

Evidence of resilience in families of children with autism

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Abstract

Background Family resilience is a growing field of inquiry, investigating factors that contribute to a family's becoming stronger in spite of dealing with adversity. Despite the growing interest in studying family resilience, the topic has not been explored in families with children who have disabilities. This report, a part of a larger study – using both quantitative and qualitative methodologies – is an examination of factors of family resilience in the families of children with autism. Evidence of family resilience such as family connectedness and closeness, positive meaning-making of the disability, and spiritual and personal growth were identified and examined in this part of the study.

Method The study uses a survey methodology, analysing responses to several rating scales and written responses to three open-ended questions. Survey respondents consisted of 175 parents and other primary caregivers of a child with autism – ages between 2 and 18 years.

Results Results suggest identification of specific resilience processes, such as: making positive meaning of disability, mobilization of resources, and becoming united and closer as a family; finding greater appreciation of life in general, and other people in specific; and gaining spiritual strength.

Conclusions This study presents evidence that a considerable number of families of children with autism display factors of resilience – reporting having become stronger as a result of disability in the family.

Keywords autism, disability, family, meaning, resilience, strength

Introduction

During the past decade, a number of family researchers have been interested in finding why some families facing adversity manage to function well and come out stronger, while others when faced with a similar situation do not (Cowan *et al.* 1966; McCubbin *et al.* 1988; Walsh 1996; Patterson 2002). This has led to the development of a field of inquiry called family resilience. Resilience has been described as the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful (Walsh 1998). The concept of family resilience and its focus on factors leading to a family's well functioning in view of a crisis is part of a movement in positive psychology (Seligman & Csikszentmihalyi 2000) towards identifying factors of health as opposed to factors of pathology (Antonovsky 1987; Antonovsky & Sourani 1988) that has been the traditional approach in developmental and clinical psychology.

Family resilience has been looked at either as an interaction of two groups of risk and protective

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factors (Rutter 1987), or as a flexible process indicating the family's strength at different points during the life cycle of the family, and within different circumstances (Walsh 2003). This latter approach considers a family resilient when it demonstrates strength, even if it may not demonstrate the same attribute at another point in time (Walsh 2003). Several key factors which contribute to a family's becoming resilient are: (1) making meaning of adversity, (2) affirming strength and keeping a positive outlook, and (3) having spirituality and belief system (Walsh 1998). In addition, for a family to rebound in face of a challenging situation, the family needs to possess certain organizational qualities, such as flexibility, connectedness, communication and being able to utilize resources (Walsh 2003).

Although family resilience has not been directly studied in the disability field, there is increasing evidence that families of children with disabilities demonstrate a great degree of strength, articulating the positive contributions of disability to their family's life and well-being (Skinner *et al.* 1999; Scorgie & Sobsey 2000; Taunt & Hastings 2002; Hastings *et al.* 2005). Summers *et al.* (1988), in calling for a strength-based approach to studying families of children with disabilities, explained that there were many families with children with severe disabilities who did quite well with or without interventions from service providers. In their own experience of working with families of children with developmental disabilities, these authors found that many parents managed to make a positive adaptation to having a child with a disability. Such parents had successful marriages and emotionally well-adjusted children both with and without disabilities. These authors also reported that some parents found the disability of their children to be a growing experience in learning humility, patience, compassion, acceptance of, and respect for, others. Many family members even went as far as to provide support to other families or service providers (Summers *et al.* 1988).

Interestingly enough, some researchers have actually claimed that some of the grim generalizations of the negative and overwhelming experiences of families of children with disabilities have not been supported by the actual data. Scorgie & Sobsey (2000), for example, examined studies on divorce

rates between parents of children with and without disabilities. According to these authors, the results of divorce studies had been, at best, inconsistent, and while some studies had found that divorce was slightly higher among parents of children with disabilities, others reported that the rate was significantly lower among the parents of such children. In their own study of families of children with disabilities, Scorgie & Sobsey (2000) identified what they called 'transformations' or life-changing experiences of parents of children with disabilities. They defined two types of transformations in these families: personal transformation and relational transformation. Personal transformation often meant that the family members gained new roles – in the family, in the community and in their careers. Their personal transformation also meant that they acquired new traits, such as an ability to speak out and advocate for the child with a disability, or found new convictions and faith. Relational transformation for the families referred to changes in the ways parents and family members of children with disability related to other people. Parents in the study reported stronger marriages, healthy family outcomes and acquisition of gained friendship networks with other families who had children with disabilities.

Taunt & Hastings (2002) examined two aspects of families' positive experiences of raising a child with a disability. First, they asked parents to report on the positive impact of the child with a disability on themselves, siblings and the extended family members; and second, they asked parents about their opinions on the future of the child with the disability. In the first instance, parents reported a number of positive effects on themselves and other family members, such as change of perspective on life, increased sensitivity, support for each other, opportunities to learn, improved family dynamics, increased confidence and assertiveness, and strengthened religious faith. In the second instance, although some parents expressed anxiety or fear about the future of the child, the majority of families expressed generally positive attitudes towards the future of their children with disabilities.

In a study of the parents of medically fragile children (Patterson & Garwick 1994), parents selectively attended to the positive aspects of their child's personality and behaviours, while minimizing the limitations or health problems. They focused

on: (1) the child's warmth and responsiveness; (2) the child's tenacity and perseverance; (3) the closeness felt in the family unit by pulling together to manage; (4) the assertiveness and skill that parents developed in response to caring for the child; and (5) the growth in empathy and kindness in the siblings.

From analysing the studies that consider positive contributions of disability to the family (i.e. Summers *et al.* 1988; Behr & Murphy 1993; Patterson & Garwick 1994; Scorgie & Sobsey 2000; Taunt & Hastings 2002), one common factor emerges. That is, parents and other family members articulate their own positive perceptions about having a child with a disability. In the conceptualization of the Double ABCX (McCubbin *et al.* 1983) and family Adjustment and Adaptation Response (Patterson 1988) coping models, the way that a family member (i.e. parent) perceives, appraises and makes meaning of the disability of his/her child determines whether the parent is able to utilize family's resources, arrange its structure, and ultimately balance – or fail to balance – the family's resources against the demands and stressors of having a child with a disability. In some cases, the event is only experienced as stressful according to the meaning that one attributes to the event. In a similar way, some resources only exist because the individual perceives them as resources (Patterson 1988).

Forming specific and global perceptions of the experiences of having a child with a disability in the family may predict successful or unsuccessful family functioning (Summers *et al.* 1988). Similarly, Behr & Murphy (1993) indicated that different perceptions in the parents were significantly related to their reports of family satisfaction. In their study, parental perceptions consistently had a stronger relationship to their sense of well-being in the family than other family variables traditionally studied, such as the age of the child, the severity of the child's disability, and the marital status of the parents.

From the studies presented here, it could be expected that many families of children with disabilities positively adjust and adapt to the phenomenon of disability through cognitive coping and positive perceptions, and therefore might be considered resilient. In a large study to substantiate these

expectations, the investigator examined the role of parental perceptions and the relationship of these perceptions to the family quality of life utilizing quantitative methodologies.¹ Concurrently, the investigator used qualitative methods to gain further insights into the perceptions of families of children with autism, as well as identifying possible factors which could be identified as factors of resilience. In this paper, the concurrent qualitative results are reported. The theoretical framework used for categorization of thematic data in this study is the Walsh's (1998, 2003) theory, which considers the following components as those belonging to resilient families: (1) making meaning of adversity, (2) affirming strength and keeping a positive outlook, and (3) having spirituality and belief system. The portion reported here represents findings on these key organizational qualities and resilience factors in a group of families of children with autism.

Method

Participants

The first stage of this research involved collecting data from 175 mothers, fathers, including single parents, and other biological caregivers of children with autism. The selection criteria for the participants were based on: (1) the child's diagnosis of autism (autism spectrum disorder), and (2) the child's age – the required age for participating in this study for the child was between 2 and 18 years. The participants were recruited from the Autism Society of Illinois's members (mailing list), parents of children enrolled in the Chicago Public School's Autism Programs, and parents of children with autism in one private Therapeutic Day School which exclusively served students with autism from families with low socio-economic status (SES). As can be noticed from examination of Table 1 displaying the demographic profile of the participants, the sample was biased, in that white upper-middle class families were over-represented. It is important to note that this was not a random sample. Although it was expected that the participants from the

¹ Bayat, M. (2005). How family members perceptions of influences and causes of autism may predict assessment of their family quality of life. Unpublished dissertation. Chicago: Erikson: a Graduate School in Child Development.

Table 1 Demographic characteristics of the sample ($n = 175$)

Variable/characteristic	<i>n</i>	%	Mean
Ethnicity			
African American	27	16	
Asian American	6	3	
Hispanic	21	12	
Other	10	6	
White	111	63	
Level of education			
Primary diploma	5	3	
High school diploma	57	33	
Professional certificate	25	14	
College degree	48	27	
Graduate degree	41	23	
Annual income (thousands of dollars)			
0–40	33	23	
41–60	22	16	
>60	86	61	81
Household size (# members in the family)			
<4	14	8	
4	128	74	
>4	30	18	
Marital status			
Single	10	6	
Divorced	16	9	
Married	141	81	
Others	6	4	
Relationship to the child			
Fathers	30	17	
Mothers	134	77	
Other caregivers	11	6	
Age (years)			41

Therapeutic Day School and those families whose children were enrolled in Chicago Public Schools would provide a more representative sample, only 35% of all participants were from Chicago public schools. The majority of those deciding to participate belonged to the Autism Society of Illinois.

From the total number of participants ($n = 175$), 16% were African American, 12% were Hispanic, 3% were Asian Americans, and 63% were white. The sample included 17% fathers ($n = 30$), 77% mothers, and 6% biological (siblings and extended family members) primary caregivers of a child with autism.

In terms of education, 57% of all participants had a high school diploma, 25% had a professional or vocational certificate, 48% had a college degree, and 41% had a graduate degree. Although this

study included families with low income, more than 50% of participants had gross income above \$60 000 per year. The average income for the families in this study was \$81 000 per year. Over 70% of the participants had household sizes of four members or larger.

Child's characteristics

From the total number of autistic children involved in this study, 80% were male. The average age of the children was 10 years for the males and 11 years for the females. Eighty-three per cent of children had a diagnosis of autism spectrum disorder; the rest had a diagnosis of either Asperger's syndrome or pervasive developmental disorders. In terms of severity of autism, which was measured by the parental report based on the Childhood Autism Rating Scales (Schopler *et al.* 1980), 53% of children had moderate to severe autism. Sixty per cent of children had some sort of aggressive behaviours from mild to severe. Table 2 displays the child's characteristics.

Services received by the children

Children received a variety of services inside and outside of school. The majority of children (57%) attended public schools. The most common methods used in schools were Picture Exchange Communication System, Applied Behaviour Analysis, and Treatment and Education of Autistic and Related Communication Handicapped Children. On average, children received 28 h of school per week. Some children received therapies outside school. Table 3 displays the types of services received by children, and parental satisfaction with services.

In terms of satisfaction with services, the majority of parents reported satisfaction with the services (75%). Children who received therapies outside school, received an average of 2.5 types of therapy per week. Children could receive more than one type of therapy, inside or outside of school. Table 4 displays types of therapy services received by children.

Measures

The qualitative measures are drawn from a content analysis of the form consisting of three questions

Variable	(N = 175)		
	n	%	Mean age
Child's gender			
Male	141	80	10
Female	34	20	11
Child's age (years)			
2–5	43	25	
5–8	42	24	
8–14	57	33	
14–18	32	18	
Diagnosis			
ASD (autism)	146	83	
Asperger's syndrome	10	6	
PDD	19	11	
Severity of autism (socialization) – CARS	(N = 173)		
Has no difficulty relating to others	27	15	
Non-responsive to adults	83	47	
No initiative	56	32	
Consistently aloof and unaware	7	4	
Severity of autism (communication) – CARS	(N = 171)		
Normal communication	15	9	
Severity of autism (communication) – CARS	(N = 171)		
Occasional linguistic errors	64	37	
Minimum speech	47	28	
No speech	43	26	
Aggressive behaviours	(N = 175)		
None	57	33	
Occurs infrequently	39	22	
Occurs sometimes	65	37	
Occurs frequently	14	8	

Table 2 Characteristics of the children in the study as reported by the participants

ASD, autism spectrum disorder; CARS, Childhood Autism Rating Scales; PDD, pervasive developmental disorders.

used to solicit written responses of family members about their perceptions of disability and their family functioning. This form consisted of three open-ended questions, which asked parents: (1) to describe the positive and/or negative effects of autism on their family life; (2) to describe the positive and/or negative effects of autism on their personal life; and (3) to describe the child.

Procedures

Participants were recruited from various sources within the state of Illinois. The primary sources of recruitment for the subjects consisted of the Autism Society of Illinois, and Autism Programs in the Chicago Public Schools. Twelve hundred surveys were mailed via Chicago Public Schools, 700

surveys were mailed via the Autism Society of Illinois, and 200 surveys were mailed through the private schools and other sources.

All families received a packet containing a consent form explaining the study and the questionnaire instruments. The families from Chicago Public Schools received the surveys in both the English and Spanish language, because it was speculated that this population was more likely to have Latino families.

Analysis

From a total of 175 participants, 167 responded to the three open-ended questions. The first two questions asked the participants what they thought the

Table 3 Description of services received by children

Variable	(N = 175)		Mean
	n	%	
Type of services received			
Home-based services	8	5	
Specialized preschool	18	10	
Centre-based early intervention	4	2	
Home-based services	8	5	
Preschool with inclusion model	5	2	
Regular preschool	4	2	
Special education (school age)	73	42	
School age inclusion	36	21	
Regular school (mainstreaming)	19	11	
Type of school			
Public	99	57	
Private	21	12	
Other	4	2	
Not identified	51	29	
Hours of services			
School hours per week			28
Therapy hours outside school per week			2.5
Methods used in school			
ABA	43	25	
DIR	15	9	
RDI	4	2	
Methods used in school			
TEEACH	35	20	
Pyramid (PECS)	68	39	
Unidentified	10	5	
Parental satisfaction with the services received			
Extremely dissatisfied	5	3	
Dissatisfied	13	8	
Neither satisfied nor dissatisfied	24	14	
Satisfied	95	57	
Extremely satisfied	30	18	

ABA, Applied Behaviour Analysis; PECS, Picture Exchange Communication System; TEEACH, Treatment and Education of Autistic and Related Communication Handicapped Children; DIR, Developmental Individual Differences Relationship-based; RDI, Relationship Development Intervention.

effect of autism was on their family and on themselves personally. The last question asked participants to describe the child with autism in three or four sentences. Respondents were mothers, fathers and other biological primary caregivers of the child. The demographic profile matched that of the total participants. Responses varied in length and com-

Table 4 Types of therapy received by children

Therapies used at home or outside school	Total N = 175	
	n	%*
Counselling	21	12
Diet	28	16
Occupational therapy (sensory integration)	105	60
Medication	48	27
Physical therapy	21	12
Social skills training	71	41
Speech therapy	131	75
Other therapies	23	13

* Cumulative percentage >100, as children may receive more than one type of therapy.

plexity. In general, they were relatively short, and answers to each question contained no more than a paragraph or a few sentences.

The qualitative analysis took place in two phases. In the first phase of the analysis, all answers relative to each question were transcribed in separate folders, with each response carrying an identifying code. Data were coded by the investigator and a graduate student. One-half of the coded statements ($n = 240$) were examined for inter-rater reliability between the two raters. Reliability was established at 80%.

The data in each folder were first analysed separately. The initial analysis yielded a division of data in each folder into three or four large categories. This categorization of responses was based on the types of answers received. The data corresponding to questions one and two yielded identical categorization. This was realized early during the initial analysis of data, where it became apparent that responses to the first two questions usually fell into categories of: (1) defining the effects of autism on the family or self as negative; (2) defining the effects of autism on the family or self as positive; (3) defining the effects of autism on the family or self as neither positive nor negative; and (4) defining the effects of autism on the family or self as both positive and negative. For the last question, description of the child, the answers were categorized into three categories: (1) those responses which described the

Table 5 Family members' perceptions of the effects of autism on the family unit vs. the effect of autism on the person as described by participants

N = 167	Negative (%)	Positive (%)	Neither negative nor positive (%)	Both negative and positive (%)
Family	30	28	8	34
Person	21	39	6	34

child in positive terms; (2) those describing the child in both positive and negative terms; and (3) those describing the child by his/her functioning or developmental level. As family members did not describe the child completely in negative terms, a negative category was not created for this topic.

After this general categorization, the data were quantified to give a percentage of the responses falling into each category. This was performed to achieve a sense of whether or not the overall perception of the family members regarding the effects of autism on their personal and family life was more negative, more positive, neither, or both.

No quantitative analysis was performed on examining the relationship between responses of the participants and their socio-economic and ethnic status for this data set. However, within the content analysis the data were repeatedly checked for the relationship between the orientation of statements (positive or negative) and socio-economic and ethnic background of the participants. No relationship was found between income or racial background and the way family members perceived effects of autism on the family or self via this systematic check. Table 5 displays the percentages of the response orientation.

In the second phase of the analysis, the content of each folder was further analysed for identification of categories and subcategories. Textual data were closely examined for identification of themes. Lists of categories were created and themes were described under each category. Those themes that repeatedly emerged throughout the data formed large and fundamental categories of the study. Several smaller themes that were repeated less frequently were identified as well, which were nevertheless important for further examination. Although most statements within the data were short and not

detailed, they were complex in nature, and often represented multiple themes. It was common, however, that a certain theme often dominated an entire statement. This determined the thematic categorization of that statement. In instances where two or more themes were equally emphasized within one statement, the statement was placed under two thematic categories for further evaluation and analysis. A partial result of the secondary analysis is brought here.

Findings

Thematic categorization

Four categories and 18 subcategories were identified within the data. Table 6 displays categories and themes.

Eleven of these themes contained ideas and issues related to the family. Five of these themes met description of resilience factor (Walsh 1998) and were placed under category labelled 'family resilience'. Table 7 displays the percentage of responses under each theme in this category. Five themes were related to issues concerning the parent and four themes were related to those pertaining to the child, which were placed in their respective categories. It is important to note here that 11 of 18 subcategories had positive orientation, indicating strength in the family. However, only five of 11 themes met the criteria based on Walsh's (1998, 2003) description of resilience factors.

Evidence of family resilience

Pulling resources together, being connected

Two necessary factors for resilience are the family's ability to pull resources together, and the family

Table 6 Categorization of the data

Categories	Subcategories
The family	Relationships
	Meeting daily goals, events
	Behaviour problems
	Financial burden and fights with the system
	Acceptance and adjustment over time
Family resilience	Many lessons learned
	Pulling resources together, being connected
	Making meaning out of adversity
	Change of world view
	Affirmation of strength and becoming more compassionate
The parent	Spiritual experience and belief system
	From careers put on hold to careers in special needs
	Depression vs. love and adjustment over time
	Becoming an advocate
	Worries about the future
The child	Honour
	Source of pride
	No friends
	Hard working

Table 7 Percentage of responses in family resilience subcategories

Subcategories of family resilience	% of responses
Pulling resources together, being connected	62
Making meaning out of adversity	63
Affirmation of strength and becoming more compassionate	39
Spiritual experience and belief system	45

members being connected. In the data, the investigator frequently discovered that these organizational factors were often interconnected. In many instances, connectedness was an end result of the families working together. Families commonly pulled their resources together, became united and cooperated with each other for the good of the child. About 62% of families defined themselves as becoming closer as a result of having a child with a disability. One mother described: 'While the initial diagnosis was devastating, ultimately it did bring our family closer together. We work together to

support our children and close ranks when necessary to protect them. Our priorities have shifted and we no longer sweat the small stuff'.

Some families found that it was not always easy to unite and work together. They persevered, however, and in the end, found themselves stronger and closer:

My son's autism has made our family life tougher, emotionally and financially. Each member has to devote additional time and effort to help him, and learn how to live peacefully in such environment. Through working together, we all learned how to help my son together. In some sense, this also makes our family closer, because an individual cannot handle the toughness alone.

In other situations, working together led to more understanding and, possibly, stronger relationships between the members:

My marriage is much stronger. We tend to fight less about little things because our focus is on [our son]. We realize the importance of staying together because [our son] benefits from both of our strengths. . . . We take care of ourselves through diet and exercise and plan evenings/dinners out every Saturday to get through the tough times. We cannot imagine life without [our son]. We are grateful to have him in our lives.

Some families found that autism in one of the children brought the siblings closer together, to the degree that some siblings sacrificed their personal freedom to care for their sibling with autism, 'Autism has made us stronger and more cohesive. My children are very protective of their sister even though juggling is common and sometimes important events are missed'. One mother said, 'Autism has brought me and my two boys closer together. [We] learned to compromise our family events . . . but we work together'.

For families to be able to work together and utilize their resources well, they must have had two other qualities: being flexible and communicating well with one another. These two qualities are necessary, because family members need to be flexible enough to accept necessary role and responsibility changes as a result of diagnosis of their child with a disability, and need to communicate with each other in order to successfully meet new demands on

the family. A great number of families not only perceived themselves as 'close' and united, but also managed to adjust and function well over time. Each family is different in the length of time it requires for its family adjustment and adaptation. The data analysis of other themes in this study indicated that, for many families, it took roughly 2 years after the initial diagnosis to come to terms with the disability and learn to adjust to the demands of autism. For many families, motivation to help the child improve and the child's progress in development was an important vehicle for the adjustment and well functioning of the entire family.

Making meaning of adversity

Making meaning out of adversity is known as a key process in family resilience. We found that families often reflected about what having a child with autism meant for them. Resilient families often make positive meaning out of adversity. The families studied not only made positive meaning of their child's disability, they also articulated many contributions and lessons learned as a result of disability. Families' meaning making frequently resulted in a changed world view to a positive outlook of life in general, and an appreciation of smaller daily gifts and accomplishments in specific. This change in perspective might happen at some point in time, perhaps a couple of years after diagnosis, when families tend to have adjusted to the demands of the disability. Representing 63% of all textual data, becoming more compassionate, less selfish and more caring, and becoming mindful of individual differences and finding healthier perspectives in life were among the most-cited lessons learned by the individuals in this study. The types and nature of these lessons varied from being personal or social; spiritual and inspirational; or in form of having gained specific qualities, such as strength or new perspectives; and finally autism having been a life-altering experience.

Change of world view

Forming a smaller theme in this category, some families discussed their experiences in terms of having learned some important philosophical lessons about the meaning of life, the purpose of

existence, and what matters most. Some statements were made at a collective level – at the level of the family. Although it was not clear whether the family members had communicated these ideas with each other, it was clear that the family members had some common and collective experiences. One mother said, 'Autism has made me more aware for my reason and purpose of existing'. In most cases, the family found specific awareness, 'It has made us aware of how fortunate we are and not take anything for granted. Each success no matter how small, just makes our day. We have been given a truly special gift'. One mother said, 'Autism has made us realize how precious and great to make each day. We love life'.

Making progress in light of a severe disability could give families new perspectives. A mother said, 'Our family now remembers small progress and acknowledges how lucky we are. The diagnosis, though not something we would have liked to hear, has made us more grateful for what we do have'. One father said, '... our family has grown more to appreciate many simple things in life'. Another father remarked, 'When we first became aware of our son's probable diagnosis the depression was overwhelming, but didn't last long. As Niche said, "that which doesn't kill me makes me strong."' A mother described her son in these terms, 'My son is, as I have come to realize, my teacher. He is teaching me patience, acceptance, and how to see how much I have, instead of what I am missing'.

Although it is less clear how families come to change their world view or family paradigm, it is clear that at some point, perhaps a couple of years after the initial diagnosis, when families tend to have become adjusted, family members realize a shift in their outlook of life. These experiences should not be taken lightly, as a quest for finding higher meanings or becoming more appreciative of the small gifts of life is a goal not many individuals claim to be able to achieve easily.

Affirmation of strength and becoming more compassionate

About 39% of families articulated affirmation of strength as a result of the disability in the family. This was usually articulated through citation of various lessons learned. Becoming less judgemental,

more compassionate and more patient were some of the attributes gained as cited by the families. Appreciating those who are different was an important lesson for the family members, especially the siblings. A 12-year-old sibling of a child with autism said, 'I don't think I would've been as sensitive if I didn't have [my brother]. When my friends make fun of "retards," I tell them not to. I think I accept differences better as a result of this'. Another sibling, 13 years old, expressed her feelings in a similar way, 'I've definitely become more aware of people in general. I love my brother to death, and I know that I've become a more caring person because of him'. A mother of a 7-year-old boy reflects on the learned awareness of her non-autistic children in general, '... our children continue to learn from his difficulties that he overcomes, and it opens their eyes to the difference and hardships others go thru'. A father of an 11-year-old boy said, 'I know that I have become more compassionate towards people with special needs and their families. I have always been social with others. However, I am more social towards people and families with special needs'. Becoming more compassionate, less selfish and more caring, and becoming mindful of individual differences and finding healthier perspectives in life were cited as affirmation of strength by the participants.

Spiritual experience and belief system

Having a spiritual belief system – the final resilience process – was evident from many statements made by the parents. While some family members gained a conviction of their faith, others found new spiritual belief. Family members commonly experienced spiritual awakening or strengthening while living with or raising a child with autism.

In our data, a large group of statements (45%) made some reference to God, or spiritual gains, as a result of having a child with autism. Some of the statements referred to spiritual meaning making. For example, one mother said, 'I feel God made my child, and he does not make mistakes'. Another mother explained, 'Life is not easy, but God gave us this and we will deal with it'. One mother discussed her new spiritual understanding of the purpose of existence, 'Autism has increased my previous belief that all lives are intended to be

here. No life or disabilities are mistakes'. One father said, '... I feel if there is a God, he meant to create [my son] and gave me the honor to be his father'. Another father remarked, 'We see how blessed we are to teach and take care of someone who does not always understand. This is something that is hard to explain to a lot of people'. There were instances when autism became a clear vehicle for getting close to God, 'For my family, it has brought us closer, closer to God, closer to each other. We are there for each other'.

Discussion

This study provides evidence that, despite extraordinary challenges faced by families of children with autism, a number of these families show evidence of resilience. The data from this study overwhelmingly support positive aspects of raising a child with autism. Because the theoretical framework used in this study was Walsh's resilience theory, the themes of resilience identified and brought here were only those specified within this theory. It should, however, be noted that there were additional important strength factors – not brought in this report – such as parents becoming active advocates for their children, or parents articulating having a child with a disability as a source of pride and honour. It is feasible to consider these factors as characteristic components of resilient families. These same factors have previously been identified by research as features which are considered as positive contributions of disability to the family, as well as aspects of family strengths. Because the theory of family resilience has not been articulated in the disability field, it is difficult to understand how the two constructs of family strength and family resilience might be similar or different from one another. A major point of difference between the two might be the question of whether or not factors of strength and resilience have come about as a result of disability in the family, or whether these factors existed within the family dynamics prior to the phenomenon of disability. This temporal factor might be important because definition of resilience points to the phenomenon of 'coming out of adversity strengthened'. A thorough discussion of this topic is outside the purpose of this paper.

From data presented in this study, it is apparent that, unlike the popular assumption that because of the major stressors of raising a child with a severe disability such as autism, their families may not function at an optimal level, some families of children with autism may be considered resilient families, families who grow out of adversity strengthened, and with a more positive outlook. Confirming the existing research on the positive contributions of disability to the families, this study found that either the family as a unit, or individuals within the family, often changed for the better, by having learned important lessons which might have life-altering consequences for them.

Limitations

One of the major limitations of this study concerns the demographic profile of the sample. In this study, about 63% of the participants were from middle- to upper-class white families. The low representation of the lower-SES group in the sample might be due to the writing requirements for this survey, as such populations often prefer face-to-face interview to paper-and-pencil surveys. Because this study did not employ personal interviews as a supplement to written responses, the study lacks prolonged engagement and opportunities for triangulation and multiple checks, which are standards of rigour in qualitative studies. In addition, when working with textual data, unlike interview procedures, there is no opportunity for further prompting of the participants for expansion, clarification of responses or narration of related stories which could be used in further analysis. Thus, caution is advised in generalization of the findings.

Further, the study looked at individual reports regarding the family as a unit. Any study of family as a unit requires examination of all family members' ideas, attitudes or, as is here the case, perceptions. In studying families of children with disabilities, when feasible, the opinion of the child with a disability should also be included in the study. In this study, the report of only one family member, mostly the parent, was used to describe and represent the opinion of the family as a unit. Had the study used reports from all family

members, the results could potentially have been different.

Implication for research and practice

Although due to methodological and sample size limitations, generalization of the findings is cautioned, this study might be considered as a small step towards encouraging further research with a more diverse sample of families, including families of children with other intellectual disabilities. Because operationalizing family resilience in quantitative research has been considered problematic (Haan *et al.* 2002), it is advisable that further research either employ mixed methodologies, like that of Lietz (2006), or use qualitative methodologies with smaller sample of family members, where there are opportunities for face-to-face interviews and multiple data collection, and deeper analysis. In addition, longitudinal designs might be necessary in order to understand the process of resilience, which might change in different points of time and as families adjust to various stressors during transition times. In this study, factors of resilience which were identified are unique to the family unit. Further research should attempt to understand how individual resilience factors might contribute to the resilience in the family, and how these factors might be strengthened within the family to promote further strength of the family.

The findings have implication for provision of strengths-based services for family members of children with disabilities. In working with families of children with disabilities, service providers often focus on alleviating the problems. This focus often misses opportunities of growth, and detracts from utilizing families' strengths and building on the positive when providing intervention (Blundo 2001). Working with families needs to capture the whole experience of families, and not just the negative experiences. Service providers, who interface with families of children with disabilities, can communicate to them a conviction that these families can be resilient, the same way that they could communicate a negative conviction (Lietz 2006). This could give families a more positive outlook and hope. Families of children with severe disabilities such as autism face many challenges and have different needs. It is important not only to provide

crisis intervention services for their immediate emotional and practical needs, but to acknowledge their strengths, utilize their own resources, and help them recognize their own capacities for resilience. For example, articulation of factors of strengths by the family members is only one way of family's recognition of their own resilience. Working with families to recognize their strengths might happen gradually and piece-by-piece (Green 1982). No matter what the technique and how long the process, capitalizing on the factors of resilience gives service providers a new avenue of intervention, which would promote further health and growth of the family. Policies need to articulate the importance of strengths-based approach and promotion of resilience factors in working with families of children with disabilities.

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