

“Something you have to do” - Why do parents of children with developmental disabilities seek a differential diagnosis?

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This basic interpretive study addressed the reasons why parents seek a differential diagnosis for their child who has a developmental disability. Fourteen parents were interviewed about why they sought a label for the disabilities of their child. Participants included six parents of children with identified genetic conditions, three parents of children with diagnosed autism spectrum disorders, and five parents of children with unidentified developmental disabilities. Parents described searching for a diagnosis because of the importance of “knowing,” understanding the cause for the disability, gaining knowledge about future expectations and appropriate interventions, and gaining access to funding or specific services. An application to Patterson’s (1988, 1989) Family Adjustment and Adaptation Response model (FAAR) is presented.

The value of labels has been debated in the literature (Gillman, Heyman, & Swain, 2000; Lauchlan & Boyle, 2007; McDermott, Goldman, & Varènné, 2006; Watson, in press) and many theorists disagree about the value of labelling a disability. However labels can serve an important function in providing information regarding strengths and weaknesses (Griffiths & Watson, 2004), as well as in accessing services and funding. Families often embark on a major quest for a differential diagnosis for their child, but the American Association on Mental Retardation (AAMR; 2002) reports that 30 – 40% of individuals with developmental disabilities do not have a specific diagnosis. Consequently, many families may search for a differential diagnosis for a prolonged period of time or never receive a specific label for the disability of their child.

This study is an investigation of the family experience of the diagnostic process and asks what meaning a differential diagnosis provides to

families. More specifically, it seeks to understand why families search for a differential diagnosis for their child. For the purposes of this study, the term *differential diagnosis* will refer to a specific diagnosis, such as Angelman syndrome or autism, contrasted with a nonspecific diagnosis such as global developmental delay. The present study extends the literature on family adaptation to diagnosis of a disability by using an interpretivist perspective (Merriam, 2002) to examine the ways in which families adapt to their child’s differential diagnosis or lack of differential diagnosis. I interviewed both families of children with a differential diagnosis as well as families of children who are still looking for a specific diagnosis. Following the interviews, I analyzed the data using thematic analysis (Merriam, 1998).

Literature Review

The following literature review begins with a brief description of the theoretical approaches typically applied to research on families of children with developmental disabilities and then addresses research conducted specific to differential diagnosis. The Double ABCX model of family functioning (McCubbin & Patterson, 1983, 1987) will be discussed, followed by the Family Adjustment and Adaptation Response (FAAR; Patterson, 1988, 1989) model. This theoretical discussion will be followed by the limited literature on differential diagnosis and families.

Research on the experience of parenting a child with a disability often applies the Double ABCX Model of family functioning (McCubbin & Patterson, 1983, 1987). Several variations of this model have been proposed, but the basic model describes how families adjust and adapt to crisis situations. The model proposes that familial adaptation (*XX*) to a crisis is shaped by the following factors: severity of the stressor (e.g., severity of the child’s disability) and pile-up of demands or additional life stressors (*aA*); the family’s resources, capabilities, and strengths (e.g., social support) (*bB*); and the family’s subjective definition of the stressor and its effect on the family (*cC*). Each of these factors build up over time, explaining the double *a*, *b*, *c*, and *x* factors. This subjective meaning reflects the family’s values and previous experience in dealing with change and crisis (McCubbin & Patterson, 1987). Hodapp, Dykens, and

Masino (1997) state that, although this model has proven useful, many aspects remain vague, specifically, the individual characteristics of the child, which influence the *aA* and *bB* factors. Such a critique is relevant to the present study, which focuses on differential diagnoses and the concerns of families with specific kinds of developmental disabilities.

The FAAR model (Patterson, 1988, 1989; Patterson & Garwick, 1994, 1998) is similar to the Double ABCX model (McCubbin & Patterson, 1983, 1987) and may be considered an elaboration, amplification, or reconsideration of the model. While the Double ABCX Model considers how various factors interact to produce a degree of adaptation at any given time, the FAAR model is focused on the balance of these factors and how the resulting state of adaptation develops over time. An important component of the model is called *appraisal*, which plays an essential role in moderating child and environmental factors. Appraisal is how an event is perceived by an individual, how one evaluates a situation in terms of its relevance to oneself, such as one's goals or well-being (Lazarus, 1966). From an interpretivist perspective, appraisal might be seen as a lens through which parents view their child and other environmental factors. The presence of appraisal as a factor in the model implies that "objective" measures of child factors such as age, intelligence, diagnosis, and behaviour may be less significant in determining parental responses than the parents' interpretation of these characteristics. One parent may view the same differential diagnosis and the same behaviour as catastrophic, while another may view it as a minor concern. While parental predisposition and parental choice may be important factors in parental appraisal, professionals, social contacts, and the world in general may play a major role in influencing parental appraisals of their children's conditions. Therefore, research that looks at the effects of specific diagnoses on parental responses may reflect unique child characteristics but might equally reflect the socially-constructed and shared appraisals that influence parental responses.

The FAAR singles out two important factors in appraisal more precisely, situational meanings and global meanings (Patterson, 1988, 1989). Situational meanings refer to specific appraisals of challenges and resources in a specific circumstance (e.g., getting help for the child at

school, responding to in-law criticism of parenting) while global meanings refer to a more general set of cognitive beliefs about family, community, and life in general (Patterson). In a reformulation of the FAAR, Patterson and Garwick (1994) proposed that global meanings can be further divided into family identity and family worldview. Family identity addresses how the family views itself, including relationships, roles, and norms. Family worldview addresses how the family interprets reality, their core assumptions about their environment, and their existential beliefs, such as their purpose and place in life. Situational meanings and global meanings continuously interact with each other. Global meanings act as templates that help determine how an individual will respond to specific situations. Successes or difficulties in applying situational meanings produce frequent refinements and occasional reformulations of global meanings.

Both situational and global meanings are significant for the present study because they can add to or reduce stressors or strains that may occur. Specific to the diagnostic process, Patterson (1989) states that, for a diagnosis to be accepted, it must somehow fit with the family's existing set of beliefs, which are integral to their worldview. Therefore, if a family is not comfortable with a diagnosis or does not understand the diagnosis, this will upset both their global and situational meanings, which may lead to disruption in functioning, called maladaptation.

Addressing meaning is important for both parents and for interpretive research. In a study of parents of children with Asperger syndrome, Pakenham, Sofronoff, and Samios (2004) found that parents' ability to ascribe meaning to their child's disability and their own parenting experiences had a significant influence on their experiences. Parents in this study adapted better when they were able to make meaning of the disability. The emphasis on meanings in the FAAR model is therefore imperative for studying family experience and critical in an interpretivist study, since the study endeavors to understand the meaning of differential diagnosis to the family. The following section will outline the limited research that has been conducted on families and their search for differential diagnosis.

Diagnosis Research

Most people seek explanations for events and experiences that they regard as illness or disability for several reasons. Griffiths and Watson (2004) discuss the perceived benefits of differential diagnosis, including increased support for families, caregivers, and the individual; knowledge regarding the individual's learning challenges and strengths; as well as knowledge regarding medical or mental health risks and resiliencies. Clinically, it can be important to know about genetic diagnoses because the underlying genetic mechanisms are related to phenotypic differences among individuals with different etiologies for a genetic syndrome or any other condition (Summers & Pittman, 2004) and many disorders are associated with specific medical conditions that can affect quality of life. It is essential to recognize that these benefits are apparent, whether the differential diagnosis is of genetic origin or not. Differential diagnoses provide information and may allow families to make more informed decisions about their child's health and supports.

In Gillman et al.'s (2000) study of individuals with developmental disabilities, their families, and professionals, it was found that parents of children with disabilities sought a differential diagnosis in order to relieve the stress or ambiguity of the unknown and in the belief or hope that identification and classification of the symptoms would result in treatment, intervention, and social support. Families also believed that a differential diagnosis would finally lead to an improved quality of life for the family and the individual. Gillman et al. also talk about a hierarchy of disabilities, discussing how some labels are more stigmatizing than others. These authors provide the example of a hearing or visual impairment, which is often perceived as less stigmatizing than a learning difficulty. They further maintain that families may search for an alternative label that is regarded by the person or society as less disgraceful. It is also critical to recognize that some labels might be more stigmatizing to the child and some labels, such as Fetal Alcohol Spectrum Disorder, may be more stigmatizing to the parent.

Burden (1991) postulates that not having an understandable cause for a disability is one of the reasons parents may experience guilt in reaction

to having a child with a disability. Burden suggests that when the etiology of the disability can be satisfactorily explained, there will be a reduction in guilty feeling, but as long as the etiology “remains shrouded in mystery, the likelihood of self-blame is greater” (p. 333). This is supported in Burden’s study of psychosocial transitions in the lives of parents of children with disabilities. Burden studied three groups of mothers in London, England. One group of mothers were recipients of service after the differential diagnosis of the child’s disability, a comparison group consisted of mothers whose children had been similarly diagnosed but did not have professional support until the child was 2 years of age, and a third group of mothers whose children’s disabilities had not been formally diagnosed participated in the study. Burden found that mothers of children without a differential diagnosis had more difficulty working through their feelings of anger and guilt than mothers in the other two groups. Mothers in this group also reported higher levels of family crisis and were less successful than other groups in working through these crises.

Families have also cited benefits to receiving a differential diagnosis for their child. In their questionnaire study of 254 families of children with Fragile X syndrome, Carmichael, Pembrey, Turner, and Barnicoat (1999) found that most families considered having a diagnosis a benefit rather than a disadvantage. Families have reported benefits of receiving a differential diagnosis, including appropriate intervention (Carmichael et al.; Poelmann, Clements, Abbeduto, & Farasad, 2005), contact and support from other families (Carmichael et al.; Wilcox, 1991), and help explaining to their friends (Carmichael et al.; Gillman et al., 2000). Being informed also plays a part in parents’ sense of control, which has been found to contribute to parents’ positive adaptation to having a child with a disability (Knox, Parmenter, Atkinson, & Yazbeck, 2000). When parents do not know what is unique about their child, they feel a lack of control over the situation because they do not have the pertinent information to help their child (Knox et al.). Patterson (1989) highlights the importance of control when looking at the resources of a family. Resources include intelligence, knowledge and skills, time, health, and other factors, but also a sense of mastery, which Patterson describes as the belief that one has some power over the circumstances of one’s life. If one has limited

resources, then this can lead to maladaptation. Maladaptation is also the result when families have difficulty attributing meaning to an experience.

The meaning a differential diagnosis provides to the family can contribute to coping processes and social support (Pakenham et al., 2004). Even when the formal information is “unpalatable” (p. 12), Leonard (1999) has found that parents prefer “knowing” to the frustration and anxiety associated with the uncertainty of not knowing what is wrong with their child. Although there have been a few studies on the benefits of receiving a differential diagnosis, little is known about the effects on the family of nonspecific developmental delays or disabilities of unknown etiology (Keogh, Garnier, Behnheimer, & Gallimore, 2000).

Trute (2005) believes that the greatest stressor for parents is “not knowing” and this contributes to the fear and anxiety experienced by parents. Not knowing may take several forms; this could include not knowing how or why the child has a disability, not knowing what to expect in the future, or not knowing if there is something useful that would help the child. Not knowing is also a concern for parents of children with diagnoses such as autism or pervasive developmental disorder (PDD) because these diagnoses are made on strictly behavioural grounds (Lord & Risi, 2000), leaving many parents wondering whether the diagnosis of autism is “correct.” In other disabilities, such as Angelman syndrome, the diagnosis can be genetically confirmed in 80% of cases, but 20% of cases are diagnosed clinically and there is often uncertainty about the correctness of the diagnosis (Williams, Lossie, Driscoll, & the R.C. Phillips Unit, 2001). Rett syndrome, PDD, and childhood autism have been cited as mimicking conditions for Angelman syndrome (Williams et al.).

It is vital to recognize, however, that seeking a differential diagnosis is rarely a positive experience for most families. Several researchers describe the negative perceptions of parents in dealing with professionals while seeking a diagnosis for their children (Leonard, 1999; Pianta, Marvin, Britner, & Borowitz, 1996; Poelmann et al., 2005; Watson,

manuscript in preparation; Woolfe & Bartlett, 1996). Leonard also describes parents who discover the differential diagnosis by accident or parents whose doctors have withheld the diagnosis in trying to protect the family, thus resulting in a negative experience.

Although many researchers have theorized about the perceived benefits of receiving a differential diagnosis, few studies have actually asked families why they want a diagnosis and what meaning a diagnosis would provide. Moreover, little is known about the experience of families who do not receive a differential diagnosis and an exploration of this experience is significant. The following study addresses the meaning of a differential diagnosis and why families seek such a diagnosis for their child.

Methodology and Methods

Methodology

A basic interpretive approach, drawing from phenomenology and symbolic interactionism, was chosen to address the research questions because the overall purpose of this methodology is to understand how people make sense of their lives and their experiences (Merriam, 2002). Such an approach allows researchers to uncover what meaning individuals attribute to their experiences, how people interpret their experiences, and how they construct their worlds (Merriam).

Constructionism underlies this approach to research and recognizes that individuals construct reality in interaction with their social worlds (Merriam, 2002). As discussed by Crotty (1998), “meaning is not discovered but constructed. Meaning does not inhere in the object, merely waiting for someone to come upon it... Meanings are constructed by human beings as they engage with the world they are interpreting” (pp. 42-43).

Procedure

I recruited family members through respondent-driven or snowball sampling, a technique often used in hidden populations that are difficult for researchers to access (Salganik & Heckathorn, 2004). Families were contacted through disability support organizations such as the Association for Community Living and the Canadian Angelman Syndrome Foundation. I also used word of mouth, communicating with professionals I knew who might know families interested in participating in the study.

Participants

Fourteen parents participated in the study, representing 13 families of children with developmental disabilities. A family was defined as anyone the parents considered to be a member of their family and all family members were invited to participate. Although extended family or other individuals were open to partake in the interviews, parents, specifically mothers, made up most of the participants. Twelve participants were mothers and two were fathers. Unfortunately, busy time schedules prevented meeting with two additional fathers who wanted to participate. Please note that when referring to family members, including children, identifying information has been changed and pseudonyms have been used.

Families had children with a range of developmental disabilities. Six parents who participated represented five families who had children with specific genetic disabilities: Shannon and Gillian both have a child with Angelman Syndrome; Stuart and Francine are also the parents of a daughter with Angelman syndrome; Tom and Kathy both have daughters with rare chromosomal abnormalities. Three participating parents, Ingrid, Collette, and Farah, participated who had children with diagnosed autism spectrum disorders, ranging from PDD to Asperger syndrome, with two of these families having two children with disabilities. Finally, five participating parents, Nina, Judy, Deborah, Theresa, and Phoebe had children with unidentified disabilities or nonspecific developmental delay. Differentiating between the types of

disabilities became more complicated than I had anticipated; I originally thought it would be clear about how to identify families, but the distinction between groups was a blurred continuum. Nina, for example, disagreed with the differential diagnosis of their child, while Phoebe and Deborah were certain of an autism spectrum disorder diagnosis, but an official label has never been given. The above categorization represents the manner in which I thought it best to classify families and this grouping corresponded as closely as possible with parents' own beliefs about the label for their child.

Interviews

I invited parents to participate in individual semistructured interviews. Stuart and Francine, married, were interviewed separately in order to allow each parent a chance to speak. Trute (1995; 2005) has found gender differences in mothers' and fathers' reactions to disability and recommends interviewing parents separately to facilitate a more in-depth analysis of each parent's meanings of the experience. Most interviews were conducted face to face but, for some parents, the majority of correspondence occurred over the phone or via e-mail due to busy time schedules. In-person interviews took place at the convenience of participants and in locations agreed upon by both the parent and me, such as coffee shops, family homes, and participants' places of employment.

The interview process began with an orienting interview, where the participant and I went over the study description and consent was discussed. This orienting interview typically took place over the phone. Following this initial orienting interview, a semistructured interview was conducted, as described below, lasting approximately one hour. Follow-up questions were asked of the participant, using e-mail and telephone conversations.

The semistructured interviews blended more and less structured questions (Merriam, 2002) and each interview involved three segments. I first asked families to describe their son or daughter and to tell a favorite family experience. The goal of this first segment was to establish rapport

with the parent while allowing the participant to discuss either strengths or weaknesses of his/her child and how these characteristics have affected the family. The second part of the interview focused on the process of learning the child's diagnosis; I asked the parent to chronicle the diagnostic process, including their initial concerns about their child's development; recalling any emotional experiences related to receiving or failing to receive a differential diagnosis; and asking parents to assess any changes in their thoughts or feelings between the initial suspicion of a developmental disability and a differential diagnosis. For families who had failed to receive a differential diagnosis for their child, questions were adapted to reflect this. Before concluding the interview, I asked parents to discuss their child's developmental progress since the diagnosis or lack of diagnosis, including any experiences that have helped or hindered themselves and/or the family. This question provided an opportunity for families to give recommendations for making the diagnostic process better for families.

Consent and Ethical Issues

I received informed consent from all participants and I also revisited consent throughout the research process. I employed "process consenting" (Munhall, 1989), which allows the researcher and participant to assess consent throughout the study. This provides more protection and freedom of choice for participants since unforeseen issues inevitably arise and risk can never fully be anticipated. This is especially true when dealing with sensitive issues. Such an approach to consent allows the participant the freedom to withdraw from the interview or study at any time and ensures that the participant has a say in confidentiality throughout the research process.

Absolute confidentiality cannot be guaranteed, but I took reasonable measures of ensuring privacy throughout the study. I changed participant names and any other identifying information for data presentation, plus interview transcripts and recordings were kept in a locked filing cabinet to ensure safety of the information. I also invited participants to read the transcripts to ensure accuracy. Since parents

were consulted throughout the study, they were also able to make changes as needed to ensure confidentiality to the best possible extent.

Analysis of Interview Data

I digitally recorded all interviews and transcribed the contents verbatim. I reviewed digital recordings and transcripts several times to familiarize myself with the content of the interviews, plus listened to the recordings carefully in order to enhance the written word by the nuance and tone conveyed on the recordings (Heneghan, Mercer, & DeLeone, 2004). Because I was both the researcher and interviewer, I had more insight and in-context knowledge and was thus able to establish a variety of important links between the research questions and the data gathered (Litosseliti, 2003).

After careful transcription and thought, I conducted a thematic analysis on the interview transcripts (Merriam, 1998) by reviewing transcripts, making notes and comments throughout. A codebook was kept, including a detailed description of the code, inclusion and exclusion criteria, and exemplars of real text for each theme (MacQueen, McLellan, Kay, & Milstein, 1998).

I followed Merriam’s levels of analysis, beginning with a descriptive account, followed by category construction, then making inferences. A descriptive account is a narrative that conveys the meaning the researcher has derived from studying the topic of interest. The second level of analysis is the construction of categories or themes. However, before themes may be created, codes must be organized as a way to organize the data. According to Merriam, “category construction is data analysis” (p. 180), supporting Miles and Huberman’s (1994) statement that “coding is analysis” (p. 56). Ryan and Bernard (2003) recommend looking for repetitions in the data, as well as looking for transitions and linguistic connectors. In speech, pauses and changes in voice tone may indicate a transition and connectors may indicate a new theme. I also compared and contrasted participants’ responses in order to uncover themes. DeSantis and Ugarizza (2000) make the important distinction between the terms categories, factors, variables, and themes, critiquing

much qualitative research that confuses these terms, thus compromising methodological rigor. DeSantis and Ugarizza define a theme as “an abstract entity that brings meaning and identity to a recurrent experience... A theme captures and unifies the nature or basis of the experience into a meaningful whole” (p. 362). Once themes emerged from the data, inferences were made and I summarized the data. A summary of the data now follows.

Findings

Parents sought a diagnosis for many reasons and spoke about the meaning a differential diagnosis had for them. Five themes emerged from the interviews. These themes included the importance of “knowing” and having a name; knowing the cause for the disability; understanding future expectations; obtaining knowledge regarding appropriate interventions; and gaining access to funding or specific services. Each of these themes will be discussed in turn.

“It was something you have to do”- The Importance of “Knowing” and Having a Name

Many families could not articulate why they needed to “know,” yet they felt the pressing desire to have a differential diagnosis for their child; the search was described as simply something you “have to do.” Parents discussed the need to receive a diagnosis because their child was ill, they knew something was wrong, or they felt that having a name would make it easier to explain their child’s behaviour to others.

Eleven of the parents reported knowing that something was “going on” with their child and were concerned because their son or daughter was missing developmental milestones. Some parents discussed simply having a sense that something wasn’t “quite right.” As Tom, the father of a child with a rare genetic disorder, recalled, “She just wasn’t growing and I remember [my wife] was so concerned about... When she missed a certain number of milestones, our concern grew and grew and grew.”

Theresa, the mother of a son with an unidentified developmental delay, remembers suspecting for a long time that her son had some presenting issues, but “it wasn’t until he was probably two or more that we knew what it was. As a mother, I think I always knew something was wrong, for some reason right off the bat, I just sort of knew, I just sort of had a feeling.” Many parents shared this sentiment and almost all families discussed the suspicions they had regarding their child’s development. Shannon, the mother of a son with Angelman syndrome, remembers:

I just knew there was something wrong because he wasn’t progressing like other children. At five months old he still was unable to hold his head, he could not focus his eyes, he cried a lot, and he also had feeding issues.

Although parents suspected there was something going on with their child, doctors told seven of the participants that nothing was wrong or they were advised to be patient, that their child would catch up on his/her milestones. They felt this type of advice lead them to doubt their abilities as parents or to question their instincts. Consequently, some parents felt that a diagnosis would validate their concerns. As Judy, the mother of a daughter with unidentified developmental delay, recounted, “So, I quickly got busy and thought this is stupid, I’m not wrong, it’s not me! I know this. So then I finally got myself a pediatrician and we started the saga.”

When doctors finally began to listen or started to become concerned themselves, resulting in a differential diagnosis, five parents reported relief because it substantiated their anxiety. A diagnosis also allowed them to explain to family and friends why their child acted differently than other children. As two mothers of children with autism spectrum disorders remember, “Her siblings kept saying, ‘What’s wrong with her?!’” (Farah); “A diagnosis meant justification that his odd behaviour was for a reason... It just made it easier to explain his behaviour” (Collette). Having a name also made it easier for parents to explain their child’s medical vulnerabilities when they had to go to the Emergency room, which was quite a common occurrence for many families. Kathy reported being able to say, “This is what is the matter,” which facilitated

getting the proper medical care for her child in a more expedient fashion. Being able to provide a name, parents felt, would also enable understanding regarding the etiology or cause of the disability, which is the next theme.

"Of course you think, 'It's all my fault'" - Knowing a Cause for the Disability

One of the main reasons families sought a diagnosis was to know what caused their children's behavioural difficulties or delays. Recognizing a cause or etiology was important for parents because of the risk to future children and because, without knowing the reason for the disability, nine of the 14 parents wondered if they had done something to cause their child's delays or unique conduct. Thus, receiving a diagnosis helped to reduce feelings of guilt or parental blame.

The risk to future children was important for many parents if they were planning on having another child and two parents sought a differential diagnosis when they found out they were pregnant again. Judy, the mother of a daughter with an unidentified delay, remembers, "[The doctor] really had no answers apart from the fact that 'no, it's not genetic,' which was good because I was pregnant again... that was the only reason for the relief." Theresa, another mother of a son with unidentified developmental delay, recounts:

because we were thinking at that time of having another child and we were seriously thinking of not having another child if there was a chance that the child would be mentally challenged like Curtis is. And we went to [the doctor] and he said "No, nothing congenital, just a freaky thing that happened."

It is important to note that none of the families who participated in the study had children whose disabilities were described as congenital, so there were no feelings of guilt or resentment toward family members of spouses. The term, "congenital" will be discussed in the conclusion section of this paper. Parents also talked about the fear that they had done something during pregnancy or after the child was born to cause

the disability and no family reported such parental treatment factors to be the cause of the disability.

Knowing the cause therefore alleviated a lot of blame for families, being informed that their child’s disabilities were not due to something the mother had done during pregnancy or a failure of the family to provide sufficient or appropriate stimulation after birth. Deborah was concerned about her son’s delays and was worried that it was because he had fallen off his change table when he was an infant. Phoebe, Shannon, and Theresa reported being concerned because they had had colds or other types of infections during pregnancy and worried if that was what instigated their child’s behaviours. Mothers were reassured to find out from medical professionals that this was not the case. Tom’s wife, Diane, had cancer and worried that this was what caused her daughter’s disabilities, but when it was revealed that the disability was a chromosomal abnormality, the family was relieved. Diane died shortly after her daughter received a differential diagnosis, but Tom recalls:

She, we wondered whether the cancer was implicated in this; the doctors, well most doctors, said it had nothing to do with it.... she really took it on herself that she had done something. I mean she didn’t - she never had a drink, she didn’t smoke or anything like that. It was also important for her to know if her cancer was implicated and it wasn’t - that was what Diane wanted to hear.

A differential diagnosis also provided information for families about characteristic behaviours associated with the disability, which alleviated blame because some parents felt that it was perhaps the home environment that had caused their child’s behavioural differences. As Tom, the father of a daughter with a chromosomal abnormality, recounts:

She was extremely sociable with adults. I naturally assumed that this was because I was older when she was born so that my friends didn’t have little friends running around. It was my second marriage, so she didn’t have brothers and sisters.

So I assumed this was because she just didn't have experience with children her age. And that turned out to be one of the characteristics of some children with Williams syndrome, which blew me away - you wouldn't think that that would be genetic in any way. It actually took a lot of guilt from me because I was blaming myself for this problem.

Although Tom's daughter does not have Williams syndrome but has a deletion on the same chromosome, doctors told him that his daughter's features were very similar. Knowing that individuals with Williams syndrome are often sociable with adults alleviated his feelings of responsibility for her disability due to his advanced age as a father. This benefit to differential diagnosis brings us to the next theme, which is the information provided regarding future expectations.

"What you might expect down the road"- Obtaining Information Regarding Future Expectations

Parents also reported seeking a differential diagnosis in order to receive information about what to expect for their child. Stuart, Tom, Theresa, Kathy, Gillian, Francine, Shannon, Nina, Judy, and Deborah all wanted information about life expectancy, medical vulnerabilities, and behaviours typical of a specific disability. Kathy, the mother of a daughter with a rare chromosomal abnormality, summarizes this meaning nicely:

To find out what syndrome she has would give you your viewpoint on their life, like, what you have to look forward to, like this they could have, or that they could have, so you know what's gonna come ahead of you, what you have to deal with. It's the unknown that's very difficult because you're going day by day, like, you don't know if um... if you're Down syndrome, this can happen, that can happen. If you're this syndrome, this can happen, this happen. Without a definite knowledge of what she has, you're flying day by day. And you don't know the outcome, you don't

know, like, her life expectancy. You don't know that, well, by the time she's a teenager she's, you know, not going to be able to do this or that, or whatever. So, it's a total unknown.

Medical vulnerabilities were a major concern for parents. Many differential diagnoses, especially genetic syndromes, are associated with specific health issues and knowing these susceptibilities allows families to be prepared. As Stuart, the father of a daughter with Angelman syndrome, discussed, “But on the upside, you know Down syndrome life expectancy is lowered because of cardiac problems, and Michaela will have a normal life expectancy. Here are the things you can expect - you can expect seizures, severe cognitive delays, and she won't talk.” When Michaela was first diagnosed, she had not had any seizures but the family knew that this was quite common. Because of this advance knowledge, when she had her first seizure at three years of age, the family was prepared.

A differential diagnosis also allowed families to organize for the future. As Stuart remembers, “That part of it was the hardest part of it. Trying to figure out what her future was going to be.” Kathy, Francine, Stuart, Deborah, Theresa, Tom, and Shannon were all concerned about what will happen to their child when they are gone, such as who will take care of him/her and if the child will require out-of-home care. However, a differential diagnosis gave families information about life expectancy and level of functioning so that they could arrange for such events. Theresa and Deborah were not successful in receiving a differential diagnosis, but one of the reasons for seeking such a diagnosis was this expectancy information.

It is significant to point out that this is where some parents differed in their desires. For Theresa, Collette, Ingrid, Gillian, and Deborah, there was some comfort in knowing about future expectations. However, Shannon, Kathy, and Francine wanted the differential diagnosis but did not want to know specifics about the future. As Kathy, the mother of a daughter with a rare chromosomal abnormality, recounts, “not knowing is kind of nice because then you don't have this time date stuck in you saying, ‘OK, by this time they deteriorate.’” Francine, Shannon, Stuart,

and Gillian discussed not wanting to become involved in parent-professional groups because they did not want to associate their child with “that population” and were fearful to see older children with the same label. Francine, the mother of a daughter with Angelman syndrome, remembers, “For a long time I didn’t even look up anything about Angelman syndrome because I didn’t want to be associated with that group of people.” Having information about future prognosis was quite frightening for many families and not knowing was a bit of a relief. Although Shannon, Kathy, and Francine were content with not knowing predictive information, the rest of the parents sought this kind of knowledge. Prognostic information allows families to know about future expectations and thus what kinds of supports or interventions are going to be required:

There are some people who never know what’s wrong with their child and I think that knowing what’s wrong, at least give us a hint that, “hey, OK,” here are some typical problems that Angelman children run into. We should be aware of that so that we can be proactive in dealing with those problems. I think that’s really important and I am glad we got the diagnosis for that reason. (Stuart, father of daughter with Angelman syndrome)

Such information regarding future expectations also allowed families to be proactive in accessing early intervention programs or targeted treatments to maximize their child’s learning, which is discussed in the next theme.

“How do I teach her?”- Obtaining Information Regarding Interventions

One of the main reasons parents wanted a differential diagnosis was to find out what types of interventions would be appropriate for their child. A differential diagnosis also made remediation more urgent and would provide pertinent information regarding the specific strengths and weaknesses of the child, so as to select the most appropriate form of remediation. Parents ultimately wanted to do whatever they could to help their child function in society and learn important skills. As

Francine remembers, “We were fortunate in a way because we got the diagnosis early, because we knew we couldn’t push her too much, but at that same time, we knew we needed to do certain things to make sure she was active and cognitively engaged.” Obtaining a differential diagnosis was thus helpful in knowing the child’s possible capabilities and limitations so as to tailor the supports appropriate to the child’s skill level and potential.

A differential diagnosis could also provide parents with information on how to implement a behavioural program at home so that they could support their child and alleviate some of the developmental gaps and delays that might have been apparent. Judy, the mother of a daughter with unidentified developmental delay, remembers,

I kept thinking of how is she going to manage, because that speaks to function as opposed to this diagnosis. The label didn’t mean that much to me. Because this diagnosis, I mean developmental delay, what does that mean? I was searching more for that functional data, you know, how do I teach her to function?

At the beginning, Judy was seeking a diagnosis for her child, but after several years of testing which never resulted in a differential diagnosis, all she wanted was information about how to help her daughter. She went on:

Finally I said, that’s enough, you know, none of this running back and forth because we had the [occupational therapist], physio[therapist], psychologist, doctors, speech therapist, whole gamut. Finally I thought about this and I thought, “You know, never mind what it is, what she’s got, what it’s called, or whatever, we just have to get on with raising this child!” ... you have to get on with this, forget about trying to fix her, how do we teach her?

This last story brings us to the final theme regarding why parents sought a differential diagnosis. Specific diagnoses are often associated with

specialized intervention programs and differential diagnoses are required in order to access services and funding. Consequently, many families sought a differential diagnosis in order to be eligible for money or restricted programs.

"The label was much more important for funding purposes than it was for anything else" - Gaining Access to Funding or Specific Services

One of the most significant reasons parents initiated the diagnostic process was the perceived need for a label in order to receive funding dollars. With funding comes access to services and many families searched for a differential diagnosis in order to obtain government money, as well as admission to specific programs, or eligibility for supports in the school system.

For Phoebe, Collette, Shannon, Farah, Ingrid, and Deborah, a differential diagnosis was sought in order to be eligible for provincial funding. Collette, the mother of two sons with autism spectrum disorders, asserts, "It just meant continued funding for schooling to us." Kathy, who has a daughter with a rare chromosomal abnormality, echoed Collette's reasons, "Yeah, you know for her [*government assistance*], and she is also supported with [*provincial funding body*] so she needed [a diagnosis] for that. Also for the school system, she needed [a diagnosis] for her aide, without that, there wouldn't have been any funding."

Farah, the mother of a daughter with an autism spectrum disorder, recalls seeking a differential diagnosis for financial support and to receive help in the school system:

My efforts finally landed my daughter funding for two years and with the extra assistance, [she] began to develop and use pragmatic communication at school. At this time, I think the extra individual interaction helped her become more aware of who she was and what was going on around her. Having a definite diagnosis worked in our favour at this time because I was able to then access a psychiatrist who came

into the school to educate the teachers and, in turn, the teachers made the students aware of my daughter’s autism.

Thus, a differential diagnosis was important in order to gain access to services in the school system. A label was also imperative for eligibility for specialized intervention programs as discussed by Judy: “When I started, in order to qualify for the [*specific intervention program*], we needed to have that diagnosis, medical model stuff, so you have to have a diagnosis.”

Eligibility for specialized programs is where parents’ experiences became very interesting and almost all parents had different stories regarding the need for a differential diagnosis to access services, or if a nonspecific diagnosis was sufficient. Stuart and Francine, parents of Michaela who has Angelman syndrome, felt the need for an additional autism diagnosis, even though their daughter already had a differential diagnosis. Stuart recalls, “Everyone kept saying, try to get her diagnosed as having autism because she will get wonderful therapy that way.”

Deborah, the mother of a son with an undiagnosed autism spectrum disorder, recalls that funding bodies “wanted a label” in order to qualify for government dollars and admission to certain assistance programs. Her son meets almost all of the DSM-IV criteria for autism, but her son’s official diagnosis is a severe communication deficit. Deborah discussed how the difference between a diagnosis of autism and one of severe communication deficit affected access to services and she has “used the label [of autism] because ‘it’s good enough for them.’” For Deborah and her son, a formal diagnosis of autism was not required in order to receive the supports they desired, but Shannon and Theresa reported being unsuccessful in qualifying their child for restricted intervention programs due to their child’s differential diagnosis or lack thereof. Theresa and Deborah reported having to lie or really fight to access these services.

Parents thus seek a differential diagnosis for many reasons. Receiving a formal diagnosis for the disabilities of one’s child reduces ambiguity regarding cause and future expectations, provides information regarding

appropriate interventions, and allows access to funding or disability services. These themes will be elaborated below, with reference to Patterson's (1988, 1989) FAAR model. The article concludes with recommendations for future practice and research.

Conclusion

The stories families tell incorporate cognitive factors that go beyond the definition the family gives to the stressor (that is, the onset of the disability) as families search for meaning in a life that, in many ways, has been shattered by the presence of added demands, multiple losses, changed routines, roles, and expectations. (Patterson & Garwick, 1998, p. 73)

Developmental disability and family functioning interact continually in a pattern over time. Families "go through repeated cycles of adjustment-crisis-adaptation" (Patterson & Garwick, 1994, p. 132), seeking to achieve balance, a state that is influenced by the meanings families attribute to their situation, as well as to their own identity as a family and to their view of the world (Patterson & Garwick, 1994). The family attempts to maintain balanced functioning by using its resources to meet its demands, including stressors and strains. According to Patterson and Garwick (1994), "The meanings the family ascribes to what is happening to them (demands) and to what they have for dealing with it (capabilities) are critical factors in achieving balanced functioning" (p. 132).

Medical practitioners are key to providing information regarding the etiology, prognosis, and recommended interventions for the differential diagnosis. Such information allows the family members to reach a "shared definition" (Patterson, 1989, p. 113), an unambiguous understanding of the disability which, in turn, may accelerate their ability to adapt to the diagnosis. On the basis of the FAAR, Patterson predicts that, when a family faces the stress of a major illness or disability in one of its members, the family moves into a crisis. From the perspective of the FAAR model, the family's recovery from crisis could be facilitated by the way medical professionals relate to the family.

Patterson asserts that there are several things that might be helpful but, most relevant to the present study, she states that medical practitioners can help families by reducing the ambiguity about what is happening, resulting in less family strain.

Reaching a “shared definition” appears to be what families are seeking when trying to find a name for the disability of their child, which crosses several of the themes discussed by parents. A shared definition means that the diagnosis is free from uncertainty and there is information provided regarding the condition, such as etiology, treatment, and prognosis. Having a name for the differential diagnosis provided the parents in this study with information regarding future expectations, a finding supported by Burden (1991) and Poelmann et al. (2005). There is always the hope that diagnosis will yield a finding pointing toward something useful, such as how best to provide supports for their children and how to access specialized services. Knowledge regarding the future appears to give parents some sense of control (Knox et al., 2000) and parents need to feel like they are doing everything possible to help their child (Burden). Patterson (1989) asserts that a sense of control is crucial for family adaptation. Even though the information provided may be incorrect, even the illusion of having some information can make planning easier and give parents a sense of greater control.

It is important to note that the meaning behind a differential diagnosis was the same for families with and without a specific diagnosis for their child. Regardless of their level of success with receiving a diagnosis, parents’ reasons behind the search were similar; however, there were some interesting differences between the different types of disabilities. Parents with autism spectrum disorders or suspected autism spectrum disorders seemed to seek access to interventions and funding support, while parents of children with more severe disabilities seemed to focus more on the future expectations and medical issues.

A lack of differential diagnosis can aggravate or complicate other problems. For example, the parent may feel that there is something wrong with medicating or treating the child in a particular way, but it is harder to argue effectively when the diagnosis is unclear. The treatment issue needs to be resolved, but it is hard to determine until the diagnostic

foundation can be trusted. Families who did not have a differential diagnosis, Theresa, Deborah, Barb, Judy, and Phoebe, felt frustrated with not knowing the “best” way to provide intervention for their child.

The need for a differential diagnosis also became very important for accessing specific services and parents sought a label for their child for this reason, some with greater success than others. Shannon, for example, has a son with Angelman syndrome, but there are no specialized treatments for this differential diagnosis; she sought access to autism services, but without an official autism spectrum disorder, her son did not qualify for the programs. Theresa has a son with a nonspecific disability and this mother discussed the difficulties in gaining access to intervention because her son did not meet the specific program criteria. Certain diagnoses are associated with differential funding or intervention programs and it makes sense to have specialized programs tailored to specific developmental needs, but when someone has similar presenting issues, it seems unfair to restrict that individual from service because medical professionals are unable to identify a specific gene that causes their disability or apply a formal label. The same is true for individuals who have a differential diagnosis but the diagnosis is so rare that there are no specific interventions, as described by Shannon above. As this study demonstrated, parents are seeking a diagnosis in order to access the best treatment for their child, but many were unable to do so because of how funding bodies are set up (Burden, 1991; Gillman et al., 2000).

One theme deserves significant mention and that is the issue of a differential diagnosis relieving guilt. Several families reported the relief they felt when they determined the specific diagnosis because this often led to knowledge regarding the etiology and cause of the disability. These findings are similar to Burden’s (1991) study, where mothers of children without a differential diagnosis had more difficulty working through their feelings of anger and guilt than mothers of children with a specific diagnosis. However, as with Burden’s study, all parents interviewed described causes that were not congenital or the result of something they had done. There appears to be some confusion about the word, “congenital” and the causes of disabilities. Six parents from five families participated in the study whose children had genetic disorders,

and there is the possibility that the disabilities were inherited from one of the parents. Angelman syndrome, for example, is commonly caused by a deletion on the maternal copy of the 15th chromosome, but can be due to four other causes. Parents did not report if medical professionals went over this information or it was deemed relevant. Furthermore, Theresa and Deborah reported that their medical practitioners assured them that their child’s disabilities were not genetic, a concern of the parents because they were planning for another child. However, the children of both these parents have unknown disabilities and there is always the possibility that an unknown genetic condition caused the child’s disabilities. Parents’ experiences would of course be different if medical practitioners had informed them that their child’s disabilities were due to maternal drinking, inherited from one of the parents, or the result of some type of family environmental cause. Future research should look at the experiences of families of children with Fetal Alcohol Spectrum disorder or inherited disabilities such as Fragile X syndrome, to see if meanings are the same. Furthermore, interviewing the medical practitioners would be beneficial to see what information regarding genetics is actually given to parents.

The present study addressed the meaning behind a differential diagnosis and investigated the experiences of parents of children with and without specific labels. Only 14 parents were interviewed and future research needs to interview more parents and to look more in depth at the reasons why parents seek a differential diagnosis. Future research should also look further into what the meanings are for different types of diagnoses, such as autism spectrum disorders versus more severe disabilities associated with more medical vulnerabilities. Further, Keogh et al. (2000) state that we know little about the families of children with nonspecific disabilities, yet for 30 - 40% of individuals with developmental disabilities, the specific cause is unknown (AAMR, 2002). The current study is a start, but more information is required about these families. The word, “family” is also important to discuss. I attempted to include all family members when recruiting participants, but only parents participated in this study, and participants were mostly mothers. Interviewing all family members, including the child with the

developmental disability, would be important to see if all family members have the same reasons for seeking a diagnosis.

It appears that parents are seeking a differential diagnosis for their child for several reasons. Parents express the need to “know” in order to alleviate guilt and what to expect about their child’s future, they want to know what caused the disability, they desire knowledge regarding appropriate interventions, and they seek a label in order to access funding or specific services. It is important for medical practitioners to know what parents desire when beginning the diagnostic process so that they can provide relevant information to families regarding the disabilities. As reported elsewhere (Poelmann et al., 2005; Watson, manuscript in preparation), parents feel medical professionals provide too much pessimistic information about disabilities and not enough information about intervention. Providing the desired information will facilitate greater family adaptation to the disability and the best supports for the child.

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