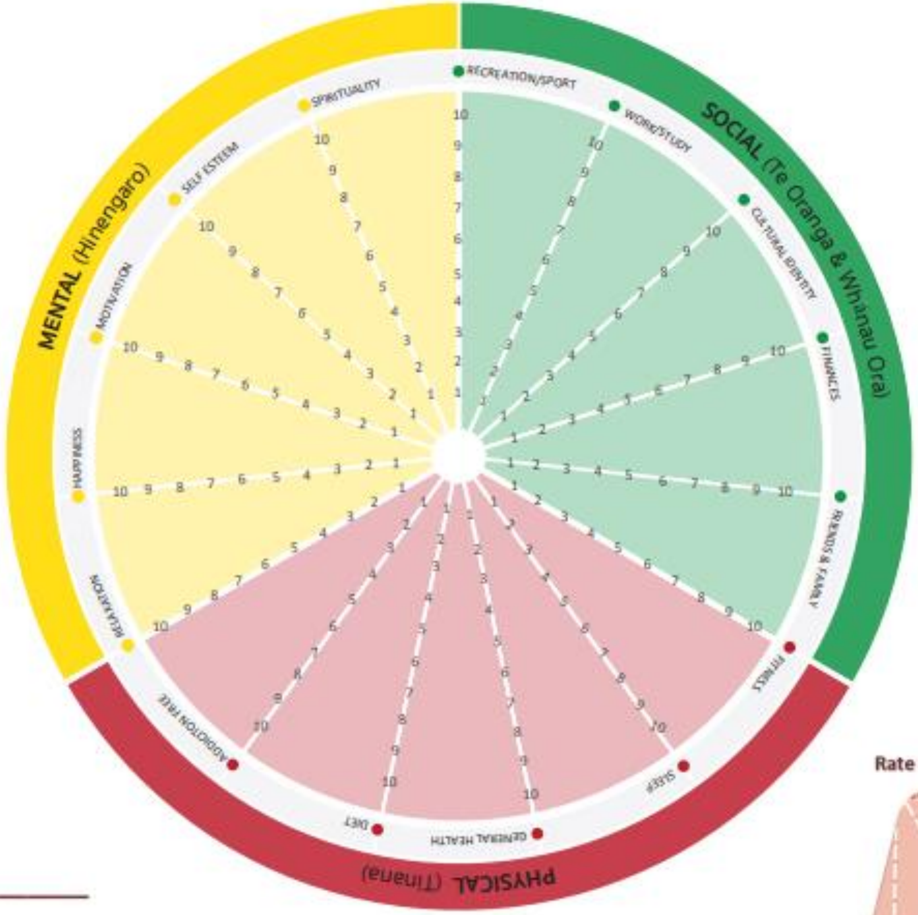
QUALITY OF LIFE SCALE (QOL)

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

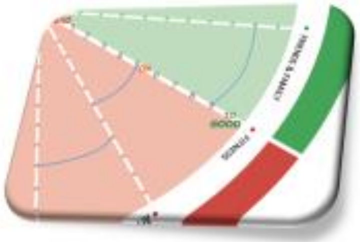
	Delighted	Pleased	Mostly Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
1. Material comforts home, food, conveniences, financial security	7	6	5	4	3	2	1
2. Health - being physically fit and vigorous	7	6	5	4	3	2	1
3. Relationships with parents, siblings & other relatives- communicating, visiting, helping	7	6	5	4	3	2	1
4. Having and rearing children	7	6	5	4	3	2	1
5. Close relationships with spouse or significant other	7	6	5	4	3	2	1
6. Close friends	7	6	5	4	3	2	1
7. Helping and encouraging others, volunteering, giving advice	7	6	5	4	3	2	1
8. Participating in organizations and public affairs	7	6	5	4	3	2	1
9. Learning- attending school, improving understanding, getting additional knowledge	7	6	5	4	3	2	1
10. Understanding yourself - knowing your assets and limitations - knowing what life is about	7	6	5	4	3	2	1
11. Work - job or in home	7	6	5	4	3	2	1
12. Expressing yourself creatively	7	6	5	4	3	2	1
13. Socializing - meeting other people, doing things, parties, etc	7	6	5	4	3	2	1
14. Reading, listening to music, or observing entertainment	7	6	5	4	3	2	1
15. Participating in active recreation	7	6	5	4	3	2	1
16. Independence, doing for yourself	7	6	5	4	3	2	1

Appendix Three: Meke Meter

The MEKE meter!™



Rate each section and draw a line across it



Name: ____________________

Date: ____________________

Used with permission.

Appendix Four: Consent Form

Renal Services

Participant Information Sheet

Study title:	**‘Examining the characteristics of multimorbidity as a uniquely disparate population group in Health Care’**		
Locality:	**Hastings Hospital, Hawke’s Bay, HBDHB, New Zealand**		
Lead investigator:	**Janine Palmer, Nurse Practitioner** **Renal Service HBDHB.**	Contact phone number:	**06 878 1622 /** **0272260281**
Principal Supervisor:	**Dr Clare Harvey PhD** **Central Queensland University**		
Associate Supervisor:	**Dr Shona Thompson, PhD**		

Please let us know if you need an interpreter.

You are invited to take part in a study to help us understand what the effects of living with multiple medical conditions has on your everyday life and how this affects you. In health, the combination of these multiple medical conditions is also known as multimorbidity, chronic conditions or long-term conditions.

This invitation has 6 pages that includes the Participation Information Sheet and a consent form. The Participant Information Sheet will help you decide if you would like to take part. You do not have to take part in this study if you do not wish to. It is your choice to participate in the study. If you do not want to take part, you do not have to give a reason, and it will not affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time without having to explain why and it will not affect the care you receive.

It sets out why we are doing the study, how you will be involved, what the benefits and risks to you might be, and what would happen after the study ends. I will go through this information with you and answer any questions you may have. You do not have to decide today whether you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. If you are unhappy to have your information collected and stored for the purposes of the study, you will not be able to participate in the study.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to help health professionals such as nurses and doctors, who care for patients who have many medical conditions at the same time, to understand how this affects you and your ability to live your life. Some of these medical conditions may include, kidney disease, diabetes, heart conditions, breathing conditions, pain, depression, and anxiety as well as many other health problems.

We are also interested in how this affects people from different cultures and ethnicities and if there are any differences or other concerns, we need to be aware of.

It is my hope that this study will help health professionals such as doctors and nurses, to understand what works best for you in the health system and if, how and what we may need to change in the health system for this to improve how we care for you.

There is no financial funding associated with this study.

The study has been approved by the following ethics committees:

HBDHB ethics committee, Māori Health Unit and Pacific Health Unit

Central Queensland University Human and Ethics Research Committee Project # xxx

New Zealand health and disability ethics committee (HDEC) .

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been asked to participate in this study because you are a patient of the Renal Service at Hastings Hospital and have several medical conditions.

There are two ways in which you could participate in the study.

The first part of the study does not require anything of you, other than your consent to access information from any hospital admissions you may have had in the last year. This is to gain an understanding of how many times you may have been in hospital, for how many days and the number of appointments at the hospital you may need to go to. We will also use this information and compare this to people with similar conditions in Cairns, Queensland Australia. We are comparing this with people in Cairns to gain an understanding of different ethnic groups and cultures and to be able to look at a much larger number of people.

The second part of the study is to invite you to a hui (meeting), with the lead investigator (Janine Palmer) to talk about how these conditions affect you and what it has been like for you.

You are able to bring along any support person to help you, such as whanau or friend, and a support person from Māori Health, Pacific Island Health Unit or any other cultural support you may feel you need.

You can attend a hui (meeting) in either a group with other participants or as a meeting with just yourself and the lead investigator.

Attendance at a hui (meeting with others) may take up to 2 hours and about one hour for an individual meet.

The all meetings with the lead investigator will be recorded and transcribed. You will be offered the opportunity to review the typed record that relates to your interview to ensure it is correct.

Participating in this study will not affect any care you are currently receiving from the Renal Service or hospital.

The results of this study will be used by the lead investigator to complete a degree called Doctor of Philosophy and will also be published in health journals and in conference presentations to help other health professionals in their understanding of caring for people with multiple health conditions. Your experience/information will not be able to be recognised or identified in these publications or presentations.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

There may not be any benefit to you personally being involved in this study. The benefits of participating in the study will be to help health professionals understand how to improve the care we provide to you. This may help the people who provide money and funding to health services, to understand any changes we may need to make within the health system.

The risk may include the inconvenience of coming to a meeting with the lead investigator. Talking about how your health affects you may also be emotional for you and could make you unhappy or sad. If this happens, we have a psychologist and a social worker we can refer you to for help with this.

You are also invited to bring a whānua member or friend and a cultural support person to support you.

Being involved in this study should not affect your family or whānau.

If at any time you are unhappy with being a part of the hui or meeting, you will be able to stop. Information gathered from you or your experiences may still be included in the study but you will not be able to be identified.

WHAT WILL HAPPEN TO MY INFORMATION?

During the Study, your identifiable information is held by the Lead Investigator and will be stored in a locked facility at the Renal Service at Hastings Hospital and also in the secure online data base known as 'the Cloud' managed by Central Queensland University. After the study it is transferred to a secure archiving site at Central Queensland University and stored for at least 15 years, then destroyed. Your coded information will be entered into electronic case report forms and sent through a secure server to the sponsor. Coded study information will be kept by the sponsor in secure, cloud-based storage. All storage will comply with local and/or international data security guidelines.

An approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative may want to review your relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study. This is part of ensuring the study is being conducted correctly and safely.

WHO PAYS FOR THE STUDY?

Your participation in this study will not incur any cost to you. If you agree to come to a meeting, we will provide a petrol voucher to help with the cost of coming to the meeting.

This study is being supported by Central Queensland University and Hawkes Bay District Health Board.

WHAT ARE MY RIGHTS?

It is your choice to participate in the study. If you do not want to take part, you do not have to give a reason, and it will not affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time without having to explain why and it will not affect the care you receive.

You have the right to access the information we have collected about you in the study at any time.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

All information provided to the investigator will be kept confidential. Your information may be included in a larger study between New Zealand and Australia on people with multiple health conditions, but you will not be able to be identified in any other study. You will be identified by a unique study number that only the lead investigator will know belongs to you. Your information from the study will be kept for up to fifteen years locked in a secure place.

The information gathered could be used for future presentations or publications and you will not be able to be identified in these publications or presentations.

Once you have completed the study, you will receive written notification that the study is finished. The study findings will be made available to you within six months of completing the study if you wish to have a copy of this.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns, or complaints about the study at any stage, you can contact:

Investigator:	Janine Palmer
Position:	Nurse Practitioner
Locations:	Renal Service, Hastings Hospital, Hawkes Bay DHB
Telephone number:	06 878 1622 / 0272260218
Email:	janine.palmer@hawkesbaydhb.govt.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone:	0800 555 050
Fax:	0800 2 SUPPORT (0800 2787 7678)
Email:	advocacy@hdc.org.nz

For Māori health support please contact :

Name: Māori Health Unit

Telephone number: 06 878 8109 ext 5779

Email: admin.maorihealth@hbdhb.govt.nz

For Pacific health support please contact:

Name: Pacific Health Unit

Telephone number: 06 878 8109 ext 2412

You can also contact the Hawkes Bay District Health Board Research Unit if you have any questions or concerns:

Phone: 068788109 ext 6628

Appendix Four: Renal Services   Consent Form

If you need an INTERPRETER, please tell us.
If you are unable to provide interpreters for the study, please clearly state this in the Participant Information Sheet

Please tick to indicate you consent to the following and sign the form at the bottom of the page and tick the boxes to indicate you agreement with the following:

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.		
I have been given sufficient time to consider whether or not to participate in this study.		
I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study.		
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.		
I consent to the research staff collecting and processing my information, including information about my health. If you tick no, you will not be able to participate in the study.	Yes ☐	No ☐
If I decide to withdraw from the study, I understand that the information collected about me up to the point when I withdraw may continue to be processed if I am happy for that to happen		
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	Yes ☐	No ☐

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
I know who to contact if I have any questions about the study in general.		
I understand my responsibilities as a study participant.		
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:

I hereby consent to take part in this study.

Participant’s name:

Signature: Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant and have answered the participant’s questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher’s name:

Signature: Date:

Appendix Four: Participant Invitation Flyer

Invitation to Join a Research Study

Living with Multiple Medical Conditions

The study is being run by Janine Palmer, Nurse Practitioner, in the Renal Service.

I am interested in understanding your experience in living with multiple medical conditions and what makes things harder, or easier for you.

Your involvement would include meeting with a researcher to talk about your experience. This would take about an hour. Your information will be kept private.

If you are interested in being a part of this study, please let the reception staff at the Renal Clinic know. They will take your phone number and Janine will contact you to talk about what is involved.

Appendix Four: Semi Structured Interview Questions

Renal Services
Participant Interview Questions

Study title: **'Examining the characteristics of multimorbidity as a uniquely disparate population group in Health Care'**

Locality: **Hastings Hospital, Hawke's Bay, HBDHB, New Zealand**

Lead investigator: **Janine Palmer, Nurse Practitioner**

Renal Service HBDHB.

Contact phone number: **06 878 1622 / 0272260281**

Principal Supervisor: **Dr Clare Harvey PhD**

Central Queensland University

Associate Supervisor: **Dr Shona Thompson, PhD**

---

1. How does your health conditions affect your everyday life?
2. What do you struggle with the most?
3. In the last year when dealing with doctors and nurses for your health conditions, what has been good about this?
   What has been bad about this?
4. If you could change something about how your health conditions are managed by doctors and nurses, what would you change and why?
5. What other things make living with your health condition good or bad?

Appendix Five: Triage Analysis

Triage analysis

The purpose of this analysis is to identify the utilisation of ED services as an indication of need for care. Triage categorises are used to identify emergent or immediately life-threatening need for care as indicated by Triage one and two (time critical), Urgent care (potentially life-threatening with adverse outcomes from delay) indicated by Triage 3 and non-urgent care (potentially serious or complex) indicated by 190 Triage 4, with Routine care (less urgent or administrative issues) indicated by Triage 5 (Australasian College for Emergency Medicine, 2016). Due to the low number of presentations in Triage 1 and to enable the model to work, Triage 1 and 2 have been combined and is presented by Triage 2. The data looks at whether there are differences between the proportion of visits within each triage category presenting to the ED in renal patients with higher care needs (i.e., one or previous hospital admissions) and renal patients presenting to the ED with no history of hospitalisation (hospitalisation infers admission). Renal patients who do not have a history of hospital admission (as a proxy of level of care) could potentially be accessing primary care first and if presenting to the ED would either not differ from expected values or present with more urgent care requirements as indicated by triage codes (<3). The null hypothesis and alternative hypothesis therefore are given as follows:

Null Hypothesis (H0): There is no significant difference in the expected and observed distribution of patients across triage categories (Triage 2, Triage 3, Triage 4, and Triage 5) for cohort groups (EDpresent and Admit) in their presentation to the emergency department.

Alternative Hypothesis (HA): There is a significant difference in the expected and observed distribution of patients across triage categories (Triage 2, Triage 3, Triage 4, and Triage 5) for cohort groups (EDpresent and Admit) in their presentation to the emergency department.

ED presentation was collected from **294 renal patients**, categorized into two subset groups (EDpresent n = 91 and Admit n= 201) based on their triage assessment. **A total of 702 ED** visits were recorded (Table A). A chi-square test of homogeneity was run, to compare the multinomial probability distributions of the triage codes of the two subset groups. Post hoc analysis involving pairwise comparisons using multiple z-tests of two proportions with a Bonferroni correction was applied to take into account multiple comparisons (i.e., multiple z-test of two proportions). Statistical significance was accepted at $p < .0125$ (Leard Statistics, 2017). Odds ratios were calculated to measure the effect size of significant variables. Bayes factor was used to provide an indication of the probability of the data under the null hypothesis relative to the alternative. Dividing 1 by the Bayes factor reported in SPSS provides an indication of the probability of the data under the alternative hypothesis relative to the null. Values greater than 1 support the alternative hypothesis, with values greater than 3 indicating a change in beliefs that has substance (Field, 2013, p. 862).

Table A

*Triage Code * cohort group Crosstabulation*

	Cohort group		
Triage Code	**EDpresent**	**Admitgp**	**Total**
Triage <2			
Count	12a	122b	134
% within cohort group	8.40%	21.80%	19.10%
Triage 3			
Count	53a	261b	314
% within cohort group	37.10%	46.70%	44.70%
Triage 4			
Count	66a	1 55b	221
% within cohort group	46.20%	27.70%	31.50%
Triage 5			
Count	12a	21b	33
% within cohort group	8.40%	3.80%	4.70%
Total			
Count	143	559	702
% within cohort group	100.00%	100.00%	100.00%

Each subscript letter denotes a subset of cohort group categories whose column proportions do not differ significantly from each other at the .05 level.

Results

A chi-square test of homogeneity was run, with an adequate sample size established according to Cochran (1954). The two multinomial probability distributions of triage codes for each subset group were not equal in the population, $\chi^2(3) = 30.608$, $p < .001$. The Bayes factor strongly supports the alternative hypothesis, $BF_{01} = 13454$. Observed frequencies and percentages of the triage codes recorded for each renal subset are presented in Table 13.

There was a statistically significant difference in the proportion of visits in the group 2 with a Triage code of 4 than observed in the group 3 (n = 66, 46.2% versus n = 155, 27.2%), p < 0.125. A significant difference was also found in the proportion of visits coded as Triage <2 within the group 3 than the group 2 (n = 122, 21.8% versus n = 12, 8.4%), p < .0125. The odds of a visit being coded as Triage 4 in the group 2 (versus the group 3) is approximately 2.21 times higher. Whereas, the odds of a visit being coded Triage 2 in the group 3 (versus the group 2) is approximately 3.0 times higher.

There were no statistically significant differences in the proportion of visits with Triage code 3 in the group 2 than the group 3 (n = 53, 37.1% versus n = 261, 46.7%), or the proportion of visits with Triage code 5 in the group 2 than the group 3 (n = 12, 8.4% versus n = 21, 3.8%), p > .0125.

Appendix Five: LOS Analysis Using Negative Binomial Regression with Robust Estimations

Multivariate analysis and specifically a negative binomial regression is used as it offers several advantages over univariate analysis when considering multiple independent variables on the dependent variable. It allows for the consideration of interactions, controls for confounding factors, improves precision and predictive power, allows for the identification of independent effects of each variable on the dependent variable, while controlling for the effects of other variables, and provides a more comprehensive understanding of the relationships between variables (Chebana & Ouarda, 2011, Winkelmann, 2000).

Methods

The dataset comprises hospital records for 201 patients including the dependent variable "AdSumLoS_Days,". Hospital length of stay is defined as the total number of days a patient has spent in hospital over the one-year study period. A negative binomial regression model with a log link function and robust estimates was used to estimate the influence of predictor patient variables on the days hospitalised. The choice of a negative binomial regression model was due to evidence of overdispersion (variance greater than the mean) in the count data with a Poisson regression model (Weaver et al., 2015). Robust estimates were used to mitigate potential violations of the assumption of homoscedasticity (Kenne Pagui et al., 2022; Ingabire et al., 2022). Several categorical predictor variables were included in the model, including "Ethnic" (Ethnicity), "Age" (Age category), "Gender" (Gender M/F), "NzQuintile" (Socioeconomic Quintile 1-5), and "BSC" (Morbidity Count).

Due to low patient numbers in some categories of age and ethnicity the following aggregate categories have been used:

- Four age bands are represented: age band <25-44 (Age =2), age band 45-64 (Age = 3), age band – 65+ (Age= 4).

- Ethnicity represents the following ethnic groups: Māori and Pacifika, European and other.

To assess the presence of influential outliers, standardized deviance, leverage, and Cook's distance were used to examine residuals. On analysis three records were considered highly influential outliers and removed. Hospital records for 198 patients were included in the analysis. Model diagnostics are provided in Appendix Five.

The Model

The Akaike Information Criterion (AIC) was used to compare Poisson and negative binomial regression models and models including interactions (ethnicity and quintile; age and gender). The AIC for the model is a measure of model fit and parsimony, and the lower value indicates a better-fitting model. Given the data overdispersion, the negative binomial regression model (NBM) had a better fit than Poisson's model with an AIC value of 1148.695 compared to 1597.148 respectively. A comparison of the log likelihood ratio chi-square of the Poisson and NBM was also significant ($p<.001$) favouring the NBM.

The full NBM model containing predictors when compared to the intercept only model accounted for approximately 14% more of the variance. Together the predictors in the NBM model account for a significant amount of variance in the model (likelihood ratio $\chi2(13) = 139.283$ $p < .001$).

The Wald Chi-Square statistic assesses the significance of each predictor variable in the model (Table B). The predictor variables, "Age" and "BSC" show significant effects on the dependent variable "AdSumLoS_Days" ($p < 0.001$). However, variables such as "Ethnic", "Gender", and "NzQuintile" did not have significant effects on the length of stay ($p = .699$, $p = .167$, $p = .828$ respectively). The interaction effect of Age and Gender was also not significant ($p = .4386$). An interaction for ethnicity and quintile was not included in the model due to insufficient cell counts for reliable estimates.

Results

The results for the significant variables in the model are presented in the form of Incident Rate Ratios (IRR). The IRR (exp[B]) provide an intuitive interpretation of the effect size of the coefficients of the variables found to be significant in the model. The count of hospitalisation total days, while holding all other variables in the model constant, for each significant variable is as follows:

- Patients aged 65+ had a positive and significant influence (b = .696., se .2420, 95% CI .222 - 1.170, $p = 0.004$) on the count of the number of days hospitalised. The IRR indicates the number of days hospitalised is 2 times higher than the <25-44 age band (IRR = 2.006, 95% CI 1.248 - 3.223).
- Patients aged 44-64 had a positive and significant influence (b = .720, se 2634, 95% CI .203 - 1.236, $p = 0.006$) on the count of the number of days hospitalised. The IRR indicates that the number of days hospitalised is 2 times than the <25-44 age band (IRR =2.054, 95% CI 1.226 - 3.441).
- Patients with higher co-morbidity counts had a positive and significant influence on the count of the number of days hospitalised as follows:
  - 4 body systems count (b = 2.152, se .1707, 95% CI 1.819 - 2.488, $p < 0.001$). The IRR indicates that the number of days hospitalised is 8.6 times higher than those with one system count (IRR: 8.615, 95% CI 6.165 - 12.037);
  - 3 body systems count (b = 1.382 se .1753, 95% CI 1.014 - 1.765, $p < 0.001$). The IRR indicates that the number of days hospitalised is 3.9 times higher than those with one system count (IRR: 3.984, 95% CI 2.819 - 5.630, $p < 0.001$)
  - 2 body systems count (b = 1.178 se .1392, 95% CI .906 - 1.451). The IRR indicates that the number of days hospitalised is 3.2 times higher (IRR: 3.249, 95% CI 2.474 - 4.268, $p < 0.001$) than those with one system count.

Other variables including ethnicity, gender and quintile and the interaction of age and gender were not significant. However, there were some patterns of interest as follows:

- The beta coefficient for Europeans and other ethnicities was negative, but not significant, suggestive of less days hospitalised than Māori and Pacific (b -.056, s.e. = .1441, 95% CI -.338-.227, p = .699)
- The beta coefficient for Males was negative, but not significant, suggestive of less days hospitalised than Females (b -.141, s.e. = .2774, 95% CI -.684-.403, p = .612)
- The beta coefficients for both quintiles 4 and 5 were positive, but not significant, suggesting more days hospitalised than quintile 1 (b -.004, s.e. = .3457, 95% CI -.674-.681, p = .992 and b -.129, s.e. = .3257, 95% CI -.509-.768, p = .691)

- Whereas, both quintiles 3 and 2 were negative, but not significant, suggesting fewer days hospitalised than quintile 1 (b -.064, s.e. = .3569, 95% CI -.763-.636, p=.858 and b -.030, s.e. = .3277, 95% CI -.672-.612, p = .928)

The estimated marginal means provides an average of the number of days hospitalised (AdSumLoS_Days) for each level of the predictor variables while holding all other variables in the model constant. The overall estimated mean for the total number of days spent in hospital over the data capture period was 9.53 days (se .929, 95% CI 7.88 - 11.54) and for each variable~~s~~ as follows:

- Ethnicity:
  - Māori and Pacifika 9.27 days (SE = 1.209, 95% CI 7.18 - 11.97)
  - Other ethnicity 9.80 days (SE = 1.091, 95% CI 7.88 - 12.19)
- Age:
  - 65+ (age group 4) 12.81 days (SE = 1.498, 95% CI 10.18 - 16.11)
  - 45-64 (Age group 3) 11.15 days (SE = 1.498, 95% CI 8.57 - 14.51
  - <25-44 (Age group 2) 6.07 days (SE = .948, 95% CI 4.47 - 8.24)
- Gender:
  - Females 10.43 days (SE = 1.296, 95% CI 8.18 - 13.31)
  - Males 8.71 days (SE = .959, 95% CI 7.02 - 10.81)
- Quintile:
  - 5 is 10.77 days (SE = .945, 95% CI 9.06 - 12.79)
  - 4 is 9.49 days (SE = 1.354, 95% CI 7.18 - 12.55)
  - 3 is 8.88 days (SE = 1.606, 95% CI 6.23 - 12.65)
  - 2 is 9.18 days (SE = 1.602, 95% CI 6.50 - 12.97)
  - 1 is 9.46 days (SE = 3.013, 95% CI 5.07 - 1766)
- Body Systems Count:
  - 4 is 25.27 days (SE = 4.180, 95% CI 18.28 - 34.95)
  - 3 is 11.269 days (SE = 1.935, 95% CI 8.45 - 16.17)
  - 2 is 9.253 days (SE = 1.310, 95% CI 7.28 - 12.48)
  - 1 is 2.93 days (SE = .307, 95% CI 2.39 - 3.60)

Table B

Parameter Estimates

			95% Wald Confidence Interval		Hypothesis Test		95% Wald Confidence Interval for Exp(B)	
Parameter	B	Std. Error	Lower	Upper	Sig.	Exp(B)	Lower	Upper
(Intercept)	**0.715**	**0.3632**	0.003	1.426	**0.049**	**2.043**	**1.003**	**4.164**
[Age =4.00] 65+	0.696	0.2420	0.222	1.170	0.004	2.006	1.248	3.223
[Age =3.00] 45-64	0.720	0.2634	0.203	1.236	0.006	2.054	1.226	3.441
[Age =2.00] <25-44	0[a]					1		
[Ethnic =5.00]	-0.056	0.1441	-0.338	0.227	0.699	0.946	0.713	1.255
[Ethnic =3.00]	0[a]					1		
[Gender =2] Female	-0.141	0.2774	-0.684	0.403	0.612	0.869	0.504	1.497
[Gender =1] Male	0[a]					1		
[NzQuintile =5]	0.129	0.3257	-0.509	0.768	0.691	1.138	0.601	2.155
[NzQuintile =4]	0.004	0.3457	-0.674	0.681	0.992	1.004	0.510	1.976
[NzQuintile =3]	-0.064	0.3569	-0.763	0.636	0.858	0.938	0.466	1.889
[NzQuintile =2]	-0.030	0.3277	-0.672	0.612	0.928	0.971	0.511	1.845
[NzQuintile =1]	0[a]					1		
[BSC =4]	2.153	0.1707	1.819	2.488	0.000	8.615	6.165	12.037
[BSC =3]	1.382	0.1765	1.036	1.728	0.000	3.984	2.819	5.630
[BSC =2]	1.178	0.1392	0.906	1.451	0.000	3.249	2.474	4.268
[BSC =1]	0[a]					1		
[Age=4.00]*[Gender=2]	0.102	0.3156	-0.517	0.720	0.747	1.107	0.597	2.055
[Age=4.00]*[Gender=1]	0[a]					1		
[Age=3.00]*[Gender=2]	-0.222	0.3589	-0.925	0.481	0.536	0.801	0.396	1.618
Age * Gender	0[a]					1		
(Scale)	1[b]							
(Negative binomial)	0.407	0.0587	0.307	0.540				

Dependent Variable: AdSumLoS_Days

Model: (Intercept), Age, Ethnic, Gender, Quintile, BSC, Age * Gender

a. Set to zero because this parameter is redundant.

b. Fixed at the displayed value.

Appendix Five: Univariate Variables – Length of Stay

Summary of univariately independent variables on Number of days Hospitalised (LoS)

Variable	**p-value**	**Test type**	**Test value**
Age	$p = .002$	Spearman's	$r_s = .221$
Quintile	$p = .020$	Spearman's	$r_s = .166$
Body systems count	$p < .001$	Spearman's	$r_s = .639$
Gender	$p = .596$	Mann-Whitney	$U = 4562.50$
Ethnicity	$p = .169$	Mann-Whitney	$U = 5410.50$

Appendix Five: Correlation Matrix

Correlation matrix of independent variables (multicollinearity VIF <5)

Coefficients		Collinearity Statistics	
Model		Tolerance	VIF
1	MAORI(Pc)	.727	1.375
	European(OTHER	.914	1.095
	Quintile = 1.0	.891	1.123
	Quintile = 2.0	.754	1.327
	Quintile = 3.0	.771	1.298
	Quintile = 4.0	.823	1.215
	Gender	.928	1.078
	Age <24-44	.936	1.068
	Age <45 - 64	.806	1.241
	Age 65+	.825	1.212
	Body systems count =2.0	.855	1.170
	Body systems count =3.0	.884	1.131
	Body systems count =4.0	.937	1.068
	Body systems count =7.0	.951	1.052

a. Dependent Variable: Sum of Total Length of Stay - Days

Appendix Five: Model Diagnostics