



Original article

Care needs of caregivers of the elderly with early-stage dementia

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Abstract

Objective: This study aimed to identify the care needs of family caregivers of elderly patients with early-stage dementia and examine support measures.

Materials and Methods: We conducted a self-administered questionnaire survey with 115 primary caregivers of outpatients who visited A City Community General Support Center or B University Hospital Department of Neurology for memory loss consultation. The questionnaire content included demographic characteristics, the care needs scale for caregivers of the elderly with early-stage dementia (Care Needs Scale), and the Japanese short version of the Zarit Burden Interview. The Medical Ethics Committee of Fukuoka University approved this study (approval number: M047). Of the 115 participants, 104 were included in the analysis after excluding 11 respondents with missing data. We divided the participants into a young group (under 65 years of age) and an old group (65 years of age or older) and compared the variables and each scale score using the Mann–Whitney U test. We also compared the correlations between the total score and subscale scores of the Care Needs Scale and each variable, in addition, we performed multiple regression analyses using the total score of the Care Needs Scale as the dependent variable.

Results: The young caregivers wanted to know how to take care, prevent deterioration, and deal with symptoms of early-stage dementia. They were trying to balance caregiving with work and housekeeping and reduce the stress and burden of long-term care. Older caregivers were confused about caregiving and wanted someone to talk about their situations.

Conclusion: Both groups shared that the family's lack of understanding about caregiving and personal and role strains were associated with the care needs of caregivers of the elderly with early-stage dementia.

Key words: elderly with early-stage dementia, young caregiver, old caregiver, care needs

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Introduction

In Japan, the population is rapidly aging, and the proportion of the elderly population is estimated to reach 33.3% by 2036¹⁾. As the elderly population increases, the number of patients with dementia is also increasing. By 2025, 1 in every 5 people aged 65 and over, that is, approximately 7 million people, is estimated to have cognitive dysfunction²⁾. The increasing number of elderly people with dementia is

a major social issue because it increases the care burden as well as medical and long-term care costs.

When considering measures against dementia, the pre-dementia stage, known as mild cognitive impairment (MCI), has gained attention. MCI is defined as “a state in which subjective symptoms such as memory loss and disorientation are present, but daily life is independent without cognitive impairment”³⁾. While cognitive function in elderly individuals with MCI is more likely to decline, it often recovers with proper interventions⁴⁾. Therefore, early detection and focused intervention at the pre-MCI stage are essential⁵⁾.

With the early diagnosis of dementia, the number of people with early-stage dementia and MCI has increased in the community. For the person with dementia and family members, the initial stage of dementia is difficult to recognize. The family experiences considerable impact and anxiety when starting to notice abnormalities and suspect dementia. Numoto⁶⁾ states the importance of support for the elderly to live toward integrating their lives in their way and ending

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their long lives with satisfaction while accepting physical changes. As Minooka⁷⁾ mentions, living with dementia is a painful experience as if it were reversing human development. Even those who have already gained integration may face a previously resolved crisis again and enter a process of despair⁸⁾.

The new Orange Plan aims to establish dementia care pathways, improve the response of primary care doctors to dementia, and establish an initial-phase intensive support team⁷⁾. However, the infrastructure of long-term medical care to realize a society where people with dementia can continue to live in their community, while their will is respected, is insufficient^{9, 10)}. We need to solve aging-related problems in various aspects of society¹¹⁾. Supportive practices with direct involvement are required to meet those needs. Although the potential for appropriate care interventions to maintain, ameliorate, and prevent dementia in elderly individuals requiring community support is substantially high, efforts to treat early-stage dementia are insufficient¹²⁾. Providing timely and appropriate medical and long-term care according to the condition of dementia and establishing a system for early diagnosis and intervention are necessary¹³⁾. Petersen *et al.* described the concept of MCI in 1995; they mention that this early phase is the most critical time to prevent dementia due to the lack of standard treatment¹⁴⁾. In the pre-dementia stage of MCI, 14–44% of people recover their cognitive function with appropriate measures¹⁵⁾. In contrast, individuals develop dementia if treated incorrectly during the pre-dementia stage¹⁶⁾. To receive an early diagnosis, a decline in cognitive function and living function needs to be noticed timely by the person with dementia or the family. The early diagnosis and intervention allow the elderly to “continue to live in their own way in a good environment in their community as long as possible”. However, most patients are diagnosed after progression to mild-to-moderate dementia. Even if the family members feel “something strange” about the aged person living together, they do not seek a diagnosis because they think it is a part of the cognitive decline with aging¹⁷⁾. Thus, it is important to know that we can delay cognitive decline and maintain cognitive function by taking appropriate care measures in the pre-diagnosis stage¹⁸⁾.

Kawanishi *et al.*¹⁹⁾ investigated the needs related to dementia care from prevention to post-onset life for middle-aged and elderly people in the community and found the following needs: (1) providing information for dementia care, (2) introducing preventive activities incorporated into daily life, (3) consideration for anxiety about developing dementia, (4) promoting cooperation between medical institutions, and (5) support for envisioning a realistic outlook for life after onset. Aoyagi²⁰⁾ states that the acquisition of the knowledge and information necessary for dementia care depends on the information acquisition ability of family caregivers,

even though support for such caregivers has expanded with community-based integrated care systems. Matsumoto²¹⁾ suggests that the medical-related needs of family caregivers include “daily life-related needs”, “observation needs based on the medical knowledge”, and “needs for a sense of security”. Teraoka²²⁾ reports that family caregivers can [build a subjective strategy] from the experience of taking care of a person with dementia patient at home, [manage to continue long-term care], and [give meaning to the care experience]. However, if there is [disturbance of family relations over long-term care] or [difficulty in using services], family caregivers [control to protect the safety of the care recipient], such as concealing dementia and closing the door. The author states that the support meeting the needs of the entire family, protecting the safety and independence of the care recipients as well as the lives of the family caregivers, should be examined.

This study aimed to identify the care needs of family caregivers of elderly patients with early-stage dementia and examine support methods for improving and maintaining cognitive function by providing appropriate care during early-stage dementia.

Early-stage dementia is a state of MCI one step before the onset of dementia, characterized by self or family complaints of memory loss and preserved general cognitive functions¹⁸⁾. A family caregiver is the primary caregiver who mainly cares for the person with early-stage dementia (also referred to as a caregiver).

Materials and Methods

Subjects and survey contents

We conducted a self-administered questionnaire survey with 115 primary caregivers of outpatients who visited A City Community General Support Center or B University Hospital Department of Neurology for memory loss consultation. The questionnaire items on demographic characteristics included age, sex, and subjective health status of caregivers and age, sex, and care-level status for long-term care insurance of care recipients. We also evaluated the care needs of caregivers of the elderly with early-stage dementia using the Care Needs Scale created by Kimura *et al.*¹⁸⁾ based on their previous study using the Family Caregiver Care Needs Scale by Matsumoto *et al.*^{23, 24)} for reference. The Care Needs Scale consists of 3 subscales and 14 questions, and it is a 4-point scale ranging from 4 (strongly agree) to 1 (disagree). Its Cronbach's α reliability coefficient was 0.85 in this study. We also used the short Japanese version of the Zarit Burden Interview (J-ZBI-8) developed by Uemura *et al.*²⁵⁾. The J-ZBI-8 consists of eight questions that measure personal and role strains. Its reliability and validity are verified.

Ethical considerations

We explained the purpose and contents of this study to the subjects in written and oral forms and informed them that we would use the obtained data and personal information only for research purposes. We started the study after obtaining consent from all the subjects. The Medical Ethics Committee of Fukuoka University approved this study (Reference Number: M047).

Analysis methods

We included 104 of the 115 participants after excluding 11 respondents with missing data. We divided the participants into a young group (under 65 years of age) and an old group (65 years of age or older), and compared the Care Needs Scale and J-ZBI-8 scores using the Mann–Whitney U test. We also examined the correlations between the total and subscale scores of the Care Needs Scale and each variable, the J-ZBI-8 scores, and personal and role strains with Spearman's rank correlation coefficient. In addition, we performed multiple regression analyses using the total score of the Care Needs Scale as the dependent variable. We used SPSS Statistics Ver.27 for statistical analysis.

Results

Summary of subjects

The summary of subjects is shown in Table 1. The younger age group comprised 54 participants with a mean age of 54.3 years. The older age group consisted of 50 participants with a mean age of 74.3 years. Regarding relationships with care recipients, spouses and children accounted for 80% of both age groups. In addition, 90% of the participants in both age groups were healthy. No significant differences were observed in sleep satisfaction, sleeping hours, and work status. A significant difference was found in the mean age of the care recipients, which was 81.5 and 85.9 years in the young and old age groups, respectively. A significant difference was also found in the care-level status of long-term care insurance between the two age groups, with a higher care level in the older age group.

Care needs scale and J-ZBI-8 score

For the Care Needs Scale of caregivers, the mean score of the older age group was significantly higher for the question “I want someone to talk about long-term care” in the subscale of “Confusion and consultation” ($P=0.02$). However, the mean score of the younger age group was significantly higher for the question “I want to know how to deal with repetitive behaviors” in the subscale of “Care methods and deterioration prevention” ($P=0.02$). No significant differences were observed in the questions in the subscale “Family's lack of understanding”. Comparing the scores of the three subscales between the two age groups, the mean

score for “Confusion and consultation” was significantly higher in the older age group ($P=0.04$).

For the J-ZBI-8 scores, no significant differences were found in any question and personal and role strains (Table 2).

Correlations between care needs scales and variables

In the young group, significant correlations were observed between the subscale scores of “Family's lack of understanding” and “Care methods and deterioration prevention” and the total score of the Care Needs Scale and the scores of all questions and personal and role strains of the J-ZBI-8 scale.

In the older age group, significant correlations were observed between the subscale score of “Confusion and consultation” on the Care Needs Scale and all the J-ZBI-8 scale scores except for the questions of “Do you feel that you don't have enough time for yourself because of caregiving?”, “Do you feel stressed because you need to do housekeeping and work in addition to caregiving?”, and “Do you feel that you have lost control of your life since the start of caregiving?”. Significant correlations were also observed between the subscale score of “Family's lack of understanding” on the Care Needs Scale and nighttime awakening, the subscale score of “Confusion and consultation” and the care-level status, and the subscale score of “Care methods and deterioration prevention” and the age and the health status of caregivers.

Strong correlations were observed between the total score on the Care Needs Scale and the J-ZBI-8 question, “Do you feel uncertain about what to do with the care recipient?” ($r=0.72$) and personal strain ($r=0.74$) in the older age group. Moreover, the subscale score of “Family's lack of understanding” was strongly correlated with personal strain ($r=0.70$) and the total J-ZBI-8 score ($r=0.71$). The subscale score of “Care methods and deterioration prevention” was strongly correlated with the J-ZBI-8 question, “Do you feel uncertain about what to do with the care recipient?” ($r=0.769$) (Table 3).

Multiple regression analyses

We performed multiple regression analyses using the total Care Needs Scale as the dependent variable for the young and old age groups. The predictor variables in the younger age group were the relationship to the care recipient, the work status, and the J-ZBI-8 questions of “Do you feel that you do not have enough time for yourself because of caregiving?” and “Do you feel stressed because you need to do housekeeping and work in addition to caregiving?”. The adjusted coefficient of determination was 0.35. The predictor variables in the older age group were the age of the caregiver, the relationship to the care recipient, the presence or absence of nighttime awakening, the care-level status for

Table 1 Summary of subjects

	Young group Mean	Old group Mean	P-value
Sex ¹⁾			
Male	12	12	0.50
Female	42	38	
Age of caregiver	54.3 (5.19)	74.3 (6.58)	
Living status ¹⁾			
Living together	52	2	0.30
Not living together	46	4	
Relationship to care recipient ¹⁾			
Spouse	14	14	0.84
Child	28	26	
Grandparent	0	1	
Sibling	1	1	
Other	11	8	
Health status ¹⁾			
Very healthy	2	6	0.13
Healthy	44	39	
Not very healthy	7	5	
Not healthy	1	0	
Nighttime awakening ¹⁾			
Yes	28	33	0.10
No	26	17	
Sleep satisfaction ¹⁾			
Very satisfied	2	0	0.27
Satisfied	37	38	
Not very satisfied	13	12	
Not satisfied	2	0	
Sleeping hours ²⁾	6.26 (0.89)	6.48 (0.84)	0.19
Work status ¹⁾			
Working	38	16	0.48
Not working	25	25	
Sex of care recipient ¹⁾			
Male	17	14	0.69
Female	37	36	
Age of care recipient ²⁾	81.5 (5.83)	85.9 (7.34)	0.001
Care level status for long-term care insurance ¹⁾			
Never applied	9	4	0.02
Currently applying	6	2	
Support level 1	7	5	
Support level 2	7	10	
Care level 1	18	9	
Care level 2	4	9	
Care level 3	0	6	
Care level 4	2	1	
Care level 5	1	4	

¹⁾Mann–Whitney U test, ²⁾Student’s t-test.

long-term care insurance, the J-ZBI-8 questions of “Do you feel that you do not have enough time for yourself because of caregiving?”, “Do you feel that your social life opportunities have decreased because of caregiving?”, and “Do you

feel embarrassed over the care recipient’s behavior?”, and the J-ZBI-8 total scores. The adjusted coefficient of determination is 0.62 (Table 4).

Table 2 Care needs scale for caregivers of the elderly with early-stage dementia

Subscales	Questions	Young group Mean	Old group Mean	P-value
Family's lack of understanding	My family doesn't help with caregiving and housekeeping.	3.2	2.9	0.55
	I don't have support from my neighbors.	2.9	2.7	0.66
	My family doesn't understand about caregiving for dementia.	3.4	3.0	0.85
	I don't have enough time for myself because of caregiving and housekeeping (working).	3.0	2.9	0.99
	I can't maintain a balance between caregiving, housekeeping, and working.	2.8	2.8	0.66
	I want my family to understand I am in caregiving for early-stage dementia.	2.4	2.5	0.91
Confusion and consultation	I am anxious about future caregiving.	2.6	2.7	0.79
	I want someone to talk to about caregiving.	2.1	2.7	0.04
	I am concerned about my health.	2.2	2.3	0.63
	I want the care recipient to do what he/she can do.	1.6	1.6	0.36
Care methods and deterioration prevention	I want to know how to prevent memory loss and deterioration.	1.7	1.7	0.21
	I want to know about symptoms such as memory loss and abnormal behaviors and treatment of dementia.	1.6	1.6	0.26
	I want to know how to deal with repetitive behaviors.	2.3	1.8	0.02
	I want to know good care methods.	2.6	2.6	0.73
Subscales	Family's lack of understanding	11.5	11.6	0.89
	Confusion and consultation	11.7	12.7	0.04
	Care methods and deterioration prevention	9.9	10.3	0.50
Total score		33.9	33.6	0.84

Mann-Whitney U test.

Discussion

In this study, we identified the care needs of the caregivers of elderly patients with early-stage dementia and compared them with those of young and old caregivers. The correlation between the variables in the multiple regression analysis using the total Care Needs Scale score as the dependent variable suggests that care needs have distinctive characteristics between the two age groups.

Care needs characteristics of caregivers in the young and old age groups

As shown in the Summary of subjects, the age and care-level status of the care recipients were significantly higher in the older age group. However, there was no difference in their relationships with care recipients. In both age groups, the most common relationship was that of the child, followed by that of the spouse. The mean age of care recipients in the older age group was 85.9 years, that is, more than 10 years older than the healthy life expectancy²⁶. Even if the care recipient had early-stage dementia, older patients tended to have a higher care-level status and lower self-care ability, suggesting that the care burden could be much higher in the older age group.

For the Care Needs Scale, the mean score for "I want someone to talk to about caregiving" in the subscale of

"Confusion and consultation" was significantly higher in the older age group. This suggests that older caregivers are likely to be confused by caregiving due to a lack of knowledge about the symptoms of early-stage dementia but have no one to talk to about their worries²⁷. In contrast, the mean score for "I want to know how to deal with repetitive behaviors" in the subscale of "Care methods and deterioration prevention" was significantly higher in the younger age group. This shows that young caregivers want to actively deal with early-stage dementia and maintain a balance among caregiving, working, and housekeeping. It seems that they hope to stop the deterioration and prevent the increase and prolongation of caregiving in the future²⁸.

Correlations and factors associated with care needs of caregivers

Regarding the correlation between the total Care Needs Scale score and the subscale scores and variables, no correlations were observed in the demographic summary of caregivers and care recipients and the subscale of "Confusion and consultation" in the younger age group. The subscale score of "Family's lack of understanding" was somewhat strongly correlated with the J-ZBI-8 scale of "Do you feel stressed because you need to do housekeeping and work in addition to caregiving?", role strain, and total J-ZBI-8 score. Young caregivers were not worried about whether they had someone to talk to about caregiving, suggesting that they

Table 3 Correlation coefficient

Total score and subscales	Young caregivers				Old caregivers			
	Total score	Family's lack of Understanding	Confusion and consultation	Care methods and deterioration prevention	Total score	Family's lack of understanding	Confusion and consultation	Care methods and deterioration prevention
Age of caregiver	–	–	–	–	–	–	–	0.300*
Health status of caregivers	–	–	–	–	–	–	–	0.283*
Nighttime awakening	–	–	–	–	–	–0.289*	–	–
Care level status for long-term care insurance	–	–	–	–	–	–	–0.317*	–
J-ZBI-8 Question1	0.329*	0.328*	–	0.296*	0.493**	0.550**	–	0.445**
J-ZBI-8 Question2	0.365**	0.360**	–	0.270*	0.523**	0.525**	0.342*	0.449**
J-ZBI-8 Question3	0.528**	0.637**	–	0.472**	0.454**	0.545**	–	0.321*
J-ZBI-8 Question4	0.437**	0.436**	–	0.346*	0.592**	0.596**	0.345*	0.478**
J-ZBI-8 Question5	0.370**	0.558**	–	0.283*	0.425**	0.430**	–	0.379**
J-ZBI-8 Question6	0.382**	0.409**	–	0.379**	0.499**	0.518**	0.330*	0.388**
J-ZBI-8 Question7	0.318*	0.430**	–	0.339*	0.574**	0.574**	0.339*	0.564**
J-ZBI-8 Question8	0.321*	0.301*	–	0.318*	0.723**	0.617**	0.524**	0.688**
Personal strain	0.489**	0.468**	–	0.440**	0.742**	0.695**	0.494**	0.650**
Role strain	0.500**	0.645**	–	0.456**	0.596**	0.640**	0.320*	0.511**
JBI total score	0.563**	0.612**	–	0.503**	0.686**	0.705**	0.393**	0.596**

Spearman's rank correlation coefficient ** $P < 0.01$ * $P < 0.05$.

Table 4 Multiple regression analyses

		Standard error	Standardized coefficient β	t-value	P-value	95% confidence interval	
						Lower limit	Upper limit
Young group	Relationship to care recipient	0.6	0.193	1.682	0.099	–0.197	2.216
	Work status	1.428	0.243	2.104	0.041	0.133	5.877
	J-ZBI-8 Question14-1	1	0.267	2.094	0.042	0.083	4.104
	J-ZBI-8 Question14-3	0.734	0.351	2.768	0.008	0.556	3.508
	R						0.634
	R ²						0.402
	Adjusted R ²						0.352
Old group	Age of caregiver	0.123	0.199	2.048	0.047	0.003	0.502
	Relationship to care recipient	0.615	0.29	2.945	0.005	0.57	3.055
	Nighttime awakening	1.584	–0.18	–1.991	0.053	–6.352	0.045
	Care level status for long-term care insurance	0.367	–0.277	–2.995	0.005	–1.84	–0.358
	J-ZBI-8 Question14-1	1.39	–0.491	–2.429	0.02	–6.183	–0.569
	J-ZBI-8 Question14-4	1.675	–0.638	–2.375	0.022	–7.361	–0.596
	JBI total score	0.474	2.01	4.294	0	1.078	2.991
	J-ZBI-8 Question14-6	1.43	–0.488	–2.252	0.03	–6.109	–0.333
	R						0.825
	R ²						0.681
Adjusted R ²						0.619	

may obtain information from the Internet to learn the symptoms of early-stage dementia and solve care-related problems²⁹). The subscale score of “Family’s lack of understanding” was strongly correlated with the stress on multitasking,

the role at home, and the overall burden of caregiving. These results suggest that the family is unlikely to understand the required time, stress, and general burden associated with caregiving during early-stage dementia³⁰).

In the older age group, significant correlations were observed between the subscales of “Family’s lack of understanding” and nighttime awakening, “Confusion and consultation”, and the care-level status and “Care methods and deterioration prevention” and the age and health status of caregivers. Older caregivers are likely to be isolated in the community without the support of other family members and someone to talk to about caregiving³¹. In addition, older caregivers were concerned about their health because of caregiving. The total score and the subscale scores of “Family’s lack of understanding” and “Care methods and deterioration prevention” on the Care Needs Scale were strongly correlated with the following J-ZBI-8 scales: “Do you feel uncertain about what to do with the care recipient?”, personal and role strains, and total scores. The results suggest that the family’s lack of understanding regarding caregiving and knowledge about care methods for early-stage dementia may increase the stress and burden on caregivers³¹, who are struggling alone.

In the multiple regression analyses using the total Care Needs Scale score as the dependent variable, the predictors were work status and the J-ZBI-8 score for “Do you feel stressed because you need to do housekeeping and work in addition to caregiving?” in the younger age group. The predictors in the older age group were the age of caregivers, nighttime awakening, the care-level status, and the J-ZBI-8 scores of “Do you feel that your social life opportunities have decreased because of caregiving?” and “Do you feel embarrassed over the care recipient’s behavior?”. Caregiving is a burden for young caregivers to continue working and for older caregivers to participate in social activities³¹.

Support for care needs of caregivers of the elderly with early-stage dementia

In this study, we divided caregivers into young and old age groups and compared their care needs. The mean age of the young group was 50, and 70% of young caregivers were working. As shown in the high score for the question “I want to know how to deal with repetitive behaviors”, young caregivers had a positive attitude toward learning care methods and preventing deterioration at early-stage dementia. They were stressed about caregiving, housekeeping, and working and did not have enough time for themselves because of caregiving. Therefore, it is important to provide information on how to deal with early-stage dementia and prevent deterioration for young caregivers to decrease caregiving burden and continue their job³². The selective use of appropriate services may allow caregivers to predict the future. The mean age of the older group was mid-70s, and they were worried that they would not be able to continue caregiving if their health status declined. In addition, they had no one to talk to about caregiving and were confused about caregiving for early-stage dementia. Their quality of life de-

creased because of a lack of social life and insufficient time for themselves³⁰. Family understanding, gratitude to the caregiver, and role-sharing are keys for caregivers to secure their own time. Using long-term care services and including specialists in the support team from the onset of early-stage dementia are essential to reduce the caregiving burden. Care managers should assess the needs of caregivers and provide support to those qualified for government long-term care³³. However, government office workers or local social workers should introduce community general support centers and outpatient memory loss clinics for counseling services for those not qualified for government long-term care³⁴.

Conclusion

In this survey study for the primary caregivers of “the elderly with early-stage dementia”—a phrase that is difficult to define. The term was defined based on the opinions of psychiatric and neurological doctors and nurses. The subjects were selected by nurses at the hospital and public health nurses for memory loss consultations at the Community General Support Center. There was a limitation in subject selection, and bias may have occurred throughout the process. However, we obtained a certain level of outcome from the study regarding the care needs of caregivers of elderly patients with early-stage dementia. The participants were divided into younger and older age groups, with both groups exceeding 50 participants; however, it is undeniable that sample size considerations are a limitation of the analysis.

The company plans to increase the number of participants, conduct further research to prevent cognitive decline, maintain and improve cognitive functions, and support caregivers.

This study identified the care needs of the caregivers of elderly patients with early-stage dementia. We clarified these characteristics by dividing the participants into young and old age groups.

Young caregivers want to learn how to manage early-stage dementia, prevent its progression, and deal with symptoms to prepare for the future. They seek ways to balance caregiving with working and housekeeping and reduce the stress and burden of continuing long-term care. However, older caregivers are confused about caregiving and want someone to talk about their worries. They are concerned about caregiving-related nighttime awakening and its influence on their health.

The family’s lack of understanding about caregiving was commonly observed in both age groups, suggesting that personal and role strains are associated with the care needs of caregivers of the elderly with early-stage dementia.

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Ethics approval and consent to participate: The study was initiated after obtaining consent from all the participants. This study was approved by the Fukuoka University Medical Ethics Committee (ref. No. M047).

Consent for publication: We obtained consent to publish.

Data availability statement: All anonymized subject data used in this study are included in the text.

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