‘We don't know what tomorrow will bring’: Parents' experiences of caring for a child with an undiagnosed genetic condition

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Abstract
Background: Families and healthcare professionals caring for a sick or disabled child without a definitive diagnosis face unique challenges, particularly in relation to managing uncertainty, access to healthcare and coordination of care. There has been little research exploring the impact this has on families, their support needs or their experience of health services.

Methods: This qualitative interview study included interviews with 14 mothers of children with undiagnosed genetic conditions. Transcripts were analysed using thematic analysis.

Results: Four themes emerged, uncovering overlapping patterns in the data: (1) living with complexity amidst uncertainty—‘We don’t know what tomorrow will bring’; (2) parental role—‘I do everything I can’; (3) parental role—‘Not coping is not an option’; and (4) support needs—‘There’s lots of help that just isn’t out there’.

Conclusions: The results clearly demonstrate the stresses faced when caring for a child with an undiagnosed genetic condition. Some themes are shared with the experience of other families caring for children with complex needs. However, parents were doing all they could for their child in the context of a life of uncertainty, with the absence of a clear diagnosis clearly causing additional stress that impacted on the whole family. Impact on their emotional and physical well-being was evident; they described times of feeling stressed, worried and anxious. They were confused due to being overloaded with information and frustrated by a lack of care coordination. Parents did not appear to prioritize their own well-being and held back their emotions to protect themselves and others. As a result, they had many unmet needs, particularly relating to emotional support.

Keywords
child disability, genetics, parent, qualitative research methods
1 | INTRODUCTION

Around 6000 children are born every year in the United Kingdom with a syndrome that does not have a name (All Party Parliamentary Group [APPG] on Rare, Genetic and Undiagnosed Conditions, 2016). About half of children with learning disabilities and approximately 60% of children with multiple congenital problems do not have a definitive diagnosis to explain the cause of their condition (APPG on Rare, Genetic and Undiagnosed Conditions, 2016). Although progress continues to be made in the field of genetics, the majority of families who enter a genomic sequencing project will wait years to receive a diagnosis, with some waiting for one which will never come, or receive a result that is ambiguous (Mollison et al., 2020) or incorrect. For example, 79% of the respondents of the 2016 SWAN ( Syndromes Without A Name) UK charity members’ survey stated that they had children who were participating in genetic research studies, but only 12% of those had received a diagnosis (APPG on Rare, Genetic and Undiagnosed Conditions, 2016). Whilst searching for a diagnosis, families may see numerous professionals, across different specialties and hospitals (Rare Disease UK, 2016). The absence of a clear diagnosis presents unique challenges for families and health services particularly in relation to managing uncertainty (Macnamara et al., 2019), access to healthcare (Baumbusch et al., 2019) and coordination of care (Currie & Szabo, 2019a). There has been little previous research focusing upon the impact of having a child with an undiagnosed genetic condition on families, the support families require and how they experience health services.

The limited research in this area has already highlighted the emotional impact of not having a diagnosis. Parents in Spillmann et al.’s (2017) study reported feelings of frustration and worry that something relevant to their child’s management was being overlooked due to them being undiagnosed. Patients and parents have reported not feeling in control of their situation and describe feeling isolated and uncertain about what the future holds (Rare Disease UK, 2016). Furthermore, parents who experience greater uncertainty have been described as feeling less in control over their child’s medical condition, which may in turn lead to less effective coping and poorer adaptation (Madeo et al., 2012). Conversely, McConkie-Rosell et al. (2018) suggest that parents of children with undiagnosed conditions maintain positive coping self-efficacy and are more tolerant of uncertainty; however, this came at a high emotional cost to them, with at least a third experiencing depressive symptoms and anxiety.

The absence of a diagnosis has been identified as a significant barrier to accessing coordinated care and appropriate treatment (Rare Disease UK, 2016). Effective coordination of care is particularly important for patients with multiple health problems, given that they are likely to be seen by different specialty teams, possibly across different clinic locations. Care may be poorly coordinated and fragmented, leaving patients and families feeling lost within the healthcare system, repeatedly having to recount their story to professionals who may know little about their child’s condition, and not knowing who to turn to to have their questions answered, or for information (Baumbusch et al., 2019; Rare Disease UK, 2013). There can also be significant financial and social consequences for patients and their families, attending multiple clinics and appointments, travelling long distances and missing school or work as a result (Rare Disease UK, 2013). Coordination and communication between doctors and various agencies was one of the biggest challenges families faced (Genetic Alliance UK, 2018). Despite coordination of care being previously identified as a key priority for improving services for patients with rare diseases and their families (Department of Health, 2013), there has been a resultant lack of action, with patient care continuing to be poorly coordinated (APPG on Rare, Genetic and Undiagnosed Conditions, 2017).

As part of a wider evaluation of the role of a newly appointed clinical nurse specialist to support families who have a child with an undiagnosed genetic condition, interviews with parents were undertaken to explore their needs and experiences prior to receiving this support. These findings are the focus of this paper. The use of co-design with key stakeholders, including families, to influence the nature of the role and how it was implemented in practice has been described elsewhere (Oulton et al., 2020).

1.1 | Aim

This study aimed to explore parents’ needs and experiences of caring for their child with an undiagnosed genetic condition.

2 | METHODS

2.1 | Design

We utilized a qualitative approach with semi-structured interviews.
2.2 | Recruitment of participants

The participants (n = 14) were recruited from a larger study evaluating the role of a nurse specialist to support families who had a child with an undiagnosed genetic condition. Every family (n = 75) seen by the nurse specialist between May 2016 and July 2018 received information about the evaluation and a baseline questionnaire. Questionnaires were returned by post to the evaluation team, and contact details for parents who had indicated on their questionnaire (n = 19) that they were interested in participating in an interview were passed on to the research team. The researcher contacted the families by text message to arrange a convenient time to speak. A follow-up message was sent a week later to anyone who had not responded.

2.3 | Interviews

Two researchers (S. A. and A. W.) conducted the interviews, both with prior experience of interviewing parents of children with long-term health conditions. The semi-structured interview schedule comprised broad, open-ended questions that explored the parents’ views, including experiences of services, their perceived needs, the impact of having a child with an undiagnosed condition on themselves and their family and the way they managed day-to-day life. Examples of questions included: ‘Can you tell me a bit more about your greatest sources of stress at the moment?’; ‘What areas of need do you and your child have?’ and ‘What is your current experience of services at (hospital name)?’ Interviews were audio-recorded with permission. Parents were given the option of being interviewed over the telephone or face to face, at home or at the hospital.

2.4 | Ethical considerations

The study was approved as a service evaluation by the NHS Hospital Trust. Written consent was obtained from each participant, and consent was discussed prior to the start of each interview.

2.5 | Data analysis

Audio recordings of interviews were transcribed verbatim. Thematic analysis (Coffey & Atkinson, 1996) was used as it retains closeness to data from the interviews and enables categories, which represent participants’ perceptions, to emerge in a systematic way. Analysis was undertaken by three members of the research team (S. A., F. G. and K. O.). The transcripts were read many times allowing for familiarization with the data, whilst obtaining a general sense of the whole story. Relevant comments were highlighted within the text, and annotations were written in the margins. The highlighted comments (or summaries of the comments) were grouped into meaning units. These meaning units were condensed, and each was labelled with a code. Agreement and understanding were gauged during discussions until consensus was reached; there were few discrepancies.

3 | RESULTS

Fourteen parents (all mothers) were interviewed within the first 6 months of receiving support from the nurse. Each had a child with an undiagnosed genetic condition aged between 14 months and 8 years at the time of the interview. Interviews were conducted at the participants’ home (n = 3), at the hospital (n = 3) and by telephone (n = 8). Interviews lasted between 25 min and 1 h and 40 min.

Parents spoke in-depth about what being the parent of a child with an undiagnosed genetic condition was like; they described the impact on their lives and their needs. Inevitably, in these accounts, there are many similarities with parents caring for a child with a complex condition, because this is exactly what parents were describing, caring for a child who had a complex condition. It is the significance of a diagnosis for legitimizing illness, a concept already described (Jutel, 2009), that underlies these stories from parents. Diagnosis matters, the absence of which leaves families without a road map to help them navigate services. Without a ‘diagnostic label’, as is recounted here, parents continue to search for something that is missing and reflect on how the ‘missing label’ impacts on their lives and reduces their access to services and support that meets their needs. Four themes capture these accounts, uncovering overlapping patterns in the data.

3.1 | Living with complexity amidst uncertainty—‘We don’t know what tomorrow will bring’

Uncertainty was central to all parents’ accounts of what life was like having a child with an undiagnosed condition. Whereas a few parents had had some indication antenatally that their child may have a health condition, most had not expected their child to have any problems. They were therefore unprepared for the complexity and number of different health issues their child had following the birth, describing the ‘problems’ coming one after another.

One mother compared her own experience of uncertainty with that of a family member with a diagnosed health condition:

I’ve got a nephew that has Down’s syndrome, so at birth it was a very big shock, but they knew which direction they’re going in. With us, it’s constantly, either we’re finding out new thing, and it’s all that difficulty and doubt. What’s wrong with this child? We don’t know what tomorrow will bring. (Participant 6)

Having multiple and diverse co-morbidities necessitated input from many different specialists; parents described seeing numerous clinical teams based within different hospitals and services:
She's not really under one specialist, that's, really, the thing, I can say, that we're not in the team of neurology... because she's got a neurological condition, and she's got a hearing impairment, and her vision is delayed, so there are so many global things. (Participant 6)

Frequent appointments and tests were common and time consuming for families as often they lived far from the specialist hospitals. They expressed feeling ‘bombarded’ (Participant 8) by these, as well as overwhelmed by information and meeting so many different professionals. This experience was extremely stressful, confusing and frightening for parents:

Things were coming one after the other, you know, and they were finding some problems, so that was very terrifying for me, and there was lots of prognosis of what's going to happen as well, which wasn't nice. First half year, I was constantly stressed and, you know, worried because I didn't know what was going to happen. (Participant 11)

Another parent starkly described feeling that her child was ‘being hunted’ and whilst she had good days, there are also ‘moments of absolute blind panic, terror’ (Participant 10).

At first, the mothers presumed the tests and referrals to different teams would provide answers about their child’s health condition and were frustrated that these answers were not forthcoming. However, as time went on, they came to accept that their child might never receive a final clinical diagnosis:

This is right at the beginning of our journey, so at that point I was still in a place, I'm probably in a different place now, but I was still expecting answers and expecting people to do tests and be able to tell me what was wrong. (Participant 2)

Not having a diagnosis also made the future uncertain for all of these families. A diagnosis was seen to enable families to compare their child to other children with the same condition, providing an idea of prognosis and what to expect, for example, to begin to anticipate symptoms and how they might be managed:

To have a syndrome without a name is to be constantly on the back foot, not knowing what's going to happen next. Not knowing how to treat. Actually, that's quite scary. (Participant 3)

We don't know what's a side-effect and what's a symptom because there is not a single other child we can go, 'Oh, this is what happens.' (Participant 1)

Furthermore, some of the children's health conditions were known to be life limiting, yet not having a clear diagnosis left parents unsure about just what that meant for their child in terms of their life expectancy:

The doctors just occasionally, kind of, throw a diagnosis into the ring and say, 'It could be this, it could be that.' One of the diagnoses that they were thinking maybe it could be had a very, very awful prognosis, and the general life expectancy was two or three years. (Participant 2)

Such uncertainty surrounding their child's prognosis meant that when their child was unwell, parents were often anxious about whether it was a minor illness or something more serious:

I think that's the bit that I find hardest, is the not knowing when something's minor and major and not knowing, when (child's name) says, 'I'm in pain, my tummy hurts,' is that just something that's going to pass or is that something that is going to become something bigger? That's the bit that I think is the hardest in this. (Participant 2)

However, faced with an uncertain future, parents focused on living 1 day at a time rather than looking too far ahead. One parent continued to work to provide a different focus for them outside of caring for their child; however, most mothers did not work; many described being unable to due to the demands of caring for their child. This could have financial implications; one parent described having to move to an area where houses were more affordable. Maintaining a positive outlook was important, with many parents describing themselves as ‘lucky’ in comparison with others. These parents focused on the good things in their lives and compared themselves with others who they perceived as less fortunate than themselves.

Living with a constant sense of ‘not knowing’ was a significant and challenging aspect of the parental experience that, as described in the following section, infiltrated into every aspect of life.

### 3.2 Parental role—‘I do everything I can’

Mothers all described having a strong maternal role, undertaking the main caring responsibilities for their children and becoming the experts on their needs and care, often because their partners were working. Caring for their child was often extremely demanding, taking up all of their time. They had to manage and balance risks to their child whilst still allowing them to experience childhood and have fun. They saw their sole purpose as caring for their child, keeping them safe and protecting them; this meant being constantly vigilant. They were faced with making decisions and undertaking tasks beyond their expertise; one parent spoke about needing a ‘legal degree and an engineering degree to put his equipment together and to figure out what you're meant to be doing at any given time’ (Participant 1).
Mothers used words such as ‘battling’ and ‘fight’ (Participant 1) to describe their struggle to get the services their child needed; this included local community services and appropriate educational provision. Although a few children had recently been referred to a paediatrician who would take on a care coordination role, for others, it was the parents who were expected to fulfil this role, which was demanding and time consuming:

We come into contact with just shy of 40 professionals actually across the board in various ways, and they were totally stuck so under the title of lead professional they put my name. I was like, ‘Well this is rather telling.’ (Participant 1)

Clinic letters, reports and test results were often not passed between teams, so parents took on this responsibility, trying to keep everyone involved in their child's care informed and up to date:

There’s so just many different people involved, and nobody was really joining any of those dots in a way that made me feel really-, I still do to an extent, but I felt like it was all on me to keep everybody in the loop. I spend a lot of time photocopying notes and handing them to people, and emailing them across. (Participant 2)

One parent showed the researcher a huge folder containing all her child’s health-related information, clinic letters and reports that she took to appointments in case that information was needed. Another parent described how she presumed keeping everyone informed was part of her role as a mother. Most mothers subsequently described how, at times, they had felt overloaded with information, which left them confused.

Parents valued being given clear information and appreciated professionals taking the time to provide careful explanations; however, this did not always happen. Parents were sometimes unsure who to ask for an explanation or where to go for reliable information, resulting in searching the internet and finding information that was sometimes more worrying, inaccurate or even describing a poorer prognosis for their child than they had been given. For example, one parent had Googled ‘problems with muscles’, and the results revealed that this was ‘life threatening’ (Participant 11). Over time, parents learnt to use medical terminology; however, this did not always mean that they understood what it meant:

I think people think I understand more than I do. I was asking him (anaesthetist) questions and he was like, ‘Have you got a medical background?’ and I’m like, ‘No, I don’t. I’ve been reading a lot, that’s why you might think that.’ I felt like I kind of just went into this mould of, I need to become a doctor at home. (Participant 8)

Unmet communication needs were exacerbated due to the number of clinical teams families were interacting with, leaving parents often unsure as to who was the most appropriate professional to contact about particular health issues. Parents also described being reluctant to contact professionals as they did not want to ‘bother’ them, and this left them with unresolved worries about their child:

I just didn’t really know who to turn to or where to go because we’ve got so many different teams and none of them have bowel as a speciality. It could have been nothing, or it could have been something, and I, kind of, was just flipping out a little bit in my own head of, I don’t know who I’m supposed to talk to, I don’t know who I’m meant to talk to. (Participant 2)

3.3 Parental role—‘Not coping is not an option’

The uncertainty of living with a child with an undiagnosed condition impacted on the emotional and physical well-being of parents and all aspects of family life, putting stress on family relationships and leaving parents with less time for their other children. This impact was further exacerbated by the family’s situation and any issues they were already faced with, such as a parent having a long-term health condition themselves, pregnancy, multiple siblings and being a single parent.

Parents subsequently described times of feeling extremely stressed, worried, anxious and helpless. For some, the stress was ongoing, whilst others had periods of calm, with stress linked to their child being unwell or receiving bad news about their child’s prognosis. Although a few mothers were receiving therapy or counselling, overall parents reported a lack of formal emotional support available. Despite parents’ sharing their feelings during the interviews, they reported a tendency not to discuss their feelings with others; one mother, for example, described ‘shutting down’ and not allowing her emotions to surface:

... for me, I don’t want to talk about, because I don’t want to hear the words of where I know this could go. I don’t want to say it because talking about it isn’t going to change it. (Participant 10)

Holding back emotions was not only about protecting themselves but also about protecting others and not wanting to upset other people:

I find it hard to talk to people who were invested in it, because [child’s name]’s their grandchild, or my brother’s niece. I find it tricky to talk to people about what’s going on for her because I don’t want to put anymore burden on them. As much as I want to talk to people about it, I don’t want to make them feel any worse about anything, and some of it’s really hard to take. (Participant 2)
It was evident that parents always put their child’s needs before their own; they felt they had to be ‘strong’ and just get on with things:

You have to be really strong as a parent for your child and if you’re going to be there sobbing like a boring person, then it’s not really going to help in your day-to-day life. (Participant 8)

It was also important for mothers to feel like they were ‘coping’; ‘not coping’ was not an option:

You’ve got so much going on with your child, it’s really stressful. Everyone will say, ‘How do you deal with it all, (parent name)? How do you deal with it all?’ and it’s, like, ‘Well, you just do.’ (Participant 4)

The impact on parents of always seeming to cope was that they could feel alone and isolated; support mainly came from their partner and sometimes from their extended family, and going out could be difficult due to their child’s health.

3.4 | Support needs—‘There’s lots of help that just isn’t out there’

Mothers had many unmet needs. This included emotional support for them and their close family and practical support. One particular cause of frustration was the lack of a holistic overview of their child and family:

... the focus has always been very much on (child’s name), how’s her rash, how’s her movement, what’s the latest test? It has been very, academic is the wrong word, but very just going through the motions ... I can’t remember speaking to a health professional who stopped and said, ‘How are you doing? How is this for you?’ (Participant 2)

Parents did not always know what services were available, how to access them or what they should ask for. The complexity of their child’s condition and the lack of diagnosis meant that they did not ‘fit’ easily into any one service. This had sometimes led to a lack of support for the family as they ‘fell straight through the cracks’ (Participant 1), leaving parents to manage things themselves. This was further complicated by their own needs and those of their child being unpredictable and often changing from day to day, with ‘ad hoc needs at ad hoc times’ (Participant 10).

Parents wanted practical information to be available, and they wanted to have systems in place so that they could draw upon the experiences of other parents who have a child with a disability:

Different things like car seats or even pushchairs or day-to-day things that you need, like a ‘sippy’ cup and, you know, just different spoons. It sounds like really basic things but really, I’ve been through so many of them to finally find one spoon. (Participant 8)

Although social media provided one way of mothers connecting with other families with a child with an undiagnosed condition, some mentioned they would have welcomed a parent support group so they could meet other parents with children with undiagnosed conditions.

Most of the families had experienced a lack of coordination in their child’s care. Information was not shared between departments even within the same hospital, leaving parents frustrated at the lack of ‘joined up’ care (Participant 10). Sometimes miscommunication had occurred; this had led to one child having their surgery cancelled at short notice. Parents were left to take on a coordination role, passing information between teams and professionals. Appointments were not coordinated, resulting in families experiencing frequent and multiple hospital attendances causing significant disruption to family life, as this parent explains:

So, appointments are not coordinated, so they are on random days of the week, of course that for me means taking time off work every time. We had one recently where I got back from genetics at 8:00 pm, turned around to drive back to go to gastro at 6:00 am the next morning, because no one seems to have the same information on us as well, and different teams seem to have different information. (Participant 1)

The appointments were also at inconvenient times, particularly for families who lived far from the hospital; rearranging them was not always straightforward and could leave families waiting months for another appointment. A key worker role, someone ‘inside the NHS’ who could ‘get hold of the right people’ (Participant 8), would have helped to streamline care for families:

I think it would lead to an increased sense of reassurance to know that there is a point of contact as well, particularly if we did have an emergency or did become suddenly inpatient, somebody who has that overview. (Participant 8)

Parents felt this type of support would have been of particular benefit at first when they were feeling overwhelmed, unsure about who to contact and learning how to navigate services.

4 | DISCUSSION

This study aimed to gain a deeper understanding of parents’ experiences of caring for their child with an undiagnosed genetic condition,
the impact on their lives and their needs. The parents in this study described doing everything they could for their child in the context of a life of uncertainty and complexity. Similar to other studies, and studies involving parents of children with a rare disease, we heard mothers speak of their isolation, but also their determination to do everything for their child, becoming the ‘expert’ in their child’s care (Currie & Szabo, 2019a, 2019b). Consistently, we heard how a mother’s sense of love and devotion for their child, a sense of duty and a lack of choice all contributed to leading them to just ‘get on with it’, similar to findings reported by Courtney et al. (2018) and Oulton and Heyman (2009). Navigating key activities in the healthcare system, receiving inadequate information and poor care coordination, described here, parallels a small but growing body of research focusing on children with a rare disease (Baumbusch et al., 2019).

What differs for the mothers in our study, noted earlier by Graungaard and Skov (2007), is how their experiences are underpinned by continuing diagnostic uncertainty, searching for certainty, not knowing which services would help their child the most, feelings of isolation and being unable to share their stories with other parents as they have ‘no name’ for their child’s medical condition.

The influence of this searching and living with uncertainty had an impact on parents and the extended family. Mothers spoke of the physical and emotional challenges of caring for their child, leaving no time for themselves, having to cope by continually focusing on the positive. Life for everyone was uncertain and unpredictable, leading to many ‘strains’—financial, emotional and physical. They described times of feeling extremely stressed, worried, and anxious.

The healthcare system seemingly failed to relieve any of their uncertainties; at times this merely led to more stress. Some described being faced with misinformation, information overload or inadequate information, leading to many parents undertaking their own research from different sources (Barton et al., 2019).

The emotional burden of searching for answers, frustration with a lack of diagnosis and the helplessness of being unable to improve their child’s quality of life, was evident across the mothers’ narratives. Emotional support was an unmet need for these parents; some had support within their family, but others did not want to ‘burden’ other people or found others did not understand. Parents of children with a rare disease reported worrying about how their child affects their mental health, but they are rarely asked by professionals about this impact (Rare Disease UK, 2018). For parents of children without a diagnosis, accessing appropriate support is often challenging as the absence of a diagnosis can hinder the identification of appropriate support services. Parents have previously expressed frustration over difficulties accessing social support, with many believing it would be more accessible if their child had a medical diagnosis (Lewis et al., 2010).

For families with rare diseases and new syndromes, social networking has been described as a valuable strategy; identifying and communicating with families with the same syndrome or similar phenotype has been described as extremely helpful (Inglese et al., 2019). Where there is no diagnosis, isolation is felt more powerfully. Connecting parents with additional resources, or identifying a key worker/navigator, is increasingly being described (Ogourtsova et al., 2019). The importance of care coordinators is well established; indeed, Lewis et al. (2010) found that parents who had access to professional support had a less traumatic experience accessing services than those who did not. Many of the families in this study had not previously had a lead professional to coordinate their child’s care; subsequently, it fell to the mother to take on this role. This was time consuming and stressful, with these mothers having to learn how to navigate health and care systems. In the future, the newly appointed nurse specialist would help to navigate these systems to provide more coordinated care for these families along with emotional and practical support. A further publication is planned to report on the impact this role had for families receiving care from this nurse.

4.1 | Limitations

There are some limitations of this study that should be considered. Participants were recruited through a single service provider, which may limit the generalizability of these findings. In addition, these findings are based on the experiences of mothers; it is important to also consider the importance of fathers’ experiences, which may be different. We acknowledge that some of the themes cannot be explained solely by the fact that these children did not have a diagnosis; some would be described by parents of children with complex needs who do have a diagnosis. However, it is clear that the lack of diagnosis raises unique issues that adds to the challenges faced by other groups of parents.

5 | CONCLUSION

During these interviews, parents revealed in considerable depth their experience of parenting a child with an undiagnosed genetic condition, the subsequent impact and their associated needs. They spoke about doing everything they could for their child in the context of a life of uncertainty and complexity. Impact on the emotional and physical well-being of parents was evident. They described times of feeling extremely stressed, worried and anxious, which was sometimes unremitting, as well as feeling confused as a result of being overloaded with information and frustrated by a lack of care coordination. Parents described not having the time to prioritize their own well-being, instead holding back their emotions to protect themselves and others; they coped as it was important they did so for their child, not coping was not an option. As a result, parents had many unmet needs, particularly the need for emotional support, where the absence of a diagnosis meant that families were constantly trying to find their ‘best fit’, a diagnostic place, which legitimized their access to support and services that might reduce their isolation.

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AUTHOR CONTRIBUTIONS
This was a collaborative study involving all of these authors: Susie Aldiss collected the data, analysed and interpreted the data, drafted and revised the article and did the final approval. Prof. Faith Gibson contributed to the design, data analysis and interpretation, drafted and revised the article and did the final approval. Sophie Geoghegan analysed and interpreted the data, revised the article and did the final approval. Anna Jewitt interpreted the data, revised the article and did the final approval. Tara Kerr Elliott analysed and interpreted the data, revised the article and did the final approval. Dr. Anna Williams analysed and interpreted the data, revised the article and did the final approval. Dr. Jo Wray contributed to the design, data analysis and interpretation, drafted and revised the article and did the final approval. Dr. Kate Oulton conceived the study, contributed to the design, acquisition of data, data analysis and interpretation, drafted and revised the article and did the final approval.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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