Person-centred care as a technology of compliance:
A critical investigation of how nurse navigators care for people with complex conditions

by

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Thesis

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Professor Clare Harvey

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RHD Thesis Declaration

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Nature of Candidate’s Contribution, Including Percentage of Total

In conducting the study, I was responsible for completing the literature search and performing the quality appraisal on results. This publication was written by me. I formed the research question, collated the literature, analysed the data, and interpreted the results. My contribution to this article is approximately 80%.

Nature of Co-Authors' Contributions, Including Percentage of Total

My co-authors, Associate Professor Adele Baldwin and Professor Clare Harvey reviewed and critiqued the manuscript, edited, and added to the discussion of the paper.

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Co-authors contributed approximately 10% each to the manuscript.

From ‘A Picture paints a thousand words. The state of play in personalised medicine told in cartoons’ by, European Alliance for Personalised Medicine, n.d.

Abstract

The incidence of chronic disease is increasing across the globe, and therefore, healthcare costs are rising. To meet the growing health needs of individuals and communities, governments are seeking new ways to deliver care that is centred on reducing hospital presentations and promoting self-efficacy in individuals. Health services have introduced the concept of person-centred care as a method of working with the person and their family, ensuring that their care needs are met, with the view of translating this care into reduced hospital presentations. One new model of care which aims to support those with chronic care needs is the Queensland Health nurse navigator service. The role of the nurse navigators is to provide integrated care to people who are frail and have complex care needs, many of whom have multiple chronic conditions, to work between multiple services, public and private health systems, and across both short-and-long term timeframes, to meet the complex health needs of individuals referred to the service. Currently, individuals are eligible for navigation if they meet certain hospital usage markers such as repeated admissions, emergency department presentations and fail to attend appointments. As per the Nurse Navigator Toolkit, person-centred care is the first key role principle of the nurse navigator service. While person-centred care appears to offer individuals and families more choice, respect and integration of care, the concept is philosophical in nature. It remains rhetorical, with nurses reporting a tension between the tasks they must achieve, and the care they want to provide. The fragmented and complex nature of the health systems translates to reduced access and engagement of vulnerable populations, leaving them at risk of poor-quality care, separation from healthcare services and a reduced voice in their care. Despite the promise of person-centred care, care that centres on the medical, psychosocial, *and* social needs of the person has not been realised. This research applies a Foucauldian philosophy to the task of critically interrogating the concept of person-centred care. It applies Fairclough's *Critical Discourse Analysis*, investigating levels of healthcare discourse, and exploring the hierarchy of power in relation to people with chronic complex disease. Discourse across the micro, meso and macro levels is critiqued, including, but not limited to, interviews with nurse navigators, media reports, hospital policies economic data, hospital usage data, national and international policies and frameworks and parliamentary Hansards. This discourse was chosen to understand the individual and system level factors which contribute to how individuals are moulded, or in this case, responsibilised.

Text is examined for its relational, experiential, and expressive features, investigating social relations and world views. Through exploring the concept and ideology of person-centred care, this research uncovers how the concept is discursively positioned to meet the agenda of health services, rather than vulnerable people.

The findings clearly show that person-centred care exists within a complex matrix of power relations and government agendas, living alongside the ideals of new public management efficacy, productivity, and efficiency. Person-centred care is one of several discursive strategies in place to promote individual compliance, whereby the individual is moulded into the ideals of the rational citizen, thus a technology of government. Furthermore, nurse navigators have been made responsible for the provision of person-centred care yet have little autonomy and authority to inform wider system changes that are required to enact it. Nurses themselves are subjected to fiscal management and rationing.

The outcome of this research encourages health services to view person-centred care as having benefits beyond fiscal outcomes. Nurse navigators are well placed to inform wider system changes necessary to better support the needs of people with multimorbidity, therefore enacting person-centred care at the meso and macro levels.

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I remember my supervisors telling me that a PhD pulls you apart and puts you back together again, and this is precisely how it happened for me. Not only did I move positions, careers, and cities, we battled the COVID-19 pandemic. This journey has made me stronger and more committed to the profession of nursing than ever. But of course, one never does this alone, and so there are many people that I would like to acknowledge in this thesis.

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Byrne, A-L. (2021, April 20th). *Applying critical discourse analysis to nursing research.* [Conference Presentation]. Virtual Health Workforce Academy 2021, Australia.

Byrne, A-L. (2021, October 22nd). *Person-centred care as a technology of compliance: How health services harvest biopower through language.* [Conference Presentation]. Central Queensland University School of Nursing Midwifery and Social Sciences Research Symposium 2021, Australia.

List of Publications Contributed to During Candidature (Relevant to Project)

Sobolewska, A., **Byrne, A-L**., Harvey, C., Willis, E., Baldwin, A., McLellan, S., & Heard, D. (2020). Person-centred rhetoric in chronic care: A review of health policies. *Journal of Health Organisation and Management, 34*(2), 123–143. https://www.doi.org/10.1108/JHOM-04-2019-0078

Byrne, A-L., Hegney, D., Harvey, C., Baldwin, A., Willis, E., Heard, D., Judd, J., Palmer, J., Brown, J., Heritage, B., Thompson, S., & Ferguson, B. (2020). Exploring the nurse navigator role: A thematic analysis. *Journal of Nursing Management, 28*, 814–821. https://www.doi.org/10.1111/jonm.12997

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Byrne, A-L., Harvey, C., & Baldwin, A. (2021). Nurse navigators and person-centred care: Delivered but not valued? *Nursing Inquiry,* Ahead of press. https://www.doi.org/10.1111/nin.12402

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Harvey, C., Baldwin, A., Brain, D., Heritage, B., Forrest, R., Brown, J., Willis, E., Palmer, J., Hegney, D., Heard, D., **Byrne, A-L**., Ferguson, B., Judd, J., McLellan, S., Thompson, S., & Bishop, N. (2021). *Queensland health nurse and midwife navigator evaluation: Detailed final research report.* Central Queensland University, Townsville, Australia. https://www.cqu.edu.au/ISBN978-1-921047-92-3

Harvey, C., Baldwin, A., Heritage, B., Brown, J., **Byrne, A-L**., Heard, D., Willis, E., Forrest, R., Brain, D., Judd, J., & Ferguson, B. (2020). Queensland health nurse navigator evaluation progress report. February 2020. Central Queensland University. Townsville, Australia. https://www.cqu.edu.au./ISBN978-1-921047-90-9

Glossary of Terms

Chronic Disease	Broadly defined as a health condition which lasts more than one year in duration that requires ongoing medical attention or limits activities of daily living or both (Australian Institute of Health and Welfare [AIHW], 2014).
Citizen/citizenship	Citizenship is a society's legal recognition of the democratic equality of its members. A citizen is an autonomous subject entitled to exercise rights and expected to fulfil responsibilities (Olsen, 2008, p. 1).
Discourse	Deeper than written text or speech, it is the sum of text and action and formal ways of thinking (Fairclough, 2015).
Model of Care	The defined parameters of which care within a particular service is delivered. A model of care will usually define its population group, access points, key stakeholders, referral pathways and define its outcomes (Agency for Clinical Innovation, 2013).
Multimorbidity	The co-occurrence of two or more chronic health conditions within an individual (Australian Institute of Health and Welfare [AIHW], 2020a).
Neoliberalism	A time and state of government with centralised state power which result in authoritarian approaches to surveillance, security, and prevention (Liebenberg & Ungar, 2013) as well as free markets.
Nurse Navigator	A senior registered advanced practice nurse working in Queensland Australia, caring for people with complex care needs (Queensland Health [QH], 2018a).
Responsibilisation	The self-management of risk by an individual, at the exclusion of government support and input (Liebenberg & Ungar, 2013).
Social Prescribing	The practice of linking people with social services as part of their traditional medical treatment. For example, art classes, water aerobics or social groups (Hayes, 2020).
Structural Vulnerability	The social determinants of health perspective as a foundation and builds on the wider range of critical social science of medicine and public health theory, highlighted by terms such as "structural violence," "racial disparities in health," "eco-social models of health," "upstream factors in health," "fundamental social causes of health," and "social suffering" to expand and define more practically the diversity of forces, both external and internal to the clinical encounter, that can sabotage the health of patients regardless of the conscious intentions of the caregiver or the patients (Bourgois et al., 2017 p. 4).
System	A term I use to denote the hospital and health system as an entire unit (including macro, and meso structures) from government to health care institutions.
Quality of Life	The standard of health, happiness and comfort experienced by an individual (World Health Organization, 2012).

Table of Acronyms and Initialisms used in Thesis

ABC	Australian Broadcasting Corporation
ABF	Activity Based Funding
ACN	Australian College of Nursing
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
BPF	Business Planning Framework
CDA	Critical Discourse Analysis
CST	Critical Social Theory
DALY	Disability Adjusted Life Years
DRG	Diagnostic Related Group
ED	Emergency Department
EPP	Expert Patient Program
FTA	Fail to attend an appointment
GBP	Great British Pounds
GDP	Gross Domestic Product
GP	General Practitioner
HCQ	Health Consumers Queensland
HHS	Hospital and Health Service
ICN	International Council of Nurses
LNP	Liberal National Party
LOS	Length Of Stay
MBS	Medical Benefits Scheme
MOC	Model of Care
NHFB	National Health Funding Body
NHPF	National Health Performance Framework
NHS	National Health Service
NN	Nurse Navigator
NNs	Nurse Navigators (plural)
NP	Nurse Practitioner
NPM	New Public Management
NSI	Nurse Sensitive Indicators

OCNMO	Office of the Chief Nursing and Midwifery Office
OECD	Organisation for Economic Cooperation and Development
PBS	Pharmaceutical Benefits Scheme
PCC	Person-centred Care
PHC	Primary Health Care
PIP	Practice Incentive Payment
PLY	Productive Life Years
PPH	Potentially Preventable Hospitalisation
PREM	Patient Reported Experience Measures
PROM	Patient Reported Outcome Measures
QH	Queensland Health
QIP	Quality Improvement Payment
QLD	Queensland
QNMU	Queensland Nurses and Midwives Union
QNU	Queensland Nurses Union
QOL	Quality Of Life
RACGP	Royal Australian College of General Practitioners
RCT	Rational Choice Theory
RHD	Research Higher Degree
RN	Registered Nurse
ROGS	Report On Government Services
ROI	Return On investment
SDH	Social Determinants of Health
SFP	Standards For Practice
SOP	Scope Of Practice
SP	Social Prescribing
SROI	Social Return On Investment
TIC	Trauma Informed Care
UK	United Kingdom
UN	United Nations
USA	United States of America
UTI	Urinary Tract Infection

WHO	World Health Organization
WHOQOL	World Health Organization Quality Of Life
YLD	Years Lost due to Disability
YLL	Years of Life Lost

Language and Grammar Choices used in This Thesis

Critical Discourse Analysis is an interrogation and exploration of language, and an analysis of how language positions people and people position language. It is therefore important for me to clarify the language choices that I have made throughout this thesis. These were carefully considered and here I will explain these choices. This should be considered in conjunction with the Glossary of Terms above.

Patient, Person, Individual

Person-centred care is often referred to as patient centred care and vice versa. However, I agree with the work of Slater (2006) who found that repositioning the language of person-centred care better aligns it with social models of care, seeing the person as a whole and not simply the sum of their illnesses. Throughout this thesis I have used the terms *person*, or *individual*; this was a conscious choice on my behalf to position the person as more than a patient. It is my intent to use respectful language that acknowledges and attempts to address the power imbalances that exist within the institution.

At times, it becomes necessary for me to clarify exactly who I was referring to, and in these situations, I referred to the person as a patient which provides some clarity to the reader. Quotes and excerpts have remained unchanged, and I believe offer a stark contrast to my own style of writing, thus offering some insights into how people are viewed in the health institution.

Long Term Conditions, Chronic Health, and Chronic Disease

There is some variation in the literature around the term *chronic disease*, *chronic health condi*tion and *long-term conditions*. You will note that I have used the term *long-term conditions* in the literature review; this was a specific request from the publication reviewer. However, for the bulk of the thesis I have tried to be consistent with the policy, frameworks, and procedures around chronic disease and have hence used this term.

I have attempted to narrate the lived experience of nurse navigators so as not to limit the experiences of chronic disease to the disease processes alone.

First Nations Peoples

I acknowledge the First Nations people of Australia and recognise their elders, past present and future, as the custodians of the lands on which I have lived and worked.
I use the term First Nations person in recognition of their place in Australia's history and future. This thesis is inclusive of, but not limited to First Nations peoples and their experiences. I take care in this thesis not to write First Nations peoples (or indeed any group) into a social space.

Referencing

This thesis uses the Australian Psychological Association (APA) 7th Edition referencing.

Grammar and Quotations

Acronyms and initialisms are used in this thesis as per the table above. These are not used at the beginning of sentences.

Quotations are formatted as per the APA 7th edition referencing guide. Quotations with fewer than 40 words are embedded into the sentence within double quotation marks. Quotations with 40 words or more begin as a new paragraph with a 1.27 cm indent.

Anecdotes consisting of *Author's field notes* and the *Nurse Navigators* begin as a new paragraph with a 1.27 cm indent and are in italics.

Chapter One—Opening

> *If you want a service to be patient centred, it can't just be one nurse, or one team of nurses … every single nurse needs to take the model of care [where] the patient is at the centre. All the doctors, all the allied health, all the pharmacists, everyone needs to do it, for it to truly be a successful model.* Nurse Navigator.

Health services throughout the world are now describing their models of care as 'person-centred' and are therefore asking their staff to deliver care which meets the individual needs of the people they care for. However, the above quotation raises several questions around the concept of person-centred care (PCC); What does it mean to deliver PCC and person-centred service? How is PCC practised and where do the benefits of such practices lie? Who practises PCC and for whom is it designed?

This thesis is a critical interrogation of the concept of PCC in chronic disease management, however in achieving this, a broader assessment, analysis, and dialogue is presented. With this in mind, I have commenced this thesis by providing an introduction to the context of Australian healthcare, chronic disease management and the introduction of PCC as a model for improving the engagement and efficacy of the person.

The World Health Organization (WHO) positions health as the fundamental right of every human being (WHO, 1946). The right to health, and to healthcare, is set in the international Universal Declaration of Human Rights (United Nations [UN], 1948), within which every citizen is born free, with the right to a "standard of living adequate for the health and wellbeing of himself and his family" (p. 6). This declaration has been widely accepted across the developed world, including in Australia (Australian Human Rights Commission, n.d.). The focus of the Declaration is on disadvantaged and marginalised populations (WHO, 2017) who are often the most vulnerable within a society.

As a part of the right to health, the Australian people, as citizens, have access to and use of Australia's healthcare. Although there are some out-of-pocket expenses for the individual, care is provided through universal healthcare which covers physician's costs in the hospital system and primary health care, pharmaceuticals, and services such as social support (Glover, 2020). The Australian Government, as the custodian of its citizens, is responsible for healthcare funding, and within some discourse, is responsible for the prevention of disease and illness to maintain health across the life continuum (Australian Institute of Health and Welfare [AIHW], 2018a). This responsibility is complicated by a growing prevalence of chronic disease, which requires significant care resources. Indeed, chronic disease is now the cause of 90% of all deaths in Australia (WHO, 2011). Chronic disease is broadly defined as a health condition which lasts more than one year in duration that requires ongoing medical attention or limits activities of daily living, or both (AIHW, 2014). Over 11 million Australians live with at least one chronic condition and 4.9 million live with two or more chronic conditions, known as multimorbidity (AIHW, 2020a). The ageing population, coupled with the advances of modern medicine, means that more Australians are now living with long term, complex conditions which require significant care, support, and health care resources (Entwistle, 2018).

Australian health care is built on the WHO's Ottawa Charter for Health Promotion (1987) (AIHW, 2014).. The charter is a seminal document which recognises the rights of each person, the changing demographics of people and their health needs, articulating a political commitment to health equity and social justice (WHO, 1987, p. 17). It places a focus on health promotion, education, and reorienting health services to meet the growing demands of those with chronic health conditions. Providing this level of healthcare to the population comes at significant cost.

Healthcare is funded through citizen taxation (Glover, 2020) and therefore revenue to fund healthcare is finite. This has consequences for resource allocation and service development, which often fail to reach marginalised and vulnerable populations (Kirigia, 2009). The Australian Government spent AUD$185 billion on health services and goods in 2017–18, which equates to AUD$7,485 per person (AIHW, 2020c). Australian healthcare expenditure is escalating beyond the rate of the population growth (AIHW, 2018a) with healthcare costs representing 16.3% of total government spending (Parliament of Australia, 2019). Healthcare spending has thus become a focus of governments who must effectively balance a limited budget and meet the needs of its citizens.

Distinct population groups in Australia have been identified as requiring a disparate amount of healthcare resourcing. That is, people with multiple chronic conditions, those over the age of 65 years and First Nations Australians, incur higher health care costs relative to their population size (AIHW, 2018a). These costs are incurred through emergency department presentations, hospitalisations, failure to attend appointments, frequent general practice visits and duplication of care (AIHW, 2019b; Organisation for Economic Cooperation and Development [OECD], 2017a). Thus, models of care designed to manage care in the community have been created to target these population groups with the aim of avoiding hospitalisation, known as preventable hospitalisation, thereby decreasing associated costs (Australian Commission on Safety and Quality in Healthcare [ACSQHC], 2017).

In addition to the current models and methods of care, governments have also employed more covert methods of managing healthcare budgets, such as managing workforce and workloads, business processes and decision making, and quality improvement processes. Programs which aim to empower the person, increase their level of health literacy, and therefore their engagement with their own health care have also been introduced (Lorig, 2002; Rogers et al., 2008). Collectively, these are examples of the principles of new public management (NPM) which aims to streamline services into efficient, effective, and productive systems (Lapuente, 2020). Taken from the private business sector, NPM aims to organise the sectors and services of the healthcare industry, focusing on the business (revenue versus expenditure) side of healthcare (Dawson & Dargie, 1999; Bergh et al., 2014). Since its inception in the 1980s and 90s, NPM has permeated all facets of healthcare including policy, procedure, workforce models, and administrative work (Lapuente, 2020).

The Australian healthcare system is aimed at addressing disease priority areas; singular diseases and individual body systems (Department of Health, 2019c). An example is the service areas that are often defined as cardiac, renal, or respiratory services whereby the patient enters the system, receives treatment, and is discharged back to their primary health care provider located in the community. Evidence shows that the current healthcare model, known as the biomedical model which focuses on curative treatment does not meet the whole-of-life treatment needs of people with multiple chronic conditions, or those with long term coordinated care needs (Shippee et al., 2018). The current system creates disjointed services, resulting in people getting lost within the system, falling between the cracks of existing structures, and being excluded from care by system barriers (Sheridan et al., 2012).

To address these issues, new models of care have been introduced. The purpose of these models of care are twofold: to address the structural barriers that traditional models of care create for vulnerable populations, and to reduce the service usage and associated costs of frequent users of health services. Models such as Wagner’s Chronic Care Model (1998) emerged and were embraced by health institutions with the aim of implementing services which better align with the needs of individuals. These frameworks saw the emergence of care coordination, integration, and case management models, which aimed to coordinate and manage health care for individuals by fostering communication and integration between professionals (Askerud & Conder, 2017; Wagner, 1987). These models usually involve having a designated care/case manager allocated to an individual for a set period based upon severity of illness. The health professional, and the individual and their family, work together to set goals and to problem solve (Ehrlich et al., 2009). Case management as a general concept is the process of assessment and planning, advocacy, facilitation, and coordination of the utilisation of resources that promotes cost-effective and quality outcomes (Ahmed, 2016). Many of these models utilise nurses as the care/case managers (Askerud & Conder, 2017) and aim to build self-efficacy and determination in individuals, families, and communities (Peikes et al., 2009). Most define the method of care delivery as PCC.

Person-centred care is a complex concept linked to high quality health services and care delivery (ACSQHC, 2018; Peart et al., 2019). Person-centred care offers a philosophical and ethical framework under which patient participation and decision making is fostered within a respectful and mutual clinician-patient relationship (Kitson et al., 2013). Thus, PCC is discursively positioned as the dominant method of care delivery for chronic disease management (Pulvirenti et al., 2014; Peart et al., 2019). Despite its wide acceptance as fundamental in contemporary healthcare discourse, PCC remains conceptual in nature and is ill defined particularly in relation to the providers and receivers of care.

Many of these models remain focused on the reduction of healthcare costs with healthcare service usage focused on “episodes of care” which are tied to one particular service, for example, mental health (Eager, 1997, p. 105). This can be challenging for people who engage with multiple, separate services (Fuller, 2017). In fact, many care coordination models are not able to demonstrate hospital avoidance with research suggesting that hospital avoidance as a measure means that PCC is not prioritised (Askerud & Conder, 2017; Bleich et al., 2015; Chapman et al., 2009; Vanderboom et al., 2015). In fact, despite positive outcomes for individuals and their families, researchers argue that care coordination and integration increase care costs overall (Esterman & Ben-Tovim, 2002; Fillion et al., 2012; Ehrlich et al., 2009).

Amongst the changes described above, the role of the nurse and the role of the patient are also being revised. Nurses are increasingly employed in care coordination and integration roles and are often discursively positioned as responsible for the delivery of care which is centred on the person's holistic needs (Gachound et al., 2012; NMBA, 2016). This can be a challenge for nurses, who are often conflicted between the tasks within their role description, for example, observations, documentation, and audits and the caring side of their role which seeks to provide care tailored to the person's clinical, social, and material needs, for example, family considerations, financial or travel considerations related to accessing healthcare (Edvardsson et al., 2014). Likewise, the role of the patient has also been reframed with national policy now positioning the individual as a resource to be activated to become self-effective and self-managing. To achieve this, PCC positions the individual as part of the healthcare team and at the centre of decision making (Bala et al., 2017; Trajkovski et al., 2012). However, with this empowerment comes more responsibility. How this is operationalised within vulnerable populations with complex disease is yet to be fully understood.

Despite the emerging models of care and changes to practice that encourage comprehensive care, areas of the Ottawa Charter remain unfulfilled particularly the areas focused on creating healthy environments and reorienting health services. Thompson et al. (2017) found that the onus remains on personal responsibility and behaviour change of the individual rather than on societal-wide system changes. In recognition that service structures are complex and fragmented, models of care have continued to evolve with the introduction of the nurse navigator (NN). In Australia, NNs are senior registered nurses employed to engage with high needs patients across the care continuum delivering PCC (QH, 2018a). Although the concept of nurse navigation is not a new one, there are few examples of navigator roles that work across multiple chronic conditions and services. Nurse navigators and navigation models of care will be discussed in detail in Chapter Two.

Rationale for This Research

This research is an exploration of PCC as a philosophy of care, and a method of nursing practice. To explore this topic, the research is positioned with the NN service, an autonomous nurse-led service designed for those with complex multimorbidity (QH, 2018a). The research acts as an exploration and critique of the history and circumstances of how PCC and chronic disease models of care, and thereby the role of NNs, have evolved with the view to advancing the practice of person-centred care. This is important, given that the care of people with chronic conditions is dependent upon individualised, coordinated care that centres on their holistic needs rather than just those offered within a biomedical model of care (WHO, 2002; Clinical Excellence Queensland, 2017a; Martinez-Gonzalez et al., 2014). Nurses are now asked to deliver PCC in their daily practice (Nursing and Midwifery Board of Australia [NMBA], 2016); however, how this is achieved and what it means to deliver PCC is yet to be fully understood. Investigating and interrogating the enablers and barriers of PCC in practice opens an avenue to bring the concept into one which reflects the value of genuinely partnering with people to meet their health needs.

This research applies a critical social theory focus investigating the concepts through a Foucauldian lens. The research will apply Fairclough's (2015) Critical Discourse Analysis (CDA) to examine ideology, power, and social relations across divergent social orders within the Australian healthcare system. Foucault, a French philosopher, was a post structuralist concerned with notions of truth and power. Truth, he believed, was a mobilisation of power in that what we know to be and understand as true within our society is carefully constructed and embedded via power relations (Foucault, 1987a). Foucault believed that by investigating our history and origins we can understand the political, social, and economic influences which perpetuate any given truth claim. The investigation allows us to understand this truth, bringing to light the power within it and a space to advocate for alternatives. Foucault summarises this: "Maybe the target nowadays is not to discover what we are, but to refuse what we are" (Foucault, 1982, p. 216).

One way that the truth is perpetuated is through discourse, as language and action. An individual's experiences are constructed through language; therefore, language analysis provides an avenue for the exploration of people's lived experiences including where they are positioned in society, the resources available to them and their outcomes. Language perpetuates ideologies within society (Fairclough, 2015). Therefore, CDA becomes an appropriate method of exploration and interrogation, with reference to divergent ideologies and power relations.

This research explores the power relations that people with chronic and complex disease, and the NNs who care for them, exist within. It explores the political, social, and economic factors that influence the social worlds that people exist within and how these worlds collide with the healthcare system. An examination of the hierarchy of influences across discourse is mapped and presented. The thesis presents how PCC within chronic disease management has been reframed, using tools and models which advocate for self-management, efficiency, and productivity. This thesis provides a detailed analysis of the role of the nurse, specifically the NN, within this space. The findings presented in this thesis are expansive and move throughout several social worlds. They suggest that PCC is part of a government strategy used to ensure compliance and behaviour change. In this way, people within the navigator service, patients and nurses included, are subjected to forms of power and control, intensifying the marginalisation that people face within a rigid healthcare system.

The next chapter provides a history of navigation models that includes the Queensland NNs, thus grounding the thesis in the core functions and practices of these senior registered nurses.

Chapter Two—Rise of the Navigator

Summary of Chapter

Part of the exploration of a concept/social truth is understanding the history of its being (Foucault, 1972). In this chapter, I have investigated the recent history of the NN service with the intention of providing deeper insight into my chosen cohort and of exploring the landscape within which PCC in the NN service exists. It acts as a brief history of the present (Foucault, 1972) for NNs who manage chronic disease through PCC.

This chapter provides the background for the Queensland Health NN service. To do this, I have critically appraised the internal and external conditions which led to the development of Queensland NNs, the first such model to be introduced in Australia. This chapter discusses the history of navigation models of care, as well as the relevant political and policy implications of their introduction.

Navigation: A Brief History

Navigation models were conceived in the context of cancer care within the United States of America (USA) after the American Cancer Society (1989) found gross disparities in life expectancy of cancer patients in poorer populations. One of the initial recommendations from the society advocated for the establishment of a "patient advocate and referral services to help poor patients navigate the health system and manage personal problems that result from cancer treatment*"* (American Cancer Society, 1989, p. 264). From this, the first navigation model was developed in 1990 in Harlem, New York, in the form of a breast cancer navigator. The goals of the program were to provide access to screening and examinations and timely access to diagnosis and treatment. The main impact measure for this program was to improve life expectancy (Freeman, 2004).

More than 10 years later, the *Voices of a Broken System Report* (2001) detailed issues with the complex funding flows of the USA market model of healthcare and the disparity of cancer treatments for those of diverse socio-cultural backgrounds. The report highlighted the inequity in cancer treatments and survival rates of marginalised groups as well as the inherent bias and discrimination within the system. The report recommended changes to medical coverage and access and included the recommendation of a community-based navigator that would help people to “obtain cancer information, screening, treatment, and supportive services” (National Institute of Health, 2001, p. 37). Patient navigation as a method of saving lives thus gained attention at the national and international level, sparking the emergence of new navigation models of care (Freeman, 2004).

In 2005, the *Patient Navigator Outreach and Chronic Disease Prevention Act,* an amendment to the United States Public Health Services Act, provided access to funding which allowed for the expansion of navigator models. These subsequent models included the development and implementation of specific services to follow up on abnormal findings, facilitate involvement of community organisations, notify individuals of clinical trials, and help coordinate patients through relevant systems and funding providers (Patient Navigation Outreach and Chronic Disease Prevention Act, 2005). Funding was made available to models which “utilize[d] [*sic*] patient navigator services to overcome significant barriers in order to improve health care outcomes in their respective communities’’ (Patient Navigation Outreach and Chronic Disease Prevention Act, 2005, p. 4). The growth of the navigation model in the USA led to international interest.

New navigation models emerged throughout the developed world, including the British Columbia Patient Navigation Model (Pederson & Hack, 2011), the Community Matrons model (Chapman et al., 2009), and oncology NNs (Case, 2010). As the model grew in popularity, it was considered for other areas of healthcare outside of cancer care. Pedersen and Hack (2011) concluded that “patients who are diagnosed with any chronic illness could benefit from the interventions depicted in the model. According to the [British Columbia Patient Navigation Model], navigation can be enacted by different professionals based on the healthcare systems context” (p. 204). This paved the way for navigation models to be implemented in areas such as chronic disease and in locations outside of the hospital.

Navigation models are all founded on a similar ethos, viz., the acknowledgement of the health system as a fragmented and uncoordinated institution which often fosters delays in information and care, particularly for vulnerable populations (Fillion et al., 2012; Koh et al., 2011). Thus, early navigation models centred on facilitating access to care, reducing unnecessary delays (Pedersen et al., 2014; Fillion at al., 2012; Case, 2011) and filling in information gaps (Korber et al., 2011). The intent of the navigator role is to also include the social, cultural, and emotional aspects of care. Part of the navigator's work is getting to know the person as an individual and meeting their previously unmet needs born from disengagement and distrust in the healthcare system (Pederson et al., 2014; Fillion et al., 2012).

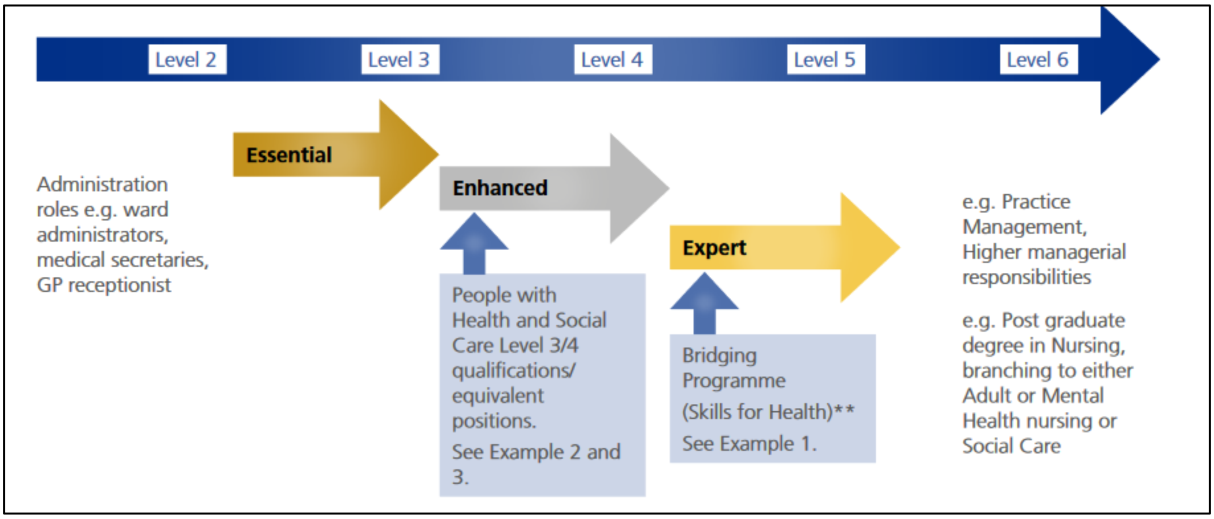
The emergence and development of navigation signalled an important shift in the recognition that health care and social care are inextricably linked, especially to address the social determinants of health that impact on management of care (Carter et al., 2018). In this way, navigation became "anticipatory guidance" (p. 84) stemming from a genuine connection and understanding of a person's needs. Within the array of literature, PCC emerged as a concept closely linked with navigation, thus driving the notion of a patient/nurse partnership (McMurray & Cooper, 2016; Pedersen & Hack 2011; Hannan-Jones et al., 2019). In fact, Fillion et al. (2012) describe PCC as the key distinction between case management and navigation: "The professional navigator role corresponds to a more comprehensive medical or social model of case management that values humanization of the care trajectory and empowerment of the patient and family" (p. 59). While this is certainly the case, this thesis will also highlight NNs as potential system change agents, a point discussed later in this chapter.

The rising costs of health care, particularly related to chronic disease management, health services moulded the navigation model, aligning it with financial and human resources deficits to capitalise on the model's success. Hence, the outcomes measures and the expectations of professionals delivering the program changed. The original measures for the service included life expectancy, access to treatment and follow up care (Freeman, 2004). However, there was a shift in the measured outcomes to hospital specific metrics such as hospital avoidance (Pedersen & Hack, 2011; Valaitis et al., 2017). Furthermore, measures such as self-efficacy, autonomy, and self-control began to be incorporated into service measures and outcomes (Fillion et al., 2012).

The role of the navigator has also evolved, with frameworks now describing a gradient of appropriate navigators. Recently, the United Kingdom has articulated the role of the navigator through the development of a competency framework which describes a variation of navigators: essential, enhanced and expert. This leaves the role of the navigator open to different models and health professionals, which has the potential to save on workforce costs. For example, some services have employed "lay navigators" or community members to help their population groups access and navigate care (Meade et al., 2015). The framework for levels of navigators is demonstrated in Figure 1 below.

Figure 1

Professional levels of navigation



Note. From *Care Navigation: A competency framework,* by National Health Service, 2016, https://www.hee.nhs.uk/sites/default/files/documents/Care%20Navigation%20Competency%20Framework_Final.pdf

A summary provided by The Change Foundation (2013) provides an important point on navigation programs:

> As the lens widened from cancer care navigation to chronic disease management overall, the emphasis shifted—rather than a singular focus on the patient's needs, stated goals are now often more system-related … tighter case management to prevent hospital admissions or readmissions, acceleration of hospital discharges, more effective use of hospital system resources, and better patient education. Therefore, health system navigator has become a more accurate term … (p. 8).

The work of Fillion et al. (2012) supports this notion, stating that "[p]rior to implementation, adopters have to ask themselves which kind of model they want to implement and which outcomes they want to measure" (p. 67). In expanding the navigator model, Canadian researchers asked the question: "Are we looking at the idea of health system navigators because our delivery is disorganized [*sic*] and unintegrated, or would a more integrative system of care eliminate the need for navigators in the first place?" (The Change Foundation, 2013, p. 9). This thesis has investigated these issues in relation to the Queensland context of NNs with particular reference to how PCC has been embedded into service objectives.

In the more recently developed and implemented patient navigation programs, the primary aim now appears to be to reduce hospitalisation and service usage. However, in much the same fashion as case coordination and integration, researchers have found that navigation does not necessarily decrease hospitalisations and costs (Gordon et al., 2019) with the scope and breadth of the impact of NNs being difficult to define. The modifications to the navigation model are indicative of competing government and healthcare agendas.

The Australian Agenda of Chronic Disease Management—the Journey to Navigation and Person-Centred Care

Alongside the evolution of contemporary models of care, Australian governments have explored new methods of chronic disease management, particularly those that have the potential to meet the specific healthcare needs of vulnerable populations. This evolution led to the introduction of a NN model in Queensland.

In conjunction with the WHO objectives of providing foundational health promotion (WHO, 1987) several policies, strategies, and frameworks emerged to meet the growing needs of people with chronic health conditions. Simultaneously, other factors in Australia necessitated the need for more PCC which addressed the position of the patient as a vulnerable and passive actor in the health institution to one of active inclusion in care.

The *National Strategic Framework for Chronic Conditions* (AHMAC, 2017) aims to improve the health and wellbeing of Australians by focusing on prevention, and therefore providing efficient, effective care through optimisation, and targeting priority populations with First Nations people listed as the top priority. This built on the *Closing the Gap* reform (Council of Australian Governments [COAG], 2008) which aimed to narrow the gap in life expectancy between First Nations and non-First Nations people in Australia through seven priority areas, viz., early childhood, schooling, health, economic participation, healthy homes, safe communities, and governance and leadership. The agreement itself poses a dichotomous idea of health and wellbeing measures and targets. On one hand, the key message is one of partnership, engagement, and collaboration, while on the other hand it professes to "increase economic and social participation wherever possible, and promote personal responsibility, engagement, and behaviours consistent with positive social norms" (COAG, 2008, p. 23).

Twelve years later, *Closing the Gap* was reported as a failure, as it did not close the gap in life expectancy, nor did it meet many of the key performance measures (Harris, 2020). This triggered a review of the strategy and a new agreement. The key principles are now listed as shared decision making, building a strong community-controlled sector, improving mainstream sectors, First Nations led data and socioeconomic outcomes (Closing the Gap in Partnership, 2020). Criticisms of such plans centre on the discoursal positioning of such populations as O'Neil et al. (1998) explains:

> Epidemiological portraits of Aboriginal sickness and misery act as powerful social instruments for the construction of Aboriginal identity. Epidemiological knowledge constructs an understanding of Aboriginal society that reinforces unequal power relationships; in other words, an image of sick, disorganised people and communities can be used to justify paternalism and dependency (p. 230).

One method adopted by health services to involve First Nations and non-First Nations people in their healthcare, is the concept of PCC. I have explained the concept of PCC and its history and significance in Chapter Three. In this chapter, I have focused on how PCC intersects with chronic disease management and NNs. PCC in this context is important given that for First Nations peoples' health and wellbeing are intrinsically linked to family, country, and kin, and therefore, care that is person-centred must include these considerations (National Aboriginal Community Controlled Health Organisation, 2021).

Changes to the Queensland public health system were implemented after a series of events highlighted the need for greater patient input into care and service design. The Forster report (2006) highlighted flaws in recruitment and administrative processes for medical professionals, as well as the power imbalances which impeded both the nurse and the patient voice and found that QH processes allowed for harm to go unaddressed. Political influences such as the Forster report (2006) led to the creation of bodies like Health Consumers Queensland (HCQ). Originally formed under the government as a health advisory committee, HCQ was transitioned to a non-government organisation in 2015 (Health Consumers Queensland, 2016). It is now primarily focused on the education of consumers and staff members in working with people to co-design care and systems with the goal of:

> Consumers and community partnering with the health system for consumer-centred health care for all Queenslanders. We are committed to a health system which delivers quality and safe health services and values the voice of consumers in how health services are designed and delivered (HCQ, 2021, para. 1).

This transition marked an important turning point for the consumer movement where people seeking care were recognised as important to system design and to the quality of care services. Events such as these also led to the development of national standards around consumer engagement (ACSQHC, 2018). Within these standards, person-centred health services are described as services which have elements of person-centred governance, strategy, staff capability, technology and measurement which focus on consumer needs (ACSQHC, 2019).

While PCC is clearly articulated in government and health service documents, how PCC is operationalised is not as clear. Sobolewska et al. (2020) identified several national and Queensland state frameworks, strategies, and processes which articulate person-centred care in relation to chronic disease management. These are provided in Table 1 below.

Table 1

Identified chronic disease frameworks in Australia which utilise person-centred care.

Framework	Level
Australian Commission on Safety and Quality in Health Care- Patient centred care: Improving quality and safety through partnerships with patients and consumers	Commonwealth
National Strategic Framework for Chronic Conditions	Commonwealth
Bilateral agreement between the commonwealth and Queensland State	Commonwealth and State
Queensland Health Budget 2018–2019	State
My Health Queensland's future; Advancing health 2026	State
Specialist outpatient strategy	State
Health and Wellbeing strategic framework	State
Nurse Navigator Toolkit	State
Hospital and Health Service strategic plan	Local

Note. Adapted from "Person-centred rhetoric in chronic care: a review of health policies", by A. Sobolewska, A-L. Byrne, C. Harvey, E. Willis, A. Baldwin, S. McLellan, & D. Heard, 2020, *Journal of Health Organisation and Management, 34*(2), 123–143. https://www.doi.org/10.1108/JHOM-04-2019-0078

The Australian healthcare system spans across federal, state, and local government sectors making the design and delivery of healthcare complicated. The findings of this review are available in Appendix A[1]. In short, the review concluded:

> Although person-centred care as an approach is well articulated in health policies, there is still no definitive measure or approach to embedding it into operational services. Complex funding structures and competing priorities of the governments and the health organisations carry the risk that person-centred care

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[1] I am the second author on this article.

> as an approach gets lost in translation. Three themes emerged: the patient versus the government; health care delivery versus the political agenda; and health care organisational processes versus the patient (p. 1).

The elements of PCC, consumer engagement and equity in care influenced the introduction of the Queensland NN service. Importantly, the move was also politically motivated, as I have detailed below.

The Political Promise

The political influences of the Queensland NN model can be traced to 2012 when the Liberal National Party (LNP) held the premiership in Queensland. The LNP won the Queensland election led by Campbell Newman who assumed the role of Premier of the state from 2012–2015. It was a “tumultuous” time for the political party (Newman, n.d., para. 6). The reduction of 2,754 full time equivalent staff positions (Queensland Government, 2012), which is the equivalent of 14,000 public sector jobs, was precipitated by the 2012/13 QH budget. The reasons listed for such cuts were listed as the failed payroll implementation, which was estimated at AUD$230.2 million (The Conversation, 2012). Of the number of staff cut, approximately 1800 nursing and midwifery positions were made redundant (Mirage News, 2020). This decision was met with strong union and public opposition (News Corp Australia, 2012), and thus became the key focus of the Queensland Labor Party’s election campaign with the promise of a new NN service rendered. Hence, out of the context of job cuts in the public health sector, the NN model was born. This was supported by the Queensland Nurses Union [QNU] with the NN being described as a health investment, able to contribute to productivity and participation (Queensland Nurses Union, 2015).[2]

> The introduction of Nurse Navigator positions will be a positive means of addressing the current difficulties in accessing and traversing the health system.

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[2] Now known as the Queensland Nurses and Midwives Union (QNMU).

> This is just one practical method of giving people more information and ultimately better care (QNU, 2015, p. 9).

The potential of NNs were discussed particularly in the context of what they could offer to other QH initiatives as well as to the people of Queensland:

> These roles will reduce barriers to access that patients may face, as well as help educate and empower them, so that they are better prepared to manage their own health care needs. (Queensland Parliament, 2015c, p. 1).

Nurse navigators were described as distinctly different to other nursing positions with a fundamental role in the delivery of PCC for people with complex vulnerability.

> We think we need a game-changer—we absolutely do—because it is better for patients, but it is also better for the sustainability of the healthcare system. So we absolutely welcome this initiative as a start (Queensland Parliament, 2015a, p. 13)

Nurse navigators were rolled out in Queensland as part of the *Nursing Guarantee Policy* (under the Hospital and Health Boards Act, 2016). They were part of a suite of nursing and midwifery specific strategies including the Business Planning Framework (discussed in Chapter Eleven) and nurse-to-patient ratios (Hospital and Health Boards Amendment Bill, 2016) under which “Queensland’s public sector health facilities … ensure patient safety and quality care” (Office of the Chief Nursing and Midwifery Officer, 2016, p. 1). The promise was fulfilled, with the Palaszczuk government employing 400 NNs across Queensland (QNMU, 2019) at a cost of AUD$116 million (Layt, 2019). Nurse navigator positions are now present in all hospital and health services (HHS) within Queensland. The NN model represents an innovative, yet costly model of care for Queensland, and once rolled out from the Office of the Chief Nursing and Midwifery Officer (OCNMO), the service was handed over to each HHS to embed as business as usual.

Nurse Navigators, Queensland, Australia

The Queensland Health NN service was born from the political, social, and institutional climate described above. Nurse navigators are senior nurses who manage the care of people with complex multimorbidity and frailty. Nurse navigators are appointed to “an advanced practice nursing and/or midwifery position [and] demonstrate a specialised clinical expertise and/or specialised skill set” (Queensland Industrial Relations Commission, 2015, p. 84) and also engage with people requiring complex management of comorbid conditions with the aim of improving engagement, self-efficacy and decreasing hospital admissions (Gordon et al., 2019; QH, 2018a), given that navigated people have significant chronicity, complexity, fragility and have intensive care needs (QH, 2018a). This enrolment criteria ensures that navigated patients are the sickest of the sick, requiring high levels of hospital resource use and care support. There are many reasons why navigated patients seek care, for example chronic pain or other long-term conditions. The specific conditions and challenges reflect yet another layer of complexity in health provision and health disparities. As such, specific health issues are not discussed in depth in this thesis.

To achieve the level of care that navigated people require, NNs are governed by four key role principles. These are to:

(1) Coordinate patient centred care;
(2) Create partnerships;
(3) Improve patient outcomes; and
(4) Facilitate systems improvement (QH, 2018a).

The aim of these four principles is to achieve the service goal of hospital avoidance through improved self-efficacy. Nursing navigators, working to their full scope of practice and autonomy, work similarly to a case manager in that they address the needs of the person which are often entwined with long term disengagement and mistrust of the health service (Byrne et al., 2020). Given that the NN is charged with implementing and delivering PCC to particularly vulnerable people, the service provides a prime landscape for the investigation of the concept of PCC in practice.

Importantly, in addition to providing clinical care, Queensland Health NNs are also asked to improve the individual's capacity to be active participants in their care:

> Enhance health literacy to support patients and their families to make informed decisions about their health care options, including Advanced Care Planning (QH, 2018a, p. 5).

The complete Nurse Navigator Toolkit is available in Appendix B.

In line with the discussion above, the pilot NN model implemented in Queensland showed that navigation was likely to *increase* costs, at least in the interim, as previously disconnected patients with multi-morbid conditions reengaged with the system and their unmet needs were addressed (Gordon et al., 2019; Horny et al., 2017). The model of care itself often displays a contrast in the role principles of NNs, viz., PCC, and the way that the service is measured, for example, hospital avoidance. This is the starting point for the analysis of the NN and PCC in practice.

In addition to improving capacity in the person, their family and community, NNs are also tasked with acting as change agents for larger system wide change.

> The [Model of Care] MOC can also be used to flag areas for system improvement. There may be a certain cohort of patients that seem to fail progression at a certain point of the journey. The Nurse/Midwife Navigator should use this as an opportunity to facilitate system improvements to address the issues brought about during the navigation journey for this cohort of patients (QH, 2018a, p. 6).

This is a significantly important point which differentiates the Queensland Health NN service from other navigator models. In fact, while other models have placed an emphasis on knowing and navigating the system (Pedersen & Hack, 2011; Freeman, 2004; Fillion et al., 2012) no other working model has placed priority on *changing* the system.

In summary, this chapter highlights that there are multiple international, national, and state legislations, strategies, events and influences which have framed the way chronic disease management and PCC are described, shaping the way that care is coordinated and managed. The social, political, economic, and medical minutia has created the landscape for NNs, to emerge as one potential solution to a system plagued with issues (The Change Foundation, 2013). This demonstrates the complexity of the space in which PCC, and indeed NNs, exist. These influences are further discussed and interrogated within the international, national and Queensland contexts.

Chapter Three—Whose Centre is it Anyway? Defining Person-Centred Care in Nursing: An Integrative Review

Summary of Chapter

The following chapter is an integrative systematic literature review which has been published in *PLOS One* (Byrne et al., 2020). The literature review was conducted early in the thesis as a method of investigating the meaning and purpose of PCC and asks the simple question: *What does PCC mean*? The literature review uncovered three major themes around how PCC is defined: *People, power,* and *practice.*

I acknowledge that CDA does not normally support a full literature review. However, because PCC is a subject that does not have a consistent definition or understanding, it is interpreted and enacted differently. I wanted to explore this in more detail so that I had some consistency in my interpretation and discussion in this thesis. Additionally, as part of the CDA process, it was important to first identify the literature (used within the critical evaluation of the research), explore the context it exists within and understand how it is currently presented to nurses and to the wider healthcare sector.

This review aimed to achieve a broad view of how PCC is defined for nursing practice, and therefore was not limited to NNs. This was a conscious decision and aimed to achieve an overarching understanding of the elements of PCC and how it is practised by nursing as a profession. The findings of this literature review are used throughout the thesis and contribute to the discourse which is critically analysed throughout.

PLOS ONE

RESEARCH ARTICLE

Whose centre is it anyway? Defining person-centred care in nursing: An integrative review

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Abstract

Aim

The aims of this literature review were to better understand the current literature about person-centred care (PCC) and identify a clear definition of the term PCC relevant to nursing practice.

Method/Data sources

An integrative literature review was undertaken using The Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Scopus and Pubmed databases. The limitations were English language, full text articles published between 1998 and 2018 within Australian, New Zealand, Canada, USA, Europe, Ireland and UK were included. The international context off PCC is then specifically related to the Australian context.

Review methods

The review adopted a thematic analysis to categorise and summarise themes with reference to the concept of PCC. The review process also adhered to the Preferred Reporting System for Meta-Analysis (PRISMA) and applied the Critical Appraisal Skills Programme (CASP) tools to ensure the quality of the papers included for deeper analysis.

Results

While definitions of PCC do exist, there is no universally used definition within the nursing profession. This review has found three core themes which contribute to how PCC is understood and practiced, these are *People, Practice and Power.* This review uncovered a malalignment between the concept of PCC and the operationalisation of the term; this misalignment was discovered at both the practice level, and at the micro, meso and micro levels of the healthcare service.

Conclusion

The concept of PCC is well known to nurses, yet ill-defined and operationalised into practice. PCC is potentially hindered by its apparent rhetorical nature, and further investigation of how PCC is valued and operationalised through its measurement and reported outcomes is

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needed. Investigation of the literature found many definitions of PCC, but no one universally accepted and used definition. Subsequently, PCC remains conceptional in nature, leading to disparity between how it is interpreted and operationalised within the healthcare system and within nursing services.

Introduction

Healthcare is changing, for both providers and recipients of care, with ongoing challenges to traditional roles and power balances. The causative factors of changes to the way healthcare is provided are complex, but one contributing factor is easier access to healthcare information and better-informed populations [1] whereby people as healthcare consumers have access to healthcare information through multiple media. On the surface, consumers are no longer seen as passive recipients of care, but rather as valuable and active members of the healthcare team. The concept of Person-Centred Care (PCC) is used to describe a certain model for the role of the patient within the healthcare system and the way in which care is provided to the patient [2,3]. Globally, there is continued advocacy for person-centred, individualised care [4], with the contemporary term for PCC being frequently presented in healthcare discourse, and frequently associated with the safety and quality of healthcare service provision [5,6]. Indeed, partnering with consumers within a person-centred framework is now a fundamental requirement for Australian healthcare services, meaning that they cannot achieve accreditation without demonstration of PCC [7]. Hence, PCC is now seen in healthcare service strategy and models of care, designed to support the voice of the patient and the role of the healthcare service in engaging with patients [6]. PCC also forms part of the Australian nursing professional standards [8] yet is paradoxically described as an 'extra' to nursing practice [9], taking a back seat to nursing tasks and errands that make up the day to day regime of the nurse.

Despite the discourse around PCC, and the requirements of PCC within healthcare, there appears to be no universally accepted definition of the term. This leaves the concept open to interpretation and potential confusion, particularly when personnel, in this case nurses, attempt to operationalise it. This review investigated the meaning of PCC with reference to nurses across different practice settings and specialities. To further facilitate the understanding [10] and theory development of the concept of PCC, this review adopted an integrative review methodology [11].

Background

In the late 1950's and 60's, PCC, and care for the entire self was first described in the context of psychiatry, such as in Rogers' 'On becoming a person' [12]. Patient-centred medicine was a term first coined by psychoanalyst Michael Balint. Balint was instrumental in the education of general practitioners around psychodynamic factors of patients and challenged the traditional illness-orientated model [13]. Balint's challenge extended beyond the traditional healthcare model to include both the physical and psychosocial as part of the practitioner's role. Balint explained; *"Here, in additional to trying to discover a localized illness or illnesses, the doctor also has to examine the whole person in order to form what we call an 'overall diagnosis.' The patient, in fact, has to be understood as a unique human-being."* [13 p269].

The idea of caring for the whole person, and the divide between traditional medical practice and the psychosocial needs of the patient was discussed by Engle in 1977. He wrote; *"The dominant model of disease today is biomedical. . .It assumes disease to be fully accounted for by*

Aim

The aim of this literature review was to understand better from the literature how nurses operationalise the definition of PCC.

Search questions

This literature review sought to answer the following questions:

- Is there a commonly/generally accepted definition for PCC that is used by nurses?
- How do nurses operationalise PCC in practice?

Search strategy

An integrative literature review was conducted using the terms Person Cent* Care OR Patient Cent* Care AND Nurs* AND Definition OR Meaning OR understanding OR Concept. The search was expanded to include similar terms and concepts such as patient/person-centredness and personalisation. A major subject heading of 'patient centred care' was used within the searches. This review is positioned within the nursing discipline; therefore, articles were included if they were specific to nursing or if they included nursing texts in the review. English language, full text articles published between 1998 and 2018 were included. Publications from Australia and New Zealand, Canada, USA, Europe, UK and Ireland were included to gain an understanding of PCC in the western context. The Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Scopus and Pubmed databases were searched. This search is registered with PROSPERO (ID number 148778) and was completed in March 2019. While the search strategy includes international literature, this will be related back to the Australian context, in order to understand how PCC operates within Australia.

Data extraction

The framework, from Whittemore and Knafl [11], describes a comprehensive review, identifying the maximum number of eligible primary sources and requires the researcher to explicitly justify decisions made in the sampling. Using this framework, a total of 1817 articles met the search terms, highlighting the volume of literature available on the concept of PCC. Table 1 provides the scope of inclusions and exclusions. From this, 255 articles were selected for review.

Table 1. Inclusion and exclusion criteria.

Inclusions	Exclusions
Articles related to Nursing or included nursing	Articles relating to Midwifery and 'women-centred care'
All nursing specialty areas including stroke, Intensive care, aged care, acute care, operating theatres chronic disease	Concept analysis for concepts such as 'self' and 'cultural competence', 'compassion' or 'empowerment' where these were discussed in isolation
Staff and patient perceptions	Trial registrations and study protocols
Person-centred care frameworks	Professional role development and leadership
Family centred care	Digital health and integrated technology
	Articles where PCC was not major subject; for example, aggression and hand hygiene

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deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioural dimensions of illness." [14 p379]. The biopsychosocial model proposed provided a new basis for care which included care of the mind and body. Over the succeeding years, this model of care and the notion of patient centre care continued to evolve, with many iterations of the term moving with the changing climate of healthcare systems.

PCC gained significant traction through the Institute of Medicines (IOM) 2001 report 'Crossing the Quality Chasm: A New Health System in the 21st Century' [15] as a key element of quality healthcare. The IOM provided one of the first contemporary definitions, stating that PCC *"encompasses qualities of compassion, empathy and responsiveness to the needs, values and expressed preferences of the individual patient"* [15 p48]. The World Health Organization continues to advocate for integrated care that is in tune with the patient's wants and needs through the framework on Integrated People-Centred Care. This includes the vision that *"all people have equal access to quality health services that are co-produced in a way that meets their life course needs"*. [5] This framework aims to improve engagement of people and communities, strengthen governance and accountability, reorientate the model of healthcare, and coordinate services across sectors [5], seeing people as important contributors and decision makers over their own care.

More recently, the Australian Commission on Safety and Quality in Health Care (ACSQHC) defines PCC as an *"innovative approach to the planning, delivery, and evaluation of health care . . .[involving] mutually beneficial partnerships among health care providers, patients, and families."* [2 p13]. Thus, PCC has become an integral element of care from a quality, planning and practice level, and therefore appears prominently in Australian healthcare service discourse and associated models of care, often presented as an underpinning philosophy for the way in which nursing care is provided [3]. The concept of PCC continues to evolve, notably in the change to 'person' rather than 'patient' in recognition of the whole person, not simply the disease process. Other variables such as Family-centred care are used more in the context of aged care and paediatrics [16,17].

As the term has become more common in healthcare discourse, frameworks have emerged to allow the term to be operationalised into practice. There are several person-centred nursing frameworks including the Senses [18], VIP [19], 6 C's [20], The Burford Model [21] and McCormack and McCance's framework [22]. These frameworks describe elements such as attributes of staff, methods of interactions, coordination of care and services, the care environment and consideration of outcomes of care. These examples provide insight into attempts to operationalise PCC, into individual practice and healthcare service provision.

Nurses are the healthcare professionals who spend the most time with people and are therefore in a position to act as their advocates, with nursing staff managing the continuity of care [23]. This review seeks to investigate the meaning of person-centred nursing practice, and acts as a starting point for a wider study into the concept of PCC for people with long term conditions. Consumers of healthcare navigate a complex and fragmented system, with fragmentation leading to patients feeling lost, and a decrease in the quality of services offered [24]. This places even greater importance on a partnership between provider and receiver, particularly in the face of increasing chronicity/complexity of care. Within this fragmented and complex system, the patient must always remain at the centre of their care. Hence, there is a need for a robust definition to ensure PCC is more clearly operationalised and care delivered is designed around the needs of the patient, rather than trying to make the patient fit within the system.

This review uses the term person rather than patient in recognition of the person as a whole. Where clarity is required, the term healthcare consumer is used; a term frequently used in Australia.

After removal of duplicates, 203 articles were subjected to full review. A further refined strategy excluded Key Performance Indicators (KPI), service measures, assessment tools and validations as the goal was defining the term, rather than to assess how it is measured; these represented a large proportion of the articles within the search. A total of 44 articles were subjected to quality review. To ensure adequate rigour, reliability and relevance, all articles were evaluated against the Critical Appraisal Skills Programme (CASP) systematic and qualitative review checklists [25,26] by the lead author and reviewed by a senior researcher on the team. The relevance of the papers and the quality of the reviews/articles themselves was appraised. All articles were appraised against the aims of this review. Following this, a total of 17 articles were included in the final review. Fig 1 provides the summary for the search process while S1 File provides the PRISMA checklist.

Using the previously identified framework that allowed for data from diverse methods and approaches to be analysed and compared, a constant comparison method was used to convert data from different categories into patterns, themes and relationships. The data is thus displayed below in Table 2 to encompass the full depth of the concept and to provide new understanding, and its implications to practice [11]. Table 2 demonstrates the characteristics of the articles reviewed including their design methods, populations and findings.

Findings

This review set out to investigate if a universal definition of PCC for nursing exists and is used; what was uncovered was a deeper understanding of the concept and operationalisation of PCC, highlighting a malalignment between concept and reality. Three (3) core themes were identified in the review process, each of which is comprised of two (2) sub-themes. These three core themes of *People, Practice, and Power*, with the respective sub-themes are discussed are summarised in Table 3.

Theme 1: People

Unsurprisingly, the most common threads in the literature about PCC relate to people and, consistent with the philosophy of PCC, is described as basic, human kindness and respectful behaviour [22,27,28,29]. The core theme of People comprises two sub-themes: *Recognising uniqueness* and *Partnerships*.

Recognising uniqueness. PCC, as the name suggests, is care that is considered and based on the individual person, who is the recipient of care. Prominent in the literature are the concepts of personhood, individuality and uniqueness [16,28,30]. Individuality, and the sense of self, understands that each person has their own unique wants, needs and desires [16,29] Personhood reinforces and values the complete person, with an understanding that illness affects the entire person [31]; an holistic consideration of the person that extends to family interventions and involvement [27,32] described as developing and maintaining trust within the family unit [33,34]. Uniqueness is central to this subtheme as recognition of the person as a unique being leads to unique and tailored care, based on the needs of the whole person [16,29].

Partnership. The literature discusses the need for a relationship between healthcare provider and healthcare receiver as a way of facilitating information, knowledge and decision making. The term 'relationship' is prominent in the literature including the terms therapeutic relationship [16], clinical relationship [35] and partnership [29,36,37]. This is described in the contexts of cohesive, cooperative teams [29,32], mutuality between provider and receiver [38], and the balance of power and the sharing of knowledge [16]. These themes are further developed through the practice of the nurse and are thus carried forward to the next theme, Practice.

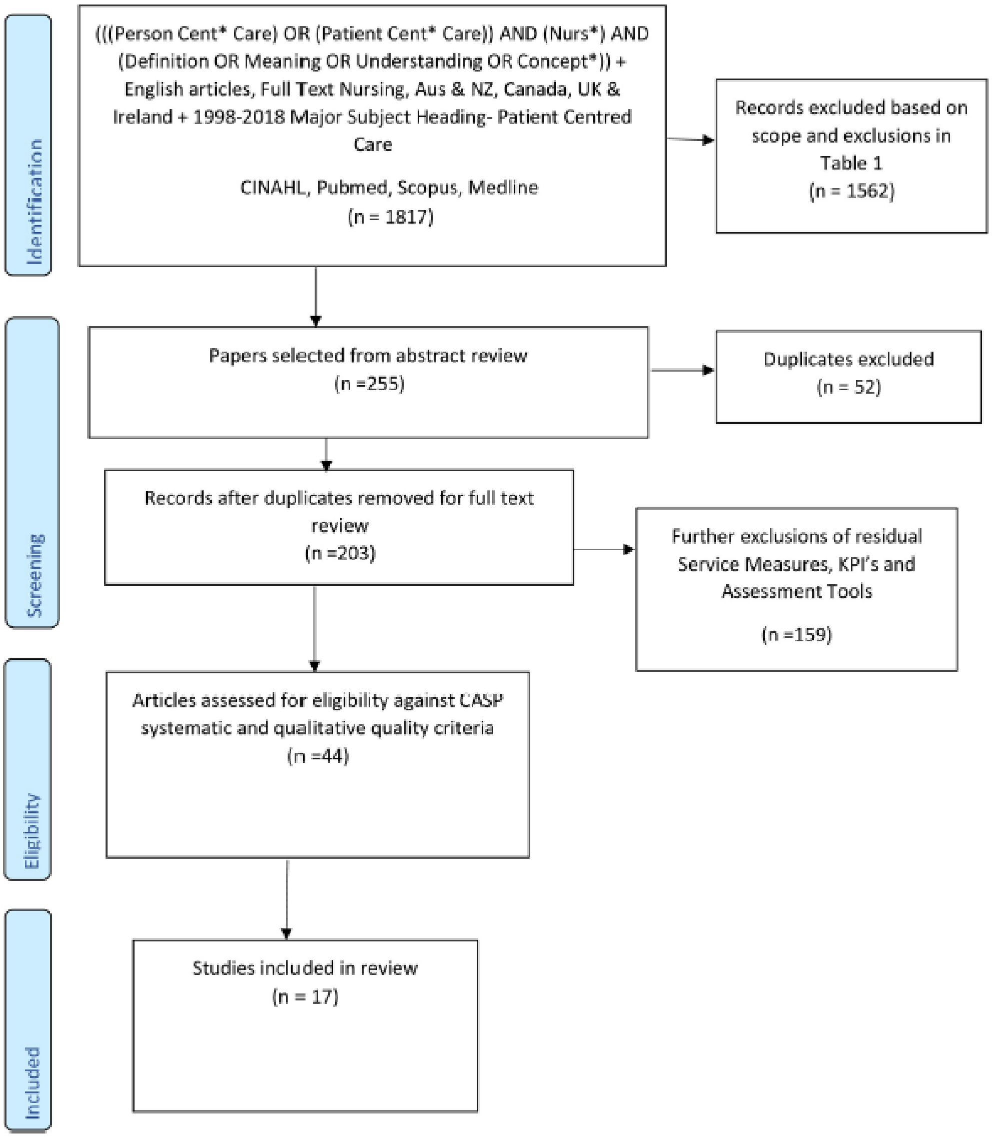

Fig 1. Literature review search process.

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Table 2. Literature review findings.

Authors, year, location	Population	Design methods	Findings/Comments	Common authors and articles
LITERATURE REVIEWS				
Slater, L (2006) AUS	Search of term Person/patient-centeredness personhood or related words CINAHL, Ovid, Science direct, Medline, Blackwell Synergy and Wiley Interscience	Systematic Review and Concept Analysis	Recognition of Personhood; Individuality, Self, Rational Decision Making, Reflection on available choices, Needs, wants and desires Evidence of a therapeutic relationship between person and health provider; Mutuality, Decisions are valued, power is balanced, therapeutic relationship Respect for Individuality of the person Uniqueness, Individuality, 'person' not 'patient', own values, autonomy, cultural needs Provision of care that reflects professional ethical standards Autonomy, dignity, privacy, rights Identification and reinforcement of the person's strengths and positive aspects rather than the weaknesses and problems Valued, wellness v's Illness, the person as a whole Acknowledgement of the person's lived world Lived experiences, current experiences, person's story Empowerment of the person to make their own decisions about their health Shift of power, Providing knowledge, ability to make decisions, respect for final decisions Definition: Not provided; Advocates strongly for the term 'Person' rather than 'Patient or 'Client' as a salute to not only the person's right to care but to have choices as to how it is perceived and provided.	• Downs (1997) the emergence of the Person in dementia research • Ford & McCormack (2000) keeping the person in centre of nursing • Kitson (1999) The essence of nursing (part I and II) • Kitwood (1997) the experience of Dementia • McCormack (2003) A Conceptual framework for person-centred practice with older people • Nolan, Keady, Aveyard (2001) Relationship-centred care is the next logical step • Price (2004) demonstrating respect for patient dignity • Stewart (2001) towards a global Definition of patient-centred care

McCormack, McCance (2006) Ireland	Developed from 14 case studies of nurse-patient relationships and other work by authors (used to develop framework) Acute care setting, though authors have considerable work in aged-care	Systematic iterative process	Prerequisites Attributes of nurses, professional competence, developed interpersonal skills, being committed to the job, clarity in belief, values and knowing self and insight The Care Environment Supportive organisation systems, sharing of power and potential for innovation and risk, workplace culture, quality of leadership, thorough evaluation Person-centred Process Having a sympathetic presence, sharing decision making, engagement, working with the patient's beliefs and values, providing for physical needs Definition: Not provided- provides a framework for PCC in practice which hence forms meaning in nursing practice	Influential authors with multiple papers leading to this framework • McCormack (2001) Negotiating partnerships with older people- A person-centred approach • McCormack (2003) A conceptual frame work for person-centred practice with older people • McCormack (2004) Person-centeredness in Gerontological nursing: an overview of the literature • McCance (2003) Caring in nursing practice: the development of a conceptual framework • Mead & Bower (2000) Patient Centeredness: a conceptual framework and Review of the empirical literature • Nolan, Davis, Brown, Keady & Nolan (2004) beyond person-centred care: a new vision for gerontological nursing
Lawrence, Kinn (2012) UK	Review of PCC in stroke literature Medline and Psychinfo, AMED, ASSIA, BNI, Cochrane, DARE, CCTR, CINAHL, Embase between 1994–2010 21 studies	Systematic mixed methods	Meaningfulness and relevance Understanding patient experience Ascertaining priorities, concerns and patient goals Quality of experience Measuring person centred care support The need to understand the experience of caregivers Family centred interventions Quality participation activities Communication Communication with impaired adults and families Definition: PCC- 'Identifies individual's communication skills and utilises appropriate and effective communication strategies in all interactions between the health-care professional and the individual. Identifies outcomes that are valued and prioritized by individuals. Identifies outcomes that reflect the desire quality of participation. Monitors and measures outcomes at appropriate times and points om the rehabilitation process. Uses the s resultant information to inform the patient/health-care professional's decision-making process.	• Mead & Bower (2000) Patient-centeredness: a conceptual framework and review of the empirical literature • Kennedy (2003) Patients are experts in their own field • Gillespie Florin, Gillam (2004) How is Patient-centred care understood by clinical, managerial and lay stakeholders responsible for promoting this agenda • Mead & Bower (2002) Patient-centred Consultations and outcomes in primary care • Lawrence (2009) Patient-centred stroke care: young adults and their families

(*Continued*)

Table 2. (Continued)

Authors, year, location	Population	Design methods	Findings/Comments	Common authors and articles
Kitson, Marshall, Bassett, Zeitz (2013) AUS	Key and seminal texts from Nursing and Medical looking at patient-centred care search of CINAHL, Scopus, Medline between 1990–2010. 60 papers included	Narrative review and Concept Analysis	Patient participation and involvement; Patient participating as a respected and autonomous individuals- respect for patients, values preferences, expressed needs, patient as a source of control, patient actively involved and participation, autonomy Care Plan based on patient needs- Care customised, according to needs and values, transition to community Addressing a patient physical and emotional needs- physical comfort, physical care, emotional support, alleviation of anxiety Relationships between health professionals; Genuine clinician relationship, open communication, knowledge, clinical expertise v patient experience, health professional skills and knowledge, cohesive and co-operative team professional The context of care- core systems; Policy and practice, continuum language, access, barriers to PCC, supportive organisational systems, therapeutic environment Definition: Not provided: Though found consistent themes between nursing and medicine. Conclude that there are core elements that transcend professional boundaries, though different professions place greater importance on certain elements. Nursing tends to accentuate respect for patient values and beliefs	• Balint (1969) the possibilities of patient centred medicine • Edvardsson, Nay (2010) cute care for Older: challenges and ways forward • Epstein (2000) the science of person-centred care • Institute of Medicine (2001) Crossing The quality chasm • Kitson (2002–2010) recognising Relationships; The need for system changes; Defining the fundamentals of care • Marshall, Kitson & Zeitz (2012) patient views on patient-centred care • McCance, Slater, McCormack (2009) Using the caring dimensions of inventory as an indicator of person-centred nursing • McCormack (2003–2004) A conceptual Framework for person-centred practice nursing; Researching nursing practice: does person-centredness matter? Person-Centeredness in gerontological nursing • McCormack & McCance (2006) Development of a framework for person-centred nursing • Mead & Bower (2000) Patient-Centeredness: a conceptual framework and review of the empirical literature • Nolan, Davis, Brown, Keady, Nolan (2004) beyond person-centred care: a new vision for gerontological nursing • Price (2006) exploring person-centered Care • Stewart (2001) toward a global Definition of patient centred care • Zeitz, Kitson et al (2011) working together to improve the care of older persons

Morgan, Yoder (2012) USA	Concept analysis of PC, CINAHL, Medline, Pubmed and Cochrane review 50 articles included	Systematic concept review	Holistic Recognises and values the whole person Illness affects the whole person Individualised Understanding the person's life situation and their abilities Decision making and control Respectful The 'right' thing Recognising the individual as competent to decide Offering choice Empowering Promotes self-confidence and self determination Definition: Not provided however advocates for providing clarity in the concept as a way of improving PCC in acute care.	• Balint (1968) The possibilities of Patient-centered medicine • Douglas & Douglas (2005) Patient-Centered improvements in healthcare-built environments • Edvardsson, Koch & Nay (2009) Psychometric evaluation of the English language person-centered climate questionnaire- patient version • Hobbs (2009) A dimensional analysis of patient-centered care • Institute of Medicine (2001) Crossing the quality chasm • Kitson (1986) Indicators for quality in Nursing care- an alternative approach • McCance (2003) caring in nursing Practice: the development of a conceptual framework • McCormack and McCance (2003) A Conceptual framework for person centred practice with older people • Mead & Bower (2000) Patient-centeredness: a conceptual framework and review of the empirical literature • Rogers (1961) on becoming a person • Slater (2006) Person-centredness: A concept analysis • Stewart, Brown, Weston, McWhinney, McWilliam, Freeman (1995) patient-centered medicine: transforming the clinical method

(Continued)

Table 2. (Continued)

Authors, year, location	Population	Design methods	Findings/Comments	Common authors and articles
Lusk, Fater (2013) USA	CINAHL, PsychInfo and Medline for search of combination of terms Patient-centred, power and research 2001–2010 extended by hand search. 24 articles included	Review and Concept Analysis	Attributes of healthcare providers; caring, moral and ethical behaviour, faith and hope, sensitivity, trust, relationships, teaching and learning, listening Autonomy; The right to make decisions, creative problem solving, individuality The lived experience; Understanding and working within the lived experience Power; Decision making, individualised care, shared decision making, unique individual Outcomes Biophysical markers, physical and social health, access to care and care coordination, care and costs Definition; The provision of care incorporating contextual elements and including the attributes of encouraging patient autonomy, the caring attitude of the nurse, and individualising patient care by the nurse. Behaviours fundamental to the provision of PCC include communicating and listening, treating the patient as a unique individual, respecting values and responding to patient needs.	• Epstein, Fiscella, Lesser, Stange (2010) Why the nation needs a policy push on patient-centered health care • Hobbs (2009) A dimensional analysis of patient-centered care • Institute of medicine (2003) crossing the quality chasm: a new health system for the 21st century • McCormack, Karlsson, Dewing, Lerdal (2010) exploring person-centeredness

Jakimowicz, Perry (2015) AUS	Reference to intensive care nursing. CINAHL, Psychinfo, Medline, Pubmed between 2000–2014 28 articles included	Systematic review concept analysis	Biomedical Nursing Routines, complex care, patient survival, nursing knowledge and expertise, technical aspects Patient Identity Maintaining personal identity, understanding vulnerability, treating the patient as unique, fear, lack of control, participation Compassionate Presence Presence while caring, emotional support, allaying fear and anxiety, humanistic, spiritual Professional presence Professional and ethical standards, protect the patient, safety and quality of care, communication, patient advocacy, privacy Definition: Not provided but differentiates the practice of PCC in the technical environment of the ICU. Core themes listed above, however, are consistent with other areas of nursing	• Dewing (2002) from ritual to relationship: a person-centred approach to consent in qualitative research with older people who have dementia • Esmaeili, Cheraghi, Salsali (2014) Critical care nurses understanding of the concept of patient-centered care in Iran nurses • Hobbs (2009) A dimensional analysis of patient-centered care • Kitson, Marshall, Bassett, Zeitz (2013) What are the core elements of patient-centered care? • Kitwood (1997) Dementia reconsidered the person comes first • McCormack (2003) a conceptual Framework for person-centered practice with older people • McCormack and McCance (2010) person centered nursing: theory and practice • Mead & Bower (2000) patient Centeredness: a conceptual framework and review of the empirical literature • Nolan, Davis & Grant (2001) working with older people and their families • Rogers (1961) on becoming a person • Stewart (2001) toward a global definition of person-centered care • World Health Organization (2014) Who global strategy on people-centered and integrated health services

Castro, Van Regenmortel, Vanhaecht, Sermeus, Hecke (2016) Europe	Systematic review of Pubmed, Web of science, Embase for Patient empowerment' 'patient participation' 'patient centre' and 'patient-centredness' along with 'conceptual definition'. 20 definitions of patient empowerment, 13 of patient participation and 20 of patient centredness were included.	Systematic review and concept analysis	Relationships; Partners, mutuality, family Shared Decision Making; Knowledge sharing, power Attributes; Communication, respect, values, choices, empathetic, respectful, compassionate, non-judgemental Uniqueness; Expectations, individual, needs, values, beliefs Outcomes; Biopsychosocial, holistic, sharing of clinical knowledge Definition: Patient-centredness is a biopsychosocial approach and attitude that aims to deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge.	• Balint (1964) The doctor his patient and the illness • McCormack & McCance (2006) Development of a framework for person-centred nursing • Mead & Bower (2000) patient-Centeredness: a conceptual framework and review of the empirical literature • Lusk & Fater (2013) A conceptual Analysis of patient-centered care • Bassett, Kitson, Marshall & Zeitz (2013) What are the core elements of patient-centred care? A narrative review and synthesis of the literature • Morgan & Yoder (2012) A concept Analysis of person-centered care • Stewart (2001) towards a global Definition of patient-centred care

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Table 2. (Continued)

Authors, year, location	Population	Design methods	Findings/Comments	Common authors and articles
Arakelian, Swenne, Lindberg, Rudolfsson, Vogelsang (2016) Europe	Perioperative nurses' perspectives of PCC Systematic review of Pubmed, CINAHL 2004–2014 23 articles included	Integrative review	Being recognised as a unique entity and being allowed to be the person you are Entire body, being an individual with a name, dignity and respect, being seen as unique, getting to know the person tact and discretion, creating conditions to see the person as an individual Being considered important and person wishes taken into account Self-control and dependency, sharing a story and creating a relationship, connecting, listened to, giving the person time and information, asking questions and appreciating personal belief The presence of the nurse is calming and prevents loneliness, promotes wellbeing Ease anxiety, reduce the feeling of being alone, taking care and being close, being welcomed and expected, feeling safe, feeling like an equal Being close to and being touched by the nurse Emotionally and physically present, staying close and touching patient, creating a feeling of security Definition: PCC means 'being respected as a unique person, being showed consideration, tact and discretion and being taken seriously. Being expected and welcomes by the perioperative nurse when arriving. . .leads to a warm and relaxed atmosphere. . . having access to one's own nurse. . . preventing feelings of loneliness.'	• Brooker (2003) what is person-centred care in dementia • Ekman et al (2011) Person-centered care ready for prime time • Eriksson (2007) becoming through suffering-the path to health and holiness • Price (2006) exploring person-centered care

Kogan, Wilbur, Mosqueda (2016) USA	Chronic Disease and functional limitation. Review of literature from CINAHL, Medline, Cochrane, Pubmed 1990–2014 132 included	Systematic review and analysis of themes for definition and for measurement tools	Holistic Care Whole person care, respect and value, choice and dignity, self determination Purposeful living Encouragement and continued social roles Coordinated care Integrated, focused and targeted, multidisciplinary, connected physical health and support services Involving family and friends Definition: Not provided, however advocates for a clear definition as a method of guiding PCC practice and measurements.	• World Health Organization (2013) Towards Person-centred health systems: an innovative approach for better health outcomes • Institute of Medicine (2001) Crossing The quality chasm: a new health system for the 21st century • Epp (2003) person-centred dementia Care: a vision to be refined • Li & Porock (2014) Resident outcomes Person-centered care: A narrative review of interventional research • Brooker (2004) What is person-centered care in dementia • McCormack & McCance (2010) Person-centered Nursing: theory and practice • Edvardsson, Winblad, Sandman (2008) Person-centered care for people with Alzheimers • Edvardsson, Sandman, Borell (2014) Implementing national guidelines for person centered care of people with dementia in residential aged care • Epstein, Fiscella, Lesser (2010) Why the nation needs a policy push on patient-entered health care.

QUALITATIVE REVIEWS				
Edvardsson, Fetherstonhaugh, Nay (2010) AUS	Interviews with aged care staff, people with early onset dementia and family members of patients with dementia N = 67	Interview and thematic analysis	Promoting a continuation of self Being the person you are and supporting people to continue this Acknowledging the person as valuable, respect, creating opportunities to do likeable things and make decisions Preservation of self Knowing the person Knowing history, preferences, needs and interest and particularities, translating this into practice Welcoming Family Developing and maintain trust, actively communicating, creating opportunities for beneficial teamwork Providing meaning activities Providing meaningful content, self-esteem, creating a feeling of being able to participate, being sensitive Being in a personalised environment Personalising the environment and the care, recognition, person behind the disease Experiencing flexibility and continuity Flexible care and outcomes, adapting care, staff being available, present and willing Definition: Not provided but provides key elements for aged care patients.	

(*Continued*)

Table 2. (Continued)

Authors, year, location	Population	Design methods	Findings/Comments	Common authors and articles
Gachoud, Albert, Kuper, Stroud, Reeves (2012) Canada	General internal medicine. Interviews with nurses, social workers and medical professionals N = 28	Comparative study, interpretive phenomenological approach	Person centred practice as a philosophy of care Values based and driven, underpinning practice, an element of caring practice, values held by the physician PCP and collaboration Holistic practice, good communication, patient advocacy, patient autonomy, shared decision making, empowerment, quality of care, family involvement and a rapport with the patient Definition: Looks at Person-centred Practice (PCP). Definition not provided but found that nurses and social workers both position themselves as providers of PCC and PCP. Found that Medical Officers were happy to see themselves as lower in the hierarchy of PCP, seeing it as more of a nursing practice	
Marshall, Kitson, Zeitz (2012) AUS	Surgical unit from the patient's perspectives N = 10	Interviews and thematic analysis	Staff Being attentive, being helpful and timely, making an effort, meeting needs and being nice, connectedness, relationships, communication and advocacy Systems Resources, physical environment, workload, senses of loss of control, ward culture empowerment, waiting Definition: Not provided. Finds that PCC model needs to be integrated, incorporating both existing definitions and conceptualisations of PCC which are largely informed by professionals and the meanings and understandings patients give to PCC.	

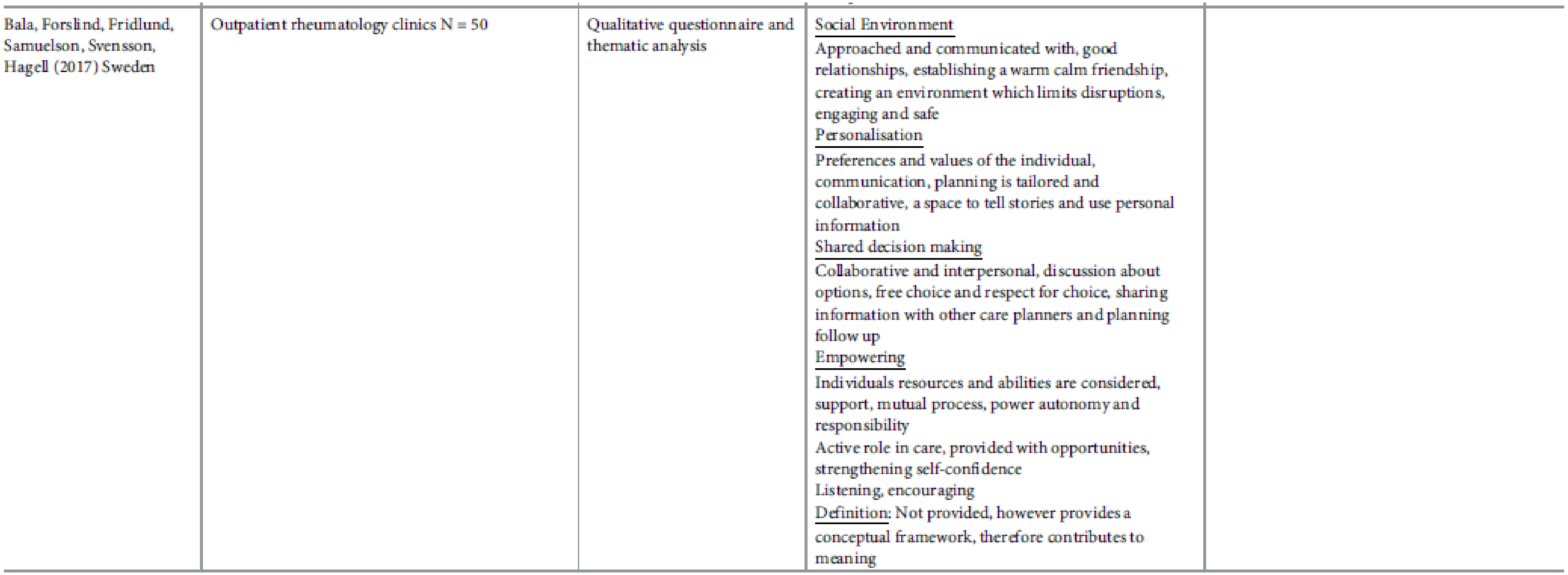
Trajkovski, Schmeid, Vickers, Jackson (2012) AUS	Neonatal Nurses in acute hospital setting N = 33 from nurses' perspective	Focus groups and qualitative interpretive approach	Getting to know parents and their wishes Individualising care based on knowledge of the family unit, trusting relationships, conversations, acknowledgement of each family as different, cultural sensitivity Involving the family in care Share information and guiding families, respect, facilitating the relationship, entire family as decision makers Finding a happy medium Involving parents and caring for an unwell patient (infant), priority of care, communications, adequately prepare families Transitioning support across the continuum Empowering families to feel confident, parent involvement, support for the family, fluid relationship that changes with needs, empowerment, acting as role models Definition: Not provided. Places importance on the application of family centred care and the need for ongoing organisational support, guidance and education.	

Edvardsson, Varrailhon, Edvardsson (2014) Sweden	Swedish nurses in aged, long term care N = 436	Anthropological free listing and qualitative content analysis	Promoting decision making Involvement in decision making, activities, offering choice, respecting preferences, understanding patient history, respecting residents view point, respecting lifestyle choices and routines Promoting meaningful life Individually targeted life, involvement in everyday life tasks, creating activities, sharing knowledge, playing games, listening, having appropriate space and activities Promoting a pleasurable living Little extras, experience, pleasure, being careful Promoting personhood Life stories and meaningful interaction, seeing the resident as valuable, making eye contact, using name, greeting and acknowledging the person, sharing a meal or a coffee Asking questions and taking interest Definition: Defines PCC as a philosophy of care and a culture rather than singular interventions.	

(*Continued*)

Table 2. (Continued)

Authors, year, location	Population	Design methods	Findings/Comments	Common authors and articles
Ross, Tod, Clarke (2014) UK	Nurse perspectives of PCC Acute medical ward Semi structured interviews N = 14	Semi Structured interviews and thematic analysis	Characteristics of relationships Being friendly and approachable, finding the time to listen and talk with patients, freely give information and ease anxiety Team contributions Personal qualities of staff Relationships are valued, respect for beliefs, being recognised as important, patient stories, flexibility in ward routine, role modelling Respecting the principles of PCC Recognising the importance of personal wishes and values and being considerate of decisions, supporting the person to ask questions, being an advocate, responsive assessments, dignity Definition: Characteristics of relationships, personal qualities of staff and respecting the principles of PCC act together to shape the philosophy of care in the medical ward. In turn the philosophy influences how staff perceive and facilitate PCC.	



Bala, Forslind, Fridlund, Samuelson, Svensson, Hagell (2017) Sweden	Outpatient rheumatology clinics N = 50	Qualitative questionnaire and thematic analysis	Social Environment Approached and communicated with, good relationships, establishing a warm calm friendship, creating an environment which limits disruptions, engaging and safe Personalisation Preferences and values of the individual, communication, planning is tailored and collaborative, a space to tell stories and use personal information Shared decision making Collaborative and interpersonal, discussion about options, free choice and respect for choice, sharing information with other care planners and planning follow up Empowering Individuals resources and abilities are considered, support, mutual process, power autonomy and responsibility Active role in care, provided with opportunities, strengthening self-confidence Listening, encouraging Definition: Not provided, however provides a conceptual framework, therefore contributes to meaning	

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Theme 2: Practice

PCC is a product of person-centred practice, particularly in the context of nursing. However, the ability to practice PCC is influenced by professional and system factors. The core theme of Practice is comprised of the sub-themes *Doing* and *Space*.

Doing. 'Doing' refers to the complex interplay of professional attributes, behaviours and tasks that makes up the daily remit of the nurse; that is, the 'doing' of nursing is a combination of these things within the care environment. Personal attributes of nursing staff emerge as a common element in the literature related to PCC. The literature describes attributes such as communication, respect, values, empathy, compassion and non-judgemental behaviour [9,29]. Lusk and Fater [7] further describe such attributes as caring, faith and hope, trust, relationships, teaching, learning and listening. In describing a framework to facilitate the practice of person-centred care, McCormack and McCance [22] discussed professional competence, interpersonal skill, job commitment and professional insight. Others have extended this to include understanding vulnerability, fear, the patient identity [30] and highlight the need to recognise the person as competent to make decisions [31]. This view, centred on dignity and privacy and the moral and ethical behaviours of the nurse [16,28], facilitates the relationship and balance of power with the person. Delivering whole person care includes elements such as

Table 3. Summary of integrative review themes.

Theme	Subtheme	Findings
People	Recognising Uniqueness	• The person is an individual with unique needs from the healthcare team • The need to develop and maintain trust • Care is tailored for the person
	Partnership	• A professional relationship is formed • Mutuality between provider and receiver is fostered
Practice	Doing	• Professional attributes of the nurse such as respect, compassion and non-judgemental behaviour • Professional competence in practice • Recognising the person as competent to make decisions and valuing the lived experience of the person • Meeting the physical and emotional needs of the person
	Space	• Being flexible and offering choice while creating opportunities for the person to engage • Freely giving information and finding time to listen and engage • Opening the space for PCC despite competing priorities • Positioning PCC as the major priority in care
Power	Power Over One's Care	• Balancing the power between the provider and the receiver; A marriage between provider and receiver allowing for a sharing of knowledge • Fostering autonomy and participation
	The Power to Practice PCC	• Healthcare systems and environments must be conducive to PCC • Systemic barriers such as workplace culture, leadership, policy must be addressed • The measurement of PCC in its current form may be more system centred, hence perpetuating task orientation among other things

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respect for the individual [16], and planning care that is based on individual needs [25]. In practice, this is described as the person being valued for their lived experience, life stories [9,16] and the continuation of self [34]. Kitson et al. [35] describe this as addressing both the physical and emotional needs of the person and alleviating anxiety.

Space. The existing literature alludes to the idea of opening a space to practice PCC. The literature describes this as being flexible within the care, offering choice [9,31], and creating opportunities for people to engage [34]. Practicing PCC involves freely giving information to the person [36] and finding the time to listen and engage with them [36,39], which implies that PCC is a proactive way of delivering nursing care. Gachoud et al. [32] found that nurses see themselves as most important in delivering PCC, with Doctors playing a lesser role in PCC practice. This understanding creates a concept whereby nurses are pivotal in creating an environment in which the person can truly engage.

While PCC is an individual practice method, the environment within which nurses' practice must be considerate and supportive of the delivery of PCC as a significant priority; a view supported by McCormack and McCance [22] in their description of organisational systems and leadership within PCC. Despite competing priorities and the associated tasks of daily practice, nurses must find and open a space to practice PCC as an essential element of the profession. Interestingly, PCC within the literature is often discussed as an addition to nursing tasks. Edvardsson et al. state that promoting PCC in aged care includes doing 'little extras' [9 p50], such as understanding the patient's life story, making eye contact and using the person's name. Marshall et al. found that nurses describe PCC as 'making the effort' and 'going the extra mile'

[37 p2667], being helpful and timely with care and attention. Others describe making choices available [16], ascertaining priorities [27] and doing the 'right' thing [31].

Theme 3: Power

PCC as a concept is about balancing power between the provider and receiver of care. The notion of PCC is imbued with connotation of power, discussed in relation to all elements of the care and is intertwined in some way with all themes within this review. The sub-themes of Power are the *Power over one's care* and the *Power to practice PCC*.

Power over one's care. The idea of power balance is discussed in the literature and includes the sharing of knowledge [29], respect for decision making and individualised care based on these decisions [28,17]. Further to this is the notion of the person having 'active' involvement in the care process [22,35]. This is described through identification of the person's strengths and reinforcing this through the care continuum [16,38]. In addition to this, the literature describes empowerment, promoting the sense of self efficacy [31,33,37], supporting the person to be as self-managing as possible [36] or to have a level of autonomy in their care. Here, the person holds the power in care planning and decision making throughout the care journey and there is a responsibility of knowledge transference and the maintenance of personal autonomy [35]. This is apparent in the literature through concepts such as control, rights, patient involvement and participation [27,33,35]. PCC, however, places importance on a marriage between provider and receiver as a process of sharing knowledge, rather being entirely self-governing, in which the provider (as the custodian of knowledge) has an obligation to impart knowledge.

The power to practice PCC. The need for care systems to be innovative and make a commitment to PCC comes through in the literature [22], as well as the need for the environment to allow for flexibility and to factor time and space to practice PCC [9,36]. This is a significant shift from the traditional biomedical model, whereby emphasis on personal choice [33] and partnerships [17] must be considered within all layers of the healthcare system. Barriers and enablers including workplace culture, leadership [22], policy and practice, organisational systems, environment [28,35], workload, and ward culture [37] were identified. The literature also included topics around cost [28], care coordination [28,33] and of course, outcomes of clinical care provided [27,29,30].

Jakimowicz et al. [30] noted the conflict between system standards, benchmarking and the provision of PCC in a time poor environment. Consistently, the literature discussed the idea of measuring PCC as a method of quantifying this important element of nursing practice amongst the myriad of measurable tasks nursing time is allocated to. The need and ability to measure PCC is cited as crucial for quality improvement of care [31, 38]. This review excluded articles related to the measurement of PCC as the primary aim was to find how PCC was defined, however this was still very much a part of the discussion around the meaning and practice of PCC. Morgan and Yoder [31] discussed several measurement tools, finding them to align more with the *effect* of care rather than the care directly. Lawrence & Kinn [27] found that outcome measures used where often in line with the needs and requirements of clinicians, auditors and researchers, or hospital clinical outcomes [33], rather than with the goals of the patient. Outcomes vary from self-care, patient satisfaction, well-being and improved quality of care [28,31,38] to improved adherence and decreased hospitalisation [29]. This highlights competing priorities within the nursing profession and demonstrates that nursing time is conflicted between what they 'should' do and what they 'must' do, hence highlighting a nurses limited power to practice PCC in the context of the system standards.

Discussion

The review demonstrates that the concept of PCC is indeed a method of providing care, or the way in which nurses deliver care. To be person-centred, the nurse must recognise the person as unique, form meaningful partnerships, open a space within the doing of their day to involve and engage with the person, allowing the person control and power of their care.

It is interesting to note that while the existing literature covers a wide variety of clinical areas, and patient and staff perspectives, there were indeed core common themes of PCC. Despite the core concepts associated with PCC taking on more importance within certain clinical areas; for example, continuation of self in aged care [9,34], patient advocacy for intensive care [30], or communication in stroke care [27], they are consistent across specialities with the themes building on one another. Perhaps the reason why PCC has been so widely accepted is that the characteristics are simple, kind, human interactions, valuing both the person and the care provider. While definitions of PCC exist, there is no one universally used definition of PCC in nursing practice, potentially compounding a degree of separation between practice and healthcare systems. The findings demonstrate a tension between the theory and the conceptualisation of PCC, and as a result, the operationalisation of the term at both the practice level and a wider healthcare service level.

At the practice level, the theory/practice gap for PCC was evident. The theory/practice gap includes elements of practice failing to reflect theory, perceptions of theory being irrelevant to practice, and ritualistic nursing practice. Consequences of the theory/practice gap can greatly influence nursing practice and collaboration [40]. In the context of PCC, the theory/practice gap is apparent in the challenge of translating the ideas of PCC into a concrete concept. It is of significance that PCC is seen as 'extra' or additional to nursing tasks when these professional behaviours are in line with the Australian Nursing Professional Standards [8], which requires that they are an intrinsic element of the nursing profession. In fact, to be a registered nurse in Australia one must demonstrate respect for the person as the expert, respect autonomy and "*share knowledge and practice that supports person-centred care*" [8]. This highlights an important matter for consideration; why are core elements of PCC being viewed as 'going the extra mile' rather than a core competency for nurses? Certainly, from the perspective of the professional standards, PCC should not be the road less travelled, but rather the daily standard practice of nursing. One answer to this may be the task orientation of the contemporary nursing culture that sees nurses required to meet organisational time allocations for care [41]. Sharp, McAllister and Broadbent [42] uncovered a tension between PCC and nursing culture, finding that nurses were increasingly bogged down with tasks and processes, taking them away from the people that they provide nursing care for. These authors found that this led to a feeling of frustration and helplessness in nurses who appear to have accepted the culture of auditable, measurable activities and processes, particularly within the climate of organisational accreditation requirements. This activity-based nursing environment manifests in missed nursing care largely related to patient centred elements, e.g. discharge planning, communication within the healthcare team, absence of adequate patient education on key factors of care such as medication guidance, functional assessment and so on [43,44].

Further, it is apparent that the concept of PCC cannot be isolated from other philosophies of nursing practice and in fact, is embedded in other approaches to nursing care. For example, as outlined by Kim [45], nursing is defined by dimensions, rather than characteristics. If PCC is considered as a dimension, a complex, interwoven mix of characteristics, then it is possible to gain some concrete understanding of PCC in the context of all clinical areas. The five dimensions proposed by Kim reflect the 'human' side of nursing practice, and like the general interpretation of PCC, shows how human interactions, values and knowledge combine to provide care. Kim goes on to say that these dimensions vary with individual nurses and changing clinical situations; which seems to fit with the current confusion about PCC giving choice and decision-making power to patients. As found in this review, PCC attempts to balance the power between providers of care and receivers, giving choice and decision-making power. Yet the focus on nursing tasks and prioritisation of these tasks is evident, demonstrating the malalignment between concept and practice, where research has identified that the current task-oriented system of nursing does fail to meet the care needs of patients [46].

Nursing practice, however, is only one element of delivering PCC within the healthcare system. This disparity extends between the concept of PCC and its ability to exist within the current healthcare system itself, where time to care is explicitly rationed through budgets that do not allow for individualised person-centred care [47].

The notion of PCC is one centred on mutuality and a balance of power; a distinct move from the paternalistic biomedical model to a biopsychosocial model that is guided by the person, rather than the disease process. However, in current healthcare services, care is often system centred. That is, care is organised, funded and coordinated in a way that meets the needs of the system or service [28,33]. System fragmentation is understood to have significant influence on people accessing care, whereby people with long-term and complex conditions are most vulnerable to the negative impact from the lack of care coordination and cohesion [48].

In Australia, complex funding models are central to the concept of system fragmentation which begins at the Commonwealth and State funding levels [48], making it difficult for patients to navigate the system. System silos remain a significant issue for healthcare services and for the delivery of care, with Medicare models remaining fragmented for specialist services [49]. The States are the healthcare system managers, yet the federal government holds the responsibility of leading primary healthcare. This presents a challenge in provided collaborative and integrated services, particularly for those with long-term conditions [50]. The OECD highlight the importance of reducing system fragmentation in order to *'Improve the co-ordination of patient care.'* [50 p1].

Indeed, system fragmentation leads to an increased 'treatment burden', whereby poor treatment coordination, ineffective communication and confusion about treatments can contribute to poor health outcomes and greater levels of cost, time, travel and medications for the person [51] Sav et al. [51] discuss the need for individualised and coordinated services across specialities as a requirement for reducing treatment burden. In addition to this, the Australian Charter of Healthcare Rights prescribes the rights of those seeking care in any Australian service and includes the right to access, respect, communication and participation [52]. Accreditation of healthcare services is conditional to evidence of multi-level partnerships with consumers of health. Positive partnerships (PCC) are clearly linked to improved access to care, which in turn leads to reports of positive experiences and better-quality healthcare. Of critical importance at an organisational and government level, the standards also describe this partnership as a mechanism for reducing hospital costs through improved rates of preventable hospitalisation and reducing hospital length of stay [7].

Potentially Preventable Hospitalisations (PPH) place considerable economic and resource burden on the healthcare system, with approximately 47% of PPH being attributed to long-term conditions [53]. Thus, reducing preventable hospitalisation is a measurable target for healthcare services under the National Healthcare Agreement as a way of controlling the escalating costs of care and maintaining sound fiscal management of public services [54]. In line with the ACSQHC standard *Partnering with Consumers*, PCC has been introduced to some services as a mechanism for improving communication between services and those with long term conditions. What is less clear, is how care tailored to the individuals wants and needs of the patient (PCC), exists within a system predominately focused on reducing variation and the associated costs of care. While the philosophy of PCC naturally fits within the care environment, understanding how effective it is, how the person is included and how outcomes important to the person are captured, take a lower precedent to the measure of reduced hospital costs, self-efficacy and reduced hospitalisation. Capturing what is important for the individual presents a difficult task for services providing population-based care.

These system wide constraints provide a considerable challenge to nurses in their attempts to operationalise the concept of PCC. Nursing, it seems, has become task orientated, a sentiment supported by Foe & Kitson who found that nurses are constrained by a 'checklist' mentality, whereby completing and documenting tasks is seen as more important than engaging with the person [55 p100]. These tasks and checklists align with the requirements of the National Standards for hospital accreditation. An example of this is the need to collect data on the use of invasive devices or the allocated time intervals in which screening (such as skin inspection and falls risk) must occur; for example within eight (8) hours of admission [7]. Indeed, policy and procedure for nursing practice reflect that of the need of accreditation and national policy requirements as opposed to the needs of individual people. While partnering with consumers is an important element of the standards [7], quantifying the way in which healthcare services and indeed nurses engage with patients is less clear. Kitson states '*Nursing theory, it would seem, has been limited by the profession's ability to systematically document the complexity and richness of what happens when nurses and patients (and their careers) interact*' [35 p99], an issue it seems stemming from the fact that nursing interventions promoting person-centred, compassionate care are poorly described, with little to no consensus on the term, and interventions that do exist are poorly evaluated [56]. On top of this, nurses are generally not encouraged, nor enabled to reflect on practice in order to generate new insights and nursing practice [35]. Molina-Mula et al. [23], discuss the nursing profession as being the key to professional teamwork models, meeting the needs of patients and thereby increasing their personal decision-making capacity. However, it is possible that PCC is hindered by the level of professional autonomy, time and space afforded to nurses [57]. Indeed, the malalignment discussed herein, demonstrates that nurses may be hindered at higher levels of system compliance or difficulties in coordinating care services, which permeates nursing culture and ultimately nursing practice, limiting their ability to provide PCC that is individualised to the people seeking care.

Finally, while this review excluded articles related to the measurement and indicators of PCC, this is undoubtedly linked to its perceived meaning and how it is operationalised. This review demonstrates that the understanding of PCC is made up of how and where PCC appears in healthcare discourse and shows that PCC is potentially skewed by how it is(n't) measured and the outcomes that are(n't) reported as a product of PCC. This finding presents a framework within which further investigation of the concept of PCC (Meaning, Practice, Measures, Outcomes) within healthcare services could be undertaken. This proposed framework will be applied by the author to conduct further research into the role of PCC within nurse-led service for people with long-term conditions.

Implications for practice

This review highlights the dominant discourse around the concept of PCC yet uncovered the idea of malalignment between the rhetoric and the reality of the concept. Further exploration of the alignment between healthcare services and the goal of PCC may prove beneficial in ensuring the practice of PCC is fostered from all levels of the healthcare service. The above provides a rationale for why the definition of PCC should be provided, given that the concept is currently somewhat nebulous in nature. A consistent definition, with reference to all levels of the healthcare service including practice, will ensure that the concept stays true to the philosophy of compassionate and balanced care. Any definition provided should carefully consider how PCC is measured and prioritised within the healthcare system, which has the potential to move the concept from its current rhetorical nature, to a genuine commitment and priority of nurses and services. Lastly, the review provides a basis for the importance of nursing education and workforce development of the concept and the practice of PCC, given the apparent barriers that nurses may face in delivering PCC.

Limitations

This integrated review was limited to articles relating to the nursing profession and hence has excluded reviews on PCC in relation to other disciplines. Practice related elements such as procedure, service measures and outcomes of PCC were excluded from this review as the aim was to find a generalised way of defining the term. Furthermore, only one framework met the criteria of the search strategy and was included, there are however, several frameworks for PCC in nursing and hence some elements of PCC and their definitions may have been excluded.

This review was performed with published literature only, with no investigation of grey literature undertaken. PCC is often discussed in healthcare service literature, including procedure, service profiles and service strategy. This information will undoubtedly have an impact on how nurses understand and practice PCC within their own area and within their service. This review was designed to investigate a universal definition of PCC as described in the literature and hence chose to limit this to an academic search. The practice of PCC from a policy to practice perspective perpetuates meaning and will be the subject of further research for the author.

This review was conducted as a starting point for the author's research higher degree (PhD) studies, and hence the search strategy and quality processes were completed by one person. All elements of the review were discussed at length with academic supervisors to ensure adequate rigor and accuracy throughout the search, review and integrative process.

Conclusion

The concept of PCC is well known to nurses, yet ill-defined and operationalised into practice. Healthcare service policy and care provisions, and indeed nursing services, need a clear definition of PCC in order to work toward embedding it into practice and into models of care in a meaningful and genuine way. However, PCC is potentially hindered by its apparent rhetorical nature, and further investigation of how PCC is valued and operationalised through its measurement and reported outcomes will serve the philosophy of PCC well. Investigation of the literature found many definitions of PCC, but no one universally accepted and used definition. Subsequently, PCC remains conceptional in nature, leading to disparity between how it is(n't) operationalised within the healthcare system and within nursing services. In light of the malalignment discovered within this review, a universal definition of PCC is not provided herein; instead, this review highlights the need for further investigation of PCC between the levels of the healthcare service (at the micro, meso and macro levels) and how this influences the critical work that nurses do in supporting people through their healthcare journey.

Supporting information

S1 File. PRISMA checklist.
(DOC)

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Moving the Literature Review Forward

The literature review has found that *people, power,* and *practice* are fundamental to how PCC is defined and practised within the nursing profession, highlighting a misalignment between rhetoric and reality. The literature review provides justification for why the definition of PCC should be provided, given that the concept is currently somewhat nebulous in nature. A consistent definition, with reference to all levels of the healthcare service including practice and system change, will ensure that the concept stays true to the philosophy of compassionate and balanced care. Any definition provided should carefully consider how PCC is measured and prioritised within the healthcare system.

What has emerged from the above literature review is that there are different interpretations of PCC depending on the level of hierarchy. For example, views of PCC are seen to differ between the written policy, organisational implementation, and on-the-ground action. What this discrepancy suggests is that there are separate actions of how PCC is represented depending on who has control of it.

Chapter Four—Philosophy and Methodology

> Historical descriptions are necessarily ordered by the present state of knowledge, they increase with every transformation and never cease, in turn, to break with themselves (Foucault, 1972, p. 5).

Summary of Chapter

This chapter describes the methodological design applied to the research. It details and positions the population group used for the research, as well as positioning the researcher. This chapter introduces and explores the use of Foucault's notions of governmentality and biopolitics which act as the philosophical lens of the research. The chapter explains in detail how the philosophy, methodology, and methods combine to explore and interrogate the concept of PCC within the NN service.

Methodological Design

To unravel the views and counterviews of what PCC is and is not across social orders, Foucault's view of relational, interactional, and contextual power underpins this study (Foucault, 1987a; 2001; 2008a). The research scrutinises hidden and multiple truths around the concept of PCC and the conditions under which this concept is legitimised. This includes the social spaces created the problems and solutions that are simultaneously proposed and addressed through government discourse, and the effects this has on stakeholders in society.

A review of the literature undertaken for this study identified that while patients are the focus of PCC, they have the least control over it. The meaning and practice of PCC is clouded with multiple interpretations, highlighting a disconnect between rhetoric and practice and suggesting the need for a space to be created for the delivery of PCC (Byrne et al., 2020). Moreover, it has been found that the descriptions and understanding of PCC in government documents are not consistent (Sobolewska et al., 2020).

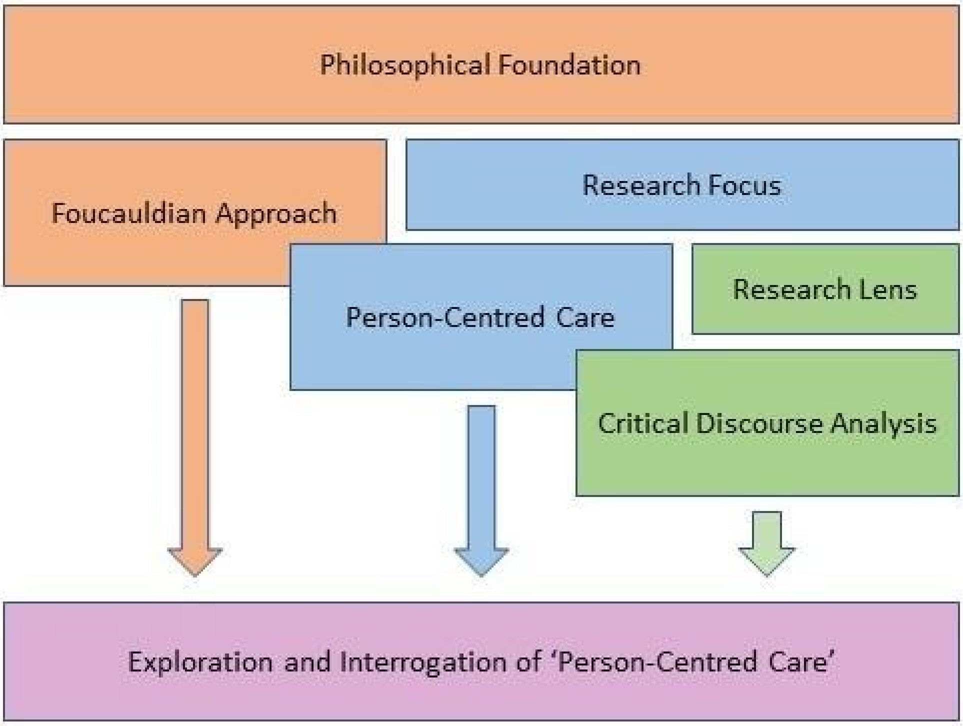
The government, as the broker of healthcare delivery, has directed that PCC be implemented across the healthcare system. This research is therefore an exploration and analysis of the political, biopsychosocial, and individual worlds that exist under the banner of PCC for those delivering it to vulnerable populations. My research explored PCC in the health care setting by pursuing the following questions:

(1) Under what conditions and circumstances does PCC exist?
(2) How is PCC expressed?
(3) What technologies legitimise PCC?
(4) What social brackets does PCC exist within but also create?
(5) What impact does PCC have on society, people accessing health care, and health workers providing that care?
(6) What are the enablers and barriers to PCC in practice, and how do these influence genuine partnerships?

The investigative method adopted for this study was guided by Fairclough who advises the use of CDA to examine power differentials within society and the effects that discursive practices have on the different levels of social orders (Fairclough, 2001).
To better understand the ontological focus and theories underpinning this research,
I have explained in detail the philosophical foundation, methodology and method as summarised in Figure 2 below.

Figure 2

Research methodology



Note: From *Health (il)Literacy: Structural vulnerability in the nurse navigator service,* by A-L. Byrne, C. Harvey, & A. Baldwin, 2021, *Nursing Inquiry,* Ahead of Press, https://doi.org/10.1111/nin.12439

The intent of this investigation is not to provide a judgement on, or to propose any particular alternative to the concept of PCC, although this will form a part of the discussion, but instead to bring to light the conditions under which PCC exists, and thus how alternatives may be possible. To achieve this, my analysis of discourse is juxtaposed with examples of alternative social worlds that bring together the experiences of people, their backgrounds, and their world views as influencing their perceptions of PCC (Povinelli, 2011; Fairclough, 2001). CDA departs from the conventional research process, in that analysis and discussion occur and are presented simultaneously, to provide a robust and rigorous exploration of a social construct. This leads to a significant impact at the level of the individual; the citizen, the person (Fairclough, 2001). Thus, this research is presented in an atypical format to that of a traditional thesis.

Figure 2 provides an overview of the research approach, depicting how the philosophy, research focus and research lens merge together throughout the research.

The underpinning philosophical framework is that of Foucault’s governmentality and biopolitics (Foucault, 2001; 2008b). Although PCC should place the person in the centre of care and decision making, the literature found that this was not always the case. This thesis uncovers differing views of PCC depending on location of care and the positioning of the patient within that care; therefore, Foucault’s views have been used in this study.

A Foucauldian Informed Philosophy: Governmentality and Biopolitics

Michel Foucault (1926–1984) was a French philosopher associated with post-structuralist and post-positivist approaches to history and research. Post-structuralism is an ideology that centres on a critique of the logical structures that underpin social institutions such as politics, economics, healthcare, and science (Crick, 2016).

Foucault’s philosophies were oppositional to the rise of the structuralist views which were further solidified post World War II. Despite being born into a wealthy family, Foucault had a particular disdain for bourgeois society, morality, and culture, believing it to be responsible for the marginalisation of groups. Foucault became a beacon of political activism, particularly in the 1970s, however his entire life and works were dedicated to challenging power, knowledge, political influence and naturalised truth. Foucault positioned himself within the critical enquiry of philosophy. He was influenced by the works of Kant, Bataille, and Blanchit in his belief that any given subject is the product of historical, social, and political (among other features) influences, and not purely metaphysical. Foucault was influenced by Friedrich Nietzsche’s concepts of the history of the body and the relationship between knowledge and power.

Foucault used Jeremy Bentham's Panopticon as a concept for philosophical reform and social activism. The notion of surveillance, power and control fuelled his critical view of society, with reference to inequality, domination, and social norms. Foucault explains:

> The critical ontology of ourselves has to be considered not, certainly, as a theory, a doctrine, nor even as a permanent body of knowledge that is accumulating; it has a to be conceived as an attitude, an ethos, a philosophical life in which the critique of what we are is at one and the same time the historical analysis of the limits that are imposed on us and an experiment with the possibility of going beyond them (Foucault, 1987b, p. 50).

Foucault offered a new way of thinking around the concept of enlightenment. He defined enlightenment as a "modification of the pre-existing relation linking will, authority, and the use of reason" (Foucault, 1987b, p. 35). Enlightenment, and the idea of reason, is seen by Foucault as a political problem. Foucault describes Kant's conclusions on enlightenment as a "rational despotism with free reason," where the best guarantee of obedience and conformity will be to allow autonomous reason if it is within the limits of universal reason (Foucault, 1987a, p. 37). Herein, Foucault proposed questions to delve within and outside of the political, social and cultural spheres of influence; "How are we constituted as subjects of our own knowledge? How are we constituted as subjects who exercise or submit to power relations? How are we constituted as moral subjects of our own actions?" (Foucault, 1987a, p. 49).

Foucault's concept of power differs from traditional notions. Power is not something that is owned and divested, thus it is not a sovereign act; rather power is everywhere and is neither a structure nor an agency. Foucault explains the mobilisation of power as the perpetuation of truth:

> Truth is a thing of this world: it is produced only by virtue of multiple forms of constraint. And it induces regular effects of power. Each society has its regime of

> truth, its ‘general politics’ of truth: that is, the types of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true (Foucault, 1987a, p. 73).

Power is a central theme for Foucault and for critical social enquiry, thus I have continued to come back to the notion of power throughout this chapter.

Foucault offers a profoundly social and critical view of any given topic or issue. In the context of those who occupy dominated social spaces, for example patients, Foucauldian enquiry provides a platform to investigate how historical, social, and political mechanisms influence the spaces and roles that actors can occupy. This is particularly relevant to the notion of PCC, which at face value aims to balance the power between the dominator and dominated. Two Foucauldian concepts that fit with the inquiry of PCC, and in particular the exploration of actors, power, and domination, are governmentality and biopolitics.

Governmentality

Central to Foucauldian philosophy is the idea that access to power and knowledge shapes society; knowledge is created by those in power, the discourse from which becomes a norm in everyday practice, so that the rules of our societal systems both constitute and are constituted by what we know and accept to be. These societal systems, including rules and governance set forth by a ruling body, contain an order of discourse that is adopted by society and accepted by people as the norm (Foucault, 2001). This is what forms the basis of the creation and the formation of knowledge (Hook, 2001). Foucault expressed that there are, always, multiple truths in society, created by those in power but also challenged by those existing within it. Dominant truth claims are perpetuated through discourse (as action and text), and constantly ordered and reordered through societal systems such as science, education, law, media, economic ideologies, and ultimately perpetuated through an unconscious acceptance by the general population (Rabinow, 1987). In this way, *the truth* is shaped and reshaped through the discourse of everyday life (Fairclough, 2009). These truth claims can be accepted or challenged, and it is these tensions within society that create a space to examine what is, and what needs to change (Hook, 2001). Thus, truth is not a single point of power, but rather it transcends politics and institutions to become a socially formed phenomenon (Foucault, 1991a). The concept of PCC centres on the idea that the person is fundamental to decision making (Slater, 2006) and capable of making such decisions (Morgan & Yoder, 2012). However, the practice of PCC is also informed by the nurse and the organisation (Byrne et al., 2020, p. 12). It can be argued therefore, that PCC is both an object and a subject, influenced by interpretations handed down through levels of health care hierarchy (Byrne et al., 2020).

Governmentality takes place in a period of neoliberalism. The era of neoliberalism is primarily focused on free markets; “the freeing of markets from state intervention and regulation” (Fairclough, 2013a, p. 11) which places priority on reducing state responsibility for providing social welfare. Fairclough describes this as a:

> Restructuring of relationships between economic, political, and social domains including the extension of markets into social domains such as education and focusing the role of the state government on strengthening markets and competitiveness (Fairclough, 2013a, p. 11).

Governmentality is referred to as the conduct of conduct, describing a state of administration in which control by those in power is divested to the population through knowledge transference in the form of codes of conduct and ways of being. This is achieved using what Foucault terms *Techne*, or technologies, which are the methods and tools that governments use to mobilise any given truth. An example is the policies that the government provides to direct health services on the practice of PCC. Rose (1996) describes technologies as:

> Assemblages of social and human relations, hybrids of knowledge, instruments, persons, systems of judgement, buildings, and spaces, structured by a practical rationality governed by a more or less conscious goal, and underpinned by certain assumptions about human beings (p. 26).

Foucault says that technologies can be broadly categorised as technologies of economy, technologies of illness and cure, technologies of susceptibility, and technologies of enhancement (Rose, 2007). Technologies function together, and each one requires modification of individual skills and attitudes. Thus, PCC could be described as a technology of illness and cure. However, it could also be that of economy, i.e., the reasons for creating policy that supports better utilisation of health care services; or a technology of enhancement through the patient using power to enhance personal control over health care provision.

Governmentality dictates how subjects (people in society) act and behave (Muller, 2017). The governmental regime of power forms complex systems and institutions (orders) which target the population (people) to assume the role of actors within a societal order (Foucault, 1991b). These actors within society are all subject to the power of government. The government captures our attention and feelings of inclusion by giving us the freedom to take on a policy or act, thereby giving it meaning in our everyday world. Thus, actors perpetuate the government’s bidding through our institutions such as schools, police, laws, and health; although we have been given the freedom to implement it, we also conform to it. Flaskas and Humphreys (1993) identified power as unavoidable because it exists throughout all social relationships. Power is also recursive and perpetuated in society (Fairclough, 2001). The ideology of those in power transcends both institutions and customs (Burchell et al., 1991). In simple terms, governmentality is the power over the household, by way of measures and institutions or *Techne*, which form our understanding of any given social order, and hence our behaviour within it (Davisch & Vanheule, 2014). It assumes that a person (or patient) will choose to behave in a certain way because they have been conditioned to do so, even though they believe it is their own choice (Foucault, 2007).

Biopolitics

Governments in Australia manage all public health services. They decide on how services are to be provided and what is to be funded through annualised central budgets, policy and the promulgation of acts related to service and practice (AIHW, 2016). Health services provide care to people who need medical and health support. Foucault (2008b) refers to the production of the social body (or population) as Biopolitics; a driving force in the creation of conduct, order, and policy. Foucault's position in this is described in the following quotation:

> The disciplining techniques of the liberal state articulate the population as a collection of productive bodies, risky bodies, consumptive bodies, and so on and focuses on strategies to optimize [*sic*] these capacities … Biopolitics refers directly to the biological body and considers governance of the self, health and well-being, issues of longevity, birth, and mortality … (Muller, 2017, p. 8).

Biopolitics and Governmentality enable the "examination of how power is associated with certain forms of knowledge through discourse" (Butler, 2019, p. 1). Biopolitics is not simply about ruling, but rather how ideas, ways of being and controls are embedded into social constructs in the context of bodies and health. It allows professionals, such as those in health care, to have the right to own the knowledge that the institution has created or developed and enact this on the government's behalf. This in turn enables the individual to self-regulate their actions based on the knowledge provided to them, and thus the common acceptance of a problem is achieved. This level of self-surveillance/agency ensures that subjects become responsibilised and self-policing, hence upholding the construct of government (Crossley, 2005). The subtlety of governmentality and biopower is such that the exercise of power is deeply ingrained through society and is seen as normal, thus it transcends political power. Zuckert (1995) described it thus,

> Taken as a whole, the modern state apparatus exercised much less evident coercion than medieval monarchs, but it has much greater power to shape and determine the lives of its individual citizens (p. 187).

The investigation of historical factors, tools and strategies is what Foucault describes as an archaeology of knowledge, with the investigation of the mechanisms of power being a genealogy of knowledge; these allow researchers to look back in history to understand the situation today (Foucault, 1972). Thus, Foucault (1972) says that no decision can be made today without knowing how it became:

> The analysis of the discursive field is orientated in a quite different way; we must grasp the statement in the exact specificity of its occurrence; determine its conditions of existence, fix at least its limits, establish its correlations with other statements that may be connected with it, and show what other forms of statements it excludes (p. 28).

Foucault describes several methods to achieve a historical analysis and genealogy of knowledge on a given topic. Foucault describes methods such as the analysis of power dynamics between a person and the intended audience, analysis of authority, identifying points of incompatibility in discourse, and exploration of the function, the rules, and conditions the discourse requires to be appropriate and legitimised (Foucault, 1972). Foucault described his work as a toolkit available to researchers and this is how I have used his work (Foucault, 1981). Building on from this framework, the use of CDA is a logical approach to my study.

Critical social theory

Critical Social Theory (CST) (which includes discourse analysis) revolves around people and is concerned with the inequalities and injustices within everyday social arrangements. The agenda of CST is transformative; The evaluation of political activity involves assessing how things may be changed for the improvement of those with less power within society (Freeman & Vasconcelos, 2012). This is achieved through a reflective and critical assessment of dynamics and relationships between the economic, political, and social systems that define how people live. Critical social theory challenges historic and emerging ideologies by exploring the perceptions and experiences of those within society (Freeman & Vasconcelos, 2012). This critique and interrogation provides a platform on which researchers can take action toward transforming existing social forms to improve conditions for those within them (Manias & Street, 2001). This thesis does not follow the work of any particular critical theorist, but is instead critically orientated, commensurate with and guided by a Foucauldian lens. This stance is particularly suited to this study as it explores the power within and behind the discourse of person-centred care; a concept which discursively aims to balance the power between care provider and receiver. The allows for the exploration of the topic in a broad sense, allowing for the analysis to consider many critical theories, which are applied in the discussion. This critical orientation supports the investigation of the term person-centred care across the micro, meso and macro levels of the social orders. Foucault’s approach to power, society and truth fits within the CST agenda and provides an intricate link between investigation and social change (Wandel, 2009). Critical discourse analysis (CDA), a methodological framework, provides the avenue for the investigation of language, text, and discourse across social, economic, and political orders (Fairclough, 2013a; 2013b).

Critical Discourse Analysis

> Critical discourse analysis is essentially dealing with an oppositional study of the structures and strategies of elite discourse and their cognitive and social conditions and consequences, as well as with the discourses of resistance against such domination … it goes beyond the usual methodological criteria of observational, descriptive, and explanatory adequacy (van Dijk, 1995, p. 19).

Critical discourse analysis has become the general, umbrella term for an approach to the exploration of text and talk. Evolving from linguistics, CDA takes a “socio-political conscious and oppositional way of investigating language, discourse and communication” (van Dijk, 1995, p. 17). While there are different methodological approaches to CDA, the usual characteristics of such a study follows a criterion of:

- Being problem focused rather than paradigm-orientated;
- Has a focus on relationships between discourse and society;
- Focuses on relations of power, dominance, and inequality;
- Explores underlying ideologies; and
- Attempts to uncover what is implicit or hidden in the relationship between discourse and ideology (van Dijk, 1995; Wodak & Meyer, 2008).

Critical discourse analysis is generally not characterised as a school of thought, but rather an approach to studying discourse (van Dijk, 1995). Approaches can vary, for example, mediated discourse analysis (Scollon, 2001), discourse-historical approach (Wodak & Meyer, 2008), social actors’ approach (van Leeuwen, 2008), socio-cognitive approach (van Dijk, 2009), normalisation of discourse (Krzyzanowski, 2020) and dialectical-relational approaches (Fairclough, 2015). What CDA theories share is the principle that language is a social practice which is simultaneously determined by social structure and contributes to maintaining or changing the social structure (Wodak & Meyer, 2008; Krzyzanowski, 2016). Indeed, CDA researchers primarily investigate the way discourse reproduces power domination over others, in this case nurses and patients, and how these dominated actors may resist (Wodak & Meyer, 2008; Wodak & Krzyzanowski, 2008).

While there are many parties involved in CDA, I prefer the work of Fairclough and his definition:

> By ‘critical’ discourse analysis, I mean discourse analysis which aims to systematically explore often opaque relationships of causality and determination between (a) discursive practices, events and texts, and (b) wider social and cultural structures, relations and processes; to investigate how such practices, events and texts arise out of and are ideologically shaped by relations of power and struggles over power; and to explore how the opacity of these relationships between discourse and society is itself a factor securing power and hegemony (Fairclough, 1995, p. 132).

Wodak and Meyer describe Foucault as a theoretical “godfather” of CDA, seeing text as a manifestation of social action which is determined by social structures and norms (2008, p. 10). Foucault’s philosophy is that power is a systemic characteristic of society and that through government technologies, it is exercised with intention aimed at the level of population, not the individual (Wodak & Meyer, 2009). Thus, technologies strategically serve a social function.

In the case of this thesis, the health care system is a government institution charged with caring for the population, while sustainably managing finite resources. Text within the institution harbours obvious as well as hidden relationships of power, control, and ideology. Waller (2006) explains; “discourse can define the roles of social actors—as someone who can (or cannot) bring about a change in a condition or as those who are (or are not) knowledgeable” (p. 7). Text production and dissemination are seldom the work of one person and discursive differences are negotiated through text and action thus CDA allows for the investigation of power, social orders, hidden truth, oppression, and social inequality (Wodak & Meyer, 2009).

Positioning the Researcher; Analyst, Nurse, Citizen, Person

> Interpretations are generated through a combination of what is in the text and what is 'in' the interpreter, in the sense of the members' resources which the latter brings to interpretation (Fairclough, 2015, p. 155).

Within social research, the competing epistemologies, and ontologies "[require] researchers to consider their own orientation to knowledge and truth" (O'Leary, 2017, p. 6). This is particularly important when using CDA as the researcher becomes part of the findings. This needs to be acknowledged and the analyst must be able to step aside when examining discourse (Fairclough, 2001). Ontology refers to the nature of the person's reality, giving rise to what there is to know about the world (Agarwal, 2015). Ontology is inclusive of the individual's existing assumptions and how these are used to view the world (Baldwin, 2014) which provides insight into what we think "exists" (O'Leary, 2017, p. 5). Epistemology is concerned with ways of knowing about the world and focuses on learning and reality and what forms the basis of our knowledge (Agarwal, 2015). A personal epistemology points to how the person comes to understand the world (O'Leary, 2017) and how that person believes that knowledge is gained (Baldwin, 2014). In addition to this, axiology refers to a researcher's values and ethics (Wahyuni, 2012). This can be broadly summarised as "situating oneself in the world" (Baldwin, 2014, p. 3), therefore I have provided a summary of my background, my experiences, and the positioning on which I have formed my views of the world and my stance for this research.

I was born in a rural area of north-west New South Wales, Kamilaroi Country, and spent my early childhood roaming around rural and isolated areas. My father was a cotton farmer and we moved by season. We eventually settled in the Hunter Valley where

I completed school and university, the first in my family to do so, and I earned my Bachelor of Nursing in 2008. After working for several years in busy metropolitan hospitals and emergency departments, marrying a fellow nurse, and having two children, I felt the call of the outback. In 2015, I moved my young family to a remote outback town called Dirranbandi, Queensland and we quickly fell in love with the region. It was during my time as a remote area nurse that I found my passion for long term, chronic conditions, and health disparity. Inequity of access and socioeconomic vulnerability became very apparent to me as chronic conditions are rampant in the area. Travel to specialist appointments was incredibly complicated and laborious and people would return to the community exhausted, relieved to be home, often vowing to never return to the city. While the disparities of rural/remote health were clearly apparent, I was also struck by the unique opportunities available to the health service of smaller population sizes which allowed for care to be flexible and individualised and provided by nurses who really belonged to the community. I was both energised and inspired by the people I met and with whom I worked.

My family and I later pursued opportunities in Townsville, Bindal and Wulgurukaba Country, Birragubba Nation, where we entered back into the metropolitan style health care system; my husband as a frontline nurse and myself as a nurse consultant. Several differences can be observed between remote and regional/metropolitan services, namely the acuity, volume of people and pace of the services provided, and I observed these differences in my own practice and the practice of others. I became acutely aware of the motivation to discharge, to ensure compliance in the digital electronic medical record, and just how little authentic time the nurses were able to spend with the person. Location aside, the profession of nursing and the art of caring that is person-centred should remain the same. Thus, NNs, who are state-wide, from all locations, services, and with varying personal and clinical backgrounds are suitable for the investigation of PCC.

Research itself holds power and is not immune to the political and social climate it is located within (O'Leary, 2017). For qualitative methods, the researcher must consider themselves in relation to the research and decisions made through the process. They are as much a part of the discourse as the research itself. Foucault explicitly explains that the analyst/philosopher is herself part of this process (Foucault, 2008a). The researcher thus has the responsibility to show how they are a part of the process as both an element and an actor. In line with this, Fairclough states that exploration of text is a "matter of seeing discourse as part of a process of social struggle, within a matrix of relations of power" (Fairclough, 2001. p. 163). Fairclough (2015) described the researcher as an "insider"; however, there is a distinct need to be conscious of the analysis and decision made.

I have held several positions within my career, from a frontline nurse to a nurse manager and nursing director addressing health services strategic vision through initiatives, frameworks, compliance measures and metrics. I am now a lecturer and researcher, teaching the next generation of nurses the art and science of nursing. I have existed in different social spaces within my career, though one social space I have not occupied is that of patient. Each social space exists between differing ideological positions (Fairclough, 2015; Wodak & Meyers, 2009) where context and interpretation are important. It is vital, therefore, to be aware of several elements that I will bring to analysis and interpretation. These include the typology of social situations, types, and groups that I belong to or have belonged to, the power I have held and continue to hold around this topic, and what is 'in' me as an interpreter, my background knowledge, and ideologies, which Fairclough refers to as "members resource" (Fairclough, 2015, p. 155). There is, however, an obligation to be aware of sensitive information and be careful to remain objective (Saidin & Yaacob, 2016) through recognising my own assumptions and rationalisations, and to work within the gaps between theories and society (Fairclough, 2015). For these reasons, I have identified myself as the analyst and part of the research itself; I position myself as a conscious insider.

Positioning the Researcher Within the Data Population

This thesis draws data from a wider research project evaluating the efficacy and sustainability of the NN service across Queensland (Harvey et al., 2019). The relationship between the evaluation study and my own research is discussed in detail in Chapter Five. From the literature review undertaken for this research, PCC has been applied without considering its implementation (Byrne et al., 2020). There is a lack of consistency in the definition of PCC and its application by health professionals.

My research is a starting point for investigating the barriers and enablers to achieving PCC in practice, through exploration of its implementation and how it came to be.
As Foucault, (1972, p. 4) says:

> The history of the concept is not wholly and entirely that of its progressive refinement, its continuously increasing rationality, its abstraction gradient, but that of its various fields of constitution and validity, that of its successive rules of use, that of the many theoretical contexts in which it developed and matured.

My research explores the views presented by Molina-Mula et al. (2018) and Rushton and Edvardsson (2020) who state that nurses can “break the rigid design of sections or professional skills and adopt a model of teamwork that meets the needs of the patient and increases their decision-making power” (Molina-Mula et al., 2018, p. 2), but that further exploration of factors which inhibit nursing practice of PCC is needed. Indeed, the extensive research of Rushton and Edvardsson (2020) concluded that further analysis of the “mechanisms, procedures, instruments, techniques, technologies and vocabularies, or *Techne*, of government, relevant to person-centred care that are used to conduct the conduct of nurses and impose limits on what nurses can and cannot do*”* is needed to further drive the agenda of PCC; and so, I carry the baton forward.

In summary, this thesis will investigate the notion of PCC in relation to NN, who care for those with multiple chronic conditions. Person-centred care exists within our current and past histories, and while it attempts to balance power for patients, it must move beyond the rhetoric. Foucault's notions of governmentality and biopolitics are well placed to investigate how the discourse or PCC forms part of a social order that may (not) improve the lives of marginalised people.

Chapter Five—Exploring Person-centred Care Through Text and Action

> A social institution is (among other things) an apparatus of verbal interaction or an order of discourse (Fairclough, 2013a, p. 40).

Summary of Chapter

This chapter defines the study design, using Fairclough's analysis of power across orders of discourse in society. Discourse is the sum of text and action that makes up societal life and activity (Fairclough, 2001). Critical discourse analysis as a methodology connects language analysis to the study of society and supports the search for holistic and social meaning that is often hidden and taken for granted, and is part of everyday life (O'Leary, 2017). Critical discourse analysis's ontological focus centres on the understanding that a person's experiences and outcomes are constructed by discourse (Fairclough, 2001). The subject can then be uncovered and understood in ways that have not been considered, to allow for alternative meanings to be explored and adopted (Evans-Agnew et al., 2016).

Applying Critical Discourse Analysis

Critical discourse analysis is concerned with how power operates behind and within discourse. The power that is investigated is not just persuasion or manipulative, but is ideological in nature (Wodak & Meyers, 2009). Therefore, discourse is viewed as a stake in social struggle. Critical discourse analysis raises to consciousness how language contributes to the domination of some citizens by others (Fairclough, 2015). Language is driven by social conditions and the relationship between the participants, in other words, "social conditions determine properties of discourse" (Fairclough, 2015, p. 53). These ideologies can, and do, become dissociated from their social base as they become naturalised into the order of society. Language and action are central to this process as the ideology is perpetuated and becomes embedded into the social context. Therefore "micro" or local level interactions are dependent on a higher "orderliness" (Fairclough, 2013a, p. 37).

Person-centred care represents a specific ideology within healthcare. This ideology permeates the people within the healthcare system and forms the basis for partnerships and for practice; both the practices of the healthcare professionals and the practices of the patient (Byrne et al., 2020).

Critical discourse analysis is particularly well suited to the investigation of discoursal strategies, i.e., strategies that are formed by the government which are designed to mitigate the effects of any government crisis or issue and strategies for the longer-term repair and modification of neoliberal capitalisms (Fairclough, 2013a). Critical discourse analysis has a significant role in the investigation of strategies as they are strongly discursive in nature, and they encompass imaginaries of change for new practices and systems. Of particular importance to PCC is the fact that the critical exploration of strategies includes the interrogation of "narratives and arguments which interpret, explain and justify the area of social life they are focused upon; its past, its present and its possible future" (Fairclough, 2013a, p. 18). The goal of CDA in this context is grounded in the investigation of humanistic wellbeing, which is achieved through exploring growing inequalities of wealth, growth, and security (Fairclough, 2013a). Critical discourse analysis allows for the investigation of the "emergence of discourses" (p. 19), and links this to future practices and systems. "Critical discourse analysis can provide particular insights into the struggle between different strategies for transforming society through rhetorically orientated analysis of how strategic differences are fought out in dialogue" (p. 19). Fairclough describes this form of knowledge production as "value-driven" (p. 20) in that this form of interrogation uncovers how social forms can simultaneously enhance wellbeing, and for others, place limits on it (Fairclough, 2013a).

Analysis of discourse across Fairclough's social orders (2001) allows for the investigation and discovery of disparity. For this study, PCC is identified across three levels of social orders: government, service, and nurses (see Table 2 below). Macro level analysis will include regulations and government driven frameworks which provide guidance for the management of PCC (specifically relating to chronic disease and PCC) from a system level. The meso level analysis will consider those in charge of creating procedures for the delivery of care within which PCC is located, viz., the health service. Analysis of the micro level examines the practices of PCC within the nursing profession and within the NN service. The micro level includes NN narrative from the evaluation study of NNs (Harvey et al., 2019) which includes NNs from across all 16 HHSs in Queensland, within metropolitan, regional, rural, and remote locations. Thus, this analysis uncovers the hidden conditions and circumstances of PCCs existence by looking for differences and similarities in how PCC is described, interpreted, and enacted. Table 2 demonstrates how the social orders of discourse guide the analysis, while Table 3 provides my sampling inclusions and exclusions for the research.

Table 2

Overview of social orders and orders of discourse to be examined

Social Orders	Orders of Discourse	Sources of Discourse/Data
Micro (Nurses and Nursing Practice)	Nursing Practice and PCC in motion	• Interviews with NNs • Media reports • Nursing organisations and clinical body reports and associated discourse.
Meso (Health Services in Queensland)	Health organisation, leadership, and strategy	• Hospital policies • Models of care and procedures • Economic data • Quality initiatives and management of care • Emergency department utilisation • Data and other hospital metrics as collected by the evaluation study.

Social Orders	Orders of Discourse	Sources of Discourse/Data
Macro (Government and Health Service)	Political climate and environment internationally and nationally Government views and directives	• International and National regulations, policies, strategies, and frameworks in relation to PCC, chronic disease management and NNs • Parliamentary Hansards • Health service enquiries.

Note. Adapted from *Language and Power*, (3rd ed.) by N. Fairclough, 2001, Pearson Education Ltd.

Table 3

Sampling inclusions and exclusions

Inclusions	Exclusions
NN positions listed above	Midwifery Navigators[3]
Nurse Practitioners employed as NN/NP	Nurse navigator positions defined to a specific service or niche area which do not necessarily demonstrate navigation from their immediate service. For example • Perioperative • Inpatient flow • After Hours • Medical Imaging • Pre-admissions[4].
All Queensland Health HHSs, including metropolitan, regional, rural, and remote locations	Non-government services included in the data collection but outside of the navigator service, for example: • National Disability Services • Primary and Community Services • Social Prescribing Services • General Practice Nurses.

This framework allows for analysis of experiential, relational, and expressive values of PCC as it is presented, understood, and implemented by players located at different levels of the healthcare hierarchy (Fairclough, 2001). PCC can be examined through the

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[3] Midwifery is a unique and separate profession from nursing, with its own defined philosophy of ‘women centred care.’ Thus, the sample has excluded midwifery data.

[4] Funding is provided to each individual Hospital and Health Service (HHS) from the Office of the Chief Nursing and Midwifery Officer (OCNMO) for a defined number of navigators. While a toolkit and suggested guidelines exist for the service, the HHS is free to implement nurse navigators as they see fit for their services. Some metropolitan services have thus used navigator positions for more acute inpatient areas, filling the needs of locally defined specialties but not necessarily staying true to the navigation model set out by the toolkit.

relationship that occurs between the social orders and the orders of discourse (see Table 4). The focus of analysis is on PCC as it is situated within the social orders, the meaning for which is replicated and reproduced through action and text by the players, in this case NNs. Thus, how NNs understand PCC and adapt it to the management of care, is influenced by micro, meso, and macro forms of power and discourse. In this way the analysis of the discourse can identify how hidden dominance endures through the health system, and how NNs adapt to it, given that their focus is supporting patients through the system which we know to be fragmented.

Table 4

Overview of formal features and relationships of discourse to be analysed

Dimensions of meaning	Values of features	Structural effects
Contents	Experiential	Knowledge/beliefs
Relations	Relational	Social relations
Subjects	Expressive	Social identities

Note: Adapted from *Language and power*, (3rd ed. p. 131) by N. Fairclough, 2015, Pearson Education Ltd.

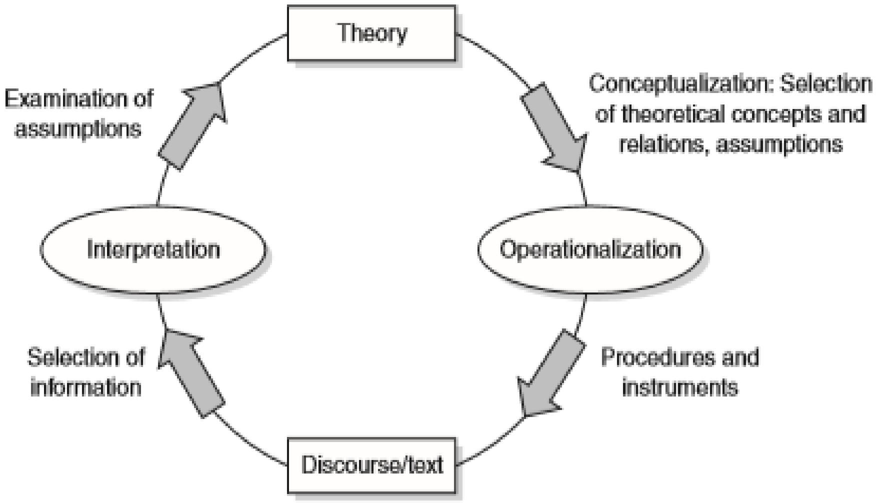
Critical discourse analysis is a methodological framework under which different methods of data collection can be used. Indeed, multiple methods of data collection across various levels of discourse allows for better validation of data for complex social issues (Fairclough, 2001).

To achieve this, a progressive analysis across the social orders occurred. Documents were analysed under the framework defined in Table 2 using several analysis techniques. Analysis techniques varied and included lexicon choices and linguistic meaning, classification of social actors and authorities, the functionalisation of the text, mapping, and comparison of texts. These techniques were used at the level of the text and were then considered in relation to their experiential, relational and expressive features. This process thus allowed for the exploration of the structural effects of the concept, including what knowledge, social relationships and social identities are created (see Table 4).

Critical discourse analysis is strongly based in theory (Wodak & Meyer, 2009). Indeed, data collection, analysis, interpretation, and theory occurred in an iterative and constant process. Figure 3 demonstrates the circular process of CDA.

Figure 3

Critical discourse analysis as a continuous process



Note: From *Critical discourse analysis* (p. 24) by R. Wodak & M. Meyer, 2009, Sage.

This circular process was used when accessing and analysing data sources. This ensured that analysis occurred across a wide variety of texts and discourses, throughout the social orders. The constant and iterative process of CDA ensured that the ideologies embedded within the discourse and hidden truths became apparent with the analysis and discussion.

Ultimately, every action and occurrence of language and ideology contributes to the production of macro structures. Within the institution, the person is not necessarily a member, but an outsider that takes part in institutional interactions in accordance with the social norms and rules. My thesis thus demonstrates how people make discourse and discourse makes people (Fairclough, 2013a; Wodak, 2008).

Ethics Clearance and Access to Information

This research received ethical clearance through the Central Queensland University Human Research Ethics Committee application number 0000021623 on the 8th October 2019 (see Appendix C). This clearance allowed me to access data and interviews from the state-wide NN evaluation, a separate study in which I was involved. To demonstrate how research bias was reduced and anonymity was maintained, I will describe below the relationship between the research projects, the accessibility of data, and my role within each.

Nurse navigator state-wide evaluation

The state-wide NN evaluation study was led by Harvey et al. between 2018 and 2021. Ethical clearance was provided by Darling Downs Human Research Ethics Committee HREC/18/QTDD/8. Additionally, each HHSs (n = 16) independently conducted a Site-Specific Assessment to approve the study within their service.

As part of the evaluation study, I was employed as a research officer and was part of the operational team of the research project. My role consisted of qualitative data collection only, through interviews, policy, procedure and literature, data management, publication, and report writing. Below is a full schedule of the data collected for the evaluation study and the time periods of data collection. This is published in a study protocol listed in Appendix D (Harvey et al., 2019).

Table 5

Data collection and time period for state-wide NN evaluation

Data Collection	Cohort	Type	Time Points	How and Where	Research Question
Patient data related to hospital avoidance and service utilisation	All consented patients n = +/- 2400 Comparison group /HHS n = +/- 135	Quantitative Economic	Baseline; 6; 12; 18; 24 months	Hospital information systems Excel Spreadsheet	1, 2, 3, 4, 6
EQ-5D-5L Quality of life	All consented patients	Quantitative	Baseline & upon leaving the navigator service	RA/Research team – online/phone/postal Survey Monkey™	4, 6
Meke wellness meter	All consented patients	Quantitative	Baseline; 6; 12; 18; 24 months	RA/Research team – online/phone/postal Survey Monkey™	1, 2, 4, 6
Meke wellness meter	1 family member per cohort 1 participant	Quantitative Economic	18 months	RA/Research team – online/postal/phone Survey Monkey™	1, 2, 4, 6
Flanagan's QoL	All consented patients	Quantitative Economic	Baseline; 6; 12; 18; 24 months	RA/Research team – online/phone/postal Survey Monkey™	1, 2, 4, 6
Flanagan's QoL	1 family member per cohort 1 participant	Quantitative Economic	18 months	RA/Research team – online/postal/phone Survey Monkey™	1, 2, 4, 6
Client health related narratives	All consented Cohort 1 participants	Qualitative	One per patient	RA/Research team – online/phone/postal Survey Monkey™	1, 2, 3, 4
Navigators Position (Registered Nurse, [RN]); N; CNS; NP); Specialty (general; R&R; community; MH; Midwifery; acute; rehab) HHS	n = +/- 120	Quantitative	Baseline; 6; 12; 18; 24	Participant on consent to participate	2, 4, 6
Vignettes	Navigators	Qualitative	6; 12; 18; 24 months	Online – Survey Monkey™	1, 3

Data Collection	Cohort	Type	Time Points	How and Where	Research Question
Case studies	Navigators	Qualitative	12; 24 months	Online – Survey Monkey™	1, 3
Resilience and wellbeing survey	Navigators	Quantitative	Baseline; 6; 12; 18; 24 months	Online – Survey Monkey™	5
Equity responsive checklist **(6 monthly review)**	Navigators and team	Qualitative	6; 12; 18; 24 months	Online – Survey Monkey™	1, 2, 3
Hospital policies **(6 monthly review)**	Navigators and team	Qualitative	6; 12; 18; 24 months	Online – Survey Monkey™	4, 6
Action learning groups (Monthly meetings)	Navigator team and manager	Qualitative	Monthly	Online – Survey Monkey™	2, 3, 4
Policy documents related to coordination **(6 monthly review)**	Navigators and team	Qualitative	12;24 months	Hospital team with researchers	4, 6

Note: From *The evaluation of nurse navigators in chronic and complex care*, by Harvey et al., 2019, *Journal or Advanced Nursing, 75*(8), 1792–1804. https://doi.org/10.1111/jan.14041

As part of my role as research officer, I undertook interviews with consenting patients, carers, NNs and other professional staff, and government and non-government organisations. All participants signed a consent form and were provided with an information sheet. Considerations were given to the time and location of interviews, which were conducted in QH professionals' offices and/or meeting rooms or neutral locations such as coffee shops across all hospital and health service locations in Queensland. Some interviews were conducted online via Zoom.

Other members of the research team also conducted interviews with participants in which I was not involved; however, I conducted approximately 50% of all the project interviews in one-on-one and group session formats. In addition to this, I also chaired a monthly rural and remote navigator meeting which was created to further collect data and explore the unique nature of navigation in rural settings. I chaired 13 of these meetings. While the concept of PCC was not the specific focus of interviews, it naturally formed part of many interviews, as this is the first role principle of the NN. In many ways this allowed data and information pertaining to PCC to be uncovered and discussed organically and within the social order that NNs exist within, leading to rich data collection around the concept. In discussions with my supervisors during my own doctoral study, they indicated that there was no distinction between the interviews I had conducted and those of others. Given the large number of interviews undertaken for this project many of which I had conducted myself, and that the topics were so closely aligned to my research, I did not conduct any independent interviews for my own research. The evaluation data set offered ample data for exploration.

The qualitative research for this evaluation was managed in a central repository, de-identified and migrated into one document for reports and publications. The final data set was held on a CQUniversity server in a secure file location and is to be held for five years post research conclusion. Only those who were identified on the research data plan have access to the data.

Research undertaken for this thesis

Ethical clearance was provided by Central Queensland University Human Research Ethics Committee application number 0000021623 on the 8th October 2019. This ethical clearance allowed me to access data from the NN evaluation discussed above for independent assessment and analysis as per the philosophy, methodology, and methods set out in this thesis. Ethical approval was for the access and analysis of NNs and associated data only, excluding the use of patient and carer data.

Although I was an investigator on both projects, they represent two distinctly different bodies of work with their own focus and research questions. The qualitative data accessed for my research was amalgamated into a large document with other interviews which I had not conducted. While I built an initial and ongoing rapport with many NNs across the state of Queensland, I was careful to analyse data as an entirely separate process in my own body of work. Additionally, my supervisors made a decision not to allocate any further project interviews to me once I commenced my own final data analysis.

My doctoral research analysis was done in conjunction with other data accessed through the evaluation project allowed by my ethical clearance, the current literature as discussed in my literature review and within the thesis, as well as the political, economic, and social environment where the NNs sit. It is this point which sets my work distinctly aside from the NN evaluation as the entire healthcare system with its macro, meso and micro influences became a part of the analysis.

The use of the data from the NN evaluation has allowed for the triangulation of data; where the accounts and narratives of NN, as well as quality of life measures and hospital avoidance metrics are analysed against the discourse of politicians, executives, and other health care professions, therefore investigating, and interrogating where divergence and congruence of PCC exists (see Table 2). Indeed, my study's philosophical lens and methodology ensures that the two studies differ greatly in terms of what they are investigating.

To remain objective between the two projects I only accessed deidentified, bulk data related to NNs from the evaluation study. Independent supervision meetings were set up and analysis was conducted through a constant process of data evaluation, exploration of other literature and discussion with the supervision team. This allowed me to analyse the dataset with specific reference to PCC, which is not an outcome of the NN evaluation study. Data for my study is held on a secure CQUniversity data server which is only accessible to me and my supervision team. In line with the CQUniversity data management policy, data for this project will be held for five years post project completion.

In summary, potential sources of bias were carefully considered and strategies to avoid these were implemented. Below in Table 6 is a summary of potential bias as described by Simundic (2013), Smith and Noble (2014) and Hammersley and Gomm (1997) and how these were managed in the research process.

Table 6

Potential sources of bias within research and strategies employed to avoid this

Type	Description	Strategy
Data Collection bias/Sample bias	Selection of data or inclusion of data samples is open to bias based on preconceived notions or thoughts. Data is selected for its application to preconceived notions.	Study designed around macro, meso and micro levels of analysis, allowing for analysis of data across a wide range of social worlds and perceptions. Wider data (in the form of literature) is used around the nursing population in general to allow for a more generalised application. Care consideration applied to inclusion and exclusion of data as stated in Table 2. NN across all 16 hospitals and health services were invited to participate.
Responder bias	Responders are guided toward a particular answer or narrative through their knowledge of the research, the questions, their perceived desirability of the stance or their feelings of safety.	The data set for this study was taken from the NN evaluation, with no interviews or case studies undertaken which specifically set out to talk about PCC. This allowed the concept to be uncovered and explored organically, as a part of the role of the NN and healthcare system.
Researcher bias	The researcher has bias throughout sampling, collection and analysis which may be due to culture, position within the research, perceived benefits, or other contributing factors. Includes unconscious and conscious bias.	Data was de-identified and amalgamated into one document for analysis. The data was taken as a whole and viewed under the guiding questions set out in section Chapter Four. A constant and iterative process of evaluation and analysis was undertaken whilst reviewing the literature on the topic (See Figure 3). Careful attention has been applied to my position within the research and I have declared my social positioning, past present and future, within the thesis. Regular supervision meetings were held to review and discuss concepts and interpretations.

Type	Description	Strategy
Publication Bias	A preference for publishing positive results in research, as well as selecting journals which are less rigorous, or using the same journal for findings despite a better fit being available.	A range of journals was used for publication, selected by using Journal Article Name Estimator and diversifying the study findings. See list of publications in this thesis. https://jane.biosemantics.org/ Only Q1, peer reviewed journals were considered for the publications in this thesis.
Funding Bias	A bias based on the relationship with funders. This bias might impact upon results or dissemination of results.	This research was funded through the Research Training Scheme supported by the Australian Government and facilitated through Central Queensland University. A scholarship was obtained at year two of the study by the Australian College of Nursing. All funding has been declared. The funding bodies posed no limits on the research direction or dissemination of results. Pertinent literature related to nursing and PCC has been included in the thesis regardless of its affiliation with funding.

Validity, Reliability and Rigour

Although Breeze (2011) found limitations with CDA in ascertaining the impact of discourse through text alone, when interdiscursivity is applied to analysis, combinations of genres, discourses and styles as choice become present and are defined by the social orders as described by Fairclough (2001). Therefore, the methodology defined in this thesis is a rigorous method of investigation.

The proposed framework for this study allows for a balance of information and identification of the boundaries at which changes in views, perceptions, and practises are occurring. Clear research statements and questions maintained the focus of analysis as with traditional modes of research. Additionally, as a student of research, my supervisors supported the rigours of analysis through questioning and critiquing my work.

Person-centred care is a topic worthy of exploration and one that has the potential to improve the lives of the people that health services care for. We can only begin to make change once we have understood the historical, political, economic, and social climate that this ideology belongs to. Herein, the thesis applies the methodology stated above, starting with a broad mapping of the wide political, economic, and social environments in which the concepts of PCC, chronic disease management and the NN roles exist.

Chapter Six—Establishing Connections Across Time and Space

Summary of Chapter

Person-centred care is influenced by multiple factors across many time points and social spaces, all of which influence how the concept is positioned, adopted, and utilised. It was therefore essential to explore, analyse and demonstrate this complexity as a method of interrogating the competing agendas present within the system. Person-centred care exists within a complicated and fragmented system and is enacted by players who are (re)created by existing and historical power relations.

In this chapter, I have mapped the complexity of the healthcare system within which PCC is located and operates. I have completed two mapping activities which demonstrate the hierarchies of influence related to chronic disease management, NNs and PCC.

Hierarchies of Influence—How and Where Person-centred Care is Located

Like any large organisation, QH is a multilayered system that devolves management to identified business units across each HHS. Such large organisations direct activity within them through standardised policies and procedures by which workers must comply, and through which unconscious practice becomes routine (Kearney et al., 2019). This helps to maintain the infrastructure and acceptance of the overarching policies that drive the organisations (Fairclough, 2001).

The subject of PCC is one such policy located within the organisation of QH. It traverses across the social orders and is located in a space that attempts to reposition the role of the patient within a health system that is fragmented and disorganised (Mathur, 2013). The policy of PCC emerges against a backdrop of history which created a subordinate patient who complies with traditional biomedical directives (Phillips et al., 2020). Thus, in reading policy, procedure, and associated literature for my study, it became clear that a mapping process was needed to understand how PCC evolved over time and how the health system embeds it into policy. This exercise allowed me to map the history of the present health system to understand and situate the social, political, and institutional factors that inform and form NNs and their service. This examination follows Fairclough's social orders (2001) identified as micro, meso and macro levels of hierarchy that make up the complexity of society.

Foucault (1972) states that history within discourse is not always as self-evident as it appears, meaning that historical analysis allows for the exploration and interrogation of ideology and philosophy. Indeed, the archaeology of knowledge allows one to identify how this knowledge is diffused across philosophical concepts, social problems and political influences that act as "concentric circles that surround works" and relate them to one another (p. 137). This leads into the exploration of discourse from a genealogy perspective which specifically investigates elements of power, in this case, the political nature of discourse and the power battles that are fought in and over discourse (Fairclough, 1993). The exploration and comparison of historical and present factors which impact upon the delivery of PCC for those with chronic conditions is thus integral to its understanding.

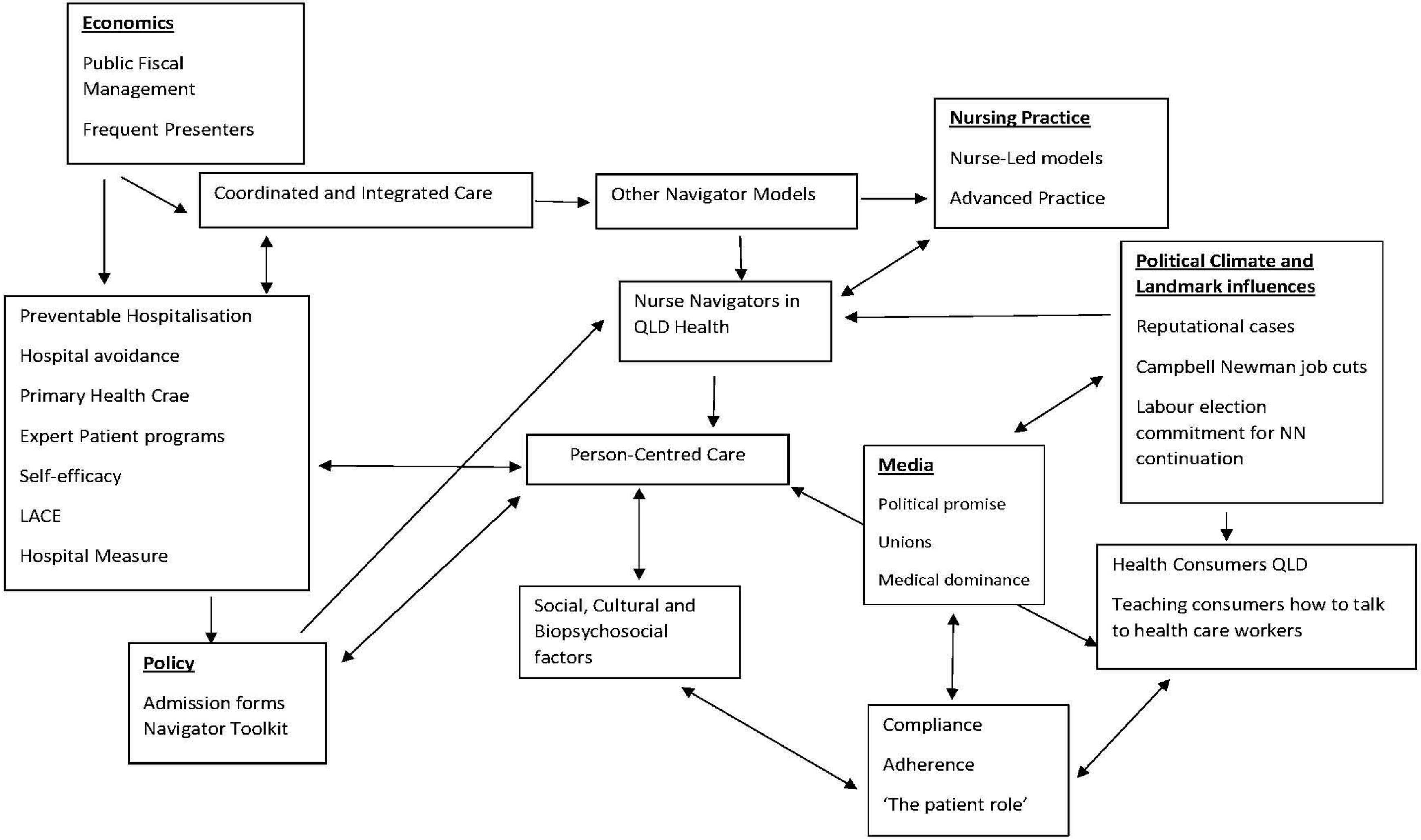
Mapping the Institutional Factors Related to Person-centred Care

Using Fairclough's concept of social order and engagement (Fairclough, 2013b; 2015), Figure 4 outlines a mapping activity known as fuzzy cognitive mapping that was used to brainstorm and refine the influencing factors within the health system that impact the NN work. The use of mapping allows a researcher to generate theory, describe systems and influences, increase the awareness of marginalised voices, and can be used to improve patient engagement and PCC (Andersson & Silver, 2019). This mapping activity was a useful exercise in clarifying and articulating the landscape under which NNs, as the deliverers of PCC, were created.

To achieve this, an iterative process of mapping, refining, and re-mapping was adopted. As defined in Figure 3, mapping became a process which complimented the reading and analysis process. Common themes were grouped under the broad headings listed below, providing a landscape snapshot of factors which have influenced and continue to influence chronic health management, the NN service, and of course how PCC is practised. It demonstrates the intricate and connective nature of chronic disease discourse and practice around PCC and how NNs have been positioned to offer a solution to the challenges of the health service.

Figure 4

Factors influencing the NN service and their delivery of person-centred care



Mapping Neoliberalism

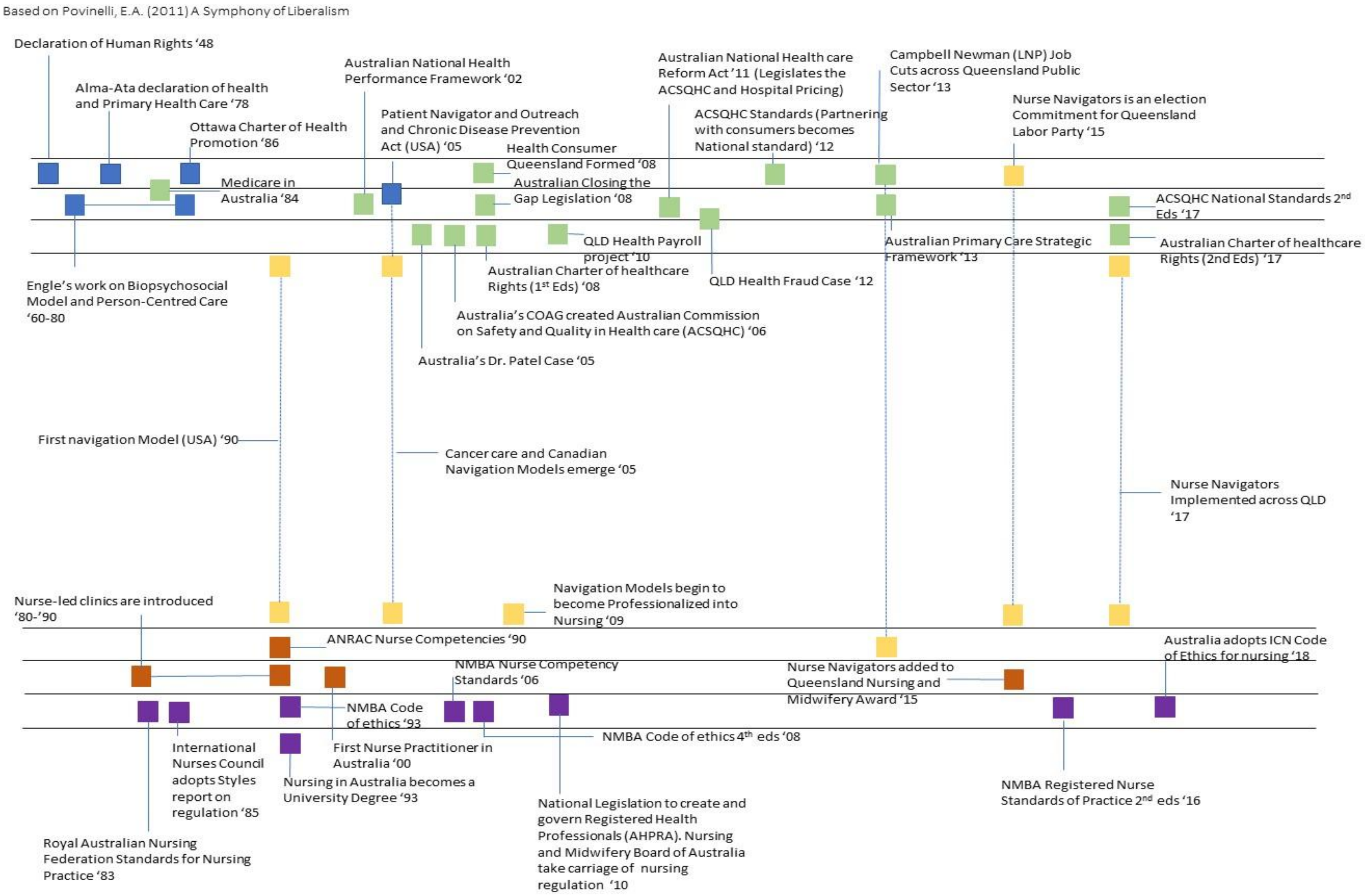
Liberalism, as described by Foucault (2008), is intrinsically linked with government regime, citizen rights, responsibilities, freedoms, and conduct. Liberalism is thus a moulding of politics, economy and ideologies and is understood broadly as the limitations of government. Additionally, Foucault describes liberalism as a practice, where the limitations of government are enacted by both citizens and authorities, together defining the limitations of government practices (Foucault, 2008). Neoliberalism on the other hand, is the practice and limitations of government and citizens in bringing about and embedding market reforms, such as privatisation, deregulation, and trade (Povinelli, 2011). This is important as the effects of neoliberalism can be felt across all locations of society, but particularly so for those of diverse socio-cultural backgrounds. Indeed, poor health is secondary to social and political factors, including employment, economic opportunity, geographic location among many other factors, which leave some members of society at a disproportionate disadvantage (Schofield, 2015).

In her work *Economies of Abandonment*, Povinelli (2011, p. xvi) described and mapped the influences of liberalism as a "symphony" to track the movements and ideologies of government markets in relation to each other (Khalidi, 2017). The analogy of a symphony suggests an orchestrated control over a subject and the music stanza represents the powerful factors that control it (Povinelli, 2011). There is not a time or a place where liberalism occurs as it is always occurring and moving forward (Khalidi, 2017). This view is supported by Foucault who states that power is not owned but that it is everywhere (Foucault, 1982). I have used Povinelli's stanza to plot out the factors that may identify where the power and control of PCC lies, as well as the government, institutional and social influences which intersect for NN and for PCC.

Figure 5 presents a symphony of neoliberalism in a timeline of events leading up to the implementation of NNs. My symphony represents a conceptual approach to identifying touch points of power that may or may not have a direct influence on how PCC is interpreted, established, and enacted in QH. In my symphony, the top stave identifies factors that may contribute to the macro and meso level influences of government and health service on PCC. The bottom stave maps the trajectory of nursing through these years. The middle, represented in yellow, demonstrates the connection between the two worlds, viz., NNs as drivers of PCC. My intent was not to draw or infer symmetry between the two, but to set the stage for the analysis. My symphony will guide the analysis by exploring the multiple tension points and challenges that influence PCC.

Figure 5

A symphony of neoliberalism; chronic disease, nurse navigation and person-centred care



Note: Adapted from *Economies of abandonment: Social belonging and endurance in later liberalism*, by E. A. Povinelli, 2011, Duke University Press.

While this map is by no means exhaustive, the symphony demonstrates a landscape of NPM efficiency, efficacy, and productivity, and highlights several precipitating events such as social, political agendas and ideologies which have created the conditions under which NNs work and deliver PCC. For example, events such as a Patel case (a rogue Queensland Doctor found guilty of working out of scope and harming/killing patients) led to the formation of Health Consumers Queensland, an advocacy group for patients. The enquiry into Patel found that there was no clear process for nursing staff or patients to escalate concerns, among many other systemic failures (Queensland Government, 2006). Similarly, The Queensland Health payroll software rollout, a product not fit for purpose with many errors, cost the health service millions of dollars. These costs were used to justify the reduction of nursing and midwifery staff across the sector (Wardill, 2012). It is these national and local events, that have all led to the healthcare climate in which the people of Queensland seek care within.

I have expanded on this throughout the analysis. The subsequent chapters detail the symphony of social orders and associated discourses which influence the health service direction, chronic disease management, nursing performance and practice, and the approach to delivering PCC.

Chapter Seven—Burden; Whose Burden is It?

Summary of Chapter

It is important to understand the complexity of the health system, including the funding flows, revenue streams and transactional nature of the Australian system. Therefore, this chapter presents the context under which Australian chronic disease management, the NN role and PCC exist. I begin this chapter by providing a mapped example of a typical NN journey with a complex person. This is then used to demonstrate the complexity and fragmentation of the Australian healthcare context, including hospital and general practice environments.

The chapter presents an analysis and discussion around the concept of *burden*, demonstrating a tension between the business of healthcare and the needs of a person with multiple morbid conditions. The analysis depicts a competing notion of burden, which is compounded by multiple agendas and influences. This is then discussed in relation to the introduction of PCC as a health service agenda, depicting the competing dialogues and notions surrounding the concept.

Mapping the Patient Journey

This mapping activity (demonstrated in Figure 6 below) depicts a navigated person’s journey, demonstrating tension between the government burden and the individual’s burden. My intention behind this inclusion is twofold: firstly, it depicts the complexity of an individuals, families and communities’ burden when trying to manage the social, medical, and quality of life aspects of care, and secondly, it also demonstrates the challenges that NNs face in managing care within these competing agendas. As described by A. Clarke (2005), this is relational mapping where each element of the map is positioned in relation to others depicting the quality of the relationship. Further to this, I would suggest that this mapping also demonstrates the journey of the person, as described by Kelly et al. (2012) in their *Managing Two Worlds Together* mapping tool kit. The map in Figure 6 is not intended to give the reader full insight into the person’s journey, but rather a snapshot of the consistent complicated and at times chaotic nature of navigation work, demonstrating the need for higher critical thinking, knowledge, and skill in negotiation and mediation.

The mapping is based on a NN case-study. It maps the journey of a person with multiple complex diseases including renal failure, liver disease and mental illness. The NN reported that the person was labelled as difficult and had been discharged from multiple services in the past. The person was referred to the NN service as a last resort. They had a socially complex past and had fleeting engagements with the healthcare service. The NN spent considerable time with the person to build a trusting relationship. The mapping depicts the social aspects of the person’s care that the NN needed to address to meet the needs of the individual. This included housing, disability support, hospital services, community services, mediation between housing and general practice services and much more. The mapping demonstrates the gravity and complexity of the work that NNs do that goes beyond immediate clinical work and how they work within the tension point of fiscal burden and social burden. It also demonstrates the duplication of care that NNs aim to reduce by being the central conduit of care between the person’s physical, social, and mental health care needs. For example, the NN effectively acted as mediator between the person and the GP allowing for continuity and liaised with aged care services and private housing to ensure a safe discharge location. This mapping demonstrates that these elements are very often linked and that working within a PCC framework means committing to working with the person to address these needs. Significant advocacy of the NN is shown, highlighting the barriers to care.

Figure 6

Navigating the patient journey

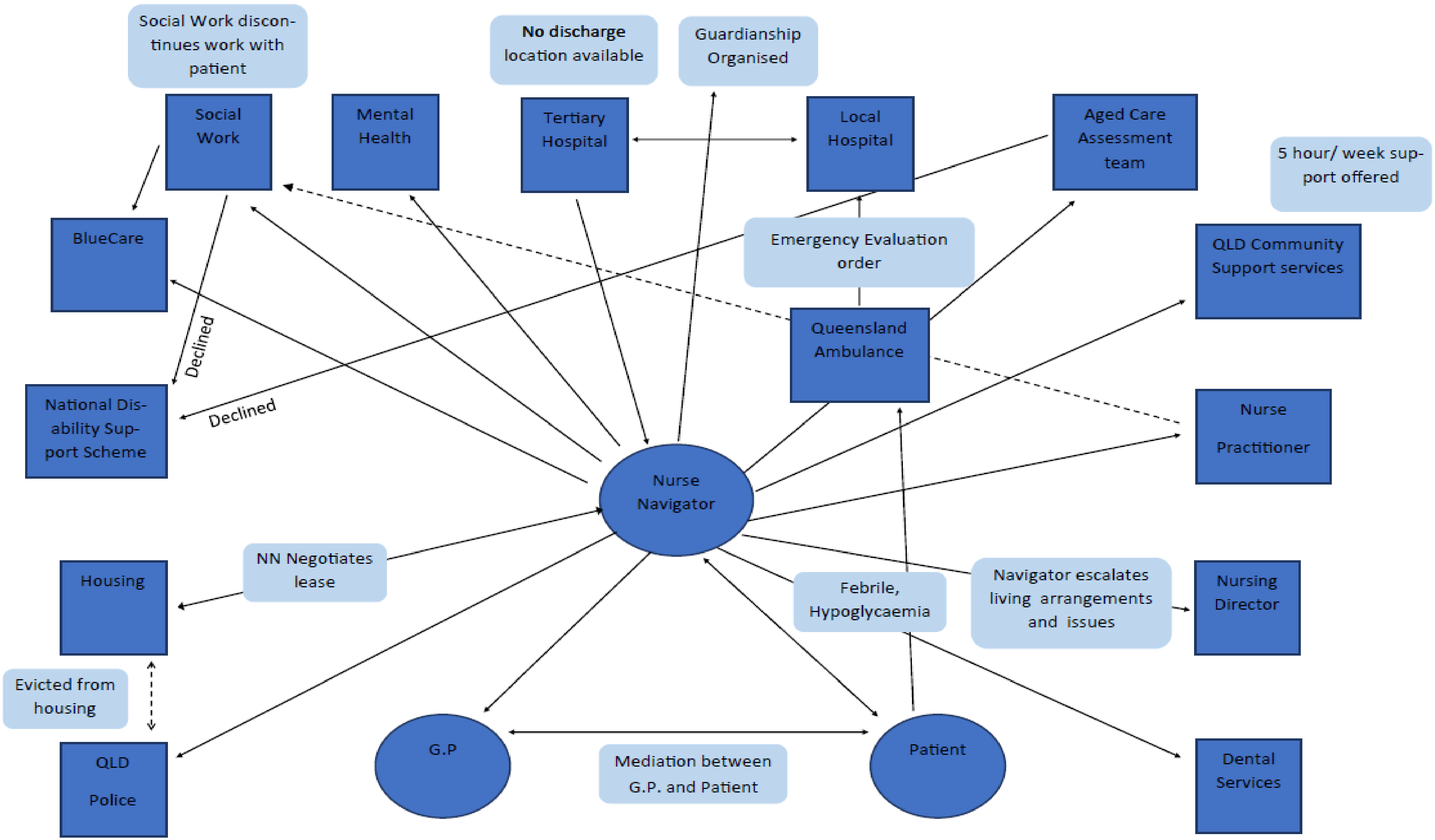


Figure 6 demonstrates the complexity of a person living with chronic disease, and the complexity of the NN role in providing care. It also demonstrates that duplication of care, engaging with siloed services and bridging gaps within a person's life is a difficult task and shows that for many people, health is a complicated and delicate orchestration of social, psychological, family, community, and medical elements.

The mapping shows that on multiple occasions the person was declined services due to not qualifying for certain eligibility criteria. It also shows that being declined for such services had a significant impact on other areas of the person's life, for example, the ability to be discharged to a safe location or the ability to receive ongoing support services in the community.

What this figure also shows is that it is not the person at the centre of care, but in this case, the NN, who acts as a centre point of care coordination. It is the navigators who work as the conductor, using their knowledge of the system to transition between services, advocate and negotiate. It is the NNs' practices which pulls all elements toward the person, thereby reducing system fragmentation and duplication. In this way, it is the NN who champions PCC.

Figure 6 is a clear demonstration of the patient's journey and experiences in the context of complex multimorbidity. To fully understand how this occurs for people with complex conditions, one must understand the complex context of the Australian healthcare system.

The Australian Healthcare Context

Australia has a hybrid model healthcare system: a mix of the welfare state model where healthcare is funded through tax dollars and where the government is responsible for health and care; the market model where individuals in partnership with private insurers have responsibility for their own healthcare. Australians can purchase private insurance on top of the publicly available universal healthcare system known as Medicare

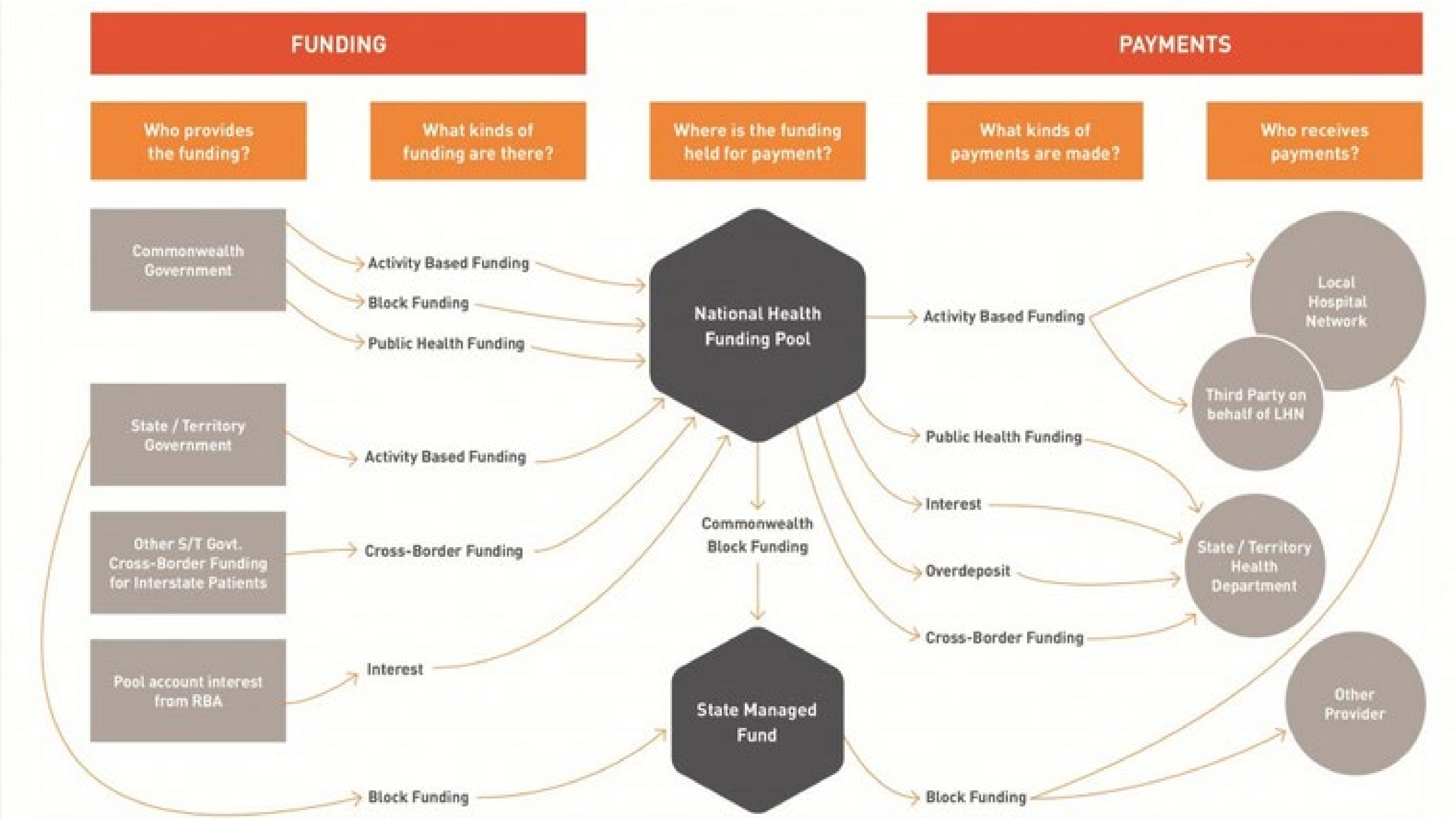
(Dixit & Sambasivan, 2018). Healthcare in Australia is the joint responsibility of the Commonwealth, States and Territories, is described as "nationally unified and locally controlled," and is prescribed by the National Health Reform Agreement (COAG, 2011. p. 4).

The Australian healthcare system like many in the developed world is divided into specialist services or disease silos whereby payment structures support the management of single-disease care (Harrison et al., 2016). For example, separate services and Models of Care (MOC) exist for diseases such as diabetes, kidney disease and respiratory care. This is generally referred to as the biomedical model where specialists focus on one organ or disease. However, the changing climate of healthcare has rendered the biomedical model insufficient (Fuller, 2017). This traditional model is a curative one (Khoury, 2015) ill designed for those with chronic conditions.

In the context of rising chronic disease rates, healthcare models are evolving. Further emphasis is being placed on health promotion and prevention, self-management, social support, and system design (Davy et al., 2015; Australian Health Ministers Advisory Council [AHMAC], 2017). Despite these new models, it is difficult to clearly identify the optimal combination of care in chronic care models (Davy et al., 2015). One barrier that remains is the current funding models for care, as demonstrated in Figure 7 below, which outlines just how complicated care service and delivery is and how difficult it is to define and locate chronic care within it.

Figure 7

Commonwealth national health reform funding and payment flows



Note: From National Health Funding Body [NHFB] Annual Report 2012–2013 by National Health Funding Body, 2013, https://www.publichospitalfunding.gov.au/nhfb-annual-report-2012-13/1-introduction

The Commonwealth and State Governments provide finance primarily through Activity Based Funding (ABF), whereby funding is allocated based on patient acuity and the number of services provided to the person (Eager, 2011). The intent of ABF is to improve the transparency and efficiency of funding contributions of the Commonwealth and State Governments (Independent Hospital Pricing Authority [IHPA], 2018). This is achieved through the allocation of Diagnostic Related Groups (DRG) used to classify and code a person by presenting a problem diagnosis. The classification systems used[5] code and classify patients into groups, providing a cohort of related types of patients treated and the resources required (IHPA, 2019a). Generally speaking, ABF provides more funding for more complex and complicated acute care diagnoses, for example, a patient requiring a transplant would generate a higher cost weight than someone treated for hypertension (IHPA, 2019b). Therefore, ABF perpetuates the biomedical model of care through the process of episodes of acute care, whereby the person is admitted for their ailment, treated, and discharged, at the end of which the episode is complete and funding is allocated. This problem-based funding is common across many countries and fails to acknowledge the patient as a whole entity (Mold, 2017). This type of funding model has many limitations for people with multiple chronic conditions.

In summary, health systems are designed around fee for service and single care provision is “hyper-specialised” (Vetrano et al., 2018. p. 1351) and ill designed for those with complex chronic diseases. This opens the space for uncertainty around care processes and care planning.

Medicare

The Australian universal health care system is known as Medicare. Australians access Medicare for public hospital treatment and admissions, medications, and services by doctors, specialists, and other health professionals. Medicare covers essential medical

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[5] International Statistical Classification of Disease and Related Health Problems, tenth revision, Australia Modification [CD-10-AM] and Australian Classification of Health Interventions [ACHI].

care with the full list of medical services prescribed on the Medical Benefits Scheme (MBS). Additionally, Medicare includes the Pharmaceutical Benefits Scheme (PBS) which provides subsidies for medications, making them available at a lower cost (Department of Health, n.d.a). However, the PBS still attracts out-of-pocket expenses on prescriptions with the amount varying according to the medication prescribed. Although there are thresholds for people obtaining medications, there are still some out-of-pocket costs to the person.

Medicare is funded through Australian citizens' taxation, whereby a person is taxed 2% of their income, with additional surcharges and levies applied to those who earn over a certain threshold, or who do not hold private health insurance (Parliament of Australia, 2016). A person entering the hospital system in Australia will pay no out-of-pocket costs in the public system for their care unless their care is considered elective, and the person uses private health insurance[6].

General practice and primary health care

General practice in Australia is community-based (primary care) and is designed around fee for service agreements between the general practitioner (GP), the patient, and the government. General practices in Australia operate as private businesses. Billing for an appointment is managed through Medicare item numbers detailed in the MBS. Medicare pays a rebate to the practice of 85% of the agreed fee for service, while the patient pays 15%. In some circumstances a practice will bulk bill the patient meaning there are no out-of-pocket costs for the patient and only the fee for service amount of the Medicare rebate is applied. Practices can allocate the fees for services independently and can choose to charge above the allocated price in which the costs are borne by the patient. GPs are paid between 63–75% of Medicare billings (Royal Australian College of General

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[6] Elective care is considered non-emergency care, such as an elective knee replacement. It can be obtained through private health insurance in the public system with out-of-pocket costs, or by going on a public waiting list with no out-of-pocket costs.

Practitioners, 2019a) with the remaining 25–37% going to the practice. Thus, practices are motivated to maintain high volumes of short appointments to maintain revenue. Policies exist to ensure the equity and access of GP services available for the community; however, this fee for service model is not without its critics with some believing that fee for service and co-payments exclude subgroups and reduce access for patients (Eckermann & Sheridan, 2016). Additionally, care coordination and integration are often neglected as small appointment times do not allow for this (discussed further in Chapter Nine).

As originally described by the WHO in the Alma-Ata agreement (1978), primary health care is considered the most appropriate avenue to screen, manage, and maintain health (AHMAC, 2017). In the Australian healthcare context, primary healthcare is predominantly the domain of community-based general medical practitioners. Understanding the importance of general practice in managing those with chronic conditions, the government has previously allocated payments to practices in the form of Practice Incentive Payments (PIP). If a practice meets a certain requirement for patients, additional funds are provided to the practice. An example of this is the diabetes cycle of care (Item 2517), under which a person is managed for 11–13 months with regular appointments, assessments, review, and education, at the end of which the GP receives the incentive payment (Department of Health, n.d.b). However, several incentive payments, including incentives for asthma and diabetes management, quality prescribing, cervical screening, and aged care access were ceased in August of 2019. Practices were moved to Quality Improvements Incentive (QIP) which is “a payment provided to practices to undertake continuous quality improvement through the collection and review of practice data” (Department of Health, 2019b).

Another strategy directing care is the National Strategic Framework for Chronic Conditions (AHMAC, 2017), which positions the future of chronic disease management in the primary care sector through better surveillance, detection, and management.

The strategy also recognises that significant changes to current systems are required to achieve this (AHMAC, 2017). Yet, research by Callander et al. (2017) showed that people with chronic conditions in Australia are more likely to disengage with healthcare because of the costs involved with it. For example, people living with long term respiratory conditions had 109% higher out-of-pocket health care costs than those without a respiratory condition. Indeed, people with a long-term respiratory condition are 6–16 times more likely to forgo health care. The results were similar across other chronic conditions. When compared with Canada, the United Kingdom, Germany, France, Norway, Sweden and Switzerland, Australians rated the highest in costs and disengagement from health care, suggesting that cost was a barrier for people accessing health services in Australia (Callander et al., 2017). This demonstrates that while a portion of healthcare costs in Australia are covered under Medicare, costs are complex and cannot always be predicted and assumed, with the costs of travel, medications, and specialists often unaccounted for.

Chronic Disease in Australia—Factors Informing Healthcare Agendas

Many individual, social, cultural, and political factors impact on the life expectancy and general health and wellbeing of the individual. Kern and Friedman (2008) noted that individuals who demonstrated high levels of conscientiousness by being persistent, organised, and disciplined, demonstrated significantly higher longevity. Conversely, social disparities, known as social determinants of health, such as low income, poor educational achievement, poor living conditions and lack of employment, can negatively impact upon a person's health and wellbeing (AIHW, 2016; Kim & Kim, 2018). These factors contribute to social exclusion and health inequities, all influencing how a person engages with healthcare (WHO, 2008). Chronic disease, and associated disability and death is often described as a burden on a country's resources and on individuals, families, and communities. However, it appears that the burden described is distinctly different for the government and individuals.

In the discourse related to chronic disease, the term burden is used with reference to Disability Adjusted Life Years (DALY). To quantify a disease's impact, the Years of Life Lost (YLL) secondary to premature death, and the Years Lost due to Disability (YLD), equate to the DALY. That is; DALY = YLL + YLD (AIHW, 2019b). Thus, the burden of a chronic disease is quantified by the mortality and the disability of the condition. However, the burden of one's disease cannot be summarised into just a mortality statistic as these do not capture the emotional and social loss which can contribute to the capacity of an individual to cope and maintain their health (Holicky, 1996). Additionally, the level of disease burden is inversely associated with the funding of care and therefore, the planning, organisation, and access to health care (Marttila et al., 2010). In fact, in rural and remote or low socioeconomic areas often have deceased funding associated with health services, impacting upon service delivery and access. Social determinants of health also impact on the health choices available to people. The cycle of chronic disease, therefore, is not just about the person and their lifestyle or environment, but also about access to care and how much cost is personally incurred against how much a country can provide for publicly funded health care (Cockerham et al., 2017). This is particularly true for vulnerable people in society.

Multimorbidity

People with multimorbidity are even more vulnerable within the current system. Multimorbidity is a term used to describe the presence of two or more coexisting chronic conditions in an individual (van den Akker et al., 2001) and complex multimorbidity is the presence of three or more conditions affecting three or more body systems (Harrison et al., 2016). People living with multimorbidity have an increased risk of marginalisation because they experience fragmentation of care, inadequately planned care, and polypharmacy, which leads to reduced quality of life and disengagement from healthcare (Prados-Torres et al., 2018). Although it is commonly accepted that multimorbidity is synonymous with older adults, recent literature shows that many young people are now living with multimorbidity impacting on adults of active working age (Lowe et al., 2016). This further compounds the burden of disease at a personal, community and national level as people with chronic conditions have a progressively reduced capacity for active work and therefore have lower income (Larkin et al., 2020) adding to the cycle of chronic disease burden. It is estimated that half of people presenting to general practice appointments and around one-third of the Australian population live with multimorbidity (Harrison et al., 2016). First Nations people have higher rates of multimorbidity, often manifesting in much younger ages than other population groups. First Nations people are 2.5 times more likely to be admitted to hospital with multimorbidity (Broe & Radford, 2018).

First Nations Australians

First Nations Australians are over-represented in chronic disease statistics (AIHW, 2015b). Additionally, First Nations people are more likely to be developmentally vulnerable, have lower retention rates of schooling, have lower rates of employment and higher rates of homelessness (AIHW, 2015b). First Nations people also have an increased biomedical risk with an increased prevalence of lower birth weight, increased rates of obesity, and higher cholesterol and blood pressure readings. Indeed, First Nations Australians are 2.1 times more likely than non-First Nations Australians to report their health as fair or poor (AIHW, 2015b). Not only are First Nations Australians more likely to develop chronic conditions, but the onset of these conditions occurs earlier in life (AIHW, 2015b). Therefore, First Nations men and women's life expectancy is 8.6 and 7.8 years respectively lower than national averages in Australia (AIHW, 2019a) greatly impacting their quality of life (Broe & Radford, 2018). In fact, 80% of the mortality gap between First Nations people and non-First nations people can be attributed to chronic disease (AIHW, 2011).

First Nations people are particularly vulnerable to social inequality due to historical factors, and the harms of systematic and interpersonal racism and discrimination. First

Nations people are particularly vulnerable to social inequality due to historical factors, and the harms of systematic and interpersonal racism and discrimination . Historical disregard for cultural practices has heightened the lack of engagement, leading to health and social inequalities that are the visible part of a very complex disparity (Arcaya et al., 2015).

Culture is central to First Nations people’s lives with cultural obligations to family and kin and social sharing being incredibly important. Additionally, First Nations cultures have a complex and multifaceted connection with Country and land and this connection to Country is intrinsically linked to cultural life and identity (Ganesharajah, 2009). This means that travelling large distances for healthcare appointments and treatment is complicated, which in the case of chronic care is common, as specialists are in metropolitan areas. This means that not only is the cost for care much higher, but also that people have to leave Country creating a cultural disconnect for remote-living First Nations people and their communities (Davy et al., 2017). This complicates a deep-seated mistrust of health services which are designed around western concepts that generally do not demonstrate an understanding of the First Nations cultures of Australia (Liaw et al., 2011). Within many First Nations cultures there is an expectation to provide money, food, and accommodation to family regardless of individual circumstance. Indeed, part of maintaining cultural identity is the need to conform to family behaviours and doing otherwise is seen as being “less aboriginal” (Waterworth et al., 2015, p. 8). For First Nations people, health is a complex concept which centres on family, kin, Country and spiritually (AIHW, 2020e) meaning that health and healthcare are intricate concepts. Despite the barriers that First Nations people face, they continue to not only survive, but to thrive in their communities, using cultural, spiritual, and family norms to support health and wellbeing (Povinelli, 2011; Usher et al., 2021).

Trauma

Trauma may include rape, domestic/family violence, childhood sexual abuse and physical assault (Elliot et al., 2005) or historical trauma, such as continued racial disparity (Chamberlain et al., 2019). Trauma is also experienced when systems, such as healthcare, do not accommodate a person's cultural or holistic health care needs (Browne et al., 2012). It is widely acknowledged that health behaviours are heavily impacted by historical or current trauma with mental health issues, homelessness, communicable diseases, unemployment, and family problems prevalent in those affected by trauma (Elliot et al., 2005; Jacobs et al., 2013; Wilson et al., 2017). Trauma is also prevalent with refugees and other displaced people with the impacts of vicarious trauma felt across the physical, social, and cultural aspects of a person's life (Patel et al., 2012) thus, "trauma survivors are the majority of clients in human service systems" (Elliot et al., 2005, p. 462).

The impact of trauma is significant and multifaceted. There is a clear link between trauma and ongoing chronic conditions including sleep disorders, cardiovascular and respiratory issues to name a few. Indeed, trauma influences the person's worldview, including beliefs about their future and expectations for their life (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014).

Health services that marginalise the person run the risk of retraumatising them, hence undermining any chance of making a difference in the person's life (Browne et al., 2012). Re-traumatisation can occur in any number of coercive practices such as incarceration, seclusion and forced medication compliance (Bateman et al., 2013; Browne et al., 2011). Central to trauma informed care is safety so that the person feels psychologically and physically safe in the health service (Australian Institute of Family Studies, 2016; Browne et al., 2012). Thus, services must demonstrate inclusiveness, choice, and control, with considerable time and commitment placed on recovery (Wilson et al., 2017). Noting the congruence with PCC, Wilson, and colleagues (2017, p. 341) state:

> [t]rauma-informed care offers an explanatory model through which to understand and respond to consumer behaviour through collaborative and sensitive therapeutic relationships. Its major point of separation from the still-to-be-embedded constructs of recovery and person-centred care is that trauma informed care (TIC) education and training are seemingly more accessible for nurses to translate into their practice.

Historical and social trauma is closely associated with psychological and chronic illness and disease (Sotero, 2009), therefore, caring for those with chronic conditions must include an element of trauma informed care.

The Queensland Context

Like many other states and territories in Australia, most of Queensland's population is densely clustered around the major cities with around 15.3% of the population living in regional, rural, or remote areas. Of the state's population, 4.6% identify as First Nations people, higher than the national percentage of 3.3%. After accounting for differences in age between populations, the death rate of First Nations Australians was 49% higher than non-First Nations Australians (QH, 2018b). In Queensland, multimorbidity is prevalent in both young and old, e.g., 13% of those between 15–44 years report two or more chronic conditions as do 33% of 45–64-year-olds, and 75% of those aged 65 years or older (QH, 2018b). This has led to increasing pressures on hospital services and therefore increasing healthcare costs.

Thus, hospital services have been under increasing scrutiny and pressures to meet demand. In 2017–18, eight (8) million people presented to an Australian hospital emergency department: 3.4% higher than the previous year (AIHW, 2018b). That is 22,000 presentations each day accounting for a considerable amount of expenditure, overtreatment, and decreased access for those with a need for emergency services. Governments have proposed measures to decrease emergency presentations as it is generally accepted that many of the ailments and injuries allocated to triage categories four and five[7] could be managed by effective general practice as 82% of non-urgent patients do not require admission (QH, 2019).

Beyond the emergency department, hospital readmissions are seen as a consequence of low-quality care and discharge planning, progression of disease, reduced accessibility of GPs and home-based care among other factors (Reed et al., 2015).
Therefore, coordinated, integrated care services and home-based care have been introduced to mitigate emergency department usage and Potentially Preventable Hospitalisation (PPH), particularly in the case of patients with chronic conditions. PPHs are admissions to a hospital that could have been avoided with effective primary health care or self-care measures. In the Queensland Hospital Admitted Patient Data for 2012--2014, 11% (n = 5488) of all hospital admissions were identified as preventable of which 45.3% (n = 2486) were patients with chronic conditions, making it important to ensure timely access to primary care that helps to avoid unnecessary hospital admissions (Harriss et al., 2019). The task of providing appropriate and timely access to healthcare is a difficult one, particularly given the complexities of not only the system, but also the complexities of individuals and communities accessing care.

Understanding the Australian healthcare context and the factors influencing healthcare for the population, I now turn the debate to unpacking the tension between the government burden and the individual's burden.

The Government Burden in Relation to Chronic Disease

The need for systemised and ethical care emerged after World War II (1939–45) as a result of morbidity from war wounds and human rights atrocities. During this time, the UN

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[7] Triage categories are used to sort patients by urgency and clinical need, where a triage category one (1) is an immediate medical emergency. A triage category four and five (semi and non-urgent), are those with no respiratory or circulatory distress, with a normal level of consciousness, with the national benchmark for wait times set at 60 and 120 minutes respectively.

was formed with the express purpose of maintaining international peace and security through developing relations among nations (UN, 1945). Importantly, the UN Constitution sought to reaffirm the human rights of every individual person and to *save* future generations from the devastation of war which led to the Alma-Ata agreement (UN, 1945). The Alma-Ata agreement defined health as a human right and highlighted the importance of the physical, mental, and social wellbeing of people (WHO, 1978).
This still stands today.

The UN Constitution describes health as “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” and prescribes health at its highest attainable standard as a human right “regardless of racial, social, or political standing” (WHO, 1946, p. 1). The constitution states that it is governments who have the responsibility for the health of its citizens through the provision of adequate health and social actions (WHO, 1946). This rights-based approach to healthcare seeks to ensure that health services and policy, prioritise the needs of those who are most disadvantaged and to provide greater equity (WHO, 2017). These goals are reiterated through the Agenda for Sustainable Development (2030) which aims to improve the health and wellbeing for individuals with particular reference to those who are disadvantaged (UN, 2015). Thus, the philosophy underpinning Australian health systems is to “prevent disease and other ill health and injury and to maintain health—not just to treat illness—so that people remain as healthy as possible for as long as possible” (AIHW, 2018a, p. 5). Therefore, the *burden* for the government is the management of this responsibility, with the costs associated in achieving them.

The business of caring

In Australia in 2015–16 a total of AUD$160 billion was spent on healthcare with a further AUD$10 billion spent on capital improvements. Of this figure, AUD$66 billion was spent on hospital care and AUD$59 billion on primary healthcare. Total health expenditure in this year was greater than the growth of the Australian population, with per capita spending increased to 22% and the population increased by 17% (AIHW, 2018a). The total health expenditure to Gross Domestic Product (GDP) in Australia is 9.6% higher than the OECD average of 9% (AIHW, 2018a). It is difficult to quantify the costs of chronic disease alone; however, the total yearly cost in Australia is cited as between AUD$27 billion (AIHW, 2014) and AUD$34 billion (Australian Health Policy Collaboration, 2014) though these are likely conservative figures. The cost of chronic disease extends beyond that of healthcare expenditure and includes lost Productive Life Years (PLY). This includes lost income and taxes and increased welfare payments with Schofield et al. (2016) modelling further costs of AUD$20.5 billion lost by 2030 in Australia. A significant portion of these costs is attributed to multimorbidity.

Multimorbidity is associated with significant increases in resource use and healthcare costs. Those with multimorbidity have higher use of primary care and specialist services, greater medication use, hospital admissions and emergency department presentations (Hajat & Stein, 2018; McPhail, 2016) leading to expensive and fragmented care. Understanding the impact of chronic conditions and multimorbidity places greater importance on health prevention and promotion and this is the premise of the National Strategic Framework for Chronic Disease Management (AHMAC, 2017). Prevention of chronic disease, including education, counselling, disease detection, surveillance and preparing for disaster, is an important component of the modern healthcare system. However, in 2015 Australia's percentage of health expenditure for preventative care was 2.6% of the total budget, lower than the OECD average. The requirements for health prevention are significant, with one study in the USA finding that belonging to a low socioeconomic status requires USD$2500 per person per year to protect against obesity (Miranda et al., 2008). In the Australian context, it is estimated that every AUD$1 spent on health promotion saves AUD$5 in healthcare spending within five years (Australian Health Promotion Association, 2016).

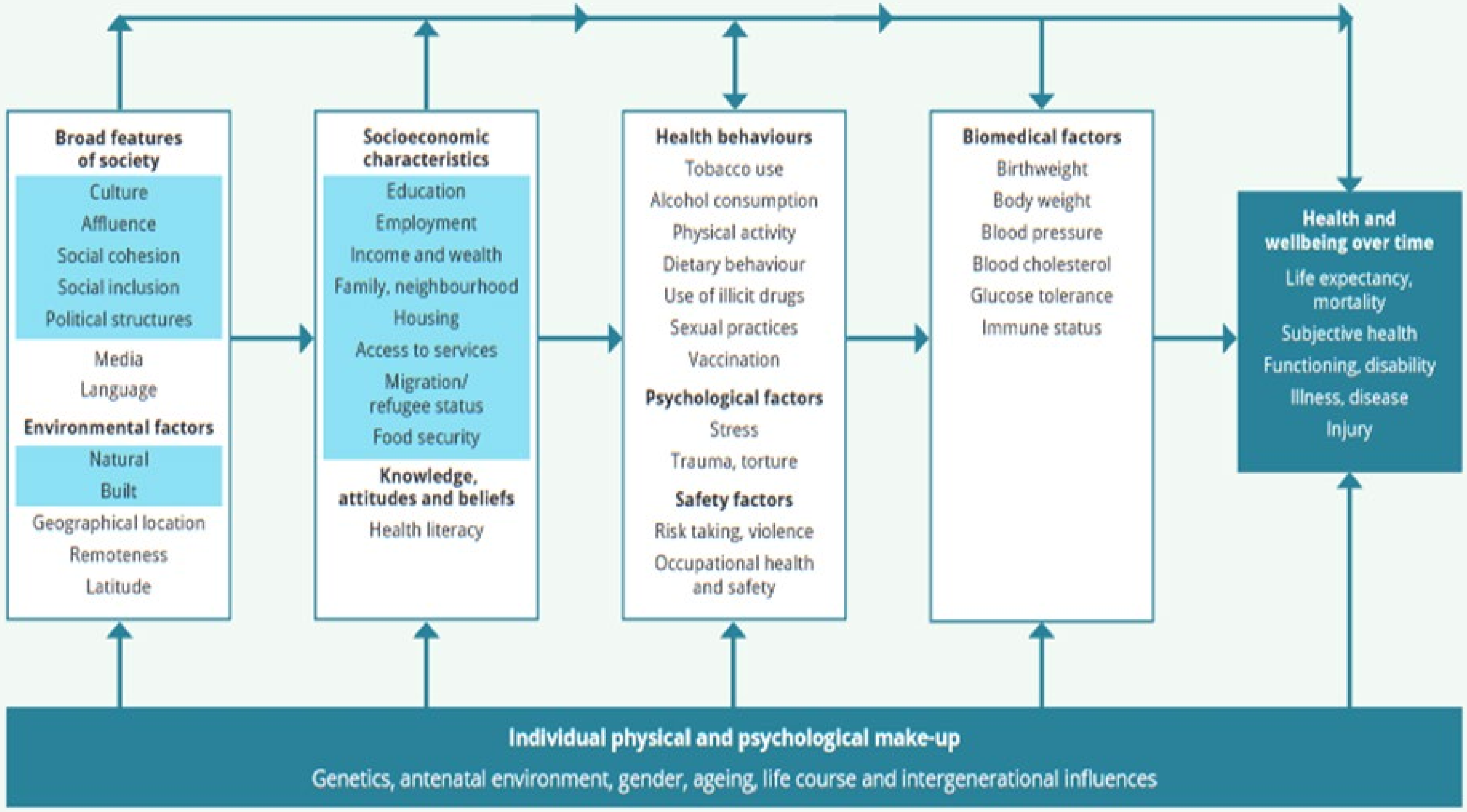
The economic and productivity costs of chronic conditions are significant, yet Australian spending on preventative measures is lower than the OECD average. This is complicated by the funding and healthcare models within Australia depicted in Figure 7 above. Healthcare funding and associated MOC often do not acknowledge the social burden of disease, which is pivotal for people who live with chronic disease. In terms of health care planning, the determinants of health add a dimension that describes how social impact affects health outcomes. It is this point that is often omitted from traditional models of healthcare.

Social Burden—Individuals, Families and Communities

The social determinants of health (SDH) are described as the circumstances in which people live, work, grow and age, as well as the systems and structures in place to deal with illness (AIHW, 2016; Schofield, 2015). The WHO (n.d.) defines the SDH as income, education, employment, life conditions, food security, housing, early childhood development, social inclusion, structural conflict, and access to healthcare. The conditions in which people live and die are all moulded by political, social, and economic influences, among other factors (Schofield, 2015; Office of Disease Prevention and Health Promotion, 2020). All of these factors influence how people maintain health and their capacity to access health care. When people are unwell for long periods of time, these social determinants are extenuated and impact negatively on quality of life and coping with illness. Understanding the social determinants is important for healthcare systems to identify health priorities, to plan for, and to allocate funding to services (Ahnquist et al., 2012; Figueroa et al., 2020). Social inequity and inequality accounts for the significant gap between life expectancy and morbidity between socioeconomic/cultural population groups. This disparity is not only seen in poorer countries across the world, but also in developed countries, where there geographical and cultural differences impact on care delivery (Queensland Aboriginal and Islander Health Council, 2021). People with lower levels of education, lower earning occupational status, and specific races and genders are known to have challenges with accessing care and health. This is what Browne et al. (2012, p. 2) described as “the conditions and processes by which particular populations are affected by structural inequities and structural violence in ways that result in a disproportionate burden of ill health and social suffering.” This means that for many people, their health is impacted by their social world and environment, as well as health systems that lack the resources and MOC to support their ongoing health needs. These societal, economic and health behaviours and their relationship to health and wellbeing are summarised in Figure 8, demonstrating the factors related to this burden. In regard to PCC, all elements shown in Figure 8 should be a consideration of care provision, as demonstrated previously in Figure 6, *Navigating the patient journey.*

Figure 8

Factors contributing to social determinants of health



Note: Blue shading highlights selected social determinants of health.

Note: From *Australia's health,* by AIHW, 2018a, https://www.aihw.gov.au/getmedia/7c42913d-295f-4bc9-9c24-4e44eff4a04a/aihw-aus-221.pdf.aspx?inline=true

When viewed at the level of the population, the burden of disease is considerably worse amongst people of low socioeconomic status, depicted above in Figure 8.

Low socio-economic status is indicative of low-income levels due to reduced or low paying employment and low levels of education (Manstead, 2018). Behavioural factors such as cigarette usage rates are significantly higher in those experiencing homelessness, First Nations people, and those living with a mental illness, further compounding wellbeing (AHPC, 2014). Additionally, social, and cultural influences contribute to chronic disease, for example Christakis and Fowler (2007) found clustering of people with obesity, meaning that those closer to obese individuals were at increased risk of developing the condition. Geographic isolation is also a factor related to the distance away from healthcare services and the economy of smaller country regions.

The DALY burden of chronic disease in Australia is greater for those living in the Northern Territory, living in remote and very remote areas and those in low socioeconomic areas (AIHW, 2015a) with these population groups having higher rates of disability and morbidity.

Quality of life

While the government works to provide suitable health services within finite financial restrictions, the individual burden of chronic disease impacts on their quality of life, upon individuals, families, and communities. In keeping with their definition of health, the WHO (2019, p. 1) defines quality of life (QOL) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” This definition understands QOL in the context of a person’s physical and psychological health, social, personal relationships and environment which is in keeping with the broad settings in which health occurs. Quality of life for the individual is summarised as their experience against their expectations (Calman, 1984) in that the person in some way reconciles their life against an ideal with social and cultural factors impacting on this. At times this may differ from that of the opinion of medical officers or healthcare systems allowing for tension to arise between what the person sees as important and what the service believes it can offer as the best value in care.

QOL is a very personal and subjective concept. Quality of life is intrinsic to health and wellbeing, yet wellbeing and chronic disease can coexist if sufficient psychological support is provided (Liao & Brunner, 2016). The quality of one's life is important to people, with studies suggesting that people with chronic conditions are consistently willing to trade life expectancy for a better QOL (Tong et al., 2013). Quality of life is generally assessed by a person's ability to attend to their activities of daily living in an independent way, hygiene, shopping, their personal affect, anxiety and/or depression, their ability to cope and manage their disease, and factors of daily life such as pain and sleep issues (Burns et al., 2017; Allen et al., 2016; Paddison et al., 2012). In summary, QOL is the person's ability to live a life that is meaningful to them in the context of frailty and declining health. The focus of care, therefore, should be about the wellbeing of the patient and how they manage their daily life.

Those with multimorbidity experience reduced QOL at rates higher than those with a chronic condition with significant impact on health and wellbeing (Makovski et al., 2019; Pati et al., 2019; Fortin et al., 2004). Along with significant impairment to QOL, multimorbidity increases the person's anxiety and decreases their capacity for self-management. This leads to multiple medication requirements (polypharmacy), multiple medical specialist input and increasing functional impairment (Hussain et al., 2018).

The burden of disease, including the emotional impact is also felt by their carers (Nacul et al., 2011). Caring for such conditions leads to carer strain (Leggett et al., 2011). Although there is some awareness of the important role that families and carers play in care provision (Essue et al., 2010) many carers are unpaid, with a significant proportion of care responsibilities being performed by a spouse or parent or even a child. This impacts on a family's total income and from a government perspective, the amount of taxation generated from the individual and the family (Brimblecombe et al., 2020). Complying with treatment regimens is laborious for the person with multiple issues compounding their care experience including financial matters, time and travel, access, and medications (Sav et al., 2013). Indeed, carers provide support in essential elements of the person's life, including their activities of daily living and social and spiritual support. Due to the time commitment provided to caring, carers are less likely to engage in full time work and they are thus associated with lower socioeconomic status (OECD, 2011). A study by Carers Australia (2015) found that the total replacement of informal carers in Australia in 2015 was AUD$60.3 billion, meaning carers provide considerable economic relief to government services.

Using Person-centred Care to Ease the Burden of Chronic Disease

The tension mentioned in the previous section that exists between government and individuals' priorities and agendas, however, raises the question of how PCC is intended, and the purpose of its introduction into healthcare services. What is clear from the discourse and above analysis is that healthcare exists within a fiscally managed system, designed around single episodes of acute care and fee for service models. Hence, health services have introduced collaborative and integrative MOC to manage particularly vulnerable and costly individuals. Coordinated care planning and integration of services can improve the management and biopsychosocial outcomes of chronic conditions such as diabetes (Huang et al., 2014), improve survival (Ramachandran et al., 2018) and quality of life (Smith et al., 2002). As suggested from previous studies, there is mounting evidence linking care coordination and home-based services to reduced emergency department presentations (Bielska et al., 2018), reduced hospital length of stay and readmission rates (Diplock et al., 2017). Though, in the context of complex care and multimorbidity, this is debated (Smith et al., 2002; Plant et al., 2015). This is considered further in Chapter Eight.

Mofizul Islam et al. (2014) identified that the burden of out-of-pocket expenses was relative to income, affecting most commonly, those with low incomes, particularly those with chronic conditions who require ongoing and frequent visits to the GP. The authors further noted that with higher medical expenses, families went without other necessities, which in turn forced people to make choices between their own health care needs and everyday living needs of their family. This represents a vicious cycle as these choices impact upon health and vice versa. However, within the current acute care system, social-cultural care and support is lacking with care reliant on disease silos and specialists. In fact, delivering PCC to individuals remains conceptual with no clear definition, communication, or implementation of how this should occur (see Chapter Three).

Within the discourse, it appears that a dominant purpose of PCC is the building of self-efficacy and determination. When considered in the context of Foucault, evidence of biopower is uncovered. Biopower, as a form of governmentality, is a form of self-regulation, where governments foster their citizens to “regulate their economic activity, their production [and] price” (Foucault, 2008, p. 7). In this case, health services, as government factions, have placed a focus on controlling a person’s cost of care, related to the production value, including the *potential* value that they bring. This is evidenced by the discussion around carers in Australia and the lost taxation from people with chronic disease (discussed in the “Australian Healthcare Context” section). It could be the case that citizens are engaged in PCC as a method of self-regulation, and further to this, as a method of what Foucault (2008) refers to as responsibilisation and moralisation. I expand on this point in Chapters Twelve and Thirteen.

On the other hand, PCC could be operationalised under the discourse of human rights, social inclusion, equity, and health as a social construct, addressing QOL and wellbeing. I argue later that this is what the NN service has done. What is missing from the health service discourse is exactly how services, within the strict funding flows and service models, ensure that care reflects the needs of people with multimorbidity, is culturally sensitive and trauma informed. In fact, how the social aspect of care is included at all in current health system processes and flows is opaque. In this way, only the government burden is being addressed.

In summary, this chapter has explored the Australian healthcare context and the nuances which complicate chronic disease management in Australia. It demonstrated the complexity of care for people in the NN service, depicting the compounding factors and influences which contribute to the person’s health and wellbeing. It has highlighted the fragmentation of the current system and the need for NNs to champion care for individuals and their families. Having described the Australian healthcare context, the opportunity for people to get lost in the system has been uncovered and highlighted. This is at odds with the notion of PCC.

This chapter has argued that a tension between the government burden as predominantly an economic one, and the individual burden which centres on the social aspect and quality of life exists. This tension fuels not only government and health service decision making, but also the person’s engagement with health services, access, and equity. Person-centred care appears to be included within this tension as a method of improving productivity and economic value within individuals.

Chapter Eight—New Public Management: The Paradox of Managing Public Health Budgets to Deliver Effective Services

Summary of Chapter

In Chapter Seven, I introduced the concept of a rising tension between fiscal management and individual health care needs. To demonstrate the roots of this tension, I will expand on this argument across the ideologies introduced across neoliberalism and the view of healthcare as a free market.

In this chapter, I present the economy of care dominated by NPM ideology and first introduced to Australia nearly 40 years ago. This business model is important to understand, as it locates the nurse and the patient within a fiscally driven process that fails to accommodate value-based needs. It is in this setting that the delivery of PCC is located, and so it is important to understand the interwoven agendas that inform the meaning of PCC.

Nurse navigators describe the constraints of the healthcare system through examples such as travel, access, referral processes and separated specialist appointments. Nurse navigators reported that many of the barriers to their service are financial ones, i.e., the referral pathways, scheduling of appointments and associated revenue contributes to the fragmentation of the system.

Nurse navigators often described a clash between the philosophy of the service (as in the delivery of PCC) and the fiscal management of the service that focuses on hospital generated outcomes related to inpatient occasions of service. The NNs were able to demonstrate cost savings through careful navigation in a number of areas including, for example, patient travel. The final NN report (Harvey et al., 2021, p. 27) states:

> Travel from Pormpuraaw to Cairns, with an accompanying escort via Royal Flying Doctor Service. The navigator-arranged discharge plan enabled the client to

> return home to Pormpuraaw in a timely manner, rather than remaining in Cairns throughout the wet season, saving **$10,080**—the majority of which was from avoided accommodation costs—which would have been directly funded by the Patient Transport Subsidy Scheme.

NNs described the patients' cultural needs as part of their motivation for looking at alternative ways of providing care, which is not accommodated in the fiscal strategies of health services. This heralds further discussion about how NPM ideology has permeated economic decisions that are not acknowledging the human side of care, particularly in chronic care that is also remotely managed and culturally driven.

New Public Management; a Movement, a Social Commentary, and Organisational Reform

New public management has been defined by Dawson and Dargie (1999) as a movement, a social and academic commentary, and as an organisational reform in the public sector. The NPM movement commenced in the late 1980s through to the 1990s and within the health context, focused on the escalation of costs, alongside disorganised management, and on the delivery of effective services.

Over the last four decades public services in many OECD countries have undergone radical transformation using management principles created from for profit, commodity driven organisations to drive a result-based ethos. Performance is viewed as input and process and fiscal management is paramount. New public management represents a specific ideology, or belief system that seeks to contain publicly funded expenditure (Barzelay, 2000). NPM centres on the belief that business practices will work to enhance both the efficiency and efficacy of public organisations, and whilst not necessarily making a profit, focus on managing a defined and often annualised budget by reducing duplication of services and waste within the process of care provision (Alford & Hughes, 2008). However, public entities operate differently to their private counterparts with respect to regulation, policy, and worker autonomy often due to administrative and political accountability and control (Lapuente & Van de Walle, 2020). Private hospitals are owned and managed by private companies operating for profit, in contrast to the publicly funded, government-run hospitals (AIHW, 2016).

Under the NPM ideology, health systems and services adopted lean management processes. Lean methodologies are defined as those that reduce waste and associated costs which are implemented across all aspects of the business, in strategies such as the three Es, viz., economy, efficiency, and effectiveness, and the best value model (Rashman & Radnor, 2005). Derived from the Toyota car manufacturing process, lean systems were designed to be streamlined, efficient, standardised and continuously improving (Kimsey, 2010; Toyota, n.d.). Importantly, in a lean system, everyone within it is responsible for integrating lean principles and methods. For lean processes to be adopted, Kimsey described the need for a “questioning and problem-solving mind” along with the need to address “unused human potential” (2010, p. 54). However, as Radnor and Osborne (2013) point out, the role of the customer in a business is relatively easy to define and therefore, so is value. Yet, within a health service, the role of the patient is not so straightforward and thus value is more difficult to define and achieve. In fact, it is difficult to assess the implications of lean processes on patient outcomes, as lean outcomes are usually consolidated under economic, efficiency and productivity measures (Ljungblom, 2014, p. 193). For the person with complex conditions, this means conforming to diagnostic related group predications that determine a common trajectory based on a body systems approach. It does little to acknowledge individual economic or cultural circumstances, or illness responses that are typical of a person with multiple simultaneous chronic conditions (Quiñones et al., 2019). The important factor here is that self-effective people with simple diagnosis that resolve over a short time will thrive within the NPM ethos. This is due to their ability to manage their health and care time in line with the ideologies of NPM: efficiently, productively, and effectively. On the flip side of this, SDH are not given adequate weight in health promotion or care, and therefore those who may struggle to manage their health are subject to structural and social vulnerability leading to poorer health outcomes (MacGregor & Wathen, 2014). Dawson and Dargie (1999) point out that while the movement was quickly adopted in public services across the OECD countries, in the case of individuals living with chronic disease, multimorbidity is seen as problematic because they do not fit with disease specific guidelines (Kenning et al., 2013).

Referring to Figure 5, a symphony of neoliberalism, NPM, and the quasi-privatisation of health services, acts as the setting and major ideological critique of this thesis. I argue that it is within this NPM ideology that NNs and PCC exist, and it is this framing that provides the insight into the challenges and tensions in the delivery of PCC features.

New Public Management in Australia: Measures, Markers, and Risk

Like many developed countries, Australia's healthcare expenditure has been described as uncoordinated and ineffective, supporting the OECD suggestion that: "a significant share of health spending in OECD countries is at best ineffective and at worst, wasteful" (OECD, 2017b, p. 2). The OECD identifies the major causes of wasteful expenditure in health care as duplication of care across multiple and siloed services, and repetition of diagnostic tests, as secondary to uncoordinated care. Other examples provided by the OECD are overdiagnosis and overtreatment[8] and low value-care, whereby the care provided is likely to be ineffective for a group of patients, or the patient receives treatment they do not want (OECD, 2017b). In recent years, the term potentially preventable hospitalisation (PPH) has been introduced, whereby a person's admission may have been avoided through the provision of an appropriate intervention such as early disease management (AIHW, 2019b). Around 748,000 admissions are classified as PPH in Australia annually (AIHW, 2019b) with the average cost of admission being

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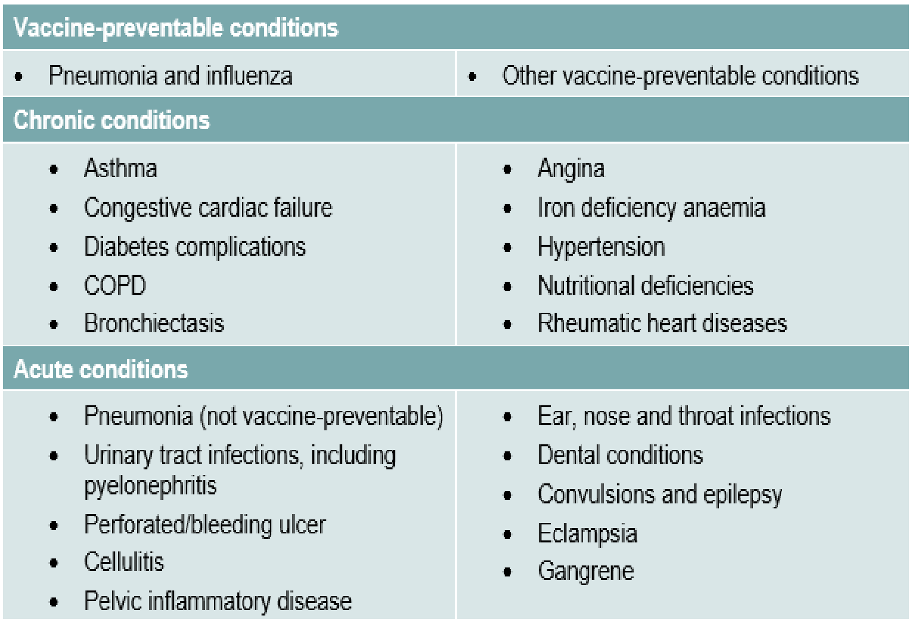
[8] For example, imaging for headaches and proton pump inhibitor use in the emergency department.

AUD$5,027. The average length of stay is 2.4 days equating to AUD$2,094 per day and this accounts for considerable healthcare costs (IHPA, 2021).

In line with the NPM ethos, PPH is a key performance indicator of the Australian National Health Performance Framework (NHPF) and is aimed at maintaining the efficacy and efficiency of public services. While not linked to any specific policy of funding, the NHPF acts as the performance assessment, planning and benchmarking of the health sector (National Health Performance Committee, 2002). The NHPF covers three domains: health status, determinants of health, and health system performance. Indicator PI 22 showed that selected potentially preventable hospitalisations provide the identified conditions for PPH (see Figure 9) as well as a benchmark of 8.5% of total hospital admissions, meaning that health services must actively work to reduce their PPHs to less than 8.5% of all admissions (AIHW, 2019b).

Figure 9

Potentially preventable hospitalisation indicators



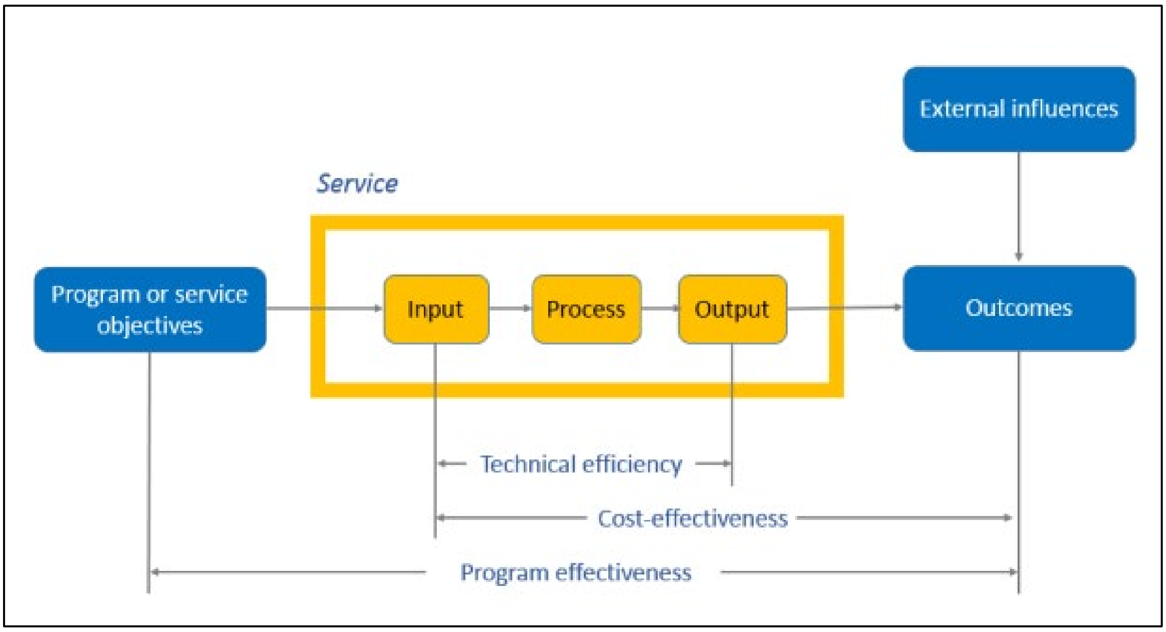
Vaccine-preventable conditions	
Pneumonia and influenza	Other vaccine-preventable conditions
Chronic conditions	
Asthma Congestive cardiac failure Diabetes complications COPD Bronchiectasis	Angina Iron deficiency anaemia Hypertension Nutritional deficiencies Rheumatic heart diseases
Acute conditions	
Pneumonia (not vaccine-preventable) Urinary tract infections, including pyelonephritis Perforated/bleeding ulcer Cellulitis Pelvic inflammatory disease	Ear, nose and throat infections Dental conditions Convulsions and epilepsy Eclampsia Gangrene

Note: From "*A guide to the potentially preventable hospitalisations indicator in Australia*" (p. 23) by Australian Commission on Safety and Quality in Health Care, 2017, https://www.safetyandquality.gov.au/sites/default/files/migrated/A-guide-to-the-potentially-preventable-hospitalisations-indicator-in-Australia.pdf

Regional areas of Queensland are particularly vulnerable to PPH with one study finding that 11% of all hospitalisations were classified as preventable, accounting for AUD$32.7 million of expenditure, highest amongst First Nations people (Harriss et al., 2019). The fundamental premise within this framework is that a functioning, efficient and effective primary health care system will see a reduction in the need for hospitalisations. This forms part of the ideology of efficient systems, working in cohesion to produce efficient outcomes. This can be further exemplified by Figure 10 below which demonstrates the service process model as defined by the Australian Health Performance Framework (2017).

Figure 10

Program logic model for technical efficiency, cost-effectiveness, and program effectiveness



Note. This figure demonstrates the program logic model to follow the service process employed in the Report on Government Services (ROGS). The ROGS service process model depicts the relationship between technical efficiency, cost-effectiveness, and program effectiveness. From "The Australian Health Performance Framework." (p. 9), by the national Health information and performance principal committee, 2017, https://www.aihw.gov.au/getmedia/1c95574c-ac07-4126-8b7c-31eb29d9b381/OOS318_Attachment-1.pdf.aspx

Preventable admissions and emergency department (ED) utilisation have subgroups of patients who have been identified as high risk. These are patients over the age of 65 years who account for 22% of all ED presentations. First Nations people who account for 6.7% (AIHW, 2018b) are considerably high in numbers when compared to their population percentages. Likewise, 65% of people over the age of 85 are admitted (AIHW, 2018b). This means that a relatively small cohort of people account for a large portion of spending, placing greater importance on the need to manage this demographic of people with chronic conditions. This gives rise to services which target these high cost/high usage individuals. One tool used to identify those at risk of service usage and associated costs is the **L**ength of stay, **A**cuity on admission, **C**omorbidity and **E**D (LACE) (van Walraven et al., 2010) index which has been found valid in targeting interventions to prevent readmission (Gruneir et al., 2011). A similar framework is used in the NN service.

Lexicon as a method of new public management

Frequent presenters to ED, and those requiring frequent admission, have been termed 'superusers' within the literature (Hanna et al., 2019; Gil et al., 2018). This term infers an overuse or disproportionate allocation of resources and is often linked to the problem of ED overcrowding or other resource issues. This was described by Hanna et al. (2019) as:

> A growing body of literature exists studying ED clinical superusers. These individuals are generally young adults or seniors and have higher rates of poverty, lower levels of education, greater incidence of chronic disease, and higher rates of non-ED healthcare use … Multi-morbid chronic disease, in particular, has a stronger association with frequent ED use among men. In many cases, frequent ED use is considered inappropriate, and thus may be a fruitful area for reduction in wasteful healthcare resources (Hanna et al., 2019, p. 162).

Superusers are presented as a problem for health services in managing costs and resource allocation with the problem extending to workforce satisfaction and moral/ethical distress, as this quotation from Puch et al. explains:

> Emergency nurses often are frustrated when caring for patients who have long-standing social, substance abuse, or behavioural issues. Many of these patients are frequent ED consumers and have learned demanding behaviours out of their dissatisfaction with the health care system and their perceived unmet needs. They absorb massive amounts of time and resources and frequently place emergency nurses in situations that pose ethical dilemmas and/or create moral distress (2010, p. 344).

The lexicon used in these two quotations focuses on the patient as the problem, despite the understanding that many individuals have social determinants that affect how they cope with their illness. It is this problematising of the patient as a consumer that embeds an ethos of wasteful social and health behaviours, perpetuating the idea that this is the individual's problem. The solution is then described through self-management to realise efficient management of health resources. The Nurse Navigator Toolkit states that admitted people should be "establishing independence" (QH, 2018a, p. 6)

The term superuser is often located within American literature and appears in published as well as publicly available discourse (see Boodman, 2013 for Kaiser Health News). In Australia, the term 'frequent flyer' is colloquially used to indicate a person who presents to emergency and/or has frequent admissions (Australian Healthcare and Hospital Association, 2011; Stafford, 2019). The eligibility criteria for the NN centres on frequency of admission and usage, as this statement suggests:

> Referrals are received from many sources from a multitude of service providers, consumers, and non-government organisations. Eligible consumers can also be proactively pulled into these services using hospital data such as emergency

> department data to identify frequent presenters (EDIS, FrequentED), and Queensland (QLD) government statistical branch data suggested candidates for nurse navigator recruitment report generated every three months identifying those at risk of increased admissions and readmission, increased length of stay (LOS) and frequent presentations to ED (Central Queensland Hospital and Health Service, 2019, p. 13).

Common characteristics of frequent presenters are those with chronic health needs and those of low socioeconomic status with increased mortality and morbidity (Shannon et al., 2020). Frequent presentations are always viewed as inappropriate and preventable, and thus, it can be argued that individuals can experience discrimination when going to hospital just because they are there (Shannon et al., 2020). In fact, labels, such as frequent flyer or superuser, embody the social, political, and cultural values within an organisation, meaning that frequent presenters may be viewed as wasteful and irresponsible, even though they have multiple care needs (Joy at al., 2016). This form of stigmatisation often occurs through, and is perpetuated by, discourse (Stangl, 2017).

A consistently used principle of these services is the delivery of PCC as the underlying method of engaging with consumers and in transferring skills of health literacy and self-efficacy to the patient (New South Wales Health, 2020; Pulvirenti et al., 2014).

Coordinated and Integrated Care: A Response to Fragmentation in Healthcare?

Coordinated and integrated care models recognise that for some people, care is complex, fragmented, and difficult to manage (Joo, 2014; Ehrlich et al., 2009; Ahmed, 2016; Askerud & Conder, 2017). Fragmented care has been described as the “Achilles’ heel” of healthcare (Ehrlich et al., 2009, p. 625). Healthcare sectors in Australia often work in isolation of each other, largely as a result of the business model which allocates funding to individualised services. This fragmentation model has resulted in duplication of care, absent or delayed services, reduced access to care, and disempowerment and frustration of the individual trying to access care (Primary Health Care Advisory Group, 2015; Sheridan et al., 2012). Hospital care, as discussed in Chapter Seven, is set up in specialist disciplines and this limits the amount of cross collaboration or engagement that can occur. The siloed structured of health care means that those with chronic conditions requiring multi-specialist input have higher rates of hospitalisation, higher incidence of departure from best quality care, higher healthcare spending, polypharmacy and have less input into their care (Frandsen et al., 2015; Sheridan et al., 2012). Health services have therefore looked to more integrated MOC delivery.

Conceptually, care coordination acknowledges the importance of three cogs in the healthcare wheel: the need for coordination and management of healthcare services for an individual to create continuous care, the need for coordination of providers through teamwork and shared knowledge, and the need for coordination of service delivery organisations within an integrated network (Ehrlich et al., 2009, p. 625). To facilitate this, there is usually a care/case manager who takes ownership of the person's journey and acts as a central point of contact and facilitation. The philosophy of coordinated care is that it holistically encompasses social and medical care, is planned, evaluated, involves advocacy and strong communication, and is person-centred (Ahmed, 2016; Askerud & Conder, 2017; Vanderboom et al., 2015). Care coordination programs are commonly seen in mental health, chronic and complex disease, and disability services (Bleich et al., 2015; Valaitis et al., 2017; Esterman & Ben-Tovim, 2002). Many services utilise nurses as the primary coordinators of the elements of social and medical care (Vanderboom et al., 2015; Askerud & Conder, 2017). To meet the objectives of patient engagement, holism, and working within a biopsychosocial sphere, care coordination models work closely with individuals and families and reengage them through building trust (Byrne et al., 2020), working on crisis and long-term issues, referring to other services, attending appointments, liaising with the multidisciplinary team, and improving the health and wellbeing of the family unit (Askerud & Conder, 2017; Ahmed, 2016). This is the same for the NN:

> *By the time we get the patients, they're … so broken by their interaction with the system. They grieve for things they've lost, and they feel guilty. They don't forgive themselves, so I focus on their emotional wellbeing and try to deal with that. It's the old oxygen on the plane thing; get your oxygen first then give it to everybody else.* Nurse Navigator

Despite this, the outcomes measures of coordinated and integrated care focus on self-efficacy that is measured through a reduction in hospital usage as a method of decreasing health care expenditure, as this statement suggests.

> Previous fatal illnesses have become long term conditions owing to improvements in technology and medicine, and the ageing population is living longer despite multi-morbidities. Both issues create a burden that the current healthcare system, both nationally and internationally, may be unable to cope with in the future (Askerud & Conder, 2017, p. 420).

While the demographics of the patient has changed, and advances in modern medicine have contributed to a higher life expectancy, the healthcare system remains episodic and acute based, siloed, and fragmented (Mold, 2017). Models and methods have evolved in response to this, however little change within the system is noted, evidenced by this statement:

> A number of people with chronic disease require higher intensity care because of personal characteristics that increase their vulnerability. This applies especially to the socioeconomically disadvantaged and to those who present with a comorbid mental health condition and multimorbidity … In addition to a compromised quality of life and an increased risk of social isolation, these individuals have

> problems complying with treatment, adopting healthy behaviours, and managing their health (Chouinard et al., 2013, p.2).

Thus, the individual within the healthcare system is positioned as a problem because they cannot take care of themselves, and they are expensive to keep. Despite the health services encouraging care coordination, they paradoxically argue that coordination is an expensive model of care. This is because the measure of success is focused predominantly on hospital admission reduction rather than a whole-of-care approach. Yet, a person with chronic disease will need hospitalisation at some point regardless of how well their care is managed. While there are examples of programs that report reduced hospitalisation (Joo & Liu, 2016; Joo, 2014), there is a plethora of evidence to suggest that coordinated care does not reduce hospital usage (Esterman & Ben-Tovim, 2002; Askerud & Conder, 2017; Vanderboom et al., 2015; Bleich et al., 2015; Plant et al., 2015; Peikes et al., 2009). Thus, PCC is invisible in NPM strategies that aim to reduce wasteful use of services. Yet, NNs appear to have found other ways of managing high risk, vulnerable people, even though their role requires a reduction in hospital admissions. It is more person centred and it takes time for the individual to trust the health professional as this NN described:

> *So, the mother was also severely abused. But she never talked about it. I had some information about it, but she'd shut off emotionally and she was exceptionally difficult to deal with. And that was why, but it was her daughter who I think to some degree, she trusted me a lot. And she offloaded on me and on everything, it was a two-hour phone consult and that took me a very long time to process [her needs].* Nurse Navigator

Many coordinated care programs and models utilise nurses as case managers or the central point of liaison. In fact, while coordination and case management were being developed (circa 1980s), so too was the role of the nurse in managing clients. Nursing was thought to closely align to case management through the process of assessment, planning, implementation, and evaluation (White & Hall, 2006). However, this was not a smooth journey for nurses. Constant role changes and a lack of clear role definition and development lead to role confusion and a lack of cohesion between nursing practice and organisational priorities. Lamb found that case management was “limited in theory and focused on outcomes” (Lamb, 1992, p. 152). Later, Smith (2011) found that role confusion and role conflict still exists in such positions. In Chapter Eleven, I have explained how this remains the case for NNs.

The presence of NPM within healthcare poses a particular conundrum for nurses, who represent the highest number of healthcare professionals and those closest to physical care of the person (AIHW, 2020d) and in that respect, to PCC. The role of nurse managers and nurses has changed under the impetus of NPM discourse with clinical tasks such as patient education taking a back seat to rationed care, work routines, costs, and standardisation (Bergh et al., 2014). Bergh et al. (2014) found that patient education was rendered an invisible task under the discourse of NPM. Within NPM, nursing care and skill are devalued with policy a driving force in conforming nurses within the language of managerialism (Hewison, 2001).

Nurse navigators have expressed similar tensions:

> *My core values that are [important to my] patient, it’s what they want. It’s them, not me. And I feel like their values are being questioned or being labelled [and] I don’t like that … then I’ll just say I don’t care what happens [with managers] because it’s about the patient. And that’s why I hate the term complaint … people roll their eyes when I see them, ‘they’re gonna FTA [Fail to attend an appointment].’ I’m like, ‘don’t do that … you don’t understand’.* Nurse Navigator

Nevertheless, nurses are utilised in many new models which aim to decrease service usage and self-efficacy. Pederson et al. (2011) states:

> The increasingly tightening fiscal barrier is part of the impetus behind developing a comprehensive patient navigation model. One benefit of patient navigation is the reduction of emergency resource use or specialist time. The reduction would occur as a result of the education, emotional support, or information provided by the navigator (p. 204).

The authors go on to say that while navigation models are not exclusive to nurses, those that do utilise nurses place emphasis on understanding the physical and psychosocial needs of the person through an "empathetic communication style" (p. 205). This solidifies the role of the nurse as one of caring and empathising while considering the whole person (mind and body). Divergence starts to become apparent when looking at the way such models are measured and therefore valued.

What is Value? Measuring the Efficiency, Outputs, and Value of Care

Most coordinated care programs report positive patient outcomes including meeting the unmet social, cultural, and biomedical needs of patients (Ehrlich et al., 2009, Esterman & Ben-Tovim, 2002), improved quality of life, patient satisfaction (Bleich et al., 2015) and self-management (Askerud & Conder, 2017). Askerud and Conder (2017) state that the "availability, accessibility, trust and communication [that] the nurse case manager offered for people are indicative of patient centred care" (p. 427). However, this level of care may come at increasing service costs, secondary to reengagement of the person to services and addressing unmet needs (Esterman & Ben-Tovim, 2002; Ehrlich et al., 2009). This level of reengagement and liaison comes from solid clinical practice and support provided by the nurse, yet this type of work is often unaccounted for with no key performance indicator representing its value and not considered in service funding.

For nurses, the tensions lie within doing what they feel is right for the person versus what is right for the system as the following NN quote suggests.

With reference to health service funding and the work NN do:

> *They're happy for us to do the obvious nursing stuff around the edges, but when it comes to actually implementing plans or making changes, they're not that greatly engaged with the aspect, and I think some of that is driven by funding and the impact that that potentially has on their pocket.* Nurse Navigator

NNs feel insecure about their future and are motivated to demonstrate the value that they add to the system, as the field note below describes:

> *Recurrent theme—ongoing funding and backfill. NNs express that they feel the need to 'justify' themselves via the research in the hopes they will be able to save their positions. Finance officers only look at the numbers.* Author's field note

The numbers referred to in the author's field note above are the number of hospital admissions prevented and cost savings. Researchers have questioned the validity of hospital avoidance as a measure of success for such services stating that they are "misguided" and that care coordination is a more functional model (Esterman & Ben-Tovim, 2002, p. 470).

> It is clear from this review that the practice of coordinated care as it pertains to chronic disease has not yet advanced nor the more philosophical thinking about equity across different populations, the rights of individual health consumers, the values through which individuals view their health, the importance of consumers working toward their own health goals and the notion of consumer-driven health care (Ehrlich et al., 2009, p. 626).

Research completed by the AIHW supports this work, finding that PPH increases in First Nations people, the elderly and those living in remote areas. For this reason, PPH is not always an effective measure of care with higher rates of disease and lifestyle factors contributing to a genuine need for hospital services (AIHW, 2020b). Based on the intake criteria, navigated people are complex, with multimorbidity, requiring multiple service needs. The measure of hospital avoidance and admission may very well be misguided for this cohort, and instead, I will suggest in later writing a measure more commensurate with multimorbidity and structural social disparity.

In summary of this chapter, the social side of care is an important factor in care coordination and one with important outcomes that closely aligns with the concept of PCC. However, its appearance in evaluation measures is difficult to quantify and is thus absent from many coordination models including the NN service. Within the discourse and the ethos of the hospital system, hospital admissions are now accepted as preventable and there is evidence that this has contributed to a changing role of the individual with chronic conditions and the nurse. This has been perpetuated through the deeply ingrained NPM movement which has legitimised health services as a business of efficiency, efficacy, and productivity. At the height of the NPM movement, Dawson and Dargie (1999, p. 472) asked, “is health just another commodity?” This remains a valid question in today’s context. This has a flow on effect seen in the way that chronic care models and services are (re)framed.

Chapter Nine—(re)Framing Chronic

Summary of Chapter

In this section I will continue with the analysis of discourse related to NN and PCC by exploring how chronic health management has been framed and reframed. It presents the way that healthcare MOC, healthcare professionals and individuals have been created and recreated as services and people belonging within the healthcare institution therefore, demonstrating how technologies of government work to conform people into ideals.

This chapter demonstrates how all elements of healthcare are considered as resources, including people, structures, space, and time, uncovering the context and conditions which inform how PCC is viewed and practised by nurses. It presents an argument that health services have moved away from the responsibilities of health care in favour of NPM principles of efficiency and productivity and paints a narrative of the effects that this has on individuals and families. This argument is then juxtaposed against how NNs view and practise PCC.

(re)Positioning Chronic Disease Management in Primary Health Care; Reality for Those with Multimorbidity

In Chapter Seven I discussed the positioning of PHC as the central coordination point for health, surveillance, and the management of care. The GP, who is a medical doctor, is located in a community practice setting and is situated as the manager of primary health care in Australia, which encompasses being the first entry point to care, provision of early intervention of care, and coordinator of out of hospital care (AHMAC, 2017). However, there is evidence of a disconnect between medical models and medical practice and the original remit of PHC as directed by the Alma-Ata. The declaration positioned PHC as the *responsibility* of governments and a *duty* of individuals:

> Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organisations and the whole world community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice (p. 1).

And

> The people have the right and duty to participate individually and collectively in the planning and implementation of their health care (p. 1).

The excerpts above set the scene for PHC as the way forward for health and wellbeing, and in that sense, equity, and social justice. It suggests that PHC will address all facets of health through a coordinated and person-centred approach to care. Yet, people with multimorbidity are recognised as vulnerable to social and cultural inequalities, as well as structural vulnerabilities related to the delivery of health care from multiple points of service (Harvey et al., 2020). The Australian Government has acknowledged GPs as the central coordinator of complex care (Department of Health, 2014), yet NNs refer to the difficulties their patients have in accessing and receiving the care they need from the GPs. This NN said:

> *There's the complexity of the relationship between the GP, who is seen as God in the facility. There's a high turnover of staff. So, there's almost a constant re-engagement with the staff, or with the facility manager, or even where the GP might change over to another GP, there's that re-engagement with another GP, who, to be honest, they're happy for us to do the very obvious nursing stuff around the edges, but, when it comes to actually implementing plans or making changes, they're not that greatly engaged with that aspect, and I think some of*

> *that is very driven by funding and the impact that that potentially has on their pocket.* Nurse Navigator

Thus, patients who are struggling to access care through their GPs experience increased stress as they often have nowhere to turn to for information and advice, as one NN indicated:

> *So, once a person's left the hospital, trying to liaise back to the treating team is complex, often they're not interested, GPs are historically difficult to get hold of to discuss [care].* Nurse Navigator

People with multimorbidity experience reduced QOL at rates higher than those with one chronic condition and this significantly impacts on health and wellbeing and the ability of a person to cope with their illness (Makovski et al., 2019; Pati et al., 2019). The NNs also noted that people often become overwhelmed and anxious dealing with multiple providers. They find it difficult to manage their care and to maintain control of their care and this in turn affects their QOL, as the NN noted:

> *That patient is quite anxious and quite stressed, and I think she was quite happy when she could see that someone was doing something to make these appointments … making sure that these three clinics with that we were communicating with and trying to make sure everything was okay because there's a lot of frustration, a lot of anger and anxiety.* Nurse Navigator

Thus, the additional stress of dealing with the difficulties of accessing health care increases the person's workload for self-management and contributes to functional impairment (Hussain et al., 2018). This is seen in the NN dataset QOL measure, demonstrated later in this chapter.

In addition to the challenges of accessing care when required from the GP, research has shown that families of those living with multimorbidity spend significant amounts of their yearly income on healthcare (>10%). Not coping and not getting timely access to care they can afford means that patients are less able to cope with life and illness, meaning that their quality of life is reduced. The financial burden, therefore, can extend to lost income due to being unable to work, lost functional capacity and increased mortality and morbidity (Sambamoorthi et al., 2015).

The principles of PHC in Australia aim to address these inequalities. The principles describe a system which is comprehensive, equitable and fair, recognises the broader socioeconomic and environmental impacts on health, is coordinated and collaborative, addresses societal influences to promote health and wellbeing, supports informed citizens, and is designed around the long term needs of the population (Public Health Association Australia, 2014). Yet the promise of this through PCC is not visible in the discourse or in the experiences of NNs and the people they care for.

There are several known barriers to PHC in Australia. Recommendations to strengthen PHC include a greater focus on social issues, more detailed focus on management and prevention of chronic disease, and a restructure of fees and co-payments (van Gool & Hall, 2016). General practitioners in Australia typically make their revenue from high volume, short appointments, averaging 10.7 minutes (Deveugele et al., 2002) thus maximising Medicare billing. What is missing from these short consultation times is the exploration of psychosocial/cultural factors and disease management (Lemon & Smith, 2014). Under the billing/revenue structure, time becomes an important resource that must be managed by the business to capitalise on revenue.

Time as a problem, releasing time as the solution

Viewing time as a resource has led to some interesting changes to health care delivery internationally. Changes are occurring with how general practices are managing their clientele and their staff workloads. In 2015 in response to growing population demands and a decreasing GP workforce, a report was commissioned by the Primary Care

Foundation that found four key issues with bureaucracy in practices, getting paid, processing information from hospitals and other providers, keeping up to date with changes, reporting other information, and supporting patients to navigate the National Health Service (NHS). The central problem amounts to time in relation to income, rather than patient need, thus the solutions revolve around “releasing time”, i.e., reducing social presentations and increasing medical consultations (Clay & Stern, 2015, p. 4). From the foreword:

> All of the ideas highlighted in this report take time, effort and in some cases, additional resources. But taken together, they could release a lot of time and effort, freeing GPs to deliver the job they were trained to do and care so passionately about (Clay & Stern, 2015, p. 4).

One of the strategies advocated for in the report aims to reduce the number of presentations to GPs, labelling certain presentations as “potentially avoidable GP consultations” (p. 6). To distinguish between what is and is not avoidable, a separation of medical and psychosocial is described:

> Overall, 27% of GP appointments were judged by respondents to have been potentially avoidable, with changes to the system around them. The most common potentially avoidable consultations were amenable to action by the practice, often with the support of the Clinical Commissioning Group. The biggest three categories were where the patient would have been better served by being directed to someone else in the wider primary care team, either within the practice, in the pharmacy or a so-called ‘wellbeing worker’, e.g., care navigator, peer coach, health trainer or befriender. Together, these three which could be improved by more active signposting and new support services accounted for 16% of GP appointments (p. 7).

As such, one key recommendation out of this report is the idea of social prescribing (SP) for those with chronic disease and mental health conditions. Social prescribing centres on linking frequent GP presenters with community and non-government social supports to facilitate improved wellbeing. Kilgarriff-Foster and O'Cathain (2015) state:

> General Practitioners (GPs) report that over 20 percent of consultations involve dealing with patients' psychosocial needs … GPs can feel unable to manage these because of time constraints, a limited knowledge of available support and because referral to traditional psychological services may not be appropriate (p. 127).

An interesting point is raised here: if the GP has a limited knowledge of services available, how is the *patient* to know what is available? Who is responsible for knowing what services are available and linking the patient to these? The idea of having limited time and capacity legitimises the use of SPs from the GP's financial perspective:

> Primary care patients present both medical and psychosocial problems to GPs. Responding to psychosocial problems, such as social isolation and housing issues is often beyond the capacities of healthcare professionals and too complex to address within the time constraints of the consultation … [Social Prescribing] has the potential to improve the health and wellbeing of service users and to reduce health resource use (Pescheny et al., 2018, p. 1)

And

> A recent influential report for UK GPs has suggested that SP is one of the ten high impact actions to release capacity (Loftus et al., 2017, p. 100).

This statement not only positions SP as a more financially viable option than GPs for social care, but it also suggests that the GPs can only deal with one part of a person: the medical/clinical side. Yet psychosocial issues are linked to health and wellbeing with many people turning to their GP for assistance. As with care coordination, the evidence for SP is dichotomous with little evidence available that it reduces the use of GPs or decreases polypharmacy (Loftus et al., 2017). In the United Kingdom, there is evidence that SP is on average GBP£20 more expensive per person compared with usual care (Kilgarriff-Foster & O’Cathain, 2015) and that it does not improve health and wellbeing (Carnes et al., 2017). While SP is viewed favourably by individuals (Carnes et al., 2017), it is not effective in reducing GP workload (Husk et al., 2019).

Contrary to this, NN interviews identify that they address the unmet needs of the individual, needs that have not been addressed by the GP or the hospital system. In fact, some navigators have reported patients being banned from GPs for non-compliance and non-payment. One NN explains:

> *I did beg and plead with the other GP there. He would take her over … she has a unique personality; she needs a strong doctor. Since then, probably about six to eight weeks ago, I received the call to say that the practice could no longer provide a service to [patient], because of her, quote, drug seeking behaviour and abuse towards doctors and staff. So the plan was that they would continue seeing her for another three more sessions and then discharge her from their practice.* Nurse Navigator

The discourse described has outlined that PHC is not supporting chronic care patients and that the Australian system of GPs as the primary point of care is dysfunctional. Under the current model, care is not about the patient’s multiple and often social needs, but it is about the time which is dictated by the revenue that practices receive from patient occasions of service. General practices do receive revenue for chronic disease management in the form of Chronic Disease Management Plans, however, revenue available on these plans is capped at every 12 months and at the completion of a care cycle (Department of Health, 2021). In fact, the uptake of such care plans is relatively low with a study by Holden et al. (2012) finding that GPs feel that chronic disease care plans require phone calls and organisation which takes up too much time. One participant of this study stated:

> From a business perspective, CDM is not optimal for profit (Holden, 2012, p. 975).

Separation of mind and body

Time and revenue are the focus of care in the current system, not PCC. Time as a resource is problematised and thus preventable GP appointments and SP become suitable solutions to this problem. This is done through the separation of the biomedical and the psychosocial. Articles refer to SP work as “non-clinical” (Pescheny et al., 2018, p. 1) and “non-medical” (Loftus et al., 2017, p. 100), thus embedding a truth claim that social support cannot be provided in general practice. *Pulsetoday*, a general practice website described the evidence behind SP as a “mess” (Price, 2017, para. 2). However, some GPs are supportive of programs which reduce workload, accountability, and time:

> The great thing about social prescribing here in Gloucestershire is that the receptionists can identify and refer the patients, without them coming to me. Or if they ask me for a housing matter, I can just bat them straight to the social prescriber. These people are reducing my workload, and although the evidence base may not be there, I really strongly think we should be increasing the evidence base, not throwing out the baby with the bathwater. There is precious little else that genuinely reduces the rubbish I have to wade through on a daily basis—social prescribing is a huge benefit to let me get on with the medical side of it, and actually feel I can pass them on to someone who can help them with the social side of things. Absence of evidence is not the same as evidence of absence. Get working on creating a decent evidence base before dissing this one! (Proud Cardigan, 2017, p. 1).

Seen within this discourse is a need to get on with the ‘medical side of it’, which perpetuates a hierarchy of importance for GP matters which does not include holistic care. Policy makers in the United Kingdom are moving forward with SP by offering social packages within the Health Secretary’s New Deal for General Practice (NHS, 2015) in the form of care navigators. Their role, and the role of SP, is described as:

> [S]upporting people to overcome chronic illness and unhealthy lifestyle; enable people to learn new skills; support people to become less grant dependant and find work; provide tools to create an enterprising community; and allow more costs efficient and effect use of NHS and social care resources (p. 47).

These goals are similar to those of the NN service in Queensland, yet SP in the UK can be any care worker with minimal experience. The UK plan to move SP forward harbours importance to Australian healthcare. Australia has adopted UK based programs and MOC, e.g., the Productive Ward (NHS, n.d.; Davis & Adams, 2012). United Kingdom based models are using lay persons or non-health professionals as social prescribers, yet Australia is currently using health professionals such as social workers, occupational therapists (PCCS, 2020) and of course NNs. What NNs can bring to care as professional, clinically experienced nurses is a holistic knowledge of the medical system, system processes and disease trajectories to the care of the individual. Nurse navigators combine this with skills in negotiation and engagement to pave the way for care throughout multiple systems. It is the high level of clinical decision making and professional maturity that NNs bring to the position which merges the medical and the psychosocial/cultural elements of care (Harvey et al., 2021).

SP is now making headway in Australia, with the Royal Australian College of General Practitioners (RACGP, 2019b) supporting its implementation:

> Social prescribing is already happening in Australia, with small pockets of innovation and a small number of trials underway across the country.

> Many health practitioners already incorporate social prescribing into their daily practice, but it is not supported or recognised by the funding mechanisms and structures in the health system (p. 6).

Advocacy for changes to current funding models to incorporate social care into GP work is absent from the RACGP document. The only discussion around funding in this document is within the context of providing finance for SP positions.

In the Australian context, the discourse around SP is expressed as holistic care for the person, e.g., "When frequent patients come to us seeking a chat and reassurance, we provide that immediate social outlet. We then look for ways to help them reengage, to stop them falling out of society" (Nespolon, 2019, para. 6). While social isolation and loneliness is cited as the problem which SP can overcome, the measures of such a program alludes to a problem of frequent GP appointments and an associated decrease in GP time, rather than addressing the unmet needs of a patient as the below media excerpts suggest:

> Participants came an average of one visit fewer over a three-month period after the social intervention (Hendrie, 2018, para. 16).
>
> Social prescribing has seen outcomes in reduced emergency department usage, reduced inpatient admissions, reduced general practice over-attendance, [and] reduced GP workload (Larter, 2019, para. 5).

This suggests that Australia's adoption of SP is based on the benefits of GP and hospital reduction. How GPs coordinate SP into their medical care is less clear. This is an important point given that coordination of care by Australian GPs is already fragmented, with only 57.4% of those people receiving coordinated care in Australia reported that this was from their GP (Australian Bureau of Statistics [ABS], 2020). This represents a malalignment between the principles of PHC and the reality of care in Australia demonstrating care coordination and integration of care is not currently prioritised.

Herein lies a tension point of PCC delivered within the discourse of PHC and chronic disease management. General practitioners are moving away from managing the psychosocial and prioritising traditional medical work, i.e., diseases of the body. On the other hand, NNs, positioned alongside the hospital system, are filling some of the gaps with psychosocial and cultural PCC. Where GPs are working to separate the medical from the social, NNs are working to bring it back together in a holistic way. It appears that the value of such nursing positions in general practice has been stifled due to the funding method of time as revenue.

The above framing of chronic disease management in PHC leads to a particular positioning of people with chronic disease, both the person as a patient and as a citizen.

(re)Positioning the Role of Patients/Citizens

NNs are tasked with delivering four key role principles: coordinating patient centred care, creating partnerships, improving patient outcomes, and facilitating systems improvements (QH, 2018a). As discussed previously, the role is designed around bridging the disconnect between hospitals and GPs in care that serves to manage complex people. In Australia, despite the discussion about GPs moving away from social care, the number one reason for people presenting to a GP is psychological concerns with the issue of consultation times raised in one Australian Broadcasting Corporation (ABC) news report:

> At the moment, there's really only one [Medicare] item number for mental health issues, which is a 20 minute consultation … In other words, you can sort out all mental health issues in 20 minutes—which we all know is not true. Without longer subsidised consultations, Dr Nespolon said many GPs were being forced to cram

> patients with complex needs into short appointments, charge patients for more time, or wear the out-of-pocket cost themselves (Willis, 2019, para. 9).

The (in)ability to self-care is described as a contributing factor in the utilisation of GP time and services in the UK:

> Part of it might be reduced self-care, I think. It used to be the case that most people learned how to look after themselves, passed on family remedies ... There is less of that ... When you are ill, the first port of call ... It is not your mum or dad, it is the GP (The Kings Fund, 2016, p. 25).

Foucault (2008b) argues that under governmentality and biopolitics, there is a move to activate patients to foster self-control and efficacy, utilising the potential of the citizen within the healthcare arena. To exemplify this, I refer to a UK based curriculum known as the Expert Patient Programme (EPP). The EPP, based on early works around self-efficacy and motivation, was introduced to the UK in the early 2000s in line with NPM ideologies and targeted those with chronic illness. The five management skills of the EPP include problem-solving, decision making, resource utilisation, formation of patient-professional partnership and taking action. The EPP was designed to build self-efficacy and health competence often referred to as health literacy through a six-week course delivered by lay volunteers (Rogers et al., 2008). While on the surface, recognising and appreciating the expertise of patients within their own illness is a positive step for person-centredness, inside the rhetoric of the program were subtle amendments to the role of the patient as a self-managing person who takes ownership and responsibility for their care.

> People are more likely to change their behaviour and have confidence in doing so if they perceive those around them, including their health care providers, to be supportive. All it takes is a kind word and a notice of even small accomplishments (Lorig, 2002, p. 815).

The management skills above urge patients to not only lead a healthier lifestyle, but to take responsibility for their choices and their use of health resources. The underlying assumptions of the program are that those with chronic conditions are capable of and willing to take control of their health and that control of one's health will lead to a reduction in healthcare usage (Greener, 2008). However, given the social, cultural, and economic influences of health and wellbeing, self-efficacy may not always be achievable. Clarke alluded to this in stating:

> New Labour likes to see people being busy and active citizens [and this has] been promoted across a variety of intersections between the state and members of society. Active citizens were a means of reducing cost activity pressures on the National Health Service—becoming 'expert patients', taking on managing their own lifestyle and wellbeing, and requiring less direct attention from hospitals and general practitioners.' (J. Clarke, 2005, p. 448).

This positioning of the patient as a responsible citizen was described by the NNs. Some suggested that patients with chronic conditions were viewed with stigma and judgement as they had 'allowed' themselves to become unwell. However, many people in the NN service describe a whirlwind life of trying to manage their own health needs as well as that of their family. The structures of the healthcare system necessitate the need for people with chronic conditions to manage multiple services and appointments often with little support or guidance and often discounts structural issues for ascribing responsibility to the individual under NPM. When people are unable to manage this, they are listed as a ”failure” (Byrne et al., 2020). Referring back to Figure 6, it is clear that for some, managing their health and social wellbeing is a complicated and delicate balancing act.

Clarke makes the connection between empowerment and responsibilisation; the citizen enjoys the rights afforded to them only through their own responsible behaviours and choices. The citizen is thus “moralised”; a responsible citizen makes good choices while an irresponsible citizen will make bad decisions, such as smoking cigarettes or consuming alcohol (J. Clarke, 2005, p. 451). This positions those who make ‘bad’ decisions as wilfully irresponsible; a notion which ignores the fact that choice is determined by the distribution of resources, opportunities, culture, and other social determinants and structures (J. Clarke, 2005; Bourgois, 2017). Additionally, the expectation of self-care may remove the need to review and adjust the social, political, and economic aspects of policy and procedure. Wilson et al. (2007) warned of this paradox:

> First, there is the continuing biomedical, dualistic discourse of the separated mind and body with expert patients expected to self-manage their disease as a separate entity from the rest of their life. Second, the contemporary discourse of the biopsychosocial model and patient centred care has created a situation where patients are expected to disclose details of their psychosocial life to the doctor and make behaviour changes for disease prevention and management purposes. Thus, empowerment becomes problematic when there is a focus on changing an individual’s behaviour rather than societal structures (p. 434).

With time as a resource and a finite commodity within the healthcare structure, patients/citizens are increasingly required to take responsibility and ownership for their care. However, this ownership does not represent more power. Lorig (2002) cited a telling quotation from the Medical Self-Care Magazine some years ago which professed that “physicians would get off their pedestals when patients got off their knees” (p. 815). This is telling, given that pedestal is defined as the foundational support of an object and is also used to describe someone who is uncritically admired (Dictionary.com, 2020). Herein lies the reiteration of medical dominance and the articulation of the role of patient, passive and subordinate, yet self-effective and self-managing. With patients now expected to avoid hospital and general practices, individuals have little option other than to manage themselves. This draws into question what the role of PCC is, especially for those who may be unable or unwilling to manage their own care in conjunction with several specialists. It may be the case that citizens are expected to never become a patient at all. Thus, PCC as described in health policy, remains invisible.

Indeed, Foucault discusses the rise of medicine, and the medical gaze as an omnipotent concept within which people exist:

> Medicine will no longer be confined to a body of techniques for curing ills and of the knowledge that they require; it will also embrace a knowledge of *healthy man*, that is, a study of *non-sick man* and a definition of *model man* (Foucault, 1973, p. 34).

However, as I have expressed in this chapter, this medical gaze is not solely driven by the health institution or the people within it, but rather the political authority that governments have over health and wellbeing, designed around the “model man” (Foucault, 1973, p. 34). This model man is not a sick one.

One element that is absent from the discourse is the notion of time from the patient perspective. In the person’s context, concepts such as wait times, waiting lists, access times to GPs and specialists are absent. The person is discursively positioned in the centre of care, yet their time and spaces are not accounted for in healthcare structures. This leads to a disconnect between services and people, who enter and exit at finite points. Patient time is represented linearly, which may not be consistent with PCC.

In this way, the person themselves is viewed as a resource to be activated. Nurses are viewed in the same way.

Managing the Resource of Nursing

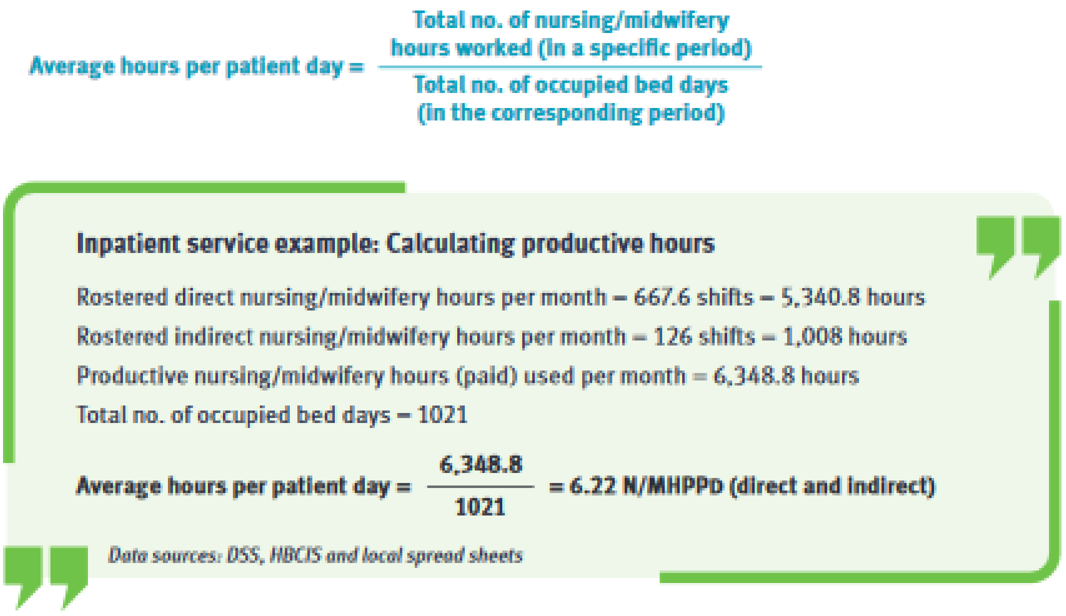
In 1999, a ministerial taskforce on nursing recruitment and retention found that QH had no means of effectively analysing and managing staffing level requirements, and subsequently recommended a planning model for nursing to be developed. The first publication of the Business Planning Framework (BPF) occurred in 2001 and over subsequent years, was negotiated between QH and the QNU (now known as the Queensland Nurses and Midwives Union [QNMU]), becoming a part of the enterprise bargaining agreement for nurses in the state. The BPF is described as:

> A systematic process for examining an organisation and its environment in order to best allocate resources to meet service demand. A business plan (sometimes referred to as an operational plan) is the working document that articulates the strategies for achieving the goals of the service. It is through the use of this process that nursing resources will be allocated to most appropriately manage workloads (QH, 2008, p. 3).

Research conducted in partnership with the QNU found that nurses in Queensland were most concerned about workload and the skills mix of nursing expertise (Hegney et al., 2006). Hence, continued advocacy of the QNU saw the introduction of nurse-to-patient ratios through an amendment of the *Queensland Hospital and Health Boards Act* (2011) enabling this. This change ensured that facilities not only need to comply with prescribed ratios of nursing and midwifery hours, they also must comply with workload provisions as a way of ensuring adequate staffing levels (QH, 2016a). The BPF ensures that each unit has a service profile (a document detailing the unit, the type of care, the number and skills mix of nurses and future direction of the unit), and a numerical resource allocation. To create the resource allocation, nursing hours are divided into two factions; productive hours, e.g., direct clinical activities, home visits, medication administration, documentation, and non-productive hours like annual leave, professional development leave and sick leave, to account for a variety of tasks required and entitlements of the nurse. The BPF is then used as a reconciliation between service usage/demand and nursing hours, providing a method to balance the supply and demand of nursing (QH, 2016a). Figure 11 below provides one example where admission activity for the unit or ward is divided by the number of nursing hours worked (see Appendix E).

Figure 11

Calculating average hours per patient day



$$\text{Average hours per patient day} = \frac{\text{Total no. of nursing/midwifery hours worked (in a specific period)}}{\text{Total no. of occupied bed days (in the corresponding period)}}$$

Inpatient service example: Calculating productive hours

Rostered direct nursing/midwifery hours per month – 667.6 shifts – 5,340.8 hours

Rostered indirect nursing/midwifery hours per month = 126 shifts = 1,008 hours

Productive nursing/midwifery hours (paid) used per month = 6,348.8 hours

Total no. of occupied bed days – 1021

$$\text{Average hours per patient day} = \frac{6{,}348.8}{1021} = \text{6.22 N/MHPPD (direct and indirect)}$$

Data sources: DSS, HBCIS and local spread sheets

Note: From *Business planning framework: A tool for nursing and midwifery workload management* (5th ed.) by Queensland Health, 2016a, https://www.health.qld.gov.au/__data/assets/pdf_file/0035/666908/bpf.pdf

The BPF is now a mandatory nursing workforce allocation tool used across QH, legitimising the idea of nursing as a resource, with this resource being essential to health service productivity and patient safety. The discourse suggests that appropriate nursing resource allocation will manage workforce spending, while also ensuring that there are enough nurses to manage patient care and safety (QH, 2016a; Olley et al., 2018; Driscoll et al., 2019). However, those patients with chronic conditions, and those with multimorbidity, require more time, coordination, and congruence from healthcare providers to effectively manage their care (Petrakaki et al., 2018; Pulvirenti et al., 2014; Pedersen et al., 2014).

While the BPF provides a method for nurses to escalate workforce concerns, the document is now primary geared toward the management of nurses and midwives as resources:

> The BPF is the process for hospital and health services to manage nursing and midwifery workload supply and demand, including how a service: calculates its nursing and midwifery human resource requirements; develops and implements strategies to manage nursing and midwifery resource supply and demand; evaluates the performance of its nursing and midwifery resources; [and] reports workloads and escalates variances/issues/discrepancies (QH, 2016a, p. 4).

Absent from these workforce calculations is the time, space, and structure that nursing *care* requires; calculating nursing hours by task does not quantify the rich and diverse work (or care) that nurses do daily, and this is particularly essential with patients who live with multiple chronic conditions where care extends well beyond the hospital walls.

This is also demonstrated by one NN who stated:

> *Well, the HHS is a financial institution. Yes, we're not funded. Hospital avoidance is not rewarded or funded by many in a lot of ways. So, what the app we've designed is going to do is actually allow us to collect all this information. It's been running for a month now and we're going to take that to the informatics team and our revenue team and actually pull it apart now to see what it is that we do.* Nurse Navigator

This has been highlighted in the literature with one study suggesting that "failure to understand what nurses do and measure these activities accurately, routinely and in a standardised manner, hinders any attempts to address workload issues at a national level in an effort to retain staff" (Duffield et al., 2006, p. 21). Importantly, what the BPF and workload tools do not specifically account for is the time that nurses spend with individuals outside of traditional tasks; the time they spend talking to them, getting to know them, and ascertaining their goals and needs; in other words, PCC. The BPF positions care in relation to safety, quality and optimal outcomes but falls short of providing a space in which nurses can practice PCC, and have this time genuinely acknowledged. Quantifying nursing care is difficult as one participant in a study by Vanderboom et al. (2015) stated:

> A lot of what we do is not easily measured. How do you measure nursing presence? We can look at the number of hospital readmits. Did we decrease that? But sometimes getting team members and multidisciplinary team members to buy into what we do without giving them a tangible piece of evidence that says this impacts this … and I can't always provide that for them, but I wish I could, because I know we make a difference. (p. 21).

This is an issue identified in the literature review in Chapter Three, in which Kitson et al. (2013) and Blomberg et al. (2016) identified limitations in capturing the richness of nursing practice which often leads to services being poorly evaluated. It also uncovers an ideology that the nursing profession should be managed to maintain optimal service and nursing performance.

One solution proposed to the problem of nursing time is programs such as the Productive Ward, where nurses are provided with the tools to improve workflow and work processes within their unit, thereby 'releasing time to care' (Davis & Adams, 2012, p. 354). Lean principles are applied to nursing processes and tasks, thereby streamlining services, and reducing waste (Davis & Adams, 2012). The ideology perpetuated with such programs is that efficient, productive services are better for nurses and for patients, while in reality, there is little evidence that lean programs and processes impact on patient care, or improve time spent with individuals (Brackett et al., 2013; Harvey et al., 2016).

Managing workload, fatigue and safe staffing levels is important. However, the unconscious effect that such frameworks have is that they legitimise the rationing of nursing care, the need to manage nursing hours and performance, and pigeon-holes the context and work of nursing itself. This work intensification was expressed by the NNs, for example:

> *We needed three days at the minimum so we can do service planning, entering the data, reviewing the data; all that. Not only have you got to answer the phones and help and problem solve and do the do the things the people are asking, then you've got to document it and data collect it and you know? So sometimes, that's more the burden than actually being able to get on with it.* Nurse Navigator

It is clear that nurses and NNs feel the pressures of the tension point between PCC, nursing tasks and what counts as productivity within their role.

Nurse Navigators as Drivers of PCC

I have discussed how services, including hospital systems and PHC, have framed chronic disease MOC within the time and resources available to them. This section will investigate the same framing of chronic care management from the perspective of the NN. In line with the above, the analysis investigates the notion of time to care, and how NNs use their time to address unmet needs and provide holistic services and support.

NNs in Queensland were introduced with the role principle of coordinating PCC, and with the purpose of reducing hospital usage. Early in the implementation process for NN, Beth Mohle, state secretary for the QNU stated in parliament:

> The way that we see the NN role is that they have a critical role to play in ensuring better coordination of care across the care continuum. We think that patient centred care really effectively in our current system is paid lip-service to. We talk about it, but we do not really do much to bring effect to it and we think all health professionals have a role to perform to ensure better coordination of care and to ensure that the patient is genuinely put at the centre of health and aged care decision making. We think that the NN role is an important potential

> game-changer in that regard to work across the whole continuum—acute, primary health care and aged care (Queensland Parliament, 2015b, p. 13).

As discussed in Chapter Two, the NN service started as an election commitment, with a pledge for 400 NNs across the state, to reduce hospital admissions (Hawker Britton, 2017). While the role was originally developed and implemented centrally through the OCNMO, each of the 16 HHSs across Queensland are independent entities and had ownership of how and where NNs were implemented within their service. Therefore, service and outcomes measures vary between HHSs; for example, some rural and remote health services utilise NNs for retrieval follow up and all discharge against medical advice occasions, while some metropolitan services use NN in specialist areas such as patient flow and radiology[9]. The measure of hospital avoidance, however, is consistent across all HHSs. This raised some concern for NNs who felt that the care coordination, engagement, and liaison work that they do with patients was not particularly valued by service managers (Byrne et al., 2021).

NNs work within a holistic, person-centred model to reengage the patient and their families. While they do sit outside of traditional hospital silos, they sit with the hospital sector and are therefore beholden to hospital funding structures and decisions, as well as to traditional nursing frameworks and discourse. Where NNs allocate their time and priorities is an important consideration in the delivery of PCC. One NN explained:

> *And so where we are at the moment has taken us all this time to get there, and this is where the navigator role is amazing. We have time to dig into people's lives and their past and work out what we can do to make their life, give them more quality of life and help them help themselves. We have that time. And I find that is the most amazing thing that nurse navigators can do.* Nurse Navigator

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[9] See inclusions and exclusions Table 3

Along with complex chronic conditions, almost all navigated patients have complex social, family, and cultural lives, who feel ostracised from care services leading to mistrust of providers (Byrne et al., 2020). The social elements of people's lives are often the most pressing and the most prioritised by NNs as expressed by one participant:

> *I did meet with her first and look, straight away, it was chaos. And the chaos has never stopped, which is probably a reflection of how I've managed her because it has been chaos. Most of the issues have been particularly social issues. So I'm just going to park that just for a moment … focus on her medical issues because that's what I'm supposed to do.* Nurse Navigator

This notion of prioritisation of care has led to a consistent debate about the need for senior nurses to fill the role of NN. In the NN evaluation, the justification of having a senior level nurse as NN is clear; the clinical expertise, and knowledge of the broader healthcare environment being essential to prioritising what is often complicated and multifaceted. Figure 12 below demonstrates how NNs achieve this through the continuum of care.

Figure 12

Nurse navigator continuum of care

Time Frame	Patient Journey	Navigator Intervention
First navigator meeting	Patient expresses feelings of abandonment; Mistrusts the health system; disengaged with care; multiple unmet needs impact on the capacity to cope with health conditions often resulting in FTA and DAMA.	Navigators undertake comprehensive assessment. They use effective communication skills e.g., listening, reflecting. They demonstrate authentic care through their frequent assessment of person and family often across multiple levels of clinical and social unmet needs.
0–6 months *Intensive*	Patient begins to work with the navigator; dependent on the navigator for support with medical appointments, understands care and medications; coordination of care; travel arrangements; housing; financial issues.	Frequent assessment continues, where care and unmet needs are prioritised. Navigators guide the patient, reaffirming their decisions, supporting them with education and advocating for them when meeting with the health care team.
6–12 months *Managing*	Patients now reengages with the health care team and services, working with the navigator to deal with issues and chronic conditions, becoming independent in managing care. Still needs the support of the navigator, but on their own (patient) terms. Often results in reduction in ED presentations and hospital LOS.	Ongoing assessment; graduated support; advocating; authenticity; reaffirming continued, but more at the patient's request rather than actively intervening.
Post 12 months *Maintaining*	Patient settles into a routine with the health care team. Requires contact with the navigator for information sharing and support only as needed.	Monitoring; maintaining contact on the patient's terms.

Note: From "*Queensland health nurse and midwife navigator evaluation*" by Harvey et al., 2021, Central Queensland University, ISBN978-1-921047-92-3

Currently, NNs are employed as level seven nurses (experienced, senior nurses in the health service, who's clinical and health system knowledge sets them apart from the level of the RN and the Clinical Nurse[10]), yet managers of the HHS have raised the issue of the financial viability of such a role. Social models in other countries use lay persons to provide social linkages, and as a result, NNs have consistently found themselves

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[10] Nurses in Queensland are allocated to levels 1-13, denoting their role, seniority, and autonomy. For example, a registered nurse is a level five, a clinical nurse is a level six, while a Director of Nursing is a level 10.

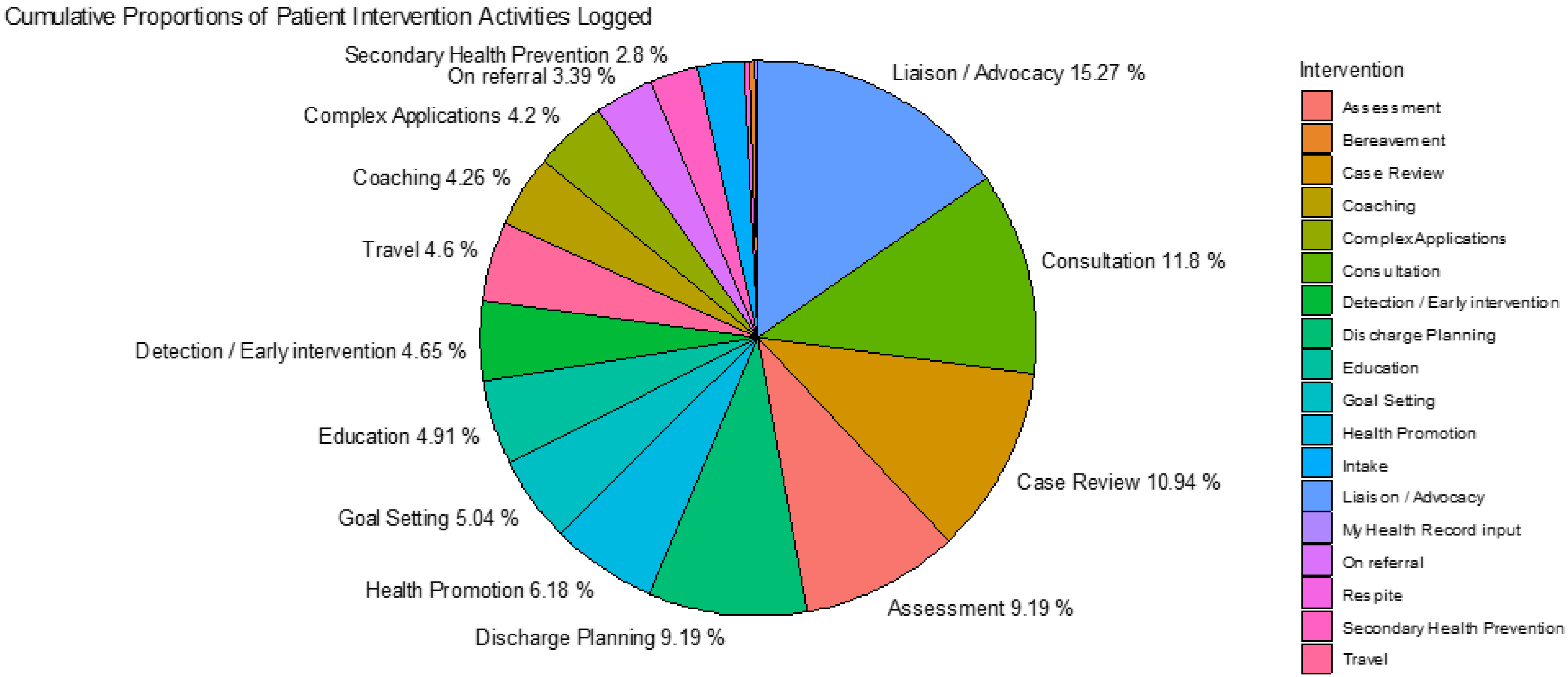
defending their work, even though they are providing everything they were asked to do using the principles provided in the Queensland Health Nurses' Navigator Toolkit, i.e., PCC (QH, 2018a). This constant questioning about what they actually do has caused NNs to express concern about their positions, and whether or not the role of NN is sustainable, as this NN indicated:

> *The constant informal scrutiny [from the financial officers], and the uncertainty [of our jobs] is an inefficiency in itself. Because that is absolutely psychologically wiping us out. We are not working to our normal user capacity because we are constantly being asked to show evidence of what we do … we are exhausted by the bullshit.* Nurse Navigator

With the above in mind, I now draw the argument to the work that NN do, and how they prioritise their time to provide care. A time and motion study was conducted by the evaluation team as part of the NN state-wide evaluation (Harvey et al., 2020). Figures 13 and 14 below describe the patient intervention activities, expected outcomes, and system activities recorded by NNs over a one-month period.

Figure 13

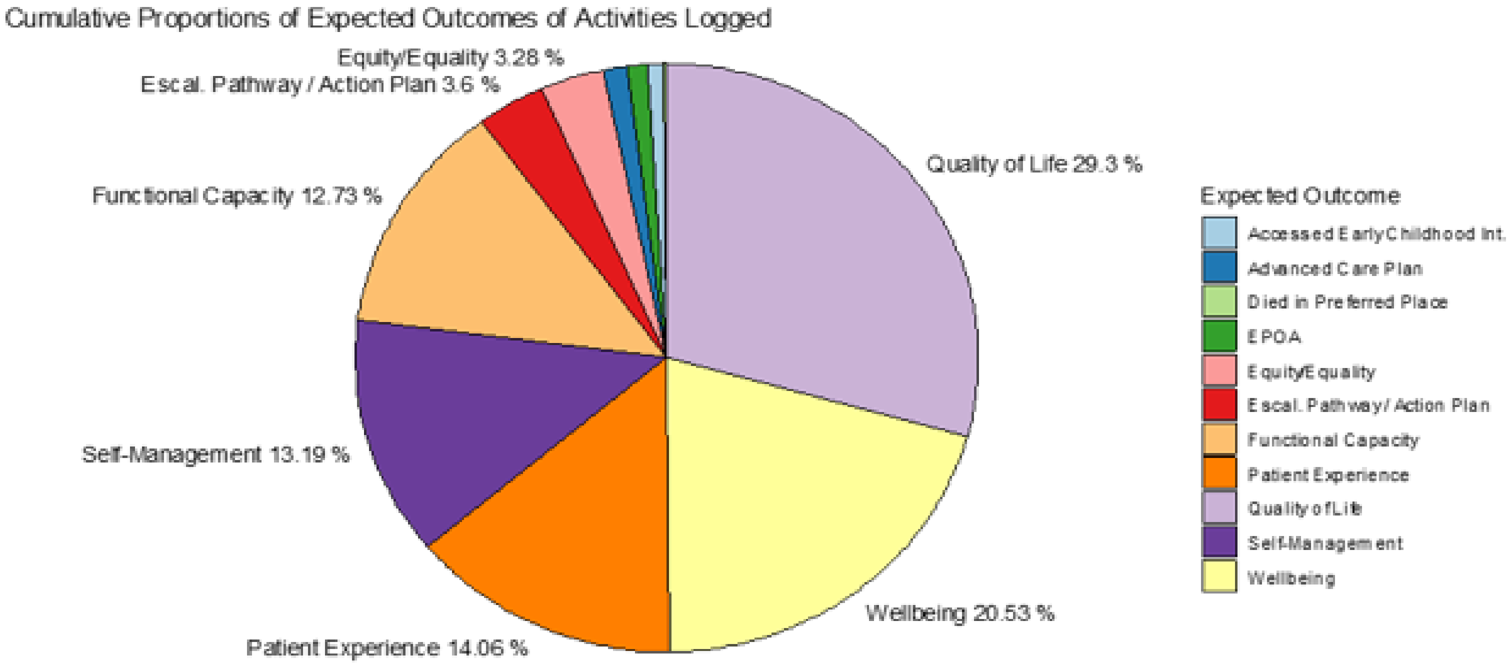
Cumulative proportions of expected outcomes of NN activities logged



Note: From Queensland health nurse navigator evaluation. Interim report: October 2020 by Harvey et al. (2020). ISBN 978-1-921047-90-9.

Figure 14

Cumulative proportions of system activities logged by NN



Note: From Queensland health nurse navigator evaluation. Interim report: *October 2020* by Harvey et al. (2020). ISBN 978-1-921047-90-9.

The dominant patient interventions that NNs recorded were liaison/advocacy, consultation, case review and assessment. These activities were recorded against expected outcomes, of which the vast majority related to QOL, wellbeing and experience. To achieve this, NNs spent a significant amount of time on information sharing, data collection, and networking with other healthcare providers. While discharge planning, self-efficacy and education formed part of the NN role, these were tasks peripheral to liaison, advocacy, building QOL, and navigating the system with and on behalf of the patient. This demonstrates that the work that NNs do is more aligned with their role principles, PCC, than with the outcomes measure of self-efficacy and hospital avoidance. This tension point is discussed within the narrative as one NN described:

> *People don't want to work together even though they say it's patient centred. I'm already cynical, I'm like yeah, right, you're so full of it. Because I see what you do. And I'm like you're not patient centred because you're not even interested in having other people come in, you know, have discussions. And I get that people are like all time poor … but we still have to try and figure it out. Everyone else is time poor too … but we [NN] make the time because we have to. We try and think of different things and how we're going to get our patients help … you have to make it priority.* Nurse Navigator

In this way, NNs demonstrate that they are "championing" PCC, as they mitigate and navigate the system barriers that patients with multimorbidity face (Byrne et al., 2021, p. 4). What NNs do is adjust the expectations of time as a resource, particularly within cultural contexts. This is expressed through the NN narratives:

> *You understand the cultural philosophy … people write it off as Islander time, they write it off as Murri*[11] *time. But you get it, and you know, it's not offensive, it's not obstructive, it's not non-compliant, it is what it is.* Nurse Navigator

And

> *And these people [patients] have all got amazing stories when you talk to them and unpack them—my patients aren't super-duper trusting, I would say. They are needy, difficult at times, and end-stage respiratory failure, but once you unpack everything and you start to form a relationship with them, hearing their story, is incredible … and we [general health professionals] take no time to hear their story. And because they [patients] are so breathless, it takes a long time for them to be able to get the whole story out. So, I might have three or four runs of hearing [patient stories]. But the level of trust in the system seems to be quite low. And so, they [patients] think, well, why should I tell you? You don't care, you don't. So, the calls I get from consultants are often about those people; the ones who they know that something's not quite right. And so that's when the [NN] role starts to get involved, to find out what's actually going on in the background.*
> Nurse Navigator

One model of care document identified the need for NN care to occur at the right time, by the right person, close to home (Central Queensland Hospital and Health Service, 2019, p. 12). What NNs demonstrate is that it also needs to be the right *amount* of time.

With workforce resourcing and nursing workload divided into productive/non-productive and direct/indirect hours through the BPF, the work that nurses do, and the coordinating of patient care across the system, is subjected to a hierarchy of discourse (see Appendix E). Justifying the time and space to work outside of these traditional

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[11] Murri time is a colloquial term used to describe the informal way that First Nations people view time.

structures is a difficult task for NNs, who become responsible for managing the person's needs (through PCC) and responsible for reducing admissions to hospital. In this way, NNs become accountable for the work they do, and the work they do not (or cannot) do. Nurse navigators choose to use their time to respond to the needs of the person, whether that be social, medical or both. This is significant, given that NNs are beholden to hospital key performance indicators and funding models. The tension point for NNs is in utilising their senior nursing roles to advocate for individuals and system change, while having no power to do so. On one hand, NNs state:

> *I want to be there for them to help them through the health service because these appointments are important. I see my role as being there for them really, in assisting them through the process, making that process easier for them so they feel like they are important, that they are heard, and that they are present.* Nurse Navigator

Juxtaposing this narrative, I return to the UK based SP discourse, where one doctor described caring for an individual's psychosocial needs as "left-wing rubbish":

> We all know this left-wing rubbish will only encourage patients, keep them away from our surgeries—what we need is a £5 charge per patient—I could then work half time with my feet up ... bliss (Leigh, 2017, p. 1)

The two thoughts could not be further opposed and understanding that the discourses are from separate worlds and professions, they are both part of the discourse of authority, institutions, and actors.

In summary, the introduction of NPM principles into healthcare has seen systems, models and roles all geared toward the efficient and effective management of services, where costs and resources are viewed as finite, and those who use services must do so fiscally. One major resource that is harvested is time. Further to this, there is a movement away from the utilisation of health services, and a responsibilisation of patients and clinicians, in this case NNs. Self-surveillance and management have become the accepted strategy to keep people away from hospital and the general practice, with new roles being created to address the psychosocial needs of a person. NPM encompasses the complete tenet of the health system, thus PCC exists within these parameters.

Not only have chronic care models and delivery of care been reframed under the NPM movement, tools and measures have also been created to ensure the efficient and effective system, which increases the activation and participation of the individual. One such tool is that of health literacy.

Chapter Ten—Health (Il)literacy; Structural Vulnerability in the Nurse Navigator Service

Summary of Chapter

This thesis is an investigation and interrogation of how certain documents, frameworks and concepts work to legitimise the care of people with multiple chronic conditions through the delivery of PCC. As alluded to throughout the thesis, a number of technologies of government work to instil a truth of self-management and self-efficacy in navigated individuals and their families. One such tool is that of health literacy. Due to the frequency and embedded nature of health literacy within both chronic disease models and PCC, it was necessary to further explore the concept and its relationship to the NN service. The following article (published on 08/07/2021) investigated this concept.

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Beyond Health Literacy

This chapter chose one health service tool, health literacy, to demonstrate the ways in which ideologies, roles and truths are embedded into institutions and into society at large. The chapter suggests that there is an ideology of compliance around the concept of health literacy and perceptions that individuals would look after themselves if they had the literary capacity to do so. However, as the chapter suggests, these perceptions have been disproved in the NN service. The positioning of people in the NN service as illiterate only acts to further perpetuate them as people in deficit and in some way wasteful and recalcitrant. In this way, both NNs and individuals are responsibilised, as NNs are made responsible for improving health literacy and individuals are made responsible for managing their own care. This leads to further structural and social vulnerability for marginalised people. The relationship between PCC and health literacy suggests that PCC is also a technology of compliance, a significant finding for this thesis. I now detail an argument for how these persuasive forms of coercion have occurred by using nurses to deliver PCC.

Chapter Eleven—The Professionalisation of Nursing: Power and Dominance

> In a given society, there is no general type of equilibrium between finalized activities, systems of communication, and power relations. Rather, there are diverse forms, diverse places, diverse circumstances, or occasions, in which these inter-relationships establish themselves according to a specific model (Foucault, 1983, p. 217).

Summary of Chapter

In the lead up to the final evaluation of the NN role, NNs described how they are now being realigned to fit in with the HHS based on structure and financial oversight. In some HHSs, NNs have now been relocated to specific specialists' services adding further HHS specific constraints to what the role can achieve. In the final report of the NN evaluation (Harvey et al., 2021), it is proposed that NNs across Queensland had saved over AUD$ 110 million dollars whilst also providing effective care to patients. Despite this outcome, NNs have no authority to contribute to role development moving forward, nor are they acknowledged for their work in developing a novel role that has potential to continue saving money and aligning the care of patients living with chronic and complex conditions.

This chapter will specifically analyse the power relations which nurses and NNs are subjected to within the system demonstrating that nurses, as professionals "are always much more and much less than themselves" (Stronach, 2010, p. 110). In this chapter, I argue that NNs are subjected to traditional forms of power and control that constrain their practice and the practice of PCC.

Nurses as (Efficient and Productive) Professionals

Nursing has always been described as a caring profession with care being the fundamental premise of the role. The International Council of Nurses states that "nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well, and in all settings" (International Council of Nurses [ICN], 2002, para. 1). The care in nursing is subject to moral, ethical, and social connotations, with nursing as a profession becoming synonymous with healing and compassion. The nursing code of ethics (ICN, 2012, p. 2) states that the nurse "demonstrates professional values such as respectfulness, responsiveness, compassion, trustworthiness, and integrity" with their primary professional responsibility being to the people receiving care.

In the same way that chronic disease models have been reframed within the NPM ethos, the profession of nursing has also been subjected to the influences of productive and efficient systems (Bergh et al., 2015). Despite care and caring being discursively positioned as fundamental to the profession of nursing, there has been a shift in the way that nursing time, resources, and work have been defined and managed.

While health services moved to the NPM ethos, nursing as a vocation underwent significant changes[12]. Nursing experienced a period of professionalisation whereby it was restructured around individual accountability in terms of tasks, finance, and quality of care. One major change was the training of nurses which moved away from hospital-based training and into the university sector. This move was fuelled by several social, political, and professional influences, including the predicted nursing workforce shortage, economic reform, and the quality movement (Grealish, 2012). Additionally, the onus on lifelong learning was discursively positioned as an important resource within the health service. Although there is an expectation of ownership of learning by any profession in their quest to become a profession, nurses have accepted the larger responsibility. The professional learning that nurses obtain is intrinsically linked to organisational position and risk aversion which has led to nurses accepting without

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[12] Refer to Figure 5 - a Symphony of Neoliberalism.

question the responsibility and accountability this holds, regardless of environmental factors which are largely out of their personal control (Rudge, 2013; Suhonen et al., 2018).

During the professionalisation period the work of Benner articulated the training of nurses as a gradient from novice to expert and expressed a perpetual need for ongoing education and experience. This advocated for a competency-based approach to nursing (Benner, 1984).

> A competent nurse and a proficient nurse will not approach or solve a clinical situation in the same way. It is not that proficient nurses have internalized the rules and formulas learned during the earlier stages of skill acquisition; they are no longer using rules and formulas to guide their practice. They are now using past concrete experiences much like the researcher uses paradigms (Benner, 1982, p. 406).

Influencing the change in nursing preparation was the ICN decree for a globally mobile workforce whereby nurses are adequately and universally trained to facilitate nursing migration. Originally stemming from the European UN, the Bologna Process (European Commission, n.d.) aimed to ensure equivalent education for nurses through consistent processes and outcomes. The process expanded internationally and influenced the underpinnings for a global nursing workforce (Davis, 2008).

Foucault describes the controls of subjects as technologies of the self (2008a). Competency standards are technologies that ‘manage’ nursing practice. As Fairclough (2001) argues, it is practices such as competencies that help to collectively define and organise a profession’s performance while also shaping and reshaping policy and practice over time through, e.g., curriculum development, and professional role development. This practice of perpetuating and shaping a profession was demonstrated by Grealish (2012) who uncovered the social, political, and professional implications of nursing competency standards, finding that they served a specific purpose within the professionalisation of nursing, ultimately becoming the method of classifying nursing performance in accordance with systemic health requirements. In so-doing, competencies became the avenue by which the health institution changed the discourse of the nursing profession, embedding quality improvement into the competencies and other forms of economic control. While nurses adopted these changes as important to effective patient care as a profession, they unconsciously reinforced the financial order of care as defined by the system. Eventually, as Fairclough (2001) notes, it is difficult to define where the original discourse started and who still has the power over it. Grealish (2012) noted that after consideration nursing standards excluded caring, empathy, sensitivity, and the consideration of the patient as a “passive actor” (p. 27) moving nursing competence from one of tactile skill and task to one of knowledge and critical thinking. Simultaneously, lean management practices associated with NPM embedded quality improvement processes, which used competencies to align with nursing pathways that provided a streamlined, directed approach to care, aimed at reducing costs associated with care delivery. This created a shift of nursing practice from emotional labour such as caring, to one of cost efficiency by using competencies to redescribe nursing practice (Davis & Adams, 2012). As Rudge (2013) notes, nurses’ desires to give good care still overrides the realisation that care cannot be fully delivered under a system that dictates what care is, based upon a financially defined diagnostic outcome, rather than a patient response to treatment. This is the tension that NNs face when being measured by financial outcomes. Nurse navigators don’t see the ongoing and subconscious perpetuation of professional practice that has realigned to financial directives because of their patient focus. The following anecdote from a NN shows how this is the case:

> *Hospital avoidance is a term that’s thrown around a lot, and really it depends on how you define it. Truthfully from a clinical perspective, our intention was to treat*

> *some minor subacute things, like [Urinary Tract Infection]s (UTIs), respiratory tract infections, cellulitis. That was always the initial plan. Truthfully in reality what we're finding is it's actually quite difficult to achieve. The reason for that I guess is that particularly with our cohort who are very elderly, they're all in residential facilities, something as simple you would think as a UTI isn't simple in reality, because oftentimes it's not just about going in and writing a script. It's about they're not eating and drinking for several days. They potentially have had some renal impairment as a result of it. So there's a lot of compounding factors.* Nurse Navigator

The subtle realignment that nurses are not realising can be seen in the evolution of national competency standards for nurses. In 2016, the competency standards were re-branded as the Registered Nurse Standards for Practice (SFP) (Nursing and Midwifery Board of Australia [NMBA], 2016). Critique of the competency standards centred on how they were operationalised into practice and their misalignment to speciality fields and to more senior nurses (Terry et al., 2015). Standards for practice provided a one-size-fits all requirement of nursing practice regardless of practice area and level of experience, whereas competency standards seemed to align more with nurses looking to be registered for the first time (Cashin et al., 2017). The standards have been widely accepted by nurses as a legitimate indicator of safe practice with nurses seeing the standards as a reflection of the professional role (Terry et al., 2015).

Investigation of the standards is a key element of understanding the importance of nursing work and of what legitimises PCC, thus below I have completed a document comparison between the 2006 competency standards and the 2016 SFP. Table 7 demonstrates the results importance to my research, viz., the role of the patient transforms to one of equal ownership and responsibility and the role of the nurse moves away from resource allocation, management, and system change; both changes appear to empower the nurse and the patient, yet I have argued do not.

Table 7

Comparison between 2006 National competency standards for the registered nurse and the 2016 registered nurse standards of practice

2006 National competency standards for the registered nurse	2016 Registered nurses’ standards for practice
2.1d Recognises and accepts the rights of others. 2.3a Demonstrates respect for individual/group common and legal rights to healthcare. 2.3c Considers individual/group preferences when providing care. 2.3e Advocates for individuals/groups when right are overlooked and/or compromised. 2.4c Protects the rights of individuals and groups and facilitates informed decisions.	2.2 Communicates effectively, and is respectful of a persons’ dignity, culture, values, beliefs, and rights. 2.3 **Recognises that people are the experts in the experience of their life.** 2.5 Advocates on behalf of people in a manner that **respects the persons autonomy and legal capacity**. 3.2 Provides the information and education required to enhance **people’s control over health**.
2.4a **Identifies when resources are insufficient to meet care needs of individuals/groups.** **2.4f *Recommends changes to policies, procedures, and guidelines when rights are compromised*. 7.1a Uses **resources effectively and efficiently in providing care**. 7.8 Uses health care resources effectively and efficiently to promote optimal nursing and health care.	2.4 **Provides support and directs people to resources to optimise health related decisions.** 4.4 Assesses the resources available to inform planning. 5.5 **Coordinates resources effectively and efficiently for planned actions.**[13]

Note: From “*National c*ompetency standards for the registered nurse” by Nursing and Midwifery Board of Australia, 2006, https://www.nursingmidwiferyboard.gov.au/codes-guidelines-statements/professional-standards.aspx ; “Registered nurses’ standards for practice” by Nursing and Midwifery Board of Australia, 2016, https://www.nursingmidwiferyboard.gov.au/codes-guidelines-statements/professional-standards.aspx

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A subtle change to both nurse and patient is noted, particularly in points 2.4, 4.4. and 5.5 where nurses no longer “identify” insufficient resources or “recommend” changes to policies, but rather “use” resources “effectively and efficiently” (NMBA, 2006, pp. 3–6; NMBA, 2016, pp. 4–5). This shifts the role of the nurse to one which adapts their

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[13] Note- the SFP amalgamated the subcategories of the older competency standards, therefore the numbers in this tables are somewhat misaligned.

approach to care based on existing resources, rather than leading or initiating change. This shift in discourse is in keeping with NPM lean thinking approaches where the responsibility of care delivery is divulged to the worker in ways that nurses subconsciously accept and then adapt to the change without questioning it (Urban, 2014; Fairclough, 2015).

Within the language of the SFP, the patient moves from a passive recipient to an active contributor within the healthcare team. This provides insight into how PCC is mobilised within the discourse of nursing whilst also shifting the accountability of care away from the organisation. Cashin et al. (2017) highlighted the shift to more person-centred language within the SFP and the introduction of cultural competence. While it discursively positions people at the centre of decision making and care, patients are still subjected to power relations with the person becoming a responsible expert.

This demonstrates that within the healthcare structure nursing is increasingly aligned with resources management rather than being agents for change, and with this, the refocusing of nurse manager work from nursing quality to financial efficiency (Newman & Lawler, 2009). An example in Table 7 is the shift from nurses "[identifying] when resources are insufficient" to "assess [and coordinate] the resources available to inform planning" and the removal of standard 2.4f "Recommends changes to policies, procedures and guidelines when rights are compromised" (NMBA, 2006, p. 3; NMBA, 2016, p. 5).

An observational study found that while nurses demonstrated the SFP within their daily work, their ability to manage resources and to have oversight of the person's care was less visible. Importantly, the authors were unable to determine whether the drivers for planning care were related to the patient's preference or to the organisational demands (Cashin et al., 2017). Supporting these findings is international literature identifying negative correlations between a reduced skill mix and poor quality of care in locations where lean management practices are upheld (Ball et al., 2014). This is representative of a deeper issue where nurses are directed to work under the SFP within an ethical structure which prescribes the rights of individuals, *autonomy, beneficence, justice,* and *non-maleficence (*NMBA, 2008). Yet, ethics is not a consideration for health services when implementing lean processes and thinking (Roodehghan et al., 2018). In fact, the NPM movement and lean thinking requires “minimalistic ethics,” where fiscal management becomes central to care rather than those resources required for safe, effective care (Ljungblom, 2014, p. 193). Minimalist ethics describes a “pacification of morality” which Callahan explained is the reprioritisation of moral conducts in times of hardship:

> If life is going poorly, someone obviously must be at fault, if not the government, then my neighbour, wife, or child. The warm, expansive self, indulgent of the foibles of others, gives way to the harsh, competitive self; enemies abound, foreign and domestic. It is not so much that the “least well-off” cease to count (though they do), but that all imagine they are now in that category (1981, p. 261).

Ethically, NNs are responsible for the coordination of care. Nurses, including NNs, are governed by the ICN code of ethics (2012) in that they must “respect human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect” (p. 2). At times, practicing ethically can be at odds with defined processes and procedures. In one example, a NN reported a case where a First Nations person was transferred to a larger hospital for treatment. The person was made palliative and was admitted for comfort care as their condition deteriorated. Given the cultural significance, the NN attempted to transfer the person back to their home base hospital, allowing them to die on Country. Despite the NNs best efforts and advocacy, referral and transfer of care procedures inhibited this. Despite continued advocacy and negotiation from the NN, regarding transport costs, the hospital’s capability and the patient’s clinical needs were cited as reasons as to why the transfer back home was declined. The person died off Country and their body was later repatriated back home for burial, a matter that is totally against all cultural practices for First Nations Australians.

This demonstrates that NNs often face ethical, moral, and cultural dilemmas in terms of working with the person to achieve their wants and needs and working within the constraints of the system. This is described as a clash between the ethical practice defined within their role description and the SFP, and the authority, processes and policies that are set forth by the institution. This is often a reflection of the cost and service utilisation of care versus the ethical and person-centred elements of care. Nurse navigators use the ethical standards to underpin their decision making which is precisely what the code of ethics asks nurses to do. Even when processes and policies impede care, NNs advocate on behalf of the person and attempt to find ways to meet the needs of the person and their family. In this way, they walk the tightrope between care and process. This demonstrates that NNs are practicing PCC, taking it from the abstract to reality.

When considering their role from the perspective of the NN Toolkit, the NN role is pivotal in reducing hospital admissions and improving the experiences of patients. Yet, when the COVID-19 pandemic emerged, NNs were redeployed leaving nurses stressed because they worried about how their patients would fare without the navigation support. Not only was this practice occurring in the pandemic, but routinely NNs spoke of being redeployed to fill senior nursing role leave such as the director of nursing, yet NNs were never allocated leave relief. This begs the question of what authority a NN has in ensuring PCC, and where their responsibilities lie. The patient and the nurse are structurally vulnerable, and PCC is a misnomer.

Ethics, in the context of nursing practice, can be viewed as “inside in,” not rich enough to provide omnipotent guidance to all clinical situations, and “outside in” where virtue is following prior principles consistent with “merely a process of following the correct rule” (Stronach, 2010, p. 113). How nurses deliver PCC to individuals inside a system focused on lean productivity is unclear, suggesting a tension between the care of nursing and the daily demands of the job. In fact, the power relations that exist sees nurses assessing available resources to “effectively and efficiently” plan care (NMBA, 2016, p. 5) rather than ethically or holistically. This places nurses in a no-win situation where, as a professional, they are tasked with providing optimum care based on expert assessment of patient needs and as an employee they must uphold the agreed organisational targets (Harvey et al., 2017).

This paradox of nurses’ responsibility can be traced back to the accountability of the profession with the SFP prescribing multiple lines of accountability and responsibility. The SFP states that nurses are accountable and answerable to “the people in their care, the nursing regulatory authority, their employers, and the public. Nurses are accountable for their decisions, actions, behaviours and the responsibilities that are inherent in their nursing roles.” (NMBA, 2016, p. 2). This is summarised as professional, ethical, legal and employment accountability (NHS, 2014). This level of accountability is translated into nursing practice through audit and “tick box” documentation as well as accountabilities across the nursing hierarchy. In this way, nurses carry a disproportionate responsibility of care and patient outcomes which leads to a fear of potential blame (Hiscox, 2019, p. 2). This is also seen in the NN service in the form of data collection, to monitor, track and justify their positions.

Gaining Professionalisation, Yet Retaining Subordination

> Professionals are not just set in motion between simple polarities. They are also systematically pinned down in terms of different types of knowledge stages of development and typologies of role, such as the ‘extended’ versus the ‘restricted’ (Stronach et al., 2010, p. 111).

The ideology of the optimal performance of nursing is carried through the SFP and through frameworks such as the BPF as discussed in Chapter Nine. It is also a notion perpetuated through the discourse of peak bodies such as the Clinical Excellence Division and the Australian College of Nursing (ACN). The advancing education, scope and role of the nurse is recognised and utilised in services, and this is often demonstrated through nurse-led, advanced practice roles. In Australia advanced nursing practice is often positioned within the discourse of the nurse practitioner (NP); a master's prepared nurse with a credentialed endorsement to their nursing registration allowing them to work with an expanded scope to that of a RN in assessment, planning, implementation, diagnosis, and evaluation (NMBA, 2016). However, advanced practice, as a general concept, can be demonstrated by those without an endorsement.

> Registered nurses may work at levels of advanced practice nursing–where the work is of high complexity and the level of supervision may be lower than that of beginner registered nurses. It is essential that [these] registered nurses are clinically and educationally prepared to perform at those levels (NMBA, 2013, p. 1)[14].

While some confusion exists around advanced practice nursing roles, it is not subordinate to medical care, yet appears to be discursively positioned as such (Lovink et al., 2019; Clinical Excellence Division, 2017a). Nurse-led MOC and advanced practice offer some solutions to the issues created by the current system structures, workforce shortages and the biomedical model. These include chronic disease management, health promotion and self-management programs (Khair, 2017). The actual premise behind advancement of nursing was not to replace existing services but to enhance them. Thus, in theory, nurse-led services should be autonomous and there should be no delegation of care from the medical officer, but rather an independent professional

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[14] This has now been changed and the NMBA now lists advanced practice as neither a role nor a title, in line with the ACN whitepaper.

assessing the need for care and initiating that which suits the person most as this statement suggests:

> Interdisciplinary teams, not doctors, deliver modern healthcare. Doctors bring their particular skills to the team, but no longer sit at the apex of a hierarchy, delegating to other professions. Although it may feel uncomfortable to relinquish the traditional notion of medical control, doctors must embrace and support the development of better health care, regardless of the professional training of those who deliver it (Benger & Hoskins, 2005, p. 1).

In the 16 years since this statement was made, advances in nurse-led MOC have occurred, an example being the NN, yet advanced nursing practice remains stifled with arguments largely raised around the expense of the role or its perceived impingement on other healthcare roles. For example, nurses and midwives are not able to claim Medicare billing in the public sector and those in private practice must have a collaborative care arrangement in place (Medicare, 2020b). In fact, only nine billing numbers exist for NPs (Medicare, 2020a) and none exist for advanced practice nurses. Medically-led care remains the dominant care method in Australia. Case in point is that the Queensland Government Clinical Excellence Division describes nurse-led services as:

> A model of care indicated where there are service gaps due to high demand and/or workforce shortages. Nurse-led clinics are beneficial when: the waiting lists for a specialist outpatient appointment are long; high demand and/or workforce shortages in some specialities; advanced skills and knowledge contribute to maintenance of optimal patient health especially in chronic conditions (Clinical Excellence Queensland, 2017b, p. 1).

Nurse navigators also contribute to the advanced practice confusion. where they are allocated to an advanced practice position as per the state award (Queensland Industrial

Relations Commission, 2015) but are afforded little authority to work to such scope. I have expanded on this point below.

A form of pseudo-power that Foucault (1991a; 2001) refers to emerges where the role of the registered nurse is extended in terms of skills and responsibilities yet is not expanded to support the creation of a professional career pathway within a system which maintains the traditional dominant/subordinate relationship of medical officers and nurses. An examples of this in Australia is the NP practice. Although hailed as an important step forward for nurses and for PCC, the role of the NP has been constrained by legislation that sees them continuing to require the goodwill of a health service or medical officer to practice (NMBA, 2021). Additionally, although NPs have provider numbers that allow them to prescribe and order diagnostic tests, they are constrained by the local decisions made about what they can or cannot prescribe. This example was clearly identified in the NN evaluation where NPs hired into NN positions in aged care practice may not admit aged care residents to hospital. Patients are admitted via the ED or the general practice. This creates a duplication of services that is not necessary, is expensive and delays the immediacy of care (Harvey et al., 2020). Furthermore, NPs in NN positions are unable to attract any revenue through billing as the positions are located in the public hospital sector. This undermines and constrains both NNs and NPs in relation to what they can do to achieve PCC and efficiency in care. Furthermore, by endorsing a NP into an NN position, it further undermines the role of the NN and the NP.

Nurse-led models are shown to improve care coordination, integration (McMurray & Cooper, 2017; Cope et al., 2015), risk factor management (Allen, 2014) patient satisfaction, quality of life and symptom control (Chen et al., 2018; Baker & Fatoye, 2017). Given the evidence to support nursing practice and nurse-led MOC, the fact that they are discursively positioned as subordinate to traditional methods provides insight into the power relations of the health service. The fact that SFP and NP practice arrangements were endorsed by nurses shows just how embedded and accepted the subordination of nursing is. It also highlights the limited power nurses have in making health system changes and the profession's inability to lead nursing in change. In terms of PCC, this means that when nurses see deficits in care, they are incapable of having any influence in changing it. This has been evidenced in the international research around missed nursing care, (Rudge, 2013; Harvey et al., 2020; Bail et al., 2009).

In addition to policy and legislation which perpetuate much of the subordination of nurses, other professions place a focused agenda of their own profession. The Australian Medical Association (AMA) has opposed any nursing role that frees itself of medical control, e.g., in 2011 the AMA released clear position statements on the role of the nurse and the role of the medical officer.

> Doctors have the ability to apply skills and expertise in the context of an increasingly multidisciplinary, team-based approach to health care. While responsibility for the actions of those in the team may be diffuse, the role of a doctor is characterised by their capacity to assume ultimate responsibility for a patient's care. The team will therefore look to the doctor for leadership in designing and supervising the patient's overall health care plan (AMA, 2011, p. 2).

Solidifying the social identity of the medical officer leaves little room for the advancement of nurses, and indeed, the AMA have clearly articulated their criticism for advanced nursing roles:

> The AMA does not support a role for the independent nurse practitioner …
> A debate on the issue of nursing career paths and recognition of nurses' specialist training is valid. It is not, however, a valid argument for models of legislated roles for independent nurse practitioners where levels of independence remove the general practitioner as central to delivery of primary care (AMA, 2005, p. 1).

The reality remains that the profession of nursing is an "oppressed group," with this oppression impacting upon professional self-concept and therefore the work that nurses do (ten Hoeve et al., 2013, p. 296). Nurses are often viewed as objects of productivity rather than subjects of patient care (Rudge, 2013). Furthermore, the ACN which is the national peak advisory body for nursing in Australia, advocate for changes in the way nursing is viewed and utilised, but in doing so have perpetuated the view that nursing is in deficit and is a profession which needs to be rationed and utilised within the system rather than an agent of change. Deficit, as described by Foucault, is a form of discoursal positioning of individuals which see them as lacking some trait or information rather than placing the deficit on structures of society (Roger et al., 2015). In this context, nurses have been positioned in deficit in terms of clinical practice and leadership.

The ACN white paper entitled *A new horizon for health service: Optimising advanced practice nursing* (2019), identifies several health service issues including fragmentation, general practice business models and bulk billing, referral processes and clashes in private and public funding and access. The solution offered to these issues is that of nursing scope of practice (SOP) with the ACN arguing that nursing is underutilised:

> [T]his nurse is not working to the full SOP: their clinical service potential is unrealised and underutilised. That this occurs in a health system under pressure, with consumers who are under and poorly serviced, and where policy is missing the mark for innovation service models, is a serious waste of public money. Advanced practice nurses are a solution, hiding in plain sight (ACN, 2019, p. 20).

Indeed, NNs are one such solution. They are considered advanced in their roles (Queensland Industrial Relations Commission, 2015) but hold no authority or autonomy in decision making, e.g., NNs must work to a strict criterion of who can enter their service and are governed by the performance criteria of their individual health services.

While the ACN white paper does advocate for changes in funding models, it is largely focused on reframing the advanced practice nurse as “neither a role nor a title” (ACN, 2019, p. 6), but rather someone who can work to the full scope of nursing practice, filling gaps within the current system. This positioning of nursing is not new and is not indicative of a new horizon with the advanced practice nurse being subjected to the same power relations and constraints as that of the NP. An example of how nursing is discursively positioned as in deficit is seen below:

> Recognition that nursing is a costly health service resource that is underutilised. Many advanced practice nurses are not working to their full clinical capacity and this is a waste of the health dollar and missed opportunities for effective clinical services (ACN, 2019, p. 25).

Practice development of the nursing profession is often portrayed as emancipatory as is seen in the ACN whitepaper, yet nurses still bear the responsibility of the role, their work and deeper change (Rudge, 2011a). This can be seen in the emergence of the NN role as well where they were introduced as an election commitment that promised to end the woes of unnecessary hospital admissions, yet professionally sold as a nursing expert who would provide PCC:

> A new nurse-led service model has been introduced into Queensland’s public health system to assist patients with complex health care needs in navigating to and from their referring primary care provider through to hospital, community and back home again. This service model puts patients at the centre of care and supports the patient’s journey through an increasingly complex healthcare system (QH, 2018, p. 3).

The NNs embraced the professional role because they could see the benefits for the person as this anecdote identifies:

> *It's been a long road but making a difference to people and being a part of their journey, it's well worth it.* Nurse Navigator

Yet, the professional role and its contribution to care has been overwhelmed by the focus of hospital avoidance, something that the NNs are being held to account for (Byrne et al., 2020).

Throughout the NN narrative, the inconsistency of nursing leadership was noted. Services with inconsistent leadership expressed frustration, role confusion and anxiety around job sustainability. Conversely, services with strong, consistent leadership expressed clear direction, support and decision making. This is evidenced by the anecdotes below from NNs:

> *I guess the key example and real disappointment, was the first time that our executive director of nursing met with us … They met with us as a service was only just last year, so three years into the four-year service was the first time he met us as a group, and in that same conversation was when we were told that we'd all have to be reapplying for our positions again. Even though we've been through all of the various recruitment previously to come into that position … then we haven't seen [him] since … there's been some great advocacy from OCNMO more than a local level. It's been a real struggle to [achieve] the level of support and advocacy and recognition of what the role entails.* Nurse Navigator

And

> *We are very lucky to have strong leadership in our service and to be a part of a stand-alone team. Our executive knows what we do and advocate for our roles. [They] let us get on with the job.* Nurse Navigator

It appears that for some services, NNs are moulded and framed as resources within the system rather than professionals who traverse it. This framing and utilisation of nurses without consideration of changes to the broader systems which confine practice, does not account for their value in supporting individuals from disengagement to reengagement in care or the professional standing of an expert nurse as part of the chronic care team. Continued advocacy for advanced nursing is an important element of change and is particularly important to nursing models which demonstrate PCC. The danger lies in leveraging nursing where higher system change is required, as the ACN whitepaper appears to have done.

Innovation in nursing practice and models within the current system requires a significant shift from traditional models and policies as well as a shift in how nursing is regarded and supported. A report by the Commonwealth of Australia on nursing workforce sustainability states:

> There is a large volume of national, state and territory legislation which directly and indirectly places restrictions on the scope and range of workforce functions that can be performed by nurses. These include Drugs and Poisons, Radiation Safety, Mental Health, Public Health and Health Service Acts, plus other less obvious pieces of legislation. Review and amendment of workplace policies, industrial agreements and legislation may be required to further facilitate workforce reform and productivity improvement (Commonwealth of Australia, 2014, p. 34).

Nurse-led chronic care models offer much in the way of satisfaction and quality outcomes yet hospital markers such as cost efficiency and reduced hospitalisation are more difficult to prove, potentially due to these services meeting long term, unmet needs borne from the constraints of the traditional medical system (Baker & Fatoye, 2017; Esterman & Ben-Tovim, 2002). Once again, I refer to the evidence that care coordination which many nurse-led services offer may even increase costs due to meeting these long-term needs (Ehrlich et al., 2009).

Meeting the needs of the individual is precisely what PCC aims to achieve. As identified in the literature review (see Chapter Three) workforce roles, fiscal management and compliance impede PCC. Indeed, despite increased spending on integrated care, the promise of clinical services that improve patient satisfaction and quality of life remains unfulfilled (Vetrano et al., 2018). This is because while most of these services advocate for PCC, they are measured on hospital usage metrics such as those being applied to the NN service. Stronach et al. describe this as professionals juggling economies of performance and ecologies of practice (2010, p. 121) where nurses are discursively positioned as simultaneously accountable for practice and performance. Nurse’s view caring as viewing the person behind the patient, i.e., PCC. This is a sophisticated marriage of care and science, existing within the health sphere of which some elements they can control, and others they cannot (Andersson et al., 2015). Nurses must prioritise care between patient groups often making moral and ethical decisions based on the person’s situation, age and the perceived good that care can achieve. Failure to do so can lead to moral distress and missed care, impacting care delivery and professional practice (Suhonen et al., 2018).

Within the social relations and identities of the health institution, nurses are now asked to support and provide PCC, yet have limited power over the system to create change and be innovative within their roles. This then begs the question: how does this reposition the value of PCC and whom does it benefit?

Power and Autonomy—Nurse Navigators as System Change Advocates?

While the position of the NN is exposed to the same organisational confinements and challenges as traditional nursing positions, NNs demonstrate consistent and determined advocacy. The tension point between care and process appears to be addressed in the NN method of delivery where system mitigation and working within and beyond financial constraints become part and parcel of delivering PCC.

The issue raised at several times during the evaluation was that each HHS, being an independent entity with individual boards, meant that each NN service is professionally aligned to their independent health service's agenda and requirements. As part of this alignment a need to account for NN time emerged as one NN described:

> *I'll pass that by my boss of course … among quality things … we have to account for our time … they do want us spending more time face to face with our clients, even though I do have other [duties]. Yeah, as we said, finding the time anyway.*
> Nurse Navigator

Despite this, NNs have demonstrated skill and competence in working outside of traditional services and specialist silos[15]. In attempting to deliver PCC, NNs uncover barriers to effective care, including lean thinking and health hierarchy, power dynamics, cultural and social relations, and the need to adjust the expectations of time, space, and structure.

Power inside of the lean system

Nurse navigators exist within the current culture of the health system, a deeply ingrained institution with unspoken rules and regulations, often around the use of resources and finances, which categorise people, or actors according to Foucault, as per the role they must play (Foucault, 2001; Waller, 2006). Nurses are players within this institution informed by the power relations, structures, and politics. These dictate the way they may and may not practice and how they are to position themselves in relation to other professionals and the people they care for based on the traditional biomedical model led by the medical specialist (Glasdam et al., 2015).

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[15] See Table 3 (inclusions and exclusion of the research). In this section I am referring to those services who have set up NN as an independent service as opposed to those who have set up the service as CNC type roles.

The ideology of NPM is one of having a “well-run” system which smoothly and efficiently operates with all actors abiding by the structures and rules of their roles (Rudge, 2011b, p. 1). The structures, policy and procedures of the smooth system are viewed as business as usual; however, their constraint and coercive nature can also be viewed as forms of objective violence which result in oppression and alienation of certain groups (Zizek, 2009; Rudge, 2011b). An example is that the introduction of the clinical audit, which is so well embedded into the healthcare culture and into nursing practice that it is now viewed with a sense of urgency and accountability. Rudge (2011b) explains:

> The audit culture rife in the healthcare systems world-wide has meant that power and the possibility of change has been co-opted in the service of the smooth operation of the system and into systems of accountability (such as evidence-based nursing or practice development) which are not about intelligent nursing, or the development of nursing knowledge. Instead, change management in the healthcare organisation is driven by tensions between the act of change and its incompleteness, or an incomplete understanding of the material and political forces behind the need for change. Moreover, all tensions are glossed over by the continuous enactment of ‘progress’ or performances of ‘progress’ at work (p. 174).

This highlights the reality that while nursing practice, certainly in the NN space, is grounded in the principles of social justice, their existence within a system designed within NPM principles makes it very difficult for nurses to make change.

The barriers to service processes and limitations are highlighted by one NN:

> *So how do we incorporate all of that and make them [processes] so that the kids still get fed and we find ways around that … your kids won’t be starving because in a small community we’ll get our brother over here to see if he can give the kids some food. So I think that’s where we need to come up with some sort of*

> *solution. Because these gaps [reference to closing the gap] never gonna close. We could be here another hundred years, we'll never close the gap if we don't actually believe what I in my heart as an Aboriginal person, and as a health professional, is that we won't have any changes in the next hundred years if we don't start actually addressing the underlying issues … I know with doctors, it's sad to say but they don't see anything below their nose.* Nurse Navigator

Nurse navigators have demonstrated that to meet their role principles, viz., PCC, they need to adapt and work around processes and MOC which includes the professional and physical spaces available to them. One NN described the key to navigation as finding the space and time to develop a therapeutic relationship:

> *We [the system] make them feel like they're a burden, but we're here to try and help you and help the community. Maybe I just need to go into the community, like … pathways or Centrelink, you know, and sit there … Maybe what we need to do [is] go to the woman's shelter, just for a space and then go out to the homes.* Nurse Navigator

This demonstrates that NNs align themselves to the needs of the community, and in doing so can consider innovative solutions to the problem of space. Yet NNs are employed by acute hospital services that require inpatient activity to attract government funds, therefore, working outside of these spaces is considered unfunded. The space to provide care among this healthcare infrastructure is described:

> *He's been very lucky that he has someone he's partnered with [from] an IT perspective, who has this amazing ability to pull reports and fields and automate processes. I think there's so much that could be automated. Then the clinician has more time to focus on the patient that actually needs help and needs the support that only a human can deliver.* Nurse Navigator

And

> *Just the basics of okay, can we have a chair and a desk in community health? Systems aren't already in place for that to happen. You've got to email that Practice Manager and then wait … why can't you create a calendar and just book rooms that way? You still have to oversee it because otherwise everybody will be greedy … do something that is more visible and is easily managed. It's like stay in your lane, stay in your lane.* Nurse Navigator

Both excerpts highlight the discord between sectors, a known cause of health service and care delivery fragmentation and disengagement (Sheridan et al., 2012).

Nursing as a profession has been moulded within the NPM movement and discursively framed as both the deliverers of care and a resource within the health system. Nurse navigators appear to have reframed themselves with the caring faction of the nursing role, seeing the need to change the system and its traditional processes to deliver PCC. This important point has been articulated by Mold (2017) and Bourgois (2017) who found that health care needs to be refocused with a greater emphasis being placed on meaningful activities and personal growth and development through value-based care which addresses structural vulnerabilities, i.e., system structures which exclude and marginalise population groups. Nurse navigators offer a working model of value-based PCC.

While NNs are working to collaborate across different sectors and sections of the health institution, the parameters of their work have stifled their ability to deliver care. A good example of this is caseload number which have been allocated to NNs. In a previous version of the Toolkit, NNs were prescribed a caseload of "approximately 40 patients" across different levels of the care trajectory, intensive, managing, maintaining, transitioning, and discharged (QH, 2016b, p. 19). This number was removed from the toolkit in 2017. The Office of the Chief Nurse described this decision as allowing different services the flexibility to adjust numbers as they saw fit (Nurse Navigator Meeting, 2020). This opened the space for each HHS to prescribe their own performance indicators against NNs:

> *[Redacted HHS] has increased each NNs caseload to 60 patients each. NN has told us that the financial officers 'ran the numbers' and that they need to each have 60 patients to make the service financially viable. NN are angry and anxious and do not believe they can manage 60 patients, given what they need to do for each one. They fear they will lose their positions if they cannot manage.* Author's file note

Caseload numbers have been a source of debate in health services for some time, with no solid consensus on this achieved. The Kings Fund (2011) found that caseload numbers are dependent on multiple factors including the person's condition, the number of high-risk patients, the person's socioeconomic demographic, their geographical location and the community characteristics, and the need for 'non-clinical' activities (p. 19). A case load of 50 people has been found to be the upper limit where services start to become reactive rather than proactive (The Kings Fund, 2011).

Those NNs who have been allocated lower caseloads have expressed that this is key to the relationship they create with individuals, as one NN expressed:

> *I think from my mind they key part of the navigator's ability to achieve that is having the time to spend with the patient and not be overburdened with the expectations to just take on more and more patients.* Nurse Navigator

Research suggests that caseload numbers of between 1:9–20 people is optimal for increased self-efficacy and hospital avoidance:

> Studies that have not reported reductions in hospitalisation have reported higher caseloads, and it has been argued that in programs where the ratio is 1:20–40,

> case managers do not have sufficient time to provide the individualised support that is required to help people adapt to community living (Department of Health, 2006, para. 4).

Nurse navigators offer a point of difference to traditional nursing models, yet this is not accommodated within the system as value in care does not translate to value in money. As the ACN described, advanced practice nurses are now viewed as expensive and underutilised, hence decisions to increase workload and performance quotas (ACN, 2020). Therefore, the delivery of PCC is not valued by health services unless it is paired with the reduction of hospital admissions and therefore a reduction in health service costs.

Demonstrating value within a fiscally managed system

In the context of NPM and an institutional identity of fiscal management and efficiency, NNs offer a model which is highly value-based. Value, however, is difficult to define. The NN service cannot necessarily demonstrate a reduced spending to the bottom line, typically known as “dark green dollars,” but rather efficiencies and reduced duplications in care, known as “light green dollar”, that is an overall service cost benefit (Martin et al., 2009, p. 2).

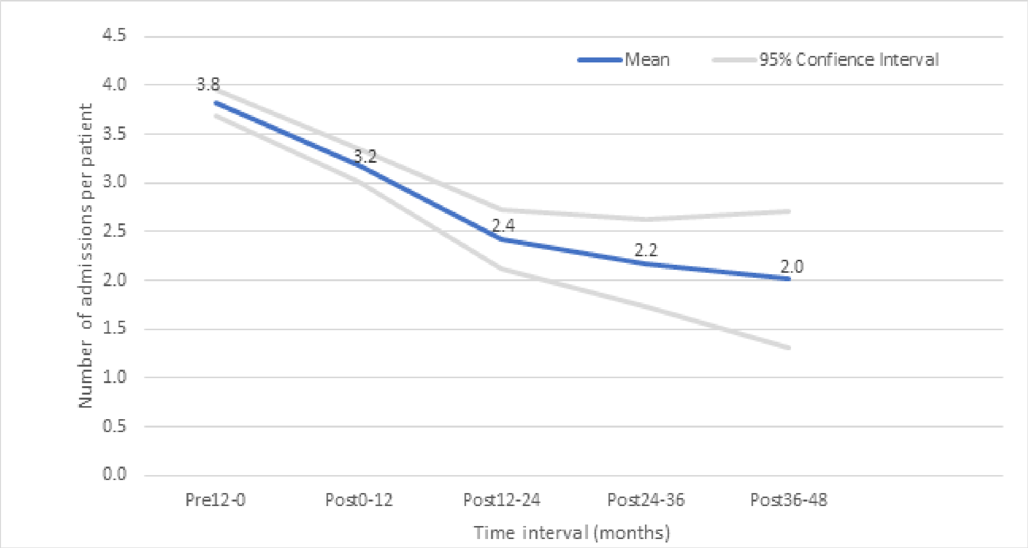
In fact, as we have discussed, designating the navigator as a nurse ensures that the role is heavily influenced by financial and lean thinking processes whereby the nurse must justify their position and their work in terms of hard dollars. However, the interim reports from the NN evaluation demonstrate the following reductions:

- NNs reduced the LOS for patients by an average of one day.
- NNs reduced inpatient admissions by approximately 0.5 admission days.
- NNs reduced admissions via the ED by 0.5–one admission days.
- NNs reduced ED presentations by one fewer presentation in the navigation period.

When evaluated against the Return on Investment (ROI) framework, which takes into account the above hospital measures as well as mental wellbeing and care optimisation, the NN final report demonstrated a return on investment for the service. Figures 15 and 16 below demonstrate these findings.

Figure 15

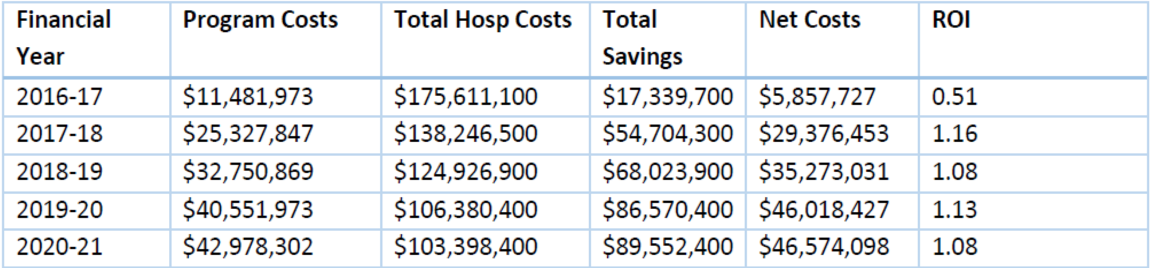
Admissions per navigated patient over time



Note: From Queensland health nurse and midwife navigator evaluation. Detailed final research report by Harvey et al. (2021). ISBN 978-1-921049-92-3

Figure 16

Return on investment for NN



Financial Year	Program Costs	Total Hosp Costs	Total Savings	Net Costs	ROI
2016-17	$11,481,973	$175,611,100	$17,339,700	$5,857,727	0.51
2017-18	$25,327,847	$138,246,500	$54,704,300	$29,376,453	1.16
2018-19	$32,750,869	$124,926,900	$68,023,900	$35,273,031	1.08
2019-20	$40,551,973	$106,380,400	$86,570,400	$46,018,427	1.13
2020-21	$42,978,302	$103,398,400	$89,552,400	$46,574,098	1.08

Note: From *Queensland health nurse and midwife navigator evaluation. Detailed final research report* by Harvey et al. (2021). ISBN 978-1-921049-92-3

The NN report explains that where ROI is greater than or equal to 1, the returns generated are greater than or equal to the costs of the service implementation. When

ROI is less than 1 a net loss from the implementation is evident (Harvey et al., 2021). As demonstrated in Figure 16, the NN service has demonstrated a ROI every year post implementation.

Nowhere is the human/social value of care measured in any hospital budget, yet chronic care requires an enormous amount of hidden coordination to realise the actual hospital avoidance success seen by the NNs. It is prudent to note that the NN evaluation also includes data which have not demonstrated significance, e.g., LOS in ED, did not wait for service and failure to attend measures. These can be found in the final NN evaluation report available as Appendix F. The findings above, however, do demonstrate some improvements in hospital measures with a ROI. This is no small feat given the demographic of people that NNs care for, the complexity of the system and the social investment that NNs are required to put into the therapeutic relationship. This is demonstrated by the NN anecdote below:

> *I've linked her in with a transcultural mental health team in Brisbane, but they're a secondary team and they have a cultural worker, but the primary team must be the local community mental health team. However, they don't think she has the mental health and need. They say that all that she's going through is normal grief processes from the disability of her daughter. So, if they don't stay open the transcultural mental health team aren't allowed to remain active with her. The allied health team … they say that she's mentally unwell so that she's not ready for care. But the mental health team say that's not the case. So, I've got this conflict going on between them, and meanwhile the daughter is now 15 months old and hasn't had any therapy for about six months and we know early intervention is the most important.* Nurse Navigator

This once more calls into question the measures of such a service and while these are positive trends in hospital reduction, they are not consistent with the main outcome of the service which is person-centred, value-based care. In turn, this makes discounting the improvements that NNs have achieved easier for health services. It also allows health services and decision makers to discount the value that senior nurses bring:

> *The navigator is a silver bullet. We can be used in multiple different roles because of the system knowledge that we have. So, for example, from next week, I'll still be doing my navigating as an informatics sort of role. I'll be doing the commissioning for the COVID vaccination clinics, and also providing backfill for nursing informatics as manager, team leader as well. So yeah, just that there's a sort of standard expectation that you have those skill sets, you have that knowledge set, so you can be used in that way.* Nurse Navigator

While NNs are demonstrating a return on the investment in terms of value-based care, it is difficult to articulate into the strict economic measures of the hospital system. Once again, the tension between care and health services is clear.

Chapter Twelve—Interpreting the Discourse within the Social Orders (Discussion)

> The idea of 'power behind discourse' is that the whole social order of discourse is put together and held together as a hidden effect of power (Fairclough, 2001, p. 48)

Summary of Chapter

This thesis has investigated and interrogated the concept of PCC in relation to NNs and in doing so, has uncovered the wider implications for nursing practice of chronic disease in the Australian healthcare system. Fairclough (2001) contends that within a unified institution the practices and the people within a social order need to be working together. This is done through the normalisation of dominant discourse (Krzyzanowski, 2020) as action and text that sees the actors within a social order accepting and perpetuating the common regulations of the system. In the case of how PCC is enacted and interpreted in the Australian health services, there are two opposing discourses: first the dominant discourse within which care is allocated and directed, and the other is how it is received by patients and enacted by NN. Each chapter has built on and consolidated the concept of PCC into one which enhances the rationalisation of health services as a business which can and must be managed within the NPM ethos of efficiency, productivity, and efficacy. How the person, as the recipient of care, factors into this ethos is far more opaque within the discourse. The results are in opposition to the conceptual meanings of PCC described in the literature review.

I have framed my discussion by using an excerpt from the British political satire 'Yes, Minister,' which was televised on the BBC from 1980 to 1984. The episode in question sees the Minister visit a newly opened hospital. A transcript is provided below in Figure 17.

Figure 17

The hospital with no patients

Mrs Rogers: And this is J theatre …

Minster: How much did all this cost?

Mrs Rogers: Together with radiotherapy and Intensive care, two and quarter Million.

Minster: Isn't it appalling that it's not being used?

Mrs Rogers: Oh no, a very good thing in some ways- prolongs its life, cuts down running costs.

Minister: But there are no patients.

Mrs Rogers: No, but the essential work of the hospital still has to go on.

Minster: Aren't patients the essential work of the hospital?

Mrs Rogers: Running an organisation of 500 people is a big job, Minister.

Minster: But if they weren't here, they wouldn't be here!

Mrs Rogers: What?

Minister: This just won't do. Either you get some patients for this hospital, or I shall close it.

Mrs Rogers: Yes, well minister, in the course of time-

Minister: - No, not in the course of time Mrs Rodger, now! Get rid of 300 of your people, get some Dr's and Nurses and get some patients!

Mr Fraser: Now look here, without those 300 people this hospital just wouldn't function.

Minister: Oh, you think its functioning now?

Mrs Rogers: Minster it's one of the best run hospitals in the country. It's up for the Florence Nightingale award!

Minister: And what, pray, is that?

Mrs Rodgers: It's won by the most hygienic hospital in the area.

Minister: No, Mrs. Rogers, I've said my last word. 300 staff must go.

Mr Fraser: You mean 300 jobs lost?

Mrs Rogers: We couldn't do any serious surgery with just a skeleton medical staff anyway.

Minster: Well don't do any serious surgery! I don't care if you do varicose veins, hernias, piles, do something!

Mr Fraser: Do you mean 300 jobs lost?

Minister: Yes, I do Mr. Fraser. A hospital is not a source of employment, it is a place for healing the sick!

Mr Fraser: Well, it's a source of employment for my members, and you want to put them out of work, do you? Is that what you call a compassionate society?

Minster: I'd rather be compassionate to patients then to your members.

Mr Fraser: Right, we'll come out on strike.

Minster: Very well, do that! What's it matter, who could it harm? Do please, come out on strike! The sooner the better. Take the administrators with you while you're at it. I'll be sure not to pay you!

Note. From *Get some patients*- Yes Minister, BBC, 1980–1984.

https://www.youtube.com/watch?v=x-5zEb1oS9A

As is the nature of satire, the ridiculous notion of a hospital with no patients delights the audience. While the skit is absurd in nature, it highlights an issue that remains relevant to healthcare some 40 years later; hospitals are big business. They strive to be viewed as hygienic, well-run facilities which manage the life of their products, offering jobs and security for hundreds of staff members. Doctors, nurses, and patients as providers and receivers of care are viewed in this skit as financial liabilities. This thesis has uncovered that nurses and patients are in many ways, still seen as such.

To bring the thesis discussion together, NVivo software was used to amalgamate the analysis chapters into a representative word cloud. Figure 18 represents the results of this thought process.

Figure 18

Word cloud of thesis analysis

It is fitting that this discussion starts with both the elements of *people* and *care* as the core foundations of modern health care. Yet, like the hospital with no patients, we may well be in danger of moving into an era of *no care*. The discussion below is presented under three broad headings: (1) defining and locating the person in PCC, (2) responsibilising nurses as moral custodians, and (3) care as system-centre versus PCC. Each social order and their sub themes are now discussed in greater detail.

Discussion Point One—Defining and Locating the Person in Person-Centred Care

The discourse interrogated within this thesis opens an ideological dilemma of where the person is located within the system that espouses the notion of PCC. Fairclough (2015) states that ideology is developed through rhetoric and is reproduced and perpetuated through the interpretations and enactment by shared members of groups, in this case health services and people working within it. The discourse which is reproduced is indicative of the social cognitions of group members and their relationship to, and within, those institutions, therefore perpetuating unequal power relations, where the dominant discourse becomes normalised through everyday practice (Fairclough, 2015).

This issue is particularly relevant to the NN service given the complex social and medical nature of the admission criteria of people into the NN service. Navigated patients often are admitted to the service through referrals from in-patient touch points, particularly emergency department, the criteria for the service being frequency of admissions. Therefore, people in the NN service occupy a space in which they are viewed as wasteful, risky, and wilfully non-compliant and colloquially termed ‘frequent fliers’, the NN being called in as a ‘last resort’ to managing their care. Navigated people are viewed as representing the biggest risk to health service in terms of utilisation and cost. The tension is that the health system aims to change the people within the system, from a financial imperative, but they do not challenge the existing and/or traditional policy or workforce structure. Waters et al. (2017) found that policy is constructed through the analysis of problems that underpin risk management in an organisation which are political and institutionally decided upon. Person-centred care has been drawn into this as a solution by creating compliance around a policy that places responsibility on the individual even though the system is too rigid to support person-centred needs. The power of PCC is not with the person, rather it is with the government, which is in keeping with Foucault (2008a) who argued that governments control the conduct of individuals even though they create a rhetoric that gives the impression that people as citizens are in control and able to make rational decisions about themselves. Choice, therefore, is a pseudo-biopower.

Rational choice and homo economicus

The concept of PCC brings into consideration the rational choices that people make, and their decision-making processes. Rational Choice Theory (RCT) purports a simplistic view of the human psyche: man will make decisions based on a rational and meticulous understanding of what will maximise his preference (Scott, 2000). That is, preference is an inherent quality which does not require interactions with others, but rather is within the individual. This rational human is known as homo economicus, a being with the infinite ability to make rational decisions intrinsically linked to his economic worth (Mill, 1836; Urbina & Ruiz-Villaverde). Rational choice theory aims to explain and predict human behaviour and action. It is applied to many areas of society including public policy, institutions, and laws, which are all based on the assumption of individual rationality with roots in utilitarianism (Bransen, 2001; Hardin, 2001). Rational choice theory considers financial outcomes as final/total states, i.e., “they are sensitive to total wealth, not changes in wealth” (Mellers, 2001, p. 3318) and this is how governments as policy makers view its use. Thus, rational choice theorists aim to quantify human behaviour in a way that “determines the most efficient means of achieving any given end(s)” (Zuckert, 1995, p. 180).

While theorists such as Opp (2020) utilise RCT to explain social phenomena, the sociological view of health identifies considerable limitations and covert and overt forms of power and control within its use. Indeed, Foucault believed that rational choice within the context of modern science is responsible for forming the way that truth is discovered, therefore controlling the conditions under which people live. This is a form of coercion and discipline (Foucault, 1978, as cited in Zuckert, 1995).

Tversky and Kahneman (1992) later supported by Manzo (2013) agree:

> The logic of choice does not provide an adequate foundation for a descriptive theory of decision making. We argue that the deviations of actual behaviour from the normative model are too widespread to be ignored, too systematic to be dismissed as random errors, and too fundamental to be accommodated by relaxing the normative system … perhaps the major finding of the present article is that axioms of rational choice are generally satisfied in transparent situations and often violated in non-transparent ones (1986, p. 272).

Being a rational person is upholding citizenship. The citizen is afforded certain rights such as healthcare in return for upholding social responsibilities (Olsen, 2008). Citizenship is often expressed as a liberal-democratic view of its people including its political and legal structures. However, according to Foucault, citizens are a construction of the social orders, institutions, and spaces that they belong to (Foucault, 2008). Therefore, citizens are constantly moulded and formed to fit the changing landscape of a political environment. Citizens are moulded through choice architecture which dictate and constrain the potential choices available, nudging individuals toward a specific predictable behaviour which simultaneously forbids other options. The citizen is free to make whatever choice is available but is covertly persuaded in one direction[16] (Forberger et al., 2019). In this way, the government can control the level of risk associated with any given choice through the creation of obedient citizens (Foucault, 1979). Nurse navigators talk about how choice is not an option for people with chronic conditions. Indeed, NNs reported that newly referred people were frustrated and exhausted as the healthcare system is complicated and fragmented. Examples of this are people who have not been

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[16] An example of nudging in society can be seen in supermarkets, where fresh food, fruits and vegetables are located at the front of the store, or in cigarette regulations which mandate plain packaging and warnings. Choices are still available to the citizen; however, they are covertly persuaded in this choice (Donnelly, 2010; Esmark, 2018).

able to get to appointments, who have conflicting messages from each of their multiple specialists or are given multiple conflicting medications from different specialists.

Rational choice theory is void of value judgements and strictly quantitative in nature. Likewise, positivist medicine and the concept of biology and risks, born from insurance technologies, has given rise to the normal person, and therefore an abnormal person. This ideology can be traced back to the 19th century where Gordon, using the work of Foucault, explains it was used to exhort the working class to adopt the wealthy class position of “individual life” and viewed health and disability as “professional risks of human existence” (1991, p. 35). Schofield (2015) explains that the historical division of labour is one factor which has contributed to socioeconomic status and explains that the risk of lower paid, laborious jobs in unsafe and unsanitary conditions is one way in which poor health “gets into people’s bodies” (p. 58). In fact, the division of labour in society sees a small number of people become wealthy while others live with consistent and prolonged stress. As discussed in Chapter Seven, it is not then simply the individual social factors which impact on a person’s health and wellbeing, but also the social relations that always operate throughout every element of society (Schofield, 2015) dictated through the regime of governmentality (Foucault, 2008). This poses a major issue for governments attempting to ensure the health and wellbeing of all citizens.

The outcome of such positioning of citizens is that those who can adhere to the notion of positive choice compliance, and self-care do well and live long with the system working within their needs. On the other hand, those who cannot are destined for failure and when that failure occurs, they have “no one to blame … but themselves” (Zuckert, 1995, p. 187). This assumes that the person has limitless knowledge of all relevant choices and their alternatives whilst also assuming that systems and institutions will activate people to contribute to the greater social good (Altman, 2012). This is an extension of discipline and punishment in the neoliberal climate (Foucault, 1979; Wacquant, 2015), institutional relocation of resources and the deeply embedded truths of rational citizens collectively created the conditions of conduct, therefore the conditions for discipline.

In keeping with the notion of risk taking, the person’s life as a whole, not just their labour power, are factors in their human capital (Foucault, 2008a; Gordon, 1991). In this way, citizens are a resource to be managed and their human capital will be harvested by the government. All citizens are viewed as potential economic beings and thus all institutional elements focus on how best to obtain this from the people, and this is what Foucault calls *biopower* (Foucault, 2008). Thus, governmentality is always pressed upon society invoking the population’s biopower.

There is no more costly or risky human being than those with multiple chronic conditions, and this has been clearly described throughout this thesis. This thesis has demonstrated the costs of caring for those with chronic disease, including productivity loss and reduced workforce participation, extending to the family unit as members take on carer responsibilities (Business Council of Australia, 2011). The Business Council of Australia (2011) estimates that eliminating chronic disease would increase the national full-time workforce and productivity by 10%. Therefore, the problem of chronic disease is not simply one of care costs, but one of societal engagement and citizenship. Chronic diseases impeded the production of biopotential and biopower leaving the business, in this care health services, open to risks. Thus, Foucault’s observations stand true as “governing the poor” is more aligned with maintaining markets than with the wellbeing of people (Procacci, 1991, p. 157).

Of course, some glaringly obvious elements are missing from the utopian economic man; these are the social, psychological, cultural inequalities and structural barriers which determine a person’s health, wellbeing, and thus economic outcomes. Institutions view property as equal across those who participate in social responsibilities. The truth, however, is that for many, participation is never even an option. Further to this, Foucault argues that this non-participation, economic depravity, and social exclusion is expressly connected to the growth of wealth, where some become wealthy because others are not. This is what Foucault called liberal freedom (Guizzo & Vigo de Lima, 2015).

Importantly, Tversky and Kahneman (1986) found that humans are not rational in decision making and for my analysis this includes health providers and healthcare receivers. The narratives of NNs used in this thesis support this conclusion indicating that people, particularly marginalised populations, are complicated and are influenced by multiple factors. Some of these factors are personal choices, others are government-imposed limitations on how a person lives, works, and dies. We are, at all times, at the mercy of government rationality. Indeed, Urbina and Ruiz-Villaverde (2019) explain that individuals respond to conducts, social, cultural, and environmental elements of their lives when making choices. Homo Economicus, the rational self, does not fit into modern life and is an outdated and inadequate way of portraying the complex nature of human behaviour and decision making, yet continues to dominate economic theory and thus other agencies, including the notion of PCC. Person-centred care assumes that all people can and want to care for themselves, can make health related decisions and change their behaviour. Moving away from the concept of RCT would take considerable paradigm shifts in behavioural, institutional, political, and ecological economics (Urbina & Ruiz-Villaverde, 2019). People with chronic disease now make up the majority of those in healthcare and can no longer be viewed as excess human capital, the *others* within society.

This research has located and defined the person as the citizen. I will now locate those within the navigator service.

Irrational choices: Others in society

Given that patients prior to referral to a NN are unable to employ rational decision making about their care, it can be argued that they sit outside of the defined parameters of citizenship and, they are positioned as societal *others*. Where members of the citizen group are considered rational, people in the NN service are positioned as *irrational others*.

Othering is a form of dialectical positioning where there is an *us* and *others*. For instance, when data is collected about an ethnic minority, or a model of care is specifically designed around high needs people, it contributes to a body of literature which creates subordinate *others* (Schofield, 2015). This is because the people who create such discourse are often not a part of these community groups and therefore, the discourse positions minority groups as *others*. The power within this otherness is hidden as the discourse is naturalised/normalised within the context of which it is written (Foucault, 1978; Kryzanowki, 2020). This form of segregation and division can be crude or sophisticated in nature, where the other is seen as either inferior and/or alien to the self (Brons, 2015; Johnson et al., 2004). In health services, the marginalisation of certain ethnic and minority groups is also defined as a form of othering (Johnson et al., 2004). One example is where NNs report that they need to attend appointments with patients so that they are talked *with*, rather than *at*. The majority of the NNs reported that patients felt that they were not part of the discussion and if they were, the medical jargon being used was outside of their normal understanding. This meant that patients often left the appointment without clear knowledge of what was discussed or what they were directed to do. This translates to feelings of anger and hopelessness. However, from the institution standpoint, this often led to labels such as *non-compliant.*

The discursive positioning of such people places them into what Povinelli (2011) refers to as social brackets, where peoples' worlds are constructed through the way that they enter or exit public policy, procedure, and public opinions. Importantly, people do not simply exist within their brackets, they persist. They do not just occupy the space at the periphery of the dominant social world, they thrive (Povinelli, 2011). The people within the NN service told them how they really appreciated the navigator's input into treatment conversations because they no longer felt like an outsider.

For people prior to engagement with the NN service, the idea of Povinelli's "camouflage and espionage" offers an appropriate analogy (2011). Camouflage describes the act of hiding within an environment via an "embodied disguise" (p. 112) while espionage is being spied upon, looking into the lives of social worlds that perhaps do not belong to the norm (Povinelli, 2010; 2011). In the case of people living with complex chronic disease, their embodied disguise is that of the bracket or space that the service creates for them, where the health care environment harbours certain expectations of the person and creates services that connect with these expectations. The espionage in this case is often an unconscious part of the health team who have not met the needs of the person, have not provided the care they require, or have used processes to exit them from the service. A NN supports this here:

> *The patient really doesn't understand what is being said and what they are supposed to do. They [patients] don't speak up, but when we attend those appointments with them, we notice that the doctors take more time to explain it to them.* Nurse Navigator

The health structure, therefore, has not been flexible enough to deal with complex people. Indeed, it is clear from outpatient processes that appointments are dedicated by time and not by the individual's concern. The NN has bridged this gap in care, because they work with the person and not the specialist area the appointment is located in.

Sociologists define the merging of population groups, e.g., the elderly, those with chronic disease, First Nations people, and the structures and practices within these as *intersectionality,* where a human being is shaped by the interaction of social locations "within a context of connected systems and structures of power" (Foucault, 1978; Scofield, 2015; Hankivsky, 2014, p. 2). People within the NN service are an intersectional group living within that social bracket. The bracket in question has been defined and driven by health service utilisation and costs and these are brought about through the individuals service utilisation, admissions, and appointment compliance. Espionage is used to identify, define and order navigated people as requiring additional support from the NN.

The health service as an institution in Australia is ill equipped for people with multimorbidity. Services are designed around fee for service, single episodes of care where the person enters with an ailment or illness, receives treatment, and exits the service. It is linear and PCC is nebulous at best. Deeper than this, however, the discourse presented in this thesis has in many ways demonstrated that people are expected to be self-effective, active citizens whose choices allow them to engage in economic outputs where a person’s health is intrinsically linked to their economic potential. Where patients see the health service as an entity which will provide health, governments view health as a commodity. With this in mind, where the patient fits, is an important consideration. One could well suggest that governments do not want patients at all; however, ABF structures would suggest otherwise. The ideal patient in the health service is one which is self-determined, compliant, with infrequent use of the hospital, who engages with single services as needed and when acutely unwell. Under the gaze of governmentality (Foucault, 2008a) this is the appropriate behaviour under which people should conform, the conduct perpetuated from government. Maintaining this current system and trying to mould people with multimorbidity into it is ineffective at best and irresponsible at worst. These are the structures that contribute to the vulnerability of people in the NN service.

This, however, is at odds with the way that PCC is understood and described in policy and popular texts that describes partnership, offering of choice, working within a social framework, and viewing the person holistically, with purposeful living (Kogan et al., 2016; Slater, 2006; Jakimowicz & Perry, 2015; Arakelian et al., 2016).

Patient compliance through person-centred care versus system change through person-centred care

The NN success shows how patients are referred to NN services because there is nothing else that can be done for them. The people within the service are described as non-compliant to their care and treatment, have failed to attend appointments and are frequent visitors to hospital. Within a year of navigation, the picture of the patient is very different. The navigator evaluation clearly shows how the patient reengages with the health care team when their voice is heard, when they can contribute to their care, and when the team includes them in the decision making (Harvey et al., 2021). Managing 'compliance' has nothing to do with control and everything to do with giving the patient information about their condition and choice in how care is managed.

The data presented have offered multiple examples of compliance, particularly from the Nurse Navigator Toolkit which has expressed the need for self-care, self-management, and transition to community care. This is also evident in the literature review which uncovered that PCC should include elements of autonomy, empowerment and active participation and decision making (Slater, 2006; Kitson et al., 2013; Castro et al., 2016). In this way, the burden of healthcare management is located with the person and the NN, under which PCC becomes an avenue for compliance. Thus, the NN service uphold governmentality by engaging in what Foucault termed self-surveillance, an "invisible but unverifiable" form of power normalised through judgements and social ordering (Foucault, 1979, p. 204).

Summary; the person's location in person-centred care

The analysis has located the person in PCC, in the case of the NN service, the person's discursive position is that of an *other*. Navigated people are positioned as requiring behaviour change, described here in the NN Toolkit as:

> [Fostering] and [encouraging] active patient engagement in the development of health care goals which promote self-management and seek to improve health literacy … The more the patient understands what they need to do, the more likely they are to believe in their ability to actively influence their health (QH, 2018, pp. 5, 8).

While on the surface PCC appears to recognise and respect the choices that people are free to make, it is more aligned to the notion of compliance and harvesting the best economic outcomes of the person within society. In this way, PCC is a strategy of the government which sees people responsible for their healthcare and the role of the government and health institution as one of redirecting citizens into that social position. Choice is the product of structures within society and can thus create vulnerable populations. Next, I will highlight how nurses are made responsible for delivering PCC and how this limits change within the system.

Discussion Point Two—Responsibilising Nurses as Moral Custodians of PCC

While this research has argued that the person is primarily responsible for remaining well and out of hospital, the NN is not immune from scrutiny. They have been delegated the responsibility to make changes that ensure compliance and reduce avoidable hospital admissions in a group of people with considerable high care needs. A tension therefore exists between NNs and health services through conflicting messages. On the one hand, NN are supporting the patient by navigating care, and on the other they are required to reduce hospital admissions. The evaluation of their role shows how they have reduced hospital admissions and helped the patient to reorganise their lives around their illness, predominantly, multiple specialist appointments and outpatient visits. The PCC aspect of this is driven by the partnership fostered between the individual and the NN, and not by their multiple medical specialists associated with their clinical management. The system is still driven by medical dominance ensuring that PCC, chronic disease management and ultimately the reduction of hospital usage becomes the responsibility of NNs, and not that of an entire system.

This section will specifically focus on the way that time, space, and structures make NNs responsible, but also vulnerable to a system designed around fiscal management and medical dominance. In effect, NNs become vulnerable to a structure that expects them to solve an unsolvable problem of keeping sick people out of hospital. The traditional narrative of nursing care forms part of that vulnerability as this next section explores.

Nursing subordination powerlessness

In 1893, the Nightingale pledge was created and later adapted and implemented in nursing graduation and pinning ceremonies. The pledge, originally created by Lystra Gretta, offers an interesting historical view of nursing.

> I solemnly pledge myself before God and in the presence of this assembly, to pass my life in purity and to practise my profession faithfully. I will abstain from whatever is deleterious and mischievous and will not take or knowingly administer any harmful drug. I will do all in my power to maintain and elevate the standard of my profession and will hold in confidence all personal matters committed to my keeping, and all family affairs coming to my knowledge in the practice of my calling. With loyalty will I endeavour to aid the physician in his work and devote myself to the welfare of those committed to my care (Miller, 2004).

Nurses have a long history of subordination. The role has traditionally been seen as an extension of the physician, recognising the medical professional as the head of the institution as evidenced by the Nightingale pledge above. Nurses have typically supported and enhanced the biomedical model of care having limited decision making and autonomy in practice (Murray, 2018). However, nursing has been through a period of professionalisation where the scope of the nurse and the duties performed by them has been rapidly developed and supported through university training and through the SFP. I referred to the use of competencies in previous chapters to discuss how systems have directed the profession. However, nursing as a profession has also been bought into that narrative by accepting this responsibility for care even though they have had little influence on these changes in care (Harvey et al., 2018).

As Rudge (2103) noted, nurses desire to please and their focus is on the patient even when fiscal resources dictate how they operate. This value script has been acknowledged throughout nursing history and it is at odds with contemporary fiscal management of health care (Nelson & Gordon, 2004; Waring et al., 2010). Nursing has always been subject to political influence throughout history where changes to nurses work is directly related to what is happening in the political arena of that time (Nelson, 2001). Nursing practice and advanced practice nursing autonomy continues to be the subject of political, institutional, and cultural influences and power relations (see Chapter Eleven).

NNs were established out of a promise by the government in power saying that:

> A re-elected Palaszczuk government will continue to deliver on its commitment to employ 400 Nurse Navigators for the important work of ensuring patients with chronic illnesses find the care most appropriate to their needs at an estimated cost of $72 million each year (Queensland Labor Party, 2017, p. 4).

Nurse navigators took on their role with a view to changing the way care is provided, encouraged by a NN Toolkit that spoke the language of patient care. Four years on, the evident success of the NN and their value as change agents is not acknowledged by those who have power to allow the role to either grow and mature. The political position has moved on and the HHS are looking to reduce annual budget blowouts. Nursing is silent on their plight as this NN stated:

> *Managers get it or at least they articulate that they get the value of navigation and they support what we do, how we do it, and that sort of thing, it's when it's the next level up that we then get the pushback and the questioning, and obviously, that flows back down the trail.* Nurse Navigator

The fact remains that within the current system, nurses are part of a power relationship which affords them little authority and recognition. They are aligned with the inner workings of the hospital, positioned as resources within it while also being responsible for the care delivered, traversing across non-government and government organisations that interfaces social, clinical, and material needs. It is now recognised that nurses are in the profession that spend the most time with patients and have a considerable role to play in the quality and safety of healthcare (Burston et al., 2013). However, as we have found with the BPF, nursing tasks and the time they take are monitored. While this is positive for workload and clinical safety (McHugh et al., 2021) this also controls the way that nurses work. Indeed, Allen (2014) suggested that care organisation work, i.e., care outside of the task's, accounts for 70% of all nursing work, a fact which is not taken into account with workload calculations.

The historical subordination of the nursing profession ensures that the value of nursing care is not recognised nor realised. Powerlessness is apparent at all levels of the system including the funding models, the hierarchy of the systems including professional lines and decision making, as well as the legislation and professional standards of nursing (McInnes et al., 2017). Nurses themselves are not immune to these power relations and often enthusiastically uphold their traditional roles, contributing to the constructs of government and institutions. For NNs, this has come in the form of "vertical discounting" from within their profession and oppression from superiors (Anderson et al., 2019, p. 1206). An example of this is provided in the field note below:

> *NNs express that they feel unsupported by other nurses, particularly those in other senior nursing positions. One NN told me that she asked for help from a level 6 nurse [clinical nurse, one level below the NN], and the nurse said to her 'What could I possibly teach a level 7 nurse.'* Author's field note

The effect of such positioning is referred to as "lateral othering" (Anderson et al., 2019, p. 1204; Foucault, 1978) where NNs have become *others* within the institution and within the profession. This suggests that nurses are not only at odds with administrators and with other health professionals, but they are at odds with themselves. This is supported in the literature by Roberts and Schiavenato (2016) who found that othering is present in nursing through a sequential process leading to marginalisation and exclusion of both nurses and of patients. Hence, the dominant-subordinate relationship is reinforced and perpetuates a "difference" with the identity of the NN (Roberts & Schiavenato, 2016, p. 178). This is destabilising for the position, as they not only have to show outcomes and justify themselves to administrators, but to all professions including their own. It also devalues the work they have done and the patients they care for. In his way, the nursing profession is contributing to maintain the macro structure (Fairclough, 2015) rather than embracing change. This is a form of governmentality where members of social groups, in this case nurses as part of the healthcare team, are positioned and remoulded to uphold the constructs of government (Foucault, 2008). Nurses do this because of the deeply ingrained cultural and organisational norms.

The converse to being an *other* is to belong and to have a sense of belongingness to the profession and the culture within which one works. Belonging is important to individuals who have a higher sense of self-esteem and self-actualisation when they belong. However, in order to belong, there is at times a need to conform, often being tied with the professional identity (Levett-Jones et al., 2007; Fitzgerald, 2020). This may provide some insight into the challenges that the nursing profession faces in that they conform to feel that they belong to the traditional health structures. The novel role of the NN and the non-traditional work that they do, as discussed in Chapter Eleven, has posed an alternative method and model of care delivery which is, indeed, person-centred. However, as we have seen, their implementation into the traditional system has been a difficult one and has created anxiety for NNs who were brought into the role with no real preparation by the services. Yet, the turnover rates of the NNs are low because the role removes them from the traditional system. As this NN indicated:

> *Most of the original team is still in place [after four years]. I think it's about a nurse grade seven role that doesn't include managing a team of 50 people under you is always very appealing. I also think from our perspective as a service that we have a team that is really passionate for clients that we look up to much like the other nurse navigators. But because we're specialists, nurse navigators, we're using the skills that we've developed throughout our career on these [systems] barriers.*
> Nurse Navigators

Despite this payoff, NNs are in the same difficult space as the NP who came before them in Australia (Harvey, Driscoll, & Keyzer, 2011). In the case of the NP model in Australia, Torrens et al. (2020) found that team dynamics acted as the major barrier *and* the facilitator to embedding the model (2020). Likewise, these findings are supported by the work of Harvey (Harvey, 2010; Turner, 2007) finding that autonomy in NP practice remains largely rhetorical in nature with the medical officer remaining the head of healthcare.

These elements combined were referred to earlier in the thesis as the economies of performance and ecologies of practice of the nurse, where NNs are on one hand viewed as objects of productivity and yet asked to make changes to the person's life that would support hospital avoidance. This is another way that nurses are destabilised, which contributes to the structural vulnerability that people face (Levett-Jones et al., 2007) as nurses are hindered from using their potential to make system wide changes or to provide autonomous services to vulnerable people. In this way, NNs are actors and victims within and of their system which retains the nursing position of the Nightingale pledge—superordinate and devout.

The responsibilisation of nurses: Is leadership present?

Nurse navigators are given the authority to navigate but not to change any structural barriers that impede care. Despite the lack of authority, NNs are increasingly made responsible for moulding the person to fit the ideals of citizenship. This is done through technologies of government (Foucault, 1979) such as health literacy assessments which view a person's ability to manage their care and the system as a reflection of the cultural and economic status, therefore becoming a problem of the individual rather than a problem of the system. The NN mostly ignore this activity because they suggest it does little to address the real reasons for disengagement with health care. In fact, most NN argue that many of the people they care for are health literate; the issue is with the fragmented care that they struggle to negotiate (Byrne et al., 2021). Yet, NNs are responsibilised as they become the panacea for deficiencies in person-centredness, behaviour change, self-efficacy and ultimately hospital avoidance.

Responsibilisation is the effect of self-management of risk by an individual at the exclusion of government support and input (Liebenberg & Ungar, 2013). The study by Gachound et al. (2012) described a hierarchy within PCC whereby nurses see themselves as most important to PCC and medical officers happily accept a lower importance of person-centred practice (see Chapter Three). While this could be a result of spending the most time with patients, it may also be the result of subtle discourses and positions of power within the healthcare institution. Despite this, NNs have aligned themselves to the care of their role description providing what they feel is an ethical/social model of health, at times deliberately disrupting the system to achieve this. In this way, they hold the ethics of care in higher regard than the fiscal management of the system. One NN described their focus on holistic care:

> *Nurse Navigation has for this family been a shared journey where the couple are very capable, proactive, and forthright but the Nurse Navigation Service has provided a considered expertise around healthcare—both the inpatient and outpatient experience with almost everything you could possibly imagine in-between. A respectful and professional relationship built on trust, to find a way to problem solve the complexity of dealing with healthcare issues across the continuum. A true patient journey that at times seemed more like a roller coaster for all of us.* Nurse Navigator

The discourse within the ACN whitepaper demonstrates that nursing is now being viewed as in deficit, a resource "hiding in plain sight" (ACN, 2019, p. 20), an underutilised resource which can solve some of the problems of the health system. This is not new, with literature suggesting that nurses are discursively positioned as responsible for social welfare (Anderson et al., 2021) in building self-care within individuals (Petrakaki, 2018) and self-care and their own compassion fatigue (Edwards & Goussios, 2021). However, the solution of nursing is a heavily controlled and coerced one and one which can easily be remoulded, should the appropriate outcomes not be realised. This is an example of what Fairclough calls relational and identity functions, where the social identities of groups are moulded and remoulded based on well-defined social parameters and norms (Fairclough, 1993). In this case, nurses are established in their social order within the institution of the hospital with little power to exercise autonomy.

Therefore, the responsibilisation of NNs is threefold. They are responsible for the delivery of care to the individual, responsible for themselves their practice and profession, and responsible for achieving hospital avoidance. These areas require wider system change, collaboration, and macro level transformation, yet have fallen at the feet of nurses to achieve. An example of this was described by a NN in capturing the money they have saved in regard to patient travel to specialist services from remote regions:

> *And we were able to catch the financial efficiency by sitting with our manager for patient travel. It is not particularly accurate, but it gives us some level of understanding so I can talk to the navigators, and ask, how long was that client here for? How many appointments did they come in? And were you able to cluster [appointments]? … and we could work out how many travel dollars were saved by reducing their [patient] time away or reducing the number of times they had to come down [to regional hospital] or by increasing how long they were able to stay in community.* Nurse Navigator

With the responsibility and accountability sitting squarely with NNs we move further toward the "death of the social" (Rose, 2006, p. 327) where all members of society are individualised and responsibilised, yet the health system sees them only from a population perspective, with no responsibility to provide individualised, or person-centred, care. The right to health is provided only under the social contract of the responsible citizen (Foucault, 2008a). An example of the disconnect is described by this NN:

> *And like most hospitals, the people only work in the hospital, they don't actually see the person in their own environment when they're well. Which is what we do. I've done a lot of home visits with this particular lady. And to the GP. So I've got to know her quite well. I suppose one of my challenges is we have a certain GP to liaise with the nursing homes and they do a clinical profile. Half the time it is not accurate. They don't actually pick up the phone and say hey, we're doing this. Can you give us some insight?* Nurse Navigator

Therefore, person-centred practice remains theoretical, a point uncovered in the literature review. Deeper than this, the practice of person-centredness within the context of responsibilisation, is largely detached from the principles of ethics in care (Sihto, 2020). On the other hand, nursing is heavily positioned with the moral, ethical function of health acting as “buffers” from the effects of the system on patients (Nelson, 2004, p. 18).The discourse herein moralises nurses and their practice and ignores the presence of power relations. Indeed, nurses have a highly developed “virtue script”[17]“ (p.204) which in many ways has overshadowed the skills and knowledge that the profession brings while also responsibilising them as ethical employees (Nelson, 2012; Fairclough, 1993). When these responsibilities sit firmly with nurses, it liberates others from needing such virtue and ethics. Again, this uncovers the minimalistic ethic of NPM; of the fiscal and ethical war within healthcare, the fiscal seems to have won. Ultimately, the ideologies within this makes nurses, NNs and the entire NN service a contributing factor to, and a product of, structural vulnerability.

Smith (2020) wrote about the structural vulnerabilities that health staff face in the context of COVID-19 which include a lack of resources, lack of flexibility in models and the obstacles of the fragmented system. However, as we have seen, NNs are working among these vulnerabilities all the time, themselves being positioned as finite resources. One of the keys to changing this and the positioning of nursing in general is leadership. An example of this was described by a NN:

> *Just use the navigators to take them offline to do the COVID support. The patients, you know, patients are angry because they can't find a navigator.* Nurse Navigator

While nursing leadership is encouraged through the hierarchy of positions with the institution, e.g., Nurse Unit Manager [NUM], Nursing Director and Executive, this thesis has uncovered a sense of powerlessness in nursing which extends to senior NNs and beyond, referred to as puppets with pseudo-power by Harvey (2010). Nurses have expressed this stating concerns that nursing tasks swallow the larger purpose that the profession brings and its power to influence (Brownlee, 2016). This analysis, I would

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[17] The Nightingale pledge is a solid example of this.

suggest, has demonstrated that our nurse leaders such as chief directors, peak bodies, and unions among others, have perpetuated the discourse that nurses can and must be used to fix and maintain the current system as opposed to identifying the barriers and changing them. The research highlights the fact that nurses need to have a more prominent voice in any change within the system and this will require top tier leadership alongside political and system redesign. For nurses to realise PCC and for PCC to be real, it is not enough to simply say that PCC is valued; nursing leadership must demonstrate it. Goldberg and Page (2006, para. 5) sum this up nicely by stating "[a]t the very top we need leaders with vision, who are guided by principles, and who will take the courageous steps to engage those who want to make a difference."

A time for change: Person-centred care as a new healthcare model

> "Chronic disease and illness can be seen as medical, societal and personal constructions to manage the irreversible protracted failure of the body… Understanding and reframing the social construction of chronicity, the major driving force in health system transformation, is an urgent challenge." (Martin & Peterson, 2009, p. 583)

Health is not simply a scientific, biological construct, it is a social construct. The thesis has explored multiple ways in which health is constructed as a commodity, a resource, and a goal with responsibility. While discourse often positions health in terms of risks and influences, it often fails to explicitly explain and act upon the notion that health is constructed by governments where the context of a person's life outside of their control affects their health and wellbeing. Conrad and Barker (2010) found that illness itself is often socially constructed and defined by certain ideals and knowledge around normality and abnormality. According to Schofield, (2015) there is an abundance of ways in which health is constructed and deconstructed within society including the SDH, class, gender, ethnicity, and indigeneity. However, it is not these factors alone which create ill health. On its own, gender or ethnicity do not pose a physiological threat to any one person's health. It is the associated norms, structures, rules, roles, policies, and politics which create such health divides (Scofield, 2015) and this is structural vulnerability (Bourgois et al., 2017).

Critical discourse analysis is the discovery of power and social struggle insofar that it raises to consciousness how language contributes to the domination of some citizens by others (Fairclough, 2015). This is precisely what has been uncovered: people with multiple morbid conditions are excluded from care within the current model. The context of the efficient system allows for the struggles that people face to go unaddressed. This requires completed system design. It is apparent that the biomedical model, on which the current health system is created, is inadequate for our modern world within which multimorbidity is escalating annually and requires a team of health practitioners (O'Conner et al, 2018). What is needed is a model of care within a system structured on a socially constructed, value-based model of health. This model is one which specifically addresses life changing events that come with chronic conditions. As we have seen from the NN dataset, this includes housing, finances, family trauma, employment, travel, and isolation among many other factors. A socially constructed model of care takes the view that the above circumstances are intrinsically interrelated and part of the social, family landscape within which the person lives (Guzys & Arnott, 2014). This is guided by the ethical practice of social justice, ensuring the equity of health and care for vulnerable people (Guzys & Arnott, 2014). This is one way in which structural injustices could start to be addressed. As one NN said:

> *Even though we've got all the research on social determinants of health, this is actually a real-life model that places importance on all those social determinants just as much as on the hospital avoidance. And the navigator services is actually one model that does that*. Nurse Navigator

Molina-Mula et al. (2017) stated that nurses have the potential to break the deeply ingrained culture of the healthcare system, bringing teams and professionals together to increase the participation and decision making of patients. This thesis has demonstrated a significant potential to achieve this with NNs breaking traditional silos and designs within their daily work. This, however, has not been easy and how much this disruption has been valued by health services is yet to unfold. The NN role in Queensland is still in its infancy with the model evolving and changing to meet the needs of the health service. While permanent funding for NNs has been provided by the state government, how health services use this funding, and how they use NNs in the long term is unclear. In this way, NNs and the people that they care for are vulnerable to the decision makers within the system.

Adding to the discussion above, the dominance of the medical profession remains an ongoing challenge for other professions' autonomy, funding models and system structures which are all designed around the medical officer as the leader (Ovretveit, 1985; Wranik & Haydt, 2018; Kenny & Adamson, 1992). This is largely because the medical profession has the dominant economic value in the system being able to bill for services and create revenue (Kenny & Adamson, 1992). Once more, the argument of NPM and the neoliberal climate of productivity, efficiency, and efficacy dominates. Social programs, for all their value and compassion-based outcomes, will always need to prove their economic value to the market for this is the climate that all services live within. Introducing PCC to healthcare is not immune to this with the concept itself contributing to a strategy of fostering economic viability from the individual. Povinelli (2011) warned of this:

> Once again progressive critics should be sceptical of the compassion of market neoliberalism. And once again, given the sensibleness of this scepticism, we need to ask why the rhetoric of sacrificial love can have such a powerful illocutionary force, nonetheless. In previous chapters I noted that social welfare is

> neither a success nor failure in the abstract. It is a socially mediated way of assessing the social world. If neoliberalism understands all social investments that do not have a clear end—a projectable output value—as failing economically and morally, then it might be hard to defend social programs which presuppose a world in which the state should care for the most vulnerable. In a similar way, the question ‘is the sacrifice worth it?’ can be answered in the affirmative only if a specific relationship between violence and redemption defines the social imaginary of suffering and dying (2011, p. 184).

In many ways, NNs have served their purpose. They commenced as an election promise rising from a discourse of the job losses for the Newman government. Their defined objective of reducing hospital admissions has also been realised, however, the model is seen as a costly one, as socially constructed care is a departure from their traditional medical model and still requires significant support, negotiation, and navigation. It also requires people to periodically re-engage with services as needed where the NN role may not be welcome. The market value of the NN is therefore not easily defined or explained and this places the service at risk of being discontinued. Povinelli explained this:

> If a social welfare program, for instance can be shown to lengthen life and increase health but cannot at the same time be shown to produce a market value, this lengthening life and increased health is not a value to be capacitated (2011, p. 22).

A cautionary tale

Governments and health services as macro structures are at an essential junction. Nurse navigators are delivering on their role expectations as described in the NN Toolkit and have implemented a genuine, working model of PCC. They are partnering with individuals and families and working within the gaps of the fragmented system. However, their market value or economic outcomes cannot be easily reconciled. This point acts as a forewarning; should the NN service be disbanded, it will uncover the raw agenda of economics and fiscal management at the same time discounting the value of PCC, ethical practice, and the social challenges that individuals face. The removal of this service would be potentially catastrophic to the vulnerable people they care for who have consistently expressed that they would be lost without their navigator; lost to the system, lost inside of their social bracket, and lost as a citizen.

Summary: Nurse Navigators Caught in the Middle

NNs themselves are a product of a system which has failed our most vulnerable people. They are positioned in the middle of competing social worlds, often acting as conduits of care for those at the margins of the health system. Nurse navigators have aligned themselves to the ethical and social work of their role offering an alternative model of care. However, they themselves are vulnerable to a system which is predominantly concerned with fiscal management of services and tangible financial outcomes. The voice of senior clinical nurses has not been heard and not acknowledged. Nor has that of the patients. Person-centred care, and nursing authority to enact it, remains silent. Despite the rhetoric of PCC, the actions of the health services demonstrate the exact opposite. Nurses are a commodity to be used and patients are not central to health service values.

Discussion Point Three—Care as System-centre Versus Person-centred

The final discussion point of this thesis will focus on *care* within the healthcare system which evidenced from the above discussion, is now founded upon the ideologies of NPM. The notion of system centred care was alluded to in the literature review, with the study findings also locating PCC in practice, conditional to the time, space, power, and structures of the healthcare system. It suggests that the health institution that is inward facing, largely focused on itself.

The public health system is government owned and operated. Influences across the social and political agendas have ordered and reordered Australian healthcare to try and meet the needs of our changing population and the changing political agendas. There is no doubt that this is a difficult task and comparatively, Australian healthcare fares well. Australia ranks 9th on the global Health Care Index which ranks infrastructure, professional competencies, costs, medicine availability, environment, access to clean water, sanitation, and government intervention on risks such as tobacco use (Healthcare Channel, 2020). Australia also has the fifth highest life expectancy of OECD countries and the lowest rates of smoking among people aged over 15 (AIHW, 2018a). However, health disparities remain. First Nations people, people of lower socioeconomic status, people in rural/remote or regional areas, those with a disability and those with multimorbidity live with health and wellbeing well below the standards of care provided to most Australians. The reality is that our current healthcare system, and that of many developed countries, are not designed for these vulnerable people, least of all for a chronic disease “pandemic” (Koehring, 2017, para. 2). While certainly chronic diseases have grown in proportion, it is not a pandemic, thanks to our increased life expectancy and modern medicine, this is our new norm. Whilst managing chronic healthcare is prominent in policy discourse, this study has uncovered that the systems and structures around chronic healthcare are not aligned with this.

In Figure 5, I mapped a genealogy (Foucault, 1972) of our health system, of nursing history and key events that impact health care service, calling it symphony of neoliberalism. Returning to this in analysis allows for reflection on the competing interests, events, and political ventures that have contributed to the current system. Indeed, the NN service is a result of the fragmented system, a maelstrom of ideals and changes working to try and maintain the financial viability of the current system. While PCC is one of these ideals, its rhetoric is overshadowed by the biomedical model. In this way, the NN service is a result of the perpetuation and maintenance of the macro structure and is not about those who live within the micro level of society (Fairclough, 2015).

The rhetoric of person-centred care, the reality of the biomedical model

I have argued that PCC remains largely rhetorical, acting largely as a technology of compliance. The technology of PCC is a driver of biopower under governmentality. This modern form of power is far more covert which functions to reinforce, control, monitor, organise and optimise the forces under the institution. These pathways of power triangulate and traverse the spaces and positions people occupy. Biopower, therefore, is a part of capitalism allowing for “the controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes” (Foucault, 1978, p. 140).

Modern healthcare relies on neat, solvable problems “in which the context is not critical” (Mold, 2017, p. 2). However, for people in the NN service, context is everything. Living at the intersection of the norms of society, inside of defined social brackets, is a risk to, and the source of, their poor health and wellbeing. Herein lies the tension that health services are complex and fragmented in nature, ill-equipped to manage the needs of people with multimorbidity, and yet there is little room to change systems to reflect the needs of the evolving demographic of the population. These issues run deep throughout this analysis and runs across political, economic, structural, and professional lines. Deeper than this, I suggest this thesis has uncovered an overt disregard for the social elements of health and wellbeing. Medical officers feel ill equipped to handle such matters, focusing on the business side of their practice where the patient support is defined by time and cost (Gachound et al., 2012; Whitty et al., 2020).

Providing responsive, person-centred services that meet the complex needs of the person is a difficult task. The government burden is a big one to shoulder though the purpose is clear, “prevent disease and other ill health and injury and to maintain health, not just to treat illness, so that people remain as healthy as possible for as long as possible" (AIHW, 2018a, p. 5). It is not enough to simply say that care is person-centred, it must be deconstructed and reconstructed into a system which specifically addresses the well-known, systemic barriers to care. Ignorance to this is unjustifiable.

The linear system—where is the centre of care?

This research has produced multiple key findings. Of note is the finding that healthcare in Australia is linear. Current funding models, methods of care and siloed hospital structures align with a simplistic concept of health utilisation that involves the person entering the system, being provided care and cure, and exiting. These transactional occasions of service are similar across the hospital and primary care sectors. Once the person exits the service, revenue is generated.

This thesis has discussed the discursive movements of healthcare planning and positioned this argument in the content of NPM. Healthcare systems are now designed to generate the best financial performance, generating revenue in the private sector, viz., general practice and reducing expenditure in the public sector. The reduction of healthcare costs is reliant on a strong primary healthcare sector with the GP being the central point of care and coordination. On the other hand, the general practice is a business which generates revenue from frequent, short appointments as discussed in Chapter Nine. General Practitioners are private business owners relying on government subsidies through Medicare and patient out-of-pocket co-payments, meaning that for some patients, care may be unaffordable and difficult to access (Sheridan et al., 2012). While this system is in place, it is reasonable to expect that the system will always be biomedically orientated and financially driven. In this context, the introduction of PCC and NNs could be described as an inauthentic attempt to bridge known gaps.

Researchers have suggested changes to funding including alignment of health services with value-based healthcare where hospitals and physicians are paid based on their patient outcomes (Teisberg et al., 2020). However, the AMA have been clear in their position statement on such changes:

> Fee for service has proven to be an effective funding model over many years and should remain the primary source of funding for general practice services. It works effectively for the majority of patients, providing autonomy and choice, as well as access to care based on clinical need (AMA, 2016, para. 15).

This translates to bulk appointments and population-based health care where the individual with complex social needs is vulnerable. In fact, the in-and-out model of care equates to a successful *business* model, but an ineffective source of *care*. The freeing of this healthcare market as described in Foucault's Governmentality (2008a) under NPM, has limited the benefits for individuals and communities placing the principal outcome with the business as a financial one.

These tension points presented above are not new findings. The issue of PHC and health care funding are well known and debated (see Department of Health, 2019a). It is no doubt a complex and challenging issue to overcome and will require significant investment in reform and change. However, the structures of the current system are so well and deeply ingrained within the institution that it has been accepted. Additionally, the current system is ardently supported by peak medical bodies as already highlighted. This means that any changes to the current system which have been proposed often maintain the elements of fee for service. An example is healthcare 'homes' which have been proposed to be managed by GPs; care in the home is facilitated using allied health and nursing services contracted or employed by the GP, whereby the patients are cared for in the home making it a hospital avoidance strategy (Australian Government, 2021).

Despite its seemingly innovative nature the healthcare home centres on the current fee for services being retained:

> The medical home should build on the strengths of the existing Australian general practice based primary care system, which as demonstrated benefits. Data from the OECD demonstrating that it is one of the most efficient and highly performing health systems in the world (AMA, 2015, para. 3).

This is poignant and provides context and insight into how macro systems work to maintain the current systems, making changes to microstructures in order to uphold the larger agenda (Fairclough, 2015). The same is unfortunately true for the NN service and for PCC. Nurse navigators are indeed working within the fragmented gaps that have been created by the current system. Rather than working to fix these, NN are plugging holes.

The NN service was built on the principles of primary health care which includes access to care, participation, health promotion, and intersectoral cooperation (Public Health Association, 2014), taking on the care coordination role that GPs alone cannot achieve (see Chapter Three). However, it is telling that the NN service has been located in the hospital space, as the current funding and business models of general practices are not suitable to fund such an initiative, nor to meet the coordination needs of the person. In the short term this is unlikely to change. In fact, while the NN service is an exemplary model for PCC, it works in isolation. The NN service is yet another initiative which does nothing to change the structures of the healthcare system despite the efforts of this group of nurses, instead, plugging the gaps, acting as a band-aid solution to a failing system (The Change Foundation, 2013). Person-centred care is also operationalised as an initiative designed to plug gaps, as it reframes the role of the patient within the system rather than changing the system.

With this in mind, how can we position the person at the *centre* of care when there is no centre? The system is not cyclic, and it manages people from one point to another. Each occasion of service is viewed in isolation, e.g., in—fix—out. Other than being the subject of care and the object of revenue, people have limited say in how services are designed. However, I would suggest that the person is key to the necessary changes in the system and PCC could be the ideal vehicle for system change which is required for large scale disruption at the macro level. Despite the intent to provide PCC, the current system, power relations, and the AMA's strong position statement retaining our current revenue methods are persistent challenges. It is therefore understandable that at the completion of this research I remain sceptical that any significant change will be championed.

"Yes Minister" (see Figure 17) serves as a reminder that *care* is the essential work of the health institution, and that care belongs to the individuals and communities which governments serve. Health services should heed the warning of the hospital with no patients, realising that a fiscal system is not necessarily a functional system. Person-centred care has become dissociated from its original social base. Where it once offered hope for medical and psychiatric care, it is now one of the many ways in which people are ordered within the health institution. Fairclough (2013a) describes every action and occurrence of language and ideology as foundational to upholding macro structures. In this way, PCC upholds the construct of the institution as a macro structure and is indeed a technology of government.

Critical Summary and Recommendations

This section brings the discussion to a close, drawing on the points raised to provide recommendations for the health industry, across the social orders.

Person-centred Care Revealed: An Ethical and Fiscal War

Australian healthcare is complex. Our growing and ageing population ensures that the demographic of people seeking healthcare is changing. Chronic disease for close to 90% of the population will dictate how they live and how they die (WHO, 2011). Our healthcare system needs to be equipped to support the health and wellbeing of the people including those who are most vulnerable. Just like the hospital with no patients described in Figure 17, we have a system that is ill equipped to do the job of its purpose; provide health*care*.

Person-centred care in the NN service is a technology of compliance. It is a strategy, as part of a suite of strategies within a service aimed at changing the behaviour of the individual, to ensure the best economic outcome of any individual person. In this case, the most costly and risky people in healthcare are those positioned as *others* within the economic society. This is because health is viewed as a commodity where the ideal patient in the health service is one who is self-determined, compliant, an infrequent user of the hospital and who engages with single services when acutely unwell. The intention of the NN service is to form a relationship with the individual and help them to journey through the system, all the while instilling positive coping strategies and health behaviours which improves their QOL and the service bottom dollar.

Nurse navigators have demonstrated their commitment to the notion of PCC through their consistent and dogged efforts to provide just and ethical social care. This has been significantly challenging for the services. Nurse navigators are subjected to forms of medical dominance and within their own profession are positioned as lateral *others* leaving them vulnerable to the system, yet also responsible for changing the individual and the system while having no authority to do so. They are caught in the middle of an ethical and fiscal war where the two concepts are juxtaposed, and within the current system, are unlikely to reach a compromise. This leaves people with multimorbidity, frailty, social and cultural vulnerability at a further disadvantage.

The healthcare system as a government institution is inward facing, complex and complicated. It is ill equipped to manage chronic conditions and therefore vulnerable members of our society who are also most at risk of chronic conditions are further marginalised by the healthcare system. The system itself is transactional and linear designed around medically dominated fee structures. The potentials of models such as the biomedical model or PCC have not been effective in changing the health system to meet the needs of vulnerable and marginalised people. Instead, the introduction of PCC, and indeed the NN service, have reiterated and reinforced the current service structures. This, and the above discussion, has demonstrated that NNs and PCC are both products of and contributors to structural vulnerability in the health care institution.

Recommendations

I make the following recommendations for nursing practice, the health care system, and to the government and political institutions responsible for healthcare in Australia.

(1) The NN service should be viewed as an exemplary model of PCC and used as an avenue to identify barriers and enablers to care coordination across the health system. Healthcare providers have at their fingertips a working model of PCC and expert senior nurses with detailed knowledge of the fragmentation that people experience. Capitalising on this knowledge could be the best use of the NN service to date—a direct avenue into the experiences and challenges that the most vulnerable members of society face. The lived experiences and data from the NN service should be considered when deconstructing and reconstructing systems and structures.

(2) This thesis has highlighted the far-reaching impact of the lack of a clear definition of PCC. Instead of a top-down approach from overarching bodies, individual health services should consider exploring and adopting a working definition of PCC. Defining PCC at the provider level may drive the change, taking it from the abstract to the realised. In this way, it may provide essential clarity to providers and inform system change in a meaningful way. The literature review provided in this thesis provides insights into the essential elements of a definition of PCC. Accordingly, the key factors in developing a definition of PCC which centres on system change and advocacy are already apparent . This definition must be critically orientated

and must consider the power imbalances present in the sector. Indeed, PCC could be the new framework for health system change and this offers an exciting avenue for health services to take forward. The depth of PCC, and how it is used in radical system redesign is yet to be considered.

(3) Person-centred care requires its own set of measures which are not designed on financial outcomes. Person-centred care is philosophically separate from NPM ideologies of fiscal management and therefore how it is measured will need consideration. Avenues such as Patient Reported Outcome Measures and Patient Reported Experience Measures (PROM/PREM) and value-based healthcare offer some interesting insights, though require critical appraisal to ensure alignment.

(4) Health system policy, frameworks and initiatives which advocate for PCC in the chronic disease space should be re-evaluated. As found in the thesis and the article by Sobolewska et al. (2020), PCC is rhetorical based on compliance and self-management. The work of Sobolewska et al. could be extended to critically appraise how chronic disease management in Australia could be supported through the provision of genuine PCC. Again, lessons learned from the NN service could provide insight into this realignment.

(5) Nursing leadership should focus on nursing emancipation. Nursing leadership needs to focus on how nursing practice, skill, and knowledge can negotiate changes within and outside the system. Business planning and associated policies and frameworks should be reviewed and revised to optimise the autonomy of nurses and the benefit of the time and space required to practice PCC. I would suggest that many of these frameworks have hindered nursing practice and therefore careful consideration of the effects of such planning and frameworks, some of which I have revealed in this thesis, is important work.

(6) Funding models for Australian healthcare need urgent review and reform as they are a significant source of inequity, fragmentation, and structural vulnerability. Fee for service models, particularly in PHC, should be reviewed and amended. In addition, the role of nursing in PHC, which is the product of funding models, should be reconsidered. Again, NN as a working model can provide a benchmark for how nursing can be utilised as care coordinators and aligning this with PHC will have benefits to individuals and to general practice.

(7) Further investigation and investment in socially constructed, value based MOC are needed. Social models of healthcare should be considered as a foundation of Australian chronic disease management which address the traditional medical structures and silos of health care. Further research is needed in this area.

(8) New public management principles should not be omnipotent. Healthcare is a human right and care should be the underlying premise of health institutions. At the very least, governments should consider more socially grounded investment strategies such as social ROI. I maintain that a complete government and institutional change is required to embed PCC but appreciate the radical nature of such claims.

Person-centred care and indeed the NN service offer an exciting and highly valuable avenue for health services. Aligning the principles of PCC to wider meso and macro structures offers many potentials to health service and most importantly, could contribute to the equity and social justice of marginalised Australians.

Factors Influencing this Thesis

Limitations

While the thesis has demonstrated an investigation of discourse across a wide variety and hierarchy of text and actions, there are limitations of the research which must be acknowledged.

Firstly, this thesis did not use patient interviews. It may seem futile to investigate PCC while not exploring the perceptions of patients; however, the reasons behind this were threefold: (1) the ethical clearance for this study was granted on the notion of a document analysis of data from the NN evaluation, excluding patient data and this research was specially designed to view how nurses and NN practised PCC. (2) There is a plethora of research available on how PCC is perceived and accepted by patients. (3) NNs in the evaluation study as the custodian of PCC acted as the patient voice.

Secondly, this research is specifically related to the concept of PCC as it pertains to nurses, specifically NNs. Other health professions have their own body of discourse around the concept of PCC which may differ from the meanings portrayed in this thesis. In addition to this positioning, the research within the NN service as senior registered nurses sitting outside of traditional specialist services may have limited the application of this research. However, given that NNs are governed by the same SFP, ethics, and practice guidelines as other nurses, I would suggest that PCC in relation to other Australian nursing services will have similar findings.

There are a number of avenues of PCC that have not been explored in this research including hospital measures such as PROM/PREM. These were not analysed within the thesis as they are not a measure used in the NN service. However, critical appraisal of such measures and how they contribute to patient outcomes is an area that future research should focus on. I would also suggest that trying to measure a concept which is clearly ill defined and utilised is a moot point and our efforts are better placed in focusing on system redesign through PCC, thus creating a new space to measure such interventions.

Lastly, this thesis took place in the context of a global pandemic and the associated changes and challenges of COVID-19. This context is an important consideration which no doubt impacted the NN service and the individuals they care for. However, the context and complexity of COVID-19 is expansive and as a result, there was inadequate time and space in this thesis to give due attention and respect to the impact of COVID-19 on the workforce and chronic health services. Therefore, the specific context of COVID-19 is beyond the scope of this research.

Chapter Thirteen —Conclusion

This research explored the concept of PCC as it relates to NNs and to those with multiple chronic conditions. Building on the research of Rushton and Edvardsson (2019) it set out to explore the technologies, mechanisms, procedures, and structures which legitimise the use of the term, and how the concept positions people and practices in relation to the healthcare system. What was uncovered was much deeper than the philosophy of PCC that we have come to understand.

Person-centred care positions people in the NN service as societal *others,* characterising them by their use of hospital services and aiming to change their behaviour to that of the rational citizen. In this way, PCC is a technology of government.

The research has uncovered overt and covert forms of persuasion and control which can be broadly characterised as power and power relations. It has also uncovered the potential for the Australian healthcare system to change, capitalising on the concept of PCC to do so. Person-centred care is operationalised by nurses through their practice with NNs demonstrating the barriers and enablers of this as a complicated combination of time, space, and structures. The research has demonstrated that vulnerable Australians, as well as NNs themselves, are victims of social and structural vulnerability and that social models of healthcare, and considerable changes to our current structures, are essential to the delivery of truly PCC in Australia.

Despite this, NNs have demonstrated a commitment to PCC and to working at the margins of the healthcare system to meet the needs of our most vulnerable people.
I conclude this research with the following anecdote provided by a NN during the evaluation and a reminder that health*care* must always see the person:

> *It has taken a lot of work, liaison, and effort to encourage other health care providers and services to see [the patient] as a person with human problems.*
> Nurse Navigator

The health system, and those within it, must see the value of PCC beyond financial benefit.

Final Reflections

As I reflect on this research journey, I consider the ideological changes that I have been through. I started this research as a nursing director and manager in a rural health service, and I have finished it as a nurse academic. I look back at my time in the health service, particularly on my leadership positions, and I realise that I was very much a part of the institution and that I toed the line of my defined role within it. I believed in the order of the institution and was unquestioning in my approach to the work that I did.

This process has opened my eyes to the wider influences of health and wellbeing and how these concepts are immersed within our social minutia. Seeing discourse and ideology from a more removed position was essential to this. I needed the space, time, and a perspective shift to be able to see how the institution positions people and how we as nurses uphold these ideals. Many times during the research my supervisors had to remind me to take my clinician ‘hat’ off. They saw what I could not: how deeply indoctrinated nurses become and how strongly our sense of care and duty pervades our professional identity.

Reflecting on this, I believe that the institution, as inward facing, is a victim of itself. The institution has become so complex and complicated that it cannot see the forest for the trees. Positioning people at the centre of a healthcare system would require widespread change and disruption and strong leadership from political levels. This thesis has shown that it is not just the institution that upholds these roles, but also our peak bodies who have assumed their designated roles, perhaps not seeing the influence they have to make such changes. Leadership requires courage and at times, dogged persistence. I feel that we as nurses can learn a lot from Queensland NNs.

As a woman in healthcare, and now academia I also reflect on the role of gender in this research. Given the historical nature of this research, I was reminded that the role of nursing is heavily influenced by the fact that it is a female dominated workforce. While I have not touched on this in this thesis, I do feel that the relations of power that nurses exist within are a product of this, and I would call on future research to consider this when interrogating such issues in the nursing profession.

I now believe that the nursing profession, despite the changes to practice roles and MOC, is no closer to advancing nursing practice. In fact, interrogating the SFP and other documents has highlighted to me just how stuck within the system we are and we as a professional body have allowed this to occur, even endorsing this. My supervisor wrote in her thesis that changing the way that nursing practice is viewed is a steep mountain to climb. Nearly 12 years later as I complete my thesis, we may have climbed a little higher, but the summit is not in sight. Having been involved in the NN project since it started in 2018, I am left feeling somewhat cynical that the work that they have done will not be valued by health services. I now see how NPM has pervaded all facets of the healthcare industry and how it has subverted the sense of caring within it. Despite these strong words and feelings toward the healthcare system in Australia, I do remain optimistic: I see an opportunity for a radical and complete system redesign ensuring that the system is fit for purpose. And so, I commit myself to the climb, knowing that small and steady steps, advocacy, and research could contribute to equity and social justice for marginalised Australians.

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Appendix

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