The experiences of adults living with hemodialysis: a thematic synthesis

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Abstract

Background and objectives

In-center dialysis patients spend significant amounts of time on the dialysis unit; additionally managing ESKD affects many aspects of life outside the dialysis unit. To improve the care provided to patients requiring hemodialysis their experiences and beliefs regarding treatment must be understood. This systematic review aimed to synthesise the experiences of patients receiving in-center hemodialysis.

Design, setting, participants, and measurements

Embase, MEDLINE, CINAHL and PsychINFO, Google scholar and reference lists were searched for primary qualitative studies exploring the experiences of adult patients receiving treatment with in-center hemodialysis. A thematic synthesis was conducted.

Results

17 studies involving 576 patients were included in the synthesis. 4 analytical themes were developed. The first theme "a new dialysis dependent self" describes the changes in identity and perceptions of self that could result from dialysis dependence. The second theme, "a restricted life", describes the physical and emotional constraints patients described as a consequence of their dependence. Some patients reported strategies that allowed them to regain a sense of optimism and influence over the future and these contributed to the third theme, "regaining control". The first three themes describe a potential for change through acceptance, adaption and re-gaining a sense of control. The final theme, "relationships with health professionals" describes the importance of these relationships for in-center patients and their influence on perceptions of power and

support. These relationships are seen to influence the other three themes through information sharing, continuity and personalized support.

Conclusions

This synthesis has resulted in a framework that can be utilized to consider interventions to improve patients' experiences of in-center hemodialysis care. Focusing on interventions that are incorporated into the established relationships patients have with their health care professionals may enable patients' to progress towards a sense of control and improve satisfaction with care.

Introduction

Globally the incidence of end stage kidney disease and the numbers requiring renal replacement therapy are increasing[1]. In the United States the majority are treated with in-center hemodialysis[2]. Patients receiving hemodialysis have a higher mortality rate and reduced quality of life compared with the general population[2, 3]. While there has been some reported improvement in survival in recent years[2, 4] studies have shown no improvement in patient reported quality of life[3]. Deficiencies in satisfaction with hemodialysis care have also been demonstrated[5-7]. Satisfaction with care is unrelated to many of the clinical outcomes prioritised by physicians and there is increasing evidence that outcomes commonly used in research and measured by registries may not be of importance to patients[6-9]. There is growing interest in measuring outcomes that are of interest to patients through patient reported outcome and experience measures. Studies utilising these tools report measures of quality of life, ratings of satisfaction with care or severity of chosen symptoms; however these attempts to quantify the experiences of

patients do not provide the depth of insight into patients' experiences that can be gained through qualitative methods.

Previous syntheses of qualitative research have explored the perspectives of patients with CKD on particular issues (including end-of-life care[10], vascular access[11] and dietary restrictions[12]) or specific patient groups such as peritoneal dialysis patients[13]. While most patients requiring dialysis treatment receive in-center hemodialysis no previous qualitative synthesis has focussed on their experiences. Through synthesising studies we aim to develop a comprehensive understanding of the influence in-center dialysis dependence has on patients' lives. This knowledge will better inform strategies to provide patient centered care and patient valued treatment and research outcomes.

Materials and Methods

This study is reported following the Enhancing transparency in Reporting the synthesis of Qualitative research (ENTREQ) guidance[14].

Selection criteria

Primary qualitative studies exploring the experiences of adults aged 18 or older receiving in-center hemodialysis were eligible for inclusion. Studies including patients receiving other forms of renal replacement, home hemodialysis exclusively, or the views of health professionals were excluded. As the views of CKD patients and their carers may differ[15] we excluded studies in which the views of carers were sought. To ensure relevance to current care the search was limited to papers published in the past 20 years. Articles not written in English or for which the full text was not available were also excluded.

Literature Search

Medical subject heading (MeSH) terms and text words for hemodialysis and chronic kidney disease were combined with terms found to be effective in identifying qualitative studies[16]. The initial search findings were combined with further terms including quality of life, patient satisfaction, patient experience and patient expectations to identify relevant studies (Appendix 1). Searches were performed in Embase, MEDLINE, CINAHL and PsychINFO in January 2015. Google Scholar and reference lists of relevant papers and reviews were also searched. Titles and abstracts were screened by one reviewer (CR), and full texts of potentially relevant studies were obtained and assessed against the inclusion and exclusion criteria by two reviewers (CR and an independent reviewer).

Quality Appraisal

All papers were assessed against the Critical Appraisal Skills Programme (CASP) qualitative research checklist[17]. There is little consensus on which approach to appraising qualitative research offers the best validity[18], however the CASP checklist is a recognised tool and has been used previously in systematic reviews of qualitative research[19, 20]. Two authors (CR and JS) independently appraised included studies using the CASP checklist and disagreements were resolved through discussion. All studies satisfied the initial two screening questions and were considered relevant to the review. As there are currently no accepted methods for the exclusion of studies based on their appraisal score all studies were included in the synthesis[20, 21].

Synthesis of Findings

This synthesis was approached from a critical realist perspective, which accepts the existence of an independent social world that can only be understood through the interpretations of both research participants and researchers[22]. Thematic synthesis is not restricted in its use to a particular methodology and is an established method which aims to preserve a transparent link between primary studies and conclusions; it was therefore considered an appropriate method of synthesising qualitative research for this review[21, 23]. All text within the results sections of the papers were coded line-by-line by CR, coding was then reviewed by JS. Line by line coding allowed the translation of findings from one study to another[21]. Codes were developed to represent new concepts until all the data from the included studies had been coded. The final codes were then examined for similarities and grouped into 14 descriptive themes (Table 3) [21]. These were analysed to consider the effects of dialysis dependence on the participants' lives to form analytical themes. Draft descriptive and analytical themes were developed by CR and presented to all members of the research team. Through discussion the descriptive and analytical themes were developed and finalised. Analysis was managed using NVivo version 10.

Results

Literature Search

Our search yielded 1369 articles from which 17 studies[24-40] involving 576 patients were included in the synthesis (Figure 1). The characteristics of included studies are shown in Table 1. The studies were published between 1998 and 2015 and included patients between 19 and 93 years. Studies were conducted in Europe (n=9), North America (n=5) and Australasia (n=2) and Asia (n=1).

Quality Appraisal

Two papers satisfied all 10 items on the CASP checklist[17] (Table 2). One paper satisfied only 5 items, however results were well illustrated through patient narratives. Consideration of the relationship between the researcher and participants was the least reported of the domains on the checklist; consequently authors may not have considered this potential source of bias. Most studies reported a sufficiently clear and rigorous approach to data analysis, however in 4 studies insufficient information was reported. The value of the research was clearly reported in all studies.

Synthesis

Analysis resulted in 14 descriptive themes, which contributed to 4 analytical themes: a new dialysis dependent self, a restricted life, regaining control and relationships with health professionals. The descriptive themes identified in each study are shown in Table 4. Selections of quotes to illustrate each theme are given in Table 5.

A new dialysis dependent self

Participants described how dialysis dependence had caused changes in many aspects of life, which consequently led to changes in their perception of self.

Changing identity

When commencing hemodialysis some participants struggled with feelings of vulnerability and their dependency on both dialysis treatment and caregivers[24, 26, 28-32, 35-40]. The "assembly line"[26] nature of dialysis and lack of interest shown by dialysis unit staff could also result in a loss of identity[24, 26, 28, 35]. Interference with earlier roles in society and social networks could also affect their personal identity. Those required to

give up employment reported this affected their sense of self as reliable and able to provide for their families[29, 35, 40]. Additionally dialysis was seen to affect the physical self through the creation of vascular access and other changes in appearance [25, 29, 36, 37, 39].

Impact on family roles and relationships

Participants valued family support but some reported that their role or relationships within the family had changed as a consequence of their dialysis dependence. Participants expressed frustration as dialysis resulted in a lack of time, energy or required relocation which resulted in them being unable to care for family members or carry out family duties[27-29, 35]. Some participants were now dependent on family for care or assistance and worried that they had become a burden to them[28-30, 37, 38]. Participants who thought their dialysis dependence had restricted their families' activities, such as holidays, also reported guilt [29, 30, 35].

Changing social world

Dietary and fluid restrictions, time spent on dialysis, and symptoms such as fatigue affected participants' abilities to engage in previously enjoyed social activities [28, 29, 32, 33, 35, 36, 39, 40]. Some participants were reluctant to discuss dialysis dependence with others or perceived they lacked understanding and compassion [25, 27, 31, 32]. Consequently this resulted in difficulties maintaining social connections and friendships. However, the dialysis unit could also provide a new social framework through the development of friendships with staff and patients [26, 28-30, 34, 35, 38].

Changing future

Participants explained that with dialysis commencement they had lost ambitions for the future such as enjoying retirement and travelling [28, 29, 37, 39]. With a diagnosis of end stage kidney disease, and consequent dependence on dialysis, patients are confronted with their own mortality [28-32, 35, 37, 39]. This may be reinforced by the deaths of other patients on the dialysis unit[30, 31, 39]. The future became uncertain, as they feared complications or premature death[28-31, 34, 35, 39]. Those waiting for a transplant also had to cope with the uncertainty of when or whether they would receive a kidney[31, 32, 34]. Many participants described feeling unable to plan for the future and consequently chose to "live in the moment"[28, 30-32, 36].

A restricted life

Dependence on dialysis presented new physical and emotional challenges to living life as they would choose.

Constraints on time and diet

The scheduling and time required for dialysis treatment restricts opportunities for employment, holidays and social activities. Additionally patients have fluid and dietary restrictions to which they are expected to adhere. These restrictions were often cited as sources of distress and adversely affected quality of life[24, 25, 28-31, 33, 35-37, 39, 40]. Participants described weighing up adherence to these restrictions against effects on their quality of life[28, 30, 35-37, 39].

The impact of symptoms

Some participants reported physical symptoms such as fatigue and pain[24, 25, 27-30, 32-37, 39, 40], or emotional symptoms including depression, anger, and isolation [24, 27-30, 32-40]. Physical symptoms such as fatigue were seen to further restrict the opportunities and time available to participate in desired activities[21,24,29,30,33] and were reported to have deleterious effects on mental well being [23,24,29,33]. Many symptoms were seen to result from or be exacerbated by dialysis, and some expressed anxiety about the deterioration in health they experienced despite on-going dialysis treatment [30, 31, 35, 39].

Loss of choice and freedom

Some participants associated the need for dialysis with feelings of incarceration and powerlessness[24, 25, 28, 29, 32, 34-36, 39]. They reported a loss of freedom to live life as they desired. Maintaining the dialysis regimen became a job that they had no choice but to do[28, 31, 33, 34, 36, 39, 40]. Participants described losing time, not only to having treatment, but also to travelling, waiting and recovering from their treatment[28-35, 37, 39, 40].

Regaining control

Some participants described how with time they had regained a sense of optimism and influence over the future.

Gaining own expertise

With time participants developed their own knowledge and abilities and this was seen as important for regaining control[26, 28-31, 34, 36]. For some this knowledge came through testing boundaries set by health care professionals[24, 26, 27], while others reported health care professionals facilitated their personal abilities or knowledge acquisition[30, 33].

Participants stressed the importance of their expertise being acknowledged by professionals to allow shared decision making[24, 26-28, 32, 34, 38-40]. Making their own treatment decisions[26, 28, 32] or developing confidence in staff so decisions could be entrusted to them, were seen as an important ways in which control could be gained[28].

Accepting dialysis dependence

A process of acceptance of dialysis dependence was a common theme across studies. Participants reported differing routes to acceptance; for some it was resignation that there was no other option to stay alive[27, 28, 30, 36, 38, 39]; whereas some chose to see the positives and viewed dialysis as a "gift"[25] providing life[25, 29-31, 35, 38, 40]. Support from family, friends and professionals was seen as important in coming to this acceptance[30, 37, 40]. Some were able to find optimism and hope for the future and this was seen to facilitate acceptance[28, 31, 35]. For many hope was related to future transplantation[29, 30, 32, 34-37].

Accommodating dialysis

Some participants found they were able to adjust to life on dialysis. They reported the importance of adapting other activities around dialysis and making the most of the time when not at the dialysis unit [21,27,28,30,32,34,35]. Others felt it was important to utilise the time spent on dialysis for activities such as study[30, 35]. The process of adjustment required participants to change their personal expectations[30, 31, 35, 38, 39] and was seen as an on-going process as new problems and changes in health were encountered[30, 31].

Relationships with health professionals

This final theme describes the importance of relationships with health professionals.

Information sharing

Some participants wanted more information from their healthcare providers[24, 26, 27, 29, 30, 33, 36]. They described feeling that information was not given freely, or was kept from them[26, 27, 38]. This contributed to uncertainty and conflicted with their attempts to obtain control[24, 26-28, 36, 39]. Some participants were reluctant to ask questions or worried that this would be seen as complaining[24, 27, 28, 40]. As experts in their life circumstances, participants wanted to be listened to and involved in decisions about their care[24, 26, 28, 30].

Building relationships with health professionals

Due to the frequency of contact with professionals on the dialysis unit participants built relationships with staff, gaining a source of support[28, 30, 38]. Patients expressed that it was important to be seen as a whole person, not just a patient[24, 26, 28, 30, 35], and valued being cared for by staff they knew well [30, 32, 34]. Developing personal relationships also promoted confidence in care, reducing anxiety when attending dialysis[28, 34, 35].

The balance of power within relationships

Some participants described an asymmetry of power between professionals and patients when decisions regarding care were made[24, 26-28, 30, 39]. Some described feeling like passive recipients of care due to a lack of dialogue with professionals, deficiencies in understanding, or a sense of powerlessness[24, 27, 28, 30, 40].

Seeking expertise

Health professionals were valued for their expertise and skills, both technical and interpersonal[30, 32-36]. Consequently participants described anxiety when new or

inexperienced staff were encountered[30, 32, 34]. Ready access to the expertise of specific professionals, such as doctors, was also important[30, 33].

Summation of these themes

The first three analytical themes can be seen to describe a journey of change through patients' initial realisation of their new and altered self, encountering the challenges to lifestyle that dialysis presents, followed by a potential acceptance and adaptation to regain a sense of control [41]. This process of adjustment evolves over time in response to new health challenges and changes in life circumstances. Consequently an individual's transition along this pathway is likely to be subject to fluctuation over time. The fourth theme of 'relationships with health care professionals' can be seen to influence (either positively or negatively) the other three themes and therefore the potential for change. The influence of these relationships is therefore significant when we consider how health professionals can make meaningful changes to care, or cause harm through a lack of attention to their influences on these other areas. These key themes therefore provide a new framework that can be used to focus strategies for improvement in care (Figure 2).

Discussion

Physician led research has historically focused on biomedical measures of the dialysis process, and prioritised blood test results or mortality as important outcomes. In contrast, the current framework has been developed from research exploring patients' experiences of dialysis dependence; as such it provides an opportunity to consider research and clinical outcomes that are likely to be of importance to patients. While dialysis-requiring ESKD is recognised to be associated with increased mortality and changes in other clinical parameters, relatively less attention has been paid to the

psychosocial impacts of starting dialysis[42-44]. The need for further research into the psychosocial impacts of CKD was also highlighted in a study of patients' priorities for health research[9].

Maintenance of roles in society and family have been reported as critical for maintaining hope in patients with ESKD and patients have deemed the provision of information on how to maintain these roles as a more important focus for care than its clinical effectiveness[45]. Greater levels of social support have also been associated with improved quality of life, satisfaction with care and rates of hospitalisation[46].

The restrictions placed on patients as a result of their dialysis dependence have significant impacts on their lives and patients may be willing to accept a reduced life expectancy in exchange for fewer restrictions[8]. Interventions that minimise the impact of these restrictions should therefore form an important part of care. Flexible scheduling of treatment and access to holiday dialysis may positively impact on patients' ability to live their lives around treatment[47]. The symptoms that patients experience are also seen to restrict their lives. These symptoms may be under recognised by health care professionals[48] and have been shown in other studies to be associated with reduced quality of life and increased mortality[49, 50]. Improved recognition of these symptoms may consequently lead to improved quality of life, however, there is limited evidence regarding effective strategies for managing such symptoms and further research is warranted[51].

This synthesis also highlights the importance that patients place on their relationships with health professionals. This requires professionals to be aware of the need for many patients to foster relationships that enable on-going information provision, communication and support. A perceived lack of information sharing has also been linked with reduced satisfaction with care [7, 52,53]. In common with other studies this synthesis highlights problems with information sharing between health professionals and patients with CKD[6, 7, 52, 54].

Gaining knowledge is facilitated by effective communication with health professionals and was seen by some as fundamental to maintaining a sense of control. For several participants developing self-care abilities was also an important aspect of adjustment and resulted in a sense of control over their dialysis dependence. In other health care settings obtaining a sense of control has been linked to improved outcomes, the adoption of self-care and health promoting activities[55-57]. While adequate information provision and promotion of self-care may be important to encourage control for some patients, further research into other interventions that promote control in the hemodialysis population are needed.

The themes reported in this synthesis were well represented across the studies. There were no clear differences between included age ranges, geographical area or time of publication. The results of this synthesis share similarities with two previous studies reporting the experience of patients living with CKD and peritoneal dialysis[13, 58]. Both studies also emphasized the importance of realization, acceptance and adaptation to

gaining control[13, 58]. However building relationships with health professionals did not appear to be of such importance in these studies. Patients living with pre-dialysis CKD or other forms of renal replacement therapy are likely to spend less time with, and have reduced dependence on health professionals. The nature and influence of these relationships may consequently be different and confer more significance for those on in-center hemodialysis.

Limitations

Most of the studies included in this synthesis did not report ethnicity, socio-economic groups or educational level. Additionally we excluded studies that were not published in English. As we excluded studies that included participants on other forms of renal replacement therapy the views of some in-center patients have been excluded from this review, additionally due to the difficulties in searching for qualitative studies the search strategy may not have identified all relevant studies, however the themes identified were well represented across included studies supporting the validity of the findings.

Conclusion

This synthesis of patients' experiences of living with hemodialysis has resulted in a framework that can be utilized to consider interventions to improve patients' experiences of care. The framework suggests that focusing on interventions that are incorporated into the established relationships patients have with their health care professionals may enable patients' to progress towards a sense of control and improve satisfaction with care.

Disclosures

None

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Figure 1. Results of search strategy and identification of included studies

Figure 2. Framework of the experiences of adults living with hemodialysis

Table 1. Included Studies

Study	Country	Year	Number	Age	Gender	Duration of dialysis	Population	Data Collection	Method
Aasen et al.[24]	Norway	2012	11	>70	4 F 7 M	4 1 year or less; 3 1-2 years; 4 4-6 years	5 hospital units	Interviews with open ended questions	Critical discourse analysis
Al-Arabi[25]	USA	2005	80	>18	Not reported	Not reported	Community based out-patient dialysis center	Semi-structured interviews	Naturalistic inquiry methods
Allen et al.[26]	Canada	2011	7	38-63	3F 4M	Not reported	2 hospital units	Field observation, interviews and focus groups	Participatory action research
Anderson et al.[27] *	Australia	2012	241	> 20	116 F 125M	Not reported	9 hospital renal wards and 17	Semi-structured interviews	Thematic analysis

							associated dialysis centers		
Axelsson et al.[28]	Sweden	2012	8	66-87	3 F 5 M	15 months to 7 years	2 university hospital dialysis clinics and 2 smaller satellite centers	Serial qualitative interviews	Phenomenological hermeneutical method
Calvey and Mee[29]	Ireland	2011	7	29 - 60	Not reported	1 month to 5 years	Not reported	Interviews using open-ended questions	Colaizzi's phenomenological method
Curtin et al.[31]	USA	2002	18	38 to 63	8 F 10 M	16 to 31 years	Recruitment not clear	Semi-structured interviews	Content analysis
Gregory et al.[30]	USA	1998	36	19-87	18 F 18 M	Mean of 2.66 years	1 university teaching hospital unit	Semi-structured interviews	Grounded theory

Hagren et al.1[32]	Sweden	2001	15	50-86	8 F 7 M	6 <1 year 4 1-3 years 5 >3 years	1 dialysis unit	Semi-structured interviews	Content analysis
Hagren et al. 2[33]	Sweden	2005	41	29 to 86	15 F 26 M	Not reported	3 hospitals	Semi-structured interviews	Content analysis
Herlin and Wann-Hansson[34]	Sweden	2010	9	30-44	4 F 5 M	Not reported	1 public hospital and 2 private clinics	Interviews	Giorgi's phenomenological method
Kaba et al.[35]	Greece	2015	23	Mean age 62	65% M	Average 5.7 years	2 hospital dialysis centers	Interviews	Grounded theory
Karamanidou et al.[36]	UK	2014	7	32-68	4 F 3 M	2 to 7 years	1 renal satellite unit	Semi-structured interviews	Interpretive phenomenological analysis
Lai et al.[37]	Singapore	2012	13	39-63	7 F 6 M	2-5 months	1 dialysis center	Semi-structured interviews	Interpretive phenomenological analysis
Mitchell	UK	2009	10	2 20-30;	5 F	2<1 month;	1 medium	Semi-	Content analysis

et al.[38]				1 30-50; 5 70-80; 2 >80	5M	6 1-3 months; 2 4-6 months	sized renal unit	structured interviews	
Russ et al.[39]	USA	2005	43	70-93	26 F 17 M	Not reported	2 dialysis units (1 inner-city and 1 private)	Interviews	Phenomenological analysis
Shih and Honey[40]	NZ	2011	7	46 -77	Not reported	4 to 10 years	1 satellite dialysis unit	Semi-structured interview	Heideggerian hermeneutical analysis

***Demographic information relates to a larger study from which descriptions of those on hemodialysis are reported in this paper.**

Table 2 Results of CASP checklist appraisal

	Clear statement of aims	Appropriate methodology	Appropriate design	Appropriate recruitment strategy	Appropriate data collection strategy	Relationship between researcher and participants adequately considered	Ethical issues been considered	Rigorous data analysis	Clear statement of findings	Value of research
Aasen et al.[24]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes
Al-Arabi[25]	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes
Allen et al.[26]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes
Anderson et al.[27]	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Unsure	Yes	Yes
Axelsson et al.[28]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Calvey and Mee[29]	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Yes
Curtin et al.[31]	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes

Gregory et al.[30]	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes
Hagren et al.1[32]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Hagren et al. 2[33]	Yes	Yes	Yes	Yes	Yes	Unsure	Unsure	Yes	Yes	Yes
Herlin and Wann-Hansson[34]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kaba et al.[35]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Karamanidou et al.[36]	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes
Lai et al.[37]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Mitchell et al.[38]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Russ et al.[39]	Yes	Yes	Yes	Unsure	Unsure	No	No	Unsure	Yes	Yes
Shih and Honey[40]	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes

Table 3 Codes contributing to descriptive and analytical themes

Analytical theme	Descriptive themes	Contributing codes
A new dialysis dependent self	Changing identity	Altered body image
		Dependence and vulnerability
		Loss of identity
	Impact on family roles and relationships	Effects on family
		Guilt
	Changing social world	Impact on involvement in social world
		Lack of understanding from social world
		New social networks
	Changing future	Loss of future plans and ambitions
		Uncertainty
		Facing the threat of death
A restricted life	Constraints on time and diet	Desire for quality of life
		Restrictions imposed
	The impact of symptoms	Emotional impact
		Physical symptoms
		Deterioration in health over time

		Fear of things going wrong
	Loss of choice and freedoms	Incarceration
		Work of maintaining the dialysis regimen
		Time lost
Regaining control	Gaining own expertise	Testing boundaries
		Using test results to make decisions
		Shared decision making
		Critical events as motivators
		Developing own knowledge and abilities
	Accepting dialysis dependence	Gift of life
		Future hope
		Finding satisfaction in life
		Striving for normality
		Utilising time on dialysis
		Living on borrowed time
		Peer comparison
	Adjusting and accommodating dialysis	Gaining control
		Improvement in health at initiation of dialysis
		Seeing the dialysis unit as a place of safety and security

		Time as an agent to normalisation
		Release from burden of PD
		Being realistic
Relationships with health professionals	Information sharing	Knowledge requirements
		Uncertainty about the future
		Information sharing
	Building relationships with professionals	Continuity of care
		Being seen as a whole person
	Balance of power within relationships	Asymmetry of power
		Passivity
	Seeking expertise	Health care professionals' knowledge and skills
		Access to health care professionals

Table 4. Themes identified in each study

(Number refers to the number of extracts coded at each theme in the included papers)

Themes	Aasen et al.[24]	Al-Arabi[25]	Allen et al.[26]	Anderson et al.[27]	Axelsson et al.[28]	Calvey and Mee[29]	Curtin et al.[31]	Gregory et al.[30]	Hagren et al.1[32]	Hagren et al. 2[33]	Herlin and Wann-Hansson[34]	Kaba et al.[35]	Karamanidou et al.[36]	Lai et al.[37]	Mitchell et al.[38]	Russ et al.[39]	Shih and Honey[40]	**Total number of extracts**	**Number of studies**
Changing identity	3	6	2	0	6	5	13	7	5	2	2	4	2	5	1	3	4	70	16
Impact on family roles and relationships	0	7	0	4	3	4	0	8	5	1	0	1	3	3	3	1	1	44	13
Changing social world	0	4	3	10	4	5	3	6	1	3	5	3	1	3	5	1	4	61	16
Changing future	0	0	0	1	3	6	11	5	3	0	8	4	1	6	0	12	0	60	11
Constraints on time and diet	2	9	0	0	5	2	5	8	0	2	0	5	7	5	0	7	6	63	12
The impact of symptoms	2	1	0	9	5	7	5	15	6	4	5	10	7	10	5	7	8	106	16
Loss of choice and freedoms	2	3	0	0	5	2	2	2	6	5	8	1	2	3	0	13	5	59	14
Gaining own expertise	7	0	12	2	4	1	2	16	6	1	2	0	5	0	1	1	4	64	14
Accepting dialysis dependence	1	11	0	3	4	9	12	22	1	1	3	9	15	5	10	15	7	128	16
Adjusting and accommodating	0	18	1	1	9	2	39	20	5	2	3	6	16	1	5	19	5	152	16

dialysis																			
Information sharing	10	1	8	9	6	1	2	13	2	2	0	1	6	2	5	17	5	90	16
Building relationships with professionals	7	0	9	1	10	1	0	12	9	3	6	5	2	0	1	0	1	67	13
Balance of power within relationships	18	0	12	2	4	1	2	16	6	1	2	0	5	0	1	1	4	75	8
Seeking expertise	1	0	0	0	0	0	0	9	3	2	3	1	2	0	0	0	0	21	7

Table 5 Illustrative Quotations

A New Dialysis Dependent Self

Theme	Illustrative Quotation
Changing identity	*"I think dialysis is a detriment to maturity. I think you are placed over and over again in a dependent situation where you re-enact childlike relationships. From the machine to the staff, to the medical system, to the system that makes it all run, you know."* [31] *"There are a lot of things that we (dialysis patients) need to sacrifice. You can not work, you can not offer anything to your family."*[35] *"Looking at their (established patients') scars, I feel so scared. How do you expect me to go out in the public? I hide myself."* [37]
Impact on family roles	*"My wife would have preferred it in another way. To go out, to go to a tavern, to be able to go on holidays. It's not only that you suffer but you also make others suffer."*[35]

and relationships	*"I don't want to start leaning on [daughter]… I don't find it easy, to be honest…I don't want to maker her life a misery"* [38] *"I think that I am going to give a lot of trouble to my siblings, giving a lot of problems to your loved ones. They have to take time off (work) to do this and that for me… so I became a burden."* [37]
Changing Social World	*"A lot of times your friends, your so-called friends, they don't really have time for you, you know, "cuz they go on with their own lives and, you know you're sitting around feeling tired. So that's not a good feeling. Lots of times friends drop you when you can't do anything."*[25] *"I can not meet my friend John any more. Because I cannot eat, I cannot drink, and I think to myself if I go out with John who drinks and eats, I will be tempted and eventually drink. And I did this once, I drank three ouzos. And the result was I had to go home and collapse. So I can not socialize with him."*[35] *"I got used to coming here and it is necessary for me to come, to meet with these fellows and the*

	staff."[35]
Changing Future	*"Now there is a lack of purpose . . . I have nothing to look forward to at the moment."*[37] *"How long will I live? It was the only thing I thought of - how long could one live with dialysis."* [32] *"It has a hold on my life since I can't plan ahead and say, 'this is for sure."*[31]

A restricted life

Theme	**Illustrative Quotation**
Constraints on time and diet	*"Time is the worst part of it, because it takes too much time. From you, that is. You can't do anything spontaneous, you become very tied down"*[33] *"If you are supposed to really follow that regime, I would rather cut a couple of years off my lifespan. ... There is almost nothing you could eat. ... I certainly don't become worse/more ill because of that. ... With moderation of course, you see, it can't be like you can't take even a slice of bread with cheese or two during the day. ... That much I don't think it means. ... I don't say that I just don't care, you see, but*

	they observe those test reports then... phosphate and... calcium, perhaps, but then I get scolded a bit.... They say that now you have to pull yourself together; this doesn't go well. Now you destroy your years ... but this is my choice. ... My wife was really confused in the beginning and just tried to take care and follow those lists. 'We don't do it,' I said. ... I am not able to do this." [24]
The impact of symptoms	"Itching is...the way it's been for the last couple of years makes me so depressed, you couldn't understand. I almost jumped the other night – from the balcony. If it hadn't been for my wife I would have jumped. That's how tired I am of it." [33] "This disease is very difficult, and no matter how hard you try, no matter how much strength you have, you will be weighed down with anxieties and get depressed. You are losing your self-control. I personally very often feel depressed because I asked "why me?"'[35]

Loss of choice and freedoms	*"It is mostly a mental strain. After all, I have no pain then, but one feels like being put a little bit into prison, if one could use an ugly word like that"*[24] *''Having to be here three days a week is what I call a 'command performance, no sooner do I start feeling better then I'm anticipating coming back again the next day. But there's no choice, no modifying the experience."*[39]

Regaining Control

Theme	Illustrative Quotation
Gaining own expertise	*"Now when I understand the machine, what the machine really does, I can go in and change the parameter...that makes me feel like I am contributing to my treatment"* [34] *"You're the doctor. I'm the patient, and let's see how we can work this together. I want to be an influence on that decision. I want to help make the decisions because I think I have a lot of [to] input on my situation"*[26]

Accepting dialysis dependence	*"It's a very different life, but I am willing to live it. I am willing to face whatever this different life brings about. I'm very aware of the drastic change in lifestyle . . . I cannot go back to the way it used to be. . . . It's like I have—I've lived two lives. One life when I was healthy and then this life with this illness."*[31] *"So I'm just really, really, lucky, or I could be pushing up the daisies."*[38] *"When I got sick, and started with hemodialysis, I felt that I had to use the time. I started to study and therefore I have a life outside the dialysis. Now the dialysis is just a little part of my whole life and the other is with my studies, that is the real me... The dialysis is just something that I do in between"* [34]
Adjusting and accommodating dialysis	*"It's hard at first but you get used to it ... if people are socializing and you can't maybe have as much as them or ... you can't do what they are doing ... but you have got to be grown up about it and realize well it's one of those things where you have just got to put up with so ... it's hard but it's ... you just have to get on with it ... Cause I've been doing it for so long now ... it's more natural now than if I was,*

	you know, not ill ..."[36] *"I think you've got to be realistic...I've just got to readjust my life and do what I can"* [38]

Relationships with health professionals

Theme	Illustrative Quotation
Information sharing	*"[Doctors] think you don't know what you are talking about. You're not supposed to question."* [30] *"I want more information. ... Nurses do not tell me anything, other than the blood percentage. ... They could talk more about the illness and how it develops".* [24] *"I can't fathom it. I can't look at my kidney, put it in my hand, and examine it myself. Why do I have to be on dialysis? What is kidney disease? How much of it [i.e., the disease] do I have to have before I need to be on dialysis? I ask these questions, but their only answer is to tell me to be here, to take water out of me. But that's not an answer! I'm left dangling."*[39]
Building	"*When I first started the dialysis I was crying a lot. It was the head nurse who helped me to go through*

relationships with professionals	*it and she was there for me listening to my problems. Without her I couldn't continue."*[35] *"The personal chemistry must work for me...otherwise they are not allowed to canalise my fistula....[laughs] ...I must have faith in that person, faith is very important..."* [34] *"They make one round, we only have it on Tuesdays, but then we also go through everything once a month with the nurse and the doctor, that's fantastic. That creates more of a personal relationship, there's a little chatting about all sorts of things as well, at least when I'm sitting there."* [32]
Balance of power within relationships	*"You're [doctor] not listening to the whole situation. You took a piece of it, made your analysis, made your decision, and you've moved on. But I'm still here living with whatever you left me with."*[26] *"If you come in and need a lot of drainage (ultrafiltration), they say 'why do you need so much' and start nagging me. Well I know that I've been bad, but it's impossible to stop yourself when you're thirsty. I've told them 'would you last on five dl a day?', then they'll tell me 'but we're healthy!' As if I didn't know."* [33]

Seeking expertise	*"I get so nervous when there are new nurses that are supposed to learn...they really don't know how to do it, so they talk to themselves to remember, and then you get nervous yourself. Then I start to think: do they really put the tubing right? So then I get a little bit worried."* [34] *"But the fact of the matter is that if someone can't get my needle in place – which actually does happen. Some people can't do it at all. But then there are those who get it right every time."* [33] *"In my experience, you don't see many doctors…Most of them, I must say, they all know their work, they're all good…if you can get them to come in to you."* [30]

Figure 1. Results of search strategy and identification of included studies

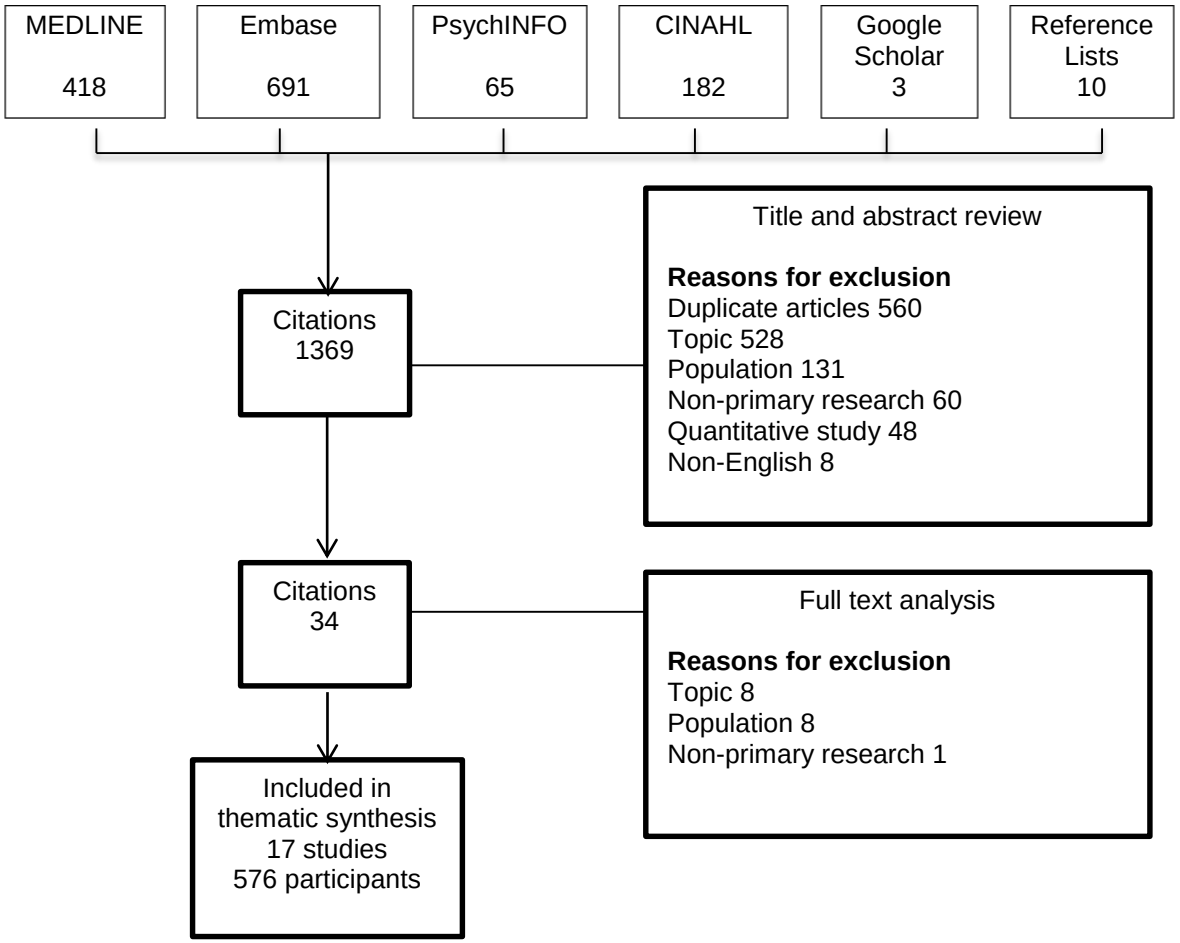
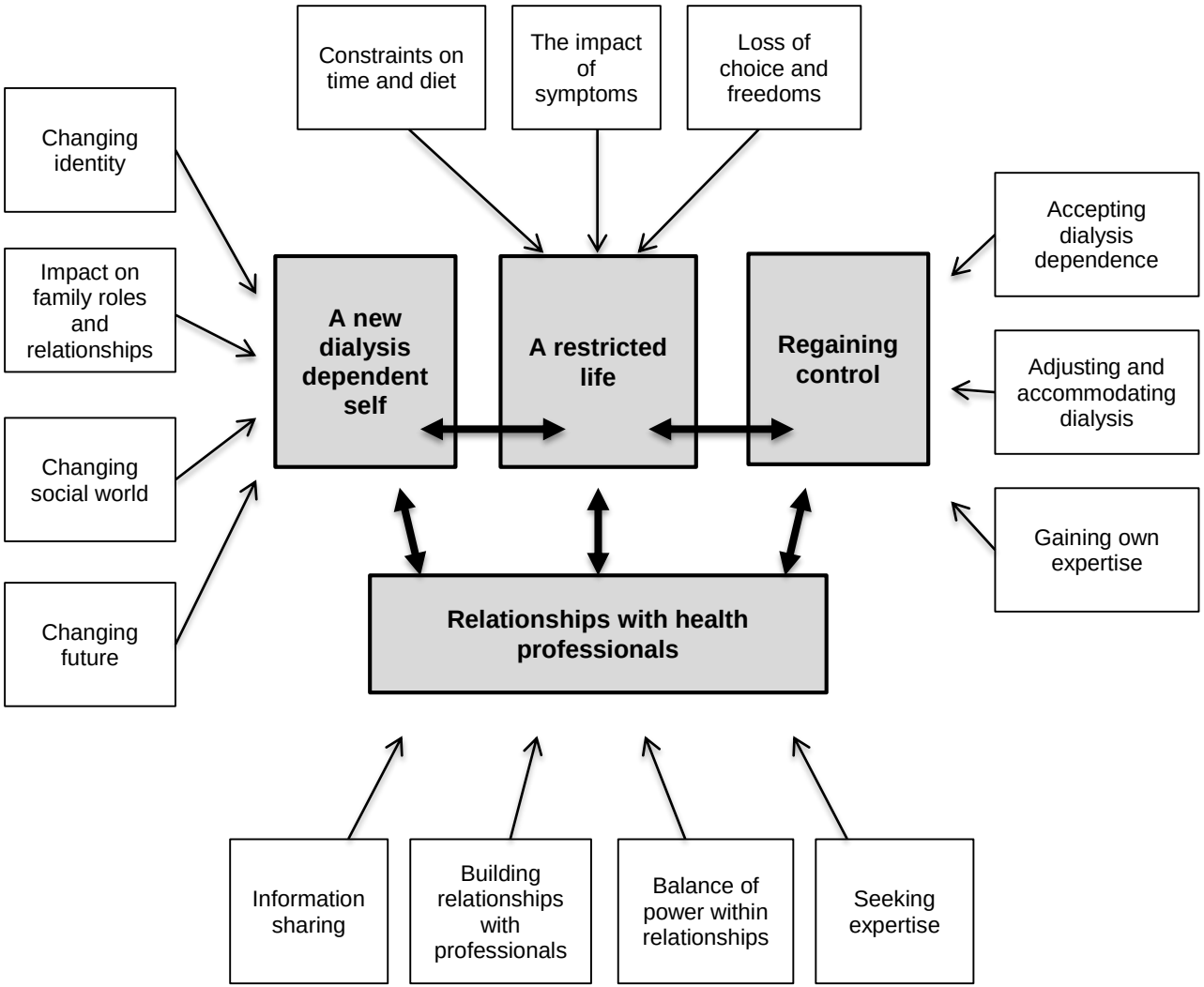


Figure 2. Framework of the experiences of adults living with in-center hemodialysis



Appendix 1 - Search String

1. hemodialysis/ or hemodialysis patient/ or hemodialysis.mp.

2. h?emodialysis.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

3. exp chronic kidney disease/th [Therapy]

4. 1 or 2 or 3

5. interviews.mp. or interview/

6. finding.mp.

7. incidental finding/ or finding.mp. or case finding/*

8. qualitative.mp. or qualitative analysis/ or qualitative research/

9. 5 or 7 or 8

10. 4 and 9

11. quality of life.mp. or "quality of life"/

12. patient satisfaction.mp. or patient satisfaction/

13. society/ or patient/ or hospital/ or patient experience.mp. or therapy/

14. total quality management/ or health care quality/ or patient experience.mp. or patient care/

15. expectation/ or patient expectations.mp. or patient attitude/

16. 11 or 12 or 14 or 15

17. 10 and 16