



Health literacy of Samoan mothers and their experiences with health professionals

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ABSTRACT

INTRODUCTION: Patient and health professional engagement is a crucial factor for the effectiveness of service delivery and the management of care. Low health literacy amongst Pacific peoples is likely to affect their engagement with health professionals.

AIM: To explore the health literacy of Samoan mothers and their experiences with health professionals in primary care.

METHODS: Twenty Samoan mothers and caregivers living in Auckland were interviewed about their experiences when engaging with health professionals. Semi-structured interviews guided by open-ended questions were conducted with individual participants in either Samoan or English. The interviews were recorded, transcribed and analysed.

RESULTS: A key finding was the significance of the health professionals' role, in particular general practitioners, in providing resources and information to participants. Many participants recognised their general practitioner as their primary source of information. The findings revealed the negative experiences participants faced while engaging with general practitioners and shared how this affected their ability to manage care. Themes about enablers of open communication with health professionals included mothers understanding their rights as patients and being acknowledged as an expert on their child's health. Themes about barriers to open communication with health professionals included limited consultation time, language barriers, medical jargon, closed answers, power relations and the shame associated with not fully understanding.

DISCUSSION: This research can inform health care engagement practices with patients. This study is relevant to health-care providers, development of health resources, health researchers evaluating health-care communications between providers and patients, to inform culturally appropriate and effective health-care delivery. The importance of shared responsibility in addressing issues of health literacy is noted, shifting the focus to everyone involved in providing and receiving information and in making decisions and managing care.

KEYWORDS: Health literacy; primary health care; child health; qualitative research; Pacific health; Pacific child health: service delivery; communicable and non-communicable diseases

Introduction

Health literacy contributes to poor health experience and to poor health outcomes in Pacific children. The burden of disease is higher for Pacific children than other New Zealand children, and the differences are

increasing.¹ There is a strong linkage between low health literacy and poor health. According to Statistics New Zealand and the Ministry of Pacific Island Affairs survey, close to 90% of Pacific adults aged ≥ 15 years had poor health literacy skills.

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WHAT GAP THIS FILLS

What is already known: Low health literacy is associated with poor health experiences and outcomes. Approximately 90% of Pacific people in New Zealand have low health literacy. Pacific children in New Zealand have the highest rates of infectious and chronic diseases.

What this study adds: This study shows the effect of the health literacy of Samoan mothers engaging with health professionals and its effect on their child's wellbeing and the management of their care.

Pacific adults were less likely to have good health literacy skills than non-Pacific and Māori adults.¹⁻³ The Pacific child cohort has disproportionately high ambulatory sensitive hospitalization rates compared to non-Pacific children and these figures remain significantly higher for Samoan children, who are the largest Pacific group.^{2,4,5}

Health literacy is defined as having access to health information, understanding it and consequently being able to act on it.^{6,7} Health literacy is important in the prevention, management and treatment of health conditions. It plays an important role in the timeliness of treatment and reducing demand on emergency departments. Low health literacy is identified as an area of necessary focus in increasing access and improving the quality of health-care services.²

Communication between parents and health professionals is one of the most important interactions in the health system when considering the health of children.⁸⁻¹⁰ There is limited research on the effects of health literacy on the health of Pacific families and children. Understanding the experiences of Samoan mothers during this crucial time of information exchange in the consultation room with a health professional and addressing these experiences directly may improve consultations for all involved, improve communication and, in turn, health outcomes for Pacific people in New Zealand. The aim of this study was to explore experiences of Samoan mothers in primary health care and, in particular, their experiences when interacting with health professionals.

Methods

The study sample comprised 20 women who met the selection criteria: Samoan females; self-identifying as

Samoan; living in Auckland; being or having been the primary caregiver for children; and with previous or current access to a general practitioner (GP).

The snowball method of sampling was used to recruit participants. Information about the research was circulated in community and network settings using social media sites such as Facebook, Instagram and email. Participant information forms were provided to interested women and informed consent was obtained from women before being interviewed by the researcher, F. H. Pio.

Interviews

Semi-structured interviews were carried out in English and Samoan with individual participants, capturing meaningful dialogue that elicited their understanding and interpretation of the research topic. Field notes and memos, as permitted by participants, were noted during each interview and were used as an addition to the audio recordings.^{11,12}

Analysis

Interview recordings were transcribed, translated and analysed by F. H. Pio immediately after each interview. Analysis was guided by a constructivist grounded theory approach. This used the five key processes: initial coding, line-by-line coding, focused coding, comparative methods and memo writing.¹³

Ethical approval

Ethics approval for this research was sought and granted by the University of Auckland Human Participants Ethics Committee in December 2015 (Reference 016031).

Results

Interviews revealed enablers of and barriers to open communication between the mothers and health professionals. From the mothers' perspective, their experiences with a health professional affected their decisions and ongoing care of children.

Enablers of open communication between mothers and health professionals

Communication between health professionals and participants determined their engagement and understanding of what was discussed during the consultation.

‘I don’t read information given because it’s too much for me, and I don’t have time. I wait to go and see the doctor for him to tell me what I should do. It’s important that I understand him and he gives me a chance to explain how I’m feeling and what I think.’ [Participant 3]

‘Communication with the doctor is two ways. We work things out together so it’s really important that is right because if not, its downhill from there. I go home not understanding what is happening to me or my baby and I don’t know what to do or why I should do things.’ [Participant 14]

Mothers understanding their rights as patients

Some participants understood their rights as patients; this set their expectations of care and service received. When mothers understood their rights, they actioned these through asking questions for clarity of instructions, information and responding to health professionals.

‘I feel I can communicate openly with my doctor because I know I have rights, if they got a problem with it then too bad - we’re supposed to know because it’s our right to know.’ [Participant 2]

Patient rights were associated with ‘standing up for themselves’ when the services did not meet their expectations. Standing up for themselves became even more important when it concerned their children’s health.

‘With our children, you just don’t know what’s happening to them or how they are feeling. So, it’s better to be safe than sorry. Me as a mother I am responsible for my babies: that’s why I would never be taken aback when it comes to standing up for them.’ [Participant 14]

Even though participants shared that understanding their rights as patients and mothers provided leverage in communication, they still claimed experiencing barriers with communication.

‘I know my rights but I still find it hard to catch up to what the doctors are saying. They need to be person-focused, like focus on me and what I need. But they don’t make an attempt to try and see if I do understand.’ [Participant 6]

Health professionals acknowledging the mother’s expertise

Participants appreciated positive affirmation and acknowledgment from health professionals that they, as mothers, were doing a good job in caring for their children and are acknowledged as the experts.

‘My doctor asks me what is happening at home. He asks what I think about the current medication my child is taking and how that is working for her. He tells me that I need to look after myself to be the best help for my kid. You know I really think it’s important that all doctors do that, they talk to the parents and ask what they think because they really are the ones that are there most of the time with the kids at home and the kids tell them what’s going on.’ [Participant 6]

Barriers to open communication with health professionals

Participants noted that communication with health professionals determined how they received information, and their ability to understand and use the information. All mothers emphasised the factors that restricted open communication with health professionals.

Limited consultation times

Nearly all participants responded there was not enough time to have proper conversations with doctors. During the consultations, they felt unheard, rushed and provided with little assurance that the information given was sufficient for the care of their child.

‘When I talk, doctors only listen for about two minutes then they turn around and tap on their computer, they listen to the symptoms and then they have an answer. After that, time has passed. I don’t feel like I’m being listened to because they don’t ask if I understand and they’re typing while I’m talking and then they impose a solution but they never ask oh is that what you meant? They

don't check, like they just want me out of there.'
[Participant 19]

Language barriers

Difficulty in communicating with health professionals was heightened for participants who had limited English.

'They ask me 'can you read and write and speak in English?' or what is your primary language? Once I said English, I think they assume I will understand everything they say. The only measure is primary language. My mother-in-law she has been in New Zealand for a very long time but her English is still poor and so she will say English and she can speak it but when they point her to those resources she cannot understand.'
[Participant 20]

For some participants, despite language barriers posing a barrier, there was no preference to go to a Pacific (or more specifically, a Samoan) doctor due to trust and confidentiality issues.

'Even though I might not understand at times, but I would never go to a Samoan doctor. Maybe if I have to I would prefer a New Zealand born Samoan but not one from Samoa. They might be talking behind my back to others. They might know my family and you never know when they might mention something in conversation. I would always go to a Palagi doctor. At least I know they will try to help.'
[Participant 15]

Use of medical jargon instead of layman terms

Participants shared how the use of medical terms was a barrier to open communication. Most participants reported that both verbal and written messages were too complicated.

'I don't understand medical terms, I guess us Islanders associate big words with extremes. Say if you heard something really big, then you think man its really bad I must be on guard. Not having that knowledge is a barrier because then you are so stuck on that big word that you don't understand and then your mind is running.'
[Participant 7]

When health professionals give closed answers to questions

Participants responded that health professionals were often reactive in the delivery of information. Information was provided when participants asked for it, but responses were often closed answers.

'They don't openly talk with me until I ask. I ask an open-ended question, she responds with a closed answer, no detail. If I ask a question, I have a feeling that she wants to get rid of me and get another patient and I get so angry because I had my husband who was critically ill and I always want to find out about everything. I'm his primary carer so I am responsible for whatever happens and having a doctor like that just really makes me angry and confused.'
[Participant 13]

Power relations between patient and health professional

Across all participants, doctors were the most referred to and trusted source of health information. Most participants valued health professionals, in particular GPs. Participants often felt intimidated about questioning or disagreeing with doctors because they felt inferior to people with medical knowledge.

'If I don't agree with something, it's really hard for me to ask questions or tell the doctor because you know when you're upset you just don't think or feel that it's the right time to tell him that. I feel that I'm a patient; I don't have any medical experience so it's really hard for me to tell him who graduated and has medical expertise that this is not right.'
[Participant 17]

Shame in not being able to fully understand

Many participants admitted to concealing that they did not fully understand what a health professional was telling them, or what they had to do. Many mothers did so because they did not want to feel incompetent.

'I just go yes, yes most times. It's very hard for me to ask him to repeat himself again. I want to look like I understand the first time. If I misunderstand something, I just pretend that I do understand and walk out. I don't do anything really but come home and feel that I've just wasted my money.'
[Participant 17]

Frustration and anger

Frustration and anger were reasons for instinctively agreeing with a health professional. This was noted as being the result of confusion and being rushed.

‘When English is not your first language and you have these doctors talking in big words, it is confusing. You go to the doctors to get better but then when they are talking a whole different language and they don’t bother to make it simple or check that I don’t get it, that makes me angry and then makes me sick. So I came in sick and now I’m leaving sick and angry.’ [Participant 5]

Wasting the doctor’s time

It was noted that when doctors seemed in a hurry to get participants to leave consultations, participants internalized the rush as their fault, and this left these participants feeling they were wasting the doctors’ time.

‘Yes, I did that because we got a bad vibe from the doctor. It was obvious from her body language that ‘I am busy, I’ve got a lot of people waiting in the waiting area, you need to get out of here.’ That sort of thing where their body language says it all – is when I just say yes, so I can quickly get out so I don’t bother them. Some of that stuff comes from the cultural perspective of being respectful that I don’t bother them with my problems when really it’s their role and job.’ [Participant 19]

Mothers’ recommendations and strategies for managing care

Most mothers noted that the GP instructions coupled with written health information was an issue for the correct use of medications.

‘Medication is an important part of caring for my child and family, there needs to be more emphasis on it because we don’t understand how to use it, compromising the care that we give. With English being an issue and big words by the doctor it can be a mess and stop my child from getting better.’ [Participant 16]

Many mothers explained that health professionals need to respect and value mothers’ views about health-care decisions for their children.

‘Health professionals need to understand that we know our bodies and those of our children. To be treated with respect, compassion and ingenuity goes a long way. A doctor who is considerate, takes their time to ask me how I am, how are things at home, and takes time to explain things to me so that I understand is more valuable to me.’ [Participant 19]

Most mothers also highlighted that there needs to be user-friendly resources such as simple coloured charts, diagrams, interactive activities and written information in both Samoan and English that help patients understand illness, risk and protective factors and ways to manage ongoing care for their children.

A picture paints a thousand words; pictures that show what our body looks like inside and what’s happening when we are sick can really stick in my mind. Having pictures that support verbal information will help me to understand why something is happening and by knowing what’s happening this will encourage me as a parent to follow through with doctors’ instructions because I know how and why I should do things.’ [Participant 12]

Discussion

The mothers participating in this research shared that GPs are their primary source of health information and health resources. They shared their polarized experiences with their GP that had affected ongoing relationships and the management of their child’s health care. Consistent with other research, communications between parents and health professionals (GPs) are an important interaction between mothers and the health system when considering the health of children.^{8–10}

Participants highlighted the factors that enabled a positive relationship with their GP. These included: understanding rights as a parent and patient; trust; and rapport with a GP or other health professional. Participants indicated they were likely to build rapport with a doctor who cares, who is patient-centred, trustworthy and a good listener. Other research supports this view that health professionals’ understanding and acknowledgment of patient values and cultures lead patients to trust their advice and recommendations about their

diagnosis and then carry out self-care instructions.¹⁰

For many participants, their negative experiences with GPs outweighed the positive accounts commending existing interaction experiences. They highlighted specific communication barriers: limited consultation times; closed responses to participant questions; language barriers; the persistent use of medical jargon; and power differentials between the parent and health professional. All these factors are related to the health system, practice clinic and health professionals. All participants experienced at least one of these factors, with many encountering three or more barriers on routine visits.

The mothers emphasised that time constraints have an effect on many other issues that they experience. Their key concerns during consultations were feeling rushed, not being able to finish voicing their concerns and not being listened to. Dealing with patients with limited health literacy takes time, a commodity in short supply in most medical practices.¹⁴ The findings of this study contradict other research finding that consult time is irrelevant because the time allocation for each visit is set.¹⁵ This study highlights that time is a factor that contributes to patient understanding and engagement with health professionals and patient–doctor communication patterns affect the health outcomes of patients.¹⁶

All participants described experiencing overuse of medical terms in written information in the form of resources and verbal instructions from health professionals. Medical language is known to confuse even people who are English-proficient and have tertiary qualifications.¹⁵ Participants highlighted how such language creates confusion around the diagnosis, treatment and care management and can cause unnecessary anxiety as ‘big words’ are associated with extreme conditions. Numerous studies have highlighted that the use of medical jargon coupled with limited patient health literacy leads to confusing communication, making patients less likely to acquire the knowledge they need.^{9,17–19}

Health professionals need to build relationships with patients, respect and value their

understandings and views and involve them in decision-making of ongoing care. This will help enable patients to be more comfortable in engaging with health professionals. User-friendly resources such as simple coloured charts, diagrams, interactive activities and written information in both Samoan and English is also needed to help patients to understand how to manage their children’s medical problems.

The many deterring behaviours that participants face during the brief moments of health professional interaction can discourage patients to continue going to see their GP for child health issues and negatively affect their confidence to manage the ongoing care of their child. Many participants admitted to hiding that they do not fully understand what their health professional has discussed or is expecting of them. This is not uncommon, as it has been explored in recent studies.^{8,14,19} Social stigma and shame is associated with low health literacy and is reinforced with health professionals’ assumptions of patient levels of understanding. The power imbalance between the parent and health professional, as perceived by participants, coupled with the stigma of low health literacy, resulted in participants feeling hesitant to ask their health professionals questions for clarity or more information.⁸ Health professionals need to emphasise key messages and provide clear instructions in simple everyday language.

Strengths and limitations

We could find no other qualitative study focusing on the health literacy of Samoan mothers in relation to their experiences in primary care with health professionals in New Zealand. This work is important because health literacy has been identified as a key issue for most Pacific people. Health literacy in the context of Samoan mothers and its relationship to child health is also a novel approach.

Both the study’s design and its small sample size of 20 Samoan mothers mean that the results from this research cannot be generalized to all Samoan mothers. Additionally, the sample only recruited Samoan mothers; therefore, it is acknowledged that the results from this research cannot be generalized to other Pacific mothers.

Conclusion

This research explored health literacy of Samoan mothers, specifically when engaging with health professionals. Participant discussions highlighted the effect that engagement with health professionals can have on decision-making and the ongoing management of care. The findings from this research indicated that low health literacy intensifies the repercussions of existing barriers in health care. Additionally, addressing health literacy has the potential to improve patient and parent experience in health care and health outcomes for children.

Competing interests

The authors declare no competing interests.

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