

Exploring Home-Visit Rehabilitation for Terminally Ill Patients With Cancer: Insights From Japanese Care Managers

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Abstract

Background: Care managers (CMs) play a vital role in planning, managing, providing family support, and coordinating services for individuals in need, particularly in the field of palliative care. To implement home-visit rehabilitation for terminally ill patients with cancer effectively, it is essential for the care plan created by the CM to be incorporated into the system. Collaboration with the CM is key to ensuring the successful implementation of rehabilitation. Despite this necessity, there is a lack of studies investigating the background and challenges preventing progress in this area. Therefore, this study aimed to clarify the current status of home-visit rehabilitation for terminally ill patients with cancer, focusing on CMs. By identifying associated factors, we aim to suggest guidelines for promoting the use of home-visit rehabilitation to maintain and improve the quality of life of terminally ill patients with cancer in their home settings.

Methods: A self-administered survey was mailed or distributed directly to CMs. It collected the following 11 types of information: gender, age, years of work experience, basic job title, working form, office management system, experience with home-visit rehabilitation (including for terminally ill patients with cancer), perception and importance of this service, and reasons for not implementing it for terminally ill patients with cancer. T-tests or chi-square tests were conducted to examine the association between home-visit rehabilitation experiences and sociodemographic data, as well as the relationship between home-visit rehabilitation for terminally ill patients with cancer, sociodemographic data, and perceptions of and need for home-visit rehabilitation.

Results: Out of 520 questionnaires distributed across seven regions in three prefectures, 388 were returned, resulting in a response rate of 74.6%. After excluding incomplete responses, data from 357 respondents were considered valid. Age ($p = 0.004$), years of work experience ($p < 0.001$), and working form ($p < 0.001$) were found to be related to home-visit rehabilitation experience. A significant association was identified between home-visit rehabilitation experience for terminally ill patients with cancer and years of work experience ($p < 0.001$), and the perception ($p < 0.001$) and necessity ($p = 0.001$) for home-visit rehabilitation.

Conclusions: These results suggest that promoting palliative rehabilitation for terminally ill patients with cancer in home care requires actively encouraging CMs to develop a shared understanding of the services and their role.

Categories: Family/General Practice, Palliative Care, Oncology

Keywords: cancer, care manager, home-visit rehabilitation, palliative rehabilitation, terminally ill

Introduction

The population of Japan is expected to decline after peaking in 2008, but aging will continue to rise rapidly. The aging rate is projected to increase from 20.2% in 2020 to 30.3% in 2025 and 35.3% in 2040, surpassing that of major European countries and the United States [1,2]. This demographic shift presents a significant challenge, particularly regarding the increasing number of deaths among older adults and the urgent need for adequate support.

The Ministry of Health, Labor and Welfare's Survey on Attitudes Toward Medical Care in the Final Stage of Life [3] revealed a strong desire among many individuals to remain at home even when requiring nursing care. Despite this preference, a significant number of people ultimately die in hospitals [1]. This trend is not unique to Japan but is also observed in other countries [4, 5]. Providing medical care services and creating a conducive environment for individuals to remain at home, whether in Japan or elsewhere, is crucial.

In Japan, individuals in need of care can receive a range of services, including some medical services through the universal long-term care insurance system. Care managers (CMs) are the professionals

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responsible for introducing and managing these services. CMs play a vital role in care planning, management, family support, and service coordination for individuals requiring assistance [6–8]. In the field of home palliative care, in particular, CMs must possess a solid understanding of medical knowledge and the roles of medical professionals. However, the content of the care plan may vary depending on a CM's work experience, work style, and previous background in the medical or nursing fields. In the field of rehabilitation, the Classification of Cancer Rehabilitation by Dietz [9] divides rehabilitation into four phases: preventive, restorative, maintenance, and palliative, indicating the role rehabilitation should play at all stages of the disease. Palliative rehabilitation, one of these phases, is essential for maintaining and improving quality of life (QOL) while respecting the wishes of terminally ill patients with cancer and their families [10]. Occupational therapy in palliative care also aims to promote independent living and maintain QOL for as long as possible [11].

In many countries, including Japan, there is a growing recognition of the importance of providing optimal palliative care to support patients with advanced illnesses and their caregivers who wish to remain at home [5]. Several palliative care initiatives for the community have been implemented in Japan as well [12,13], and improved communication and cooperation among regional healthcare professionals, along with increased confidence in the system's ability to care for cancer patients at home, have been identified as key outcomes of these regional palliative care programs. However, despite these efforts, palliative rehabilitation in the home setting remains under-recognized and underutilized. It has been noted that CMs need to serve as coordinators of multidisciplinary teams, including medical and nursing care professionals. However, the main collaborators for CMs are often doctors and nurses, with low rates of collaboration with therapists [14]. As noted, collaboration with the CM is critical for implementing effective home-visit rehabilitation for terminally ill patients with cancer. Despite this necessity, there is a lack of studies investigating the background and challenges preventing progress in this area. Therefore, it is pertinent to clarify the current situation to address these issues effectively.

Therefore, this study aimed to clarify the current status of home-visit rehabilitation for terminally ill patients with cancer, focusing on CMs. By identifying associated factors, we aim to suggest guidelines for promoting the use of home-visit rehabilitation to maintain and improve the QOL of terminally ill patients with cancer in their home settings.

Materials And Methods

Survey participants

The survey targeted CMs operating in western Japan within the service areas of home care support clinics that offer home-visit rehabilitation services and promote home medical care.

Survey methodology

The purpose of the survey was explained in advance. Unmarked, self-administered survey forms were then distributed through the staff of home-visit rehabilitation facilities that agreed to participate (see Appendix for the survey (Appendix A - Japanese version, Appendix B - English version)). These forms were distributed either by mail or in person, and completed surveys were collected via the same methods. We did not send out reminders by mail.

Survey items

The survey included the following 11 questions: gender, age, years of work experience, basic job title, work style, office management system, home-visit rehabilitation experience, home-visit rehabilitation experience for terminally ill patients with cancer, perception and importance of home-visit rehabilitation for terminally ill patients with cancer, and reasons for not implementing home-visit rehabilitation for a terminally ill cancer patient.

The perception of home-visit rehabilitation for terminally ill patients with cancer was rated on a four-point scale from "not at all" (one point) to "very much" (four points). The importance of home-visit rehabilitation for terminally ill patients with cancer was rated on a four-point scale from "not at all" (one point) to "very much" (four points). In addition, respondents were asked to provide their reasons for not implementing home-visit rehabilitation for terminally ill patients with cancer.

The survey items were finalized after consultation with a co-researcher specializing in end-of-life and palliative care. A pretest involving six CMs working in the field was conducted to assess the clarity of the questions, ease of response, and content validity.

Statistical analysis

Initially, we calculated basic statistics for the participants' attributes and the scores for each survey question. A t-test was conducted, after confirming normality, to compare the differences in age and years of work experience between participants with and without experience in home-visit rehabilitation (including for terminally ill patients with cancer).

In addition, we conducted a chi-square test to determine whether there was an association between home-visit rehabilitation experience and office management system (single or establishment), working form (full-time or part-time), and basic qualifications (medical profession or care worker). Another chi-square test examined whether differences existed in the perception and importance of home-visit rehabilitation for terminally ill patients with cancer based on the presence or absence of home-visit rehabilitation experience for this patient group.

We used IBM SPSS Statistics for Windows, version 24.0 (released 2015, IBM Corp., Armonk, NY) for all statistical analyses. All p-values were two-tailed, with significance set at $p < 0.05$.

Ethical considerations

This study was approved by the Ethical Review Committee of Call Medical Clinic Fukuoka (approval number: YC 2013-01). The questionnaire was anonymous and accompanied by a letter of intent explaining the purpose of the study and privacy protection measures. Each questionnaire was mailed with a note emphasizing consideration for the respondents. Returning the completed questionnaire was considered as providing consent.

Results

Response rate

Out of 520 questionnaires distributed across seven regions in three prefectures, 388 were returned, resulting in a response rate of 74.6%. After excluding incomplete responses, data from 357 respondents were considered valid.

Respondents' characteristics

Table 1 presents the demographic characteristics of the respondents. Of the 357 respondents, 56 (15.7%) were men, and 301 (84.3%) were women. The average age was 47.8 ± 9.4 years, ranging from 27 to 70. Individuals in their 40s and 50s accounted for 65.5% of the sample. The mean number of years of work experience was 5.5 ± 3.8 years, with 121 (33.9%) having less than four years of experience.

Item (mean ± SD)		N	%
Sex	Men	56	15.7
	Women	301	84.3
Age (47.8 ± 9.4)	20-29 years old	3	0.01
	30-39 years old	75	21
	40-49 years old	115	32.2
	50-59 years old	119	33.3
	60-69 years old	44	12.3
	Over 70 years old	1	0
Years of work experience (5.5 ± 3.8)	Less than one year	18	5.0
	□ Less than four years	121	33.9
	□ Less than seven years	88	24.6
	□ Less than 10 years	60	16.8
	□ Less than 13 years	56	15.7
	□ Less than 14 years	14	3.9
Working form	Full-time employment	315	88.2
	Part-time work	42	11.8
Office management system	Single	95	26.6
	Establishment	262	73.4
Home-visit rehabilitation experience	Yes	299	83.8
	No	58	16.2
Home-visit rehabilitation experience for terminally ill patients with cancer	Yes	98	27.5
	No	259	72.5
Image of home-visit rehabilitation for terminally ill patients with cancer	I can't picture it at all.	10	2.8
	I can't imagine much.	121	33.9
	I can imagine a few.	187	52.4
	I can image very much.	39	10.9
Necessity for home-visit rehabilitation for terminally ill patients with cancer	I don't feel it at all.	5	1.4
	I don't feel much.	88	24.6
	I feel it a little.	200	56.0
	I feel it very much.	64	17.9

TABLE 1: Demographic characteristics of the respondents

Regarding home-visit rehabilitation experience, 299 respondents (83.8%) answered affirmatively, while 58 (16.2%) indicated no experience. For home-visit rehabilitation specifically for terminally ill patients with cancer, 259 (72.5%) responded negatively, while 98 (27.5%) had experience in this area.

The distribution by occupation is presented in Table 2. In total, 92 respondents (23.3%) were in the medical profession, while 296 (74.9%) were in the nursing profession. Among them, 223 (56.5%) were caregivers, representing 56.5% of the total (7 non-respondents were excluded).

Basic qualifications	N	Classification	%
Nurse	54		
Practical nurse	10		
Public health nurse	6		
Dental hygienist	8		
Pharmacist	3		
Nutritionist	5		
Registered Dietitian	3		
Occupational therapist	2		
Physical therapist	1		
Total	92	Medical profession	23.3
Social worker	51		
Care worker	223		
Social welfare officer	8		
Helper level 2	5		
Helper level 1	2		
Livelihood support consultant	3		
Psycho-social worker	3		
Kindergarten teacher	1		
Total	296	Nursing profession	74.9

TABLE 2: Occupational distribution of the respondents

Factors associated with home-visit rehabilitation experience

The mean age of the respondents with experience in home-visit rehabilitation was 48.5 ± 9.0 years, compared to 44.1 ± 10.3 years for those without experience, indicating a significant difference between the two groups. Similarly, the mean years of work experience for respondents with home-visit rehabilitation experience were 5.9 ± 3.7 years, compared to 3.2 ± 3.5 years for those without experience, also showing a significant difference. In terms of working form, respondents with experience were highly represented across both full-time and part-time work, as well as full-time and concurrent work, with significant differences observed. However, no significant relationships were found for office type and basic qualifications (Table 3).

	Experienced	No experience	p ^a
Mean age (standard deviation)	48.5 (9.0)	44.1 (10.3)	0.004
Mean years of work experience (standard deviation)	5.9 (3.7)	3.2 (3.5)	□0.001
	N (%)	N (%)	p ^b
Office management system			0.746
Single	81 (27.1)	14 (24.1)	
Establishment	218 (72.9)	44 (75.9)	
Working form			□0.001
Full-time	272 (86.3)	43 (13.7)	
Part-time	27 (64.3)	15 (35.7)	
Basic qualifications			0.602
Medical profession	67 (82.7)	14 (17.3)	
Care worker	228 (85.1)	40 (14.9)	

TABLE 3: Factors associated with home-visit rehabilitation experience

a: t-test, b: chi-square test

Factors associated with home-visit rehabilitation experience for terminally ill patients with cancer

The mean age of respondents with experience in home-visit rehabilitation for terminally ill patients with cancer was 49.2 ± 8.8 years, while for those without experience, it was 47.2 ± 9.5 years, exhibiting no significant difference. However, the mean years of work experience for respondents with experience was 6.9 ± 3.7 years, compared to 4.9 ± 3.6 years for those without experience, indicating a significant difference. In addition, there was a significant association between home-visit rehabilitation experience for terminally ill patients with cancer and both the perception of and necessity for such services (Table 4).

	Experienced	No experience	p ^a
Mean age (standard deviation)	49.2 (8.8)	47.2 (9.5)	0.064
Mean years of work experience (standard deviation)	6.9 (3.7)	4.9 (3.6)	□0.001
	N (%)	N (%)	p ^b
Basic qualifications			0.087
Medical profession	28 (34.6)	53 (65.4)	
Care worker	66 (24.6)	202 (75.4)	
Perception			□0.001
High	82 (36.3)	144 (63.7)	
Low	16 (12.2)	115 (87.8)	
Necessity			0.001
Yes	85 (32.2)	179 (67.8)	
No	13 (14.0)	80 (86.0)	

TABLE 4: Factors associated with home-visit rehabilitation experience for terminally ill patients with cancer

a: t-test, b: chi-square test

Reasons for not introducing home-visit rehabilitation for terminally ill patients with cancer (multiple answers allowed)

The most frequently cited reason was “the patient’s family does not want it,” followed by “lack of knowledge about rehabilitation” and “increased financial burden” (Figure 1).

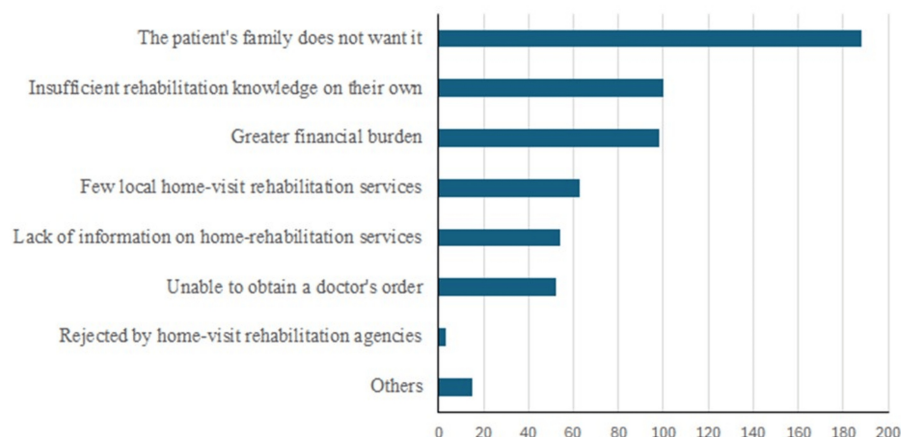


FIGURE 1: Reasons for not introducing home-visit rehabilitation for terminally ill cancer patients

Discussion

Home-visit rehabilitation

Our study revealed that age, years of work experience, and working form were associated with home-visit rehabilitation experience among CMs. Older workers and those with more years of experience tended to have more opportunities for home-visit rehabilitation. This trend may be attributed to the diverse care plans that experienced CMs have encountered throughout their careers. In terms of working form, full-time workers had a higher percentage of home-visit rehabilitation experience compared to part-time workers. This could be due to full-time workers being involved in more cases as care support specialists, working longer hours, and having easier access to knowledge and information on local medical and nursing care, including home-visit rehabilitation.

Studies have reported that joint range of motion training, muscle strengthening, and walking are the top three expected components of home-visit rehabilitation according to CMs, with an emphasis on functional recovery training [15]. In a survey of users, prevention of functional deterioration and exercise guidance were also cited as reasons for initiating home-visit rehabilitation programs [16]. However, in addition to these functional approaches, home-visit rehabilitation encompasses physical therapy to manage movement, occupational therapy to facilitate environmental engagement and independent activities, and speech-language therapy to improve eating, swallowing, and communication. Conducting lifestyle function assessments to address activity limitations and participation restrictions in real-life daily situations is also integral to home-visit rehabilitation.

Another crucial role of CMs is to reduce the burden of caregiving by offering referrals and guidance to family members and caregivers on how to provide assistance. However, inadequate service infrastructure presents a challenge, characterized by a shortage of human resources in both home-visit rehabilitation facilities and therapists, as well as the current dependence on the discretion of CMs [7]. This study highlights the impact of CMs' knowledge and experience on the implementation of home-visit rehabilitation. To promote home-visit rehabilitation effectively, it is essential for each therapist to have a clearly defined and unique role, and for professionals to articulate the content and goals of home-visit rehabilitation in a manner that CMs and other home support staff can easily understand. This collaborative approach is crucial for the successful promotion of home-visit rehabilitation.

Home-visit rehabilitation for terminally ill patients with cancer

Despite a high perceived value and necessity for home-visit rehabilitation for terminally ill patients with cancer, the survey revealed that more than 70% of respondents had not implemented such services. The main reasons cited were "the patient's family does not want it," "lack of knowledge about rehabilitation," and

"increased financial burden."

Regarding "the patient's family does not want it," many families may associate rehabilitation strongly with functional training, making it difficult to envision what it entails at home. This challenge may also arise when "one's own knowledge of rehabilitation is insufficient," making it hard for CMs to explain its role to patients and families. This suggests a lack of opportunities to establish a shared understanding of the content and role of home-visit rehabilitation services for terminally ill patients with cancer. Therapists need to actively engage with CMs to address this gap.

The issue of "financial burden" is not limited to terminally ill patients with cancer but extends to those in the maintenance phase as well [15]. CMs must tailor care plans within the patient's financial means. This reflects the CMs' empathetic approach, considering the financial strain on patients and families, particularly during the terminal stage of cancer when both nursing and medical costs increase. These findings underscore the importance of clearly defining the role of rehabilitation and emphasizing its necessity.

No association was found between basic qualifications and home-visit rehabilitation experience for terminally ill patients with cancer, consistent with the results of a previous study [14]. However, this study is the first to identify an association with years of work experience. In addition, individuals with experience in home-visit rehabilitation tended to have a more positive perception and a greater sense of its necessity compared to those without such experience. These findings suggest that understanding of home-visit rehabilitation for terminally ill patients with cancer is gradually deepening through the practical experiences and involvement of CMs.

This study was conducted in a limited area covering three prefectures and seven regions, which restricts the generalizability of the findings. To obtain broader insights, a nationwide survey would be necessary. In addition, the reasons why terminally ill patients with cancer and their families may refuse home-visit rehabilitation have not been examined in this study. Future research should expand the participant pool and identify factors that either promote or hinder the adoption of home-visit rehabilitation for terminally ill patients with cancer. Despite these limitations, this study has provided valuable insights into the current challenges surrounding the implementation of home-visit rehabilitation for terminally ill patients with cancer in Japan. It is hoped that these findings will contribute to promoting home-visit rehabilitation to help maintain and improve the quality of life for terminally ill patients with cancer in the future.

Conclusions

This study examined the factors associated with home-visit rehabilitation experiences among CMs. The results revealed that age, years of work experience, and work type were related to home-visit rehabilitation experience. A significant association was identified between home-visit rehabilitation experience for terminally ill patients with cancer and years of work experience, as well as the perception and necessity for home-visit rehabilitation. These results suggest that to promote the use of home-visit rehabilitation for terminally ill patients with cancer, it is necessary to encourage CMs without experience in introducing this service to deepen their shared understanding of its benefits.

Appendices

Appendix A

選択肢のない問題では()に該当する言葉や数字を答えてください。選択肢がある場合にはそれぞれ正しいと思うもの、あなたの考えに一番近いと思うものを1つを選び、番号を○で囲んでください。

● あなた自身及び所属についてお尋ねします。以下の質問項目にそれぞれお答えください。

問1. 年齢 () 歳

問2. 性別(1,2より選び丸で囲んでください。)

1)男

2)女

問3. 介護支援専門員としての実務経験年数 () 年

問4. 基本資格(複数回答可)

医師	准看護師	社会福祉士
歯科医師	理学療法士(PT)	介護福祉士
薬剤師	作業療法士(OT)	歯科衛生士
保健師	言語聴覚士(ST)	柔道整復師
看護師	栄養士	管理栄養士
あん摩マッサージ指圧師	義肢装具士	その他()

問5. 勤務形態

1)常勤・専従

2)常勤・兼務

3)非常勤・専従

4)非常勤・兼務

問6. 事業所の型

1)単独型

2)併設型

問7. 訪問リハビリテーションサービスの導入経験

1) 訪問リハ・訪看 I 5共に有

2) 訪看 I 5のみ有

3) 訪問リハのみ有

4) 無

※ 1)~3) を選択した方は、問8にお進み頂き、その後問9にお進み下さい。

※ 4)を選択した方は、直接問9にお進み下さい。

問8. 終末期がん患者に対する訪問リハビリテーションサービス導入の経験

1) 訪問リハ・訪看 I 5共に有

2) 訪看 I 5のみ有

3) 訪問リハのみ有

4) 無

FIGURE 2: Survey form - Japanese version (page 1)

● 終末期がん患者に対する訪問リハビリテーションについて、あなたのお気持ちをお尋ねします。

		全くイメージできない	あまりイメージできない	少しイメージできる	とてもイメージできる
問9.	終末期がん患者に対し、訪問リハビリテーションで何を行うかイメージできる。	1	2	3	4
問10.	終末期がん患者に対する、訪問リハビリテーションサービスの必要性を感じる。	1	2	3	4

問11. 終末期がん患者に対して、訪問リハビリテーションサービス導入に至らない理由として当てはまると思われるものを丸で囲んでください。(複数回答可)

- ・要介護度の限度額を超えてしまうから
- ・経済的負担が大きくなるから
- ・地域の訪問リハビリテーションサービスが少ないから
- ・地域内の訪問リハビリテーションに関する情報が不足しているから
- ・本人家族が希望しないから
- ・自分自身のリハビリの知識が不十分だから
- ・事業所に断られたから
- ・医師の指示が得られないから
- ・その他

()

問12. 終末期がん患者に対して、作業療法士はどのようなことができると思いますか。ご自由にお書き下さい。

FIGURE 3: Survey form - Japanese version (page 2)

Appendix B

For questions with no options, please answer with the word or number that corresponds to the (). If there are options, please choose the one you think is correct or the one that is closest to your idea, and circle the number with a circle.

We will ask you about yourself and your affiliation. Please answer the following questions.

Q1. Age

Q2. Sex
1) Men 2) Women

Q3. Number of years of work experience as a long-term care support specialist

Q4. Basic qualifications (multiple answers possible)
Doctor Associate nurse Social worker
Dentist Physical therapist (PT) Care worker
Pharmacist Occupational therapist (OT) Dental hygienist
Public health nurse Speech therapist (ST) Judo therapist
Nurse Dietitian Dietitian
Anma massage therapist Prosthetist and orthotist Others

Q5. Working form
1) Full-time 2) Part-time

Q6. Office management system
1) Single 2) Establishment

Q7. Home-visit rehabilitation experience
1) Yes 2) No
If you selected 1), please proceed to Q8 and then Q9.
If you selected 2), please go directly to Q9.

Q8. Home-visit rehabilitation experience for terminally ill patients with cancer
1) Yes 2) No

FIGURE 4: Survey form - English version (page 1)

● We would like to ask you about your feelings regarding home-visit rehabilitation for terminally ill patients with cancer.

		I can't picture it at all.	I can't imagine much.	I can imagine a few.	I can image very much.
		1	2	3	4
Q9.	Can you image of home-visit rehabilitation for terminally ill patients with cancer?				
		I don't feel it at all.	I don't feel much.	I feel it a little.	I feel it very much.
		1	2	3	4
Q10.	Do you feel necessity for home-visit rehabilitation for terminally ill patients with cancer?				
Q11.	Please circle the reasons that apply to why you have not introduced home-visit rehabilitation for terminally ill patients with cancer. (Multiple answers possible)				
	•Because it would exceed the maximum amount of nursing care required. •Because the financial burden would be too great. •Because there are few home rehabilitation services in the area. •Because there is a lack of information about home rehabilitation in the area. •Because the person's family does not want it. •Because I don't have enough knowledge about rehabilitation myself. •Because the business office refused. •Because I can't get a doctor's instruction. •Others				
Q12.	What do you think occupational therapists can do for patients with terminally ill patients with cancer? Please write freely.				

FIGURE 5: Survey form - English version (page 2)

Additional Information

Author Contributions

All authors have reviewed the final version to be published and agreed to be accountable for all aspects of the work.

Concept and design: Hitoshi Okamura, Fumiko Kaneko, Kazuya Saita, Satoko Sakaguchi

Critical review of the manuscript for important intellectual content: Hitoshi Okamura, Fumiko Kaneko, Kazuya Saita, Satoko Sakaguchi

Supervision: Hitoshi Okamura

Acquisition, analysis, or interpretation of data: Satoko Sakaguchi

Drafting of the manuscript: Satoko Sakaguchi

Disclosures

Human subjects: Consent for treatment and open access publication was obtained or waived by all participants in this study. Ethical Review Committee of Call Medical Clinic Fukuoka issued approval YC 2013—01. The questionnaire was anonymous, accompanied by a letter of intent explaining the purpose of the study and privacy protection measures. Each questionnaire was mailed with a note emphasizing consideration for the respondents, and the response and return of the questionnaire was considered consent.

Animal subjects: All authors have confirmed that this study did not involve animal subjects or tissue.

Conflicts of interest: In compliance with the ICMJE uniform disclosure form, all authors declare the following: **Payment/services info:** This research was supported by the Yumi Memorial Foundation for Home Health Care. **Financial relationships:** All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. **Other relationships:** All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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