The Lived Experience of Parenting a Child With Autism in a Rural Area: Making The Invisible, Visible

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Derived from the Greek word “self,” autism is a neurological disorder where children seem to be enclosed in their own world. Affecting boys three to four times more than girls (Beauchesne & Kelley, 2004; Behrman, Kliegman, & Jenson, 2000), a once-thought rare condition is becoming progressively more common. Characterized by the impaired ability to engage in social interaction, impaired communication, restricted interests, and repetitive behavior, children diagnosed with autism face an incapacitating life-long disability (Behrman et al., 2000; Committee on Children with Disabilities, 2001).

Although some research detailed the lived experience of what parents of children with autism face (Cashin, 2004; DeGrace, 2004; Glass, 2001; Gray, 1993, 1994, 2002; Woodgate, Ateah, & Secco, 2008), the majority of this work involved urban parents. Few authors had researched the experiences of families of children with autism living in rural areas (O’Callaghan, Allister, & Wilson, 2005; Scott-Findlay & Chalmers, 2001; Skinner & Slifkin, 2007). Moreover, no research was found on the parenting experiences of parents parenting a child with autism in a rural area was undertaken. This article describes the essence of the parents’ experience.

Method

The philosophy of hermeneutic phenomenology as discussed by van Manen (1990) was used to guide this inquiry. Hermeneutic phenomenology is “essentially a philosophy of the nature of understanding a particular phenomenon and the scientific interpretation of phenomena appearing in text or written word” (Speziale & Carpenter, 2007, p. 88), phenomenology being the lived experience and hermeneutics being the interpretation of the essence of life (van Manen, 1990). The aim of hermeneutic phenomenology is to explore human phenomena to understand the structure or essence of the lived experience (Dowling, 2007; Ray, 1994; Speziale & Carpenter, 2007).

Ethical Considerations

The University of Manitoba Education/Nursing Research Committee approved the study. Both written and verbal consent was obtained from each participant, and all efforts were made to uphold confidentiality.

Sampling and Recruitment

This study took place in a mid-Western Canadian province and incorporated families from rural areas who were parenting a child with autism. An intermediary from two urban centers who provided resources for children with autism and their families was asked to assist with the recruitment of participants. In total, 191 letters of invitation were sent out to potential participants. Of this group, 28 families responded, with a final sample size of 26 families because two families responded after the interviews were completed. The first author completed all interviews, with the majority conducted in the homes of the participants, while two were conducted at mutually agreed-upon locations.

All participating 26 families took part in semi-structured, open-ended interviews that were audio-tape-recorded. In total, 22 interviews were done by mothers alone, two were-completed with both the mother and father present, and two were complet-ed by fathers. Study information, as well as demographic and consent forms, were distributed prior to the start of the first interview and

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reviewed with each participant. Parents were asked to describe what it was like to parent a child with autism in a rural community and to explain their thoughts and feelings, their challenges and opportunities, and their needs.

Participating families were from all regions of the mid-Western province and lived between 15 and 800 kilometers away from an urban city. Participants ranged from 26 to 50 years of age, and the majority of participants were Caucasian. Thirty-three children within the 26 participating families were given the diagnosis of autism spectrum disorder. Additionally, 13 children had co-morbid diagnoses, including developmental delay, attention deficit hyperactivity disorder (ADHD), Tourette syndrome, and ventricular tachycardia. Of the participating children, 21% were non-verbal, while the remaining 79% were verbal or displayed some form of speech. The majority of the children with autism were boys (88%), and the children ranged in age from 2 to 23 years old.

Data Analysis
All field notes and interviews were transcribed verbatim and analyzed. Thematic statements were isolated using van Manen’s (1990) selective highlighting approach. By selecting appropriate phrases and capturing specific statements, the meaning of the experience emerged. Collaborative analysis between both authors was an ongoing process. Once potential themes had been identified, the first author worked in collaboration with each participant in a follow-up reflective interview. The draft description of the themes began as a starting point for the author and participant and allowed for further sharing of the lived experiences. Both authors then reviewed the follow-up interviews and further refined and finalized the themes. The end result was the development of a narrative description of the essence of the parents’ experience.

Results

The Essence of the Experience

The essence of making the invisible, visible emerged as what it was like to parent a child with autism while living in a rural area. Parents shared that although autism was an invisible condition, they, in fact, made it visible in their constant battles to ensure that their child received the best quality of life within a community that supported and valued their child. Parents emphasized that the invisibility of autism made it difficult to obtain a diagnosis, gain needed support, and explain their child’s behaviors.

They have no clue because “C” looks perfectly normal. He walks. He talks. He doesn’t have, you know, a stumbler or a limp, so you can’t see a physical disability. (P17)

Autism was not a visible disability to members of the rural community. When the negative characteristics of autism were displayed (e.g., tantrums, meltdowns, yelling, disruptive behavior), the majority of the community members related it to bad parenting or to having an uncontrollable child. As one parent noted, “Most people look at you and they just think he’s a bad kid. Because he looks normal. He acts normal, well somewhat normal, and talks normal” (P11). Autism was invisible to the untrained eye yet visible in ways that people deemed as undesirable.

Parents felt that community members were unaware and uneducated of the difficulties they faced when parenting a child with autism. Over-stimulation and needing time to decompress, challenging new environments, and difficulties with communication were all obstacles encountered by participating parents. Behavioral issues, tantrums, screaming, and physical violence toward themselves and others were further occurrences for children with autism. Difficulties in social settings and no concept of safety led to the need for vigilant parenting by participants. Parents also described their children’s challenging ritualistic behavior and picky eating habits. One parent expressed: “Different people have said he sure doesn’t look autistic...He doesn’t act autistic, but I said that’s why it’s called a spectrum. When you see him on a bad day then you’d see autism” (P15). In making the invisible, visible, parents had to overcome three barriers: 1) he’s not the Rain Man, 2) society’s lack of knowledge and understanding, and 3) doing it on our own.

He’s Not the Rain Man

To make autism visible, parents first had to come to understand and accept the diagnosis of autism. When asked about prior knowledge of autism, parents were extremely limited in their understanding of this disorder. The majority of the parents made reference to the movie Rain Man (1988), starring Dustin Hoffman and Tom Cruise, as their only connection to autism. As one parent stated: “He’s not Rain Man. That’s what I thought because that’s all anybody knows about autism” (P9). “He’s not the Rain Man” was the reaction of the majority of parents. Parents only knew the extremes of autism: the head banging, the rocking, and the lack of emotion. Parents had difficulty relating their child to the character played by Dustin Hoffman, and as one parent stated: “I thought of Rain Man...I thought, well he’s not banging his head against the wall” (P19).

This limited and lack of knowledge of autism by parents led to initial reactions of denial, fear, and shock. One parent described the diagnosis as: “It was just numbing...the first thing I did was totally deny it. ‘Cause I couldn’t figure out how can you sit and watch my kid for five minutes and give me a diagnosis that is so bizarre” (P22). Parents started their journey in denial and confusion and had difficulty comprehending how their child who displayed many different characteristics than the Rain Man could still be diagnosed with the same disorder.

I was willing to entertain it, but at the time, I didn’t think it was that serious because he didn’t have, you know, he makes eye contact, and he smiles a lot, and he likes to be around people...at the time my knowledge of autism was so limited. (P19)

Besides denial and confusion, parents described a variety of other initial reactions. Parents grieved and defined the diagnosis as a “death in your family. You still have that person here. But something dies” (P22). Other parents mourned and stated: “I just cried when she told me that” (P20). While others were left devastated and felt like “your world falls apart...and what dreams you have for your child are gone” (P14). Parents also displayed feelings of anger.

I was so angry and so insulted, and when we left there, I remember looking at him through the rear view.
Eventually, all participating parents had to learn acceptance. As one parent explained it: “I cried for about a week straight. Then I kind of got to that place where we were just going to work with it” (P2). To reach this acceptance, parents had to understand autism and had to learn from their child. From the Internet to libraries to family and close friends, any information about autism was sought. One parent shared: “And then within two days, I was at the library looking for information… I was like, okay now, I have to figure this out, I have to find out where we’re going and where we’re at” (P13).

Over time, parents learned that autism was a spectrum and that a child diagnosed with this disability displayed an array of characteristics that were exhibited in multiple ways and discovered that “it’s kind of like, so he has autism, and he has autism, but they’re totally different” (P22). With a thorough understanding of autism, parents were relieved to finally put a name to what they knew was atypical in their child; one parent stated: “It scared the heck out of us. But it was good that we had a name for it” (P25). By comprehending autism, parents were able to alleviate their frustrations in exchange for reason. They understood autism, and therefore, could better understand their child. By progressing through denial and fear of the diagnosis to acceptance, the true meaning of having a child with autism became visible to parents.

Society’s Lack of Knowledge And Understanding

Another barrier identified by parents was their rural community’s lack of knowledge and understanding. This resulted in families of children with autism facing a stigma of being different. To battle this stigma, parents taught their communities about autism while continuously advocating on their child’s behalf. According to the participants, the stigma that families experienced was more often due to the lack of understanding of autism rather than to people being judgmental.

Lack of knowledge, and that’s the biggest thing, like when I’ve gone up to those people or when we’ve had telehealth sessions, or when I was on the radio, and just the most common thing was that people just didn’t know what it was. (P4)

Community members became afraid of what they did not know, and people “were scared of the autism” (P14). Participating parents became vulnerable to premature judgments that were described by one participant as “people will make judgments. Most of their judgments were of ignorance. They don’t even know what it is” (P15). Most parents perceived that others viewed them to be “bad parents” and their children with autism to be “bad children.” One parent expressed: “the things that would really frustrate me are just people that automatically assume that he’s just a bad child if he’s misbehaving in public” (P4). Another mother stated: “If I take him into the store now, and he’s 7, and he’s this big, and he starts acting up, then I’m the bad parent, right?” (P16). Although parents acknowledged it was society’s lack of understanding that led to these judgments, parents nonetheless felt angry and disheartened. One participant reinforced: “You get home, and you’re just destroyed because it replays in your mind, and it is like why are people so ignorant? I know they don’t understand, but how do I make them understand?” (P22).

Making the invisible, visible was one way parents were able to help their child become an accepted member of their rural community and enabled the best possible life for their child. Families found that the best strategy was to be open, honest, and to share the diagnosis of autism with their community. The more parents talked about autism, and the more they explained and taught the community, the more support they received. Through this openness, one parent described their community as: “It’s more of a welcoming community now like we’re finding that we’re not being judged as much” (P4). By making autism visible, communities became more knowledgeable and understanding, and instead of sending feelings of isolation and stigmatism, communities became a family of support.

Doing It on Our Own

From diagnosis to treatment to advocating, “doing it on our own” emerged as the third major barrier in the essence of making the invisible, visible. From initial diagnosis, parents felt they were on their own. One participant stated: “I feel like there should be someone following him, and I don’t know if they typically do; it’s kind of like they diagnose them, and then you’re done” (P23). Parents used their surrounding environment to seek out as much information as they could. Parents used the media, Internet, TV, books, close friends, and relatives. Following diagnosis, parents searched to find what was offered for their child, what services were obtainable, and how they were able to access them.

All parents received a diagnosis of autism for their child and were never seen again by the specialist or even a pediatrician or rural physician for any follow up in regards to the diagnosis of autism.

That to me is frustrating because I’ve often used the analogy if you were diagnosed with cancer even though it would be the nurses that might give you the treatment and the radiation specialist who give you the radiation, you’d still be followed up by your doctor, and that just doesn’t seem to exist. (P15)

Parents stressed that a follow-up appointment soon after the diagnosis period with the specialist or their child’s physician would have provided the opportunity for them to further discuss and learn more about autism. Multiple parents mentioned that “they should really have, after the diagnosis, some type of book or something” (P5). Parents were thrown into the world of autism with limited knowledge regarding the characteristics and demands of this diagnosis.

Parents had to be the one to advocate for their child; they had to battle the health care system along with the educational system. To parents, “the system” referred to the array of appropriate services, including health care professionals and the educational settings that were designed to enable success in children with autism but were often inaccessible. Getting the required support and services only came through persistence and determination.

I applied and was denied, I was applied and denied, applied and
Parents were on their own with educating themselves, seeking out services, and finding respite workers. As one parent described the difficulty of obtaining a respite worker: “He told me right off the bat that he did not have anybody that could come out here and that if I wanted someone, I’d probably have to do my best to find them” (P1).

Participating families believed that in terms of autism, rural communities had less of everything and lacked services and resources. Rural communities lacked diversity of services and professionals who were able to work with children with autism. Although living rurally meant they did not have access to certain services and resources, parents learned to use all they had to their advantage. Overall, participating parents believed when living in a rural community and parenting a child with autism, they were often on their own in terms of resources, services, and fulfilling their everyday needs of parenting a child with autism.

Discussion

The Essence of the Experience

Making the invisible, visible emerged as the ultimate essence of parents’ lived experience of parenting a child with autism while living in a rural area. Ray (2001) first introduced the phenomenon of making the invisible visible in the context of childhood chronic illness. Specifically, Ray (2001) described the invisible work required by parents in parenting a child with a chronic illness or disability and the skilled responsibilities parents assume that need to be made visible. However, instead of having a focus on the disability itself, Ray (2001) described parents’ experiences of making the invisible responsibilities and challenges that incur when caring for a child with disabilities visible. Comparable to the study by Ray (2001), parents parenting a child with autism spoke to the time and commitment spent preparing their child to function in the social world and in their community. Parents described the consuming daily activities, such as grooming, dressing, and communication, that all took longer with a child with autism. Although they did not have to learn specific medical aspects as did the parents in Ray’s (2001) study, they had to be vigilant, consistent, and prepared for the unknowns of autism.

In the context of autism, the invisibility of autism is documented throughout the literature (Cashin, 2004; Glass, 2001; Gray, 1993, 2002; Midence & O’Neill, 1999; Woodgate et al., 2008). Parenting a child with autism can be a challenging and frustrating experience due to the invisible nature of the disability. Gray (1993, 2002) found that the invisibility of autism was associated with increased stress in families, causing a sense of isolation. Exacerbating this stress in Gray’s (1993, 2002) studies was the extreme disruptive behavior and social inappropriateness of the child with autism. Many parents in this rural study had similar feelings and experiences as those described by Gray (1993, 2002).

Comparable to the research of urban parents by Woodgate et al. (2008) and Gray (2002), rural parents described similar feelings of isolation when autism was invisible in their community. Fortunately, for parents in this rural article, this isolation felt from others dissipated once autism became visible in their community. Unlike the article by Woodgate et al. (2008), parents of rural communities failed to use the term “isolation” to define life with autism, rather to only use the word to describe the lack of available professional support and services. The support rural communities provided enabled parents a sense of inclusion, and therefore, disbanded the sense of isolation that was described by the urban parents of research by Woodgate et al. (2008), Gray (2002), and Mackey and Goddard (2006). A discussion of each theme of the essence will be examined by incorporating a comparison of previous research findings to those of this article.

He’s Not the Rain Man

Limited knowledge and understanding of autism by participants led to initial reactions of fear, denial, and shock. Sen and Yurtseyer (2007) explored the initial reactions of rural parents when they first learned their child was disabled. Similar to rural parents of children with autism in this article, shock, denial, suffering, and depression were described as primary reactions of parents in the article by Sen and Yurtseyer (2007). Further, Midence and O’Neill (1999) described reactions of confusion and feelings of guilt and despair by the rural parents of children with autism. However, both above mentioned articles described the importance of parents reaching acceptance. In this article of rural families, autism became visible to parents by the research and education they sought. In understanding autism, parents became empowered to make the right choices for their child, allowing them to provide the best life possible. Understanding autism enabled parents to understand their child.

Society’s Lack of Knowledge And Understanding

Society’s lack of knowledge and understanding was cause for concern for participating families as well as families in past urban studies (Gray, 2002; Woodgate et al., 2008). Difficulties, including embarrassment in social settings, hostile or insensitive reactions from the public when the child behaved inappropriately, and feelings of being judged by other parents based on their child’s actions, were all described in the literature due to the invisibility of autism (Cashin, 2004; Glass, 2001; Gray, 1993, 2002). Gray (1993, 2002) explained how the normal appearance of a child with autism, combined with the lack of knowledge from society, increased the incidents of hostile remarks to parents in regard to any unwanted and inappropriate behavior from their child. Further, Midence and O’Neill (1999) found that the “invisible condition” of autism made things worse for parents regarding the lack of an understanding by society. The difference found in the articles by Cashin (2004), Glass (2001), Gray (1993, 2002), and that of this rural article was that once autism became visible within the communities, parents reported a decrease in stigmatism. Instead of feeling isolated and alone, families were embraced by a community that supported them. Nevertheless, as evidenced in this article, Gray (2002) concluded that increasing the public awareness of autism may reduce the stigma attached to parenting a child with autism, and therefore, decrease the sense of isolation, in
Doing It on Our Own

Doing it on our own emerged as the third major barrier to the essence of making the invisible, visible. Woodgate et al. (2008) discovered that urban parents parenting a child with autism had similar feelings to the parents in this article and described the essence of parenting a child with autism as “living in a world of our own” (p. 1078). Parents in the article by Woodgate et al. (2008) believed they were on their own for all aspects of daily living, especially those related to the difficulties and challenges of parenting a child with autism. Further, Mackey and Goddard (2006) also found that mothers parenting a child with intellectual disabilities described feelings of being on their own. Participating rural parents faced multiple challenges and barriers with few resources; getting the required support for their child with autism only came through persistence and determination.

Limitations

There are two key limitations with respect to this article. Primarily, researchers did not interview professionals and parents within the community who were responsible for implementing the programs put in place to enhance the lives of children and families parenting a child with autism. Although parents from diverse ethnic backgrounds participated in the study, the majority of the participants were Caucasian mothers. While the purpose of purposive sampling was to invite the primary caregiver, having a sample consisting mostly of mothers may limit findings. Nonetheless, variety was found within the ages of participants, material status, and educational background.

Implications

Findings from this article provided new insights into the lives of rural parents parenting a child with autism. In addition, this article provided grounding for future research. Rural literature looking at parenting a child with autism was extremely rare, and future research is warranted to further the findings. In addition, increased research on living rurally and parenting a child with disabilities or special needs is crucial. Research to assess the knowledge level and experience that rural health care and social providers have about autism would identify gaps in the field of autism and continue to make visible this invisible disability.

Practice

This study reinforces that more support is needed for rural parents with children with autism. Support is especially warranted in the immediate time after initial diagnosis and in follow up to assess coping strategies and needs of parents. A toolkit specifically designed for families living in rural communities could be made to contain valuable information in terms of specific resources available, accessible services, and links for support both within the community and for professional organizations. Further, a nurse or social worker who is able to work with families from diagnosis through transition times and within the school system would provide immense support for these rural families.

Educating nurses and health care professionals, families, friends, and communities who lack the knowledge of autism should be top priority to help promote an understanding of what autism means to the parents and the demands it places on daily life. Additionally, rural nurses and other health care and social service providers should be assessed on their level of knowledge of autism and be provided with opportunities to further their knowledge and obtain strategies to enhance the lives of parents parenting a child with autism. Technology, such as delivery of health-related services and information via telecommunications, should be used more frequently to disperse knowledge and education in regards to autism to parents, health care professionals, and communities.

Nurses and other health care and social service providers need to understand that parents know their child best and they need to listen to parents and validate their concerns. Collaboration between health care professionals is crucial, as well as being open-minded to the different treatment options and types of support available. Further, increased education and training on autism and developmental milestones is also warranted for all nurses, especially those in primary health care.

References


