

Renal dialysis abatement: lessons from a social study

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Aim: This study aimed to examine the reasons why some people chose to abate (i.e., stop or not start) renal dialysis, together with the personal and social impact of this decision on the person concerned, and/or their families. **Method:** A qualitative design based on the principles of Grounded Theory was employed. Semi-structured interviews were conducted with sixteen patients and/or carers (depending on whether the patient was able to be interviewed) where the issue of dialysis abatement was being considered, or had recently been decided. **Results:** Of 52 participants considered for entry into the study 41 were ineligible, with impaired cognition, rapid medical deterioration, and inability to speak sufficient English being the main reasons for exclusion. The desire not to burden others and the personal experience of a deteriorating quality of life were crucial elements in the decision to stop or decline dialysis. The problem of prognostic uncertainty and a sense of abandonment were also prominently expressed. **Conclusions:** From this small Australian sample, it appears that there would be considerable potential benefit from a more proactive and open approach to end-of-life issues, with incorporation of the clinical and health promoting principles of palliative care into renal dialysis practice. The high number of exclusions shows how sick and unstable this population of patients is, but the issue of data gathering from people whose main language is not English requires attention. *Palliative Medicine* 2005; **19**: 389–396

Key words: palliative care; patient attitudes; qualitative research; renal dialysis; treatment withdrawal

Introduction

Uremia is a fatal illness, for which hemodialysis with the artificial kidney is a palliative.¹

While Norton's early definition of renal dialysis as a form of palliation is literally correct, technical advances, greater access and community expectation have made dialysis almost routine life-sustaining treatment for end-stage renal failure. Consequently, the notion of it as death-delaying therapy has become obscured, and it has been suggested that dialysis programs tend to shy away from death and dying issues.^{2,3} It is therefore not surprising that there have been relatively few publications actually addressing death and dying in this context.⁴

Largely as a result of the aging population, sicker patients, often with multiple comorbidities (most notably

diabetes), are being considered for dialysis. This trend also means that the issue of dialysis abatement becomes more prominent, with a consequent need for a more proactive consideration of end-of-life care and decision-making. There is evidence of rising involvement of palliative care teams with end-stage renal failure patients.^{5,6}

The term 'abatement', adopted by Weir,⁷ which will be used throughout this paper, encompasses both non-initiation and cessation of medical treatment. This appears to be an important distinction in clinical decision-making behaviour,⁸ but not in terms of outcome, where death can clearly result from both non-initiation and cessation of medical treatment.

It appears that nephrology programs are now increasingly having to face what they have primarily set out to avert: the death of their patients.⁹ Research on dialysis abatement is relatively limited and has so far mainly come from North America, with some contribution from the UK,¹⁰ and two Australian case studies.^{11,12}

It is clearly important that there is access to palliative care for those who find that dialysis is an unacceptable burden, particularly when their general

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medical condition is deteriorating. At present the pathways to palliative and terminal care may be unclear in renal programs. As the decision to abate dialysis will usually lead inevitably to the death of the patient, this is a momentous decision, and almost nothing is known about this experience from the patient and family's perspective. We therefore set out to explore the reasons people offered to explain their decision to abate dialysis, together with the personal and social impact of the process of dialysis abatement.

Method

This was an exploratory, referral-based study, using a qualitative methodology. It consisted of semi-structured interviews with patients and/or relatives, where renal dialysis abatement was being considered, or had just taken place. The aim of this study was to understand, from the patients' perspective, the reasons for, and, issues surrounding their decision to either stop or not start dialysis. This understanding required an approach free from any preconceived assumptions that health professionals might hold surrounding this issue of treatment withdrawal/refusal. Grounded Theory as a qualitative research method provides an alternative way of understanding participants' beliefs and actions from those offered in the clinical setting.¹³ Grounded Theory enabled us to explore phenomena as they occurred naturally in the participants' everyday life situations. 'Theoretical sampling' was not employed in this study. The luxury of sampling choices according to emerging themes or theories along the way was simply not possible due to the nature and difficulties encountered in recruiting participants for this study. All referrals made were potential candidates regardless of the accumulated data collection. The omission of theoretical sampling emphasises the phenomenological aspects in the methodologies of Grounded Theory. Although we make no claim to generalize from these findings the resulting analysis has produced a fertile mixture of valuable and revealing emotional and social reasons and responses to dialysis abatement as well as the identification of important barriers and challenges to further social research in this area.

Patients were recruited from the renal units of two large Australian tertiary hospitals in Melbourne (Monash Medical Centre-Southern Health, and Royal Melbourne Hospital-Melbourne Health) over an 18-month period between February 2003 and August 2004. Ethics approval was obtained from both hospitals' Human Research and Ethics Committees. The Research Officer attended rounds and meetings with the two units, and was notified of potential participants by the renal unit staff. This was therefore a referral-based study. Patients and family members were informed about the study, and

were either introduced to the Research Officer in the hospital setting or agreed to her making a home visit at a mutually convenient time. Family interviews were conducted separately from the patient to gain a further indication of the context of patient decision-making. Although such perspectives do not always accurately reflect the patient's experience, they can serve our understanding by providing greater detail of the social or emotional tensions and nuances that might influence the patient's experience.

Semi-structured interviews were therefore conducted in participants' homes (except for one patient, who only agreed to be interviewed whilst waiting for consultation in the outpatient renal clinic). This helped to overcome transport difficulties and eliminate associations with hospitals that might have prevented participants from speaking freely in the hospital setting. Interviews took as long as participants required. Most were between one to one and half-hours. After a clear setting out of the purpose of the interview, participants were free to nominate issues. Then open-ended questions were introduced in a manner suited to the particular interview. The research yielded a large amount of data, which was transcribed, coded and analysed. From the first interview, data was collected, coded, categorized, compared and analysed until theoretical explanations of the participants' experience was developed.

Recruitment was a significant challenge, of the 52 patients identified during the study period as being potentially eligible for inclusion, 41 did not participate, hence, only 11 patients were actually interviewed. The reasons for non-participation fall into three broad categories: communication difficulties, poor and deteriorating medical condition, and staff or patient reluctance, as set out below.

Communication difficulties

- Insufficient command of English (10 patients).
- Dementia, intellectual impairment or other organic brain syndrome (9 patients).

Poor medical condition

- Rapid medical deterioration (9 patients).
- Unwell at scheduled interview times (3 patients).

Staff or patient reluctance

- Denial of kidney problem and ambivalence about their decision (4 patients).
- Concerns by renal unit staff about appropriateness of prospective patient participation (4 patients).
- Depression and overwhelming feelings of anger (2 patients).

Family and/or carer participant exclusions were due to:

- Children with familial disease and feeling uneasy about participation (1 family).
- Patient interviewed preferred children not to be contacted (3 patients).
- Patient interviewed did not have family or carer to be interviewed (1 patient).

Results

The final number of participants was 16. Multiple interviews per participant resulted in 34 interviews being conducted. The interviewees consisted of nine females and seven males. The patients' ages ranged from 57–89 years, the median age was 77 years. Three patients were from non-English speaking backgrounds, and two of these were women.

The participants were divided into three groups: 1) patients who had discontinued renal dialysis therapy ($n=4$), 2) patients who decided to abate dialysis ($n=7$) and 3) the spouses of these patients ($n=5$). The first group was drawn from the nephrology units at two tertiary hospitals where the research officer approached the patients directly to seek their participation. Interviews were conducted with four patients in this group. The second group consisted of seven patients with progressive chronic renal failure who had not yet commenced dialysis, but had expressed a strong desire to not commence dialysis when the need arose. For this group, the research officer obtained contact details from the renal team following careful consultation regarding the appropriateness of each patient's involvement. For five patients who were not hospital inpatients, telephone calls were made to ascertain willingness to participate. Two patients were approached at the renal outpatient clinic. The third group consisted of five participant spouses. One woman whose husband had suffered from dementia, and could not himself be interviewed, agreed to an interview two months following the death of her husband. Agreement to all spousal participation was obtained at the first interview with the patient.

For all of the three groups, interview times were arranged and information and informed consent forms were given to participants and completed prior to the interviews taking place. Participants retained a copy of each. With permission from each participant, all interviews were audiotaped and later fully transcribed. To ensure patient confidentiality, pseudonyms were used for each interview. Other identifying characteristics such as participants' language spoken, names of their spouses, friends, homes or workplace institutions were also changed.

The main themes identified are set out below.

Poor quality of life, pain and suffering

For those patients withdrawing from dialysis, there was an overwhelming sense of profound suffering associated with the dialysis treatment itself. One participant stated: 'I just want relief from all of this pain and suffering'. While these patients described the technical problems and excruciating pain associated with their dialysis treatment, their decision was made in the context of the personal experience of their declining health. The decision to discontinue dialysis was not made suddenly. Each patient described the years or months of building up to their decision. They also described themselves as 'protecting others' from such contemplations. Their contemplations were never discussed with family or health professionals until their decision to withdraw dialysis was fully made.

These patients faced difficulties in discussing their concerns to discontinue dialysis with either their families or health professionals. One woman attributed her difficulty in discussing this with her daughter as being due to their families' religious beliefs. Another woman was uncomfortable discussing the futility of her dialysis treatment with her children because they were also suffering from her familial renal disease and two of them were also facing the prospect of dialysis therapy themselves. The families' discomfort with discussing dialysis abatement was a reason to not participate in the study itself. Another patient felt a sense of loyalty to the health professionals for all they had done for him. He equated his giving up of the treatment as akin to suicide. In the end it was his failing health that made him make the decision, he stated:

I knew what the procedure was before I started. I had been told that if at any time I wanted to give up, well, I could give up. But I didn't want to because to me it was akin to taking my own life, which I didn't want to do. But anyway things caught up to me. I got so sick; I couldn't eat or drink. I was going down hill, so I said to the boss [a peritoneal dialysis nurse] I said, I'm sorry [PD nurse] I said but I think I have reached the end of the tether. I just couldn't cope any longer. I made the decision (male, 81 years old).

The decision, then, to withdraw dialysis was often made alone. It appears that it was far more difficult for the patients to discuss their decision to withdraw dialysis with others than it was for those withholding from dialysis. Even though their nephrologists reassured patients that they had the option to discontinue treatment at any time, the decision to 'give up' treatment appeared to carry heavier moral and ethical burdens for the patient. Their sense of loyalty to health professionals and their families appeared to make the decision more

difficult than it did for those who had never commenced dialysis treatment.

Desire not to be a burden

One overlapping theme across those withdrawing and withholding dialysis, was the overwhelming sense of not wishing to be a burden to their family. Patients described how busy their children and grandchildren were. Three out of the four patients withdrawing from treatment lived alone and relied on their children for help with their home duties, daily living needs and dialysis therapy. All three of these patients had felt that they had been such a burden to their children and subsequently also requested that the researcher not approach their children to participate in the study as this would 'tip them over the edge'.

The desire not to be a burden was a prominent contributory reason for patients choosing not to commence dialysis in the first place. They expressed concern about the disruption that dialysis would cause to their family life.

Well I couldn't see that it was really going to achieve anything apart from disrupting everybody's life. And I didn't even care about living longer I just wanted every thing to go along without any hassles. I wouldn't consider it under any circumstances (female, 82 years old).

No like I said when we came home we sat down and had a talk, just Alice and meself there and we thought about it, I thought about it and ah, I didn't want to go on that dialysis to be a burden to Alice. You know three days a week and five hours or whatever. And I say I didn't want to put that on her because she had enough putting up with me as it was (male, 77 years old).

This group of patients were all over 77 years of age, and tended to see dying as a natural course that they would prefer to take, rather than to burden their children with issues relating to dialysis therapy. These patients were also not prepared to make the necessary lifestyle changes.

I see it as a natural course. You see, I have no loyalty. I mean my children are grown up now and they have got their husbands and their children. And there is nothing to make me think oh I had better stay around. I have been able to help with the girls when they have had their babies and looking after them and so on, with no effort. And that's in the background now (female, 85 years old).

I made my decision because I couldn't see myself sitting over there for five hours every day for three days. There is nothing worse. So I said no. I just

couldn't bear going on it for three days a week and I couldn't see meself going back and forth three times a week, waiting for a taxi to get home and there and waiting for a taxi to get back. No it's not for me (male, 78 years old).

And another thing is that you need someone to take you there and bring you back. And you have one day on and one day off. You know you have the dialysis one day and then you are practically dead the next. Dialysis the next and dead the next and dialysis the next day. And it is no life really, I mean I'd rather be dead (female, 85 years old).

One's age was a significant factor that could impact on their decision. Those over 75 years of age felt that undergoing dialysis would not only be a waste of resources to the community but also felt that it would adversely affect their quality of life. They considered that they would not cope well on dialysis because of their age and their limited physical capacity.

We are living longer and we are becoming quite a problem. In general we older people are presenting quite a problem. And it is a bit of a problem for us to know what to do (female, 85 years old).

The idea of it that eventually it's going to kill me it never phased me at all because I am at the down hill side of my life anyhow, I have a good life. When my time comes I'll just choof off and that's it. I'm 83 this year. I have always been pretty fit. Lots of walking and gardening. We have been very lucky (female, 82 years old).

If I was 60 years old I'd say yes I would have probably taken it but not at 75. Anyway I might last another five years. I'd like to know what the real symptoms are before you suffered a near [pause], nobody will tell me the real symptoms (male, 78 years old).

If I was much younger I would consider it, but not when you get to this age and not when you can't get around or anything and that (female, 89 years old).

Doctor–patient issues: prognostic uncertainty and a sense of abandonment

Two aspects of the doctor–patient interaction were prominently expressed by patients: prognostic uncertainty, and a sense of abandonment if dialysis was not considered.

They can't tell you, you know, how long you have to go. You see this is quite true, they don't know. With all the modern stuff and all that, they still don't know (male, 78 years old).

For 55% of the sample, the patient's actual survival was considerably longer than the medical prognosis given. One patient, who ceased haemodialysis after 13 months, was given a prognosis of two to three weeks, but is still alive over 18 months later. This patient felt that the medical staff had abandoned her. She stated:

I don't know. That's really the funny thing when I say I want to go home, they say go home, never send a letter that I come see the doctor or anything, that's really ah ha ha ha... Go home and die. Isn't that funny? You see. This where you see the doctor don't care. If they have a little bit consideration they will say, oh ring her up send a letter to come to see how she is going. No, no, no nothing [angry]. Well that's what they say, two, three weeks they give you. [LONG PAUSE] Nothing. That's what happened, once you leave hospital nobody care. But the girls ringing up all the time from dialysis to see how I am going (female, 67 years old).

Even in hospital she felt a sense of abandonment, she couldn't understand why all of her medications had been suspended, she stated:

I said to the nurses; 'where is my medication'. She took the history, everything and scratch, scratch, scratch, scratch. I asked her; 'you can not give me when I'm cold or in pain, I want my medication'. And the doctor come and say, 'why you want your medication, why you want the girls do the blood pressure?' I want to know everything. I said, 'I'm not yet dead' (female, 67 years old).

The impact of these prognostic discrepancies on patients' lives have ranged from sleep disturbances to financial costs, a whimsical distrust of medical science, to outrage and anger at the medical profession.

A couple of times I tell Dr D that was bad guessing, you guessed wrong there. He said that they can't give any guarantees of time and that sort of thing. When he guessed 6–12 months, I thought I have to clean out my wardrobe. And um then I found I wasn't sleeping and then I was ordered sleeping tablets. I use to lay awake so they gave me Serepax and I still take it who cares if I'm an 80-year-old junkie. Once the sleeping tablet kicks in I'm right (female, 82 years old).

There's two things he said, 'you've gotta have dialysis and you could last for a number of years' and I said what if I don't take dialysis. He said, 'you've got three weeks to live'. He cost me money too, Dr C because I gave me car away. I sold up all me shares because my shares had gone up and I thought to meself I'll sell the lot. I thought to meself, if I go then Agnes will have to pay all the taxation. Well, we might as well share the

tax and I sold the bloody things and they are up now double the price now [laughing]. Doubled the price about two months ago (male, 78 years old).

Because he say to me a long time back in 1996, ah, he say, I have two months to live because kidney don't work. And then after he say, 'see V, I was wrong. You are still here'. He say, 'I made a big mistake' and this and that. I was meant to say, 'are you a doctor or a butcher?' [Laughing]. They were wrong. I just kept going (male, 69 years old).

Well apparently like the doctor like told me like he says, that was about six or eight months ago he said, the way your kidneys are facing he said you'd have about two months to live. Then I smartly turned around and said to him well I'll die when I'm ready not when you tell me (male, 77 years old).

Two men even decided not to start dialysis as they viewed it as harmful; each believing it was responsible for the deaths of their friends. Two men chose not to commence dialysis because their nephrologists could not guarantee that it would actually benefit them because of their other comorbidities.

I've got half a dozen complaints and they said any one of those can kill you before your dialysis will. I said well that's not for me if you can't guarantee going through all of that three hours, like for three days a week for three or five hours. Whatever, if you can't guarantee me that's gonna fix me, I said I'm wasting me time. So I said no. I wouldn't do it, it was a guessing game sort of thing (male, 77 year old).

I have got too many problem and if I have dialysis I last much less (male, 69 years old).

This prognostic unpredictability also affected those who were receiving palliative care at the hospital. Each expressed their desire for their deaths to come quickly and be pain-free after having been told by their nephrologists that their prognosis was so uncertain, and they feared a long slow dying process.

I don't know what happens when you stop dialysis. The doctor said it varies so much. I just want it to happen quickly. I'm just waiting and hoping it'll be quick, that's about it really (female, 63 years old).

The prognostic uncertainty also had an impact on the spouses in this study. The wives described their ongoing difficulties and concerns with regard to preparing the patient's diet and medication regimen. As the patients described themselves as more or less living on borrowed time the wives felt that any changes to the patient's medical condition would be a direct result of their care. As one of them explained, the blood tests will eventually prove what harm has been done, by diet and, or,

medication, the patient has ingested. Their world of cooking, preparing food and the timing of medications was extremely difficult and they often felt that they were not adequately educated or equipped by the hospital to prepare for this very regimented lifestyle. The positive feedback from one spouse about the manner of disclosure is a reminder that what happens in hospital will always be remembered by the family and can have an impact on the grieving process. Once again, however, this study represents a small sample of this renal dialysis abatement population. We do not know the prognostic accuracy of those who were not able to participate in this study. This suggests that future studies of actual and predicted survival rates in this population might have important and fruitful benefits for future communication with these patients and families.

Discussion

This small sample of patients contemplating dialysis abatement indicates that quality of life, and the burden of treatment are decisive factors in their decision to reject dialysis. The recruitment challenges faced in this study also reveal the fragile nature of the patients' medical condition during dialysis abatement. Dementia or other organic brain syndromes and medical deterioration can serve as barriers to effectively communicating with patients during this time, and are clearly common in this patient population.

The difficulties encountered with recruiting patients may also be partly attributed to reticence to refer patients, due to concerns about raising end-of-life issues. It was also significant that some patients refused to participate because of anger towards health professionals. Two patients were openly angry while four others were ambivalent or confused about their relationship with their health care providers. This may highlight tensions within the patient–professional relationship. These tensions may result from the increasing need to discuss death and dying, and barriers to conversations in the patient–professional relationship.¹⁴

Four patients refused to accept that they had kidney problems and this led to family conflict and ambivalence about their decision to not commence dialysis. Two of these patients also had misunderstandings about the study; they were convinced that the aim of the study was simply to coerce them to change their mind and to commence dialysis. On two other occasions, the family had dissuaded the researcher to follow through with interviews as they considered that the patient was too unwell to participate at the scheduled interview time. Other 'gate-keeping' decisions by families concerned the patient's anger towards medical and nursing staff and the patient's ambivalence regarding their decision to with-

hold dialysis. In addition, nine patients were not included in the study due to their dementia and 12 others were missed because of their rapid medical deterioration. The exclusion of these patients supports the dialysis abatement literature that states that family members frequently become the primary decision-makers because many patients lack the capacity to speak for themselves because of dementia, other organic brain syndromes or a generally poor medical state.³

Discontinuation of dialysis is now regarded as a common cause of death. It is claimed that one in four deaths of patients in the USA with end-stage renal disease is preceded by a decision to withdraw dialysis.³ In Canada, dialysis withdrawal is second only to cardiovascular complications among end-stage renal patients as a cause of death, and in the USA it is third, after cardiovascular and infectious deaths.¹⁵ This trend is evident in Australia where dialysis discontinuation is the second most common cause of death for those on dialysis (22%), after cardiac events (44%).¹⁶ Dialysis discontinuation is becoming more common as the dialysis population increases and becomes older with more significant comorbid conditions.¹⁶

The findings of this small sample of patients supports a previous study that has linked dialysis discontinuation to variables such as comorbidities and age at commencement of dialysis.¹⁷ While other studies have linked dialysis discontinuation with socioeconomic status;¹⁸ marital status; renal diagnosis; dissatisfaction with lifestyle; pain and the upcoming need for surgery.^{19,20} Bajwa and associates concede that dialysis discontinuation appears to be more of an existential problem that cannot be described accurately by general risk-factor analysis.²¹ It has become apparent that dialysis discontinuation occurs at varying rates across dialysis programs. The reason for higher rates of dialysis discontinuation in certain dialysis programs is unclear.³

It is only recently that the process of dialysis discontinuation has been recognized as an important component to providing for a 'good' death.²² Cohen cites Weisman²³ and Cassem²⁴ in their definition of a 'good' death, as being one that an individual might choose if there were a choice. Such a death is relatively pain free, brief and purposeful, allowing for resolution and reconciliation. Cohen reminds us that in the past, medicine has been unable to abandon the notion of success as being measured solely in terms of survival times. Achievement of a 'good' death ought to also become another measure of success for medicine.²⁵

It is apparent in this study that many patients experience ambivalence regarding their decision and often their plight is compounded by prognostic uncertainties. Renal unit staff can also take heart from this study, that where appropriate, and with sensitivity, if they take the risk of proactively enquiring about burdens of

treatment, and comorbidities, raising the possibility of dialysis abatement, and are open about end-of-life issues, patients and families will often be relieved.

Glare and Virik²⁶ suggest that earlier involvement of palliative care consultative services, particularly those in acute hospitals, might improve care and decision-making at the end of life. Collaborative management earlier in the illness trajectory can offer support, and gentler transitions to dialysis abatement and terminal care, with appropriate symptom control. Palliative care services can offer a care program that addresses the problem of patients and families feeling abandoned when dialysis therapy is to be discontinued or not initiated. Joint management between palliative care and nephrology also has the potential to promote well-being and chronic pain management for those on dialysis, not only for end-of-life care but also during maintenance dialysis therapy. Patients have described the chronic pain and suffering associated with undergoing renal dialysis therapy that could benefit from symptom control. Imminent death should not be the sole grounds for referral.

There is a relative absence of broadly based community and professional discussion of the relationship between renal failure and death, particularly for very ill patients with multiple comorbidities. Health promoting palliative care approaches involve palliative care and other health providers working with local governments, health care institutions, workplaces, schools, clubs and the media to encourage death and bereavement education.²⁷ This can and should include non-malignant diseases as well as cancer. These findings point to the need to promote policy changes to the renal management of end-of-life care. Techniques of doing this include clinical guidelines, advance directives, advanced care planning, peer mentoring programs, clinical and health promoting palliative care initiatives^{28,27} and bereavement support in order to help patients and families to have a smoother path through the process of dying from dialysis discontinuation or non-initiation, if such decisions are taken.

Acknowledgements

This study was supported by an NHMRC Palliative Care Short Study Grant.

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