



ORIGINAL ARTICLE

# Advance care planning for 600 Chinese patients with end-stage renal disease



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## KEYWORDS

advance care planning;  
dialysis;  
palliative care;  
renal failure

**Abstract** *Background/purpose:* There is increasing recognition of the need to integrate advance care planning (ACP) into end-stage renal disease (ESRD) care with attention to medical, ethical, psychosocial, and spiritual issues but publications comparing patients who chose renal replacement therapy (RRT) and renal palliative care (RPC) is scarce. We here share our experience on ACP for ESRD patients in a center with renal replacement and palliative programs in place.

*Methods:* From June 2006 to December 2011, ESRD patients were empowered to make an informed choice of future medical care in a structured ACP that was emphasized to be an ongoing process. Patients who opted for RRT and RPC would be followed up at the predialysis clinic and the one-stop multidisciplinary RPC clinic, respectively. This was a single-center study in a secondary care hospital. A total of 600 patients (265 RRT, 335 RPC) were enrolled and followed up over a median of 782 days.

*Results:* The majority of patients and relatives declined dialysis because of perceived physical burden. Only 1.6% of palliative care patients changed their decision and commenced dialysis. Baseline characteristics differed between patients who chose RRT or RPC. Survival declined according to the modified Charlson comorbidity index scores. Older age, mental incompetence, hyperlipidemia, high modified Charlson comorbidity index, low estimated glomerular filtration rate, and low albumin were important independent predictors of poor survival. Factors affecting the ACP decision were discussed in the Chinese culture context.

*Conclusion:* A structured ACP could empower the patient to make an informed decision on the management of ESRD.

背景：於末期腎病患者的照顧中加入關注身心社靈和倫理問題的預設照顧計劃(ACP)受到日益重視，但有關比較接受腎替代療法和接受腎臟紓緩治療文獻討論為數不多。作為同時提供腎透析服務以及腎臟紓緩治療的部門，本文旨在分享我們為末期腎病患者討論預計照顧計劃的經驗。

方法：自二零零六年六月至二零一零五月間，透過有組織的預設照顧計劃討論，末期腎病患者會被鼓勵就未來的治療計劃作出知情選擇。選擇腎透析和腎臟紓緩治療的病人會分別於透析預備門

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診和一站式跨科際腎臟紓緩治療門診去覆診。本研究於一家二級醫院進行。總共有六百病人參與此研究，當中265名接受腎透析，335名接受腎臟紓緩治療，其中位跟進日數為782日。

結果：大部份病人和家屬之所以拒絕腎透析是由於預計的身體負累，只有百分之一點六接受腎臟紓緩治療會改變主義而接受腎透析。選擇腎透析和腎臟紓緩治療的病人在基本的身體狀況有明顯分別。生存率亦隨著修改版查爾森共病量表的分數而下降。年長、精神自主能力缺欠、高血脂、修改版查爾森共病量表分數高、腎小球濾過率低、白蛋白低均屬重要暨獨立的因素以預計較差的生存率。本文亦會探討在中國文化處境下影響預設照顧計劃討論的因素。

結論：有組織的預設照顧計劃討論能幫助病人在末期腎病的醫療方向作出知情的選擇。

## Introduction

The global prevalence of end-stage renal disease (ESRD) is increasing. In the USA, older patients comprise the fastest growing population initiated on renal replacement therapy (RRT) with the proportion older than 70 years rising from 19.2% in 2000 to 24.9% in 2012. In the UK, up to 25% of patients commenced on RRT are aged over 75 years.<sup>1</sup> Irrespective of age, more patients with multiple comorbidities were commenced on RRT. In the USA and UK, 40% of dialyzed patients had diabetes mellitus (DM).<sup>1,2</sup> Despite prolonged survival, dialyzed patients suffered impaired quality of life (QOL) with physical and psychological morbidities.<sup>3–5</sup> Older patients had the worst outcomes with heightened mortality, and poor functional status and QOL.<sup>2</sup> Death from withdrawal of dialysis had been increasing, especially among elderly, and accounted for 25% of RRT mortality in the USA and 19% in the UK.<sup>1,2</sup> In the past decade, the increasing number of elders being started on RRT and the increasing dialysis withdrawal rate called upon the option of no dialysis.<sup>6</sup> The latest Renal Physicians Association practice guideline affirmed patient's right in refusing initiation of dialysis in care planning.<sup>7</sup> While recognizing the appropriateness of nondialytic treatment in some patients, it is prudent to provide them with access to active palliative care to evade sense of abandonment.<sup>8</sup>

Life expectancy in Hong Kong is among the longest in the world. The median age of incident RRT patients rose from 56 years to 60 years, while DM among incident and prevalent patients had increased from 26.2% and 20.8% in 1996 to 46% and 33.7% in 2011, respectively.<sup>9</sup> Patients not commenced on dialysis were historically categorized as receiving conservative management. It was only in recent years that public palliative care service was funded to serve patients with ESRD.

To make an informed choice in accordance to their own values and preferences, patients should be provided with adequate information and empowered to decide on their medical care based on weighing of burdens and benefits.<sup>7,10</sup> Advance care planning (ACP) is part of the comprehensive ESRD care with attention to ethical, psychosocial, and spiritual issues related to starting, continuing, withholding, and withdrawing dialysis.<sup>11</sup> In Hong Kong, the importance of integrating ACP into the ESRD care had been recognized.<sup>12</sup> Nevertheless, the quality of ACP is affected by various factors. Firstly, ACP is an operator-dependent process and affected by the facilitator's communication skills and rapport with the patient. Secondly, initiating ACP at a suitable time along the disease trajectory requires careful

consideration; the patient may be unprepared when too early or unable to participate in lucid discussion when too late. Thirdly, unlike completing an advance directive, the ACP process can be variable and unstructured when clinicians are not trained relevantly.

We report our experience in constructing and implementing a structured ACP process for patients with ESRD in a center with a renal palliative care (RPC) program. With designated ACP facilitators, early engagement of patients and families, defined scope of prognostic assessment, information giving and discussion, as well as standardized documentation for ongoing care, patients were empowered to make informed choices.

## Methods

We recruited all adult (aged  $\geq 18$  years) patients who underwent ACP from June 2006 to Dec 2011. Clinicians conventionally refer diabetics with serum creatinine  $\geq 350\mu\text{M}$  or nondiabetics with serum creatinine  $\geq 450\mu\text{M}$  for ACP, but patients presenting late with overt symptoms and limited life span were encountered. The first ACP interview mostly took place in a designated clinic and facilitated by an experienced nephrologist and a medical social worker (MSW). Supplemented by pamphlets, the scope of discussion included delivery of information on diagnosis, prognosis, treatment options and their benefits and burdens. End-of-life issues were discussed only if there were urgent clinical needs. Factors affecting prognosis were assessed at baseline. This included the cause and irreversibility of renal failure, estimated glomerular filtration rate (eGFR), comorbidities and modified Charlson comorbidity index (mCCI),<sup>13</sup> biochemical parameters, and functional and socioeconomic statuses. The patient's values and preferences were explored and caregiver distress identified. The MSW served to provide on-site emotional support, facilitate family discussion, provide timely information on social resources and act as the link person to follow on patient's care plan. The patient and family were invited to complete the Medical Outcomes Study—Short Form Health Survey Questionnaire (SF-36),<sup>14</sup> Social Support Survey (SSS),<sup>15</sup> and Caregiver Strain Index (CSI).<sup>16</sup> SF-36 was not performed for all hospitalized patients to avoid undue clinician effect on patient response. With participation and support by family members, the patient was empowered to make an informed choice of future medical care, including RPC if the patients decided to forgo dialysis.<sup>8</sup> Reasons for patients forgoing dialysis were classified into physical, psychological, and social burdens by the consensus

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