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ACCEPTED FOR PUBLICATION IN JOURNAL OF FAMILY NURSING

Parent Experiences and Preferences when Dysemelia is Identified During the Prenatal and Perinatal Periods: A Qualitative Study into Family Nursing Care for Rare Diseases

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Keywords: family-centered care, communication, dysmelia, rare diseases, parents, family nursing

Biographical Paragraphs

Judith Johnson, PhD, ClinPsyD, is a clinical psychologist and lecturer at the School of Psychology, University of Leeds and Lecturer at the Bradford Institute for Health Research, Bradford Royal Infirmary, United Kingdom. She is interested in understanding how healthcare professionals can be trained and supported to provide a better experience of healthcare to patients and their families. She has a particular interest in the role of communication in this context. She is also interested in healthcare staff wellbeing and interventions which can support this, including resilience training. Recent publications include:

Johnson, J., & Panagioti, M. (in press). Interventions to improve the breaking of bad or difficult news by physicians: A systematic review and meta-analysis. *Academic Medicine*.

Johnson, J., Hall, L. H., Berzins, K., Baker, J., Melling, K., & Thompson, C. (2018). Mental healthcare staff well-being and burnout: A narrative review of trends, causes, implications, and recommendations for future interventions. *International Journal of Mental Health Nursing*, 27, 20–32. doi: 10.1111.imn.12416

Johnson, J., Adams-Spink, G., Arndt, T., Wijeratne, D., Heyhoe, J., & Taylor, P. (2016). Providing family-centered care for rare diseases in maternity services: Parent satisfaction and preferences when screening identifies dysmelia. *Women and Birth*, 29(6), e99–e104. doi: 10.1016/j.wombi.2016.04.007

Olivia Johnson, BSc(Hons), is a support worker at Cygnet Hospital Bury in Greater Manchester, United Kingdom. Her research and clinical interests focus on mental health, with a particular emphasis on the relationship between mental health and offending behavior. Recent publications include:

Heyhoe, J., Reynolds, C., Dunning, A., Johnson, O., Howat, A., & Lawton, R. (2018). Patient involvement in diagnosing cancer in primary care: A systematic review of current interventions. *British Journal of General Practice*, 68(668), e211-e224. doi: 10.3399/bjgp18X695045

Johnson, J., Louch, G., Dunning, A., Johnson, O., Grange, A., Reynolds, C.,...O'Hara, J. (2017). Burnout mediates the association between depression and patient safety perceptions: a cross-sectional study in hospital nurses. *Journal of Advanced Nursing*, 73(7), 1667-1680. doi: 10.1111/jan.13251

Jane Heyhoe, PhD, is a Senior Research Fellow at the Bradford Institute for Health Research, Bradford Royal Infirmary, United Kingdom. She has particular interests in developing strategies to assist and improve diagnosis across a range of clinical contexts and settings and in the role of cognition and emotion in clinical judgement. Recent publications include:

Johnson, J., Adams-Spink, G., Arndt, T., Wijeratne, D., Heyhoe, J., & Taylor, P. (2016). Providing family-centered care for rare diseases in maternity services: Parent satisfaction and preferences when screening identifies dysmelia. *Women and Birth*, 29(6), e99–e104. doi: 10.1016/j.wombi.2016.04.007

Heyhoe, J., Birks, Y., Harrison, R., O'Hara, J. K., Cracknell, A., & Lawton, R. (2016). The role of emotion in patient safety: Are we brave enough to scratch beneath the surface? *Journal of the Royal Society of Medicine*, 109, 52-58. doi: 10.1177/0141076815620614

Charlotte Fielder was born with a shortened forearm and a missing hand and considers herself informed by her disability rather than defined by it. In 2012, she was appointed to the board of EDRIC (The European Dysmelia Reference Information Centre) an umbrella organization which brings together limb difference groups and those affected by congenital limb loss. After two years as a director, she stood down and was invited back as EDRIC patron. She is the author of 'Shared Experiences' written for families affected by upper limb difference with proceeds going to UK based charity Reach. She joined Battersea Dogs and Cats Home in July 2015 heading the Volunteering and Fostering Department. She sits as an Assembly Member at NCVO (National Council For Voluntary Organisations).

Alice Dunning, BSc(Hons), is a doctoral student at School of Psychology, University of Leeds and the Bradford Institute for Health Research, Bradford Royal Infirmary, United Kingdom. She is interested in levels of wellbeing among healthcare professionals and how this may be supported through interventions. Recent publications include:

Heyhoe, J., Reynolds, C., Dunning, A., Johnson, O., Howat, A., & Lawton, R. (2018). Patient involvement in diagnosing cancer in primary care: A systematic review of current interventions. *British Journal of General Practice*, 68(668), e211-e224. doi: 10.3399/bjgp18X695045

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Abstract

Several rare diseases are regularly identified during the prenatal and perinatal periods, including dysmelia. How these are communicated to parents has a marked emotional impact, but minimal research has investigated this. The purpose of this study was to explore parent experiences and preferences when their baby was diagnosed with dysmelia. Twenty mothers and fathers were interviewed. Data was analyzed using thematic analysis. The overriding emotion parents experienced was shock, but the extent of this was influenced by several factors including their previous experience of disability. Four key needs of parents were identified, including the need for signposting to peer support organizations, for information, for sensitive communication, and for a plan regarding their child's care. Parents wanted immediate information provision and signposting to peer support, and for discussions regarding possible causes of the dysmelia or termination (in the case of prenatal identification) to be delayed until they had processed the news.

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Declaration of Conflicting Interests: The authors declare that there is no conflict of interest.

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Introduction

Rare diseases are defined as those which affect less than 1 in 2000 people (Eurodis, 2014). However, between 5000 and 8000 rare diseases exist (Eurodis, 2014) and it is estimated that 1 in 17 people will be affected by one of these during their lifetime (RareDiseaseUK, 2017). Several rare diseases including Fragile X, Duchenne Muscular Dystrophy, Phenylketonuria, and congenital hypothyroidism are regularly identified during the prenatal and perinatal periods. Depending upon the type of disease, these can be diagnosed via prenatal testing or may be identified in the postnatal period via newborn blood spot screening or clinical observations.

Dysmelia is group of rare diseases where the distinguishing feature is congenital limb reductions, which is regularly identified during the prenatal and perinatal periods. Dysmelia occurs in 6-8 in 10,000 births (Gold, Westgate, & Holmes, 2011; McGuirk, Westgate, & Holmes, 2001) and is diagnosed by ultrasound scan in around 30-50% of cases (Holder-Espinasse et al., 2004; Johnson et al., 2016). Most individuals with dysmelia have only one only affected limb; upper limb differences are more common than lower limb differences and the pattern of the limb deficiency is not usually symmetrical (McGuirk et al., 2001). In rare cases there is a complete absence of a limb; more commonly part of a limb or the digits are affected (Gold et al., 2011). Caring for a child with a limb difference may require families to make practical adaptations, for example considering prostheses or adapted furniture, cutlery, or other specialized equipment. It can also carry an emotional and psychological impact, and feelings of isolation are common (Kerr & McIntosh, 2000). While the genetic contribution to some rare diseases is clear, the causes of dysmelia are heterogeneous, including fetal constraint, vascular disruption, chromosome abnormalities, and teratogens (e.g., Thalidomide) (Chen, 2006).

Parent experiences of healthcare provision and staff communication when any fetal anomaly or birth defect is identified can have a profound emotional impact, with negative experiences contributing to heightened stress (Askelsdóttir, Conroy, & Rempel, 2008; Fleming, Knafl, & Van Riper, 2017). Parent preferences for care at this time include the use of clear but sensitive language by healthcare providers (Asplin, Wessel, Marions, & Öhman, 2012; Lalor, Devane, & Begley, 2007); receiving verbal and written information about the abnormality (Alkazaleh et al., 2004; Asplin et al., 2012; Lalor, Begley, & Galavan, 2008); and experiencing minimal delays between identification of the initial problem and the communication of this to parents (Alkazaleh et al., 2004). However, services often fail to deliver this and parents frequently report experiencing delays (Askelsdóttir et al., 2008; Mitchell, 2004; Van der Zalm & Byrne, 2006); confusing information (Asplin et al., 2012; Oscarsson, Gottvall, & Swahnberg, 2015); insensitive language from staff (Fleming et al., 2017; Mitchell, 2004); and feeling unsupported (McKechnie, Pridham, & Tluczek, 2016).

The majority of research into parent experiences of diagnosis during the prenatal and perinatal periods has focused on abnormalities which occur more commonly, and there is a lack of research into experiences of rare disease diagnosis. Understanding this is important as communicating news of a rare disease can be particularly challenging; specialist knowledge about these abnormalities is rarely available in local services and healthcare providers may struggle to know how to communicate a diagnosis which they feel under-informed about (Andrews, Williams, VandeCreek, & Allen, 2009). This can cause anxiety in healthcare providers (Simpson & Bor, 2001) and amplify parental stress (Andrews et al., 2009). It can also hinder parental decision making and care-giving. In the case of dysmelia, prenatal identification may require expectant parents to make life-changing decisions around whether to receive invasive testing or a termination, and 20-50% of pregnancies where dysmelia is identified are terminated (Gold et al., 2011; Holder-Espinasse et al., 2004; McGuirk et al.,

2001). Postnatal identification requires parents to provide appropriate care for a child with a disability without any time for information gathering or preparation. Improving healthcare provision at the point of diagnosis is of key importance to ensuring parents are supported with these challenges, but minimal research has investigated this.

Of the studies which have been conducted in parents of children with dysmelia, it is clear peer support groups are highly valued and parents appreciate being given contact information for these organizations, or 'signposted' to them (Johnson et al., 2016; Kerr & McIntosh, 2000). However, no study has provided an in-depth understanding of parents' initial experiences and preferences for communication of a dysmelia diagnosis, whether these vary when diagnosis is made in prenatal services compared to postnatal services, and whether fathers describe different experiences and preferences to mothers. Such information is imperative for family nurses working with childbearing families; it can help nurses anticipate stressors these families and families receiving other rare diagnoses may experience, and enable the identification of resources which may be beneficial for them (Veltri, Wilson-Mitchell, & Bell, 2015). It can also inform the practice of family nurses involved in the communication of rare diagnoses or the facilitation of therapeutic conversations in this context to support and promote family relationships (Bell, 2016). Concomitantly, recent research suggests that most parents continue to be dissatisfied with the care they receive at this time (Johnson et al., 2016). The way in which diagnoses are communicated during the prenatal and perinatal periods can have a lasting emotional impact (Chaplin, Schweitzer, & Perkoulidis, 2005), and as such there is a need to provide healthcare staff with recommendations for how to approach this important aspect of healthcare. This study sought to address these issues by conducting one-to-one semi-structured interviews to explore parent experiences and preferences when their baby was first diagnosed with a limb difference.

Parents were recruited who had learned of their baby's limb difference during both the prenatal and postnatal periods.

Methods

This study used qualitative methods to explore parent experiences when their baby was diagnosed with dysmelia, a group of rare diseases characterised by congenital limb reductions, and to understand how family focused care for these families could be improved.

Participants and Recruitment

We recruited mothers and fathers of children with dysmelia who were aged 5 or under. These parents were based in the United Kingdom and were recruited via a purposeful sampling method. Parents responded to study advertisements which were distributed via third sector organizations for families with children with dysmelia (e.g., Reach) and social media (Twitter and Facebook). Recruitment continued until data saturation was reached.

Research Design

A semi-structured interview schedule was developed, consisting of open-ended questions with additional probe questions. The interview schedule focused on three areas: parents' general experiences of being informed their baby had dysmelia; their experiences of information received at diagnosis and feelings of preparedness when their babies were born; and improvements which parents believe could have been made to the practices of communicating the diagnosis. Semi-structured interviews were chosen in order to facilitate an open dialogue with parents while eliciting information relevant to the study aims. Interviews were conducted by researchers AD, OJ, and JJ and the guide was piloted during two mock interviews with JH and CF. CF has lived experience of dysmelia and has experience of interviewing parents of children with dysmelia in non-research settings. These pilot interviews were used to refine the fluency of the topic guide.

Data Collection

Interviews were conducted via telephone between November 2016 and March 2017. Telephone interviews were chosen in order to enable access to parents nationwide. As dysmelia is a rare disease it was predicted it would not be possible to access an adequate number of parents within a commutable distance. Furthermore, previous research suggests that telephone interviews result in a similar quantity, depth, and nature of responses as those gained by face-to-face interviews, and are perceived as more convenient by some research participants (Sturges & Hanrahan, 2004). Interviews lasted from 25 minutes to 75 minutes and were audio-recorded and transcribed.

Data Analysis

Thematic analysis was used to analyze the data. This is a flexible approach which achieves a rich and complex description of the dataset, capturing the most enduring themes (Braun & Clarke, 2006). Thematic analysis was chosen as it is suitable for gaining an understanding of parents' overall experiences and identifying areas for service improvement. Our analysis followed the six steps outlined by Braun and Clark (2006). First was familiarization with the data, where transcribed data were read and re-read, with initial ideas noted down. Second was generation of initial codes; interesting aspects of the data were coded systematically across the dataset and data was then organized according to these codes. This was completed by JJ with all transcripts independently double coded by OJ or AD and a further 10% of transcripts independently triple coded by JH. During this process, codes were cross-checked and refined. Third was the collation of codes and the generation of emergent themes. Fourth was the refinement of themes through meetings held between researchers (JJ, AO, AD, JH). These checked that themes worked at the level of the extracted data and the overall data set, and created a thematic map. Fifth was the agreement of final codes through discussion and consensus (Barbour, 2001), and sixth was the production of the report and the identification of compelling data extracts for theme representation (Braun & Clarke, 2006).

An essentialist approach to epistemology was used, whereby data was understood as a means of theorizing motivation, meaning, and experience. This viewed the lexicon of participants as a direct intention of communicating experience and its associated meaning.

Ethics

The study was approved by the School of Psychology Ethics Committee at the University of Leeds, UK (ref no: 16-0278; date approved: 25-10-2016). Parents were provided with information sheets and asked to return consent forms in a stamped addressed envelope. Given the sensitive nature of the research, parents were contacted after the completion of the study in order to ensure they had not experienced any psychological harm as a result of their participation. No parents reported negative effects of research participation, but if this had occurred, the researcher would have signposted them to a relevant support organization.

Results

Participants

A total of 51 parents responded to the advertisements and 23 parents completed interviews. One interview recording was inaudible and two interviewees were ineligible due to having a child aged over 5, resulting in a final sample of 20 interviews for analysis. We did not ask potential parents who initially expressed interest but did not participate to give a reason, however, some stated they were unable to participate due to busy schedules. Nine parents were fathers, 11 were mothers, with a mean age of 35.35 ($SD = 4.27$). All parents identified as White British. Parents were located across the United Kingdom, including Scotland, Wales, northern England, and southern England. No participants were co-parents with other participants; each participant represented a separate child. Nineteen children were aged between 1 and 57 months ($M = 25.00$, $SD = 18.51$), with the remaining child unborn at the time of interview. Most children had one affected limb ($n = 17$; 85%), with the remaining

having two (n = 2; 10%) and four (n = 1; 5%) affected limbs. Children had a range of specific dysmelia diagnoses, including Amniotic Band Syndrome (n = 3; 15%), Symbrachydactyly (n = 3; 15%), Poland Syndrome (n = 2; 10%), and Transverse Absence (n = 1; 5%). The remaining children had received no specific diagnosis (n = 11; 55%). Eight (40%) children were diagnosed via prenatal ultrasound, with the remaining 12 (60%) diagnosed at the time of birth.

Thematic Analysis

The thematic analysis resulted in the identification of five themes (see Table 1).

[insert Table 1 about here]

Influencing factors. Most parents responded to the discovery of their child's limb difference with feelings of shock or panic. However, the extent of this depended on a range of other contextual and situational factors.

Timing of detection. The most prominent influencing factor was the timing of detection; parents were more likely to be shocked and to describe a range of distressed emotions when the limb difference was not discovered until birth. Parents whose baby's limb difference was identified by ultrasound scan found that this allowed for processing of the news, emotional preparation for the birth, and meant postnatal care was more likely to be organized ahead of time.

...finding out before helped us cope because you can just prepare yourself... you can also prepare your friends and family around you. (P1; Mother; ultrasound detection)

Parents whose baby's limb difference was identified at birth described their shock being compounded by the stress and exhaustion of the birth process. Furthermore, fathers in this situation described feeling under more pressure than if it was identified prenatally, as their partner was recovering from the birth or providing for the immediate care needs of the baby. This left them to manage and address the news of the limb difference with less support:

I was concerned about my wife because it was quite a difficult birth and I just went very cold... I didn't know how to react - I didn't know if I should even hold her at first... but my wife was quite distressed so I was really sort of concentrating on her at that time. (P17; Father; Identified at birth)

... the mother is feeding and getting used to being a mum for the first time; meanwhile as a dad I've been... trying to find out these other things and then relaying it back to my wife. (P18; Father; Identified at birth)

The influence of previous experiences on reactions. Parents described how their previous experiences influenced their reaction to the news. Experience of knowing someone with a disability was described as a factor which reduced anxiety; conversely, having no previous experience of disability was described as a factor accentuating feelings of shock and panic.

I had first-hand experience watching someone with an upper limb difference growing up... so I saw... that it was absolutely fine and that there was an abundance of ability. (P2; Mother; ultrasound detection)

I was just really, really terrified because I'd never been around a disability and I felt... I'm not equipped for this. (P4; Mother; Ultrasound detection)

Some parents thought that having had a previous healthy child increased their feelings of shock about the news, but most felt this reduced their stress, as they already had basic knowledge about caring for children:

...if it was your first baby it probably would have been worse.... Your second one is kind of like oh we're here again and... you know they're going to be okay. (P19; Father, Identified at birth)

...this is my first child as well... I was not only worrying about what I was going to do with the hand but how I was going to look after a baby at all. (P4; Mother; Ultrasound detection)

Expectations of the scan or birth. Some parents described how they had anticipated their scans or the birth of their child with excitement and had prescribed expectations about this. Parents who held these expectations said these increased their sense of shock and sadness when the event did not go as envisaged:

... for a long time afterwards watching programmes like [UK reality television show about birth]... I remember just being in absolute tears because... they have these amazing birthing experiences and... I felt very robbed of that. (Mother; P13; Identified at birth)

The influence of other complications on reactions. Several parents described their baby's limb difference as occurring within a context of other stressors, such as pregnancy problems, fetal health concerns, or other health concerns with their new baby. When these were present, they compounded the stress parents experienced when their baby's limb difference was identified:

...he was early and it happens but we had all the stress of that anyway and that was scary as hell. (Mother, P14; Identified at birth)

Need for signposting to peer support. News of their child's limb difference often engendered a range of negative emotions and worries in parents. They described feeling worried about their child's future and the things they may not be able to do, with the most common concern relating to future bullying. Some parents also described feeling alone in their problem due to the rare nature of dysmelia, and described feeling 'different' from other parents:

...you start thinking the obvious, 'oh is he going to get bullied'. (Father, P19; Identified at birth)

...we didn't do any antenatal classes because I didn't want to be in a room full of other parents moaning about how sick they were during pregnancy and that's all they had to deal with. (Mother; P1; Ultrasound detection)

Parents felt a need for reassurance. Most parents said that engaging with peer support organizations helped to provide this by offering information, a feeling of community, and reducing feelings of aloneness. Being able to see older children and adults with limb differences living full lives reduced their worries about their child's future:

...it [peer support] makes you feel like you're not alone. It makes you feel like others understand. (Mother; P1; Ultrasound detection)

...it is reassuring because you can see the other kids [with limb differences]... and they're all happy and running around and doing the things that other kids can do. (Father; P15; Identified at birth)

...once we found the [peer support] organizations we did get quite a lot of information... they've both got Facebook pages so if you've ever got any queries, just post on the page and other people can reply that are in a similar situation. (Father; P7; Ultrasound detection)

Some parents said that they had initially been ambivalent about engaging with peer support organizations, either because they did not feel they needed this kind of support, or because they were afraid being part of these organizations labelled their child as 'disabled'.

More mothers than fathers initially sought out peer support. However, all parents said any ambivalence they felt was dispelled upon engaging with these organizations.

...whereas my wife was more looking for support and she found [peer support organization]...I was like... I don't know what the need is for it; but then actually meeting...other families and seeing the other kids interacting together you go actually yeah it is fantastic support. (Father; P16; Identified at birth)

Most parents found these organizations through their own searching. However, this usually meant there was a delay, and they would have liked to have been immediately signposted to these by health professionals:

If I'd have known about [peer support organization] on day one – [if] I'd been given a leaflet or something and seen the information - I probably would have felt a lot better. (Mother; P9; Identified at birth)

Need for information. On learning the news of their child's limb difference, most parents were keen to gain as much information as they could about the condition. Mothers in particular described searching online, some intently, to educate themselves as much as possible:

I basically came home and Googled within an inch of my life after the twenty weeks scan. (Mother; P4; Ultrasound detection)

I basically spent the first few weeks of [my daughter's] life on the internet on my own. (Mother; P11; Identified at birth)

However, need for information was influenced by personal coping style, and a minority of parents preferred to process the news slowly:

I would be the one that was on the internet constantly... he [the baby's father] was really worried you know but he'd rather not look at stuff because it might accentuate the worry. (Mother, P11; Identified at birth)

Some parents expressed disappointment regarding the lack of information they received from health providers. Some parents described having unanswered questions and feeling that staff did not try hard enough to find answers for them. When staff did not initially have relevant information, parents felt they should do an internet search to find this:

...where they don't know a lot about it they should... get information about it. I mean I'm not a doctor, my wife's not a doctor and we were able to get information about it just by going on Google. (Father; P7; Ultrasound detection)

...if you are... a nurse and you saw what had happened... it doesn't take a lot to just Google and look in their manuals and see what it is and then offer a bit of support. (Mother; P10; Identified at birth)

In particular, parents expressed a desire for written information, as the shock of the news often meant they did not have questions until later on, once they had had time to mentally process the information. Several parents said that even a pamphlet signposting them to a relevant peer support organization would have been a major improvement:

...even if there was a leaflet in the hospital about limb difference... then you could look into it yourself. (Father; P20; Identified at birth)

Parents also expressed a desire for receiving balanced information about their child's disability. Several parents who had the limb difference identified prenatally felt the presentation of the information was overly negative:

...it kind of made us feel like we were silly for being so positive.... they kept trying to bring the negatives... they were constantly pushing our positives away. (Mother; P2; Ultrasound detection)

Need for clear and sensitive communication. Several parents acknowledged the challenge of communicating difficult news, particularly when a condition is rare and unexpected. However, around half of parents reported experiencing insensitive language or statements from healthcare providers. These parents said that when this occurred it had a strong and lasting impact on them. In particular, some parents who discovered the news of the limb difference at birth were quickly asked questions regarding medication or drugs they had been taking, or whether they were closely related to their partner. Parents felt the timing of these questions was inappropriate and said this compounded feelings of guilt they had for causing their child's disability which lasted even after they were told by other healthcare staff they were not responsible for this.

...while I was being sewn up on the operating table he [the doctor] asked me what medication has been taken, so my first thought was that this is my fault, and although I know now that it wasn't that... that thought is still there, that maybe I have done something wrong, that I have taken the wrong thing. (Mother; P13; Identified at birth)

Where the limb difference was identified prenatally, some parents felt the sonographer avoided communicating this to them by asking them to come back on another day or bringing another sonographer in to the scan room first to speak with them. In half of parents where the limb difference was prenatally identified, a second sonographer was invited in without explanation or introduction. These experiences roused anxiety and suspicion in parents and led to a negative experience of receiving the news.

Parent: ...first of all they invited somebody else into the room and being in healthcare myself I know that that's dodgy...

Interviewer: ... how did you feel at that at that time?

Parent: Terrified! I think I probably started crying I knew that there was something wrong. (Mother; P1; Ultrasound detection)

Where the limb difference was not found until birth, most parents identified this themselves. However, in some cases parents did not see this first and felt that healthcare providers attempted to conceal this by wrapping the baby in a blanket. In one case, staff did not comment on the limb difference at all. This avoidance heightened parental distress:

they didn't say anything about it... we were just basically handed a child and left to it... so that's where our sort of pain started because at that point we didn't know what was going on. (Father; P17; Identified at birth)

A large minority of parents said they were first told the news in vague terms, for example that there was something 'wrong' with their baby. When this happened, it engendered feelings of anxiety and panic. In contrast, when parents were told in simple terms that their child had a limb difference, this minimized distress:

...the ultrasound sonographer turned to the other one and said 'yep I think you're right', and they said that 'okay we've detected a problem' and having had a previous miscarriage before... I thought the worst, and [then] they said we just can't see his or her left hand ... and we just went oh okay had a big smile on our face. (Father; P6; Ultrasound detection)

Some parents commented on the challenge of then communicating the news of their child's limb difference to their friends and family:

we didn't tell people she was born until a day later because we just didn't know what to say. (Mother; P13; Identified at birth)

Most parents where the limb difference was identified prenatally were unhappy with the conversations they had with healthcare providers regarding termination. They felt the

timing of this discussion was insensitive, and it was introduced as an option too soon, prior to the presentation of adequate information about their child's likely degree of disability.

...maybe just even if they had leaflets about limb deficiencies but they didn't, it wasn't like that, it was just basically 'your kid is going to be disabled and here are the options... and you basically have it or you can get rid of it'. (Mother; P5; Ultrasound detection)

Need for a plan. Most parents described experiencing delays in accessing appropriate healthcare for their child. The cause of these delays stemmed variously from delays in referrals being made for them by relevant healthcare providers; long waiting lists to see specialists; and care being refused to them. Around half of parents described feeling that the onus to organize their child's care was on them, with most of these parents describing accessing appropriate care as a 'fight' or a battle'.

I still get upset... because everything's a massive battle, we don't get any help even now... I'm still trying to get him into the limb centre in [hospital name] which I didn't even know about until I joined you know [peer support organization]. (Mother; P5; Ultrasound detection)

Around half of parents also described experiencing a lack of information sharing between healthcare professionals (HCPs); for example, they found that their community HCPs did not know about their baby's limb difference, which in a few cases resulted in HCPs making insensitive statements. Usually the failure in information sharing was due to HCPs not reading information which had been sent to them, rather than a failure in this information being recorded in the first place.

...when he went for his [hip] operation... the anaesthetist went 'oh where's his arm?' And I went 'what do you mean where's his arm he hasn't got one' and she went 'oh I'm sorry I've just never seen one so severe'.. I was like that's horrible yeah keep

digging... you know what the hell do these people not read the notes? (Mother; P5; Ultrasound detection)

Parents expressed a desire for more joined-up care between healthcare providers. Around half of parents said they would have liked to have someone who could act as a point-of-contact or a care-coordinator for them. Although no children received a care coordinator, a small number of parents were provided with phone numbers for HCPs they could contact with any queries about their child's health. When this occurred, it was viewed positively and reduced anxiety. In particular, parents expressed a desire for a plan of care for their child. They were keen to know what intervention options were open to their child as soon as possible and the timeline on which these would become available. Parents who were discharged from hospital without knowledge of what the next steps of care were for their child found waiting to hear about referrals extremely challenging.

I just can't believe that you're let go from a hospital with nothing, absolutely nothing, with a child born with some sort of deformity that you don't know what it is, you don't know what the diagnosis or prognosis is and you're told that you have to wait eight months to find out any information. (Mother; P11; Identified at birth)

Parents also expressed a desire to understand the purpose of appointments which they were offered and tests their child received. Some described finding that appointments and tests became a 'burden' with no apparent purpose; where the purpose of appointments and tests was understood parents felt more confident about their child's care and experienced less anxiety in relation to this. They were also more likely to cooperate with healthcare professionals:

The kind of more common consultants that you just meet sat in a room... I just lost respect for them and got to the stage where I thought do you know what I don't even

want to go to the appointments because they are so pointless. (Father; P6; Ultrasound detection)

Discussion

Minimal research has investigated how news of rare disease diagnoses should be communicated during the prenatal and perinatal periods, and recent survey research suggests parents have a poor experience of healthcare at this time (Johnson et al., 2016). This study used qualitative methods to explore parent experiences when their baby was diagnosed with dysmelia, a group of rare diseases characterised by congenital limb reductions, and to understand how this area of healthcare care could be improved. Consistent with previous research in congenital anomalies (McKechnie et al., 2016), findings suggested that the overriding emotion parents experienced when hearing the news of their baby's limb difference was shock. However, the present study significantly extended this by identifying that the extent of this shock was influenced by several factors including previous experience of disability, whether this was their first child and whether the limb difference was identified by prenatal ultrasound or after birth. Findings also significantly added to previous research in this area by identifying four clear needs of parents at this time, including the need for signposting to peer support organizations, for information, for sensitive communication, and for a plan regarding their child's care.

The present study is the first to qualitatively explore differences in the experiences of parents when congenital anomalies are identified in the prenatal period compared with after birth, and helps to explain results from survey research suggesting that parents have a poorer experience when anomalies are identified at birth than prenatally (Johnson et al., 2016). When identification was made by ultrasound scan, parents had time to emotionally prepare for the arrival of their child; some made contact with peer support organizations and made arrangements for postnatal appointments with specialists. When identification was not until

birth, parents received the news when they were exhausted and emotionally vulnerable. Fathers in particular described finding this timing difficult, as their partner was recovering from the physical strain of birth or a caesarean section, and they often felt under pressure and unsupported. Healthcare professionals in these settings were also described as less prepared; parents more commonly described them as being shocked, avoiding communicating the diagnosis, and asking insensitive questions relating to the potential cause of the limb difference.

This study is the first we are aware of which recruited both mothers and fathers about their experience of communication of a congenital diagnosis, and interviewed these separately. As discussed above, findings highlighted the differing roles of mothers and fathers when the limb difference was identified at birth, and suggested that fathers in this situation may be in particular need of support. Apart from this, few notable differences in experiences or preferences were found. Mothers more commonly described seeking peer support organizations than fathers, but the benefits of engaging with these organizations were equally voiced by both mothers and fathers. Similarly, while more mothers said they sought information online, both mothers and fathers described a need for information and were disappointed when this was not forthcoming from healthcare professionals. Instead, individual differences in coping style emerged as being an important factor in the experiences and needs of individuals; while some parents had a strong and immediate drive to gain information, others preferred to process the news slowly and were at risk of feeling overwhelmed if too much information was presented too quickly. This is consistent with previous work by Lalor et al. (2008) which found that parents receiving news of a prenatal diagnosis fall into two main groups of ‘monitors’ and ‘blunters’. An important contribution of the present study is the finding that both groups appreciated the offer of written information by healthcare professionals, which met the immediate information needs of ‘monitors’ but

also allowed 'blunters' to process this in their own time. Parents acknowledged that in the case of rare diseases, such information may not be readily available, but were grateful when healthcare providers searched for information online on their behalf and printed this off.

Previous research has stated that sensitive but clear communication is important when communicating news of a congenital diagnosis (Fleming et al., 2017; Lalor et al., 2007). The present study extends this by identifying specific ways in which healthcare providers can communicate news of a rare diagnosis in a way which can minimise shock in parents. First, where previous guidance for breaking difficult news emphasizes the importance of delivering a 'warning shot' first (Baile et al., 2000), parents in the current study did not appreciate this and preferred it when the news was communicated directly and succinctly. They were already alerted to the discovery of something unexpected by the behaviour of healthcare professionals, and at this point preferred simply to be told, for example, the sonographer could 'not see a right hand'. When parents were first told there was something 'wrong', this increased their anxiety and led them to think their baby had died or had clear systemic health problems. Second, where previous studies have highlighted the importance of not making insensitive statements (Chaplin et al., 2005; Fleming et al., 2017), the current study suggests that the impact of insensitive questions can be equally or more upsetting, and any questions relating to the cause of the limb difference should be delayed until parents have had time to recover from feelings of shock. Third, the present findings suggest that when the limb difference is identified prenatally, healthcare providers should not immediately discuss termination. Several parents were offered a termination before they had had time to process the news or research the likely implications of this, and found this distressing. Sensitive communication at this time should focus on information provision and allow for the processing of this first. Furthermore, the present study found that when news was

communicated succinctly and appropriately, this provided a model for parents when they were subsequently communicating the diagnosis to their family and friends.

Findings from the study highlight the importance of peer support organizations for parents of children with dysmelia, supporting previous survey research (Johnson et al., 2016; Kerr & McIntosh, 2000) and extending this by providing an understanding of the functions of peer support for this group. First, parents found peer support organizations were an important source of information and advice about dysmelia, which was lacking in healthcare services. Second, parents said receiving a rare diagnosis made them feel alone and different; engaging with other families in a similar situation provided a community of people with a shared experience where they felt understood and comfortable. Third, parents found that meeting older children and adults with similar disabilities to their own child was reassuring and addressed worries they held about their child's future. Parents felt that one simple improvement healthcare services could make to the practice of communicating news of a rare disease would be to immediately provide information about such organizations.

Implications for Family Nursing Practice and Future Research

The current study suggests there is a need to improve communication when dysmelia is diagnosed during the prenatal and perinatal periods. The study significantly extends previous knowledge in the area of family nursing practice by identifying that experiences in postnatal services are particularly poor, and contribute to feelings of shock and distress in parents. However, present findings suggest that the introduction of some simple specific communication practices could lead to significant improvements in this area. Parents said their experience could have been improved by being immediately provided with printed information about dysmelia and the details of peer support organizations at the time the limb difference was identified. They also said they felt less anxiety when the news of the limb difference was delivered succinctly and without the preamble that something was 'wrong'.

This is in contrast to existing frameworks for news delivery which emphasize the importance of delivering a ‘warning shot’ prior to specifying difficult news (Baile et al., 2000), and demonstrates the need for research into news delivery which explores specific diseases and situations. Furthermore, the present study suggests that staff working with childbearing families should delay asking questions about potential causes of the dysmelia or discussing the option of termination (in the event of prenatal identification) until parents have had time to recover from the shock of the diagnosis and to consider the potential implications of this. In identifying the emotional and practical needs of parents at this time, these findings can support family nurses working with childbearing families to anticipate the likely stressors they will experience, which include the insensitive communication of the diagnosis, worries for their child’s future wellbeing, and feelings of isolation. They also identify resources which family nurses can provide for these families, most importantly information surrounding the diagnosis and contact details for support organizations.

Furthermore, these findings can help family nurses leading brief, time-limited therapeutic conversations with these families (Wright & Leahey, 2013) to understand how best to focus these discussions, and highlight the importance of addressing feelings of shock and normalizing the experience. McKechnie and colleagues (2016) offer an example of the 15-Minute Family Interview (Wright & Leahey, 2013) using a guided-participation approach for this population of families. In addition, guidelines for family nursing practice are offered by the International Family Nursing Association (IFNA) for generalist family nursing practice (2013) and advanced nursing practice with families (2015). These resources may have relevance for the communication of other rare diseases with parents during the prenatal and perinatal periods, where similar difficulties are likely to occur.

Future research is needed to develop and adapt existing news delivery interventions to train staff in the communication of rare diseases during the prenatal and perinatal periods. A

recent meta-analysis suggests such interventions are effective for improving the delivery of difficult news in other healthcare settings (Johnson & Panagioti, 2018), but present findings suggest existing frameworks are not appropriate for these situations in their current state. Recommendations from the current study should be used to inform the development of such interventions.

Limitations

The study had several strengths, including the inclusion of fathers as well as mothers and the recruitment of parents with relatively recent experiences (within the last five years). However, we were unable to recruit parents from non-white ethnic minority backgrounds, and findings may not generalize to this group. Future research should recruit parents from these groups as a priority.

Conclusions

Minimal research has investigated the experience of parents when their baby is diagnosed with a rare disease during the prenatal and perinatal periods. The present study sought to understand the experiences and preferences of parents when their baby was diagnosed with dysmelia, a group of rare diseases characterized by congenital limb differences. Consistent with previous research, the overriding emotion described by parents at this time was shock. However, the present study extended previous research findings by identifying that the extent of this shock was influenced by previous experiences of disability, prior pregnancy complications and whether this was their first child. It was also accentuated when the limb difference was not identified until birth. The present study also extends existing knowledge in this area by identifying four key needs of parents at this time: the need for signposting to peer support, the need for information, the need for sensitive communication, and the need for a plan regarding their baby's care. Parents wanted information and signposting to peer support to be provided immediately, and any discussions

regarding potential causes of the limb difference or the possibility of termination (in the case of prenatal identification) to be delayed until they had had time to process the news and overcome their shock. More research is needed about the efficacy of family focused interventions for addressing the needs of parents receiving a diagnosis of a rare disease of a child.

References

- Alkazaleh, F., Thomas, M., Grebenyuk, J., Glaude, L., Savage, D., Johannesen, J.,... Windrim, R. (2004). What women want: Women's preferences of caregiver behavior when prenatal sonography findings are abnormal. *Ultrasound in Obstetrics & Gynecology*, 23(1), 56-62. doi: 10.1002/uog.906
- Andrews, E. E., Williams, J. L., VandeCreek, L., & Allen, J. B. (2009). Experiences of parents of children with congenital limb differences with health care providers: A qualitative study. *Rehabilitation Psychology*, 54(2), 217. doi: 10.1037/a0015651
- Askelsdóttir, B., Conroy, S., & Rempel, G. (2008). From diagnosis to birth: Parents' experience when expecting a child with congenital anomaly. *Advances in Neonatal Care: Official Journal of the National Association of Neonatal Nurses*, 8(6), 348-354. doi: 10.1097/01.ANC.0000342768.94734.23
- Asplin, N., Wessel, H., Marions, L., & Öhman, S. G. (2012). Pregnant women's experiences, needs, and preferences regarding information about malformations detected by ultrasound scan. *Sexual & Reproductive Healthcare*, 3(2), 73-78. doi: 10.1016/j.srhc.2011.12.002
- Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). SPIKES—a six-step protocol for delivering bad news: Application to the patient with cancer. *The Oncologist*, 5(4), 302-311. doi: 10.1634/theoncologist.5-4-302
- Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *British Medical Journal*, 322(7294), 1115.
- Bell, J. M. (2016). The central importance of therapeutic conversations in family nursing: Can talking be healing? [Editorial]. *Journal of Family Nursing*, 22(4), 439-449. doi: 10.1177/1074840716680837

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa
- Chaplin, J., Schweitzer, R., & Perkoulidis, S. (2005). Experiences of prenatal diagnosis of spina bifida or hydrocephalus in parents who decide to continue with their pregnancy. *Journal of Genetic Counseling*, 14(2), 151-162. doi: 10.1007/s10897-005-0488-9
- Chen, H. (2006). ~~Dysmelia (Limb Deficiency/Reduction)~~ Atlas of Genetic Diagnosis and Counseling (pp. 312-322). Totowa, NJ: Humana Press.
- Eurodis. (2014). What is a rare disease? Retrieved from <https://www.eurordis.org/content/what-rare-disease>
- Fleming, L., Knafl, K., & Van Riper, M. (2017). How the child's gender matters for families having a child with congenital adrenal hyperplasia. *Journal of Family Nursing*, 23(4), 516-533. doi: 10.1177/1074840717735499
- Gold, N. B., Westgate, M. N., & Holmes, L. B. (2011). Anatomic and etiological classification of congenital limb deficiencies. *American Journal of Medical Genetics Part A*, 155(6), 1225-1235. doi: 10.1002/ajmg.a.33999
- Holder-Espinasse, M., Devisme, L., Thomas, D., Boute, O., Vaast, P., Fron, D.,...
Manouvrier-Hanu, S. (2004). Pre-and postnatal diagnosis of limb anomalies: A series of 107 cases. *American Journal of Medical Genetics Part A*, 124(4), 417-422. doi: 10.1002/ajmg.a.20359
- International Family Nursing Association (IFNA). (2015). IFNA Position Statement on Generalist Competencies for Family Nursing Practice. Retrieved from <https://internationalfamilynursing.org/wordpress/wp-content/uploads/2015/07/GC-Complete-PDF-document-in-color-with-photos-English-language.pdf>

International Family Nursing Association (IFNA). (2017). IFNA Position Statement on Advanced Practice Competencies for Family Nursing. Retrieved

from <https://internationalfamilynursing.org/2017/05/19/advanced-practice-competencies/>

Johnson, J., Adams-Spink, G., Arndt, T., Wijeratne, D., Heyhoe, J., & Taylor, P. (2016).

Providing family-centered care for rare diseases in maternity services: Parent satisfaction and preferences when screening identifies dysmelia. *Women and Birth*, 29(6), e99–e104. doi: 10.1016/j.wombi.2016.04.007

Johnson, J., & Panagioti, M. (in press). Interventions to improve the breaking of bad or difficult news by physicians: A systematic review and meta-analysis. *Academic Medicine*.

Kerr, S. M., & McIntosh, J. (2000). Coping when a child has a disability: Exploring the impact of parent-to-parent support. *Child: Care, Health and Development*, 26(4), 309-322. doi: 10.1046/j.1365-2214.2000.00149.x

Lalor, J., Begley, C. M., & Galavan, E. (2008). A grounded theory study of information preference and coping styles following antenatal diagnosis of foetal abnormality. *Journal of Advanced Nursing*, 64(2), 185-194. doi: 10.1111/j.1365-2648.2008.04778.x

Lalor, J. G., Devane, D., & Begley, C. M. (2007). Unexpected diagnosis of fetal abnormality: Women's encounters with caregivers. *Birth*, 34(1), 80-88. doi: 10.1111/j.1523-536X.2006.00148.x

McGuirk, C. K., Westgate, M.-N., & Holmes, L. B. (2001). Limb deficiencies in newborn infants. *Pediatrics*, 108(4), e64-e64. doi: 10.1542/peds.108.4.e64

McKechnie, A. C., Pridham, K., & Tluczek, A. (2016). Walking the “emotional tightrope” from pregnancy to parenthood: Understanding parental motivation to manage health

- care and distress after a fetal diagnosis of complex congenital heart disease. *Journal of Family Nursing*, 22(1), 74-107. doi: 10.1177/1074840715616603
- Mitchell, L. M. (2004). Women's experiences of unexpected ultrasound findings. *Journal of Midwifery & Women's Health*, 49(3), 228-234. doi: 10.1016/S1526-9523(03)00490-2
- Oscarsson, M., Gottvall, T., & Swahnberg, K. (2015). When fetal hydronephrosis is suspected antenatally—a qualitative study. *BMC Pregnancy and Childbirth*, 15(1), 349. doi: 10.1186/s12884-015-0791-x
- RareDiseaseUK. (2017). About rare diseases. Retrieved from <http://www.raredisease.org.uk/what-is-a-rare-disease/>
- Simpson, R., & Bor, R. (2001). 'I'm not picking up a heart - beat': Experiences of sonographers giving bad news to women during ultrasound scans. *Psychology and Psychotherapy: Theory, Research and Practice*, 74(2), 255-272. doi: 10.1348/000711201160867
- Sturges, J. E., & Hanrahan, K. J. (2004). Comparing telephone and face-to-face qualitative interviewing: A research note. *Qualitative Research*, 4(1), 107-118. doi: 10.1177/1468794104041110
- Van der Zalm, J., & Byrne, P. (2006). Seeing baby: Women's experience of prenatal ultrasound examination and unexpected fetal diagnosis. *Journal of Perinatology*, 26(7), 403-408. doi: 10.1038/sj.jp.7211540
- Veltri, L., Wilson-Mitchell, K., & O'Mahoney, J. (2015). Family nursing with childbearing families. In J. R. Kaakinen, A. Tabacco, D. P. Coehlo, S. M. H. Hanson & R. Steele (Eds.), *Family health care nursing: Theory, practice and research* (5th ed., pp. 357-388). Philadelphia, PA: F. A. Davis.
- Wright, L. M., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention* (6th ed.). Philadelphia, PA: F. A. Davis.

Table 1
Themes, subthemes, descriptions and example quotes.

Themes	Description	Subthemes	Example quote
Influencing factors	The extent of parents' shock at the news depended on a range of contextual factors.	Timing of detection (prenatal vs. at birth)	"... <i>finding out before helped us cope because you can just prepare yourself... you can also prepare your friends and family around you</i> " (P1; Mother; ultrasound detection)
		The influence of previous experiences on reactions	" <i>I was just really, really terrified because I'd never been around a disability and I felt... I'm not equipped for this</i> " (P4; Mother; ultrasound detection)
		Expectations of the scan or birth	"... <i>for a long time afterwards watching programmes like [UK reality television show about birth] ... I remember just being in absolute tears because... they have these amazing birthing experiences and... I felt very robbed of that</i> " (Mother; P13; Identified at birth)
		The influence of other complications on reactions	"... <i>he was early and it happens but we had all the stress of that anyway and that was scary as hell</i> " (Mother, P14; Identified at birth)
Need for signposting to peer support	Peer support organisations provided a sense of community and reassurance.		"... <i>it [peer support] makes you feel like you're not alone. It makes you feel like others understand</i> " (Mother; P1; ultrasound detection)
Need for information	Most parents were keen to gain as much information as they could about their baby's condition.		" <i>I basically came home and Googled within an inch of my life after the twenty weeks scan</i> " (Mother; P4; ultrasound detection)
Need for clear and sensitive communication	Parents described the strong emotional impact of insensitive comments or questions.		"... <i>while I was being sewn up on the operating table he [the doctor] asked me what medication has been taken, so my first thought was that this is my fault, and although I know now that it wasn't that... that thought is still there, that maybe I have done something wrong, that I have taken the wrong thing</i> " (Mother; P13; Identified at birth)
Need for a plan	Parents expressed a need to receive a plan for their child's healthcare.		" <i>I just can't believe that you're let go from a hospital with nothing, absolutely nothing, with a child born with some sort of deformity that you don't know what it is, you</i>

*don't know what the diagnosis or prognosis
is and you're told that you have to wait
eight months to find out any information"*
(Mother; P11; Identified at birth)
