“To die is better for me”, social suffering among Syrian refugees at a noncommunicable disease clinic in Jordan: a qualitative study

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Abstract

Background The conflict in Syria has required humanitarian agencies to implement primary-level services for non-communicable diseases (NCDs) in Jordan, given the high NCD burden amongst Syrian refugees; and to integrate mental health and psychosocial support into NCD services given their comorbidity and treatment interactions. However, no studies have explored the mental health needs of Syrian NCD patients. This paper aims to examine the interaction between physical and mental health of patients with NCDs at a Médecins Sans Frontières (MSF) clinic in Irbid, Jordan, in the context of social suffering.

Methods This qualitative study involved sixteen semi-structured interviews with Syrian refugee and Jordanian patients and two focus groups with Syrian refugees attending MSF's NCD services in Irbid, and eighteen semi-structured interviews with MSF clinical, managerial and administrative staff. These were conducted by research staff in August 2017 in Irbid, Amman and via Skype. Thematic analysis was used.

Results Respondents describe immense suffering and clearly perceived the interconnectedness of their physical wellbeing, mental health and social circumstances, in keeping with Kleinman's theory of social suffering. There was a 'disconnect' between staff and patients' perceptions of the potential role of the NCD and mental health service in alleviating this suffering. Possible explanations identified included respondent's low expectations of the ability of the service to impact on the root causes of their suffering, normalisation of distress, the prevailing biomedical view of mental ill-health among national clinicians and patients, and humanitarian actors' own cultural standpoints.

Conclusion NCD patients recognised the psychological dimensions of their illness but may not utilize clinic-based humanitarian mental health and psychosocial support services. Humanitarian agencies must engage with NCD patients to elicit their needs and design culturally relevant services.

Introduction

Since it began in 2011, the conflict in Syria has resulted in the displacement of approximately 6.1 million people within Syria and over 6.5 million refugees into neighbouring countries, including Jordan [1]. The high burden of chronic non-communicable diseases (NCDs) such as diabetes, hypertension and cardiovascular disease among the affected population has been a key feature of the health sector response to the Syria crisis [2]. Humanitarian actors have limited experience in managing NCDs and have needed to develop specific tools, and programmatic and clinical guidance [3, 4].

Armed conflict has a profound impact on refugees' mental health due to their exposure to violent and traumatic events, forced displacement and ongoing daily stressors [5–7]. There are surprisingly few reliable studies on the burden of mental disorders and psychological distress among Syrian refugees in Jordan, but evidence does suggest elevated levels of mental disorders among Syrian refugees in Turkey and Lebanon [8–10], while reduced functioning has been recorded among Syrian urban refugees compared to host populations in Jordan (IMC, 2017). Guidance for mental health and psychosocial support (MHPSS) interventions to protect or promote psychosocial well-being and/or prevent or treat mental disorders in humanitarian emergency settings was developed in 2007 [11]. Specific MHPSS guidance has also been produced for the humanitarian sector in relation to the Syria crisis [11, 12].

People living with NCDs are at higher risk of mental health disorders in any context, due to direct effects on the brain or as a result of the disability, impaired functioning and chronic ill health related to the NCD [13]. Equally, mental disorders, such as depression, are also independent risk factors for development of poorer outcomes related to physical NCDs (Berthold et al., 2014; Kuper et al., 2002; Prince et al., 2007); and having a co-morbid mental disorder is associated with reduced help-seeking, poorer treatment adherence, and poorer prognosis for chronic physical conditions (Barnett et al., 2012; Gunn et al., 2012; Moussavi et al., 2007; Ngo et al., 2013; Schackman et al., 2007). For conflict-affected populations, psychological trauma and the daily hardships of forced migration may increase their vulnerability to both mental and physical ill-health [21]. Physical NCDs may be impacted upon by the loss of control over daily life, financial difficulties, the breakdown of social networks and attendant harmful coping mechanisms, such as smoking and excess alcohol use [22–24].

Social suffering is a valuable explanatory framework to help understand mental and physical health needs.[25] It captures the close links between personal and societal problems and between individual and collective experiences to allow for a holistic view of health within a socio-political context [25, 26]. Analysis of individual narratives through the perspective of social suffering may shed light on how respondents make meaning of their health and broader conditions.

The advantages of integrating MHPSS and physical health services have gained increasing attention and MHPSS integration into general primary and secondary services is underway [27–30]. However, it is not clear how well the need to manage interconnected physical NCDs and mental health issues has been recognised, either in terms of the Syrian refugee response or more widely in humanitarian settings, and the evidence to guide such integrated responses is lacking. Given the psychosocial stressors and the rising global burden of NCDs impacting conflict-affected populations, this is an important gap. Designing relevant and effective interventions requires an understanding of both service users' and providers' perspectives. This paper aims to examine the interaction between physical and mental health of patients with NCDs at a Médecins Sans Frontières (MSF) clinic in Irbid, Jordan, in the context of social suffering.

Methods

Study setting

This paper is part of a wider evaluation, using the RE-AIM implementation framework, of the NCD services provided by the humanitarian agency MSF in Irbid, Jordan [31]. Almost 680,000 registered Syrian refugees fled to Jordan, of whom, 21% live in Irbid governorate, outside of formal refugee camp settings. MSF initiated the NCD service in 2014 in response to the high burden of NCDs and the barriers Syrians faced in accessing government health facilities. The service targeted patients with one or more of the following: cardiovascular disease, chronic respiratory disease or diabetes types 1 or 2 and provided free services, which included consultations by appointment, medications, laboratory testing and health education using context-adapted evidence-based clinical guidelines. While the majority were Syrian refugees, 30% of patients were from the Jordanian host population, in accordance with government requirements. A MHPSS service was incorporated in 2016 as staff recognised that patients' MHPSS needs were significantly affecting their ability to engage with NCD care. The service consisted of individual counselling and group psycho-education sessions delivered by trained Jordanian counsellors with psychology qualifications, supported by an MSF supervisor, and it initially focused on mental health in relation to medication adherence. However, a significant burden of untreated mental health problems, ranging from psychological distress, anxiety, depression, psychosis, suicidality, and self-harm were identified by MSF staff that was not being addressed by their own or other available services, and so the MSF service evolved to encompass a wider range of mental health needs.

Study design and data collection

A qualitative study design was used, based on semi-structured interviews and focus group discussions conducted in August 2017. Adult patients attending NCD medical appointments were purposively selected to reflect different NCD diagnoses, genders, nationalities and those accessing different aspects of the NCD service. A convenience sample of patients from the waiting room was also invited to participate. Both Syrian and Jordanian patients were included, reflecting the fact that it is UNHCR policy to provide equitable access to MHPSS services to both host and forcibly displaced populations [32]. From a research perspective, it is important to understand potential differences in these populations' attitudes or help seeking behaviour and how this may impact on care delivery. All patients interviewed attended the general MSF NCD service, while only one participant accessed the MHPSS component. A purposive sample of clinical, managerial and administrative staff was also interviewed, aiming to include staff from each cadre, national and international, past and present.

Topic guides for the semi-structured interviews and focus groups are presented in Supplementary Material 1. While these contained limited prompts on mental health, the interviews covered mental health in significant detail because participants focussed on it and interviewers then explored the issues raised.

Sixteen semi-structured interviews with adult NCD patients (eight women, and eight men; including six Jordanian and ten Syrian patients), and two same-sex focus groups were conducted with a different group of eight female and eight male adult Syrian NCD patients (moderated by same-sex research assistants). All had NCDs (mainly hypertension and/or diabetes) and refugees had been in Jordan for between three and five years. Eighteen interviews were conducted with MSF staff from a range of clinical, managerial and support roles. See Supplementary Material 2 for further participant details.

The semi-structured interviews were conducted in Arabic by SE or a male research assistant or in English by EA, depending on participant language preference. Interviews were conducted at the MSF clinics (for patients) and at MSF offices or via Skype (for staff); one patient of the home visit service was interviewed at home. The interviews were audio recorded and field notes were taken. Arabic language interview transcripts were translated by research team members. Each translation was cross-checked by a second translator and by one of the Arabic-speaking interviewers.

Analysis

A thematic analysis approach was applied using NVivo 11. Initial codes and themes were generated and revised in an iterative process. Patient interviews were analysed for differences in responses between genders and by nationality (Syrian vs. Jordanian), age and NCD diagnosis. Staff interviews were analysed for differences in national versus international staff and MHPSS versus other clinical staff's responses. Patient quotes were labelled according to the patient gender and country of origin for context. Staff quotes were not labelled in order to protect the confidentiality of staff respondents.

Ethics

Written consent was obtained and information sheets were provided. A referral mechanism was in place for patients who expressed health or protection needs during interviews. Confidentiality was assured by use of private spaces for interview and removal of all identifying information from written documentation. Focus group participants were asked to respect the confidentiality of all participants, while being informed that the research team could not guarantee against residual disclosure. Ethical approval was provided by the Ministry of Health in Jordan, the MSF Ethics Review Board, and the Ethics Committee of the London School of Hygiene and Tropical Medicine.

Results

Both Jordanian and Syrian patients described the interconnectedness of their mental and physical health, and demonstrated similar attitudes to mental health services. The Syrian patient accounts differed from Jordanian accounts with respect to describing the high burden of distress among their community, barriers to help seeking associated with displacement and their expectation that they should suffer from poor mental health as a result of their circumstances. Themes that emerged were similar for men and women. The findings of the qualitative analysis are described for patient and staff interviews, categorized into a coding tree (Supplementary Material 3).

Patient interviews

Impact of war and social stressors on mental health:

Syrian respondents all reflected on the suffering the war in Syria had caused themselves and their community. Men and women expressed suffering in similar terms, such as anger, sadness, grief, hopelessness or even a passive death wish, while both sexes described physical symptoms, which may be associated with psychological distress (tiredness, poor appetite). Respondents recounted a number of sources of psychological distress, including concern for family members remaining in Syria, bereavement and witnessed suffering or traumatising images. Separation and loss of families was frequently cited as a source of suffering.

‘When I am upset, I have trembles in my body, you know every one of us in different places, some people here, others still in Syria,’ Syrian female patient.

The collective suffering of the Syrian people was described by Syrian respondents:

‘…all the incidents that occurred in front of us, like killing and destroying. What should I say, something can’t be imagined by the brain…the suffering, which our people went through wasn’t witnessed by any other people in the earth.’ Syrian male patient.

They perceived that others in their community experienced similar psychological, (‘all people have anxiety, not only me’) or physical manifestations of suffering (‘we are all tired as Syrians. We were destroyed’). Further examples of the language used to describe mental distress are given in Supplementary Material 4.

Daily stressors were mentioned by both Jordanian and Syrian respondents including economic hardship, lack of available employment and working restrictions (the latter were specific to Syrians). Syrian male focus group participants explained:

‘Patient 05: We do not have money, our finances are bad, and they all (other facilities) take money, only here (at the MSF clinic) they do not take money.

Patient 01: For us as refugees, you do not have any work chances, you only have to be young and work in construction; work depends on physical powers, and we all here do not have this.’

A Syrian woman described her financial worries and ways of coping:

Sometimes poor finance also this makes me anxious, sometimes I keep all the day awake talking to myself from where I will get money to buy some stuff for home, so I go to our neighbour and ask him to give me 5 (Jordanian dinar) and I tell him once I have money I will pay you back

Interconnectedness of physical and mental health:

Both Syrian and Jordanian patients consistently described their health in terms of interconnected physical, psychological and social dimensions. Many Syrian and Jordanian interviewees linked the onset of their illnesses with specific traumatic events. A Jordanian woman attributed the onset of her hypertension with the sudden death of her brother, while for Syrians, the psychological distress of their war and refugee experience were directly linked with the onset or poor control of their NCD condition:

‘The hypertension goes high not all the time but when I get sad and remember my sons in Syria and they tell me what happens with them I keep crying and crying then my hypertension goes high or goes down… then I take a hypertension pill to settle down whenever I read some news about them,’ female Syrian patient.

Emotional instability and low mood were seen as negatively impacting on blood sugar control in diabetes, while “good psychological status” was needed to avoid symptoms:

‘I say my diabetes is not because of food… bad emotional status can increase the sugar level especially if the one is always tired,’ male Syrian patient.

‘I had (diabetes when in Syria) but not as now because the mental status and the mood was better than here in Jordan…you know when one is in his country, things are different’, male Syrian patient.

Some felt that improving their psychological health could benefit their physical health, possibly to a greater degree than medications.

‘Let me tell you, I have tried when I am mentally comfortable, everything is good and it helps more than medication.’ Syrian male patient

A Syrian male patient described how his social circumstances, mental health and physical health were closely interlinked, and particularly how his own wellbeing impacted on the wider social network:

‘When someone is surrounded by comfortable things, he has money and things good then he feels good and his life is happy, so he speaks with others and feels fine with them and communicates with them. He feels like others… when anyone has love and trust with others, he’ll help him to stay in a good mood...When the human feels bad, even appetite will be affected, if the family had bad mood, it affects the human, the mood of any person affects all his life and also it affects the human’s health,’ Syrian male patient.

One Jordanian male respondent described this relationship linearly, in that poor finances caused depression and sadness, which in turn worsened diabetes and hypertension.

Psychological distress impacting on NCD care:

This social suffering translated into difficulties in engaging with the healthy living advice provided in the NCD clinic. Syrian respondents described being too preoccupied with thoughts of Syria or not feeling psychologically or economically equipped to follow lifestyle advice:

Interviewer: ‘has anyone of you changed his lifestyle after he found about his disease?’

Male focus group participant: ‘nothing changed…we don’t feel comfortable, always thinking about what happened at our country’

‘Because of circumstances I cannot follow this plan… I mean the psychological circumstances, I’m out of hard circumstances so all of this affects, and when the financial situation is difficult as well.’ Syrian male respondent.

One female focus group participant expressed thoughts of death and lack of motivation to engage in self-care:

Every time I come here, they advise me take care of yourself and I always tell them to die is better for me.

While several patients, particularly males, attributed their difficulties with smoking cessation or following dietary advice to a “weak will”, staff were more likely to explain it in relation to psychological distress and lack of agency, as discussed further below.

Seeking help from MHPSS services or other sources of support:

The majority of patients were unaware that any MHPSS services were offered by MSF (with no difference in response by gender, nationality or age). Only one interviewee (a Jordanian who had studied psychology at university) had attended individual counselling while another had joined a group session in the MSF waiting room.

During interviews, respondents were told about the MHPSS service by the interviewer and asked for their thoughts. Despite the majority of participants describing their health previously in terms of both physical and psychological dimensions, the majority did not consider the clinic as the place to seek help for mental health issues. A number of potential explanations for this were identified.

The key reason seemed t have been a perceived separation from the biomedical services offered by the clinic, which bore no relation to their suffering and distress. Despite a female Syrian patient becoming tearful when describing her family’s separation (‘you can say that most of the days I feel upset, I’m so sensitive… when I am upset I have trembles in my body, you know every one of us in different place, some people here others still in Syria ’), she maintained that she did not need the MSF MHPSS services, especially since her biomedical care was in order: ‘my lab test results always good… so everything is OK’.

Most Syrians agreed that mental health issues held no place in the biomedical model of care provided at the clinic, which was well organised and focussed on interpreting clinical data and prescribing, as illustrated here:

‘… if I told them (that I feel upset or can’t sleep), they don’t react because it’s not their business...their mission is to give me medication only,’ Syrian respondent.

There was a sense also that respondents sought to normalise their distress as similar to that of others in their community:

‘Honestly (I have complained about anxiety) for four years…This is the first time I tell... but what to tell about this, all people have anxiety not only me, everybody that comes here say he or she has anxiety, all people have anxiety and I am like them, what shall I do?’ Female Syrian patient.

Since there was a perceived inevitability to their distress, which had known and inalterable root causes, both male and female Syrians questioned the utility of bringing these issues into the medical consultation:

‘What would I tell them about this, and how could they help? We do not feel comfortable in our situation, in our country situation. I have members of my family still in Syria, how do you think my psychological status will be, would I be comfortable...? So what would I say to them here, that I have family still in Syria, what would they do? Or how can they help? I only say thanks Allah for everything’ Female Syrian patient.

Some were pragmatic in their responses, saying that if they knew why they felt distressed, there was no reason to speak to a counsellor about it:

Interviewer: ‘OK sir, if you feel that you are not comfortable or upset or your mood is not good, do you tell them in the clinic?’ ‘(I do not, since) the reasons for sleeplessness are known.’ Male Syrian patient.

Among the minority of respondents who were aware of MSF MHPSS services, one described their content as follows:

‘You go to see them, there is psychiatrist or counsellor, you explain to him your situation and he listens to you, so you express your feelings.’ Male Syrian patient

This perception of the service as a passive counselling service to explore feelings was not in keeping with MHPSS staff’s description of a more active process involving problem solving, motivational interviewing and Cognitive Behaviour Therapy (CBT) techniques.

In contrast, another Syrian male patient expected MSF would offer medication as the solution to psychological ‘disease’:

Interviewer: ‘when you feel anxious or having sleeping disorders, do you share this with the staff at the clinic and ask for their help?’

Patient: ‘If the disease was clear we tell them and they give us medications, and if not…they tell us that they do not have medication for this disease.’

For some patients, psychological distress was described as a private matter and, therefore, more appropriate to seeking support at home rather than in clinic, as illustrated by one Jordanian male, who expressed anxiety: ‘I do not think this (clinic) is a proper place (to seek help for psychological issues)… these are personal things.’

Among the minority of patients who commented on coping strategies and sources of support to manage their distress, most relied on family or religion.

‘I did not try (to talk to someone at the clinic about anxiety) because I have sons and daughters and I have good relation with them.’ Jordanian Female Patient

Many patients discussing distressing topics such as bereavement and loss concluded by referring to how Allah is ultimately the only source of a solution to their troubles:

‘Our situation is miserable and we can’t have emotional comfort. Never. It’s our destiny to be in a big crisis and our problems can’t be solved except by Allah, (not) even the researcher, (or) even the doctor. All the people have problems. May Allah help all people…May Allah protect us all,‘ Syrian female patient.

Staff interviews

The findings from staff interviews included here focus on how staff perceived the mental health of their patients, the barriers to patients accessing the MHPSS service and the impact of mental ill-health on the provision of physical NCD care. Staff recognised a high burden of mental health problems amongst their patients. Multiple staff reported recent incidences of patients presenting to them with suicidal ideation or having experienced gender-based violence, which compounded poor mental health.

Interaction between mental health and physical health:

The majority of staff respondents, both medical and MPHSS, perceived the Syrian patient population as experiencing traumatic events and ongoing daily stressors which were interlinked with their physical health and impacted on care delivery for physical NCDs. They described patients’ exposure to violence, their loss or separation from family members, social isolation and the breakdown of traditional community structures. National staff accounts emphasised the repeated losses experienced by patients and MHPSS staff in particular reiterated patients’ belief in the causal link between psychological stress and the onset or exacerbation of their NCD condition:

‘You find out that these patients not only suffer from hypertension, diabetes, they are refugees who lost almost everything, especially when they keep saying that they had these diseases because of their circumstances like (losing a child), and they blame themselves for everything’.

One national staff member agreed with the patient perspective that suffering was inevitable given the circumstances (‘…they were exposed to war and their current situation is very bad…they are refugees so they will have some sort of mental problems.’).

Staff described the chronic daily stressors to which Syrian patients were exposed, including poverty and indebtedness; vulnerability to exploitation; crowded, poor-quality living conditions; and social isolation. Some considered financial pressures and the inability to work in Jordan as the key psychosocial challenge facing Syrians and that this impacted directly on their mental and physical health.

The financial challenges, the social challenges, are the most important factor in anxiety existence and other psychological disorders for NCD patients, which can affect their medical readings for blood pressure and sugar …

Psychological distress impacting on NCD care:

Staff reported how financial hardship was both a source of distress and directly prevented patients engaging in lifestyle change such as formal exercise activities and buying healthy foods. In contrast to patient accounts of the interlinked physical, psychological and social dimensions of health, one national staff member felt that patients were unwilling to admit to a psychological component to their illness and this prevented them availing of MHPSS services.

Unfortunately I see that people are not capable of admitting that they have psychological aspect that would affect their bodies, you have to admit this and ask for help, inform the staff that I need someone to support me through psychological counselling or support.

Both national and international staff respondents emphasised that medication adherence was negatively impacted by psychosocial issues related to patients' war and refugee experience:

To be honest the social side, the loss, the situations they have been in, affect them a lot. This is one of many things that affects their adherence to medications or treatment in general.

'And then… intimate partner violence…yeah, the lady has diabetes but…the reason she is not taking her medicine is …all these other home psychosocial factors…'

In addition to reducing adherence, non-medical national staff members perceived that psychological comorbidity directly impeded the effectiveness of NCD medications:

…anxiety and other psychological disorders for NCDs patients, which can affect their medical readings … despite taking medications… the tension medications will not do their effect.

Several staff perceived the futility of promoting lifestyle change when their patients were dealing with traumatic war experience:

'As I was hearing the stories I thought…this man's problem is not that he's smoking too much. His problem is that he … experienced sexual violence, physical violence in prison in Syria… these two are linked.'

Staff described how Syrian patients' hopelessness for their future either in Syria or Jordan, their disempowerment and disengagement from their current existence in Jordan, and their lack of meaningful daily activity, all impacted on their motivation to care for their health.

This certain population of people they don't have much hope in their future life so they don't really...some of them they just don't care about improving their status to be better because they think that life has ended since they left Syria.

One respondent offered an example a young man's lack of social support and harmful coping strategies, and how this created a cycle of deteriorating physical and mental health:

He is not familiar with living in an apartment. If he has been used to a small village in rural environments, without support from family or society is inclined just to get very fed up, to get feelings of hopelessness, sitting in the apartment all day, going next door to smoke the shisha, by taking Shawarma in the corner shop, and just gets larger, more of these, and aggravate the disease and hypertension, which in turn aggravate the feelings of hopelessness…

By contrast, hope and engagement in the future, more common among Jordanians, was seen by one clinician as improving self-motivation and, therefore, clinical outcomes.

I see some Jordanian patients their blood sugar readings are lower, their blood pressure is more controlled and most important they want to control their disease, they care to control their diseases and that is for me the main difference. They have something to look to…. they look forward to tomorrows, but the Syrians here, they don't as much.

Once Syrians started to settle for the longer-term in Jordan, their outcomes improved, according to another staff member.

And now, I think in this year I notice a lot of changes in the patient. In the last six months maybe… maybe some patients find job or find house. And they leave the talk about the return to Syria…and they try to adapt for their new situation and to find a new solution for their life. So they want to change it now. The effect on their health.

Seeking help from the MHPSS service:

Staff's perception that patients would not seek help from MSF's MHPSS service was consistent with patient accounts.

According to staff respondents, there were several barriers to patients receiving MHPSS services. These included: lack of awareness; initial distrust or lack of engagement by doctors; perceived stigma surrounding mental ill health; and cultural barriers limiting women's attendance at MHPSS. Since most women could not attend MSF services without an accompanying male family member, the latter was a particular issue for victims of intimate partner violence.

Referrals to MHPSS services were initially made only via MSF national staff doctors and referral rates were very slow. In explaining this, doctors cited their own initial distrust in the service due to their belief that only medical specialists should diagnose mental disorders and their reluctance to label patients with mental health diagnoses, partly because they perceived their patients' distress as a natural response to their circumstances:

It is good to have the mental health department and the counsellors but sometimes they may diagnose and they may diagnose incorrectly and I ask them many times please don't diagnose because you are not a psychiatrist, you are a counsellor and we are referring this patient to you for maybe CBT or for more psycho-social support more than diagnosing and suggesting medications.

Accounts from service supervisors (who were all international staff) shed further light on these attitudes. They underlined the fact that mental health was traditionally the preserve of hospitals and specialists in Jordan and emphasised their perception that national doctors compartmentalised physical and mental ill health. They felt a large burden of psychological morbidity among the Irbid cohort was going unrecognised by the national clinical staff. In response to this, a formal screening tool was introduced into the programme in late 2017.

Several staff reported that there was stigma associated with mental ill health among the patients and broader society, which may be in keeping with the local biomedical view of mental health care observed by international staff. National staff worried that patients perceived a referral to the MHPSS service as labelling them 'crazy':

'There is a wrong assumption that when you say to a person that say I would refer you to a mental health specialist they'd think the first thing that comes up in their head is that I'm not crazy'.

Some staff overtly mentioned a perception of stigma in the community around mental health problems and a lack of social acceptance, which could lead to patients failing to attend MHPSS appointments:

Many patients will not accept this… because of the stigma. Especially in my first period here because I was new to the patients they were not accepting this but with time, with building a good relationship with them, many patients were referred.

It was notable, however, from staff accounts, that psychosocial interventions framed as "living well" with diabetes programmes, delivered by both health education and MHPSS staff who taught pragmatic skills, such as problem solving and inter-family communication, were well accepted by patients. Staff also reported modifying their language to minimise the stigma associated with referral to MHPPS services and distinguish them from psychiatric services:

'Patients think that if we referred him for the mental health, they think maybe … it's a psychiatric or something like that. We tell him it is for support'.

This included reassurance that patients were not being labelled as abnormal or 'noticing something wrong' compared to others and that is it was "socially ok to go" to counselling services.

Staff recounted additional efforts made by the MSF team to address access barriers. They described running training sessions for all clinical staff and promoting dialogue between MHPSS staff and their medical colleagues. In addition, they expanded referral rights to nurses and social workers and engaged in awareness raising and promotion of self-referral through waiting room psycho-education sessions.

Discussion

This study describes how Syrian refugees living with NCDs in Jordan connected their psychological and social suffering with their physical illnesses, yet most did not perceive the MSF NCD service as a space to address their mental health. We will discuss patient and provider accounts from the explanatory perspectives of the Syrian cultural context, social suffering and social hope. The latter are not new concepts [26, 33, 34], but we apply them to the experience of Syrian refugees in Jordan and in the context of a programme for physical NCDs delivered by a humanitarian actor. We will then discuss operational implications for the humanitarian sector, given that little is known about how humanitarian agencies should best integrate mental health care into chronic disease services in culturally relevant ways.

Interconnection of mental health, physical health and social circumstances as social suffering

There is plentiful evidence from high-income settings that the incidence of mental ill-health is greater in people with NCDs and vice versa, while individuals with comorbid physical illness and mental health disorders experience poorer outcomes including decreased medication adherence, greater functional impairment, increased risks of complications and early mortality (Prince et al., 2007; Ziegelstein et al., 2000; Robinson et al., 2013). Furthermore, there is an increasing body of evidence linking stressful life events or chronic perceived stress to the onset of chronic physical disease, such as diabetes [37, 38]. However, what is clear in our study is how respondents linked their physical and mental health with their social world and with social suffering specifically.

The concept of social suffering links physical ill health with social problems and individual experience with collective experiences [25, 26]. In conflict settings, this implies that social, cultural, political, and economic issues are intertwined with matters of public health [39]. Kleinman has proposed social suffering as a “social theory of global health” with several important implications. These are that socio-political and socio-economic factors may be directly implicated in causing disease; the social or bureaucratic infrastructure designed to manage disease can actually cause or worsen suffering; pain and suffering are not limited to the individual but may extend to the wider family or community network; and, finally, conditions should be defined holistically, combining physical, mental and social aspects, and, thus, they should be addressed holistically, incorporating both health and social policy responses [25]. Consistent with this theory, participants in our study could not separate the social and political context, which was responsible for them suffering trauma, poverty and powerlessness, from their physical health [26, 40].

Syrian and Jordanian patients, as well as staff, described psychological distress as a cause or exacerbating factor in physical ill health. Whilst Jordanians made this link in relation to their individual circumstances, in these interviews Syrian respondents additionally linked their physical and mental health to the collective experience of their community. The Syrian experience of their physical health in this setting occurred on a backdrop of the structural violence of displacement and of their refugee status in Jordan. The poverty and social disadvantage experienced by many Syrians in Jordan may have impacted on their physical NCDs, and this is echoed in findings from other contexts. For example, depression and diabetes have been found to intersect more frequently in low income populations because of the strong relationship between depression and poverty [41].

The concept of social hope links resilience and wellbeing to social context and access to resources, both at the individual and community level [26]. Social hope is demonstrated in those Syrians who had settled in Jordan and were able to access resources. Finding work and housing was seen by staff as positively impacting patients' NCD outcomes, through increasing motivation to change and through building hope for a new life in Jordan. In contrast, many refugees were observed as being in a state of entrapment, both as a result of the structural barriers to improving their health and the internal conflict about whether to accept living in Jordan or to continue to hope for eventual return to Syria. Hage describes the enemy of social hope as 'a sense of entrapment, of having nowhere to go' [42]. In our study, staff observed how patients were trapped between a desire to return to Syria and the knowledge that their lives there had been destroyed [42].

Hassan et al explored the cultural context around mental health and psychosocial wellbeing of Syrians affected by the conflict [12]. The explanatory model offered by patients in our study is in keeping with the 'sociocentric' and 'cosmocentric' understandings of the person described by Hassan as common in the Syrian population [12]. From this perspective each individual is linked to every other creature created by Allah and there are two dimensions to every individual: the universal dimension governed by the will of God and the social dimensions governed by rules of conduct [12]. The patient accounts illustrate these concepts as applied to health, where health of the individual is affected by other people and events and, in turn, an individual's health affects the whole family and community, which chimes with the theory of social suffering.

Uptake of MSF mental health and psychosocial services

One key finding was that all but one of the patients interviewed were not aware the MHPSS service existed. The NCD service evaluation from which this study was drawn found that uptake of the MHPSS service was well below the perceived need [43]. Our broader findings imply that patients attending the MSF programme generally valued MHPSS services less than consultations for their physical health conditions. Financially precarious families were willing to spend time and money to attend NCD medical consultations but not MHPSS appointments [43].

Several explanations for this emerged from our interviews. First, the belief that the MSF service had no power to address the root causes of their suffering, and therefore could not help. In contrast to MHPSS services, the physical NCD service was tangible, involving medication, medical tests and numerical results. Some patients expressed a preference for this approach, which may have offered them a sense of control over at least one aspect of their lives, in the context of a prevailing sense of hopelessness and general lack of control over their daily circumstances.

However, Hassan suggests that awareness of mental health and seeking help from MHPSS services is increasing, particularly amongst urban Syrians, and she places more emphasis on stigma as a barrier to help seeking [12]. While MSF staff commented on the influence of stigma around mental health issues, indications of stigma were less overt in our patient interviews. Some participants expressed intense emotion during the interviews, but when the MHPSS services were offered, dismissed them as unnecessary. This may reflect a desire to normalize their own distress as similar to everyone else in their situation, for fear of being thought of as different. This is in keeping with Hassan's description of how emotional suffering is perceived as an inherent aspect of life in Syria, but it is the labelling of distress as 'psychological' or 'psychiatric' that is a source of shame and fear for the individual and the family [12, 44]. Staff identified that referral to the MHPSS service could be associated with patients' fear of being labelled 'crazy', as was found in other studies of Syrian refugees in Jordan, and staff members spoke of reassuring patients that their symptoms were not 'abnormal' [44].

The doctors' gate keeping role over referral to the MHPSS service may also have contributed to low uptake, due to doctors' initial lack of trust in the MHPSS service, their reluctance to label patients with a psychiatric disorder (appearing to want to protect them from stigmatisation) and their belief that exclusively doctors should diagnose mental disorders. The latter has been observed in other settings, where medical professionals have resisted efforts to task shift care to other cadres of staff [45]. The national doctors' apparent biomedical approach to mental ill health, which dichotomised physical and mental health conditions, may also have played a part. In our study, international supervisors commented that the MHPSS approach is relatively new in Jordan, where mental health care has traditionally been delivered by psychiatrists in hospitals [44].

The lack of engagement with MSF MHPSS services may also reflect patients preferring to use their own culturally-relevant coping mechanisms and resilience and/or that the offered MHPSS services were not culturally-relevant [46–49]. Perception of mental health problems for some Syrians may have been influenced by the Islamic teaching that people should surrender and entrust themselves to the will of an omnipotent God. Hassan notes a view widely held by Syrian Muslims that hardship provides an opportunity to grow and to strengthen one's faith, which may help them to accept and show patience in the face of harsh reality. However, the notion of human weakness is related also to the idea of taklif or entrusting, which she suggests can help to find motivation and drive to cope with hardship [12].

Implications for integrated MHPSS and NCD services in humanitarian settings

While the link between physical and psychological ill health has been well established in conflict-affected settings, we don't yet know how best to respond to this duality in a culturally relevant and integrated way. The humanitarian sector has sought to ensure that MHPSS interventions are both evidence-based and culturally relevant by adequately recognising local forms of stress, support and healing [11, 50]. Continued efforts are required to ensure psychological therapies are adapted, relevant and effective in different socio-cultural contexts.

WHO has stated that there are potential synergies for addressing NCDs and mental health together and have recently included mental health as one of the "big five" NCDs as part of their broader health agenda in low and middle income countries [29, 51]. Furthermore, while the potential benefits of integrating MHPSS into services for physical health have also been recognised in humanitarian settings, including improving access, reducing stigma and improving outcomes for physical conditions, there is little evidence to guide us on how to do this [28, 52]. Lessons learned from the MSF experience in Jordan may be useful both in adapting their specific programme and also in guiding the humanitarian sector more broadly.

While MSF is implementing evidence based MHPSS approaches within their NCD service in Jordan, we have identified the need for greater engagement with NCD patients and the Syrian refugee community to explore how these services could better meet their needs. Further exploration is required of how distress is expressed in this population in relation to personal, cultural and social meanings and how such idioms of distress intersect with physical NCD and psychological symptoms [53, 54].

The MSF team has begun to address the lack of awareness and access to the current service through the addition of ad hoc group psychoeducation sessions in clinic waiting rooms and the extension of referral rights to nurses, nutritionists and social workers. It may also be helpful to extend the group "living well sessions", framed around a physical illness like diabetes, which seemed a more acceptable vehicle to foster problem solving, communication skills and peer support. These were delivered by health educators and MHPSS staff and could serve as an opportunity to deliver a multidisciplinary approach by also involving clinicians and to develop joint guidance on integrated physical and psychological NCD care. MSF may also consider expanding psychosocial support services into non-clinical settings, such as community halls, women's programmes or schools to increase their acceptability and accessibility.

The daily stressors, financial precarity, the myriad barriers to accessing care experienced by Syrian refugee NCD patients in Jordan and the potentially harmful decisions they make as a result of stretched finances have been well documented in our own and others' studies [43, 55–58]. The free care provided by MSF goes some way to alleviating the NCD-related financial burden affecting their current cohort. However, while we acknowledge the high cost of delivering NCD care, MSF may consider developing approaches to increase coverage of their current service by decentralising aspects of care to the community level, or, indeed, by attempting to address, where possible, some of the socio-politically induced suffering, including daily stressors, experienced by Syrian refugees in Jordan.

Further prospective research is required to design and evaluate culturally relevant approaches to integrating physical and psychological NCD care, engaging patients in the process from the outset. More work is also need to better understand community and patient idioms of distress, and needs in relation to mental health services and supports, to explore how mental health influences help-seeking behaviour and self-management of NCDs and how providers of NCD care can address (where possible) the ongoing causes of suffering such as daily stressors.

Limitations

Patient participants' lack of awareness of the MHPSS service prior to interview meant that no conclusions about the patient experience of the actual service could be drawn. As a result, the findings are predominantly characterised by patient preconceptions of what the service might entail and descriptions of their help seeking behaviour. An alternative sampling strategy could have been to purposively sample from users of the MHPSS service, but could have risked masking the wider lack of awareness about the MHPSS service. As the focus of the interviews was on broader programme implementation, using the RE-AIM framework, and not solely on mental health, we did focus the entire interview on participants' mental health concerns. However, the framework provided enough flexibility to capture themes related to mental health and the broader socio-political humanitarian environment and served to highlight the importance participants placed on mental health in relation to their NCD management. A greater number of interviews could potentially have been performed but it was felt that theoretical saturation was achieved in relation to our key themes.

Conclusions

The findings of this study suggest that humanitarian actors must better anticipate mental health needs when designing programs for patients with NCDs. Furthermore, healthcare providers must examine local perspectives and needs in relation to psychosocial issues and co-design effective, person-centred approaches that are culturally relevant, drawing on pre-existing coping mechanisms and that are acceptable and accessible to both providers and patients.

Declarations

Ethics approval and consent to participate

Approval for the conduct of this study was granted by the Jordanian Ministry of Health, London School of Hygiene and Tropical Medicine Ethics Review Committee (approval number: 15868) and by the Médecins sans Frontières Ethics Review Board. All participants gave informed, written consent to particpate in this study.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available in order to protect participant confidentiality but are available from the corresponding author, with the consent of Médecins sans Frontières, and on reasonable request.

Competing interests

EA undertook this work as part of a research fellowship funded by Médecins sans Frontières. The other authors declare that they have no competing interests.

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Authors' contributions

EA, KJ, MT, PP and BR conceived of and designed the work. SE and EA collected the data. LM and EA analysed the data and drafted the work, with LM, EA and BR substantially revising it. All authors read and reviewed the final manuscript.

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Abbreviations

CBT	Cognitive Behavioural Therapy
DM	Diabetes Mellitus
HTN	Hypertension
MSF	Médecins sans Frontières
MHPSS	Mental Health & Psychosocial Support Network
NCDs	Non-Communicable Diseases
NGOs	Non-Governmental Organisations
RE-AIM	Reach, Effectiveness, Adoption, Implementation and Maintenance
UNHCR	United Nations High Commissioner for Refugees

WHO	World Health Organization

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