Matsumura et al., Int J Nurs Clin Pract 2025, 12: 430
https://doi.org/10.15344/2394-4978/2025/430

International Journal of
Nursing & Clinical Practices

Case Report Open Access

Special issue: Case Study on Psychiatric and Mental Health Nursing

Supporting a Male Family Caregiver through a Community-Based Integrated Support Program for People with Dementia and their Families: A Case Study from Japan

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Abstract

Background: Male family caregivers of people with dementia often face social isolation, emotional distress, and challenges in caregiving, yet few studies have examined effective support strategies for them. This case study explored the experiences of an elderly male caregiver who participated with his wife in an integrated support program for people with dementia and their families, adapted from the Meeting Centres Support Program (MCSP).

Methods: The participant was an 80-year-old man caring for his wife with moderate dementia. The couple attended six sessions over 12 months. Data were collected using pre- and post-program questionnaires (UCLA Loneliness Scale, GHQ-12, Zarit Caregiver Burden Interview), field observations, and semi-structured interviews. Quantitative data were analyzed descriptively, while qualitative data thematically.

Results: Staff promoted discussion and provided empathic support. Initially, the participant spoke about caregiving challenges only when prompted, but gradually began to share his thoughts spontaneously. He described feeling "able to speak freely," suggesting his need for emotional connection was fulfilled. His wife's participation also improved her social engagement, which he viewed positively. Although loneliness slightly increased, mental health and caregiving burden scores remained stable throughout the year.

Conclusion: This single-case study suggests that integrated support program based on MCSP may provide meaningful psychosocial benefits for male caregivers of people with dementia. Individualized encouragement and a psychologically safe group atmosphere appeared to promote emotional expression, reduced anxiety, and improved family communication. While quantitative changes were limited, qualitative findings indicated emotional growth and enhanced relational well-being. Further research with larger samples and longitudinal designs is needed to verify these effects and clarify effective support strategies for male caregivers.

Publication History:

Received: October 25, 2025
Accepted: November 11, 2025
Published: November 13, 2025

Keywords:

Male caregiver; Dementia; Social isolation;Caregiver burden; Community care; Family care; Meeting Centres Support Program(MCSP); Case study

Introduction

The symptoms of dementia bring significant changes not only to the person with dementia but also to the lives of family members and those around them. The progression of dementia and the emergence of behavioral and psychological symptoms of dementia (BPSD) increase the caregiving burden on family caregivers [1,2]. When families find it difficult to cope with such symptoms, home-based care becomes challenging [3], and in some cases, it may become impossible to continue living in their familiar community. Moreover, family caregivers themselves often experience problems such as depression and insomnia [4,5], making support for families caring for people with dementia critically important.

Among family caregivers, male caregivers are particularly prone to isolation and caregiving difficulties [6]. In particular, when the care recipient is a spouse, male caregivers tend to have lower life satisfaction and poorer mental health [7]. Given this, it is important to clarify what types of support are effective for male family caregivers; however, research in this area remains limited.

Town A, located in the Kansai region of Japan, is a small municipality with a population of approximately 7,000, facing both an aging population and population decline. In pursuit of becoming a "community where people can live with peace of mind even with dementia," various dementia-related initiatives are being implemented. One such initiative is the *Integrated Support Program for People with Dementia and Their Families*. This case report aims to describe the process experienced by a couple—specifically, a male caregiver supporting his wife with dementia—who participated in this program, and to explore the meaning of the support provided within it.

The Meeting Centres Support Programme, which served as the basis for the Integrated Support Program, was developed in the Netherlands in 1993. It welcomes people with dementia and their families as a single unit, enabling multiple families to share experiences and feelings alongside the person with dementia. Previous studies have reported that participation in the program reduces feelings of helplessness among family caregivers and delays institutionalization [8]. In Japan, model projects for this program began in 2020, and it has been implemented as a community support service since 2022. Reported outcomes include reduced caregiver burden and improved quality of life [9]. However, studies focusing specifically on male family caregivers remain scarce.

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Citation: Matsumura M, Tokui M (2025) Supporting a Male Family Caregiver through a Community-Based Integrated Support Program for People with Dementia and their Families: A Case Study from Japan. Int J Nurs Clin Pract 12: 430. doi: https://doi.org/10.15344/2394-4978/2025/430

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Conducting this study may help identify what kinds of support are effective for male family caregivers of individuals with dementia and clarify the challenges involved in providing such support.

Objective

This case study aims to describe the one-year course of participation in an integrated support program for a couple affected by dementia and to explore the perceived significance of this program for the male caregiver.

Methods

Case presentation

Mr. B is an elderly male (in his 80s) residing in a small town in the Kansai region of Japan. He is the primary caregiver for his wife, who has been diagnosed with moderate dementia.

His wife's symptoms include short-term memory impairment, insomnia, reduced motivation, and irritability. She attends a day service program once a week but otherwise spends most of her time at home, having minimal interaction with others.

Mr. B expressed a desire for his wife to have more opportunities to engage with people. The public health nurse, who was also concerned that Mr. B might be struggling to communicate effectively with his wife, suggested participation in an integrated support program. Following this recommendation, Mr. B decided to join the program together with his wife.

Intervention

The program was based on the Meeting Centres Support (MCS) model developed in the Netherlands and was adapted to a format that could be implemented by Japanese municipalities.

Public health nurses and care managers (community comprehensive support centers) invited individuals suspected of having dementia and their family caregivers who were considered in need of support. Although the program sought consistent participation by the same members, some participants withdrew or joined during the course. Each session was attended by three to six participants.

Sessions were held once every one to two months at the town's health center and facilitated by public health nurses, care managers, and visiting nurses. The program content was determined collaboratively through discussion among participants and staff, covering a wide range of activities such as music, cooking, and hiking. Each session was designed for people with dementia and their caregivers to participate together.

One staff member was assigned to every one or two participants to observe their behavior and provide individual communication or information when needed. During sessions, staff prioritized creating a supportive and psychologically safe environment rather than applying specific therapeutic techniques.

Data collection

Data were collected through questionnaires, field observations, and semi-structured interviews.

Questionnaires

Participants completed self-administered questionnaires before the first session and after the program concluded. These included:

The **Japanese version of the UCLA Loneliness Scale (Version 3; 10-item)**, which assesses loneliness across a wide age range, including older adults (higher scores indicate greater loneliness) [10].

The **Japanese version of the General Health Questionnaire (GHQ-12)**, which identifies neurotic or depressive tendencies and evaluates mental health status (higher scores indicate poorer mental health) [11].

The **Japanese version of the Zarit Caregiver Burden Interview (ZBI)**, which measures the physical, psychological, and financial burden experienced by caregivers [12].

The reliability and validity of all three scales have been previously established.

Participant observation

The researcher attended each session as a participant observer. Detailed field notes were written immediately after each session, including the date, time, program content, participants' names and relationships, and observations of both the participants and their spouses (facial expressions, verbal exchanges, and behaviors). The researcher also attended post-session staff meetings and recorded the staff's assessments and impressions.

Semi-Structured interviews

Brief semi-structured interviews were conducted individually in a private room immediately after the completion of the program. The main questions were:
“What stood out to you during your participation?”
“What changes did you notice in yourself after participating?”
Interview lasted approximately 12 minutes.

Data collection period

Data were collected between March 2024 and March 2025.

Data analysis

Qualitative data (field notes and interview transcripts) were analyzed using thematic analysis. Two researchers independently coded the transcripts and iteratively developed a coding framework through discussion. Discrepancies were resolved by consensus.

Quantitative questionnaire data were analyzed descriptively by comparing pre- and post-intervention total scores.

Ethical considerations

The study was approved by the ethics review committee of the affiliated institution (Approval No. 24-2). Written informed consent was obtained from both Mr. and Mrs. B prior to participation. All data were anonymized and identifying details were removed to ensure confidentiality.

Results

Participants' behaviors during the program and the support provided (Table 1)

Table 1 presents a summary of the participants' behaviors and the types of support provided by staff across six program sessions. Each session varied in content and participation, reflecting the evolving interaction patterns between Mr. B and his wife.

First session

In the first half of the session, participants freely discussed their daily lives while drinking tea, followed by simple indoor sports games in the second half. The wife initially appeared somewhat tense, but when staff members brought up topics she enjoyed, she gradually became more talkative and humorously expressed mild frustrations about Mr. B's daily behavior. Mr. B listened with a smile, showing no signs of irritation or displeasure.

During the games, the couples formed teams and cheered each other on while also encouraging other groups with smiles. No indications of relationship strain were observed between Mr. and Mrs. B.

Second session

On this occasion, only Mr. B attended; his wife was scheduled to participate but could not get up that morning. The session involved a hike to a nearby temple. Mr. B appeared cheerful and engaged in pleasant conversation with the staff during the walk.

While walking, Mr. B confided to a staff member, "My wife takes sleeping pills, but she often wakes up in the middle of the night saying she sees something, as if she's having hallucinations. When I tell her there's nothing there, she sometimes responds harshly or even becomes violent." He added that his wife had no recollection of these events the next morning, which left him feeling confused.

Hearing this, the staff member recognized challenges in Mr. B's approach to his wife but refrained from offering prescriptive advice. Instead, the staff member listened empathically, showing understanding of his difficult circumstances.

Third session

To facilitate the wife's participation, the program time was changed to the afternoon. Mr. and Mrs. B arrived a little before the scheduled start. That day's session involved a tea gathering to discuss and decide the next activity. Compared to the previous session, Mr. B's hearing seemed to have worsened; he occasionally failed to respond to questions from staff or other participants and sometimes did not react even when others referred to him.

As the oldest participant and someone who enjoyed conversation, Mr. B was asked to deliver closing remarks, which he accepted with modest hesitation. Since his wife was seated beside him, staff refrained from asking him directly about her condition, and Mr. B made no comments about his wife's symptoms or caregiving difficulties.

Fourth session

This session consisted of a hike to a nearby park. Mr. B appeared cheerful throughout and naturally assumed a leadership role, taking the initiative in choosing the route and leading the group. However, he tended to walk ahead at his own pace, without paying attention to his wife or the other participants. Staff intentionally used these moments to walk alongside Mr. B and ask about his wife's recent condition. Mr. B mentioned that he felt her dementia symptoms were progressing but noted that she continued attending medical appointments and day care without issue. Staff informed him that he could consult privately whenever needed.

Previously, Mrs. B rarely went out and often appeared tense or expressionless when interacting with people other than her husband. During this hike, however, she looked relaxed and talked freely about plants and animals that caught her interest, showing less self-consciousness around others. Mr. B watched her with a pleased expression.

Table1: Summary of the Couple's Participation and Behavioral Changes.

Session	Number of Participants	Program Content	Overview of the Couple's Behavior
1st	4	Informal talk about daily lifeand simple indoor games	The wife humorously expressed some dissatisfaction toward her husband, but he responded with a smile, and their interaction remained calm and friendly. During the game, they encouraged each other, and no difficulties in their relationship were observed.
2nd	4	Hiking to a nearby temple	The wife was absent (she could not get up). The husband enjoyed the walk with a smile. When prompted by staff, he confided that his wife often experienced visual hallucinations and occasionally displayed violent behavior at night.
3rd	6	Tea party and discussion	The husband had difficulty responding to others due to worsening hearing loss but shyly agreed when asked to give closing remarks. He made no comments about his wife's symptoms.
4th	4	Hiking to a nearby park	The husband walked at his own pace apart from his wife. When staff asked about her condition, he said her dementia seemed to be progressing. The wife appeared cheerful and interacted naturally with other participants, while the husband watched her with a pleased expression.
5th	3	Making sweets	The wife took the lead in cooking, and the husband, though inexperienced, seemed to enjoy participating. They celebrated the success of their sweets together. The husband also shared personal difficulties with other members, which had not been seen before.
6th	5	Cooking-based program	The husband participated despite poor health and worsening hearing loss. The wife actively interacted with others. The husband paid little attention to her condition and mainly talked about himself.

Fifth session

This session involved baking sweets. Although Mr. B usually handled meal preparation at home, his wife took the lead during the activity. Mr. B struggled somewhat with the unfamiliar steps of baking but participated cheerfully. He did not seem preoccupied with his wife's progress and shared in joy when their sweets turned out well.

Despite his hearing difficulties, Mr. B opened up to other members about his personal challenges, sharing some of his worries. Such self-disclosure had not been observed in previous sessions.

Sixth session

This final session also involved a cooking activity. Mr. B shared with other members that he had recently been ill, was undergoing treatment, and that his hearing loss had worsened.

He expressed some concern about his wife's declining short-term memory. Nevertheless, during the session, Mrs. B appeared cheerful and actively interacted with other participants. She was so engaged that she wrote a note to herself to remember the next session and took it home. Mr. B, however, paid little attention to her condition and mainly spoke about himself.

Participants' Mental Health Status and Perceived Caregiving Burden (Table2)

Table 2 shows changes in the participant's loneliness, mental health, and caregiving burden before and after the program. On the Japanese version of the UCLA Loneliness Scale (Version 3, 10-item), the participant's score increased from 17 before the program to 23 after the program, indicating a slight rise in perceived loneliness.

On the GHQ-12 (General Health Questionnaire, 12-item version), the score changed minimally from 0 to 1, suggesting little change in mental health status.

On the Japanese version of the Zarit Caregiver Burden Scale, the score remained stable at 1 before and after the intervention, indicating no notable change in perceived caregiving burden.

Table 2: Assessment Scores Before and After the Program

Assessment Scale	Pre-program Score	Post-program Score
Japanese version of the UCLA Loneliness Scale (Version 3, 10-item)	17	23
GHQ-12 (General Health Questionnaire, 12-item)	0	1
Japanese version of the Zarit Caregiver Burden Interview	1	1

Results of the short interview

Mr. B initially explained that his wife began attending the group as an opportunity to interact with neighbors. He had been concerned about her tendency to stay at home and rarely go out. However, he expressed great joy at a recent change—his wife now looks forward to attending the group.

Since joining, Mr. B observed that his wife has begun reminiscing about places they used to visit before her dementia diagnosis. He also mentioned that they have recently started planning sports activities and outings together.

Mr. B himself stated that his greatest joy in participating in each session was the friendliness and openness of the staff and other participants, which allowed him to speak freely and comfortably.

Discussion

This case study examined the individual support provided to a male family caregiver who participated in an integrated support program for people with dementia and their families, as well as the changes observed in him over the course of one year. Throughout the program, staff created opportunities for Mr. B to discuss his difficulties and emotions, supporting him through active listening and an empathetic attitude. In the first three sessions, Mr. B talked about his challenges mainly in response to staff questions. However, from the fourth session onward, he began to voluntarily share his own and his family's difficulties. In the interview following the fifth session, he also expressed happiness about being able to talk openly with other participants. These observations suggest that Mr. B's need for communication and emotional connection was partially fulfilled through participation in the program. Furthermore, the individualized encouragement from staff and the group's psychologically safe atmosphere appeared to play key roles in facilitating this outcome.

Male family caregivers sometimes experience a strong sense of responsibility to manage the daily lives of older adults with dementia on their own, accompanied by anxiety and distress over the progression of dementia symptoms [13]. In addition, their social support networks tend to diminish, increasing the risk of isolation from both the community and family members. They continue to provide care under these uncertain circumstances, highlighting the importance of addressing their caregiving-related concerns and emotional burdens [14]. In this case, the staff's supportive involvement and the group's open atmosphere likely helped create a space where Mr. B could interact with others, allowing him to express not only caregiving-related concerns but also personal worries that might otherwise have remained unspoken.

Mr. B initially joined the group because he was concerned that his wife had become homebound, with limited activity and little social contact. However, after participating in the program, he reported that his wife began to look forward to attending the sessions, and they even started planning recreational activities and trips together. The fulfillment of Mr. B's initial expectations suggests that the program contributed to reducing his anxiety and perceived caregiving burden by improving his wife's engagement and his own sense of connection.

However, quantitative assessments using scales of mental health and caregiving burden showed little change in his overall physical and psychological condition. Mr. B's scores indicated that he had minimal mental health concerns and low caregiving burden prior to the intervention, and he appeared to maintain this condition throughout the year despite his wife's symptom progression. In contrast, his loneliness score increased, which did not correspond with his observed behavior during the sessions or the content of his interviews. Previous studies on similar programs have reported decreased loneliness among participating caregivers [15]. Therefore,

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this finding should be interpreted cautiously, and further research with a larger sample is needed to verify the mechanisms and factors influencing such outcomes.

Strengths, Limitations, and Challenges of the Study

This study is one of the few case studies focusing on male family caregivers. It collected and analyzed data on the needs of a husband caring for his wife with dementia in the community, as well as the support available to him. This approach clarified both the needs of male caregivers and potential methods of support.

However, as a single-case study, generalizing these findings to caregivers with different backgrounds is limited. Nonetheless, multiple descriptions in prior studies align with these findings, suggesting a certain degree of validity.

A future challenge is to accumulate further research on support for male family caregivers, whether individual or group-based, to more clearly identify its effectiveness and remaining challenges.

Conclusion

In summary, this single-case study suggests that integrated support program for people with dementia and their families adapted from the Meeting Centers Support Program may offer meaningful psychosocial benefits to male caregivers of people with dementia. Through individualized encouragement and a psychologically safe group atmosphere, the participant was able to express his emotions, share his caregiving experiences, and regain a sense of connection with others. While quantitative outcomes showed little measurable change, qualitative observations suggested emotional growth and improved communication within the family.

However, given the single-case design, further research with larger samples and a rigorous evaluation is required to confirm these observations.

Conflict of Interest (COI)

The authors declare no conflicts of interest relevant to this research.

Author Contributions

Maiko Matsumura: Conceptualization, Methodology, Data collection, Date analysis, Writing – original draft.

Minori Tokui: Conceptualization, Date analysis, Writing – review and editing, Supervision.

Funding

This study was supported by a grant from the Osakagas group Welfare Foundation.
URL: https://www.osakagas.co.jp/company/efforts/fukushi/jyosei/kenkyu_detail.html

Acknowledgments

The authors sincerely thank all individuals who cooperated in the conduct of this study, and especially Mr. and Mrs. B for their participation.

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