



Original Article

Experience of a Renal Palliative Care Program in a Hong Kong Center: Characteristics of Patients Who Prefer Palliative Care to Dialysis

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Background: A renal palliative care (RPC) program was developed in a local center as an option for patients with end-stage renal disease (ESRD) who may not benefit from dialysis or who do not prefer dialysis. The model involved collaboration between the palliative care and renal teams, and the RPC program was introduced as an option in the advance care planning (ACP) interview during which treatment benefits, burdens, predicted prognosis and the patient's preferences were discussed. Patients who preferred palliative care to dialysis were recruited into the RPC program. An interdisciplinary team approach was adopted and the Renal Palliative Clinic comprised the core component among the full spectrum of services.

Methods: This was a retrospective study of the characteristics of ESRD patients who were interviewed for ACP between August 2007 and the end of 2008 and who preferred palliative care to dialysis.

Results: A total of 96 ESRD patients were interviewed for ACP during this period, among which 36 patients opted for dialysis while 60 patients chose RPC. In both groups, around 97% of patients were mentally competent and involved in ACP. The patients who chose RPC, as compared with the patients who opted for dialysis, were older (74.1 ± 8.7 years vs. 56.3 ± 10.0 years, $p < 0.001$), included more widowers (40.0% vs. 2.8%, $p < 0.001$), were more financially dependent on their family (65.0% vs. 36.1%, $p < 0.001$), had a higher incidence of diabetes mellitus (73.4% vs. 41.6%, $p = 0.002$), and had a higher modified Charlson Comorbidity Index (9.5 ± 1.9 vs. 6.9 ± 3.1 , $p < 0.001$). More RPC patients relied on assistance to walk and had a constant caregiver at home. The decision for RPC was primarily the patient's in 41.7%, while it was a shared family decision in 56.5%. The reasons given for declining dialysis were perceived undue physical burden in 60.1%, social burden in 53.4%, and psychological burden in 56.8%, while 35.1% of patients cited all of the above reasons for their decision. By the end of 2008, 30 (50.0%) RPC patients had died, after receiving palliative care for a median duration of 132.5 days (range, 3–437 days; interquartile range, 115.0). They all lived with their choice of RPC until death.

Conclusion: The RPC program, introduced as an option in ACP, was appropriate in meeting the preferences and needs of a significant proportion of ESRD patients and their families. [*Hong Kong J Nephrol* 2009;11(2):50–8]

Key words: advance care planning, dialysis, end-stage renal disease, Hong Kong, palliative care

背景：在本地的一所醫療中心內，院方為透析效益有限或不願接受透析的末期腎病 (ESRD) 患者，提供腎病的紓緩治療 (RPC、renal palliative care) 選項。此計劃需要紓緩醫療人員及腎科人員的共同參與，他們會在預立醫療計畫 (ACP、advance care planning) 訪談時，根據病人狀況對 RPC 的適用性進行商討，涉及的考慮因素包括治療效益、負擔、及患者的預後與意願；其後，決定選擇紓緩治療 (而非透析) 的患者會被納入 RPC 計劃中。RPC 計劃採取跨科別的方式實施，相關的各種服務主要由腎病紓緩診所 (Renal Palliative Clinic) 提供。

方法：這是一項回溯性研究，對選擇紓緩治療 (而非透析) 的 ESRD 患者特徵作出歸納，這些病人均曾經在 2007 年 8 月至 2008 年終期間接受 ACP 訪談。



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結果：上述期間共有 96 位 ESRD 患者接受了 ACP 訪談，其中 36 人選擇透析，60 人選擇 RPC。在兩組病人中，均有約 97% 患者的精神狀況容許 ACP 的順利進行。相比於選擇透析的病人，選擇 RPC 者的特徵包括：年齡明顯較高 (74.1 ± 8.7 歲 vs. 56.3 ± 10.0 歲、 $p < 0.001$)；較高的鰥夫比例 (40.0% vs. 2.8%、 $p < 0.001$)；財政須倚賴家庭的比率較高 (65.0% vs. 36.1%、 $p < 0.001$)；糖尿病的比率較高 (73.4% vs. 41.6%、 $p = 0.002$)；及較高的修正版 Charlson 共病指數 (modified Charlson Comorbidity Index) (9.5 ± 1.9 vs. 6.9 ± 3.1 、 $p < 0.001$)。此外，選擇 RPC 者較多需要步行的輔助，且有固定的居家照料者。在選擇 RPC 的病人中，41.7% 是基於病人自己的決定，56.5% 是與家人討論後的結果。病人不選擇透析的原因包括：病人察覺到透析對身體的負擔 (60.1%)、社交負擔 (53.4%)、及心理負擔 (56.8%)；有 35.1% 患者的決定是同時基於上述因素。至 2008 年終，共有 30 (50.0%) 位選擇 RPC 的病人去世，他們在死前均未曾改變選擇 RPC 的決定，且已持續接受紓緩治療達中位數 132.5 天 (範圍 3–437 天；四分位差、115.0)。

結論：作為 ACP 的選項之一，RPC 計劃可望為相當比例的 ESRD 患者及其家屬，提供治療意願與需求的滿足。

INTRODUCTION

How humans have dealt with failing kidneys is a fascinating story. Until only a few decades ago, renal failure was a death sentence. In the 1950s, artificial kidneys were created, including some innovative ones converted from pressure cookers [1]. In the 1960s, costly dialysis treatment was provided by rationalization, explicitly or implicitly [2]. From the 1970s, more equitable access to dialysis was possible with the development of lower cost, high quality dialysis clinics. The contemporary principle of acceptance for dialysis is based on the balance of benefits and burdens of treatment and the best interests of the individual patient.

It was also during the 1970s that the modern palliative care movement began, when the limits of medical technologies and death as a natural process were recognized. Palliative care has evolved in its definition and scope of application to extend beyond the realm of incurable cancer. As defined by the World Health Organization, palliative care provides support to patients and families facing life-limiting illness by integrating the physical, psychosocial and spiritual aspects of care through an interdisciplinary approach. Moreover, palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications [3].

Though dialysis is potentially life-saving and life-prolonging, patients on dialysis can die prematurely. U.S. national data have shown that patients on dialysis lived only 25% as long as age-matched controls. Mortality in the first year of dialysis has emerged as a major concern, with greatest loss at 2–4 months after initiation of dialysis treatment [4].

Despite dialysis, there is progression of underlying diseases, accelerated atherosclerosis, emergence of complications, or progressive decline in functional status or quality of life (QOL). The burden of end-stage renal disease (ESRD) is related to the comorbid conditions, symptom distress, dialysis treatment and the caregiving process. Studies overseas have reported the stress and burden of patients on dialysis and their impaired QOL [5,6]. In the NECOSAD (The Netherlands Cooperative Study on Adequacy of Dialysis) study of 226 dialysis patients, the symptom burden as reported by patients, when added to other variables, accounted for one third of perceived QOL [6]. Psychiatric morbidity of anxiety and depression are also common in the dialysis population [7].

In the U.S., 25% of all ESRD deaths resulted from withdrawal or discontinuation of dialysis [8]. Patients who died from discontinuation of dialysis were reported to suffer from symptoms of pain, confusion, dyspnea, nausea, twitching and diarrhea in the last week of life [9]. Factors related to discontinuation of dialysis include: (1) patient factors such as declining physical functioning, unrelieved symptom burden, deteriorating QOL; (2) socioeconomic factors such as decrease in social support, death of spouse or caregiver, and change in employment status; (3) disease or treatment factors such as comorbidities, complications and their chronicity; and (4) institutional factors such as culture of the dialysis center [10].

In Hong Kong, peritoneal dialysis (PD) is the mainstay of dialysis treatment, constituting 50% of all renal replacement therapy. Withholding dialysis is more common than withdrawal of dialysis. The incidence of diabetes mellitus was 44% in patients newly commenced on renal replacement therapy in 2008. Both the mean and median age of new dialysis patients have increased

from around 48 years to 56 years over the last decade. Age-stratified survival data show that older PD patients perform worse; for those >75 years old, half had died before the end of the third year of dialysis [11].

Limited local data concur with some overseas studies that the disease burden of ESRD is considerable [12–15]. Local dialysis patients were found to be distressed by emotions such as guilt and helplessness, role reversal, financial constraints, changes in body image and the burden of performing PD [12]. In a recent local study of 179 ESRD patients [13], it was found that patients on long-term dialysis and those on palliative care shared similar symptom profiles and distress. The QOL as measured by the *Medical Outcomes Study 36-item Short Form Health Survey* was also significantly impaired in both groups as compared with the Hong Kong population and correlated negatively with the number of symptoms.

Although the palliative care needs of ESRD patients have been increasingly recognized [16], their access to palliative care remains limited and varies from area to area. In Hong Kong public hospitals, the palliative care service is offered mainly to advanced cancer patients. Aging of the population and increasing prevalence of multiple chronic diseases are global challenges in health care and no less challenging in Hong Kong. It is projected that, by 2033, 26.8% of the Hong Kong population will be above the age of 65 [17]. The prevalence of chronic illnesses increases with age, and by the age of 65, this is almost 60% [17]. As technology can only do so much, it is imperative that action is taken now to formulate a model of renal palliative care (RPC) that is appropriate for patients' needs.

A MODEL OF RPC RELEVANT TO HONG KONG

In the Caritas Medical Centre, a regional hospital in Hong Kong with more than 1,000 beds, a RPC program was piloted with the collaboration of palliative medicine specialists and nephrologists. In local practice, ESRD patients are referred to nephrologists for discussion of dialysis treatment if their serum creatinine is >350 µmol/L in diabetics and >400 µmol/L in non-diabetics. Our designated medical social worker would join the nephrologist in the advance care planning (ACP) interview. The ACP process requires the participation of patient and family members, and involves lucid communication of facts and information, paying heed to their values and preferences, and finally formulating a care plan with defined treatment goals (Figure 1). A prudent decision to initiate or withhold dialysis hinges on individualized consideration of the treatment benefits, burdens, predicted prognosis and personal preferences of the patient. In light of the life-saving nature of dialysis, clear communication of the facts and information with regard to burdens and prognosis are important in shaping realistic expectations from dialysis treatment, which is, at its least, a panacea for ESRD. We introduced our RPC program with defined objectives as an option to replace passive withholding of dialysis. The medical social worker serves to offer onsite emotional support, facilitate family discussion, provide timely information on social resources, and acts as the link between patient and family members and the health care team in subsequent care. Information pamphlets are given to patients and family members as supplementary material. The

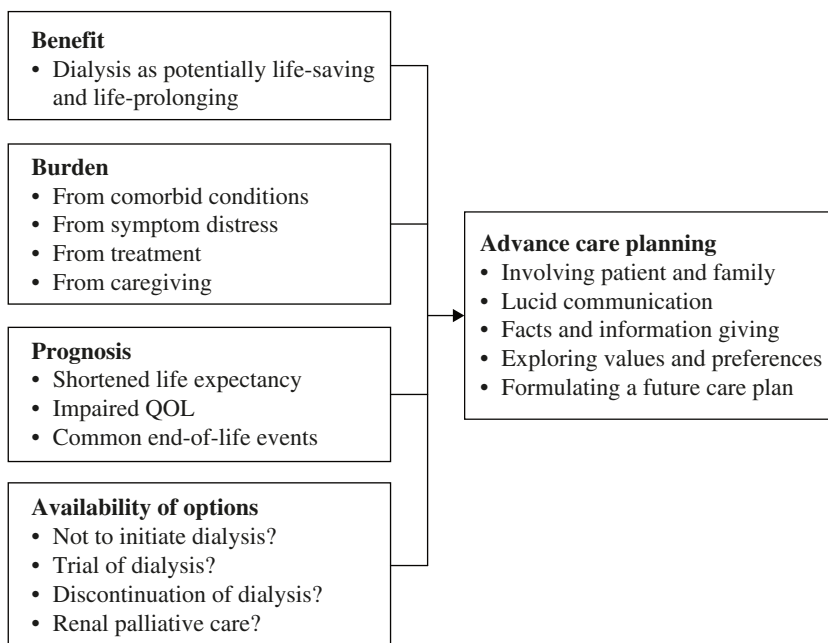


Figure 1. The advance care planning process in end-stage renal disease. QOL=quality of life.

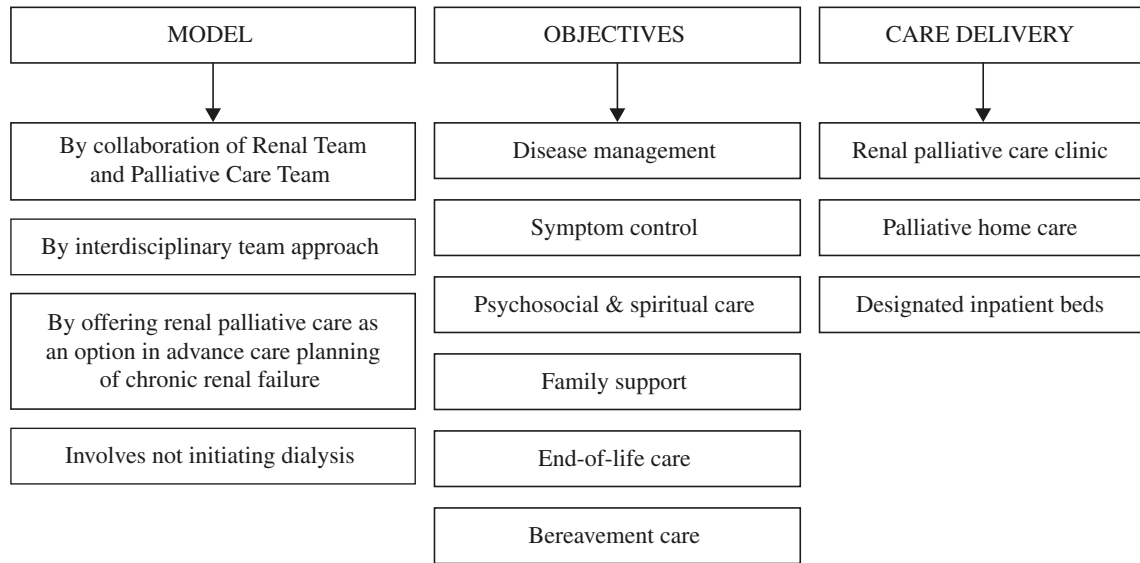


Figure 2. The model of the renal palliative care program in Caritas Medical Centre, Hong Kong.

ACP process may involve several rounds of discussions before any decision is made.

The model has adopted an interdisciplinary team approach that is pertinent to palliative care (Figure 2). The care delivery encompasses outpatient care, home care and inpatient care. The RPC clinic is the core component of the RPC program, which is a one-stop clinic involving the team work of a nurse experienced in renal or palliative care, a palliative medicine specialist and a designated medical social worker. The nurse is responsible for assessing physical and psychological symptoms, while the physician follows up on symptom control, disease management, and the concerns or perplexities related to the decision to forgo long-term dialysis. The medical social worker is responsible for providing or updating supportive measures with regard to the tangible, informational and emotional aspects. Patients are referred to palliative home care, dietitian, and clinical psychologist if appropriate; or admitted to designated beds for management of acute events and end-of-life care. Bereavement support is provided to family members as appropriate.

In RPC, the paradigm shifts from managing the failing kidneys to caring for patients suffering from ESRD, meaning that needs are not just defined by a specific disease or failing organ, but should also include patient's distress and suffering from the perspective of human personhood. Therefore, the treatment goals extend beyond disease management and symptom control to an emphasis on psychosocial care and QOL.

OBJECTIVES

The objectives of this study were to review the characteristics of ESRD patients who decided to enter the

RPC program and to compare them with those of ESRD patients who chose to undergo long-term dialysis.

PATIENTS AND METHODS

This was a retrospective chart review of ESRD patients who were interviewed for ACP from August 2007 to the end of December 2008. Data collected included demographics and socioeconomic data. Comorbid conditions and disabilities were scored using the modified Charlson Comorbidity Index (CCI). The CCI has been validated in ESRD and is a composite score of multiple comorbid conditions and age. Comorbid conditions are scored from 1 to 6, and a score of 1 is added for each decade above 40 years of age. In the modified version, the item of myocardial infarction is replaced by cardiovascular disease [18]. Parameters related to the ACP discussion and the dying process were also collected. Descriptive statistics were used and comparison between groups was done using the χ^2 test when appropriate. SPSS version 11.0 (SPSS Inc., Chicago, IL, USA) was used for statistical analyses. All tests were two-tailed, and a p value <0.05 was considered statistically significant.

RESULTS

From August 2007 to December 2008, a total of 96 patients underwent ACP and made their treatment choices; 60 patients chose RPC and 36 patients opted for dialysis. The demographic characteristics of the patients who chose RPC and those who chose dialysis are listed in Table 1 for comparison. Patients who chose RPC were significantly older (74.1 ± 8.7 vs. 57.0 ± 10.0 years;

Table 1. Demographic characteristics of patients who chose renal palliative care (RPC) and patients who chose renal replacement therapy (RRT)*

	RPC (n=60)	RRT (n=36)	p
Male:Female	1:0.94	1:0.5	NS
Age (yr)	74.1±8.7	57.0±10.0	<0.001
Marital status			<0.001
Single	0 (0.0)	4 (11.1)	
Married	35 (58.3)	27 (75.0)	
Widowed	24 (40.0)	1 (2.8)	
Divorced	1 (1.7)	4 (11.1)	
Household members			NS
Living with relatives	46 (76.7)	32 (88.9)	
Living alone	10 (16.7)	4 (11.1)	
Living with non-relatives	4 (6.6)	0 (0.0)	
Constant caregiver			0.001
Spouse	18 (30.0)	5 (13.9)	
Children/children-in-law	15 (25.0)	2 (5.7)	
Maid	6 (10.0)	5 (13.9)	
Relatives	2 (3.3)	0 (0.0)	
Provided by NGO	4 (6.7)	0 (0.0)	
Self care	15 (25.0)	24 (66.7)	
Place of abode			NS
Public housing	44 (73.3)	22 (61.1)	
Private housing	15 (25.0)	12 (33.3)	
Elderly home	1 (1.7)	2 (5.6)	
Financial support			<0.001
Social welfare	19 (31.6)	10 (27.8)	
Dependent on family	39 (65.0)	13 (36.1)	
Self reliant	2 (3.4)	13 (36.1)	
Comorbid conditions			
Hypertension	49 (81.7)	29 (80.6)	NS
Diabetes mellitus	44 (73.4)	15 (41.6)	0.002
Congestive heart failure	18 (30.0)	6 (16.7)	NS
Ischemic heart disease	15 (25.0)	7 (19.4)	NS
Acute coronary syndrome	14 (23.3)	5 (13.9)	NS
Hyperlipidemia	14 (23.3)	9 (25.0)	NS
Peripheral vascular disease	8 (13.3)	1 (2.8)	NS
Peptic ulcer/gastritis/esophagitis	17 (28.3)	10 (27.8)	NS
Cerebrovascular accident	9 (15.0)	6 (16.7)	NS
Chronic lung disease	9 (15.0)	6 (16.7)	NS
Dementia	5 (8.4)	1 (2.8)	NS
History of fracture	4 (6.7)	1 (2.8)	NS
History of or active cancer	5 (8.3)	5 (13.9)	NS
Psychiatric illness	3 (5.0)	2 (5.6)	NS
Chronic liver disease	1 (1.7)	4 (11.1)	NS
No. per patient	3.9±1.8	3.4±1.9	NS
CCI	9.5±1.9	6.9±3.1	<0.001

*Data presented as mean ± standard deviation or n (%). NS=not statistically significant; CCI=Charlson Comorbidity Index.

$p < 0.001$), comprised a greater number of widowers (40.0% vs. 2.8%; $p < 0.001$), and were more financially dependent on their family (65.0% vs. 36.1%; $p < 0.001$). The majority (75%) of RPC patients relied on a constant caregiver of any kind, while only 33.3% of patients who chose dialysis did so ($p = 0.001$). Comorbid conditions were equally prevalent, except for diabetes

mellitus which was more prevalent in RPC patients (73.4% vs. 41.6%; $p = 0.002$). The modified CCI, which takes age into consideration, was significantly higher in RPC patients than in dialysis patients (9.5 ± 1.9 vs. 6.9 ± 3.1 ; $p < 0.001$). Patients in both groups, however, did not differ in place of abode and household members.

Table 2. Advance care planning of patients who chose renal palliative care (RPC) and patients who chose renal replacement therapy (RRT)*

	RPC (n=60)	RRT (n=36)	p
Who decided			0.001
Mainly the patient	25 (41.7)	30 (83.3)	
Patient & family	34 (56.6)	5 (13.9)	
Doctor	0 (0.0)	0 (0.0)	
Guardian	1 (1.7)	1 (2.8)	
Mental capacity at time of first ACP discussion			NS
Competent	58 (96.7)	35 (97.2)	
Mentally incompetent	2 (3.3)	1 (2.8)	
Functional level at time of first ACP discussion			0.001
Able to walk independently	37 (61.7)	33 (91.7)	
Able to walk with assistance or walking aid	23 (38.3)	3 (8.3)	
Chair- or bed-bound	0 (0.0)	0 (0.0)	

*Data presented as n (%). ACP=advance care planning; NS=not statistically significant.

As for the ACP interviews, 96.7% of patients who chose RPC and 97.2% of patients who chose dialysis were mentally competent at the time of ACP and able to participate in the discussion, but a shared decision with family members occurred more often in the RPC patients (56.6% vs. 13.9%; $p=0.001$). More patients in the RPC group required assistance in walking or mobilization (38.3% vs. 8.3%; $p=0.001$) (Table 2). Disputes with family members occurred in the cases of three patients who chose RPC, but consensus was eventually reached after further discussion of the patients' own preferences and values.

During the ACP interviews, patients who chose RPC were asked about their main consideration for declining long-term dialysis. Patients declined dialysis because of perceived undue physical burden in 60.1%, social burden in 53.4%, and psychological burden in 56.8%; and a combination of all these factors was reported by 35.1% of patients.

By the end of 2008, 30 RPC patients (50.0%) and five dialysis patients (13.9%) had died. Among the RPC deaths, patients had received RPC for a median duration of 132.5 days (range, 3–437 days; interquartile range, 115.0 days); they all lived with their decision to withhold dialysis until death. All except one patient had a do-not-resuscitate (DNR) in place and cardiopulmonary resuscitation (CPR) was not performed. The only patient without DNR had a sudden cardiac arrest and was proclaimed dead after CPR failed in the Accident and Emergency Department. None of the deaths occurred in the intensive care unit.

Among the RPC deaths ($n=30$), the major event accompanying death was uremia in 10 patients (33.3%), acute coronary event or congestive heart failure in eight patients (26.7%), sepsis in seven patients (23.3%), gastrointestinal bleeding in five patients (16.7%), and cerebrovascular accident in two patients (6.7%). In the dialysis group, three of the five deaths received CPR;

one had a sudden cardiac arrest at home, and two received mechanical ventilation in the intensive care unit.

DISCUSSION

Our results showed that ESRD patients who preferred RPC to long-term dialysis were older and functionally more dependent, had more diabetes mellitus and higher CCI. This group also had more widowers and was more financially dependent on family. Around 97% of patients were able to join in the ACP discussion, and in more than half of those who chose RPC, it was a shared decision between the patient and family members. Patients who declined long-term dialysis perceived considerable physical, psychological and social burdens related to the treatment.

The profile of our patients who chose RPC was one at greater risk of adverse outcome from dialysis. Various factors have been reported to be predictors of poor survival in chronic dialysis, including advanced age, pre-existing comorbidities, impaired QOL scores, lower socioeconomic status, and biological parameters [19–22]. Overall, our ESRD patients had multiple comorbidities, with hypertension, diabetes mellitus and cardiac disease being the most prevalent ones. In the U.S., patients with the trio of chronic renal failure, diabetes mellitus and congestive heart failure are seven times more likely to die than those without any of them [4].

Patients who chose RPC were significantly older in our study. While age should not be the sole criterion used in deciding whether or not to go on dialysis, it has been reported that ESRD patients above the age of 75 years with high comorbidity score had no survival advantage when commenced on dialysis [19]. Another study found that mortality of dialysis patients was associated with age ≥ 80 years, but the mental QOL of these elderly were comparable to their counterparts in

the general population [20]. Recently, in the U.S., walking disability in terms of having to use walking aids or having a history of fall, though deceptively simple, has been found to be a predictor of adverse outcomes in the dialysis population [4]. Impaired QOL scores as assessed by the *Medical Outcomes Study 36-item Short Form Health Survey* were also reported to be predictors of poor outcome of chronic dialysis [21,22], especially among diabetics [23].

Chronic kidney disease is a strong predictor of adverse cardiovascular outcomes, and amongst our RPC patients who died, cardiac events were common at the end of life. Sudden cardiac arrest is not uncommon in dialysis patients, but the outcome of CPR has been shown to be far less promising than in other hospitalized patients [24]. Discussion of CPR with ESRD patients during the ACP process is therefore highly relevant.

When deciding to forgo dialysis, patients and their family members are facing stresses and dilemma. Patients have to let go of a "life-saving" treatment, and face the uncertainty of dying in pain and suffering without dialysis. Patients often fear that they would be "nobody's patient" once they have made the decision against dialysis. Family members, especially children, often feel obliged, out of filial piety, to agree to life-saving or life-prolonging treatment. They fear that making a decision against dialysis means that they are making a decision to hasten the patient's death. Patients and family members often struggle to comply with each other, and the patient might hesitate to express views or preferences that are different from those of family members. With facilitation of open discussion, mutual understanding is possible.

It is common in Chinese culture for a medical decision to be a shared decision among family members rather than an individual decision as an expression of personal autonomy [25]. This is more so in elderly patients as they often willingly rely on their children to act for them. Although such family-based decisions occurred more often in the RPC group than in the dialysis group (56.6% vs. 14.9%), we also found that many older patients were candid in expressing their views if prompted, and 41.7% of RPC patients clearly stated that they could decide on their own.

Overall, our patients and families appreciated the opportunity to engage in ACP with the health care team and to have the choice of palliative care to alleviate their sense of abandonment and the feeling that "nothing can be done". The children of elderly patients felt that something could be done for their parents while respecting their wishes.

Irrespective of the decision made, both patients and family members then had to adjust to the subsequent changes. For those who chose dialysis, the care process and placement would be taken over by domestic helpers or homes for the elderly for the more dependent patients;

or accommodated by the patient or family members at home. For patients who decided against dialysis, the transition from curative to palliative care along the disease trajectory was brought to the fore. While the focus is on QOL in palliative care, patients were also confronted with the finitude of life and anticipatory grief as patients coped with the dying process and families prepared for death.

Our discussion of the care plan did not stop after the decision to forgo dialysis, but would be continued as renal function and functional status deteriorated, or when patients and family members had second thoughts about their medical decision at any time along the care process. The RPC team members adopted an open attitude with respect to patients' choices, and discussion on the option of dialysis should never be evaded. In our experience, patients who changed their minds would do so very early on; two patients changed to dialysis before they attended the RPC clinic and three patients changed to RPC after being introduced to predialysis education. Patients and family members were educated that thoughtful preparation earlier on rather than emergency dialysis at a critical juncture was in their best interests. The open attitude toward discussion on dialysis after entering the RPC program also enhanced their sense of control. Such open discussions served more to confirm than shake their choice of palliative care.

Clinically and practically, deciding on when to refer patients with non-cancer diseases to palliative care is not easy. In the contemporary model of relating the trajectory of chronic debilitating diseases to health care needs, palliative care is an integral part of the care delivery system and of increasing relevance as the disease progresses in terms of symptom progression, psychosocial issues arising, caregiver burden and anticipatory grief [26]. This exemplifies that palliative care provision is based on needs and not limited to a specific illness, and the transition of treatment goals from curative to palliative is a continuum and not an abrupt cutoff only when death is imminent. Predictions of decline are more reliable in cancer as the disease trajectory is one of relatively stable health until the last 3 months of life, when patients experience a more rapid decline till death. For non-cancer diseases, however, the course is far less predictable, and can range from being a lingering type as in dementia, to one that is interrupted by acute exacerbations as in organ failure [27]. Clinicians tend also to be reluctant to proclaim non-cancer diseases to be incurable, and patients may find that palliative care is not so much associated with being a death sentence as it would be if they had cancer. Practically, there is a plausible concern that with extension of palliative care to non-cancer diseases, too early referrals may overwhelm the existing system when patients live longer than predicted, while late referrals may limit benefits of palliative care to the end-of-life phase.

In the U.K., prognostic indicators are being developed as part of the Gold Standards Framework, a national program to improve end-of-life care, to facilitate such referrals. In ESRD, referrals to the palliative care service can be initiated based on estimated prognosis, personal choice and needs. The criteria include patients who do not opt for renal replacement therapy because of personal choice, fragility and comorbidities, and patients with symptomatic renal failure. In assessing the fragility and prognosis of patients or to trigger referral to palliative care, one can apply the surprise question, "Would you be surprised if this patient were to die in the next 6–12 months?", as an indicator. This is an intuitive question integrating comorbidities, social and other factors [28]. In our model, the RPC program first interfaces with disease management at the time of ACP, when patients were at stage 4 or 5 chronic renal failure. This has the merits of introducing palliative care as an integral component of care for ESRD, empowering patients and families to make their own choices, facilitating transition to palliative care service, shifting the focus of care to symptom relief and QOL, and allowing time to address their psychosocial and spiritual needs while preparing for death and dying. While we did not explicitly include the surprise question in our model, patients recruited into the RPC program died after a median of around 4 months. Our initial experience was that patients with well established stage 5 chronic renal failure might deteriorate before they could benefit from the program. Overall, we found our model workable in selecting patients who would benefit from palliative care.

The outcome indicators of RPC remain to be explored. Symptom relief is an important goal to achieve, but more evidence is required to shed light on palliation of difficult symptoms in ESRD. Measuring QOL may be difficult when the patient's condition declines further. As death approaches, the quality of dying may be more reflective of the end-of-life care provided. Before good evidence is available, it is imperative that palliative care is developed as a treatment option in ESRD. RPC, as an active course of care for patients suffering from ESRD, is only an option if it exists. Until then, not to initiate dialysis remains a passive withholding of dialysis.

CONCLUSION

The RPC program, introduced as an option in ACP, was appropriate in meeting the preferences and needs of a significant proportion of ESRD patients and their families. More studies are warranted to ascertain the economic implications and efficacy of RPC, the survival and outcome of patients who choose palliative care and not dialysis, and the best way to palliate symptoms related to ESRD.

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