

Opting out of dialysis – Exploring patients' decisions to forego dialysis in favour of conservative non-dialytic management for end-stage renal disease

Angeline S. T. Seah FRCP, FAMS, DPM,*† Fiona Tan MScClin,‡ Subramaniam Srinivas MBBS, ABIM (Nephrology, Internal Medicine),§¶** Huei Yei Wu MRCP, FAMS, DPM†† and Konstadina Griva MSC, PhD‡‡

*Adjunct Assistant Professor, Yong Loo Lin School of Medicine, National University of Singapore, Singapore, †Department of Geriatric Medicine, Khoo Teck Puat Hospital, Singapore, ‡Clinical Psychologist, Institute of Mental Health, Singapore, §Consultant, Division of Renal Medicine, Department of Medicine, National University of Singapore, ¶Assistant Professor, Department of Medicine, National University of Singapore, **Consultant, Division of Nephrology, National University Health System, Singapore, ††Senior Consultant & Head, Department of Palliative Medicine, Tan Tock Seng Hospital, Singapore, and ‡‡Associate Professor, Department of Psychology, National University of Singapore, Singapore, Singapore

Abstract

Correspondence

Dr Konstadina Griva
Assistant Professor
Department of Psychology
National University of Singapore
Faculty of Arts & Social Sciences
Block AS4, #02-28, 9 Arts Link
Singapore 117570
Singapore
E-mail: psygk@nus.edu.sg

Accepted for publication

28 March 2013

Keywords: conservative management, decision-making, dialysis, palliative

Background Dialysis prolongs the life of people with end-stage renal disease (ESRD), but for patients who are elderly and suffer multiple comorbid illnesses the benefits of dialysis may be outweighed by its negative consequences. Non-dialytic conservative management has therefore become an alternative treatment route, yet little is known on patients' experience with choosing end-of-life treatment.

Aims To gain insight into the decision-making process leading to opting out of dialysis and the experience with conservative non-dialytic management from the patients' perspective.

Design Qualitative study using semi-structured interviews. Interpretative phenomenological analysis was undertaken as the framework for data analysis.

Setting/Participants $N = 9$ ESRD participants who have taken the decision to forego dialysis were recruited from the advanced care programme under the National Healthcare Group, Singapore.

Results Participants discussed life since ESRD diagnosis, and the personal and contextual factors that led them to choose conservative management. The perceived physical and financial burden of dialysis both for the individual but most importantly for their family, uncertainty over likely gains over risks which were fuelled by communication of negative dialysis stories of others, coupled with sense of life completion and achievement led them to refuse dialysis. All participants took ownership of their decision despite contrary advice by doctors and were content with their decision and current management.

Conclusions Study highlights the factors driving patients' decisions for conservative non-dialytic management over dialysis to allow medical professionals to offer appropriate support to patients through their decision-making process and in caring them for the rest of their lives.

Background

A global increase in the prevalence of end-stage renal disease (ESRD) due to an ageing population and a worldwide epidemic of chronic diseases has resulted in many patients being considered for renal replacement therapy.¹ Singapore, a small country with a rapidly ageing population and a high incidence of diabetes, has the fifth highest incidence of ESRD in the world with approximately 750 patients diagnosed each year.²

Akin to a death sentence before the advent of renal replacement therapy, ESRD can now be treated with kidney transplantation or dialysis. Each of the renal replacement therapies requires lifestyle modifications in terms of long-term compliance to medications, dietary restrictions and accommodation of dialysis schedules. Potentially creating employment problems, social isolation, dependency on others, strained family relationships and financial stress, some struggle with the decision of whether to commence dialysis, in effect rejecting a potentially life prolonging intervention in the face of an advanced, progressive, life-limiting condition with a significant symptom burden.³

Conservative management can only aim to palliate symptoms and complications of ESRD, avoiding factors that can accelerate the deterioration of renal function and addressing psychosocial and spiritual issues of patients and their families.

In older patients with worse comorbid loads and poor general condition, there is great uncertainty on survival benefits versus the physical and psychological costs of dialysis.^{4,5} Clinicians are hence faced with the dilemma of whether to recommend dialysis and extension of life at all costs. For patients who doubt that they will genuinely gain from dialysis and feel that remaining

alive while struggling with the burden of dialysis is not in line with their life goals, the decision to decline dialysis becomes an informed end-of-life choice.

Public interest and curiosity may be aroused in questioning an individual's reasons for what appears to be the refusal of a life-sustaining measure, yet little is understood about the decision process from patients' perspective. The majority of previous studies focused on the underlying reasons from the physician's perspective, in a decision which is very much physician-centred,^{6,7} or derived data from administrative databases rather than directly from patients.⁷ A further concern relates to the under-representation of culturally and linguistically diverse patient samples. The only study to directly assess patients' reasoning behind dialysis refusal was conducted in Netherlands with Caucasian patients.⁸ Results highlighted the importance of personal values towards life and death, yet the pertinent organizational and cultural specificities make it hard to extrapolate to other settings. In Singapore, dialysis is fee for service with subsidies determined on basis of means testing and family income. Practical and financial considerations may hence become more important when considering dialysis. Moreover, the cultural values of collectivism and interdependence in Asian cultures, as well variation in beliefs about health and illness highlight the need to further explore decision making in non-Western patients. This information can potentially inform the development of culturally sensitive decision support programmes both in the local context and also in most Western settings where there are substantial numbers of ESRD patients from an Asian background.

This study aims to examine the patient's decision-making process and reasons for

declining dialysis, their beliefs and feelings of the value and impact of conservative management in our local context.

Methods

Participants

Participants for this cross-sectional qualitative study were recruited from ESRD patients referred to palliative care (advance care planning programme) from the renal departments of 3 public hospitals in Singapore (September 2010 – June 2011). All eligible patients during the study window were invited to participate, targeting between seven and nine participants.

Ethics approval was obtained from domain-specific review boards (DSRB) of the participating hospitals and written consent obtained from all patients.

Inclusion criteria were chronic kidney disease stage 5 (glomerular filtration rate <15 ml/min), decision made to decline dialysis after counselling with hospital renal teams, ability to communicate verbally with researchers and permission granted by their renal and palliative physicians.

Exclusion criteria were inability to give consent due to dementia or other mental illnesses, inability to communicate verbally with researchers or deemed by clinicians to be too unwell or to be too distressed to participate.

Data collection

All patients meeting the inclusion criteria were invited to participate by their renal or palliative attending physician, with a brief explanation of the study and its requirements. An information sheet in English and simplified Chinese was administered and followed up by a phone call approximately a week later from a coordinator to address any questions and ascertain interest in participation. When verbal or written consent was given, the contact details were sent to the researcher, who contacted participants to arrange a time for the interview.

Semi-structured interviews were conducted using an interview schedule as a guide while

allowing the interview to take its own direction. Prompts assisted participants, if needed, in responding to questions. Interviews were conducted by the second author (FT) who is trilingual in English, Mandarin and Hokkien dialect. A translator was used for one interview conducted in the Teochew dialect.

Interviews took place at a location of the patient's choice, away from the hospital, and lasted between 45 and 90 min. These were digitally recorded and transcribed verbatim including pauses, laughs and other significant non-verbal information. Interviews conducted in Mandarin or dialects ($N = 8$) were first transcribed into Chinese before being translated into English for data analysis. All respondents received a nominal sum of reimbursement for their participation.

Data analysis

Interpretative phenomenological analysis (IPA) was applied as the framework for data analysis using an iterative process of idiographic thematic analysis, integration and interpretation⁹:

In brief, the left-hand margin recorded the initial descriptive analysis and any reflexive comments. Initial notes were then condensed as themes in the right-hand margin (completed independently by two researchers, with any differences resolved through discussion). This process was carried out with each transcript to ensure themes were not imposed. Themes were compared across the transcripts and clustered into 'superordinate' themes/categories. Findings were then talked over with the clinician researcher (AS) and followed by discussion in which all three interdisciplinary researchers (FT: clinical psychology; KG: health psychology; AS: geriatric and palliative medicine) 'interrogated' the findings relative to existing research and their field of expertise.

Results

There were 40 patients referred to Advanced Care Programme during the period of study. Twenty-eight patients were excluded due to

dementia resulting in inability to communicate verbally, confusion and actively dying, and 1 patient had schizophrenia. None were denied permission by their attending physicians or deemed to be too distressed to participate. Twelve were available for recruitment, of which three patients initially showed interest but later declined. Two patients expressed concerns that family members may not be comfortable with the interviewer coming into their house to conduct the interview, and another patient was fearful that the researcher's role was to encourage him to opt for dialysis, despite repeated reassurances that it was not the case.

The sample comprised nine patients (Table 1), all from a Chinese background with five men and four women, ranging in age from 61 to 84 years (median of 81). Six participants were conversant in Mandarin, 1 in Hokkien, 1 in Teochew and 1 in English.

Analysis of the qualitative data yielded several themes, which were grouped into three main categories: 'The impact of ESRD', 'Making the Decision' and 'Feelings towards their choice of treatment' (see Table 2). Each of the themes is illustrated below using quotes derived from the participant's transcripts.

The impact of ESRD

Participants discussed vividly about the changes that ESRD has brought upon their lives and their coping responses to these changes. The issues most talked about were that of symptomatic burden associated with

the disease, followed by costs required to manage their illness.

The physical and financial burden

'I feel nauseous sometimes... I have headaches too [] My chest has been painful, which may be due to the lack of blood. (NSK). I feel physically weak ... I might be able to walk in the morning, but my body will ache as the day goes on' (LHL).

Participants shared concerns about the expenses. They felt that although it costs less not being on dialysis, expenses for consultations and medications are considerable. Most were open to assistance. Participants reported: 'The injections are very expensive' (LAS); 'Every time my daughter collects medication on my behalf, it's going to cost her If I can get some help with that... it'll be the best' (LHL).

Coping – limiting worrisome thoughts and contentment

In tandem with discussion on symptoms and costs, participants spoke of engaging in coping techniques, which helped them conceptualize this life-limiting diagnosis and remain positive during the period of their end-of-life. These were related to living life in the moment and enjoying simple pleasures with family and friends. Shifting their focus away from physical limitations, participants chose to concentrate on the aspects of lives or activities that remained untouched by their physical troubles.

'I'm taking it day by day now. I have enough to eat and enough to wear, that's good

Table 1 Study participants

	Pseudonym	Gender	Ethnicity	Age	Time since Kidney Disease diagnosis (years)	Language used to conduct interview
R1	AAG	M	Chinese	81	10	Hokkien
R2	GSK	M	Chinese	69	10	Mandarin
R3	HBL	F	Chinese	82	10	Mandarin
R4	LAS	M	Chinese	76	5	Mandarin
R5	NSK	M	Chinese	61	8	Mandarin
R6	LHL	F	Chinese	82	4	Mandarin
R7	THE	F	Chinese	84	1	Teochew
R8	WCY	M	Chinese	77	2	Mandarin
R9	AV	F	Chinese	70	6	English

Table 2 Summary of results

Superordinate themes	Subordinate themes
Impact of ESRD	Physical and financial burden of condition Coping techniques – limiting worrisome thoughts and contentment
Making the decision	Immediate rejection of dialysis Personal ownership of decision Balancing odds and reaching decision: Age and life completion Financial and physical burden of dialysis Unacceptability of being a burden to the families Stories of suffering and burden inflicted by dialysis Inevitability of death
Feelings towards their choice of treatment	Satisfaction with decision Appreciation for medical teams

enough for me. My son treats me very well, so I am very contented' (GSK); 'What's the point of thinking so much? Live each day as it comes... I love watching television programs. When my daughter visits me... she'll accompany me' (LHL).

Focusing on the present while avoiding ruminating on what lays ahead was a common way of coping with poor prognosis and imminent demise. 'With a disease like this, what is the point of thinking so much when you decided not to go on dialysis?' (NSK).

Some appeared to accept a new definition and state of health, encompassing both functional capacity to social and family life.

'I can still meet my friends below the block to chitchat' (NSK); 'It hasn't affected my family life, my relationship with my wife is very good' (LAS).

'No, not any effect. I just have to take my medication and have regular injections, I can still eat my meals and sleep' (HBL).

Making the decision

This category refers to the decision-making process from deliberation to determination or

verbalization of this decision, that is, the context, the parties involved and patients' reasons for rejecting dialysis.

Immediate rejection of dialysis

All but one of the participants reported that they rejected dialysis immediately when it was offered as a treatment option upon diagnosis of ESRD. There was no struggle to make sense of the situation or extensive deliberation on treatment alternatives. Patients straightaway refused dialysis and clearly communicated this to their physicians.

'Well, the doctor did encourage me to go on dialysis, but I said "no" I knew from the start that I did not want to go through dialysis if my kidneys ever failed' (NSK).

Participants were knowledgeable of basic dialysis procedures, that is, scheduling and access. Yet what weighed greatly in their decision to immediately reject dialysis were their perceptions of others' lived experiences or information garnered through friends, family or the media, rather than the procedural information provided in medical consultations. Hearsay and lay stories shared via various non-medical sources relayed the pain and trauma of dialysis, the burden afflicted on patients and families, as well as unsuccessful treatment outcomes thereby reinforcing preconceived fears and anxieties about dialysis. 'I have seen my friends go through dialysis and the shows on television. The people on dialysis look so weak and helpless' (THE).

These often biased accounts served to form a negative impression on the participants' minds well before they have been educated by their medical team about the process and benefits of dialysis.

Personal ownership of decision

Participants indicated that they were the ones who made the decision themselves. 'I made the decision myself' (NSK, LAS, GSK, AAG, THE, AV); 'no one made the decision for me' (LHL).

Only after the decision was made, they proceeded to inform their family members of this

decision and elicit their views. ‘Then I discussed it with my family... My life belongs to me, but also to everyone else, so I discussed with them...’ (WCY).

In all of these patients, family members were found to be supportive of the decisions that they made: ‘my wife said that it would be difficult for me to attend regular dialysis sessions and not pursuing dialysis is a good option’ (LAS); ‘...with my sons and daughters. They all mentioned that I shouldn’t go on dialysis’ (AAG). The approval by family reinforces their decision and also serves to reassure patients that family support will be rendered at difficult times ahead and that family well-being and harmony is preserved.

Although families’ stance was in unison with patients’ decision, participants indicated that their medical teams strongly encouraged dialysis. When patients’ informed health care professionals of their decision to decline dialysis, they felt as though they were being pressured to change their decision. These feelings contributed to patients’ reluctance to approach and seek support from their medical team during their decision-making process as their decision is against doctors’ recommendations. Participants reported: ‘There is really nothing to discuss with the doctor. [] the doctor is wary and persuaded me to accept dialysis []... all they would do is to encourage me to go on dialysis and tell me the benefits of dialysis’ (LAS); ‘He just kept encouraging me to go on dialysis [] he told me that I was still young, why don’t I consider dialysis’ (NSK).

Balancing the odds in reaching the final decision

Major considerations in the final decision to reject dialysis were age and the sense of life completion, financial and physical costs of dialysis, perceived pain and suffering inflicted by dialysis, and the inevitability of death.

Age and life completion

Patients who felt age played a factor and had a strong sense of life completion indicated: ‘I’m so old... there is no use for dialysis’ (AAG). One participant explains: ‘If I was younger...

in my forties or fifties, I will opt for dialysis... but not now at this age, where I don’t have a care in this world’ (THE).

The sense of life completion was strong in the participants who said that they have achieved everything they have wanted in life. They had a strong sense of contentment and felt that they have had enough. For instance, they have children or grandchildren who are grown and independent; hence, they do not have reasons to actively try to increase their life span. The participants of this study noted: ‘I am already 60 plus years old, my children are big... There is no need for me to consider so much’ (NSK); ‘I’m 77 years old and I don’t have any more concerns’ (LAS).

The idea of having led a complete life and fulfilment of life goals seems to be coincident with that of decrease in death anxiety. ‘yes. I am not afraid of death [] If it is my time to die then I’ll die. It’s time to go when my time is up’ (LAS); ‘I said no (dialysis), die never mind, I’ve seen everything already, my children have grown up, my grandchildren. God has given me everything already, that’s more than enough’ (AT).

Financial and physical cost of dialysis

Many feel that the financial, time and physical cost of dialysis outweighs the benefits. Financial concerns were vividly voiced. Dialysis incurs substantial costs even when subsidies may be granted for financially needy patients.

‘Even if financial assistance or a grant is available, you will still need to come out with two-thirds of the cost. How can I ever afford it? [] it really has got to do with the financial concerns’ (LAS); ‘that’s the predominant issue’ (NSK).

‘Rich people have the luxury to spend their money on dialysis in order to extend their lives by 1–2 years, but for poor people like us, the sooner we pass on the faster we will be released from our burdens’ (LAS).

Participants also described dialysis as costing a lot of time: ‘It’s very troublesome. I need to go to the dialysis centre 2–3 times a week [] it’s a waste of time [] you want me to sit there for 2 h is enough to scare me half to death’ (THE).

Unacceptability of being a burden to the families

Dialysis was discussed as a family burden. Participants' concerns that they would be a burden stems from the amount of money required from the family for dialysis and the support needed for them to attend dialysis. Being financially dependent on their spouse or children to support daily and medical needs, they may perceive that their families do not have the financial means to support an additional dialysis cost.

'I did not want to be a great burden to my children [] ... my children will still be burdened financially' (GSK).

In addition, they may not think that it is realistic for their children to take time out from employment regularly to bring them for dialysis in case it inconveniences them in earning a living. Their primary concern was primarily on family's well-being and resources rather than extending life.

'If I go on dialysis, I will be a burden to my entire family. I rather not be a burden [] their livelihood will be impacted [] my son just got married, so I don't want to be a burden to him' (NSK).

There was a sense of self-sacrifice for the common good of the family, 'So I told myself that I did not want it' (GSK); 'I am old, I do not need to be spending so much of my family's money' (HBL).

Concerns were also raised for the emotional stress for their significant others and the disruptiveness of accommodating dialysis into family routine. 'everyone is working and it is too troublesome for them to bring me to dialysis' (HBL); 'Money is a small issue, because there are financial aids, the main problem is burden on family...I thought that my wife would have a hard time and a lot of stress, she needs to take care of the whole family...' (WCY).

The stories of suffering and burden inflicted by dialysis

Participants recounted stories, which contributed to their decision to decline dialysis: 'I

have heard of others going through dialysis for a while, but they give up on it too. They stopped their dialysis treatment [] they gave up because they couldn't tolerate the pain. It was too painful [] it's a very painful process and it makes me scared after listening to it' (NSK); 'people tell me it's a painful and physically draining process' (HBL). One patient shared that she learned of the dialysis process through television shows: '... and the shows on television... the people on dialysis look so weak and helpless' (THE).

Several patients witnessed others going through personally: 'This is because I have seen others on dialysis, and it looks like they are suffering' (GSK); 'I've seen friends around the neighborhood who went for dialysis, they were rather active prior to dialysis... but after going through dialysis, they become yellow... they didn't go out and move as much. I don't want that to happen to me [] I also have this relative who was in her forties, she was diagnosed with kidney failure and she bought the machine to have dialysis done at home. There was nothing wrong with her prior to starting dialysis. After she started, she began to bloat and after some time... she passed away in the hospital. That's why I knew even before the diagnosis of kidney failure if a day will come that I need dialysis, I will reject it' (THE).

'...I visited my friend, who's a kidney patient, after the dialysis... water dialysis, they put the tube in and take out, then she's got diabetes blister, she suffered a lot. Whole life. No changing. Nothing. I said I'd better die, whole life no cure, no nothing, no point, I say...' (AV).

Many had the fixed belief that dialysis is a painful process: 'They get poked and prodded all over their arm till there is nowhere left to poke' (NSK); 'They use instruments and keep poking you and poking you with needles. It's scary just looking at it [] scared of the pain' (LHL).

Inevitability of death

Participants expressed pragmatism in that the amount of trouble they have to experience will

not lead to a prolonged lifespan or prevent death, which is inevitable: ‘... dialysis won’t cure you [] it still doesn’t change anything [] you will have to go through dialysis until the day you die’ (NSK); ‘even if I go on dialysis it will not prolong my life for many years’ (LAS); ‘if I’m meant to die, why should we waste the time and money?’ (THE); ‘they have been on dialysis for more than 10 years, they are still receiving dialysis up till today and at the end, they still have to die’ (GSK).

Feelings towards palliative management

During the interview, participants also spoke about their feelings towards their treatment decision, as well as the health care services they have been receiving. Participants reported satisfaction with regard to their decision and much appreciation for the services they have received thus far from the hospital and home hospice teams.

Satisfaction with decision

Participants expressed satisfaction with their decision to pursue conservative management: ‘I thought that it was a good decision, I am happy with it’ (HBL); ‘I’m very happy! Going on dialysis is like staying in prison’ (THE).

Participants were aware that their life was precarious and uncertain; yet there was no outward verbal or non-verbal expression of distress, worry or dread of their present condition and/or the prospect of deteriorating.

‘I have accepted my condition and I’m not insistent on anything anymore’ (THE). I am living happily now. If you live...you live, if you die...you die’ (WCY).

Although no regret was voiced, there was also a sense of resignation and a reluctance to dwell on the topic: ‘I am satisfied, what can I do if I’m not satisfied?’ (LHL); ‘There is nothing I can do about it. I do not regret because this is my life’ (NSK).

Participants’ reasons for their satisfaction with conservative management include the flexibility it gives them, lesser intrusion to their daily life and less pain, while giving them the

opportunity to have greater control over their lives and continue to build relationships. This allowed them to maintain some normality in a life-changing situation in terms of social interactions and engaging in daily family life. ‘I’m at home, I can spend time with my children and grandchildren [] this is the kind of life I want to live, rather than to be stuck in a dialysis centre’ (THE); ‘Freedom’ (LHL); their medical management/regime is perceived as effective yet non-intrusive which reinforced their decision and allows them to feel ‘normal’ and essentially not sick. ‘I like that my body feels a lot healthier after my injections. Even with my kidney problems, I can’t really feel that there is something wrong with me’ (LAS); ‘I feel like a normal person. The only difference is that I take medicine in the morning and evening’ (AAG).

They were able to rationalize and explain their decision showing awareness of basic dialysis procedures. ‘I prefer conservative management. With dialysis, each treatment session takes approximately 4 h to complete and you need to attend dialysis session 2 to 3 times a week. It’s too burdensome. And you don’t stop at dialysis treatment, you will still need to have injections and accumulating costs are just too high []’ (LAS).

Appreciation for medical teams

Their satisfaction with their decision is inextricably linked with the positive experiences of the programme and meaningful relationships with palliative care personnel. Participants shared their appreciation for the team of doctors, nurses and counsellors who were responsible for their care, emphasizing their commitment to support the patient at a humanistic level in addition to provision of core clinical care. Patients valued the support from professionals who were seen caring, positive and sensitive to the individual. ‘Everyone has been so helpful and they have been great to me. The doctors and counsellors come frequently and explain things to me as well’ (NSK); ‘The nurses have been so kind and good to me [] they answered any questions I

had and would help me whenever I needed help' (HBL).

Discussion

This qualitative study gained an in depth insight into the experience and decision-making process of ESRD patients managed without dialysis. The findings revealed the complex interplay of personal values (life appreciation; sense of completion; concern for family well-being), social influences (lay perceptions) and contextual/organizational factors (health care policies) underlying patients' choice and experience with declining dialysis.

Life with ESRD entails the reconciliation of physical suffering with coping strategies to promote acceptance of a new life and a changing state of health. As disease progresses, patients experience more symptoms due to uraemia and fluid retention yet manage to tailor life around them and continue valued daily activities. Focus is shifted away from physical domains to non-physical aspects of life such as spending time with family, contentment with fulfilment of basic needs and enjoyment of relationships. As all these patients are under the care of palliative teams, it is uncertain whether medical care ameliorated their symptoms or their disease has not caused any symptoms as yet and whether palliative counselling played a part in the shift of focus away from physical symptoms targeting the growth of non-physical domains to improve global quality of life. Previous studies in other patient populations have similarly shown that the process of accommodating to illness often involves recalibration of internal standards and/or reprioritization of life domains.^{10,11} These shifts reflect a beneficial process for patients as a mark of positive adaptation and acceptance of changing health.

Participants were aware of their diagnosis and demonstrated not only an ability to accept the reality of facing their end-of-life, but also held the responsibility for decision to reject dialysis themselves.¹² Similar to a review of the Hong Kong Registry¹³ where it was found that patients who withhold dialysis are far more

common than those who discontinue, this population in Singapore rejected dialysis straight away when the topic was broached. While holding personal responsibility may reflect the ethos and culture of the group surveyed, prevalent local values of frugality and pragmatism may underscore the decision of these participants in putting family and society before self and protecting their families and medical teams from the consequences of their failing health by taking sole responsibility for the decisions. This may be similar to findings from an Australian study¹⁴ which showed that patients tend to 'protect others' during the contemplation phase until their decision was fully made.

Even though patients immediately rejected dialysis without any deliberation, it is still important to recognize that the deliberation process may have started well before the need for dialysis was formally brought up in medical consultations. Lay stories and mass media give rise to preconceived ideas before communication with the medical team. Although patients did not have any first-hand experience with dialysis, they discussed vividly the trauma and futility of dialysis. Lay perceptions and hearsay constituted living proof that dialysis is painful, unsafe and cannot extend life. This form of communication was more influential than information provided in the context of medical consultations. Carefully planned and timed education is therefore critical in clarifying misperceptions and preparing patients to make well-informed decisions. To this end, peer supporters, as yet underutilized source of information within medical settings, may be a useful addition to existing programmes. Moreover, the content of such programmes needs to be carefully structured so as to cover both procedural information as well as information about the subjective experience of life on dialysis as the latter is highly valued by patients.

It is also important to recognize that despite the lack of decisional conflict and reports of satisfaction with the decision, the process of arriving at a decision may be difficult journey, more so when protecting their families and perhaps even protecting the medical team who

have rapport with them and may have certain expectations of them. With these issues in mind, it is important that patients are supported by non-judgmental counselling and that consideration of all the relevant facts is presented in an unbiased and acceptable manner. Patients seem to fear that doctors would strongly recommend dialysis and pressure them into accepting, resulting in a reluctance to discuss their decisions and the consequences. Further communication barriers may stem from a need to avoid conflict as they feel they may be going against the doctor's recommendations, compounded by a general reticence perhaps due to culture. Health care professionals could work towards projecting a more neutral standpoint by being more open to understand the patient's perspective in declining dialysis and improving communication skills to avoid one-sided flow of information from health care professionals. This will create an avenue for patients to continue to receive support and discuss options with their doctors, facilitating their ability to overcome any barriers associated with dialysis or palliative management. Improved communication may also serve to identify and address inaccuracies and misunderstandings about dialysis fuelled by biased information through hearsay and lay stories.

Personal and cultural values were the main drivers for patients' decision to reject dialysis. The exigencies of dialysis were evaluated not solely against gains/burden to the individual but most importantly after consideration of family well-being.^{12,15,16} Previous work has highlighted the importance of beliefs about dialysis burden and costs⁸; yet what is unique in this study is that the notion of burden in patients from Asian background is more embedded into the context of family in line with the values of interdependence and collectivism, which emphasize family well-being over that of the individual. Decisions are taken by the individual but are driven by a strong sense of being beholden to family. Health care policies in our local context may serve to reinforce the sense of obligation as dialysis costs are borne by the immediate family. Medical

subsidy is determined not solely on individual means but also on immediate family income. The increased emphasis on family well-being highlights the need to more carefully align educational sessions to these cultural values and to tailor decisional support on treatment options with reference to both individual and their family. Connecting to this, early input and direct engagement of family may be a valuable addition to existing pre-dialysis education programmes.

When with advanced age obligations towards family have largely been met,^{5,17} patients express a sense of life completion and contentment that comes with achievement of goals that explain the lack of motivation to prolong life and a preference to maintain status quo.¹⁸ Interestingly, these patients demonstrated a sense of resignation or acceptance of the transience of life and showed an unwillingness to prolong life at any cost. They did not demonstrate anger against the medical profession but instead showed appreciation towards both the palliative and renal teams despite the medical teams not fulfilling the traditional roles of saving lives. When queried about their feelings towards their choice of treatment, the participants disclosed satisfaction and very little regret. They accepted the shortening of longevity as a trade-off for greater freedom and less burden of medical care, less perceived pain and suffering and being less of a burden to family and society.

Despite the above findings, which support the idea that elderly patients prefer conservative management as more in line with personal goals and values, medical professionals, however, need to exercise caution to avoid over-generalizing that elderly patients are not interested in dialysis. Concerns about the financial and overall burden to family weigh heavily on patients' decisions. Assessment processes should therefore be robust enough to find out the needs and preferences of the patients and to communicate financial resources available in supporting them especially in settings where dialysis cost is borne largely by the individual.

Limitations

There were recruitment difficulties. A considerable number of patients were deemed not eligible due to dementia. This is common in cases of dialysis abatement.^{19,20} Although challenging, future research should explore decision-making process for this non-cognitively intact segment of population not represented in our sample as this may be driven by different factors and/or agendas. Related to this, although we invited all eligible patients irrespective of ethnicity, our respondents were all Chinese. Greater effort is needed to reach out to the other major ethnic groups (Malay, Indians and Eurasians) of the local community. Culturally and linguistically competent researchers and health care providers may be at better position to elicit participation and most importantly facilitate education and decision support programmes. Finally, this is a single point cross-sectional study. Given that the decision-making process around dialysis in ESRD patients is known to be fraught with ambivalence and that decisions may change, longitudinal studies are warranted to explore how patients' decisions and experience with palliative management may change throughout their disease trajectory, although these participants have not changed their decisions to date.

Conclusion

In this group of ESRD patients declining dialysis and progressing towards end-of-life, their decision-making process shows a logical and consistent flow based on their understanding of disease and the effects of dialysis, guided by values of the importance of family, the sense of life completion and the transience of life. As health deteriorates, they are better able to accept a different definition of health focusing contentment on basic physical fulfilments in relevant life domains.

Understanding these issues that patients face will allow medical professionals to offer appropriate support to patients through their decision-making process and in caring them for the

rest of their lives. Physicians are often focused on the curative paradigm and find that their guidance is not needed if the end point is death; however, the end-of-life is often where medical support and guidance is most indispensable.

Acknowledgements

This work was supported by an educational grant (Consultancy Levy Fund) from National University of Singapore to FT and the NUS Academic Research Fund (start up) [FY2007-FRC5-006] to KG, both of which are gratefully acknowledged. The authors also thank Dr Tonia Griva, Roland Chong, the health care professionals and the participants for their support in this study.

Conflict of interest

The Authors declare that there is no conflict of interest.

References

- 1 Grassmann A, Gioberge S, Moeller S, Brown G. ESRD patients in 2004: global overview of patient numbers, treatment modalities and associated trends. *Nephrology, Dialysis, Transplantation*, 2005; **20**: 2587–2593.
- 2 National Kidney Foundation Singapore. Understanding End Stage Renal Disease [Internet]. 2009 [cited 2012 Mar 27]. Available from: http://www.nkfs.org/index.php?option=com_content&task=view&id=72&Itemid=101.
- 3 Murtagh FEM, Addington-Hall JM, Edmonds PM *et al.* Symptoms in advanced renal disease: a cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. *J Palliat Med*, 2007; **10**: 1266–1276.
- 4 Munshi SK, Vijayakumar N, Taub NA, Bhullar H, Lo TCN, Warwick G. Outcome of renal replacement therapy in the very elderly. *Nephrology, Dialysis, Transplantation*, 2001; **16**: 128–133.
- 5 Murtagh FEM, Cohen LM, Germain MJ. The “No Dialysis” Option. *Adv Chronic Kidney Dis*, 2011; **18**: 443–449.
- 6 Leggat JE Jr, Bloembergen WE, Levine G, Hulbert-Shearon TE, Port FK. An analysis of risk factors for withdrawal from dialysis before death. *Journal*

- of the American Society of Nephrology, 1997; **8**: 1755–1763.
- 7 Fujimaki H, Kasuya Y, Kawaguchi S *et al.* Refusal of initiation of dialysis by elderly patients with chronic renal failure. *Jpn J Geriatr*, 2005; **42**: 417–422.
 - 8 Visser A, Dijkstra GJ, Kuiper D *et al.* Accepting or declining dialysis: considerations taken into account by elderly patients with end-stage renal disease. *J Nephrol*, 2009; **22**: 794–799.
 - 9 Lyons E, Coyle A. Analysing qualitative data in psychology [Internet]. Sage Publications Ltd; 2007 [cited 2012 Sep 8]. Available from: http://books.google.com.sg/books?hl=en&lr=&id=ImxS-Qu_VkC&oi=fnd&pg=PR5&dq=Analysing+Qualitative+Data+in+Psychology&ots=nqsnQ69DuP&sig=1Q9TKqGBjgNTmSc418OT-iCk2WY
 - 10 Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Social Science and Medicine*, 1999; **48**: 1507–1515.
 - 11 Schwartz C, Bode R, Repucci N, Becker J, Sprangers M, Fayers P. The clinical significance of adaptation to changing health: a meta-analysis of response shift. *Quality of Life Research*, 2006; **15**: 1533–1550.
 - 12 Noble H, Meyer J, Bridges J, Kelly D, Johnson B. Patient experience of dialysis refusal or withdrawal – A review of the literature. *J Ren Care*, 2008; **34**: 94–100.
 - 13 Neely KJ, Roxel DM. Palliative care/hospice and the withdrawal of dialysis. *J Palliat Med*, 2000; **3**: 57–67.
 - 14 Ashby M, op't Hoog C, Kellehear A *et al.* Renal dialysis abatement: lessons from a social study. *Palliative Medicine*, 2005; **19**: 389–396.
 - 15 Johnston S, Noble H. Factors influencing patients with stage 5 chronic kidney disease to opt for conservative management: a practitioner research study. *Journal of Clinical Nursing*, 2012; **21**: 1215–1222.
 - 16 Noble H, Meyer J, Bridges J, Kelly D, Johnson B. Reasons renal patients give for deciding not to dialyze: a prospective qualitative interview study. *Dial Transplant*, 2009; **38**: 82–89.
 - 17 Chan CH, Noble H, Lo SH, Kwan TH, Lee Slan, Sze WK. Palliative care for patients with end-stage renal disease: experiences from Hong Kong. *Int J Palliat Nurs*, 2007; **13**: 310–314.
 - 18 Maslow AH. A theory of human motivation. *Psychological Review*, 1943; **50**: 370–396.
 - 19 Kurella M, Mapes DL, Port FK, Chertow GM. Correlates and outcomes of dementia among dialysis patients: the dialysis outcomes and practice patterns study. *Nephrology, Dialysis, Transplantation*, 2006; **21**: 2543–2548.
 - 20 Murray AM. Cognitive impairment in the aging dialysis and chronic kidney disease populations: an occult burden. *Adv Chronic Kidney Dis*, 2008; **15**: 123–132.