Health-Related Quality of Life and Disability among Older People with Chronic Kidney Disease

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Abstract

Background

Chronic Kidney Disease (CKD) has been characterised into five stages with CKD5 defined as an estimated glomerular filtration rate (eGFR) of $< 15\text{ml/min/1.73m}^2$ and includes those receiving renal replacement therapy (RRT) (dialysis and transplantation) or those who are eligible for RRT but are not receiving treatment. In New Zealand (NZ) approximately 1000 individuals commence dialysis each year, with the majority aged between 65-74 years. Māori experience a two-fold higher rate of CKD5 compared to non-Māori. CKD5 has a potential to have a negative effect on an individual's health-related quality of life (HRQoL). CKD5 is associated with disability. Little research has been completed to understand the impact of HRQoL on disability in people aged ≥65 years with CKD5.

Aims

The aims of the Health and Disability Study (H&D Study) presented in this thesis are to describe cross-sectional associations between HRQoL and disability among a cohort of older New Zealanders with CKD5, and to determine which factors at recruitment, including HRQoL, have the potential predict disability outcomes 12 months later; and to describe the HRQoL and disability outcomes for an older Māori cohort with CKD5.

Methods

A rapid review was completed to identify important models of HRQoL and disability, with a scoping review completed to identify existing research investigating HRQoL and disability in CKD patients. The dialysis outcomes in those aged ≥65 study (DOS65+ Study) was an "accelerated longitudinal" cohort which aimed to determine the HRQoL of those aged ≥65 years with CKD5, to aid in developing evidence-based guidelines for the management of CKD5 in older adults. This study analysed the baseline characteristics of the 225 participants in the DOS65+ Study to determine associations between HRQoL (EQ-5D-3L) and disability (WHODAS 2.0). Participants who were followed to 12 months (n=156) were analysed using modified Poisson regression with robust standard errors to identify which factors at recruitment, including HRQoL, predict disability outcomes 12 months later. Descriptive analyses were used to describe the Māori cohort (n=49) and their outcomes.

Results

Of the 223 participants analysed at baseline, those with 3 or more comorbidities were more likely to be disabled as were those with moderate-severe problems with the EQ-5D-3L dimensions of mobility, self-care, usual activities and anxiety/depression. The multivariable analyses indicate that those disabled at baseline were at an 86% higher risk of being disabled at 12 months. The HRQoL dimensions of self-care and mobility at baseline predicted disability at 12 months by 31% and 38% respectively. Dialysis vintage of ≥2 years was associated with lower disability. Within the Māori cohort, HRQoL and disability at baseline appear important in predicting disability at 12 months, however this result is limited due to small sample size.

Discussion and Conclusion

Issues with EQ-5D-3L mobility, self-care and disability at baseline predict disability at 12 months in this cohort. The EQ-5D-3L and WHODAS 2.0 allow for patients to determine how they perceive their HRQoL and disability which may be important in improving patients' clinical experiences and therefore outcomes. Patient participation in assessing these HRQoL components and baseline disability could help with CKD5 education and planning for RRT.

Key words: Health-related quality of life, disability, chronic kidney disease stage five, aged ≥65

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“I can do all things through Christ who strengthens me” Philippians 4:13 NIV

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List of Abbreviations and Acronyms

ANZDATA	Australian and New Zealand Dialysis Transplantation registry
BMI	Body Mass Index
CI	Confidence Interval
CKD	Chronic Kidney Disease
CKD5	Chronic Kidney Disease Stage Five
DHB	District Health Board
DOS65+ Study	Dialysis outcomes in those aged ≥65 years study
ESKD	End Stage Kidney Disease
eGFR	Estimated Glomerular Filtration Rate
GFR	Glomerular Filtration Rate
HALex	Health and Activities Limitations Index
HD	Haemodialysis
H&D Study	DOS65+ Health and Disability Outcomes Study
HRQoL	Health-related Quality of Life
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
KDIGO	Kidney Disease: Improving Global Outcomes consortium
KDQoL	Kidney Disease Quality of Life Instrument
NHP	Nottingham Health Profile
nMnP	Non-Māori/Non-Pacific
NZ	New Zealand
MCS	Correlated mental health
PCS	Correlated physical health
PHARMAC	Pharmaceutical Management Agency

PD	Peritoneal dialysis
QWB	Quality of Well-being Scale
RR	Relative risk
RRT	Renal Replacement Therapy
SIP	Sickness Impact Profile
SF-36	Medical Outcomes Study 36 Item Short form (SF-36)
WHODAS 2.0	World Health Organisation Disability Assessment Schedule 2.0

1 Chapter One: Introduction and Background

This chapter provides a brief introduction to the burden of chronic kidney disease (CKD) globally and in New Zealand (NZ), and focuses on those aged ≥65 years. Following this the Dialysis Outcomes in those aged ≥65 years Study (DOS65+) will be explained (1); the DOS65+ Study is the ‘parent’ study that led to the DOS65+ Health and Disability Outcomes Study (H&D Study) described in this thesis. The terms health-related quality of life (HRQoL), disability and CKD will be introduced, before discussing the sub-cohort embedded in this thesis relating to older Māori with CKD and issues of health and disability associated with renal replacement therapy (RRT). Te Whare Tapa Whā (2), a Māori model of health and well-being, will also be outlined. The overall aims of this thesis will be discussed, and a summary of the research approach will be provided. This chapter will conclude by providing an overview of the subsequent chapters that are introduced in this thesis.

1.1 Introduction to CKD Globally and in New Zealand

In order to standardise the definitions of CKD, the Kidney Disease: Improving Global Outcomes consortium (KDIGO) have categorised kidney disease into five stages related to kidney function (3). Stage five is considered most severe and stage one is considered least severe. In most of the CKD outcomes literature, CKD is described as when the estimated glomerular filtration rate (eGFR) is <60ml/min/1.73m^2 (stage 3 or below). From the DOS65+ Study and therefore the H&D Study, we focused specifically on chronic kidney disease stage five (CKD5) where individuals either had an eGFR < 15ml/min/1.73m^2 and were pre-dialysis and/or individuals who were on dialysis. CKD5 is also known as end stage kidney disease (ESKD). For clarification, the abbreviation ‘CKD5’ will be used in this thesis when specifically focusing on those with chronic kidney disease stage five and the abbreviation ‘CKD’ will be used when discussing chronic kidney disease more generally.

Globally, 10% of the population is affected by some form of CKD with the majority having CKD stage 3 (4). CKD is the 18th cause of global deaths, resulting in 16 per 100,000 deaths as of 2013 (5). CKD is a worldwide problem and globally there has been a steep increase in the number of individuals with CKD in both absolute and relative terms (6, 7). The rise of CKD has been attributed, in a large part, to the rise in diabetic kidney disease rates (8). In those aged ≥65 years, vascular disease has been a prominent cause of the rise in CKD (8). Related to the rapid rise of CKD in the past two decades, there has also been an increase in the proportions of older individuals (aged ≥65 years for the purposes of this thesis) reaching CKD5 and commencing dialysis to manage this (9). Dialysis removes smaller molecular weight solutes that are normally excreted by the kidneys, as well as controlling salt and water homeostasis to maintain a stable but impaired internal environment in an individual. It does not replace normal kidney function (10). In England and France, researchers have estimated that among older individuals (aged ≥70 years) dialysis has the potential to extend life by an average of approximately 2 years (11, 12). Due to the nature of CKD5, as well as the interventions to manage CKD5 (dialysis), it has a large potential to have a negative effect on an individual’s HRQoL and can be quite overwhelming (1). This is because CKD5 (dialysis) often results in significant changes in lifestyles which is often difficult for patients to accept, and it is a painful and invasive treatment (13). Additionally, it is known that disability, related to comorbidities, is prevalent amongst many CKD5 patients (14) and that those with CKD5 are often known to be encumbered by physical limitations, which often manifest as disabilities (15). However, it appears that limited research has investigated relationships between health-related quality of life (HRQoL) and disability among older individuals’ with CKD5, who are either pre-dialysis or on dialysis (8).

In NZ, CKD is prevalent in approximately 12-14% of the population. Only a small proportion of these individuals will end up with CKD5 and require dialysis. From the latest Australian and New Zealand Dialysis and Transplantation registry (ANZDATA) (16), the incidence of new patients in 2017 commencing dialysis was 615 and the total number on RRT was 4658 (2768 on dialysis and 1890 with a transplant). Of those incident dialysis patients, 38% were aged ≥65 years (older) and 53% of the prevalent patients on dialysis were aged ≥65 years (16). By 2051 it is expected that there will be 1.4 million older people in NZ (17), therefore the number of older individuals with CKD5 who may require dialysis will continue to rise (8). The increase of older patients on dialysis in NZ has significant implications for those affected and their families. This is because dialysis has been found to be very overwhelming to patients and their families (8).

In NZ through taxation the NZ healthcare system is funded by the government to allow for universal access. Dialysis is expensive and therefore results in significant economic costs for the NZ government. Dialysis treatment is estimated to cost approximately \$65,000-\$80,000 per year, per individual (1). Annually over \$56 million is spent on dialysis patients aged over ≥65 years in NZ. This does not include the costs related to hospitalisations and comorbidities (1). As a result of this, CKD5 poses a significant health burden that is not restricted to those with the disease but expands to NZ society.

1.2 Introduction to the Dialysis Outcomes in those aged ≥65 years Study (DOS65+)

This thesis will use data from the DOS65+ Study. The DOS65+ Study is an “accelerated longitudinal” cohort which aimed to determine the HRQoL of older patients with CKD5, to compare and contrast survival between different treatment options and to develop evidence-based guidelines for management of older patients with CKD5 (1, 18).The study recruited ‘prevalent’ New Zealanders with CKD5 at the study’s commencement and additionally recruited ‘incident’ New Zealanders as the study data collection phrase proceeded in an accelerated fashion. The DOS65+ Study was designed to measure a range of outcomes such as HRQoL, measured by the EQ-5D-3L (19, 20) and disability, measured by World Health Organisation Disability Assessment Schedule (WHODAS 2.0) (21). To be eligible for inclusion, participants in the DOS65+ Study had to have either commenced dialysis or been diagnosed with CKD5 and undergone pre-dialysis education (1). The protocol is further explained elsewhere (1) and is further explained in section 4.1 (Chapter 4). This thesis presents independent analyses of certain data collected from the DOS65+ Study. For clarity the DOS65+ Health and Disability Outcomes Study, which refers to the independent analyses and literature reviews presented in this thesis, will be referred to as the H&D Study. The H&D Study is explained in the Methods (Chapter 4).

1.3 Health-Related Quality of Life (HRQoL) and Disability

As will be elaborated on in the literature review (Chapter 3), there is limited information describing the relationships between HRQoL and disability outcomes among older people with CKD5. As will be discussed in the aims (section 1.6), HRQoL and disability are the main predictor and outcome variables respectively in this thesis, therefore it is important to understand what is meant by these terms. However, it is important to note that there is not a single, agreed upon definition or conceptualisation of HRQoL (22) and defining disability continues to be contested (23). The key frameworks, models and theories for HRQoL and disability have therefore been explored in a rapid review of the literature (presented in Chapter 2), to help inform the subsequent H&D Study analyses.

1.4 Chronic Kidney Disease Stage Five (CKD5)

Within NZ, individuals with CKD5 are managed as part of a multidisciplinary team. Unless very symptomatic, they are initially managed medically to reduce the impact of CKD5 and to control or reduce their associated symptoms. At the same time, individuals are educated with respect to on-going management for their CKD5. This includes an active conservative care pathway where symptoms continue to be actively managed medically but a decision not to undertake dialysis is made. Alternatively, RRT options include:

Dialysis, either haemodialysis (HD) or peritoneal dialysis (PD), or renal transplantation is discussed and commenced when appropriate. The DOS65+ Study population only included individuals on dialysis (HD or PD), or those still on an active medical management pathway (1).

Briefly, HD involves pumping blood through a semipermeable membrane while dialysis fluid is pumped past the other side in the opposite direction. This allows for the removal of unwanted solutes from the blood (24). A dialysis machine acts as the ‘kidney’ and the blood stream is accessed through an intravenous (jugular) catheter or needling an arterio-venous fistula. This treatment is completed three times a week on average (25). Within NZ, approximately 1 in 5 HD patients dialyse at home (26).

PD is where an individual has a dialysate (a balanced salt solution) infused through a tunnelled catheter through the abdominal wall into the peritoneal cavity. Unwanted solutes and water diffuse down a concentration gradient from capillaries across the peritoneal membrane (a semipermeable membrane into the dialysate). The dialysate is regularly exchanged four times a day (24). PD has the distinct advantage of allowing home based dialysis and within NZ, 66% of individuals receiving dialysis (both PD and HD) were home based as of 2019 (27).

1.5 Importance of this Research for Māori

In NZ, Māori (the indigenous people of NZ) continue to experience sustained inequities in health care access, treatments and outcomes compared to non-Māori (28). The Treaty of Waitangi, signed by the British Crown and Māori representatives in 1840, committed to ensuring Māori had at least the same rights and privileges as non-Māori, which encompasses health in a more contemporary context (29). Principles of the Treaty of Waitangi are included in health and disability legislation; however, Māori still experience lower rates of access to health services than non-Māori despite increased need (30). Additionally, Māori life expectancy is 7.1 years less than non-Māori (31).

Māori have a 2-fold higher rate of CKD5 and often present at an earlier age than NZ Europeans (32, 33). Māori experience reduced life expectancy whilst dialysing even when socioeconomic, demographic and geographical factors are considered (34). Currently there is limited knowledge relating to Māori experiences with CKD5 particularly related to HRQoL and disabilities (1, 35). Within the DOS65+ study, there was a decent Māori representation (36). As such, a sub-cohort of this H&D Study is focused on the health and disability of Māori participants.

1.5.1 Te Whare Tapa Whā

Given that this thesis explores Māori HRQoL and disability associated with CKD5, it is important to understand how Māori perceive and view health. A popular model is Te Whare Tapa Whā which represents a holistic approach to health and well-being (30, 37, 38, 39). This model consists of four dimensions or pillars which represent four sides of a house, reflecting that if one dimension is weak or diminished then a person does not have optimal health and well-being (39, 40). The dimensions are:

> Taha Wairua: This means the spirituality of a person is essential to who they are. Spirituality allows for an important link to ancestors to be made and provides future direction (37, 39).
>
> Taha Hinengaro: This concept refers to mental health. It stresses that thoughts, feelings and ways of the mind cannot be separated from the body or the soul. The way an individual feels is important for their state of health (38, 39).

Taha Tinana: This represents the physical body. Physical health is important and considers the biomedical needs of the body (30), however it is noted that this is highly connected to the mind and soul. When the mind, body and soul interact positively, this allows for positive health outcomes (39).

Taha Whānau: For full health to be realised, the relationship between individuals and their whānau (family or wider social networks) must be recognised. Whānau wellbeing is improved by individuals' being well (37, 39).

Acknowledgement and understanding of the Te Whare Tapa Whā will enable it to serve as a framework for the interpretation of the findings from the literature review, and in particular the findings that focus on Māori.

1.6 Overall Aim

The main aim of the H&D Study is to investigate the association between dimensions of HRQoL and disability, and to determine if HRQoL and/or other factors act as potential predictors of disability in people with CKD5 aged ≥65 years in NZ at 12 months follow up. This will aid in developing knowledge to inform both nephrology professions and patients with respect to the impact of dialysis on their life.

The specific objectives of this research are to:

a) Describe characteristics of the H&D Study participants at baseline and to determine cross-sectional associations, if any, between health-related quality of life (HRQoL) and disability among a cohort of older New Zealanders with CKD5 at the time of recruitment (baseline);

b) Determine, which, if any, factors at recruitment (baseline), and including HRQoL, predict disability outcomes 12 months later;

c) Describe key characteristics (including HRQoL and disability) at recruitment (baseline) and again 12 months later for older Māori patients with CKD5.

1.7 Research Approach

As mentioned, the H&D Study analyses data from the DOS65+ Study. In the DOS65+ Study, all participants were interviewed first at time of recruitment to the study and again 12, 24 and 36 months later. Analyses undertaken as part of the H&D Study are focused on data collected in the DOS65+ Study at baseline (interview 1) and again at 12 months (interview 2).

Quantitative analyses will be used to examine associations between HRQoL and disability. Other variables such as sex, ethnicity and age will also be analysed. Analyses will be completed to determine which factors at baseline, including HRQoL, predict disability in the H&D Study cohort of CKD5 patients aged ≥65 at 12 months. Descriptive analyses will be completed within the Māori cohort.

Very little research has been completed investigating predictors of disability in CKD5 patients, therefore this research will provide new evidence regarding the long-term disability outcomes in CKD5 patients within the NZ CKD5 context.

1.8 Overview of the Thesis

This thesis will detail a rapid review (Chapter 2) which aims to provide understanding of what is meant by HRQoL and disability, informed by the current literature to inform the subsequent H&D Study analyses. Following this, a scoping review of the literature will be presented (Chapter 3) to determine the relationship between HRQoL and disability respectively in people with CKD5, respectively, specifically in those ≥65 years and to help identify potential predictors of outcomes and confounders to consider in the H&D Study. The study design and methods of the empirical work will be presented in the Methods (Chapter 4) before the Results are presented (Chapter 5). The thesis is concluded with the Discussion and Conclusions (Chapter 6).

1.9 Summary

This chapter has detailed the prevalence of CKD globally and within NZ It has introduced the reader to the DOS65+ Study and has described CKD5. It has also provided an introduction of the importance of this research for Māori. Additionally, the overall aim and research objectives and the research approach have been discussed.

2 Chapter Two: Rapid Review

This chapter aims to identify key frameworks, models and theories underpinning both health-related quality of life (HRQoL) and disability from sources identified through a rapid literature review (41). Firstly, the methods of the rapid review are presented, followed by a discussion of the main findings relevant to the HRQoL and disability research undertaken in this thesis.

2.1 Review Methods

Rapid reviews, with a narrative synthesis, allow for inclusion of a comprehensive range of literature (42, 43), in this case pertaining to HRQoL and disability. As mentioned, the aim of this rapid review is to identify key frameworks, models and theories underpinning health-related quality of life (HRQoL) and disability.

Ovid, PubMed, Google Scholar and CINHAL databases were searched during this review. The search terms are presented in Tables 2.1 and 2.2 below. Additionally, to identify key Māori frameworks, models and theories relating to HRQoL and disability, each term in the following tables was searched with the Boolean “AND” Māori (variations of this term such as Maaori, Maori and Māori were also included). Several books focused on HRQoL and disability that were identified via journal bibliographies and recommended by supervisors were also included.

Table 2.1 Search terms used to identify HRQoL literature

Health Related Quality of Life	Quality of Life	Health status
Health-Related Quality of Life	QOL	Generic health
HRQOL	Health	EQ-5D
HRQoL	Perceived health	General health

Table 2.2 Search terms used to identify disability literature

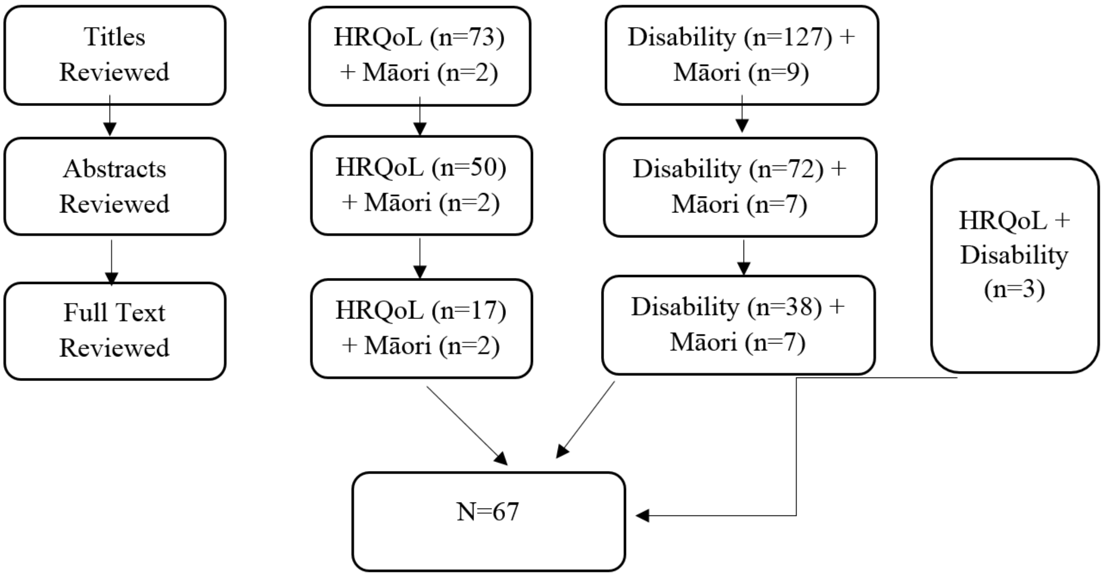
Disability	Disabilities	Disability evaluation
Disabled	Handicapped	Physically challenged
Disab*	Disabled persons	Physically disabled
Physically handicapped	WHODAS 2.0 or WHODAS II or WHODAS	Impairment

In PubMed, when the terms “health related quality of life” and “disab*” were searched there were 328,361 and 208,202 results, respectively (as of 01/04/2018). As a result of the large number of results, the search was narrowed by adding the Boolean phrase “AND” followed by “define” or “definition” to the search. When this did not yield a manageable number of articles (the target being fewer than 300 results for each search), the “allintitle” restriction was added.

2.2 Rapid Review Results and Source Selection

In addition to identifying key frameworks, models and theories underpinning HRQoL and disability, sources had to be available in English. Initially sourced items were screened on the basis of their titles, then abstracts, and the full texts of remaining sources were then reviewed.

Figure 2.1 Flow diagram of source selection



* The numbers in the figure represent the number of items selected at each stage of the review process.

As presented in Figure 2.1, after title and abstract screening a total of 67 full-text sources were assessed for eligibility and were all relevant for inclusion in the rapid review. Tables I (1-5) in Appendix I summarise the sources on HRQoL (n=17), HRQoL and Māori (n=2), disability (n=38), disability and Māori (n=7), and HRQoL and disability (n=3). These tables also summarise the main aims, findings and conclusions from each of these sources.

2.3 HRQoL History

The term health-related quality of life (HRQoL) has developed over time and followed use of the term quality of life (QoL) (44). QoL is a term that appears to have increased in use from the 1940s (45-47) to depict the view that there is more to having a ‘good life’ than simply being financially secure (47). QoL can be perceived as the degree to which an individual’s needs are met (48) and involves elements aggregating together to form an overall perception of an individual’s QoL (49). QoL can be conceptualised in various ways which include:

1) The philosophical perspective related to human existence.
2) The ethical perspective related to the sanctity of life.
3) The economic perspective which assesses QoL through evaluating economic growth.
4) The sociological perspective which emphasises the relationship between the individual and their circumstances.
5) The psychological perspective which defines QoL as an individual’s self-appraisal of their life and goals (45).

As the focus on patients’ wellbeing has increased over time, it has become clear that measures of mortality and morbidity are no longer sufficient to represent changes in population health (50). Research was first published on QoL in 1957 (45), and it became a key word in medical databases from 1975 (46). The term HRQoL became increasingly popular in the mid-1980s, and the number of HRQoL articles has continued to increase (46). For example, when HRQoL is searched as a key word in Ovid between 1902 and 1999 there are 1,395 results but searching between 2000 and 2018 finds 29,293 results as of May 2018.

2.3.1 Key Frameworks, Models and Theories of HRQoL

The aim of this rapid review is to present key models, theories and definitions of HRQoL. As of yet, there is not a single agreed upon definition or conceptualisation of HRQoL (22). Wilson and Cleary are often regarded as the first to develop a model of HRQoL (22). They noted that most conceptualisations of HRQoL include the dimensions of physical functioning, social functioning, mental health and general health perceptions. Concepts such as vitality, pain, and cognitive functioning were also identified as important in determining an individual's HRQoL. Wilson and Cleary summarise their model of HRQoL with the idea that there are five causal factors which interact to influence HRQoL. These are biological/physiological factors, symptoms, functioning, general health perceptions and overall QoL (22). These factors are said to be on a continuum and each of the factors plays a different role in influencing the HRQoL of a person, depending on the circumstances of the individual.

More recently, Karimi et al described four different models of HRQoL that they identified from the literature (50). Firstly, they noted that HRQoL can be defined according to how well a person functions and their perceptions of their physical, mental and social well-being (50). Secondly, HRQoL is often considered to be a subset of QoL, wherein QoL is seen as an all-inclusive concept incorporating all factors that impact upon people's lives, whereas HRQoL only incorporates factors that are part of the individual's health (50). Thirdly, HRQoL is self-perceived and well-being relates directly to the presence of disease or treatment. In this definition, it appears that an individual must be experiencing disease in order to have their HRQoL affected. Lastly, HRQoL can be seen as a means of valuing or 'measuring' health, whereby different values (i.e. utilities or preference weights) are assigned to different health states (50). This last model aids us in understanding how HRQoL may be measured.

As a result of health professionals and researchers becoming more aware that patients' needs extend beyond the physical body, HRQoL has also been defined as a measure of wellness (51). However, defining HRQoL as a measure of wellness is quite subjective, so instead HRQoL has been referred to as the psychological, social and physical factors that directly impact health (48). It is important that HRQoL is considered in a subjective, multidimensional and dynamic fashion (45), with personal priorities and experiences being considered (49). The ability of an individual to conclude what their HRQoL is, is important (52) which is why it is often seen as a subjective measure.

Lastly, HRQoL can be seen as not only something that is important to the individual but as something that can be perceived by a group or influenced by the environment. The Centres for Disease Control and Prevention defines HRQoL as "an individual's or group's perceived physical and mental health over time" (53). It is important that the determinants of the HRQoL of the population be understood in order to improve individuals' and populations' HRQoL (49).

Table 2.3 provides a useful summary of the various ways HRQoL has been described.

Table 2.3 Summary of the key definitions, frameworks, models and theories of HRQoL

	Wilson and Cleary 1995	**Karimi and Brazier 2016**	**Kaplan and Reis 2007**	**Dempster and Donnelly 2008**	**Centres for Disease Control and Prevention**
Components mentioned					
Cognitive Function	✓		✓		
Mobility	✓	✓			
Self-care	✓	✓			
Usual activities	✓	✓	✓		
Pain/Discomfort	✓		✓		
Anxiety/ Depression	✓				✓
Biological	✓	✓	✓	✓	✓
Physiological	✓	✓	✓	✓	✓
Symptoms	✓	✓	✓		
Social/Support	✓	✓		✓	
General health perceptions	✓	✓	✓		✓
Patient Preferences	✓				✓
Assigning values to health		✓			
Holistic perspective				✓	
Definition	Not available	One definition is to signify the utility associated with health, and secondly HRQoL is viewed as the way health affects quality of life.	Measures of wellness that are specifically about health can be defined by HRQoL.	Not available	HRQoL is an individual's or group's perceived physical and mental health over time.
Model	Biological and physiological variables interrelate and implicate the symptoms, functions and health perceptions of an individual, which are in turn impacted by environmental and individual characteristics influencing overall HRQoL.	Not available	Not available	Not available	Not available

	Wilson and Cleary 1995	**Karimi and Brazier 2016**	**Kaplan and Reis 2007**	**Dempster and Donnelly 2008**	**Centres for Disease Control and Prevention**
Theory	Biological and social sciences relate, and both are important dimensions in determining HRQoL.	Distinguishing between QoL and HRQoL is important. HRQoL is about all aspects of health. QoL is about all aspects of life.	Not available	HRQoL should be measured formally as there are good reliable tests and it provides a complete assessment of a person’s health and well-being.	Not available
Measures discussed	Not available	SF-6D and EQ-5D	This source lists many measures.	SF-36 and NHP Generic and specific instruments.	Not available

2.3.2 Applications of HRQoL

Various frameworks, models and theories of HRQoL need to be understood in order to apply the concepts of HRQoL. HRQoL is increasingly being used to assess health outcomes globally (54, 55) and measures of HRQoL are often used in clinical trials (22). HRQoL is an important concept to consider when planning, implementing and evaluating both health care and social policies (44). HRQoL is an important outcome; medically an individual may be improving however if the treatment required is decreasing HRQoL significantly, there is a potential that the medical intervention needs to be re-evaluated. Therefore, HRQoL is a concept that is considered in a wide array of settings, nationally and globally.

Within NZ, HRQoL is often used as a measure in research that focuses on patient care, as well as at a governmental level such as in policy and planning development (56). For example, the pharmaceutical management agency (PHARMAC) uses HRQoL as an important consideration when planning which pharmaceuticals and treatments it will fund (56). PHARMAC is the NZ Crown agency which decides which health-related products including medicines are subsidised within the publicly funded health system to those providing public health care (56).

There is little merit in considering HRQoL as an outcome unless it can be measured (47, 52). Due to the large increase in interest about HRQoL, this has resulted in a number of valid and reliable measures of HRQoL being developed.

2.3.3 HRQoL Measures

There are various measures of HRQoL available. However, when choosing which measure to use for a study it is vital that the measurement goals are clearly defined and that the measure is valid, reproducible and easily interpreted (55). Additionally, the reliability, responsiveness (48) and breadth of the measure should be considered (57). There are also different ways to collect HRQoL data. This information can be collected from clinician assessments of individuals HRQoL, whānau assessment of HRQoL and an individuals’ assessment of HRQoL, however it is commonly regarded as important that personal priorities and views are considered (49) when contemplating HRQoL. This is due to only the individual truly being able to understand their own HRQoL.

HRQoL can be measured through generic (non-disease specific) measures and non-generic (disease specific) measures. Generic measures include the Medical Outcomes Study 36 Item Short form (SF-36) (58), Sickness Impact Profile (SIP) (59), Nottingham Health Profile (NHP) (60), Health Utilities Index (HUI)(61) , EQ-5D (62), Quality of Well-being Scale (QWB) (63) and the Health and Activities Limitations Index (HALex) (51, 64). Additionally, HRQoL questionnaires exist that are tailored for specific diseases, such as the kidney disease quality of life instrument (KDQoL)(65). Due to the large range of HRQoL measures, this rapid review will focus only on the main measures used. Currently, the EQ-5D and the SF-36 have been the most widely used measures of HRQoL (66).

The EQ-5D was developed by the EuroQoL group as a short and user-friendly measure of HRQoL that can be self-reported by participants (20). The non-disease specific (i.e. 'generic') nature of this measure allows it to be used alongside disease-specific measures, in healthy and unwell populations alike (20). The EQ-5D has five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression (20). The main strengths of the EQ-5D are that it is quick to administer and complete, as well as easy to measure.

There are two main versions of the EQ-5D available. The EQ-5D-3L has three response levels per dimension indicating whether the respondent has ‘no problems, moderate problems or extreme problems’, whereas the EQ-5D-5L has five response options – ‘no problems, slight problems, moderate problems, severe problems or extreme problems'(62). The EQ-5D can be completed by the individual verbally by pen and paper or through online modes. Additionally, it can also be completed as proxy by others such as clinicians or loved ones. This measure also allows for an understanding of an individual's overall rating of health according to social value sets ascribed to each of the possible health states; there are 243 possible health states with the EQ-5D-3L and 3125 states with the EQ-5D-5L. In the EQ-5D-3L, a health state of 'no problems' with any of the five dimensions is equivalent to perfect health and is allocated to a preference (utility) weight index score of 1.0; a value of 0 is equivalent to dead, and individuals with 'extreme' problems across the five dimensions can have index scores of less than 0 (67). Index scores from groups of people can be used in economic analyses such as cost utility analysis and allows for focusing priorities for health care (67).

Within NZ, index weights for different health states (68) of the EQ-5D-3L have been derived (56). Additionally, due to the EQ-5D being a non-disease specific measure this allows for comparisons of HRQoL in different disease groups and across different countries. There are over 170 countries that have used the EQ-5D (69). A limitation of the EQ-5D measure is that it was not originally developed to be a measure of HRQoL, but simply as a measure of health status (20) so it may not include all areas of health that impact HRQoL.

The SF-36 is another common measure of HRQoL. This survey takes approximately 3-5 minutes to complete and consists of 8 dimensions comprising physical functioning, role limitations-physical, bodily pain, general health, vitality, social functioning, role limitations-emotional and mental health. (57). The strengths of this measure are that it is quick and easy to complete and allows for comparisons between groups due to its standard questions. Additionally, it is multidimensional (57). The limitations of the SF-36 measure include that it may not allow for the detection of small changes in specific disease states, (57) and like the EQ-5D it was not originally intended for a measure of HRQoL but to be used as a health status survey (46). Other limitations include the fact that there is no overall social preference weight. Correlated physical health (PCS) and correlated mental health (MCS) scores have been developed to summarise the information across the eight dimensions (70), however they can behave in a contradictory manner making interpretation of the results difficult. A shorter version of the SF-36 is available, this is known as theSF-12. From the SF-36 and the SF-12 the SF-6D can be generated which allows for preference based scoring, however (71) it is important to note that these measures were not developed with the idea of developing preference based scoring, unlike the EQ-5D (71).

2.3.4 Māori Perspectives of HRQoL

Despite there being a large amount of published literature on HRQoL, very little of this literature discusses Māori perspectives of HRQoL, or Māori HRQoL specifically. Māori views of the EQ-5D as a measure of HRQoL have begun to be investigated (72). Harwood has suggested that there is little evidence that commonly used European measures such as the EQ-5D are meaningful for Māori (73). A key issue in using the EQ-5D is that it may not capture health of indigenous populations such as Māori, due to Māori health being holistic and all-encompassing and including the range of characteristics captured in Te Whare Tapa Whā (see section 1.5.1, Chapter 1) (72).

In a survey, 66 Māori were asked to evaluate the EQ-5D. Participants were recruited via snowball sampling in the year 2000 from Dunedin and Wellington. The average age of these participants was 41 years- over half were female and a large proportion of this sample were students. Three quarters of the participants considered the EQ-5D adequate which suggests the content was found to be valid (72). A ‘dead’ variable was added to this survey to determine how Māori would respond to having to rate this and the survey found that many participants did not value ‘dead’. This may have been due to an unwillingness to place a value on being dead, or due to being unaware of the need to do so. This suggests that there is potentially a lack of validity for Māori for placing a value on being ‘dead’. Five participants were interviewed after this survey and at the time did not believe that the way they viewed health was any different to non-Māori (72). Although this study is valuable, it had a small sample size of mostly students, limiting the generalisability of these findings.

Very little research has been conducted about Māori perspectives of HRQoL, which demonstrates that further research is necessary not only to understand Māori HRQoL but to also understand what is important when measuring HRQoL for Māori. It is interesting to note, that as shown by a systematic review which analysed 41 studies that examined HRQoL in indigenous populations, only three studies used indigenous-specific measurements to measure HRQoL (74). Indigenous populations, including Māori, are likely to consider further dimensions of health that lie outside traditional measures (74). This indicates the need for further understanding of HRQoL perceptions, not just for Māori, but for indigenous populations globally.

2.3.5 HRQoL in this Thesis

As described, there are various frameworks, models and theories for HRQoL. This chapter does not aim to develop a new model or definition of HRQoL, but simply aims to determine which model, framework or theory will usefully inform the research questions addressed in this thesis. Firstly, the concept of HRQoL used in this research follows the widely agreed upon (various) frameworks, models and theories that HRQoL is influenced by physical function, ability to perform usual activity, mental health and general health perceptions (see Table 2.3). As concepts of pain/discomfort and cognitive function have also been identified as contributing to overall HRQoL, these have also been included in conceptualising HRQoL in this H&D Study (22). It is also important that an individual’s subjective view on their own HRQoL is considered when determining HRQoL, as it can be collected from clinicians or whanau’s assessment. Figure 2.2 shows a summary of how HRQoL will be viewed in this thesis.

Figure 2.2 HRQoL depicted for this thesis

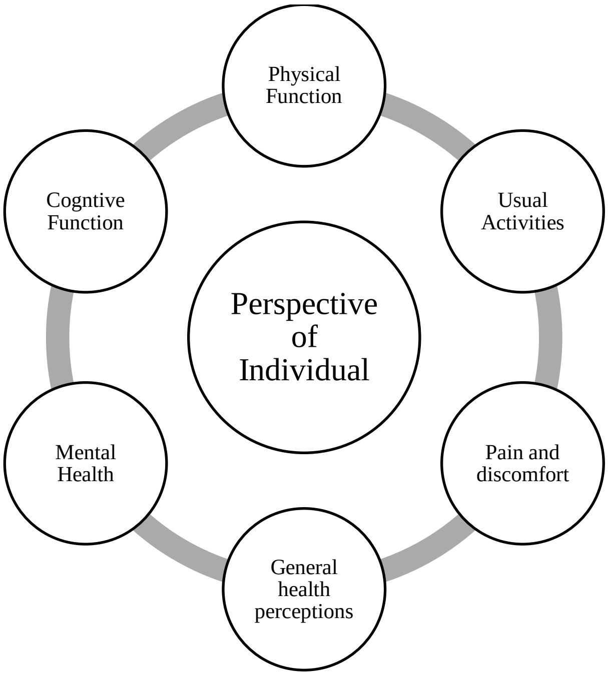


*Figure 2.2 displays how HRQoL will be viewed in this thesis. The individual’s perception is important in influencing how each element on the outside of the circle is represented.

2.4 Disability

Worldwide, over 1 billion people experience disability, with between 110-190 million experiencing extreme disability (defined by an individual’s level of difficulty in mobility, self-care, pain, cognition, interpersonal activities, vision, sleep and energy) (75). In NZ, 24% of adults report some form of disability and 59% of adult’s ≥ 65 years’ experience disability (76). Despite significant levels of disability, how to best define disability continues to be contested (23). It is important that disability is clearly defined in this thesis as it is the key outcome variable in the analyses.

2.4.1 Key Frameworks, Models and Theories of Disability

There are a number of different frameworks, models and theories of disability. For example, models include the moral/religious, medical/individual, social/political, rehabilitation (77), experts, rights-based, economic and consumer models (78). This review will focus on three widely used models of disability, specifically, the medical model (77), social model (77) and the World Health Organization’s (WHO’s) model (21, 79).

One prominent model of disability is the ‘medical model’, sometimes also referred to as the ‘individual’ model (77). This model views disability as impairments resulting from a ‘problem’ with a part of the body (80), meaning that disability results from the departure from normal anatomy or physiology (81). Nagi proposed an early draft of the medical model of disability (82). Disability was seen to result from disease, and this disease and its resulting pathology was what needed to be treated in order to reduce the disability and aid in ‘returning the patient to normal functioning” (82, 83). The medical model explains disability as something that is the result from functional deviations that are not considered ‘normal’ medically (84). One major criticism of the medical model, with its curative orientation, is that it necessarily positions disability as being viewed as a weakness and always as a negative health state (85). Disability is positioned as an issue solely to do with the individual with the ‘disability’, and there is no role of society in influencing this ‘disability’. The medical model of disability often results in the individual and their family bearing all responsibility for this disability and being expected to adapt to meet the needs or expectations of society.

Alternatively, the social model of disability positions disability as a social construct (86); this model is often understood to have developed as a reaction against the medical model (85). This model became particularly prominent in the 1970s and 1980s (80). In this model physical, mental, or learning impairments are viewed as the inability to function at what is considered ‘normal,’ and disability is the disadvantage or restrictions society then places on those who are ‘impaired’ resulting in their exclusion (80). In 1976, the British Union of Physically Impaired against Segregation declared disability as a phenomenon imposed on top of people’s impairments. They suggest that disability is a form of social oppression whereby those with impairments are excluded and isolated from participating in society (77). This has resulted in society devaluing and fearing disability (87). One way in which the social model can be understood is that no matter an individual’s level of physical, mental, or emotional functioning, disablement is the result of the societal environment failing to interact with individuals (88). One criticism of the model raised by both Palmer (2011) and Shakespeare (2006) is that it may not adequately address the medical needs related to the underlying impairments. This has the potential to lead to a lack of understanding of the proportion of disabled people who need access to health and social services (84, 89). The social model requires a socio-political approach in order to change environments, therefore implying there needs to be a change in the way society views disability (77). A strength of the social model is that it challenges the discriminatory, and individually located, way in which disability can be portrayed under the medical model (90).

The World Health Organization (WHO) has developed various models of disability. In the 1980s, WHO first published the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which aimed to distinguish between impairments, disability and handicaps (91, 92). In this model impairment was defined as “any loss or abnormality of psychological, physiological or anatomical structure or function” (91). Disability was defined as “any restriction or lack (resulting from impairments) of ability to perform an activity in the manner or within the range considered normal for a human being” (91). Lastly, the ICIDH model defines handicap as “a disadvantage for a given individual, resulting from an impairment or a disability that prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual” (91). The ICIDH became popular in research and public health and was frequently used to conceptualise the health status of people in a wide variety of settings, such as in rehabilitation research, in the clinical setting and in the non-medical setting (93). However, the ICIDH model also has its challenges. One of these challenges is that the definitions of disability, impairment and handicapped are supposedly linked in a linear fashion, wherein the definitions were criticised due to their overlapping with each other (91). The idea of being ‘handicapped’ from this definition was also regarded as pejorative. In this definition, the cause of disability and handicap was an individual’s impairment, therefore problems encountered in daily living were attributed to personal flaws (77). The ICIDH model was regarded by some as overlooking the social aspects of disability, and it was not viewed as flexible or inclusive by disability scholars (92).

As a result of criticism of the ICIDH, the model went through a series of redevelopments. In the early 2000s, the ICIDH was re-developed into the WHO International Classification of Functioning, Disability and Health (ICF) (91). This was a more inclusive approach, involving a number of disabled people in developing this new model (91). According to the ICF model, disability is related to impairments in functioning, activity limitations, and participation restrictions. It is also noted that environmental and personal factors influence all of these components (79). The ICF also describes participation restrictions in nine dimensions of: 1) learning and applying knowledge, 2) general tasks and demands, 3) communication, 4) mobility, 5) self-care, 6) domestic life, 7) interpersonal interactions and relationships, 8) major life areas, and, 9) community, social and civic life (94). This ICF model of disability addresses both functions, and the social model of disability. This model has become popular and has been recognised in 191 countries, including NZ, and translated into many languages (91). The ICF model allows for a common language when describing disabilities across different countries (79), and across different time periods (95). However, despite the ICF being updated there are still criticisms of this model which include the fact that the model is still quite individually located, and there is little room within this model for developing an understanding as to how environments may in fact be the cause of disability (77). The ICF acts as a tool only to explore how the environment interacts with individual lives rather than allowing for investigating the direct impact of the environment (77).

2.4.2 Disability is Important

It is important to come to an understanding of the various frameworks, models and theories of disability, because disability is a major issue in society. In NZ, approximately 1.1 million people experience disability (76). People usually seek help not because of the health condition, but because of the impairments, limitations or restrictions (i.e. the disability) resulting from the health condition (96). Additionally, disability is costly at both personal and societal levels (23). Those with disabilities are often disadvantaged and experience large inequities (97). For example, in New Zealand, those who are considered ‘disabled’ are more likely to have lower incomes than those who are not disabled. Approximately 45% of adults considered disabled were employed in 2013, compared to 72% of non-disabled adults (76). At a societal level, $300 billion annually is spent on disabled individuals in the United States of America (98). In NZ, 24% of adults experience disability (76). As a result of the costs of disability, and more importantly the associated burden for the individuals and their families, it is vital that disability can be detected and measured. Through focusing on disability as an outcome it is then possible to identify opportunities to intervene to reduce disability wherever possible.

2.4.3 Disability Measures

As with HRQoL, it is useful to consider approaches to measuring disability. The physical limitations can be assessed clinically, however this does not enable the individual to express how disability impacts them. Therefore, it is important to be able to measure disability from the perspective of the individual and how they perceive it to impact their lives. In response to the different models of disability, there are different ways to measure disability (86).

For example, from the medical model perspective there has been measures such as the Karnofsky Performance Scale wherein an individual's disability is assessed by a clinician. Through clinicians' use of this scale, it allows them to have an improved understanding of a patient's needs, abilities and ways of progression (99). However, in this measure the patient is not asked what their perspective of their functioning and ability is. Following this, in the social model of disability, Gale Whiteneck's CHIEF (Craig Hospital Inventory of Environmental Factors) measure has been used. This measure looks at the ability of an individual to participate in society (100), and is done from the perspective of an individual rather than the clinician.

One of the main measures of disability is the WHODAS, which has been further developed into WHODAS 2.0. This measure was developed in response to the ICF model of disability. It is a generic assessment useful for measuring health and disability across cultures in a standardised way (96, 101). WHODAS 2.0 measures six different dimensions which include cognition, mobility, self-care, getting along, life activities and participation (102). It is a useful measure as it provides an individual's perspective on how their disability affects them and can be used with both disabled and non-disabled people (103).

2.4.4 Disability for Māori

In this rapid review, I endeavoured to identify sources that focused on disability and models of disability specifically for Māori. As with HRQoL, few sources were identified. As per the Treaty of Waitangi, Māori have the same right to equal health outcomes as non-Māori do (73, 104). One third of Māori experience disability (76, 105) and as a result of the large proportion of Māori experiencing disability, there is a need for services to provide Māori focused and appropriate care. Currently, there are few models of disability specifically for Māori (105) or literature that explores what may be acceptable models of disability for Māori.

2.4.5 Māori Models of Disability

In NZ and internationally, the dominant models of disability include the medical/individual, social and ICF models. However, these models often do not consider the health needs of disabled Māori, or other indigenous populations. This is despite the fact that there is a larger proportion of disabled Māori and that disabled Māori have a higher proportion of unmet needs (105). When disability is viewed under the medical model, this leads to a focus on the medical needs of individuals and this is often from the perspective of the numerically dominant (non-Māori) culture of society. Despite Māori comprising 15% of the NZ population, often the medical model is used in care leading to the needs of the tangata whenua (people of the land, indigenous populations) not being met (106, 107). In contradiction to partnership and rangatiratanga (right to exercise authority) promised in the Treaty of Waitangi (104), NZ currently follows a strongly Anglo-European structure and therefore this often leads to the exclusion of Māori values (108).

When developing a model of disability for Māori, it is crucial to understand that Māori have unique cultural needs and ways of viewing health. For example, Te Whare Tapa Whā (see section 1.5.1, Chapter one) is a Māori model of health developed from a Māori traditional world view (30, 37). As a result of the medical model of disability, dominating health care in NZ, and Māori viewing health through a traditional lens, barriers do exist when considering potential models of Māori disability. These barriers include poverty, access, environmental, legal, institutional and attitudinal barriers (109).

A community based model has been proposed wherein the concepts of wairua, hinengaro, taha tinana and whānau of Te Whare Tapa Whā could underpin the development of a community based disability model (108). In this model, taha wairua links health to unseen and unspoken energies. Without this spiritual awareness, the mind and body can be open to illness. It aids in providing a link between whānau, the environment and a person's health and wellbeing. Taha hinengaro reflects that thoughts, feelings and emotions are essential in determining health. Thought and expression are seen to arise not only from experience but are produced in response to an experience. The third dimension of Te Whare Tapa Whā is taha tinana which acknowledges physical health. Physical health is also often considered central to non-Māori models of health, however there is an important difference. Body parts such as the head are considered tapu (sacred or protected) and others are considered noa (non-sacred, unprotected). Therefore, this can be important to consider when providing care to Māori to ensure tapu are respected. The final dimension is taha whānau and directly contributes to illness and wellness. Māori gain identity and a sense of purpose through their families. Often when an individual is severely disabled in NZ this leads to dependence on the health system for care, however this threatens whānau connection and can lead to the individual losing or diminishing their sense of identity and purpose that is key for well-being (108).

A community-based model encompassing taha wairua, taha hinengaro, taha tinana and taha whānau would allow for further development of the idea that the person comes first, rather than impairment. This model would involve treating people as part of a community. Through developing a community-based model based on the concepts of Te Whare Tapa Whā this would allow for a holistic approach to be taken to ensure culturally appropriate services for all New Zealanders. It would be able to be adopted for all cultures and needs and would allow for equitable access for people with differing abilities and ethnicities (108), allowing for disability to be viewed more positively (110).

More recently, Hickey and Wilson (2017) have developed Whānau Hauā as an alternative approach to conceptualising indigenous disability (105). This approach is informed by te ao Māori and provides a Māori view of disability. Whānau Hauā can be seen as an umbrella term that is suitable for disabled Māori. The term whānau includes those genealogically connected by common ancestors, those with a common or similar experience, and those who provide care and support that traditional whānau provides (105). The term ‘hau’ means mind or gale and the ‘ā’ refers to the motivation that drives the wind. The changing winds leads to a changing environment (105). Balance or peace is found in the whānau despite hauā consistently changing (105). This model is similar to the social model of disability wherein the barriers of daily life are not due to the disabled person but due to society. Whānau Hauā however involves a cultural dimension wherein whānau are needed to restore balance (105). It is positive to see the development of a Māori model of disability.

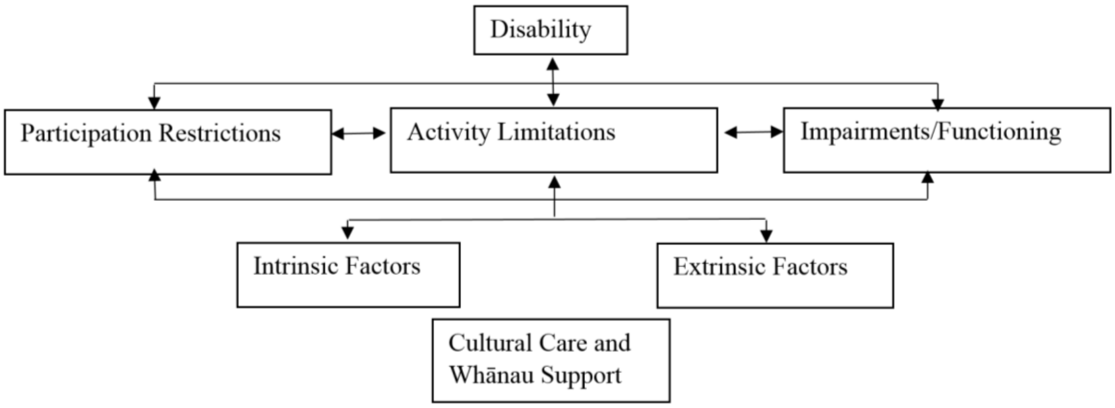
Currently in NZ, the He Korowai Oranga Māori Health Strategy is in place, which aims for Māori families to be able to achieve maximum health and well-being, and be provided with a supportive environment to allow for full participation and to gain maximum rehabilitation (111). The NZ Disability strategy is based on the social model of disability and in Objective 11, it aims to promote the participation of Māori (109). Additionally, Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan is in place. This aims to reduce the barriers Māori face and is partnered with key Māori disability stakeholders (111). Despite progress towards developing disability care appropriate for Māori, there is still a lack of collaboration between ministries regarding Māori disability policy. Disabled Māori have found that often they have to be extremely proactive to access appropriate care due to the many barriers (109). Therein Māori models of disability require the need for incorporation of cultural care to be considered and have an emphasis placed on whānau support.

In summary, although Māori models of disability have been developed, more work needs to be done to ensure Māori models of disability are developed and applied in practise and to ensure disabled Māori receive appropriate care. Māori are tangata whenua and were promised equal rights, and therefore equal health outcomes as non-Māori (104). Yet one third of Māori are disabled and Māori frequently experience unequal access to services and there is a lack of culturally appropriate services (105). Therefore, further work needs to be done to acknowledge and use Māori models of disability.

2.4.6 Disability in this Thesis

The different models of disability are often accompanied by strong histories and perspectives (89, 112, 113). The medical model of disability tends to place all responsibility for the disability on the individual and their family. It is still important to address the medical needs often associated with disability (89). The social model of disability also provides an important perspective. The social model of disability views disability as the restrictions placed on individuals and their families due to the structure of societies (77). Lastly the ICF model considers disability according to impairments in functioning, activity limitations and participation restrictions but fails to address how to act to change the environment which would improve access for those with disability (77). Additionally, Māori models of disability discuss the need for the incorporation of cultural care, as well as placing a large emphasis on whānau support (105, 108). Therefore, for the purposes of this thesis, disability will be conceptualised with both extrinsic and intrinsic factors (recognising the importance of the social model of disability, but also recognising the health condition that has led to the individual experiencing ‘disability’) and will follow the model depicted in the ICF with a focus on impairments, activity limitations and participation restrictions (79). As discussed, the Māori model of disability points to cultural care and whanau support and has therefore this has been included as a part of our model as these have the potential to influence an individual’s perception of disability within this cohort. Figure 2.3 below shows a summary of the way disability will be viewed in this thesis.

Figure 2.3 Disability depicted for this thesis (building on the WHO ICF model (114)



2.5 HRQoL and Disability

Although the aim of the rapid review was to identify articles that discussed models or theories of HRQoL and disability separately, opportunistically three sources were found that discussed both HRQoL and disability. These sources discussed whether HRQoL and disability are seen as linked or as separate concepts. In some models, HRQoL has been viewed as an umbrella concept that encompasses impairments, disabilities and handicaps (115). Additionally, impairments have been seen to give rise to “handicaps”, which in turn results in disability which determines HRQoL (116). Others have argued, that HRQoL and disability should be viewed as separate concepts due to being developed separately for a different purpose (23).

In the H&D Study, HRQoL will be considered as a possible predictor of disability. This is because health conditions such as CKD5 often result in functional limitations (which are included in most HRQoL measures, such as the EQ-5D) and these are explicitly considered aspects that make up the ICF model of disability (section 2.4.1).

Disability, according to the social model of disability arises from society's responses to health conditions/functional limitations. Therefore, it is important to understand that there are indeed relationships between HRQoL and subsequent disability at the individual level. The ICF model of disability, which we are predominantly focusing on in this thesis suggests there ought to be such relationships. If these relationships do exist, then being able to consider HRQoL (i.e. through the EQ-5D measure in this study) means that this will help provide an early opportunity in identifying groups of CKD5 patients who may be at risk of developing subsequent disability. From this it may mean that early initiatives can be taken to reduce the subsequent disability. This thesis will enable an understanding of whether HRQoL can act as a predictor of disability and if so, subsequent research could investigate initiatives to improve HRQoL and potentially prevent or reduce further disability.

2.6 Conclusion

As established in section 2.3.5 and displayed in Figure 2.2, an individual's HRQoL is subjective and is formed by elements such as physical function, ability to perform usual activities, mental health, general health perceptions, pain/discomfort and cognitive function. It is plausible that if an individual's perception of their HRQoL is negative this will likely impact the ICF. Therein it is feasible that HRQoL is examined as a possible predictor of disability.

This chapter has summarised some of the key frameworks, models and theories underpinning both HRQoL and disability. This chapter has detailed the methods of the rapid review and provided a discussion on the importance of analysing HRQoL and disability. Information was provided which discussed various models, theories and definitions, as well as discussing how HRQoL and disability are measured. The available evidence surrounding Māori perspectives was analysed. This allowed depictions of how HRQoL and disability will be considered in the H&D Study.

3 Chapter Three: Scoping Review

The H&D Study aims to describe associations between HRQoL and disability among a cohort of older New Zealanders with CKD5, and to determine which (if any) factors, including HRQoL, predict disability outcomes 12 months later. Additionally, the study aims to investigate disability outcomes specifically for older Māori with CKD5. This chapter presents findings from a scoping review of the literature that was undertaken to aid in informing the planning of statistical analyses for the H&D Study. Specifically, this chapter presents the methods and results of the scoping review focused on HRQoL and disability among people aged ≥65 years old diagnosed with CKD5.

3.1 Methods

Scoping reviews enable for the assessment of the breadth and quality of published research available on a topic, (41), as well as facilitating clarification of the key concepts (117). They are also useful for identifying knowledge gaps (117, 118). Scoping reviews also allow for clarifying of the quality and quantity of literature and often sorts sources by study design (41), which is how this scoping review is presented. In contrast rapid reviews do not allow for identification of knowledge gaps (118). This thesis aims to address some of those knowledge gaps.

This scoping review has been conducted as suggested by Arkey et al (2005) and Levac et al (2010). Therein five steps of implementing a scoping review have been implemented. The five steps are as follows:

Step 1: Identify the research question

Step 2: Identify the relevant studies

Step 3: Study selection

Step 4: Charting data

Step 5: Collating, summarising and reporting the results (118).

This scoping review aimed to identify papers about ‘HRQoL and CKD’ and ‘disability and CKD’ in those aged ≥65 years.

To identify the relevant literature (step 2), database searching was conducted between February 2018 and May 2018. To ensure the scoping review was feasible within the timeframe for a Masters project, it was necessary to limit the literature search to four databases; (Ovid, PubMed, Google Scholar and CINHAL); to the time period of January 2000-May 2018, and to literature published in English. Additionally, the search was restricted to publications focused on human participants. Reference and bibliographic lists of the eligible papers were searched to determine if any further papers should be included; this helped to ensure relevant papers were not missed. The search terms are presented in Tables 3.1, 3.2 and 3.3. The HRQoL terms and disability terms were independently searched for alongside the CKD terms as shown in Figure 3.1. Identification of papers discussing HRQoL or disability for Māori CKD patients was also completed when the search terms in Tables 3.1, 3.2 and 3.3 were combined with the Boolean "AND" Māori (this term includes terms such as Maaori, Maori and Māori).

Figure 3.1 Diagram demonstrating the search strategy

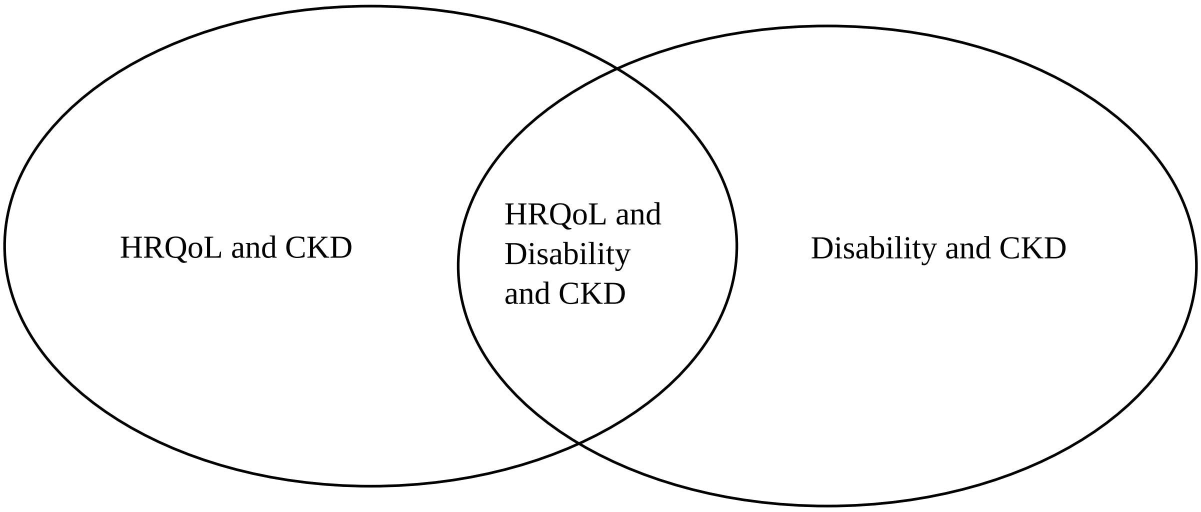


Table 3.1 Search terms used to identify HRQoL in literature

Health Related Quality of Life	Quality of Life	Health status
Health-Related Quality of Life	QOL	Generic health
HRQOL	Health	EQ-5D
HRQoL	Perceived health	General health

Table 3.2 Search terms used to identify disability in literature

Disability	Disabilities	Disability evaluation
Disabled	Handicapped	Physically challenged
Disab*	Disabled persons	Physically disabled
Physically handicapped	WHODAS 2.0 or WHODAS II or just WHODAS	Impairment

Table 3.3 Search terms used to identify CKD in literature

Chronic kidney disease	ESRD	Chronic renal failure
CKD	End stage kidney disease	Chronic renal dysfunction
End stage renal disease	ESKD	Chronic renal insufficiency
End stage renal failure	Renal insufficiency	Kidney failure chronic
Dialysis	Renal conservative care	Peritoneal dialysis
Haemodialysis		

3.1.1 Results and Source Selection

As shown in Figure 3.1 ‘HRQoL and CKD’ and ‘disability and CKD’ searches were completed separately. Through this search strategy, papers that discussed both HRQoL and disability in CKD patients were also sourced opportunistically. These sources were analysed separately. For step three of the scoping review (study selection) sources were screened based on their titles and then abstracts. The full texts of the remaining sources were then reviewed.

Below are the inclusion and exclusion criteria for eligible sources. It is important to note that initially, the search was not limited to those ≥65 years of age in order to ensure minimal sources were missed. During screening of the abstracts, the following criteria were applied.

Inclusion Criteria:

- Discussed CKD with either a focus on HRQoL or disability (the source needed to include measures and/or theories; and not just discuss these in passing).
- The participants in the study had to have CKD5. However, in cases where there was a clear sub-category reporting CKD5 patients, that source could be

included. Occasionally sources were included, such as reviews when the CKD status was unknown.

- Additionally, the participants had to be ≥65 years of age. In cases where there was a clear category separating the results into different age groups, including the ≥65 years age group, the article could be included.

Exclusion Criteria: Literature focused on the following topics was excluded:

- Different drug therapies, for example literature that specifically focused on treatments aside from dialysis and non-dialysis.
- Transplant patients, since there were no transplant patients in the H&D Study.
- Surveillance, prevention or incidence of CKD. This scoping review focused on those with CKD.
- Primarily on other diseases or health issues, like cardiovascular disease or falls prevention, since CKD was the population of interest.
- Economic costs of dialysis therapy and disparities in access to care rather than the care itself.

Figure 3.2 and 3.3 are flow diagrams that demonstrate the search results for ‘HRQoL and CKD’ and ‘disability and CKD’ respectively.

Figure 3.2 Flow diagram of scoping review for HRQoL and CKD in those aged ≥65 years.

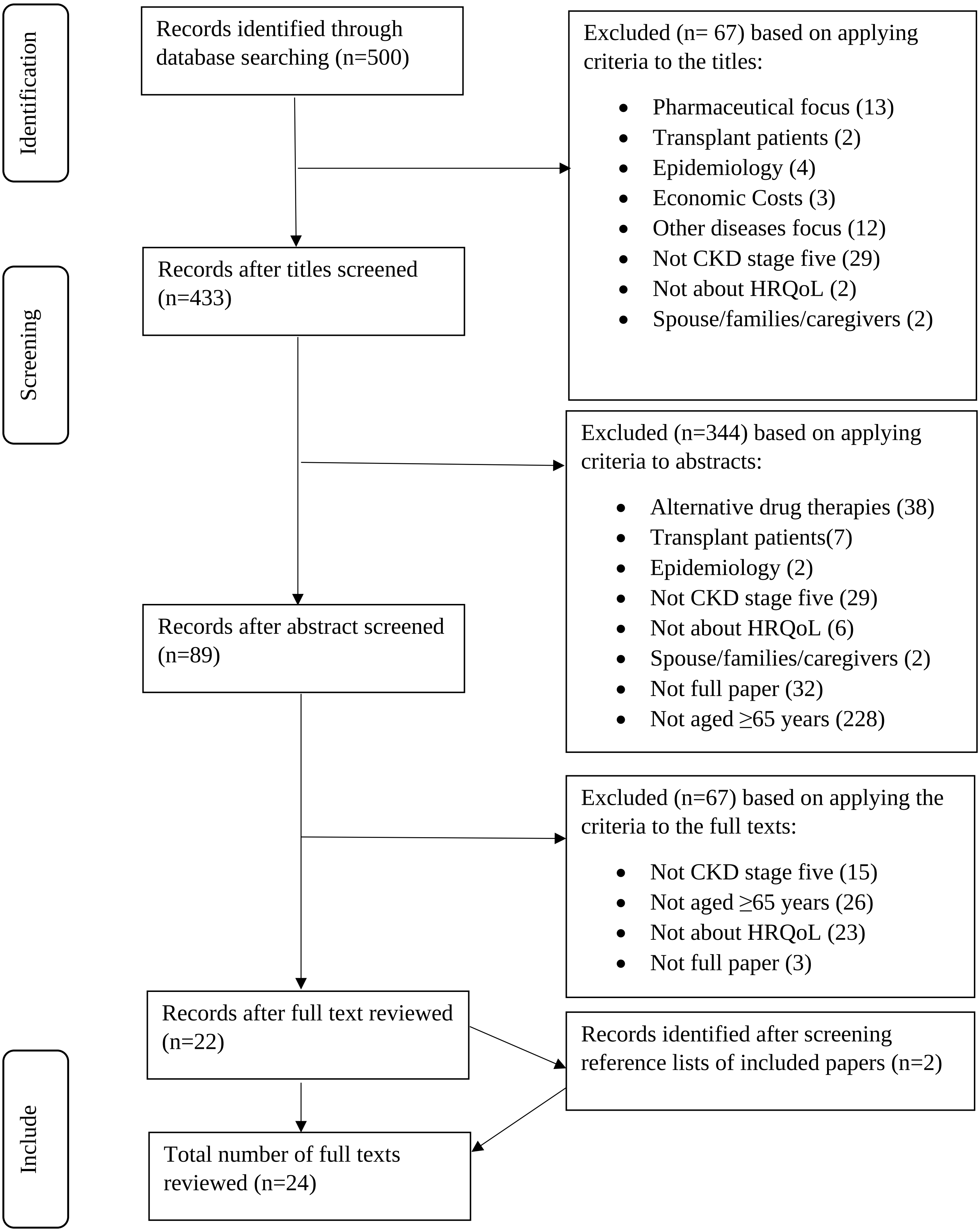
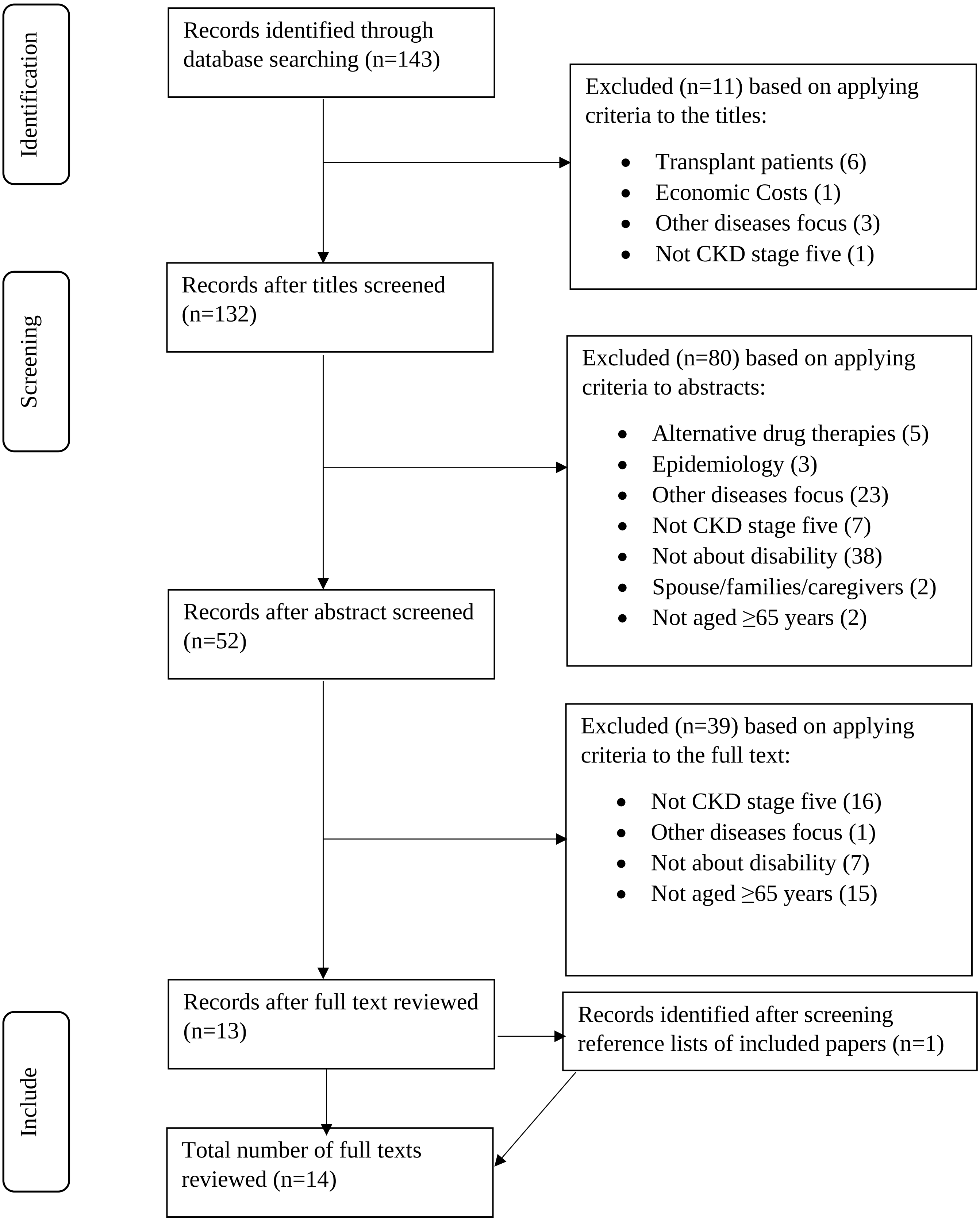


Figure 3.3 Flow diagram of scoping review for disability and CKD in those aged ≥65 years



After applying the inclusion and exclusion criteria, 24 sources were identified which focused on HRQoL and CKD, and 14 articles on disability and CKD. Two articles discussing both HRQoL and disability were found; no additional papers were found after screening the reference lists of these two papers about HRQoL and disability.

When the search was repeated for Māori, a total of 130 sources were found. After screening the titles, 50 remained. Abstract screening resulted in three papers remaining for full text assessment, which discussed either HRQoL or disability and CKD for Māori. No additional papers were found after screening the reference lists of the three included Māori papers.

Following the identification of papers, as per steps 1-3 of completing a scoping review, charting the data (step 4) has been completed. In Appendix II the aim, study design, number of participants/number of papers reviewed, methods, inclusion/exclusion criteria, key findings and strengths and limitations of each paper is identified. This appendix shows the results of the 24 papers about 'HRQoL and CKD', the 14 papers about 'disability and CKD', the 2 papers about 'HRQoL and disability in CKD' and the 3 papers about 'HRQoL and disability in Māori with CKD' presented in Tables II (1-4). Following this the papers were summarised, and the results are reported upon as follows in step 5. The papers were grouped by study design and the results that were focused upon, concentrated on how HRQoL and disability were defined and then analysed in the CKD population.

Of note not all papers included in this scoping review focused on CKD5. Studies included in this scoping review, that did not focus on CKD5 specifically were still important in developing an understanding of 'HRQoL and CKD' and 'disability and CKD' and therefore were included. Tables 3.4 and 3.5 enable the reader to easily identify the CKD status included in each paper. It is important to distinguish between papers that focused on CKD5 and general CKD papers, as the H&D Study focused on CKD5. When comparing the results of the H&D Studies to the results of studies included in the scoping review (Chapter 6), the papers that focused on CKD5 will be more relevant.

Table 3.4 CKD status of the 24 papers regarding ‘HRQoL and CKD’

Bibliography Details	**CKD Stage five***	**CKD status known ****	**CKD status unknown *****
Apostolou, T. (2007)	✓		
Balogun, S. A., et al. (2017)	✓		
Boateng, E. A. and L. East (2011)	✓		
Brown, E. A., et al. (2010)	✓		
de Jonge, P., et al. (2003)	✓		
Elliott, B. A., et al. (2014)	✓		
Finkelstein, F. O., et al. (2012)	✓		
Glover, C., et al. (2011)	✓		
Griva, K., et al. (2014)	✓		
Harris, S. A., et al. (2002)	✓		
Iyasere, O. U., et al. (2016)	✓		
Kanamori, H., et al. (2012)	✓		
Kutner, N. G. and S. V. Jassal (2002)	✓		
Lamping, D. L., et al. (2000)	✓		
Loos, C., et al. (2003)	✓		
Naik, N., et al. (2012)	✓		
Phillips, L., et al. (2001)	✓		
Ronsberg, F., et al. (2005)	✓		
Tyrrell, J., et al. (2005)	✓		
Unruh, M. L., et al. (2008)	✓		
Finkelstein, F. O., et al. (2009).		✓	
Ghiasi, B., et al. (2018)			✓
Unruh, M. L. and R. Hess (2007)			✓
Unruh, M. L., et al. (2005)			✓

*CKD stage five; represents sources that describe those with CKD5

**CKD status known; represents sources wherein CKD is known and discussed, however CKD is not solely CKD5. Often various stages of CKD are compared and contrasted, however in doing so CKD status is always clearly identified.

***CKD status unknown; represents sources that have not clearly identified the CKD status discussed.

Table 3.5 CKD status of the 14 papers about ‘disability and CKD’

Bibliography Details	**CKD Stage five***	**CKD status known****	**CKD status unknown*****
Bossola, M., et al. (2018)	✓		
Cook, W. L. and S. V. Jassal (2008)	✓		
Farragher, J. and S. V. Jassal (2012)	✓		
Farrokhi, F. and S. V. Jassal (2013)	✓		
Jassal, S. V., et al. (2008)	✓		
Kutner, N. G., et al. (2000)	✓		
Tappe, K., et al. (2001)	✓		
Tawney, K. W., et al. (2003)	✓		
Fried, L. F., et al. (2006)		✓	
Cook, W. L. (2009)			✓
Greco, A., et al. (2014)			✓
Intiso, D. (2014)			✓
Lam, M. and S. V. Jassal (2015)			✓
Shlipak, M. G., et al. (2004)			✓

*CKD stage five; represents sources that describe those with CKD5

**CKD status known; represents sources wherein CKD is known and discussed, however CKD is not solely CKD5. Often various stages of CKD are compared and contrasted, however in doing so CKD status is always clearly identified.

***CKD status unknown; represents sources that have not clearly identified the CKD status discussed.

3.2 HRQoL and CKD Scoping Review

A total of 24 sources focused on HRQoL and CKD. Of these sources, 12 were reviews. The following paragraphs describe the way these papers defined HRQoL, and how HRQoL was related to CKD. Due to several papers focusing on the differences between HD and PD patients this will be also discussed, as well as considering findings specific for those ≥65 years or over. Finally, the strengths and limitations of the papers will be discussed, before identifying possible knowledge gaps that this thesis can help address.

3.3 HRQoL Defined

In Chapter 2, the rapid review resulted in HRQoL being defined as comprising of physical function, ability to perform usual activities, mental health and general health perceptions. It is important that HRQoL is measured from the individual's perspective and that it is based on an individual's experience of HRQoL (see Figure 2.2). Of the 24 papers identified in the scoping review, 13 provided an in-depth description of the definition they used for HRQoL.

Papers included in the HRQoL scoping review identified physical health, symptoms, functional status, activities of daily life, mental well-being and social health (119, 120), as important elements of HRQoL. Some sources specified that HRQoL was related specifically to a medical condition and/or its treatment (121-125), supporting the idea that HRQoL is specifically about health, as identified in the rapid review (48). Additionally, as described in the rapid review, a large majority of the sources included in this scoping review, identified the need for HRQoL to be reported from the view of the individual, whose health was being affected (126-128).

Eleven papers did not explicitly define HRQoL, although they often discussed the measurements used, or how the measurements used had to act to engage a person's values (129). These papers did note that HRQoL was an important outcome measure, particularly in CKD treatment decisions (130-140).

3.4 HRQoL and CKD

Of the 24 papers about HRQoL and CKD, six were cross-sectional, six were longitudinal cohorts, eight were narrative or rapid reviews, and four were systematic reviews.

3.4.1 HRQoL and CKD in Cross-Sectional Studies

The main limitation of cross-sectional studies is that they do not allow for an understanding of how HRQoL may develop and change as the disease progresses (141). However, they still provide useful insights into how those with CKD perceived their HRQoL, and the factors that may be associated with HRQoL. In a cross-sectional study completed in French Lorraine, 169 participants aged ≥65 years who were just initiating dialysis were investigated to determine the effect of pre-dialysis education on HRQoL outcomes (138). They found that those who were not warned of their need for dialysis and therefore had very little pre-dialysis education, were likely to have poorer HRQoL (138). The SF-36 was used to assess HRQoL and it was found that there was a difference across all dimensions of the SF-36 (138). Patients with planned dialysis had improved scores for all eight dimensions of the SF-36 and this was statistically significant for the components of physical function and vitality. The variables that were adjusted for in their analysis included age, sex, and comorbid conditions. Importantly, the researchers noted that it was possible that these associations were only observed due to those with unplanned dialysis having more clinical complications than those with a planned start to dialysis (138), which may confound the results.

A Singaporean study included 201 patients with 74 being aged ≥65 years and 127 being younger than 65 years. This study compared younger patients to those aged ≥65 and found that those aged ≥65 reported better HRQoL, despite often having worse clinical findings (142). The SF-12 (an abbreviated form of the SF-36) was used in this study. After controlling for education, employment, dependence on a carer, comorbidities and phosphate levels, older patients were found to have improved HRQoL on the two physical and mental (including anxiety and depression) dimensions of HRQoL compared to the younger cohort (142).

In a qualitative study of 31 individuals from Minnesota, it was noted that HRQoL was largely dependent on how individuals viewed their health (129). Qualitative interviews enabled for perspectives from individuals at different stages of dialysis therapy. Those who had just initiated dialysis reported to be thriving. This is because they were still able to maintain positive social connections. One participant stated that "I am enjoying life as I live it, it's still a good life" (129). However, as an individual's disease and dialysis progressed, individuals instead reported to be merely surviving, mostly for the benefit of loved ones. As time spent on dialysis therapy began lengthening, participants began questioning if continuing dialysis therapy was what was best for them. One participant noted that "I'm just tired all the time, I don't ever feel good" (129). It is helpful to gain insight about how individuals' perspectives may change depending on their stage of the disease (129).

Lastly it has been noted that non-dialysis factors such as frailty, morbidity, falls, hospitalisations (135), underlying kidney disease, other pathologies such as cardiovascular diseases and the process of aging may also affect the HRQoL of CKD5 patients (128). Tyrrell et al completed a study of 51 French dialysis patients over the age of 70. They concluded that cognitive impairment and depressive mood are frequent within their cohort of dialysis patients (128). Additionally, the type of dialysis may be important in influencing HRQoL. In a study completed in England and Northern Ireland, 251 dialysis patients (129 PD and 122 HD) were included and the SF-12 was used to measure HRQoL. This study found no difference in HRQoL between HD and PD patients according to the SF-12. The researchers also measured treatment satisfaction and found that PD patients had higher levels of satisfaction than HD patients (135).

3.4.2 HRQoL and CKD in Longitudinal Cohort Studies

There were six papers that reported the HRQoL of CKD patients in longitudinal cohort studies. The main advantage of longitudinal cohort studies is that they allow for an assessment of the development or change of disease or condition, and therefore they allow for understanding of how HRQoL progresses in those with CKD over time (141). These cohort studies, focused mainly on comparing groups. One paper compared those on HD and PD (134), two simply examined older people with CKD5 (120, 137), and three compared older to younger patients (136, 139, 140).

In a study completed in the UK, by Harris, comparisons were made between HRQoL in 96 HD and 78 PD patients (134).The SF-36 was used to assess HRQoL. After adjusting for time on dialysis, age, sex social class, comorbidity and baseline SF-36 scores this study found that PD patients were more likely to meet the criteria for adequate HRQoL within the first three months (134). However, at 6 and 12 months there was no difference between the HRQoL in HD and PD participants. A limitation of this study is that there was potentially selection bias, as there were both medical and social factors and individual preferences which may affect the dialysis chosen and therefore the outcomes. Additionally, there was a 30% non-participation rate, and those who did not participate were more likely to have more comorbidities than those who did participate, resulting in a potential selection bias (134).

Following this, again in the UK, a 12-month prospective cohort study was completed that analysed the outcomes of 221 patients with CKD5 aged over 70 years (137). At 12 months, there were 125 CKD5 patients and their HRQoL was assessed with the SF-36. The study found that the MCS scores of older CKD5 patients were not significantly different to the general UK older population, both at the initial stage of dialysis, and at 3 months of follow-up and after being on dialysis for some years (137). A limitation of this paper is that the focus was on mental HRQoL, and this study did not go into detail about any other elements of HRQoL.

Additionally, in the Netherlands, a study was undertaken with 80 dialysis patients who were followed up to determine what factors predicted their HRQoL. A total of 60 patients were followed to 12 months (120). This study focused on determining if INTERMED predicted HRQoL at 12 months. INTERMED is an observer-rated instrument that classifies information from a structured medical history. This considers biological, psychological, social and health care needs which lead to a score that indicates a patient care needs (120). There are 20 variables with a score of 0-3 each. INTERMED scores of less than 21 were classed as low and a score of 21 or more as a high INTERMED score. A high INTERMED score, age and diabetes were found to predict poorer HRQoL in dialysis patients at 12 months. HRQoL was measured by the SF-36, and patients with high INTERMED scores, were likely to have poorer physical and mental health according to the MCS and PCS scores among surviving patients. However, this paper was somewhat limited due to its small sample size and, there was no assessment of HRQoL using the SF-36 at baseline. Since baseline HRQoL is likely a predictor of HRQoL at 12 months, this is a potential confounder of the relationship seen in this study (120).

Three papers compared the HRQoL over time of older adults with those who were not older. A retrospective cohort was completed in Scotland between 1 January 1994 and 31 December 2003 (139). Within this study, a small sub-analysis was completed for 45 HD patients, where they compared the SF-36 scores of the 6 patients who were over 80 years of age and the SF-36 scores of 39 participants under 80 years of age. They found that the six older patients had a tendency towards similar social functioning and mental health, but poorer physical health than their younger counterparts. However, a limitation of this sub-analysis is the small sample size (139). The small sample size may have contributed to the results not being statistically significant making it impossible to draw reliable conclusions from the findings.

In a study completed in the USA for HD patients, those aged ≥70 years were compared to patients younger than 70 years of age. At baseline, 1813 (98%) completed a KDQoL survey (140). It is one of the few studies that had a comprehensive follow-up and analysis of HRQoL for a longer period of time. This study found that younger patients had a similar decline in KDQoL HRQoL scores compared to those patients aged ≥70 years' (140).

Lastly, a cohort study was undertaken in Japan with 211 HD patients (72 were aged ≥65 years and 139 were under the age of 65) (136). This was also a three-year prospective study where HRQoL was assessed through 10 items, in a measure unique to the study. The participants were asked to assess each item on a VAS scale of 0-100 (136). The 10 items were health conditions, appetite, sleep, mood, memory, family relationships, friendship, economic status, life satisfaction in daily life and happiness (136). Similarly, to Unruh et al (2008), as this study found no difference between HRQoL in those aged ≥65 years and those under 65 years. This was demonstrated by the VAS scores of any of the 10 items not being statistically different in those aged ≥65 years when compared to those under 65 years. This study also found that there was no significant change in the HRQoL score in older patients over the period of three years (136). A limitation of this study was once again a smaller sample size. In addition, despite the measure of HRQoL being comprehensive, due to the score being unique and not standardised, this limits comparability with other HRQoL studies in CKD5 patients.

3.4.3 HRQoL and CKD in Review Studies

Amongst the studies included in this scoping review there were a number of review studies. Of these, eight were of a narrative or rapid nature, where detailed methods and article inclusion criteria were not well described. This is a limitation as it is difficult to replicate the searches. It is also difficult to determine if these reviews meet the inclusion and exclusion criteria for this scoping review. However, despite these possible limitations, these reviews were included in the scoping review to search for relevant information about HRQoL in CKD that is potentially useful to informing the H&D Study.

All reviews concluded that HRQoL is important to routinely measure among CKD patients (119, 122, 124-127, 143, 144). It has been discussed that it is vital for patient reported outcomes such as HRQoL, be incorporated into the care of CKD patients (122) as this may allow for the dialysis team to identify target areas in order to improve HRQoL outcomes (125, 126).

Additionally, the reviews identified important variables that may be crucial in influencing HRQoL in CKD patients. HRQoL has often been found to be dependent upon the severity of comorbid conditions as well as physical decline over time (119). Other factors that may influence CKD patients' HRQoL outcomes include physical symptoms, depression, anxiety, sleep disturbances, energy and vitality, sexual functioning, marital and family discord, social functioning, spirituality, burden of illness and care, satisfaction of care and time of recovery after each dialysis session (122, 143, 144). It is also thought that the types of dialysis may impact HRQoL, with HD patients reporting worse health status compared with other dialysis modalities (127). It may also be that the HRQoL of patients can influence the timing of the initiation of dialysis (125).

It has been found that older adults have similar HRQoL in CKD5 compared to their younger cohort (119), however it is possible that there is a different reference point between older and younger patients in terms of HRQoL (124). This means there is a potential that the reasons for older adults experiencing the same, or improved HRQoL, compared to younger patients, could be due to their different perceptions about HRQoL. Therefore, it is important to note that, when measuring HRQoL in patients, it is important to ensure the measure is valid, reliable and sensitive to change due to change in a patient's outlook (125).

3.4.4 HRQoL and CKD in Systematic Reviews

Four of the reviews were done in a systematic fashion, where the reviews included an in-depth description of how they were completed and their inclusion and exclusion criteria was discussed (123, 131, 132, 145).

One review noted that few studies have focused on HRQoL in older patients (131). This study re-confirmed findings of other studies wherein the mental component of HRQoL in older patients was similar to, or higher than, age-matched controls of younger individuals (131). Additionally, this study concluded that more research is necessary to fully understand older adults HRQoL, and it was noted that there is little understanding of HRQoL in the cognitively impaired or those with a functional impairment, as often these individuals are not included in studies (131).

In one systematic review, a total of 17,200 individuals with CKD participated in 45 studies in which they had their average HRQoL estimated through meta-analysis (145). The researchers concluded that HRQoL in CKD patients was lower than the general population, suggesting that more work is necessary to improve HRQoL in CKD patients (145). Despite the systematic nature of this review, it does have its limitations as it is unclear whether all the patients included in the meta-analysis were CKD5 or were aged ≥65 years. This study did note that HRQoL did not decrease over time (145).

Two of the systematic reviews focused on characteristics of appropriate measures of HRQoL in CKD5 patients. Both papers discuss generic and specific HRQoL measures (123, 132). These studies suggested that there was no simple answer to determine the best way to measure HRQoL in CKD5 patients. However, they did note that measurement needed to address all of the health issues a CKD5 patient had if possible (123). Due to the diverse array of patients' needs this may not be possible which is why standardised measures of HRQoL may be more important.

3.4.5 Summary of HRQoL and CKD

To summarise, of the 24 papers that discussed HRQoL in CKD patients it was positive to see that, of the papers that defined HRQoL, definitions aligned with the conceptual findings of the rapid review. An important finding was that the HRQoL of individuals changes over time depending on how their disease progresses. Comorbidity and physical decline were associated with poorer HRQoL. Those who had less dialysis education were more likely to have a poorer HRQoL. There was no difference in the HRQoL in HD and PD patients.

The scoping review also indicates that no studies published before May 2018 have investigated HRQoL as a predictor of disability outcomes for CKD patients. In one study (120) the researchers focused on determining what factors predicted HRQoL in CKD patients. This thesis will help address this knowledge gap by determining if HRQoL predicts disability in CKD patients at 12 months. HRQoL has the potential to be easily measured at baseline, and if it is found to be associated with disability this would aid in informing patients, and their family’s choices regarding CKD treatment. It was also positive to see that of the 24 papers regarding HRQoL and CKD only four were not strictly focused on CKD5.

3.5 Disability and CKD Scoping Review

As presented in Figure 3.3, there were 14 papers identified that discussed disability and CKD in those aged ≥65 years. The following sections aim to describe how disability was defined and how disability has been related to CKD. The papers will be described and examined according to the study design the paper followed. The strengths and limitations of the studies will be discussed before considering the knowledge gaps which the H&D study may help to address.

3.6 Disability Defined

The rapid review established the position that when defining disability, it is important that disability will be conceptualised with both intrinsic and extrinsic factors (recognising the importance of the social model of disability, but also recognising the health condition that has led to the individual experiencing ‘disability’). Additionally, it will follow the model depicted in the ICF with a focus on impairments, activity limitations and participation restrictions. The rapid review also acknowledged environmental and cultural factors that influence an individual’s disability (see Figure 2.3). It is therefore important to identify how disability is defined in the CKD literature included in this scoping review.

Of the 14 papers identified, six did not clearly define disability. However, they all acknowledged that disability is an important concept, and described various measures that could be used (146-150). Additionally, Farragher (2012) discussed how one of the main aims of measuring disability and taking it into consideration was to allow for the development of rehabilitation methods to prevent further disability (151).

Of the eight papers that did define disability, the majority focused on the individual model of disability, with disability being defined as an individual’s ability or lack of ability to perform necessary tasks without assistance (14, 152, 153). Daily necessary tasks can refer to eating, transferring from a bed to a chair, dressing and undressing and personal hygiene (154). Disability was often viewed as the inability to maintain homeostasis (153) as the result of the cumulative decline in physiological systems during a lifetime (155). Despite it being well-known that disability is caused by numerous events and pathologies at many different stages of life, the articles in this review tended to attribute disability to age-related deterioration and comorbidity (156). This is possibly due to the specific focus on those aged ≥65 years. Additionally, as well as disability resulting in the absence of normal function (15, 157), in some cases, an individual is only thought to be disabled if the impairment results in death, or if the disability lasts more than 12 months (157). As identified in the rapid review, disability can take different forms, in all different phases of an individual’s life. Only one of the 14 papers discussed the social model of disability, saying that disability can lead to the inability to perform social roles (15).

Therefore, it can be concluded that these papers provided a good overview of the medical model of disability but were lacking information regarding the social model of disability. Of the 14 sources, none of the sources explained the ICF model of disability or used WHODAS 2.0 to measure disability.

3.7 Disability and CKD

Of the 14 papers about disability and CKD, two were cross-sectional, four were longitudinal cohort studies, seven were reviews and one was a systematic review.

3.7.1 Disability and CKD in Cross-Sectional Studies

Of the 14 papers, two were cross-sectional studies. As mentioned previously, a limitation of cross-sectional studies is they do not allow for follow-up, so long term outcomes cannot be understood (141), which is a limitation of the following two studies. In the first cross-sectional study (completed in Canada) (146), the mean age of the participants was 75 years and there were 162 participants, most of whom were male. These participants were assessed for disability and difficulty in performing self-care tasks with the Barthel and Lawton scales (146). All of the participants were completing HD and the results showed that; eight had no disability, 69 required help at times but did not consider themselves disabled and 85 had a disability (146). This cross-sectional study therefore demonstrated that disability is prevalent in the older adults on HD and this makes self-care difficult (146). The study advised that strategies needed to be implemented to identify older CKD5 patients that were at risk of disability, to help limit their disability and allow for interventions to be put in place to make daily living easier (146).

The second cross-sectional study was completed in the USA and the participants who had a GFR of above 30ml/min/1.73ms^2, (which indicates that they did not have CKD5) were compared to those with no CKD at all. The study was included despite the participants not having CKD5 due to the large sample size of 5,888 adults aged ≥65 years and it provided valuable insight into disability in the CKD population (154). In the unadjusted analysis both fragility and limitations in daily living activities, which was how disability was measured in this study, were found to be associated with CKD severity. After adjusting for demographic characteristics (age, sex, ethnicity and education) and comorbidity it was found that older adults with CKD were three times more likely to be frail than those with a renal function of above 60 ml/min/1.73ms^2 (154). As a result of the cross-sectional nature of this study and, despite the strong link between fragility and disability in those with CKD, it is difficult to know the causal direction of this relationship and to understand the biological mechanisms contributing to this association (154). However, it can be concluded that preventing fragility which is often associated with disability in those with CKD is likely to lead to improved outcomes. It is important to note that disability was discussed in more of an individual sense than as defined in the ICF paper.

3.7.2 Disability and CKD in Cohort Studies

Prospective cohort studies provide an opportunity to determine how disability develops and changes amongst people with CKD. Of the four cohort studies, one focused on how disability in CKD5 patients impacts on survival (152). The remaining three papers focused more on illustrating how disability developed in CKD patients (147, 150, 158).

In a prospective cohort study by Bossola et al (2018) the researchers aimed to evaluate if functional impairment was a significant risk factor in reducing survival in patients with CKD5, specifically patients on HD (152). All patients in the dialysis and transplant registry from 2008-2013 in Italy were eligible (the population was not strictly aged ≥65 years) provided they had been dialysing for at least 90 days. In five years of follow up, 122 patients died in the cohort of 3356 patients. The strength of this study was the large sample size; however it is important to note that the follow-up period varied between participants. In these patients, functional impairment (which was determined by the physician) was a risk factor for reduced survival (152). Additionally, through measuring with the Karnofsky performance scale index, it found that functional impairment had the potential to be prevented or reversed through rehabilitation (152). Therefore, this study concluded that functional impairment, and therefore disability in CKD5 patients reduced survival; however, rehabilitation has the potential to reduce the functional impairment (152). Therefore, they advised that early identification of patients who could benefit from rehabilitation to reduce their functional impairment is important (152).

Cohort studies have also been conducted to determine if CKD is independently associated with disability. Fried et al (2006) aimed to assess if CKD was associated with disability. A prospective cohort in Pennsylvania and Tennessee recruited 2,135 men and women aged between 70-79 years with CKD. Those with a CKD function of above 60ml/min/1.73ms^2 were compared to those with a function of below 60ml/min/1.73ms^2 (158). In this comparison, more advanced CKD was found to be associated with disability (functional impairment) independently of comorbidity, body composition and tests of strength and physical performance. This may be due to the heightened inflammatory state of CKD patients (158). Fried et al concluded that CKD severity was associated with impaired physical function, which is a risk factor for disability. It was suggested that further work needs to be completed to determine how to reduce the development of disability in those with CKD (158). It is possible that rehabilitation as recommended by Bossola et al could provide a solution. Similarly, in a prospective cohort study completed in urban Georgia, 112 prevalent renal failure patients on HD were compared with 286 age matched controls (150). This study found that CKD5 patients had a higher level of impairment at three years (after adjusting for baseline impairment) than non-CKD5 patients (150). Again, this study advised that care for those with CKD5 needs to focus on preventing functional impairment and therefore disability (150). Once again, disability was seen in a more individual sense than the way it is viewed through the ICF lens.

In the final prospective cohort study of 167 patients from Toronto Canada (57% male, all ≥65 years of age), 83% of the patients depended on others for help (147). This study aimed to determine if a quick four item scale was useful for measuring disability. This four-item scale asked about walking, transferring, bathing and dressing (147). It was found that this measure was useful for predicting severe disability and increased mortality (147). However, the researchers did note that this measure did not take into account, difficulties in stair climbing, which may be an important indicator of physical disability. This paper demonstrates that the four-item scale may be useful for measuring disability in CKD5 patients and that the majority of patients in this study had some form of disability (147). Once again emphasising the need for intervention, to not only reduce disability, but to determine effective ways to measure disability.

3.7.3 Disability and CKD in Review Studies

As explained when HRQoL was discussed above, the limitations of the following review studies are their methods are not clearly described, and therefore their inclusion/exclusion criteria are not clearly outlined. This makes it difficult to determine if the papers included in these reviews and therefore the reviews met the inclusion criteria for this thesis. Since these reviews still provide a useful insight into disability in CKD patients they have been included.

There were seven reviews and the majority of these focused on how older adults with CKD develop and experience disability. Initially the cause and embodiment of disability will be discussed before proceeding to describe the proposed methods to prevent disablement in CKD patients.

It is known that disability is very prevalent in CKD5 patients (14) and that it can lead to accelerated aging, hospitalisations and reduced survival (156). Disability in older CKD5 patients can be thought of as being caused by a combination of factors, including issues directly related to their clinical condition, including weakness, low energy and low activity often associated with CKD5. This combined with common geriatric syndromes like falls, cognitive impairment, incontinence and the use of many medications often leads to poor outcomes, including disability and hospitalisation in older CKD5 patients (153). Therefore, it can be understood that disability and fragility is often associated with poor physical performance in CKD patients (155), independent of age, gender and comorbidities (149). Additionally, CKD5 patients are often on dialysis and this often results in low energy, limited spare time (due to the time spent dialysing), psychological adjustment to their new situation and enforced immobilisation which contributes to disability and functional decline (151). Therefore, from these reviews, disability is very prevalent in CKD patients.

The reviews were valuable as they included many suggestions and methods aimed at reducing disability among CKD patients. A common suggestion was physical activity. It is well-known that physical activity decreases among dialysis patients and decreases with age (155). Greco et al (2014) concluded that physical exercise training programmes have been found to be effective in reducing and preventing disability in CKD patients (155).

Rehabilitation was also suggested as an important method in reducing disability in CKD patients. Rehabilitation often provides a holistic approach to an individual and aims to allow for independent living and autonomy (149). Methods of rehabilitation can include regular exercise, such as walking, and nutritional changes. Other methods include cognitive rehabilitation, education, psychosocial intervention and environmental modifications (151). Additionally, more individual focused rehabilitation strategies can include occupational therapy, gait training and joint mobilisation (149). It has been concluded that rehabilitation is a possibility in older patients and that it has the potential to decrease disability and improve outcomes (14). It can also be noted that dialysis education, oral supplements, antidepressant therapy and pain medication can also aid in improving dialysis outcomes in geriatric patients (14).

Lam et al (2015) takes a different view, proposing that in order to allow for the best outcomes, comprehensive assessments of geriatric CKD patients ought to be taken before initiating dialysis (156). This could allow more individualised, patient centred interventions to prevent disability and improve health in geriatric CKD patients. Additionally, Tawney et al discussed that preventing disability altogether in CKD5 patients would be the best solution (15). It is important to further understand how disability and fragility can occur in CKD5 patients in order to know where it is best to intervene to optimise physical performance and independence in geriatric CKD5 patients (153). In order to prevent disability, it is important to understand what factors may act to cause, or act as predictors of disability in CKD patients. This is an area that this H&D Study aims to address, therefore helping to address an important knowledge gap.

3.7.4 Disability and CKD in Systematic Reviews

One of the 14 papers was a systematic review (157). This review was undertaken because in the USA all individuals with CKD5 are eligible for disability benefits, and there have been questions about whether this alone is enough to diagnose disability. Therefore, this systematic review was completed to determine which factors were valuable predictors of disability and working status in CKD5 patients (157). A total of 27 databases were searched for records up to the year 1998 and only 14 had any indication of predictors of employment for CKD5 patients. After adding the authors' exclusion criteria (including having to be under 65 years, due to employment), 10 studies remained in their review (157). The studies were all cross-sectional and were all very different from each other and therefore it was concluded that finding factors that predicted disability in CKD5 patients was too difficult so no conclusions were made. However, as a part of this study the United States Renal Data Systems (USRDS) were analysed which did note a decrease in those with CKD5 working, suggesting CKD5 does result in disability severe enough for individuals to stop work (157). Despite the systematic nature of this review, the research question of this review sought to determine predictors of working status in CKD5 patients, rather than predictors of disability in CKD5 patients. This suggests that this thesis will be important in developing an understanding of what factors predict disability in CKD5 patients.

3.7.5 Summary of Disability and CKD

It can be concluded that it is well-known that disability is prevalent among CKD patients and that this can contribute to poorer outcomes. Many papers suggest the use of physical activity and other rehabilitative strategies to reduce disability in this population. A limitation of the papers included in this scoping review was they did not have a broad view of what disability is and were largely focused on the individual model of disability, rather than encompassing the ICF model. Of the 14 papers included, 6 did not strictly discuss CKD5, and although they aided in developing our understanding of disability in CKD patients, it is important to note this difference, as the H&D Study focuses on the CKD5 population. No sources included in this scoping review focused on factors that acted to predict disability in CKD patients. This thesis aims to address this knowledge gap by establishing potential predictors of disability in this population. By determining which factors may predict disability, this may aid in developing rehabilitation strategies, which could potentially target predictors of disability (once identified) rather than disability.

3.8 HRQoL and Disability in CKD

Opportunistically, two papers have been identified that discussed both HRQoL and disability in CKD5 patients. Fidan et al (2016) aimed in their study to assess HRQoL in patients on HD using the KDQoL in order to determine its relationship with musculoskeletal problems, hand disability and depression (159). A total of 50 patients from Turkey were included in the study and those under the age of 65 years were compared to those aged ≥65 years. This study found that all patients had some form of musculoskeletal problems, with older patients having poorer physical functioning than younger patients and that all of these patients experienced low HRQoL scores (159). This implies that disability and poor physical functioning are linked with poor HRQoL. As a result of the cross-sectional nature of this study it is difficult to determine which direction this association is. Additionally, the sample size of 50 is small.

The second study that analysed both HRQoL and disability was completed in Korea and involved a sample of 1,616 patients from 27 hospitals in 2012 (160). This study aimed to evaluate the differences in HRQoL, fragility and disability according to dialysis modality (160). It found that disability was more common in PD patients than HD patients. In terms of HRQoL, sleep, social interaction and social support were better in HD patients, but patient satisfaction and staff support was improved in PD patients (160). This study was completed in a retrospective nature, was not restricted to the ≥65 year's population and once again did not allow for a direct link to be made between whether HRQoL impacts on disability in CKD5 patients.

3.9 Sources that Discussed Either HRQoL or Disability in Māori CKD Patients

It is also important to identify and understand the evidence that discusses either HRQoL or disability for Māori. Two of the three studies identified were qualitative and asked about Māori patients’ experiences with CKD5 (161, 162). Shih interviewed seven rurally based Māori patients and their whānau (family) about CKD5 experiences. This research revealed four main themes of Māori experience with HD and CKD5. These were learning to face fear, coping with stress from regular dialysis, having to learn, adjust and change attitudes towards their illness and finally that family support was very important (161). Walker et al echoed some of these themes in the qualitative study where 13 Māori CKD5 patients were interviewed (162). This study found that Māori with CKD5 can experience a sense of whakamā (disempowerment and embarrassment). Embarrassment was often felt by Māori as there was a stigma that kidney disease was self-induced, and sickness was associated with weakness. Disempowerment was felt due to delayed diagnosis. Additionally, a sense of loss of whakamana (sense of self-esteem and self-determination) was felt in Māori participants. Whakamana was felt when Māori had the opportunity to involve whānau and peers in their treatment and were able to build relationships and trust with the medical professionals (162). These ideas align well with the holistic view that Māori people have of health which includes the importance of wairua (spirit), hinengaro (mind), tinana (body) and whānau (30, 37). As a result of the stress and fear Māori may face with dialysis, there is the potential for decreased HRQoL and disability among the Māori population on CKD5.

The third study that presented findings relating to CKD5 for Māori analysed the effects of intense blood pressure measurements in a community based model of care compared to usual clinical care (163). This study was a randomised control trial (RCT) of Māori and Pacific patients and followed patients up at 12 months and then at four years after the intervention. It was found that short term (12 month follow-up) intense blood pressure control, followed by usual care did not translate into a reduction in long term mortality but was associated with reduced hospitalisations (163). This was an important finding as it was noted that as a result of the intervention, initially it was seen that there was less end organ damage. However, it was found that after four years of follow-up there was no difference between the intervention and control groups. This demonstrated that the intervention did not aid in improving long term HRQoL and disability for Māori and Pacific peoples with CKD5. The study did note, however, that if the intervention could have been commenced earlier in the disease progression and maintained longer term it may be effective in achieving improved outcomes and therefore less disability. However, the costs and benefits of this intervention for the health system, health professionals and patients would need to be explored before this could be a plausible intervention (163).

Therefore, it can be concluded from the limited information that Māori with CKD5 experience adverse health outcomes. The three studies did not explicitly describe or define HRQoL and disability. There is a need for more research investigating the outcome for Māori with CKD5 and this H&D Study will contribute to this.

3.10 Conclusion

This scoping review has allowed for an understanding of how the literature has presented ‘HRQoL and CKD’ and ‘disability and CKD’. The main findings were that HRQoL may change with an individual’s stage of CKD and that it has not previously been considered as a predictor of disability. Additionally, disability is highly prevalent in CKD patients and it is recommended that these patients be provided treatment for rehabilitation however no work has been done to understand what predicts disability in these patients. Very little research has been done investigating HRQoL or disability in Māori with CKD.

The H&D Study presented in this thesis is therefore novel, as previously there has been no research that has prospectively analysed if HRQoL and other factors have the potential of being predictors of disability at 12 months. Despite disability frequently being used as a predictor, in the H&D Study we have used HRQoL as a predictor, as the ICF model of disability suggests that there ought to be relationships between HRQoL and disability. Examining HRQoL as a predictor of disability, may enable early identification of CKD5 patients who may be susceptible to disability, through analysing their HRQoL and therein, adjusting their care accordingly. Additionally, we will provide information concerning Māori experience with CKD5 in terms of HRQoL and disability.

4 Chapter Four: Methods

This chapter will begin with an overview of the methods of the DOS65+ Study, including a brief explanation of the design, recruitment and inclusion/exclusion criteria used. This chapter then describes the methods used in the H&D Study, focusing on the explanatory, predictor and outcome variables and the statistical analyses.

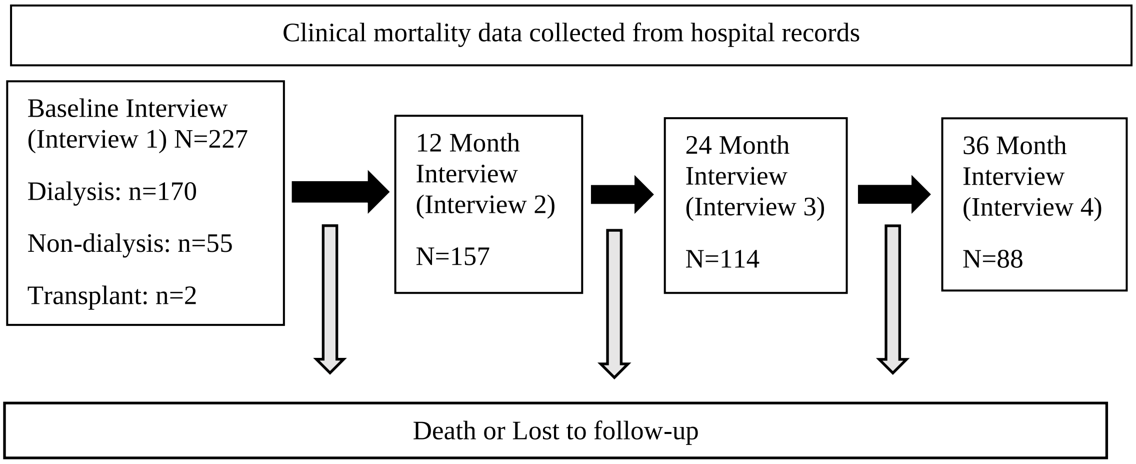
4.1 The Dialysis Outcomes in those aged ≥65 Study (DOS65+)

The DOS65+ Study provided the participants and the data for the H&D Study. The data collection for the DOS65+ was completed between 2010 and 2016 (see Figure 4.1) and the DOS65+ Study protocol has been published previously(1, 18).Therefore, this section provides a brief overview of DOS65+ relevant to the H&D Study.

The aims of the DOS65+ Study (1) were to:

1) "determine the impact of age, sex, ethnicity duration of dialysis, satisfaction with health services and comorbidity on the HRQoL in older (≥65 years) patients with chronic kidney disease"
2) "compare and contrast survival, health service utilisation, costs and HRQoL outcomes of older patients with CKD according to the type of renal replacement therapy including modality (haemodialysis versus peritoneal dialysis) and location (home versus facility) or maximal conservative therapy (no dialysis)"
3) "develop evidence-based guidelines for optimal management of older patients with severe CKD" (p 2) (1).

Figure 4.1 Diagram of the DOS65+ illustrating the clinical mortality and interview data collection points.



4.1.1 Ethical Approval

DOS65+ received ethical approval from the New Zealand Multi-Regional Ethics Committee. The approval number is MEC/10/084, and the trial was registered under the Australian and New Zealand clinical trials registry at ACTRN12611000024943. I (the MPH researcher) signed a confidentiality agreement before accessing de-identified data for H&D Study analyses.

4.1.2 DOS65+ Methods in Brief

The DOS65+ Study was an “accelerated longitudinal design” comprising of both cross-sectional and longitudinal components. Baseline interviews were conducted with patients who met the inclusion criteria, and clinical information was sourced from medical records and collected by professionals with approval for such access. Follow-up interviews were completed at 12, 24 and 36 months after the initial interview with participants who were still alive.

4.1.3 Inclusion/Exclusion Criteria

Eligible DOS65+ patients were approached by their nephrology team. Participants were eligible if they had CKD5, were aged ≥65 years, and were being treated at either Middlemore, Hawkes Bay or Dunedin Hospitals for CKD5. Eligible participants had to be; on dialysis for over 90 days prior to the first interview; have commenced renal replacement education- including an active conservative pathway; or presenting acutely and requiring immediate dialysis indefinitely (1). All consenting patients were contacted by telephone to arrange an interview, and all interviews were completed either by telephone or face to face by the DOS65+ research interviewer team (1).

Patients were excluded if they were unable to give informed consent or were unable to participate in a telephone or face-to-face interview. Additionally, they were excluded if they had an inter-current illness requiring hospitalisation within two weeks of the survey date and if this affected the patient’s ability to take part, as judged by the opinion of the physicians (e.g. for a terminal diagnosis or a serious cognitive impairment making an interview impossible) (1, 18).

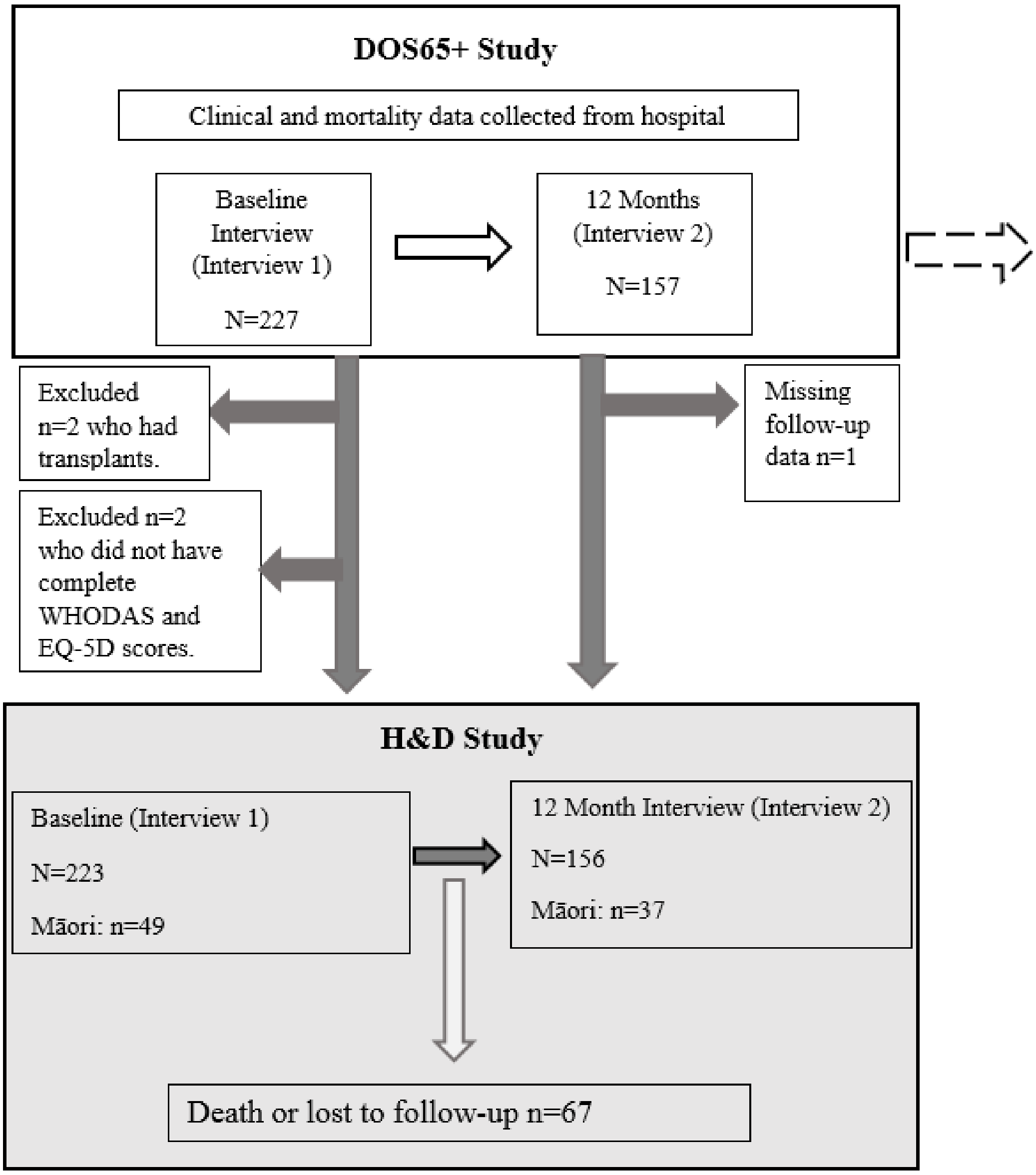
4.2 H&D Study

The H&D Study is focused on exploring associations between HRQoL and disability, and to determine which factors at baseline (interview one) predict disability outcomes 12 months later (interview 2) (see Figure 4.1). Importantly, the H&D Study includes a specific focus on analysing HRQoL and disability outcomes for Māori participants. Overall, this H&D Study aims to investigate the association between the dimensions of the HRQoL and disability and to determine if HRQoL and/or other factors predict disability in people with CKD5 aged ≥65 years in NZ. This will aid in developing knowledge to inform both nephrology professionals and patients with respect to the impact of dialysis on their life.

4.2.1 H&D Study Participants

A total of 227 participants were recruited into the main DOS65+ Study, of whom 50 were Māori. H&D participants included all DOS65+ unless they had received a kidney transplant. Transplant patients often experience an improved HRQoL compared to non-transplant patients (164), and it would have been inappropriate to include the patients who received a transplant in the H&D analysis where the goal was to understand longer-term HRQoL and disability outcomes for people with CKD5. Participants were also excluded from the H&D Study analyses if they did not have complete data available for the potential predictor of interest (the EQ-5D-3L; see section 4.3.1) or the outcome of interest (the WHODAS 2.0; see section 4.3.2). Figure 4.2 illustrates the H&D study in relation to the DOS65+ Study.

Figure 4.2 Diagram of the H&D Study in relation to the DOS65+ Study, indicating the numbers of participants at each data collection points



4.3 Predictor, Outcome and Explanatory Variables

The H&D Study aimed to determine if associations exist at baseline (Interview 1) between HRQoL and disability, and to determine which if any factors including HRQoL predicts disability outcomes 12 months later (Interview 2); and to describe associations specifically for Māori participants. HRQoL acts as the main predictor, disability as the main outcome variable and explanatory variables have the potential to be both potential predictors and confounders.

4.3.1 Predictor Variables

The main objective of this thesis was to determine if HRQoL predicted disability outcomes 12 months later. For the purposes of this thesis HRQoL was measured using the EuroQoL's EQ-5D-3L (69). The EQ-5D-3L is brief, and easy to administer and the various dimensions of the EQ-5D-3L can be considered as predictors of disability and easily interpreted unlike the SF-36. Additionally the EQ-5D-3L is useful as it is applicable to a range of health conditions and treatments including dialysis and CKD (1, 62, 69). The EQ-5D has been tested for applicability in the Māori population and has been found to be acceptable (72).

In the EQ-5D-3L, participants were asked if they have no problems, moderate problems or extreme problems with the five dimensions of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The participants were asked to report their HRQoL based on how they were feeling that day. They were also asked to rate their own health state on a visual analogue scale, with 0 representing the worst imaginable health state and 100 being the best imaginable health state (19, 67).

Cognitive function has been identified as an important factor influencing HRQoL, as it was identified as a key factor in HRQoL by Wilson and Cleary (1995) and Kaplan and Kies (2007) (see Chapter 2) (22, 51). Therefore, an additional question in the same format as the EQ-5D-3L questions, asked participants to report their cognitive functioning. The question asked participants if they had no problems, moderate problems or were unable to perform intellectual activities. Cognitive activities included remembering, concentrating, thinking and solving day-to-day problems (36, 165, 166).

Initially for the analysis of the EQ-5D-3L and the cognitive functioning question, the categories of no, moderate and extreme problems were presented separately in our first table of descriptive analysis. For the remainder of the analysis the categories of moderate and extreme problems were combined, creating a new category of 'moderate-severe problems'. This was due to sample size restrictions. Analysis was completed with each domain of the EQ-5D-3L separately, to allow for the development of an understanding of which components, if any, are important in predicting subsequent disability. The overall EQ-5D-3L health rating was not included in the H&D Study analyses, because the overall aim was to specifically investigate dimensions of HRQoL that act to predict disability. Additionally, it was not possible to ascertain what respondents actually consider when responding to the VAS scale and it can often be misunderstood and misinterpreted (67).It is not possible to ascertain what an individual is considering when providing an overall score. Additionally, practically it is not useful to health services who may wish to implement strategies to reduce subsequent disability, as the EQ-5D-3L overall health rating does not allow for an understanding of what HRQoL dimensions may be acting to impact on disability.

4.3.2 Outcome Variable

The main outcome of interest for this H&D Study is disability. This was measured using the WHODAS 2.0. As described in the rapid review (Chapter 2), this is a brief 12 item questionnaire, and it is one of the few measures specifically designed to measure disability according to the WHO ICF model of disability (1, 167, 168). It provides a generic (overall) standardised assessment of self-reported disability (96, 101). This measure has been translated into 47 languages (including Te Reo Māori; the Māori language) and is used in 27 areas of research (169). Being a self-reported measure the WHODAS 2.0 provides individuals' perspectives on how their disability affects them, and the measure can be used in both disabled and non-disabled people (169).

The WHODAS 2.0 measures six different dimensions which include cognition, mobility, self-care, getting along, life activities and participation (170). Participants were asked about how much difficulty (while using any aids or appliances they have access to) they have across the six different dimensions over the past 30 days. In each question participants were asked to rate their response with a 0,1,2,3 or 4 which correspond to no issues, moderate issues, severe issues or extreme issues or cannot do respectively. The WHODAS 2.0 allows for the responses to be scored numerically, allowing participants to have a maximum sum of 48 (maximum disability) and a minimum sum of 0 (no disability). For those missing a response to one question the average of the remaining 11 responses was imputed in place of the missing response when calculating the overall WHODAS 2.0 score (171, 172). Scores were not calculated for participants with two or more missing responses. Participants who had a WHODAS 2.0 score of 0-9 were classified as experiencing 'lesser/no disability', and those with a score of 10-48 were classified as experiencing 'considerable disability' (171).

4.3.3 Explanatory Variables

The scoping review aided in identifying key potential explanatory variables. The explanatory variables identified that were important in the scoping review and that were included in this H&D Study are: sex, age, comorbidities (138, 159, 160), ethnicity, dialysis vintage (140), living arrangements (134), and type of dialysis/dialysis location (133, 135, 160).

Often the studies in the scoping review did not focus on HRQoL and disability specifically or considered aspects that were not relevant to the aims of the H&D Study largely due to their biomedical nature. For example, variables found in the scoping review, but not included in the analyses include; haemoglobin, serum albumin, urea, creatinine (160), phosphate levels (130), dose of dialysis, dialysis flux and diabetic status (140).

A list of the explanatory variables used in the H&D Study is given below, including the justification when necessary, as to why they were used, how they were measured and what was asked. The majority of these variables were asked using questions from the NZ Census (173).

1) Sex: Participants were grouped as male or female (173).
2) Age group: All participants were aged ≥65 years and were grouped into 65-74 years and 75+ years as determined by participants date of birth (173).
3) Ethnicity: Data was collected using the NZ census question, which allows multiple ethnic groups to be specified. Ethnic groups that could be selected were New Zealand European, Māori, Samoan, Cook Island Māori, Tongan, Niuean, Chinese, Indian or ‘other’, wherein they had a free text option if their ethnicity was not included in the list. In this thesis, participants were grouped into three groups: Māori, Pacific and Non-Māori/Non-Pacific (nMnP). If a participant selected more than one ethnic group, they were prioritised into one of these three groups using NZ statistics ethnic prioritisation guidelines. For example, if an individual identifies as both Māori and NZ European, they would be classified as Māori (173, 174).
4) Living arrangements: Individuals were asked about whether they lived in the same household as others, and if so what their relationship with them was. For example, spouse or civil union partner, mother and or father, son(s) and or

daughter(s), flatmates(s). In this thesis, those who lived alone were grouped together and those who lived with others were grouped together (173).

5) Dialysis vintage: Duration of dialysis was provided from the clinical data collected for all participants. This was categorised into non-dialysing at the start of the study, less than 2 years on dialysis and ≥2 years or more on dialysis (1)
6) Number of comorbidities: Information about comorbidities was collected from the clinical data. In this study participants were grouped into those with 0-2 comorbidities and those with 3+ comorbidities (36). Comorbidities included cardiovascular disease, cerebrovascular disease, peripheral vascular disease, diabetes, lung disease, cancer (excluding skin cancer), musculoskeletal disease and other (which included cognitive impairment, peripheral neuropathy, Parkinson’s disease, depression, bipolar disorder, substance abuse, gastrointestinal disease, diabetic retinopathy, legally blind and hearing disability).
7) Dialysis location: This was categorised into home, in-centre or non-dialysing (1).

The explanatory variables are important to take into consideration, as some may act as confounders when determining if HRQoL variables do in fact predict disability. Additionally, these variables have the potential to act as independent predictors of disability, so these variables were controlled in the multivariable analysis. However, in addition to the explanatory variables, in order to gain an improved understanding of who the study sample represented, additional variables have been used in the basic descriptive statistics and univariate analysis. They were not considered explanatory variables due to the reasons discussed below and due to the small sample size. If all these variables were included this would have resulted in limited statistical power. These are described below;

1) Treatment Type: Participants were asked what type of dialysis they used; either HD or PD (1). A sub-analysis was completed comparing the outcomes for those on dialysis, so this variable was included in these sub-analysis models. However, in our main analyses this variable was excluded, as type of dialysis is often determined by dialysis location. Therefore, only dialysis location was included in our models of the entire cohort.

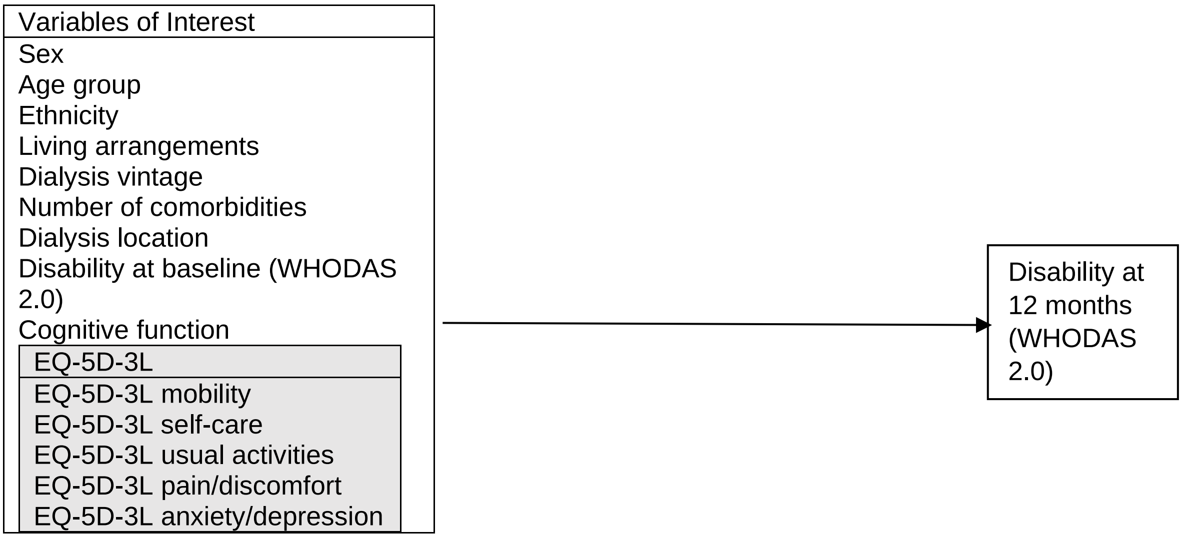
2) District Health Board (DHB): Depending on the location of the treating hospital, participants were assigned a DHB of either Counties Manukau, Hawkes Bay or Southern. This was not considered to be an explanatory variable as the sample size of the H&D Study restricted the number of variables that could be used in the analyses (1).
3) Adequate Income: Participants were asked if their income adequately met their everyday needs for accommodation, food, clothing and other necessities. They were asked if they had not enough income, just enough income, enough income or more than enough income. This was further categorised into two groups of just or not enough and enough or more than enough (175). The cohort is all ≥65 years and therefore all receive a universal superannuation, so to a degree are all in a similar financial situation, therefore it is not considered as an explanatory variable.
4) Body mass index (BMI): BMI information was calculated from participants' medical records of weight and height information. Those with a BMI <30 were grouped together and those with a BMI ≥30 were grouped together. This is well-linked to the ethnicity (176) and is not known to be a significant factor in dialysis outcomes (177).
5) Highest educational qualification: Participants were asked about their highest qualification, including not having completed one. In this thesis, participants were grouped into those with school education and those with a tertiary education (173). This was not considered an explanatory variable as the sample size of the H&D Study restricted the number of variables that could be accommodated.

4.4 Statistical Analyses

Initially, descriptive analyses (n, %) were completed to gain an understanding of the study cohort. Further baseline (see Figure 4.1) descriptive analyses (n, %) were then completed to compare the characteristics of those with 'lesser/no disability' (WHODAS 2.0 <10) and 'considerable disability' (WHODAS 2.0 ≥10). Chi-square tests were used to examine the differences in the respondent characteristics (explanatory variables) by the disability status (outcome variable). Following the baseline descriptive analyses, analyses were undertaken to determine which baseline variables predicted the disability at 12 months (using WHODAS 2.0). The relative risks (RR) of disability at 12 months was estimated using modified Poisson regression with robust standard errors (178). This method was used because it allows direct estimation of relative risks for disability(178).

Initially, a univariate analysis was done to assess the association of each explanatory variable with experiencing ‘considerable disability’ compared to ‘lesser/no disability’. Following this, a multivariable model was built to identify a subset of explanatory variables associated with the outcome, while considering collinearity and accounting for the possible confounding effects between them. Table 4.1 shows all the variables that were initially included. The backward selection procedure was used to eliminate variables using a p-value threshold of less than or equal to 0.1 to retain variables. This procedure does not allow for assessment of the appropriateness of the included variables and did not fix any of the explanatory variables because we did not have a priori hypothesis to do so. Therefore, in the results chapter the model presented has no variables fixed. Then another two models were built using the same procedure except that in the first model age, sex, ethnicity and the five EQ-5D-3L dimensions were fixed, and then the second model built only fixed EQ-5D-3L dimensions were fixed. The purpose of the subsequent models was to determine if fixing the variables had any impact upon the models. These analyses are only presented in the Appendix III.

Table 4.1 Variables investigated in the multivariable prospective model



Direct comparison of disability outcomes between HD and PD patients which excluded non-dialysing patients was undertaken, as the literature revealed this comparison to be important and provides clinically valuable information that can be more comparable to those in the literature (134). First basic descriptive statistics was completed (n, %), then a univariate analysis using chi-square tests was conducted to compare the characteristics between HD and PD patients Additionally the Poisson regression explained above was completed with this sub-cohort of patients to determine if any variables that predicted disability were different in this sub-cohort compared to the entire sample that included non-dialysing patients.

Following this, analyses were completed to compare participants who were followed up to 12 months to those who were lost to follow-up. Reasons for loss to follow-up included refusal to participate, being too unwell for a follow-up interview, or due to dying between the baseline interview and follow-up. Chi-square tests were used to compare the characteristics of those who were followed up to those who were not.

4.5 Analysis of the Māori Cohort

As described in objective c, an aim of this thesis was to conduct specific analyses of the Māori data. Due to the smaller number of Māori participants (DOS65+ recruited 50 Māori), initially basic descriptive (n, %) statistics were completed. Analysis was also completed comparing Māori who were classified as having ‘lesser/no disability’ to those who were experiencing ‘considerable disability’ at baseline. This analysis was completed again at 12 months and the chi-square test was used. Following this, the results were discussed in as much detail as possible.

All analysis was completed using Stata 15.1 ® software (StataCorp 2017) (180).

4.6 Summary

This chapter explained the methods used in this thesis. First an overview of the ‘parent’ DOS65+ Study was provided, before describing the predictors, outcome of interest, and other explanatory variables that were focused on in the H&D Study. The chapter concluded with an explanation of the statistical analyses for the entire cohort, and for the Māori participants specifically.

5 Chapter Five: Results

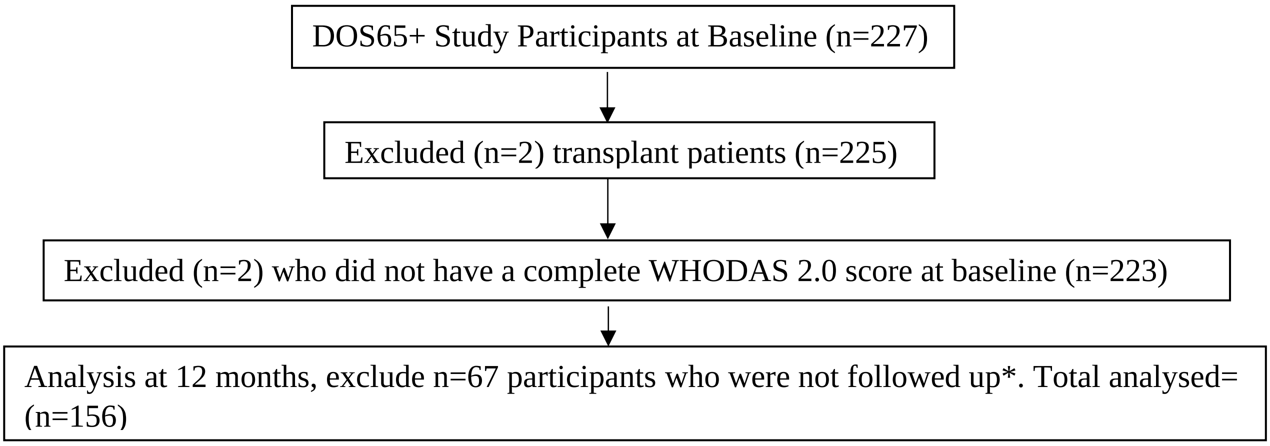
This chapter presents the results and describes associations or otherwise between HRQoL and disability, among a cohort of older New Zealanders with CKD5 pre-dialysis or on dialysis. The results also identify the factors which predict disability outcomes 12 months later. A separate analysis focused on these outcomes for older Māori patients with CKD5 is also presented.

5.1 Study Participants

At baseline there were 227 participants included in the DOS65+ Study. Two participants were excluded because they were transplant patients and two participants were excluded due to not having a complete WHODAS 2.0 score, leaving 223 participants at baseline. At 12 months, 157 participants remained in the study; 66 participants were lost to follow up or had died. A missing data point meant that only 156 participants were included in the final multivariable model.

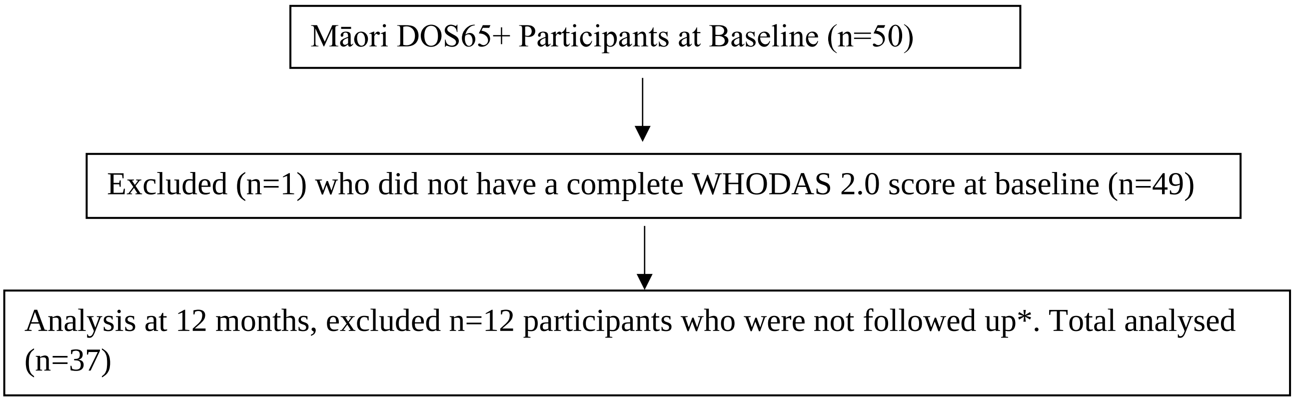
Separate analysis of the Māori cohort was completed. Māori were over-sampled, resulting in 50 Māori participants in the H&D Study. One participant did not have complete EQ-5D-3L or WHODAS 2.0 scores; 49 Māori remained at baseline. At 12 months, 37 Māori participants were followed up, with 12 Māori participants either lost to follow-up or having died by 12 months. Figures 5.1 and 5.2 illustrate the participants included in the H&D Study.

Figure 5.1 H&D Study participants



*Participants who were not followed up included those who were lost to follow-up, due to no longer wanting to participate, due to being unable to be contacted, missing data or due to death.

Figure 5.2 H&D Study Māori participants



*Participants who were not followed up included those who were lost to follow-up, due to no longer wanting to participate, due to being unable to be contacted or due to death.

5.2 Participant’s Characteristics at Baseline

Descriptive information was collected prior to the outcome data for the 223 participants who had completed WHODAS 2.0 and EQ-5D-3L measures at baseline (time of recruitment into the study). Table 5.1 details the basic demographics, HRQoL and disability variables for these participants. The mean of the WHODAS score was 11.72 (95% CI 10.67-12.78). The median was 11 (minimum value 0 and a maximum value 38), with an inter-quartile range of 5 to 17. The standard error was 0.54 and there was an overall standard deviation of 8.02.

Table 5.1 Baseline descriptive characteristics of the 223 participants

Variable	n	%
Sex		
Male	143	64
Female	80	36
Age group		
<75 years	150	67
75+ years	73	33
Ethnicity		
Non-Māori, Non-Pacific	122	55
Māori	49	22
Pacific	52	23
DHB		
Counties Manukau	150	67
Hawkes Bay	29	13
Otago	44	20
Dialysis location		
Home (HD+PD)	68	31
In-centre	92	41
Non-dialysis or training*	63	28
Dialysis vintage		
Non-dialysis	55	25
<2 years	87	39
≥2 years	81	36
Treatment type		
Haemodialysis	108	48
Peritoneal dialysis	60	27
Non-dialysis	55	25
Number of comorbidities		
0-2	104	47
3+	119	53
Adequate income**		
Just or not enough	120	54
Enough or more than enough	102	46
BMI		
<30	121	54
30+	102	46
Highest educational qualification		
School	110	49
Tertiary	113	51
Living arrangements		
With others	191	86
Alone	32	14
Disability at baseline (WHODAS 2.0)		
WHODAS <10	101	45
WHODAS ≥10	122	55
EQ-5D-3L mobility		
No problems	90	40
Moderate problems	123	55
Severe problems	10	5
EQ-5D-3L self-care		
No problems	163	73
Moderate problems	45	20
Severe problems	15	7
EQ-5D-3L usual activities		
No problems	91	41
Moderate problems	113	51
Severe problems	19	8
EQ-5D-3L anxiety/depression		
No problems	181	81
Moderate problems	40	18
Severe problems	2	1
EQ-5D-3L pain/discomfort		
No problems	121	54
Moderate problems	96	43

Severe problems	6	3
Cognitive function		
No problems	152	68
Moderate problems	66	30
Severe problems	5	2

*The non-dialysis group contained 8 participants who were in the process of training for dialysis (less than 90 days); hereafter, this group is simply called ‘non-dialysis’. To clarify, this is only the case in the dialysis location group. The dialysis vintage and treatment type group include these 8 participants in the dialysing variable.

** Adequate income has one individual missing; therefore, the total number of participants presented in this group is 222.

A higher proportion of H&D Study participants were male, and in the under 75 years age group (Table 5.1). A larger proportion of participants were on HD (48%) compared to PD (27%). The majority of participants lived with others (86%). Additionally, a large proportion of the participants came from the Counties Manukau DHB (the largest renal unit in NZ).

At baseline, 45% of the H&D Study participants reported WHODAS 2.0 Scores <10 indicating ‘lesser/no disability’, and 55% of participants had WHODAS 2.0 ≥10, indicating ‘considerable disability’. The majority of participants reported no problems with self-care, anxiety/depression according to the EQ-5D-3L, or problems with cognitive functioning. However, 51% reported moderate problems with usual activities, and 43% of participants had moderate problems with pain/discomfort. For the remainder of the analysis the moderate and severe categories were combined due to sample size restrictions.

5.2.1 Disability at Baseline

Table 5.2 compares the characteristics of participants with ‘lesser/no disability’ (WHODAS 2.0 <10) to those with ‘considerable disability’ (WHODAS 2.0 ≥10) at baseline. The number and percentages are shown, as well as the chi-square p-values.

Table 5.2 Disability described at baseline (n=223)

Characteristic	WHODAS 2.0 <10		WHODAS 2.0≥10		P-value
	N	%**	n	%**	
Sex					0.729
Male	66	46	77	54	
Female	35	44	45	56	
Age group					0.554
<75 years	70	46	80	53	
75+ years	31	42	42	58	
Ethnicity					0.566
Non-Māori, non-Pacific	50	41	72	59	
Māori	25	51	24	49	
Pacific	26	50	26	50	
Highest educational qualification *					0.467
School	66	44	84	56	
Tertiary	34	49	35	51	
DHB					0.122
Counties Manukau	74	49	76	51	
Hawkes Bay	13	45	16	55	
Otago	14	32	30	68	
Treatment type					0.942
Non-dialysis	26	47	29	53	
Haemodialysis	48	44	60	56	
Peritoneal dialysis	27	45	33	55	
Dialysis vintage					0.681
Non-dialysis	27	49	28	51	
<2 Years	37	43	50	57	
≥2 Years	37	46	44	54	
Number of comorbidities					<0.000
0-2	61	59	43	41	
3+	40	34	79	66	
BMI*					0.958
<30	55	46	65	54	
30+	46	45	56	55	
Dialysis location					0.765
Home (HD+PD)	32	47	36	53	
In centre	39	42	53	58	
Non-dialysis	30	48	33	52	
Adequate income					0.704
Just or not enough	56	47	64	53	
Enough or more than enough	45	44	57	56	
Living arrangements*					0.035
Live others	92	48	99	52	
Alone	9	28	23	72	
EQ-5D-3L mobility					<0.000
No problems	65	72	25	28	
Moderate-severe problems	36	27	97	73	
EQ-5D-3L self-care					<0.000
No problems	89	55	74	45	
Moderate-severe problems	12	20	48	80	
EQ-5D-3L usual activities					<0.000
No problems	66	73	25	27	
Moderate-severe problems	35	27	97	73	
EQ-5D-3L pain/discomfort					0.013
No problems	64	53	57	47	
Moderate-severe problems	37	36	65	64	
EQ-5D-3L anxiety/depression					0.001
No problems	92	51	89	49	
Moderate-severe problems	9	21	33	79	
Cognitive function					<0.000
No problems	83	55	69	45	
Moderate-severe problems	18	25	53	75	

*There were 4 individuals missing in the highest education qualification characteristic variable and one individual missing data in the BMI and adequate income variable.

**Row percentages are presented.

Two-thirds of those with 3 or more comorbidities were experiencing ‘considerable disability’. Those who had moderate-severe problems with EQ-5D-3L mobility were more likely to have higher WHODAS 2.0 scores, as were those with problems with EQ-5D-3L self-care, EQ-5D-3L usual activities, and EQ-5D-3L anxiety/depression.

5.3 Predictors of Disability at 12 Months

Of the 223 H&D Study participants at baseline, 157 participants completed follow-up interviews at 12 months. Sixty-six participants were either lost to follow-up or had died prior to the 12 month interview.

5.3.1 Univariate Analyses

Table 5.3 presents the relative risks of WHODAS 2.0 ≥10 (considerable disability) at 12 months according to baseline characteristics. The relative risks were estimated using modified Poisson regression. Of the 157 participants followed to 12 months after baseline, one did not have information about dialysis vintage available in their clinical record and is therefore not included in the analyses for that variable. As described in the methods, only 156 participants were included in the final multivariable model (as displayed in Figure 4.2 (Chapter 4) and Figure 5.1) However, 157 participants were able to be included in the univariate analyses. Additionally, two participants did not provide information about their level of education and therefore these individuals are not included in the analyses for that variable in Table 5.3 below. The mean WHODAS 2.0 score for the 157 remaining at 12 months was 11.76 (95% CI 10.50-13.02). The median was 11 (minimum 0 and maximum value 33), with an interquartile range of 5-17. The standard error was 0.64 and the standard deviation was 8.05.

Table 5.3 Univariate analysis of risk of WHODAS 2.0 ≥10 representing 'considerable disability' after 12 months follow-up according to characteristics of the participants (n=157)

Variable	Relative Risk	95% CI	P-Value	Overall P-Value*
Sex				
Male	Ref			
Female	1.31	1.00-1.70	0.047	
Age group				
<75 years	Ref			
75+ years	1.16	0.88-1.52	0.295	
Ethnicity				
Non-Māori, Non-Pacific	Ref			0.870
Māori	0.91	0.65-1.29	0.613	
Pacific	0.95	0.67-1.35	0.784	
Highest educational qualification (n=155)				
Tertiary	Ref			
School	1.27	0.90-1.78	0.172	
Treatment type				
Non-dialysis	Ref			0.255
Peritoneal Dialysis	1.04	0.75-1.45	0.817	
Haemodialysis	0.81	0.58-1.12	0.208	
Dialysis vintage (n=156)				
Non-dialysis	Ref			0.151
<2 years	1.06	0.78-1.45	0.693	
≥2 years	0.77	0.53-1.11	0.195	
Number of comorbidities				
0-2	Ref			
3+	1.21	0.92-1.59	0.171	
BMI				
<30	Ref			
30+	1.22	0.93-1.60	0.155	
Dialysis location				
Non-dialysis	Ref			0.958
Home (HD+PD)	1.00	0.70-1.44	0.979	
In centre	1.04	0.75-1.45	0.795	
Adequate income				
Enough or more than enough	Ref			
Just or not enough	1.08	0.82-1.42	0.585	
Living arrangements				
With others	Ref			
Alone	1.19	0.85-1.67	0.307	
EQ-5D-3L mobility				
No problems	Ref			
Moderate-severe problems	1.98	1.42-2.76	<0.000	
EQ-5D-3L self-care				
No problems	Ref			
Moderate-severe problems	1.67	1.32-2.11	<0.000	
EQ-5D-3L usual activities				
No problems	Ref			
Moderate-severe problems	1.89	1.35-2.64	<0.000	
EQ-5D-3L pain/discomfort				
No problems	Ref			
Moderate-severe problems	1.25	0.96-1.64	0.100	
EQ-5D-3L anxiety/depression				
No problems	Ref			
Moderate-severe problems	1.21	0.90-1.63	0.212	
Cognitive function				
No problems	Ref			
Moderate-severe problems	1.35	1.04-1.76	0.022	
Disability at baseline (WHODAS 2.0)				
WHODAS <10	Ref			

WHODAS ≥10	2.24	1.64-3.07	<0.000

*Overall p-value refers to the p-value which was calculated when there was more than one p-value presented for an explanatory variable.

The univariate analyses indicate that sex (although this was borderline as the 95% CI included 1.00), EQ-5D-3L mobility, EQ-5D-3L self-care, EQ-5D-3L usual activities, cognitive function and ‘considerable disability’ at baseline may predict disability 12 months later. Univariate analyses did not demonstrate a difference in risk of disability for dialysis type (HD and PD), dialysis vintage or those dialysing at home or in centre compared to non-dialysing patients. Multivariable analyses were then undertaken to provide understanding of factors that may independently predict disability outcomes at 12 months.

5.3.2 Multivariable Analyses

Three models were completed in the multivariable analyses. Table 5.4 shows the results of the multivariable model with no variables being fixed. Additionally, but not presented here, the models were rerun with age, sex, ethnicity and all EQ-5D-3L dimensions fixed, and again with only the EQ-5D-3L dimensions fixed (Appendix III; Tables III) (1-2). These sub-analyses produced results similar to those in Table 5.4 and are not discussed again, as the focus is on Table 5.4. The final multivariable model portrays the results of only 156 participants, as one participant was missing a value for dialysis vintage.

Table 5.4 Multivariable analysis of variables predicting WHODAS 2.0 ≥10 representing 'considerable disability' at 12 months (n=156)

Variable	Relative Risk	95% CI	P-value	Overall P-value
Sex				
Male	Ref			
Female	1.31	1.03-1.67	0.014	
Dialysis vintage				
Non-dialysis	Ref			
<2 years	0.54	0.24-1.21	0.023	0.091
≥2 years	0.39	0.17-0.88	0.048	
Dialysis location				
Non-dialysis	Ref			
Home (HD+PD)	2.29	1.00-5.21	0.048	0.014
In centre	1.75	0.80-3.85	0.160	
EQ-5D-3L mobility				
No problems	Ref			
Moderate-severe problems	1.38	1.00-1.89	0.048	
EQ-5D-3L self-care				
No problems	Ref			
Moderate-severe problems	1.31	1.04-1.67	0.025	
Disability at baseline (WHODAS 2.0)				
WHODAS <10	Ref			
WHODAS ≥10	1.86	1.36-2.53	<0.001	

Variables included but not retained; age, ethnicity, number of comorbidities, living arrangements, EQ-5D-3L usual activities, EQ-5D-3L pain/discomfort, EQ-5D-3L anxiety/depression and cognitive function.

The key findings of this multivariable model are that, provided other variables in the model remained unchanged, those who were disabled at baseline have an 86% increased risk of disability 12 months later (RR=1.86, 95% CI=1.36-2.63; p<0.001), when compared to those with 'lesser/no disability' at baseline. Those with EQ-5D-3L self-care problems have a 31% higher risk (RR=1.31, 95% CI =1.04-1.67; p=0.025) of disability and those with EQ-5D-3L mobility problems have a 38% higher risk (RR=1.38, 95%CI =1.00-1.89; p=0.048) of disability compared to those with no problems at baseline. Females were at a 31% higher risk of 'considerable disability' at the 12 month follow-up (RR=1.31, 95%CI=1.03-1.67; p=0.0137) compared to men.

When considering dialysis vintage, patients dialysing for a shorter period of time (0-2 years) had no statistically significant difference in risk of disability compared to the non-dialysis group (RR=0.54, 95%CI =0.24-1.21). However, those dialysing for 2 or more years had a 61% (RR=0.39. 95%CI 0.17-0.88) lower risk of 'considerable disability' 12 months later compared to the non-dialysis group. Additionally, those dialysing at home were 2.29 (RR=2.29, 95%CI 1.00-5.21) times as likely to experience 'considerable disability' at 12 months compared to those not dialysing, although this was not statistically significant.

5.4 Outcomes for Older people on Dialysis

Clinically, it is important to make comparisons between outcomes between HD and PD patients. As demonstrated in Chapter 3, much of the literature had focused on such comparisons. In the H&D Study, 168 patients were on dialysis (HD =108, PD =60) at baseline (interview one), 52 had died, were too un-well or were lost to follow-up at 12 months, leaving 116 dialysing patients with data available at 12 months.

5.4.1 Descriptive Analyses

Initially, descriptive analyses and chi-square tests were undertaken to compare the characteristics of these groups. Understanding the difference in outcomes between HD and PD may help individuals, clinicians and whānau decide which treatment is best. Location has been removed from analysis, as location of dialysis therapy in NZ is often determined by the type of dialysis, with those on HD being more likely to dialyses in-centre and those on PD often dialysing at home (9).

Table 5.5 Baseline descriptive statistics of HD (n=108) and PD (n=60)

Variables	Haemo-dialysis	%*	Peritoneal Dialysis	%*	P Value
Sex					0.053
Male	63	59	44	41	
Female	45	74	16	26	
Age group					0.595
<75 years	78	66	41	34	
75+ years	30	61	19	39	
Ethnicity					0.004
Non-Māori, Non- Pacific	43	52	40	48	
Māori	30	77	9	23	
Pacific	35	76	11	24	
Dialysis vintage					0.108
<2 years	49	57	37	43	
≥2 years	58	72	23	28	
Number of comorbidities					0.854
0-2	52	65	28	35	
3+	56	64	32	36	
Living arrangements					0.620
With others	98	65	53	35	
Alone	10	59	7	41	
EQ-5D-3L mobility					0.373
No problems	41	60	27	40	
Moderate-severe problems	67	67	33	33	
EQ-5D-3L self-care					0.584
No problems	73	63	43	37	
Moderate-severe problems	35	67	17	33	
EQ-5D-3L usual activities					0.088
No problems	36	56	28	44	
Moderate-severe problems	72	69	32	31	
EQ-5D-3L pain/discomfort					0.285
No problems	65	68	31	32	
Moderate-severe problems	43	60	29	40	
EQ-5D-3L anxiety/depression					0.931
No problems	87	64	48	36	
Moderate-severe problems	21	64	12	36	
Cognitive function					0.538
No problems	65	63	39	38	
Moderate-severe problems	43	67	21	33	
Disability at baseline (WHODAS 2.0)					0.945
WHODAS <10	48	64	27	36	
WHODAS ≥10	60	65	33	35	
Disability at 12 months (WHODAS 2.0)					0.280
WHODAS <10	38	73	14	27	
WHODAS ≥10	39	60	26	40	
Participants not followed for 12 months	31	61	20	39	

*Row percentages are presented

A higher proportion of people on PD were Māori or Pacific. There was a tendency for more females on HD, however this was not statistically significant. With these exceptions, and with this relatively small sample, HD and PD patients had similar characteristics. There is no statistically significant difference in disability between HD and PD patients at baseline or 12 months.

5.4.2 Multivariable Analysis of Disability Outcomes among Dialysis Patients (HD or PD) only

Multivariable analyses were undertaken to consider which, if any, variables predicted disability 12 months later among the dialysis (HD or PD participants) only. Cognitive function had to be removed from these analyses in favour of other variables due to the smaller sample size. Table 5.6 shows the multivariable analyses with no variables being fixed.

Table 5.6 Multivariable analyses of variables predicting WHODAS 2.0 ≥10 representing ‘considerable disability’ at 12 months, among older dialysis patients (HD and PD) only (n=116)

Variable	Relative Risk	95% CI	P-value
Dialysis vintage			
< 2 years	Ref		
≥2 years	0.73	0.55-0.98	0.036
EQ-5D-3L self-care			
No problems	Ref		
Moderate-severe problems	1.38	1.03-1.85	0.030
EQ-5D-3L usual activities			
No problems	Ref		
Moderate-severe problems	1.54	0.99-2.40	0.058
Disability at baseline (WHODAS 2.0)			
WHODAS <10	Ref		
WHODAS ≥10	1.62	1.10-2.38	0.015

Variables included but not retained in the model; sex, age group, ethnicity, number of comorbidities, living arrangements, EQ-5D-3L mobility, EQ-5D-3L pain/discomfort, and EQ-5D-3L anxiety/depression.

From these analyses it can be seen that among current dialysing patients those who were disabled at baseline are at a 62% (RR=1.62, 95%CI 1.10-2.38, p=0.015) higher risk of being disabled compared to those with ‘lesser/no disability’. Additionally, those dialysing for 2 or more years had a 27% (RR=0.73, 95%CI 0.55-0.98, p=0.036) decreased risk of experiencing disability compared to those dialysing for <2 years. Those with problems with EQ-5D-3L self-care at baseline were at a 38% (RR=1.38, 95%CI 1.03-1.85, p=0.030) higher risk of being disabled at 12 months compared to those with no problems. The EQ-5D-3L domain of usual activities shows that those with moderate-severe problems with usual activities at baseline were at a 54%

(RR=1.54, 95% CI 0.99-2.40, p=0.058) higher risk of disability, however this result did not quite reach statistical significance.

5.5 Analyses Māori Cohort

5.5.1 Māori Descriptive Analyses

One of the aims was to conduct a separate analysis of outcomes for Māori participants. The descriptive characteristics of the Māori participants of the H&D Study is shown are Table 5.7. There were 49 Māori participants with complete WHODAS 2.0 scores at baseline.

Table 5.7 Baseline characteristics of the Māori cohort (n=49)

Variable	n	%
Sex		
Male	28	57
Female	21	43
Age group		
<75 years	40	82
75+ years	9	18
Highest education qualification		
Tertiary	15	31
School	33	69
Adequate income		
Just or not enough	34	69
Enough or more than enough	15	31
Living arrangements		
With others	36	73
Alone	13	27
Treatment type		
Haemodialysis	30	61
Peritoneal Dialysis	9	18
Non-dialysis	10	21
Dialysis vintage		
<2 years	19	39
≥2 years	20	41
Non-dialysis	10	20
Number of comorbidities		
0-2	20	41
3+	29	59
BMI		
<30	19	39
30+	30	61
Dialysis location		
Home (HD+PD)	10	20
In-centre	27	55
Non-dialysis	12	25
EQ-5D-3L mobility		
No problems	19	39
Moderate-severe problems	30	61
EQ-5D-3L self-care		
No problems	37	76
Moderate-severe problems	12	24
EQ-5D-3L usual activities		
No problems	23	47
Moderate-severe problems	26	53
EQ-5D-3L pain/discomfort		
No problems	24	49
Moderate-severe problems	25	51
EQ-5D-3L anxiety/depression		
No problems	44	90
Moderate-severe problems	5	10
Cognitive function		
No problems	32	65
Moderate-severe problems	17	35
Disability at baseline (WHODAS 2.0)		
WHODAS <10	25	51
WHODAS ≥10	24	49

There was a higher proportion of Māori males than females, and the majority of Māori were under the age of 75 years. Additionally, a large proportion (69%) of Māori had just or not enough income. The majority of Māori were on HD and had 3 or more comorbidities. Very few Māori had problems with EQ-5D-3L self-care, EQ-5D-3L anxiety/depression; or cognitive function at baseline. However, a larger proportion of Māori had problems with EQ-5D-3L mobility and EQ-5D-3L usual activities. There was a similar proportion of individuals with ‘lesser/no disability’ and those with ‘considerable disability’.

5.5.2 Univariate Analyses

Due to the small sample size it was not possible to conduct multivariable analyses. Instead univariate analyses was undertaken to investigate associations between Māori who had ‘lesser/no disability’ at baseline and those had ‘considerable disability’ at baseline (interview 1). The results are shown in Table 5.8.

Table 5.8 Disability described at baseline in the Māori participants (n=49)

Characteristic	WHODAS 2.0 <10		WHODAS 2.0 ≥10		P-value
	n	%	n	%	
Sex					0.680
Male	15	54	13	46	
Female	10	48	11	52	
Age group					0.299
<75 years	19	48	21	52	
75+ years	6	67	3	33	
Highest educational qualification					0.613
Tertiary	7	47	8	53	
School	18	55	15	45	
DHB					0.561
Counties Manukau	20	56	16	44	
Hawkes Bay	4	40	6	60	
Otago	1	33	2	67	
Treatment type					0.573
Non-dialysis	5	50	5	50	
Peritoneal Dialysis	6	67	3	33	
Haemodialysis	14	47	16	53	
Dialysis vintage					0.037
<2 years	6	32	13	68	
≥2 years	13	65	7	35	
Non-dialysis	6	60	4	40	
Number of comorbidities					0.027
0-2	14	70	6	30	
3+	11	38	18	62	
BMI					0.684
<30	9	47	10	53	
30+	16	53	14	47	
Dialysis location					0.812
Home (HD+PD)	6	60	4	40	
In-centre	13	48	14	52	
Non-dialysis and Training	6	50	6	50	
Adequate income					0.305
Enough or more than enough	6	40	9	60	
Just or not enough	19	56	15	44	
Living arrangements					0.682
With others	19	53	17	47	
Alone	6	46	7	54	
EQ-5D-3L mobility					0.002
No problems	15	79	4	21	
Moderate-severe problems	10	33	20	67	
EQ-5D-3L self-care					0.038
No problems	22	59	15	41	
Moderate-severe problems	3	25	9	75	
EQ-5D-3L usual activities					0.015
No problems	16	70	7	30	
Moderate-severe problems	9	35	17	65	
EQ-5D-3L pain/discomfort					0.032
No problems	16	67	8	33	
Moderate-severe problems	9	36	16	64	
EQ-5D-3L anxiety/depression					0.603
No problems	23	52	21	48	
Moderate-severe problems	2	40	3	60	
Cognitive function					0.315
No problems	18	56	14	44	
Moderate-severe problems	7	41	10	59	

*Row percentages presented

These univariate analyses presented in Table 5.8 suggests that problems related to EQ-5D-3L mobility, EQ-5D-3L self-care, EQ-5D-3L usual activities and EQ-5D-3L pain/discomfort are all associated with disability at baseline compared to those with no problems. Similarly, those with 3 or more comorbidities are associated with being more disabled than those with 0-2 comorbidities ($p=0.027$). Additionally, those who had been dialysing for more than 2 years were associated with lower disability at baseline ($p=0.037$).

At 12 months there were 37 Māori participants, and again univariate analysis was undertaken to compare those who had ‘lesser/no disability’ at 12 months compared to those experiencing ‘considerable disability’ at 12 months.

Table 5.9 Baseline characteristics of Māori participants who had ‘lesser/no disability’ compared to those who were disabled at 12 months (n=37)

Baseline Characteristics	WHODAS 2.0 <10		WHODAS 2.0 ≤10		P-value
	n	%	n	%	
Sex					0.014
Male	12	67	6	33	
Female	5	26	14	74	
Age group					0.509
<75 years	13	43	17	57	
75+ years	4	57	3	43	
Highest educational qualification					0.836
Tertiary	5	50	5	50	
School	12	46	14	54	
DHB					0.534
Counties Manukau	14	45	17	55	
Hawkes Bay	2	40	3	60	
Otago	1	1	0	0	
Treatment type					0.351
Non-dialysis	2	25	6	75	
Peritoneal Dialysis	3	43	4	57	
Haemodialysis	12	55	10	45	
Dialysis vintage					0.001
<2 years	2	15	11	85	
≥2 years	12	75	4	25	
Number of comorbidities					0.900
0-2	8	47	9	53	
3+	9	45	11	55	
BMI					0.286
<30	8	57	6	43	
30+	9	39	14	61	
Dialysis location					0.860
Home (HD + PD)	3	43	4	57	
In-centre	10	50	10	50	
Non-dialysis	4	40	6	60	
Adequate income					0.447
Enough or more than enough	4	36	7	64	
Just or not enough	13	50	13	50	
Living arrangements					0.659
With others	13	48	14	52	
Alone	4	40	6	60	
EQ-5D-3L mobility					0.006
No problems	11	73	4	27	

Baseline Characteristics	**WHODAS 2.0 <10**		**WHODAS 2.0 ≤10**		**P-value**
	n	**%**	**n**	**%**	
Moderate-severe problems	6	27	16	73	
EQ-5D-3L self-care					0.383
No problems	14	50	14	50	
Moderate-severe problems	3	33	6	67	
EQ-5D-3L usual activities					0.035
No problems	11	65	6	35	
Moderate-severe problems	6	30	14	70	
EQ-5D-3L pain/discomfort					0.147
No problems	10	59	7	41	
Moderate-severe problems	7	35	13	65	
EQ-5D-3L anxiety/depression					0.774
No problems	15	47	17	53	
Moderate-severe problems	2	40	3	60	
Cognitive function					0.501
No problems	12	50	12	50	
Moderate-severe problems	5	38	8	62	
Disability at baseline (WHODAS 2.0)					<0.001
WHODAS <10	14	70	6	30	
WHODAS ≥10	3	18	14	82	

*Row percentages were presented

The H&D Study shows that a greater proportion of Māori who were disabled at baseline also experienced ‘considerable disability’ at 12 months. A higher proportion of Māori females were disabled at 12 months compared to Māori males. In Table 5.9, those who dialysed for ≥2 years experienced decreased disability compared to those who had been dialysing for <2 years. Additionally, those with moderate-severe problems with EQ-5D-3L mobility and EQ-5D-3L usual activities problems had a greater likelihood of being disabled compared to those with no problems.

As with the overall cohort, aspects of HRQoL appear to be associated with disability among the Māori cohort. However, as a result of the small sample size, further research is needed to determine if HRQoL does predict disability for Māori or whether this association is confounded by other factors.

5.6 Comparison of Participants Remaining in the Study at 12 months to Baseline only Participants

Due to a large proportion (42%) of H&D Study participants lost to the 12 month follow-up, the characteristics of those followed to 12 months were compared with those only interviewed at baseline. Pearson’s chi-square test was used compare the characteristics of the 67 participants who were not followed to 12 months with the 156 participants interviewed with complete data.

Table 5.10 Characteristics of participants followed-up at 12 months (n=156) compared to baseline only participants (n=67)

Baseline characteristics	Baseline (n=67)	%*	Followed to 12 months (n=156)	%*	P-value
Sex					
Male	45	67	98	63	0.535
Female	22	33	58	37	
Age group					
<75 years	43	64	107	69	0.520
75+ years	24	36	49	31	
Ethnicity					
Non-Maori, Non-Pacific	34	51	88	56	0.314
Maori	13	19	36	23	
Pacific	20	30	32	21	
Dialysis vintage					
Non-dialysis	15	22	39	25	0.358
<2 years	29	43	58	37	
≥2 Years	22	32	59	38	
Missing	2	3	0.0	0.0	
Dialysis location					
Non-dialysis	15	22	48	31	0.444
Home (HD+PD)	22	33	46	29	
In centre	30	45	62	40	
Number of comorbidities					
0-2	25	37	79	51	0.067
3+	42	63	77	49	
Living arrangements					
With others	56	84	135	87	0.564
Alone	11	16	21	13	
EQ-5D-3L mobility					
No problems	21	31	69	44	0.072
Moderate-severe problems	46	69	87	56	
EQ-5D-3L self-care					
No problems	46	69	117	75	0.327
Moderate-severe problems	21	31	39	25	
EQ-5D-3L usual activities					
No problems	26	39	65	42	0.690
Moderate-severe problems	41	61	91	58	
EQ-5D-3L pain/discomfort					
No problems	32	48	89	57	0.202
Moderate-severe problems	35	52	67	43	
EQ-5D-3L anxiety/depression					
No problems	55	82	126	81	0.817
Moderate-severe problems	12	18	30	19	
Disability at baseline (WHODAS 2.0)					
WHODAS <10	21	31	80	51	0.006
WHODAS ≥10	46	69	76	49	
Treatment type					
Non-dialysis	15	22	40	26	0.772
Haemodialysis	20	30	40	26	
Peritoneal Dialysis	32	48	76	49	
Cognitive function					
No problems	43	64	109	70	0.403
Moderate-severe problems	24	36	47	30	

*Column percentages have been presented

The only statistically significant difference between those followed up for 12 months and those who only had a baseline interview was in baseline disability. It appears that a higher proportion of those disabled at baseline were lost to follow-up. Additionally, it appears that there was a tendency towards a higher proportion of individuals with higher comorbidities and impaired EQ-5D-3L mobility to not be followed up for 12 months (interview 2), however neither of these differences were statistically significant.

Analysis was also completed to compare Māori who were followed-up to 12 months to those who were not. A total of 12 Māori participants were not followed up to 12 months. A greater proportion of Māori females were followed up at 12 months, and there were no other differences between the two groups (see Table III (3) in Appendix III).

5.7 Conclusion

Within the entire H&D Study cohort, it is apparent that ‘considerable disability’, EQ-5D-3L self-care and EQ-5D-3L mobility problems at baseline predict disability at 12 months. Dialysing for greater than 2 years was associated with a lower risk of disability. In the univariate sub-analysis of dialysing patients, it was apparent that there was no significant difference in disability at 12 months between HD and PD patients. However, in the multivariate analysis home dialysis (which is predominantly PD) was associated with a greater degree of disability. For the smaller sample of Māori participants, HRQoL and baseline disability also appear to be important in predicting disability at 12 months.

6 Chapter Six: Discussion

This chapter discusses the key findings and conclusions of the H&D Study. Firstly, the results of the H&D Study are summarised according to the three main objectives identified in Chapter One and discussed in relation to other studies. Following this, the strengths and the limitations of the H&D Study are considered, and then the implications and recommendations for further research are presented. This chapter closes with the final conclusions.

6.1 Results

The key findings from this H&D Study are summarised in relation to each of the H&D Study objectives below.

6.1.1 Objective One

Describe characteristics of the H&D study participants at baseline and determine cross-sectional associations, if any, between health-related quality of life (HRQoL) and disability among a cohort of older New Zealanders with CKD5 at the time of recruitment (baseline);

At the time of recruitment, the majority of participants reported no problems with self-care (73%), anxiety/depression (81%) according to the EQ-5D-3L, and also to a question about cognitive functioning (68%). A total of 59% of participants reported moderate-severe problems with usual activities and 46% of participants had moderate-severe problems with pain/discomfort according to the EQ-5D-3L (Table 5.1, Chapter Five). Apostolou et al (2007) identified that physical decline (119), which could be associated with reduced ability to perform usual activities and lead to pain/discomfort, is important in influencing HRQoL. The cross-sectional results from the H&D Study suggest that consideration of patient's issues with usual activities and perceptions of pain/discomfort may be important when attempting to enable individuals to maximise their HRQoL. Additionally, at baseline, 45% of participants had 'lesser/no disability' and 55% of participants had 'considerable disability' (Table 5.1), which suggests that disability is prevalent among those with CKD5.

To further consider associations between HRQoL and disability at baseline participants with 'lesser/no disability' were compared to those with 'considerable disability' by the predictor and explanatory variables in terms of unadjusted associations (Table 5.2). Analysis at baseline demonstrated that those who had moderate-severe problems with EQ-5D-3L mobility, EQ-5D-3L self-care, EQ-5D-3L usual activities, EQ-5D-3L pain/discomfort, EQ-5D-3L anxiety/depression, and cognitive function also experienced ‘considerable disability’ at baseline. This was also found in those with three or more comorbidities. This observation did not control for confounders. However, it demonstrates that those with moderate-severe problems with HRQoL at baseline appeared to also experience disability. As identified in section 3.7.1 (Chapter 3), Cook et al (2008) in a cross-sectional analysis found that disability was prevalent in older adults on HD and this makes self-care difficult (146). Fidan et al (2016) found that disability and poor physical function appeared to be linked to poor HRQoL, however this study had a very small sample size of 50 people and focused on hand disability. Additionally, the participants average age was 56 therefore these results may not be directly applicable to those aged ≥65 years (159). Little is currently known about the relationship of HRQoL and disability in CKD5 patients, but the H&D Study findings align with findings from research conducted previously, that HRQoL is cross-sectionally associated with disability among people with CKD5(146, 159).

6.1.2 Objective Two

Determine, which, if any, factors at recruitment (baseline), including HRQoL, predict disability outcomes 12 months later;

After establishing that disability is an important issue at baseline in the H&D Study cohort, the H&D Study aimed to determine baseline predictors of disability at 12 months. A univariate analysis (Table 5.3) was completed to assess the risk of baseline ‘considerable disability’ at 12 months of follow-up according to the explanatory and predictor baseline characteristics of the participants. The unadjusted univariate analysis indicated that sex, EQ-5D-3L mobility, EQ-5D-3L self-care, EQ-5D-3L usual activities, cognitive function and ‘considerable disability’ at baseline predicted ‘considerable disability’ 12 months later.

Multivariable analyses determined the factors that independently predicted disability at 12 months in the CKD5 patients of the H&D Study. Females had a 31% higher risk of ‘considerable disability’ at 12 months compared to males (Table 5.4). In contrast, to the studies identified in the scoping review (section 3.7.2 and 3.7.3), it appears that the majority of the papers did not note a difference between males and females (146, 158). Females traditionally were the homemakers among older New Zealanders, and therefore they may do more around the home than males, meaning that their perception of being disabled could be greater than males. However, this a hypothesis and further research needs to be undertaken to try and understand what underpins the risk of disability for females with CKD5.

There was a trend for those who dialysed at home (Table 5.4) to be more likely to experience ‘considerable disability’ than those who were not dialysing which may initially seem counter-intuitive. In NZ, PD is often available to people who are more unwell which may act to explain this finding. Within the H&D Study cohort, most home dialysis patients were on PD, which is a simpler dialysis modality and allows for independence at home, despite often having significant comorbidities and disabilities. Individual preferences with clinical guidance largely dictate the treatment chosen and therefore the outcomes (134).

In terms of HRQoL, participants who had moderate-severe problems with mobility and self-care as measured by the EQ-5D-3L (Table 5.4) were more likely to experience ‘considerable disability’ at 12 months compared to those with no problems with these dimensions at baseline. Therefore, it appears the EQ-5D-3L mobility and EQ-5D-3L self-care can be useful in predicting subsequent disability for CKD5 patients. This is a novel finding since no previous studies identified in the literature search used HRQoL as a predictor of disability. Previously de Jonge et al (2003) investigated if INTERMED could be used as a predictor of HRQoL (120), however no studies have investigated if HRQoL could be used as a predictor in CKD5 patients. The H&D Study findings suggest that future research could investigate the use of the explicit assessment of mobility and self-care in the clinical review and pre-dialysis education of individuals with CKD5 as they approach the need for renal replacement therapy. This could allow patients and nephrologists to use the experiences of others to aid the decision making of those who are investigating RRT.

Individuals with ‘considerable disability’ at baseline had a significantly (86%) higher risk of experiencing ‘considerable disability’ at 12 months compared to those with ‘lesser/no disability’ at baseline (Table 5.4). Although the scoping review found literature reporting that patients with CKD5 often experience disability (150, 158), previous studies have not clearly identified disability as a predictor of later disability in CKD5 patients. Therefore, this H&D Study contributes a significant finding through demonstration of disability as a predictor of later disability in CKD5 patients. These results are important for future patient and family education, when discussing the potential impact of dialysis on the individual, to reduce any possible misunderstanding as to the ‘benefits’ of dialysis with respect to existing disabilities.

Additionally, in this H&D Study, those who dialysed for ≥2 years had a 61% (RR=0.39, 95% CI=0.17-0.88) (Table 5.4) lower risk of having ‘considerable disability’ compared to those who were not dialysing. A plausible explanation for this is related to this being a self-selected group with improved survival (increased dialysis vintage) due to likely having little or no comorbidities upon commencing dialysis. To expand, those who were healthier when they commenced dialysis appeared more likely to have improved outcomes in the longer term, in terms of disability. However, this study did not have access to those individuals’ health data at the time they commenced dialysis. This study used an ‘accelerated longitudinal’ design with both prevalent dialysis participants who had been on dialysis for variable time periods as well as incident patients newly presenting with CKD5 at time of recruitment(18). In NZ, survival after commencing dialysis in the 65-74 year old age group is 87% at 12 months, 73% at 2 years and 37% at 5 years (181). For those aged 75-84, survival is 81% at 12 months, 64% at 2 years and 19% at 5 years (181). The result from the H&D Study demonstrates another important finding for informing patients and their families about the impact of dialysis. For those individuals, who are healthier, with “lesser/no disability” at the initiation of dialysis can expect advantageous outcomes

Additionally, a small sub-study was completed (section 5.4) that only analysed the dialysis population (HD and PD) as clinically it is important to make comparisons between the dialysis modalities. Basic descriptive analysis found that HD and PD participants had similar HRQoL and disability results (Table 5.5). This echoes the results of papers identified during the scoping review which found no substantive differences in outcomes between HD and PD patients (134, 135). Upon completing the multivariable analysis of the HD and PD patients (Table 5.6), similar results were seen as for the entire H&D Study sample (i.e. HD, PD and non-dialysing CKD5 participants) (Table 5.4). Specifically, for the dialysing participants, dialysis vintage of 2 or more years lowered the likelihood of ‘considerable disability’ at 12 months and moderate-severe problems with EQ-5D-3L self-care and ‘considerable disability’ at baseline predicted ‘considerable disability’ at 12 months in the dialysing patients (Table 5.6).

6.1.3 Objective Three

Describe key characteristics (including HRQoL and disability) at recruitment (baseline) and again 12 months later for older Māori patients with CKD5;

Due to the limited sample size, it was not possible to undertake multivariable analysis for the Māori cohort. However, the univariate analysis demonstrated that Māori who had moderate-severe problems with EQ-5D-3L mobility, EQ-5D-3L self-care, EQ-5D-3L usual activities and EQ-5D-3L pain/discomfort had a higher likelihood of experiencing ‘considerable disability’ compared to Māori with no problems at baseline. Also, a greater proportion of Māori with three or more comorbidities were ‘considerably disabled’ 12 months later compared to those with 0-2 comorbidities (Table 5.8). The same analysis was completed for the 37 Māori who were followed up at 12 months. Māori females had more disability at 12 months than Māori males. Once again, dialysing for 2 or more years at baseline was associated with less disability at 12 months, and participants with moderate-severe problems with EQ-5D-3L mobility and EQ-5D-3L usual activities at baseline were more likely to experience ‘considerable disability’ at 12 months. Those who experienced ‘considerable disability’ at baseline were also associated with ‘considerable disability’ at 12 months in the Māori cohort (Table 5.9). There has been very little previous research identifying HRQoL and disability in Māori. Walker et al (2016) and Shih et al (2010) have previously demonstrated that Māori may experience stress and fear when dialysing (161, 162). This stress and fear was found to be minimised when Māori experienced whakamana, which is a sense of self-esteem and self-determination. This often occurs when whānau, are involved and when relationships can be built with medical professionals (162). Therefore, the H&D Study shows that Māori with CKD5 experienced ‘considerable disability’. The H&D Study has added to the limited literature about Māori CKD5 experiences; it would be beneficial to have more research focused on Māori outcomes with larger sample sizes. Additionally, it would have been useful if this research investigated methods in which the Māori model of health, Te Whare Tapa Whā could have been incorporated into the care of Māori with CKD5.

Briefly the results have been assessed to compare the results of the Māori cohort to the entire H&D Study cohort. In the multivariable analysis of the 156 participants who were followed to 12 months, it was encouraging to see that ethnicity was not retained in the multivariable analyses (Table 5.4). This indicates that Māori had no observed difference in terms of experiencing ‘considerable disability’ at 12 months compared to Pacific and non-Māori/non-Pacific groups after adjusting for other confounders. This result has limited generalisability due to the small sample size of the Māori cohort included in the H&D Study. As discussed above, further research regarding Māori CKD5 experiences and outcomes is important and could aid in improving outcomes for Māori.

6.2 H&D Study Strengths and Limitations

6.2.1 Strengths

One key strength of the H&D Study is the use of two literature reviews; the rapid review enabled definitions of HRQoL and disability to be summarised and understood for the purposes of this thesis. This ensures the definition of HRQoL and disability were appropriate to use as measures in this study.

The scoping review provided an understanding of the broad range of literature related to ‘HRQoL and CKD’ and ‘disability and CKD’. It clearly demonstrates the gap in the literature that the H&D Study aimed to fulfil in that no previous studies identified what factors including HRQoL predicted disability in CKD5 participants.

The EQ-5D-3L was used as a valid measure of HRQoL (20). The five dimensions are mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Cognitive function was added to the H&D Studies HRQoL measure due to being identified by Wilson and Cleary (1995) and Kaplan and Ries (2007) as an important domain of HRQoL (22, 51). The EQ-5D-3L has previously been used and recognised in NZ (56) and has been tested for appropriateness in the Māori population (72). Additionally, the EQ-5D-3L allows for individuals to provide their perspective on their HRQoL. Therefore, it was a quick and easy measure to administer to CKD5 patients.

Disability in this thesis was conceptualised primarily around the ICF model and therefore the brief 12-item WHODAS 2.0 was an appropriate measure to use. It is also useful as it is a generic assessment of measuring disability across cultures and is used in a standardised way (96, 101) and again is gathered from the perspective of the individual. It includes the concept of cognition, mobility, self-care, getting along, life activities and participation (114) and has the potential to be easily administered to the CKD5 population.

A strength of this study was that prior to the DOS65+ Study a smaller pilot study was completed to test the questionnaire and the measures used in the DOS65+ Study (1). This ensured that the measures used in the DOS65+ Study and therefore the H&D Study was satisfactory to older New Zealanders including Māori.

Another strength of the H&D Study is that I had the privilege of having access to a large robust dataset that was gathered in the DOS65+ Study. This allowed for a wide range of explanatory variables to be considered and included being able to access (de-identified) DOS65+ Study clinical and mortality data about H&D participants.

Finally, we have confirmed statistically some findings that may have been known by clinicians intuitively; that disability in CKD5 patients predicts future disability and that self-care and mobility problems are also important in predicting disability. No previous studies have demonstrated these findings. We also focused on the relationships between HRQoL and disability for Māori. The sample size of Māori was small however these results add to the small body of research completed in the past and act to suggest that further research is necessary.

6.2.2 Limitations

Bias

Selection bias is likely to have been an issue in this study, as participants selected for the DOS65+ Study were excluded if they had an inter-current illness requiring hospitalisation within two weeks of the survey data and if this affected the patient’s ability to take part of judged by the opinion of the physician (1, 18).This suggests that the CKD5 population in the H&D Study is potentially healthier than the total population of older New Zealanders with CKD5. Therefore, the H&D cohort are likely to experience better HRQoL and less disability than the total population. This means the findings of the H&D Study are likely to be underestimating the true strength of the associations and relationships due to the participants included being heathier participants at baseline.

It is possible that misclassification bias may have occurred in terms of dialysis location; eight individuals who were ‘in training’ were included in the non-dialysis group. ‘In-training’ means that they had not been dialysing for more than 90 days. Some of these eight participants may have dialysed very little and some may be near the end of the 90 days. Therefore, some of these participants may have been better included within the dialysing group. However, given the small number of participants in the ‘in training group’, this is unlikely to have significant effects on the overall results of the study.

Loss to follow-up, including death, would contribute to bias in this study. Of the 223 individuals who provided baseline data, 67 were loss to follow up or had died. They were more likely to experience disability, three or more comorbidities, and impaired EQ-5D-3L mobility at baseline, compared to those (156 individuals) who were able to be followed up at 12 months (Table 5.10). These were the characteristics associated with disability at 12 months (Table 5.4). Therefore, it is possible that the results presented in this thesis are underestimating the effects of disability, comorbidity or moderate-severe problems with EQ-5D-3L mobility in predicting disability at 12 months. To further explain this, as demonstrated in Table 5.10, 79% of those not disabled at baseline were followed to 12 months, whereas 62% of those who were disabled were followed to 12 months. Table 5.4 demonstrates that those disabled at baseline were more likely to be disabled at 12 months. Therefore, this means that if we had retained more participants who were disabled at baseline in our analysis, we would have observed an even larger RR in table 5.4. This loss-to-follow-up has therefore likely resulted in the underestimation of the relationship between baseline disability and disability at 12 months. Within the Māori population, there was no observed difference between Māori followed to 12 months and those who were not, apart from more Māori females being followed for 12 months.

Confounding

The H&D Study had a small sample size. A total of 156 participants were followed up for 12 months, and due to the size of the sample, there were a limited number of explanatory/confounding variables that could be controlled for in the multivariable model. The scoping review provided many potential explanatory variables, and although a larger number of them were clinical issues so were not relevant to the aims and objectives of the H&D Study (160), a few additional variables may have been useful to include such as education, had the sample size been larger. Additionally, some categories were broad groups (e.g. age was categorised into those aged 65-75 years and those aged ≥75 years). It may be that such groupings are too large. However, due to the sample size and the scope of this thesis it was not possible to undertake the modelling with narrower age groups. Increasing the number of categories may have reduced the statistical power, as would have adding more explanatory variables. There may be a risk of other unknown residual confounders relevant to the objectives influencing the results of the H&D Study.

Additionally, although Māori were oversampled relative to the NZ CKD5 population in general, due to their only being 49 Māori participants at baseline in this study. Therefore, this small number of participants precluded any multivariable analysis to control for potential confounders that have the potential to modify the observed associations. Having identified this limitation, the H&D Study has highlighted associations for Māori, and signals potential ways forward for future research.

6.3 Implications

In the scoping review it was suggested that further effort is necessary to integrate HRQoL measures into standardised clinical care with the purpose of improving patient outcomes (122, 144). HRQoL is complex and spans many dimensions. The H&D Study investigated the HRQoL dimensions of the EQ-5D-3L which include mobility, self-care, usual activities, pain/discomfort, and anxiety/depression and also investigated cognitive functioning. Individuals may have problems with all dimensions or just some dimensions of HRQoL. By investigating which areas of HRQoL individuals have problems with, and then intervening in the particular area or areas of concern, (126)could be a useful way in improving HRQoL in CKD5 patients and preventing disability. Through managing clinical knowledge, effective coordination of patient care and through improving HRQoL in areas of a patients need, (125) this may result in improved outcomes in CKD5 patients.

The H&D Study findings, if supported by research elsewhere, indicates that assessment of mobility and self-care should be included in the clinical review and pre-dialysis education of individuals with CKD5 as they approach the need for renal replacement therapy. A potential method of assessing mobility and self-care (as well as other dimensions of HRQoL) could be to provide patients with the EQ-5D-3L questionnaire or other HRQoL measures in routine clinical assessments of older patients with CKD5 in NZ and potentially in other countries (20, 62). This would allow for patients to express their perspective on their HRQoL and could aid in informing health professionals about what areas a particular patient may require more assistance in.

Additionally, it is important to inform patients and their families about the impact of comorbidities and how this may affect their HRQoL on dialysis. Pre-existing disability will more likely progress with time on dialysis. Conversely, for those individuals, who are healthier, with little or no disabilities at the initiation of dialysis, should expect little significant deterioration in their clinical status. Additionally, in the scoping review it was identified that disability in CKD patients could be reduced through rehabilitation (152). Therefore, it is possible that rehabilitation strategies could be advised for those with earlier stages of CKD to reduce their disability before they reach CKD5. These rehabilitation strategies could be aimed at enabling patients to maintain their self-care and mobility as these were the main two HRQoL dimensions that appeared to predict disability in this study. Additionally, disability predicted disability, so investigating strategies to reduce disability would also be valuable. However further research would be needed to determine whether intervening to promote self-care, mobility and to reduce disability could be areas for interventions to reduce adverse disability outcomes. It would have also been beneficial to follow-up the participants for longer, such as for 24 and 36 months as the DOS65+ study intended. This would allow for determining if the results observed are long lasting. However, this was not possible within the scope of this thesis. The H&D Study suggests that further research investigating rehabilitation strategies and having increased follow-up is likely to be a valuable direction for future research.

The H&D Study also enabled me to build upon the small body of research regarding Māori experience with CKD5 and demonstrated that baseline disability and the EQ-5D-3L dimensions of mobility, self-care, usual activities and pain/discomfort predicted disability in the Māori population. However, due to the sample size, it was not possible to determine how confounders may have influenced these associations. It was encouraging to see that in our multivariable model it appeared that Māori did not experience greater disability than non-Māori/non-Pacific and Pacific within those aged ≥65 years.

6.4 Future Research

The H&D Study has provided novel research in investigating predictors of disability in the CKD5 population and in particular investigated if HRQoL dimensions could be predictors of disability. The scoping review identified many various rehabilitation strategies including regular exercise, such as walking, education, environmental modifications (151), occupational therapy, gait training and joint mobilisation (149) to prevent disability in those with CKD. However, it is difficult to determine which rehabilitation strategies may actually work in NZ. It has been suggested that whānau support (162) could potentially be important, particularly in the Māori population. From the results of this research, it is possible that rehabilitation could be targeted at mobility, self-care and baseline disability. Further research could investigate if this would be effective. It would be beneficial if future longitudinal cohort studies of a larger sample size that evaluate the effectiveness of rehabilitation targeting mobility, self-care and disability. Additionally, it would be advantageous to see cohort studies that investigated these predictors of disability to help confirm the findings from the H&D Study.

The research questions that remain unanswered particularly when considering the Māori population are which factors predict disability in the Māori CKD5 cohort and upon identifying predictors, which interventions would be effective in improving health outcomes for this group. To answer these unanswered questions, it would be useful to further investigate Māori experiences both in a quantitative and qualitative fashion with HRQoL and disability in CKD5 patients. This thesis identified an association that HRQoL and baseline disability were associated with subsequent disability for Māori. Further research could be based upon these findings to evaluate if this association is replicable. A larger sample of Māori CKD5 patients would be useful to explore this. Additionally, the Māori health model Te Whare Tapa Whā could be valuable when designing future research for Māori with CKD5. Te Whare Tapa Whā represents a holistic approach to health and well-being and considers Taha Wairua (spiritual), Taha Hinengaro (mental), Taha Tinana (physical) and Taha Whānau (family). This model of Māori health could be used to aid in informing the selection of potential predictors of outcomes that are specifically important for the Māori population for example. Once specific predictors for Māori have been replicated/confirmed and in conjunction with qualitative research then interventions can start to be designed and implemented to improve outcomes specifically for Māori.

6.5 Final Conclusions

In summary the main aim of the H&D Study was to investigate the association between HRQoL and disability and to determine if HRQoL and/or other factors predict disability in people with CKD5 aged ≥65 years in NZ at 12 months.

This study clearly demonstrates that the EQ-5D-3L mobility, EQ-5D-3L self-care and ‘considerable disability’ at baseline were associated with higher rates of ‘considerable disability’ at 12 months. Additionally, baseline disability was the strongest predictor of disability at 12 months. Intuitively this may seem obvious to clinicians, however this is the first known time that it has been confirmed prospectively in a clinical study. The findings of the H&D Study do aid in developing knowledge that may inform nephrology professionals and patients with respect to the impact RRT may have on their life.

Additionally, this study focused on the EQ-5D-3L and the WHODAS 2.0 measures which assess HRQoL and disability respectively from the perspective of the patient rather than the health professionals. Although nephrologists and the nephrology team are experts and very attuned to the needs of their patients, the literature reviews enabled for an understanding that an individual’s rating of their HRQoL and disability is very important (49, 77). Therefore using the EQ-5D-3L and WHODAS 2.0 which are both robust, easy to understand and easy to administer measures (62, 182) allows for an assessment of patients perspectives which may improve the clinical experience and recommendations for the patients.

Also, of interest is that individual’s aged ≥65 years with increased dialysis vintage were associated with decreased disability risk. This suggests that the individuals in this older age group, who are healthier, with ‘lesser/no disabilities’ at the initiation of dialysis, should not expect any significant deterioration in their clinical status.

Within the Māori analyses, baseline problems with EQ-5D-3L mobility, EQ-5D-3L self-care, EQ-5D-3L usual activities, EQ-5D-3L pain/discomfort and ‘considerable disability’ were associated with ‘considerable disability’ at 12 months. Of importance, it was very positive to see that in a multivariable model Māori with CKD5 did not experience greater disability than non-Māori/non-Pacific and Pacific.

The H&D Study has significantly demonstrated in a group of older people with CKD5 both on dialysis or pre-dialysis, that self-reported EQ-5D-3L measures of mobility, self-care and ‘considerable disability’ impact upon subsequent disabilities at 12 months. Patient and family participation in assessing these HRQoL components and baseline disability would help with CKD5 education and planning for renal replacement therapy.

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Appendix I: Tables to Support the Rapid Review

Table I (1): Overview of the Rapid Review of literature discussing HRQoL

No.	Bibliography Details	Aim	HRQoL areas discussed	Overall HRQoL Conclusions	HRQoL Measurement
1.	Title: Research Methods in Health. Investigating Health and Health Services. Chpt 2 pp 36-37 Author: Bowling A Buckingham: Open University Press; 1997.	This book aimed to establish social research on health and sociological and psychological concepts and approaches.	The importance of measuring HRQoL when assessing health outcomes and dimensions that shape HRQoL.	Emotional, psychological, physical and social well-being are all important dimensions in determining HRQoL. A large range of measurements have been developed to assess the above dimensions.	Not applicable (NA)
2.	Title: EuroQol: the current state of play. Author: Brooks R Health Policy. 1996;37.	This book aims to describe the results of EuroQol's 1987 discussion about creating a non-disease specific instrument for measuring HRQoL.	This source describes EuroQoL in detail, the strengths of the measurement and the reasons it was developed.	The EuroQoL group designed the EQ-5D as an instrument that could be self-completed by the participants. Five dimensions that are important in determining HRQoL include mobility, self-care, usual activities, pain/discomfort and anxiety and depression. This measurement is short and user friendly.	EQ-5D
3.	Title: EQ-5D concepts and methods: a developmental history. Authors: Kind P, Brooks R, Rabin R Netherlands 2005.	The aim of this book is to describe the development of the EuroQoL instrument, as well as assessing this instrument and the effective methods of using this instrument.	Very comprehensive coverage of the uses and development of the EQ-5D.	The EuroQoL instrument has two distinct tasks in terms of measuring HRQoL. Firstly it allows for information to be gained on how an individual rates their current health state and secondly it applies a tariff to the social value of health states which can be used alongside cost data in the planning context when determining priorities for health care.	EQ-5D

No.	Bibliography Details	Aim	HRQoL areas discussed	Overall HRQoL Conclusions	HRQoL Measurement
4.	Title: Definition of Health-Related Quality of Life Centers for Disease Control and Prevention 2017.	This source defines HRQoL.	NA	"Health-related quality of life (HRQOL) is an individual's or group's perceived physical and mental health over time."	NA
5.	Title: Selecting a measure of health related quality of life. Authors: Dempster M, Donnelly M Soc work in health care.2000;32(1):45-56.	This paper aimed to assist social workers to make informed choices about the appropriate measure of HRQoL.	Quality of life was defined. The purpose of measuring HRQoL as well as generic and condition-specific measures was discussed. This source also discusses issues to evaluate when choosing a HRQoL measure which includes assessing validity, reliability and responsiveness.	Quality of life (QoL) is often perceived as the degree to which human needs are met. This includes physical, social, economic, and psychological needs. HRQoL refers to these needs in relation to health. Most attempts of defining QoL and HRQoL are based on WHO's definition of health. What matters is what the patient feels rather than what the doctors think the patient ought to feel.	Medical Outcomes Study (SF-36) and Nottingham Health Profile Part 1 (NHP)
6.	Title: Health-related quality of life: A primer for gastroenterologists. Authors: Eisen G, Richard G Ame J Gastroenterol. 1999;94(8):2017-21.	This article provides a definition for HRQoL and the techniques for its measurement and the tools available for this task.	Described HRQoL and reasons to measure HRQoL. This source describes the strengths of psychometric instruments for measuring HRQoL and the information that is important for this including validity, reliability, responsiveness, and coverage. Additionally, generic and specific HRQoL measures for different diseases where discussed.	QoL is not a new concept and it has always been attempted to be incorporated by health care professionals in order to achieve the patient's wellbeing. HRQoL includes physical function, somatic sensation, psychological state and social interactions that affect one's health status. Measures of HRQoL are subjective.	SF-36 and Sickness Impact Profile (SIP)
7.	Title: Quality of life as an outcome measure in nursing research: 'may you have a long and healthy life'.	The aim is to provide an understanding of the difference between the definition of QoL and	It discusses how QoL is a term that has emerged from WW2 when it became apparent that longevity of	QoL is "a person's perception of their health status and aspects of their life that are considered important in relation to their expectations of normal living".	SF-36, SIP, NHP

No.	Bibliography Details	Aim	HRQoL areas discussed	Overall HRQoL Conclusions	HRQoL Measurement
	Authors: Harrison M, Juniper E, Mitchell-DiCenso A. Can J Nurs Res. 1996;28(3):49-68.	what contributes to QoL, which is aimed to assist with nursing evaluations on patient's outcomes.	life was important along with QoL. Nurse's roles in ensuring QoL are discussed. This source also discusses various HRQoL instruments and the quality of these instruments and the fact that there are both generic and specific measures.	This source notes that QoL has already became important in planning, implementing and evaluating both health care and social policies.	
8.	Title: Health-Related Quality of Life in Old Age: How to Define it, How to Study? Preparation for Aging. Authors: Jylhä M. Springer; 1995:139-44.	The aim was to discuss the background of HRQoL in gerontological research, to analysis theoretical and methodological principles in HRQoL and analysis the struggles of looking at empirical research.	This source describes past QoL research generally and specifically in the older population, it describes different concepts and measures as well as outlining the need for careful analysis of QoL.	This paper questions the validity of talking about HRQoL if we cannot measure it. HRQoL was able to emerge as medicalisation was no longer enough to paint a picture of an individual's health. A great deal of emphasise of having a 'good functioning' level predicts QoL. This paper concludes that many authors emphasis that QoL is multidimensional and of a subjective phenomenon.	
9.	Title: Quality of life: concept and definition. Authors: Kaplan R, Ries ACopd. 2007;4(3):263-71.	Four Objectives: 1) Definition of HRQoL 2) Measurement of HRQoL 3)Relationship between exercise and HRQoL in general 4) Relationship between exercise and HRQoL in COPD patients.	This paper defines HRQoL, how QoL is measured and the differences between these measures. Additionally, estimation of HRQoL and physical activity in the population and in COPD patients is discussed.	Over the past years new methods to measure wellness have been developed and these are often quantitative. Since these measures are generally used to evaluate health status in general the term HRQoL is used. QoL is a term that continues to grow in the medical literature.	Many including EQ-5D, NHP, SIP and SF-36
10.	Title: Health, Health-Related Quality of Life, and Quality of Life: What is the Difference?	This paper aims to determine the history and	The history of the various terms is discussed as are the definitions and	The terms QoL and health status preceded the use of HRQoL.	EQ-5D and SF-36

No.	Bibliography Details	Aim	HRQoL areas discussed	Overall HRQoL Conclusions	HRQoL Measurement
	Authors: Karimi M, Brazier J PharmacoEconomics. 2016;34(7):645-9.	definitions of the terms HRQoL, QoL and health.	differences between the three terms and measures.	WHO definition of health was important for the development of the EQ-5D. There are at least four definitions of HRQoL which include: 1) How well a person functions in their life and his or her perceived wellbeing in the physical mental and social dimensions of health. 2) QoL is an all-inclusive concept incorporating all factors that impact upon an individual's life whereas HRQoL only include factors that are part of health. 3) HRQoL are aspects that are self-perceived and are related to or affected by the presence of disease or treatment. 4) HRQoL refers to the values assigned to different health states.	
11.	Title: Quality of life: a concept analysis. Author: Meeberg G J Adv Nurs1993;18:32-8.	To stimulate further thought on what was meant by QoL in the health care context.	How QoL is referred to in the literature is discussed as is dictionary definitions of this terms and cases are discussed.	QoL cannot be used as an outcome unless it is clearly defined. QoL was first used after WW2. QoL has subjective components which include a personal satisfaction, however there are objective components that are necessary in shaping ones QoL which include outside forces such as socioeconomic status.	
12.	Title: Definitions of Quality of Life: What Has Happened and How to Move On. Author: Post M TopSpinal Cord Inj Rehabil2012;20(3):167-80.	To show how the concepts of HRQoL and QoL have evolved over time and various ways these terms have been defined and measured and to provide recommendations on how to be consistent when completing QoL research.	This paper described QoL in medicine and discusses the many different variations and models of QoL. Additionally, QoL in spinal cord injury research is discussed.	QoL is a term that was introduced in medical literature in the 1960s and is a term that has become increasingly popular in recent decades. QoL is a term that evolved from the WHO definition of health in 1947. In QoL more than just a medical issue needed to be considered but the patients subjective experiences also needed to be evaluated.	NHP, SIP, SF-36

No.	Bibliography Details	Aim	HRQoL areas discussed	Overall HRQoL Conclusions	HRQoL Measurement
				Researchers need to be clear about the concept and operationalisation of QoL in their studies.	
13.	Title: Environmental and health-related quality of life: conceptual and methodological similarities. Author: Rogerson R Soc Sci Med 1995;41(10):1373-82.	This source aimed to develop a conceptual framework of QoL in both environmental and health studies.	The background of QoL is discussed in relation to health and the environment. Environmental QoL is discussed as is what HRQoL is.	Conceptualising QoL is difficult. QoL should be viewed holistically, which may involve components aggregated together to form a whole. When defining QoL, two major components are at play which include those which relate to the internal psychological-physiological mechanism which produces a sense of satisfaction and gratification at the individual and or community level and communities or social groups which are external but result in internal satisfaction. Environmental QoL considers the priorities and preferences of population groups.	
14.	Title: Statistical issues encountered in the comparison of health-related quality of life in diseased patients to published general population norms: problems and solutions. Authors: Rose M, Koshman M, Spreng S, Sheldon R J Cli. Epidemiol.. 1999;52(5):405-12.	To investigate statistical issues when comparing HRQoL measured using SF-36 in a diseased group to the population norms and to facilitate comparisons with the general population.	This study primarily discusses the strengths and limitations of the SF-36 health survey.	HRQoL is important in clinical epidemiology, clinical trials and general health care research. SF-36 and EuroQoL have now widely been accepted to measure HRQoL. Overall SF-36 can be used to compare HRQoL of the “diseased” population to the “normal” population but care must be taken to not misuse statistics and make erroneous assumptions about the data.	SF-36
15.	Title: A concept analysis of health-related quality of life in young people with chronic illness. Authors: Taylor R, Gibson F, Franck L	This paper aimed to critique existing analysis of QoL and discuss why a definition is specifically needed for young people with chronic illness.	This paper discussed what QoL was as well as critiques to the concepts of QoL. Additionally, HRQoL in young people with chronic illnesses was discussed,	QoL is a term that became very popular after WW2. A persons QoL can be influenced by many factors and often the terms QoL and HRQoL are used interchangeable. Five perspectives of QoL were proposed in this paper:	

No.	Bibliography Details	Aim	HRQoL areas discussed	Overall HRQoL Conclusions	HRQoL Measurement
	J Clin. Nurs. 2008;17(14):1823-33.		although this section was not relevant to this thesis.	1) The philosophical perspective related to the nature of human existence; this provides a definition of a good life. 2) The ethical perspective focuses on the sanctity of life. 3) The economic perspective equates QoL to the assessment of economic growth. 4) The sociological perspective emphasises the social aspects of QoL and the relationship between individuals and their circumstances. 5) The psychological perspective relates QoL to an individual's appraisal of life and fulfilling life goals.	
16.	Title: On assessing responsiveness of health-related quality of life instruments: guidelines for instrument evaluation. Authors: Terwee C, Dekker F, Wiersinga W, Prummel M, Bossuyt P Qual Life Res. 2003;12(4):349-62.	This study aimed to evaluate responsiveness and to evaluate the issues with responsiveness in relation to the HRQoL instruments.	HRQoL and its importance of an outcome measurement. A literature review about responsiveness was completed and a methodology of assessing responsiveness was developed.	HRQoL is now considered to be one of the most important outcomes in clinical studies. Four important steps for developing a useful HRQoL include 1) defining the measurement goals of the instrument 2) testing longitudinal validity 3) testing longitudinal reproducibility 4) Assessing interpretability of score changes on the instrument.	
17.	Title: Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. Authors: Wilson I, Cleary P Jama. 1995;273(1):59-65.	A conceptual model and an understanding of patient's health outcomes is discussed in this paper.	This discusses how it is necessary to develop a conceptual model of HRQoL so that health professionals can intervene to improve HRQoL, it describes a conceptual model and describes the various factors contributing to this model.	HRQoL is increasingly used as an outcome measure for clinical trials. Increased usage of HRQoL is due to increased valid and reliable measures. How can physicians and health professionals intervene to improve HRQoL. Biomedical models focus on the biological agents contributing to QoL. QoL is distinct from health but also related to it.	

No.	Bibliography Details	Aim	HRQoL areas discussed	Overall HRQoL Conclusions	HRQoL Measurement
				HRQoL includes dimensions of physical, social, role functioning and mental and general health perceptions. Another important concepts include vitality, pain and cognitive functioning.	

Table II (2): Overview of the Rapid Review of literature discussing HRQoL focused on Māori

No.	Bibliography Details	Aim	HRQoL areas discussed	Overall HRQoL Conclusions	HRQoL Measurement Discussed
1.	Title: Rehabilitation and indigenous peoples: the Māori experience. Author: Harwood, M. Disab Rehabil 2010;32(12):972-977.	The main aim of this article was to present a perspective for Māori to improve rehabilitation services to improve their health and wellbeing.	Discusses how EQ-5D may not be applicable to indigenous populations.	It is noted that tools to measure outcomes are necessary to not only plan service but also to gauge the effectiveness of treatment and care. There is limited evidence or literature about measures of indigenous health outcomes. Further work is required to overcome tension in using outcome measures with indigenous peoples that have been developed and validated in European nations like EQ-5D-3L or are clinical in nature. These measures may not allow for meaningful information about Māori HRQoL to be collected.	EQ-5D
2.	Title: The validity and reliability of EQ-5D health state valuations in a survey of Māori. Authors: Perkins M, Devlin N, Hansen P. Qual Life Res. 2004;13(1):271-4.	The aim of this source was to determine if EQ-5D was adequate in capturing the health state of the Māori population.	This discusses the EQ-5D, the validity of the EQ-5D in different populations and discusses the strengths and weakness of using the EQ-5D in the Māori population by portraying the results of a small study.	EQ-5D is an internationally recognised health state measurement, a key issue is to determine if this is a valid instrument for other QoL instruments. Three quarters of the 66 participants considered the EQ-5D model adequate. However, there may be underlying differences between the health state preferences of Māori and others.	EQ-5D

Table I (3): Overview of the Rapid Review of literature discussing disability

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
1.	Title: Definitions, concepts, and measures of disability. Author: Altman B Annals of Epid 2014;24(1):2-7.	The aim of this paper is to analyse concepts and definitions surrounding disability.	This paper discusses the variety of disability definitions and ways that these definitions can be translated into measurement.	It is generally agreed that no matter an individual's level of physical, mental or emotional functioning disablement is the result of the persons interaction with his or her environment. Disability is contributed to impairment it is also a social construct. It is necessary to examine the complete process associated with the development of disability. The term disability has become a shorthand expression to represent a variety of different aspects of the disability process, including the disease progression and the limitations caused by the environment. There are many different definitions of disability and it is important to translate these into the correct measurement.	
2.	Title: Relevance of disability models from the perspective of a developing country: An analysis. Author: Amponsah-Bediako K. Dev Country Stud.2013;3:121-32.	This article examines various models of disability and explains the diverse perspective surrounding how disability is understood. Additionally, it focuses on disability in developing countries, specifically Ghana.	Initially a literature review is described, which entails the models of disabilities and the practical implications of these models.	The models of disability are numerous and include: the medical, charity, social, expert, right-based, religious/moral, economic, customer, and rehabilitation models. The models are based on two fundamental philosophies which the first sees disabled individuals dependent on society and the second views disabled people as customers to what society has to offer.	
3.	Title: Qualitative profiles of disability.	This study identified profiles of functional disability paralleled by	Explain what this study has defined disability as.	Disability can be defined as difficulty or inability to perform basic activities essential for daily and independent living. Functional disability is specifically about physical, emotional and cognitive aspects	World Health Organization Disability

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
	Authors: Annicchiarico R, Gilbert K, Cortés U, Campana F, Caltagirone C. JRehabil Res Dev 2004;41(6):835-45.	increasing levels of disability. This study developed four definitions for different classes of disability.	Described the sample population measured and the analysis.	which interact to cause disability. Personal and environmental factors are also discussed. The scientific community lacks consensus on the best way to measure disability.	Assessment Schedule 2.0
4.	Title: Exploring Disability; second edition. Author: Barnes C Cambridge CB2 1UR, UK Polity Press; 2010; 341 pages.	The aim of this book was to provide an up to date, wide-ranging and critical review of key issues and debates relevant to sociology studies of disability.	This book aims to introduce disability, look at different models, and different theories of disability as well as looking at barriers. Additionally, routes to independent living and the politics of disability are discussed in this book.	The individual medical model defines impairment as lacking part of a limb or having a defective bodily mechanism, disablement as the loss or reduction in functional ability and handicap as the disadvantage or restriction of activity caused by disability. Impairment is lacking part a limb or having a defective mechanism of the body and disability is the disadvantage or restriction of activity caused by a contemporary social organisation which takes little account of people with impairments.	
5.	Title: Exploring Disability. Barnes C & Mercer G UK Polity Press; 2010; 341 pages.	The main aim of this book is to describe disability, to describe the development of disability models.	Chapter 2 discusses various models of disability.	In the medical model of disability this can be viewed as impairment which means having a defective part of the body, disablement which is the loss or reduction of functional ability and handicap which is the disadvantage or restriction of activity caused by disability. Alternatively, the social model of disability sees impairment as having a defection affecting function and disability is the disadvantage or restriction of activities in society due to society excluding those who are different.	
6.	Title: Beyond (Models of) Disability? Author: Beaudry J J Med Philos 2016;41(2):210-28.	The aim of this paper was to discuss disability, the social and medical models and critique these models.	Begin by discussing the various models of disability. Following this critique of the models are discussed.	The concept of disability is better left open-ended and broad in scope to encompass various ethical issues. The social model of disability took off in the 70s in response to the medical model. The social model of disability portrays disability as a social phenomenon caused by social oppression and prejudices rather than by individuals with impairments.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
				A key criticism of the social model of disability is that it separates impairment from the individual and some people experience disability as an individual rather than it being a social problem.	
7.	Title: Implications for public health research of models and theories of disability: a scoping study and evidence synthesis. Berghs M, Atkin K, Graham H, Hatton C, Thomas C 2016; 195 pages.	The aim of this source was to examine the literature of theories and models of disability.	This study completed a scoping review of disability.	Models of disability include the medical model which views impairment as the problem of the individual. Following this, the human rights model assesses fundamental human rights of individuals with disabilities. The social model which differs impairment (physical/mental/sensory) and disability (oppression causes socially).	
8.	Title: Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. Authors: Bickenbach J, Chatterji S, Badley E, Ustun T Soc Sci Med. 1999;48(9):1173-87.	This study aimed to review and critique models of disability and trace the development of disability with the instrument of International Classification of Impairments, Disabilities and Handicaps (ICIDH).	Disablement models and strategies for advocacy has been discussed. Minority groups are discussed as is the ICIDH.	This source discusses the social and medical models of disability. In the 1980s the ICIDH began which acted as an international classification of disablement. This models disablement as a sequence of levels. The pathological issue is known as impairment and if this limits an individual ability to perform activities to what is considered as “normal” this is disability. Handicap is defined as a disadvantage due to impairment or disability that prevents fulfilment of the role that is considered normal for that individual.	
9.	Title: Reflection on the definition of impairment and disability as defined by the World Health Organization. Authors: Brandsma J, Lakerveld-Heyl K, Van Ravensberg C, Heerkens Y DisabilRehabil. 1995;17(3-4):119-27.	ICIDH is gaining worldwide acceptance inside and outside of medicine. This article analyses the definitions of disability and impairment.	Describes ICIDH development. Following, this the WHO definition of impairment, disability is explained in various context such as health experience, abnormality, structure and function. This article concludes that there needs to be re-wording of the WHO definitions and it	Since the introduction of the ICIDH the concepts ‘impairment’, ‘disability’ and ‘handicap’ have become increasingly accepted to monitor health status. ICIDH has been criticised for its overlap with the International Classification of Diseases (ICD). Consensus on definitions is mandatory for communication, research and educational process. Impairment “in the context of health, an impairment can be defined as a loss or deviation of an anatomical	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
			is necessary to harmonize various characteristics of a definition.	structure or a physiological or psychological function taking into consideration the age of the person.” Disability “in the context of health, a disability can be defined as a loss or deviation, in both qualitative and quantitative way, of expected or desired activity performance or behaviour of a person, taking into consideration age, gender, physical, and social, and cultural environment.”	
10.	Title: Disability/Postmodernity Authors: Mairian C, Shakespeare T New York, NY 10038: Mairian Corker, Tom Shakespeare and the contributors 2002; 2002.	This book aims to explore the theoretical perspectives of disability. The second section discusses culture and lastly it concludes with disabled children’s perspectives.	This book describes the social model, the model of impairment and various cultures of disability.	It is believed that disability studies can only benefit from the critical, reflexive exchange of ideas between those who bring different theoretical perspectives and different biographies.	
11.	Title: The utility of the International Classification of Functioning, Disability and Health checklist for evaluating disability in a community-dwelling geriatric population sample. Authors: Dernek B, Esmaeilzadeh S, Oral A Int JRehab Res. 2015;38(2):144-55.	The main aim was to investigate disability in community dwelling individuals aged 65 years and over through using the ICF and WHODAS II schedule to compare how these measures and see if ICF checklist can be used to describe disability.	Disability as measured by the ICF and WHODAS II was compared as measures in older populations.	They concluded that the “ICF checklist has the potential to be used in a field setting, provided that some modifications are made.”	WHODAS II and ICF checklist.
12.	Title: Prospective outcomes of injury study. Authors: Derrett S, Langley J, Hokowhitu B, Ameratunga S, Hansen P, Davie G, et al.	The aim was to quantify factors leading to disability outcomes after an injury in New Zealand.	This paper discusses the concept of disability. It discusses disability in NZ, the financial costs of injury, injury-related disability research and outcomes.	Definitions and conceptions of disability have continuously been contested. Originally disability was seen to be about individuals, however from the 1960s disability began to be viewed as an issue of the environment and social perceptions of it. Individuals with disabilities helped develop the ICF model. However, the ICF does not consider the subjective experience of quality of life.	ICF and WHODAS II

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
	Inj Prev(1353-8047)2009;15(5):351.				
13.	Title: World Health Organization disability assessment schedule 2.0: An international systematic review. Authors: Federici S, Bracalenti M, Meloni F, Luciano J. DisRehab 2017;39(23):2347-80.	This systematic review aimed to examine research and the practical applications of WHODAS 2.0.	Provided a background about what disability is, and the methods and results of the systematic review.	WHODAS 2.0 is useful to use alongside other measures and has been translated into 47 languages and used in 27 different areas of research. WHODAS 2.0 was developed from pooling together ICF items together to gain the areas of cognition, mobility, self-care, getting along, life activities and participation. WHODAS 2.0 has proven to be useful globally. No minimal clinically important difference (MCID) has been created for WHODAS 2.0 as of yet.	WHODAS2.0
14.	Title: World Health Organization Disability Assessment Schedule II: contribution to the Italian validation. Authors: Federici S, Meloni F, Mancini A, Lauriola M, Olivetti Belardinelli M Disabil Rehabil. 2009;31(7):553-64.	The aim of this study was to provide an assessment of the usefulness of WHODAS 2.0 in Italy.	This source discusses the different models of disease and the developments of the ICF and ICIDH. This study has participants and looks at the reliability of the measurement.	WHODAS 2.0 is useful for measuring disability in both normal and disabled people. The strengths of WHODAS 2.0 is that it rates a person’s disability from the patient’s perspective rather than from a clinician’s point of view. The study acts to confirm that the six main dimensions measured are the most valid measures of disability.	WHODAS 2.0
15.	Title: Disability identity development model: Voices from the ADA-generation. Authors: Forber-Pratt A, Zape M.	A qualitative study was completed to explore how disability identity was developed in college students with disability.	This article discusses important landmarks in developing disability decisions. This study also describes the results of interviewing 17 college students qualitatively to	Understanding what disability means is important and could enable families of those who are disabled be better equipped. It takes a while to process and develop disability identity.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
	Disab Health J 2017;10(2):350-5.		describe how they view their disability.		
16.	Title: Description of the person-environment interaction: methodological issues and empirical results of an Italian large-scale disability assessment study using an ICF-based protocol. Authors: Francescutti C, Gongolo F, Simoncello A, Frattura L BMC public health. 2011;11 Suppl 4:S11.	To define disability and to develop a way to use a theoretical model of disability empirical.	This study aimed to define disability, and then break down this definition of disability, before developing an ICF protocol. This study concluded that it is possible to plan empirical studies in which theoretical advances and operative goals on disability in a person-environment framework.	Disability can be defined as the result of an interaction between a person and the environment directly. The ICF model shows the links between the relevant "health components" and allows information related to health conditions to be collected which included participation, environment and personal factors. The UN definition stated that "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." Disability should always be considered as a dynamic process.	
17.	Title: A new social perspective on disability and its implications for rehabilitation. Author: Gill C Occup ther in health care. 1987;4(1):49-55.	The aim of this study was to contrast the traditional medical model with the new interactional or socio-political model of disability. Disability is also experienced from the view of those in the disability minority group.	This paper discusses how those with disability have become increasingly able to describe or define disability for themselves.	Traditionally disability has been conceptualised by the medical model. The socio-political model defined disability as influenced by the social environment. Disabled people regardless of their medical diagnosis have acknowledged that society devalues and fears disability.	
18.	Title: DSM-5 and the assessment of functioning: the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0). Author: Gold L	The article aimed to review the implications for forensic psychiatric evaluations and assessed the DSM-5.	Describes the DSM-5 and gives and introduction into WHODAS 2.0	WHODAS 2.0 is the best measure of disability for routine clinical use. WHO makes a distinction between medical and psychiatric disorders and the term disability encompasses impairments, activity limitations and participation restrictions.	WHODAS 2.0

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
	J Am AcadPsychiatry and the Law Online. 2014;42(2):173-81.			WHODAS 2.0 is designed to be applicable to all health conditions. It can also be self-administered. WHODAS 2.0 is reliable, responsive to change and applicable globally.	
19.	Title: Perspectives on disability & rehabilitation: contesting assumptions' challenging practice. Authors: Hammell K. Edinburgh: Churchill Livingstone/Elsevier; 2006.	This book aims to expose ideologies and power that have been essential to rehabilitation professionals.	This book discusses the assumptions of rehabilitation, the theoretical model of disability, it describes impairment.	There are many models of disability including the moral/religious model of disability, followed by the individual/medical model, the social/political model of disability and the rehabilitation model.	
20.	Title: Is there a coherent social conception of disability? Author: Harris J J Med Ethics. 2000;26(2):95-100.	The aim is to examine and reject different conceptions of disability based on social factors, but it also analyses physical and mental conditions.	The social model of disability is discussed, additionally disability and discrimination are discussed as is reproductive freedom and congenital deafness.	A major weakness of seeing the social model of disability as completely floored is that if all the issues of society causing disability are removed are there in fact no disabling features remaining. Disability is caused by prior choices of the agent or of the agent’s parents. Disabling elements are harmful to the person and consequently that person has strong rational preference not to be in such condition. Most disabilities fall far short of something that awful that life is not worth living.	
21.	Title: Counting disability: global and national estimation. Authors: Kostanjsek N, Good A, Madden R, Üstün T, Chatterji S, Mathers C, et al DisabRehabil. 2013;35(13):1065-9.	The purpose of this paper was to determine the number of individuals with disabilities, how disabilities are defined, and how it can be measured.	Disability is difficult to count and measure as it is so broad. This source discusses methodology of the world report for multinational measurements of disability prevalence.	To improve the quality of disability information it is recommended that concepts of disability are based on the ICF. Measuring and counting those with disability is difficult as it is multidimensional and a continuum. ICF definitions of disability are used to estimate the global prevalence of disability.	ICF

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
				About 1 billion people have disabilities with extreme difficulties being experience by 110-190 million. Environmental factors play a considerable role in causing disability. The ICF acknowledges that every human can experience some level of disability.	
22.	Title: The definition of disability: what is in a name? Author: Leonardi M, Bickenbach J, Ustun T, Kostanjsek N, Chatterji S. Lancet. 2006;368 North American Edition(9543);1219-2.	To discuss the need for a global, all-inclusive definition for disability.	Acknowledgement of the need for a common agreement of disability.	When a common definition of disability is reached it should be applicable to all people and should not stipulate what causes this disability. Only when disability is defined can issues of health and social policy be tackled. The ICF provides a consistent conceptualisation of disability. The current UN Convention does not defined disability but rather people with disabilities. When defining disability, we should be careful to distinguish objective descriptions of disability from an individual's satisfaction with that experience. ICF conceptualisation of disability is useful for bringing everyone closer to a goal of defining disability equally.	
23.	Title: Comparing the Disability Creation Process and International Classification of Functioning, Disability and Health models. Authors: Levasseur M, Desrosiers J, St-Cyr Tribble D.	The aim of this paper was to compare the disability creation process (DCP) with the International Classification of Functioning, Disability and Health (ICF).	This source described the DCP model and the ICF model. Following this it goes on to describe the similarities between the DCP and the ICF models.	The DCP model is an explanatory model of the causes and consequences of disease and is based on the interaction between individuals and their environment. The ICF model dates to the 1980s when the ICIDH was published. The terms impairment, disabilities and handicap were introduced to combat the medical model. The ICF has nine dimensions for participation.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
	Can J Occup Ther. 2007;74(SPEC. ISS. OCT.):233-42.			Both the ICF and DCP are universal and they attempt to describe the complex phenomenon of human functioning. The DCP is based on the anthropological model of human development and disability which maintains that disability is dynamic and interactive between personal and environmental factors. Whereas the ICF is an integration of the medical and social models.	
24.	Title: Understanding how disability is defined and conceptualized in the literature. Authors: Lutz B, Bowers B RNJ 2003;28(3):74-8.	To know how to define disability it is important that it is understood how people with disability perceive their lives.	The rehabilitation and the social model of disabilities are explored. This source then goes on to define disability.	The rehabilitation model takes the approach that human beings need to be able to function at a level that is considered optimal. The social perspective began to arise in the 1960s, the goal was to shift disability from the burden on the individual to a burden on society.	
25.	Title: Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. Authors: Madans J, Loeb M, Altman B BMC public health. 2011;11 Suppl 4:S4.	The paper describes the work completed by the Washington Group who are investigating disability.	The Washington group is described as is, their view on disability statistics. Ways of measuring disability were discussed. The Washington Short Set was also discussed, and it's testing and uses were analysed.	There is a need for a comparable population-based measure of disability to be used for individual countries for international comparisons. The main purpose of the Washington Group is to promote and co-ordinate international co-operation in the area of health statistics. Disability is complex to measure as it is complex process and not a static state. They conclude that the short set of questions which has been tested in many countries provides a comparable mechanism for identifying those with disability.	The Washington Group Short Set-Consistent with ICF.
26.	Title: From disablement to enablement: conceptual models of disability in the 20th century. Authors: Masala C, Petretto D	The purpose of this article is to describe conceptualisations of disability.	This was a review of the literature and describes the various ideas of disability that have contributed to different developments of disability.	The current ICF model of WHO has been recognised and translated in 191 countries. In the 1960s there became a major reflection on the relationships between pathologies and functional consequences.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
	Disab Rehab. 2008;30(17):1233-44.			The ICIDH aimed to analyse, describe and classify the consequences of diseases, and distinguished between impairments, disabilities and handicaps. This was the first internationally shared issue. The environment-disabled model is when the environment is the largest contributor to disability. From the 1990s the idea of disablement became enablement. The National Centre for Medical Rehabilitation Research (NCMRR) developed a model that focused on individuals and the way they adapt in their own families. The ICF is used world-wide, and further analysis is needed to clarify the concept of functioning and its link with the environment and personal characteristics to identify the individual, the environment and the individual-environment interaction.	
27.	Title: Disability, nursing research and the importance of reflexivity. Author: Northway R J Adv Nurs. 2000;32(2):391-7.	This source discusses the importance of reflexivity in disability research.	This source discusses reflexivity and the need for reflexivity in disability research. This source discusses why reflexivity is important for disability researchers and definitions of disability.	Disabled people challenged the individual model of disability. The social model argues that people with impairments are prevented from social life due to physical, social and economic barriers, so it is society rather than the individual causing disability. If nurses view disability in a non-reflexive manner this will lead to a very limited understanding of what is meant by disability. Self-reflection of nurses is necessary to allow nurses to enhance the care of disabled people rather than being part of the problem.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
28.	Title: Models and measurement in disability: an international review. Authors: Palmer M, Harley D Health Policy and Plann. 2011;27(5):357-64.	The article describes the theoretical basis and methods of disability measurement.	This source discusses the medical and social models of disability, the ICF and how disability is measured.	Social model of disability is important for assessing the equalisation of opportunities. The measurement of disability has important implications for law and policy. Different models serve different purposes. The social model has been criticised for failing to address impairment. Disability is no longer perceived as a purely medical phenomenon.	Impairment screens, functioning screens, the Washington Group General Measure of disability Activities of daily living.
29.	Title: The problem of disability definition: Commentary. Author: Pfeiffer D J Disab Policy Stud. 1993;4(2):77-82.	The aim of this article is to discuss disability definitions.	This source discusses the weaknesses of having disability definitions.	The ICIDH has become very popular in research and public health. There are different terms for disabled and handicapped, and these terms mean different things to different people. Disability should be defined on a case-by-case basis because the discrimination occurs on an individual basis. The conclusion was that there is little chance that the oppression of disability community will remain if the disability definition remains.	
30.	Title: The problem of disability definition: Again. Author: Pfeiffer D Disab Rehab. 1999;21(8):392-5.	This source aims to discuss the problem of disability definitions again.	This source describes the progression of disability.	In the 1970s disability was a chronic condition which prevented a person from working. In the 1980s this became an issue as those working disabled people were not included but still needed protection. In 1973 the Rehabilitation act amended this by saying disability is when a person with a physical or mental impairment which limited a major life activity, however not all those disabled are limited at all times.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
				Simply stating the definition used does not give the analyst the license to make recommendations and conclusions for all people with disabilities, but only those included in the specific definition used.	
31.	Title: Models of disability: A brief overview. Authors: Retief M, Letšosa R. HTS 2018;74(1):8.	This article sought to provide a brief overview of the nine most dominant models of disability.	This source talks about disability theology in a church setting and describes the purposes of various models of disability. This source describes the nine most common models that exist.	Models of disability provide definitions, explanations of the causes, provide information on perceived needs, they guide the formulation and implementation of policy, they are not neutral, they determine how academics may study disability, they shape self-identity and can cause prejudice and discrimination. The models that are most common include the religious model, the medical model, the social model, the identity model, the human rights model, the charity model, and the economic model.	
32.	Title: Disability reconsidered: the paradox of physical therapy. Authors: Roush S, Sharby N PT. 2011;91(12):1715-27.	The aim of this article is to explore models of disability from the perspective of the academic discipline and to look at how to improve functioning with such a diverse disability background.	First disability and the paradox of physical therapy is described followed by descriptions of the moral model, medical model and the social model of disability.	The moral model of disability equates disability with sin, loss of faith or a test of faith. The medical model places disability in anatomy or physiological departures from what is considered normal. The idea is to ‘fix’ the problem. The social model shifts the perspective from the individual to the environment and its role in amplifying impairments.	
33.	Title: Models of disability: their influence in nursing and potential role in challenging discrimination. Author: Scullion P J Adv Nurs . 2010;66(3):697-707.	The aim of this paper was to discuss the medical and social models of disability associated with the experience of disabled people as citizens and patients.	This paper discusses background to disability, how the search was completed before a discussion around disability.	WHO 2001 set out to provide international language for disability: a multidimensional phenomenon resulting from the interaction between people and their physical and social environment. Disability in nursing has traditionally been viewed as the medical model, this can lead to disability be seen as a personal problem, and can cause undermining and alienating effects, can lead to invalidation and abuse and unequal opportunities.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
				The social model of disability allows the discriminatory way disability is looked at to be challenged. In NZ the social model guides nursing education.	
34.	Title: Disability Rights and Wrongs. Author: Shakespeare T New York, NY 100016: Routledge. 2006.	This book aims to conceptualise disability, to describe disability and bioethics, to describe the social relations of disability.	This book conceptualises disability.	Agreeing with a certain model of disability often influences the way in which one treats disability. Disability is complex and is an interaction between individual and structural factors. Disability is a complex set of intrinsic and extrinsic factors are at play.	
35.	Title: Debating disability. Author: Shakespeare T J Med Ethics. 2008;34(1):11-4.	This study explores the political nature of disability research. Disability is an emerging field of enquiry and constructive debate is welcomed.	This source discusses the medical and social models of disability primarily.	Disability is a complex, scalar and multi-dimensional phenomenon. There can be an unhelpful focus on the social model. It is necessary for the structural approach of disability to be understood.	
36.	Title: Measuring health and disability: Manual for WHO disability assessment schedule WHODAS 2.0. Author: Üstün T World Health Organization; 2010.	The aim of this source was to describe the reasons for WHODAS 2.0, the development and testing of this measure.	This source describes why disability is important to measure and the development and testing of WHODAS 2.0.	WHODAS 2.0 is a generic assessment for measuring health and disability across cultures. It was developed from the ICF. It is difficult to define and measure disability. WHODAS 2.0 was needed to address the need for a standardised way to measure health and disability across cultures.	WHODAS 2.0
37	Title: Exploring the role of contextual factors in disability models. Authors: Wang P, Badley E, Gignac M Disab Rehabil 2006;28(2):135-40.	The aim of this was to define and categorise the types of relationships that contextual factors have within models of disability according to the WHO ICF.	Various contextual factors are analyses to determine how they affect the disability process.	A mediating factor occurs when an issue arises from an activity limitation which in turn affects the level of participation. A moderating factor is when the effect of activity limitation on participation depends on its presence or level.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
38.	Title: International Classification of Functioning, Disability and Health Geneva World Health Organization. Author: World Health Organization 2001:299.	This book contains the International Classification of Functioning, Disability and Health known as the ICF and its aim is to provide a unified and standard of describing health and health status.	This book describes the aims of the ICF and the different components, has detailed classification and definitions of body functions, structures, activities and participation and environmental factors.	The ICF aimed to provide a scientific basis for understanding and studying health states, to establish a common language, to permit comparison across countries and to provide a systematic coding scheme for health information systems. Impairments: are problems in body function or structure as a significant deviation or loss. ICF joins both the social and medical model.	

Table I (4): Overview of the Rapid Review of literature discussing disability in Māori

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
1.	Title: Rehabilitation and indigenous peoples: the Maori experience. Author: Harwood M Disab & Rehab. 2010;32(12):972-7.	This article aimed to present perspectives of Māori on rehabilitation services for Māori.	He Korowai Oranga is discussed in the context of rehabilitation.	He Korowai Oranga overall aim is for Māori families to achieve their maximum health and well-being. Māori have a right to equal access of health care and outcomes as non-Māori. Whānau is very important for Māori families. A safe, supportive environment is important for full participation, in order to gain the most out of rehabilitation.	
2.	Title: Replacing medical and social models of disability by a communities-based model of equal access for people of differing abilities: A Maori perspective. Author: Hickey H	This paper aims to discuss how the social model of disability should be replaced with a communities-based model were equal access is provided for those with differing abilities. In NZ this should further be	Disabled Māori treatment is discussed, as is the medical model of disability and how it has progressed into a model as with the social model. It also discusses the limitations of the social model of disability. Three Māori models of health are examined to	Disabled Māori are often treated less favourably than non-Māori, thus leaving their whānau being obliged to accept approaches to providing culturally sensitive care. The issue of appropriateness and equity needs to be addressed. However, this is impossible without a Māori model of disability. The limitations of the social model of disability is that in society there are many different groups of	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
	He Puna Korero: J Maori and Pacific Develop. 2006;7(1):35.	informed by Te Whare Tapa Whā.	inform disability. The different models are then compared.	people with different values, so it is difficult to make them all feel accepted. Te Whare Tapa Whā included four dimensions which are taha wairua (spiritual), taha hinengaro (thoughts and feelings), taha tinana (the physical dimensions) and taha whanau (family). Te Wheke represents the family and eight tentacles to show eight different important dimensions of life. Ngā Pou Mana has four pillars which include family (whanaungatanga), cultural heritage (taonga tuku iho), the physical presence (tea o turoa) and the indisputable land based (turangawaewae). The concepts of wairua, hinengaro, taha tinana and whānau could underpin the development of a communities-based model of equal access for people with differing abilities. This will allow for equity.	
3.	Title: "Whānau Hauā: Reframing Disability From an Indigenous Perspective." Authors: Hickey, H. and D. Wilson (2017) Mai Journal 2017; **6**(1): 82-94.	To critically examine current approaches to working with disabled Māori and the experiences of these disabled persons.	The social and medical and ICF models of disability were discussed.	Disabled persons have a range of barriers to face. In NZ Māori experience very high disability with 33% being disabled. Introduce Whānau Hauā as an alternative indigenous framework. Indigenous disabled persons have experiences and challenges that non-indigenous persons do not.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
				Disability was not always acknowledged by Māori. Despite Māori having higher levels of disability they are more likely to have unmet needs. Whānau Hauā is informed by Te ao Māori and it provides a Māori perspective on disability This acts as an umbrella term suitable for disabled Māori. It adds a cultural dimension to restore meaning to people's lives.	
4.	Title: Maori Concepts of Disability. Authors: Kingi J, Bray A Dunedin Donald Beasley Institute Incorporated 2000. 29 pages.	To explore a Māori world view of disability.	This source explores qualitative interviews of Māori individuals to gain their view and understanding of disability.	Issues surrounding power, control and equity are needed to be addressed to help develop services that achieve good outcomes for Māori and issues surrounding power, control and equity are needed to develop this relationship with Māori people. Disability is a symptom of wider and broader concepts within the Māori society. The loss of land, unhelpful government policies and loss of knowledge of whakapapa and identify and the ongoing effects of colonisation has continued to have a disabling effect on them as the Tangata Whenua. The dominant model of disability in NZ is the biomedical model of health and Tangata Whenua needs are not met when the needs differ from dominant culture. Tangata Whenua must manage their own initiatives and develop their own services so that they have the dignity of choice between mainstream or kaupapa Tangata Whenua services to support persons with disabilities and their whanau.	
5.	Title: Maori Experience of Disability and Disability Support Services.	The aim of this chapter was to describe Māori understanding of	This source discussed Māori understanding of disability and disability support, data issues, impairment among	The NZ disability strategy distinguished between disabilities and impairments with individuals not having disabilities but rather physical, sensory, neurological, psychiatric, intellectual or other	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
	Authors: Ratima K, Ratima M Haoura: Maori Standards of Health IV A study of the years 2000-2005 [Internet]. Wellington Te Rōpū Rangahau Hauora a Eru Pōmare.	disability and disability support services.	Māori, the evolution of disability support services for Māori.	impairments and disability is the process which happens when one group of people create barriers that don't take into account the way others live. Māori experience wide disparities when it comes to disability. For Māori a secure cultural identity is key for having good health. Māori experience a lot more impairment than non-Māori and have a lot more unmet need. Māori have distinctive needs when it comes to disability which include social and cultural requirements.	
6.	Title: At a cultural crossroads: lessons on culture and policy from the New Zealand DISABILITY STRATEGY. Author: Wiley A Disab & Rehab. 2009;31(14):1205-14.	The aim of this article was to determine if there has been a promotion of participation of disabled Māori. It also looks at culturally appropriate resources of disabled Māori.	This source discusses the NZ disability strategy, the methodology of this study, and the findings and recommendations from the various groups of people interviewed as well as discussing recommendations for the future.	Disabled Māori in NZ experience less employment and less income, which can have a direct and profound impact on people's lives. Objective 11 of the New Zealand disability strategy aims to promote participation of disabled Māori. This model is based off the social model of disability, so society rather than the individual needs to adapt. There is a lack of collaboration between ministries regarding disability policy and Māori with disabilities. Most service providers were providing some sort of training to advance cultural awareness and sensitivity among staff. Consumers painted a different picture as extreme pro-activeness was needed to access services and there were very little consumer needs established.	

No.	Bibliography Details	Aim	Disability areas discussed	Overall Disability Conclusions	Disability Measurement Discussed
				Most caregivers felt very unsatisfied with the services provided. Unless covered by ACC caregivers are not actively funded. Society is not homogenous therefore disability should not be either, disability needs to be both effective and culturally appropriate.	
7.	Title: Prevalence and predictors of disability for Māori 24 months after injury. Authors: Wyeth EH, Samaranayaka A, Davie G, Derrett S Aust NZ J Publ Heal. 2017;41(3):262-8.	The study aimed to investigate post injury disability and predictors in Māori Prospective Outcomes of Injury Study Participants.	Describes the issue of disability in the Māori population. This paper then describes the prospective outcomes injury study.	There are large disparities between Māori and non-Māori disability outcomes and there is little research into disability in Māori or indigenous people post injury. Disabled Māori have difficulties accessing health services which influences long term disability.	WHODAS II

Table I (5): Overview of the Rapid Review literature discussing both HRQoL and disability

No	Bibliography Details	Aim	HRQoL and Disability Concepts	HRQoL and Disability Conclusions
1.	Title: Disability in older adults 3: Policy implications. Authors: Chiriboga DA, Ottenbacher K, Haber DA J. Behav. Med. 1999;24(4):171-80.	This source sought to determine if the concept of disability was important from a public policy perspective. Additionally, it discusses the importance of physical activity in reducing disability.	The extent to which an individual's capability are improved influences both the medical quality of life (QoL) and allows for successful aging.	

No	Bibliography Details	Aim	HRQoL and Disability Concepts	HRQoL and Disability Conclusions
2.	Title: The contribution and impact of the International Classification of Functioning, Disability and Health on quality of life in communication disorders. Author: Cruice M Int J Speech Lang Pathol. 2008; 10(1/2):38-49.	The aim of this source is to evaluate the contribution of the impact of the International Classification of Functioning, Disability and Health on quality of life in communication disorders.	It was recommended that HRQoL be linked to other models. HRQoL is the final outcome wherein impairments give rise to disabilities which result in handicaps which influence overall HRQoL. The characteristics of individuals and environments are also important. HRQoL can also be viewed as an umbrella concept, encompassing impairments, disablement and handicap. Modelling quality of life alongside the ICF disablement framework has not come without its concerns. Disablement frameworks need further development. The ICF focused on the individual person therefore encouraging clinicians and researchers to think beyond their own discipline.	QoL and HRQoL and wellbeing or subjective experience has not been focused on evaluation and intervention. Overall quality of life is seen in some way as representing an aggregate of components of functioning, activity and participation. QoL is not another level of the ICF, the ICF framework helps to structure what individuals can and cannot do, QoL reminds us to consider who the individual is and what he or she wants to be. These concepts are separate, and the ultimate goal is to allow an individual to dictate there personal and environmental lifestyles and go from there.
3.	Title: Clinical and public health perspectives and applications of health-related quality of life measurement. Author: Ebrahim S Soc Sci Med1995;41(10):1383-94.	The purpose was to look at HRQoL measures and the specific purposes of HRQoL measurement are considered in detail and an alternative approached using impairment, disability and handicap model of disease consequence is proposed.	HRQoL is the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy. A strength of HRQoL it allows for a patient centred view of disease. HRQoL is an umbrella concept that encompasses impairment, disability and handicap, HRQoL is a less clear concept.	Impairment, disability and handicap provide a model of the consequences of diseases which has considerable advantages over the HRQoL model for clinical and public health purposes.

Appendix II: Tables to Support the Scoping Review

Table II (1): Overview of Scoping Review of literature discussing 'HRQoL and CKD'

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
1.	Apostolou T (2007). Quality of life in the elderly patients on dialysis. Int urol nephrol. 2007; 39(2):679-83.	To describe how QoL varies amongst the elderly. Age is noted as a key determinant of QoL.	Literature Review, the number of papers was not identified, and the inclusion/exclusion criteria was not detailed.	QoL data suggests that older patients have similar levels of social functioning and mental health as younger dialysis patients usually have poorer physical function.	HRQoL should include physical health, symptoms, functional status, activities of daily life, mental well-being, social health, including social role functioning and social support networks.	The SF-36, KDQoL and erythropoietin was mentioned.	No. of papers was not identified, no numbers to support results, additionally the search strategy was not identified.	Great summary of factors that influence HRQoL and how this acts to predict CKD outcomes.
2.	Balogun, S. A, et al. (2017)."Quality of Life, Perceptions, and Health Satisfaction of Older Adults with End-Stage Renal Disease: A Systematic Review." J Am Geriatr Soc 65(4): 777-785.	To explore the QoL, perceptions and health satisfaction of older adults with CKD stage five.	Systematic Literature Review of 23 papers. Pubmed: January 1994 to December 2014. Human, 65+ years, CKD stage five. Eight methodology standards.	Older adults should not be excluded from renal replacement therapy based on age. Older adults had a lower physical functioning of HRQoL scores. Little is known about QoL perceptions in elderly with cognitive or functional or terminal impairment due to being excluded from the studies.	Frequently mentioned but not defined.	Structured qualitative interview, SF-36, health practitioner interview, KDQoL, Nottingham Health Profile Survey, Depression rating scale, WHO quality of life survey, visual analogue scale, global QoL assessment	A limitation is that this paper did not clearly define what HRQoL was, despite using it as a key measure and refereeing to QoL and HRQoL numerous times.	Systematic, accurate reporting of the data. A good synthesis of the overall findings of the 23 papers included. No meta-analysis to base claims off, but a thorough synthesis of the papers included.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
3.	Brown, E. A., et al. (2010). "Broadening Options for Long-term Dialysis in the Elderly (BOLDE): differences in quality of life on peritoneal dialysis compared to haemodialysis for older patients." Nephrol Dial Transplant 25(11): 3755-3763	HRQoL is an important outcome for older people, however little is known about the differences on QoL on haemodialysis and peritoneal dialysis in older age groups.	Cross-Sectional, multi-centre study quantitative scales. 140 Participants Inclusion: 65+, had been on dialysis for at least 90 days, had not been hospitalised for 30 days. Patients with clinically obvious cognitive impairment or with a life expectancy of less than 6 months were excluded.	Quite similar QoL scores, if not slightly better in PD patients. Greater PD should be available to older patients. Improved education would allow for the correct choice by patients, as they will know what suits them best to maintain the aspects of life they value.	Described measures to assess HRQoL rather than providing and explanation of HRQoL.	Short Form 12 Mental and Physical Component Summary scales, Hospital Anxiety and Depression Scale and Illness Intrusive Ratings.	Patients not representative of the dialysis population, as mostly white Europeans collected (UK based study). Selected HD patients to match PD patients. Cross-sectional nature of study, sick PD patients can transfer to HD. Doesn't allow for assessment of why patients choose treatments that they did.	Clear selection criteria, quantitative results, good analysis of limitations of the study. Many measures of HRQoL were used to gain an appropriate idea of HRQoL in these patients.
4.	de Jonge, P., et al. (2003). "A simple risk score predicts poor quality of life and non-survival at 1 year follow-up in dialysis patients." Nephrol Dial Transplant 18(12): 2622-2628.	Risk factors of poor QoL outcomes were studies at one year follow up.	Quantitative Cohort Study Baseline 80 participants, 60 participants who were alive at 1 year. Dialysis patients, outpatient unit Amsterdam November-December 1999.	Age, diabetes as a comorbid condition and a high INTERMED score was associated with a poorer QoL.	QoL in CKD patients is often threatened by multiple biological and psychosocial stresses thus needs to be evaluated during dialysis.	SF-36 and INTERMED which is a baseline survey which is an observer-rated instrument that classified information from a structured medical history, includes four dimensions: biological, psychological,	There was no baseline QoL score, and since this is a powerful predictor of QoL this is an important limitation. Patients view not accounted for well in INTERMED. Limited number of patients. Also, not strictly 65+	INTERMED more objective so not reliant on patients' temporal views. Patients who refused follow up were compared to those who did not refuse and they did not find any differences in

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
						social and healthcare.	although this was a subcategory.	the baseline variables.
5.	Elliott, B. A., et al. (2014). "Shifting responses in quality of life: people living with dialysis." Qual Life Res 23(5): 1497-1504.	To investigate the life experiences and QoL of people living with dialysis.	Qualitative interviews at a cross-sectional point in time in Minnesota. 31 interviews, 20 dialysis patients who had been on dialysis for at least 6 months, and 11 with family members.	When QoL was poor those on dialysis reconsidered if it was even worth it. Initially thrived on dialysis before just surviving. QoL should be assessed through ongoing assessment.	QoL assessment engages a person's values and priorities.	HRQoL was measured through a qualitative questionnaire.	Results should be considered with caution. There was a limited ethnic diversity.	Interviews provided a rich description of their life experiences and there evolving QoL. Qualitative interviews add insights into the patients QoL experiences.
6.	Finkelstein, F. O., et al. (2012). "Assessing and improving the health-related quality of life of patients with ESRD." Nat Rev Nephrol 8(12): 718-724.	Define HRQoL and the effect of CKD on HRQoL.	Narrative review, the number of papers was not described nor was the inclusion/exclusion criteria.	Assessment of HRQoL gives key information about CKD patients and routine assessment of patient reported outcomes should begin.	HRQoL can be defined as the extent to which an individual's usual or expected physical, social, emotional wellbeing is affected by a medical condition or its treatment.	Discussed the generic measures of SF-36 and the Health Utility Service. KDQoL is a specific measurement.	A large limitation is the methods of the review, the inclusion and exclusion criteria of the papers and the number was not included.	Provide a great summary that defines HRQoL in the context of CKD.
7.	Finkelstein, F. O., et al. (2009). "Health related quality of life and the CKD patient: challenges for the nephrology	The present review addressed by focusing on strategies that can be used to	Mini Review, the number of papers was not detailed nor was the inclusion/exclusion criteria.	Increasing interest in assessing HRQoL in CKD patients and it is now mandated in the United States. Focus needs to be on developing strategies to improve HRQoL.	HRQoL can be defined as the extent to which ones usual or expected physical, social or emotional wellbeing is affected by a	Use of HRQoL has become an important measure in CKD patients. KDQoL is frequently used.	Once again this paper had not described methods of paper selection, the number of papers included or the search strategy.	This paper provides a comprehensive list of various studies that could be used to improve the QoL of CKD patients.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	community." Kidney Int 76(9): 946-952.	improve HRQoL in of CKD patients.			medical condition or treatment.			
8.	Ghiasi, B., et al. (2018). "Quality of Life of patients with chronic kidney disease in Iran: Systematic Review and Meta-analysis." Indian J PalliatCare 24(1): 104-111.	The aim of this study was to evaluate the quality of life of patients with CKD in Iran through meta-analysis.	Systematic review from May 2005-May 2017. 17,200 individuals in 45 reviewed studies. . Databases searched included ItanMedex, SID, Magiran, IranDoc, medlib, Science Direct, Pubmed, Scopus, Cochrane, Embase, Web of Science and Medline. “CKD patients” “CKD” and “Quality of life” keywords used. Excluded based on non-random sampling, insufficient data and statistical population other than in patients with CKD.	Mean QoL score of SF-36, HRQoL and KDQoL-SF was 60.31, 51.60 and 50.37% respectively. QoL was poorer compared to other diseases. CKD patients had a lower mean QoL score compared normal people. Intervention measures should take place to improve HRQoL.	QoL is multidimensional and impacts physical performance, emotional, physical, fatigue, mental, social, physical and general health.	SF-36, KDQoL-SF and KDQoL-SFTM	Due to the differences in scores of HRQoL criteria it was not possible to come up with an average HRQoL score in CKD patients.	Provided meta-analysis so a statistical approach to support claims about QoL.
9.	Glover, C., et al. (2011). "Understanding and assessing the impact of end-stage renal disease on	The validity of various instruments used to measure HRQoL in ESRD population	Systemic review with a meta-analysis, searched in Medicine (1950-2009). 378 citations reviewed however final number	The SF-36 which is often seen as the gold standard measure does not cover all the issues important in the CKD stage five population. The KDQoL is the best specific measurement	HRQoL must include physical mental and social wellbeing if the WHO definition of health is used and it is often thought that in a clinical	The measures discussed included the generic measures of SF-36, EQ-4D, WHO QoL assessment and	The final number of papers included was not clear.	Great logical approach to the inclusion of papers. Great diagrams summarising how HRQoL impacts

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	quality of life: a systematic review of the content validity of self-administered instruments used to assess health-related quality of life in end-stage renal disease." Patient 4(1): 19-30.	was explore.	included is not clear. WHOQoL appears to be most valid in terms of the content validity. Searched terms in English, terms that were searched included words such as CKD stage five, HRQoL and measures. Articles relating to oncology and paediatrics were excluded.	and is suggested to be used. The EQ-5D does not include treatment specific issues, sleep, sex, cognitive function, body image and finances but can be self-administered and is quick.	setting the health state is what is impacting an individual’s QoL.	disease specific measures of KDQoL and the derivatives KDQoL-SF and KDQoL-36.		HRQoL and also a table summarising the different measures.
10.	Griva, K., et al. (2014). "Age is not a contraindication to home-based dialysis - Quality-of-Life outcomes favour older patients on peritoneal dialysis regimes relative to younger patients." J Adv Nurs 70(8): 1902-1914.	To compare QoL, anxiety and depression between older (≥65 years) and younger (<65 years) patients across automated peritoneal dialysis and continuous ambulatory peritoneal dialysis.	Cross-sectional Study with 201 patients from the Peritoneal Dialysis Centre in Singapore General Hospital. . Patient reported outcomes from patients undergoing PD for a minimum of three months, aged over 21, no dementia or psychiatric diagnosed, not hospitalised at time of assessment or preceding 3 weeks and able to communicate in	Older patients had better QoL compared to younger patients despite worse clinical findings. All patients regardless of age can do well on PD.	QoL plays an important role in healthcare and plays an important role in treatment decisions and similar endpoints.	KDQoL, WHOQoL and Short form and Hospital anxiety and depression scale. Additionally, demographic information was collected.	Not strictly 65+ but splits the sample into those over and under 65+. Cross-sectional design. Certain sub-groups had a smaller sample size. May be selection bias in terms of the way disease treatment is allocated therein affecting HRQoL.	Clear inclusion and exclusion criteria and results. No differences between those who participated and those who refused in terms of gender, ethnicity and PD modality.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
			English, Mandarin or Malay. Excluded based on stroke, dementia, hearing difficulty and hospitalisation.					
11.	Harris, S. A., et al. (2002). "Clinical outcomes and quality of life in elderly patients on peritoneal dialysis versus hemodialysis." Perit Dial Int 22(4): 463-470.	To compare clinical outcomes and QoL in elderly patients on PD and HD in the North Thames Dialysis Study.	12-month prospective cohort study. 174 patients that were 70+ in the UK. Quantitative longitudinal data collected. 70 years older and 90 days of uninterrupted dialysis that defines chronic dialysis. Recruited from May 1995 and December 1996. Excluded if terminal ill with life expectancy less than 6 months, psychosis, cognitively impaired.	Clinical outcomes of QoL are similar in elderly people on PD and HD. The apparent advantage of PD is often misleading and may be contributed to residual renal function not assessed when looking at adequacy of HD. PD is useful in older patients as well as HD.	The way HRQoL is measured was described but what it is and what it means for this study was not detailed.	Sociodemographic information was collected. Dialysis outcomes was assessed at baseline 6- and 12-months using UK renal association guidelines. Mortality and hospitalisations. QoL using SF-36 and KDQoL.	Non-participants were more likely to have 2 or more comorbid conditions. Only observation, may be selection bias in treatment types. HRQoL definition not detailed.	No differences between sociodemographic factors, late referral, or major comorbidity between those on dialysis and not on dialysis. Longitudinal design to understand the progression of HRQoL.
12.	Iyasere, O. U., et al. (2016). "Quality of Life and Physical Function in Older Patients on Dialysis: A Comparison of Assisted Peritoneal	Compare QoL and physical function between older patients on assisted PD and HD.	Observational quantitative cross-sectional study. 251 (129 PD and 122HD) from England and Northern Ireland. PD patients were required to have assistance and HD	No differences between QoL and physical function between older patients on assisted PD compared to HD, expect for treatment satisfaction which is higher in PD patients. QoL in these patients may be influenced by non-	The measures were well described.	Age, sex, diabetes, dialysis vintage, ethnicity, index of deprivation. Frailty was assessed used clinical frailty scale, SF-12, Hospital anxiety	The cross-sectional design means it is limited to association and no causality. Not longitudinal study and therefore cannot determine	Has a larger sample size, and has many good measures and predictors of QoL.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	Dialysis with Hemodialysis." Clin J Am Soc Nephrol 11(3): 423-430.		patients eligible if they required hospital transport to attend dialysis sessions. 60 years old, dialysis for more than 3 months, free of hospitalisation for 30 days. Cognitive impairment, unable to understand English, life expectancy less than 6 months were excluded from the study.	dialysis factors including frailty. PD should be considered as an alternative to in-centre HD for older patients, at least from the viewpoint of QoL.		and depression scale (HADS), RTSQ, physical function.	outcomes, use of health care resources and overall costs.	
13.	Kutner, N. G. and S. V. Jassal (2002). "Quality of life and rehabilitation of elderly dialysis patients." Semin Dial 15(2): 107-112.	The review summarises literature about QoL and rehabilitation of elderly patients on chronic dialysis and considers the implications of this information for clinical practice.	Narrative review. This paper does not describe the number of papers nor how they were selected.	Ideally individuals decline can be slowed by screening, rehabilitation therapy and maintenance care. Elderly patient's mental health has been shown to be better compared to their younger peers. Preventive and rehabilitation models are important for prompting healthy aging and patient QoL on dialysis and will help the cost burden.	A broad definition was used. Patients assessed functioning and well-being is variously referred to as HRQoL.	SIP and SF-36	A limitation is the number of papers reviewed and the inclusion/exclusion criteria was not available.	The main advantage of this paper is it discussed a method for potential ways to improve the HRQoL of individuals.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
14.	Lamping, D. L., et al. (2000). "Clinical outcomes, quality of life, and costs in the North Thames Dialysis Study of elderly people on dialysis: a prospective cohort study." Lancet 356(9241): 1543-1550.	Undertook a comprehensive assessment of outcomes in patients over 70 years on RRT.	12-month prospective cohort study of 221 participants with CKD stage five and at 12 months there was 125 participants who survived to 12 months. Recruited from May 1996 to December 1996 in the UK. Patients 70+ with CKD, who started dialysis during the recruitment period and patients who had been on dialysis for at least 90 days were included.	Age alone should not be used as a barrier to referral and treatment and dialysis should be used as a barrier to referral and treatment. Indicators rather than chronological age should be used to see if they benefit from treatment. Mental QoL of patients was the same as non-dialysis peers but physical ability was lower.	Again, HRQoL was not defined for this paper	Sociodemographic information was collected, other disease information was collected, survival time, hospital admission rates. QoL assessed with SF-36.	QoL results were presented and briefly discussed but not in detail. Additionally, HRQoL was not defined for this paper.	This was a prospective cohort allowing for an understanding of the progression of the disease.
15.	Loos, C., et al. (2003). "Effect of end-stage renal disease on the quality of life of older patients." J Am Geriatr Soc 51(2): 229-233.	To assess the effect of CKD on QoL.	Controlled quantitative cross-sectional study. 169 CKD patients who started dialysis and 169 sex matched non-CKD controls. Sampled between 1997 and 2001 from France. 70 + and with CKD who went under planned or unplanned first dialysis. Creatinine clearance less than 15 mL/min.	If dialysis initiation was planned this led to QoL being no worse than other diseases, however for unplanned dialysis this led to severely impaired QoL. Pre-dialysis care is important to optimise.	Previous studies discussing QoL has been discussed and how QoL in this study has been measured.	SF-36, comorbid conditions, clinical symptoms and laboratory findings were obtained from medical records.	Potential selection bias when recruiting non-CKD population as they were selected form the hospital.	Paper provided fantastic data on CKS patients and non-CKD patients and the differences between planned and unplanned CKD.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
16.	Naik, N., et al. (2012). "Measurement of health-related quality of life in the care of patients with ESRD: isn't this the metric that matters?" Semin Dial 25(4): 439-444.	This review will detail how carefully contrasted questionnaires with equivalent reliability as long annual surveys such as KDQoL can be more quickly completed using novel technology.	Narrative review. The number of papers was not discussed nor was the inclusion/exclusion criteria.	Those unable to complete the HRQoL forms had a substantially higher risk of death.	WHO defines HRQoL as the state of one's well-being in the areas of physical health, mental health and a global sense of one's health. It is subjective and often dependent on how a person views their health.	KDQoL, SF-12	A significant limitation of this study is there is no information about how papers were selected into this study or the number of papers of the inclusion, exclusion criteria.	This discusses the history of HRQoL in CKD patients.
17.	Phillips, L., et al. (2001). "Health-related quality of life assessment in end-stage renal failure." NT Research 6(3): 658-670.	The need to assess routinely individualised QoL in patients with CKD in view of the radical changes which treatment imposed upon them and it also presents	Review article, likely a rapid review. The number of papers reviewed, and the inclusion/exclusion criteria was not discussed.	There is much debate over how QoL should be defined and measured.	HRQoL is more than just an assessment of health status. Rather it is the relative importance given by individuals themselves to assess the impact of disease on their life.	Psychological, psychological, physical scales have all been used as well as the NHP and SF-36. Additionally, disease specific measures of Leicester Uremic Symptom Scale, KDQoL and Kidney disease questionnaire,	The limitations of this review are it has not discussed the number of papers collected, what type of review it is, or the inclusion/exclusion criteria of the papers to be included.	This paper discusses treatment of CKD, QoL, approached towards health related, assessment, types of health-related treatment scales, measures sued in CKD and what these measures have

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
		an overview of health related assessment which have been used in CKD patients.				renal quality of life profile, KDQoL and renal treatment satisfaction questionnaire.		suggested the impact of CKD is. Paper provides a great table demonstrating all measures used to assess HRQoL in CKD patients.
18.	Ronsberg, F., et al. (2005). "Renal replacement therapy in the over-80s." Age & Ageing 34(2): 148-152.	To characterise Scottish dialysis patients aged 80 years and over at the time of their first treatment and to compare their outcomes with those of patients with other serious illness.	Quantitative retrospective cohort survey between 1 Jan 1994 and 31 December 2003 in Scotland. 465 patients received dialysis. 62 were aged 80 years or over. 39 of these completed the questionnaire and 6 did not. Controls had lung cancer and MI. . Included those over the age of 80 who were on dialysis or who had lung cancer or an MI as the control group.	Age is no longer seen as a contraindication to treatment. QoL in older dialysis patients have similar social functioning and mental health but poorer physical function than their younger dialysis counterparts.	HRQoL was described as a measure however the definition was not strictly discussed.	QoL was measured in dumfries cohort using the SF38 questionnaire.	The sample size in this study was too small to make any definite conclusions. A large cohort study would be advantageous in developing a true understanding. Used an unhealthy group to make comparison with.	The strengths of this paper are they collected information on QoL in the 80+ dialysis patients.
19.	Tyrrell, J., et al. (2005). "Older patients undergoing dialysis	This study evaluated cognitive impairments,	Cross-sectional quantitative survey of 51 outpatients from France receiving dialysis.	Almost half the cognitively impaired patients were depressed. HRQoL should be monitored in elderly	QoL is a term where an individual classifies there QoL based on	QoL assessment of NHP, also used depression	It was not clear whether poor QoL was related to dialysis directly, the	Assesses cognitive impairment which is often an excluded

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	treatment: cognitive functioning, depressive mood and health-related quality of life." Aging & Mental Health 9(4): 374-379.	depressive mode and self-reported QoL in older dialysis patients (>70 years).	There was a psychologist section. Collected from Grenoble between September 1999 and March 2000. HD or PD. 70+. Excluded patients not fluent in French and those who had marked visual or hearing impairment (5 of 56).	dialysis patients using sale report measures, as this will improve our understanding of how dialysis affects life.	their subjective experience.	scale and two cognitive tests.	underlying kidney disease, other pathologies or the ageing process. Longitudinal study would be helpful.	population in studies. The suggestion that HRQoL is important to monitor is helpful.
20.	Unruh, M. L. and R. Hess (2007). "Assessment of health-related quality of life among patients with chronic kidney disease." Adv C K D 14(4): 345-352.	The aim of this review was to examine the conceptual model and definitions of HRQoL and issues regarding the measurement of HRQoL which have implications in CKD patients. The review also shows how CKD may be	Review, likely a systematic narrative review. The number of papers and inclusion/exclusion criteria was not described.	Translating the knowledge from HRQoL research that this is often impaired in the CKD patients into clinical practise would be useful for including outcomes. It is often difficult to know what measure to analysis HRQoL in.	HRQoL pertains to the health demands that are related to health or disease. Provide a useful figure of HRQoL in CKD patients.	Generic measures like the SF-36, SIP, NHP. Also, disease specific measurements.	This paper does not have the number of papers included or the methods of how papers were included or excluded for this review.	Very in-depth assessment of HRQoL in CKD patients. This paper assesses the strengths of such assessment of HRQoL in these patients.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
		helpful to assess						
21.	Unruh, M. L., et al. (2008). "The influence of age on changes in health-related quality of life over three years in a cohort undergoing haemodialysis. " J Am Geriatr Soc56(9): 1608-1617.	To assess the extent to which persons aged 70 and older undergoing HD had greater changed in HRQoL to younger patients over 3 years.	Quantitative longitudinal cohort 1813 (98%) of HD patients completed baseline surveys. This study occurred in the United States. 15 clinics, included people 70+ years and under 70 years as a comparison group, who were on HD.	HRQoL scores in HD patients over the age of 70 years were better than in the younger patients. There was no substantial decline in relationship between age and average HRQoL decline over 3 years.	There was information describing how HRQoL has previously been described in HRQoL research.	Index of wellbeing, KDQoL-LF, SF-36.	Not strictly 65+, but only uses younger patients as a comparison group. May be survivor bias due to the assessment of prevalent HD cases.	This is of longitudinal design completed over the period of three years. This study also collected a wide range of data.
22.	Unruh, M. L., et al. (2005). Psychosocial factors in patients with chronic kidney disease: Health-related quality of life in nephrology research and clinical practice. Seminars in Dialysis, Wiley Online Library.	The review aims to address issues and discuss emerging concepts in the domain of HRQoL assessment in the ESRD population.	Narrative review, the number of papers reviewed, and the inclusion/exclusion criteria was not discussed,	HRQoL is a useful assessment of how one's life is going and how it would be best to assess or decide on treatment and improving this treatment.	HRQoL assess the QoL of a person that refers to their health and is highly dependent on what an individual thinks HRQoL is. It is important to understand the conceptual model of HRQoL when assessing it.	SF-36, KDQoL, Choices Health Experience Questionnaire (CHEQ), CHOICE.	The number of papers and the method of selecting and including papers in this study was not discussed.	This paper once again has a great diagram acting to describe HRQoL. This paper has described potential roles for HRQoL assessment in dialysis care and traits of an ideal HRQoL instrument in assessing CKD patients.
23.	Boateng, E. A. and L. East (2011). "The	The systematic review	Systematic Review. 26 of the 574 studies were	There is no simple understanding about which dialysis modality	HRQoL was not strictly defined. QoL is a	They discussed disease specific HRQoL	The limitation of this review is only	This study has been able to conclude that

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	impact of dialysis modality on quality of life: a systematic review." J Ren Care 37(4): 190-200.	aims to generate evidence on which dialysis modality: in-centre haemodialysis, or peritoneal dialysis improves QoL and ESRD.	included. Medline, CINAHL and EMBASE were searched from their inception to July 2010 for studies that compared QoL in both HD and PD patients. Studies were selected if they involved adults ESRD patients on dialysis, papers that compared HD and PD, papers that evaluated QoL as a primary or secondary outcome with a validated tool and reported QoL separately for HD and PD. Excluded if they reported on just a component of QoL, did not specify the QoL toll and did not separate QoL measures for HD and PD patients.	improves QoL, HD and PD are comparable to each other in terms of QoL.	multidimensional tool that requires multidimensional tools for assessment.	measures and generic HRQoL measures included the CHOICE Health Experience Questionnaire (CHEQ). KDQoL, SF-36, WHOQoL-BREF, Spitzer QL-index and EuroQoL (EQ-5D).	observational studies could be included. Due to different measurements of HRQoL specific measures could not be used.	cohort studies are the best for understanding information, this study also provided methods and had a very systematic method of searching and analysing the papers.
24.	Kanamori, H., et al. (2012). "Comparison of the psychosocial quality of life in haemodialysis patients	Due to the increasing number of HD patients with an increasing mean age	3-year prospective quantitative cohort study follow. 211 HD patients (72 elderly and 139 non-elderly patients). 20 patients excluded	No difference in VAS scores between elderly and non-elderly patients. They had to be on HD. There were no issues in the elderly patients with HRQoL.	HRQoL was not distinctly defined however it has been found that there are many different elements of disability.	Used the visual analogue scale, participants were asked to rate each indicator from 0-100, 10 items were assessed	A limitation of this paper is it wasn't strictly 65+ and they found no real association in any of the HRQoL issues	The strengths of this study are it was prospective and they have mostly focused on QoL outcomes and

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL was described	How HRQoL was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	between the elderly and non-elderly using a visual analogue scale: The importance of appetite and depressive mood." Geriatr Gerontol Int 12(1): 65-71.	in Japan. The assessment of their psychosocial status and QoL is therefore becoming more and more important along with laboratory data or comorbidities.	due to not complete questionnaires. Taigenkai Hospital and Kita-Eijinkai Hospital recruited from 2000-2003			which included appetite, sleep, mood, memory, family relationships friendship, economic status, life satisfaction in daily life and happiness.	in the elderly patients. Although this may be an important result. Also, the sample size was relatively small.	different elements of QoL that are important.

Table II (2): Overview of Scoping Review of literature discussing 'Disability and CKD'

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
1.	Bossola, M., et al. (2018). "Functional impairment and risk of mortality in patients on chronic hemodialysis: results of the lazio dialysis registry." J Nephrol: 1-10.	Quantify the occurrence of functional impairment in incident HD patients and analyse the long-term	Quantitative cohort study 5479 long term (incident patients) on dialysis units in Lazio (1/1/2008 and 31/12/2013) (Italy). Followed until 31 December 2015. Excluded if less than 18, residency outside Lazio, renal transplantation or	Functional impairment is a highly prevalent condition in haemodialysis patients and that it is associated with reduced survival. Functional impairment may be prevented or reversed in elderly patients. Identify patients who benefit from treatment early.	Functional ability refers to a person's ability to perform basic tasks without assistance.	Karnofsky Performance Scale Index. Demographic information was also collected.	Not exclusively 65+,but has age groups clearly separated. Extracted data, so individuals were not asked. Some participants follow up was very short if they were enrolled at	The strengths of this paper include the fact that it is a cohort study with many participants and a significant follow up period.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
		survival according to the patient's functional status.	death within the first 3 months of dialysis, duration of HD or hemodiafiltration less than 9 weeks.				the end of the study.	
2.	Cook, W. L. (2009). "The intersection of geriatrics and chronic kidney disease: frailty and disability among older adults with kidney disease." Adv C K D **16**(6): 420-429.	To examine the prevalence of frailty and disability among older adults with CKD and highlight opportunities for prevention and intervention and identify where there needs to be further work.	Review, the number of papers was not reviewed, and the inclusion/exclusion criteria were not described.	Further work is needed to categorise the relationship between kidney disease and frailty and to identify opportunities to intervene. The concept of frailty is highly important for CKD patients, especially those on the end stages. High disability burden in those with CKD and is linked to increased mortality. Fall incidence is higher in older adults.	Frailty is a clinical state of vulnerability to stressors that results from diminished physiologic reserves and compromised ability to maintain homeostasis in dynamic conditions. Disability is defined as difficulty or dependency in performing activities essential to independent living.	The definition was defined as difficulty or dependency in performing activities essential to independent living.	The limitation of this paper is the methods of this literature review were not explained and the way papers were included was not detailed.	It was positive to see that they mentioned that a limitation of current literature its cross-sectional nature of measurement, despite disability being a dynamic state. A great section specifically focusing on older adults.
3.	Cook, W. L. and S. V. Jassal (2008). "Functional dependencies among the elderly on	The aim of the study was to measure the specific pattern of ADL and	Cross-sectional quantitative study 168 Participants. Of 182 haemodialysis eligible patients, 3 excluded due to no	Factors associated with having disability is one or more ADL, including the inability to perform a TUG test within 10s, abnormal cognition, polypharmacy	Disability was not strictly defined however it was measured by ADLs, independent (requiring no aid)	Disability was measured through the activities in daily living (ADL and IADL, respectively):	A limitation is it is a cross-sectional study do we can only understand information	The strength of this study is it outlines which elements are associated with disability.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	hemodialysis." Kidney Int **73**(11): 1289-1295.	IADL, functional deficits in older dialysis patients, to characterize the proportion of patients with one or more disabilities in the four core ADL self-care tasks (bathing, dressing, transfer from bed to chair and walking in the home) and to identify clinical variables that are associated with functional dependence.	interpreter, due to death (n=4), with-drawn consent (n=1) and prolonged hospitalisation (n=1). All patients were aged 65+.	and having fewer years of education. There was no relationship between diabetes, gender, depressive symptoms cause no disability.	and dependence (is requiring help from one another).	IADLs involve household management tasks such as shopping, housecleaning, laundry, meal preparation, transportation, telephone use, and management of medications and finances, whereas ADLs are self-care tasks comprising bating, grooming, dressing etc.	happening at a point in time.	
4.	Farragher, J. and S. V. Jassal (2012).	This review outlines the causes	Seminars in dialysis, the number of patients reviewed	Rehabilitation can delay or prevent the onset of disability and	Disability was not strictly defined by the article alluded	Disability was not strictly discussed but a	The main limitation of the paper is that	The strengths of this paper are they have

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	"Rehabilitation of the geriatric dialysis patient." Semin Dial **25**(6): 649-656.	of disability in elderly dialysis patients and demonstrates the impact rehabilitation could have using a case example.	was not discussed, nor was the inclusion/exclusion criteria.	dependence and describes the utility of rehabilitation in practise. There are often subtle hints in functional decline that would be useful to be noticed.	to disability frequently in the way that the aim of rehabilitation is to prevent disability.	diagram describing how rehabilitation can aid in preventing disability and looking at case-by case examples became helpful in illustrating this.	although it uses a case study to discuss rehabilitation and its importance, disability is not defined and the number of papers and their inclusion criteria are not discussed.	used a case example to talk through how they may go about rehabilitating an individual and how this case by case scenario may be able to be translated into practise.
5.	Farrokhi, F. and S. V. Jassal (2013). "Routine use of an abbreviated 4-item scale to assess dependence in essential activities of daily living amongst elderly hemodialysis patients: a validation study." Int Urol Nephrol **45**(1): 259-264.	The objective of the study was to validate results of 4 item using a self-report scale against the results of formal assessment for disability using the Barthel Index.	Cohort Study of 167 participants. Patients were 65 years or older and had been receiving chronic maintenance HD over 12 months, followed prospectively for at least 2 years.	The 4-item scale is a simple, valid screening test for disability, it could be used as a screening tool. Although stair climbing may be overlooked. Previous studies show that dialysis leads to disability. Patients with severe disability had significantly higher risk of death after correlation for age, comorbidity and dialysis vintage.	Disability was not really defined clearly but methods to measure it were discussed.	Activities of daily living (ADL), the Falls Efficacy Scale (FES). 4 item scale was validated against the Barthel Index.	A limitation of the study is they don't really discuss the prospective results.	A strength of the study is that it is a cohort, it has 167 participants and it has used a measure to evaluate a new measure and had identified disability as being an issue for CKD patients.
6.	Fried, L. F., et al. (2006). "Chronic kidney disease	To assess whether CKD was associated	Prospective quantitative cohort study.	CKD is associated with the development of functional impairment independent of	Disability wasn't explicitly described however	Functional limitation was based on measuring	Not exclusively CKD stage five but does split the results into	Excluded those with functional limitations at the start so we

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	and functional limitation in older people: health, aging and body composition study." JAGS**54**(5): 750-756.	with incident physical limitation.	2135 aged 70-79 without functional limitations and participants were contacted every 6 months. Included participants aged 7—79 with no difficulty in performing activities of daily living, in walking a quarter mile, and upstairs, no plans to move and no cancer in prior three years. No criteria based on kidney function. Participants excluded if they had coronary heart disease, low ankle arm index, depressed, arthritis and diabetes.	comorbidity, body composition and tests of strength and physical performance, this may be due to the inflammatory state in CKD.	functional limitation was.	baseline function (difficulty in walking, difficulty in performing activities, step difficulty) and then asked about this and the change throughout the cohort.	different disease severities. Additionally, they had no inclusion/exclusion criteria based on kidney function. They noted that participants were more likely to be excluded if they were older, black, lower education. The worse a kidney function the more functional limitation. Low numbers with CKD stage five.	could look at incident cases. Could adjust for a broad range of clinical variables. Recommended that future studies looked at ways to reduce this disability.
7	Greco, A., et al. (2014). "Frailty, disability and physical exercise in the aging process and in chronic kidney disease." Kidney Blood	The aim of this review was to examine and discuss how and when physical exercise may	Narrative review, the number of papers reviewed, and the inclusion/exclusion criteria was not discussed.	Physical exercise has been found to be effective in preventing frailty and disability in this population. Elderly and CKD patients are both affected by an impaired physical performance that may be reversed by physical exercise with an	Frailty is a state of vulnerability to poor resolution of homoeostasis after a stressor event and is a consequence of cumulative decline in many physiological	Disability was not described directly however it is noted that exercise could help improve endurance and exercise training could help CKD patients.	The major limitation of this paper is that it did not include the inclusion/exclusion criteria or list the number of papers include in this review.	This paper outlined how fragility, exercise and disability affect CKD patients.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	Press Res **39**(2-3): 164-168.	positively affect frailty and disability both in CKD and elderly patients.		improvement of the survival rate.	systems during a lifetime.			
3.	Intiso, D. (2014). "The rehabilitation role in chronic kidney and end stage renal disease." Kidney Blood Press Res **39**(2-3): 180-188.	The aim of this review was to highlight the effect of rehabilitation in CKD patients.	Narrative review. The number of papers reviewed, and the inclusion/exclusion criteria was not discussed.	It is recommended that exercise training should be implemented in CKD patients to help reduce disability occurrence. Age, hypertension and diabetes are key predictors of secondary CKD. CKD associated with increased risk of functional impairment.	Rehabilitation is the use of means aimed at reducing the impact of disabling and handicapping conditions and enabling those with disability to achieve optimal social integration.	Disability was not directly measured or defined however the association of how disability is caused is well discussed.	The major limitation of this paper is the number of papers and the inclusion/exclusion criteria of the papers is not described in detail.	They describe how as rehabilitation is used this allows for improved outcomes for those with CKD.
.	Jassal, S. V., et al. (2008). "Geriatric hemodialysis rehabilitation care." Adv C K D **15**(2): 115-122.	Provide background information about functional status in older dialysis patients and to discuss the utility of geriatric dialysis rehabilitation.	Narrative review. The number of papers reviewed and the inclusion/exclusion criteria was not discussed.	Older dialysis patients were at higher risk than usual of accidental falls and subclinical spinal fractures both of which lead to mobility limitations and functional disability or death. Rehabilitation has the potential for improvement.	Functional disability is defined as the inability to perform daily tasks. Disability is defined as a restriction or lack of ability to perform an activity in a normal manner.	How disability was measured was not discussed in detail.	The review did not describe the number of papers included and the inclusion/exclusion criteria of the papers was not described.	This paper has a great diagram explaining the disability process in dialysis patients.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
10.	Kutner, N. G., et al. (2000). "Functional impairment, depression, and life satisfaction among older hemodialysis patients and age-matched controls: a prospective study." ACRM **81**(4): 453-459.	To compare change over time in functional impairment, depression and life satisfaction among older dialysis patients and age-matched controls.	Prospective Cohort Study. 113 Prevalent renal failure patients on in-centre haemodialysis and 286 controls across a period of three years. All patients were older than 60 years. Cases had been receiving dialysis at the baseline interview in 1988. Had to be living in Georgia. They could not be living in a nursing home, not receive a transplant or experienced return of renal function.	Dialysis patients compared to controls reported more functional impairment at baseline and at follow-yup after adjusting for baseline impairment and covariates. Older patient's life satisfaction at 3-year follow-up was similar to life satisfaction of those not on dialysis.	Disability as a definition is not specifically discussed, however it is alluded to and measured through the physical impairment index.	Disability was measured with a functional impairment index. They also collected information on non-renal health problems, depression and life satisfaction.	This paper is not exclusively 65+ although is 64-88 in the dialysis cohort and 59-88 in the non-CKD cohort.	High response rate of cases of 95% at baseline. Only 80% of controls were sampled at baseline.
	Lam, M. and S. V. Jassal (2015). "The concept of frailty in geriatric chronic kidney disease (CKD) patients." Blood Purif **39**(1-3): 50-54.	The aim of this study was to discuss fragility and its development in the CKD population.	Review. The number of papers and the inclusion/exclusion criteria was not described.	Elderly patients with CKD have a higher prevalence of frailty compared to those with normal renal function. Key factors were unintentional weight loss, weak grip strength, self-reported exhaustion, and slow gait speed and low energy expenditure. Social vulnerability can cause fragility. No simple steps to stop frailty.	Frailty was defined as irreversible age-related deterioration. Comorbidity is an etiologic risk factor for frailty, and disability is an outcome of this condition.	The frailty score index is a score based upon the total number of deficits from a list of 70 components of health, this list excludes renal disease.	A limitation of this paper is they did not describe the methods involved in selecting papers for his review, additionally frailty is the focus and alludes to disability.	A strength of this study is that they describe how the presence of frailty in CKD patients.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	Shlipak, M. G., et al. (2004). "The Presence of Frailty in Elderly Persons with Chronic Renal Insufficiency." AKJD**43**(5): 861-867.	To determine if chronic renal insufficiency (CRI) would be associated with a greater prevalence of frailty and disability in the elderly.	Cross-sectional analysis in a cohort fashion of 5,888 community-dwelling adults. 5,888 community-dwelling adults. Aged 65 or older in four clinical centres in the United States. Not institutionalised, expected to remain in current community for more than three years, not under active cancer treatment and informed consent.	Elderly patients with CKD have a high prevalence of frailty, which may signal their risk for progression to adverse health outcomes. Those with CKD are three times as likely to be frail compared to those with normal renal function. Fatigue, weakness and weight loss may be subtle pre-uremic consequences of even mild chronic kidney disease.	Disability is defined as any self-reported exhaustion, measured weakness, slow walking speed and low physical activity. It is also defined as any difficulty in ADLs, including eating, transferring from bed to chair, mobility inside the home, dressing, bathing and using the toilet.	Defined frailty through weight loss, poor endurance and energy.	Not exclusively CKD stage 5, actually there wasn't enough of these patients to do their analysis. This study is cross-sectional.	This study recommended that more is done to understand the pathway which leads to frailty and disability on the CKD population.
13.	Tappe, K., et al. (2001). "Disability under Social Security for patients with ESRD: an evidence-based review." Disabil Rehabil **23**(5): 177-185.	This study analysis whether those with CKD should automatically be eligible for the disability benefits under the social security act.	Systematic review Initially 3491 documents, 503 relevant articles were read. Only 14 of the articles contained information about CKD stage five and the ability to work. 27 databases were included, from the date of their development to December 1998. Articles were selected based on exclusively focusing on CKD stage five,	Employment was significantly less likely among patients with peripheral vascular disease, pulmonary disease, limitations in performing at least one activity of daily living and HIV or AIDs. Not enough information to allow for conclusion above whether the disability criteria should be changed.	The law describes disability as the inability to perform any substantial gainful activity by reason of any medically determinable physical or mental impairment that can be expected to result in death or that has lasted or can be expected to last for a continuous period of not less than 12 months.	Disability was measured with a performance of activity score.	Not specifically the 65+, however they split the results into 65+ and those not 65+. The study was never able to identify what ability meant. It is difficult to measure inability. Not enough information on employment status as an outcome measure.	This was a very clear systematic review, with hood inclusion and exclusion criteria.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How Disability was described	How Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
			and employment status..					
4.	Tawney, K. W., et al. (2003). "Disablement and rehabilitation in end-stage renal disease." Semin Dial **16**(6): 447-452.	The review focused on the disablement process, particularly in CKD patients.	Review, the number of papers reviewed, and the inclusion/exclusion criteria was not discussed.	Patients with CKD are still encumbered by physical limitations in numerous daily activities, which combine to reduce patient QoL. There is a need for rehabilitative interventions to restore or rehabilitate individuals with CKD.	Pathology represents the presence of disease; impairment reflects the anatomic or structural abnormalities of the impairments. Functional limitations result from impairment and cause the inability to perform usual takes, which leads to disability which is the inability to perform social roles.	The paper aimed to model the disablement process.	Major limitation of this paper is it did not include the number of papers reviewed, how they were included or define the type of review it was.	This paper identifies some key factors for the disablement process in CKD and provides some great tables and diagrams to illustrate this. Overall this is a fantastic paper.

Table II (3): Overview of Scoping Review of literature discussing 'HRQoL and Disability in those with CKD'

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL and Disability was described	How HRQoL and Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
1.	Fidan, F., et al. (2016). "Quality of life and correlation with musculoskeletal problems,	The aim of this study was to investigate HRQoL in patients with HD	Cross-sectional study of 50 patients Exclusion were the presence of chronic conditions such as cancer, amaurosis, chronic hearing loss,	All patients had one or more musculosketal problem. Physical functioning depends mainly on the age, severity of comorbid conditions, depression,	This paper doesn't detail how HRQoL or disability can be described but explains measures used to	The KDQoL, the duruoux hand index (DHI), visual analog scale (VAS) and beck depression inventory (BDI).	Limitation is it is not strictly 65+ and it's a relevantly small sample size.	The strength of this study is it is one of the few studies that analysed HRQoL and disability.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL and Disability was described	How HRQoL and Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	hand disability and depression in patients with hemodialysis." Int J Rheum Dis **19**(2): 159-166.	with KDQoL and to determine the relationships with conventional clinical measures, musculoskeletal	HIV or neurological diseases.	locomotor findings and hand disability of HD patients. The KDQoL is related to the clinical status and functional ability of HD patients and it can be used as a sensitive health status measure of clinical evaluation. Patients over 65 had poorer KDQoL-36 than those under 65. Physical functioning dependent on age, comorbid conditions, depression, musculoskeletal problems and hand disability.	measure HRQoL and disability.	Also collected demographic		
2.	Kim, J. C., et al. (2017). "Sp637effect Of Dialysis Modality On Frailty Phenotype, Disability, And Health Related Quality Of Life In Maintenance Dialysis Patients." Nephrol Dial Transpl	The aim of the present study was to evaluate the differences in HRQoL, frailty and disability according to dialysis modality in the Korean population.	Cross-sectional study of Korean dialysis patients in 27 hospitals or dialysis centres in Daegu/Kyungsangpook. 1,616 patients were recruited. 1250 were HD patients and 366 were PD patients between July and December 2012. Excluded if under 20 years old, receiving dialysis for less than 6 months, having a	No significant difference in frailty between patients treated with the two dialysis modalities, disability was more common in PD than HD patients. This is regardless of physical functional status. Type of PD may influence the outcome.	These were not defined however the way they were measured was discussed.	Demographic and laboratory data were collected about age, sex, comorbidities, frailty, disability and HRQoL scales. Disability was assessed with the activities of daily living (ADLs) scores.	A limitation is it was not exclusively 65+. Retrospective nature not evaluate frailty phenotype.	The strengths of this study were the large sample size and the ability to measure a large range of data measured.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL and Disability was described	How HRQoL and Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	32(suppl_3): iii351.		history of hospitalisations, being unable to walk, unable to communicate or not having laboratory findings.					

Table II (4): Overview of Scoping Review of literature discussing 'HRQoL and Disability in Māori with CKD'

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL and Disability was described	How HRQoL and Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
1.	Shih, L. (2010). "How does dialysis treatment affect the lives of rural Maori patients?" Kai Tiaki Nursing NZ 16(10): 12-14.	The aim of this study was to determine how Māori perceive there dialysis care.	Qualitative Interviews. 7 Māori HD patients, were chosen from the 26 patient's receiving dialysis at the units. Consent forms were sent to patients who had been on dialysis for more than three months and who had no other major health issues that would impede the interview process like deafness.	CKD management for Māori should consider individuals, families and communities holistically. The strength of Māori communities is built on the well-being of each family. There were four main themes from the study were facing fear, stress from requiring dialysis, having to learn, adjust and change your attitude and family support is most important.	HRQoL and disability wasn't described in detail.	HRQoL and disability wasn't described in detail however it would it still provides a useful insight into individual's experience.	Not strictly about HRQoL or disability.	Provides personal perspective on dialysis and the issues associated with it.
2.	Tan, J., et al. (2015). "Long-term effectiveness	The aim of this study was to determine	Randomised Control Trial. 65 Māori and Pacific patients with either	The main findings are that the unique benefits found were that the community-based	Once again, a limitation is it did not discuss HRQoL and	Not specifically but viewed as online outcomes.	The limitations of this study are that they were not exclusively	This study analysed the effect of a community-

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL and Disability was described	How HRQoL and Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	of a community-based model of care in Māori and Pacific patients with type 2 diabetes and chronic kidney disease: a 4-year follow up of the DElay Future End Stage Nephropathy due to Diabetes (DEFEND) study." Intern Med J **45**(8): 843-849.	longer term outcomes of a community approach to try and overcome some of the barriers of poor health care for Māori and Pacific peoples.	uncontrolled hypertension and CKD stage 3 or 4, 33 received community-based intervention of home visits and 32 received usual care. Intervention group received monthly home visits. 65 Maori and Pacific patients were included for uncontrolled hypertension and CKD stage 3 or 4.	intervention did not translate to longer term community based benefits.	disability in detail however it was still important to include this paper as it specifically looks at long term outcomes from a potential intervention.		65+, or CKD stage five and it was a relatively small sample size	based intervention on BP and CKD outcomes 4 years post trial in the Maori and Pacific communities which is a unique study and aided in allowing for understanding the development of HRQoL and disability.
3.	Walker, R., et al. (2016). “Maori patient’s experience, values and perspectives of chronic kidney disease.” . Nephrology, Wiley-Blackwell 111 River St,	The aim of this study was to explore and describe Māori patients experience and perspectives of CKD, as these are largely	Qualitative Interviews. 13 Māori patients with CKD and who were either nearing the need for dialysis or had started dialysis within the last 12 months. Face-to-face semi structures interviews with purposive sampling and thematic analysis.	The Māori concepts of whakamā (disempowerment and embarrassment) and whakamana (sense of self-esteem and self-determination) provide an overarching theme. Developing sustaining relationships. Māori patients with CKD experienced marginalisation within the NZ healthcare system.	This was not described in detail however still an important concept are discussed that allude to how disability is described.	Qualitative interviews so this information was only included if individuals mentioned this information.	The limitation of this paper is no in-depth discussion on disability and HRQoL.	This study again provides a great insight into Māori perspectives towards dialysis and explains how whakamāna is important.

No	Bibliography Details	Aim	Study Design	Key findings and conclusions	How HRQoL and Disability was described	How HRQoL and Disability was measured or discussed	Limitations of the paper	Strengths and relevance of the paper
	Hoboken 07030-5774, NJ USA	unknown for indigenous groups with CKD.						

Appendix III: Tables to Support the Results

Table III (1) Multivariable analysis of variables predicting WHODAS 2.0 ≥10 representing 'considerable disability' at 12 months (n=156) with age, sex, ethnicity and the EQ-5D-3L variables fixed.

Variable	Relative Risk	95% CI	P-value	Overall P
Sex				
Male	Ref			
Female	1.27	0.99-1.62	0.052	
Age group				
<75 years	Ref			
75+ years	1.06	0.80-1.39	0.694	
Ethnicity				
Non-Māori, Non-Pacific	Ref			0.921
Māori	1.01	0.73-1.38	0.975	
Pacific	1.08	0.75-1.55	0.696	
Dialysis vintage				
Non-dialysis	Ref			0.015
<2 years	0.53	0.25-1.14	0.103	
≥2 years	0.38	0.18-0.83	0.015	
Dialysis location				
Non-dialysis	Ref			0.061
Home (HD+PD)	2.25	1.03-4.94	0.042	
In centre	1.65	0.77-3.56	0.201	
EQ-5D mobility				
No problems	Ref			
Moderate-severe problems	1.31	0.93-1.86	0.126	
EQ-5D-3L self-care				
No problems	Ref			
Moderate-severe problems	1.31	1.03-1.67	0.028	
EQ-5D-3L usual activities				
No problems	Ref			
Moderate-severe problems	1.28	0.91-1.80	0.152	
EQ-5D-3L pain/discomfort				
No problems	Ref			
Moderate-severe problems	1.00	0.77-1.31	0.988	
EQ-5D-3L anxiety/depression				
No problems	Ref			
No problems	1.00	0.75-1.33	0.994	
Disability at baseline (WHODAS 2.0)				

WHODAS <10	Ref		
WHODAS ≥10	1.73	1.25-2.40	0.001

Variables included but not retained; number of comorbidities, living arrangements and cognitive function

Table III (2): Multivariable analysis of variables predicting WHODAS 2.0≥ 10 representing 'considerable disability' at 12 months (n=156) with the EQ-5D-3L variables fixed.

Variable	Relative Risk	95% CI Lower	95% CI Upper	P
Sex				
Male	1			
Female	1.28	0.96	1.55	0.107
Age group				
>75 years	1			
75+ years	1.08	0.83	1.41	0.547
Ethnicity				
Non-Māori, Non-Pacific	1			
Māori	0.89	0.64	1.24	0.508
Pacific	0.98	0.69	1.40	0.904
EQ-5D-3L mobility				
No problems	1			
Moderate-severe problems	1.36	0.94	1.96	0.104
EQ-5D-3L self-care				
No problems	1			
Moderate-severe problems	1.19	0.95	1.48	0.135
EQ-5D-3L usual activities				
No problems	1			
Moderate-severe problems	1.26	0.88	1.81	0.207
EQ-5D-3L pain				
No problems	1			
Moderate-severe problems	1.06	0.82	1.37	0.650
EQ-5D-3L anxiety				
No problems	1			
Moderate-severe problems	0.98	0.73	1.32	0.912
Disability at baseline (WHODAS 2.0)				
WHODAS <10	1			
WHODAS ≥10)	1.69	1.20	2.39	0.003

Variables included but not retained; living arrangements, number of comorbidities, cognitive function and dialysis vintage.

Table III (3) Characteristics of Māori participants followed up to 12 months (n=37) compared to baseline only participants (n=12)

Variable	Baseline(n=12)	%	Followed till 12 months (n=37)	%	P value
Sex					0.035
Male	10	36	18	64	
Female	2	10	19	90	
Age group					0.861
<75 years	10	25	30	75	
75+ years	2	22	7	78	
Dialysis vintage					0.656
Non-dialysis	2	20	8	80	
<2 years	6	32	13	68	
≥2 years	4	20	16	80	
Dialysis location					0.744
Non-dialysis	2	17	10	83	
Home (HD+PD)	3	30	7	70	
In-centre	7	26	20	74	
Number of comorbidities					0.200
0-2	3	15	17	85	
3+	9	31	20	69	
Living arrangements					0.890
With others	9	25	27	75	
Alone	3	23	10	77	
EQ-5D-3L mobility					0.656
No problems	4	21	15	79	
Moderate-severe problems	8	27	22	73	
EQ-5D-3L self-care					0.962
No problems	9	24	28	76	
Moderate-severe problems	3	25	9	75	
EQ-5D-3L usual activities					0.807
No problems	6	26	17	74	
Moderate-severe problems	6	23	20	77	
EQ-5D-3L pain/discomfort					0.456
No problems	7	29	17	71	
Moderate-severe problems	5	20	20	80	
EQ-5D-3L anxiety/depression					0.179
No problems	12	27	32	73	
Moderate-severe problems	0	0	5	1	
Disability at baseline (WHODAS 2.0)					0.456
WHODAS <10	5	20	20	80	
WHODAS ≥10	7	29	17	71	

Variable	Baseline(n=12)	%	Followed till 12 months (n=37)	%	P value
Treatment type					0.900
Non-dialysis	2	20	8	80	
Haemodialysis	8	27	22	73	
Peritoneal Dialysis	2	22	7	78	
Cognitive function					0.909
No problems	8	25	24	75	
Moderate-severe problems	4	24	13	76	

***Row percentages have been presented.**