Pictures and Perspectives - A Unique Reflection on Interdialytic Weight Gain

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Abstract

Background: People undergoing haemodialysis are required to follow a complex treatment regime that includes dietary and fluid restrictions. Of these restrictions, interdialytic weight gain is often used as a marker for measuring adherence. Historically, research into interdialytic weight gain has focussed on interventions devised by clinicians and utilised quantitative methodologies with little consideration being given to how these people deal with fluid restrictions.

Aim: The purpose of this study is to examine perspectives of managing interdialytic weight gain and describe the meaning of fluid restriction for people on haemodialysis.

Method: This research used a qualitative study that involved in-depth interviews to elicit patients’ stories. Participants were invited to use images to support their story telling. Data were analysed using an iterative theming process.

Results: Themes that arose from preliminary data analysis include magnitude of loss, constant struggle and transition to acceptance. Transition to acceptance is not a linear progression to understanding and compliance but a multifaceted, tortuous struggle unique to individuals and largely dependant upon support, belief in a life worth living and willingness to engage in surveillance and maintenance behaviour.

Conclusion: Appreciating the impact and meaning of fluid restriction for people on haemodialysis will assist health professionals to identify support strategies that facilitate healthy fluid gain behaviours.

INTRODUCTION

Chronic illness that disrupts or causes the loss of bodily functions encroaches on a person’s understanding of self. It is often characterised by adjustment to new forms of knowledge, high levels of uncertainty (Mishel, 1990) and challenges to a person’s understanding of their own identity (Seymour, 1989). Turner (1996, p.220) suggested that “disease which entails a loss of self is the most proximate and universal form of human estrangement”. Chronic illness requires individuals to revise their sense of self and their relation to the world (Seymour, 1989). The individual uses this process to find meaning in the transformation from their old self to their new self.

The progression from chronic kidney disease to end stage kidney disease (ESKD) requires the individual to make profound adjustments to their accepted way of living (Curtin, Mapes, Petillo, & Oberly, 2002). In order to support people living with ESKD it is imperative to understand the personal meaning of disruption and the nature of their experience living with renal disease. Unfortunately, nursing staff tend to make assumptions about understanding the life experiences of those they care for (Molzahn, Northcott, & Dossetor, 1997).

This paper describes the meaning of fluid restriction and the perspectives involved in managing Interdialytic Weight Gain (IDWG) for a small group of people undergoing haemodialysis in a regional dialysis unit. The motivation for this research was to provide a voice for those who undertake haemodialysis so that clinicians caring for them will be able to comprehend, not assume they understand the disruption that managing IDWG causes to these people’s lives.

BACKGROUND

People undergoing haemodialysis are required to follow a multifaceted and often evolving treatment regime that includes dietary and fluid restrictions that are complex and often difficult to comprehend. Fluid restriction is suggested to be the most difficult component of self management for people with ESKD (Johnstone & Halshaw, 2003; Sharp, Wild, & Gumley, 2005).

IDWG is influenced by many factors including environmental, nutritional, behavioural, biological and psychological (Hwang, Wang, & Chien, 2007; Sarkar, Kotanko, & Levin, 2006). The consequences of high IDWG and associated chronic fluid overload include intradialytic cramping and hypertensive episodes, left ventricular hypertrophy and congestive heart failure, hypertension, acute pulmonary oedema, and increased mortality (Leggat, 2005; Movilli, Gaggi, Zubani, et al. 2007; Oldenburg, Macdonald, & Perkins, 1988; Saran, Bragg-Gresham, Rayner, et al. 2003). These co-morbid burdens further erode the quality of life for people on haemodialysis.

Much of the attention to IDWG in the renal literature is focused on predictors of non-adherence, managing the intradialytic consequences of excessive IDWG or interventions to decrease IDWG. The majority of research has focused on interventions devised by clinicians to decrease IDWG. This reflects a positivist approach to health management and research which discounts people’s perspectives or experiences. Health professionals do not have exclusive ownership over ideas about health and disease (Seymour, 1989). In fact, interventions devised by clinicians to improve health outcomes may have less impact because patients do not identify such measures to be related to their own perceptions of their experience (Casey, Johnson, & McClelland, 2002; Seymour, 1989). Although a number of qualitative studies have examined the experience of living with ESKD (Curtin et al. 2002; Faber, 2000; Hagren Pettersen, Severinsson, et al. 2001; Hagren, Pettersen, Severinsson, et al. 2005; Lindqvist, Carlsson, & Sjoden, 2000;
Adherence to fluid restrictions necessitates a heterogeneous array of adaptations to entrenched behaviours and health beliefs (Kaveh & Kimmel, 2001). Behavioural based adherence is a multidimensional phenomenon influenced by health beliefs and attitudes, patient-health provider relationships, knowledge base, social support structures, coping skills and relationships, self efficacy, locus of control, and satisfaction with factors influenced by the treatment regime (Brown & Fitzpatrick, 1988; Cameron, 1996; Lindberg, Wikström, & Lindberg, 2007; Mok & Tam, 2001).

METHOD

Research Question

What is the experience of managing interdialytic weight gain (IDWG) for people on haemodialysis?

Design

This study utilised a mixed method design incorporating qualitative and quantitative data. The qualitative phase reported here aimed to identify themes, patterns and behaviours that characterise the meaning attached to people's experiences of managing their fluid weight between dialysis sessions. Approval was gained from the Hunter Area Human Research Ethics Committee prior to commencing the study. Informed consent was obtained from the participants prior to them being interviewed. Participants were asked to bring an artifact (eg: photograph, montage, or statue) to the interview that they felt would further assist the researcher in understanding their experiences.

Participants were drawn from a population of 70 community satellite haemodialysis patients. Eligible participants were classified as adults over 18 years of age who undergo community based haemodialysis; who were able to provide informed consent; and who speak English well enough to be able to share their experiences without difficulty. Potential participants were excluded from the study if previous diagnoses indicated impaired mental capacity. Eleven participants were excluded from the initial randomisation: five because they did not speak fluent English; two due to diagnosed cognitive impairment. An additional four participants were excluded because they had been on haemodialysis for less than four weeks.

Seven participants, six of whom were female, were randomly selected by choosing every third person on the eligibility list. Their ages ranged from 39-82 years old with a mean age of 65.6 years (SD ±15.9). Their average length of time on haemodialysis was 2½ years (range: ten months to six years, SD ± one year and eight months), with two patients previously having had renal transplants. The mean IDWG was 1.16kg (range: 0.15 - 2.1kg, SD ±0.77) with three patients having a mean monthly IDWG >1.6kg.

Data Collection

In-depth interviews of up to one hour duration were conducted by a single researcher in order to maintain interview style, consistency and to avoid potential data collection bias. Questioning style was congruent with the aim of the study and consisted of a series of broad, open ended, exploratory questions as well as probing questions to further explore or clarify points that were raised throughout the interview.

Each interview commenced with the question Can you tell me what it is like to deal with fluid restrictions as part of your day to day life? If the participant brought an artifact to the interview, the following question was asked at an appropriate time during the interview Please explain the meaning behind the artifact that you brought along today in terms of your experience with managing fluid gain?

Data Analysis

Interviews were analysed using an iterative process of reading, coding and interpreting to identify themes that described shared and divergent experiences, strategies/behaviours and barriers to effective management of IDWG. Preliminary themes that emerged were tested by identifying examples across interviews to ensure that themes were well grounded and representative of all stories.

Findings

Themes emerging from preliminary data analysis included magnitude of loss, constant struggle and transition to acceptance. Participants experienced each of these themes in varying degrees and at varying stages of their illness trajectory. Nine associated sub-themes (see Figure 1) were also identified which were found to be inextricably linked. Due to the volume of data generated only the superordinate themes will be considered.

![Emergent Themes](image)

**Figure 1: Summary of results with three superordinate themes and nine sub-themes**

Constant Struggle

All participants identified that their experience with managing IDWG, whether they successfully managed it or not, was a constant struggle. Metaphors using 'battle' terminology were used consistently by the majority of participants when explaining their tortuous struggle. The 'battle' is not physical, rather it is an existential struggle with the desires of self and the realities of living with fluid restriction. The 'battle' metaphor was reflected by a wide range of expressions including: 'occasional win', 'it beats me', 'it's a constant battle', 'fighting nature' and 'I was really fighting it'.
Participant 2, an 82 year old male highlighted his challenge in the present tense and described his personal experience using a ‘battle’ metaphor. The nature of explaining both the struggle and his transition to acceptance were highlighted by his use of present and past tense to describe the experience:

Very trying, very trying. I do my best but I don’t manage very well...I’m getting used to it... I have the occasional win, it beats me more than I’d like it to... It’s a constant battle.

Participant 3, a 55 year old female, highlighted the unnaturalness of the struggle. Fighting nature is like fighting against yourself and it takes strength:

…it’s like fighting nature all the time because you want to drink all the time. You have to have a really strong will to do that... I get to the stage where I fantasise about it...

Participant 1, an 80 year old female described her early experiences with managing IDWG and the emergent symbolic theme of her struggle with unwanted restraint:

I felt as if I was tied up. You know I wasn’t as free and I was being brought in and tied up with the restrictions that I had to undergo.

Participant 3 designed a montage (see Artifact 1) to describe the paradox she experiences ‘almost all the time’:

I was thinking this guy, a man in the desert crawling along with his tongue hanging out. That’s how I feel, almost all of the time... You know not only do I feel like that but I’m doing this fantasising about drinks. And if I go into a shop and see those big walls of fridges with drinks in it. It’s really embarrassing I just sit there waiting to be served and I just look at it all and I think, you know, to me that’s just like heaven. And um, that’s the story of my obsession about fluids.

The narrative informing artifact 1 illustrates clearly the struggle participants endure: the dichotomy between the ‘thirsty’ man in the desert and the mirage of desired fluid. The struggle between wanting to the point of obsession and knowing that surveillance and maintenance behaviours are required in order to maintain well being.

Magnitude of Loss

Loss was consistently associated with loss of function and loss of social interaction as a consequence of having to manage IDWG.

Participant 1 elaborated on the impact fluid restriction has had on her:

I think a loss of independence and a loss of just that ordinary bodily function is a big thing...I’ve had to say goodbye to that and goodbye to that, goodbye to taking as much fluid as I want to, goodbye to participating in my community activities as much as I would like to, goodbye to the community that I’m not living in with anyone else.

Participant 4, a 69 year old female described her experience of loss using a distinctly Australian landmark and a story of a family holiday to the Northern Territory (see artifacts 3 and 4):

Ayres Rock it’s nine kilometres around, we walked and I remember how thirsty we were...what you’d done socially before fluid restriction you can’t do now... you know and our happy hour, well we really looked forward to our happy hour when we pulled into a caravan park and that defines it more than anything, the things that you can’t do... those days are over... those social days have gone.

The artifact was not solely used to identify loss, it was also used to describe her constant struggle:

I think it was sort of the loss of freedom and I think during that early stage of my dialysis I would have been what you might classify as ‘tense’. I lost some of my buoyancy and I tie all that up with freedom and perhaps in the early stages I didn’t want to talk about it very much and as far as the ‘tied up’ business goes it was sort of, it goes with the word ‘restricted’. I was restricted and symbolically that would have been I was tied with a rope.
Participant 3 also described the experience of social restriction:

…it’s frustration…socially limiting. If I go to a party I’m an absolute party pooper because I suck ice all night.

Participant 5, a 57 year old female also alluded to social loss. However, as with all participants a relationship between living through the struggle and dealing with the weight of loss was clearly evident. Participants identified an existential struggle related to their loss that required them to redefine their identity particularly within social contexts:

‘It’s like when we go out with our friends on their boat sometimes and everybody is just socially drinking and I sit there and I can’t do that and it’s warm and it’s lovely, and you feel like doing it, but you can’t, and yeah, I suppose it’s a feeling that you’ve done that always in your life. Everyone told you that drinking lots of water was really good for you and suddenly everybody’s telling you you’re not allowed to do that…’

Participant 5 further described:

I feel cross being where I am at. Because I can’t live my normal life like I used to. I can’t just drink whatever I want to drink whenever I want to drink it … we weren’t massively social, but we did sort of go out quite a bit and that sort of thing… you just know that you can’t do that like you used to...It’s not only how much, it’s what you can have. I really loved soups and casseroles and wet food, what I would call wet food…I enjoy wet food and I can’t have wet food.

Transition to Acceptance

Transition to acceptance was not identified as a linear progression to understanding and adherence but a multifaceted, tortuous struggle unique to each participant. It consisted of three dependent sub-themes: support, consequence and a belief in a life worth living.

Participant 1, who successfully manages her IDWG, reflected on her transition to acceptance:

I was really fighting it, but I couldn’t release myself from what was binding me. I couldn’t say, ‘well I’ll just get rid of those ropes or whatever, no this is going to be how it is, but you’re going to have to release yourself from that, otherwise you’re going to go down a negative path’, and so I did release myself from that and become more free and I don’t think about that now very much… I said to myself, ‘It’s either accept it and go along with it or accept the result of not co-operating with the dialysis business’ and I came to an acceptance…I mean negative things can bind you, that’s what the negativity that was binding me and making me less free and I think it was more or less by pondering about it and trying to find a way out of this restriction and it was to let go and just go with what was happening to me and enjoying the support and friendship I was getting and living as normally as I could.

Participant 1 concluded with reference to the symbolism of artifact 2 that her acceptance had released the bonds of fluid restriction:

There’s less, the rope is down there much more…Now that I’ve released myself from some of those shackles, the word is ‘acceptance’ of the reality of what my life is now. It’s changed from what it was and I say in the journey situation, I’m walking a different road but I still have some of these things from the other life there too to help me.

Participant 2, who admitted continuing to struggle in managing IDWG, realises his transition to acceptance is not complete. He acknowledges that he is on the right track but that the psychological challenge continues as he attempts to successfully manage his day to day fluid maintenance activities:

…the challenge is in the mind. That one has to realize that that’s it and that’s part of it you know. You’ve got to realize that you’ve got this and be practical about it but if, first of all you’ve got to have it sorted out in your mind what you’ve got to do and try to impose that onto your physical state.

There was also evident that the transition to acceptance was also influenced by perceived consequences of failure to adhere to fluid restrictions and not maintaining adequate IDWG. Participant 3 elaborated:

I’ve worked out what I can and can’t do in certain stages of the dialysis cycle. So I just work around that.

She said that her motivations were influenced partly by consequences:

Long term the heart thing. Short term if I’m over my dry weight when I come to dialysis and I have to take off a lot I cramp really badly and it makes it very unpleasant and its easier just to keep your weight down a bit and have a reasonable dialysis where you don’t cramp.

Personal belief that life was worth living for various motivations was also evident. Participant 2 suggested:

I accept it as part of the deal, it is part of living longer and if I don’t, if I don’t do it, well obviously it’s going to be detrimental to myself and my family.

Participant 4, who had struggled with all aspects of her treatment regime identified that despite the continued pressures that it placed on her life she has come to accept it. Her rationale for acceptance is multifaceted, it is about doing the ‘right thing’ in addition to goals that she still wants to achieve. In particular she wants to see her great grandchildren. At the time of the interview she had just become a grandmother for the first time:

…I have accepted this as part and parcel of my life so the fluid is yeah, I think about it a lot but it’s, I accept it. It was a big deal, but it’s not a big deal now. I’m handling it… I want to be there a bit longer for my girls, my grandkids, my great grandkids… with the fluid restriction I think if I’m going to come here four hours, three times a week and go home and drink what I want, eat what I want then it’s a complete waste of time, I’m wasting.
The nurses' time, I'm wasting the doctors' time and I'm wasting my time, so while I'm on dialysis I try to do the right thing.

Participant 6, a 39 year old female asserted her reason for maintaining adequate IDWG is because:

... I want to live longer, yeah. I'm too young, like I'm too young to go now. I don't want to go now, like yeah.

DISCUSSION

The aim of this study was to describe the meaning of fluid restriction and perspectives of managing interdialytic weight gain for people on haemodialysis. As clinicians, our express focus should be on people as they identify themselves, not as medical entities; the meaning of their experiences for themselves, not as clinical subjects (Seymour, 1989). Therefore it stands that we can more deeply understand our patients' experiences by examining their experiences of their bodies and how they interpret and make sense of their own bodily disturbances, in this case the loss of the ability to drink what ever they want!

The use of artifacts afforded a descriptive mechanism for participants to reflect on their experiences with managing IDWG. The addition of this data collection method was chosen to augment participants' stories and acknowledges the often ineffable nature of understanding peoples' illness experiences. It serves as a powerful medium to assist clinicians in better appreciating the impact that managing IDWG has on these people’s lives. Images can capture an essence or fundamental characteristic of human experience that is not easily expressed in words. Visual images are remembered and have immense power to dictate a narrative that informs, educates and persuades others (Lester, 2006). Affording participants the opportunity to share their experience in this way we circumvented the natural tendency of clinicians to assume that they 'know' what the patient needs. The power of the narrative behind the artifacts assists in addressing the disparity of understanding that exists between clinicians and patients.

This study considered a specific aspect of managing ESKD, namely managing IDWG. The themes that emerged are consistent with studies that have described the broader experience of living with ESKD. Curtin and Mapes (2001) identified that vigilant oversight of care was one of the common characteristics of long term dialysis survivors. Our findings were consistent with this theme. We found that regardless of the degree of loss identified by participants, surveillance and maintenance behaviours supported their transition to acceptance of healthy fluid gain behaviours.

This study’s findings also further validated themes identified by Lindqvist, et al. (2000) and Hagren, et al. (2005). Hagren, et al. (2005) described both major themes: ‘not finding space for living’ and ‘attempting to manage restricted life’ and a sub-theme of ‘loss of freedom’. ‘Not finding space for living’ consisted of two sub-themes: ‘struggling with time-consuming care’ and ‘feeling that life is restricted’. Lindqvist, et al. (2000) identified four main themes in investigating perceived consequences of living with ESKD including ‘deprivations of one’s normal life’ which included an associated sub-theme of loss.

Limitations of the Study

As with most qualitative research the generalisation of our findings to the wider haemodialysis population may be limited. However the consistency of our findings with previous studies considering the broader experience of living with ESKD suggests that this group of participants would not be unrepresentative of other people living with ESKD.

The analysis of this study’s preliminary findings may be viewed by some members of the research community as minimalistic. This is deliberate. The presentation of the findings is grounded in the cultural and philosophical term mimesis. Mimesis, historically has been an evolving concept with links to the arts including literary creation, sculpture and theatre. From an Aristotelian viewpoint it is concerned with the effect any of these artistic forms has on its audience (Woodruff, 1992). Where Plato attempted to eradicate the notion of mimesis or using the Latin equivalent imitation or imitation in the narrative, Aristotle embraced it (Kirby, 1996). In theatrics, Aristotle suggested that the audience responded emotionally to the actor’s mimesis in order for them to experience empathy or understanding of the character (Lear in Rorty, 1992). Findings from this study have been deliberately presented in this way to augment the cathartic process so that health professionals not only consider the meaning and experience of managing IDWG but how they interact with their patients. The intention of the combination of artifacts and the participants’ narratives is to enable the reader to temporarily enter the participants’ reality. Therefore it is vital that the participants’ own words are used to describe their experiences and that the researchers minimised any potential bias derived from their assumptions.

Suggestions for Future Research

To the authors’ knowledge, this is the first study to explore the meaning of fluid restriction and perspectives of managing interdialytic weight gain for people on haemodialysis. Therefore further qualitative studies are required to validate our findings and identify additional relationships between themes. During the course of this study further avenues for research have become evident. Firstly, it would be sensible to conduct a systematic comparison between people who achieve ‘acceptable’ IDWG and those who do not. Follow up studies could then be devised to test interventions that are specifically designed to support people who struggle in achieving ‘acceptable’ IDWG. These studies would be based on patients’ perspectives and experiences not clinicians’ assumptions. Such interventions may prove successful considering clinician-devised interventions to improve health outcomes have less impact because patients do not identify such measures to be related to their own perceptions of their experience (Casey, et al. 2002; Seymour, 1989).

Secondly, it would be worthwhile to further explore the theme of transition to acceptance in relation to theorems of behaviour change, notably the trans-theoretical model. The trans-theoretical model of behaviour change suggests that the adaptation of addictive behaviours requires an individual to progress through various non-linear stages (Prochaska & Velicer, 1997). Further research in this area would have practical benefits to patients as health professionals seek to develop successful strategies to support healthy fluid gain behaviours.

Real World of Practice

To create a culture of shared care where the patients and the health care team work in partnership to achieve mutually acceptable goals it is vital for the health care team to engage with their patients. We need to appreciate their experiences, health
beliefs, attitudes and expectations of both their illness and treatment and to work in partnership (Constantini, 2006).

Health care staff can improve their dialogue with patients about interdialytic fluid management by appreciating both the patients’ experience and their positioning along the continuum of transition to acceptance. Avoiding the use of negative and paternalistic language within this dialogue will enhance partnership in health management and the attainment of mutually acceptable fluid maintenance goals. Customised strategies can then be identified to support individual patients and assist them to understand and accept fluid restriction while simultaneously engaging successfully in healthy fluid gain behaviours. Our role as clinicians is to assist people living with the complexities of dealing with IDWG to understand themselves in the context of their own reality.

CONCLUSION

To support people living with ESKD it is imperative to understand the personal meaning of disruption and the nature of their experience of living with renal disease. This study enabled a small group of people undertaking haemodialysis to describe the meaning they attached to fluid restriction and their perspectives of managing IDWG. The study identified the themes of magnitude of loss, constant struggle and transition to acceptance. Participants experienced each of these themes in varying degrees and at varying stages of their illness trajectory.

Transition to acceptance was not identified as a linear progression to understanding and compliance but a multifaceted, tortuous struggle unique to individuals and largely dependant upon support, belief in a life worth living and willingness to engage in surveillance and maintenance behaviour. Understanding where patients are positioned along this continuum will assist nursing staff to identify strategies to support patients, to help them understand and accept fluid restriction and to engage in healthy fluid gain behaviours. The transition from understanding the experience of the patient to using that understanding to inform support strategies will augment nursing practice, improve patient outcomes and provide support and direction for future research.

References


