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Facilitators and barriers to treatment with haemodialysis among persons in mid-adulthood: an Interpretative Phenomenological Analysis

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Abstract

Background: The quality of life of persons on haemodialysis is often limited by the restrictions imposed by their medical regimen. These restrictions may negatively influence patients' adherence to their treatment. Therefore, in an effort to improve patient adherence to treatment, there is the need to explore the patients' perceptions of facilitators and barriers in relation to their experience of haemodialysis.

Objectives: The purpose of the study was to explore the perceived barriers and facilitators of the haemodialysis experience of persons in mid-adulthood.

Participants and Design: A qualitative design was used. Semi-structured interviews were conducted with seven participants in the mid-adulthood phase (40-65 years). The transcribed texts were analysed using an Interpretative Phenomenological Analysis (IPA) approach.

Results: Three main themes were identified from the analysis: 'Social network outside the renal unit,' 'The renal setting as a context' and 'Qualities relating to staff'. Facilitators identified include: support from family and work colleagues, caring and knowledgeable staff and consultation with patients when planning out the treatment schedule. Barriers to treatment include: discomfort with the needling process, intrusion of haemodialysis on family time, lack of privacy in the renal unit and staff that do not take their concerns seriously.

Conclusion: This study demonstrated the need for healthcare professionals to allocate time and space, where persons on haemodialysis may discuss personal issues that relate to their care experience in a private care setting. By identifying and exploring the barriers and facilitators of patients on haemodialysis, healthcare professionals may formulate individualised care plans which may improve patients' adherence to their haemodialysis treatment.

Keywords: haemodialysis, interpretative phenomenological analysis, lived experiences, qualitative

INTRODUCTION

With the development of renal replacement therapies, the lives of persons with end-stage renal disease (ESRD) has been prolonged (1). Haemodialysis (HD) treatment requires the patient to attend a hospital for about 3 times a week for a 3 to 4 hour session (2). During this treatment waste products from the blood are removed into the dialysis fluid and then discarded (3). Due to an aging population and the increased incidence of persons with cardiovascular disease and diabetes, the number of cases of persons on dialysis is rising by 5% per annum (4). However, non-adherence to HD treatment remains an issue, with estimates between 25% and 86% of patients non-adherent to their treatment (5). Furthermore low levels of adherence have also been correlated with an increased risk of patient mortality (6).

Thus, health professionals face a major challenge in targeting the low adherence to treatment of patients with ESRD (7). Hence there is a need to go beyond describing rates of adherence and explore reasons for non-adherence from the patients perspective (8). This is of particular relevance, as the illness perceptions of patients are potentially modifiable and have been linked to non-adherence and even survival in patients with ESRD (9). Furthermore, these illness perceptions play a critical part in evaluating the effectiveness of a coping procedure, such as undertaking haemodialysis (10). Such an evaluation would include determining barriers and facilitators affecting the successful performance of the treatment (11). As a consequence of this process, patients may then maintain or alter their illness perceptions, as well as their coping procedures. Hence, the present study contributes to the available literature by exploring the

perceived facilitators and barriers in undertaking HD, as there is a dearth of research regarding the treatment perceptions of individuals with ESRD (12).

To date qualitative studies on persons undergoing haemodialysis for ESRD, tend to focus on the quality of life of these individuals (13). Moreover these studies often target heterogeneous groups of individuals in the early, mid and late phase of adulthood collectively (14-16). However exploring the experiences of adults with HD collectively fails to acknowledge that their experiences are influenced by age (17, 18), since different life issues are encountered at different phases of a person's life (13).

Hence, the present study contributes to the available literature, by exploring the perceived barriers and facilitators to HD, in patients during mid-adulthood. This phase is described as a contemporary phenomenon (19), usually lasting between the ages of 34 and 60 years (20). It is a stage during which there is an increased concern about one's body, as well as an increased reflection about the meaning of life (21). Moreover the concerns experienced during mid-adulthood are of particular relevance to persons on haemodialysis who express a loss of purpose in life (22), a sense of vulnerability (15) and changes in their body function and image (13). Consequently there is a need to explore the patient's appraisal of their experience on HD, at a phase when adults are particularly susceptible to being negatively affected by this treatment. In addition, a review of the literature has indicated only one qualitative study (22) which focused specifically on the barriers and facilitators to treatment with HD in mid-adulthood (39-63 years). The sample consisted of 9 ethnic Chinese and 4 Malay patients who have been undergoing HD for 6 months or less. This study identified, experiencing of negative symptoms (e.g., fatigue and muscle cramps), intrusion of haemodialysis on their preferred lifestyle (work, social life); time consuming treatment and the discomfort associated with needling of access sites as barriers to

treatment. Conversely, aspects identified as facilitating the experience of haemodialysis were informational and instrumental support (e.g., accompaniment to HD sessions) from family, friends and health care professionals.

Therefore, the present study extends research to date by focusing on the perceived barriers and facilitators of persons in mid-adulthood with ESRD and who have been on haemodialysis for more than one year.

MATERIALS AND METHODS

This qualitative study was conducted on participants receiving haemodialysis within the renal unit, which represents a specialised health care context. Interpretative phenomenological analysis (IPA) was the methodological framework used as it elicits rich and contextually grounded understanding of a phenomenon (23) based on the individual's lived experiences and the meanings that they attribute to them.

IPA is based on three major philosophical influences of phenomenology, hermeneutics, and ideography (24). Phenomenology addresses the subjective experience of how individuals make sense of their own life experiences. Hermeneutics considers the interpretative process with the researcher "trying to make sense of the participants trying to make sense of their world" (25, p. 51). Ideography addresses the importance of understanding the unique experiences of the individual, within a particular context. An idiographic enquiry thus involves homogeneous samples with individuals who have experience of the phenomenon (24). Our study participants

represent a reasonably homogenous sample as they were all patients within a specific age range (i.e., mid-adulthood) undergoing HD in a hospital setting.

Seven interviews were conducted: 3 with female participants and 4 with male participants. The age of participants ranged between 40-65 years. Inclusion criteria were that participants: (i) received haemodialysis for 3 times a week (ii) have been on haemodialysis for at least 1 year (iii) were aged between 40-65 years (i.e., mid-adulthood) and from both genders. Six of the participants were living with a spouse/partner and one was single, living with her parents.

Three of the participants have been on haemodialysis for less than 2 years, two patients between 3-7 years and the remaining 2 patients between 10-15 years. Additionally, 3 participants from the total sample were in full time employment.

DATA COLLECTION

Data were collected through semi-structured interviews with chronic haemodialysis patients. The interviews were audio-taped and were held in a private room at the renal unit in hospital. Pilot work was conducted with 2 participants to test the effectiveness of the interview schedule and time required for completion. The actual study was then conducted with 7 participants and the interviews lasted between forty and sixty minutes. The interview consisted of an open-ended question, 'Can you tell me about your experience of living with haemodialysis'. This question enabled participants to commence the interview by describing their own unique view of this experience. Follow-up questions were then asked to enable further clarification and/or

elaboration such as: ‘Can you elaborate further on this...’, ‘Can you give an example...’, and ‘What has this experience meant to you’ This paper focuses specifically on what the participants described as facilitators or barriers of their dialysis experience.

DATA ANALYSIS

Data from interview transcripts were analysed using interpretative phenomenological guidelines outlined in Smith et al. (24). Primarily the audio-recorded interviews were transcribed verbatim . This process involved several readings of the first transcript, noting down any initial thoughts and key phrases used by participants that capture their experiences. This primary analysis was conducted by the first author to enable immersion in the data.. The next stage consisted of coding on the annotated transcript, in which patterns and connections across the data were noted. These codes were then grouped into themes or subthemes depending on conceptual similarities and differences (Table 1). This procedure was conducted independantly by both authors to enhance rigour and then discussed to arrive at a consensus.

Yardley’s (26) criteria were applied in this study to address issues of rigour. Transparency is demonstrated through the inclusion of verbatim excerpts from each participant.

ETHICAL CONSIDERATIONS

Prior to conducting this study, ethical approval (approval number: 014/11) was granted from the University of Malta Research and Ethics Committee and permission was also obtained from the hospital authorities. Potential participants were initially approached by the Nursing Officer at the renal unit and provided with an information letter explaining the nature of the study and the right to withdraw from this study at any point during the research. Those participants who

expressed willingness to participate were then contacted by the first author. Before the interview each participant was provided with the opportunity to ask any questions. A consent form was then signed, indicating voluntary participation in the study. Pseudonyms were applied throughout the study to maintain participants' confidentiality.

RESULTS

Aspects influencing the haemodialysis experience

All the participants identified various facilitators and barriers that influenced their haemodialysis experience. Three main themes were identified from participant responses. The first theme deals with the patients' social network outside the renal unit, the second theme focuses on the renal unit as a context and the final theme describes qualities in staff providing care. The main themes and corresponding subthemes relating to facilitators and barriers of the haemodialysis experience are outlined in Table 1. These will now be described in the following sections.

Table 1: Themes and subthemes relating to facilitators and barriers of the haemodialysis experience

Themes	Subthemes
Social network outside the renal unit	Being a burden on work colleagues Disrupted family life Support from family and friends
The renal setting as a context	Lack of privacy Interacting with peers
Qualities relating to staff	Staff competence Accessible staff

Social network outside the renal unit

In this theme the respondents highlighted aspects relating to family and work which have an impact on their experience of haemodialysis.

Being a burden on work colleagues

Three participants highlighted their concern in having to leave work early, to attend their haemodialysis session. Consequently their colleagues had to complete any unfinished work for them. This resulted in a very frustrating situation as described by Steve:

“I know that I have to attend for haemodialysis, otherwise I will die and without work I cannot maintain my family. As I have to leave work early, they [work colleagues] will have to finish what I do not manage to do.....This is not fair on them”

Disrupted family life

However, persons on HD not only struggled with work related issues, but also many of them described the negative impact of spending less time with their family due to their treatment. For instance as described by Karl:

“ I attend one of the sessions on a Sunday so that I do not miss another day of work....Before I suffered kidney failure, I used to spend Sundays outdoors with my family, but since I became sick, I have to deny myself the family outing to come for haemodialysis...”

Support from family and friends

Although HD as a treatment had an impact on their daily life, however all participants described examples of support which facilitated their experience of HD. One of the participants Daniela, explained that her husband was a great source of support as he encouraged her to attend the

renal unit for treatment. She emphasised that this encouragement helped her as she would recall his words whilst undergoing treatment.

“Before I leave, my husband always fills me with a positive attitude that everything is going to be fine during the four hours of the treatment....his words really sustain me when I feel frustrated and fed up during the session....In fact when I am fed up, I always remember his words when he tells me: ‘if you feel upset during the session, remember that the machine is allowing you to continue living and so we can continue enjoying each other’s company’”

Whilst Steve described the support of colleagues at work in the following excerpt:

“They tell me not to worry [at leaving unfinished work]....they are a real support for me and sometimes even call me during the treatment, to put my mind at rest that all is fine at work”

The renal setting as a context

In this theme the respondents described how being dialysed next to another person enables them to occupy their time, however it also prevents them from being able to discuss personal matters with the staff.

Lack of privacy

Four participants explained how the structure of the renal unit deprived the patient of a measure of privacy and this caused them concern. This is because every patient is dialysed next to two other patients, with only the dialysis machine separating them. This may be a source of embarrassment as described by Daniela:

“It is very embarrassing for me when I have to discuss a personal issue with the staff...although there is a machine in between each station, there is not enough space to stop anyone overhearing what I would be saying...and I am certain that they would be listening because afterwards they would ask me about it or pass comments....”

Additionally, whilst some participants did not mind discussing their health problems in front of other patients, all the participants agreed that they did not feel comfortable discussing personal and private matters. Such personal issues often relate to difficulties in relating family and work related issues with the need to attend and undergo HD. As described by Christopher:

“I do not mind discussing my health problems with the nurses in front of the other patients....because they all attend the treatment because they are sick.... but if I have to discuss personal matters in front of the other patients, then that bothers me that I can be overheard...so I do not discuss personal matters during the treatment but after the session when I can talk to a nurse privately....”

Interacting with peers

Participants such as Karl however also acknowledged that being dialysed next to other patients could be perceived as facilitating their experience of HD, as it enabled them to interact with other patients and thus occupy their time.

“Conversations during haemodialysis help me not only to avoid looking at the clock but are also learning experiences. For example during my last session I was chatting with a patient who has been on dialysis for the past 5 years and he explained to me what I can do to prevent myself from having a drop in blood pressure...”

Qualities relating to staff

All the respondents described how qualities in staff facilitated or posed a barrier to their experience of dialysis.

Staff competence

All the participants cited various positive comments regarding the professional attitude of the nurses, and declared that the majority of the nurses were caring, supportive, and knowledgeable.

This can be illustrated by Steve's excerpt:

“Personally I have never come across more professional and more dedicated nurses as the ones at the renal unit.... Apart from being very caring and professional they are also very knowledgeable about their work, and can answer all my questions about the kidneys or about the dialysis machine...”

Annette also expressed her appreciation that nurses would consult patients as described in the following excerpt:

“Nurses in charge of the treatment scheduling consult patients on their preferred dates [for haemodialysis]. This helps us continue living our lives as normally as possible and is so important for emotional healing and helping us to accept our condition”

However, five of the participants also had some negative comments to make. They mentioned that there are a few nurses who do not have the same level of professionalism and skill as their

colleagues. For instance Daniela described how she expected nurses to be close to their allocated patients during the final critical thirty minutes of HD, as it was during this period that a patient's blood pressure could plummet. She perceived that having a nurse present, would enable immediate action to be taken if an emergency should arise. Adrian however described experiencing anxiety at the start of a HD session until he knew which nurse would be needling him, as this influenced whether the needling process would be painful or not. He stated that:

“Some really hurt me whilst others do not, I don't know why because they are all trained in the same manner. It is not a question of experience because there are new nurses with whom I experience no pain, whilst there are veterans who really frighten me because they end up hurting me”

Adrian continued to describe how he normally is his 'usual self' whilst awaiting his turn for HD, however after a bad experience he dreads attending for the following HD session:

“There are times when I get tense and upset. This happens after experiencing a bad session in a previous appointment, such as experiencing cramps or a low blood pressure. That makes me anxious for the following session. I get more and more anxious as the time approaches for me to leave home, and I am quite tense on entering the waiting area ...”

One participant (Annette) emphasised that it is important that nurses are knowledgeable about the physiology of the kidneys and how the machine functions, but in addition they should be aware about the emotions and sentiments experienced by patients. The need to actively listen to the patients is explained by Emma:

“The nurse may know all there is to know about the renal function and how a machine works but s/he can never understand what I am feeling at that point in time...from experience I know that

my blood pressure just suddenly drops and as soon as she [the nurse] removed the cuff I felt very dizzy and my mind was foggy...I asked her to check my blood pressure and she just walked off, leaving me wrestling with my mind and body to stay alert and not pass out ”

Accessible staff

Two participants, who attend the unit in the afternoon, expressed their dismay that they did not have the opportunity to consult a doctor or their nephrologist as Steve described.:

“Since I attend the afternoon sessions, I can never meet my consultant or his doctors because they visit the unit in the morning.....so I either have to wait three months for an outpatients appointment or I have to go for a private appointment.....”

Such findings may reflect the limited time available for communication with particular physicians, during which time patients could discuss their concerns.

DISCUSSION

The present study provides an insight into the various facilitators and barriers which are experienced by patients in mid-adulthood on HD. The following three themes emerged from an analysis of participants transcripts: the social network outside the renal unit, the renal setting as a context and qualities relating to staff.

The Social Network outside the renal unit

Participants in this study identified the support provided by work colleagues and family as facilitating their experience of HD, by encouraging them to attend for HD sessions. Furthermore,

although three participants described feeling frustrated at having to leave work early to attend HD sessions, they appreciated that their colleagues completed any unfinished work for them. Additionally, attending for a HD session during the weekend, enabled them to decrease the amount of time spent away from work, however this curtailed the time that they could spend with their family. Furthermore, findings in the present study were consistent with previous research (12, 15, 16, 27), as participants perceived HD as something on which they were dependant, but additionally as an object of frustration, due to the restrictive effect that it had on their lives. In fact, HD treatment gave the participants little space for living, because the dialysis treatment was perceived as a repetitive procedure and time-consuming. However one participant (Annette), emphasised that the burden experienced in undertaking HD, could be mitigated by involving patients in decision making. She explained that allowing patients to select their preferred dates and times for dialysis assisted them in negotiating HD into their lifestyle and enabled them to live 'life as normally as possible'. Moreover supporting patients in negotiating a treatment into their lifetyle has important implications for persons in mid-adulthood, who gauge their self worth in relation to their contributions to social units such as the family, work and the community (20).

The renal setting as a context

The present study contributes to the extant literature by demonstrating that the renal unit emerges both as a potential barrier, as well as facilitator of the patients experience. Four participants described that being dialysed next to other persons enabled them to interact with others and thus occupy their time. However, all participants expressed their concern that the structure of the renal unit deprived them from a measure of privacy, in which they could discuss personal and private matters with a health professional. These findings thus highlight that participants value

the role of the health professional, not only to clarify any queries relating specifically to how the 'kidney and the machine functions' but also regarding personal and private matters. Consequently patients should be provided with the opportunity to discuss personal experiences which relate to their HD experience with a professional and in a setting which provides them with a measure of privacy.

Qualities relating to staff

The participants in this study described the majority of staff as caring, supportive, well skilled and knowledgeable and this facilitated their experience of HD. However, some participants commented that not all nurses showed the same degree of professionalism and this made them anxious. These results concur with those of Hagren et al. (28) who demonstrated that not all nurses were providing good quality care to the patients and as a result this made the patients anxious. Furthermore, the study participants stated that they expected nurses to be present especially during critical periods of their treatment (the final thirty minutes of HD), when participants could experience distressing symptoms, such as a sudden fall in blood pressure. Hence, it is important that staff working in a renal setting to address patient concerns regarding symptom burden, both due to the link with emotional distress in patients, as well as hindering their adaptation to HD (29).

The present study however also extends findings from Lai et al.'s (22) study on persons with ESRD in mid-adulthood. In their study participants who had been on HD for less than 6 months, recounted narratives which were dominated by symptom burden, loss of purpose in life and intrusiveness of HD on their lifestyle. However in the present study, persons in mid-adulthood who had been on HD for more than one year, tended to focus more on attempting to manage any

restrictions imposed on their life due to HD. Patients strived to achieve this through support obtained from family, friends and health professionals, as well as taking an active role in decision-making regarding their treatment.

Thus through an exploration of the barriers and facilitators identified by patients on HD, health professionals may gain valuable insight which would enable them to provide the necessary support and understanding to persons following this treatment regimen..

LIMITATIONS

As typical of IPA research, the study was undertaken with a small sample of participants and thus the findings obtained cannot be generalised to a wider population. However, the aim of the study was not to generalise the findings but rather to provide an in depth exploration of the perceived barriers and facilitators of HD.

IMPLICATIONS FOR PRACTICE

It is important that nurses and healthcare professionals understand the patients perceived barriers and facilitators of their experience on HD, as this may have an impact on their adherence to treatment. By gaining such insight, individualised care plans can be formulated which target the unique needs of the patient. Furthermore, patients should be provided with the opportunity to discuss any issues privately with the health professional and not in the presence of other patients. This requires the development of a culture of care in which health professionals and patients collaborate in achieving an effective strategy to enhance patient adherence to treatment.

CONCLUSION

This study has described the perceived barriers and facilitators that patients in mid-adulthood experience within a renal setting. This study suggests that patients struggle to negotiate HD into their lifestyle and that family, colleagues and professionals may serve as sources of support. The renal care setting has been identified both as a facilitator (enabling patients to occupy their time whilst on HD) but also as a barrier (as patients cannot discuss personal matters in privacy with a professional). Qualities in staff may also facilitate the patients experience of HD but may also serve as a barrier, such as when professionals do not address the patients' concerns.

Hence health professionals should acknowledge that each patient is unique and thus any support provided must be fine tuned to the individual patient's needs. Thus, health professionals should explore the patients' appraisal of their treatment regimen, which includes their perceptions regarding facilitators and barriers to their HD experience and in conjunction with the patient formulate a care plan that targets the concerns raised.

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