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Abdulkerim, S., Albari, M., MacKenzie, A., & Thurston, A. (2021). Report on a survey of mobility disability among Syrian refugees living in Turkey. *International Journal of Educational Research Open*, 2(2), Article 100059. <https://doi.org/10.1016/j.ijedro.2021.100059>

Published in:

International Journal of Educational Research Open

Document Version:

Publisher's PDF, also known as Version of record

Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

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Title: Report on a survey of mobility disability among Syrian refugees living in Turkey

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ARTICLE INFO

Keywords:

Syrian refugees
Mobility disability
VQF-25 Questionnaire
Mobility and life-space questionnaire

ABSTRACT

More than 5.6 million people have fled Syria since the start of the Civil War in 2011, seeking refuge in countries such as Jordan, Lebanon and Turkey. Turkey has approximately one percent of the world population but hosts nearly 15 percent of the global refugee population. The country currently has 3.6 million Syrian refugees, the largest number of registered foreigners under temporary protection. In this paper, we report on the findings of VQF-25 Questionnaire, Mobility and Life-space Questionnaire that was distributed in 2020 to Syrian refugees living under temporary protection in refugee camps in Turkey. To date, there is very limited, if any, research specifically on mobility disability among Syrian Refugees in Turkey. The results show that far fewer women than men completed the questionnaires. 68% of respondents have a mobility score of between 6 and 58%.

Introduction

According to the [United Nations Human Commissioner for Refugees \(2018, online\)](#) (UNHCR), more than 5.6 million people have fled Syria since the start of the Civil War in 2011, seeking refuge in countries such as Jordan, Lebanon and Turkey. The crisis began when the Syrian government violently sought to quell public demonstrations in support of two teenagers who were arrested for anti-government graffiti in a Southern town in Syria ([UNHCR, 2018](#)). The demonstrations were also inspired by the 2010–11 Arab Spring uprisings in Egypt, Tunisia, Libya, Bahrain and Yemen where anti-government demonstrations demanded respect for human rights, better living standards, greater democracy and the end of oppressive authoritarianism. Within two months of suppressing the uprising in April 2011, the first refugee camp opened in Turkey ([UNHCR, 2018](#)), and Syria's Arab Spring quickly descended into a complex, brutal and intractable civil war which continues to the present.

Turkey has approximately one percent of the world population but, according to [Amnesty International \(2020, online\)](#), it hosts nearly 15% of the global refugee population. It is also one of the largest humanitarian assistance providers in terms of percentage of gross national income. Turkey currently has 3.6 million refugees, the largest number of registered 'foreigners under temporary protection' (a legally ambiguous status) anywhere in the region, with 64% of all Syrian refugees (55% male, 45% female) ([LSHTM, 2020](#)). In 2020, over 98% of Syrians lived in urban, peri-urban and rural areas, while less than 2% resided in seven temporary accommodation centers ([UNHCR, 2020, online](#)). The

majority live in Turkey's South-eastern provinces such as Gaziantep, Şanlıurfa and Hatay, and the capital city, Istanbul, is host to 50,000 Syrian refugees ([Amnesty International, 2020](#)).

Refugees are at a high risk of developing mental health illness such as depression, anxiety and posttraumatic stress disorder, as well conflict-related injuries that impact on mobility, access to employment and healthcare ([London School of Tropical Hygiene & Medicine \[LSHTM\], 2020, online](#)). These barriers, along with loss or damage of assistive devices and breakdown in social structures, exacerbate the negative experiences of disability and the displacement of people who are already marginalized and socially excluded as a consequence of their refugee status. In this paper, we report on the findings of a visual and mobility questionnaire that was distributed in 2020 to Syrian refugees living under temporary protection in refugee camps in Turkey. To date, there is very limited, if any, research specifically on mobility disability among Syrian Refugees in Turkey and so this research is the first of its kind.

Disability type and prevalence among Syrian refugees in Turkey

Disability is a prevalent feature of all human lives; at some point, we may all have to live with a disability either temporarily (depression, for example) or permanently. According to the World Health organization (WHO), disability has three central and enduring features: 1. it is a *global public health issue*, affecting one in seven people worldwide; 2. it is a *human rights issue* as people with a disability are among the most discriminated people in the world, 'often experiencing violence, prejudice and denial of autonomy as well as facing barriers to care'; and

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disability is a *development priority* because of its prevalence in low income countries where disability and poverty 'mutually reinforce each other' (WHO, 2020, online).

The UN Department of Economic and Social Affairs (2018, p.24) states that, despite the progress made in recent years, 'persons with disabilities continue to face numerous barriers to their full inclusion and participation in the life of their communities'. People with disabilities experience 'disproportionate levels of poverty', lack 'access to education, health services, and employment' (p.24). In non-conflict situations, people with disabilities can expect to meet barriers to inclusion because of discrimination and stigma associated with disability, and to have inadequate access to assistive technology, essential services, rehabilitation and support for independent living, all of which are essential to the full and equal participation of persons with disabilities (p.24). In conflict situations, such as the war in Syria, and where people are forced to flee their homes to live in refugee camps or to seek asylum, these problems are intensified, and obstacles to inclusion are compounded further by language barriers, cultural differences, isolation within camps in the host country, discrimination and racism, and risk of deportation (Amnesty International, 2020, online).

Definitions of disability vary, and different researchers will use different classifications. The International Classification of Functioning, Disability and Health (ICFHD)(WHO, 2001) explains disability as resulting from the interaction between individuals with a health condition, such as depression, and personal and environmental factors, including prejudicial attitudes, inaccessible transportation, limited social support and conflict. People with disabilities also tend to experience poorer health outcomes than their able-bodied peers, to have less access to education and work opportunities, and are more likely to live in poverty than those without a disability. Very often, people with disability do not receive the healthcare services they need.

In 2019, the London School of Tropical Hygiene and Medicine (LSHTM) undertook a study on the prevalence of disability (all ages) and mental health disorders (children) among Syrian refugees living in Istanbul, Turkey. The researchers followed the ICFHD developed by the WHO discussed above. The researchers used a population-based survey to estimate the prevalence of disability based on 80 clusters of 50 people who were selected through random sampling methods (total sample size of 4000). Eligible survey participants (aged 2 and older) were interviewed for self-reported disability using the Washington Group Short Set 'Enhanced' and Child Functioning Module (p.7). Every child aged 8-17 was interviewed for self-reported symptoms of common mental health disorders.

The researchers found that the overall prevalence of disability was 24.3%, and 52% had a mobility disability (p.7). Sixty percent of the study households included at least one member with a disability. Forty two percent of people with self-reported functional limitations reported the cause to be related to the war in Syria. With respect to mental health issues, 73% attributed elevated symptoms to violence, injury or trauma in Syria (40%) or Turkey (33%). Illness/disease was the most commonly reported reason for vision (49%), hearing (38%), and mobility (52%) difficulties (p.8). Children aged 7-17 years met the criteria for elevated symptoms of anxiety (8.9%), depression (12.4%), and/or PTSD (11.5%) (p.8).

Unsurprisingly, adults with disabilities were significantly less likely to have engaged in paid work. They were significantly more likely to report poor physical health/disability and mental health as the reason for not working than people without disabilities. These disabilities limited their activities and participation in, for example, the community, places of worship, work and education, and transport (p.10).

There are over 600,000 Syrian refugees in Jordan (UNHCR, 2020) and approximately 1.5 million Syrian refugees in Lebanon (Human Rights Watch, 2020, online). The prevalence of disability among the Jordanian and Lebanese populations are not dissimilar to the prevalence rates among Syrian refugees in Istanbul reported above. Humanity and Inclusion and iMAPP (2018) collected quantitative

from 6381 persons of randomly sampled 1159 households in Azraq and Zaatari camps and Irbid, Jordan, between October 2017 and January 2018. Using the UN's Convention on the Rights of Persons with Disabilities' (UNCRPD, 2006) definition of disability (which closely follows the ICFHD. See above) 22.9% of surveyed Syrian refugees aged 2 years and above had disabilities (1374 persons out of 6003 persons); 62% of sampled households included at least one member with disabilities; 29.9% of persons with disabilities reported illness or disease as the primary cause of functional difficulties (p.1). Just over 24% (24.7) reported that the Syrian conflict contributed to their illness/disease, injury and malnutrition. The most commonly reported disability was walking, followed by anxiety, depression, fatigue and visual impairment. There were also gender differences in the types of disabilities reported by men and women. More females (34.6%) than males (24.7%) had disabilities related to illness or disease; while more men had disabilities relating to injuries (14.7%) than females (7.1%), suggesting males' higher exposure to risks of injuries during conflict (p.1).

With respect to persons who experience functional difficulties despite assistive devices, the data show that 22.6% of those who use glasses, 19.0% of those who use hearing aids and 71.0% of those who use mobility aids continue to experience significant difficulties seeing, hearing and walking. The reasons for these functional difficulties were accounted for by inappropriate fitting of assistive devices and lack of regular maintenance and repair of the devices (p.2).

Humanity and Inclusion and iMAPP (2018) also undertook research on disability among Syrian refugees in Lebanon, collecting quantitative data from 2495 people from 506 randomly samples households in an urban setting in Bar Elias, the Informal Tented Settlements (ITS) in Bar Elias and Aarsal in December 2017. In this case, and with very similar results to Jordan, 22.6% of surveyed Syrian refugees aged 2 years and above had disabilities (529 persons out of 2338 persons); 26.8% of persons with disabilities reported illness or disease as the primary cause of functional difficulties. 38.9% reported that the Syrian conflict was the cause of their illness/disease, injury and malnutrition (p.1). As with the Syrian refugees in Jordan, the most common disabilities were anxiety, followed by depression, walking, fatigue and visual impairment (p.1). Once more, more women reported disabilities related to illness or disease (28.3%) than men (25.5%); while 17.7% of men reported injury as the cause of their disability compared to women (9.3%) (Humanity & Inclusion & iMAPP, 2018, p.1), no doubt as a result of men's higher exposure to risks of injuries during conflict.

The researchers also found that 18.9% of those who use glasses, 35.0% of those who use hearing aids and 65.4% of those who use mobility aids experience significant difficulties seeing, hearing and walking. The reasons for these continuing difficulties are related to poor infrastructure, and service providers' capacity to deliver and fit adequate devices, and problems long term with maintenance and repair (p.2).

Research data so far demonstrates that the prevalence of disability among Syrian refugees in the three countries in which they are displaced are similar: namely, illness, injury, mobility disabilities, mental health, aural and visual impairments, and lack of access to and repair of assistive devices. We will now report on the design of the research undertaken in Turkey.

The journey into vision impairment for people with acquired loss has been reported to be one in which changes in mobility, self and life can have negative impacts on mental health. Unless the individual with acquired vision impairment is able to accept the changed sense of self, and make adaptations to life, there can be mental health consequences (Thurston, McLeod & Thurston, 2013). Therefore, this research aimed to investigate the effects of acquired vision impairment for Syrian refugees in terms of their mobility and answer the following research questions:

What are the effects of vision impairment for Syrian refugees on mobility and life functioning?

What resources are required to help vision impaired Syrian refugees adjust to their disabilities?

Research design

The design selected for this research was survey methodology. This was selected for a number of reasons. Firstly, we wanted to research a population that was representative of the vision impaired Syrian refugee. It was also a pragmatic decision as Covid 19 made close contact for face-to-face data collection problematic during the period of the project.

Methods

Instruments

Two types of questionnaires were used for this study. The Visual Functioning Questionnaire-25 (VFQ-25) (Mangione et al, 2006), and Mobility and Life Space Questionnaire (Stalvey et al, 1999). The surveys were modified so as to be relevant to Syrian refugees, were translated into Arabic by two of the authors, themselves Syrian academics living in Turkey under temporary protection, who collected, collated and analyzed the findings in 2020.

The VFQ-25 is a public document, available to all researchers to use without charge. The VFQ-25 consists of a base of 25-vision targeted questions, representing 11 vision-related constructs, and a single-item general health rating question. The average time taken to complete the questionnaire was nine minutes.

The second questionnaire used was the Mobility and Life Space Questionnaire, devised by Stalvey, Owsley, Sloane and Ball (1999) but modified here to take account of the different living conditions of the refugees. The questionnaire included two groups of questions depending on where the refugees were located. Part 1: *Life Space in Urban and Rural Areas* is a 9-item closed questionnaire about how participants use space in and around their living space for which only 'Yes' or 'No' responses are required. For example: 'During the past 3 days, have you been to other rooms of your home besides the room where you sleep?' 1 = Yes 2 = No.

The second group of questions, Part 2: *Life Space in the Camps* is also a 9-item closed questionnaire about space mobility but was targeted to refugees living in refugee camps. There were again only two options, 'Yes' or 'No'. For example: 'During the past 3 days, have you been to another unit besides the unit of in which your family sleeps?' 1 = Yes 2 = No.

The next set of questions, Part 3: *Daily Life Activities* is a 12-item closed questionnaire on whether participants can make tea or coffee, buy groceries or play football (see Appendix 3). Question 13 was an open-ended question on whether there was anything the respondents wished they could do but no longer can, such as play football. It took on average seven minutes to complete this questionnaire.

Sample size

The sampling size was estimated using the following website: <https://www.qualtrics.com/blog/calculating-sample-size>, which gave 385 as an appropriate sample size for 3.6 million Syrians living in Turkey. The number of collected responses was 495 for the first survey, while the number of collected responses for the second survey was 567.

Data and analysis

The data analysis process was divided in two analyses according to the questionnaire. The first analysis was related to VFQ-25 Questionnaire, while the second analysis was related to Mobility and life-space Questionnaire.

Data analysis for the first questionnaire, VFQ-25

A composite score was found for every participant based on the answers for the 25-questions. The scoring procedure are performed on two-step process:

First, original numerical values from the survey are re-coded following the scoring rules outlined in Table 1. All items are scored so that a high score represents better functioning. Each item is then converted to 0 to 100 scales so that the lowest and highest possible scores are set at 0 and 100 points, respectively. In this format, scores represent the achieved percentage of the total possible score, for example, a score of 50 represents 50% of the highest possible score.

In step 2, items within each sub-scale are averaged together to create the 12 sub-scale scores. Table 2 indicates which items contribute to each specific sub-scale. Items that are left blank (missing data) are not taken into account when calculating the scale scores. Sub-scales with at least one item answered can be used to generate a sub-scale score. Hence, scores represent the average for all items in the sub-scale that respondent answered.

The Composite Score Calculation:

To calculate an overall composite score for the VFQ-25, simply average the vision-targeted sub-scale scores, excluding the general health rating question. By averaging the sub-scale scores rather than the individual items we have given equal weight to each sub-scale, whereas averaging the items would give more weight to scales with more items.

An example of scoring procedure for the answers given in Fig. 1, is shown as follows:

Scoring example- Fig. 1:

Items 5, 6, and 7 are used to generate the near activities sub-scale score (Table 2). Each of the items has six response choices. Response choice 6 indicates that the respondent does not perform the activity because of reasons that are unrelated to vision. If a respondent selects this choice, the answer is treated as missing and an average of the remaining items is calculated. Response choice 5 indicates that an activity is so difficult that the participant no longer performs the activity.

This extremely poor near vision response choice is recorded to "0" points before taking an average of all three items. To score all items in the same direction. Table 1 shows that responses 1 through 5 for items 5, 6, and 7 should be recorded to values of 100, 75, 50, 25, and 0, respectively. If the respondent is missing one of the items, the person's score will be equal to the average of the two non-missing items.

Formula:

$$\text{Mean} = \frac{(\text{score for each items with a non - missing answer})}{\text{Total number of items with non - missing answers}}$$

Example:

$$\text{with responses converted } \frac{(25 + 100 + 25)}{3} = 50$$

Analyses of the life-space questionnaire

The life space questionnaire is reported to have good reliability, and to have construct and criterion validity in a sample of adults with test, retest reliability being 0.80 for the overall instrument in a sample of 200 adults aged > 55 years old, 112 males/88 females, 34 African Americans, 166 White Americans, over a period of three years (Stalvey et al., 1999).

The Capability Scores were assessed based on Q1 to Q12. The scoring procedure is as follows: for one participant, if all answers are yes, then the capability score of 100% is set, while if all answers are no, then a score of 0%, is set. Thus, if only six answers are yes, then the capability score of 50% is set. Similarly, if all answers are yes to questions 15 to 23, a 100% mobility score is set. If all answers are no, a mobility score of 0% is set. If six answers are yes, then the mobility score is 50%.

In addition to finding these scores, statistical data was found using Excel. Built in functions, such as *maximum*, *minimum*, *average*, and the standard deviation are used. For more clarity, the normal distribution

Table 1
Example scoring key recording of items.

Item number	Change original response category	To record value of
1, 2, 4, 15c	1	100
	2	75
	3	50
	4	25
	5	0
	6	0
2	1	100
	2	80
	3	60
	4	40
	5	20
	6	0
5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 16a, A3, A4, A5, A6, A7, A8, A9	1	100
	2	75
	3	50
	4	25
	5	0
	6	*
17, 18, 19, 20, 21, 22, 23, 24, 25, A11a, A11b, A12, A13	1	0
	2	25
	3	50
	4	75
	5	100
	6	0
A1, A2	To	To
	100	100

Table 2
Method of averaging of Items to generate VFQ-25 sub-scales.

Item number	Change original response category	To record value of
1, 2, 4, 15c	1	100
	2	75
	3	50
	4	25
	5	0
	6	0
2	1	100
	2	80
	3	60
	4	40
	5	20
	6	0
5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 16a, A3, A4, A5, A6, A7, A8, A9	1	100
	2	75
	3	50
	4	25
	5	0
	6	*

curve of the set of data are also plotted and depicted in the findings section.

Qualitative instrument

Data was collected on wellbeing and general life functioning using both open questions in the initial survey, and an 18-item, open free text answer questionnaire on vision loss sent to a sub-group of the sample. The questions in each questionnaire ranged from how the participant’s sight deteriorated, how the participant learned about the vision loss, to how the participants feel about their wellbeing, identity, sense of belonging, relationships with family and counseling.

Analysis of qualitative questionnaire

Data was analyzed using open coding to look for emergent themes. This was done by collating all responses and looking at the themes that emerged (following the method of grounded theory proposed by Strauss and Corbin (1990). Quotations are presented for eight participants, who were asked for follow-up data on their responses.

Results

The results section is divided into two parts according to the questionnaire type. The first finding is related to VFQ-25 Questionnaire, while the second finding is related to Mobility and Life-space Questionnaire.

Sample composition

The sample was composed of 345 males and 112 females, and was widely distributed across 25 provinces in Turkey. The numbers in each province are not reported here to prevent unintentional disclosure. There were 382 respondents living in cities, 87 living in rural areas and 26 living in refugee camps.

Results of the VFQ –25 questionnaire

Four hundred and ninety participants responded to the first questionnaire VFQ-25. The gender distribution indicated that the number of

5. How much difficulty do you have reading ordinary print in newspapers? Would you say you have:

- No difficulty at all..... 1
- A little difficulty 2
- Moderate difficulty 3
- Extreme difficulty(4)
- Stopped doing this because of your eyesight..... 5
- Stopped doing this for other reasons or not interested in doing this..... 6

Fig. 1. Example of VFQ-25 Scoring Algorithm for Near Activates Sub-Scale.

6. How much difficulty do you have doing work or hobbies that require you to see well up close, such as cooking, sewing, fixing . . . ? Would you say you have:

- No difficulty at all.....(1)
- A little difficulty 2
- Moderate difficulty 3
- Extreme difficulty 4
- Stopped doing this because of your eyesight..... 5
- Stopped doing this for other reasons or not interested in doing this..... 6

7. Because of your eyesight, how much difficulty do you have finding something on a crowded shelf? Would you say you have:

- No difficulty at all..... 1
- A little difficulty 2
- Moderate difficulty 3
- Extreme difficulty(4)
- Stopped doing this because of your eyesight..... 5
- Stopped doing this for other reasons or not interested in doing this..... 6

Table 3
Results of averaging items.

No	Scale	Sample size	Arithmetic means	Variance	Standard deviation
1	General Health	392	26.5	611	27.0
2	General Vision	392	26.5	611	49.4
3	Ocular Pain	391	60.7	329	60.7
4	Near Activities	385	48.8	611	48.8
5	Distance Activities	384	52	661	52.0
6	Social Functioning	379	61	818	60.9
7	Mental Health	390	53.6	486	53.8
8	Role Difficulties	344	59.3	724	59.3
9	Dependency	345	55.8	844	55.8
10	Driving	67	46.9	1414	42.9
11	Color	371	66.3	889	67.1
12	Peripheral Vision	376	53.2	776	53.9

females was significantly fewer than the number of males, 25.9% compared to 74.1%. The low response can be explained by the fact that Syria is a conservative society; men travel, women tend to stay at home. Many more men were also involved in the war compared to women and so were more vulnerable to mobility disability. Research by the UNHCR (2016) reported that in refugee populations women, the elderly and the less educated often have less access to mobile phones and the internet, and that access is often determined by cultural and social norms. However, even in non-refugee populations, women in low and middle-income countries are 21% less likely to own a mobile phone than men (p.16).

According to the procedure explained in the data analysis section, the VFQ Composite Score is found as 53.2% which is quite low.

The 12-sub-scale scores are calculated and tabulated in Table 3. In addition to the sample size, arithmetic mean, variance, and

standard deviation are also calculated and listed in the same table.

The normal distribution curves for the 12-sub-scales are plotted in Fig. 2. The distributions show a general trend that reveals floor effects for all sub-scales, with the normal distribution shifted to below/above the expected mean dependent upon the directionality of the scales. It indicates that for the refugee sample surveys:

- General health is lower than population means.
- General vision is reported to be poorer than population means.
- Ocular pain is reported to be higher than population means.
- Near and distance activities roughly map on population means.
- Social functioning shows is reported to be higher than population means.
- Self-reported mental health is similar to reported population means.
- The refugees reported more role difficulties

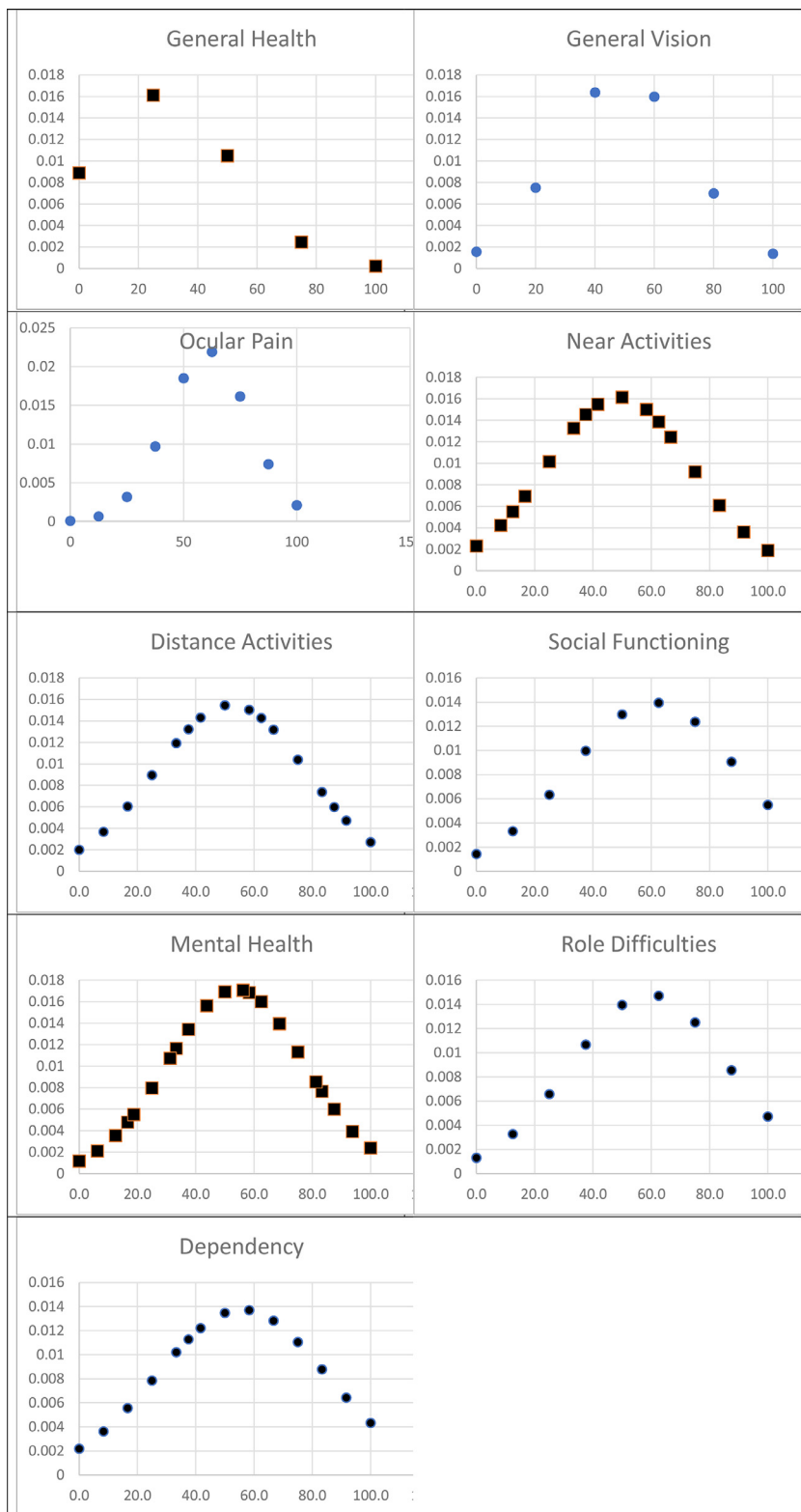


Fig. 2. Normal distribution for the 12-sub-scale of VFQ-25.

The refugees reported higher than usual dependency on help from others.

Previously reported NEI VFQ scores in the German Guttenberg Health Study indicated that mean scores across the scales were 86.94 (Nickels, Schuster & Singer, 2017). Our sample, means were considerably lower than these means.

Results of the life space questionnaire (Q1-Q25)

Capabilities

Syrian refugees showed similar capabilities responses to those previously reported for this instrument. With minimum reported Capability

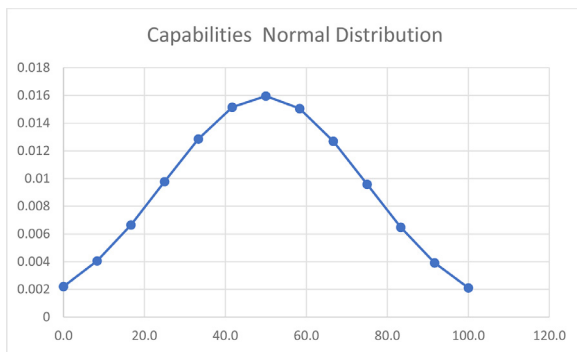


Fig. 3. Normal distribution curves for participant capabilities.

Score of 0%, maximum Capability Score of 100%, mean, the Capability Scores of 49.8% (SD 25) reported by the respondents, are very similar to previous populations. The normal distribution curves for participants based on capability score is plotted in Fig. 3.

Mobility scores

The mobility scores revealed a different pattern to those of Capabilities. With a minimum and maximum Mobility Score of 0 and 100%, respectively, it was found that mean reported Mobility score was 32% (SD 26). The normal distribution curve presented in Fig. 4, showed floor effects for the Syrian refugee sample.

Overall, the Life Space Questionnaire means were lower than previously reported for post-stroke populations where mean scores in a population of 34 post-stroke patients were between 62.2 and 63.15 (Yang et al., 2017). The scores are also lower than the mean scores reported for a geriatric population of 3892 community dwelling mean aged 71–98 years-old, where mean scores reported on the Life Space Questionnaire were ranged from 41.7 to 64.5 (Crowe et al., 2008).

Qualitative data on the effects of visual impairment on wellbeing and identity

The participants were also asked to respond to an 18-item questionnaire on vision loss. The questions ranged from how the participant's sight deteriorated, how the participant learned about the vision loss, to how the participants feel about their wellbeing, identity, sense of belonging, relationships with family and counseling. Eight people were followed up to expand on their responses to the questionnaire. The responses of most participants in the initial survey were brief or closed (yes, no). This may reflect their reticence to give out potentially disclosive information, or their literacy level. However, the more detailed follow-up questionnaire responses from the eight identified respondents produced data that could be coded.

Help from counseling

Access to counseling was rare. Only one of the participants sought counseling. One participant was advised to control their diabetes, while the remainder did not seek help because services were non-existent, there was no treatment available, or regarded it as a natural affliction. None of the participants were offered practical help and would have preferred counseling when they were first diagnosed. The majority of respondents agreed that the emotional impact of vision loss should be taken into account by those who diagnose the problem and counseling should be offered in support groups, face-to-face or by which ever method yield the best results. Counseling has been reported to be effective at promoting better mental health for those experiencing acquired vision impairment (Thurston et al., 2013). However, the absence of services may be having a negative long-term impact on Syrian refugees.

Effects on mood

Reporting a change in mood was common amongst participants:

I am no longer confident ... and I am depressed about this and the fear that I feel. I cannot do anything because of the lack of money. I was doing sport, but my determination has weakened, and I stopped because of my vision. Participant 7

Yes, my psychological state has changed a lot because I can no longer work, drive a car or work on a computer. Participant 8

Activities

Respondents reported the sort of therapeutic activity in which they were able to engage, although it was reported that there were few such activities.

No, I do not have [any activities] because I cannot afford basics or good food ... I am jobless and in a lot of debt. Transport costs, going to hospital and rent, the debts are accumulating because I do not have a breadwinner and I have a family. Participant 6

One participant explained that they do 'spiritual things'.

Sense of self

The majority of participants' sense of self has also been impacted. One described how they felt that they were 'less than others'; another that they would be able to do 'lots of things' if they could 'see well'.

Yes, I was very active and confident. I practiced sports. I was a football club player and a sports teacher. When I lost my sight, I became frustrated. Participant 7

With respect to their relationships with their family, place in society and how others treat them then this did present some challenges for participants:

The general feeling is frustration and sometimes sadness from being treated with others' pity. Participant 5

Of course, society makes you feel that you are a consumer and not a producer, and this is very annoying. Participant 4

Changes in sense of self and relationships with other have previously been reported to have an impact on those with acquired sight loss (Thurston, Thurston & McLeod, 2010). The Syrian refugee group will, no doubt, have a similar journey to make, as Thurston, Thurston and McLeod attested in their own research (2010). A vital part of the journey into sight loss is the ability to come to terms with the loss and experience a new sense of self, and education is an essential part of the process. However, Syrian refugees face the additional challenge that resources (such as mobility training and low vision aids) are not available. Without mobility training and access to low vision aids to help with reading documents, accessing the curriculum, and negotiating the school or higher education (or workplace) environment, this will prove very difficult.

Conclusion

The main challenge in conducting this research was in reaching people displaced and dispersed over a large geographical area. Initially, few responded to the surveys that were put out on social media. However, the response rate improved when the first two researchers took out paid advertisements and used their networks to contact people. The length of the survey was also inhibiting, and we found that respondents were unwilling to complete both questionnaires. Nevertheless, a good response rate to both surveys was obtained. By contrast, the sample used to follow up the qualitative questionnaire was very low, and further work

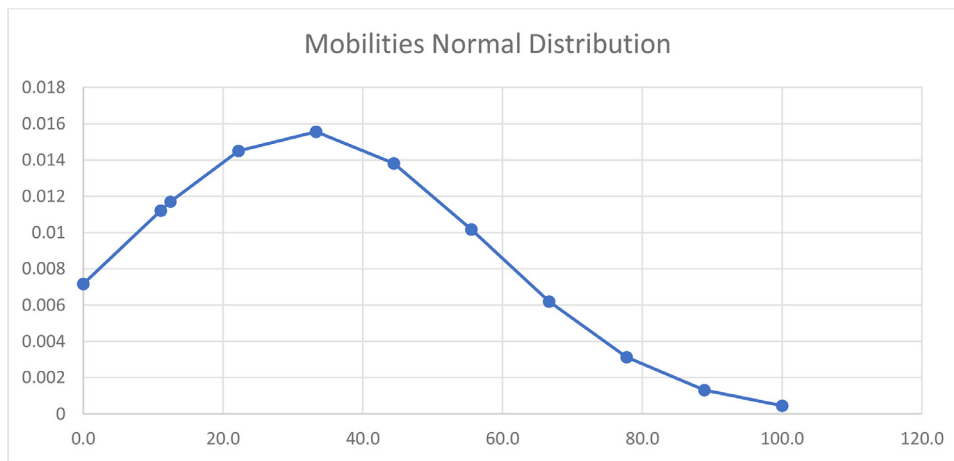


Fig. 4. Normal distribution curve of participant capabilities.

is required to explore in more detail the mobility and lifestyle issues reported in the main sample.

Despite these challenges and limitations, the survey allowed us to obtain a data on disabled Syrians refugees which can be used for further analysis. The international comparisons indicate that this sample of disabled Syrian refugees is particularly vulnerable. They report lower mobility and multiple socio-emotional issues with vision impairment. There is also evidence that there is little, if any, health, rehabilitation, education and mental health help available to them. And we know that the role of education in helping those with disability has been found to be important to sense of self, wellbeing, confidence and motivation. For example, a systematic review of 23 studies concluded that education had an important role to play in the route to employment (Nevala, Pehkonen & Teittinen, 2019). Education is also cited as being vital to best practice by the Council of Europe (2003).

The civil war and the subsequent forced displacement of five million Syrians in neighboring countries has exposed them to trauma, unemployment, poverty, loss of social support and primary care, as well as to education. Turkey has played a significant humanitarian role in giving refuge to such a large percentage of Syrian refugees; nevertheless, it remains clear that they need access to education, medical services, health care and employment if they are to lead lives on the basis of equal dignity and respect, and achieve human flourishing.

Declaration of Competing Interest

There are no conflicts of interest. In recognition of the importance of reflexivity in the process of the research, two of the authors are Syrian refugees and one of the mentors has cognitive vision impairment. This was always acknowledged by the team, and they sought not to bias their selection of instruments and interpretation of the data as a consequence of their place within it.

Funding statement

The authors were supported by CARA, the Council for at Risk Academics, and mentored by the third and four authors, academics from Queen's University, Belfast, UK. The authors received a small grant of circa £3000 to collect the data.

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