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ORIGINAL ARTICLE

Current Status of Family Caregivers Providing Excretion Care for Older People Requiring Care while Using Multiple Home Life Support Services

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ABSTRACT

To clarify the current status of family caregivers providing excretion care for older people requiring care while using multiple home life support services. We conducted semi-structured interviews with 10 family caregivers who had provided or were providing excretion care for older people requiring care while using multiple home life support services, and qualitatively analyzed the interview data. The family caregivers' current status of providing excretion care and thoughts/feelings about such care were summarized into 6 categories: [utilizing equipment that supports excretory function], [aiming for excretory care that protects the dignity of people requiring care], [finding it burdensome to assist with excretory movements], [facing difficulties in adjusting the defecation rhythm], [finding it burdensome to deal with urinary and fecal incontinence], and [finding it burdensome to provide excretion care for older people with dementia]. The status of home life support service use by these family caregivers was represented by 6 categories: [complex services], [relationships with professionals], [rest for family caregivers themselves], [emotional support], [physical and mental limitations], and [various caregiving and living challenges]. The results revealed that, as excretion care is provided several times a day, including the night-time, temporary use of services does not reduce the burden of excretion care on family caregivers in home care, even if the services are combined according to individual circumstances. On the other hand, building good relationships with professionals and receiving emotional support through the use of home life support services was suggested to be an important support for these caregivers to continue caregiving.

Keywords: Older people requiring care, Excretion care, Family caregivers, Home life support services

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1. Introduction and Purpose

Japan faces the urgent necessity of establishing community-based integrated care systems that enable older people to maintain their dignity and continue to live their own lives in their familiar communities even when they become care-dependent. As background to this, the Japanese population is aging at a rate unparalleled in other countries, and the national demand for medical and long-term care services is expected to increase further after 2025, when the baby boom generation will reach the age of 75 or older. In such a situation, the establishment of systems to appropriately provide various life support services, including medical, care, and welfare services, in everyday life settings is increasingly required, with a view to reducing the burden of medical and long-term care. However, it is not easy for older people to continue to live in their familiar communities, and independence/dependence in excretion is one of the factors that influence the rate of discharge from a hospital/facility to home^{1,2)}. Furthermore, among the care procedures that family caregivers find burdensome, excretion care particularly increases the sense of burden, and is a major predictor of unsuccessful home care³⁾. For older people to continue to live in their familiar communities even when they become care-dependent, the establishment of support systems that help these people maintain their independence in excretion as long as possible, leveraging their own strengths, and that prevent caregiving burdens on their family caregivers from increasing is essential.

In previous studies on excretion care provided by family caregivers, the caregivers regarded direct physical care, such as diaper changing, as a serious burden at all times⁴⁾. Incontinence among care-dependent people, which requires toilet use several times a day, including the night-time, was shown to deprive caregivers of leisure time, leading to various problems, including a worsened relationship between the caregiver and care-receiver, sleeping disorders, and social isolation⁵⁾. Regarding defecation, the high prevalence of diarrhea and constipation among older people requiring care is a factor that increases the social and economic burden on family caregivers^{6,7)}, suggesting that excretion care is a physically and mentally burdensome care procedure for family caregivers. Thus, the burden of excretion care on family caregivers has been noted in several studies. In developed countries in Europe and the United States, continence advisors who have knowledge and skills in excretion management play a central role in disseminating the knowledge to professionals, and contribute to excretion care for older people requiring care using multifactorial strategies⁸⁾. However, in Japan, there are no professionals who play such a role, and family caregivers provide home care using home life support services.

However, as mentioned earlier, while there have been studies on the burden of caregiving related to family excretion care, there have been few studies that have clarified the actual situation of family caregivers who provide excretion care while combining multiple home life support services. Therefore, the researcher considered it necessary to examine how the burden of excretory care could be reduced by combining multiple home life support services and how the home support services should be designed to reduce the burden of excretory care. Therefore, this study aims to clarify family caregivers' current status of providing excretion care for older people requiring care while using multiple home life support services, as well as their thoughts/feelings about such care.

2. Definitions of Terms

In this study, "family caregivers" were defined as family members who are currently living with and mainly providing excretion care for people requiring care or have done so in the past.

3. Subjects and Methods

3.1. Study and procedures

3.1.1. Study Design

In anticipation of the inclusion of older family caregivers, we adopted a semi-structured interview-based qualitative descriptive study design as a method that is less burdensome than a descriptive questionnaire and that enables accurate representation of excretion care provided in the past.

3.1.2. Research collaborators

We planned to examine approximately 10 family caregivers who were providing excretion care for older people requiring care while using multiple home life support services at the time of the study or had done so in the past. We selected 3 long-term care insurance-covered facilities in a single city by opportunistic sampling, and asked the care manager of each consenting facility to introduce 3 family caregivers. Among these family caregivers, we included those who met the following criteria for research collaborator selection:

<Criteria for research collaborator selection>

- Aged 20 or older who is currently providing excretion care for an older adult requiring care or have done so in the past
- Being able to understand and communicate with others
- Main caregiver
- Coordinating home life support services for an older adult requiring care

3.1.3. Ethical Considerations

We orally explained to the research collaborators the study purpose and ethical considerations using a written document, and obtained their consent. The explanation included that their participation in this study was voluntary, and that they would not be disadvantaged in any way even if they did not cooperate in the study. We asked them to designate a day when the session would not interfere with their caregiving or other activities, and interviewed them on that day in a place where their privacy would be protected. We analyzed the collected data after replacing them with ID numbers and converting them into a format that would prevent the identification of individuals. The study was approved by the Ethics Committee of the Faculty of Health Science and Nursing, Juntendo University (approval number: 4-05).

3.2. Data collection

We conducted semi-structured interviews with consenting family caregivers individually face-by-face or using Zoom. Each interview session lasted for 16 to 44 (mean: 29) minutes, and started after obtaining the interviewee's permission for the use of an IC recorder. In addition to the basic attributes of family caregivers, the survey items included caregiving period, relationship with the caregiver, experience of caregiving, age of care-receivers, care grade of care-receivers, nursing care services used, and primary disease. The level of nursing care required is an indicator of the degree of need for nursing care, which is determined at the time of application for nursing care certification under the public long-term care insurance system in Japan, and is classified into five levels from 1 to 5. The higher the stage, the greater the need for nursing care. The interview examined the "current status of excretion care provided by family caregivers and their thoughts/feelings about such care" and "status of home life support service use", in addition to the research collaborators' basic attributes. The interview period was from August to October 2022.

3.3. Data analysis

This study aimed to retrieve the feelings about excretory care from the narratives of the study subjects. Therefore, it was a qualitative descriptive study, "a comprehensive summary of an event in the everyday language in which such an event occurs". We created narrative records from the interview data, and extracted semantic parts from each research collaborator's statements, focusing on the "current status of excretion care provided by family caregivers and their thoughts/feelings about such care" and "status of home life support service use", and summarized and coded the extracted parts using the research collaborators' own words as much as possible not to change the meaning of the context. Subsequently, we compared similarities and differences among codes, and increased their levels of abstraction to create and name subcategories and categories. In order to improve the reliability and validity of data analysis, this research shared the analysis process among three researchers, and repeated four times for confirmed and examined it. performed all analytical processes under the supervision of a person with experience in home nursing studies and qualitative research.

4. Results

4.1. Outline of research collaborators (Table 1)

Among the 10 family caregivers, 3 had experience of caregiving, and 7 were also providing care at the time of the study. There were 1 male and 9 females, with a mean age of 62.7 and mean caregiving period of 7.3 years. As for their relationships with the care-receivers, 7 were daughters, 2 were spouses, and 1 was a son. The mean age and mean care grade of the care-receivers were 79.4 years and 3.4, respectively. The family caregivers used multiple home life support services, including home-visit nursing, home care, short stay, day, and daycare, and multifunctional small-scale home care services, combining 2 to 4 of these. The most common primary disease was dementia, in 5, and then cerebral infarction, in 3.

Table 1. Outline of participants

Subjects	Age	Sex	Caregiving period (years)	Relationships with care-receivers	Experience of caregiving	Age of care-receivers	Care grade of care-receivers	Nursing care services used	Primary disease
A	50	F	3	Daughter	Provided care in the past	60	3	Day care services, Short stay	dementia
B	70	F	25	Spouse	Provided care in the past	60	4	Short stay, Assistive products	cerebral infarction
C	50	F	7	Daughter	Also currently providing care	80	3	Home nursing, Multifunctional small-scale home care service, Assistive products	dementia
D	50	F	5	Daughter	Also currently providing care	70	2	Home nursing, In-home rehabilitation, Multifunctional small-scale home care service	cerebral infarction
E	50	F	6	Daughter	Also currently providing care	80	4	Home nursing, Home nursing care, Multifunctional small-scale home care service, Assistive products	disuse
F	50	F	10	Daughter	Also currently providing care	70	5	Home nursing care, Multifunctional small-scale home care service	dementia
G	70	F	3	Spouse	Also currently providing care	80	3	Multifunctional small-scale home care service, Day care services	cerebral infarction
H	60	F	8	Daughter	Also currently providing care	90	1	Home nursing care, Day-care center, Multifunctional small-scale home care service	dementia
I	70	F	5	Daughter	Also currently providing care	90	4	Home nursing care, Multifunctional small-scale home care service, Assistive products	dementia
J	60	M	1	Son	Also currently providing care	80	5	Home nursing, In-home rehabilitation, Day care services	progressive supranuclear palsy

F: Female; M: Male

4.2. Current status of excretion care for older people requiring care provided by family caregivers and the latter's thoughts and feelings about such care (Table 2)

A total of 191 codes were identified and classified into 6 categories and 22 subcategories. In the following paragraphs, these categories and subcategories are shown in [] and < >, respectively. In addition, quotations from the summaries are shown in { }, and each alphabetic character in () indicates the research collaborator who stated it.

The current status of excretion care provided by family caregivers and their thoughts/feelings about such care were summarized into 6 categories: [utilizing equipment that supports excretory function], [aiming for excretory care that protects the dignity of people requiring care], [finding it burdensome to assist with excretory movements], [facing difficulties in adjusting the defecation rhythm], [finding it burdensome to deal with urinary and fecal incontinence], and [finding it burdensome to provide excretion care for older people with dementia].

[Utilizing equipment that supports excretory function] explains that the caregivers provided excretion care using various measures, such as utilizing self-help devices, selecting suitable diapers, and adjusting the environment for excretion. As stated {I installed an L-shaped bar by the bedside, and frequently used a urinal tube (B)}, they performed excretion care, <utilizing self-help devices for excretion>, such as urinals, portable toilets, and waterproof sheets. Furthermore, as stated {I used to select diapers with the care-receiver's comfort in mind (C)}, they also selected diapers while considering the care-receivers' conditions and assessing their ADL, with a view to <tailoring diaper choice to the care-receiver's needs>. On the other hand, the statement {I didn't know how to change the diapers, so I asked the helper to teach me the method, and I got much better at it at the end (E)} revealed that they lacked knowledge of excretion care methods in the beginning, and needed to perform excretion care based on advice from others, such as <seeking guidance on diaper-changing and other care methods>. Thus, while performing excretion care using various measures, the family caregivers developed <expectations for the development of more convenient and comfortable diaper products>, <finding it burdensome to clean toileting-related welfare equipment>, as stated {Portable toilet cleaning is burdensome, especially at home (D)}. {We can't put a handrail on it, because our toilet room is a bit small (E)} and <finding it difficult to improve one's living environment> also represent the difficulty they faced in enabling the care-receivers to excrete in the toilet.

[Aiming for excretory care that protects the dignity of people requiring care] recounts that the family caregivers provided excretion care while respecting older people requiring care. As stated {Nevertheless, if he still wants to go to the toilet, I can't tell him to hold it in or defecate in his diaper (J)}, they performed such care, with <providing excretion care while respecting the care-receiver> as the foundation, rather than giving priority to their own convenience. Furthermore, as stated {Leaving him in soiled underwear felt pitiful, so I had a strong desire to change his underwear as soon as he emptied his bowels (A)}, they performed care for <maintaining cleanliness and preventing skin problems> in consideration of the mental and physical impact of urinary/fecal incontinence. On the other hand, <realizing the difficulty of toileting intervention in terms of self-esteem> represents their thoughts and feelings when the care-receivers refused to use diapers or were reluctant to be assisted with excretion, as stated {He hated excretion assistance by his own child (C)}.

[Finding it burdensome to assist with excretory movements] outlines the family caregivers' situation regarding excretion assistance, including guiding the care-receivers to the toilet and helping them put on and take off clothes when toileting, as well as their burden of providing excretion assistance repeatedly. As represented by {I guided him to the toilet. When he was still able to walk independently, I helped him walk to the toilet and sit on the toilet seat (F)} and <assisting with each movement for excretion>, they assisted the care-receivers to execute each movement for excretion according to the

latter's ADL. Additionally, as represented by {I figured I had to let him do it on his own as much as possible because it was something we do every day (G)} and <aiming at independent excretion>, they provided assistance to promote the care-receivers' independence while reducing caregiving burdens, rather than providing full assistance. On the other hand, the statements {When he became unable to walk, I couldn't take care of him by myself anymore (I)} and {He wanted to go to the toilet whenever he woke up, so I had a hard time sleeping during the nighttime (J)} highlight their sense of burden in such assistance, represented by <finding it burdensome to assist in toileting> and <finding it burdensome to assist with excretion during the nighttime>. They also provided excretion assistance while <realizing the physical burden of providing excretion assistance many times a day>, as stated {Excretion care was burdensome, because it should be performed many times a day (D)}.

[Facing difficulties in adjusting the defecation rhythm] refers to the family caregivers' efforts and difficulties to address diarrhea/constipation as an excretory disorder characteristic of older people by adjusting their defecation rhythms. As stated {Multifunctional small-scale home care service staff also checked on it, and I also checked on it at home. When he had difficulty emptying his bowels, I did something to manage it (D)}, they addressed this problem <using various preventive measures against constipation>, including recording bowel movements, encouraging fluid intake, and reviewing diet. On the other hand, they dealt with such a situation while <finding intervention for constipation difficult>, as stated {He doesn't have the strength to empty his bowels, and dementia prevents him from understanding when I tell him to drink water (F)}. Moreover, the use of laxatives for constipation also led to diarrhea as a vicious cycle, resulting in <finding the adjustment difficult, as constipation and diarrhea repeat>, as stated {Laxatives cause diarrhea (E)}.

[Finding it burdensome to deal with urinary and fecal incontinence] reveals the family caregivers' psychological distress due to the physical burden of dealing with urinary/fecal incontinence, such as assisting the care-receivers to put on and take off clothes and changing bed sheets, as well as fecal odor. As stated {As a countermeasure against urinary incontinence, I put waterproof sheets on the bed, but one sheet wasn't enough, and I had to replace it many times (A)} and {The most annoying thing was that after fecal incontinence, he tried to clean up the mess by himself, and his hands and clothes got sticky (B)}, they dealt with urinary/fecal incontinence while <finding it burdensome to deal with urinary/fecal incontinence>. In particular, as the statement {The smell of stool made me sick, so I wore a mask and gloves when assisting with excretion (H)} reveals, they coped with the situation while <finding it burdensome to manage fecal odor>.

[Finding it burdensome to provide excretion care for older people with dementia] represents excretion care for older people with dementia, who are able to defecate on their own, but are unable to recognize the toilet, and require assistance in this respect. As represented by <accompanying the care-receiver who is unable to recognize the toilet due to dementia>, the family caregivers devised various measures, such as {Since he did not know where the toilet was, I moved my bedroom to a place where I could see the toilet to keep an eye on him (G)}. However, when the situation became difficult, as stated {As dementia progresses, he doesn't even know he has to use the toilet, so he does it in the bathtub (F)}, they struggled with it while <finding excretion in places other than the toilet problematic> and <finding excretion assistance for older people with dementia difficult>, especially {When walking on his own, he makes stops and refuses to use the toilet (C)}.

Table 2. Current status of excretion care for older people requiring care provided by family caregivers and the latter's thoughts and feelings about such care

Categories	Subcategories	Summaries (191 codes)
Utilizing equipment that supports excretory function (36)	Utilizing self-help devices for excretion (9)	I installed an L-shaped bar, and frequently used a urinal tube.
	Tailoring diaper choice to the care-receiver's needs (8)	I choose diapers while observing the care-receiver's condition.
	Seeking guidance on diaper-changing and other care methods (5)	I asked the helper how to change the diapers.
	Expectations for the development of more convenient and comfortable diaper products (6)	I want them to develop products that make diaper changing easier.
	Finding it burdensome to clean toileting-related welfare equipment (4)	Portable toilet cleaning is burdensome.
	Finding it difficult to improve one's living environment (4)	If our living environment had been properly maintained, taking him to the toilet would have been out of the question, because he would have been able to excrete independently.
Aiming for excretory care that protects the dignity of people requiring care (24)	Providing excretion care while respecting the care-receiver (10)	I patiently wait until he has a bowel movement, and this may be the difference between facility and home care. Nevertheless, if he still wants to go to the toilet, I can't tell him to hold it in or defecate in his diaper.
	Maintaining cleanliness and preventing skin problems (3)	I change unclean underwear immediately, because it may cause rashes.
	Realizing the difficulty of toileting intervention in terms of self-esteem (11)	I had to say "please" to have him put on a pad. He hated excretion assistance by his own child.
Finding it burdensome to assist with excretory movements (47)	Assisting with each movement for excretion (10)	I guided him to the toilet, and assisted him in sitting and wiping.
	Aiming at independent excretion(1)	I figured I had to let him do it on his own as much as possible because it was something we do every day.
	Finding it burdensome to assist in toileting (16)	Toileting assistance became burdensome after he became unable to walk. When he became unable to walk, I couldn't take care of him by myself anymore.
	Finding it burdensome to assist with excretion during the nighttime (10)	I have to change diapers many times at night due to urinary incontinence. Toileting assistance at night was the most hated and burdensome, because I had to wake up from sleep.
	Realizing the physical burden of providing excretion assistance many times a day (10)	Excretion care was burdensome, because it should be performed many times a day. (It happens several times a day), so it is also tough for me.
	Facing difficulties in adjusting the defecation rhythm (34)	Using various preventive measures against constipation (15)
Finding intervention for constipation difficult (11)		I adjusted his fluid intake and diet, but it was difficult to resolve his constipation. He doesn't have the strength to empty his bowels, and dementia prevents him from understanding when I tell him to drink water.
Finding the adjustment difficult, as constipation and diarrhea repeat (8)		The difficulty of adjusting laxatives results in fecal incontinence. Laxatives cause diarrhea.
Finding it burdensome to deal with urinary and fecal incontinence (30)		Finding it burdensome to deal with urinary/fecal incontinence (25)
	Finding it burdensome to manage fecal odor (5)	Soft stools stain pajamas and sheets, and leave a lingering odor even after wiping and drying. It is indeed burdensome.
Finding it burdensome to provide excretion care for older people with dementia (20)	Accompanying the care-receiver who is unable to recognize the toilet due to dementia (4)	Since he did not know where the toilet was, I moved my bedroom to a place where I could see the toilet to keep an eye on him.
	Finding excretion in places other than the toilet problematic (10)	It was quite burdensome to deal with urination each time. As dementia progresses, he doesn't even know he has to use the toilet, so he does it in the bathtub.
	Finding excretion assistance for older people with dementia difficult (6)	When walking on his own, he makes stops and refuses to use the toilet. Sometimes 5 urine pads are stacked.

4.3. Status of home life support service use among family caregivers providing excretion care for older people requiring care (Table 3)

A total of 102 codes were identified and classified into 6 categories and 19 subcategories. In the following paragraphs, these categories and subcategories are shown in [] and <>, respectively. In addition, quotations from the summaries are shown in { }, and each alphabetic character in () indicates the research collaborator who stated that.

The status of home life support service use by family caregivers providing excretion care for older people requiring care was represented by 6 categories: [complex services], [relationships with professionals], [rest for family caregivers themselves], [emotional support], [physical and mental limitations], and [various caregiving and living challenges].

[Complex services] explains that the family caregivers performed excretion care utilizing long-term care insurance services in accordance with their family circumstances. The statement {I have to work. If I have to become a caregiver at the same time, I can't do it without using these services (D)} represents their reason for utilizing <day services>. They had also been using <welfare equipment> to improve one's living environment to make it easier for the care-receivers to use the toilet, as stated {I have taken all possible measures, such as making the room barrier-free and changing the toilet (B)}. Furthermore, seeking excretion assistance as part of home life support services, rather than performing excretion care by themselves, they provided excretion care utilizing <home-visit services>, as stated {I ask the helpers to take him to the toilet whenever they come (E)}.

[Relationships with professionals] recounts that the presence of home life support service staff provided mental support for the family caregivers to perform excretion care. As stated {A good relationship is important (G)}, they realized the importance of a <good relationship with home life support service staff>, which enabled them to consult about anything. The statement {The support from the care manager was very helpful (A)} also shows that <trust in home life support service staff> helped them continue excretion care.

[Rest for family caregivers themselves] explains that the family caregivers providing excretion care continued caregiving while taking breaks and spending private time to rest their body and mind. As stated {Making use of short stays helped me relax (A)}, <ensuring rest for family caregivers themselves> helped them continue to provide care. <Ensuring leisure time for family caregivers themselves>, such as {I enjoy my hobbies and travel for a change, utilizing short stays (H)}, was another of their attempts.

[Emotional support] indicates that the family caregivers were aware of the importance of continuing caregiving while receiving emotional support by having someone to talk to or complain to. They received <psychological support from family members and staff>, as stated {It is important to improve the home environment, but the presence of someone to rely on is also important (D)}. On the other hand, they felt that they had <no other family members to complain to>.

[Physical and mental limitations] revealed that the caregivers felt limitations in their caregiving while providing excretion care several times a day, including the night-time, showing negative emotional reactions to endless excretion care, such as disappointment. The statement {I (the caregiver) got sick, possibly due to stress (J)} outlines <physical and mental disorders from stress> among these caregivers, and {I felt so miserable, asking her, "Mom, why can't you do it anymore?"}. I can understand why homicide due to caregiver fatigue occurs (I) represents their <emotional reactions such as disappointment and anger>. In addition, due to <anxiety about endless caregiving>, they felt <limitations in caregiving>, as stated {I tried my best to take care of him at home without admitting him to a nursing home, but I couldn't do it anymore (E)}.

[Various caregiving and living challenges] showed that the challenges faced by family caregivers vary according to the circumstances of each family, and there are challenges not only related to caregiving but also to their living conditions. The statement {The most important thing for facility admission is money (I)} represents the <economic challenge> they faced. Those who did not have a family member to help them with caregiving perceived <the burden of taking on the responsibility of caregiving alone>, as stated {It was quite hard to perform caregiving alone (F)}. Additionally, the statement {Sometimes

the time when the pick-up bus came to take him to the day service and the time when I came home from work didn't coincide, which put me in trouble (J)} reveals that they perceived various challenges, such as <challenges in balancing work and caregiving> and <challenges related to home life support services>. Other challenges include <challenges related to people requiring care>, as stated {The facilities do not admit people with a low care grade, but excretion assistance for these people is more burdensome (A)}, and there was also hesitation to use the services due to <feeling reserved or uncomfortable when using home life support services>, as stated {I had a staff member change his underwear, but I felt uncomfortable asking them to come over simply to change underwear (C)}.

Table 3. Use of home life support services and related challenges among family caregivers providing excretion care for older people requiring care

Categories	Subcategories	Summaries (102 codes)
Complex services (32)	Day services (17)	I have to work. If I have to become a caregiver at the same time, I can't do it without using these services. Having a job, I had him go (to the day service) during the day.
	Welfare equipment (10)	I have taken all possible measures, such as making the room barrier-free and changing the toilet.
	Home-visit services (5)	I ask helpers to take him to the toilet whenever they come.
Relationships with professionals (16)	Good relationship with home life support service staff (4)	A good relationship is important.
	Trust in home life support service staff (12)	The support from the care manager was very helpful. Trust with home service providers is really important.
Rest for family caregivers themselves (11)	Ensuring rest for family caregivers themselves (9)	Making use of short stays helped me relax. I had him use the overnight care service, because I (the caregiver) didn't want to get exhausted.
	Ensuring leisure time for family caregivers themselves (2)	I enjoy my hobbies and travel for a change, utilizing short stays.
Emotional support (9)	Psychological support from family members and staff (8)	It is important to improve the home environment, but the presence of someone to rely on is also important. (When I complain,) I can feel refreshed, and be a little bit kinder. Because I had someone to talk to, I was able to manage the situation.
	No other family members to complain to (1)	I can't complain at home. I can't say these things to my husband.
Physical and mental limitations(13)	Physical and mental disorders from stress (6)	I (the caregiver) got sick, possibly due to stress. Caregiving is harder mentally than physically, and sometimes I can't stop crying.
	Emotional reactions such as disappointment and anger (3)	I felt so miserable, asking her, "Mom, why can't you do it anymore?". I can understand why homicide due to caregiver fatigue occurs.
	Limitations in caregiving (1)	I tried my best to take care of him at home without admitting him to a nursing home, but I couldn't do it anymore.
	Anxiety about endless caregiving (3)	I find it burdensome to come to terms with the situation, such as considering when to shift to home care. It is also worrisome that we do not know how long this situation will continue.
Various caregiving and living challenges (21)	Economic challenge (4)	The most important thing for facility admission is money.
	The burden of taking on the responsibility of caregiving alone (9)	No one was helping me, and there were no helpers. It was quite hard to perform caregiving alone.
	Challenges in balancing work and caregiving (4)	It was difficult to work a full-time job due to the short hours of day service.
	Challenges related to home life support services (1)	Home-visit care services can only help my father, and that's not good enough for us.
	Feeling reserved or uncomfortable when using home life support services (2)	I had a staff member change his underwear, but I felt uncomfortable asking them to come over simply to change underwear.
	Challenges related to people requiring care (1)	The facilities do not admit people with a low care grade, but excretion assistance for these people is more burdensome.

5. Discussions

Family caregivers had previously been regarded as a means to fulfill the needs of people requiring care. Being inevitably forced to change their lifestyles, such caregivers tended to be isolated and socially excluded⁹⁾. Today, however, with the generalization and enhancement of the long-term care insurance system, family caregivers are also recognized as recipients of support, and “provision of sufficient life support for caregivers” has become an urgent issue¹⁰⁾. This study examined family caregivers providing excretion care while using multiple home life support services to clarify the current status and challenges of excretion care provided by such caregivers as a basis for discussing what is necessary to support excretion care for older people requiring care in Japan’s community-based integrated care system.

The family caregivers used [complex services] according to their circumstances, and attempted to provide better excretion care for older people requiring care by [utilizing equipment that supports excretory function], [aiming for excretory care that protects the dignity of people requiring care]. On the other hand, when providing excretion care, they bore various burdens, such as [facing difficulties in adjusting the defecation rhythm], [finding it burdensome to assist with excretory movements], [finding it burdensome to deal with urinary and fecal incontinence], and [finding it burdensome to provide excretion care for older people with dementia]. In addition, as the community environment surrounding family caregivers is markedly changing, they were suggested to face [various caregiving and living challenges], and realize [physical and mental limitations] in caregiving. In short, the results revealed that, as excretion care is provided several times a day, including the night-time, temporary use of services does not reduce the burden of excretion care on family caregivers in home care, even if the services are combined according to individual circumstances. Despite these various burdens, the family caregivers engaged in caregiving, [aiming for excretory care that protects the dignity of people requiring care], with a sense of mission unique to family caregivers who believe that some types of excretory care can be provided only at home, as stated {I patiently wait until he has a bowel movement. This is the difference between facility and home care}. At the same time, this sense of mission made them hesitate to use home life support services, as represented by <feeling reserved or uncomfortable when using home life support services>. Family caregivers’ sense of mission can also be understood as their sense of self-blame, which has been reported to result in a sense of isolation. Fujio et al.¹¹⁾ identified the difficulty of support interventions to address [sense of mission to care] among caregivers who feel obligated to provide care on their own as a challenge in family caregiver support from the perspective of care managers. The present study examined the current status of excretory care from the perspective of family caregivers, and revealed challenges similar to those of family caregiver support perceived by home life support service providers. On the other hand, as stated {I just told him that he smelled bad. I knew this hurt him, but I myself was stressed to the point of exhaustion}, the family caregivers provided excretion care with both positive and negative feelings about caregiving, and the latter included anger and worry. A previous study reported that, as one of the main problems faced by family caregivers of older people requiring care with incontinence, they aim to provide care that respects care-receivers while coming to terms with the current situation, apart from their and the care-receivers’ feelings of embarrassment about care intervention for incontinence as a private act of a person¹²⁾, which is similar to the results of the present study.

Thus, although temporary use of services may not be enough to reduce the burden of excretion care on family caregivers in home care, the family caregivers in this study attempted to ensure rest for themselves by using these services, and, above all, they realized the necessity of emotional support, as stated {The presence of someone to rely on is also important}. Hirose¹³⁾ described that family caregivers themselves desire to have their own existence and achievements recognized, and develop an ambiguous mentality that mixes both positive and negative feelings about a certain situation and their previous

relationships with care-receivers over time. Also in the present study, family caregivers continued caregiving while balancing it and their own lives by receiving [emotional support] and taking [rest for family caregivers themselves] through the use of home life support services. Among these family caregivers, 70% used multifunctional small-scale home care services, including day, overnight, and home-visit care services provided by the same staff members, which facilitates relationship-building between users and staff¹⁴). This may have enabled the family caregivers to build a <good relationship with home life support service staff>, providing emotional support for them. It is said that because excretory care involves a sense of shame not only for the patient but also for the family, there is a tendency for people to try to hide it from society and to provide excretory care on their own¹²). However, in this study, family caregivers received emotional support from professionals and were able to continue caring by confiding their complaints about caregiving, saying that they were able to manage because they had someone to talk to. In order to help family caregivers continue caregiving, it is important for professionals to build a trust-based relationship with them in the process of continuous support, and to promote favorable caregiver-care-receiver relationships, focusing not only on caregiving burdens, but also on positive feelings of both parties about their relationships¹⁵). The present study did not clarify whether professional support for family caregivers was provided from this perspective, but it highlighted the importance for professionals to intervene in the mental aspect of family caregivers when supporting them. Furthermore, Nagai et al.¹⁶) described that caregiving stress is influenced by the presence of a caregiving partner and/or supporter and the availability of consultation services, and that a system for each caregiver to be supported by multiple persons is crucial. The results of the present study also suggest that the presence of not only home life support service staff, but also family members and others to complain to provides [emotional support], and helps caregivers continue caregiving despite [physical and mental limitations].

Concerning this multiple supporter system, we believe that collaboration only among home life support service providers may have limitations in supporting family caregivers. For community-based comprehensive care systems to effectively work, “self-help, mutual-help, cooperation-and-assistance, and public-assistance” initiatives that address various life challenges are required. In order to reduce the burdens on caregivers, it is indispensable to alleviate their sense of restraint and ensure the presence of supporters who perform caregiving on their behalf³). The establishment of systems to link “self-help, mutual-help, cooperation-and-assistance, and public-assistance” initiatives to each other and provide support may also be necessary for this purpose. There should also be major changes to the social concept of caregiving. Caregiving may be something that anyone can do, but it should not be carried out by family members alone. Family caregiver support should aim to help these caregivers lead a fulfilling life themselves, and perform care to the extent that their lives are not affected.

6. Study Limitations and Future Challenges

The results of this study are limited in their generalizability, as daughter-in-law caregivers were not included as family caregivers, and there was a bias in the home life support services used. However, the study has a certain significance in clarifying family caregivers' thoughts and feelings about excretory care and the characteristics of such care for each care grade, and in discussing the effectiveness of home life support services. In the future, to further increase the accuracy, we will longitudinally collect data, with more extensive caregiver attributes and a wider range of care facilities, and continuously discuss the effectiveness of home life support services toward excretion care that satisfies both the older people requiring care and their family caregivers.

7. Conclusions

The family caregivers providing excretion care for older people requiring care while using multiple home life support services adopted various approaches to make such the care protected the care-receivers' dignity. However, as excretion care is provided several times a day, including the night-time, temporary use of services was shown to be insufficient to reduce the burden of excretion care on these caregivers in home care, even if the services were combined according to individual circumstances. On the other hand, building good relationships with professionals and receiving emotional support through the use of home life support services was suggested to help them continue caregiving.

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