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Asylum seekers' and refugees' experiences of accessing health care: a qualitative study

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Title Page

Title: Asylum seekers' and refugees' experiences of accessing healthcare: a qualitative study

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Abstract

Background

Asylum seekers and refugees often experience poor health in host countries. The United Nations High Commissioner for Refugees requires hosts to ensure these sanctuary seekers have access to basic healthcare.

Aim

To identify barriers and facilitators that affect access to healthcare by asylum seekers and refugees in Wales.

Design and Setting

Participatory research approach using qualitative focus groups across Wales, which hosts 10,000 refugees..

Method

Eight focus groups with asylum seekers, refugees and support workers and volunteers.(n=57)

Results

Specialist NHS-funded services and grant-aided Non-Governmental Organisations (NGOs) facilitate access to healthcare, including primary care. Most asylum seekers and refugees understand the role of general practice in providing and coordinating care but are unaware of services out of hours. Reported barriers include: language difficulties, health literacy, unrecognised needs, and the cost of travel to appointments. Participants recognise the importance of mental health, but were disappointed by the state of mental healthcare. Some fear seeking support for mental health from their GP, but few are aware they have the right to move practice if they were unhappy. Written information about healthcare is not as accessible to refugees as to asylum seekers. While some participants read such material before consulting, others struggle to access information when in need. Few participants are aware of health prevention services. Even when they know about services like smoking cessation, these services' difficulty in accommodating asylum seekers and refugees is a barrier.

Conclusion

Main barriers are: availability of interpreters; knowledge about entitlements; and access to specialist services.

Box 1.

An asylum seeker is someone who makes a request to the authorities in the country where he/she has arrived to seek protection (asylum) under the UN Refugee Convention 1951^{4,5} and is waiting to receive or appeal a decision on their claim for refugee status. Asylum seekers' movement and right to work are restricted; they receive limited financial support from the state.¹⁶ Once a claim for asylum is approved, a person is granted refugee status and can access a wider range of public funds, choose where they live, and seek employment. A refugee is someone who has been recognised under the 1951 Refugee Convention as a refugee. In the UK, refugees, asylum seekers and refused asylum seekers are entitled to receive care free of charge in the same way as any other patient.

Keywords

Asylum seeker; Refugee; General practice; Healthcare delivery; Mental health; Language

How this fit in

Asylum seekers and refugees (ASRs) often experience poor health in host countries as they navigate unfamiliar health systems, often with limited language proficiency.^{1,2,3} This qualitative research explores their healthcare needs, barriers to access, and facilitators. Support from specialist NHS-funded services and volunteers facilitate access to healthcare. Remaining challenges include knowledge about entitlements, availability of professional interpreters, and access to specialist and preventative services.

Introduction

Minimum standards set by the United Nations High Commissioner for Refugees (UNHCR) require host nations to ensure ASRs⁴⁻⁶ (see Box 1.) have access to basic healthcare.^{7,8} Persecution and the journey to sanctuary affect ASRs' health. Many have experienced trauma and present with mental ill-health, infections and chronic diseases.^{9,10,11} Improved access to healthcare can prevent the spread of infection and deterioration in health,^{12,13} and reduce the costly burden on secondary care.¹⁴ Wales has a long history of welcoming those fleeing persecution. Since 2001, the UK Home Office dispersal policy has brought asylum seekers to Wales, and the Syrian Vulnerable Persons Resettlement Scheme¹⁵ has been relocating refugees to Wales since 2015. It is estimated that there are some 10,000 refugees in Wales,¹⁶ about 0.3% of the population; in 2019 the National Asylum Support Service (NASS) was supporting approximately 2,626 asylum seekers in Wales.¹⁷ On arrival in Wales, asylum seekers (AS) undergo health assessment by specialist AS nurses, including vaccination and tuberculosis screening. Most receive NASS¹⁸ accommodation in one of four dispersal areas in Wales – Cardiff, Newport, Swansea and Wrexham. Local AS nurses then register asylum seekers with general practices and signpost them to other services including dentists. Refugees who arrive in Wales through a national settlement programme¹⁵ rely for support on the third sector, who can access short-term funding from the Home Office.

ASRs' experience and entitlements are shaped by the UK's rights-based approach to healthcare,¹⁹ and access to health care remains free to most ASRs. Nevertheless, barriers arise from ignorance around entitlements,²⁰⁻²² fear of having to pay for services,^{21,22} perceived discrimination,^{2,3} fear of deportation,³ and difficulty accessing interpreters.²¹ Challenging appointment systems^{3,23} and restricted access to specialist care lead some to seek emergency care, or avoid care altogether.^{1,24}

To the authors' knowledge no qualitative study has been conducted with recent and long-term ASRs living in Wales about their experience of healthcare (primary, community and secondary care). The Welsh Government has ambitions to create a more equal and healthier Wales²⁵, and the country is seeking to become the world's first Nation of Sanctuary.¹⁵ To this end, Public Health Wales commissioned a study¹⁶ to identify barriers and facilitators that affect the ability of ASRs to access healthcare in Wales, aiming to inform new policy interventions that can improve the health and wellbeing of ASRs.

Methods

Study design

We adopted participatory research through co-production²⁶ as the overarching study design. We conducted eight focus groups with ASRs, support workers and volunteers to explore their experience of accessing healthcare.^{27,28} The focus groups formed part of a larger mixed methods study (reported elsewhere)²⁹, including a survey, delivered with the involvement of peer researchers and Patient and Public Involvement (PPI) representatives from the ASR community. They informed our research questions, recruitment methods, study information and focus group interview schedule (see supplementary material). They also validated study findings in light of their understanding and experiences of healthcare at a stakeholder event attended by health professionals, researchers and Public Health Wales and presented findings at the Health Services Research conference.

Conceptual framework

We identified no existing theoretical models of access to healthcare which feature immigration policy or legal status. We draw on the model of Levesque et al.³⁰ (Figure 1) which identifies five dimensions of service accessibility: Approachability, Acceptability, Availability, Affordability, and Appropriateness; and five dimensions of patients' ability to access services: Ability to perceive; Ability to seek; Ability to reach; Ability to pay; and Ability to engage. We used this framework to interpret our qualitative data about ASRs' access to healthcare.

Setting

We conducted focus groups across the four main urban dispersal areas, one semi-urban area and two rural areas.

Recruitment and sampling

We used convenience sampling to recruit participants to the study. We followed GRIPP2 guidelines³¹ for lay involvement in research and recruited two PPI representatives and four development officers from relevant Non-Governmental Organisations (NGOs) – British Red Cross, Displaced People In Action, Ethnic Youth Support Team and Welsh Refugee Council – to engage the study population.

ASR completing our survey were invited to join a focus groups. Our initial aim was to include only ASRs, however, in some instances participants requested that their support workers or volunteers be present to facilitate participation. The volunteers and support workers were able to clarify certain issues raised by the participants in relation to their access to services.

Data collection

We developed a semi-structured focus group topic guide devised and piloted with peer researchers (see supplementary material). We used health-seeking scenarios to encourage participants to discuss general health issues. One experienced qualitative researcher (AK) led all eight focus groups, with two researchers (TK, WA) taking written notes and helping with interpretation. We took written consent from all participants prior to the focus groups. We asked questions in English and, when necessary, translated questions and interpreted responses from Kurdish (through a professionally trained interpreter), Arabic (through co-author WA – Ph.D. nursing student, native speaker), Bengali, Punjabi, Urdu (through co-authors TK (medical student) and AK (who was a qualified professional interpreter)) and Tigrinya (through a native speaker). With participants' consent, we recorded and transcribed the discussions in English. Swansea University Medical School Ethics Committee gave ethical approval.

Analysis

We used framework analysis,^{32,33} informed by Lévesque's model,³⁰ and facilitated by NVivo qualitative data analysis software (Version 12). Two of us (AK, BAE) independently read transcripts to identify and refine themes. We resolved discrepancies in interpretation by discussion and referred unresolved discrepancies to an experienced qualitative researcher (AP). Peer researchers and PPI members were involved in review of themes and PPI members are co-authors and were involved in the write up of the study.

Results

The eight focus groups across Wales had a total of 57 participants; 50 were ASRs (see Table 1) and seven were ASR support workers and volunteers. To overcome cultural barriers, two groups were female only, and two male only. Twenty four people identified as asylum seekers and 26 as refugees. One person identified as a 'destitute asylum seeker' having exhausted all appeal rights. Thirteen people had been living in the UK for more than five years with one person still seeking asylum for themselves and their family for 14 years. A high proportion of study participants were able to communicate in English, reflecting their length of stay in the UK. Focus groups included a minimum of three ASRs and one support worker and a maximum of eight ASRs and two support workers. The focus groups lasted between 45-80 minutes.

To maintain anonymity, we identify quotations by focus group number, migration status, gender and place of origin.³⁴ Where participants contributed through an interpreter, we report this interpretation.

We report findings under four major themes: navigating the system (Levesque's ability to seek and engage³⁰); language and communication (ability to reach³⁰); matching expectations to NHS resources (ability to pay and to engage³⁰); and mental health (ability to perceive and to seek³⁰).

1 Navigating the system (ability to seek and engage)

ASRs described a range of specialist staff who facilitated access to services or were able to communicate patients' needs to health professionals in times of crisis. These included nurses, health visitors, social workers, community support workers funded through Home Office grants, and volunteers. All participants had received help to register with a general practice and most had received support to attend appointments with GP, dentist or secondary care, though some participants were unaware of out-of-hours GP services and instead used the emergency department (ED). Participants spoke very positively about this support:

FG 1: When we were in [area] it is a really good system there. ... everybody has one centre where they meet and you can discuss all your appointments (GP and secondary care) and they follow up on everything. Here you have to start afresh on your own (Asylum seeker, female, West Africa)

FG 8: (through interpreter): At night time, the volunteers come if we ask for help (Refugee, female, Middle East)

The GP telephone system was an additional barrier. Many used support services or made appointments in person, taking more journeys and time to see a GP:

FG 7: You ring them and they don't answer for ages. Sometimes you have to go early morning to the surgery to make an appointment. Or if you try and book an appointment they are giving you an appointment after a week or two weeks. Health Visitors can help. They can ring and make appointment or talk to the surgery (Asylum seeker, male, South Asia)

However, the sustainability of non-statutory support is questionable. In a non-dispersal area, we found that one NGO was withdrawing support for Syrian refugees after two years and this concerned some

of the participants as they were still developing their English speaking skills. Support from volunteers was tenuous:

*FG 8: There is only probably six to eight of us volunteers left. We started with 12 to 14.
(Female, volunteer)*

2 Language and communication (ability to reach)

Feeling anxious and unwell exacerbated the language barrier and affected communication during consultations, even for participants with conversation skills.

Participants generally felt reassured when interpretation was available during consultations, either in person or via a telephone language service, to enable them to understand the advice and treatment. However, not all participants rated interpreters highly. Sometimes interpreters spoke a different dialect or could not interpret medical terms fully:

FG 4: When we go to GP, ... a woman is there to interpret for us. ... she is not able to interpret properly ... she don't know lots of words (Asylum seeker, male, South Asia)

Some participants reported being sent home from the surgery or hospital without treatment, because no interpreters were available. In other cases, practitioners and patients relied on relatives or on Google Translate to interpret consultations, not always accurately:

FG 6: (through interpreter): I went to see the doctor and he used Google Translate. The doctor thought it was a stroke but it was my tooth (Refugee, male, Middle East)

One participant reported clinicians relying on a 12-year old child's ability to speak English, though the parents could not, leading to them becoming distressed and anxious. The child, a Syrian refugee, had been referred to hospital to repair damage caused by a bullet wound and her consent was sought before undertaking the operation which health professionals would not ordinarily do for patients who could speak English:

FG 5: (through interpreter): I ask for an interpreter but [hospital] said your daughter knows English so there is no need. The doctors think my daughter would understand the situation and they took her consent. I made a big mistake, next time I will not allow them to do anything without an interpreter, I have to understand what is going on (Refugee, male, Middle East)

There was some mention of the value of written information in languages other than English:

FG 5 (through interpreter): When my wife was in labour, the hospital provided me with information about induction of labour in Arabic. What is the procedure, what is the side effect (Refugee, male, Middle East)

However, many participants said they did not find leaflets helpful, but would prefer information on health on a website – including audio versions – or delivered in person through courses by NGOs and drop-in sessions with Health Visitors:

FG 1: It's good when people can come and talk, like in [NGO] 'cause we have a lot of courses there [Asylum seeker, female, Sub-Saharan Africa]

However, for many, language barriers remained to accessing health promotion and mental health services. There was an awareness that learning to speak English was fundamental to independence, especially accessing care.

FG 8: The Home Office have said right from the start we've got to make them independent. Picking up a phone is much more difficult to make an appointment. (Volunteer, female)

3 Matching expectations to NHS resources (ability to pay and engage)

Although people from developing countries generally reported viewing the care they received in Wales positively, there were some misconceptions about the role of the health service, for example, a perception among some that secondary care was only available for seriously ill people. For those participants originating in countries with quite well developed health systems, there could be frustration at coming across services which were different in Wales, such as pharmacists not prescribing medication. Participants often misunderstood the role of NHS gatekeepers. Some bypassed the GP and went straight to the emergency department (ED) to access specialist care. Others suggested that the service was poor because it was free at the point of care:

FG 6: In Syria you can go to a private doctor and he will see what the problem is but here you have to wait months (Refugee, male, Middle East)

One participant made a positive comparison between the more considered approach to medication in Wales compared with what happened in her home country:

FG 8 (through interpreter) As Arabs, we like medication for any condition. Medication is like sweets...here the GP wait and see if problem gets better, that's good (Refugee, female, Middle East)

Participants reported times when access to care was denied, or they felt chronic conditions were mismanaged:

FG 7: The health service is very good for children. For adults not so good. My husband went to the pharmacy for some pain relief; they did not give him anything. We went to the doctor; the doctor shows a lack of compassion. (Refugee, female, Middle East)

FG 1: After two or three weeks the problem happened again and they gave her a course of more tablets. We ask for a specialist to resolve the problem and not just to give tablets. This is not good treatment (Asylum seeker, male, Middle East)

One participant reported more extreme challenges associated with engaging with the health service, when a call to NHS111 was understood as threatening undesired consequences:

FG 6 (through interpreter) I had a bad experience. I called 111 because my child had injured his eye so they told me (it was 3am) "If you don't bring her to the hospital we are going to have to call the police." So I called the neighbours to take me to hospital (Refugee, female, Middle East)

Other challenges to engaging with health care were very particular to the ASR group. Dispersal of asylum seekers disrupted continuity of care:

FG 4: When [son aged 5] was in England, he was seeing [mental healthcare], so when I come here we told them many times [he needs mental healthcare], but they didn't do anything. I have shown [GP] lots of pictures of [son] self-harming, but they will not respond (Asylum seeker, male, South Asia)

Dissatisfied participants were unaware that they could change their GP or dentist; asylum seekers believed they needed permission from NASS to change provider:

FG 4: I wanted to change my GP but I haven't got any letter from Home Office (Asylum seeker, female, South Asia)

The cost of proprietary medicines like infant paracetamol was a challenge for asylum seekers. Though patients' travel costs to health care can be reclaimed, awareness of the process was low, and family members are not covered:

FG 1 [through interpreter] I don't even have enough money to eat and provide essential things for my family, and I have to spend most of this money on travel going in and out of the hospital (Asylum seeker, male, Middle East)

One refused asylum seeker (without public funds) believed he had no free access to GP or dentist, and relied on donations from parishioners to cover the £60 cost of dental treatment. Participants understood that they were responsible for their health, and healthcare was for illnesses. They described remedies for treating minor ailments, like herbs and vinegar to treat colds and fever. They avoided going out in bad weather to prevent ill health. Participants mentioned the importance of eating fresh food and taking exercise, but wanted support to do this well. They mentioned volunteering, sport and keeping busy as ways to build resilience against mental health problems.

FG 2: You need to look after yourself because you cannot easily get access to the GP so you have to make sure that you stay healthy (Refugee, male, Middle East)

4 Mental health and trauma (ability to perceive and seek)

Participants in this study were happy to talk about mental health, though very few talked about their sanctuary-seeking journeys. Instead, they focused on stress caused by isolation and uncertainty. One elderly participant had lost his first wife in Syria. Now he was living in Wales on a low income, his second wife had been diagnosed with cancer, and his children and grandchildren were still in refugee camps in Jordan. He was not the only participant to report feeling helpless:

FG 8 (through interpreter): I like to be in big city. I want to be in contact with Arabic young people because it is difficult to express myself in English. Transportation is difficult here and (I'm) very lonely [Refugee, female, Middle East]

FG 5 (through interpreter): the experience that I have is killing me every day [Refugee, male, Middle East]

Participants generally talked about feeling sad rather than feeling mentally unwell. They acknowledged mental wellbeing as key to staying healthy, but struggled with the weather and the perceived isolation associated with modern technology. However, some refugees believed, once physiological and safety needs were met, they should forget the past, concentrate on the present, and trust God to prevent mental ill health.

FG 7 (through interpreter): We leave our problems behind and not remember the past, and be grateful for what we have. As Arab people we do not complain about mental health. Our religion helps us to overcome all these problems (Refugee, female Middle East)

Some participants mentioned that they would not talk to their GP or other health professionals about mental health, fearing it would instigate prescribed medication which they believed would be detrimental to long term health and make matters worse. They preferred a psychosocial response to mental healthcare:

FG 7: I would not go to the GP with mental problems. Because it will cause more depression. because they will prescribe tablets (Asylum seeker, female, East European)

FG 7: If my son was sad, I would talk to him, show more kindness and give him hugs. (Refugee, male, South East Asia)

While some recognised that healthcare might help, they found access to mental healthcare a challenge, experiencing long waits or no care at all.

FG 2: I think it's very hard to get mental health support here ... from my experience [seeking mental health support for teenage daughter] (Asylum seeker, male, South East Asia)

Participants reported that mental health services did not generally offer counselling or therapy through interpreters. Participants who had received counselling reported mixed feelings:

FG 1: I don't think I need more counselling. I felt it helped me, but sometimes you don't want to talk about stuff, and when you do talk, it is more distressing because ... you are going back to it. (Asylum seeker, female, Central Africa)

Discussion

Summary of findings

This is the first study to explore the views of ASRs across Wales about healthcare. In terms of navigating the system, most understood the role of general practice in providing and coordinating care but were unaware of some services such as out of hours.²² They valued the role of specialist NHS-funded services and grant-aided Non-Governmental Organisations (NGOs) in facilitating access to healthcare. Difficulties with language and communication featured strongly as barriers to healthcare, alongside health literacy, unrecognised needs, and the cost of travel to appointments. Written information about healthcare is limited in accessibility to those with language needs, and few

participants were accessing preventative health services.³⁵ Typically, ASRs framed their responses through the perspective of their home country, leading to some mismatch between expectations and what they experienced.²⁴ Participants recognised the importance of mental health, but many did not see it as something for which they would seek support from a GP. Others expressed disappointment at the state of mental healthcare.

Strengths and Limitations

We cannot generalise our findings to all ASRs. We probably underestimated barriers to access, as service users were more likely to participate. However, we judge that our use of peer researchers to recruit participants across Wales ameliorated this potential bias. We recognise that focus groups may have inhibited some views. However, we used hypothetical health scenarios to ease people into discussions and found most responded to these situations as they were not directly referencing their personal experience. Many participants were not able to communicate their views in English, and though we provided interpreters and ensured that we used short sentences, we were not always able to use a professional interpreter.

Comparison with Literature

Understanding user perspectives is vital when exploring ways to improve the delivery of health care.³⁶ We found that Levesque et al's conceptual framework of access to healthcare provided a useful framework for organising our data, to identify barriers and enablers faced by ASRs. Although the model does not include migration as one of the determinants operationalising access to health care, we found that it functioned well in helping us to examine the experience of ASRs. Our results are consistent with previous findings that:

- many participants used NGOs for support;^{3,37}
- though refugees had housing and income, many suffered post-resettlement stress;³⁸
- unmet expectations generate mistrust of GPs, resulting in repeat visits or ED attendances;^{1,39}
- weak interpretation services weakens consultations;^{2, 19, 40}
- interpreters cannot interpret all medical terms.^{2,41}

We found that ASRs' first point of contact with health services with frontline staff such as GP receptionists, emergency paramedics and pharmacists was often weakened by a lack of effective interpretation.

Most ASRs openly discussed mental health and wellbeing, contrary to previous work.⁴² They confirmed that their migration journey had contributed to poor health.⁴³ Nevertheless, recent migrants preferred to forget the past once they were safe and sound. Unexpectedly some ASRs were wary of consulting GPs for mental health; less surprisingly language barriers deterred others from accessing

mental healthcare.⁴⁴ Fortunately several ASRs recognised that good mental health enhances coping strategies when integrating into new communities.^{45,46}

Implications for practice and research

Since the 1951 Refugee Convention⁵, the UNHCR has promoted the right of refugees everywhere to have the same access to healthcare as the host population. The Welsh Government has sought to operationalise this principle in its 2019 plan for a Nation of Sanctuary for refugees and asylum seekers,¹⁵ which includes a requirement for all ASRs to have access to health services (including mental health services) throughout their sanctuary seeking journey. Our research suggests the implementation of a multi-agency systems approach to achieving this goal. To facilitate patient-centred care, not only during GP consultations but also in interactions with other practice staff, access to competent interpretation is crucial. To improve experience of care, manage expectations, and reduce distrust we recommended continuity of care,⁴⁷ flexibility in the appointment system,^{3,23} and education about entitlements targeted at both ASRs and health providers at all levels in particular the legal entitlement to interpretation services.

ASRs need continued investment in support services including specialist health professionals, NGOs and volunteers provide patient centred care that tailors consultations to need. Such support should continue until ASRs are familiar with services and achieve basic English language proficiency. The added cognitive load experienced by patients trying to speak in English during consultations can inhibit understanding and communication⁴⁸. ASRs recognised that these services had enabled them to navigate an unfamiliar system of care and were there to advocate on their behalf.² So mainstream healthcare providers need to work closely with these support services who understand how best to respond to ASRs. They should also offer access to interpreters in situations where mental health care is sought rather than waiting for people to become proficient in English before providing care as it may take some ASRs a number of years to reach language proficiency.⁴⁹

Finally, commissioners and service providers should encourage innovative ways of caring for refugees and asylum seekers; and evaluate any such innovation rigorously. This is especially pertinent at this time when remote GP consulting is increasingly being used due to the Covid-19 pandemic. This is an added layer of complexity and the impact of such changes on ASRs needs to be fully evaluated. There is potential risk that remote GP consulting may increase health inequality by reducing access to interpreters with the added barrier of digital poverty which can prevent online access in the first place.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

AK, LC and RF designed this study. AK and RF organised the focus groups. AK conducted the focus groups with support from TK and WA. AK and BAE analysed the data. AK drafted the manuscript with support from BAE, AP and ITR, and comments from all co-authors. All authors have seen and approved the final version.

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Table 1 – Characteristics of participants in focus groups of 50 asylum seekers and refugees

ASR characteristics	No (%)
Gender	Female 24 (48%) Male 26 (52%)
Age range	21-68
Length of stay in Wales	Between 3 days and 6 years
Length of stay in UK	Between 1 month and 14 years
Countries of origin	
Albania	2 (4%)
Afghanistan	5 (10%)
Angola	2 (4%)
Bangladesh	1 (2%)
Ethiopia	4 (8%)
Iran	2 (4%)
Iraq	1 (2%)
Libya	1 (2%)
Malaysia	2 (4%)
Pakistan	2 (4%)
Syria	26 (52%)
Vietnam	1 (2%)
Zimbabwe	1 (2%)
Spoke English	22 (44%)