What informs decisions regarding home dialysis: a qualitative descriptive study of patients from Greek backgrounds in a hospital-based haemodialysis unit

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Submitted: 3 May 2016, Accepted: 15 June 2016

Abstract

Background
An audit of dialysis patients in the renal service revealed that 20% of hospital-based patients were from a Greek background in comparison to 7% in the home dialysis group. A study to provide the opportunity to increase the uptake of home dialysis therapies in people with advanced chronic kidney disease (CKD) from a Greek background was conducted in 2015.

The main aims of the study were to provide a better understanding of the factors that inform decisions of people from Greek backgrounds regarding dialysis and to identify the enablers and barriers to choosing home dialysis for this group.

Methods
This qualitative descriptive study involved participant interviews. The participants were a convenience sample of patients on hospital-based haemodialysis who are from Greek backgrounds.

Results
Ten interviews supported by a Greek interpreter were conducted. There were seven male and three female participants and the average age was 78 years. They had migrated to Australia on average 53 years ago. Interview themes identified were: not understanding; the doctor told me; doing for the husband; and not in my house.

Conclusions
Age at dialysis commencement and cultural influences impacted the participants’ dialysis choices. Further work is being done to address the main themes in an effort to support people from Greek backgrounds in their dialysis decision making.

Keywords
Home dialysis therapies, Greek-speaking patients.

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Introduction

As a proportion of the total population, Australia’s overseas-born population has grown steadily from 1 in 10 (10%) in 1947 to more than 1 in 4 (28%) at 30 June 2014 (Australian Bureau of Statistics, 2015). The proportion of migrants from different countries varies considerably between regions and between Local Government Areas (LGAs). In the catchment area for our renal dialysis service, the community profile data indicates that between 51% and 54% of the residents were born overseas and speak a language other than English at home. Greek is the most common non-English language spoken at home in the main LGAs (NSW Government, 2011).

The increasing diversity of the population presents challenges for health care providers as we struggle to accommodate the needs of the culturally and linguistically diverse (CALD) patients we care for. For our renal dialysis service this is evident when making the comparison between people who perform dialysis at home (home haemodialysis and peritoneal dialysis) and people who have dialysis in the hospital. An audit of the patients who have attended the predialysis clinic over the past 10 years was conducted in 2014. The findings revealed that people from CALD backgrounds were less likely to choose home dialysis therapies, even though they all received predialysis assessment and education in the predialysis program. This finding was most significant in the Greek-speaking group. Further audit of current dialysis patients revealed that 20% of hospital-based haemodialysis patients were from a Greek background, in comparison to only 7% in the home dialysis group. It must be noted that some of the people on the hospital-based haemodialysis program may have originally been on peritoneal dialysis (PD) and then transitioned.

A study was conducted to assist in explaining why people from Greek backgrounds were not choosing to have home-based therapies. This paper imparts the findings of this study.

Literature review

Home dialysis

Home dialysis therapies include PD and home haemodialysis (HHD) with the alternative dialysis therapies requiring the patient to attend a hospital or satellite unit for haemodialysis. Home dialysis patients provide their own dialysis treatments, thus enhancing autonomy and flexibility and negating the need to travel to a dialysis unit where they are at increased risk of exposure to pathogens and potential diseases (Kidney Health Australia, 2012).

Those using HHD have lower mortality rates (Marshall et al., 2011), experience less hospitalisation, and have fewer dialysis-related complications than satellite or hospital-based patients (Kidney Health Australia, 2012). The clear and consistent benefits of more intensive HHD on a number of biochemical, physical and psychological parameters have also been established (Rosner, 2010).

Consumer choice is an imperative to the success of home dialysis therapies as adherence to the treatment regimen is pivotal to successful outcomes. Perceptions of lifestyle advantages and quality of life remain the primary factors that influence the dialysis choices of patients (Lee et al., 2008; Ludlow et al., 2012).

It is beyond the scope of this paper to discuss the benefits of home dialysis therapies in any detail. The support for home dialysis therapy over a unit-based therapy has been repeatedly reported in the literature. Literature addressing the dialysis of people in Greece was sourced to provide further understanding of why people from Greek backgrounds are reluctant to choose home dialysis therapies.

Dialysis in Greece

A survey of European dialysis units was conducted in 2003 (Kafkia et al., 2005). The European Practice Survey findings revealed that all 74 Greek centres that responded offered haemodialysis (in hospital); none offered HHD and only 33% offered PD. Although the exercise was to be replicated every three years, there has been no indication in the literature that it has been repeated. A review of the European Registry data (ERA-EDTA Registry, 2015) states that for prevalent patients at 31 December 2013 by established therapy, 21% had a functioning transplant, 74% were on hospital/centre haemodialysis and 5% on PD. There were no patients on HHD. This represents a reliance on hospital-based haemodialysis and a very small uptake of home dialysis therapies. The findings represent what is happening in Greece and would affect the information received by potential patients if they were to contact family or friends in Greece for advice or search the internet for information in Greek.

The prevalence of HHD as a proportion of all dialysis care varies globally. HHD is common in Australia and New Zealand but is rare or unavailable in other parts of the world, including parts of Europe. The reasons for the wide variation in uptake are unclear, although higher HHD use is characterised by local advocacy and experience, combined with service centralisation and favourable reimbursement (Tong et al., 2012).

A number of publications about quality of life indicate that social support and the support of family and friends is a priority for Greek dialysis patients (Gerogianni & Babatsikou, 2014). A study addressing the problems of people on haemodialysis in Greece found that issues related to socialisation and...
restrictions on eating and drinking caused most problems. For Greek people, being able to go out, eat, drink and socialise is particularly important culturally and this finding can be extrapolated to people from Greek backgrounds living in Australia. The researchers were surprised to find that most patients reported acceptance of the dialysis because it meant that they were alive (Kaba et al., 2007). This may be linked to the strong community and extended family networks of Greek people and the teachings of the Greek Orthodox Church (Greek Welfare Centre Community Services [NSW], 2014).

There are no published studies which specifically focus on the decision making and experiences of people from Greek backgrounds receiving dialysis in the Australian context. Therefore, the aims of this research were:

- to provide a better understanding of the factors that inform decisions about dialysis of people from Greek backgrounds;
- to identify any barriers or enablers to people from Greek backgrounds choosing home therapies; and
- to identify suitable educational strategies to support people from Greek backgrounds to consider home therapy in the future.

It is hoped that the findings from this study will provide the opportunity to increase the uptake of home dialysis therapies. The group who will be the target of the study are those from a Greek background referred to our renal dialysis service for the management of stage 4–5 chronic kidney disease (CKD), that is, those who are enrolled in the predialysis program and are actively making decisions about a future dialysis option.

**Methods**

The qualitative descriptive study was conducted using a purposeful, convenience sample of 10 patients from Greek backgrounds in the hospital haemodialysis unit of a major Sydney renal service. Greek background is defined as people who speak Greek as their first language at home. The study was conducted between May and December 2015. Ethics approval was granted to undertake a low, negligible-risk research study.

Primary nurses in the dialysis unit were asked to identify patients under their care from Greek backgrounds. A research nurse with the support of a Greek-speaking registered nurse approached patients for recruitment. Patients were given the participant information and consent form, translated into Greek. Once the patient had consented to the study, the interviews were scheduled and a Greek interpreter was arranged, if required. The interviews were conducted in a quiet area of the unit while the patient was receiving haemodialysis. The interviews were audiotaped and transcribed.

Guiding questions for the interview were compiled by a steering committee, which was convened to oversee a wider project aimed at improving HHD and PD uptake in people with advanced CKD from a Greek background. The steering committee included a representative from the project partner (Sydney Greek Welfare Centre), a nursing unit manager, clinical nurse consultant, a nephrologist and a nurse with a Greek background. The steering committee underwent cultural awareness training prior to the study commencement.

**Data analysis**

The demographic data from the patient interviews was recorded on an Excel spreadsheet to enable easy descriptive analysis. Thematic analysis was used to analyse the interview transcriptions. Thematic analysis involved searching the data to find repeated patterns of meaning and encompassed coding the transcripts, searching for themes, revising the themes and defining and naming the themes (Braun & Clarke, 2006).

**Results**

**Demographic data**

Ten interviews were conducted with people from Greek backgrounds. There were seven males and three females and the average age was 78 years, range 58–88 years. All had migrated to Australia on average 53 years ago, mainly in the 1950s and 1960s. None of the participants held professional jobs and none were currently in paid employment. The average length of time on all forms of dialysis was 5.3 years (range 1–11.9 years). Three of the participants had been on PD prior to commencing hospital-based haemodialysis. Of the participants, eight were married and two were widowed. A Greek interpreter was required for seven of the interviews. An interpreter was not used if the patient said they did not require one (Table 1).

**Thematic analysis**

A review of the interview data identified four main themes: *not understanding; doing for the husband; doing what the doctor said; and not in my house.*

1. **Not understanding**

The theme not understanding was evident in all interview transcriptions. Participants were concerned about having dialysis at home because they felt they would not be able to understand what was required due to the language barrier and the perceived difficulty of the treatments. Evident across all interviews was the idea that dialysis, especially haemodialysis,
is something that should be done in hospital where there is medical and nursing support.

One patient had been on PD previously and experienced communication issues when dealing with dialysis-related problems:

> Every night I had problems (wife). Oh my God. I had problems with the machine and someone there was very hard to talk to me. When they talk to me they get very angry but I could not read it. He said just put it there and I did not understand. This [haemodialysis] is harder and I would not know what to do (P2).

Another patient openly stated that they did not feel like they would be able to perform dialysis at home:

> Maybe, maybe we are not smart enough to know what to do. We do not have the brains (P9).

### 2. Doing for the husband

It was stated in three interviews and implicit in the other interviews with the men that the wives took on the role of carer, in addition to fulfilling domestic duties. One wife who was present at the interview with her husband stated that she would be scared of HHD because she would not like to put the needles in. When asked if she would be expected to do HHD for her husband she said, “I am the one who does his washing, I do the cooking and cleaning. I do everything and I would not be able to do the dialysis (P1 wife).”

When asked if it is common that women are expected to do everything for their husbands, she replied:

> Yes that is right. I do everything and he relaxes and has coffee with his friends. This is the same for other Greek women my age. He has worked and given us money but I haven’t (P1 wife).

Another wife was not part of the interview, choosing to sit away while the researcher spoke to her husband. When the issue of HHD was raised, his wife interjected and said:

> There is no way I can do it. I did the other dialysis. Do not make me do this one. It is too hard and I am too worried (P5)

At a later point in the interview, the participant was asked about why he did not choose HHD after his PD failed:

> When I was in the home my wife would see something and she would panic. I cannot let her help me again. She cannot help me that way. It is too hard for her (P6).

A general observation has identified that the support for Greek men by their wives is evident on the haemodialysis unit as most will accompany their husbands and stay until the dialysis is complete.

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Table 1: Demographic data for 10 participants interviewed
3. Doing what the doctor said

Nine of the patients interviewed had attended the predialysis clinic for education and assessment prior to commencing dialysis. They felt that they had adequate to good education about dialysis options. When asked about their decision to have hospital-based haemodialysis or PD in the first instance they claimed that the decision was not theirs but the doctor’s to make. Two participants said:

The doctor told me to do it and so I did what he said (P1, P4).

Another participant stated:

Whatever the doctor told me I did. He knows better than me and I need to listen to him and do what he suggests. I am not a doctor so I don’t know what to do (P8).

4. Not in my house

One patient was adamant that he did not want dialysis at home because he did not want his family and friends to see it:

They said that I can do it at home but I said to them I can’t. I said I cannot because I have kids but I will learn everything here. I even learnt the needles. I cannot say that my children cannot come to my home — never, ever. (P1)

I do not want a machine like the hospital at home for everyone to see. I come here and no one knows where I have gone (P1).

The issue of not having dialysis at home was reinforced by another patient, who also stated that he did not want any machines or medical equipment in his house:

Dialysis is for the hospital and my home is for my family and friends (P9).

Discussion

Demographic analysis identified that all of the participants were born in Greece and immigrated to Australia in the 1950s and 1960s. A large influx of Greek immigrants to Australia occurred in this period following the Greek civil war (NSW Government, 2011). In addition, the immigrants tended to live in Greek communities, which provided them with the support of others who shared, understood and appreciated their cultural values. To counter feelings of loss and isolation, they socialised with people who could converse in Greek rather than learn English (Greek Welfare Centre Community Services [NSW], 2014).

The participants reflected the number of new arrivals who were employed in secondary industry and have been strongly represented in unskilled and semi-skilled occupations. This historical understanding suggests why the participants had a very poor grasp of the English language, despite having been in the country for many years.

The participants’ limited command of English underpins the theme of not understanding. One area which may assist people in choosing and inevitably conducting home therapies is the access to written materials in Greek. In addition, the health care interpreter services are always utilised, but the time they can spend is restricted. Educational information is available in Australia in Greek. The generic booklets published by Kidney Health Australia are available in Greek but there is limited information which would assist people to choose home rather than hospital-based therapies. A further issue arises when the patient is not literate in Greek as is the case with most study participants. Photo sheets may assist with the patients’ understanding of the two home dialysis options but if patients are to go home without the ability to read or write English or Greek, it leaves them at risk, unless they have the support of family members who can assist with the procedure and be available in an emergency.

The theme doing what the doctor said supports the notion of the high status that medical doctors have in the Greek community. If the nephrologist presents home therapies as a feasible option, it is likely that the patient will consider it as a suitable choice. The doctor is also the one who knows what to do when the patient is not understanding.

Doing for the husband and not in my house are themes that represent the social values of the elderly Greek community. It was identified from discussion with the Greek Welfare Centre staff that these findings from the study were to be expected. In essence, we as health care professionals should not be changing cultural beliefs but working with them. Increasing the cultural awareness of renal health care workers involved in supporting patients and carers in decision making regarding dialysis options would assist them in understanding why elderly people from Greek backgrounds do not choose to perform home therapies.

Predialysis and home dialysis programs that address health literacy and cultural and social values may reduce fears and build confidence in making decisions to undertake home dialysis (Walker et al., 2015). Promoting the Greek community’s awareness of CKD management and the benefits of choosing a home therapy may also go some way to changing their view of dialysis as something provided by hospital staff.

As the new generations of people from Greek backgrounds reach their later life it is envisaged that they would be able to speak English and some of the strong cultural norms seen as barriers to home therapies will have lost their impact. Unfortunately, this situation will not occur for 10–20 years, so
there is a need to address them now to provide the opportunity for people to access the best care possible.

This study was conducted in a single dialysis service with a small sample size. Despite the limitations, the findings could be generalised to other Australian renal services that provide dialysis care for patients from Greek backgrounds.

Conclusion

Home dialysis therapies have been established as the most beneficial methods of dialysis delivery for many reasons, including improved health benefits and quality of life. People from Greek backgrounds within our renal service have not been accessing home dialysis therapies and the reasons are now clear. Cultural norms are seen to guide the decisions of people from Greek backgrounds in this older age group. Cultural influences are not something that can or should be altered but identified and supported.

As a result of the research, specific educational materials addressing home dialysis have been developed and translated into Greek. These documents, coupled with a greater understanding of the findings related to Greek culture, have been integrated by staff in the Renal Options Clinic. This focused education, taking into consideration cultural and social values, is required to support patients in their decision making and confidence to perform home therapies.

Acknowledgements

I acknowledge the South Eastern Sydney Local Heath District Multicultural Unit for funding to conduct the research as part of a larger project. Thank you to the staff from the Greek Welfare Centre who provided support and guidance in the conduct of the research and broader project.

References


