RESEARCH REPORT

HEALTHCARE NEEDS AND BARRIERS OF PERSONS WITH DISABILITIES:

AN EXPLORATORY STUDY AMONG SYRIAN REFUGEES, PALESTINE REFUGEES FROM SYRIA, AND LEBANESE

Maysa Baroud
Ola Mouheildine

annd
Arab NGO Network for Development
شبكة المنظمات العربية غير الحكومية للتنمية

AUB POLICY INSTITUTE

Issam Fares Institute for Public Policy and International Affairs

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Maysa Baroud
Project Coordinator, Refugee Research and Policy Program, Issam Fares Institute for Public Policy and International Affairs, American University of Beirut

Ola Mouheildine
Project Coordinator, Arab NGO Network for Development

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RESEARCH TEAM

Maysa Baroud, Project Coordinator, Refugee Research and Policy Program, Issam Fares Institute for Public Policy and International Affairs, American University of Beirut

Ola Mouheildine, Project Coordinator, Arab NGO Network for Development

Widyan Al Shaar, Researcher, Refugee Research and Policy Program, Issam Fares Institute for Public Policy and International Affairs, American University of Beirut

Amira Hassan, Group Leader, Informal Group of Persons with Disabilities in Baalbek

Khaled El-Tawil, Group Leader, Informal Group of Persons with Disabilities in Abou Samra, Tripoli

Lina Bakir, Group Leader, Informal Group of Persons with Disabilities in Baddawi, Akkar

Walid Badawi, Group Leader, Informal Group of Persons with Disabilities in Riyaa', Bekaa

EXPERT PANEL

Fayez Okasha, Activist, Advisor and Trainer on the Rights of Persons with Disabilities, and Group Leader, Informal Group of Persons with Disabilities in Bar Elias, Bekaa

Nasser Yassin, PhD, Director of Research, Issam Fares Institute for Public Policy and International Affairs, American University of Beirut, and Assistant Professor of Policy and Planning, Faculty of Health Sciences, American University of Beirut

Toufic Rizkallah, Assistant Director, Programs for Lebanon at World Rehabilitation Fund

Yara Mourad, MPH, Program Manager, Refugee Research and Policy Program, Issam Fares Institute for Public Policy and International Affairs, American University of Beirut

Zahra Bazzi, Programs Manager, Arab NGO Network for Development

Ziad Abdelsamad, Executive Director, Arab NGO Network for Development

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ABSTRACT

Persons with disabilities (PwDs) have special healthcare needs and face a number of barriers to accessing healthcare. In Lebanon, they are among the most marginalized and vulnerable groups, and their needs, including their healthcare needs, are seldom met. In light of the Syrian refugee crisis and the impact it has had on Lebanon, PwDs are at a greater risk of being excluded from public services including healthcare services. Furthermore, there is little data available on the healthcare needs of PwDs in Lebanon and on the barriers they face when accessing healthcare services. This research report discusses the findings of an exploratory study which aimed to characterize the healthcare needs of PwDs and injuries in Lebanon and to assess the barriers they face to accessing healthcare. The research study was participatory in nature and was conducted in partnership with five informal, not-for-profit, unregistered groups of PwDs and injuries based in the Bekaa and North Lebanon governorates. A mixed methods approach was employed comprised of both quantitative and qualitative research tools for PwDs and injuries and healthcare service providers. Study participants included 82.7% Syrian refugees, 6.5% Palestine Refugees from Syria (PRS), and 10.7% Lebanese PwDs and injuries. The study shed a light on the healthcare needs of Syrian refugees, Palestine Refugees from Syria (PRS), and Lebanese PwDs from the Bekaa and North Lebanon governorates, and on the barriers they face to accessing healthcare and visiting healthcare centers in Lebanon. It also identified protection issues that they face when accessing healthcare and the coping strategies they turn to when they are not able to obtain the services they need. The study showed that the two most commonly cited needs among PwDs were permanent medications and medical consultations, while the two most commonly cited barriers were financial ability and limited specialized services for persons with disabilities. The report concludes with a number of recommendations based on the study findings.

LIST OF ACRONYMS AND ABBREVIATIONS

ANND	Arab NGO Network for Development
CRPD	Convention on the Rights of Persons with Disabilities
FGD	Focus group discussion
ICF	International Classification of Functioning, Disability and Health
MoPH	Ministry of Public Health
MoSA	Ministry of Social Affairs
NCDA	National Council for Disability Affairs
NGO	Non-governmental organization
PHC	Primary healthcare
PRS	Palestine Refugee from Syria
PwD	Person with disability
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Emergency Fund
UNRWA	United Nations Relief and Works Agency
WFP	World Food Programme
WHO	World Health Organization
VASyr	Vulnerability Assessment of Syrian Refugees in Lebanon

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INTRODUCTION

Since the onset of the war in Syria in 2011, over a million refugees have fled to Lebanon. The Government of Lebanon estimates that 1.5 million Syrian refugees and 34,000 Palestine Refugees from Syria (PRS) are residing across Lebanon today, the majority of which are children and youth up to the age of 17, and women (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018; UNHCR, 2018). At almost 1 in 4, this is the highest number of refugees per capita in the world. The Lebanese government has adopted a 'no-camp policy' (UN Habitat, Issam Fares Institute for Public Policy and International Affairs, 2015), and so, almost 87% of refugees live in 251 of the most vulnerable and poorest localities in Lebanon, in urban and rural settings, in Palestinian refugee camps, and in informal tented settlements (Atkis Strategy, 2016; United Nations Development Programme, 2017). This large influx of refugees has increased pressure on Lebanon's public institutions and already weak infrastructure. In addition, public services, including those provided by the public health sector, are overstrained (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018). The crisis has had the strongest impact on the most marginalized and vulnerable groups, including on persons with disabilities (PwDs) (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2014; Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018; United Nations High Commissioner for Refugees, United Nations Children's Emergency Fund, World Food Programme, 2017).

The United Nations High Commissioner for Refugees (UNHCR) has no specific classification mechanism for identifying refugees with disabilities, and so the total number of Syrian refugees with disabilities residing in Lebanon is unknown. Based on a national-level representative survey conducted in 2017, an estimated 14% of surveyed Syrian refugee households reported that they had at least one member with a disability, of which 5.7% were children or youth up to the age of 24 (United Nations High Commissioner for Refugees, United Nations Children's Emergency Fund, World Food Programme, 2017), while approximately 10% of PRS households reported having at least one member with a disability (Abdulrahim, Harb, & UNRWA, 2015). Regarding the distribution of Syrian refugee households with a member with a disability at the governorate level, 5.0% were living in North Lebanon, 4.1% in Akkar, 2.7% in Bekaa, and 2.9% in Baalbek-Hermel (United Nations High Commissioner for Refugees, United Nations Children's Emergency Fund, World Food Programme, 2017). Among Lebanese, an estimated 10% of the population or close to 400,000 individuals, live with a disability (Lebanese Civil Society's Coalition, 2015). Refugees with disabilities and injuries, as well as host community members with disabilities, are particularly prone to marginalization, discrimination, and exclusion, and within this group, children and youth with disabilities are more likely to face protection issues and social isolation (United Nations High Commissioner for Refugees, United Nations Children's Emergency Fund, World Food Programme, 2017).

The Convention on the Rights of Persons with Disabilities (CRPD) stipulates that States party to the Convention should "recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" (United Nations, 2006). Further to this, States party to the convention "shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation" (United Nations, 2006). Lebanon is a signatory of both the CRPD and its Optional Protocol but has not ratified either (United Nations Department of Field Support Geospatial Information Section, 2016). As such, PwDs are among the most marginalized and vulnerable groups in Lebanon and their needs are seldom met. Lebanon lacks national-level targeted interventions for PwDs, and there is a dearth of data available on PwDs and the barriers they face to accessing services. In an emergency context like the one Lebanon is currently facing, PwDs are at a greater risk of being excluded from public services including healthcare services. Though a number of Lebanese ministries and humanitarian agencies provide healthcare services for PwDs in Lebanon, PwDs still face several barriers to accessing healthcare in Lebanon. As such, this study set out to:

- Assess the healthcare needs of Lebanese an drefugees with disabilities and injuries in Lebanon
- Determine the barriers to healthcare access faced by Lebanese and refugees with disabilities and

injuries in Lebanon

- Identify the protection issues that Lebanese and refugees with disabilities and injuries face when accessing healthcare in Lebanon

PwDs, or households who have a member with a disability, are more likely to live in poverty as a result of additional costs related to their condition, such as for healthcare (Braithwaite & Mont, 2009; Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018; Mont & Cuong, 2011). Furthermore, studies have shown that PwDs, among other vulnerable groups, face more difficulties than persons without a disability do when accessing healthcare, and that these difficulties are due to socioeconomic status rather than to the disability itself (Trani, Bakhshi, Noor, Lopez, & Mashkoor, 2010; Trani et al., 2011). Multiple barriers reduce access to healthcare by PwDs, including costs of care, lack of trained personnel and healthcare providers, negative or bad attitudes of healthcare providers, lack of specialized services, inadequate drugs or equipment, physical accessibility of the healt hcare facilities, direct exclusion, lack of transportation, distance from healthcare facilities, and poor quality of services (Chalah et al., 2016; Eide et al., 2015; UNESCO, 2013; Van Rooy et al., 2012; World Health Organization, 2011). Due to their increased likelihood of being exploited, discriminated against, being exposed to violence and abuse (domestic and sexual), and to being excluded from services, persons with disabilities require additional protection, especially in an emergency context (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018; UNHCR, 2011; United Nations High Commissioner for Refugees, United Nations Children's Emergency Fund, World Food Programme, 2017).

Refugees and asylum seekers report facing additional barriers when accessing healthcare in a host country, including mistrust of healthcare providers, perceived (in)effectiveness of healthcare services, cultural and language barriers, inadequate insurance coverage, lack of knowledge about services available, and discrimination by health professionals (Hadgkiss & Renzaho, 2014; Vermette, Shetgiri, Al Zuheiri, & Flores, 2015). Among refugees with disabilities the complexity of service systems in the host country also acted as a barrier to healthcare access (Fellin, King, Esses, Lindsay, & Klassen, 2013; Mirza et al., 2014). It is noteworthy to mention that the latter studies were conducted in the West. A study conducted among refugees with disabilities in a camp setting in Jordan found that lack of specialized services, scarcity of local healthcare options in the host country, and the bureaucracy involved with requesting specialized care, all acted as barriers to accessing healthcare for refugees with disabilities. In addition, and as per service providers interviewed in the same study, the shortage of resources available for the humanitarian response also acted as a major barrier (Mirza, 2017).

THE LEBANESE HEALTHCARE CONTEXT

As per the Lebanese law 220/2000 on the Rights of Disabled Persons, PwDs can register for a disability identification card, provided by the Ministry of Social Affairs (MoSA), so long as they meet the definition[1] for disability proposed by the law (Republic of Lebanon, 2000). Though the law does not explicitly specify that a PwD has to be Lebanese to obtain a disability identification card, Lebanese authorities only issue cards to Lebanese (Lebanese Civil Society's Coalition, 2015). In principle, cardholders have access to almost all healthcare services to be covered in full by relevant Ministries, including at the primary and secondary levels, and rehabilitation services. Up to May 2015, only 90,583 Lebanese PwDs had been issued an identification card, and reports show that even with the card, PwDs are denied care by multiple organizations who cite late reimbursements by Ministries as the main reason for this denial (Raef & El-Husseini, 2015; UNESCO, 2013). Other reasons for a lack of cooperation of healthcare organizations include limited financial allocation by the relevant ministries to these organizations, and to the lack of clarity concerning the extent of coverage (UNESCO, 2013).

Vulnerable Lebanese and both registered and unregistered Syrian refugees, including those with disabilities, can access primary healthcare (PHC) services at a nominal fee. PHC is available through the Ministry of Public Health's (MoPH) network of PHC Centers (n=208) and through PHC facilities and dispensaries run by non-governmental organizations (NGO) and the MoSA, respectively (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018). A large number of the PHC centers within the MoPH network provide routine vaccinations, medications for acute conditions, and reproductive supplies to Syrian refugees for free, and just under half of the MoPH centers (n=101) subsidize certain PHC services, such as consultations, for refugees and vulnerable Lebanese. In addition, mobile medical units provide PHC services to refugees living in several informal settlements and in distant rural areas. PRS access PHC free of any charges through United Nations Relief and Works Agency (UNRWA) Health Clinics (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018).

Hospital care for Syrian refugees is available through a network of 50 hospitals and secondary care facilities. Coverage is limited to subsidized obstetrics and life-threatening care, in which case the UNHCR covers between 75-90% of the hospital fees, based on household vulnerability. Some organizations provide support for other types of services, including surgical services for cleft lip and palate, clubfeet, and reconstructive surgery for burns. In terms of services provided to PwDs in particular, laboratory tests are subsidized and a number of NGOs provide specialized services for refugees with disabilities, such as physical therapy, and prosthetic and orthotic devices, hearing aids, and eyeglasses, as part of rehabilitative support (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018). PRS have access to secondary and tertiary care through UNRWA. For secondary care, they are covered fully at Palestine Red Crescent Society hospitals, and up to 90% at public or private hospitals. For tertiary care, PRS are covered up to 60%, with a ceiling of USD5000 per service (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018).

Still, many beneficiaries face difficulties covering their share of the cost of services (10-25%) due to their financial ability, and find themselves borrowing money to cover their healthcare costs (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018). Cost is also a barrier to accessing healthcare among Lebanese, and has been reported as a barrier, particularly among Lebanese youth with a disability (UNESCO, 2013). Previous studies conducted among refugees registered with the UNHCR in Lebanon found that inability to pay fees was the most common reported barrier to accessing healthcare among those suffering from acute or chronic conditions (Johns Hopkins University Bloomberg School of Public Health & Médicins du Monde, 2015; UNHCR, 2017). Refugees also

1 The law 220/2000 defines a PwD as any "person whose capacity to perform one or more vital functions, independently secure his personal existential needs, participate in social activities on an equal basis with others, and live a personal and social life that is normal by existing social standards, is reduced or non-existent because of a partial or complete, permanent or temporary, bodily, sensory or intellectual functional loss or incapacity, that is the outcome of a congenital or acquired illness or from a pathological condition that has been prolonged beyond normal medical expectations" (Republic of Lebanon, 2000). This definition of disability in law 220/2000 is based on a person's medical condition, and fails to acknowledge social and legal barriers which stand in the way of PwDs living normally (UNESCO, 2013).

reported high out of pocket payments for visits to private clinics, for non-generic medications, and for hospitalizations, and that in some cases the high costs for the latter services acted as barriers to their access (Johns Hopkins University Bloomberg School of Public Health & Médicins du Monde, 2015). Furthermore, there was a lack of knowledge among a large number of survey respondents regarding the healthcare services available to them (UNHCR, 2017). It has also been noted that a large number of the MoPH PHC centers are not accessible to those with a physical disability. At the national level, there is a limited number of specialized professionals and service providers. Moreover, the high demand for services has placed a heavy burden on healthcare organizations in Lebanon in terms of infrastructure and financial sustainability, with the public health sector accumulating debt because of persons unable to cover their share of healthcare costs (Government of Lebanon, UN Resident and Humanitarian Coordinator for Lebanon, 2018).

Though cost is a major barrier to accessing healthcare among Syrian refugees in Lebanon, refugees also face other barriers to accessing healthcare. These include registration status, transportation difficulties, long distances to healthcare centers, short working hours at centers, availability of trained personnel, inadequate provider equipment, unavailability of drugs, and long waiting times (Calvot & Merat, 2014; Johns Hopkins University Bloomberg School of Public Health & Médicins du Monde, 2015; UNHCR, 2014). Among Syrian refugees with disabilities, a needs assessment conducted in the Bekaa in 2012 found that, at the time, a number of those interviewed were in need of assistive devices, sometimes urgently, and that there was a general lack of knowledge about the types of services available to refugees, including about health services (MPDL Movement for Peace, 2012). Further to this, a study conducted in 2013 among Syrian refugees in Lebanon and Jordan, including those with disabilities and injuries, found that participants expressed concerns about access to basic healthcare services and that there was a lack of specialized services, including rehabilitation support, and psychosocial or mental healthcare services, for persons with impairments and injury (Calvot & Merat, 2014). The study also found that the living conditions of families with a member with a specific need were impacted greatly when they were not able to meet their basic needs, such as income, shelter, and healthcare (Calvot & Merat, 2014)

RESEARCH METHODOLOGY AND DESIGN

The present study aimed to characterize the healthcare needs of PwDs and injuries in Lebanon, and to assess the barriers they face to accessing healthcare by using a cross-sectional study and employing a mixed methods approach comprised of both qualitative and quantitative research tools for PwDs and injuries and healthcare service providers. The research was supplemented by workshops with groups of PwDs and injuries, and a roundtable discussion with service providers. A national workshop was also held, which brought together representatives of ministries, local and international NGOs, and persons with disabilities, and which aimed to discuss the outcomes and recommendations of the research project, and to move from these to a more concrete strategic action plan to be used for advocacy purposes. The research study was participatory in nature, and was conducted in partnership with five informal, not-for-profit, unregistered groups of PwDs and injuries based in the Bekaa and North Lebanon governorates of Lebanon. The informal groups were distributed as follows: Baalbek, Bar Elias and Riyaq in Bekaa, Abou Samra, Tripoli in North Lebanon, and Baddawi in Akkar, which also correspond to the study locations.

Study Context and the Participatory Research Process

The research partners in the project had been working as informal groups since 2014, in order to improve the living conditions of PwDs and injuries in their local communities. A few of the groups' members had long been advocates for the rights of PwDs through their work with civil society organizations in Lebanon. In their work for this project, the informal groups were supported by the Arab NGO Network for Development (ANND)[2], which served as a platform for the groups to advocate and raise their voices by leading various activities to build the groups' capacities, including awareness sessions, psychosocial sessions, advocacy workshops, and advocacy campaigns. As part of the work that they were doing with ANND, the groups identified protection, health, and legal as the main sectors in which PwDs, particularly, refugees with disabilities, face challenges while obtaining services. The groups ultimately selected health as the topic for their research project based on their personal experiences and that of members within their communities, and because they felt that this was a sector within which they could have a more tangible and positive impact on their communities.

An inclusive research team was established which included 22 research partners identified from among these informal groups of PwDs. Research partners were involved, to different degrees, in the conceptualization of the project, as well as in all research stages, including in the research design, data collection, analysis, and dissemination stages. The informal groups played an essential role in developing the data collection tools and in collecting data from Lebanese and refugee men, women and children with a range of disabilities and injuries. Their inclusion in the research process aided in the selection of the most adequate research tool for the project, based on their knowledge and experiences, as well as in the development of the actual research questionnaire. The groups were also involved in the development of a research questionnaire for healthcare and services providers working with PwDs, which was developed to validate the findings from the questionnaire on healthcare services for PwDs.

At the onset of the project, all research partners received training on research methodologies, ethical considerations when conducting human subjects' research, consent/assent processes, coding and conducting survey questionnaires, and on developing a research plan. During this training research partners were also introduced to, and discussed the definitions of key terms in the questionnaire, including that of the different disability categories. After the quantitative data collection phase was finalized, research partners received a training on data analysis, whereby they assisted in determining some of the data relationships to be assessed, and learned how to interpret results. During the same workshop, an activity was conducted to identify our research partners' recommendations to improve healthcare access for PwDs and injuries in Lebanon. Furthermore, a small group of the research partners participated in a focus group discussion (FGD), to further explore healthcare needs and barriers they confront to accessing healthcare. Research partners also received training on facilitating discussions, and facilitated different sessions at the initial

2 The Arab NGO Network for Development is a regional network of NGOs, which aims at strengthening the role of civil society, enhancing the values of democracy, respect of human rights, and sustainable development in the region.

dissemination event for the project. A plan on how and when to use the research project outputs was also co-developed with the participants.

Study Tools

A face-to-face questionnaire[3] was designed in partnership with and to be administered by our research partners, which included both closed-ended and open-ended questions. The questionnaire aimed to assess the healthcare needs of PwDs and injuries, as well as the barriers that they confront when accessing healthcare. The questionnaire consisted of five sections. The first section included questions about the participant's socio-demographic characteristics (gender, age, educational level, marital status, employment status, monthly income, expenditure on health, etc.), but also questions about the types of aid they receive, and who they receive this aid from. The second section enquired about the participant's disability, with questions about the type of disability, the cause of disability, and level of performance in daily activities. The third section on healthcare assessed healthcare status, self-reported healthcare needs, access to healthcare services and healthcare centers, barriers to accessing healthcare services, the types of healthcare information received, and the costs of healthcare. The fourth section covered protection issues faced while obtaining healthcare services. The final section was open-ended, and asked participants to share their recommendations for improving access to healthcare for PwDs in Lebanon. The questionnaire on health services for PwDs was developed and administered in modern Arabic. Translation to English and back-translation to Arabic was conducted to ensure accurate translation of the tool. It was piloted with members of the informal groups, and adjusted accordingly. It was reviewed and validated by an expert panel consisting of academics, civil society representatives, and service providers.

A semi-structured FGD guide was developed by the core research team, which aimed to grasp a deeper understanding of some of the informal group members' personal experiences while obtaining healthcare services in Lebanon, and to validate the findings from the questionnaire. FGDs were chosen because they allow for a deeper exploration of individual experiences, take advantage of group interactions, and allow participants to discuss their perceptions and attitudes towards a specific topic, ensuring that their voices are heard (Bryman, 2016; Ward, Nichols, & Freedman, 2010). Furthermore, the open-ended nature of FGDs allows for identification of barriers and challenges specific to the local context. The guide prepared for the discussion included themes from both the literature and the study questionnaire. Translation and back-translation was conducted to ensure accurate translation of the tool. The guide was reviewed and validated by an expert panel consisting of academics, civil society representatives, and service providers. The FGD was conducted in Modern Arabic.

In addition, and in partnership with the informal groups of PwDs and injuries, a self-administered questionnaire was designed for healthcare service providers, which aimed to assess healthcare services provision for PwDs by different establishments. The questionnaire included both closed-ended and open-ended questions, divided into two sections. The first section enquired about the respondent's occupation, their personal experience while providing services to PwDs and injuries, and whether they had received any specialized training in that regard. The second section asked about the types of healthcare services provided for PwDs and injuries at the establishment where the respondent worked, the difficulties faced when providing healthcare services to PwDs and injuries, referrals, follow-ups, barriers to healthcare access among PwDs and injuries, and recommendations for improving access to healthcare for PwDs in Lebanon. The questionnaire for health services providers was administered in modern Arabic or English, based on the participants' preference. Translation and back-translation was conducted to ensure accurate translation of the tool. It was reviewed and validated by an expert panel consisting of academics, civil society representatives, and service providers.

Research Participants and Data Collection

For the questionnaire on healthcare services for PwDs, the study population included all Lebanese, Syrian, and Palestine Refugees from Syria with disabilities or injuries residing in Baalbek, Bar Elias, and Riyaq in Bekaa, and Tripoli and Baddawi in North Lebanon. Purposive and snowballing sampling techniques were used to recruit participants to fill out the questionnaire. Participants were identified from among lists of PwDs and injuries pertaining to the networks established by each one of the informal groups. Participants were also recruited through snowball sampling via participants who knew of other PwDs in the same community.

3 Please contact Maysa Baroud at mb95@aub.edu.lb to obtain a copy of the questionnaire or for any further information.

Participation in the study was completely voluntary, and respecting participants' autonomy was a key component of the consent process. Participants were ensured that their participation in the study would have no negative consequences on them or their families, and that their privacy and confidentiality would be maintained. Written informed consent was obtained from all participants before administrating the paper-based survey. For the healthcare service provider questionnaire, purposive sampling was used to recruit participants, and to ensure diversity of expertise among service providers and the establishments where they work.

Twenty-two research partners, which had received training on obtaining consent and administering questionnaires with closed- and open-ended questions, conducted the data collection. In each location, a group leader, who also attended the training and participated in the data collection, supervised the research partners. A total of 494 questionnaires were filled and returned from all five study locations. Only questionnaires with a signed consent form were included in the analysis. In the situation where a PwD was not able to answer the questionnaire, and for PwDs under the age of 18, their parent or guardian answered the questionnaire. Wherever possible, research partners classified respondent's disability based on physician's diagnosis.

Data Analysis

For the questionnaire on healthcare services for PwDs, descriptive and bivariate analyses (Pearson's Chi-squared test, two-sided test of equality for column proportions) were used to summarize participant characteristics, and to assess healthcare needs, access to healthcare, barriers confronted when accessing healthcare, and protection issues, by participant characteristics, such as nationality, age, or disability type, where relevant. For the healthcare service provider's questionnaire, descriptive analyses were used to assess participant and establishment characteristics. Analysis was conducted using SPSS Statistics 24. A 95% confidence interval and P-value ≤ 0.05 was used for statistical analysis. The FGD was transcribed verbatim and translated into English for the purpose of analysis. A thematic analysis approach was used to synthesize and analyze the data obtained from the FGD, as well as for some of the open-ended questions included in the paper-based questionnaires for PwDs and injuries.

Limitations

Some major limitations of our study should be noted. Due to both time and resource constraints, the majority of interviews were conducted with PwDs from within the networks of our research partners, the informal groups of persons with disabilities. Though this method of purposive sampling may have helped us in reaching individuals who would have otherwise been difficult to reach, the fact that respondents were mostly within the direct network of these informal groups may have introduced a sampling bias, such that PwDs who are not within the groups' networks were less likely to be selected. The latter could also explain the under-representation of Lebanese respondents, and of respondents with mental and/or intellectual disabilities. Furthermore, due to the sampling method selected, our results are not representative of all PwDs in Lebanon. We acknowledge that PwDs are a diverse population (Iezzoni, 2011), and that a single questionnaire covering all types of disabilities may not have captured the issues and barriers faced by the different disability classes. Despite all the latter, findings from our study reflect those from the literature, especially in relation to the barriers faced, and can serve as a starting point for further investigations into the healthcare needs and barriers to healthcare access faced by PwDs in Lebanon. Future studies must target both Lebanese PwDs, and also PwDs with mental and/or intellectual disabilities. Studies should also included PwDs from across Lebanon. It is noteworthy to mention that a study conducted by Handicap International in 2013 found that the highest proportion of refugees with impairments was found in the two governorates covered by our study (Calvot & Merat, 2014). The authors suggest that this could be due to a policy whereby refugees who were arriving to Lebanon with an injury were directed to these areas for initial treatment (Calvot & Merat, 2014).

There appears to have been some confusion in some of the questionnaires with the questions on employment and current monthly income, whereby some of the guardians/parents answered these questions as if they were addressed to them rather than the PwD they were filling out the questionnaire for. For this reason, we assume that current monthly income in this study could refer to the current monthly income of the parent/guardian filling out the questionnaire or the household income, especially in the case of children, or to the current monthly income of the PwDs him/herself. Furthermore, to amend for the confusion with the

question on employment, we only report occupation status for questionnaires that were filled by PwDs themselves, and not those filled by a proxy. There were also some mistakes observed in the filling out of questionnaires by our research partners, which suggest that there was a need for a more thorough training. The latter was not possible due to the time and resource constraints on the project; still, future projects should invest more time for training research partners.

The use of a quantitative method over a qualitative method is a limitation in and of itself. Although participants were given the chance to list the needs they had or barriers they faced other than those in the pre-defined lists in the questionnaires with the "Other" option, very few actually did. For this purpose, a FGD was conducted with some of the research partners and enumerators to validate our research findings. The FGDs provided us with real-life examples of respondent experiences from the field and allowed us a more thorough understanding of the questionnaire results; still, future studies should be accompanied by a qualitative study component to ensure that we are better able to capture context-specific needs and barriers.

Finally, despite clearly explaining to participants that this study was solely for research purposes, and that no aid would be provided for participation, refugees asked about aid a number of times during the interview process. Experience from other projects conducted with refugees suggests that participants are sometimes inclined to answer questionnaires with aid in mind. The latter could have influenced the needs reported by participants, since these were self-reported, as well as may have resulted in the over-selection of certain barriers over the selection of others from the pre-defined list, such as financial ability. Nevertheless, other studies have cited financial ability as a barrier to healthcare access among PwDs (Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Eide et al., 2015) and among Syrian refugees (Ay, Arcos González, & Castro Delgado, 2016). Albeit anecdotal, experience also points to research fatigue among refugees in Lebanon, this too could have biased the way that questionnaires were answered. In the future, further stress should be placed on the research nature of any such study.

RESULTS

Data collection took place over a period of eight weeks, between August and September 2017. A total of 495 questionnaires on healthcare services for PwDs were completed and returned, of which 20 were excluded after data cleaning[4] , resulting in a total number of 475 eligible questionnaires. The majority of participants were Syrian refugees (82.7%), while 6.5% were PRS, and 10.7% were Lebanese[5] . There were 207 participants (44.2%) for whom the questionnaire had to be filled by a proxy respondent, either a parent or a guardian, depending on the person's age and/or disability.

Demographic Characteristics and Healthcare Condition of Study Population

Respondent sociodemographic characteristics are detailed in Table 1 and Table 2. Among Syrian respondents, 60% were male, while among Lebanese and PRS, 68% were male. Regarding age distribution, a significant number of Syrian participants were aged 0-6 (n=56, 15%), while 45% were over the age of 24. As for PRS and Lebanese respondents, the majority were adults, with 61% of PRS over the age of 24, and 59% of Lebanese over the age of 24. The majority of respondents had only received a primary level education (35% of Syrians, 32% of PRS, and 32% of Lebanese); still, many had not received any form of education at all (31% of Syrians, 32% of PRS, and 14% of Lebanese). The majority of Syrian respondents were from the Beqaa area (67%), while among those who reported their accommodation type, 27% reported living in informal tented settlements. The majority of PRS were from North Lebanon (90%), particularly from the Baddawi and Nahr el Bared camps, while Lebanese respondents were approximately equally distributed between the Beqaa (47%) and North Lebanon (53%) governorates.

Among Syrian respondents, 42% had a motor disability, 17% had a sensory disability (where sensory includes a visual, hearing, or speaking impairment), 10% had an intellectual or mental

4 Questionnaires for which invisible disability was selected as the disability type (n=10) were excluded from the analysis since there was some confusion among the enumerators concerning the definition for this disability. Questionnaires with multiple missing responses or with missing consent forms (n=1) were also excluded.

5 Though the aim of this study was to include a representative number of Syrian, PRS and Lebanese persons with disabilities, the sampling method resulted in the inclusion of a majority of Syrian refugees.

Table 1. Demographic characteristics

		Nationality							
		Syrian		Palestine refugee from Syria (PRS)		Lebanese		Total	
Gender	Male	227	60%	21	68%	28	68%	276	61%
	Female	154	40%	10	32%	13	32%	177	39%
Age	0-6	56[C]	15%	0	0%	2	4%	58	13%
	7-14	94	25%	7	23%	5	10%	106	23%
	15-24	58	15%	5	16%	13	27%	76	16%
	24‹	173	45%	19	61%	29	59%	221	48%
Level of education	Primary	129	35%	10	32%	16	32%	155	35%
	Preparatory	34	9%	3	10%	8	16%	45	10%
	Secondary	9	2%	4[A]	13%	4	8%	17	4%
	Vocational	4	1%	2	6%	3[A]	6%	9	2%
	University	4	1%	0	0%	4[A]	8%	8	2%
	Did not attend school	112[C]	31%	10	32%	7	14%	129	29%
	Other	73	20%	2	6%	8	16%	83	19%
Average household size		2.48 ± 6.06		1.77 ± 4.60		2.78 ± 5.56			
Marital status	Single-Not married	241	63%	17	55%	35	69%	293	63%
	Married	124	32%	12	39%	12	24%	148	32%
	Separated or divorced	5	1%	0	0%	4[A]	8%	9	2%
	Widowed	14	4%	2	6%	0	0%	16	3%
Occupation	Working full-time or part-time	12	6%	2	12%	15[A]	44%	29	11%
	Casual employment	20	10%	1	6%	2	6%	23	9%
	Student	2	1%	0	0%	0	0%	2	1%
	Not working	176[C]	84%	14	82%	17	50%	207	79%
Monthly income	Less than $200	210[C]	58%	18	64%	18	38%	246	57%
	$200-$399	91	25%	8	29%	22[A]	46%	121	28%
	$499-$599	5	1%	0	0%	1	2%	6	1%
	More than $600	0	0%	0	0%	2	4%	2	1%
	Prefer not to answer	58	16%	2	7%	5	10%	55	13%
Date of arrival	Arrived on or before 2014	322	90%	29	97%	N/A	N/A	351	91%
	Arrived in or after 2015	34	10%	1	3%	N/A	N/A	35	9%
Governorate	Beqaa	264[B,C]	67%	3	10%	24[B]	47%	291	61%
	North Lebanon	129	33%	28[A,C]	90%	27[A]	53%	184	39%
Type of accommodation	Apartment or other building type	219	73%	21		44	100%	284	78%
	Tent	82	27%	0	0%	0	0%	82	22%

n=475; the number of missing varies by characteristic
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different from Syrian at p ‹ .05
B Significantly different from PRS at p ‹ .05
C Significantly different from Lebanese at p ‹ .05
N/A: Not applicable

disability, and 32% had a multiple or complex disability (defined as a person who has two or more disabilities). Among PRS, 39% had a motor disability, 10% had a sensory disability, 16% had an intellectual or mental disability, and 35% had a multiple or complex disability. Among Lebanese respondents, 49% had a motor disability, 16% had a sensory disability, 2% had an intellectual or mental disability, and 33% had a multiple or complex disability. The majority of respondents reported that the cause of the disability was congenital or genetic: 35% of Syrians, 42% of PRS, and 51% of Lebanese. Significantly more Syrian respondents (17%) than Lebanese (2%) reported a war injury as the cause of their disability. In terms of performance of daily activities, 51% of Syrian respondents reported always needing help to perform the activities of daily life; this was significantly more than reported by Lebanese (32%). Furthermore, 20% of Syrian respondents reported suffering from a non-communicable disease, such as diabetes, cardiovascular disease, hypertension, asthma, and immunodeficiency, while this was the case for 35% of PRS, and 14% of Lebanese respondents.

Table 2. Health related characteristics of respondents

		Nationality					
		Syrian		*Palestine refugee from Syria*		*Lebanese*	
Type of disability	Motor disability	164	42%	12	39%	25	49%
	Sensory disability	65	17%	3	10%	8	16%
	Intellectual or mental disability	39	10%	5	16%	1	2%
	Multiple or complex disability	125	32%	11	35%	17	33%
Cause of disability	Congenital or genetic	138	35%	13	42%	26	51%
	During childbirth	61	16%	4	13%	3	6%
	Accident	47	12%	5	16%	9	18%
	War injury	67[C]	17%	0	0%	2	4%
	Chronic disease	45	11%	3	10%	4	8%
	Other	35	9%	6	19%	7	14%
Performance of daily activities	No help needed	44	12%	11[A]	37%	14[A]	28%
	Help needed sometimes	142	37%	8	27%	20	40%
	Help needed all the time	195[C]	51%	11	37%	16	32%
Suffering from a non-communica-	Yes	84	21%	11	35%	7	14%
	No	309	79%	20	65%	44	86%

n=475; the number of missing varies by characteristic
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different from Syrian at p < .05
B Significantly different from PRS at p < .05
C Significantly different from Lebanese at p < .05

Livelihoods, Income, and Assistance

The survey assessed the livelihoods and income of respondents at the individual level, as well as the types of assistance that respondents were receiving. Concerning occupation status, which is reported only for questionnaires filled by the PwD him/herself (n=261), only 17% of Syrian respondents reported being employed (either full-time, part-time or on a casual basis), while this was the case for 19% of PRS, and 55% of Lebanese (Table 1). Significantly more Lebanese PwDs than Syrians were employed. Over 50% of Syrian respondents had a current monthly income of less than USD200, while more than 60% of participating PRS had a current monthly income[6] of less than USD200. Among Lebanese respondents, 38% had a current monthly income of less than USD200, while 46% had a current monthly income of USD200-399.

When asked how they utilized their monthly incomes, 89% of Syrian respondents reported spending their income on food, followed by 62% on rent, and 54% on health services. This is in line with findings from the Vulnerability Assessment of Syrian Refugees (VASyr) in Lebanon 2017, whereby food, rent, and healthcare accounted for the top three household expenditures of Syrian refugee households (World Food Programme, United Nations Children's Fund, United Nations High Commissioner for Refugees, 2017). Among PRS, 89% reported spending their income on food, 75% on clothes, and 64% on rent, while among Lebanese, 79% reported spending their income on health services, while 56% reported spending their income on food and on household expenses (Table 3). When those who reported utilizing their monthly income on health expenditures were asked which of their healthcare needs they covered from their monthly incomes, 89% of Syrian respondents reported utilizing their monthly income for medications, while this was the case for 83% of PRS, and 75% of Lebanese (Table 3). As such, medications comprise the largest out of pocket healthcare related spending for our study sample. Despite the latter, 62% of all respondents reported that they avoided getting certain medications due to their cost (Table 6).

Over 55% of Syrian respondents reported receiving assistance from external sources (Table 4). Of those Syrian respondents who cited the source of external assistance, the majority cited the UNHCR (n=183; 46.6%). Of those Syrian respondents reporting receiving assistance, 87% received external support for food, in the form of food vouchers, while only 18% reported receiving external support for healthcare. Among PRS, 90% reported receiving assistance, mainly from the UNRWA (n=26; 83.9%) and in the form of financial assistance, and of those reporting receiving assistance, only 8% reported receiving external assistance for healthcare. Among Lebanese respondents, less than 10% reported receiving any kind of assistance, with this assistance being healthcare related, or other (Table 4). The majority of Lebanese participations (90%) reported being registered with the MoSA of Lebanon for a Disability Card (Table 4).

6 There appears to have been some confusion with the survey question regarding current monthly income, whereby some of the guardians/parents answered this question as if it were addressed to them rather than to be answered about the PwD. As such, these values should be interpreted with caution, and could refer to the current monthly income of the parent/guardian filling out the questionnaire or the household income, especially in the case of children, or the current monthly income of the PwD him/herself.

Table 3. Respondent distribution of monthly expenditure and breakdown of expenditure on healthcare services

		Nationality							
		Syrian		Palestine refugee from Syria		Lebanese		Total	
Household expenses	Yes	185	53%	14	50%	24	56%	223	53%
	No	163	47%	14	50%	19	44%	196	47%
Rent	Yes	217[C]	62%	18[C]	64%	4	9%	239	57%
	No	131	38%	10	36%	39[A,B]	91%	180	43%
Car	Yes	11	3%	1	4%	5[A]	12%	17	4%
	No	337[C]	97%	27	96%	38	88%	412	96%
Education	Yes	72	21%	10	36%	11	26%	93	22%
	No	276	79%	18	64%	32	74%	326	78%
Food	Yes	309[C]	89%	25[C]	89%	24	56%	358	85%
	No	39	11%	3	11%	19[A,B]	44%	61	15%
Clothes	Yes	178	51%	21[A]	75%	20	47%	219	52%
	No	170[C]	49%	7	25%	23	53%	200	48%
Mobile phones	Yes	131	38%	16	57%	20	47%	167	40%
	No	217	62%	12	43%	23	53%	252	60%
Health services	Yes	187	54%	16	57%	34[A]	79%	181	43%
	No	161[C]	46%	12	43%	9	21%	238	57%
Other	Yes	9	3%	1	4%	0	0%	10	2%
	No	339	97%	27	96%	43	100%	409	98%
Breakdown of expenditure on health services									
Physiotherapy	Yes	7	4%	0	0%	0	0%	7	3%
	No	171	96%	18	100%	24	100%	213	97%
Surgery	Yes	3	2%	0	0%	1	4%	4	1%
	No	175	98%	18	100%	23	96%	216	99%
Medications	Yes	159	89%	15	83%	18	75%	192	87%
	No	19	11%	3	17%	6	25%	28	13%
Kinetic aids or compensatory devices	Yes	5	3%	1	6%	1	4%	7	3%
	No	173	97%	17	94%	23	96%	213	97%
Medical devices (earplugs, glasses, etc.)	Yes	4	2%	0	0%	4[A]	17%	8	4%
	No	174[C]	98%	18	100%	20	83%	212	96%
Laboratory tests, X-ray and other imaging	Yes	17	10%	1	6%	5	21%	23	10%
	No	161	90%	17	94%	19	79%	197	90%
Medical consultations	Yes	11	6%	1	6%	5[A]	21%	17	8%
	No	167[C]	94%	17	94%	19	79%	203	92%
Diapers	Yes	22	12%	2	11%	2	8%	26	12%
	No	156	88%	16	89%	22	92%	196	89%
Transportation	Yes	4	2%	0	0%	3[A]	13%	7	3%
	No	174[C]	98%	18	100%	21	88%	213	97%

n=475 for breakdown of monthly expenditure; multiple responses possible; missing: 56; n=220 for breakdown of expenditure on health services
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different from Syrian at p < .05
B Significantly different from PRS at p < .05
C Significantly different from Lebanese at p < .05

Healthcare Needs

The assessment of participant self-reported healthcare needs revealed that participant needs were not always being met. Our research partners confirmed this during the focus group discussion, based both on their personal experiences, and on the stories they had heard from the field. The top two self-reported healthcare needs of Syrian respondents were permanent medication (55%) and medical consultations (54%) (Table 5). Syrians with a motor disability reported requiring permanent medication (63%) and/or physiotherapy (56%), in addition to other healthcare needs. Among Syrians, 42% reported avoiding getting physiotherapy due to the cost (Table 6). The top two self-reported needs for Syrian respondents with a sensory disability were medical devices (55%) and/or medical consultations (45%), while for those with an intellectual or mental disability these were permanent medications (59%) and/or medical consultations (54%). For Syrian respondents with a multiple or complex disability, these were medical consultations (59%) and/or permanent medications (55%). When asked about their self-reported healthcare needs, the top two needs among PRS respondents were medical consultations (58%) and/or medication (52%). Further details about PRS respondent self-reported healthcare needs can be found in Table 5. Similarly for Lebanese respondents, permanent medications (59%) and/or medical consultations (57%) were also the top two self-reported healthcare needs (Table 5). Further details about Lebanese respondent self-reported healthcare needs are found in Table 5. Respondents also reported other healthcare needs (n=20) including psychological treatment, speech therapy, and diapers.

Respondents who reported that they were in need of healthcare service(s) were also asked whether they received the healthcare service(s) or not (Table 7). Not all those who reported needing a service specified whether they received it or not, but of those who responded, many reported not receiving the service at all, for example, 64% of respondents in need of permanent medications reported not having received these medications. Some respondents reported receiving a specific service only once, for example, 9% of respondents reported receiving permanent medications only once. Very few respondents reported receiving services regularly; this was the case for only 12% of respondents who reported needing permanent medications (Table 7). More than 70% (n=79) of respondents reported not receiving a surgery that they were in need of. Furthermore, 55% (n-47) of respondents reported not receiving a kinetic aid or compensatory device, while 72% (n=58) reported not receiving a medical device they were in need of (Table 7), the lack of which can impact the way and quality of life of PwDs.

Table 4. Share of respondents receiving assistance by nationality

		Nationality							
		Syrian		Palestine refugee from Syria		Lebanese		Total	
External support or help received	Yes	215[C]	56%	28[A,C]	90%	4	9%	247	53%
	No	171[B]	44%	3	10%	43[A]	91%	217	47%
Type of support received among those receiving external support									
External support received is financial	Yes	72	36%	24	100%	0	0%	96	42%
	No	128	64%	0	0%	3	100%	131	58%
External support received is healthcare related	Yes	36	18%	2	8%	2[B]	67%	40	18%
	No	164	82%	22[C]	92%	1	33%	187	82%
External support received is for education	Yes	2	1%	0	0%	0	0%	2	1%
	No	198	99%	24	100%	3	100%	225	99%
External support received is for food	Yes	173	87%	0	0%	0	0%	173	76%
	No	27	14%	24	100%	3	100%	54	24%
Other type of external support is received	Yes	5	3%	0	0%	1[A]	33%	6	3%
	No	195[C]	98%	24	100%	2	67%	221	97%
Support to Lebanese									
Registration with Ministry of Social Affairs to obtain a *disability card	Yes	N/A	N/A	N/A	N/A	43	90%	43	90%
	No	N/A	N/A	N/A	N/A	5	10%	5	10%

*n=475; the number of missing varies by variable. N/A: Not applicable. *This question was only asked to Lebanese participants.*
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different than Syrian at p < .05
B Significantly different than PRS at p < .05
C Significantly different than Lebanese at p < .05

Table 5. Services reported as needed by nationality and disability type

	Motor disability		Sensory disability		Intellectual or mental disability		Multiple or complex disability		Total	
(Syrian (n=393	n=164		n=65		n=39		n=94			
Physiotherapy	92	56%	8	12%	14	36%	51	41%	165	42%
Surgery	64	39%	25	38%	7	18%	43	34%	139	35%
Medication	103	63%	21	32%	23	59%	69	55%	216	55%
Kinetic aid or compensatory device	55	34%	8	12%	9	23%	33	26%	105	27%
Medical device	33	20%	36	55%	7	18%	35	28%	111	28%
Laboratory tests, X-rays, or other imaging	64	39%	26	40%	18	46%	49	39%	157	40%
Medical consultation	89	54%	29	45%	21	54%	74	59%	213	54%
I don't need any medical assistance/service									0	0%
Palestine Refugee from Syria ((n=31	n=12		n=3		n=5		n=11			
Physiotherapy	7	58%	0	0%	0	0%	4	36%	11	35%
Surgery	2	17%	1	33%	0	0%	0	0%	3	10%
Medication	8	67%	1	33%	3	60%	4	36%	16	52%
Kinetic aid or compensatory device	8	67%	0	0%	0	0%	3	27%	11	35%
Medical device	1	8%	2	67%	2	40%	4	36%	9	29%
Laboratory tests, X-rays, or other imaging	4	33%	1	33%	2	40%	6	55%	13	42%
Medical consultation	4	33%	3	100%	4	80%	7	64%	18	58%
I don't need any medical assistance/service									1	3%
(Lebanese (n=51	n=25		n=8		n=1		n=17			
Physiotherapy	13	52%	0	0%	0	0%	7	41%	20	39%
Surgery	5	20%	1	13%	0	0%	4	24%	10	20%
Medication	18	72%	1	13%	0	0%	11	65%	30	59%
Kinetic aid or compensatory device	4	16%	2	25%	0	0%	8	47%	14	27%
Medical device	4	16%	4	50%	1	100%	2	12%	11	22%
Laboratory tests, X-rays, or other imaging	10	40%	1	13%	0	0%	9	53%	20	39%
Medical consultation	16	64%	4	50%	0	0%	9	53%	29	57%
I don't need any medical assistance/service									2	4%

Multiple responses possible

Perceived Barriers to Accessing Healthcare Services and to Visiting Healthcare Centers

The survey also identified the perceived barriers to accessing healthcare services and to visiting healthcare centers for persons with disabilities in Lebanon, revealing that persons with disabilities and injuries in Lebanon are confronted with a variety of barriers to accessing healthcare services, with PwDs facing multiple barriers at a time (Table 8). While some of these barriers also acted as barriers to respondents' visiting healthcare centers, the survey revealed additional barriers to visiting healthcare centers as reported by the PwDs (Table 9). For both barriers to accessing healthcare services, and those to visiting healthcare centers, barriers were grouped as follows, a) financial barriers, b) structural barriers, and c) personal barriers (Table 8, Table 9). Financial barriers included participants' financial abilities, and the lack of coverage for medical

Table 6. Healthcare services avoided due to their cost

		Nationality							
		Syrian		Palestine refugee from Syria		Lebanese		Total	
Certain medications	Yes	240	63%	18	64%	20	47%	278	62%
	No	138	37%	10	36%	23	53%	171	38%
Imaging and laboratory tests	Yes	210[C]	56%	17[C]	61%	13	30%	240	53%
	No	168	44%	11	39%	30[A,B]	70%	209	47%
Surgery	Yes	176[B]	47%	4	14%	15	35%	195	43%
	No	202	53%	24[A]	86%	28	65%	254	57%
Physiotherapy	Yes	158	42%	9	32%	15	35%	182	41%
	No	220	58%	19	68%	28	65%	267	59%
Medical devices	Yes	108	29%	10	36%	12	28%	130	29%
	No	270	71%	18	64%	31	72%	319	71%
Medical consultation	Yes	4	1%	0	0%	2	5%	6	1%
	No	374	99%	28	100%	41	95%	443	99%

n=475; missing=26. Multiple responses possible.
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different than Syrian at p < .05
B Significantly different than PRS at p < .05
C Significantly different than Lebanese at p < .05

Table 7. Number of respondents reporting a specific service as required and whether or not they received it

	Receiving Status								
	I did not receive assistance/the service		I only received assistance/the service once		I received assistance/the service multiple times, but it was not enough		I still receive assistance/the service regularly		
Permanent medication	125	64%	18	9%	29	15%	24	12%	196
Medical consultation	114	70%	16	10%	24	15%	10	6%	164
Physiotherapy	87	60%	10	7%	44	31%	3	2%	144
Surgery	79	74%	19	18%	8	8%	1	1%	107
Laboratory tests, x-rays, or other imaging	82	77%	14	13%	9	8%	2	2%	107
Kinetic aids or compensatory devices	47	55%	36	42%	3	3%	0	0%	86
Medical devices	58	72%	16	20%	5	6%	2	2%	81

Not all those who reported needing a service specified whether they received it or not; missing varies by specific service required.

and specialized services such as imaging and laboratory tests. Structural barriers included the physical environment of healthcare centers, particularly, their accessibility, limited specialized services for PwDs, inadequate medical care, non-responsive centers, long waiting times to obtain a service, and the remote location of centers. Personal/cultural barriers included a lack of training or knowledge among staff and employees on how to deal with PwDs, lack of trust and credibility, lack of information among PwDs about healthcare services and centers, and legal status.

Table 8. Reported barriers to accessing healthcare among respondents by nationality

		Nationality							
		Syrian		Palestine refugee from Syria		Lebanese		Total	
Financial barriers									
Lack of coverage for medical services where some services are not free	Yes	220	57%	17	59%	26	54%	263	57%
	No	167	43%	12	41%	22	46%	201	43%
Financial ability	Yes	329[B,C]	85%	19	66%	22	46%	370	80%
	No	58	15%	10[A]	34%	26[A]	54%	94	20%
Specialized services such as imaging and laboratory tests are not covered	Yes	133	34%	13	45%	10	21%	156	34%
	No	254	66%	16	55%	38	79%	308	66%
Structural barriers									
Limited specialized services for persons with disabilities	Yes	215	62%	19	68%	31	69%	265	57%
	No	133	38%	9	32%	14	31%	156	43%
Health centers are not equipped to accommodate persons with disabilities (engineering and (infrastructure	Yes	78	20%	5	17%	3	6%	86	19%
	No	309	80%	24	83%	45	94%	378	81%
Permanent medications not available	Yes	167	43%	8	28%	16	33%	191	41%
	No	220	57%	21	72%	32	67%	273	59%
Personal/cultural barriers									
Staff are not properly trained to deal with persons with disabilities	Yes	87[B,C]	22%	1	3%	7	15%	95	20%
	No	300	78%	28[A]	97%	41[A]	85%	369	80%
Lack of information about the healthcare services and health-care centers available	Yes	118	30%	8	28%	12	25%	138	30%
	No	269	70%	21	72%	36	75%	326	70%
Lack of trust and credibility	Yes	138[C]	36%	10	34%	7	15%	155	33%
	No	249	64%	19	66%	41[A]	85%	309	67%

n=475. Multiple responses possible. The "Limited specialized services for persons with disabilities" barrier was not provided in 46 questionnaires due to a photocopying error. There are 11 missing for all barriers.
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different than Syrian at p < .05
B Significantly different than PRS at p < .05
C Significantly different than Lebanese at p < .05

Among Syrian respondents, the single greatest barrier to accessing healthcare was financial ability (85%); this was significantly higher than for both PRS and Lebanese respondents. Lack of medical coverage for services that are not free (57%) and limited specialized services for persons with disabilities[7] (62%) were also top barriers for Syrian respondents. Significantly more Syrian respondents than Lebanese respondents reported trust and credibility (n=138; 36%) as a barrier to accessing healthcare, and more Syrians than both PRS and Lebanese reported staff not being trained to deal with PwDs (22%) as a barrier to accessing healthcare. Among PRS, the major barriers to accessing healthcare were both financial ability (n=19; 66%), and the limited specialized services for PwDs (68%). Among Lebanese respondents, these were limited specialized services for PwDs (69%), and lack of medical coverage for services that are not free (54%). The least reported barriers to accessing healthcare among all three nationalities were health centers not being equipped to accommodate persons with disabilities (19% among all respondents), which was related to engineering and infrastructure, and staff not being properly trained to deal with persons with disabilities (20% among all respondents). When asked how the barriers to accessing healthcare have affected their health, survey respondents reported suffering complications, loss of motor or other functions, inflammation, and/or psychological stress.

The most commonly reported barrier to visiting healthcare centers among Syrian respondents was also financial ability (90%); this was significantly higher than for Lebanese respondents (Table 9). This was also the most commonly cited barrier to visiting healthcare centers among PRS (87%), for whom it was also significantly higher than for Lebanese. Still, the greatest barrier to visiting healthcare centers cited by Lebanese respondents was also financial ability (60%). The second most commonly cited barrier to visiting healthcare centers was the fact that some centers require a fee (Syrians: 57%; PRS: 80%; Lebanese: 53%). Significantly more Syrian respondents (33%) than PRS (7%) and Lebanese (15%) respondents reported that long waiting times for obtaining a service acted as a barrier to visiting healthcare centers, while significantly more Syrians than Lebanese (26%) reported centers not responding to the specific case (45%) as a barrier. For 35% of Syrian and 33% of PRS respondents, their legal status was a concern for access to services based in the capital.

Though primary healthcare centers within the MoPH network do provide acute medications free of charge to Syrian refugees and vulnerable Lebanese, they do not provide permanent medications or medications for chronic conditions—permanent medications were reported as both a need and a barrier to accessing and visiting healthcare centers among respondents. One other commonly cited need was medical consultations. It is noteworthy that almost 100 primary healthcare centers within the MoPH network do provide medical consultations for a subsidized price or almost free of charge, still, centers may lack the specialized services required by PwDs, and these should be afforded to them. Almost 65% of respondents reported not visiting a healthcare center in the past year though almost all participants reported needing a healthcare service, suggesting that they may be avoiding certain healthcare services due to the barriers identified from this study. The lack of information regarding the services available (discussed in more detail in the below section), coupled with the

7 The "Limited specialized services for persons with disabilities" barrier was missing from 46 questionnaires due to a photocopying error

Table 9. Reported barriers to visiting healthcare centers among respondents by nationality

		Nationality							
		Syrian		Palestine refugee from Syria		Lebanese		Total	
Financial barriers									
Financial ability	Yes	349[C]	90%	26[C]	87%	28	60%	403	87%
	No	37	10%	4	13%	19[A,B]	40%	60	13%
Some centers require a fee	Yes	220	57%	24[A]	80%	25	53%	269	58%
	No	166[B]	43%	6	20%	22	47%	194	42%
Structural barriers									
Health centers not equipped to accommodate persons with disabilities (engineering and infrastructure)	Yes	64	17%	3	10%	4	9%	71	15%
	No	322	83%	27	90%	43	91%	392	85%
Long waiting time to obtain the service	Yes	126[B,C]	33%	2	7%	7	15%	135	29%
	No	260	67%	28[A]	93%	40[A]	85%	328	71%
Lack of adequate medical care	Yes	179	46%	13	43%	14	30%	206	44%
	No	207	54%	17	57%	33	70%	257	56%
Centers are located in remote areas that are difficult to reach	Yes	101	26%	13	43%	11	23%	125	27%
	No	285	74%	17	57%	36	77%	338	73%
Centers did not respond to the specific case	Yes	172[C]	45%	11	37%	12	26%	195	42%
	No	214	55%	19	63%	35[A]	74%	268	58%
Personal barriers									
Lack of knowledge among employees regarding how to deal with persons with disabilities	Yes	97	25%	4	13%	9	19%	110	24%
	No	289	75%	26	87%	38	81%	353	66%
Lack of trust and credibility	Yes	131	34%	13	43%	9	19%	153	33%
	No	255	66%	17	57%	38	81%	310	67%
Legal status is a concern for access to services based in the capital	Yes	136	35%	10	33%	N/A	N/A	146	35%
	No	250	65%	20	67%	N/A	N/A	270	65%

n=475; missing=12. Multiple responses possible. N/A: Not applicable
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different than Syrians at p< .05
B Significantly different than PRS at p< .05
C Significantly different than Lebanese at p< .05

fact that certain services are not free or may require an extra fee suggest that the perceived need to spend out-of-pocket on healthcare services when income is already low, may be acting as an additional barrier to healthcare access.

Information on Healthcare Services

Though lack of information about the healthcare services and healthcare centers available was not a top barrier to accessing healthcare cited by the PwDs (30% among all respondents), only 7% of respondents reported using the available hotline for obtaining information on healthcare services, while 20% reported not receiving any information on healthcare services at all. The majority of respondents obtained information on healthcare services from their community (54%), and from a directory of services (34%) prepared and distributed by the informal groups who were our partners in the research (Table 10). In fact, sharing of information by word of mouth and via community members is common in refugee communities (Internews, 2013). The latter could be facilitated for PwDs through the designation of community leaders from among respected community members or already existing structures within communities, and through the development of networks for information sharing among them using text-messaging (SMS) or social media such as WhatsApp. Within our context, the role of these community leaders can be similar to the one that the informal groups have already been playing within their communities. Alternatively, and as discussed further in the Recommendations section, a directory of services may be developed to provide information on the healthcare services available to PwDs in Lebanon.

As per the VASyr 2017, over 80% of refugee households reported receiving refugee-related information through text-messaging (SMS), while over 80% reported being active on social media, such as WhatsApp. The

Table 10. Number of respondents receiving health information by type of health information received

		Nationality							
		Syrian		Palestine refugee from Syria		Lebanese		Total	
Text message	Yes	60	15%	0	0%	3	7%	63	14%
	No	328	85%	31	100%	43	93%	402	86%
Hotline	Yes	30	8%	0	0%	3	7%	33	7%
	No	358	92%	31	100%	43	93%	432	93%
WhatsApp	Yes	57	15%	1	3%	10	22%	68	15%
	No	331	85%	30	97%	36	78%	397	85%
Advertisements and distributed handouts	Yes	31	8%	2	6%	9[A]	20%	42	9%
	No	357[C]	92%	29	94%	37	80%	423	91%
Directory of services distributed by groups	Yes	134	35%	9	29%	16	35%	159	34%
	No	254	65%	22	71%	30	65%	306	66%
Visits by humanitarian organizations	Yes	52	13%	2	6%	4	9%	58	13%
	No	336	87%	29	94%	42	91%	407	88%
Information offices in community centers	Yes	11	3%	0	0%	4[A]	9%	15	3%
	No	377[C]	97%	31	100%	42	91%	450	97%
Health centers	Yes	48	12%	2	6%	4	9%	54	12%
	No	340	88%	29	94%	42	91%	411	88%
Community	Yes	212	55%	19	61%	20	43%	251	54%
	No	176	45%	12	39%	26	57%	214	46%
No information about health services received	Yes	74	19%	9	29%	8	17%	91	20%
	No	314	81%	22	71%	38	83%	374	80%

n=475; missing = 10; multiple responses possible

latter could also serve as platforms for sharing of healthcare services information for persons with disabilities. When implementing these types of technologies, a number of factors should be taken into consideration, including, accuracy of number directories, phone sharing, and lack of service coverage in a number of areas, including camps (Internews, 2013), but also the health beliefs and experiences of refugees and PwDs, and their literacy levels (Talhouk et al., 2016). It must be noted that the latter method may not be suitable for all kinds of disabilities, for example, for those with visual impairments, in which case the role of a community leader would prove beneficial. At the healthcare provider level, this would require coordination and information sharing, possibly through the current working groups and networks on health and for PwDs, to avoid duplication of services and to ensure that PwDs are kept up to date on the services available to them.

Table 11. Exposure to a protection issue by disability type among those that reported being exposed to a protection issue

		Disability classification									
		Motor disability		Sensory disability		Intellectual or mental disability		Multiple or complex disability		Total	
Physical violence	Yes	6	5%	2	4%	0	0%	3	3%	11	4%
	No	113	95%	48	96%	25	100%	99	97%	285	96%
Psychological violence	Yes	39	33%	15	30%	8	32%	28	27%	90	30%
	No	80	67%	35	70%	17	68%	74	73%	206	70%
Sexual violence	Yes	1	1%	2	4%	1	4%	1	1%	5	2%
	No	118	99%	48	96%	24	96%	101	99%	291	98%
Financial exploitation	Yes	55	46%	26 [D]	52%	16 [D]	64%	30	29%	127	43%
	No	64	54%	24	48%	9	36%	72 [B,C]	71%	169	57%
Exclusion from services	Yes	43	36%	22	44%	7	28%	59 [A,C]	58%	131	44%
	No	76 [D]	64%	28	56%	18 [D]	72%	43	42%	165	56%
Gender discrimination	Yes	15	13%	8	16%	4	16%	11	11%	38	13%
	No	104	87%	42	84%	21	84%	91	89%	258	87%
Discrimination by type of disability	Yes	18	15%	8	16%	8	32%	16	16%	50	17%
	No	101	85%	42	84%	17	68%	86	84%	246	83%
Verbal violence	Yes	3	3%	0	0%	0	0%	2	2%	5	2%
	No	116	97%	50	100%	25	100%	100	98%	291	98%

n=475; missing= 179. Multiple responses possible
Analysis by two-sided test of equality for column proportions. Tests assume equal variances
A Significantly different than motor disability at p< .05
B Significantly different than sensory disability at p< .05
C Significantly different than intellectual or mental disability at p< .05
D Significantly different than multiple or complex disability at p< .05

Protection Issues

The questionnaire uncovered a number of protection issues faced by PwDs during the healthcare process (Table 11). The most commonly cited protection issues, as cited by respondents were exclusion from services (44%), financial exploitation (43%), and psychological violence (30%). Although less common, respondents also reported facing other forms of protection issues, including physical (4%) and sexual (2%) violence, gender discrimination (13%), discrimination by type of disability (17%), and verbal violence (2%) while receiving healthcare services. When assessed by disability type, significantly more participants with a sensory disability (52%) and significantly more participants with an intellectual or mental disability (64%) than those with a multiple or complex disability (29%) reported being financially exploited while receiving healthcare. Among participants with a multiple or complex disability (58%), significantly more reported feeling excluded from services than those with a motor (36%) or intellectual or mental disability (28%). These findings are alarming, and conducting a more comprehensive assessment of protection issues faced by refugees with disabilities when they are obtaining healthcare services is crucial. This especially considering that PwDs face multiple additional protection risks due to their needs being unmet, related to education, shelter and livelihoods, among others. A comprehensive assessment would allow for evidence-based recommendations to develop a monitoring mechanism at the organizational level, and for the introduction of proper response mechanisms.

Coping Strategies

Refugees and host community members turn to both negative and positive coping strategies to deal with their unmet needs (Oxfam, 2015; World Food Programme, United Nations Children's Fund, United Nations High Commissioner for Refugees, 2017). In this study, participants reported adopting several coping strategies in response to their unmet healthcare needs (Table 12). For example, significantly more Syrians (60%) and PRS (63%) than Lebanese (26%) reported turning to relatives or friends for financial assistance as a means of coping with the lack of health services. Participants also cited abandonment of treatment or medication (55%), and the sale of possessions or property (32%) as means of coping with the lack of services and unmet needs. Significantly more PRS (30%) than Lebanese (5%) reported using their savings to cope with the lack of health services, which was also reported as a coping strategy for 15% of Syrian respondents. While both Syrians and PRS reported working on illegal migration (Syrians=22%; PRS=33%) and/or returning to Syria for access to services and medicines (Syrians=8%; PRS=7%), the latter were not reported by any Lebanese. A smaller percentage of participants reported turning to natural therapy or herbal treatment (14%) and begging (7%) as a means to cope with their healthcare situation, while 7% of Lebanese reported obtaining a loan from a bank.

Healthcare Utilization Characteristics of Respondents

The majority of respondents used public transportation (78%) to reach healthcare centers (Table 13). Where healthcare centers were available, 38% of respondents reported that these are easy to reach, with 39% of respondents reporting that it takes them 16-30 minutes to reach their nearest healthcare center. Significantly more PRS than Syrian and Lebanese respondents reported that it was very easy for them to reach healthcare centers, which could be explained by the availability of UNRWA primary healthcare facilities within Palestinian refugee camps. Despite ease of reach of centers, 49% of respondents reported that they did not visit a healthcare center once in the past year (Table 13). Concerning at-home visits by healthcare providers, over 70% of respondents reported that a healthcare provider did not visit them once in the past year.

Respondent Recommendations

Respondents were asked to give two recommendations that in their opinion would improve the reality of healthcare for persons with disabilities in Lebanon. Many of the recommendations made by respondents focused on their immediate healthcare needs. Respondents requested provision of a variety of medical services, such as psychological support, medical consultations, medications, kinetic aids, medical devices, and surgeries. Respondents highlighted the importance of allocating funding to secure medical services for persons with disabilities in full and as needed, and the need for securing these medical services free of charge. Several respondents recommended that persons with disabilities be provided with financial support, either in the form of free medical services, or in the form of a monthly income to cover living expenses. Recommendations also included the introduction of medical insurance programs for persons with disabilities

Table 12. Number of respondents turning to specific coping mechanisms as a means of coping with the lack of health services

		Nationality							
		Syrian		Palestine refugee from Syria		Lebanese		Total	
Working on illegal migration	Yes	83	22%	10	33%	0	0%	93	21%
	No	289	78%	20	67%	43	100%	352	79%
Returning to Syria for access to services and medicines	Yes	28	8%	2	7%	0	0%	30	7%
	No	344	92%	28	93%	43	100%	415	93%
Abandoning treatment or medication	Yes	205	55%	16	53%	25	58%	246	55%
	No	167	45%	14	47%	18	42%	199	45%
Sale of possessions or property	Yes	132[C]	35%	8	27%	4	9%	144	32%
	No	240	65%	22	73%	39[A]	91%	301	68%
Begging	Yes	31	8%	1	3%	1	2%	33	7%
	No	341	92%	29	97%	42	98%	412	93%
Looking for a suitable job to have an income	Yes	75	20%	16[A,C]	53%	6	14%	97	22%
	No	297[B]	80%	14	47%	37[B]	86%	348	78%
Savings	Yes	55	15%	9[C]	30%	2	5%	66	15%
	No	317	85%	21	70%	41[B]	95%	379	85%
Asking relatives or friends for financial assistance	Yes	222[C]	60%	19[C]	63%	11	26%	252	57%
	No	150	40%	11	37%	32[A,B]	74%	193	43%
Natural therapy or herbal treatment	Yes	56	15%	4	13%	4	9%	64	14%
	No	316	85%	26	87%	39	91%	381	86%
Loan from a bank	Yes	0	0%	0	0%	3	7%	3	1%
	No	372	100%	30	100%	40	93%	442	99%

n=475; missing = 30. Multiple responses possible.
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different than Syrians at p< .05
B Significantly different than PRS at p< .05
C Significantly different than Lebanese at p< .05

Table 13. Respondent healthcare utilization characteristics

		Nationality							
		Syrian		Palestine refugee from Syria		Lebanese		Total	
How often did a healthcare provider visit you in the past year?	Not once	278	71%	28	90%	41	87%	347	74%
	One time	46	12%	1	3%	2	4%	49	11%
	Two times	31	8%	2	6%	1	2%	34	7%
	Three times	10	3%	0	0%	1	2%	11	2%
	More than three times	24	6%	0	0%	2	4%	26	6%
How many times did you visit a health-care center in the past year?	Not once	179	47%	15	50%	32[A]	65%	226	49%
	One time	53	14%	3	10%	5	10%	61	13%
	Two times	52	14%	0	0%	2	4%	54	12%
	Three times	10	3%	3[A]	10%	0	0%	13	3%
	More than three times	87	23%	9	30%	10	20%	106	23%
Where healthcare centers are available, how easy are these centers to reach?	Very easy	35	9%	11[A,C]	37%	5	10%	51	11%
	Fairly easy	152	39%	9	30%	19	39%	180	38%
	Neither easy nor difficult	93[B]	24%	1	3%	13[B]	27%	107	23%
	Somewhat difficult	74	19%	3	10%	8	16%	85	18%
	Very difficult	32	8%	2	7%	4	8%	38	8%
	Centers are unreachable	3	1%	4[A]	13%	0	0%	7	2%
How long does it take you to reach your nearest health-care center?	Less than 15 minutes	101	26%	18[A,C]	64%	16	32%	135	29%
	minutes 16-30	159[B]	41%	4	14%	18	36%	181	39%
	minutes 31-45	74	19%	4	14%	9	18%	87	19%
	minutes 46-60	29	8%	0	0%	4	8%	33	7%
	More than 60 minutes	23	6%	2	7%	3	6%	28	6%
What method of transportation do you use to access healthcare centers?	Public transportation	300[C]	80%	26[C]	93%	26	52%	352	78%
	Private transportation	45	12%	1	4%	20[A,B]	40%	66	14%
	Multiple methods	8	2%	0	0%	0	0%	8	2%
	Other	21	6%	1	4%	4	8%	26	6%

n=475; Missing varies by variable.
Analysis by two-sided test of equality for column proportions. Tests assume equal variances.
A Significantly different than Syrians at p< .05
B Significantly different than PRS at p< .05
C Significantly different than Lebanese at p< .05

Table 14. Healthcare service provider characteristics

		Healthcare service provider											
		Director or manager of an establishment		Manager or coordinator of a division		Mental health professional		Healthcare provider		Public or community health professional		Total	
Type of establishment	Foundation	0	0%	0	0%	0	0%	2	17%	0	0%	2	6%
	Non-governmental or humanitarian organization	0	0%	4	67%	1	20%	2	17%	8	100%	15	46%
	Primary healthcare center	1	50%	0	0%	3	60%	2	17%	0	0%	6	18%
	Hospital or medical center	1	50%	2	33%	1	20%	6	50%	0	0%	10	30%
Ever provided health services to a PwDs	Yes	2	100%	5	83%	2	40%	9	75%	3	38%	21	64%
	No	0	0%	1	17%	3	60%	3	25%	5	63%	12	36%
Ever received any kind of training on disability and on how to deal with PwDs	Yes	1	50%	3	50%	1	20%	6	50%	1	13%	12	36%
	No	1	50%	3	50%	4	80%	6	50%	7	88%	21	64%

and the elderly, while Lebanese respondents recommended improving the Ministry of Social Affair's disability card. Providing adequate housing for persons with disabilities was also recommended.

Respondents made organizational-level recommendations, directed at both healthcare centers and organizations, such as the United Nations, that provide services to refugees and persons with disabilities. One respondent highlighted the importance of coordination between associations, the United Nations, UNRWA and the MoSA for some disabilities. Respondents recommended that organizations register and follow-up with persons with disabilities, suggesting that there be a special file for persons with disabilities at organizations that includes all the information on their specific case. For example, one respondent stated that "The concerned institution[s] should endeavor to search and take care of these cases and to provide nearby centers for monitoring". They also requested that they be provided with information on the services available to them from different organizations, and that a hotline be available for them. Many of the refugees proposed that organizations facilitate travel or resettlement for them to obtain the treatment they require abroad, suggesting that they feel like they are not receiving the services they require here in Lebanon. Respondents further recommended the introduction of monitoring and accountability mechanisms, both at the healthcare provider and institutional levels, to ensure fairness in the treatment of persons with disabilities.

Respondents underscored the limited availability of specialized services for persons with disabilities at healthcare centers in Lebanon by recommending that specialized healthcare centers be established that offer a number of specialties and the right type of expertise, for example by "[Providing] special healthcare centers for the treatment of people with disabilities to avoid exacerbation of the [health] situation, and [which offer] different specialties". For respondents, the importance of establishing specialized centers was closely related to their health status and its deterioration. Respondents also suggested improving both healthcare centers and the services they provide. At a structural level, respondents recommended modernizing and improving the infrastructure of healthcare centers to make them more accessible for persons with disabilities, underscoring the need to ensure physical access to healthcare centers and organizations. Respondents pointed to distance and transportation as barriers to reaching healthcare centers, recommending that transportation to healthcare centers be provided for persons with disabilities. One respondent recommended the introduction of specialized mobile clinics for persons with disabilities.

Respondent recommendations did not only focus on healthcare, rather, they suggested multiple barriers they face which affect their living conditions and ability to meet their own healthcare needs. Respondents also recommended the establishment of schools that provide special programs to meet the needs of persons with disabilities. For example, recommendations focused on the need for schools that provide speech therapy for those with a speaking or hearing disability, or on educational programs for persons with autism. Respondents highlighted the importance of establishing clubs or centers that offer recreational activities for persons with disabilities, such as those with an intellectual or mental disability, to alleviate the burden on them and their families, or the introduction of vocational schools especially designed for persons with disabilities, which would in turn prepare them to join the workforce. Respondents also recommended the creation of job opportunities fit for persons with disabilities

Healthcare Service Providers

A questionnaire was prepared for healthcare service providers in order to assess their perceptions regarding healthcare access for persons with disabilities in Lebanon. The questionnaire covered the difficulties faced by providers when providing healthcare services to PwDs, as well as the provider's perspective regarding the barriers faced by PwDs when obtaining healthcare services.

Service Provider Profiles

A total of 33 healthcare service providers (Table 14) employed at 16 different establishments across Lebanon responded to the healthcare service providers' questionnaire. These included providers working at the organizational or departmental management levels, mental health professionals, healthcare providers, including doctors, nurses, physiotherapists, and community midwifes, and public or community health professionals working at foundations (n=2), non-governmental or humanitarian organizations (n=15), primary healthcare centers (n=6), and at hospitals or

medical centers (n=10). Among service providers responding to the questionnaire, 64% had directly provided services to PwDs, while only 36% had received any kind of training on disability and how to deal with persons with disabilities. Provider responsibilities ranged from patient examination and assessments, developing care plans, rehabilitation and quality control, psychosocial support and psychotherapy, providing educational sessions, and providing awareness and guidance among other tasks.

Providers were asked about the difficulties they face when serving persons with disabilities. For those who had provided health services to PwDs, difficulties included awareness on how to deal with PwDs and were also related to training, communication, lack of cooperation from family members, the physical and psychological strains of caring for PwDs, demotivation, and patient safety. Some of the difficulties mentioned by providers were related to the establishment where they work or to the PwDs themselves, but which affected their work in one way or another. These included insufficient funding, lack of necessary resources, structural issues, lack of specialized equipment, lack of services or lack of coverage for certain services, care coordination, the financial ability of PwDs, and the impact this has on follow-up and continuity of care, as well as difficulties with transportation to and from establishments.

Establishment Characteristics

The establishments included in the study covered North Lebanon and/or Akkar, Bekaa, Beirut, Mount Lebanon, where some of the establishments covered multiple governorates (Table 15). All 16 of the establishments provided services to Syrian refugees. Some of the establishments also provided services to Lebanese (n=15), Palestinian Refugees from Lebanon (n=9), and PRS (n=7). The establishments provided services for a broad range of disabilities, including persons with motor disabilities, visual, hearing or speech impairments, intellectual or mental disabilities, and multiple or complex disabilities, where a single establishment usually provided services to multiple disability types. The most commonly covered disability type in our sample was intellectual or mental disability (81%), followed by motor disabilities (56%). Of the establishments (n=16) represented in this study, 44% had a special department for persons with disabilities, 44% had a funding source for PwDs, and 50% conducted a needs assessment on the needs of PwDs before establishing any health program or project. Concerning continuity of care, 88% had a referral system to refer PwDs to other establishments for services that they were not able to provide, and 88% had a follow-up system to follow-up with PwDs after a service had been provided (Table 16).

Perceptions of Healthcare Providers on the Barriers to Accessing Healthcare Services for PwDs

Healthcare service providers were asked about their perceptions regarding the barriers to healthcare services for PwDs (Table 17). The two most commonly agreed upon barriers by providers included the location of centers in remote areas, which are difficult to reach (69%), and difficulty in accessing centers, since centers are not equipped with the right type of engineering (66%). There was some overlap between the perceived barriers to accessing healthcare for PwDs cited by healthcare providers and those cited by PwDs. Over half of the providers surveyed acknowledged that the fees required by some centers were difficult for PwDs to cover. Concerning communication, 25% of providers believed that PwDs faced difficulties in communicating with health service providers or other staff, while 53% reported that the lack of specialized employees acted as a barrier to healthcare access for PwDs. Furthermore, 44% of providers stated that lack of training to deal with PwDs acted as a barrier.

Healthcare Provider Recommendations from the Provider Survey

We also asked healthcare providers to give recommendations that in their opinion would improve access to healthcare services for PwDs. There was an overlap between the recommendations made by healthcare service providers and those made by survey respondents. Providers recommended offering financial aid and services to PwDs such as medications, kinetic aids, and medical devices free of charge. They also recommended continuous funding to establishments providing services to PwDs, and more financial support from the MoPH. Providers confirmed the importance of having staff that are properly trained to deal with PwDs, and recommended continuous training for employees. They highlighted the importance of communication in this regard, and recommended that establishments should have specialized personnel who are able to deal with and communicate with persons with all types of disabilities. To increase awareness among PwDs regarding the services

available to them, providers recommended "advertising about the existence of services that [PwDs] can benefit from as widely as possible, as they often do not know that they have special services..."

A number of providers recommended the establishment of specialized centers, across the country, to provide healthcare services to PwDs. It was also recommended that service providers coordinate their work in order to ensure that all the needs of PwDs are met. Further to this, providers recommended addressing the accessibility and engineering issues at existing establishments by structurally equipping centers to receive PwDs, and by ensuring that centers have the appropriate equipment to treat PwDs. Providers recommended facilitating access to appointments and services for PwDs, and following-up cases, and one provider even recommended "providing home services for [PwDs] who are unable to travel for a variety of reasons (disability, illegal papers, transportation)". Finally, providers recommended the implementation of Law 220/2000.

Table 15. Establishment characteristics

	Type of establishment									
	Foundation		*Non-governmental or humanitarian organization*		*Primary healthcare center*		*Hospital or medical center*		*Total*	
Governorates covered										
North Lebanon and/or Akkar	0	0%	2	13%	0	0%	2	13%	4	25%
Bekaa	1	6%	1	6%	5	31%	0	0%	7	44%
Beirut	0	0%	0	0%	0	0%	1	6%	1	6%
Mount Lebanon	0	0%	1	6%	1	6%	0	0%	2	13%
Multiple governorates	0	0%	2	13%	0	0%	0	0%	2	13%
Nationalities covered										
Lebanese	1	6%	5	31%	6	38%	3	19%	15	94%
Palestine Refugee from Lebanon	1	6%	3	19%	3	19%	2	13%	9	56%
Syrian	1	6%	6	38%	6	38%	3	19%	16	100%
Palestine Refugee from Syria	0	0%	3	19%	2	13%	2	13%	7	44%
Disabilities covered										
Motor disability	1	6%	4	25%	2	13%	2	13%	9	56%
Visual impairment	0	0%	2	13%	2	13%	0	0%	4	25%
Hearing impairment	0	0%	2	13%	2	13%	1	6%	5	31%
Speech impairment	0	0%	3	19%	2	13%	2	13%	7	44%
Intellectual or mental disability	1	6%	4	25%	5	31%	3	19%	13	81%
Multiple or complex disability	0	0%	3	19%	1	6%	2	13%	6	38%

n=16; multiple responses possible for nationalities covered and disabilities covered; missing varies by variable.

Table 16. Healthcare utilization characteristics of establishments

	Foundation		Non-governmental or humanitarian organization		Primary healthcare center		Hospital or medical center		Total	
Special department for persons with disabilities at establishment	1	6%	3	19%	1	6%	2	13%	7	44%
Funding for services for persons with disabilities within the establishment	0	0%	4	25%	1	6%	2	13%	7	44%
Needs assessment on the needs of persons with disabilities conducted before establishing any health program or project	1	6%	4	25%	1	6%	2	13%	8	50%
Referral of persons with disabilities to other centers or institutions for services that establishment does not provide	0	0%	6	38%	5	31%	3	19%	14	88%
Follow-up with persons with disabilities after a service has been provided	0	0%	6	38%	5	31%	3	19%	14	88%

Table 17. Barriers faced by persons with disabilities when receiving health services as per service providers

		Count	%
Centers are located in remote areas which are difficult to reach	Yes	22	69%
	No	10	31%
Difficulty in accessing centers, since centers are not equipped with the right type of engineering	Yes	21	66%
	No	11	34%
Difficulty in obtaining appointments	Yes	8	25%
	No	24	75%
Difficulty in communicating with the health service provider or other staff members	Yes	8	25%
	No	24	75%
Health service providers do not have the appropriate training to deal with persons with disabilities	Yes	14	44%
	No	18	56%
There are no specialized employees, for example, to communicate with persons with disabilities who have a hearing or visual impairment	Yes	17	53%
	No	15	47%
Difficulty in paying fees required by some centers	Yes	18	56%
	No	14	44%

CONCLUSIONS

This exploratory study shed a light on the healthcare needs of Syrian refugees, PRS, and Lebanese persons with disabilities from the Bekaa and North Lebanon governorates, and on the barriers they face to accessing healthcare services and visiting healthcare centers in Lebanon. The study showed that the two most commonly cited needs among PwDs were permanent medications and medical consultations, while the two most commonly cited barriers were financial ability and limited specialized services for persons with disabilities. Though the study population was mainly comprised of Syrian refugees, there was, to a certain extent, an overlap between the needs and barriers identified across all three nationalities included in the study. Still, future studies should aim to include a more representative sample of persons with disabilities in Lebanon, stratified by nationality, age, gender, governorate, and/or disability type. Future studies should also assess the perceived accessibility of services reported as needed, and not only on the barriers to healthcare access. A combination of perceived accessibility to services and perceived barriers would better inform healthcare planning at a national level, both for Lebanese and refugees with disabilities and injuries. Despite its limitations, the study, through its participatory approach, allowed for a more nuanced understanding of the barriers faced by PwDs when accessing healthcare. Our inclusive methodology, whereby our research partners participated in all steps of the research process, from developing the questionnaire to co-presenting the study findings, enabled us to capture the needs and barriers within the local context, enabling data collection to be as representative as possible given the study limitations. The project also served as a capacity building exercise for both the researchers and research partners. The findings of our study have a number of implications for practice, discussed in detail in the recommendations section below. The below recommendations however, must go hand in hand with implementation of Law 220/2000, and the ratification of the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

RECOMMENDATIONS FOR IMPROVING HEALTHCARE ACCESS FOR PERSONS WITH DISABILITIES IN LEBANON

The following recommendations[8] are based on the study findings, and on the recommendations emerging from the PwD survey, the PwD workshops and FGD, the healthcare provider survey, and the stakeholder roundtable and national workshop.

Unifying Disability Classification

It is recommended that the MoSA and MoPH adopt a unified and systematic method for classifying disability, which reflects the diversity of PwDs in Lebanon. This may be based on the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), including its more recent Rehabilitation Set, which incorporates different environmental factors to describe disability (Prodinger et al., 2016; World Health Organization, 2001). The ICF may also be used for collecting data on disability, and is used for this purpose in the WHO's World Report on Disability, and for monitoring implementation of the United Nations' Convention on the Rights of Persons with disabilities (Bickenbach, 2011; World Health Organization, 2011; World Health Organization, 2015). In addition, eligibility for the disability card should be based on a comprehensive and systematic instrument, such as the WHO Disability Assessment Schedule. This will ensure that all eligible PwDs obtain a disability card and will facilitate their access to healthcare services. This same classification should be used upon registering a refugee with the UNHCR and UNRWA and other humanitarian organizations, to ensure that refugees with disabilities and injuries receive the services they require, be they healthcare related or otherwise. Special registration should be available for PwDs who lack necessary documentation, or who are not registered with any organizations, since PwDs are classified as a vulnerable group. In special cases, services should be provided in lieu of documentation or registration with any organization based solely on the classification of a disability.

Financing and Providing Services in an Equitable Manner

Financing should focus on the provision of health services in a systematic and equitable manner and should be based on a comprehensive study of the healthcare needs of PwDs in accordance with internationally acceptable standards. Furthermore, it is necessary to conduct a national-level study to collect data on PwDs from across all governorates in Lebanon, including on their health needs, in order to inform budgeting and to develop long-term national-level programs, targeted interventions, and specialized services and facilities. This will ensure that budgets are allocated in an equitable and efficient manner. As also recommended elsewhere (UNESCO, 2013), an autonomous fund should be allocated for the provision of healthcare services to PwDs within the MoPH budget. Budget allocation and financial decisions should be regulated by the National Council for Disability Affairs [9](NCDA). When developing programs, healthcare services for PwDs must remain individualized, that is, the services must correspond to each individual's specific needs. In line with the efforts of the Health Working Group for the Syria Refugee Response in Lebanon, it is imperative that governmental organizations and the humanitarian sector coordinate their response and the services they offer in order to avoid duplication of services, and to better manage donor funds. In addition to providing healthcare services to PwDs in full and as needed, an effort should be made to ensure that PwDs who are not able to reach healthcare organizations still receive the care they require. This can be achieved by providing transportation for PwDs to healthcare organizations, by ensuring that at-home or residential services are available to them, or by expanding the geographical coverage of and providing healthcare services through mobile clinics.

8 These recommendations were previously published in December 2017 in a policy brief for the same project, and have been updated in this research report to include the recommendations emerging from the stakeholder roundtable and national workshop.

9 The NCDA is the institution responsible for all disability policies in Lebanon and for their implementation; it is comprised of officials from the MoSA, including the minister, representatives from disability organizations, representatives from organizations which provide services to PwDs, PwDs, and ministerial appointees (Article 19, 2015; Republic of Lebanon, 2000).

Introducing a Comprehensive Monitoring and Accountability System

The Disability Monitor[10] at the MoSA Social Development Centers should be activated, and Social Development Centers should be monitored in order to ensure that disability cards are distributed in a fair manner. The MoSA, in collaboration with the MoPH, should expand its Disability Monitor to include all healthcare organizations, and an accessible and anonymous system for submitting complaints on discretions (such as on protection issues) should also be available at these organizations. This same complaint system should be implemented at all humanitarian organizations. Furthermore, it is recommended that the NCDA, currently an institution within the MoSA (Republic of Lebanon, 2000), become an independent institution within the Lebanese government. This will allow the NCDA to make decisions (program-related, budgetary, or other) independently from, but in collaboration with, all relevant ministries. The NCDA should develop accountability channels with clear lines of accountability for all stakeholders providing services to PwDs including ministries, healthcare organizations, and healthcare providers, which cover the quality of care they provide and ensure equitableness in service delivery. Funders may also play a role in the latter by holding providers accountable for the quality of care they provide to PwDs, for example, through conditional contracting. Communication channels must be established between different government bodies, but also with relevant stakeholders to facilitate the latter.

Equipping Healthcare Centers and Organizations and Training Staff Members

In order to guarantee accessibility of healthcare services, both public and private healthcare organizations must become equipped structurally, including healthcare centers, clinics, dispensaries, and hospitals, among others. It is also important that public institutions such as ministries, and other service providers such as NGOs, are equipped structurally to receive PwDs. Equipment and services available at all the latter organizations should also be accessible for PwDs, and patients should be followed-up after receiving care. To ensure continuity of services, especially where organizations are not able to provide a PwD with all the services s/he needs, a referral system should be introduced. Furthermore, ministries and donors should ensure that specialized services for PwDs are available at these centers and institutions. Conditional contracting may be used to ensure that centers are equipped and accessible. Healthcare centers must recruit qualified and specialized staff that are aware of the needs of PwDs and how to deal with these needs. The Ministry of Education and Higher Education must integrate educational and training programs on disability and rehabilitation into vocational, undergraduate and graduate curriculums for all healthcare providers. At the healthcare organizational level, continuous training on the provision of appropriate medical care and rehabilitation for PwDs must be given to all healthcare professionals, but also to all staff who deal directly with PwDs, which includes training on effective communication with PwDs. Incentive schemes may be introduced to encourage organizations and providers to improve accessibility and quality of care.

Providing Relevant and Accessible Information

A directory on healthcare services available to PwDs in Lebanon must be developed and distributed to all PwDs, either at healthcare organizations, or directly to their residences, via service providers. The directory should contain relevant information concerning the organizations providing healthcare services to PwDs in Lebanon, the types of services provided, their cost, and what services are covered by which organizations. This directory should be prepared after mapping all service providers in Lebanon and identifying the types of services that they provide, through conducting a service availability and readiness assessment. Information in the directory should be accessible. The mapping of services and the directory may serve as a basis for the development of a referral system for patients. Alternatively, information on the services available can be shared through community leaders, through SMS or WhatsApp technologies.

10 The Disability Monitor was an initiative by the MoSA and a number of PwDs' organizations meant to monitor implementation of the law 220/2000 at municipalities, social development centers and other institutions for PwDs.

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The Issam Fares Institute for Public Policy and International Affairs (AUB Policy Institute), American University of Beirut

P.O.Box 11-0236 Riad El-Solh I Beirut, Lebanon

961-1-350000 ext. 4150

+961-1-737627

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