Renal Replacement Therapy: Why Patients Say "No"

Dear Editor,

Introduction

Renal replacement therapy is the usual standard of care for patients with end-stage renal failure (ESRF). This treatment, which includes peritoneal and haemodialysis, is the means to prolong life in ESRF patents.

Singer reported that physicians withheld dialysis more than they withdrew it.[1] Yet, research on dialysis abatement has mainly been on the withdrawal of dialysis.[2] In an Australian study by Micheal Ashby,[3] 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.

There is a saying in Singapore "One can die, but cannot fall ill".[4] This saying is often quoted by patients with chronic illnesses who lament on the cost of treatment. While many patients qualify for subsidies after means testing, the financial burden can still be hefty.

The aim of the study is to understand reasons why suitable patients in Singapore decline renal replacement therapy (RRT). Our hypothesis is that most patients decline RRT for financial reasons.

In understanding the reasons why patients decline RRT, we hope to be better able to counsel patients on their treatment options and address their misgivings and concerns. It may also impact the way we shape our future healthcare policies.

Materials and Methods

This is a retrospective cross-sectional study. The study population was taken from the Palliative Care database in an acute hospital in Singapore. The eligible patients had ESRF and declined dialysis between January and December 2011. Patients who were medically deemed unsuitable for dialysis were excluded from the study.

The medical records were reviewed for demographic and medical information. The communication records were examined for reasons stated by patients or their family for declining RRT.

The reasons found are grouped into categories and each patient may have more than one reason cited for refusing dialysis.

Results

The demographic information, medical data and reasons for declining dialysis are showed in Table 1. Most of the patients had a Modified Charlson comorbidity index (CCI) of at least 5. This is expected since most of the patients had ESRF secondary to diabetes (2 points for diabetes with end-organ damage) and majority of these patients would have had diabetes for at least 3 decades after the age of 40 (1 point for every decade of diabetes over the age of 40). Majority of the patients have a modified CCI of less than 8.

The results showed the most common category of reason stated was the lack of family and social support. Examples of reasons stated in this category include having no carer to administer peritoneal dialysis or transport patients for haemodialysis.

Only 4 patients refused dialysis because they did not want to be a burden. The patients who were included in this category said they were "old already" and they do not want to be a burden to their family.

While all the 24 patients were consulted and counselled on the initiation of RRT, 3 of the decisions refusing RRT were made by their family members for the patients. One of the 3 patients had no personal preference to treatment. The remaining 2 patients had indicated preference to initiate on RRT, but had left the decision to their family as they felt that the family would be the one taking on the burden of caring for them should they initiate RRT. All 3 families had declined dialysis for the patients due to the lack of family or social support. The main problem faced by this group of patients was that there was no identified caregiver who could administer peritoneal dialysis or assist in the transportation of the patient to the dialysis centre for regular haemodialysis 3 times a week.

Discussion

We found that the main reason why patients or family decline RRT was the lack of family and social support. This is in contrast to our hypothesis that most patients decline RRT because of financial reasons. This result is also in contrary to the results found in the study by Micheal Ashby (quoted above), which found that the fear of being a burden is a common reason for patients to refuse dialysis.

Table 1. Characteristics, Demographics and Reasons Stated for Refusing Dialysis

Demographics	Data
Gender	
Male	12
Female	12
Age (Years)	
Range	45 – 87
Mean	69
Median	71
Calculated Creatinine Clearance (mLs/min/1.73m^2)	
Range	3.4 – 15
Median	7.7
Modified Charlson Comorbidity Index	
Range	3 – 12
Number of patients score <8	19
Number of patients score >8	5
Race	
Chinese	15
Malay	8
Indian	1
Religion	
Muslim	8
Buddhist	6
Christian	5
Hindu	1
Taoist	3
No Religion	1
Mobility Status	
Independent	14
Walking Stick	4
Wheel Chair	8
Reasons why RRT was not initiated	**Number of times reason was stated**
Lack of Family or social Support	10
Financial Concerns	6
Fear of Pain	5
Fear of being a burden	4
Reasons not known	4

Most of the reasons found in the category of lack of social or family support were logistic in nature. These mostly include the lack of caregivers and the lack of resources for the transportation of patients for haemodialysis. The reason why financial constraints were not the top reason for declining RRT cannot be ascertained. The author postulates that this could be due to increasing aid for dialysis by welfare organisation or it could be due to the fact that the patients selected do not belong to the financially needy group of patients.

This is one of the first quantitative studies to identify reasons why patients refuse RRT in Singapore. However, only descriptive statistics were used in view of the small number of patients in the study. This being a retrospective study, we were unable to ascertain certain characteristics of patients, including the presence of mood disorder that might provide more insight as to why patient refuse dialysis.

Despite the limitations, this simple study shows clearly that the lack of family and social support is the main reason why patients refuse RRT. Future studies may prospectively study both patients who agree and decline RRT and their similarities and differences both socially and medically.

Healthcare professionals who counsel the patients should actively address social and caregiver issues during pre-dialysis counselling. While efforts have been made to reduce the cost of dialysis, more can be done socially to help the support the patients and their family logistically in order to allow more of these patients to have dialysis.

The lack of family and social support, rather than financial issues is the reason why patients decline dialysis. More must be done to improve social structures which help support patients and their families who desire treatment, particularly if it has been shown that it is a means of prolonging life meaningfully at this stage.[5]

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