

# Types of vicarious learning experienced by pre-dialysis patients

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## Abstract

**Objective:** Haemodialysis and peritoneal dialysis renal replacement treatment options are in clinical equipoise, although the cost of haemodialysis to the National Health Service is £16,411/patient/year greater than peritoneal dialysis. Treatment decision-making takes place during the pre-dialysis year when estimated glomerular filtration rate drops to between 15 and 30 mL/min/1.73 m<sup>2</sup>. Renal disease can be familial, and the majority of patients have considerable health service experience when they approach these treatment decisions. Factors affecting patient treatment decisions are currently unknown. The objective of this article is to explore data from a wider study in specific relation to the types of vicarious learning experiences reported by pre-dialysis patients.

**Methods:** A qualitative study utilised unstructured interviews and grounded theory analysis during the participant's pre-dialysis year. The interview cohort comprised 20 pre-dialysis participants between 24 and 80 years of age. Grounded theory design entailed thematic sampling and analysis, scrutinised by secondary coding and checked with participants. Participants were recruited from routine renal clinics at two local hospitals when their estimated glomerular filtration rate was between 15 and 30 mL/min/1.73 m<sup>2</sup>.

**Results:** Vicarious learning that contributed to treatment decision-making fell into three main categories: planned vicarious learning, unplanned vicarious learning and historical vicarious experiences.

**Conclusion:** Exploration and acknowledgement of service users' prior vicarious learning, by healthcare professionals, is important in understanding its potential influences on individuals' treatment decision-making. This will enable healthcare professionals to challenge heuristic decisions based on limited information and to encourage analytic thought processes.

## Keywords

Education, self-efficacy, decision-making, vicarious learning, long-term condition

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## Introduction

End-stage renal disease (ESRD) requiring life-changing treatment decision-making affects 108 people per million of the UK population every year. This equates to 6891 individuals commencing treatment annually in the United Kingdom<sup>1</sup> and 1.4 million globally.<sup>2</sup> The single most common cause of renal failure is diabetic renal disease affecting 26% of individuals.<sup>1</sup> ESRD occurs when individuals' renal function declines and their estimated glomerular filtration rate (eGFR) drops to between 15 and 29 (mL/min/1.73 m<sup>2</sup>), below 30% of normal function, and is called chronic kidney disease stage 4 (CKD 4) at this point. The treatment options for established renal failure are transplantation (Tx), haemodialysis (HD), peritoneal dialysis (PD) and conservative management.

HD and PD treatment options are in clinical equipoise,<sup>3</sup> although the cost of HD to the National Health Service

(NHS) is £16,411/patient/year greater than PD.<sup>4</sup> Over the past decade, there has been a rise in HD treatment<sup>5,6</sup> in the absence of patient support in making their own treatment decisions. Both types of dialysis have diverse and extensive life-long implications for individuals that fundamentally change the way they experience life.<sup>7</sup>

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A review of the renal and long-term condition self-management literature identified effective components in self-management education that support service user decision-making. Self-efficacy theory<sup>8</sup> was predominant in the literature and underpinned the development of self-management interventions.<sup>9</sup> The key components central to Bandura's self-efficacy theory are mastery experience, vicarious learning, emotional arousal and verbal persuasion. These elements coalesce to enhance self-efficacy and informed decision-making and assist in developing the skills to cope, adjust and adapt to a chronic disease state. Theory-based interventions were shown to improve knowledge, self-efficacy and self-management, resulting in improved clinical outcomes and decision-making across long-term conditions.<sup>10</sup> The use of lay educators has also been shown to improve self-efficacy levels beyond healthcare professional (HCP) delivery.<sup>11</sup> Additionally, peer support provides realistic practical information about the lived experience and is helpful in decision-making.<sup>9,12,13</sup> It is important to note that predicting the rate of renal decline is complex and fraught with complicating factors and is accordingly an imprecise science. Guidelines recommend that the education of renal patients should be individualised, with high-quality information, to facilitate informed treatment decision-making.<sup>14</sup>

The aim of this article is to focus on one major theme emerging from a broader qualitative interview study of service user experiences of pre-dialysis education and treatment decision-making. Here, we identify and present examples of vicarious learning reported during the pre-dialysis year.

## Methods

### Study design

Unstructured interviews, guided by grounded theory methodology, were conducted during participants' pre-dialysis year.

### Study context

When the eGFR of people, attending the renal clinic, drops below 30 mL/min/1.73 m<sup>2</sup>, they are referred to the pre-dialysis clinical nurse specialists (CNSs).

Usual care during the time of this interview study was to offer one-to-one information from the CNS and an invitation to attend a group delivered information session to enable them to arrive at treatment decisions. The information delivered aimed to enhance patients' mastery and vicarious learning by offering individuals the opportunity to increase their knowledge and understanding of kidney failure and treatment options, see the treatment options in action, talk to fellow patients and peer presenters, meet the multidisciplinary renal team through signposting sessions and visit the dialysis units to see patients receiving treatment. This

study received ethical approval from the National Research Ethics Committee for the West Midlands (REC reference 09/H1206/82).

### Recruitment

In all, 20 participants over 18 years of age with an eGFR <30 mL/min/1.73 m<sup>2</sup> were interviewed. Participants were sampled theoretically. Data were jointly collected, coded and analysed in order to decide what data to collect next and from whom, to develop emergent themes and theory. Individuals were recruited, face-to-face by the researcher, at their routine renal low clearance clinic appointment, at two centres. Low clearance clinics cater for individuals whose eGFR has dropped <30 mL/min/1.73 m<sup>2</sup> and who need to make decisions about their choice of renal replacement therapy. Four individuals declined to participate. All participants gave written consent to participate. Recruitment occurred between September 2010 and September 2011.

### Data collection

Participants were offered a choice of location for interviews; 19 were interviewed in their own homes and 1 in the researchers' hospital office. Two participants had a partner present, and their contribution to the interview was clearly identified in transcript analysis and use of narrative. In accordance with grounded theory methodology,<sup>15</sup> unstructured interviews utilised emergent themes to elicit patients' views and opinions. This provided the flexibility to clarify and explore views, resulting in a greater depth of understanding.<sup>16</sup> Interviews sought to explore participants' subjective experiences of the pre-dialysis journey; therefore, the method of sampling was pivotal. Theoretical sampling provided the opportunity to develop concepts in terms of their dimensions, properties and variation and to identify concept relationships.<sup>17</sup>

### Data analysis

Interviews were digitally recorded and transcribed verbatim. A summarised copy of the interview transcript was offered to participants. Data analysis involved open coding, constant comparison and axial coding (Appendix 1) and was supported by memo writing. The desire to understand the pre-dialysis experience remained the focus. However, it was the concepts emerging from the interviews that continued to direct the theoretical sampling process. With each subsequent interview, the properties and dimensions of concepts and emergent themes were developed.<sup>18</sup> Data collection continued until theoretical saturation was achieved. The use of secondary coders permitted exploration of the level of agreement between coders, and hence the inter-rater reliability with which codes were applied. Qualitative data analysis software NVivo 9 was utilised to organise transcript data.

**Table 1.** Participant characteristics and interview statistics.

	Sample percentage	Number	Time
Participants		20	
Male	50	10	
Age (mean years)			61
Ethnic background			
White	70	14	
Asian	25	5	
Afro-Caribbean	5	1	
Interviews completed		20	
Mean interview length (min)			55

## Results

### *Characteristics of participants*

In all, 20 participants aged between 24 and 80 years were recruited. Interviews lasted on average 55 min. Half the participants were male, and 70% (n=14) were White, 25% (n=5) Asian and 5% Afro-Caribbean (n=1) (Table 1).

Individuals' self-reported breadth and depth of renal knowledge varied widely, ranging from those who were unaware of their renal condition and the implications to individuals with extensive knowledge gained through familial renal disease experiences. Vicarious learning emerged as individuals expressed their pre-dialysis considerations. The range of vicarious learning, learning from other people with renal disease, which had been, and continued to be, experienced by participants fell into three categories: (1) planned vicarious learning, (2) unplanned vicarious learning and (3) historical vicarious experiences.

Planned vicarious learning opportunities were pre-arranged events. Pre-dialysis patients had the chance to meet with current patients undergoing treatment.

Unplanned vicarious learning occurred in a multitude of environments, including clinic waiting rooms, during in-patient stays and through hospital-related acquaintances.

Two distinct types of historical vicarious experience emerged: first, the experience of a close family member undergoing renal treatment and, second, individuals who had themselves suffered a life-threatening condition prior to developing renal failure. Examples of these vicarious learning experiences are presented.

### *Planned vicarious learning*

A structured patient information day was offered to all pre-dialysis patients to aid their treatment decision-making process. During the planned education sessions, existing renal patients, representative of the local renal population, became vicarious role models. They shared their treatment experiences alongside HCPs on the pre-dialysis information day and had a considerable impact on attendees. Participants

commented on trust, reality and truth in peer-delivered information and appreciated their ability to 'tell it how it is', as only those with first-hand experience can: 'The patients presenting on the education day gave a more realistic impression' (Male, aged 71). Service user involvement in the information day was vital for consolidation of treatment understanding through vicarious learning and realistic presentation of treatment options, and gave participants the opportunity to talk to patients as they underwent dialysis: 'The education day put me in the right frame of mind about PD' (Male, aged 32), and 'Being able to see the set-up is more helpful' (Female, aged 49). 'I know the staff, and the nurses know about that sort of thing but it's different when it's the truth from a patient about how it's affected them' (Female, aged 58).

Participants' clearest recollection of the pre-dialysis information day was the stark reality of their predicament. Their lasting impression was of the peer presenters and homogeneity between the peers and participants:

When I went up the other day [to the PD unit] there was this lad there, he said he could forget he was on dialysis now and you can tweak it. I could relate to him it was realistic advice. (Male, aged 32)

Participants using relatedness terms conveyed the influence of homogeneity on perceptions of their own abilities to cope. Planned vicarious learning importantly reassured participants about coping with, and adjusting to, treatment. This helped them to normalise a daunting concept: 'It was interesting to see machines and the size of them and people talking, sleeping and getting on with it' (Male, aged 71).

For one married couple attending the pre-dialysis information day, there was one peer presenter but two differing interpretations: 'The guy made it look easy [PD], except he was fit' (Male, aged 64, diabetic bilateral below knee amputee) as opposed to 'It [PD] would be the final straw. I already do everything and there's my mother upstairs' (Wife and carer). So, planned vicarious learning opportunities can diametrically influence perceptions of confidence to cope with treatment.

### *Unplanned vicarious learning*

Unplanned vicarious influences on decision-making began to emerge later on in the interviews as its importance emerged in the data. It was not possible to confirm this with more participants as they had already been interviewed. Nonetheless, unplanned vicarious learning led to heuristic decision-making: 'When I was in [hospital] a gentleman was having PD removed and HD started due to repeated infections. It put me off a bit' (Male, aged 69). Identification between patients with similar cultural backgrounds resulted in decision-making that was demonstrably peer-influenced: 'Me friend, he been on haemodialysis for ten years. He said if you ever have

kidney problems don't go on it. It was painful for him' (Male, aged 64).

An unplanned peer encounter occurred for one female during the pre-dialysis information day tour of the HD unit. This encounter confirmed her concerns of not being able to cope with dialysis at home. She later reported,

I went into the dialysis unit and spoke to a female patient. She talked about going onto PD and didn't like it. She was me to a tee ... living on her own and panicking and was happy when she changed to haemo. I will listen to what they [HCPs] say and think about it but I won't let them [HCPs] talk me into it [PD]. (Female, aged 63)

Again, identification with someone similar to herself was influential.

These unplanned instances potentially present a greater propensity for misunderstanding and miscommunication of treatment information, with individuals using potentially uncritiqued information upon which to base important and expensive treatment decisions.

### *Historical vicarious experiences*

Participants with polycystic kidney disease (PCKD) had a family history of the condition and carried with them a great deal of prior experience. For one participant, familial vicarious experience during her formative years affected her life choices. Her mother had PCKD, and she assisted her in performing 'traumatic' home HD and her sister had PCKD with extensive treatment experience. She reveals the impact: 'I tend to do everything myself ... because I have a disease I don't want to be involved with somebody because it would involve them dealing with it. My sister's husband had a breakdown' (Female, aged 56). These outcome expectations influenced decisions beyond purely treatment choice.

The data illustrate another participant's decision-making founded on the needs of others as well as avoiding the treatment her mother had:

The consultant said, would you do home dialysis? And I said no! I ain't doing what my mum done I am not having the same as what she had ... Everything was done so I could be there for my mum. And I said no it's too much, not for me, it's the effect on other people. (Female aged 41)

The powerful images created by both participants, of their formative years being dominated by parental dialysis demands, are translated into their consideration of potential outcomes and treatment decisions.

Experience of prior life-threatening illness had a bearing on individuals' ability to cope with their current health situation. Having survived non-Hodgkin's lymphoma, one participant reflects,

I felt completely out of control due to chemotherapy. This time I'm making the decisions, so I arranged a visit to a haemodialysis

unit and visited a local neighbour on peritoneal dialysis and saw how PD works and how HD works and is set up ... I think if I hadn't been through, what I've been through, I would have found the thought of it [dialysis] much more daunting. (Female, aged 49)

Reflection on her personal healthcare experience, following a major illness, heightened her need to maintain autonomy and control. The gravity of prior illness frames individual's perspectives and responses to their renal diagnosis: 'I had my first heart attack in 1973. All the years and what I've been through I just accept it. My heart has always over-powered my other problem' (Male, aged 71).

For another participant, extensive hospital experience from birth influenced his initial considerations: 'I'm waiting for a transplant from my mum. If I need treatment, the PD tube at home, I'm not confident to do that. I'd start in hospital without a doubt' (Male, aged 24). However, following attendance at the pre-dialysis information day, he reflects,

From seeing that fistula I thought no way. I'll go for the tube in my tummy [PD]. HD and going in to have dialysis, with work it's not practical. Overnight is a more practical option, its convenient more than anything. (Male, aged 24)

The planned vicarious learning opportunity revealed the reality of each treatment option creating a shift away from earlier heuristic decision-making.

## **Discussion and conclusion**

### *Discussion*

This study has identified three major ways in which people with end-stage renal failure experience vicarious learning. These were planned, unplanned and historical.

Planned vicarious learning was experienced in an organised manner, as the presentation of treatment options by peers aimed to increase both treatment option understanding and informed treatment decision-making. Conversely, unplanned vicarious learning occurred in a variety of settings and tended to be negatively perceived.

Familial and life-threatening illness experience appears to be indelibly etched in individuals' minds. Educators need to be mindful and fully explore and acknowledge individuals' vicarious learning and level of expertise if they are to facilitate engaged treatment option discussions.

Identifying the types of vicarious learning, experienced by people with established renal failure, and their potential influence on treatment decision-making approach is important when considered in the context of the wider decision-making literature.

Heuristic decision-making is based on limited information in order to reduce cognitive burden.<sup>19</sup> A multitude of influences have been found to influence the decision-making process, including the impact of living with a long-term condition and the potential for discrepancy between service user

and HCP expectations.<sup>20</sup> The potential for heuristic decision-making to result in decision regret has been identified when individuals feel they could have made better choices had they considered more information and weighed the pros and cons.<sup>21</sup> Incorporation of these analytic processes into treatment decision-making facilitates a more robust process of considering different types of information and enables service users to arrive at better-informed decisions,<sup>22</sup> and the inclusion of risk benefit data is advocated.<sup>23</sup> Incorporation of analytic information has been found to significantly increase knowledge, promote active decision-making and result in informed treatment decision-making and decision satisfaction.<sup>24</sup> Exploration of individuals' vicarious learning experience and the influence it has had on their decision-making process provides the opportunity to avoid treatment decisions based on limited or inaccurate information.

Self-efficacy has emerged in the literature as an important characteristic of self-management success.<sup>7,10,25,26</sup> The emphasis in supporting self-efficacy within interventions to date has been focused on mastery experience.<sup>27–29</sup> Mastery experience, it is argued, can more effectively facilitate the development of a strong sense of efficacy.<sup>8</sup> However, in the pre-dialysis cohort, where mastery of treatment is not yet an option and the emphasis is on treatment decision-making, our extended theory emerging from this study is that 'Throughout the pre-dialysis phase of the renal patient journey, vicarious learning has an influence and impact on individuals' treatment decision-making'. If people with ESRD are to be supported in their decision-making, the impacts of their vicarious learning experience need to be recognised early on by pre-dialysis educators and planned vicarious learning facilitated during the pre-dialysis period.

Our findings contrast with Foster et al.<sup>30</sup> who found only weak vicarious learning impacts from a lay-led, chronic disease self-management programme. The peers with whom our participants associated in hospital settings or through family history were considerably more homogeneous than those in the Foster et al.'s<sup>30</sup> study, and this may account for the difference in impact. Self-efficacy is more robustly influenced by greater homogeneity between individuals.<sup>8</sup> The ability of pre-dialysis individuals to gain insight into treatment options, and how to cope, from the experience of other patients has been previously identified.<sup>18</sup> Additionally, peer influence, it has been argued, helps conceptualise dialysis reality<sup>13</sup> and offers hope for the future,<sup>12</sup> and this study further consolidates these findings.

### Study limitations

This study was part of a bigger PhD study,<sup>7</sup> with a number of aims in addition to the grounded theory study, and this may have influenced data collection and analysis. The specific context of one urban cohort, with a demographic composition reflecting the local population, limits the generalisability of findings. This grounded theory study sought depth of

understanding from a cohort of 20 individuals; although theoretical data saturation was achieved, generalisation of study findings is limited by the grounded theory methodology. Although secondary coding was employed, a single researcher only coded the majority of the data, increasing the risk of analysis bias. The grounded theory approach facilitated the development of new theory; however, the potentially important role of unplanned vicarious encounters only emerged in the later interviews, and the robustness of this emerging theory requires further investigation.

### Conclusion

HCPs need to be aware of individuals' vicarious learning experience and the influence it may have on decision-making if they are to encourage analytic and more permanent treatment decisions. However, it needs to be acknowledged that PD is the much cheaper treatment option and produces clinically equivalent outcomes.<sup>3,4</sup> Considered decision-making leads to more permanent decisions<sup>24</sup> and avoids costly changes of treatment regime such as surgical fistula formation.

We recommend that vicarious experiences should be explored and future positive vicarious learning facilitated in pre-dialysis education. We hypothesise that unplanned vicarious learning results in more heuristic decision-making than planned vicarious learning. Further research should explore the influence and impact of vicarious learning type on individuals' treatment decision-making rational and satisfaction. Additionally, there is wider applicability of these findings to other long-term conditions where treatment decisions are needed, for example, insulin initiation in type 2 diabetes.

### Practice implications

Exploration and acknowledgement of service users' prior vicarious learning by healthcare professions can be important in understanding the influence upon their decision-making. This will enable HCPs to challenge heuristic decisions based on limited information and to encourage analytic thought processes. Peer involvement in pre-dialysis education needs to be tailored to reflect the demographics of the attending participants if we wish these peers to be influential. Attention to clinical environments for patients with different needs could arrest ill-considered decision-making resulting in future lower patient treatment costs.

### Declaration of conflicting interest

I confirm all patient/personal identifiers have been removed or disguised so that the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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## Appendix I

### Worked example of open coding, constant comparison and axial coding

<p><b>Open Coding</b></p> <p><i>Loss of control.....</i></p> <p><i>Maintaining autonomy.....</i></p> <p><i>Pro-active behaviour.....</i></p> <p><i>Vicarious Learning.....</i></p> <p><i>Developing treatment decision based on lifestyle implications....</i></p> <p><i>Initial struggle with diagnosis information.....</i></p> <p><i>CNS intervention helpful.....</i></p> <p><i>Hope.....</i></p> <p><i>Misconception.....</i></p> <p><i>Established coping skills.....</i></p> <p><i>Reducing enormity of dialysis due to prior experience.....</i></p> <p><i>Remains a daunting prospect</i></p>	<p>"I felt completely out of control due to chemotherapy. This time I'm making the decisions so I arranged a visit to a haemodialysis unit and visited a local neighbour on peritoneal dialysis and saw how PD works and how HD works and is set up...when I saw the consultant in clinic I informed him of my choice and was prepared to argue the case...if I'd been able to see her [CNS] within a week of diagnosis it would have been really helpful. Her simple comment of being able to keep you alive for a 30 to 40 years and I thought, oh wow I was thinking 10 years and I'm only 49...<u>I think if I hadn't been through, what I've been through, I would have found the thought of it [dialysis] much more daunting</u>".</p> <p>Interview 1, Female, Aged 49.</p>	<p><b>Axial Coding</b></p> <p>Prior experience is driving this pro-active approach and the need to maintain autonomy. Defensive approach to medical establishment due to experiencing loss of control. Outcome expectations based on previous potentially life limiting illness.</p>
<p><b>Constant Comparison</b></p> <p>Acknowledging her own ability to cope based on prior experience. This ties in with another participant who had experienced life threatening illness and has developed extensive coping strategies, including self goal setting.</p>		