

Title Exploring fathers' perceptions of parenting a child with Asperger syndrome

Abstract

This study explores Irish fathers' perceptions of parenting a child with Asperger syndrome (AS). Ethical approval was granted by the service provider, and Husserlian phenomenological approach facilitated the exploration. Data were collected through semi-structured interviews of nine fathers in the West region of Ireland. Data were transcribed and analysed using Colaizzi's (1978) method. The study highlighted that parenting a child with AS is an arduous task, but while there are difficulties, many positive aspects to their parenting experience were reported. Overall, the study highlights the importance of listening to parents and their initial concerns regarding their child's development.

Keywords

Asperger syndrome, autism spectrum disorder (ASD), disability, fathers' perceptions, parental stress

Introduction

Parents of children with disabilities encounter very unique and challenging situations while raising their child, which may cause elevated stress levels (Trute et al., 2007). As a population group, parents of children with an autism spectrum disorder (ASD) experience higher stress levels than those of the general population or indeed parents of children with other disabilities (Weiss, 2002). Equally, some parents report positive aspects of their experience raising a child with a disability or ASD (Scorgie and Sobsey, 2000; Tehee et al., 2009). Asperger syndrome (AS) is classified as a subtype of ASD; therefore, the unique characteristics of this disorder are not often considered or understood, highlighting the fact that research on the stress experienced by parents specific to children with AS is sparse (Pakenham et al., 2004). Children with AS, in comparison with children with Autism, acquire language skills early in life, which often masks the child's difficulties. Indeed, AS has often been described as a lesser disability and delays are often reported in receiving a diagnosis, resulting in increased stress for parents (Howlin, 2003; Marshall, 2002; Pakenham et al., 2004). AS is a pervasive developmental disorder characterised by lack of social understanding, an inability to hold reciprocal conversations and an intense interest in a particular subject (Schnur, 2005). Communication skills, independent living skills, social adjustment and motor clumsiness are distinct characteristics (Cummins et al., 2005; Howlin, 2000), but people with AS have intelligence and language within the normal range of functioning (APA, 2000).

Quite often people with AS are denied services due to the fact that they are articulate, do well academically and appear bright (Carter, 2009). However, their low levels of skill in social settings impinge on their ability to make and sustain friendships, recognise and cope with bullying and successfully guide them through the complex social environment (Stichter et al., 2010). In addition, people with AS may be extremely sensitive to sounds, tastes, smells and sights, may prefer to wear specific types of clothing and eat only

certain foods (Lemer, 2011). With regards to social development, people with AS experience difficulty and often become victims of teasing and bullying and experience significant social exclusion (Carter, 2009). The resulting high levels of distress experienced as a result of anxiety, lack of social and emotional insight and underachievement are reflected in the high rates of mental ill-health (Anderson, 2007). People with AS have a normal to high intellect but are affected to different degrees in the way they think, communicate, relate to others and understand the world around them. While the majority of people with AS are in mainstream activities/service, such as the educational systems and the health care systems, they often require specialist support from intellectual/learning disability services.

Background

The prevalence rates of AS are not well documented, in the United Kingdom; Baird et al. (2006) reported a prevalence rate of 116 per 10,000 for ASD. Baird et al. (2006) identify that many of the children measured meet the criteria of AS; so it is assumed that the prevalence rates of AS are similar. In Ireland, no prevalence rates have been detected, and general statistics regarding intellectual disability identified 27,324 people with a disability (Kelly, 2012). However, the National Disability Survey (NDS; Central Statistics Office (CSO), 2008) indicates 50,400 people with a disability in Ireland. These statistical sources present different rates, and Doody and Doody (2012) identify the reasons for the differences based on the methodology used in both collection methods. While accurate prevalence data for AS and ASD in Ireland are not available, the Health Service Executive (HSE, 2011) estimates through the 2006 national census data (CSO, 2007) and the NDS (CSO, 2008) that there is a prevalence of 1.1% for ASD in Ireland, and of which, 38% are aged between 0 and 17 years. Traditionally, the care of people with intellectual disability in Ireland revolved around a long-stay hospital care model; however, the negative effects of institutional living gave rise to a move towards community care (Doody, 2007). Since 1980s, service provision for people with intellectual disability has changed, developed and grown in Ireland, and these changes were influenced by politicians, health professionals and the general public debating ways in which services for people with intellectual disability would be delivered. Given the move away from congregated settings (HSE, 2011) and an inclusive education system, children with disability remain in the family home with an assessment of need and support services available. However, while most children remain at home, few studies exist pertinent to the experience of parents while parenting a child with AS and those studies that are available are predominantly focused on mothers and some included both parents (Little and Clarke, 2006; Tehee et al., 2009; Yamada et al., 2007). The present study sought to explore the perceptions of fathers' parenting their child with AS, because despite increased research related to AS, there are gaps in the literature with regard to the fathers' perspectives. Existing studies tend to use samples of which fathers are a component of their sample (Kalyva, 2010; Sciutto et al., 2012) in identifying the perspectives of family as a whole. While these studies create an understanding from the family perspective of parents of children with AS, they fail to present the unique perspective of fathers.

Methods

Aim

The study aimed to explore the perceptions of Irish fathers caring for a child with AS.

Research design

In accordance with the aim of the study, a qualitative phenomenological approach was chosen, as it is considered appropriate in examining the qualities of human experience (Green et al., 2007). In the phenomenological approach, Husserlian descriptive phenomenology approach was chosen, as the focus of the study was on the description of the fathers' perceptions rather than on the interpretation of their views. This method focuses on the human experiences (Polit and Beck, 2010), seeking to describe the participants' views, while acknowledging that only they who experience the phenomena are capable of communicating it to the outside world (Higginbottom, 2004; Parahoo, 2006). Additionally, it is often used when little is known about a topic and accumulates evidence from a fresh perspective (Higginbottom, 2004; Lo Biondo-Wood and Haber, 2010). Thereby, allowing the researcher access the participant's lifeworld to gain a deeper understanding of their experience (Balls, 2009).

Ethical issues

Ethical approval was obtained from the Clinical Research Ethics Committee University Hospital and the researchers employers in line with the internal policy of the research site. It was also important to consider the rights of participants in the study to minimise and avoid harm or discomfort to participants (Polit and Beck, 2010). The participants were sent an invitation letter informing them of the purpose, nature of the study and identifying the benefits, potential discomforts, their right to abstain from participating and their right to withdraw. This letter had a tear off slip to return in a stamped addressed envelope, to identify the persons' interest in participating in the study. The interested fathers were then contacted by telephone in order to clarify any further queries or questions as well as aiding the development of a trusting relationship. The date and time of the participant's choice was agreed for the interview and each participant received a signed copy of the consent form.

Participants and recruitment

An information leaflet and invitation letter to participate in the study were mailed to a purposive sample of 16 fathers, and of them, 14 responded. After contacting respondents to further explain the research study and process, nine fathers took part in the study. Written informed consent was obtained and confidentiality was protected. Participants' had the right to withdraw at any time without prejudice. Table 1 lists the demographic details of the participants, using pseudonyms to protect their identities. Participants were recruited from the Mid-West region of Ireland, which included participants from both rural and urban areas.

Table 1. Demographic details of participants.

Participant	Age (years)	Carer status	Gender of child	Age of child	Other children
Karl	50–59	Full-time carer (unemployed)	Male	10	Daughter
Ben	40–49	Works from home (family business)	Male	17	A son and a daughter
John	40–49	Employed works Monday to Friday	Male	10	Son
Tom	50–59	Part-time work	Male	11	Step-daughter
Barry	50–59	Works from home (family business)	Male	18	Son (pervasive development disorder)
James	40–49	Full-time employment	Male	17	Two daughters and a son
Cormac	50–59	Works away from home and is absent for periods	Male	18	Three sons
Darragh	40–49	Works away from home in another county	Male	10	Son
Tony	50–59	Full-time employment	Female	9	Two daughters

Data collection

Data were collected by semi-structured interviews utilising an interview guide of six open-ended questions and probing participants' responses. The questions were developed by the researcher based on subject matter unfolding from the literature. All interviews were conducted in a venue of the participant's choice and lasted between 60 and 90 minutes. Interviews were audio-recorded and provided participants' with the opportunity to fully describe their experiences. However, it is worth recognising that data may have been influenced by the fact that some participants' were known to the first author who conducted the interviews. This was the case due to the author's prior practice experience with families, thereby care was taken to ensure that no pressure was exerted on participants and assurances made in relation to their continued service provision regardless of participation.

Data analysis

Data were transcribed verbatim to maintain data integrity and analysed using Colaizzi's (1978) sixstep method of analysis that is widely used in nursing (Doody, 2012; Hilliard and O'Neill, 2010; Scrafton et al., 2012). This method differs from other more frequently used methods of data analysis, in that, it not only examines the meaning of an experience through deciding on essential themes for respondents, it also validates the results by returning the analysis to study respondents for proof of accuracy. The process involved the first author conducting the analysis manually by transcribing each interview verbatim

followed by reading and re-reading the transcripts, extracting significant statements and phrases, formulating meaning of the significant statements, organizing meanings into themes, integrating results into a rich description of the experience, formulating a structure of phenomenon and seeking validation from participants who compare the descriptive results with their lived experiences (Doody, 2012). The research team members reviewed the transcripts independently and the findings were compared and discussed until consensus reached pre-validation by fathers. As recommended by descriptive phenomenology, the researcher put aside her own beliefs, refrained from making judgements about what she heard or observed and remaining open to data as it was revealed (Streubert and Carpenter, 2011). A reflective diary was also kept throughout the process in order to identify early detection of bias and assist in the presentation of true and reflective accounts of the participants experience.

Results

Through analysis, three key themes emerged from the data: ‘the journey, from awareness to having a diagnosis’, ‘living with a child with AS’ and ‘the impact of services’. Themes were formulated by placing descriptors on the participants’ statements and organising the meanings into themes. The themes and sub-themes are highlighted in Table 2 and the themes presented utilise direct quotations from the participants.

Table 2. Themes and sub-themes.

Themes	Sub-themes
The journey, from awareness to a diagnosis	Not playing with others Social skills deficits Delayed speech Behavioural difficulties Sourcing information
Living with a child with Asperger syndrome	Rigid routines Food fads Academically bright The future A sense of pride
The impact of services	Lack of knowledge Financial cost Waiting lists

The journey, from awareness to having a diagnosis

Throughout the interviews, all participants reported that there were signs from an early age that ‘things were not quite right’ with their child and noticeably so by the age of three. Some fathers had concerns at a much earlier age as their children had medical needs in line with ‘dietary issues’, ‘skin conditions’ and ‘asthma’. The main indicators reported by participants that ‘things were not right’ were: their child was not sleeping,

lack of eye contact, poor social skills, language delays, motor skill deficits and difficulties attaining activities of daily living, such as toilet training. In the study, five of the participants reported that the concerns arose as a couple discussing them and four participants recalled their spouse raising the concerns initially.

‘ would say my wife pushed it more than I did, she had been bringing him to get his ears tested, she was adamant that there was something different from our two other kids, a year and two older. (Ben)’

While there was an awareness that something may be wrong there was also a denial among some of the participants. This denial was more of an avoidance as one of the participants articulated.

‘We didn’t want to think about it, we were trying to say ‘ah, this will be alright, it’ll go away. (Tony)’

However, awareness for some only truly arose when they were in discussion with their nurse, who was able to identify where the issues were.

‘We were told by the nurse that there was no reaction or interaction occurring from him or reaction or interaction from him to us. (Darragh)’

In addition to becoming aware that there was a problem, participants also spoke of their frustration when dealing with behavioural difficulties and how others may perceive their child’s difficulties differently. One father spoke about their son’s ‘initial explosion’. He said

‘Most people would interpret it as boldness or a lack of control but it really isn’t that at all, it is just the initial reaction. (Karl)’

Overall having the sense that something was not right but not having any diagnosis was quite frustrating for participants. This frustration stemmed from not knowing what was going on with their child.

‘It was very frustrating for me and my wife because he wasn’t interacting with kids and animals . . . and he was kicking the cat and being violent towards the cat and stuff like that. (Tom)’

During this period of awareness, fathers reported having difficulties finding suitable preschool settings and primary school settings appropriate to their children’s needs. Two fathers spoke of how the family contemplated relocating in order to meet the needs of their child and having to ‘revisit their plans’ very quickly as a result of their son’s condition. All participants reported the children had language delays, social interaction deficits and behavioural difficulties that were clearly indicating some difficulties, but not plainly identifying the children as having AS.

‘When my son was young, he had some difficulty with toileting and he had some difficulties with development. (Cormac)’

‘We sent him to playschool but that didn’t work out and even school wasn’t working, we may as well have kept him at home, he just couldn’t work in it at all as regards to the socialisation. (Barry)’

During this time, three participants said that their children were referred to a special language class in a mainstream primary school. This class offered children with language difficulties an opportunity to spend 2 years in supported education; for some families, this meant travelling a considerable distance to the school each day. Upon completion of these 2 years, children then reverted back to mainstream primary school in their own community. This service was invaluable to the participants and assisted in developing their language and social skills.

‘For someone that we didn’t think would actually talk and now at this stage who won’t stop talking. (Tony)’

The remaining children all attended mainstream primary school with the support of a special needs assistant and parents considered carefully the best school option available and would continually question their choices in light of future needs.

‘Where is the right place to send him, we visited a special school and about ten national schools around the area, we are going through a big decision at the moment because we are changing his school with a view to the future. (John)’

The time from the initial recognition that something was different to the time when families received a diagnosis ranged from 3 to 8 years, clearly indicating a lengthy process.

‘He was born in . . . we knew beforehand there was something serious, he got his diagnosis in . . . 7 years later. (Barry)’

Participants spoke about being referred to health-care services such as occupational therapy, speech and language therapy and pediatricians. However, some children were school age before they were referred to a psychologist and the participants who had been referred prior to school age commented on the waiting lists for services. After waiting for a long period for a psychological assessment, a diagnosis was given. However, this diagnosis often identified the children as having attention deficit hyperactivity disorder (ADHD), pervasive developmental delay (PDD) or an ASD and not specifically AS. This then resulted in participants having mixed reactions when they then received these diagnoses.

‘My wife rang, she wasn’t so upset but I was stunned. (Ben)’

‘It was actually a relief, now there is a reason why he doesn’t do things. (James)’

As the AS diagnosis was a slow gradual process, participants reported having adjusted to their child's way of being by the time they received the diagnosis. However, all the participants reported knowing very little about ASD and AS except for its media portrayal, which is often of a burden.

'My understanding of autism would have been very sketchy, probably based on the media portrayal and the worst case scenario. (John)'

'I wasn't aware of the spectrum, therefore I thought this was a great burden to carry and I thought I wouldn't be able to carry it (Ben)'

Initial assessments in many cases diagnosed their children with ADHD, PDD or ASD, not specifically Asperger. Participants identified that they spent a lot of time trying to gather information about their child's condition. This desire and need for information was evident with all the participants. To gain this information, participants engaged in their own research on the Internet, in books and by watching television (TV) or by discussing it with the professionals they met.

'I went on the internet, printed out thousands of pages of information. (Ben)'

'You have to engage as best you can with people to find out what is available, what is the diagnosis, why my son was different. (Cormac)'

Three of the participants openly expressed relief at finally having the diagnosis, as it enabled them to gain a deeper understanding of their child, and they were then able to look at their child's presenting difficulties in a different way. However, some fathers also expressed feelings of guilt as they had assumed some of their child's presenting difficulties were just 'boldness'.

'It was actually a relief because I didn't feel that he should be doing this or he should be doing that, now I understand all the things that I couldn't explain for years beforehand. (James)'

Five participants were able to relay significant details about their child's journey to a diagnosis, while others were not. This was due to their adoption of a more indirect and passive role. Four of the fathers, in particular, spoke about how their spouse managed all the child rearing activities on a day-to-day basis including the appointments, dealing with the schools and the sourcing of information in relation to their child and then discussing it with them.

'If it was a practical thing, I look after it, if something needed to be done in terms of fixing the central heating I would crack on to it, if something needed to be done in terms of our son, my wife would find out about it and we would talk about it, we always respected each others decisions. (Darragh)'

Five of the participants in this study work outside the home on a full-time basis, while two fathers worked away from home for periods of time. This indicates that 75% mothers remain the primary carer for their child on a daily basis. However, in the present study, it is also seen that some fathers are taking a more active role in child care activities and clearly have an awareness of the time, resources, interventions and effort required in relation to meeting the needs of their child. The fathers who worked outside the home, on the other hand, clearly saw their role, as one support to their spouse.

Living with a child with AS

When participants were asked to describe what it is like for them living with their child with AS; one participant acknowledged it was 'no different from parenting their other children'. Seven participants openly identified the positive aspects of living with their child with AS. Identifying how bright, funny, honest and interesting their children can be. Participants spoke proudly about their children's academic abilities and achievements, their hopes for the future and their children's ability to show affection. Participants spoke of 'huge moments' such as 'receiving the hug' or their child asking a question for the first time. In addition, participants spoke of how they also learned from their children as it enabled them as a family to engage in conversations that might not necessarily happen due to the sensitive nature of the subject (e.g. sex education), because of their child's inability to recognise it as a somewhat embarrassing topic thereby bringing it out into the open.

'We were all talking about this stuff in a very open way than you would otherwise, so it was cool, it was good. (Ben)'

Participants also spoke about the difficulties they encounter on a day-to-day basis. These included inflexible routines, narrow interests and obsessions, dietary issues and food fads, sleeping difficulties, behavioural difficulties, sibling rivalry, homework issues and having to engage in therapy programmes.

'There is no down time, there is always a demand. (Karl)'

When discussing the need for routine, one participant spoke of his child's request for a weekly dinner menu so he would know on a day-to-day basis what he would be having for dinner. If there was a deviation in the menu, his son would become extremely upset and it took months to find the simple solution of putting 'if available' next to each daily selection. All the participants spoke of the need for routine and any break from this routine would create great distress or awkward social encounters.

'If we had visitors he would say they're not here again, are they, I thought they'd be gone home. (Tom)'

Typical to children with AS is the engagement in narrow interests; however, due to the nature of AS, there is often an inability to read social cues in relation to engaging people in conversation.

‘If its something that he’s interested in he’d talk fanatically about it and won’t understand that no one really wants to know about that. (James)’

Dietary issues and especially food fads are another area typical to children with AS, but not included in the diagnostic criteria. One participant spoke about his son’s very restricted diet due to allergies and how, as a result, the family themselves were limited in attending family outings and occasions. While other participants identified the difficulties around food fads and meal times.

‘His appetite is different to ours altogether, if we are eating a dinner he won’t stay in the kitchen, he goes into another room. (Barry)’

When discussing living with a child with AS, the amount of time spent in meeting their child’s needs goes far beyond the needs for other siblings. This has obvious implications for time spent as a couple and with their other children within the home. All the participants in this study had other children, and the participants described how some of their other children have expressed feelings of resentment and embarrassment towards the child with AS.

‘Life is about my son most of the time, if I pick up the phone I will ask how is he today? How did he get on? Did he go to school ok? How is he now? What’s he doing? What’s he at?, that has become our life as a couple, if someone said you can’t talk about him I don’t know what we would talk about. (John)’

‘I have had situations where my daughter (other child) will deliberately do something bold or wrong, just to get any attention. (Karl)’

The participants in this study clearly identified positive aspects associated with parenting a child with AS, and although difficult aspects are also evident from the stories told, the hope expressed by participants was a coping strategy in itself for them.

‘Academically there is no bother, he excels. (Tom)’

‘She is unbelievable, she’s very interesting and will interest you in what she wants to talk about. (Tony)’

Regarding the future, all the participants expressed education as a key factor supporting their child to live life in the future and there was a clear drive to ensure their child received a good education. Six participants perceived their child to be bright and academically capable and this gave them greater hope for their future and that of their child. However, three of the participants had concerns about their child’s reading, writing skills, mathematical competencies and overall academic abilities. This created anxiety among the three participants as they were concerned about getting their child through the educational system as they felt this would increase their child’s coping skills and support their individual learning styles. Their concerns related to the social construct in the school

setting, such as developing friendships, being exposed to bullying and maintaining their child's confidence and self-esteem.

'I want him to be able to cope and I want to be able to know that he can go smoothly from one school to another and continue on because then he will thrive. (John)'

The importance of receiving a good education foundation undoubtedly has implications for children becoming more independent. However, reservations were expressed about participants' children gaining full independence in the future, participants felt their children will always need some level of support into adulthood. Participants were concerned regarding their child not being as 'street wise' or as 'smart' as other children, which invariably caused them some concern with regard to the type of friends they may choose or their child's ability to make the right decisions, while living away from home. Some participants spoke of their efforts to promote their child's independent and living skills but this caused conflict as their wife's overprotective nature hindered these efforts.

'She still dresses him, she shouldn't be doing it. (Tom)'

'I would push him more than my wife, I would like him to do more and he does you know and he will have to in the future, and he needs to be able to mix with others and get on in life. (James)'

While discussing their child's future, participants spoke about how they hoped that, at some point in the future, their child would meet a partner and settle down. Many participants discussed the possibility, or probability even, of giving some level of support to their child in the future and how they had no problem with such a scenario. In this study, another area highlighted by the participants was their child's inability to play team sports. Children with AS traditionally have difficulty engaging in team sports and thus have a tendency to opt out at a very early age. Participants saw sport as a major father-child activity, where fathers develop strong relationships with their child by introducing them to sporting matters, developing a common interest and forming a focus for communicating together. Consequently, the participants in this study had to find other activities, where father-child bonding could occur. Some participants spoke of how they continued to bring their child to sporting activities in the hope that they would develop an interest, while others had clearly found other activities that enabled them to bond with their child. Participants also saw sporting activities as another way for their child to develop friendships and independence. In this study, the issues around sport were not a concern for the father of the only girl in the study, where his relationship was not in any way contingent on a common interest in sport. Two participants spoke of their child learning to drive and how that task would increase their child's independence. Regardless of father-child bond, all the participants expressed concerns about their child having no or few friends.

'He doesn't have the benefit of sport, other lads would have the GAA (Gaelic Athletic Association), and they would have friends, he doesn't like football, he doesn't

like soccer, he doesn't want to be a team player, he wouldn't have many friends. (Darragh)

In this study, the participants expressed their wish that their child be well educated, have friends, be independent in the future and, in short, be well equipped for a life without their parents.

The impact of services

When participants were asked what services should be doing to support them, most spoke about the length of time it took professionals to diagnose their child. All but one participant expressed anger and frustration at professionals and the fragmented services they receive. Participants spoke about constantly finding themselves on waiting lists for services and having to 'fill the holes' in service provision by attending services in a private capacity using their own private funding. Participants spoke about the inability of professionals to recognise AS due to the professionals' lack of knowledge in the area.

'Give those people the training to spot it and be aware of it even if they are only suspicious they need to be able to diagnose it earlier or not misdiagnose it. (Tony)'

All the participants spoke of having to constantly fight for services for their child and some recalled their spouses leaving 'no stone unturned' when attempting to get the right supports put in place. Throughout the interviews, participants spoke about struggling with behaviour difficulties with their child and delays in receiving a diagnosis. This delay created some regret for participants as they recalled the ways in which they had dealt with behaviour prior to diagnosis and how they looked at the behaviour in a different way after diagnosis. Participants spoke about the implications of having a supportive educational system; the importance of having open communication between teachers and parents, where information regarding their child on a daily basis was shared through the use of a communication notebook. Participants identified the significance of showing a united front as a couple when meeting professionals, doctors, therapists and teachers alike. However, professionals can also be difficult to work with also as one participant spoke of their disappointment when his child's teacher failed to accept the advice of other professionals in attempting to help his child who can experience some behavioural difficulties in school. Three participants spoke about the benefits of their child attending a specialised language class for 2 years and how the teachers and staff there were perceived as knowledgeable and effective in supporting their child's educational needs. All the participants praised the respite service that their child attended and expressed how the service represented more than just a respite service for their child, but rather a place where their child is learning social skills, independent living skills and meeting friends. All children who use the respite service refer to it as their 'club'. Although participants saw respite as beneficial to the whole family, most expressed its benefits in terms of their child and what they were gaining from it and how they look forward to it on a monthly basis.

'The club here is a god send, he loves it so much, it is getting him used to dealing with situations that are different to his day to day stuff. (John)'

In conclusion, the participants in this study felt that many of the professionals they have met have little or no understanding of the multiple needs of a child with AS. However, there is also a recognition that services and the staff within these services have become better educated in recent years due to an increasing awareness of the condition and its characteristics.

Discussion

Parent perceptions of parenting a child with disabilities have been studied extensively in populations of children with disabilities and chronic illness and are more often examined under the auspices of parental stress (Trute et al., 2007). Although some researchers have examined the perceptions of parents as a whole, little has been documented in relation to the perceptions of parents with AS. The lack of empirical studies on the fathers' role of parenting their child with a disability limits our understanding of how a father explains, adapts and copes with the challenges (Hatton and Emerson, 2003). Most investigators have sought to examine either both parents or the primary carer, which in most cases tends to be the mother; however, this study sought to explore the perceptions of fathers while parenting their child with AS. The fathers' in this study found themselves on a different journey to the one we all hope and dream for when we have children. Their journey has taken a different pathway from the initial awareness of something being different about their child, the accommodations they have made in order to support their child and family and the trials and tribulations that are evident throughout their journey. Children with AS are traditionally perceived as high-functioning compared to many other children on the ASDs due to their acquisition of language and generally high intelligence quotient. This leads to the belief that AS is a lesser disability (Anderson, 2007). However, parents often experience difficulties in language delays, behaviour and social interaction far outside the diagnostic criteria, which at times requires parents to access specialist interventions such as doctors, consultants, psychologists, speech and language therapists and occupational therapists (Epstein et al., 2008).

The findings of this study clearly indicate that fathers of children with AS recognised or discussed fears with their spouse, arising from their spouse's observations that there was something different about their child from a very early age. However, the process of diagnosis took months and years of referrals, waiting lists, private consultations and, in most cases, misdiagnosis. In many instances, fathers reported dealing with behavioural difficulties and social skills deficits in their children, while they continued in their struggle to find out what was going on, but not formally receiving a diagnosis until their child was much older than when the concerns were first raised. In the present study, many of the children attended mainstream educational facilities, but it was found that their social interaction deficits had an impact on their overall functioning in mainstream classrooms. This finding was also supported by Epstein et al. (2008).

Fathers spoke about having to wait between 3 and 8 years for an accurate diagnosis and most fathers expressed relief at finally receiving an accurate diagnosis of AS for their child. Many had also realised by that time that their child was less affected than they had originally feared. Broadly speaking, fathers were not able to relate the minute details of

their journey to a diagnosis and would often defer to their spouse if the investigator needed more clarification. Whether this is as a result of their spouse engaging more directly in child-rearing activities or indicative of a different style of coping is a matter that needs further investigation. Interestingly, different styles of coping may be seen as predictors of adaptation in mothers of children with PDD (Weiss, 2002). Whether it serves as a predictor of adaptation in fathers of children with AS is unclear. Many fathers spoke about their drive to attain as much information as possible after receiving the diagnosis via the Internet, books, professionals dealing with their child and the TV. This instrumental style of coping becomes more obvious in their motivation to put in place what is needed for their child with regard to therapy, preschool, school, third-level education and the future. Being the father of a child with AS can be a demanding task, where the pressure of having to deal with day-to-day difficulties, attempting to access services, attending appointments and engaging in therapy programmes culminates in increased pressures being placed on the whole family unit. Similar to the findings of Yamada et al. (2007), this study found that these demands are placed on a family of a child with AS and the stress posed by these demands can have an impact on family functioning. In this study, many fathers reported their spouse engaging in many of these activities and their role as fathers was seen as a supporting role to their spouse. Whether this level of demand on mothers has implications for their mental health, as referred to by Yamada et al. (2007) and reinforced by some of the fathers included in this study, is a matter that requires further investigation.

Although many fathers discussed the arduous task of parenting a child with AS, many fathers also spoke about the positive aspects of parenting their child. The pride and emotion expressed by fathers was evident in their language and intonation during the interviews. Many fathers recognize how 'happy' their child appears to be despite facing adversity every day in school, in social situations and at times with their health. Great pride was also expressed by many fathers of the present study with regard to their child's academic abilities, despite their difficulties in having to deal with their child's individual learning styles. This finding was also supported by Little and Clark (2006) in their study on the wonders and worries of parenting a child with AS and non-verbal learning disorder.

Educational achievement, involvement in sporting activities and the future were of particular concern for this sample of fathers. For most of the fathers, a good education is vital in reaching personal independence. Some of the fathers expressed concerns in relation to their child's lack of interest in reading, writing and mathematics as well as their inability to understand concepts. Many also expressed concern with their child's lack of independent skills and discussed the efforts they were making to achieve this goal. However, fathers spoke about times when they were hindered by their spouse's overprotective nature, while attempting to teach these skills. Not having a sporting interest means that the fathers in this study had to find new ways of developing father-child relationships. Finding other ways of increasing their child's physical stamina was initiated by some fathers, while others continued in their efforts to include their child in sporting activities. Being a team player is also seen as an opportunity for their child as it enables them to meet friends with similar interests and guards against social isolation in

the future. Many fathers in the present study acknowledged the fact that their child would require some level of support in the future and, although they expressed not having a problem with this, they also hoped their child would be given every opportunity to be happy, to gain an education, to become as independent as possible and to have friends or, in some cases, have someone to share their life with in the future.

The impact that services made on the lives of these fathers' children varied with many fathers speaking about the lack or fragmented nature of services and the constant struggle they or their spouse experienced in trying to access these services. Concerns about the knowledge of the professionals they were dealing with and their inability to identify AS were also expressed. This concern was also voiced by mothers in Gray's (2003) qualitative study where they experienced several negative effects as a result of not receiving a quick diagnosis. The implications of receiving a late diagnosis meant that the fathers in the present study often dealt with behaviours differently to the way they dealt with behaviours after receiving the diagnosis, and this caused them some concern. They also spoke about how the educational system was ill-equipped to meet their child's individual learning styles and how these struggles placed a huge onus on parents to meet the needs of their child, especially in relation to periods of transition in their child's life, dealing with peers and behavioural difficulties. Three fathers spoke about the positive impact a special language class had made on their child's educational advancement, which promotes the idea that the targeted interventions can have a positive impact.

Limitations

It must be made clear that there are limitations to the present study. First, only fathers whose children avail of a respite service were interviewed for this study. This particular service may be unique to this sample of fathers and therefore may pose difficulties for the generalisation of results. Second, only nine fathers were involved in the study and this sample size can be considered small. Third, fathers were asked to report on past experiences over a period of years and retrospective accounts can often be recalled in a more favourable manner.

Implications for practice

There is little research carried out in relation to children and teenagers with AS and research on life-course outcomes is even more limited. This study sought to capture the experiences of fathers, while parenting their child and, as a result, has generated more topics for further research. The findings of the present study may be used to improve holistic nursing practice as well as promoting family-centred care by recognising and fostering the role of fathers in parenting their child. If we are to become truly family-centred as services, we need to be able to listen and embrace the expertise of parents as the people who know their child best so that when concerns are expressed with regard to a child's behaviour and characteristics, these concerns will be addressed and investigated in a family-centred way. It also has implications for the future educational needs of staff and professionals dealing with and supporting families of children with AS, especially during periods of awareness, when receiving a diagnosis, dealing with behavioural difficulties, transitions in the educational system and the future.

Conclusion

Fathers have a vital and important role to play in parenting their child with AS. Too often, the father's role is seen as invisible or an extension of the mother's role. However, this sample of fathers showed resilience, adaptability and acceptance of their child despite attesting to the fact that parenting their child can be a demanding task; they expressed huge joy and pride as well as sadness and frustration, and they highlighted the importance of support structures in health and education systems in order to appropriately recognise and meet the needs of their child.

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