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(Citation)
Ageing & Society,44(6):1410-1434

(Issue Date)
2022-09-01

(Resource Type)
journal article

(Version)
Accepted Manuscript

Psychological distress in sons as resident carer of older mothers in Japan

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Keywords

psychological distress; carer / caregiving; thematic analysis; qualitative; sons

Financial support: This study was supported by the Univers Foundation (grant number: 17-01-166).

Conflicts of interest: The Authors declare none.

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Ethical approval was first obtained from the Institute Review Board of the Graduate School of Health Science, Kobe University (No. 552).

Abstract

In Japan, caregiving sons are noted for their high rates of abuse of care recipients. This study revealed, for the first time, the difficulties unique to sons caring for their mothers. All sons used long-term care insurance services. However, they provided care that could not be covered by such public services while harbouring psychological distress. In this study, we interviewed 13 sons living with their older mothers as the primary carer and conducted a thematic analysis focusing on their psychological distress. As part of our study findings, we have identified nine themes during analysis: uncomfortable feelings that cannot be mitigated as a son; feeling of futility in being unrecognised as a carer; fear of losing something important; a strong sense of responsibility for one's mother's life; disappointment in being unable to obtain understanding and cooperation from one's siblings in providing care; irritation and anger towards one's wayward mother; guilt about treatment of one's mother; sense of exhaustion due to demanding care and experiencing hopelessness and despair. Thus, it is important to understand what psychological distress carers experience and to consider possible approaches for their support. The study findings provide suggestions for long-term care support in regions, such as East Asia, where the numbers of son carers are increasing inevitably owing to declining birth rates and ageing population, as in Japan.

Keywords: psychological distress; carers/caregiving; thematic analysis; qualitative; sons

Background

As the older population worldwide is set to increase in the near future, the question of how to deal with various care requirements of older people who require nursing care is a common and important issue (Ophir and Polos 2021). Caring for older individuals requires a long-term commitment to accommodate various functional declines due to ageing, and it can vary from livelihood support to physical support, money management, hospital visits, and shopping. Therefore, a wide variety of support is required. Furthermore, such care can have a major impact on the carer's physical and psychological health (Riffin, Van Ness and Wolff 2017). Karantzas and Simpson (2015) noted that governments worldwide find it difficult to meet medical demands and that, in many instances, the family takes on the role as the primary carer of older individuals. According to previous studies, family carers experience a loss in their own quality of life (QOL) as they are consumed with responsibility, feeling isolated and spending more time caregiving, which could be detrimental to their own physical and mental health (Duggleby *et al*. 2011; Sambasivam *et al*. 2019). To ensure the QOL of older individuals requiring long-term care, it is extremely important for carers to maintain their own psychological and physical health. In many East Asian countries, including Japan, conforming to the patriarchal norms of care and gender roles is considered a motivation for providing care. Female family members, such as the wife or daughter-in-law, have primarily undertaken the role of the carer (Chee and Levkoff 2001; Lai 2010; Takagi, Silverstein and Crimmins 2007). However, in East Asian countries, birth rates have been exceptionally low, and women's increased participation in society has led to a tendency to marry later, have fewer children or stay unmarried (Jones 2019). As a result, their perception of the long-term care role is also changing. In Japan, the long-term care insurance system introduced by the government in 2000 helped free women who married their eldest son from the normative obligations of traditional primary carers. Japan has a long-term care insurance system that entitles all individuals aged 65 years and older to receive various nursing care services, by paying 10% of their out-of-pocket expenses. Beneficiaries can use this system by making an application at any time to receive the services they require based on their capacities for the activities of daily living. The certified level of nursing care insurance is determined based on an evaluation of an individual's physical and psychological condition. The level 'requiring assistance' comprises two sublevels aimed at preventing nursing care. The level 'requiring care' also termed as 'requiring long-term care' comprises of five sublevels, which range from (1) requiring the lightest care to (5) requiring the most intensive care; the usage limit fee is set according to the certified level of nursing care. Services provided under long-term care insurance include at-home services, home-visit nursing health care, community-based services and institutional services. These services are provided according to the needs of the care-recipient (Health and Welfare Bureau for the Elderly, Ministry of Health, Labour and Welfare 2016). In Japan's long-term care insurance system, support for family caregivers is positioned as a voluntary implementation of community support projects. Additionally, 'the Act on the Prevention of Elder Abuse, Support for Caregivers of Elderly Persons and Other Related Matters' that came into effect in 2006 includes support for carers from the perspective of early prevention; however, it is difficult to state that comprehensive caregiver support is institutionalised.

According to a survey on the relationship of primary carers caring for parents, the spouse of the eldest son decreased from 17.2% to 7.3% over a period of 10 years beginning 2010 (2013, 2019 Comprehensive Survey of Living Conditions, Ministry of Health, Labour and Welfare). Moreover, the number of home-based service users of long-term care insurance increased 3.9

times from 2000 to approximately 3.78 million (Ministry of Health, Labour and Welfare, 2020), and the socialisation of older people's care progressed to some extent. However, as the older population increases and long-term care insurance's financial expansion in the future with government policies shifts to home medical and nursing care (Nakatani 2019; National Council of Reform of Social Security Report 2013), it is believed that the proportion of adult children adopting the role of primary carers will further increase, regardless of traditional gender roles in long-term care. Adult children carers can have a stressful experience in being the primary carer of aged parents, which may lead to depression, anxiety and other adverse effects (Amirkhanyan and Wolf 2006; Lin and Giles 2013; Wawrziczny, Duprez and Antoine 2020). When a child takes on the role of caring for a parent, it reverses their previous relationship and places the child in a difficult situation that they have never experienced before. In such an experience, emotional problems may arise between the parent and the child, including frustration towards the parent (Ar and Karanci 2019; Funk 2010; McDonnell and Ryan 2014; Zienba and Lynch-Sauer 2005) and strained relationships (Donorfio and Sheehan 2001; Funk 2010); moreover, it is possible that deterioration of relationships can have a negative impact on care. Kwak, Ingersoll-Dayton and Kim (2012) noted that sons and daughters who are primary carers feel considerable stress when they come into conflict with one another regarding care. Despite the fact that long-term care is a heavy burden for the primary carer, even when siblings share the carer role, difficulties often arise in how to share caregiving responsibilities that involve decision-making, which, in turn, can cause distress arising from conflict (Lashewicz and Keating 2009; Tadangelo *et al*. 2018). Son *et al*. (2007) noted that the relationship between objective stressors and the health outcomes of the carer is mediated by the carer's subjective evaluation of stressors. Liu *et al*. (2019) examined how the level of depressive symptoms of long-term caregiving differs with the sex of the child caring for the aged parent, as well as the presence or absence of employment. The authors reported that unemployed sons who provide long-term care tended to exhibit particularly high depression levels. Therefore, they noted that it is important to consider the personal feelings of the carer regarding caregiving when they are tied to such a role. Earlier studies revealed that in the patriarchal culture of East Asian countries, a sense of duty remains in which the eldest son's family cares for the aged parents (Lin and Yi 2013); the stronger the sense of duty, the greater the burden felt during caregiving (Lee *et al*. 2018). Furthermore, Tokunaga, Hashimoto and Tamiya (2015) stated that in the traditional family system, it is known that when a man becomes the primary carer, the risk of abuse increases due to limited care skills and overwhelming responsibility. These studies indicate that for carers to continue to providing care while maintaining their physical and mental health, it is vital for each carer to acknowledge their personal stressors and understand how such stressors make them feel.

In recent years, in Japan, attention has been drawn negatively to sons providing care. Although the proportion of sons who provide care is low, at 11.8% of all carers (2019 Comprehensive Survey of Living Conditions, Ministry of Health, Labour and Welfare), the rate of abuse is the highest for caregiving sons (39.9% of 17,249 cases of abuse). Furthermore, 76.3% of older individuals who were abused were women (2018 survey results for the state of treatment based on the 'Act on the Prevention of Elder Abuse, Support for Caregivers of Elderly Persons and other Related Matters' of the Ministry of Health, Labour and Welfare). Lopez-Anuarbe and Kohli (2019) revealed, in quantitative research on the care burden of male carers, that son carers felt more of an overwhelming mental burden compared with husband carers. This study suggests that there may be specific factors underlying the high rate of abuse of mothers by son carers. However, among previous studies of caregiving sons, there are only a few qualitative studies that elucidate their experience with older mothers (Harris 1998; Campbell 2010). Therefore, this study focuses on the following research questions:

(1) Is there an unknown psychological distress peculiar to the caregiving son?

(2) What kind of psychological distress is it?

In this study, we used the following definition for psychological distress: the unique, discomforting emotional state experienced by an individual in response to a specific stressor or demands that result in either temporary or permanent distress to an individual (Ridner 2004).

Methods

Study design

We used a qualitative research method to understand the psychological distress experienced by sons who provide care for aged mothers during their caregiving life. Qualitative research is an academic approach used to describe and offer meaning to life experiences from participants' perspectives (Zuzelo 2012). The sampling method used was purposeful sampling. We accessed several male carers' groups that may have primary caregiving sons residing with their older mothers. We conducted face-to-face, semi-structured interviews with sons who consented to participate in our study. Inductive thematic analysis following Boyatzis was used for data analysis. Inductive thematic analysis is a method for generating code from raw data. It allows a flexible approach as it is not tied to a theoretical framework and can lead to high-quality data analysis through its code generation and analytic processes (Boyatzis 1998). This study was conducted according to the Standards for Reporting Qualitative Research (O'Brien *et al*. 2014).

Participants

The study participants included 13 sons with experience of providing care as the primary carer while residing together with their aged mothers in their 80s or 90s. All caregiving sons belonged to a peer support group comprising only male carers. Participant’s inclusion criteria include sons caring for their mothers, primary carers, mothers in need of care and caring for three years or more.

The participants were aged between 50 and 70 years and had cared for their mothers for 3–16 years. All participants had obtained long-term care insurance services. 13 caregiving sons included two sons who placed their mothers in a residence and four who completed end-of-life care. Among all participants’ mothers, 11 were living with dementia.

Recruitment and sampling

The internet had been searched for a peer support group for male carers, and their representatives were contacted to verify if they had caregiving sons. Eight groups had one or two caregiving sons. Five were referred by the representatives, and seven were directly asked by us after joining these support groups’ meeting. One of the participants was introduced by a university teacher in our laboratory. Eight peer support groups were diverse. Two groups were launched by the Social Welfare Council, one group was launched by municipalities and three groups were launched by non-profit corporations. One group was set up voluntarily, and the last one was set up by the Regional Comprehensive Support Centre with a public organisation. The purpose and significance of the study, coupled with the procedure and protection of personal information, were explained to the sons, in addition to the fact that they can opt out of the study at any time. After our explanation, we conducted interviews on specific dates, times and locations convenient for the participants.

Data collection

We conducted semi-structured interviews in a private room for 1–2 hours using an interview guide and fact sheet. Participants were informed of their rights, and written consent forms were signed by them prior to the interviews. The interviews were conducted at the participants’ homes, at nearby public halls or private room in coffee shops or the meeting rooms used as an activity base for peer support groups according to the participants' choice. The interview questions were open-ended and the responses recorded using a digital recording device. We asked participants to talk about their experiences over time, from the start of caregiving. During their narration, we asked questions and guided participants to talk primarily of experienced difficulties, frustrating matters, feelings that could not be tolerated, issues that they were not aware of how to deal with, changes in the perception of and relationship with their mothers and awkward and uncomfortable feelings. Sample questions were as follows: 'What was the first difficulty you experienced and how did you deal with it?', 'What was it about your mother that was frustrating or intolerable to you?', 'Have you ever felt unsure of what to do?', 'How do you feel about your future outlook?', 'How do you feel about your mother?', 'Do you feel that your relationship with your mother has changed?', 'What is the task that makes you feel resistance and why?' and 'Is there anyone you can rely on?'

Analysis

We conducted analyses using Boyatzis' thematic analysis using an inductive approach (Boyatzis 1998). Verbatim records were created from recorded interviews. The verbatim records were read several times; on grasping the content, we extracted data involving psychological distress, which we then coded. The data of one individual were analysed, and similar data from the second and subsequent individuals were summarised as a code. Furthermore, new codes that had not been summarised in the existing similar data were added as required. After extracting the codes from all verbatim records, we raised the level of abstraction and created new codes. Upon repeatedly comparing and examining new codes, we extracted the themes. When raising the level of code abstraction, we created definitions for each code and verified the validity of the analysis. During the analysis, no new code appeared from the 12th participant. It also included caregiving sons of various backgrounds (married, unmarried, divorced and bereavement of wife). Most of the patterns of the characteristic data of the caregiving sons could be comprehended from participant responses. Each process was supervised by an experienced researcher. To support the analyses, we used MAXQDA 18.2 software.

Ethics

Ethical approval was obtained from the Institute Review Board of the Graduate School of Health Science, Kobe University (No. 552).

Results

Table 1 provides the background characteristics of 13 caregiving sons, aged 50–79 years and cohabiting with their mothers during the caregiving period. Five caregiving sons had a wife; one wife was bedridden and two wives were of de facto marriages. Two sons were widowers and five were unmarried. All 13 participants were eldest sons. Irrespective of the presence or absence of a wife, all sons provided care as the primary carer. Three participants were working at the time of the interview, whereas the remaining participants left their jobs after commencing care. Their mothers were in their 80s or 90s. The caregiving period lasted 1–13 years; 11 mothers were living with dementia. The level of required assistance in the nursing insurance system has been found to vary widely, from level 1 to 5. From the interviews describing psychological distress felt by the sons while caring for their mothers, the following nine themes were created (Table 2): (1) uncomfortable feeling that cannot be mitigated as a son; (2) feeling of futility in being unrecognised as a carer; (3) fear of losing something important; (4) a strong sense of responsibility for one's mother's life; (5) disappointment in being unable to obtain understanding and cooperation from one's siblings in providing care; (6) irritation and anger towards one's wayward mother; (7) guilt about the treatment of one's mother; (8) sense of exhaustion caused by demanding care and (9) experiencing hopelessness and despair.

(INSERT TABLE1 HERE)

(INSERT TABLE2 HERE)

Theme 1: Uncomfortable feelings that cannot be mitigated as a son

Mr H did not want to perform continence care for his mother. However, he took on the role of caregiving alone as the primary carer, and therefore, was unable to avoid continence care, which occurred several times on a daily basis. Having no choice, he kept providing care while feeling that he had nowhere to go. Similarly, Mr J & Mr I initially felt a strong sense of reluctance towards excretion care of their mothers. However, they stated that having left with no choice, their reluctance eventually lowered as they tried their best for excretion care.

> …Now that I think of it, I have good memories, but at the time, I was uncomfortable…After all, it was between different genders. Moreover, the fact that it was my own mother. (H)

> I felt very uncomfortable about my mother's continence care. I was very

> uncomfortable at first, but I got used to it before long. I had no choice because there was no one to do it for me. (J)

> I felt uncomfortable in the beginning… (care for defecation). I felt it was dirty and smelly. (I)

Mr D had his own family and was financially independent; however, his wife died five years ago. His children had left home; currently, he lived with his mother to provide care. He experienced complex feelings that he found difficult to manage about being an adult son living together with his mother for many years to come.

> …You know how some people are very clingy and close to their mothers…but I think it's gross for a grown man to be close to his mother like that. Because I am the complete opposite… My mother has her life, and I have my life, and it makes me feel unpleasant not knowing how much longer we have to share the same space and time together. (D)

The caregiving sons considered 'the care of their mothers' incontinence' and 'living alone with their mothers' as something they did not want to undertake. However, they felt compelled to do so and were distressed as a result.

Theme 2: Feeling of futility in being unrecognised as a carer

All caregiving sons performed caregiving with utmost effort. In doing so, Mr D participated in cooking classes, and each day, he planned nutritional meals and sweets with enthusiasm. Mr A created menus to feed his mother her favourite foods, even if she could only eat a small amount due to gastrostomy. However, despite giving up their own time to provide care with utmost effort, the response they hoped for was not obtained.

> Saying that she wants to return to the countryside probably implies that being cared for here is uncomfortable. (A)

His mother would thank his older sister when she would come occasionally, but to him, who looked after her every day, she took the caregiving for granted, which made him feel worthless.

> (When my older sister visited) my mother would be happier, like a fool. If my older sister came, mother would say sorry, sorry, and thank you. She wouldn’t say anything to me. It was always like that. (D)

Furthermore, when the elder sister believed that the son just cared for his mother for money, she showed her displeasure as follows:

> (My older sister) thought of me like a little brother who couldn’t be trusted. Because I quit work before I got my pension, she thought that I would probably use up our mother’s money…So my sister quickly took the money, and instead of my mother’s bankbook, she did the paperwork to make two cards, one for the bank and one for the postal savings, so my older sister could manage it herself… (D)

They felt that their mothers and siblings should be particularly appreciative of their hard work and dedication. However, the fact that they were not appreciated or even acknowledged was a source of immense frustration.

Theme 3: Fear of losing something important

Several caregiving sons were worried that they might lose something important to them that will be hard to replace, as a consequence of spending most of their time caring for their mothers. A caregiving son in a de facto marriage could no longer leave his mother alone who was rescued by the police while wandering. ‘Fear of losing one’s wife as a result of caregiving’ was created from the son’s anxiety that his wife might abandon him while he is involved in taking care of his mother who has dementia. A caregiving son who behaved with extreme consideration so that his wife would not become sick of living with her mother-in-law (with dementia) and leave, could not express his distress to his wife.

> My mother has dementia, but I don’t want it to bother others, and at that time (when rescued by the police for wandering) I decided that I had to take care of her. From that day onwards, I kept quiet, and (I took my mother into our care) with the determination that I had to take care of her, and if that meant that my wife would leave, so be it…I have to think about my wife, not just about the caregiving itself, I

> have to think about everyone else as well. After all, I had to make time and a place for my wife. When she comes home and is always being told the same thing by my mother, it would be emotionally tough for her, so I always take my mother out. (N)

> I don't burden my family (wife and step-son), either. So, it's me who hand-washes my mother's dirty underwear from incontinence. I'll tell my wife it's no big deal because the washing machine would do the washing…So, my point is, I would always make sure that my wife would never have to wash (my mother's dirty underwear). (N)

Participants' experiences also revealed 'fear of losing one's work as a result of caregiving' as their greatest stress, which was connected with their unexpected absence from work to accommodate the sudden decline in their mothers' health, who were previously well. There is no paid holiday for caregiving, and losing employment because of caregiving would lead to financial hardship and hence, they continued to work. Several sons felt compelled to resign after starting caregiving. As a minority gender in the family caregiving workforce, most sons found it difficult to openly discuss that they were caring for their mothers. Moreover, employers are often less accommodating and understanding about such cases.

> (The thing that was most stressful when working was) when my mom got unwell suddenly, and I had to take her to seek medical care. So I would have to take time off…In particular, when I took too much time off, when I took about 3 days off one week, the CEO said to me, 'Are you taking more days off?', and that 'If you took more days off, I would have to tell HR', and I thought that would be serious, so I told him that I would not take time off anymore. The CEO didn't say anything to me after that. Because I had said that 'I will not take time off anymore'. (I)

> I didn't have time to sleep, so I thought it (balancing work and long-term care) was impossible. After all, I didn't have time to sleep after finishing the housework. …There was no such thing (granny leave). (D)

> I was not considered important by the company (retirement wasn't stopped). …There was no room to think that it was financially okay (about retirement). Mother has dementia and father has such a condition (end of lung cancer)… It's a

> difficult situation, right? (B)

Furthermore, Mr. J watched his mother slowly lose her memories of fun family holidays as a result of dementia, and expressed his feeling at losing his mother he once knew.

> I've been watching that kind of condition (memory disorder due to dementia) for almost 10 years, and the last memory (with her own family) gradually fades.... Her nostalgia is gradually fading. … To describe how I felt, I'd have to say loneliness. (J)

Their jobs, their loving wives and their once vibrant mothers were equivalent of a purpose in life and precious memories for them, and the fear that they might lose something significant while caring for their mothers was distressing.

Theme 4: A strong sense of responsibility for one's mother's life

When providing care at home or during medical treatments at an institution, their mothers' physical condition deteriorated, and they were unable to eat. Therefore, multiple caregiving sons had to decide whether their mothers would undergo a gastrostomy. Other sons faced the choice of whether their mothers should be on a ventilator. It was an extremely difficult choice for them and entailed heavy responsibility. As primary carers, they were forced to make important decisions that could affect the future of their mothers.

> I hadn't asked about my mother's personal wishes, so the question about whether to give her life-sustaining care made me really troubled…In the end, my decision would end her life, if she didn't get treated, if she didn't wear a mechanical ventilator. (E)

Two caregiving sons stated the following when they were forced to decide whether their mothers should undergo gastrostomy.

> My greatest distress was deciding whether or not for my mother to undergo gastrostomy. (A)

> The most difficult decision is whether to have my mother undergo gastronomy… I

> thought it would be better not to make a gastrostomy than to prolong life and become bedridden. ‘Instead, if she can’t eat (at all), your mother can only live for about half a year because it’s just a drip of nutrition’. I was told by the nurse. (J)

The son, who usually takes care of his mothers on his own, spoke about his responsibilities, which he will have to handle alone when his mother is sick.

> If there are many people who can help, I can divide care, but even now, if his mother’s condition gets worse, I can’t say that you help me there, so that’s hard. (C)

They felt a huge responsibility as their decisions and judgements affected their mother’s life, and the fact that they had to endure the consequences of their decisions alone led to distress.

Theme 5: Disappointment in being unable to obtain understanding and cooperation from one’s siblings in providing care

Several caregiving sons harboured feelings of ‘anger towards siblings for their uncooperativeness in caregiving’. Although it does not mean that there was absolutely no contact between their mothers and their siblings, they felt unsatisfied with the frequency of contact, the details of involvement with their mothers and their siblings’ lack of trust in caregiving sons.

> …I got a phone call (from my younger brother) once every 3 to 4 months… I got so angry, he really needed to get a grip …he could have at least called more often… (L)

> …All in all, she (my older sister)’d only talk, and did not help at all with caregiving…I would get into arguments with her. I wondered why I was the only one who had to provide care. (B)

> No, I don’t know. My sister stopped coming home once our mother’s care began. I hope she always comes, but she won’t. (H)

Furthermore, one carer was disappointed in his younger brother who continued to have an attitude as though he wished to end a one-way relationship that had existed at the start of caregiving. The caregiving son stated that he had given up hopes on mending the relationship.

> If a small thing like this triggered such a rage—I believe that there was some built-up tension between (my little brother and his wife) and our mother…In around 2010, they had moved, but they never called me. So when I called (my younger brother) at his home, I heard the automated message that the number was 'not in use'. I went to the city hall to find out their address…I went to visit telling them I wanted to talk about something, but he just said that 'we have nothing to talk about'. And that was it, nothing more…I stopped mending the relationship. It's like they don't want to get involved. (I)

They wanted their siblings to help care for them as children born of the same mother, or at least attempt to understand how difficult it was and to think more about their mothers. However, their feelings were not conveyed to their siblings and they felt discouraged, sad and angry.

Theme 6: Irritation and anger towards one's wayward mother

All four caregiving sons who felt great distress and irritation towards their mothers were caring for mothers living with dementia. They were mostly complaining about how stubborn their mothers are, who, most of the time, would insist on what they wanted, repeat themselves many times, occasionally become aggressive, fail to go to the bathroom and wander and get agitated at night. With these repeated episodes, the sons became emotionally unable to cope and became irritable and unable to shake off feelings, leading them to verbally and physically abuse their mothers.

> …Once she starts going on and on complaining, I sometimes feel like I would go insane….Recently, I'm always shouting, because I am irritated…Let's say I take her to the toilet. I'd ask her to wait a bit until I can free my hands (from cooking). But she won't be able to wait. She would just scream out 'I've finished, I've finished'. (I)

> (I'm annoyed by my mother) When I was pulling my bed against the wall, my mother hated it because there were a lot of ticks on the wall (though it wasn't true), she was stubborn, and she never listened to me… (G)

A caregiving son with a bedridden wife stated the following, as he compared caregiving for his partner to caregiving for his mother living with dementia.

> Well, if I had to say which was harder in one day, I would say caregiving for my mother. My (bedridden) wife is not selfish, and although it's sad that we can't communicate with each other anymore, it is not that emotionally hard, but my mother repeats herself over and over again, like always saying that she's hungry. (A)

According to the narratives of caregiving sons who took charge of their mothers living with dementia, the thought of murdering their own mother has crossed their minds, as they often suffer from lack of sleep due to repeated episodes of their mothers wandering at night.

> I put her to bed, say 'go to sleep', she goes to sleep, but would later open the door to go somewhere, and so when I put her back to bed again, I'd say like 'I'm gonna kill you', and I've even gone to strangle her. Situations do in fact occur that makes me feel that way. (K)

They were physically and mentally exhausted by the repeated problems related to communication difficulties with their mothers living with dementia and behavioural and psychological symptoms of dementia. They could not escape from caring for their mothers and were psychologically trapped in a situation where they were constantly irritated and prone to anger. This frustration was not dissipated and was directed toward their mother, thereby leading to verbal abuse (intemperate language) and violence.

Theme 7: Guilt about the treatment of one's mother

Mr E, who cared for his mother after she underwent surgery for gastric cancer, often took his mother to the hospital when she complained of abdominal discomfort; however, the cause was not detected initially. He regretted blaming his mother and telling her that her repeated concerns were imaginary.

> What I regret the most is why I couldn't be gentler to her…In the end, I couldn't be gentle because I couldn't understand how she felt. I bet she was in pain. If that were the case, I should have treated her differently. (E)

Mr I stated the following about getting irritated at his mother who was selfish and acted at her own pace, regardless of the carer’s business or fatigue.

> （After I struck out at her） I felt very bad about it. And that I did it again. (I)

Mr B was asked in his 30s by his mother if she could rely on him in her old age and had accepted her request. However, his mother sustained a femoral fracture that placed her in a wheelchair, and she required complete assistance to go to the bathroom, in which he felt limited in at-home care, and thus, decided to place his mother in an institution. He stated that he felt guilty about being unable to perform his obligations as the eldest son, failing to keep his promise.

> It was probably when my mother was about 60, I can remember her saying half-jokingly ‘look after me when I get old’…While I felt that I wanted to look after my mother, I was also cowardly in that I didn’t, because I placed my mother in an institution…I do feel bad about that. (B)

They have accepted and taken on the responsibility of caring for their mothers as part of their duty as the eldest son and have been conscious of meeting the expectations of their mothers and being kind to them. However, they felt that they were not living up to these expectations and were immature, and felt guilty.

Theme 8: Sense of exhaustion caused by demanding care

Five of 13 caregiving sons experienced fatigue from caregiving to the extent that they felt that they had reached their limit. They stated that they had to do physical caregiving and housework, work at night, assist with going to the toilet and deal with wandering, thus making them physically and emotionally exhausted. Two caregiving sons spoke in detail about their severe fatigue for caregiving for over 10 years. They had been spending most of their time caregiving after they decided to leave their jobs. Even if the burden of caregiving was so great that it caused them to become mentally and physically unwell, they were confined to performing housework and providing care, leaving them with no alternative.

> In particular, while caregiving one-on-one, and I was exhausted, I thought that I might die if (she got up at night and) I had to look after her bedpan. (D)

> I can't sleep (wandering in the middle of the night). So I'm mentally tired. Oh, what should I do? Let's pretend not to see… (N)

One participant was so physically and emotionally tired that despite using the temporary care service, it did not provide respite. He stated as follows:

(On using temporary care), for the first 2–3 days, I mostly slept. It was like I no longer had any energy to do anything. I felt that I had fallen apart. (I)

They mostly performed their care alone as the eldest son's responsibility, except for the use of care insurance services, and there was no one to take turns. Because their lives revolved around caring for their mothers, they were overwhelmed with physical care and housework on a daily basis without being able to fully rest their bodies and minds.

Theme 9: Experiencing hopelessness and despair

Unmarried caregiving sons without children were anxious about their future, feeling 'anxiety about their own old age' when they could not think of anyone to care for them when they imagined themselves grow old like their mothers did before their eyes.

> …I'm getting old too, and I'm alone. I am the carer right now, but I get anxious when I think about who will look after me when it's my turn to need help when I get really old. (C)

Caregiving sons of mothers living with dementia felt 'anxious about exacerbation of dementia symptoms' as they wondered if they can deal when more symptoms related to the disorder might appear in the near future.

> I'm first anxious about how she will progress as is. Maybe she will become a baby again, because we know that about dementia. I wonder how she will progress, and whether I will be able to cope at that time. (N)

Caregiving sons who do caregiving alone felt 'anxiety about emergencies that can occur in caregiving alone'. They were scared of breaking down or falling ill themselves because they could not rely on their mothers to do anything, such as calling an ambulance. A close second concern was whether they could correctly handle a sudden change in their mothers' health at home by themselves.

> I do not want to think about it, but I am anxious about what I should do if I fell ill at home and would not be able to respond. I absolutely think we all have this fear…Because if the parents reach that kind of age, the children become very old too, including me. (C)

The time spent by caregiving sons on care differs on an individual basis; however, the time spent is enormous. For many years, sons were unable to consider time for themselves since their days were packed with daily work that they performed routinely just to keep going, without knowing how long it would continue. From the data of sons speaking of their state of mind in being unable to think of their own life in relation to the continued caregiving in the future, we have determined the code 'fear of losing one's own life as a result of caregiving'. The sons were found to be pessimistic regarding their future prospects and expressed a desperate state of mind.

> I feel as if my world, and what I want to do in it, disappears slowly (as a result of caregiving). (I)

> If I perform caregiving for 11 years, then one-seventh of my life is taken up by caregiving. I feel like—aw shit!...How much can you torment a child? It's an older version of child abuse. I'm mentally abused. (D)

Although they used long-term care insurance services, they still found themselves in a situation where they did not have sufficient free time. With no means to prevent or solve future undesirable situations, they felt anxiety and despair as they envisaged the bad situations that could happen to them.

Discussion

This study focused on the psychological distress experienced by caregiving sons who serve as their mothers' primary carer. Our findings revealed that the psychological distress of caregiving sons was not only affected by the demands of care but also by various factors, such as participants' uncomfortable feelings as sons; the heavy responsibility carried by the eldest son; negative feelings caused by their relationships with their mother, siblings, and wife and anxiety about their own future. A scoping review focusing on male caregivers revealed stress-related outcomes of caregiving; it was demonstrated that male carers, whether husbands or sons, had lower levels of depression and fewer depressive symptoms than female carers (Robinson *et al*. 2014). However, the findings of the current study revealed that some male carers were exhausted while taking on the responsibility of caring for their mothers as they did not receive support of their close relatives, and thus, felt hopeless about the future. This review has not focussed on caregiving sons in research as female and husband carers; however, our study strongly suggests that we need to find ways to support them. Several caregiving sons were determined to have 'uncomfortable feeling that cannot be mitigated as a son' while caring for their mothers. Psychological experiences revealed by caring sons included uncomfortable sensations encountered when helping their mothers with going to the toilet. Twigg describes that women are allowed access to the body because bodywork, such as dealing with bodily waste, is closely tied to women's lives through motherhood and nurturing; however, men's access to the female body involves a sense of threatening or sexual invasion (Twigg, 2000); Twigg's findings supports the findings of this study.

Furthermore, the parent–child relationship is reversed through continence care, which many carers experience as suffering and embarrassment (Santini, Andersson and Lamura, 2016). From the present study, it is conceivable that caregiving sons experience reversal of the parent–child roles through continence care of their mothers, wherein they are confronted with the fact that the 'mother who had raised them' now is required 'to receive continence care from them', and in this context, they may feel the pain of being forced to transform the image of their mothers. Additionally, family members caring for an older care-recipient must touch the genital area of an older care-recipient of the opposite sex, which is embarrassing and unpleasant for both the carer and the care-recipient (Hayder and Schnepp, 2008; Santini, Andersson and Lamura, 2016). Moreover, Hayder and Schnepp (2008) reported that invasion of the care-receiver's privacy was not a simple task, and that a considerable effort was required to become accustomed to it (Hayder and Schnepp, 2008). In the present study, they were extremely reluctant to help with going to the toilet. It is suggested that they overcame this resistance by becoming familiar with and acquiring care skills that enabled them to recognise and adapt to the care as an everyday necessity rather than an unanticipated requirement.

One caregiving son experienced feelings of discomfort about living with his mother and spoke of distress in continuing to share time and space together with his mother in the future. It suggests that, for this caregiving son, he thought that one element of being an independent adult man was keeping physical distance from his mother. It is conceivable that continuing to cohabit with his mother went against his internalised notion of an adult son (physical distance from their mother, e.g. by having a separate home), which was unpleasant. This uncomfortable feeling is the first finding revealed by this study. Formal carers and home health nurses will need to carefully assess the possibility of psychological distress felt by sons who care for their mothers.

‘Futility in being unrecognised as the carer’ is a theme comprising stories of caregiving sons who provided care on a daily basis with all their effort, without any gratitude from their mothers. The sons were in a situation where they had to spend most of their time each day providing care. They felt bitter at being unrecognised by their mother and their siblings, despite cherishing their mothers and providing care, which could have led to a decrease in self-esteem. Sugihara *et al*. (2008) reported that most Japanese men tend to identify purpose in life with their employment. Therefore, losing the working role might lead to psychological distress. Work is the economic basis for leading one’s life and might provide caregiving sons with a sense of satisfaction and purpose. Caregiving sons who occasionally took leave to care for their mothers feared losing the jobs they cherished, as they had worked hard to maintain their reputation in their workplaces. In Japan, it is rare for men to take some time off work for caregiving (the proportion of men among individuals who take leave for family care is only 0.07%; Ministry of Health, Labour and Welfare 2020). At present, taking a leave from work for caregiving is disadvantageous for the employee’s career. We believe that inflexibility and lack of accommodation and understanding in the workplace increase the fear. Furthermore, some caregiving sons felt ‘fear of losing one’s wife’. Coutinho *et al*. (2017) deduced that negativity in marital relationships has major adverse effects on the body and mind; deterioration of the relationship with one’s wife as a result of caring for one’s mother would be extremely stressful for caregiving sons. Fear of losing one’s wife made caregiving sons perform all the duties related to caregiving by themselves, which they had regarded as unpleasant for their wives. For the son’s wife, the care-recipient is a mother-in-law; the wife may have negative feelings about living together with her. Furthermore, we can easily imagine that the couple’s time together will be reduced, due to the overriding nature of caring for a mother with dementia. Fear of losing something vital to oneself, such as an employment or a wife, can lead to bearing a painful burden alone. Caregiving sons who care for mothers with dementia spoke about their fear of losing one's mother. This was similarly reported in earlier qualitative research examining the experiences of sons and family members caring for the older with dementia (Harris 1998; Van Wijngaarden *et al*. 2018). Boss (1999) noted that when family memories and emotions are lost because of dementia, the family members experience 'ambiguous loss' due to psychological absence wherein 'a loved one is physically but not psychologically present', and such grief cannot be resolved. It is conceivable that the caregiving sons experienced emotions allied with grief, as described by Boss. Weiss (1973) described emotional loneliness arising when close and intimate relationships are lacking, as well as social loneliness arising when individuals are not able to connect well to social networks (e.g. workplaces, relatives, friends and neighbours). Most caregiving sons were in a situation without a spouse, providing care alone while living with their mothers. Caregiving sons who had quit their jobs, had no spouse and spoke of disappointment with their siblings could be emotionally and socially isolated. Previous studies have suggested that caregiving sons rarely have a male role model for caregiving, and that they are not skilled in negotiating and organising the allocation of caregiving, such as putting problems involving caregiving into words and arranging support. Thus, they risk experiencing conflict within the family with regard to caregiving (Harris 2002; Kwak *et al*. 2012). When they contacted their siblings after they were overwhelmed with their caregiving-related stress, they were more than a little upset about the unbalanced sharing of caregiving roles. This may explain why neither their cry for help nor their requirements to be understood was effectively communicated when they did attempt to contact their siblings. Vasileiou *et al*. (2017) reported that the caregiving situation can exceed the carer's abilities, and that a sense of responsibility towards the care-receiver is associated with loneliness, despite the fact that caregiving sons are solely responsible for important decisions taken while caring, which may have reinforced their sense of responsibility. In terms of emotions felt towards their mothers, several caregiving sons spoke of having experienced irritation often while caring for their mothers. In this study, all participants provided care while using long-term care insurance services. However, we reported that many participants could not get sufficient mental breaks in daily life, and therefore, fell into a state of mind of being trapped by built-up irritation. They felt irritated at times when they were busy and wanted their mothers to wait but they would not and when their mothers would stick to their own claims and continued to demand. The findings of previous research suggest that men may perform caregiving as a 'work' (Kramer and Thompson 2002), and there is a risk prioritising rationality and efficiency over consideration of the care-receiver's needs (Saito 2017). This may be the root cause of frustration among caregiving sons, as unexpected time delays and happenings during the day's care schedule prevent them from performing their 'work' on time. Our study findings contrast from those of the previous studies, which revealed that children living with a parent with dementia in care do not suffer from schedule changes (Wawrziczny, Duprez and Antoine 2000). Violence and verbal abuse occurred when individuals could not cope well. When their irritation could not be released in a healthy manner, it turned into anger and inability to control violence and verbal abuse as a means to stop their mothers' demands and abnormal behaviour. Furthermore, we reported that the experience of violence and verbal abuse left them with feelings of regret and self-reproach, which trapped the caregiving son. When the caregiving son raises a hand towards an older mother, there is an obvious difference in strength; the socially accepted norm that 'older should be taken care of, and parents should be respected (Hashizume 2000)' is broken. This is believed to harm the son's internal morality as well as hurt him as an individual. Previous research has found that traditional norms of 'masculinity'—'physical toughness, self-reliance and restrictive emotionality'—hinder men's access to psychological support (McCuske, Galupo 2011). (McCusker, Galupo 2011). The violence and verbal abuse they committed in this study may have occurred as a result of being alone, with no means of releasing their frustration in the face of a lack of psychological support. Participation in a peer support group may have some effect on long-term care stress, but it may not be timely support and caregivers might be too busy to participate. Building a support system that supports the care relationship will be necessary, including distancing or relativising the carer-care receiver relationship. All study participants were eldest sons, and some caregiving sons spoke of the sense of guilt. In Japan, before World War II, civil law stipulated that the eldest son's wife was responsible for the care of the parents in exchange for the eldest son's inheritance (Takagi and Silverstein 2006; Takagi *et al*. 2007). After the war, this system was abolished, and the guidance as to who should carry out the role of caregiving remained vague (Tsutsui, Muramatsu and Higashino 2013; Lee 2016). However, in part, the way of thinking remains: that the eldest son's household must look after their parents. Possibly, the cause of guilt is not keeping one's promise to continue caring for their mothers and lies in the 'sense of duty as the eldest son to care for their parents'. Caregiving sons who experienced a 'sense of exhaustion' performed most of the housework and caregiving, despite using long-term care insurance services; such housework and caregiving caused extreme fatigue. As indicated by previous studies, caregiving activities are time-consuming to the extent that one does not have time to rest; lack of sleep, caused by help with going to the toilet at night and dealing with wandering, was determined to be a cause of severe fatigue in carers (Hayder and Schnepp 2008). We reported that demanding caregiving negatively impacted the physical and mental strength of caregiving sons to the extent that they questioned whether they would die themselves. Despite using day-care services and temporary stay services, the burdens, such as help with going to the toilet at night, are considerable and better night-time care supports are especially desirable.

Caregiving sons felt anxious about reaching their old age, exacerbation of their mothers' dementia symptoms and coping with emergency situations. The psychological distress of caregiving sons is not only limited to feelings about their present situation; it is caused by picturing how the future will evolve, as they imagine it from their present situation. Lin, Chen and Li (2013) reported that becoming the carer for a parent is an event where the carer's own time for leisure, social life and other pleasures is lost to caregiving.

According to McAuliff (2020), perceived caregiving burden is associated with depression (McAuliffe, 2020) and exhaustion to the extent that caregiving sons are unable to imagine a fulfilling life in their own old age, which, in turn, may deprive them of their will to live.

The strengths of this study are threefold. First, the unknown psychological distress of sons who care for their mothers as primary carers is revealed. Second, the cultural aspects of the traditional Japanese family system and relationship between sons and their mothers were among the key factors contributing to psychological distress. Third, it was observed that physical and verbal abuse occurred when carers were psychologically alone in their caregiving. The study findings provide suggestions for long-term care support in regions such as East Asia, where the number of son carers is increasing inevitably because of declining birth rates and ageing population, as in Japan. With the expected rise in the number of caregiving sons in the near future, it is assumed that supporting them will be vital to alleviate the psychological discomfort represented in this study.

Based on the results of this research, I would like to propose four types of support for caregiving sons. The first is to build a system that allows them to consult or express their concerns online 24 hours a day. This study revealed that violence and verbal abuse against their mothers were caused by the caregiving sons being mentally cornered. However, even if a long-term care consultation desk is set up at the Community Comprehensive Care Centre, few sons will go out for daily consultation in a situation where they do not have time. Furthermore, at present, participation in the peer support group is a fixed day, i.e. once or twice a month, and it may not be possible for caregiving sons to participate owing to their mothers' care and housework. Men have a tendency to keep their problems to themselves (McCusker & Galupo, 2011), thus creating a system that allows them to consult at any moment is vital to avoid accumulation of small daily stresses. Second, since sons continue to provide endless care, having a few weeks of time to be completely free from long-term care is important on a regular basis from the beginning of long-term care. As the current long-term care insurance system limits the amount of services that can be used at the long-term care level, it is necessary to improve the system so that the respite period can be secured. Third, if caregiving sons have siblings, we propose that care management services include opportunities to coordinate relationships between siblings from an early stage to ensure understanding and cooperation in caring for them. Finally, we propose the development of an assessment sheet to identify the risk of violence and verbal abuse based on the psychological distress identified in the results of this study.

Limitation of the study

Participants of this study were caregiving sons who had already used long-term care insurance services and were receiving support through participation in peer support groups. Furthermore, they were financially independent. We believe that this research should be expanded to include caregiving sons without financial independence who rely on their parents' pensions and caregiving sons who do not participate in peer support groups to better understand the psychological distress of caregiving sons and support strategies.

Conclusion

In this study, an unknown psychological distress of sons who take care of their mothers as primary carers has been revealed.

Caregiving sons were responsible for their mothers' care, as there is still a family tradition in Japan that the eldest son's family takes care of the parents. Their inability to rely on their siblings and having to take care of their mothers at night and perform housework left them exhausted and despairing. This distress accumulates, resulting in violence and verbal abuse. The study findings revealed that there are caregiving sons who undertake the responsibility of caring for their mothers in a harsh environment, and that violence and verbal abuse by sons may significantly be influenced by the environment in which they are psychologically alone in caring for their mothers while sustaining physical exhaustion. In Japan and other East Asian countries where the number of caregiving sons are expected to increase in the near future, this study will be a valuable source of information that strongly emphasises the need to establish a caregiving support system for mothers.

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Table 1: Summary of caregiving sons

Subject	Age	Spouse	Employment status at the time of the interview	Age group of mother	Level of required assistance*	Years of caregiving	Mother with dementia	Mother's disease/condition
A	60+	Yes	Self-employed	90+	Long-term care 3	3 years	Yes	Dysphagia and gastrostomy
B	60+	No	Unemployed	90+	Long-term care 4	8 years	Yes	Unoperated femoral neck fracture
C	60+	No	Unemployed	80+	Long-term care 5	6 years	Unknown	Schizophrenia
D	60+	No	Unemployed	90+	Long-term care 1	7 years	Yes	-
E	50+	No	Part-time job	80+	Long-term care 1	8 years	Yes	Gastric cancer
F	50+	No	Public servant	80+	Long-term care 1	9 years	Yes	-
G	60+	Yes	Unemployed	90+	Long-term care 3	10 years	Yes	After surgery for intestinal obstruction
H	60+	No	Unemployed	80+	Long-term care 5	11 years	Yes	Femoral neck fracture
I	60+	No	Unemployed	90+	Long-term care 5	12 years	Yes	Cerebral ischaemia and cardiac bypass surgery, with aspiration pulmonitis
J	70+	Yes	Unemployed	90+	Long-term care 5	13 years	Yes	Heart disease
K	70+	Yes	Unemployed	90+	Long-term care 5	14 years	Yes	
L	60+	No	Unemployed	80+	Long-term care 4	15 years	Unknown	Atrial fibrillation, disturbance of consciousness following surgery for extradural haematoma
M	50+	Yes	Unemployed	80+	Long-term care 2	16 years	Yes	Depression

* Certification level : Long-term care 1 is the lightest care, and long-term care 5 is the heaviest care.

Table2: Summary of themes

Theme	Code
Uncomfortable feelings that cannot be mitigated as a son	Uncomfortable feeling about toileting care of one’s mother who is an individual of the opposite sex. Feeling independent as an adult male but trapped in that one cannot leave one’s mother.
Feeling of futility in being unrecognised as a carer	Feeling of uselessness in being unable to provide a satisfying life for the mother at home. Feeling of being worthless in that the older sister is thanked but oneself is not and that one’s caregiving is taken for granted. Feeling of futility in not being trusted by the older sister as the carer.
Fear of losing something important	Fear of losing one’s wife as a result of caregiving. Fear of losing one’s work as a result of caregiving. Fear about losing the parent–child relationship due to dementia.
A strong sense of responsibility for one’s mother’s life	Heavy responsibility in having to make the decision for the mother to wear a mechanical ventilator. Difficulty making the decision on one’s own about gastrostomy to prolong life.
Disappointment in being unable to obtain understanding and cooperation from one’s siblings in providing care	Anger towards one’s siblings for their uncooperativeness in caregiving. Disappointment towards one’s siblings who cut ties at the start of caregiving for the mother.
Irritation and anger towards one’s wayward mother	Irritation towards one’s mother who manipulates her son by acting selfishly and on her own accord. Anger at losing control of oneself and hurting one's mother. Irritation that one immediately hits one's mother.
Guilt about the treatment of one’s mother	Guilt in being unable to be gentle to one’s mother. Regret in shouting at and raising a hand on one’s mother. Sense of guilt in being unable to keep one’s promise to keep caring for one’s mother as the eldest son.
Sense of exhaustion due to demanding care	Fatigue caused by lack of sleep as a result of caregiving at night. Exhaustion of energy because of demanding care.
Expriencing hopelessness and despair	Anxiety about one’s own old age. Anxiety about exacerbation of dementia symptoms. Anxiety about emergency situations that can occur in caregiving alone. Fear of losing one’s own life as a result of caregiving.