

Parents Need More Support: A Qualitative Study of the Experiences of Australian Parents Who Are Waiting for Surgical Intervention for Their Children With Otitis Media

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Abstract

Objective: To explore the experiences, expectations, and motivations of parents/caregivers of children with otitis media who were booked to undergo tympanostomy tube insertion. **Method:** A cross-sectional cohort study was conducted using semistructured interviews with 39 parents. Interviews were conducted via telephone and analyzed for key themes. **Results:** Three themes emerged that incorporated a range of subthemes: (1) the impact of the child’s underlying condition on the family, (2) the cues and prompts that influenced parents to seek intervention, and (3) the parents’ expectations of the health-care system. The child’s otitis media disrupted the day-to-day functioning of the family and the child’s well-being, but despite this, the families found ways to adapt and cope. Parents were influenced by their friends, family, and medical practitioners when making treatment decisions and had differing expectations of the health-care system. **Conclusion:** Parents need support during their child’s illness to help with pressures placed on the family and also in making health-care decisions for their child. Clinicians should consider these issues when discussing treatment options with parents.

Keywords

qualitative research, child, otitis media, ear health

Introduction

Otitis media (OM) is ubiquitous in childhood. In Australia, OM (“ear infection”) is one of the most common pediatric problems managed by general practitioners (GP) (1–3). It has been estimated during the first 5 years of life, the incidence in Australia is nearly 2 episodes per child per year (2). Parents caring for unwell children during their first 5 years of life are estimated to cost the Australian economy AUD\$189.2 million per year for income lost (2). Furthermore, the economic burden of OM on the Australian public health system is between AUD\$100 and AUD\$400 million per year (4).

Caused by the build-up of fluid in the middle ear, OM is usually preceded by a cold or sore throat that spreads into the structures of the middle ear. The condition primarily manifests as either acute OM (AOM) that causes pain, fever, and irritability (5); and OM with effusion (OME) that typically

presents with pain-free hearing loss (6); as well as balance impairment (7) and speech and language delays (6). Both are initially managed with conservative approaches. Current recommendations advise AOM be managed with analgesic pain relief, with antibiotics only prescribed in specific

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situations, such as when severe fever is present (8), while OME should be managed with watchful waiting for 3 months to allow the infection to resolve spontaneously (9). However, recurrent episodes of AOM over a 6-month period or OME lasting more than 3 months duration are both considered appropriate indications for tympanostomy tube insertion (8,9). Tympanostomy tubes (“grommets”) are small tubes that are placed in the tympanic membrane (“eardrum”) to allow the ventilation of the middle ear structures and assist in the resolution of OM.

Medical practitioners recommend these conservative and surgical treatment options in accordance with recognized guidelines; however, ultimately treatment decisions are made by the parents of the children affected (10). The experiences of parents influence their decisions, and this may include their own experiences or those of their children. A key influence on decision-making in the health-care setting is the impact of illness on quality of life. Thus far, most research investigating the impact of OM on children’s quality of life has relied on structured questionnaires or telephone surveys (11–15). Most of these have primarily focused on the physiological impact of the illness on the child. However, treatment conversations with parents should also include the broader impacts of the child’s condition. To date, there has been a paucity of research on these broader social impacts. The purpose of this research was to explore the experiences of parents who had a child booked to undergo tympanostomy tube insertion for the management of OM.

Method

This was a cross-sectional, cohort study using qualitative methodology to analyze semistructured interviews. The research was based in grounded theory (16) and not positioned within a specific or theoretically driven qualitative framework (17). The results are reported using commonly accepted principles (18,19) and in accordance with the Standards for Reporting Qualitative Research (20). The study was approved by the Human Research Ethics Committee of the Women’s and Children’s Health Network.

Participants

Interviews were conducted with the primary parent or caregiver (hereafter referred to as “parents”). Parents were eligible for inclusion if their child was younger than 10 years, the child had been added to the surgical waiting list, but not yet undergone surgery, at the Women’s and Children’s Hospital, Adelaide, South Australia, between September 1, 2008, and November 10, 2008, for planned tympanostomy tube insertion for the treatment of AOM or OME, and the parent consented to participate in a telephone interview. Language spoken was not an exclusion criterion, with certified translators used for those participants who spoke a language other than English. Parents were not eligible to participate if their child had a pre-existing predisposing condition, such as

Down Syndrome. In households with more than one parent, parents were asked to nominate who would be contacted for interview. All participants provided written informed consent to be contacted for interview.

Interviews

Interviews were conducted via telephone, with participants located in their home, and the interviewer located in a private room at the Women’s and Children’s Hospital. All interviews were conducted by the author (J.H.S.) and audio-recorded with participant consent. Participants were contacted at their nominated interview times, which they specified during the written consent process conducted in the outpatient department. Interviews were conducted within 3 weeks of the date of consent, between September 1, 2008, and November 18, 2008. Consent was verbally confirmed prior to the interview commencement. Demographic data were collected during the interview about the child, the participant, and the household structure. Interviews were conducted using a standardized topic guide (see Appendix). Topics covered included the parents’ experiences, the impact of the illness on the child and family, and the decision-making process leading to the surgery booking. Participants were recruited until data saturation was achieved and no new information emerged during the interviews.

Thematic Analysis

Digital audio-recordings were transcribed verbatim after each interview. The following iterative approach was applied to describe and interpret participant views. The thematic analysis commenced with deidentified transcripts reviewed, and preliminary codes identified. Coded information was organized into categories of related codes. This initial analysis was conducted by 1 researcher (J.H.S.) with in-depth discussions throughout the process with a second researcher (M.O.K.). Once the first-pass analysis was complete, additional iterations of code and category development were reviewed and discussed further (J.H.S. and M.O.K.). These codes and categories were further refined and tested against the transcriptions, with recoding performed to ensure clarity and consistency of coding. This process was repeated until no new codes or categories were identified as emerging from the transcripts. Each theme was reviewed to ensure it accurately encapsulated the codes and categories ascribed to it. A theme description was developed to summarize the main concepts. Quotes reflecting themes were extracted as exemplars and are presented herein.

Data Management

The first analysis phase was performed using hard-copy transcriptions; however, once categories were identified, data were imported into NVivo 8 (version 8.0.335.0, SP4, QSR

Table 1. Characteristics of the Participants and Their Children.^a

Characteristic	Total
Child demographics	
n	39
Age, years, mean (SD)	3.2 (0.5-8.1)
Male, n (%)	27 (69.2%)
English, n (%)	38 (97.4%)
Publicly funded, n (%)	36 (92.3%)
Childcare/school, days/week, median (range)	3 (1-5)
Parent demographics	
Age, years, mean (SD)	30.4 ± 4.6
Mother of child, n (%) ^b	36 (92.3%)
Married/de facto, n (%)	25 (64.1%)
Smoker, n (%)	11 (28.2%)
Currently in paid employment, n (%)	18 (46.2%)
Highest level of education	
Did not complete high school	13 (33.3%)
High school	12 (30.8%)
Tertiary education ^c	14 (35.9%)

Abbreviation: SD, standard deviation.

^an = 39.

^bOther interviewees were the child's father or guardian.

^cTechnical, trade or Technical and Further Education (TAFE) certificate, or university degree.

International Pty Ltd, Doncaster, Victoria). The software was used to organize the themes and interview excerpts.

Results

A total of 39 parents were interviewed. Interviews ranged in duration from 8 minutes to 43 minutes, with the median length of 16.5 minutes. The characteristics of the parents and their children are presented in Table 1. Three main themes emerged: (1) the impact of the child's underlying OM on the family, (2) the cues influencing parents to seek intervention, and (3) the parents' expectations of the health-care system. Each theme was comprised of several sub-themes (Table 2).

Theme 1: The Impact of the Child's Underlying OM on the Family

Disruption to the family's functioning. All parents spoke in detail of the impact the child's OM had on the family. Sleep deprivation impacted on parents' ability to work effectively and often resulted in lost income due to work absences to care for their child. These absences were financially compounded by paying for childcare, despite the child not attending as well as the costs of attending medical appointments and purchasing medications. In the most extreme cases, parents were asked to permanently remove their child from childcare due to repeated absence, while others left employment due to strained working relationships.

The child's OM caused significant changes to the family dynamic, with tension among family members being common. These tensions not only occurred between the child and

the parent, but also between the child and their siblings and between the parent and other household adults. Disruptions to social relationships with friends, extended family, and the wider community were also discussed. Social isolation and feeling unsupported were common, with parents describing their social network did not understand the extent of how OM impacted on the child and their family. All parents expressed worry and concern over the health of their child and the direct impact of the OM on the child's well-being and development. Furthermore, most parents described themselves as frustrated and stressed when discussing how the condition impacted on themselves.

Disruption to the well-being of the child. Children were not only affected physically but also emotionally and socially. Parents described a range of physical symptoms, most commonly pain and daytime somnolence, and observed altered behavior and mood, including aggression, depression, irritability, and inattention. Children expressed verbal and physical aggressive behavior toward siblings and other household members. Communication difficulties including mispronunciation, speech delays, and hearing impairments were the cause of frustration for both child and parent. Other symptoms commonly discussed were clumsiness and imbalance.

Adaptations and coping strategies. Parents had various coping strategies, including the modification of activities to compensate for the impact on the household. Increasing the television volume, liaison with teachers so children sat at the front of classroom, or spending time reading with the child were practical ways parents coped with hearing and speech issues. Adaptations to sleeping arrangements within the household included parents delegating caring based on employment responsibilities. Parents spoke of daytime napping to compensate for late nights spent caring for the child. Parents acknowledged the importance of spending dedicated time with other household members, including spending time with other children and their spouse. The result was a constant balancing act between caring for the child and their needs and spending time looking after themselves and the other household members.

Theme 2: The Cues Influencing Parents to Seek Intervention

Influence of health-care providers. Parents discussed the cyclic nature of infections and the limited treatment options. Over time, parents became frustrated and dissatisfied with repeated and prolonged antibiotic treatment. This frustration was amplified if the benefit was no longer apparent and included concern about the development of antibiotic resistance. Parents were not content with conservative management, had less confidence in the opinions of GPs, especially locums, and placed higher value on the opinion of a specialist ENT surgeon. When describing surgeons as "experts,"

Table 2. Themes and Subthemes.

Themes	Categorical Codes	Quotes
Theme 1: The impact on the family		
Disruption to the family's day-to-day functioning	Sleep deprivation	Childcare wouldn't take him anymore and so I had to take [him] out of that childcare and find somewhere else. (p10) It affects his sleep patterns because he's a very restless sleeper. (p23)
	Disruption to employment Disruption to mealtimes Altered social activities Strained family relationships	
Disruption to the physical, emotional, and social well-being of the child	Emotional and behavioral changes	I think her sisters probably don't understand when [she's] in pain from ear infections, and don't understand why [she] can't talk properly (p22) He mumbles and he basically he knows exactly what you're saying but it's like he is trying to get it out but he can't. (p26) We have to, you know, talk louder to him and then I spend a lot of one-on-one time with him reading books. (p23)
	Physical impact, pain, and weight loss	
	Absences from schooling Limitations on social activities	
Adaptions and coping strategies	Environmental changes	In this past year, she probably hasn't been sleeping still quite as well as what we sort of had expected, umm, and we have been working through with an occupational therapist balance and those type of things which has obviously helped a little bit. We're also gone to 'it take two to talk' course. (p22)
	Dietary alterations	
	Sleep pattern modification	
Theme 2: Cue to Seek Intervention		
Influence of health-care providers	Limited treatment options	When he gets sick or change the weather, like gets cold or runny nose he can't move and he want to sleep and he, we give him like a [sic] antibiotic or Panadol syrup or paracetamol (p56) Yeah, on antibiotics just too much trying to get rid of the infections the whole time. (p26)
	Dissatisfaction with conservative management General practitioners (GPs) vs surgeons	
Influence of family history	Medical history of parent influence decisions	I asked if he could do a referral to see [doctor] because [doctor] said to me last year because of the history of the other two kids he said that he'd most probably see them before they turned two and things because of them having the severe reflux and everything. (p21)
	Medical history of child influence decisions	
	Medical history and opinions of other family and friends	
Different family, different response	Response to condition differs from family to family	He's had to gone onto antibiotics which I hate, like I hate [putting people] on antibiotics, not good for them. (p24) Oh my goodness, too many too count. Way too many to count. He, it's been going on for nearly two years now and, like I said, [doctor] sees him at least once every fortnight, . . . on a lot of antibiotics. (p28)
Different doctor, different outcome	Inconsistencies in medical advice	Last year I suspected that he couldn't hear properly and, umm, I did take him to another GP and they didn't really do much about it, umm, and then when he started [kindergarten] his teacher, umm, started noticing that he couldn't hear quite as much as the other kids . . . I did take him to the doctor last year and, umm, I guess, then the doctor had said 'oh you know I just think he's a normal child saying "what?" all the time' and things like that so initially I wasn't very happy then because, I mean, I went away and thought 'well okay maybe he's right he's just being a normal child' and then looking back on it now, umm, you know, that this has all happened, you know, it sort of makes me a bit angry that he didn't take it more serious. (p23)
	Health-seeking behavior until receive expected treatment or referral	
Theme 3: Expectations of the health-care system		
Expectations of the appointment	Time between referral and appointment	The only thing that I had an issue with was when they were going on strike because my appointments got changed, . . . it was about, umm, 8 months . . . and the dates got changed. (p39) The waiting time is too long. It's sometimes, you'll be waiting to an hour maybe longer, an hour and a half with children and they can get a bit restless. (p11)
	Waiting time on the day of appointment	
	Time with the surgeon during consultation	
Expectations of the surgery	Surgery will cure the condition	I believe the doctors so, . . . we believe that this helps [him] to be, be like a normal kids (p56) It helps him to hear and, umm, he has no pain in his ears after he has it done. (p39)

(continued)

Table 2. (continued)

Themes	Categorical Codes	Quotes
Experiences of waiting	Waiting for general practitioner appointments	It took quite a few times of me screaming 'come on, please, his ears really aren't that good' so, but yeah, finally we got it. (p51)
	Waiting for treatment to be effective	Obviously I would prefer him get them done as soon as possible but I know the public system, you have to wait, so, I mean, I'm,
	Waiting for referral to a specialist	I'm just happy to know that he's obviously going to get that little bit of relief. (p28)
	Waiting in the clinic waiting room	
	Waiting for surgery	
The possibility of other options	Publicly funded versus private insurance	We do have private health insurance. I thought about doing it... but they said 'three months' and I was happy with that. (p51)
	Public system waiting times	The waiting list wasn't much different so I could've paid the money to go private but it would've been about the same wait. (p39)
	Surgery in another country	We thought of going to the private but our GP said it's not so, you can be like waiting can be done and if you feel like frustrated waiting for a long time we could go. My husband actually prefers me to go to India either to do, instead of doing it here (p59)

parents spoke of how they “know what they are talking about” regarding treatment options.

Influence of family history. Parents' past experiences influenced the urgency they placed on getting a referral from their GP. These included their own medical history, the medical history of their other children or spouse, and the opinions of trusted others. Perceived related family medical history or the potential to circumvent repeated episodes of disease were both influences on parents requesting surgical intervention. When their GP did not refer, parents sought referrals from elsewhere. Parents who had no prior experience with surgery were less open to acceptance of surgical intervention, with some seeking a second opinion before accepting surgery would be necessary.

Different families, different responses. While the children often had similar symptoms and diagnoses, families responded differently. The household dynamic, individual personalities, financial circumstances, and their coping strategies and ability to cope all influenced their response to their child's OM. Despite this, each parent described reaching a “tipping point,” where the equilibrium of caring for the child could no longer be balanced against the disruption to the family. At this point “enough was enough,” and more definitive treatment was requested. They spoke of having to convince their GPs to refer them to a specialist using words such as “fight,” “push,” and “demand.” The cue to seek intervention was underscored by parent stress, fatigue, and difficulty in the provision of ongoing care.

Different doctors, different outcomes. Most families attended 1 regular medical clinic but not always the same doctor. Parents spoke about inconsistencies in the medical opinions they received regarding their child's recurrent OM. Initially, they were accepting of the treatment plan recommended by

the GP; however, over time, they would seek alternative advice. When this occurred, they expressed dismay and anger the GP persisted with conservative management. Parents felt doctors did not appreciate their knowledge on the severity of the condition. When they did not get the desired outcome, parents would “shop around” and seek out a doctor that would refer for surgery.

Theme 3: The Parents' Expectations of the Health-Care System

Expectations of the appointment. The time between referral and appointment in the surgical clinic was deemed too long, with many parents recounting additional bouts of illness and absences from school/preschool during this time. However, parents were less bothered if they had an appointment booked soon after referral. Despite speaking about the time waiting in the clinic on the day of their appointment, parents expressed empathy with the other attendees and the workload of the staff. Parents spoke about the insufficient time spent with the surgeon during the consultation stating they felt “rushed” and the doctor did not spend “enough time” with the child. Typically, parents expected the outcome of the surgical consultation to be surgery. However, there were those surprised when their child needed surgery, mainly parents of children with OME who, despite acknowledging their child had hearing problems, often did not realize the severity of the condition.

Expectation of the surgery. All parents expected surgery to improve their child's quality of life. They believed the surgery would improve eating, sleeping, and hearing; the pain associated with the child's condition would be reduced, and the number and severity of episodes would decrease. Some parents believed surgery would cure their child and prevent any further episodes of illness. Parents based their

expectation of improvement in information provided by their doctors.

Experiences of waiting. Waiting was central to the experience of parents—for appointments, for treatments to work, for a referral, in the clinic waiting room, and, finally, for surgery. Parents were reluctant to wait for an appointment when it was difficult to see their regular GP, instead choosing to seek medical care from another doctor or clinic.

Parents expressed that GPs often did not appreciate the severity of the child's condition; they would have to demand a referral, and if it was not forthcoming, they would seek a second opinion. Many parents expressed disappointment when surgeons advised a "watch and wait" approach, since most already experienced this process with their GP. If the child did not have active infection at the time of the surgical consultation, parents felt they would wait longer for surgical intervention. When discussing waiting in the hospital clinic, the main concerns were about parking costs and keeping young children occupied. When children were added to the waiting list, parents were concerned at the projected length of wait for surgery and that the child's condition would continue or worsen in the interim. However, while many expressed disappointments with waiting for surgery, many conceded that waiting should be expected in the public health system.

Options available. Many parents considered the option of privately funded surgery; however, most were not in a financial situation to pursue this option. Some parents had previously had private health insurance but had canceled it due to the financial burdens of caring for their child. Others had not considered surgery in the private sector because they knew they would get treatment through the public system, despite having health insurance. Nonetheless, many would explore the option of privately funded surgery if they had to "wait too long," especially if the child's condition worsened during the waiting period.

Discussion and Conclusion

Discussion

Herein, this article reports the results of a cross-sectional, qualitative study involving interviews with parents of children booked to undergo tympanostomy tube insertion for the management of OM. The research has shown there are significant social and financial implications associated with caring for a child with recurrent OM. Disruptions to family functioning were practical, emotional, and social. For the children affected, OM caused a combination of lethargy, daytime somnolence, hearing impairment, imbalance, speech delays, and/or pain. These are all well-documented physical side effects of OM and are often considered when making the decision for surgical intervention (6,7,21,22). However, our findings also show OM has a severe impact

on parental emotional and social well-being. Work absences, financial burden, and sleepless nights due to caring for a sick child impacted on the overall harmony of the familial unit. These impacts have been shown to be consistent internationally. Parents from various countries, located across all continents, indicated their child's OM impacted on their sleep and resulted in parental workplace absences, leading to substantial financial impact on the family unit (14). In Malaysia, OM has been associated with a negative impact on the quality of life of parents with financial implications for both the patients and the society (23). Parents across Europe have reported having altered daily schedules and less leisure time due to their child's OM (24). Despite family disruption being a major issue for parents of children with OM, research from New York showed that in a retrospective review of medical records, medical practitioners attributed only 2.2% of tympanostomy tube insertions being due to severe disruption of the family life (25). Indeed, there are documented differences in the parental and medical practitioner perceptions of the intensity of OM as a health problem (26). However, the evidence demonstrates that OM has a greater social impact than the medical profession may acknowledge.

The heavy burden of OM for families is concerning and can often leave parents feeling helpless (14) and disempowered (27). Furthermore, as our findings show, the chronicity of OM can damage confidence in treatment efficacy and parental competency and create fear about impact on their child's development (27). Currently, the lack of Australian clinical guidelines for OM leaves medical practitioners reliant on guidelines published by international agencies (5,6,28) which clinicians interpret and apply in accordance with their own clinical judgement, leading to inconsistencies in care between medical practitioners. This can result in increased anxiety, confusion, and frustration among patients as was evident in this study. Parents expressed displeasure with "watchful waiting" and the requirement for a minimum number of episodes per year before a referral was provided. In other studies, parents have expressed eagerness for surgery for their child's recurrent throat infections (29), reluctance to wait for their child to "grow out of" their medical condition (30), and that as parents become more familiar with the health-care system, their confidence to negotiate for surgical intervention increases and they become more assertive (26).

Empowering parents early in the OM treatment journey may help alleviate much of the confusion and anxiety experienced when conservative management fails, and surgery is needed. In fact, research suggests 75% of parents wanted to be more involved in treatment decisions for their child's OM (31). The incorporation of best practice evidence and patient preferences into consultations, improving patient knowledge and patient-clinician communication, and the reduction in the use of inappropriate treatments can be achieved through shared decision-making (32). Better involvement of parents may avoid the decisional regret regarding treatment choices they have been shown to experience (33). To date, shared

decision-making research has focused on the provision of treatment information to parents. For example, research conducted by the Mayo Clinic will assess the use of decision aids to facilitate discussions on the disease trajectory and the treatment options available (34). This builds on research which has shown that while parents are often satisfied with the verbal provision of information during treatment consultations, they also want to receive supplementary printed information (35). The additional information most (93%) parents want to receive is OM symptomology and the risks and benefits of surgery (35,36). Furthermore, when information is not adequately provided by clinicians, parents turn to alternative sources of information. Mainly this includes friends and family (35), but up to 56.5% of parents use the Internet as their primary source of information (36).

Less research has focused on how “patient preferences” influence shared decision-making for childhood illnesses. Patient preferences for treatment are not just related to treatment information but also the experiences of patients with the illness and their experiences and expectations of the health-care system. Families’ interactions with the health-care system have been shown to influence their management decisions for their child’s OM (26). Empowering parents during consultations may also reduce the perception of feeling uninformed and reduce decisional conflict (32). Previous research has found parents’ opinions on OME treatment are influenced by differing perceptions of anticipated risks and benefits, with some parents thinking surgery is a simple fix, and others having concerns about possible physical consequences of surgery (37).

Study Limitations

Our research is limited by the inclusion of only those participants who had already made the decision for their child to undergo surgery. In addition, recruitment of participants occurred through the Women’s and Children’s Hospital—the main children’s hospital in the region and often a preferred choice regardless private health insurance status. Indeed, most of the study participants had opted for the surgery to be publicly funded. Therefore, it can be argued that the issues presented herein are only representative of those who do not have private health insurance and are managed in the public health system. Therefore, further investigation into the experiences of parents who choose not to pursue surgical intervention, or who choose to use private health insurance, will provide an additional layer of understanding that was outside the scope of this study. In addition, postsurgical outcomes and the long-term satisfaction of parents with their decision to pursue surgery for their child was not investigated. Future research should continue to use qualitative methods to explore these topics, thereby providing clinicians with a deeper understanding of the impact OM has on the broader family unit, during different stages of the clinical journey.

Conclusions

Unlike much of the previous research conducted on this topic, which has implemented quantitative methodology, the findings presented in this article were developed through qualitative methods. The findings support and complement other research in this field but provide an additional layer of deeper understanding on the way in which OM impacts on children and their family. A better understanding of parental experience leading to children with OM being listed for surgical intervention will equip clinicians with additional knowledge for their conversations with parents. However, continued research into methods of providing consistent and clear information during the decision-making process, as well as for how to empower families, is needed for this common, but often debilitating, childhood illness.

Appendix

- What has been happening with [child]?
- How do you feel about [child] going onto the surgical waiting list?
- How does [child’s] medical problems affect [child] usual activities?
- How does [child’s] medical problems affect [child] interaction in the family?
- How do you think the operation will help?
- How happy have you been with the service that you’ve received so far from the hospital?
- Before coming to the Women’s and Children’s Hospital, did you think about going to see a private specialist?
- How happy were you with the referral process from your general practitioners (GP) through to the hospital?
- Was it the GP’s decision or your decision to get [child] referred to the ENT clinic?
- Do you have any other comments?

Authors’ Note

J.H.S. designed the study, conducted data collection and analysis, and drafted and approved the manuscript. M.O.K. designed the study, conducted data analysis, and revised and approved the final manuscript. M.S. designed the study and revised and approved the final manuscript. P.A.B. designed the study and revised and approved the final manuscript. This is a qualitative study, and therefore the data generated are not suitable for sharing beyond that contained within the report. Further information can be obtained from the corresponding author. Women’s and Children’s Healthcare Network Human Research Ethics Committee.

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