Healthcare Concerns of Parents of Individuals With Fragile X Syndrome
Preliminary Results From Qualitative Data Analyses

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Abstract

Background. *Medical problems of individuals with intellectual disabilities (ID) have been increasingly recognized in recent years. However, less attention has been give to the needs of individuals in different diagnostic groups. The purpose of this study was to explore the healthcare experiences of parents of children with fragile X syndrome in Ontario. The main objectives of the study were (1) to identify the challenges and successes parents face when accessing healthcare services for their children with ID; and (2) to identify suggestions and strategies to enhance access and quality of healthcare services for children with ID.*

Methods. *Qualitative data were obtained from parents during a focus group conducted with five mothers, two fathers and one foster mother of children with fragile X syndrome.*

Results. *Four main themes emerged which described parents' experiences when accessing healthcare services for their child and/or children with fragile X syndrome. They include: (1) sensing something is not right; (2) negotiating the healthcare system; (3) dealing with healthcare professionals; and (4) parents as active agents.*

Conclusions. *Parents made a number of suggestions of ways that healthcare professionals could deal more effectively with parents. They recommended that (a) doctors need to receive more education about intellectual disabilities; (b) doctors need to take extra time to provide appropriate information and care for children with fragile X syndrome; and (c) patience is a necessary trait for all healthcare professionals who provide care for children with special needs.*

Adults with an intellectual disability (ID) have been found to have more frequent medical problems, higher rates of mortality and different disease profiles than age matched peers without ID (Beange, McElduff, & Baker, 1995; Jansen, Krol, Groothoff, & Post, 2004; Wallace 2001). In addition, higher rates of mental disorders (Holland & Koot, 1998) and untreated physical disorders (Barr, Gilgun, Kane & Moore, 1999; Van Schrojenstein Lantman-de Valk, Metsemakers, Haveman, & Crebolder, 2000) such as hypertension, hypothyroidism, vision deficits, and epilepsy have been reported. While organic factors related to the ID contribute to these differences, environmental, behavioural and social factors also need to be considered (Kastner, Nathanson, & Friedman, 1993). Comparative studies have been limited because health problems often are defined differently across studies. In addition, sampling differences can affect results. For example, some types of health problems occur more frequently in some types of ID than others (Jansen et al., 2004). The purpose of this study was to investigate the experiences of parents in their efforts to access healthcare for their children with fragile X syndrome.

Fragile X syndrome is the most common inherited form of intellectual disability affecting both males and females. Females are often carriers, whereas males are usually affected (Lee, Mackenzie, & Holden, 2003). The FMR1 gene responsible for the syndrome is located on the X chromosome. In 1991, researchers discovered that individuals with fragile X syndrome have a larger FMR1 gene than those without the syndrome. This difference is due to expansion of trinucleotide repeats (CGG). Males with full mutation of the FMR1 gene usually have moderate to severe intellectual disabilities They also exhibit language, social and behavioural problems including attention deficits, impulsivity, and anxiety (Rogers, Hehner, & Hagerman, 2001). Between 25 and 35% of cases meet the criteria for autism (Bailey et al., 1998). Females tend to function intellectually in the mild to average range. However, they experience frequent difficulties in executive functioning, as well as social anxiety (Hagerman & Cronister, 2002). Prevalence estimates vary from 1/1200 - 1/6000. The rate of full mutations in Caucasian males is approximately 1/4000 whereas, the numbers of carrier females or those with the permutation are lower (1/200 - 1/500) (Skinner, Sparkman, & Bailey, 2003).

Although the etiology of fragile X syndrome has been known since 1991, the features are not readily recognized and delayed diagnosis continues to be a problem. British and American research has documented the challenges faced by parents who often recognize that their child is "different" from other children. These parents have difficulty receiving a diagnosis because

doctors often are reluctant to acknowledge that such differences are significant (Bailey, Skinner, & Sparkman, 2003; Carmichael, Pembrey, Turner, & Barnicoat, 1999; Skinner, Sparkman, & Bailey, 2003) and because fragile X is less well known than other developmental disabilities such as Down syndrome (York, von Fraunhofer & Sedgwick, 1999). While not all children with fragile X syndrome have medical problems, a number of disorders frequently coexist with the diagnosis. These include chronic otitis media, low muscle tone leading to flat feet and scoliosis, cardiac problems including heart murmurs and hypertension, early puberty, early menopause, urinary tract infections, hernias and large testes in males, as well as seizure disorder and behaviour disorders (Lee et al., 2003).

The purpose of this study was to explore the healthcare experiences of parents of children with fragile X syndrome in Ontario. The main objectives of the study were (1) to identify the challenges and successes these parents face when accessing healthcare services for their children; and (2) to identify suggestions and strategies to enhance access to and quality of healthcare services for children with ID.

Method

Participants

Volunteers for this study were solicited at a conference on Developmental Disabilities in Ontario. Five mothers, two fathers and one foster mother of children with fragile X syndrome volunteered to participate in a focus group. The participants' children included one female and seven males ranging in age from 5 to 23 years (mean age = 12.9 years). Participants shared their experiences of accessing healthcare services including dental care for their child and/or children with an intellectual disability.

Research Approach and Data Collection Methods

This study was approached from the interpretive paradigm and used predominantly qualitative methods. The interpretive paradigm recognizes the existence of multiple realities and seeks to describe the perceived meanings of people's experiences (Higgs, 1998). As such, this study aimed to describe the experiences of parents of children with fragile X syndrome in accessing healthcare services. Qualitative methods were given priority in this study because they allow the exploration of topics that have not been well defined (Creswell, 1998).

A focus group is a semi-structured group interview, held in an informal setting, with the purpose of collecting information on a specific issue (Streubert & Carpenter, 1999). This method of data collection was determined to be a cost-effective and efficient initial strategy for gathering information about a number of parents' experiences of accessing and receiving healthcare services for their children.

Accordingly, a focus group guide was developed consisting of approximately six open-ended questions regarding the parents' experiences in accessing health care services including diagnostic services, services from family physicians, hospital emergency, inpatient and outpatient services. This focus group moderated by the first author lasted approximately one and one half hours, during which time all participants were encouraged to share their experiences. The discussion was recorded and transcribed verbatim.

Data Analysis Procedure

Patton (2002) explains that qualitative data analysis involves three general steps. First, transcripts are read through to get an overall sense of what is being discussed. This is then followed by a systematic identification and application of codes or labels to lines of text: a similar idea or concept will be labelled or "coded" with the same word. Preliminary codes are then confirmed, refined or refuted as more text is coded. The comparison of previously coded text to newly coded text is referred to as "constant comparative method," a key analysis method used in grounded theory (Strauss & Corbin, 1998). Inductive analysis occurs when the codes or labels are derived from the text, rather than from a pre-existing framework.

Following this general method of analysis and constant comparison, data analysis of the first focus group transcript involved the following steps:

1. After reading the transcript to obtain an overall sense of what was talked about, two investigators read the transcript independently, this time looking at each line of text in order to identify a label or code that captured the main idea. This is referred to as line-by-line, "open coding" (Strauss & Corbin, 1998).
2. The two investigators then compared the codes they assigned to each unit of text. Discrepancies were discussed and a common code or label was agreed upon.
3. One of the investigators reviewed the agreed upon codes and combined similar codes to form 27 main categories with approximately 109 sub categories.

4. A third investigator reviewed the codes and their text to confirm their accuracy and fit. Any discrepancies were discussed and clarified.
5. Two investigators then studied the categories and sub-categories to consider how they related to each other in order to begin conceptualizing main themes and their sub-themes. This is referred to as "axial coding" (Strauss & Corbin, 1998).
6. Peer debriefing among the three investigators occurred to review ways to conceptualize the main themes that emerged from the focus group. During this process, potential investigator biases or assumptions were identified and challenged and codes and themes were always linked back to the text which supported them.

Through this intensive process of reviewing, discussing and conceptualizing the data collected and the codes which emerged, four main themes, with two to three sub-components each, were identified from the first focus group. These themes are summarized in the results section.

Enhancing Rigour

In qualitative research, rigour refers to the extent to which the researcher attended to and confirmed the information gathered (Streubert & Carpenter, 1999). In this study, one means of data verification has been employed, namely the use of investigator triangulation (Creswell, 1998), in which three analysts were used to enhance the accuracy of interpretation of the data collected. In addition, member checking was carried out whereby the data gathered were reviewed by two focus group participants and another parent of a child with fragile X syndrome. Two parents had been at the focus group and a third was not. The parents who had attended the focus group were asked to comment on whether we had accurately represented the discussion during the focus group. All parents were asked to comment on our findings in light of their own experiences.

Results

Four main themes emerged describing parents' experiences when accessing healthcare services for their child and/or children with fragile X syndrome: (1) sensing something is not right; (2) negotiating the healthcare system; (3) dealing with healthcare professionals; and (4) parents as active agents. Each of these themes and their main sub-components are described below with examples from the parents' experiences.

Sensing Something Isn't Right

Parents and teachers were the main component of this theme. Before a child had received a formal diagnosis of fragile X syndrome, parents and/or teachers noticed differences in the child. One mother of two children with fragile X described how she first noticed that her son's development was unusual. She said:

> *...By the time* [he] *was three and a half, he could see, he could hear, he could talk...*[but he was] *not making much sense with his words, so I just went to our family doctor and I* [asked if we could] *refer him to a speech therapist, which he did right away.*

Another mother of one affected and 2 unaffected children said:

> *...I noticed when* [my son] *was about six months, he wasn't crawling or anything yet, so I took him to his paediatrician. He referred us to* [a hospital] *which is the closest place for us.*

The important role a teacher played in recognizing a problem with her son was described by one mother:

> *...in kindergarten, the teacher started commenting that* [he] *wasn't functioning at an appropriate level. I just figured, he* [has] *always been at home with mom and dad...So, I didn't really do anything in junior kindergarten. Senior kindergarten, the next teacher, same thing. He's not up to par with the other kids, so we got a referral to a pediatrician.*

While parents often are the first to sense that something isn't right with their child, one mother experienced fear when doctors were interested in conducting developmental testing on her son whom she had brought to the hospital with the stomach flu:

> *I got a little upset with* [the medical staff] *because I didn't want to have anything wrong with him.*

Both the recognition that the child has a problem and the fear which sometimes accompanied that realization were found to be components of the parents' first phase in seeking assistance through the healthcare system

Negotiating the Healthcare System

The second main theme entitled, negotiating the healthcare system, consisted of the following subcategories: (a) entry into the healthcare system including referrals; (b) testing including genetics testing, misdiagnosis and accurate diagnosis; and (c) availability of services including waiting lists for services, lack of services, and distance to travel to receive services.

A common experience shared by most parents involved being placed on waiting lists before the child received appropriate services. As one mother stated:

> *[My son is] having a psychoeducational assessment [done]. That's the big pain, that waiting list for everything. Everything. Waiting list for behavioural therapy, waiting list for everything.*

Other challenges faced by one parent when accessing healthcare for her foster child involved the lack of services in rural areas and the distance needed to travel to the nearest services. The foster mother explained,

> *I live in [a small town] in the middle of nowhere, but we've been very fortunate to make contact with a specialist paediatrician who does outpatient clinics at our local hospital…*

Misdiagnosis of the child's disability was another challenge for parents. One mother shared the following experience:

> *…the first thing they told us was that he was deaf. They did hearing tests, they said yeah he's deaf. We'll set you up with a specialist, have him fitted for hearing aids and I said just a minute…is there not some other test you can do because I think he just doesn't understand what you want him to do and that's why he's not responding…[later] it came out his hearing was perfect, there wasn't a thing wrong with it.*

Dealing with Healthcare Professionals

The third main theme emerging from the data involved parents' positive and negative experiences of dealing with their child's healthcare providers.

Positive experiences. Parents identified patience, taking the time to deal with families, and providing information and support as valuable characteristics in healthcare providers. One mother said:

My paediatrician has the patience, and he takes the time.

She continued to describe her satisfaction with her children's doctor:

> [The doctor we have now] *is great…we see him for sure once a year. If* [you] *have any other questions* [or] *if there's any help you need, he says, just call me and I'm here and we'll get through this. He said if you need anything from the school let us know, we're there to help.*

Negative Experiences. The negative experiences some parents faced when dealing with healthcare professionals included doctors' lack of knowledge of intellectual disabilities, doctors' disinterest in learning about intellectual disabilities, and a lack of guidance and/or direction from healthcare professionals for parents' caring for their child with fragile X syndrome. A mother of a younger child with fragile X shared her observation of the healthcare system's lack of familiarity with fragile X syndrome:

> *I just find that anytime you do approach anyone, nobody's ever really heard of fragile X, and, so it means nothing…And my family doctor wasn't even interested in learning about it either, which is why he switched.* [*Authors' note:* i.e., the doctor suggested they find a different physician wth more expertise in the area.]

For this same mother, the challenges she faced in accessing healthcare for her child with fragile X did not end after having received an accurate diagnosis:

> *I haven't had much of "you need to do this, you need to do that". I'm sort of expecting someone to tell me what you need to do for this kid…I don't know…my kid has fragile X, what do you want me to do now?...The developmental pediatrician gave me the diagnosis, but never said, OK, let's do this now, let's do this now. He never said, we need speech therapy, we need this, we need that.*

Parents as Active Agents

In the process of accessing healthcare for their children some parents became active agents who acted as role models for healthcare professionals and who persisted in finding appropriate care for their children. According to a mother of two children with fragile X syndrome:

> *[The healthcare professionals] always notice where I'm positioned with the [children]. If I take them to the hospital, I'm very close to them, and I'm constantly talking to them and using humour and keeping them distracted with humour and conversation and so then they [healthcare professionals] pick up on that and they do it too which is good.*

Member Checking: Parents' Feedback on the Results

Two focus group participants and another parent of a child with fragile X syndrome reviewed the data gathered, the model and main themes. Both parents who attended the focus group felt that we had represented the discussion accurately. One parent said, "Well done! When are you going to have another focus group?" The parent who had not attended the focus group said, "Right on! These are similar to the experiences I've gone through". Reading the results summary prompted a number of additional comments from these parents about diagnostic issues and interactions with medical professionals. Two parents spoke of their experiences obtaining a diagnosis.

One parent whose daughter is now an adult described the long process of obtaining a diagnosis. She said,

> *We went to different hospitals in three major cities and didn't find out until she was 13. It was the teacher who had a pamphlet about fragile X and then we took her to have the blood test.*

The other parent indicated that it isn't enough just to have the diagnosis.

> *…Once you have it, you need explanations about what fragile X is going to mean and its impact… what behaviours to expect and how to deal with them.*

Both parents indicated that professionals need to be educated about fragile X and that parents often bear this responsibility. One mother said,

> *The doctors are fine with her but they don't understand that she can't explain. She understands what is being said but she can't express her feelings etc.*

The other mother suggested that parents need to learn how to connect with professionals in order to educate those who will be working with their child;

teachers as well as doctors. She described how the doctors she had met were not very familiar with fragile X. One time, however, she was surprised and pleased that a doctor asked her to bring in information about fragile X. She said,

> *People are familiar with Down syndrome so I tell them that people with Down syndrome have an extra X chromosome but people with fragile X syndrome have a damaged X chromosome.*[*]

Parents' Recommendations for Changes in Service Delivery

When parents were asked what advice they would give healthcare professionals to facilitate how they deal with parents who have a child with fragile X syndrome, three recommendations were made: (1) doctors need to receive more education about intellectual disabilities; (2) doctors need to take extra time to provide appropriate information and care for children with fragile X syndrome; and (3) patience is a necessary trait for all healthcare professionals who provide care for children with special needs.

Discussion

Recent research has highlighted that parents of children with fragile X syndrome experience stress related to their child's behaviour, family cohesion, financial issues and mothers' mental health (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond & Murphy, 2004; Johnston, Hessl, Blasey, Eliez & Erba et al., 2003). However, this study focused specifically on the concerns of parents when attempting to access healthcare for their child with fragile X syndrome. Interestingly, parents focused primarily on the issue of diagnosis when asked about healthcare.

The experiences of the parents in this sample echo those of reports in the literature regarding the time lapse between parents first noticing that something is unusual about their child's development and obtaining the diagnosis of fragile X syndrome. Kan et al. (1990) reported that on average, the diagnosis was not made until after the age of three and later. Recent studies (Bailey et al., 2000; 2003) with over 300 families indicate that parents first become concerned about their child's development between 9 and 13 months of age; however, professional acknowledgment of delay comes between 21 and 24 months on average. Parents often wait until the child is between 32 and 35 months on average before receiving the diagnosis

[*] *Editor's note*: People with Down syndrome have an extra chromosome 21.

of fragile X syndrome. In this study, one mother described how her child's disability was first recognized by a teacher rather than a doctor. However, in several cases, it was the parents themselves who sensed something was not right with their child.

The American Academy of Pediatrics Committee on Children with Disabilities, (2001) has highlighted the need for physicians to work with parents to facilitate early recognition of developmental delays and to help families obtain appropriate diagnostic and intervention services. Systematic and early developmental screening using standardized measures has also been recommended over standard monitoring (Mirrett, Bailey, Roberts, & Hatton, 2004).

Although medical interventions with individuals with ID have been determined to be within the scope of general practice (Beange & Bauman, 1990), family physicians face many barriers including the need for extra time to meet the complex needs of people with ID and reliance on the perceptions of caregivers. Parents who reported positive experiences with their physicians described patience, accessibility and willingness to talk or listen as positive characteristics. Parents' reports of negative experiences highlighted physicians' lack of knowledge of fragile X syndrome. Similarly, an Australian survey (Phillips, Morrison, & Davis, 2004) found that general practitioners felt that their training was inadequate and that health care for persons with ID was deficient in a number of areas: behavioural or psychiatric conditions, human relations, sexuality issues, complex medical problems and preventative and primary health care. The most frequently suggested topics for further education included syndrome-specific medical problems. The comments of one parent in this study suggest that parents can act as role models for physicians who are unfamiliar with children with fragile X and uncertain of how best to relate to them.

Two developments in the past 10 years could help to address some of the needs of medical practitioners. In 2000, a fragile X checklist was published for use by family physicians (Maes, Fryns, Ghesquiere, & Borghgraef, 2000). Although the checklist is only a screening tool, given the importance of early detection and diagnosis, it would increase awareness of fragile X syndrome among family physicians and facilitate referrals to specialists who could provide genetic counselling and assistance with various interventions.

Similarly, the American Academy on Pediatrics, has developed a set of guidelines for paediatricians working with children already diagnosed with fragile X syndrome (American Academy of Pediatrics, Committee on

Genetics, 1996). The guidelines highlight routine examinations that should be carried out at varying stages in development (i.e., infancy to one year, early childhood to five years, later childhood to 13 years and adolescence to early adulthood). In addition, they provide guidelines for counselling families during pregnancy. Although developed for paediatricians, such guidelines also could be helpful for family practitioners who may be caring for individuals of varying ages with fragile X syndrome and their families.

The results of this study are limited by the relatively small sample size and by the unrepresentative nature of the sample (i.e., all participants were attending a conference on developmental disabilities). However, the views expressed by participants are similar to those expressed in other studies. Both highlight the need for more medical education if the healthcare needs of individuals with fragile X syndrome and their families are to be met and the need for parent and physician collaboration in this process.

The findings reported in this paper are part of a larger qualitative study focusing on healthcare experiences of parents of individuals from 3 disability groups: Down syndrome, autism, and fragile X syndrome. We began by examining the healthcare experiences of parents who have children with fragile X syndrome because it is still relatively unknown and individuals with this syndrome have defining physical features that are not as well known. As well, fragile X syndrome, in contrast to autism has a clear genetic etiology. Comparative analyses are currently being conducted to investigate differences between the groups in terms of their efforts to access healthcare and their experiences with health care professionals.

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