The lived experience of haemodialysis patients who have had a new arteriovenous fistula cannulated in a satellite unit

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Abstract
The purpose of this study was to investigate the lived experience of people diagnosed with end-stage renal disease (ESRD) who have a new arteriovenous fistula (AVF) cannulated for haemodialysis (HD). People on HD depend on health care workers to cannulate their AVF on average three times per week. This qualitative, hermeneutic, phenomenological study was informed by the underpinnings of Heidegger and Gadamer (Gadamer 1975, reprinted 2006). Purposive sampling was utilised to select participants who were having HD in a satellite unit. Open-ended interviews were conducted with six patients who had been on HD for a period of not more than two years. A thematic analysis was undertaken and a total of nine themes emerged: fear; surrender; bracing for the worst pain; lifeline; loss of control; you are just a number; body invasion; altered body image; and sense of hope. These findings indicate that people who are started on HD experience psychological and emotional difficulties such as fear and anxiety related to their condition and the complex treatment process.

Keywords
Haemodialysis, arteriovenous fistula, lived experience, satellite unit, cannulation.

Introduction
Haemodialysis (HD) patients who have had an arteriovenous fistula (AVF) established are likely to experience physical and psychological trauma when the vessel is cannulated. Lai et al. (2012) and McCann et al. (2008) suggest that HD patients also experience psychosocial disturbances and instability as they try to adjust to a new and totally different lifestyle filled with challenging demands and expectations. It is clear that patients diagnosed with chronic kidney disease (CKD) should be prepared emotionally, psychologically and physically before cannulation of the AVF.

Background
Although there has been substantial quantitative research conducted on the wellbeing of patients with end-stage renal disease (ESRD) undergoing HD, addressing issues such as depression, quality of life and non-adherence to fluid-intake restrictions (Cukor et al., 2006; Lok, 1996; Sharp et al., 2005; Welch, & Austin, 2001), none has investigated the experience of having needles inserted into a newly created AVF. The qualitative research on this population indicates they have complex needs. Polascheck (2003a) conducted a study on patients living on home HD and discovered that the participants...
felt loss of independence and were uncertain about their future life. In another study, Richard and Engebretson (2010) found that participants were mostly concerned about their vulnerability and that they mistrusted health care providers and that they needed more information and support from health providers. The results from these qualitative studies were substantiated by Calvey and Mee (2011) in their study that found participants were mostly concerned about losing their sense of self, especially their future self. In other studies (Giles, 2005; Hagren et al., 2005; Lai et al., 2012) findings indicated that participants raised concerns such as living a restricted life with limitations on diet and fluid intake, travel, work, social activities, being dependent on other people and the need for social support. These results were substantiated by Clarkson and Robinson (2010) who found that most of the participants experienced psychological and functional disturbance, with marked social isolation, hopelessness, anger, frustration and generalised fatigue. However, there is very limited information which addresses the patient’s perspective of their experiences with the actual cannulation, thus the purpose of this study was to explore the lived experience of patients with ESRD who have undergone cannulation of an AVF in a satellite unit.

Methodology

The qualitative approach allows researchers to collect in-depth data in order to understand patients’ illness experiences. Phenomenology is an interpretive methodology which seeks to reveal meanings that are hidden in the lived experiences of humans (Oiler, 1982). The use of interpretive phenomenology in this study allowed illumination of the phenomena, while preserving the uniqueness of the particular experience (Schneider et al., 2012). In addition, it provided an ontological understanding of what it means to have large-bore needles inserted into a newly created AVF to get dialysis treatment.

Methods

The setting for this study was a four-chair unit set in regional South Australia which caters for a total of 16 patients. A convenience sample was recruited, which was comprised of four females and two males, with ages ranging from 44 to 75 years. They had experienced the initial cannulation of their AVF from three to 12 months prior to the interviews.

Prior to conducting this study, ethical approval was sought and obtained from both the Regional Health Authority and The University of Adelaide. Consistent with the hermeneutic phenomenological approach, data were collected through taped interviews and field notes (Dowling, 2007). The six HD patients who participated in this study were given pseudonyms. Open-ended questions were used to capture detailed accounts of the participants’ experiences. The interviews were conducted in the side room to minimise background noise, lasted between 30 and 60 minutes and were all audio-taped. The opening question was, “I understand you had a fistula created for dialysis treatment; would you tell me more about that?” In addition to audio-taping the conversations, field notes were written. These included a summary of the participants’ emotions, facial expressions, tone of voice, meaningful metaphors as well as recalled body language displayed during the interviews as they related their experience of undergoing cannulation of a new AVF.

A thematic analysis of the data was undertaken. The six steps for data analysis developed by van Manen (1990) were followed whilst fusion of horizons by Gadamer (1975, reprinted 2006) was also incorporated. The use of the interpretive phenomenological analysis enabled the researcher to enter the participants’ life world so as to understand and give an accurate account of their experience of undergoing cannulation of a new AVF in a satellite unit (Smith, & Osborn, 2003).

To ensure trustworthiness, the principal researcher transcribed all the tapes verbatim whilst the conversations were contemporaneous to allow the voices of research participants to be represented. The completed scripts were then given to the respective participants to read through and comment where necessary to ensure credibility. The researchers jointly considered the analysis and agreed on the themes.

Findings

A qualitative analysis of the data revealed nine themes. These were generated from the rich descriptive information given by the participants and are presented together with supporting verbatim quotes to facilitate understanding of how the interpretations emerged from the data.

Theme 1: Fear

Patients experiencing chronic illnesses such as ESRD and who require constant interaction with health care staff often feel vulnerable because they depend on the staff to sustain their health and wellbeing. Participants vividly remembered and gave an in-depth description of their memories and feelings of the time they were started on dialysis.

I was very scared when the specialist told me that I would be started on haemodialysis because I did not know what that was going to do to my body. My fear got worse when they told me that I would be moved to a smaller unit closer to home (Bertha, p. 1, 10–11).

Theme 2: Surrender

Some of the participants felt that even though they were anxious, confused and uncertain about the whole procedure
they had no alternative other than to surrender to the health care providers.

All I can remember on the very first day is that I tightly closed my eyes and surrendered my arm to the nurse and then I waited for the big pain to come. I remember hearing her telling me to relax and not hold my breath (Bertha, p. 1, 20–21).

Theme 3: Bracing for the worst pain

The majority of the participants in this study reported pain as one of their worst fears when they started on dialysis. They mentioned that they were given local anaesthesia before cannulation so as to minimise the pain, but some felt that the local anaesthetic was as painful as the actual cannula. Others blamed staff for causing the pain and bruising:

The needle is tiny but I guess the damn thing is equally painful ... then I would feel the big needles being pushed in ... I still feel pain when they [the nurses] hit a nerve, whoa, that is painful (Jonah, p. 1, 20–21).

Other participants also expressed negative experiences during the early days of AVF cannulation:

I used to dread coming for dialysis due to fear of the painful needles but now I am getting better. Maybe it’s because my fistula was still soft but now it is well developed and I am no longer getting any bruises as I did initially (Juliet, p. 1, 29–30).

Participants also blamed health care staff for their technique during cannulation, as related by Bertha:

I do as I am told when it comes to caring for my fistula because if it packs up then that will be the end of my life. I have to protect it and I have been taught how to check for signs that it is working well, even when I am at home. I have even taught my partner ... how to check my fistula ... (Bertha, p. 2, 15–17).

Theme 4: Lifeline

A functional AVF is necessary to achieve successful HD. The majority of the participants expressed their awareness of the critical importance of the vascular access. The participants’ stories portrayed sub-themes like fear of losing the AVF, displaying concern, self-awareness and taking responsibility:

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Participants also described how much they valued their fistula:

I will do anything to protect my fistula, because without it I might as well kiss life goodbye. The fistula is my soul mate so we will stick together no matter what ... I know that without a fistula I will die because I won’t be able to do dialysis ... (Juliet, p. 1, 33–34).

Theme 5: Loss of control

Patients experiencing chronic conditions like ESRD requiring HD three times per week have to reorganise their daily routine around their treatment time. The participants in this study felt that this new treatment schedule causes dependency on the health care providers and family members. The sub-themes that emerged included loss of sense of pride, loneliness and vulnerability, fear of self-regard and positive identity as well as disruption of daily routine.

This disease has separated me from my friends because I have to attend this silly dialysis in order to live. I had to give up my job because my energy levels are always low ...

... I have to depend on nurses to stick the needles in my arm and the doctors to tell me which tablets to take so that I can live ... you know it just sucks to lose your independence and keep on wondering what the future holds for you ... (Marie, p. 1, 22–24).

Theme 6: You are just a number

Several participants felt that they were not given enough attention or valued by the nurses. The sub-themes that emerged were self-pity, and feeling disrespected, dejected and lost.

... nobody talks to you, you feel like you are just a number, you know. No respect at all, even for the elderly. I have done a lot for this country and I deserve some respect. (Boris, p.1, 21–23).

Theme 7: Body invasion

Many participants felt vulnerable due to the fact that their bodies had been invaded as a result of the ESRD.

... how can those big needles not hurt when they pierce my skin huh? They are the biggest needles I have ever seen in my life. ... I am getting needles three times per week to live ... (Bertha, p. 1, 33–34).

Theme 8: Altered body image

Some participants struggled to cope with their new body image after the creation and cannulation of the new AVF and they vented their irritation through their stories.
Theme 9: Sense of hope

Even though the majority of the participants in this study portrayed mostly negative and painful experiences, some appreciated the service received and expressed their gratitude. They trusted the health care workers to care for them and give them a future.

*I could have been dead if it was not for this treatment so my heart goes out to all the health staff. I am really honoured to have such a great team because now I get to see my grandkids growing* (Marie, p. 1, 34–35).

Discussion

The purpose of this study was to investigate the lived experience of patients who had experienced cannulation of a new AVF for HD in a satellite unit. HD can cause emotional and physical disturbances to patients with ESRD who come in for regular dialysis. The unit is full of machines and there is the constant noise of alarms that require immediate response from staff. Patients feel very vulnerable in such environments; therefore it is important that they are empowered with education pertaining to their disease process and treatment outcomes (Clarkson & Robinson, 2010). Richard and Engebretson (2010) in their study exploring how patients negotiate living with an AVF, reported that dialysis clients mistrusted health care workers and that the reasons for this require investigation.

The findings of this research were consistent with those of the study by Richard and Engebretson (2010) in that all participants in this study expressed feelings of fear and mistrust of the health care workers, the system and the equipment. The emotions displayed were mostly fear of the unknown and a feeling of uncertainty towards the whole process but they had no option other than to surrender to the treatment in the hope of getting better. The fact that they were unwell and had undergone an invasive procedure to create the AVF was overwhelming for the clients who also had to cope with being transferred to a new unit for their treatment.

Although participants realised that they had to rely on health care staff for their wellbeing, they still felt sceptical about the whole process because they did not know what was in store for them. Even though some admitted that they were given comprehensive information about the procedure prior, that did not stop them from worrying. In a study by Kaba et al. (2007), one of the participants referred to “a road with no end”, where there was constant uncertainty or fear of the unknown. Similarly, a study by Polaschek (2003b) regarding the experience of living on dialysis also found that participants shared the feelings of uncertainty due to their chronic illness.

This study identified surrender as one of the main themes. They indicated their fear and mistrust of the unfamiliar faces, “big needles” and the noises from the “big machines”, but because they wanted to get better they “surrendered” to the health care providers. Some of the participants described traumatic experiences with nurses having difficulties cannulating the AVF, resulting in a “blown-up” AVF and large bruises. This is consistent with Hagren (2005), and Richard and Engebretson (2010), who identified vulnerability amongst their participants due to the fact that they had to depend on the expertise and competency of the nurses to cannulate their AVF.

Pain was another experience endured by all participants, with one describing it as “bracing for the worst pain”. Two participants related how they associated each needle with pain, even though the first two provided local anaesthetic prior to the large needle being inserted. The experience was scary as much as it was painful because the needles were inserted whilst the participants watched. One participant was concerned with the size of the needles (big and long) and they felt that the needles were “thrown like a rocket”, indicating the technique used by the staff made them feel even more vulnerable.

Another important finding from this study was that participants felt they had lost control of their lives. They indicated that they had to depend on nurses to cannulate their AVF, on doctors to manage their medication and on their families to help them manage in their new routine. They expressed that their life was restricted because they had to attend HD three times per week. This is congruent with Clarkson and Robinson (2010), Hagren et al. (2005), and Heiwe et al. (2003), who found that HD patients often lose control of their lives due to continued physical and mental fatigue which limits their activities.

The participants in this study identified the AVF as their lifeline. Even though they experienced some problems such as pain and bruising, they acknowledged that it was essential. This was congruent with Giles (2005, p. 30) who reported that there was a “struggle between the lived-body and the dialysis machine” but still the participants depended on the machine to save their lives.

Another important element highlighted in this study was body invasion and altered body image. Lok (1996) indicated that clients with AVFs experience stigma because of the swelling and numerous bruises related to the AVF.

Participants in this study also described emotional events that led to the emergence of the theme “you are just a number”. They felt disrespected by the providers who were too busy...
“rushing around”. The participants also felt that they were disrespected because they were “too young or too old”. The feelings depicted by these participants seem to focus on fear of the new environment and also being unsure of the responsibilities of the staff.

One limitation of the study to consider is the time lapse between the first cannulation and the interview date; this could have affected the stories related by the participants.

This study revealed the meaning of having a new AVF cannulated for HD. These findings could be utilised for further research into how to alleviate the fear, pain and feeling of just being a number, which were expressed by the participants. Research into how to start and build support groups for dialysis patients, especially in regional units, would be worthwhile.

**Conclusion**

The research revealed patients having their AVF cannulated for the first time experience an array of emotional and distressing experiences. It is evident that patients commencing HD require considerable psychological and emotional support, especially when the AVF is still new. While there is substantial research concerning the process of HD, this research focused on the patients’ experiences of the first cannulation of their AVF.

Staff need to recognise how traumatic this experience may be for the patients. Fear and pain were identified as the major problems for participants in this study. It is imperative that staff are empathetic and give as much information as possible to clients and their families before, during and after HD, to reduce the anxieties that emanate from fear of the unknown.

**References**


