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Protocol for a qualitative study exploring haemodialysis dependent patients' arteriovenous fistula experience, values and concerns in Sydney, Australia

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ABSTRACT

Introduction The experiences of patients from culturally and linguistically diverse backgrounds, with chronic mental illness, disabilities or who identify as sexual or religious minorities are under-represented in clinical research on arteriovenous fistula (AVF) for haemodialysis access. A greater understanding of the experiences, values and concerns of these diverse patient groups are needed to provide haemodialysis access care that addresses the needs of all haemodialysis-dependent patients. This study seeks to describe a broad range of patient experiences related to the creation, care and surveillance of AVFs, including interactions with healthcare teams.

Methods and analysis This qualitative study will use semistructured interviews with individual patients purposefully selected to provide a diverse patient population. A deliberate strategy will be used to recruit a demographically broad range of participants. Thematic analysis of interview transcripts, using a constant comparative methodology, will generate themes that describe patient experiences, values and concerns. Findings from this study will give a nuanced insight into the experiences of patients on haemodialysis with respect to their AVF.

Ethics and dissemination Ethical approval for this study was provided by the Sydney Local Health District Human Research Ethics Committee (REGIS identifier: 2021/ETH00362, CH reference number: CH62/6/2021-033). Results will be made available to the participants, local health district, funders and other researchers through various hospital and academic forums. Data will also be published in peer-reviewed journals and be part of a larger body of work looking into patient-reported outcome measures for patients with AVF.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This qualitative study interviews patients about their experiences and values related to the care of arteriovenous fistula for haemodialysis, with the aim of strengthening our understanding of patient-centred outcomes.
⇒ Patient experiences from under-represented population groups, such as patients of cultural or linguistic diversity, with chronic mental illness or from other minority groups are underrepresented in current arteriovenous fistula research.
⇒ There is a need for a greater understanding of the experiences, values and concerns of diverse patient groups in order to provide haemodialysis access care that addresses the needs of all haemodialysis-dependent patients.
⇒ We purposefully aim to recruit a broad cohort of patients, to provide diversity in reported patient experiences.
⇒ Limitations include reduced transferability due to the geographical and social context, single-centre data collection, and interviews conducted in English language.

INTRODUCTION

Maintenance of vascular access for haemodialysis (HD) is an important part of providing high quality care for patients with end-stage kidney disease (ESKD).[1] A native arteriovenous (AV) graft or fistula is the preferred vascular access for safe, ongoing long-term HD. A well-functioning, permanent arteriovenous fistula (AVF) has been linked to improved clinical outcomes, quality of life, and survival and is integral to patients on HD ongoing health and well-being.[2 3]It is difficult to separate the AVF element of experience from the overall illness experience of ESKD and HD. Large, population-based studies describe that 20%–30% of hospital care for patients on HD is related to their vascular access.[4 5] AVF are associated with high complication rates and frequent reinterventions are required to maintain vascular access, which accounts to increased health expenditure.[6–8] On average, approximately 50% patients with an AVF will require an

open or endovascular surgical procedure to address access insufficiency including occlusions, stenoses or other complications that limit the function of the AVF for effective HD.[9 10] This additional burden of illness, in addition to HD, contributes to considerable stress and anxiety for patients.[11 12]

AVF care benefits from a cohesive multidisciplinary approach including the patient and family, nurses, nephrologists and vascular access surgeons.[13] The role of the vascular access surgeon in ongoing fistula monitoring is being evaluated as older models of care had surgeons relegated to reactive management rather than proactive care through continuous management.[14] A multidisciplinary clinic for monitoring AV fistula function has been trialled and evaluated in Australia.[15] This study used point of care ultrasound (POCUS), and input from renal physicians, vascular access surgeons, trainee surgeons and renal specialist nurses. Their study concluded that significant cost savings were realised through decreased emergency and revision surgeries, and so decreased admissions at their centre.[15] Other centres have looked at integrated clinic models with POCUS prior to surgery,[16] and for ongoing outpatient review.[14] Each of these studies demonstrated cost benefits of a single-centre multidisciplinary clinic. These studies did not include patient-reported outcomes or measure the impact that this model of care has on patients, their values and expectations for the ongoing care of their fistula.

An important consideration in health service research are the experiences of patients, the values they bring to HD vascular access surgery, and the outcomes that matter to them.[11] Patient-reported outcome measures (PROMs) and patient-reported experience measures report the patient outcomes and experience of the patient without interpretation.[17 18] Incorporating PROMs into AV fistula care can provide many benefits. Knowledge of patient outcomes and experiences enhance shared decision-making through increased communication and in turn, provides patients with increased health literacy and insight.[19] As clinicians develop a greater understanding of patient experiences, they can use this knowledge to form nuanced predictions of disease trajectories and enhance patient-centred decision-making.[19 20] There is a growing understanding of patient experience of ESKD and HD.[21] Patients experience anxiety and fear related to both HD and their AVF, ongoing management and disease progression.[22 23] The psychoadaptive strategies that patients adopt during this experience likely affect self-management of their health and associated stressors.[24] Qualitative studies into patient experiences of HD and AVF care have demonstrated patients feel very dependent on their fistulas reporting that it becomes their 'lifeline' that ensures they can continue to dialyse.[25] Themes arising from patient interviews include the physical and mental impacts of having a fistula such as bodily disfigurement and the way that their fistula affects their life and social capacity. Other themes related to the vulnerability of patients on HD being dependent on their fistula, the intrusion on their body and the consequences of fistula complications.[11 21]

A key omission in published AVF research are the experiences of patients from cultural and linguistically diverse (CALD) background.[26–28] Analysis of a population-based health administrative database showed that of patients having AVF's formed in New South Wales, Australia between 2010 and 2012, more than one-third were born in a country other than Australia.[29] To a greater or lesser extent, the barriers to care may be different for patients on HD who are from populations that typically underrepresented in clinical research, such as patients from diverse cultural, racial, or linguistic backgrounds, who identify as lesbian, gay, bisexual, transgender, queer and intersex, who are of advanced older age, or have chronic mental illness.[27] It is important to consider how a patients' cultural and linguistic background interacts with other aspects of their identity (such as age, gender or sexuality) and what impact these intersectional factors have on their experiences of the health system and their AVF care.[30 31]

Study aims

In this qualitative study, we aim to:

1. Explore the lived experiences of patients in inner-city Sydney on HD relating to their AVF care.
2. Examine the extent that AVF care impacts on the overall health and well-being of patients on HD.
3. Explore what patients on HD anticipate their future AVF care will involve.
4. Develop a theoretical framework to explain and contextualise the study findings related to the experiences, values and concerns of a diverse cohort of patients who are on HD.

METHODS AND ANALYSIS

Study setting

This qualitative study using semistructured interviews with patients affiliated with an inner-city tertiary referral hospital in Sydney, Australia. Most HD in Australia is provided in universally accessible, government funded public hospital system either in-hospital units, satellite centres or supported home dialysis.[29] There are no direct costs for outpatient or hospital care. In our centre, HD vascular access care is provided by vascular access surgeons and renal nurses in a regular integrated multidisciplinary clinic. Regular ultrasound surveillance is performed for most patients, with an endovascular first approach to fistula maintenance. Patients engage frequently with their vascular access surgeons for surveillance and to discuss issues with their AVF. Within the HD cohort at our centre, 70% of patients were born in a country other than Australia, speak a language other than English as their primary language at home, or identify as having a cultural background that is not Anglo-Celtic. Italian, Greek and Chinese are the predominant cultural backgrounds, with growing representation from patients from the Indian subcontinent, Asian nations other than China and Middle

Eastern nations. In our unit, most patients of CALD backgrounds are multilingual and speak English with variable levels of proficiency. The patient cohort is older, with an average age of 70 years old.

Recruitment of participants

Patients will be eligible to participate if they are:

(1) Over 18 years old; (2) Are on HD using a functioning AVF or graft; (3) Able to provide informed consent and (4) Speak English proficiently to participate in an interview about their healthcare.

Sampling

A purposeful sampling method will be used to recruit patients with a diverse range of ages, comorbidities, gender and cultural and linguistic backgrounds. Potential patients will be directly recruited if they are known to both the renal and vascular surgical teams in either inpatient, satellite or home HD setting. Capacity to consent will be established by an experienced clinician who will assess a patient's capacity to understand the clinical research proposal including expected risks and benefits, and by review of the clinical notes to ensure the patient provided consent themselves for formation of their AVF.

The eligibility of potential participants will be screened by review of the electronic medical record during vascular access clinic or HD appointments. After screening, suitable patients will be provided a printed patient information statement and discussion about the project will follow. If they agree to participate, an interview time suitable for the patient and investigator will be arranged. Patients may request a family member or carer to be present during the interview. Consent will be completed more than 24 hours after the invitation to participate, using the e-consent platform in Research Electronic Data Capture (REDCap).[32 33]

This study aims to include a diverse patient sample by expanding recruitment to purposefully include multilingual patients from CALD backgrounds. Interviews will be conducted in English. CALD participants will be eligible to participate if they feel comfortable communicating with the investigators in English without an interpreter. An interpreter will be arranged to explain and complete consent if patients have low written English proficiency or on request.

Previous studies have shown data of sufficient richness and depth can be obtained from between 10 and 16 patient interviews.[34] We will seek to interview 10–12 patients initially, with preliminary review of transcripts to ensure sufficient data quality and quantity, with the possibility of further recruitment if data lacks richness or depth.

Patients on HD are frequently asked to participate in clinical research projects. We are conscious that study fatigue is a risk when researching this patient population. To reduce this, we will provide patients opportunity to participate in interviews at times that are convenient to them, with a support person. Interview questions will be limited and focused, to reduce interview time and potential for distress caused by unnecessary interrogation. The voluntary nature of the interviews and right to ask questions will be emphasised throughout the interviews, and the option to decline participation at any time reiterated. It is recognised that research participants discussing emotive topics in in-depth interviews may become emotionally distressed. Table 1 describes the Distress protocol for management of a participant's emotional distress during or after the interview.

Table 1 Distress protocol

Scenario	Action
The participant has a short, self-limiting period of emotional distress in response to a difficult topic	1. Pause the interview 2. Ask the participant if they would like to take a break or stop the interview completely 3. If the participant expresses a wish to continue the interview and is able to do so without undue distress, allow them to do so 4. If the participant wishes to stop the interview, ask if they would like to continue the interview at a later time or date or withdraw from the study. 5. At the end of the interview, offer to refer them to the renal/vascular social worker.
The participant has an extended period of emotional distress.	1. Stop the interview 2. Ask if they would like you to call a support person 3. Stay with the participant until they are calm. 4. Refer them, with their permission, to the renal/vascular social worker. 5. With permission, notify the renal team. 6. Call the next day to check on their well being 7. Offer them the option to withdraw from the study. 8. Report to the ethics committee as an adverse event.

Patients may withdraw from the study at any time without providing a reason, with no impact on their medical care or surgery. If a patient withdraws from the study prior to the transcript analysis, all their data will be removed. If a patient withdraws after thematic analysis, it will not be possible to remove their interview data but all clinical data beyond essential demographic information is deidentified.

Study findings will be disseminated in peer-reviewed publications, through conference proceeding and incorporated into patient and clinician education programmes, clinical pathways and hospital policies, procedures and guidelines where relevant. Participants will be informed of the summarised final study findings in the regular hospital-based ESKD patient newsletter which will include information on how patients can access the final publication.

Data collection and handling

Patient interviews will be conducted by the first author (BMS) face to face or via telephone or videoconferencing,

depending on patient preference. Interviews are anticipated to be between 40 and 80 min in duration and because of the possibility of fatigue, patients will be given the option to do the interview in one or two sittings. Patients may choose to do the interview during HD, or at another time of their choice. All interviews will be audio recorded as part of the consent of participants. Field notes may also be taken during and after the interviews to record key observations and document the interviewer's experience.

The study time frame will be 18 months from 1 June 2021 to 31 December 2022. Interviews will be conducted over the first 6 months of the study.

The interview will be semistructured using an interview guide as follows:

1. When you think about your fistula, what thoughts come to mind?
2. Describe how and what changed in your life after you had a fistula formed.
3. Can you remember the conversations you had when you first had your fistula made? How did you feel at that point? Have your feelings towards your fistula changed since then?
4. Have you had your fistula suddenly stop working or have a major problem so you couldn't dialyse? How did this make you feel? Did you anticipate this might happen?
5. Have you needed to have procedures like an angiogram or a stent to keep your fistula working well? Do you think you will need to have an operation on your fistula at some stage in the future? How does this make you feel?
6. Who would you get help from if there was an issue with your fistula? Who is responsible for your fistula care?
7. How do you feel when you have an ultrasound of your fistula?
8. What have been the best things and the hardest things about your fistula?

Additional prompting and probing questions will supplement the semi structured interview guide. The interview guide was piloted with two patient representatives and refined to its current form according to their suggestions. As the interviews proceed, interview questions will be adapted and refined, following constant comparative analysis methods. The interviews will be recorded using a digital voice recorder to ensure accurate capture of interview content and allow verbatim transcription and subsequent analysis.

All interview transcripts will be deidentified using a code for linking to the patient record number. Participant characteristics, including demographic information such as age, gender, cultural background, AVF status will reported but not aligned to individual patient codes or quotes to reduce the risk of reidentification. The use of quotes (where necessary) will be carefully selected and edited to ensure that any identifiable information is not used. Participants will be allocated a pseudonyms to protect the identity of the participant and those they may report, for example, if a participant is discussing a particular surgeon, the quote may revert to the pronoun of 'they' rather than 'she' as the current gender inequity in the employment of surgeons might make it easier to identify whom the comment related to.

Audiorecordings of interviews will be transcribed verbatim, and files uploaded into REDCap, a secure, web-based software platform to support data capture for research studies.[32 33] Study participants will be allocated a study enrolment number, and this will be used to deidentify all study documents. A master record key will be maintained in REDCap, with access restricted to the principal investigator and study coordinator. Records will be maintained for 5 years after the study completion, in accord with National Health and Medical Research Council responsible conduct of research guidelines.[35] After this period, records will be deleted and destroyed using a secure document destruction service in accord with administering organisation's standard operating procedures for confidential record destruction.

Analysis and methodological framework

Qualitative content analysis will be used to determine key themes arising from participant interviews. A constant comparison technique will be used to identify units of meaning and categorise current and emerging themes. As new themes evolve, this constant comparison will validate the themes through a series of repeat iterations. Transcript coding and initial analysis will be performed by two researchers (BMS and SM). Findings will be discussed at length by all the researchers for consensus. A qualitative research software program, Quirkos V.2.4.2,[36] will be used to visualise the themes and subthemes. Microsoft (MS) word will be used to facilitate data analysis including data reduction, data display and conclusion drawing, and verification.[37] Deconstruction, reconstruction and reorganisation of themes and subthemes using hierarchical heading styles to populate the navigation pane and provide additional data display. MS word functionality supported by other data display strategies will result in enhanced data verification and conclusion drawing.

This study design and analysis references the Consolidated Criteria for Reporting Qualitative Research checklist.[38]

Patient and public involvement

During the design of this study, the opinions regarding the development of this protocol were sought from a few selected long-term HD patients known to the research team. It was with these patients that the original need for the area of research was discussed. They were involved in the validation of the pilot questions, endorsing the appropriate setting and method of the semistructured interviews for the best patient involvement experience. These patients have been updated the progress of the protocol, and will be offered access to the published data when it is available.

Researcher characteristics

All three team members are health professionals with experience working with patients, especially those in the dialysis setting. Two of the previous researchers have significant previous qualitative research experience, which they will bring to this study. Some patients may be well known to two of the team members, but the member conducting interviews will be relatively new to the team and so should not have past encounters influencing analysis. It is expected that some assumptions from previous clinical experience will influence initial analysis, but by repeat iterations and discussion for consensus. These assumptions should be replaced by the findings from patients.

Ethics and dissemination

Ethical approval for this study was provided by the Sydney Local Health District Human Research Ethics Committee (REGIS identifier: 2021/ETH00362, CH reference number: CH62/6/2021-033). Results will be made available to the participants, local health district, funders and other researchers. Results will be presented in various settings such as patient education, hospital-based forums and academic symposiums. Findings will also be published in peer-reviewed journals as well forming the foundation of further patient-reported outcome research.

DISCUSSION

This qualitative study will provide important Australian patient perspectives on the experience of HD and maintaining a functioning AVF.

The theoretical framework that will be developed from this study will be useful for clinicians and healthcare providers can address the patient-centred concerns for HD with regard to their current and future AVF needs. In particular, this project will more clearly establish how patients perceive the role of their surgeon in their AVF care, how they interact with and value their care teams, and how regular ultrasound imaging influences their experience of illness and healthcare. These rich, nuanced insights into patient perspectives will allow development of more patient-focused models of care, that incorporate discussions and shared decision making through communication and collaboration.

Disproportionately high adverse outcomes occur in certain groups of patients on HD, such as the very old, those from CALD backgrounds, or who have complex psychosocial needs. These patient groups are underrepresented in the existing literature about the patient perspective on HD and AVF. This project seeks to hear the voices and perspectives of patients who are part of these minority groups, and to better address health inequities from a patient-centred model of care.

The term CALD is broadly used in Australia and is often synonymous with 'ethic minority groups'.[38] CALD individuals are defined as people who were either born overseas, or had parents born overseas, in countries outside those defined as 'mainly English-speaking' or who speak a language other than English at home.[39] Australian First Nations peoples are considered separate to the definition of CALD. In this protocol, the term CALD is used with a recognition of its limitations.[40] The term is both too broad to identify aspects of culture or race that may be more vulnerable to visible discrimination, does not recognise Australian First Nations People, and is too narrow to encompass the rich diversity of culture that is outside of the dominant Anglo-Celtic majority Australian population. CALD Australians represent over one third of the population but are often excluded or under-represented in clinical research.[30] The reasons for this underrepresentation are numerous, and include the perceptions of researchers, poor or limitations in study design, lack of resourcing and access to care, and patient's health literacy and preferences.[28 40]

The lack of representation of diverse patient groups in clinical research has implications for the generalisability of research findings and may result in the research translation not reaching the most vulnerable groups. Patients of CALD backgrounds experience considerable ESKD-related health inequities compared with Australians of Anglo-Celtic background.[31 40] Even more striking are the inequities in ESKD-related outcomes experienced by Australian First Nations people.[41]

One of the barriers to including CALD patients in qualitative research is the potential for miscommunication or inaccurate language interpretation when identifying themes through transcripts which have been translated at transcription.[31 40] Qualitative data analysis relies on a semiotic understanding of language, and thus people who have limited English proficiency are often unable to be included in studies which are usually in a diverse cultural and linguistic setting. A loss of meaning and inaccuracy in understanding may be a risk with the use of interpreters. While the gold standard of qualitative research in CALD populations is to have interviewers who are fluent in the nominated language and culture of the participants, this is not always possible.[42 43] Many people of CALD backgrounds, especially those who are second generation CALD Australians, are multilingual, and speak and engage with their health providers in English.[38] Despite this, they still may encounter barriers to equitable healthcare. To decrease the inequities in healthcare access and outcomes, it is imperative to understand the values and concerns of patients from different backgrounds through qualitative research, especially in a diverse and multicultural society.[28 30] This study purposefully includes CALD patients with proficiency in speaking English. This project findings will help provide an evidence base for the important elements of care for providing age-friendly, culturally-safe, inclusive therapeutic environments that promote patient engagement and participation in the care and maintenance of their AVFs. However, by excluding patients who do not conduct their dialysis care in English, it is recognised that the perspectives for all patients of different cultural and

linguistic backgrounds are not captured and hence, the transferability of our findings may be reduced.

Several other limitations exist within this research project. The principal investigator is the senior clinician responsible for the HD vascular access clinic, and hence there is a risk of selection bias. Purposeful sampling will seek to provide a representative sample by enrolling patients who are cared for by different surgeons, of variable durations of HD, and with a range of multimorbidity. This is a single centre study, and so there will be some limitation in the generalisability, but in turn will be give invaluable local insight for further service provision. Study applicability may be limited by the geographical and social context of this study. This study will seek to have participants with a broad range of cultural backgrounds, however, the transferability of findings across other cultural groups must be acknowledged. Likewise issues with people with cognitive impairment is also arise as a limitation. Certain aspects of patient experiences will not be reflective of patient experiences in other countries due to the particularities of Australia's universal healthcare system.[12 21] Similarly, by excluding patients who do not have capacity to consent, such as patients with significant cognitive impairment, the study applicability to a very vulnerable group of patients may be limited. It is important to note that patients on HD have regular clinical encounters with both surgeons and renal physicians. Patients without capacity to consent to the routine, regular intervention of HD are few, as supportive care is the standard treatment pathway for this group of patients. As the primary study goals are to assess the experiences, values and concerns of patients who consent to HD, we anticipate that there will be a low rate of patients excluded for incapacity to consent.

This protocol is the first stage of an overall body of research that aims to lead to further, clinically applicable findings. It is the hope that this qualitative study will provide valuable data on patient experiences and values, that will form the foundation for further research into patient-centred models of care and can be used to expand the research to multiple sites, producing richer and more generalisable data. As part of the translation of these research findings, we anticipate developing PROMs, which could be used assessing current models of care and in future HD access clinical trials. This would build research for new models of care that provide for the needs of the diverse population of patients on HD.

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