As a neurodevelopmental condition resulting from prenatal alcohol exposure, fetal alcohol spectrum disorder (FASD) affects approximately 4.9 to 11.7 per 1000 children and adolescents globally. Primary impacts of FASD (e.g. impairments in cognition, motor, speech, language, and social development, and difficulties regulating responses to sensory stimuli) can affect individuals' participation in daily activities, such as self-care, school, leisure, and social interactions. Without appropriate supports, individuals with FASD can experience secondary challenges, such as disengagement from school, lack of independence, alcohol and/or other substance abuse, mental health problems, and involvement with the justice system.

**Original Article**

**Lived experiences of adolescents with fetal alcohol spectrum disorder**

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**Abstract**

**Aim:** To explore the lived experiences of adolescents with fetal alcohol spectrum disorder (FASD) to understand: the ways in which their challenges influence daily functioning; and the personal assets and external resources that facilitate participation.  

**Method:** Semi-structured interviews were conducted with four adolescents (one identified as non-binary, one male, and two female) with FASD aged 13 to 15 years. A photo elicitation approach facilitated participation, whereby adolescents first took photographs of their daily activities and environments. Photographs were subsequently used to generate discussion during the interviews. Data analysis involved using interpretative phenomenological analysis to generate themes.  

**Results:** Two superordinate themes and three subthemes relating to participants' lived experiences emerged from the interviews: (1) ‘anxiety challenges participation’ (subthemes [i] ‘need for external support’; [ii] ‘the power of positive relationships’; and [iii] ‘talents and interests facilitate participation’) and (2) ‘importance of a unique identity’.  

**Interpretation:** Findings illustrated the barriers adolescents experienced regarding their daily functioning and independence. Additionally, incorporating strengths into daily activities appeared to reduce anxiety and improve participation, and adolescents desired for their unique characteristics to be recognized and appreciated. To support adolescents with FASD, service providers should consider incorporating strengths-based approaches and an explicit focus on facilitating the development of positive self-identities.

As a neurodevelopmental condition resulting from prenatal alcohol exposure, fetal alcohol spectrum disorder (FASD) affects approximately 4.9 to 11.7 per 1000 children and adolescents globally. Primary impacts of FASD (e.g. impairments in cognition, motor, speech, language, and social development, and difficulties regulating responses to sensory stimuli) can affect individuals' participation in daily activities, such as self-care, school, leisure, and social interactions. Without appropriate supports, individuals with FASD can experience secondary challenges, such as disengagement from school, lack of independence, alcohol and/or other substance abuse, mental health problems, and involvement with the justice system.
The International Classification of Functioning, Disability, and Health defines activity as ‘the execution of a task or action’ and participation as ‘involvement in a life situation’. Participation can be facilitated or hindered by an individual’s personal factors (e.g. motivation, interest, preferences, skills), social interactions, and environmental factors. The International Classification of Functioning, Disability, and Health emphasizes functioning over disability, promoting holistic approaches to intervention. Aligning with this framework, resilience theory and strengths-based interventions encourage empowering individuals to identify and use their personal assets (e.g. abilities, interests, personality), external resources (e.g. social supports, community factors), environments, and activities to develop their capabilities to improve activity performance. Current research has focused on identifying and addressing participation barriers experienced by children and adolescents with FASD; however, consideration of factors that facilitate their participation is limited. Furthermore, few studies have explored the lived experiences of children and adolescents with FASD. Considering an individual’s perspectives can help clinicians to determine what is important to the individual, understand the individual within the context of their relationships and circumstances, and use these insights to inform care. Additionally, it has been established that family-centred practice should be collaborative between the therapist, child, and family. To develop goals that are meaningful to children with FASD and interventions that address these goals, it is important to include a focus on children’s lived experiences.

The overarching aim of the present study was to gain insight into the lived experiences of adolescents with FASD, with additional sub-aims of describing: (1) the ways in which their challenges influenced daily functioning; and (2) the personal assets and external resources that facilitated participation.

METHOD

The current study is reported according to the consolidated criteria for reporting qualitative research guidelines (Appendix S1). Ethics clearance was granted from The University of Queensland (2019000170) and Children’s Health Queensland (HREC/18/QCHQ/46648). As participants were under 18 years old, caregivers provided written informed consent and adolescents provided verbal assent before the interviews.

Research team and reflexivity

Four occupational therapists and one clinical psychologist conducted the current study. Except for the first author who was a PhD candidate, all authors hold a PhD. The last author had previously met two participants during other research activities; however, all interviews were conducted, transcribed, and analysed by the first author, who had no previous relationships with any of the participants. Participants were advised of the researcher’s qualifications and experience, research aims, and participation instructions.

Study design

Interpretative phenomenological analysis (IPA), a thematic approach founded on phenomenology, hermeneutics, and idiography, was used. Both descriptive and interpretative, IPA uses the hermeneutic theory of interpretation to understand the ways in which participants make meaning of their experiences and their perspectives of a phenomenon. Aligned with idiography, IPA considers each participant’s reflections individually before conducting a cross-case analysis of all interviews. Themes and interpretations relating to participants’ lived experiences are identified and written as a narrative supported by quotations from participants. As this study aimed to explore the lived experiences of adolescents with FASD, IPA was deemed to be an appropriate approach.

Participants

Participants were adolescents diagnosed with FASD aged between 12 and 18 years and were recruited using purposive homogenous sampling from The University of Queensland neurodevelopmental assessment clinic and Australian FASD support organizations (National Organisation for Fetal Alcohol Spectrum Disorders and the FASD Hub Australia). Children over 7 years old can provide assent to participate in research; however, children under 9 years old often have not developed the capacity to assess and reflect upon their skills and abilities. Additionally, individuals with FASD often have cognitive, speech, and language difficulties that may further complicate their ability to discuss personal experiences.
experiences. As this study required participants to articulate and reflect upon their circumstances, adolescents were recruited. IPA recommends a small participant sample to enable detailed analysis of each case individually. Six caregivers of potential participants discussed the research project with the first author via phone or email.

Four families agreed to participate. Two of the adolescents, though interested in the study, were reported by their caregivers as feeling anxious about engaging in interviews and one declined to converse directly with the researcher, instead relaying answers through their caregiver. Consequently, caregivers were present during these two interviews to facilitate participation.

Table 1 presents a summary of the participants and caregivers present during the interviews. Pseudonyms are provided to protect participants’ privacy.

### Data collection

Semi-structured interviews were conducted using photo elicitation, an approach used with children and adolescents with disabilities to support them in making meaning of their world and reflecting upon their experiences, even when they may not have the capacity to discuss abstract concepts. Photo elicitation provides children with control over the photographs taken and discussed, and has been used with IPA to support understanding of lived experiences.

Participants were asked to take photographs of their daily activities and environments (e.g. home and community areas, artwork, projects, mealtimes, books) for 2 weeks before the interviews, then chose photographs to share and discuss with the interviewer. Adolescents were asked to take the photographs themselves and avoid photographing people or identifiable features (e.g. school signage) for privacy. Example photographs are provided in Figures 1, 2, and 3.

Interviews were conducted by the first author for 45 minutes to 1 hour via Zoom (because of COVID-19 restrictions) using an interview guide (Appendix S2), which was provided to participants in advance. Photographs were viewed one at a time and the researcher asked questions relating to the activities and environments shown, with probing questions used to elicit further information (e.g. “Tell me about this photo?; “When do you usually do this activity?”). After all photographs were viewed, additional questions explored adolescents’ daily routines, activities, perceived strengths and challenges, and influences of these on daily functioning (e.g. “What do you find challenging to do during the day?; “What do you feel your strengths are?”). The adolescent who relayed answers through their caregiver became anxious during the interview and was unable to continue. A second appointment was arranged, and the interview was successfully completed. Interviews were audio and video recorded with permission and transcribed verbatim, and field notes were made during and after the interviews.
Data analysis

Data analysis followed guidelines set out by Smith et al.\textsuperscript{13} whereby each interview was analysed individually, followed by a cross-case analysis. The photographs were not analysed as they were used purely to facilitate participation in the interviews.

Individual analysis involved the first author reading each transcript multiple times and making descriptive, linguistic, and conceptual comments.\textsuperscript{13} Descriptive notes described the content of the interview (e.g. ‘unable to discuss home and leisure activities’), linguistic notes highlighted participants’ language use (e.g. ‘lots of repetition of words/phrases’), and conceptual notes speculated on data interpretation (e.g. ‘difficulty communicating verbally so expresses self through art instead?’).\textsuperscript{13} The second and third authors also independently reviewed the first and last transcripts. Discussion and comparison of their exploratory comments with the first author ensued to confirm that notation strategies were congruent across the authors.\textsuperscript{13,20}\textsuperscript{13,20} The first author subsequently identified and grouped emerging themes, creating an overarching list of themes for each participant.\textsuperscript{13} These lists, along with interview extracts, were discussed among all authors until a consensus on themes was reached. While all authors agreed upon the content for each theme, there were minor discrepancies between the theme names. To reach consensus, authors reviewed relevant quotations and descriptions together to develop appropriate labels.

During the subsequent cross-case analysis, the first author compared all four lists of themes to identify connections and created a final overarching list of superordinate themes and related subthemes.\textsuperscript{13}\textsuperscript{13} The final group list and corresponding extracts were then discussed with the research team to finalize themes.

RESULTS

Two superordinate themes were generated from the interviews. The first identified anxiety as a primary barrier to the adolescents’ participation in activities. Three subthemes (external supports, talents and interests, and positive relationships) emerged as elements that helped adolescents to overcome anxiety and participate in activities. The second superordinate theme (importance of a unique identity) highlighted a significant factor in the adolescents’ lived experiences. The themes are presented in Table 2 and Figure 4 and discussed below.

Anxiety challenges participation

Anxiety was the main barrier to participation in daily activities reported by participants and resulted in participants avoiding activities or requiring caregivers to support engagement, particularly during social situations. Jamie stated that anxiety made ‘answering questions [and] making decisions’ difficult, as social demands ‘don’t really compute well with [me] … I can’t hold conversations a lot, it’s very hard for me to talk sometimes … How do people hold conversations? Like it’s genuinely confusing to me’. Busy environments were also stressful: ‘I can’t be in big places for too long or I freak out.’

Taylor appeared to need planning, order, and predictability to reduce their anxiety. For example, after shopping for groceries (which could be stressful for Taylor because of the busy and unpredictable environments), Taylor reported a need to stack purchased items perfectly to calm themselves: ‘I hate when the tuna cans get put upside down so the writing’s upside down … It just bugs me.’

Mackenzie’s and Jamie’s anxiety also resulted in difficulty providing detailed answers during the interviews. They often responded with single words or short statements and required the interviewer to ask probing questions to facilitate further discussion. Mackenzie also reported difficulty sleeping because ‘I can’t turn my brain off’.

Although interested in participating, Dakota became anxious about being on camera using Zoom and conversing directly with the researcher. Dakota opted to stay off camera, relaying answers and comments via their caregiver, Hazel, who advised that Dakota was experiencing ‘anxiety and stress’ regarding the camera and speaking with the researcher.

Although anxiety posed a significant barrier to adolescents’ participation, there were factors that assisted them with overcoming their anxiety and participating in activities. These factors comprise three subthemes.
Subtheme 1: Need for external support

Adolescents needed external supports and resources to perform activities. For example, Jamie found that listening to music helped to reduce their anxiety, reporting: ‘If I ever did meet [interviewer name] in real life, [they would] probably see me with one headphone.’

Taylor ‘like[d] script[s]’ to prepare for conversations and provide organized responses. For example, Taylor’s caregiver, Olivia, reported that Taylor was ‘not keen on [hosting a radio show];’ however, as the show was scripted, Taylor agreed to participate, reporting that it was ‘very amazing’. When asked unexpected questions during the interview, Taylor appeared unsure how to respond and often repeated words: ‘I was thinking I’d just do flame, I was thinking I’d just do flame up it, because it’s got some nice shapes in it, you can get some good, some good, some nice flow.’ Olivia also supported Taylor’s emotional regulation, for example, when Taylor became distracted during the interview, Olivia recognized that they needed a break and suggested: ‘Do you want to just step out for a sec?’ Taylor then left the interview to jump on the trampoline, a strategy that Olivia reported can assist Taylor to regulate their emotions.

Organization and consistent routines were revealed as effective strategies to support participation for two adolescents. Dakota required their caregiver (Hazel) to assist with managing their anxiety by limiting unstructured time during the day: in addition to school, Dakota trained in gymnastics 5 days per week, and weekend and holiday activities were planned in advance. Hazel also positioned Dakota out of camera view during the interview so that Dakota felt more comfortable participating, reporting '[Dakota] doesn't want to see [themselves], so I'm going to turn off the video … I could be the relay person.'

Superordinate theme 2: Importance of a unique identity

Adolescents needed a sense of self and personal identity. For example, Jamie described their bedroom as a place to relax and engage in creative hobbies: ‘My bedroom is the things I like, and I like my friends.’

Taylor reported feeling comfortable with their unique identity: ‘This one I did all on my own.’

Subtheme 2: The power of positive relationships

Positive relationships played a substantial role in supporting participants in their daily lives. Caregivers and friends often assisted adolescents in performing activities, managing emotions, and engaging in social interactions.

Jamie reported the value of close friendships, citing a particular friend as one of their main supports when feeling anxious or distressed: ‘I always turn to my, like, my good, good friend.’

Mackenzie also reported on the importance of close relationships, noting: ‘I … go shopping and out to the beach and that … [with] Mum.’

Dakota further described their unique identity: ‘I could be the relay person … [Dakota] can hear you, but I can relay.’

Table 2: Themes generated from interviews

| Contributing participants | Quotations from interview transcripts |
|---------------------------|--------------------------------------|
| Superordinate theme 1: Anxiety challenges participation |
| Jamie                    | ‘I can’t be in big places for too long or I freak out.’ |
| Taylor                   | ‘There were lots of anxieties and things.’ |
| Mackenzie                | ‘I can’t turn my brain off.’ |
| Dakota                   | '[Dakota] really doesn’t want to see any photos, but you can talk to them.' |
| Subtheme 1: Need for external support and environmental adaptations |
| Jamie                    | ‘If I ever did meet [interviewer name] in real life, [they would] probably see me with one headphone.’ |
| Taylor                   | ‘Having a routine is very important … We have schedules and that to make sure that [Taylor] knows everything that’s happening. So that really helps a lot.’ |
| Dakota                   | '[Dakota] doesn’t want to see [themselves], so I’m going to turn off the video … I could be the relay person.' |
| Subtheme 2: The power of positive relationships |
| Jamie                    | ‘I always turn to my, like, my good, good friend.’ |
| Taylor                   | ‘That’s actually Mum reading [to me].’ |
| Mackenzie                | ‘I … go shopping and out to the beach and that … [with] Mum.’ |
| Dakota                   | ‘I could be the relay person … [Dakota] can hear you, but I can relay.’ |
| Subtheme 3: Talents and interests facilitate participation |
| Jamie                    | ‘Sometimes if I just sketch whilst I’m doing [an activity], ’cause it also helps me focus a lot. And also, doesn’t get me a lot more moody than I already am.’ |
| Taylor                   | ‘I was … writing a review on one of my cameras.’ |
| Mackenzie                | ‘I’m good at art.’ |
| Dakota                   | '[Dakota] has competed competitions locally, in state teams … There are some skills that only you can do, and others can’t in your level, isn’t there?’ |
| Superordinate theme 2: Importance of a unique identity |
| Jamie                    | ‘My bedroom is the things I like, and I like my friends.’ |
| Taylor                   | ‘This one I did all on my own.’ |
Taylor’s strong relationship with Olivia was evident throughout Taylor’s interview as they often had easy banter between them, laughing and making jokes:

**Olivia:** So, [Taylor] was interviewed on the [radio show] and they said, ‘[Taylor’s] got a great voice for radio.’

**Taylor:** They didn’t say I had a great face for radio (laughs).

**Olivia:** Yeah (laughs).

This relationship enabled Olivia to support Taylor to take opportunities they would normally avoid, for example, hosting the radio show. Olivia stated: ‘I helped very much with [Taylor] to work through it all … there were lots of anxieties.’

Mackenzie enjoyed going to the beach or shops with their caregiver, Leah, while Hazel assisted Dakota to participate in activities that they found stressful. Dakota also reported that they enjoyed school lessons when taught by teachers who took the time to get to know them and ‘made [lessons] fun’.

**Subtheme 3: Talents and interests facilitate participation**

Participants reported that incorporating their strengths or interests into activities supported their participation in tasks they would typically avoid. Jamie enjoyed creating art and often sketched at school when feeling frustrated or to help them engage in tasks that were overwhelming: ‘Sometimes I just sketch whilst I’m doing [classroom activities], ’cause it also helps me focus a lot. And also, doesn’t get me a lot more moody than I already am.’ Jamie also used this strategy to facilitate their participation in the interview by sketching while they were talking to the researcher.

Taylor enjoyed photography and completing art-related projects at home and Olivia based Taylor’s schooling around these passions to support their learning. For example, Taylor initiated writing ‘a review about one of [their] cameras’, even though Taylor dislikes writing: ‘I don’t write anything I don’t want to.’ Much of Taylor’s interview focused on discussing their projects and Taylor expressed pride in their achievements: ‘They come up pretty good … That was a fairly good achievement.’

Dakota enjoyed gymnastics and was successful in competitions at state and national levels. Even though there were changes to the structure and activities of Dakota’s gymnastics classes that they disliked and their peers left, Dakota’s passion encouraged them to continue attending.

**Importance of a unique identity**

The desire for a self-expression of their unique identity was evident throughout Jamie’s and Taylor’s interviews. Adolescents' responses and photographs expressed their personalities and interests through creative mediums, their personal appearance, and their individual home environments.

Jamie enjoyed decorating their clothes, ‘cut[ting] and dy[eing] [their] own hair’ and tattooing themself, while their bedroom, ‘the place where [Jamie felt] safe’, allowed freedom to express their personality. The walls and furniture were styled with artwork and posters and often featured Jamie’s friends: ‘My bedroom is the things I like, and I like my friends’, signifying the value they placed on relationships. Jamie also reflected upon their use of art to convey emotions.
and values: ‘That’s a drawing I made … I based it off a character that I was really obsessed with. And it kinda reflected how I felt… It’s kinda like a “don’t really judge a book by its cover” kinda thing.’

Taylor also emphasized the importance of having their own identity, often highlighting their unique personality characteristics, values, and strengths. While Olivia drew parallels between Taylor and their father, Taylor focused on their differences, for example, expressing pride in their own resourcefulness and organization compared to their father: ‘I get old bits that [father] just wouldn’t use and [father] would throw out … I have [my own shed workbench] all organized, a lot better than Dad’s bench.’

**DISCUSSION**

The current study aimed to understand the lived experiences of adolescents with FASD. Of particular interest was how their challenges and personal assets and external resources influenced participation in daily activities. Two superordinate themes were identified from adolescents’ interviews: (1) ‘anxiety challenges participation’ and (2) ‘importance of a unique identity’.

The first superordinate theme identified that adolescents’ anxiety impacted their confidence and independence, with participants identifying that they frequently required assistance from caregivers to participate in activities. Similarly, Salmon and Buetow’s study found that anxiety resulted in adolescents with FASD becoming socially isolated and struggling to engage at school.

One subtheme, ‘need for external support’, revealed that strategies implemented by caregivers, such as establishing routines, modifying the environment, and providing structure and organization, alleviated anxiety and assisted adolescents to participate in their daily activities. Likewise, caregivers in studies by Brown et al. and Watson et al. reported needing structured environments for their children with FASD to manage behaviours and support them in following routines. Additionally, a paper by Kalberg et al. recommended that, because of the executive functioning impairments associated with prenatal alcohol exposure and the interplay with a young person’s environment may impact participation in leisure activities, particularly social situations where adolescents experienced a sense of belonging because of shared interests. For example, a study by Burles et al. found that being independent and recognized for their abilities, rather than their deficits, was essential to the positive self-identity of a young adult with FASD.

Participants discussed the importance of developing positive relationships with family and friends. Taylor and Mackenzie spent much of their leisure time with caregivers, and Jamie turned to friends for support when overwhelmed. Social supports were a key facilitator for adolescents in the present study to manage anxiety and perform activities, including completing schoolwork, social participation, and taking on new opportunities. This finding was consistent with other literature. For example, Stade et al. noted that children with FASD felt supported by their caregivers and recognized the advocacy role that they took on, and one child reported that their caregivers assisted their attention to engage at school.

The second superordinate theme, ‘importance of a unique identity’, illustrated participants’ desire to be appreciated as individuals. Jamie and Taylor used art to express their individuality, and Jamie also created artwork to communicate their emotions. Jamie’s appearance and styling of their bedroom exhibited their talents and self-expression and suggested that Jamie valued having a unique identity apart from their family and peers. Taylor’s comparisons to their father indicated their need to be recognized for their own skills. This theme of a unique identity arose from Jamie’s and Taylor’s interviews as more than simply showing their differences; it was their desire to be individuals standing out from others and to have their talents appreciated. This was a key part of these adolescents’ lived experiences, and previous research has found that developing a positive self-identity was essential to facilitating participation in leisure activities, particularly social situations where adolescents experienced a sense of belonging because of shared interests. For example, a study by Burles et al. found that being independent and recognized for their abilities, rather than their deficits, was essential to the positive self-identity of a young adult with FASD.

Limited previous research has investigated self-identity as a focus of intervention for children and adolescents with FASD, yet developing a unique identity is an important part of adolescence in general. The neurodevelopmental impairments associated with prenatal alcohol exposure and the interplay with a young person’s environment may impact the development of a positive self-identity for individuals with FASD. Negative self-identity could increase anxiety or lead to low mood symptoms and hence reduce participation in daily activities. Reid et al. therefore recently highlighted the importance of strengths-based approaches for individuals with FASD to facilitate the development of a positive self-identity.

**LIVED EXPERIENCES OF ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER**
Clinical implications

Consistent with previous research, this study highlighted the barriers anxiety posed to the daily functioning of adolescents with FASD, and the need for external supports to facilitate participation in activities. Caregivers and close friends were the main support people for adolescents in the present study and assisted adolescents in managing anxiety and performing activities they found challenging. It would hence be beneficial for clinicians to consider promoting positive relationships between children and their social networks and assist caregivers and other support individuals to implement routines and predictability.

Unique to this study was the focus on participants’ strengths. Supporting strengths-based approaches, adolescents emphasized the importance of using their talents and interests to enhance motivation and assist participation in activities. Anxiety was a significant challenge, often resulting in adolescents avoiding activities; therefore, this finding reinforces recommendations for clinicians to identify the personal assets and external resources of children and adolescents with FASD, support them to recognize their own strengths, and harness these in intervention. Additionally, adolescents highlighted a desire for their unique characteristics to be recognized by others, an important factor for many young people, yet not well researched in the FASD population. The themes derived from this study suggest that incorporating the strengths of children and adolescents with FASD into interventions and daily activities and developing positive self-identities can facilitate participation.

Limitations

One limitation of this study was that the participant sample was self-selected. Photo elicitation may have attracted participants with artistic interests and may not have appealed to participants with other interests. Future studies could consider alternative data collection methods, such as creating a video diary or providing written, drawn, or pre-recorded answers, to reduce anxiety related to conversing with unfamiliar researchers. Using Zoom to conduct the interviews allowed recruitment from interstate and could have either facilitated or impacted engagement for the adolescents. Some adolescents may have felt more comfortable with Zoom rather than in-person interviews, whereas other adolescents may have felt overwhelmed. One adolescent became anxious; however, it was unclear whether an in-person interview would have supported engagement as they found conversing with unfamiliar people in general stressful. In-person interviews may have allowed for more flexible approaches to conversations, such as walking, playing games, or utilizing other interests during the interviews; however, face-to-face discussions could also have been more anxiety-provoking for some adolescents. Additionally, increasing the involvement of people with lived experience throughout the research process (e.g., design of the methodology and analysis of the results) could be considered for future research studies.

Conclusion

This study provides insights into the lived experiences of adolescents with FASD, particularly that anxiety impeded and strengths facilitated participation in daily activities. Additionally, adolescents wanted their unique characteristics to be appreciated by others. By focusing on the personal assets and external supports of adolescents with FASD, as well as their challenges, clinicians can better understand the benefits of incorporating strengths-based approaches into intervention. It is recommended that future interventions consider harnessing children’s talents and interests, supporting a positive self-identity, establishing strong social supports, and implementing predictability and structure to facilitate participation in daily activities.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION
The following additional material may be found online.
Appendix S1: Consolidated criteria for reporting qualitative research (COREQ) checklist.
Appendix S2: Interview guide.

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