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# Medical and nursing interventions influence a caregiver's willingness to continue home hemodialysis: a multicenter cross-sectional survey

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## Abstract

**Background** In Japan, home hemodialysis (HHD) has several benefits, including a favorable prognosis, enhanced quality of life (QOL) of patients, and cost-effectiveness. However, the caregiver's burden in assisting patients on HHD is significant, which influences their decision to continue HHD. This study focused on the relationship between medical and nursing interventions, caregiver resolve to continue HHD, and caregiver quality of life, aiming to create support strategies for caregivers.

**Methods** A multicenter cross-sectional survey was conducted on caregivers of patients on HHD from 150 HHD facilities in Japan. The caregiver's intent to continue HHD was assessed using a four-tier response scale that evaluated aspects such as caregiver–healthcare provider meetings, caregiver breaks, treatment discussions, difficulty in HHD initiation, and post-initiation medical support. Caregiver QOL was evaluated using the Short-form Health Survey, eight domains (SF-8). Statistical analysis involved  $\chi$ -squared tests, independent *t*-tests, and propensity score matching.

**Results** The study achieved a caregiver participation rate of 55.6%. Results indicated that caregivers who were inclined to continue HHD were significantly more likely to receive respite outpatient dialysis and had a better understanding of HHD mechanics as explained by healthcare professionals; however, propensity score matching revealed limited generalizability. There was no significant difference in the SF-8 scores before and after propensity score matching among the groups.

**Conclusions** This study highlights that there are a small number of caregivers who have little motivation to continue HHD and emphasizes the crucial role of support from healthcare professionals. Comprehensive support, including respite dialysis and detailed HHD information, may affect HHD sustainability.

**Keywords** Home hemodialysis, Caregiver, Willingness to continue

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## Background

In Japan, the prevalence of patients on maintenance hemodialysis (HD) has increased to approximately 350,000, while that of patients on home hemodialysis (HHD) exceeds 740 [1]. HHD has several benefits, including a favorable prognosis, enhanced patient quality of life (QOL) [2, 3], and cost-effectiveness [4], as it mitigates the increasing costs of dialysis treatment. In Japan, HHD patients perform dialysis using the same machines and dialysis methods as center dialysis, and a caregiver is essential during HHD to ensure safety. Caregiver is someone who helps patient with things they cannot do during HHD, operates the equipment according to the patient's requests, and deals with problems that arise [5]. In Japan, caregivers are mainly family members, and caregivers, including non-medical professionals, must assist with dialysis. Hence, a caregiver's burden is one factor leading to patients withdrawing from HHD [6].

Support for caregivers and assessing their QOL are important, as they are integral to sustaining HHD. Even in countries such as Canada and the USA where caregivers are not obligated to perform HHD, healthcare institutions employ various measures to reduce caregiver stress [7, 8]. Previous studies have shown that lessening this strain correlates with a patient's QOL and support from health professionals and family [9]. The Japanese Association of Dialysis Physicians, which established the standard for HHD management in Japan, describes the requirement of support for caregivers during the induction phase of HHD [5]. However, the actual medical and nursing interventions for caregivers that facilitate HHD and the influence of QOL remain underinvestigated.

Addressing the burden on HHD caregivers and determining specific medical and nursing actions that influence their continuation with HHD and QOL are essential. A prior study revealed that HHD caregivers feel overwhelmed due to their involvement during treatment, their sense of duty, and their relationship with the patient [7]. Nevertheless, dedicated medical and nursing support for HHD is already being instituted in HHD facilities [10, 11], which might impact a caregiver's commitment to continuing HHD. Investigating the relationship between the medical and nursing support received by HHD caregivers and their dedication to continuing HHD in various centers would offer insights into the specialized care approaches that may reduce caregiver stress. This information could revolutionize the support system for HHD caregivers and potentially promote HHD in Japan, where caregivers are indispensable.

This research aimed to identify the relationship between medical and nursing interventions, caregivers' resolve to continue HHD, and their QOL in a multicenter cross-sectional survey.

## Participants

The study participants included caregivers of patients on HHD from 150 facilities, including 74 facilities published in the list of home hemodialysis facilities on the Japanese Society for Home Hemodialysis website, 56 facilities that are JSHHD members, and 20 facilities where HHD is implemented. Caregivers were eligible for study inclusion if they responded to the distributed survey. Nonresponsive participants were excluded.

## Methods

The total number of inquiries from each HHD supervisor was followed by mailing the corresponding paper surveys to the facilities. The surveys were given to patients on HHD and their caregivers, and the completed forms were mailed back to the researcher; this phase was conducted from 8 March–31 May 2022.

## Measurement

To evaluate a caregiver's intent to continue HHD, a four-tier response scale was used. Affirmative responses were grouped as "willing to continue HHD," whereas negative ones were categorized as "reluctant to continue HHD."

The questionnaires asked about scheduled meetings for caregivers and healthcare providers, periodic breaks for caregivers during in-center dialysis (respite dialysis), opportunities for caregivers to discuss their anticipations regarding future treatment with other patients on HHD or caregivers, perceived difficulty of introducing HHD training, and the perceived sufficiency of post-HHD initiation medical support. Additionally, prior information about HHD by healthcare providers and their perception of whether HHD-related instructions or explanations were provided throughout their knowledge. Knowledge consisted of HHD (three items), pretreatment preparation (two items), initiation (three items), ongoing treatment (five items), termination (four items), and others (five items).

Caregiver's QOL was determined using the Short-form Health Survey, eight domains (SF-8), which is a validated tool that was designed to assess the health-related QOL. The SF-8 comprises eight domains: physical functionality, physical role (constraints due to physiological well-being), bodily discomfort, general health perceptions, vitality (energy versus fatigue), societal interaction, emotional role (limitations due to emotional factors), and psychological well-being. Each domain of the SF-8 uses either a 5- or 6-point Likert scale. Response variations differ by domain and range from "constantly" to "never" or from "exceptional" to "suboptimal." Scoring involved established methodologies that produced

individual scores for each domain. Cumulatively, these scores describe the Physical Component Summary (PCS) and the Mental Component Summary (MCS).

### Statistical analysis

Missing information on the participant's characteristics was complemented using the IBM SPSS Missing Values option based on the missing-at-random assumption to minimize missing bias. To ensure internal validity, we created 20 assigned designs with missing values, combined the averaged values, and adjusted the standard error to reflect the inside and outside of the complement (Supplementary Material 1: Tables 1–3). The main outcome was determined by the  $\chi$ -squared test and the independent *t*.

Propensity score matching was used to identify the “willing to continue HHD” and “reluctant to continue HHD” groups, adjusted for confounding factors. We then matched caregiver age, caregiver gender, patient age, patient gender, duration of care, duration of HD, and duration of HHD, with the “reluctant to continue HHD”

group as a control. The  $\chi$ -squared test and the independent *t*-test were used to compare the “reluctant to continue HHD” and “willing to continue HHD” groups.

Statistical analyses were performed using SPSS software (ver. 28.0, IBM Corp., Armonk, NY, USA). The significance threshold was set at 0.05.

### Results

Overall, 67 (44.67%) facilities responded to the questionnaires. Regarding the caregivers survey, 298 out of the 536 (55.6%) caregivers participated. Table 1 presents the profiles of the caregivers and their respective patients on HHD. The mean age of the patients of caregivers in the “reluctant to continue HHD” group ( $62.8 \pm 2.2$  years) was notably higher than those in the “willing to continue HHD” group ( $57.1 \pm 0.6$  years) ( $p < 0.05$ ). However, this difference disappeared after propensity score matching. No other significant differences were observed between the caregiver- and patient-related variables across all groups.

Table 2 shows the variations in caregiver support offered by HHD facilities. The “willing to continue

**Table 1** Participant characteristics

	Overall ( <i>n</i> = 298)	Reluctant to continue HHD care group ( <i>n</i> = 18)	Before propensity score matching		After propensity score matching	
			Willing to continue HHD care group ( <i>n</i> = 280)	<i>P</i> -value	Willing to continue HHD care group ( <i>n</i> = 18)	<i>P</i> -value
<i>Caregiver information</i>						
Age (years)	57.6 ± 0.7	61.5 ± 2.2	57.3 ± 0.7	0.07	60.7 ± 11.6	0.98
Sex (men, %)	62.0 (20.8)	4.0 (19.0)	58.0 (20.9)	0.84	2 (11.1)	0.33
Employment (yes, %)	201.1 (67.5)	14.3 (67.8)	186.8 (67.4)	0.96	11 (61.1)	0.48
Spouse of the patients (yes, %)	244.6 (82.1)	14.4 (68.2)	230.2 (83.1)	0.11	15 (83.3)	0.50
Living together with patients (yes, %)	284 (95.3)	18.1 (85.8)	266.0 (96.0)	0.46	17 (94.4)	0.50
Other family members requiring care (yes, %)	25.9 (8.7)	2.1 (10.0)	23.8 (8.6)	0.84	3 (16.7)	0.11
Duration of care (month)	82.0 ± 4.4	90.6 ± 14.2	81.3 ± 4.7	0.54	115.2 ± 92.8	0.45
Presence of other HHD caregivers (yes, %)	51.7 (17.3)	4.1 (19.4)	47.6 (17.2)	0.79	1 (5.6)	0.32
<i>HHD patients information</i>						
Age (years)	57.5 ± 0.6	62.8 ± 2.2	57.1 ± 0.6	0.01	59.8 ± 10.5	0.43
Sex (men, %)	225.9 (75.8)	13.5 (64.0)	212.4 (76.7)	0.20	14 (77.7)	0.50
Employment (yes, %)	212.3 (71.2)	11.8 (55.9)	200.5 (72.4)	0.13	13 (72.2)	0.63
Duration of hemodialysis or peritoneal dialysis before HHD (month)	150.2 ± 6.7	191.6 ± 24.8	147.1 ± 6.9	0.08	200.3 ± 139.0	0.69
Duration of HHD (month)	82.1 ± 4.0	102.6 ± 14.5	80.6 ± 4.2	0.14	115.2 ± 92.8	0.50
HHD frequency (times/week)	4.7 ± 0.1	4.6 ± 0.2	4.7 ± 0.1	0.43	5.1 ± 1.2	0.17
HHD time (h)	4.6 ± 0.1	4.4 ± 0.4	4.6 ± 0.1	0.57	4.1 ± 1.8	0.37
Long-term care insurance accreditation (yes, %)	21.6 (7.2)	1.0 (4.7)	20.6 (7.4)	0.65	0 (0)	0.50

HD, hemodialysis; HHD, home hemodialysis

**Table 2** Results of the support of HHD facility for caregiver

	Overall (n = 298)	Reluctant to continue HHD care group (n = 18)	Before propensity score matching		After propensity score matching	
			Willing to continue HHD care group (n = 280)	P-value	Willing to continue HHD care group (n = 18)	P-value
Whether opportunities were set up for a meeting for caregivers and healthcare providers (yes,%)	173.7 (58.3)	11.4 (54.0)	162.3 (58.6)	0.70	11 (61.1)	0.58
Whether opportunities for in-center dialysis (respite dialysis) for caregivers to take a break (yes,%)	156.0 (52.3)	5.4 (25.6)	150.6 (54.4)	0.02	8 (44.4)	0.19
Whether opportunities were set up for caregiver to talk about their future dialysis treatment and life with HHD patients (yes,%)	155.1 (52.0)	8.9 (42.2)	146.2 (52.8)	0.36	11 (61.1)	0.13
Whether opportunities were set up for caregivers to discuss their future dialysis treatment and life with other HHD caregivers (yes, %)	99.2 (33.3)	6.4 (30.3)	92.8 (33.5)	0.78	10 (55.6)	0.08
Whether they found the HHD induction training difficult (yes, %)	155.3 (52.1)	12.0 (56.9)	143.4 (51.8)	0.67	10 (55.6)	1.0
Is the support of your healthcare providers after starting HHD sufficient? (yes, %)	260.5 (87.4)	15.5 (73.5)	245.1 (88.5)	0.07	15 (83.3)	0.20

HHD” group (54.4%) answered significantly more positively regarding the provision “Opportunities for in-center dialysis (respite dialysis) for caregivers to take a break” compared with the “reluctant to continue HHD” group (25.6%;  $P < 0.05$ ). This difference disappeared after propensity score matching. No other variables showed significant differences between the groups.

Table 3 shows the disparities in caregiver’s knowledge among HHD facilities. Caregivers were asked to choose between their perception of whether they had been briefed about HHD by their healthcare provider before making the decision to have HHD and whether they had been provided with each item of knowledge about HHD. The “willing to continue HHD” group (91.9%) was significantly more represented in the query “Was HHD elucidated by your healthcare providers before selecting HD?” compared with the “reluctant to continue HHD” group (73.9%;  $P < 0.05$ ) as well as in the query “Understanding of dialysis mechanics?” (73.3% versus 52.1%;  $P < 0.05$ ); this difference also disappeared after propensity score matching. No additional variables showed significant differences between the groups.

Table 4 presents the results of the SF-8. Before and after propensity score matching, both PCS and MCS did not exhibit significant differences across groups.

## Discussion

This investigation showed that a caregiver’s motivation to continue HHD may be influenced by the provision of respite during in-center dialysis and comprehensive explanations before initiating HHD, particularly for caregivers of older patients. Propensity score matching revealed that all findings were statistically nonsignificant, with limited generalizability of these outcomes. Nonetheless, these findings highlight the important role of healthcare providers’ support especially for caregivers of elderly patients. Additionally, this study highlighted that the number of caregivers reluctant to continue assisting is small but indicates the presence of caregivers who need support. This emphasizes the necessity for appropriate interventions for these caregivers. Given the pivotal role of caregiver’s support in sustaining HHD, healthcare providers should offer tailored support to HHD caregivers.

Caregiver’s support is an important aspect of HHD management. HHD caregivers frequently experience the burden of both assisting with treatment and managing emotional stress. Previous studies have identified several stressors in HHD caregivers, including anxiety about adverse events, the pressure of treatment assistance, social isolation, and altered patient–caregiver dynamics [7, 12]. Increased caregiver’s burden

**Table 3** Medical and nursing interventions for caregivers during the introduction stage of HHD and caregiver motivation

	Overall (n = 298)	Reluctant to continue HHD care group (n = 18)	Before propensity score matching		After propensity score matching	
			Willing to continue HHD care group (n = 280)	P-value	Willing to continue HHD care group (n = 18)	P-value
Was HHD explained by your healthcare providers before you decided on HHD? (yes, %)	270.1 (90.6)	15.6 (73.9)	254.5 (91.9)	0.02	15 (83.3)	0.19
Knowledge: kidney and CKD (yes, %)	206.0 (69.1)	11.0 (52.1)	195.1 (70.4)	0.09	13 (72.2)	0.30
Knowledge: how dialysis works (yes, %)	214.0 (71.8)	11.0 (52.1)	203.1 (73.3)	0.05	14 (77.8)	0.16
Knowledge: self-management of HHD (yes, %)	203.0 (68.1)	10.9 (51.7)	192.2 (69.4)	0.10	13 (72.2)	0.30
Preparation: supplies (yes, %)	206.0 (69.1)	15.0 (71.1)	191.1 (69.0)	0.85	14 (77.8)	0.50
Preparation: priming (yes, %)	179.0 (60.1)	11.3 (53.6)	167.8 (60.6)	0.53	11 (61.1)	0.74
Start of HHD: assistance with puncture (yes, %)	236.0 (79.2)	17.1 (81.0)	219.0 (79.1)	0.84	15 (83.3)	1.0
Start of HHD: connection of circuits (yes, %)	193.0 (64.8)	10.4 (49.3)	182.7 (66.0)	0.14	12 (66.7)	0.49
Start HHD: mechanical operation of initiation (yes, %)	209.0 (70.1)	12.0 (56.9)	197.1 (71.2)	0.18	14 (77.8)	0.28
During HHD: BP measurement (yes, %)	182.0 (61.1)	11.4 (54.0)	170.7 (61.6)	0.50	11 (61.1)	1.0
During HHD: Checking the machine (yes, %)	173.0 (58.1)	9.4 (44.5)	163.7 (59.1)	0.20	12 (66.7)	0.31
During HHD: dealing with alarms (yes, %)	230.0 (77.2)	13.4 (63.5)	216.6 (78.2)	0.14	15 (83.3)	0.22
During HHD: preparing meals (yes, %)	187.0 (62.8)	14.9 (70.6)	172.1 (62.1)	0.44	12 (66.7)	0.72
During HHD: record (yes, %)	169.0 (56.7)	11.4 (54.0)	157.7 (56.9)	0.80	9 (50.0)	0.74
End of HHD: end mechanical operation (yes, %)	217.0 (72.8)	15.0 (71.1)	202.0 (72.9)	0.87	14 (77.8)	0.70
End of HHD: assistance with needle removal (yes, %)	228.0 (76.5)	16.1 (76.3)	212.0 (76.5)	0.98	14 (77.8)	1.0
End of HHD: clean up machines (yes, %)	190.0 (63.8)	15.0 (71.1)	175.1 (63.2)	0.48	11 (61.1)	0.48
End of HHD: cleaning of machine (yes, %)	183.0 (61.4)	12.9 (61.1)	170.2 (61.4)	0.97	11 (61.1)	1.0
Other: check when requesting goods (yes, %)	155.0 (52.0)	10.0 (47.4)	145.1 (52.4)	0.65	10 (55.6)	0.51
Other: disposal of refuse (yes, %)	212.0 (71.1)	16.0 (75.8)	196.1 (70.8)	0.63	13 (72.2)	0.50
Other: attendance during routine maintenance (yes, %)	182.0 (61.1)	11.2 (53.1)	170.8 (61.7)	0.45	13 (72.2)	0.48
Other: reporting in case of problems (yes, %)	176.0 (59.1)	11.9 (56.4)	164.2 (59.3)	0.79	12 (66.7)	0.73
Other: dietary management (yes, %)	178.0 (59.7)	11.3 (53.6)	166.8 (60.2)	0.55	12 (66.7)	0.73
Other: management of medicines (yes, %)	103.0 (32.6)	5.2 (24.6)	97.8 (35.3)	0.33	6 (33.3)	0.72

CKD, chronic kidney disease; BP, blood pressure

is also linked to HHD discontinuation [13]. Moreover, the patient–caregiver relationship is vital for continuous HHD [14], with a stronger relationship fostering a positive attitude toward HHD [12, 15]. Even in regions

where an assistant is not required for HHD, the presence of a relative or helper is common, underscoring the need for strategies to alleviate caregiver's burden [12]. Thus, healthcare providers recognizing

**Table 4** Results of quality of life of caregiver measured by SF-8

	Overall (n = 298)	Reluctant to continue HHD care group (n = 18)	Before propensity score matching		After propensity score matching	
			Willing to continue HHD care group (n = 280)	P-value	Willing to continue HHD care group (n = 18)	P-value
PCS	48.2±7.3	48.3±7.9	48.9±0.4	0.87	48.2±6.8	0.99
MCS	48.1±6.4	47.0±7.9	48.1±0.4	0.77	49.2±4.7	0.36

PCS, Physical Component Summary; MCS, Mental Component Summary

and addressing caregiver's burden is critical for the continuation of HHD.

This study suggests that a patient's age is associated with a caregiver's desire to continue providing care. Older patients on HHD are more prone to HHD withdrawal due to technical challenges and comorbidities, such as heart disease, which impede their ability to maintain HHD [16]. Furthermore, dialysis complications, such as repeated punctures and hypotension, add to a caregiver's mental stress [7]. Conversely, younger patients with fewer comorbidities may undergo HHD more independently, thus lessening caregiver stress. Therefore, healthcare providers must consider both the patient's age and the caregiver's burden particularly for older patients necessitating extensive support.

The study also explored the influence of caregiver's gender, a key demographic factor, on the intent to continue HHD. In Japan, caregivers are often female and typically the patient's spouse [15]. Although the number of women working in Japan is increasing, the proportion of household chores shared by women still exceeds 80% [17]. If a female caregiver not only does housework but also provides HHD assistance, the burden on the caregiver is expected to increase. Future considerations of the burden of HHD caregivers should include cultural factors such as gender roles.

Respite dialysis, a facility for caregivers to take a break from assisting, was found to be an important factor in motivating caregivers to continue HHD care, especially in older patients. To prevent caregiver's burnout, which contributes to HHD withdrawal, support from healthcare providers, as well as social support networks, are vital [7, 13]. Respite dialysis can decrease caregiver's burden from treatment continuity concerns and complication management [7]. Additionally, negative attitudes toward HHD are associated with prolonged hospital stays and the need for additional respite dialysis [13]. While this study corroborates these findings, the lack of comprehensive support systems, such as peer support and caregiver-provider meetings, emphasizes the need for multifaceted caregiver's support strategies [15]. Effective caregiver's support must include counseling to alleviate mental stress, maintain

patient-caregiver relationships, and reduce social isolation [12, 14].

This study revealed an association between an adequate explanation of HHD to caregivers of elderly patients with their willingness to continue care. Previous studies have highlighted the inadequacy of HHD information and decision-making support for caregivers [12]. In the USA, a presidential order in 2019 promoted HHD, but barriers, such as nephrologists' limited experience, hinder a patient's choice for HHD [18]. Healthcare providers' attitudes also significantly influence HHD selection [10, 19], underscoring the importance of comprehensive dialysis education. Thus, providing detailed information on renal replacement therapies is essential for patient and caregiver support.

This study has some limitations. The study only included caregivers who responded to the survey and were involved in medical care, potentially introducing selection bias. Nonrespondents may have had a lower motivation for continuing HHD, which was not fully represented in the results. Additionally, the number of caregivers who had low motivation to continue HHD was small (18), with some missing values, leading to low statistical power. Precision analysis and addressing missing values and bias in larger samples would be necessary. Future research should include a wider range of medical professionals, noncooperative patients, and caregivers.

Additionally, because the questionnaire was distributed after confirming the number of caregivers at each facility, there may be multiple caregivers for one patient. This could not be omitted in this investigation. However, only a few caregivers matched the patient's attributes, so in most cases there was only one caregiver for each patient. Since we did not confirm the occupations of the caregivers, it is possible that some caregivers could include medical professionals.

## Conclusion

This study highlights the existence of a small number of cases that require comprehensive caregiver support in HHD. Effective and continuous caregiver support programs, respite dialysis, and adequate information provision may affect HHD sustainability. Future strategies



should aim for more inclusive and effective caregiver assistance to improve HHD continuity.

#### Abbreviations

HHD	Home hemodialysis
QOL	Quality of life
PCS	Physical Component Summary
MCS	Mental Component Summary

#### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s41100-024-00555-x>.

Supplementary Material 1.

#### Acknowledgements

We would like to thank the study participants for their cooperation. We also express our gratitude to the Department of renal dialysis staff for their cooperation during this study.

#### Author contributions

Research idea and study design: S.K, H.Y.; data acquisition: S.K, H.Y.; data analysis/interpretation: S.K, H.Y, A.N.; and statistical analysis: H.Y, A.N.; supervision or mentorship: Y.M, S.N. Each author contributed important intellectual content during manuscript drafting and revision, agreed to be personally accountable for the individual's contributions, and ensured that questions about the accuracy or integrity of any portion of the work, even one in which the author was not directly involved, were appropriately investigated and resolved.

#### Funding

Not applicable.

#### Availability of data and materials

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

#### Declarations

##### Ethics approval and consent to participate

To ensure ethical adherence, paper-based surveys remained anonymous, and participants were informed that nonparticipation would entail no adverse effects. Participants' responses were considered consent. This study was approved by the Japanese Society of Home Hemodialysis Ethics Committee (JSHHDECN A-001).

##### Consent for publication

Not applicable.

##### Competing interests

The authors declare that they have no competing interests.

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Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Received: 11 January 2024 Accepted: 27 June 2024

Published online: 06 July 2024