

The Lived Experiences of End Stage Renal Disease (ESRD) Patients for Decision Making for Palliative Care Treatment

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Received: October 30, 2019; Published: November 12, 2019

Abstract

Aim: (a) To describe the phenomenon of lived experiences of End Stage Renal Disease patients; and (b) to explore factors related to decision-making for treatment.

Design: Phenomenology approach.

Method: We interviewed twelve patients diagnosed with ESRD in a regional hospital from June 2012 - November 2012 in Kowloon central cluster of Hong Kong, about their perception of decision-making in treating ESRD. Semi-structured, face-to-face interviews with audiotaped recording were carried out among a purposeful sampling of ESRD patients who were undergoing renal palliative care. The data were transcribed verbatim and underwent thematic analysis.

Results: In reviewing lived experiences of decision-making for treating ESRD, four main themes emerged from the data; they were: (a) predisposing factors - health beliefs/health attitudes, demographic characteristics (b) enabling factors - healthcare system, insurance, financial status, availability of treatment options, health demands and (c) medical demands -evaluated health condition and perceived health status (d) quality of life- physical, psychological, social well-being and level of life satisfaction. When participants were asked about the effects of ESRD, clinical manifestations with varied degrees of severity were identified. They included (1) poor sleep quality, (2) anorexia, (3) bone ache, (4) dizziness; (5) shortness of breath on exertion; (6) fatigue, and (7) fluid retention. In the process of decision-making for treatment, the significant aspects focused on: (i) discussion with family members, (ii) discussion with healthcare professionals, (iii) information of the ESRD and its treatment options and (iv) sharing with peer patients which attributed to the structure of meaning of lived-experiences.

Conclusion: All patients were satisfied with their choice of renal palliative care. The main considerations for their treatment choice were effectiveness of treatment, freedom from pain and quality of life.

Keywords: End-Stage Renal Disease; Palliative Care; Decision-Making

Abbreviations

ESRD: End-stage renal disease; CRF: Chronic Kidney Disease; RRT: Renal Replacement Therapy; HD: Hemodialysis; PD: Peritoneal Dialysis; RT: Renal Transplantation; GFR: Glomerular Filtration Rate; RPC: Renal Palliative Care

Introduction

End stage renal disease or end-stage renal failure is the latest stage of chronic kidney disease and accounts for the 6th leading cause of death in Hong Kong [1]. In Hong Kong, the number of ESRD patients increased, from 76,945 in 2006 to 113,840 in 2009. ESRD patients suffer from permanent and irreversible damage of kidney function. Although large numbers of patients with ESRD exist worldwide, studies on the factors that influence patients' preferences for treatment are limited.

Patients suffering from ESRD confront different challenges including the choice of extending life, being a burden to family, confronting clinical symptoms and quality of life. Patients with ESRD may choose from a variety of Renal Replacement Therapy (RRT), namely haemodialysis (HD), peritoneal dialysis (PD) or kidney transplantation (KT). Yet some patients with progression to ESRD may not be presented with adequate information on treatment options or given sufficient time in discussing management alternatives with their families [2].

Background

Chronic kidney disease is a progressive condition that results in significant morbidity and mortality. Because of the important role the kidneys plays in maintaining homeostasis, chronic kidney disease can affect multi-organs [3]. As kidney function deteriorates, patients develop complications related to fluid overload, electrolyte and acid-base imbalances and the build-up of blood urea nitrogenous waste [4]. Eventually some patients need renal replacement therapy in order to sustain their lives.

Renal replacement therapy

In Hong Kong, the prevalence of diabetic nephropathy stands at around 49% and also notable increasing number of elderly patients requiring dialysis treatment [1]. In concerning the PD first standard policy in Hong Kong, PD is the primary treatment option for ESRD patients, which involves passing dialysis fluid into the peritoneal cavity through a peritoneal access. It is a relatively simple technique that can be carried out at home with the frequency of three to four times daily, but peritonitis is commonly encountered by patients [5]. HD is a more invasive therapy, requiring surgically established vascular access such as arteriovenous fistula. During the process of HD, pumped blood is circulated through a dialyzer that contains a semi-permeable membrane across which fluid and solute transfer occurs. Most HD is carried out in a hospital setting two to three times per week for a period of 4 - 6 hours [5]. Patients with RRT therapy should keep to a strict dietary intake as well as fluid limitation in compliance with the dialysis treatment. RT using deceased kidney or live-kidney is considered to be non-dialyzable RRT [1]. However, the organ donation rate is relative low as compared to the demands in Hong Kong [1]. Hence, waiting for a deceased kidney donation is unpredictable.

Whatever treatment modality they choose, they will still encounter many others complications, either originated from the disease pattern or secondary to the treatment undergone. ESRD patients often experience guilt, helpless, sadness, role reversal, stress from a financial perspective, and change in body image and stress in performing home-based dialysis [6]. Many studies have revealed that end-stage organ failure patients share common health concerns with other patients who are at the end stage of life. The common signs and symptoms are pain, dyspnea and fatigue. Palliative care, a new initiative non-dialysis care, with relief of disease distress and psychological stress provided to patient and family members [7,8].

Decision making for treatment

In making treatment decisions, patients have to address several considerations and concerns. Firstly, in confronting the treatment, there is fear, due to false beliefs, a sense of threat to life, concern about damage to self-image, and fear of physical limitations. Secondly, they will seek further information which includes opinions of family members, professional confirmation, and alternative treatments. Thirdly, they will consider how best to live with the therapy including worsening symptoms, family support, and financial impact. All these concerns reflect the difficulties that ESRD patients encounter and in return, all these factors will influence the treatment choice [9].

The problematic timing of information about treatment options and synchronous establishment of dialysis access seems to inhibit the choice of other treatments such as palliative care [10]. Likewise, patients seldom alter their treatment of choice due to their preference to maintain the status quo.

With the implications of holistic care on the bio-psychosocial and spiritual well-being, palliative care enhances the lifelong experience of patients and carers' potential [11].

Objectives of the Study

- To understand the significance of lived experience for palliative care treatment decisions made by ESRD patients.
- To explore the factors influencing End Stage Renal Disease treatment decisions.

Methodology

Phenomenology offers descriptive analyses of mental phenomena and studies the structure of various types of experience ranging from perception, thought, memory, imagination, emotion, desire, and volition to bodily awareness, embodied action, and social activity and linguistic activity [12]. The method of phenomenology with the Husserl's approach was applied which involves the study of structures of consciousness as experienced from the first-person point of view [12,13].

Sampling

The study followed purposeful sampling in phenomenological inquiry [14]. The targeted ESRD participants were recruited based on their experiences of palliative care for sharing cases with rich information for in-depth study. Twelve participants were recruited for face-to-face interviews with saturation principles adopted [15].

Data collection

Face-to-face interviews guided with open-ended questions were conducted by researchers. The interviews allowed access to the informants' worlds and were an excellent source of data. The first interview was conducted to acquire the participants' initial descriptions of their experiences and the second to validate the transcribed data after the researcher read the interviews.

An interview protocol was applied with core and open-ended questions as follows:

- Starting questions:
 - How did you feel once you were diagnosed with end stage renal disease?
 - What seemed to help you to cope with end stage renal disease?
 - What is your view on treatment decision making?
 - What factors did you consider in making your treatment decision?
 - With whom you will discuss
- Ending the interview:
 - Please feel free to share anything more with me.

Open-ended interviewing allowed the researchers to follow participants' lead, ask clarifying questions, and facilitate the expression of their lived experience. Interviews usually ended when participants believe they had exhausted their descriptions.

According to Husserl, the state of universal sense may be accomplished by applying the process of bracketing, through the process of bracketing the universal essences represents the true nature of the phenomenon under investigation [16,17].

Data generation continued until the researcher perceived saturation had been achieved, when no new themes emerged from the participants and the data was repeating. The actual number of participants exceeded the anticipated number for the sake of rich and in-depth data collection. The taped interview was then read and transcribed from Cantonese into English.

Data analysis

Data collection through interviews was designed in order to collect multiple perspectives of the respondents [18]. Showing analytical rigor in the stages of coding, thematic analysis was applied for, 'identifying and reporting patterns within the data analysis [19]. Themes within data can be identified either in an inductive 'bottom up' way or in a deductive 'top down' way.

There are three main reasons for applying an inductive approach: (1) to condense extensive raw text data into a concise format; (2) to establish clear links between the research objectives and the summary findings derived from the raw data; and (3) to develop a model about the underlying structure of experiences which are observed in the raw data [20].

Rigor of data collection

The data collected through interviews with ESRF patients were analyzed based on a three-stage procedure suggested in the studies [21] which includes (1) preparing the data for analysis by transcribing, (2) reducing the data into themes through a process of coding and (3) representing the data.

The themes were identified through a rigorous process of data familiarization, data coding, theme development and revision [19].

First, data familiarization was internalized through transcription and translation of the interviews. All interviews were translated verbatim, directly into English, by the researcher.

Second, the transcripts were coded as the researcher listened to the recordings. When satisfied with the codes generated, they aligned them with the research questions, using the data-driven coding in order to identify patterns of meaning.

The third stage involved theme development. At this stage, coded recordings were read and reread to identify significant patterns of meaning and potential themes. The preliminary analysis came up with four main categories with subcategories such as availability of access, resources available, available information and support and so on. Part of the flexibility of thematic analysis is that it enables the themes and their prevalence to be determined in a number of ways [19].

Fourth, these 13 categories were aggregated into 11, then into 7, and were further reduced into the 4 most referred to categories include predisposing factors affecting decision making, personal enabling perception of level of illness, available resources and quality of life.

Validity and reliability

Qualitative studies explore the concepts and categories from the data given by the informants. Different strategies were adopted to ensure the plausibility and credibility of the process of data collection, coding and data analysis. Four criterion of trustworthiness described by Lincoln and Guba (1985) were applied in this study, including confirmability, credibility, dependability and transferability [21].

The researcher had to make sense of all the data, without damaging the context of the phenomenon being studied. On the other hand, another researcher rich in qualitative study experience was invited to do the data analysis by coding and development of theme. The meetings were held aiming at consensus of theme development. Table 1 briefly defines these criteria and individual measures adopted to ensure the trustworthiness of the data and findings.

Criterion	Description	Specific measures adopted
Confirmability	It refers to the objectivity of the data.	Researcher intuited and brackets the concept of treatment decision-making.
Credibility	The findings truly reflect informants' experiences of the phenomenon under investigation.	Verifying informants' statements. Validation of the data and finding was established through further interview and peer debriefing.
Dependability	It reflects the stability of data collected over time and over situations	One expert in qualitative analysis reviewed the informant's transcripts and analyses at random. Comparison of the findings was made.
Transferability	It refers to the possibility of applying the findings into other settings.	A clear description and explanation of the methodology and the findings was provided to enable the reader to make judgments in view of applicability to other settings.

Table 1: Description of trustworthiness of data and finding and specific measures adopted.

Ethical considerations

According to Richard and Schwartz (2002), the participants were provided with relevant and adequate information of the study prior to signing the consent form [22]. All patients participated in this study on a voluntary base with anonymity maintained. Ethical approval was attained from the Ethical Committee of the study hospital prior to the launching of this study.

Results

Demographic characteristics of informants

As shown in table 2, 12 Chinese end stage renal disease patients were recruited, of whom five were male and seven were female. The ages of twelve informants ranged from 61 - 87 years with mean age of 72 years. Eleven of them received education at primary or below level and one received university level education. Five of them were retired seven of them were homemakers. Eleven of them were financially supported by family caregivers. All informants had a history of hypertension, and nine had diabetic mellitus and hyperlipidaemia. Three informants experienced the symptoms of gout. Three of them had no religious beliefs while nine of them were Buddhist.

Themes and sub-themes of experiences of informants

The experiences recalled by the informants were identified as situated structure. Four major themes finally emerged after the data analysis. These were: (1) predisposing factors (2) enabling factors (3) perceived medical needs factors and (4) quality of life. Illustrative descriptions showing the themes and sub-themes are highlighted in table 3.

Theme one: Predisposing factors of decision-making

The informants recalled their concerns in treatment decision-making with several descriptions of the situated structure. First, demographic characteristics such as seniority. Second, family structure. Third, self-role of decision-making. Fourth, nature of therapy and the necessity of surgical operation. Fifth, health beliefs.

“ESRD is a chronic disease with multiple organ involvement. Symptoms such as anorexia, fatigue, shortness of breath and fluid retention will progress”.

“I live with my only son in a very small apartment with limited household facilities. In the day time, my son goes to work and I stay alone in the apartment” (Informant 1).

Characteristics	Number	%
Sex		
Male	5	42
Female	7	58
Age		
61-70	1	8.3
71-80	9	75
81-90	2	16.7
Education level		
Primary	11	91.7
University	1	8.3
Marital status		
Married	12	91.7
Single	1	8.3
Religion		
Buddhist	9	75
None	3	25
Occupation		
Retired	5	41.7
Housewife	7	58.3
Time between Treatment decision making and the interview		
2 weeks	3	25
1 - 3 months	5	33.3
4 - 6 months	4	41.7

Table 2: Demographic characteristics of informants.

Themes	Sub-themes
Predisposing factors of making treatment decision	Key person of decision -making (role)
	Social environment
	Health related information
	Health attitude
	Communication
	Family members
Enabling factors of making treatment decision	Person / family
	Accessibility of treatment
	Treatment available
	Professional bias
	Sharing with patient peers
Perceived medical needs factors	Evaluated health status
	Perception of health
Quality of life	Sustenance of current style of living
	Free from pain and disease symptom stress

Table 3: Themes and sub-themes of experiences of decision making of palliative care services

The informant expressed that she could not tolerate the day-to-day dialysis therapy at home. In addition, the home environment was not favorable for home-based dialysis therapy. Furthermore, the indication of surgical operation for placement of dialysis catheter was rejected by the informants.

Key decision-making persons

The patient, family members and healthcare professionals are the key persons involved in treatment decision making. The prior key person is the patient himself/herself to determine the treatment modality preference.

“I am the key person who fully perceives what happens inside my body. I am responsible and have the right to make palliative care treatment decisions” (Informant 1).

“Yes, I made the treatment decisions myself. My offspring needed to work. I’m old enough” (Informant 2).

It is something troublesome, I really feel the disease is a troublesome matter. It requires me to go here and there, even staying at home is still troublesome..... (Informant 3).

Unfavorable social environment

The financial implications are a concern in making treatment decisions. His wife cared for him with minimal assistance for daily activities.

“My offspring needed to work. I sense the procedure of dialysis therapy is very complicated.....” (Informant 1).

“Peritoneal dialysis therapy: financial constraint is my concern, I am supported by my younger brothers financially” (Informant 3).

A majority of the informants expressed that they could sustain their present clinical condition under the care of the palliative team. They expressed they were old enough and preferred to die peacefully. Health beliefs provide one means of explaining how social structure might influence enabling resources, perceived need, and subsequent use (Mechanic 1979).

Health-related information

Patient knowledge, as one of the factors influencing patient participation in healthcare decision-making.

“Is it necessary to hire/buy a machine to perform kidney dialysis? Troublesome! Obsession! Yes, really true. It really affects my daily life” (Informant 1).

“The process of kidney dialysis must be strictly adhered to; otherwise, it will end up with infection (certainly true)” (Informant 2).

“.....Any dialysis related information provision facilitates your treatment decision-making?... No use!” (Informant 3).

“The demonstration and details of PD should be enriched. For example, the first step of the procedure...

The second step of the procedure...

The general conditions of home-based dialysis

What procedures are related to self-care dialysis?” (Informant 4).

“...re, even stay at home is still troublesome. This kind of therapy (RPC) is good, that’s why I do not discuss it with my family members” (Informant 5).

“How frequent is dialysis? Machine-assisted or manual? When is the placement of peritoneal catheter? What is the site of access insertion?”

“More information will facilitate the diabetic mellitus” (Informant 6).

“There is inadequate therapy-related information for reference” (Informant 7).

“Healthcare professionals should provide health-related information. The most important issues can be highlighted for my reference. I will choose according to my particulars.....” (Informant 8).

“I perceive the service of RPC is quite comprehensive. However, the staff at SOPD did not provide any explanation of palliative care. They just urge you to decide either PD or RPC. At RPC, staff provides a thorough explanation to the clients” (Informant 9).

“I will attend the demonstration of PD procedures if provided” (Informant 11).

Critical health literacy, in particular, are important in reporting involvement in medical decision-making. As such, the acquisition of information of treatment options were expressed to facilitate the decision making of ESRD patients.

Attitude of healthcare professional

“Now my general condition is stable, I only needed to have drug compliance and dietary compliance. It’s no need to bother my family members. Condition is not critical! Really it is not critical, try to keep it (kidney dialysis) postponed as late as possible” (Informant 4).

“I fully understand and perceive the function of all the internal organs. That’s my favorite interest. I have read many books about fortune telling. I really predict accurately the life span of an individual.....” (Informant 6).

“I have panic about the DM which impairs the nutrients entering into the tissue, resulting in organ failure” (Informant 9).

Health beliefs: Patient decisions are influenced by their personal value as shown below.

“My drive for living is consistent. In view of my kidney disease, I can read many health-related books and practice different types of ‘Che’ exercise. I have tried to incorporate what I have learned from the Chinese Medicine into the treatment of my kidney disease. Still my blood sugar level is poorly controlled.....” (Informant 5).

“The advantages of western medicine are mainly treating infection, operation emergency treatment. While Chinese medicine focus on the regaining of resources and strength.....action is slow and gradual.....” (Informant 8).

“My physical strength is not bad as compared with those with same age” (Informant 9).

Patient values should include patients’ priorities, life philosophy and their background. Current decision support tools, such as patient decision aids, should consider these new dimensions when clarifying patient values.

Communication: What is required by patients and their carers are good communication and information such as clear advice on settling emergency situations, what to expect and the steadfast continuity of relationships as companions on the journey with the patients. This valuable trusted relationship and supportive role should be well established.

“Healthcare professional communication will probably enhance the understanding of palliative care. It’s really good!” (Informant 4).

“Discussion with family members. Yes, the most trustworthy person who supports me” (Informant 6).

In facing the issues of decision-making for treatment, the informants expressed and discussed their concerns with the family members or significant others. Different view of disease treatment were also collected for consideration. In addition, the informants considered the treatment availability and accessibility.

Theme two: Enabling factors for making treatment decisions were

It was common for the informants to focus on the accessibility of treatment. However, due to impact of under-communication, some of the available treatments were not accessible to them. One informant stressed that the specialty out-patient department and the Renal Palliative Care Clinic differed greatly in terms of logistic and patient care.

Person/family

“My son persuaded me to have PD therapy. I refused because I have seen others who are undergoing dialysis suffer, such as cleansing the wound. Need to sterile the accessories is really troublesome!” (Informant 4).

“It is troublesome to have kidney disease which requires frequent admission into the hospital” (Informant 7).

Informants acknowledge the advanced chronic disease, the disease trajectory and its treatment in the process of decision-making for treatment options.

Accessibility of treatment

“RPC. I did not realize such a therapy was available until the new doctor interviewed me. I have enquired about the difference of services between SOPD and RPC. There is a big difference. 2 times of attendance are required at SOPD while one stop service is provided at RPC. Overall the health related information is inadequate. I attended this clinic as soon I was referred. Even anemia can be treated.....” (Informant 3).

Treatment availability

“It’s impossible for me to have a renal transplantation. In addition, I perceive the effects of PD as insufficient.... RPC is the only therapy I can adopt in which I have to take the drug and have the dietary restriction” (Informant 5).

Professional referral

“The doctor instructed me to prepare psychologically for a short life span....”

“I know the nature of kidney disease. All my family members know my condition. Dr. Cheung referred me to RPC which is dialysis free therapy. I then came to attend the RPC. I had never heard about RPC before” (Informant 5).

Timely professional referral plays an important role in the process of treatment options.

Sharing with patient peers

“Going through the process of treating kidney disease alone is challenging. What makes it easier?”

“It’s good to communicate with other kidney disease patient” (Informant 4).

“Discussion with friend may be useful. Three cobblers deserve to win a wise man. Its meaningful, peer sharing is a good thing. But my friend conveyed the message that daily dialysis is troublesome” (Informant 6).

“Discussion with family members. Yes, the most trustworthy person who supports me” (Informant 8).

“Healthcare professional communication will probably enhance understanding. It’s really good!.....” (Informant 9).

The experiences of other patients greatly influences the decision making of patients and caregivers.

Availability of treatment

In Hong Kong, under the 'PD First' policy, the majority of ESRD patients has the primary arrangement of PD therapy unless it is contra-indicated by conditions such as history of multiple abdominal surgeries, malignancy of abdominal organ, failed PD therapy or peritoneal mal-function. As a result, the only therapy that the majority can choose is PD therapy under the care of the Hospital Authority. An informant emphasized that patients with inefficient PD therapy still require drug compliance and dietary restriction in the course of therapy.

Theme three: Perceived medical need factors

Need for care was perceived with the enhancement of knowledge and health education, objective evidence and clinical status. Evaluating health status with objective data was another factor influencing the perception of medical needs. An informant claimed that he was in stable clinical condition as referred to the laboratory reports. He preferred no dialysis therapy.

"I'm satisfied with what I have achieved. All offspring are married with lots of grandchildren. I have prepared psychologically for my death".

"My son persuaded me to have PD therapy. I refused because I have seen others who are undergoing dialysis suffer, such as cleansing the wound. Need to sterile the accessories, it really troublesome!" (Informant 5).

"I know my creatinine level is higher, but it doesn't affect me much. Nothing special, only caution in diet" (Informant 9).

Perception of health

"An unhappy person may present with many illness, one after the other. Now I'm happy and I can sleep well and eat well" (Informant 6).

"I have lived with my wife in a small flat for over 45 years. Currently, my health condition is stable and same as before. I can resume my usual style of living" (Informant 10).

"I prefer to incorporate Chinese medicine in controlling my kidney disease" (Informant 11).

No obvious physical symptoms of distress or disturbance of daily living were perceived by the informant as nothing abnormal was detected from the disease.

Theme four: Quality of life

Rehabilitation services are provided for patients with chronic illness to prevent complications and maximize functional status. After acute events such as spinal cord injury, stroke or amputation, rehabilitation efforts are concentrated early, followed by periodic reassessment and intervention. However, ESRD patients require continuous management to slow down clinical deterioration and preserve functional abilities.

Physical functional status is only one component of quality of life, but it is relatively easy to assess objectively and often can be improved by simple interventions. Problems with psychological well-being and social role performance are more complicated to assess and treat. Every aspect of quality of life can be affected by declining physical function and may improve with increasing physical function.

The global definition of quality of life consists of satisfaction with life and a personal feeling of well-being or happiness [23]. To this group of informants, quality of life was simply the sustenance of their current style of living, free from any signs and symptoms of kidney disease.

Sustenance of current style of living was revealed by informants as follows:

“Does kidney dialysis provide me with more comfort? The problem is still unsolved” (Informant 1).

“I have attempted this RPC and I don’t want to attempt others. I prefer a simple and non-troublesome therapy. Now I am feeling comfortable and it is not difficult receiving palliative care. It’s really true.....” (Informant 1).

“Palliative care really benefits me. Those who suffer from kidney disease should cherish the number of days they have to live” (Informant 8).

“Now this RPC is still good for me. I try to keep.....

.....I am old enough, let nature take its course.

.....RPC can solve the problems I encounter. It helps my anemia. How convenient it is.....” (Informant 10).

“I will choose palliative care. The decision is up to me.

Yes, I prefer palliative care even as a second choice.

I feel really good (palliative care)” (Informant 11).

Freedom from pain and signs and symptoms of kidney disease

“My cherishing hope is freedom from pain and ability to eat well and no problems sleeping” (Informant 5).

“An unhappy person may present with many illnesses. One after the other. Now I’m happy and I can sleep well and eat well” (Informant 6).

“My relatives have the experience of PD therapy at home.....he couldn’t go down-stair, no freedom! Now I do not receive kidney dialysis therapy, however, I’m free to travel, even to Canada” (Informant 9).

Physical functional status is only one component of quality of life, but it is relatively easy to assess objectively and often can be improved by simple interventions. Problems with psychological well-being and social role performance are more complicated to assess and treat. Every aspect of quality of life can be affected by declining physical function and may improve with increasing physical function.

When they were asked about the effects of ESRD, both mild and severe clinical manifestations were identified by the informants. The symptoms included (1) poor sleep quality, (2) anorexia, (3) bone ache, (4) dizziness; (5) shortness of breath on exertion; (6) fatigue, and (7) fluid retention.

In the process of decision-making for treatment, the significant insights identified were: (1) discussion with family members, (ii) discussion with healthcare professionals, (iii) self-role, (iv) information about ESRD and its treatment options and (v) sharing with peer patients, which attributed to decision making.

Discussion

Nephrologists report that patients’ choice of treatment options should play an important role in the selection of RRT for ESRD. However, an incomplete presentation of treatment options is an important reason for under-utilization of home dialysis therapies and probably delays access to transplantation [24]. Improvement in ESRD education could provide timely access for potential ESRD patients to various RRT.

Decision-making for treatment option

Another study of Elizabeth (2011) showed that a rather complex treatment decision-making may be a four-phase process. In the initial phase, patients encounter disease related signs and symptoms [25]. During the second phase, patients may acquire more information and

knowledge of the disease. They will trust healthcare professionals during the third phase. Consequently, the patient decides on a treatment option.

In the process of treatment decision making, both medical and non-medical factors may affect the treatment modality selection. Lifestyle, personal experiences, financial issues, comorbid disease, healthcare professional referral, and the availability of treatment options each play an important role in decision-making [26].

To a certain extent, treatment decision-making is significantly related to the utilization of health services. A conceptual framework for examining healthcare utilization rates is provided by Andersen's behavioral model (1995) which composes three main categories of variables that seek to explain medical care utilization patterns [27].

Predisposing factors include sociodemographic characteristics, health beliefs and attitudes about illness. Health beliefs are expressed in terms of knowledge, value and attitudes that may impact the subsequent perception of demand and use of health services.

In addition, treatment decision making can be categorized as either patient and significant others' preference of treatment modality [28]. Older adults appear to have a greater interest in and concern for health, to have a greater tendency to adopt the sick role when ill, to be more skeptical about physicians, and to have more religious-oriented health beliefs [29]. Nine out of twelve informants in this study were Buddhist. They expressed the desire to let nature takes its course. They believed that health and death are determined by god.

All the informants made their own treatment decisions. which was difference from Beach, Duggan and Moore's study in which only 13% participants preferred to make all final decisions alone [30]. In this study all of them were aged with fruitful life experience and they could demonstrate their capability in decision-making for treatment.

Cancer patients' participation in their own treatment decision-making process is associated with improved health-related quality of life [31]. In the process of decision making, patients reported having ample treatment information, being very involved in their treatment decision making and having positive expectations about the treatment outcomes.

Association of individual health belief and health care utilization

There is an association of health belief and the utilization of healthcare services.

For instance, Informant 9 claimed that he could maintain his daily living with dietary limitations and drug compliance for the time being. He would not consider peritoneal dialysis unless his condition deteriorated and active medical management was deemed necessary.

Informant 11 had confidence in the efficacy of Chinese Medicine in managing his chronic illness with the substitution of 'che exercise'. However, he simultaneously adopted a routine schedule of laboratory screening tests for evaluating his clinical condition. In the course of disease development, health behavior may be affected by acquired health- related knowledge and education. The additional knowledge might influence the original treatment preference as well as expectations of treatment efficiency.

Chinese culture and religion-oriented perspectives

Cultural factors strongly influence patients' reactions to serious illness and decisions about end-of-life care [32].

Behavior, one psychosocial factor, contributes to improving or compromising health. It develops under the influence of characteristic traits and family norms. On the other hand, behavior can be altered by the factors of personal experience, environment, medication and religious directives. In Chinese, the most senior will bear the image of being a master/mistress of the family, being respected by the younger generation. The informants in this study were aged with fruitful experience in the society. Consequently, they played an active role in treatment decision-making with ease.

Taoism teaching emphasizes that ‘people cannot fight against nature’. We can only respect the power of nature and accept what comes our way, while Confucian and Buddhist teachings also promote the need to remain calm and self-restrained and to exhibit little emotion even in crisis or traumatic situations [33]. Informant 5 emphasized she expected to receive the therapy without disturbing her current style of daily living. She prepared to die peacefully with no regrets.

Patients who played an active role in decision making were more satisfied with their treatment choices than other patients. They might benefit in identifying their preferences for participation in decisions and tailoring the decision-making process [34].-

Religion beliefs and rehabilitation

Specific facets of religious and spiritual belief systems do play direct and specific roles in predicting rehabilitation outcomes. Furthermore, the influence of religion and spirituality on rehabilitation outcomes is partly due to its indirect effects on social support and coping. The study by CDC showed that older people who are religious tend to enjoy better physical and mental health than older individuals who are not involved in religion [35]. Church-based support is defined as spiritual, tangible and informational support that is exchanged among people who worship together [36].

Religion and spirituality

Most physicians believe that religion and spirituality often help patients to cope, gives them a positive state of mind and provides emotional and practical support via the religious community [32]. Similarly, religion and spirituality involvement is associated with improved quality of life and reduction in anxiety, depression, and substance abuse [37].

Health related information and education

Education of patients early in the course of chronic kidney disease offers many potential benefits for patients and healthcare professionals, including improved treatment outcomes, reduced anxiety, greater prospects for continued employment, improved timing for the start of dialysis, and a greater opportunity for intervention to delay disease progression [38], for instance, active patient education of erythropoietin injection with improvement of patient compliance may maximize the success of treatment.

Awareness of the factors associated with decision making in the treatment of chronic kidney disease can provide health professionals with evidence on how best to deliver education programs for patients and their families; it may also enhance communication and improve the capacity for patient and family involvement in shared decision making.

By respecting the patient’s values, spirituality and relationship dynamics, the healthcare professional can elicit and follow cultural preferences [39].

Enabling variables: Enabling variables include factors that might facilitate the use of services by individuals with a predisposition for utilization. Another equally important consideration is the distinction between physician-initiated and patient-initiated utilization. The patient-physician relationship is part of the critical underpinning of stable societies. Informants put their relationships with their doctors as second only to that with their family members [40].

Enabling variables also include healthcare system characteristics that may influence the accessibility and acceptability of services. These system characteristics may have a significant effect on the utilization patterns of younger and older patients. Limited options of choice are indicated under several clinical conditions. For example, patients are advised to have HD because of their contraindications like bowel disease, colostomies, repeated abdominal surgeries. Whereas patients are encouraged to consider PD because of difficulties of establishing native vascular access, allergy response to anticoagulant, severe cardiac manifestation and unstable myocardial condition. These are all considered better PD candidates.

Medical need factors including indicators of health status, perceived medical need and health status. Taylor (1983) describes a theory of cognitive adaptation to explain an individual's adjustment to threatening events in order to return to his or her previous psychological functioning [41]. Adaptation includes a search for meaning, efforts to gain mastery of the situation and self-enhancement by perceiving personal benefit from the situation. It is also common for the patients to experience cognitive distortions, negative automatic thoughts and idiosyncratic illness.

In the process of management of end-stage renal disease, adjustment is a process that is likely to start at the time of diagnosis and gradually resolve in the pattern of a grief reaction. However, the disease process with its inevitable and advanced complications and clinical interventions with their own benefits and side effects is likely to drive a process of intermittent or continuous adjustment.

The idea of capitalizing on suffering and pain in life as an opportunity for psychological and spiritual growth is commonly held among Chinese people [42]. During the stage of adaptation, they will try to attain related knowledge and get alternate benefits of solving the symptoms.

Not wishing to be a burden to their family

Patients described how busy their children and grandchildren were. Patients withdrawing from treatment lived alone and relied on their children for help with their home duties, daily living needs and dialysis therapy. The dialysis patient felt that they had been such a burden to their children for help with their home duties, daily living needs and dialysis therapy [43].

In addition, one's age was a significant factor that could impact their decisions. Ashby's study (2005) found that 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 [43]. They considered that they would not cope well on dialysis because of their age and their limited physical capacity.

Kidney dialysis may not prolong the life expectancy of patients over 75 years old with multiple comorbidities [44]. There is no definite evidence of dialysis life expectancy for reference. This group of patients were all, except one, over 73 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.

Outcomes for people with ESRD are dependent on meaningful engagement with patients, family members, carers and high quality preparation for the chosen modality of renal replacement therapy or conservative kidney care. That needs a committed, skilled and adequately resourced multi-professional team working with "activated" patients.

Rehabilitation and quality of life

The aims of rehabilitation include improvement of physical functioning and quality of life. The latter includes physical, psychological and social functioning (including work), as well as sense of well-being and satisfaction with life [45].

The functional status of ESRD remained stable during the last year of life but declined steeply in the last three months of life [46]. This has important clinical implications in that the steep functional decline indicates that healthcare services need to rapidly respond to changing needs in this population.

Further elaboration of this theme from the informants was carried out when they were asked to describe what and how to facilitate their treatment decision-making. No informant in this study preferred to delegate the responsibility to the physician. Treatment preferences and satisfaction with information provided by healthcare professional were also explored.

First, the majority of patients had a history of hypertension, gout, dyslipidaemia and diabetic mellitus. All of them expressed their fear of pain and suffering from severe symptoms of renal failure. Chronic renal failure and dialysis have a very significant effect on the cardio-

vascular system, causing multiple abnormalities. Patients undergoing regular dialysis have a cardiovascular mortality rate approximately three times higher than that of those without uremia. The increased mortality is associated with increased atherosclerotic heart disease and myocardial infarction, left-ventricular hypertrophy and congestive cardiac failure. Metabolic bone and joint disease is also common among dialysis patients [47].

Second, some of the patient experienced uncertainty and lack of support from healthcare professionals. In the treatment selection process, factors affecting patient selection were presence or absence of basic resources such as quality and timing of information, prior placement of dialysis access, social support and family support systems [48]. Nurses can support the modality selection process by identifying and reducing threats and by enhancing or altering basic resources.

Third, many patient found the doctor's treatment recommendations such as palliative care to be the most influential factor in treatment decision-making. In addition, family members were regarded as the most reliable and trustworthy persons for discussion and sharing of ideas prior to any treatment decision-making.

Family appears to play an important role in treatment decision-making among elder patients [49]. This family influence appears to contribute to (racial or ethnic group differences) in treatment received. Hence, healthcare professional should empower and acknowledge family members as potential key participants in treatment decision-making.

During the process of rehabilitation, however, some patients find it necessary to seek medical advice for different levels of psychological stress originating from the course of long-term treatment or the disease pattern of ESRD [50].

Symptom management, decision making, proactive plan of care

Palliative care services should be provided according to the needs of patients and carers. Yet this requires a holistic assessment, followed by interventions and well planned care. People prefer to be free from symptoms, feel secure and supported, with good information and proactive care planning. All these aspect of care are connected to deeper levels of the dying process such as loving relationships, retaining dignity, self- worth, and spiritual peace.

Implications of the Study

Some of the informants had knowledge deficits and difficulty in understanding the health-related information provided. In light of these findings, healthcare professionals should know how to plan interventions as well as facilitate patient empowerment. Outcomes for people with ESRD are dependent on meaningful engagement with patients, family members, caregivers and high quality preparation for the chosen modality of renal replacement therapy or conservative kidney care. The preferred patient service needs a committed, skilled and adequately resourced multi-professional team acting with patients and families.

The results of this study provide valuable input in developing palliative care for ESRF patients. The study also enhances communication between healthcare professionals and patients or relatives, as well as improving the patients' capacity for involvement in shared decision making during the care planning.

Limitations of the Study

- Elderly informants may experience difficulty in expressing their lived experience of treatment decision making with rich and in-depth data.
- In addition, the frail condition and fatigability of informants in palliative (non-dialysis) care may make them physically intolerant to long interviews and unable to provide comprehensive data.

- In the application of descriptive phenomenology, the process of establishing meaning units has a degree of subjectivity which is correlated with the attitudes of the researcher who had been working in the renal specialty for a very long period and processes relative knowledge of the phenomenon under investigation.
- All informants are ESRD patients who had chosen palliative care, which limit the generalization of findings to other settings.
- In addition, there is difficulty in translation from Cantonese into English with appropriate linguistic meaning. There is a possibility of alteration of the essence through the conversion process from one language to another.

Conclusion

In the absence of absolute clinical contra-indications, the treatment of choice should be the modality that best accommodates the patients' preferences for their daily activities and lifestyle. They view flexibility, independence and feelings of security as key factors in determining choice of modality, with maintenance of a normal life without limitations of physical function being a major goal.

Awareness of the factors associated with decision making in the treatment of chronic kidney disease can provide health professionals with evidence on how best to deliver educational programs for patients and their families; it may also enhance communication and improve the capacity for patient and family involvement in shared decision-making.

Acknowledgements

The research team would like to thank all the participants for sharing their lived experiences of decision making for treatment of ESRD.

Conflict of Interest

The authors declared no conflicts of interest.

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Volume 1 Issue 3 December 2019

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