

Building trust: Delivering health care to newly arrived refugees

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ABSTRACT

This paper reports on a qualitative research project that investigated the barriers and enablers for refugees accessing primary healthcare within one year of their arrival in Australia. The study documented the experiences of five families from five different cultural backgrounds (Afghan, Burundian, Iraqi, Rohingya, and Somali), who were resettled in Brisbane, Australia. Peer interviewers conducted face to face interviews, using semi-structured questionnaires, to document the experiences of 31 individuals (15 females). Data from these interviews were supplemented with data gathered from the interviewers themselves. A thematic analysis identified six key themes: trust in services, language and interpreting, health system literacy, service integration, what is working, and what is needed. Most participants reported basic knowledge of the health system but relied heavily on family and friends for advice beyond this very basic level. The implications of this are discussed. This study contributes greatly to our understanding of the issues facing refugee families accessing primary health services at a time when they are especially vulnerable. The importance of building trust between refugee communities and the health system emerges as an overriding imperative for health service development. Recognising the factors that facilitate this process offers an opportunity for improved health care in the future.

Keywords: refugees, primary health care, health care access, trust, health literacy, qualitative research

BACKGROUND

Between 2000 and 2009, Australia received about 126,000 refugee and humanitarian entrants; ten percent of them settled in Queensland, mostly in the greater Brisbane metropolitan area (DIAC, 2010b). Currently, the humanitarian settlement program is equally allocated between Africa, Middle East and Asia. Most new arrivals have complex health needs (Smith, 2006; Tiong, Patel, Gardiner, Ryan, Linton, Walker et al., 2006) which can be the result of trauma and torture in home countries, difficult and prolonged experiences in refugee camps, and poor access to preventive and other health services (Foundation House, 2007). Many refugees have lived in refugee camps for over ten years prior to arrival in Australia and have had limited access to health services.

Some research has been undertaken in Australia looking at the experience of refugees accessing primary health services (Department of Human Services, 2009; Neale, Ngeow, Skull, & Biggs, 2007; Sheikh-Mohammed, MacIntyre, Wood, Leask, & Isaacs, 2006). Some have reported general satisfaction with the health system while others have reported a poor opinion (Department of Human Services, 2009). Language and cultural issues, health beliefs and unfamiliarity with health systems are well documented barriers to access health care (Neale et al., 2007; Sheikh-Mohammed et al., 2006). General Practitioners (GPs) have also reported difficulties in providing service to refugees including difficulties with interpreters, time constraints, and refugees' lack of familiarity with the Australian health system (Johnson, Ziersch, & Burgess, 2008).

A range of models of refugee health care service provision exist across Australia (Woodland, Burgner, Paxton, & Zwi, 2010). In 2009, Queensland Health and Mater Health Services established Refugee Health Queensland (RHQ), a specialised assessment service for newly-arrived refugee and humanitarian entrants during the first 6 months of settlement (Queensland Health, 2008). RHQ is also aiming to establish itself as a "beacon" practice to provide clinical support and information to GPs who deliver services to refugees (Jackson, Askew, Nicholson, & Brooks, 2008; Kay, Jackson, & Nicholson, 2010).

Although refugees arriving in Brisbane have access to a health assessment on arrival, it is not known whether they feel well equipped and confident to engage and remain engaged with GPs and other health services. This study investigated the barriers and enablers to access primary healthcare among refugee families within one year of arrival in Australia.

METHOD

Design and sampling

This qualitative study was conducted in Brisbane in 2010, and involved five families who entered Australia under the Refugee and Humanitarian program in the past year, holding a Visa 200. This visa is for “people who are subject to persecution in their home country and who are in need of resettlement” (DIAC, 2010c). This meant they were entitled to the support of the Integrated Humanitarian Settlement Strategy (IHSS)(DIAC, 2010a). Services provided under the IHSS include: (i) on-arrival reception and orientation; (ii) information and referral to other service providers including healthcare services; (iii) assistance with accommodation and basic household goods; and (iv) short-term torture and trauma counselling. Services are generally provided for six months. Refugees arriving on Visa 200 are permanent residents with access to Medicare.

All participants had received health assessments at RHQ Brisbane Clinic. Purposive sampling was used to select participants from the discharge records of RHQ. As part of the intake procedure for RHQ Brisbane Clinic, all patients are invited to provide voluntary, informed consent to participate in future research projects. Of those patients who consented to being contacted again, one family from each of the following cultural backgrounds –Afghan, Burundian, Iraqi, Rohingya and Somali was invited to participate. This selection reflects the cultural background of the recent refugee arrivals to Brisbane (DIAC, 2010b). Consent was confirmed when peer interviewers contacted each family and after the interviews were completed. Full ethical approval was obtained from the Mater Health Services Human Research Ethics Committee.

Peer interviewer model

The study used a peer interviewer model. This model has been found to be effective in undertaking research in “hard to reach” populations (Elliot, Watson, & Harries, 2002), including refugee populations (Correa-Velez & Onsando, 2009). Five bilingual peer interviewers were selected to match the cultural and linguistic background of each of the five participating families. They attended a training workshop on basic skills for the ethical conduct of research focusing on issues of informed consent, privacy, confidentiality and duty of care. Supervision and support was provided to the peer interviewers by the principal investigators.

Data collection

Data was collected through face-to-face semi-structured interviews. Peer interviewers conducted the interviews at each participant's home, in the participants' preferred language recording the results in English.

Interview questions were developed following a review of the literature (Department of Human Services, 2009; Neale et al., 2007; Sheikh-Mohammed et al., 2006) and were further refined through discussions with the peer interviewers. The interview questions were used as a guide and were not intended to proscribe the conversation. A range of topics were covered including health needs, use of health services including specialist care, barriers and facilitators to accessing care, advice they would offer other newcomers, and the best sources of advice and guidance. The peer interviewers were encouraged to record their observations and reflections (Patton, 2002).

Five interviews were conducted. Information was provided by one or two adult members of the family but included the health and healthcare experiences of all members of the household. Interviews lasted from one to five hours. The experiences of a total of 31 individuals (15 females) were covered by the study. Their ages ranged from 2 to 45 years; 18 were children aged 17 or younger. All had been in Australia between six and twelve months.

Once all interviews had been completed, the research team met to record their reflections and to ensure that saturation was achieved. The peer interviewers' insights from their own experiences as refugees themselves provided a valuable perspective. The discussions from this meeting were transcribed by the principal investigators.

Data Analysis

Data from participants' interviews, and peer interviewers' field notes were analysed using content and thematic analysis (Patton, 2002). Two researchers (PP and DS) independently read all the transcripts to identify broad themes. Common themes were grouped together into key categories. Consensus was sought through discussion.

RESULTS

Six key themes emerged from the data: trust in health services, interpreting and language issues, health system literacy, service integration, what is working well, and what is needed. These are reported in turn. Direct quotes are included in italics below. Quotes from participants are coded as Family 1 to 5. Quotes from peer interviewers are coded PI 1 to 5.

Trust in health services

The refugee families reported that their decisions about seeking health care were intimately related to the issue of trust. First impressions created when first interacting with the health providers were essential to developing this trust, in particular feeling welcome and respected.

We ... appreciated the warm welcome... different from what we experienced in Africa. (Family 2)

Trust was then confirmed in the development of the ongoing relationships with the health service as a whole including administrative, nursing and medical staff.

[We appreciated the] kindness of medical personnel. (Family 2)

Relaxed attitude of receptionist and health workers did help. (Family 5)

The professionalism of the health service was integral to building trust.

When I saw the GP he requested an interpreter... he asked me properly and friendly and then gave me treatment. It was helpful for me. (Family 3)

The capacity of the health service to make good use of a support team and targeted community referrals was important. This is particularly relevant for very recent arrivals who receive support through the Integrated Humanitarian Settlement Support team.

[The health service was] trying to help me in different ways and in different things as much as they could – they start to help by contacting my case worker to facilitate contact with a solicitor. That was very helpful to me. (Family 4)

Parallel to the concept of trust was the idea of “safe places”. “Safe places” were identified as being friendly to people of a particular community. The place was considered “safe” because of the shopping and other services available there beyond the health service, which had developed a higher profile within

their community. Even if a person did not live there they would travel there and avail themselves of the amenities located in this “safe place”.

They go to a GP who sees lots of people from our community. A friend helps with interpreting. The woman does not want to see a GP who is closer to her home. (PI 5)

Failure to develop a relationship of trust affected the delivery of health care. Sometimes the doctor did not appear to hear what the patients’ concerns were, did not take an adequate history and therefore did not attend to the health needs appropriately.

GP did not check well and give birth control injection, she was 3 months pregnant. (PI 3)

Community GP did not listen and did not take them seriously. Felt [GP] was not respectful of them. (PI 1)

At other times patients did not understand the rationale for medical procedures and were left confused.

I complained why they take six different specimens for blood tests. (Family 2)

The most powerful brokers between patient and system were community members (friends) and family. Refugee families reported being prepared to travel long distances to a doctor who had developed good relationships with a trusted other.

I requested a referral to a GP based on a friend’s advice. (Family 4)

We primarily seek help from relatives and friends for assistance. We have strong ties with our friends and relatives so we seek help from them. (Family 5)

Patients clearly have a (mostly unacknowledged) role in educating their doctors about their histories and their cultures. Once a good link has been made with a GP the families were reluctant to move elsewhere.

It gets tiring to have to explain yourself all the time. There is a reluctance to accessing a new health professional because of having to re-explain one self and to go over painful complex history. (PI 5)

In some cases, previous experiences had an enduring corrosive impact on the capacity to trust the Australian health system. For example, the manner in which health assessments were conducted overseas as part of the refugee application process were sometimes traumatising in themselves.

They experienced stress and trauma in refugee camp but they did not want this recorded as a health issue.... [The family was] traumatised by health system in visa application process – trust in health professionals very low. Still fear being returned. (PI 2)

Interpreting and language issues

Some people would only access GPs who spoke their language circumventing any issues to do with language. However there seems to be low expectation on the part of newly arrived refugees that the GP should engage an interpreter for them.

We don't get interpreters at our current GP. We have to use friends; also my husband's limited English helps. (Family 5)

This was compounded by ineffective follow up communication.

System sends follow up letters in English – client is not connected to any service by then. It sits on the shelf unread for months. (PI-2)

Expectations of interpreting are quite low. In fact the presence of an interpreter was reported as something “wonderful” rather than an expectation to receive an appropriate level of service.

At first I worried because of the language barrier. But when I arrived I saw everything was highly organized like there was an interpreter waiting for us and everything was facilitated for me and for the family. (Family 4)

A significant issue emerged in the course of the study about the quality of the interpreting. This was partially related to the linguistic competence and diligence of the interpreter.

Sometimes the interpreter does not interpret the actual issues. (PI 5)

In part the issue was a structural issue related to the lack of access to accredited interpreters.

We had to wait for interpreter for a while, sometimes for a long while. (Family 3)

Sometimes the issue related to the professional behaviour of the interpreter.

The interpreter kept saying “Why did you come here? You ripped off the system. Your area has no problems”. (Family 1)

Health literacy

The need to improve health system literacy within refugee communities was identified. One participant had not even been given the most basic health access information.

Family not shown how to get to medical centre. (PI 5)

Even when the health provider had extended their service to accommodate the needs of their refugee patient, there was a fear that this could potentially bring repercussions. One family was concerned that they had violated the system by needing to be specially accommodated.

The doctor/nurse was upset due to the delays but still helped us. (Family 2)

Other concerns were raised about the way health care was provided in Australia, in particular the frequency of testing and other interventions. These procedures were often regarded as unnecessary duplication by the participants.

Concern about immunizations – they were given immunizations in the camp. (PI 2)

Distress that they were checking bloods again. (PI 2)

When adequate information during the consultation was provided then the participants reported satisfaction and enhanced confidence.

He [Interviewee] was very confident ...based on good knowledge. (PI 4)

This study highlighted the significant gap between expectations of health service and the reality of the Australian health system. An example of this was the usual practice of Australian doctors to give lifestyle advice. It is an accepted notion in Australian general practice that a consultation provides an opportunity for health promotion and prevention (Murtagh, 2003). This can lead to dissatisfaction.

They were not happy with the GP. They say we wanted medicine for pain – especially for his back. But the GP was saying to drink water. (PI 1)

It was even felt that this approach to health care could deflect attention from more immediate needs.

Somali women have joint pain – but they are used to working hard. They need physio massage exercise. Doctor's instead check cholesterol. (PI 5)

Concerns were raised in relation to the health providers' knowledge. Participants directly questioned the adequacy of the Australian doctors' knowledge about refugee health and the health issues as part of the refugee experience. .

Doctors don't know our past – e.g. malaria that it is still in the blood. (Family 5)

[There is] limited knowledge of the experiences and health profiles of refugee communities. (PI 4)

Concerns were also raised in relation to health provider's knowledge about cultural approaches to health. Awareness of how the community would normally address a specific health issue could enable a health provider to understand the pathway prior to seeking formal health care.

We believe in spiritual trust. We firstly address any health matters by prayer and trust in spirituality. (Family 2)

Service integration

Health service integration is an essential aspect of quality health care. One family reported how poor communication between health services had left them feeling disempowered and lost.

Poor communication between [one service] and GP – it was mishandled in the first instance. (Family 2)

Referral information did not pass on the proper channels. I was referred to Pathology but due to lack of interpreter I did not know how to deal with it. (Family 2)

Good communication within the health system is a prerequisite for accessing specialists. Some families were able to access specialist care smoothly because of the effectiveness of the referral protocol.

The GP advised that the children need to see a specialist in regard for their throat. He made a referral to the hospital to see a specialist and he sent a fax and did everything that someone can do. (Family 4)

Others found accessing specialists very difficult.

The younger son has a problem with his kidney. They have a problem getting a specialist appointment. (PI 1)

[He] missed a specialist appointment. He did not know that specialist appointments are hard to get and therefore more important than class. (PI 3)

What is working well

All families had received intensive targeted support in the first few months after their arrival in Australia. They had since been “discharged” from the intensive support system and were now independently managing their lives including their access to health care.

Most participants reported that they were happy with the service they had received. In particular they appreciate having a health assessment soon after arrival.

I feel very comfortable when they checked everything I mean blood, hearing, skin and different exams. That gave me a sense of comfort. (Family 4)

Quick assistance for immunisation plus records keeping was appreciated. (Family 2)

They reported that they now have a good understanding of the system.

Understand about role of interpreter, 000 and ambulance. (Family 3)

Knows the importance of other services other than nurses and GPs – e.g. pharmacy. (Family 5)

They also reported confidence about accessing services independently.

We are happy to use community services e.g. immunization and growth monitoring for our children. (Family 2)

What is needed

Participants were highly motivated towards independence and wished to feel in control of their own health issues. Having copies of their health records was one suggestion aimed at addressing this.

Can we have a health check review or update of our health report? (Family 2)

Most suggestions related to health education and access to more information.

I would like to know about healthy food, reaction of medicine and a healthy lifestyle and some more health information needed in daily life. (Family 3)

I wish if there were some courses that could run in TAFE about medical issues. Like what is MEDICARE and what is the difference between the medical centre and the private doctor. (Family 4)

[We need to know about] prevention measures to obesity and diabetes. (Family 5)

DISCUSSION

This qualitative study has found that the overriding issue in the provision of primary health care for newly-arrived people from refugee backgrounds is the development of trust between the patient and the health service. Other themes can be understood as mediators to improving trust with health and cultural literacy being key.

Trust was established through multiple avenues including the extension of simple kindness. It involved all staff in the practice. It also involved the provider addressing health holistically. The inclusion of “non-clinical” issues such as linking to community programmes was important in enhancing rapport. The association of a practice with a “safe place” or the recommendation of others from the refugee’s community also strengthened trust.

The literature on health literacy indicates that low literacy is linked with poorer health outcomes (DeWalt, Berkman, & Sheridan, 2004; Safer & Keenan, 2005) including poorer health status, higher levels of chronic disease, and higher hospital admissions (Adams, Appleton, & Hill, 2009). Limited research has been undertaken with migrant and refugee communities around health literacy (McMichael & Gifford, 2009; Zancheta & Poureslami, 2006) however surveys undertaken in major developed countries including Australia show that around 50 percent of adults have low health literacy (ABS, 2006). Diversity clearly adds an extra dimension (Andrulis & Brach, 2007).

Nutbeam (2009) articulates a useful model of health literacy which extends beyond reading (functional literacy). It looks at the ability of patients to interact with health professionals and to exercise control over

their daily situations (interactive literacy). It includes a focus at a community level on how individuals and communities engage in public discourse on health issues to impact policy and practice (critical literacy).

The study indicates that health orientation on arrival is working well. However, this study also demonstrates a high degree of reliance on relatives and friends from the refugees' communities for health information including assessment of the quality of care. It raises the question about the level of functional health literacy of the relatives and friends. It suggests merit in developing programmes that effectively enhance the functional, interactive and critical health literacy of individual members and refugee communities as a whole (Nutbeam, 2009).

These refugee families valued their independence in their healthcare access and appreciated being included in the management decisions. The data confirms the importance of identifying the expectations of the refugee patient so that the specific health issue can be addressed in the consultation (DHS, 2009). Although there was interest in learning about preventive health, it was quite clear that for some, the emphasis on preventive health issues was not a part of their expectations of care. Overall, these families valued the health assessment provided by the specialised refugee health service.

This study clearly indicates the importance of education for healthcare providers. Questions were raised about the level of clinical knowledge and the relevant cultural knowledge of the primary healthcare providers. Australian trained doctors may be unfamiliar with the health needs and cultural profiles of refugees. However it is imperative that they redress this. Patients themselves are an important source of cultural information for the health provider but this is a significant expectation to have of a newly-arrived refugee. Given most people who enter Australia under the Refugee and Humanitarian Program have experienced trauma at some level, health practitioners need to be versed in the clinical presentation of such trauma (Benson, 2004) and to appreciate the corrosive legacy of trauma in building trust (Gardiner & Walker, 2010).

Other studies have described the difficulties that exist in a consultation when English is a second language (Flores, 2005; Karliner, Jacobs, Chen, & Mutha, 2007; Phillips, 2010). Language is the mechanism through which literacy can be established and through which trust is built. The participants in this study cited difficulties negotiating healthcare even when professional interpreters were available because of poor quality in the interpretation or unprofessional conduct. The refugee patient is particularly vulnerable in such a situation. Both patient and provider will benefit from the increased availability of

health-trained interpreters. Providers need to be aware of the difficulties that can arise in interpreting and be sensitive to cues suggesting problems.

Although this study provides valuable insights a number of limitations are recognised. A small number of families were interviewed and the sampling was not designed to be representative of all newly arrived refugees in Brisbane. The similarities in the experiences of each of these family groups from very different cultural groups reveal the commonality of their experiences.

The peer interview model has advantages in enabling communication and in positively impacting on rapport. However, there are also potential pitfalls in this design (Pitts & Smith, 2007). The model created an “embedded-ness” of the peer interviewer that may have skewed results. The peer interviewers were expected to adhere to shared cultural mores. Some topics were taboo – for instance asking about a pregnant woman’s experience of health service was inappropriate for a male interviewer. It is unknown whether results would change if the limitations of location and gender were addressed.

IMPLICATIONS FOR POLICY AND PRACTICE

This study contributes to our understanding of the issues facing newly-arrived refugee families accessing health services in the community. It emphasises that building trust between community and system is the overriding imperative for health service development. Some of the important facilitators of the development of trust were non-clinical including the attitude of the care providers, the quality of language support and the integration of social issues into the consultation. These approaches need to be further explored.

The study also confirms the importance of building health literacy but recognises that both the patient and the provider need education if quality healthcare is to be provided. The importance of fostering community health literacy is also reinforced. Strategies to build health literacy should go well beyond production of “low context” information such as pamphlets and web sites.

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CONFLICTS OF INTEREST

There are no conflicts of interest.

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