Mental illness in Palestinian refugees living in refugee camps in Jordan: barriers to access and use of mental health care services and recommendations to overcome such barriers.

Callum McKell

### **Abstract**

### Aim

To review barriers to access and use of mental healthcare services in Palestinian refugee camps in Jordan, in order to provide recommendations to overcome such barriers.

### Introduction

There were 19.5 million refugees across the world in 2014. Refugees often experience traumatic events, which combined with stressful living conditions in refugee camps such as violence and overcrowding, results in higher prevalence of mental illness than in other populations.

Of the world's refugees, 5.1 million are Palestinians, 2.1 million of which reside in Jordan following the Arab-Israeli conflicts.

The long-term nature of Palestinian refugees in Jordan means many of the population have lived their whole lives in camps, and so have been continually exposed to stressful living conditions. This has resulted in many Palestinian refugees being at risk of developing mental illness.

Barriers to Arab populations accessing and using mental healthcare services are known of, however little literature has identified barriers and solutions to overcome them specifically in Palestinian refugees in Jordan.

### Methods

16 qualitative semi-structured interviews were conducted with medical professionals working at health centres in Baqa'a refugee camp during May 2015. Thematic analysis was used to analyse interview transcripts.

### **Findings**

Barriers were identified in all 16 interviews. Resource and financial deficits were the most commonly identified barriers. Sex, stigma, religion and culture were also identified as barriers to access and use of mental healthcare.

### Discussion

All participants identified high prevalence of mental illness in the refugee population, although quantitative research is still required to clarify its true extent. Mental health services in the refugee camps were found to be inadequate for providing needed care, with similar issues seen in other Arab states.

Barriers identified in this report are primarily social and cultural, rather than previous research which places more emphasis on organisational factors.

Recommendations to overcome identified barriers are presented.

# Contents

List of figures	5
List of tables	5
List of acronyms	5
1. Introduction	6
1.1 The global plight of refugees	6
1.2 The global burden of mental illness	6
1.3 MI in refugees	7
1.4 MI in Palestinian refugees in Jordan	7
1.5 Barriers to access and use of MH care services	7
1.6 Aims and Objectives	8
Aim	8
Objectives	8
2. Methods	9
2.1 Study Design	9
2.2 Study Location	9
Jordan	9
Baqa'a Refugee camp	9
2.3 Sampling and Study Participants	10
2.4 Data collection	11
2.5 Data Analysis	11
2.6 Methodological limitations	11
3. Findings	12
3.1 The prevalence and types of mental illness in Baqa'a refugee camp	12
Prevalence	
Types of MI	12
MI in different age cohorts	12
3.2 MH services available	13
MH provision	13
Treatment for MI	
3.3 Barriers to access and use of MHC	14
Stigma	14
Sex	
Religion	15
Resource and financial deficits	
4. Discussion	17
4.1 The prevalence and types of MI	
Recommendation 1: Further Research	17
4.2 MH services available	
Recommendation 2: Integration of MHC into general practice	18
4.3 Barriers to access and use of MHC	
5. Competing interests	
Reference list	
Appendix	
Interview question guide	

# List of figures

Figure 1. Global distribution of refugee populations by regions	.6
List of tables	
Гable 1. Inclusion and Exclusion Criteria1	0
Table 2. Barriers1	4

# List of acronyms

MI Mental illness
MH Mental health

MHC Mental healthcare

UNRWA United Nations Relief and Works Agency

PTSD Post-traumatic stress disorder

GBV Gender based violence

### 1.Introduction

### 1.1 The global plight of refugees

There were 19.5 million refugees across the world at the end of  $2014^{(1)}$ . This had increased by 2.9 million persons from  $2013^{(1)}$ , largely due to the on-going Syrian conflict<sup>(1,2)</sup>.

A refugee is defined as: 'A person who owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country'(3).



Figure 1. Global distribution of Refugee populations by regions. Adapted (1,4,5).

### 1.2 The global burden of mental illness

Mental illness(MI), a disturbance in the psychological and emotional well-being<sup>(6)</sup> of an individual, is highly prevalent across the world, with  $29.2\%^{(7)}$  of the global population experiencing a MI at some point in their lives.

### 1.3 MI in refugees

The experiences of refugees that drive them from their home nations are often traumatic, in particular the effects of war<sup>(8)</sup>. This combined with stressful living conditions in refugee camps such as overcrowding, violence and lack of employment<sup>(9)</sup> results in the prevalence of MI in refugees being high relative to other population groups<sup>(9-11)</sup>. Studies have identified up to 43% of refugees as having MI<sup>(9,10)</sup>.

### 1.4 MI in Palestinian refugees in Jordan

Of the world's 19.5million refugees<sup>(1)</sup>, 5.1million are Palestinians<sup>(1,12)</sup>, displaced as a result of the 1948 and 1967 Arab-Israeli conflicts<sup>(12)</sup>. The Palestinian refugee diaspora is spread across the Middle East, with refugees in the Gaza strip, West Bank, Lebanon, Syria and Jordan<sup>(13)</sup>. Of these, 2.1million Palestinian refugees live in Jordan<sup>(13)</sup>.

Despite the long-term duration of Palestinian refugees in Jordan, 370,000 Palestinians continue to live in refugee camps, as they cannot afford to leave<sup>(13)</sup>. Consequently many Palestinian refugees are second generation, and so have not fled the Palestinian Territories, nor been exposed to conflict<sup>(12)</sup>. They have however lived their lives entirely in refugee camps, and so been continually exposed to highly stressful conditions, including poverty, violence and overcrowding<sup>(9,14)</sup>, all of which are known to have damaging effects on mental health(MH) in refugees<sup>(15-19)</sup>.

### 1.5 Barriers to access and use of MH care services

Barriers to Arab-refugees accessing mental health care(MHC) are known of, in particular stigma and lack of education<sup>(20,21,22)</sup>. Such barriers are detrimental to MH, preventing refugees accessing MHC, and so exacerbating MI<sup>(20-22)</sup>. However,

such research, specific to Palestinian refugees in Jordan remains woefully unexplored<sup>(22)</sup>.

### 1.6 Aim and Objectives

**Aim:** To review barriers to access and use of MHC services in Palestinian refugee camps in Jordan, in order to provide recommendations to overcome such barriers.

### **Objectives:**

- To identify the prevalence and types of MI in the refugee population of Baqa'a Palestinian refugee camp in Jordan
- 2. To identify the MH services available in Palestinian refugee camps in Jordan
- 3. To identify barriers to access and use of MHC in Palestinian refugee camps in Jordan
- 4. To offer recommendations for improvement of MHC in Palestinian refugee camps in Jordan

# 2.Methods

### 2.1 Study Design

This study uses a cross-sectional, qualitative design. The barriers investigated in this study will be better understood using a qualitative methodology, as this will allow questions to be asked that seek to understand the 'what, how or why' (23) of such barriers, and not just quantifying them.

### 2.2 Study Location

### Jordan

Jordan is a middle-income country $^{(24)}$  located in the Middle East. Jordan hosts ten Palestinian refugee camps $^{(12,13)}$ .

### Baqa'a Refugee Camp

Located 20 kilometres north of Amman, Baqa'a refugee camp is the largest Palestinian refugee camp in Jordan, home to 104,000 Palestinians over a  $1.4^2$  kilometre area<sup>(13,25)</sup>. Of the 16 interviews conducted in this study, 14 were conducted in health centres at Baqa'a, with the remaining two conducted at the headquarters of the United Nations Relief and Works Agency(UNRWA) in Jordan.

### 2.3 Sampling and Study Participants

Participants interviewed for this study were purposively sampled, using a UNRWA director as a gatekeeper. The following inclusion and exclusion criteria were applied:

Table 1.Study Criteria

Inclusion Criteria	Exclusion criteria
<ul> <li>A doctor, nurse or medical professional with regular patient contact at a health centre in Baqa'a Camp</li> <li>Medical staff working for the Field Health Programme at UNRWA headquarters in Jordan</li> </ul>	<ul> <li>A non-medical professional</li> <li>Palestinian refugees</li> </ul>

Research suggests a sample of 12-15 interviews is required<sup>(26-29)</sup> to reach saturation in qualitative research. In this study, a sample of 16, including one focus group were interviewed.

Participants were recruited by the gatekeeper, and shown the research information sheet before meeting the researcher, so to have time to consider consenting to the study.

No refugees were asked to participate in this study. Considering the stressful experiences many have faced and would have to recall in an interview, combined with the relative inexperience of the researcher to interview vulnerable persons, this would be unethical practice. Instead medical professionals involved in delivering health care to the refugees were interviewed.

### 2.4 Data collection

Data was collected over three weeks in May 2015, using semi-structured interviews. Interviews ranged from 40 to 60 minutes in length, and were audio recorded.

A translator was used in seven of the 16 interviews, and was familiarised with the question sheet, so to improve interpretation<sup>(30-32)</sup>.

Ethical approval was granted by the University of Leeds and UNRWA. All participants were given information sheets, in both English and Arabic, to read before the interviews, and signed a consent form to acknowledge they understood the aim of the study and any possible uses for data.

### 2.5 Data Analysis

Thematic analysis<sup>(23,33)</sup> was used to analyse the data. This involved the 'cut and paste technique', with all 16 interview transcripts printed out and cut into sections under broad themes<sup>(23,33)</sup>. Broad themes were identified using deductive reasoning, as they resulted from the question matrix(see appendix) and the research objectives. Following this, more specific codes, also based on the question matrix, were noted within the broad themes and data reclassified under the codes<sup>(23,33)</sup>. Data not classified under any of the deductive codes were then inductively coded.

### 2.6 Methodological limitations

 Use of purposive sampling may have biased the results of the study, as the gatekeeper chose whether or not a participant was asked for interview.
 As such, the selection of participants may have been biased and so affected the resulting data. 2. Use of a translator for some of the interviews may have caused loss of accuracy, as whilst a literal translation was instructed, this may not have always occurred<sup>(23)</sup>.

# 3.Findings

### 3.1 The prevalence and types of MI in Baga'a refugee camp

### Prevalence

The prevalence of MI in Palestinian refugees was acknowledged to be high by all participants. However, the extent to which participants deemed it was prevalent fluctuated significantly. No participant knew of an official figure for MI prevalence in Baqa'a or Palestinian refugees in Jordan. Several stated prevalence to be between 20-50%, with three participants estimating it to be as high as 75%. Such variation may reflect misunderstanding in staff of what constitutes MI, or lack of diagnostic standards.

Under diagnosis was also reported by four participants, whom identified lack of knowledge in refugees on MI and social pressures as reasons for this.

'Many of them have these disorders hidden, which they do not admit for many reasons'. Participant 8.

### Types of MI

Depression and anxiety were reported as the most prevalent MI in the refugees, with every participant naming depression and 11 anxiety. Psychosomatic illness was also noted, but with only three participants describing it.

One participant noted that unlike in other refugee populations, PTSD is not a MI found commonly in Palestinian refugees in Jordan. This is potentially reflective of the long term and relatively safe residency of this group to compared to others less fortunate.

### MI in different age cohorts

Teenagers were described as a cohort particularly at risk, due to lack of education and less opportunities to enjoy themselves. One participant noted at this age, refugee teenagers start to compare themselves to Jordanians and realise that they have less opportunity and legal rights.

Women aged 15-40 was another specific cohort identified by several participants. Young marriage and caring for multiple children when still young, whilst in poverty and frequently being victims of gender based violence(GBV) causes stress and MI in many women of this age.

'She will get engaged and she doesn't know how to lead a life and when she gets baby she will be unnatural how to do the motherness. At the age of 14/15 being a mother is a big problem for her'. (Focus-Group).

### 3.2 MH services available

### MH provision

No dedicated staff or clinics for MH at UNRWA health facilities in Baqa'a exist. Subsequently, refugees with MI are often referred to government hospitals. However, this is often unaffordable to many refugees, as UNRWA only subsidises refugees admitted to hospital – and MH patients are seen as outpatients.

The costs to refugees of transport to appointments, both in Baqa'a and at the government hospital, are also prohibitive. Given the long term nature of MIs, and the numerous follow-up appointments required, this is often too expensive and difficult for refugees, and so their illnesses worsen.

'Sometimes patients when they come here(Baqa'a) they do not have 1JD(£0.95)... for the bus, so they are walking great distances.... Many cannot afford to come back for follow up appointments, so they give up. Mental health needs more follow up, more visits'. Participant 5.

### Treatment for MI

Despite lack of MH services, some treatments are available from General Practitioners in Baqa'a, although many participants expressed little confidence in prescribing medicines for MI, citing lack of necessary medicines, knowledge and prescribing guidelines.

Medications are free from the health centres in Baqa'a, however many participants blamed charges at government hospitals as a deterrent to more advanced treatment, with many of the refugees who are referred unable to afford to buy medicines there, and consequently continue to suffer.

No counseling for MI is provided at Baqa'a. Lack of training in counseling, insufficient funds and the large amount of patients seen by staff per day were reasons for this.

'I have too many patients in a day, often more than 80 a day. I don't have enough time to stay and talk'. Participant 8.

### 3.3 Barriers to access and use of MHC

Specific barriers were identified in all interviews, as shown in Table 2.

Table 2.Barriers

Barriers	Interviews in which identified
Stigma	1-4,6-9,11,12,15,16(n=12)
Sex	1-9,11-16(n=15)
Religion	1,2,4-9,12,14-16(n=12)
Resource and financial deficits	1-16(n=16)

### Stigma

12 participants mentioned stigma as a significant barrier to access and use of MHC. Stigma affects both sexes, however women are much more affected than men. Men, should they require MHC, may go to see a doctor on their own, under the guise of another illness. Women however must seek permission from their fathers or husbands, and justify why they need to go to a doctor. A woman admitting MI is a source of great embarrassment to men, and so women whom admit to a MI are often divorced, or her husband marries another wife, making her a lesser wife.

'They think if they seek this kind of assistance they will be considered crazy, and disqualified totally from social acceptance....the whole family could be disqualified from society'. Participant 9

### Sex

Being a woman was identified by all except one participant as a barrier. In addition to the threat of divorce, younger women known to have had a MI will not be able to marry ever-such is the shame of MI. Many women also try to hide MI as they fear, or rather, they know they will be beaten for having an illness which if publically known would shame her family.

Men were described as facing far fewer barriers, although MI is still controversial for them. However, men are still able to marry and be socially accepted after their MI, unlike women.

'No one will marry a girl if she is known to have had a mental illness. Mental health does not affect men as much – they can still marry. It is more of a problem for women'. Participant 3

### Religion

Amongst Muslim Palestinians certain interpretations of Islam exist as major barriers to accessing and using MHC.

Many participants mentioned how through misunderstanding and ignorance, Muslim refugees often do not access care, contrary to the teachings of the Qur'an. 'There are proverbs in....Islam books that encourage people to look for treatment. A good believer will not wait'. Participant 2

Instead, many refugees believe MI to be a punishment, and so do not access medical help.

'They think I am sick, because I did something wrong and God wants to punish me,.

And if I go to seek treatment this is against God's will'. Participant 8

Consequently, most refugees at first do not go to doctors for help, but rather spiritual healers. This is also more desirable as there is no stigma attached to visiting a spiritual healer, as people will largely assume refugees are visiting them for religious counsel, not treatment. Furthermore, doctors are seen to take a long time to cure MI, where as spiritual healers claim to heal instantly.

Participants described how refugees, through their misunderstandings of Islam and MHC, believe more in the power of spiritual healers than doctors. As a result, many refugees are exploited by these healers, paying more than they would in a hospital, for exorcism methods including being beaten with a stick.

### Resource and financial deficits

Every participant mentioned resource and financial deficits as a key barrier to providing MHC to refugees. More training, employing specialists, improving referral systems and drug selection were the resources mentioned as essential to improving care. However, UNRWA simply cannot afford to fund these resources.

'We have chronic financial resources....This is a real challenge'. Participant 1.

MH was also described as being so underfunded that sometimes health centres cannot even afford psychiatric drugs for patients.

'We have some medication for depression...sometimes it is available for one month then for two months we don't have it'.(Focus-Group)

### 4.Discussion

### 4.1 The prevalence and types of MI

Albeit unspecific in quantity, all participants in this study identified a high prevalence of MI in the Palestinian refugee population of Jordan, typically between 20-50%. This high prevalence correlates with previous research into Arab refugee populations<sup>(11,15-19)</sup>. However, whilst other studies have found rates of up to 94.9% of refugees having anxiety and 40% depression<sup>(18)</sup>, there is a fundamental difference between other Arab refugee populations and Palestinians in Jordan:exposure to war and conflict. Whilst the significantly increased anxiety levels in other populations<sup>(18)</sup> reflects exposure to traumatic events, the similar rates of depression suggests that the psychological impact on Palestinians of living long-term in refugee camps, exposed to stressors such as violence, poverty and overcrowding<sup>(9)</sup>, is perhaps as likely to cause depression as exposure to conflict.

With many of the world's 19.5million refugees<sup>(1)</sup> living in camps, this finding has an important implication for refugee MHC, showing the powerful effect of living conditions in refugee camps on MH. As such, refugee camps particularly in Jordan, must be better managed to reduce living stressors known to impact negatively upon MH.

It is however important to acknowledge that prevalence figures in this report are estimates, not proven figures, with no literature having yet quantified the true prevalence. Therefore whilst this finding is shocking and important for refugees MH, it is limited by lack of quantifiable data on the observed effect.

### Recommendation 1: Further research

UNRWA should conduct quantitative research using data from medical records, consultations in camp health centres and public surveys that seeks to determine the true prevalence of the different types of MIs present in Palestinian refugee

camps in Jordan. Knowing the true extent is key to understanding the effect of camp conditions on MH, and formulating strategies to reduce these.

### 4.2 MH services available

The need to improve the quality and affordability of MHC, whilst reducing stigma was identified by many participants as essential to improving MH. Such needs have also been noted in other Palestinian and Arab refugee populations across the Middle East<sup>(11,20-22,34)</sup>. This suggests medical professionals, particularly general practitioners in refugee camps throughout the Middle East are severely lacking in MH training, resources and treatment knowledge<sup>(20-22)</sup>. This is particularly problematic considering many Arabs will refuse referral to specialist care to avoid the stigma of MI<sup>(20)</sup>. Integration of MHC into general practice has been suggested in Kuwait<sup>(21)</sup> as a way to reduce stigmatisation, however this can only be effective if staff are sufficiently trained with appropriate resources, and services are affordable to refugee populations.

### Recommendation 2: Integration of MHC into general practice

To overcome the barrier of stigma against use of specialised services, and to improve MHC offered in Palestinian refugee camps, UNRWA should integrate MHC into general practice at its health centres in Jordan. This approach should consist of hiring a psychosocial counselor for each health centre, more training for staff on MHC, and implementing protocols for management of MI.

### 4.3 Barriers to access and use of MHC

Barriers in many Arab populations to accessing MHC are well documented<sup>(20-22)</sup>. However, very little literature has investigated MH and barriers to MHC use in Palestinian refugees in Jordan<sup>(11)</sup>.

Previous literature cites barriers to accessing MHC to be primarily organisational<sup>(22,35,36)</sup>, with lack of training and insufficient political will seen as the biggest obstacles. However, this report concludes that in UNRWA, the

political will is present to improve MHC, but the knowledge required and financial means are not.

Socio-cultural barriers have also previously been described<sup>(20-22,35)</sup>,although literature places a lesser emphasis on these barriers compared to this study. Furthermore, this report adds knowledge about the impact of socio-cultural barriers on accessing and using MHC in Palestinian refugee camps in Jordan. In particular, it offers improved understanding of the impact of sex, religion and spiritual healers as barriers. Applying these findings to other Arab refugee populations, in particular those who continue to be displaced by the Syria conflict<sup>(2)</sup> may help in establishing MH services that are culturally sensitive and are not as impeded by barriers.

### 5. Competing interests

The author declares no competing interests. This research was self-funded.

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# **Appendix**

### 1. Interview question guide

# <u>Investigating barriers to accessing and using mental health services for refugees in Jordan</u>

# Interview guidance sheet Interview number: Date of interview: Place of interview: Duration of interview: Persons present during interview (ie researcher, translator and interviewee (who remains anonymous)): Occupation (and position/ grade within profession and refugee camp) of participant: Type of involvement, if any, with the Jordanian government, the UN or any other humanitarian NGO or body: Nationality: Any notable events that are spoken of or that occur during the interview:

### The interview

### Introduction:

- 1. Researcher states their name and asks for confirmation of participants name (which will remain anonymous)
- 2. Researcher reminds the participant of the aim of the study: 'To review barriers to access and use of mental health care services in Jordanian refugee camps, in order to provide recommendations to overcome such barriers'.
- 3. The information sheet and the consent form are reviewed by the researcher and participant to confirm informed consent. Any questions the participant may have are answered, and the participant is asked to confirm they are happy to proceed to the questions.
- 4. The participant is reminded that they may stop the interview at any time, and that they decline to answer a question without giving reason for doing so.

The participant will be asked a series of questions, and will encouraged to expand on conversational points off the script should they not elaborate much, or if they mention information that is of particular interest to the researcher's aims and will be of benefit to the study. Each question and sub questions will relate to an objective of the study.

### **Ouestions:**

- 1. Based on your experience working with refugees in the camp, how common or big is the problem of mental illness in refugees?
- What types of mental illness do you think (or know) are most common?
- Do some refugees have more than one type of mental illness?
- Do you know if mental illness affects a particular age cohort in the camp? Or all ages evenly?
- Do you think prevalence of mental illness in the refugee population increases whilst living in the camps?
- 2. What facilities or services for mental health are available in the camp?
- Are there clinics for mental health needs available?
- Is treatment, such as counseling or prescription medication available? What types are there?
- Are there support groups available?
- Do you know of any camp community support groups?
- Are many refugees able to access mental health care?
- Are there personnel available to provide services?
- 3. What factors do you know of or think influence people not to use existing mental health services in the camp?
- Does Arab or Palestinian cultures discriminate against/ make it less acceptable
  to use of such services in your opinion? Ask about family values, peer pressure
  / discrimination / stigma, gender and sex, feelings towards 'western style
  medicine'.
- Does religion have an impact on refugee's decisions to seek and or use mental health care?
- Are there resource / financial deficits which limit the ability to deliver such
- Do you know of any other factors which stop refugees accessing or using mental health care?
- 4. Based on our conversation so far, what do you want to improve about mental health care offered in the refugee camp?
- What could be done to improve and / or increase mental health services offered?
- Do you think more clinics, staff, money etc are needed? Should mental health care be integrated more with other care to reduce stigma?
- Should there be a policy change in how refugee's mental health is cared for?
- Do you think the refugees / authorities would welcome a greater emphasis on mental health in the camp? Or would there be resistance to being more open about it?

End of interview. Summarise main talking points. Ask if anything else the participant would like to add. Thank you.