National Institute for Health and Care Excellence

Final

RRT and conservative management

Evidence review for information, education and support

NICE guideline NG107

Qualitative evidence review

October 2018

Final

This evidence review was developed by the National Guideline Centre

Disclaimer

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1 Information, education and support

1.1 Review question: What information, education and support is important for people for whom RRT or conservative management may be appropriate, and their families/carers?

1.2 Introduction

The NICE guideline on patient experience in adult NHS services (CG138) outlines the key principles of general care. It is important to identify and address the unique needs of people with specific conditions and those following the identification that an adult, child or young person may require renal replacement therapy or conservative management. Information and support is required to enable people to make the decision of whether to commence renal replacement therapy or not and if RRT, what modality of renal replacement therapy to use. Information and support can help to ensure that the person makes the right decision for themselves or their child and this in turn can lead to better outcomes including adherence to treatment.

1.3 Characteristics table

For full details see the review protocol in appendix A.

Table 1: Characteristics of review question

Objective	Provide evidence of the types of information, education and support that the population values in this situation to inform recommendations for healthcare professionals to insure these topics are appropriately covered
Population and setting	Adults and children who are being assessed for RRT or conservative management, or who are undergoing RRT or conservative management, their families, carers and healthcare professionals
Context	Any type of information, education and support described by studies
Review strategy	Synthesis of qualitative research. Results presented in narrative 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 nine qualitative studies were included in the review;[23, 26, 30, 36, 39, 48, 57, 60, 88, 96, 99, 100, 103, 107, 109, 115, 118, 127, 129, 132, 135, 139, 149, 156, 168, 169, 173, 195, 198, 201, 212, 213, 223, 224, 240, 244, 245, 252, 261] 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.

Four studies were with children between the ages of 2 and 16 (and their parents), thirty three studies were with people aged 25 to 70 and two studies were with people aged 70 and over.

Two studies were on the pre-RRT population, two studies involved a mix of people pre and during RRT. Five studies involved those undergoing any form of RRT. Eight studies involved those undergoing either HD or PD (two with the input of carers). Eight studies involved those who had received a transplant. Twelve studies involved those undergoing HD only (two with the input of carers). One study involved those who had opted for conservative management.

As a large number of papers were identified for this review, inclusion was halted once thematic saturation was reached. Saturation is the point at which no new information emerged from studies that were found to match the review protocol, see the methodology chapter for more information. These studies are listed in Table 31.

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
Barnieh 2014[23]	Interviews	189 participants, patients, caregivers and healthcare professionals. 48% on clinic HD, 17% home HD, 12% PD, 19% healthcare professional. Age 18 to >80 Canada	To synthesise the views of Canadian patients on or nearing dialysis and those caring for them	
Berzoff 2008[26]	Focus groups	2 patient groups, 2 family groups (one bereaved and one non-bereaved) and two health care professional groups. US	To elicit and provide for the needs of dialysis patients and their families throughout the trajectory of their illnesses.	Population details/characteristic not reported. 36 participants in total.
Bourbonnais 2012[30]	Interviews	25 patients on HD, 31 to 80+yrs, ESRD, Canada	To provide an overview of pain experienced by patients undergoing maintenance dialysis.	
Browne 2016[36]	Focus groups	29 participants on dialysis - 14 male, 15 female. Age 18-69 years US	To determine perceived barriers and facilitators to kidney transplant that dialysis patient's experience.	
Calestani 2014[39]	Semi-structured interviews	53 patients, 18-75yrs, stage 5 CKD UK	To explore patients' views and experiences of kidney transplant listing	
Clarkson 2010[48]	Interviews	10 patients from dialysis support group, over 18yrs (mean 52yrs), PD	To explore the lived experience of patients with ESRD to	

Study	Design	Population	Research aim	Comments
		and HD USA	determine if they are adequately educated about their illness	
Davison 2006[57]	Interviews	19 participants with ESRD: aged 44-88 (mean 64 years) Canada	To understand hope in the context of advance care planning from the perspective of patients with end stage renal disease.	
DePasquale 2013[60]	Interviews	68 patients with ESRD, 62 family members, 18+yrs US	To elicit patient and family member views regarding information they felt should be featured in educational resources informing RRT selection decisions.	
Griva 2013[88]	Interviews and Focus groups	37 patients, 21yrs and above, on HD Singapore	To explore cultural perspectives on facilitators and barriers to treatment adherence in HD patients.	
Harwood 2005[96]	Interviews	11 patients, 61 to 89yrs, ESRD Canada	To identify the implications for patient education and support needed in the care of patients with CKD.	
Heck 2004[99]	Interviews	31 participants, kidney transplant recipients, 19 to 71yrs Germany	To examine the psychosocial effects of living donor kidney transplantation for donors and recipients under successful as well as complicated circumstances.	
Henry 2017[100]	Interviews	168 patients, starting HD USA	To characterise the experiences of patients beginning RRT	
Hughes 2009[103]	Interviews	20 participants (18 patients and 2 carers), aged 26 - 80 years,	To explore kidney patients experiences of receiving	

Study	Design	Population	Research aim	Comments
		receiving peer support, pre-RRT UK	individual peer support.	
Jennette 2009[107]	Focus groups	47 patients, aged 21-80 years, HD or PD USA	To ascertain barriers and facilitators to choices other than in centre HD and psychosocial and educational issues which may affect the choice	
Kaba 2007[109]	Interviews	23 patients, ESRD, Greece	To explore how Greek patients receiving long-term haemodialysis perceive their problems and to describe the impact of haemodialysis on these patients' lives.	
Korus 2011[115]	Focus groups	8 adolescents aged between 13 to 17 years, mean age = 15yrs , ESRD, Canada	To explore information needs of adolescents who have undergone kidney transplantation	
Lai 2012[118]	Interviews	13 patients, 39 to 63 years, ESRD, Singapore	To explore the lived experiences of incident haemodialysis patients in Singapore.	
Lee 2008[127]	Focus groups	6 focus groups involving 27 HD patients and 18 relatives, mean age 54 ± 16.2 years	To explore patients' experiences with different dialysis modalities and investigated issues related to the patient's choice of modality	
Lin 2005[132]	Interviews	12 patients, 28 to 53yrs, ESRD South Taiwan	To describe the experiences of making a decision about HD among a group of Taiwanese with ESRD.	
Lonargain 2017[135]	Interviews	6 patients, mean age 45, received transplant from deceased donor UK	To explore the psychological experiences of receiving a kidney transplant from a deceased donor	

Study	Design	Population	Research aim	Comments
Low 2014[139]	Interviews	26 people close to those undergoing CM UK	To investigate how conservative management interacted with ideas of ageing in the experience of conservative management	
Lenci 2012[129]	Interviews	4 patients, aged 75 - 88 years, on PD for 2-5yrs. US	To explore how elderly patients experience life on PD.	
Mitchell 2009[149]	Interviews	10 patients, aged 20->80 years, on HD. US	To identify factors identified by patients as helpful in the transition onto haemodialysis.	
Morton 2011[156]	Focus groups	34 participants, >18 years, pre-dialysis, dialysis and caregivers Australia	To rank the most important characteristics of dialysis on which patients and caregivers make decisions	
Orr 2007[169]	Focus groups	26 kidney transplant recipients aged 18+yrs UK	To explore the experience of living with a transplanted kidney.	
Orr 2007[168]	Focus groups	26 kidney transplant recipients aged 18+yrs UK	To explore patients' lived experience in relation to medication adherence.	Same population as Orr 2007
Polaschek 2003[173]	Interviews	6 patients, 20 to 60+yrs, ESRD New Zealand	To contribute towards enabling health professionals to provide more effective support to people who are living with ESRD.	
Rygh 2012[195]	Interviews	11 patients: 8 patients with PD; 3 with APD and 5 with CAPD; 3 patients had HHD. Norway	To examine the patients’ need for information and guidance in the selection of dialysis modality, and in establishing and practicing home dialysis.	
Salter 2015[198]	Focus groups	36 patients on HD, aged 18 - 65+, 3 in the <65	To explore perceptions of dialysis and KT	

Study	Design	Population	Research aim	Comments
		had a previous transplant US	among African American adults undergoing haemodialysis, with particular attention to age- and sex-specific concerns.	
Schmid-Mohler, 2014[201]	Interviews	12 kidney transplant patients, median age 52yrs Switzerland	To explore the concept and the presence of self-management tasks mastered by patients in the early phase after kidney transplant.	
Small, 2010[212]	Interviews	21 patients, ESRD, 20-70+yrs Namibia	To describe the experiences of patients receiving HD for CKD.	
Sondrup, 2011[213]	Focus groups	6 patients, 3 patients on PD and 3 patients on HD, aged 30-69yrs Canada	To better understand patient perceptions and possible barriers related to choosing independent dialysis therapies.	
Tong, 2010[223]	Interviews	22 kidney transplant patients, aged 12-19 years (mean age=15.6) Australia	To explore adolescent perspectives following kidney transplantation and to elicit strategies from them on ways to improve service delivery and support for adolescent transplant recipients.	
Tong, 2011[224]	Interviews	Parents of 20 children with CKD Australia	To explore the experiences of parents who have children with CKD.	
Walker, 2016[240]	Interviews	52 participants (43 pre-dialysis patients; 9 care-givers) who ranged in age between 22 and 79yrs Australia	To describe patient and caregiver perspectives of the economic considerations that influence dialysis modality choice, and elicit policy-relevant	

Study	Design	Population	Research aim	Comments
			recommendations	
Welch, 2014[244]	Interviews	21 carers of HD patients, aged 27-78 years, 5 male, 16 female. US	To identify and describe the needs, concerns, strategies, and advice of family caregivers of persons on daily home haemodialysis.	
Wells, 2013[245]	Interviews	10 patients with ERF on dialysis, aged 13 - 17yrs UK	To explore the lived experiences of adolescents with ERF undergoing dialysis and identify potential barriers to effective treatment	
Wilson, 2012[252]	Focus groups	19 patients, aged 30 - 50+, most were 50+ (79%), transplant recipients and transplant listed US	To examine patients' perceptions of the delivery and format of a kidney transplant education program in a clinical setting.	
Yngman-Uhlin, 2016[261]	Interviews	8 patients in haemodialysis treatment, aged 33-53 years Sweden	To explore the experiences of haemodialysis patients who are waiting for a kidney transplant.	

See appendix D for full evidence tables.

1.4.4 Qualitative evidence synthesis

1.4.4.1 Narrative summary of review findings

1.4.4.1.1 Content of information

Review finding 1: Areas of information

People made specific mention of the following as being important areas of information they appreciated or would have appreciated:

- Symptoms – what they may experience and how to manage them
- Prognosis – the likely long term consequences of their disease and life expectancy, particularly in the context of transplant
- Mode of access – the benefits and harms of different types of vascular access
- Modality of RRT – the benefits and harms of different modalities of RRT and conservative management
- Services – availability of support and transition from paediatric to adult
- Adherence – the importance of adherence and consequences of non-adherence

- Transplant listing – the actual practicalities of listing
- How to approach potential living donors
- Impact on lifestyle – of any modality choice, including limitations on travel, sexual activity
- Acute situations – what to expect and how to handle them
- Diet and lifestyle – advice on diet and lifestyle choices to improve their health, including impacts of alcohol and substance abuse
- Kidney function and CKD – a basic understanding of their disease
- End of life care
- Psychological impact – including the effects on donor and recipient in transplantation

Explanation of quality assessment: moderate methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of moderate confidence in this finding. See qualitative evidence summary tables for individual breakdown.

Review finding 2: Depth and timing of information

People in general reported receiving less information than they would like. However they noted that due to the large amount of information available and pertinent to RRT, if all the information is provided simultaneously it can be difficult to digest. People noted that they would prefer to begin receiving information about RRT earlier in the treatment pathway than they typically did. People also reported that it is useful to have follow-up meetings after information is provided, in order to insure the information is understood.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of high confidence in this finding.

1.4.4.1.2 Format of education/information

Review finding 1: Personalisation

People appreciated when information provided to them was tailored to their circumstances, for example not all people want the same amount of information on their prognosis.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of high confidence in this finding.

Review finding 2: Classes/tours

People appreciated formal education methods like pre-dialysis classes and tours of facilities before beginning RRT. People who did not receive these classes (for example in some cases those who received a transplant) noted that they felt they would have benefited from them.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of high confidence in this finding.

Review finding 3: Multiple formats

People noted that they found it useful when information/education was provided in multiple formats, for example with leaflets supported by one to one discussions. However in general people reported that they did not receive enough in person time with healthcare professionals to discuss decisions.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of high confidence in this finding.

Review finding 4: Peer support

Peer support was frequently reported as being a useful format of providing information or education. However in some cases it was noted that it was important that the peers in question provided information/education in an open, unbiased and supportive manner.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of high confidence in this finding.

Review finding 5: Target of education/information

People and their family/carers both noted that it was useful to have information and education that was aimed both at a person undergoing RRT/CM and also at their family or carer, with aspects tailored to each. This applied particularly if a living kidney donor was involved and needed information around the process themselves.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; minor concerns about inadequacy due to lack of depth. There was a judgement of moderate confidence in this finding.

1.4.4.1.3 Decision-making

Review finding 1: Availability of choice

People reported that they did not always feel like all options that should have been available to them, were available. In some cases this was felt to be due to biases from healthcare professionals (for example in dissuading people from pursuing transplantation) and in others it was due to the resources available at their particular centre (for example in terms of home dialysis).

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of high confidence in this finding.

Review finding 2: Reversibility

People felt it was particularly important that the reversibility of any decisions they made was made clear. This was noted in the context of choosing conservative management over dialysis.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; minor concerns about inadequacy. There was a judgement of moderate confidence in this finding.

1.4.4.1.4 Practical support

Review finding 1: Transport

People noted that the availability of transport affected their ability to engage with RRT and was a significant psychological stressor during RRT. The impact of transport difficulties was particularly severe for older and frailer people undergoing RRT.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of high confidence in this finding.

Review finding 2: Finances

People noted that their financial status and ability to access financial support affected their engagement with RRT. People reported hidden costs of RRT including certain aspects of their dialysis (for example electricity costs) and dietary requirements.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; minor concerns about relevance; minor concerns about inadequacy. There was a judgement of moderate confidence in this finding.

1.4.4.1.5 Psychological support

Review finding 1: Awareness and availability of support

People reported that they felt that their healthcare professionals were not always aware of the emotional and social distress associated with their RRT. People reported that feeling depressed, dependent on others and having limited employment possibilities all contributed to a heavy psychological impact. People reported that having someone to talk to was really important, for some this was family or peers but for others a healthcare professional was necessary.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of high confidence in this finding.

1.4.5 Qualitative evidence summary

1.4.5.1 Content of information

Table 3: Summary of evidence – Areas of information: Symptoms

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
4 studies	Combination of interviews and focus groups, all 25 to <70, all during RRT.	People mentioned information on what they may experience and how to manage them as an area they appreciated or would have appreciated.	Limitations	Minor to moderate concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 4: Summary of evidence – Areas of information: Prognosis

Study design and sample size	Finding	Quality assessment

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Areas of information					
7 studies	Combination of interviews and focus groups, all 25 to <70, all during RRT.	People mentioned information on the likely long term consequences of their disease and life expectancy, particularly in the context of transplant as an area they appreciated or would have appreciated.	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 5: Summary of evidence – Areas of information: Mode of access

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
5 studies	Combination of interviews and focus groups, all 25 to <70, all	People mentioned information on the benefits and harms of different types of vascular access as an area they appreciated or would have appreciated.	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
	during RRT.			coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 6: Summary of evidence – Areas of information: Modality of RRT

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Areas of information					
5 studies	Combination of interviews and focus groups, all 25 to <70, all during RRT.	People mentioned information on the benefits and harms of different modalities of RRT and conservative management as an area they appreciated or would have appreciated.	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
			Adequacy	No concerns about adequacy	

Table 7: Summary of evidence – Areas of information: Services

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
1 study	Focus groups, 25 to <70, during RRT.	People mentioned information on the availability of support and transition from paediatric to adult as an area they appreciated or would have appreciated.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 8: Summary of evidence – Areas of information: Adherence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
2 studies	Combination of interviews and focus groups, all 25 to <70, all during RRT.	People mentioned information on the importance of adherence and consequences of non-adherence as an area they appreciated or would have appreciated.	Limitations	Minor to moderate concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 9: Summary of evidence – Areas of information: Transplant listing

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
2 studies	Interviews,	People mentioned information on the actual practicalities of listing	Limitations	Minor concerns about	MODERATE

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
	all 25 to <70, all during RRT.	an area they appreciated or would have appreciated.		methodological limitations	
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 10: Summary of evidence – Areas of information: How to approach potential living donors

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Areas of information					
1 study	Focus groups, 25 to <70, during RRT.	People mentioned information on how to approach potential living donors an area they appreciated or would have appreciated.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 11: Summary of evidence – Areas of information: Impact on lifestyle

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
4 studies	Combination of interviews and focus groups, all 25 to <70, all during RRT.	People mentioned information on of any modality choice, including limitations on travel, and sexual activity as areas they appreciated or would have appreciated.	Limitations	Minor to moderate concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
			Adequacy	No concerns about adequacy	

Table 12: Summary of evidence – Areas of information: Acute situations

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Areas of information					
2 studies	Interviews, all 25 to <70, all during RRT.	People mentioned information on what to expect with acute situations and how to handle them as areas they appreciated or would have appreciated.	Limitations	Minor to moderate concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 13: Summary of evidence – Areas of information: Diet and lifestyle

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
3 studies	Combination of interviews and focus groups, all 25 to <70, all during RRT.	People mentioned information on advice on diet and lifestyle choices to improve their health, including impacts of alcohol and substance abuse as areas they appreciated or would have appreciated.	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 14: Summary of evidence – Areas of information: Kidney function and CKD

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
1 study	Focus groups, 25 to	People mentioned information to gain a basic understanding of their disease as an area they appreciated or would have	Limitations	Moderate concerns about methodological	MODERATE

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
	<70, during RRT.	appreciated.		limitations	
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 15: Summary of evidence – Areas of information: End of life care

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
1 study	Interviews groups, 25 to <70, during RRT.	People mentioned information on end of life care an area they appreciated or would have appreciated.	Limitations	Minor about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

Table 16: Summary of evidence – Areas of information: Psychological impact

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Areas of information					
1 study	Interviews, 25 to <70, during RRT.	People mentioned information on the psychological effects on donor and recipient in transplantation an area they appreciated or would have appreciated.	Limitations	Severe concerns about methodological limitations	LOW
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about	

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

Table 17: Summary of evidence – Depth and timing of information

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Depth and timing of information					
15 studies	Combination of interviews and focus groups, mix of 25 to <70 (n=14) and over 70 (n=1), all during RRT	People appreciate more complete information, provided in stages from an earlier starting point to avoid being overwhelmed	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

1.4.5.2 Format of education/information

Table 18: Summary of evidence: Personalisation

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Personalisation					
6 studies	Combination of interviews and focus groups, a mix of 2 to 16 years old (n=1) 25 to <70 years old (n=5), all during RRT.	People appreciated when information provided to them was individualised and tailored to their circumstances.	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 19: Summary of evidence: Classes/tours

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

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
5 studies	Combination of interviews and focus groups, a mix of 25 to <70 (n=4) and over 70 (n=1), all during RRT.	People appreciated formal education methods like pre-dialysis classes and tours of facilities before beginning RRT.	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 20: Summary of evidence: Multiple formats

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Multiple formats					
7 studies	Combination of interviews and focus groups, all 25 to <70, all	People noted that they found it useful when information/education was provided in multiple formats, for example oral and written	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very 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
	during RRT.			coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 21: Summary of evidence: Peer support

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Peer support					
14 studies	Combination of interviews and focus groups, all 25 to <70, both pre-RRT (n=1) and during RRT (n=13).	People valued peer support as a useful format of providing information or education when presented in an open, unbiased and supportive manner.	Limitations	Minor and moderate concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
			Adequacy	No concerns about adequacy	

Table 22: Summary of evidence: Target of education/information

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Target of education/information					
1 study	Focus groups, 25 to <70, during RRT.	People and their family/carers both noted that it was useful to have information and education with aspects tailored to each individual.	Limitations	Moderate concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

1.4.5.3 Decision-making

Table 23: Summary of evidence: Availability of choice

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Availability of choice					
5 studies	Combination of interviews and focus groups, all 25 to <70 and during RRT.	People reported that they did not always feel like all options that should have been available to them, were available.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 24: Summary of evidence: Reversibility

Study design and sample size	Finding	Quality assessment

Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Reversibility					
1 study	Interviews, 25 to <70, during RRT.	People felt it was particularly important that the reversibility of any decisions they made was made clear.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	Minor concerns about adequacy	

1.4.5.4 Practical support

Table 25: Summary of evidence: Transport

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Transport					
3 studies	Interviews, mix of 25 to <70 (n=2)	People noted that the availability of transport affected their ability to engage with RRT and was a significant psychological stressor during RRT.	Limitations	Minor concerns about methodological limitations	HIGH

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
	and over 70 (n=1), both pre-RRT (n=1) and during RRT (n=2).		Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor concerns about relevance	
			Adequacy	No concerns about adequacy	

Table 26: Summary of evidence: Finances

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Reversibility					
2 studies	Interviews, 25 to <70, both pre-RRT.	People noted that their financial status and ability to access financial support affected their engagement with RRT.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No or very minor concerns about coherence	
			Relevance	Minor concerns about	

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

1.4.5.5 Psychological support

Table 27: Summary of evidence: Awareness and availability of support

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
Reversibility					
7 studies	Combination of interviews and focus groups, mix of 25 to <70 (n=6) and over 70 (n=1), all during RRT.	People reported that they felt healthcare professionals were not always aware of the emotional and social distress associated with their RRT. People reported that having someone to talk to was important.	Limitations	Minor concerns about methodological limitations	HIGH
			Coherence	No or very minor concerns about coherence	
			Relevance	No or very minor 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	No 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 1.7) 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 committee noted that the majority of evidence was from the point of view of people undergoing RRT and there was little healthcare professional input identified in the studies.

The findings that people generally wanted more information than they were provided with may be influenced by the type of participants that agree to be interviewed for qualitative studies (selection bias). The committee agreed that these participants are in general more likely to be from the groups of people who want the most information about their care, whereas in reality there will be some groups of people whose preference is to receive relatively little information.

The quality of evidence ranged from low to high for the different review findings. The majority of the evidence was high or moderate quality, with evidence downgraded due to methodological limitations and concerns regarding adequacy. The nature of the methodological limitations varied between studies but generally included concerns over lack of detail on data collection or ethical approval methods.

1.7.1.2 Findings identified in the evidence synthesis

The committee noted that people reported a preference for individualised information but also appreciated a variety of presentation formats. The committee agreed that in their experience, in general written information represented more generic information, while face to face discussions allowed for greater personalisation.

The review identified the timing of information as an important consideration. The committee confirmed that this is consistent with their experience. People require a considerable amount of time to digest all the available information around the options for RRT or conservative management. Decisions around RRT often have to be made well in advance of the actual requirements for RRT (for example creating access for haemodialysis may need to be done at least 6 months prior to initiation of RRT). However, providing information too early in the treatment pathway may risk causing anxiety for some people who will actually never require RRT. Based on the findings of this review, the committee chose to make recommendations that healthcare professionals aim to provide information early enough that people's choices are not limited and their decision making is fully informed when the appropriate time comes.

The review identified some specific aspects of information that people felt they had not been provided with. They felt they did not receive enough information about the practicalities of some aspects of RRT, particularly the transplant listing process. The committee agreed this was an area that some people felt was not discussed enough. Information is required on a number of areas for example with respect to ‘information on treatments’, areas could include the number of session per day/week, who performs the treatment and the equipment that is required. With respect to ‘how treatments may affect lifestyle’ information is required on for example impact on holidays or trips away from home, work or studies and on the ability to care for others. The committee noted the information should be presented factually to allow the person to judge whether this represents a benefit of the treatment, for example for some people short more frequent sessions would be a benefit and for others a disadvantage.

People reported in the review that at times they felt that not all options were made available to them and they were not always sure why this was the case. The committee agreed that there will be some situations in which not all options will be appropriate or available for all people and that it was important that healthcare professionals have honest discussions with people when this is the case.

In the review, people frequently reported the psychological impact of starting RRT and making decisions around it was significant, this was supported by the committee’s experience, particularly the lay members. The committee chose therefore to make recommendations that healthcare professionals recognise this impact and be able to discuss support options available to help people deal with it. In the review people reported that sometimes the most useful support was from their friends or family but at other times, the support of a healthcare professional was required.

The committee noted some findings that did not appear in the evidence but which they felt were important based on their experience. The committee agreed on the importance of discussing the implications of RRT decisions on fertility and family planning. The committee also noted that in their experience people may begin the decision making process with misconceptions around RRT that should be addressed before progressing further.

1.7.2 Cost effectiveness and resource use

Health economic studies were not sought as this was a qualitative review. The recommendations generally provide guidance regarding the content of information and support specific to people who require RRT or conservative management in line with the general principles of provision of information already established in the existing NICE Patient Experience Guideline and so were not considered likely to have a substantial resource impact over and above this.

1.7.3 Other factors the committee took into account

The committee raised a concern that there was a gap of information for the age group of 16-25 year olds, due to lack of evidence. The experience of the committee was that this is an important group within RRT and a lot of problems this review addresses would be specific to this group. For example, they are more likely to stop adhering to their medication and are a group that therefore need more advice. The committee confirmed that the recommendations were applicable to children and young people and that information and support should be tailored to their needs.

The committee highlighted that psychological problems can impact on how people cope with, and understand the need for renal replacement therapy, and this can in turn influence treatment decision-making. It is important for health professionals to make the time in appointment to explore whether psychological support may be required.

The committee noted that people who start dialysis in an unplanned way frequently carry on using the same modality at the one they started on. Typically this is HD through a central venous catheter. One reason for this is that they are not provided with information on, or given the opportunity to discuss, switching to another modality.

The committee had a concern with the term ‘information’, as that is usually associated with just giving a leaflet, when support, advice and an explanation is also needed. Supporting information with visits to units providing RRT may also be valuable.

The committee noted that it needs to be conveyed that information is an on-going process and not just a ‘one-off’. The committee stated that information should not be limited to treatment decisions, but perhaps addressed as life decisions. The committee noted that it was good practice to send people a copy of correspondence between health and social care professionals.

The committee noted that care of people approaching the need for, or receiving RRT, requires a skilled multi-professional team. Examples of members include social workers and welfare support workers.

The committee were aware of the recommendations on enabling patients to actively participate in their care in NICE’s guideline on Patient experience in adult NHS services: improving the experience of care for people using adult NHS services (CG138). The committee also highlighted that people may require information and support on their medications and were aware of the NICE guideline on Medicines Optimisation (NG5).

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Appendices

Appendix A: Review protocols

Table 28: Review protocol: Information, education & support

Field	Content
Review question	What information, education and support is important for people for whom RRT or conservative management may be appropriate, and their families/carers?
Type of review question	Qualitative
Objective of the review	Provide evidence of the types of information, education and support that the population values in this situation to inform recommendations for healthcare professionals to insure these topics are appropriately covered
Eligibility criteria – population / disease / condition / issue / domain	Adults and children who are being assessed for RRT or conservative management, or who are undergoing RRT or conservative management, their families, carers and healthcare professionals Evidence to be reported separately for the pre-RRT and during/post-RRT or conservative management populations and based on age (<2, 2 to <16, 16 to <25, 25 to <70, 70 and over)
Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	Any information, education or support specified in studies
Eligibility criteria – comparator(s) / control or reference (gold) standard	Not applicable
Outcomes and prioritisation	Themes will be derived from the evidence identified for this review and not pre-specified. However for information to guide the technical team, relevant themes may include: Barriers to good care Facilitators of good care Decision making Preferred format of information provision Content of information Impact of treatment on lifestyle Information sources other than healthcare professionals (e.g. support groups, online resources) Information around transitions between forms of RRT Impact of transport on care Psychological support
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	
Proposed sensitivity / subgroup analysis, or meta-regression	Not applicable
Selection process –	No duplicate screening was deemed necessary for this question, for

Field	Content
duplicate screening / selection / analysis	more information please see the separate Methods report for this guideline. 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.
Data management (software)	• CERQual was used to synthesise data from qualitative studies. • Endnote was used for bibliography, citations, sifting and reference management.
Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, CINAHL, PsycINFO Date: All years Language: Restrict to English only Supplementary search techniques: backward citation searching Key papers: Not known
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	Not applicable
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	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. 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: the manual.

Field	Content
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), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 29: Database date parameters and filters used

Database	Dates searched	Search filter 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
PsycINFO (ProQuest)	1806 – 11 December 2017	Qualitative studies

Medline (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/
12.	editorial/
13.	news/
14.	exp historical article/
15.	Anecdotes as Topic/
16.	comment/
17.	case report/

18.	(letter or comment*).ti.
19.	or/11-18
20.	randomized controlled trial/ or random*.ti,ab.
21.	19 not 20
22.	animals/ not humans/
23.	Animals, Laboratory/
24.	exp animal experiment/
25.	exp animal model/
26.	exp Rodentia/
27.	(rat or rats or mouse or mice).ti.
28.	or/21-27
29.	10 not 28
30.	"patient acceptance of health care"/ or exp patient satisfaction/
31.	Patient Education as Topic/
32.	((information* or advice or advising or advised or support*) adj3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)).ti,ab.
33.	(information* adj2 support*).ti,ab.
34.	((client* or patient* or user* or carer* or consumer* or customer*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion*)).ti,ab.
35.	or/30-34
36.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
37.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
38.	(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.
39.	or/36-38
40.	29 and 35 and 39

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/18-25
27.	10 not 26
28.	patient attitude/ or patient preference/ or patient satisfaction/ or consumer attitude/
29.	patient information/ or consumer health information/
30.	patient education/
31.	((information* or advice or advising or advised or support*) adj3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)).ti,ab.
32.	(information* adj2 support*).ti,ab.
33.	((client* or patient* or user* or carer* or consumer* or customer*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion*)).ti,ab.
34.	or/28-33
35.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
36.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
37.	(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.
38.	or/35-37
39.	27 and 34 and 38

CINAHL (EBSCO) search terms

S1.	(MH "Renal Replacement Therapy+")
S2.	((renal or kidney) n2 replace*)
S3.	(hemodiafilt* or haemodiafilt* or (biofilt* n1 acetate-free)
S4.	hemodialys* or haemodialys*
S5.	((kidney* or renal) n3 (transplant* or graft*))
S6.	capd 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 masters 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 "Consumer Satisfaction+") OR (MH "Patient Education") OR (MH "Health Education")
S12.	((information* or advice or advising or advised or support*) n3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*))
S13.	(information* n2 support*)
S14.	((client* or patient* or user* or carer* or consumer* or customer*) n2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion*))
S15.	S11 OR S12 OR S13 OR S14
S16.	(MH "Qualitative Studies+")
S17.	(MH "Qualitative Validity+")
S18.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S19.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S20.	(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*)
S21.	S16 OR S17 OR S18 OR S19 OR S20
S22.	S10 AND S15 AND S21 Limiters - English Language; Exclude MEDLINE records

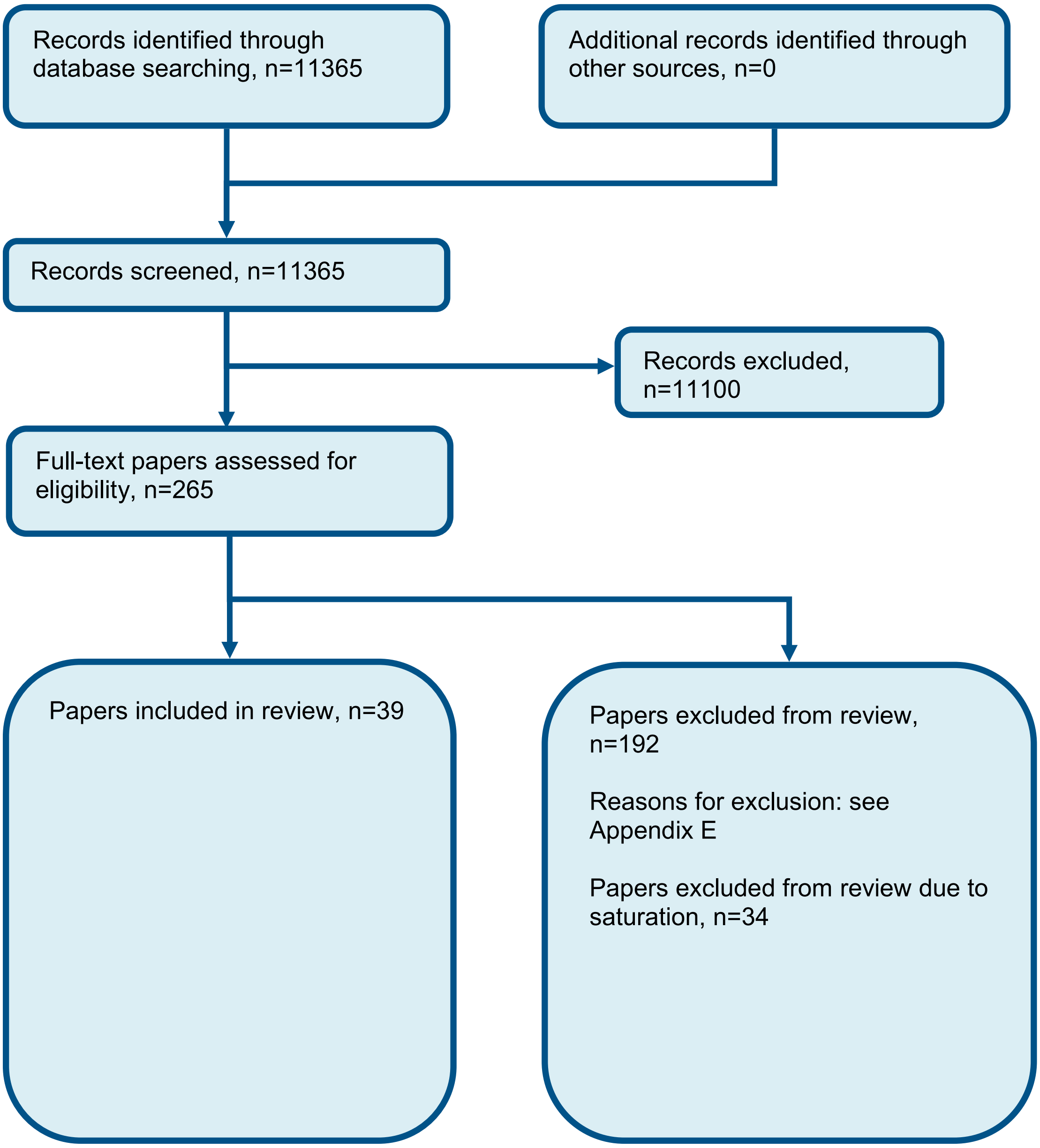
PsycINFO (ProQuest) search terms

1.	(SU.EXACT.EXPLODE("Dialysis") OR TI,AB((renal OR kidney) NEAR/2 replace*) OR TI,AB(hemodiafilt* OR haemodiafilt* OR (biofilt* NEAR/1 acetate-free)) OR TI,AB(hemodialys* OR haemodialys*) OR TI,AB((kidney* OR renal) NEAR/3 (transplant* OR graft*)) OR TI,AB(capd OR dialys*) OR TI,AB(artificial NEAR/1 kidney*))
2.	SU.EXACT("Client Education") OR SU.EXACT.EXPLODE("Client Attitudes") OR TI,AB((information* or advice or advising or advised or support*) N/3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)) OR TI,AB(information* N/2 support*) OR TI,AB((client* or patient* or user* or carer* or consumer* or customer*) N/2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion*))
3.	((su.exact.explode("qualitative research") or su.exact("narratives") or su.exact.explode("questionnaires") or su.exact.explode("interviews") or su.exact.explode("health care services") or ti,ab(qualitative or interview* or focus group* or theme* or questionnaire* or survey*) or ti,ab(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* near/3 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*)))
4.	1 and 2 and 3
5.	Limit 4 to English

.

Appendix C: Qualitative evidence selection

Figure 1: Flow chart of qualitative study selection for the review of information, education and support



Appendix D: Qualitative evidence tables

Study	**Barnieh, 2014**[23]
Aim	To synthesise the views of Canadian patients on or nearing dialysis and those caring for them
Population	189 participants, patients, caregivers and HCPs. Age 18 to >80, 48% on clinic HD, 17% home HD, 12% PD, 19% HCP
Setting	Canada
Study design	Qualitative; Text based survey
Methods and analysis	Secondary analysis of survey data using thematic content analysis, consensus based resolution on disagreements between researches on theme synthesis
Findings	Format of education/information: People felt that HCPs did not always explain things in 'layman's terms'
	Availability of choice: Some people reported that they did not think that all choices were made available to them because of the limited resources at their centre
	Awareness and availability of psychological support: People felt that more emotional support at the beginning of RRT would be useful (e.g. a counselling session) and that this would be useful both for the patient themselves and their caregivers
	Depth and timing of information: People generally wanted more information earlier in their pathway with the aim of getting their decisions made sooner or avoiding progression
	Information on acute situations: People felt they weren't given enough information about the potential acute situations that can occur on dialysis
	Information on diet and lifestyle: People felt they weren't given enough information about diet and lifestyle advice (e.g. what they can and cannot eat)
	Information on lifestyle and carer impact: People wanted more information about how they could travel on each mode of RRT
	Information on lifestyle and carer impact: People wanted more information about how RRT would affect their 'sexual vitality' and how this could be managed

Study	Barnieh, 2014[23]
	Information on prognosis: People wanted more information about their likely prognosis on RRT
	Information on risks and benefits: People wanted a thorough explanation of the risks and benefits of all RRT options available to them
	Information on symptoms: People felt they weren't given enough information about symptoms that arise whilst on dialysis and how to manage them (e.g. itching, restless legs)
	Peer support: People appreciated being able to talk to peers about how they arrived at their treatment decisions
Limitations and applicability of evidence	Moderate limitations due to research methods. Study conducted in Canada

Study	Berzoff 2008[26]
Aim	To elicit and provide for the needs of dialysis patients and their families throughout the trajectory of their illnesses.
Population	2 patient groups, 2 family groups (one bereaved and one non-bereaved), and two HCP groups. Patients receiving maintenance dialysis, family members, and bereaved family members.
Setting	USA
Study design	Qualitative; focus groups
Methods and analysis	Secondary analysis of survey data using thematic content analysis, consensus based resolution on disagreements between researches on theme synthesis
Findings	Individualised information: Although all of the bereaved families and families still coping with dialysis wanted more information, not all patients wanted to know their prognoses or the trajectories of their illnesses.
	Information on diet and lifestyle: Patients also wanted to know about what they could and could not do nutritionally, physically, and psychologically.
	Information on prognosis: Both patients and families added that they also wanted more education about the trajectory of the illness, including side effects, emphasizing that knowledge was empowering.

Study	**Berzoff 2008[26]**
	Information on risks and benefits: Patients and families both wanted more education from health care providers than they thought they had received. They wanted education on the procedure of dialysis, on the trajectory of the illness, on the side effects of the medications, on pain control, and on discontinuing dialysis.
	Information on symptoms: Almost all patients and families wanted to know about pain control.
	Source of support: For others, the idea of peer support arose as being even more useful. Family members reported needing someone who had walked in their shoes.
	Format of support: A theme emerged about offering support groups that were peer led and even telephonic. One family member said "Groups can help patients talk about DNRs. It would have been really helpful”. Another said “Groups can make you feel less alone, less vulnerable."
	Format of support: One idea for a support group was to hold it telephonically. A family member also suggested that the groups should be homogenous, i.e. an older group and a younger group.
	Support: Every patient and family wished that more support from health care professionals had been forthcoming.
Limitations and applicability of evidence	Minor limitations due to data collection. Study conducted in the USA

Study	**Bourbonnais 2012[30]**
Aim	To provide an overview of pain experienced by patients undergoing maintenance dialysis.
Population	25 patients, 31 to 80+yrs, ESRD. Majority 61+yrs, time on HD ranged from 3 months to 30 yrs
Setting	Canada, hospital
Study design	Qualitative; interviews
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 mins. Patients were interviewed at the bedside in the respective dialysis unit.
Findings	Awareness and availability of psychological support: Healthcare professionals need to be aware of the emotional and social pain patients sometimes experience. Participants experienced

Study	**Bourbonnais 2012**[30]
	psychosocial distress due to depression, limited social support, limited employment possibilities, as well as physical symptoms
	Awareness of symptoms: Healthcare professionals need to demonstrate to patients they understand they may experience pain and that they don't have to live with it. Participants were unsure whether to tell professionals they had pain or not.
	Transport: Patients sometimes have to rely on transportation for the disabled to get treatment. Many participants in this study were elderly and dealt with transportation issues.
Limitations and applicability of evidence	No notable limitations. Study conducted in Canada

Study	**Browne 2016**[36]
Aim	To determine perceived barriers and facilitators to kidney transplant that dialysis patients experience.
Population	29 participants, age 18-69 years - 14 male, 15 female, 25 African American. Participants were on dialysis, and were willing and able to participate in the session.
Setting	USA
Study design	Qualitative; focus groups
Methods and analysis	The group moderators used an interview guide which included probes about patient interest in kidney transplant as a treatment modality, concerns or barriers patients have about getting a kidney transplant, and facilitators or ways that dialysis team members can help patients get kidney transplant. The moderators audiotaped and trained research assistants transcribed all group discussions.
Findings	Availability of choice: Patients expressed the importance of advocacy and encouragement from dialysis team members related to kidney transplant. Many patients in all three groups lamented that some dialysis professionals' behaviours were a discouragement to pursuing kidney transplant.
	Depth and timing of information: Patients in all three states claimed they felt overwhelmed with information that dialysis teams give patients, and that information about kidney transplant is not presented in a meaningful way.
	Individualised information: Patients in all three groups agreed that they need more, and better, information and education from their dialysis centres about kidney transplant. The majority of patients agreed that they do not receive enough information about kidney transplant from their dialysis teams, or that the information they do receive was often not helpful or pro forma.

Study	**Browne 2016[36]**
Limitations and applicability of evidence	No notable limitations. Study conducted in the USA

Study	**Calestani 2014[39]**
Aim	To explore patients' views and experiences of kidney transplant listing.
Population	53 patients, 18-75yrs, stage 5 CKD. Mean age 52yrs, 57% male, 30% on waiting list, 25% had transplant, 26% being assessed for listing.
Setting	UK, renal units
Study design	Qualitative; Semi-structured interviews
Methods and analysis	Semi-structured interviews, face to face, in centre or in person's homes, topic guide informed by literature review, refined in an iterative manner included person's health history, information provision, support. Thematic analysis based on data-driven inductive approach undertaken.
Findings	Availability of choice: Patients felt going through assessment for transplant listing was inevitable and not really a choice
	Depth and timing of information: Patients felt that they were not provided with as much information as they would have wanted, they had to be proactive and ask for more
	Depth and timing of information: Patients reported that at times they were given too much information at once or too quickly
	Information on transplant listing process: Patients did not know how the transplant listing process worked and wanted to know more about it and their place on it
	Decision support: Patients felt that interaction time with healthcare professionals was limited and therefore discussions on choice were not carried out in depth
	Format of information: Patients reported receiving information via leaflets, DVDs and for some education sessions. Others found out more from peers or the internet. They generally reported that concise leaflets were helpful alongside in person discussions
Limitations and applicability of	Minor limitations due to ethical consideration

Study	**Calestani 2014**[39]
evidence	

Study	**Clarkson 2010**[48]
Aim	To explore the lived experience of patients with ESRD to determine if they are adequately educated about their illness
Population	10 patients, over 18yrs, PD and HD, 26-85yrs old, dialysis support group from Oklahoma, >3 months on dialysis, 4 on PD and 6 on HD
Setting	USA, support group
Study design	Qualitative; interviews
Methods and analysis	5 open-ended questions derived from authors' past experience.
Findings	Information on adherence: Patients wished they had been given more information about how to manage the side effects and medication regimen around dialysis and the impacts of non-adherence
	Information on lifestyle and carer impact: Patients wished they had been told to prepare for lifestyle changes for both patient and their caregiver
Limitations and applicability of evidence	Moderate limitations due to research methods and data richness. Study conducted in the USA

Study	**Davison 2006**[57]
Aim	To understand hope in the context of advance care planning from the perspective of patients with end stage renal disease.
Population	19 participants: aged 44-88 (mean 64 years), 11 were women. 19 patients with end stage renal disease purposively selected from the renal insufficiency, haemodialysis, and peritoneal dialysis clinics.
Setting	Canada
Study design	Qualitative; interviews
Methods and analysis	Open ended interviews explored participants' experiences through discussions about prognosis, end of life care, and hope and typically lasted 60-90 minutes. Interviews were transcribed and validated against the recorded material by the interviewer.
Findings	Timing of information: Participants needed information to be provided earlier in their illness, especially before the initiation of dialysis.
	Source of information:

Study	Davison 2006[57]
	All participants were prepared to discuss end of life issues and looked to their healthcare providers for information; most patients wanted more information. By providing information, health professionals helped patients to imagine possibilities for a future that were consistent with their values, which in turn gave hope.
	Content of information: Participants wanted more information about their prognosis and illness and, specifically, how interventions could sustain roles and relationships.
	Peer support: Relationships with health professionals, family, and friends were vital to being able to sustain hope for many patients.
	Benefits of support: The emotional and practical support individuals offered provided a broader context within which the participants could “be themselves” and integrate their experiences of illness into their daily lives.
	Source of support: Maintaining relationships through working or contributing to community or family was often mentioned as a key way in which hope was sustained.
Limitations and applicability of evidence	Minor limitations due to data collection. Study conducted in Canada

Study	DePasquale 2013[60]
Aim	To elicit patient views regarding information they felt should be featured in educational resources informing RRT selection decisions.
Population	68 patients, 62 family members, ESRD, 18+yrs. All had been on RRT for at least 1yr or had received a kidney from a live donor. Pre ESRD (54yrs 13ppl), HD (25 to 70yrs 20ppl), PD (13ppl 25 to 70yrs), Tx (22ppl 20 to 70yrs).
Setting	USA
Study design	Qualitative; interviews
Methods and analysis	Structured group interviews to obtain tabulated and open ended feedback were conducted and audiotaped. There were 3 stages; stage 1 explained the purpose of the interview and posed open ended questions, stage 2 participants revealed their 3 selected most important factors and stage 3 participants circled 3 factors they felt should be presented in educational resources about RRT options.
Findings	Educational resources: Factors pertaining to the effect of RRT on patients' experiences with treatment delivery. Nine patient groups selected at least one factor pertaining to patients’ experiences with initiating RRT treatment delivery. One mentioned more education is needed for new patients, for example difference between fistula and catheter and their purpose.

Study	**DePasquale 2013**[60]
	Information on prognosis: Factors pertaining to the effect of RRT on patients morbidity/mortality. All ten patient groups selected at least one factor pertaining to the effect of RRT on patients' morbidity or mortality. One stated 'it's something that everyone needs to know' and that it's not a lost cause and 'you can definitely live longer'.
	Information on symptoms: Symptom information prior to RRT. Five patient groups selected at least one factor pertaining to the influence of RRT on symptoms patients might experience. One stated there needed to be more awareness of what happens to a person leading up to kidney failure.
	Educational resources: Factors pertaining to the effect of RRT on patients' symptoms. Five patient groups selected at least one factor pertaining to the influence of RRT on symptoms patients might experience. One stated there needed to be more awareness of what happens to a person leading up to kidney failure.
Limitations and applicability of evidence	Moderate limitations due to ethical approval and research design. Study conducted in the USA.

Study	**Griva 2013**[88]
Aim	To explore cultural perspectives on facilitators and barriers to treatment adherence in HD patients.
Population	37 patients, 21yrs and above, on HD. Patients had been undergoing treatment for a min of 6 months
Setting	Singapore
Study design	Qualitative; Interviews and Focus groups
Methods and analysis	The study was stopped when themes were saturated. Interviews were conducted first followed by focus groups. Interviews were scheduled first to allow the interviewer greater exposure to patient perspectives and sociocultural context before embarking on group discussions in a more dynamic setting. Individual interviews lasted approx 60 mins. A standardised semi-structured interview schedule and protocol were developed to ensure consistency. Each focus group consisted of 6 to 7 patients and lasted approx 90 mins.
Findings	Importance of communication: Patients emphasised the importance of having regular contact with the renal dietician to review progress and discuss how to manage their disease.
	Lack of knowledge: Patients described limited understanding of the dietary guidelines and the necessary modifications which needed to be made due to biochemical levels. Patients described lack of knowledge regarding the nutritional value and content of different types of food and difficulty in managing dietary principles.

Study	**Griva 2013**[88]
	Communication difficulties: Patients reported communication difficulties with dialysis providers. They reported feeling rushed, misled or not listened to.
	Peer support: Participants spoke about seeking information from other patients either known to them through personal contacts or those in dialysis centres.
	Peer support limitations: Patients highlighted that limitations placed on the timetabling and scheduling of dialysis sessions can limit meaningful interaction.
	Benefits of family support: Participants indicated that family support and the consideration of family well-being were critical aspects of adhering to self-management principles.
	Importance of information: Patients reminded themselves of the risks and complications of treatment non-adherence to reinforce self-discipline and their commitment to follow through with treatment recommendations.
	Concerns about safety: Patients expressed concerns about the adverse effects of medications and their overuse by healthcare professionals.
Limitations and applicability of evidence	No notable limitations. Study conducted in Singapore.

Study	**Harwood 2005**[96]
Aim	To identify the implications for patient education and support needed in the care of patients with CKD.
Population	11 patients, 61 to 89yrs, ESRD. Mean age = 72.7yrs
Setting	Canada, The London Health Sciences Centre
Study design	Qualitative; interviews
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 mins.
Findings	Educational resources: Professionals should be aware not all engage in personal learning and so should ensure all patients engage, as they identify the importance of needing to learn more. Participants identify the importance for themselves and others of needing to learn more about renal disease to prepare for dialysis and listening to advice.

Study	**Harwood 2005**[96]
	Support for family members: Family members should be included if possible when educating about renal failure. Patients found it helpful and supportive when their spouses learnt about renal failure
	Impact of treatment on lifestyle: Healthcare providers need to fully understand the impact of CKD on the individual. Some patients reported dissatisfaction with their healthcare providers regarding perceptions of their care.
	Psychological support: It is important for patients to have someone to talk to. Some patients experienced psychosocial stressors with one stating 'it would have been good to have someone to talk to'. One reported patients should be asked about their concerns.
	Format of information: Other interactive formats should be considered such as tours of dialysis units in delivering information, and someone to relay information to patients if they are unable to read. Some viewed touring the dialysis unit as important and some found attending classes as helpful.
	Content of information: Procedures should be explained in detail. Lack of information and uncertainty was identified by 5 of the 11 patients.
	Facilitators for good care: Patients identified needing time to absorb information and adjust to the approaching dialysis. Some reported how it was hard difficult to grasp and absorb the information.
	Barriers to good care: Lack of information and dissatisfaction with their healthcare providers regarding perceptions of their care. Lack of explanation of results, not being completely honest, kept in the dark about the seriousness of the problem and not being clear about when dialysis would occur were problems patients described.
	Transport issues: Transportation issues of the patients need to be taken into consideration. Transportation issues was recorded by some as psychosocial stressors.
Limitations and applicability of evidence	No notable limitations. Study conducted in Canada

Study	**Heck 2004**[99]

Study	Heck 2004[99]
Aim	To examine the psychosocial effects of living donor kidney transplantation for donors and recipients under successful as well as complicated circumstances.
Population	31 participants, kidney transplant recipients, 19 to 71yrs. Living donors and recipients included, median donors age was 50 yrs, median recipients age was 32.
Setting	Germany
Study design	Qualitative; interviews
Methods and analysis	Semi-structured interviews were conducted after transplantation.
Findings	Content of information: The importance of fully informing recipients and donors beforehand about psychological risks. Recipient and donor should be fully informed about general psychological risks with regard to the live donation.
	Psychological support: The importance of informing patients that symptoms can worsen. The participants should be prepared for the possibility that psychological problems, which existed prior to the operation, can even be amplified at times after the transplantation.
Limitations and applicability of evidence	Severe limitations due to ethical approval, role of the researcher, data collection, data analysis and richness of data. Study conducted in Germany.

Study	Hughes 2009[103]
Aim	To explore kidney patients experiences of receiving individual peer support.
Population	20 participants (18 patients and 2 carers), 13 female and 7 male, 26 - 80 yrs, receiving peer support, pre-RRT. Conducted at 2 large teaching hospital renal units in South London, with peer support services for patients on the pre-dialysis care pathway.
Setting	UK, teaching hospital renal units in South London
Study design	Qualitative; interviews
Methods and analysis	Qualitative, semi-structured telephone interviews with 20 people who had received peer support. Open-ended general questions were used to elicit an account of the peer support encounter and the respondents assessment of it in their own words. The interviewer maintained a conversational style allowing the order of questions to be determined by the flow of the interview. Probing techniques were used to keep the interview on track and to clarify details; silence was employed judiciously to elicit more information; and follow-up questions were asked occasionally to prompt elaboration of initial answers.
Findings	Timing of preparation: People put-off definitive procedures for as long as possible (e.g. creation of access) because of fear and denial

Study	Hughes 2009[103]
	Awareness and availability of psychological support: People reported being well informed about the technical and physical aspects of RRT but not about the emotional aspects. They would have appreciated "sitting down with someone who knows about kidney disease and who would listen to your concerns for 10-15 minutes".
	Depth and timing of information: Some people described having a lack of knowledge about RRT, the options, how their condition progressed - at the time of preparation for initiation of RRT
	Peer support: People appreciated the emotional support provided by support groups
	Peer support negative experiences: Two patients were critical of their peer supporters and described being frightened by what they had seen and heard.
	Peer support benefits: "Most saw peer support as a way of accessing practical information about treatment for kidney disease; finding out about personal experience of treatment; or asking about things the doctors wouldn't know the answer to."
	Unreliable information sources: Some respondents who had friends or family members with kidney disease mentioned informal networks as a source of information that was not always accurate or encouraging
	Peer supporter as a role model: Two younger women with children emphasized the importance of having met someone with similar family circumstances. Other accounts indicated that perceived similarities had helped establish understanding and identification, enabling respondents to imagine themselves in the peer supporters shoes.
	Peer support: The majority felt the peer supporter had listened and enabled them to ask questions. Respondents valued peer supporters' candour in answering their questions.
	Peer support benefits: Almost all respondents identified being reassured or encouraged and gaining in confidence or strength as key benefits
	Peer support benefits: The majority of respondents had spoken to a peer supporter at the time they were making a decision about treatment
	Peer supporters offer hope for the future:

Study	**Hughes 2009**[103]
	Identifying with a peer supporter who was coping with treatment and had re-established the routines of everyday life also helped to normalize living with kidney disease and, for some, offered hope for the future.
Limitations and applicability of evidence	No notable limitations.

Study	**Jennette 2009**[107]
Aim	To ascertain barriers and facilitators to choices other than in centre HD and psychosocial and educational issues which may affect the choice
Population	47 patients, 18+, USA, HD or PD. 12 on PD, 35 on HD, majority female, majority African American, ages from 21 to 80
Setting	USA, in centre or home
Study design	Qualitative; focus groups
Methods and analysis	Mixed methods, scripted discussion guide, 60-90 minutes, grounded theory for analysis.
Findings	Availability of choice: Patients reported that they often felt like they did not have a full choice available to them Some patients said their choice was limited by family members, others by healthcare professionals and others that there was no choice available at all.
	Classes/tours: Patients would have appreciated pre-dialysis education classes; classes were available for transplant patients in the centre in question but not for dialysis.
	Depth and timing of information: Patients reported that they felt they did not receive full information about the emotional and physical toll that dialysis would take on them.
	Depth and timing of information: Patients wanted more in depth education to increase their engagement, for example about the numbers on their dialysis machine
	Format of information: Patients appreciated reading materials and videos but some had difficulty understanding the materials and wanted a person to help guide them through it
	Peer support: Patients reported that peer mentors had been extremely helpful in helping them cope with their disease.

Study	**Jennette 2009**[107]
Limitations and applicability of evidence	No notable limitations. Study conducted in the USA

Study	**Kaba 2007**[109]
Aim	To explore how Greek patients receiving long-term haemodialysis perceive their problems and to describe the impact of haemodialysis on these patients' lives.
Population	23 patients, ESRD. Mean age = 62yrs, all receiving HD
Setting	Greece
Study design	Qualitative; interviews
Methods and analysis	Face to face interviews were conducted in a private room on the HD ward after dialysis treatment, lasting 30-60mins. All were audiotaped and patients were asked to speak about problems, feelings, thoughts, attitudes, and how they handled their daily activities.
Findings	**Facilitators for good care/psychological support:** Participants feelings to be taken into consideration. Awareness of their dependent status while maintaining their autonomy as individuals can lead to the delivery of more sensitive care to the patients.
	Facilitators for good care: The importance/effect of a good nurse/patient relationship. Most patients wanted to discuss the importance of good care received by nurses and how it affected their condition. It is valuable for the nurse to listen to the dialysis patients and hear their views, and incorporate these views in care planning.
Limitations and applicability of evidence	No notable limitations. Study conducted in Greece

Study	**Korus 2011**[115]
Aim	To explore information needs of adolescents who have undergone kidney transplantation
Population	8 adolescents aged between 13 to 17yrs, mean age = 15yrs , ESRD. Mean age at the time of transplant = 10yrs
Setting	Canada, hospital clinic or meeting room
Study design	Qualitative; focus groups

Study	**Korus 2011[115]**
Methods and analysis	Five focus groups were separately conducted, 2 with adolescents, 2 with parents and 1 with healthcare professionals, with a semi structured interview guide to lead the discussion. Interviews lasted between 40 and 75 mins with all being conducted in a private quiet room in the hospital clinic or meeting room. All interviews were audio taped.
Findings	Information sources: Patients found it important to hear stories of hope and real life stories from other transplant recipients. Patients wanted to know that despite all they had to learn and do that they could still lead a normal life.
	Psychological support: Patients reported the need to have access to physical or tangible resources. Patients reported meaningful social support helped them cope with transplantation, through instrumental and emotional support.
	Format of information: Patients wanted information provided on a website or computer based teaching program with options for additional information. Some patients reported that the option for tours of the hospital or a step by step procedure of the transplant experience, introduce the transplant team members and hear real life transplant stories.
	Barriers to good care: Possible breakdown in communication needs to be acknowledged and not being fully prepared for procedures and not being listened to by the healthcare team. Participants stated they weren't told what to expect. One stated 'they said it wouldn't hurt but it did'.
	Content of information: Patients wanted to receive information gradually and not be overwhelmed. They would rather come back regularly than have it all 'thrown at them' and that they deserve to know what’s going on with them in detail and at a good pace.
	Information sources: Patients wanted information provided on a website or computer based teaching program. Patients wanted the option for a tailored information.
	Content of information: Patients wanted to know the consequences of not adhering to medication and treatment regimes. Patients thought this very important and that those about to embark on transplantation should know the serious consequences.
	Impact of treatment on lifestyle: Patients overwhelmingly stated they wanted to know everything there was to know about their disease and treatment. They wanted to know the prognosis for future and impact on school, job and family
	Content of information: Patients overwhelmingly stated they wanted to know everything there was to know about their disease and treatment. They wanted to know about potential complications, side effects of the medications and procedures, how to maintain a healthy lifestyle, what the

Study	**Korus 2011**[115]
	expected outcome was for transplant recipients
	Information about transition: Patients wanted specific information. They wanted information about transition to adult health care services
	Format of information: Patients wanted a variety of options on how they received knowledge. They felt some teens may want to see pictures of other teenagers undergoing transplant, watch video clips or hear about complications experienced by other patients.
	Facilitators for good care: Patients thought 1:1 time with transplant team members was helpful. Patients wanted additional information sources as well, without losing 1:1 time
Limitations and applicability of evidence	No notable limitations. Study conducted in Canada

Study	**Lai 2012**[118]
Aim	To explore the lived experiences of incident haemodialysis patients in Singapore.
Population	13 patients, 39 to 63yrs, ESRD. Mean age = 52yrs, all initiated HD with a temporary CVC
Setting	Singapore
Study design	Qualitative; interviews
Methods and analysis	Semi-structured interviews were conducted with open ended questions. Sessions ranged from 35 to 50mins and were audio recorded.
Findings	Source of information: Patients sought informational support from fellow established haemodialysis patients. The majority of patients sought informational support about issues surrounding end stage renal disease from fellow established haemodialysis patients.
Limitations and applicability of evidence	Minor limitations due to ethical consideration. Study conducted in Singapore

Study	**Lee 2008**[127]
Aim	To explore patients’ experiences with different dialysis modalities and investigated issues related to the patient’s choice of modality

Study	**Lee 2008**[127]
Population	6 focus groups involving 27 HD patients and 18 relatives, mean age 54 ± 16.2 yrs. Three patients were in a pre-dialysis stage and the other 24 had been on dialysis for 6 ± 6.8 years.
Setting	Denmark
Study design	Qualitative; focus groups
Methods and analysis	Each focus group comprised patients on one type of dialysis, i.e. CHD, self-care CHD, HHD, CAPD/APD, aAPD or pre-dialysis patients. Based on a semi-structured interview guide, the group discussions centred on advantages and disadvantages of dialysis modalities, problems experienced and their (possible) solutions and patient involvement in choice of modality. The interview material was fully transcribed and analysed.
Findings	Education content: Patients who had not attended pre-dialysis education programme wished they had had the opportunity to do so.
	Lack of information: The CHD patients received no formal pre-dialysis education. All were dissatisfied with the information received.
	Education timing: Patients emphasized that timing of dialysis education was important.
Limitations and applicability of evidence	No notable limitations. Study conducted in Denmark.

Study	**Lenci 2012**[129]
Aim	To explore how elderly patients experience life on PD
Population	4 patients (1 female, 3 male), 75 - 88 yrs, on PD for 2-5yrs. All had been on PD for an average of a 2-3 years. Patients on self-care PD.
Setting	USA
Study design	Qualitative; interviews
Methods and analysis	In-depth interviews were conducted to better understand the issues, opinions, concerns, and feelings from the patient's perspective. A structured interview of approximately 1 hour covered 7 domain topics: initiating dialysis, knowledge of dialysis, physical condition, social support, psychological support, experience of dialysis, and communication and coordination between the nephrologist and the primary care physician. Interview data and field notes were transcribed and then analysed by domain topic to identify common patterns and key themes about the patients' experiences with PD.
Findings	Psychological support: All of the patients interviewed cited specific examples of things that they continue to do besides deal with ESRD. Patients mentioned a

Study	**Lenci 2012**[129]
	strong support system from family, friends or other groups.
	Content of information: Full and detailed description of the treatment before it starts is important for patients to achieve a real understanding of what they should expect. The simplicity of a treatment option or the availability of assistance seems to lead to better adherence for patients.
Limitations and applicability of evidence	Moderate limitations due to data collection and ethics. Study conducted in the USA.

Study	**Lin 2005**[132]
Aim	To describe the experiences of making a decision about HD among a group of Taiwanese with ESRD.
Population	12 patients, 28 to 53yrs, ESRD. Mean age = 38.9yrs, had all begun HD within previous 6 months
Setting	South Taiwan
Study design	Qualitative; interviews
Methods and analysis	Semi structured interviews with open ended questions were conducted either in the participants' homes or the HD centre and lasted from 50mins to 2.5hrs.
Findings	Source of information: Getting opinions of family members. Participants took into account the opinions of their family members when making decisions about haemodialysis.
	Source of information: Seeking professional confirmation. When participants learned about the need for haemodialysis treatment, many sought second opinions from other healthcare providers.
	Content of information: Exploring alternative treatments. Based on the understanding that western medicine treats the symptoms whereas Chinese medicine cures the problems, most participants sought help from Chinese herb medicine, folk treatment, or herbal remedies.
Limitations and applicability of evidence	Minor limitations due to ethical consideration. Study conducted in South Taiwan.

Study	**Lonargain 2017**[135]

Study	**Lonargain 2017**[135]
Aim	To explore the psychological experiences of receiving a kidney transplant from a deceased donor
Population	6 patients, mean age 45, received transplant from deceased donor. Receiving post-transplant care, had received transplant <24 months previously, all white British
Setting	UK, NHS renal services
Study design	Qualitative; interviews
Methods and analysis	Semi-structured interviews, analysed with interpretative phenomenological analysis. Topic guide from literature review. Mean interview duration 60 minutes
Findings	Peer support: People reported that significant amounts of their support came from their family and from their peers through support groups.
Limitations and applicability of evidence	Moderate limitations due to data richness.

Study	**Low 2014**[139]
Aim	To investigate how conservative management interacted with ideas of ageing in the experience of conservative management
Population	26 people close to those undergoing CM. Mean age 63, 15/26 women, 17/26 white British
Setting	UK, tertiary renal centres
Study design	Qualitative; interviews
Methods and analysis	Narrative approach, 20-90 minute interviews, analysed thematically along a chronological pattern, themes independently generated by other researchers in addition for consensus.
Findings	Support: Younger and fitter caregivers felt like they could provide all the support necessary for people on CM but older caregivers required help from family for activities of daily living and accessing healthcare.
	Information on acute situations: People would have appreciated more information about how to deal with any acute or emergency changes in the patient's health.
	Decision support: People felt that the decision to choose CM was partly based on the idea of it more accurately reflecting 'natural ageing' but also based on the availability of dialysis should a person change their mind.
	Support: People felt that continuity of care or at least optimum information sharing was particularly important for CM, this was particularly

Study	**Low 2014**[139]
	relevant for establishing which healthcare professional was responsible for looking after what aspects of the patient.
Limitations and applicability of evidence	No notable limitations.

Study	**Mitchell 2009**[149]
Aim	To identify factors identified by patients as helpful in the transition onto haemodialysis.
Population	10 patients, 5 males and 5 females on HD. Age 20->80 years. 10 patients, five males and five females who had been on haemodialysis for between one week and six months.
Setting	UK
Study design	Qualitative; interviews
Methods and analysis	Individual semi-structured interviews conducted. The interviews covered participants' experiences of daily activities, thoughts, feelings, and social life, focussing on what, if anything had helped them cope across these domains. The interviews lasted between 30 and 50 minutes. All interviews were audio-taped and transcribed verbatim, the interpretive content analysis of the text was supported by three researchers reading all the transcripts and developing an initial categorisation with supporting quotations.
Findings	Source of support: Instrumental support (practical help) was identified as being particularly important. Neighbours were mentioned more often than family as a source of practical support. This arises possibly as a consequence of reluctance by patients to rely on family members, in case they become a burden.
	Awareness and availability of psychological support: Younger participants highlighted benefits arising from having someone to talk to about their emotional difficulties. It was not generally felt that emotional support needed to be provided by professionals, unless someone lacked friends or family to provide such support.
	Information on prognosis: Patients emphasised the importance of having questions addressed, with clear and honest explanations about the nature of the illness, its management, treatment and what could go wrong.
Limitations and applicability of evidence	No notable limitations.

Study	**Morton 2011**[156]

Study	Morton 2011[156]
Aim	To rank the most important characteristics of dialysis on which patients and caregivers make decisions
Population	34 participants, >18, pre-dialysis, dialysis and caregivers. Mean age 60, mix of pre-dialysis, dialysis (50%) and caregiver (50%) opinions.
Setting	Australia
Study design	Qualitative; focus groups
Methods and analysis	Mixed methods, quantitative ranking of factors with qualitative explanation of rationales. Nominal group technique. Thematic analysis per Boyatzis.
Findings	Information on lifestyle and carer impact: Patients prioritised impact on survival, convenience/flexibility, impact of a fistula/needling and ability to travel as the most important factors in their decision making.
	Information on lifestyle and carer impact: Caregivers prioritised convenience/flexibility, staff support and ability to travel as the most important factors in their decision making.
Limitations and applicability of evidence	Minor limitations due to data richness. Study conducted in Australia.

Study	Orr 2007[169]
Aim	To explore the experience of living with a transplanted kidney.
Population	Kidney transplant recipients aged 18+yrs. All had a transplanted kidney, time since transplant ranged from 2 to 8 years, mode age=60+
Setting	UK
Study design	Qualitative; focus groups
Methods and analysis	4 focus groups were conducted using a guided discussion and lasted for 1hr and were audiotaped.
Findings	Content of information: Patients frequently drew comparison with others whose transplant had been successful. Participants were determined to stay positive. Downward comparison was used in relating the benefits of their present situation to being on dialysis.
Limitations and applicability of evidence	Minor limitations due to data richness

Study	Orr 2007[168]
Aim	To explore patients' lived experience in relation to medication adherence.
Population	26 patients, 18+yrs, kidney transplant recipients. Time since transplant ranged from 2 to 8 years, mode age=60+
Setting	UK
Study design	Qualitative; focus groups
Methods and analysis	4 focus groups were conducted using a guided discussion and lasted for 1hr and were audiotaped.
Findings	Source of support: Some patients described how their partners took responsibility for remembering medication. Paramount importance was placed on taking medication, although there was admission that tablets were missed through forgetting. Some patients required support from those close to them, such as their spouse to remind them to take their medication.
Limitations and applicability of evidence	Minor limitations due to data richness

Study	Polaschek 2003[173]
Aim	To contribute towards enabling health professionals to provide more effective support to people who are living with ESRD.
Population	6 patients, 20 to 60+yrs, ESRD. All successfully on self-care dialysis in their homes, HD
Setting	New Zealand
Study design	Qualitative; interviews
Methods and analysis	Three semi structured interviews lasting an hour were conducted in their homes and were taped.
Findings	Facilitators for good care: Healthcare professionals need to assure patients they know understand what the patient is feeling and not treat everyone the same. Patients weren't able to discuss with renal stuff the alterations they made to the therapeutic regime in order to negotiate the requirements of treatment into their lifestyles. One patient stated 'they (nurses) treat everyone the same but you know your own body'.
	Content of information: The importance of being straightforward and honest to patients. Patients expressed sensitivity when they perceived that they had not been fully informed about their condition, therapy or its effects. Sometimes they expressed a sense of having been misled by the optimism of the dominant professional viewpoint. One patient said ‘I might have thought of not going

Study	**Polaschek 2003**[173]
	on if I had known that this would be the future'.
Limitations and applicability of evidence	No notable limitations. Study conducted in New Zealand

Study	**Rygh 2012**[195]
Aim	To examine the patients' need for information and guidance in the selection of dialysis modality, and in establishing and practicing home dialysis.
Population	11 patients: 8 patients with PD; 3 with APD and 5 with CAPD; 3 patients had HHD. Three patients had HHD; were two women and one man, aged 36-60 years, all working. They spent four to five days, 16 to 20 hours a week, on dialysis.
Setting	Norway
Study design	Qualitative; interviews
Methods and analysis	In-depth interviews with eleven patients established in home dialysis. The interviews were audio-taped and transcribed verbatim, except for the HHD interviews, which lasted for several hours.
Findings	Source of information: Observation of and listening to other patients' experiences were often more influential on their choice than information from health professionals.
	Timing of information: Patients wanted information about the possibility of home dialysis, as well as information about different modalities, at an earlier stage
Limitations and applicability of evidence	No notable limitations. Study conducted in Norway

Study	**Salter 2015**[198]
Aim	"To explore perceptions of dialysis and KT among African American adults undergoing haemodialysis, with particular attention to age- and sex-specific concerns."
Population	36 patients, 18 (assumed not stated) - 65+, 22 male, 14 female, on HD, 3 in the <65 had a previous transplant. All African American, 11 men <65, 9 women <65, 11 men >65 and 5 women >65
Setting	USA

Study	**Salter 2015**[198]
Study design	Qualitative; focus groups
Methods and analysis	Formative work for focus group script development included a review of the literature, expert opinion from a multidisciplinary advisory panel, pilot testing in mock focus groups, and further refinement based on pilot test results. FGDs were conducted at the Johns Hopkins Hospital with a moderators and assistant staff present. At each FGD, a moderator asked guided questions to encourage discussion about participants' attitudes and concerns about dialysis and transplantation. Each session lasted approximately two hours. Because conversations were intended to be free flowing, not every participant answered each question.
Findings	Lack of communication: Participants felt that the technicians did not explain procedures clearly even when asked
	Lack of information: Patients indicated that medical professionals provided very little information about transplantation
	Need for more information: Despite an overall lack in their desired level of knowledge about KT, several participants expressed interest in transplantation
	Lack of healthcare professional support: Most participants reported that their nephrologists did not answer questions and spent inadequate amounts of time with them.
	Peer support: For some participants, fellow dialysis patients provided emotional support beyond what they were receiving from their friends and family. Many participants described how dialysis patients encouraged one another and formed close bonds
	Limited support: Most (mainly <65yrs) described limited support from family and friends with friends finding it difficult to understand and expecting them to continue their normal responsibilities
	Barriers to good care: Many participants felt that dialysis centre technicians treated them poorly.
	Lack of education: Some participants tried to educate themselves about renal disease and dialysis
	Benefits of family support: In contrast to the younger adults, the older men stated they were able to talk about their dialysis with family and felt this helped them to cope.
Limitations and applicability of evidence	Minor limitations due to data collection. Study conducted in the USA

Study	Schmid-Mohler 2014[201]
Aim	To explore the concept and the presence of self-management tasks mastered by patients in the early phase after kidney transplant.
Population	12 patients, Median age = 52yrs. All kidney transplant recipients
Setting	Switzerland
Study design	Qualitative; interviews
Methods and analysis	Semi structured interviews were conducted with open ended questions and all were audiotaped.
Findings	Content of information: The importance of being straightforward and honest to patients. Patients expressed a desire for their health care professional to take their need for information and participation in care into account. 'I don't believe in positive thinking. I want facts so that I can prepare myself mentally'.
	Content of information: Patients wished they had received more information about the post-transplant period and had been better informed of what to expect. Some patients expected that life would return to the way it was before the first symptoms of renal insufficiency, but had to adjust these beliefs and adopt more realistic expectations.
	Psychological support: Patients reported certain strategies as helpful when dealing with instability and uncertainty. Emotional support and adjusting ones thoughts by speaking with others was helpful. The exchange with peers helped patients not to feel alone or marginalised.
	Source of information: Patients reported not having a consistent physician provider. Patients reported receiving contradictory information from different physicians, hindering progress and trust with medical doctors.
Limitations and applicability of evidence	No notable limitations. Study conducted in Switzerland

Study	Small 2010[212]
Aim	To describe the experiences of patients receiving HD for CKD.
Population	21 patients, ESRD, 20-70+yrs.
Setting	Namibia, study conducted at the only HD facility in Windhoek and one of only 3 in Namibia.
Study design	Qualitative; interviews

Study	**Small 2010**[212]
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.
Findings	Financial barrier: Some of the participants encountered periods of limited funds. Some of the participants experienced the effects of the hidden costs of dialysis, such as specific dietary requirements including specific, more costly food groups.
	Transport issues: Many patients had to rely on taxis as a means of transport. One patient had to be dialysed three times a week, and had to pay for taxis to and from the hospital.
Limitations and applicability of evidence	Minor limitations due to rigor of research design. Study conducted in Nambia

Study	**Sondrup 2011**[213]
Aim	To better understand patient perceptions and possible barriers related to choosing independent dialysis therapies.
Population	6 patients, 3 patients on PD and 3 patients on HD. 4 men and 2 women. 30-69yrs. Patients who were currently on an independent dialysis therapy, previous patient at the Kidney Function Clinic within the past five years, and 19 years of age or older
Setting	Canada
Study design	Qualitative; interviews
Methods and analysis	Open-ended questions on the topic of independent dialysis therapies, and the education materials and information provided to patients regarding dialysis options. The data analysis method for review of the focus group transcriptions involved use of an “interpretive descriptive” approach. Focus group transcriptions were independently reviewed. Emerging themes were agreed to by consensus.
Findings	Technical support: Patients wanted assurance that there is adequate support at home for technical issues. Patients expressed the fear of going home after training and the uncertainty of being able to problem-solve machine errors or medical complications.
	Source of support: Participants would have appreciated more support from healthcare professionals. When considering RRT options, participants expressed a desire to know that the care team supports their decisions regarding dialysis treatment selection.
	Education content: Patients expressed a lack of preparation for initial dialysis (resulting from inadequate orientation or education materials). They did not feel sufficiently prepared for some limitations of dialysis and wished they had more specific information at the predialysis level.

Study	**Sondrup 2011**[213]
	Education content: Participants suggested education on what each therapy involved, including some of the drawbacks.
	Peer support: Participants expressed a need for peer support at each stage of the dialysis trajectory from patients who were already on independent dialysis.
	Education content: Education material needs to focus on specific lifestyle aspects presented in a positive way that explains the benefits of home dialysis instead of the pros and cons of different modalities.
Limitations and applicability of evidence	No notable limitations. Study conducted in Canada

Study	**Tong 2010**[223]
Aim	To explore the experiences of parents who have children with CKD.
Population	Parents of 20 children with CKD. Children ranged from 0 to 18yrs, mode= 15-19yrs for the patients. Parents had to be >18yrs. Pre RRT, HD, PD, Tx
Setting	Australia
Study design	Qualitative; interviews
Methods and analysis	An in-depth interview was conducted lasting 1hr, using a question guide. All interviews were digitally recorded.
Findings	Sources of support: Sources were primarily the immediate family and other parents of CKD children. Parents found reassurance in talking with their child's specialist. Sources included family, friends and the community who provided practical and emotional support
	Psychological support: Parents experienced heightened uncertainty and emotional stress in hospital. Parents found it difficult to manage their child's psychological issues and felt they lacked support and information regarding depression and aggression in children with CKD.
	Content of information: Some parents identified information needs they felt were unmet. They wanted information about: CKD, treatment procedures for dialysis and transplantation, other parents' experiences of CKD, dietary advice, warning about complications in dialysis and transplantation, how to access financial and practical assistance, and managing their child's psychological and behavioural problems.

Study	**Tong 2010[223]**
	Format of information: Parents suggested that information should be made available online and communicated through clinicians, parent networks, health care professionals, pamphlets and videos.
	Communication: Parents appreciated specialists who were attentive and honest. This gave parents the reassurance and ability to entrust their child into the specialist's care.
	Educational resources: Home visits, education and support were appreciated.
	Source of information: Most sought information about the illness and treatment from specialists, but some parents avoided asking questions for fear of being labelled as troublesome and of jeopardizing their relationship with staff.
Limitations and applicability of evidence	Minor limitations due to ethical consideration. Study conducted in Australia.

Study	**Tong 2011[224]**
Aim	To explore adolescent perspectives following kidney transplantation and to elicit strategies from them on ways to improve service delivery and support for adolescent transplant recipients.
Population	22 patients, 12-19years old (mean age=15.6), 12 male, 10 female. Age at transplantation ranged from 3 to 17 yrs. Twelve received a kidney from a parent donor and 10 from a deceased donor.
Setting	Australia
Study design	Qualitative; interviews
Methods and analysis	Individual face to face in-depth interviews were conducted. On average, each interview lasted between 30 min to 1 hr and was conducted by the same person. Participants were given the option of being interviewed at home or in the hospital and also whether to have their parents present. All interviews were digitally audio recorded and transcribed verbatim.
Findings	Psychological support: Some of the adolescents felt their personality and temperament had changed after transplantation. Some were teased about changes in their physical appearance such as sudden weight gain
	More information: Participants felt doctors and other transplant recipients should impart broader knowledge about the technical, medical, and experiential

Study	Tong 2011[224]
	aspects of transplantation
	Specific information needs: Two older participants said information about alcohol, drugs, and substance use would be important and relevant particularly for the older adolescents.
	Impact of treatment on lifestyle: Participants were advised by their doctors to refrain from playing contact sports and felt some disappointment about being unable to play sports.
	Format of information: Some suggested a booklet to contain information and explain what's going on.
	Information sources: Patients appreciated the opportunities to connect with other transplant patients through formal events such kidney camps, Transplant Games, or informally during visits to the hospital. Learning what to expect before having a transplant provided participants much needed reassurance.
	Support: Being able to form and maintain friendships with school peers or colleagues was very important to the participants. Having friends who were understanding, supportive and caring promoted confidence, positive coping behaviours and social adjustment among the participants.
	Sources of support: Adolescents across all ages valued the support they received from their parents.
	Content of information: Participants mentioned that information was important to equip and prepare other patients their own age for what would happen during and after the transplant.
Limitations and applicability of evidence	No notable limitations. Study conducted in Australia.

Study	Walker 2016[240]
Aim	To describe patient and caregiver perspectives of the economic considerations that influence dialysis modality choice, and elicit policy-relevant recommendations.
Population	52 participants (43 patients; 9 care- givers) who ranged in age between 22 and 79yrs. Participants were “pre-dialysis” and had received formal pre-dialysis education regarding renal replacement therapy modalities; or had commenced dialysis within the previous 12

Study	Walker 2016[240]
	months; or were a family member or caregiver.
Setting	Australia
Study design	Qualitative; interviews
Methods and analysis	Semi-structured interviews with pre-dialysis or dialysis patients and their caregivers, at three hospitals in New Zealand. Interview transcripts were analysed thematically.
Findings	Lack of information: Pre-dialysis patients lacked certainty about the upcoming costs of dialysis. They described a lack of explicit information about additional expenditure and financial support which meant they were not aware of any out-of-pocket costs or how to plan for them. Some home dialysis participants felt that information regarding the additional home electricity costs had purposefully not been shared with them and expressed betrayal by this lack of disclosure, while others were unaware that there would be additional costs.
	Financial barrier: Participants found it difficult to access financial support and navigate social support systems. Many felt disempowered by the system, and worn down by the need to continually justify their requirement for assistance. For some, the time and expense that was required to gather all the documentation to apply for assistance resulted in them not completing this process and not receiving the assistance to which they were entitled.
	Source of support: Some participants appreciated their employer's flexibility and support to allow them to commit to home dialysis training.
Limitations and applicability of evidence	No notable limitations. Study conducted in Australia.

Study	Welch 2014[244]
Aim	To identify and describe the needs, concerns, strategies, and advice of family caregivers of persons on daily home haemodialysis.
Population	21 carers of HD patients, aged 27-78 yrs, 5 male, 16 female. 21 unpaid adult caregivers defined as family members or significant others who assumed primary responsibility for caregiving. Five individuals were "past" caregivers of patients who had returned to outpatient haemodialysis treatments. Patients had been receiving daily home haemodialysis on average for over 2 years.
Setting	USA
Study design	Qualitative; interviews
Methods and analysis	Semi-structured interviews took approximately 60 min to complete. Telephone interviews were audio-recorded and professionally transcribed verbatim into Word documents and reviewed by one member of the team for accuracy. Interview transcripts were entered into HyperRESEARCH TM software, and qualitative content analysis was used to code the data.

Study	Welch 2014[244]
Findings	Support: The need for 24-hr availability of a nurse or physician was extremely important.
	Format of support: Caregivers indicated that support groups were helpful.
	Source of education: The majority of caregivers had extraordinary praise for the training and support they received from the nurses at the home dialysis unit. These nurses provided one-to-one individual training on an outpatient basis.
	Support for carers; Several past caregivers indicated a need for caregiver screening by dialysis staff prior to initiation of daily home haemodialysis.
Limitations and applicability of evidence	No notable limitations. Study conducted in the USA.

Study	Wells 2013[245]
Aim	To explore the lived experiences of adolescents with ERF undergoing dialysis and identify potential barriers to effective treatment
Population	10 patients, aged 13 - 17yrs (4 males, 6 females). Five participants were undergoing HD (mean age=16) and five on PD (mean age=15). All children lived with at least one parent.
Setting	UK
Study design	Qualitative; interviews
Methods and analysis	Qualitative photo elicitation interviews were conducted to explore the significance of the images and the young person's experiences. Interviews were analysed using descriptive thematic analysis.
Findings	Barriers to good care: Some felt healthcare professionals underestimated their ability to accept and cope with their illness.
	Sources of support: Parents supported young people both emotionally and practically. Relationships with family, friends and healthcare staff played an important role in the young people's lives.
	Facilitators of good care : Hospital staff also played a key role, including teachers, youth workers and nurses. Being able to trust healthcare staff was valued highly.
Limitations and	No notable limitations.

Study	Wells 2013[245]
applicability of evidence	

Study	Wilson 2012[252]
Aim	To examine patients' perceptions of the delivery and format of a kidney transplant education program in a clinical setting.
Population	19 patients, aged 30 - 50+, most were 50+ (79%), transplant recipients and transplant listed. 7 - transplant recipients, 7 - listed for tx, 5 - in evaluation for tx
Setting	USA
Study design	Qualitative; focus groups
Methods and analysis	Participants were invited after recruitment to discuss their experience with the educational component of their transplant evaluation. Patients were invited to participate in one of the following focus groups - 1) transplant recipients, 2) listed - patients who are on the waiting list for DDKT and 3) in evaluation - patients who are in the evaluation stage and waiting to be listed. The focus group discussions were audiotaped and then transcribed verbatim.
Findings	Education format: The 'group format' allowed participants to learn from others' questions.
	Education format: Most thought the program should stay as a '1 day' program. Some suggested a shorter more condensed program and others the same length or longer with more detail
	Further support: Some suggested using a brief 'follow up' meeting as patients may have questions after they go home, read the handouts, watch the video and search the internet etc
	Overwhelming information: Most did not remember the content of the presentation, except after the focus group facilitator listed the content of the presentation slides. Most described the program as overwhelming, technical, long, rushed and overloaded.
	Specific information needs: Participants were at various levels of knowledge about kidney transplant. Some indicated their need for statistics but others felt they didn't need such information.
	Need for more information: Some transplant listed patients expressed the need for more basic information such as the functions of the kidneys etc and information about living donor kidney transplants and the exchange program.
	Lack of information:

Study	Wilson 2012[252]
	Most patients in evaluation felt the program did not adequately address how to approach family members and others about living donor kidney transplant.
	Need for specific information: Some transplant evaluation patients needed more information about the actual surgery and related risks for living donors and recipients
	Information format : Participants stated that the printed materials and handouts they received during the education program were useful to refer to afterwards.
	Information sources: Most were in favour of using an online video on kidney transplant for patients and family to watch before the education program to help them get ready for the program and use after as a reference. The combination of both a video and in-person education program would be most beneficial
	Format of information: Most prefer having a copy of the slides before the education program. Most thought materials given beforehand should include information about the types of kidney donation so patients and families can consider the option of LDKT early
	Information sources: The patient advocate component was useful, informative and inspirational
	Need for specific information: Some indicated the need for specific education for companions and potential donors.
	Provision of information: Some listed patients thought information about the exchange program should be sent to the potential donor rather than the patient, and to donors who are told they're not a match
	Support from staff: Most thought the staff were approachable and were willing to answer their questions, and that the program staff thoroughly explained everything.
	Support: Bringing a companion to the education program provided moral support and assistance in remembering important information, asking questions, keeping things filed and organised and keeping the patient on track with medications, diet, follow-up visits etc.
	Lack of education: Most patients in evaluation had lack of knowledge and overwhelming concern about the risks to the donor.
	Education layout: Some suggested rearranging the education program content to allow more time in the group session for more detailed information and discussion.

Study	Wilson 2012[252]
	Importance of support: Most stressed the importance of encouraging patients to bring a companion or more with them to the education program
	Information format: Some suggested the use of an agenda and a formal invitation letter for the education program, allowing patients and their companions to know what to expect. The invitation letter should encourage the patient to bring a companion and instruct patients and family members to review the materials and video and prepare questions
	Education format: Some transplant evaluation patients suggested covering diet, insurance and financial issues only in individual meetings, allowing more time in the group education program for more detailed discussion
	Education format: Some listed patients suggested a short preliminary meeting to prepare for the education day and give time to think about questions
Limitations and applicability of evidence	Moderate limitations due to data collection and ethics. Study conducted in the USA.

Study	Yngman-Uhlin 2016[261]
Aim	To explore the experiences of haemodialysis patients who are waiting for a kidney transplant.
Population	8 patients, 7 males, 1 female, patients in haemodialysis treatment. Patients with haemodialysis for at least six months with experiences of waiting for kidney transplantation during that time.
Setting	Sweden
Study design	Qualitative; interviews
Methods and analysis	Interviews performed by the second author starting with one opened-ended question: ‘Can you describe what it is like to wait for a kidney transplant?’ follow-up and clarification questions were asked, such as ‘Could you tell me more about?’ The audiotaped interviews were verbally transcribed by the second author. Transcripts were analysed by means of a descriptive content analysis method.
Findings	Source of information: The patients also searched for information about national transplantation outcomes on the Internet by themselves, and this made them feel secure about the success rate.
	Content of information: Patients expressed frustration about silence from the transplantation unit and the lack of information regarding how long they had to wait and how patients were given priority.

Study	**Yngman-Uhlin 2016[261]**
	Support: The informants emphasised the importance of health care personnel being available and being good listeners.
	Support benefits: Informants described that being continually informed by the physician and surgeon reduced their anxiety about transplantation.
Limitations and applicability of evidence	No notable limitations. Study conducted in Sweden.

Appendix E: Excluded studies

E.1 Excluded qualitative studies

Table 30: Studies excluded from the qualitative review

Reference	Reason for exclusion
Aasen 2012[2]	No relevant themes identified
Aasen 2015[1]	No relevant themes identified
Ahsanuddin 2015[5]	Incorrect study design
Al-Arabi 2006[6]	No relevant themes identified
Allen 2011[8]	No relevant themes identified
Amerena 2009[9]	No relevant themes identified
Anderson 2008[11]	No relevant themes identified
Anderson 2009[13]	No relevant themes identified
Anderson 2012[12]	No relevant themes identified
Anderson 2013[10]	No relevant themes identified
Asgari 2011[14]	No relevant themes identified
Auslander 2001[15]	Incorrect study design
Axelsson 2012[17]	No relevant themes identified
Axelsson 2015[16]	Incorrect study population (relatives of deceased ESRD patients)
Badzek 1998[18]	Incorrect study design
Bailey 2016[19]	No relevant themes identified
Baillie 2013[20]	No relevant themes identified
Bandiziol 2008[22]	Incorrect study population
Bass 1999[24]	No relevant themes identified
Bergjan 2016[25]	No relevant themes identified
Blogg 2008[27]	No relevant themes identified
Borzou 2014[29]	No relevant themes identified
Braj 1999[31]	No relevant themes identified
Breckenridge 1995[32]	No relevant themes identified
Breckenridge 1997[34]	No relevant themes identified
Breckenridge 1997[33]	No relevant themes identified
Bristowe 2015[35]	No relevant themes identified
Buldukoglu 2005[37]	No relevant themes identified
Burnette 2009[38]	No relevant themes identified
Calvey 2011[40]	No relevant themes identified
Calvin 2000[41]	No relevant themes identified
Calvin 2004[42]	No relevant themes identified
Campos 2007[43]	Not in English
Cases 2011[44]	No relevant themes identified
Chong 2016[47]	No relevant themes identified
Cohen 1996[49]	No relevant themes identified
Conley 1981[50]	Incorrect study design
Coombs 1993[51]	Incorrect study design

Reference	Reason for exclusion
Costello 2014[52]	Incorrect study population
Curtin 2001[53]	No relevant themes identified
da Silva Alencastro 2013[55]	No relevant themes identified
Da Silva-Gane 2014[54]	No relevant themes identified
Davison 2015[56]	No relevant themes identified
de Guzman 2009[58]	No relevant themes identified
de Rosenroll 2013[59]	No relevant themes identified
Ekelund 2010[61]	No relevant themes identified
Elliott 2012[62]	No relevant themes identified
Erlang 2015[63]	No relevant themes identified
Feldman 2013[64]	No relevant themes identified
Franklin 2003[65]	No relevant themes identified
Ganji 2014[66]	No relevant themes identified
Ghadami 2012[67]	No relevant themes identified
Ghahramani 2014[68]	No relevant themes identified
Ghahramani 2014[69]	Incorrect study design
Gibbons 2017[70]	No relevant themes identified
Giles 2003[71]	No relevant themes identified
Giles 2005[72]	No relevant themes identified
Gill 2012[73]	No relevant themes identified
Gill 2014[74]	No relevant themes identified
Glidewell 2013[75]	No relevant themes identified
Godbold 2013[76]	Incorrect study population
Goldade 2011[78]	Incorrect study population (CKD stages 2 - 5)
Gordon 2001[80]	No relevant themes identified
Gordon 2001[79]	No relevant themes identified
Gordon 2009[81]	No relevant themes identified
Gray 1988[82]	No relevant themes identified
Greer 2012[84]	No relevant themes identified
Greer 2015[83]	No relevant themes identified
Griffin 1995[85]	No relevant themes identified
Grijpma 2016[86]	Incorrect study design
Griva 2013[87]	No relevant themes identified
Guerra-Guerrerro 2014[89]	No relevant themes identified
Gullick 2017[90]	No relevant themes identified
Gurklis 1995[91]	No relevant themes identified
Hagren 2001[92]	No relevant themes identified
Harrington 2016[95]	No relevant themes identified
Haspeslagh 2013[97]	No relevant themes identified
Hathaway 1990[98]	No relevant themes identified
Herlin 2010[101]	No relevant themes identified
Horigan 2013[102]	No relevant themes identified
Iles-Smith 2005[104]	No relevant themes identified
Ismail 2013[105]	No relevant themes identified
Johnston 2012[108]	No relevant themes identified

Reference	Reason for exclusion
Kazley 2014[111]	No relevant themes identified
Kazley 2015[110]	No relevant themes identified
Kierans 2005[112]	No relevant themes identified
King 1998[113]	Incorrect study design
Klassen 2002[114]	No relevant themes identified
Krespi 2004[116]	No relevant themes identified
Ladin 2017[117]	No relevant themes identified
Lam 2014[119]	No relevant themes identified
Landreneau 2004[122]	No relevant themes identified
Landreneau 2006[120]	No relevant themes identified
Landreneau 2007[121]	No relevant themes identified
Lazenby 2017[124]	No relevant themes identified
Ledebo 2008[125]	Incorrect study design
Lee 2007[128]	No relevant themes identified
Lewis 2010[130]	Incorrect study design
Lin 2015[131]	No relevant themes identified
Lindqvist 2000[133]	No relevant themes identified
Lindsay 2014[134]	No relevant themes identified
Louis 1997[136]	No relevant themes identified
Lovink 2015[138]	No relevant themes identified
Luk 2006[141]	No relevant themes identified
Maguire 2011[142]	No relevant themes identified
Majeed-Ariss 2017[143]	No relevant themes identified
Manias 2007[144]	Incorrect study population
McCarthy 2009[145]	No relevant themes identified
McCarthy 2010[146]	No relevant themes identified
McDonald 2015[147]	Incorrect study population
Medway 2015[148]	No relevant themes identified
Monaro 2014[150]	No relevant themes identified
Moran 2009[154]	No relevant themes identified
Moran 2009[153]	No relevant themes identified
Morton 2010[155]	No relevant themes identified
Moustakas 2015[157]	No relevant themes identified
Murray 1999[158]	No relevant themes identified
Murray 2016[159]	No relevant themes identified
Nakamura-Taira 2013[160]	No relevant themes identified
Ndlovu 1998[161]	No relevant themes identified
Noble 2000[164]	No relevant themes identified
Noble 2013[163]	No relevant themes identified
O'Grady 2010[165]	Incorrect study design
O'Hare 2016[166]	No relevant themes identified
O'Neill 1991[167]	Incorrect study design
Ouellette 2009[170]	No relevant themes identified
Piccoli 2010[171]	Incorrect study population
Piyasut 2010[172]	No relevant themes identified

Reference	Reason for exclusion
Polaschek 2006[174]	No relevant themes identified
Polaschek 2007[176]	No relevant themes identified
Polaschek 2007[175]	No relevant themes identified
Poursanidou 2003[177]	No relevant themes identified
Pradel 2003[178]	No relevant themes identified
Prakash 2013[179]	Incorrect study design
Prieto 2011[180]	Not in English
Pungchompoo 2013[181]	No relevant themes identified
Rajkomar 2014[182]	No relevant themes identified
Rantanen 2008[183]	Incorrect study design
Rich 2017[184]	No relevant themes identified
Richard 2009[185]	No relevant themes identified
Richard 2010[186]	No relevant themes identified
Rix 2013[188]	No relevant themes identified
Rosenthal 2016[190]	No relevant themes identified
Rubin 1997[191]	Incorrect study design
Ruppar 2009[192]	No relevant themes identified
Russ 2007[193]	No relevant themes identified
Russell 2003[194]	No relevant themes identified
Sadala 2010[197]	No relevant themes identified
Sadala 2012[196]	No relevant themes identified
Schipper 2014[200]	No relevant themes identified
Schober 2017[202]	No relevant themes identified
Seah 2015[204]	No relevant themes identified
See 2014[205]	No relevant themes identified
Shahgholian 2015[206]	No relevant themes identified
Sheu 2012[207]	No relevant themes identified
Shih 1998[208]	No relevant themes identified
Shubayra 2015[209]	No relevant themes identified
Sloan 1996[211]	No relevant themes identified
Spigner 2011[214]	No relevant themes identified
Sturesson 2014[215]	No relevant themes identified
Tam-Tham 2015[217]	No relevant themes identified
Taylor 2016[218]	No relevant themes identified
Teruel 2015[219]	Not in English
Tong 2009[226]	Incorrect study population
Tong 2011[222]	No relevant themes identified
Tong 2013[225]	No relevant themes identified
Tong 2015[221]	No relevant themes identified
Tonkin-Crine 2015[227]	No relevant themes identified
Tonkin-Crine 2015[228]	No relevant themes identified
Traino 2014[229]	No relevant themes identified
Trivedi 2016[230]	No relevant themes identified
Urstad 2012[232]	No relevant themes identified
Velez 2006[233]	No relevant themes identified

Reference	Reason for exclusion
Wachterman 2015[235]	No relevant themes identified
Wadd 2014[236]	No relevant themes identified
Walker 2012[237]	No relevant themes identified
Walker 2012[238]	No relevant themes identified
Wanicha 2016[241]	No relevant themes identified
Waterman 2006[242]	No relevant themes identified
Weichler 1993[243]	Incorrect study design
Wiederhold 2011[246]	No relevant themes identified
Wilkinson 2014[248]	No relevant themes identified
Wilkinson 2016[247]	No relevant themes identified
Williams 2012[250]	Incorrect study population
Williams 2016[249]	No relevant themes identified
Wilson 2015[251]	No relevant themes identified
Wright Nunes 2015[256]	No relevant themes identified
Yilmaz 2010[259]	No relevant themes identified
Yngman-Uhlin 2010[262]	No relevant themes identified
Yodchai 2011[263]	No relevant themes identified
Yu 2013[264]	No relevant themes identified
Ziolkowski 2016[265]	No relevant themes identified

Table 31: Studies identified but not included in the qualitative review due to saturation being reached

Reference
Aasen 2012[3]
Aghakhani 2014[4]
Al Nazly 2013[7]
Baillie 2015[21]
Bonner 2012[28]
Chenitz 2014[45]
Chiaranai 2016[46]
Goff 2015[77]
Hagren 2005[93]
Hanson 2017[94]
Jablonski 2007[106]
Lawrence 2013[123]
Lederer 2015[126]
Lovell 2017[137]
Luk 2004[140]
Moran 2011[152]
Moran 2016[151]
Noble 2017[162]
Rix 2014[187]
Romyn 2015[189]
Sauve 2016[199]

Reference
Sciberras 2016[203]
Sieverdes 2015[210]
Subramanian 2017[216]
Thomas 2016[220]
Tweed 2005[231]
Vestman 2014[234]
Walker 2016[239]
Wilson 1994[253]
Winterbottom 2014[254]
Wong 2009[255]
Xi 2011[257]
Xi 2013[258]
Yilmaz 2011[260]