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A qualitative exploration of obtaining informed consent in medical consultations with Burma-born women

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ABSTRACT

Background. Conciliatory attitudes, respect for medical professionals and avoidance of being direct can make health consultations with Burma-born patients difficult to navigate. Coupled with linguistic barriers, this may make the sensitive nature of many women's health consultations challenging. Little is known about current practices for obtaining informed consent in this context. The objectives of this study were to explore current practices, barriers and strategies to obtaining informed consent in medical consultations with women born in Burma. **Methods.** Purposive and snowball sampling was used to recruit health practitioners (n = 15, 2 male, 13 female) of different ages, years of professional experience, and country of origin, from clinics in Victoria that see a high volume of Burma-born patients. Thirty to sixty minute semi-structured interviews were conducted with four general practitioners, eight nurses and three interpreters, and de-identified audio recordings were transcribed for inductive thematic analysis. **Results.** Five key themes were generated: (1) cultural cognisance; (2) influence of community; (3) skilful navigation of communication; (4) favourable consultation attributes; and (5) individual tailoring of consent conversations. Differing cultural expectations, and linguistic and educational barriers, were highlighted as challenges to obtaining informed consent, whereas thoughtful utilisation of non-verbal communication, and intentional customisation of consent conversations were identified as facilitators. **Conclusion.** The findings of this study provide practical ways to optimise the informed consent process within the Australian primary healthcare context, and reinforce that accepted Western-based practices for obtaining informed consent are not a 'one-size-fits-all' process.

Keywords: Asia, asylum seeker, cross-cultural, ethics, migrant, Myanmar, refugee, women's health.

Introduction

Throughout this paper, the term 'Burma-born' is used to acknowledge that many people born in the country formally known as Burma, do not recognise the current country name of Myanmar, nor do many identify culturally as 'Burmese'.

Burma provides the second largest number of humanitarian entrants to Australia (Department of Home Affairs 2022), and this obligates healthcare providers to be equipped to meet their needs.

Literature about cross-cultural consent is often framed in an Eastern versus Western cultural paradigm (Nie 2001). This can over-simplify cultural nuances that affect voluntary informed consent. Apart from some dated literature from the Chinese context, very little literature pertains to other South-East Asian cultural subgroups (Nie 2001; Raposo 2019).

In a World Health Organization study of five South-East Asian countries (including Burma), the authors identified the importance of, and often overriding weight of, familial consent in many aspects of a patient's management (World Health Organization. Regional Office for South-East Asia 2000). Given shifts in culture take time, this paper, though dated, is still relevant. It found clinicians were reluctant to discuss medical details if patients were deemed unlikely to understand (World Health Organization.

Regional Office for South-East Asia 2000). This, coupled with persistent acceptance of paternalistic norms, carries significant implications for populations with high levels of patient illiteracy.

Cultural education materials and guidelines for Australian and New Zealander clinicians acknowledge that conciliatory attitudes, respect for medical professionals and an avoidance of being direct can make health consultations with Burma-born persons difficult to negotiate (Dziedzic 2006; Camplin-Welch and Lim 2007; Monash University Faculty of Medicine Nursing and Health Sciences 2009).

Informed consent requires both patient and doctor to have the same understanding of the treatment and to consent to follow the same course (Tai and Lin 2001). Given the differences in understanding of autonomy and consent across cultures, this mutual understanding may be difficult to achieve.

Those who are Burma-born originate from a unique, highly militarised country, with a typically quiet and solicitous cultural heritage (Camplin-Welch and Lim 2007; Monash University Faculty of Medicine Nursing and Health Sciences 2009); therefore, the establishment of true voluntary informed consent, for western clinicians, is likely to require a unique set of clinical strategies. This study aimed to explore how clinicians navigate this issue.

Methods

The aim of this study was to explore current barriers, strategies and current practices for cross-cultural consent in medical consultations with Burma-born women. A qualitative study design was approached through an interpretivist paradigm. The primary researcher conducted this study as part of advanced training in general practice, and the research team included experienced qualitative researchers in the field of women's health and refugee health.

Purposive and snowballing sampling were utilised. Staff at primary care clinics and refugee health clinics in Victoria who see a high volume of Burma-born patients were approached by researchers by phone or email. Researchers also reached out to their own networks. A call for expressions of interest was communicated in both an institutional distribution, as well as direct emails to potential participants. Interested candidates were sent a subsequent email with the plain language statement and consent form. Compensation for participant's time was provided in the form of a voucher to the value of one-hundred Australian dollars.

Participants were Victorian-based GPs, nurses and interpreters who regularly saw Burma-born patients, or who had significant clinical experience with Burma-born patients. The interview schedule focused on the three main research questions, exploring barriers, strategies, and current practices for obtaining informed consent with Burma-born women. Some questions also explored decision-making and the optimisation of consent practices.

Ethical issues identified for consideration were: discomfort of participating practitioners if they felt their practice was being called into question; and discomfort of interpreters if sensitive cultural subjects were touched on in the interview. This was addressed by asking non-confrontational interview questions and advising participants they could skip questions or withdraw from participation at any point.

De-identified data collected were in the form of: audio-recorded, semi-structured interviews of 30–60 min; interview transcripts; and researcher field notes. Phone and video-call interviews were audio-recorded using a digital recorder; interviews were transcribed verbatim by a third-party transcription service and reviewed by the primary researcher for accuracy. Coding of transcribed interviews was conducted by the primary researcher using the program 'Quirkos'.

The primary researcher was responsible for inductive coding of transcribed interviews, subsequent reflexive thematic analysis (Braun and Clarke 2021), and generation of initial themes via an iterative process. Final consensus on themes was reached through deliberation between authors.

During interviews, coding and data analysis, the primary researcher was aware that her own limited experience in migrant and refugee health, and etic perspectives as someone living in their own country of birth, would influence her comprehension of themes generated from the data.

Ethics approval

Ethics approval for the study protocol, recruitment materials and interview schedule was granted by the University of Melbourne Human Research Ethics Committee. Audio-recorded verbal consent was obtained from all participants.

Results

A total of 15 participants (13 female, 2 male) were recruited. Data saturation was achieved upon thematic exhaustion. The cohort of participants included four GPs, eight nurses and three interpreters. Participants varied in age, years of experience, country of origin and setting of clinical experience. Following coding and analysis of interview data, five main themes, and ten subthemes were identified (Table 1). To contextualise the results, it is important to remember that valid clinical consent must be: informed, voluntary, specific, and given by someone who has capacity to understand all relevant information and decisions (Australian Commission on Safety and Quality in Health care 2020).

Table 1. Themes and subthemes.

Themes	Subthemes
Cultural cognisance	Compliance
	Deferring decisions
Influence of community	Influence on individual agency
	Influence within the consultation
Skilful navigation of communication	Verbal
	Non-verbal
Favourable consultation attributes	Access to appropriate interpreters
	Consultation times
Individual tailoring of consent conversations	Education and health literacy
	Customised consent

Cultural cognisance

Compliance

A common sentiment was that Burma-born women 'just say yes' to everything. Reasons given for this propensity to say 'yes' were: respect and trust of healthcare professionals; a low level of education; a desire to acquire the end result despite low understanding; a tendency for politeness and compliance; gratitude for access to health care; concerns that declining would impact their visa status; not understanding that what was offered was not mandatory; and a diffidence borne of decades of conflict in Burma.

> They are just so wanting to embrace anything that's offered to them in terms of looking after themselves, that they will say yes anyway, regardless of what it is, because they think we've never had this, and this is such a privilege to have that kind of thing. (Nurse 6)

> Important to acknowledge that they've had decades of conflict . . . they're used to authority in some way being in control of their lives . . . there's that real disempowerment that they've experienced over many, many decades and I think that can be an issue. (Nurse 5)

One strategy identified to address this was to ask yes or no questions, where the expected answer is no.

> 'Would you like to refuse this intervention?' Then if the answer is yes, 'Tell me why'. (GP 2)

Participants identified that Burma-born women could be reluctant to ask questions of a doctor, believing it rude. Giving permission to ask questions was identified as a means of cultivating an open dialogue.

Deferring decisions

Several stories were shared of women deferring their decisions to their doctor, or others, including bi-cultural workers and interpreters, or a husband or family member. This deferral was put down to poor understanding, lack of confidence, or a cultural expectation to defer to a male.

> The women have been brought up to always divert lots of decisions around health and the wellbeing of their families, to the male in the family. It is still fairly considered by a lot of the Burmese women, particularly the older women, to be their duty just to do what the partner or husband is going by. (Nurse 7)

Some participants identified that Burma-born women have experienced a lower social standing than men, and as a result have had less opportunity to exercise individual autonomy. Though clinicians often attempt to speak with a woman by herself in medical consultations, it was noted that sometimes removing the husband or support person could cause more distress to women.

> Generally, when we offer for the person to be seen by themselves, they don't say no, so the woman and the partner will comply with the request. But very quickly after being separated, within a few questions, within a few minutes, there's discomfort from the women . . . it might not be husband. It might be mother. It might be sister . . . it's palpable, the comfort when their family member is let back into the room. (GP 2)

Influence of community

Influence on individual agency

Community influence can impact informed consent in a number of ways. Community knowledge was cited as helpful for women in building health literacy, and the benefit of community-based education sessions was identified as something that made women feel more comfortable in attending, and asking questions.

> I think they got confidence coming together as a group to hear information, and then, when they went back for the second time, for the test itself, that it was not as daunting, not as intimidating. (Nurse 1)

It was also identified that community opinions on taboo issues like pregnancy termination could influence how honest a woman was about her wishes.

> Termination and marriage breakdown are really difficult, because the community's quite against either of those things. So, it makes it really hard for those people to seek support, and even when they do, they often change their minds, because if someone in the community figures it out, then it's really difficult. (GP 1)

Influence within the consultation

Being aware of community taboos, and the interpreter's position within the community, is also important for clinicians to understand patient–interpreter dynamics. Iterating the nature of confidentiality in the appointment was noted as important and recognising that an interpreter's views on sensitive issues may influence how much is communicated to and from patients, particularly if an interpreter is older, male and has religious affiliations.

> [Pastor interpreters] didn't always interpret correctly, and often would put their own moral judgements into situations . . . so who your interpreter is, and whether or not you understand about this deference to senior people, it affects whether you're going to be able to get true informed consent. (GP 1)

Another important cultural feature to understand interpreting dynamics, was that of 'losing face'; the reluctance of an interpreter to admit to not understanding. This lack of understanding could then influence the accuracy of information conveyed to patients.

> If you're in a position of authority . . . you lose face if you don't know something . . . therefore the translators aren't telling the doctors that they don't know the word. They're just making it up and creating confusion. (GP 1)

Skilful navigation of communication

Verbal

Given the diversity of linguistic groups in those who are Burma-born, having a trained accredited interpreter in the correct language is critical. Further to this, commonly identified consent strategies were using simple words, and the teach-back technique. One participant outlined a means of identifying shared responsibility in the teach-back technique by confirming the adequacy of a clinician's delivery, rather than insinuating a patient's deficiency in understanding.

> Just so I feel comfortable that I've explained this technique to you properly, can you just tell me what did I just explain...it does acknowledge that communication is a two-way process. It often isn't the fact that they're non-English speaking, it may be the way we're actually communicating the information. (Nurse 5)

Lack of direct translations in several Burma-born languages, for words significant to the consent process, pose a challenge for clinicians and interpreters. Some challenging terms to translate that were identified were: iron deficiency; Down Syndrome; and cervix. Some interpreters had developed work around descriptions for anatomical terms. The following illustrates an interpreter clarifying the anatomy relevant to a cervical screen:

> I used to reassure that this is not a uterus. This is the tip, end of the uterus tip. This is the cervix part. (Interpreter 1)

Participants spoke to the importance of a true partnership with interpreters, in navigating linguistic difficulties and cultural dissonances.

> I actually talk to the interpreters about them being really pivotal in this three-way conversation for me to be able to provide a service, particularly for this patient to be understanding everything . . . if they're uncomfortable with a particular thing, tell me. If I've said something that's culturally going to be jarring for them, please tell me so that we can reword. (Nurse 7)

> Ensuring that you've spoken to the interpreter prior and briefed them about what the situation is going to be, that is going to be discussed. Because it can be tricky for interpreters when they're unsure of the situation if language is utilised and they're not quite sure of the meaning . . . They may say, when you say this word are you speaking of this or that, and you can then give the context and they may use even a different phrase or a different word. (Nurse 5)

Non-verbal

Non-verbal communication was identified as an important cue for clinicians and interpreters in gauging a patient's understanding and comfort. Utilising non-verbal communication in the form of visual aids (such as pictures, diagrams and models) was also common.

Additionally, several participants described a non-verbal technique, specifically as an aid to the consent process. Utilising a pre-agreed upon, non-verbal hand signal, provides a patient with the means of non-verbal withdrawal of consent. This can help to overcome language and cultural barriers.

> You've got clients who can't hear the interpreter from the phone from the clinical chair. You've got clients who are quite reserved and don't want to speak loudly, you've also got past trauma of sexual assaults that are involved, so people don't want to give you a reason why to stop. So, everybody knows a stop sign, everybody knows if you put your hand up you can stop. (Nurse 2)

Favourable consultation attributes

Access to appropriate interpreters

Preferentially engaging female interpreters and not using a family member as an interpreter were stressed. A barrier that was noted by several participants was access to an appropriate interpreter at the appropriate time. An important point identified by one participant was that even if a patient does not require an interpreter, they may have a family member present whom they may want involved in decision-making who does need an interpreter.

> Sometimes the patient may understand English well and may not require the interpreter, but it may be necessary for the family members to have the interpreter present . . . particularly in paediatrics . . . it's important that if it's the mother only that doesn't understand English, that an interpreter is provided for her language support. (Nurse 5)

Face-to-face interpreters were the consensus preference, due to the ability to read body language and utilise diagrams. However, given the close-knit nature of the Burma-born community, having a phone interpreter for sensitive conversations or taboo topics was identified as preferable.

> The positive to [phone interpreters] is that they have no idea who the client is, there's no connection to them at all, maintaining confidentiality a hundred per cent. There's no fear of repercussions of saying something that might be share even though it shouldn't be shared. (Nurse 2)

The crucial role of the interpreter or bi-cultural worker as a cultural conduit was identified by a number of participants.

> Because interpreter at that moment, can be not just a language broker, especially a person that helps them to cross the bridge . . . the way the interpreter conveys to the patient is really important. If they directly convey what the doctor says, then the patient will have difficulty understanding . . . you need to be providing, interpreting more culturally appropriate so that the patient could understand. (Interpreter 2)

Consultation times

Having extended consult times or multiple consults for the consent process, were identified as ways of facilitating a good informed-consent process. Funding was cited as a potential barrier to extended consultation times with doctors, and supplementing a doctor's limited time with an extended nurse consultation as a facilitator.

> So they would come in and the first consult will be introducing the idea . . . then the second consult, we'll check their understanding again and get their consent . . . and then a third appointment will be the actual procedure. (Nurse 3)

> [Nursing consult] anywhere between 30 minutes and an hour. .[GP appointments] go for about 10 minutes, but more often than not, they will go for 15, 20 minutes at most. (Nurse 3)

Extended consult times was cited as helpful for rapport building, as was avoiding doing anything invasive at an initial consult.

> If the doctor is someone known to the woman and they have developed a relationship over some time, that means the woman does trust the doctor and believes that the doctor has her best interests at heart . . . Also that she feels able to decline consent to ask and clarify and have some negotiation between them. (GP 4)

> To keep more conversation first and maybe leave the more touch feel thing for the next consult, so they feel a bit more comfortable. (Nurse 1)

Individual tailoring of consent conversations

Education and health literacy

Low levels of education and health literacy in many women who are Burma-born were cited as a barrier to informed consent. Many participants identified that the consent process needed to start at the very basics, including basic female anatomy.

> They'll often have no idea about their female anatomy. No one's ever taught it to them. (GP 1)

> They might have had six kids, but they're not sure how they got pregnant. (Nurse 7)

Several participants explained that a paucity of literacy skills, even in their own language, could affect several aspects of the informed consent process. This ranged from the utility of written materials to requiring a signature for written consent.

> It's tricky because some of the Burmese women are illiterate in their own language, so written explanation in their own language is sometimes not the most appropriate. (Nurse 7)

> I'd say 20% to 30% of clients don't have a signature, so to write with a pen is really difficult for them. (Nurse 2)

Not only this, but several participants noted the importance of needing to teach Burma-born women about the consent process, to address paternalistic expectations they may have from accessing healthcare overseas.

> The professionals try to explain everything, and after finishing that, they just reply, 'Please tell the total, please do the best, because I don't know which way is the best.' So I need to explain more than that. In here, nobody can decide on behalf of you. They will explain to you how many treatments or how many management

> you can choose, these are the consequences, these are the results . . . So the decision should be made by you only. (Interpreter 1)

Customised consent

To address this tendency to defer to a doctor's recommendation, one clinician's strategy was to customise the consent conversation by starting the conversation with a direct question regarding the preference they intended to identify.

> It's easier to answer the 'do you have difficulty taking a tablet'. So wording it in different ways, where it seems as though it's part of the history and part of the information, that it's the patient's duty, the patient's responsibility. So, there's no confrontation in them feeling the need to say, doctor, it's up to you. (GP 2)

To avoid information overload, an advantageous strategy for complex topics like antenatal screening, was first to learn about the individual's values and preferences. This allows the clinician to tailor the provision of information to only that which is most important for the patient.

> Rather than striving for the ideal and failing spectacularly, I think tailor the consent to things that are really important for this person. So, now with antenatal screening, I usually start off with, 'What would you do if your child had a disability, had a severe disability?'..you can build an argument and a consent process around what's important for her, rather than just giving all the information. (GP 2)

This strategy deviates from accepted Western-based practices, including the notion that provision of all relevant information is necessary for true informed consent. Mindfulness of potential past traumas was also identified as an important consideration when tailoring information to what is necessary, and not what is most comprehensive, to avoid re-traumatising patients.

> Cervical cancer is caused due to human papilloma virus and you could have contracted this through sexual activity that you did years ago, and it could trigger some past trauma. So it's about how much information do you give without re-traumatising the client but gaining informed consent. (Nurse 2)

Also, contrary to Western standards of non-directive counselling, for sensitive topics like termination, one clinician identified the need to give women permission to consider the taboo option in order to learn their true feelings.

> So, if I stuck to true consent guidelines and acted as a completely independent arbitrator and laid the options down, I'm not sure that that consultation would have gone as well . . . I packaged the options in terms of, 'It sounds like you've had a very difficult time, and many women in your position would choose to want a termination. Is that something that you'd like to talk about, or would you rather talk about keeping the pregnancy?' . . . she was basically telling me what she wanted without directly saying it, and was fishing for a way to be provided with a solution. So that went well, a lot of observers might say that wasn't true impartial consent. (GP 2)

Due to the diversity of language, culture and education among different Burma-born women, participants noted that cultural and individual differences will affect to what extent the above findings apply to informed consent for Burma-born women.

Discussion

International research on obtaining informed consent in medical consultations with refugees is scarce. The aim of the current study was to address this knowledge gap by exploring the lived experience of healthcare workers, and provide qualitative evidence on cross-cultural consent that may improve Burma-born women's experience of accessing health care in Australia. Our research questions centred around barriers, strategies and current practices to obtaining informed consent.

Some identified barriers have been discussed in medical literature previously. These include: language barriers (Forrow and Kontrimas 2017); different cultural understanding or conceptualisation of consent (Raposo 2019); paternalistic expectations (Murgic *et al.* 2015); and low health literacy and education (AMA Foundation 2007; Heerman *et al.* 2016).

Many strategies identified are in line with accepted clinical practices across cultures for consent. For example, using pictorial representations and models to explain anatomy (Heerman *et al.* 2016); using a professional interpreter of the correct language (NAATI 2021); and using a gender-concordant interpreter for women's health discussions (Migrant Refugee Women's Health Partnership 2019).

The results of this study posit five clear concepts that lend themselves to transformation into cross-cultural medical practice. The first two comprise the importance of a clinician's awareness of cultural influence and community influence within the consultation. Western-based informed consent practices assume a level of education and ease of exercising autonomy, which may discomfort a woman who is Burma-born. Similarly, when discussing sensitive topics, it is important for a clinician to recognise both internal and external conflicts that may arise for a Burma-born woman if her wishes go against community norms.

Third is that skilful navigation of communication is pertinent for cross-cultural informed consent. Congruent findings in sexual and reproductive research have stressed that appropriate reproductive health terminology and non-verbal communication cues can facilitate a more meaningful consent process (Tuteja *et al.* 2022).

Fourth, structural interventions such as bolstering access to interpreters and increasing consultation time can effectively improve the consent process. It is well documented that such interventions can dramatically improve service delivery to people of refugee background (Barron *et al.* 2010; Abbato *et al.* 2018; Botfield *et al.* 2018).

Finally, individualising the informed consent process to adapt to the patient needs is quintessential cross-cultural medicine. Western culture-based ideology of what constitutes an ideal informed consent process, does not hold true for everyone. For Burma-born women, accepted norms like presenting all available options or providing non-directive counselling may overwhelm and impair a woman's capacity to understand, or compromise her agency to choose a more culturally taboo option. Parallel findings of culturally modifying the consent process to be population-specific has been previously reported (Nakkash *et al.* 2009; Hugman *et al.* 2011*a*, 2011*b*).

One interesting culturally neutral finding was that of utilising a hand held up to signal withdrawal of consent during invasive gynaecological procedures. This sensitively accommodates for the distressingly prevalent exposure of women, and migrant women in particular, to sexual violence. This trauma-informed practice allows a non-verbal withdrawal of consent, without re-traumatising a woman by requiring her to vocalise to stop the procedure.

While conducting interviews, and coding and analysing data, the primary researcher was mindful of exercising reflexivity. It is important to acknowledge the limitations of approaching the topic under study from an etic individual's perspective. Another limitation to be considered is that the ideas expressed were from the perspectives of practitioners and interpreters, not patients themselves. Therefore, data that makes reference to the feelings or beliefs of Burma-born women are partially inferred.

In conclusion, the findings from this study contribute insights and practical approaches to informed consent for Burma-born women in the Australian healthcare context. In particular, the utilisation of non-verbal communication and individually tailoring consent conversations are practical skills that can be implemented within the primary care context in Australia. This study will help to inform the increasingly crucial cross-cultural consultation skill-set of Australian healthcare workers, and build upon a limited scope of existing literature in the area of cross-cultural informed consent. The authors propound that greater cross-cultural skills education should be considered for inclusion in general practice registrar training. Future research that explores the views of diverse refugee populations on informed consent, and transformational work on tailored consent delivery interventions could help to improve Australian health service delivery.

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Data availability. The data that support this study cannot be publicly shared due to ethical or privacy reasons.

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