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博士論文

Current situation and challenges regarding the social participation of Syrian refugees with disabilities in urban areas of Jordan

（ヨルダン都市部在住の難民障害者の社会参加についての現状と課題）

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Introduction

The conflict in the Syrian Arab Republic has been ongoing since 2011. Since the war broke out, many Syrians have evacuated abroad as refugees. As of January 2015, more than 4.9 million Syrians were registered as refugees in Syria's neighboring countries—Jordan, Lebanon, Iraq, and Egypt [1,2]—with the number in Jordan totaling 635,324. Approximately 78% of Syrian refugees in Jordan live in urban areas, including the governorates of Amman [3], Irbid and Mafraq. In recent years, the number of refugees in urban areas has been increasing [2]. It is reported that many Syrian refugees in urban areas have difficulty accessing health care services due to the rapid increase in the population and insufficient social resources [4]. According to an investigation by Handicap International, 22% of refugees registered with the United Nations High Commissioner for Refugees (UNHCR) have some kind of functional disorder, while 6% have severe functional disorders [5]. These Syrian refugees with disabilities (person with disabilities, or PWDs) are in a vulnerable social position [6]. They need not only basic support, such as housing, livelihoods, food and human rights, but also specific support such as rehabilitation services and the provision of orthoses [5].

Community-based organizations (CBOs) in urban areas carry out support programs for Syrian refugees with disabilities in cooperation with the Jordanian government and international agencies [7]. In those organizations and agencies, occupational therapists work in support program for Syrian refugees with disabilities in urban area. However, there are no studies demonstrating whether these programs comply with the needs of PWDs and their families, and promote their health and social participation. Therefore, we conducted the present study to identify the health conditions of PWDs and the situations of their and their families' social participation through semi-structured interviews. Furthermore, we analyzed the results using a community-based rehabilitation (CBR) matrix on the themes of the PWDs' health conditions and social participation [8]. The purpose of the present study was to clarify challenges of provision of support by health professional including occupational therapist for Syrian refugee with disabilities and their families.

Methods

1. Participants

The subjects of the study were Syrian refugees with disabilities (PWDs) and their families in the governorates of Amman and Irbid in Jordan. Twenty-five participants were chosen randomly for this study from a list of Syrian refugee with disabilities, which was provided by the nongovernmental organization Mobility Solution. We explained that the study would comprise recorded interviews, followed by analysis of the interview data. We received letters of consent and acceptance from 12 participants, and conducted the study interviews with them.

2. Questionnaire and Interview

This study involved the use of a questionnaire and a recorded semi-structured interview in Arabic. The interview was conducted with each participant individually between August 2014 and December 2016. The questionnaire inquired about the name, sex, age, diagnosis, transfer status, duration of stay in Jordan, refugee status, and income of the PWDs and his/her family members. The semi-structured interview was conducted with an interview guide. The interview covered the health condition of the PWD ("Has your health condition changed between living in Syria and Jordan?"); his/her relationships with members of the community ("Do you have any relationships or support from members of the community?"); recognition of the disability by the PWDs and his/her family members ("What do you need regarding your disability?"); current difficulties faced by the PWDs and his/her family members ("Do you face any difficulties in your daily life?"); knowledge and recognition of the type of support available from the host community by the PWDs and his/her family members ("Do you know of any assistance programs provided by the Jordanian government or NGOs?"); and the needs of the PWDs and his/her family members ("What kind of support do you expect from the Jordanian government and NGOs?") (Table 1). The interviews were recorded by IC recorder.

Table1. Interview guide to Syrian refugee with disabilities (Person With Disabilities: PWDs) and their family

Topics	Question
Health condition of the PWDs	"Has your health condition changed between living in Syria and Jordan?"
His/her relationship with the community	"Do you have any relationships or support of the community?"
Recognition of the disability by the PWDs and his/her family members	"What do you need regarding your disability?"
Current difficulties faced by the PWDs and his/her family member	"Do you face any difficulties in your daily life?"
Knowledge and recognition of the type of support available from the host community by the PWDs and his/her family members	"Do you know of any assistance programs provided by the Jordanian government or NGOs?"
the needs of the PWD and his/her family members	"What kind of support do you expect from the Jordanian government and NGOs?"

3. Data Analysis

The interview data were then analyzed. The analysis was conducted by three researchers familiar with the international health field, and comprised the following two phases. First, the researchers listened to the interview data and transcribed the contents. For the language bias, we conducted back-translation. The transcriptions were then coded to identify elements of each participant's comments about health and social participation. The codes were sorted into sub-categories and categories, and the relevance of each category was analyzed. The codes were then classified into components of the CBR matrix (Fig. 1)[8]. Then, we analyzed the tendencies and challenges of the social participation of the Syrian refugees with disabilities and their families.

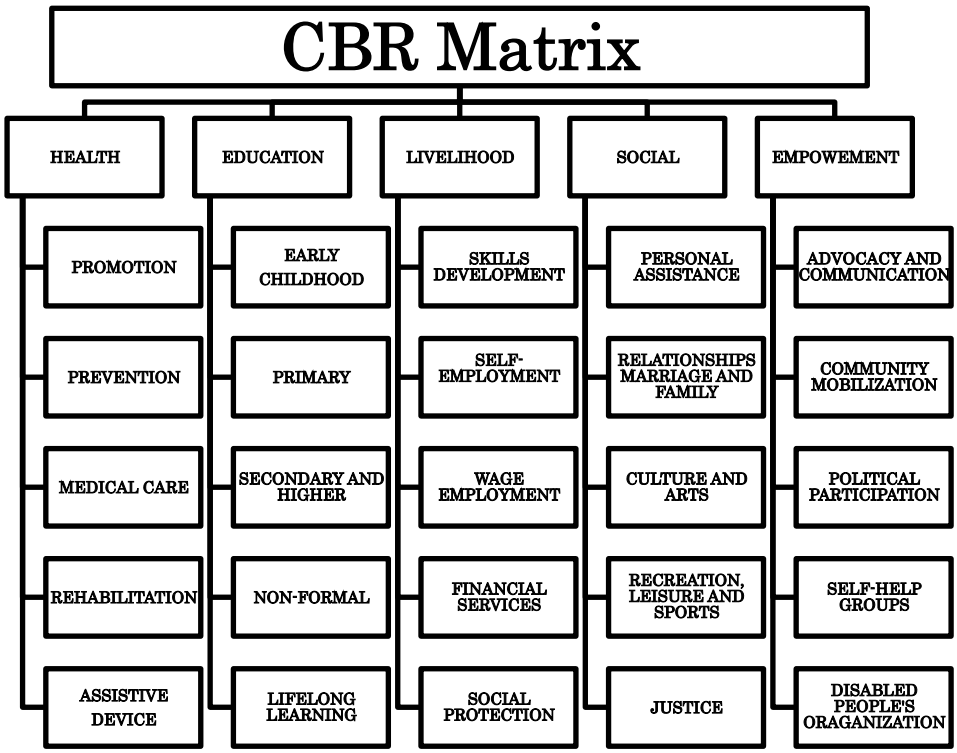

Fig. 1. Community-Based Rehabilitation Matrix (WHO 2010)

4. Ethical Considerations

The study carried out the research with the approval (Number 309) of the Kobe University Ethical Committee.

Results

1. Characteristics of Participants

There were 12 participants, all male. Amount of interview time was 301 minutes. Median of interview time and SD were 24±5.9 minutes. Their mean age was 20.5 ± 12.9 years (range: 15–56 years), and their mean duration of stay was 1.7 ± 0.4 years. All of the participating PWDs had physical disorders. Five of the participants had dependence in transferring motion and seven of the participants had independence in transferring motion. All the participants were registered as refugees by the UNHCR. Two of the PWDs' families had incomes, while 10 families did not have incomes (Table 2).

Table 2. Profile Characteristics of Participants(21.Aug.2014~28.Dec.2016)

No	Gender	Age	Diagnosis	Status of transfer	Duration of stay(year)	Registration	Interviewees	Income	Interview time
1	M	20	Spinal Cord Injury	Dependence	1.4	UNHCR	Brother	Employment(Father)	27min
2	M	21	Spinal Cord Injury	Independence(W/C)	1.5	UNHCR	PWDs	None	20min
3	M	56	Head Injuary	Dependence	1.9	UHNCR	Brother	None	21min
4	M	37	Cerebrovascular Disease	Dependence	2.1	UNHCR	Brother	None	33min
5	M	13	Spinal Cord Injury	Dependence	2	UNHCR	Father	Employment(Father)	19min
6	M	39	Spinal Cord Injury	Independence(W/C)	2.4	UNHCR	PWDs	None	29min
7	M	18	Peripheral Nerve Disorder	Independence	1.4	UNHCR	PWDs	None	37min
8	M	20	Peripheral Nerve Disorder	Independence	1.3	UNHCR	PWDs	None	22min
9	M	33	Cerebrovascular Disease	Independence	2.3	UNHCR	PWDs	None	30min
10	M	19	Spinal Cord Injury	Dependence	2.2	UNHCR	PWDs	None	19min
11	M	15	Peripheral Nerve Disorder	Independence	1.2	UNHCR	PWDs	None	18min
12	M	43	Peripheral Nerve Disorder	Independence	0.7	UNHCR	PWDs	None	26min

2. Health conditions and social participation

A total of 621 codes relating to the health conditions and social participation of the subjects were extracted from the transcriptions. From the codes, 10 sub-categories and 5 categories were classified along with the "current situation of social participation of the Syrian refugees with disabilities and their families in urban areas" (Table 3). Then, the categories, subcategories, codes, and personal narratives were described as 【category】, [subcategory], and 『personal narrative』, respectively.

Table 3. Current situation about social participation of Syrian refugee with disabilities and their family member in urban area

Sub-category【10】	Category【5】
Difficulty in receiving medical treatment in Syria Difficulty in receiving health care services in Jordan	Lack of health care for PWDs in urban areas
Lack of recognition of disorders among PWDs and their family members Lack of information about health care services among PWDs and their family members	Insufficient health literacy of PWDs and their family members
Vulnerable position of Syrian refugees Limitation of PWDs' activities due to their physical disabilities	Restriction of social participation of PWDs and their family members
Deterioration of health condition High risk of disuse syndrome	Spreading of disuse syndrome
Long time required for nursing care Variety of nursing care	Care burden on family members

The category 【Lack of health care for PWDs in urban areas】 comprised two sub-categories: ［Difficulty in receiving medical treatment in Syria］ and ［Difficulty in receiving health care services in Jordan］. One family member of a PWDs talked about ［Difficulty in receiving medical treatment in Syria］ as follows: *『Our hospital in Syria was destroyed by bombing, so nobody can get treatment even if they're injured. There are no doctors, so it's impossible to have an operation』*. One family member of a PWDs talked about［Difficulty in receiving health care services in Jordan］ as follows: *『My son was able to have an operation in Jordan, but he couldn't receive rehabilitation treatment at the hospital. He could have rehabilitation at a private hospital, but we can't afford the medical fees』*.

The category 【Insufficient health literacy of PWDs and their family members】 comprised two sub-categories: ［Lack of recognition of disorders among PWDs and their family members］ and ［Lack of information about health care services among PWDs and their family members］. One family member of a PWDs talked about［Lack of recognition about disorders among PWDs and their family members］ as follows: *『The doctor said that rehabilitation would be necessary after discharge from the hospital. But we don't know what we should do』*. One family member of a PWDs talked about［Lack of information about health care services among PWDs and their family members］as follows: *『Actually there is little information available. Especially I'm in a country that I don't know anything about. I can't go anywhere.』*

The category 【Restriction of social participation of PWDs and their family members】 comprised two sub-categories: ［Vulnerable position of Syrian refugees］, ［Limitation of PWDs' activities due to their physical disabilities］. One family member of a PWDs talked about the ［Vulnerable position of Syrian refugees］ as follows: *『We have limitations in many areas including work and education, because I can't work and*

I can't pay my house rent.』. One PWDs talked about ［Limitation of PWDs' activities due to their physical disabilities］as follows: 『*I can't even go outside, because I have a disabled foot*』.

The category 【Spreading of disuse syndrome】 comprised two sub-categories: ［Deterioration of health condition］ and ［High risk of disuse syndrome］. One family member of a PWDs talked about ［Deterioration of health condition］ as follows: 『*The wounds (bed sores) on my son's body are hard to cure*』 and 『*He has stiff joints (contracture)*』. One PWDs talked about the ［High risk of disuse syndrome］as follows: 『*I spend most of my time in bed. I can't look after myself, so I need support from my family*』.

The category 【Care burden on family members】 comprised two sub-categories: ［Long time required for nursing care］ and ［Variety of nursing care］. One family member of a PWDs talked about the ［Long time required for nursing care］as follows: 『*We have to attend to his nursing care 24 hours a day. It's very hard…*』. One family member of a PWDs talked about the ［Variety of nursing care］as follows: 『*Because my son can't look after himself, I need to help him go to the toilet, change his clothes, and so on. Of course, if he goes outside, we have to support him.*』

3. Evaluation of health conditions and social participation using the CBR matrix

We classified the codes in this study into components of the CBR matrix (Health, Education, Livelihood, Social and Empowerment). Some 444 codes were thus classified. Of these, 160 codes were classified into the component "Health" (seven codes under "Promotion," two codes under "Prevention," 56 codes under "Medical care," 60 codes under "Rehabilitation," and 35 codes under "Assistive devices"); 25 codes were classified into the component "Education" (14 codes under "Early childhood," 11 codes under "Primary education," zero codes under "Secondary and higher education," zero codes under "Non-formal education," and zero codes under "Lifelong learning"); 119 codes were classified into the component "Livelihood" (zero codes under "Skills development," nine codes under "Self-employment," 36 codes under "Wage employment," 39 codes under "Financial services," and 35 codes under "Social protection"); 105 codes were classified into the component "Social" (66 codes under "Personal assistance"; 35 codes under "Relationships, marriage and family"; zero codes under "Culture, arts and recreation"; zero codes under "Leisure and support"; and four codes under "Justice"); and 35 codes were classified into the component

"Empowerment" (29 codes under "Advocacy and communication," zero codes under "Community mobilization," six codes under "Political participation," zero codes under "Self-help groups," and zero codes under "Disabled people's organization") (Table 4). Then, the components of the CBR matrix and the personal narratives were described as "components of the CBR matrix" and 『personal narratives』.

Within the component of "Health," one PWDs talked about "Promotion" as follows: *『I started to suffer bad health after I came to Jordan』*. One PWDs talked about "Prevention" as follows: *『I don't know how I can prevent health impairment』*. One PWDs talked about "Medical care" as follows: *『We can't get check-ups at the hospital, because we have no money』*. One PWDs talked about "Rehabilitation" as follows: *『We don't have any opportunity to receive rehabilitation』*. One PWDs talked about "Assistive device" as follows: *『There are no wheelchairs for going outside』*.

Within the component of "Education," one family member of a PWDs talked about "Early childhood" as follows: *『I haven't let my child go to school since we came to Jordan』*. One PWDs talked about "Primary education" as follows: *『I can't go to school because I can't walk』*.

Within the component of "Livelihood," one PWDs talked about "Self-employment" as follows: *『Refugees can't work in Jordan』*. One PWDs talked about "Wage employment" as follows: *『We need to get permission in order to work』*. One family member of a PWDs talked about "Financial services" as follows: *『There are no organizations that lend money』*. One PWDs talked about "Social protection" as follows: *『The social situation of refugees is vulnerable』*.

Within the component of "Social," one PWDs talked about "Personal assistance" as follows: *『There aren't many caregivers in our family』*. One PWDs talked about "Relationships, marriage and family" as follows: *『We don't have much interaction with members of the community』*. One PWDs talked about "Justice" as follows: *『There is little information about the rights of persons with disabilities』*.

Within the component of "Empowerment," one PWDs talked about "Advocacy and communication" as follows: *『I don't know who I should tell about my difficulties』*. One PWDs talked about "political participation" as follows: *『There are no opportunities to take part in politics』*.

table 4. Cord classification of CBR Matrix component

compornents	elements	code	original data
health(160)	promotion	7	I started to suffer bad health after I came to Jordan
	prevention	2	I don't know how I can prevent health impairment
	medical care	56	We can't get check-ups at the hospital, because we have no money
	rehabilitation	60	We don't have any opportunity to receive rehabilitation
	assistive devices	35	There are no wheelchairs for going outside
education(25)	early childhood	14	I haven't let my child go to school since we came to Jordan
	primary	11	I can't go to school because I can't walk
	secondary and higher	0	
	non-formal	0	
	lifelong learning	0	
livelihood(119)	skils development	0	
	self-employment	9	Refugee can't work in Jordan
	wage employment	36	We need to get permission in order to work
	financial services	39	There are no organizations that lend money
	social protection	35	The social situation of refugees is vulnerable
social(105)	personal assistance	66	There aren't many caregivers in our family
	relationships marriage and family	35	We don't have much interaction with members of the community
	culture and arts	0	
	recreation, leisure and sports	0	
	justice	4	There is little information about the rights of persons with disabilities
empowerment(35)	advocacy and communication	29	I don't know who I should tell about my difficulties
	community mobilization	0	
	political participation	6	There are no opportunities to take part in politics
	self-help groups	0	
	disabled people's organization	0	
total		444	

Discussion

The study identified that the social participation of Syrian refugees with disabilities (PWDs: persons with disabilities) and their families in urban area is often restricted. The findings suggested that insufficient health care services and health literacy, disuse syndrome, and burdens of nursing care might be correlated to the level of social participation of PWDs and their families.

In general, governments normally guarantee the basic human rights and physical security of citizens. However, in the case of refugees, this safety net often disappears [9]. Almost all Syrian refugees are in a vulnerable position in terms of social participation, for example, with regard to health care access, education, and livelihood. In particular, persons with disabilities face disproportionate risks in disaster situations such as the Syrian conflict and are often excluded from relief and rehabilitation processes [10]. Furthermore, PWDs face limitations to their activities due to their physical disabilities.

Nearly six years of conflict in Syria have resulted in the destruction of countless livelihoods and health care services [11]. Therefore, there are more than 4.9 million Syrians who have migrated to Syria's neighbors as refugees, as of January 2017. In Jordan, host communities and humanitarian organizations are grappling with the challenge of accommodating significant numbers of Syrian refugees over the long term [12]. Furthermore, many of the participants had difficulties accessing health care services due to the lack of medical care providers, the need for transportation to medical institutions, and the medical expenses required. It was considered that these factors might lead to a lack of health care for PWDs in urban areas.

Some of the participants had incorrect understandings of their disorders, and lacked information on health care services. These situations may be based on a lack of information on social resources in residential areas, such as how to access health care services and how to apply for them. Insufficient orientation by medical providers about rehabilitation, nursing care and prevention relating to their disorders may be contributing factors to the insufficiency of health literacy among PWDs and their families.

Lack of health care and insufficient health literacy are connected with the spread of disuse syndrome. Some of the participants presented disuse syndrome in the form of joint contracture, muscular atrophy, or bedsores. Almost none of the participants had information on disuse syndrome and approaches to its treatment and prevention.

Furthermore, as almost all the PWDs had physical disabilities and needed support for transportation, they tended to spend their daily lives at home. These factors may have contributed to the deterioration of their health conditions and the high risk of disuse syndrome. Almost all the participating PWDs needed support from their families in basic daily activities such as eating, washing, going to the toilet, grooming, and transportation. Therefore, family members of PWDs must be able to provide a variety of nursing care for a long period of time. Subsequently, some family members had difficulties accessing social resources or employment due to their engagement in nursing care.

This study indicated that each category had some degree of relevance. PWDs and their family members may face restrictions in social participation due to their vulnerable positions as refugees and also limitations to their activities due to their physical disabilities. Such restrictions might result in difficulties in gathering information on health care or accessing health care services. The insufficient health literacy and lack of health care of PWDs might result in the spread of disuse syndrome. The deterioration of PWDs' health conditions and the onset of disuse syndrome might in turn increase the care burden on their family members. Disuse syndrome among PWDs and the increasing care burden they require from their family members are thus linked to the restrictions on the social participation of PWDs and their family members (Fig. 2).

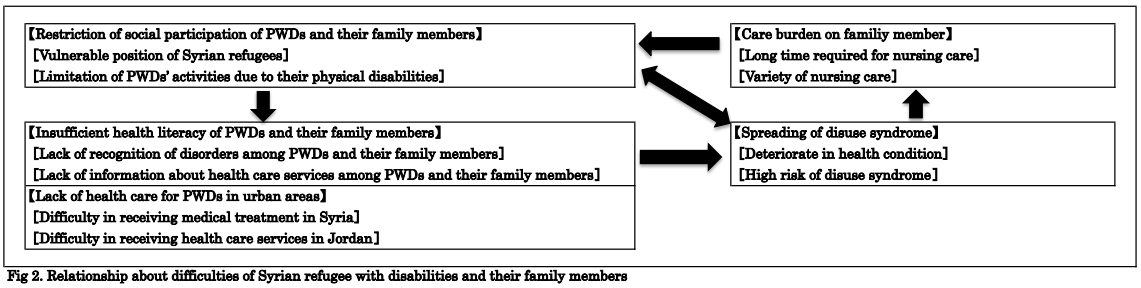

Fig 2. Relationship about difficulties of Syrian refugee with disabilities and their family members

We elucidated our study on the social participation of PWDs using a community based rehabilitation (CBR) matrix [8]. PWDs and their family members had difficulties in terms of education and livelihood, just like refugees in normal health. Furthermore, they had little recognition of the prevention of disuse syndrome and health promotion, difficulties in receiving personal assistance, and lack of empowerment. From the results of the evaluation using the CBR matrix, it can be suggested that health professionals need to guide preventive measures and the promotion of health among PWDs, and cooperate with them in their empowerment.

Our study was limited by the small size of the sample. The recruitment of subjects for the study was difficult, because the participants were afraid to have their social status revealed. However, this was the first time for a study to be conducted on the current situations of the health and social participation of Syrian refugees with disabilities and their family members in urban areas.

Conclusions

Our current study concluded that Syrian refugees with disabilities presented disuse syndrome related to their health conditions, and that they and their family members faced restrictions in terms of social participation. Furthermore, it was indicated that the PWDs' insufficient health literacy, lack of health care services, disuse syndrome, vulnerable positions as refugees, limitations on activities due to physical disabilities, and care burden on their families might be related to the restrictions in social participation that they experienced. It is essential that health professionals including occupational therapists provide knowledge and health services concerning the prevention of disuse syndrome and support for the empowerment of Syrian refugees with disabilities.

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