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Barriers and enablers of access to diabetes eye care in Auckland, New Zealand: a qualitative study

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ABSTRACT

Objective To explore the barriers and enablers to accessing diabetes eye care services among adults in Auckland.

Design This was a qualitative study that used semistructured interviews. We performed a thematic analysis and described the main barriers and enablers to accessing services using the Theoretical Domains Framework.

Setting The study took place in two of the three public funding and planning agencies that provide primary and secondary health services in Auckland, the largest city in Aotearoa New Zealand.

Participants Thirty people with diabetes in Auckland who had experienced interrupted diabetes eye care, having missed at least one appointment or being discharged back to their general practitioner after missing several appointments.

Results We identified barriers and enablers experienced by our predominantly Pacific and Māori participants that aligned with 7 (of the 14) domains in the Theoretical Domains Framework. The most reported barriers were transport issues, lack of awareness regarding the importance of retinal screening, time constraints, limited and/or inflexible appointment times and competing family commitments. Enablers included positive interactions with healthcare providers and timely appointment notifications and reminders.

Conclusions Diabetes eye services could be made more responsive by addressing systemic barriers such as service location and transport links, appointment availability and meaningful information to aid understanding.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We gathered first-hand insights from people with diabetes experiencing interrupted services and used a strength-based approach to emphasise the active role that health services can play in mitigating barriers to access.
- ⇒ We applied the commonly used Theoretical Domains Framework to analyse our findings, which highlighted some key health system barriers that did not readily map to the Framework.
- ⇒ A potential limitation is the focus on the Auckland region, so the findings may not reflect the situation in other parts of the country with different demographics and diabetes eye care models.

INTRODUCTION

Diabetic retinopathy is a common microvascular complication of diabetes which occurs when blood vessels at the back of the eye swell and leak. In the advanced stage, new blood vessels grow on the surface of the retina and when these vessels break and bleed into the vitreous, vision can be impaired.[1 2] Globally, diabetic retinopathy was the fifth leading cause of vision impairment in 2020 and was the only one of the five leading causes that increased in prevalence over the past 30 years.[3] Much of the vision loss from diabetic retinopathy can be prevented with good diabetes control, alongside early detection and timely treatment of any retinopathy that develops.[4 5]

Unfortunately, diabetes eye care services are not accessible to all population groups. This disparity in access contributes to some population groups being relatively underserved by services,[6] with subsequent increased risk of vision loss from diabetic retinopathy.[7 8] Systematic reviews of studies reporting barriers to diabetes eye care across a broad range of countries have identified barriers that include patients having competing priorities, being disconnected with general diabetes care and feeling under- or misinformed about the services, as well as services not being timely and not sharing data in a way that promoted quality care.[7 9]

Neither of these systematic reviews included studies from Aotearoa New Zealand (hereafter New Zealand), where diabetes eye care services are less accessible to Māori and Pacific peoples compared with other New Zealanders, which contributes to these groups experiencing higher rates of retinopathy.[10 11] As part of a project to develop strategies to improve access to diabetes eye care in Auckland, we wanted to understand the experiences of people with diabetes when accessing diabetes eye care. The aim of this study was to explore the barriers and enablers to accessing diabetes eye care services among adults with diabetes in Auckland, New Zealand.

METHODS

This study sits within the constructivist-interpretivist research paradigm. In this paradigm, researchers assume that any reality of a phenomenon is constructed by individuals within their social-historical contexts, and therefore there could be multiple and valid realities of a phenomenon.[12] The rich and meaningful understanding of these multiple realities is often hidden but can be brought to the surface through interactive researcher-participant dialogues.[13] In constructivist-interpretivist research, researchers seek to understand how people think and act in everyday life and therefore the study focuses on people and their settings holistically.[14 15] In this study, experienced qualitative researchers and service providers shared a commitment to generate evidence that would advance knowledge to address inequity in diabetes eye care and collaborated to understand the barriers and enablers of diabetes eye care services from the perspective of people disconnected from services.

Study design

This was a qualitative study of people living with diabetes who were experiencing interrupted diabetes eye care. We used the most recent version of the Theoretical Domains Framework[16]—which has 14 domains and 84 theoretical constructs—to identify and analyse the barriers and enablers of access. The framework has been used to study determinants of behaviours of health professionals and patients and to support the design of theory-informed interventions across a wide range of healthcare settings and clinical behaviours.[17]

Study context

This study took place using data from two of the three funding and planning agencies that provide public, primary and secondary health services in Auckland, the largest city in New Zealand—Te Whatu Ora Health New Zealand Te Toka Tumai Auckland and Te Whatu Ora Health New Zealand Counties Manukau (previously known as Auckland District Health Board and Counties Manukau District Health Board, and hereafter referred to as Te Toka Tumai Auckland and Counties Manukau, respectively). More than 1 million residents live in the area covered by these two agencies, including 17% of the national Māori population, 74% of the Pacific population and 28% of the population with diabetes.[18 19]

The Diabetic Retinopathy Screening, Grading, Monitoring and Referral Guidance released by the national agency, the Ministry of Health, in 2016 provides overall clinical guidance to providers, while allowing regional variation in the way services are delivered.[20] For example, the retinal screening service in Te Toka Tumai Auckland is predominantly delivered through a hospital-based clinic, whereas services are decentralised in Counties Manukau, being available at the main clinical centre as well as at geographically dispersed community and mobile clinics.[21]

Sampling strategy

We recruited people with diabetes residing in Te Toka Tumai Auckland and Counties Manukau areas who were disconnected from diabetes eye care. In Te Toka Tumai Auckland, people with interrupted care were identified during a community eye health study in a suburb with a high Pacific and Māori population.[22] During this community-based study, participants with diagnosed diabetes were asked when they had their last eye appointment for diabetes (retinal screening or ophthalmology clinic). Participants whose last appointment was more than 2 years ago were considered eligible for our study. In Counties Manukau, the diabetes retinal screening service lead provided a list of people who missed at least one retinal screening appointment in 2023. We randomly selected people from these two lists and contacted them, and recruitment continued until data saturation was reached (no new barrier/enabler was identified). Participants were provided a voucher to acknowledge the time and insights they provided to the study.

Ethical aspects

Ethical approval was obtained from the Health and Disability Ethics Committee (Ref: 2022 FULL 12178), and locality approval was obtained from Te Toka Tumai Auckland (Ref: 21/NTB/97) and Counties Manukau (Ref: CM Health Research Registration Number 1422) District Health Boards. All potential participants were provided the participant information sheet outlining the study and participants provided informed consent prior to the commencement of data collection. Participants who were unable to provide written consent prior to the interview provided verbal consent before the interview commenced.

Data collection

A research assistant with extensive experience in community engagement and qualitative data collection conducted one-to-one phone interviews with all participants between October 2022 and March 2023. The interviewer used a semistructured interview schedule (online supplemental appendix 1) that was developed by a member of the research team with extensive experience in qualitative research (PS), with input from clinicians (RM and DS), a Māori health researcher and general practitioner (GP; MH) and a population eye health researcher (JR).

The probing topics in the interview guide (online supplemental appendix 1) regarding the barriers and enablers that participants experienced were framed around the domains outlined in the Theoretical Domains Framework (online supplemental table 1).

Two trial interviews were conducted prior to the data collection, and the interview guide was refined accordingly. Revisions were only minor to terminology and question flow, so we included these trial interviews in the study. Participants were invited to have family members with them during the interview.

Data processing and analysis

All interviews were audio-recorded, and transcribed using the online software, Otter.ai. The software-generated transcripts were checked and verified by a team member who was not involved in the interviews. The transcripts were fully anonymised with a pseudonym code assigned to each of the participants before loading the files into NVivo 12 for further coding and analysis. Data coding and analysis were done by two experienced qualitative researchers (PRS and MP), with input from other team members.

We used thematic analysis to identify, analyse and report recurring themes and patterns, following a structured approach.[23] Initially, the interview transcripts from the two areas were organised into separate files within the NVivo software prior to initiating the coding process. To prepare for analysis, a member of the research team (MP) thoroughly immersed herself in the data by reading and re-reading the transcripts multiple times. All interview transcripts were coded into the domains outlined in the Theoretical Domains Framework using a deductive coding framework. Subsequently, the researcher initiated the coding process, analysing the text line-by-line, grouping codes into subthemes and themes, and then mapping them to the relevant domains.

The identified themes and subthemes were organised into an Excel table categorised by domains and study areas, and whether they represented barriers or enablers (online supplemental table 2). Prior to assigning a theme to a specific response, team members (MP and PRS) engaged in discussion to reach a consensus. Any uncertainties were discussed with a third team member (JR). In addition, we analysed the identified themes separately for the participants from Te Toka Tumai Auckland and Counties Manukau areas to identify variations in the reported barriers or enablers. The study is reported according to the standards for reporting qualitative research (online supplemental appendix 2).[24]

Patient and public involvement

Patients or the public were not involved in the design or conduct of our research.

RESULTS

We conducted interviews with 30 people, 11 in Te Toka Tumai Auckland and 19 in Counties Manukau. One participant was a New Zealand European in their 50s, while the remaining participants were self-identified as Pacific (including Tongan, Samoan, Fijian, Cook Islander and Niuean) and/or Māori ethnicity. Participants were aged between 21 years and 70 years (median 62 years). Two of the 30 participants had a family member join them for the interview.

The barriers and enablers to accessing diabetes eye care services reported by participants mapped to 7 of the 14 domains of the Theoretical Domains Framework as outlined below. Initials of the participants' alphanumeric pseudonym associated with the quotes below ('AD' and 'CD') represent Te Toka Tumai Auckland area and Counties Manukau area, respectively. The full list of themes, subthemes and supporting quotes are presented in online supplemental table 2).

Environmental context and resources

The environmental context and resources domain was identified as the most dominant among the seven domains mapped in this analysis, with all participants reporting at least one barrier or enabler in this domain influencing their access to diabetes eye care services. These barriers included individual travel and transport challenges such as financial constraints for travel, lack of a personal vehicle and unreliable public transport, while a transport enabler was the discount for public transport for older people. Time constraint was another common barrier expressed by participants, particularly in terms of work commitments and caregiving responsibilities, but also in terms of having many other appointments for other comorbidities. Family-related constraints included being dependent on family members for help to attend diabetes eye care appointments.

Some participants revealed that they were unable to attend their retinal screening appointment due to financial constraints such as difficulties in affording petrol or other travel expenses, including fees for the car park (which are charged at Te Toka Tumai Auckland but not in Counties Manukau), while others reported transport constraints such as distance to the clinic, lack of personal vehicle or unreliability of public transport due to delays or cancellations.

> *To get there and back and the parking. The parking [cost] is too much. They don't have a standard amount, but it's increasing.… There's no money for that. Sometimes I have to go look around for coins around the house to help out with those type of appointment. AD105*

In contrast, some of the older participants reported free public transport due to their aged-pensioner status as an enabler (people aged 65 years and older can travel on public buses and trains for free). Fewer participants from Counties Manukau reported challenges related to travel and transport compared with participants in (more centrally located) Te Toka Tumai Auckland, explaining that clinic locations were conveniently situated near their homes, and there was ample availability of free parking in the Counties Manukau area. Moreover, the presence of multiple locations and sites, both fixed and mobile, provided patients in the Counties Manukau area with the flexibility to change their appointment location and time as needed.

> If I can't make the Mangere Town Center one, I can go to the super clinic. Or I can go to Clevedon Drive. They always have locations. If I can't make my appointment. I always ring and say this time is not good for me. I can go to another location or change my time. CD203

Fourteen participants mentioned time constraints due to other commitments as a barrier to accessing healthcare appointments. Planned (such as childcare) and unplanned/emergency family commitments were common issues. Work commitments were also identified by some of these participants as creating a challenge to allocate time for healthcare appointments, particularly for those participants who owned their own businesses. Furthermore, a considerable number of participants noted the limited availability of weekend appointments and inconvenient appointment times as factors that hindered their ability to attend.

> I am a busy mom, single mom. I have two family members with complex health needs. Sometimes I can't make it there [eye clinic]. I missed the appointment because the time is not suitable. Around two o'clock, I'm just waiting to pick up the kids [from school]. CD214

> I have missed a few. Just because I'm so loaded [with commitments] right now, so busy. CD219

Dependency on family members was sometimes cited as a potential barrier due to the myriad of commitments held by other family members. More than one-third of participants, mainly older people, relied on family members to provide practical support in their healthcare journey, including attending appointments, providing transport and helping to communicate with healthcare providers.

> My daughter was working, that's why I call to cancel the appointment and rebooked another time. CD214

> I'm not driving you know I have to get my husband or family members to take me over there. AD103

Finally, many participants expressed the challenge of managing multiple health conditions simultaneously, necessitating multiple visits to various providers or, occasionally, hospital admission which prevented them from attending some appointments. For example, one participant revealed their struggle with mobility due to issues with their knees, another shared their experience with recurring appointments with a heart specialist and another recalled missing an appointment due to hospitalisation.

> Because of my feet, I can hardly walk with my knees. The knees have given up on me. CD210

> Two appointments that I missed was because I was admitted at the hospital. AD207

Professional role and health system characteristics

Participants held a diverse range of perceptions regarding their interactions with the healthcare system. While some expressed positive views about their communication with eye care professionals and the flexibility offered in choosing appointment times and locations (in Counties Manukau), others encountered barriers stemming from insufficient information during the booking process, unclear communication and extended waiting times or uncertainty regarding clinic queues. Several participants felt that they did not receive sufficient information about their appointments at the time of booking, suggesting that more details would help them understand the purpose and nature of their upcoming appointments.

> They [eye clinic] don't go in to the details on what they're going to do with your eyes. When you get to see a patient, and you're making an appointment for the patient, they must tell the patient what the appointment is about not to say 'oh, you've got to come in on Friday 10 o'clock to xxxxx clinic [who] will see [you] then'. CD213.

Moreover, some respondents expressed concerns about the potential for lengthy and uncertain waiting times at the clinic. This led to their decision not to attend their appointments.

> Can't sit in the waiting room for a couple of hours waiting and all that sort of stuff. CD217

> We don't know how long we're going to be inside there. You know, if we haven't allocated our timing, but still, we go there and we still wait. We don't go in go straight in, but we still have to wait. AD105

Some participants reinforced the importance of clear and effective communication, which supported them to attend eye care appointments.

> I've had a good experience with the ones I've been to and at the Manukau super clinic I wouldn't hesitate to go back in the future. CD201

> I love the communication between me and the staff, what you call the eye person. AD209

However, one participant raised concerns about communication barriers for people not fluent in English (the predominant language used in health services).

> My parents, they don't know how to communicate in English. CD206

Several participants also noted that health professionals used clinical terminology during their appointments that was unclear, and they felt overwhelmed or anxious when confronted with complex medical language.

> I'm not a doctor. And I'm sitting here thinking that what on earth they are talking about. They use all these clinical words, then I think oh my gosh, what are they saying? When they have a Māori nurse or a Pacifica nurse they explain in very simple terms." CD213

Knowledge and information sharing

The third most dominant domain related to challenges with knowledge and awareness regarding diabetes eye care, including the necessity for and recommended frequency of retinal screening and the potential consequences of not attending appointments. Several participants highlighted that the purpose and scheduling of appointments were not always clear, particularly about the difference between routine eye checks and diabetic eye screening. Additionally, many participants acknowledged that they lacked a comprehensive understanding of their diabetes and the potential consequences of missing appointments.

> A struggle not understanding what the appointment is for, understanding what to call the frequency or the need for the appointments. CD201

Some participants expressed a need for more detailed explanations about diabetic eye screening from their GP when referred and when discussing their diabetes, and from the screening service when appointments are booked.

> I just think just take a little bit more time explaining things because, you know, we don't know about the eye checkups. We don't say anything after like, okay, this is the way vision is or this is the best. CD207

Life circumstances

The main subtheme that emerged relating to life circumstances was a lack of social or family support. Several participants reported challenges in accessing social support services, including those delivered by government agencies such as Work and Income New Zealand, affecting their financial ability to attend hospital appointments. One participant who was unemployed at the time of the interview said they did not get unemployment support so was financially dependent on their spouse, which limited their ability to arrange hospital/clinic visits.

> Sometimes I've got no money at all because my wife gets paid every fortnight and when that time always be like for my appointment and things, I have to cancel it…. I tried to get support from WINZ, even my doctor wrote letters to them about my condition, but they said, no, they cannot help. AD101

Additionally, one participant outlined that the absence of family support meant they needed assistance from elsewhere.

> No family support, would be nice to have a network group that can support people. CD203

Behavioural regulation and communication (reminders/notifications)

The behavioural regulation domain encompasses the experiences with the notification system. Eleven participants expressed support for receiving reminders and notifications, which assisted them in remembering their appointments. However, the notification system does not always align with participants' needs, in terms of text messages on mobile phones not being appropriate and/or preferring physical letters over electronic communication.

> It is so nice they call or text to remind the patient. CD207

> I would like if they can send me the letter like they used to do before. I'll be happy because I'm not very good on the phone, even if I need to text, I do not know how to text. AD101

Furthermore, some participants noted that they did not receive timely notifications, either receiving them too late or too early.

> Sometimes we get a late message. That doesn't fit in with daily routines. AD208

Memory, attention and decision process

Eight participants indicated that memory, attention and decision process-related issues posed a significant challenge in attending appointments, despite receiving notifications. For example, forgetfulness was attributed to various factors, such as difficulties in remembering the appointment date and time.

> I forgot my appointment. That's why I missed the last one. They sent me a letter, they sent me a message, (but) I forgot. CD208

Belief about consequences

This domain relates to patient's attitudes and perceptions regarding the potential consequences of not attending their retinal screening appointment. While some participants were aware of the potential consequences of not checking their eyes regularly, many participants did not view screening appointments as significant events that can safeguard them from serious health conditions, such as vision impairment or blindness.

> You will need more awareness of that to teach you, you know what's going on in if you don't attend all your appointments or anything, what will happen to you? CD207

DISCUSSION

In New Zealand, retinal screening is an important component of diabetes care, as reflected by it being publicly funded by the Ministry of Health and included as one of the quality standards of diabetes care.[20] This study offers insights into the barriers and enablers to accessing retinal screening services among people living with diabetes in two large health areas of Auckland. Our participants are predominantly identified as Pacific and Māori, who are over-represented among those underserved by diabetes eye care services,[11] but whose voices and experiences are not often elevated in eye health research.[25] The most dominant themes of the Theoretical Domains Framework that encompassed the barriers and enablers expressed by participants are related to their environmental context and resources, the role of providers, and the knowledge and information sharing about their condition and its consequences. The key factors contributing to access to retinal screening reinforced findings from other settings and included participants experiencing travel/transport issues, time constraints and dependency on family members; factors relating to health provider and the health system included the service delivery model, communication strategies and locations of eye clinics.[7 9 26–31]

The policy context into which our findings speak is driven by the recently launched Pae Ora (Healthy Futures) Act 2022 and the New Zealand Health Strategy, which emphasises the role of the health system in improving equity and access through people-centred approaches.[32] One of the priorities outlined in the Strategy for the next 10 years is to address barriers to access by delivering services closer to where people live, and by making primary and community health services flexible and more responsive.[33]

Our findings highlight the need for more geographically accessible services in retinal screening services, drawing on evidence from elsewhere.[34 35] For example, as found elsewhere,[29] travel and transport challenges were commonly reported by participants. However, the nature and extent of these differed for participants from the two study areas, being much more frequently reported by participants from Te Toka Tumai Auckland compared with Counties Manukau, and more consistently linked to parking. A key difference between the two models is the decentralised model in Counties Manukau, with a number of dispersed community-based and mobile facilities with plentiful (and free) parking, compared with the model in Te Toka Tumai which is predominantly run from a single hospital setting with a relatively expensive car park that is often full.

To make diabetes eye care more flexible and responsive, there is a range of effective service delivery strategies that could be upscaled or trialled in New Zealand.[31] For example, reminder systems are already in place in our study areas,[21] but they could be strengthened further by leveraging emerging health information technologies to match individual preferences. In the future, patients could receive multiple reminders, such as sending letters in addition to emails and sending messages to multiple mobile numbers to reach patients as well as their family members.[36] Appointments for retinal screening could be combined or spaced relative to appointments that patients have with other specialties, based on patient preference. Strategies to expand the locations, as well as the days or hours of available services, would help address the time constraints expressed by participants.[6] Information technology could also help to manage expectations around waiting times after arrival at the screening site, by using simulated models or a real-time scheduler.[30 37] Artificial intelligence/chatbots could be available for patients to schedule appointments if they prefer other scheduling options.[38] Efforts such as these to expand the health service options available would demonstrate responsiveness to the recommendations from the Waitangi Tribunal which highlighted that providing more options was one strategy for New Zealand's legislative, policy and administrative framework to better achieve health equity for Māori.[39]

Other effective—and potentially cost-effective—interventions could focus on capacity strengthening of service providers, including their ability to provide more and clearer information on diabetic eye disease and its consequences, as well as system-level changes such as incorporating translators and patient navigators into the provider team.[40] Any communication strategies in these two locations must include messages that make it clearer that the publicly funded retinal screening service does not replace the need for a routine eye examination, particularly for the detection and correction of uncorrected refractive error, which receives no public funding for adults.[41] These interventions could help to improve meaningful information sharing and reduce the communication- and language-related barriers we identified in this study and that mirror findings from studies conducted in other ethnically diverse settings or among immigrant populations.[9 28 42]

Recent advances in camera technology may also help address some of these barriers. Historically, the camera technology required the pupils of all patients to be dilated in order to acquire images that were of sufficient quality to ensure an acceptable sensitivity and specificity of the graded images.[43] More recently, cameras have been developed that are capable of generating images through nondilated pupils that are as good as, if not better than was achieved using conventional photography through a dilated pupil.[44] If these cameras were adopted into retinal screening programmes, patients accessing care would not be temporarily incapacitated by pupil dilation after retinal photography. As patients would then be safe to drive themselves home once the images had been acquired, the need for them to bring a support person to drive them home will be removed.

Incorporating handheld portable cameras into retinal screening services for selected, high-risk groups could increase accessibility even further. Although these systems may not produce images that allow precise grading of retinopathy in all patients, the images are often of sufficient quality to facilitate the reliable identification of people with suspected sight-threatening retinopathy.[45 46] These systems could be integrated with telehealth platforms within primary care or community locations. If such an approach were implemented, retinal screening programmes could be integrated into existing healthcare hubs, bringing care closer to home and reducing the number of appointments people need to attend to access care.[47 48] This approach would also support the preference of Māori and Pacific with eye problems to seek care from their GP clinic.[22]

Our findings must be interpreted in the context of several limitations. Our study was restricted to two areas of the country, so it may not reflect the issues facing people in other regions, which are geographically and demographically different, with different models of diabetes eye care. Second, we aimed to explore barriers and enablers experienced by patients at different stages of diabetes eye care, including commencing and returning to retinal screening, and progressing to ophthalmology care when treatment was indicated. However, the stories shared by participants were limited to retinal screening services and did not reflect the experiences of people requiring treatment for diabetic retinopathy. The barriers for people requiring treatment may be more extensive given the non-attendance rate at the ophthalmology diabetes clinic at Counties Manukau (9%) was more than twofold as high as retinal screening (4%) in 2019/2020 (pre-COVID-19).[21] Finally, while the Theoretical Domains Framework offers a comprehensive structure to identify factors that influence behaviours, our findings illuminated elements related to characteristics of the health system not explicitly addressed in the framework which we believed were important to capture. To include these elements, we condensed the barriers and enablers related to healthcare providers and health system characteristics into the 'social/professional role and identity' domain of the framework and renamed it as 'professional roles and health system characteristics' domain.

CONCLUSIONS

Our findings align closely with evidence from other settings and demonstrate that many of the barriers to accessing diabetic retinal screening services are related to the environmental context and resources of the patients in the context of a health system that could do more to address access challenges. While some of the identified barriers—such as lack of social support—may require multisectoral interventions, many are modifiable through changes to the way services are delivered.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Consent obtained directly from patient(s)

Ethics approval This study involves human participants. Ethical approval was obtained from the Health and Disability Ethics Committee (Ref: 2022 FULL 12178), and locality approval was obtained from Te Toka Tumai Auckland (Ref: 21/NTB/97) and Counties Manukau (Ref: CM Health Research Registration Number 1422) District Health Boards. Participants gave informed consent to participate in the study before taking part.

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Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information. Our findings are derived from the qualitative primary data collected during the study. The details are presented in Supplementary Tables 1 and 2.

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