

BARRIERS TO ACCESSING AND CONSUMING MENTAL HEALTH SERVICES FOR PALESTINIANS WITH PSYCHOLOGICAL PROBLEMS RESIDING IN REFUGEE CAMPS IN JORDAN

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SUMMARY

Background: The Baqa'a refugee camp is the largest in Jordan, home to some 104,000 Palestine refugees. Barriers to accessing and consuming mental health services in Arab-refugees are well documented in the literature however few studies have been conducted hitherto to identify barriers for Palestine refugees with psychological problems residing in refugee camps in Jordan.

Aim: To identify the barriers to accessing and consuming mental health services for Palestine refugees with psychological problems residing in Baqa'a refugee camp in Jordan and to formulate policy recommendations to overcome those barriers.

Methods: 16 qualitative, semi-structured interviews were conducted with healthcare professionals working at health centres for Palestine refugees in Jordan, 14 of which were in health centres at Baqa'a refugee camp and the remaining two at the Field Office of the United Nations Relief and Works Agency (UNRWA) in Amman, Jordan. All the interviews were recorded and transcribed and thematic analyses conducted. Ethical approval was granted by the University of Leeds and UNRWA.

Results: 16/16 (100%) respondents reported that resource and financial deficits were the most common barriers that contributed towards the treatment gap. Sex (15/16, (94%)), stigma and religion (12/16, (75%)) and culture (10/16, (63%)) were other major barriers identified.

Discussion: Our findings help to elucidate the contributory factors towards the treatment gap between Palestine refugees with psychological problems residing in Baqa'a refugee camp in Jordan and mental health services therein. Policy recommendations based on our results are formulated and are discussed in this research paper.

Key words: global mental health - refugees - Palestinians - trauma - psychology - mental health policy

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INTRODUCTION

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' (UNHCR. Convention and Protocol Relating To The Status Of Refugees. <http://www.unhcr.org/3b66c2aa10.html>).

Of the world's 19.5million refugees, 5.1million are Palestinians (UNHCR. Facts and Figures about Refugees. <http://www.unhcr.org.uk/about-us/key-facts-and-figures.html>), displaced because of the 1948 and 1967 Arab-Israeli conflicts (UNRWA. Palestine Refugees. <http://www.unrwa.org/palestine-refugees>). The Palestine refugee diaspora is spread across the Middle East, with refugees in the Gaza strip, West Bank, Lebanon, Syria and Jordan. Of these, 2.1million Palestine refugees live in Jordan (UNRWA, Jordan, <http://www.unrwa.org/where-we-work/jordan>).

MENTAL ILLNESS IN PALESTINE REFUGEES

Mental illness (MI), a disturbance in the psychological and emotional well-being of an individual (WHO. Mental Health: a state of well being. http://www.who.int/features/factfiles/mental_health/en/), is highly prevalent across the world, with 29.2% (Steel et al. 2014) of the global population experiencing a MI at some point in their lives.

The trauma of conflict that drives refugees from their home nations combined with stressors in refugee camps such as overcrowding, violence, poverty and lack of employment are all factors that contribute to the high prevalence of psychological problems in refugees relative to other groups. Studies have revealed that up to 43% of refugees experience mental illness (Lurie 2009, Tribe 2002).

Despite the long-term duration of Palestine refugees in Jordan, 370,000 Palestinians continue to live in refugee camps, as they cannot afford to leave (<http://www.unrwa.org/where-we-work/jordan>).

Consequently, many Palestine refugees are second generation, and so have not fled the Palestinian Territories, nor been exposed to the Arab-Israeli conflicts (www.unrwa.org/palestine-refugees). They have however lived their entire lives in refugee camps, and so been perpetually exposed to highly stressful conditions, including poverty, unemployment, violence and overcrowding (Lurie 2009, Miller & Rasmussen 2010), all of which are known to have significantly negative effects on mental health (MH) in refugees (Al-Krenawi et al. 2007).

Whilst research shows the prevalence of MI fluctuates significantly between different Arab-refugee populations (Al-Ghzawi et al. 2014, Karam et al. 1998), Post Traumatic Stress Disorder (PTSD) and depression are the most commonly observed forms of MI in Arab refugees (Elbedour et al. 2007, Karam et al. 1998, Khamis 2005).

BARRIERS TO ACCESSING AND CONSUMING MH CARE SERVICES

Barriers to Arab-refugees accessing and consuming mental health care (MHC) are well described in the literature, in particular stigma and lack of education. Such barriers are detrimental to MH, preventing refugees accessing and consuming MHC, and consequently exacerbating MI (Dalky 2012, Almazeedi et al. 2014). However, research, specific to Palestine refugees in Jordan is woefully neglected (Nasir & Al-Qutob 2005).

As such, further research to investigate the prevalence of MI, in particular barriers to accessing and consuming MH services in Palestine refugees in Jordan is required, to better understand the situation and to formulate solutions. Indeed, the United Nations Relief and Works Agency (UNRWA), the agency responsible for Palestine refugees reports that they are, ‘...painfully aware of the lack of mental health care provision...’ for this vulnerable group (Vickers & Masri 2005).

AIM

To identify the barriers to accessing and consuming mental health care services for Palestine refugees with psychological problems residing in refugee camps in Jordan and to formulate policy recommendations to overcome those barriers.

METHODS

We used a cross-sectional, qualitative study design. The cultural and other types of barriers to accessing and consuming mental health services for Palestine refugees with psychological problems residing in refugee camps in Jordan 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’ of such barriers, and not just quantifying them. Indeed, this approach will produce data that will be far more

poignant for policy recommendations than statistics from a quantitative analysis (Green & Thorogood 2014).

Study Location

Jordan is a middle-income country located in the Middle East. Jordan hosts ten Palestine refugee camps (www.unrwa.org/palestine-refugees & <http://www.unrwa.org/where-we-work/jordan>), all of which are situated in the north of the country.

Including MI, the prevalence of non-communicable disease (NCD) has risen significantly in the Palestinian and global refugee population, a result of increasing urbanization of refugees. This is particularly apparent in Palestine refugees, with the incidence of hypertension, diabetes mellitus and other NCD’s rising quickly in this population (Amara & Aljunid 2014).

Baq’a Refugee Camp

Located 20 kilometres north of the capital city Amman, Baqa’a refugee camp is the largest Palestinian refugee camp in Jordan, home to 104,000 Palestinians over a 1.42 kilometre area (<http://www.unrwa.org/where-we-work/jordan>). Of the 16 interviews conducted in this study, 14 were conducted in health centres at Baqa’a refugee camp, with the other two conducted at the headquarters of UNRWA in Jordan.

Sampling and Study Participants

Participants interviewed for this study were purposively sampled, using an UNRWA official as a gatekeeper. The following inclusion and exclusion criteria were applied in table 1.

Table 1. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion criteria
A doctor, nurse or medical professional with regular patient contact at a health centre in Baqa’a Camp	A non-medical professional
Medical staff working for the Field Health Programme at UNRWA headquarters in Jordan	Palestine refugees resident in Baqa’a and/or that are patients at the UNRWA health centres

Research suggests a sample of 12-15 interviews is required (Guest et al. 2006, Denscombe 2014, Green et al. 2005) to reach saturation. In this study, a sample of 16, including one focus group were interviewed, an appropriate figure as 15 or more interviews are required in more heterogenous datasets (Denscombe 2014, Green et al. 2005).

Participants were recruited by the gatekeeper, and shown the research information sheets to read (in both the English and Arabic languages) before the interviews and signed a consent form to acknowledge they understood the aim of the study and any possible uses for data.

Ethical approval was granted by the Leeds Institute of Health Sciences Research Ethics Sub-committee, University of Leeds (FMHREC-14-3.2) and UNRWA in April 2015.

Due to limitations imposed by the ethics committees, it was not possible to recruit refugees to participate in this study, as such health care workers in Baqa'a camp and UNRWA headquarters in Jordan were interviewed. Future research directly interviewing Palestine refugees is urgently needed.

Data collection

Data was collected over three weeks in May 2015, using semi-structured interviews. Open questions from a question matrix, informed by previous mental health research in Arab communities, were asked. 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 familiarized with the question sheet, to improve interpretation (Björk Brämberg & Dahlberg 2013). The translator was chosen by UNRWA from the local area after enquiring on behalf of the lead researcher. The translator was instructed to translate literally and to not elaborate. Interviews with translators yielded as much data as those without, so did not seemingly affect data collection, although some loss of meaning may have occurred through translation (Hadziabdic et al. 2014). During all interviews, notes on any body language and emphasis of wording were made to avoid loss of meaning (Munhall 2012). A pilot interview was also conducted, which led to some small changes in the interview structure and questions.

Data Analysis

Thematic analysis was used to analyze the data. The 'cut and paste technique' was applied during analysis, with all 16 interview transcripts printed out and cut into sections under broad themes. Broad themes were identified using deductive reasoning, as they resulted from the question matrix 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 (Green & Thorogood 2014, Cassell & Symon 2004). Data not classified under any of the deductive codes were then inductively coded.

Methodological limitations

- Use of purposive sampling may have biased the results of the study, as the gatekeeper chose whether a participant was asked for interview. As such, the selection of participants may have been biased and so affected the resulting data.
- Social desirability phenomenon (Grimm 2010), when an individual answers in a way that is per-

ceived to be more socially acceptable than their true belief, is also a limitation. This is particularly relevant to this study, considering questions were asked concerning religion – a very delicate topic in the Middle East.

- 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, leading to some miscommunication (Green & Thorogood 2014).
- Lack of Arabic and Islamic cultural knowledge of the lead researcher may have caused the data and its context to be slightly misinterpreted, and so reduced the accuracy of the findings.

FINDINGS

In this section, subheadings represent the broad themes – which were identified during thematic analysis, and also the objectives of the study. Headings within a broad theme represent codes (Green & Thorogood 2014, Cassell & Symon 2004). Extracts of interviews will be used throughout the section to add 'depth' and to evidence findings (Corden & Sainsbury 2006).

The prevalence and types of MI in Baqa'a refugee camp

Prevalence

The prevalence of MI in Palestine 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 Palestine 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.

*'If you know you have a problem you will try to treat it. But if you do not know you have a problem, this problem will be complicated by lack of treatment'.
Participant 6.*

*'Many of them have these disorders hidden, which they do not like to 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 out of the 16 participants naming anxiety. Psychosomatic illness was also noted, but with only three participants describing it. Despite being less prevalent, psychosomatic illness is viewed as

a serious problem however, with many refugees masking underlying MI with physical symptoms.

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

*'Of course, the refugees in Jordan have a better situation than those in Lebanon, Syria or the West Bank, because the others have a lot of crises, on and off, reminding them of their original plight'.
 Participant 2.*

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 others, and realize that compared to Jordanians, 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 is married to one man, but she feels she is married to the whole family. She must care for all of them. She must care for his parents'.
 Participant 8*

*'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 it is a very big problem for her'.
 16 (Focus-Group)*

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 for many refugees, as UNRWA only subsidizes refugees admitted to hospital – and MH patients are mostly 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 for mental health, so they give up. Mental health needs more follow up, more visits'.
 Participant 5*

Lack of communication between government hospitals and Baqa'a health clinic was also mentioned by a participant as a major issue in managing MHC. This results in doctors not being able to follow-up the progress of their patients, leaving them unaware of the MH status of a refugee, and if further follow-ups or treatment are necessary.

Treatment for MI

Despite lack of MH services, some treatments are available from General Practitioners in the clinics, 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 centers 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 was found to be 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.*

Barriers to accessing and consuming MHC

Specific barriers were identified in all interviews, with resource and financial deficits the most commonly identified, as shown in Table 2.

Table 2. Barriers

Barriers	Interviews in which identified
Culture	1,2,4-7,11,14-16 (n=10)
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)

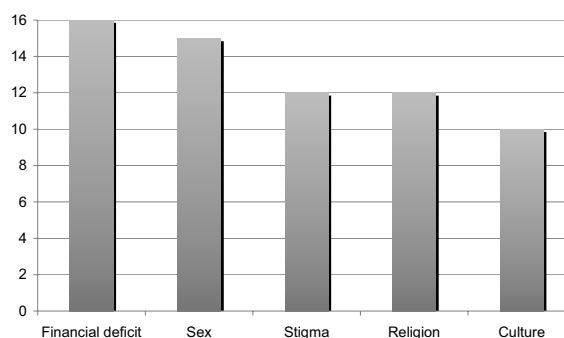


Figure 1. A bar chart illustrating the barriers identified in interviews of all 16 study participants (16=100%). These barriers prevent Palestine refugees accessing and using mental healthcare services in refugee camps in Jordan

Culture

10 participants found Palestinian culture to be a significant barrier to accessing and consuming MH services, and noted that this culture is shared in all Arab states.

They described MH as being more discriminated against than in non-Arab cultures. Several stated the refugees simply do not believe in MI at all, instead perceiving it to be a spiritual manifestation. Lack of education was suggested as the reason for this. Increasing public awareness and education on MH to all ages was suggested to improve this.

Stigma

12 participants labeled stigma as a significant barrier to accessing and consuming 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 who admit to a MI are often divorced, or her husband marries another wife, making her a 'lesser' wife.

Stigmatization also leads to social marginalization in the refugee population, with a sufferer labeled as 'crazy'. Often, the sufferer's entire family is also condemned by the community. As such, both sexes refrain from accessing MHC, as the social ramifications of being caught doing so are highly damaging.

'They think if they seek this kind of assistance they will be considered majnoon [crazy], and disqualified totally from social acceptance... And his daughter and son will suffer. They think psychological disorders are genetic. So, 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 MI will not be able to marry at any point in their life – such is the shame of MI. Many women also try to hide MI as they fear, or rather, they know they will be beaten as a punishment 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. So it is more of a problem for women.'
Participant 3

Religion

Participants were unaware of any Christian Palestinians in Baqa'a. However, amongst Muslim Palestinians, certain interpretations of Islam exist as major barriers to accessing and consuming MHC.

Many participants mentioned how through misunderstanding and ignorance, Muslim refugees often do not access care, which is contrary to the teachings of the Qur'an.

'There are proverbs in Christian and Islamic books that encourage people to look for treatment. A good believer will not wait.'
Participant 2

Instead, many refugees believe MI to in fact 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, or that is my destiny. 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 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, whereas 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.

Some participants did not identify religion as a barrier. This may be a result of social desirability phenomenon (Grimm 2010), so avoiding being seen as wrongly criticizing Islam, despite the anonymity of participants.

Resource and financial deficits

Every participant mentioned resource and financial deficits as a key barrier to providing MHC to refugees. More training for staff, 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 centers 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. Sometimes we must interrupt the programme for 2 or 3 months.'

16 (Focus-Group).

DISCUSSION

The prevalence and types of MI

Albeit unspecific in quantity, all participants in this study identified a high prevalence of MI in the Palestine refugee population of Jordan, typically between 20-50%. This high prevalence correlates with previous research into Arab refugee populations (Al-Krenawi et al. 2007, Al-Ghzawi et al. 2014, Karam 1998, Elbedour et al. 2007, Khamis 2005). However, whilst other studies have found rates of up to 94.9% of refugees having anxiety and 40% depression (Elbedour et al. 2007), there is a fundamental difference between other Arab refugee populations and Palestine refugees in Jordan: exposure to war and conflict. Whilst the significantly increased anxiety levels in other populations (Elbedour et al. 2007) 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 (Lurie 2009), is perhaps as likely to cause depression as exposure to conflict.

With many of the world's 19.5million refugees (<http://www.unhcr.org.uk/about-us/key-facts-and-figures.html>) living in camps, this finding has an important implication to international health, showing the powerful effect of living conditions in refugee camps on MH, and how 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 prevalence of MI in Palestine refugees in Jordan. As such, whilst this finding is concerning and important for refugees health, it is limited by lack of quantifiable data on the observed effect.

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 Palestine and Arab refugees across the Middle East (Dalky 2012, Almazeedi 2014, Nasir & Al-Qutob 2005, Okasha 2003).

This suggests medical professionals, particularly in general practice in refugee camps and throughout the Middle East are severely lacking in MH training, resources and treatment knowledge (Dalky 2012, Almazeedi 2014, Nasir & Al-Qutob 2005). This is particularly problematic considering many Arabs will refuse referral to specialist care to avoid the stigma of MI (Dalky 2012). Integration of MHC into general practice has been suggested in Kuwait (Almazeedi 2014) as a way to reduce stigmatization, however this

can only be effective if staff are sufficiently trained with appropriate resources, and services are affordable to refugee populations.

Barriers to accessing and consuming MHC

Barriers in many Arab populations to accessing MHC are well documented (Dalky 2012, Almazeedi 2014, Nasir & Al-Qutob 2005). However, thus far very little literature has investigated MH and barriers to its use in Palestine refugees in Jordan (Vickers & Masri 2005). Previous literature cites barriers to accessing MHC to be primarily organizational (Nasir & Al-Qutob 2005, Saraceno et al. 2007, Al-Krenawi & Graham 1999) with lack of training and insufficient political will seen as the biggest obstacles. Social barriers, such as stigma and lack of education are mentioned (Dalky 2012, Almazeedi 2014, Saraceno et al. 2007), although literature places less emphasis on these barriers, unlike the findings of this study. This report however concludes that in UNRWA, the political will is present to overcome barriers, but the knowledge required and financial means are not. Furthermore, this report adds knowledge about the impact of social barriers on accessing and using MHC in Palestinian refugee camps in Jordan. In particular, it offers improved understanding of the impact of sex, Islam 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 may help in establishing MH services that are culturally sensitive and are not as impeded by barriers.

POLICY RECOMMENDATIONS

Policy recommendations to overcome the barriers to accessing and consuming mental health services for Palestine refugees residing in refugee camps in Jordan are directed to the primary stakeholder of this report, UNRWA. They include:

- UNRWA avails a greater MHC budget and allocates more resources to MHC provision, and better integrates MHC into primary care.
- Education of Palestine refugees (in schools and at community events) to challenge mental health stigma and encourage help-seeking behaviour, and further training of refugee camp doctors to identify and treat mental illnesses.
- UNRWA engaging in dialogue with local religious leaders such as Imams, to use their considerable social influence to mount public health campaigns led by Imams and doctors. Through events such as sermons at Friday Prayers, these campaigns should focus on decreasing stigma surrounding MI, use of spiritual healers and misunderstandings that religion discourages treatment for mental illnesses.

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Contribution of individual authors:

Callum McKell was lead investigator of the study, obtained ethical approval, designed the study and collected and analysed data and wrote the study.

Ahmed Hankir contributed to the review of the literature sections and edited the study.

Ishtaiwi Abu-Zayed jointly designed the study with Callum McKell, obtained ethical approval from UNRWA, facilitated data collection and edited the final paper. Raeda Al-Issa facilitated data collection for the study in Jordan through organising interviews and translating from Arabic to English.

Amjad Awad facilitated data collection for the study in Jordan through organising interviews and translating from Arabic to English.

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