Published in final edited form as:

J Ren Care. 2017 March ; 43(1): 29–36. doi:10.1111/jorc.12185.

EXPERIENCES OF PATIENTS UNDERGOING DIALYSIS WHO ARE FROM ETHNIC AND RACIAL MINORITIES

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SUMMARY

Background: Approximately 500,000 people in the United States are affected by end-stage kidney disease (ESKD), 53% of whom are Black or Latino. ESKD significantly impacts psychosocial health and quality of life. However, few studies address the psychosocial aspects of ESKD, especially among black and Latino adults. This study sought to understand the psychosocial context of living with ESKD among black and Latino adults who reside in a medically underserved community.

Study Design: A qualitative study.

Setting and Participants: Participants were recruited from a dialysis centre in East New York, Brooklyn, a medically underserved community.

Methodology: Descriptive phenomenology was used as a qualitative approach for capturing the experiences of patients who received dialysis in this community.

Analytical Approach: Open-ended interviews were audio-taped, transcribed, coded and analysed using standard qualitative techniques.

Results: Data saturation was achieved at 36 participants. The following five themes emerged: the transition to dialysis is abrupt and unexpected; denial is often an initial response; dialysis is the new normal and in order to survive one must forget the past and press forward; dialysis changes everything and impacts the entire family; strength was often found in faith and family.

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AUTHOR CONTRIBUTIONS

JM, CBF, BS, CR, CW: Principal Project Leaders, conceived study, participated in design and coordination, read and approved the final manuscript. JM, CBF, NN, RC, BS, CR, CW, ZF: Participated in design and coordination, undertook interviews, helped to draft manuscript, read and approved the final manuscript. CBF, JM, NN, PK, KU, RC, CR, BS, CW, ZF: Analysed the data, helped to draft manuscript and approved the final manuscript.

CONFLICT OF INTEREST

The authors do not have any conflict of interest to disclose.

Limitations: This study was conducted in one setting and may need to be expanded to other sites to capture the experiences of patients cared for in other settings.

Conclusion: These findings have practical implications for informing patient-centered models of care that are more responsive to the psychosocial needs of patients with ESKD living in medically underserved communities.

Keywords

Chronic kidney disease; Environment; Haemodialysis; Psychosocial; Quality improvement; Self-management/Self-care

BACKGROUND

Each year in the United States, approximately 100,000 new patients are diagnosed with end-stage kidney disease (ESKD) which for many people, results in a life on dialysis (Saran *et al.* 2015). The incidence of ESKD is highest among racial and ethnic minorities. (Martins *et al.* 2002; Benabe & Rios 2004). Black and Latino patients have 1.4–3 times the rate of ESKD, respectively (Burrows *et al.*, 2008). Black and Latino patients are more likely to start dialysis at a younger age and are less likely to be placed on a kidney transplant list (Alexander & Sehgal 1998, 2001; Hall *et al.* 2011) consequently, black and Latino patients spend a considerably greater proportion of their lives on dialysis. The number of people who are on dialysis is likely to increase given the rapidly growing epidemic of diabetes, a leading cause of ESKD among racial and ethnic minority populations (Boyle *et al.* 2001). If these current trends continue, by the year 2030, the number of patients with ESKD may reach over two million (Szczzech & Lazar 2004). Primary prevention of ESKD is critical to halting this trend. However, for those who develop ESKD, understanding factors that influence their overall experience on dialysis is essential to developing targeted solutions and preserving their quality of life.

In recent years, there has been a paradigm shift toward greater focus on the patient experience. National agencies such as the Patient-Centered Outcomes Research Institute and the Centres for Medicare & Medicaid Services have called for research and programmes that improve quality of life and the dialysis experience for patients (Fleurence *et al.* 2013; Nissenson 2014; Selby & Slutsky 2016). Understanding patients' experiences is paramount to developing patient-centered and responsive solutions. This study sought to gain a better understanding of the psychosocial context of life on dialysis from the perspectives of Black and Latino patients. The ultimate goal is to use these data to inform clinical guidelines, to set new priority areas for research and create innovative patient-centered programmes that address the values, beliefs and priorities of patients who are from racial and ethnic minorities.

METHODS

Qualitative research is an approach that is well-suited for understanding the social and contextual factors that affect the psychosocial health of patients on dialysis (Tong *et al.* 2014). This study uses descriptive phenomenology, a qualitative approach that aims to

capture a specific phenomenon or event from the perspectives of those who have experienced it (Creswell 2013; Tong *et al.* 2014). Phenomenology allows for an in-depth look into the lives of patients on dialysis and elicits their perspectives and interpretations of psychosocial challenges that they have endured and adjustments that they have made (Kleiman 2004; Rapport & Wainwright 2006).

STUDY SETTING AND PARTICIPANTS

This study was conducted at the Nephrology Foundation of Brooklyn, a dialysis centre located in East New York, Brooklyn (NFB-East). East New York is a medically underserved community; one-third of the residents live below the poverty line and one-fourth have not completed high school (Olson *et al.* 2006).

Participants were accrued through purposive sampling, an approach used to select study subjects that can provide the greatest insight into the research question (Devers & Frankel 2000). A purposive sample is a non-probability sample whereby participants are selected because they are deemed as having the most knowledge, understanding and experience of the phenomenon of interest. For the purpose of this study, participants were selected specifically because they had been on dialysis and thus, were able to provide greater insight into different aspects of life on dialysis (Tongco 2007). The advice of providers, nurses and social workers at the dialysis centre were sought in identifying patients who would be willing to participate in individual interviews and share their experiences. Patients who were identified were approached by a member of the research team to obtain informed consent. Participants were adults, who had been on dialysis for more than six months, were referred by their provider and who provided consent. Ineligible participants were those who were feeling ill at the time of dialysis (back ache or fatigue) or who did not provide consent.

Members of the research team included providers, nurses, researchers and community advocates for dialysis patients. This team developed and piloted sample interview questions and probes. A review of the literature was conducted to identify sample interview questions that had been included in previous qualitative studies on patients' experiences on dialysis (Hagren *et al.* 2001). A final set of items were developed and was administered to participants by the study co-principal investigators. It was explained to participants that this study was to better understand their experiences on dialysis and to learn what health professionals can do to improve the lives and overall quality of life of patients who are on dialysis. The following open-ended were asked to stimulate a discussion:

1. What are some of the challenges that you have experienced as a result of being on dialysis? (Patients were also asked to provide detail on strategies they used to overcome or cope with challenges)
2. What do people on dialysis need in their lives in order to be healthier, live healthier or just be more comfortable with dialysis?
3. What are some of the things doctors or nurses need to know in order for them to help patients on dialysis and their family members cope with dialysis?

In order to give participants sufficient time to talk, the number of questions were limited and designed to be broad, brief and open-ended. These items often led to the discussion of other

topics such as what changes they had to make to deal with dialysis and the impact that dialysis had on interactions with family.

ANALYTIC APPROACH

Individual open-ended qualitative interviews were conducted at the chair-side while patients were undergoing dialysis. The duration of the interviews ranged from 20 to 90 minutes. The variation in duration was due to the fact that some participants provided very detailed and in-depth responses while others provide more succinct and precise responses. The interviewer sat in a chair that was adjacent to the participant. Participants were asked to describe their experiences on dialysis, to discuss challenges that they faced, accommodations they made and to share recommendations on how the experience of dialysis can be improved for other patients and their family. All interviews were conducted in English.

All interviews were audiotaped and responses were transcribed verbatim. A series of standard qualitative techniques were used for data analysis. Responses were read line-by-line and codes were then assigned to each response. Codes are descriptive labels or tags that represent key concepts conveyed in the data. Codes can be actual responses (in vivo codes), selected words from the transcripts, or words that represent key concepts. Similar codes were then grouped into categories. Each category was then reviewed to identify underlying dimensions or subcategories that could be grouped to form new categories. All final categories were reviewed and overarching themes were generated. Themes are recurring and unifying statements that represent the overall meaning or essence of the lived experience of dialysis (Bradley *et al.* 2007).

In order to ensure trustworthiness of data, detailed notes of all interviews and coding processes were maintained as field notes. When there were discordant views regarding the interpretation of data, the team reviewed the raw data and new categories were derived until consensus was reached (Graneheim & Lundman 2004; Boutin-Foster 2005). Study findings are reported in accordance with the Consolidated Criteria for Reporting Qualitative studies (COREQ) (Tong *et al.* 2007). The study was reviewed and approved by the Institutional Review Board for the responsible and ethical conduct of research.

THE TRANSITION TO DIALYSIS IS ABRUPT AND UNEXPECTED

There was a common sentiment among participants that the onset of dialysis was abrupt and unexpected. Some participants did not know that they had kidney failure. Others attributed their symptoms to other illnesses or conditions. In several instances, the first dialysis was done emergently in the hospital setting. The following responses illustrate this finding:

For me, I didn't know I had kidney failure until I had kidney failure, dialysis was just thrown on me.

When I was in the hospital, the doctor said 'you have to start dialysis tomorrow'. I did not even know what dialysis was.

Overall, there was a feeling of being ill-prepared for what was about to transpire. As participants discussed the onset of dialysis, they also provided their perspectives on how to better prepare other patients. As an example one participant stated:

Doctors can help people transition into this new way of life more easily, the whole experience is traumatic.

Participants were aware of the precursors of kidney disease such as diabetes and hypertension. However, they perceived a lack of information on ESKD and dialysis itself. One example is:

All of the pamphlets are about high blood pressure, heart disease, diabetes. There is never nothing about kidney failure and I really think there needs to be more (information) put out there.

DENIAL IS OFTEN AN INITIAL RESPONSE

Although the actual placement on dialysis seemed abrupt, some participants confided that they had been told of their need for dialysis but were initially in denial. One participant simply stated, *'They warned me. Had I listened maybe I would not be here today'*. Another example that supports the theme of denial is the following:

I was in denial. I said 'no that's not me, that's for other people'. Then a year later, my feet started to swell. I couldn't walk 10 feet. I could not put on shoes or tie them up. I had excessive weight gain. Eventually, when they did it, they did emergency dialysis.

FORGET THE PAST AND PRESS FORWARD

There was a theme of resignation to being on dialysis as a 'new normal' way of life. Participants said they learned how to 'just deal with it'. One participant stated: *'It's not difficult, I am resigned to the fact that this is now my life. I had a few days to think about it'*. This appeared to be a conscious way of dealing with the reality of being on dialysis. A recurring theme was 'forgetting the past and pressing forward'. There was an undercurrent of completely abandoning their goals rather than simply delaying or deferring their goals. Some exemplary responses include:

So I guess I am kind of going with the flow instead of being ambitious and having all these goals that you know you can't (pause), you know what I mean.

The only way to survive this is to basically forget about your past and start fresh from here and go forward.

DIALYSIS CHANGES EVERYTHING AND IMPACTS THE ENTIRE FAMILY

Participants described how being on dialysis meant changing almost every aspect of their life. They described the challenges and psychosocial context of health behaviour change. They described the dynamic social and cultural factors that influenced the ability to make lifestyle modifications. Participants had to make modifications in their dietary and fluid intake. Participants described the challenges of giving up certain foods that they were accustomed to eating.

The restrictions of a lot of foods, like cheese and bananas, I used to love bananas. That kind of disappointed me a little bit.

That diet is almost unrealistic. How can you tell someone to stop eating bread and they grew up on bread.

My problem is liquids, as long as I have been on dialysis that is the one thing that is the most difficult. I have tried everything. I have tried sucking on ice, buying a certain water bottle, a certain size cup.

The influence of cultural practices was described. Participants shared some of their eating patterns that were deeply rooted in cultural norms. The following examples describe the cultural factors that may influence the process of making dietary modifications.

I am from West Indian descent, so there are certain things I can't have anymore that I have loved since I was little. All the spicy stuff, the hot curry stuff, you know the macaroni and cheese. You just can't have it anymore.

I am Puerto Rican. You know and the rice and beans, Pasteles. Now you know, I have Pasteles just once a year.

Participants described social determinants that presented barriers to making and adhering to lifestyle modifications. Participants described the challenge of balancing the need to eat healthy meals with other basic necessities such as paying rent, paying for transportation, or owning a telephone.

The true question is could we truly afford to eat healthy? The answer would be no. It is more expensive to eat healthy than it is to eat garbage and to make the belly full.

My husband just lost his job and it's been really tough. Getting to the food pantry is tough and some of them are closed. I don't have carfare for a bus. I can't get to where I have to go. Within the first 3 days of getting our checks the money is gone. I pay the rent and our phone because that is so important.

In describing how dialysis changed all aspects of their lives, there were several discussions on the impact of dialysis on the entire family unit. Participants expressed gratitude for the involvement of family members in their care. However, juxtaposed with the tremendous appreciation for the critical role that family members played was a concern of being a burden.

Sometimes I just cry and rather die than go through this. What could I do? It's tough on my family, my children and my husband.

It's kind of tough. I feel so sorry for my husband. He has to spend a lot of time with me to give me my medication, my insulin, because I have diabetes.

Being on dialysis limited the spontaneity of social interactions and some participants felt as if they were left out of certain activities. Participants felt that they had to make more pragmatic decisions. Social interactions were limited due to participants' physical health, constant fatigue or the practicalities of needing to be near a dialysis unit.

In my personal family we are used to saying, oh let's go to the movies or let's go hang out. I know I get tired and we can't take that long walk. So, I either get excluded or the entire trip gets derailed and I feel bad about that.

My family, my husband's side is all from Trinidad. I would love to go but I can't go there. Unless, I make all these arrangements to find a dialysis centre there and since I know I am finally at a decent place here health-wise, why would I jeopardise that to go somewhere where the quality of dialysis is poor.

These responses provided an example of the total impact that dialysis also had on the individual and their entire family.

STRENGTH WAS OFTEN FOUND IN FAITH AND FAMILY

An important theme that emerged was the reliance on faith and family for strength. The resolve to live was driven by their spiritual foundation and relationships with their family. As previously described, there was a strong sense of resignation among some participants. However, among others, there was a firm resilience that was rooted in spirituality.

One participant stated: *'I gotta go on. I got kids. I got grandbabies. I think that is what keeps me going, my grandbabies'.*

Other responses that demonstrated spirituality as a source of their strength are:

I try to deal with it and ask the Lord to give me strength.

I went to church and testified. It had to be God giving me that strength because I was wondering where am I getting this strength.

When asked what do people on dialysis need most, one respondent stated:

Strong faith, my mother, and a strong foundation.

DISCUSSION

In the United States, approximately 500,000 people have ESKD and are undergoing dialysis (Ojo 2014; Saran *et al.* 2015). This study provided insight into the lived experiences of patients on dialysis and identified several factors that should be considered in developing patient-centered and culturally relevant interventions. Several themes emerged from this qualitative study that depicted the cognitive and emotional processes that underlie the experience of dialysis. Overall, there was a general sentiment that the onset of dialysis was abrupt and unexpected. Many participants in this study described hospitalisation as the first time they heard about kidney failure. This is consistent with prior studies which demonstrate that among patients admitted to the hospital, only half knew they had either stage 4 or 5 kidney disease (Saunders *et al.* 2015). Similar to previous qualitative studies, this study also supports the finding that patients often feel ill-prepared for dialysis (Schell *et al.* 2012).

The perceived abrupt onset of dialysis calls for interventions that begin earlier in the trajectory of renal disease. Pre-dialysis education may help to identify patients who are in denial about their risk of dialysis and enable them to develop healthy and adaptive coping strategies. Research that identifies barriers to referring patients to nephrologists or vascular teams for fistula placement may help patients to prepare for dialysis (Campbell *et al.* 2008). Developing interventions for patients who are in late stages of kidney disease or at imminent risk for dialysis offers new opportunities for education of patients. Early intervention may

delay the onset of dialysis and improve survival (Devins *et al.* 2005; Patwardhan *et al.* 2009). Intervening in the pre-dialysis phase may also help patients to develop adaptive coping styles which may minimise denial.

An important aspect of this study was the focus on black and Latino patients recruited from a medically underserved and low resource community. The experiences of these participants reinforced the tremendous impact of the social determinants of health (Kimmel *et al.* 2013). Income level, housing, employment, transportation, neighborhood safety, social support, language fluency, culture, access to technology are all well-established determinants that if left unaddressed, can thwart best efforts to improve health outcomes (Bell *et al.* 2010; Friel *et al.* 2011; Friel & Marmot 2011; Hill *et al.* 2013). In this study, a lack of income, unemployment and food insecurity were social determinants that were described as impacting the ability to make healthy lifestyle choices. Interventions that address the psychosocial needs as well as physical needs are essential.

Another important consideration was the influence of culture. Participants described challenges to adhering to dietary recommendations that resulted from entrenched cultural practices. For example, respondents lamented over giving up traditional Latin American or West Indian dishes. Participants provided specific examples of meals that they had to avoid such as cheese. For patients undergoing dialysis excessive consumption of cheese that is rich in phosphorus can lead to metabolic and bone related abnormalities (Uribarri & Calvo 2003; Kalantar-Zadeh *et al.* 2010). Early involvement of key stake-holders such as patients, nutritionists, family members and clinicians can be helpful in designing healthy alternatives and culturally- tailored advice on how to eat these items in moderation.

LIMITATIONS OF THE STUDY

There are limitations of this study that should be considered such as the small sample size, recruitment from a single site and a focus on racial and ethnic minority groups. The study included 36 participants which reflects the point of data saturation. (Devers & Frankel 2000) The likelihood that new data would emerge if additional participants were interviewed for this study is low. Another potential limitation is that this study focused on black and Latino patients from one dialysis centre. Incorporating white patients would be helpful in determining whether there are similar experiences among white patients on dialysis or among diverse populations from different socioeconomic backgrounds. A more diverse sample would contribute additional perspectives. However, for this study, the focus on racial and ethnic minorities was intentional as this is the group that is most severely impacted by ESKD among patients in our practice.

Notwithstanding the aforementioned limitations, the results of this study are timely and align with current trends in health care redesign. Emerging Models of ESKD care such as Seamless Care Organizations (ESCOs) offer the promise of improving the dialysis experience, quality of life and clinical outcomes. The assessment of the patient experience will be a metric for fundamentally judging quality of care. Results from this study can help to delineate specific aspects of programs that matter most to patients (Nissenson 2014). As new models of care for patients with ESKD are developed, this study can provide guidance in selecting the optimal timing for programme implementation, in developing key

programme components and in identifying key stakeholders that can enhance care for patients.

IMPLICATIONS FOR PRACTICE

New models of care should consider including employment programmes that can help patients to develop or identify new skills rather than abandoning prior goals. New models of care may need to consider programmes that link patients to careers or provide peer role models on working and remaining engaged in the workforce while on dialysis. Participants in this study discussed the role of their family and the potential for caregiver burden. A review of studies that focused on caregiver interventions found a dearth of studies that specifically addressed the psychosocial needs of caregivers of patients with chronic kidney disease or who are on dialysis (Tong *et al.* 2008). There is a need for new models of care to address the psychosocial needs of family members as well as patients to minimise caregiver burden. New models of care should also acknowledge the role of spirituality and faith in helping patients to endure the dialysis experience. Partnering with faith-based institutions may provide additional assistance and support for many patients who rely on their spirituality and faith for strength.

CONCLUSION

This study described the lived experiences of black and Latino adults with ESKD who were undergoing dialysis. Experiences were described across a spectrum of cognitive responses that included denial, resignation and reliance on faith. Each experience provides an important lever for creating new patient-centered models of care. Understanding the totality of experiences of living on dialysis is a preliminary step to improving overall quality of life for patients on dialysis and ultimately to reducing disparities in ESKD.

ACKNOWLEDGEMENTS

We would like to thank all of the participants who shared their narratives with us.

FINDINGS

Data saturation or the point at which no new data emerged with successive interviews was reached at 36 participants (Strauss & Corbin 1990). The mean age of participants was 53 ± 12 years; 50% were female; and the average number of years on dialysis was 4.9 ± 6 years. The following five themes emerged following data analysis: the transition to dialysis is abrupt and unexpected; denial is often an initial response; dialysis is the new normal and in order to survive one must forget the past and press forward; dialysis changes everything and impacts the entire family; strength was often found in faith and family.

Biography

Carla Boutin-Foster graduated from Downstate Medical College and completed her residency training in Internal Medicine at the New York Presbyterian Hospital. After residency, she completed a Master of Science degree in Clinical Epidemiology at the Weill Graduate School of Medical Sciences. She currently serves as co-director of this program. Dr Boutin-Foster is currently the Associate Dean in the Office of Diversity Education and Research and will oversee pipeline programmes designed to increase the number of underrepresented minority students in biomedicine and biomedical research. Her research provides a laboratory in which students and junior investigators can develop hands-on skills in conducting health disparities research and develop their own line of scientific inquiry.

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