

## Original Article

# Perceptions of Elderly Japanese on the Effect of In-Home Health Care Services on their Quality of Life

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**Abstract:** In Japan, a growing percentage of elderly individuals are being transitioned from hospital-based to community-based or in-home care. In this study we identified factors affecting the quality of life of elderly people receiving two types of in-home care. Fourteen subjects (age, 78.1±5.0 years) received narrative approach-based, occupational therapy, and 15 subjects (age, 78.7±5.4 years) received non-narrative, non-occupational therapy for 1 year. Subject perceptions on their therapy were evaluated by the content analysis of unstructured and narrative interviews. Main differences in subject narratives were observed for treatment experience, but not for disease or injury experience. In particular, we found that the relationship with the therapist, resumption of activities, communication improvements, acceptance of life events, mental stability and positive outlook are important determinants of quality of life. In conclusion, the quality of life of elderly receiving in-home care can be improved through personal growth and beneficial relationships with supporters.

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**Key words:** Functionally impaired elderly, In-home care, Occupational therapy, Narration, Psychosocial rehabilitation, Quality of life

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## INTRODUCTION

In Japan, government policy is shifting health care for the growing percentage of elderly individuals from hospital-based to community-based or in-home care. The provision of adequate health care and individualized support for the elderly is a prerequisite in the management of a greying society, as is striving to maintain happiness in old age. In the face of a “super-aging” society<sup>1</sup> and given that quality of life (QoL) is largely subjective and therefore difficult to measure via objective testing, the quality of in-home health care requires critical evaluation and effective improvement strategies.

Conventional treatment guidelines based on evidence-based medicine (EBM) have been demonstrated to be effective.<sup>2</sup> However, EBM has also become the subject of controversy,<sup>3</sup> as it is not applicable to all patients or diseases. One example is the physical and mental ailments of elderly individuals at the end of life. Recently, it has been argued that narrative-based medicine,<sup>4</sup> in which patients provide detailed narratives to enable physicians to better understand patients’ circumstances in order to formulate

a holistic treatment approach, should be included into guidelines to broaden the range of evidence in EBM.<sup>5,6</sup>

In line with this development, we have been researching the relationship between the use of narrative-based in-home care services and the QoL of elderly individuals using quantitative and qualitative methodologies. We have shown that while individuals with high and rising QoL scores were predominantly users of narrative-based occupational therapy care services, the use of non-narrative, non-occupational health care services was related to low rising and declining QoL scores, suggesting the importance of narrative-based occupational therapy in the improvement of overall QoL.<sup>7</sup> Factors affecting QoL in elderly home care users remain relatively unexplored.

Here, to reveal factors affecting QoL, in-depth interviews were conducted to survey the perspectives of elderly subjects receiving either narrative-based occupational therapy or non-narrative, non-occupational in-home care. The results complement previous findings and have implications for future health care policies for the elderly.

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## METHODS

### Study Design

A qualitative content analysis study was conducted to explore elderly individuals' perspectives on their in-home care. The study is a follow-up to 2 quantitative studies investigating the QoL of elderly people who were about to receive or had received two types of in-home care. In the first study, the QoL of 200 elderly individuals was investigated before the start of their in-home care services.<sup>8</sup> The second study investigated the QoL of 136 subjects from the same subject pool who received either narrative-based occupational therapy or non-narrative, non-occupational in-home care. In that study, the Philadelphia Geriatric Center Morale Scale (PGC-MS) was used to measure QoL and showed that the QoL scores of the participants changed in five different patterns (or QoL categories) over one year.<sup>7</sup>

The present study was based on subject data from these five QoL categories: 1) high score (PGC-MS score consistently high); 2) low score (PGC-MS score consistently low); 3) rising score (PGC-MS score rose steadily); 4) declining score (PGC-MS score declined steadily); and 5) low rising score (PGC-MS score initially low, but increased gradually). Subjects were selected and interviewed from each of these QoL categories to provide individual in-depth perceptions on their in-home health care, and explored the factors affecting their QoL.

### Subject Selection

For the first study, 200 subjects were selected from 12 home health care centers in the Kansai region of Japan. Subjects whose Mini Mental State Examination<sup>9</sup> scores were less than 24 points were excluded, and those with no major problems in physical status, communication abilities or cognitive functions were selected. After excluding subjects who were hospitalized, or had relocated or died, 136 subjects were able to partake in the second study. For the present investigation, three subjects who had received narrative-based occupational therapy and three who had received non-narrative, non-occupational in-home care for 1 year were randomly selected from each of the five QoL categories (two subjects in case of the non-occupational therapy group in the rising QoL score category), generating 10 groups with 29 subjects in total.

### Treatment Characteristics

Subjects in the narrative-based occupational therapy group had received a weekly visit of 60 min duration by a licensed occupational therapist. The services provided included a physical treatment program, such as training in getting out of bed, moving the extremities or walking with crutches, training for bathing, toileting or dressing, as well as cooking, handicraft, and gardening. They also included a narrative treatment program comprising empathic listening, discussion on the treatment program based on "client-centered therapy", and discussion

on the treatment goals based on a "collaborative therapeutic relationship" between the client and therapist. Subjects in the non-narrative, non-occupational therapy group had received 1 to 5 weekly visits of 60 to 90 min in length by two or three nurses or care workers. Neither a physical nor a narrative program was provided; instead, services included cleaning, laundry, shopping, cooking, management of oral administration, and assistance for dressing, grooming, toileting or meals.

### Data Collection Period and Method

Data were collected between May and October 2014 within 6 months of completion of the 1 year of in-home care. Subjects were interviewed for 60 min at their homes. First, subjects were asked how in-home health care services had affected their life throughout the past year. Following this question, subjects were permitted to talk freely (unstructured interview). The interviewer then asked questions that focused on the context of their speech (narrative interviews). The interviews were audio recorded and transcribed into their written records.

### Data Coding

Coding and categorization were performed using three processes: 1. Open coding: tentative codes were assigned to themes obtained from collected data. 2. Search for categories (themes): themes obtained from open coding were categorized, and tentative codes were modified and converted to coordinate and unified codes. 3. Focal coding: data were reviewed in consideration of obtained themes, and codes were assigned. Finally, codes with similar characteristics were placed in the same category. Coded narrative data extracted from transcripts of the interviews and PGC-MS scores for the one-year period were subject to analysis.

### Data Analysis

Each case was analyzed by conferral among one home-visiting physician, one psychiatrist (HT), two occupational therapists (MI and KH), one clinical psychotherapist, one nurse and two health care workers who jointly conducted the coding process in reference to the works of Esterberg and Ezzy.<sup>10,11</sup> For data analysis, we referenced the subject and structural methods of narrative analysis used by Nomura.<sup>12</sup> Specifically, through the processes of "extraction of events in temporal order," "extraction of narratives suggesting causal relationships between events" and "coding",<sup>13,14</sup> we extracted key themes and categories from subjects' narratives, which we then used to analyze how subjects felt about their health care service. Analyses were performed on the basis of two axes: the first axis consisted of the 5 QoL categories, and the second axis consisted of the 2 home health care conditions, narrative-based occupational therapy and non-narrative non-occupational therapy.

## Informed Consent and Ethical Approval

Subjects signed an informed consent form before the interview was scheduled. The present investigation was approved by the Ethics Committee of Osaka Prefecture University (2012-OT-17).

## RESULTS

### Subject Characteristics

The 29 subjects consisted of 11 males and 18 females with a mean age of 78 years. Additional subject characteristics are listed in Table 1.

### Extraction of Events in Temporal Order

From subjects' narratives, three key themes emerged: disease experience, injury experience and treatment experience (Table 2). Regarding disease experience, many subjects had experienced stomach cancer, cerebral infarction or other serious diseases. Although the subjects suffered different disease profiles, they reported a similar degree of discomfort and suffering. No particular differences were found between QoL categories or treatment groups. Regarding injury experience, the subjects reported discomfort due to their inability to independently take care of themselves. However, no particular differences between QoL categories or treatment groups were found.

In contrast, with regard to treatment experience, substantial found. As Table 2 shows, in the high score category, subjects in the occupational therapy group mainly expressed

their gratitude towards their occupational therapists, while non-occupational therapy / high QoL subjects acknowledged acceptance of their situation. Rising QoL subjects positively and joyfully talked about their daily lives. Occupational therapy / low QoL subjects reported being satisfied with their secure lives, while non-occupational therapy / low QoL subjects tried to think positively of their situation. Declining QoL subjects were dissatisfied with their situation and felt lonely. In contrast,

Table 1 Subject characteristics.

Characteristic	Occupational therapy group	Non-occupational therapy group
Male (N)	6	5
Female (N)	8	10
Age (mean, SD)	78.1±5.0	78.7±5.4
Care level † (frequency)	1(2) 2(5) 3(2) 4(4) 5(1)	1(1) 2(8) 3(3) 4(3) 5(0)
PGC-MS ‡ (mean)	9.00	8.59
MMSE § (mean)	24.5	24.0

Footnotes: † Level of care defined as the amount of time per day required for care according to Japan's nursing care insurance law: 1 (30 to 50 minutes), 2 (50 to 70 minutes), 3 (70 to 90 minutes), 4 (90 to 110 minutes), 5 (110 minutes or more), ‡ Philadelphia Geriatric Center Moral Scale, § Mini Mental State Examination

Table 2 Subject narratives according to key themes.

QoL <sup>†</sup> category	Treatment group	Key themes		
		Disease experience	Injury experience	Treatment experience
High score	Occupational therapy	- I was hospitalized many times. Each time I fell, I suffered a fracture.	- I spend most of my time lying or sitting.	- I can remain mentally sound because the therapist is very kind.
	Non-occupational therapy	- I felt lonely when I underwent stomach cancer surgery because I was alone.	- I am quick to tire and can no longer drive a car.	- The disease gives me the opportunity to consider how I can improve my life.
Rising score	Occupational therapy	- I cannot move my hand due to cerebral infarction.	- I do not want others to see my illness.	- I could once again begin to enjoy my life since the therapist began teaching me Braille. - The therapist made a chair that allows me do embroidery with one hand. Since then, I have been feeling good.
	Non-occupational therapy	- I have Parkinson's disease. I feel as if I am turning into a robot.	- I completely rely on the helper.	- I am enjoying my life more than ever before, and I am looking forward to the rest of my life.
Low rising score	Occupational therapy	- I have difficulties in moving due to rheumatism.	- I spend most time sitting in a wheelchair, which is very tiring.	- I have developed a more positive attitude towards life since I started playing folk music again.
	Non-occupational therapy	- I haven't urinated since I had my kidneys removed.	- I consider why I am living when I see elderly dialysis patients.	- I enjoy sharing time with the helper.
Declining score	Occupational therapy	- I have been receiving home oxygen therapy for a year. - I feel sick after dialysis.	- I am always in bed except when doing rehabilitation with the therapist.	- I feel empty when I exercise alone, and I must refer to the exercise menu the therapist prepared for me.
	Non-occupational therapy	- I ate melon-bread during educational hospital admission because I felt frustrated.	- Because I have diabetes, I am always told that I should not do this and that.	- I want to live as I please. - I am not happy to be alive.
Low score	Occupational therapy	- I have been confined to bed since I lost consciousness due to myocardial infarction.	- It is exhausting and depressing to be confined to the bed.	- Even though I am in a difficult situation, I am able to live thanks to the work of many people.
	Non-occupational therapy	- The left side of my body is paralyzed.	- I do not think the paralysis on the left side of my body will ever be cured.	- I have stopped thinking about my future since the onset of this disease.

Footnotes: † quality of life

low rising QoL and low QoL subjects were found to be mentally stable and to hold positive attitudes about their care.

### ***Extraction of Narratives Suggesting Causal Relationships between Events***

Narratives suggesting causal relationships between events differed between QoL categories (Table 3). Occupational therapy / high QoL subjects were mentally and physically exhausted due to events such as the death of a partner or repeated fractures. However, upon having spent time with their occupational therapists, the subjects gave statements such as “I do not feel lonely.” Furthermore, although non-occupational therapy / high QoL subjects had also undergone difficult experiences, they

positively accepted their situation, providing statements such as “Being sick gives me the opportunity to meet new people, thus making life more enjoyable than I had expected.” Occupational therapy / rising QoL subjects began learning Braille as recommended by their occupational therapists, or resumed embroidery. Non-occupational therapy / rising QoL subjects reported that health care workers helped them maintain a positive attitude and gave them hope for the future. Occupational therapy / low rising QoL subjects stated “After using home health care services for one year, I’ve finally become a little accustomed to this lifestyle”, and non-occupational therapy / low rising QoL subjects reported similar statements such as “I have gotten used to home health care services”, suggesting that they

**Table 3** Subject narratives suggesting causal relationships between events.

QoL <sup>†</sup> category	Treatment group	Narratives	Characteristics
High score	Occupational therapy	<ul style="list-style-type: none"> <li>- When I sit in front of my Buddhist altar and talk to my deceased husband about the therapist, I no longer feel lonely.</li> <li>- The therapist cooked with me after my husband passed away. I can remain mentally sound because the therapist is very kind.</li> <li>- I am grateful to the helper for helping me clean my house, wash my clothes, and do the cooking.</li> <li>- I am grateful to the therapist for helping me have a normal life.</li> </ul>	<ul style="list-style-type: none"> <li>- The occupational therapist helped subjects maintain a positive attitude.</li> <li>- Subjects were grateful to the occupational therapist.</li> </ul>
	Non-occupational therapy	<ul style="list-style-type: none"> <li>- The helper enables me to concentrate on treatment.</li> <li>- I am grateful to have nursing care insurance.</li> <li>- The disease gives me the opportunity to meet people and enjoy my life.</li> </ul>	<ul style="list-style-type: none"> <li>- Subjects were grateful to the helper.</li> <li>- Subjects were satisfied with their current situation.</li> </ul>
Rising score	Occupational therapy	<ul style="list-style-type: none"> <li>- The occupational therapist helps me stay physically and mentally positive.</li> <li>- I do not hesitate to go out or meet people any more.</li> <li>- I am learning Braille from the therapist. This allows me to think I am useful to someone and enjoy my life.</li> <li>- The therapist made a chair that allows me to do embroidery with one hand.</li> </ul>	<ul style="list-style-type: none"> <li>- Support and activities from the occupational therapist helped subjects stay confident.</li> <li>- Subjects' vital functions were improved and subjects' social participation was encouraged.</li> </ul>
	Non-occupational therapy	<ul style="list-style-type: none"> <li>- I completely rely on the helper. This allows me to relax and have a positive attitude.</li> <li>- I am glad to have a helper I can rely on.</li> <li>- I am enjoying my life more than ever and looking forward to the rest of my life.</li> </ul>	<ul style="list-style-type: none"> <li>- Subjects felt secure when they relied on the helper.</li> <li>- Subjects experienced hope for the future (positive feeling).</li> </ul>
Low rising score	Occupational therapy	<ul style="list-style-type: none"> <li>- I did not know how home rehabilitation would improve my life.</li> <li>- I was worried what the helper would do, and what the helper would say about me to others.</li> <li>- I have gotten used to home health care services after having them for a year.</li> <li>- I have developed a more positive attitude towards life since I started playing folk music again.</li> <li>- I have gotten used to home health care services and enjoy spending time with the helper.</li> </ul>	<ul style="list-style-type: none"> <li>-Subjects were anxious about home rehabilitation and having helpers.</li> <li>- Subjects needed time to accept home health care services.</li> <li>- Good relationships with occupational therapists and helpers were important for improvement in subjects' QOL.</li> </ul>
	Non-occupational therapy	<ul style="list-style-type: none"> <li>- At first, I worried whether the helper would really support me.</li> <li>- The helper always supported me with a smile.</li> <li>- I have gotten used to health care services.</li> </ul>	<ul style="list-style-type: none"> <li>- Subjects trusted their helpers and were also grateful to them.</li> </ul>
Declining score	Occupational therapy	<ul style="list-style-type: none"> <li>- I am always in bed except when doing rehabilitation with the therapist.</li> <li>- The therapist is supportive of me, but my family is not. I have no motivation to do anything except for rehabilitation.</li> <li>- I want the therapist to explain to my family that I am not happy to be always confined to bed.</li> <li>- I was upset when my son accused me of only pretending to be a good person when in the company of the therapist.</li> <li>- My family does not understand how sick I feel after dialysis.</li> </ul>	<ul style="list-style-type: none"> <li>- Subjects were upset to know that their families did not understand them.</li> <li>- Subjects were hesitant to ask occupational therapists to do things.</li> </ul>
	Non-occupational therapy	<ul style="list-style-type: none"> <li>- I feel as if instructions from nurses are orders. My nurse is dominant and always keeps an eye on me. Also, because my nurse tells everything to my family, I do not tell anything to my nurse.</li> <li>- The nurses treat me in a businesslike manner and are angry with me each time they come. I am dissatisfied.</li> </ul>	<ul style="list-style-type: none"> <li>- Subjects were dissatisfied with their nurses.</li> </ul>
Low score	Occupational therapy	<ul style="list-style-type: none"> <li>- The occupational therapist is kind and always creates such a joyful atmosphere in which I can forget my pain.</li> <li>- I feel content and fulfilled during occupational therapy.</li> </ul>	<ul style="list-style-type: none"> <li>- Subjects were satisfied with occupational therapy.</li> <li>- Subjects accepted suffering from pain or paralysis.</li> <li>- Subjects were grateful to have security in life.</li> </ul>
	Non-occupational therapy	<ul style="list-style-type: none"> <li>- I enjoy socializing with the occupational therapist and nurse.</li> <li>- I do not think the paralysis on the left side of my body will ever be cured. However, I am grateful for those who support me.</li> </ul>	<ul style="list-style-type: none"> <li>- Subjects accepted suffering from pain or paralysis.</li> <li>- Subjects were grateful to have security in life.</li> </ul>

Footnotes: <sup>†</sup>quality of life

required a longer duration to accept changes in life than rising QoL subjects. Occupational therapy / declining QoL subjects initially reported statements such as “I feel good when having a rehabilitation session with the therapist”, suggesting that these subjects experienced good relationships with their occupational therapists. However, towards the end of the study they made statements such as “I want my therapist to explain to my family that I am not happy to always be confined to bed”, suggesting dependence and dissatisfaction with their therapists. Non-occupational therapy / declining QoL subjects made statements such as “I feel as if instructions from nurses are orders.” Occupational therapy / low QoL subjects stated “feeling low” and “lonely after the occupational therapist leaves,” while non-occupational therapy / low QoL subjects expressed statements such as “I do not think the paralysis on the left side of my body will ever be cured.” Subjects in both groups said negative things; however, occupational therapy subjects also expressed their gratitude stating remarks such as “Even though I am uneducated and poor, my therapist treats me with dignity.” Similarly, non-occupational therapy subjects held positive attitudes and expressed their gratitude with statements such as “I am very grateful to my therapist for supporting me.”

#### *Extraction of Categories from Narrative Themes*

Categories extracted from subjects’ narratives are presented in Table 4.

On brief overview it would seem that there would have been substantial differences in the categories between the high QoL subjects and low QoL subjects. However, subjects in both QoL categories consistently expressed their gratitude to others. Furthermore, there were no substantial differences between the

treatment groups, demonstrating that subjects in both groups shared similar thoughts.

#### **DISCUSSION**

We explored the perceptions of elderly individuals receiving in-home health care services and attempted to uncover factors responsible for changes in or the ongoing stability of their QoL. As a major result, differences in subjects’ narratives between the QoL categories and treatment groups were only observed for treatment experience, suggesting treatment experience has a larger impact than either disease experience or injury experience. Subjects in both treatment groups expressed their gratitude to persons of different occupations and similarly established good relationships with them. Such expression of gratitude went hand in hand with other positive statements, which suggested the subjects experienced mental stability and held a positive outlook. These findings suggest that establishing a good relationship with the therapist / health care worker / family may be the key factor to improving QoL. It is notable that although subjects in both the occupational therapy and non-occupational therapy groups of the low rising QoL category had initially expressed feelings of doubt and anxiety towards in-home health care services, their QoL eventually improved. This suggests that in-home care services should be administered on a long-term basis, as some individuals may require a substantial period of time to become accustomed to the service.

Even though motivators differed between the occupational therapy group and non-occupational therapy group, the act of meeting with the care supporter is considered to have helped subjects stay confident and enjoy life. The rising QoL score eventually exceeded that of the high QoL score.<sup>7</sup> We consider

Table 4 Categorization of subject narratives.

QoL <sup>†</sup> category	Treatment group	Categories
High score	Occupational therapy	“Acceptance of life events” “joyful and positive attitude towards life”
	Non-occupational therapy	“Acceptance of life events” “Satisfaction with life”
Rising score	Occupational therapy	“Regaining of self-esteem” “Regaining of joy of life” “Communications improvement”
	Non- occupational therapy	“Hope for the future” “Harmony with others”
Low rising score	Occupational therapy	“Anxieties about unknown environments” “Expression of self-efficacy” “Feeling of security with others”
	Non- occupational therapy	“Anxieties about unknown environments” “Positive expectancy disconfirmation effects <sup>‡</sup> ”
Declining score	Occupational therapy	“Suffering due to the inability to live independently”
	Non- occupational therapy	“Suffering due to the inability to live independently”
Low score	Occupational therapy	“Gratefulness to all possible events”
	Non- occupational therapy	“Gratefulness to all possible events”

Footnotes: <sup>†</sup> quality of life, <sup>‡</sup> Subjects felt satisfied (dissatisfied) when health care services were better (worse) than their expectations.

that this is related to the subjects' changes in life and their willingness to accept these changes. Occupational therapy / declining QoL subjects and non-occupational therapy / declining QoL subjects complained about their families and caretakers. Such complaints were likely to indirectly reduce their willingness to accept changes in life. We observed that although the subjects understood that the nurses were working hard, the subjects strongly expressed that they did not feel understood by their nurses. Furthermore, the subjects interpreted the nurses' advice to mean that they were being coldly ordered around.

Subjects of both treatment groups in the low QoL score category provided narratives suggesting "gratitude towards any possible event", accepted their situations and expressed gratitude towards their supporters. We consider this passively grateful attitude responsible for the stability observed in their QoL scores. From this perspective, subjects in both treatment groups maintained a "stable feeling of self-esteem," as Rosenberg described.<sup>15</sup>

Occupational therapy / rising QoL subjects expressed many narratives suggesting "regaining self-esteem," "regaining joy of life," and "communication improvement." This was considered attributable to learning Braille and embroidery. Resuming activities enabled subjects to recognize what they could do to regain joy in their lives. "Communication improvement" in rising QoL subjects was also found to be related to resumption of activities. Judging from the subject narratives, if occupational therapists were to encourage elderly to engage in hobbies or other joyful activities, the QoL of the elderly would improve.

Non-occupational therapy / rising QoL subjects provided narratives suggesting "hope for the future" and "harmony with others." QoL scores in the non-occupational therapy group improved despite that there was no "resumption of activities." We consider this related to the subjects' gratitude toward and reliance on their supporters. Therefore, it appears that relationships with occupational therapists and health care workers greatly affect subject QoL regardless of the receipt of occupational therapy.

In the low rising QoL category, occupational therapy and non-occupational therapy subjects provided narratives suggesting "anxiety toward unknown environments." Occupational therapy subjects gave narratives that suggested "expression of self-efficacy" and "feeling secure around others." In the non-occupational therapy group, "expectancy disconfirmation effects" were seen.<sup>16</sup> We consider that while subjects initially expected health care workers to provide support out of a sense of duty alone, they noticed that the health care workers always smiled during visits, thus exceeding the subjects' preconceived expectations.

Occupational therapists understand how to maintain and improve mental functions in those suffering from physical function impairments,<sup>17</sup> and learn from many clients that

accepting difficulties in life enables an acceptance of death and the living of a joyful life.<sup>18,19</sup> Occupational therapists should therefore maintain a sense of modesty and establish the good relationship required to provide individualized treatment on the basis of sympathy and collaboration. If occupational therapists do not try to understand the thoughts and ideas of their clients, or if they treat them unilaterally and dominantly, the clients might lose the chance to become independent or to attain mental and physical recovery, or might even fall into depression.

With consideration to the limited scope of this study, the factors affecting QoL in elderly individuals receiving in-home health care that emerged here were quality of the relationship with the therapist / health care worker / family, resumption of activities / hobbies, communication improvement, acceptance of life events / self, mental stability and positive outlook. Previous studies that investigated the perspectives of older, healthy people living at home on QoL also found that social relationships, activities and psychological wellbeing were among the factors that influenced QoL.<sup>20,21</sup> Similarly, Breggin stated that we can achieve relief through a combination of our personal growth and beneficial relationships with others based on "empathic love".<sup>22</sup> In line with this, the present findings suggest that elderly individuals who receive home health care services can improve their QoL through a combination of personal growth and beneficial relationships with their supporters.

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