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How do people with multiple long-term health conditions experience the self-management approach to health care?

A thesis presented in fulfilment of the requirements for the degree of

Doctor of Philosophy

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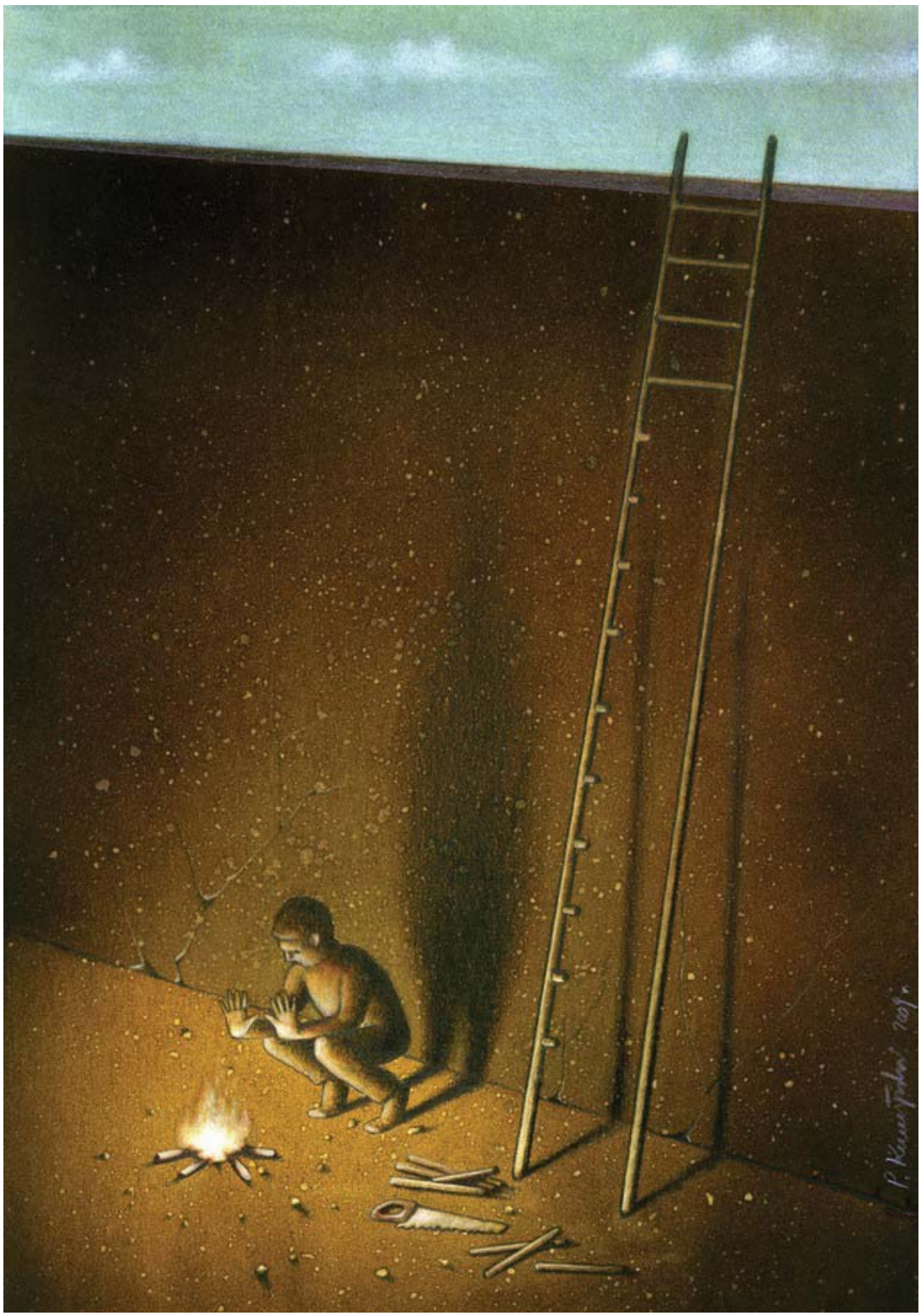

Figure 1. **PawelsKuczynski37**

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Abstract

The health system in New Zealand has devised approaches intended to meet the needs of people with long-term conditions (LTCs) based on the international theories of the Chronic Care Model (CCM) and a self-management framework (Bodenheimer, Wagner, & Grumbach, 2002b; Lorig, 1993; Wagner, 1998). LTCs and multimorbidity are socially patterned so often people with several LTCs are also contending with chaotic lives as well as the implications of their Illnesses. The self-management framework is based on the assumption that everyone has the agency or freewill to make the daily decisions that would benefit their health and ignores the powerful effect of social context. Because the behaviours recommended to optimise health are so entwined with a person's social context, LTCs are particularly sensitive to the social determinants of health.

This multiple case study follows the complex lives of sixteen people with several significant long-term health conditions using the theories of both Cockerham (2005, 2010, 2013b) and Link and Phelan (1995, 2010) to explore their experiences. Ongoing contact with the patient-participants comprised two interviews, four-weekly contacts and interviews with their primary health care clinicians. The patient-participants' stories reveal complex, entangled lives marked by loss, poverty and daily challenges. They are significantly constrained by the overwhelming social contexts of their lives and reduced to survival mode by their cumulative losses across the four domains of the Whare Tapa Wha model. Personal agency is neither a choice nor readily achieved. They are left too exhausted to work their way through a health system that does not recognise their needs, empower them or compensate for their lack of energy.

The weary patient-participants in this study bear little resemblance to the idealised expert patient of the self-management framework. Clinicians are left manoeuvring to compassionately and pragmatically support the patient-participants as best they can within an unhelpful system.

The findings however do surface examples of care that are valued by both patient- and clinician-participants that sit outside the self-management approach. These valued aspects are explored alongside the harm reduction, recovery and palliative models of care. These all offer contributions towards an approach that would optimise the quality of life for people with significant, multiple LTCs.

An exploration of this re-awakened approach to care is described. Care that is

constricted self-management approach could wrap around the patient and support them to use their residual agency in a direction of their choosing. Clinicians would be released from their current programmed response be able to more fully utilise their clinical expertise. Clinicians and patients would have the freedom to be more pragmatic around quality of life and the issues that matter to the individual with LTCs.

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This is dedicated to my Mummy, Margaret West (1943-1963). I hope that somewhere, she is proud.

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List of Abbreviations

ACC The Accident Compensation Corporation is the New Zealand Crown entity which administers the universal, no-fault accidental injury scheme

CCM The Chronic care model is the most widely utilised framework for offering health care to people with LTCs (Wagner, 1998).

CPAP Continuous positive airway pressure is a treatment typically used for breathing conditions such as sleep apnoea that uses mild air pressure to keep the airways open. A mask, attached by tubing to a motor, is worn over the nose and mouth

DHB District health boards are responsible for providing or funding the provision of health services in their district (Ministry of Health, 2016a)

GP A general practitioner is an appropriately qualified medical graduate who has particular knowledge and skills to provide personal, family, whānau and community-orientated, comprehensive primary care (The Royal New Zealand College of General Practitioners, 2016)

HbA1c Glycated haemoglobin measurement of the average blood glucose over the previous three months obtained via a blood test. Judged to be the most reliable way to measure glycaemic control in people with a of diabetes or as a diagnostic test

LTC Long-term conditions are health conditions that are progressive, life-long and limiting in terms of quality of life. They can rarely be cured, only controlled (Welsh Assembly Government, 2006)

MRSA Methicillin-resistant *Staphylococcus aureus* is a bacterium that is resistant to many antibiotics. In hospitals it can cause life-threatening infections, pneumonia and surgical site infections, therefore patients with an MRSA infection are cared for in isolation

PHO Primary health organisations are funded by DHBs to ensure the provision of essential primary health care services, mostly through general practices, to those people who are enrolled with the PHO (Ministry of Health, 2016a)

PN Practice Nursing is a sub speciality within nursing concerned with primary health care provision for individuals, the family and the community, … usually based within a general practice setting (New Zealand Nurses Organisation, 2007)

WHO The World Health Organization

Glossary of Māori terms

Hauora	Health, wellbeing or health care. Hauora is also used extensively as a description of health care systems and health organisations including the Manatū Hauora [Ministry of Health]
Hoha	Something tiresome or tedious
Hui	Conference or meeting
Kanohi ki te kanohi	Face-to-face
Kaumātua	Respected Māori elders
Kōrero	A talk or speech. For this research, it means patient narratives
Māori	The indigenous people of New Zealand
Mana	The prestige, reputation or esteem a person holds
Manaakitanga	Hospitality, kindness and support
Marae	The traditional meeting house for Māori communities
Mauri	The term that can be used in several ways. For this study, mauri is used to mean the dynamic life force, life energy or essence that everything and everyone has.
Pae Ora	A list of principles described by Sir Mason Durie (1985, 2001) that contribute to a healthy future for Māori. The principles are: Mauri Ora - healthy lives, Whānau Ora, healthy families, Wai Ora, healthy environment
Pākehā	A term for non-Māori, which tends to mean people of European descent.
Taha hinengaro	The psychosocial context of a person's thoughts and feelings
Taha tinana	Physical aspects of health
Taha wairua	Often summarised as spirituality but also relates to an individual's faith, sense of purpose and vitality
Taha whānau	Concerns the social influences on health as well as extended family (Glover, 2005; Rochford, 2004)

Wananga	A tertiary education institution, which provides education in a Māori cultural context
Whakamā	A psychosocial construct that is often understood as shyness, modesty or embarrassment
Whakapapa	Often translated as genealogy, “whakapapa can be likened to a map of existence.” (O'Hagan, Reynolds, & Smith, 2012, p. 59). In the context of research recruitment, whakapapa sampling means establishing and maintaining relationships
Whānau	An extended family group
Whanaungatanga	Interconnectedness or belonging. The term has traditionally concerned kinship relationships but can also mean something that can be shared between people with a common purpose (O'Carroll, 2013)
Whare	A building
Whare Tapa Wha	A model of health also developed by Durie (1985, 2001) that features in many health policies in New Zealand. The model uses the image of the four walls of a house (whare) to describe four interdependent aspects of health. These are taha hinengaro, taha tinana, taha wairua and taha whānau, described above.

Te Reo Māori is an official language of New Zealand Aotearoa. Both Māori and non-Māori, when speaking English, also regularly use many Māori words.