Parents of Children with Autism using an Email Group: A Grounded Theory Study

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Abstract

Parents of children with autism have difficulties obtaining adequate information and support to guide them in the care of their children. However, the growth of communication technologies such as email has created greater opportunities for accessing such resources. This article presents a grounded theory analysis of the messages sent to an email group by parents of children with autism. The core category emerging from the analysis indicates that the group functioned in making sense of autism. The core category comprises four categories: searching for meaning; adjusting to changes; providing support and encouragement; and narrative sharing of experiences. Although email groups function as a social support mechanism, we suggest that this is not the only legitimate function: such groups may contribute towards the development of parental representations of autism.

AUTISM is a pervasive developmental disorder estimated to have a prevalence of 18.7 per 10,000 children (Fombonne, 1999). It is characterized by stereotyped patterns of behaviour and impairments in reciprocal social relationships and communication (American Psychiatric Association, 1994). In children, these attributes of autism are often associated with challenging behaviours such as sleep problems, self-injury and temper tantrums (Randall & Parker, 1999), and have been shown to exacerbate levels of parental stress (Koegel et al., 1992; Rodrigue, Morgan, & Geffken, 1990; Sharpley & Bitsika, 1997). Furthermore, in comparison to parents of children with Down syndrome or normally developing children, Sanders and Morgan (1997) found parents of children with autism to perceive greater levels of stress. These perceptions of stress are associated with issues relating to child rearing, demands for time and family opportunities.

In the subsequent care and treatment of their children, parents need to interact with a diverse range of organizations and professionals such as psychologists, health care practitioners, teachers and social workers. However, when parents were asked to rate the overall help received at the time of their child's diagnosis of autism or Asperger syndrome,[1] almost half rated it as being inadequate (Stirling & Prior, 1999). Moreover, a similar number reported that they had not been told where they could access further support or information should they need to. This is surprising, as in addition to offering expert help at times of crisis, parents also rely on such formal supports to help attain order in their lives (Gray, 1994).

In addition to formal assistance by statutory agencies, family and friends may provide social support. Social support encompasses functional aspects of social interaction (e.g. providing emotional support) and structural character- istics of social networks (e.g. the existence of social relationships). In a review of the effects of social support on health, Cohen (1988) outlined how perceived availability of support (i.e. the perception that support would be available if it was needed) might reduce the influence of stressful events, whereas social integration might be of benefit irrespective of whether a person is stressed. Consequently, when social integration is lacking, an increased sense of alienation and decreased perception of control might occur. Moreover, in a recent qualitative study focusing on the experiences that parents encounter in the diagnosis of their children's autism, Midence and O'Neill (1999) found that confusion and an inability to make sense of their child's behaviour often results in isolation from family and friends. Such isolation may occur as a consequence of the victimization perspective (Silver, Wortman, & Crofton, 1990), whereby relatives and friends have difficulty in providing effective support because their own sense of vulnerability to negative life events is brought into focus.

Although social support may affect well- being, Sharpley and Bitsika's (1997) survey of parents of children with autism indicates that it is not the involvement with family members per se that determines the value of this support. Instead, lower levels of parental anxiety and depression, and higher confidence in dealing with their child's difficulties, are associated with support from family members perceived as having greater expertise in understanding the child's difficulties and needs. Although there is a paucity of research addressing the support that parents and families of children with autism provide for each other, studies looking at the experiences of parents of children with other developmental difficulties or chronic illness show that there are numerous benefits of such mutual assistance. Support groups may be of benefit to parents in the offloading of negative emotions, for sharing common experiences, and in obtaining specific information about care and treatment (e.g. Bennett & De Luca, 1996; Smith, Gabard, Dale, & Drucker, 1994). However, even when such networks exist, lack of available time, travel difficulties and childcare constraints can make it difficult for parents to seek and receive such support (Burke & Cigno, 1996; Smith et al., 1994).

Because of the growth of communication technologies such as the Internet, innovative ways of transcending these physical, social and informational barriers have been created. For example, the World Wide Web has created opportunities for obtaining information that would once have been inaccessible to lay people, and the existence of networks such as news- groups, chatrooms and discussion groups has enabled parents to write (or 'talk') to large

groups of other parents either in real time (by synchronous communication) or time delay (by asynchronous communication). By joining such groups, it is possible for parents to interact and develop new relationships with other Internet users facing similar experiences at any time of the day or night, irrespective of geographical location.

The benefits of using email discussion groups as a means of social and psychological support are increasingly being documented (Braithwaite, Waldron, & Finn, 1999; Finn, 1999; Sharf, 1997; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000). For example, Braithwaite et al. used a modified version of a social support taxonomy to code the types of messages exchanged by people with physical disabilities using an asynchronous computer-based support group. The most prominent types of support on offer were emotional and informational. Although this study demonstrated an overlap with the type of support shown to occur in more traditional settings, the methodological approach was primarily concerned with the verification of existing social support theory. However, humour, poetry and non-verbal cues were also found to be in use, suggesting the existence of other salient features in the dynamics of these groups.

Although many of those participating in online groups may never have met, the characteristics of shared social understanding and sense of community are prevalent. For example, Jones and Lewis (2000) used content analysis to explore the function of an Internet discussion group used by the parents of people with Down syndrome. As well as being used as a discussion forum, the group was used by the parents to communicate a sense of celebration, to advocate seeing the child rather than the handicap, to share hope and optimism, for becoming the agents for change, and to provide a validating and supportive environment. A further analysis of the messages involved interpreting the meaning of parents' experiences; by doing this, Jones and Lewis found that the group was used to convey a shared sense of positive adaptation to having a child with Down syndrome. Given that the majority of messages specifically asking for help were sent to the list outside usual working hours, it can be seen that traditional biomedical models of practice are insufficient. Jones and Lewis see these findings as indicative of how traditional pathological models towards disability are inappropriate, and suggest that professionals could benefit from participating in such groups.

To summarize, it has been shown that, although parents see formal support networks as being important in coping with the stresses of caring for a child with autism, they often do not receive adequate support through such networks. Although parents of these children can become increasingly socially isolated from family and friends, particularly at the time of diagnosis, little research has been aimed at exploring the particular support that parents provide for each other. From the studies of other childhood disabilities, there are certain benefits to informal support networks, but childcare constraints can result in difficulties in obtaining such support. However, as Internet technologies become increasingly accessible, more people encountering disabilities in their lives are using such technologies to retrieve information and communicate with others facing similar situations. Because of such developments, our aim in the present study was to illuminate the functions of an email group used by parents of children with autism.

Method

Qualitative perspective
A symbolic interactionism methodology (Blumer, 1969) was used, as it sees social interaction, rather than the isolated individual, as being central for the generation and modification of meaning. Accordingly, experience of reality is intersubjective. This approach is based upon the premise that, in negotiating meaning, language is used, and, in modifying these interpretations, thought is used. We believe that this perspective was relevant in addressing our research questions as it acknowledges the impact of interpretive processes (e.g. email discussions) and social contexts (e.g. parents' lives) in which meanings and actions are negotiated.

Situating the study population
Individual participants were not recruited to partake in the study: instead, all messages posted over a 3-month period in 1998 to an international email discussion list used by parents of children with autism were collected and viewed.

Over this period, 6142 messages were posted from 374 email addresses.

Although permission to join the list had been obtained from the list moderator, membership was not required to view the messages, as they constituted publicly available accounts. Therefore, our study can be classed as a form of naturalistic observation. However, we were aware of the contentious ethical issues relating to privacy, confidentiality and informed consent involved in obtaining information from Internet sources. For example, there is a possibility that those participating in email groups believe that the information they post to email lists remains private. King (1996) refers to this as the *perceived privacy* factor, whereby users believe that their messages will be read only by other members of the group, despite the public nature of certain groups. The relative anonymity provided by electronic communication, such as not being physically visible, and the choice of whether to reveal one's name, may encourage the revelation of intimacies that would be withheld in other social environments. There are difficulties in obtaining guidelines to address such specific ethical considerations. With the approval of our institutional ethical review board, we decided that it was sufficient to remove details that might identify the participants (such as names, locations and email addresses), and label each email address with an alphanumeric code (e.g. R28).

Data collection and analysis procedures

Blumer (1969) suggests that to study group life:

> One has to know these worlds, and to know the worlds one has to examine them closely. No theorizing, however ingenious, and no observance of scientific protocol, however meticulous, are substitutes for developing a familiarity with what is actually going on in the sphere of life under study. (p. 39)

In order to comply with this standpoint, and to move from providing descriptive accounts of parents' experiences towards the development of theory, aspects of a grounded theory approach (Strauss & Corbin, 1998) were used for data collection and ongoing analysis.

In observing the messages sent to the discussion list, we adopted non-participant roles, thus becoming what is described in the computer-mediated communication literature as 'lurkers'. This allowed the parents to continue to use their discussion group at their own free will, asking questions and discussing topics of their own choice rather than those specified by us. The advantage of this method was that the material collected remained authentic: it was not affected by the research process, and was not framed in any way by our research interests. The aim was to observe the discussion produced, rather than to produce the discussion.

The messages were collected from the email list and entered into the qualitative data analysis package, QSR Nud•ist. To allow for manageability of the data, the 6142 messages were initially sorted into 44 temporary groups according to the email subject heading given by the parents. However, in accordance with the grounded theory approach, the purpose of subsequent analysis was not to place individual messages into categories: rather, the aim was to abstract categories from the underlying concepts found within messages.

Because of our non-participant observer roles, we deviated from Strauss and Corbin's (1998) method of sequentially alternating between data collection and analysis (whereby the findings from the first analysis shape subsequent inquiry). Nonetheless, data collection and analysis occurred concurrently. By reading the messages recurrently line by line, asking sensitizing questions (e.g. 'What's happening here?'), and theoretical questions (e.g. 'How does what this parent is saying here connect to what has been said elsewhere?'), concepts were developed to capture the essence of what was being stated. Theoretical comparisons of concepts were made; doing so involved using the *flip-flop technique* and *systematic comparisons* (Strauss & Corbin). These are methods for developing concept properties: the former involves searching for perspectives that diverge from what has already been established; the latter involves comparing incidents in the data to incidents recollected from experience or from the literature. This process of open coding was repeated, and recurrence of concepts was seen as being indicative of shared meaning, allowing for the development of higher-order categories. Once the categories were identified, *axial coding* was commenced in order to denote how these

categories might relate to each other at a conceptual level.

An analysis method described by Strauss and Corbin (1998) for enabling the optimal theoretical return is *theoretical sampling*. This is a method for looking at the data selectively according to emerging theory. Because of the nature of our data collection method, we engaged in theoretical sampling by examining our cumulated archive of messages using the QSR Nud•ist text and index search facilities. The text search was used for exploration and automatic coding of messages. The index search then enabled us to explore the patterns of coding, the relationships between emergent categories, and the similarities and differences between texts coded at various categories. These procedures increased the opportunities for discovering variations in the emerging concepts and categories, and were central in developing our theoretical understanding of parents' experiences. Analysis ceased when no new data relating to the categories were found, their properties were well developed and the relationships between categories had been validated and established. This is known as *theoretical saturation* (Glaser & Strauss, 1967).

Findings

Making sense of autism

The core category emerging from the analysis relates to how parents use the discussion list as a means of *making sense of autism*. This comprises

the categories *searching for meaning*, *adjusting to changes*, *providing support and encouragement*, and *narrative sharing of experiences*. Each category comprised subcategories (see Table 1); extracts of what the parents wrote have been selected to portray elements of these underlying components.

Searching for meaning

Searching for meaning encompasses the continuing efforts involved in understanding autism. The discourses in searching for meaning centre upon validating concerns, reciprocating concerns, representations of autism, causes, cures and religious explanations. These discourses appear to reflect how parents' experiences contribute towards the development of their understanding of autism, as well as towards that of others reading the messages.

Validating concerns The analysis suggests that the discussion group is pivotal in validating that parents' concerns are genuine. Although messages are predominantly sent by parents of children already diagnosed as having autism, this is not always the case. Indeed, as parents develop an increased awareness that their child might not be developing normally, many seek validation of concerns from other parents on the email list before and during the process of seeking validation from health professionals.

Once diagnosis has been given, parents are faced with autism's ambiguities and complexities, and the search for meaning continues. For

Table 1. Components of the core category *making sense of autism*

Category	Subcategory
Searching for meaning	Validating concerns
	Reciprocating concerns
	Representations of autism
	Perceptions of cause
	Anticipating cures
	Religious explanation
Adjusting to changes	Establishing a sense of normality
	Dealing with uncertainties
	Coming to terms with and adjusting to autism
Providing support and encouragement	Providing information and solving problems
	Networking and cybersocial interaction
	Emotional and esteem support
	Using humour
Narrative sharing of experiences	Sharing experiences: telling it as it is
	Surviving autism

some parents, the diagnosis can lead to feelings of loss and uncertainty, and this is interpreted as confounding their search rather than verifying it. One parent wrote:

> It's with pain and sadness that I write that our son has been formally diagnosed with moderate to severe autism. Although we knew he acted that way, it is one thing to say he 'acts' like it and to say 'he is'. We are in mourning again . . . (R28)

Despite recognizing that the child might have autism prior to diagnosis, to be told that it is autism generates an unexpected sense of loss and bewilderment. Parents have conceptions of normal child development that enable them to recognize that their child is positioned outside this normal range (Avdi, Griffin, & Brough, 2000). With the diagnosis of autism, they are faced with the reality of having to care for a child with a disability that they know little or nothing about.

Although the future is perceived as being uncertain, communicating with others can help parents to deal with subsequent life transitions. By comparing their situations with those of others, parents develop a focus on the unique qualities of the child, and this helps them develop a renewed coherence in their lives. Consistent with findings of the Jones and Lewis (2000) study, seeing the child rather than the disability forms part of this process. Thus:

> Getting the diagnosis makes everything seem more of a reality—and there is a grieving process, but you hit the nail on the head when you said 'he is still the same boy'. He is your little boy—your gift from God, yours to love and protect and help prosper. The key is to remember that each of us prospers in different ways. (R66)

At this interactional level, it can be seen that email serves to validate, redefine and make comprehensible parental concerns.

Reciprocating concerns As concerns are validated, shared worlds of meaning and mutual understandings are established between the parents. Reciprocating concerns therefore represents the way parents evaluate their experiences against those of others, based upon an intersubjective cultural and socially derived awareness. Against a background of unique situations and knowledge, making sense of these experiences is enhanced by the opportunities that email provides for making social comparisons. Participation creates opportunities for individuals to compare their experiences with those of others which are often more stressful or difficult than their own, as shown in the next extract:

> . . . For your information, my child is considered 'high functioning' (a term I dislike) so my day to day which I just described is a walk in the park compared to many other parents on this list. (R68)

Wood (1996) suggests that social comparisons encompass thinking about similarities and differences concerning social information in relation to the self; the goals of making such comparisons include processes of self-evaluation, self-improvement or self-enhancement.

Other concerns reciprocated in the search for meaning centre upon the cultural obligations of seeking out the technical competence (Parsons, 1951) of health professionals. When inappropriate, incomplete or out-of-date information concerning autism is obtained instead of concrete answers, these expectations are not realized. For some parents, this leads to a sense of disappointment and disillusionment; however, other parents recognize that professionals cannot be expected to have all the answers. One parent expressed this poignantly:

> In reality, they [the doctors] are simply trying to make themselves seem less ignorant and impotent. Ask your specialist what causes autistic disorder? She will not know. Ask your specialist how the human brain processes sensory input and handles communication. She will not know. Ask your specialist what her own future will hold. She cannot say. The truth is, your child has a disorder which we do not yet understand. Since we do not understand what causes it, we do not know how to effectively prevent or treat it . . . (R68)

Many parents perceive that their own expert knowledge is deemed as being valueless by health professionals. However, they do not believe that they should enter the doctor–patient relationship with an asymmetry of knowledge in order to then relinquish all decision

making to the professionals. Medical authority is questioned, and there is a sense of scepticism resulting from the perceived shortcomings of health professionals. Without a valid framework for understanding autism, email becomes a viable alternative for reciprocating their concerns, as is illustrated by the comments of this parent:

> Thanks for your help—I would be LOST without the Internet and these support groups. I have learned so much that doctors and educators kept us in the dark about! (R198)

Representations of autism A recurring theme in these messages relates to the construction and distribution of autism representations. In this sense, *representations of autism* reflect the way parents' constructions of autism compare with and challenge those held by others (such as health professionals and the general public). Email allows for the creation, sharing and interpretations of autism, and forms part of the quest for understanding what autism is. This is shown in the following remarks:

> These folks are working from some ancient view of autism, I think. The idea is that social relationships are disordered—that is not the same thing as non-existent. (R11)

> The psychologist we went to says it is a myth that all autistic kids are socially isolated—our son is very connected to us, but still is autistic. (R22)

> I was told also that my son had TOO good eye contact and that he was TOO loving with us as most autistics don't like to be touched. It is very difficult when learned medical professionals won't listen . . . (R109)

> We were told he could not be autistic because he made eye contact. He was diagnosed with a complex speech disorder, and we where [sic] told he would always have severe speech impairments. 4 years later, his speech is much better . . . (R34)

Being a parent of a child with autism who shows emotion, hugs, and appears socially connected are some of the factors that bear no relation to their representations of autism previously generated from their own experiences, health professionals or current literature. Accordingly, parents use the list to dispel the myths surrounding autism, and in doing so they identify the unique yet ambivalent qualities of their child.

Perceptions of cause In the absence of an accepted cause, autism becomes a conundrum that requires explaining, rationalizing and solving. Finding the cause becomes of central importance: it provides hope for prevention and possible cure. This process involves using email to share substantiated research findings alongside parents' lay models of causation. These models of causation construe autism as originating from an assortment of internal factors, such as genetics and mothers' behaviour during pregnancy, to external factors such as environmental factors, immunization and diet. These models are reinforced or negotiated by their lay networks on the email list, and also in their own lives beyond the Internet. For example:

> . . . Could cow's milk been an additional factor, one that played a role in triggering the autism? I started [child] on cow's milk at seven months, that was the day before the autism started . . . (R4)

> There's a group of us parents with high cheekbones, pale skin, and B12 problems. I have asked mothers who have digestive complaints and a strikingly similar appearance (friends of mine) to try B12 orally, after hearing them all complain about the same thing—they all have yeast problems, and none of them wants to eat . . . Most of the moms like this are strikingly pale blondes, not white skinned, almost transparent skinned . . . (R8)

Anticipating cures For some parents, searching for meaning also encompasses a belief that autism can be cured. Accounts regarding this possibility are shared and debated, and references are made to reports of unconventional treatments successfully curing autism. This is demonstrated in the following interaction between three of the parents:

> I was an autistic child and my disorder continued as an adult. I have been cured of this, mostly with self-help measures . . . (R51)

> Miracles do occur. But why believe every one that claims they were autistic. (R2)

I think this lady means well and only understand [sic] what she's been through. She may or may not be autistic but she deserves a chance to be heard. We may not like or agree with what she has to say. So what? And if you think she needs a better education regarding autism, then give her an education!!!! But we don't need to be rude. You have to admit that even though autism appears to be neurobiological disorder, the medical community DOES NOT HAVE ALL THE ANSWERS. (R52)

Although some parents take a sceptical view of such beliefs, others attempt to be tolerant of such ideologies, especially because many of their concerns cannot be addressed satisfactorily by traditional medicine. Indeed, the prospect of cure appears to derive from conceptions based upon models of acute illness and their focus on medical treatments and hopes for panaceas. Consequently, this view is limited in the realm of developmental disability and creates unrealistic expectations. When these expectations are not achieved, parents are left in a state of prognostic limbo.

Religious explanations The associations between understanding autism and spirituality were apparent in some of the messages sent to the list. Religion tended to be used as a way of expressing a positive attitude in understanding autism, and included beliefs that the child was 'a gift from God', or that 'God doesn't make mistakes' (R28). These causal connections assume that having a child with autism is influenced by some higher moral purpose; this is shown in the following extract:

Sometimes struggles are exactly what we need in our life. If God allowed us to go through our life without obstacles, it would cripple us. (R82)

However, not all parents believed that autism could be attributed to such deliberate interventions:

Getting a little sick of all of this struggling. Hasn't made me stronger—just bitchier, heavier, a debtor, and I think I have lost a grand total of three years of sleep. God can take his struggles and . . . Sorry—having a bad day today. Thanks for letting me vent. (R59)

Adjusting to changes

Although caring for a child with autism is sometimes seen as being stressful by parents, a sense of coming to terms with their situation emerges from the messages. This adaptation process involves regaining coherence and taking control over events, and involves restructuring of their lives.

Establishing a sense of normality Although children with autism often appear physically no different from any other child, there are behavioural and cognitive factors that parents have to explain to others. Although efforts are aimed at making their children's conduct comprehensible and acceptable, this does not always ensue. Instead, a paradoxical striving for normality emerges: parents want other people to accept their children for who they are, but other people endeavour to enforce their models of normality on these children. Consequently:

Does anyone feel like they have to make excuses for the way their child is? AHHHHHH why do I feel that I have to . . . People everywhere insist on forcing [our daughter] to act normal no matter how many times I explain SHE'S AUTISTIC!!!!! It's like they ignore everything I just said and go to [daughter] and want her to look at them and stuff. (R233)

. . . Don't you just love when people tell you there's nothing wrong with your child and there he is doing something incredibly weird? And you're making him weird even though there's nothing wrong with him? Don't you just love reality? (R177)

Such stories exemplify the everyday struggles faced by parents when people appear to ignore behaviour that does not appear normal, or insist upon treating the child like any other child, and not as a child with autism. This produces an unexpected dissonance for some parents, who are then compelled to highlight the existence of abnormal behaviour, rather than reinforcing a state of consonance. This situation can result in what Birenbaum (1970) refers to as the *courtesy stigma* whereby the family is stigmatized by association with the child's disability. This is shown in the following extract:

. . . If it was a nt [neurologically typical] child then it would be looked upon as a 'bad parenting job'. And that's how society and the public looks at things like this. I've even been told I don't punish my child enough! . . . It just goes to show you that THEY don't understand, and it's OUR job (needless to say) to make THEM understand. It's a shame for it to be this way. And when I do have to deal with the evil eye of the public for instance when she goes into rages (the bear hug hold) I just look at them and stare right back. And if a comment is made, I tell them go ahead call protective services. Call the police. You're only going to make yourself look stupid. She's autistic, then I get the blank look, duhhh what's that?? Then have to explain if they say the movie *Rainman*, then . . . they assume that every autistic is like that . . . You get 'ohh I'm soo sorry to hear that' etc. etc. Oh it's like 'go blow it out your ear', don't want the pity . . . just want understanding. (R91)

The way the child with autism behaves presents a stigma that requires managing in social settings, and parents have to develop ways of handling how, when, and to whom they disclose that the child has autism. Rather than seeing the disability as something that needs to be explained in order to make the child acceptable (Goffman, 1963), some parents focus on ways in which others need to consider adjusting their thinking:

How about a T-shirt for you that says, 'My child is autistic. . . . DEAL WITH IT'. (R94)

Parents incorporate strategies to normalize the effects of autism so that they can carry on as normal. 'Not letting it get to you' is shown to be a common approach, and represents a process of negotiation (Radley, 1994) whereby parents actively adjust to the challenges of autism so that they can manage these situations as best as they can.

Dealing with uncertainties The ceaseless uncertainties and feelings of anxiety associated with autism are highlighted in many of the messages. Everyday life previously taken for granted becomes disrupted, and the future may sometimes appear ambiguous. For some parents, autism appears to have taken over the mundane expectations of normality, as demonstrated in the following:

I am down today since we will be celebrating my son's fourth birthday on Monday. As I looked at the table set up with the beautiful cake that my sister-in-law made and all the matching tableware with trucks and cars, I realised that my son won't even know or care about how great everything looks. It was a real kicker . . . (R40)

In this preceding extract, the birthday celebration (a familiar event in a child's lifespan) presents the parent with the unexpected realities of autism. It demonstrates how some parents have inadequate knowledge or information to predict what might or might not occur as a result of autism. The analysis shows that when these uncertainties are realised, parents use email to either express confusion or to demonstrate transitions to higher levels of understanding. When confusion is expressed, other parents send messages to share how they too have experienced similar feelings. These interactions can help develop aspects of coherence. This is shown in the continuation of the previously quoted message:

I have only been fighting this battle for 2.5 years which is nothing compared to you. It is so hard and the progress so slow and minute. Your story reminded me that there is always hope and I don't know how far my son will go. He still only has a few words, but it is still a few more than last year. I am so happy for you and your sons and will keep the faith that some day my son will be headed down the same path as yours. Thanks for the hope and inspiration. (R40)

Coming to terms with and adjusting to autism As the impact of being a parent of a child with autism becomes normalized into their lives, the analysis shows that some parents appear to develop a sense of coherence and of coming to terms with autism. For some, this stems from the fact that there is no viable alternative to taking each day as it comes. This involves an assimilation of new values and meaning in learning to live with autism, as shown in the following extracts:

. . . Grant me the serenity to accept the things I cannot change. The courage to change the things I can. The wisdom to know the difference . . . (R227)

. . . You have to maintain this delicate balance of being realistic about what is happening, but also having hope in order to do everything you can for your child, because the truth is your child is capable of so much more than others might believe, and it will give you strength to do whatever you feel might help. You just keep trying, and then perhaps in the end you have to accept some things, but you know you gave him your best efforts . . . (R38)

Providing support and encouragement

Factors that demonstrate how parental needs and concerns are addressed by the interactions of other parents are coded under this category. These include the direct actions that parents are required to follow to manage their child's autism, as well as advice and methods for solving problems, and offers of support and encouragement in coping with the challenges experienced in caring.

Providing information and solving problems

In order to optimize the development of cognitive and behavioural skills of children with autism, parents require adequate guidance and support from the statutory agencies. Although messages indicate that parents seek this information as best as they can, they face difficulties in obtaining the help they need. Receiving inadequate information and resources that enable them to develop knowledge and mastery of complex interventions can add to feelings of distress, frustration, confusion and hopelessness. By using the list to exchange up-to-date information, these inadequacies are overcome through the process of rationalizing and learning from each other's experiences, planning, and seeking choices to address these perceived problem situations. In this way, the group acts as a forum for parents to work together in trying to resolve problems:

Don't wait, go, go, go with intervention. This is not heart surgery, the choices here are not clearly defined by the exact diagnosis. There are so many camps, no specific answers. Start with your child. What does your child like? What is the hardest thing for you to deal with? You can change treatment approaches later as you learn more about what works for you and your child. The important thing is to start and BE INVOLVED. You have to decide what works and what doesn't. It is not a decision you can delegate. If the doctors had the answers, they'd go on Oprah and get rich. (R92)

Parents use the discussion list to become informed about management regimens, and to address the problems that result from these regimens. By doing this, they are able to form judgements about the benefits and limitations of treatments, and possibly overcome the conflicting advice gained from health professionals. As one parent stated:

You're lucky to have gotten online so quickly and found this list. My son was diagnosed at the same age as yours (he's now 2 and a half) and I've found so much information and support here that the grieving phase for my son lasted only a short time. The parents here helped me through the worst of the crisis so I could move past the disillusionment of not having my 'dream family' and focus on helping my son. . . . You'll hear horror stories on this list about the other kind. Welcome, and please feel free to contact me if you need a boost. (R87)

Additionally, unlike traditional support groups, email accessibility and availability is possible without the constraints of time and distance. Information can be sought and shared at any time of the day or night according to when needs occur. This next account provides an insight into these important aspects:

Hello guys! It's now 1: 25 am and I have been listening to [son] scream his bloody brains out for almost an hour. I am very frustrated and. . . . I am close to putting him in the sewing room in the basement (heated and perfectly acceptable playroom) so that I don't have to listen to him. (R121)

Networking and cybersocial interaction

The analysis shows that many parents encounter difficulties with family members and friends, who are not always seen as being supportive of their concerns:

My dad has yet to even say 'hi' to our son, yet actively plays with our nt daughter. My sister denies there is anything wrong that love and

family won't fix, and my mom just 'doesn't want to talk about it'. We get wait and see, all that is wrong will vanish in a few years, wait and see. My friends sympathise, but just can't/won't get involved . . . and that leaves my wonderful, supportive loving hubby and I holding the bag on what's wrong with this child. (R28)

These experiences of disregard, denial and not being believed contribute towards perceptions that other people cannot understand what they are going through, and this leads to a breakdown of past reciprocities. Consequently, parents who also have little contact with other parents of children with autism may experience feelings of isolation:

I am new to the world of autism. We live in [town] and I feel as though no-one has even heard the word before up here. (R58)

In light of this isolation, the analysis shows that email assumes an extraordinary significance in lives of these parents:

If it weren't for this computer and lists like this one, we would have no avenues of support/communication . . . And for the few threads of stitching you add to our lives, we thank you. Keep talking!!!! (R28)

Saw your post to the list. I live in [town], so not close by miles, but close on the computer. You have my support, and cyber-shoulder anytime you need it . . . (R59)

Recognizing that other parents' experiences are similar to their own indicates a sense of universality occurring within the group. Yalom (1985) has described the concept of universality as being of therapeutic value for ameliorating isolation. Yalom suggests that groups offer opportunities for learning from others that are not available in individual settings

Emotional and esteem support A sense of concern and caring towards each other was conveyed in the messages, as shown in the following extracts:

I will be thinking of you as you go through the process that I remember as being so devastating, just reading your post brought back a rush of sadness and grief for the child I had

envisioned my son to be, that I keep pretty much compartmentalised so I can continue my day to day functioning. There will be grief but it can be survived. No matter what happens, what diagnosis you are given try to remember that the child you love and hold in your heart has not changed. The child you envisioned was a phantom, the child you love is what is real. (R41)

. . . I wish I had some good info for you, but here's some hugs {{{}}}. (R11)

Punctuation marks, or 'emoticons', are used to convey physical contact (such as using {{}} to convey hugging in the preceding extract), or to express facial expression (such as :-) to indicate a smile).

Attributes of validating capability and self-concept are also shown; this is demonstrated in the reciprocal conveyance of pride expressed towards each other's capabilities of managing their child's care. Social identity theory posits that individuals derive their self-concept from identification with salient groups to which they belong (Hogg & Abrams, 1990). Accordingly, the more one identifies with a group, the greater are the implications for preserving self-esteem. Individuals favour self-validating reactions from others (Aronson, 1969; Festinger, 1957), and discrepant reactions are reinterpreted, devalued or dismissed (Kulik, Sledge, & Mahler, 1986). The ensuing stability of self-identity provides a sense of equivalence in one's ability to function in everyday social life:

. . . We have a very different set of circumstances to live with than most people. And as a result, we sometimes have to lose a battle here and there in order to continue the campaign to eventually win the war. Don't be hard on yourself; you have really tried, and now it's time to try something else. (R77)

The analysis demonstrates that belonging to a network of mutual obligation (Cobb, 1976) exists, and association with this network results in a sense of being cared for, loved, esteemed and valued. These factors are symbiotic in preservation of identity and development of therapeutic relationships

Using humour Many of the messages sent to the group contain jokes. Humour is used to

describe the experiences faced in caring for a child with autism, as well as the experience of using email:

> WHAT THE DOCTOR SAYS AND WHAT HE REALLY MEANS: 'Wellllll, what have we here'—Since he hasn't the foggiest notion of what it is, the Doctor is hoping you will give him a clue. (R9)

> You might be a child of the 80s if . . . you have deep, personal relationships via computers with people you've never met in real life before. (R9)

These messages appear to be attempts at alleviating some of the experienced negative or unexpected encounters faced by parents of children with autism (such as the incompetence of health professionals, and the dependence on computers shown respectively in the preceding extracts). The responses to these messages indicate that those receiving them look forward to reading them. In a survey of participants of a newsgroup discussing television soap operas, Baym (1995) found that the light-heartedness of humorous messages was a factor that led people to continue using the group. Although the messages we analysed were sent to an email group encompassing a different purpose, a tentative conclusion can be made that humour might also provide a similar function.

Narrative sharing of experience

The social sharing of experiences relates to those messages that are narrative in nature. These narratives are representative of sequences of events explained in the form of stories.

Sharing experiences: telling it as it is These messages are biographical accounts and updates concerned with the experiences of being a parent of a child with autism, and relate to the interpersonal context and the effects of autism on their lives. These messages can be viewed as postmodern diaries (Avery, 1999) whereby on first glance they appear as calls for communal support, but then on closer inspection are actually soliloquies. Parents appear to be motivated by the need to share their stories, or to utter their thoughts aloud without addressing any person in particular. Some of these stories are told many years after their first occurrence, others provide updates on progress or are sent by newcomers as means of introduction:

> Update on [son]: He continued to self abuse for two more weeks and had to be restrained. He was taken off of the Ketongenic diet and his Depakote was increased—he was having visible seizures at this time (we saw the neurologist). He was put on Clonidine and Zyprexia (we saw the psychiatrist) which is an atypical neuroleptic. His self-abuse has stopped, his bruises and fracture are healing and he is much happier. He no longer screams 24/7. He is thrilled to earn tokens in his system and choose a snack. He remains gluten free and is almost casein free again . . . (R12)

From these narratives, it can be seen that disability is embedded in the social worlds of these parents (Kleinman, 1988).

Surviving autism Caring for a child with autism can become an unrelenting task for parents, and despite encountering barriers in this process, foremost are the endeavours for taking charge. Sharing the details of these experiences appears to serve an important function in describing how they manage to survive autism:

> . . . There's nothing easy about having autistic children. It's not fun. It's not glamorous. The money stinks. The hours are long. There's frequently few, if any, to say 'well done' after you've accomplished a minor miracle. Yet, after nearly 30 years of living, and for lack of a better word, 'surviving' autism, you honestly do get stronger. The impossibly difficult becomes acceptable and doable. Life for us has become more than acceptable. It actually has become quite wonderful at times. (R82)

> I feel like I just survived a war. (R12).

The level of trust that develops between the parents enables them to describe the crude realities of living life with a child who has autism so that other parents may understand, justify and manage their own experiences of autism. Although there are 'bad days', there are also 'good days' which are shown to be important in enabling parents to see their situation positively:

I have two very special moments: the first time [daughter] kissed me on her own at age three and the first time she initiated 'I love you' without echoing or prompting when I was putting her to bed one night . . . (R21)

Discussion

The present study aimed to examine the functions of an email discussion list used by parents of children with autism. Although we found that the group provided an interactive social network, email also served other functions. In particular, the ways in which parents validated and reciprocated their concerns indicated that email allowed parents to intervene and reappraise their situations with other parents in ways that might not have been possible previously. Parents were shown to be active in their attempts at making sense of autism, and this involved searching for meaning, adjusting to changes, providing support and sharing experiences. Such findings supplement the growing body of literature concerned with the multidimensional functions of email groups (Braithwaite et al., 1999; Shaw et al., 2000). Indeed, when individuals join other email forums, such as those concerned with recreation or work, they do not do so solely as a means of addressing support needs (although this might occur). As shown in the present study, we cannot assume that parents of children with autism join such groups in order to obtain social support alone.

The analysis reveals that in their search for meaning of autism, parents' messages convey aspects of validating and reciprocating their concerns, representations of autism, perceptions of cause, anticipations of cure and religious explanations. From studies of people facing chronic illness, Leventhal and colleagues (Leventhal, Diefenbach, & Leventhal, 1992; Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997) have developed a self-regulation model to describe how cognitive representations are actively constructed to explain illness, and how such representations can predict and regulate coping. These representations comprise five attributes, aspects of which were also shown within the parents' messages in the present study: identity (i.e. beliefs about symptoms and diagnosis); consequences (i.e. the perceived implications); timeline (i.e. the perceived time frame for the development and duration); causes (i.e. perceptions about causes); and control (i.e. beliefs about treatments). According to this model, these attributes shape the processes of coping, and contribute to the appraisal of coping outcomes. In addition, subjective processing systems function independently to create emotional representations, as well as subsequent procedures for coping and coping appraisal. Consequently, it is suggested that email groups may contribute towards the development of parental perceptions of autism, and subsequent procedures and evaluations of coping.

While the self-regulation model is criticized for disregarding the sociocultural context (Marks, Murray, Evans, & Willig, 2000; Ogden, 1995), Leventhal et al. (1997) maintain that these processes do not occur in a social vacuum. Accordingly, if we are to understand the functions of an email group used by parents of children with autism, then we cannot isolate what they write about from their social and cultural contexts. If we instead accept that thoughts and actions are socially constructed and reconstructed (Blumer, 1969), then it can be seen that parents' messages are shaped by their everyday experiences; moreover, what parents write about may consequently shape these everyday experiences. Indeed, Moscovici (1984) suggests that common-sense shared beliefs are formed and maintained through *communicating* with others, thus allowing for the development of socially constructed representations.

Within the context of the present study, it can be suggested that email functions as a mechanism for allowing psychological constructions to be socially distributed, thus leading to the genesis, spreading and transformation of representations within different social groups. However, in examining the way in which features of the Internet affect human behaviour, Wallace (1999) suggests that interactions with like-minded others may lead to biased discussions and exaggerated perceptions of the rightness of opinions and beliefs. Although we did not specifically aim to examine whether this occurred in the present study, it appears that more credence is given to the diverse range of information concerning autism sent by parents to each other than to that obtained from their encounters with health professionals. Davison

and Pennebaker (1997) concluded that patients experiencing chronic illnesses have turned to computer support groups in order to fill the void created when encountering the world of medicine, which is seen as being far removed from their experiences of suffering and contextual concerns of everyday life.

The narrative component of email may also give temporal organization and coherence to experiences (Carr, 1986), and may function as a means of making sense of chaotic episodes in life (Conway, 1997). The paradoxical descriptions of the child as normal on the one hand and as being different on the other demonstrate the dissonance faced by parents in their encounters with other people. Although parents deal with autism in different ways based upon their cultural, social and personal circumstances, communicating with others may help them develop an inner sense of continuity. As such, these messages demonstrate what Frank (1995) calls *quest narratives* in which individuals encounter crisis and change that lead to revelation of the contingencies and mysteries of life. This function of writing narratives has been shown to help people gain meaning about such experiences, and improve sense of personal coherence, self-esteem, sense of control of situations and optimism (Pennebaker & Keough, 1999).

Although the level of involvement with the email group may or may not guide the development of subsequent attitudes or actions, making sense of shared experiences occurs partly from the social context that parents have chosen to become part of. This interdependency suggests that their discursive constructions and interpretations may contribute towards shaping how parents find meaning and then adapt to autism within the contexts of their everyday lives. Having said this, although autism is an important part of their lives, perhaps causing it to be reconfigured, it is not necessarily always a central or isolated concern. Parents also have other common concerns and lifestyle issues that other families not experiencing autism are faced with, and these are interwoven into their messages. Such interchanges unrelated to health and disability can promote relational communication and friendships (Finn, 1999), and may help overcome some aspects of social isolation found to be encountered by parents of children with autism (Intagliata & Doyle, 1984). Indeed,

a particular advantage of email is that it can provide immediate access to resources without limit of time or place.

There are some limitations to the specific approach that we adopted. In particular, we did not confirm whether the categories emerging from the messages were perceived as such by the parents themselves. Nor were we able to verify the true identity of participants (such as whether all the people participating in the group were genuinely parents of children with autism). Although not examined in the present study, the authors also wish to point out that in addition to the benefits of email group and Internet use, potential for harm has been shown to occur at individual, relational and group levels (Waldron, Lavitt, & Kelley, 2000). First, harm to the individual occurs from misunderstandings occurring as a consequence of limited non-verbal and verbal feedback, excessive dependency on the network and undervaluing of external expertise. Second, relational harm may result from the hyperpersonal nature of online communication and its potential for creating impressions that developing relationships are safe, when they could in fact be harmful. Third, the potential of harm to the group occurs from intrusions by those who would not usually be part of the group, but whose identities remain unknown because of the anonymity presented in using email. In addition, a study by Kraut et al. (1998) indicates a relationship between increase in Internet use and decline in social and psychological well-being. Herein lies the paradox: a technology aimed at increasing social involvement is instead associated with decline in family communication, decline in the size of social circles, increased feelings of depression, and disengagement from real life. These researchers speculate that virtual relationships lead to negative psychological reactions: they do not provide adequate support.

Conclusions drawn from other studies highlight the potential benefits that can be gained by encouraging those facing illness or disability to join email groups as a way of obtaining additional forms of support, or as an adjunct to treatment (Braithwaite et al., 1999; Finn, 1999). Although the present study found that overlap exists between the type of support offered within an email group for parents of children with autism and that shown to exist in more

traditional settings (Cohen, 1988), we have also shown that other equally significant functions are in existence. These are based upon the opportunities that parents have for writing about the experiences they face, and how they understand, interpret, transform and live with these experiences as a consequence of being involved with an email group. Future research could consider how representations change over time in individuals using such groups, and the effect that this has on outcome variables such as coping and well-being.

Notes

1. Asperger syndrome is characterized by (a) qualitative impairments in social interaction and (b) restricted, repetitive, and stereotyped patterns of behaviour, interests and activities. There is no associated delay in cognitive function, adaptive skills or language (American Psychiatric Association, 1994).

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