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Original Article

Abstract

Background: An increasing body of research has sought to determine the impact of Disorders of Sex Development (DSD) on the family of the affected child. Little is currently understood about the support needs of the family and how well these needs are met.

Methods: Interpretive Phenomenological Analysis was used to analyse semi-structured interviews with eight mothers of children with DSD about their experiences of support.

Results: Four master themes emerged which encapsulated (a) the stages in their child's development when mothers most needed support, (b) the importance of developing an understanding of the child's condition, (c) the lack of acknowledgement of the emotional needs of the parent and (d) the importance of having close and trusted networks for support. Continuity and availability of support were considered important and while all participants prioritised maintaining privacy about the condition, a minority felt that this impacted on the level of support they received.

Conclusions: Key time points for support were identified and while some felt that they were well supported others felt that the support available did not meet their emotional needs. Clinical implications and directions for future research were considered.

Keywords

Disorders of sex development, support needs, social support, family factors, maternal experiences

Introduction

Disorders of sex development (DSD)¹ are a class of congenital conditions in which the development of chromosomal, gonadal or anatomical sex is atypical (Lee, Houk, Ahmed & Hughes, 2006). The condition is most often identified in newborns or adolescents, however an increasing number of individuals present either antenatally or during childhood (Brain et al., 2010). Affected newborns typically present with atypical genitalia, and those who are identified in adolescence present with atypical sexual development during the pubertal years, such as delayed puberty (Ahmed et al., 2011).

The diagnosis of a DSD presents a range of unique challenges to the individual, as well as to parents and professionals (Brain et al., 2010). The need for assessment and management by a multidisciplinary team has been emphasised (Ahmed et al., 2011; Brain et al., 2010; Lee et al., 2006) and may include gender assignment at birth, genital reconstructive surgery, sex steroid replacement, and psychosocial management (Lee et al., 2006).

DSD and wellbeing

Research on outcomes and interventions has predominantly centred on issues such as gender assignment, psychosexual outcomes including gender role and gender identity, and ethical considerations related to treatment. Although less is known about

¹ The authors acknowledge that other terminology, such as intersex, is often preferred by people with these conditions. The DSD terminology has been used here as this is the language which would most likely be used in first explaining conditions to parents within the medical settings in which diagnosis takes place. It is recognised that later in the process the terminology used should be a negotiation (Jenkins & Short, 2017).

the impact of DSD on quality of life and mental wellbeing, an increasing field of literature demonstrates inconsistent findings across a number of DSD (Wisniewski & Mazur, 2009). While a number of studies indicate that wellbeing is unaffected (Berenbaum, Bryk, Duck, & Resnick, 2004; Hines, Ahmed & Hughes, 2003), elsewhere, it has been reported that adults with DSD demonstrate an impaired quality of life, increased distress and self-harm, and that individuals struggle with the experience of managing privacy around the condition and developing acceptance (Brinkmann, Scützmann, Schacht, & Richter-Appelt, 2009; Johannsen, Ripa, Mortensen, & Main, 2006; MacKenzie, Huntington, & Gilmour, 2009).

The impact of DSD on parents

Research has sought to understand the impact of DSD on the parents of affected children. A range of possible negative outcomes have been demonstrated, such as overprotection of the child, an increase in perceived child vulnerability and parenting stress, and reduced self-esteem and psychological stability (Duguid et al., 2007; Kirk et al., 2011). Additionally, high levels of post-traumatic stress symptoms have been identified in parents of children with DSD, with 31% of mothers, and 18% of fathers meeting the threshold for caseness of post-traumatic stress disorder (Pasterski et al., 2014).

Genitoplasty, the degree of masculinisation of the genitalia and the developmental stage of the child have all been shown to be related to parental wellbeing

(Wolfe-Christensen et al., 2012) and overprotective behaviour (Fedele et al., 2010; Hullman, Fedele, Wolfe-Christensen, Mullins, & Wisniewski, 2011). While these studies begin to give a useful understanding of the impact on parents there is a reliance on self-report questionnaires which use cross sectional data. Where objective measures are used there is a lack of consistency, limiting comparison between studies.

Additionally few studies have given consideration to the developmental stage of the child in understanding parental responses. A number of qualitative studies have explored parental emotional response to the diagnosis of a DSD. These responses have included shock, grief, anger, guilt and shame (Slijper, Frets, Boehmer, Drop, & Niermeijer, 2000). In addition, the parental struggle to negotiate a coherent sex identity for their child, and parental difficulties in sharing their story with others have been highlighted (Gough, Weyman, Alderson, Butler, & Stoner 2008; Sanders, Carter, & Goodacre, 2007). Crissman et al. (2011) explored the early parental experience of having a child with DSD and identified the gender assignment process, decisions about genital surgery, disclosing information about the child's condition and interacting with healthcare professionals as salient aspects of the process for parents.

Family coping and support

It is well established that some parenting characteristics are predictive of children's wellbeing when they have a chronic health condition (e.g. Colletti et al., 2008). Specifically, parental overprotection (Hullmann, Wolfe-Christensen, Meyer,

McNall-Knapp, & Mullins, 2010) and higher levels of parenting stress (Colletti et al., 2008) are related to poorer emotional, behavioural and social adjustment for children with chronic illness. Additionally, parental adaptation to a child's health condition is key for the subsequent wellbeing of the child (Carmichael & Alderson, 2004).

Therefore, reducing stress and increasing adaptation and coping skills for parents can have important implications for the child and the family. With empirical research from the childhood chronic illness literature emphasising the importance of social support and the opportunity to share worries about the illness (Gannoni & Shute, 2010; Tak, & McCubbin, 2002; Ware, & Raval, 2007) it may also be important for parents of those with DSD to communicate with others and to access support in order to achieve improved family coping and, in turn, positive child adaptation and wellbeing.

Parent support and DSD

While no studies to date have specifically looked at the process or impact of support for the parents of those with a DSD, an intricate picture is emerging through studies assessing the effect of DSD on the family. Such studies have pointed towards reduced coping skills, social support and communication with medical professionals among parents of children with DSD (Duguid et al., 2007). Additionally, tensions may exist between maintaining privacy for the child, which has been identified as increasing parental stress (Crissman et al., 2011), and disclosing the condition in order to access social support. The need for support from professionals has been highlighted as an

important factor in coping (Liao & Boyle, 2004; Sanders, Carter, & Goodacre, 2011). Parents' perceptions about how helpful it is to seek support from relatives are variable (Duguid et al. 2007).

Rationale and aims

Despite the acknowledgement that families of children with DSD experience unique challenges requiring support, very little is currently understood about the specific needs and wishes for support amongst parents. It is also not understood how the need and type of support may vary throughout the child's development. It is therefore important to better understand family support needs and when in the child's development these needs are greatest. While it is acknowledged that the experiences of both mothers and fathers are important, research has indicated that mothers may exhibit more stress than fathers in relation to their child's DSD, particularly when genitoplasty has not taken place (Fedele et al., 2010) and they have also reported higher levels of stigma in comparison to fathers (Rolston, Gardner, Vilain, & Sandberg, 2015). Additionally, within Western culture, mothers tend to be the primary caregiver for the child and may be more likely to access support in the context of child illness (Ware & Ravel, 2007). For these reasons, this study focused on mothers' experiences of accessing support. Ensuring a better understanding of support needs will enable services to better target their support and also to provide support which is more closely

attuned to the needs of the parents. Therefore, this study aims to address the following research questions:

1. What are the support needs of mothers of children with DSD and how do these change over time?
2. How well have their support needs been met and was anything missing?

Method

Design

As this research aimed to understand the experience of participants in an exploratory and in-depth manner, a qualitative methodology was chosen using semi-structured interviews. Interpretive Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) was selected as a method of analysis as it enables the exploration of the meaning of a particular experience and an understanding of how the participants make sense of this experience within their personal and social worlds (Smith & Osborn, 2007).

Semi-structured interviews are considered an appropriate means of collecting data for IPA analysis (Smith et al., 2009). The interview schedule was developed with the exploratory nature of the research question in mind and following guidance on IPA interview schedules (Smith et al., 2009). Questions were developed based on previous literature and discussions with a clinical psychologist working in the area and the schedule was piloted and revised prior to interviewing the first participant. Following

the pilot, helpful prompts were identified, as well as questions to get a better sense of the family as a whole. A question about what it would be helpful for other parents to know about accessing support was also added. Prompts and follow up questions were utilised in all interviews.

Participants

An opportunistic and homogenous sample of eight women participated. Inclusion criteria specified that all participants were the biological mother and primary caregiver to a child with a DSD diagnosis², that the child was diagnosed a minimum of six months ago and that the child was aged between 6 months and 18 years, inclusive.

Relevant information about the participants' children is displayed in Table 1. All of the mothers were white British, aged 35 - 45 years, were in a long term relationship with the father of the affected child and had at least one other child, with one family having four children. Two of the mothers interviewed had two children with a diagnosis of DSD.

Insert Table 1

Procedure

² Males with Congenital Adrenal Hyperplasia (CAH) were included as parents and children access the same services and can be expected to face similar psychological challenges

Participants were recruited through one NHS hospital and three charitable organisations. Ethical approval for this study was obtained from the National Research Ethics Committee and the Research and Development Department at the NHS trust through which participants were recruited.

Participants recruited through the NHS were identified by the clinical psychologist in an endocrinology paediatric clinic and provided with information about the study. They were then either contacted by the first author or they initiated this contact depending on their preferences. Participants recruited through the three charitable organisations made direct contact with the first author in response to brief information displayed in closed internet forums or emails sent out by the charity.

Following the participant providing informed consent, semi-structured interviews took place with the first author, lasting between one and two hours. Interviews were audio recorded, transcribed and analysed using Interpretative Phenomenological Analysis (IPA; Smith et al., 2009). Emerging themes were used to develop initial super-ordinate themes and connections across the cases were considered. Transcripts were re-read to ensure that the themes were captured within the text and suitable quotes for themes were identified.

Validity issues were considered throughout the research process and in the writing of the report. Sensitivity to context was achieved both by familiarisation with relevant literature and also through discussions with a clinical psychologist of the

potential difficulties faced by the sample. Commitment and rigour was considered in the selection of the sample and in the care taken with the analysis process, which was thorough and conducted as per IPA guidance (Smith et al., 2009). A research diary was kept by the first author and the first author also underwent a bracketing interview. Bracketing interviews are a strategy in which the researcher is interviewed themselves about the proposed topic of the study in order to investigate their presuppositions concerning the research project (Roulston, 2010). While it is acknowledged that the researcher cannot fully 'bracket' off their knowledge or beliefs, it is hoped that generating an awareness of these prior to commencing interviewing provides increased subjectivity and transparency. Prior to completing the analysis, the first author revisited the bracketing interview and the research diary in order to consider carefully any factors that could influence interpretation of the data. These included the first author's belief about support in times of difficulty and consideration of how having a child with a long term health condition might feel, particularly for a condition which carries stigma. Finally, an independent audit trail was completed of the analysis process to further determine validity (Smith et al., 2009).

Results

The analysis resulted in four master themes, each with a number of related sub-themes. These are described below and illustrated with quotes from the interview transcripts.

Master theme one: evolving support needs

This first master theme encapsulates the evolving challenges and areas of need which are faced by the mothers as their child develops.

Developing support needs. Participants identified periods of time in the child's development when they had felt particularly in need of support and also aspects of their child's future development about which they currently had worries. Five participants spoke about the years following birth as a particular time of need, while adolescence was the period of the child's development which was most frequently talked about by participants:

“she's sort of started to hit puberty now and there are lots and lots of issues around that... so I am going to need to access something I think at that point”

Seven participants also identified the need for support in communicating with their child about the diagnosis:

“as they get older I want to know the right things I should be saying to help them to come to terms with it... I'll need support to help talk about it”

The prospect of surgery also created worry and the need for support from professionals. Although separate from the development of the child, two participants identified the prospect of having another child as a time at which they needed additional support.

Emotional support needs shifting. Three participants identified a sense of the diagnosis being on the mother, or the family, rather than the child:

“R: It sounds as though one of the things which has been good with the nurse is her acknowledgement that this is something which is also having an impact on you as well as your children

P: I think especially when they're so young, because they have absolutely no understanding, so really it is you, even though it's not your diagnosis, it is you that's dealing with it and coming to terms with it, not them at all... they don't have clue what's going on”

With this was the notion that the need for emotional support was initially within the family. However, there was an impression from the participants that this changed over time, and this was acknowledged in their dialogue about the child's emerging need for emotional support and a private space:

“beyond that really to her teenage years and beyond to adulthood, it's really about helping her and... allowing her to see that there can be a useful relationship with (professionals) if she chooses to have that”

Learning curve. Six participants referred to a learning curve which occurred in the period initially after birth and across the first few years of the child's life. For some participants, this seemed particularly salient around the giving of injections.

Master theme two: seeking understanding

This second master theme depicts the process of seeking knowledge and understanding about the child's diagnosis and seeing this as a means of both coping and ensuring the best for the child.

Uncertainty brought by the diagnosis. All participants spoke about the uncertainty that the diagnosis created. This included a lack of awareness about the existence of DSD conditions, as well as the sense of uncertainty that was created around the child's future:

"knowing what to expect... looking to the future, that kind of gets taken, but not replaced with anything"

There was a sense of relieving this uncertainty by gaining knowledge about the condition and its treatment and that with a thorough understanding came the power to ensure the best for the child.

Professionals facilitating understanding. Participants viewed professionals as people who could support their understanding of their child's condition, its causes and the treatment. For four participants, there was a sense that their understanding was not well facilitated:

"R: It sounds as though you take an approach of wanting to find out the facts and core information about how your children will be assessed...."

P:...what is it that you're measuring, what it is that you're looking for, I just don't really understand and still these are questions that are not really being answered"

Attempts to understand the cause of the condition were hindered by the use of jargon, “*all this medical jargon... it does blind you with science*” and the timing of such explanations, “*He did explain, but you’re just not in the right frame of mind to take anything in*”.

Participants spoke of communications with professionals which they felt facilitated their understanding well, or when they felt well guided by professionals around important decisions:

“this was the first time we’d actually been explained the process of what actually happened when the baby is formed and why the chromosomes do that, and what it means”

Independently seeking information. Participants spoke about their search for information aside from contact with professionals. This most frequently took the form of the internet. For two participants this was in response to a lack of information from professionals:

“I’d go back (from an appointment) and read another medical article, or you know, Google the effects of low cortisone production and try and [SIGHS] make myself feel better”

The majority of participants felt that the information available on the internet was not helpful and had a negative impact or that they would rather hear the information from a professional:

“I started reading quite a lot of posts that people had put up and I didn’t find that at all useful cause I found it all very negative and quite depressing to be honest”

For a small number, the information on the internet was felt to be beneficial as it helped them to understand the condition.

Master theme three: parental emotional needs in a medical setting

This third master theme encapsulates the participants’ need for ongoing emotional support within a medical system which prioritised the physical health of the child.

Emotional impact of the diagnosis. All participants reported a strong emotional response to the diagnosis reporting that it was “*painful*” and “*it was just a frightening place*”. For three participants, the longer term impact on their wellbeing was identified, “*that triggered the depression... really*” as well as the sense of isolation that caring for a child with DSD created, “*I just kind of feel quite alone*”.

Parental emotional support needs unacknowledged. The majority of participants expressed a sense that while the medical care their children received was very good, the emotional impact on the parents and family was not well acknowledged among professionals:

“R: Who were your main sources of support at that time[diagnosis]...and how did they meet those needs?”

P...we're so blessed to have been able to get the medical support for her that we did but I think there is some aspects that are really quite overlooked with supporting the parents really and trying to keep the parents sane through the whole thing"

Attempts to establish how parents were coping were felt to be limited. It was felt that at times professionals did not notice the signs that participants were in need of emotional support and therefore opportunities to offer support were missed.

Not feeling heard. In the context of their needs not being met, six participants referred to a sense of not feeling heard by professionals, which at times related to power differentials between the medical professionals and the patients or families:

"a lot of things get, can get brushed off, you know"

"and I'll say things like (...), and have done since I can remember, 'but she's still really rough and tough and aggressive' and err it will just be fobbed off with, 'oh well you know'"

At times this related to power differentials between the medical professionals and the patients or families. A minority of mothers indicated that they felt that at times their concerns were seen as overprotective or over the top.

Intermittent support. Participants expressed a need for ongoing and continuous support. A sense that support was 'there' and 'available' seemed important in helping participants to feel well supported, particularly when participants felt that there was an

individual clinician whom they could contact when they were concerned. Some participants expressed that support was only forthcoming in the context of a crisis:

“that’s just crisis control that’s just you know, getting you through the hardest days, I don’t think anybody really grasps that the other days are pretty bloody hard as well”

It was also expressed that while there was good support available at the time of diagnosis, this seemed to dissipate as time went on:

“to start with I sort of thought that (the support) was fine but then I think as the times gone on... I’ve actually felt more alone, because I guess to start with there’s that initial kind of buzz... and then it all just sort of peters off and you’re just kind of left to get on with it”

Valuable experiences addressing emotional needs. Although not all participants felt that they had been well supported overall, six participants identified some interactions or experiences, outside of those with family or friends, which had clearly been of value to them emotionally. These had occurred to some extent with medical professionals, however clearer examples of this occurred in the process of meeting or hearing about the experiences of other mothers of children with DSD, either on the internet, via support groups or facilitated groups. What seemed to be important in all these interactions was that it reduced feelings of isolation, or being the ‘only one’:

“just the fact that you know that someone else is going through that. I know it’s silly but, I don’t know, it just relieves you a bit, you just think oh yes someone else knows exactly how I feel and that... helps, really helps... talking to the other parents, just knowing that actually he’s not the only child... like that”

Participants also spoke of the acceptance which seemed to be present when talking to other mothers of DSD children, and the importance of having their own feelings and responses to the diagnosis normalised.

For participants who had not experienced a support group or talking with other mothers in the same situation there was a sense that this could be helpful, and such a process was likened to their experiences of other supportive groups which had created a sense of acceptance:

“I went to a breast feeding support group when I had my first (child) and it was the best possible thing cause we just all used to go talk about what was crap, have a whinge, have a cup of tea and feel better (umm) and there’s no way to do that with this, cause nobody understands”

Master theme four: close support networks

This fourth master theme encapsulates the nature of the support networks that participants identified and the conflicts which sometimes existed for participants in maintaining privacy around the condition and within the support network.

Privacy over support. All participants expressed strong protective feelings towards their children which seemed to be in relation to the child's future and the social implications of the condition. This resulted in participants talking minimally about their child's diagnosis:

“you kind of keep it minimal, cause you know she's going to have to grow up and deal with this and you know, you don't want people knowing her innermost secrets”

Maintaining privacy for the child seemed a priority for all participants:

“irrelevant of what I want to share with such and such or this is a burning issue that I feel like I want, you know, my friends to know or whatever, erm that's not my priority”

Three participants felt that this privacy was directly limiting in how much they were able to talk about their child's condition and in the level of support that they were able to utilise but it was also acknowledged that 'telling people' did not equate with being supported, *“with some people, why would I be telling them... they're not going to be any support to me”*

Support network. Six of the participants identified a small network of individuals who were recognised as their main supports. Who was in this network seemed largely based on who was trusted, and close enough to the participant to know about the condition and offer support and as such support networks tended to be predominantly made up of

family and close friends. However three participants also identified a professional who was deemed to be a key source of support:

“the endocrine nurse... I would say she’s been the biggest support, she is amazing, she is a wonderful lady”

Variations and limitations in the kinds of support that individuals in the network could provide were identified, acknowledging that emotional, practical and medical support often came from different individuals.

Of those who had a ‘network’ two participants expressed that it provided ‘enough’ support. However those who seemed to lack a sense of a support network around them identified isolating themselves from those who could offer support, and the strain that the diagnosis had placed on family relationships:

“it pushed us to the edge and quite a few times we very nearly did split up, this being a major factor in it”

Impact on typical parental supports. Five participants seemed to vocalise that the child’s diagnosis had a negative impact on how they accessed typical parental supports available through universal services and within their own family and social context, such as the baby clinic, mother and baby groups and utilising family or friends to look after the child. Attendance at such groups seemed to act as a reminder or emphasise the child’s diagnosis:

“to go to something that I thought was going to be nice and getting him weighed, turned into something horrific... I just felt so different... I found it quite hard”

Difficulty in relinquishing control over administering medication also seemed to influence how readily mothers left their child in the care of others.

In summary, there was a clear sense of the emotional impact and the uncertainty that the diagnosis had on participants, and their desire to learn and understand the condition was generally poorly facilitated by professionals. Many participants felt that their emotional needs went unacknowledged within the medical system and while for some this was met adequately elsewhere, others felt their emotional needs were unmet. The need for continual support to be ‘there’ was emphasised.

Discussion

The purpose of this study was to develop an understanding of the support needs of mothers of children with DSD and to appreciate how these may change over time. It also aimed to understand how well mothers’ experiences of support had met their needs and to identify aspects of support which may have been lacking. The results suggested that mothers of children with DSD have varying support needs which evolve over time and include the need to understand the condition, as well as the need for emotional support for the family and the child. While some mothers have had valuable experiences of support from small networks of individuals, others found their emotional

needs largely unmet. The results will be considered below in relation to the research questions and existing literature.

Support needs

The themes 'evolving support needs', 'seeking understanding', and 'parental emotional needs in a medical setting' offer relevant information in understanding the support needs of participants and how these needs may change over time in relation to the child's development. Overall, participants identified two key ways in which they needed to be supported: firstly to be supported in developing an understanding of their child's condition, their future and the treatment implications and, secondly, to be supported emotionally.

Parents identified a number of times when they felt that their need for support was increased. The need for support at the time of birth and in the year or so following birth was significant and this was emphasised by the idea of the 'learning curve'. Other times at which increased support had been sought or was anticipated included surgery, adolescence, communicating with the child about the diagnosis and having other children. The need for support around the time of birth and surgery has been identified in previous literature (Crissman et al., 2011; Sanders et al., 2007) and the importance of developing understanding, and learning to manage medication is particularly important in improving the self-efficacy of parents of children with the DSD diagnosis Congenital Adrenal Hyperplasia (Fleming, Rapp, & Sloane, 2011; Mitchelhill et al., 2013).

Parental anxiety about puberty and adolescence in children with DSD has also been reported elsewhere (Crissmann et al., 2011).

A key task at this time which was identified by the participants in the present study concerned communicating with the child about the diagnosis. The importance of children understanding and receiving a full disclosure of their diagnosis has previously been reported (Slijper et al., 2000; Sutton et al., 2006) and research has identified that children with a genetic condition wish to know about their condition and its causes by the age of 12 (Szybowska, Hewson, Antle, & Babul-Hirji, 2007).

Experiences of support

In considering participants' experiences of support and how well their support needs were met the themes of 'close support network', 'emotional needs in a medical setting' and 'seeking an understanding' were relevant.

Consistent with previous research, participants strongly associated with feelings of protection towards their child (Kirk et al., 2011) and maintaining privacy about their child's diagnosis in order to protect them from possible negative social and emotional outcomes (Crissman et al., 2011; Sanders, Carter, & Goodacre, 2012). While maintaining privacy about DSD has been identified as stressful for parents (Crissman et al., 2011), only a minority of participants felt that maintaining privacy impacted negatively on the support they received, acknowledging that others being aware of the condition does not equate to being supported.

Though many participants identified a close support network, predominantly consisting of family, few felt that this adequately met their needs. Previous research has suggested that parents have not found it helpful to talk to relatives (Duguid et al., 2007) and the limitations of the support network identified by participants in this study may further explain the limitations to the support that family can offer. This idea that parents may feel isolated and struggle to talk with family may be related to the idea of unexpected transitional change (Burnham, 1986). Within this, due to these unusual family circumstances, it is harder to draw on the extended family, community support or extant knowledge, which in turn can create isolation.

The majority of participants described difficulties in having their emotional needs acknowledged within the medical setting. For some participants, not only did they feel that medical professionals did not understand the emotional impact of the diagnosis, some also felt that professionals missed opportunities to offer support. Similar findings have been reported in areas of childhood chronic illness, where professionals lack the time or training to address non-medical factors in care (Farmer, Marien, Clark, Sherman, & Selva, 2004).

The importance of support which generated feelings of acceptance and reduced feelings of isolation was identified and occurred occasionally with medical professionals, but predominantly through contact with other mothers in a similar situation. For mothers to find a space where these supportive qualities exist is clearly

important and parent support groups may be one such space. The value of parent support groups in child chronic health is widely accepted. The potential benefits for parents of children with DSD have been highlighted here and previously by Lee et al. (2006), although complexities in accessing support or advocacy groups around DSD have been identified (Lee & Houk, 2010).

The majority of participants spoke about the need for ongoing and continuous support rather than crisis based support. The importance of knowing that support was there should it be needed seemed central to participants feeling well supported and several participants felt that it would be helpful to have an allocated worker who could be the main point of contact taking an overall view of the child's care.

Participants' understanding of the condition and its cause was often poorly facilitated by professionals. Previous research has highlighted the importance of gaining information from the medical team in reducing the stress of parents of children with DSD in the early stages of diagnosis (Crissman et al., 2011). Factors contributing to the poor facilitation of understanding identified in this study are similar to those that have previously been reported including too much information at an inappropriate time (Sanders et al., 2011), the use of technical language (Crissman et al., 2011) and difficulties in communicating with professionals (Duguid et al., 2007). Participants also spoke of their own search for information, which although positive for some, proved negative and difficult to contextualise for others. While no previous literature appears

to address the potential benefits, or otherwise, of seeking information regarding DSD on the internet, Lee and Houk, (2010) recently identified the need for a cautious approach to information available from support and advocacy groups, particularly in light of the changing treatment of DSD conditions.

Limitations and areas for further research

While this study benefitted from participants whose children were at a range of developmental stages, the variation in time since diagnosis may have impacted on the mother's adjustment to their child's diagnosis and the treatments received. While it is felt that participants in this research reported a wide range of experiences regarding support, it is acknowledged that the opportunistic nature of this sample may have resulted in a bias for mothers who were, at the time of the interview, generally coping with their child's diagnosis.

Further research should seek to expand on the impact of DSD on the family. This could usefully look at the experiences and needs of fathers, as research in other areas of child health has indicated that mothers and fathers may differ in their responses to child illness (Knafl & Zoeller, 2000) and fathers are an under-represented group in child health research (Ware & Raval, 2007). Research could also consider the impact on siblings given that for some DSD, siblings may be carriers of the condition. Understanding when and how families address this with siblings and how they are supported in this process is important. It is also acknowledged that this sample of

white-British mothers does not reflect the ethnic diversity of parents accessing services for children with DSD in the UK and it would be useful to explore the impact of DSD within families of other ethnic or cultural backgrounds.

Clinical implications

The consensus statement on management of intersex disorders (Hughes et al., 2006) highlights psychology as a core member of the multidisciplinary team in providing treatment to these individuals. The findings of the current research reveal clear and important clinical implications for those working with individuals with DSD and their families which may inform best practice guidelines in the future.

There is a need to develop awareness among all professionals working with these families about the potential emotional impact and the need to make emotional support available. It needs to be understood that the medical system does not readily facilitate the emotional support which families may require and therefore this needs to be given particular consideration in addition to the medical care which is provided.

Training needs to be provided to professionals in contact with these families to ensure that they have the necessary skills to identify when the family or parents may need emotional support and to provide basic emotional support. These professionals need to know how and where to refer families or parents who may need more extensive or specialist support, and families should routinely, and regularly be offered the option

of meeting with a clinician who can support the emotional needs of the parents as these change throughout the child's development.

Parents need to be provided with detailed information about the aetiology and course of the diagnosis and information regarding both the physical and psychosocial implications. While this may be usefully done through the use of resource packs or books, this needs to be carefully facilitated by professionals. While mothers want accurate and clear information about the child's future, this needs to be managed in a therapeutic manner which aims to contain parental anxiety and support the parent to tolerate the uncertainty which the diagnosis can bring for them. In addition, to aid this process of understanding parents or carers should be offered a follow up appointment shortly after the diagnosis in which more detailed discussion about the diagnosis and its implications can take place. Reducing isolation among mothers of children with DSD is important and in the correct environment, contact with other mothers appears to facilitate acceptance and understanding. Hospitals which offer specialist DSD clinics should set up means by which parents can be in contact with other parents of children with DSD. This may be achieved through a 'pairing' basis or the facilitation of parent support groups.

As continuity of support was identified as key, a means of providing support outside of medical appointments is required. This could be achieved by allocating a

clinician who is available outside of these appointments to be a main point of contact who can deal with concerns or signpost to other professionals or services.

Conclusions

This is the first study to specifically explore the support needs and experiences of mothers of children with DSD. Key support needs included facilitating knowledge and emotional support. Periods of time in the child's development when these needs were most prevalent were identified. Participants outlined the difficulties in accessing emotional support in a medical setting and discussed how these needs were, for some, met elsewhere, either in small support networks or through mothers with shared experience. While privacy about the condition was a priority, few felt that this directly impacted on support. These findings add to the existing literature on parental experiences of having a child with DSD and expand our understanding of the role of support. The findings have important clinical implications for professionals working with families of children with DSD.

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