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THE USE OF ONLINE PARENT SUPPORT GROUPS BY PARENTS OF CHILDREN WITH AUTISM[*]

Kazım ALAT[**]

ABSTRACT

Parents of children with autism experience high levels of stress, anxiety, frustration and dissatisfaction. Following the diagnosis in their children families make changes in their lives. After diagnosis parents employ different coping strategies such as use of treatment services, support from other members of the family or personal network or use of religious coping mechanisms. In addition to these strategies parents also use parent support groups as a way of coping. Parents of children with special needs have long been using parent support groups in order to gather new information, share their experiences with other group members, or get emotional support. Among these groups face-to-face support groups provide their members with the opportunity to share their experiences, support each other, obtain new information, and create a network of parents with similar interests or concerns. Online parent support groups provide the same support in online environment with the advantage of participating discussion any time they want and from anywhere in the world. The first section of this article focuses on parents' experiences of raising a child with autism. The second section reviews studies on face-to-face and parent support groups and discusses advantages and disadvantages of these groups. Conclusions and recommendation are made based on literature.

STRUCTURED ABSTRACT

Parents of children with autism experience high levels of stress, anxiety, frustration and dissatisfaction. Following the diagnosis in their children families make changes in their lives. After diagnosis parents employ different coping strategies such as use of treatment services, support from other members of the family or personal network or use of religious coping mechanisms. Having a social and emotional support network provides a coping resource for these parents. In addition to these

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[**] Yrd. Doç. Dr., Ondokuz Mayıs Üniversitesi. El-mek: kazim.alat@gmail.com

strategies parents also use parent support groups as a way of coping. Through the use of adaptive coping strategies and social support and with the help of similar parents/support groups parents of children with disabilities can overcome difficulties associated with their child's condition.

Parents of children with special needs have long been using parent support groups in order to gather new information, share their experiences with other group members, or get emotional support. Among these groups face-to-face support groups provide their members with the opportunity to share their experiences, support each other, obtain new information, and create a network of parents with similar interests or concerns. Parents in these groups meet at a regular frequency at a local community center, church, library, school, or a member's house and led by an experienced parent or by professionals. Therefore, physical presence at these meetings becomes an important factor in the effectiveness of the group and the group's longevity. Research focusing on the benefits of face-to-face self-help groups on parents of children with disabilities reveals inconsistent findings. Some studies indicate that members of self-help groups report gain benefits. However, depending on the groups' goals and commitment, energy, and the skills of individual members these benefits can vary greatly.

Online parent support groups provide the same support in online environment with the advantage of participating discussion any time they want and from anywhere in the world. Group members ask questions about specific problems, share their experiences, and receive support from other group members. Research has shown that parents of children with disabilities use these groups in order to create a social network where they can receive informational, emotional, and esteem support, and share their experiences. Because of the online nature of support in online parent support groups, the quality or quantity of social support may be different in these groups.

Online support groups are believed to have some advantages and disadvantages compared to face-to-face support groups. However, most research on advantages and disadvantages of online support groups is based on samples such as individuals with psychological problems, addiction problems, disabilities, abuse survivors, and so on. In the context of parent support groups, the advantages and disadvantages of oPSGs, to some extent, are expected to be different. For example, for most parents therapeutic features might be the least important feature, whereas 24-hour availability of the oPSG, or a wide range of responses might be considered as an advantage.

The probability of receiving misinformation is one of the disadvantages of online self-help groups. Therefore, factors such as source of information, sender, and face validity of information might have an impact on parents' decision-making process. The credibility of information in online support groups received little attention and future research needs to investigate how participants of these groups form perceptions of credibility. Other disadvantages include privacy related issues, noise, negative emotions, large volume of email, and lack of physical contact and proximity.

It can be concluded that online parent support groups have the potential to deliver useful social support messages to their members. These messages include informational, emotional, and network support. Online parent support groups fill the gap where traditional sources (e.g., immediate family members, friends, and professionals) fail to provide support for these parents. Online parent support groups offer advantages over face-to-face support groups such as being able to participate from diverse geographical locations, use of archived messages, convenience of computer-mediated communication, benefits without participating in discussions, and therapeutic effects. On the other hand, there are some disadvantages of these groups, such as the impracticality of computer-mediated communication, possibility of receiving misinformation, and lack of nonverbal cues resulting in misunderstandings. Online parent support groups will be most beneficial when parents have a solid understanding of these potential advantages and disadvantages.

Being a member of online parent support groups is an educating experience that may result in a change in the nature of support. While in the beginning of their memberships, parents tend to only seek information; in later stages they may begin offering support for novice members. Moreover, using online parent support groups as a venue, parents may start advocating for their rights and launch community awareness campaigns, or found local disability associations.

Keywords: parent support groups, online social support, parents of children with autism

OTİSTİK ÇOCUĞU OLAN EBEVEYNLERİN ÇEVRİMİÇİ SOSYAL DESTEK GRUPLARI KULLANIMLARI

ÖZET

Otistik çocukların ebeveynleri yüksek düzeyde stres, kaygı, hayal kırıklığı ve hoşnutsuzluk yaşarlar. Bu aileler çocuklarına tanı konulduktan sonra hayatlarında değişiklik yaparlar. Tanı sonrasında ebeveynler tedavi hizmetlerinin kullanımı, kişisel ağları ya da aile üyelerinden destek ya da dinsel başa çıkma mekanizmalarının kullanımı gibi farklı başa çıkma mekanizmaları kullanırlar. Ebeveynler bu stratejilere ek olarak bir başa çıkma mekanizması olarak sosyal destek gruplarını da kullanırlar. Özel gereksinimli çocuk sahibi ebeveynler uzun zamandır sosyal destek gruplarını kullanarak yeni bilgiye ulaşma, diğer grup üyeleri ile deneyimlerini paylaşma ve duygusal destek alma imkânına sahiptirler. Bu gruplar arasında olan yüzyüze destek grupları üyelerine deneyimlerini paylaşma, birbirlerine destek olma, yeni bilgilere ulaşma, benzer ilgi ya da kaygıyı paylaşan ebeveynler ile birlikte bir ağ oluşturma imkânı sunmaktadır. Çevrimiçi ebeveyn destek grupları da benzer desteği çevrimiçi sunmakla birlikte üyelerine istedikleri zaman ya da dünyanın neresinden olursa olsun tartışmalara katılma imkânı sunar. Bu makalenin ilk kısmında ebeveynlerin otistik bir çocuk yetiştirme ile ilgili deneyimlerine değinilmektedir. İkinci kısımda ise yüzyüze ve çevrimiçi destek grupları ile ilgili çalışmalar gözden geçirilmekte ve bu grupların avantaj ve dezavantajları tartışılmaktadır. Ayrıca literatürdeki bilgiler ışığında sonuç ve önerilere yer verilmektedir.

Anahtar Kelimeler: ebeveyn destek grupları, çevrimiçi sosyal destek, otistik çocuğu olan ebeveynler

Introduction

It has been well documented that families of children with autism experience high levels of stress, anxiety, frustration, dissatisfaction (Boyd, 2002; Gray, 2002, 1994; Simmerman, Blacher, & Baker, 2001; Solomon, Pistrang, & Barker, 2001) and typically make changes in their social lives following the diagnosis of autism (Gray, 2002). Some parents have expressed that having a child with a disability brings an extra burden to a family's daily life (Innocenti & Kwisun, 1992). Family members may face emotional difficulties (e.g., depression, anger) or social difficulties (e.g., stigmatization) (Gray, 1993; 2002). When symptoms of disability first appear, parents experience an intensely stressful period and sometimes try to seek more accurate diagnosis and/or better treatment (Gray, 2002).

In times of distress, parents' personal social network provides a coping resource and contributes to the well-being of these parents (Dunst, Trivette, & Cross, 1986). A personal social network may include informal sources such as immediate family members, relatives, friends, parent support groups, and formal sources, such as, health care professionals, educators, and social service professionals (Valentine, 1993).

Experience of Parenting a Child with Autism

Research has shown that parents of children with autism become concerned about their children's development or social and communicative behavior as early as one or two years of age (Coonrod & Stone, 2004). However, there is usually an average of 4.8 months of time between first parental concerns and seeking professional help (Coonrod & Stone, 2004). Following the diagnosis of autism, parents experience intense levels of stress. Some parents try to seek a more accurate diagnosis (Gray, 2002). Initial reactions after diagnosis may include shock, emotional stress, anxiety, depression, denial, fear, and guilt (Gray, 1994; Sharpley & Bitsika, 1997). Midence and O'Neill (1999) also add that some parents might feel relieved because after the diagnosis they know what is "wrong" with their child so that they can focus on what to do. Families may also experience social rejection or stigma (Gray, 2002, 1994). Gray (1994) notes that this type of socialization problem is especially common among mothers of children with autism.

After diagnosis, parents employ different coping strategies such as use of treatment services, support from other members of the family or personal networks (Gray, 2002, Simmerman, et al., 2001) or use of religious coping mechanisms (Tarakeshwar & Pargament (2001). Having a social support network provides parents a way to reduce their stress as a result of having a child with disabilities. Social support networks also help parents by providing information on a specific topic, offering physical assistance (e.g., child care, transportation) or emotional support (Valentine, 1993). Studies have shown that social support networks have a mediating influence on parents' well-being and help them gain positive attitudes towards their child (Dunst, et al., 1986). In contrast, lack of social support networks might result in parents' withdrawal from the community and higher levels of stress and depression (Sanders & Morgan, 1997).

Parents can use a variety of coping strategies to overcome difficulties that they experience related to their child's condition. Having a social and emotional support network provides a coping resource for these parents (Solomon, et al., 2001). The most common coping strategies that parents use are treatment services and support from other members of the family or personal network (Gray, 2002; Simmerman, et al., 2001; Solomon, et al., 2001). Other types of coping strategies include the use of religious support (Bennet, DeLuca, & Allen, 1995; Bennet & DeLuca, 1996; Tarakeshwar & Pargament, 2001), social withdrawal, and various forms of individual attainment and activity (Heiman, 2002). For example, for religious families having a child with a disability can be seen as a blessing—an opportunity to teach them unconditional love, understanding, and compassion (for a parent account see, Welteroth, 2001). Mahoney and O'Sullivan (1992) suggest that religious interpretation of having a child with disability may enhance family relationships and provide these families an effective coping mechanism.

Through the use of adaptive coping strategies and social support and with the help of similar parents/support groups parents of children with disabilities can overcome difficulties associated with their child's condition (Dyson, 1997). For example, in parent-to-parent programs (P-P), parents can be matched to parents who have children with similar conditions and are expected to support each other. A trained, veteran parent is matched to a parent who newly enrolled in the program (Aibinder, et al., 1998; Kerr & McIntosh, 2000; Santelli, Turnbull, Marquis, & Lerner, 1997).

Tarakeshwar and Pargament (2001) investigated the use of religious coping in families of children with autism in Ohio, USA. The authors administered a set of questionnaires that measure identified stressors of autism, psychological adjustment, stress-related growth, and religious coping. A subsample of participants was also interviewed for their use of religious coping. Study results suggested that the use of positive religious coping was associated with stress-related growth and religious outcomes, whereas negative religious coping was associated with increases in depressive affect, anxiety, and poorer religious outcomes. The authors also suggest that the results of the study provide useful information for professionals to help parents by using their religious beliefs and practices as a resource.

Raising a child with disability can be challenging for many parents. Endler and Parker (1990) list several coping strategies such as task-oriented, emotion-oriented, and avoidance-oriented coping. Task-oriented coping can be viewed as an active and adaptive process in which individuals focus on changing the situation or problem, whereas in emotion-oriented coping, individuals often focus on self-blame or wish fulfillment and negative aspects of the problem. In avoidance-oriented coping, individuals avoid confronting a stressful situation by using distraction or social diversion. Obviously, both emotion-oriented and avoidance-oriented coping strategies do not help individuals to solve problems effectively. In another study using similar coping strategies model, it was found that coping strategies and parental stress and mental health weres closely associated (Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005). Based on the survey results of 89 parents of preschool children and 46 parents of school-age children with autism the authors found four dimensions of coping: active avoidance coping, problem-focused coping, positive coping, and religious/denial coping. The authors suggest that intervention programs should aim to teach parents the use of positive coping skills.

Overview of the Parent Support Groups

During the last two decades, parent support groups have received great attention from researchers (Krauss, Upshur, Shonkoff, & Hauser-Cram, 1993). Medical-pathological model of disability that was dominant two decades ago began losing its popularity and social model of disability (Dowling & Dolan, 2001; Oliver, 1996) has become widely adopted. As a consequence, more emphasis has been placed on parent empowerment and family support (Dunst, et al., 1986; Dunst & Trivette, 1987) and social support networking (Sarason, Sarason, Shearin, & Pierce, 1987).

According to Social Systems Model of Family Functioning (Dunst, et al., 1986), members of the family and individuals from ecological systems surrounding the family influence each other, both directly and indirectly. Using this theoretical framework researchers implemented early intervention programs that aimed to empower parents. Results of these studies often suggested positive outcomes for these parents (Clifford, Minnes, 2013; Dunst, Trivette, & Deal, 1988; Telleen, Herzog, & Kilbane, 1989).

Parents of children with special needs have long been using parent support groups in order to gather new information, share their experiences with other group members, or get emotional support (Bull, 2003; Huws, Jones, & Ingledew, 2001; Solomon, et al., 2001). Face-to-face PSGs usually hold regular meetings and sometimes invite a professional to teach them new behavioral techniques (Solomon, et al., 2001). Face-to-face parent support groups are usually run by parents, parent-founded disability associations and related institutions, and serve parents living in a certain geographical region. Online support groups, on the other hand, enable parents from diverse geographic locations and time schedules to form a virtual support group where they can meet other parents with similar problems or using similar coping strategies.

Although there are many studies focusing on the use of computer-mediated support groups by individuals with certain types of disability, illness, or addiction, few studies have focused on the use of online support groups by parents of children with special needs (Baum, 2004; Han & Belcher, 2001; Huws, et al., 2001). Wright and Bell (2003) note that study of online support groups is a relatively new phenomenon.

Self-Help Groups and Support Groups

The terms *support group, self-help group,* and *mutual help groups* have been sometimes used interchangeably in the literature. Kurtz (1997) makes a distinction between self-help groups and support groups. According to Kurtz, a self-help group is “a supportive, educational, usually change-oriented mutual-aid group that addresses a single life problem or condition shared by all members. … Professionals rarely have an active role in the group’s activities, unless they participate as members (p. 4).” On the other hand, support groups have been defined as “groups that meet for the purpose of giving emotional support and information to persons with a common problem. They are often facilitated by professionals and linked to a social agency or a larger, formal organization” (Kurtz, 1997, p. 4). Self-help groups and support groups for parents of children with autism and other developmental disorders have been studied by social scientists from various disciplines such as psychology and counseling (Solomon, et al., 2001; Huws, et al., 2001), communication (Wright & Bell, 2003), nursing (Kerr & McIntosh, 2000; Baum, 2004; Han & Belcher, 2001), and social work (Tichon & Shapiro, 2003). Smith and colleagues (1994) make a distinction between *parent support groups* and *self-help groups*. These authors admit that the two groups are alike and they both pursue advocacy for change and professional input on child rearing and stress management. However, according to Smith and colleagues, the “intended support” feature of parent support groups is the main feature that distinguishes it from self-help groups. Throughout this article the term “online parent support group” (oPSG) will be used to refer to online parent groups founded and moderated by the parents of children with autism.

Face-to-face Support Groups

Face-to-face or mutual aid support groups aim to provide their members with the opportunity to share their experiences, support each other, obtain new information, and create a network of parents with similar interests or concerns. Face-to-face support groups can be founded by parents, parent-founded disability associations, schools or universities, or local or regional healthcare and social work agencies. These groups can be led by an experienced parent or by professionals. Parents in these groups meet at a regular frequency at a local community center, church, library, school, or a member's house. Therefore physical presence at these meetings becomes an important factor in the effectiveness of the group and the group's longevity (King, Stewart, King, & Law, 2000). Sometimes face-to-face parent support groups invite professionals to inform them about a specific topic.

Parent-to-parent (P-P) programs are also similar to parent support groups. However, in these programs pairs of matched parents are expected to help each other. Usually, a trained, experienced parent is matched to a parent who is newly enrolled in the program (Aibinder, et al., 1998; Santelli, et al., 1997). Aibinder and colleagues (1998) report that perceived sameness, comparable situations, availability of support, and mutuality of support are the factors that contribute to the effectiveness of P-P programs. Logistic barriers (e.g., parents' busy life, lost phone numbers, long distances), situational differences (e.g., lack of perceived sameness), and individual preferences and values have been listed as factors that prevent successful helping relationships between parents.

Research focusing on the benefits of face-to-face self-help groups on parents of children with disabilities reveals inconsistent findings (Krauss, et al., 1993). King, et al. (2000) indicate that members of self-help groups report gaining benefits. However, depending on the groups' goals and commitment, energy, and the skills of individual members these benefits can vary greatly.

Solomon, et al. (2001) studied six parent-run support groups for parents of children with disabilities in the U.K. Before focus group meetings researchers administered a series of questionnaires to measure satisfaction, group climate, and group impact. Sample of the study consisted of 56 parents (52 mothers and 4 fathers) with an average of 3.9 years of participation in support groups. Analysis of the focus group discussion revealed that parents experienced positive changes in relationships with the outside world and gained knowledge. The authors argued that through support group participation, identity change emerged in sociopolitical, interpersonal, and intraindividual domains.

In another study conducted in Greece, mothers of children with special needs displayed increased self-esteem and decreased levels of depression after receiving social support and help (Makri-Botsari, Polychroni, & Megari, 2001). In addition, mothers who were engaged in organized social interaction with other mothers displayed positive coping strategies more frequently. The authors noted that although the initial aim of the study was to include both mothers and fathers, this was impossible because of the absence of fathers in such support groups.

Bull (2003) conducted an interview-based study to find out the experiences of British parents of children with dyslexia, attention deficit disorder, and multiple learning and health difficulties. Bull concludes that reasons for joining a support group could be classified into three groups: a need for information after recent diagnosis, a specific recommendation to join by an educational professional, and a need for receiving emotional support. Parents who were seeking information through support groups expressed the highest level of satisfaction with the support group. However, parents with higher levels of parental stress expressed dissatisfaction with the group. Bull notes that parental stress might be experienced as a consequence of children's learning difficulties, thus, parents would benefit from different types of intervention, such as family therapy. Parents who were in personal and family crisis were found to be frequent participants of group meetings. Making friendship with other parents or feeling comfortable in the group were other factors that influenced participation of the parents (Bull, 2003).

In a study investigating parental opinions about attending parent support groups in the U.S., it was found that what parents liked most was meeting other parents, sharing feelings, and receiving information about resources and discussing their child's disability (Smith, et al., 1994). Parents reported that parent support groups were most helpful when the child was "better," whereas, at the time of a family crisis, hospitalization, or when their child was “worse” parents did not find parent support groups helpful. However, given the study’s low return rate (18%) and small sample size (*n* = 45) it is hard to make generalizable conclusions.

There are several methodological limitations to these studies. Studies focusing on face-to-face parent support groups consisted primarily of mothers (Boyd, 2002; Krauss, et al., 1993; Makri-Botsari, et al., 2001; Rodrigue, Morgan, & Gefken, 1990; Simmerman, et al., 2001; Solomon, et al., 2001). The inclusion of fathers in research in the future would help us better understand the breadth of experiences of parents in self-help parenting groups. Second, the uniqueness of the sample makes participant recruitment a challenging task for the researchers. Parents of children with disabilities are also overwhelmed by the researchers’ request to participate in studies. Because of small sample sizes and low return rates in survey studies the results cannot truly reflect the experiences of majority of parents in these groups.

Online Support Groups

During the last two decades, online support groups emerged in such various forms as ListServs, email lists, and social media sites (Finfgeld, 2000; Hyman, 2003). Online support groups provide participants the opportunity to ask questions about specific problems, share their experiences, and get emotional support from other members of the group. The interaction of these groups can be in synchronous or asynchronous mode. In *synchronous communication* mode members have a chance to participate in real time interaction (e.g., chatting—using instant messaging applications or videoconferencing). In this type of communication message reading and writing occur simultaneously. Therefore, participants have relatively short time to formulate their ideas and respond to other participants. *Asynchronous communication*, however, does not occur in real time. Thus, members using this medium as an advantage can participate in discussions anytime they want and from anywhere in the world. Asynchronous communication can occur in such forms as ListServ or e-mail groups, web-based discussion boards and groups, or social media (Finfgeld, 2000; Hyman, 2003).

Research has shown that parents of children with disabilities use oPSGs in order to create a social network where they can receive informational, emotional, and esteem support, and share their experiences (Baum, 2004; Huws, et al., 2001; Han & Belcher, 2001). The literature suggests that because of the online nature of support in oPSGs, the quality or quantity of social support may be different in these groups (Braithwaite, Waldron, & Finn, 1999). Also, for special populations, different types of support were reported to be used. For example, for people with disabilities who experience mobility or communication problems, social and emotional support might be the important features of these groups (Braithwaite, et al., 1999), whereas for the victims of abuse cases, where anonymity is a crucial issue, emotional support becomes the main type of social support. In the context of parent support groups, Huws et al. (2001) reported that parents use informational, emotional, and esteem support. However, this research did not address when parents stop seeking support from traditional sources (e.g., immediate family members, neighbors, educators, professionals etc.) and begin seeking support from oPSGs. Therefore, understanding the types of support parents seek from the oPSGs will help educators and professionals to improve their practice and allow them to better implement new intervention programs. In fact, Jones and Lewis (2000) suggest that professionals could participate in online parent support groups in order to gain insight on how traditional pathological models of disability are inappropriate in helping parents of children with disabilities.

Online support groups are mostly utilized by psychotherapy and counseling groups (e.g., smoke cessation groups, sexual abuse victims), patients of chronic or life threatening diseases/symptoms (e.g., AIDS, cancer), and people with special needs or parents/relatives of individuals with special needs. Relatively few studies have focused on the use of online PSGs for the parents of children with special needs (Baum, 2004; Han & Belcher, 2001; Huws, et al., 2001; Tichon & Shapiro, 2003). Since the medium of communication is different for online PSGs than for conventional support groups, it is important to consider what the research shows concerning the technology.

Huws and colleagues (2001) analyzed the messages of British parents of children with autism who were members of an email discussion group. Based on data over a three-month period, the authors identified four major themes: searching for meaning, adjusting to changes, providing support and encouragement, and narrative sharing of experiences. The first theme, searching for meaning, includes efforts of searching for a better understanding and explanation of autism. The authors concluded that email messages not only provide an interactive social network but also provide a way that parents can validate and reciprocate their concerns about the cause and treatment of autism. The second theme, adjusting to changes, refers to the efforts made to establish a sense of normality or deal with uncertain conditions. The third theme, providing support and encouragement, reveals that online support groups provide a variety of support and encouragement to its members, including informational, emotional, and esteem support. The final theme, narrative sharing of experiences, includes sharing messages in a narrative form so that other parents can learn the details of experiences they have had.

In a study investigating the use of an online support group by parents of children with cancer, Han and Belcher (2001) found that the benefits of online support groups included getting information, sharing experiences, receiving general support, expressing feelings, and gaining accessibility. The researchers administered an online survey to the parents of children with cancer ($n = 73$) from three online self-help groups. It was noted that computer usage was highest primarily among parents from relatively high socioeconomic status. Even though the sample represented both genders, the fact that the majority of the participants (75%) were women limits the generalizability of the results. Han and Belcher also pointed out that little is known about the use of computer-based self-help groups by these parents.

Another research investigating online PSGs is in the nursing field. Baum (2004) administered an online survey to the primary caregivers ($N = 114$) of children with special health care needs from over 100 different online parent support groups in the U.S. The study sample was predominantly “white, married, well-educated female in their late 30’s” (p. 383). Most of these participants were living in urban settings and had relatively higher income. The children in Baum’s study had mainly physical disabilities and rare disorders, or psychiatric disorders. The researcher reports that the overall satisfaction with the online support group was high (93%) and factors such as getting usable ideas, improved caregiver-child relationship, and finding people to trust were found to be strongly associated with the satisfaction of the participant.

Examining online support group messages as research methodology has been employed in various studies. For example, Tichon and Shapiro (2003) examined the online messages of Australian children who had siblings with special needs. The researchers employed both qualitative and quantitative methods. In qualitative analyses each message was analyzed according to topic, types of social support, and nature of the self-disclosure. Later, the researchers coded each message according to pre-defined types of social support, such as emotional, informational, and social companionship. Based on postings over a period of 3 months, the researchers proposed a three-stage model of self-disclosure in online social support. According to this model, at Stage 1, self-disclosure is used to elicit social support from group members. In Stage 2, using self-disclosure group members start providing social support. In the final stage, group members use self-disclosure to create a reciprocal social companionship relationship.

Using similar methodology Jones & Lewis (2001) investigated the use of an online discussion group by parents of individuals with Down syndrome. Based on a 5-month period of email data collected in 1998, the researchers found six major themes including: sense of celebration, seeing the future before the handicap, a sense of hope and optimism for future, parents as agents of change, the role of discussion group, and a constantly validating and accepting environment. They also found that the majority of help messages were posted to the group outside of working hours. Authors concluded that parents were requesting help when alternative sources of assistance were not available. One drawback of this study is that the authors did not provide detailed information about the number and characteristics of the group members.

Studies of online parent support groups mostly focused on analyzing relatively shorter periods of time (e.g. three months) (Huws, et al., 2001) and analyses did not focus on the progress of these support groups. Solomon and colleagues (2001) note that it is possible to see a change in the nature of support over time. Therefore, by examining email messages over a longer period, it is possible to uncover group dynamics throughout a group's progress over time.

Another important issue related to support types is the perceived satisfaction with the support group. researchers studying conventional support groups indicated that perceived satisfaction with the PSG was found to be associated with several factors such as the condition of child (Smith, et al., 1994) and parental stress (Bull, 2003). Similarly, in a study conducted in Turkey, perceived social support was found to be related to burnout levels of mothers of children with mental handicaps. However, although some researchers indicated that parents reported high levels/rates of overall satisfaction with the oPSGs (Baum, 2004), for online PSGs the factors that contribute to the perceived satisfaction were not clearly demonstrated.

Online support groups are believed to have some advantages and disadvantages compared to face-to-face support groups (Finfgeld, 2000). However, most research on advantages and disadvantages of online support groups is based on samples such as individuals with psychological problems, addiction problems, disabilities, abuse survivors, and so on. In the context of parent support groups, the advantages and disadvantages of oPSGs, to some extent, are expected to be different. For example, for most parents therapeutic features might be the least important feature, whereas 24-hour availability of the oPSG, or a wide range of responses might be considered as an advantage.

Finfgeld (2000) groups advantages of online support groups into two categories: a) *Convenience factors*. These factors include the ability to send and receive messages practically anytime and anywhere in the world. Online groups also provide higher levels of anonymity and conceal sociodemographic factors such as age, race, and income level. However, some researchers argue that having a computer is also an indicator of relatively higher socioeconomic status (Finfgeld, 2000) and those without access to a computer and the Internet have less opportunity to participate in these online self-help groups. b) *Therapeutic factors.* Participation in online communication has therapeutic advantages as well. Parents do not have to be at the meeting at the same time and they can participate in discussion whenever they want. Even though they do not participate in discussion for various reasons (e.g., feeling uncomfortable or being shy) they can continue to read messages until they feel ready to participate in the conversation. Another advantage is that the use of online communication helps people overcome the interpersonal discomfort that some people may feel in face-to-face communication.

The probability of receiving misinformation is one of the disadvantages of online self-help groups. Therefore, factors such as source of information (e.g., news, web site, journal articles), sender (e.g., well-known group member, a professional, etc.), and face validity of information (e.g., a PDF file, web site, or forwarded email) might have an impact on parents' decision-making process. Wright and Bell (2003) note that credibility of information in online support groups received little attention and future research needs to investigate how participants of these groups form perceptions of credibility.

Other disadvantages include privacy related issues, noise, negative emotions, large volume of email, and lack of physical contact and proximity (Han & Belcher, 2001). In online communities disclosure, a great amount of personal details may pose a threat to the message sender. Online archives of these communities also can be used by researchers or marketers. Wright and Bell (2003) note that the effects of privacy concerns in online support groups is one of the most important issues that needs to be investigated in future research.

Analysis of email messages has a potential to uncover issues that are discussed by parents of children with autism. Other data collection techniques, such as interviews, focus groups, or surveys may not be convenient for samples that are geographically distributed or samples with diverse characteristics. Moreover, in the above mentioned techniques there is always the possibility of receiving "desired" answers from participants. However, analysis of email archives has potential to provide naturally occurring discourse in a chronological manner (Sixsmith & Murray, 2001).

Conclusion

Online parent support groups have the potential to deliver useful social support messages to their members. These messages include informational, emotional, and network support. Online parent support groups fill the gap where traditional sources (e.g., immediate family members, friends, and professionals) fail to provide support for these parents.

Online parent support groups offer many advantages over face-to-face support groups. These advantages include being able to participate from diverse geographical locations, use of archived messages, convenience of computer-mediated communication, benefits without participating in discussions, and therapeutic effects. On the other hand, there are some disadvantages of these groups, such as the impracticality of computer-mediated communication, possibility of receiving misinformation, and lack of nonverbal cues resulting in misunderstandings. Online parent support groups will be most beneficial when parents have a solid understanding of these potential advantages and disadvantages.

Being a member of online parent support groups is an educating experience that may result in a change in the nature of support. While in the beginning of their memberships, parents tend to only seek information; in later stages they may begin offering support for novice members. Moreover, using online parent support groups as a venue, parents may start advocating for their rights and launch community awareness campaigns (Pearson & Sternberg, 1986), or found local disability associations.

Online qualitative research provides a relatively new way to investigate the experiences of parents of children with disabilities. Although online qualitative research offers some advantages such as the use of online archives, access to parents from diverse locations, and being less intrusive, it also poses some methodological and ethical challenges, such as "probability sampling, measurement validity, protection of confidentiality, and other facets of ethical research involving human subjects" (Cassel, Jackson, & Cheuvront, 1998, p. 77). For example, in the case of the current study, in addition to parent members of the oPSG, there were non-parent members as well. Before conducting research, a careful examination is needed to distinguish parent and non-parent members of these groups. Moreover, these types of oPSGs make it difficult to administer online surveys. Therefore, it is important that researchers take necessary measures before conducting the study.

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