

The Experiences of Rural Residents in choosing to have Dialysis in a Hospital Setting.

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ABSTRACT

Background

Chronic Kidney Disease is a worldwide public health problem often resulting in the need for life sustaining renal replacement therapy. NSW Ministry of Health have benchmarked 50% of all dialysis patients should be using home based therapies as their renal replacement therapy. Why do rural residents who require dialysis choose hospital based over home-based dialysis? This study describes this lived experience of people living in rural New South Wales who have chosen to dialyse in a hospital setting.

Method

A qualitative approach of descriptive phenomenology, the collection of data from individual interviews with sixteen participants who undergo haemodialysis in the Orange, Bathurst and Forbes Dialysis Units was analysed using Colaizzi's method.

Results

There were four emergent themes that described this lived experience: Diagnosis and Facing Dialysis, Deciding on a Dialysis Option, The Hospital Dialysis Experience and The Home Dialysis Experience-Real or Virtual.

Conclusion

The complexity of the lived experience of choosing a dialysis option was highlighted by the physical, psychological and social aspects of living with a chronic disease and needing life sustaining treatment. Evidence that patients and their families need more support especially during the pre-dialysis stage was apparent. While most participants described their preference to dialyse in a hospital setting as it best suited their physical and emotional needs, there was evidence that not being able to train for home haemodialysis in Orange was a major barrier to the consideration of this home based option.

Implication for Practice

Enhance pre-dialysis support with the services of a Renal Social Worker and increase the possibility of patients choosing home haemodialysis by having an option to train in Orange instead of Sydney.

Keywords: dialysis, home based, hospital, descriptive phenomenology, rural

EXECUTIVE SUMMARY

Implications

The study provides insight into the physical, psychological and social complexities of living with chronic kidney disease which requires life sustaining dialysis. It also explores rural residents' experiences of choosing to dialyse in a hospital setting in the Western NSW local health district. Findings from the study suggest that improvements to the patient and family journey, especially in the pre-dialysis stage will increase the possibility of patients choosing home haemodialysis.

Recommendations

From an economic perspective, the provision of home based therapies is more cost effective for healthcare services than hospital based treatment. Though it is not possible for all people who require dialysis to choose a home base therapy it is possible for the Orange, Bathurst, Forbes Renal Network to better support the pre-dialysis renal patient and increase the possibility of patients choosing home haemodialysis.

A Renal Social Worker would be able to provide support and maximise the psychosocial functioning and adjustment of patients who are experiencing chronic kidney disease requiring dialysis. This service would be invaluable to the pre-dialysis patient and their family as well as providing ongoing support if required for those patients who are already dialysing either at home or in a hospital setting. Support services are paramount to any home therapies service.

Home Haemodialysis Training provided in Orange would alleviate the patient's need to travel and stay in Sydney for six to eight weeks to train. This could be achieved by the Sydney home haemodialysis trainer training patients at the Orange Dialysis Unit.

Promote a Shared Haemodialysis Care initiative for those patients who want to dialyse in the hospital and actively participate to varying degrees in the dialysis treatment process. During the course of caring for a patient receiving routine haemodialysis, renal staff would teach patients who wanted to participate how to carry out the different tasks associated with their dialysis. This initiative can be beneficial to both patients and staff with patients' feeling empowered and staff experiencing a decreased workload once the patient is able to carry out the taught tasks.

Context

Chronic Kidney Disease is a worldwide public health problem often resulting in the need for life sustaining renal replacement therapy. NSW Ministry of Health have benchmarked 50% of all dialysis patients should be using home based therapies as their renal replacement therapy. Keeping people at home and out of hospitals can be instrumental to a person's physical and psychological wellbeing. For the person requiring dialysis this could be viewed

as of major importance, to be able to perform this treatment at home especially for those people living in rural areas. Why then do rural residents who require dialysis choose hospital based over home-based dialysis? This study describes this lived experience of people living in rural New South Wales who have chosen to dialyse in a hospital.

Approach

A qualitative approach of descriptive phenomenology, the collection of data from individual interviews with sixteen participants who dialyse in the Orange, Bathurst and Forbes Dialysis Units was analysed using Colaizzi's method.

Findings

There were four emergent themes that described the lived experience of the participating rural residents: Diagnosis and Facing Dialysis, Deciding on a Dialysis Option, The Hospital Dialysis Experience and The Home Dialysis Experience-Real or Virtual. Evidence of the complexity of this lived experience was present in all themes.

INTRODUCTION

Chronic Kidney Disease is a worldwide public health problem often resulting in the need for renal replacement therapy. The NSW Ministry of Health have benchmarked that 50% of all dialysis patients should use home based therapies as their renal replacement therapy.¹ At present the renal network of Orange, Bathurst and Forbes is failing to meet this benchmark with between 20% -25% of patients dialysing at home. Chronic Kidney Disease, as the name states is a chronic disease and treatment is ongoing to sustain life.

The importance of achieving this benchmark from an economic point of view cannot be understated. The starting cost per patient per year for home based therapy is approximately \$49,137 compared to \$79,072 for hospital dialysis. Kidney Health Australia has estimated that over the next 10 years the increase in people dialysing at home will lead to a net saving of \$379 - \$430 million for the health system.²

The aim of this study is to gain an understanding of the experiences and perceptions of rural residents in the Orange, Bathurst and Forbes area who choose hospital over home environment for their dialysis. This information can be used to guide recommendations for improvement of this renal network's home therapies service.

BACKGROUND

The renal network of Orange, Bathurst and Forbes covers an area of 8,824.4 square kilometers with a population of 85,746 people. The distance from a dialysis unit can be considerable and travelling three times per week to attend dialysis can be an added burden on rural people.

Keeping people at home and out of hospitals can be instrumental to a person's physical and psychological wellbeing.³ For the person requiring dialysis in a rural area, the ability to have treatment at home, could be viewed as of major importance. However, with only one in five people who require dialysis choosing to dialyse at home, this would seem to be a complex decision and experience for rural residents.

Understanding the perspective of these patients will guide delivery of health services to this patient group.

Literature Review

Results of a search revealed that the literature appears to have very little to say about dialysis modality choice in rural Australia. An online search focused on electronic databases such as Journals @ Ovid, PubMed, ProQuest and Nursing Allied Health Source. Keywords used were home based dialysis, haemodialysis, renal replacement therapy, modality choice, peritoneal dialysis, rural Australia. No publication time frame was placed on this search so as

to capture a greater scope of papers. In 2010, Kidney Health Australia conducted a census to investigate the experiences, perceptions and preferences of people dialysing in Australia.⁴ Rural areas were included in this study however; the data presented does not differentiate between the areas. Data collection was via a closed question survey tool with little provision for participants to express their concerns. The survey did identify that people maybe more likely to consider home dialysis if there was clinical and financial support provided by the health service.

The availability of data regarding how a person decides and or the influences on dialysis modality choice from a patient's perspective is limited.⁵ A study from Denmark looked at patients' views regarding choice of dialysis modality. The study concluded that a focus on pre-dialysis patients and closer consideration of patients' preferences and current lifestyle will move more patients to have home based therapies.⁶ A United Kingdom study, explored the area of predicting a patient's choice of dialysis modality by examining factors that influence this choice. This study identified early referral for counseling and education as a key factor regarding a patient's choice of modality.⁷ Researchers from another study in the United Kingdom, studied the influence of non-modifiable factors such as age and degree of co-morbidity on modality choice which included conservative management and highlighted the importance of pre-dialysis education to empower patients to choose self-care therapies.⁸ Similarly, an American study in 2002 explored factors that are perceived by patients as being important in influencing their choice of dialysis modality and concluded early education from a framework of strategies based on the patients' concerns was required.⁹ A variety of barriers experienced by patients in Canada in relation to the uptake of home based dialysis were described as knowledge, attitude and skills.¹⁰ A more recent study described decision making in the context of a chronic illness and suggested patients felt they did not need to engage with the decision regarding a dialysis option until symptomatic.¹¹

While many of the chronic kidney disease patients' influences and concerns regarding choice of modality for renal replacement therapy are universal, Australia and especially rural Australia is unique and therefore further investigation was required.

The aim of the study was to explore and describe people's experiences in choosing to dialyse in a hospital setting, explore and describe people's experiences in choosing not to dialyse at home and to identify areas of concern unique to the rural setting of Orange, Bathurst and Forbes.

Methodology

A qualitative study of descriptive phenomenology is the methodology used to underpin this study. Phenomenology research has disciplinary roots in both philosophy and psychology and is concerned with the lived experiences of humans.¹² It is the lived experience that gives meaning to each individual's perception of a particular phenomenon and therefore presents to an individual what is real in their life.¹³ Through the process of in-depth conversation with those who are living the experience, one learns and constructs meaning of the experience.

The phenomenological approach does not aim to explain or discover causes but instead clarify meanings of phenomena from lived experiences.¹⁴

Heideggarian (interpretive) and Husserlian (descriptive) are the two main philosophical stances underpinning the phenomenological methodology. Each approach reflects insight into the meaning of the phenomena being studied with the researcher listening to the participants' descriptions of their lived experience; however, the aim of the each approach is different. With the interpretive method, researchers use their prior knowledge and insight to interpret and uncover meaning of the described phenomenon with the goal of producing a textual representation of the relationships and meanings between knowledge and the contextualised experience.¹⁵ Using a descriptive method; researchers do not use prior knowledge or make any interpretations, instead researchers analyses and divides the descriptions of the phenomenon given into "distinct meaning-laden statements"¹⁶ (p.8). From these statements, the researcher selects those meanings that are essential to the phenomenon and brings written description of the phenomenon from the discovery of the essential meanings and their interrelationship.¹⁶ In view of the fact that there is very little published literature regarding dialysis choices by rural Australian residents; this researcher has never experienced chronic renal disease or the necessity to have life sustaining dialysis; the different aim underpinning interpretive and descriptive phenomenology, a descriptive approach is best suited to gain an understanding of the experiences and perceptions of rural residents in the Orange, Bathurst and Forbes area who choose hospital over home environment for their dialysis.

METHOD

Study Design

The study design used was a descriptive method using a qualitative interviewing approach. Data were obtained from individual interviews with participants who dialysed in the Orange, Bathurst and Forbes Dialysis Units and were analysed using the Colaizzi method.¹⁷

Participants and Setting

All patients (n=60) who dialysed at the Orange, Bathurst and Forbes Units in October 2013 received a written invitation including a "Participant Information Sheet" (Appendix 1) and "Participant Consent Form" (Appendix 2). The invitation was placed on the patient's table by nursing staff before the patient arrived for dialysis. This is usual practice for the delivery of information of interest to patients in the units. Participants either contacted the researcher or asked a dialysis staff member at the dialysis unit to contact the researcher to express a willingness to participate in the study. The researcher then contacted the participant to arrange for the completion of the consent form and interview date. Sixteen patients responded and all became participants.

Demographic Characteristics of Participants

Gender	Age	Length of time on dialysis:
Male: 8	30-40 yrs = 1	1-2 yrs = 3
	40-50 yrs = 1	2-3 yrs = 2
Female: 8	60-70 yrs = 5	3-4 yrs = 3
	70-80 yrs = 6	4-5 yrs = 3
	80-85 yrs = 3	5-7 yrs = 2
		7-8 yrs = 2
		10.5 yrs = 1

The interviews were conducted in the participants' hospital dialysis unit (Orange, Bathurst or Forbes) while they were having dialysis so as not to disturb their non-dialysis days. The researcher was based at the Orange Dialysis Unit and routinely visited the Bathurst and Forbes Dialysis Units as part of her role. People having dialysis have no restriction on what activities they can do while on the machine other than remaining chairbound and finding interesting things to do to pass the time. To ensure the participants' privacy during the interview, a single room was offered to participants from the Orange Dialysis Unit. However, all participants declined stating they were happy to be interviewed in the unit. There were no single rooms available in Bathurst and Forbes Dialysis Units so the participant's dialysis machine and chair were arranged to provide maximum privacy for the interview.

Data Collection

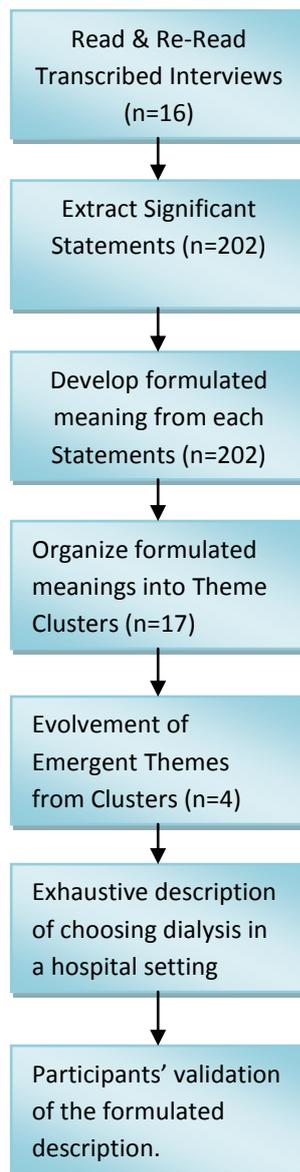
Data were collected through face to face semi-structured interviews. The researcher personally conducted each interview using a schedule of questions which also allowed the freedom to follow up points as necessary. Interviews ranged from 15 minutes to 40 minutes in duration and were digitally recorded. Each interview was transcribed verbatim by the researcher and each transcription was checked against the audio recording for accuracy. During the transcription phase data were de-identified to maintain the participants' privacy and anonymity. Although two participants became emotional during the interview process, both declined the offer to cease the interview and wanted their experiences heard.

Gaining access to a phenomenon as a lived experience required this researcher to engage in a process of bracketing of preconceptions and meeting the phenomenon with an open mind. Although the researcher was aware that some aspects of preconceptions are subconscious and therefore hard to identify, this awareness can be viewed as a form of bracketing. Other forms of bracketing used by the researcher throughout all phases of this study, not just the data collection and analysis phases were a reflexive journal and memoing. Feelings, thoughts, observations and comments were written and reflected upon.^{18,19}

Data Analysis

Colaizzi's approach to data analysis was deemed most suited to this study and was utilized for a descriptive analysis of the phenomenon.¹⁷ Each verbatim transcript was read multiple times to gain a feel for what was being said. Two hundred and two significant statements pertaining to the phenomenon were extracted from the transcripts and developed into formulated meanings that reflected the lived experiences of those choosing to have dialysis in a hospital setting. Seventeen theme clusters resulted from the formulated meanings which then evolved into four emergent themes.

1. Diagnosis and Facing Dialysis
2. Deciding on a Dialysis Option
3. The Hospital Dialysis Experience
4. The Home Dialysis Experience-Real or Virtual.



Data Analysis Stages

Ethics Approval

Ethics approval was granted by the Greater Western Area Health Service Human Research Ethics Committee on the 20th June 2013.

Ethics Reference Number: *HREC Project No. HREC/13/GWAHS/17*

Site Specific Approval was granted on 3rd October 2013

SSA Application No. SSA/13/GWAHS/57

FINDINGS

The purpose this report is to describe the lived experience of rural residents in choosing to dialyse in a hospital setting. The focus of this section is the themes that underpin this experience; diagnosis and facing dialysis, deciding on a dialysis option, the hospital dialysis experience and the home dialysis experience-real or virtual.

Diagnosis and Facing Dialysis

When asked about their experience of being diagnosed with chronic kidney disease and eventually needing renal replacement therapy, many participants described feelings of shock, fear, sadness, denial as well as feeling physically unwell.

....it was a shock to the system when I found out of course, you know that it was happening to me (Participant 12, L. 18-19)

*mhhh bit of a shock. yeah *pause* yeah sorta knew it was comin' (Participant 9, L. 11-12)*

Participant 11 describes feeling shocked a second time when the need arose to recommence dialysis after experiencing acute dialysis two years previously.

So I knew, that was the first time I had anything to do with it. It was the shock more than anything, the shock the second time (Participant 11, L93-95)

One participant spoke about a feeling of anger at this time.

Actually I was abit cranky because Dr....said it should have been picked up earlier and it wasn't by the other doctors I've seen um but I mean I got over that pretty quick I think that was good (Participant 13, L5-7)

Participants talked about feeling fearful and not knowing what was involved with dialysis.

Scared me to death. I was going to the doctor and he told me a few times, you need to be on dialysis. I kept saying no, kept saying no because it terrified me the thought of it. (Participant 14, L5-7)

I hated it, didn't want any part of it. Scared. It scared me yeah....nuh had no idea what it was. (Participant 16, L5-7)

Me doctor never told me anything (Participant 8, L26)

Concerns of mortality and the effects of pending dialysis were also expressed.

*.....*long pause* I think the main one (feeling) was how long are you going to last on it. I mean I've been on it 7 years now.....what exactly health wise, how the effect would have on me.(Participant 3, L 25-28)*

...if I wanted to stay alive I knew I had to go through it (Participant 5, L10-11)

...they did tell me if I didn't want to do it (dialysis) I didn't have to do it um I think personally if I hadn't had (son) at home I may not have done it, if I had been on my own um I probably wouldn't have, I don't know. (Participant 13, L 45-48)

Feelings of sadness, denial and feeling physically unwell during this time of their journey toward dialysis were verbalised by many of the participants.

Yeah sad, scared, nervous, yeah very emotional at the time (Participant 16, L10)

Even when they showed me the machines and all that, I couldn't take it in, you know how you sorta put a block on your mind? (Participant 5, L12-13)

I kept putting it off until I couldn't anymore. I felt like death warmed up, so then I went over to (town), started off over there and that was the beginning (Participant 14, L8-10)

Participants spoke of their acceptance of the need to have dialysis.

Well I felt pretty crook and um I thought if it was going to help you know um you know what else could you do? (Participant 2, L17-18)

I just thought, oh well I gotta do what I gotta do, my doctor once said to me "are you depressed about it?" I said "no, I don't think so, I don't know what it's like to be depressed" (Participant 13, L 55-57)

...um talked it over with the wife and she said "well its gotta be done" (Participant 4, L7)

I've known for years cuz my mother had kidney failure, she died, she refused to have dialysis and I thought what's the point in refusing? I'll may as well have it and be done with it. If it prolongs my life I can see my grand kids grow up abit more, that's the way I thought about it. (Participant 11, L 17-22)

I remember saying to my wife "I'll handle this bloody dialysis standing on me head ya know, cuz I'd already been through prostate cancer and I thought if I can handle prostate cancer I'll be able to handle this ya know. (Participant 8, L 20-25)

The gamut of emotions experienced by the participants during the time of diagnoses of chronic kidney disease and the eventual need to have ongoing life sustaining treatment can be likened to the grieving process. Shock, fear, sadness, denial and anger are all psychological responses to the loss of their kidney function and life as they knew it.²⁰ Grief and loss often becomes an intricate part of this lived experience as people diagnosed with chronic kidney disease learn to live with the psychological changes to their world. Although each participant's experience of loss and grieving is unique to them, there is a commonality of emotions associated with this shared experience. Pelletier-Hibbert & Sohi, (2001) described living with chronic kidney disease as a "dynamic experience characterized by periods of stability, instability, and regained stability during the course of the illness trajectory" (P.441).²¹ Acceptance of life with chronic kidney disease and facing dialysis also forced participants to face their mortality with the realization that they required dialysis to sustain their life.

Deciding on a Dialysis Option

During this stage of their journey, participants talked about having no choice, choosing hospital dialysis by default as they did not want to dialyse at home and support during this decision time.

Some participants describe having no choice as they needed dialysis to live.

No, no it wasn't a real decision, the fact that I had to do it (Participant 12, L61)

While two other participants describe having no choice regarding dialysis modality as the medical profession made it for them.

Well (nurse) suggested I get the both done but Dr.... only wanted me to get the one done so that's why I had peritoneal, the only choice I had really (Participant 9, L27-29)

No well no I had no idea what they were talking about, they just said I had to go have this thing put in me, um, then they told me how to do it and everything like that and I had all the stuff (peritoneal)at home (Participant 13, L69-71)

Many participants chose not to dialyse at home and therefore the decision to dialyse in a hospital was by default. At this point in time, most participants had the choice of peritoneal dialysis or hospital haemodialysis with the option of future home haemodialysis. Participants described family and friends influencing their choice of dialysis option, threat of infection, body image and not feeling confident with their ability to perform dialysis at home.

One participant described no choice due to unsuitability for peritoneal dialysis.

No I had no choice come to hospital and that was it (Participant 5, L65-66)

Participants talked about how family, friends and even acquaintances influenced their decision on choosing a dialysis option.

Wife didn't really want me to have the other one, whatcha call it, cuz infection, she's a nurse, she didn't want me to have whatcha call it, peritoneal, she just wanted me to do this one (Participant 15, L35-37)

...did know a woman whose husband had haemodialysis at home and um she said to me if I had dialysis at all she felt that haemodialysis was the best bet and also she said if you went to a hospital and had it done if anything happened to go wrong you are on the spot to get medical attention mmmm(Participant 2, L49-52)

Yes ah yes years ago a fellow at work had dialysis and was doing it at home and he said it was very awkward so I thought I would never do it at home (Participant 4, L54-55)

They (family) just said no we can't do it at home (Participant 1, L83)

*Well *long pause* I heard abit about it, I had a friend who was on it arr and a lot of people told me even doctors told me you gotta be exceptionally clean that you could pick up a germ or something like that. I'm an animal lover so I've got animals at home. Arrrr that's not the real reason I just decided I was never ever interested in having a tube in the stomach (Participant 6, L90-94)*

Another participant also verbalised body image concerns.

*well stuck at home with a stupid bloody tube in my stomach the thought turned me off every *pause* when I talked about it (Participant10, L94-95)*

Participants expressed not feeling confident with performing dialysis at home.

Umm I would not have peritoneal on my mind at all.(Participant 14, L29-30)

I thought arr I thought to myself it's a lot to remember I kinda looked into it abit (Participant 8, L99-100)

I had the offer of having it at home but no it was too much so I have it here (Participant 4, L30-31)

Participants talked about concerns and support or the lack of support during the time of deciding on a dialysis option.

....yeah I had good support then.....I had concerns about how crook I was feeling, how crook I can feel now but that's all part and parcel of the disease apparently (Participant 10, L 34-37)

Had concerns but no one to turn to really (Participant 9, L23)

I rang up the Kidney Foundation and the lady there was very nice and she explained it to me (Participant 2, L 9-10)

Yeah well me wife never accepted it. She still can't handle it. She gets upset when I go to dialysis (Participant 8, L32-33)

Dialysis modality choice is a complicated process involving many different factors. Different studies have looked at decision making and what influences patients' choice during this time.^{8,10,5,11} Many of the factors or experiences described by the participants in this study were similar to those reported in other studies. Participants' described their lived experience during this time as feeling they had "no choice" because they needed dialysis to continue to live or choice was dictated by medical contraindications or being excluded from the decision due to medical professionals preference for a certain modality. Further description of their experience involved participants not feeling confident in learning and performing the skills necessary to dialyse at home and therefore dialysis in the hospital was chosen by default. Many participants described how other people's experiences with home dialysis greatly influenced their decision to choose hospital based dialysis. During the experience of choosing a dialysis option, participants described feeling supported by family, health care professionals or a support group. This experience however, was not shared by all participants with descriptions of not knowing where to turn and family members being unable to accept the need for dialysis.

The Hospital Dialysis Experience

When describing their hospital dialysis experience, participants spoke of staff, safety, social, death and dying, the downside of dialysis and looking to the future. Staff, safety and social aspects of the participants' experiences are all closely linked with the staff being viewed as providing safe treatment as well as forming part of a social group that participants describe as "Family"

*Well if anything does happen to go wrong well I get looked after *laugh* and um um I um think the company too and the nurses are all so good and helpful and um you are sorta mixing with other patients so you are not completely on your own (Participant 2, L 72-75)*

*The staff, they are good up in (town) too, they look after you here. It might sound funny *laugh* but it's like an outing for me ya know, I get up, get a taxi out here, feels like a break away.if I feel flat and I'm coming out here it gives me a lift. The nurses are good here, there's no problems. (Participant 10, L 77-81)*

*Yes yes just how they treat ya *laugh* just like home really (Participant 4, L 64)*

I won't say I don't enjoy being here because they're part of me family now cuz I spend so much time here see (participant 6, L 131-132)

There's the fact that I can go out to it and you've got people here that can give me treatment straight away. Um I find the girls are very friendly, it's quite a friendly area, we are all like family here actually. We all talk to one another and if anyone's sick we

*get abit upset about it and *nervous laugh* yeah so apart from that, I think that, I don't know, it's just the safety feature more than anything you know, if anything goes wrong someone is here to help you (Participant 3, L 51-56)*

Some participants viewed staff as being able to share the responsibility of their chronic disease.

They (staff) are very good. They rouse on me when I need rousing on (Participant 11, L 159)

Well I get looked after so well and all bloods are done and any appointments I've got with doctors, they organize it all and it is a load off my mind (Participant 14, 32-33)

*Often they (staff) will say something to me and I'll say whatever you want to do, you're the boss *laugh* (Participant 13, L 106-107)*

Participants expressed their thoughts on dialysis and death and dying.

*...you know you gotta come if you want to live...umm that's how I've attacked things and I'll keep on doing it *nervous laugh* until it's my turn (Participant 5, L 129-131)*

*...if I want to live I have to have dialysis, that simple, three times a week, five hours a time. If I want to die just don't come in simple as that *laugh* yeah. (Participant 10, L123-125).*

..it's something you gotta do if you want to continue to live on you can't just shut the door (Participant 12, L 93-94)

*...I think I'm just resigned to the fact that I'm doing it to whenever. I haven't got any worries if I was to get crook and die tomorrow it wouldn't worry me so *pause* I can't do anything to change it (Participant 13, L 136-138)*

Like I tell ya what, in the four years, I've never ever felt like pulling the pin now I think that's good because sometimes you'd reckon it would get you down but it's never done. (Participant 8, L 165-167)

Two participants spoke of dealing with the death of other patients.

When they (other patients) die well it's abit of a shock but as I said everybody is put here for some reason, that was their time and I've always been like that, no fuss over losing (Participant 5, L113-115)

*...I mean I'm old *laugh* so I mean um you could get ran over crossing the road so I mean I gotta accept the fact that we are all going to die so you know what difference does it make but you know I'm enjoying myself. I do get depressed now and again particularly if somebody dies that I started with or anything but the ones I've started off*

*with now have all past away so umm you know you just gotta accept the jolly of life
(Participant 2, L 119-124)*

Participants described the downside of hospital dialysis as the time involved, needles, being immobile during treatment and the inability to travel away from home.

The time it takes and people will tell ya, I know what you are going through and they don't. I say have you been you know glued to your seat for five hours with needles stuck in ya and you just gotta stay there until your time is up sorta thing and yeah I dread the time, I dread that it takes other parts of your life that you're trying to do. (Participant 12, L 100-104)

Travelling backwards and forwards...yeah the time it takes. Big day (Participant 16, L 39-40)

*The needles *laugh* and say if a new nurse came and I had to um have her and she hasn't had me before and its more painful like until you get use to it (Participant 14, L 48-49)*

*...they come with a smile and they stick a needle in ya *laugh* (Participant 8, L87)*

Some days I think it's a bloody nuisance and gotta sit here with my arm still. Couple of times I've been asleep and sorta jumped and one come out and made a bloody mess....(Participant 1, L 115-117)

*Having to come three times per week *laugh* yeah....I mean the fact that I've got it in my arm and I can't sorta knit or sew and I just gotta read and things like that is abit difficult cuz you can't move your arm....(Participant 3, L91 – 95)*

*The time *laugh* you know you gotta be here. Yes we use to travel around a lot, quite a lot, we would go away three months at a time but now we can't even go for a week (Participant 4, L38-40)*

*I think the three days coming over, it ruins everything cuz I can't, I like to travel around abit.....when I was on peritoneal I travelledI just carted all the stuff with me and it was quite good, now I sorta can't go anywhere and it gives me the shits *laugh* to be honest (Participant 13, 93-98)*

Participants described looking to the future in terms of a kidney transplant, possible new treatments and wanting to witness the birth of great grand children.

Yeah hopefully. We tried hubby but he had something as a kid and his kidneys are damaged from that so they would not take his in case he needs it. (Participant 16, L 70-72)

*Well I'm getting close to the transplant list and that's exciting for me....I'd like to maybe go on a cruise one day. I'd like to visit Ireland one day but I can't do any of that until I get a kidney and all goes well you won't see me for dust *giggle* (Participant 14, L 65, 74-76)*

Yes yes (on transplant list) you know there's a chance, small one but (Participant 9, L70)

Having experienced peritoneal and haemodialysis, this participant expressed hope for the future in terms of the development of new treatments for renal replacement therapy.

Not knowing what's happening in the future, any possibility of any other treatments (Participant 9, L68-69)

The desire to witness the birth of great grand children in the future was expressed by participants. This desire is closely linked to the participants' acceptance of mortality and the need to have dialysis.

*It's just something you gotta accept and get on with and besides that I'd like to see a great grandchild *laugh* I've got grand children but I'd like to see the first one anyway. I don't think I'll have all that long to wait (Participant 2, L155-157)*

I realise the fact that it's keeping me alive um and I've be alive long enough to have a great granddaughter which is great and um yeah mainly just that you know you just accept that it happens.(Participant 3, L 111-113)

Previous qualitative studies have reported aspects of living with hospital haemodialysis as loss of freedom and increased dependence, the encroachment on dialysis patients' time and space and being "at home in the dialysis unit"^{22,23,24,25}. The lived experience of dialysing in a hospital described by the participants in this study did have some similarities to those studies. Participants described the time involved, being immobile during treatment, the inability to travel away from home and needles as being the downside to their dialysis. Three of these descriptives are related to a loss of freedom in some way where as the describing of time spent travelling to and from dialysis and the actual treatment time were felt as encroaching on their space for living.

Hospitals are often viewed as cold and frightening, however the participants in this study described it as a place just like home and the staff and other patients as family. Similarly, the participants described feeling safe in the hospital setting as staff would deliver prompt treatment if required and that they felt well looked after. The lived experience of attending regular life sustaining treatment was described by participants as a social outing and the dialysis unit was a place to socialise with other people such as staff and other patients. Being part of this social group also involved experiencing the emotions associated with the death of other patients in this group. Facing their own mortality was described by many participants as "if you want to live" furthermore, participants described being aware of the risk of death and

having the option to withdraw from dialysis. Many participants described looking to the future as part of their lived experience of dialysing in a hospital. For some, it was the prospect of receiving a kidney transplant while others wanted to see the birth of another generation in their family.

Although not wanting to dialyse at home, two participants expressed a desire to learn and participate in their dialysis treatment in the hospital setting. Literature shows involvement of people with a chronic disease in their own care is important, resulting in a sense of empowerment and a reduction in levels of anxiety and depression.^{26,27}

The Home Dialysis Experience- Real or Virtual

Participants spoke of exploring the option of dialysing at home and deciding on hospital based dialysis by default as they felt unable to overcome perceived obstacles to home based therapy.

Well the fact is my husband wasn't that young um and I thought I would be better off in the hospital, I um we also didn't have a sterile area where you could put a machine, we would have to do a fair bit like pull up carpet and putting down lino and things like that and possibly um we weren't sure of the water supply and how much that would cost and I just felt safer in the hospital (Participant 3, L44-48)

I'm there on my own, what do I do, there are a lot of things, I looked right into having it at home even to the stage where I got a quote for the plumbing to be done and ah it turned me off, there is too many things that could happen (Participant 6, L 178-180)

Ah I think it would be pretty awkward really ah you must have the house altered but you know to do dialysis at home but I don't think I'd be able to do it. It would be too much on my wife....honestly I can't see any good about doing it at home (Participant 4, L 45-49)

Just if anything goes wrong, I know everyone here yeah, they are trained if anything happens, where at home yeah hubby would have to train to know what to look for yeah which he is prepared to do but I need to get the fear of needles away first (Participant 16, L 31-34)

*I wanted to be home that's why I got the tube *pointing to stomach* ...well after I had all this infection so much trouble it really panicked me a little bit cuz there's alot involved with doing it at home and I live on my own and at the time I didn't think I could handle it at home. It was easier to come here and do it. I still have thoughts of trying to do it at home and managing it and if things went wrong I would have no one to help me (Participant 11, L 111, 114-118)*

Participants spoke of exploring home dialysis option after commencing hospital based dialysis.

I did ask about it but that's as far as I went with it, never got any answers that made me, convinced me I was better off...in the tummy, the way he explained it I wasn't very impressed with that anyway (Participant 10, L 70-75)

I have explored the thing about having it at home but I was told, what I was told was some people who done it at home prefer to come back to the hospital to have it so I stuck to the hospital (Participant 10, L67-69)

I've got nowhere to put it. I have really. It would have gone in the lounge room. I don't think it would be a really nice spot as people would walk in and here you are sitting up there with all this thing hanging around you arrr no I was never, I was interested but then I weighed it all up. Once I started on dialysis and could see the things that could happen to me that turned me off (Participant 6, L 185-189)

Some participants from this study have experienced home dialysis in the form of peritoneal dialysis (PD) and were able to describe this experience firsthand while other participants were asked to visualise how their life would be different if they were to dialyse at home.

*Home is easier, it was still time consuming, it had to be on time, every four hours, night time one was different....If I was asked which do I prefer I'd say haemo, a lot of people would think I'm crazy but nuh only because I got sick twice, the bug in the tummy was rare *laugh* yeah topped the ranks there. Haemo, ya sorta do ya time, it's a long time but PD is every day, you have to stop what you are doing, go home and do it yeah. It's easier travelling with PD (Participant 16, L 53-54, 65-69)*

I got peritonitis and I went to hospital in (town) and I was there for, I forget how long now. I went back home and they didn't put me back on peritoneal...I wouldn't mind going back onto peritoneal. I liked it (Participant 13, L 81-82, 88)

Participants talked about how their lives would be different if they were to dialyse at home. The reality for most of these participants would be home haemodialysis as peritoneal dialysis would not be an option due to medical unsuitability.

None. None absolutely none expect I probably, to be honest with you I'd worry, I'd worry all the time cuz sometimes I'm a bleeder (Participant 6, L175-176)

I'd do it at night time, have time with the kids, wouldn't have to travel as far, only to doctors' appointment or something yeah the day is free instead of being here (Participant 16, L 42-44)

*Probably you could pick your time when you did it, maybe at night, not during the day....I'd be worried I would move my arm of a night. It would come out *laugh* and we would have blood everywhere (Participant 3, L 98-99, 101-102)*

*It wouldn't be different but it would be abit more convenient, go on the machine when all your works done, go away and come back. Some people go on at night but I wouldn't sleep with the machine going, too dangerous, if one of these come out *pointing to needles* you'd die pretty quickly (Participant 15, L 71-74)*

It would be alot difference, for a start I would be tied to the house because I can't drive myself anywhere (Participant 14, L 53-54)

Well the only thing that would be different would be the travelling, I wouldn't have to travel over and back....The only way my life would actually be different would be if I was on peritoneal (Participant 13, L 113-114, 121)

Bad for me. I'd be there with no support if something goes wrong, all by myself (Participant 9, L56)

Participants also expressed concerns of having to go to Sydney for six to eight weeks to be trained to perform home haemodialysis.

It's a matter of getting down there and staying there you know, if I could do it up here and be trained it would be a lot better (Participant 2, L 69-70)

*Yes we don't have anyone we could stay with, we would have to pay for accommodation even when I went down to have this thing choked *pointing to fistula* like three days down there costs a lot of money (Participant 3, L 119-121)*

I wish we had a training unit in Orange, it would be easier, I could travel down each day be home at night. I think a lot more people would do home dialysis if it was closer. It is very expensive to stay in Sydney.(Participant 16, L 78-80)

The complexity of factors involved in choosing a dialysis modality not only involves the patient and their perceptions but also the health care system. When describing the lived experience of exploring home based dialysis, participants in this study felt the perceived obstacles of their safety, altering the home, additional pressure on family to provide support during home treatment and having to go to Sydney for an extended period to learn how to perform home haemodialysis outweighed the perceived benefits of convenience, more available time and less traveling associated with attending treatment. The participants who had experienced home based dialysis in the form of peritoneal dialysis also described the experience of having an infection associated with this form of dialysis. For one participant, this experience resulted in not being prepared to continue dialysing at home due to the fear of becoming sick again from an infection while for the other participant this form of dialysis became medically contraindicated.

The Lived Experience of Choosing to Dialyse in a Hospital Setting – an exhaustive description.

The start of the journey for those people who choose to dialyse in a hospital setting is when they receive a diagnosis of chronic kidney disease. The physical and psychological changes to their world become an intricate part of their lived experience. Feelings of shock, fear, sadness, denial and anger are experienced responses to the loss of their kidney function and life as they knew it. The acceptance of life with chronic kidney disease requiring dialysis results in the lived experience of people facing their mortality with the realisation that without dialysis their life cannot be sustained.

During the time of choosing a dialysis modality, the lived experience included feelings of no choice because of the need for dialysis to continue to live or choice was dictated by medical contraindications or being excluded from the decision due to medical professionals' preference for a certain modality. The experiences of other people in relation to home based dialysis greatly influenced choosing a dialysis modality. Lack of confidence in their ability to learn and perform the skills necessary to dialyse at home and therefore, feeling that the choice to have dialysis in the hospital was made by default formed another part of this multifaceted lived experience. Furthermore, not all people experienced the support of family or health care professionals during this lived experience with descriptions of not knowing where to turn and family members being unable to accept the need for dialysis.

The lived experience of exploring home based dialysis was described as the perceived obstacles of safety, altering the home, additional pressure on the family to provide support during home treatment and having to go to Sydney for an extended period to learn how to perform home haemodialysis outweighed the perceived benefits of convenience, more available time and less traveling associated with attending treatment.

Staff, safety, social, death and dying, the downside of dialysis and looking to the future all form part of the lived experience of dialysing in a hospital. The time involved, being immobile during treatment, the inability to travel away from home and needles were the experienced downside of dialysis. Three of these descriptives are related to a loss of freedom in some way where as the describing of time spent travelling to and from dialysis and the actual treatment time were felt as encroaching on their space for living. Staff, safety and social aspects of this lived experience are all closely linked with the staff being viewed as providing safe treatment as well as forming part of a social group that are describe as family. The lived experience of attending regular life sustaining treatment was described as a social outing and the dialysis unit was a place to socialise with other people such as staff and other patients. Being part of this social group also involved experiencing the emotions associated with the death of other patients in this group. Facing their own mortality was described as if you want to live, furthermore, there was an awareness of the risk of death and having the option to withdraw from dialysis. Many described looking to the future as part of their lived experience of dialysing in a hospital. For some, it was the prospect of receiving a kidney transplant while others wanted to see the birth of another generation in their family.

Health Service Perspective

From an economic perspective, the provision of home based therapies is better suited to the health services' budget when compared to the provision of hospital based treatment. While it is not possible for all people who require dialysis to choose a home base option, a health service initiative such as, Peritoneal Dialysis First see those people who are suitable for peritoneal dialysis being offered this modality as their initial dialysis option. This initiative has been successful in other countries and should not be viewed as a competition between the different modalities but rather playing a complementary role in achieving the patients' long term goals.^{28,29} Pre-dialysis education is key to improving the utilization of home based therapies especially peritoneal dialysis.⁷ A timely referral from the nephrologist and pre-dialysis education supporting home based dialysis are important first steps.

STUDY STRENGTHS

The use of phenomenology although regarded by some as limited due to the inability to generalize, provided a rich description of the lived experience of rural residents in choosing to dialyse in a hospital setting. This will add to the limited body of knowledge regarding this phenomenon by providing a valuable insight into the lived experience. Open-ended interviewing techniques, tape recordings and verbatim transcriptions increased the accuracy of the description of each participant's experience and together with the exhaustive description statement feedback to the participants added to the rigor of this study.

STUDY LIMITATIONS

The researcher was known to all participants and while this may encourage open discourse, there is the potential for participants not to be totally open about their experience. Due to time constraints, feedback was not obtained from a second researcher concerning the collapsing of data into themes.

CONCLUSION

This study highlights the complexity faced by people in choosing either home based or hospital dialysis options. While not all participants had a choice due to their medical unsuitability for home based dialysis, other participants decided the obstacles associated with dialysing at home outweighed the benefits. Personal safety associated with home haemodialysis was expressed as a major obstacle with participants describing the hospital setting best suiting their physical and emotional needs. However, there was a desire by some participants to be more actively involved in their dialysis treatment in the hospital setting. Travelling and staying in Sydney for an extended period to train was identified as an area of concern for those participants who were considering the home haemodialysis option.

RECOMMENDATIONS

A Renal Social Worker would be able to provide support and maximise the psychosocial functioning and adjustment of patients who are experiencing chronic kidney disease requiring dialysis. This service would be invaluable to the pre-dialysis patient and their family and would increase the uptake of choosing home based therapy as people would feel more support than is currently provided. Support services are paramount to the success of any home therapies service. Furthermore, the services of a social worker could be utilized if required, by those patients who are already dialysing either at home or in a hospital setting.

Home Haemodialysis Training provided in Orange would alleviate the patient's need to travel and stay in Sydney for six to eight weeks to train. This could be achieved by the Sydney home haemodialysis trainer training patients in the Orange Dialysis Unit.

Promote a Shared Haemodialysis Care initiative for those patients who want to dialyse in the hospital and actively participate to varying degrees in the dialysis treatment process. During the course of caring for a patient receiving routine haemodialysis, renal staff would teach patients who want to participate, how to carry out the different tasks associated with their dialysis. This initiative can be beneficial to both patients and staff with patients' feeling empowered and staff experiencing a decreased workload once the patient is able to carry out the taught tasks.

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Appendix 1

PARTICIPANT INFORMATION SHEET

THE EXPERIENCES OF RURAL RESIDENTS IN CHOOSING TO HAVE DIALYSIS IN A HOSPITAL SETTING

Invitation

You are invited to participate in a research study to understanding the experiences of rural residents living in the Orange, Bathurst and Forbes area in choosing to have dialysis in a hospital setting.

The study is being conducted by Michelle Manning, Clinical Nurse Consultant, Orange Dialysis Unit, Orange Health Service.

Before you decide whether or not you wish to take part in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. 'What is the purpose of this study?'

The purpose is to investigate why people choose to dialyse in a hospital setting, identify areas of concern people may have when choosing where to have their dialysis including any concerns unique to the rural setting and make recommendations on how to address these concerns.

2. 'Why have I been invited to participate in this study?'

You are invited to participate in this study because you dialyse in a hospital and you live in the Orange, Bathurst and Forbes area.

3. 'What does this study involve?'

If you agree to participate in this study, you can phone Michelle, 63693774, or ask one of the dialysis staff to phone Michelle. Michelle will arrange a suitable time with you to answer any questions you may have and to sign the attached Consent Form.

You will be asked to take part in an audio recorded interview with Michelle during dialysis on a day to suit you. To ensure privacy during the interview, a single room will be used in the Orange Dialysis Unit. Due to no single rooms being available in the Bathurst and Forbes Dialysis Units, your dialysis machine

and chair will be arranged to provide privacy for the interview. The length of the interview will be approximately 30 – 45 minutes however; this is entirely up to you.

This study will be conducted over a 22 month period- September 2012 to June 2014- it is anticipated your interview will be conducted during the period July 2013 to September 2013.

4. 'Are there risks to me in taking part in this study?'

There are no known risks involve in participating in this research.

If you experience any emotional distress from talking about your experience, the interview will be ceased or you can stop at anytime. A counsellor through the Social Work Department will be available to you within 30 minutes or at a later date, if you feel you need it. For the Forbes participants, counselling will be available through a video link up with the Orange Social Work Department.

5. 'Will I benefit from the study?'

This study aims to further knowledge which may improve future renal services of the Orange, Bathurst and Forbes network; however it may not directly benefit you.

6. 'How is this study being paid for?'

The study is being funded by the Health Education & Training Institute (HETI)

7. 'Will taking part in this study cost me anything, and will I be paid?'

Participation in this study will not cost you anything, nor will you be paid.

8. 'What if I don't want to take part in this study?'

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

9. 'What if I participate and want to withdraw later?'

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. Data that had been collected will be used due to the fact it is not identifiable and it would be near impossible to determine your data from other participants.

If you decide to withdraw, it will not affect the treatment you receive then or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

10. 'How will my confidentiality be protected?'

Michelle and any staff member you tell will know you are participating in this study. On the day of your interview, the dialysis staff and patients on the shift will know.

The only identifiable information collected about you in connection with this study will be your consent form. It will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researcher named above will have access to your form which will be held securely at Orange Health Service. Interview transcripts will not be identifiable and direct quotes from the transcripts will be incorporated into this research anonymously.

11. 'What happens with the results?'

If you give your permission by signing the attached consent form, I plan to discuss/publish the results in the development of renal services in the Orange/Bathurst/Forbes network, peer-review journals and at local, state or national conferences. The information will be presented in such a way that you cannot be identified.

Results of the study will be provided to you, if you wish. You will be asked at the end of your interview if you would like a copy.

12. 'What should I do if I want to discuss this study further before I decide?'

Contact Michelle on 63693774 or 0409024167.

13. 'Who should I contact if I have concerns about the conduct of this study?'

This study has been approved by Greater Western Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact The Executive Officer who is the person nominated to receive complaints from research participants. You should contact them as follows and quote HREC reference number HREC/13/GWAHS/17

Executive Officer

Greater Western Human Research Ethics Committee

Western NSW Local Health District

PO Box 143

BATHURST NSW 2795

Telephone: (02) 6339 5601

Fax: (02) 6339 5606

Email: ethics.committee@gwahs.health.nsw.gov.au

Thank you for taking the time to consider this study.

If you wish to take part in it:

- **Contact Michelle: Phone 63693774, Mobile 0409024167**
- **Or ask a Dialysis Staff member to contact Michelle.**
- **Michelle will arrange with you a time to answer any questions and for you to sign the attached Consent Form.**

This information sheet is for you to keep.

Appendix 2

PARTICIPANT CONSENT FORM

THE EXPERIENCES OF RURAL RESIDENTS IN CHOOSING TO HAVE DIALYSIS IN A HOSPITAL SETTING

The name and purpose of the research project has been explained to me. I understand it and agree to take part.

I understand that I may not directly benefit from taking part in this study.

I understand the statement in the Participants Information Sheet regarding “Are there risks to me in taking part in this study?”

I understand that while information gathered during this study may be published, I will not be identified and my personal details will remain confidential.

I understand I can withdraw from this study at anytime and that it will not affect the treatment I receive then or in the future.

I understand the statement in the Participants Information Sheet concerning receiving no payment for participating in this study.

I understand that the interview will be audio digitally recorded.

I freely agree to participate in this study

Participant's name (please print):

.....

Signature:

Date:.....

Greater Western Human Research Ethics Committee

Western NSW Local Health District

PO Box 143

BATHURST NSW 2795

Telephone: (02) 6339 5601. Fax: (02) 6339 5606

Email: ethics.committee@gwahs.health.nsw.gov.au