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ORIGINAL ARTICLE

Challenges of “Young Carer Support” in Japan and Role of Community-based Integrated Support Centers

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ABSTRACT

To clarify the challenges of young carer support among professionals engaged in community-based integrated care in the eastern area of Shizuoka Prefecture, Japan, as a basis for determining the role of community-based integrated support centers in such support. We conducted an open-ended web questionnaire survey, involving 87 professionals who had participated in a young carer support training seminar planned by a community-based integrated support center, and performed quantitative text analysis to identify the challenges of young carer support. Fifty-one professionals responded (response rate: 58.6%). The 5 most frequent words were led by “necessary” (32), followed by “collaboration” (27), “think” (26), “educational institution” (22), and “support” (17). Through co-occurrence network analysis, 4 network groups, <challenges in grasping young carers>, <challenges of the community>, <challenges related to support systems>, and <challenges related to collaboration>, were formed. The results indicated the necessity of organizing support systems that enable the identification of young carers through the establishment of laws and systems, and promoting collaboration between the community and health, medical, welfare, and education fields to support young carers in communities. Community-based integrated support centers are expected to play a pivotal role as a base for facilitating such collaboration.

Keywords: Japan, young carer support, challenge, community-based integrated support center, role

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1. Introduction

In Japan, the long-term care insurance system launched in 2000 has changed the perception of long-term care from something to be solved within the household to an issue to be addressed by society. With the revision of the Long-Term Care Insurance Act in 2005, community-based integrated support centers were established as consultation and support offices close to community residents, and various initiatives have been promoted to date to ensure that care receivers covered by long-term care insurance and their families can continue to live comfortably in their familiar communities. According to the Ministry of Health, Labour, and Welfare, as the community environment surrounding care receivers and family caregivers undergoes significant transformation, it has become an urgent issue to promote support measures and projects for family caregivers from a new perspective¹⁾. Community-based integrated support centers are expected to play a key role in this.

The Organization for Economic Cooperation and Development (OECD) reports that many developed countries are more advanced than Japan in terms of supporting family caregivers²⁾. The United Kingdom was the first country in the world to conduct a status survey involving young carers, who are often overlooked in society among family caregivers, after 1990, and the 2001 national census reported that the number of young carers in the UK was 175,000³⁾. Similar surveys, studies, and legislations have also been administered in other Western countries⁴⁾. On the other hand, in Japan, the overall status of young carers has not yet been determined, and the first survey to clarify the status of junior and senior high school students was conducted in 2020, followed by an elementary school and university student questionnaire survey in 2021⁵⁾. The results revealed that 4-6% of elementary school to university students were young carers, and the care receivers were their grandparents or parents. The frequency of care was most often daily, ranging from less than 1 hour to more than 8 hours. Furthermore, the most common answer when asked about support for young carers was “I don't know”, and there was a demand to nurture an environment that facilitates consultation, such as the provision of dedicated consultation services for young carers.

When searching for Japanese literatures on young carers without limiting the period, the topic appears in some articles only after 2018, except for a survey conducted in 2014 to assess welfare professionals' perceptions⁶⁾. However, the majority of these studies involved elementary, junior, and/or senior high school students or young carers themselves, and few targeted professionals in community-based integrated care. This literature review highlighted the necessity of collaborating with community residents and support institutions as a nursing role⁷⁾.

In the present study, we examined the challenges of young carer support, involving professionals engaged in community-based integrated care, who had participated in a young carer support training seminar in the eastern area of Shizuoka Prefecture, Japan. We also aimed to provide a basis for determining the role of community-based integrated support centers in such support. During the young carer support training seminar, some young carers spoke of their own experiences. The definition of young carers in this study was that provided by General Incorporated Association Carers Japan: children under the age of 18 who undertake caregiving responsibilities similar to those of adults when their family members require care, including household chores, caring for family members, caregiving, and emotional support⁸⁾.

2. Subjects and Methods

2.1. Study and Procedures

2.1.1. Study Design

We conducted an open-ended web questionnaire survey, and performed content analysis of the questionnaire results.

2.1.2. Study Period

From October 1 to November 30, 2022.

2.1.3. Subjects

The subjects were 87 professionals who had participated in a young carer support training seminar held as a function-enhancement project of Mishima Kita Community-based Integrated Support Center in FY2022. During the seminar, some young carers spoke of their experiences.

2.1.4. Study Items

As basic attributes of the subjects, we examined their sex, age, current job type, type of services provided by the current facility, and years of experience in the current job. We also conducted an open-ended survey on the provision of young carer support, details of support approaches, and challenges of such support.

2.1.5. Ethical Considerations

After obtaining consent from the organizer of the training seminar, we explained the voluntary nature of study cooperation and anonymity to participants of the seminar in writing and orally. We regarded submission of a completed questionnaire as consent. The study was approved by the Ethical Committee of the institution the researcher belongs to (approval number: 4-04).

2.2. Data Collection

We conducted a web questionnaire survey and collected responses using Google Form.

2.3. Data Analysis

We performed content analysis of free descriptions using KH Coder 3, text-mining software developed by Higuchi⁹⁾, focusing on challenges of young carer support. For the analysis, we prepared each respondent's answers as a single dataset. Next, based on the results of morphological analysis, we specified the following words as compound words to be extracted: "educational institution", "medical institution", "welfare institution", "child welfare committee member", "community-based integrated support center", "young carer", "young carer support", "care manager", "long-term care insurance office", and "school teacher". For text-mining analysis, we calculated the number of occurrences of each word, and performed co-occurrence network analysis. Based on these calculations, we created a list of the 50 most frequently used words. In the co-occurrence network analysis, we used sentences as the unit of aggregation, with the minimum number of occurrences set to 3 and the minimum number of documents set to 1. We focused on word-word co-occurrence relationships, and selected co-occurrence relationships based on the 50 highest Jaccard coefficients for analysis. It should be noted that co-

occurrence network analysis explores the relationships of word pairs based on similar occurrence patterns. Networks are visualized by connecting words with strong co-occurrence relationships using lines. In a co-occurrence network, the thickness of lines corresponds to the degree of co-occurrence relationships measured by the Jaccard coefficient, with thicker lines signifying stronger co-occurrence relationships. In addition, the size of the circles in the network is proportional to the number of occurrences of each word, with larger and darker circles representing more frequent words.

3. Results

3.1. Basic Attributes (Table 1)

Among the 87 participants of the training seminar, 51 responded (response rate: 58.6%). There were 44 (86.2%) females, 6 (11.8%) males, and 1 (2.0%) with no answer for sex. The average age was 51.2 ± 8.9 (29-67). There were 32 (62.7%) welfare, 8 (15.7%) medical, 3 (5.9%) health, 6 (11.8%) educational, and 2 (3.9%) other professionals. The most common type of services provided by the current facility was home care support services, with 21 (41.2%) respondents. The most common number of years of experience in the current job was more than 1 year but less than 5 years, with 17 (33.3%) respondents.

Table 1. Basic Attributes

Item	n	%
Sex		
Female	44	86.2
Male	6	11.8
N/A	1	2
Age a)		
	51.2±8.9 [29-67]	
Current job type		
Welfare professional	34	66.7
Medical professional	7	13.7
Health professional	6	11.7
Educational professional	3	5.9
Others	1	2.0
Type of services provided by the current facility		
Home care support services	21	41.2
Community-based integrated support center services	12	23.3
Administrative services	6	11.8
Social welfare council services	3	5.9
Educational institution services	3	5.9
Care services	2	3.9
Others	4	7.8
Years of experience in the current job		
Less than 1 year	3	5.9
More than 1 year but less than 5 years	17	33.3
More than 5 years but less than 10 years	15	29.4
More than 10 years	16	31.4

a) Mean ± SD [minimum - maximum]

3.2. Analyzed Words

The total number of words analyzed by text mining (total number of analyzed words) was 2,007, and the number of different words (number of word types) was 464. Note that these numbers do not include common words that are used in most sentences, such as particles and auxiliary verbs.

3.3. Word Frequency (Table 2)

Table 2 lists the 50 most frequently used words, led by “necessary” (32), followed by “collaboration”, “think”, “educational institution”, “support”, “oneself”, “feel”, “child”, “care”, and “community”. The number of occurrences ranged from 32-10 among the top 10, 9-4 among the top 11-32, and 3-2 among the top 33-50 words.

Table 2. Frequent Words (Top 50)

Rank	Extracted words	Number of occurrences	Rank	Extracted words	Number of occurrences
1	necessary	32	25	care manager	4
2	collaboration	27		school teacher	4
3	think	26		training	4
4	educational institution	22		important	4
5	support	17		disability	4
6	oneself	12		many	4
7	feel	11		welfare	4
	child	11	33	assistance	3
9	care	10		counselor	3
	community	10		awareness	3
11	related	9		medical care	3
12	child welfare committee member	8		medical institution	3
	system	8		share	3
14	family	7		personal	3
	school	7		inform	3
	institution	7		situation	3
	difficult	7		close	3
	welfare institution	7		voice	3
19	administration	6		the person him/herself	3
20	information	5		transmit	3
	consultation	5		field	3
	community-based integrated				
	support center	5		health	3
	grasp	5		understanding	3
	problem	5	49	case	2
25	help	4		caregiving	2

3.4. Co-occurrence Networks (Figure 1)

There were 4 co-occurrence network groups, representing <challenges in grasping young carers> (Figure 1), <challenges of the community> (Figure 2), <challenges related to support systems> (Figure 3), and <challenges related to collaboration> (Figure 4). These network groups were formed based on the descriptions in the questionnaire, which contained words constituting these networks.

The network group <challenges in grasping young carers> (Figure 1) consisted mainly of the following words: “*child welfare committee member*”, “*community-based integrated support center*”, “*grasp*”, “*care manager*”, “*information*”, “*personal*”, “*school teacher*”, “*close*”, “*training*”, and “*counselor*”. Descriptions containing these words (*in italics*) included: “Young carers may not tell the truth, so it is necessary for *counselors*, class teachers, and *child welfare committee members* to collaborate”, “We need to make young carers aware of the presence of *community-based integrated support centers* and *care managers*”, “We have to *grasp* the actual situation”, “We have to make *school teachers* and community residents *close* to young carers notice their situation”, “Holding *training seminars* through *collaboration* among *community-based integrated support centers*, *school teachers*, and *care managers* may be helpful”, and “The *child welfare committee members* always complain that there are barriers related to *personal information*”.

The network group <challenges of the community> (Figure 2) consisted mainly of the following words: “*care*”, “*community*”, “*the person him/herself*”, “*voice*”, “*school*”, “*awareness*”, “*share*”, “*disability*”, and “*inform*”. Descriptions containing these words (*in italics*) included: “It is necessary to create a *community* that does not see children as manpower for care”, “This should be considered a *community* issue”, “I think that the *voice of the person him/herself* is very important”, “It is necessary for the *child welfare committee member*, *school*, residents’ association, and children’s association to collaborate and inform the parties concerned of the situation”, “Consultation and support offices that comprehensively support *care*, parenting, people with *disabilities*, and mental health are required in the *community*”, and “We have to encourage young carers to *share* their thoughts about continuing to provide *care*”.

The network group <challenges related to support systems> (Figure 3) consisted mainly of the following words: “*child*”, “*system*”, “*support*”, “*medical institution*”, “*field*”, and “*understanding*”. Descriptions containing these words (*in italics*) included: “I don’t know how we can understand and empathize with the thoughts of *children*”, “We have to build appropriate *support systems* surrounding *children*”, “*Support systems* across *fields*, covering disabilities, children, and *medical institutions*, are required”, and “It is difficult to address this issue without mutual *understanding* of other fields among professionals”.

The network group <challenges related to collaboration> (Figure 4) consisted mainly of the following words: “*necessary*”, “*collaboration*”, “*think*”, “*educational institution*”, “*support*”, “*welfare institution*”, “*administration*”, “*related*”, and “*institution*”. Descriptions containing these words (*in italics*) included: “Collaboration with *educational institutions* is essential”, “*Collaboration* between *educational institutions* and *welfare institutions* is difficult”, “There are many *institutions* requiring *collaboration*, including *administration*, *welfare institutions*, and *educational institutions*”, and “It is necessary for *related institutions* to provide support through *collaboration*”.

In addition, as frequent words, “necessary”, “collaboration”, “think”, “educational institution”, “welfare institution”, “support”, “feel”, “child”, “care”, and “community” were drawn. As words with stronger co-occurrence relationships, “collaboration” and “educational institution”, “support” and “system”, “close”, “school teacher”, and “training”, and “personal” and “information” were drawn with thicker lines.

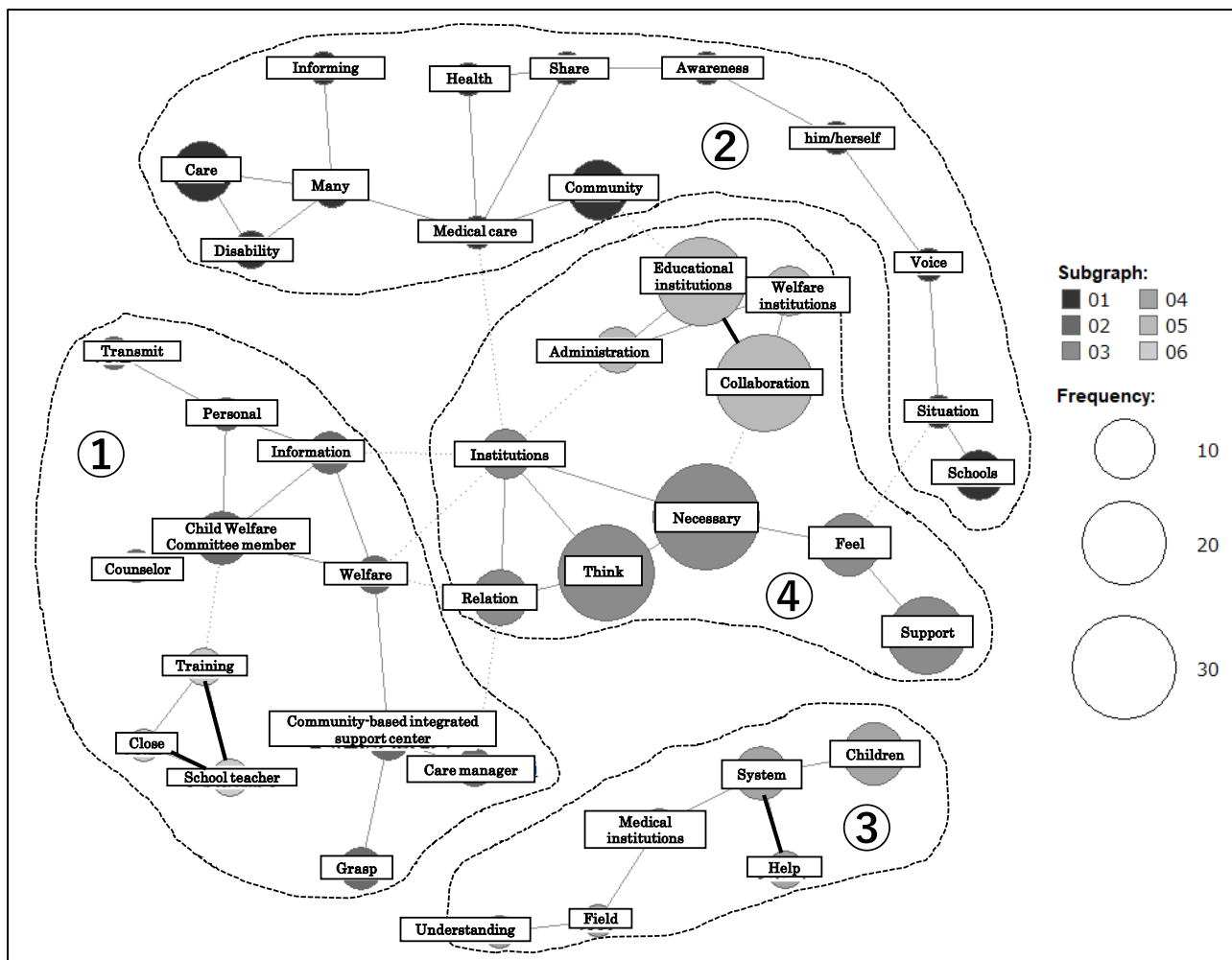


Fig1. Co-occurrence network of young carer support issues (Top50)

4. Discussion

The professionals engaged in community-based integrated care in the eastern area of Shizuoka Prefecture, Japan, described 4 categories of challenges in terms of young carer support: <challenges in grasping young carers>, <challenges of the community>, <challenges related to support systems>, and <challenges related to collaboration>.

First, concerning <challenges in grasping young carers>, conceptual analysis of young carers in Japan showed that these children have [overburdened roles and responsibilities] to carry out [various care tasks], in addition to caregiving, including housework, money management, and language interpretation, and they also make [efforts to maintain the household] to protect other family members from being forgotten. On the other hand, while developing [complex emotions], such as the desire to escape from reality and a feeling of guilt for having such a desire, they also increase their [unawareness of the situation] without anyone noticing¹⁰⁾. These characteristic attributes of young carers make it difficult to grasp them. In the present study, some respondents of the questionnaire described the necessity for “child welfare committee members”, in addition to “community-based integrated support centers” and “care managers” from the welfare field and “school teachers” and “counselors” from the educational field, to grasp young carers. A previous survey involving school counselors indicated the necessity of improving methods to identify young carers using various social resources, as well as through schools¹¹⁾.

It is also important that community-based integrated support centers and child welfare committee members be recognized as social resources for the identification of young carers. Also, as strong co-occurrence relationships were observed among the words “close”, “school teacher”, and training” in the present study, young carer support requires opportunities for learning in a familiar environment. In this respect, holding training seminars on young carer support may be expected of community-based integrated support centers.

With regard to <challenges of the community>, one of the respondents stated that the problem of young carers should be considered as a community issue. As a community issue, some researchers noted that the preceding requirements for the conceptual analysis of young carers are influenced by the premise of Japan’s [community care policy], and that there are [family systems and dynamics] that produce young carers¹²⁾. Another survey on the role of psychiatric social workers reported that the problem of young carers requires an approach that considers not only the child him/herself, but also the whole family¹³⁾. In our previous study, family systems and relationships were also identified as a [whole family issue] in family caregiver support¹⁴⁾. However, in the present study, there was a strong co-occurrence relationship between the words “personal” and “information”, and barriers to “personal information” were noted. It is also undeniable that there is a sense of resistance to interventions for family issues, according to a general public awareness survey¹⁵⁾. As a clue to resolving <challenges of the community> in young carer support, a contact point that can provide comprehensive support across fields is needed, and community-based integrated support centers may be able to function as such a contact point.

As for <challenges related to support systems>, we would also like to emphasize the need for laws and systems to build cross-field support systems like those described for <challenges of the community>. Various other countries have established systems to support young carers. For example, the UK government enacted the Children and Families Act in 2014, allocating a section of Article 96 for young carers to specify their right to support. This act also obliges local authorities to assess the needs of young carers in communities¹⁶⁾, which simultaneously allows these authorities to reach out to children suspected to be young carers. A similar legal framework is also desired in Japan, where community-based integrated support centers can play a leading role in conducting such assessments. The results of analysis in the present study also revealed a strong co-occurrence relationship between the words “support” and “system”, suggesting that establishing support systems is an urgent task in young carer support.

Lastly, regarding <challenges related to collaboration>, some respondents of the questionnaire stated that collaboration between health, medical, and welfare institutions and educational institutions is difficult, but essential. In particular, the strong co-occurrence relationship between the words “collaboration” and “educational institutions” highlights the necessity of collaboration between educational and other fields. The Manual for Young Carer Support through Multi-institutional and Interprofessional Collaboration, created by the Ministry of Health, Labour, and Welfare, also illustrates the need for collaboration among educational, elderly welfare, child welfare, disability welfare, medical, and other health/welfare fields, with a focus on young carers and their families¹⁷⁾. In addition, a previous study on collaboration among supporters for comprehensive carer support has been reported [information aggregation (formal and informal)] and [role division and common understanding] as factors that promote collaboration¹⁸⁾. Thus, community-based integrated support centers are also expected to fulfill their role as a hub for information summaries related to formal and informal young carer support and for the role as division and common understanding in collaboration among related institutions.

In short, the results of the present study indicated the necessity of organizing support systems that enable the identification of young carers through the establishment of laws and systems, and promoting collaboration between the

community and health, medical, welfare, and education fields to support young carers in communities. Community-based integrated support centers are expected to play a pivotal role as a base for facilitating such collaboration.

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