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The experiences of adults who are on dialysis and waiting for a renal transplant from a deceased donor: a systematic review

Abstract

Background Kidney transplantation has been recognized as the best renal replacement therapy option for people with end stage renal disease. With an estimated 170,000 people waiting for a kidney transplant around the world and a limited supply of donor organs, the waiting time is often prolonged for many years. **Objectives** The aim of this review was to examine the existing evidence of patients' experiences of living on dialysis and waiting for a renal transplant from a deceased donor. **Search strategy** The search strategy aimed to find both published and unpublished studies through electronic databases, reference list searches and the World Wide Web. Extensive searches were undertaken of the CINAHL, Embase, Medline and PsychInfo databases of published literature, the Cochrane Database of Systematic Reviews and the Virginia Henderson International Nursing Library, OpenGrey and the New York Academy of Medicine databases of unpublished literature. **Methodological quality** Each study was assessed for methodological quality by two independent reviewers using the Joanna Briggs Institute Qualitative Assessment and Review Instrument checklist. Disagreements between the reviewers were resolved through discussion or with a third reviewer. **Results** A total of 12 studies were included in the final review. Thirty-seven findings from the 12 studies were extracted and aggregated into 11 categories and then into three synthesized findings. The three synthesized findings were: People who are waiting for a kidney transplant from a deceased donor are affected by the experience of living on dialysis with end stage renal disease and its impact on their physical health and normal activities of living. The experience of waiting for a kidney transplant from a deceased donor impacts a person's psychological wellbeing People who are waiting for a kidney transplant from a deceased donor place value on relationships and being part of a community. The experience of waiting for a renal transplant from a deceased donor while living on dialysis with end stage renal disease changes a person's relationships. **Conclusions** Synthesized findings of the review conclude that people who are waiting for a kidney transplant from a deceased donor live with the physical effects of a life limiting chronic illness and dialysis therapy. Waiting for a kidney transplant is psychologically challenging. People waiting for a kidney transplant value knowledge, although the information they require to alleviate the uncertainty they feel is not available. The dynamics of relationships with family and friends are affected by the experience of waiting for a kidney transplant. People can feel isolated from others leading a 'normal' life, while new relationships are developed within the medical team and community of dialysis patients.

Disciplines

Medicine and Health Sciences | Social and Behavioral Sciences

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The experiences of adults who are on dialysis and waiting for a renal transplant from a deceased donor: a systematic review

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Executive summary

Background

Kidney transplantation has been recognized as the best renal replacement therapy option for people with end stage renal disease. With an estimated 170,000 people waiting for a kidney transplant around the world and a limited supply of donor organs, the waiting time is often prolonged for many years.

Objectives

The aim of this review was to examine the existing evidence of patients' experiences of living on dialysis and waiting for a renal transplant from a deceased donor.

Inclusion criteria

Types of participants

This review considered studies that included adult patients aged 18 years and over who had been on dialysis (hemodialysis or peritoneal dialysis) for up to 15 years and who were waiting for a renal transplant from a deceased donor.

Types of intervention(s)/phenomena of interest

The phenomena of interest were the experiences of adults waiting for a renal transplant from a deceased donor and more specifically, the impact of waiting on their lifestyle and day to day living.

Types of studies

This review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Types of outcomes

This review considered studies that included the experiences of people who were waiting on dialysis for a kidney transplant from a deceased donor.

Search strategy

The search strategy aimed to find both published and unpublished studies through electronic databases, reference list searches and the World Wide Web. Extensive searches were undertaken of the CINAHL, Embase, Medline and PsychInfo databases of published literature, the Cochrane Database of Systematic Reviews and the Virginia Henderson International Nursing Library, OpenGrey and the New York Academy of Medicine databases of unpublished literature.

Methodological quality

Each study was assessed for methodological quality by two independent reviewers using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) checklist. Disagreements between the reviewers were resolved through discussion or with a third reviewer.

Data collection

Qualitative data was extracted from papers included in the review using the standardized data extraction tool from JBI-QARI.

Data synthesis

Qualitative research findings were pooled to generate a set of statements that represented the aggregation and categorizing of these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a comprehensive set of synthesized findings that can be used as a basis for evidence-based practice.

Results

A total of 12 studies were included in the final review. Thirty-seven findings from the 12 studies were extracted and aggregated into 11 categories and then into three synthesized findings. The three synthesized findings were:

1. People who are waiting for a kidney transplant from a deceased donor are affected by the experience of living on dialysis with end stage renal disease and its impact on their physical health and normal activities of living.
2. The experience of waiting for a kidney transplant from a deceased donor impacts a person's psychological wellbeing
3. People who are waiting for a kidney transplant from a deceased donor place value on relationships and being part of a community. The experience of waiting for a renal transplant from a deceased

Conclusions

Synthesized findings of the review conclude that people who are waiting for a kidney transplant from a deceased donor live with the physical effects of a life limiting chronic illness and dialysis therapy. Waiting for a kidney transplant is psychologically challenging. People waiting for a kidney transplant value knowledge, although the information they require to alleviate the uncertainty they feel is not available. The dynamics of relationships with family and friends are affected by the experience of waiting for a kidney transplant. People can feel isolated from others leading a 'normal' life, while new relationships are developed within the medical team and community of dialysis patients.

Implications for practice

There is limited evidence from the review to support the development of recommendations for clinical practice. Healthcare workers caring for people who are waiting for a kidney transplant from a deceased donor should be mindful of the physical and lifestyle effects of living on dialysis with ESRD. Wherever possible, information should be provided to alleviate the stress and anxiety related to the uncertainty of waiting. The experience of waiting is stressful and people waiting for a kidney transplant may require support and reassurance. It is important to recognize that there are people within communities who may also benefit from receiving information and encouragement. Significant community members should be included in invitations to appointments and education sessions with the consent of the person being treated.

Implications for research

Future studies should be undertaken exclusively with people waiting for a kidney transplant from a deceased donor. Qualitative research designs such phenomenology and grounded theory could be used to investigate the psychological experience of waiting and the relationship between hope, uncertainty and knowledge. Quantitative studies using validated tools could also be conducted. By producing more evidence relating to this significant specific patient population, interventions to improve the experience of waiting could be developed and trialled.

Keywords

Kidney/renal failure, kidney/renal transplant, quality of life, experiences, deceased donor transplant, cadaveric transplant, qualitative, dialysis

Introduction

Background

Chronic kidney disease (CKD) is a progressive, irreversible condition diagnosed on the basis of a reduced glomerular filtration rate (GFR), abnormalities in the composition of the blood or urine, or abnormalities in imaging.¹ A diagnosis of CKD requires a GFR of $<60\text{ml/min/1.73m}^2$ and the presence of kidney damage for a period of at least three months.² Chronic kidney disease is categorized into five stages based on the GFR. Stage five CKD is also known as end stage renal disease (ESRD) and is said to occur when the GFR is $<15\text{ml/min/1.73m}^2$ and when renal replacement therapy (RRT) is required in order to support life.^{2,3} Treatment choices for RRT include hemodialysis (HD), peritoneal dialysis (PD) or kidney transplantation. Kidney transplantation has been recognized as the best RRT in terms of morbidity, mortality and quality of life (QOL).^{4,5} At the end of 2013 it was estimated that over 170,000 people around the world were waiting for a kidney transplant.⁶

Donor organs for kidney transplant are available from either a living or a deceased donor.⁷ The process of transplantation from either a living or a deceased donor is protected with legislation including global agreements¹³ and national and regional laws.⁸⁻¹⁰ Some parts of the world allow the pre-emptive listing of patients to receive a deceased donor transplant before they start dialysis, while others, including Australia, do not allow patients to be put on a waiting list until they have commenced dialysis.¹⁰

Because there are more people waiting than there are available organs, the waiting time is often prolonged for many years. Due to the nature of the organ allocation process it is possible, although rare, for a person to receive a donor organ after only a few months.¹¹ The average waiting time for a kidney transplant from a deceased donor ranges from 3.1 to four years.^{11,12}

With other solid organ transplants such as liver, heart or lung, people die if an organ does not become available, but with kidneys, dialysis is able to maintain the patient's life for many years.¹³ While it is positive that dialysis is available to keep a patient alive while waiting for a transplant, the length of time spent living on dialysis while waiting for a transplant has been shown to impact both physical¹⁴ and psychological aspects of the QOL of patients.^{15,16} Studies have found that increased time on dialysis is a strong independent risk factor for increased patient mortality and graft failure following renal transplantation.¹⁷ People on dialysis have been shown to have multiple stressors in their lives with depression thought to be the most common psychiatric abnormality.¹⁸ Meta-analysis of 52 studies reporting on the QOL of people based on the different types of RRT indicated that scores for patients on dialysis (HD and PD) were lower, indicating a poorer QOL, compared to those with a functioning renal transplant.¹⁹

There are a small number of qualitative studies exploring the experience of waiting for a transplant of organs other than kidneys²⁰⁻²⁶ but this experience may be fundamentally different because transplantation of organs such as the liver, heart and lung are lifesaving procedures undertaken when there is an impending and significant threat to life. The experience of waiting in this context may not be the same as waiting for a kidney where life can be maintained with dialysis for an indefinite period of time.

Similarly, studies examining the experiences of patients waiting for a transplant from a living donor^{27,28} are also different to this population because the donor is usually known to the recipient, either a relative or someone with an altruistic motive for donating²⁹, and the dynamics of the relationship between the donor and the recipient alter the experience of waiting.³⁰ Waiting for a transplant from a living donor is an active process with a finite goal, compared to waiting for the unclear, indefinite end point in the case of a transplant from a deceased donor.³¹

Qualitative studies that have examined the experiences of people on dialysis who are waiting for a deceased donor renal transplant have shown that symptoms of anxiety and depression increase during the waiting period.¹⁶ Although some primary research has been conducted on this population, these studies have not been systematically reviewed. The purpose of this review is to examine the existing evidence of patients' experiences of living on dialysis while waiting for a renal transplant from a deceased donor, in order to underpin the development of effective supportive interventions.

Prior to commencement of this review a search was performed through the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, the Cochrane Library, CINAHL, Medline and PsycInfo to ensure that no such previous systematic reviews had been published.

Objectives

The objective of this systematic review was to synthesize qualitative evidence relating to the experiences of adults with ESRD who are on dialysis and waiting for a renal transplant from a deceased donor.

Inclusion criteria

Types of participants

This review considered studies that included adult patients who were aged 18 years and over when they started dialysis, in order to examine the experiences of adults rather than children or adolescents. It only considered studies including people who were waiting for a renal transplant from a deceased donor and who had been on dialysis (HD or PD) for up to 15 years. The advent of erythropoietin in the mid-1980s combatted the effects of

anemia associated with ESRF and considerably improved the QOL of people on dialysis.^{32,33} Around the same time advances in immunosuppressive medication meant that transplantation became a feasible option with good outcomes for more people.³⁴ Therefore studies of people who have been on dialysis for up to 15 years were included, because people who were on dialysis for longer than 15 years may have had experiences that are not typical today. This review considered studies if it was evident from the participant selection information or findings section that participants were waiting for a transplant from a deceased donor.

This review did not consider patients receiving dialysis for acute renal failure, patients who were waiting for a transplant from a living donor or people waiting for a pre-emptive transplant from a deceased donor.

Phenomena of interest

This review considered studies that investigated the experiences of adults who are waiting for a renal transplant from a deceased donor including the impact that waiting for a transplant had on lifestyle and day-to-day living.

Context

This systematic review considered studies involving adults with ESRF who were on either HD in a hospital or a satellite unit or at home, or on PD, and who were waiting for a kidney transplant from a deceased donor.

Types of studies

This review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was employed in this review. An initial limited search of MEDLINE and Embase was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms was undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. Only studies published in English were considered for inclusion in this review. Studies published from 1985 to 2013 were considered for inclusion, which reflected the advances in both dialysis and transplantation previously mentioned.

The databases searched included:

CINAHL (Cumulative Index to Nursing and Allied Health Literature) (1985 – 2013)

MEDLINE (Medical Literature Analysis and Retrieval System Online) (1985 – 2013)

Embase (Excerpta Medica Database)(1985 – 2013)

Cochrane Database of Systematic Reviews

PsycINFO (Ovid)

The search for unpublished studies included:

ProQuest Dissertations and Theses

OpenGrey

Virginia Henderson International Nursing Library

New York Academy of Medicine

Initial keywords to be used were: kidney/renal failure, kidney/renal transplant, quality of life, experiences, not living donors, waiting, qualitative, dialysis

A detailed search strategy has been reported in Appendix I.

The literature search was carried out in consultation with the librarian at Wollongong University. Separate search strategies were carried out for each database and references were entered into Endnote. All duplicate references were removed.

Method of the review

Papers were read in full and assessed by two independent reviewers for methodological validity using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II) prior to their inclusion in the review. No disagreements between the reviewers occurred and therefore the involvement of a third reviewer was not required. In order to include only high quality studies, a cut off value of Mean minus one Standard Deviation was used.

Data collection

Data was extracted from papers included in the review using the standardized data extraction tool from JBI-QARI

(Appendix III). The data extracted included specific details about the phenomena of interest, populations, study methods and outcomes relating to waiting for a kidney transplant. If participants in the study included both those waiting and those not waiting for a transplant, only findings that specifically related to waiting for a transplant were extracted. The level of credibility of the findings was deemed to be “unequivocal” where the finding was supported either by reference to comments made by the participants or by the use of direct quotations of the participant’s words. Where the finding was made without reference to words spoken by the participants, but with logical progression from other findings and comments the finding was deemed “credible”. In the two studies where all the participants were waiting for a transplant^{35,36} there was a total of eighteen findings of which 14 were “unequivocal” and four were “credible”. In the other ten studies where the participants included both people waiting and not waiting for a kidney transplant³⁷⁻⁴⁵ a total of fifteen findings were found relating to waiting for a transplant. One of these was a “credible” finding while the other fourteen were “unequivocal”.

Data synthesis

Qualitative research findings were pooled using JBI-QARI. This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice.

Results

Search results

There were 887 studies identified from the search strategy and 17 from other sources. Following removal of 33 duplicates the majority of the remaining papers were excluded based on a review of the title and abstract against the inclusion criteria. A total of 16 studies were deemed potentially eligible for the review and full text of these studies was obtained. The 16 studies were critically appraised for methodological quality using the JBI QARI critical appraisal checklist for interpretive and critical research (Appendix II). Based on the JBI-QARI assessment of methodological quality, the calculated mean quality score was 16.88 (SD 2.28) (Table 1), therefore the quality threshold score was calculated to be 14.6. Two studies with scores below the quality threshold were excluded.^{46,47} A further two papers were excluded as two of the studies resulted in the publication of two papers each,^{15,48} therefore only one paper for each study was included. This left a total of 12 studies included in the review. The search process for the review is included below in Figure 1 and the critical appraisal scores are recorded in Table 1.

PRISMA 2009 Flow Diagram

Figure 1: Flow-chart for the search and study selection process

Table 1: Methodological quality scores

JBI critical appraisal checklist for interpretive and critical research											
Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Overall Appraisal Value
Included studies											
Calvey D, Mee L., 2011	2	2	2	2	2	0	1	2	2	2	17
Dekkers W, Uerz I, Wils J-P., 2005	2	2	2	2	2	2	1	2	1	2	18
Hagren B, Pettersen I, Severinsson E, Lützén K, Clyne N., 2001	2	2	2	2	2	1	1	2	2	2	18
Herlin C, Wann-Hansson C., 2010	2	2	2	2	2	1	2	2	2	2	19
Kaba E, Bellou P, Iordanou P, Andrea S, Kyritsi E, Gerogianni G, et al., 2007	2	2	2	2	2	0	0	2	2	2	16
Landreneau KJ, Ward-Smith P., 2007	2	2	2	2	2	0	2	2	2	2	18
Moran A., 2008	2	2	2	2	2	2	2	2	2	2	20
Polaschek N., 2000	2	2	2	2	2	2	2	2	2	2	20
Rittman M, Northsea C, Hausauer N, Green C., 1993	2	2	2	2	2	0	1	2	1	2	16
Sadala MLA, Bruzos GAdS, Pereira ER, Bucuvic EM., 2012	2	2	2	2	2	0	0	2	2	2	16
Shih LC, Honey M., 2011	1	2	2	2	2	0	0	2	2	2	15
Yu H, Petrini MA., 2010	1	2	2	2	2	2	0	2	2	2	17
Excluded studies											
Murray LR, Conrad NE, Zarifian A., 1999	0	2	2	2	2	0	0	2	1	2	13
Wells SA., 2009	1	2	2	1	1	0	0	2	2	1	12
Moran A, Scott A, Darbyshire P., 2011	2	2	2	2	2	1	2	2	2	2	19
Polaschek N., 2003	2	2	2	2	2	0	0	2	2	2	16
Where "Yes" = 2, "No" = 0 and "Unclear" = 1											

Description of included studies

All 12 studies included in this review used varying qualitative designs. Seven studies adopted a phenomenological methodology^{35,39,41-45}, three were interpretive^{36,38,49}, one used grounded theory⁴⁰ and one virtue ethics.³⁷ Two of the studies were theses and 10 were published papers.

All the studies used interviews as the method of data collection. Data collection took place in the dialysis unit in seven studies^{35,38-40,42,43,45}, and in the participant's home in three.^{36,37,44} Two studies^{41,49} did not report where data collection took place. Data analysis methods included Colaizzi's⁵⁰ seven step framework for phenomenological analysis^{35,41,45}, Diekelmann, Allen and Tanner's⁵¹ seven stage hermeneutical analysis process^{42,43,49}, interpretative phenomenological analysis³⁷, interpretive content analysis³⁸, Ricour's⁵² three stage hermeneutic method⁴⁴, McCracken's⁵³ analytic categorization³⁶, Giorgi's⁵⁴ descriptive phenomenological method³⁹ and theoretical sampling.⁴⁰

The number of participants ranged from six³⁶ to 23⁴⁰ with a total of 151 participants in all 12 studies. Participant ages ranged between 20 to 82 years.^{35-45,49} Of the 12 studies included in the review, two specifically stated that all the participants were waiting for a transplant. In the remaining ten papers the participants included both those waiting and those not waiting for a transplant. Therefore only findings that specifically related to waiting for a transplant were extracted from these 10 papers and included in the review.

The characteristics of each study are described in Table 2.

Table 2: Summary of included studies

Study	Methodology	Methods	Participants	Phenomena of interest
Calvey D, Mee L., 2011	Phenomenology	In depth semi-structured interviews	7 HD patients who were waiting for a transplant chosen through purposive sampling (age 29-60). All participants were waiting for a kidney transplant	To step into the lives of HD patients once they step outside the dialysis unit
Dekkers W, Uerz I, Wils J-P., 2005	Virtue ethics	Semi-structured in-depth interviews	7 people with end stage renal disease and on dialysis (ages 55-82). An unknown number of participants were waiting for a kidney transplant	<ol style="list-style-type: none"> 1. What are the moral challenges faced by patients with an ESRD? 2. Do patients with an ESRD implicitly or explicitly speak in terms of virtue, when they are invited to tell the story of their illness and asked how they cope with the challenges of their illnesses? 3. Are there elements in the patient's stories that can be interpreted in terms of Aristotelian virtue ethics?
Hagren B, Pettersen I, Severinsson E, Lützén K, Clyne N., 2001	Qualitative interpretative	Semi-structured interviews	15 patients, at least 3 months on maintenance HD (<1year - >3 years), age range 50-79years. An unknown number of participants were waiting for a kidney transplant	Patient's experiences of suffering from ESRD
Herlin C, Wann-Hansson C., 2010	Phenomenology	Interviews	9 HD patients aged 30-44 years. Eight participants were waiting for a kidney transplant.	How HD patients between 30 and 45 years of age experienced their dependence on HD treatment
Kaba E, Bellou P, Iordanou P, Andrea S, Kyritsi E, Gerogianni G, et al., 2007	Grounded theory	Interviews	23 HD patients, average age 62, average length of treatment 5.7years. An unknown number of participants were waiting for a kidney transplant	To explore how Greek patients receiving long-term HD perceive their problems and to describe the impact of HD on these patients' lives
Landreneau KJ, Ward-Smith P., 2007	Phenomenological approach, exploratory descriptive	Interviews	20 randomly selected HD patients, age range 21-77, on dialysis from 1-5 years. An unknown number of participants were waiting for a kidney transplant	To explore what patients on HD perceive concerning choice among renal replacement therapies: transplantation, HD and PD

Moran A.,2008	Hermeneutical phenomenology	Interviews	16 participants aged 31-66 years and on HD 10 months-5 years. At least 10 participants were waiting for a transplant.	Accurate, detailed and in-depth description of the person's experience of ESRD and HD therapy
Polaschek N., 2000	Critical, interpretive	Interviews	Six Pakeha men living on home HD for more than one year and no longer than ten years aged from their late 20s-60s. All participants were waiting for a kidney transplant.	The concerns of Pakeha men living on home HD
Rittman M, Northsea C, Hausauer N, Green C.,1993	Heideggerian phenomenology	Interviews	6 dialysis patients aged 39-58 years, on dialysis 3-14 years (5 male, 1 female, 5 white, 1 black). An unknown number of participants were waiting for a kidney transplant.	The meanings of living with chronic renal failure as described by patients and the related nursing implications
Sadala MLA, Bruzos GAdS, Pereira ER, Bucuvic EM., 2012	Phenomenology	Narrative interviews	19 participants aged 20-77, on PD for at least 6 months. An unknown number of participants were waiting for a kidney transplant.	The meaning of PD as experienced by patients with chronic renal failure
Shih LC, Honey M., 2011	Qualitative, interpretive	Semi-structured interviews	Seven participants aged 46-77 years, on HD for 4-10 years. An unknown number of participants were waiting for a kidney transplant.	To explore the impact that dialysis has on Maori and their whanau/families
Yu H, Petrini MA., 2010	Phenomenology	Semi-structured in-depth interviews	16 HD patients selected by purposive sampling, age 49-74 years, on dialysis for 3 months to 7 years. 6 participants were waiting for a kidney transplant.	To provide basic information concerning life experience and perceptions of ESRD in patients undergoing HD

Categorization and synthesis of qualitative research findings

From the 12 studies included in the review a total of 37 findings were extracted (Appendix V) and aggregated to form 11 categories. From the 11 categories three synthesized findings (meta-syntheses) were derived as illustrated in Figure 2 – QARI graph.

Synthesized findings

Meta-synthesis

Findings	Categories	Synthesized findings
<u>Facing the world of renal failure and dialysis treatment (U)</u>	<u>Dependence and loss of control</u>	<u>Physical health and normal activities of living</u> People who are waiting for a kidney transplant from a deceased donor are affected by the experience of living on dialysis with ESRD and its impact on their physical health and normal activities of living
<u>The altered interrelationship of autonomy and dependence involved in living on dialysis: Dependence on the dialysis machine (U)</u>		
<u>The altered interrelationship of autonomy and dependence involved in living on dialysis: Their new healthcare relationships (U)</u>		
<u>The mortal, fragile self: facing their own mortality (C)</u>	<u>Mortality</u>	
<u>The mortal, fragile self: the issue of transplantation (U)</u>		
<u>Bodily self. Participants' descriptions of how they perceived themselves and the physical changes they had gone through (U)</u>	<u>Physical health</u>	
<u>Negotiating the requirements of dialysis to fit their lifestyle and the limitations involved (U)</u>	<u>Restricted life</u>	
<u>Total lack of freedom (U)</u>		
<u>Waiting for a kidney: Being on hold (U)</u>		
<u>Mental self. Participant's perceptions of themselves leading to feelings of powerlessness, worthlessness and low self-confidence. (C)</u>	<u>Character and state of mind</u>	<u>Psychological health</u> The experience of waiting for a kidney transplant from a deceased donor impacts on a
<u>Being on the waiting list for a kidney transplantation (C)</u>	<u>Hope</u>	
<u>Facing the world of renal failure and dialysis treatment (U)</u>		
<u>Future hopes (U)</u>		
<u>Gaining a sense of existential optimism (C)</u>		

<u>Gratitude – hope (U)</u>		person's psychological wellbeing									
<u>Maintaining hope (U)</u>											
<u>The ongoingness and uncertainty of life on dialysis and the hope of a transplant: The expectation of a transplant (U)</u>											
<u>Waiting for a kidney: Living in hope (U)</u>											
<u>Choice (U)</u>	<u>Knowledge</u>										
<u>Knowledge (U)</u>											
<u>The growing/learning self (U)</u>											
<u>Functional self. The impact on what participants perceived to be their normal routines and their varying roles in life. (U)</u>	<u>Life losses</u>										
<u>Lost dreams. The loss of dreams introduced elements of sadness leading to anger and bitterness in the descriptions of perceived loss of planned future dreams (U)</u>											
<u>The ongoingness and uncertainty of life on dialysis and the hope of a transplant: Experiencing life on dialysis as ongoing (U)</u>											
<u>Psycho-social aspect: Anxiety (U)</u>	<u>Stress and anxiety</u>										
<u>Stress from HD (U)</u>											
<u>An Uncertain Future (U)</u>	<u>Uncertainty</u>										
<u>Being on the waiting list for a kidney transplantation (U)</u>											
<u>Gaining a sense of existential optimism (C)</u>											
<u>The ongoingness and uncertainty of life on dialysis and the hope of a transplant: Uncertainty about the future (U)</u>											
<u>Uncertainty (U)</u>											
<u>Waiting for a kidney: Uncertainty (U)</u>											
<u>Feelings of loneliness (U)</u>		<u>Relationships and community</u> People who are waiting for a kidney transplant place value on relationships and being part of a community. The experience of waiting for a									
<u>Social self. The impact of HD on family and friends and the impact of family and friends on the lives of participants (U)</u>											
<u>The altered interrelationship The altered interrelationship of autonomy and dependence involved in living</u>											

<u>on dialysis: Changing personal relationships (U)</u> <u>The altered interrelationship of autonomy and dependence involved in living on dialysis: Their new healthcare relationships (U)</u>	kidney transplant from a deceased donor while living on dialysis with ESRD changes a person's relationships
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Synthesized finding 1: People who are waiting for a kidney transplant from a deceased donor are affected by the experience of living on dialysis with ESRD and its impact on their physical health and normal activities of living.

People who were waiting for a renal transplant from a deceased donor were suffering from ESRD and were on dialysis. All of the studies referred to the impact that living on dialysis had on the participants' physical wellbeing including their normal lifestyle and activities of living. This meta-synthesis was created from four categories: "physical health", mortality, "dependence and loss of control", and "restricted life" with a total of 10 findings.

Findings relating to physical health were reported in two studies.^{35,36} The physical symptoms of ESRD and the effects of dialysis included general lack of energy, fatigue, an altered sleep pattern, itching and restless legs syndrome, hypotension, dizziness, loss of appetite, nausea, vomiting, anaemia, weakness, breathlessness and general malaise.³⁵ Participants reported changes to their body image, particularly relating to the placement of the dialysis access and the symptoms of uremia.³⁵

Following on from the theme of physical health was the concept of mortality. Two findings from one of the studies showed that participants comprehended their own mortality and their dependence on RRT to maintain their lives³⁵. They were also aware that transplantation could only be achieved by the death of a donor and so what they were waiting and hoping for could only be brought about by the death of another.³⁵

Two of the studies contained three findings related to dependence and loss of control.^{36,44} Participants voiced their feelings of dependence upon people such as family, friends and hospital staff to cope with the dialysis regime, and also dependence on the dialysis machine in order to stay alive while they were waiting for a kidney transplant.³⁶ Loss of control is a concept that is similar to dependence. Participants reported experiencing loss of control in being unable to influence when a donor organ would become available for them.⁴⁴

Three studies reported findings related to life on dialysis while waiting for a kidney transplant being a restricted life.^{36,39,42} People felt that while they were waiting for a transplant that their life was 'on hold'.⁴² They were unable to travel freely as they were restricted by the dialysis therapy^{36,39} and they guarded the days in between dialysis sessions in order to have a "normal" life.³⁶

Synthesized finding 2: The experience of waiting for a kidney transplant from a deceased donor impacts a person's psychological wellbeing

This meta-synthesis was created from six categories containing a total of 23 findings: hope, uncertainty, knowledge, life losses, stress and anxiety, and character and state of mind. Findings showed that the experience of waiting for a kidney transplant from a deceased donor had both a positive and negative effect on a person's psychological wellbeing.

The most commonly reported finding was that waiting for a kidney transplant gave people hope. Eight studies reported findings relating to hope.^{35-39,42-44} The expectation of getting a transplant one day helped people to cope better with the experience of living on dialysis while they waited. Findings showed that people believed their lives would return to normal after a transplant and that they would be able to resume all the normal activities that they could not do while they were waiting on dialysis.

Six studies reported findings about uncertainty.^{35,36,38-40,42} It is not possible to predict when a donor kidney will become available, so people who were waiting for a kidney transplant experienced feelings of insecurity and doubt about whether the transplant would ever happen and whether everything would go well when it did occur.

Because the thought of getting a kidney transplant gives people hope, the uncertainty surrounding when it will happen causes people to experience stress and anxiety while they wait. The two concepts are interrelated. Two studies reported findings about stress and anxiety.^{45,49} If a kidney transplant was not valued so much, the ambiguity about timing would not have had such an impact on the people concerned.

Two studies reported three findings relating to knowledge.^{35,41} When the person learned more about renal disease, particularly the dialysis routine and kidney transplantation, they were able to cope better with the experience of

waiting for a kidney transplant. Sources of knowledge mentioned were nephrologists, dialysis nurses and other dialysis patients⁴¹, although it was noted that information gained from other dialysis patients was often out of date and inaccurate.

Two studies reported three findings related to the concept of loss.^{35,36} These were lost time³⁶, lost dreams³⁵, and loss of income and financial independence.³⁵ All these contributed towards an overall sense of loss in the participants.

One study found that certain character traits helped some people cope better with living on dialysis and waiting for a transplant.³⁵ The ability to maintain a positive outlook was felt to be important in preventing depression while waiting for a kidney transplant.

Synthesized finding 3: People who are waiting for a kidney transplant from a deceased donor place value on relationships and being part of a community. The experience of waiting for a renal transplant from a deceased donor while living on dialysis with ESRD changes a person's relationships

The third meta-synthesis is derived from just one category with four findings.^{35,36,39} Families and relationships were a source of strength and encouragement³⁶ but ESRD and living on dialysis while waiting for a kidney transplant could have a negative impact on family relationships with some participants describing feelings of being a burden to their loved ones.³⁵ Waiting for a transplant caused people to feel isolated by the unusual situation they lived with. This made it difficult to form new friendships and led to feelings of loneliness.³⁹

Discussion

The aim of this review was to gain insight into the experiences of people who are waiting for a renal transplant from a deceased donor with the objective of creating evidence to underpin the development of interventions to improve the experience of waiting. The 12 studies included in the review generated 37 findings which were then developed into 11 categories and three synthesized findings.

The first synthesized finding showed that people who were waiting for a kidney transplant from a deceased donor were profoundly affected by the experience of living on dialysis with ESRD. The disease and resulting dialysis therapy both had a great impact on their health and normal activities of living. End stage renal disease is a chronic medical condition characterized by a decline in kidney function to a point where RRT, in the form of either dialysis or transplantation, is necessary in order to maintain life.^{3,55} The symptoms of ESRD include anaemia, itch, bone pain, hypertension, fatigue, decreased urine output, loss of appetite, oedema and breathlessness.⁵⁶ As well as symptoms of the disease, the effects of the dialysis therapy itself are also intense, including hypotension⁵⁷, infection⁵⁸ and fatigue.⁵⁹ End stage renal disease is a chronic, life-limiting illness. The findings showed that people with ESRF have had to consider their own mortality and accept the fact that without dialysis their own kidney function is insufficient to support life. Linked with the experience of facing their own mortality, people waiting for a kidney transplant had an awareness that their transplant would only occur if somebody else died. *"Somebody is dead and I'm alive with their kidney ... that doesn't seem right to me".*³⁵

In addition to the bodily effects of ESRD and dialysis, the findings also showed that dialysis therapy led to a restricted life with people feeling out of control and dependent on carers, medical staff and machines. The home-based dialysis therapies PD and home HD had been proven to provide the best outcomes in terms of patient quality of life.⁶⁰ However they are still time-consuming treatments that require a level of commitment and skill on the part of the patient. When transport and time spent waiting were added onto the treatment time for hospital-based therapies, all dialysis therapies could have a negative impact on normal activities of living. The length of time required to be spent in treatment affected a person's ability to maintain gainful employment. The ability to work was further restricted when medical appointments, emergencies and malaise were considered, as was the ability to go away on holidays.^{36,39} For some people the restrictions on travel mean a separation from loved ones who live overseas or a long distance away.^{42,49}

The second synthesized finding is that the experience of waiting for a kidney transplant from a deceased donor had a psychological effect on a person's wellbeing. Often this was a positive effect with many of the studies reporting that waiting for a renal transplant gave people hope that dialysis would not be for ever.^{35-39,43,44} People believed that when they got a transplant they could return to something like the freedom they had before they became unwell. *"The hope of a kidney transplant provided the participants with the possibility of returning to a normal life in the future. In addition, it provided them with the strength to endure the experience of being a renal patient".*⁴²

People waiting for a kidney transplant from a deceased donor experience high uncertainty. This includes uncertainty about both the timing and the outcome of the transplant. Uncertainty can result in people experiencing increased stress and anxiety, waiting and hoping for the transplant to happen but having no assurance. The median waiting time for a kidney transplant from a deceased donor ranges from 3.1 to four years.^{11,12} Study findings showed that providing people with information about average waiting times might contribute to increased psychological pressure. People learned from observation of others that waiting the average length of time did not always mean that it was their turn next. *"I tried hard to keep up on the waiting list for many years; I feel aggravated sometimes. I have been on the transplant list for many years and nothing happened. I hope the next one may be me but I am always disheartened".*⁴⁹

Study findings showed that people who were waiting for a kidney transplant gained a psychological benefit from the acquisition of knowledge. Knowledge helped them regain some level of control in their lives. Well informed patients were better able to make choices regarding their care while lack of knowledge was a source of anxiety and stress. In some senses the uncertainty experienced by people waiting for a kidney transplant resulted from a lack of knowledge. While it was not possible to provide all the facts and figures to alleviate these patients' fears, it was evident that people benefitted from having information made available to them. Health practitioners who cared for people waiting for a kidney transplant should recognize that being on the transplant list brought about both positive and negative feelings. The effect of waiting for a kidney transplant provided hope as well as uncertainty, stress and anxiety.

The third synthesized finding was that people who were waiting for a kidney transplant were part of a community and placed value on relationships with family and friends. The experience of waiting for a kidney transplant changed those relationships. Study findings referred to the participant's social networks of family, friends and the staff and other patients at the dialysis unit.^{35,36,39} These communities were a source of strength and support for participants. Just as the participant had to adapt to the effect of living with ESRD and dialysis, the family members and friends also had to adapt, often taking on the role of carer for the person waiting for a kidney transplant. Some people

accept and value these changes in the dynamics of their relationships. *"[It's a] terrific amount of teamwork, it's so much easier with some helping, much more pleasurable, quicker if you work as a team."*³⁶ For others this increased reliance on others was a source of anxiety and guilt. *"Why did she marry me, if she married someone else she'd get out ... she wouldn't be living this kind of life ... how unfortunate she was."*³⁵ The unusual situation of waiting for a kidney transplant meant that participants who were single found it difficult to establish relationships with new acquaintances, reporting feelings of loneliness and isolation.^{36,39} Medical communities were another important source of support. People waiting for a kidney transplant from a deceased donor drew inspiration from positive relationships with friends, family members, other dialysis patients and healthcare workers.

Limitations of the review

Of the 12 studies included in this review, two included data that was entirely from people who were waiting for a kidney transplant. In the other 10 studies the participants included some people who were waiting along with some who were not. These studies were included in the review because some of the findings illuminated the experience of waiting for a transplant, but in order to exclude evidence from people who were not waiting for a transplant, only findings that specifically mentioned waiting for a kidney transplant were included in this review. This means that there may be more findings that provide evidence into the experience of waiting for a kidney transplant but which were omitted from the review because it was not possible to tell which category of participant the evidence came from.

Conclusion

There is little high quality evidence to describe the experiences of people waiting for a kidney transplant from a deceased donor. There are, however a number of high quality studies describing the experience of living on dialysis and many of these provide insights into the experience of waiting for a transplant.^{35-45,49}

Synthesized findings of the review conclude that people who are waiting for a kidney transplant from a deceased donor live with the physical effects of a life limiting chronic illness. Dialysis therapy also causes physical side effects and restricts a person's normal life. Waiting for a kidney transplant is psychologically challenging. The transplant is hoped for as it is perceived as providing an escape from dialysis and a return to normal life, but the uncertainty surrounding the timing and outcome of the transplant causes people to feel anxiety and stress. People waiting for a kidney transplant value knowledge, although the information they require to alleviate the uncertainty they feel is not available. They exist in communities and value their relationships with others. The dynamics of these relationships are affected by the experience of waiting for a kidney transplant. People can feel isolated from others leading a "normal" life, while new relationships are developed within the medical team and community of dialysis patients.

Implications for practice

There is limited evidence from the review to support the development of recommendations for clinical practice. Healthcare workers caring for people who are waiting for a kidney transplant from a deceased donor should be mindful of the physical and lifestyle effects of living on dialysis with ESRD. Wherever possible, information should be provided to alleviate the stress and anxiety related to the uncertainty of waiting. Staff should consider that the experience of waiting is stressful and that people waiting for a kidney transplant may require support and reassurance. It is also important to recognise that people exist within communities who may also benefit from receiving information and encouragement. By acknowledging the importance of relationships to people who are waiting for a kidney transplant, healthcare workers should aim to include the patient's family and friends in their care and provide the best source of role modelling behavior. Significant community members should be included in invitations to appointments and education session with the consent of the person being treated. (Level 1 evidence⁶¹)

Implications for research

Future studies should be undertaken exclusively with people waiting for a kidney transplant from a deceased donor. Qualitative research designs such as phenomenology and grounded theory could investigate the psychological experience of waiting, and the relationship between hope, uncertainty and knowledge. Quantitative studies using validated tools could also be conducted. By producing more evidence relating to this significant specific patient population, interventions to improve the experience of waiting could be developed and trialled.

Conflict of interest

There were no conflicts of interest for this systematic review.

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Appendix I: Search strategies

Medline search strategy

1. kidney failure.mp. or exp Renal Insufficiency/
2. peritoneal dialysis.mp. or exp Peritoneal Dialysis/
3. kidney transplantation.mp. or exp Kidney Transplantation/
4. Kidney Failure, Chronic/ or Renal Dialysis/ or haemodialysis.mp. or Kidney Diseases/
5. renal dialysis.mp. or exp Renal Dialysis/
6. waiting list.mp. or exp Waiting Lists/
7. (tissue and organ procurement).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
8. quality of life.mp. or exp "Quality of Life"/
9. experienc\$.mp. or Social Support/ or Depression/
10. adaptation.mp. or Adaptation, Psychological/ or Adaptation, Physiological/
11. Attitude to Health/ or Attitude/ or Attitude to Death/ or attitude.mp.
12. uncertainty.mp. or exp Uncertainty/
13. life change events.mp. or exp Life Change Events/
14. self care.mp. or exp Self Care/
15. self concept.mp. or exp Self Concept/
16. self efficacy.mp. or exp Self Efficacy/
17. interpersonal relations.mp. or exp Interpersonal Relations/
18. activities of daily living.mp. or exp "Activities of Daily Living"/
19. 1 or 2 or 3 or 4 or 5 or 6
20. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
21. 19 and 20
22. limit 21 to (english language and humans and "all adult (19 plus years)")
23. limit 22 to ("qualitative (maximizes sensitivity)" or "qualitative (maximizes specificity)" or "qualitative (best balance of sensitivity and specificity)")

Embase search strategy

1. kidney failure.mp. or exp kidney failure/
2. peritoneal dialysis.mp. or exp peritoneal dialysis/
3. kidney transplant\$.mp. or exp kidney graft/
4. kidney failure.mp. or exp kidney failure/
5. renal dialysis.mp. or exp renal replacement therapy/
6. waiting list.mp. or exp hospital admission/
7. quality of life.mp. or exp "quality of life"/
8. society/ or experienc\$.mp. or follow up/
9. local adaptation/ or social adaptation/ or adaptation/ or adaptation.mp.
10. attitude to sexuality/ or social attitude/ or attitude to illness/ or attitude to death/ or attitude.mp. or attitude to health/ or attitude to life/ or attitude/ or attitude to change/ or attitude to disability/ or patient attitude/
11. Mishel Uncertainty in Illness Scale/ or uncertainty.mp. or uncertainty/ or Mishel Uncertainty in Illness Theory/
12. life change events.mp. or exp life event/
13. self care.mp. or exp self care/
14. self concept.mp. or exp self concept/
15. self efficacy.mp. or exp self concept/

16. interpersonal relations.mp. or exp human relation/
17. activities of daily living.mp. or exp daily life activity/
18. 1 or 2 or 3 or 4 or 5 or 6
19. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
20. 18 and 19
21. limit 20 to (human and English language and adult <18 to 64 years>)
22. limit 21 to ("qualitative (maximizes sensitivity)" or "qualitative (maximizes specificity)" or "qualitative (best balance of sensitivity and specificity)")

CINAHL search strategy

1. kidney failure
2. Renal Insufficiency
3. peritoneal dialysis
4. kidney transplantation
5. Renal Dialysis
6. haemodialysis
7. Kidney Disease
8. waiting list
9. quality of life
10. experience
11. adaptation
12. Attitude to Death
13. Attitude to Health
14. uncertainty
15. life change events
16. self care
17. self concept
18. self efficacy
19. interpersonal relations
20. activities of daily living
21. S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8
22. S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20
23. S21 and S22
24. S23 Narrow by Subject: - all adult

PsychInfo

- 1 exp "activities of daily living"/
- 2 ("activities of daily living" or ADL).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 3 exp Behavior/
- 4 (behavior* or behaviour*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 5 exp Cognition/
- 6 cognition.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests &

measures]

7 exp affective disorders/

8 mood*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

9 exp "Quality of Life"/

10 ("quality of life" or qol).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

11 exp interpersonal relationships/

12 "interpersonal relation*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

13 "social interaction*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

14 "social support*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

15 (wellbeing or "well being").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

16 exp satisfaction/

17 exp Client Satisfaction/

18 satisfaction.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

19 stress*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

20 depress*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

21 exp adjustment/

22 psycholog*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

23 exp Emotions/

24 emotion*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

25 anxi*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

26 exp Lifestyle/

27 ("life style" or lifestyle*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

28 exp Uncertainty/

29 uncertaint*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

30 exp death attitudes/

31 exp Health Attitudes/

32 attitude.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

measures]

33 experience*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

34 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33

35 exp organ transplantation/

36 ((kidney* or renal) and (transplant* or donor* or provider* or survivor*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

37 35 or 36

38 cadaveric.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

39 37 and 38

40 (kidney* or renal).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

41 35 or 40

42 exp tissue donation/

43 "unrelated donor*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

44 42 or 43

45 41 and 44

46 39 or 45

47 exp kidney diseases/

48 ("renal replacement therap*" or RRT or "dialysis patient*").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

49 ((renal or kidney*) and dialysis).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

50 hemodiafiltration.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

51 (hemodialysis or HD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

52 ("peritoneal dialysis" or PD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

53 hemofiltration.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

54 47 or 48 or 49 or 50 or 51 or 52 or 53

55 "kidney failure".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

56 ("end stage renal" or "end-stage renal" or ESRF or ESRD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

57 "chronic kidney".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

measures]

- 58 55 or 56 or 57
- 59 54 or 58
- 60 34 and 37 and 59
- 61 ("300" or "320" or "340" or "360" or "380" or "390").ag.
- 62 60 and 61

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- 1 MeSH descriptor: [Activities of Daily Living] explode all trees 3488
- 2 "activities of daily living" or ADL 5596
- 3 MeSH descriptor: [Behavior] explode all trees 43674
- 4 behavior* or behaviour* 46843
- 5 MeSH descriptor: [Cognition] explode all trees 6160
- 6 cogniti* 25934
- 7 MeSH descriptor: [Mood Disorders] explode all trees 8381
- 8 mood* 8900
- 9 MeSH descriptor: [Quality of Life] explode all trees 13007
- 10 "quality of life" or qol 31258
- 11 MeSH descriptor: [Interpersonal Relations] explode all trees 3707
- 12 "interpersonal relation**" 1603
- 13 "social interaction**" 672
- 14 "social support**" 3413
- 15 wellbeing or "well being" 5477
- 16 MeSH descriptor: [Personal Satisfaction] explode all trees 373
- 17 MeSH descriptor: [Patient Satisfaction] explode all trees 7896
- 18 satisfaction 17684
- 19 stress* 21813
- 20 depress* 52675
- 21 MeSH descriptor: [Adaptation, Psychological] explode all trees 3442
- 22 psycholog* 58469
- 23 MeSH descriptor: [Emotions] explode all trees 10387
- 24 emotion* 7899

25	anxi*	20388	
26	MeSH descriptor: [Life Style] explode all trees	2365	
27	"life style*" or lifestyle*	5086	
28	MeSH descriptor: [Uncertainty] explode all trees	75	
29	uncertain*	8838	
30	MeSH descriptor: [Attitude to Death] explode all trees	101	
31	MeSH descriptor: [Attitude to Health] explode all trees	21982	
32	attitude	11676	
33	experience*	39675	
34	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 212836		
35	MeSH descriptor: [Kidney Transplantation] explode all trees	3147	
36	(kidney* or renal) and (transplant* or donor* or provider* or survivor*)	9940	
37	#35 or #36	9940	
38	cadaveric	692	
39	#37 and #38	519	
40	kidney* or renal	36166	
41	#35 or #40	36166	
42	MeSH descriptor: [Unrelated Donors] explode all trees	2	
43	"unrelated donor"	195	
44	#42 or #43	195	
45	#41 and #44	25	
46	#39 or #45	542	
47	MeSH descriptor: [Renal Replacement Therapy] explode all trees	7312	
48	"renal replacement therap*" or RRT or "dialysis patient"	1530	
49	(renal or kidney) and dialysis	7982	
50	hemodiafiltration	311	
51	hemodialysis or HD	6993	
52	"peritoneal dialysis" or PD	15327	
53	hemofiltration	519	
54	#47 or #48 or #49 or #50 or #51 or #52 or #53	28910	
55	MeSH descriptor: [Kidney Failure, Chronic] explode all trees	3151	
56	"end stage renal" or "end-stage renal" or ESRF or ESRD	1723	

57	"chronic kidney"	1427	
58	#55 or #56 or #57	4948	
59	#54 or #58	30640	
60	(#34 and #37 and #59)	1125	
61	MeSH descriptor: [Living Donors] explode all trees	265	
62	#60 not #61	1089	
63	MeSH descriptor: [Empirical Research] explode all trees	358	
64	"qualitative research" or "qualitative stud**"	1230	
65	"interpretive research" or "interpretive stud**"	1	
66	"critical research" or "critical stud**"	33	
67	"qualitative descriptive"	15	
68	"grounded theor**"	53	
69	"case stud**"	1740	
70	"action research"	209	
71	ethnograph*	101	
72	phenomenolog*	142	
73	#63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72	3373	
74	#60 and #73	31	
75	#62 and #73	28	
76	MeSH descriptor: [Waiting Lists] explode all trees	307	
77	MeSH descriptor: [Watchful Waiting] explode all trees	77	
78	wait*	5480	
79	#76 or #77 or #78	5480	
80	#60 and #79	88	
81	#62 and #79	88	
82	#74 and #79	15	
83	#75 and #79	15	

Appendix II: Appraisal instruments

QARI appraisal instrument

JBIR QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice-versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

Appendix III: Data extraction instruments

QARI data extraction instrument

**JBI QARI Data Extraction Form for Interpretive
& Critical Research**

Reviewer Date

Author Year

Journal Record Number

Study Description

Methodology

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Method

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Phenomena of interest

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Setting

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Geographical

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Cultural

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Participants

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Data analysis

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.....

Authors Conclusions

.....

.....

Comments

.....

.....

Complete

Yes ☐

No ☐

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete

Yes ☐

No ☐

Appendix IV: Excluded studies

1. Moran A, Scott A, Darbyshire P. Waiting for a kidney transplant: patients' experiences of haemodialysis therapy. Journal of Advanced Nursing. [Research Support, Non-U.S. Gov't]. 2011 Mar;67(3):501-9.

Reason for exclusion: Study reported in "Moran A. The person's experience of end stage renal disease and haemodialysis therapy [Ph.D.]. Ann Arbor: Dublin City University (Ireland); 2008"

2. Murray LR, Conrad NE, Zarifian A. Perceptions of kidney transplant by persons with end stage renal disease/Research critique/Investigators' response. ANNA Journal. 1999;26(5):479-84+.

Reason for exclusion: Methodological quality score falls below the threshold of 14.6. Congruity between philosophical perspective and research methodology not stated, the researcher's cultural/theoretical perspective not stated and the influence of the researcher on the research and vice-versa not addressed.

3. Polaschek N. Living on dialysis: concerns of clients in a renal setting. Journal of Advanced Nursing. 2003;41(1):44-52.

Reason for exclusion: Study reported in "Polaschek N. The concerns of Pakcha men living on home haemodialysis: a critical interpretive study. Wellington: Victoria University of Wellington; 2000."

4. Wells SA. Occupational performance of Mexican Americans with end-stage-renal-disease living on dialysis in the lower Rio Grande Valley [Dr.P.H.]. Ann Arbor: The University of Texas School of Public Health; 2009.

Reason for exclusion: Methodological quality score falls below the threshold of 14.6. Lack of congruity between stated philosophical perspective and research methodology and between the research methodology, methods and interpretation of results. The researcher's cultural/theoretical perspective is not stated and the influence of the researcher on the research and vice-versa not addressed.

Appendix V: Table of data extraction findings

Data extraction table				
Reference	Calvey D, Mee L. The lived experience of the person dependent on haemodialysis. Journal of Renal Care. 2011 Dec;37(4):201-7.			
Number	Finding (verbatim from author)	Illustration from text and page number	Unequivocal/credible/ unsupported (U/C/Un)	Possible category
1	An uncertain future	The enormity of life dependent on hemodialysis left the participants feeling as though there was no future ahead. They reported feelings of shock and fear, and finding themselves in a place of great uncertainty. pg 202 [Some] participants described experiences of having their future returned to them by dialysis ... a lifeline to being alive. Pg 203	U	Uncertainty
2	Lost dreams. The loss of dreams introduced elements of sadness leading to anger and bitterness in the descriptions of perceived loss of planned future dreams	<i>M, "watching my children growing up and not being able to go out with them and show them what to do ... I never did that with my children ... something I would have liked to give them . not being able to do that, sort of irks me now".</i> Pg 203	U	Loss
3	Future hopes	Hope for the future lay mostly in the prospect of one day receiving a transplant and getting back to a normal life. The hope of receiving a kidney transplant was dominant in this study" Pg 203	U	Hope
4	Bodily self. Participants' descriptions of how they perceived themselves and the physical changes they had gone through	<i>J, "my skin changed ... you feel dirty ... no matter if you have a shower ... I never feel clean".</i> pg 204 The physical bodily change due to the placement of the HD access in this study, for some, brought distress. Pg 204	U	Body image
5	Mental self. Participant's perceptions of themselves leading to feelings of powerlessness, worthlessness and low self-confidence.	Strength and state of mind was thought to be of great importance. Pg 204 Depression was seen by the participants of this study as the outcome of not maintaining a positive outlook. ... although they admitted feeling depressed at times, it	C	Mental health

		certainly did not appear to be a leading concern. Pg 204		
6	Functional self. The impact on what participants perceived to be their normal routines and their varying roles in life.	<p><i>T, "you're basically working around the dialysis, like it's stuck in my head"</i> Pg 204</p> <p>They saw their ability to do things hindered by the loss of three days from the week. The impact on functional self was more evident when the participants considered the negative effect on their ability to work, resulting in loss of wages and inability to be counted as reliable. Pg 204</p>	U	Normal life/loss
7	Social self. The impact of HD on family and friends and the impact of family and friends on the lives of participants	<p><i>M' "Why did she marry me, if she married someone else she'd get out ... she wouldn't be living this kind of life ... how unfortunate she was"</i> Pg 204</p> <p>Participants felt greatly restricted in terms of not having freedom to travel. Pg 204</p> <p>Many participants were finding it difficult becoming part of the social atmosphere, feeling alienated by things like fluid and dietary restrictions. Pg 204</p> <p>Some participants felt a responsibility to keep up a good face ... Thus as well as being strong for themselves they had to be strong and support their families. Pg 204</p>	U	Social life/community
8	Mortality and the fragility of life	<p><i>J "I really thought I was finished ... I saw the blood drain from my body into this machine ... I saw my life's blood flow out, it was a shock an absolute shock."</i> Pg 205</p> <p>The participants in this study conveyed a strong realisation that life is fragile and can be lost very quickly. Pg 205</p>	C	Mortality
9	Mortality and the issue of transplantation	<p>The issue of kidney transplantation provided hope for all the participants.</p> <p>Mike had not only faced his own mortality but spared thoughts for the kidney donors respectfully acknowledging that for him to receive such a gift meant somebody would be losing their life. Pg 205</p> <p><i>A "somebody is dead and I'm alive with their kidney ... that doesn't seem right to me".</i></p>	U	Mortality

10	Growing/learning self	Participants described their experiences of commencing treatment, beginning with little or no knowledge of renal failure or dialysis, slowly acquiring a degree of knowledge and experience and becoming more adaptive to the changing routine. Pg 205	U	Knowledge
Reference	Dekkers W, Uerz I, Wils J-P. Living Well with End Stage Renal Disease: Patients' Narratives Interpreted from a Virtue Perspective. Ethic Theory Moral Prac. 2005 2005/11/01;8(5):485-506.			
1	Gratitude – hope	<p>... participants explicitly mentioned that getting on dialysis had saved their lives. Pg 496</p> <p>Many felt grateful for the support they got from relatives and friends and for the care they got at the hospital. Pg 497</p> <p>Hope is important ... one participant intentionally tried to be optimistic, to hope for the best, to look on the bright side. For her hope also meant getting a kidney transplan.t Pg 497</p>	U	Hope
Reference	Hagren B, Pettersen I, Severinsson E, Lützén K, Clyne N. The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease. Journal of Advanced Nursing. 2001;34(2):196-202.			
1	Gaining a sense of existential optimism	<p>Many [patients] experienced fear of what would happen if the HD did not work or if they could not get a new kidney. Pg 200</p> <p>However waiting for kidney transplantation and not knowing when this would be was a profound cause of suffering. But for some the possibility of getting a new kidney gave hope.</p>	C	Mortality/hope
Reference	Herlin C, Wann-Hansson C. The experience of being 30-45 years of age and depending on haemodialysis treatment: a phenomenological study. Scandinavian Journal of Caring Sciences. 2010;24(4):693-9.			
1	Total lack of freedom	The total lack of freedom was always present in the thoughts of the patients and they were forced to learn to live with it. The participants expressed that they did not	U	Loss/future hope

		live fully. Pg 695 <i>"In the future when I am transplanted I think I will have more freedom. Then I can do what I want ... leave town ... order a vacation without thinking of the need of HD"</i>		
2	Feelings of loneliness	Three ... had lost a partner after they started in HD treatment. Finding a partner after they started on HD treatment was ... hard. Five ... [said] having a job was helping them to feel less lonely. Pg 696 <i>"...how do you say it? Should you say it at once? 'I'm going in HD treatment and waiting for a new kidney!' Or should you say it after a week or a month? Pg 696</i> <i>"To work is something I think is very important It is the social side ... that you get out ... otherwise it would have been hard ... if I had no work to go to" Pg 696</i>	U	Social life/loss
3	Being on the waiting list for a kidney transplantation	Being on the waiting list for many years and not knowing for how many years one had to wait was described as the worst part. Feelings of uncertainty because of not knowing if they would get a kidney or not were always on their mind. Pg 696 <i>"The future for me is a transplantation that I am waiting for, and then I hope that everything will work out fine" Pg 697</i> Many were afraid of the surgery and ... medications. Others were worried of complications ... such as rejection. Pg 696 <i>"To be transplanted means that I have to go through another complicated surgery ... and after that it is not for sure that it will work out"</i>	C	Uncertainty/hope
Reference	Kaba E, Bellou P, Iordanou P, Andrea S, Kyritsi E, Gerogianni G, et al. Renal nursing. Problems experienced by haemodialysis patients in Greece. British Journal of Nursing. 2007;16(14):868-72.			
1	Uncertainty	Even though patients considered that their treatment was going well at that point, they all expressed some anxiety about potential problems that could arise or the prospect of premature death. Pg 870	U	Mortality, anxiety, transplant gives hope for a normal life, uncertainty

		<p><i>"This is a road with no return. You are walking in the path and there is only in front, there is no left, no right to go. Now I am trying a bit because my daughter-in-law is pregnant, and I have something nice to expect. I pray I can get a transplantation soon so I can relax for 5 or 6 years."</i> Pg 870</p> <p>Although they had not yet received a transplant they were confident that they would do so and it would be successful, freeing them from dialysis. Pg 870</p>		
Reference	Landreneau KJ, Ward-Smith P. Perceptions of adult patients on hemodialysis concerning choice among renal replacement therapies. Nephrology Nursing Journal. 2007;34(5):513.			
1	Knowledge	<p>Knowledge regarding renal replacement therapy was obtained from a variety of sources. The most frequent source mentioned was ... health care professionals, specifically the physician. Another frequent source mentioned was the transplant surgeon. The dialysis nurses also mentioned as a source. Pg 516</p> <p><i>"They asked me would you want a kidney transplant? And I said yes I would because I didn't want to do this all my life"</i> Pg 516</p> <p><i>"They told me about the risks ... and it's just a risk between life and death. That's mostly what I know about it you know. They were nurses"</i> Pg 516</p> <p>Much of the knowledge shared by participants revealed outdated and inaccurate medical information. Pg 516</p>	U	Knowledge/community
2	Choice	<p>One must consider and incorporate the medically appropriate time to present the types of renal replacement therapies and the patient's option to choose. Pg 517</p> <p><i>"My choice was to have HD. And I am on the list for a kidney transplant, and I've been on the list for several years"</i></p> <p>... participants knew about transplantation after they started dialysis and talked with their 'dialysis doctor'</p>	U	Choice/uncertainty

		about transplantation. This may be a factor of different physician's opinions or philosophies concerning the promotion of different types of renal replacement therapies. Pg 517		
Reference	Moran A. The person's experience of end stage renal disease and haemodialysis therapy [Ph.D.]. Ann Arbor: Dublin City University (Ireland); 2008.			
1	Waiting for a kidney: Living in hope	<p>The hope of a kidney transplant provided the participants with the possibility of returning to a normal life in the future. In addition, it provided them with the strength to endure the experience of being a renal patient. The information received from healthcare professionals in relation to the average waiting time for a kidney transplant contributed to the participants' experience of living in hope. Pg 173</p> <p>Seeing other patients being called for a transplant and leave the dialysis unit contributed to Danny's experience of hope. These patients served to reassure him that one day he would also be called for a transplant. Pg 174</p> <p><i>"You're living in hope [of getting a transplant], you just feel like it could be tomorrow, it could be a year from tomorrow, it could be any day... That's the way I think, it [the transplant] will happen but you have to wait."</i> Pg 176</p>	U	Hope/knowledge
2	Waiting for a kidney: Uncertainty	<p>The participants' accounts specifically conveyed how the information they had received from the healthcare team about the average waiting time for a kidney transplant contributed to their uncertainty. Pg 178</p> <p>It is important to point out that the average waiting time for a kidney transplant is merely an estimate, and many patients wait well beyond this time frame. However, it seemed that several of the participants interpreted the average waiting time to mean the "actual" waiting time for a kidney transplant. While this belief allowed the participants to live in hope as they initially waited for a kidney transplant, it did not sustain their hope in the long-term. When the participants either reached or exceeded the "expected" date for a kidney transplant, they became uncertain. Pg 178</p>	U	Uncertainty

		<p><i>"I get days when just the thought of coming here...I could just turn the car around and drive off home and not bother...and you think well how come some people...I've seen them go and have a transplant and they're gone, and I'm still here. "Why am I still here? Why am I here? Sometimes I think maybe I'm going to be waiting a long time, I better just get used to the idea. Pg 180</i></p> <p><i>"You just get to a stage where you think it's [the transplant] never going to happen...you go into the dialysis unit and you hear somebody was called [for a transplant] and you'd be delighted for them but still your heart would drop when it wasn't you." Pg 181</i></p>		
3	Waiting for a kidney: Being on hold	<p>As a result of the experience of uncertainty, some participants were unable to contemplate possibilities in the future. Moreover, the limitations and restrictions imposed by HD therapy prevented them from performing many of the everyday activities they took for granted in the past. Consequently, the participants described their experience of being on hold while they waited for a kidney transplant. Pg 185</p> <p>The absence of a definite endpoint to the wait meant that David was unable to contemplate any possibilities for the future. Pg 187</p> <p>Embedded in Jeff's account of being on hold was the fear of missing out on the call for a kidney transplant. <i>"You're on hold so you are...it's just a big waiting game now ... waiting for that call [for a transplant]...you never leave the phone, you have the phone with you 24/7..." Pg 188</i></p> <p>He described his experience of waiting for a transplant as being held back in a time, which revolved around the repetitive regime of dialysis therapy. Pg 188</p> <p><i>"My life is on hold...very, very much so...I can't plan anything, can't go anywhere...I'm waiting for the phone to ring...when are you going to get that call for a transplant" Pg 189</i></p>	U	Impact of dialysis on life/uncertainty/loss

Reference	Polaschek N. The concerns of Pakcha men living on home haemodialysis: a critical interpretive study. Wellington: Victoria University of Wellington; 2000.			
1	Suffering from the symptoms of CRF and dialysis pg 204	<p>Dialysis is supposed to remove the symptoms of CRF by replacing their renal function according to the dominant discourse. However, despite excellent treatment, all of these men reported some troubling symptoms while living on dialysis. Pg 204</p> <p>General lack of energy ... an altered sleep pattern ... itching and restless legs ... hypotension ... general non-specific malaise. Pgs 205-206</p> <p>Although these men suffered from a range of symptoms they generally tended to downplay them. The tendency to initially underestimate their symptoms probably reflects the fact that, as they live with the symptoms on an ongoing basis, they have become an aspect of their lives that are coped with in part by being "normalized". Pg 207</p>	U	Physical health
2	Negotiating the requirements of dialysis to fit their lifestyle and the limitations involved Pg 210	<p>All of these men reported that it actually had a significant impact on their lifestyle. Pg 210</p> <p><i>"I jealously guard the in-between days, I hate them being taken away from me, I feel I've lost a day. It's my lifeline, but I want to have a normal life during the day"</i> Pg 212</p> <p>All mentioned the inability to travel on holidays as the most obvious limitation caused by living on HD. Pg 213</p> <p>For most of the men the negotiation required to integrate the requirements of renal replacement therapy into their weekly schedule not only influenced their regular pattern of living but also resulted in some alteration of their dialysis or other aspects of the treatment regime in order to manage it in their lives. Pg 214</p>	U	Impact on normal life/knowledge/travel
3	Experiencing life on dialysis as ongoing	The many hours of their lives taken up by the treatment were the obvious focus of their sense of enduring a life on dialysis. ...most felt it was time wasted which they	U	Loss (of time)

		<p>could better use for other activities. Pg 217</p> <p><i>"it feels like a waste of time, on dialysis the machine runs your life."</i> Pg 218</p>		
4	Uncertainty about the future	<p>A developing understanding, contrary to the optimism of the professional viewpoint, of the limitations of the efficaciousness of dialysis as a therapy for CRF gave rise to a sense of uncertainty about the future. Pg 219</p> <p><i>"I often wonder how long you can do this for.. there seems almost no hope of a transplant; in my age bracket perhaps the chances lessen, there's a certain amount of urgency as you get older."</i> Pg 220</p> <p><i>"I might not have thought of going on if I had known that this would be the future, or come of at a certain point."</i> Pg 221</p>	U	Uncertainty
5	The expectation of a transplant	<p>...these men looked forward to a different event that would both break the routine and address their uncertainty. They coped with the ongoingness and uncertainty of living on dialysis through their hope of a kidney transplant. Pg 222</p> <p><i>"Dialysis is a stepping stone until you get the transplant."</i> Pg 222</p> <p>Other than Mark and Owen the men showed almost no recognition of the degree of uncertainty about receiving a transplant, let alone any awareness of the potential problems with transplantation itself not only the possibility of the transplanted kidney failing to function for some reason but also the long term complications associated with transplantation such as increased risk of life threatening infections or cancers. Pg 223</p> <p>They coped through their hope that life on dialysis did not have to be accepted as permanent but was rather provisional, because they would in the future receive a transplant to enable them to escape from dialysis. Pg 224</p>	U	Hope

6	Changing personal relationships	<p>The men's accounts suggested that living on dialysis had affected their relationships with their families and friends. Generally they tended to emphasize the ordinary character of their relationships, such as the understanding of friends who accommodated their dialysis in planning social activities or the easy acceptance of their treatment by grandchildren playing around the machine while they were dialysing. Pg 226</p> <p>...their relationship with their partners, all well established, remained strong, but had altered somewhat in character. Their wives had adapted their own lifestyles to be present in the house when the men were doing their treatment. Pg226</p> <p><i>"...terrific amount of teamwork, it's so much easier with some helping, much more pleasurable, quicker if you work as team."</i> Pg 227</p> <p>All of the men recognized some costs to their partners from them being on dialysis, whether in terms of limiting their own activities or the stress of having to cope with their husband's illness and its treatment. Pg 227</p>	U	Social life/relationships/dependence
7	Their new healthcare relationships	<p>While affirmed in their autonomy in managing their own dialysis at home, their awareness of the limited support actually available to them indicated their dependence on renal staff. Pg 228</p> <p>Although they felt positive about their relationship with health care professionals, these men were sensitive to any perceived lack of being fully informed about their condition, therapy or its effects. Sometimes they expressed a sense of having been misled by renal health professionals. Pg 230</p>	U	Dependence/knowledge
8	Dependence on the dialysis machine	<p><i>"I'd feel the extra day, my body tells me I need the dialysis machine, I don't deviate, it's not worth your while."</i> Pg 231</p> <p>However, despite this common strategy of seeking to manage their lives on dialysis by maintaining a strict therapeutic regime, they are still regularly reminded, by</p>	U	Dependence

		residual symptoms, limitations in their ordinary lives caused by the therapeutic regime and occasional unexpected events underlining the uncertainty of life on dialysis, of their dependence on the therapeutic regime for their continued wellbeing. Pg 232		
Reference	Rittman M, Northsea C, Hausauer N, Green C. Living with renal failure. ANNA Journal. 1993;20(3):327-31; discussion 32.			
1	Maintaining hope	<p>Patients described hope as a significant aspect of coping ... having a transplant, to get a job again, yet to be discovered treatments that would help them continue to live. Pg 329</p> <p>Suffering from the pain and disability of renal failure is attenuated by hope and sustains individuals in daily living. Pg 329</p>	U	Hope/future
Reference	Sadala MLA, Bruzos GAdS, Pereira ER, Bucuvic EM. Patients' experiences of peritoneal dialysis at home: a phenomenological approach. Revista Latino-Americano Enfermagem. [Article]. 2012;20(1):68-75.			
1	Facing the world of renal failure and dialysis treatment	<p>They described their anguish in the face of death; and the perception that they were launched into an unknown and frightening world, without escape. The treatment proposed by the healthcare team was the only way to survive but, in practice, it appeared painful and aggressive, drastically limiting their activities and social life. In addition, it would last for a long and unpredictable time, until an unlikely kidney appeared to have a transplant. Pg 71</p> <p>Forced changes encompassed the whole organization of their world, involving their home, job, social gatherings. Additionally, they financially affected the family: they had to leave or change their job. Pg 72</p> <p>The young revealed hope in soon having a kidney transplant: dreaming of a future free from catheters, from bags and from the dialysis machine: <i>"Well, what was more important to me was when I Joined the transplant waiting list to have an organ from a corpse. And I'm waiting."</i> Pg 72</p>	U	Impact on life/loss of freedom/hope

Reference	Shih LC, Honey M. The impact of dialysis on rurally based Māori and their whānau/families. Nursing Praxis in New Zealand. 2011;27(2):4-15.			
1	Stress from HD	<p>Some participants admitted to reduced adherence to advised therapeutic regimes because of the costs of care. Pg 7</p> <p>Most participants could not maintain employment because of their poor health and the need for dialysis. Pg 7</p> <p>Participants and their families found the dialysis regimes and associated travelling stressful. Pg 7</p> <p><i>"You miss out on a lot of things you used to do in the past. You lose your social life, you can't go visiting or go away."</i> Pg 7</p> <p>While being on the transplant list resulted in hope for participants, the consequences of long waiting times and perhaps not receiving a kidney transplant were very stressful. Pg 7</p> <p><i>"I tried hard to keep up on the waiting list for many years; I feel aggravated sometimes. I have been on the transplant list for many years and nothing happened. I hope the next one may be me but I am always disheartened"</i> Pg 7</p> <p>Being on the kidney transplant list was found to bring hope; however the long wait for a kidney transplant is a stressful process. Pg 8</p>	U	Effect of dialysis on life/hope/uncertainty
Reference	Yu H, Petrini MA. The HRQoL of Chinese patients undergoing haemodialysis. Journal of Clinical Nursing. 2010;19(5-6):658-65.			

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1	Psycho-social aspect: Anxiety	<p>Among [the patients waiting for a kidney transplant], the longest waiting time was nearly five years. All of them showed different level of anxiety when they talked about transplantation. Pg 662</p> <p><i>"I do not know how long I will have to wait, I have heard of some who had to wait more than eight years. I cannot imagine having to wait so long...I get upset and lose my temper when I think of that. But who can tell me how long I will have to wait? I am really worried about that". Pg 662</i></p>	U	Uncertainty
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