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# Patients' perspectives of home and self-assist haemodialysis and factors influencing dialysis choices in Singapore



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# **Abstract**

**Background:** The rise in end stage kidney disease (ESKD) prevalence globally calls for a need to deliver quality and cost-effective dialysis. While most are familiar with centre-based haemodialysis (HD), there is a move to increase uptake of home-based modalities (peritoneal dialysis (PD) or home haemodialysis (HHD)) and self-assist haemodialysis (SAHD) due to the economic, clinical and lifestyle advantages they confer. However, HHD and SAHD are not yet widely adopted in Singapore with majority of patients receiving in-centre HD. Although much research has examined patient decision-making around dialysis modality selection, there is limited literature evaluating patient's perspectives of HHD and SAHD in Asia where the prevalence of these alternative modalities remained low. With this background, we aimed to evaluate patient's perspectives of HHD and SAHD and the factors influencing their choice of dialysis modality in Singapore to determine the challenges and facilitators to establishing these modalities locally.

**Methods:** Semi-structured interviews were conducted with 17 patients on dialysis from a tertiary hospital in Singapore in this exploratory qualitative study. Data collected from one-to-one interviews were analysed via thematic content analysis and reported via an interpretative approach.

**Results:** The findings were segregated into: (1) factors influencing choices of dialysis modality; (2) perspectives of HHD; and (3) perspectives of SAHD. Modality choices were affected by environmental, personal, social, financial, information and family-related factors. Most perceived HHD as providing greater autonomy, convenience and flexibility while SAHD was perceived as a safer option than HHD. For both modalities, patients were concerned about self-care and burdening their family.

**Conclusions:** The findings provided a framework for healthcare providers to understand the determinants affecting patients' dialysis modality decisions and uncovered the facilitators and challenges to be addressed to establish HHD and SAHD modalities in Singapore.

**Keywords:** Dialysis modality, End stage kidney disease, Haemodialysis, Home haemodialysis, Self-assist haemodialysis

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#### Introduction

There is a rising prevalence of end stage kidney disease (ESKD) globally with about 2.6 million people on dialysis worldwide and numbers are expected to double by 2030 [1, 2]. Dialysis contributes substantially to healthcare expenditure with high-income countries spending 2–3% of yearly healthcare budget on treatment provision [3, 4].

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Therefore, cost-effective options like home-based dialysis (including peritoneal dialysis (PD) and home haemodialysis (HHD)) should be considered.

HHD offers greater patient autonomy, economic benefits, treatment-related flexibility and has been associated with improved quality of life and survival [5-7]. Both home and self-care haemodialysis (HD) cost US \$42057 per year of therapy per patient which is less costly as compared to US \$51252 for in-centre HD [8]. HHD also allows frequent dialysis which is more physiological and is associated with improved clinical parameters [9]. Despite its advantages, global uptake of HHD remains low due to concerns of housing constraints, social isolation, apprehension of self-care and family burden [10, 11]. In developed nations in Asia, prevalence of HHD is much lower ranging from 0 to 0.41% as compared to 2.1% in the United Kingdom and 9.4% in Australia [12, 13]. Low utilisation of HHD is a lost opportunity to improve quality adjusted survival rates and decrease healthcare expenditures [14].

An alternative modality, self-assist haemodialysis (SAHD), requires patients to perform HD on their own (or with the help of caregivers) in the dialysis centre under the supervision of dialysis nurses. SAHD can potentially alleviate nursing manpower strain, improve patient ownership, hospitalisation and mortality rates [15]. Similar to HHD, SAHD programs are not yet widely established in Asia.

Although much research has examined patients' decision-making around dialysis modality selection, there is limited literature evaluating patient's perspectives of HHD and SAHD in Asia where the prevalence of these alternative modalities remained low. Singapore has one of the highest rates of ESKD worldwide, ranking first globally for diabetic kidney disease related ESKD [16]. It also ranks third in the world for population density with 8358 people per km<sup>2</sup> after Monaco and Macau [17, 18]. With the competing requirements for land resources in a limited land area of approximately 700 km<sup>2</sup>, promoting home-based dialysis will alleviate the strain on dialysis facilities and provide a more sustainable dialysis care delivery system in Singapore [17, 19]. Consequently, the government has adopted a PD preferred approach to reduce the demand for manpower and infrastructure for dialysis treatment. However, majority of patients continue to receive in-centre HD treatment and home dialysis continues to be underutilised with only about 13% of prevalent patients on PD and almost none on HHD [20]. There is also no established SAHD program locally.

In Singapore, a family-centred model of decisionmaking is adopted as in other Asian societies with both patient and family arriving at a mutually agreed treatment plan after receiving information despite the patient being competent [21]. An emphasis on individual and family responsibility frames the policy structures in Singapore with national healthcare saving schemes like MediSave which mandates citizens to set aside a portion of their income to pay for their own or immediate family members' medical expenses [22, 23]. In addition, policies dictating eligibility for medical subsidy for dialysis takes into account immediate family income besides individual income, reinforcing the family-led decision practice. With this background, we aimed to evaluate patient's perspectives of HHD and SAHD and the factors influencing their choice of dialysis modality in Singapore to determine the challenges and facilitators to establishing these modalities locally.

# **Material and methods**

#### Design

A qualitative methodology was adopted to allow in-depth exploration of individual experiences and perspectives. Semi-structured interviews comprising of open-ended questions were conducted to allow participants to freely discuss issues uniquely important to them while allowing comparable results to be generated for analysis (See Additional file 1 for Topic Guide for Interview).

#### Sample

Patients receiving HD or PD were recruited from Singapore General Hospital, a tertiary hospital in Singapore. Patients were excluded if they were below 21 or above 80 years old, have cognitive impairment, unstable medical conditions precluding them from participating in anhour long interview or were unable to provide informed consent. Purposive sampling method was used to provide a broadly representative sample of patients with respect to gender, dialysis modality and ethnicity. Patients were first approached by physicians during consults or via phone calls. Those who agreed to participate in the study were then contacted via phone by the interviewer.

Among 23 prospective participants, six were excluded (one declined participation, three were uncontactable and two did not meet the inclusion criteria due to unstable medical condition as one had an urgent operation scheduled during the interview period while the other was not well enough to participate in an hour-long interview). In total, 17 participants were recruited.

# **Data collection**

All patients were provided written information about the study and were informed verbally of the purpose of the research by the interviewer. Written informed consent was obtained before the interview. The interviewer was a bilingual public health student with relevant knowledge of HD and previous experience of conducting interviews

with members of the public. Majority of the interviews took place in the hospital and were mostly conducted in English between March to May 2019 (three were conducted in Mandarin). The mean length of the interviews was 39 minutes (range 14–64 minutes). Interviews were audio-recorded with field memos made after each session. While most of the interviews were one-to-one, four were conducted in the presence of caregivers with minimal participation from them. All interview materials were stored securely to ensure data confidentiality.

#### Data analysis

Interviews were transcribed verbatim using broad playscript transcription conventions [24]. The interviews conducted in mandarin were also transcribed and translated by the interviewer. Transcripts were not sent to the participants for further checking and editing. As people's underlying epistemological assumptions are varied, an interpretative approach was used to report the study findings. The interviews were coded using QSR NVivo 12 software and were analysed inductively and deductively via thematic analysis to allow identification of patterns within and across data in relation to participants' experience and perspectives [25]. Throughout the analysis process, line-by-line coding was done for each interview transcript. The assigned codes were constantly compared with each other and similar codes were categorised together into sub-themes and finally into differing themes which became more evident with the analysis.

To strengthen the reliability of the findings, transcripts were also coded by a fellow public health student with experience in qualitative research and a high degree of agreement was attained. By the final interview, thematic saturation was achieved as no new themes were generated in relation to the study aims. In total, 3 study areas and 16 themes were generated from the analysis.

#### **Ethical considerations**

This study abided by the Declaration of Helsinki and was approved by SingHealth Centralised Institutional Review Board (2018/3157).

#### Results

The baseline characteristics of the participants are shown in Table 1. Majority are males, Chinese and receiving HD. In addition, most are married, unemployed and have secondary education and above.

The findings were segregated into three broad study areas (A) factors influencing choice of dialysis modality, (B) perception about HHD and (C) perception about SAHD. The sub-themes leading to the derivation of the different themes are shown in Table 2.

**Table 1** Baseline characteristics of study population

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Characteristics	n=17	
Age (years)	58 (33–74)	
Female sex	4 (23.5)	
Ethnicity		
Chinese	11 (64.7)	
Malay	5 (29.4)	
Indian	1 (5.9)	
Marital status		
Married	13 (76.5)	
Single	4 (23.5)	
Employment status (employed)	5 (29.4)	
Highest education level		
Nil	1 (5.9)	
Primary	1 (5.9)	
Secondary	7 (41.2)	
High school	5 (29.4)	
Graduate/postgraduate	3 (17.6)	
Dialysis modality and centre		
Haemodialysis	10 (58.9)	
Private centre	9 (52.9)	
VWO centre	1 (5.9)	
Peritoneal dialysis	7 (41.2)	
Dialysis vintage (years)	2.5 (3 months-9 years)	

The data are presented as the median (interquartile range) for age and dialysis vintage and the number of patients (%) for the other variables

VWO voluntary welfare organisation

These themes jointly addressed the factors that could affect patient's decision-making and provided an insight into their understanding of HHD and SAHD. Examples of quotes generated from the interviews are shown in Additional file 2. All quotes by patients are presented with the accompanying ID number, gender, approximate age and treatment type (HD/PD).

# (A) Factors influencing choice of dialysis modality Theme 1: environmental factor

Environment was an important consideration for those receiving home dialysis who were concerned about clean-liness to minimise risk of infections. The ability to upkeep hygiene standards and the availability of sufficient space to accommodate dialysis equipment and consumables were concerns commonly raised by patients. In addition, presence of a robust support system was also a determining factor:

"If there's assurance and they can tell me that I do (dialysis) at home and the support is there, then probably no harm in trying".

(P12, Female, 60s, PD)

Ang et al. Renal Replacement Therapy

**Table 2** Overview of study areas and themes

Study areas	Themes	Sub-themes
(A) Factors influencing choice of dialysis modality	1. Environmental factor	a. Availability and efficiency of support system
		b. Housing and storage space requirements
		c. Hygiene and cleanliness requirements
		d. Risk of undesirable medical outcomes
	2. Family-related factor	a. Burden to the family
		b. Competency of caregiver
		c. Involvement of caregiver
		d. Presence of caregiver
	3. Financial factor	a. Cost
		b. Insurance coverage
		c. Subsidies
	4. Information-related factor	a. Advice obtained
		b. Information gap
		c. Knowledge about modality
	5. Personal factor	a. Lack of decisional power
		b. Perceived convenience
		c. Personal belief and preference
		d. Self-efficacy
	6. Social factor	a. Social connections
(B) Perception about HHD	1. Comfort and convenience	b. Comfort at home
( ) · · · · · ·		c. Reduce travel time and cost
	2. Freedom and flexibility	a. Better time management
	,	b. Greater autonomy
		c. Liberation from strict dialysis schedule
		d. More frequent dialysis
	3. Compromised patient care	a. Inefficient or absence of help seeking platform
		b. Receiving lower standards of care
		c. Slow reaction or inability to react during emergencie
	4. Difficulties in self-management	a. Complexity of dialysis procedure
	3	b. Fearful of self-needling
		c. Low self-efficacy
		d. Physiological difficulties
	5. Housing space requirement	a. Space for storage
(C) Perception about SAHD	1. Less risky than home modalities	a. Presence of medical professionals
(1), 1. (2)	,	b. Improved knowledge
	2. Changes in resource utilisation	a. Reduced nursing manpower
	3. Apprehension about self-care	a. Low self-efficacy
		b. Fearful of self-needling
	4. Family and caregiver burden	a. Onerous responsibility imposed on caregivers
	, <u>.</u>	b. Perceived redundancy of caregiver
		c. Wasting caregiver's time
	5. Time-related inflexibilities	a. Inflexible dialysis schedule
	2e reaced internation	b. Travel time required

# Theme 2: family-related factor

The burden imposed on family members and caregivers was a crucial factor for patients deciding between PD or HD:

"If can do (dialysis) myself would be the best, I will do for sure. But if need other people's help, I need to consider. [...] The biggest consideration is my family members".

(P10, Male, 50s, HD)

Besides, confidence in performing home dialysis was also affected by patients' perceptions of their caregivers' competency. Caregivers may be fearful of performing dialysis and were perceived as less competent than dialysis nurses by patients.

#### Theme 3: financial factor

As Singapore adopts a co-payment scheme for health-care financing, treatment cost for a lifelong treatment like dialysis, would be a major consideration when deciding between modalities. Consequently, individual's access to insurance coverage and financial subsidies plays an important role in decision-making:

"For the haemo(dialysis) I know that it's about \$1,500 more, but at that time [...], I know I can claim from the company insurance. But now that I'm not working, let's say you ask me to do a choice again, I may consider water (referring to PD)". (P2, Female, 50s, HD)

#### Theme 4: information-related factor

In addition, information obtained by patients helped to guide their decision-making. Though patients value nephrologists' advice, some physicians were viewed as preferentially promoting PD. Patients also sought their family's opinion and are interested to hear the experiences of fellow patients with ESKD. While self-reading and observing fellow patients were alternatives of gathering information, some patients reported that information and guidance provided were lacking, resulting in reliance on preconceptions rather than facts to aid decision-making:

"Frankly I think when we are being put in dialysis ah, the explanation is not there, we actually learn through the day to day and the hard way". (P12, Female, 60s, PD)

Education level was also perceived to affect the understanding of treatment options.

#### Theme 5: personal factor

Inevitably, personal priorities in life, beliefs and preferences will shape patient's decision-making process. The necessity to have medical professionals present during dialysis, ability to have more family time, and aesthetic concerns of unsightly arteriovenous fistulas on arms were cited considerations by patients. Freedom and ability to avoid restrictive dialysis schedules were also desired:

"All I know is that [...] because of my lifestyle, I wanted to move around, I wanted to be free, I don't

want to be shackled to a machine". (P17, Male, 40s, PD)

Convenience is also important with most considering travelling time to dialysis centres, treatment duration and ease of self-management when choosing dialysis modality. Interestingly, some patients perceived that they had no choice and lacked decisional power, deferring to physician's recommendations for their decision.

#### Theme 6: social factor

The presence of social interaction also affected patients' decision-making as the social connection provided by the healthcare team and fellow patients during dialysis helped to place patients at ease:

"How they portrayed themselves, not as a nurse, but as a friend. [...] It's the bond". (P3, Female, 30s, HD)

#### (B) Perception about HHD

#### Theme 1: comfort and convenience

HHD was viewed as a modality that can confer comfort and convenience as dialysis is performed in a familiar environment. Besides, HHD also saves travelling time and minimises expenditure:

"Yeah I will definitely want that because it saves my time going to the dialysis centre. [...] I save on my lunch outside [...] at home I don't have to have extra expenses".

(P9, Male, 60s, HD)

# Theme 2: freedom and flexibility

Patients also perceived HHD as providing more flexibility, greater autonomy, and lesser disruption to work and daily schedules, allowing improved time management:

"Actually, to be able to do (dialysis) at home is better la. I can do it anytime and no need to wait for Mon, Wed, Fri or Tues, Thurs, Sat schedules". (P11, Male, 40s, HD)

In addition, they are attracted to the option of frequent dialysis with HHD allowing them to perform additional sessions if they should feel unwell.

# Theme 3: compromised patient care

Conversely, opponents of HHD were concerned about substandard care with the absence of medical professionals during dialysis as they fear that help may not be readily available if support platforms are lacking. Patients are also concerned about caregivers' lack of medical expertise and their inability to handle emergencies:

"The nurses themselves sometimes may not be able to needle you, you know. [...] What else to say just a domestic helper? Or your family member"? (P14, Female, 50s, HD)

#### Theme 4: difficulties in self-management

Similarly, apprehension of performing dialysis due to the procedure's complexity was an added barrier to HHD. Patients lack confidence to gain the appropriate skills for self-management and the idea of self-cannulation was also daunting to some:

"You have to needle yourself, will be scared.. one has to have the courage to do so". (P11, Male, 40s, HD)

Furthermore, physiological limitations due to comorbidities, ageing and cognitive impairment will also deter self-management.

# Theme 5: housing space requirement

Finally, lack of housing space to accommodate the machine and dialysate solutions also makes HHD less favourable:

"I can't imagine la, at home. You got to stock your everything [...] (in) the house [...]". (P4, Male, 70s, HD)

# (C) Perception about SAHD

#### Theme 1: less risky than home modalities

SAHD on the other hand is perceived as a safer treatment than home modalities as patients feel more reassured with the presence of nurses during treatment:

"Because the professionals are there. [...] A bit safer, a bit at ease. [...] If (something) goes wrong, there are professional help there".
(P3, Female, 30s, HD)

In addition, the training required for this modality provides learning opportunities for patients, allowing them to be more involved in their treatment.

# Theme 2: changes in resource utilisation

However, as SAHD involves a reduction in nursing manpower with the focus on self-management, patients perceived this as a compromise in care:

"If too many patients, then (nurses) rush here and there, our care is also compromised". (P10, Male, 50s, HD)

#### Theme 3: apprehension about self-care

Similar to the perceived difficulties of self-management in HHD, patients also lack confidence in performing dialysis independently despite nursing supervision in the dialysis centre. Most were deterred by the procedure's complexity and the fear of self-cannulation.

# Theme 4: family and caregiver burden

With SAHD, patients who are less independent would require their family to assist them with treatment. Patients perceived this as increasing their carer's burden and they also queried the need for their caregivers' presence when there are nurses in the centre:

"In that case, 2 persons are wasting their time. I, as a patient and why have I got to bring a caregiver down there and then the nurses help you"? (P9, Male, 60s, HD)

#### Theme 5: time-related inflexibilities

As SAHD is performed in a dialysis centre, it is less accommodating as patients would need to adhere to fixed slots unlike HHD. In addition, the need for travelling to the centre also makes SAHD a less favourable option.

# Comparison of preference between HHD and SAHD

Comparing the two modalities, patients who favoured HHD value convenience, comfort of performing dialysis at home and flexibility in planning their schedules. Conversely, patients who preferred SAHD were concerned about home hygiene and are reassured by the presence of medical professionals during treatment. Overall, most patients still prefer their current dialysis modality and hold reservations to converting to new modalities.

#### **Discussion**

Our study findings reveal that environmental, family, financial, personal, social and information-related factors influence patient's decision for dialysis modality. These findings corroborate the results of previous studies which demonstrated patient's personal preferences including preferred lifestyle, beliefs and knowledge of the modalities as pivotal in their decision-making, with a preference for minimal intrusiveness to maintain "normal" life routines [26–28]. Harwood et al. similarly reported that family and extent of caregivers' involvement are considerations in the decision-making for dialysis modality with patients being mindful of how their decision would affect their family as well as the level of support they require [28]. Presence of a

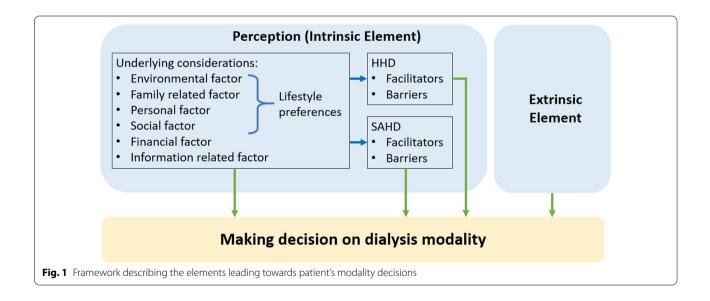
suitable home environment, availability of support systems or infrastructures and presence of social interaction have also been reported to influence decision for home dialysis [29]. Conversely, financial-related factor is not consistently reported in previous studies likely related to differences in healthcare financing in various countries. These findings reinforce the complex interplay of factors influencing dialysis selection involving multiple parties (patients, families, and healthcare professionals), socio-economic structures, and patients' preferences [30]. They also highlight the importance of considering the Asian family and patient as a unit in the decision-making process which is complex, requiring continuous patient engagement in addition to providing information and understanding patients' perceptions [30]. Though the process could be a family affair, the patient ultimately has autonomy in decision-making.

Patients perceived HHD as conferring greater autonomy, freedom and flexibility with minimal disruption to daily routines hence allowing continuation of employment. Being able to perform dialysis in the comfort of their homes and the convenience it confers serve as pull factors. However, patients were apprehensive of self-management and were fearful of self-cannulation. Due to the absence of medical professionals at home, care was perceived as sub-optimal with increased risk of infections. In addition, the lack of immediate medical support should "emergencies" or catastrophic events occur also add to their apprehension. Burden on caregivers and the availability of a support network to render timely assistance were also cited concerns. Published literature demonstrated similar findings of patients' perceptions towards HHD. Freedom, flexibility and greater self-control were commonly stated advantages [10, 31]. Conversely, social isolation, low self-efficacy with lack of familiarity, fear of needling, disrupted sense of normality and perceived complexity of HHD were push factors [31–33].

From patients' perspective, the greatest advantage of SAHD versus HHD was the reassurance provided by medical professionals' presence in the centre though concerns such as increased family caregiver burden, difficulties with self-management and additional time and cost incurred from travelling to dialysis centres were also highlighted. A New Zealand study reported that most patients will choose centre-based HD by default as it is the most promoted and recognised dialysis modality to date [34]. Besides, patients' perceived inability to make decisions could also result in them opting for the more common dialysis modality. Hence, SAHD is likely to appeal to patients as it is performed in-centre in the presence of dialysis nurses.

The 3 broad study areas can be fitted into a framework with factors influencing dialysis modality choices forming the underlying considerations which shape patient's perceptions and understanding of HHD and SAHD, affecting their eventual modality choices (Fig. 1). External factors such as reimbursement system, available infrastructures and government schemes though not within the scope of our study, are essential factors that would affect patients' choice in a co-payment healthcare system in Singapore.

Considering the factors that influence patient's choice of dialysis modality, we highlight the challenges and facilitators of establishing HHD and SAHD program in Singapore as shown in Table 3. Environmental factor plays an important role in HHD. Patients from countries with higher uptake of HHD appear to raise more



**Table 3** Challenges and facilitators of establishing HHD and SAHD in Singapore

Factors influencing dialysis modality decision	HHD	SAHD
Environment		
Challenges	Home modification requiring approval from relevant authorities Need for a clean home environment and space to store dialysis supplies Presence of adequate medical and technical support systems	
Facilitators		Performed in-centre hence need for home modifications and space constraints will not be a concern
Financial		
Challenges	Funding mechanism not explicit as program is not com- monly offered and adopted locally Additional cost from power and water usage as well as home modifications Cost of training program	Cost of training program
Facilitators		Available funding mechanism which is similar to conventional HD as treatment is performed in-centre
Family		
Challenges	Increased family caregiver burden for patients who are less independent Concerns about caregiver's competency to perform dialysis	
Facilitators		
Personal		
Challenges	Difficulties and apprehension of self-care Concerns of sub-optimal care and increased risk of infec- tions	Difficulties and apprehension of self-care Concerns of sub-optimal care with reduction in manpower in-centre Need for travelling to dialysis centre Fixed time slots
Facilitators	Greater autonomy, freedom and flexibility Minimal disruption to daily routines Comfort and convenience Option of having more frequent dialysis	Assurance provided by presence of medical staff during dialysis sessions Increased involvement in care
Social		
Challenges	Social isolation	
Facilitators		Social interactions maintained as dialysis is performed incentre
Information		
Challenges	Patients' knowledge gap of HHD and SAHD Delivery of information on dialysis modalities at an appropriate timing that is tailored to patients' needs	
Facilitators	Patients value family, nephrologist and fellow patients' opinions	

HHD home haemodialysis, SAHD self-assist haemodialysis, HD haemodialysis

concerns regarding practical and technical aspects of HHD such as insufficient space to store equipment and supplies, need for home modifications e.g. plumbing and electricity and quality of water supply [34–36]. Home modifications can be challenging especially if patients are tenants as this can lead to rent increase or eviction [37]. Interestingly, no patients raised concerns about home modifications required for HHD in our study apart from space concerns, highlighting the knowledge gap. In Singapore, majority of residents live in public housing, which are high-rise apartments due to land scarcity and

home modifications will require approval from relevant authorities which will be a barrier for HHD. Establishing a HHD program locally will therefore require changes in housing policies to facilitate infrastructure set-up. SAHD on the other hand is performed in-centre and will not require home modifications. As highlighted in the study findings, presence of a robust technical and medical support system is a pull factor for patients opting for home dialysis and will help to increase acceptance and confidence of HHD locally. Access to on-call nurses, close supervision with remote monitoring and increased home

visiting during commencement phase of HHD can help patients overcome their apprehension [34]. Similarly, having a structured training program that is individualised to patient's learning style and preferred pace will help empower patients for HHD and SAHD [38].

Finances are an essential consideration for dialysis modality selection in the setting of co-payment healthcare financing in Singapore. Locally, HD treatment in private centres cost approximately \$2500 (USD\$1792) per month while PD treatment cost ranges from \$1100 (USD\$790) to \$1800(USD\$1295) monthly [19]. Sources of funding for in-centre HD and PD treatment in Singapore include healthcare saving schemes e.g. MediSave, MediShield Life schemes and private health insurances. MediShield Life is a mandatory medical insurance scheme for all Singapore citizens and Permanent Residents and can be utilised to assist in payment for expenses incurred from hospitalisations and government approved outpatient dialysis treatments [39]. Patients can withdraw up to \$450 (USD \$323) per month for dialysis treatments from their MediSave accounts [40]. They can also claim up to \$1000 (USD \$717) per month for dialysis treatments from MediShield Life [39]. For financially needy patients, funding can also be obtained from voluntary welfare organisations (VWOs) subjected to financial assessments by the organisations. In addition, the Ministry of Health (MOH) also provides subsidies for dialysis treatment according to household means testing with a slightly higher subsidy available for PD treatment [41]. The remainder of payment after exhausting the above funding sources will be out-of-pocket. The funding mechanisms will be similar for SAHD which is performed in-centre. However, as HHD is not a commonly offered and adopted modality in Singapore currently, the means of financing is not explicit. In addition, patients on HHD will not be eligible for VWO funding as well as MOH subsidies which only cater to patients receiving incentre HD and PD.

Additional out-of-pocket costs are pertinent when considering home dialysis. Though delivery of dialysate for home dialysis is provided by the vendors monthly in Singapore, the cost of delivery is already included in the packaged price and patients are required to pay for any additional delivery required in the month. Patients should also be informed about hidden costs from increased power and water usage in HHD in addition to cost incurred from home modifications as they perceived lack of transparency as a breach of trust [37]. Therefore, clear and standardised information should be delivered to patients during dialysis modality discussions [37]. Provision of reimbursement programs to assist patients with set-up costs for home dialysis can aid uptake of these modalities and current available

funding mechanisms will need to be revised to incentivise patients to adopt HHD. Assistance provided to access these financial support systems and navigate the social support systems will help reduce the economic barrier for home dialysis uptake. The United States Centres for Medicare and Medicaid Services bundled payment system is a successful example of how incentivisation of home dialysis can help increase uptake by 10-20% [37].

With the emphasis on a family-centred model of decision-making in Asian societies, the burden on family members is a major consideration for patients in their dialysis modality selection. Consequently, to encourage patients who are less independent to consider HHD or SAHD, it is important to address caregivers' emotional needs to alleviate concerns for patients and family [38]. Interventions to render caregiver support and provide information about potential challenges can assist caregivers in making informed choices and pre-empt problems [38]. Alternatively, as HHD and SAHD involves self-care, patients who are independent and value autonomy and flexibility can be preferentially encouraged to consider these modalities with the assurance of the option of switching to in-centre HD when they are less physically able to self-care, hence reducing the burden on family members. Concerns of caregiver's competency to perform dialysis can be addressed with structured training programs for caregivers to increase patient's confidence.

Patients' lifestyle, preferences and priorities influences their decision for dialysis modality. A systematic review revealed that lifestyle and psychosocial preferences often triumph medical and at times financial considerations in patient's decision-making process [42]. A modality that minimises disruption to patient's lifestyle will increase treatment satisfaction and adherence which will help improve overall patient outcomes and quality of life. Consequently, to those patients who value flexibility, freedom and convenience, home dialysis including HHD should be encouraged. Flexible timings for dialysis can also be offered in SAHD programs to help promote this modality. Though dialysis centres will need to increase capacity to accommodate patients on SAHD with flexible dialysis timings in addition to catering to routine in-centre HD patients with fixed time slots, nursing manpower shortages can be alleviated in the long run should the number of patients on self-care increase. To maximise resource utilisation, Diapriva Amsterdam dialysis centre, for instance, combines nocturnal HD program resources with their SAHD program with patients on self-care dialysing in the day at flexible timings. Having the option of more frequent dialysis with SAHD can also motivate patients to opt for this modality since this was a cited pull factor for HHD in our study.

Psycho-emotional barriers such as difficulties and apprehension with self-management which are common themes that surfaced when patients shared their perspective of HHD and SAHD, will need to be overcome to increase acceptance of these modalities locally. It is therefore not surprising that most patients are keen to continue their current dialysis modalities and hold reservations to switching modalities. The notion of self-care is yet to be widely adopted in Singapore. A combined effort by physicians, nurses and allied healthcare workers is required to help motivate and encourage patients to take more ownership of their health and participate in their care locally. For a start, patients can be encouraged to engage in various degrees of partial self-care depending on their comfort level and abilities to promote the concept of "do-what-you-can". A new dialysis centre launched in Dec 2021 in Singapore has started a self-care initiative whereby more active and mobile patients will monitor their blood pressure and blood sugar levels, and learn proper handwashing steps before preparing and laying out the supplies required for dialysis.

To empower patients, training for SAHD could similarly be conducted in incremental stages (e.g. beginner, intermediate, advanced) based on patients' competency levels. In Texas, the "empowered independent dialysis" program allows patients to be involved in simple tasks such as recording of vital signs or putting aside needles and supplies at the beginner level [43]. When patients feel more confident, they could then proceed to the intermediate level such as priming the machine and eventually towards the advanced level of self-cannulation. This is a potential strategy to guide patients systematically, empowering them through building confidence in self-care. In addition, nominating patient champions to encourage peer learning can also help to promote the uptake of SAHD.

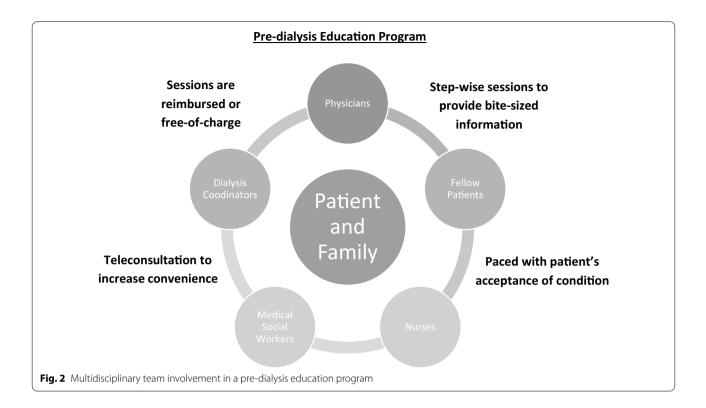
Besides personal factors, patients value social interactions when considering dialysis modalities. As SAHD is performed in-centre, patients will have opportunities to interact with fellow patients and healthcare workers during their dialysis sessions. Social isolation on the other hand is a commonly cited deterrent to HHD as patients missed the companionship and support from fellow patients [29]. However, Agar et al. reported that patients do adjust on home dialysis and rarely return back to incentre dialysis due to loss of relationships [44]. Organising group activities for patients on HHD to share their experiences and interact with fellow patients can also be considered to reduce social isolation.

Availability and the delivery of information regarding dialysis modalities influences patient's eventual decision for dialysis modality. Though most patients are resourceful in gathering information, a significant

number relied on advice provided by nephrologists, family and fellow patients with ESKD. This was consistent with findings from Griva et al., a local study exploring patients' perspectives on dialysis modality decision-making, which also identified a significant knowledge gap among patients [30]. Interestingly, a minority of patients felt that information and guidance provided were lacking with a few stating that they were not provided options. The latter was reported by Dahlerus et al., a cross-sectional study examining factors that affect 180 patients' decision in choosing dialysis modality, demonstrating the asymmetrical relationship with their physicians [26]. Similarly, a local paper exploring perspectives on decision-making amongst elderly with ESKD also highlighted that patients felt that they were not in a position to question doctors' recommendations or negotiate care [45].

These studies highlighted that improved efforts are required to refine current educational and communication strategies to aid patients make informed modality choices including alternative modalities like HHD and SAHD. This is an important pillar to help establish HHD and SAHD programs locally. In our study, the knowledge gap is evident as no patients raised concerns about home modifications required, need for additional time for training or improved health outcomes as a pull factor for HHD. Patients' education is crucial as studies have demonstrated improved knowledge of dialysis modalities can help increase uptake of home-based modalities [28]. Emphasis on the advantages of home dialysis including survival benefits of HHD can help patients overcome their fears of the confronting nature of the treatment.

Consequently, a carefully timed and structured patientcentred pre-dialysis education program with increased involvement from nephrologists and fellow patients with ESKD in addition to medical social workers, nurses and dialysis coordinators can help to equip patients with the relevant knowledge (Fig. 2). In particular, the doctor's role in empowering patients in decision-making is crucial and studies have shown that treatment choices could be shaped by how doctors present the treatment options available [46, 47]. As patients value physicians' input, individual physicians' biases towards HHD due to limited exposure during medical training could affect patients' perceptions towards HHD [48]. HHD could be deliberately portrayed by physicians as a more "complex, harder to learn" option [34]. Hence, education to increase physicians' awareness and receptiveness towards HHD and SAHD can help increase acceptance of these modalities locally as their "recommendation" of the modality can help validate patients' decision [38]. By delivering information in a way that demonstrate their understanding of the patient in the context of their lives, physicians



can increase patient's trust in their recommendation for home dialysis as well [34].

In addition, efforts should be made to increase engagement of patients in the decision-making process to balance the patient-doctor relationship and to encourage patient's participation in self-care. Indeed, focusing on improving health literacy skills of patients via improved interpersonal and communication aspects of these healthcare encounters can potentially aid patients in their decision for dialysis modality. Goh et al. reported the association of severe treatmentrelated decisional conflict—a state associated with individuals changing their mind, regret, lack of knowledge and blame for bad outcomes, in pre-dialysis chronic kidney disease patients in Singapore and health literacy skills related to communication and engagement with healthcare providers [49, 50]. Consequently, a collaborative multi-disciplinary team and patient-centric approach is crucial to provide holistic support for decision-making and avoid pure physician-led paternalism or family-led determination [51]. Though Kidney Disease Outcomes Quality Initiative (KDOQI) recommend discussing renal replacement therapy options with patients at stage 4 chronic kidney disease for early planning, timing of the pre-dialysis program would need to be paced with patients' acceptance of their condition for sessions to be fruitful [52]. The program can be conducted step-wise to allow patients and families time to assimilate information and clarify their queries. Sessions could be held as teleconsultations for convenience to increase participation rates. As recommended by Griva et al., provision of reimbursements or free pre-dialysis education will also improve attendance rates since current sessions are charged [30].

Taking into account the factors influencing patients' decision for dialysis modality, we propose a 4-pronged approach to provide a comprehensive overview in the pre-dialysis program to deliver structured information to help patients individualise their decision-making: (1) Providing adequate information regarding modalities; (2) Financial counselling; (3) Exploring family and home set-up; 4) Elicit individual preferences and priorities (Fig. 3). The program should cater to patients' knowledge needs, address the requirements of each modality including HHD and SAHD, and also acknowledge individual's lifestyle, beliefs and preferences. Information provided should be tailored to patient's and family's education level and be conducted in their preferred language to ease understanding. Visual aids such as videos or hands on demonstration of the dialysis procedure can help improve patient's comprehension. For those who are literate, reading materials could be provided. The delivery of information in terms of timing, quantity and depth is crucial since most patients felt ill-equipped despite receiving information through pre-dialysis education [34].

# **Provision of Adequate** Financial Counselling Information Elicit Individual Explore Family and Home Set-up **Preferences and Priorities** Fig. 3 Four-pronged approach for pre-dialysis education program

As patients value the experiences of fellow patients, arranging interactive sessions with befriender groups will provide opportunities for peers to share their anecdotal experiences [49]. These sessions will be especially helpful for modalities like HHD and SAHD to help patients overcome their fears of self-care as fellow patients can provide information that are more personal e.g. impact of each modality on quality of life, lifestyle, family life, employment, activity levels, etc. Assurance from peers via interaction or video testimonials can also increase patient's confidence and help address practical queries [34]. Befriender groups can also provide emotional support during patients' treatment journey. A subsequent concluding session with their physicians whom most patients rely on for advice, can help clarify misconceptions and address inaccurate expectations to avoid

erroneous decisions and help avoid decisional conflict. In this study, some patients perceived physicians as promoting PD over their interests. This serves as a sobering reminder to the healthcare team of the importance of presenting a balanced view of the available treatment options available. Renal transplantation which offers patients the best outcome should however be highlighted as first-line treatment to eligible patients. Pressure to choose home dialysis when told that facility units were at full capacity was reported in a qualitative study exploring patient and caregiver perceptions on home dialysis [34]. While advocating home dialysis may be beneficial from the nation's perspective, information needs to be framed appropriately in a neutral manner with tactful communication to avoid being seen as coercive [53].

Given the impact of financial consideration on patient's decision for dialysis modality in Singapore, provision of comprehensive financial counselling can assist patients to understand their eligibility for subsidies, insurance coverage and treatment costs. In addition, understanding patient's social set-up, identification of a caregiver for dependent patients, as well as exploring home environment's suitability for home dialysis are crucial for the selection of a suitable dialysis modality. Finally, it is crucial to elicit patients' preferences and priorities which influences their decision for dialysis modality. The multidisciplinary team will therefore benefit from additional training in shared decision-making, bias awareness and communication skills to support patients in making decisions that are consistent with their values and preferences [28]. Readily eliciting patients' input and active listening in addition to decreasing didactic content can improve the quality of communications by healthcare providers and also foster and hone patients' communicative health literacy skills [50].

In Singapore, there are 120 community dialysis centres islandwide with approximately 1 centre per 5.8km<sup>2</sup>. With the readily available and accessible resources, most patients may opt for in-centre HD rather than homebased therapies to reduce burden of care. To ensure sustainability of dialysis delivery in Singapore, home-based modalities should be promoted. With the current local prevailing attitudes favouring dialysis in a facility as a safer option as well as the fact that self-care in haemodialysis is still in its infancy locally, introducing SAHD can be the initial step to gaining acceptance for HHD since the training that patients require is similar for both modalities. In all, development of patient-focused education programs and resources which highlight the pros and cons of different modalities, establishment of robust medical and technical support systems as well as alteration of policies to remove barriers in combination with good patient selection are crucial to effectively engage, empower and incentivise patients to consider home dialysis. These changes and implementations will take time and establishing a SAHD program locally will likely be a more achievable short-term goal.

This is the first qualitative study in Singapore exploring patients' perceptions towards HHD and SAHD to evaluate the feasibility of establishing these modalities locally. In addition, the study included participants from multiple ethnic backgrounds which provided diversity of the experiences and factors reported. The study population was predominantly male and Chinese which is reflective of the demographics of dialysis patients in Singapore [20]. However, the small sample size in this single-centre study and the possibility of selection bias as clinicians may select patients who

were more motivated to participate in healthcare-related studies, will limit generalisability of the findings. In addition, there are no available socioeconomic data of both HD and PD patients in Singapore though data published by a VWO locally which provides treatment for majority of HD patients did report unemployment in 76.2% of patients dialysing in their centres [54]. Hence with majority of interviewed patients being unemployed in the study, the views of the patients may not be representative. Finally, the differences in medical practice, financial reimbursement or healthcare funding systems related to ESKD, dialysis modality utilisation and service delivery models will also affect generalisability of the findings.

#### Conclusion

The study provided a framework for healthcare providers to understand the determinants affecting patients' dialysis modality decisions and also uncovered the facilitators and challenges to be addressed to establish HHD and SAHD modalities in Singapore. Improvement in health care services provision and alignment of policies are required to help establish HHD locally and introducing SAHD may be a more achievable short-term goal. Future quantitative studies to ascertain patients' acceptance in addition to qualitative studies evaluating healthcare providers' perceptions can provide a more holistic view on the feasibility of establishing HHD and SAHD as alternative dialysis modalities locally.

#### Abbreviations

ESKD: End stage kidney disease; HD: Haemodialysis; PD: Peritoneal dialysis; HHD: Home haemodialysis; SAHD: Self-assist haemodialysis; KDOQI: Kidney disease outcomes quality initiative; VWO: Voluntary welfare organisation; MOH: Ministry of Health.

#### Supplementary Information

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**Additional file 1.** Topic Guide for Interview: List of questions asked during the interview conducted with participants.

**Additional file 2.** Themes, Sub-Themes and Examples of Quotes: Examples of quotes from participants for the themes and sub-themes generated from the analysis.

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#### **Author contributions**

YTIA, SWSG, CHL and PL designed the study. YTIA collected, entered and analysed the data. SWSG, CHL, CCP, HLLC and PL contributed to data acquisition and interpretation. YTIA and PL drafted the manuscript. SWSG, CCP and HLLC reviewed the draft. All authors read and approved the final manuscript.

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#### Availability of data and materials

The datasets used and/or analysed in the current study are available from the corresponding author on reasonable request.

#### **Declarations**

#### Ethics approval and consent to participate

This study abided by the Declaration of Helsinki and was approved by Sing-Health Centralised Institutional Review Board (2018/3157). Informed consent was obtained from all individual participants.

#### Consent for publication

Not applicable.

#### Competing interests

The author(s) declare that they have no competing interests.

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