Asian Journal of HUMAN SERVICES

Printed 2020.1030 ISSN2188-059X

Published by Asian Society of Human Services

October 2020

Vol. 19

ASIAN SOCIETY OF HUMAN SERVICES

Asian Society of Human Services

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DOI: http://dx.doi.org/10.14391/ajhs.19.1
Asian Journal of Human Services, VOL.19 1-10

ORIGINAL ARTICLE

Structuring the Effects of Functional Recovery Care in a Private Home with Care Services for Older People

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ABSTRACT

This study aimed to structure the effect of functional recovery care in a private home with care services for older people by analyzing employees' narratives. Interviews with employees of the facility revealed the following structure: By adopting [elaborate methods for evidence-based care] or functional recovery care, employees realized [improvements in residents' mental and physical functions] and the [calmness of residents' lives in the facility], and such a realization resulted in [employees' increased motivation and sense of fulfillment]. [Employees' increased motivation and sense of fulfillment] [promoted professional awareness] and [organizational growth], promoted [approaches and awareness toward future development], and contributed to the [further enhancement of the organizational capacity]. The results clarified a structure, where functional recovery care in a private home with care services for older people leads to employee and organizational growth.

＜Key-words＞
structuring, effect, functional recovery care, private home with care services

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Asian J Human Services, 2020, 19:1-10. © 2020 Asian Society of Human Services

Received
June 8, 2020

Revised
July 10, 2020

Accepted
July 27, 2020

Published
October 30, 2020

I. Introduction

In Japan, residential homes with and without care services are currently available as private homes for older people. When using home care services based on the Long-term Care Insurance System, subsidies are allocated, corresponding to the category ‘daily care for specific facility users’. In recent years, while delays in the construction of Long-term Care Insurance-covered facilities have been noted, the numbers of private (residential) homes for older people and their residents have steadily increased; the values, which were 276 and 30,792, respectively, in 2008, increased to 12,570 and 482,792, respectively, in 2016 1). On comparing the national mean Care Grade and that of insurance-covered facility users, the former is still lower, at 2.2, but grades 4 and 5 account for more than 25%, revealing the increasing demand of older people requiring care for such homes. Residential homes for older people are regarded as new locations for the older people to relocate to from their long-lived-in homes 2). Furthermore, it is expected that the homes will accommodate needs related to the comprehensive community-based care system as key to social insurance system reform to prepare for 2025, when all baby-boomers will be aged 75 or over. In such a situation, care approaches in these homes should be reviewed, covering the concept of ‘private’ but unaccustomed homes, in addition to that of ‘facilities’.

Considering such a situation, we examined the relationships among the nutritional status and mental and physical functions of those living in a private home with care services for older people in 2015 3). Furthermore, in 2017, we provided an interdisciplinary intervention for these residents through interprofessional collaboration, which was effective to maintain/improve their Alb levels as a motor function parameter, and increase their quality of life (QOL) 4). After this interventional study, employees of the facility continued their independent approaches to make nutrition management, exercise, and hydration care take root as functional recovery care. Now that 1 year has passed, positive effects on residents, including improved bowel control, increased toilet use for excretion, improved conversation abilities of those with dementia, and a reduced prevalence of falls, are being achieved in the facility.

The purpose of the present study was to structure the effect of functional recovery care in this private home with care services for older people by analyzing employees' narratives. Functional recovery care aims to enhance care-dependent older people's mental and physical functions through 4 basic care approaches, covering <hydration>, <nutrition>, <excretion>, and <exercise> 5).

II. Subjects and Methods

1. Study and Procedures

1) Study Design

Qualitative inductive study design (Interview survey semi-structured interview method)

2) Study Period

Between January 1, 2019, and February 28, 2019

3) Subjects

Employees of a private home with care services for older people operated by Tokyu Land Corporation.

4) Study Items

Basic attributes: basic license, gender, age, years of experience, years of service

Interview method: An about 30-minutes semi-structured interview session using an interview guide was held for each of the care staff.

Study items:

(1) Have there been any cases, where you realized the effects of functional recovery care? If there have been such cases, please describe them in detail.
(2) What is your view on the effects of functional recovery care?
(3) Are you willing to continue to provide functional recovery care?
(4) What challenges are there in continuing to provide functional recovery care?

5) Ethical Considerations

This study was conducted with the approval of the Ethics Committee of the Faculty of Health Science and Nursing, Juntendo University (approval number: 30-12). The study facilities and subjects were previously provided with written and oral explanations of the study objective, methods, voluntary cooperation, participants' right to withdraw at any time, and measures to ensure anonymity to obtain their consent.

2. Data Collection

We asked the manager of a private home with care services for older people operated by Tokyu Land Corporation, where the representative researcher participates in case conferences as an advisor, to select appropriate employees for this study.

3. Data Analysis

The interview data were organized as narrative records, which were carefully read and divided into minimum paragraphs with semantic contents as units for analysis. These units were encoded, focusing on the effects of functional recovery care, and classified into categories based on similarities with enhanced abstractness after careful deliberation on the data and codes to determine the characteristics and names of these categories. To enhance their validity, repeated discussions were held between the principal investigator and co-investigator. The relationships among the categories were further examined for structuring by examining similarities and differences among them.

III. Results

1. Basic Attributes (Table 1)

The interviewees were 7 care staff members belonging to facilities with the following basic qualifications: nurse: 2, physical therapist: 1, and care worker: 4. There were 3 (42.9%) males and 4 (57.1%) females. Their average age was 38.43±10.3 years. The mean length of experience was 10.71±7.65 years, ranging from 2 to 25 years. The mean of length of service experience was 2.71±1.60, ranging from 1 to 5. The mean duration of an interview session was 29.25 ±11.46 minutes, ranging from 12 to 41 minutes.

<Table 1> Basic attributes

Basic license	Sex	Age	Years of experience	Years of service	Interviewed time [min]
Physical therapist	Male	41	9	2	36.56
Nurse	Female	49	25	5	41.42
Care worker	Female	30	8	1	24.32
Care worker	Female	24	2	2	13.80
Nurse	Female	50	16	5	24.18
Care worker	Male	30	5	2	12.02
Care worker	Male	45	10	2	15.12
Ave.		38.43±10.3	10.71±7.65	2.71±1.60	29.25±11.46

2. Categorization of the interview data (Table 2)

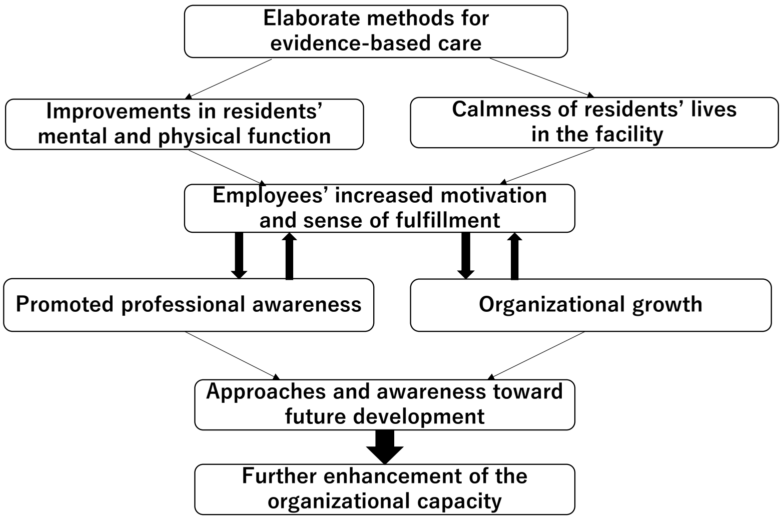
From 386 codes (“ ”), 49 sub-categories ({ }), 27 categories (< >), and 8 core categories ([ ]) were created. [Further enhancement of the organizational capacity] was the most frequent core category, consisting of 70 codes, which were summarized into <awareness enhancement and intention-sharing among employees>, including {promoting the sharing of intentions among all employees}, and <improvement of team performance through interprofessional collaboration>, including {resolving the challenges of interprofessional collaboration}. [Approaches and awareness toward future development] was the second frequent core category, consisting of 58 codes, which were summarized into <further approaches>, including {desiring to further improve residents’ lives}, and <maintenance of awareness>, including {inheriting these approaches as the tradition of this home}. [Elaborate methods for evidence-based care] consisted of 54 codes, represented by <functional recovery care as a foundation>, including {a foundation for health and life}, <elaborate methods for individualized care>, including {adopting elaborate methods for individualized hydration care}, and <awareness of evidence-based care>, including {becoming able to consider evidence for care}. [Promoted professional awareness] consisted of 53 codes, represented by <changes in employees’ awareness to adopt more independent approaches>, including {employees’ more independent approaches}, and <distress and difficulty in disseminating>, including {difficulty in promoting understanding among other employees}. [Enhancement of residents’ mental and physical functions] consisted of 41 codes, represented by <improvements in residents’ physical functions>, including {realizing improvements in residents’ activity levels and walking ability}, and <improvements in residents’ cognitive function>, including {realizing improvements in residents’ communication skills}. [Organizational growth] consisted of 40 codes, represented by <team efforts centered on core members>, including {adopting team approaches}, and <immaturity as an organization>, including {unpreparedness of the organization to provide approaches as it is supposed to do}. [Employees’ increased motivation and sense of fulfillment] consisted of 36 codes, represented by <impact of employee enthusiasm>, including {realizing the impact of employees’ enthusiasm}, and <employees’ sense of fulfillment increased by fulfilling residents’ desires>, including {desiring to fulfill residents’ desires}. [Calmness of residents’ lives in the facility] consisted of 34 codes, represented by <residents’ confidence and calm lives>, including {recognizing each resident’s true personality}, and <residents’ increased motivation and independence>, including {realizing residents’ increased independence}.

<Table 2> Effects of functional recovery care

Core categories	Categories	Codes
Further enhancement of the organizational capacity	Awareness enhancement and intention-sharing among employees	45
	Improvement of team performance through interprofessional collaboration	25
Approaches and awareness toward future development	Further approaches	36
	Maintenance of awareness	22
Elaborate methods for evidence-based care	Functional recovery care as a foundation	16
	Elaborate methods for individualized care	14
	Awareness of evidence-based care	10
	Dissemination to support health and overall life	8
	Loss of motivation and confidence due to reduced independence	6
Promoted professional awareness	Changes in employees' autonomy	19
	Insufficient awareness and knowledge among staff	17
	Distress and difficulty in disseminating	14
	Employees' own growth	3
Improvements in residents' mental and physical functions	Improvements in residents' physical functions	17
	Improvements in residents' cognitive function	13
	Deterioration in residents with urinary tract infections	11
Organizational growth	Team efforts centered on core members	19
	Lack of leadership	5
	Immaturity as an organization	5
	Established as business	4
	Cooperation request to family	4
	Organization support	3
Employees' increased motivation and sense of fulfillment	Impact of employee enthusiasm	15
	Employee satisfaction	13
	Employees' sense of fulfillment increased by fulfilling residents' desires	8
Calmness of residents' lives in the facility	Residents' confidence and calm lives	25
	Residents' increased motivation and independence	9

3. Structuring the effects of functional recovery care in a private home with care services for older people (Figure 1)

Based on the 8 core categories, the effect of functional recovery care in the private home with care services for older people was structured as follows: Adopting [elaborate methods for evidence-based care] or functional recovery care, employees realized [improvements in residents' mental and physical functions] and [calmness of residents' lives in the facility], and such a realization resulted in [employees' increased motivation and sense of fulfillment]. [Employees' increased motivation and sense of fulfillment] led to [promoted professional awareness] and [organizational growth], promoted [approaches and awareness toward future development], and contributed to the [further enhancement of the organizational capacity].



<Figure1> The structure of the Effects of Functional Recovery Care in Private Homes with Care Services for Older People

IV. Discussion

The 7 interviewed employees' length of work experience after obtaining a basic qualification was 10 years or longer, but their duration of working in the study facility was shorter than 3 years. The results clarified a structure, where functional recovery care in a private home with care services for older people leads to employee and organizational growth.

[Elaborate methods for evidence-based care] or functional recovery care through employees' independent approaches was a background factor contributing to such a structure. One employee stated: "I am becoming able to develop methods and measures to manage residents who lack sufficient hydration", which was classified into the category

<elaborate methods for individualized care>. The necessity of adopting elaborate methods for functional recovery care among employees may be attributed to the textbooks without theory construction for such care used in care worker schools 6) and consequently insufficient knowledge of practical methods for support 7). Thus, the employees, who were expected to provide functional recovery care without sufficient knowledge of related theories and methods of support, may have needed to devise and adopt elaborate methods. Providing functional recovery care using these methods, the employees realized [improvements in residents' mental and physical functions] ("I feel that residents' frequencies of excreting using toilets are increasing", "Residents' activity levels are increasing as a result of hydration promotion", and "Communication with residents is becoming easier") and the [calmness of residents' lives in the facility] ("Hydration care seems to have made residents' facial expressions more peaceful" and "I recognized each resident's true personality"). Such a realization may have led to [employees' increased motivation and sense of fulfillment] ("Other employees are also highly motivated to do their jobs", "I think this approach has a clear effect, and it increases employees' motivation", and "We are promoting hydration care to fulfill residents' desire to walk"). Concerning [improvements in residents' mental and physical functions] and the [calmness of residents' lives in the facility] realized by employees through functional recovery care, it has been reported that regaining independence with functional recovery increases residents' QOL 8). In another study examining the recognition of care among care workers, they recognized care from 3 perspectives: communication, physical conditions, and QOL, and supported people requiring care to lead an independent and high-quality personal life 9). In the present study, the employees realized improvements in residents' QOL as an outcome of their approaches, and this may have led to [employees' increased motivation and sense of fulfillment]. According to the two-factor theory 10,11) widely used in job satisfaction research, 2 independent (hygiene-and motivation-related) factors influence job satisfaction and dissatisfaction. Based on this, the realization of the [improvements in residents' mental and physical functions] and [calmness of residents' lives in the facility] may have increased employees' satisfaction with their jobs.

Subsequently, [employees' increased motivation and sense of fulfillment] led to their own and organizational growth. Categories [promoted professional awareness] ("My thoughts were not so deep in the beginning", "I had been very distressed until this project was disseminated", and "I began to adopt more independent, proactive approaches") and [organizational growth] ("An increasing number of employees adopt team approaches" and "Such care has taken root in our daily duties") explain that employees' perception that their approaches positively influence residents' lives increases their job satisfaction at a professional level 12), and their perception that the facility where they work is providing high-quality care also increases their job satisfaction at an organizational level 13).

Such job satisfaction at professional and organizational levels among employees promoted [approaches and awareness toward future development] ("We will maintain such awareness, and adopt further approaches" and "I want to inherit these approaches as the tradition of this home"). Analysis of the employees' narratives also revealed some future-oriented challenges, such as the [further enhancement of the organizational capacity] ("After all, interprofessional collaboration is essential for functional recovery care in nursing homes for older people" and "It is working well, but I also have to admit that there are various challenges of interprofessional collaboration"). Structuring the effects of functional recovery care in a private home with care services for older people, the necessity of long-term perspectives and approaches for all those involved in care provision to participate in for organizational improvement 14) was highlighted.

Acknowledgment

This study was conducted as part of the Chair of Gerontology: Applied Medicine and Health Science based on an agreement for comprehensive collaboration between Juntendo University and Tokyu Land Corporation. The authors heartily thank all those who cooperated with the study.

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Human Services

DOI: http://dx.doi.org/10.14391/ajhs.19.11
Asian Journal of Human Services, VOL.19 11-23

Original Article

Advance Care Planning in Japan;

Survey of the Primary Care Physicians' View

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ABSTRACT

Background: This study reports a critique of advance care planning (ACP) by primary care physicians (PCP) in the at-home medical-care field in Japan.

Methods: A cross-sectional survey was designed from previous research, piloted, revised, and sent out to all PCP during April and May 2019. The target participants were all the total 914 PCP registered online nationwide in Japan. After piloting, there were 28 question items with five Likert scale, plus some open-ended response items, treated by factor analysis to discover the leading essential characteristics of ACP.

Results: The mean scores for each of the 28 items ranged from 3.73 to 4.85, and the leading 18 items were analyzed to reveal there were five factors. These were;- 1. Trust in the Doctor-Patient Relationship, 2. Building-up Cooperation, 3. Enlightenment and Awareness of ACP, 4. Level up Views on Life and Death among Health Care Providers, and 5. Patient and Family Preparedness for Death. The inter-factor correlation ranged from 0.06 to 0.44, and Cronbach alpha coefficient ranged from 0.74 to 0.95. Findings showed that more PCP, than not, considered the important characteristics to be (a) Experience of bereavement with someone close, $p < 0.01$, (b) Attached home visiting nurse office, $p = 0.04$, and (c) Medical fee point as home care supporting clinic, $p = 0.02$.

Conclusion: A total of five factors were statistically discovered to be necessary for ACP in Japan, and a total of three statistically confirmed basic characteristics.

< Key-words >
Advance Care Planning, Primary Care Physician, End-of-Life, Decision-Making, Japan

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Asian J Human Services, 2020, 19:11-23.

Received
July 6, 2020

Revised
August 18, 2020

Accepted
August 25, 2020

Published
October 30, 2020

I. Introduction

Japan has the highest proportion of old-aged people in the world, and there is consequently increasing interest in planning for and delivering medical and care support for these people.1) Further it is becoming clear that old-aged patients and their families need guidance as to their various medical and care choices. Such medical and care support guidance should be from healthcare providers in a timely manner in advance of their making their decisions. The government Ministry of Health, Labour and Welfare has proposed Advance Care Planning (ACP) guidelines to be the most suitable and best decision support model and encourages the promotion of ACP throughout Japan.2)

ACP guidelines improve the quality of end-of-life care, increase patient and family satisfaction, and reduce stress, anxiety, and depression in surviving relatives.3,4) ACP increases the availability of in-hospital palliative care,5) and increases end-of-life care at home.6) Moreover, patients want to talk about their prognosis with both their primary care physician (PCP) and their specialist doctor,7) but only 27.3% of physicians are aware and practice ACP.1,8) One of the advantages of ACP is that the patient can convey their own wishes about end-of-life care, to their family and to their PCP and care providers.

For ACP to proceed seamlessly among various health-care providers, it is important to know the PCP view in charge of the patient's future medical needs and treatment. While some studies have explored the use of ACP through surveys on visiting-nurses and at-home care-providers, 9-12) there has been no research yet exploring what are the essential characteristics of ACP in Japan from the perspectives of the PCP in the at-home medical field. Therefore, this study set out to investigate what PCP consider to be the basic characteristics in practicing ACP, and to rate the various aspects of ACP.

II. Methods

1. Study design and Participants

This cross-sectional study was conducted during April and May 2019. The self-administered questionnaires involved all 914 PCP registered online nationwide in Japan with home-care support clinics (retrieved March 2019).13) Of the total 914 registered, there were 45 registrations with insufficient postal-address data, and the survey was consequently sent out by letter-post to a total of 869 registered PCP.

Responses were received from 203 (giving a low response rate of 23.4%). Among these 203 returns, there were only 188 with complete data, with usable responses to all 28 items (giving a valid response rate 92.6%) to be included into this study using factor analysis.

2. Questionnaire

As no validated research tools existed for achieving the objectives of our study, the questionnaire was developed based on the previous study with key words end-of-life, decision-making and ACP.14-28) The 21 of 28 questions are based on previous study and seven of 28 questions added after pilot test.

A pilot test found that PCP suggested to add additional more-detailed questions more-specifically relating to the current at-home health-care issues in Japan, and a further seven question items were added to make a usable survey instrument consisting of 28 questions with closed-responses on a five-point Likert scale (1 very-unnecessary, 2 unnecessary, 3 neither unnecessary nor necessary, 4 necessary, and 5 very necessary). The 28-item survey was then again piloted for final checking by three PCP and two university researchers in the at-home medical field.

3. Statistics analysis

The final questionnaire had 28 variables with high internal reliability at Cronbach alpha at 0.89. These 28 variables with an I-T correlation over 0.2 were then selected for factor analysis.

Factor analyses was to seeks the least number of factors which can account for the common variance (correlation) of a set of 28 variables, Student’s t-test analyses was to seeks the difference between each variance and participants’ basic characteristic. We were conducted with SPSS (version 23) and significance level was less than 0.05.

Primary analysis made 28 variables account for the common variance, which the number of principal components selected by Kaiser criterion and Scree Plot. The construct validity of factor analyzed with Kaiser-Meyer-Olkin (0.76) and Bartlett tests ($p < 0.01$).

Secondary analysis made the difference between the principle component and participants’ basic characteristic, Gender, Age, Experience of doctor, Experience of PCP in home medical, Experience of bereavement with someone close, Number of doctor in clinic, Attached home visiting nurse office, Number of patients, Number of death certification in home, Medical fee point as home care supporting clinic.

4. Ethical considerations

This study protocol was approved by the institutional review boards of Kio university (No: H30-21), with participants’ consent implied by the return of the questionnaires. This study was performed between April and May 2019; with a cover letter clearly stating the purpose of this study, the right to refuse to participate, strict safeguarding of the data except for the publication of anonymous statistically analyzed data, which does not specify individuals. According to the university ethics committee regulations, informed consent was not required in this study. It was assumed that each subject agreed to join the study of his/her own free will by returning the answered questionnaire.

5. Definition of ACP in this study

This research defined ACP was a process whereby a patient, in consultation with health care providers, family and important others, makes decisions about his or her future medical and care. The role of PCP in ACP was almost being defined, as central within the context of the physician-patient relationship, providing information to makes decisions about patients' future medical and care.[29]

III. Results

1. Participant basic characteristic

Table 1 shows basic characteristics. Study participants had a mean age of 57.3 (SD = 9.7), experience of PCP in home medical 17.7 (SD = 9.3) years. As the situation of the clinic, number of patients had 320.1 (SD = 1,149.8), number of death certification in home had 36.4 (SD = 47.1) from January 2018 to December 2018. The percentage of participants' clinic with attached the home visiting nurse office was 35.1%, and the medical fee point as home care supporting clinic was 96.8%.

<Table 1> Participant Characteristic

Variable	N	Item	n	%	Mean ± SD	Median
Gender	188	Male	174	92.6		
		Female	14	7.4		
Age / yrs	187				57.3±9.7	59.0
Experience of doctor / yrs	187				30.9±9.2	32.0
Experience of primary care physician in home medical / yrs	187				17.7±9.3	17.0
Experience of bereavement with someone close	182	Yes	171	94.0		
		No	11	6.0		
Number of doctors in clinic (include part-time)	185				3.5±3.8	2.0
Attached home visiting nurse office	178	Yes	66	37.1		
		No	112	62.9		
Number of patients*	176				320.1±1,149.8	104.0
Number of death certification in home*	179				36.4±47.1	19.0
Medical fee point as home care supporting clinic	187	Yes	181	96.8		
		No	6	3.2		

*: The data period is from January 2018 to December 2018

DOI: http://dx.doi.org/10.14391/ajhs.19.11
Asian Journal of Human Services, VOL.19 11-23

2. Necessary for ACP from primary care physicians' view

Table 2 shows necessary for ACP from PCP's view. The mean scores for each variable ranged from 3.73 to 4.85, and Item-Total correlations (I-T correlation) ranged from 0.21 to 0.63. The top five variables with the highest averages were patients 'preparedness for own death', 'improved care system', 'revision of medical fees (upgrade evaluation)', 'citizens awareness reform on life and death', 'level up views on life and death among doctors'.

In this study, factor analysis (principal factor method, pro-max rotation) was performed for all 28 variables because there were no variables under 0.2 with I-T correlation. The number of five factors was determined both Kaiser criterion (= eigenvalue) over 1.0 and reference of with good cohesion of meaning among variables in each factor. The requirement of deleting variables are 1) factor loading of each variable was less than 0.35, 2) variables showed similar factor loadings for multiple factors. The factor analysis was repeated under the same conditions (principal factor method, pro-max rotation) until there were no more variables to be deleted. As a result, 18 of 28 variables remained finally.

<Table 2> Necessary for ACP from Primary Care Physicians' View (N=188)

No	28 Variables	Mean*	SD	I-T correlation
1	patients' preparedness for own death	4.85	0.48	0.25
2	improved care system	4.81	0.43	0.63
3	revision of medical fees (upgrade evaluation)	4.81	0.45	0.50
4	citizens awareness reform on life and death	4.77	0.46	0.38
5	level up views on life and death among doctors	4.70	0.60	0.54
6	treatment decisions are made involving patient wishes	4.60	0.63	0.40
7	cooperation with home visiting nurse office	4.49	0.80	0.36
8	family preparedness for patient death	4.48	0.78	0.21
9	construction of information sharing system	4.48	0.72	0.48
10	cooperation between hospital and clinic in home medical field	4.46	0.79	0.40
11	cooperation between clinics	4.41	0.73	0.39
12	training in ACP	4.41	0.74	0.52
13	system for obtaining ACP specialized consultation and advice	4.41	0.70	0.42
14	hospitalized beds are available when the patient condition changes	4.41	0.77	0.57
15	explanation sufficiently to the family on clinical course	4.37	0.74	0.34
16	education on life and death in educational institutions	4.37	0.69	0.53
17	level up views on life and death among medical staff	4.36	0.80	0.56
18	cooperation with care managers on long-term care insurance law	4.34	0.70	0.40
19	appropriate transition from hospital to home medical field	4.27	0.78	0.53
20	family education on medical and care support for patients	4.22	0.90	0.59

No	28 Variables	Mean*	SD	I-T correlation
21	medical staff need adequate time to cope	4.21	0.78	0.31
22	treatment decisions are made involving family wishes	4.16	0.71	0.37
23	emergency hospital beds are secured	4.10	0.88	0.52
24	easy-to-use services in long-term insurance when needed	4.06	0.91	0.57
25	24-hour medical treatment in clinics	4.04	0.90	0.34
26	system to introduce smoothly patients who need home medical support	3.94	0.86	0.54
27	explanation sufficiently to the family about the condition and treatment of patient	3.91	1.02	0.36
28	family can provide medical and care support to patient	3.73	1.04	0.41

*: Five-point Likert scales about necessary for ACP 1('very-unnecessary') 2('unnecessary') 3('neither unnecessary nor necessary') 4('necessary') 5('very necessary')

3. Factor analysis on findings for ACP

Table 3 shows factor analysis on findings for ACP. Of the five extracted factors, the first factor consisted of four variables, we named "Trust in the Doctor-Patient Relationship". The second factor consisted of five variables, we named "Building-up Cooperation". The third factor consisted of five variables, we named "Enlightenment and Awareness of ACP". The fourth factor consisted of two variables, we named "Level up Views on Life and Death among Health Care Providers". The fifth factor consisted of two variables, we named "Patient and Family Preparedness for Death".

The inter factor correlation ranged from 0.06 to 0.44, the Cronbach alpha coefficient of each factor ranged from 0.74 to 0.95.

<Table 3> Factor Analysis on Findings for ACP

No	18 variables remained of necessary for ACP†	Factor loading*				
		1	2	3	4	5
Factor 1 "Trust in the Doctor-Patient Relationship" (α= 0.76)						
15	explanation sufficiently to the family on clinical course	0.93	-0.01	-0.10	-0.03	0.03
27	explanation sufficiently to the family about the condition and treatment of patient	0.90	0.06	-0.07	-0.07	0.05
6	treatment decisions are made involving patient wishes	0.61	-0.02	0.21	0.04	-0.06
22	treatment decisions are made involving family wishes	0.43	0.01	0.09	0.11	-0.09
Factor 2 "Building-up Cooperation" (α= 0.77)						
23	emergency hospital beds are secured	0.01	0.82	-0.08	0.05	0.16
14	hospitalized beds are available when the patient condition changes	0.04	0.80	0.01	0.03	0.14
10	cooperation between hospital and clinic in home medical field	-0.02	0.59	0.06	0.02	-0.11
7	cooperation with home visiting nurse office	0.05	0.45	0.05	0.00	-0.25
18	cooperation with care managers on long-term care insurance law	-0.03	0.40	0.19	0.05	-0.19
Factor 3 "Enlightenment and Awareness of ACP" (α= 0.74)						
12	training in ACP	-0.02	-0.04	0.76	-0.02	0.12
9	construction of information sharing system	0.03	0.18	0.60	-0.13	-0.01
13	system for obtaining ACP specialized consultation and advice	-0.04	0.19	0.57	-0.16	-0.01
16	education on life and death in educational institutions	-0.03	0.03	0.53	0.21	0.03
4	citizens awareness reform on life and death	0.16	-0.23	0.46	0.22	0.01
Factor 4 "Level up Views on Life and Death among Health Care Providers" (α= 0.95)						
17	level up views on life and death among medical staff	0.00	0.03	-0.01	0.96	-0.02
5	level up views on life and death among doctors	0.00	0.07	-0.05	0.92	0.02
Factor 5 "Patient and Family Preparedness for Death" (α= 0.81)						
1	patients' preparedness for own death	-0.04	-0.04	0.08	0.07	0.83
8	family preparedness for patient death	0.02	-0.04	0.04	-0.06	0.77
Inter-Factor Correlation						
Factor 1		1				
Factor 2		0.31	1			
Factor 3		0.26	0.44	1		
Factor 4		0.21	0.36	0.40	1	
Factor 5		0.10	0.06	0.10	0.20	1

* principal factor analysis, pro-max rotation

†: Excluded: Factor loading less than 0.35: No.19 (0.34), 20 (0.34), 24 (0.34), 28 (0.34), 21 (0.29), 3(0.27). Variables showing similar loadings on multiple factors: No.2, 11, 25, 26.

4. Factor scores and participant characteristics

Table 4-1 shows factor scores and participant characteristics (individual situation), table4-2 (clinic situation) and factor's mean score. As for individual situation, the mean score of “Trust in the Doctor-Patient Relationship” (p <0.01) was significantly higher PCP who had no experience of bereavement with someone close. As for clinic situation, the mean score of “Building up Cooperation” (p =0.04) was significantly higher clinic which attached home visiting nurse office, and “Trust in the Doctor-Patient Relationship” (p =0.02) was significantly higher clinic which medical fee point as home care supporting clinic.

<Table 4-1> Comparison of Basic Characteristics (Individual Situation) and Factor’s Mean Score

	Gender			Age / yrs			Experience of doctor / yrs			Experience of primary care physician in home medical / yrs			Experience of bereavement with someone close		
	Male (n=174)	Female (n=14)	*p*	≧59 (n=99)	＜59 (n=88)	*p*	≧32 (n=96	＜32 (n=91)	*p*	≧17 (n=94)	＜17 (n=93)	*p*	Yes (n=171)	No (n=11)	*p*
Factor 1 (4 variables, 20 score)	18.79	19.00	0.65	18.68	19.00	0.17	18.69	18.95	0.28	18.66	18.95	0.23	18.78	19.55	< 0.01
Factor 2 (5 variables, 25 score)	22.81	23.65	0.19	23.16	22.55	0.07	23.11	22.62	0.14	22.96	22.80	0.63	22.90	22.18	0.32
Factor 3 (5 variables, 25 score)	21.56	21.50	0.93	21.65	21.47	0.65	21.43	21.71	0.47	21.40	21.72	0.42	21.57	21.09	0.57
Factor 4 (2 variables, 10 score)	8.09	8.21	0.80	7.94	8.27	0.20	8.04	8.16	0.64	7.99	8.23	0.36	8.08	7.91	0.76
Factor 5 (2 variables, 10 score)	8.48	8.86	0.37	8.52	8.50	0.91	8.50	8.51	0.98	8.62	8.40	0.33	8.66	7.73	0.08

Student t-test

<Table 4-2> Comparison of Basic Characteristics (Clinic Situation) and Factor’s Mean Score

	Number of doctor in clinic (include part-time)			Attached home visiting nurse office			Number of patients*			Number of death certification in home*			Medical fee point as home care supporting clinic		
	≧2 (n=116)	＜2 (n=69)	*p*	Yes (n=66)	No (n=112)	*p*	≧104 (n=88)	＜104 (n=88)	*p*	≧19 (n=90)	＜19 (n=89)	*p*	Yes (n=181)	No (n=6)	*p*
Factor 1 (4 variables, 20 score)	18.84	18.78	0.80	18.73	18.88	0.54	18.77	18.88	0.68	18.79	18.81	0.94	18.85	17.33	0.02
Factor 2 (5 variables, 25 score)	22.90	22.83	0.84	23.35	22.73	0.04	22.99	22.85	0.70	22.81	22.95	0.68	22.88	22.50	0.69
Factor 3 (5 variables, 25 score)	21.66	21.46	0.64	21.45	21.67	0.60	21.66	21.50	0.70	21.74	21.34	0.32	21.58	20.83	0.51
Factor 4 (2 variables, 10 score)	8.11	8.13	0.95	8.15	8.12	0.90	7.66	8.22	0.35	8.08	8.12	0.86	8.07	8.50	0.56
Factor 5 (2 variables, 10 score)	8.45	8.58	0.57	8.45	8.52	0.79	8.56	8.56	1.00	8.47	8.63	0.46	8.49	8.67	0.78

Student t-test, *: The data period is from January 2018 to December 2018

IV. Discussion

This study was the first nationwide in Japan to investigate the leading characteristics of ACP from the perspective of the PCP. PCP working in the at-home care field found 25 of 28 items with a mean rating of 4.0 or higher-indicating they are necessary. A statistical factor analysis on all 28 items found five factors: 1 Trust, 2 Cooperation, 3 Awareness of ACP, 4 Level up Views on Life and Death among Health Care Providers, and 5 Preparedness for Death.

Of interest, findings showed that 'explanation sufficiently to the family about the condition and treatment of patient' (No. 27) was rated as 3.91, not so high in this research. In Japan, there was a high prevalence of entrusting all decisions to the family (known as 'omakase').30) Therefore, for 'Good Death' in Japan, it is important to have a good family relationship through spending enough time with one's family.26) Another of our results also suggested that family structure differences can affect their end-of-life preferences.31) Thus, the family has some influence on the end of life care in Japan. However, most PCP working in the at-home care field were ambivalent and reported that the family was not 'neither unnecessary nor necessary' for ACP. The cause for this matter requires further investigation.

Shared-decision-making (SDM) in practice between the doctor and patient is widely recognised in Western countries, but very much less so in Japan.32,33) The notable absence of SDM in Japan may be the underlying reason for our PCPs to respond that more trust is needed: we found that the leading factor-1 was 'Trust in the Doctor-Patient Relationship'. Building and maintaining a good doctor-patient relationship should be perhaps introduced into medical education in Japan.

We identified the three differences of PCP characteristics and ACP. The previous research showed doctors' opinions and attitudes on obtaining the advance directives regarding the end of life treatment differenced by their age.34) However, in our study results, age differences were not found in all five ACP factors.

The overall findings from this study indicate that increased cooperation could benefit the current ACP field. The PCP working in the at-home care field throughout Japan report that more cooperation can help health care providers to work better seamlessly in teams. However, there were several limitations. First, the response rate was only 23.4%. Second, ACP has a wide meaning as a concept and there are multiple definitions, we selected one definition that clearly describes the role of the doctor in ACP, however this one might not be held universally. Third, this research is only a questionnaire survey, triangulation research is necessary to increase the confidence and reliability of this results.

Acknowledgment

The authors thank all the respondents who completed the questionnaire. There was no incentive or reward offered in this respect, so we appreciate they freely donated their valuable time and shared their views to answer and comment in this study. We had many useful comments in the open-response final-section in our questionnaire. Many of these comments will help inform future research. This research was funded by a Grant-in-Aid for Scientific Research C (grant number 17K12199) from the Ministry of Education, Culture, Sports, Science and Technology-Japan.

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Human Services

DOI: http://dx.doi.org/10.14391/ajhs.19.24
Asian Journal of Human Services, VOL.19 24-41

ORIGINAL ARTICLE

Communication Gaps in Intersectoral Healthcare Professional Collaboration for Hospital Discharge Process of Patients With Dementia

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ABSTRACT

The objective of this study was to discover communication gaps in interprofessional collaboration and examine ways to fill these gaps to mitigate communication difficulties in interprofessional collaboration during the discharge of patients with dementia (PWD) from hospital. The survey results obtained from 401 doctors, nurses, medical social workers (MSW), care managers, and visiting nurses were statistically analyzed. The analysis indicated the significant differences in “having knowledge of dementia” ($p < .01$), “hospital discharge tends to be short notice” ($p < .001$), and “sufficient time spent in interprofessional discussions for the discharge of PWD” ($p < .01$). As for the “things given importance upon discharge of PWD”, “cardinal symptoms of dementia” ($p < .01$), ”feelings of the patients” ($p < .001$), “feelings of family members” ($p < .001$), ”feelings of healthcare professionals” ($p < .01$), “support system for their families” ($p < .05$), and “support system for the patients” ($p < .05$) were significantly different, suggesting communication gaps among intersectoral healthcare professionals. It is critical to understand interprofessional differences in perspectives and thoughts about PWD to minimize communication gaps in interprofessional collaboration during discharge of PWD from hospital.

<Key-words>
patients with dementia, hospital discharge planning, interprofessional collaboration, communication, communication gap

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Asian J Human Services, 2020, 19:24-41.

Received
February 14, 2020

Revised
August 28, 2020

Accepted
October 1, 2020

Published
October 30, 2020

I. Introduction

The Ministry of Health, Labour and Welfare (MHLW) [1] is promoting the establishment by 2025 of comprehensive systems to provide support and services that aid in the protection of dignity and independent living among the elderly (community comprehensive care system) in 2016, and therefore, the practice of team medical care and nursing care by health, medical and welfare practitioners is becoming ever more important. MHLW[2] introduced "A Comprehensive Strategy for the Promotion of Dementia Measures Towards a Community Friendly to the Elderly with Dementia, among others (The New Orange Plan)" for PWD with the principle idea of creating a society in which the desires and intentions of dementia persons are respected and they can continue living in familiar areas and environments as much as possible.

Therefore, comprehensive and continuous in-home medical and care support must be provided when PWD are discharged to go back to their home. Furthermore, delivery of appropriate services such as discharge planning and post-discharge support through interprofessional collaboration among medical healthcare and social workers within the region would be critical.

Yet nurses, pharmacists, radiologists and others who participated in team medical care training have expressed views on how it is "difficult to interact and collaborate with people in other fields" and how "communication is fundamental to multidisciplinary collaboration and cooperation, yet is the greatest challenge". Previous studies have outlined how role stress is experienced in collaborative work with care managers or nurses at elderly homes[3], and how interprofessional collaboration can be challenging due to diffidence in the face of other professions and an inability to share information between team members[4]. Despite the need for interprofessional communication in team medical care, the level of achievement is still far from sufficient in practice.

In collaborative practice, information gaps occur due to differences in the amount of information that is conveyed or heard but not understood, as well as the degree of consultation and sharing that takes place; gaps in understanding occur due to different approaches to collaboration and professional role as well as different approaches and models (medical versus lifestyle) with respect to patients and how they should be prepared for discharge from the hospital. Such gaps in understanding explain why essential information is not conveyed, leading in turn to information gaps[5]. Therefore, when it comes to interprofessional collaboration in discharge planning for PWD, their differences in goals, perspectives on patients care, and ideas about whether to live at home or local houses are thought to lead into communication gaps, from which communication difficulties caused. Of all the communication gaps, particularly the gap in the level of understanding of dementia patients and their symptoms was thought to be substantial in the discharge process of patients with dementia relative to general patients.

A communication gap can be defined as differences in knowledge, perspective, or lack of information leading to discrepancies in intended meaning which hinder supposedly mutually understandable communication[6]. Communication gaps can be classified into “information gap” where intended information is not conveyed properly, and “recognition gap” where cultural background, values, experiences, or recognition of problems differ between an originator and receiver of a communication[7]. PWD herein are patients hospitalized in a general ward who exhibit cardinal symptoms (e.g., memory impairment, disorientation) or behavioral and psychological symptoms (e.g., wandering, delusion, delirium, sleep impairment) of dementia.

II. Objective

The objective of this study is to investigate the methods to fill in communication gaps in interprofessional collaboration for hospital discharge of PWD by first finding out about the existing communication gaps.

III. Method

1. Research design

A cross-sectional study using a self-administered independent questionnaire of the International University of Health and Welfare.

2. Respondents

Total 2,500: 500 each of doctors, discharge support nurses, medical social workers (MSW), care managers, and visiting nurses employed nationwide at acute care hospitals with less than 400 beds.

Doctors, nurses and care managers were asked one by one from one hospital. In addition, the care manager, from the home office, visiting nurses, from the visiting nursing station, was asked by one each.

3. Research period

July to August 2017

4. Content

In the study, we created a survey based on the results obtained from previous researches to further investigate the communication gaps among intersectoral professionals engaging in the discharge process of PWD.

The response format used the 10-point Likert scale ranging from 1 strongly disagree to

10 strongly agree. The attributes were the profession, number of years employed, age, sex, number of employees in the organization, the feasibility of interprofessional collaboration for the discharge of PWD.

5. Data collection

Surveys were sent to hospitals listed on the Japan Hospital Association roster, home care support service providers listed on nationwide rosters, and visiting nurse service providers listed on rosters maintained by prefectural health and welfare offices. Selections were made so as to avoid overlap between municipalities and achieve a balance in managing organizations. Requests for participation were sent by mail together with questionnaires and return envelopes to the director at each hospital or facility. Responses were collected on an anonymous basis by individual return envelope. Consent of the director was assumed upon the distribution of the questionnaires to respondents, and consent of the respondents was assumed upon return of the questionnaires by mail.

6. Analysis

Collected survey data were statistically analyzed using SPSS 23 software (one-way ANOVA, multiple comparisons).

7. Ethical considerations

All researchers involved in this study have abided by the Declaration of Helsinki and the Ethical Guidelines for Medical and Health Research Involving Human Subjects. The letter of request sent to respondents stated the purpose and method of research and explained that the study would be conducted only with permission of the respondent, that results would be strictly kept in locked storage until being shredded and destroyed after the later of 5 years following the conclusion of the study or 3 years from the final presentation of research, that results would be used only for purposes of this study, and that, although results would be presented at symposiums and in academic journals, data would be statistically processed so that no individual information would be unidentifiable. The letter further explained that participation was voluntary, that there were no unfavorable consequences to not responding, and that responses should be posted only with consent. There are no conflicts of interest associated with this research, and this study has been approved by the International University of Health and Welfare IRB (Approval Number: 17-Ig-24).

IV. Results

1. Respondents

There were 401 respondents in total: 38 doctors, 69 nurses, 71 MSW, 134 care managers and 89 visiting nurses (16.0% response rate). Doctors ranged in age from their 30s to 70s, with most in their 50s, while nurses and MSW ranged from their 20s to 60s with most nurses in their 40s and 50s and most MSW in their 30s. Visiting nurses and care managers ranged from their 20s to 70s with most in their 40s and 50s. Breakdown of sex, specialty and qualification are shown in Table 1.

<Table 1> Basic attributes

Item		Doctor (n=38)		Nurse (n=69)			MSW (n=70)			Care manager			Visiting Nurse (n=89)		
		number (person)	rate(%)		number (person)	rate(%)		number (person)	rate(%)		number (person)	rate(%)		number (person)	rate(%)
Sex	Female	37	97.4		5	7.2		25	35.7		39	29.1		3	3.4
	Male	1	2.6		64	92.8		45	64.3		95	70.9		86	96.6
Age	20s	0	0		1	1.4		9	12.9		1	0.1		1	1.1
	30s	3	7.9		12	17.4		31	44.3		14	10.4		4	4.5
	40s	5	13.2		25	36.2		20	28.6		36	26.9		36	40.4
	50s	16	42.1		27	39.1		10	14.3		63	47		39	43.8
	60s	11	28.9		3	4.3		1	1.4		20	14.9		9	10.1
	70s	1	2.6		0	0		0	0		1	0.1		1	1.1
	Unknown	0	0		1	1.4		0	0		0	0		0	0
Specialties · Qualification	Physician	13	34.2	Nurse	69	100				Nurse	20	14.9	Care manager	38	42.7
	Surgeon	2	5.3	Nurses' aide	0	0				Care worker	92	68.7	Social worker	2	2.2
	Orthopedist	2	5.3	Others	4	5.8				Social worker	21	15.7	community health nurse	5	5.6
	Specialist in brain	6	15.8							Others	15	11.2	Others	7	7.9
	Neurologist	6	15.8												
	Others	9	23.7			*Multiple answers						*Multiple answers			*Multiple answers
Length of service (years)	>10	0	0		1	1.4		44	62.9		61	45.5		3	3.4
	10-20	5	13.2		18	26.1		18	25.7		68	50.7		14	15.7
	20-30	11	28.9		25	36.2		9	12.9		1	0.1		41	46.1
	30-40	19	50.0		21	30.4		—	—		—	—		24	27.0
	40<	3	7.9		1	1.4		—	—		—	—		5	5.6
	Unknown	0	0		3	4.3		0	0		4	3		3	3.4

2. Understanding of Dementia and Patients With Dementia

The means and standard deviations for the "understanding of dementia and PWD" by each question for all professionals are as shown in Table 2.

The "(4) PWD often behave differently at hospital and at home" had a higher mean value of 8.2 than the other items with the lower mean values ranging from 5.5 to 6.6.

One way ANOVA was performed to evaluate the differences among the professions. The results showed the significant difference in "(1) Have knowledge of dementia" ($p < .01$), "(2) Have knowledge of supportive care for symptoms of dementia" ($p < .05$), "(6) Discharge date tend to be short-notice for PWD " ($p < .001$), and "(7) Sufficient time spent in discussing the discharge plan for intersectional collaboration of PWD ” (p < .01) while no significant difference was evident in the other questions (NS) (Table 2).

<Table 2> Understanding of Dementia and Patients
With Dementia: mean and SD (all professions)

	number	Mean ± SD	
(1) Have knowledge of dementia	399	6.6 ±1.74	**
(2) Have knowledge of supportive care for symptoms of dementia	400	6.5 ±1.73	*
(3) Understand life with dementia	399	6.5 ±1.72	
(4) PWD often behave differently at hospital and at home	400	8.2 ±1.65	
(5) Know ways to provide discharge care for PWD	400	6.2 ±1.74	
(6) Discharge date tend to be short-notice for PWD	397	6.3 ±2.35	***
(7) Sufficient time spent in discussing the discharge plan for intersectional collaboration of PWD	397	5.9 ±1.86	**
(8) Sense some difficulties in interprofessional collaboration for discharge process of PWD	374	5.5 ±2.17	

One-way layout analysis of variance *p＜. 05 **p＜. 01 ***p＜. 001

Based on the results obtained by multiple comparison for “(1) Have knowledge of dementia”, doctors 7.2 (SD = 1.89) and MSW 6.1 (SD = 1.78) were significantly different at 1% significant level, doctors and nurses 6.1 (SD = 1.73) were significantly different at 5% significant level, and care managers 6.8 (SD = 1.70) and MSW 6.1 (SD = 1.70) were significantly different at 5% significant level (F = 4.972, df = 4, p < .05) (Table 3). The findings suggest that the doctors perceived themselves to have more knowledge of dementia than the nurses or the MSW, and the care managers perceived themselves to have more knowledge of dementia than the MSW.

As for the “(2) Have knowledge of supportive care for symptoms of dementia”, the care managers 6.7 (SD = 1.75) and the MSW 6.0 (SD = 1.80) were significantly different at the level of 5% (F = 2.832, df = 4, p < .05) suggesting that the care managers perceived themselves to have more knowledge of care for symptoms of dementia than the MSW.

As for the “(6) Discharge date tend to be short-notice for PWD”, the visiting nurses 7.1 (SD = 2.08) and doctors 5.2 (SD = 1.97) were significantly different, and the visiting nurses and the MSW 5.5 (SD = 2.21) were significantly different at the level of 0.1% (F = 7.642, df = 4, p < .001). The care managers 6.7 (SD = 2.52) and doctors 5.2 (SD = 1.97), the care managers and MSW 5.5 (SD = 2.21) were also significantly different at the level of 1% (F = 7.462,df = 4, p < .01). Hence, the visiting nurses and care managers recognized that discharge date tend to be short-notice for PWD.

As for the “(7) Sufficient time spent in discussing the discharge plan for intersectional collaboration of PWD ”, the visiting nurses 5.3 (SD = 1.95) and doctors 6.6 (SD = 1.64), and the nurses and care managers 5.9(SD = 1.99) were significantly different at the level

DOI: http://dx.doi.org/10.14391/ajhs.19.24
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of 5% (F = 4.249, df = 4, p < .05), suggesting that the visiting nurses perceived more than the doctors or care managers that the discharge plan for PWD was not sufficiently discussed.

<Table 3> Understanding of Dementia and Patients With Dementia

		number	Mean ±	SD	F	
(1) Have knowledge of dementia	Doctor	37	7.2	1.89		*
	Nurse	67	6.1	1.73		
	visiting nurse	90	6.8	1.58	4.972	**
	Care manager	134	6.8	1.70		*
	MSW	71	6.1	1.78		
(2) Have knowledge of supportive care for symptoms of dementia	Doctor	37	6.7	1.91		
	Nurse	68	6.2	1.55		
	visiting nurse	90	6.7	1.64	2.832	
	Care manager	134	6.7	1.75		*
	MSW	71	6.0	1.80		
(3) Understand the life with dementia	Doctor	37	6.6	1.83		
	Nurse	68	6.2	1.52		
	visiting nurse	90	6.7	1.68	2.315	n・s
	Care manager	133	6.7	1.73		
	MSW	71	6.2	1.79		
(4) PWD often behave differently at hospital and at home	Doctor	37	8.0	1.52		
	Nurse	68	7.9	1.77		
	visiting nurse	90	8.3	1.64	1.226	n・s
	Care manager	134	8.3	1.66		
	MSW	71	8.1	1.59		
(5) Know ways to provide discharge care for PWD	Doctor	37	6.4	1.90		
	Nurse	68	6.0	1.38		
	visiting nurse	90	6.1	1.93	.877	n・s
	Care manager	134	6.4	1.71		
	MSW	71	6.2	1.75		
(6) Discharge date tend to be short-notice for PWD	Doctor	37	5.2	1.97		***
	Nurse	68	6.1	2.18		**
	visiting nurse	88	7.1	2.08	8.065	
	Care manager	133	6.7	2.52		***
	MSW	71	5.5	2.21		**
(7) Sufficient time spent in discussing the discharge plan for intersectional collaboration of PWD	Doctor	37	6.6	1.64		
	Nurse	68	6.0	1.67		**
	visiting nurse	88	5.3	1.95	4.249	
	Care manager	133	5.9	1.99		*
	MSW	71	6.0	1.56		
(8) Sense some difficulties in interprofessional collaboration for discharge process of PWD	Doctor	37	4.8	1.96		
	Nurse	68	5.9	2.05		
	visiting nurse	82	5.7	1.90	2.666	n.s.
	Care manager	120	5.2	2.36		
	MSW	67	5.7	2.25		

One-way ANOVA host hoc assay (multiple comparison) *p < .05, **p < .01, ***p < .001

3. Things Emphasized in Discharge of PWD

The mean values and standard deviations for the “things emphasized in the discharge of PWD” are as shown in Table 4.

Of the things emphasized in discharge of PWD, the followings had the higher mean value of 8.0 or above: (1) illness and its symptoms that lead to hospitalization, (2) cardinal symptoms of dementia (e.g., memory impairment, disorientation), (3) behavioral and psychological symptoms of dementia (e.g., wandering, delusion, delirium, sleep impairment), (4) feelings of PWD, (5) feelings of PWD family, (7) support system for PWD, (8) support system for PWD family, (10) financial condition, (12) circumstances unique to each PWD and their family.

One way ANOVA was performed to evaluate the differences among the professions. The results suggested that (2) cardinal symptoms of dementia (e.g., memory impairment, disorientation) (p < .01), (4) feelings of PWD (p < .001), (5) feelings of PWD family (p < .001), (6) feelings of healthcare professionals, (p < .01), (7) support system for PWD (p < .05), (8) support system for PWD family (p < .05), (9) support system for community (p < .001), (11) issues such as hospital occupancy (p < .01), and (13) experiences of MSW or care managers (p < .05) were significantly different (Table 4).

<Table 4> Things Given Importance Upon
Discharge of PWD: mean and SD (all professions)

	number	Mean	± SD	
(1) illness and its symptoms that lead to hospitalization	394	8.3	1.62	
(2) cardinal symptoms of dementia (e.g., memory impairment, disorientation)	396	8.3	1.56	**
(3) behavioral and psychological symptoms of dementia (e.g., wandering, delusion, delirium, sleep impairment)	397	8.6	1.42	
(4) feelings of PWD	397	8.3	1.72	***
(5) feelings of PWD family	398	8.7	1.28	***
(6) feelings of healthcare professionals	391	7.0	1.88	**
(7) support system for PWD	396	8.8	1.34	*
(8) support system for PWD family	396	8.7	1.38	*
(9) support system for community	389	7.1	2.06	***
(10) financial condition	397	8.3	1.60	
(11) issues such as hospital occupancy	389	6.8	2.14	**
(12) circumstances unique to each PWD and their family	394	8.4	1.40	
(13) experiences of MSW or care managers	386	6.3	2.21	*

One-way layout analysis of variance *p<. 05 **p<. 01 ***p<. 001

Based on the results obtained by multiple comparison for “(2) cardinal symptoms of dementia (e.g., memory impairment, disorientation)”, the doctors 7.6 (SD = 1.70) and the visiting nurses 8.8 (SD = 1.36) were significantly different at the level of 1% (F = 4.455, df = 4, p < .01), doctors 7.6 (SD = 1.70) and care managers 8.4 (SD = 1.61) were significantly different at the level of 5% (F = 4.455, df = 4, p < .05) (Table 5). The findings suggest that the visiting nurses and care managers placed more importance on the cardinal symptoms of dementia (e.g., memory impairment, disorientation) than the doctors.

As for the “(4) feelings of PWD”, the visiting nurses 8.7 (SD = 1.43) and doctors 7.3 (SD = 1.93), as well as care managers 8.5 (SD = 1.70) and doctors were significantly different at the level of 1% (F = 7.475, df = 4, p < 0.01). In addition, the visiting nurses 8.7 (SD = 1.43) and the MSW 7.7 (SD = 1.83) were significantly different at the level of 1% (F = 7.475, df = 4, p < 0.01), the care managers 8.5(SD = 1.70) and the MSW 7.7 (SD = 1.83) were significantly different at the level of 5% (F = 7.475, df = 4, p < 0.05). The findings suggest that visiting nurses and care managers placed more importance on the feelings of PWD than the MSW and doctors. As for the “(5) feelings of PWD family”, the visiting nurses 9.1 (SD = 1.15) and the care managers 9.0 (SD = 1.25), as well as the visiting nurses and the doctors 7.9 (SD = 1.50) were significantly different at the level of 1% (F = 6.826, df = 4, p < 0.01). The findings suggest that visiting nurses and care managers placed more importance on the feelings of the PWD family than the doctors.

In addition, as for the “(6) feelings of healthcare professionals”, the visiting nurses 7.3 (SD = 1.92) and the doctors 6.1 (SD = 1.88) were significantly different at the level of 1% (F = 3.646, df = 4, p < 0.01), the nurses 7.2 (SD = 1.81) and the doctors, as well as the MSW 7.1(SD = 1.76) and the doctors were significantly different at the level of 5% (F = 3.646, df = 4, p < 0.05). The findings suggest that the visiting nurses, nurses, and MSW emphasized more on the feelings of healthcare professionals than the doctors.

DOI: http://dx.doi.org/10.14391/ajhs.19.24
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<Table 5> Things Given Importance Upon Discharge of PWD

		number	Mean	± SD	F	
(1) illness and its symptoms that lead to hospitalization	Doctor	38	7.8	1.74	1.499	n.s.
	Nurse	68	8.3	1.57		
	visiting nurse	89	8.5	1.60		
	Care manager	129	8.4	1.58		
	MSW	70	8.2	1.65		
(2) cardinal symptoms of dementia (e.g., memory impairment, disorientation)	Doctor	38	7.6	1.70	4.455	
	Nurse	69	8.2	1.58		**
	visiting nurse	90	8.8	1.36		*
	Care manager	129	8.4	1.61		
	MSW	70	8.2	1.49		
(3) behavioral and psychological symptoms of dementia (e.g., wandering, delusion, delirium, sleep impairment)	Doctor	38	8.2	1.45	1.955	n.s.
	Nurse	69	8.5	1.52		
	visiting nurse	89	8.9	1.31		
	Care manager	131	8.6	1.43		
	MSW	70	8.6	1.38		
(4) feelings of PWD	Doctor	38	7.3	1.93	7.475	
	Nurse	69	8.3	1.56		**
	visiting nurse	90	8.7	1.43		**
	Care manager	130	8.5	1.70		**
	MSW	70	7.7	1.83		*
(5) feelings of PWD family	Doctor	38	7.9	1.50	6.826	
	Nurse	69	8.6	1.31		***
	visiting nurse	90	9.0	1.15		***
	Care manager	131	9.0	1.25		
	MSW	70	8.5	1.15		
(6) feelings of healthcare professionals	Doctor	38	6.1	1.88	3.646	*
	Nurse	69	7.2	1.81		**
	visiting nurse	88	7.3	1.92		*
	Care manager	126	6.8	1.88		
	MSW	70	7.1	1.76		
(7) support system for PWD	Doctor	38	8.3	1.31	2.357	
	Nurse	69	8.9	1.23		*
	visiting nurse	90	9.0	1.18		
	Care manager	129	8.7	1.54		
	MSW	70	8.8	1.20		
(8) support system for PWD family	Doctor	38	8.2	1.39	2.756	n.s.
	Nurse	69	8.9	1.19		
	visiting nurse	89	8.9	1.22		
	Care manager	130	8.8	1.50		
	MSW	70	8.5	1.44		
(9) support system for community	Doctor	38	7.4	1.54	5.141	
	Nurse	68	7.8	1.60		
	visiting nurse	89	7.5	1.83		**
	Care manager	124	6.5	2.26		*
	MSW	70	7.0	2.36		
(10) financial condition	Doctor	38	7.7	1.37	2.161	n.s.
	Nurse	69	8.2	1.46		
	visiting nurse	90	8.2	1.61		
	Care manager	130	8.4	1.73		
	MSW	70	8.6	1.50		
(11) issues such as hospital occupancy	Doctor	38	6.9	1.76	3.302	
	Nurse	69	7.4	1.81		*
	Health visitor	86	6.4	2.52		*
	Care manager	126	6.5	2.25		
	MSW	70	7.1	1.74		
(12) circumstances unique to each PWD and their family	Doctor	38	7.9	1.17	2.256	n.s.
	Nurse	68	8.2	1.37		
	visiting nurse	90	8.6	1.32		
	Care manager	128	8.5	1.51		
	MSW	70	8.3	1.39		
(13) experiences of MSW or care managers	Doctor	38	6.8	1.73	2.767	
	Nurse	67	6.8	2.03		
	visiting nurse	90	6.4	2.31		*
	Care manager	123	5.9	2.44		
	MSW	68	6.4	1.91		

One-way ANOVA host hoc assay (multiple comparison) *p < .05, **p < .01, ***p < .001

4. Things considered critical for interprofessional collaboration in the discharge of PWD

The mean values and standard deviations for “the things considered critical for interprofessional collaboration in the discharge of PWD” are as shown in Table 6.

The mean values were high, 8.0 or above, for all the items except for the “(6) collaborative leadership” and “(7) resolving the interprofessional conflict”.

One way ANOVA was performed to evaluate the differences among the professions. The results indicated that “(8) joined conference” was significantly different ($p < .001$), while no significant difference was evident in the other items (NS) (Table 6).

<Table 6> Things Considered Critical for Interprofessional Collaboration: mean and SD (all professions)

	number	Mean	± SD	
(1) expertise knowledge	395	8.1	1.62	
(2) expertise	395	8.2	1.58	
(3) interprofessional communication	395	8.8	1.37	
(4) common goal setting	394	8.6	1.54	
(5) defining the role of each profession	393	8.1	1.70	
(6) collaborative leadership	387	7.5	1.77	
(7) resolving the interprofessional conflict	389	7.4	1.90	
(8) joined conference	393	8.3	1.67	***

One-way layout analysis of variance *p<. 05 **p<. 01 ***p<. 001

Based on the results obtained by multiple comparison for the “(8) joined conference”, the nurses 8.9 (SD = 1.28), MSW 8.5 (SD = 1.48) and doctors 7.5 (SD = 1.56) were significantly different at the level of 1% ($F = 4.569$, $df = 4$, $p < .01$). The nurses 8.9 (SD = 1.28) and care managers 8.1 (SD = 1.89) were significantly different at the level of 5% ($F = 4.569$, $df = 4$, $p < .05$) (Table 7). The findings suggested that the nurses and MSW considered a joined conference for discharge planning more important than the doctors. Furthermore, the nurses (discharge planning) considered a joined conference more important than the MSW.

Things considered critical for interprofessional collaboration in the discharge of PWD are shown by profession from highest to lowest priority according to their mean scores in Figure 1.

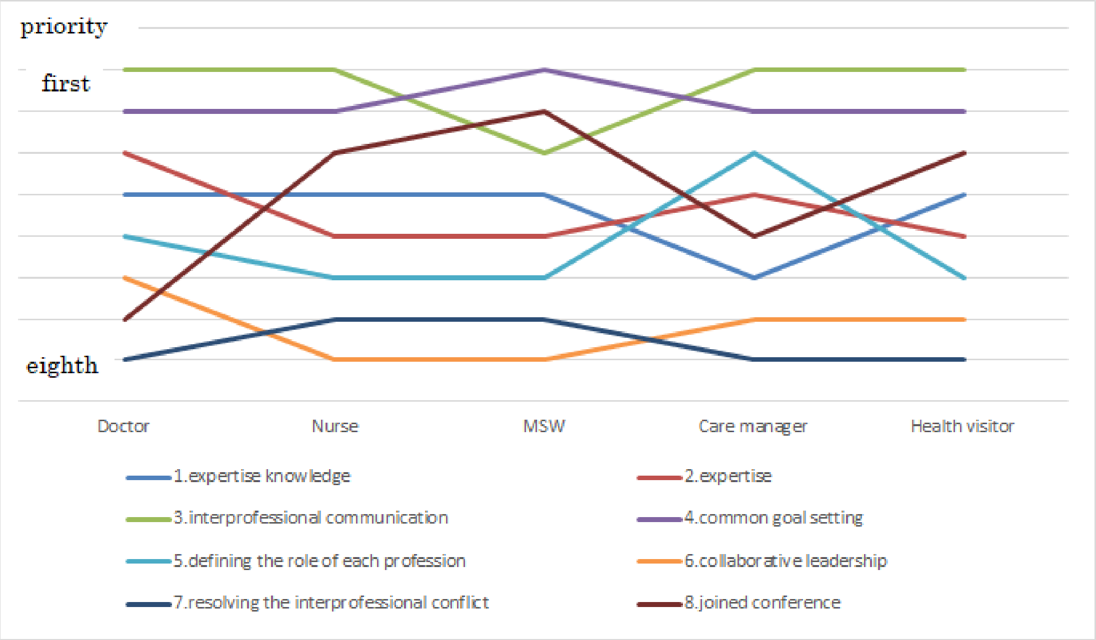
All professions except MSW answered that the “(3) interprofessional communication” is their top priority followed by “(4) common goal setting”. The order of priority for “(8) joined conference” varied among the professions. The care managers placed a high priority on “(5) defining the role of each profession” than the other professions.

<Table 7> Things Considered Critical for Interprofessional Collaboration Upon Discharge of PWD

		number	Mean ±	SD	F	
1) expertise knowledge	Doctor	38	7.7	1.63	2.265	n.s.
	Nurse	68	8.5	1.40		
	visiting nurse	89	8.3	1.53		
	Care manager	132	8.0	1.73		
	MSW	68	7.9	1.65		
2) expertise	Doctor	38	7.8	1.52	1.974	n.s.
	Nurse	68	8.5	1.35		
	visiting nurse	90	8.3	1.53		
	Care manager	131	8.1	1.71		
	MSW	68	7.9	1.59		
3) interprofessional communication	Doctor	38	8.5	1.25	2.329	n.s.
	Nurse	68	9.1	1.21		
	visiting nurse	90	8.9	1.25		
	Care manager	131	8.8	1.51		
	MSW	68	8.4	1.42		
4) common goal setting	Doctor	38	8.1	1.40	2.066	n.s.
	Nurse	69	9.0	1.29		
	visiting nurse	89	8.7	1.51		
	Care manager	131	8.5	1.69		
	MSW	67	8.5	1.52		
5) defining the role of each profession	Doctor	38	7.7	1.53	1.188	n.s.
	Nurse	68	8.3	1.59		
	visiting nurse	89	8.2	1.64		
	Care manager	130	8.2	1.76		
	MSW	68	7.8	1.82		
6) collaborative leadership	Doctor	38	7.7	1.62	1.984	n.s.
	Nurse	67	7.8	1.40		
	visiting nurse	89	7.8	1.69		
	Care manager	125	7.4	1.94		
	MSW	68	7.2	1.89		
7) resolving the interprofessional conflict	Doctor	38	7.2	1.66	1.000	n.s.
	Nurse	68	7.5	1.71		
	visiting nurse	88	7.6	2.01		
	Care manager	129	7.2	1.98		
	MSW	66	7.3	1.90		
8) joined conference	Doctor	38	7.5	1.56	4.569	***
	Nurse	67	8.9	1.28		***
	visiting nurse	89	8.4	1.65		*
	Care manager	131	8.1	1.89		
	MSW	68	8.5	1.48		

One-way ANOVA host hoc assay (multiple comparison) *p < .05, **p < .01, ***p < .001

DOI: http://dx.doi.org/10.14391/ajhs.19.24
Asian Journal of Human Services, VOL.19 24-41



<Figure 1> Things Considered Critical for Interprofessional Collaboration Upon Discharge of PDW (The order of priority by profession)

V. Discussion

1. Understanding of Dementia and Patients With Dementia

Understanding of dementia and PWD was different in perception by job type, with “Have knowledge of dementia.” and “Have knowledge of supportive care for symptoms associated with dementia.” Moreover, perceptions including the symptoms that are not regarded as dementia at home are diagnosed as dementia in the hospital and considered a problem or, symptoms that are not dementia are diagnosed as dementia might lead to the recognition, patients with dementia are increasing8). In this way, even if you think that you are “Have knowledge of dementia” or ”Have knowledge of supportive care for symptoms of dementia”, the dementia and symptoms of dementia are not as texted, and each person's symptoms are different.

It was also thought that there was a difference in the perception of job categories by actually experiencing PWD, as if they recognized that “PWD is different in the behavior of hospitals and homes.” As Arita et al.9) note, in most hospitals, for any one patient, there are multiple directly and indirectly involved personnel who hail from multiple specialties and multiple positions. Interactions with the patient differ for each profession, and acquired information is limited and changes over time. Differences in perceptions for [Patient] may be related to differences in the quality and quantity of information that can be obtained by each profession depending on the patient’s condition and response.

With respect to patient discharge from the hospital, visiting nurses perceived most strongly that “Discharge date of PWD tend to be short-notice”, followed by care managers, with doctors having the weakest perception. Since schedules are determined by doctors based on the treatment program, they do not perceive that patients are discharged suddenly. For practitioners that have to follow the doctor’s orders and make arrangements for discharge with families and other parties outside of the hospital, however, the perception is that there is not enough time to prepare.

2. Things Given Importance Upon Discharge of PWD

As discharge coordination for PWD, the visiting nurses and care managers placed more importance on the cardinal symptoms of dementia (memory impairment, disorientation, among others), feelings of PWD, their families, and healthcare professionals than the doctors. Hosoda[10)] noted that team medical care consists of the following four components: (1) expertise-oriented component to utilize expertise of each field, (2) patient-oriented component to prioritize patients’ needs, (3) occupation-oriented component to include various occupations to make up a team, and (4) cooperation-oriented to focus on various professionals to work together collaboratively on equal footing. Depending on which component each professional emphasizes, antinomic tension may rise, or there may be a case where fulfillment of one component may lead to unfulfillment of another component. Such variation of emphasis by each profession is thought to cause communication gaps.

It is also reported that despite the families’ willingness to care PWD at home upon their hospital discharge, they are also reluctant of discharge considering the burden on the families[11)]. Therefore, it was thought that the average of care managers and visiting nurses who were actually involved with the family was higher, and this difference in perception also led to a communication gap.

Saito et al.[12)] state that interprofessional collaboration in the continuity of hospital discharge support is critical because the post-discharge life of PWD can vary substantially depending on many factors such as severity of dementia, the conditions of behavioral and psychological symptoms, medication requirement, residing family members, or financial status. Therefore, it is important to examine further the ways to provide help and support for PWD by the improved interprofessional collaboration to reduce the anxiety of PWD and their families upon discharge.

3. Things Considered Critical for Interprofessional Collaboration in Discharge of PWD

In what I think is important in the cooperation between occupations for the discharge of PWD, there was a difference by the occupation albeit in “Joint conference”. In many cases when elderly patients with dementia are discharged from the hospital, their husband or wife also tend to have dementia. Furthermore, the number of older adults living alone has been increasing recently, which might lead to difficulties in discharge coordination for patients with dementia.

Matsuoka[13)] stated that most patients with dementia are older adults having various chronic diseases and a decline in physical functions. Therefore, an interprofessional team approach is required for managing their physical and various psychological and social care needs, including problems related to nursing care.In this way, it is important to work together between occupational positions toward the discharge of PWD, and in fact, the coordination of discharge of PWD was not so important. I think that it is connected though it is important that the cooperation between occupational categories is difficult in the schedule.

Things considered most critical by all the professionals except MSW for interprofessional collaboration in the discharge of PWD was “communication” followed by “sharing the same goal”. Although most of the professionals are aware of the importance of communication, having effective communication is difficult which may be the exact reason why such communication is valued.

Communicational skill education in medical consultation interviews for doctors, for instance, began in the early 1990s and gradually pervaded from there. According to Nagashima et al.14), however, communication education provided for doctors before and after graduation is mainly to give medical consultation and not to promote effective dialog skills. For visiting-nurses renewed Investigative Commission for Enrichment of Basic Nursing Education15) released in 2007 incorporated educational curriculum for better communication abilities. Although communication education nowadays is advancing, as shown above, additional education is necessary not only for the communication between healthcare professionals and patients or their families but also for the communication between healthcare professionals. Not only knowledge but communication skills and abilities must be cultivated deliberate communication.

4. Minimizing Communication Gaps in Interprofessional Healthcare Professionals

The study found that there are differences in perceptions of dementia and PWD among medical and welfare professionals. As Hosoda16) says, specialists often have a different educational background with their own different values and opinions which may be one of the reasons why interprofessional collaboration can be difficult. Although more education on communication or interprofessional collaboration is becoming more accessible through lectures and practical training, they are still conducted independently for each profession. Hence, there should be more opportunity for various professionals to learn together. Although acquiring knowledge through a lecture is essential, the essential part of gaining understanding in communication is understanding by knowledge gained from actual experiences by seeing and feeling via practical training at the workplace. Such experiences also help each other to understand and learn the role of each profession.

One of the examples of different values and ideas of each profession is that medical professionals value more of the traditional “medical model (pathological model)” focusing on individuals undergoing struggling life circumstances whereas social welfare workers tend to value more of "ecological model" than "pathological model". The "ecological model" aims to understand problems by emphasizing the humans and environmental transaction, and enhancing adaptability and tolerance-responsiveness of humans through intervening the interface between humans and environment for better transition quality17).

While medical professionals try to resolve issues by focusing on the problems an individual may be having and its cause, social welfare professionals not only focus on the weaknesses adverse conditions of their clients but also focus on their clients' ability (including not only individual but also groups and local communities), willingness, preference, available social resources and other strengths. The early part of hospitalization starts with team medical treatment care model to aim for the earliest recovery possible. When full rehabilitation process begins as the condition gradually ameliorates, the medical model is not sufficient in terms of support for post-discharge life of PWD, which requires alternation of the medical model into the biological, psychological and social model18). The approaches for PWD and their discharge process need to be changed accordingly as PWD undergo different phases from hospitalization to discharge.

VI. Conclusion

The results indicated that there was a significant difference in "Have knowledge of dementia" ($p < .01$), "Discharge date tend to be short-notice for PWD" ($p < .001$), and "Sufficient time spent in discussing the discharge plan for intersectional collaboration of PWD" ($p < .01$), suggesting the differences among professionals. A statistically significant differences were evident in the following things that are considered critical upon discharging PWD: "cardinal symptoms of dementia" ($p < .01$), "feelings of PWD" ($p < .001$), "feelings of PWD family" ($p < .001$), "feelings of healthcare professionals" ($p < .01$), "support system for PWD family" ($p < .05$), and "support system for PWD" ($p < .05$) suggesting the communication gaps among intersectoral healthcare professionals.

Communication gaps in interprofessional collaboration for hospital discharge process of PWD result in communication difficulties. Therefore, gaining an understanding of various perspectives of each profession about PWD leads to filling up the communication gaps.

Acknowledgments

The author sincerely thanks everyone who contributed to this research and publication. This study is part of research funded by a three-year (2013-2015) Grant-in-Aid for Scientific Research (Grant-in-Aid for Academic Research; Foundational Research C; Item Number: 25463369) from the Japan Society for the Promotion of Science.

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Human
Services

DOI: http://dx.doi.org/10.14391/ajhs.19.42
Asian Journal of Human Services, VOL.19 42-54

Original Article

Quality of Life During Chemotherapy in Japanese Patients with Unresectable Advanced Pancreatic Cancer

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ABSTRACT

Objectives: To assess the quality of life (QoL) in Japanese patients receiving standard chemotherapy for unresectable pancreatic cancer.
Patients and Methods: This prospective observational study included 30 Japanese patients with unresectable pancreatic cancer (PS 0–1) who were starting standard first-line chemotherapy. QoL was assessed using the European Organization for Research and Treatment for Cancer Quality of Life Core Questionnaire, version 3.0. Anxiety and depression were measured using the Hospital Anxiety and Depression Scale. Assessments were performed at baseline, 2 weeks, and then monthly during chemotherapy.
Results: At baseline, the global health status (GHS) score was low (50/100), and 9 patients (30%) were experiencing significant levels of mental distress. Scores for the GHS, five functional scales (physical, role, emotional, cognitive, and social), nine symptoms (fatigue, nausea and vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties), anxiety and depression generally did not deteriorate during chemotherapy. However, the QoL scores varied during chemotherapy according to the patients' characteristics. Patients who achieved tumor control tended to have well-controlled QoL scores. A high survival rate was significantly associated with having a high baseline GHS score.
Conclusions: Japanese patients with unresectable pancreatic cancer might maintain their QoL during standard chemotherapy, with tumor control being associated with well-controlled QoL. In addition, a high QoL at baseline was associated with a good prognosis.

<Key-words>
quality of life, pancreatic cancer, chemotherapy, anxiety, depression

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Asian J Human Services, 2020, 19:42-54.

Received
July 14, 2020

Revised
September 9, 2020

Accepted
October 2, 2020

Published
October 30, 2020

I. Introduction

Pancreatic cancer is the fourth leading cause of cancer-related death in Japan, with approximately 34,000 deaths estimated in 2017.1) While the number of patients is increasing, the 5-year survival rate remains as low as 7%, as most diagnoses occur at late disease stages.1)

The standard regimens for patients with unresectable pancreatic cancer are oxaliplatin / irinotecan/ fluorouracil/ leucovorin (FOLFIRINOX) or gemcitabine/nab-paclitaxel (GnP), which have improved QoL and overall survival (OS) relative to those for gemcitabine monotherapy in Western patients with advanced pancreatic cancer.2-5) Although phase II studies of FOLFIRINOX and GnP in Japanese patients with metastatic pancreatic cancer revealed equivalent efficacies to those reported in the original studies,6,7) the effects on the QoL remain unclear. Furthermore, FOLFIRINOX treatment may reduce the QoL, based on reports of elevated rates of toxicity in Japanese patients relative to those in Western patients (grades 3–4 neutropenia: 77.8% vs. 45.7%, febrile neutropenia: 22.2% vs. 5.4%).2,6) Thus, a modified FOLFIRINOX regimen (mFOLFIRINOX) has been generally used in Japan, as a phase II study of the mFOLFIRINOX regimen revealed a comparable response rate to that of FOLFIRINOX, with fewer adverse events.8,9)

In patients with advanced cancer, it is important to decide the treatment considering both benefits and risks according to individual needs.10) Since the prognosis of patients with advanced pancreatic cancer is very poor, their QoL should be considered as important as their duration of survival.

Additionally, among patients with various cancers, the overall prevalence of psychological distress is approximately 35%, and patients with pancreatic cancer have the poorest mental health on the basis of their anxiety and depression.11) Since psychological distress can interrupt chemotherapy,12) physical, psychological, social, and spiritual aspects of care should be considered for patients with advanced incurable cancer.10) Therefore, the present study investigated the QoL, based on multiple dimensions, in Japanese patients who were receiving standard chemotherapy for unresectable advanced pancreatic cancer.

II. Methods

1. Study design and Patients

This prospective observational study evaluated Japanese patients with unresectable advanced pancreatic cancer and an Eastern Cooperative Oncology Group performance status (ECOG PS) of 0 or 1. ECOG PS is a simple useful scale to evaluate a patient's physical condition. It is commonly used to decide the indication of chemotherapy, and ECOG PS 0–1 means that the daily living abilities are almost preserved.13,14) All patients were treated using FOLFIRINOX, mFOLFIRINOX, or GnP as first-line chemotherapy. The study period was between January 1, 2016 and January 31, 2018.

2. Treatment regimens

The FOLFIRINOX regimen consisted of oxaliplatin (85 mg/m^2 as a 2-h intravenous infusion) followed by *l*−leucovorin after 30 min (200 mg/m^2 as a 2-h intravenous infusion), irinotecan (180 mg/m^2 as a 90-min intravenous infusion), and fluorouracil (an intravenous bolus of 400 mg/m^2 followed by a dose of 2,400 mg/m^2 as a 46-h continuous intravenous infusion) once every 2 weeks.[2)] The mFOLFIRINOX regimen involved reducing the irinotecan dose to 150 mg/m^2 and omitting the intravenous bolus of fluorouracil.[8,9)] The GnP regimen consisted of nab-paclitaxel (125 mg/m^2 as a 30-min intravenous infusion) followed by gemcitabine (1,000 mg/m^2 as a 30-min intravenous infusion) on days 1, 8, and 15, and every 4 weeks.[4)]

3. Assessment of treatment response

Contrast-enhanced computed tomography scans were reviewed to evaluate antitumor response according to the Response Evaluation Criteria in Solid Tumors (RECIST) version1.1[15)] at baseline and then every 2–3 months afterwards. Patients were divided into progressive disease (PD) and non-PD depending on the best response during the first-line chemotherapy.

4. Evaluating the QoL

The patients' QoL was assessed using the European Organization for the Research and Treatment of Cancer QoL Questionnaire C-30 (EORTC QLQ-C30) version 3.0[16)] and the Hospital Anxiety and Depression Scale (HADS).[17)] The EORTC QLQ-C30 version 3.0 tool is a self-administered 30-item questionnaire for patients with cancer[16)] that evaluates the global health status (GHS), five functional scales (physical, role, emotional, cognitive, and social), and nine symptoms (fatigue, nausea and vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties). Responses to the questionnaire were transformed into scores of 0–100 according to the scoring manual, with higher scores for the GHS and functional scales indicating better levels of functioning, whereas higher scores for the symptom scales indicating worse symptoms. The validity of the Japanese version of the EORTC QLQ-C30 was established in a previous study.[18)]

The HADS questionnaire consists of 14 items and evaluates the degrees of anxiety and depression.[17)] Each item is rated on a 4-point scale (0–3), with a maximum score of 21 for anxiety and a maximum score of 21 for depression. Scores ≥11 on either subscale are considered to indicate "significant" psychological morbidity, whereas scores of 8–10 represent "borderline" morbidity and scores of 0–7 represent "normal" levels. The validity of the Japanese version of the HADS was also established in a previous study.[19)] The assessments were performed at baseline, 2 weeks, and then monthly after the initiation of chemotherapy.

5. Statistical analysis

Data are presented as medians (range) or numbers (percentage). Inter-group comparisons for each factor were preformed using the Mann–Whitney *U* test for continuous variables and the χ^2 test or Fisher's exact test for categorical variables. For continuous variables, the medians were used as the cutoff points to create categorical factors. The Friedman test followed by the Dunn–Bonferroni post-hoc test was used to evaluate longitudinal changes in the QoL scores. The OS interval was defined as the time from the start of chemotherapy to death from any cause, and was censored at the last follow-up for surviving patients. Differences in OS were evaluated using the Kaplan–Meier method and the log-rank test. The Cox proportional hazard model was applied to evaluate the effect of the GHS score while adjusting for potential confounding factors. *P*-values <0.05 were considered statistically significant. All analyses were performed using IBM SPSS software (version 22.0; IBM Corp., Armonk, NY).

6. Ethical considerations

This study was conducted with the approval of the institutional review board of Saga-Ken Medical Centre Koseikan (approval number: 16-02-2-01). All the patients provided written informed consent before enrollment into the study.

III. Results

1. Patient characteristics

Thirty patients were enrolled in this study; their baseline characteristics are shown in Table 1. The median age was 64 years (range: 47–79 years), and 60% of the patients were men. The median body mass index (BMI) was 20.7 kg/m^2 (range: 15.7–26.2 kg/m^2) and 16 patients (53.3%) had BMI <21 kg/m^2. All patients had an ECOG PS of 0 at baseline. Twenty-three patients (76.7%) had distant metastases, and the most common site of metastasis was the liver (40%). Eight patients were treated using FOLFIRINOX, 12 patients were treated using mFOLFIRINOX, and 10 patients were treated using GnP, as first-line chemotherapy. Seventeen patients (56.7%) subsequently received second-line chemotherapy and 6 patients (20%) received third-line chemotherapy. The median duration of follow-up was 6.0 months (range: 1–16 months).

<Table 1> Baseline characteristics of the 30 patients

Age, years	64 (47–79)
Male, n (%)	18 (60)
BMI, kg/m^2	20.7 (15.7–26.2)
ECOG PS 0, n (%)	30 (100)
Working, n (%)	16 (53.3)
Pancreatic tumor location, n (%)	
Head	13 (43.3)
Body	10 (33.3)
Tail	6 (20)
Multicentric	1 (3.3)
Stage, n (%)	
Locally advanced	7 (23.3)
Metastatic	23 (76.7)
Metastatic sites, n (%)	
Liver	12 (40)
Lungs	3 (10)
Peritoneum	4 (13.3)
Other	4 (13.3)
Biliary stent use, n (%)	8 (26.7)
Opioid use, n (%)	9 (30)
Non-opioid use, n (%)	11 (36.7)
Celiac plexus block, n (%)	4 (13.3)
First-line regimen, n (%)	
FOLFIRINOX	8 (26.7)
mFOLFIRINOX	12 (40.0)
GnP	10 (33.3)

Data are expressed as medians (range) or numbers (percentage).
BMI, body mass index; ECOG PS, Eastern Cooperative Oncology Group performance status; FOLFIRINOX, oxaliplatin/irinotecan/fluorouracil/*l*-leucovorin; mFOLFIRINOX, modified FOLFIRINOX; GnP, gemcitabine plus nab-paclitaxel.

2. Baseline QoL

The baseline scores for each scale are shown in Table 2, with median scores on the functional scales ranging from 66.7 to 86.7. In contrast, the median GHS score was only 50 (out of a possible 100), and patients had poor scores for the symptom scales regarding fatigue, pain, insomnia, appetite loss, constipation, and financial difficulties (median: ≥33.3). The median anxiety score was 7 and the median depression score was 8. Seven patients (23.3%) had borderline anxiety and 7 patients (23.3%) had significant anxiety. Twelve patients (40%) had borderline depression and 5 patients (16.7%) had significant depression. Thus, a total of 9 patients (30%) had clinical levels of mental distress (significant anxiety or depression, based on scores ≥11).

DOI: http://dx.doi.org/10.14391/ajhs.19.42
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<Table 2> Changes in quality of life scores based on the EORTC QLQ-C30 and HADS tools from baseline to 6 months

	Baseline	0.5 month	1 month	2 months	3 months	4 months	5 months	6 months	*p* value
EORTC QLQ-C30									
Global health status	50.0 (16.7–91.7)	50.0 (0–100)	50.0 (0–91.7)	50.0 (0–100)	50.0 (0–83.3)	50.0 (33.3–91.7)	58.3 (8.3–100)	58.3 (16.7–91.7)	0.989
Physical function	86.7 (53.3–100)	80.0 (33.3–100)	80.0 (26.7–100)	80.0 (26.7–100)	80.0 (26.7–100)	80.0 (53.3–100)	86.7 (13.3–100)	86.7 (33.3–100)	0.953
Role function	83.3 (33.3–100)	83.3 (0–100)	66.7 (0–100)	66.7 (16.7–100)	66.7 (0–100)	66.7 (33.3–100)	66.7 (0–100)	66.7 (33.3–100)	0.095
Emotional function	66.7 (33.3–100)	83.3 (33.3–100)	83.3 (8.3–100)	83.3 (41.7–100)	70.9 (50–100)	91.7 (66.7–100)	83.3 (50–100)	83.3 (50–100)	0.036*
Cognitive function	83.3 (33.3–100)	83.3 (33.3–100)	83.3 (16.7–100)	83.3 (33.3–100)	83.3 (0–100)	83.3 (50–100)	83.3 (16.7–100)	66.7 (0–100)	0.942
Social function	66.7 (0–100)	66.7 (0–100)	66.7 (33.3–100)	66.7 (16.7–100)	66.7 (0–100)	66.7 (33.3–100)	66.7 (33.3–100)	83.3 (0–100)	0.218
Fatigue	33.3 (0–88.9)	33.3 (0–88.9)	44.4 (0–77.8)	33.3 (0–88.9)	33.3 (11.1–77.8)	33.3 (11.1–55.6)	33.3 (0–100)	33.3 (0–77.8)	0.659
Nausea and vomiting	0 (0–50)	16.7 (0–50)	0 (0–83.3)	16.7 (0–100)	0 (0–83.3)	0 (0–50)	0 (0–33.3)	0 (0–66.7)	0.339
Pain	33.3 (0–100)	0 (0–66.7)	16.7 (0–83.3)	16.7 (0–100)	16.7 (0–100)	0 (0–66.7)	0 (0–100)	0 (0–83.3)	0.106
Dyspnea	0 (0–33.3)	0 (0–33.3)	33.3 (0–66.7)	0 (0–66.7)	0 (0–33.3)	0 (0–33.3)	0 (0–33.3)	0 (0–33.3)	0.591
Insomnia	33.3 (0–100)	0 (0–100)	33.3 (0–100)	33.3 (0–100)	33.3 (0–100)	33.3 (0–100)	33.3 (0–66.7)	33.3 (0–66.7)	0.639
Appetite loss	33.3 (0–100)	33.3 (0–100)	33.3 (0–100)	33.3 (0–100)	33.3 (0–100)	16.7 (0–100)	33.3 (0–100)	0 (0–100)	0.632
Constipation	33.3 (0–100)	33.3 (0–100)	0 (0–100)	33.3 (0–100)	33.3 (0–66.7)	33.3 (0–66.7)	33.3 (0–100)	33.3 (0–100)	0.222
Diarrhea	0 (0–66.7)	33.3 (0–100)	0 (0–100)	33.3 (0–66.7)	0 (0–100)	0 (0–33.3)	0 (0–66.7)	0 (0–66.7)	0.031
Financial difficulties	33.3 (0–100)	33.3 (0–66.7)	33.3 (0–66.7)	0 (0–100)	33.3 (0–100)	33.3 (0–66.7)	33.3 (0–66.7)	33.3 (0–100)	0.942
HADS									
Anxiety	7 (1–13)	5 (0–13)	5 (0–14)	6 (0–15)	7 (0–12)	4.5 (0–9)	5 (0–15)	5 (0–12)	0.040
Depression	8 (0–15)	7 (0–15)	9 (0–15)	9 (0–15)	8 (0–15)	8 (0–13)	8 (0–17)	8 (0–14)	0.361

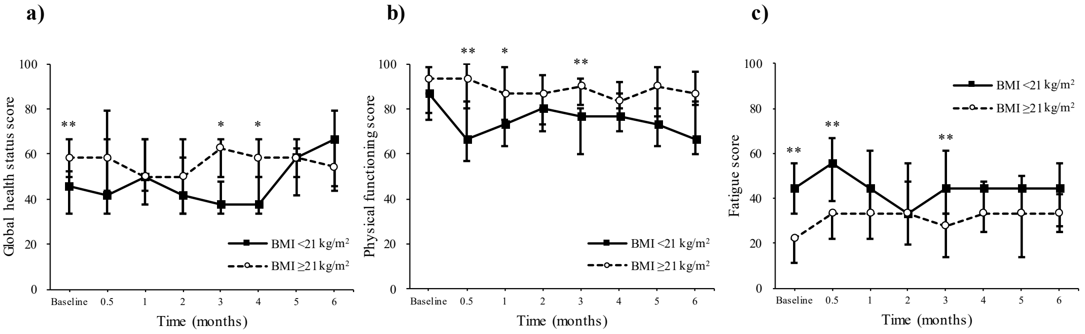
Data are expressed as medians (range). Differences in the median values were evaluated using the Friedman test, and *p*-values of <0.05 were considered statistically significant. The QLQ C-30 scores for each scale range from 0 to 100.
The HADS scores for each scale from 0 to 21.
* Baseline vs. 4 months based on the Dunn–Bonferroni post-hoc test (p=0.032).
EORTC QLQ-C30, European Organization for the Research and Treatment of Cancer QoL Questionnaire C-30; HADS, Hospital Anxiety and Depression Scale.

3. Changes in the QoL during chemotherapy

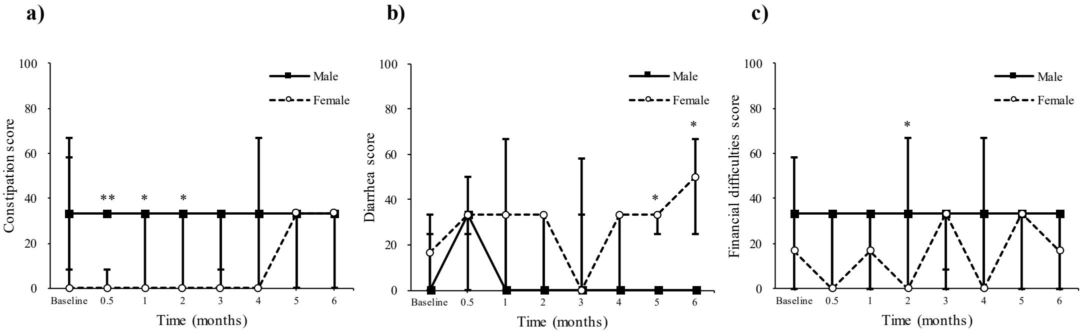
The scores for the GHS, the five functions, and the nine symptoms did not generally deteriorate during chemotherapy (Table 2). In addition, the emotional function scores were improved at 4 months after starting chemotherapy, relative to baseline levels (p=0.032). Pain was well-controlled using opioids and celiac plexus blocks (Table 1). Although the anxiety scores fluctuated, there was a trend toward improvement after starting chemotherapy. However, the depression scores remained high.

Patients with lower BMI (<21 kg/m^2) had poorer GHS and physical function scores, as well as greater fatigue, relative to those in patients with higher BMI (≥21 kg/m^2) (Fig. 1a-c). Constipation was more commonly observed in men, whereas diarrhea was more common in women (Fig. 2a, b). Financial difficulties were more common in men and younger patients (<65 years) (Fig. 2c, 3a), especially in younger male patients (Fig. 3b).

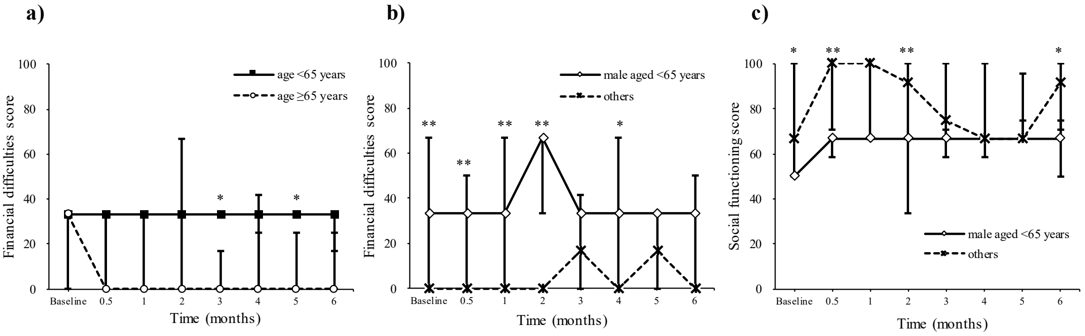
Similar tendencies were observed for reduced social functioning (Fig. 3c). Tumor control was associated with better function scores, as well as well-controlled pain, nausea/vomiting, appetite loss and constipation (Fig. 4). There were no significant differences in QoL scores according to the first-line regimen.



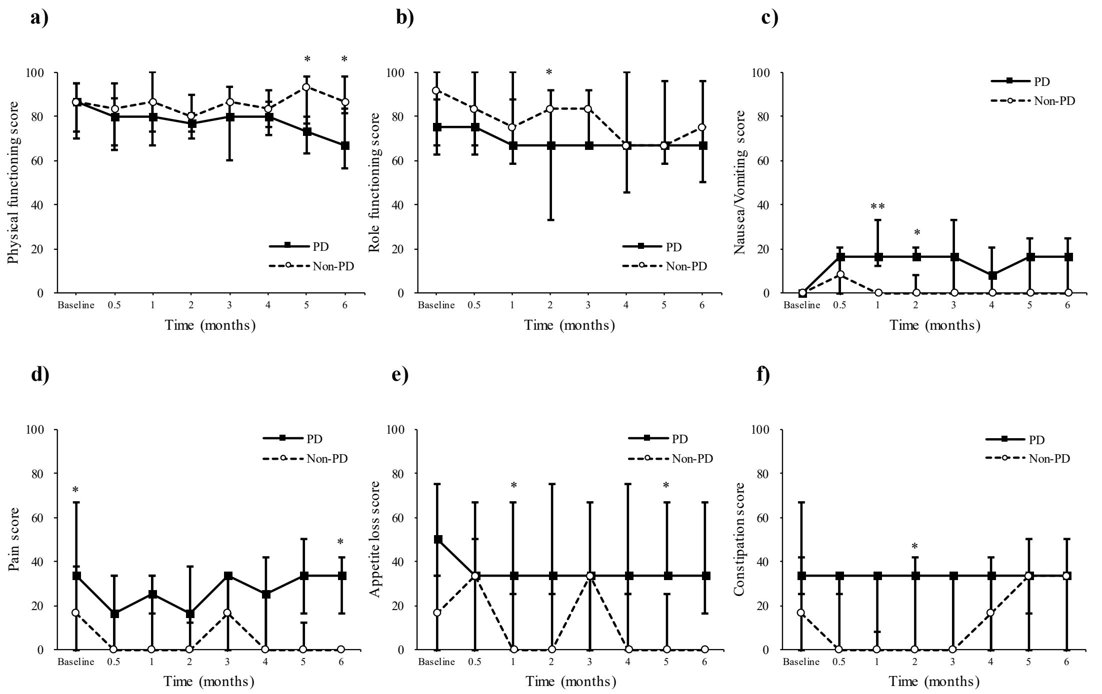
<Figure 1> Changes in quality of life scores according to the Body Mass Index. Data are expressed as medians (interquartile range). BMI of <21 kg/m^2 (n=16) vs. BMI of ≥21 kg/m^2 (n=14). *p<0.05, **p<0.01 from the Mann–Whitney *U* test. BMI, body mass index.



<Figure 2> Changes in quality of life scores according to sex. Data are expressed as medians (interquartile range). Male sex (n=18) vs. female sex (n=12). *p<0.05, **p<0.01 from the Mann–Whitney *U* test.



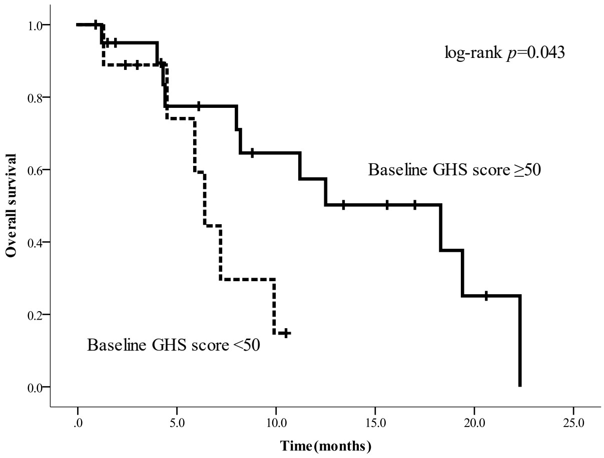
<Figure 3> Changes in quality of life scores according to age and sex. Data are expressed as medians (interquartile range). Age of <65 years (n=17) vs. age of ≥65 years (n=13). Males who were <65 years old (n=11) vs. others (n=19). *p<0.05, **p<0.01 from the Mann–Whitney *U* test.



<Figure 4> Changes in quality of life scores according to the progressive disease (PD) status. Data are expressed as medians (interquartile range). The best overall response during treatment was defined as progressive disease (PD) or all other results (Non-PD). PD (n=12) vs. Non-PD (n=12). *p<0.05, **p<0.01 on the Mann–Whitney *U* test.

4. Survival according to the baseline GHS score

We observed a significant difference in OS according to the baseline GHS score (median OS: 18.3 months for scores ≥50 vs. 6.4 months for scores <50, p=0.043) (Fig. 5). The multivariate cox regression analysis revealed that GHS score was an independent predictive prognostic factor (HR: 4.355, 95% CI: 1.178, 16.106, p=0.027; Table 3). There were no significant differences in the baseline characteristics of patients with GHS scores ≥50 and <50 (Table 4); however, the BMI tended to be lower in patients with GHS scores <50 (median [range]: 19.1 [15.7–22.6] kg/m^2 vs. 21.3 [16.0–26.2] kg/m^2).



<Figure 5> Kaplan–Meier survival curves according to the baseline global health status (GHS) score. The median survival was 18.3 months in patients with GHS scores of ≥50 (n=20) and 6.4 months in patients with GHS scores of <50 (n=10).

<Table 3> The Cox proportional hazard analysis of factors related to overall survival

parameters	adjusted HR (95%CI)	p value
GHS score≥50	4.355 (1.178, 16.106)	0.027
Age	1.105 (1.006, 1.213)	0.036
Sex (Female)	2.330 (0.670, 8.105)	0.183

HR, hazard ratio; 95%CI, 95% confidence interval.

<Table 4> Baseline patient characteristics according to their global health status score

	Baseline global health status score		p value
	<50 (n=10)	≥50 (n=20)	
Age, years	64 (48–77)	64 (47–79)	0.846
Male, n (%)	5 (50)	13 (65)	0.461
BMI, kg/m^2	19.1 (15.7–22.6)	21.3 (16.0–26.2)	0.061
Working, n (%)	7 (70)	9 (45)	0.260
Pancreatic tumor location, n			
Head/body/tail/multicentric	5/3/1/1	8/7/5/0	0.399
Metastasis, n (%)	9 (90)	14 (70)	0.372
Metastatic sites, n			
Liver/lung/peritoneum/other	5/0/2/2	7/3/2/2	0.547
Biliary stent use, n (%)	2 (20)	6 (30)	0.682
Opioid use, n (%)	3 (30)	6 (30)	1.000
Non-opioid use, n (%)	6 (60)	5 (25)	0.108
Celiac plexus block, n (%)	1 (10)	3 (15)	1.000
First-line regimen, n			
FOLFIRINOX + mFOLFIRINOX vs. GnP	5/5	15/5	0.231

Data are expressed as medians (range) or numbers (percentage). Differences were evaluated using the Mann–Whitney *U* test for continuous variables and the χ^2 test or Fisher's exact test for categorical variables. Differences were considered statistically significant at *p*-values of <0.05. BMI, body mass index; FOLFIRINOX, oxaliplatin/irinotecan/fluorouracil/ *l*-leucovorin; mFOLFIRINOX, modified FOLFIRINOX; GnP, gemcitabine plus nab-paclitaxel.

IV. Discussion

This prospective study evaluated the longitudinal changes in the QoL of Japanese patients who were receiving chemotherapy for unresectable advanced pancreatic cancer. These patients already had low QoL values before starting chemotherapy, especially in terms of the GHS and mental distress scores. However, these scores generally did not worsen during the chemotherapy treatment, which suggests that Japanese patients with advanced pancreatic cancer can maintain their QoL during standard chemotherapy, as previously observed in Western patients.3,5)

The rate of mental distress (30%) in the present study was comparable to that in previous studies (13–50%).20,21) For example, patients with pancreatic cancer may develop depressive symptoms before receiving a diagnosis of cancer.22,23) and a literature review has indicated that the pathophysiology can involve immunological effects (production of anti-serotonin antibodies), hormonal effects (increased urinary serotonin excretion), paraneoplastic effects (production of a false neurotransmitter), and biochemical effects (acid-base abnormalities, anemia, and metabolic abnormalities).24) Interestingly, while the depression score slightly improved immediately after starting chemotherapy, it subsequently regressed and then remained fairly consistent throughout the rest of the clinical course, regardless of the therapeutic effect. This suggests that various clinical and biological factors might influence mental status, which should be monitored in patients receiving chemotherapy for advanced pancreatic cancer. It has been reported that cognitive behavioral therapy might benefit cancer patients, mentally and physically, with an improvement in the QoL.25) Therefore, it may be prudent to consider combining pharmacological therapy with nonpharmacological treatments, such as cognitive behavioral therapy.

The patients' characteristics were also associated with variability in QoL scores. For example, patients with lower BMI (<21 kg/m^2) had poorer GHS and physical function scores, with greater fatigue during chemotherapy. Furthermore, the effects on defecation were variable, with men typically experiencing constipation and women typically experiencing diarrhea. In addition, younger men (<65 years old) tended to experience the worst financial difficulties and lowest social functioning, which may be related to their role in supporting families. Therefore, these patients should be educated regarding the available social support systems.

Some studies have indicated that the baseline QoL can be used to predict survival outcomes.3,26) Similarly, the present study revealed that high baseline GHS scores were associated with good OS among patients receiving chemotherapy for advanced pancreatic cancer. Thus, the GHS score might be useful as a prognostic factor before starting chemotherapy for advanced pancreatic cancer, although further studies are needed to evaluate this possibility.

The present study has several limitations. First, the sample size was relatively small, limiting the power of the analyses. Second, the study did not include a control group that did not receive standard chemotherapy. Thus, the findings might not generalize to all Japanese patients with pancreatic cancer. Nevertheless, the present study provided a prospective longitudinal evaluation of the QoL, and we are not aware of any similar studies that have examined multiple dimensions of the QoL in Japanese patients receiving chemotherapy for advanced pancreatic cancer. In clarifying the QOL of patients in multiple dimensions, including those that involve physical, psychological and social aspects, medical and nursing care may be improved.

V. Conclusions

The present findings suggest that Japanese patients with unresectable advanced pancreatic cancer can maintain their QoL while receiving standard chemotherapy. Furthermore, tumor control was associated with improved QoL in this setting and the patients' QoL scores varied during chemotherapy, depending on various characteristics. In addition, high QoL at baseline was associated with a good prognosis. Therefore, we believe that it is important to monitor QoL before and during chemotherapy in patients with advanced pancreatic cancer.

Acknowledgments

The authors would like to express our deepest gratitude to the patients for their participation in this study. In addition, the authors would like to thank the colleagues who helped collecting the data.

Conflicts of Interest and Sources of Funding: The authors declare that they have no conflicts of interest. This research was not supported by any funds or grants.

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Human
Services

DOI: http://dx.doi.org/10.14391/ajhs.19.55
Asian Journal of Human Services, VOL.19 55-62

Short Paper

Examining the Relationship between Selective Mutism and Autism Spectrum Disorder

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ABSTRACT

The purpose of this study is to examine the relationship between Selective Mutism (SM) and Autism Spectrum Disorder (ASD). We conducted an individual questionnaire survey of kindergarten and elementary school teachers about the children with SM (n=17), children with ASD (n=12) and children with Typical Development (TD) (n=12) in their classes. The questionnaire included screening tests for SM, using the Selective Mutism Questionnaire-Revised (SMQ-R), and ASD, using the Autism-Spectrum Quotient (AQ). The results showed that in the SMQ-R, the scores for children with SM were significantly higher than those for other children. Meanwhile, in the AQ, the children with SM and ASD scored significantly higher than the children with TD, but no difference was observed between the two. This suggests that many children with SM are likely to show ASD traits. In future, to support children with SM, we need to find effective approaches to both the SM and ASD aspects of their condition.

<Key-words>
Selective Mutism, Autism Spectrum Disorder, Communication Problems, Relationship

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Asian J Human Services, 2020, 19:55-62. © 2020 Asian Society of Human Services

Received
June 5, 2020

Revised
September 15, 2020

Accepted
September 29, 2020

Published
October 30, 2020

I. Introduction

Selective Mutism (SM) refers to a difficulty speaking in social situations, despite having no problem in speaking ability generally. The problem first appears when children start to lead a social life, such as starting kindergarten or elementary school. There is a wide range of presentations of SM, from being able to speak to certain classmates, to only being able to communicate through facial expressions, or even having no means of expression at all. SM is thought to appear through a complex interaction between personality factors such as extreme anxiety and nervousness, and environmental factors such as home situations.1) In the Diagnostic and Statistical Manual of Mental Disorders, Fifth edition (DSM-5), SM is classified as an anxiety disorder. In the past, comorbid developmental disorders and SM were not diagnosed together2); however, in the updated edition, the DSM-5 had allowed for multiple diagnoses.

It has been suggested that SM may be related to Autism Spectrum Disorder (ASD). Kristensen reports that 68.5% of children with SM are suspected of having some kind of developmental disorder/delay, of which 7.4% show characteristics of Asperger Syndrome.3) Wintgens refers to children with SM showing ASD tendencies as “Complex Selective Mutism,” suggesting this is a subtype of SM.4) These previous studies provide new perspectives to understand the issues children with SM have in social situations. However, the discussion in Kristensen focuses only on the presence or absence of characteristics of other disorders/delays coexisting with SM3), and does not mention what effect these characteristics have on daily life, or how they are related to SM. In recent years, Steffenburg et al. have pointed out that 63% of children with SM show ASD tendencies5), but the relationship with the degree of SM has not been explored.

In this study, we conducted a questionnaire survey of kindergarten and elementary school teachers in city B about the behavioral characteristics of children with SM, children with ASD and children with Typical Development (TD) in their classes, with the purpose of examining the relationship between SM and ASD.

II. Subjects and Methods

1. Selection of subjects

A written survey request was distributed to kindergartens (n=17) and elementary schools (n=41) in B city. First, we investigate the number of children with SM attending these schools. Illustrative examples, based on the diagnostic criteria of the DSM-5 were provided to gauge the teachers’ level of understanding regarding SM. These examples explained that SM refers to social situations in which a child is consistently unable to speak or move, such as during kindergarten or school, despite being able to speak naturally at home. The identification of children with SM was based solely on the views of the school personnel, regardless of the presence or absence of a formal SM diagnosis. In cases in which a child had been given this diagnosis, survey respondents were asked to provide this information. For classes where there were applicable children, we asked the class teacher to answer an individual questionnaire (see below). We received responses from 51 schools or kindergartens (response rate 87.9%) and confirmed that there were 20 children with SM in 13 schools or kindergartens.

Subsequently, the previous questionnaire was sent again to the classroom teachers of children with SM, and they were asked to evaluate children with TD and ASD in the same class. Then, one typically developing child of similar age was randomly chosen, irrespective of gender. Additionally, children with a formal ASD diagnosis from a medical facility were selected, irrespective of gender. Ultimately, responses were received from ten kindergartens and elementary schools (76.9% response rate) regarding 17 children with SM (including two with formal diagnoses). Responses regarding 12 children with TD and 12 children with ASD were also received. There were no omissions or missing values in the teachers' responses to either questionnaire (Table 1).

In the survey request document, we made it clear that 1) the responses received would be processed statistically, and 2) the privacy of children and teachers would be respected. The respondents participated in the survey voluntarily.

＜Table 1＞ Characteristics of Participants

	SM Group (n=17)	ASD Group (n=12)	TD Group (n=12)
Age Median (min-max)	7.3 (4.1-10.8)	8.1 (4.7-11.4)	6.8 (4.6-11.7)
Sex M/F	7/10	10/2	4/8

2. Questionnaire

Cover sheet: Age, gender

Degree of SM: We conducted the Selective Mutism Questionnaire-Revised (SMQ-R). This is a screening test designed to ascertain the degree of SM.6) We used the version translated into Japanese.7) This test is made up of three areas: School, Home/Family and Public/Social. In this study, we asked the six questions in the "School" area. The responses were on a four-point scale (Never: three points; Seldom: two points; Often: one point; Always: no points) making a total of 18 points (a higher score indicating a more severe degree of SM).

Tendency to ASD: We conducted the Autism-Spectrum Quotient (AQ) Japanese Children's Version.8) The AQ is a screening test designed to ascertain ASD traits.9) It is made up of five areas (Social Skill, Attention Switching, Local Details, Communication and Imagination), with ten questions in each area (total 50 questions, 50 points). In this study, we asked 40 questions, excluding the ten questions in the Communication area. These were excluded because many of the questions in the Communication area are based on the assumption that the subject speaks. The responses were on a four-point scale (definitely agree, slightly agree, slightly disagree, definitely disagree), scored based on the instructions, making a total of 40 points (a higher score indicating a higher tendency to ASD).

3. Statistical tests

Comparisons between two groups were done using the Mann-Whitney U test. The three groups were compared using the Kruskal-Wallis test, and where a significant difference was found between groups, the Bonferroni method was applied. Spearman's correlation analysis was performed to examine the correlations. Statistical significance was defined as a p value of less than 0.05 in all cases.

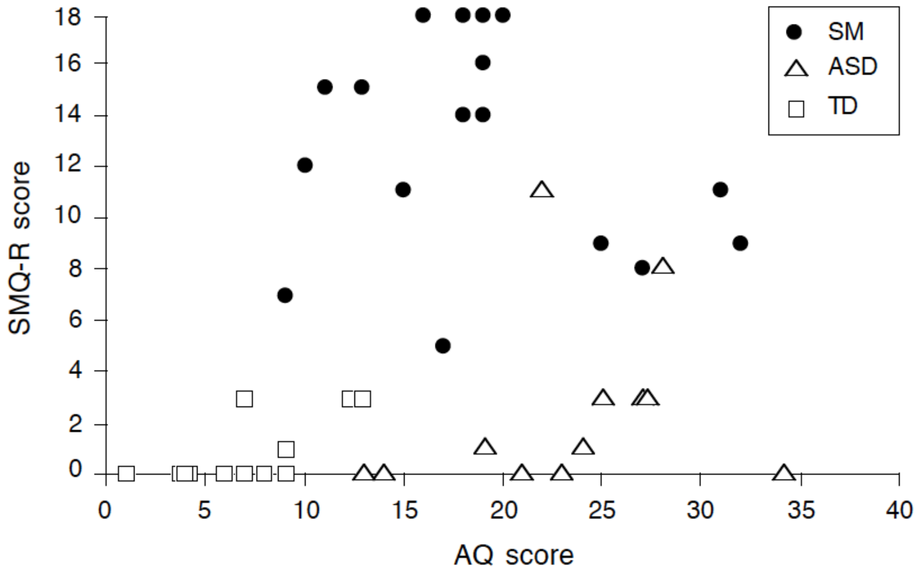
III. Results

Figure 1 shows the distribution of the SMQ-R score and AQ score for the three groups. The distribution shows general patterns for each of the three groups. For the SM group, the SMQ-R score and AQ score are both distributed at the high end (upper right of the graph). For the ASD group, the SMQ-R score is distributed at the low end, and the AQ score is distributed at the high end (lower right of the graph). For the TD group, the SMQ-R score and AQ score are both distributed at the low end (lower left of the graph).

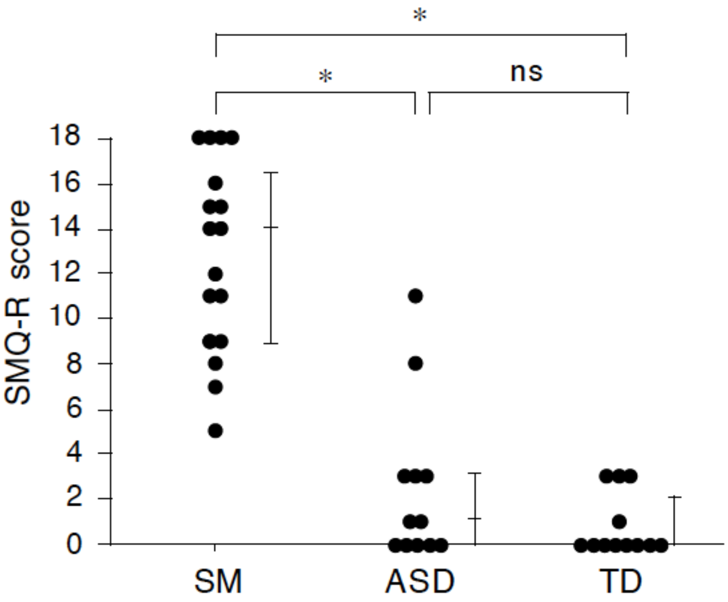
The median value (minimum-maximum) of the SMQ-R score was 14.0 (5.0-18.0) for the SM group, 1.0 (0-11.0) for the ASD group and 0 (0-3.0) for the TD group. Because a significant difference was observed between the groups ($p<0.01$), we performed a multiple comparison. The result showed that the SM group scored significantly higher than the ASD group ($p<0.01$) and the TD group ($p<0.01$), but no significant difference was found between the ASD group and TD group (Figure 2).

The median value (minimum-maximum) of the AQ score was 18.0 (9.0-32.0) for the SM group, 23.5 (13.0-34.1) for the ASD group and 7.0 (1.0-13.0) for the TD group. Because a significant difference was observed between the groups ($p<0.01$), we performed a multiple comparison. The result showed that the SM group and ASD group both scored significantly higher than the TD group ($p<0.01$), but no significant difference was found between the SM group and ASD group (Figure 3). In terms of differences between the SM group and ASD group in the four areas of the AQ, for Attention Switching only, the ASD group scored significantly higher than the SM group ($p<0.01$), but for the other areas, no significant difference was observed (Figure 4).

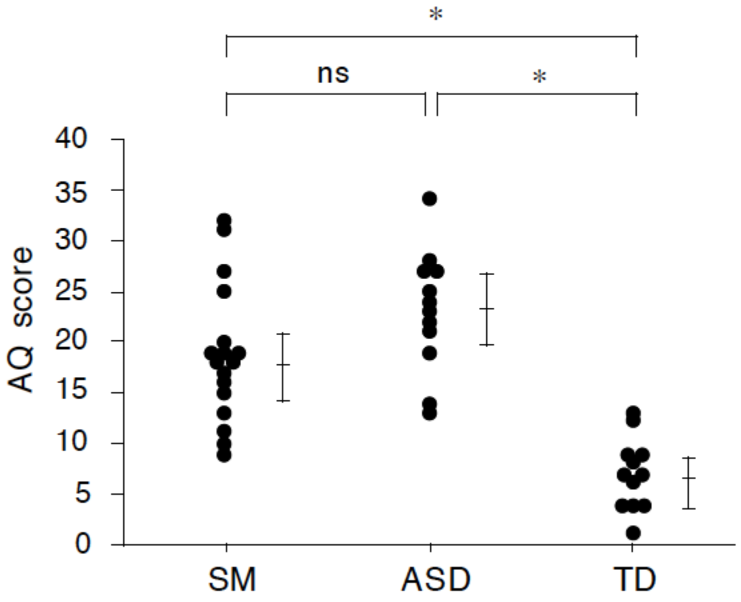
When we examined the correlation between the SMQ-R score and AQ score for the SM group, we did not find any correlation between the two scores (*r*=-0.20).



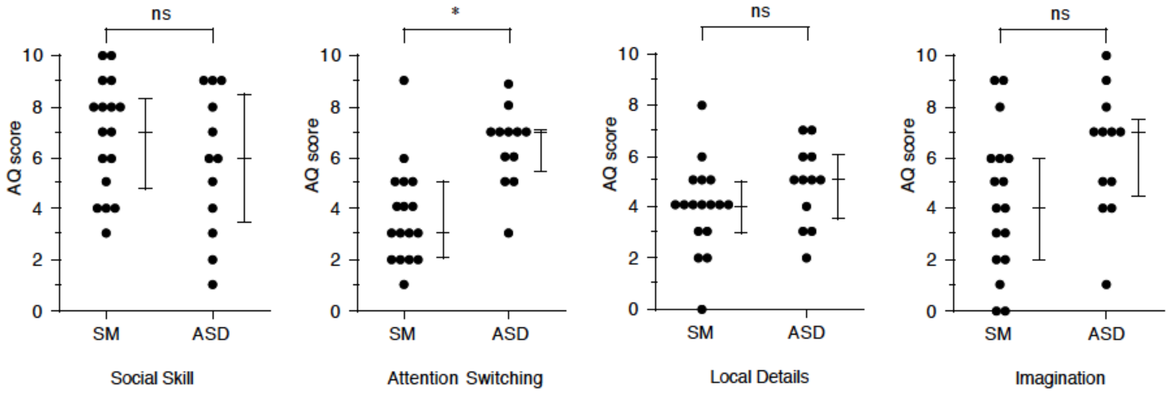
＜Figure 1＞Distribution of SMQ-R and AQ score in SM, ASD, and TD groups



＜Figure 2＞SMQ-R score in SM, ASD, and TD groups Each bar indicates the median with range from the 25th to 75th percentiles.
＊,p＜0.01; ns, not significant



<Figure 3>AQ score in SM, ASD, and TD groups Each bar indicates the median with range from the 25th to 75th percentiles.
*,p<0.01; ns, not significant



<Figure 4>AQ subscale score in SM and ASD groups Each bar indicates the median with range from the 25th to 75th percentiles.
*,p<0.01; ns, not significant

IV. Discussion

The purpose of this study was to examine the relationship between SM and ASD. We asked kindergarten and elementary school teachers to evaluate the degree of SM (SMQ-R) and tendency to ASD (AQ) for children with SM, children with ASD and children with TD in the same class.

Comparing the SMQ-R scores, the SM group had a significantly high score, and there was no difference between the ASD group and TD group. This shows that children in the SM group have difficulty communicating verbally in social situations, in other words, have a severe degree of SM. Meanwhile, comparing the AQ scores, the SM group and ASD group both scored significantly higher than the TD group, but no difference was found between the SM group and ASD group.

In the AQ, the cut-off point for ASD is set as 25 points (out of a maximum 50 points).8) In this study, although we excluded the questions in the Communication area (maximum 40 points), the median values were 18.0 for the SM group and 23.5 for the ASD group, so both values were close to the cut-off point. It has previously been suggested that SM and ASD are related, and Steffenburg et al. pointed out that 63% of children with SM show characteristics of ASD.5) Similar results were obtained in this study.

Since we did not find any correlation between the SMQ-R score and AQ score for the SM group, it cannot be said that a higher (or lower) degree of SM is linked to a higher (or lower) tendency to ASD. Furthermore, in the comparison of AQ scores for each area for the SM group and ASD group, no difference was found between the two groups in the three areas, except for Attention Switching. Baron-Cohen points out that there are individual differences in AQ scores.10) In fact, if we focus on the distribution of AQ scores for the SM group and ASD group (Figure 4), there were variations in the scores in each area for both groups. These facts suggest that children with SM and showing ASD traits exhibit behavioral traits of ASD in general, and not in a particular area.

From these findings, we can conclude that although children with SM are likely to display a tendency to ASD, no correlation can be found between the degree of SM and the tendency to ASD. Therefore, when considering specific strategies to support children with SM, it is first necessary to measure the state of SM and ASD on independent scales.

Our finding that “many children with SM show a tendency to ASD” will provide a new perspective in considering support strategies. In other words, to help children with SM adapt to school life, we need to offer support that includes approaches to ASD traits, not just approaches to the inability to speak. This approach is seldom attempted currently. To help children with SM to adapt to school life, the authors suggest to explore effective approaches from both the “inability to speak” and “ASD tendency” aspects. This could be an opportunity to reconsider the core problems in school life for children with SM.

Due to the small sample size, future research should replicate this study using a larger sample. Additionally, research involving participants with a formal medical diagnosis of SM would allow us to bolster the validity of these results.

Acknowledgment

This work was supported by JSPS KAKENHI Grant No. 18K02747.

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Human
Services

DOI: http://dx.doi.org/10.14391/ajhs.19.63
Asian Journal of Human Services, VOL.19 63-72

Short Paper

A Study of the Measures Taken by Local Governments for Care Prevention;

Examination by Questionnaire Survey

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ABSTRACT

In Japan, the aging population has increased, prompting local governments to develop care preventive programs for older adult residents. However, this localized approach makes it difficult to determine the types of care preventive programs that have been developed throughout the country. Therefore, this study carried out an inventory survey of care preventive programs that were certified by the local government as having long-term care rates of 15.0% or less. The response rate of the questionnaire survey by mail was 39.5%. The results indicate that the most frequent care preventive activity was exercise. Local governments implemented care preventive programs that older adult residents tried and continued to use until participation rates for the programs were reduced for environmental maintenance. Additionally, local governments focused on developing care preventive programs that provided resident-based activities in the area.

<Key-words>
preventive care, program, older adult residents, local government, questionnaire

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Asian J Human Services, 2020, 19:63-72.

Received
August 25, 2020

Revised
October 4, 2020

Accepted
October 7, 2020

Published
October 30, 2020

I. Introduction

In 2018, the aging population of Japan was the highest on record, with older adults accounting for 28.4% of its population (Statistics Bureau of Japan: September 15, 2019). The proportion of Japan's population that is 65 years or older is the highest of any country worldwide.1) The increase in the aging population continues, and it is estimated that one out of every three Japanese residents, or 33.3%, will be older adults in 2036.2) Japan is now a full-scale aged society, for which the care insurance system was developed in 2000 to provide security to older adults by guaranteeing them living and healthcare facilities in the Great Society. The annual expense totals for the care insurance system increase yearly; annual expenses were 4.4 trillion yen for 2001, but increased to 10.2 trillion yen in 2018, and are expected to be more than double, or to be 2.3 times the 2018 total, in 17 years.3) The care insurance system covers half of the annual expense total for the care insurance provided and levies a tax. Officials worry that increases in the aging population will lead to accumulating healthcare expenses. Therefore, experts believe that the extension of healthy life expectancy by the promotion of care prevention is essential for restraining increased expenses in the social security system.

The care insurance system provides all services to older adults aged 65 years and older except for payments and also now provides general care prevention services. As one of the care prevention policies, community support projects started in 2005 in the municipalities. From the viewpoint of the promotion of care prevention and comprehensive functional enhancement in the area, community support projects increased care prevention services and daily life support services as determined by each municipality, which provided expanded services beginning in 2011.4) Additionally, it was decided to conduct community support projects in all municipalities by April 2017 through a revision of the care prevention policies in 2014. The general care prevention services are mainly provided by the local governments after being wrested from the control of the national government.5) The general care prevention services include the following: the "function improvement of the exercise device" that is centered on a diseased joint or the fall prevention program, the "oral cavity function improvement" that is centered on chewing and swallowing or the dentistry program, and "nourishment improvement" that is mainly centered on improving the decline in bodily functioning or the hypoalimentation program. In addition, it is thought that depression is triggered by empty weakening and occurs primarily among those who are homebound. There are multiple "homebound prevention" programs, including "cognitive functional decline prevention" and "depression prevention." Care prevention services are described as model programs in "a care prevention manual" produced by the Ministry of Health, Labour and Welfare. The local governments that manage the enforcement of the businesses evaluate the local services. However, in many local governments, the evaluation of services is infrequently conducted. The statistical report that determines whether an area needs long-term care does not indicate the care prevention services provided in the area. Therefore, I performed a questionnaire survey with a care prevention menu among the local governments where the long-term care need was low. This selection approach was considered to be effective for capturing the services provided by these local governments.

II. Methods

1. Participants

There were 1,571 insurers (the local governments including the inter-jurisdictional affiliation) in the list of 7th period insurer insurance standard amount (Ministry of Health, Labour and Welfare).[6] There were 296 participants in this study having certification for 15.0% or less of the long-term care rate among insurers. The certification rate for long-term care in Japan was 18.3%. To investigate effective efforts to prevent long-term care, I surveyed 296 insurers with a low certification rate for long-term care.

2. Data Collection

I investigated via questionnaire the enforcement situation for care prevention services among study participants. The questionnaire investigation provided descriptive data that was analyzed using qualitative analytic techniques. I mailed the questionnaire and the greeting card to participants printed on green paper, in reference to a previous study in which the response rate was higher when the survey and letter were printed on green paper than on white paper.[7] The questionnaire was mailed in June-July of 2019. The questionnaires were sent on June 10 and again on July 8 with a deadline for response. If there was no reply to the first mailing, I attached a demand letter on July 22 and mailed it to the local government, that is, the care welfare section bureau or the care prevention person in the department, with a deadline for response of August 5.

The questionnaire contained items regarding the care prevention menu provided to the participants. Questionnaire items included: “I regarded this activity as important to include in the menu for care prevention,” “This approach was thought to be effective for care prevention in all menu items,” and “This is the care prevention enforcement menu that I carried out the most.” In addition, I inquired about the population from the local government and the number of participants per each menu item.

The Grounded Theory approach that Glaser & Strauss proposed for use in the field was adopted as the analysis method.[8] Grounded Theory categorizes a phenomenon and considers the properties of the category. As many categories as possible are created from the data, and it is recommended that the researcher organizes the data in various ways to expand upon the properties of each category. I unified the fluctuations of the words from the free descriptions provided by the respondents.

I also performed text mining of the provided data. I created a word cloud in which the size of a word reflected its appearance frequency in the text. In addition, I developed a co-occurrence network where words were grouped depending on the degree of their co-occurrence and positioning in a sentence. I used the User Local text mining tool for analysis.

3. Ethical Considerations

When I mailed the questionnaire to participants, I enclosed a study request document that described the purpose of the study and stated that the submission of the enclosed survey was voluntary. The document also explained that I obtained consent for the responses, and there was no disadvantage of refusing to answer any of the questions. The study was approved by the Tokai Gakuen University Ethics Committee (2020-6).

III. Results

1. Response rate of questionnaire

A total of 56 insurers responded to the first mailing, which produced a response rate of 18.9%. As a result of mailing the demand letter, I obtained responses from 61 local governments. In summary, I received responses from a total of 117 local governments (69 cities, 39 towns, 8 villages, 1 regional union) in the entire country. The response rate of the questionnaire was 39.5%.

2. Questionnaire responses

The number of "care prevention enforcement menus" obtained from the 117 local governments was 613. The 613 menus were classified into 15 categories, which were further classified into four core categories. The results are displayed in Table 1. One-third or more of the menu items were related to "exercise," and there were many activities performed in a classroom format. In addition, there was a wide variety of activities related to nourishment, cognitive function, and oral function.

<Table 1> Classification of the care prevention enforcement menus carried out most frequently

Category		Core Category
1	Exercise that is mainly focused on resistance training	Class-based preventive care activities
2	Nourishment improvement classroom, cooking class	
3	Brain training, dementia prevention classroom	
4	Oral function improvement	
5	Care prevention through music	
6	Composition model classroom	
7	Physical fitness test	Counseling and enlightenment activities regarding care prevention
8	Visiting lecturer	
9	Care preventive lecture	
10	Health counseling	
11	Salon activity	Care preventive activity as a place for the community
12	Community-based social program	
13	Services such as daycare	
14	Home healthcare services	
15	Program for promoting long-term care prevention	More highly advanced care preventive activity

The question, “I regarded this as important to include in the menu for care prevention” included 235 responses, which were classified into 17 categories, which were further classified into five core categories. The results are shown in Table 2. Most answers were related to “menu contents.”

<Table 2> Classification of the importance of menu inclusion for care prevention

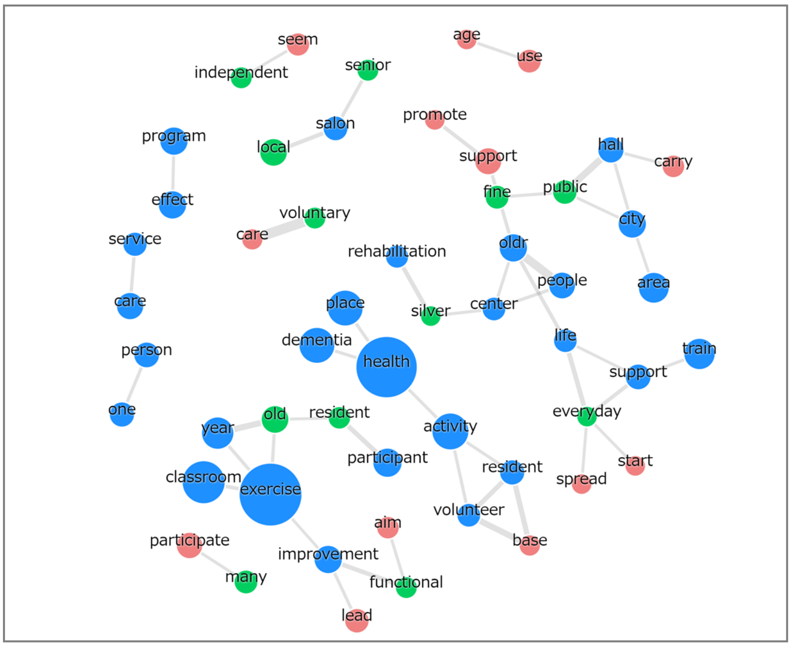
Category		Core Category
1	Devising the menu for care prevention	Development of the care prevention menu
2	Importance of functional recovery care	
3	Importance of dementia prevention in particular	
4	Homebound prevention	
5	Care preventive exercises developed by local government	
6	Choice of the full menu made available to the user	Menu that will maintain users' interest
7	Contents to continue at home, and participants to be able to perform	
8	It is fun and can be continued safely	
9	Instruction by specialists such as physical therapists	Goal-oriented business development
10	Integrated business development	
11	Evaluation of the care prevention business	
12	Easy to participate in the environment and the atmosphere	Environmental maintenance of the care preventive activity
13	Consciousness enlightenment to be able to wrest care prevention	
14	The community element upon which personal relationships are formed	Resident-based community formation through the care preventive activity
15	City planning to take root in the area through the care preventive activity	
16	The creation of meaning through social participation will improve quality of life	
17	Resident-based care preventive activity by preventive care leader training	

There were 160 answers to the question, "The approach that was thought to be effective in care prevention for all menu items." A total of 160 responses were classified into 15 categories, which were further classified into five core categories. The results are shown in Table 3. Additionally, the word cloud is shown in Figure 1 and the co-occurrence network is shown in Figure 2.

<Table 3> Classification of the approach that was thought to be effective in care prevention for all menus items

Category		Core Category
1	Exercise for muscular strength improvement	Main care prevents physical activity
2	Ikiiki 100 years-old exercises	
3	Classroom that carries out various types of activities	
4	Cognitive training	Development of care prevention menu
5	The classroom where a specialist provides a lecture	
6	Development of individual menu with a job rehabilitation specialist	
7	Environmental maintenance with a location and transportation that make participation easy	Environment maintenance and creating an atmosphere that is easy to participate in
8	Creating a casual atmosphere in which participants can participate	
9	Salon activity	The care preventive activity that took root in the area
10	Development of a support system for older adult residents in an area	
11	Maintenance of an opportunity for going out and social participation	
12	Human relations that are built through active engagement in an activity	
13	Resident-based activities organized by the volunteer	Care preventive activity by voluntary groups
14	Support for personal training of care prevention specialist and start-up of voluntary groups	
15	Opportunity to continue care prevention after class, and gather socially	

<Figure 1> The word cloud about the menu effective most



<Figure 2> The co-occurrence network about the menu effective most

IV. Discussion

The results of this investigation revealed that the menu of care preventive practices in local governments with a low care authorization rate included many exercise items. Local governments supported the care preventive approach for older adult residents in an area, and the approach connected residents with voluntary activities. In addition, the activity that was thought by the local government to be most effective for care prevention was healthy activities consisting mainly of exercise in which older adult residents found participation easy. Additionally, it is thought that it is effective to develop a voluntary activity that takes root in the area. In Kim's review of exercise interventions in the older, aerobic exercise and balance training mainly performed for community-dwelling elderly and also community-based intervention program has potential effect on their subjective well-being.9) In addition, the conclusion of the report by CHO et al. is regular exercise intervention in physical and mental function is a key point for successful aging in oldest-old adults.10) The results of this study were considered to support these reports.

In Japan, where a further increase in the aging population is predicted, a situation may arise in the future where care preventive activities may have to depend on the individual and collective efforts of local inhabitants given the social security budget restraint of the country. In some local governments that participated in this study, activities organized by residents have been already established. Voluntary activity among residents will become increasingly essential in the future. Local resources are utilized effectively, and it is expected that sustainable activities are being structured and offered to residents. To summarize, the care preventive approach by local governments involves carrying out various activities, many of which provide residents with opportunities for physical activity. Local governments focus on exercise as an effective resident-based care preventive activity. Future studies should explore the approach adopted by other countries that have a large aging population for developing care prevention programs. The results of this study may help them to propose more effective activities for their citizens.

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Human
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Asian Journal of Human Services, VOL.19 73-88

REVIEW ARTICLE

Current Status of Supporting Children and Families Needing Home Health Care;

From the Viewpoint of a Coordinator

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ABSTRACT

Despite the fact that advances in Japanese medical technology have saved lives in childbirth, the number of children requiring medical care due to some sort of disorder or disease continues to increase every year. Because children, unlike adults are still growing and developing, educational support and community support are required in addition to medical and nursing care. This study set out to analyze the role and function of coordinators by reviewing papers concerning support for children and families who need at-home medical care in Japan, so as to clarify the current situation and challenges pertaining to them. In terms of research design, the literature review made use of *Igaku Chuo Zasshi* (ICHUSHI-Web), Medical Online, and CiNii Articles. The keywords used were "medical care," "children," "at-home," "coordinator," and "community" (in Japanese). This resulted in the identification of 189 papers. Of those, 18 papers conforming to the objectives of this study were selected as targets for analysis. The following four groups were generated with regard to support for children in need of medical care: Support for parents and children as well as co-resident family members, Support for integrated healthcare networks, Educational support, and Support for challenges entailed by continuing to live at home. Focusing not only on mothers and children, but also on all co-resident family members provides a deeper understanding of at-home treatments and leads to smoother transition to at-home care. Also, cross-institutional and cross-disciplinary cooperation and collaboration with healthcare and welfare providers, communities, and government agencies is essential for continuing to provide support for children who require medical care at the society and community level. Care manager with the specialty of the child is necessary. Moreover, an educational approach can help families become aware of children's developmental challenges and foster an awareness of roles within the family unit.

<Key-words>
medical care, child, at home, coordinator, nursing

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Asian J Human Services, 2020, 19:73-88.

Received
August 13, 2020

Revised
October 8, 2020

Accepted
October 8, 2020

Published
October 30, 2020

I. Study Background and Purpose

Japan has become a “super-aging society” with an increasingly declining birthrate. The proportion of heads of household aged 65 or older is projected to increase to over 30% in 2030, and to exceed 40% in 2040.1) Furthermore, the rate of population aging (the ratio of the population aged 65 or older to the total population), which is 26.6%, is projected to reach 36.8% by 2045, when it is estimated that approximately 4 in 10 people will be elderly.1)

Conversely, with regard to the declining birthrate, as of June 2020 the annual number of births in Japan was 865,234, which was 53,166 less than the previous year (2018), and the lowest number ever recorded since surveys began in 1899. The total fertility rate (TFR, calculated as the number of children a woman is expected to have over the course of her life) was 1.36.2) This has also decreased over the previous year.

The number of individuals who, although born safely, require ongoing postnatal medical care due to some sort of disorder or disease is increasing year after year. It is thought that this is because advances in medical technology have made possible the survival of children who might previously have died. However, while the number of elementary and junior high school students who, though their lives were saved, require constant medical care, was 5,901 in 2006, this number rose to 8,750 in 2014. Moreover, the number of cases requiring at-home artificial respirators rose from 812 in 2010 to 2,126 in 2013.3)

Japan’s Ministry of Health, Labor and Welfare (MHLW) defines children in need of medical care as “children with severe disabilities who, in the context of advances in medical technology, after being hospitalized in a NICU for an extended period, make continued use of devices such as artificial respirators or gastrostomies and require ongoing medical care such as the suction of sputum or tubal feeding.”3)

Thus, as a measure to address the increasing number of children in need of medical care, the Collaborative Base Project for Children’s At-Home Medical Care was launched in 2013.4) This project was aimed at expanding services at medical institutions overseeing at-home medical care for children and others, the construction of a collaborative system for medical care, welfare, and education in the community, and the establishment of a coordinator function able to provide welfare services in cooperation with medical care. Furthermore, the “Law to Partially Amend the Act on the Comprehensive Support for the Daily and Social Life of Persons with Disabilities and Child Welfare Act” came into force in June 2016.5) Under this amendment, local governmental bodies are expected to liaise and coordinate with various professions and institutions to improve the system so that children in need of medical care will be able to receive appropriate support in a variety of related fields including health, medical care, disability welfare, childcare and education in accordance with their physical and mental situation.

This study set out to analyze the role and function of coordinators from papers concerning support for children and families who need at-home medical care in Japan, so as to clarify the current situation and challenges pertaining thereto.

II. Research Methods

1. Study design:

Literature survey

2. Criteria for document selection:

We used ICHUSHI-Web, Medical Online, and CiNii Articles, eliminating any duplicate results. In terms of the search window, we restricted the search to original papers, case studies, and review articles published before 2020 and after it was announced in 2013 that a coordinator function was to be established to carry out support tailored to individuals for child patients and families in conjunction with institutions affiliated with the MHLW's Collaborative Base Project for Children's At-Home Medical Care.[4)] The search terms "medical care," "children," and "at-home" (in Japanese) returned 106 hits, "coordinator," "community," and "children" 78 hits, and "medical care" and "coordinator" 5 hits. A total of 189 papers were extracted. Of these, 18 papers conforming to the objectives of this study were selected as targets for analysis.

3. Method of analysis:

The materials selected for analysis were classified by title, author, publication, objective, subject, method, and results in order of the year of publication. For analytical perspective, the content of research results from Japan were coded after extracting passages relating to support for children requiring medical care and their families and coordinator functions and roles. Codes were classified, named, and grouped based on similarity. The selection of target documents, creation of summaries, classification of codes, and naming were determined after investigation by the researchers.

4. Ethical considerations:

Data collected from the literature used in this study adheres to copyright and is clearly attributed in the reference literature and citation literature.

III. Results

1. Extraction of targets for analysis

A total of 189 articles were extracted based on the literature selection criteria. Of these, 18 papers conforming to the objectives of this study were selected as targets for analysis.

2. Results of analysis

1) Results from analysis of the target papers

The extracted materials were divided according to purpose, target, content relating tospecific interventions, and results and future challenges (Table 1).

From these, 3 reports were found to deal with the improvement of parent-child and family relationships and continuation of appropriate at-home medical care in interventions for post-discharge mothers and children14,23) and cohabitating family members.24) There were 2 reports concerning the success of post-discharge support by demonstrating management functions in the construction of community medical systems 16,19) and 4 reports concerning the enhancement of community coordinator activities and the role of coordinators.15,22,26,28) There was also 1 study of care time for children with severe disabilities requiring medical care18), 1 paper describing a pre-discharge approach for the families of children with infant spinal muscular atrophy25), and 2 reports on the current situation for children with severe physical and mental disabilities requiring at-home medical care.29,30) In terms of papers concerning challenges in the construction of support systems, the training of coordinators, and the need for administrative measures, 1 article described the current situation of at-home medical care for newborn infants20), and 3 articles described the current situation with regard to community-based support. 21,27,31) One paper concerned a survey of mothers of children requiring at-home care with reference to coping behavior in times of disaster.17)

<Table 1> Analysis of the literature

consecutive number	object	subject	method	Result & future implication
1	Family support of the nurse for the medical neglect	A mother and a 11-year-old girl with mild intellectual disability who goes to the school with special support	Nurses focused on the skin trouble which was one of the causes that deteriorated the mother and child relationship. They also supported both mother and kid, the suitable way of how the mother treats the kid and the bridging care between hospital and community during the discharge period.	Parent-child relationship had improved, and appropriate medical care was provided seamlessly after the discharge.
2	Research about a role, the function of the local coordinator for the "period for integrated study" activation	The local coordinator and school personals in 748 public schools in Niigata Prefecture	Questionnaire survey	228 responses were obtained (response rates 31.4%, valid response rate 30.5%). The improvement of activities of local coordinators has related to the activation of the "period for integrated study". Local coordinators connect public school needs and activities to communities, and vise versa. These coordination skills and the ability to manage with local teachers can lead to the activation of the "period for integrated study". In addition, the critical role of local coordinators were found; sharing the human resource information in community with neighbor schools and planning on the "period for integrated study" at the beginning of the year so securing the human resources throughout a year without shortness.
3	Characteristic of the participation of the public health center health nurses in community-based integrated care systems construction in comparison with that of other professionals	Public health nurses and other professions among 372 public health centers across Japan who are in charge of duties relating to community-based integrated care system	An anonymous questionnaire was conducted by mail. It compares the involvement of public health nurses and that of other professions into the creation of community-based integrated care system and consists of 32 items including the participants' attributes and which duties they are in charge of.	148 public nurses and 163 other professionals responded, and there are no significant differences on the age and the length of experience between two groups. The most common duty those two groups involved in was the duty relating to the middle term construction of the community-based integrated care system, followed by the beginning term among public health nurses whereas the end term among other professionals. Public health nurses engaged significantly more than the other professionals on 12 items ($p<0.001$), and specifically public health nurses showed the great significance with the item on the education for the community professionals, with the moderate significance on the management role for the community-based integrated care system, and the low significance on the collection and distribution about the related information.
4	Coping actions at the time of the disaster such as a home care child and typhoon of the family to need medical care	Seven mothers of the home care child who need medical care	An interview with the analysis of the KJ method was conducted	92 pieces of unit labels were gained, and after seven phases of group formation, six labels were generated and the relations of those six labels were mapped. Specifically, six male and two female home care children at age of 1-18 living in Okinawa Prefecture participated. Six children experienced blackout, One kid experienced evacuation to the hospital, another evacuated to the hill. As for the coping actions at the time of typhoon, the important point was placed in security and securing power supply. It was showed that they need the detailed support along the disaster cycle.
5	Medically dependent severe motor and intellectual disabilities: Time study of medical care	33 ward staff taking care of seriously ill mind and body child with a disability (SMID)	The study carried out every minute for 48 hours. It compared the data between SMID patients who need medical care on a daily basis and who do not	As for the time of caring, those for SMID depending on the medical care and general SMID were about the same, while it was 10 times longer than the latter the time of the medical care. As for the duties about the time record and the exchange of the information on care, the SMID depending on medical care needed four times more frequently than the general SMID patients.
6	Report about the discharge support of the child and mother needing respirator management by the tracheotomy and nourishment management by gastrostoma	A mother and kid who was born as asphyxia neonatorum, and need respirator with tracheostomy and nourishment management by gastrostoma	A case study which analysed the conversation between the mother and visiting nurses	A period required for discharge adjustment was six months and was shorter compared with conventional intervention. What is more, there was no re-adimssion due to the lack of the support and the education for the skills aquirement by mothers. The discharge support team provided mental supports through interviews to the families. Moreover, with the cooperation with visiting nurses, they organized cares needed at home, which lead to the assurance among the families. The cooperation with other professionals and building the support system resulted in successful discharge.

consecutive number	object	subject	method	Result & future implication
7	The current situation and approach of the home medical care of the newborn baby in the Kinki area	53 hospitals in Kinki area in Japan having Neonatal Intensive Care Unit	A questionairre was conducted on Februry in 2015 about 1) the situation of long term admission, 2) present illness and the number of kids treated at home with outpatient department, 3) a person in charge of the expendable supplies, 4) the presence of home doctor, 5) the participants for the discharge conference, 6) the use of respite care , 7) types of respiratory machine used at home, etc.	44 hospitals responded (response rate 83%). 1) 34 patients stayed longer than one year at hospiral. 2) 235 patients were using respiratory, 516 were on oxygen, 286 were with gastrostoma, 58 needed nutritional management through a central venous line and 6 required home autoperitoneal perfusion therapy. 3) outpatient nurses and Supply Processing & Distribution staff 4) Seven facilities had home doctor department. 5) Doctors, nurses, medical social workers, public health nurses and home visiting nurses 6) four hospitals responded all the patients use respite care while 29 falicities as occasionary and nine hospitals answered infrequently. 7) 32 facilities (57%) responded as using Philips respiratory In short, there is a neccessity of improved system construction surrounding the home care for the neonatal infants considering the current insufficient situation.
8	The role of public health nurses and the likage between maternal and child health and preschool education: the examination about the project and its promotion implimented during the year 2010-2012	Public health nurses for the child with a developmental disability	The middle term revision of a project called "network building for the chiopmental disability" in town B was conducted. Reviewing the first phase of the project during the year of 2010 and 2012, it was examined the role of public health nurses and the likage between maternal and child health and preschool education.	As for the new projects, namely, visiting consultation, an overal consultation for development, consultation at the year four and induvisual support plannning, it is found crucial to build the relationship between childcare workers/clinical psychologist and parents. Moreover, it was showed that public health nurses played important role to help constructing relationship indirectly. Tasks for the future are standardising the screening test at one and hald years old, three years old and four yeard old, improving skills of childcare workers and public health nurses and strengthening cooperation among the concerned departments for the continuation of the progect.
9	The actual situation of the early support at special support schools: the coordication of early support among related organizations; From the analysis of the inventory survey results to special support schools across Japan	Special support schools across Japan	Questtionaire about the placement of the special support education coordinator, the supported area's actual situation, the cooperation between public health and social welfare	The school area where more than 500,000 people who need special support had few consultation by the visit to a school and patrol consultation by a nursery school and a kindergarten. While the special school which has no special support education coordinator had further fewer ratio of consultation by the visit to a school and patrol consultation by a nursery school and a kindergarten during a year in comparison with the school with at least one special support education coordinator.
10	Support to mother of the child who became the peritoneum dialysis introduction by the postponement of the renal transplantation	A mother of the child whose renal transplantation became the postponement, and chose peritoneum dialysis introduction	Nurses performed support to decision making for the peritoneum dialysis introduction and provided preparation support toward the home care while confirming the psychology situation of mother. Setting a goal with mother, nurses helped them to image life at home affirmatively along with confirming their reactions.	Grasping mothers' psychological situation appropriately and enhancing self-efficacy allows them to assume the positive results. It also enables them to make decisions and raises their motivation. It is found effective to build the cooperative relationship and to work out for the shared goal with mothers as the preparations for the transition to the home care.
11	The at-home shift support for families who have a child treated at NICU and requires medical care	A child with laryngomalacia, congenital hypothyroidism, epilepsia & chronic lung consition, etc Family construction: Parents (office worker & housewife), two female siblings at 3 & 5, grandparents and ancle	A questionnaire about evaluations for the hospitalized nursing practice to the mother one year after the discharge and a semiconstructed-interview based on the answer above questionnaire performed. Nurses performed the at-home shift support that aimed at the whole family who lived together as well as parents soon after the birth of the child and promoted to become attached to the child.	It led the smooth at-home shift for nurses to have approached at the whole family who lived together as well as parents for the care.

consecutive number	object	subject	method	Result & future implication
12	Support for the discharge adjustment of the child needing medical care in the home care;One consideration of the process until a discharge and the approach to a family	A 1-year-old girl who rehospitalized for preparations of home care and the family: A baby who had diagnosed as spinal cord-related amyotrophy and underwent tracheotomy in other facilities before the hospitalization	The parents almost acquired the necessary medical care after four months during the hospitalization. After two times of in-hospital staying out with medical facilities and at home, they discharged after six months	As for the support before the discharge including when to discharge, nurses' initiated supports were effective. The adjustment of the schedule on the basis of the life rhythm of the family and the instruction of the care method suited at home during hospitalization were also effective. In addition, it is found crucial to comfirm the necessity care with families before the discharge.
13	The current situation and problesm of dischaege support for children at NICU	The 167 cases that perinatal support coordinators consulted from May, 2012 to April, 2013 were analyzed	By the introduction of the perinatal support coordinator, the cooperation between NICU, obstetrics and pediatrics were gained and they introduced the screening to all hospitalization child at the time of hospitalization	By the introduction of the coordinator, the cooperation between other professionals and the regional alliances were forged. In addition, the screening to all hospitalization children at the time of hospitalization enabled to properly select the patients in need and to clarify their necessary supports, whicih in turn, lead to the early intervention.
14	Problem for a medical practitioner to support children needing home medical care; Findings from a questionnaire in Tokyo	Pediatricians in Tokyo	Questionnaire about the home medical care	For the conduct of at-home medical treatment, it needs to be more organized 1) the cooperation with related hospitals and nighttime medical service 2) the construction of the backup system for doctors including substitute personnels 3) the maintainence of training system for nurses 4) the maintainence of medical care materials' supply
15	The way of pediatrics nursing at outpatient department	40 members of the families of children who need home medical care and travel to a outpatient deaprtment	Questionnair based on "a family life ability assessment scale"	About 50% of the respondents answered that they assess children's health status "frequently" or "often", and about 90% of the respondents replied that they are dealing with childrens' change in their status "well" and "fairly". Approximately 20% of respondents did not have the confidence about home medical care knowledge, and about 30% responded that they did not have confidence regarding home medical care skills. Only about 30% of families answered they use local social resources. Overall, as for the outpatient nursing care in the future, it would be important that nuses properly assess the need for supports along with the childrens' developmental stage and their families' situation, and that nurses play a role of coordinator to consult children and their family to the approprеate support devision.
16	The current situation of the children with severe motor and intellectual disabilities (SMID）at-home medical treatment	29 serious case of SMID children during at-home medical treatment who hospitalized shortly to a ward for pupils with disability called Himawari during July, 2011 to June, 2012	Questionnaire about the age, sex, disease severity, mean hospitalization, the underlying disease in conjunction with SMID, main medical care of the childrens with SMID	The average age was 10.1 years with 15 boys and 14 girls. Eleven (38%) were at severe status, 13 (45%) were quasi-supercritical and the average length of stay was 4.2 days. the underlying disease in conjunction with SMID were fetal brain injury in 12 cases (41%), perinatal/neonatal brain injury in 13 cases (45%), and acquired brain injury in 4 cases (14%). The main medical cares were tracheotomy management in 18 cases (62%), artificial ventilation support in 11 cases (38%), gastrostomy nutrition in 23 cases (79%), and tube feeding in 5 cases (17%).
17	Coping strategies and difficulty of a child and the family at home medical care	A family who has a 4-year-old girl needing home medical care (at-home oxygen therapy & intratracheal suction)	An interview about the use of daily goods for care, the way of supplies and management of necessity equipments, the purchase of the medical tools, difficulty by the house space and its coping strategies and the limitation among family members by giving care during the period from July to August of 2011.	Various difficulties and coping strategies were talked and it was found that all the care provision and judgement were incharged by the family. Medical staff should provide the necessity information for families with kids at home medical care in order to secure their safety and quality of life. Moreover, they should also suggest the safe environment suited at each home by observing childrens' action in a bathroom, living room, bedroom, etc.

consecutive number	object	subject	method	Result & future implication
18	The current situation and problem of the local support of the child needing medical care	The subjects of the study were three nurses, three health nurse, four nursery staff, five teacher, one physical therapist, one occupational therapist, one speech clinician (in total 23) who are working in public health centers, nursing facilities & special support schools	The semi-structured interview was conducted for around 30 minutes for each person about how to deal with the increase of the child with medical care and the various needs from diversified families	About the increase of the child with medical care and the various needs from diversified families, it was observed that there is the gap between high family expectation and the role of each professionals and that the staff provide insufficient information about pedicatrics and they lack the technical knowledge in the associated facilities. As for the problem of the caring at home support systems in the area, it was infurred more needed the provision of technical information and smooth communication between local facilities and hospitals, upbringing of the coordinator who support continuation of the caring at hospital and home and building networking of the whole area including municipals.

2) Support for children in need of medical care

A total of 16 Middle groups making up four large groups were generated as a result of categorizing 62 codes extracted from the target materials (Table 2). The following four groups were generated with regard to support for children in need of medical care: Support for parents and children as well as co-resident family members, Support for integrated healthcare networks, Educational support, and Support for challenges entailed by continuing to live at home, and codes in parentheses. Difficult-to-understand passages are supplemented by words in *italic text.*

Support for parents and children as well as co-resident family members; Support involving (1. approaches that targeted both mothers and children) and (8. the construction of relationships enabling cooperation with affected mothers) (7. led to acceptance and decision-making *by appropriately grasping the mother's psychological situation and increasing her self-efficacy*). In addition, the fact that (9. working *with affected mothers* towards a common goal was effective in supporting preparations for providing at-home care) and (11. led to a smooth transition to being at home by positioning not only parents but all co-resident family members as the focus of care).

Support for integrated healthcare networks; The fact that (15. adjusting schedules based on families' life rhythms from the time of hospitalization was effective) and that (20. the coordination of practical post-discharge care was carried out in cooperation with visiting nurses) (29. demonstrated a management function in the context of building a regional medical care system). Conversely, (26. a discrepancy existed between the roles of individual professionals and excessive expectations on the part of the family at the various institutions with respect to the increasing number of children in need of medical care and the diversification of families' needs). (28. Environmental accommodations surrounding at-home medical care for newborns inside and outside the hospital were insufficient) and (33. there was a demand for detailed support keyed to the disaster cycle).

Educational support; In other words, (35. The community coordinators connected communities with school needs and initiatives) and (40. the role of community coordinators is to collaborate with teachers and share information about local human resources not only with their own schools but also other schools). Moreover, securing local professional personnel entailed (45. *the necessity of* training coordinators to support the continuation of at-home care).

Support for challenges entailed by continuing to live at home; Even though (22. building a medical care back-up system that includes relief personnel is a challenge *for implementing at-home medical care*) and (50. it is important to identify necessary supports in accordance with the stage of a child's growth and development and family situation), it became clear that (55. there was a lack of information provision and specialist knowledge on pediatric medical care) and that (57. In this situation the determination and implementation of medical care was being left entirely to family members). Furthermore, (58. It is necessary to strengthen systems for collaboration among institutions with regard to the continuation of projects) which entailed (61. *The necessity of* creating networks for the entire community, including local government agencies).

<Table2> support of children needing medical care

NO.	cord
1	Approaches that targeted both mothers and children
2	Approach of suitable how to contact mothers for the child
3	Grasping mothers' psychological situation appropriately
4	Enhancing self-efficacy of mother
5	"Grasping mothers' psychological situation appropriately and enhancing self-efficacy of mother" allows them to assume the positive results
6	"Grasping mothers' psychological situation appropriately and enhancing self-efficacy of mother" It also enables them to make decisions
7	led to acceptance and decision-making by appropriately grasping the mother’s psychological situation and increasing her self-efficacy
8	The construction of relationships enabling cooperation with affected mothers
9	Working with affected mothers towards a common goal was effective in supporting preparations for providing at-home care
10	"The bridging care between hospital and community during the discharge period." Parent-child relationship had improved
11	led to a smooth transition to being at home by positioning not only parents but all co-resident family members as the focus of care
12	"The bridging care between hospital and community during the discharge period." appropriate medical care was provided seamlessly after the discharge.
13	Almost organizations in the related were hospitals
14	As for the support before the discharge, the instruction by the nurses in hospitalwas effective
15	Adjusting schedules based on families’ life rhythms from the time of hospitalization was effective
16	The teaching of the care method at home was effective from all over the hospitalization
17	It was important that I performed confirmation of the care that a medical person needed with a family before the discharge
18	By the introduction of the coordinator, the cooperation of Interprofessional Work into NICU, obstetrics and the pediatrics became closer.
19	A discharge support team supported carefully the children's family that concern and a change in discharge by a consultation.
20	The coordination of practical post-discharge care was carried out in cooperation with visiting nurses
21	"The coordination of practical post-discharge care was carried out in cooperation with visiting nurses" It was connected in security and satisfaction to home care
22	Building a medical care back-up system that includes relief personnel is a challenge for implementing at-home medical care
23	SMD which depended on the medical care and SMID which I depended on medical care for in time for medical care of general SMD were longer 10 times than general SMID
24	As for the duties about the time record and the exchange of the information on care, The SMID depending on medical care needed quadruple of more frequently than the general SMID patients.
25	The main medical care in conjunction with the severe psychosomatic disorder was tracheotomy management 18 cases (62%), artificial respiration assistance 11 cases (38%), Nourishment from gastrostoma 23 (79%), tubal feeding five (17%)
26	A discrepancy existed between the roles of individual professionals and excessive expectations on the part of the family at the various institutions with respect to the increasing number of children in need of medical care and the diversification of families’ needs
27	A high-risk seriously ill child was managed at home a lot became clear, the current situation
28	Environmental accommodations surrounding at-home medical care for newborns inside and outside the hospital were insufficient
29	Demonstrated a management function in the context of building a regional medical care system
30	Collecing information and showed a dispatch function
31	Skill up (I need reinforcement) of a childminder, the Pablic Health nurse
32	As for the coping action at the time of the disaster, an important point was placed in security and the securing of power supply
33	There was a demand for detailed support keyed to the disaster cycle
34	"By the introduction of the coordinator" The regional alliances came to be carried out positively, too
35	The community coordinators connected communities with school needs and initiatives
36	"An area coordinator" I show coordinates function to connect local seeds with a school
37	"An area coordinator" I showed a function to manage with a teacher and participated in activation of the time
38	I put up time a year in a beginning of the fiscal year
39	It is important that the construction of the relationships such as a childminder and a protector, a protector and the psychology person
40	The role of community coordinators is to collaborate with teachers and share information about local human resources not only with their own schools but also other schools
41	"An area coordinator" It is the main point that finds local human resources premeditatedly
42	Showing education of the function of the community specialist jobs
43	The lower the special education support school where 0 people than that where one or more people of full time teachers for community supports the ratio that the consultation at school
44	There was little annual number of times of the consultation by the patrol to a nursery school, a kindergarten, too
45	the necessity of training coordinators to support the continuation of at-home care
46	The maintenance of a cooperation hospital, the hospital accepting a patient by night is a problem
47	For enforcement building a medical care back-up system that includes relief personnel is a challenge for implementing at-home medical care
48	For enforcement, Education for nurses
49	For enforcement, he maintenance of the supply system of medical materials at home, and giving medical care
50	It is important to identify necessary supports in accordance with the stage of a child's growth and development and family situation
51	The medical practitioner knows the invention of the technique that fitted a lifestyle and a child
52	It is necessary for the medical practitioner to give information so that a family needing home medical care can live a high quality life by security
53	Observation of the action of the child in a bathroom, living, the bedroom
54	It is a role demanded from a medical practitioner to tell the need to fix the safe environment of the child to a family
55	There was a lack of information provision and specialist knowledge on pediatric medical care
56	Enforcement and the judgment of the medical care are entrusted all to a family
57	In this situation the determination and implementation of medical care was being left entirely to family members
58	It is necessary to strengthen systems for collaboration among institutions with regard to the continuation of projects
59	The need of the provision of information each other, expert knowledge from the medical
60	The important to carry coordinates position such as leading it to the appropriate window for an affected child, a family to be able to receive necessary support
61	The necessity of creating networks for the entire community, including local government agencies
62	The need of the measures of states

IV. Discussion

1. Support for parents and children as well as co-resident family members

With regard to support for children in need of medical care, by positioning not only mothers and children but all co-resident family members as the focus of care, we can deepen the understanding of at-home medical treatment, which will lay preparations for at-home medical treatment and facilitate a smooth transition to at-home care. Miyata6) points out that at-home medical care for children, in comparison with the adult case, necessitates an understanding of the diversity of illness and changes that arise with growth. This demonstrates that parents require support characterized not only by an understanding of their children's disease and disability, but which also takes into account their children's growth and development. In particular, in support for families with siblings, there is a need to understand that the parents' gaze may tend to dwell on the child in need of medical care, and thus to clarify roles in the family in order to help siblings live their lives free of anxiety or confusion. It is thus necessary to help mothers find time to be involved with siblings, as well. Moreover, in order to lighten the burden of nursing care, it is necessary to provide support that makes it possible to consider the use of social resources when necessary, such as respite care and care that involves night-time suction of sputum and postural management.

Also, it is important to continue providing support so that mothers and co-resident family members will be able to achieve emotional and psychological stability in the context of daily care. When family members experience emotional or psychological instability, this is likely to be transmitted to the child and elicit a reaction. Yoshimi et al.7) reported that it was possible to help children and families by holding discussion until both parties were satisfied, facilitating "self-determination", and setting nursing life goals for both the child and family members. Hosoi8) suggests the need for an all-encompassing or holistic form of pediatric medical care that takes an overall view of the child, one that takes a bird's eye or comprehensive perspective that includes environmental and social factors. It is necessary to stay in close contact with families and undertake cross-institutional and cross-disciplinary collaboration with healthcare, welfare providers, educators, and the like in order to provide support that enables self-determination while ascertaining the needs of children, their mothers, and other co-resident family members. Beyond the medical care aspect, there is a need for a nursing care lifestyle that has a view of the child's growth and development as well as interactions with non-family members and participation in the local setting that are tailored to the child's age. Moreover, we believe that there will be an increasing demand for a coordinating role that will engage in such cross-institutional and cross-disciplinary collaboration will be increasingly required.

2. Support for integrated healthcare networks

Engaging in cross-disciplinary collaboration to coordinate post-discharge care will facilitate a sense of security and satisfaction for at-home medical treatment. Nakamura9) notes the importance of governmental cooperation in building systems for providing children with at-home medical care. He suggests the necessity of establishing a strong coordinator function to develop and link medical care with welfare services, and also suggests that building infrastructure for providing children with at-home medical care is a project that should be sustained in the future. Also, Shimabukuro10) suggests that this is not only medical care, but at heart an engagement with lifestyle infrastructure, and that what is necessary are social and community initiatives that involve not only mental and psychological perspectives, but encompass education, leisure, and government, as well.

In order to accommodate and support children in need of ongoing medical care in society and the community, cross-institutional and cross-disciplinary collaboration and cooperation between healthcare, welfare, communities, and governments will be essential. The current situation is dire, with insufficient resources for everything to be handled solely by medical and welfare personnel. We believe that the provision of support by capturing the professionalism not of care managers who provide support to the elderly, but people like educators, nursery teachers, and regional medical professionals in a multifaceted way from the perspective of children (i.e., the growth and development of their physical and mental health) and their parents would arguably facilitate more comprehensive support. Further, we believe that it will be necessary to establish venues for the regular sharing of information through cross-institutional and cross-disciplinary collaboration so that policies will not be biased toward either children or parents.

In the future, we believe higher expectations will be placed on coordinators who play a coordinating role and function specialized for children who require medical care.

3. Educational support

Children in need of medical care require educational support from the perspective of still being in the process of growing and developing. Hoshino11) noting the increasing transition to at-home care for children in need of medical care, points out that a societal response is therefore required, and that the training of coordinators in relation to children in need of medical care is desirable. In the context of at-home support after discharge from hospital, there is a perceived need for coordinators who will be able to provide a reassuring point of contact and consultation, which includes being a point of contact for local consultation as well as arranging admittance into medical care in the case of emergency. In addition, we believe there will be a demand for roles and functions that connect community seeds with schools and manage them together with teachers, and which create links with community professionals to coordinate medical care and educational support. It may also be necessary for potential medical staff (including alumni and those still able to work) and educators in the community to proactively push forward with measures to connect childcare, medical care, and welfare services.

This manner of educational approach will help to foster families with an awareness of the developmental challenges their children face, as well as to cultivate a sense of roles within the family unit. We also believe that it can be expected that families will discover effective and economical methods from their own experience of daily care.

4. Support for challenges entailed by continuing to live at home

The development of an integrated system of cooperating and admitting hospitals, as well as medical staff and medical materials has been pointed to as the current state of at-home medical care. Miyata[12)] notes that with the diversity of disease, the extent and burden of medical care is significant, which results in a high degree of nursing. In addition, because institutional and community systems are as yet poorly developed, there is a dearth of both support and cooperation, and the reality of the situation is that at-home medical care and services are not keeping up with demand. In particular, she points out the relatively small number of medical institutions and home-visit nursing stations responsible for overseeing at-home medical care for children, and the fact that the training and participation of personnel remain a challenge. Also, Maeda[13)] has pointed out that despite the fact that the welfare coordinators who provide lifestyle support for children receiving at-home medical care are counseling professionals, unlike care managers in the long-term care insurance system, they face systemic difficulties making connections with medical care.

Based on the above, it seems that support for children in need of medical care has a need for comprehensive support measures on the part of medical care, welfare services, education, and society that involve not only medical care but also education as well as local government. Moreover, it will be necessary to train coordinators to provide support for children in need of medical care. Currently, medical coordinators are people like physicians, nurses, and care support specialists who obtain their own certifications from non-profits and other professional bodies to become medical coordinators, but there is no national certification. Another challenge is that the quality of individual coordinators is only evaluated by the qualifications for coordinating comprehensive support measures on the part of medical care, welfare services, education, and society.

Finally, because the determination and elimination of medical care are currently left to families, medical practitioners feel that mothers require parental education with regard to the observation, treatment, and response to their children’s symptoms. Regardless of the degree of competence of professional cooperation, parents will always be involved with their children on a passive footing. We argue the need for a perspective on training parents that is oriented to fostering knowledge and independence to the extent that they will be able to deal with their children’s symptoms even in the absence of medical personnel.

DOI: http://dx.doi.org/10.14391/ajhs.19.73
Asian Journal of Human Services, VOL.19 73-88

Acknowledgment

I thank Yuko Sato teacher and the Yasuko Arai teacher who participated in this study.

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Human
Services

DOI: http://dx.doi.org/10.14391/ajhs.19.89
Asian Journal of Human Services, VOL.19 89-100

REVIEW ARTICLE

A Study on the Papers of Menstruation Scales;

The Development of a Scale for Menstrual Abnormalities

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ABSTRACT

The purpose of this study was to examine the scales used in medicine and nursing studies related to menstruation in Japan and overseas, and to obtain indications for the development of a scale for menstrual abnormalities.

For our search of overseas papers, we used CINAHL with Full Text and combined searches of "Menstruation" with "female", "Factor Analysis", "Adolescent", "Scale" and "Premenstrual tool", from which we chose 6 papers out of 67 results. For papers from Japan, we used Ichushi's web version, and combined searches of "menstruation" with "scale" and "factor analysis", from which we obtained 12 pieces of papers from 20 results. We covered a total of 18 papers (12 domestic and 6 overseas) for our study.

We found scales for issues such as menstrual symptoms and menstrual pain, behavior during menstruation, premenstrual syndrome (PMS) diagnosis, menstrual self-care, and premenstrual dysphoric disorder (PMDD); however, we were not able to find any scales for abnormal menstruation.

Since we could not find a scale specializing in menstrual abnormalities, we determined that there is a need to develop one to help encourage women who have abnormal menstruation but have not had a medical examination to make the choice to visit a medical institution.

Received
July 31, 2020

Revised
October 14, 2020

Accepted
October 14, 2020

Published
October 30, 2020

＜Key-words＞
menstruation, scale, menstrual abnormality, review

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Asian J Human Services, 2020, 19:89-100. © 2020 Asian Society of Human Services

I. Introduction

The background of Yamamoto's survey up until now is as follows: when we created a self-care scale for young females with menstrual pain, the multiple regression analysis showed that "females who have more severe menstrual pain are less likely to perform self-care", which suggested that females with strong menstrual pain cannot treat themselves, so a gynecological examination is necessary.1)

According to a survey conducted by the Japan Association for the Advancement of Working Women, 27.1% of females under the age of 25 visited a gynecologist for menstrual abnormalities, while 55.9% did not do anything. 43.1% of females under the age of 25 had "somewhat serious" or "serious" menstrual pain; however, their gynecologic consultation rate was just 13.6%, and 28.8% did not do anything for their pain.2)

Thus, in young females under the age of 25, the gynecologic consultation rate was less than 30% even when they had menstruation abnormalities, and it was about 10% even when they had strong menstrual pain. This suggests that they sometimes overlook their menstruation abnormalities. If there were a scale that provides an indication of menstrual abnormalities, it may lead to an increase in the consultation rate of young females as well as the early detection of gynecological diseases such as hormone abnormalities or endometriosis, and it could help prevent infertility in advance.

According to Fujito, menstrual abnormalities are roughly classified into the following abnormalities: abnormal starting time of menarche or menopause, abnormal amount of discharged blood, abnormal duration, abnormal cycles, and abnormal symptoms. In some cases, only one of these abnormalities appears, but in other cases, multiple abnormalities may appear.3)

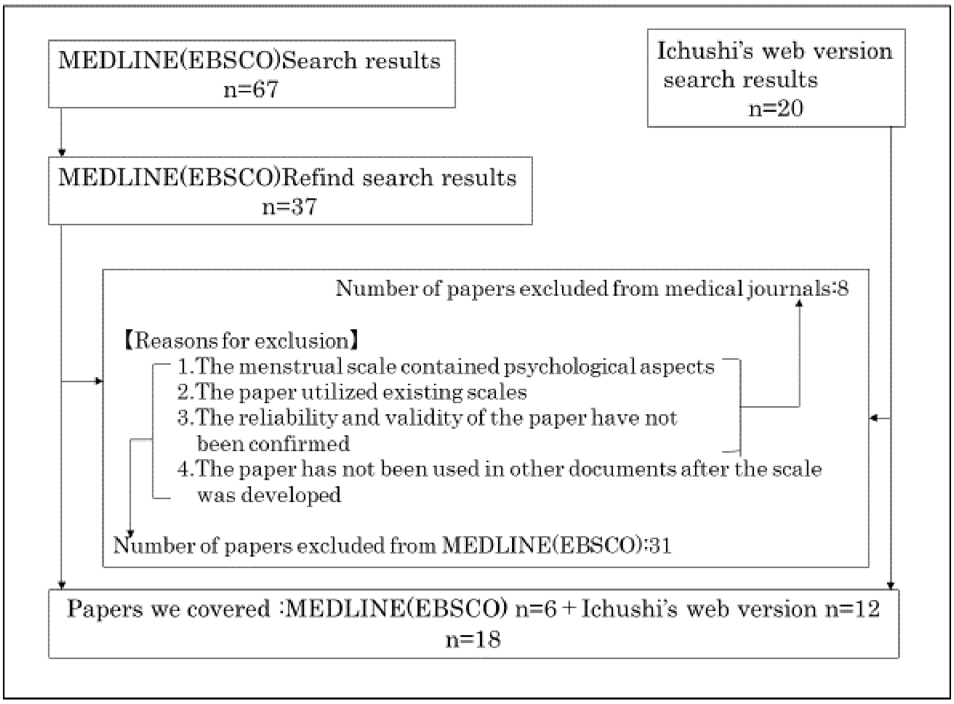
If young females know more about the abnormal menstrual conditions that require them to visit a clinic instead of just leaving it as it is, it may lead to early consultations and prevent gynecological diseases or future infertility.

The purpose of this study was to examine the scales used in medicine and nursing studies related to menstruation in Japan and overseas, and to obtain indications for the development of a scale for menstrual abnormalities.

II. Research method

For our search of overseas papers, we used CINAHL with Full Text and input the keywords, "Menstruation" and "female" and "Factor Analysis" and "Adolescent" and "Scale" or "Premenstrual tool" 67 papers were identified in this search. We selected original papers which were published from any searchable year up to March 2019, and then from among the results we searched for papers from academic journals with abstracts, and finally we selected 37 papers. From those 37 papers, we excluded papers that focused on the development of psychology-related menstruation scales, papers that used existing scales, those whose reliability and validity were not confirmed, and papers which were not utilized in other papers after the development of the scale mentioned in the paper; thus, finally 6 papers were left.

As for domestic papers, we used Ichushi's web version, and searched for original articles from all searchable years up to March 2019 by inputting the keywords "menstruation" and "scale" and "factor analysis". From the 20 results obtained from the search, we excluded any papers on the development of a menstruation scale from a psychological viewpoint and any papers which utilized existing scales. We selected 12 scales which were created by developing Japanese versions based on existing scales and whose reliability and validity were verified. We covered a total of 18 papers which included 6 pieces from overseas and 12 domestic papers, and examined the structural concept of the scales used, the measurement methods and the number of items, the reliability and validity as well as the related items.



<Figure 1>　Flowchart that shows how we selected papers

III. Results

1. Domestic and international measures for menstruation and it's trends

Overseas, the Menstrual Distress Questionnaire (MDQ), Menstrual Symptom Questionnaire (MSQ), Menstrual Attitude Questionnaire (MAQ), Adolescent Menstrual Attitude Questionnaire (AMAQ), Premenstrual Assessment Form (PAF), and Premenstrual Symptoms Screening tool (PSST) have been frequently used (Table 1).4-9)

<Table 1> Major measuring instruments for menstruation that were created overseas

NO	Scale name (Number of documents that used the scale)	Author / Year	Number of items / measurement method	Structural concept, etc.
1	MDQ(173) (Menstrual Distress Questionnaire)	Moos R. 4)/(1968)	47 Six-choices	Menstrual symptoms were classified into these eight factors: pain, ability to concentration, changes in behavior, autonomic nervous response, water retention, negative emotions, mood elevation, and control.
2	MSQ(27) (Menstrual Symptoms Questionnaire)	Chesney MA & Tasto DL. 5) /(1975)	25 Two-choices	Primary dysmenorrhea was classified into two factors: congestive-type and convulsive-type.
3	MAQ(22) (Menstrual Attitude Questionnaire)	Brooks-Gunn J & Ruble Diane N. 6) /(1980)	33 Five-choices	The attitude when perceiving menstruation was classified into five factors: debilitating, troublesome, natural, predictable, and that menstruation did not affect their attitude.
4	PAF(51) (Premenstrual Assessment Form)	Halbreich U, Endicott J, Schacht S, et al. 8) /(1982)	95 Six-choices	It was used to evaluate pre-menstrual status and it was classified into three factors: changes in mood, behavior, and changes in physical condition before menstruation.
5	AMAQ(4) (Adolescent Menstrual Attitude Questionnaire)	Morse JM, Kieren D & Bottorff J. 7) /(1993)	58 Five-choices	It was created by adding 11 specific items about the menstrual attitudes of the adolescent age group to the existing MAQ, etc.
6	PSST(47) (Premenstrual Symptoms Screening Tool)	Steiner M, Macdougall M & Brown E. 9) /(2003)	19 Four-choices	It was developed to measure severe PMS and PMDD. It was classified into two factors: premenstrual symptoms and social situations.

In Japan, the following scales are listed in order of how frequently they are used: the Japanese versions of the MDQ, MMDQ, PMDD Rating Scale, the Dysmenorrhea Self-care Scale for Nursing Students, and the Japanese version of the MAQ (Table 2).10-14)

<Table 2> Measuring instruments for menstruation in Japan

№	Scale Name	Author / Year	Number of items / measurement method	Structural concept, etc.
1	Japanese version of MDQ (Menstrual Distress Questionnaire)	Akiyama & Kayashima 10) /(1979)	47 Six-choices	Menstrual symptoms were classified into these eight factors: pain, ability to concentration, changes in behavior, autonomic nervous response, water retention, negative emotions, mood elevation, and control.
2	Japanese version of AMAQ (Adolescent Menstrual Attitude Questionnaire)	Suzuki 16) /(1998)	41 Five-choices	Adolescent women's' attitudes toward menstruation were measured. It was classified into 5 factors: positive emotions, negative emotions, recognition of symptoms and changes in menstruation, moodiness and secluding oneself, and feelings of embarrassment.
3	Japanese version of MAQ (Menstrual Attitude Questionnaire)	Noda 14) /(2001)	13 Five-choices	The attitude when perceiving menstruation was classified into four factors: it is debilitating, the denial of menstrual influence, it is natural, and it is troublesome.
4	Japanese version of MSQ (Menstrual Symptoms Questionnaire)	Namba 15) /(2003)	15 Six-choices	It was classified into four factors: depression tendencies, emotional instability, pain, and extraordinariness.
5	PMDD Rating Scale	Miyaoka, Akimoto & Ueda et al. 12) /(2009)	17 Four-choices	It was developed by referring to the PSST. It was classified into two factors: premenstrual symptoms and social situations.
6	Examination of Menstrual Views -The trials of creating a Menstrual View Scale-	Shibata, Matsuda & Ishikawa 17) /(2009)	24 Six-choices	A menstrual view scale was created and it was classified into three factors: feeling embarrassment for menstruation, views on behaviors during menstruation, and the negative effects of menstruation.
7	MMDQ (Modified MDQ)	Watanabe, Okumura & Nishiumi 11) /(2011)	10 Four-choices	It was created to measure menstrual support functions and it changed the Japanese version of the MDQ. It was classified into four factors: emotional support I, emotional support II, instrumental support, and mutual support.
8	An attempt to create a scale for searching the cause of menstrual changes	Shibata, Inoue & Mori 18) /(2012)	9 Five-choices	In order to clarify the cause of mental and physical changes during menstruation and to answer questions about menstruation, a causal search scale for menstrual changes was created. It was classified into three factors: physical environment, living environment, and sexual environment.
9	An attempt to create a self-care measurement scale for nursing students to use during menstruation	Yamauchi & Takama 13) /(2012)	20 Five-choices	Menstrual self-care was categorized into four factors: resting the mind during menstruation, resting the body during menstruation, behaviors coping with physical changes during menstruation, and monitoring actions during menstruation.
10	Development of a health literacy scale for sexually mature women - An examination of its reliability and validity on female workers-	Kawata, Hatashita & Kinjo 19) /(2014)	21 Four-choices	The Health Literacy Scale was developed for the prevention and early detection of diseases specific to the female genitals. It was classified into four factors: the selection and practice of women's health information, menstrual self-care, knowledge about the female body, and professional consultations on their sex lives.
11	Premenstrual syndrome (PMS) during childcare Development of self-management measures and an examination of its validity and reliability	Hamasaki & Tokiwa 20) /(2018)	38 Five-choices	A self-management scale for premenstrual syndrome during childcare was developed. It was classified into five factors: premenstrual emotional instability, changes to positive postmenstrual emotions, changes in menstrual status with the support of their husband, premenstrual weakness, and unpleasant premenstrual physical symptoms.
12	The development of a self-care scale for menstrual pain in young women	Yamamoto 21) /(2019)	23 Five-choices	A self-care scale for menstrual pain in young women was created. It was classified into six factors: perception of self-efficacy, intention to improve menstrual pain, self-care that can be achieved by making lifestyle changes, self-care using medicine, expected level of burden needed to improve menstrual pain, and feelings about self-care treatment.

One characteristic of its trends is that most of the scales that are actively used are those created in the 1900s. The MDQ, which is widely used overseas and in Japan, was developed more than 50 years ago.

Secondly, the MDQ, MSQ, MAQ, and AMAQ were first developed overseas, and then Japanese versions were created later. The same applies to the PSST. The PMDD Rating Scale was created in Japan based on the PSST.

2. The structural concept of menstruation scales

There are many scales that evaluate pre-menstrual or menstrual indications, including menstrual symptoms, PMS, behavior during menstruation, measuring women's stress levels during menstruation, measuring their self-care during menstruation and measuring the degree of PMDD; however, no scales were found that focused on menstrual abnormalities.

3. Factors that are related to the scale items

Among the items that were concurrently measured, there were correlations in age and childbirth history in the MDQ.Furthermore, the MDQ related to menstrual cycles was divided into parts 1 and 2, and the correlations of the five major factors (pain, autonomic nervous response, water retention, negative emotions, and control) were compared according to timing before and during menstruation.4)

There was a correlation with symptoms of depression in the MSQ.5)

The MAQ correlated with the MDQ.6)

The AMAQ had a correlation with the reliability coefficient in the six main items (negative emotions, positive emotions, dealing with menstruation in daily life, symptoms of menstruation, acceptance of menarche and openness).7)

In the Japanese version of the MSQ, menstrual cycles, whether or not the respondent joined an activity club, the presence or absence of a romantic partner, the age when menarche started, the number of menstruation days and the regularity of periods affected correlations.15)

In the Japanese version of the MAQ, there were correlations in optimism, pessimism, self-esteem, satisfaction with their gender, and stress.14)

In the MMDQ, we performed a t-test on the items which were unrelated to the 13 self-care items, and we found that there were significant differences in 7 items.11)

In the PMDD Rating Scale, the depression scale showed a correlation.12)

In the Health Literacy Scale, the rate of having a cervical cancer examination showed a correlation.19)

In the self-care, there were correlations with eating, sleeping, and bathing habits and the degree of menstrual pain.21)

IV. Discussion

1. Trends in the menstrual scales

Many menstrual scales that evaluate pre-menstrual and menstrual symptoms have been developed, including the Menstrual Distress Questionnaire (MDQ), Menstrual Symptom Questionnaire (MSQ), and the premenstrual dysphoric disorder (PMDD) Rating Scale. However, there were no scales that can determine menstruation abnormalities comprehensively, thus, the necessity for the development of such a scale was suggested.

The MDQ of Moos is a scale widely used in Japan and overseas, and it has eight domains for observing menstrual symptoms, which are 1) pain, 2) ability to concentration, 3) changes in behavior, 4) autonomic dystonia, 5) water retention, 6) negative emotions, 7) mood elevation and 8) control, along with 47 items that get evaluated using 6 possible scores. The scores of those 8 domains showed a slight correlation in age and childbirth history. In developing a scale for menstrual abnormalities, we think that the parts that correspond to the symptoms of menstruation should be referred to when creating a draft scale.

As well as the MDQ, which is now widely used in Japan and overseas, the MSQ, MAQ, PAF, and the AMAQ were all developed overseas in the 1900s. The MDQ was developed in 1968 and over 50 years has passed since its development. I think that the mechanism of menstruation does not change; however, the environment surrounding modern females has changed drastically compared to 50 years ago. It is conceivable that the exact same symptoms of menstruation 50 years ago cannot be applied to measurements used for modern women. Thus, we need a scale for menstruation that is suitable for modern women.

Regarding menstrual scales, their background is that the Japanese versions were developed after overseas versions were created. The MDQ was developed in 1968, and then the Japanese version of it was developed in 1979. The AMAQ was developed in 1993, and then Japanese version of it was developed in 1998. The MAQ was developed in 1980, and then the Japanese version of it was developed in 2001. The PSST was developed in 2003, and based on it, the PMDD Rating Scale was developed in Japan in 2009. These trends suggest that they are adopted in Japan within a few years at the earliest and within 20 years at the latest.

In many cases, they were first developed overseas and then adopted in Japan.

But this time it will be important to facilitate the usage of this scale for menstrual abnormalities, which will be originated in Japan, from Japan to overseas countries.

2. The structure concept of menstruation scales

Most menstrual scales have aimed to measure the symptoms before and during menstruation, as well as self-care, but there were no scales that focused on abnormal menstruation.

The examined items were divided and limited to specific areas for each scale, such as symptoms for menstrual periods, behaviors, and self-care; there were no scales that could comprehensively evaluate menstrual status. In modern times, women often have multiple menstrual abnormalities. There is a need for a scale that considers such situations.

3. The actual conditions of dysmenorrhea

Since menstrual abnormalities are often not serious enough to be life-threatening, they have been underestimated. However, if menstrual abnormalities are left untreated, it can decrease the quality of life in women's daily life and it may poorly affect their future chances for pregnancy.

According to Momoeda, women with functional dysmenorrhea are 2.6 times more likely to develop endometriosis in the future. One of the reasons is that early endometriotic lesions might not be detected through pelvic examinations or image diagnosis, so in some cases, they are diagnosed as functional dysmenorrhea. The risk of onset increases as time passes from their first menstruation until pregnancy, and if endometriosis develops, 30 to 50% of them become infertile. -Paraphrased- For this reason, women with strong dysmenorrhea should start treatment at an early stage.22)

Enatsu estimated that the number of females with dysmenorrhea throughout Japan is 8 to 10 million, and the number of females with endometriosis is 2 to 4 million. However, the annual estimated number of patients who receive treatment for dysmenorrhea and endometriosis is less than 800,000, which is only about 10% of the number of suspected cases. If women do not visit medical institutions within an appropriate time, a delayed diagnosis of endometriosis may cause them to start receiving treatment during advanced stages of the condition.23)

Such low gynecologic consultation rates may increase the risk of progress being made with the illness but without the hidden disease behind the dysmenorrhea being discovered.

In particular, young women under the age of 25 are part of the next generation that will get married and pregnant. In present times, women are more likely to receive higher education due to lifestyle changes, and they are marrying later and giving birth later. In contrast, sexual maturity has onset earlier. Mori et al. stated that 90% of females first have menarche between the ages of 11 and 15.24)

As they give birth later and later, the period of time between their first menarche and giving birth for the first time gets bigger. Therefore, it has become necessary to maintain fertility for a longer period of time.

4. Content related to scales

In the case of menstrual symptoms, the content that was measured in menstruation scales was the content that aimed to confirm the menstrual state first, and next are the items that are necessary for evaluation (example: self-care items etc. in the case of self-care).

According to Miyazaki, the factors related to the symptoms associated with menstruation were “sleep”, “meals”, and “health management”. Furthermore, associations with mental state, perception of menstruation, personal characteristics, maternal awareness, and stress were also examined.25)

What items should be measured together in a menstrual abnormality scale? Specifically, it should be created focusing on the following: if the period of menarche or the menstrual cycle is within a normal range or not, if the amount of bleeding, the condition of dysmenorrhea or the condition of premenstrual syndrome is within a normal range or not; it is necessary to have a scale structure in which they will be guided to a gynecological examination if their score is higher.

5. Understanding of abnormal menstruation

Before developing a scale for menstrual abnormalities, it is necessary to see how well women are aware of them.

Ebina et al. stated that the items that female high school students do not receive guidance on during menstruation education are “premenstrual syndrome” (26.9%) and “menstrual abnormalities” (17.6%). Premenstrual syndrome is also a symptom of abnormal menstruation, so it is clear that knowledge about abnormal menstruation is insufficient.26)

Tsujimoto et al. investigated the level of knowledge about menstruation that college students have, and the information they wanted to get most were symptoms and conditions (for irregular menstruation and menstrual pain), general knowledge, contraception, premenstrual syndrome, and the relationship between menstrual pain and endometriosis.27)

Most of the things they wanted to know more about were related to menstrual disorders, making it clear that college students lack knowledge about menstrual disorders.

Currently, menstruation education is provided during the upper grades of elementary school; however, there is very little agreement regarding what constitutes abnormal menstruation. In addition, students from high school to university have fewer chances to receive education on menstruation even though they are actually in the age range that is most likely to have functional dysmenorrhea. It is necessary to set scale items that allow them to confirm the status of each menstrual abnormality one by one.

If there is a scale that can measure menstrual abnormalities, it will help them determine if it is better to immediately consult a doctor about their condition or whether they can just continue to monitor it for a while. If they can roughly gauge the standards for when medical examinations are needed after using the scale, they will understand that they are better off having a gynecological examination and may be motivated to have one.

However, for menstrual abnormalities, specialized knowledge in gynecological fields such as an abnormal pituitary system and the differentiation of gynecological diseases will be required. Therefore, prior to the development of the scale, we have to proceed while under the supervision of specialists who are familiar with gynecological medicine, including gynecologists who are studying not only maternity and midwifery but also menstrual disorders. It is important to advance the development of the scale while embracing the opinions of specialists on menstrual abnormalities.

V. Conclusion

There are no scales that specifically examine menstrual abnormalities while also comprehensively observing menstrual conditions.

There is a need to develop a scale for menstrual abnormalities so that those who have not had a gynecological examination in spite of having abnormal gynecological symptoms can make the decision to visit a clinic.

This study is to be added and revised to a paper which was presented at the 60th Japan Society of Maternal Health Conference.

This research was supported by grants from JSPS JP20K19147.

We declare that there are no conflicts of interest associated with this paper.

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Human Services

DOI: http://dx.doi.org/10.14391/ajhs.19.101
Asian Journal of Human Services, VOL.19 101-111

REVIE ARTICLE

Review the Framework of Intellectual Disability from a Physiological / Pathological Perspective in Japan

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ABSTRACT

In Japan, in order to realize inclusive education, teachers involved in special education need to have expertise to meet the diverse needs of children. However, as a result of the survey, it has been pointed out that a sufficient cooperation system has not been established with information on children's disability status is required to be shared reliably by related organizations. Therefore, this study aimed to reviews the framework of intellectual disability in Japan and to reviews the definition of intellectual disability on a physiology / pathology perspective. According to the classification of ICD-11, one of the neurodevelopmental disorders include intellectual disability and autism spectrum disorder (ASD). Schizophrenia, Epilepsy and Down Syndrome (DS) are separate categories and are not included in intellectual disability. Therefore, the low intellectual function found in some people with DS or Epilepsy should not be equated with intellectual disability as a neurodevelopmental disorder. In conclusion, to promote special education in the future, it is necessary for teachers to understand children's diseases and disorders physiologically/pathologically.

Received
August 7, 2020

Revised
October 3, 2020

Accepted
October 3, 2020

Published
October 30, 2020

＜Keywords＞
intellectual disabilities, physiology, pathology, disorder of intellectual development, ICD-11

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Asian J Human Services, 2020, 19:101-111.

I. Introduction

In Japan, in order to realize inclusive education, teachers involved in special education need to have expertise to meet the diverse needs of children. In addition, it is required to build a collaborative system with professionals outside the school, including those in the fields of medicine and welfare1).

In intellectual disability education, cooperation with the medical field is an issue. A survey on collaboration between special needs education and other occupations2) also shows that special needs teachers are aware of the need for multidisciplinary collaboration. However, as a result of the survey, it has been pointed out that a sufficient cooperation system has not been established. Teachers may also not understand what advice to seek from out-of-school professionals. Even in such a case, it has been pointed out that the cooperation only in the form causes confusion in the cooperation partner3). Special needs education is education for children with disabilities, and cooperation with the medical field is indispensable. In particular, information on children's disability status is required to be shared reliably by related organizations. Children with intellectual disabilities have the largest number of enrollments in Japanese schools. Intellectual disability has the largest number of children in schools in Japan, and its definition has changed significantly in recent years.

This paper reviews the framework of intellectual disability in Japan and reviews the definition of intellectual disability from a physiology / pathology perspective.

II. Intellectual Disabilities in Japan

Internationally, the definition of intellectual disability has changed significantly. When the International Classification of Diseases was revised from the 10th version (ICD-10) to the 11th version (ICD-11) in 2019, Intellectual disability was classified as Neurodevelopmental disorder under the name of "Disorder of intellectual development". This indicates that intellectual disability was defined as a disorder of neurodevelopment as well as Autism Spectrum Disorder and Attention Deficit / Hyperactivity disorder.

However, in Japan, intellectual disability is regarded as a different framework from developmental disability, which is a peculiar situation by international standards5). The Ministry of Education, Culture, Sports, Science and Technology defined intellectual disability as a condition in which the development of intellectual functions such as memory, reasoning, and judgment was significantly delayed, making it difficult to adapt to social life. On the other hand, developmental disorders are autism, Asperger's syndrome and other pervasive developmental disorders, learning disabilities, attention deficit hyperactivity disorder and other similar disorders of brain function, and the symptoms usually develop at a young age. It is defined as being specified by a government ordinance. This definition is based on ICD-10. With the revision of the law in 2007, special needs education has newly targeted developmental disabilities in addition to intellectual disabilities and physical disabilities, health impairment, visual disabilities, and hearing disabilities. However, the Ministry of Education, Culture, Sports, Science and Technology has stated that the administrative definition of the term developmental disability is different from the academic definition, which is a cause of confusion.

Children with intellectual disabilities are categorized as either general education or special education based on Intelligence Quotient (IQ) and degree of adaptive function. The classification does not take into account the diminished diseases and disorders, physiological and pathological features that cause the decline in intellectual function. However, in recent years, many children with developmental disabilities such as Autism spectrum disorder (ASD) and Attention-Deficit Hyperactivity Disorder (ADHD) who have no delay in intellectual function have been enrolled in special needs schools for intellectual disabilities6), and the specialization required of teachers has become extremely wide.

III. Intellectual Disability in Physiology / Pathology

1. Disorders of Intellectual Development: DID (Intellectual disability)

According to ICD-114), change the term [Mental Retardation, ICD-10(2016)] to [Disorders of Intellectual Development (DID)]. Therefore, Intellectual disability is indicated as Disorders of Intellectual Development (DID). Moreover, DID is similar to [Intellectual Developmental Disorder: IDD] used by DSM-5(Diagnostic and Statistical Manual of Mental Disorder-5th version, 2013). Table 1 shows the description and classification of DID.

DOI: http://dx.doi.org/10.14391/ajhs.19.101
Asian Journal of Human Services, VOL.19 101-111

＜Table 1＞ ICD-11(International Classification of Diseases- 11th version) for Intellectual disability (Disorders of intellectual development)

Description for DID	Disorders of intellectual development are a group of etiologically diverse conditions originating during the developmental period characterised by significantly below average intellectual functioning and adaptive behavior that are approximately two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardized tests. Where appropriately normed and standardized tests are not available, diagnosis of disorders of intellectual development requires greater reliance on clinical judgment based on appropriate assessment of comparable behavioral indicators.
Division for DID	06 Mental, behavioral or neurodevelopmental disorders ≫Neurodevelopmental disorders 6A00 Disorders of intellectual development 6A00.0 Disorder of intellectual development, mild 6A00.1 Disorder of intellectual development, moderate 6A00.2 Disorder of intellectual development, severe 6A00.3 Disorder of intellectual development, profound 6A00.4 Disorder of intellectual development, provisional 6A00.Z Disorders of intellectual development, unspecified

(WHO, International Classification of Diseases-11th, 2019)

1) Autism Spectrum Disorder: ASD

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social interactions and communication, as well as restricted activities, such as repetitive stereotypic behaviors7).

According to ICD-114), there is a description and classification of ASD(Table 2).

＜Table 2＞ ICD-11(International Classification of Diseases- 11th version) for ASD

Description for ASD	ASD is characterized 1)by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication. 2)by a range of restricted, repetitive, and inflexible patterns of behavior, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational, or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities.
Division for ASD	06 Mental, behavioral or neurodevelopmental disorders ≫Neurodevelopmental disorders 6A02 Autism spectrum disorder 6A02.0 Autism spectrum disorder without disorder of intellectual development and with mild or no impairment of functional language 6A02.1 Autism spectrum disorder with disorder of intellectual development and with mild or no impairment of functional language 6A02.2 Autism spectrum disorder without disorder of intellectual development and with impaired functional language 6A02.3 Autism spectrum disorder with disorder of intellectual development and with impaired functional language 6A02.5 Autism spectrum disorder with disorder of intellectual development and with absence of functional language 6A02.Y Other specified autism spectrum disorder 6A02.Z Autism spectrum disorder, unspecified

(WHO, International Classification of Diseases-11th, 2019)

2) Down Syndrome: DS

Down Syndrome (DS) is a disorder caused by trisomy of human chromosome 21 (Hsa21) and presents various anomalies of the cardiovascular, respiratory, organs, hematological, immune, musculoskeletal systems8). Therefore, DS is related to congenital heart diseases (CHD), Alzheimer's diseases (AD), learning and memory disorders, leukemia, cancers and Hirschsprung disease (HD)9).

＜Table 3＞ ICD-11(International Classification of Diseases- 11th version) for Down syndrome

Description for DS	Trisomy 21 is a chromosomal abnormality, characterised by the presence of a third (partial or total) copy of chromosome 21, which clinical manifestations include variable intellectual deficiency, muscular hypotonia and joint laxity, often associated with facial dysmorphism and variable malformations (essentially heart and digestive) and a risk of complications (epilepsy, leukemia, auto-immune and endocrine pathologies, earlier aging and Alzheimer disease. Inclusions: Down syndrome
Division for DS	20 Developmental anomalies ≫Chromosomal anomalies, excluding gene mutations LD40 Complete trisomies of the autosomes LD40.0 Complete trisomy 21

(WHO, International Classification of Diseases-11th, 2019)

3) Epilepsy

Epilepsy is considered the chronic neurological disease characterized by the recurrence of seizures, and associated with stigma, psychiatric comorbidity. Majority of epilepsy people are young age (<18 years), medically intractable epilepsy being present in nearly one-fourth of them10-12).

＜Table 4＞ ICD-11(International Classification of Diseases- 11th version) for Epilepsy

Description for Epilepsy	The group of conditions characterised as being in or associated with the nervous system. At least 2 unprovoked (or reflex) seizures occurring more than 24 hours apart.
Division for Epilepsy	08 Diseases of the nervous system ≫Epilepsy or seizures 8A60 Epilepsy due to structural or metabolic conditions or diseases 8A61 Genetic or presumed genetic syndromes primarily expressed as epilepsy 8A62 Epileptic encephalopathies 8A63 Seizure due to acute causes 8A64 Single seizure due to remote causes 8A65 Single unprovoked seizure 8A66 Status epilepticus 8A67 Acute repetitive seizures 8A68 Types of seizures 8A6Y Other specified epilepsy or seizures 8A6Z Epilepsy or seizures, unspecified

(WHO, International Classification of Diseases-11th, 2019)

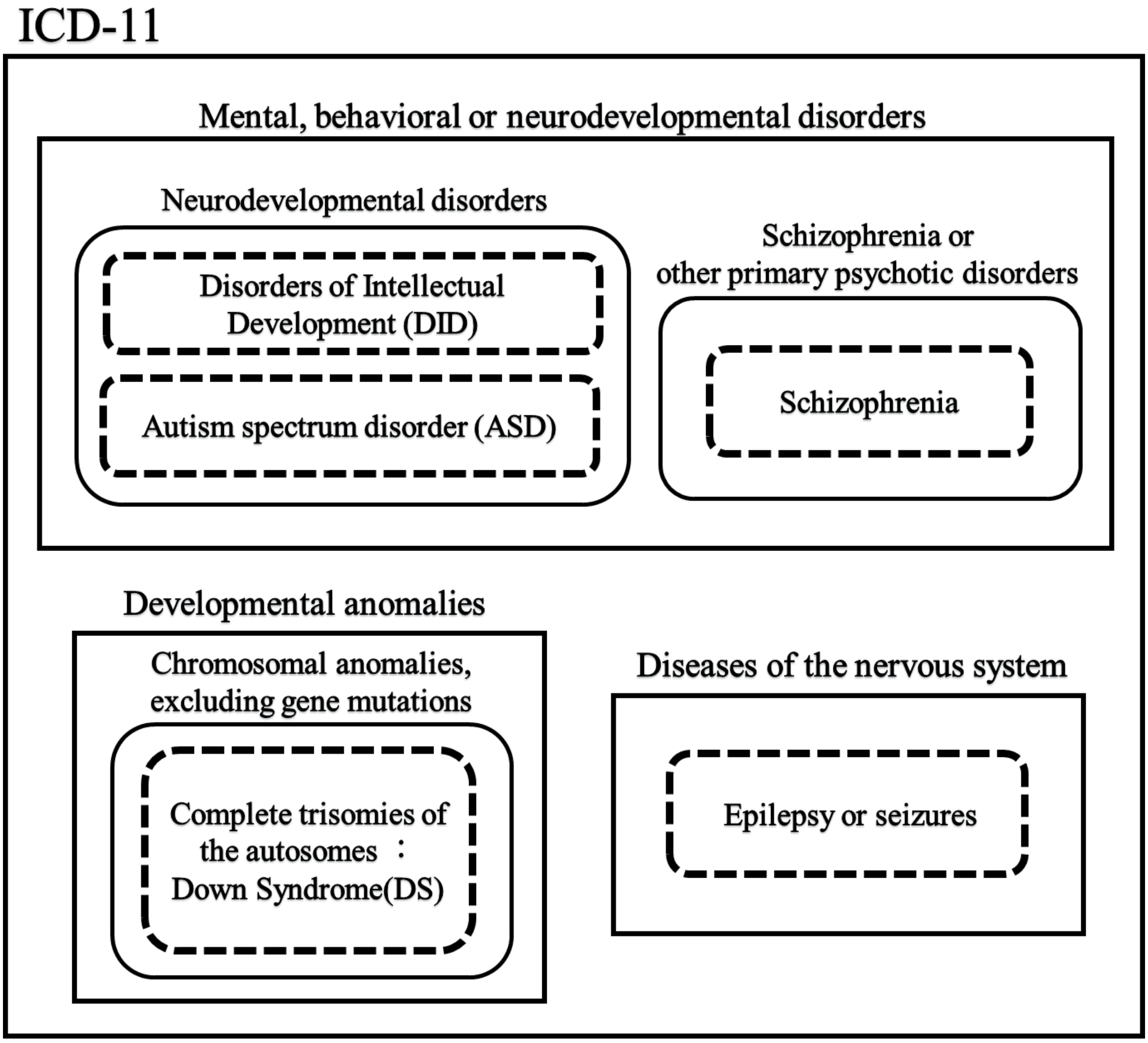
4) Schizophrenia

Schizophrenia is a severe mental disorder characterized by multiple psychiatric symptoms (such as, hallucinations, delusions, disorganized speech) and negative symptoms13). Although an exact cause of schizophrenia is unknown, risk factors associated with the development of the disorder include genetic and environmental factors14). Table 5 shows the details of Schizophrenia examined using ICD-11.

＜Table 5＞ ICD-11(International Classification of Diseases- 11th version) for Schizophrenia

Description for Schizophrenia	Schizophrenia is characterised by disturbances in multiple mental modalities. 1) Thinking (e.g., delusions, disorganisation in the form of thought), 2) Perception (e.g., hallucinations), 3) Self-experience (e.g., the experience that one's feelings, impulses, thoughts, or behavior are under the control of an external force), 4) cognition (e.g., impaired attention, verbal memory, and social cognition), 5) Volition (e.g., loss of motivation), 6) Affect (e.g., blunted emotional expression), 7) Behavior (e.g., behavior that appears bizarre or purposeless, unpredictable, or inappropriate emotional responses that interfere with the organization of behavior). 8) Psychomotor disturbances, including catatonia, may be present. Persistent delusions, persistent hallucinations, thought disorder, and experiences of influence, passivity, or control are considered core symptoms. Symptoms must have persisted for at least one month in order for a diagnosis of schizophrenia to be assigned. The symptoms are not a manifestation of another health condition (e.g., a brain tumor) and are not due to the effect of a substance or medication on the central nervous system (e.g., corticosteroids), including withdrawal (e.g., alcohol withdrawal).
Division for Schizophrenia	06 Diseases of the nervous system ≫Schizophrenia or other primary psychotic disorders 6A20 Schizophrenia

(WHO, International Classification of Diseases-11th, 2019)



Edited and Adapted from ICD-11(WHO, International Classification of Diseases-11th,2019)

＜Figure 1＞ Summary of Diseases based on ICD-11

Figure 1 shows the summary results for disease (Epilepsy or seizures) and disorder (DID, ASD, Schizophrenia, Complete trisomies of the autosomes; DS) at ICD-11. In summary, one of the neurodevelopmental disorders include intellectual disability and autism spectrum disorder (ASD). Schizophrenia, Epilepsy and DS are separate categories and are not included in intellectual disability (Figure1).

IV. Conclusion

According to the classification of ICD-11, intellectual disability as a neurodevelopmental disorder has no physiological or pathological diagnostic criteria and is diagnosed by psychological intelligence tests and behavioral evaluation. Therefore, the low intellectual function found in some people with Down Syndrome or epilepsy should not be equated with intellectual disability as a neurodevelopmental disorder. Similarly, educating children of different backgrounds in the same way is inconsistent with the idea of special education to provide education tailored to individual educational needs. In order to understand the educational needs of children enrolled in special needs schools for intellectual disabilities, it is necessary to have a physiological / pathological understanding of the causative diseases and disorders that cause the decline in intellectual function. And it will be necessary to provide educational support according to the intellectual and adaptive functions of each child. When special needs education targeted developmental disabilities, Japanese special needs schools changed their policy to accept all types of disabilities. If children with various disabilities are enrolled in one school, their educational needs will also diversify. In Japan, intellectual disability is centrally defined by the decline in intellectual function. In order to promote special needs education in the future, it will be necessary for teachers to understand the diseases and disorders of children physiologically / pathologically.

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Human Services

DOI: http://dx.doi.org/10.14391/ajhs.19.112
Asian Journal of Human Services, VOL.19 112-126

Case Report / Activity Report

A Study on the Grief Work of an Elderly Woman Who Encountered the Unexpected Death of her Spouse at Home

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ABSTRACT

The purpose of this study is to clarify characteristics of the grief process, and the adjustment to a new life of an elderly woman who encountered the unexpected death of her spouse at home. Semi-structured interviews were conducted and data were analyzed using Steps for Coding and Theorization (SCAT).

The elderly woman experienced difficulties in thinking and acting in an ordered way. The response of the police and the autopsy imaging procedure had confused and irked her, and she had not been given much time to bid her husband farewell before his body was removed. Features related to the unexpected death scene were "unforgettably shocking" for her, but more that, the personality and memories of her husband became "unforgettably important and precious." This was one of the facilitative factors of grief work. Her current life was constructed as a mixture of "a life that can be continued without being aware of the absence of the spouse," "a life of recognizing the absence of the spouse," and "a life of acquiring a new object of love or a new role." She adjusted to a new life, by rendering various matters and the local community, such as traditional customs of death and cooperation of locals, useful as the facilitative factors of grief work.

As the size and role of the local community had diminished, it became evident that it was necessary to focus on other facilitative factors of grief work. This included resilience, prior relationship with the spouse, family's functioning, and role acquisition.

＜Keywords＞
elderly women, spousal bereavement, unexpected death, grief work

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Asian J Human Services, 2020, 19:112-126. © 2020 Asian Society of Human Services

Received
August 7, 2020

Revised
October 2, 2020

Accepted
October 3, 2020

Published
October 30, 2020

I. Introduction

In older age, various experiences of loss accumulate. Elderly people are more likely to experience “loss of mind and body,” “loss of an economic base,” “loss of social connection,” and “loss of a purpose of living.” In Japan, the sources which “support the minds” of elderly adults are spouses and partners, 65.3%; children, 57.4%; and grandchildren, 17.9%.1)

Grief is a series of emotional reactions that occur in the bereavement of an individual who has experienced the expected loss of a person close to them.2) The digestion of grief and its process are referred to as grief work.3) It is translated as “hitan-no-shigoto” (sagyō) or “mo-no-shigoto” (sagyō) in Japanese.

The characteristics and trends of the grief process in elderly women who have experienced the death of significant others, and their adjustment to a new life for themselves, has previously been clarified. After spousal bereavement, elderly women tend to talk repeatedly about their days with their husbands, the sadness of their loss, their depression and loneliness, thus promoting their grief work.4) In addition, memories of the husband, hobbies, volunteering, and interaction with friends, contribute to the surviving spouse’s daily well-being.5)

The average life expectancy of Japanese women is more than six years longer than that of men; in 2018 the life expectancy for women was 87.32 years; and 81.25 years for men.6) The proportion of people living alone at home who are 65 years of age or older is 13.3% for men and 21.1% for women.7) Many elderly women are concerned that they may live long into old age and feel anxious regarding their personal and financial circumstances. It is, therefore, necessary to support the factors that facilitate grief work.

Harada noted that interpersonal support and rituals played an important role in the healing of families who had experienced sudden death of a family member at an emergency center.8) Differences in the causes of death may impact the physical and mental health, and grief reactions of the bereaved.9) It is thus evident that grief care should be provided to bereaved people immediately after the experience of a sudden death. The optimal methods of support have, however, not yet been clarified.

The grief characteristics, both of elderly people who have experienced the bereavement of their love object, and of people who have experienced the sudden death of others, have previously been individually identified. However, the features of grief of those who have had an unexpected bereavement at home have not been clarified. Unexpected bereavement may easily lead to prolonged grief or transition to morbid grief, following which depression and dementia may occur as a result of a decline in mental health. Therefore, it can be said that grief work, which is a sad but self-organizing task that involves self-reflection, is the key to spending a richer life in older age. Considering changes in the contexts of family structure and community impacting elderly women, it is necessary that they receive support intentionally.

It is, furthermore, meaningful to study grief work to clarify the characteristics of the grief process and the adjustment to a new life of elderly women who encounter the unexpected death of a spouse at home. It is necessary to identify the factors facilitating the smooth progress of the grief work and to clarify the contents of the needed support.

II. Purpose of the Research

The purpose of this study was to clarify the characteristics of the grief process, and the adjustment to a new life, related to unexpected death. It also aimed to clarify the contents of the support required for the smooth progress of the grief work, by means of the analysis of the case of an elderly woman who encountered the unexpected death of her spouse at home.

III. Research Method

1. Research method

This study utilized a qualitative approach. Qualitative research is used "to address clinical problems that cannot be quantitatively measured." It has also been described as a means of research that extracts qualitative data, that cannot be expressed numerically, from the research object, analyzes it using scientific methods as much as possible, and creates theory from the data to try to reconstruct reality.10) The experience of an elderly woman who encountered the unexpected death of her spouse at home is not a generalized concept because it is a rare bereavement experience. Therefore, we used this method to exploratively clarify the process of grief work, which cannot be estimated quantitatively, through dialogue with the elderly woman.

"Sudden death," refers an instance in which a person who is living a normal life and looks healthy appears to die rapidly, it may also refer to an instantaneous death due to some illness or intrinsic death within 24 hours after the onset of symptoms. Due to its characteristics, it is summarized in four points: death time, place of occurrence, cause of death, and deceased person.11) In this study, we defined unexpected death as "the sudden death of an elderly person who had no warning of about his condition and had been living a normal life at home."

2. Subjects

The study's subject was an elderly woman who encountered the unexpected death of her spouse at home. It was assumed that, unlike general bereavement after spousal care at home, an unexpected death is likely to leave the bereft spouse unprepared and uncertain as to the future.

DOI: http://dx.doi.org/10.14391/ajhs.19.112
Asian Journal of Human Services, VOL.19 112-126

3. Data collection

By using snowball sampling, we tried to recruit elderly women who continued to live at home after spousal bereavement. However, we found only one. The interview was conducted in December 2019 at the home of a research collaborator. The consent of the participant was obtained. A semi-structured interview was conducted, the contents of which were recorded on an IC recorder.

4. Interview contents

We conducted an interview survey on grief work after spousal bereavement using an interview guide. The contents of the interview are shown below.

1) Basic attributes:

- age when married, age at the time of spousal bereavement, and age at interview of the research subject.
- age when married and age at death of research subject's spouse.

2) Interview contents:

- the situation when faced with the death and the ritual situation after that
- changes in feelings during everyday life until now
- receipt of emotional and instrumental support

5. Data analysis method

1) Reasons for choosing an analysis method

The verbatim transcripts created from the interviews were analyzed using Steps for Coding and Theorization (SCAT), a method for analyzing qualitative data developed by Otani et al.12) SCAT is a research method in which valid analysis results can be obtained by repeatedly confirming and correcting one's own analysis. Compared to other qualitative research methods, it is effective for the analysis of a relatively small amount of qualitative data, such as data from only one case or the free description section of a questionnaire.12) From these, we considered that we could analyze the special experience of an elderly woman at home who encountered sudden death without having time to take care of her spouses or prepare for his death. We chose the SCAT method for this analysis.

2) Analysis procedures

(1) The text data obtained from the verbatim transcripts were sectioned for each group of contexts.

(2) The sectioned pieces were coded according to the following four steps. <1> Extraction to clarify a noteworthy phrase in the text, <2> The extracted phrase was paraphrased into a general phrase, <3> Phrases were demarcated into background, result, cause, etc. and explanation, and <4> Themes were summarized into concepts after considering the context before and after.

(3) A storyline was created based on the themes and constructs obtained by coding.
(4) While summarizing the contents of the storyline, the theoretical description was created in a short sentence. The contents coded were then compared and corrected between co-authors.

Analysts took care to include rich contextual information in the analysis process, by clearly describing the analysis process through which interpretations were made, and from which text, certainty was also ensured. The analysis by SCAT was mainly conducted by the first author, and the validity of the analysis was examined among the co-authors, based on the SCAT table created from the analysis.

6. Ethical considerations

We solicited research cooperation through snowball sampling. The voluntary consent was secured by contacting the target person who provided consent. Based on the request form and the explanation, we fully explained the purpose and significance of the research, the research method, the burden on the research subjects, and the expected results. We provided an explanation of the publication of research results and made it clear that no individual could be identified at the time of publication. We received consent also for the storage method and data disposal. This study was conducted with the approval of the Ethics Review Committee of Hirosaki University of Health and Welfare (approval number 2019-5).

IV. Results

The study's subject was an elderly woman who encountered the unexpected death of her spouse at home. When she was 18 years old, she had married her husband who had been 26 years old at the time. Her husband died at the age of 84 when she was 76. At the time of the interview, five years had elapsed since he had passed away. She was 81 years old and had been living alone at home.

In analyzing this elderly woman's story using SCAT, the text was divided into 89 categories. Of these, 32 were listener texts and 57 were the elderly woman's utterances. The text shown here is a group that demarcates the interaction in the interview by meaning. Following the interview guide, the texts that represented her thoughts in the story were organized in the following order: "situation in the face of death and subsequent mourning rituals," "memories of the spouse and what she thinks now," "changes in feelings and daily life with the passage of time," and "participation status in social relations."

Table 1 is an excerpt of the SCAT table for 25 texts that can be read as "situation in the face of death and subsequent mourning rituals."

＜Table 1＞ Interview analysis by SCAT (excerpt)

Text Raw interview data	Step＜1＞ noteworthy words or phrases from the text	Step＜2＞ Paraphrasing of words and phrases in Step<1>	Step＜3＞ Words or phrases to describe the text in Step <2>	Step＜4＞ Themes and Construct	Step＜5＞ Questions and Issues
The day to go to the hospital. I woke up at 5 o'clock and said, “We are going to the hospital.” He said "OK." I washed his hands and feet with hot water, changed his underwear, then prepared for breakfast, and went to the second floor again to talk to him, “Grandpa.” I remember it was around six. It was no good. I was very surprised.	The day to go to the hospital He said “OK” at five He already passed away at six Surprised	The beginning of a normal morning has changed A surprise to the lack of reaction	The beginning of a normal morning has changed completely A surprise in an unexpected situation	Under the special circumstances of sudden death at home In spite of having talked a while ago, never thought to face death	In the literature, it is estimated that the bereavement reactions of the bereaved are in the order of suicide>accidental death>acute death>morbid death
I was really surprised. “Wow!! what's the matter?” “Grandpa!?” I pulled my hips out. I couldn't stand.	Really surprised “Grandpa, what's the matter?” Pulled out	Surprise and confusion Calling out the spouse	Difficulty in understanding the situation Difficulty surpassing the emergency	Panic state in which clear and orderly thoughts and actions are not possible	She was able to organize and communicate the situation in order, but is that due to the passage of time?
I could not call my son. I managed to call him. Soon my son came, but we could not do anything. I also called the hospital, but after death... Even though he always went to see a doctor.	I could not call Soon my son came Calling the hospital Could not do anything after death	Lack of calmness Calling my son is my first choice Not accepted at the hospital	Upset and confused Reassuring Relief to son coming Despair	Get into a desperate situation Difficulty of coping and negotiations in unexpected aspects	How would she have survived the shocking situation without the existence of a family?
I called other hospitals, but they refused to take my husband to the hospital. While doing so, many ambulances and fire truck came. I really did not know how it was. The police investigated everything. Also, his passbook. They took a picture.	Calling the hospital If this happened, it won't help Ambulances and fire truck. Passbook was examined How was it really hard	The fact about not being accepted at the hospital Stop thinking Difficulty adjusting to things to not being normally experienced	An unthinkable experience in normal daily life Occurrence of secondary crises such as legal procedure	Upset to cope and compromise intense and specific aspects	

He died on the second floor, so at there. It was really hard.					
I could not do anything. It managed to do something by everyone. It was really hard.	I could not do anything Somehow, I dealt with	Difficulty coping with Get through the help of others	Situations that are difficult to deal with	A critical state in which not thinking or acting clearly and orderly	Does the situation of death affect the strength of the first stage (numbness, emotional crisis) that Bowlby shows?
It was troublesome. Unlike dying in a hospital‥ To find out the cause of death, where was it‥ A place to investigate when someone dies‥ We took him there, stayed overnight, and returned the next morning.	Troublesome Death different from hospital death Until the next morning	Procedures to amplify mental distress	Legal procedures secondarily amplify distress	Irksomeness of specific procedures	
The police said, "You should have taken him to the hospital if he got worse." But he was fine. He had an intestinal surgery.	Go to the hospital Despite being fine Surgical operation	Confusion about being admitted to the hospital even though he was fine	Feeling blamed for the cause of death	A sense of remorse for cause of the sudden death	
He had two surgeries. The doctor told us it is okay, but after that, he became sick. Should he have had two surgeries‥? He could not eat any food. He had lost weight.	Doctor: it's okay He should not have had two surgeries He could not eat. Thin	Relief and regret when thinking about the deterioration of the condition	Existence of emotions that changed from relief after surgery to regret	Shaking of feelings that occurred after experiencing unexpected things	
Yes‥. I was surprised.	Surprised	Surprise	Emotions that can only be expressed in one word	Expression of a frank emotion: "No way"	
I can remember that time. After we returned, a funeral director came and did everything for us.	I can remember that time Everyone helped	Possible to recall surrounding movements	The current state of mind to be able to remember	The time elapsed to be able to recollect calmly	
There was no time to grieve when there were people.	Difficult to grieve when someone is present	Expressing grief in a limited time	Time for the bereaved to face sadness	Make a compromise with the lost subject within a limited time	

After the first seven days, I felt calm. What should I say, it is a blink of an eye, a week･･	What should I say･･ In no time	The speed of progress that cannot be expressed	A series of funerals that were extremely busy	A hectic mourning ceremony until it is released from an extreme state of mind	
I cannot forget it.	I will never forget it	Unforgettable memory	Memory to remember strongly	“Death” remains as a strong memory	The meaning included in unforgettable is memory for encountering a shocking scene or thought for a lost object?
Well, at first, I cried. Later, my tears were gone. I do not know what to say.	I cried at first I have lost tears What to say	Cry, cry	Emotional expression of Lost object	Reaction to an Undeniable fact that the subject did not exist in this world	

1. Storyline

We grouped together contextualized words that reflected the themes and concepts in the story (<4> code) in the SCAT table, with the storyline as the underlying context. The storyline in the SCAT analysis is “a description of the latent meanings in the events described in the data. These are mainly composed of the thematic concepts described in <4>.”[12] Additionally, it is recommended that the <4> code is underlined to confirm that the themes and concepts in the text, coded under <4>, are all specified in the storyline. [12] A storyline was created which was related to: the “situation in the face of death and subsequent mourning rituals”; “memories of the spouse and what she thinks now”; “changes in feelings and daily life over time”; and “social involvement status.” We will also use the words and phrases described in the themes and concepts of <4> in the SCAT table for the storyline, and underline them. This indicates that the findings were derived from the analysis results.

1) Situation in the face of death and subsequent mourning rituals

Despite talking up to the last minute, she could not think of facing death, and the special situation of “sudden death” at home was a bolt from the blue. She tried to get through the intense and specific situation, however, she was in a panic state in which she could not think or act clearly and orderly. As a result, she was extremely lonely and fell into an absolute pinch of being unable to act urgently. She was confused by the irksomeness of specific procedures different from ordinary death and struggled to cope and negotiate intense and specific aspects such as the scene in which the police took a photo of his passbook.

Even though she was in a critical state where she could not think or act in a clear and orderly fashion, she tried to find a way to say "goodbye" to her deceased spouse in the limited time afforded her. After the first seven days, she managed to overwhelm the rushed mourning ceremony until she was released from her extreme mental state; however, her husband's death remained a strong memory. She suffered from difficulties with coping and negotiating with the unexpected aspects associated with his death. She also felt a sway after experiencing something unexpected, conclusively suffered from a guilty conscience for the sudden death. Now that she can remember the scene of death, she exposed the straightforward feelings of when she encountered the scene of death and it became possible to calmly recollect the reaction to an undeniable fact that her husband did not exist in this world.

2) Memories of the spouse and what she thinks now

After bereavement, feelings of respect and shock come and go. In particular, when her physical condition changed, she had to face the fact that she had no one that she could rely on. The wistful thought: "if he were alive..." amplified her sense of loss. Although emotions that slow down the adjustment to life after bereavement remain, the relationship between the couple that emerges from the spouse's positive memory is a facilitating factor that makes life after bereavement calm.

3) Changes in feelings and daily life with the passage of time

After spousal bereavement, the sense of time accelerates with the passage of time, and the arrival of the season of bereavement may cause an anniversary reaction. On the other hand, the passage of time also eased loneliness and contributed to her being able to re-immerse herself in life after the death of her spouse. She recovered her normal life and accepted her present circumstances. The feelings evoked by the passage of time led to her construction of "a life that can be continued without being aware of the absence of the spouse" and "a life of recognizing again the absence of the spouse."

In the background of daily life without feeling inconvenience, there was an existence that is the heart and soul of her own instead of her spouse, and an opportunity to go out with the humble support of the family living nearby. Family relationships that provided daily well-being and a sense of fulfillment were the driving forces that enabled her to maintain a universal and customary life. In addition, the motivation and the purpose of her life to adopt a new role in the family; and the comfort of obtaining a new attachment object reduced her loneliness even during the days she spent alone. The presence of grandchildren, who bring a sense of well-being and fulfillment to life, influence the growth of a vibrant life. Continuation of daily religious activities is also a factor that brings a sense of well-being and fulfillment.

4) Participation status in social relations

In the life after spousal bereavement, interacting with friends, interacting with the community, and continuing hobbies provided a sense of fulfillment. Experiencing continuity in communicating with the community for fun and socializing with friends were important elements of healing. Hobbies as activities which might deliver a sense of accomplishment, enriched her life without her spouse. In addition, the ease of life brought about by her sense of unity with the community created the sense of reassurance that there is a "neighborhood (*Gokinjosan* in Japanese)."

2. Theoretical description

Next, the storyline that has been made into a detailed context, and has become a complex, and structural description, is fragmented and theoretically described. This is not universal and generally accepted, but ‟what can be said from this data,[13] so we will explore the possibility of describing individual concrete analysis as a theory.

1) Situation in the face of death and subsequent mourning rituals

(1) The intense and specific situation of the unexpected death of a spouse at home complicates clear and orderly thinking and action.
(2) It is difficult to deal with intense and special situations, special procedures different from ordinary death, and separation from the lost love object within a limited time. After that, fell into a sense of self-responsibility.
(3) With the passage of time, the scene of death is remembered with the emotions associated with it and these can be expressed frankly.

2) Memories of the spouse and what she thinks now

(1) When she feels sick, I really realize that there is no one to rely on.
(2) Thoughts of ‟if he were alive"slow down the adjustment to a life after his death.
(3) Positive memories of the spouse make life after bereavement calm.

3) Changes in feelings and daily life with the passage of time

(1) There were contradictory thoughts of "a life that can be continued without being aware of the absence of the spouse"and ‟a life of recognizing again the absence of the spouse."
(2) Passage of time brings a sense of normality to life after spousal bereavement.
(3) A family relationship that is emotionally, instrumentally and evaluatively good, promotes the continuation of daily life. Acquiring new roles and attachments in the home give life vitality. Religious behavior brings a sense of peace.

4) Participation status in social relations

(1) Continuation of friends, community, and hobbies make life without a spouse vibrant.
(2) They are the elements of obtaining fun, healing, and a sense of accomplishment.
(3) The community creates a sense of reassurance that there is “neighborhood (*Gokinjosan* in Japanese).”

V. Discussion

1. Characteristics of the grief process of the elderly woman who encountered the unexpected death of her spouse at home

For the elderly woman who encountered the unexpected death of her spouse at home, the things related to the sudden death scene, such as the unexpected events, subsequent procedures, and rushed mourning rituals became “unforgettable shocking memories.” However, more than that, the personality and memories of her husband became “unforgettably important and precious memories.” This was one of the facilitative factors of grief work.

By maintaining the same living space, life rhythms, and habits as when spending time with the spouse, life after spousal bereavement is given meaning to “a life that can be continued without being aware of the absence of the spouse” and “a life as it was before.”

However, she was keenly aware of the fact that no one wanted to rely on her when she was sick, and she felt lonely in the reality that she could not go out and work in the field together with others. The loss of “the person with whom she acted” was also the loss of “the time they were able to share.” Occasionally, emptiness and recollection occurred, and the unproductive consumption of time was recognized. The process of dealing with loss begins by admitting death due to the absence of a husband. As a result, the expense as a couple becomes clear, and at the same time it begins the recognition of the awareness of losing it.14) A similar process of grief was experienced by the elderly woman who encountered an unexpected sudden death.

On the other hand, face-to-face conversations with her husband who did not exist in front of her, such as worshipping with folded hands at the Buddhist altar every morning, offering fresh flowers, going to the temple on his day of death became unintentionally incorporated into her everyday life. By starting to speak with the deceased, described as the beginning of a new relationship,15) the connection and bond with the spouse after bereavement was reconstructed as a new form of relationship with meaning and significance, “a life of acquiring a new object of love or new role” was formed, including a spiritual aspect.

2. Individual and environmental factors affecting the adjustment to a new life

In general, elderly people who live alone with family members tend to feel anxious about being a burden on them and feel confused or lonely in the face of change.16) With regard to the elderly woman in this study, her grandchildren and pet: her role in assisting with the preparation of meals for the son's family: the opportunity to go out with casual consideration, and her quick wit with her sons and other people, enabled her to find "a life of acquiring a new object of love or role." She, furthermore, considered her hobbies, for example patchwork, socializing with friends and neighbors, and her role in passing on local traditions to be "fun"and "healing."

In previous research with regard to the resilience of elderly people, the instrumental independence was found to be related to "activeness in life" and "friends/neighboring resources" and high intellectual activity was revealed to be related to an abundance of "friends/neighboring resources" in the activity capacity index.17) Elderly bereaved women who receive emotional support from their family and friends have a high degree of life satisfaction.18) In this study, it was speculated that the environmental factors of "friends/neighboring resources" increased her resilience and contributed to her adjustment to a life.

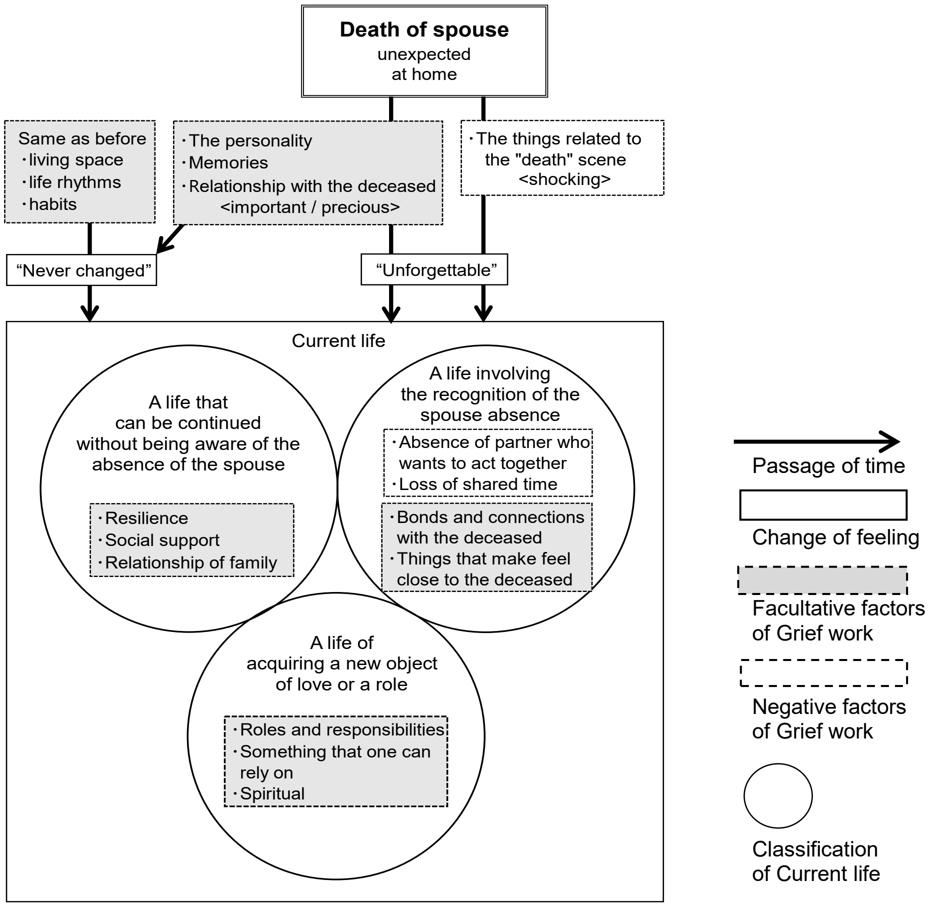
After the unexpected death of her husband, she had completed a series of mourning ceremonies with local residents for the first seven days. In her area, there continues to be traditional death involvement and customs, as well as funeral-related local community ties and cooperation. She was able to sympathize with sadness with her family and local residents, because there was spontaneous social support, so that she did not have to face her bereavement alone. This support is a facilitative factor of grief work. Furthermore, the reason why she was able to maintain a continuous connection with her community even after spousal bereavement was due to the fact that, in addition to her resilience, there were local relationships and customs in the area which enriched the community.

Grief is a normal and legitimate reaction, and individual grief work can overcome critical situations and grief, even without specific care situations and opportunities. In an elderly woman who encountered the unexpected death of her spouse at home, there were memories of events that were clearly related to the scene of death. When she was reminded of the fact that she no longer had her husband with her, her sadness and loneliness were rekindled. However, this indicated that her grief process operated in the same way as general bereavement. This is probably due to the existence of various facilitative factors of grief work that enabled her grief process to flow smoothly. These were previous life experiences and values, resilience, good family relationships, the acquisition of new roles, having fun with hobbies and community connections, customs for death remaining in the area, and good relationships and memories of the spouse before bereavement. Five years have passed since the bereavement and she has been able to calmly and objectively look back on the unexpected event that affected her. "We were having a conversation just before I realized that he was not breathing.”

The more frequently there is emotional expression, the better the mental health.19) Therefore, it is essential that support includes talking about feelings of sadness. In Japan, however, the environment surrounding individuals is changing as a result of factors such as the reduction and dilution of family functions, lifestyles, and communities. It can be said that, from the perspective of prevention, it is necessary to have intentional support so that relationship with people who need to talk about their grief can be continuously maintained. In addition, since grief may influence various factors of a person’s life, it is necessary to provide support which take into account the individual’s life experiences, values, and his or her relationship with the deceased.

In this study, the analysis target was only one case. However, the experience of unexpected bereavement at home is rare, so it is hoped that further research will expand on the findings of this case for the purposes of generalization.

Figure 1 indicates characteristics of the grief process and the adjustment to a new life for an elderly woman who encountered the unexpected death of her spouse at home.



＜Figure 1＞ Characteristics of the grief process and the adjustment of a new life of an elderly woman who encountered the unexpected death of her spouse at home

VI. Conclusions

1. The things related to the death of spouse were "unforgettably remembered as a shocking event," but more than that, the personality and memories of her husband became "unforgettably important and precious."
2. The current life was constructed by a mixture of "a life that can be continued without being aware of the absence of the spouse," "a life recognizing again the absence of the spouse," and "a life of acquiring a new object of love or a new role."
3. It became clear that an elderly woman who encountered the unexpected death of her spouse at home could follow a smooth grief process and adjust to a new life due to facilitative factors of grief work.
4. It was suggested that it is necessary to intentionally support facilitative factors of grief work because the size and the role of the local community has diminished.

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as of October 1, 2020

Asian Journal of Human Services
VOL.19 October 2020

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Presidents | Masahiro KOHZUKI & LEE, Sun Woo
Publisher | Asian Society of Human Services
#1Floor Ohara Bill, 2-11-5, Takezaki-Town, Shimonoseki-City, Yamaguchi-Prefecture, 750-0025, Japan
E-mail: ashs201091@gmail.com
Production | Asian Society of Human Services Press
#1Floor Ohara Bill, 2-11-5, Takezaki-Town, Shimonoseki-City, Yamaguchi-Prefecture, 750-0025, Japan
E-mail: ashs201091@gmail.com

ASIAN JOURNAL OF HUMAN SERVICES
VOL.19　October 2020

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Yamaguchi, Japan