CASE REPORT

A Rohingya refugee's journey in Australia and the barriers to accessing healthcare

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SUMMARY

Australia's processing of some asylum seekers on offshore detention centres has recently been brought to light by human rights organisation. While the internal politics of resettling refugees may be complex, Australia remains in the top five countries for resettlement per capita. However, these refugees remain a vulnerable patient population after immigrating. Refugee women, an understudied group, in particular experience higher adverse health outcomes.

In this case report, we follow the medical journey of KB, a 38-year-old Rohingya refugee diagnosed with type 2 diabetes mellitus—the crux of all her health issues. We explore language differences as a barrier to healthcare and its near-fatal consequences, as well as communication breakdown in the context of the misalignment of health goals between the patient and the profession. As such, improving patient health literacy and cultural competency among doctors are core interventions in improving the delivery of refugee healthcare.

We have a global responsibility to improve health literacy among refugee patients and by providing the basic standard of healthcare to every individual as a human right, which empower refugees in this regard to have a role in their health outcomes.

CASE PRESENTATION

Presenting issues

KB, a 38-year-old Rohingya refugee, is referred by her general practitioner (GP) to the Endocrine Department at a tertiary hospital in Brisbane. She presents dressed in a black traditional Islamic gown and headscarf, accompanied by her husband. This is a follow-up appointment for her diabetes management, for which she was recently commenced on insulin. She speaks Rohingya, some Burmese and some Arabic, and therefore, a Rohingya interpreter is available on the phone for the duration of the appointment. The endocrinologist and diabetes educator are also present.

KB informed the doctors that the insulin did not 'suit' her and therefore had self-ceased it. It was revealed, through the interpreter, that KB had accidentally taken 600 units of Lantus (long-acting insulin glargine) over a span of 2 days, resulting in near-fatal hypoglycaemia. KB admitted to having felt nauseous initially before losing consciousness for 30–60 min, suggesting an iatrogenic hypoglycaemic event. A second incident occurred the following day where KB lost consciousness for a

similar amount of time following insulin administration. She reported that there was no one else at home at the time of either incident, and she regained consciousness herself. On further questioning, the confusion about appropriate dosaging was attributed to two things: (1) KB reported that she did was not familiar with how the insulin pen mechanism actually worked in delivering medication, and (2) the interpreter present at the previous consultation spoke a different dialect, and thus caused the misunderstanding and misinformation regarding the exact dosage.

Background and medical history

KB was followed up several times in clinic for further history. She returned by herself for the next few appointments with an interpreter present in person.

In 2009 and under the Humanitarian Migration Programme, KB arrived as a refugee to Brisbane, Australia, from a Bangladeshi refugee camp. She had migrated with her elderly mother, husband and son. Though born in Burma (Myanmar), she had spent over 20 years in Bangladesh, fleeing ethnoreligious persecution in Burma, where the Rohingya are considered 'state-less'. She underwent a visa medical check-up in Bangladesh, a requirement before getting an Australian visa to screen for any public health risks in refugees and immigrants. On arrival, a local resettlement agency organised accommodation, financial assistance and interpreting services for the family.

A few weeks later, KB visited a GP in order to undergo a more comprehensive postarrival health assessment. Such health assessment is recommended by the United Nations High Commissioner for Refugee (UNHCR) and can be carried out by migrant health services or doctors in the community. It was here where she was diagnosed with type 2 diabetes mellitus, a condition she was unfamiliar with. The GP referred KB to endocrinologists for diabetes management on the background that KB was also trying to conceive. KB had been trying to have a child for the past 7 years, since she arrived in Australia and had a second-trimester miscarriage 2 years ago. Although she has a 20-year-old son, she wanted to have another child who she could raise in Australia. During subsequent consults and follow ups, KB told us that she believed the medical profession had fixated on her diabetes, with little attention given to her infertility; however, she was cognisant that diabetes may affect a potential pregnancy negatively. KB's desire to start a family was

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of paramount importance to her mental and physical well-being. Compliance with her diabetes management was impeded by her overriding concerns about being unable to conceive.

Social history

KB is unemployed and lives with her husband, who is a childcare worker. Her husband speaks some English and was able to act as an informal interpreter at some doctors' appointments. Her 20-year-old son lives with extended family in Brisbane. KB has friends within the local Rohingya community, as well as some interaction with local Arab and Bangladeshi communities.

KB has undertaken an English language course at a local college that is provided to all refugees for free by the Australian government. However, KB reports that she did not understand the course and thus does not feel confident to speak in English.

KB is entitled to Medicare, Australia's universal healthcare scheme, and reports that the out-of-pocket costs to access services or medications are not an imposition to her or her husband. However, she does have to rely on her husband driving her to her medical appointments.

Global health problem list

1. Refugees in Australia are a medically neglected community.
2. Language differences can act as a barrier in accessing healthcare.
3. Refugee patients lack health literacy resulting in advanced disease and increased complications.
4. Healthcare professionals in Australia do not receive adequate training in refugee health and cultural competency.
5. The growing burden of chronic diseases in low socioeconomic groups such as refugees.

REFUGEE HEALTHCARE HAS INHERENT GAPS

The Rohingya people are a persecuted ethnic minority group from Myanmar (Burma). Many, like KB, were forced to flee to Bangladesh after the Burmese authorities passed the Citizenship Act in 1982. This act denied the Rohingya the right to a nationality, access to education, health services and a variety of other restrictions.¹ Over 200 000 Rohingya refugees are currently resettled in Bangladesh, a country with already limited healthcare for its own citizens as well as a non-signatory country to any of the United Nations Refugee or Stateless Conventions. As a result, refugees are not guaranteed access to basic human rights, including healthcare.²

As part of the immigration to Australia, the humanitarian visa pathway process dictates that refugees must undergo a cursory departure health check that aims to exclude those that pose public health risks. Furthermore, the UNHCR recommends that all refugees undergo a more comprehensive and refugee-specific medical assessment on resettling in Australia. This can be carried out by any doctor or via a dedicated migrant health service and refugee health networks in Australia. However patient-specific social and psychological determinants of physical health are not always evaluated in these health assessments.³

As many other humanitarian entrants that have immigrated to Australia, KB did feel well looked after given her entitlement to Australia's universal healthcare scheme, known as Medicare. Medicare allows KB to access GP services for free, and specialist services with some out-of-pocket expense.⁴ She identified Medicare as an important protective factor in accessing healthcare given her family's current socioeconomic status (SES).

LANGUAGE DIFFERENCES CAN ACT AS A BARRIER IN ACCESSING ADEQUATE HEALTHCARE

Australia has a robust national Translating and Interpreting Service (TIS) that is free to access for healthcare professionals. This service can be accessed by doctors during consultations as well as pharmacists at time of dispensing medication. A study from South Australia demonstrated language differences as the main barrier that non-English speaking refugees identified in accessing both primary healthcare and allied health services, stressing the pivotal role of interpreter services.⁵ However, dialects within the language group are not always taken into direct consideration when organising interpreters for clinical consultations. In the case of KB, on the day she was prescribed her insulin, the Rohingya interpreter assigned by TIS for her consultation spoke an unfamiliar dialect. As a result, she reports not fully understanding the prescribed insulin dosage, in turn overdosing and leaving her with profound hypoglycaemia. In hindsight, KB believes that being provided additional written information in Rohingya, and even English, rather than relying on her own memory from the consultation, would have assisted in understanding her medication better.

DOCTORS ARE NOT TRAINED ADEQUATELY IN TIS

Many doctors may not be adequately trained in effectively using interpreter services. Gray *et al*⁶ highlight the underuse of Australia's free telephone interpreter service by practitioners. Similar to the case of KB, common errors made in medical practice involving interpreters, include: (1) using long statements that might be difficult for the interpreter to remember and adequately relay; and (2) family members are used as interpreters according to best practice guidelines.⁷ In KB's case, her husband, who has a slightly better grasp at the English language given his work at a childcare facility, was used as the sole interpreter during a few clinical consultations. Furthermore, time constraints placed on all medical appointments increase the likelihood for rushed consultations. This is a pertinent area to encourage doctors to use the correct Medicare rebate item numbers for longer consultations for refugee patients and ensuring adequate remuneration of the healthcare professional.

IMPORTANCE OF CULTURAL COMPETENCY AMONG HEALTH PROFESSIONALS CARING FOR REFUGEE PATIENTS

Despite the increasing multicultural diversity of the Australian population and the increased diversity in Australian doctors, a push for further training in cultural competency and caring for patients of refugee background is important. Goldfeld identified this lack of cultural proficiency among health professionals also existing with patients of an Indigenous background in Australia.⁸ Culturally sensitive care is essential in building trust and rapport with patients from these marginalised and vulnerable communities.⁸

Medical students should be educated regarding the importance of culturally sensitive care in their preclinical and clinical years. A basic understanding of the history of refugee communities should be provided as part of a diverse medical education in Australia.⁹

There is a need to establish frameworks to receive feedback from refugee patients regarding the quality of their care. If these avenues of information are unavailable, how else is it possible to ascertain whether it truly is a language or cultural barrier creating miscommunication, or if there is a more sinister underlying gap in our practice principle as medical professionals?

This case further illustrates a valuable learning point for healthcare professionals. KB's primary healthcare concern was infertility, while she believed that the doctors were more interested in her diabetes. On one hand this can be seen as the medical profession fixating on the disease rather than the person behind the disease. Nevertheless, we often forget that our goals as health practitioners might not align with our patients, and thus we should restructure the healthcare goals in accordance with the patient's own priorities. For example, it was striking that when asked, KB relayed her understanding of her diabetes as not knowing what diabetes was or the chronicity associated with the condition. In fact, the main reason for her attendance at medical appointments was because she believed diabetes to be a hindrance to her conception. Pregnancy is of such crucial importance to her that she sought our advice, as medical students, on other ways to increase her chances of falling pregnant.

Another important note regarding the management of diabetes is the assumption that patients have an understanding of the role their medications play. KB had limited interaction with the concept of medication given its scarcity while living in Bangladeshi refugee camps. The utility of subcutaneous insulin pens was a form of medication that did not fit into her 'concept' of medicine, which historically and culturally was always administered orally. As previously mentioned, often this disconnect between our perceptions as medical professionals of a patient's understanding against their actual understanding may be attributed to inadequate training in refugee health and especially in cultural sensitivity.

LOW SES AND REFUGEES HAVE A HIGH CHRONIC DISEASE BURDEN

A correlation exists between the social determinants of health and the prevalence of chronic conditions such as diabetes mellitus.¹⁰ By 2035, the global burden of diabetes is predicted to grow to 592 million from the estimated 382 million in 2013, and there is a disproportionate burden of diabetes among minority groups, migrants and the socioeconomically vulnerable.^{11 12} SES and social stratification are intrinsically linked to health, in turn creating a social gradient of health.¹³ As a result, adverse health outcomes within vulnerable populations^{14 15}, including refugees, transgress beyond the individual to affect whole communities.

There is significant increase in the risk of developing diabetes in refugees compared with immigrants and non-immigrants.¹² Among the factors contributing to the rising incidence of chronic diseases include changes in dietary patterns in the recipient country.¹⁶ In KB's case, she was unaware of the dietary restrictions in managing her diabetes despite seeing a dietician. Have we perpetuated the problem by creating a tailored dietary plan for KB given that it may be different from the vast majority of the Australian population? Similarly with advice on physical activity, there are important environmental factors (climate, access to recreational facilities and safety), cultural barriers (foreign workout clothing and cultural gender roles/norms) and competing priorities (food and child care) that play a role.¹⁶

Additionally, the prevalence of non-communicable diseases such as hypertension, musculoskeletal disease, diabetes and chronic respiratory disease is high among urban refugees, especially an increased incidence of undermanaged chronic conditions, infectious diseases, psychological disorders and lack of immunisation.^{11 17} Furthermore, refugees may minimise the severity of chronic health conditions, as they are not perceived as emergencies and therefore unlikely to supersede basic needs of food, shelter, legal status and employment.¹⁷ Research by

Doocy *et al*¹⁸ shows the utilisation of public health facilities in a population of Syrian refugees for diabetes was 19.3%, compared with other chronic diseases at 57.5%. Drawing from KB's case, perhaps similar barriers to accessing healthcare existed for the aforementioned refugee population?

Overall, the prevalence of diabetes is multifaceted in conjunction with other chronic conditions and health risks that lead to increased mortality rates and thus implores a global public health challenge.^{19 20} In refugee populations, the importance of early diagnosis and management is crucial since there are confounding cultural, social and educational gaps. Late onset presentation

Patient's perspective

- ▶ When I ask people in my community about diabetes they just say, 'what is that?' Some of them even say it might be a big problem or it might be a small problem; so not many people discuss (it). I don't know what diabetes is. All the doctors say I have diabetes, but no one has explained what diabetes is. Sometimes I feel like asking them this question because some people say diabetes is a big thing. In the community, other people have this problem as well so they say it's a big thing— you have to control it—you can't let it go. Sometimes I wanted to ask but I feel like I don't want to ask because it might be a big problem, might be really big, might be risky. I just don't want to hear what the doctors are saying sometimes because I feel sad if I have problems. But sometimes they don't tell me as well. I think some of them do ask me 'do you understand what is diabetes' and I say I do. Sometimes I just don't want to hear it.
- ▶ I think it affects my pregnancy as well. And sometimes I think I believe in I'm not getting pregnant because of diabetes. Sometimes I just think like that. Because I don't understand. I come from a world where people believe in medication so much, and then we think everything can be fixed with medication and I've been on medication for so long, and I'm not getting better, not getting fixed, like straight away.
- ▶ My older son, he just grown up by himself, he didn't listen to me, he didn't do what I wanted him to do. I always wanted to have a son you know that get better education, do something. So, I also wanted to have another baby because I just wanted to make him educated, because no one back home is educated. And my husband also wants the same, he also want to have a baby. I am hoping the pregnancy will happen *Inshallah* [God-willing].

Learning points

- ▶ Discordance between patient and physician's goals of treatment.
- ▶ Importance of factoring in cultural, religious, language and social issues in patient history taking.
- ▶ Effective physician training in patient–doctor communication, time management and cultural awareness may mitigate the potential of miscommunication within time-restrained consultations.
- ▶ Importance of taking dialects into consideration when using language-interpreting services.
- ▶ Miscommunication can lead to life-threatening consequences.

can lead to mismanagement of hypoglycaemia as illustrated in this case or potentially more devastating outcomes. Educating patients on disease is important for all populations but especially in vulnerable populations with lower health literacy and challenging sociocultural issues. The level of education attained is associated with low SES, fewer employment opportunities and higher incidence of disease, as such health education has a role in diabetes prevention via improved social circumstances.¹²

Contributors MJ initiated the project by finding the patient and obtaining consent from the patient at the beginning of the case report. MJ also developed a first draft/outline of the project and oversaw the project with editing and redrafting. AM attended the sessions with the patient in consult with the doctors and was primarily responsible in researching refugee health in Australia. MU transcribed the notes from the interviews into a second draft and assisted in several edits and referencing of the document.

Competing interests None declared.

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