



## Case Study

# Self-prevention and self-management of the behavioral and psychological symptoms of dementia: A case study

Yohko Maki\*

Tokyo Center for Dementia Care Research and Practices, 1 Chome-12-1 Takaido-nishi, Suginami, Tokyo, 168-0071, Japan

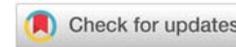
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**\*Corresponding author:** Yohko Maki, Tokyo Center for Dementia Care Research and Practices, 1 Chome-12-1 Takaido-nishi, Suginami, Tokyo, 168-0071, Japan, Tel: +81-3-3334-2173; E-mail: [y.maki@dcnet.gr.jp](mailto:y.maki@dcnet.gr.jp)

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## Abstract

Behavioral And Psychological Symptoms of Dementia (BPSD) are common in individuals with dementia and are associated with poor Quality of Life (QOL) and increased care burden for family members. Managing BPSD, particularly violent behaviors, is essential to improve the QOL for persons with dementia and their families. A 10-week intervention was conducted to empower individuals with Mild Cognitive Impairment (MCI) or early dementia to manage their BPSD independently. Two men participated in the intervention with their wives; both were violent toward their wives. Questionnaire surveys were completed before and at the end of the intervention by the participants and their wives. Case 1 with MCI acknowledged his cognitive decline, expressed self-awareness regarding his violence, and elected to stop his violent behavior to live happier with his family members. Both he and his wife reported improved QOL, and his wife reported reduced violence and care burden. Case 2 with Alzheimer's disease dementia was unmotivated to stop his violent behavior due to declined memory function and lacked awareness of his behavior. While he reported increased QOL throughout the intervention, his wife reported increased violence and care burdens. These findings suggest that when addressing BPSD in persons with dementia, recollection and self-awareness of behaviors is critical for encouraging the objective identification of violent behaviors and increasing motivation to modify behaviors. Therefore, in cases wherein individuals can reflect on their behaviors, encouraging self-management can be effective in preventing BPSD. However, when they are incapable of reflecting on their behaviors, other measures should be taken. In such cases, rather than management, encouragement and strengthening harmonious behaviors may be effective in improving their own and others' QOL.

## Introduction

Aside from cognitive functions, people with dementia experience various Behavioral and Psychological Symptoms of Dementia (BPSD), including irritability, anxiety, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes [1]. Approximately 97% of persons living with dementia experience at least one BPSD [2,3], and the presence of BPSD is associated with poor outcomes, such as decreased Quality of Life (QOL) for both persons diagnosed with dementia and their caregivers, increasing caregiver burden, long-term hospital stays, institutionalization, and misuse of medications [4,5].

Among the BPSD, aggressive behaviors may present notable challenges for the caregivers of persons with dementia

[6] to manage as many of these behaviors begin with relatively calm behavior but then escalated and develop into violence [7]. Thus, identifying the triggers for these behaviors based on assumptions from previous behaviors is reported to be helpful [6,8], as is taking preventative measures for de-escalation. However, in actual cases, identifying triggers is challenging because the manifestation of BPSD is multifaceted with various complicated factors [1]. Thus, antipsychotic medications are often prescribed, in cases when their behaviors represent a significant safety risk for persons with dementia due to its side effects, such as serious extrapyramidal side effects, including Parkinsonian symptoms (e.g., bradykinesia, akinesia, tremor, and muscle rigidity) [9] and increased mortality [10,11]. Thus, there is still a need to devise non-pharmacological approaches to manage BPSD to improve the QOL of persons with dementia and their caregivers [12].

## Self-prevention and management of BPSD for improving QOL

While efforts to manage BPSD have focused on finding the causes, persons with dementia tend to be treated as passive care recipients or those whose behaviors are managed. However, it would be desirable for persons with dementia to be as proactive in preventing BPSD as possible to improve their own and their families' QOL [13].

### Awareness of behavioral psychological symptoms of dementia

A prerequisite of behavioral self-management is that persons with dementia have sufficient cognitive function to remember what they did and said and to recognize and modify their behavior, which requires memory and self-awareness. It is well known that memory function deteriorates in persons with Alzheimer's Disease Dementia (ADD), as does self-awareness.

Anosognosia, the lack of self-awareness, is a common symptom of ADD [14–18]. As the disease progresses, persons with dementia have increased difficulty reflecting on their own actions objectively. Persons with ADD often have increasing difficulties in making themselves understood due to language dysfunction, leading some to resort to violence to force others to meet their demands. If they suffer from memory dysfunction and anosognosia, they easily forget what they did and said. Even if they remember what they did, they may have difficulty evaluating their own behaviors objectively due to anosognosia.

Thus, it is critical to reflect upon their behaviors and relationships with others at the stage of Mild Cognitive Impairment (MCI) or in the early stages of dementia when capacities of memory and self-awareness are preserved. The advantage of early diagnosis is the ability to allow them to reflect on ways to help themselves live better with progressive dementia [19]. This case study reports two cases, both of whom regularly engaged in violent behavior before the onset of MCI—one with an awareness of violence and one without. Case 1 was a man diagnosed with MCI due to ADD who was 74 years old, and Case 2 was a man diagnosed with ADD who was 78 years old (both wives were 74 years old).

## Methods

### Intervention: Group intervention

The author conducted a group intervention for older adults with MCI or mild ADD and their spouses. The inclusion criteria included having a diagnosis of MCI or ADD, producing and understanding speech normally, and having an assessed Mini-Mental State Examination (MMSE) [20] score above 20 (range 0–30). The exclusion criterion was having a diagnosis of any psychiatric disease other than MCI or ADD. The intervention consisted of 10 weekly group meetings with four pairs. The other participants included a woman with MCI (MMSE score = 26), aged 76 and her husband aged 78, and a man diagnosed with MCI (MMSE score = 30) who was aged 86 and his wife aged 86.

The purpose of the group meeting was to empower participants to reflect on the source of happiness and empower them to realize the importance of relationships with those close to them, including families and friends who supported them, as having a source of happiness and maintaining good relationships can be significant to live well with dementia [13].

In the first group session, participants were expected to reflect on their own source of happiness using the SMILE chart (Self-Management of autonomous Interdependent Life Empowerment; Figure 1), a model for self-management support [13]. The SMILE approach asks persons with dementia and their families, "What makes you happy?" and encourages them—along with others in their life—to take the initiative in improving their emotional and social health. This process emphasizes self-determination and self-management, guiding persons with dementia to independently establish a holistic goal for their own lives (i.e., the answer to, "What makes you happy?") and to consider how they can accomplish it in terms of eight components. Reorganizing one's lifestyle to encourage physical exercise and mental stimulation reportedly helps to protect against dementia onset and progression [21]. Social participation has similar effects in epidemiological research [22] and a narrative review [23]. Volunteering reportedly confers similar benefits [24].

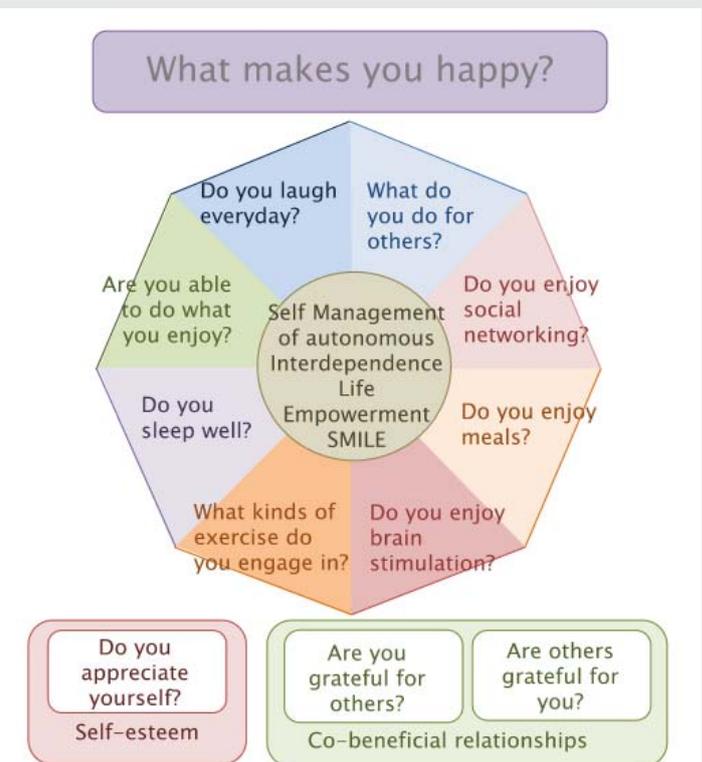


Figure 1: Self-Management of autonomous Interdependent Life Empowerment: SMILE

Participants with mild cognitive impairment/dementia and their spouses are required to identify what makes them happy. Then, they consider how to build a lifestyle to pursue their source of happiness. Through fulfilling the items, they are expected to realize that everyday life consists of reciprocal interpersonal relationships and discuss how to live well and collaboratively. As dementia deprives those affected of their independence, interdependence within family members and community, rather than independence, is encouraged.



From the outset, SMILE aims to instill interdependence over independence and emphasizes the psychological aspects of self-affirmation, reciprocity, and social reward. Its goal is to achieve “autonomous interdependence,” valuing autonomy (i.e., the ability to make one’s own decisions) over independence as people lose independence as dementia progresses. Moreover, SMILE is designed to encourage gratitude—both giving and receiving gratitude—to present participants’ relationships with others as reciprocal, allowing them to feel needed and affirm their own existence as defined by those relationships. People perceive recognition by others as a form of social reward, which boosts their motivation [25].

SMILE is also intended to give participants fresh recognition of their interdependent relationships by having them take inventory of their lives. Someone with progressive dementia will start to encounter obstacles in their life with time. SMILE does not focus on techniques to help resolve such troubles; instead, it emphasizes cultivating trust between the participants and those around them with the implicit message, “whatever might happen going forward, can be overcome by asking for help from those around you (i.e., your social support), instead of trying to solve the issues by yourself.” A person cannot prepare for all the hardships that dementia might bring; however, when a problem does occur, trust can foster a willingness to proactively search for a solution, including asking others for help. The name was partially inspired by Stage 7e of the Functional Assessment Staging Tool (FAST), an instrument used to assess ADD—“loss of ability to smile” [26]. The idea behind the name is that a person with severe ADD nearing the end of life should still retain the ability to smile

until the point they lose consciousness. This was considered a worthwhile goal because a person should be able to remain in good social health until their final days despite the inevitable loss of independence associated with dementia when they are supported by their interdependent relationships with others. Then, they were empowered to consider the challenges and obstacles to living better with MCI/dementia and determine the measures to overcome them independently. In addition, the participants were requested to express gratitude to their spouses every day. As secure relationships can be a critical factor to living well with MCI/dementia, they were expected to realize what support they need to live well and maintain co-beneficial relationships with those who support them.

From the second to ninth sessions, participants freely shared how they tried to cope with challenges, how they tried to enrich their daily living during the past week, exchanged feedback and thoughts, and encouraged each other. In the last session, the participants were requested to reflect on how to live with MCI/dementia (Table 1).

**Outcomes**

Sense of coherence (SOC) was adopted as the primary outcome of the intervention. Both the persons with dementia and their family members completed the Antonovsky’s SOC scale (score range 0–91, with a higher score indicating higher SOC) [27] at the start of (i.e., baseline) and after the 10-week intervention. This salutogenic model regards a person’s health as subject to the influence of three factors: *Comprehensibility*, the extent to which one can understand their condition and environment, *Manageability*, the extent to which they believe

**Table 1:** The process of intervention.

	Case 1	Case 2
Participant’s self-awareness of cognitive decline, the situation he was in, and his violent behavior.	He was aware of cognitive decline, vague maladaptations in his relationships with others, and his need for support in the near future. He was also aware of his violence.	His self-awareness was declining, and he lacked awareness of his cognitive decline, his understanding of the situation, and his violence toward his wife.
At the beginning of the meetingc		
What makes you happy?	Vegetable gardening; volunteering for security patrol in the community	Joining a community sport team
To make up one’s mind to live better with cognitive decline	He explicitly expressed his hope to continue vegetable gardening and volunteering for security patrol as long as possible despite declining function and to maintain a good relationship with his wife.	He explicitly expressed his hope to continue being on a sports team as long as possible but lacked self-awareness of his cognitive decline.
To consider the challenges and obstacles to living better with MCI/ dementia	Violence toward his wife	He thought that there were no challenges.
What support was needed to continue the source of happiness to live well	Psychological and mental support from his wife	He felt no need to be supported
To maintain mutually beneficial relationships with those who collaborate and support them.	He wished for a good relationship with his wife and his colleagues in voluntary activities.	He believed that he maintained a good relationship with his wife despite his violence and believed that he had good relationships with his team members as a leader.
Gratitude diary	He kept writing a one-line diary every day while his wife wrote nothing. During the process, he realized his wife’s significance.	He wrote in the diary when encouraged by his wife but did not write voluntarily.
After the intervention		
How to live better with disease	He explicitly said that he continued efforts to avoid violence to live well with his family and asked for support from his family. He also confirmed his intention to maintain his sources of happiness as long as possible.	He did not think that he suffered from cognitive decline although he realized that he had received this diagnosis.
Confidence to improve QOL in everyday lives by oneself	He was confident that if he succeeded in avoiding violent behavior, he could improve his QOL independently.	His subjective well-being was relatively high, and he felt no need to change.



they can manage things, and *Meaningfulness*, a perception of deeper significance in one’s daily endeavors. SOC is recommended as an indicator of social health in mild dementia [28] and resilience to manage the burden of care in dementia [29–33].

The other variables were also assessed, including subjective well-being using the World Health Organization–Five Well-Being Index (WHO-5; range 0–25, with a higher score indicating higher well-being) [34], hope using the Hearth Hope Scale (range 0–48, with higher scores indicating higher hope) [35], gratitude using the Gratitude Questionnaire (GQ-6; range 0–35, higher scores indicating higher gratitude) [36], loneliness with the University of California Los Angeles Loneliness Scale (range 0–80; higher scores indicating higher loneliness) [37], and social support using the Multidimensional Scale of Perceived Social Support (range 0–84, higher scores indicating higher social support) [38].

The severity of BPSD was measured using the caregiver’s report using the Neuropsychiatric Inventory Brief Questionnaire Form (NPI-Q; range 0–180, with higher scores indicating higher BPSD) [39], and burden of care was measured using the Zarit Burden Interview (ZBI; range 0–32, higher scores indicating higher care burden) [40]. As violence was not assessed on the NPI-Q, the frequency and severity of violence were measured based on the family’s report.

**Ethical consideration**

This intervention was approved by the National Center for Geriatrics and Gerontology’s Conflict of Interest and Ethics Committee (Approval No.1154).

**Results**

The total scores from the measures for both cases are shown in Table 2. Figure 2 shows changes in the scores from pre- to post-intervention. The scores were reported as percentiles, and the loneliness, BPSD, and care burden scores were reversed to show improvement from pre- to post-intervention.

**Case 1**

At the beginning of the group meeting, the participant’s violence was reported as being severe, occurring approximately

once a week, only toward his wife. Table 1 shows his sources of happiness and responses during the intervention process. His stated sources of happiness were to continue vegetable gardening and engage in volunteer security patrols within the community. However, he shared that he was aware of his declining cognitive function and expressed anxiety regarding his ability to continue engaging in these two identified sources of happiness. He said that he felt some vague maladaptation regarding his ability to communicate with others and would need support in the near future to continue participating in these activities.

In the third session, he suddenly expressed an intention to quit engaging in violent behavior. He said that he needed understanding and cooperation with his wife and that his wife was reluctant to support him due to his violent behavior. He recognized that this violence toward his wife was an obstacle to living better with his wife and decided to stop his violent behavior. He reported that he had wanted to quit being violent numerous times previously but had been unable to do so. However, he realized that due to his declining function, this could be his last chance to modify his behaviors; thus, he needed support from the group members. He also decided to keep a one-line diary to express his gratitude to his wife, although his wife said that she had no feelings of gratitude for him. In every meeting after the fourth meeting, he shared how he attempted to manage his temper and asked for advice and support from the group members; he stated that he continued to write in the diary until his wife received his gratitude. For ten weeks, he succeeded in avoiding violence toward his wife, and his wife began to think of cooperating with him.

Regarding SOC, his *Comprehensibility* score improved from 15 to 23, while his scores for *Manageability* and *Meaningfulness* were almost unchanged (14 to 13, 15 to 16, respectively). His social support (45 to 79), hope (36 to 43), gratitude (18 to 32), and loneliness (33 to 9) scores were improved, but his subjective well-being score decreased (12 to 8). He had insomnia, and the item, “I woke up feeling fresh and rested,” was rated as 0, and the item, “I have felt active and vigorous,” was rated as 1 due to his fatigue.

As for his wife, her reported care burden improved from 9 to 4 points over the course of the intervention. In addition, her

**Table 2:** Questionnaire Scores Before and After the 10-Week Intervention.

			Age (Years)	Gender	MMSE	SOC	WHO-5	Social Support	Hope	GQ-6	Solitude	BPSD	Care Burden
Case 1	Patient	Before	74	Male	26	44	12	45	36	18	47	--	--
		After			52	8	79	43	32	71	--	--	
	Family	Before	74	Female	61	20	46	38	32	58	2	9	
		After			61	15	69	38	31	65	2	4	
Case 2	Patient	Before	78	Male	23	76	21	71	38	29	72	--	--
		After			85	23	80	45	33	78	--	--	
	Family	Before	74	Female	67	16	68	33	28	64	3	12	
		After			67	17	67	35	31	69	8	15	
Total Possible Score					30	91	25	84	48	35	80	180	32

Note. Cognitive functioning on the Mini-Mental State Examination (MMSE); sense of coherence (SOC); subjective well-being on the World Health Organization–Five Well-Being Index (WHO-5); social support on the Multidimensional Scale of Perceived Social Support; sense of hope rated by the Hearth Hope Scale (Hope); sense of gratitude using the Gratitude Questionnaire (GQ-6); sense of loneliness using the University of California Los Angeles Loneliness Scale; severity of behavioral and psychological symptoms of dementia (BPSD) from the Neuropsychiatric Inventory Brief Questionnaire Form; care burden rated by the Zarit Burden Interview



self-reported social support (46 to 69), loneliness (22 to 15) scores improved, while her subjective well-being decreased (20 to 15). Her ratings for hope, gratitude, and BPSD, other than violent behavior, were nearly unchanged (Figures 2A & 2B).

**Case 2**

For Case 2, the severity of violence was augmented, possibly owing to his difficulties controlling the rage. Table 1 shows his

source of happiness—he enjoyed a community sports team as his source of happiness. He believed that he was the team leader despite his cognitive impairments and repeatedly shared this, although according to his wife, he was already unable to act in this capacity, and his perception of being the team’s leader might be maladaptive for the team. As he was unaware of his limitations and cognitive impairment, he did not ask for advice or support. He wanted to have a good relationship with his wife despite being unaware of his violent behavior. He

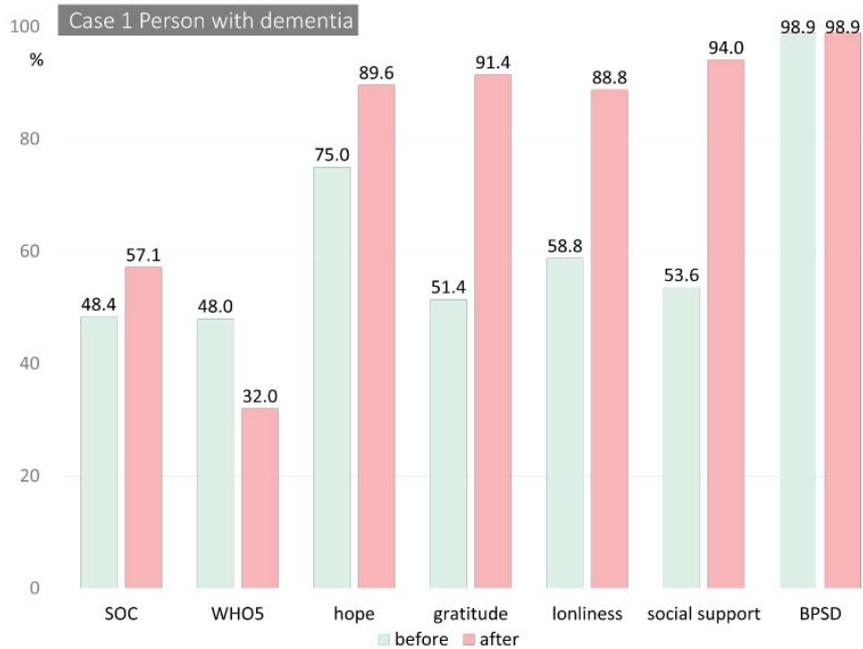


Figure 2a: Shows Case 1 scores for the participant with dementia.

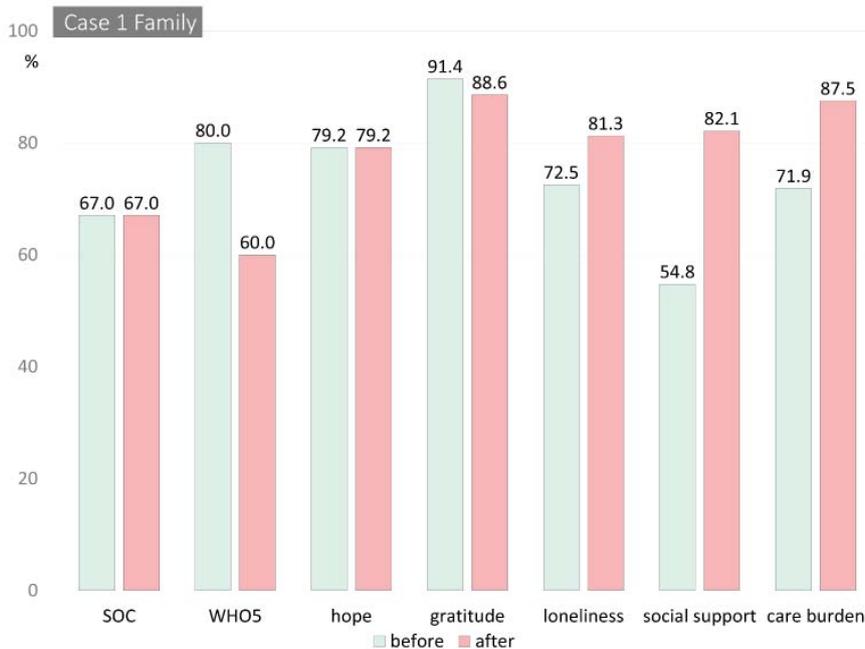


Figure 2b: Shows Case 1 scores for his wife.



was not pretending that he was not violent; rather, he entirely forgot his violent behavior that occurred a few moments previously. Because he was unaware of his violent behavior, he was unmotivated to desist this behavior. His scores on the subjective questionnaire all showed an improvement, although the reported BPSD had worsened (3 to 8; Figures 2C & 2D).

## Discussion

### Self-prevention and awareness

Case 1's self-awareness was well preserved; he was aware of his violent tendencies and could learn to control them over the

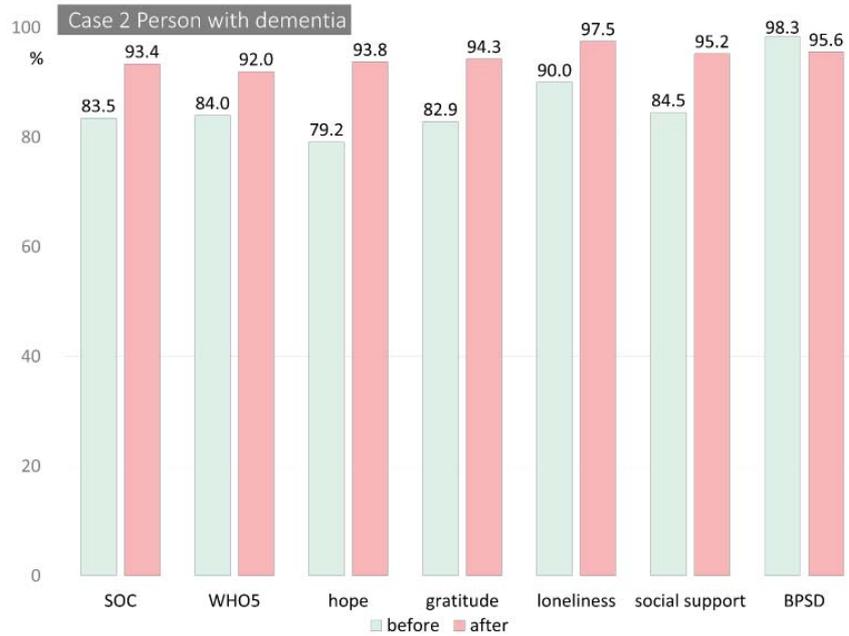


Figure 2c: Shows Case 2 scores for the participant with dementia.

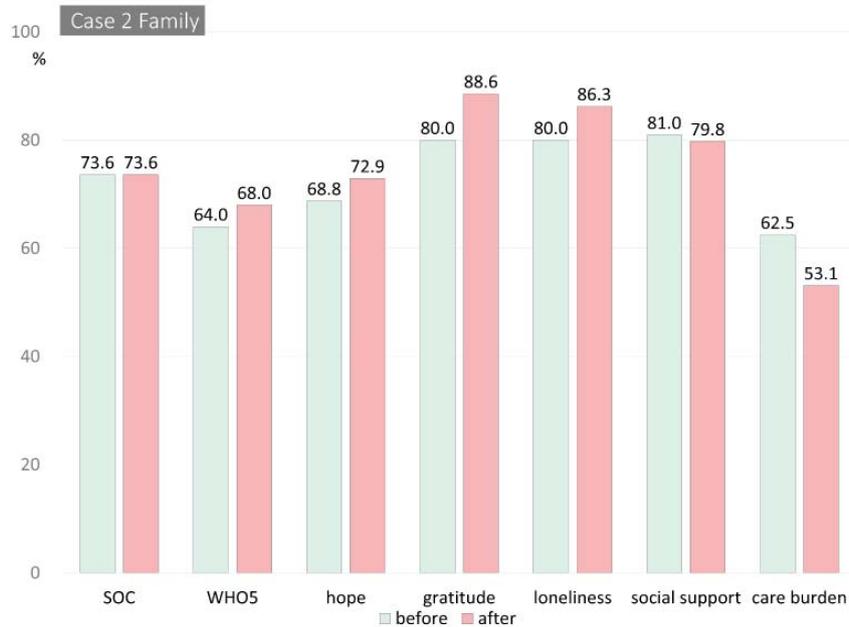


Figure 2d: Shows Case 2 scores for his wife.

Note: (Figures 2a-2d) Cognitive functioning on the Mini-Mental State Examination (MMSE); sense of coherence (SOC); subjective well-being on the World Health Organization-Five Well-Being Index (WHO-5); social support on the Multidimensional Scale of Perceived Social Support; sense of hope rated on the Health Hope Scale; sense of gratitude using the Gratitude Questionnaire (GQ-6); sense of loneliness using the University of California Los Angeles Loneliness Scale; severity of behavioral and psychological symptoms of dementia (BPSD) from the Neuropsychiatric Inventory Brief Questionnaire Form; care burden rated on the Zarit Burden Interview. The scores were reported as percentages with loneliness, BPSD, and care burden scores being reversed to show improvement from pre- to post-intervention.



ten-week intervention with encouragement from the group. The intervention's structure was likely a contributing factor, as it required him to report his process to the group and receive weekly advice for the duration of the intervention. He also explicitly stated each week that he needed his wife's support and cooperation to discontinue his violent behavior, and she also expressed her experiences and thoughts regarding her husband's behavior. Regarding SOC, his *Comprehensibility* score improved from 15 to 23. He clearly recognized his situation and declining cognitive function, could face these difficulties, and asked for support from his wife and the group members every week. After the intervention, his self-reported scores for social support, sense of hope, gratitude, and loneliness improved. His progress over the intervention suggested that he recognized that he could live well with support from his surroundings (i.e., social support), and accordingly, he reported decreased loneliness and increased gratitude to others. Overcoming his violent behavior could have positively led to improved resilience and being able to continue to challenge his declining functioning, which improved his sense of hope for living with MCI. His wife also reported improvements in social support and loneliness and reduced care burden.

In contrast to Case 1, the intervention was found to have no effect on Case 2's violent outbursts. He experienced memory decline and could not remember what he had done when he saw the bruise on his wife's arm immediately after being violent. He appeared to suffer from a decline in self-awareness. Due to his declined memory and self-awareness, it was difficult to motivate him to try and control his behavior.

As for the questionnaires, he reported an increase in all the items. A decline in response reliability is common in questionnaire studies, including research with persons with dementia who have anosognosia. Anosognosia appears to suppress the disease's impact, and those with anosognosia tend to overestimate themselves [41,42]. However, outside informants and the self-perceptions of QOL of persons with dementia have also been found to differ substantially, and to date, neither source of information has been established as being more accurate [43]. Case 2 appeared to experience anosognosia, making it difficult to ascertain that positive changes on questionnaire scores were intervention effects.

### Empowering self-management in those with self-awareness

As with Case 1, for those with sufficient self-awareness to engage in self-reflection and be motivated to modify their behaviors to live better, empowering self-decision-making and self-management can effectively modify behaviors. Thus, in the case of violence, they can decide to modify their behaviors and eliminate inappropriate habits, making it possible for them to be empowered by their self-decision-making and self-management.

One way to live better with MCI/dementia may be to identify the source of happiness, which involves confirming the will to live better in the context of declining function and being willing to receive the necessary support from others. It is desirable to consider the challenges to living better (*comprehensibility*),

decide to overcome the challenges and modify behaviors with support from others (*manageability*), and find meaning in modifying behaviors (*meaningfulness*) [21]. For a meaningful life with dementia and improved QOL, mutually beneficial relationships with those close to them are critical factors for persons with dementia.

### An empowerment approach to strengthen appropriate behaviors for those with insufficient self-awareness

As in Case 2, when self-awareness has declined, it can be difficult to motivate persons with dementia to modify their behaviors as they cannot reflect upon their behavior objectively and may not even remember their behavior. Therefore, empowering self-management cannot be effective in modifying their behaviors based on self-reflection.

Instead of trying to manage behaviors, strengthening their spontaneous behaviors can be effective. After the intervention, he began to use day services for persons with dementia to have opportunities for social interaction. Formal caregivers are typically well-trained to strengthen good communication of persons with dementia. Additionally, because his source of happiness was his participation in a community sports team, Case 2's wife became involved with the sports team to provide support. Because Case 2 had resorted to violence for a long period of time, and it is difficult to manage habitual violence without internal motivation, stopping habitual violence might require longer time. However, persons with dementia are likely to benefit from being empowered and strengthening their spontaneous words and actions to maintain good relationships with others [44,45].

### Conclusions and clinical implications

Social relationships with those close to them are critical for persons with dementia to live well with dementia. The opportunity to independently improve one's QOL is thought to be a merit of an early diagnosis of dementia [19]. During the early stage of dementia, when self-awareness is retained, empowering self-management is recommended for independently reviewing behaviors and attempting to maintain good relationships with those around them to help those with dementia live better with their diagnosis throughout the course of the disease. Once a person with dementia has difficulties with self-reflection, they may find it difficult to objectively review their behaviors and be motivated to modify these behaviors. At such a stage, persons with dementia may benefit from being empowered and strengthening their communication to be motivated to maintain good communication with others. As dementia affects independence, relationships with others and social support are critical for those with dementia to improve their QOL. Therefore, not limiting interventions to the management of BPSD and focusing on strengthening good communication is desirable to help individuals live better with dementia.

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