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An exploration of the overall quality of care of Home Enteral Nutrition (HEN) patients in the Counties Manukau district

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A Thesis in partial fulfilment of requirement for the degree of

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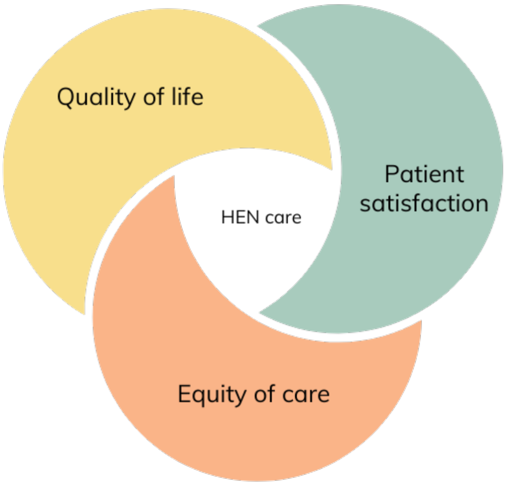
Chapter 1. Introduction

1.1. Background

The overall quality of care of Home Enteral Nutrition (HEN) patients has the potential to be a broad and complex topic because it involves several factors that may affect the health and well-being of the patient. Therefore, it is important to provide clear definitions, parameters and understanding around the concepts associated with quality care and to identify the concepts that will be used in this study. It is also important to understand the concept of enteral nutrition (EN) and where HEN fits in.

Quality of patient care is defined as "*the degree to which health services increase the likelihood of desired health outcomes and are consistent with current professional knowledge*" (WHO, n.d). Along with equitable medical outcomes, desired patient outcomes include good quality of life, patient satisfaction, and the equitable provision of care, with elements of each interlinking and forming an important part of the patient experience as a whole (Smith, 2009).



Abbreviations used: Home Enteral Nutrition (HEN)

Figure 1.1 Aspects contributing to the overall quality of patient care

Quality of life (QoL) is defined by the World Health Organisation (WHO) as "*a person's perception of their position in life within the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns*" (WHO, 1994). It is further described as a broad and multidimensional concept focusing on health status as well as social, psychological, and cultural factors. It is subjective and often viewed as a person's general well-being (Albrecht & Devlieger, 1999). Quality of life is measured using validated questionnaires, often across domains reflecting key influencing factors such as physical health, psychological health, level of independence, social relationships, and environmental considerations (Billington, 2010; Fayers & Machin, 2016).

Patient satisfaction is defined as the gap between patient expectations and their experience of care (Wolf JA, 2014), and is often viewed as the patient's perception of care (Luxford, 2012; Williams, 1994; Williams et al., 1998). Patient satisfaction encompasses the patients' subjective experiences of their encounters with healthcare providers, the care they received, and the healthcare environment (The Beryl Institute, n.d.). Patient satisfaction is commonly measured in healthcare settings to assist in the continual improvement of services (Nguyen & Nagase, 2021). In NZ, the Health Quality and Safety Commission (HQSC) undertakes regular national surveying of patients who have had recent in-patient and / or primary care experiences. The HQSC is an independent crown entity established under the NZ Public Health and Disability Act 2000. Through monitoring and reporting, and with collaboration across the health system, the HQSC works to implement quality improvement initiatives aimed at engaging the patient, promoting patient safety, and reducing inequities in health care.

The WHO define health equity as "*the absence of unavoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically*" (WHO, n.d.). Practically, this means equity of care should result in consistent and fair health outcomes irrespective of patient's gender, age, ethnicity, culture, socioeconomic circumstances, and geographical location. Health equity recognises the social determinants of health, and that not all individuals have the same starting points, or access to resources or opportunities that may influence their health. In the NZ context, equity of care is especially important due to Te Tiriti o Waitangi. Often referred to as the founding document of NZ; Te Tiriti recognises indigenous (Māori) rights, including the right to equitable health care. Ensuring health equity in NZ is paramount to both honouring the treaty and upholding the rights of Māori. As such, the NZ HQSC surveys include an equity of care question set, and the equity of primary and in-patient care is monitored quarterly. This monitoring is especially important for more vulnerable populations, such as those on EN. A patient group who faces additional factors that may potentially impact their access to, or experience of healthcare, and their health outcomes. Factors such as underlying health condition, dependence on medical support, infection risk, nutritional requirements, and dependence on others for support.

Enteral nutrition is defined as the intake of specialised feeds or liquidised food via the gastrointestinal tract (GIT) either orally or using tube feeding (TF) (Apezetxea et al., 2016). Enteral feeding is indicated in patients who have a functioning GIT yet cannot meet their nutrition requirements by only eating (Bischoff et al., 2020; Lim et al., 2018; ACI, 2012; Wong et al., 2018). Using EN is vital in maintaining their nutritional requirements and their gut function (Bischoff et al., 2020). Enteral nutrition is an essential intervention for those at risk of malnutrition, and in adults it is commonly used in patients with cancers, neurological disorders and critical illness or injury. It is also used in those with respiratory illnesses where there are increased energy requirements that cannot be met through traditional means, or malabsorptive issues where nutrients cannot be absorbed higher up in the GIT (ACI, 2012).

Whilst EN is often used as a short-term intervention in acute care settings, there are many patients with chronic illness, injury or long-term medical conditions where longer term requirements, for more than four weeks are indicated (Gramlich et al., 2018; McMahon, 2005). For many of these patients HEN is an effective way of providing nutrition support outside of the confines of the hospital setting (Green et al., 2019). However, for this option to be considered, both patients and/or their caregivers must be able to meet certain conditions to proceed with HEN (Bischoff et al., 2020; ACI, 2012). Patients must be in a clinically stable condition with potential for improvement in nutrition status (Gramlich et al., 2018). They also need to have a sanitary home environment. Patients (or their caregivers) must be mentally and physically able to safely administer HEN, and observe safe storage practices for HEN feeds and equipment (Raymond & Morrow, 2021). When administered under appropriate conditions, HEN reduces hospital readmission rates (Klek et al., 2014), allows a patient to live in familiar surroundings, and for the most part, return to their normal daily lives (Cawsey et al., 2010). Whilst allowing a greater degree of freedom in daily living, HEN is not without its disadvantages or complications. Common complaints of HEN patients (or their carers) include mechanical issues such as tube blockages, digestive issues, such as vomiting, metabolic issues such as deficiencies or excesses of micronutrients, or physical complications such as hypergranulation (Johnson et al., 2019; Lim et al., 2018; Schneider et al., 2000; Wanden-Berghe et al., 2019). These disadvantages or complications all contribute to the patient experience and their QoL.

1.2. Justification for the study

The intention of long-term HEN is to allow improved quality of life (Bischoff et al., 2020; McMahon, 2005; Raymond & Morrow, 2021), however in many studies, such as the most recent Australian study by Faruquie et al.,(2016), HEN patient QoL is reportedly much lower than that of the general population. Up until 2016, tools used to measure QoL in HEN patients have been generic and lacked specificity to the problems faced by the HEN patient, resulting in an inability to distinguish QoL thoughts or feelings about HEN, from their underlying disease (Cuerda et al., 2016). To date there have been two studies utilising this new validated HEN-specific tool; the NutriQoL. Both Apezetxea et al. (2014), and Zamanillo Campos et al. (2021), carried out studies in Spanish populations using the NutriQoL. However, NutriQoL has not been used elsewhere, meaning there is still a global shortfall in knowledge of the impact of HEN on QoL. This knowledge shortfall is further compounded by a lack of research into QoL in HEN patients in New Zealand (NZ).

With the use of HEN steadily increasing (Green et al., 2019; Johnson et al., 2019), more hospitals and health boards globally have found value in creating specific HEN teams and registries of HEN patients to ensure consistent and equitable access to appropriate care for all patients (Flood et al., 2021; Klek et al., 2011). Recently, in NZ, the country moved from a fragmented health system that was divided into twenty district health boards, to one overarching health system Te Whatu Ora, to help address inequities in access to health care in NZ in line with Te Tiriti o Waitangi. The Counties Manukau district forms part of the new Northern region of Te Whatu Ora, and geographically covers a wide area of southern and eastern Auckland, servicing around 470,000 adult patients (CM Health, n.d.). The Counties Manukau district has the largest population of Pacific peoples and second-largest Māori population under its care comparative to the other districts within NZ. (Stats NZ, n.d.). The current patient population in the Counties Manukau district is represented as follows 16% Māori, 22% Pasifika, 30% Asian, 32% NZ European/ Other (CM Health, n.d.; Stats NZ, n.d.). Nutrition support for Counties Manukau district HEN patients is managed as part of the broader Community Health Services multidisciplinary team. The team currently follows HEN service guidelines created by the Agency for Clinical Innovation (ACI) (ACI, 2012); however, these were developed specifically for New South Wales (Australia), and may therefore not cater to the specific needs or diverse makeup of the patients in the Counties Manukau district. Furthermore, due to the diversity of its population, cultural safety is paramount in ensuring equity of care (Curtis et al., 2019; Wepa, 2015). Over one-third of these patients live in areas of high socioeconomic deprivation (CM Health, 2020), and the link between income inequality and disparity in health outcomes is well documented, especially in terms of lower life expectancy at birth, higher rates of premature morbidity, and lower quality of life outcomes (Chokshi, 2018; Rose & Hatzenbuehler, 2009; Treasury, 2001). Therefore, partnering with this vulnerable patient group and exploring their patient experience is vital when considering the future of equitable service provision and equitable health outcomes.

Traditionally the healthcare system has followed a paternalistic model of care, whereby the health care practitioner regarded as the expert, tells the patient what to do based on knowledge (Gluyas, 2015). Over time this model of care has been heavily criticised, not only for its perpetuation of the imbalance of power in the health care professional, patient dynamic, but also for its lacking with regards to cultural safety. Over the past couple of decades the health care system has moved away from this model towards a system of patient-centred care (Delaney, 2018). Patient-centred care is defined by the Institute of Medicine as "*providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions*" (Institute of Medicine Committee on Quality of Health Care, 2001). Whilst patient-centred care is now a part of health care professionals training, in the UK it was shown that in practice many health care professionals can (for a number of both practical and personal reasons) be too task-oriented and in essence forget their patient-centred training (Gluyas, 2015). To the best of our knowledge, no studies in NZ have investigated the efficacy of patient care with regards to the HEN patient experience or satisfaction of HEN care. Therefore, currently we have no measure of how well the HEN services are performing with regards to meeting patient needs and expectations.

1.3. Statement of the research problem aims and objectives.

There is a current gap in research regarding QoL, equity of care, and patient experience of HEN patients in NZ. It is important to address this gap in evidence by conducting a first analysis of the current state of HEN care in NZ, and specifically in the Counties Manukau district. To ensure a comprehensive assessment is completed, we will also assess the HEN health care professionals' perceptions of their practice of equity and quality of HEN patient care. Therefore, the overall aim and objectives of this research study can be stated as follows.

Research aim – to investigate the overall quality of care of adult, long-term (> four weeks) HEN patients aged > 18 years residing in the Counties Manukau district.

Research objectives are to -

- investigate the patient's quality of life (both general and specific to HEN treatment),
- explore the patient's perception of the equity of care provided,
- investigate the patient's experience and perspectives of the HEN care service,
- explore the staff perceptions of HEN care, patient satisfaction and equity of care.

1.4. Contributors to the Research

Contributor	Contribution to thesis
Sally Pattison	Primary Researcher: study design, methodology, in-person quantitative data collection, conductor of interviews and dietitian focus group sessions, ethics application, trial registration, statistical analysis, thematic analysis, interpretation of results, author of thesis.
Prof Rozanne Kruger	Primary thesis supervisor: Funding application, study design, methodology, ethics application, trail registration, statistical analysis, thematic analysis, interpretation of results, revision and approval of thesis.
Andrew Xia	Thesis co-supervisor: Funding application, study design, methodology, ethics application, trail registration, statistical analysis, thematic analysis, interpretation of results, revision of thesis.

Marcos Mantovani	Msc candidate: study design, methodology, in-person quantitative data collection, ethics application, trial registration, patient participant information sheet and consent form .
Sophie Turner	Research assistant: in-person quantitative data collection, conductor of interviews and nurse focus group sessions.

1.5. Structure of the thesis

Chapter one provides an overview of the thesis topic, including aims and objectives. Chapter two will contain a review of the literature regarding quality of life in HEN patients, the HEN patient perspective of care and the validated tools available to measure quality of life. Chapter three will be structured as a manuscript aimed to be published in the Journal of Clinical Nutrition. The methodology and tools used for our exploratory investigation will be described, followed by the reporting of results and discussion. As we used a mixed methods approach including quantitative survey results as well as two qualitative reports, this chapter is longer than usual to allow for richness of data reporting and may result in two publications. Finally chapter four will briefly summarise the main findings and critically evaluate the research study, ultimately providing a conclusion, and recommendations for changes to future practice.

Chapter 2. Literature Review

2.1. Background

The purpose of this literature review is to comprehensively summarise and evaluate the current research and literature on the QoL, patient experiences, patient satisfaction, and equity of care, as it relates to HEN patients globally and within NZ. Relevant studies have been critically reviewed to identify themes, gaps and inconsistencies in the literature, and these findings are presented in a thematic style. Section 2.1 will introduce the topics and the different QoL tools (including a QoL tool review table), whilst section 2.2 will outline the review process. Section 2.3 will cover a review of QoL literature in HEN patients and include a HEN QoL literature review table. Section 2.4 will cover a review of patient experience literature in HEN patients and include a HEN patient experience review table. Finally, section 2.5 will briefly summarise the findings.

2.1.1. Home Enteral Nutrition

Patients who are malnourished or at high risk of malnutrition, and those requiring post-acute or long-term nutritional intervention require services known as nutrition support (Burgermaster et al., 2016; Gao et al., 2021; Ireton-Jones, 2017; Nutrition; Roberge et al., 2000). Often considered life-sustaining therapy (Burgermaster et al., 2016; NICE, 2006), nutrition support refers to any method of feeding that aims to maintain or restore a patient's nutritional status (NICE, 2006; Nutrition). This includes the use of food fortification, oral nutritional supplementation (ONS), EN, and parenteral nutrition (NICE, 2006; McMahon, 2005; Nutrition). The preferred modes of delivery are those that utilise the GIT (NICE, 2006).

Enteral nutrition is the administration of a nutritionally complete liquid formula (feed) to supplement or meet a person's daily nutrition needs (NICE, 2006; Gramlich et al., 2018); it is administered through a feeding tube into the GIT (Teitelbaum, 2005). Enteral nutrition is indicated in patients with a functioning GIT with adequate length and absorptive capacity, who are unable to meet their nutrition requirements orally through food and/or ONS, and in patients where oral intake is contraindicated (Bankhead et al., 2009; NICE, 2006; Gramlich et al., 2018; Löser et al., 1998; McMahon, 2005; O'Day, 2016; Ojo & Brooke, 2016). Evidence shows that EN, as well as maintaining structural and functional GIT integrity (McClave &

Heyland, 2009), reduces costs and improves patient outcomes, including the length of hospital stay (Baskin, 1992; Blumenstein et al., 2014; Ojo & Brooke, 2016).

Many patients require EN long-term (longer than four weeks) (Hickson & Smith, 2018) but are otherwise medically stable and can live outside of a hospital (Elfadil et al., 2021; Gramlich et al., 2018). In these cases, when EN is continued outside the hospital, it is referred to as home enteral nutrition (HEN) (Gramlich et al., 2018; Martin & Gardner, 2017; ACI, 2012). Historically, studies have shown that the primary indicator for introducing HEN in adults is an impaired ability to consume food (therefore nutrients), with the underlying pathology primarily neurological disorders, and secondarily obstructive lesions of the upper GIT (Elia, 1995; Hebuterne et al., 2003; Loeser et al., 2003; Löser et al., 1998; Wanden-Berghe et al., 2015). However, the most recent British Artificial Nutrition Survey (BANS) conducted in 2015 shows a shift in the patients underlying pathology, with the primary indicator for new HEN patients being cancers (mainly of the head and neck), followed by neurological disorders (Stratton, 2018).

Attitudes to tube feeding in patients with progressive and severe disabilities vary between countries. Philosophical, religious, and social beliefs, as well as the economy, influence such ethical considerations (Paris, 1993). The benefit must be greater than any risk to the patient (Schwartz et al., 2021), and given the significant emotional and psychosocial importance of food globally, this is often difficult for the family and caregivers of patients to reconcile (Cawsey et al., 2010; McMahon, 2005; Sarah et al., 2015). End-of-life nutrition is a sensitive issue, and it is widely acknowledged that when care has moved to be palliative, tube feeding will not improve patient outcomes or quality of life (QoL). Thus, commencing HEN is discouraged in these cases, where the focus of nutrition support moves towards comfort (McMahon, 2005; Schwartz et al., 2021).

2.1.2. Quality of life

There is no universally accepted definition of either Health-Related QoL (HRQoL) or QoL with the two terms often used interchangeably (Carr et al., 2001; Carr & Higginson, 2001; Fayers & Manchin, 2016; Phillips, 2006). Health-related QoL focuses purely on the impact of illness and treatment on a patient's QoL. Whereas, QoL is described as a much broader concept focusing on health and disease as well as social, psychological, and spiritual factors. It is subjective and often viewed as a person's general well-being (Albrecht & Devlieger, 1999). The World Health Organisation (WHO) defines quality of life as "*a person's perception of their position in life within the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns"* (WHO, 1994).

Quality of life measures are popular in clinical settings to understand the impact of interventions on patients' lives (Addington-Hall & Kalra, 2001; Carr & Higginson, 2001; Quality of life, 1991). For patients with chronic conditions, it is important that treatment and evaluations focus on the patient as opposed to the disease and that QoL guides clinical decision-making (Higginson & Carr, 2001; Schneider et al., 2000). Such considerations are important as chronic conditions are likely to influence the patients social, psychological, and physical well-being (Harris, 2012). Understanding the impact of clinical actions or the patient's experience of care, on the QoL and well-being of these patients also holds importance from a quality improvement perspective (Higginson & Carr, 2001).

Several questionnaires have been developed and validated to measure QoL, and selecting the most appropriate tool to measure QoL depends on the population studied and the research question (Hyland, 2003). Before picking a tool, the strengths and limitations should be considered to ensure the most appropriate tool is being used for the needs (Institute of & Council on Health Care, 1989). Comparisons of QoL between population groups with the same characteristics or needs may be difficult due to the wide variety of QoL tools and methods (Pequeno et al., 2020).

An evaluation of QoL tools commonly used in research with patients receiving HEN was conducted (*table 2.1)* to allow for comparison and to ensure the most appropriate tool was selected for the research population. Two key considerations of choosing the appropriate tool, were regarding validation, and specificity, these are discussed below.

QoL tool specificity

Three of the QoL tools reviewed in table 2.1 measure general quality of life: The long-form WHO QoL tool (WHOQoL-100), The short-form WHO QoL tool (WHOQoL-BREF), and the Euro QoL research foundation 5 dimensions tool with visual analogue scale (EQ-5D +VAS). Four tools were created to measure the impact of general illness on a patient's life:

the short-form medical outcomes survey - 36 (SF-36), the short form medical outcomes survey-12 (SF-12), the sickness impact profile, and the Nottingham health profile. One was created specifically for cancer patients; the European Organisation for the Research and Treatment of Cancer QoL questionnaire (the EORTC-QLQ-C30), which comes with various modules including a PEG specific module. Another, the Functional Assessment of Anorexia/ Cachexia (FAACT), is specifically for patients with anorexia and cachexia. The only QoL tool reviewed that was for use specifically with patients receiving HEN, was the NutriQoL questionnaire.

QoL tool validation

All tools reviewed had been validated for use in specific populations. One tool had been validated for use with HEN patient (the NutriQoL), but this was not validated for use with the NZ population. Three of the tools reviewed were validated for the NZ population, the SF-36, the EQ-5D and the WHOQol-BREF.

Table 2.1 Evaluation of QoL tools

Tool, country of origin & study references	Measure	Validated/ Reliability	Domains	In what population was it developed and tested?	Strengths	Limitations (incl. floor or ceiling effects)
SF-36 United States of America (McHorney et al., 1992; Ware & Sherbourne, 1992) (Frieling et al., 2013)	Short form of the Medical Outcomes Survey (MOS)	Content validity Validated for NZ	36 question items over 8 domains: 1. Physical functioning 2. Role limitation-physical 3. Pain 4. Social functioning 5. Mental health 6. Role limitations-emotional 7. Vitality (energy/ fatigue) 8. General health	Developed as a shortened version of the tools used for the MOS, utilising 20 + years of research data from the tool. Tested: Data used was from the MOS administered in 1986-1987. Sampled at a doctor's visit Patients > 18 years old with Hypertension, Type II diabetes, Congestive heart failure, or recent Myocardial infarction.	Written in language a 14-year-old could understand Only takes 5-10 minutes to complete Direct comparability with the older SF-20 Can be self- or researcher administered in person or via the phone.	Concepts omitted from the MOS: health distress, family functioning, sexual functioning, cognitive functioning, and sleep disorders. Whilst floor effects had been noted in the SF-20, they are rare for the SF-36.
SF-12 (Jenkinson et al., 1997; Ware Jr et al., 1996) (Frieling et al., 2013)	Short form of the SF-36	Content validity Reliability: Test-retest reliability 0.890 in the UK, 0.864 in US. Favourable comparison with SF-36 scales (0.63 to 0.89) Validated for NZ	12 questions over 8 domains: 1. Physical functioning 2. Role limitations-Physical 3. Pain 4. Social functioning 5. Mental Health General Health Vitality Role-Emotional	Developed using data from the MOS and the SF-36; the Physical component summary scale (PCS-36) and the Mental component summary scale (MCS-36). Tested: Data used from three longitudinal datasets that used the SF-36. Patients with Congestive heart failure > 60 years, Sleep apnoea, laparoscopic surgery < 70 years.	Reduction in patient burden Only take ~2 minutes to complete Accurate reproduction of average scores for SF-36 summary measures Official translation to Spanish, French, German, Italian and Japanese	Less accurate reproduction scores for the eight-scale profile Less reliable than SF-36 in small-group studies

Tool, country of origin & study references	Measure	Validated/ Reliability	Domains	In what population was it developed and tested?	Strengths	Limitations (incl. floor or ceiling effects)
The Sickness Impact Profile (SIP) United States of America (USA) (Bergner et al., 1976; Gilson et al., 1975)	Behaviour based measure of sickness-related dysfunction	Validity: High correlations between SIP overall scores and validity criteria Reliability: Test-retest correlations ranging from 0.80 to 0.88	Independent categories: Sleep & rest, Eating, Work, Home management, Recreation and pastimes. Physical: Ambulation, Mobility. Body care and movement. Psychosocial: Social interactions. Emotional behaviours. Alertness behaviours. Communication.	Two hundred forty-six group practice enrolees, drawn from 5 categories of medical care; home care patients, inpatients, outpatients, walk-in clinic patients and nonpatients. Two hundred seventy-eight patients of rehabilitation medicine, speech pathology, outpatients (chronic illness) and group practice enrolees.	Relies solely on individual perception of the impact of sickness Comprehensive	SIP overall scores and category scores discriminate among subsamples It does not specifically measure Quality of Life
NHP (Nottingham Health Profile) United Kingdom (UK) (Hunt et al., 1981; McDowell, 2006)	Perceived health-related problems and the extent they affect daily activities	Face and Content Validity. Reliability: Test-retest (0.75-0.88)	38 questions grouped into six domains (based on the WHO classification of disability): Physical mobility Social isolation Emotional reactions Pain Sleep Energy	Using hundreds of interviews with laypeople	Short and easy to administer – takes 5-10 minutes Sensitive enough to detect changes in the elderly Self-administered	It not a comprehensive measure of QoL May not detect minor health improvements – focuses on the negative experiences, excludes patients positive experiences of disease/ conditions. Developed and tested for use in Europe

Tool, country of origin & study references	Measure	Validated/ Reliability	Domains	In what population was it developed and tested?	Strengths	Limitations (incl. floor or ceiling effects)
EORTC-QLQ-C30 Europe (Aaronson et al., 1993; Fayers & Bottomley, 2002)	Quality of life evaluation of Cancer patients	Validity: Inter-scale correlations were statistically significant (p<0.01) Reliability: multi-item scales ranging from 0.54 to 0.86 (pre-treatment) 0.52 to 0.89 (during treatment)	9 multi-item scales: Functional: Physical, role, cognitive, emotional and social. Symptom: Fatigue, pain, nausea and vomiting. Global health and quality of life scale + single item measures	305 patients with nonresectable lung cancer from centres in 13 countries	The average time to complete is 11-12 minutes. Validated and reliable cross-culturally Self-administered Has additional modules relating to different cancers to allow increased specificity	Does not discriminate between patients with different stages of the disease Cancer specific
WHOQoL-100 (WHOQoL Group), 1994) Brazil, Canada, China, Egypt, India, Nigeria, Norway, Saudi Arabia, Sri Lanka, Thailand, UK, USA, Zimbabwe	A subjective assessment of QoL. Clinically can be used to assess the impact of a health condition on a patient's life.	Reliability: Alpha coefficients in British study ranged from 0.87 – 0.95 for all domains Test-retest reliability: 0.66 (physical health), 0.72 (psychological health), 0.76 (social), 0.87 (environmental)	100 questions over 7 domains: 1. Physical domain 2. Psychological 3. Level of independence 4. Social relationships 5. Environment 6. Spirituality 7. Overall QOL and general health	Development pilot test: across 15 field centres in 14 countries. >10,000 participants over 5 years	Culturally sensitive Comparable Available translated by the WHO	High patient burden, it is very long. Takes ~ 15-20 minutes to complete

Tool, country of origin & study references	Measure	Validated/ Reliability	Domains	In what population was it developed and tested?	Strengths	Limitations (incl. floor or ceiling effects)
WHOQoL-BREF (Billington, 2010; WHOQoL Group, 1998) Argentina, Australia, Brazil, Croatia, France, Germany, Hong Kong, India, Israel, Japan, NZ, Russia, Spain, Thailand, UK, USA, Zimbabwe	Short-form version of the WHOQoL-100	Validity: scores correlate highly (>0.89) with WHOQoL-100 domain scores	26 questions over 4 domains: 1. Physical health 2. Psychological health 3. Social relationships 4. Environment	Developed using data from 20 field centres within 18 countries Piloted on ~300 people at each field centre (~5,400 people in total). ~5/6 of those involved were persons with disease or impairment (primary care setting, hospitals and community care settings)	Validated for the NZ population. NZ specific version available. Results can be compared with WHOQOL-100. It takes ~ 5 minutes to complete	More significant patient burden than the SF-12 Individual facets within the domains cannot be assessed.
NutriQoL (Apezetxea et al., 2016) Spain	Self-rated quality of life tool specific for patients receiving H EN regardless of underlying health condition	Test-retest reliability: 0.88 (95% CI: 0.80-0.93) Validity: Low but significant corelations with items from the EQ-5D VAS	17 questions grouped into 2 dimensions: 1. Physical functioning 2. Activities of daily living Each question has two parts: a. The frequency the participant perceives a specific HEN related situation b. Assesses how important the situation is to the participant.	Developed in Spain and tested on cohorts of adult patients receiving HEN from 4 Spanish hospitals	Specific and validated for patients receiving HEN Easy to administer Can be answered by the patient, or caregiver giving similarly valid results	New, not yet validated for use in NZ population

Tool, country of origin & study references	Measure	Validated/ Reliability	Domains	In what population was it developed and tested?	Strengths	Limitations (incl. floor or ceiling effects)
EQ-5D (EuroQol-5-Dimensions) + Visual analogue scale (VAS) Europe (Perkins et al., 2004; Sullivan et al., 2020)	Evaluates generic quality of life	Valid, reliable , responsive Test-retest reliability	5 dimensions of health: 1. Mobility 2. Self-care 3. Usual activities 4. Pain and discomfort 5. Anxiety and depression + rating of overall health using a VAS	Testing in NZ on 66 participants from Māori communities, who were not fully representative of the Māori population.	Short and simple Tested for use within Māori communities Can be completed digitally, on paper, over the phone Can be completed by participant, interviewer or proxy	Ceiling effects
Functional Assessment of Anorexia Cachexia Therapy (FAACT) The Netherlands (Blauwhoff-Buskermolen et al., 2016)	A measure of nutritional quality of life + general quality of life	Validated in a prospective trial	27 questions grouped into two dimensions. 1. General 2. Anorexia/ Cachexia General questions are further broken down to assess: 1. Physical well-being 2. Social/ Family well-being 3. Emotional well-being 4. Functional well-being	Initially validated as an addition to the Functional Assessment of Cancer Therapy -general (FACT-G) questionnaire	Self-administered Focused on nutritional quality of life	Should not be used as a screening tool for clinical intervention Developed and validated specifically for use with patients who have cancer

2.1.3. The patient experience.

The patient experience is a measure of healthcare that has become increasingly popular over the years. While there may be some consensus in the literature about what it is, there is currently no standardised definition. Many agree that the patient experience encompasses all interactions when accessing healthcare (Jenkinson et al., 2002) and is influenced by the values, ideas, customs and beliefs of the organisation (Braithwaite et al., 2017). It is often viewed as the patient's perceptions of care (Wolf JA, 2014). With these generally agreed concepts in mind, the definition of patient experience currently found in the literature that may be the best fitting is that by the Beryl Institute, *'the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care'*(Beryl Institute, n.d.). The terms patient experience and patient satisfaction are not the same, although they are often used interchangeably (Price et al., 2014). Wolf (2014) describes patient satisfaction as relating to the gap between patient expectations and their experience of care. Because of this, many believe that when looking at the patient experience, the focus should be on the patient's perspective of quality of care (Luxford, 2012; Williams, 1994; Williams et al., 1998). The term quality of care also lacks a singular definition, with those found in literature varying over time. Florence Nightingale observed that quality of care depended on caring attitudes and behaviours (Meyer & Bishop, 2007). While (Donabedian, 1980) noted that quality of care was linked to the application of medical science and technology, as well as the patient's perspective. Since Donabedian's work, many other definitions have arisen, however the more recent six principles of care used by the US Institute of Medicine that care should be *safe, timely, effective, efficient, equitable* and *patient-centred (STEEEP)* (Wolfe, 2001), seem most appropriate for the NZ context.

The WHO has *patient-centredness* as one of its objectives (WHO, 2016), and in NZ, patient-centred care has also been established as a priority (Health & Disability Commissioner, 2003). The patient-centred approach includes adhering to the Health Information Privacy code of 1994 and the Health and Disability Code, which acknowledge patients' rights as integral to patient-centred care. *Safe care* relates not only to the traditionally thought of physical aspects of safety but to a holistic approach to healthcare created to acknowledge and honour the multiculturalism in NZ, referred to as cultural safety (Nguyen, 2008). There is an inherent power imbalance in the relationship between healthcare practitioner and patient, and cultural safety aims to push the balance of power to favour the patient (Brewer & Andrews, 2016). Cultural safety is a patient-centred and self-reflective approach that was developed in NZ by Māori nurses to improve health outcomes for Māori patients (Nguyen, 2008; Papps & Ramsden, 1996). Cultural safety refers to multiple aspects of care. It seeks to acknowledge the individuality of the patient and their cultural beliefs about health and health care. It also involves practitioners reflecting on their own personal cultural identity and how that may impact care. If aspects such as power, privilege and personal biases remain unchecked, achieving equity in health care may be jeopardised (Curtis et al., 2019). Cultural safety is aligned with the WHO declaration of Alma Ata, which affirms health as a fundamental human right, proclaims that people have the right of involvement in their health care, condemns inequality in health, affirms the link between economic and social development and declares that governments are responsible for population health (The declaration of Alma-Ata, 1988).

The NZ health care system aims to provide care for all based on their clinical needs. However, historically the 'inverse care law', where the availability of health care varies inversely with the population's need for it (Tudor Hart, 1971), is evident when looking at indigenous life expectancy (Cooke et al., 2007). *Health inequities* are avoidable and unfair differences in health (Braveman & Gruskin, 2003) resulting in deaths, hospitalisations, illness or injury that can be prevented (Weinstein et al., 2017). Globally, health inequities have been well documented in indigenous and minority ethnic populations including Inuit, Bedouin Jahalin, Yanomami and Aboriginal and Torres strait islanders. (Anderson et al., 2016; Gracey & King, 2009; Kirmayer & Brass, 2016; Maclennan et al., 2022). Similarly, here in NZ, Māori and Pacific peoples experience poorer health outcomes than the general population. Life expectancy at birth has been reported as on average 7 years less, Infant mortality rate as 2.9 higher, maternal mortality rate as 21.6 higher, and childhood obesity as 9.5% more prevalent (Stats NZ, n.d.) . Differences have also been document in outcomes post-surgery, and post injury. (Anderson et al., 2016; Came et al., 2019; Cooke et al., 2007; Graham & Masters-Awatere, 2020; Maclennan et al., 2022). In the last census Māori and Pacific respondents made up almost a quarter of the current NZ population (24.6%) (*Census Stats NZ*, 2018) and 38% of the population of the Counties Manukau region (CM Health, n.d.), and yet there is no evidence that the outcomes with regards to HEN care are equitable for these patient groups.

2.2. The literature review process

Three literature searches were conducted using Scopus, Discoverer and Google scholar. Literature reviewed was limited to the last twenty years (unless relevant) due the relatively small library of research on the topics. The three topics were QoL tools *(table 2.1),* QoL in HEN patients (*table 2.2*), and the patient experience of HEN care *(table 2.3*). Searches were conducted using the key words and phrases; HEN QoL, QoL in HEN patients, QoL tools, HEN patients' wellbeing, HEN patient care, equity and HEN care, HEN patient perspectives of care. Findings were exported into Endnote, and duplicates were removed. Articles were then reviewed, and any paediatric studies, and studies where home enteral tube feeding results were not easily distinguished from were removed.

2.3. Factors affecting QoL results

The ability to improve QoL is one of the criteria of HEN provision (Gramlich et al., 2018), and yet research investigating the QoL of these patients is scarce, see table 2.2. This literature review found 21 articles or abstracts on QoL in patients receiving HEN, from nine different countries. The majority (nine) of the studies were conducted in Europe; three in Spain (Zamanillo Campos et al., 2021; Apexetxea et al., 2013;Wanden-Berghe et al., 2009), three in France (Roberge et al., 2000; Schneider et al., 2000; Schneider et al., 1998), one in the Republic of Ireland (Donohoe et al., 2017), one in Italy (Gavazzi et al., 2016), and one in Germany (Loeser et al., 2003). Additionally, five studies were conducted in China (Xuejin et al., 2021; Qui et al., 2020; Liu et al., 2020; Wu et al., 2018; Zeng et al., 2017), three in the UK (Bowrey et al., 2015; Day, 2010; Jamieson et al., 1997), two in Australia (Kim & Karey, 2013; Doyle & Simmance, 2008), and two in the USA (Malone, 2002; Reddy & Malone, 1998). This literature had a mix of study designs; ten prospective studies, three randomised control trials, two retrospective studies, two cross sectional studies, two qualitative studies and two pilot studies. Findings regarding the overall impact of HEN on patient QoL are discussed below.

HEN may positively impact QoL

Results of Ten of the studies showed that HEN may positively impact QoL (Bowrey et al., 2015; Gavazzi et al., 2016; Jamieson et al., 1997; Liu et al., 2020; Roberge et al., 2000; Wu et al., 2018; Xuejin et al., 2021; Zeng et al., 2017; Zamanillo Campos et al., 2021; Donohoe et al., 2017). Of the five studies that utilised the EORT-QLQ-C30 (Liu et al., 2020; Wu et al., 2018; Zeng et al., 2017; Bowrey et al., 2015; Roberge et al., 2000; Donohoe et al., 2017), all compared HEN patients QoL to a control group at various time points post-surgery. However, there is little agreement between the studies regarding the timeframe for such post operative improvements in QoL. Bowrey et al. (2015) found that whilst patient QoL did reduce post-surgery, the reduction in QoL was less in HEN patients than in the control group. HEN patients versus the control group reported the reduction in QoL versus baseline QoL as -20 versus -21, -17 versus -21 and -5 versus -7 at six weeks, three months and six months respectively. Additionally, Wu et al. (2018) reported a significant increase in global health status in the HEN patient group three months post operatively (55.7 versus 41.8, $p = 0.001$), as did Donohoe et al. (2017), $p = 0.03$. Significant improvements in QoL were reported by Zeng et al. (2017) at four weeks and twelve weeks. Conversely, Liu et al. (2020) reported improvements in QoL at thirty days (50.64 ± 15.97 versus 48.61 ± 14.68), although not to statistical significance. The follow up for Roberge et al. (2000) was twenty eight days, and improvements in QoL in HEN patients was observed across some of the specific symptom scores; coughing and social function.

Gavazzi et al. (2016), utilised the FAACT and found improvements in QoL in both the control group, and the HEN patient group. However, mean improvements for the HEN group were greater than for the control at two months post operatively, at around 4.9 versus 2.4. Xuejin et al. (2021) found that QoL significantly improved across all variables at one month, three months and six months, when using the SF-36. As the follow up period for Jamieson et al. (1997) was between twelve and forty eight months it is difficult to understand the effects as they relate to a specific time period. However, significant QoL improvements were reported for all domains where weight gain was the goal. Utilising the NutriQoL tool, improvements in HEN QoL were reported by Zamanillo Campos et al. (2021) at two months follow up versus at recruitment (68.8 ± 14.4 versus 66.2 ± 13.8).

HEN may not negatively impact QoL

Results of two studies concluded that HEN may not have a significant negative impact on QoL (Malone, 2002; Qiu et al., 2020). Using the SF-36 and assessing HEN patients QoL versus the general population, Malone et al. (2002) found that HEN had no significant impact on the QoL of patients who were stable and had non-malignant underlying health conditions. Whilst in research by Qui et al. (2020), a minimal change in QoL for the HEN patient group at six weeks versus baseline was reported (0.19 ± 4.161, $p = 0.05$).

HEN may reduce QoL

Five studies noted a reduction in QoL for HEN patients (Kim & Carey, 2013; Reddy & Malone, 1998; Schneider et al., 1998; Schneider et al., 2000; Day, 2010). Three of these studies utilised the SF-36 (Reddy & Malone, 1998; Schneider et al., 1998; Schneider et al., 2000), however findings were not consistent. Reddy and Malone (1998) found that the general health status of HEN patients was lower than for the general population, meanwhile Schneider et al. (1998) only found significantly lower QoL across the physical and mental components (36.1 ± 9.6 and 42.2 ± 5.4 respectively, $p < 0.05$). Schneider et al. (2000) found lower QoL across the physical and mental functioning components (37.1 ± 2.1 versus 46.5 ± 1.2, $p < 0.05$) and (46.2 ± 2.6 versus 51.8 ± 0.3, $p < 0.05$) respectively. In both research studies by Schneider et al. (1998, 2000), QoL was assessed by the EuroQoL questionnaire, which also found that QoL was lower in HEN patients than for the general population. Conversely, two studies utilised patient interviews (Kim & Carey, 2013; Day, 2010). Kim & Carey (2013) found that patient QoL was impacted by HEN, and Day (2010) reported a reduction in QoL for patients with advanced malignancy.

No conclusion regarding the impact of HEN on QoL reported

The remaining four studies did not report any QoL comparisons. (Apeztxea et al, 2014; Doyle & Simmance, 2008; Loeser et al., 2003; Wanden-Berghe et al., 2009).

Table 2.2 outlines the key aspects of the relevant HEN QoL literature, including the relative strengths and weaknesses of each study. Within the literature seven factors were found to influence the patients QoL scores. These factors are discussed below.

Table 2.2 Review of literature: QoL in HEN patients

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL Measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Zamanillo Campos et al. (2021) Spain	Prospective n = 78 (58M/20F) Mean ± SD 64.3 ± 10.5	To evaluate whether the validated NutriQoL questionnaire is helpful for assessing QoL and the factors influencing HEN.	ONS + HTF (Gastrostomy, NGT, Jejunostomy) Patients on HEN > 1 month completed both questionnaires at recruitment time and then again 2 months later. SF-12 + NutriQoL	QOL reported through NutriQoL was higher on both visits (V1: $p < 0.001$ n = 78, V2: $p < 0.001$, n = 64) SF-12 total score recorded significant improvement in QOL from visit 1 to visit 2 (V1 40.7 ± 8.5, V2 42.3 ± 8.7; $p = 0.032$) General QoL from SF-12 did not correlate with any variables	The use of the HEN specific QoL tool allowed researchers to focus on areas important specifically to patients receiving HEN. Underlying disease, HEN type and HEN complications are factors which impact patients QoL. Patients QoL was reduced on the follow up when measured by NutriQoL yet improved when measured by SF-12.	Strengths: Participants may be representative of HEN patient population. Use of HEN specific QoL tool. Limitations: 18% loss of patients prior to follow up. Single centre.
Xuejin et al. (2021) China	Prospective observational study n = 166 (70M/96F) Mean ± SD 46.4 ± 16.5	To evaluate the effect of HEN on patients with malnourished intestinal failure.	All patients were supported with HEN post d/c. Pt assessments occurred at 1-, 3-, and 6-months post d/c. SF-36	Health transition scores were improved across all 3 time points. (57.4 ± 15.6 vs 61.7 ± 17.6 vs 69.3 ± 16.3, $p < 0.001$)	HEN improved nutritional status and QOL in patients with intestinal failure.	Strengths Sample size. Included multiple outcome measures (QoL, nutritional status, body composition). Limitations: No control groups. Single-centre study. Participants may not be representative of HEN patient population.

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL Measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Qiu et al. (2020) China	Randomised control trial (RCT) n = 85 (54M/31F)	To investigate the effect of whole-cause nutrition management on the prognosis and complications of chemotherapy patients with oesophageal cancer.	Intervention (n = 45) whole course nutrition management with dietitian intervention. Enteral nutrition (primary method) or Parenteral nutrition. EORTC-QLQ-C30 V3.0	Total quality of life was reportedly higher in the control group, 60.42 ± 8.2 vs59.44 ± 9.7 (p = 0.620)	Whilst the results showed changes in scores from baseline, overall higher scores for QOL were reported by the control group, yet the intervention group reported a lower negative impact on QoL in the follow up.	Strengths: Use of a control group. Limitations: Participants may not be representative of HEN patient population. Improvements in QoL may have been due to cancer treatment not HEN.
Liu et al. (2020) China	Pilot parallel-group, randomised, single-blinded clinical trial n = 50 (35M/15F) Range 57 - 70 years	To evaluate the feasibility, safety, and effectiveness of conducting an advanced nutrition pathway including extended preoperative nutrition support and one month HEN post discharge.	Enhanced nutrition support pathway additional to standard ERAS protocol: extensive preop nutrition support + HEN for 1 month postoperatively EORTC-QLQ-C30 v3.0	QoL improvements seen in physical function (7.13 ± 9.72 vs. 68.33 ± 7.68, *P* = 0.009) and symptoms of fatigue (42.27 ± 9.93 vs. 49.07 ± 11.33, *P* = 0.028)	The addition of HEN post esophagectomy may help improve patient QoL	Strengths: Use of standardised ERAS programme. Limitations: Participants may not be representative of HEN patient population. Feasibility study- a full RCT would strengthen evidence. Small sample size. Short follow up- period.

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Wu et al. (2018) China	Single-Centre, Prospective, non-randomised study n = 142 Range 45 - 80 years	To investigate the effect of 3 months of HEN on the QOL of patients with oesophageal cancer who were pre-operatively malnourished.	Intervention patients received HEN for 3 months post Ivor Lewis esophagectomy. EORTC-QLQ-C30	Mean scores (HEN vs control) Global QOL (55.7 vs 41.8, $p < 0.01$) Physical function (80.7 vs 71.2, $p < 0.001$) Role function (48.7 vs 36.8, $p < 0.001$) Social function (59.2 vs 53.7, $p < 0.05$)	HEN post esophagectomy can improve patient QoL	Strengths: Large sample size. Use of a control group. Limitations: Participants may not be representative of HEN patient population. The effect of HEN on QoL was only assessed up to 3 months.
Donohoe et al. (2017) Ireland	Prospective cohort study n = 149 Mean ± SD 62 ± 9	To analyse the impact of supplemental HEN post-oesophageal cancer surgery on patient satisfaction, QoL, and nutritional parameters.	HEN via Jejunostomy commenced day 1 postoperatively EORTC-QLQ-C30 V3.0 + EORTC-QLQ-OES18 (oesophageal cancer module)	Mean global QOL decreased (82 to 72, $p < 0.001$). In patients with weight loss > 5% BMI there was a clinically relevant decrease in QoL in physical (76.vs. 87.5, $p = 0.066$) and social (76.4 vs. 87.8, $p = 0.034$)	Inconclusive regarding the impact of weight loss on overall QoL. HEN post oesophageal cancer surgery may lead to improved QoL	Strengths: Large sample size. Limitations: Participants may not be representative of HEN patient population. Limited route of feeding access. Single centre.
Zeng et al. (2017) China	Randomised Clinical trial. n = 60 (49M/11F) Range 38 - 76 years	To understand the effect of HEN on the nutritional status and QoL of patients with oesophageal cancer post Ivor Lewis procedure.	HEN (Jejunostomy) vs Standard care (oral feeding). Pts assessed at 1-, 4-, 12- and 24-weeks post-op EORTC-QLQ C30 + EORTC-QLQ-ES18	At 12 weeks, HEN patients had higher global QOL scores, and (mostly) higher functional index scores. At 24 weeks no significant difference in scores was observed.	HEN post oesophageal cancer surgery may lead to improved QoL	Strengths: Used a control group. Limitations: Participants may not be representative of HEN patient population. Limited route of feeding access.

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Gavazzi et al. (2016) Italy	Multicentre randomised clinical trial n = 79	To investigate the impact of HEN on nutritional status QoL, and chemotherapy feasibility in patients with upper GI cancer who were malnourished	HEN vs nutritional counselling. Functional Assessment of Anorexia/ Cachexia Therapy (FAACT)	Overall FAACT scores improved at 2 months vs. baseline. No differences between groups were found.	Supports the use of HEN in post-operative upper GI patients to maintain body weight without detrimental impact on QOL	Strengths: Multicentre. Use of validated tool. Randomised. Limitations: Participants may not be representative of HEN patient population. FAACT is not a specific QoL tool.
Bowrey et al. (2015) UK	Prospective two -armed randomised control pilot ad feasibility with nested qualitative study n = 41 (36M/5F)	To ascertain the impact of HEN post esophagogastric resection.	HEN (Jejunostomy) for 6 weeks vs. routine care. EORTC-QLQ-C30 + EORTC-QLQ-OG25 + 5Q-5D-3L	Global QOL scores postoperatively were down and returned to baseline after 6 months. No differences between groups were found.	Supports the use of HEN via jejunostomy post esophagogastric resection	Strengths: Used a control group. Use of validated QoL tools. Limitations: Small sample size. Participants may not be representative of HEN patient population. Limited to jejunostomy patients. Feasibility study- a full RCT would strengthen evidence.

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Apezetxea et al. (2014) Spain	Prospective n = 140 (86M/54F) Mean ± SD 62.7 ± 15.41	To assess HRQoL in patients receiving HEN across 9 Spanish hospitals.	ONS HTF (Gastrostomy + NGT). NutriQOL	Lower QOL in cancer patients than those with neurological or malabsorption pathophysiology. 12.76 vs 18.11 vs 17.37 (p = 0.098) ONS patients reported higher QOL than HTF patients, 19.54 vs 14.00 vs 7.02 (p < 0.01) Up to 71% of patients reported increased QOL since starting HEN.	Underlying disease impacts QoL HEN type impacts QoL HEN results in increased QoL for most patients	Strengths: Large Sample size. HEN specific QoL tool. Multicentre. May be representative of HEN patient population. Limitations: No other studies to compare results to (at that time) that utilised this tool.
Kim & Carey (2013) (abstract only) Australia	Qualitative n = 8	To investigate the impact of HEN on patients post treatment for head and neck cancer.	Gastrostomy. Questionnaire and interview	Quality of life is impacted by gastrostomy feeding at home, however patients adapted well.	The level of support available to the patient impacts efficacy of HEN.	Limitation: Very small sample size. No use of validated QoL tools. Head and neck cancer specific.
Day (2010) (abstract only) UK	A qualitative approach with semi-structured interviews n = 5	To investigate the impact of HEN on the lives of people with advanced malignancy where treatment was palliative.	HEN (gastrostomy and NGT). Interview guide created based on themes identified by other QOL HEN studies.	Some reduction in QoL could be attributed to the cancer and its treatment as opposed to the HEN.	The impact of HEN on QoL changes as the patients' priorities change towards end of life.	Limitations: Very small sample size. No use of validated QoL tools. Specific to palliative cancer patients.

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Wanden-Berghe et al. (2009) Spain	Multi-centre cross-sectional study n = 276 (141M/135F) Mean age ± SD 62.7 ± 17.0	To evaluate the HRQoL of patients who receive home nutrition support.	Patients from 14 national health services in different Spanish cities. EuroQoL EQ-5D + VAS	The current state of health vs. previous 12 months (% of patients reporting same, better, worse) 40.1%, 19.1%, 40.8% QoL reported good in all dimensions by 5.7% of patients. With VAS: Lower QoL scores for women and those whose pathology was neurological.	QoL varied depending on sex and pathology. A lack of baseline data and HEN-specific QoL tools meant it was difficult to draw more meaningful conclusions. More research into the relationship between HEN and QoL is required.	Strengths: Large sample size. Multi centre. Limitations: Older study – practices may have changed. Most participants were older adults.
Doyle & Simmance (2008) (Abstract only) Australia	Retrospective n = 26	To evaluate patient satisfaction and QoL of patients receiving HEN	Service provided by the St Vincent's Health HEN team EuroQoL EQ-5D	Mean EuroQol EQ-5D score 53.8 (± 25.4) Range of scores from 0 - 100 where 100 = the best imaginable health status	The level of support available to the patient impacts QoL	Strengths: Use of validate QoL tool. Limitations: Small sample size. Older study – practices may have changed. Limited to HEN patients in aged care setting.

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Loeser et al. (2003) Germany	Study 1: Prospective cross-sectional study Study 2: Prospective longitudinal study Study 1: n = 155 Study 2: n =5 6 Mean age ± SD 64.3 ± 13.1	To assess the QOL and nutritional status of HEN patients.	PEG Study 1: initial assessment Study 2: followed up 4 months later EORTC-QLQ-C30 + EORTC-PEG + Karnofsky & Spritzer indices	Non-competent patients: reduced QOL Competent patients: linear correlation between malnutrition and physical function, $r = 0.28$ ($p < 0.005$); constipation, $r = -0.38$ ($p < 0.01$). Weight loss was significantly associated with Global health score/ QOL ($r = -0.29$)	Competency may impact patients QoL. Malnutrition and weight loss impacts patients QoL 4 months of HEN may lead to improvements in QoL and nutritional status	Strengths: Diverse patient population . Not focused on patients with one specific underlying health condition. Large sample size for initial assessment. Limitations: Older study – practices may have changed. High percentage of participants lost to follow-up.
Malone (2002) USA	Prospective study n = 17 (7M/10F) Range 23 - 73 years	To assess the health status, frequency of therapy-related symptoms, and impact of home parenteral and enteral nutrition (HPEN) on lifestyle in stable patients with no malignancy	Home parenteral + Home Enteral Patients were assessed 2x 3 years apart. SF-36	No significant difference found between PN and HEN patients. QOL reported was lower than the general population ($P < 0.05$) There was no significant difference in QOL scores across the two time periods.	Sleep, travel, and social activities may impact QoL. Stability of patients underlying pathology impacts patients QoL long term.	Strengths: Longer follow-up period. Use of validated QoL tool. Limitations: Older study – practices may have changed. Small sample size – most patients were on home parenteral nutrition.

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Roberge et al. (2000) France	Prospective n = 39 (38M/1F) Range 38 - 74 years	To evaluate the impact of HEN tube feeding on QoL in patients treated for head and neck cancer or oesophageal cancer.	NGT (80%) Gastrostomy (20%) Two evaluations day 7 & day 28 post-op. Two patient groups: Head and neck cancer & Oesophageal cancer. EORTC-QLQ-C30 + EORTC-H&N35 + EORTC-OES24	Oesophageal cancer patients: reported an improvement in social function, nausea and vomiting, insomnia, diarrhoea, and global health status/ QOL (*P* < 0.01) H&N cancer patients: Improvements across all aspects aside from swallowing. No correlation found between tumour location and QoL	HEN results in improved QoL, and improvements in some symptoms for patients with cancers of the head and neck or the oesophagus.	Strengths: Use of validated QoL tool. Limitations: Older study – practices may have changed. Small sample size. Most patients were receiving HEN via NGT – longer term use of NGT is less common now. Participants may not be representative of HEN patient population.
Schneider et al. (2000) France	Cross sectional n = 38 (24M/14F) Mean ± SD 56 ± 5	To assess the QoL, and evolution of QoL in patients receiving long-term HEN	All HEN patients (PEG and Jejunostomy) >16 years receiving treatment for > 2 months. SF-36 + EuroQoL + VAS + Purposefully created subjective questionnaire.	SF-36: lower scores than for the general population. Mental 46.2 ± 2.6 vs 51.8 ± 0.3 (p < 0.05) Physical 37.1 ± 2.1 vs 46.5 ± 1.2 (p < 0.05) EQ-5D: HEN vs Gen. pop. where 0 = worst and 1 = best: 0.54 ± 0.07 vs 0.85 ± 0.00 VAS where 0 = worst and 100 = best: 54.1 ± 4.2 vs 82.5 ± 0.03	3 conditions were identified associated with better QOL: Patients < 45 years had increased physical function. Patients > 1 caregiver had better mental health. Patients with cancer had more limitations due to mental health. QoL in HEN patient group is lower than in the general population	Strengths: Use of validated QoL tools. Diverse patient population. Assesses patient QoL vs the general population. Limitations: Older study – practices may have changed. Small sample size.

Study Reference & Country of origin	Study type/ design Sample size & Age	Aim/ objective	Intervention (including the type of tube) & QoL measure	Overall results of QoL post-intervention	Findings/ Conclusion	Strengths & Limitations
Schneider et al. (1998) France	Exploratory prospective n = 23 (13M/10F) Mean age ± SD 62 ± 17	To evaluate QOL and HEN perception in patient receiving HEN long-term (> 3 months)	Patients receiving HEN. SF-36 + EuroQoL	SF-36: Mental component summary (42.2 ± 5.4) and Physical component summary (36.1± 9.6) significantly lower ($p < 0.05$) than the general population. EuroQol: mean value (54.6 ± 19.1) significantly lower ($p < 0.05$) than the general population (84 on a 0 - 100 scale)	Whilst most patients felt a subjective positive impact of HEN on their physical and mental well-being, scores reported were lower than the general population	Strengths: Use of validated QoL tools. Not specific to one underlying condition. Limitations: Older study – practices may have changed. Small sample size.
Reddy & Malone (1998) USA	Retrospective n = 24 (10M/14F) Range 24 - 80 years	To assess the impact of HPEN on lifestyle and health status.	17 HPN 7 HEN SF-36	No significant difference between QoL scores from HPN and HEN groups. QoL of HPEN lower than general population in all areas, excluding pain, role limitations due to mental health and general mental health.	More research is required to understand if there are differences in QoL between patients receiving home parenteral and home enteral nutrition. In general, those on HPEN experienced lower QoL than the general population.	Strengths: Use of validated QoL tools. Limitations: Older study – practices may have changed. Small sample size. Not specific to HEN patients.

Study Reference & Country of origin	**Study type/ design Sample size & Age**	**Aim/ objective**	**Intervention (including the type of tube) & QoL measure**	**Overall results of QoL post-intervention**	**Findings/ Conclusion**	**Strengths & Limitations**
Jamieson et al. (1997) UK	Prospective n = 131	To assess the impact of nutrition support interventions on poorly rehabilitated patients with chronic disease.	Dietary advice, ONS, NGT, PEG or HPN. Group 1: BMI <20kg/m2- intention is weight gain. Group 2: BMI 20-25 kg/m2- intention is maintenance. Nottingham Health Profile	Group 1 recorded improvements across every QoL category that were statistically significant, Group 2 reported none.	In undernourished patients weight gain was associated with increased perception of QoL.	Strengths: Large sample size. Variety of feeding access routes. Patients had a range of underlying conditions. Limitations: Older study – practices may have changed. Single centre study (Whitechapel). Whitechapel may be considered a poorer area of London so socioeconomics and patient demographics may not be representative of the general HEN population and may impact patient QoL.

2.3.1. HEN method of access

Method of access was found to corelate to QoL in two of the studies of Spanish cohorts (Zamanillo Campos et al., 2021; Apezetxea et al., 2014). Zamanillo Campos et al. (2021) found that tube-fed patients had lower QoL score than ONS, a multivariate analysis of oral vs tube-fed resulted in an odds ratio [OR], 5.6; 95% CI 2.0–15.3; $p = .001$. Apezetxea et al. (2014) also reported similar findings, for those receiving ONS vs tube-feeding (19.54 vs. 14.00 vs. 7.02; $p < 0.001$). However, most of the HEN QoL literature did not include ONS patients, focusing on tube feeding instead. Nevertheless, patients with nasogastric tubes were found to report lower QoL than those with gastrostomy tubes (mean ± SD) 14 ± 11.7 versus 7.02 ± 15.5, in Apezetxea et al's research (2014).

2.3.2. HEN Complications

Only one paper explicitly discussed a link between HEN complications and QoL. Correlation analysis by Zamanillo Campos et al. (2021) showed that patients who experienced adverse responses to HEN reported lower quality of life than those with no complications $\rho = -.275$; $p < 0.05$. The only complication named explicitly as an issue in the HEN QoL literature was sore throats by patients with nasogastric tubes in the study by Malone, (2002). Additionally, findings by Wu et al. (2018) showed improvements in fatigue, pain, nausea and vomiting symptoms after three months of HEN, and that in that period, no severe complications of HEN occurred. It is unclear, however, what the researchers classify as severe, as they do go on to mention that some ileus may have occurred. Whilst not discussing the impacts on QoL, the study by Schneider et al. (1998) found that 58% of French patients that reported HEN complications, resulted in hospitalisations.

2.3.3. Underlying condition

Using the EuroQoL 5Q-5D questionnaire the Spanish study by Wanden-Berghe et al. (2009) found inconclusive results when QoL was analysed by the patient's underlying pathology. However, when assessed using the visual analogue scale (VAS), patients with neurological disorders reported lower QoL than patients with cancer ($p = 0.003$). However, these results are at odds with more recent Spanish studies by Zamanillo Campos et al. (2021) and

Apezetxea et al. (2014), a French study by Schneider et al. (2000) and a British study by Day (2010). Day (2010), using a qualitative approach with semi-structured interviews based on themes identified in previous QoL studies, found lower QoL scores in palliative cancer patients but concluded that the reduced QoL may have been due to the cancer treatment, as opposed to the HEN treatment. Using a HEN-specific questionnaire (the NutriQoL), Zamanillo Campos et al. (2021) ($\rho = .276$; $p < 0.05$) and Apezetxea et al. (2014) found that cancer patients had lower QoL scores than patients with neurological or malabsorptive issues (12.76 versus 18.11 versus 17.37). These two studies also concluded that the NutriQoL domains of physical functioning and activities of daily living were better predictors of patient QoL than the social life domain. However, this appears to be due to the distribution of questions across the two domains. Research by Schneider et al. (2000) suggested there may be a relationship between cancer and reduced mental health. In this study, cancer patients reported significantly lower mental health status with the SF-36 questionnaire (39 ± 12 versus 72 ± 9), than those with neurological or malabsorptive disorders. Mental health is a component of many QoL tools, and so reduced mental health may lower total QoL score.

2.3.4. Weight loss & Malnutrition

Two studies using the EORTC-QLQ-C30 questionnaire and disease-specific modules reported that weight loss or malnutrition negatively impacted patients' QoL. Donohoe et al. (2017) who used the PEG-specific module found that those that continued to lose weight (>5% BMI) reported a lower QoL over time; physical score (76.7 versus 87.5, $p = 0.066$), and social score (76.4 versus 87.8, $p = 0.034$). Additionally, Loeser et al. (2003) used the oesophageal cancer-specific module and found that patients with malnutrition and weight loss reported lower QoL than those without ($\rho = -.029$). Conversely, weight gain was associated with improved QoL in the study by Jamieson et al. (1997).

2.3.5. Sex & Age

Schneider et al. (2000) found that French patients < 45 years of age reported better physical functioning than those who were older (76 ± 10 versus 43 ± 6). Conversely, the study by Malone (2002) found no significant difference in QoL scores using the SF-36 for American patients less than 50 versus patients who were older than 50 years old. Using the NutriQol questionnaire, Zamanillo Campos et al. (2021) found no relationship between age or sex and QoL in Spanish patients. Similarly, Wanden-Berghe et al. (2009) also found no relationship between age or sex when using the EuroQoL 5Q-5D. However, this study did find lower scores for females versus males when analysed using the VAS. It is unclear if this difference in findings between the French, American and Spanish studies is due to specific practices in Spanish HEN care.

2.3.6. Patient competence & Caregiver involvement

Schneider et al. (2000) found that patients with more than one caregiver had better mental health than those with one or no caregivers, suggesting increased patient support may positively impact QoL. Conversely Loeser et al. (2003) found that competent patients had a greater QoL score than incompetent patients (Karnofsky indices 53.7 ± 11.4 versus 32.6 ± 13.1, Spritzer indices 5.74 ± 1.53 versus 1.71 ± 1.96). In this study competent patients completed their own surveys, therefore QoL was better when self-reported as opposed to proxy reported.

2.3.7. Tools used to measure QoL

Research by Zamanillo Campos et al. (2021) showed that the tool used to measure patient QoL can impact the outcome. This research found that the NutriQoL questionnaire scored significantly better on two patient visits comparative to the SF-12 (V1, $p < .001$, n = 78; V2, $p < .001$, n = 64). Although the only study to report such findings, this indicates that the QoL tool utilised potentially has an impact on the QoL result. This may be problematic when comparing the literature, as of the 21 papers reviewed, 16 different QoL tools were utilised; two versions of the EuroQoL (the EQ-5D and the EQ-VAS); two versions of the short-form medical outcomes survey (SF-36 and SF-12); five different versions of the European Organisation for Research and Treatment of Cancer questionnaire (the standard tool, the oesophageal cancer specific tool, the head and neck cancer-specific tool, the esophagogastric specific tool, and the PEG specific tool); the Nottingham health profile; the Karnofsky & Spritzer indices; the FAACT; two purposefully created questionnaires; one interview guide created based on themes identified in other QoL studies; and one HEN-specific tool.

2.4. Factors affecting the patient experience

The patient experience (which includes equitable care), impacts patient outcomes (Smith, 2009), and yet specific research into HEN patient perspectives of care is scarce, see table 2.3. This literature review found twelve studies in the HEN patient experience, from five different countries. The majority of research (six studies) was conducted in the UK (Green et al., 2019; Halliday et al., 2017; Brotherton et al., 2007; Jordan et al, 2006; Liley & Manthorpe, 2003; L'Estrange 1997). Whilst two studies were from the USA (Asiedu et al., 2018; Thompson et al., (2006)), two from Sweden (Bjuresäter et al., 2015; Martin et al., 2012, one from Singapore (Ang et al., 2019) and one from the Republic of Ireland (Boland et al., 2017). Most of the studies used interviews (nine studies), and three used questionnaires. There was a mixture of research designs. Three studies were qualitative inductive, two were based on grounded theory, two were qualitative with purposive sampling, two were mixed methodology (with purposive sampling), one was a retrospective and one used photo-elicitation.

Table 2.3 outlines the key aspects of the relevant patient experience literature, including the relative strengths and limitations of the studies. In this literature four factors were found to impact the patient experience. These are discussed below.

Table 2.3 Review of the literature: Patient perspectives of HEN care

Study Reference & country	Study type/ design	Sample size & patient age	Aim/ objective	Key themes of the patient perspectives of HEN care	Strengths & Limitations
Ang et al. (2019) Singapore	Qualitative descriptive with inductive analysis In-depth face-to-face interviews	9 Patients 9 Family/ home carers Range 46 - 71	To explore patients & home carers experiences of HEN care	▪ Lack of information and knowledge regarding PEG procedure, care and complications was a source of anxiety. ▪ Information and support for emergency situations/ HEN complications (such as balloon dislodgement) was lacking. ▪ The support from a specialised nurse was well received for tube care	Strengths: Assessment of patient & career perceptions of care. Limitations: Small sample size. Single centre.
Green et al. (2019) UK	Qualitative inductive descriptive. Semi-structured face-to-face interviews with purposive sampling	19 Patients 15 Family/ home carers Range 47 - 83	To explore patients & home carers experiences of HEN care	▪ Patients would rather be at home than in hospital for care and management of their tubes, with many patients actively avoiding admission. ▪ Patients struggled upon discharge and felt that more support to learn the care required at home was necessary / would have been helpful prior to discharge. ▪ Not enough support available from skilled / experienced health care practitioners, (either for routine visits or when things went wrong).	Strengths: Assessment of patient & career perceptions of care. Included patients under services with differing practices, to allow a more representative sample of the HEN population. Limitations: Smaller sample size.
Asiedu et al. (2018) USA	Qualitative photo-elicitation interviewing method	10 Patients 8 Family/ home carers Range 30 - 85	To understand patient and carer experiences of HEN.	▪ Initial education delivered by the HEN team reduced anxiety about caring for self. ▪ More comprehensive education and support is required to help patients avoid infections and other tube complications.	Strengths: Photo elicitation was patient driven (patients were not guided but chose to photograph what was important to them). Run through the Mayo clinic (prestigious). Limitations: Small sample size. Single centre.

Study Reference & country	Study type/ design	Sample size & patient age	Aim/ objective	Key themes of the patient perspectives of HEN care	Strengths & Limitations
Halliday et al. (2017) UK	Qualitative inductive and descriptive	15 Patients Range 52 - 74	To understand how patients and home carers live with jejunostomy feeding tubes	▪ Anxiety about accidentally removing the tube caused by discussions regarding the difficulty replacing the tube with healthcare professionals prior to discharge. ▪ Training prior to discharge was positively received. ▪ Practical support around stoma and tube care from the HEN dietitian was positively received. ▪ Support during the weekends was lacking.	Strengths: Assessment of patient & career perceptions of care. Limitations: Small sample size May not be representative of general HEN patient population (Cancer & Jejunostomy specific, & study was single centre).
Boland et al. (2017) Republic of Ireland	Retrospective multicentre qualitative study Self-administered questionnaire	33 Patients 46 Carers 9 non-disclosed No age details reported	To explore the patient experience and attitudes related to HEN care	▪ 86% of patients were discharged with written information ▪ 82% of patients were discharged with a contact number in case of HEN complications ▪ The primary source of support for > 1/3 of patients was the hospital dietitian ▪ Community based care was limited (8% from community dietitian, 10% from community nurse, 15% from nutrition and feed companies, 7% from pharmacists, and 2% from general practitioners). ▪ Most HEN complications were successfully managed in the community	Strengths: Larger sample size. Assessment of patient & career perceptions of care. Multicentre. Limitations: Self-administered questionnaire, reducing the patient's ability to express concerns outside the scope of the questionnaire.

Study Reference & country	Study type/ design	Sample size & patient age	Aim/ objective	Key themes of the patient perspectives of HEN care	Strengths & Limitations
Bjuresäter et al. (2015) Sweden	Qualitative. Grounded theory Face-to-face interviews	11 Patients Range 37 - 79	To understand patient experiences of HEN	▪ Patients who felt well supported by their healthcare team were better able to manage the restrictions and distress in their daily lives. ▪ Provision of adequate knowledge & support had a positive impact on patient well-being. ▪ Follow-up contact, emotional and practical support by health care professionals after discharge resulted in a calm & reassured daily life for patients. ▪ Many patients did not feel well prepared for life with HEN and lacked guidance & support from health care professionals, resulting in anxiety and low well-being. ▪ Patients often received contradictory advice from health care professionals resulting in lack of confidence and feelings of insecurity.	Strengths: Multicentre. Use of grounded theory Limitations: Small sample size Excluded patients with Anorexia nervosa and cognitive impairment. A number (4) of patients declined to participate due to weakness, resulting in less understanding of the experiences of this patient group.
Martin et al. (2012) Sweden	Prospective cohort study. Patient questionnaires	104 patients Mean 64	To understand patients' perspectives of living with a PEG	▪ 80% used the HEN outpatient clinic when facing complications, or questions. ▪ The home care team would be the second option for patients facing complications. ▪ Negative HEN experiences were reported more by women than men. ▪ Around 20% of patients were not satisfied with their PEG	Strengths: Large sample size – high response rate (70%) Limitations: Single centre study with short follow-up time (2 months of HEN). Neurological patients who could not independently respond to the questionnaire were excluded. Questionnaire, reducing the patient's ability to express concerns outside the scope of the questionnaire. Limited to PEG patients.

Study Reference & country	Study type/ design	Sample size & patient age	Aim/ objective	Key themes of the patient perspectives of HEN care	Strengths & Limitations
Brotherton et al. (2007) UK	Cross-sectional mixed methodology Purposive sampling Semi-structured patient interviews	28 Patients Range 20 - 91	To understand the perspectives of patients, carers, nurses & dietitians regarding HEN (PEG)	▪ 60% of patients felt they did not receive enough information before PEG insertion ▪ 73% of patients reported receiving enough support from health care professionals. ▪ Health care professionals should not assume that patients share the same perceptions as they do. ▪ Patients require appropriate / sufficient information to assist in informed decision making.	Strengths: Wide age range of participants. Wide range of underlying conditions. Also included perceptions of carers and HEN dietitians and nurses (allowing for possible cross validation). Limitations: Older study – practices may have changed. Limited to PEG patients. Single centre.
Jordan et al. (2006) Wales	Mixed methodology Purposive sampling Sem-structured interviews	20 Patients Range 24 - 84	To explore the patients' perspectives of home PEG care	▪ Inadequate initial HEN education & follow-up High ▪ Burden of treatment felt due to lack of specialised knowledge of generalist health care professionals involved in care (including those at A&E). ▪ District nurses are wonderful but lack specialised knowledge and often have to ask others. ▪ One (named) point of contact to call when there are issues would make things easier for patients. ▪ Those seen by the specialist MDT PEG team greatly appreciated the service.	Strengths: Wide age range of participants. Multi-centre. Limitations: Older study – practices may have changed. Single centre. Limited to PEG patients on HEN > 12 months. Most patients had central nervous system disorders as their underlying conditions.

Study Reference & country	Study type/ design	Sample size & patient age	Aim/ objective	Key themes of the patient perspectives of HEN care	Strengths & Limitations
Thompson et al. (2006) USA	Qualitative Purposive sampling Semi-structured interviews (phone, in-person, and written)	12 Patients Range 51 - 87	To explore what helps foster resilience in patients receiving HEN	▪ Inadequate initial HEN education & follow-up ▪ Perceived lack of healthcare providers knowledge about HEN. ▪ Inadequate knowledgeable help and support for when things go wrong. ▪ 2/3 felt their healthcare practitioners did nothing to help them adapt or cope with receiving HEN.	Strengths: Multi-centre. Identifies key characteristics for HEN patients to build resilience. Limitations: Older study – practices may have changed. Smaller sample size. Limited to self- identified resilient patients. Hard to distinguish the effects of HEN on mental health from those of underlying disease complications.
Liley & Manthorpe, (2003) England	Qualitative Grounded theory Semi-structured fact-to-face interviews	6 Patients 5 Carers Range 45 - 84	To understand the impact of HEN on Patients and carers	▪ Perceived lack of healthcare providers knowledge about HEN, a cause of anxiety. ▪ District nurses are wonderful but lack specialised knowledge and often must ask others. ▪ Lack of confidence in health care professionals resulted in patients shifting from dependence to independence more rapidly.	Strengths: Study design limited the possibility of interviewer bias. Limitations: Older study – practices may have changed. Smaller sample size. Excluded patients with < 12 weeks experience. Most patients had neurological issues as their underlying conditions. Limited to PEG patients.

Study Reference & country	Study type/ design	Sample size & patient age	Aim/ objective	Key themes of the patient perspectives of HEN care	Strengths & Limitations
L'Estrange, (1997) Northern Ireland	Qualitative Purposive sampling Patient questionnaires	39 Patients Range 21 - 96	To understand patients' perspectives of HEN care	▪ 100% felt there was adequate initial basic HEN education prior to discharge. ▪ Lack of education regarding dealing with complications. ▪ Those who didn't receive further training at home felt it would have been useful. ▪ Many district nurses lack experience in HEN. ▪ Support is required for HEN, stoma care and emotional support. ▪ Lack of clarity regarding who should replace tubes.	Strengths: Wide age range of participants. Did not exclude patients in care homes. Patients had a range of feeding tube access. Limitations: Older study – practices may have changed. Questionnaire based so patients reported experiences were limited to the scope of the questionnaire. Most patients had neurological issues as their underlying conditions.

2.4.1. Impact of HEN on daily life

Patients voiced appreciation of the benefits of HEN, such as the reduce the risk of choking, and improved nutrition in the study by Green et al. (2019), and weight maintenance and sustaining life in the study by Asiedu et al. (2019). However, many reported physical and /or psychological impacts of HEN on their daily lives, affecting their general health and well-being, these are discussed below.

Physical challenges of living with HEN

Eight of the twelve patient experience studies reviewed, discussed the physical impact of HEN on the patients. The most common complications of HEN are outlined in the standards of care and best-practice literature (Bankhead et al., 2009; Bleumenstein et al., 2014; Ireton-jones, 2017; Itkin et al.,2011; McMahon, 2005). Furthermore, the majority of those complications have also been confirmed in the studies reported in this literature review of HEN patient experiences. However, an additional finding in the research by Thompson et al. (2006) was pain. Pain was also reported by patients in the more recent study by Ang et al. (2019). It is unclear why pain was not reported more widely in the literature. Similarly, tube breakages were only reported in the study by L'Estrange (1997). However, there may have been developments in materials, manufacturing, training and education since 1997, which may explain this. Additionally, with the exception of pulmonary aspiration, tube breakage and tube leakage, all HEN complications noted, were first reported in the 1997 study by L'Estrange and have been subsequently reported as recently as 2017 onwards.

Geographical representation of studies was limited to five countries, and most reports of complications were noted across most countries. Exceptions included reports of pulmonary aspiration (Ang et al., 2019), and tube leakage (Thompson et al., 2006; Asiedu et al., 2018).

Table 2.4. lists the HEN complications reported by patients, and the supporting literature to illustrate the distribution over the years and geographic locations of such complications.

Table 2.4 Common complications experienced by HEN patients - from the patient perspectives of HEN care literature.

Complication	Supporting literature	Country
Tube occlusion	Ang et al. (2019)	Singapore
	Asiedu et al. (2018)	USA
	Boland et al. (2017)	Republic of Ireland
	Thompson et al. (2006)	USA
	L'Estrange (1997)	Northern Ireland
Skin irritation at the access site	Green et al. (2019b)	UK
	Asiedu et al. (2018)	USA
	Halliday et al. (2017)	UK
	Thompson et al. (2006)	USA
	L'Estrange (1997)	Northern Ireland
Tube dislodgement	Ang et al. (2019)	Singapore
	Green et al. (2019b)	UK
	Asiedu et al. (2018)	USA
	Boland et al. (2017)	Republic of Ireland
	Thompson et al. (2006)	USA
	L'Estrange (1997)	Northern Ireland
Tube breakage	L'Estrange (1997)	Northern Ireland
Tube leaking	Asiedu et al. (2018)	USA
	Thompson et al. (2006)	USA
Vomiting	Boland et al. (2017)	Republic of Ireland
	Thompson et al. (2006)	USA
	L'Estrange (1997)	Northern Ireland
Nausea	Asiedu et al. (2018)	USA
	Halliday et al. (2017)	UK
	Jordan et al. (2006)	UK
	Thompson et al. (2006)	USA
	L'Estrange (1997)	Northern Ireland
Diarrhoea	Asiedu et al. (2018)	USA
	Halliday et al. (2017),	UK
	Jordan et al. (2006)	UK
	Thompson et al. (2006)	USA
	L'Estrange (1997)	Northern Ireland
Constipation	Asiedu et al. (2018)	USA
	Thompson et al. (2006)	USA
	L'Estrange. (1997)	Northern Ireland
Reflux	Halliday et al. (2017)	UK
	Jordan et al. (2006)	UK
	L'Estrange (1997)	Northern Ireland
Abdominal bloating/ cramps	Asiedu et al. (2018)	USA
	Halliday et al. (2017)	UK
	Jordan et al. (2006)	UK
	Thompson et al. (2006)	USA
	L'Estrange (1997)	Northern Ireland
Pulmonary aspiration	Ang et al. (2019)	Singapore
Stoma infections	Green et al. (2019b)	UK
	Asiedu et al. (2018)	USA
	Boland et al. (2017)	Republic of Ireland
	Halliday et al. (2017)	UK
	Thompson et al. (2006)	USA
	L'Estrange (1997)	Northern Ireland

Psychological challenges of living with HEN

Seven of the twelve patient experience studies noted emotional and psychological issues associated with life on HEN (L'Estrange 1997; Thompson et al., 2006; Halliday et al., 2017; Boland et al., 2017; Jordan et al., 2006; Liley & Manthorpe, 2003; Green et al., 2019).

A lack of emotional support through coping with the loss of the pleasure of eating food was highlighted as lacking by L'Estrange (1997). Similarly, Thompson et al. (2006) and Halliday et al. (2017) noted anxiety and depression was common amongst HEN patients. Approximately 25% of the patients assessed by Boland et al. (2017), felt HEN negatively impacted their daily activities, whilst patients in the study by Jordan et al. (2006) felt controlled by their HEN routine, believing it placed physical restrictions on their lives. They reported feeling a sense of isolation, and a loss of the social aspects of their lives. Findings from patients studied by Liley & Manthorpe (2003) and Green et al. (2019) mirrored these sentiments.

Results from the SF-12 questionnaire used by Jordan et al. (2006) indicated patients had low mental health and resilience. Resilience has been identified as a key indicator of well-being with the following key characteristics:

- acceptance of their new normal situation.
- active in seeking support and demonstrate willingness to accepted it.
- maximise their own independence and take charge of their well-being journey.

2.4.2. HEN education and information for the patients

Prior to leaving the hospital

Ten of the articles reviewed discussed the impact of the information and training provided to patients prior to a) deciding to have their PEG and b) leaving the hospital with their new feeding requirements. Asiedu et al. (2018), Ang et al. (2019), Boland et al. (2017), Martin et al. (2012), Jordan et al. (2006), Liley & Manthorpe, (2003) and L'Estrange, 1997 found that for patients where the need for HEN came about suddenly (such as after a stroke), patients felt they had not been given adequate time or information to consider the proposition. Additionally, research conducted by Brotherton et al. (2007) established that 27% of patients felt they had received enough information before deciding to have their PEG inserted. All (100%) patients studied by L'Estrange (1997) felt there was adequate initial basic training prior to discharge, however this study took place in 1996, so it is feasible that practices have changed. In contrast, 19% of patients questioned by Boland et al. (2017) felt they had not received enough training prior to discharge. This was similar to themes identified by Jordan et al. (2006), Thompson et al., (2006), and Liley & Manthorpe, (2003) who found that patients did not feel they received enough training prior to discharge. The information provided during training was deemed helpful by all of the patients (100%) in L'Estrange's (1997) study, in contrast 86% of patients assessed by Boland et al. (2017) felt they were discharged with adequate helpful written information. Halliday et al. (2017) found that training prior to hospital discharge was appreciated by the patients, additionally Asiedu et al. (2018) and Bjuresäter et al. (2015) found provision of adequate knowledge had a positive impact on patients well-being and reduced anxiety.

Specifically regarding problems with HEN

A common finding amongst the literature was the desire for patients to be sufficiently prepared for handling HEN complications at home. Patients interviewed by Ang et al. (2019), L'Estrange (1997) and Asiedu et al. (2018) all verbalised the need for information and education to allow them to deal with complications. Bjuresäter et al. (2015), found that patients who had been provided with practical information about handling the daily care of HEN understood the goal of the feeding method, what to do if complications occurred and who to contact for support, and thus felt sufficiently prepared to undertake HEN.

2.4.3. Patient support

Level of support provided/ available

Half of the articles reviewed discussed dissatisfaction with the level of support provided (Halliday et al., 2017; Boland et al., 2017; Brotherton et al., 2007; Jordan et al., 2006; Thompson et al., 2006; L'Estrange et al., 1997). Jordan et al. (2006) found that patients felt that more support was required once patients were in their homes, and over a third (n=7, 36%) of the patients in the study by L'Estrange (1997) were dissatisfied with the level of support they received. Similarly Brotherton et al. (2007) found 27% of patients were dissatisfied. Green et al. (2019) reported that patients and carers often felt they had just been left to deal with it all on their own, with support from healthcare workers described as very limited. In contrast in interviews conducted by Halliday et al. (2017), patients reported receiving an appropriate level of support, with most referencing the practical support around stoma and tube care provided by the HEN dietitian.

Access to healthcare professionals

The majority of patients and caregivers questioned by Ang et al. (2019) reportedly found it beneficial to have access to follow-up support from a nutrition nurse/ known healthcare provider. Similarly studies by Jordan et al. (2006) and Boland et al. (2017) found that a single point of contact to provide follow-ups and manage the needs of patients receiving HEN might improve the patient experience. Additionally, in the 2019 study by Green et al., patients reportedly preferred being at home over the hospital. In these instances patients reported actively avoided admissions. Doing so by choosing to wait until a weekday to seek care from the home care team instead.

Experience of health care professionals

A lack of experience of health care professionals regarding HEN care was noted in four of the studies (Liley & Manthorpe, 2003; Thompson et al., 2006; L'Estrange, 1997). In the 1997 study by L'Estrange, patients noted that the HEN care experience of district nurses was insufficient. In agreement with this was the findings of Jordan et al. (2006) and Liley & Manthorpe (2003). Additionally, interviews by Liley & Manthorpe (2003) uncovered that patients felt they could quickly identify the inexperience of health care professionals. It was reported that this led to a lack of trust in the health care professionals associated with their HEN care. In such instances, however, patients reported greater self-reliance. Furthermore, self-reliance was a marker of resilience in patients reported by Thompson et al. (2006).

2.4.4. Patient suggestions for improvements in HEN care:

Only two of the papers reviewed reported patient suggestions of ways that HEN care could be improved (L'Estrange (1997); Thompson et al., 2006). Patient suggestions for improvement are outlined below to provide insight into what was found to be important in these HEN populations.

L'Estrange (1997) - UK

- Better stoma care
- Periodic review of the condition of the tube

- Periodic review of patients' swallow
- A more efficient process for ordering giving sets
- That HEN care professionals have an understanding of what the feed tastes like.

Thompson et al. (2006) - USA

- HEN care should be individualised and care should be patient-centred.
- HEN-specific staff training should be increased, including the provision of practical information.
- HEN care providers should know the various support groups and refer patients.
- HEN care professionals should be taught how to recognise depression, foster open communication and be aware of the referral pathways.
- HEN care professionals should consider their bedside manner as important.
- HEN education should occur in stages.

2.5. Summary

Understanding QoL in HEN patients and the patient experience of HEN care has been a priority in certain countries since 1997; predominantly in the UK, Europe, China, and the USA. However, results are specific to the circumstances of those studies. Circumstances such as the age of the study, the age range of participants, the country of the study, the route of HEN access, the patients underlying health conditions, and the time to follow up (or time on HEN) mean that findings may not be representative of the general (or wider) HEN population currently. As there have been no other such studies conducted in NZ to date, the results of global findings must be used for comparison.

There is currently no global protocol for specific QoL research in HEN patients. Therefore, the variation in QoL tools used for data collection among various studies may present a limiting factor when comparing results (we identified sixteen different QoL assessment tools used in the literature). Whilst the tools available do measure the same construct, they do so in differing ways, with different weighting placed on aspects such as physical, emotional, and social wellbeing. However, these studies and their findings are important for shaping (or guiding) future studies.

A few knowledge gaps have been identified from this literature review. Firstly, no studies into the patient experience had a specific focus on understanding if care and service provision was equitable (as equitable care forms part of the patient experience). Additionally, no studies into HEN patients in NZ were identified.

Chapter 3. Research Manuscript

Title: An exploration of the overall quality of care of Home Enteral Nutrition (HEN) patients in the Counties Manukau district.

3.1 Abstract

Background: Positive patient experiences such as equitable care and patient satisfaction, can lead to better patient outcomes, and patients who are more likely to engage in the future. Many patients receiving home enteral nutrition (HEN) have reported reduced quality of life (QoL) and frustrations with services. Yet previously there has been no research into the experiences of HEN patients in NZ. The aim of this study was to investigate the overall quality of care of adult, long-term HEN patients aged over 18 years old residing in the Counties Manukau district.

Methods: A total of 42 patients receiving HEN through the Counties Manukau district completed a series of questionnaires, including demographic-, the NZ WHO Quality of life (NZWHOQoL) generic QoL-, the NutriQoL HEN specific- , and patient equity and experience questionnaires. Patients were then presented the opportunity to participate in individual interviews about their experiences with HEN care until data saturation was met. Staff responsible for HEN care of this patient group were invited to share their perceptions of HEN care in focus group sessions.

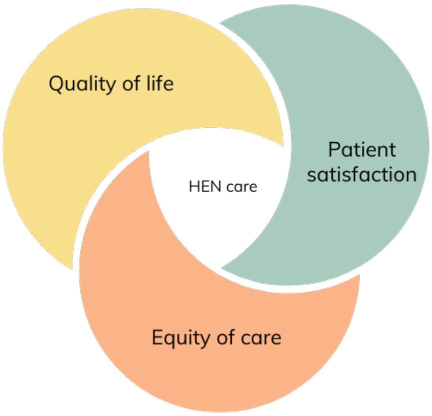
Results: Mean ± SD score of the NZWHOQoL-BREF was 2.86 ± 1.03, and 13.6 ± 8.02 for the NutriQoL. Equity of care and experience results showed unfavourable results for correct name pronunciation (76.2%), feeling well informed about treatment (78.6%), meeting cultural needs (81.0%), meeting spiritual needs (76.2%), meeting individual needs (81.0%), being treated with kindness (90.5%) and being treated unfairly (85.7%). Correlation analysis found certain patient participants related to the overall QoL score. The use of a proxy responder (e.g. a caregiver) was corelated with higher HEN QoL scores, as was longer duration on HEN. Cancer as their underlying health condition was corelated with lower HEN QoL scores, as was older age, and a marital status of previously married or separated. The same analysis for the NZWHOQoL QoL score found certain patient equity and experience metrics to correlate with the general QoL score. Where patients primary language was English, patients general QoL was higher, as was the case for when patients cultural or individual needs were met, or the length of visits met their expectations. Thematic analysis of

patient interviews revealed four themes: living with HEN, problems with HEN, HEN care, and suggestions for service improvements. Thematic analysis of the staff focus groups revealed three themes: burden of treatment, barriers to optimal care, and suggestions for service improvements.

Conclusion: General QoL was lower than for the general NZ population, yet HEN specific QoL was higher than reported in Spanish populations. Equity and experience results and results from patient interviews and staff focus groups identified key areas for service improvement and suggest there may be operational issues spilling over into the patients' space and impacting their care.

3.2 Introduction

The overall quality of care of any patient group may be broad and complex to assess, with quality of life, patient satisfaction, and equity of care all important aspects of the patient experience (figure 3.1). Quality of life refers to the general well-being of the patient, and includes physical, social, and emotional aspects. Patient satisfaction refers to the patient's perception of care and includes aspects like communication and responsiveness of healthcare professionals, timeliness of access to services, and effectiveness of treatments. Equity of care means that all patients have access to quality care tailored to their individual needs and preferences. These three seemingly separate components are interlinked and form an important part of the overall patient experience of care. This is because patients who feel they have received good-quality, equitable care that has improved their health are more likely to have positive perceptions of their care and be more likely to trust and engage in the future.



Abbreviations used: Home Enteral Nutrition (HEN)

Figure 3.1 Aspects contributing to the overall quality of patient care

Many patients are unable to consume enough nutrients orally to meet their needs. This may be due to chronic illness, because of recent surgery, or due to medical conditions such as neurological disorders and cancer. These patients are often otherwise medically stable and able to live outside the hospital, so receive HEN. Home enteral nutrition is a method of supplying nutrients using liquid feeds (or liquidised food) directly to the gastrointestinal tract via a feeding tube, such a as a nasogastric tube, gastrostomy, or jejunostomy tube. Where patients have received HEN for longer than four weeks, it is considered to be long-term. Home enteral nutrition can help prevent malnutrition and improve the overall health and quality of life for these patients.

Understanding the overall patient experience of HEN care in NZ is essential for improving overall health outcomes. Whilst one intention of long-term HEN is improved QoL, little is known about the QoL of HEN patients in NZ. The NZ population is diverse, and the Counties Manukau region is home to some of the most socio-economically disadvantaged patients in the country. Equity of care, and patient satisfaction are assessed by the NZ Heath Quality and Safety Commission (HQSC) at the in-patient, and primary-care level. However, there is a gap in knowledge regarding the outpatient and community patient groups, of which HEN patients sit within.

The aim of this study was to investigate overall quality of care of adult, long-term HEN patients aged over 18 years old residing in the Counties Manukau district. This investigation assessed the patient's QoL (general and HEN-specific), along with perception of equity of care provided, and perceptions of HEN care and the HEN service. To ensure a comprehensive assessment, we also assessed the HEN health care professionals' perceptions of HEN care, patient satisfaction, and equity of care.

3.3. Materials & Methods

3.3.1. Participants & procedures

Study design

This study was a cross-sectional observational study evaluating the impact of the HEN services provided to the patients of the Counties Manukau district community services team, using both quantitative and qualitative methodology. The first phase was focused on HEN patients, using quantitative survey research to assess patient QoL and perceptions of equity of care. This was combined with patient interviews to further explore the views, experiences, and beliefs of patients regarding quality and equity of care. The second phase involved focus groups of the health care teams involved in HEN patient care to explore their perspectives on the quality- and equity of care that they provide to HEN patients.

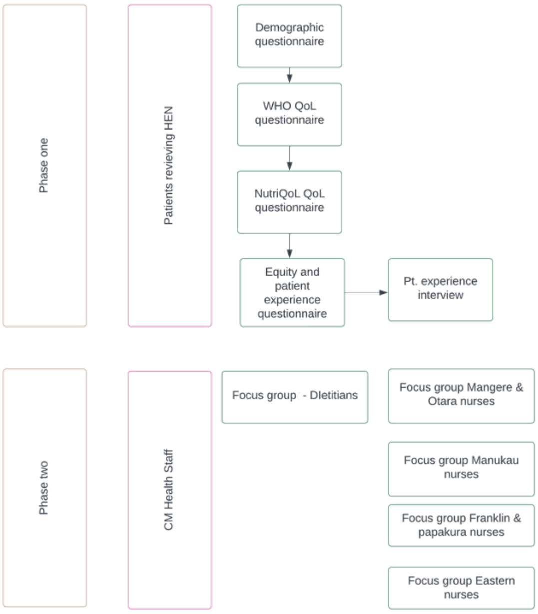
Participants and participant recruitment

The main target population was patients receiving HEN services through the Counties Manukau community health services team. Inclusion criteria were patients aged 18 years or older that had received HEN for longer than four weeks, were tube-fed (TF) either partly or solely, and with the ability to provide informed consent (or via their carers). Exclusion criteria included those receiving oral nutritional supplementation and no TF and those nearing end-of-life. Patients were identified, and eligibility was assessed using patient data from the Te Whatu Ora information system Clinical Portal. Eligible patients were invited to partake by phone call, or by their preferred method of contact (phone call, email or text message) where their underlying condition may have led to difficulties communicating verbally. Where the requirement for an interpreter was identified in the clinical portal system, the family member who the patient had nominated to act as their interpreter or proxy was contacted. Where patients were unable to communicate due to their underlying condition, their caregiver was contacted via phone. A participant information sheet and consent form were provided either via email or in person (See Appendix A1), and participants were offered a $50 koha (a gift) for their participation. Patients (or via proxy through their caregivers) who indicated a willingness to participate, were sequentially assigned a participant identification number to ensure confidentiality of information collected.

The secondary target group of interest was HEN health care professionals, including Dietetic and Nursing staff from the Counties Manukau community team. Inclusion criteria were those staff employed in the community service from these two professions in the four services bases operational in the Counties Manukau district. Exclusion criteria included research team members. Key managers were contacted and provided with a flyer and email invitation and to be passed onto their staff. Due to the small team size, all of the registered dietitians working across the four service bases were invited to take part in one focus group. However, four different focus groups were organised for the team of registered nurses working across the four service bases (Eastern, Pukekohe, Mangere, Manukau). All the nurses were therefore invited to attend a base-specific focus group session. The nursing focus group sessions were planned in conjunction with the nursing managers and were held at a time most convenient for the majority of staff to attend. Participant information sheets and consent forms were provided and signed before each of the focus group sessions (see Appendix A2).

Study process

The research was carried out in two phases (see figure 3.2). In phase one, patients were visited in their homes. They completed a consent form, followed by a series of questionnaires that were accessed and completed electronically via an iPad. These questionnaires included a demographic questionnaire, a NZ-specific QoL questionnaire, a HEN-specific QoL questionnaire, and an equity and patient experience questionnaire. The abovementioned constitutes the quantitative data. In addition, if consent was obtained, a qualitative patient interview was conducted and recorded with patients that consented. The patient interviews continued until data saturation was reached.



Abbreviations used: Patient (Pt.), Quality of life (QoL), World Health Organisation (WHO), Nutrition quality of life tool (NutriQoL)

Figure 3.2 Flow chart of data collection process

Independent of phase one, in phase two, focus groups were conducted with staff from the Counties Manukau community services teams.

Ethics Approval

Ethics approval was obtained from the Massey University Human Ethics Committee (MUHEC) on the 26th of June 2022 (HEC: Southern A Application SOA 22/20). Approval was also received from the Counties Manukau region research office (research registration number:1631).

Cultural consultation

Throughout the study design, and as part of the ethics process, cultural consultation occurred with Māori and Pacific dietitians and members of the community.

3.3.2. Study Measures & Variables

The following methods were included during the two phases of research conducted.

Phase One

Demographics questionnaire - participants self-completed a demographics questionnaire capturing data such as survey responder, gender, date of birth and ethnicity (see Appendix A3*)*.

NZ-specific QoL questionnaire - general quality of life was assessed using the NZ World Health Organisation QoL questionnaire (NZWHOQoL-BREF). The BREF is the shortened version of the WHO-100 and has been adapted and validated for use in NZ by Billington (2010). It includes 31 questions over four domains: 7 physical health questions, 10 psychological well-being questions, 4 social relationship questions, 8 environment questions, and two general health and well-being questions. As part of this, five NZ-specific questions reflect themes and values that are important to New Zealanders. These include meeting the expectations placed on yourself, ability to manage personal difficulties, control over life, feeling respected by others and feelings of belonging. As the WHOQOL was developed to be used cross-culturally, it is sensitive to any multi-cultural settings such a NZ (see Appendix A5).

HEN-specific QoL questionnaire - HEN-specific QoL was assessed using the NutriQol questionnaire (Apezetxea et al., 2016). It was created and validated for use in HEN patients by researchers in Spain in 2014. The validated NutriQoL comprises of two domains and contains 17 two-part questions. Part A assesses the patients' perceived frequency of an event, circumstance, or situation. Part B assesses the importance the patient places on that event, circumstance, or situation. The questions are framed in two domains: 1) the physical functioning and activities of daily living domain (14 questions), and 2) the social life domain (3 questions) (see Appendix A7).

Equity and patient experience questionnaire – an Equity of care questionnaire was created using relevant questions from the validated NZ HQSC patient experience data sets (HQSC, n.d) to evaluate equity of care and patient experience of care. The questionnaire assesses equitable aspects of care in line with the NZ context, and included themes such as communication, needs, values, and respect (see Appendix A9).

Patient experience interviews - patient experience interviews were conducted until thematic data saturation was reached. Interview guides were created using the following key themes; equity of the patient experience, communication about HEN, confidence in the management of HEN, and problems with HEN (see Appendix C1). Interviews were audio recorded using an iPad, and the interviewer took notes.

Phase Two

Staff focus groups - focus groups were conducted until thematic data saturation was reached. The focus group interview guide (see Appendix C2) was created with the same key themes as the patient experience interview guide. Focus groups were audio recorded using an iPad and a Dictaphone in case of audio-file corruption, and the interviewer took notes.

Phase One & Two

Standard operating procedures - standard operating procedures were created and followed by the research team for the administering of the questionnaires, patient interviews and focus groups, these can be found in Appendix C3.

Data processing

Once all of the quantitative data was collected it was downloaded into master excel spreadsheets, and coded as follows. The demographics questionnaire was coded using our own method (see Appendix A4). The patient equity and experience questionnaire were coded using guidelines provided by IPSOS NZ, who are responsible for the NZ HQSC patient experience data (see https://www.hqsc.govt.nz/resources/resource-library/adult-primary-care-patient-experience-survey-methodology-and-procedures/). The NZWHOQoL-BREF questionnaire was coded using the guidelines outlined in the user manual supplied by the NZWHOQoL team at Auckland University of Technology (see Appendix A6). And the NutriQoL was coded using the coding structure outlined by (Apezetxea et al., 2016) and provided to us by Nestle Spain (see Appendix A8).

Qualitative data recordings were sent away to be transcribed externally. Transcriptions were then reviewed, and recordings replayed (and notes reviewed) so any gaps could be filled in.

3.3.3. Statistical Analysis

Statistical analysis was conducted using IBM SPSS statistics version 29 (IBM Corp, 2022). First, data was tested for normality using the Kolmogorov Smirnov normality test. Parametric data were then summarised by mean ± standard deviation, non-parametric data were reported as frequency and percentage. Correlation analysis was run using Spearman's rank-order coefficient (ρ). Significance was represented by a p value < 0.05 or < 0.001.

3.3.4. Qualitative analysis

Thematic qualitative analysis was conducted using NVivo 1.7.1 QRS International Pty Ltd, 2022). Interview and focus group transcripts were analysed separately. This was a systematic and iterative process. Initially transcripts were read through to create researcher familiarity and context. Transcripts were then uploaded into NVivo, and common words were identified as codes. Through continued reading, connections and relationships between codes were identified, and these were grouped with like topics, to create sub-themes. These sub-themes were then reviewed, refined, and validated through a thorough exploration of the relationships within and across codes by utilising mind-mapping techniques (see figures 3.4 & 3.5). Sub-themes were then grouped with like topics and overarching key themes emerged.

3.4 Results

3.4.1 Participant characteristics

In the Counties Manukau district, 101 patients were noted as receiving HEN in the clinical portal system, of which 79 (78.2%) were eligible for this study. Of the eligible patients 42 (53.1%) consented to participate (23 males and 19 females). All 42 participants (27 patients and 15 caregivers acting as proxy) completed all questionnaires during the in-patient visit (see table 3.1). The mean ± SD age was 47 ± 21.7 years, and the mean ± SD time on HEN was 86.2 ± 88.0 months.

Overall, 17 (40.5%) patients were receiving HEN due to cancer, 14 (33.3%) due to congenital or developmental issues, and 11 (26.2%) due to neurological illness. Additionally, 27 (64.3%) patients considered themselves disabled. Routes of HEN access were mainly MIC-KEY buttons and PEGs in 36 (85.7%) patients.

Several patients (12, 28.5%) had no formal education, and 14 (33.3%) were unemployed, with 7 (16.7%) being unable to work due to their illness. Overall, 25 (45.6%) participants lived in a household with an annual income of $50,00 or less per annum.

Table 3.1 Participant characteristics

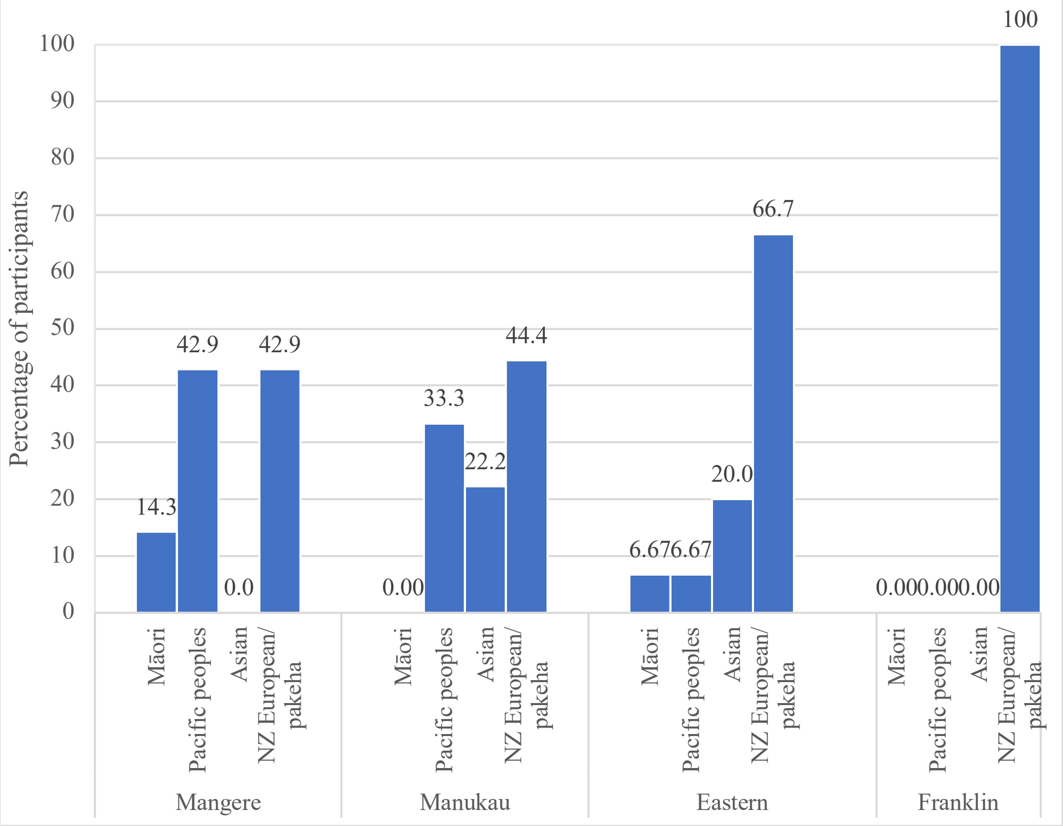
	Prospective participant pool (n = 79; eligible patients)		**Study Participants (n = 42)**		**Declined (n = 37)**	
Patient characteristics	**Mean ± SD**	**Median (25,75)**	**Mean ± SD**	**Median (25,75)**	**Mean ± SD**	**Median (25, 75)**
Age (y)	51.6 ± 21.6	57 (29,70)	47 ± 21.7	51.5 (21.8, 64.5)	53.1 ± 20.9	57.0 (30.0, 70.5)
Time on HEN (months)	74.3 ± 80.9	41 (9.50, 104)	86.3 ± 88.0	51.50 (21.8, 64.5)	79.1 ± 80.1	67 (14.5, 109)
	n	**%**	**n**	**%**	**n**	**%**
Gender						
Male	45	57.0	23	54.8	22	59.5
Female	34	43.0	19	45.2	15	40.5
Ethnic group						
Māori	5	6.33	2	4.76	3	8.11
Pacific peoples	16	20.3	7	16.7	9	24.3
Asian	12	15.2	5	11.9	7	18.9
NZ European/ pakeha	42	53.2	28	66.7	14	37.8
Unspecified	4	5.06	0	0.00	4	10.8
Community base locations						
Mangere	20	25.3	7	16.7	13	35.1
Manukau	19	24.1	9	21.4	10	27.0
Eastern	26	32.9	15	35.7	11	29.7
Franklin	14	17.7	11	26.2	3	8.11
Reason for TF (underlying condition)						
Neurological	19	24.1	11	26.2		
Cancer	28	35.4	17	40.5		
Congenital/ developmental	28	35.4	14	33.3		
Other	4	5.06	0	0.00		
Interpreter required						
Yes	6	7.59	1	2.38		
No	73	92.4	41	97.6		

Tube type				
Mic-Key	34	43.0	19	45.2
NG	6	7.59	3	7.14
NG-J	2	2.53	1	2.38
PEG	34	43.0	17	40.5
RIG	2	2.53	2	4.76
Unspecified	1	1.27	0	0.00
Age group				
18 to 24	14	17.7	11	26.2
25 to 44	17	21.5	7	16.7
44 to 64	24	30.4	14	33.4
65 +	24	30.4	10	23.8
Survey Answerer				
Participant			27	64.3
Caregiver			15	35.7
Household income per year				
Not stated			5	11.9
$20,000 or less			9	21.4
$20,001 - $50,000			11	26.1
$50,001or more			17	40.5
Highest education level achieved				
No formal education			12	28.6
Secondary school			20	47.6
Tertiary			10	23.8
Employment Status				
Employed			7	16.7
Unemployed			7	16.7
Unable to work due to illness			7	16.7
Student			8	19.0
Retired			13	31.0
Marital status				

Single	19	45.2
Married or living as married	18	42.9
Previously married or separated	5	11.9
Patient considers themselves disabled?		
Yes	27	64.3
No	15	35.7

Groupings and categories: Pacific peoples include Samoan, Niuean, Cook Island and Cook Island Māori. Asian includes Indian and Chinese patients. Neurological conditions include Inclusion body myelitis (IBM), Emery-Dreyfus muscular dystrophy, Motor Neuron Disease (MND) and Myalgic encephalomyelitis (ME/CFS). Other includes Chron's disease/ short bowel, Gastroparesis and Anorexia Nervosa. No formal education includes patients who completed primary school. Previously married or separated includes separated, divorced and widowed patients.
Abbreviations: Mic-Key, Mic-Key button low profile gastrostomy tube; NG, nasogastric tube; NG-J, nasogastric tube with extension into the jejunum; PEG, percutaneous endoscopic gastrostomy; RIG, radiologically inserted gastrostomy.

Within the four base regions serviced by the CM district, 16 (38.1%) participants resided in the Mangere and Manukau base regions. Those who reported as Māori, Pacific peoples, and Asian comprised 14 (33.4%) participants whilst NZ Europeans comprised 28 (66.7%) participants.



Values are expressed as %. Number at the top of the columns represent the %.

Figure 3.3 Recruitment breakdown by base and ethnic group

Gender played a small role in the decline rates of participants, with 49% of males and 44% of females declining involvement in the study. The distribution of decline rates by community base location was 65% of patients from Mangere, 53% of patients from Manukau, 42% of patients from Eastern, and 21% of patients from Franklin. The distribution of decline rates by Ethnic group was 100% of patients who had not specified their ethnicity in the clinical portal system. This was followed by 60% of Māori patients, 58% of Asian patients, 56% of Pacific peoples and 33% of those identifying as NZ European/ Pakeha. In some cases patients (with and without proxies, caregivers or family interpreters) declined involvement due to impending overseas trips. Meaning an appropriate visit time could not be arranged.

3.4.2 Quality of life outcomes

The NZWHOQoL results revealed that 14 (33.3%) participants reported being satisfied with their health, with a mean ± SD score of 2.86 ± 1.03 (indicating neither satisfied nor dissatisfied) (see table 3.2). For self-rated quality of life, 20 (47.6%) patients reported a good quality of life, and the mean score ± SD was 3.26 ± 0.86 (indicating neither poor nor good). The mean ± SD scores at the domain level, when viewed in line with the maximum possible scores for each domain, were lowest for physical- at 20.7 ± 5.27, followed by psychological- at 33.5 ± 6.70, social- at 14.3 ± 2.76 and highest for environmental relationships at 28.8 ± 5.

Results from the NutriQoL questionnaire showed that most participants (29, 69.0%) had a good quality of life, and the mean ± SD score was 13.6 ± 8.02.

Table 3.2 Self-reported quality of life

Quality of life	**Mean ± SD**	**N**	**%**
NZWHOQoL Self-rated health satisfaction (and scores)			
Very dissatisfied (1)		5	11.9
Dissatisfied (2)		10	23.8
Neither satisfied or dissatisfied (3)		13	31.0
Satisfied (4)		14	33.3
Very Satisfied (5)		0	0.00
Total NZWHOQoL Self-rated health-satisfaction	2.86 ± 1.03		
NZWHOQoL Self-rated QoL (and scores)			
Very poor		2	4.76
Poor		5	11.9
Neither poor nor good		15	35.7
Good		20	47.6
Very good		0	0.00
Total NZWHOQoL self-rated QoL score	3.26 ± 0.86		
D1 Physical (7 to 35)	20.7 ± 5.27		
D2 Psychological (10 to 50)	33.5 ± 6.70		
D3 Social relationships (4 to 20)	14.3 ± 2.76		
D4 Environmental (8 to 40)	28.8 ± 5.70		
NutriQoL QoL categories (and scores)			
Very bad (-51 to -30)		0	0.00
Bad (-29 to -11)		0	0.00
Regular (-10 to +10)		13	31.0
Good (+11 to +31)		29	69.0
Very good (+32 to +51)		0	0.00

Quality of life	Mean ± SD	N	%
Total NutriQoL QoL score	13.6 ± 8.02		
D1 Physical + ADL	7.98 ± 7.16		
D2 Social life	5.57 ± 2.11		

Abbreviations: NutriQoL, The nutritional quality of life HEN specific questionnaire; NZWHOQoL, the New Zealand World Health Organisation short form quality of life questionnaire. **Scoring:** For NZWHOQoL scoring, a higher score implies higher QoL (QoL and quality of health rated from 1 to 5).

3.4.3 Equity and experience outcomes

Results from the equity and care experience questionnaires (see table 3.3*)* showed that overall, 9 (21.4%) patients reported that their names were sometimes incorrectly pronounced, with 20 (47.6%) indicating that the healthcare professional did not need to ask how to pronounce their names. Only one patient (2.38%) reported not being informed about treatment, along with not being involved as much as they would have liked in their treatment and care. With regards to needs, two (4.76%) patients reported they did not have their cultural needs met, three (7.14%) patients reported not having their spiritual needs met, and one patient (2.38%) reported not having their individual needs met. Two patients (4.76%) reported they were not treated with kindness, and six patients (14.5%) felt they were treated unfairly by their nurse or dietitian.

Table 3.3 Patient equity and experience results

	Yes		**Sometimes/ somewhat**		**No**		**Can't remember/ don't know**		**This doesn't apply to me**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Was your name pronounced properly	32	76.2	9	21.4	0	0.00	1	2.38	0	0.00
Were you asked how to pronounce your name	13	31.0	6	14.3	0	0.00	3	7.14	20	47.6
Were you informed as much about your treatment and care as you would have liked	33	78.6	8	19.0	1	2.38	0	0.00	0	0.00
Was everything explained to you in a way you could understand	35	83.3	7	16.7	0	0.00	0	0.00	0	0.00
Were you treat with Kindness	38	90.5	2	4.76	2	4.76	0	0.00	0	0.00
Were you treat with respect	38	90.5	4	9.52	0	0.00	0	0.00	0	0.00
Do the HCP spend enough time with you	32	76.2	8	19.0	2	4.76	0	0.00	0	0.00
Do you have trust and confidence in your HCP	35	83.3	7	16.7	0	0.00	0	0.00	0	0.00
Do you feel comfortable to ask questions	38	90.5	3	7.14	0	0.00	1	2.38	0	0.00

Do you feel you are involved in your treatment and care as much as you would like	34	81.0	7	16.7	1	2.38	0	0.00	0	0.00
Were your cultural needs met	34	81.0	6	14.3	2	4.76	0	0.00	0	0.00
Were your spiritual needs me	32	76.2	7	16.7	3	7.14	0	0.00	0	0.00
Were your individual needs met	34	81.0	7	16.7	1	2.38	0	0.00	0	0.00
If you wanted to could you have whanau/ family involved	38	90.5	1	2.38	0	0.00	0	0.00	4	9.52
Did cost ever stop you picking up a script	3	7.14	0	0.00	39	92.9	0	0.00	0	0.00
Were you treat unfairly	6	14.3	0	0.00	36	85.7	0	0.00	0	0.00
Do you always follow Rx instructions	36	85.7	6	14.3	0	0.00	0	0.00	0	0.00

Groupings and categories*: This does not apply to me, includes the responses they did not need to ask, not applicable, and I do not want them included.* ***Abbreviations****: Rx, prescription.*

3.4.4. Relationships between the NutriQoL score, NZWHOQoL score, equity and experience scores, and patient characteristics

Spearman's rank correlation (ρ) was completed to assess relationships between the NutriQoL Scores, equity and experience scores, and patient characteristics (data not shown, see supplementary table 1 in Appendix B). There was a positive correlation between the total NutriQoL quality of life score and the proxy survey respondent, $\rho = .362$; $p < 0.05$, underlying health condition, $\rho = .369$; $p < 0.05$, and time on HEN, $\rho = .397$; $p < 0.001$. A negative correlation was observed with age group, $\rho = -.492$; $p < 0.001$, and marital status, $\rho = -.492$; $p < 0.001$. An interpretation of these results can be seen in table 3.4.

Table 3.4 Interpretation of correlation analysis between the NutriQol Qol scores and patients' characteristics

Corelation factor	Spearman's correlation (ρ)	Statistical significance	Meaning (highest QoL)	Meaning (lowest QoL)
Survey respondent	.362	p < 0.05	Caregiver	Patient
Underlying health condition	.369	p < 0.05	Congenital and developmental illnesses.	Cancer
Time on HEN	.397	p < 0.001	Longest	Shortest
Age group	-.492	p < 0.001	18 – 24 years	65 + years
Marital status	-.492	p < 0.05	Single	Previously married or separated

Previously married or separated includes divorced, separated, and widowed patients.

Correlation analysis between NZWHOQoL self-rated QoL, equity and experience scores and patient characteristics showed significance for primary language $\rho = -.322$, $p < 0.05$; if the patient felt their health care professional spent enough time with them $\rho = -.409$, $p < 0.001$; if a patient felt their cultural needs were met $\rho = -.375$, $p < 0.05$; and if a patient felt their individual needs were met $\rho = .483$, $p < 0.001$ (data not shown see supplementary table 2 in Appendix B). An interpretation of these results can be seen in table 3.5.

Table 3.5 Interpretation of corelation analysis between NZWHOOQoL QoL score and equity and experience metrics

Corelation factor	Spearman's correlation (ρ)	Statistical significance	Meaning (highest QoL)	Meaning (lowest QoL)
Primary language	.322	$p < 0.05$	English	Samoan
Visit was long enough	-.409	$p < 0.001$	Yes, definitely	No
Cultural needs were met	-.375	$p < 0.05$	Yes, definitely	No
Individual needs were met	.483	$p < 0.001$	Yes, definitely	No

3.4.5. Qualitative investigation of the patient experience and equity of care of patients receiving HEN care

Seven participants from Mangere, Eastern and Franklin base locations were interviewed (three caregivers acting as proxy, and four patients). Patients had been receiving HEN for between 7 months and 19 years. All patients interviewed were NZ European (n = 7). Four themes emerged from the interviews; living with HEN, which related to patients experiences of life with HEN, problems with HEN, which related to the problems patients had experienced, HEN care and support, which related to their experiences of the HEN service, and suggestions for improvement (see figure 3.4).

Theme 1:Living with HEN

Patients spoke about their experiences with HEN, reflecting on the times they had to adapt because of their HEN. They spoke of how their confidence in self-managing HEN changed over time, noting the advantages and disadvantages of life with HEN.

Subtheme 1.1: Transitionary periods

Adapting to life with HEN, switching feeds or regimes, and moving from paediatric to adult services were identified as periods of change. Stress and frustration were common; learning new routines and replacing food with a liquid supplement. Participants found it easy to learn the basics, but a lack of information made it difficult to self-advocate and be autonomous.

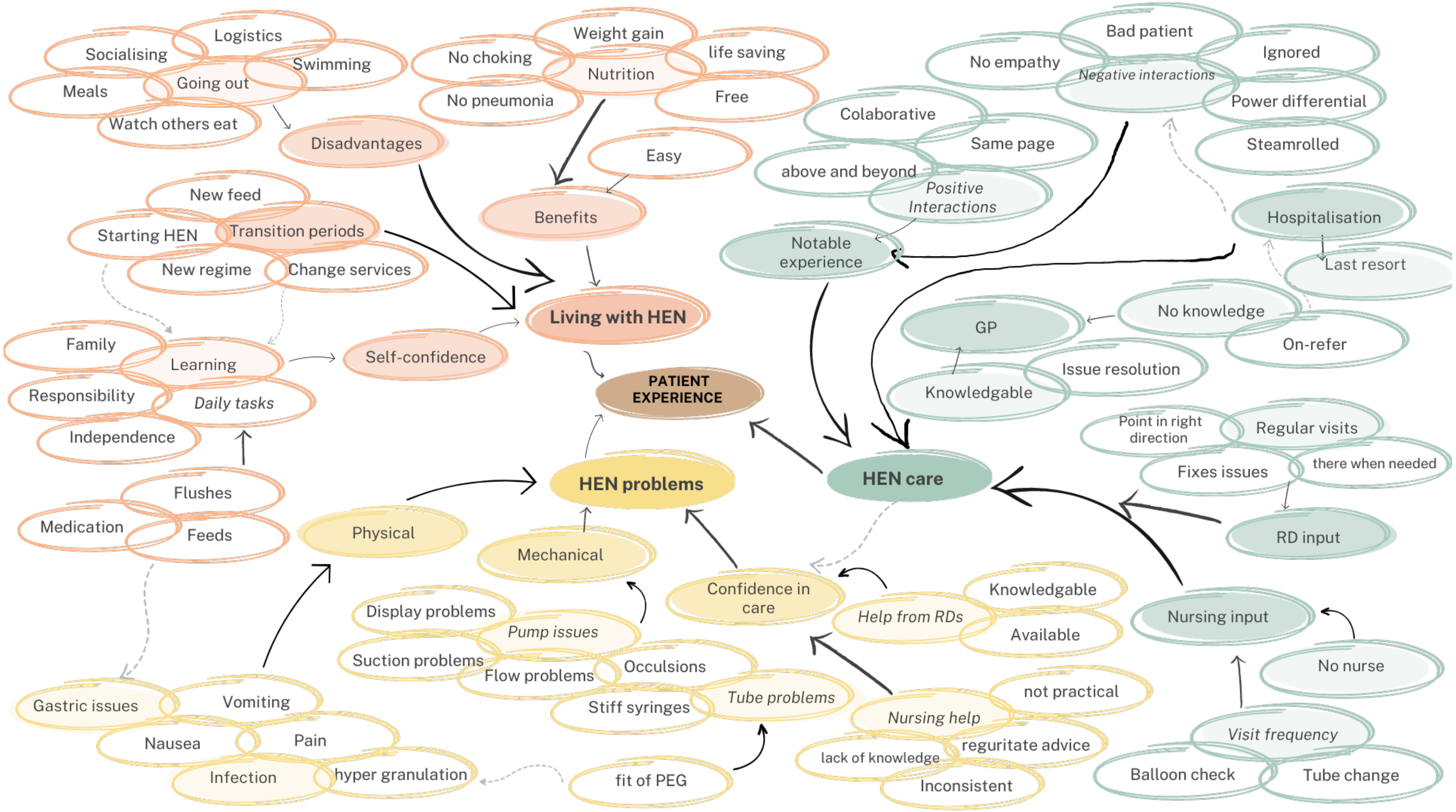
> *"Taken a while to get used to but going okay now. Frustrating, though."*
>
> *(Patient 7)*

Patients felt nervous switching to new regimes or feeding methods. Syringe and gravity feeding at mealtimes is less efficient than pump feeding during sleep. Using a syringe to feed at mealtimes can also cause nausea if too much liquid is pushed in too quickly.

> *"... now that I've moved to the daily feed...I take my time .... I don't want to shove it all in and feel sick...."*
>
> *(Patient 1)*

Patients who received HEN before age 18 had to move from paediatric to adult services. Those without caregivers had to take on new responsibilities and get used to self-advocating in an unfamiliar system.

> *"...I always had a fear of changing my tube, then I moved to the adult service and you change it yourself...no one was willing to teach me...there's just a lack of support when transferring to the adult services".*
>
> *(Patient 1)*



Common words were identified as codes, these were grouped with like topics to create sub-themes, which were then rolled up under overarching themes.

Figure 3.4 Mind map of patient interview coding and themes

Subtheme 1.2: Self-confidence

Most participants were confident with daily HEN tasks, such as feeding, flushing and administering medications. Feeding became a habit for patients looking after their own HEN.

> *"...he does it by himself now, yeah, become second nature to him...".*
>
> *(Caregiver 2)*

Subtheme 1.3: Advantages of HEN

Participants were grateful for HEN, as it was important for sustaining life, consuming nutrients safely, and managing weight. They were also appreciative of the reduced food costs and the ease of feeding.

> *"I don't have to do cooking or washing up ... I don't have to buy food, I'm grateful for that, to be honest...."*
>
> *(Patient 5)*

Subtheme 1.4: Disadvantages of HEN

Patients and caregivers spoke of their daily challenges living with HEN. Patients felt stressed taking their equipment and feeds out with them, and felt awkward feeding in public. Patients no longer enjoyed meals with others due to their inability to eat. Swimming was also of particular concern.

> *"I can't go on holiday anymore. Can't swim...family Christmas dinner, that's the hardest, everybody's got Turkey and roast, things that you love, lots of desserts, and you sit there...".*
>
> *(Patient 5)*

Theme 2: Problems with HEN

Complications were common in HEN patients' journeys. They spoke of the physical problems they had suffered, along with the mechanical issues some faced daily. Participants also spoke of their confidence in the care they received when reaching out for help.

Subtheme 2.1: Physical HEN problems

All participants reported physical problems, with most noting infection and hypergranulation. Patients felt they could not self-advocate, as they were not told about the common complications, their causes, or how to avoid them. Some participants reported weakness, gastric problems and pain; they were concerned because they did not know the cause or how to treat it.

> *"she said you're going to get hypergranulation, I didn't fully understand what that was until I did get it."*
>
> *(Patient 6)*
>
> *"…he'll complain about being sore, but I don't know what it is that's sore…."*
>
> *(Caregiver 2)*

Subtheme 2.2: Mechanical issues with HEN

Participants reported experiencing mechanical complications, such as tube and pump problems. Patients were frustrated by frequent occluded tubes and stiff syringes. Caregivers noted issues with pump suction, and mismatches between the display and the volume pumped. These were accepted as part of the HEN experience.

> *"…bit of a variation in quantity…doesn't read right, so the 280 equates to 250."*
>
> *(Caregiver 4)*

Subtheme 2.3: Confidence in health care professionals

Participants turn to the home care team for help with HEN problems. The dietitian's role was clear, but expectations about nursing support were varied. Most caregivers received regular nursing visits and felt the nurses tried their best but were inexperienced. Inconsistent advice about hypergranulation, infection, and the type of water to fill the balloon with left patients confused. Patients felt unsupported contacting the nursing team and uncertain of the given advice.

> *"…some of the district nurses have different ideas…they've got to go back and ask… sometimes leaves you wondering".*
>
> *(Caregiver 3)*
>
> *"…the nurses…I have no confidence in any of them…whether or not they know what they are doing are not, I have no idea."*
>
> *(Patient 5)*

Theme 3: HEN care and support

Participants spoke about the level and quality of care they received, citing positive and negative experiences. Some turned to their doctor for help, which could lead to hospitalisation.

Subtheme 3.1: Level of dietitian input

Participants had easy access to help from their dietitian, and if the problem was beyond their scope, they would be referred on. Dietitians had helped with feeding issues experienced in hospital and with feed shortages. Participants felt the dietitians were knowledgeable and cared about their patients.

> *"...if I ever have a problem with the chemist or with any of the feed, she is always there to help me."*
>
> *(Caregiver 3)*

Subtheme 3.2: Level of nursing input

The input participants received from the nursing team was varied. Visits ranged from fortnightly, six monthly, to not at all. Most caregivers had positive experiences and close relationships. One participant who had been under adult services for a couple of years did not realise there was a nursing team.

> *"When he was a toddler we'd get the homecare nurses...we don't have a nurse anymore...."*
>
> *(Caregiver 2)*

Subtheme 3.3: Experiences of care

Participants shared their positive and negative experiences in accessing care. In positive interactions patients said dietitians listened, explained well, and met their needs. Caregivers appreciated that the dietitians would go the extra mile to care for the patient. While, negative interactions with the nurses lacked patient-centred care and failed to meet patient needs. Patients often felt dismissed when they sought clarification of instructions that contradicted previous advice

"With the dietitian, I felt like we're on the same page; you know, we have different roles, but we're on the same page".

(Patient 6)

> *"...quite upset with the way they treated me ...she just steamrolled right over me."*
>
> *(Patient 5)*

Subtheme 3.4: Reliance on doctors

Participants felt they had nowhere to turn and would resort to paid doctor's visits to resolve problems. The doctor's advice often contradicted the nurses', causing confusion, however patients trusted their doctors more.

> *"...and that's when I finally went to the GP and got a regime of practical things that I could do ...made the difference".*
>
> *(Patient 6)*

Subtheme 3.5: Hospitalisations

Participants recalled hospitalisations to resolve recurrent problems with infection, pain, nausea and vomiting. Many issues were not resolved, causing frustration.

> *"...we have no answers; you have to go to the hospital. And then I went to the hospital, and nothing happened...they didn't have any answers...."*
>
> *(Patient 1)*

Theme 4: Suggestions for improvements

Participants detailed the practical and care-oriented improvements they would like to see. Suggestions came from a desire for autonomy, and to reduce negative experiences and frustrations

Subtheme 4.1: Care based.

Care-based suggestions centred around the nursing team. Patients would like more collaborative and patient-centred interactions. Other suggestions included adding specialised staff to the team, with one caregiver suggesting the addition of a gastroenterologist. Patients also suggested extra nursing support to assist with transitionary periods.

> *"...there needs to be more input from the patient with the nurses... the patient isn't brought into it, into that space in terms of having that chat as to okay so what can you do...."*
>
> *(Patient 6)*
>
> *"...especially learning how to change it where you get one tutorial, and then it's like you've got to remember six months later how to do it...."*
>
> *(Patient 1)*

Subtheme 4.2: Practical improvements

Practical suggestions for improvements focused on nursing care. Extra training to improve nurses knowledge and confidence was a common suggestion. One patient felt that a booklet of practical solutions to common problems could help prevent or lessen problems and keep patients out of the hospital.

> *"...the ones that don't know definitely, it doesn't hurt to have more training...".*
>
> *(Caregiver 3)*

3.4.6 Qualitative investigation of the staff perceptions of the experience and equity of care of patients receiving HEN care

We conducted five focus groups; one with the community dietetic staff (n = 6) and four with nursing staff representing Mangere (n = 6), Manukau (n = 3), Eastern (n = 3) and Franklin (n = 2). Experience with HEN in the dietitians' group ranged from 6 months to over ten years, and in the nursing groups, from 2 months to over ten years. Most nursing staff (93%) had little exposure to HEN before joining the Community team. Three themes emerged from the focus groups: Firstly, the burden of treatment, which relates to how HEN affects patients' lives. Secondly, barriers to optimal HEN care, which relates to factors that prevent optimal patient care. Thirdly, suggestions for improvements to the HEN service.

Theme one: Burden of treatment

Theme one reflected how nurses and dietitians observed the impacts of HEN treatment on patients, caregivers and families, where they recognised the difficulty of managing life with a feeding tube. The mental and social impacts on the patients' lives were of notable concern. And the often under-appreciated effect on caregivers and family. Transition points were singled out as particularly difficult for patients and caregivers.

Subtheme one: Impact on mental health

Focus group participants expressed an understanding of the emotional impact of HEN on patients who dealt with emotions like anxiety, frustration and grief. A common sentiment was that patients were not emotionally well equipped, as they were not fully aware of the impact HEN would have on their lives until they were living it, and often had difficulty adapting independently. Participants suggested this lack of proper psychological support may be because the emotional consequences of HEN had not been considered or were not well enough understood or appreciated. All participants expressed limited capacity to assist patients struggling mentally and felt ill-equipped to deal with such issues. They discussed lacking appropriate training, resources and time to address psychological issues during patient visits.

> *"...I feel like there's often a big psychological component that we feel like we're not well equipped to deal with..."*
>
> *(Dietitian 2)*

Subtheme two: The social impact of HEN

Staff observed that patients became more reclusive after starting HEN. Many were anxious to leave the house, so they stayed home, despite being advised of the importance of continuing to do what they enjoy. The patients' lack of desire to be present whilst others were eating caused them to avoid social occasions featuring food, which was an additional cause for concern. In many patients, this lack of socialisation is temporary, but for others, it becomes a part of life.

> *"Initially, for some of them, they don't go out or socialise…."*
>
> *(Nurse 13)*

Subtheme three: Patient support

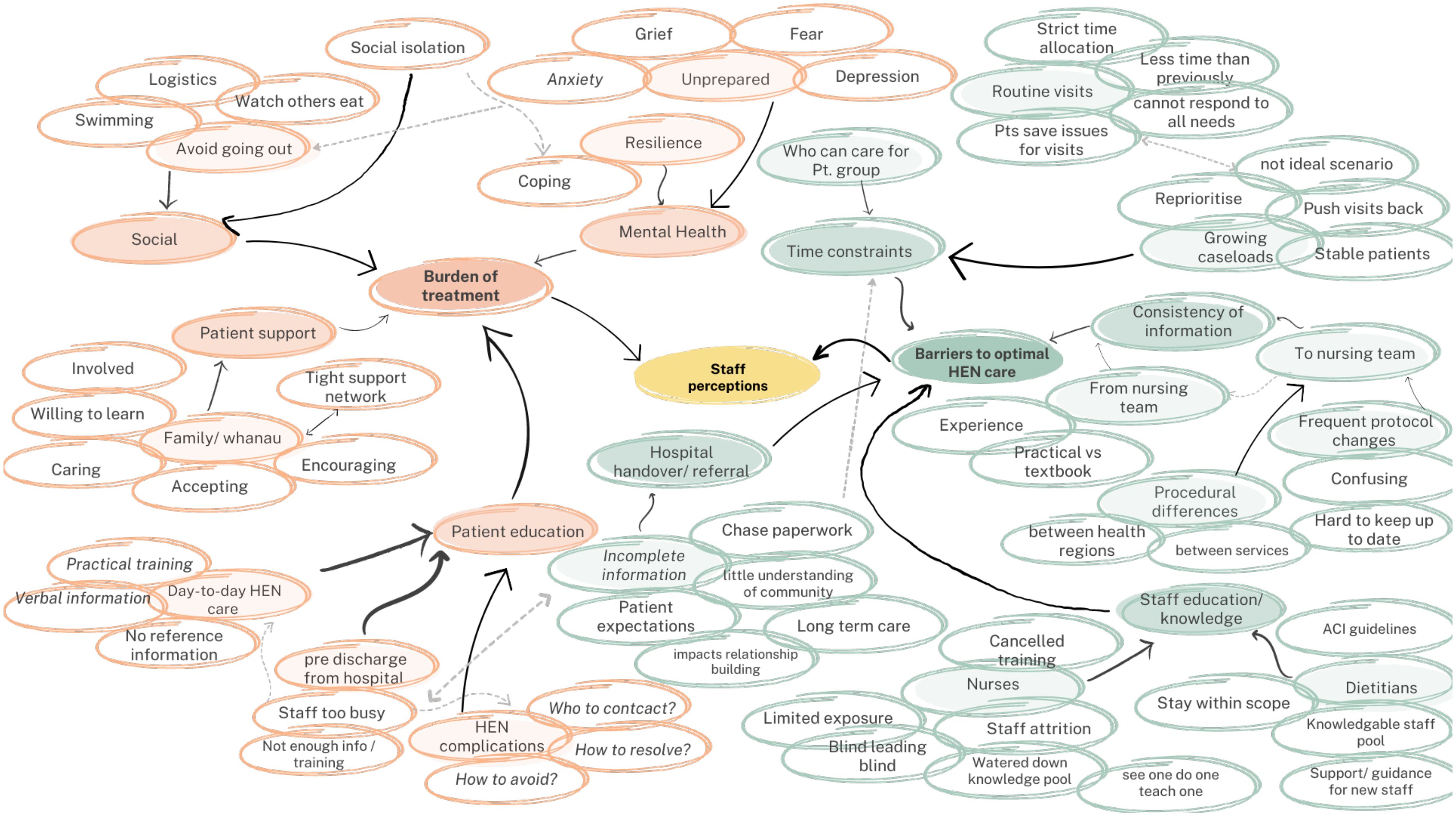
For independent patients, a tight support system provided socialisation, emotional and practical support. A supportive family was considered the most important factor in facilitating resilience. The patient's well-being improved when these support systems were encouraging, accepting, and willing to help. By involving the family from the beginning, it was possible to establish expectations about what life would entail, better preparing them. The emotional and practical implications for those becoming caregivers were also noted as important, as when patients are sick but independent, loved ones deal with the emotional implications. However, when patients require the care of a loved one, the consequences are much more significant. In addition, learning HEN may be one of many new responsibilities required in the loved one's new role as a caregiver. Therefore, adapting to life with HEN can be equally overwhelming for caregivers and patients.

> *"…multiple medical events have happened. They have to get their head around all that and the patient's dependency, who might have been independent beforehand. Just everything is overwhelming."*
>
> *(Nurse 4)*

Subtheme four: Patient education

A perception shared by staff was that the patients and caregivers needed to receive more education in the hospital, but staff were too busy. For example, whilst patients may leave the hospital with the ability to feed, they had no knowledge of the common HEN complications, how to prevent them, or whom to contact for any issues they may face with their HEN once at home. Patients were often so distracted and eager to leave the hospital that the initial verbal education may not be retained and they need to be provided with something to refer back to.

> *"Ideally, before they get discharged from the hospital, they will get education, but that doesn't happen anymore."*
>
> *(Nurse 10)*



Common words were identified as codes, these were grouped with like topics to create sub-themes, which were then rolled up under overarching themes.

Figure 3.5 Mind map of staff focus group coding and themes

Theme two: Barriers to optimal HEN care

Theme two reflected circumstances that inhibited the team's ability to care for their patients. All participants felt they could do better for their HEN patients, although they acknowledged that certain things were outside their control. The nurses were vocal about the challenges they experienced because they were frustrated at the impact on their ability to meet expectations.

Subtheme one: Time constraints

An overarching concern across all focus groups was time constraints with staff feeling like they could not spend as much time with their HEN patients as they would have liked or used to be able to. Staff noted that each visit was strictly allocated a set amount of time, impacting their ability to respond to the patient's needs. They also mentioned that patients often saved all their HEN issues for the time allocated to routine visits; this was a less than ideal scenario, considering participants also reported delaying routine HEN visits to reprioritise their caseloads.

> *"...yeah, not something we always have time for, which is again not right; you know we could avoid a lot if they give us a little bit more time."*
>
> *(Nurse 12)*

Subtheme two: Staff HEN knowledge and education

Knowledge, skills and self-confidence regarding the ability to care for their HEN patients were discussed in all sessions. The dietitians had basic knowledge after training, but gained expertise through experience over time, and the least experienced felt confident because there was a good pool of HEN knowledge and experience within the team. Their focus was nutrition care, but they acquired practical tips and tricks over time that allowed them to stay within their scope of practice whilst ensuring patients' needs were met.

> *"And as dietitians, you're in different places of your knowledge and expertise…is it nutrition care, or is it the additional components that you offer as part of HEN patient care…."*
>
> *(Dietitian 7)*

HEN was noted as a specialised area of nursing care, and expecting all nurses to possess excellent HEN knowledge was considered unreasonable by some. They discussed a need for more exposure to HEN patients during their training, as many had no experience or exposure before joining the community team. Because new staff had limited exposure to HEN, they needed training from experienced staff. With increased staff attrition since covid, the knowledge pools had become watered down. The nurses noted that sometimes it seemed like the *"blind leading the blind".* They also felt that the culture of *"see one, do one, teach one"* was unfair for specialised topics and set nurses and patients up to fail.

> *"it's quite a specialised situation, and a lot of the medical world perhaps seems to forget that all nurses don't know all things about nursing."*
>
> *(Nurse 7)*

Subtheme three: Consistency of information provided to and by the nursing team.

The nurses reflected on the underlying issues they believed contributed to inconsistencies in patient information. For example, more experienced nurses could provide more practical advice learned over time, and less experienced nurses often provided more textbook answers to patient concerns.

> *"…and I also think on our side because we've had Covid impact us and cancel all our education, not many nurses are up to scratch with the knowledge around the PEG sites, so we can't always provide consistent information, especially if you don't have a background…."*
>
> *(Nurse 2)*

The consistency of information provided to the nurses was also a contributing factor. Nurses mentioned that there had been many protocol changes, making it difficult to manage patient expectations. For example, the frequency of balloon changes varied between nine months and weekly. Which also made it difficult for the nurses to keep up to date and confused teams. Other nurses highlighted inconsistencies in procedure across the different health regions and inconsistencies in protocol from paediatric to adult care.

> *"…there are some confusing things across various DHBs…suddenly your saying no, we don't use tap water…we use sterile water...I think it's tough for people to change if they have been doing things a certain way…so consistency would be better, you know…."*
>
> *(Nurse 13)*

Subtheme four: Handovers/ referrals from the hospital

Another pressure point for the nursing team was the transfer of patients from hospital care to the home care team. Nursing staff empathised with the hospital team's busy workload but felt frustrated that they often had to spend time chasing up patient information. They reflected that a lack of understanding of community care and long-term patient needs was often reflected in the referral notes, and felt they often could not meet patient expectations due to this lack of information, which negatively impacted that initial period of relationship and trust building.

> *"Usually when they get discharged from the ward, from Gastro. Sometimes they give us the completed information, but not all the time. So you have to chase them for the information you need."*
>
> *(Nurse 10)*

Theme three: Suggestions for improvement to the HEN service

Both groups of healthcare professionals wanted to impact patient outcomes positively and discussed the observed gaps in patient care or where they had experienced barriers in providing patient care.

Subtheme one: Training and education

The dietitians' group reflected that there may be more benefits in completing their regular case studies whilst the patient was still being treated for that particular problem, allowing them to draw on the knowledge of the team and the latest research whilst reflecting on their practice.

> *"...maybe we should do more HEN case studies to reflect on how we manage those patients...it would be more useful as you're doing it...."*
>
> *(Dietitian 6)*

The nursing team's suggestions were directly addressing issues they had raised. Suggestions included training sessions from the product experts (the reps) and education days with the medical experts (the gastroenterology specialists). This planned education would ensure the reliability of the information they were provided and could provide, along with adherence to current best practices.

Subtheme two: Direct support for the patient

Participants suggested the addition of psychological support services for all HEN patients to help them navigate their emotions and provide strategies for acceptance.

> *"...if they could have psychological support post insertion...even if they have a little bit of psychological support beforehand and they're told the lived experience is something different, you know...there's still that grieving...comes and bites them on the backside later on...."*
>
> *(Nurse 14)*

As the specialised nature of HEN care was raised, there was a consensus that a specialist clinical role would be a welcomed addition to provide a subject specialist that team could consult and directly improve patient care by having a subject expert the patient could see.

> *"...more supports for our patient...if we have a specialist nurse available in Community or you know to go to in-person...."*
>
> *(Nurse 9)*

Subtheme three: Additional support for the nursing teams

Standardisation of practice was suggested to mitigate inconsistencies in information or care delivery. For example, a protocol for the timing of first contact with new patients was proposed, establishing service expectations for all staff and enabling nurses to inform patients about upcoming visits by other healthcare professionals. They also proposed guidelines for dispensing patient supplies, which according to the nurses, would offer direction to new team members and decrease their reliance on others.

> *"...because sometimes the new nurses don't know what to give...if we have a clear protocol, you know, guideline ...."*
>
> *(Nurse 6)*

3.5 Discussion

The HELP study aimed to explore and understand the quality of life and patient experience (including equity of care) of patients receiving HEN. We investigated the patient's quality of life, and experiences with HEN and HEN care. We also explored the perceptions and experiences of the dietitians and nurses involved in this patient group's care.

The impact of HEN on patients' lives

The general quality of life is lower than for the NZ population (NZWHOQoL-BREF)

Using the NZWHOQoL tool, most participants in this study rated their QoL as average or above (mean ± SD of 3.28 ± 0.86 on a 1-5 scale). This was lower than the general NZ population's rating of good QoL (mean ± SD of 4.23 ± 73.1), reported by Krägeloh et al. (2016). No other studies compare HEN patients' QoL in NZ (or using the WHOQoL tool). However, Schneider et al. (2000) found that HEN patients reported lower QoL than the general population using the EQ-5D and VAS scales. In our study, participants scores were also lower than the general population across all four domains of the NZWHOQoL (physical, psychological, social relationships and environmental). Schneider et al. (1998, 2000) and Reddy and Malone (1998) reported similar findings using the SF-36, with lower physical and mental scores compared to the general population. Additionally, no significant difference between home parenteral and HEN patients was found by Reddy and Malone (1998).

HEN specific QoL good

Using the HEN-specific QoL tool, all participants in this study rated their HEN QoL as average or above (mean ± SD of 13.6 ± 8.02 on a -52 to +52 scale). This is lower than that reported in a previous NutriQoL study by Apeztexea et al. (2016) which included patients taking ONS (mean ± SD of 14.98 ± 14.86). However, our score still falls within the category of good QoL. Additionally, our study focused solely on tube-fed patients and found a higher HEN QoL score when compared to the tube-fed patients in Apextexea et al's. (2016) study (mean ± SD of 10.5 ± 13.6). These findings indicate that our patient group experienced a better quality of life than the Spanish group. Furthermore, the reasons why are potentially explainable through the factors that we found to be correlated with better HEN QoL scores.

In the study by Apextexea et al. (2016), patients received HEN between 1 and 6 months, while our patients received HEN between 2 and 354 months. Our correlation analysis found that patients receiving HEN for the longest reported higher HEN QoL. While no other research has specifically investigated this, Wu et al. (2018) found that HEN complications reduced over time, and QoL improved.

In Apextexea et al's (2016) study, most (56.6%) patients had cancer as their underlying disease. Correspondingly, our correlation analysis also found that patients with cancer reported significantly lower HEN QoL ($\rho = .369$, $p < 0.05$). However, our proportion of cancer patients was lower (40.5%), which may have contributed to our better HEN QoL score. These findings were more strongly correlated than those of Zamanillo Campos et al. (2021), who found that patients with cancer scored lower on both visits ($\rho = .251$, $p < 0.05$) and ($\rho = .276$, $p < 0.05$). Additionally, research by Day. (2010) suggested that some of this reduced QoL may be due to the effects of cancer treatment, as opposed to tube-feeding.

Our analysis also found younger patients reported better HEN QoL ($\rho = -.492$, $p < 0.001$). This is consistent with Apextexea et al's (2016) research, where patients under 45 had higher HEN QoL, with scores falling as age increased. This may be due to better physical functioning in younger patients. As Schneider et al (2000) reported that HEN patients under 45 had better physical functioning than older patients (mean ± SD of 76 ± 10 versus 43 ± 6).

Having a proxy responder (e.g. a caregiver) was correlated with higher HEN QoL scores ($\rho = .363$, $p < 0.05$). This is at odds with Loeser et al's (2003) findings using the Karnofsy and Spitzer indices. Here, proxy responders reported lower QoL scores than when patients reported for themselves. However, most caregiver responders (n = 12, 80.0%) in our study were responsible for younger patients with developmental or congenital underlying health conditions who had been on HEN most of their lives. This may be a factor in the higher scores. There is no other research supporting higher QoL scores with caregiver (proxy) responses.

Patients previously married or separated (including those who were divorced) reported the lowest quality of life ($\rho = -.492$, $p < 0.05$). This is possibly due to the loss of companionship at home combined with the reduced socialisation due to HEN. These findings are supported by research by Zhu et al. (2018), linking loneliness and social isolation to lower quality of life in patients in China. Additionally, they bolster the importance of additional support for older patients, who may have less time on HEN and are more likely to be living alone after previously having companionship.

Impact on the patient's daily life

Thematic analysis of the patient interviews found that patients felt anxiety about their HEN, especially when it came to leaving the house. Participants in the staff focus groups supported this, identifying that patients were often too anxious to go out. These findings support research by Boland et al. (2017) and Martin et al. (2012), who also found that patients felt HEN significantly limited their daily activities. Interview participants also indicated that they no longer enjoyed socialising over meals with family and friends or doing leisure activities such as swimming. Focus group participants supported this, identifying that they often encourage patients to continue living their life. Similarly, Ang et al. (2019), Bjuresäter et al. (2015), Jordan et al. (2006) and Liley & Manthorpe (2003) found that HEN patients avoided socialising. Focus group participants indicated a substantial psychological burden of life with HEN and that patients were insufficiently supported. This finding was also reported by Bjuresäter et al. (2015), Brotherton et al. (2007) and Green et al. (2019) who found HEN patients suffered from anxiety and depression because of their HEN. Additionally, Jordan et al. (2006) and Liley & Manthorpe (2003), found that patients also suffered grief and distress at the loss of their inability to eat and the resulting social isolation. These findings further reinforce the importance of adequate psychological support for HEN patients.

HEN care

HEN care experiences

Unfavourable results from our patient experience and equity questionnaire were compared to the unweighted results of the HSQC In-patient and Primary care questionnaires from November 2022 (HQSC, n.d) . This comparison evaluated the community team's performance on specific equity and experience metrics versus the Counties Manukau region.

The study found that community HEN patients were more satisfied than hospital patients with the information provided about their treatment and care (78.6% versus 74.0%). However, they were less satisfied than primary care patients (78.6% versus 89.2%). This difference may be due to the time healthcare professionals can spend with patients, and the availability of easily accessed printed information in primary settings. Similarly, HEN patients were more satisfied than hospital patients with their individual needs being met (81.0% versus 77.1%). Yet less satisfied than primary care patients (81.0% versus 87.3%).

This may be due to the fact the patient is the initiator of visits to primary care and thus set the visit agenda. Furthermore, healthcare professionals may be more task-oriented in hospitals and community settings. This may also be the reason that regarding fairness of treatment; HEN patients were more satisfied than hospital patients (85.7% versus 84.8%), yet less satisfied than primary care patients (85.5% versus 88.6%). These results are not surprising, as the community services sit at an intersect of hospital and primary care services. The teams may face some of the similar constraints hospital teams face due to public funding. In addition to specific tasks that may be required for the patients care each visit. Moreover, it has been observed that some healthcare professionals can become too task-oriented and lose sight of their patient-centred practice (Gluyas, 2015).

We further found that HEN patients were less satisfied about being treated with kindness and understanding than hospital patients (90.5% versus 91.3%) and primary care patients (90.5% versus 94.2%). Considering meeting both cultural needs (81.0%) and spiritual needs (76.2%), community HEN patients were less satisfied than hospital patients (85.5% and 85.9% respectively) and primary care patients (91.3% and 86.3% respectively). Similarly, only 76.2% of community HEN patients reported correct name pronunciation versus hospital- (89.1%) and primary care patients (93.1%). These results all indicate that the HEN patients were less satisfied than hospital and primary care patients for treatment with kindness and understanding and having their cultural and spiritual needs met (including name pronunciation). These results may be related to the operational issues that arose during the patient interviews and staff focus groups. This would support previous research reports that high staff turner was associated with higher incidents of negative patient outcomes (North et al., 2013), and that adequate staffing were key elements to achieving patient-centred care (Kieft et al., 2014).

The fact that patients are more satisfied with their primary care experiences may further explain why they chose paid doctors' visits when seeking resolution of HEN problems.

HEN support for patients

Patient interviews and staff focus groups validated each other's experiences and perceptions of HEN support for patients. The findings showed that additional support was required around transitionary periods. However, due to time and resource constraints, community staff could not always assist. Meaning that patients often resorted to paid doctors' visits and hospitalisation to achieve resolutions. Patients also required more education about HEN complications to allow for better self-advocacy and self-care. Staff reported that current training and education provided before hospital discharge needed to be improved. These findings are congruent with research conducted by Ang et al. (2019), Boland et al. (2017), Bjuresäter et al. (2015), Jordan et al. (2016), Green et al. (2019) and Liley & Manthorpe (2003). Comprehensive training, information and support before and after hospital discharge helps patients develop self-advocacy and self-care skills. As Thompson et al. (2006) discussed, this can improve resilience and coping with HEN. Resulting in better patient outcomes, including better QoL. Patients also needed support to develop acceptance and resilience, as they reported stress, anxiety, frustration and avoiding social situations. Staff also recognised the grief and long journey to acceptance that patients faced, but noted they could not provide the level of psychological support needed.

Enablers of positive patient experience.

During staff focus groups, participants identified that a good support system was essential for positive patient experiences. However, they also recognised the psychological burden on family caregivers, which is often overlooked. This finding aligns with research by Halliday et al. (2017) and Liley and Manthorpe (2003), who found that caregivers experience stress and anxiety due to their responsibilities. Although our research did not assess caregivers' feelings, it emphasises the need for appropriate psychological and psychosocial support for caregivers of HEN patients.

Patient interviews indicated that patient-centred care from knowledgeable healthcare professionals led to their needs being met and problems resolved quickly. Discussions in the staff focus group indicated that when a strong supportive knowledge pool existed within the team, this level of care was possible. However, if knowledge is lost through staff attrition, patient experiences of care may become less favourable.

Barriers to positive patient experience

Patient interviews and staff focus groups validated each other’s experiences and perceptions of barriers to positive patient outcomes and identified areas where more support was required for nursing staff. Staff identified HEN as a specialist subject in nursing, with most having limited exposure before working in the community. Even in the community, visits were reported as infrequent, meaning that exposure was still limited. Knowledge loss due to staff attrition and training cancellations further exacerbated these problems, as evidenced by the patient's lack of confidence in the team's knowledge. These findings are consistent with North et al.'s (2013) research linking high nurse turnover in NZ with increased adverse patient outcomes. Moreover, with Kieft et al.'s (2014) study showing that clinically competent nursing staff and adequate staffing are essential for patient-centred care.

Inconsistencies in policies and procedures led to frustration among nurses and patients, leading to confusion and potential compromises in patient care. Differences between health regions and services exacerbated this issue. Patients also reported inconsistencies in the information they received, indicating a negative impact on their care. Research by Riman et al. (2023), supported these findings by highlighting the negative impact of operational issues on patient satisfaction in nursing care. Additionally, nursing staff identified that issues with missing information in the patient's referral from the hospital could negatively impact the care they receive and their initial experience with the home care nursing team. A finding supported by McDonald et al. (2018), who outlined that the appropriate coordination of care is essential for patient outcomes. Considering these challenges, the nurses suggested hiring a specialised HEN practitioner. Furthermore, research by Tracy et al. (2020) supports this, reporting that clinical nurse specialists improve patient experiences and outcomes.

Additional barriers to positive patient outcomes were investigated through correlation analysis of the equity and experience questionnaire with the general QoL results, which found four areas of significance. Firstly, the study showed that those whose primary language was English reported the highest QoL. Whereas those who primarily spoke Samoan reported the lowest QoL ($\rho = -.322$, $p < 0.05$). The results are consistent with the NZ Ministry of Business, Innovation, and Employment (MBIE) migrant survey report, which identified limited English as a challenge faced by some recent Pacific immigrants (Sin, 2018). Our research also showed that those who perceived that their nurse or dietitian did not spend enough time with them reported lower QoL ($\rho = -.375$, $p < 0.001$), and scored lower in the psychological well-being, social relationship and environment domains of the WHOQoL. Staff focus groups confirmed concerns about time constraints, acknowledging that this patient group was getting less of their attention than they would like. It is unclear if spending more time with HEN patients would lead to higher QoL score as no other HEN studies investigated this factor. The quality of time spent would need to be further investigated.

Finally, our study found lower QoL scores were associated with patients whose cultural needs were not met ($\rho = -.375$, $p < 0.05$) or whose individual needs were not met ($\rho = .483$, $p < 0.001$). Patients with unmet cultural needs reported lower psychological well-being, social relationship and environment scores on the NZWHOQoL. Whilst those with unmet individual needs reported lower psychological well-being and social relationship scores. These factors are unique to the patients and their individual experiences. They support Betancourt et al's (2003) research highlighting the link between cultural safety and communication, patient satisfaction, adherence, and health outcomes. In particular, these findings are concerning given the diverse and multicultural make-up of the Counties Manukau patient population.

In conclusion, the study shows that whilst QoL is lower in HEN patients, home tube-fed patients in the Counties Manukau region of NZ report a better HEN-specific QoL than international cohorts. Furthermore, it is possible to identify older patients who have not been on HEN very long and live alone, as being the most likely to have reduced QoL. These findings also further highlight the issues this patient group face regarding social isolation and the psychological burden of treatment, and the importance of a patient-centred approach and culturally safe practice. Additionally, the findings bolster the need for more specialised HEN care staff and adequate staff training.

Chapter 4. Discussion, conclusions and recommendations

4.1 Overview and conclusion

The overall quality of care is multifaceted, with quality of life, patient satisfaction, and equity of care all important aspects of the patient experience. Previous research internationally has shown that patients receiving HEN may experience lower QoL and frustrations with HEN services, however the current situation in NZ remains unknown. Therefore, understanding the patient's overall experience of HEN care is essential for improving health outcomes for this patient group in NZ. This study aimed to explore the experiences of patients receiving HEN care from the Counties Manukau community health teams, firstly by conducting patient surveys assessing QoL, HEN-specific QoL, patient equity and experience data, and collecting demographic data. Secondly, by conducting patient interviews to better understand the patient experience. Finally, by conducting staff focus groups with the dietitians and nurses involved in HEN care to better understand the staff's perception of life with HEN, and HEN care services.

4.2 Main findings

The first objective was to investigate the patients' QoL (both general and specific to HEN treatment). The NZWHOQoL questionnaire, validated for use within the NZ population (Billington, 2010), was used to ascertain the impact and extent of HEN on the patient's QoL. Overall, the QoL reported by the patients was neither poor nor good (3.28 of the 5 - point scale). This was lower than that reported by Billington (2010) for the general NZ population, which was good (4.23 on the 5 - point scale). These findings were not unexpected, considering a sample of the general population is likely to have a higher proportion of healthy individuals compared to our sample consisting of only participants with long-term medical conditions. Additionally, several research studies showed that long-term medical conditions and HEN lead to lower QoL than that of the general population (Reddy & Malone, 1998; Schneider et al., 2000; Schneider et al., 1998). Our study also found that the patient's primary language (English), satisfaction with the length of visit, and feeling their cultural or individual needs met were correlated with higher general QoL scores. These factors are unique to the individual patient experience and support Betancourt et al's (2003) research highlighting the link between cultural safety and communication, patient satisfaction, adherence, and health outcomes. These findings further emphasising the importance of patient-centred care and cultural safety for the diverse and multicultural make-up of the Counties Manukau patient population.

Overall, the total HEN QoL reported by our participants was good. In other studies, findings for only tube-fed patients (Apezetxea, 2014) using the NutriQoL reported the overall HEN QoL as acceptable (worse than our study findings). This difference in HEN QoL between the two studies was unexpected; however, it may be due to more extended periods of HEN treatment (up to 30 years vs up to 6 months) and lower rates of cancer (40.4% versus 56.6%) in our sample, as both were factors we found to be correlated with better HEN QoL scores. Age (older), marital status (previously married or separated), and the survey responder (patient as opposed to caregiver as proxy) were also found to correlate with lower HEN QoL results. Our study revealed that those who had been on HEN for shorter periods were typically older patients with cancer or neurological health problems who were either married or previously married. These findings highlight the need to offer this vulnerable patient group adequate care.

The second objective was to explore the patient's perceptions of the equity of care provided using the patient equity and experience questionnaire. This had been developed using the equity question set from the NZ HQSC patient experience surveys. Most responses from patients indicated positive associations with the care they received, but from the 17 questions asked 41% (7) received some negative response. At present the experiences of out-patient or community care patients are not measured routinely. Therefore, benchmarking was completed against the HQSC survey responses for the Counties Manukau district for in-patient and primary care (HQSC, n.d). This exercise revealed that HEN patients were more satisfied than hospital patients but less satisfied than primary care patients with regards to the information received about their treatment and care (78.6% versus 74.0% versus 89.2% respectively) , having their individual needs met (81.0% versus 77.1% versus 87.3% respectively), and feeling they were not treated unfairly (85.7% versus 84.8% versus 88.6% respectively). It is not surprising these results were obtained as community care lies at the intersect of hospital and primary care. As such community teams may face similar constraints as hospital teams due to public funding and visits that are usually goal oriented.

We further found that HEN patients were less satisfied than both hospital patients and primary care patients with regards to the correct pronunciation of their name (76.2% versus

89.7% versus 93.1% respectively), feeling their cultural (81.0% versus 85.5% versus 91.3% respectively) and spiritual (76.2% versus 85.9% versus 86.3% respectively) needs were met, and feeling they had been treated with kindness (90.5% versus 91.3% versus 94.2% respectively). These results may be due to fundamental differences between the service types, or some of the operational issues uncovered in the patient interviews and staff focus groups.

These results, whilst unable to be benchmarked against similar service type, still provide rich insight into the few areas where patients indicated less satisfaction. Understanding how the results relate to other health services allows us to better speculate as to the why. Although in the case of this research, some of those answers may have been provided through the additional objectives.

The third objective was to investigate the patient's experiences and perspectives of the HEN care services, which were captured using qualitative methodology, conducting individual patient interviews. Key themes supported the findings of the equity and experience survey and highlighted specific areas and times when patients required additional support, particularly psychological support. Thematic analysis identified that patients felt anxious, stressed, and often isolated themselves from society, which is supported by research from Bjuresäter et al. (2015), Boland et al. (2017), Brotherton et al. (2007), Jordan et al. (2006), Liley & Manthorpe (2003) and Martin et al. (2012). This lack of psychological support is despite evidence that patients who practice acceptance can continue to make the most of life and build greater resilience, which leads to improved QoL (Jordan et al., 2006; Thompson et al., 2006). Patient interviews indicated there were four distinct periods resulting in increased stress and anxiety, where patients needed additional support: adapting to life with HEN, changing feeds or feeding regimes, transferring from paediatric to adult services, and when dealing with HEN complications. Participants felt unprepared for complications and found it hard to be autonomous or self-advocate when more information and education were required. The research of Ang et al. (2019), Bjuresäter et al. (2015), Boland et al. (2007), Jordan et al. (2006), Green et al. (2019) and Liley & Manthorpe (2003) support these findings and highlight the importance of comprehensive education and support for HEN patients pre- and post-discharge from the hospital.

The interviews indicated that patient-centred care from knowledgeable professionals fostered patient satisfaction, supporting the research by Halliday et al (2017) . Conversely, the interviews also revealed that patient satisfaction was low when relationships were strained due to conflicting advice, a lack of confidence, and encounters that did not always feel patient-centred. These findings are of concern given the link between patient satisfaction and health outcomes discussed by Betancourt (2003).

The fourth objective was to explore the staff's perceptions of HEN care, patient satisfaction, and equity of care; this was captured using qualitative methodology by conducting focus groups with community HEN care staff. Key findings from these focus groups validated the patients' perceptions and experiences, and vice versa, highlighting some operational areas that may benefit from additional input. For example, patients reported anxiety, stress, and isolation throughout their HEN journey. Additionally, staff noted the significant psychological impact on patients and their caregivers as they adjusted to their new roles. These findings highlight a potential gap in service provision for perceived unmet patient needs, further supporting the need for specific psychological support for this patient group.

Patients also identified a need for additional support through key transition periods such as new feeding regimes or between services . Similarly, staff expressed concerns about the time constraints in providing high standards of care. This was due to staffing issues like low staff-to-patient ratios, lack of experienced staff for mentoring, and inadequate training for working with this specialised patient group which impacts their care provision. These findings highlight the gap between the ideal scenario and the reality of what is currently provided.

In addition, patients identified a requirement for better/more information and education before being discharged to home care and to help with HEN complications. Similar perceptions were raised in the staff focus groups, identifying that patients needed adequate training and information before discharge and that written information should be standardised. These findings highlight the importance of comprehensive education for this patient group before being discharged from the hospital. Patients observed inconsistencies in the advice they were given, whilst staff raised frustrations around the inconsistencies in information coming to them, such as frequently changing policies or procedures around things like balloon changes or inconsistent practices across services or health regions like the use of filtered water. These findings suggest that patient care may be impacted due to operational issues outside the staff's control.

Patients' interviews revealed that they sometimes experienced a lack of confidence in the knowledge of the nursing team. Mainly based on receiving mixed messages. In line with this finding, the staff indicated a lack of knowledge and confidence in their ability to optimally care for patients, mainly due to a lack of HEN specific training and education, and that high staff turnover resulted in the loss of HEN knowledge/expertise. It was suggested that the specialised nature of HEN care requires clinical specialist roles to be part of teams for additional support and to improve patient experiences and outcomes.

4.3 Conclusion

Whilst the quality of life of HEN patients in the Counties Manukau region was lower than for the general NZ population, HEN-specific quality of life was reportedly better than for their counterparts in Spain. Patient experiences of care were mostly good but could be improved in certain areas, such as correct name pronunciation, ensuring patients are well-informed, respecting and honouring patients' cultural and individual needs, and treating patients with kindness and respect. Patients identified a need for more support, information and education around adapting to life with HEN, changing feeds or feeding regimes, transferring from paediatric to adult services, and dealing with complications. The patients desired more autonomy and better self-advocation, which the staff focus groups validated. Patients also identified struggles with conflicting advice and a lack of knowledge within the HEN teams, which the staff focus groups again validated. Another theme identified through the interviews and focus groups was the need for psychological support for the HEN patients, pre- and post-insertion.

With regard to cultural safety and patient-centred care, the patients indicated that the care provided by the team did not always meet their needs. In support of this finding, the staff focus groups identified issues such as time restrictions for patient contact, suboptimal staffing, and the quality of referral documentation as aspects that can impact their ability to care appropriately for this patient group. Overall, these results suggest the need for additional specialised support for all staffing groups, additional provision of specialised psychological support, improved patient information and education, consistent staff training and information, and the need to address operational issues such as incomplete referral paperwork.

This is the first research of its kind in NZ and contributes to filling the research gap in terms of understanding the impact of HEN on patient's QoL and enabling assessment of patient QoL versus the general NZ population and other HEN populations. This research is also the first in NZ to assess the patient experience within the community setting. It highlights the importance of monitoring outpatient and community patient experiences along with in-patient and primary care patients. These research findings have the potential to enhance service delivery and care for this patient group and can serve as a reference point for future studies on QoL in HEN patients in NZ.

4.4 Strengths of this research

Strengths of this research include the mixed-methodological approach of qualitative and quantitative methods. The quantitative research provided data that could be interrogated to provide insights and associations, whilst the qualitative data provided a more human insight into the patient experience. Another strength of this research was the use of patient and staff perspectives through interviews and focus groups. This allowed for the validation of shared experiences and insights, which, when combined, strengthened the evidence behind the recommendations.

4.5 Limitations of this research

One fundamental limitation of this research is the small sample size (n=42), due in part to the recruitment methodology and the potential patient or caregiver burden, which resulted in many patients from the Mangere and Manukau regions declining involvement. Additionally, the small numbers of Māori, Asian and Pacific peoples represented in the sample limits the ability to study the equity and experiences of these patient groups effectively. The study size and demographic limitations stemmed from the fact that potential participant numbers and potential ethnic group representation were limited to that of the pool of HEN patients in the Counties Manukau region that met study eligibility requirements. That most of the patients in the pool identified as European or Pakeha served as a constraint in achieving diversity in ethnic representation. Additional limitations focus on data collection in that there was no representation from the Manukau base in patient interviews due to inability to recruit. Finally, due to time sensitivities in conducting the first staff focus group, the probing questions could not be tested prior to conducting the focus group, which may have resulted in less data obtained from the first group.

4.6 Recommendations for future research

In the first instance, research into the effectiveness of any proposed changes (see table 4.1) that may be enacted would be recommended to foster the continuing feedback loop and improvements in care. Secondly, due to the sample size limitations of working with a pre-defined pool of patients, research either at a regional scale or country-wide scale would be suggested to better understand (and be better informed to improve) both the quality of life and equity and care issues faced by our patients receiving HEN care in NZ.

If the study were to be undertaken again (or elsewhere in NZ), the following suggestions are based on learnings collated throughout this study:

- Patient recruitment: Taking data from the regional clinical portal is not enough. Time should be built into the project schedule for conversations with the relevant staff involved in patient care so more can be known about the patient groups, e.g., how they like to be contacted, how they like to communicate, who is the best support person to have present for them, so that a genuinely patient-centred approach can be taken to the recruitment (and data collection) process.
- Patient recruitment: Having an initial set of flyers to be distributed by staff a few months before first contact by the research team would let the patients know that their (staff) carer knows about the study and supports it, as this seemed to be a pressure point for some patients.
- Patient data collection: Include little whiteboards and dry markers in the data collection kit to assist patient communication for those who have trouble with/ or become tired from talking.
- Patient interviews: Try to ensure patients from all bases are represented in interviews by starting the patient interview process at the same time data collection starts.
- Focus groups: Build in time to pilot test the questions prior to data collection.

4.7 conflicts of Interest

None.

Table 4.1 Recommendations to Te Whatu Ora - to help improve the HEN services, based on findings of this research.

Recommendation	**Suggestions of what this may look like in practice**	**Reasons and rationale**
Formal psychological support for HEN patients (HEN Health Psychologists).	Pre-insertion consultations Group acceptance and commitment therapy (ACT) programmes. Provision of one-on-one post-insertion sessions for patients struggling to adjust to life with HEN.	Patients & healthcare professionals identified social isolation and a gap in patient need for psychological care and current HEN service. Patients and health care professionals identified issues with acceptance of the new normal/ issues adjusting to life with HEN. Those who had been on HEN the longest had the best QoL (suggesting acceptance plays a part in improved QoL). External research supports our findings and suggestions.
Creation of a checklist for transition planning from hospital to home	To include: Provision of verbal education Provision of practical training session(s) Provision of written information/ reference material Guidance on whom to contact about what issues when they are at home.	Patients and staff identified that patients needed more pre-discharge education and information. Supported by external research findings.
Needs assessment required to collaboratively create suitable educational and reference material for the patients	Some ideas include: The basics of tube feeding. Common HEN complications – how to avoid them and how to fix them. Links to helpful educational websites. Contacts and support group information for common underlying illnesses and tube feeding groups.	Patients and staff indicated this would be a valuable resource for greater autonomy and improve the patient's ability to self-advocate – both are linked with promoting increased resilience and improved QoL. Supported by external research findings.

	Guidance on whom to contact about what issues when they are at home.	
Creation of HEN specialist role(s) to work across all bases.	Direct patient support via clinics. Clinical specialist roles – provision of expert advice.	The nursing team highlighted that specialist knowledge is required for HEN care due to limited exposure to cases as a generalist (in the same way there are dedicated stoma nurses). A key support worker would ensure continuity of care for this patient group.
Create a positive learning environment to support ongoing professional development activities among the community staff involved in HEN care.	Ideas include: Education from enteral nutrition product representatives regarding products and uses. More technical education from the hospital Gastroenterology team. Education sessions run by a HEN specialist to run through case studies and increase staff HEN exposure. Creation of a national HEN learning and support network to allow knowledge sharing across regions and promote continual upskilling. Future proofing the knowledge and skill pool.	There is a reliance on more senior staff to provide knowledge, support, and HEN training; this is a critical failure point, as the departure of these staff could result in the loss of valuable knowledge and expertise and negatively impact patient care and experience. Patients highlighted a perceived need for more staff knowledge of HEN based on their interactions and observations receiving HEN care. Supported by external research findings
Additional support for patients transitioning from paediatric to adult services	Provision of additional nursing visits for training in new responsibilities such as tube changes. Provision of one point of nursing contact for the first year in the adult service (this could be a HEN specialist nurse). To provide continuity of care, build trust in the service, and empower the patient.	Presently this patient group are treated the same as adult patients who have been with the service for a while. However, they are new to the service and should be treated as such. Young adults without caregivers highlighted this transition as particularly stressful, and this sets the tone for the rest of their HEN journey with adult services.

	Treat this patient group as if they were new HEN patients and ensure they are given all the same information a new HEN patient would be given (including any written refence materials).	This additional support will help the new adult patient foster their ability to self-care and self-advocate whilst navigating a system that is new to them. Self-advocacy and self-care are associated with better resilience and better patient outcomes. External research supports our findings and suggestions.
Additional support for patients based on their characteristics	Patients with cancer as their underlying pathology. Older patients. Those who are new to the HEN service.	Correlations between lower HEN QoL indicate these groups as potentially more vulnerable.
	Patients who do not speak English as their first language.	Correlations between lower general QoL indicate that these groups may be more vulnerable.
Provision of cultural safety and patient-centred care training refreshers.	Suggested ideas: Session ensuring personal stresses and frustrations do not leach into the patient's world. Sessions about which patients may need additional support and at what times, e.g., identifying the transition periods and the patient characteristics associated with lower HEN QoL or general QoL scores.	Patients indicated through surveys and interviews, that their HEN care interactions did not always feel patient-centred. Lack of patient-centred activity was also correlated with lower general QoL scores. This research also indicates that certain patient groups may require more attention to ensure equity of patient care.

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Appendix A1: Eligible patient participation information sheet & consent form

Participant Information Sheet

HELP (Home EnteraL nutrition Performance) Study

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES MANUKAU HEALTH

Kia ora,

As a patient receiving home enteral nutrition (HEN), you are invited to take part in a research study titled “**The health, wellbeing and nutritional outcomes of long-term enterally fed patients”**. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve.

WHAT IS THIS RESEARCH ABOUT?

The number of patients receiving home enteral feeding has increased considerably in recent years. It is now estimated that the number of patients receiving enteral feeding at home is increasingly higher than in hospitals.

Patients receiving home enteral nutrition may receive adequate nutrients from the feed. However, it has been shown that the nutrients in these feeds may be digested and absorbed differently than those found in whole foods. Therefore, nutrient deficiency may develop over time, leading to physical signs and symptoms associated with not having enough of a particular nutrient or a combination of them e.g., anaemia and poor wound healing due to not enough iron and zinc. It is in our best interest to know when such deficiencies may develop, and when to test for insufficiency. Therefore, we want to investigate the timeframe of developing deficiencies.

The aim of this study is to investigate the nutrition status, quality of life, care, health, and wellbeing of long-term enterally fed patients older than 18 years in CM Health.

Thus, the findings of this study can assist in determining guidelines for timely micronutrient monitoring, and potential micronutrient replacement could be established depending on the results.

Who are we looking for?

We are looking for men and women to participate in this study. To take part in this study, you need to be:

- adults ≥18 years old,
- using percutaneous endoscopic gastrostomy (PEG), percutaneous endoscopic jejunostomy (PEJ); nasojejunal tube (NJT), or jejunostomy tube (JJ),
- on this feeding regime for longer than four weeks,
- able to give a blood sample.

What is involved in the study?

If you meet the above eligibility criteria, you will be invited to participate in the study. The study will be explained to you, and the Participant Information Sheet will be provided to you to review. When you decide to participate, a visit from the researcher at your location of choice (which will take about an hour and 30 minutes) will be organised.

At the initial (first) appointment, you can first ask any questions you may have about the study. Next, you will be asked to sign a consent form for participating in the study and complete a demographic questionnaire.

During this initial visit, we will ask you to:

- Participate in a 24-hour diet recall interview.
- Complete a physical sign and symptoms examination.
- Complete electronic questionnaires about Quality of Life, HEN satisfaction, Comorbidities, and Patient experiences with assistance from the researcher including some questions on your HEN experience.
- A blood sample will be taken from a vein in your arm by a trained person (a phlebotomist) – this may happen on the same day or we will organise a suitable time for you. We will use the blood sample to measure trace element nutrients (iron studies, zinc, copper, selenium), vitamins (vitamin B12, folate, vitamin D), markers of inflammation (C-reactive protein, albumin), and a Full Blood Count. There will be no requirements for fasting before the event.

After the initial appointment, we will ask you to:

- Participate in another four 24-hour diet recalls with the researcher, but this time over the phone, which we will organise at a time that suits you. It will include some week and weekend days. It will take about 15-30 minutes per phone interview. The last 24-h recall interview will also include a few short questions on the presence of other long-term conditions.

What are the benefits of taking part in this study?

There will be no charges made for any of the tests that you undertake. Taking part in this study will help to find out if you have any micronutrient deficiencies. This is also an opportunity for you to tell us about your journey in receiving HEN. Your insights will hopefully lead to further studies and may influence the optimal care of HEN patients. In recognition of your participation, you will receive a $50 supermarket or petrol voucher at the end of the study.

You will also receive a brief report summarising the main findings of the project via mail or e-mail after analysis of the data has been completed. If any of your blood results are outside normal parameters you will be advised to talk to your medical practitioner or at your request, we can send your results directly to them to ensure that you receive the required treatment.

What are the risks of taking part in this study?

There are no risks involved in taking part. Some people may fear having a blood sample taken or experience discomfort when the blood sample is taken. Occasionally, a slight bruise may result. We will take every measure to ensure you are comfortable and respected. You may also be accompanied by a support person if required.

Sample Handling and Storage

Samples will be stored in a secure laboratory freezer at the Human Nutrition Research Unit until completion of the study for a maximum of 10 years. Samples will be analysed by fully accredited laboratories in NZ. The data will be used only for the purposes of this project, and no individual will be identified. Only the investigators and administrators of the study will have access to personal information, and this will be kept secure and strictly confidential. Participants will be identified only by a study identification number to ensure anonymity and confidentiality of these samples. After analysis, any additional blood will be destroyed following usual procedures. However, if you prefer to rather have your blood samples, it can be returned to you if you request it.

Additionally, there may be participants who identify as Māori and if specific concerns develop, the support of Dr Bevan Erueti (Taranaki, Te Ati Haunui-ā-Papārangi, Ngāti Tūwharetoa), Associate Dean Māori, will be afforded. Dr Erueti has expressed that he is happy to act in the capacity of advisor and if required will assist and facilitate the project's Māori agenda and ensure that relational aspects of trust and appreciation are upheld with Māori participants. We are also cognisant that a diversity of beliefs and cultural concerns regarding the removal, storage and transport of tissue samples exists, and because of this, it would be more appropriate to discuss this with your whānau (family) and/or seek take advisement from hapū and iwi leaders. Nonetheless, the right to decline or withdraw from the study can be done at any stage of the project.

Data Handling

The results of the study may be published in journals, presented at conferences or at other professional forums. No individual will be able to be identified. At the end of this study, the list of participants and their study identification numbers will be disposed. Any raw data on which the results of the project depend will be retained in secure storage for 10 years, after which it will be destroyed. Results of the study will be provided to you if you wish.

Who is funding the research?

The research is funded by the Massey University Research Fund, and the CM Health TUPU Research Fund - "MAATAATUPU" Fund for new or emerging researchers.

Participant’s rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Withdraw from the study at any time,
- Decline to answer any particular questions,
- Ask any questions about the study at any time during participation,
- Provide information on the understanding that your name will not be used unless you give permission to the researcher,
- Be given access to a summary of the project findings when it is concluded.

Withdrawing from the study, should you choose to do so, will not result in any disadvantage to you.

Project contacts

If you have any further questions or concerns about the project, either now or in the future, please contact the research team.
The researchers for this study include:
Marcos Mantovani, MSc candidate; Phone: 0220881493; Email: m.mantovani@massey.ac.nz
and
Sally Pattison, MSc candidate; Email: S.Pattison@Massey.ac.nz

The lead researchers for this study are Professor Rozanne Kruger and Mr Andrew Xia.
If you have any concerns, please contact Rozanne at r.kruger@massey.ac.nz; phone +649 213 6661 or Andrew at Andrew.xia@middlemore.co.nz; +64 21 510 941.

Committee approval statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, application 22/20. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone: 04 801 5799 x 63363, email: humanethicssoutha@massey.ac.nz.

The Counties Manukau Health Research Committee has also reviewed and approved this project: research registration number 1631.

Consent Form

HELP (Home EnteraL nutrition Performance) Study

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES MANUKAU HEALTH

Declaration by participant:

I have read and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this study.

I have been given a copy of the Participant Information Sheet to keep.

Participant's name: ______________________________

Signature: ______________________ Date: ______________

Appendix A2: Staff participant information sheet and consent form

HELP study

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES MANUKAU HEALTH

HELP study- Participant recruitment form [01]
Title: Focus Group information sheet

Focus Group Information Sheet

An exploration of the overall quality of care of Home Enteral Nutrition (HEN) patients in Counties Manukau Health

Researcher Introduction
Kia Ora, my name is Sally Pattison, and I am a Nutrition and Dietetics Master's student at Massey University. I am researching the quality of care experienced by HEN patients in Counties Manukau Health.

Project description and invitation
This project is part of the Home EnteraL nutrition Performance (HELP) study. The HELP study aims to investigate the health, well-being, and nutritional outcomes of long-term enterally-fed patients within Counties Manukau Health.

The focus of this part of the study is investigating the well-being of long-term HEN patients:

1. What daily life is like for people living with HEN.
2. Exploring patient's thoughts around how fair they feel treated.
3. How the patients experience HEN care.
4. Exploring what staff think about the current standards of care and patient satisfaction.

The purpose of this qualitative study is to explore point 4, which is the staff's point of view. We would therefore like to invite you to attend a focus group to discuss the standards of care and patient satisfaction regarding HEN patient care.

Participant Identification and Recruitment
You have been selected as a potential participant due to your work with the Community Health services team. We are looking to recruit around 12-18 staff members to attend three focus groups, or until data saturation is met. We will confirm dates and times once we know participant numbers and availability. We will ensure session times are workable for you and your schedules. We will aim to have a focus group for each site.

Project procedures
We will allocate specific times and locations to conduct focus groups to suit participant's needs. This will be confirmed by email containing options. On the day, there will be a

Moderator and a Note Taker from Massey University present. We will invite participants to create a set of agreed house rules before we begin. We want to ensure that matters discussed in the focus group remain confidential once outside the focus group setting. We also wish to ensure that every participant's personal view is heard and treated respectfully and that even where opinions differ, no one leaves the focus group feeling bullied or invalidated. All staff will be free to make comments regarding the service which will remain anonymous and will not in any way prejudice their employment.

We expect that each focus group will run for around 1 hour. During that period, you will be provided with statements, questions, or prompts from the moderator. We wish to encourage discussion amongst participants in an informal manner.
The focus group will be audio recorded.

Data Management
Audio recordings from the focus groups will be transcribed, anonymised, analysed and coded for use as part of this research project.
We will ensure your personal information remains confidential to the research team members only.

The results of this study may be published or presented but not in a form that would reasonably be expected to identify any participant.
Data will be stored on a secure server and disposed of after ten years.

Participant's Rights
You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- ·decline to raise your opinion or answer any particular question;
- ·withdraw from the study (before your focus group session);
- ·ask any questions about the study at any time during participation;
- ·provide information on the understanding that we will not use your name unless you permit the researcher;
- ·be given access to a summary of the project findings when it is concluded.

Project Contacts
Please contact the researcher at any time if you have any questions about this research project

Researcher: Sally Pattison, MSc candidate. Email: S.Pattison@Massey.ac.nz

The lead researchers for this study are Professor Rozanne Kruger and Mr Andrew Xia. If you have any concerns, please contact Rozanne at r.kruger@massey.ac.nz ; phone +649 213 6661 or Andrew at Andrew.xia@middlemore.co.nz; +64 21 510 941.

Ethics Committee

Committee approval statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, application 22/20. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone: 04 801 5799 x 63363, email: humanethicssoutha@massey.ac.nz.
The Counties Manukau Health Research Committee has also reviewed and approved this project: Registration no 1631.

HELP study

HELP study- Participant recruitment form [02]
Title: Focus Group information consent form

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES MANUKAU HEALTH

Focus Group Consent form

An exploration of the overall quality of care of Home Enteral Nutrition (HEN) patients in Counties Manukau Health

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Declaration by participant:

I have read the information sheet and I have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I understand that I have an obligation to respect the privacy of the other members of the group by not disclosing any information that they share during our discussion.

2. I understand that all the information I provide will be kept confidential to extent permitted by law, and the names of all people in the study will be kept confidential by the researcher.

Note: There are limits on confidentiality as there are no formal sanctions on other group participants from disclosing your involvement, identity or what you say to others in the focus group. There are risks in taking part in focus group research and taking part assumes that you are willing to assume those risks.

3. I agree to participate in the focus group under the conditions set out in the information sheet.

Full name: ____

Date: ____

Signature: ____

APPENDIX A3: Patient demographic questionnaire

Participant Id:

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES MANUKAU
HEALTH

HELP study

Demographic and health questionnaire

Could you tell us if you are answering this survey on behalf of yourself or someone else?

Myself ☐ Someone else ☐

If you are answering on behalf of a patient, please complete the questionnaire using their details:

Demographic questions

What is your Gender?

Male ☐ Female ☐ Gender diverse ☐ Prefer not to say ☐

What is your date of birth?

dd/mm/yy ___/___ /___

What is your ethnicity?

New Zealand European	☐	Māori	☐
Cook Island Maori	☐	Samoan	☐
Tongan	☐	Niuean	☐
Chinese	☐	Indian	☐
South African	☐	Other_______________________	☐

What languages do you speak most often at home? (Please select them all)

English	☐	Māori	☐
New Zealand Sign Language	☐	Samoan	☐
Northern Chinese (incl. Mandarin)	☐	Hindi	☐
Other_______________________	☐		

IN CONFIDENCE

What suburb do you live in?

What is the highest level of education you have received?

Primary school ☐
Trade certificate/ diploma ☐
Post-graduate education ☐

Secondary school ☐
Bachelor’s degree ☐
Other______________________ ☐

What is your total <u>household</u> income received <u>from all sources before tax</u> for the last 12 months?

Loss ☐
Zero ☐
$1 - $5,000 ☐
$5,001 - $10,000 ☐
$10,001 - $15,000 ☐
$15,001 - $20,000 ☐
$20,001 - $30,000 ☐

$30,001 - $40,000 ☐
$40,001 - $50,000 ☐
$50,001 - $70,000 ☐
$70,001 – 100,000 ☐
$100,000 – or more ☐
Prefer not to answer ☐

Health questions

Have you been diagnosed with any long-term health conditions?

Yes ☐ No ☐

If the answer is yes, please let us know what they are

How long ago were you first diagnosed with your long-term health condition(s)?

Do you take any supplements?

Yes ☐ No ☐

If the answer is yes, please let us know what they are

Do you think of yourself as disabled (or as having a disability)?

Yes ☐ No ☐

Appendix A4: Coding guide for demographic questionnaire

Question	Responses (received)	Coding
Could you tell us if you are answering this survey on behalf of yourself or someone else?	Myself	1
	Someone else	2
What is your gender	Male	1
	Female	2
What is your date of birth? NB: Coded as Age range	18 – 20	1
	20 – 29	2
	30 – 39	3
	40 – 49	4
	50 – 59	5
	60 – 69	6
	70 – 79	7
	80 - 89	8
What is your primary ethnicity?	Cook Island Māori	1
	Indian	2
	NZ European	3
	Samoan	4
	Niuean	5
	Chinese	6
	Tongan	7
	Cook Island	8
	Māori	9
	European	10
What languages do you speak most often at home?	English	1
	NZ Sign Language	2
	Samoan	3
	Tongan	4
	Northern Chinese	5
	Niuean	6
	Gujirati	7
What suburb do you live in?	Otara	1
	Manurewa	2
	Favona	3
	Paparimu	4
	Takanini	5
	Mangere	6
	Beachlands	7
	Flat Bush	8
	Half moon bay	9
	Manukau	10
	Bucklands beach	11
	East Tamaki	12
	Pukekhoe	13
	Tuakau	14
	Waiuku	15

	Golflands	16
	Totara Park	17
	Pakuranga	18
	Papakura	19
	Whitford	20
	Sunnyhills	21
	Drury	22
What is the highest level of education you have received?	Primary School	1
	Secondary School	2
	Bachelors degree	3
	None	4
	Trade certificate/ diploma	5
	Community health cert	6
	Post – graduate education	7
	Te Kura Special school	8
	Special education	9
What is your total HOUSEHOLD income received FROM ALL SOURCES BEFORE TAX for the last 12 months?	$10,001-$15,000	1
	$15,001 - $20,000	2
	$50,001-$70,000	3
	$5,001-$10,000	4
	$100,000-or more	5
	Prefer not to answer	6
	$1- $5,000	7
	$70,001-$100,000	8
	$30,001-$40,000	9
	$40,001-$50,000	11
	$20,001-$30,000	12
Have you been diagnosed with any long-term health conditions?	Yes	1
	No	2
If the answer is yes, please let us know what they are	Cancer	1
	Cerebral palsy	2
	MND	3
	Cornelia de Lange syndrome	4
	Crouzon syndrome	5
	Stroke	6
	Epilepsy and intellectual disability	7
	Coeliac disease, IBM	8
	Muscular dystrophy	9
	Dysphagia from radiation	10
	Emery Dreyfus muscular dystrophy	11
	Pentalogy of Cantrell	12
	IBM	13

	ME	14
	Emmanuel syndrome	15
	Autonomic dysfunction	16
	Bilateral cystic periventricular leukomalacia	17
	Intellectual disability, physical disability, aspiration	18
How long ago were you first diagnosed with your long-term health condition(s)?	From birth	1
	2000 – 2010	2
	2010 – 2023	3
	1990 - 2000	4
Do you think of yourself as disabled (or as having a disability)?	Yes	1
	No	2

APPENDIX A5: NZ World Health Organisation QoL questionnaire

Participant Id:

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES
MANUKAU
HEALTH

HELP study

NZ WHOQOL-BREF questionnaire

This questionnaire asks how you feel about your quality of life, health, and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks.**

Part A – Generic Questions

1. How would you rate your quality of life?

1- Very poor
2- Poor
3- Neither poor nor good
4- Good
5- Very good

2. How satisfied are you with your health?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

The following questions ask about **how much** you have experienced certain things in **the last two weeks.**

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

1- Not at all
2- A little
3- A moderate amount
4- Very much

5- An extreme amount

4. How much do you need any medical treatment to function in your daily life?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

5. How much do you enjoy life?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

6. To what extent do you feel your life to be meaningful?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

7. How well are you able to concentrate?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

8. How safe do you feel in your physical environment?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

9. How healthy is your physical environment?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

The following questions ask about **how completely** you have experiences **or** where able to do certain things in the **last two weeks**.

10. Do you have enough energy for everyday life?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

11. Are you able to accept your body appearance?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

12. Have you enough money to meet your <u>needs</u>?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

13. How available to you is the information you need in your day-to-day life?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

14. To what extent do you have the opportunity for leisure activities?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

15. How well are you able to get around physically?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- An extreme amount

The following questions ask about **how good or satisfied** you have felt about aspects of your life over **the last two weeks**

16. How satisfied are you with your sleep?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

17. How satisfied are you with your ability to perform your daily living activities?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

18. How satisfied are you with your capacity for work?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

19. How satisfied are you with yourself?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

20. How satisfied are you with your personal relationships?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

21. How satisfied are you with your sex life?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

22. How satisfied are you with the support you get from your friends?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

23. How satisfied are you with the conditions of your living place?

1- Very dissatisfied
2- Dissatisfied
3- Neither satisfied nor dissatisfied
4- Satisfied
5- Very satisfied

24. **How satisfied are you with your access to health services?**

    1- Very dissatisfied
    2- Dissatisfied
    3- Neither satisfied nor dissatisfied
    4- Satisfied
    5- Very satisfied

25. **How satisfied are you with your transport?**

    1- Very dissatisfied
    2- Dissatisfied
    3- Neither satisfied nor dissatisfied
    4- Satisfied
    5- Very satisfied

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

26. **How often do you have negative feelings such as a blue mood, despair, anxiety or depression?**

    1- Never
    2- Seldom
    3- Quite often
    4- Very often
    5- Always

Part B – National Questions:

The following question asks about **how good or satisfied** you have felt about various aspects of your life over the last two weeks.

27. **How satisfied are you that you are able to meet the expectations placed on you?**

    1- Very dissatisfied
    2- Dissatisfied
    3- Neither satisfied nor dissatisfied
    4- Satisfied
    5- Very satisfied

The following questions ask about **how completely** you have experienced or were able to do certain things in the **last two weeks.**

28. To what extent do you feel respected by others?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- Extremely

29. To what extent are you able to manage personal difficulties?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- Extremely

30. To what extent do you have feelings of belonging?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- Extremely

31. To what extent do you feel you have control over your life?

1- Not at all
2- A little
3- A moderate amount
4- Very much
5- Extremely

ABOUT YOU

We would like to ask you a few general questions about yourself.

1. Are you

Male ☐ Female ☐

2. What is your **year of birth?**

3. Which ethnic group do you belong to? Select the options that most apply to you:

    Chinese ☐
    NZ European ☐
    Indian ☐
    Niuean ☐
    Tongan ☐
    Cook Island Māori ☐
    European ☐
    Māori ☐
    Samoan ☐
    Other ☐

4. What is the **highest level of education** you have completed?

    None at all ☐
    Secondary school ☐
    Primary school ☐
    Tertiary ☐

5. What is your **marital status?**
    Single ☐
    Married ☐
    Living as married ☐
    Separated ☐
    Divorced ☐
    Widowed ☐

6. What is **your** current employment status?

    Full-time work ☐
    Part-time work ☐
    Unemployed ☐
    Student ☐
    Retired ☐
    Other ☐

7. Are you **currently** ill or do you have a medical condition?

    Yes ☐
    No ☐

    If you answered **yes**, what is the diagnosis?

Appendix A6: Coding & scoring the NZ World Health Organisation QoL questionnaire

Scoring of the NZ WHOQOL-BREF

The NZ WHOQOL-BREF does not provide a single score but instead a multidomain profile. The questionnaire produces 29 individual facet scores, four domain scores, a general QOL score, and a health perceptions score (based on the questions pertaining to global QOL and general health). The 29 facet scores denote the individual's evaluation of his/her functioning in the particular area of life addressed by that facet. The four domain scores denote an individual's perception of QOL in each particular QOL domain (facets with related meaning). The WHOQOL is scored through straightforward summative scaling, with item score-reversal where necessary. At times, respondents will circle more than one answer such as by circling more than one number when they are unsure. As only some respondents will tend to do that, this may introduce a bias in the scale. For consistency, it is recommended to discard such answers (unless sample sizes are very small or the questionnaire is used as a discussion tool). Methods for obtaining facet and domain scores are shown below.

To obtain a facet score: Generally, a high score on a question implies high QOL. However, there are three negatively worded questions where the opposite is the case. To make these questions consistent with these others, these three questions need to be reverse coded. These are Questions 3, 4, and 26.

Reverse coding these items means transposing individual responses from 1 to 5, 2 to 4, 4 to 2, 5 to 1. Note that 3 remains unchanged. A more general way to express this operation is by the formula "6-x" (where x is the answer provided for a question). For example, if a respondent answered "4" on a question, "6-x" will be "6-4" and thus the new score will be "2". To avoid confusion at a later time point, it is recommended to provide clear labels as to whether items have already been reverse coded (such as "6-Q26" or "Q26r").

To obtain a group mean average for a facet, simply add the individual scores of those in the group and divide by the number of people in the group who have provided an answer for that question (which may be different from the total sample size due to missing responses on some items).

To obtain a domain score: In its item summary form (ordinal scale), each facet is taken to contribute equally to the domain score in which they reside (Tables 2 & 3). Domain scores are calculated by summing the facet scores within the domain after the above-mentioned reverse coding has been conducted for items 3, 4, and 26. For each of the domains the range of scores (minimum to maximum) will be:

Physical: 7 to 35
Psychological without NZ items: 6 to 30
Psychological with NZ items: 10 to 50.
Social without NZ items: 3 to 15
Social with NZ items: 4 to 20

Environment: 8 to 40

Table 2: Scoring procedure used when the 26-item generic questionnaire ***without*** *the five New Zealand questions has been completed.*

Domain	Equations for computing domain scores	Score
Physical	**(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18** .... + ... + ... + ... + ... + ... + ...	
Psychological	**Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)** ...... + ... + ... + ... + ... + ...	
Social relationships	**Q20 + Q21 + Q22** .... + ... + ...	
Environment	**Q8+ Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25** ...... + ... + ... + ... + ... + ... + ... + ...	

Table 2: Scoring procedure used when the 26-item generic questionnaire ***with*** *the five New Zealand questions has been completed.*

Domain	Equations for computing domain scores	Score
Physical	**(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18** .... + ... + ... + ... + ... + ... + ...	
Psychological	**Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) + Q27 + Q28 +Q29 + Q31** ...... + ... + ... + ... + ... + ... + ……+ …….+…….+……	
Social relationships	**Q20 + Q21 + Q22 + Q30** .... + ... + ... +……	
Environment	**Q8+ Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25** ...... + ... + ... + ... + ... + ... + ... + ...	

Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The two items that stand separate from the domain calculations are Question 1, which asks the respondent how they would rate their overall QOL, and Question 2, which asks how they would rate the quality of their health. These two global items are reported as separate overall items.

While domain scores provide more levels of differentiation of respondents, it may at times be more meaningful to score each item separate from its domain. Domains by themselves are rather abstract units in the sense that many do not provide specifics that can be addressed to improve one’s QOL. It is often the movement or change of individual item scores that are most useful when the test is used before (pre-test) and after (post-test) a health intervention.

There are two opinions about whether the five New Zealand national items that emerged from the New Zealand version study in 2011 should be included for analysis in their respective domains or left separate. The decision is somewhat dependent on whether the New Zealand domain data collected are to be compared to scores obtained from other country versions. While these five national items can be added to domains scores when using the NZ WHOQOL-

BREF in New Zealand, care should be taken to ensure that, when comparisons are made with other New Zealand datasets, the five additional New Zealand items are also included in domain level analyses. Likewise, when cross-cultural comparisons are made with other country data, their national items and the New Zealand items would need to be omitted from domain level analyses.

The definition of facets

Detailed definitions for each facet are annexed (Annex 1). The definitions are very useful in order to further discussion of results in reports and for discussion with patients and clients in the counselling situation. But these definitions should **not** be shared with respondents during the testing session where it is desirable that the respondent provides a rating to each item **based on their own definition** of the facet meaning. Provision of definitions for some and not for other respondents would also introduce a response bias. Also note that the WHOQOL is a subjective measure of QOL that defines QOL as a person's perceptions in contrast to health status measures that assess more objective aspects (for more detail, see Billington, Landon, Krägeloh, & Shepherd, 2010; Camfield & Skevington, 2008).

Missing data

Where more than 20% of data are missing from an assessment, it is generally recommended to discard the respondent's assessment entirely from aggregate analyses. Where less than half of items in a domain are missing, the mean of the missing items may be imputed by the other items in that domain. For example, if Q21 in the social relationships domain has not been answered, but the respondent provided scores of "3", "3", and "4" for Questions 20, 22, and 30, respectively, Q21 may be imputed by calculating the average of the other scores (3.33) and rounding it to "3". Rounding is necessary to maintain the ordinal nature of the scale. Syntax files for automatic computation of domains are available as for the WHOQOL-BREF upon request from the NZ WHOQOL Group at www.whoqol.org.nz.

Comparative analyses

A standard coding system is attached as Annex 2. Use of the coding system provided will enhance comparisons with results from other studies or datasets. Storage and analysis of data depends upon the institutional need. Some users in New Zealand are prepared to share their storage programmes. A method for the manual calculation of individual scores has been outlined above. More automated procedures for imputing data and calculating domain scores are available from the NZ WHOQOL Group at AUT. This includes assistance with other ways to present domain scores such as presenting scores in a format consistent with the WHOQOL-100.

Reference values

New Zealand data for the 26-item generic short form the WHOQOL-BREF has been collected from 12 studies completed in New Zealand from 2007 to 2012. The data pool includes 3782 individuals. The scores pertain to the 26 WHOQOL-BREF questions, but do not include the five New Zealand national items that have been subsequently developed and included in the NZ WHOQOL-BREF since 2012. The reference value information calculated consists of the mean average values and variances for each item and for each of the four domains. The studies involved people who were well. Data from sick people or those who regarded themselves as being unwell were not included. Other than international norms containing both sick and well people, there has been nothing in the past for New Zealand studies to compare scores. Additionally, comparisons with other countries have little real local value. The production of New Zealand reference values for the WHOQOL-BREF provides comparative data for New Zealand studies and health intervention that do not have comparison-group data. They also provide helpful comparative data where pre-intervention evaluations have not been conducted to obtain baseline WHOQOL-BREF values where this would be useful.

The reference values are categorised according to gender, education and age level groupings. In some categories such as occupation and ethnicity there were insufficient cases to confidently produce values. But this limitation will be rectified with time as more data are collected and included. The use of “norms” as a descriptive term is therefore avoided because of an incomplete and limited database at this time. It is not possible to compare New Zealand values with WHOQOL-BREF data from other countries because their values include both well and un-well people. Again, one is cautioned about the generalisability of these reference values because of sample bias and as yet insufficient data in some categories. This, however, will improve over time as more data will be included.

The reference values will not be released for public consumption because of possible misinterpretation of the meaning of these reference values to individual test scores where knowledgeable administrators are not present. The NZ WHOQOL-BREF will only be released to those who are responsible authorised professionals.

If you are such a person and would like a copy of these reference values please contact the NZ WHOQOL Group. We also encourage users of the NZ WHOQOL-BREF to share their data upon completion of the study with the NZ WHOQOL Group to add to the continuously growing reference values database. This will benefit all users of the scale. When providing the data, only basic demographic information (ideally in the standard format mentioned above) and the WHOQOL scores need to be provided.

APPENDIX A7: NutriQoL questionnaire

Participant Id:

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES
MANUKAU
HEALTH

HELP study

NutriQol questionnaire

These questions relate to your home tube feeding and will help us to understand the impact on your quality of life.

Mealtimes:

1.a. With HEN, I can maintain my usual mealtime (e.g., Breakfast, Lunch, Dinner, Supper)

Never ☐ Sometimes ☐ Always ☐

1.b. For me, maintaining my usual mealtime is:

Not important at all ☐ Important ☐ Very important ☐

Food characteristics:

2.a. HEN matches my preference for food characteristics (e.g., texture, colour, smell, temperature, taste)

Never ☐ Sometimes ☐ Always ☐

2.b. For me, the fact that HEN matches my preference for food characteristics is:

Not important at all ☐ Important ☐ Very important ☐

Movement:

3.a. Since I have been receiving HEN, it is easier for me to move; I feel more agile

Never ☐ Sometimes ☐ Always ☐

3.b. For me being able to move more easily and feeling more agile is:

Not important at all ☐ Important ☐ Very important ☐

Daily Tasks:

4. a. With HEN, I can continue doing my daily tasks (e.g., read the newspaper, cook, wash the car, clean, watch TV)

Never ☐ Sometimes ☐ Always ☐

4. b. For me being able to continue doing my daily tasks is:

Not important at all ☐ Important ☐ Very important ☐

Physical appearance:

5. a. Since I started HEN, I notice that my physical appearance is improving (e.g., I see myself as healthier)

Never ☐ Sometimes ☐ Always ☐

5. b. For me noticing that I am looking better physically is

Not important at all ☐ Important ☐ Very important ☐

Accessing feed:

6.a. It is easy for me to get my feed (e.g., they are available in pharmacies, it is easy for me to get a prescription)

Never ☐ Sometimes ☐ Always ☐

6. b. For me, being able to get my feed easily is:

Not important at all ☐ Important ☐ Very important ☐

Nourishment:

7.a. With HEN, I feel that I am well nourished

Never ☐ Sometimes ☐ Always ☐

7. b. For me, feeling that I am well nourished is:

Not important at all ☐ Important ☐ Very important ☐

Weight gain:

8.a. With HEN, I have gained weight

Never ☐ Sometimes ☐ Always ☐

8. b. For me, gaining weight is:

Not important at all ☐ Important ☐ Very important ☐

Social life:

9.a. HEN allows me to go out with my friends

Never ☐ Sometimes ☐ Always ☐

9. b. For me, being able to go out with my friends is:

Not important at all ☐ Important ☐ Very important ☐

Skin issues:

10.a. HEN harms my skin (e.g., dryness, irritation, infections)

Never ☐ Sometimes ☐ Always ☐

10.b. For me, harming my skin is:

Not important at all ☐ Important ☐ Very important ☐

Sleep:

11.a. HEN prevents me from sleeping well

Never ☐ Sometimes ☐ Always ☐

11.b. For me sleeping well is:

Not important at all ☐ Important ☐ Very important ☐

Physiological adaptation:

12.a. I worry about my body adapting to HEN and never being able to go back to feeding as before

Never ☐ Sometimes ☐ Always ☐

12.b. For me, the possibility of my body adapting to HEN and not being able to go back to feeding as before is:

Not important at all ☐ Important ☐ Very important ☐

Pleasure from food:

13.a. With HEN, I miss chewing and savouring food

Never ☐ Sometimes ☐ Always ☐

13.b. For me, chewing and savouring is:

Not important at all ☐ Important ☐ Very important ☐

Physical discomfort:

14.a. With HEN I experience physical discomfort due to feeding (e.g., feeling stomach heaviness, mouth dryness, acid reflux, regurgitation)

Never ☐ Sometimes ☐ Always ☐

14.b. For me, experiencing physical discomfort due to feeding is:

Not important at all ☐ Important ☐ Very important ☐

Family involvement:

15.a. With HEN, my family keeps a closer watch over my nutrition

Never ☐ Sometimes ☐ Always ☐

15.b. For me, the fact that my family keep a closer watch on my nutrition is:

Not important at all ☐ Important ☐ Very important ☐

Socialising:

16.a. With HEN, I limit my activities with my friends to those not related to eating

Never ☐ Sometimes ☐ Always ☐

16.b. For me, limiting my activities with my friends to those not related to eating is:

Not important at all ☐ Important ☐ Very important ☐

Health:

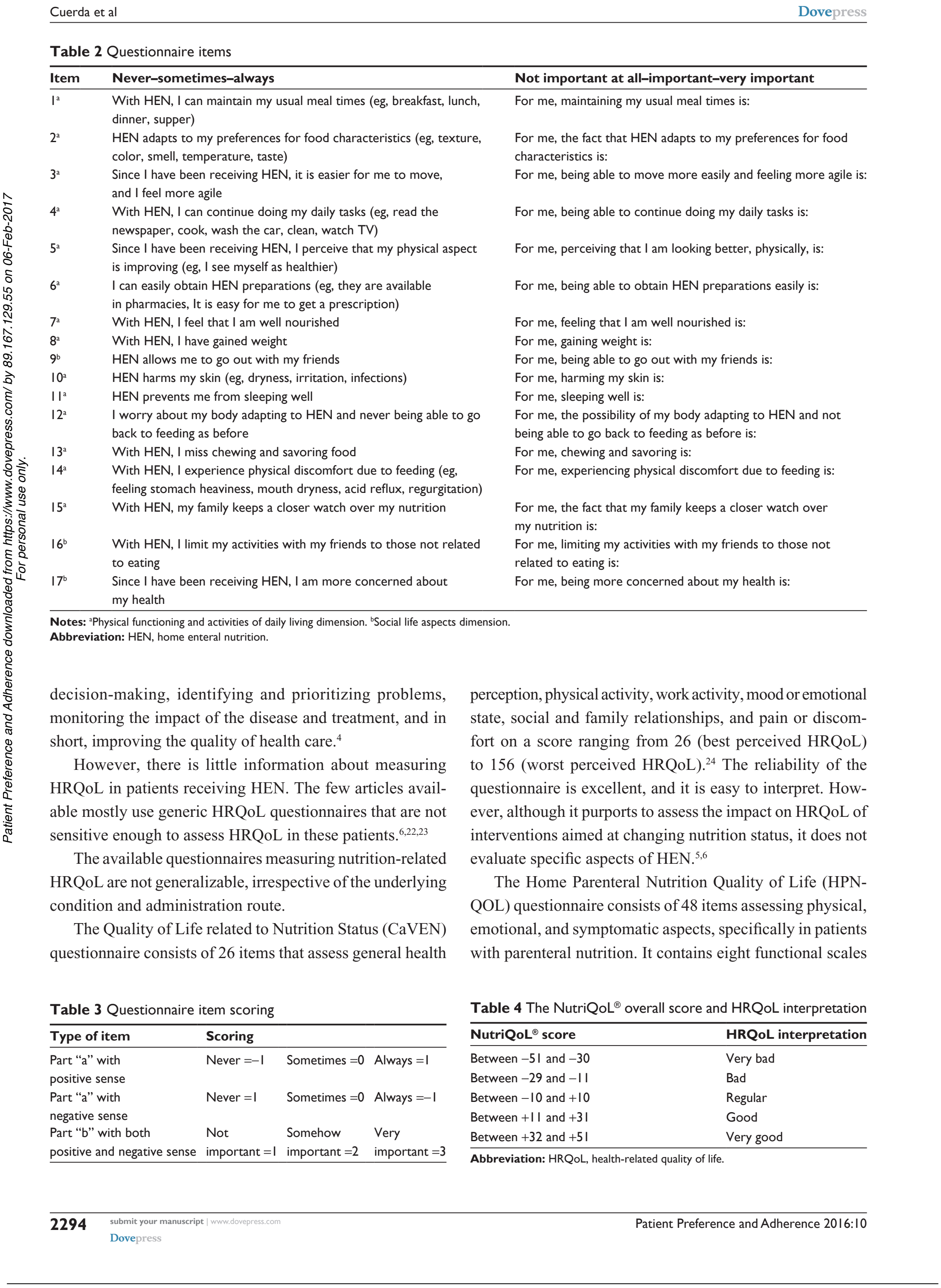
17.a. Since I have been receiving HEN, I am more concerned about my health

Never ☐ Sometimes ☐ Always ☐

17.b. For me, being more concerned about my health is:

Not important at all ☐ Important ☐ Very important ☐

Appendix A8: NutriQoL coding guide



Patient Preference and Adherence downloaded from https://www.dovepress.com/ by 89.167.129.55 on 06-Feb-2017
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Table 2 Questionnaire items

Item	Never–sometimes–always	Not important at all–important–very important
1[a]	With HEN, I can maintain my usual meal times (eg, breakfast, lunch, dinner, supper)	For me, maintaining my usual meal times is:
2[a]	HEN adapts to my preferences for food characteristics (eg, texture, color, smell, temperature, taste)	For me, the fact that HEN adapts to my preferences for food characteristics is:
3[a]	Since I have been receiving HEN, it is easier for me to move, and I feel more agile	For me, being able to move more easily and feeling more agile is:
4[a]	With HEN, I can continue doing my daily tasks (eg, read the newspaper, cook, wash the car, clean, watch TV)	For me, being able to continue doing my daily tasks is:
5[a]	Since I have been receiving HEN, I perceive that my physical aspect is improving (eg, I see myself as healthier)	For me, perceiving that I am looking better, physically, is:
6[a]	I can easily obtain HEN preparations (eg, they are available in pharmacies, It is easy for me to get a prescription)	For me, being able to obtain HEN preparations easily is:
7[a]	With HEN, I feel that I am well nourished	For me, feeling that I am well nourished is:
8[a]	With HEN, I have gained weight	For me, gaining weight is:
9[b]	HEN allows me to go out with my friends	For me, being able to go out with my friends is:
10[a]	HEN harms my skin (eg, dryness, irritation, infections)	For me, harming my skin is:
11[a]	HEN prevents me from sleeping well	For me, sleeping well is:
12[a]	I worry about my body adapting to HEN and never being able to go back to feeding as before	For me, the possibility of my body adapting to HEN and not being able to go back to feeding as before is:
13[a]	With HEN, I miss chewing and savoring food	For me, chewing and savoring is:
14[a]	With HEN, I experience physical discomfort due to feeding (eg, feeling stomach heaviness, mouth dryness, acid reflux, regurgitation)	For me, experiencing physical discomfort due to feeding is:
15[a]	With HEN, my family keeps a closer watch over my nutrition	For me, the fact that my family keeps a closer watch over my nutrition is:
16[b]	With HEN, I limit my activities with my friends to those not related to eating	For me, limiting my activities with my friends to those not related to eating is:
17[b]	Since I have been receiving HEN, I am more concerned about my health	For me, being more concerned about my health is:

Notes: [a]Physical functioning and activities of daily living dimension. [b]Social life aspects dimension.
Abbreviation: HEN, home enteral nutrition.

decision-making, identifying and prioritizing problems, monitoring the impact of the disease and treatment, and in short, improving the quality of health care.[4]

However, there is little information about measuring HRQoL in patients receiving HEN. The few articles available mostly use generic HRQoL questionnaires that are not sensitive enough to assess HRQoL in these patients.[6,22,23]

The available questionnaires measuring nutrition-related HRQoL are not generalizable, irrespective of the underlying condition and administration route.

The Quality of Life related to Nutrition Status (CaVEN) questionnaire consists of 26 items that assess general health perception, physical activity, work activity, mood or emotional state, social and family relationships, and pain or discomfort on a score ranging from 26 (best perceived HRQoL) to 156 (worst perceived HRQoL).[24] The reliability of the questionnaire is excellent, and it is easy to interpret. However, although it purports to assess the impact on HRQoL of interventions aimed at changing nutrition status, it does not evaluate specific aspects of HEN.[5,6]

The Home Parenteral Nutrition Quality of Life (HPN-QOL) questionnaire consists of 48 items assessing physical, emotional, and symptomatic aspects, specifically in patients with parenteral nutrition. It contains eight functional scales

Table 3 Questionnaire item scoring

Type of item	Scoring		
Part "a" with positive sense	Never =–1	Sometimes =0	Always =1
Part "a" with negative sense	Never =1	Sometimes =0	Always =–1
Part "b" with both positive and negative sense	Not important =1	Somehow important =2	Very important =3

Table 4 The NutriQoL® overall score and HRQoL interpretation

NutriQoL® score	HRQoL interpretation
Between –51 and –30	Very bad
Between –29 and –11	Bad
Between –10 and +10	Regular
Between +11 and +31	Good
Between +32 and +51	Very good

Abbreviation: HRQoL, health-related quality of life.

APPENDIX A9: Equity and Experience questionnaire

Participant Id:

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES MANUKAU HEALTH

HELP study

Patient equity and experience questionnaire

These questions relate to past home visits from your nurse & dietitian for your home tube feeding. When asked about an experience with your HEN care practitioner, please think specifically about interactions with your home tube feeding nurse and dietitian.

Was your name pronounced properly by your HEN care practitioner?

Yes, always	☐	Sometimes	☐
No one used my name	☐	Unsure/ don't know	☐

Did your HEN care practitioner ask how to say your name if they were uncertain?

Yes, always	☐	Sometimes	☐
They did not need to ask	☐	Unsure/ don't know	☐

Did your HEN care practitioner inform you as much as you wanted about your health condition, treatment, or care?

Yes, definitely	☐	Somewhat	☐
No	☐		

Did your HEN care practitioner explain things in a way you could understand?

Yes, definitely	☐	Somewhat	☐
No	☐		

Did your HEN care practitioner treat you with kindness and understanding?

Yes, definitely	☐	Somewhat	☐
No	☐		

Did your HEN care practitioner treat you with respect?

Yes, definitely	☐	Somewhat	☐
No	☐		

Did your HEN care practitioner spend enough time with you?

Yes, definitely	☐	Somewhat	☐
No	☐		

Did you have trust and confidence in your HEN care practitioner?

Yes, definitely	☐	Somewhat	☐
No	☐		

Did you feel comfortable to ask your HEN care practitioner any questions you had?

Yes, definitely	☐	Somewhat	☐
No	☐	Can’t remember/ don’t know	☐

Did your HEN care practitioner involve you as much as you wanted to be in making decisions about your treatment?

Yes, definitely	☐	Somewhat	☐
No	☐		

Did you feel your cultural needs were met?

Yes, definitely	☐	Somewhat	☐
No	☐		

Did you feel your Spiritual needs were met?

Yes, definitely ☐
No ☐
Somewhat ☐

Did you feel your individual needs were met?

Yes, definitely ☐
No ☐
Somewhat ☐

During the experience did you ever feel you were treated unfairly for any of the reasons below? Please select all that apply

I was NOT treated unfairly ☐
Your race or ethnic group ☐
Your gender identity ☐
A disability or physical health condition you have ☐
Your sexual orientation ☐
Your appearance ☐
Something else (please specify) ☐
____
Your skin colour ☐
Your age ☐
A mental health condition you have ☐
Your religious beliefs ☐
Your income or your family/ whanau's income ☐
Don't know/ unsure ☐

If you want to, were you able to have family/ whanau involved in discussions about your treatment and care?

Yes, definitely ☐
No ☐
Not applicable ☐
Somewhat ☐
I do not want them included ☐

The following questions are related to your prescriptions for your tube feeding

In the last 12 months was there a time when cost stopped you from picking up a prescription?

Yes ☐
No ☐

In the last 12 months, did you always follow the instructions when taking your Prescription?

Yes ☐ No ☐

If you answered no, please tell us more

THANK YOU

APPENDIX B: Supplementary results tables

Supplementary table 1. Correlation analysis of Total NutriQoL QoL score, Participant characteristics, NZWHOQoL scores and equity and experience responses.

Correlation factors	NutriQoL Total QoL
DGQ_Age_category	-.492**
DGQ Gender	0.093
DGQ_Ethnic_group	0.143
DGQ Primary_language	0.07
DGQ Suburb	-0.144
DGQ Household_income	-0.131
DGQ Underlying_Condition	.369*
DGQ Disabled	-0.15
DB Base	-0.118
DB Interpreter	0.097
DB Time on HEN (months)	.397**
DB Tube type	-0.078
EE Name_pronounciation_properly	0.043
EE Ask_name	0.213
EE Inform	-0.131
EE Explain_so_you_could_understand	0.09
EE Treatment_kindness	0.145
EE Treatment_respect	0.07
EE Adequate_time	0.041
EE Confidence	0.106
EE Comfortable_to_ask	0.123
EE Involvement_adequate	0.006
EE Needs_met_cultural	-0.277
EE Needs_met_spiritual	-0.143
EE Needs_met_individual	-0.098
EE Treat_unfairly	0.193
EE Whanau_involvement	-0.036
EE Cost_restriction_rx_collection	0.165
EE Folllow_rx_instructions	-0.059
NZWHO Q1_Rate_QoL	.483**
NZWHO Q2_Health_satiisfaction	.402**
NZWHO D4_Education	-0.201
NZWHO D5_Marital_status	-.492**
NZWHO D6_Employment_status	-0.084
NZWHO F1_Physical_health	0.223
NZWHO F2_Psychological_wellbeing	0.259
NZWHO F3_Social_relationships	0.029
NZWHO F4_Environment	0.221

Spearman's rank *p<0.05, **p<0.001

Supplementary table 2. Correlation analysis of NZWHOQoL BREF Q1, Q2 and domain scores with , Participant characteristics, total NutriQoL scores and equity and experience responses.

Correlation factors	Q1_Rate_QoL	Q2_Health_satiisfaction	F1_Physical_health	F2_Psychological_wellbeing	F3_Social_relationships	F4_Environment
DGQ_Age_category	-0.225	-0.234	0.152	0.121	0.18	0.199
DGQ Gender	0.034	0.113	-0.224	-0.004	0.002	-0.245
DGQ_Ethnic_group	0.283	0.166	0.164	.424**	.392*	.518**
DGQ Primary_language	-.322*	-0.148	-0.103	-0.247	-0.27	-0.162
DGQ Suburb	-0.094	-0.041	-0.006	0.16	-0.112	-0.074
DGQ Household_income	-0.148	-0.205	-0.031	0.237	0.177	0.078
DGQ Underlying_Condition	0.136	0.242	-0.027	-0.077	-0.161	0.017
DGQ Disabled	-0.056	-0.154	0.049	0.014	0.159	0.201
DB Base	-0.018	0.103	0.276	0.171	0.011	0.213
DB Interpreter	-0.28	-0.148	-0.058	-0.194	-0.227	-0.168
DB Time on HEN (months)	0.238	.313*	0.072	-0.009	-0.148	-0.073
DB Tube type	0.084	0.05	-0.186	-0.142	-0.096	-0.206
EE Name_pronounciation_properly	-0.183	-0.018	-0.284	-.335*	-.476**	-0.294
EE Ask_name	0.014	0.291	0.2	0.088	-0.041	0.003
EE Inform	-0.287	-0.211	-0.109	-0.22	-0.276	-.326*
EE Explain_so_you_could_understand	-0.095	0.011	-0.111	-0.251	-.417**	-0.227
EE Treatment_kindness	-0.104	0.042	0.076	-0.15	-0.241	-0.055
EE Treatment_respect	-0.106	-0.01	-0.027	-0.164	-0.249	-0.104
EE Adequate_time	-.409**	-0.21	-0.06	-.403**	-.420**	-.311*
EE Confidence	-0.195	0.041	0.042	-0.269	-.475**	-0.172
EE Comfortable_to_ask	0.001	0.128	-0.03	-0.245	-0.291	-0.134
EE Involvement_adequate	-0.285	-0.029	0.119	-0.293	-.378*	-0.117
EE Needs_met_cultural	-.375*	-0.301	-0.283	-.365*	-.494**	-.327*
EE Needs_met_spiritual	-0.084	-0.026	0.07	-0.243	-.340*	-0.153
EE Needs_met_individual	-0.221	0.041	-0.026	-.320*	-.414**	-0.225
EE Treat_unfairly	-0.051	0.009	0.069	-0.013	-0.234	-0.007
EE Whanau_involvement	-0.071	0.014	-0.11	-0.157	-0.237	-0.045

EE Cost_restriction_rx_collection	0.1	-0.028	-0.08	-0.046	-0.015	0.187
EE Follow_rx_instructions	-0.107	-0.047	0.115	0.101	-0.237	0.11
NQoL_Total_QoL	.483**	.402**	0.223	0.259	0.029	0.221

Spearman's rank *p<0.05, **p<0.001

APPENDIX C1: Individual patient interview questions

HELP study

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES MANUKAU HEALTH

HELP study participant ID # ________________
Date: ____________________________________
Start Time: _________ **End Time:** ___________
Location: _______________________________ **Interviewer:** ____________________________

Individual interview_ Question guide & Log

Themes and Questions:

Theme: Communication about HEN
Q1: Do you find it easy to talk to your Nurse or Dietitian about your tube feeding and care?

That's interesting, why do you feel like that?

Q2: How do you feel about the consistency of information you have been receiving from your Nurse and Dietitian?

Is there a specific incident you can recall where that has happened?
How did you feel?

Theme: Equity of patient experience
Q3: Do your Nurse or Dietitian help you with everything that you need them too?

Can you please tell me a bit more about that?

Q4: Have you ever experienced care from your Nurse or Dietitian that you did not like?

Was there something specific?
How did you feel?
What was it about the experience that you did not like?

Theme: Confidence in management of HEN
Q5: Which aspects of tube feeding at home do you feel most confident about managing yourself?

And why is that?

Q6: Do you feel that all the Nurses and Dietitians that you see have enough knowledge and experience to help you?

Is there a specific incident you can recall that you would like to tell me about?
How did you feel?

Theme: problems with HEN

Q7: Have you ever experienced any problems with your tube feeding at home?
How did the issue get resolved?
How long did that take?
Who helped you with that?

Q8: What could we do differently to support you?

Q9: Is there anything else you would like to say about your HEN care before we finish up?

Probing questions:

Detail oriented:
What was it like?

Elaboration:
[name] can you tell me more about..?
[name] can you please expand?

Clarification:
I'm not sure I understand what you mean by [ ], can you help me understand what that means?

APPENDIX C2: Focus group question guide

HELP study

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES
MANUKAU
HEALTH

HELP study- Focus Group # __________________
Date: ____
Start Time: __________ **End Time:** _____________
Location: ____________________________________ **Moderator:** ________________________________

Focus Group Question guide & Log

Questions:

Introduction:

- **Name**
- **Role**
- **Experience with HEN patients**
- **Frequency of seeing or caring for a HEN patient**

Q1: How do you help or care for your HEN patients?

- How do you see your role?
- Does this cover everything they need?
- Do you think there is anything missing from the service or anything you'd like to add?

Q2: What factors affect your HEN patient's ability to manage their tube feeding at home appropriately?

- How well are they coping with that?
- What are they doing really well?

Q3: What sort of problems do your patients experience with their HEN care?

- (This may be related to their nutrition or healthcare, or these might be broader problems (e.g., quality of life?)

Q4: How confident are you in your ability to care for HEN patients?

- Are there any stumbling blocks? (e.g., experience, clinical complexity)
- What help do you need to make you make you feel more confident? (e.g., support, resources, upskilling (PD), time etc.)

Q5: What do you normally do when your patients when they are experiencing problems with their tube feeding at home?

- When and how do you escalate any issues?
- How well equipped do you feel to help with these problems?

Q6: When you are explaining something to a patient or a caregiver, how do you know they have understood you?

- What strategies do you use to ensure they know what you mean or what to do?
- Communication and/or language barriers
- How do you gauge understanding

Q7: Do you feel like you are able to provide consistent care to all your patients?

- Why/why not?
- What factors might affect this?

Q8: What does culturally safe practice mean to you?

- Is there any support you would like to assist with your cultural safety?

Q9: How do you find working with the MDT including your Dietitian colleagues?

Q10: Is there anything we haven't touched on today that you would like us to know?

- Please comment on anything that would improve or support you to work more efficiently, effectively or to provide better care to your patients?

Probing questions:

Detail oriented:
What was it like?

Elaboration:
[name] can you tell me more about..?
[name] can you please expand?

Clarification:

APPENDIX C3: Standard Operating Procedures

HELP study

HELP study- Standard Operating Procedure
Title: Conducting Individual Participant Interviews

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

COUNTIES MANUKAU HEALTH

Conducting Individual Participant Interviews

---

1. Purpose

Qualitative research looks to ascertain people's experiences, interactions, behaviours, and beliefs by means of focus group discussions or individual interviews. For individual interviews, data must be collected using a standardised procedure.

2. Intended Users

Researchers and Research Assistants involved in the data collection.

3. Responsibilities

All HELP study researchers & research assistants ought to understand and be able to follow this SOP prior to conducting any Individual interviews. It is the responsibility of the PI and the Qualitative researcher to ensure that all team members involved in data collection comply with this SOP.

4. Definitions

4.1. **Participant:** Counties Manukau HEN patients eligible for the study who have consented to be involved.
4.2. **Data collection team:** Researchers and Research Assistants involved in the in-person data collection.
4.3. **In-person visit**: the initial point of data collection, occurring at the participants residence.
4.4. **Data Saturation**: the point in the research process where no new information is learned. This will be assessed by base, and once this is reached, it signals that no further individual interviews need to go ahead from participants under that specific base

5. Required Materials

5.1. Participant question guide
5.2. Audio recorder
5.3. Pen
5.4. Individual interview log sheet
5.5. Signed patient consent form
5.6. Researcher ID badge

6. Procedure

6.1. Individual participant interviews will take place at the end of the In-person visits until the base specific researcher ascertains data saturation has been met.

Interview Preparation

6.2. All individual interviews should take place one-on-one with no members of the participants health care team present. Participants may have family/ whānau present for support, but they must not influence the participants answers. If the participant is unable to communicate, the interview will take place with their advocate (and the same person who completed the equity and experience questionnaires).
6.3. Complete the individual interview log sheet, include the participants Id number, the date and time the interview will begin, the location of the interview, the recording device ID number, and that the audio check has been completed.
6.4. Test the audio recorder (audio check):
    6.4.1. It should be placed in the location where it will be for the duration of the interview.
    6.4.2. The researcher will turn on the recorder and speak for a few seconds (and ask the participant to speak also) before turning it off.
    6.4.3. The researcher will then rewind the recorder and play back to ensure the recorder is functioning and that sound quality is adequate.

Conducting the Interview

6.5. The audio recorder can be turned on once interview preparation has finished.
6.6. The interviewer should use the participant questions and prompts but can move between questions to ensure the flow of the interview. If a question has been answered as part of a previous response, the question does not need to be asked, but can be explored further if the researcher thinks it is appropriate.
6.7. The interviewer should also take notes during the interview of anything pertinent as well as anything that cannot be picked up by the audio recorder, such as facial expressions, or displayed emotions etc. These notes should be made in the spaces provided on the interview question sheet.
6.8. Where a translator is to be used, questions must still be addressed to the participant, whilst acknowledging the translator.
6.9. Before wrapping up the interview, the interviewer will ask the participant if there is anything else they would like to share related to the topic, before thanking them for their time.

Completing the interview

6.10. Upon conclusion of the interview, the researcher will turn off the audio recorder, and update the individual interview log-sheet with the time the recorder was turned off.
6.11. The audio file should be uploaded within 24 hours to the SharePoint file Audio files (92_HELP study>Study Visit Docs>Participant interviews>Audio files).

Only after the audio file has been successfully uploaded and played back in its entirety to ensure data quality can the file be deleted from the recording device.

6.12. Interview notes/ the completed interview question sheet should be placed in the individual participants file and typed up and saved in the SharePoint file Notes (92_HELP study>Study Visit Docs >Participant interviews> Notes).

Transcription of the interview

6.13. The audio file will be transcribed by the qualitative researcher and stored in the SharePoint file Transcripts (92_HELP Study>Study Visit Docs>Participant interviews>Transcripts).

6.14. For quality assurance, once the interview is fully transcribed, the research assistant will complete two random spot checks of the audio to text:

  6.14.1. These will be completed by randomly selecting a point in the interview (on the audio) and listening to 30 seconds comparing to the transcribed text.
  6.14.2. Any discrepancies must be rectified, by the qualitative researcher.
  6.14.3. The quality control check will then be completed again until the research assistant is satisfied the transcript is true to the audio file.

Conducting Focus Groups

---

1. **Purpose:**

   Qualitative research looks to ascertain people's experiences, interactions, behaviours, and beliefs by means of focus group discussions or individual interviews. For focus groups, data must be collected using a standardised procedure.

2. **Intended Users**

   Researchers and Research Assistants involved in the data collection.

3. **Responsibilities**

   All HELP study researchers & research assistants ought to understand and be able to follow this SOP prior to conducting any Focus Groups. It is the responsibility of the PI and the Qualitative researcher to ensure that all team members involved in data collection comply with this SOP.

4. **Definitions**
   4.1. **Participant:** Counties Manukau Health community team members involved in the care of HEN patients, specifically dietitians and nurses.
   4.2. **Data collection team:** Researchers and Research Assistants involved in the in-person data collection.
   4.3. **Data Saturation**: the point in the research process where no new information is learned. This will be assessed by base, and once this is reached, it signals that no further individual interviews need to go ahead from participants under that specific base.

5. **Required Materials**
   5.1. Focus group question guide
   5.2. Focus group pocket questions
   5.3. Audio recorder (x2)
   5.4. Researcher name badge
   5.5. Pen
   5.6. Focus group log sheet
   5.7. Signed participant consent forms

6. Procedure

6.1. Focus groups will take place at pre-agreed times at one of the Counties Manukau Health community bases.

6.2. Focus groups will be one hour long, and the decision to conduct another, will depend on the specific researcher ascertaining if data saturation has been met.

Focus group preparation

6.3. All focus groups should take place in private rooms with only participant members of CM Health present.

6.4. Test the audio recorder (audio check):

- 6.4.1. It should be placed in the location where it will be for the duration of the focus group.
- 6.4.2. The researcher will turn on the recorder and speak for a few seconds before turning it off.
- 6.4.3. The researcher will then rewind the recorder and play back to ensure the recorder is functioning and that sound quality is adequate.

6.5. The researcher will ensure all participants have signed consent forms and are wearing name badges.

6.6. Complete the focus group log sheet, include the participants Id numbers, the date and time the focus group will begin, the location of the interview, the recording device make(s) and model(s), and that the audio check has been completed.

Conducting the focus group

6.7. The audio recorder can be turned on once focus group preparation has finished.

6.8. The researcher will introduce the research briefly to provide context for the focus group.

- 6.8.1. Brief purpose of the study, and how the focus group will run.
- 6.8.2. Ethical issues such as anonymity, confidentiality, storage, and publication of information will be addressed.
- 6.8.3. Rules of engagement for the group will be drawn up and agreed upon, this will take no more than 2-3 minutes.
- 6.8.4. Participants will be asked to try and verbalise answers instead of relying on body language such as shaking or nodding their heads.
- 6.8.5. Participants will also be asked to try and remember to say their name before they speak, to allow easier tracking of who says what when replaying the audio later.

6.9. To record voices and names, the moderator will ask the group to go round the table and answer an ice breaker question, stating their name before answering.

6.10. The moderator should use the focus group questions and prompts but can move between questions to ensure the flow of the focus group. If a question has been answered as part of a previous response, the question does not need to be asked, but can be explored further if the researcher thinks it is appropriate.

6.11. The moderator should also take notes during the interview of anything pertinent as well as anything that cannot be picked up by the audio recorder, such as facial expressions, or displayed emotions etc. These notes should be made in the spaces provided on the focus group question sheet.

6.12. Where a translator is to be used, questions must still be addressed to the participant, whilst acknowledging the translator.

6.13. Before wrapping up the focus group, the moderator will ask the participants if there is anything else they would like to share related to the topic, before thanking them for their time.

Completing the interview

6.14. Upon conclusion of the focus groups, the researcher will turn off the audio recorder, and update the focus group log-sheet with the time the recorder was turned off.

6.15. The audio file should be uploaded on the same day to the SharePoint folder Focus Group Audio files (92_HELP Study>Focus Groups>Focus group audio files). Only after the audio file has been successfully uploaded and played back in its entirety to ensure data quality can the file be deleted from the recording device.

6.16. Focus group notes/ the completed focus group question sheet should be placed in the focus group file, and typed up and saved in the SharePoint folder, Focus Group notes (92_HELP Study>Focus Groups>Focus group notes).

Transcription of the focus group

6.17. The audio file will be transcribed by the qualitative researcher and stored in the SharePoint folder Focus Group transcripts (92_HELP Study>Focus Groups>Focus group transcripts).

6.18. For quality assurance, once the interview is fully transcribed, the research assistant will complete two random spot checks of the audio to text:

   6.18.1. These will be completed by randomly selecting a point in the interview (on the audio) and listening to 30 seconds comparing to the transcribed text.

   6.18.2. Any discrepancies will be reported to the qualitative researcher and must be rectified.

   6.18.3. The quality control check will be completed again until the research assistant is satisfied that transcription is accurate.