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Haemodialysis Patients' Perceptions of their Experience, Control and Knowledge of Fluid Management

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Summary

Background

Person-centred care is increasingly promoted, empowering patients to become more involved in their treatment rather than being passive recipients of care (Barnes et al., 2013). Haemodialysis is typically required three times a week, with fluid management decision-making occurring at each treatment session (Ahmed et al., 2017). However, no research has yet explored how haemodialysis patients' perceptions of their fluid management may impact upon this decision-making.

Objectives

This study sought to explore haemodialysis patients' perceptions of their fluid management.

Method: Design, Participants & Approach

Semi-structured interviews were conducted with 12 patients undergoing in-hospital haemodialysis treatment. These were digitally recorded one-to-one interviews to allow for verbatim transcription. The data was analysed by thematic analysis, generating thematic patterns across patients' experiences, control and knowledge of their fluid management.

Results

5 themes were produced: determining who has the expertise, impediments affecting patients' lifestyle, additional difficulty of experiencing comorbidities, perceived quality of care, and establishing consistency.

Conclusions

Despite varied levels of patient participation in their treatment, overall there appears to be a limited understanding of specific areas of fluid management. The implications for further research and the development of shared-care are discussed.

Keywords

Hemodialysis Units, Hospital

Interview

Patient-Centered Care

Patient Participation

Decision Making

Introduction

With the introduction of the Health and Social Care Act in 2012, the UK National Health Service has demonstrated a shift towards person-centred care, promoting personal care planning, self-management and shared decision-making between patients and healthcare professionals (National Health Service England, 2013). Similarly, the kidney community have outlined 17 'kidney health ambitions', including the improvement of the lifestyle for people on dialysis, better self-management and moving towards person-centred care (Kidney Health, 2017). Additionally, independent UK charities such as the Health Foundation have developed resources for both healthcare professionals and service users, promoting person-centred care (The Health Foundation, 2016).

For haemodialysis patients, one of the most common decisions that directly impacts upon their treatment is determining what volume of fluid should be removed at each dialysis session. Decisions about fluid management are based upon the concept of a target weight. For many years, the most common approach was to probe for dry weight (Canaud & Lertdumrongluk, 2012) but it is now recognised that pushing individuals to their lowest possible target weight is associated with medical complications such as developing a clotted fistula or graft, an accelerated loss of residual renal functioning, cramping and post-dialysis fatigue (Agarwal et al., 2009; Hur et al., 2013). It is also important to avoid a target weight set too high as having excess fluid increases the risk of cardiovascular comorbidities (Chazot et al., 2012).

More recently, target weight has been defined as a post-dialysis weight at which an individual can stay close to normal hydration throughout the interdialytic period with optimal control of blood pressure, without experiencing side effects or compromising residual renal function (Lindley & Keane, 2014). Deciding on a target weight is not trivial and is largely based on clinical assessment, although this approach is widely considered inadequate (Covic & Onofriescu, 2013). Nevertheless, patients may choose to become more involved in their fluid

management by deciding at each session how close they will try to get to their target weight, deciding upon how much fluid to have removed, or may enquire to have their target weight reassessed if they believe they have lost or gained flesh weight.

It is important to identify patient preferences for their involvement in medical decision-making. Orsino et al. (2003) found that 35% of haemodialysis and peritoneal dialysis patients wanted to make autonomous decisions, 42% preferred shared decision-making and 24% wanted healthcare staff to make the final decision, regarding what type of renal replacement therapy they would receive. However, of those individuals who wished to make their own decisions, only 40% experienced this, whereas healthcare professionals made the final decision for 80% of individuals who requested this (Orsino et al., 2003). This is despite evidence that dialysis patient decision-making is associated with decreased anxiety and depression, enhanced sense of hope, increased feelings of control and increased self-efficacy, understanding and compliance to treatment (Orsino et al., 2003). Flythe et al. (2014) explored patient preferences for hypothetically adopting strategies to improve fluid management, for example by increasing treatment sessions, adding an extra session or changing to nocturnal dialysis. Interestingly, it was how “bothered” patients were by their symptoms rather than the presence of symptoms which motivated patients to become more willing to adopt a strategy to mitigate fluid-related symptoms (Flythe et al., 2014).

Nevertheless, knowledge is required in order to make informed decisions and patients do not always appear to have this knowledge. Aasen et al. (2012) investigated the perceptions of elderly haemodialysis patients who stated that their healthcare team “own” the knowledge and decide how much should be shared with patients, making shared decision-making difficult. Adequate knowledge is also important as patients have reported feeling more comfortable with their haemodialysis treatment once they became more knowledgeable about it (Gregory et al., 1998). Unfortunately, these patients perceived that doctors were not to be questioned and that doctors considered patients to lack knowledge about their treatment (Gregory et al., 1998). However, more knowledge does not necessarily result in better self-management. Haemodialysis patients who had superior knowledge of their dietary phosphate restrictions were significantly less likely to adhere to them (Durose et al., 2004).

The way information is presented to patients is important. Patients may misunderstand aspects of their treatment, for instance viewing haemodialysis as a cleansing process which entirely purges their body of dangerous entities such as sodium, phosphorus or potassium (Krespi et

al., 2004). This belief appeared to lead to the consumption of food high in sodium, potassium or phosphorus during or just prior to haemodialysis (Krespi et al., 2004), as a way around food restrictions. This is despite the risk associated with eating any food on haemodialysis, which can result in a shift in blood to the stomach, lowering central blood pressure (Kalantar-Zadeh & Ikizler, 2013), irrespective of the additional risk of eating restricted foods. Whilst these patients may understand that the dialyser does remove waste products from their blood (Wileman et al., 2016), they may either not be aware of the risks of eating during or prior to haemodialysis, or may evaluate such risks as worth taking.

There are many benefits associated with improving patients' knowledge of their haemodialysis treatment, including that it can empower individuals to become confident enough to make medical decisions (Orsino et al., 2003). However, it was found that haemodialysis patients must demonstrate knowledge about their treatment, be willing to self-advocate, and understand how their body is uniquely affected by their treatment in order to take part in shared decision-making (Allen et al., 2011). For instance, the experience of having haemodialysis can vary immensely, with some individuals either feeling physically better or worse after treatment (Krespi et al., 2004).

All of these individual factors mean that patient care is complex and involving patients in the decision process equally so. Whilst there is some research investigating patient perceptions of their fluid management such as the shared decision-making of elderly patients' dry weight (Aasen et al., 2012), and patients hypothetically choosing a fluid management strategy (Flythe et al., 2014), there is still a substantial need for more research. Also, as Aasen et al. (2012)'s study sampled elderly Norwegian patients and Flythe et al. (2014)'s study sampled American patients these findings may not be generalisable to UK National Health Service patients of varying ages. In the UK National Health Service Trust that the patients in this study were recruited from, there is an opportunity to take part in "shared-care haemodialysis" in which patients are taught various skills including how to set up their own haemodialysis equipment and weigh themselves to calculate how much fluid they need to have removed. Therefore, it is possible to explore patient perceptions of individuals who are, and are not, participating in a shared-care programme.

Aim

This study aimed to explore patients' perceptions of their experience, control and knowledge of haemodialysis, in relation to aspects such as target weight and fluid management, within a large National Health Service Trust.

Design and Methods

Design

To explore this novel area of research, qualitative methodology is deemed as most appropriate to gather in-depth understanding of patients' perspectives (Elliott, 1995). Semi-structured interviews were used to generate comparable results, whilst giving individuals the freedom to discuss issues uniquely important to them (Cohen & Crabtree, 2006). The semi-structured interviews were comprised of 5 sections:

1. Investigating the patient's medical history
2. The prescription of fluid removal
3. Fluid removal itself
4. Any related symptoms or complications
5. Any miscellaneous issues an individual wanted to discuss further

Other questions unique to each interview were also asked, to clarify a response or to gain more detail on a particular topic.

Sample

We aimed to recruit 12 patients with a conscious effort to have a broadly representative sample of patients with respect to age, dialysis vintage, gender, time of treatment, and by recruiting patients from both hospital and satellite dialysis units.

Data Collection

The interviews were recorded and took place on the ward whilst the participants were having haemodialysis, with the interviewer sat beside them. The interviewer was a psychology student with relevant knowledge of haemodialysis and previous experience of conducting interviews with members of the public. The study was approved by the University of Leeds Research Ethics Committee (16-0212 on 03/08/2016). All patients were given written information about the study and provided their informed consent.

Data Analysis

The interviews were transcribed verbatim using broad playscript transcription conventions as cited in Du Bois (1991). Interviews were analysed inductively via thematic analysis because of its flexibility to identify patterns within and across data in relation to participants' experience, behaviour and perspectives (Clarke & Braun, 2017), and were analysed in accordance with the guidance of Braun and Clarke (2006). This consisted of the interviewer and a co-author separately identifying codes in each of the 12 interviews, one interview at a time, which then were discussed together to ensure reliability. By the final interview, saturation was reached as no new themes were generated in relation to patients' perceptions of their fluid management.

These codes were then further deliberated upon by all authors, and themes were produced from these codes across the dataset in relation to the research question. This was then further refined, and 5 themes were produced from the analysis, along with subthemes, each reflecting an important aspect emphasised across the interviews. Again, this process was undertaken in accordance with published guidelines (Braun & Clarke, 2006), ensuring a rigorous analysis (Clarke & Braun, 2017).

Findings

Clinical and Demographic Characteristics of the Participant Sample

N	12
Age (years)	54 (35-77)
Gender (female)	5 (42%)
Dialysis vintage (years)	6.1 (3 months - 28 years)
Comorbidities:	
- Angina	2 (17%)
- Myocardial Infarction	2 (17%)
- Coronary Artery Bypass Graft	1 (8%)
- Diabetes	3 (25%)
- Heart Failure	3 (25%)
- Smoking	1 (8%)
Part of a shared care programme	2 (17%)
Dialysis session:	

- Morning	4 (33%)
- Afternoon	6 (50%)
- Twilight	2 (17%)
Dialysis centre:	
- Hospital	5 (42%)
- Satellite unit	7 (58%)

Table 1: Patient characteristics. Data are mean (range) for continuous data or as count data

The characteristics of the patients interviewed are shown in table 1. The mean length of the interviews was 17 minutes (range: 9-34 minutes). The analysis produced 5 main themes which reflected how patients experience, control and understand their fluid management which were: determining who has the expertise, impediments affecting patients' lifestyle, the additional difficulty of experiencing comorbidities, the perceived quality of care, and establishing consistency.

Themes

Themes produced from the analysis

Main Themes	Subthemes
1. Determining who has the expertise	1.1 Trust of staff expertise in comparison to own expertise 1.2 Ability and willingness to self-advocate
2. Impediments affecting patients' lifestyle	2.1 Time confined to being in hospital 2.2 Symptoms during and in-between treatment sessions 2.3 Adherence to diet and fluid restrictions
3. Additional difficulty of experiencing comorbidities	3.1 More complicated to establish cause & effect of symptoms 3.2 Additional physical and/or psychological distress
4. Perceived quality of care	4.1 Perception of support given by staff

	4.2 Satisfaction with overall hospital care
5. Establishing Consistency	5.1 Volume of fluid to be removed 5.2 With diet and fluid intake

Table 2: Summary of main themes and subthemes

Trust of staff expertise in comparison to own expertise

Knowledge appeared to derive from experience and coincided with a good understanding of the short-term effects of removing too much or too little fluid, but limited knowledge about the long-term effects of regularly doing this. Both shared-care participants were knowledgeable about their treatment. For instance, one of these individuals perceived that she had lost flesh weight yet did not have an updated target weight, and so consequently removed more fluid than her calculation suggested should be removed to avoid having excess fluid post-dialysis:

“...so like if I need 2.6 off, I’ve been putting it up to 3.” (#12, 219-222)

Not only do staff allow her to calculate the amount of fluid she needs to have removed, but to then also adjust it accordingly, based upon her own judgement.

In contrast, some patients had only a limited amount of knowledge and motivation to become involved in their haemodialysis treatment:

“They record my weight you see, so there’s no need to ask me.” (#7, 60-61)

“They’re the boss, they know what to do.” (#7, 151-152)

This was in regard to giving consent for the volume of fluid to be removed. Evidently there were contrasts in the reliance upon staff, with some individuals appearing detached from their treatment whilst others were actively involved in this decision-making.

When fluid removal symptoms became more complex, or dissimilar to that of previous treatments, there appeared to be an increased desire for information. For instance, one individual’s tolerance of fluid removal had decreased in comparison to before his kidney transplant. When asked if he would like to know why this may be, he responded:

“I would...only because this time round it seems very different.” (#4, 131-134)

Ability and willingness to self-advocate

Patients who were willing to self-advocate appeared able to ask staff for advice or to participate in fluid management decision-making, only in a few instances did patients struggle to do this:

“Once I made it known that erm after a couple of sessions I was having the headaches...they’ve been obviously more open to me suggesting that it might need to be reduced a little bit.” (#4, 92-96)

This experience seems quite different to that of other patients who autonomously made fluid removal decisions, reflecting greater patient activation, with staff just checking that the volume would be a safe amount to remove.

Impediments affecting patients’ lifestyle

Time confined to being in hospital

Hospital treatment times were an apparent hindrance for many patients. Both shared-care individuals preferred this type of care primarily because of the decreased time spent in hospital, with increased control only briefly interpreted as a benefit. Another patient also showed determination to reduce the disruptiveness of hospital treatment time:

“I’m the only person in here who’s actually earning money, because I refuse to let dialysis stop me.” (#3, 16-18)

This patient remains employed in two jobs, one of which involves travelling around the country which requires finding other National Health Service hospitals at which to have haemodialysis.

Symptoms during and in-between treatment sessions

One negative experience of substantial side effects or one positive experience of avoiding side effects generated stable, long-term, self-prescribed rules which patients appeared to carefully follow. For example, one positive experience of pre-dilution haemodiafiltration led a patient to subsequently choose this method, for over a year by this point:

“They did it by pre-dilution and I felt better, so it might be psychological that I decide now to do pre’s.” (#11, 54-56)

Without prompting, the patient acknowledged that his choice to have pre-dilution haemodiafiltration may be psychologically, rather than medically, based. Moreover, this statement suggests that this patient has full control as to what type of treatment he has.

Adherence to diet and fluid restrictions

Most patients reported that they adhered to diet and fluid restrictions, although the degree to which they did so varied. Strategies to cope with diet and fluid restrictions tended to be unique to the individual, however one common view was that haemodialysis enabled restricted food or drink to be consumed safely:

“As long as it’s...eaten before dialysis and she says the machine sorts it out, so I’m allowed that one.” (#6, 154-156)

There was also evidence of patients asking for additional advice, if the advice they had already received was not perceived as satisfactory:

“It was the vascular ward and they...were trying to say to you, oh you can only have a litre of fluid a day... a litre a day wouldn’t be enough.” (#8, 340-345)

Thus this patient actively sought advice from renal staff, who stated that fluid restrictions could be more individualised, and so followed this (preferred) advice.

Additional difficulty of experiencing comorbidities

More complicated to establish cause & effect of symptoms

When comorbidities were present, fluid management appeared more complex with some individuals unsure as to what was causing specific symptoms. As noted by one patient, when he is tired he must work out why this may be in order to determine how much fluid to remove:

“I’ve had quite a few other clinics including ophthalmology and oncology and it, it can be difficult because all together with renal, the symptoms of all three has been that it makes you tired. So sometimes if you’re feeling tired it’s trying to work out is it down to any one of those three, is it just simply going to bed late or just not sleeping well.” (#8, 198-204)

Despite the complexities of having multiple comorbidities, this patient still took an active role in dialysis related decision-making.

Additional physical and/or psychological distress

In addition to increased complexity, patients also described how comorbidities can affect their experience of fluid removal itself:

“If my diabetes isn’t under good control...that increases the discomfort and the pain...makes it less likely for me to be able to take certain high erm volume.” (#4, 184-187)

Another patient stated that adhering to fluid restrictions was even more difficult because of his diabetes, which he believed increased his thirst.

Perceived quality of care

Perception of support given by staff

Staff were generally perceived as attentive and caring, with patients (including those not part of the shared-care programme) giving examples of shared decision-making:

“She was very nice, took my thoughts into consideration.” (#4, 69-70)

In situations where patients perceived that they received inadequate care, patients usually attributed this to the hospital being understaffed or under-resourced, rather than the staff being incompetent or uncaring. However, there were different responses as to whether staff asked for patients’ consent regarding the amount of fluid to be removed, even by patients cared for by the same staff:

“Sometimes and sometimes not.” (#2, 123)

“They always check with me that I’m happy to take that amount off.” (#3, 83-84)

Satisfaction with overall hospital care

Whilst the overall service provided by the hospital was not directly asked about, patients often brought up issues if it had subsequently affected their fluid management:

“Transport’s absolute rubbish, absolute rubbish. So if there is any problems or I’m late...it’s usually down to transport.” (#12, 44-46)

When this individual’s transport was late, she discussed how this reduced the amount of time she could have on haemodialysis and hence the amount of excess fluid she could have removed.

Another patient raised the issue of a lack of coordinated care between the hospital renal unit and their general practitioner, which had (in his view) prevented exploration of why he started to suffer from spinal disc problems at the same time as he started having haemodialysis:

“It’s pass the parcel...I’m the piggy in the middle, there’s nothing much I can do about it.”
(#11, 301-304)

Whilst the health issue goes unexplored, this patient remains unsure as to whether haemodialysis is, or is not, affecting his spinal discs.

Establishing Consistency

Volume of fluid to be removed

There were often specific volumes of fluid an individual believed would be the most they could tolerate having removed, and this seemed to be the focus of most patient participation:

“About 2.3...because I know if I take any more I get cramp.” (#10, 131-138)

Patients often emphasised that these fluid removal routines or strategies were implemented to avoid short-term symptoms, with most patients unaware of any long-term complications of continually taking off too much or too little fluid.

With diet and fluid intake

One patient noted that just “being sensible” with regards to his fluid and diet restrictions worked best for him, whereas other patients described a desire to have a consistent diet and fluid intake, and were unwilling to make any changes:

“I’m in too nice a pattern with what I eat and drink at home.” (#3, 242-243)

One patient described how she and the other patients on the ward would eat pizza on Fridays and drink Coca-Cola on Wednesdays during haemodialysis. Not only does there appear to be a sense of social belonging amongst the patients on this ward, but this behaviour also suggests a desire for consistency, as these treats were always consumed on the same days of the week. This is also consistent with subtheme 2.3 (adherence to diet and fluid restrictions) in which some patients ate discouraged foods during or prior to dialysis due to a perceived reduced risk of consuming them at this time.

Discussion

This research sought to identify what experiences, control and knowledge haemodialysis patients have of their fluid management, in relation to aspects such as their target weight and the prescription of fluid removal. The first theme, determining who has the expertise, portrayed varying combinations of patient and staff input within decision-making. Whilst previous findings have suggested that patients perceive healthcare staff to be powerful and dominant, and unable to be questioned (Aasen et al., 2012), this was far less apparent within the current study.

This less hierarchical view of staff may be partly due to initiatives such as the haemodialysis shared-care programme (Barnes et al., 2013), a nurse-led educational programme implemented across the region in which these patients receive their treatment, which has successfully managed to increase patient participation by overcoming perceived barriers identified by nurses. These nurse-identified barriers included the legality of patients making medical

decisions, worry of loss of control over patients, a negative attitude towards change, and the physical or mental capability of patients (Barnes et al., 2013).

Whilst Gregory et al. (1998) found that patients had a good understanding of both short-term and long-term side effects of their overall haemodialysis treatment, this study found an overwhelmingly poor understanding of how too much or too little fluid removal may result in long-term complications. Nevertheless, this study was consistent with other findings from Gregory et al. (1998) such as ‘critical events’ motivate patients to become more active in their treatment, due to increased self-awareness. Our study supports this finding as a change in the experience of haemodialysis often coincided with patients seeking out information to explain this change and may reflect an increase in patient activation. Patient activation describes the knowledge, skills and confidence a person has in their ability to manage their own health and care (Johnson et al., 2016), and we found varying levels of patient activation within our sample. It is vital that healthcare professionals encourage and support improvements in patient activation, as greater patient activation is associated with improved outcomes in patients with chronic diseases, including greater health-related quality of life (Johnson et al., 2016).

The second theme identified impediments affecting patients’ lifestyles, resulting from fluid management issues. Krespi et al. (2004) noted that patients discussed how they were confined to staying close to home, only able to travel for a couple of days before having to return to hospital to continue treatment. However in our study, one patient travelled around the UK attending different hospitals for haemodialysis. It is unclear how feasibly this can be arranged and whether all patients are aware of this opportunity, but it certainly brings benefits for patients. Interestingly, shared-care in this study was preferred primarily for the decreased amount of time patients had to spend in hospital, a benefit also highlighted by Glidewell et al. (2013). This is despite shared-care programmes being primarily implemented to empower patients and increase independence (Barnes et al., 2013).

When describing treatment-related impediments, the potent impact of a negative or positive experience of fluid removal became apparent, as it often appeared to generate stable, long-term, self-prescribed rules which patients carefully followed. After a negative experience, patients appeared to follow these rules to try to prevent side effects from ever occurring again. After a positive experience, patients appeared to follow these rules to try to continue to prevent any side effects from occurring. This could be an example of a safety behaviour - a behaviour carried out to prevent a feared catastrophe, which, when not experienced, results in the belief

that this behaviour prevented the catastrophe (Salkovskis, 1991). For example, by never attempting to take a specific volume of fluid off again, a patient cannot disconfirm their belief that this would cause side effects. Safety behaviours can maintain and worsen anxiety disorders (Salkovskis, 1991), and since as many as 69.3% of haemodialysis patients experience anxiety (Sqalli-Houssaini et al., 2005) this issue merits further investigation.

With respect to diet-related impediments, there were some misconceptions that haemodialysis can eradicate all negative effects of eating restricted foods. This concurs with previous research from Krespi et al. (2004) who found that patients viewed haemodialysis as a cleansing process. Gibson et al. (2016) found better knowledge of diet-restrictions amongst patients with poorer adherence and suggested that it may only be the patients who are not adhering to the restrictions who are then informed frequently about the importance of adherence. Therefore, frequent educational opportunities should be made available for all patients.

The third theme explored the additional difficulty of experiencing comorbidities. Jayanti et al. (2015) previously found that the experience of having comorbidities resulted in a decreased desire to make treatment-related decisions, however in this study patients with comorbidities varied considerably in their willingness to become involved in decision-making. Further research should explore whether patients with comorbidities do require additional support within fluid management decision-making, and if so, how to best support these individuals.

Whilst Soleymanian et al. (2017) found no significant differences in bodily pain between diabetic and non-diabetic haemodialysis patients, in our study it was reported that when diabetes was not under control, this could increase patients' perception of pain during haemodialysis. Therefore, during times where diabetic patients have poor control over their diabetes, they may need additional support to ensure they are able to remove enough fluid without being in substantial pain. One way to help manage pain during fluid removal is listening to preferred music, as this significantly decreased haemodialysis patients' perceptions of pain, as well as anxiety (Pothoulaki et al., 2008).

The fourth theme, quality of care, was an important component of patients' fluid management. Whilst it is vital that patients are offered free transport, when this transport was delayed, patients noted that this reduced the amount of excess fluid they could have removed due to shortened treatment times. Similar issues have been reported by Aswanden (2003), therefore this issue must be addressed to prevent it from negatively impacting upon fluid management. Staff were generally portrayed very positively, and when support was perceived as inadequate,

patients attributed this to understaffing. This was somewhat similar to previous findings that nursing staff were considered competent, but wards were understaffed, leading to stressed nurses and with a consequent increase in patients' stress (Gregory et al., 1998). Whilst the patients in our study did not infer a direct link between staff stress and their own stress levels, some patients did attribute the stress they experienced to how busy or under pressure staff were.

The fifth theme, establishing consistency, recognised how some patients aimed to remove a consistent amount of excess fluid at each session, whilst also achieving a consistent diet and fluid intake to ensure this. Whilst there is little discussion of this in the current literature, the motivation to establish consistency may be in order to obtain a predictable treatment experience, without unexpected side effects. Individuals may accept uncertainty of their health to different extents, and those individuals who find it more difficult to accept uncertain health may then go on to try and maximise the control they have over other aspects of their life (Campling & Sharpe, 2006). Therefore, conforming to a strict routine may be one of many coping strategies that individuals adopt when they require haemodialysis.

Study Limitations

To obtain an understanding of how patients perceive their fluid management, 12 interviews were conducted with an attempt to include participants with a range of patient characteristics, such as gender, age, dialysis vintage and from both hospital and satellite units. However due to the small sample size the results are not generalisable. We were also limited to only interviewing patients who spoke fluent English as a translator could not be provided. Furthermore, as the interviews took place within the hospital with staff in the vicinity, this may have dissuaded patients from discussing perceived negative aspects of care.

Conclusion

To conclude, this study has produced 5 themes in relation to patients' perceptions of fluid management: the first explored determining who has the expertise, and statements varied from shared-care patients making autonomous decisions, to patients who wanted minimal involvement. Nevertheless, there was an overall limited amount of patient knowledge about certain aspects of treatment. Our second theme identified impediments to everyday life, most commonly, time confined to in-hospital treatment, symptomology and adherence to diet and fluid restrictions. The third theme discussed the additional difficulty of experiencing

comorbidities when trying to establish the cause and effect of symptoms as well as increased physical or psychological distress. The fourth theme identified patients' perception of care, both with staff and with broader aspects of healthcare services and the fifth theme discussed patients common desire to establish consistency within the prescription of their fluid removal and with their diet and fluid intake. These insights support further work towards improving patient activation and a more person-centred approach to fluid management in haemodialysis.

Implications for Clinical Practice

The findings highlighted the potent impact of one very negative or positive experience of haemodialysis upon subsequent decision-making, the general satisfaction with the quality of care given by staff, yet a need for improvement in broader aspects of care such as transport and understaffing. Furthermore, whilst patient participation and willingness to self-advocate varied, there seemed to be an overall gap in knowledge of specific areas such as the long-term effects of regularly removing too much or too little fluid, and the impact of eating restricted foods prior to or during dialysis. As Gibson et al. (2016) noted, it may only be the patients who are not adhering to restrictions who are then informed frequently about the importance of adherence. Therefore, it is important that all patients are given frequent opportunities to learn more about their treatment, with improved patient education and empowerment, in order to improve engagement with fluid management and better management of patient outcomes. This increase in patient activation requires management of staff such that time is available for upskilling, enabling staff to support this process.

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Conflict of Interest:

None to declare

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