

RRT and conservative management

Evidence review for symptom recognition

NICE guideline NG107

Qualitative evidence review

October 2018

Final

*This evidence review was developed by
the National Guideline Centre*

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and, where appropriate, their carer or guardian.

Local commissioners and providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#). All NICE guidance is subject to regular review and may be updated or withdrawn.

Copyright

© National Institute for Health and Care Excellence, 2018. Subject to notice of rights.

ISBN: 978-1-4731-3107-1

Contents

1	Symptom recognition	5
1.1	Review question: What are the most important symptoms to recognise for people undergoing RRT or receiving conservative management?.....	5
1.2	Introduction	5
1.3	Characteristics table	5
1.4	Qualitative evidence	5
1.4.1	Included studies	5
1.4.2	Excluded studies.....	6
1.4.3	Summary of qualitative studies included in the evidence review	6
1.4.4	Qualitative evidence synthesis	11
1.4.5	Qualitative evidence summary	17
1.5	Economic evidence	83
1.6	Resource impact	83
1.7	Recommendations	Error! Bookmark not defined.
	Appendices	90
	Appendix A: Review protocols	90
	Appendix B: Literature search strategies	92
	B.1 Clinical search literature search strategy	92
	Appendix C: Qualitative evidence selection.....	96
	Appendix D: Qualitative evidence tables	97
	Appendix E: Excluded studies.....	122
	E.1 Excluded qualitative studies	122

1 Symptom recognition

1.1 Review question: What are the most important symptoms to recognise for people undergoing RRT or receiving conservative management?

1.2 Introduction

There is a wide variety of symptoms reported in people in late stage CKD, some of which, e.g. uncontrolled fluid overload, may indicate a need to start renal replacement therapy. There is some uncertainty regarding which symptoms healthcare professionals should be aware of and should recognise in their patients. People may also be uncomfortable talking about certain symptoms, for example sexual dysfunction. The purpose of this review is to identify the symptoms most important to people on renal replacement therapy or conservative management.

1.3 Characteristics table

For full details see the review protocol in appendix A.

Table 1: Characteristics of review question

Objective	To provide evidence of the types of symptoms that people undergoing RRT find are most important to them, particular focus on symptoms that: <ul style="list-style-type: none"> • some people may be unaware are related to their condition/treatment • are most impactful in terms of quality of life • are under-recognised by healthcare professionals
Population and setting	Adults and children who are being assessed for RRT or conservative management for later stages of CKD, or who are undergoing RRT or conservative management, their families, carers and healthcare professionals Evidence will be reported separately for: <ul style="list-style-type: none"> • Pre-RRT vs HD vs PD vs TPx vs CM • <2, 2 to <16, 16 to <25, 25 to <70, 70 and over
Context	Any themes that emerge relating to the symptoms of the target population.
Review strategy	Synthesis of qualitative research. Results presented in table format. Quality of the evidence will be assessed by a GRADE CerQual approach for each review finding.

1.4 Qualitative evidence

1.4.1 Included studies

Thirty four qualitative studies were included in the review^{1, 5, 6, 8, 12-14, 16, 19-21, 25, 26, 28, 31-34, 36, 39-41, 49-53, 56, 58, 59, 63, 67, 71, 72} these are summarised in Table 2 below. Key findings from these studies are summarised in Section 1.4.2 below. See also the study selection flow chart in appendix C, study evidence tables in appendix D, and excluded studies lists in appendix E.

Twenty eight studies explored the views of adult patients with on RRT. One study focused on the views of adolescent patients on RRT. Four studies focused on the views of patients and family members/carers on RRT. One study focused on the views of parents whose children were on RRT or considering RRT.

1.4.2 Excluded studies

See the excluded studies list in appendix E.

1.4.3 Summary of qualitative studies included in the evidence review

Table 2: Summary of studies included in the review

Study	Design	Population	Research aim	Comments
Al Nazly, 2013 ¹	In-depth semi-structured face to face interview with thematic qualitative analysis	20 to 69 years (Mean=47yrs) Jordan All on haemodialysis	To examine the lived experiences of Jordanian patients with CKD receiving HD.	Minor limitations due to country.
Barnieh, 2014 ⁵	Open ended survey distributed online with thematic qualitative analysis	18 to 80+ years (Mode=60-69yrs) Patients and carers Canada Haemodialysis	To synthesise the views of Canadian patients on or nearing dialysis and those who care for them.	Moderate limitations due to methods design.
Baskale, 2011 ⁶	In-depth semi-structured face to face interview with thematic qualitative analysis	12 to 20 years (Mean=15.5yrs) Turkey Haemodialysis	To explore how adolescents receiving HD were affected by their diagnosis and treatment.	Minor limitations due to country.
Bourbonnais, 2012 ⁸	In-depth semi-structured face to face interview with thematic qualitative analysis	31 to 90 years (Mode=61+yrs) Canada Haemodialysis	To provide an overview of pain experienced by patients undergoing maintenance dialysis.	Minor limitations
Campbell, 2016 ¹²	In-depth semi-structured face to face interview with thematic qualitative analysis following the principles of grounded theory	30 to 89 years (Mode=40-49yrs) Australia Peritoneal dialysis	To describe the beliefs, needs and experiences of PD patients about peritonitis.	Minor limitations
Cervantes, 2017 ¹³	In-depth semi-structured face to face interview with thematic qualitative analysis	30 to 78 years (Mean=61yrs) US Haemodialysis	To explore the preferences of Latino patients receiving dialysis regarding symptom management and ACP.	Minor limitations
Chiaranai, 2016 ¹⁴	In-depth semi-structured face to face interview with	18+years (Range=48 to 77 yrs)	To better understand the daily life	Minor limitations due to ethics

Study	Design	Population	Research aim	Comments
	thematic qualitative analysis	Thailand Haemodialysis	experiences of Thai patients with ESRD on HD.	
Cox, 2017 ¹⁶	In-depth semi-structured face to face interview with transcription and thematic qualitative analysis	20 to 75+ years (Mode=45-64yrs) US Haemodialysis	To describe patients' perspectives on symptoms associated with end-stage chronic kidney disease treated with thrice-weekly, in-centre HD.	Minor limitations due to ethics
da Silva Alencastro, 2013 ¹⁹	In-depth semi-structured face to face interview with thematic qualitative analysis	44 to 50 years (Median=45yrs) Brazil Kidney transplant recipients	To understand the meanings in process of renal transplantation in view of the transplanted person.	Moderate limitations due to role of researcher and rigor of data collection/methods
DePasquale, 2013 ²⁰	In-depth semi-structured face to face interview with thematic qualitative analysis	18+years (Mean=58.1yrs) Patients and family members US Pre RRT, haemodialysis, peritoneal dialysis, kidney transplant recipients	To elicit their views regarding information they felt should be featured in educational resources informing RRT selection decisions.	Moderate limitations due to ethics and research design
Ekelund, 2010 ²¹	In-depth questionnaire based semi-structured face to face interview with follow up telephone calls, with thematic qualitative analysis	26 to 84 years (Mean=61yrs) Patients and partners Sweden Haemodialysis or peritoneal dialysis	To elicit psychological and psychosocial problems existing in patients in dialysis and their partners.	Moderate limitations due to unclear role of the researcher and ethics approval
Harwood, 2005 ²⁵	In-depth semi-structured face to face interview with thematic qualitative analysis	61 to 89years (Mean=72.7yrs) Canada Haemodialysis	To identify the implications for patient education and support needed in the care of patients with CKD.	Minor limitations
Heck, 2004 ²⁶	In-depth semi-structured face to face interview with thematic qualitative	19 to 71years (Median=52yrs) Germany	To examine the psychosocial effects of living donor kidney transplantation for	Severe limitations due to ethics, role of the researcher, data collection, data analysis and

Study	Design	Population	Research aim	Comments
	analysis	Kidney transplant recipients	donors and recipients under successful as well as complicated circumstances.	richness of data
Horigan, 2013 ²⁸	In-depth semi-structured face to face interview with thematic qualitative analysis	21+years (Mode=60-69yrs) US Haemodialysis	To describe the experience and self-management of fatigue in adult patients on haemodialysis	Minor limitations
Jones, 2017 ³¹	In-depth semi-structured face to face interview with thematic qualitative analysis	55 to 88years (Median=74yrs) UK Haemodialysis	To obtain UK NHS patients' perspectives on the challenges arising from HD with the intention of identifying potential improvements.	Minor limitations
Kaba, 2007 ³²	In-depth semi-structured face to face interview with theoretical sampling analysis	18+years (Mean=62yrs) Greece Haemodialysis	To explore how Greek patients receiving long-term haemodialysis perceive their problems and to describe the impact of haemodialysis on these patients' lives.	Minor limitations
Korus, 2011 ³³	Focus group sessions with content analysis	13 to 17years (Mean=15yrs) Canada Kidney transplant recipients	To explore information needs of adolescents who have undergone kidney transplantation	Minor limitations
Lai, 2012 ³⁴	In-depth semi-structured face to face interview with interpretative phenomenological analysis	39 to 63years (Mean=52yrs) Singapore Haemodialysis	To explore the lived experiences of incident haemodialysis patients in Singapore.	Minor limitations due to country and ethics
Lee, 2007 ³⁶	In-depth semi-structured face to face interview with thematic qualitative analysis	26 to 72years (Mean=52yrs) South Taiwan Haemodialysis	To explore the fatigue experience from haemodialysis patients' perspectives.	Minor limitations due to ethics
Lin, 2005 ³⁹	In-depth semi-structured face to	28 to 53years (Mean=38.9yrs)	To describe the experiences of making a decision	Minor limitations due to country and ethics

Study	Design	Population	Research aim	Comments
	face interview with thematic qualitative analysis	South Taiwan Haemodialysis	about HD among a group of Taiwanese with ESRD.	
Lindqvist, 2000 ⁴⁰	In-depth semi-structured face to face interview with content analysis	28 to 86years Sweden Haemodialysis, Peritoneal dialysis, kidney transplant recipients	To describe the perceived consequences of illness and treatment among ESRD patients.	Minor limitations due to role of researcher
Lonargáin, 2017 ⁴¹	In-depth semi-structured face to face interview with interpretative phenomenological analysis	26 to 68years (Mean=45yrs) UK Kidney transplant recipients	To explore the psychological experiences of receiving a kidney transplant from a deceased donor.	Minor limitations
Murray, 2014 ⁴⁹	In-depth semi-structured face to face interview with content analysis	18 to 30years (Median=25yrs) UK Kidney transplant recipients	To assess the impact of ESKD on education and employment outcomes in young adults.	Minor limitations due to rigor of data analysis
Noble, 2010 ⁵⁰	In-depth semi-structured face to face interview with thematic qualitative analysis	Age not stated (25 to 70yrs assumed) Patients/carers UK Conservative management	To explore symptoms in stage 5 CKD patients without dialysis.	Moderate limitations due to insufficient information on data analysis
Orr, 2007 ⁵¹	Focus group sessions with thematic qualitative analysis	18+years (Mode=60+) UK Kidney transplant recipients	To explore patients' lived experience in relation to medication adherence.	Minor limitations
Orr, 2007 ⁵²	Focus group sessions with thematic qualitative analysis	18+years (Mode=60+) UK Kidney transplant recipients	To explore the experience of living with a transplanted kidney.	Minor limitations

Study	Design	Population	Research aim	Comments
Polaschek, 2003 ⁵³	In-depth semi-structured face to face interview with thematic qualitative analysis	20 to 60+years New Zealand Haemodialysis	To contribute towards enabling health professionals to provide more effective support to people who are living with ESRD.	Minor limitations
Schmid-Mohler, 2014 ⁵⁶	In-depth semi-structured face to face interview with content analysis	18+ years (Median=52yrs) Switzerland Kidney transplant recipients	To explore the concept and the presence of self-management tasks mastered by patients in the early phase after kidney transplant.	Minor limitations
Small, 2010 ⁵⁸	In-depth semi-structured face to face interview with thematic qualitative analysis	20 to 70+years Namibia Haemodialysis	To describe the experiences of patients receiving HD for CKD.	Minor limitations due to country
Stanfill, 2012 ⁵⁹	Focus group sessions with thematic qualitative analysis using the 'long table approach'	41 to 60+ years (Mean=55yrs) US Kidney transplant recipients	To obtain insight into recipients' perception of weight gain.	Moderate limitations due to the data not being rich and ethical approval
Tong, 2010 ⁶³	In-depth semi-structured face to face interview with thematic qualitative analysis	Parents of children on RRT 0-18years of age (Mode=15-19yrs) Australia Pre RRT, haemodialysis, peritoneal dialysis, kidney transplant recipients	To explore the experiences of parents who have children with CKD.	Minor limitations due to ethics
Winterbottom, 2014 ⁶⁷	In-depth semi-structured face to face interview with thematic qualitative analysis	18+years (Median=57.5yrs) UK Pre RRT	To understand how patients with kidney failure make their dialysis treatment decision.	Minor limitations
Yngman-Uhlin, 2010 ⁷¹	In-depth semi-structured face to face interview with transcripts analysed using a phenomenological	36 to 82years Sweden Peritoneal dialysis	To describe how patients on PD treatment at home experience tiredness linked to poor sleep in	Minor limitations

Study	Design	Population	Research aim	Comments
	reduction in four systematic steps		everyday life.	
Yodchai, 2011 ⁷²	In-depth semi-structured face to face interview with open, axial and selective coding in accordance with GT analysis	24 to 66years (Mean=45.4yrs) Thailand Haemodialysis	To explore how HD affects Thai patients with ESRD.	Minor limitations due to country

See appendix D for full evidence tables.

1.4.4 Qualitative evidence synthesis

Throughout this review wherever possible the original wording of the participants in the studies themselves has been maintained in order to preserve the intended meaning.

As this is a qualitative review the principle aim was to identify symptoms that were important to individuals. Alongside the individual symptoms, a high level summary of the frequency of the finding (in other words, did the study specifically mention a symptom as being frequently reported by the participants or not) and any additional pertinent details are presented below. However it is important to emphasise that determining the prevalence of symptoms was not the intended purpose of the review.

Pre RRT

Table 3: Review findings

Main findings	Frequency of finding	Additional details
Oedema	Infrequent	Specific mention of swollen ankles
Itching	Infrequent	Specific mention of high intensity of itching
Fatigue	Infrequent	-
Cramps	Infrequent	-
Cognitive fatigue	Infrequent	-
Moodiness	Infrequent	-
Nausea/vomiting	Infrequent	-
Pain	Infrequent	-
Sleep disturbance	Infrequent	-
Weight loss	Infrequent	-
Weight gain	Infrequent	-

Conservative Management

Table 4: Review findings

Main findings	Frequency of finding	Additional details
Breathlessness	Common	Participants associated this with fluid overload caused by renal disease and/or associated anaemia.
Gastrointestinal problems	Common	Participants reported difficulties related to incontinence and altered bowel habits.
Depression	Common	Often attributed to being unable to do things they'd previously been able to do with ease. Some were

Main findings	Frequency of finding	Additional details
		depressed due to the decision not to have dialysis.
Immobility	Common	Participants had problems with walking, standing and being active, causing problems with their self-care. Some complained of 'feeling trembly' in their legs, having a fear of falling and painful knee/hip joints.
Itching	Common	Participants found this problematic and persistent. Occasionally it led to other problems for some such as ulcers.
Fatigue	Common	Participants reported feeling tired and finding it debilitating, with daily chores, tasks and social needs not being able to be carried out with as much ease as before the condition.
Nausea/vomiting	Common	Participants suffered from this and managed it with anti-emetics medication when required. Some reported it was due to uraemia, chest infection or constipation.
Pain (including joint pain, needle pain, phantom pain)	Common	Participants reported different types of pain due to problems such as arthritis, a fractured hip, leg ulcers and cancer. Some had pain due to an unknown cause and none reported pain due to renal disease.
Oedema	Common	Some had associated breathlessness and fluid overload which affected mobility.
Weight loss	Infrequent	-
Weakness	Infrequent	-
Trembling	Infrequent	-
Sore mouth/tongue	Infrequent	-
Visual disturbances	Infrequent	-
Cognitive fluctuations	Infrequent	-
Poor balance	Infrequent	-
Poor appetite	Infrequent	-
Pins and needles	Infrequent	-
Insomnia	Infrequent	-
Incontinence	Infrequent	-
Headaches	Infrequent	-
Dry skin	Infrequent	-
Dizziness	Infrequent	-
Difficulty swallowing	Infrequent	-
Cramps	Infrequent	-
Confusion	Infrequent	-
Altered taste	Infrequent	-

Haemodialysis

Table 5: Review findings

Main findings	Frequency of finding	Additional details
Fatigue	Common	Participants complained of decreased energy and feeling tired before dialysis but even more so afterwards, stating it

Main findings	Frequency of finding	Additional details
		drains their energy.
Pain	Common	Participants reported a variety of pain problems in their back or joints and some patients mentioned the needle pain during dialysis.
Exhaustion	Common	Participants described a lack of physical energy after dialysis and not being able to do activities they wanted to do such as going out, exercising and household chores.
Depression	Common	Participants reported psychological stress and mood swings, feeling depressed because HD occupied most of their lives.
Dizziness	Common	Participants experienced a sensation of being lightheaded and dizzy in conjunction with extreme fatigue, particularly immediately after dialysis.
Malaise	Common	-
Insomnia	Common	-
Helplessness	Common	Participants described feeling this and feeling as victims of the treatment rather than it benefiting them.
Itching	Common	This was a common symptom, with some mentioning how phosphorous levels needed to be maintained to control itching, either by diet or medication.
Restless legs	Common	-
Stress	Common	Participants reported this due to having to schedule in dialysis treatment around their job and fear of dying.
Thirst	Common	Participants described how they think about this every day and how their mouth feels dry.
Cramps	Common	Participants reported cramps and muscle pain following rapid fluid removal, which could persist once they got back home.
Sexual functioning	Common	Some participants indicated they were no longer interested in sex and a larger number indicated they were sexually active, but indicated the frequency had decreased.
Anger	Infrequent	A lot of participants reported frustration with the complication dialysis put on their lives and anger with people pitying them.
Anxiety	Infrequent	Participants reported anxiety about potential problems that could arise from dialysis and the prospect of premature death.
Body image/hair growth	Infrequent	Participants described a disturbed body image, mentioning bloating, being unable to shave and having a bump on the forearm due to the needle.
Breathlessness	Infrequent	This was the reason some participants were diagnosed with ESRD and some reported it as a worsening symptom.
Cognitive fatigue	Infrequent	Some participants reported their mental strength was weakened after dialysis and described mental fatigue causing them to not hold conversations or remember conversations.
Headaches	Infrequent	Participants mentioned headaches after dialysis sessions caused by the machines and that it is too difficult going three times a week.
Discomfort	Infrequent	Participants expressed discomfort with the chairs used during dialysis, with some saying it made their joint and back pain worse, and made them feel immobilised.

Main findings	Frequency of finding	Additional details
Guilt	Infrequent	Some felt guilt as they felt they couldn't be a good wife or mother through physical limitations.
Loneliness	Infrequent	Some participants felt lonely as they couldn't socialise anymore with their restrictions blocking them from seeing their friends.
Nausea/vomiting	Infrequent	Some participants mentioned this as a worsening symptom. One parent reported how it was a struggle to feed their child as they kept vomiting and retching. Some mentioned nausea was caused by the medication.
Sleep disturbance/sleepiness	Infrequent	Most participants attributed their tiredness to sleeping problems, with some describing disjointed sleep patterns and not being able to sleep well.
Gastrointestinal problems	Infrequent	This symptom was reported but relatively infrequently and was the symptom that resulted in their ESRD diagnosis for some participants.
Vertigo	Infrequent	-
Denial	Infrequent	Most participants reported altered or negative emotional responses to dialysis including denial.
Weakness	Infrequent	Typically reported after a dialysis session, with participants mentioning feeling worn out, weak and unable to walk around.
Drowsiness	Infrequent	This symptom was reported as impacting their daily activities and employment.
Blood pressure alterations	Infrequent	Participants reported this infrequently, with hypotension as a common symptom associated with dialysis.
Heart problems (including irregular heartbeat)	Infrequent	This was reported by some participants and generally participants stated that they were willing to endure this in exchange for life.
Weight gain	Infrequent	-
Weight loss	Infrequent	-
Numbness	Infrequent	-
Moodiness	Infrequent	-
Decreased mobility	Infrequent	-

Peritoneal dialysis

Table 6: Review findings

Main findings	Frequency of finding	Statement of finding
Fatigue	Common	Participants reported low levels of energy and feeling tired after dialysis.
Itching	Common	Participants reported this as usually intense and at times leading to sleep disturbances and pain.
Abdominal pain	Infrequent	Participants reported this in relation to the dialysis process resulting in some sleep disturbance.
Anxiety	Infrequent	Some participants reported worries about complications, death and feeling afraid about future transplantations.
Body image/hair growth	Infrequent	Some participants mentioned changes in body image, specifically bloating, and being unable to shave.

Main findings	Frequency of finding	Statement of finding
Cognitive fatigue	Infrequent	Some participants reported difficulties with concentration, creativity and making decisions.
Cramps	Infrequent	Participants reported cramps in relation to the draining and refilling of the dialysis solution.
Stress	Infrequent	Participants described needing to stop whilst doing household tasks due to tiredness, which contributed to their stress.
Sexual dysfunction	Infrequent	-
Weakness	Infrequent	Participants reported gradually developing the feeling of being worn out with it coming on faster than before, with everyday tasks becoming more time-consuming.
Unstable temper	Infrequent	Some participants reported experiencing mood changes such as becoming more short-tempered due to their lack of sleep.
Moodiness	Infrequent	-
Loneliness	Infrequent	-
Nausea/vomiting	Infrequent	-
Pain	Infrequent	-
Sleep disturbances/sleepiness	Infrequent	-
Weight loss	Infrequent	-
Weight gain	Infrequent	-

Transplant

Table 7: Review findings

Main findings	Frequency of finding	Statement of finding
Fatigue	Common	Low levels of energy and feeling tired was reported by most participants as a side effect to transplant medication and after transplant operations.
Fragile skin	Common	This symptom was reported by most participants as a side effect to transplant medication.
Weight gain	Common	This symptom was reported by most participants as a side effect to the transplant and transplant medication.
Infection	Common	Most participants reported this as a side effect to transplant medication.
Moodiness	Common	Most participants reported this as a side effect to transplant medication.
Anxiety	Infrequent	Participants were worried about getting an illness after the transplant.
Body image/hair growth	Infrequent	Participants explained how they strongly disliked the effects of their medication on their appearance (e.g. bloating, hair growth) affecting their self-image and self-confidence.
Tinnitus	Infrequent	Participants reported this as an adverse effect from transplant medication with ranging severity, with one participant being unable to listen to music.
Pain	Infrequent	Participant's reported pain from surgery and transplant medication including back, joint, bones, foot or leg pain.

Main findings	Frequency of finding	Statement of finding
Stress	Infrequent	Participants reported the stress they felt in not being able to take part in their normal routine, and not being treated like other students, wanting to be treated equally.
Nausea/vomiting	Infrequent	Participants reported this but fairly infrequently, with one parent mentioning the difficulty in feeding their child.
Shakiness	Infrequent	Some participants reported this as a side effect to transplant medication.
Skin cancer	Infrequent	Some participants reported this as a side effect to transplant medication.
Itching	Infrequent	This symptom was reported relatively infrequently and, when experienced, as intense.
Swollen gums	Infrequent	Some participants reported this as a side effect to transplant medication.
Visual disturbances	Infrequent	This was reported as one of many symptoms by participants as an adverse effect from transplant medication.
Fever	Infrequent	-
Oedema	Infrequent	-
Sleep disturbance/sleepiness	Infrequent	-
Weight loss	Infrequent	-
Hallucinations/nightmares	Infrequent	-
Gastrointestinal problems	Infrequent	Participants reported this as an adverse effect from transplant medication.
Cramps	Infrequent	-
Cognitive fatigue	Infrequent	-
Crumbling bones	Infrequent	-
Depression	Infrequent	-

1.4.5 Qualitative evidence summary

Pre-RRT

Table 8: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cognitive fatigue					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about relevance	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 9: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cramps					
1	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about	

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
(People aged 25 to <70)				relevance	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 10: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Fatigue					
3 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about relevance	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 11: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Itching					
2 (People aged 25 to <70)	Individual interviews	This symptom was reported relatively infrequently and as intense.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 12: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Moodiness					
1 (People aged 25 to <70)	Individual interviews	This symptom was reported relatively infrequently.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 13: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Nausea/vomiting					
2 (People aged 2 to <16, 16 to <25, 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	MODERATE
			Coherence	Minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 14: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Pain (including joint pain, needle pain, phantom pain)					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	VERY LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 15: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Sleep disturbance/sleepiness					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 16: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Oedema					
1 (People aged 25 to <70)	Individual interviews	This symptom was reported but relatively infrequently, specifically mentioning ankles.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 17: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight loss					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 18: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight gain					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Conservative Management

Table 19: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Aching body					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 20: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Altered taste					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
			Adequacy	Substantial concerns about adequacy	

Table 21: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Breathlessness					
1 (People aged 25 to <70, 70+)	Individual interviews	Most participants reported this at times due to fluid overload caused by renal disease and/or associated anaemia.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 22: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Confusion					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 23: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Gastrointestinal problems (including constipation and diarrhoea)					
1 (People aged 25 to <70, 70+)	Individual interviews	Participants reported difficulties related to incontinence and altered bowel habits.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 24: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cramps					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 25: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Depression					
1 (People aged 25 to <70, 70+)	Individual interviews	Participants reported feeling depressed as they were unable to do things they were previously able to do.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 26: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Difficulty swallowing					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 27: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Dizziness					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 28: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Dry skin					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 29: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Headaches					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 30: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Immobility					
1 (People aged 25 to <70, 70+)	Individual interviews	Most participants suffered from this and had problems with walking or standing.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 31: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Incontinence					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 32: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Insomnia					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 33: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Itching					
1 (People aged 25 to <70, 70+)	Individual interviews	Most participants found this problematic and persistent.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 34: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Lack of energy					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 35: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Fatigue					
1 (People aged 25 to <70, 70+)	Individual interviews	Most participants reported feeling tired and finding it debilitating.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 36: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Nausea/vomiting					
1 (People aged 25 to <70, 70+)	Individual interviews	Most participants suffered from this symptom.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 37: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Pain (including joint pain, needle pain, phantom pain)					
1 (People aged 25 to <70, 70+)	Individual interviews	Participants reported different types of pain due to problems.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 38: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Oedema					
1 (People aged 25 to <70, 70+)	Individual interviews	Nearly all participants reported this symptom.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 39: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Pins and needles					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 40: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Poor appetite					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 41: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Poor balance					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 42: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cognitive fluctuations					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 43: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Visual disturbances					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 44: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Sore mouth/tongue					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 45: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Trembling					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 46: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weakness					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 47: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight loss					
1 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Haemodialysis

Table 48: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Anger					
4 (People aged 2 to <16, 25 to <70)	Individual interviews	Participants reported anger due to the complications dialysis added to their lives and people pitying them.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 49: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Anxiety					
3 (People aged 2 to <16, 25 to <70, 70 and over)	Individual interviews	Participants reported anxiety about potential problems that could arise from dialysis and the prospect of premature death.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about	

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
				adequacy	

Table 50: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Blood pressure alterations					
2 (People aged 2 to <16, 25 to <70)	Individual interviews	This symptom was reported but relatively infrequently with hypotension as one of the most common symptoms.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 51: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Body image/hair growth					
4 (People aged 2 to <16, 16 to <25, 25 to <70, 70+)	Individual interviews	Participants expressed strong dislike in changes to their appearance, such as bloating.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 52: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Breathlessness					
3 (People aged 2 to <16, 25 to <70)	Individual interviews	This symptom was reported by some participants as a worsening symptom causing them to return to the hospital and start dialysis.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 53: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cognitive fluctuations					
1 (People aged 70 and over)	Individual interviews	Participants reported concern about their memory and remembering to carry out day-to-day tasks.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 54: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cognitive fatigue					
5 (People aged 25 to <70, 70+)	Individual interviews	Participants mentioned how weakness and fatigue affected their cognitive abilities, causing difficulty in concentrating after dialysis.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 55: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cramps					
7 (People aged 25 to <70)	Individual interviews	This symptom was reported by most participants and typically reported post and during dialysis.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 56: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Decreased mobility					
1 (People aged 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 57: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Denial					
1 (People aged 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 58: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Depression					
10 (People aged 2 to <16, 25 to <70, 70+)	Individual interviews (9) and open ended survey (1)	Participants reported feeling depressed during and after dialysis.	Limitations	Moderate limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 59: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Discomfort					
1 (People aged 25 to <70)	Individual interviews	Participants expressed discomfort with the chairs during dialysis.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 60: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Dizziness					
5 (People aged 25 to <70, 70+)	Individual interviews	Participants reported dizziness as an adverse effect of dialysis.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 61: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Drowsiness					
1 (People aged 70+)	Individual interviews	This symptom was reported after a dialysis session but relatively infrequently.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 62: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Exhaustion					
3 (People aged 16 to <25, 25 to <70, 70+)	Individual interviews	Participants reported feeling exhausted after dialysis.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 63: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Fatigue					
18 (People aged 2 to <16, 25 to <70, 70+)	Individual interviews	This symptom was reported by most participants as both habitual and following dialysis.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 64: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Malaise					
2 (People aged 25 to <70, 70+)	Individual interviews	A common symptom mentioned by participants associated with dialysis.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about	

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
				adequacy	

Table 65: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Gastrointestinal problems					
2 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 66: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Guilt					
1 (People aged 25 to <70, 70+)	Individual interviews	Some participants felt guilty that they couldn't be a good wife or mother.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 67: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Headaches					
3 (People aged 2 to <16, 25 to <70)	Individual interviews	Participants reported this relatively infrequently, and after dialysis sessions.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 68: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Helplessness					
1 (People aged 70+)	Individual interviews	This was reported by numerous participants.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 69: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Heart problems (including irregular heartbeat)					
3 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 70: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Insomnia					
5 (People aged 25 to <70, 70+)	Individual interviews	This was a common symptom reported by participants at varying levels of intensity.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 71: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Itching					
5 (People aged 25 to <70, 70+)	Individual interviews	This was a common symptom reported by participants as usually intense.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 72: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Loneliness					
3 (People aged 25 to <70, 70+)	Individual interviews	Participants reported social isolation associated with lifestyle changes as a result of dialysis.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 73: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Moodiness					
1 (People aged 25 to <70)	Individual interviews	This symptom was reported relatively infrequently.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about	

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
				adequacy	

Table 74: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Nausea/vomiting					
4 (People aged 2 to <16, 16 to <25, 25 to <70, 70+)	Individual interviews	This symptom was reported relatively infrequently.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 75: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Numbness					
1 (People aged 25 to <70)	Individual interviews	This symptom was reported relatively infrequently.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 76: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Pain (including joint pain, needle pain, phantom pain)					
11 (People aged 2 to <16, 25 to <70, 70+)	Individual interviews	Most participants reported a variety of pain problems in their back or joints and pain from the needles used during dialysis.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Substantial concerns about adequacy	

Table 77: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Pleural effusion					
1 (People aged 25 to <70)	Individual interviews	This symptom was reported by some participants as a worsening symptom	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 78: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Restless legs					
2 (People aged 25 to <70)	Individual interviews	Most participants reported this symptom as fairly common.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 79: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Sexual functioning					
5 (People aged 25 to <70, 70+)	A combination of individual interviews (4) and surveys (1)	Both patients and their partners often reported changed to their sexual functioning.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 80: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Sleep disturbance/sleepiness					
3 (People aged 25 to <70, 70+)	Individual interviews	Participants reported having disjointed sleeping patterns.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 81: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Stress					
2 (People aged 16 to <25, 25 to <70, 70+)	Individual interviews	Participants reported feeling stressed due to negative emotions and employment issues.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 82: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Thirst					
2 (People aged 25 to <70)	Individual interviews	This symptom was reported by most participants.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 83: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Vertigo					
1 (People aged 25 to <70)	Individual interviews	This symptom was reported by most participants and typically reported post and during dialysis.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 84: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weakness					
4 (People aged 2 to <16, 16 to <25, 25 to <70, 70+)	Individual interviews	This symptom was reported but relatively infrequently and after a dialysis session.	Limitations	Minor limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 85: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight loss					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 86: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight gain					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Peritoneal dialysis

Table 87: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Abdominal pain					
1 (People aged 25 to <70)	Individual interviews	This symptom was reported but relatively infrequently, related to draining and refilling the dialysis solution, as well as some sleep positions.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 88: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Anxiety					
1 (People aged 25 to <70)	Individual interviews	Some participants reported worries about complications, death and feeling afraid about future transplantations.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
			Adequacy	Minor concerns about adequacy	

Table 89: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Body image					
1 (People aged 25 to <70, 70+)	Individual interviews	Participants expressed strong dislike in changes to their appearance, such as bloating.	Limitations Coherence Relevance Adequacy	Minor limitations No concerns about coherence No concerns about relevance Minor concerns about adequacy	MODERATE

Table 90: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Cognitive fatigue					
2 (People aged 25 to <70, 70+)	Individual interviews	Some participants reported sensations of being mentally tired more dominant than physical tiredness.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 91: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cramps					
2 (People aged 25 to <70, 70+)	Individual interviews	This symptom was reported by most participants and typically reported post and during dialysis.	Limitations	Minor limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 92: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Fatigue					
5 (People aged 25 to <70, 70+)	Individual interviews	Participants reported this symptom following dialysis.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 93: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Itching					
5 (People aged 25 to <70, 70+)	Individual interviews	This was a common symptom reported by participants as usually intense.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 94: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Loneliness					
1 (People aged 25 to <70, 70+)	Individual interviews	This symptom was reported relatively infrequently.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 95: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Moodiness					
1 (People aged 25 to <70)	Individual interviews	This symptom was reported relatively infrequently.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 96: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Nausea/vomiting					
2 (People aged 2 to <16, 16 to <25, 25 to <70, 70+)	Individual interviews	This symptom was reported relatively infrequently.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 97: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Pain (including joint pain, needle pain, phantom pain)					
2 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 98: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Sexual functioning					
1 (People aged 25 to <70, 70+)	Individual interviews	Both patients and their partners often reported changed to their sexual functioning.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 99: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Sleep disturbance/sleepiness					
2 (People aged 25 to <70, 70+)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 100: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Stress					
1 (People aged 25 to <70)	Individual interviews	Participants reported feeling stressed when they couldn't complete household tasks.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 101: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Unstable temper					
1 (People aged 25 to <70, 70+)	Individual interviews	Some participants reported experiencing mood changes.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 102: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight loss					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 103: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight gain					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 104: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weakness					
1 (People aged 25 to <70, 70+)	Individual interviews	Participants reported this as a gradually developing feeling.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Transplant

Table 105: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Anxiety					
2 (People aged 25 to <70)	Individual interviews	Participants reported feeling anxious after the kidney transplant as they were worried about getting an illness.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
			Adequacy	Substantial concerns about adequacy	

Table 106: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Body image/hair growth					
5 (People aged 2 to <16, 25 to <70, 70+)	A combination of Individual interviews (2) and focus groups (3)	Participants expressed strong dislike in changes to their appearance as a side effect to their medication such as bloating and hair growth.	Limitations Coherence Relevance Adequacy	Severe limitations Minor concerns about coherence Partially relevant Substantial concerns about adequacy	VERY LOW

Table 107: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cognitive fatigue					
2 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Substantial concerns about adequacy	

Table 108: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Cramps					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 109: Summary of evidence

Study design and sample size	Finding	Quality assessment
------------------------------	---------	--------------------

Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Crumbling bones					
2 (People aged 16 to <25, 25 to <70)	Focus groups	Symptom reported with no additional details.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 110: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Depression					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 111: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Dizziness					
1 (People aged 25 to <70)	Individual interviews	Some participants with a transplant described their previous experiences and reported feeling dizzy following dialysis.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 112: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Fatigue					
5 (People aged 16 to <25, 25 to <70, 70+)	A combination of individual interviews (3) and focus groups (2)	This symptom was reported by most participants as a side effect to transplant medication.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 113: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Fever					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 114: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Fragile skin					
1 (People aged 16 to <25, 25 to <70)	Focus groups	This symptom was reported by most participants as a side effect to transplant medication.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 115: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Gastrointestinal problems					
1 (People aged 25 to <70)	Individual interviews	This was reported as one of many symptoms participants reported as an adverse effect from transplant medication.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 116: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Hallucinations/nightmares					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Substantial concerns about adequacy	

Table 117: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Infection					
2 (People aged 16 to <25, 25 to <70)	A combination of individual interviews (1) and focus groups (1)	This symptom was reported by most participants as a side effect to transplant medication.	Limitations	Severe limitations	VERY LOW
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 118: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Itching					
2 (People aged 25 to <70)	Individual interviews	This symptom was reported relatively infrequently and as intense.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 119: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Moodiness					
2 (People aged 25 to <70)	A combination of individual interviews (1) and focus groups (1)	This symptom was reported by most participants as a side effect to transplant medication.	Limitations	Minor limitations	MODERATE
			Coherence	Minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 120: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Nausea/vomiting					
2 People aged (2 to <16, 16 to <25, 25 to <70)	Individual interviews	This symptom was reported relatively infrequently.	Limitations	Severe limitations	VERY LOW
			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 121: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Pain (including joint pain, needle pain, phantom pain)					
7	A combination of individual interviews (5) and focus groups (2)	Participant's reported pain from surgery and transplant medication.	Limitations	Severe limitations	VERY LOW
People aged (2 to <16, 25 to <70, 70+)			Coherence	Minor concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Substantial concerns about adequacy	

Table 122: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Sleep disturbance/sleepiness					
1	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
(People aged 25 to <70)			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Substantial concerns about adequacy	

Table 123: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Shakiness					
1 (People aged 16 to <25, 25 to <70)	Focus groups	This symptom was reported by one group of participants as a side effect to transplant medication.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 124: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Skin cancer					
2 (People aged 16 to <25, 25 to <70)	Focus groups	This symptom was reported by one group of participants as a side effect to transplant medication.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 125: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Stress					
1 (People aged 2 to <16)	Focus groups	Participants reported the stress they felt in not being able to take part in their normal routine, in being treated differently.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 126: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Oedema					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 127: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Swollen gums					
2 (People aged 16 to <25, 25 to <70)	Focus groups	This symptom was reported by participants as a side effect to transplant medication.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 128: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Tinnitus					
1 (People aged 25 to <70)	Individual interviews	Participants reported this as an adverse effect from transplant medication with ranging severity.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 129: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Visual disturbances					
1 (People aged 25 to <70)	Individual interviews	Participants reported this as an adverse effect from transplant medication.	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	Minor concerns about adequacy	

Table 130: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight gain					
4 (People aged 16 to <25, 25 to <70)	A combination of individual interviews (1) and focus groups (3)	Participant's reported rapid weight gain in the first year after the transplant.	Limitations	Severe limitations	LOW
			Coherence	Minor concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 131: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Weight loss					
1 (People aged 25 to <70)	Individual interviews	Symptom reported with no additional details.	Limitations	Severe limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns about adequacy	

1.5 Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

1.6 Resource impact

The recommendations made based on this review (see section **Error! Reference source not found.**) are not expected to have a substantial impact on resources.

1.7 The committee's discussion of the evidence

1.7.1 Interpreting the evidence

1.7.1.1 The quality of the evidence

The quality of evidence ranged from very low to moderate for pre-RRT, haemodialysis, peritoneal dialysis and transplant. For conservative management the evidence was low quality. Evidence was downgraded due to methodological limitations and concerns regarding adequacy.

1.7.1.2 Findings identified in the evidence synthesis

This qualitative review identified no critical themes but symptoms or the impact of symptoms. The committee incorporated the symptoms that were frequently reported into the recommendations.

A vast amount of symptoms were identified, with the main findings being; fatigue, breathlessness, oedema, sexual dysfunction, pain, GI problems, depression, immobility, itching, nausea, anger, anxiety, body image, headaches, cognitive fluctuations, cramps, dizziness, insomnia, restless legs, thirst, vertigo, weakness, weight gain and infection.

The committee also noted that limited information was provided on the people included in the studies.

The committee noted that people undergoing RRT or conservative management may experience a wide range of mood changes, for some people this will be predominantly low mood or depression. Some people may experience bouts of irritability or anger, particularly in the immediately post-dialysis period due to the physiological toll taken.

1.7.2 Cost effectiveness and resource use

Economic evidence was not relevant to this question.

1.7.3 Other factors the committee took into account

The committee noted that it was difficult to know if the symptoms identified could be attributed to uraemia, the treatment or to another cause for example fatigue and anxiety. Only a minority of people in the pre-dialysis population reported symptoms however this was based on three studies also contributing to HD, PD and transplant, with only one exclusively reporting pre-RRT participants. The experience of the committee was that these people

experience a wide range of symptoms due to uraemia and these are often the reasons for initiating treatment.

The committee thought that symptoms may have been under reported in the people on pre-RRT, PD and conservative management. Under reporting may occur for all treatment modalities for symptoms such as sexual dysfunction and itchiness due to people not being aware that they can be related to their condition or treatment.

The committee concluded that the symptoms reported in the studies were not comprehensive, for example there were considerably fewer symptoms reported in the pre-dialysis people (probably because people did not recognise their symptoms were due to their renal condition) and they are therefore not presented in the recommendation according to modality or conservative management. The committee wished to emphasise that the symptoms reported in the studies should not be used to help people decide what modality of renal replacement therapy or conservative management to choose. It is important to ask the person about their symptoms and to ascertain what might be due to their condition or treatment. This discussion is ongoing throughout the duration of treatment including conservative management. It is important to manage people's expectations regarding the extent to which treatment will control symptoms.

The committee discussed that it may be difficult to recognise symptoms in very young children.

References

1. Al Nazly E, Ahmad M, Musil C, Nabolsi M. Hemodialysis stressors and coping strategies among Jordanian patients on hemodialysis: a qualitative study. *Nephrology Nursing Journal*. 2013; 40(4):321-7; quiz 328
2. Amerena P, Wallace P. Psychological experiences of renal transplant patients: A qualitative analysis. *Counselling & Psychotherapy Research*. 2009; 9(4):273-279
3. Baillie J, Lankshear A. Patient and family perspectives on peritoneal dialysis at home: findings from an ethnographic study. *Journal of Clinical Nursing*. 2015; 24(1-2):222-34
4. Baillie J, Lankshear A. Patients' and relatives' experiences of peritonitis when using peritoneal dialysis. *Journal of Renal Care*. 2015; 41(3):177-86
5. Barnieh L, King-Shier K, Hemmelgarn B, Laupacis A, Manns L, Manns B. Views of Canadian patients on or nearing dialysis and their caregivers: a thematic analysis. *Canadian Journal of Kidney Health & Disease*. 2014; 1:4
6. Baskale H, Baser G. Living with haemodialysis: the experience of adolescents in Turkey. *International Journal of Nursing Practice*. 2011; 17(4):419-27
7. Beanlands H, Horsburgh ME, Fox S, Howe A, Locking-Cusolito H, Pare K et al. Caregiving by family and friends of adults receiving dialysis. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*. 2005; 32(6):621-31
8. Bourbonnais FF, Tousignant KF. The pain experience of patients on maintenance hemodialysis. *Nephrology Nursing Journal*. 2012; 39(1):13-9; quiz 20
9. Braj B, Picone G, Children HF, Cross N, Pearlman L. The lived experience of adolescents who transfer from a pediatric to an adult hemodialysis centre. *CANNT Journal*. 1999; 9(4):41-6
10. Burns T, Fernandez R, Stephens M. The experience of waiting for a kidney transplant: A qualitative study. *Journal of Renal Care*. 2017; 21:21
11. Calestani M, Tonkin-Crine S, Pruthi R, Leydon G, Ravanar R, Bradley JA et al. Patient attitudes towards kidney transplant listing: qualitative findings from the ATTOM study. *Nephrology Dialysis Transplantation*. 2014; 29(11):2144-50
12. Campbell DJ, Craig JC, Mudge DW, Brown FG, Wong G, Tong A. Patients' perspectives on the prevention and treatment of peritonitis in peritoneal dialysis: A semi-structured interview study. *Peritoneal Dialysis International*. 2016; 36(6):631-639
13. Cervantes L, Jones J, Linas S, Fischer S. Qualitative interviews exploring palliative care perspectives of Latinos on dialysis. *Clinical Journal of the American Society of Nephrology*. 2017; 12(5):788-798
14. Chiaranai C. The lived experience of patients receiving hemodialysis treatment for end-stage renal disease: A qualitative study. *Journal of Nursing Research*. 2016; 24(2):101-8
15. Clarkson KA, Robinson K. Life on dialysis: a lived experience. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*. 2010; 37(1):29-35

16. Cox KJ, Parshall MB, Hernandez SH, Parvez SZ, Unruh ML. Symptoms among patients receiving in-center hemodialysis: A qualitative study. *Hemodialysis International*. 2017; 21(4):524-533
17. Curtin RB, Johnson HK, Schatell D. The peritoneal dialysis experience: insights from long-term patients. *Nephrology Nursing Journal*. 2004; 31(6):615-24
18. Curtin RB, Mapes D, Petillo M, Oberley E. Long-term dialysis survivors: a transformational experience. *Qualitative Health Research*. 2002; 12(5):609-24
19. da Silva Alencastro LC, da Souza Freitas T, Tao Maruyama SA, Sumida Silva DR, Cabral da Silva F. The renal transplantation in view of the transplanted person. *Ciencia, Cuidado e Saude*. 2013; 12(2):356-364
20. DePasquale N, Ephraim PL, Ameling J, Lewis-Boyer L, Crews DC, Greer RC et al. Selecting renal replacement therapies: what do African American and non-African American patients and their families think others should know? A mixed methods study. *BMC Nephrology*. 2013; 14:9
21. Ekelund ML, Andersson SI. "I need to lead my own life in any case"--a study of patients in dialysis with or without a partner. *Patient Education and Counseling*. 2010; 81(1):30-6
22. Friesen D. A descriptive study of home hemodialysis spouses. *Dialysis and Transplantation*. 1997; 26(5):310+313-314+318+320+322
23. Gibbons A, Cinnirella M, Bayfield J, Wu D, Draper H, Johnson RJ et al. Patient preferences, knowledge and beliefs about kidney allocation: qualitative findings from the UK-wide ATTOM programme. *BMJ Open*. 2017; 7(1):e013896
24. Hagren B, Pettersen IM, Severinsson E, Lutzen K, Clyne N. Maintenance haemodialysis: patients' experiences of their life situation. *Journal of Clinical Nursing*. 2005; 14(3):294-300
25. Harwood L, Locking-Cusolito H, Spittal J, Wilson B, White S. Preparing for hemodialysis: patient stressors and responses. *Nephrology Nursing Journal*. 2005; 32(3):295-302; quiz 303
26. Heck G, Schweitzer J, Seidel-Wiesel M. Psychological effects of living related kidney transplantation - Risks and chances. *Clinical Transplantation*. 2004; 18(6):716-721
27. Henry SL, Munoz-Plaza C, Garcia Delgadillo J, Mihara NK, Rutkowski MP. Patient perspectives on the optimal start of renal replacement therapy. *Journal of Renal Care*. 2017; 263-269(3):143-155
28. Horigan AE, Schneider SM, Docherty S, Barroso J. The experience and self-management of fatigue in patients on hemodialysis. *Nephrology Nursing Journal*. 2013; 40(2):113-22; quiz 123
29. Jablonski A. The multidimensional characteristics of symptoms reported by patients on hemodialysis. *Nephrology Nursing Journal*. 2007; 34(1):29-37; quiz 38
30. Jennette C, Derebail V, Baldwin J, Cameron S. Renal replacement therapy and barriers to choice: Using a mixed methods approach to explore the patient's perspective. *Journal of Nephrology Social Work*. 2009; 32:15-26
31. Jones DJ, Harvey K, Harris JP, Butler LT, Vaux EC. Understanding the impact of haemodialysis on UK National Health Service patients' well-being: A qualitative investigation. *Journal of Clinical Nursing*. 2017; Epublication

32. Kaba E, Bellou P, Iordanou P, Andrea S, Kyritsi E, Gerogianni G et al. Problems experienced by haemodialysis patients in Greece. *British Journal of Nursing*. 2007; 16(14):868-72
33. Korus M, Stinson JN, Pool R, Williams A, Kagan S. Exploring the information needs of adolescents and their parents throughout the kidney transplant continuum. *Progress in Transplantation*. 2011; 21(1):53-60
34. Lai AY, Loh AP, Mooppil N, Krishnan DS, Griva K. Starting on haemodialysis: a qualitative study to explore the experience and needs of incident patients. *Psychology Health & Medicine*. 2012; 17(6):674-84
35. Lawrence C, Sharma S, Da Silva-Gane M, Fletcher BC, Farrington K. Exploring the views of patients not on the transplant waiting list: a qualitative study. *Journal of Renal Care*. 2013; 39(2):118-24
36. Lee BO, Lin CC, Chaboyer W, Chiang CL, Hung CC. The fatigue experience of haemodialysis patients in Taiwan. *Journal of Clinical Nursing*. 2007; 16(2):407-13
37. Lee C, French P. Continuous ambulatory peritoneal dialysis patients' perception of stressors. *Hong Kong Nursing Journal*. 1999; 35(1):5-11
38. Lin CC, Han CY, Pan IJ. A qualitative approach of psychosocial adaptation process in patients undergoing long-term hemodialysis. *Asian Nursing Research*. 2015; 9(1):35-41
39. Lin CC, Lee BO, Hicks FD. The phenomenology of deciding about hemodialysis among Taiwanese. *Western Journal of Nursing Research*. 2005; 27(7):915-29; discussion 930-4
40. Lindqvist R, Carlsson M, Sjoden PO. Perceived consequences of being a renal failure patient. *Nephrology Nursing Journal*. 2000; 27(3):291-7; discussion 298
41. Lonargáin DÓ, Brannigan D, Murray C. The experience of receiving a kidney transplant from a deceased donor: Implications for renal services. *Psychology & Health*. 2017; 32(2):204-220
42. Lovink MH, Kars MC, de Man-van Ginkel JM, Schoonhoven L. Patients' experiences of safety during haemodialysis treatment--a qualitative study. *Journal of Advanced Nursing*. 2015; 71(10):2374-83
43. Low J, Myers J, Smith G, Higgs P, Burns A, Hopkins K et al. The experiences of close persons caring for people with chronic kidney disease stage 5 on conservative kidney management: contested discourses of ageing. *Health*. 2014; 18(6):613-30
44. Mantulak A, Nicholas DB. "We're not going to say it's suffering; we're going to say it's an experience": The lived experience of maternal caregivers in pediatric kidney transplantation. *Social Work in Health Care*. 2016; 55(8):580-594
45. Moran A. Experiences of patients on outpatient hemodialysis therapy who are anticipating a transplant. *Nephrology Nursing Journal*. 2016; 43(3):241-9; quiz 250
46. Moran A, Scott A, Darbyshire P. Waiting for a kidney transplant: patients' experiences of haemodialysis therapy. *Journal of Advanced Nursing*. 2011; 67(3):501-9
47. Morton RL, Tong A, Webster AC, Snelling P, Howard K. Characteristics of dialysis important to patients and family caregivers: a mixed methods approach. *Nephrology Dialysis Transplantation*. 2011; 26(12):4038-46
48. Murray MA, Thomas A, Wald R, Marticorena R, Donnelly s, Jeffs L. Are you SURE about your vascular access? Exploring factors influencing vascular access decisions

- with chronic hemodialysis patients and their nurses. *CANNT Journal*. 2016; 26(2):21-28
49. Murray PD, Dobbels F, Lonsdale DC, Harden PN. Impact of end-stage kidney disease on academic achievement and employment in young adults: A mixed methods study. *Journal of Adolescent Health*. 2014; 55(4):505-512
 50. Noble H, Meyer PJ, Bridge DJ, Johnson DB, Kelly DD. Exploring symptoms in patients managed without dialysis: a qualitative research study. *Journal of Renal Care*. 2010; 36(1):9-15
 51. Orr A, Orr D, Willis S, Holmes M, Britton P. Patient perceptions of factors influencing adherence to medication following kidney transplant. *Psychology Health & Medicine*. 2007; 12(4):509-17
 52. Orr A, Willis S, Holmes M, Britton P, Orr D. Living with a kidney transplant: A qualitative investigation of quality of life. *Journal of Health Psychology*. 2007; 12(4):653-662
 53. Polaschek N. Living on dialysis: concerns of clients in a renal setting. *Journal of Advanced Nursing*. 2003; 41(1):44-52
 54. Richard CJ. Living with an arterio-venous fistula for hemodialysis. University of Texas School of Nursing at Houston. 2008. Ph.D.
 55. Sahaf RP, Sadat Ilali EPS, Peyrovi HP, Akbari Kamrani AAM, Spahbodi FM. Uncertainty, the overbearing lived experience of the elderly people undergoing hemodialysis: A qualitative study. *International Journal of Community Based Nursing & Midwifery*. 2017; 5(1):13-21
 56. Schmid-Mohler G, Schafer-Keller P, Frei A, Fehr T, Spirig R. A mixed-method study to explore patients' perspective of self-management tasks in the early phase after kidney transplant. *Progress in Transplantation*. 2014; 24(1):8-18
 57. Shih FJ, Lin MH, Lin HY, Lee CJ. Profile of the ideal nursing image during the discharge-preparation transition from kidney transplantation: Taiwanese patients' perspective. *Dialysis and Transplantation*. 1998; 27(5):269-288+312
 58. Small LF. Quality-of-life experiences from the perspective of patients receiving haemodialysis for chronic renal failure. *Health SA Gesondheid*. 2010; 15(1):187-193
 59. Stanfill A, Bloodworth R, Cashion A. Lessons learned: experiences of gaining weight by kidney transplant recipients. *Progress in Transplantation*. 2012; 22(1):71-8
 60. Tong A, Brown MA, Winkelmayr WC, Craig JC, Jesudason S. Perspectives on pregnancy in women with CKD: A semistructured interview study. *American Journal of Kidney Diseases*. 2015; 66(6):951-961
 61. Tong A, Gow K, Wong G, Henning P, Carroll R. Patient perspectives of a young adult renal clinic: a mixed-methods evaluation. *Nephrology*. 2015; 20(5):352-9
 62. Tong A, Henning P, Wong G, McTaggart S, Mackie F, Carroll RP et al. Experiences and perspectives of adolescents and young adults with advanced CKD. *American Journal of Kidney Diseases*. 2013; 61(3):375-84
 63. Tong A, Lowe A, Sainsbury P, Craig JC. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child: Care, Health and Development*. 2010; 36(4):549-57
 64. Tong A, Manns B, Hemmelgarn B, Wheeler DC, Evangelidis N, Tugwell P et al. Establishing core outcome domains in hemodialysis: Report of the standardized

- outcomes in nephrology-hemodialysis (SONG-HD) consensus workshop. *American Journal of Kidney Diseases*. 2017; 69(1):97-107
65. Tong A, Palmer S, Manns B, Craig JC, Ruospo M, Gargano L et al. Clinician beliefs and attitudes about home haemodialysis: A multinational interview study. *BMJ Open*. 2012; 2(6):e002146
66. Weiss M, Weisshaar E. Qualitative interviews on chronic pruritus in haemodialysis patients. *Acta Dermato-Venereologica*. 2014; 94(6):713-4
67. Winterbottom A, Bekker HL, Conner M, Mooney A. Choosing dialysis modality: decision making in a chronic illness context. *Health Expectations*. 2014; 17(5):710-23
68. Xi W, Harwood L, Diamant MJ, Brown JB, Gallo K, Sontrop JM et al. Patient attitudes towards the arteriovenous fistula: a qualitative study on vascular access decision making. *Nephrology Dialysis Transplantation*. 2011; 26(10):3302-8
69. Yalamanchili HB, Murray P, Awuah KT, Harden P, Finkelstein SH, Finkelstein FO. The experience of dialysis therapy among younger adults. *Advances in Peritoneal Dialysis*. 2013; 29:46-9
70. Yilmaz M, Ozaltin G. The sexual behaviors of patients receiving peritoneal dialysis treatment. *Sexuality and Disability*. 2011; 29(1):21-32
71. Yngman-Uhlin P, Friedrichsen M, Gustavsson M, Fernstrom A, Edell-Gustafsson U. Circling around in tiredness: perspectives of patients on peritoneal dialysis. *Nephrology Nursing Journal*. 2010; 37(4):407-13
72. Yodchai K, Dunning T, Hutchinson AM, Oumtanee A, Savage S. How do Thai patients with end stage renal disease adapt to being dependent on haemodialysis?: a pilot study. *Journal of Renal Care*. 2011; 37(4):216-23
73. Yodchai K, Dunning T, Savage S, Hutchinson AM, Oumtanee A. How do Thai patients receiving haemodialysis cope with pain? *Journal of Renal Care*. 2014; 40(3):205-15

Appendices

Appendix A: Review protocols

Table 132: Review protocol: symptom recognition

Question number 10

Field	Content
Review question	What are the most important symptoms to recognise for people undergoing RRT or receiving conservative care?
Type of review question	Qualitative
Objective of the review	Provide evidence of the types of symptoms that people undergoing RRT find are most important to them, particular focus on symptoms that: <ul style="list-style-type: none"> • some people may be unaware are related to their condition/treatment • are most impactful in terms of quality of life • under-recognised by healthcare professionals
Eligibility criteria – population / disease / condition / issue / domain	Adults and children who are being assessed for RRT or conservative management of established renal failure, or who are undergoing RRT or conservative management of established renal failure, their families, carers and healthcare professionals <p>Evidence will be reported separately for:</p> <ul style="list-style-type: none"> • Pre-RRT vs HD vs PD vs TPx vs CM • <2, 2 to <16, 16 to <25, 25 to <70, 70 and over
Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	Not applicable
Eligibility criteria – comparator(s) / control or reference (gold) standard	Not applicable
Outcomes and prioritisation	Symptoms will be derived from the evidence identified for this review and not pre-specified. Themes will also be extracted when they discuss the impact and recognition (by person undergoing RRT/CM or by healthcare professional) of specific symptoms. However for information to guide the technical team, relevant symptoms may include: <p>Tiredness Pain Itch Nausea Vomiting Anorexia Weight loss</p>
Eligibility criteria – study design	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient qualitative evidence is identified
Other inclusion exclusion criteria	Not applicable
Proposed sensitivity /	Not applicable

subgroup analysis, or meta-regression	
Selection process – duplicate screening / selection / analysis	<p>No duplicate screening was deemed necessary for this question, for more information please see the separate Methods report for this guideline.</p> <p>Additional qualitative studies were added to the review until themes within the analysis became saturated; i.e. studies were only included if they contributed towards the development of existing themes or to the development of new themes.</p>
Data management (software)	<ul style="list-style-type: none"> • CERQual was used to synthesise data from qualitative studies. • Endnote was used for bibliography, citations, sifting and reference management.
Information sources – databases and dates	<p>Clinical search databases to be used: Medline, Embase, CINAHL Date: All years Language: Restrict to English only Supplementary search techniques: backward citation searching Key papers: Not known</p>
Identify if an update	Not an update
Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-ng10019
Highlight if amendment to previous protocol	Not an amendment
Search strategy – for one database	For details please see appendix B
Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendices of the evidence report.
Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables).
Methods for assessing bias at outcome / study level	The methodological quality of each study was assessed using NGC checklists. Evidence was analysed using thematic analysis; findings will be presented narratively and diagrammatically where appropriate. Findings were reported according to GRADE CERQual standards.
Criteria for quantitative synthesis	Not applicable
Methods for quantitative analysis – combining studies and exploring (in)consistency	Not applicable
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
Rationale / context – what is known	For details please see the introduction to the evidence review.
Describe contributions of authors and guarantor	<p>A multidisciplinary committee developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Jan Dudley in line with section 3 of Developing NICE guidelines: the manual.</p> <p>Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines:</p>

	the manual.
Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
PROSPERO registration number	Not registered

Appendix B: Literature search strategies

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID) and CINAHL, Current Nursing and Allied Health Literature (EBSCO). Search filters were applied to the search where appropriate.

Table 133: Database date parameters and filters used

Medline (OVID)	1946 – 11 December 2017	Exclusions Qualitative studies
Embase (OVID)	1974 – 11 December 2017	Exclusions Qualitative studies
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	1991 – 11 December 2017	Exclusions Qualitative studies

Medline (Ovid) search terms

1.	exp Renal Replacement Therapy/
2.	((renal or kidney*) adj2 replace*).ti,ab.
3.	(hemodiafilt* or haemodiafilt* or haemofilt* or hemofilt*).ti,ab.
4.	(hemodialys* or haemodialys*).ti,ab.
5.	((kidney* or renal or pre-empt* or preempt*) adj3 (transplant* or graft*)).ti,ab.
6.	(capd or apd or ccpd or dialys*).ti,ab.
7.	or/1-6
8.	(mycophenolic acid or azathioprine or sirolimus or everolimus or tacrolimus or cyclosporin* or steroid or calcineurin inhibitor or anaemi* or anemi* or vitamin d or immunosuppres*).ti.
9.	7 not 8
10.	letter/
11.	editorial/
12.	news/
13.	exp historical article/
14.	Anecdotes as Topic/
15.	comment/
16.	case report/
17.	(letter or comment*).ti.
18.	or/10-17
19.	randomized controlled trial/ or random*.ti,ab.

20.	18 not 19
21.	animals/ not humans/
22.	exp Animals, Laboratory/
23.	exp Animal Experimentation/
24.	exp Models, Animal/
25.	exp Rodentia/
26.	(rat or rats or mouse or mice).ti.
27.	or/20-26
28.	9 not 27
29.	limit 28 to English language
30.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
31.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
32.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
33.	or/30-32
34.	29 and 33
35.	exp "signs and symptoms"/
36.	symptom assessment/
37.	diagnosis/ or prognosis/
38.	(clinical adj3 (manifest* or feature* or finding* or aspect* or marker*)).ti,ab.
39.	(presenting adj3 (feature* or finding* or factor*)).ti,ab.
40.	presentation*.ti,ab.
41.	(physical adj3 (manifest* or characteristic* or feature* or finding*)).ti,ab.
42.	(sign or signs or symptom* or recogni* or identifi* or complain*).ti,ab.
43.	(diagnos* or prognos* or assess* or criteria* or predict*).ti,ab.
44.	or/35-43
45.	34 and 44

Embase (Ovid) search terms

1.	exp renal replacement therapy/
2.	((renal or kidney) adj2 replace*).ti,ab.
3.	(hemodiafilt* or haemodiafilt* or (biofilt* adj1 acetate-free)).ti,ab.
4.	(hemodialys* or haemodialys*).ti,ab.
5.	((kidney* or renal) adj3 (transplant* or graft*)).ti,ab.
6.	capd.ti,ab.
7.	dialys*.ti,ab.
8.	(artificial adj1 kidney*).ti,ab.
9.	or/1-8
10.	limit 9 to English language
11.	letter.pt. or letter/
12.	note.pt.
13.	editorial.pt.

14.	case report/ or case study/
15.	(letter or comment*).ti.
16.	or/11-15
17.	randomized controlled trial/ or random*.ti,ab.
18.	16 not 17
19.	animal/ not human/
20.	nonhuman/
21.	exp Animal Experiment/
22.	exp Experimental Animal/
23.	animal model/
24.	exp Rodent/
25.	(rat or rats or mouse or mice).ti.
26.	or/11-25
27.	10 not 26
28.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
29.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
30.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
31.	or/28-30
32.	exp symptomatology/
33.	symptom assessment/
34.	diagnosis/ or prognosis/
35.	(clinical adj3 (manifest* or feature* or finding* or aspect* or marker*).ti,ab.
36.	(presenting adj3 (feature* or finding* or factor*).ti,ab.
37.	presentation*.ti,ab.
38.	(physical adj3 (manifest* or characteristic* or feature* or finding*).ti,ab.
39.	(sign or signs or symptom* or recogni* or identif* or complain*).ti,ab.
40.	(diagnos* or prognos* or assess* or criteria* or predict*).ti,ab.
41.	or/32-40
42.	27 and 31 and 41

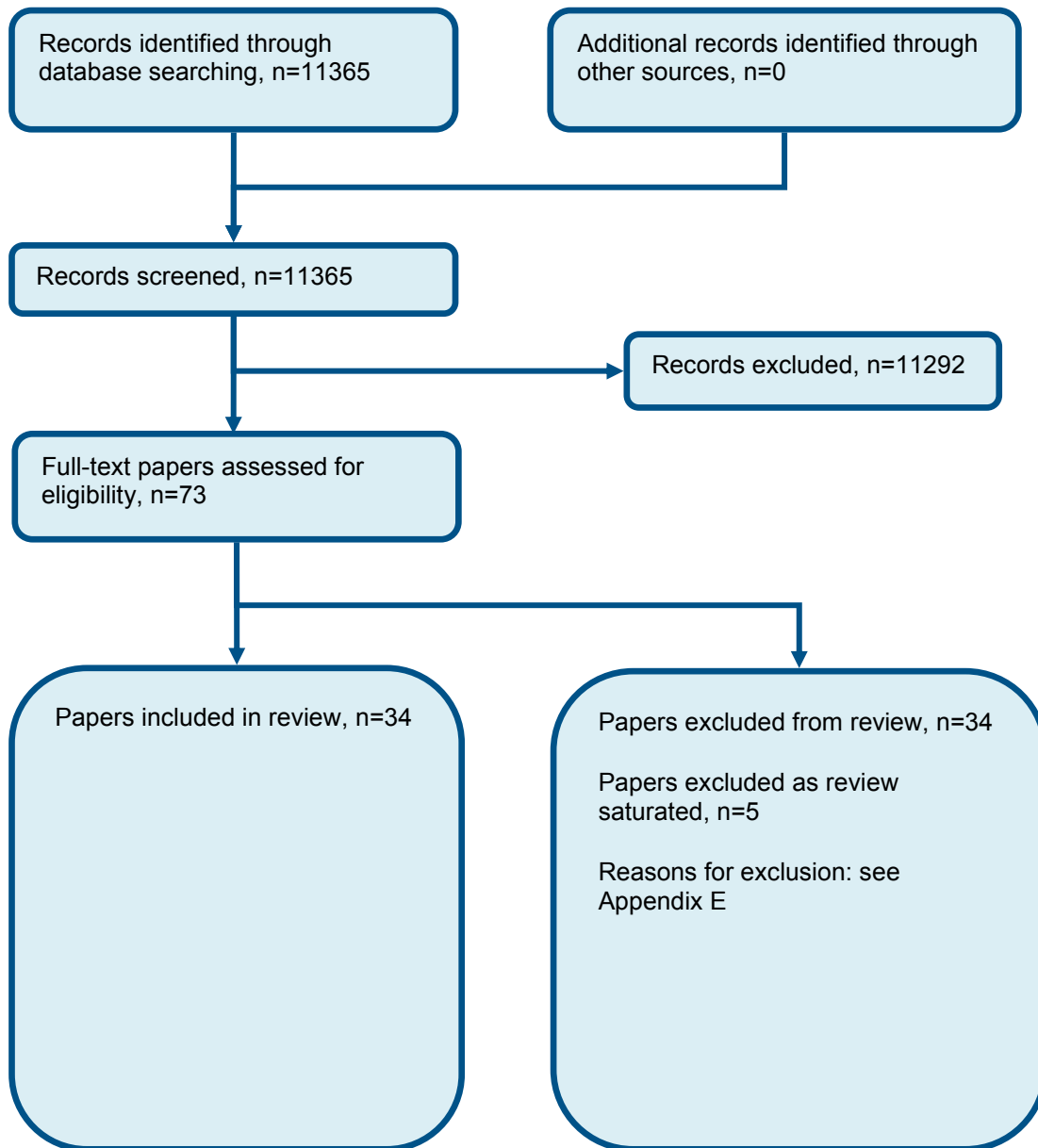
CINAHL (EBSCO) search terms

S1.	(MH "Renal Replacement Therapy+")
S2.	((renal or kidney) n2 replace*)
S3.	hemodiafilt* or haemodiafilt* or haemofilt* or hemofilt*
S4.	hemodialys* or haemodialys*
S5.	((kidney* or renal or pre-empt* or preempt*) n3 (transplant* or graft*))
S6.	(capd or apd or ccpd or dialys*)
S7.	artificial n1 kidney*
S8.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
S9.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or

	PT letter or PT listservs or PT master's thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT "questions and answers" or PT response or PT software or PT teaching materials or PT website
S10.	S8 NOT S9
S11.	(MH "Qualitative Studies+")
S12.	(MH "Qualitative Validity+")
S13.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S14.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S15.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* n3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
S16.	S11 OR S12 OR S13 OR S14 OR S15
S17.	(MH "Signs and Symptoms+")
S18.	MH symptom assessment OR MH diagnosis OR MH prognosis
S19.	TI clinical AND TI (manifest* or feature* or finding* or aspect* or marker*)
S20.	AB clinical AND AB (manifest* or feature* or finding* or aspect* or marker*)
S21.	TI presenting AND TI (feature* or finding* or factor*)
S22.	AB presenting AND AB (feature* or finding* or factor*)
S23.	TI presentation* OR AB presentation*
S24.	TI physical AND TI (manifest* or characteristic* or feature* or finding*)
S25.	AB physical AND AB (manifest* or characteristic* or feature* or finding*)
S26.	TI ((sign or signs or symptom* or recogni* or identif* or complain*)) OR AB ((sign or signs or symptom* or recogni* or identif* or complain*))
S27.	TI ((diagnos* or prognos* or assess* or criteria* or predict*)) OR AB ((diagnos* or prognos* or assess* or criteria* or predict*))
S28.	S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27
S29.	S10 AND S16 AND S28 Limiters - Exclude MEDLINE records; Human; Language: English

Appendix C: Qualitative evidence selection

Figure 1: Flow chart of qualitative study selection for the review of symptom recognition



Appendix D: Qualitative evidence tables

Study	Al Nazly 2013 ¹
Aim	To examine the lived experiences of Jordanian patients with CKD receiving HD.
Population	Adult's aged 20 to 69 years old who were on haemodialysis. The mean age was 47 years old and participant's time on haemodialysis ranged from 1 to 5 years.
Setting	Private area in a dialysis unit, Jordan.
Study design	Qualitative interview study
Methods and analysis	Face to face open ended interviews were audio taped and transcribed by the main investigator. They lasted between 40 and 60 minutes and were completed over a 15 day span. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Cramps - This symptom was reported but relatively infrequently after a dialysis session and all over the body by a participant.
	Exhaustion - Some reported feeling exhausted by the time they got home after dialysis with no energy to do anything, with this impacting their jobs and house chores.
	Headaches - This symptom was reported but relatively infrequently and after a dialysis session.
	Nausea - This symptom was reported but relatively infrequently and after a dialysis session.
	Pain - Most patients complained of the needle sticks used during dialysis and how painful they are.
	Sexual functioning - Some participants reported a loss of sexual desire and a low sex drive due to the treatment decreasing their sexual interest and behaviour.
	Weakness - This symptom was reported but relatively infrequently and after a dialysis session. One reported feeling worn out and weak.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified. There is a minor limitation due to it being conducted in Jordan.

Study	Barnieh 2014 ⁵
-------	---------------------------

Study	Barnieh 2014⁵
Aim	To synthesise the views of Canadian patients on or nearing dialysis and those who care for them.
Population	Adult's aged 18 and above who were receiving haemodialysis.
Setting	Canada
Study design	Qualitative survey study
Methods and analysis	The survey consisted of 7 open ended questions. It was distributed online via partner organisations (Kidney foundation of Canada), social media (Twitter, Facebook) or a paper version, which was available in 10 Canadian HD centres. Most were receiving dialysis in a clinic. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Depression - Some participants expressed feeling depressed due to being unable to carry out simple tasks such as making breakfast and putting on socks, and how much it impacts their everyday life. Sexual functioning - Some respondents expressed concern in how to maintain their sexuality whilst addressing erectile dysfunction or lack of sexual desire.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However there were limitations due to no ethical approval and the method being a survey, resulting in an overall moderate quality.

Study	Baskale 2011⁶
Aim	To explore how adolescents receiving HD were affected by their diagnosis and treatment.
Population	Children and adolescents aged 12 to 20 receiving haemodialysis. The mean age of participants was 15.5 years, and most received dialysis three times a week.
Setting	Turkey
Study design	Qualitative interview study
Methods and analysis	A semi-structured interview with open ended questions was conducted in a private room of the dialysis centre before, during or after their dialysis session. They lasted approximately 30-60 minutes. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Anger - Some participants reported feeling angry with people pitying them as they don't want pity. Anxiety - Symptom reported with no additional details. Blood pressure alterations - Symptom reported with no additional details. Breathlessness - Symptom reported with no additional details. Depression/withdrawal - Symptom reported with no additional details. Fatigue - Participants mentioned feeling exhausted after dialysis and feeling that they can't walk.

Study	Baskale 2011 ⁶
	Body image - Participants described feeling different from others and had concerns about their small stature and body image.
	Headaches - Participants mentioned headaches after dialysis sessions caused by the machines and that it is too difficult going three times a week.
	Nausea - Symptom reported with no additional details. Some mentioned nausea caused by medication.
	Needle pain - Participants reported needle pain as one of the worst things of being haemodialysed. One mentioned how bending the arm causes the needle area to bulge, resulting in needle pain again.
	Weakness - Symptom reported with no additional details.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified. There is a minor limitation due to it being conducted in Turkey.

Study	Bourbonnais 2012 ⁸
Aim	To provide an overview of pain experienced by patients undergoing maintenance dialysis.
Population	Adult's aged 31 and above who were receiving haemodialysis. Majority were aged 60 and above. Participants' time on dialysis ranged from 3 months to 30 years.
Setting	Canada
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews were used and were audio taped. Prompts were used by the interviewer so consistency was maintained through the interview process. Interviews lasted 25 to 75 minutes. Patients were interviewed at the bedside in the respective dialysis unit in the hospital. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Cramps - Some participants reported cramps and muscle pain following rapid fluid removal, which could persist once they got back home. The pain was so much for one participant resulting in them being unable to work.
	Depression - Symptom reported with no additional details.
	Discomfort - Participants expressed discomfort with the chairs used during dialysis, with some saying it made their joint and back pain worse, and made them feel immobilised.
	Fatigue - Participants described feeling fatigued following dialysis, associating it with so much fluid loss and finding the procedure very fatiguing.
	Loneliness - Participants reported social isolation associated with lifestyle changes as a result of dialysis, with some losing their support network as they had to move to a different city to receive dialysis treatment.
	Needle pain - Some participants reported feeling pain from the needles during the procedure of dialysis. Most however didn't mention

Study	Bourbonnais 2012⁸
	pain due to needles as they used a topical cream effective in preventing the pain.
	Pain - Most participants reported a variety of pain problems in their back or joints, with some attributing it to arthritis or being immobilised throughout dialysis.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Campbell 2016¹²
Aim	To describe the beliefs, needs and experiences of PD patients about peritonitis.
Population	Adults aged 30 to 89 on peritoneal dialysis. Most were aged 40 to 49 years, and majority (n=13) were on APD.
Setting	Australia
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews were conducted face to face and the average duration was 40 minutes. Two interviews were conducted via skype, with the rest in person. All interviews were recorded digitally. Thematic analysis following the principles of grounded theory was used to identify important thematic groupings and the relationships between them.
Findings	Itching - Participants reported severe debilitating pain associated with this, and became unable to function, describing the pain as coming on quickly and escalating rapidly to a severe level. Loneliness - Symptom reported with no additional details. Vomiting - Symptom reported with no additional details.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Cervantes 2017¹³
Aim	To explore the preferences of Latino patients receiving dialysis regarding symptom management and ACP.
Population	Adults aged 30 to 78 years on haemodialysis. Mean age of participants was 61 years. Patients received haemodialysis three times a week.
Setting	US
Study design	Qualitative interview study

Study	Cervantes 2017 ¹³
Methods and analysis	Semi structured interviews with open ended questions were conducted chairside during HD sessions and were audio recorded. Interviews lasted from 52 to 84 minutes. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Cramps - This symptom was reported but relatively infrequently and at the beginning of HD during the first year.
	Fatigue - This symptom was reported but relatively infrequently and at the beginning of HD during the first year.
	Headaches - This symptom was reported but relatively infrequently and at the beginning of HD during the first year.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Chiaranai 2016 ¹⁴
Aim	To better understand the daily life experiences of Thai patients with ESRD on HD.
Population	Adults on haemodialysis aged 18 and over, ranging from 48 to 77 years.
Setting	Thailand
Study design	Qualitative interview study
Methods and analysis	Semi structured interview guides were used with each interview lasting between 60 and 90 minutes. Interviews were conducted in Thai at locations that were designated by each participant. All interviews were audio taped. Data saturation was reached after interviewing 26 participants. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Anger - Some participants felt frustrated that it complicated their lives.
	Fatigue - Participants complained of decreased energy and feeling tired before dialysis but even more so afterwards, stating it drains their energy.
	Guilt - Some felt guilt as they felt they couldn't be a good wife or mother through physical limitations.
	Loneliness - Some participants felt lonely as they couldn't socialise anymore with their restrictions blocking them from seeing their friends.
	Pain - This symptom was reported but relatively infrequently, with a participant mentioning severe pain lasting for days after exercising, stating exercise worsens their condition.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However there were limitations due to no ethical approval resulting in an overall minor quality.

Study	Cox 2017¹⁶
Aim	To describe patients' perspectives on symptoms associated with end-stage chronic kidney disease treated with thrice-weekly, in-centre HD.
Population	Adults aged 20 and over on haemodialysis. Mean age was 54.6 years (SD=13.4 years). 20-44 years (20%), 45-64 years (58%), 65-74 years (14%), 75+ years (8%). All but two had been receiving HD for at least six months, with the mean time on treatment being 4.4 years.
Setting	US
Study design	Qualitative interview study
Methods and analysis	1:1 interviews were conducted face to face using a semi-structured interview guide and audio recorded. They lasted from 17 minutes to 1.5 hours. Process continued until thematic saturation was achieved. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Cramps - Participants explained this occurs depending on the amount of fluid taken from them during dialysis and noted that weight must be closely monitored to help prevent cramping by then adjusting how much fluid should be removed.
	Depression - Some participants reported they felt depressed during and after dialysis and dealt with depression with medication, doing an activity such as walking or giving themselves a motivational pep talk.
	Dizziness - Symptom reported with no additional details.
	Fatigue - Participants explained how after dialysis they get easily exhausted doing house tasks and how they are thinking of adapting their job hours around dialysis so they have more energy for what they want to get done.
	Gastrointestinal problems - These symptoms were reported but relatively infrequently.
	Itching - Participants described how their phosphorous levels needed to be maintained to control itching by diet or medication. High levels lead to severe itching as it dries out the skin.
	Restless legs - Symptom reported with no additional details.
	Sexual functioning - This symptom was reported but relatively heterogeneously. Some participants indicated they were no longer interested in sex and a larger number indicated they were sexually active, but indicated the frequency had decreased.
	Thirst - Symptom reported with no additional details.
Weakness - Symptom reported with no additional details.	
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However there were limitations due to no ethical approval resulting in an overall minor quality.

Study	da Silva Alencastro 2013¹⁹
--------------	--

Study	da Silva Alencastro 2013¹⁹
Aim	To understand the meanings in process of renal transplantation in view of the transplanted person.
Population	Kidney transplant recipients aged 44, 45 and 50 years old.
Setting	Brazil
Study design	Qualitative interview study
Methods and analysis	An open interview was conducted. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Fever - This symptom was reported by one participant.
	Infection - This symptom was reported by one participant
	Pain - This symptom was reported by one participant
	Oedema - This symptom was reported by one participant
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However there were limitations due to no ethical approval and lack of detail of data collection, resulting in an overall moderate quality.

Study	DePasquale 2013²⁰
Aim	To elicit their views regarding information they felt should be featured in educational resources informing RRT selection decisions.
Population	Patients and family members were included. Pre RRT, HD, PD and transplant patients were involved. Adults aged 18 and above were included.
Setting	US
Study design	Qualitative interview study
Methods and analysis	Structured group interviews to obtain tabulated and open ended feedback were conducted and audiotaped. There were three stages; stage one explained the purpose of the interview and posed open ended questions, stage two participants revealed their three selected most important factors and stage three participants circled three factors they felt should be presented in educational resources about RRT options. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Cognitive fatigue - Symptom reported with no additional details.
	Cramps - Symptom reported with no additional details.
	Fatigue - Symptom reported with no additional details.
	Itching - This symptom was reported but relatively infrequently and as intense.
	Pain - Symptom reported with no additional details.

Study	DePasquale 2013 ²⁰
	Weight gain - Symptom reported with no additional details.
	Weight loss - Symptom reported with no additional details.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However there were limitations due to no ethical approval and the rigor of the methods, resulting in an overall moderate quality.

Study	Ekelund 2010 ²¹
Aim	To elicit psychological and psychosocial problems existing in patients in dialysis and their partners.
Population	Patients and their partners aged 26 to 84 years. Mean age was 61 years. Patients were either on haemodialysis or peritoneal dialysis.
Setting	Sweden
Study design	Qualitative interview study
Methods and analysis	Questionnaire based semi structured interviews were conducted, generally at the patients home at the start of the investigation and 12 months later. Follow up telephone interviews were conducted twice, 6 and 18 months after the initial interview. The interviews were taped. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Fatigue - Symptom reported with no additional details.
	Itching - Symptom reported with no additional details.
	Sexual functioning - This symptom was reported fairly frequently by both patients and their partners.
	Sleep disturbance - Symptom reported with no additional details.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. However there were limitations due to no ethical approval and unclear role of the researcher, resulting in an overall moderate quality.

Study	Harwood 2005 ²⁵
Aim	To identify the implications for patient education and support needed in the care of patients with CKD.
Population	Adults aged 61 to 89 years on haemodialysis. Mean age was 72.7 years.
Setting	Canada
Study design	Qualitative interview study
Methods and analysis	A semi structured interview guide was used and interviews were conducted by the social worker, generally whilst the patient was receiving HD, but a different location could be used if the patient preferred. Interviews lasted 30 to 45 minutes. Thematic analysis was

Study	Harwood 2005 ²⁵
	used to identify important thematic groupings and the relationships between them.
Findings	Anxiety - This symptom was reported but relatively infrequently, with one participant describing experiencing an anxiety attack on the day of dialysis.
	Decreased mobility - Symptom reported with no additional details.
	Depression - Symptom reported with no additional details.
	Fatigue - This symptom was reported but relatively infrequently, with a participant reporting they felt tired and couldn't do anything and feeling gradually weaker.
	Malaise - Symptom reported with no additional details.
	Insomnia - Symptom reported with no additional details.
	Heart problems - Symptom reported with no additional details.
	Pain - Symptom reported with no additional details.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Heck 2004 ²⁶
Aim	To examine the psychosocial effects of living donor kidney transplantation for donors and recipients under successful as well as complicated circumstances.
Population	Kidney transplant recipients aged 19 to 71 years. Median age was 32 years.
Setting	Germany
Study design	Qualitative interview study
Methods and analysis	Semi-structured interviews were conducted after transplantation. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Anxiety - Symptom reported with no additional details.
	Body image - Symptom reported with no additional details.
	Cognitive failure - Symptom reported with no additional details.
	Depression - Symptom reported with no additional details.
	Hallucinations/nightmares - Symptom reported with no additional details.
	Nausea - Symptom reported with no additional details.

Study	Heck 2004²⁶
	Pain - This symptom was reported but relatively infrequently, with one participant reporting severe pain of the bones. Sleep disturbance - Symptom reported with no additional details.
Limitations and applicability of evidence	There were limitations due to ethical approval, role of the researcher, data collection, data analysis and richness of the data, resulting in an overall severe limitation.

Study	Horigan 2013²⁸
Aim	To describe the experience and self-management of fatigue in adult patients on haemodialysis.
Population	Adults on haemodialysis aged 21 and over. The mode age group was 60 to 69 years. The length of time they were on haemodialysis ranged from less than one year to 10-12 years.
Setting	US
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews were conducted lasting 45 to 60 minutes and were audiotaped. Interviews were conducted in a quiet private place, most often the patients' home and were in a private conference room if at the dialysis centre. At times it was more convenient for participants to be interviewed before their dialysis session. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Cognitive fatigue - Participants discussed a mental fatigue that affected their ability to remember conversations, names and their location whilst driving. This accompanied physical fatigue specifically after dialysis sessions.
	Depression - Some participants reported depression largely due to specific reasons such as loss of a loved one or job loss, noting it was well managed with anti-depressant medication.
	Dizziness - Often participants experienced a sensation of being lightheaded and dizzy in conjunction with extreme fatigue, particularly immediately after dialysis.
	Physical fatigue - Participants described a lack of physical strength and energy that made them feel lifeless, washed out, weak, and drained. Simple activities such as sitting up in a chair felt physically taxing.
	Sleep disturbance - Participants had trouble falling asleep, staying asleep and staying awake in the daytime whilst on HD.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Jones 2017³¹
--------------	--------------------------------

Study	Jones 2017 ³¹
Aim	To obtain UK NHS patients' perspectives on the challenges arising from HD with the intention of identifying potential improvements.
Population	Adults aged 55 to 88 years on haemodialysis. The median age was 74 years, and all were receiving haemodialysis three times a week. Patients had been receiving treatment for 90 days minimum prior to testing.
Setting	UK
Study design	Qualitative interview study
Methods and analysis	Individual semi-structured interviews were conducted by the principal investigator at the patient's bedside during a HD session. Each interview lasted 13-42 minutes and was audio recorded. The topic guide consisted of 12 open-ended questions developed from a review of ESRD literature and informal conversations with patients/nursing staff on the NHS dialysis ward. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Cognitive fluctuations - Multiple participants expressed concern about their memory and remembering to carry out day-to-day tasks. Majority attributed this to old age or medication.
	Depression - Some participants reported feeling depressed, disappointed and frustrated with the impact of HD on their holiday or retirement plans and how much it affects their life.
	Drowsiness - This symptom was reported but relatively infrequently after a dialysis session, impacting their daily activities and employment.
	Fatigue - Some participants reported fatigue after a dialysis session, with it impacting their daily activities and employment, and wanting to sleep post-dialysis.
	Helplessness - Numerous patients described feeling this and feeling as victims of the treatment rather than it benefiting them.
	Lack of concentration - This symptom was reported but relatively infrequently after a dialysis session, impacting their daily activities and employment.
	Dizziness - This symptom was reported but relatively infrequently after a dialysis session, impacting their daily activities and employment.
	Cognitive fatigue - Some participants reported wanting to sleep after morning dialysis and feeling like it was a waste of a day. Pain - This symptom was reported but relatively infrequently after a dialysis session, impacting their daily activities and employment.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.
Study	Kaba 2007 ³²
Aim	To explore how Greek patients receiving long-term haemodialysis perceive their problems and to describe the impact of haemodialysis on these patients' lives.

Study	Kaba 2007³²
Population	Adults on haemodialysis. Mean age was 62 years.
Setting	Greece
Study design	Qualitative interview study
Methods and analysis	Face to face interviews were conducted in a private room on the HD ward after dialysis treatment, lasting 30-60 minutes. All were audiotaped and patients were asked to speak about problems, feelings, thoughts, attitudes, and how they handled their daily activities. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	<p>Anger - Most participants reported altered or negative emotional responses to dialysis including anger.</p> <p>Anxiety - Participants expressed anxiety about potential problems that could arise from dialysis and the prospect of premature death.</p> <p>Denial - Most participants reported altered or negative emotional responses to dialysis including denial.</p> <p>Depression - Most participants reported altered or negative emotional responses to dialysis including depression.</p> <p>Fatigue - This symptom was reported by some participants and generally participants were willing to endure this in exchange for life.</p> <p>Heart problems - This symptom was reported by some participants and generally participants were willing to endure this in exchange for life.</p> <p>Insomnia - This symptom was reported by some participants and generally participants were willing to endure this in exchange for life.</p> <p>Pain - This symptom was reported by some participants and generally participants were willing to endure this in exchange for life, with some saying they couldn't sleep some nights due to the pain.</p>
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified. Minor limitation due to it being conducted in Greece.

Study	Korus 2011³³
Aim	To explore information needs of adolescents who have undergone kidney transplantation.
Population	Adolescents with kidney transplants aged 13 to 17 years. Mean age was 15 years; mean age at transplant was 10 years.
Setting	Canada
Study design	Qualitative focus group study
Methods and analysis	Five focus groups were separately conducted, two with adolescents, two with parents and one with healthcare professionals, with a semi structured interview guide to lead the discussion. Interviews lasted between 40 and 75 minutes with all being conducted in a private quiet room in the hospital clinic or meeting room. All interviews were audio taped. Content analysis was used to identify important thematic groupings and the relationships between them.
Findings	Body image - Participants explained how they strongly disliked the effects of their medication on their appearance resulting in affecting

Study	Korus 2011 ³³
	their self-image and self-confidence. Some mentioned bloating and looking chubby, resulting in them being teased or excluded, with some resorting to crash diets to try to lose weight quickly.
	Pain - Adolescents described pain and discomfort with the surgery, recovery process and various other procedures, with most stating severe pain at the time of the transplant or shortly after.
	Stress - Participants reported the stress they felt in not being able to take part in their normal routine, and not being treated like other students, wanting to be treated equally.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Lai 2012 ³⁴
Aim	To explore the lived experiences of incident haemodialysis patients in Singapore.
Population	Adults on haemodialysis aged 39 to 63 years. Mean age was 52 years.
Setting	Singapore
Study design	Qualitative interview study
Methods and analysis	Semi-structured interviews were conducted with open ended questions. Sessions ranged from 35 to 50mins and were audio recorded. Interpretative phenomenological analysis was used to identify important thematic groupings and the relationships between them.
Findings	Breathlessness - This symptom was reported but relatively infrequently and was the symptom that resulted in their ESRD diagnosis for some participants.
	Cramps - This symptom was reported by most participants and typically reported post and during dialysis.
	Fatigue - This symptom was reported by most participants and typically reported post and during dialysis.
	Gastrointestinal problems - This was reported but relatively infrequently and was the symptom that resulted in their ESRD diagnosis for some participants.
	Insomnia - This symptom was reported but relatively infrequently and was the symptom that resulted in their ESRD diagnosis for some participants.
	Thirst - This symptom was reported by most participants with one describing how they think about it every day and how their mouth feels dry.
	Vertigo - This symptom was reported by most participants and typically reported post and during dialysis.
Limitations and applicability of	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. Minor limitation due to being conducted in Singapore and ethics.

Study	Lai 2012³⁴
evidence	

Study	Lee 2007³⁶
Aim	To explore the fatigue experience from haemodialysis patients' perspectives.
Population	Adults aged 26 to 72 years, on haemodialysis. Mean age was 52 years. Patients on average had received haemodialysis for 2.6 years.
Setting	South Taiwan
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews were used and were audio taped. The data was collected in a HD department and lasted 40 to 60 minutes. Follow up interviews with each participant occurred once or twice. Participants were free to choose the venue for the interviews. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	<p>Cognitive fatigue - Some participants reported their mental strength was weakened after dialysis and perceived their fatigue was related to a decrease in their cognitive function. Most participants described they couldn't hold their attention.</p> <p>Cramps - Symptom reported with no additional details.</p> <p>Depression - Participants reported psychological stress and mood swings, feeling depressed because HD occupied most of their lives.</p> <p>Dizziness - Symptom reported with no additional details.</p> <p>Exhaustion - Most participants described a lack of physical energy and not being able to do activities they wanted to do such as going out, exercising and household chores.</p> <p>Fatigue - Participants reported habitual fatigue occurring immediately after their HD session, describing how they usually had to rest or sleep when returning home.</p> <p>Heart problems - This symptom was reported but relatively infrequently, with one participant describing feeling sore and weary after experiencing an irregular heartbeat.</p> <p>Numbness - Symptom reported with no additional details.</p> <p>Pain - Symptom reported with no additional details.</p> <p>Sleep disturbance - Most participants attributed their tiredness to sleeping problems, with some describing disjointed sleep patterns and not being able to sleep well.</p>
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified. Minor limitation due to it being conducted in South Taiwan and ethics.

Study	Lin 2005 ³⁹
Aim	To describe the experiences of making a decision about HD among a group of Taiwanese with ESRD.
Population	Adults on haemodialysis aged 28 to 53 years. Mean age was 38.9 years and all had begun dialysis within previous six months.
Setting	South Taiwan
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews with open ended questions were conducted either in the participants' homes or the HD centre and lasted from 50 minutes to 2.5 hours. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	<p>Breathlessness - This symptom was reported by some participants as a worsening symptom causing them to return to the hospital and start dialysis.</p> <p>Insomnia - This symptom was reported by some participants as a worsening symptom causing them to return to the hospital and start dialysis.</p> <p>Pleural effusion - This symptom was reported by some participants as a worsening symptom causing them to return to the hospital and start dialysis.</p> <p>Vomiting - This symptom was reported by some participants as a worsening symptom causing them to return to the hospital and start dialysis.</p>
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified. Minor limitation due to it being conducted in South Taiwan and ethics.

Study	Lindqvist 2000 ⁴⁰
Aim	To describe the perceived consequences of illness and treatment among ESRD patients.
Population	Adults aged 28 to 86 years on haemodialysis, peritoneal dialysis and with kidney transplants.
Setting	Sweden
Study design	Qualitative interview study
Methods and analysis	An unstructured interview was conducted in their homes for most, with six being interviewed by telephone. All interviews were tape recorded. Content analysis was used to identify important thematic groupings and the relationships between them.
Findings	<p>Body image - This symptom was reported by some participants with some mentioning bloating, bump on forearm due to needle and not being able to shave arms, resulting in feeling disgusted with their selves and worried about their physical appearance.</p> <p>Fatigue - This symptom was reported but relatively infrequently with one participant reporting feeling extremely tired after dialysis.</p> <p>Itching - Symptom reported with no additional details.</p>

Study	Lindqvist 2000⁴⁰
	Pain - This symptom was reported but relatively infrequently with one describing back and hip problems.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. Minor limitation due to the role of the researcher being unclear.

Study	Lonargáin 2017⁴¹
Aim	To explore the psychological experiences of receiving a kidney transplant from a deceased donor.
Population	Adults with kidney transplants aged 26 to 88 years. Mean age was 45 years. Participants were receiving post-transplant care.
Setting	UK
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews were conducted in an office within the recruiting centre or at the patients home. A topic guide was prepared to present open ended questions. The interviews were audio recorded and lasted 60 minutes on average. Interpretative phenomenological analysis was used to identify important thematic groupings and the relationships between them.
Findings	Anxiety - Participants reported feeling anxious after the kidney transplant as they were worried about getting an illness, due to an increased risk of specific illnesses associated with kidney transplants and medication. Dizziness - Some mentioned often feeling dizzy following dialysis which at times led to feeling ill the next day.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Murray 2014⁴⁹
Aim	To assess the impact of ESKD on education and employment outcomes in young adults.
Population	Adults aged 18 to 30 years with kidney transplants. Median age was 25 years.
Setting	UK
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews were conducted during clinic or home visits and were audio taped. Content analysis was used to identify important thematic groupings and the relationships between them.
Findings	Moodiness - Symptom reported with no additional details. Fatigue - Participants reported low levels of energy and feeling tired after the transplant operation and after dialysis.

Study	Murray 2014⁴⁹
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis. Minor limitations due to the rigor of data analysis.

Study	Noble 2010⁵⁰
Aim	To explore symptoms in stage 5 CKD patients without dialysis.
Population	Age not stated (25 to 70+ years assumed). Patients and carers involved who were attending the renal supportive care services.
Setting	UK
Study design	Qualitative interview study
Methods and analysis	Interview was via an in-depth open clinical consultation and tape recorded with the consent of those present. It was a person-centred approach allowing identification of key problems and experiences, which provided a chance for further clarification. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	<p>Aching body - Symptom reported with no additional details.</p> <p>Altered taste - Symptom reported with no additional details.</p> <p>Gastrointestinal problems (including constipation and diarrhoea) - Participants reported difficulties related to incontinence and altered bowel habits. Medication may have caused this for some patients and some were incontinent of urine due to unclear reasons.</p> <p>Breathlessness - Most participants reported this with it at times due to fluid overload caused by renal disease and/or associated anaemia.</p> <p>Confusion - Symptom reported with no additional details.</p> <p>Cramps - Symptom reported with no additional details.</p> <p>Depression - Some participants reported this and it was often attributed to being unable to things they'd previously been able to do with ease. Some were depressed due to the decision not to have dialysis.</p> <p>Difficulty swallowing - Symptom reported with no additional details.</p> <p>Dizziness - Symptom reported with no additional details.</p> <p>Dry skin - Symptom reported with no additional details.</p> <p>Headaches - Symptom reported with no additional details.</p> <p>Immobility - Most participants suffered from this and had problems with walking, standing and being active, causing problems with their self-care. Some complained of 'feeling trembly' in their legs, having a fear of falling and painful knee/hip joints.</p> <p>Incontinence - Symptom reported with no additional details.</p>

Study	Noble 2010 ⁵⁰
	Insomnia - Symptom reported with no additional details.
	Itching - Most participants found this problematic and persistent. Occasionally it led to other problems for some such as ulcers.
	Lack of energy - Symptom reported with no additional details.
	Fatigue - Most participants reported feeling tired and finding it debilitating, with daily chores, tasks and social needs not being able to be carried out with as much ease as before the condition.
	Nausea/vomiting - Most participants suffered from this and managed it with anti-emetics medication when required. Some reported it was due to uraemia, chest infection or constipation.
	Oedema - All but one participant reported this symptom. It was treated with small doses of oral diuretics, progressing to intravenous diuretics if no improvement. Some had associated breathlessness and fluid overload which affected mobility.
	Pain - Participants reported different types of pain due to problems such as arthritis, a fractured hip, leg ulcers and cancer. Some had pain due to an unknown cause and none reported pain due to renal disease.
	Phantom pain - This symptom was reported but relatively infrequently. A patient reported feeling this after undergoing a limb amputation.
	Pins and needles in legs - This was reported but relatively infrequently.
	Poor appetite - Symptom reported with no additional details.
	Poor balance - Symptom reported with no additional details.
	Cognitive fluctuations - Symptom reported with no additional details.
	Visual disturbances - Symptom reported with no additional details.
	Sore mouth/tongue - Symptom reported with no additional details.
	Trembling - Symptom reported with no additional details.
	Weakness - Symptom reported with no additional details.
	Weight loss - Symptom reported with no additional details.
Limitations and applicability of evidence	There were moderate limitations due to insufficient information on data analysis and data collection.

Study	Orr 2007 ⁵¹
Aim	To explore patients' lived experience in relation to medication adherence.
Population	Adults aged 18 and over with kidney transplants. The modal age was over 60 years.

Study	Orr 2007 ⁵¹
Setting	UK
Study design	Qualitative focus groups study
Methods and analysis	Four focus groups were conducted using a guided discussion and lasted for 1 hour and were audiotaped. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Crumbling bones - This symptom was reported by some participants as a side effect to transplant medication.
	Fatigue - This symptom was reported by most participants as a side effect to transplant medication.
	Fragile skin - This symptom was reported by most participants as a side effect to transplant medication.
	Body image - This symptom was reported by one group of participants as a side effect to transplant medication.
	Pain - This symptom was reported by some participants as a side effect to transplant medication.
	Lack of resistance to infection - This symptom was reported by most participants as a side effect to transplant medication.
	Moodiness - This symptom was reported by most participants as a side effect to transplant medication.
	Shakiness - This symptom was reported by one group of participants as a side effect to transplant medication.
	Skin cancer - This symptom was reported by one group of participants as a side effect to transplant medication.
	Swollen gums - This symptom was reported by some participants as a side effect to transplant medication.
Weight - This symptom was reported by most participants as a side effect to transplant medication.	
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Orr 2007 ⁵¹
Aim	To explore the experience of living with a transplanted kidney.
Population	Adults aged 18 and over with kidney transplants. The modal age was over 60 years.
Setting	UK
Study design	Qualitative focus groups study
Methods and analysis	Four focus groups were conducted using a guided discussion and lasted for 1 hour and were audiotaped. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Crumbling bones - This symptom was reported by one group of participants as a side effect to transplant medication.
	Fatigue - This symptom was reported by one group of participants as a side effect to transplant medication.

Study	Orr 2007⁵¹
	Body image - This symptom was reported by one group of participants as a side effect to transplant medication.
	Skin cancer - This symptom was reported by one group of participants as a side effect to transplant medication.
	Swollen gums - This symptom was reported by one group of participants as a side effect to transplant medication.
	Weight gain - This symptom was reported by one group of participants as a side effect to transplant medication.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Polaschek 2003⁵³
Aim	To contribute towards enabling health professionals to provide more effective support to people who are living with ESRD.
Population	Adults aged 20 to 60+ years on haemodialysis. All were successfully on self-care dialysis in their homes.
Setting	New Zealand
Study design	Qualitative interview study
Methods and analysis	Three semi structured interviews lasting an hour were conducted in their homes and were taped. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Fatigue - Most participants reported a general lack of energy and was the most significant symptom associated with ESRD.
	Blood pressure alterations (hypotension) - This was one of the most common symptoms associated with dialysis itself that participants mentioned.
	Insomnia - Most participants reported this symptom as fairly common.
	Itching - Most participants reported this symptom as fairly common.
	Malaise - This was one of the most common symptoms associated with dialysis itself that participants mentioned.
	Restless legs (nocturnal) - Most participants reported this symptom as fairly common.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Schmid-Mohler 2014⁵⁶
Aim	To explore the concept and the presence of self-management tasks mastered by patients in the early phase after kidney transplant.

Study	Schmid-Mohler 2014 ⁵⁶
Population	Adults aged 18 and over with kidney transplants. Median age was 52 years.
Setting	Switzerland
Study design	Qualitative interview study
Methods and analysis	Semi structured interviews were conducted with open ended questions and all were audiotaped. Content analysis was used to identify important thematic groupings and the relationships between them.
Findings	Gastrointestinal problems - This was reported as one of many symptoms participants reported as an adverse effect from transplant medication.
	Pain - Some participants reported back, joint, foot or leg pain as an adverse effect from transplant medication.
	Tinnitus - This was reported as one of many symptoms participants reported as an adverse effect from transplant medication with its severity varying for participants. One described it as barely noticeable whilst another suffered with it so severely they were unable to listen to music.
	Visual disturbances - This was reported as one of many symptoms participants reported as an adverse effect from transplant medication.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Small 2010 ⁵⁸
Aim	To describe the experiences of patients receiving HD for CKD.
Population	Adults aged 20 to over 70 years on haemodialysis.
Setting	Namibia
Study design	Qualitative interview study
Methods and analysis	Interviews were conducted whilst the participants were receiving treatment and all treatment areas were private. Follow up sessions were conducted after the interviews to ensure trustworthiness. All were audiotaped. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Body image - Participants reported a disturbed body image.
	Cognitive fatigue - Some participants mentioned how weakness affected their cognitive abilities, causing difficulty in concentrating after dialysis.
	Dizziness - This symptom was reported but relatively infrequently, as an adverse effect of HD.
	Exhaustion - A participant mentioned feeling exhausted after dialysis and not being able to return to their work.

Study	Small 2010⁵⁸
	Stress - Some participants reported work-related stress due to having to schedule in dialysis treatment around their work and not being able to meet some requirements of their job such as going on field trips.
	Fatigue - Some participants mentioned this symptom with one mentioning how they were too tired to clean the dishes after dialysis.
	Weakness - Some participants mentioned feeling weak and being unable to walk around.
Limitations and applicability of evidence	Minor limitations due to country and rigor of research design.

Study	Stanfill 2012⁵⁹
Aim	To obtain insight into recipients' perception of weight gain.
Population	Adults aged 41 to 60+ years with kidney transplants. Mean age was 55 years.
Setting	US
Study design	Qualitative focus group study
Methods and analysis	Two separate focus group sessions were pre-arranged to allow flexibility among patients. The allotted time for each was 2 hours, but both sessions finished in around 1hr 30mins. A survey was answered at the beginning by the participants. The discussion was audio taped. Thematic analysis using the 'long table approach' was used to identify important thematic groupings and the relationships between them.
Findings	Weight gain - Participants reported rapid weight gain in the first year after a kidney transplant, with one mentioning how it affected the joints.
Limitations and applicability of evidence	Moderate limitations due to ethics and data that's not rich enough.

Study	Tong 2010⁶³
Aim	To explore the experiences of parents who have children with CKD.
Population	Parents of children 0 to 18 years. Mode age was 15 to 19 years. Those on pre RRT, haemodialysis, peritoneal dialysis and with kidney transplants were included.
Setting	Australia
Study design	Qualitative interview study

Study	Tong 2010 ⁶³
Methods and analysis	An in-depth interview was conducted lasting 1 hour, using a question guide. All interviews were digitally recorded. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	Vomiting - One parent reported how it was a struggle to feed the child as they kept vomiting and retching.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with minor limitations due to ethics.

Study	Winterbottom 2014 ⁶⁷
Aim	To understand how patients with kidney failure make their dialysis treatment decision.
Population	Adults aged 18 and over considering RRT were included. Median age was 57.5 years.
Setting	UK
Study design	Qualitative interview study
Methods and analysis	Semi structured in depth interviews conducted. Patients were asked a series of open ended questions and were interviewed in the clinic or in their home. Most had one interview, two agreed to be interviewed at different time points in their decision making. All interviews were audio recorded. Thematic analysis was used to identify important thematic groupings and the relationships between them.
Findings	<p>Fatigue - Most patients explained they had no symptoms since diagnosis. If they reported any symptom, it was being tired.</p> <p>Itching - This symptom was reported but relatively infrequently and mentioned specifically swollen ankles.</p> <p>Nausea - This symptom was reported but relatively infrequently, and patients were unsure to attribute it to CKD or normal bodily sensations.</p> <p>Sleep disturbance - This symptom was reported but relatively infrequently, and patients were unsure to attribute it to CKD or normal bodily sensations.</p> <p>Oedema - This symptom was reported but relatively infrequently and mentioned specifically swollen ankles.</p> <p>Vomiting - A participant mentioned vomiting after feeling a pounding sensation in their head.</p>
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Yngman-Uhlin 2010 ⁷¹
-------	---------------------------------

Study	Yngman-Uhlin 2010⁷¹
Aim	To describe how patients on PD treatment at home experience tiredness linked to poor sleep in everyday life.
Population	Adults aged 36 to 82 years on peritoneal dialysis. All were on CAPD or APD.
Setting	Sweden
Study design	Qualitative interview study
Methods and analysis	The open ended interviews lasted between 25 and 51 minutes and were audiotaped. Three were carried out at the patients' homes, eleven in the hospital and one during an outpatient visit. A phenomenological reduction in four steps was used to analyse transcripts and identify important thematic groupings and the relationships between them.
Findings	Abdominal pain - This symptom was reported but relatively infrequently, related to draining and refilling the dialysis solution, as well as some sleep positions, leading to broken sleep.
	Anxiety - Some participants reported worries about complications, death and feeling afraid about future transplantations.
	Cognitive fatigue - Participants reported sensations of being mentally tired more dominant than physical tiredness, but not feeling a desire to sleep. Some reported it being difficult to concentrate, be creative and make decisions.
	Cramps - This symptom was reported but relatively infrequently, related to draining and refilling the dialysis solution, as well as some sleep positions, leading to broken sleep.
	Itching - This symptom was reported but relatively infrequently, related to draining and refilling the dialysis solution, as well as some sleep positions, leading to broken sleep.
	Fatigue - Participants described this as heaviness, weakness and reduced muscle strength, feeling tired but not being able to sleep.
	Sleepiness - Participants described how the sensations of sleep as located in the mind, feeling drowsy and longing for sleep. It was described as easier to identify before going to bed.
	Stress - Participants described needing to stop whilst doing their household tasks due to tiredness contributed to their stress.
	Unstable temper - Some participants reported experiencing mood changes such as becoming more short-tempered due to their lack of sleep.
Weakness - Participants reported gradually developing the feeling of being worn out with it coming on faster than before, with everyday tasks becoming more time-consuming.	
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified.

Study	Yodchai 2011⁷²
Aim	To explore how HD affects Thai patients with ESRD.

Study	Yodchai 2011⁷²
Population	Adults aged 24 to 66 years on haemodialysis. Mean age was 45.4 years.
Setting	Thailand
Study design	Qualitative interview study
Methods and analysis	Individual open ended interviews were conducted in the participant's homes and lasted 60-90 minutes. They were all audiotaped. Follow up calls were made if necessary. Open, axial and selective coding in accordance with GT analysis was used to analyse and identify important thematic groupings and the relationships between them.
Findings	Anger - Some participants reported this symptom.
	Body image - This symptom was reported but relatively infrequently and mentioned specifically changed self-image.
	Depression - Reported as one of the most common responses by participants.
	Fatigue - Some participants selectively withdrew from leisure and social activities due to fatigue.
	Loneliness - Some participants reported this symptom.
	Sexual functioning - Some participants commented how they have no energy for sex after dialysis treatment.
	Stress - Reported as one of the most common responses by participants. A significant source of stress was fear of dying.
Limitations and applicability of evidence	The researchers followed clear methods to ensure the validity and rigour of their qualitative analysis, with no major limitations identified. Minor limitations due to country were observed.

Appendix E: Excluded studies

E.1 Excluded qualitative studies

Table 134: Studies excluded from the qualitative review

Reference	Reason for exclusion
Baillie 2015 ³	No relevant themes identified
Baillie 2015 ⁴	No relevant themes identified
Beanlands 2005 ⁷	No relevant themes identified
Braj 1999 ⁹	No relevant themes identified
Burns 2017 ¹⁰	No relevant themes identified
Calestani 2014 ¹¹	No relevant themes identified
Clarkson 2010 ¹⁵	No relevant themes identified
Curtin 2002 ¹⁸	No relevant themes identified
Curtin 2004 ¹⁷	No relevant themes identified
Friesen 1997 ²²	No relevant themes identified
Gibbons 2017 ²³	No relevant themes identified
Hagren 2005 ²⁴	No relevant themes identified
Henry 2017 ²⁷	No relevant themes identified
Jablonski 2007 ²⁹	Inappropriate study design
Jennette 2009 ³⁰	No relevant themes identified
Lawrence 2013 ³⁵	No relevant themes identified
Lee 1999 ³⁷	Incorrect study design
Lovink 2015 ⁴²	No relevant themes identified
Low 2014 ⁴³	No relevant themes identified
Mantulak 2016 ⁴⁴	No relevant themes identified
Moran 2011 ⁴⁶	No relevant themes identified
Moran 2016 ⁴⁵	No relevant themes identified
Morton 2011 ⁴⁷	No relevant themes identified
Murray 2016 ⁴⁸	No relevant themes identified
Richard 2008 ⁵⁴	Not available
Sahaf 2017 ⁵⁵	No relevant themes identified
Tong 2012 ⁶⁵	No relevant themes identified
Tong 2013 ⁶²	Inappropriate population (CKD not focused on RRT)
Tong 2015 ⁶¹	Inappropriate population (early CKD)
Tong 2017 ⁶⁴	No relevant themes identified
Weiss 2014 ⁶⁶	No relevant themes identified
Xi 2011 ⁶⁸	No relevant themes identified
Yalamanchili 2013 ⁶⁹	Inappropriate study design
Yodchai 2014 ⁷³	No relevant themes identified

Table 135: Studies identified but not included in the qualitative review due to saturation being reached

Reference

Reference

Amerena 2009²

Lin 2015³⁸

Shih 1998⁵⁷

Tong 2015⁶⁰

Yilmaz 2011⁷⁰