# THE USE OF ONLINE PARENT SUPPORT GROUPS BY TURKISH PARENTS OF CHILDREN WITH AUTISM

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# DEDICATION

To the memory of my mother

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# ABSTRACT

Kazim Alat

THE USE OF ONLINE PARENT SUPPORT GROUPS BY
TURKISH PARENTS OF CHILDREN WITH AUTISM

Parents of children with autism have long been using parent support groups in order to gather new information, share their experiences, and receive emotional support. During the last decade, the proliferation of Internet and communication technologies enabled parents to form online parent support groups. In spite of the growing number of online parent support groups in Turkey, no study has yet investigated the use of these groups.

The purpose of this study was to explore the use of an online parent support group by the parents of children with autism in Turkey. Research questions examined the following topics: participant and network characteristics, parents' experiences and their use of the online group, perceived satisfaction with the online support, and the advantages and disadvantages of the online group. A total of 1,480 email messages posted by 140 members over a five-year period were collected and analyzed. In addition, five parents were interviewed over the phone. Data analyses consisted of descriptive data analysis of the email messages, social network analysis of the parent support network, and qualitative data analysis of the email messages and parent interviews.

Results of the study indicated that parents were using the online support group to receive or offer emotional support and information about autism and autism related problems, and to create a network of parents. Perceived satisfaction with the group support was relatively high and a number of factors contributed to the perceived satisfaction, including a sense of belonging, level of participation and number of messages, and credibility of information. It was concluded that online parent support groups can be useful sources of support for the parents of children with autism.

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# CHAPTER 1

# 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).

This study explores the use of an online parent support group by the parents of children with autism in Turkey. More specifically, parents' support messages are examined to find out how they use online parent support groups in coping with stressors of having a child with disability. Additionally, experiences of parents in regard to their children's education are investigated in this study. The chapter introduces parenting stress related to having a child with autism, and the use of online parent support groups as a way of coping.

### *Experience of Parenting a Child with Autism*

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.

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 focus often engage in 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.

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).

### *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 (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.

### *Statement of the Problem*

During the last two decades parents of children with special needs in Turkey became actively organized and involved in their children’s education and in advocating for both themselves and their children’s rights (Akkok, 1999; Kuloglu-Aksaz, 1994). New advancements in computer and communication technology (especially the use of internet and email) allowed these parents to form online parent support groups (oPSGs) to seek support for their problems, advocate for their rights and connect to other families who are experiencing the same problems. These parent support groups focus on developmental or intellectual disabilities such as autism, Down’s syndrome, attention deficit hyperactivity disorder, and learning disabilities. Although quality and level of participation vary greatly, it is possible to find many online parent support groups founded by the parents or relatives of children with special needs or volunteers/professionals.

In spite of the growing number of online PSGs in Turkey no study has yet investigated the characteristics of participants of these groups. Studies investigating oPSGs in other countries (Baum, 2004; Han & Belcher, 2001; Huws, et al., 2001) have often tended to give less information regarding the characteristics of these parents. Except for one study focusing on parents of children with autism (Huws, et al., 2001) all others have focused on the parents of children from a broad range of disabilities (e.g. Baum, 2004) and parents of terminally ill children, such as cancer and leukemia patients (Han & Belcher, 2001). Siblings or relatives of these children were also of interest to some researchers (Tichon & Shapiro, 2003). Thus, knowing the characteristics of the members of oPSGs might help us better understand the relationship between parental characteristics and the use of oPSGs.

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.

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, Gabard, Dale, & Drucker, 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.

### *Overview of the Study*

The purpose of this study is to provide a systematic description of the use of an online parent support group by the parents of children with autism in Turkey. The online parent support group (oPSG) investigated in this study was founded five years ago by a parent who has a child with autism. At the time of data collection, the online PSG had 86 members including parents, relatives, professionals, and volunteers. The oPSG communicates asynchronously via email using Yahoo!'s free Yahoogroups service (http://groups.yahoo.com/). Yahoogroups service allows individuals (group owners) to create an email distribution list, exchange email messages, and archive these messages. The data I analyzed in this study consist of archived email messages that were posted to the online PSG during the last five years.

A preliminary analysis of the data was conducted in January 2004. The results of this preliminary study were submitted to fulfill a requirement for J605 - Early Inquiry Experience course and as part of the Qualifying Portfolio for the doctorate program. Preliminary analysis of the data helped me refine research questions and create interview questions.

The current study consists of two phases. In Phase 1, archived email messages were imported into a qualitative data analysis software (Atlas.ti) and the content of the email messages were analyzed. In Phase 2, selected members of the PSG were interviewed via telephone. Interviews focused on the parents' use of oPSG and the factors that contribute to the perceived satisfaction with the oPSG.

### *Significance of the Study*

This topic is relatively new and in the context of Turkey no other study has focused on the use of online PSGs by the parents of children with special needs. Therefore, this research has potential to uncover issues related to online PSG use in Turkey and contribute to the literature. The information gathered from this study can be valuable for designing new support programs for the parents of children with special needs in Turkey. The results of the study are also expected to shed lights in parents' experiences regarding their children's education. The results of this study can be of value to researchers, early childhood special education practitioners, parents of children with special needs, and policy makers.

This study aimed to analyze a five-year period of archived email messages. Studies using similar methodology have mostly focused on examining relatively shorter periods of time (i.e. three months) (Huws, et al., 2001; Tichon & Shapiro, 2003).

Therefore using a longer period of time allowed me to help uncover group dynamics and change in the nature of support over the time. Analyses in the preliminary study had suggested that such changes could occur over time. For example, at the beginning of their membership some parents were usually seeking only informational support and emotional support. However, over time some parents took leadership roles and became unofficial moderators of the group, and finally as a "veteran" parent, they began helping new members, providing them with the information and emotional support.

### *Research Questions*

The purpose of this study is to provide a systematic description of an online parent support group used by the parents of children with autism in Turkey. More specifically the following questions were investigated in this study:

1. What are the member and network characteristics of the online parent support group?
2. How do parents describe their experience of raising a child with autism?
3. How do the parents of children with autism use the online parent support group as a way of coping, and what type of support do they receive?
4. To what degree do the parents of children with autism perceive the support they receive from online PSG as satisfactory and what factors contribute to the perceived satisfaction with online PSGs?
5. What are the specific perceived advantages and disadvantages of online parent support groups as a medium of communication?

### *Organization of the Dissertation*

In the second chapter, I review literature on the use on parent support groups with a special focus on autism and other developmental disabilities and provide the reader the context of Turkish (early childhood) special education system. In Chapter 3, I present methodological and theoretical framework for the study and data collection and analysis procedures. In Chapter 4, the results of the data analyses are provided. In Chapter 5, following a brief summary of the research results is followed by a discussion and implications for future research.

# CHAPTER 2

# LITERATURE REVIEW

In this chapter, I first briefly summarize autism and parents' experiences following the diagnosis of autism. Second, I briefly give definitions of the terms "self-help groups" and "support groups" and discuss face-to-face and online support groups in the context of parenting a child with disabilities. Third, I summarize theories on social support, communication of social support and parenting. Finally, a review of the research on Turkish parents of children with disabilities is provided. This section also includes a brief summary of the special education provision in Turkey.

## *Autism and Parental Experiences*

*Definition and etiology*. Autism is defined as qualitative impairment in social interaction and communication skills and restrictive repetitive and stereotyped patterns of behavior, interests and activities (APA, 2000). Because the biological causes of autism are not yet fully understood by research, autism is behaviorally defined and diagnosed. Diagnostic criteria require that symptoms of autism should manifest before the age of three years. The comorbidity of autism with other mental disorders and health problems are well documented in the literate. Common comorbid disorders include mental retardation, attention deficit-hyperactivity disorder (ADHD), learning disabilities, seizure disorders, chronic gastrointestinal disorders (Bonde, 2000; Morgan, Roy, & Chance, 2003). According to the Diagnostic and Statistical Manual of Mental Disorders, fourth edition, (DSM-IV-TR) (APA, 2000) autistic disorder is listed under pervasive developmental disorder category, which also includes Rett's Disorder, Childhood

Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS).

Individuals with autism have difficulty in processing sensory information. They could be over or under-sensitive to touching, cuddling, and other visual or auditory stimuli (Minshew & Goldstein, 1998). Studies have suggested that brain deficits and dysfunction in some part of the brain affect the way sensory information is processed and cause deficits in social interaction and communication skills. In their extensive research review of sensory dysfunction theories of autism, Rogers and Ozonoff (2005) identified several sensory theories of autism: over-arousal theories, under-arousal theories, perceptual inconstancy theories, and impaired crossmodal processing theories. Over-arousal theories states that children with autism are easily aroused by sensory stimuli and cannot easily adjust to changing stimuli compared to their typically-developing peers.

Under-arousal theories on the other hand assert that suppression in the limbic system causes a sensory deprivation and results in not receiving sensory and affective messages. The limbic system contains hippocampus, amygdale and other small areas of the brain which regulate behaviors, emotions, and senses. Dysfunction in these areas could lead to hyperactivity, impaired social interaction, and stereotypic motor behavior. Unlike the over-arousal and under-arousal theories, perceptual inconstancy theories states that children with autism experience abnormal and unpredictable states of arousal which lead them to have a deficit in maintaining perceptual constancy. Based on hippocampal abnormalities in autopsy studies of individuals with autism, impaired crossmodal processing theories suggest that abnormalities in the hippocampus cause the brain to process all incoming sensory information.

While the causes of autistic symptoms are not yet fully understood, several studies have suggested the relationship between measles, mumps, rubella (MMR) vaccination and autism (Wakefield, et al., 1998). Vaccination studies caused a controversial debate among the scientific and parent community. For example, opponents of vaccination studies asserted that there is no causal relationship between the MMR vaccination and the development of autistic symptoms (Fombonne & Chakrabarti, 2001; Taylor, et al., 1999). Parents report on the other hand that MMR vaccination played a trigger role in the development of autistic symptoms in their children (Ramsay, Yarwood, Lewis, Campbell, & White, 2002). However, these parental reports were discredited by some researchers and regarded as “parental recall bias” (Andrews, et al., 2002).

*Prevalence of autism*. Studies estimating the prevalence of autism report varying numbers, from as low as 8 per 10,000 to 57 per 10,000 children. The prevalence rate of autistic disorders during the last two decades increased dramatically. It has been argued that these changes may partly be due to the changes in diagnostic criteria or early studies’ focus on infantile autism versus recent studies’ focus on the whole spectrum of autistic disorders (Fombonne, 2003). The prevalence of autism in the U.S. was reported as high as 34 per 10,000 in metropolitan Atlanta, 40 per 10,000 for the Brick Township, New Jersey sample (Bertrand, Mars, Boyle, Bove, Yeargin-Allsopp, & Decoufle (2001), and 52 per 10,000 for the Minnesota sample (Gurney, Fritz, Ness, Sievers, Newschaffer, & Shapiro, 2003).

Another study conducted in the U.K. estimated the prevalence of autistic spectrum disorders, including Asperger Syndrome in children aged 5-11 years as 57 per 10,000 (Scott, Baron-Cohen, Bolton, & Brayne, 2002). Other British researchers report a prevalence rate of 16.8 per 10,000 for autistic disorder and 62.6 per 10,000 for the entire spectrum of autistic disorders (Chakrabarti & Fombonne, 2001). In another study conducted in Iceland, it is estimated that the prevalence of infantile autism/childhood autism was increased from 3.8 per 10,000 for children born in 1974-1983 to 8.6 per 10,000 for children born in 1984-1993 (Magnusson & Saemundsen, 2001). It should also be noted once again that while some studies only report infantile autism/childhood autism, or autistic disorder, others report the whole spectrum of autistic disorders including autistic disorder, Asperger syndrome, and PDD-NOS.

*Parents' experiences after diagnosis.* 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).

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.

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.

### *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. In this study the term "online parent support group" (oPSG) will be used to refer to an online parent group founded and moderated by the parents of children with autism in Turkey.

### *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 15 years, online support groups emerged in such various forms as bulletin board systems (BBS), USENET, ListServs, and email lists (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 Internet Relay Chat (IRC) or other instant messaging software—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 USENET, ListServ or e-mail groups, web-based discussion boards or groups (Finfgeld, 2000; Hyman, 2003).

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. (For a comparison of above reviewed studies see Table 1). 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.

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.

Table 1

*A comparison of studies focusing on online support groups for the parents and relatives of children with disabilities.*

| | This Study | Huws, et al., 2001 | Han & Belcher, 2001 | Baum, 2004 | Tichon & Shapiro, 2003 | Jones & Lewis, 2001 |
|---|---|---|---|---|---|---|
| Sample | Turkish parents of children with autism | International, English speaking, parents of children with autism | American parents of children with cancer | American parents of children with special health care needs | Australian siblings of children with special needs | English speaking, North American and Western European, parents of individuals with Down syndrome |
| Sample size | 124 parents, relatives, and others | 374 unique email addresses | 73 respondents | 114 respondents | 58 unique email addresses | No information available |
| # of support groups studied | 1 group | 1 group | 3 groups | Over 100 groups | 1 group | 1 group |
| Data collection | Email messages, interview | Email messages | Online survey | Online survey | Email messages | Email messages |
| Duration of collected data | Over 5 years | 3 months | -- | -- | 3 months | 5 months |
| Data analysis approach | Qualitative; developmental research sequence, social network analysis, descriptive quantitative data | Qualitative, grounded theory | Quantitative | Quantitative; qualitative analysis of open-ended questions | Qualitative | Qualitative, content analysis |
| Qualitative data analysis software | Atlas.ti | QSR Nud*ist | -- | -- | QSR Nud*ist | No information available |

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-know 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).

## *Theories on Social Support, Communication*

### *Definition and types of social support*

Social support is defined as “a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support” (Dunst, Trivette, & Cross, 1986; p. 403). Birch (1998) describes four different types of social support, including emotional, informational, material, and appraisal. Emotional support is described as the demonstration of care and sympathy towards the support recipient, or listening to support recipient and being available for emotional support. Informational support is defined as the provision of knowledge to another person or referring to appropriate source of information. Material support includes providing support recipient with an object or a tangible resource such as money, lending a book, or physical assistance. Appraisal refers to providing feedback, affirmation or praise about one’s actions.

Similarly, Cutrona and Suhr (1992) offer a five-category social support system: informational, tangible, esteem, network, and emotional support. Cutrona and Suhr also propose sub categories within each social support category. Informational support is defined as providing information, advice, referrals, situation appraisal or teaching. Tangible assistance refers to providing support in the form of a physical assistance, such as lending a book or helping perform a task. Esteem support includes messages that validate support recipient’s self-esteem, self-concept, importance and competence. Network support refers to messages that connect support recipient with new members or broaden his/her social network. Emotional support includes messages that provide intimacy, encouragement, and attachment. In their study examining types of social support in computer mediated groups for people with disabilities, Braithwaite and colleagues (1999) found that emotional support was the mostly used support type followed by the informational support whereas tangible support was the least used type of social support.

Informational support has been one of the attractive features of support groups. Sharing experiences can be a powerful way of learning, as it enables group members to reach information that cannot be easily found by conventional methods, such as reading books, or asking an expert. As Borkman (1999) describes:

> Experiential knowledge is more “awareness” than it is information that can be captured and contained in a book, library, or a computer file. Most experiential knowledge is transmitted through stories, often orally, and it is either difficult or undesirable to codify much of it in written form (p. 36).

*Sources of social support*. It has been suggested that sources of social support and extrafamily resources can be categorized in two groups: informal and formal sources (Dunst, et al., 1988). Informal sources of social support include members of the immediate and extended family (e.g., spouse, children, grandparents, and relatives), friends, neighbors, colleagues, and social groups (such as religious groups, social clubs). Formal sources of social support include professionals from medical and educational community (e.g., physicans, therapists, teachers, and social workers) and agencies that provide support to families (e.g., early intervention programs, hospitals). While parents have direct access to interact with individuals in informal social network, access to formal social networks might be direct or indirect.

### *Models and Theories of Social Support and Communication*

There are several models and theories that explain the effects of social support on personal well-being. In this section, I first summarize literature on parent empowerment and then provide literature on communication and network theories.

*Parent empowerment*. Empowerment enables parents to access information and resources and to actively participate in their child's educational process (Dempsey & Dunst, 2004). Thus, empowerment gives parents an enhanced perceived control over the stressful life events. Parent empowerment model sees parents as active, capable of making informed choices, and able to learn new skills that will help improve family functioning.

There are several ways to help parents feel empowered and teach necessary skills to promote the development of their children. These include intervention and parent training programs carried out by agencies and parent- or professional-run support groups. In their study of helpgiving styles and empowerment between Australian and American parents of children with disabilities, Demspey and Dunst (2004) report that helpgiving practices contribute to parental empowerment. Helpgiving practices were measured by a survey that asks parents' perception of the nature of the support provided by service providers. Empowerment was assessed on two dimensions. The first dimension, level of empowerment, consisted of three levels: individual, service, and community. The second dimension, expression of empowerment, was manifested as attitude, knowledge, and behavior. The authors reported that enabling practices was the only variable predicting parent empowerment in both countries. Demographic variables, such as parent age, child age, and parents' employment and educational studies did not contribute to parent empowerment.

Evidence suggests that early intervention and parent education programs have the potential to positively affect parental empowerment by supporting families (Dillenburger, Keenan, Gallagher, & McElhinney, 2002; Farber & Maharaj, 2005; Whitaker, 2002). Moreover, early intervention programs aimed at creating social support networks provide better health and well-being outcomes for the parents of children with disabilities (Dunst, Trivette, Davis, & Cornell (1988). Therefore, it is important that early intervention programs should not only provide informational support for parents, but also provide ways to create social support networks and begin to help each other.

*Effect theories*. According to these models having a social support network can reduce the negative impact of perceived stressful events. Buffering Model (Dean & Lin, 1977) states that social support buffers the negative impacts of stressful situations and provides support recipients a way of coping with stressful situations. Unlike the Buffering Model, Direct Effects Model (Schwarzer & Leppin, 1991) suggests that there is a direct relationship between social support and psychological well-being. The use of social support, in the form of companionship, empathy, and humor may help support recipients overcome the negative effects of stressful situations. Previous studies report evidence for the direct effects model. For example, Aneshensel and Stone (1982) found that having a social support network has direct effects on psychological well-being of adults in the US. However, as predicted by the Buffering Model there were no interaction effects of social support on psychological well-being of these adults. Other studies also report similar results showing the direct effects of social support (Krol, Sanderman, Suurmeijer, 1993; Burton, Stice, & Seeley, 2004).

*Network strength theories*. Another social network theory based on the strength of the relationships is the Weak Tie Network Theory (Granovetter, 1973; 1983). According to this theory, a tie connects two or more individuals in a social network. Unlike strong ties (e.g. spouse, parents, close friends, etc.), weak ties include individuals such as neighbors, colleagues, members of local community groups, support groups, and service providers (Adelman, Park, & Albrecht, 1987). Weak tie network members provide support when an individual's closer-tie (family, friends) is not available. Compared to close ties, weak tie networks are maintained infrequently and involve less intimate exchanges. Weak-tie networks are prone to dissolve easily if the medium of the communication changes (Garton, Haythortwaite, & Wellman, 1997).

Communication researchers looked at the structural features of online support groups, such as the presence of verbal and nonverbal cues. The lack of nonverbal cues in computer-mediated communication (CMC) has been investigated by numerous researchers (Gunawardena, 1995; Tidwell & Walther, 2002; Walther & Parks, 2002). Earlier theories of CMC emphasize the lack of nonverbal cues and consider CMC as being less personal and emotional. For example, Social Presence Theory (Kiesler, Siegel, & McGuire, 1984) states that because of the limited information about peoples' appearance and vocal and nonverbal features, CMC tends to be lacking social presence. It has been suggested that because of the lack of nonverbal cues, participants in CMC tend to display greater hostility towards others or send more task-oriented messages. Groups using CMC were also found to be reaching consensus less frequently (Walther & Parks, 2002).

On the other hand, some researchers claimed that the use of emoticons (emotional icons, e.g., ☺, :), ☹, :(, ;-P, etc.) or CAPITAL LETTERS could be considered as nonverbal cues in a computer-mediated communication. Emoticons, as graphic representations of facial expressions allow users to express themselves and overcome the limitations of text-based communication (Walther, D'Addario, 2001). Moreover, with recent developments in computer and interactive communication technology enabling the use of voice chat and video chat and other mixed-medium means of communication verbal cues are becoming part of CMC.

## *Early Childhood Special Education in Turkey*

In this section, I first briefly give background information about special education services and inclusive practices in Turkey. Later, I talk about the parents of children with special needs in Turkey. Lastly, I provide a summary of studies conducted on parents of children with disabilities.

### *Special Education Provision in Turkey*

Estimates have shown that up to 14% of children aged between 1 to 18 years in Turkey have special educational needs (Eripek, 1995). However, only a handful of these children are able to receive special education. Uzundemir (2000) reports that less than 10% of the school age children with special needs benefit from the educational services in Turkey. According to the Ministry of National Education (MoNE, 2004), during the 2003-2004 school year, more than 14 million students from K-12th grades were enrolled in educational institutions. As can be seen in Table 2, the majority of these students (10.4

million) were attending 1st-8th grade in urban schools. The MoNE also reports that only 64,000 students were receiving special education in government-run special education schools, inclusive programs in regular education programs, and private special education institutions. Of these students more than two thirds of them (43,300) enrolled in inclusive classrooms. These numbers clearly state that most of the students with special needs are not benefiting from the educational system.

Table 2

*Number of students enrolled in 2003-2004 school year.*

| | Total | Urban | Rural |
|---|---:|---:|---:|
| Preschool education | 358,499 | 286,107 | 72,392 |
| 1st-8th grades | 10,479,538 | 7,697,112 | 2,782,426 |
| 9th-12th grades | 3,593,404 | 3,467,334 | 126,070 |
| Total | 14,431,441 | 11,450,553 | 2,980,888 |

Adapted from MoNE (2004), p. 18.

Currently, two governmental organizations regulate special education in Turkey: Ministry of National Education (MoNE) and Social Services and Child Protection Agency (SSCPA) (Senel, 1998). In special schools with and without residential provision, MoNe provides education to visually impaired, hearing impaired, physically disabled, mentally disabled, and chronically ill students. In regular school environments, education is provided in self-contained classrooms or in inclusive classrooms (Senel, 1998). During the last decade, there has been an increase in the number of inclusive programs throughout the country. These special education services are available within the public education system; however, students must go through a series of screening and diagnosis procedures in Guidance and Research Centers that are operated by MoNE. Guidance and Research Centers are responsible for planning and implementation of special education (Senel, 1998).

Social Services and Child Protection Agency on the other hand, provides services for individuals with special needs from all age groups, supporting and protecting their rights and well-being as members of the society. SSCPA also provides protective services for at-risk children and their families. In addition, SSCPA regulates adoption and foster care services.

*Inclusive practices*. During the last two decades there have been efforts to include children with special needs into mainstream educational settings. However, implementation of these inclusive practices has always been criticized and found ineffective by researchers (Senel, 1998). Although there are policies and regulations for the education of children with disabilities, in practice educational professionals are often unclear on how to implement those policies (Sari, 2000; Senel, 1998). Even though educators express positive attitudes towards inclusive education, both parents and teachers cite several barriers to inclusion, such as the physical environment of the schools, the limitations of technological and instructional tools, teachers' lack of experience and knowledge, overcrowded classrooms, and lack of collaboration among professionals. Parents also have little input in the inclusive education process (Alat, 2005). Therefore, parent support groups can be an important place for them to discuss issues related to their child's education and get support from each other.

### *Parents of Children with Special Needs in Turkey*

Turkish parents of children with special needs became actively organized beginning in the 1960s (Sucuoglu, 1997). The initial aim of these groups was to overcome the lack of appropriate special education institutions and to found new schools for their children. Later, these parent associations made efforts to inform the public about disabilities through public awareness campaigns. Today, parent associations, along with other organizations founded by universities serve as nongovernmental organizations that provide educational opportunities and advocate for the rights of individuals with disabilities (Senel, 1998).

Due to wide availability of extended family system in Turkey, parents of children with special needs often receive extra help from extended family members in caring for their children (Akkok, 1997). However for parents from nuclear families, who are both working in urban areas, such extended family support is not likely to be available. Furthermore, the number of educational institutions available for school-age children is limited. For parents of infants and toddlers, the situation gets even worse, because educational resources are scarce for these children (Sucuoglu, 1997). As a consequence, parent support groups seem to be a support mechanism where parents can turn to, receive emotional support, and exchange information about resources.

Traditionally, women and elderly relatives were the caretakers of children in a typical Turkish family. This trend has changed in recent years due to the structural changes in the society, urbanization, increased parental employment rate, and education (Sunar & Fisek, 2005). However, a recent study reports that in a low-income Turkish sample, mothers' level of involvement in childcare was found to be higher than that of fathers' level of participation (Ozkan & Honig, 2005). Mothers reported higher levels of involvement regardless of having a child with or without a disability. It was also found that parents were more satisfied with their partners' involvement depending on the degree of their satisfaction of their own involvement and the level of child's disability.

*Studies on parents of children with special needs*. A number of studies have investigated the relationship between having a child with disability and parental stress (Duygun & Sezgin, 2003) and causal attributions to disability (Akkok, Askar, & Karanci, 1996). However, in consistence with studies conducted in other countries, the majority of these studies only included mothers (Akkok, 1997; Duygun & Sezgin, 2003).

Duygun and Sezgin (2003) investigated the effects of stress symptoms, coping styles, and perceived social support on burnout levels of Turkish mothers of children with ($n$ = 118) and without mental handicaps ($n$ = 121). Comparison of these groups indicated that mothers of children with special needs had higher levels of emotional burnout. Duygun and Sezgin also noted that the predictors of emotional burnout for mothers of children with and without mental handicaps were found to be different. For example, for mothers of children with disabilities, social support dimension of perceived social support were found to be predictor of burnout, whereas for mothers of children without disabilities, family dimension of perceived social support were found to be associated with emotional burnout. Therefore, in order to implement effective intervention programs, these factors should be taken into consideration.

Akkok and colleagues (1996) surveyed 142 parents of children with mental disabilities and autism in Turkey. Investigating the causal attributions of the parents of children with disabilities, Akkok and her colleagues found that in addition to self, family, and external factors, parents were also making causal attributions to bad luck and ill fate. Parental stress was also found to be related with parental causal attributions. For mothers, the type of child's disability and bad luck were significantly related with stress, whereas for fathers, child's age, the type of child's disability, and factors associated with self-family domain and external blame were main sources of stress.

Beginning in the 1990s, the notion of examining the family as a whole, including parents, siblings, and grandparents has resulted in several family-oriented intervention programs (Akkok, 2000). While earlier parent training programs aimed to teach parents the necessary skills to take care of their children (Akkok, 1994; Kuloglu-Aksaz, 1994), latter programs included other family members, such as siblings (Tekin, 1997). Akkok (1997) documented the experiences of mothers of children with Down syndrome who participate in a face-to-face support group. Results of this study confirmed that the social support from extended family members and immediate family support network has a positive effect on the mothers' emotional and social well-being.

In another study conducted by Erguner-Tekinalp and Akkok (2004), mothers of children with autism participated in a coping skills training program developed by the researchers. The training program consisted of one and half hour training sessions twice a week, over the period of 4 weeks. Designed as cognitive behavioral training, the program aimed to teach participants the necessary skills to understand stress and its effects, general coping strategies, problem solving skills, relaxation training, positive thinking and developing social support. Results indicated that after completion of the training program, mothers were more effectively using social support as a way of coping compared to their counterparts in control group. The researchers suggest that parent training programs may help mothers learn new cognitive skills to deal with stressful situations, develop a positive attitude towards themselves, and become more motivated for the future.

*Summary of Literature Review*

In this chapter I first review research on face-to-face support groups for the parent of children with disabilities. Studies conducted in various countries and with different samples suggest that in general face-to-face support groups provide positive outcomes for the participants of such support groups. While the majority of PSG participants expressed satisfaction with the support, participants with higher levels of stress or experiencing crisis situation expressed dissatisfaction with the PSG (Bull, 2003; Smith, et al., 1994).

Second, I review research on online PSGs for the parents of children with disabilities. Similar to face-to-face PSGs, online PSGs were reported to provide benefits for their participants, such as informational, emotional, and esteem support, and allow them to share their experiences with the other participants. Unlike face-to-face PSGs, online groups offered some advantages over face-to-face groups, including easy and convenient access and archive of old messages. Studies of online PSGs employed two types of data collection techniques: analysis of email messages (Huws, et al., 2001; Jones & Lewis, 2001) and administering online surveys (Han & Belcher, 2001; Baum, 2004). Analyzed email messages in these studies usually consisted of data collected for three to five months.

Third, I review the literature on parents of children with disabilities in Turkey. Unlike parents in industrialized countries, parents of children with disabilities in Turkey experience higher levels of scarcity in resources, in both quality and quantity. The literature review revealed that during the last decade, researchers began examining the family as a whole and started implementing family-oriented intervention programs.

The current literature is limited in a number of ways. First, studies of parent support groups (especially face-to-face groups) consisted of mostly mothers (Boyd, 2002; Duygun & Sezgin, 2003; Erguner-Tekinalp & Akkok, 2004; Krauss, et al., 1993; Makri-Botsari, et al., 2001; Rodrigue, Morgan, & Gefken, 1990; Simmerman, et al., 2001; Solomon, et al., 2001). Second, both qualitative and quantitative studies employed relatively small sample sizes (Han & Belcher, 2001; Smith, et al., 1994). This especially becomes an issue in quantitative studies. Third, studies of oPSGs that I was able to find from scientific databases included participants only from English-speaking countries. Fourth, many studies included parents of children with various disability types. For example, in Baum’s (2004) study, the sample consisted of participants from over 100 support groups for the parents of children with mainly physical disabilities, rare disorders, and psychiatric disorders. The type of disability in a child may be a confounding factor for the support group participation of parents.

# CHAPTER 3

# METHODOLOGY

In this study, a qualitative inquiry approach was chosen to study the use of an online parent support groups by the parents of children with autism in Turkey. For qualitative analysis, Spradley's (1979, 1980) Developmental Research Sequence was selected to analyze archived email messages and parent interviews. Additionally, social network analysis and descriptive quantitative data analysis were employed to investigate participant and network characteristics of the oPSG. This chapter begins with the rationale for selecting qualitative methodology as a research approach. In the following sections, research design, data collection methods, and the procedures used in data analysis are described in detail. Next, ethical considerations for conducting research are discussed. Finally, procedures to increase the trustworthiness of the data collection and analysis are described.

## *Rationale for Selecting Qualitative Methodology*

Most of the studies on online communities use quantitative methodologies, however, there are some limitations to these studies. Researchers using the quantitative approach in studying online communities and support groups have often attempted to categorize email messages based on preexisting theories and compared member participation and perceived satisfaction in terms of types of support, frequency of support behavior, and various demographical variables (Braithwaite, et al., 1999; Wright, 2000). In categorizing these support messages, researchers have extensively benefited from existing theories and models, including the Social Support Behavior Codes (Cutrona & Suhr, 1992), Weak-tie Network Theory (Adelman, et al., 1987; Granovetter, 1973; 1983), and Buffering Model of Social Support (Dean & Lin's (1977). However, placing email messages into predefined categories may result in loss of detail in the raw data. Furthermore, this type of research only allows researchers to test existing theories, but usually does not allow development of new theories.

Therefore, the qualitative inquiry approach has been selected to study parents' use of online PSGs. As noted by Mann & Stewart (2000), qualitative researchers in online settings can observe naturally occurring discourse without intervening conversations. As an inquiry technique, documentary data analysis of email messages and chat logs were employed in several studies. For example, Denzin (1999) analyzed conversations of online newsgroup members who participated in discussions in a support group for the children and co-dependents of alcoholic individuals. Denzin notes that the language in online interactions is "deliberative, stilted, formal, and clearly marked in sentences with commas, exclamation and question marks…" and thus this allows a reader to "carefully study printed words of the speaker" (p. 114).

It has been noted that archives of electronic communication can be analyzed in a similar way as conventional documents, such as letters, diaries, and other textual material (Sixsmith & Murray, 2001). Recently, personal narratives of parents of children with autism on the Internet have become a research interest (Fleischmann, 2004, 2005). Fleischmann (2004) analyzed 20 web sites created by the parents of children with autistic spectrum disorders and concluded that the primary reason for these parents to create web sites was to help other parents who are in similar circumstances. Fleischmann notes that textual analysis of the narratives on personal web sites provides a way of understanding parents' experiences and feelings.

In selecting research methodology, I adopted Spradley’s (1979, 1980) Developmental Research Sequence (DRS) method. According to Spradley, DRS as a method of data collection and analysis, allows the study of a community or a group of people and understand the meaning behind their actions and speech. DRS approach assumes that cultural groups or individuals organize their knowledge based on the culturally designated similarities and differences (Parfitt, 1996).

Spradley (1979) proposes two parallel methods of data collection: participant observation and ethnographic interview. These two methods can be used separately or together. Spradley describes three types of observation: descriptive, focused, and selected participant observation. In descriptive observation the researcher aims to describe what a typical research setting looks like or the common features of a typical research setting. Focused observation allows the researcher to focus on one or several aspects of the research setting. Using structural questions, the researcher tries to discover categories that make up a cultural scene. In selected observation, the researcher focuses on extremely narrow, small details and looks for differences among these specific cultural categories. In this study, I first started with descriptive participant observation to describe the typical research setting, the online parent group in the context of this study. Descriptive observation allowed me to find out about the demographical characteristics of the parents as well as the network characteristics and number and frequency of the email messages. Second, by doing focused observation, I was able to investigate how parents use the oPSG, the types of support they receive and the perceived advantages of the oPSG.

In alignment with different types of participant observation, Spradley proposes three levels of ethnographic interview and interview questions: descriptive, structural, and contrast questions. In the first level, descriptive interview, the researcher asks participants to describe a typical day or setting. Once enough data is collected by descriptive questions, the researcher starts asking structural questions and discovers how participants organize their knowledge. Next, by asking contrast questions the researcher tries to find out the dimensions of meaning which participants use to distinguish various concepts and objects in their typical setting. During the interviews, I used all of the above mentioned types of interview questions. Typically, interviews started with descriptive questions, and then moved on to more structural questions to find out how parents use oPSG to receive support. Finally, contrast questions allowed me to fully understand the dimension of various concepts and actions.

## *Research Design*

### *Setting*

The oPSG was founded in December 1999 by a parent who has a child with autism. The group operates asynchronously. Members can send their message to the oPSG's email address and this email is automatically distributed to all members without any intervention or approval of a moderator. Members then can respond to these messages and participate in discussions. Messages are also archived and can be accessed by any member using the group's web interface. In addition, Yahoogroups! service allows members to upload documents and photos to the oPSG web address. These files can be viewed by other members. Another feature is the database. Members have created a table where specific information such as child's age, diagnosis, medicines used, therapies received, etc. can be entered. The oPSG has a moderator who helps new members with their questions, creates and maintains databases, and deletes archived messages when necessary. Although the language for the oPSG is Turkish, some email messages in English were observed. There were some parents with different levels of fluency in English (or other languages).

### *Participants*

Participants of the research consisted of 140 current and past members of an online parent support group in Turkey. The number of the support group members had increased gradually over time. At the time of data collection and analysis (June, 2005), the PSG had 86 members. The collected data also included the messages of 54 past members.

Based on their contribution to the PSG, group members can be classified into two major categories and six groups (Table 3): 1) Active participants. This group of participants actively participated in group discussions, and sought and offered help and information regarding specific questions. Active participants include: (a) Parents and relatives of children with autism (*n* = 69). This group consisted of 33 mothers, 25 fathers and one parent with no gender information, and 10 relatives (5 females, 4 males, and 1 relative with no gender information). Most of the parents were highly educated, had white collar jobs and were living in big cities and urban areas. Of the parents, almost 30 percent (*n* = 20) lived in Istanbul and the rest lived in major Turkish cities. The mean length of membership for parents was almost three years (*M* = 35.02 months, *SD* = 16.26 months) ranging from 1 to 68 months. Sixty one parents and relatives within the active participants group comprised 49.29% of the group members.

Table 3

*Online parent support group members (N = 140).*

| | Current | Past | Total |
|---|---|---|---|
| 1. Active Participants | | | |
| Parents | 35 | 24 | 59 |
| Relatives | 4 | 6 | 10 |
| Professionals | 16 | 2 | 18 |
| Volunteers | 3 | 1 | 4 |
| 2. Inactive Participants | | | |
| One-time participants | 3 | 7 | 10 |
| No information | 25 | 14 | 39 |
| TOTAL | 86 | 54 | 140 |

(b) Professionals and volunteers. In addition to the parents and relatives, other participants of the PSG included professionals and volunteers. This group of members consisted of 17 professionals (11 females and 6 males) who worked with children with autism or other developmental disorders as psychologists, therapists, counseling center directors, etc. However, professionals in this PSG did not act as moderators or hold special expert status, but participated like regular members, making equal contribution to the discussions. In addition, there were four (2 males and 2 females) volunteers consisting of musicians and artists who wanted to contribute to the promotion of group activities.

2) Inactive participants. (a) One-time only contributors (*n* = 10). These members were characterized by their short-term membership or one-time only participation. They subscribed to the support group email distribution list, asked one or more questions and then left the group or stayed without making a contribution. Although these participants sought answers to certain questions, they usually did not introduce themselves in detail. (d) No participation. These members were the silent members of the group (*n* = 39). Although they were listed as members of the group, they never participated in conversations and never introduced themselves. Therefore, there is no demographic data about these members. Analyses of the data showed that some parents were using more than one email account. These parents were using their work or commercial Internet service provider account as a primary email address and another email account (mostly free web-based services such as Yahoo!, Hotmail, or Gmail) for back-up purposes. Because the number of inactive participants (*n* = 39) was gathered by the number of email addresses with no postings, there is a chance that some of these email addresses belonged to the members in active participants category. Also, it is possible that after spending a certain amount of time, inactive participants might have gotten involved in group discussions. For example, some of the parents expressed that they waited for a long time before posting any message to the oPSG.

### *Data Collection*

Data collection consisted of two steps. In the first step, email messages sent by the members of the oPSG were collected from the online archive. In the second step, the parent members of the oPSG were interviewed via telephone.

*PSG E-mail Archive*

Email messages posted to an online PSG over a five-year period were collected and examined in this study. From the time the group was founded in December 1999 until June 2005, 1,529 email messages had been delivered to its members. All of these messages were collected from the oPSG's online archive, using its web interface. Messages then were checked for accuracy. For example, during the preliminary analyses, about 49 messages were determined to be ineligible for data analysis. These messages included empty emails and messages that contained advertisement, spam, and/or hoaxes. The remaining 1,480 messages were then imported into a qualitative data analysis software—Atlas.ti.

*Interview with the Parents*

In order to better understand participation in oPSGs and elaborate on questions that were not easily explained by email data analysis, five parents were interviewed. The interviews were conducted in a semi-structured format (Merriam, 1998). In this format, less-structured open-ended questions guide the interview and allow respondents to express themselves in their unique way, and thus allowing the researcher to explore ideas and issues as they emerge.

Carspecken (1996) notes that through interviewing, researchers "democratize the research process" and "give the participants a voice in the research process" (p. 155). He also adds that an ideal interview should be semi-structured and allow for maximum flexibility. Carspecken suggests using lead-off questions to open-up a topic of domain and then using follow-up questions. Lead-off questions should be designed concretely with no abstract meaning. Based on Spradley's (1979) suggestions, Carspecken recommends asking a “typical day” question or a “grand tour” question followed by one of the possible follow-up questions.

In order to recruit interview participants, all parent members of the oPSG were invited to participate in the study via email. Rather than sending one bulk email to all group members, I chose to send an individualized email to each parent. This email message (see Appendix A) explained the purpose of the research and addressed their questions and concerns regarding the procedures of the study. Informed consent forms and a copy of sample interview questions were also sent as an attachment.

Overall, five parents (three mothers and two fathers) volunteered to be interviewed via telephone. After participants agreed to be interviewed, I scheduled a telephone interview. Interview questions are provided in Appendix B. All interview questions were translated into Turkish by the researcher and checked by two other doctoral students—who are currently doctoral students and native Turkish speakers. Turkish versions of the interview questions are provided in Appendix C. Interviews lasted approximately 30-45 minutes. Telephone interviews were audio taped and transcribed for analysis. Transcribed interviews were then imported into Atlas.ti software for qualitative data analysis.

During the recruitment of the interview participants, I experienced some difficulties. This was partly because of a recent incident parents had experienced prior to my call for interview participation. From my second interview participant, I learned that two weeks prior to my call, an economist–whom the parents call a charlatan–had subscribed to the oPSG, claimed that he had found a statistical model that determines the relationship between the congenital problems and developmental disabilities and the time a baby is conceived. He was interested in parents' thoughts and their personal stories about the "model." This was not welcomed by the parents. In fact many of them got angered by such a request and expressed that the economist's claims have no scientific basis and should be discussed elsewhere. When parents researched about the economist they found out that in his web site he was trying to sell software that tells the parents "the best time" to conceive a baby. In later e-mail exchanges, parents were even insulted by the intruder. Eventually, after several messages of disapproval, the intruder was banned from the oPSG. This incidence shows that parents of children with disabilities could be targets of researchers, professionals, and individuals with commercial interests. This was an unfortunate incident that happened before my call for participation in the study and made the interview participant recruitment process very difficult.

## *Data Analysis*

Data analysis consists of three sections: descriptive data analysis, social network analysis, and qualitative data analysis. Descriptive data analysis aimed to explore demographical characteristics of the oPSG members. Social network analysis aimed to analyze network characteristics and message sending patterns among oPSG members, and examine network changes over time. Qualitative data analysis was employed to understand the parents' experiences and feelings, and meaning of their actions.

### *Descriptive Data Analysis*

Descriptive data analysis was conducted to explore the demographical characteristics of the oPSG members. Email data were analyzed in a chronological manner, from the first to the last email. Each email message was analyzed and coded by the author. As each message was analyzed two groups of information were abstracted: 1) information about the oPSG members, such as gender, education, occupation, and other available demographic information. For example, when available, names of the participants were used to gather gender information, 2) information about the child such as gender, age, diagnosis, age of diagnosis, and special education history. This information helped me understand who the oPSG parents are, where they participate from, and how frequently they email to oPSG. Below are the definitions of the procedures used in quantifying participant demographics.

Gender information was gathered from either parents' self reports (e.g., "I am a mother of a 3-year old child with autism") or from their names. Duration of the oPSG membership refers to the difference between the date of data collection (April 2005) and the date participant subscribed to the online PSG. Subscription data for each member was gathered from the oPSG's web interface at Yahoogroups!. Although it is possible for a participant to unsubscribe and subscribe again with a different email address, small sample size allowed me to notice such changes and combine different email addresses under the most current one. Age information for children was gathered from participants' self reports and was adjusted for the time of data collection. For example, if a member states "I have a 3-year old son…" in 2003, the child's age was adjusted to 5 years.

### *Social Network Analysis*

In order to analyze the network characteristics and message sending patterns among network members, I employed social network analysis (SNA). SNA allows one to analyze the relationships among network members, identifying social structures and message sending patterns (Wasserman & Faust, 1994). In the following paragraphs I will first define major concepts and measures in SNA, and then I will provide the procedures to conduct SNA.

In order to conduct SNA, the first step is to create a matrix showing the relations between network members. These relations presented by a matrix are called as *sociomatrix* or *adjacency matrix* (Wasserman & Faust, 1994). According to social network theory a message from one network member (A) to another network member (B) is considered as a *relation* (also called as tie or link). Relations can be *directional* or *unidirectional*. In directional relations both the origin and destination of the message are represented. A directional relation could be shown as (A<-->B). In graphical representation, a directional relation is displayed as a line with arrowheads between two members. A sample graphic displaying the directional relations is shown in Figure 1.

On the other hand, unidirectional relations (A--B) do not give information about the origin and destination of the messages. Unidirectional relations only tell us whether there is a relation between two members or not. In unidirectional relations all messages could be coming from one person to another or both of them could be sending messages to each other. Unidirectional relations are illustrated by a line between two members that has no arrowhead. Since message origin and destination are concerns of the current study, I decided to create a matrix that shows directional relations.

Relations can be also *valued* or *dichotomous* (Wasserman & Faust, 1994). Valued relations show the strength or the frequency of the tie between two members. For example, in Table 4 that shows valued relations, it can be seen that member A has sent five messages to member B. On the other hand dichotomous relations show whether there is a relation between two members or not. In this case, values in the matrix are replaced by 1 (Yes) and if there is no relation 0 (No) value is assigned. While creating the matrix, I used message frequency values to show the relations and directions among members. That is, the numbers show the frequency of email exchanges between members. Table 4 shows a sample matrix that uses frequency values to show the strength of the directional relations between members. Figure 1 provides a graphical display of the matrix data in Table 4.

Table 4.

*Sample matrix showing directional relations.*

| | Pub. | A | B | C | D |
|---|---|---|---|---|---|
| Pub. | - | 0 | 0 | 0 | 0 |
| A | 5 | - | 5 | 1 | 0 |
| B | 4 | 2 | - | 0 | 0 |
| C | 3 | 4 | 0 | - | 0 |
| D | 0 | 3 | 2 | 0 | - |

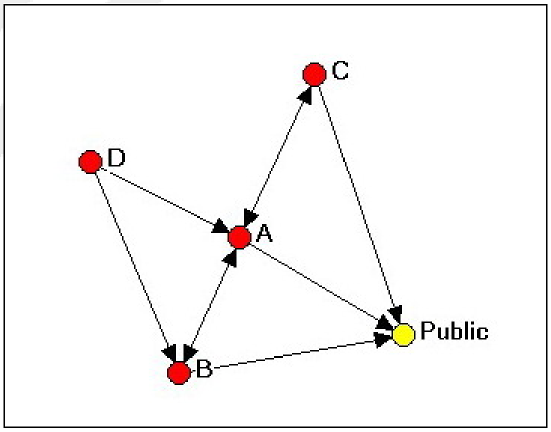


*Figure 1.* Graphical display of a matrix

Although there are many concepts and measures in SNA for the purpose of this study I will briefly review two commonly used measures: centrality and k-core. The first commonly used measure in SNA is *centrality*. Centrality measures give the most important actors within a network (Everett & Borgatti, 2005). Although there are different types of centrality measures in SNA, in the current study I used degree centrality. Degree centrality refers to the degree to which a network member is connected to the other members in the network. In a sociomatrix representing directional relations, *outdegree* is calculated as the row sum for the node (member). For example, in Figure 1, D is an example of outdegree. Note that member D has sent messages to members A and B, but has not received any message from group members. Similarly, *indegree* is computed by the column sum of the node. That is, outdegree is the sum of all messages sent to the other members of the network and indegree is the sum of all messages sent to the node by other network members. If a node has a zero indegree and non-zero outdegree this node could be called *transmitter*, whereas if a node has a non-zero indegree and zero outdegree this node is called *receiver*. Similarly, if both indegree and outdegree equals to zero these nodes are called *isolated* (Wasserman & Faust, 1994). I used degree centrality measure to determine where the interview participants stand in the oPSG in relation to other members.

The second SNA measure that I used in this study is k-core. K-core refers to "a set of nodes that are more closely connected to one another than they are to nodes in other k-cores" (Hanneman & Riddle, 2005). K-core values show network members who are connected to some number (k) of the members of the bigger network. In other words, k-core values display network members who belong to the same cliques or subgroups of the bigger network. Using k-core values it is possible to graphically show members from different subgroups.

I entered all of the matrix data in MS Excel and created a matrix similar to the one in Table 4. For each quarter of the year I used a separate sheet in the Excel document. For messages that were sent to directly all members rather than a specific group member I created another a column in the matrix titled "Public" and entered these messages under "Public" column. Overall, the matrix contains information about 101 oPSG members. Then I used UCINET software to import the matrix data from MS Excel file format for further analysis. UCINET (Borgatti, Everett, & Freeman, 2002) and NetDraw (Borgatti, 2002) software were used to conduct social network analysis and create network diagrams. Both UCINET and NetDraw are publicly available from the authors' web site. UCINET is a widely used software that computes network measures. NetDraw software uses UCINET data files to create network graphics.

### *Qualitative Data Analysis*

In the qualitative data analysis, I used Spradley's (1979, 1980) Developmental Research Sequence (DRS) method. In DRS Spradley suggests 12 steps to conduct an ethnographic inquiry. Each step in the sequence has specific guidelines for recruiting the participants, and collecting and analyzing the data. I particularly focused on the steps that are related to data analysis. In order to conduct data analysis, Spradley suggests four major tasks: a) domain analysis, b) taxonomic analysis, c) componential analysis, d) cultural theme analysis.

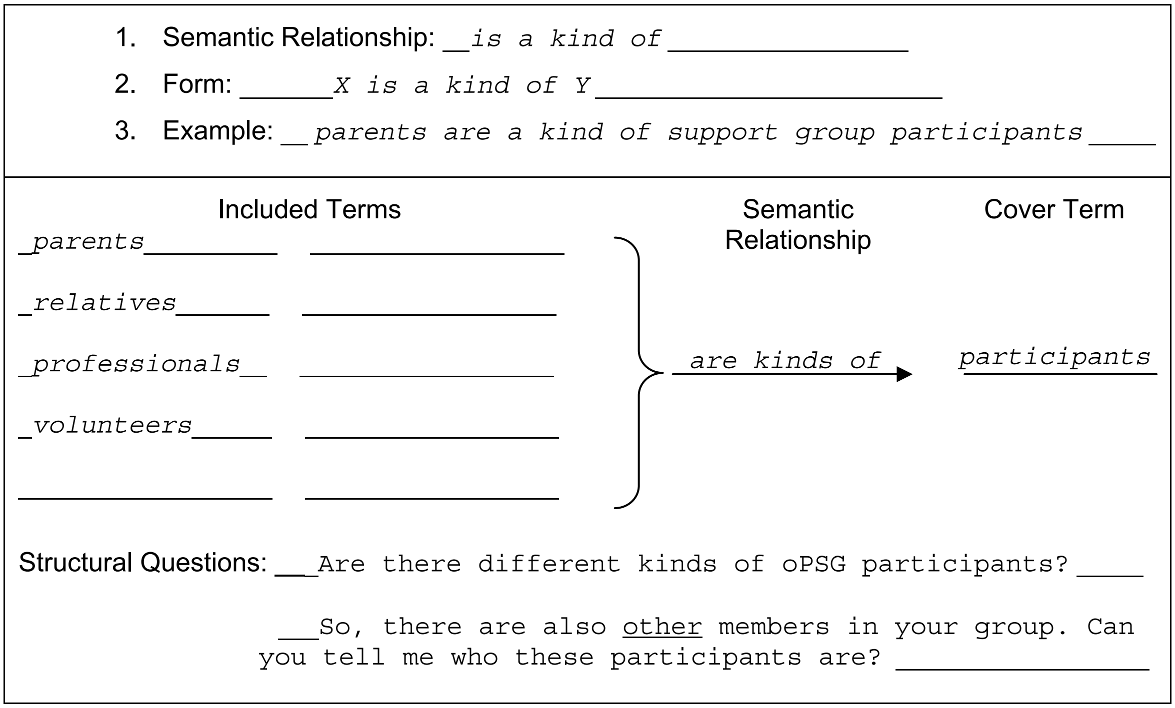
*Domain analysis*. According to Spradley (1979), a domain is "a symbolic category that includes other categories" (p. 100). A domain has three components. The first component, *cover term* refers to names for a category of knowledge. The second component, *included terms*, are terms that belong to the category of knowledge named by the cover term. For example, *support group participant* is a cover term for various types of participants named by included terms such as *parent, uncle, aunt, therapists, psychologist,* etc. The third component, *semantic relationships*, establishes a valid relationship between included terms and cover term. In the above example, "kind of" semantic relationship explains the relationship between parents and a support group participant. Table 5 lists nine universal semantic relationships (Spradley, 1979, p. 111). Through domain analysis an ethnographer searches for cultural categories in the data.

Table 5

*Universal semantic relationships.*

| | |
|---|---|
| 1. Strict inclusion | X is a kind of Y |
| 2. Spatial | X is a place in Y, X is a part of Y |
| 3. Cause-effect | X is a result of Y, X is a cause of Y |
| 4. Rationale | X is a reason for doing Y |
| 5. Location for action | X is a place for doing Y |
| 6. Function | X is used for Y |
| 7. Means-end | X is a way to do Y |
| 8. Sequence | X is a step (stage) in Y |
| 9. Attribution | X is an attribute (characteristic) of Y |

In order to conduct domain analysis, I first read each email message, identified included terms, and coded these terms in Atlas.ti. Since archived messages were in Turkish, all qualitative analyses were conducted in Turkish and only selected quotes were translated into English. Coding was done by selecting the whole sentence or sentences and then assigning a keyword (code) to the selected text. Alternatively, once identifying an included term, using Atlas.ti's search function I looked for other sentences containing the same word. For example, once identified the included term "diet," I searched for other sentences containing the word "diet" and coded these words accordingly. Although using search and code method speeds up the coding process and Atlas.ti provides an "auto code" option, this method poses some challenges. First, for many words/terms, parents were using either Turkish or English versions and in some cases they were using incorrect spelling. For this reason, sometimes I used multiple keywords to search for the same code. Second, the word found as a result of a search might not be used in the same context. Because of this possibility, I did not perform auto code option; instead I read all sentences carefully before coding. A more detailed description of the Atlas.ti software and coding procedure is provided in the next section. Next, using these included terms I was able to locate domain names. In selecting domains I particularly focused on domains that are related to my research questions. In the next step, using a domain analysis worksheet (Figure 2) allowed me to visualize the structure of a domain and uncover the semantic relationships between included terms and the cover term. The final step was the creation of structural questions. Structural questions serve different purposes. For



1. Semantic Relationship: *is a kind of*
2. Form: *X is a kind of Y*
3. Example: *parents are a kind of support group participants*

Structural Questions: *Are there different kinds of oPSG participants?*

*So, there are also <u>other</u> members in your group. Can you tell me who these participants are?*

*Figure 2.* Domain analysis worksheet (modified from Spradley, 1979, p. 113).

example, the first question in Figure 2 helps verifying the domain. The second question however is a substitution frame question. In this example the respondent is expected to substitute <u>other</u> with the names of different kinds of participants.

*Taxonomic analysis*. After domain analysis is completed, Spradley suggests demonstrating the way in which cultural categories are organized within a domain. For this purpose, using semantic relationships, the researcher develops a taxonomy of terms associated with the cover term. Thus, taxonomic analysis provides an in-depth study of the domain. Spradley notes that ethnographers either prefer to do surface analyses of many domains or in-depth analyses of a limited number of domains. Theoretical interest or strategic ethnography might be a reason for selecting several domains to study in-depth. In my data analyses, I focused on particular domains to get detailed information. Figure 3 below demonstrates the taxonomy of the kinds of support group participants. Spradley notes that a domain and the taxonomy associated with it displays a single semantic relationship. In this example, strict inclusion semantic relationship (X is a kind of Y) associates "kinds of participants" domain with taxonomical categories.

| | | |
|---|---|---|
| Kinds of Support Group Participants | One-time participants | |
| | Volunteers | |
| | Professionals | Therapists |
| | | Doctors |
| | | Psychologists |
| | Relatives | Siblings |
| | | Aunts/uncles |
| | Parents | Mothers |
| | | Fathers |

*Figure 3.* Domain: Kinds of support group participants

*Componential analysis*. Each domain has a set of attributes that distinguishes the members of a domain from each other. Componential analysis is the “systematic search for the attributes (components of meaning) associated with cultural symbols” (p. 174). Through searching for contrasts and entering this information into a paradigm worksheet, the researcher explores the attributes of terms within each category. Componential analysis provides the researcher the means by which to clarify the relationships between terms and to identify distinguishing attributes (Parfitt, 1996). Figure 4 illustrates the dimension of contrasts among the members of the oPSG.

*Cultural theme analysis*. In the final step of data analysis Spradley (1979) suggests the discovery of cultural themes from the data. Cultural themes are recurrent activities that are made up of the members of that culture and appear tacitly or explicitly. Spradley suggests various strategies to conduct a cultural theme analysis, such as cultural immersion, making a cultural inventory, making a componential analysis of folk domains, searching for similarities among dimensions of contrast, identifying organizing domains, making a schematic diagram of the cultural scene, searching for universal themes, and making comparisons with similar cultural scenes. Some of these suggestions, such as cultural immersion, do not apply to the goals of the current study, and even if they do, they raise some methodological and ethical challenges. For example, “cultural immersion,” requires becoming a member of the group, living and acting like them, and thus gives an opportunity to learn more about their culture. In online research, this translates to becoming a member of the group and exchanging messages with other group members. While technically and theoretically this is possible in online research, in this study my goal was not to become a member of the group, nor interact with study participants in the online setting. Even though there were non-parent members in the oPSG, having known the presence of a researcher would have influence on parents' interactions or make them uncomfortable. In this study, cultural theme analyses were made using the following strategies: making a cultural inventory, making a componential analysis of folk domains, searching for similarities among dimensions of contrast, identifying organizing domains.

| | Dimensions of Contrast | | | |
|---|---|---|---|---|
| Contrast Set | 1 | 2 | 3 | 4 |
| Parents | Yes | Yes | Yes | Yes |
| Relatives | Yes | Yes | Yes | - |
| Professionals | No | No | Yes | Yes |
| Volunteers | No | No | Yes | - |
| One-time Participants | No | Yes | No | No |

1. Moderator Role
    - 1.a. Yes
    - 1.b. No
2. Request help
    - 2.a. Yes
    - 2.b. No
3. Offer help
    - 3.a. Yes
    - 3.b. No
4. Attend face-to-face meetings
    - 4.a. Yes
    - 4.b. No
    - 4.c. No information available

*Figure 4. Paradigm worksheet: Kinds of participants.*

*Qualitative Data Analysis Software—Atlas.ti*

The qualitative data analysis software, Atlas.ti, was used to organize and analyze the data. Atlas.ti allows the analysis of text, image, audio, and video data and build new theories based on these analyses. Atlas.ti was developed with grounded theory in mind (Legeiwe, 1998). In order to analyze qualitative data the first step is to store these data in an electronic environment so that they can be imported into Atlas.ti. Just like many software, Atlas.ti has its own terminology. The first concept is *hermeneutic unit* (HU), which is described as an electronic container that collects and organizes all data and related information, such as codes, memos, and diagrams of a specific project. After creating an HU, data needs to be imported into Atlas.ti. In this study, all email messages were stored in a Word file and then this Word file was imported into Atlas.ti. The interface of Atlas.ti is similar to common word processing applications. The textual data is displayed on the left side of the main window (see Appendix D). From this window users can select relevant text passages and assign codes and memos to this selected text. *Codes* can be considered as keywords that are attached to quotations on the text. Codes are usually short and one code may refer to many quotations. A *memo*, on the other hand, is relatively longer than codes and may point to quotations, codes, and other memos. As can be seen in Appendix D, codes and memos are displayed on the right side of the main window, next to the textual data. By clicking on a specific code name, the program allows the researcher to retrieve all quotations attached to that code and make comparisons, print or copy-paste quotations to other word processing programs (Legeiwe, 1998). Atlas.ti software enables researchers to easily assign codes to higher-level categories and thus speeds up the process of analyzing textual data.

### *Ethical Considerations*

A number of measures were implemented to protect the identity and the rights of the study participants. First, pseudonyms were used where needed. Second, all identifying details were removed from the text or changed in the quotations. For example, information such as a participant's occupation, name of workplace, or city may reveal a participant's identity. Third, the research proposal was reviewed by the Indiana University Bloomington Campus Committee for the Protection of Human Subjects (HSC). Interview participants received an informed consent form (Appendix E) via email, which was approved by the HSC and were asked to reply back via email in order to ensure that they fully understood the purpose of the research and their rights. Qualitative researchers caution that researcher's presence in the research setting may pose potential risks to the validity and reliability of the results (Merriam, 1998). Furthermore, by being intrusive, researchers may invade participants' privacy and disrupt their lives.

## *Ensuring Trustworthiness*

Trustworthiness of the data collection and analysis was ensured by triangulation of the data sources and peer debriefing.

### *Triangulation*

In order to enhance validity of the results, researchers suggest using multiple investigators, multiple sources of data, or multiple methods to confirm the findings (Carspecken, 1996; Merriam, 1998). In order to triangulate the data I collected data from multiple sources. First, I collected data from archived email messages that were naturally occurring narratives among the members of the oPSG. Parents' email messages also provided detailed information about themselves and their children. For most parents, demographical information, such as occupation, gender, marital status, nature of child's disability, and number of siblings were available through the messages posted to the oPSG. Also available information was the frequency of email messages by each member. Second, I collected data using semi-structured in-depth interviews to gain insight on participation in oPSGs. These interviews provided rich data that were not available through archived email messages.

### *Peer Debriefing*

Asking colleagues or peers to comment on research notes and findings is also recommended to enhance validity of the results (Carspecken, 1996; Merriam, 1998). For this purpose, I shared my findings and notes (both email data and interviews) with two colleagues who are currently doctoral students in education and native speakers of Turkish. The first colleague has a background in psychology, early childhood and special education and is familiar with qualitative research methodologies. The second colleague has a background in education and instructional systems technology and is familiar with the research in online communities and qualitative analysis of online communication.

Peer debriefing was conducted in two steps. First, after identifying included terms and completing coding procedure for both email and interview data analysis, I shared my findings with two peer debriefers. Based upon peer debriefers' suggestions I have made several changes. Later, I conducted taxonomic analysis, componential analysis, and cultural theme analysis. After all qualitative data analyses completed, I shared my findings for final suggestions and made revisions based on discussions with peer debriefers. I believe peer debriefing enabled me to receive valuable feedback and improved the quality of data analysis.

### *Summary*

This chapter provided a rational for selecting qualitative inquiry as the main research methodology. Participants included members of an online support group for the parents of children with autism in Turkey. Data collection methods included collection of archived email messages and parent interviews. Archived email messages and parent interviews were analyzed using Spradleys' (1979, 1980) Developmental Research Sequence. In addition, participant and network characteristics of the oPSG were explored using social network analysis and descriptive quantitative data analysis. Finally, in order to ensure the trustworthiness of the data collection and analysis triangulation of the data sources and peer debriefing was performed.

# CHAPTER 4

# RESULTS

This chapter presents results from analyses of both archived email messages and interviews with the members of the oPSG. As described in the previous chapter, in the first step of the study email messages sent to an online parent support group over the past five years were collected from the group's web address. In addition to the email messages, collected data also included information about members' gender, group status, duration of membership, and number of messages. In the second step, five parents of the oPSG were interviewed via telephone. Data analysis included descriptive analysis of the email data, social network analysis, and qualitative analysis of the messages and parent interviews. This chapter is divided into five sections, each referring to a particular research question. In each section first I present an analysis of email messages, and then an analysis of interviews.

## Member and Network Characteristics of the Online Parent Support Group

### *Results from Analyses of Email Messages*

The online parent support group included 59 parents. Most of the parents in this group provided information about themselves, such as the city in which they live, where they work, and what kind of steps they have taken since their child was diagnosed with autism. Analyses showed that most of the parents were living in urban areas, working at white-collar jobs, and had received higher levels of education. Only two parents reported that they were single parents. All of the parents in the oPSG had a child diagnosed with autism, pervasive developmental disorder, or a child that was suspected of having autism. The ages of the children at the time of data collection ranged from 4.5 years to 25 years.

*Reasons for Participating in Support Group*

Participants reported different reasons for joining this parent support group. For parents, reasons for joining were mostly to get informational and emotional support, and to create a network of families of children with autism.

> Hello, my name is [ ], I have 6-year old twin sons. One of my sons is autistic. His name is [ ]. He was diagnosed at the age of 2½. … I learned about this group through a link from [organizational web site]. I would like to be heard by others, learn from your experiences, and to help other families as much as I can. (father, B10)[*]

> It was kind of hard, but finally I have succeeded [in subscribing to this group]. I learned about this group from [another member's name]. Because of my not-so-good computer skills I was not able to subscribe for a while. And also, because of my son's busy schedule I cannot spend much time using computer. I am still not sure if this message is going to the right group. (mother, 8E8)

> I have found your address from Mr. Deniz's [a therapist] web site. (mother, 8F3)

Professionals in the oPSG indicated that they wanted to learn more from the families. Some of them wanted to inform parents about new developments in the field. Analyses of the messages revealed that professionals were mostly added or invited to the

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[*] The first information in the parentheses reflects the member's affiliation with the group (i.e. parent, relative, professional, or volunteer). The number reflects the unique message number.

support group by parent members. Professionals provided informational support and made referrals to other professionals. Relatives and volunteers, however, wanted to help both their family members with autism as well as the children's parents.

> …I just joined the group. … My elder sister has a 6-year old son with autism. I am here to help her. Because sometimes, I think she does things that are not appropriate [for her child] and that makes me sad. I don't want to hurt her feelings, but want to make sure that she gets the scientific information. Instead of just saying "don't do that" or "it is wrong to do that" I want to show her the right way through other people's writings (about their experiences). … (relative, 87E)

> I have a 23-year-old sister. I found this group by chance and decided to become a member because of the fact that before this, I had no chance to speak to anyone with an autistic relative. [They are] very different children and it must be very hard to live with them. At least it is true for my sister. (sister, CF8)

> I know a family with an autistic kid who wanted my help. … They live in a village in [province name]. What should they do? They want their child to get proper education. ... I would appreciate your helpful comments on this. (volunteer, B4E)

### *Characteristics of the Children*

In their discussions, members of the oPSG talked about 61 children who were diagnosed with autism and related disorders. This number includes both current and past members' children. Often times, parents provided detailed information about their children. It was evident that many parent members knew the names and other specific information about the children of other group members. At the time of data collection, children's age ranged between 4 years and 25 years with an average of 10.65 years (*SD* = 4.71 years). Of these children, 37 were male and 9 were female. For the remaining 15 children, no gender information was provided by the parents. In terms of diagnosis, 40 of the children were diagnosed with autism or pervasive developmental disorder (PDD), seven children were diagnosed with autistic-like behavior, PDD, Asperger's syndrome, or developmental delay, and for the remaining 14 children no diagnosis information was available.

### *Moderator Role*

Within the group, the only individuals with certain power were the group's founder and a frequent poster, who later became one of the moderators of the group. In addition there was one more moderator, who was dealing with the technical aspects of the group. These individuals, called as owner/moderator in Yahoogroups!, could add/invite new members, remove or ban existing members, give regular members certain privileges such as uploading files (e.g., Word documents, photographs), and create group database or polls. In addition, moderators introduced new members to the group. Below is an example of a moderator message that was sent during the first year of the oPSG:

> Hello everyone,
>
> I guess you already noticed, our group is still small but growing slowly. We have a new member whose email address starts with [ ]. He sent an email and wanted to receive information about autism, so I thought it would be better if I subscribe him as a member. I don't know what exactly he needs. I hope his membership will be good for our group. Also, among the new members [ ] is my husband. It

> was kind of hard to forward every email to him, so finally I subscribed him as a member of the group. Our last member [ ] is my husband’s friend from his old workplace. He is also dedicated to try new therapy techniques. I guess, he will inform us about these soon. (mother, 7FA)

Additionally, in times of disputes and misunderstandings, moderators took responsibility and tried to help others by providing new information or pointing out to misunderstood information.

> I think, there is a kind of misunderstanding here. In this newspaper article, the author talks about gluten-free flour, not gluten-free bread. Yes, it is true that gluten-free bread has been produced for a long time. But its flour is that is imported. … (mother, A02)

### *Number of Messages*

The number of messages sent to the oPSG changed dramatically over the five-year period. As can be seen in Figure 5, during the first 3 years, the number of messages increased as did the number of memberships. The number of messages and help requests seemed to coincide with seasonal changes. For example, during summer months, messages were at a minimal level. In contrast, before or during the Fall semester, there was an influx in the number of messages. Recruitment of new members also decreased from 2004 on. In 2004, the oPSG was able to recruit only five members and in the first half of 2005, only two new members joined the group.

Overall, of the 1,480 messages sent by the members of the oPSG, 1,221 were sent by parents, accounting for the 82.50% of the total number of messages (Table 6).

Professional members contributed to almost 14% of the email messages. Professionals were the biggest source of non-parent messages.

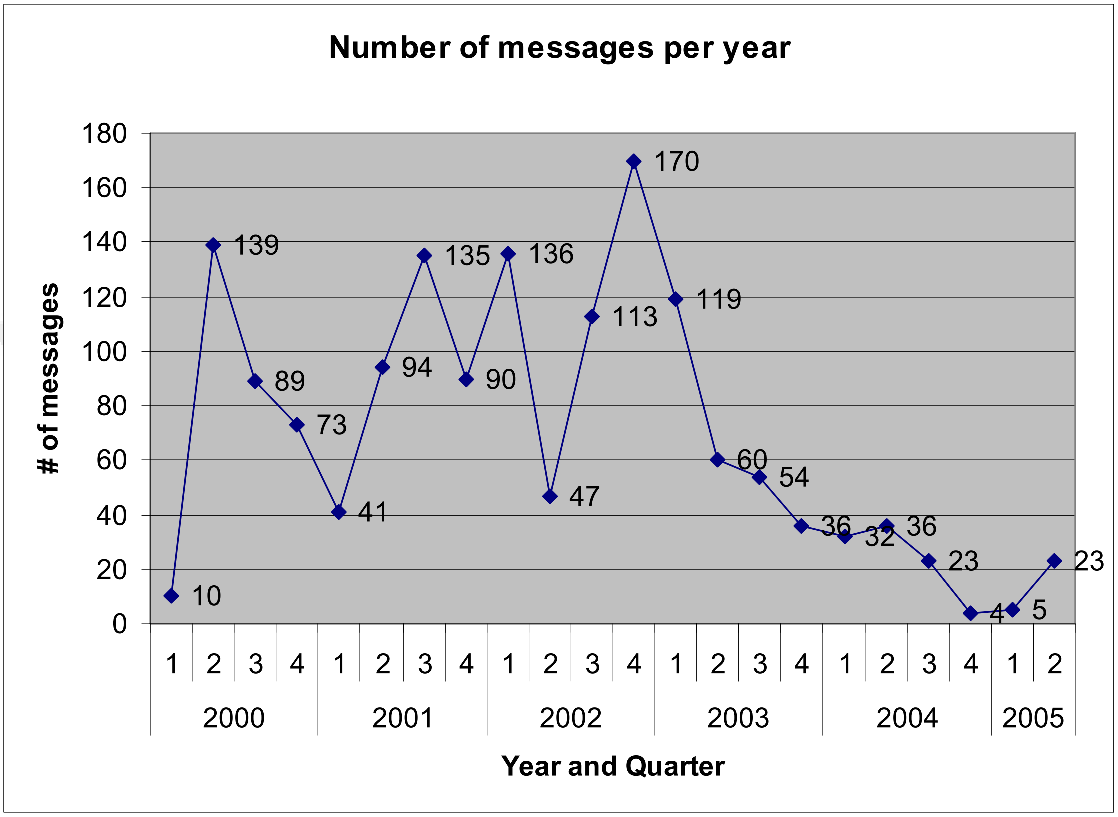


*Figure 5.* Number of messages per year and quarter between January 2000 and July 2005.

Starting from the second half of 2003 and in 2004, oPSG participation decreased sharply. Two reasons appear to be contributing to this decrease in participation. First, the launch of a similar online parent support group with a more precise discussion agenda (Applied Behavior Analysis, ABA) attracted some existing members to become a member of this new support group—which also requires moderator's/owner's approval to become a member. Although most of these parents maintained their membership in both online support groups, they tended to contribute more to the new oPSG. Second, starting from the second quarter of 2003, a number of new members, especially professionals

Table 6

*Number of messages sent by participants*

| Participant Status | Number of messages | Percentage |
|---|---|---|
| Parents | 1221 | 82.50 |
| Relatives | 31 | 2.09 |
| Professionals | 204 | 13.78 |
| Volunteers | 14 | 0.95 |
| One-time Participants | 10 | 0.68 |
| Total | 1480 | 100.00 |

joined the oPSG. Especially, on a couple of occasions these new professional members seemed to dominate discussions, “hijacked” discussion threads, and sometimes discussed among themselves. For example, while discussing hyperactivity symptoms in children with autism, discussions moved to the topic of ADHD and Ritalin use. Then one of the parents mentioned the name of an academic who is a well-known person known as a child/parent advocate. Later, some of the professionals in the group started arguing that the advocate should not be taken “seriously” because his specialization area is social psychology. Others added that he is a member of anti-psychiatry movement. Later, professionals stated discussing among themselves, whether a social psychologist is eligible to comment on this topic or not. Eventually, when discussions went on a personal level, the group moderator had to ask one of the professionals, to be more specific and offer reasons her beliefs.

*Network Characteristics and Change over Time*

First, in order to find out the most prominent members of the oPSG, degree centrality measures were computed. These measures helped me to not only identify the most important members, but also locate the interview participants in the group based on their contributions. As discussed in the Methodology chapter, there are two degree centrality measures: outdegree refers to all messages sent to the other members and indegree refers to all messages received from the other members. To determine indegree and outdegree measures Freeman Degree was computed using SNA software UCINET (Borgatti, et al., 2002). Table 7 displays top ten group members based on their indegree and outdegree scores. An interesting finding is that in addition to four mothers and four fathers, there were two professionals among the top 10 active members. Of these professionals, the male is a therapist and the female is a college professor. Except one parent, the rest of the interview participants were also among the top 10 group. The fifth interview participant, which is at the 46th rank in the list, is also shown in the table.

The centrality measures identify that most of the parents are both central (outdegree) and prestigious (indegree) in the group. Parent #1, Serpil, a mother and the moderator of the group, is the most central and prestigious member in the group. This is not surprising given the fact that she is the group's moderator. Parent #3, Yesim, is an example of a central (outdegree) group member. She has high outdegree and lower indegree scores. On the other hand, father #9, Aziz, and mother #10, Burcu are more prestigious, meaning that they receive more messages than they send.

In order to graphically present the relations (ties) among the members of the oPSG network, I created a series of graphs. In these graphs, my purpose was to display

Table 7

*Centrality Measures of the oPSG.*

| | Outdegree | Indegree | Demographics |
|---|---|---|---|
| Top Ten Members* | | | |
| 1. Serpil | 116 | 127 | Mother |
| 2. Alper** | 59 | 43 | Father |
| 3. Yesim** | 53 | 29 | Mother |
| 4. Ahmet | 45 | 48 | Father |
| 5. Aynur | 38 | 22 | Professional, female |
| 6. Selma** | 36 | 27 | Mother |
| 7. Cihan | 31 | 25 | Professional, male |
| 8. Levent** | 29 | 9 | Father |
| 9. Aziz | 28 | 42 | Father |
| 10. Burcu | 20 | 34 | Mother |
| 46. Selin** | 2 | 7 | Mother |
| Sample Statistics | | | |
| Mean | 6.88 | 6.88 | |
| Standard Deviation | 15.63 | 15.25 | |
| Minimum | 0 | 0 | |
| Maximum | 116 | 127 | |

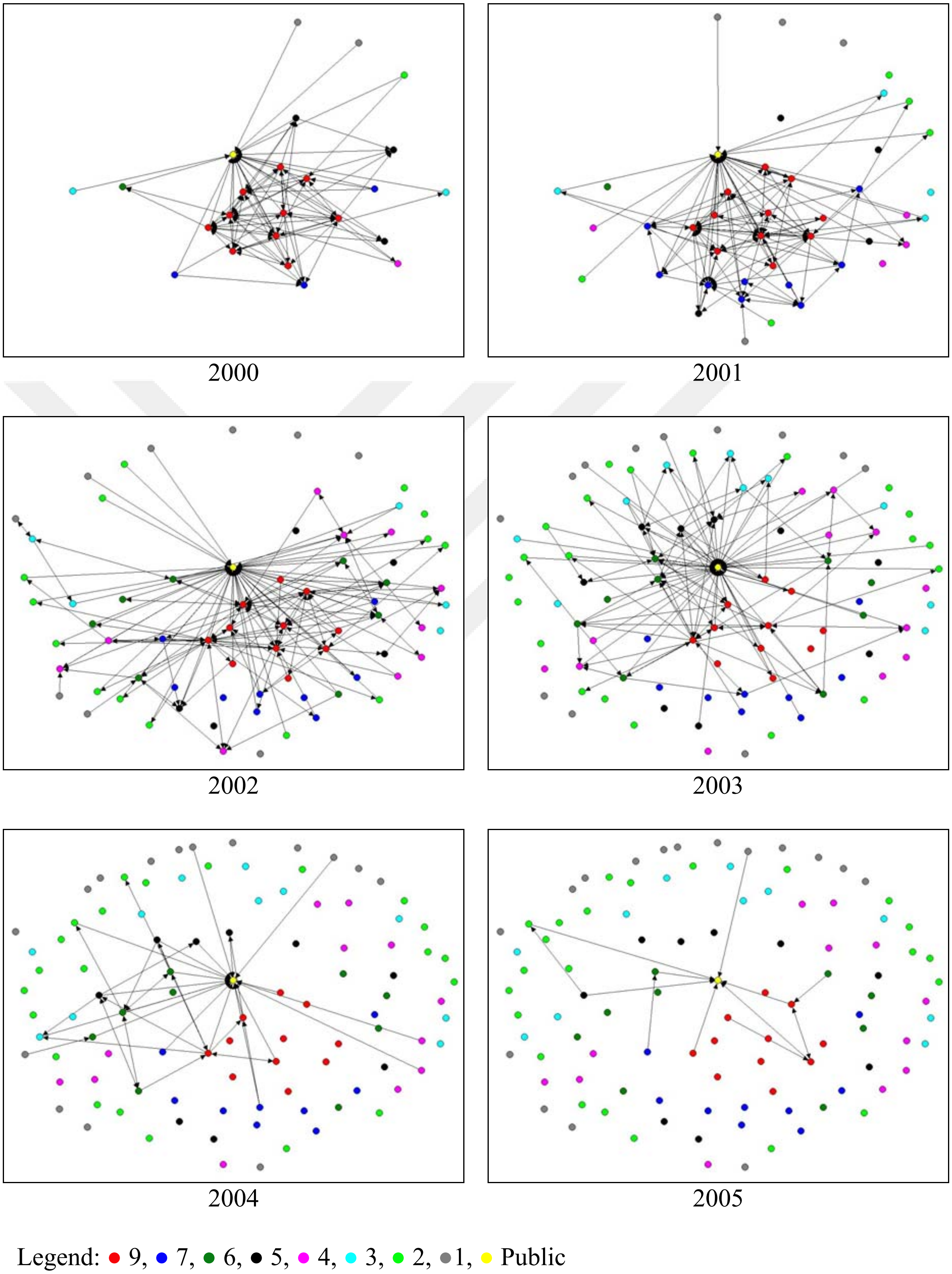
Note: * All names used are pseudonyms. ** Interview participants.

two aspects of the network: a) message sending patterns among network members, b) pattern changes over time. To achieve this, I used k-core values of each network member.

As mentioned previously in Methodology chapter, k-core values display network members who belong to the same cliques or subgroups of the bigger network.

The second SNA analysis was the computation of k-core scores. Analysis of the oPSG sociomatrix data revealed eight subgroups of oPSG members (ranging from 1 to 9 k-core values). Figure 6 presents network diagrams for each year displaying the subgroups of the oPSG. Each subgroup in the graphic is displayed by a different color. For example, the members displayed by red nodes had the highest k-core values (all with 9-core value) and belonged to the same subgroup. They can be considered as the most interconnected members and the most central agents. These members not only communicated with each other, but also communicated with the rest of the group and answered their questions. This subgroup consisted of four mothers, five fathers, and two professionals (one male, one female). Analysis of the demographic data showed that except for one parent from another city, the rest of the parents were from Istanbul, sharing similar demographical characteristics. The professionals (one therapist and one college professor) in this subgroup seemed to have developed a close relationship with the parents and accepted by them.

Creating a separate graphic for each year allowed me to visually analyze group message sending patterns over time. Note that node locations in each diagram remain in the same position across the years. However, links between nodes change for each year. During the years of 2000, 2001, and 2002, the number of communications seem to be higher, especially among members of the 9-core and 7-core subgroups. Analysis of the email messages show that these were the members who were attending the annual summer picnics and using other communication methods (e.g. telephone, chat) to



2000

2001

2002

2003

2004

2005

Legend: ● 9, ● 7, ● 6, ● 5, ● 4, ● 3, ● 2, ●1, ● Public

*Figure 6.* Graphical representation of message exchanges per year.

communicate with each other. As can be seen in the diagram for 2003, starting from this year, most of the members in the 7-core group (represented in blue) did not participate in the discussions. There is also a decrease in message sending patterns of the 9-core group. When we analyze the diagram for 2004, it is clear that most of the email exchange occurs between the newly joined members, with the exception of a few exchanges with old members. In the first half of 2005, the oPSG seems to have disintegrated, with only a few email exchanges among members.

## *Results from Analyses of Parent Interviews*

This section begins with a brief description of each interview participant. In the second section I present interview participants' opinions about the non-parent members of the group.

### *Interview Participant Descriptions*

The interview participants include three mothers and two fathers. Of these, three parents have sons diagnosed with autism, and the other, with PDD. The fifth interview participant is an old member of the oPSG, whose twin daughters were suspected to have autism. All interview participants have at least 4-year college degree or more. Except for one parent who lives in a western Turkish city, all others were living in Istanbul.

*Alper*. Alper is the father of a 13-year old son with autism. His son first started showing symptoms when he was two years old and was diagnosed at the age of three. He has been receiving therapy and special education since he was two years old. Currently, his speech is limited, he can read and write, do basic mathematics, and is very good at computers. Alper has been actively involved in online parent support groups since 1999. Formerly he was also a member of an international online support group. He joined the oPSG in March 2001 after being invited by another member of the group. Alper is one of the frequent contributors to the oPSG. He mostly sends messages about therapy techniques and outcomes, medical tests, and medications. Alper says that his wife is not a member of the oPSG, but if an interesting topic comes up, he shares this information with her. Alper works as an engineer and he is among the founding members of a local autism association.

Table 8

*Interview participant background information*

| Name* | Participant | Location | Child |
|---|---|---|---|
| 1. Alper | Father | Istanbul | 13-year old son, autism |
| 2. Yesim | Mother | Istanbul | 7-year old son, PDD |
| 3. Selma | Mother | Istanbul | 9-year old son, autism |
| 4. Levent | Father | Istanbul | 9-year old son, autism |
| 5. Selin | Mother | Big city in western Turkey | 5-year old twin daughters, developmental delay |

* All names are pseudonyms.

*Yesim*. The mother of a seven-year old son with PDD. Her son was diagnosed when he was 2½ years old. He has communication problems, but according to his mother, he is responding to therapy and his speech is improving gradually. After her son was diagnosed with PDD, she suffered symptoms of depression for a few years, but she was able to recover and focus on her work and her son's education. In her messages, Yesim usually investigates different therapy and special education options. In addition, she provides emotional support to other group members and does not hesitate to disclose her personal information, emotions, and feelings. Yesim is an engineer. She joined the support group in the Summer of 2001. She is also a member of another online parenting group that focuses on general activities for children.

*Selma*. Selma is the mother of a nine-year old son with autism. Her son was diagnosed when he was two years old. Currently, he attends a private school and receives special education. Selma joined the group in May 2000. She is one of the frequent contributors. About five years ago, she received psychological help for her depression. Selma's husband is not a member of the group; however, he is in touch with some close members of the oPSG. Selma says she forwards almost 90% of the emails to her husband. Selma works at a corporate business.

*Levent*. Levent has a 10-year old son with autism. His son was diagnosed at the age of three. His son is sensitive to auditory stimuli and displays repetitive, stereotypical behavior. Currently, he receives special education and attends a private school. Levent joined the group in May 2000. Even though he is still a member of the oPSG, after March 2004, he stopped posting messages. In addition to responding to other parents, Levent was also posting messages about the cultural events that are of interest to parents of children with disabilities, book reviews, and links from the Internet. Levent's wife, who is a teacher, was also a member of the group in 2001 and 2002, but was not frequently posting messages.

*Selin*. The mother of 5-year old twin daughters. When their daughters were 3 years old, she and her husband noticed a delay in their speech and communication skills. After visiting several physicians, they heard about the possibility of autism. Then Selin started looking for information on the Internet and found out about the oPSG. Before joining the oPSG, Selin was a member of another online parenting group. During her pregnancy, she had joined an online parenting group that focuses on pregnancy, infant and newborn care. As Selin states, in the beginning, almost all of the members were pregnant mothers. Later, they formed a very close relationship that also included the fathers and began meeting face-to-face or making phone calls. Selin has been a member of this group since 2000. Selin says she used to spend about more than 3 or 4 hours a day in her online parenting group mostly by reading emails, responding to emails and chatting (instant messaging) with other group members. Currently, she considers her friends from the parenting group to be “closer than most relatives.” Selin describes her experience with the group as follows:

> I used to spend more than 3-4 hours a day in these groups. Now that I started working again, my participation decreased sharply. I feel like I’ve left the group. We still talk on the phone. I feel like a fish out of water because we had been communicating for the past 5-6 years.

Selin was a member in the oPSG between November 2002 and January 2003. She has a college degree and works in the financial sector. Selin’s husband was not a member of the oPSG. Despite her positive experience with the online parenting group, Selin was somewhat dissatisfied with the support she received from the autism group. After learning that her daughters are not autistic and seeing improvements in their communication skills, Selin decided to leave the oPSG.

### *Opinions about Non-parent Members*

Interviewing with the parents allowed me to find out what parents think about the non-parent members of the oPSG. In general, parents seemed to be accepting other types of members including professionals. Analysis of the interviews revealed two important factors in accepting non-parent members: credibility/familiarity of the non-parent member, and the perception of potential harm vs. benefit.

First, interview participants mentioned that they know about most of the professionals, either through experiences in professional settings, or hearing about them from another parent or professional. In addition, some parents mentioned that they had their special education teachers subscribed to the oPSG, so that the teachers would have a better chance to learn about the parents' experiences. Second factor in accepting non-parent members is the perception of a potential harm that might come from these members. Parents expressed concerns about non-familiar professionals' potential of imposing their ideas or commercial interests. When asked about how she feels about non-parent members of the oPSG, Selma responded:

> Many members are not actively involved in the discussions. We investigate the individuals who have become members later or in an unusual way. As I told you before, we know each other personally. Of course, we become cautious when new people join in. It is because it makes us uncomfortable. I mean, there is a group of people in the group who inquire about the [special education] system, receive information from different sources, and then make their decisions based on this information. There are also people [parents] who are not well informed and lack critical thinking skills. It is a concern that these people can easily be influenced and misled. We are cautious about these people [non-parent members]. Some join to obtain information. Of course, it would be nice if they used that information for good. For example, there are educators and medical doctors in the group. The

> group provides them with information that might apply to their students or patients. Most doctors or educators have not done anything to bother us. When we have a problem, we contact the moderator and follow up. It is after that the related person is unsubscribed from the group.

As can be seen in above quote, new and unknown members or members who were not recruited through parents' network make them uncomfortable.

## Parents' Experiences of Raising a Child with Autism

### *Results from Analyses of Email Messages*

#### *Experiences in Educational Settings*

All parents expressed their interest in having their child placed in an inclusive educational setting and believed that their child had the right to receive education in the same setting with typical children. However, they experienced various barriers to inclusive education practices. The major obstacles were the availability of inclusive classrooms in regular education settings, and the attitudes of parents of typically developing children.

*Difficulties in finding a school*. The major problem parents had was the difficulty in finding a school for their children with autism. When parents found a school to send their kids, principals usually wanted to place their children in self-contained classrooms with a special education teacher. Parents felt that regular education teachers in most schools did not welcome children with autism and saw them as extra workload. The quotation below belongs to a mother who reports about her school search experience:

> Among these [educators], the most honest was a counselor from a big private school. She said: “Teachers that work in our school are mostly retired[†] elementary school teachers [from public schools] with a hope to work problem-free, therefore, they don’t want problem kids.” (mother, C68)

When parents found a school for their children, they were often asked to make donations. Although it is illegal to ask for donations in exchange for enrollment at a certain public school, sometimes parents faced such requests. This happened especially when parents were from another school district or had “special situations.”

> After a considerable amount of donation, we were able to register my son at a school, but it didn’t last too long. Now, he is attending a newly opened private elementary school. … (father, 81B)

> I would like to share the most wonderful thing that happened recently. This weekend, Ms. Firuzan, with whom I worked in another project, wanted my help. She said that there was an autistic kid in their school and parents of other children in that classroom did not want that kid. … I was expecting her to ask “How can we ‘NORMALIZE’ this kid?” Instead she said “we are going to set up a meeting with the parents. And WE ARE GOING TO TELL THEM, IF THEY DON’T LIKE IT THEY CAN TAKE THEIR CHILD BACK.” I couldn’t believe what I heard. She continued “we have to convince the other parents. We have to teach

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[†] Until 2000, retirement age was relatively younger for Turkish people (as early as age 38 for women and age 43 for men. In 2000, age of retirement was gradually increased to 60 for men and 58 for women (Sayan & Kiraci, 1999).

> how to live together with diverse people. And we need your help."… (mother, 8B9)

The quote below belongs to a mother who had to withdraw her son from school—in spite of the principal's positive support—after her son displayed aggressive behavior in the classroom and the teacher made it clear that she did not want the child.

> I think fighting for your rights is so important, not only for us, but also for educating the society. I don't know. Since the teacher did not want [my son], I didn't insist. Because, it is not worth it. It couldn't help my son. I've lost, cried a lot, avoided everybody, and didn't want to write you… As you have all experienced, your friend has been distracted, deceived, and politely rejected. … (mother, 9E1)

*Attitudes of other parents*. Parents expressed both positive and negative experiences in regard to other parents' attitudes. In most cases, parents of typical children did not want a child with autism in their child's classroom for several reasons. First of all, parents were worried about the possibility of physical harm that could be done by a child with autism who displayed aggressive behavior. Another reason that originates from the lack of parents' knowledge about the disability was the thought of the possibility of contamination of autism to "normal" children.

> The owner of the kindergarten was very kind to our son, because his/her child had similar problems. But later she/he confessed that other parents were not thinking in the same way about our son. Even though children welcomed our son, parents did not want him but the owner was able to convince them. (mother, 824)

Finally parents of typically developing children thought that having a child with autism in an inclusive classroom might interrupt education or monopolize so much of the teacher's time that typically developing children might not learn a lot. Parents of typically developing children in private schools in particular expressed this concern, and since customer satisfaction is an important issue in private schools, directors or principals of these schools sometimes had to convince parents of typically developing children or tell parents of children with autism to find a new school for their child.

> We had a similar situation in our son's kindergarten, too. The owner of the kindergarten was very supportive and later we learned that she advocated that the so-called normal kids have to learn to live with our kids. Of course, the case was closed before we heard anything about this. This shows that as they [normal kids] become aware of [the disability], our children will have a better chance of getting adequate education. And, even though they are different, people will accept them as members of the society. (mother, 8BB)

A frustrated parent puts it this way:

> To some extent these parents are right. Especially, those who are sending their kids to private schools. They are paying fees for that. And schools are business establishments that operate based on money. (mother, 9E1)

*Dis/Satisfaction with inclusive practices*. Parents often complained about the problems they had had regarding inclusive education. With a couple of exceptions, almost all of them had negative experiences that originated from teachers' lack of knowledge and training, unwillingness to have a child with autism in the classroom, and unsupportive school principles. It was mentioned that in some schools where inclusive classrooms were available, children with autism were treated differently. Below is a quotation from a mother:

> …As you know, our son has started school last year after [location] Guidance Research Center's contact with the local public school. The results are terrible, even worse than the previous [private] kindergarten. First, all students and teachers in these schools have to have some kind of training about special kids. Second, it is meaningless to continue this project unless they change the current isolation and discrimination practices. We have to teach our children about the society in which they are going to live. This can't be done with isolation [practices], especially, when they have breaks in different schedules than other children, or when they are kept separately from their friends during pledge time. Or when "normal" kids call them 'lunatics are coming.' :(( … (mother, 9BF)

### *Experiences with Health Care Professionals and Therapists*

*Dissatisfaction with health care professionals*. Parents felt extremely dissatisfied and often reported negative experiences with health care professionals and therapists. They found professionals, especially physicians unconcerned and unsupportive. Many parents felt that the information they received from professionals were either too technical or too simple. Some parents complained about not being well-informed by professionals:

> In fact, many techniques that are known by others are not considered if your doctor does not like them. They don't even tell you. When you hear from others, you lose your trust. I think we should have the right to choose [among different therapy techniques]. (mother, C0F)

Another parent pointed to the difficulties in communicating with doctors and dissatisfaction with the service they received:

> Thanks to you and us. Shame on those doctors who cannot communicate with us without scientific borders. … All they do is rip off our money. (mother, A81)

The following is an example of problems parents experienced with doctors who were not familiar with the symptoms of autism:

> We had experienced similar problems, too. Two ENT [Ear Nose Throat] “specialists” diagnosed our son as deaf. Reason: He does not respond when he is called upon. We know he does hear. I was so angry. … Later we took him to a Hearing Clinic, where they did some tests. His hearing, especially within the range of speaking frequencies, was found to be perfect. When I told about this to one of those specialists later, he/she simply ignored it, as if he/she was not the one who made the diagnosis (father, B8C).

*Commercial nature of therapy*. Parents also expressed complaints about the excessive fees for special education services. Some parents also brought the “love and care” aspects of the teaching profession to the attention of group members.

> Yes, I am looking for good educators, too. … In the meantime, I have found many, but I cannot believe the amount they charge. … As if they would turn the kids into a genius in an hour… And this requires a long time of education. How can I give $35[‡] three times a week? Who can afford that? It is ridiculous. … I think people should not aim to make profit in these occupations that require love and care. (mother, 98C)

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[‡] Fees are given in approximate US currency

The oPSG had been abused a few times by individuals from private testing centers and special education centers. Taking advantage of open membership to the group and not having had to get an approval from the group administrators, these individuals subscribed to the group and sent commercial emails listing their services and fees. This was not welcomed by parents. In fact, a few of the parents sent email messages to these individuals denouncing their action.

> I denounce you for sending a commercial email to this group, where, we, the families of children with special needs come together, share our emotions, ideas, joy and sorrow. This group is solely a sharing group. By sending your message here with a commercial interest, you have done the worst of advertising. … Proven with your commercially-themed message it is apparent that your goal is not to help our children but to make profit. (mother, ACB)

### *Results from Analyses of Parent Interviews*

During the interviews, parents expressed the difficulties they experienced following the diagnosis. Analysis of the interviews mostly overlaps with the analysis of the email data. Additional themes that emerged from the analyses were relief after finding the group, seeking cures for the symptoms, changes in social life, advocacy, and community level activities.

*Relief after finding the group*. After the initial shock, parents wanted to learn more about autism. Usually, their first sources of information were doctors, books, and the Internet. Later, they wanted to talk to other parents who had similar problems. Selma describes this process as follows:

> When we first joined to this group [five years ago], it was very difficult to reach parents who had experienced the same things and were knowledgeable about this topic. You would feel completely alone, in complete emptiness. First, I wanted to fill this emptiness. Second, it was to get some information from people relatively more experienced than me. At least, I thought that they would pass me on some information, names of doctors and names of therapies they had tried. At first I had these in mind. But, at later stages, I noticed that even though these exchanges [about autism and children] were great, it also helped parents to talk to each other and get some emotional relief.

Similarly, another interview participant, Levent states:

> At first it was very tough to admit his condition. We still don't want to admit it. He was such a healthy boy. But he was not playing with his peers. … When I found the group I was very happy. I wanted to learn from experienced families. Also, I thought that following email messages would help me learn about the behaviors of older children [with autism] and related educational techniques.

*Seeking cures for the symptoms*. Interview participants often expressed their search for new therapies and treatment for the symptoms associated with autism. As one parent, Levent, said:

> We tried different treatments over the past 3 years. Next month, we are going to try auditory therapy [Auditory Integration Training, AIT]. I know it is expensive, but I think it is worth a try. With the help of special education and these treatments, my son may show some improvements. … When I learn about new therapy techniques, I often try to convince our doctors to try such techniques.

Another parent, Alper, talks about different medications they tried:

> In addition to special education, we tried different medications and vitamins. For example, some vitamins and dietary supplements, such as B6, DMG, Seacure, Evening Prime Rose Oil. He received two sessions of AIT and five sessions of IVIG (Intravenous Immune Globulin, immune deficiency therapy). Based on doctors' recommendations, we tried some other medications, including nootropil, catapresan, risperdal. But we didn't see improvements in our son's conditions, so we stopped these quickly. Now we are on GFCF diet.

*Changes in social life after diagnosis*. Parents noted that after diagnosis they had to make certain changes in their lifestyle such as adjusting their schedules according to special education therapies, making certain changes in their home design, diet, or even choosing friends who are autism-friendly. As Selma states:

> Sometimes you face a lot of weird comments. Even though these comments might seem minor, they hurt you a lot and push you down to the bottom. For example, I had a similar experience recently. It is not that important, but almost 80% of the people I get in touch with know my son’s condition. A friend of mine who lives nearby, one day used a word. While talking to someone on the phone she said something like “is this kid autistic or what?” Sometimes, even tiny things like this might be important for you and makes you hurt. And after that you don’t want to share new things with that person. If you are surrounded by these kinds of people, you withdraw and begin to live in your own world.

*Advocacy and community level activities*. Some of the interview participants were also involved in founding local autism associations and advocacy groups. For example, Alper notes that with some other parents who had the same concerns they founded a local autism association and opened a special education center. Later, they hired a special education teacher. Alper tells about this new school:

> During the past couple of years, we have been educating our children in that school. We hired a British teacher. We respect her, she does her job very well. Our curriculum is mostly based on TEACCH and ABA. But we mostly prefer TEACCH. Children in our school go horseback riding, swimming, and receive individual therapy.

## Parents' Use of Support System

### *Results from Analyses of Email Messages*

Analyses suggested that parents used the oPSG for mainly three reasons: (1) to receive or offer information about autism and autism related problems, (2) to receive or offer emotional support, (3) to create a network of parents where they can provide an effective support system and advocate for both themselves and their children.

### *Informational Support*

The majority of the parents used the PSG to get informational support on issues related to sharing experiential knowledge about autism, sharing resources, referrals, and experiences of parents from other countries. Through informational support, parents were able to get new information about specific problems and check information from different sources.

*Sharing experiential knowledge*. Parents often shared experiences about their child's condition, such as dieting, toilet training, and responding to certain problems. This type of support was mostly offered by the "veteran" members of the group to the new members and parents whose children were newly diagnosed. Parents were aware that what they told was not generalizable to all children and all conditions. As one parent stated:

> First of all, it is worth to mention that we are neither specialists nor doctors; we are the parents of children with autism, just like you. I can only tell you *what we do* about this. (father, 9FE—emphasis added)

Below is an exchange between a new member, requesting referrals for special educators and an experienced member:

> Hi, I recently joined this group. I have a 2½ year old son recently diagnosed as having PDD. With the help of a two month special education program, we have made some progress and that made me happy. Since he is responding to special education, I would like to find a special educator who is not financially challenging to me. What do you do about this special education issue? Any suggestions or phone numbers you can give me? Looking forward to your response. (mother, 97F)

An experienced member of the group replied:

> Can you tell us a little bit about your son? For example, at what month did he start to walk? How is his language development? What is his name? (Usually, we all know names of the children in this group). How about his eating habits? His toilet training? Etc. etc. There are some parents in this group who have children 3-4 years older than your child. Since they have gone through these steps, they might give you useful information based on information they get from you. (father, 984)

Based on their experiences, veteran parents also provided informational support to new members. Below is an example of an advice, in its original outline, from a veteran parent to a parent who was told that his child might have autism:

> 1. I think for a child psychiatrist and developmental neurologist Dr. M. is a good choice.
>
> 2. Review what you can do after the diagnosis. First of all, with the help of a psychologist, determine the child’s developmental level and capabilities.
>
> a. If you know the child’s developmental level, he can get the appropriate education, and this could prevent you from wasting your time.
>
> b. And you can get help to cope with this new situation. Everybody knows that this is a tough period.
>
> 3. In addition to these, your child can get individual or group therapy (depending on his/her condition) from a special education specialist (special educator, psychologist, child developmental specialist, etc.).
>
> 4. Lastly, you can employ supportive therapy, such as music therapy, art therapy, and diet. … (father, BA8)

A considerable amount of information exchanged in the messages was about daily troubles such as where to find specific brand flour, how to prepare gluten-free food, or how to make children to take their medicine without resisting. For example, a parent who was emphasizing the importance of diet stated:

> Our son’s diet was completely mixed up when we were in Istanbul. During that time, I observed that his hyperactivity increased. I observed twice that after eating

> pizza, he got sleepy quickly. It is the same too, when he eats food that contains sugar. … (mother, 8B2)

> My son was also suffering from itching for a long time. I noticed that this is from the soap/detergent we were using. I have changed both face wash and laundry detergent. Now, he is okay. You might want to try this. Hope it helps. (mother, A24)

*Sharing resources*. Members of the group frequently sent messages about books, videos, or web sites to the list. These messages contained not only reference information (e.g. book name, author name, or URL) but also a review of these resources. Parents talked about the best features or drawbacks of these resources, the areas they were targeting, and benefits gained from these resources. This is shown in the following quote:

> Very well written book. I congratulate the author. … The author did not discuss about the emotional or social aspects, however, with the current scientific information, it seems well written. It could have been helpful if he did elaborate on the problems in elementary schools. Since the author is a doctor, his approach is more medical. Maybe, someday a teacher will write about these problems, too. (father, 7BF)

Parents were also sharing information from different web sites/pages either through sending links to certain web sites or copying-pasting the content of these pages. Analysis showed that parents were using multiple sources to check the accuracy and credibility of the information they have found. Depending on the content of the information, organizational or non-profit web sites, university web sites, and parent-created web sites were perceived as more credible and helpful. Below is a response to a parent who was asking for information about hyperactivity problems she had experienced with her son:

> …for hyperactivity, I am going to recommend a web site. Please read and disseminate the entire information given in the web site to others who might be interested. It is a very well designed web-site. … It is important to note that the web site's creators are parents, too. I handed in a printout of the entire website to my son's teacher, to help him/her[§] deal with hyperactivity cases in the classroom. (mother, 92B)

On the other hand, parents also expressed concerns about poorly designed web sites that provide inadequate and ambiguous information.

A group of members tried to found a library in order to reduce the cost of books and make them available to all members.

> We volunteer to found a library for group members. Let's make a list of the books we want. … Buying and sharing books will be more affordable for us and it will allow us to reach more resources. (father, D22).

In spite of these attempts, the majority of the group members did not show an interest for the idea of founding a library. However, messages suggested that some members of the oPSG were swapping books or donating books to each other.

Sharing such resources as book reviews, news critique, articles, news, web sites, and book swapping served two purposes. First, it provided members with an opportunity to review their current knowledge, refresh their memory, and learn about different points

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[§] Since Turkish language is gender-neutral, it was not possible to determine the gender of the teacher from the email message.

of view and different alternatives. Second, sharing resources allowed parents who had children newly diagnosed with autism and who were new to the group, to learn more about autism, different therapies, and acquire practical information.

*Referrals*. Referral requests were one of the most frequent types of messages on the PSG. Parents often wanted to learn about a therapist or a special educator with a special expertise in areas such as auditory integration therapy, neurofeedback, etc. Parents often replied to such referral requests with an informal evaluation of the professionals (e.g. friendliness, professionalism, accessibility) and information on the effectiveness of the treatment. Below is an email from a mother who traveled to Istanbul for treatment purposes.

> The reason I came to Istanbul is this auditory therapy. Today we had the first two sessions. … We have no choice but to try. By the way, I heard about Dr. [ ] of A University, from a woman I met there. I heard that she is quite attentive and more sensitive than other doctors we’ve met. … (mother, 883)

Sometimes parents recommended certain specialists because of their expertise in the field. This is illustrated in the following exchange:

> … By the way, I read that eating honey might result in aggressive behavior [in autistic children with casein intolerance]. But, I don’t want to mislead you. It would be better if you speak to a specialist. I know of someone from [University hospital] who is an expert in this topic. (mother, 9DF)

Parents were also making referrals to other group members who were known by their “expertise” in a specific topic. Below is a response to a new member who was asking questions about the use of medications. Here, in addition to making a personal statement about the use of medications, the respondent also invites the “expert” parent into the discussion.

> We never used any medication nor felt it is necessary but some people use them. Mr. [ ] is very well-informed about this topic. ... I am sure he will write about this and give you some suggestions. (father, 9C9)

When making referrals, parents commented about university hospitals being more trustworthy because of their non-profit status compared to privately owned institutions.

*Information about parents from other countries*. The scope of the discussions was not limited to the experiences of parents within the country. Parents in the oPSG were also very interested in seeing how parents of children with autism in other countries cope with having a child with autism. Some parents reported that they had attended meetings about the experiences of parents from different countries, or watched videos about them, and also investigated through the internet.

> Below URLs are about a 5-year old newly diagnosed child of a family who lives in the U.S. There are pictures and brief information about the child. I think being in the U.S. is not enough to get the diagnosis immediately. Based on the information I got from another list (name of an oPSG in English), even potty training still exists to be a problem. Why am I writing these? It is because… this common phrase… “If only he was in the U.S.” … “In the U.S.…” In our experience, the only different thing in our country, the source of the problems, is the society, the other people… (mother, 900)

> Tomorrow, I am going to attend a meeting titled “How American parent groups see autism.” (mother, 808)

### *Emotional Support*

Parents often shared important news and milestones that they have experienced. Sharing emotional expressions allowed parents to understand each other, to sympathize, validate feelings and develop an understanding of autism, or provide a sense of empowerment and provide encouragement for the members of the group.

*Understanding and validating feelings*. To some parents, being a member of the parent support group and sharing thoughts served as a way of validating their feelings and developing an understanding of autism and disabilities in general.

> I recently joined to the group. Having a sharing mechanism like this is very good and relieving. I have a six-year old daughter diagnosed as autistic. I am saying "diagnosed as autistic" because I am not as sure as doctors about what autism is. But the label [diagnosis] is not important; in my opinion, what is important is my daughter's happiness. … What is important? To become a person that is accepted by society as "normal", or to be happy? Why do we want them to be normal? To satisfy our ego? ... (mother, 9B3)

The same parent later continued:

> My daughter was diagnosed at the age of 22 months, since then she has participated in many special education programs, had treatments abroad [USA and Israel], diet programs, many times had AIT [Auditory Integration Training], and in addition to these, she attended kindergarten. Then, I thought to myself, who wants to interact in different settings? Me or she? We like to see them in normal [mainstream] schools? …. Wouldn't they become children who are rejected by their peers when they grow up? … (mother, 9BB)

Similarly, other parents shared their emotional experiences. Below are examples from two mothers.

> …That morning we went to school together [with my son], we were a little late. When we came to the classroom door, he looked at me and said "Mom, first I have to knock on the classroom door and then I have to apologize for being late." I couldn't believe my ears. Maybe these two sentences are just simple sentences for other mothers, but they were unbelievable to me! (mother, 939)

> …In short, it was a happy day for us. I wanted to cry so badly that I cannot even tell you. (No, I can. You would understand me the best.) (mother, 846)

*Sense of empowerment*. Having an emotional support system gave parents a sense of empowerment. Realizing that other parents experienced similar problems, parents felt that they were not alone, and had the ability to control have over challenges. This is illustrated in the following remark:

> You know what? Your presence gives me a distinct power. I was feeling so lonely and helpless, now I am happy that I have found this group. (mother, 9D7)

*Encouragement*. Group members also provided emotional support to members who were overwhelmed by the problems they faced as a consequence of the child's autism. Below is a response to a mother who was feeling depressed and expressing suicidal ideas.

> If you want, we can talk to each other. I have some suggestions. They are not different than what I said before. But, it is worth to try. … You say "I WANT TO DIE." But, your son... Think about him. If he could speak what would he say? Maybe he has no father [biological]. And the guy in his father's position [step

> father] cannot fill this gap. But he has a MOTHER. Let's try my suggestions. If they don't work, we can think of something else. (mother, 8E9)

*Networking and Advocacy*

*Networking*. Group members extended their interaction beyond the virtual email group. Email messages were used to connect parents from diverse locations or schedules and provided them an effective way of getting in touch. Networking activities included face-to-face meetings, phone conversations, and real time chats.

From the messages, it was apparent that some parents who were living in close neighborhoods were trying to hold face-to-face meetings. In addition, each summer parents organized summer picnics to meet in person, get to know each other, and share their experiences. Parents saw face-to-face meetings as a way of overcoming the limitations of online communication and thought that meeting face-to-face would allow them to talk about the problems in detail.

> Yes, we can also come to meeting on October 3rd. I guess most of us are busy with the beginning of the new school year. Let's talk about these when we meet on October, 3rd. (father, 9F8)

As pointed out by a member:

> I guess, I wrote too long. I still believe that having to tell all of these through email is not enough. Let's organize this picnic soon. We could spend a beautiful day with our children and talk in a more relaxed environment. (mother, 948)

In addition to large-scale face-to-face meetings, parents tried to build friendships with other parents living in the same city.

> By the way, we live in Ankara. Are there any other members living in Ankara? (father, B14).

Phone conversations were another way of getting connected to each other. Parents especially made both their home and cell phone numbers available through the signature lines in their email messages. Analyses revealed that parents were using phone calls to make meeting arrangements and clarify on specific issues that were discussed on the group. However, phone calls made to receive/give emotional support were relatively few.

> … For the last two days, I wanted to call Ms. [ ], but I couldn't. I think of her as my friend, in fact all of you are like that. … (mother, 9E1).

Below excerpt shows that some parents were connected to each other beyond the realm of online communication, they did call each other on the phone, worry about each other, and shared important news with other group members.

> I could reach neither Mr. [ ] nor his brother. Both of them are bounced from the group. It means that they are not following the messages. They don't respond to phone calls. Maybe they are on vacation. … (mother, B3A)

> I just learned that Ms. [ ] has lost his father this past weekend. We send our deepest condolences to his family and relatives. … (father, 99F)

As illustrated in the following quote, parents sometimes used email as an alternative to communication via telephone.

> Hi, Mr. [ ] I called you many times on the phone, but I couldn't reach you. I know you don't like it, but I think that you might use your daughter's interest in computers in a good way. I am anxiously awaiting your message. Last time, your wife mentioned a new special education school. How are the results? Any

> progress? How is your daughter's relationship with her sibling? … (mother, B8D).

During the third year of the group, parents tried to participate in real time chat sessions over the Internet and discuss their problems and socialize with new members. However, messages suggested that real time chat sessions did not go as expected.

*Advocacy*. Participants often stressed a need for advocacy for both themselves and for their children. As a consequence of the discussions, parents sent letters to politicians and columnists. In addition, some parents were also affiliated with local or national autism or disability organizations. As discussions continued over the years, parents became advocates and change agents in the society.

> Our goal should be to bring autism into the public agenda, to raise awareness of people—even for a short period of time. But how? (father, 81F)

> Of course, we should continue our battle. But, should it be individually or with organizations? … We should think about some solutions. Why don't we fill the mailboxes of parliament members, Ministry of Education, Prime Ministry Administration for the Disabled People, and others that I couldn't think of? We could do a little "task" distribution and do this systematically. (mother, 823)

It is important to note that in their discussions, parents often used words such as "our battle," "our struggle," or "our war." In one discussion devoted to the use of appropriate and politically correct vocabulary, one of the parents suggested that:

> …The word "war" might be misunderstood. (In fact it was already misunderstood). I am suggesting it to be changed to "struggle." (father, 842)

### *Results from Analyses of Parent Interviews*

Analysis of parent interviews yielded similar results to those of archive email messages. Parents were mostly using the oPSG for receiving informational, network, and emotional support.

*Informational support*. Parents expressed that they used the oPSG to learn more about autism and the experiences of parents with similar situations. Most cited types of informational support they were receiving about different therapies, referral information, special education resources available, and discipline techniques. Some parents told that in addition to the oPSG messages, they were also searching the Internet to find more information. However, for some parents, these resources on the Internet were unaccessible because of the language barrier. As Selma points out:

> I can only use Turkish resources, because my English is not good enough to do a search in English web sites. Unfortunately, the resources in Turkish are very limited. ... This is very important, because the more you know, the better chances you have. Everyday you learn new information, new therapy techniques, and new educational methods.

*Emotional support*. Analysis of interview data supported the findings of email analysis. For most parents, emotional support was an important benefit of the oPSG.

Interview participants also mentioned the importance of being a support group member for the psychological well-being of newly joined parents, whose children were newly diagnosed with autism. Levent explains this as follows:

> I think the first one or two years [after the diagnosis] are the most important. Because, that’s when you feel the loneliest, depressed, and think that no one can

> understand and help you. When you find out about other parents in a similar situation, they help you a lot, listen to your problems, and encourage you. … Sharing feelings, concerns, or social support are benefits for these new parents.

Similarly, Yesim describes how sharing experiences and feelings with other group members made her motivated:

> You feel more empowered. Loneliness is not in the nature of humankind. People who are experiencing the same things as you do, and sharing their experiences and feelings with you, all of these makes you more motivated. This is very important.

Some parents pointed out that, other types of support could be found from different sources, such as doctors, books, etc., but emotional support is only available from relatives, close friends, and group members who are experiencing similar situations. Interview participant Selin comments on the importance of emotional support:

> I think you get more emotional support. Because you don't fully trust the information you got from here. You can consult a doctor. However, the doctor does not give you emotional support.

*Change over time*. Being a member of the oPSG was an educating experience for most interview participants. Participants noted that through oPSG participation, they had learned a lot and after a certain amount of time they had changed in a positive way and began supporting parents whose children are newly diagnosed. This change over time is described by Selma as follows:

> In later years of the group, we noticed that people were asking more than just simple questions of therapies and educational experiences, they were asking

> questions about different methods we employed for certain types of behavior. Lately, group's mission has somewhat expanded. We began supporting families beyond the group that contacted us by various ways. We mostly helped them about the behavioral problems they had experienced.

## Perceived Satisfaction and Factors That Contribute to the Perceived Satisfaction

### *Results from Analyses of Email Messages*

Participants overall seemed to be satisfied with the support they received from the group. Email data analysis suggests that factors such as sense of belonging, level of participation, and credibility of information are related to the perceived satisfaction with the support group.

*Sense of belonging*. Through online support group participation, parents felt a sense of belonging to a community where their concerns were shared, thoughts were appreciated and it was possible to receive and provide support. Members of the group identified themselves as parents of "different" children and made a clear distinction with the "others." Below is a response to a parent who made an inquiry about the eligibility criteria to join the support group:

> First, let me clarify something. You are already a natural member of this group—group of parents of children with autism and those who want to support them. … (mother, B2E)

In their messages it was clear that parents had a strong sense of belonging ("us"). This sense of belonging allowed them to create a support network and advocate for their rights. Use of a shared vocabulary (mostly in capitalized or italicized form, e.g. DIFFERENT, SPECIAL, NORMAL) allowed participants to express their ideas and communicate with others. Italicized or capitalized letters and emoticons (e.g. use of symbols :), :(, etc.) served as a way of overcoming the barriers of electronic communication.

> Don't forget that we are the people who should have UNLIMITED POWER. Maybe we already have that power. (mother, 886)

Being in the same group with parents who had similar problems allowed group members to connect to the support group and feel empowered. Below is an exchange between a new member and relatively older member:

> After joining in this group and reading your messages we feel stronger. (It is kind of a therapy). I guess all of us have trouble with the idea of being alone. (mother, 82F)

A father replied:

> It is good to share something with people who have similar problems. (father, 830)

Similarly, other parents stressed the importance of experiences being told to other members.

> I will write about the difficulties I have experienced. It will help us to better know each other and help friends who are experiencing these problems now. No one helps us but us. … We should act quickly and organize. (mother, 879)

> When I found the group, I read the old messages, all at once, like a novel. Different names, different experiences, different stories, but the efforts and emotions are the same. I felt that I was not alone. (mother, BF9)

*Level of participation*. Since participation in email discussions was not mandatory, not all members of the group participated in the same way. While some parents actively participated in the discussions, majority of the participants preferred to read the messages without taking part in these discussions. Group participation also seemed to have changed from time to time. For example, during holidays and summer months, the number of messages per month seemed to have decreased. Another reason for low participation was the parents' busy schedules and their access to an Internet connection. Analysis of messages indicated that group members—especially those who were actively contributing—were not satisfied with the low participation. This is demonstrated in the following quotes:

> I wanted to check-in with the latest news. By the way, group participation has decreased in the past few weeks. I hope everything is going well. (mother, 929)

> Group is silent again. I am suggesting meeting in August, 11 or 18. … If you have any suggestions, please write so that we can organize this together. (father, B1E)

*Credibility of information*. Parents seemed to be satisfied with the information they received from the support group. Using the oPSG, the Internet, and other conventional sources, parents were able to receive information from different sources. In addition, experienced parents and professionals provided information.

Conventional sources of information such as books, journals and magazines also were regarded as sources of credible information. On the Internet, institutional web sites and non-profit organizational web sites were perceived as having credible information. As pointed out by a member:

> … and our son was diagnosed with autism. We immediately looked for information on what autism is, what we can do, what is expecting us, etc. We looked at libraries and the Internet. … Later we went to [another doctor's name] and he confirmed the diagnosis. … Approximately, four months ago while searching the Internet, we found the Autism Research Institute web site from the U.S., and requested information about autism. They sent us brochures about the institute and autism and different therapy techniques. This is where we learned about the diet. … (mother, B86)

> I am subscribed to the Autism Research Institute (ARI) Newsletter that is published in the U.S. In addition, I am a member of the ARI electronic support group. This is important, because if new therapies are developed, I know about them right away. And if it makes sense to me, I try to implement them. I also do a lot of research on the Internet. (father, 7FB)

### *Results from Analyses of Parent Interviews*

Interview participants expressed their satisfaction with the oPSG. Only one interview participant, Selin, a past group member whose twin children were suspected of having autism expressed that she did not gain much from the oPSG. Analyses revealed that several factors played an important role in perceived satisfaction with the group support. These factors include the number of messages, off-topic messages, new member recruitment/new information flow, meeting individual needs, and credibility of information.

*Number of messages*. The number of messages sent to the group was directly related to the level of group participation. Low group participation, such as no or a few emails for a few days or sometimes weeks were not welcomed by most parents. As Yesim commented:

> In general, I am happy with the group. The participation could be a little bit higher. Many people do not post messages. But we all work and have busy schedules. Therefore, this is understandable.

On the other hand, excessive amount of messages were also considered as overwhelming. As Alper states:

> I am a member of online groups since 1999. First, I was a member of [name of an international online PSG]. … At first, it was more satisfactory [being a member of oPSGs]. But you receive too many messages and your email box gets filled up quickly. Also, in the international support group, there were some off-topic messages as well.

*Off-topic messages*. As can be seen in the above quote, parents expressed their dissatisfaction with off-topic messages. Off-topic messages include forwarded jokes, forwarded news, hoax, virus warnings, and petition requests. In addition, parents expressed their dislike about emails that were commercial by nature, such as emails sent by therapy centers or special education institutions that included price information. When asked what the only negative experience was, Levent's answer was short: "Commercial, for-profit emails from professionals."

*New member recruitment/New information flow*. New member recruitment and new information flow were also found to be important factors in the level of participation and support group satisfaction. In the below quote, Levent describes an unsuccessful attempt to conduct a real-time chat.

> We tried chatting through IRC [real-time text-based chat] for a few weeks (3-5 weeks) but we couldn’t continue it any longer. The participants were always the same people. Since we already knew them, it was not that satisfying.

When new participant recruitment began to decline and group members found out that there was a new group, most of them migrated to this new group. While some of them stayed in the old group and posted same messages to both groups at the same time, others were more active in the new group. For example, although four of the interview participants were members in both groups, they reported that they were more active in the new group. When asked for his opinion about the new group, Levent said:

> I don't know. This is a new group. There are a lot of interesting people, interesting topics. Besides, most of the people whom I know from the old group [oPSG] are there, too.

*Meeting individual needs*. Analysis revealed that for some interview participants, perceived satisfaction with the group support was directly linked to their subjective experiences. Analysis revealed that while experienced parents mostly offered support to others, parents whose children were newly diagnosed or suspected of having autism seemed to be seeking support from the other members. When these parents were unable to find answers to their questions, they perceived the group support as not satisfying. Selin, who once was a member of the group states:

> To be honest, I didn’t find that group very helpful for me. Because, I finally realized that my children did not have autism. I was constantly asking questions, ‘what if this and that.’ Those people, maybe because they have disabled kids, couldn’t say anything to me, maybe they did not want to say anything. ...

> However, when I learned that my kids were not autistic, I wrote them and told that my kids were not autistic but [their speech was] delayed because they watch too much TV everyday. I did not get a response like “oh, we are happy for you!” etc. Then, I left the group.

*Credibility of information*. Parents expressed their concerns about the credibility of the information they received from the group. Results indicated that parents use several strategies to verify the credibility of the information, including checking information from different sources, and experiences of different parents to include as much diverse information as possible. When Selma was asked about how she decided whether particular information is credible or might be beneficial for her needs, she replied:

> We discuss these lots of the time. Sometimes a new therapy technique or behavioral method is suggested. Most of us are very knowledgeable about these topics. We weigh the pros and cons. Sometimes this happens during our discussion. Sometimes we use information from other sources. To be honest, you don’t fully trust every kind of information you find–whether it comes from [a member of] the group or from a doctor. You need to use your logical skills. And you need to investigate it a little bit from different sources. You have to be all ears. This is what I do to make sure the information I get is credible. But, you usually guess whom you will get the most useful information from.

## Perceived Advantages and Disadvantages of Online Medium

### *Results from Analyses of Email Messages*

#### *Advantages of Online Medium*

Online nature of the PSG gave participants the opportunity to participate in discussions whenever they wanted. Parents expressed mostly positive opinions about online communication. Benefits of online medium included the use of archived messages, flexibility of asynchronous communication, participation from diverse geographical locations, and benefits without participating in discussions.

*Use of archived messages*. Accessibility to the PSG's online archive was cited many times as an advantage.

> My first advice to you (maybe you've done this already) is to read old messages from [URL]. There, you might find useful information that is derived from the experiences of our members. (father, 963)

> I am not sure if you have read old emails or not. In my opinion, you should read these. You learn a lot of things from these messages. (mother, 98F)

> Hi, neurofeedback was discussed in this group before, on April #, 200#. You can find related messages at the group's archive at [URL], between messages [###] and [###]. I am copying some of them below. …. (mother, 84F)

Additionally, some parents indicated that they were saving important messages for future reference, as illustrated by the following quote:

> …I am collecting your messages along with Ms. [ ]’s messages and others’—which contain a lot of helpful information—in a folder. To make our son’s teacher better understand us and become a volunteer in our combat. (mother, 93E)

*Asynchronous participation*. Many parents noted that because of their busy schedules at work, it was not easy for them to attend a conventional support group. Therefore, asynchronous nature of the group discussion allowed them to participate in discussions whenever and wherever they are available. Through asynchronous communication, parents were able to carefully craft their writings, refer to books or web sites.

*Participation from diverse geographical locations*. Online format of the communication allowed parents from diverse locations and cities throughout Turkey to communicate with each other. Descriptive analysis showed that almost one third of the participants ($n$ = 20) were from Istanbul, and the rest were from other major cities. Participants were able to discuss services available in their cities and compare and contrast these services.

*Benefits without participating in discussions*. As reported earlier, some of the participants read email messages without feeling an obligation to participate in the discussions. On average, these 39 individuals (27.86%) were members of the group for more than a year ($M$ = 14.66 months, $SD$ = 7.20 months, min= 3 month, max= 40 months). Since these “silent” individuals preferred to stay as members of the group, it can be concluded that even though they were not participating, membership might have been beneficial for them. Sometimes, parents waited a long time before finally posting a message to the oPSG. An example of this is shown in the following quotation:

> Hello everybody, we have an eight-year old son with autism, too. … For a while, I was only reading emails :)) and finally I concluded that these messages are some kind of therapy for us. … (father, 8D3)

Analyses revealed that this particular member waited for five and a half months to post his first message.

*Disadvantages of Online Medium*

Most frequently cited disadvantages were impracticality of electronic communication, lack of time to follow email messages, difficulties in access to a computer, and difficulties in communicating with anonymous participants.

*Impracticality of computer-mediated communication*. For some parents, feeling not interpersonally connected with other people in the group kept them from engaging in the group discussions. Parents noted that the impracticality of sharing detailed information in a relatively short amount of time, in comparison to face-to-face communication, was a challenge for them. The analysis showed that parents who had difficulties in online communication often tried to communicate in more conventional ways of communication, such as face-to-face meetings or telephone conversations:

> First of all, it is hard to talk about everything in the electronic medium. That's why the meeting we are planning to do—if we succeed—will be very beneficial. … (father, 89C)

*Lack of time*. Most parents indicated that because of busy schedules at work or at home, they could not allocate time to go online and read messages. For example:

> ... I cannot spend too much time in front of the computer. Finally, I was able to read the messages. (mother, A23)

> Because of my busy work schedule, I did not get chance to write to group. (mother, CC8)

*Computer accessibility*. Analysis indicated that not all parents had access to a computer and internet connection at home. Some of them were using Internet connections at work. As shown in the following remark, computer access caused problems in time-critical messages:

> … Since we don't have a computer at home, we did not get the meeting information in time. [Therefore, we missed the meeting]… (father, 8A8)

> I am [ ]'s father. Since my spouse is on vacation, I am checking her email messages. Thanks for your interest. … (father, 9F5)

*Difficulties in communicating with anonymous participants*. Parents had a hard time communicating with other members who did not disclose their names or gender information. In terms of disclosing identity, the oPSG had no specific rules. Although it was not required to disclose identity, most of the participants identified themselves when they first participated in the group. With the exception of a few parents who were using nicknames, most parents signed their names in email messages. In addition, frequent contributors also included their home and cell phone numbers in the signature section of their emails. The most commonly used parent signature format was as follows:

> Selin, Mother of […..], 2 years old.

Only in two cases participants did not reveal their names and other relevant identifying information. These participants identified themselves as parents of children with autism, but used nicknames in their messages, hence making it difficult for other members to communicate:

> Dear friend, since you didn't write your name I was not sure how to call you. I agree with you in many ways. … (mother, 9B4)

Unisex names also seemed to be problematic for some members. For example in two cases where parents had a unisex name, there was confusion on how to address them[**]. While some parents were using Mr., others were using Mrs. Finally, the parent with a unisex name modified her email signature line similar to the signature format shown above.

### *Results from Analyses of Parent Interviews*

Analysis of parent interviews yielded similar results to the analysis of email messages. Interview participants listed the perceived advantages of the oPSG as using archived messages, flexibility of online communication, and being able to participate from diverse locations. Parents also expressed that discussions allowed them to brainstorm, develop new ideas, and learn new information. Yesim describes this process as follows:

> For example, one parent says: 'We have toileting problem' and describes the problem. And asks, 'Have you had this kind of problem? What have you done to solve it?' Later, another parent replies and tells about his/her experiences. Others join, too. And, they all tell about different solutions that worked for them. Finally, you learn something, you find a common ground.

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[**] In formal Turkish, usually, unknown or unfamiliar persons are called by adding a "Mr/Mrs." equivalent (bey/hanim) after their first name, such as Mr. Kazim (Kazim Bey).

For perceived disadvantages of the oPSG, parents cited lack of time to participate in discussions, receiving misinformation, and intrusion by professionals. All parents, except Selin, complained about the lack of time to spend on group communication. These parents noted that they usually spent 2-4 hours a week for the oPSG communication. On the other hand, Selin said she used to spend about 3-4 hours a day in online parenting groups before starting to work.

Interview participants were aware of the fact that all information found on the oPSG did not apply to all situations or all children in the same way. Participants pointed out that this could be a potential disadvantage for newly joining parents. As Alper states:

> The only disadvantage I can think of is the possibility of other parents' perception that everything they read in this group is correct. The technique we try and get good results may not work for them.

As noted previously, new and unknown members, especially professionals that were not recruited through parents' network made them uncomfortable. Parents indicated that although they knew most of the professionals either in person or professionally, there were a small number of them, who tried to exploit their vulnerability by sending commercially themed messages. Yesim comments on this:

> Occasionally, some people whom we call charlatans subscribe to our group and try to advertise what they are doing or selling. Or they try to impose their ideas. Recently we had such a situation. … They take advantage of us not requiring moderator approval for membership. If they want to help us, they are welcome; if they want to make a profit, they need to go somewhere else.

# CHAPTER 5

# DISCUSSION

This study examined the use of an online support group for the parents of children with autism in Turkey. Collected data consisted of information from two sources: email messages collected from the oPSG online archive and parent interviews. Online archive of the email messages consisted of 1,480 email messages posted by 140 members over a five-year period. In addition, five parents (three mothers and two fathers) were interviewed on the phone. Data analyses consisted of descriptive data analysis of the email messages, social network analysis of the parent support network, and qualitative data analysis of email messages and parent interviews.

Data analysis indicated that parents were using the oPSG to receive informational, emotional, and network support. This chapter is organized around the research questions, including questions related to participant and network characteristics, parents' experiences, parents use of the oPSG, perceived satisfaction with the oPSG, and the advantages and disadvantages of oPSGs. In the following sections, I discuss the research findings and compare them with the results of similar studies.

## *Participant and Network Characteristics*

Results showed that participants in the oPSG are typically married, well-educated, middle or upper middle class, professional parents living in big cities in Turkey. These demographic characteristics support previous research results reporting individuals from higher SES (socio-economic status) as the most frequent participants of the parent support groups (Smith, et al., 1994) or high levels of computer use among parents from higher SES (Han & Belcher, 2001).

Another important finding of this study is the relatively equal numbers of mothers (*n* = 33) and fathers (*n* = 25) in the oPSG. This is contradictory to previous research findings where mostly mothers were reported as being active participants of face-to-face parent support groups (Krauss, et al., 1993; Makri-Bottsari, et al., 2001; Rodrigue, et al., 1990; Simmerman, et al., 2001; Solomon, et al., 2001) and online parent support groups (Baum, 2004). Unfortunately, studies on online parent support groups did not focus on participant demographics. An exception is Baum's (2004) online survey of primary caregivers of children with special health needs in the US. However, in Baum's study, the sample is not homogenous in terms of the children's disabilities. The sample consisted of caregivers of children with different disabilities and disorders including physical disabilities, rare disorders, and psychiatric disorders.

Almost equal representation of both mothers and fathers in the current study may be explained by two factors: a) parents' level of education, and b) parents' access to the Internet. Studies have shown that parental involvement increases as the parents' level of education increases (Ozkan & Honig, 2005). Parents in this study were well-educated with at least a college degree or more. Furthermore, parents' access to the Internet also determines their participation on oPSGs. Also, the relatively high representation of fathers in the current study could be the result of gender-based division of parenting roles. Results showed that some parents were using their company's Internet resources to communicate with the oPSG members. This could explain where only one parent (usually father) works outside the home and the other parent (usually mother) takes care of the child(ren). In fact, some parents suggested that they have done a "task distribution" on who is to take the child to therapy or who is responsible in finding information on the

Internet. This explanation is supported by the Ozkan and Honig (2005) study which indicates that parental gender inequalities could be best understood by examining factors such as economic structure of the society, economic power, gender ideology, time availability, skill levels, and other cultural mores. The patterns of parent involvement and parenting roles change against women in lower socioeconomic class and rural families, where traditionally men are the primary bread-winners and women are child care takers (Akkok, 1994; Sunar & Fisek, 2005). Similarly, Simmerman, et al., (2001) report fathers of children with disabilities equally involved in some parenting roles such as playing, nurturing, discipline, deciding on services, and less involved in other parenting roles, including hygiene, dressing, feeding, teaching and therapy, and driving to appointments.

Another important finding of the study is that a strong identity change emerged in some parents. While some parents were strongly emphasizing the uniqueness of being a “special parent of a special child”, other parents were not very articulate about these issues. Solomon et al. (2001) also report similar identity change that had emerged in parents of children with disabilities in a face-to-face support group. During their membership, these members changed in a positive way, gaining control and agency, becoming more knowledgeable, and feeling empowered. These positive changes were expressed several times in the group, and one of the interview participants described these changes in detail.

Analyzing the oPSG messages over a five-year period provided me with an insight into the life cycle of an online parent support group. The findings revealed that during the first year of the oPSG group cohesion was high and members were actively participating in discussions. However, beginning the third quarter of 2003, group participation decreased sharply, some parents began leaving the group and finally oPSG began disintegrating. Five factors seem to be contributing to the disintegration of the oPSG. First, the oPSG was unable to recruit new members. Usually, when new members join the group, overall group participation is increases with the questions coming from new members and answers to these questions keep discussions alive. New members and new questions also provide an opportunity to brainstorm and learn new information.

Second factor is the importance of effective leadership. Leaders play an important role in recruiting new members and maintaining cohesion among group members (King, et al., 2000). Third, professionals' presence (especially those with a commercial interest) in the oPSG might have made parents uncomfortable and less willing to participate in discussions. Fourth, the presence of similar oPSGs might be a reason for parents leaving their old support group. For example, results showed that, in the third quarter of 2003 a new Turkish online PSG was founded and some of the parents migrated to the new support group.

Finally, another possibility for parents' leaving the group could be their changing needs and concerns over time. For example, most parents in the oPSG joined the group just after their children were diagnosed with autism, usually around 3-4 years old. In the course of four or five years, parents' needs and concerns may change or they could utilize other means of social support. This explanation is supported by other studies (Gray, 2002; King, et al., 2000). For example, in a longitudinal study of families of children with autism, Gray (2002) found that in the early years parents were mostly concerned about issues such as their children's inappropriate public behavior, obsession, violence and aggression, and eating or toileting. However, Gray notes that a decade later the use of treatment services were declined dramatically and parents were concerned about their children's future.

Previous research does not provide information regarding the longevity of online parent support groups, but there are several studies investigating the life cycle of face-to-face support groups. In a study examining 50 support groups, Chesler and Chesney (1995) reported that only 10% of the support groups were in operation after more than five years they were founded.

Although several studies focused on the psychosocial outcomes of support groups for the parents of children with autism (Bennet & DeLuca, 1996; Gray, 2002) only a few studies examined the support group change over time (King, et al., 2000; Solomon, et al., 2001). A notable study is King and colleagues' (2000) study on the longevity of self-help groups for the parents of children with disabilities. King and colleagues propose a model that attempts to explain structural and process variables affecting the longevity of self-help groups (Figure 7). This model states that self-help parent groups have structural and process characteristics. Structural characteristics include leadership, membership, and attendance. Process characteristics include instrumental and affective activities. According to this model, self-help groups evolve in two stages: Start-up stage and maintenance stage. In each stage, groups face several challenges that affect group development. Here, I will discuss the applicability of this model to online parent support groups.

As can be seen in Figure 7, during the start-up stage groups increase the number of their members and are characterized by high attendance and frequent meetings. In the maintenance stage, group membership reaches to a plateau or begins to decline. These changes in the membership are also supported by the current research findings. During the start-up stage, the number of membership in the oPSG gradually increased and members were frequently posting messages. In the maintenance stage, the oPSG had difficulty in attracting new members and keeping the current members in the group. As the model suggests, effective leadership could have helped the oPSG maintain high cohesion among group members.

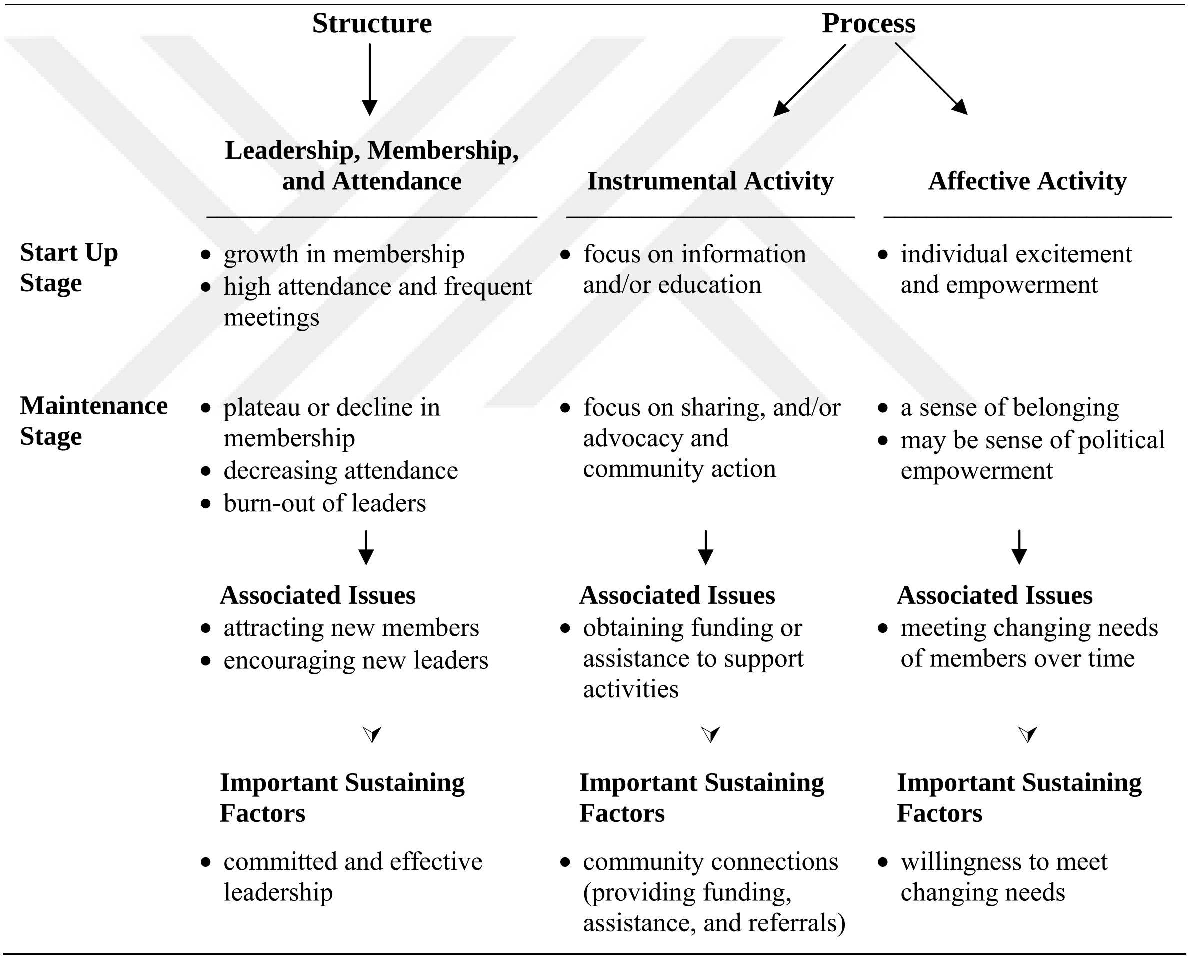

*Figure 7. A developmental model of changes in the structure, process, and issues in the maintenance of self-help groups for the children with special needs.* (Taken from King, et al., 2000, p. 237).

In terms of instrumental activities, the King et al. model states that during the start-up stage, group members focus on information and education, whereas in the maintenance stage, members focus on sharing, discussion, advocacy, and community action. Current study findings found no differences in terms of instrumental activities carried out in two stages. In both stages, parents were interested in all of the above mentioned activities. The model states challenges for instrumental activities as obtaining funding or assistance to support group activities. Because the oPSG operates online, these challenges were not issues for the oPSG.

In terms of affective activities, the current study findings support the King et al. model. During the start-up stage, parents were excited about finding a group of individuals with similar concerns and later there was a strong sense of belonging and political empowerment. For example, some parents founded local autism associations, arranged a parent meeting at a professional conference, and collaborated with columnists. However, these results only represent those who had a strong sense of belonging and empowerment and those who articulated these in the online messages. It is possible that these results do not reflect all parents' views.

Another interesting finding of the study was the presence of non-parent members in the oPSG. It is evident that there was reciprocal communication between parents in the oPSG and non-parent members. The Social Systems Model of Family Functioning (Dunst, et al., 1986) states that members of the family and individuals from ecosystems that surround the family influence each other. In the current study, although parent-to-parent support formed the core of the oPSG, parents' interactions with other group members (e.g. professionals, volunteers) enabled them to receive support from these individuals. This was mostly in the form of informational support. In return, parents provided these professionals with information which might be helpful to refine their practices. Professionals consisted of almost 13% of the all group members, which sent 14% of the all messages. In contrast, parents sent 84% of the messages. Therefore, it can be concluded that professionals could provide support for parents in online support groups as long as they do not dominate discussions and impose their ideas. Future studies should seek ways to investigate the relationship between parents in professionals in online support groups.

### *Parents' Experiences of Raising a Child with Autism*

Results suggested that most parents in the oPSG expressed their willingness to participate in their children's education. However, in many cases parents were not given such opportunities. In spite of the macro level attempts made by the Turkish Ministry of National Education to integrate children with disabilities in mainstream classrooms (MoNE, 2004), the parents' experiences show that there are several barriers to inclusive education. These barriers are difficulty in finding inclusive classrooms and attitudes of parents of typically developing children

First, all parents had difficulty in finding inclusive classrooms. Although by law every child, regardless of disability has a right to receive public education, parents' narratives displayed the problems in the implementations of laws and regulations. As data analysis suggested, sometimes principals or teachers were unwilling to accept a child with autism into their schools or classrooms. Sometimes parents had to make donations to get their child enrolled. This raises an important question regarding the education of children with disabilities: Is free public education accessible by all children with disabilities in Turkey? Is it accessible regardless of parents' socioeconomic status or children's disabilities? Unfortunately, answers to these questions were not provided by the current study. It is possible that parents from low SES may have been turned down by the schools in their district, may not have persisted to seek alternate schools/options, or may not have had funds to send their children to private educational institutions.

Ministry of National Education statistics show that during the 2003-2004 school year, there were 64,000 students (43,300 in inclusive classrooms) receiving special education in public schools. However, during the same school year, more that 14 million students were enrolled in K-12th grades. Eripek (1995) estimates that up to 14% of the Turkish children aged between 1 to 18 years have special education needs. Using this estimate, it can be concluded that roughly more than 2 million Turkish children need special education. Of these school-age children, only 10% are estimated to benefit from public education system (Uzundemir, 2000). According to the second estimation, there should be 200,000 Turkish students receiving special education. Considering these estimates, it is clear that a large percentage of the Turkish children with disabilities are not benefiting from public education.

The second barrier to inclusive education is the attitude of parents of typically developing children. Results showed that in some cases, parents of typically developing children did not welcome the presence of a child with autism in the classroom. As explained in detail in the Results chapter, these negative attitudes were caused by three factors: the possibility of physical harm to typically developing children, the possibility of "contamination" of autism—which originates from the lack of knowledge regarding autism, and consumer attitude of the parents of typically developing children. Especially in the context of private schools, these parents thought that having a child with autism could monopolize the teachers' time, hence their children might not learn as expected. These finding do not support the previous research results. For example, Tafa and Manotlitsis (2003) report that Greek parents of typically developing children had positive attitudes toward inclusion and their attitudes were not affected by their gender or level of education. This could be due to the implementation of different research methodologies. Tafa and Manotlitsis study results are based on a survey of parents of typically developing Greek kindergarten children, whereas the results of the current study are based on the perceptions of the parent of children with autism. It is also possible that in survey studies, respondents give more desirable answers than their actual beliefs.

Negative attitudes of parents of typically developing children pose two risks for inclusive practices (Stoneman, 2001). First, negative parental attitudes might affect child care center policies. Second, parental attitudes are also transferred to their typically developing children, which might result in the adoption of same negative attitudes. The study findings show that there is a strong need in Turkey for public education about disabilities.

Inclusion of children with disabilities provides them with the opportunity to develop social skills in a typically developing peer group (Odom, et al., 1996). Studies report controversial findings on the social benefits of inclusive practices. For example, in inclusive education settings, typically developing children accept their peers with disabilities and have more positive attitudes toward individuals with disabilities (Nikolaraizi, Kumar, Favazza, Sideridis, Koulousiou, & Riall, 2005). Similarly, Laws and Kelly (2005) reported a positive attitude change among 9-12 year old children towards their peers with Down syndrome. However, in Laws and Kelly study negative attitudes were also reported towards physical disabilities after being provided with information about cerebral palsy. The current research found both positive and negative attitudes toward children with autism in inclusive settings. In some cases, parents reported that their children were accepted by their peers, whereas in other cases, parents expressed that their children were being bullied because of their disabilities or the symptoms associated with disabilities. These results highlight the importance of education programs targeted at teachers, typically developing children and their parents.

In contrast to other studies (Tarakeshwar and Pargament, 2001) and parental accounts (Welteroth, 2001) reporting references to God or religion, parents in the current study made no references to God or religion in their email messages. Although parents expressed their love and affection for their children with autism, unlike the findings of other studies, none of them saw their children as "blessing" or "a gift from God." Similarly, there were no references to bad luck or ill fate. This is also somewhat different than the results of Akkok, Askar, and Karanci (1996) study that surveyed 142 parents of children with mental disabilities and autism in Turkey. In their study investigating the causal attributions of the parents of children with disabilities, Akkok and her colleagues found that parents were making causal attributions to bad luck and ill fate, in addition to self, family, and external factors. The reason for making causal attributions might be related to parents' level of education. As the level of education increases, it is expected that parents use more scientific expectations as coping strategies. To examine this hypothesis further, future studies should investigate parents with different educational levels and SES.

Results suggested that most parents in the current study were not satisfied with their experiences with professionals. Other studies report similar results suggesting that parents of children with disabilities find professionals' advice either too technical or inadequate, or lack of concern, support, and information (Case, 2000). In contrast, an advice from parents who are experiencing similar conditions may be perceived as more useful (Smith, et al., 1994).

### *Parents' Use of Support System*

Parents in the current study were using the oPSG to receive or offer informational and emotional support and to create a network of parents with similar concerns. These findings are parallel to those of Braithwaite et al. (1999) study, which reported informational, emotional, and network supports to be the most common types of social support used by online support group members.

The most commonly used type of social support in the current study was informational support. Parents used all possible sources in order to get more accurate information about autism, its causes, different therapy options, and special education resources. Informational support messages included sharing experiential knowledge, resources, advice, and referrals. Sharing of the experiences allowed parents to find information that was difficult to find from other sources, such as books, magazines, or doctors. The findings of this study support the concept of experiential knowledge (Borkman, 1999) that states this kind of knowledge is often transmitted through stories. Analyses of email messages and interviews revealed that parents highly regarded the information they got from their peers. However, they were also cautious about the generalizability of the information they received.

Emotional support was the second commonly used type of social support in the oPSG. Emotional support messages found in the current study includes encouragement, empowerment, sympathy, and validating feelings. Emotional support messages constituted an important part of social support received from the other members of the oPSG. As shown by research findings, parents feel intense stress and isolation following the diagnosis of autism in their children (Gray, 2002; Simmerman, et al., 2001). There are several ways to receive emotional support during the times of stressful events. One way is to turn to immediate family member and close friends. Another way is to receive emotional support from parents who are experiencing similar conditions. Sharing experiences with people in similar conditions help people validate feelings, reciprocate emotions, and reduce anxiety and isolation (Braithwaite, et al., 1999; Campbell & Wright, 2002; Preece, 1999). Perceived similarity is also essential to the success of parent-to-parent programs (Aibinder, et al., 1998). These were all characteristics of the emotional support exchanged by the parents in this study.

Data analyses showed that some parents continued their relationship beyond the online environment and formed friendships. These parents employed several communication methods including face-to-face communication, telephone conversations, and instant messaging. These results do not support Wright's (1999) suggestions that relationships formed in online support groups tend not to evolve into face-to-face relationships. Wright's suggestion was based on the anonymity and self-disclosure of personal information. As discussed previously, parents in this study were not concerned about keeping anonymous nor disclosure of personal information. Therefore, meeting face-to-face posed no risk for these parents.

Another important finding of the study was the change in the nature of support over time. While in the beginning of their membership most members were seeking support from other group members, in later years some of these members began offering support to other members. These findings support the results of earlier studies (Kerr & McIntosh, 2000; Solomon, et al., 2001) that report similar changes in the nature of support for the face-to-face support group members. It can be concluded that being an oPSG member is an ongoing educational experience that results in a positive change in parents.

### *Perceived Satisfaction Factors that Contribute to the Perceived Satisfaction*

A number of factors contributed to the perceived satisfaction with the group support, including the sense of belonging, level of participation, credibility of information, new member recruitment and information flow, and meeting individual needs. Determining the credibility of information found in the oPSG was a potential challenge for some parents in the study. Parents were receiving information from multiple sources, including other group members, the Internet, conventional resources (e.g., books, journals, and magazines), and from professionals. However, the presence of professionals raised concerns about the trustworthiness of the information received from these individuals. Baum (2004) argues that finding people to trust in online support groups is closely associated with the perceived satisfaction with the group. This argument is supported by the results of the current study. When professionals' messages implied a possibility of commercial interest, parents raised concerns about whether these professionals' goals were "to help them" or "to make a profit". Thus, uninvited professionals' participation in online parents support groups poses some ethical concerns.

Future research would benefit from examining the potential benefits and drawbacks of the participation of these professionals.

Perceived satisfaction with the group was also associated with the level of participation in the discussions. In general, parents seemed to be satisfied when there was an optimum level of communication among members. However, low number of messages or excessive number of messages (including off-topic messages, such as forwarded jokes) contributed to the dissatisfaction with the support group. Wright (1999) reports that participant satisfaction with the support group in online groups is positively correlated with the number of online hours per week participants reported. Although I only asked interview participants about their average weekly Internet use, analyses of qualitative data revealed similar results to the Wright (1999) study. In the current study, parents who reported their satisfaction with the support group were among the frequent contributors. In addition, according to social network analysis results, these parents belonged to 9-core or 7-core (highly connected) subgroups. Therefore, it is possible that parents who spend more time in posting or reading messages will likely to express their satisfaction. Future research should seek ways to includes parents from low participation levels.

Studies suggest that perceived satisfaction with social support is strongly correlated with physical and mental health variables (Vandervoort, 1999). It was also reported that parents found support groups more helpful when their child is in “better” condition (Smith, et al., 1994). However, when things went wrong, such as a family crisis or hospitalization, these parents did not find support groups helpful. Unfortunately, because of small sample size, the results of the current study cannot fully support these arguments.

### *Perceived Advantages and Disadvantages of Online Medium*

Findings of the study indicated that the oPSG offered many advantages compared to face-to-face support groups. One of the biggest advantages of the online parent support group cited by parents was its capability of archiving old messages. This was not mentioned by previous studies. Unlike members of face-to-face support groups, members of online groups can search or browse archived messages. By searching and reading old messages these members can find answers to their questions without asking anyone. Additionally, reading old messages gives new members an opportunity to learn group "netiquette," types of the questions asked, and what to expect from the group.

It has been suggested that through lurking, non-participating members learn the norms and "netiquette" of the group and find answers to basic questions (Finfgeld, 2000; Walther & Boyd, 2002). This was also supported by the current study. For example, some parents expressed that they observed the group communication for a while before posting any messages. Then they concluded that the messages posted to the group have therapeutic or informational value and began posting messages. Some parents expressed that observing group communication helped them identify with other parents, perceive them as being in a similar situation and thus made them comfortable in initiating conversations with other group members.

Online parent support groups differ from other types of self-help and support groups. Literature on online support groups stresses the importance of anonymity as being one of the advantages of online support groups. According to Wright (2000), anonymity in online support groups give participants a perception that there is less stigma attached to certain illness or conditions such as substance abuse problems, eating disorders, cancer and mental illnesses. This may have been an important factor where anonymity of the participants would allow them better express themselves without worrying about revealing their identities. However, this was not the case for the oPSG in the current study. In fact, parents wanted to disclose their identity, personal information, and contact information in order to get in touch with other parents. Therefore, it can be concluded that parents of children with autism (and in general parents of children with disabilities) do not fit in the stereotype of online support group participants, where anonymity is an important factor in facilitating communication.

Literature suggests that online PSGs are helpful for parents, especially for those who live far away from big cities and metropolitan areas (Scharer, 2005). However, this was not supported by the results of this research. Almost one third of the parents lived in Istanbul (n = 20), which is a big metropolis, and the rest of the parents were also from big cities. This could be explained by parents' socioeconomic status and their opportunities to access the Internet. Although Internet use is increasing rapidly in Turkey, statistics and estimates show that only 12% of the population use the Internet regularly (Cagiltay, 2005; Turkish Statistical Institute (TSI), 2006). These statistics show that a very low percentage of Turkish people use the Internet compared to the other Western and industrialized nations (TSI, 2006). One alternative way for accessing the Internet services is the use of public computing resources (e.g., Internet cafes, libraries) or school and work resources. In fact, current results of the study revealed that some parents were using their work email to communicate with the members of the oPSG.

Although online parent support groups offer many advantages over the face-to-face parent support groups, there are also many disadvantages. As documented in email analyses and interviews, parents sometimes received large volumes of emails or off-topic emails that were in the form of forwarded emails, advertisement, spam, chain email and petitions. This was perceived by some parents as overwhelming and causing dissatisfaction with the group support. Although it is possible for the technologically advanced users to block or filter some of these emails, in general, parents were not using such measures to prevent themselves from unwanted emails. Han and Belcher (2001) argue that large volumes of emails could be viewed as a disadvantage of online support groups. While this argument may be true for some parents, others welcomed large volumes of messages as long as they were related to discussion topics.

One of the disadvantages of online parent support groups cited by parents is the possibility of receiving misinformation from the group members. This potential disadvantage has also been mentioned by other researchers (Braithwaite, et al., 1999; Wright & Bell, 2003). In addition to receiving misinformation, parents may receive correct information that might not be applicable for their situation. This concern was raised by several parents noting that a specific technique or information that works for them might not work for others.

The existence of nonverbal cues in the CMC sometimes causes negative experiences. For example, it was observed that in several occasions simple misunderstandings among parents resulted in severe verbal arguments. If the same messages were exchanged in face-to-face communication, their interpretations could have been different and might not have resulted in conflict. These findings support Walther and Parks (2002) findings that because of the lack of nonverbal cues in CMC, participants tend to display greater hostility towards others. Analysis suggested that these simple misunderstandings could have been prevented by carefully writing and reading the messages. This finding does not fully support previous claims that in CMC online interactions are more formal, thoughtfully crafted, and marked in sentences with punctuation marks (Denzin, 1999). While ideally this explanation is true for most situations, some messages in the current study lacked such nonverbal cues and grammar/punctuation information.

### *Threats to Validity*

There are several threats to validity of research findings. First threat is related to the data analysis method used in the current study. For data analysis I primarily used Spradley's Developmental Research Sequence (DRS). DRS is an ethnosemantic approach (Parfitt, 1996) that explores cultural knowledge through the study of participant narratives and uncovers the meaning behind their actions and narratives. In conducting data analysis (especially in domain analysis) semantic relationships are used to discover the relationship between *cover terms* and *included terms*. Spradley (1979) suggests that the *semantic relationships* (strict inclusion, spatial, cause-effect, rationale, location for action, function, means-end, sequence, and attribution) he proposes are universal and applicable across cultures. While it is possible for some to argue that these logical structures are culture-contingent and not applicable to all cultures, I believe DRS as a methodological approach is universally applicable without being culture-contingent. However, it should also be noted that my perspective as a researcher might have been affected by sharing cultural similarities with my study participants. For example, most of the online support group members and interview participants were highly educated and living in urban settings. I can argue that most these participants are belong to middle and upper-middle class and more closer to the Western life/thinking style.

Additionally, conducting data analyses in native language and then translating only selected codes into English may pose some threats to the validity of the research findings. For example, in some instances there was no direct translation for the expressions used by parents. For these types of expressions I used possible closest meaning in English. It was also challenging to translate the quotes and write the results for the English audience. For example, in a couple of cases I had to use footnotes to explain the cultural context and language conventions associated with the quotes. Using peer debriefers was also helpful in minimizing the potential threat of translation process for validity of the study findings. Furthermore, being a native speaker and familiar with both Turkish culture and online culture allowed me to easily interpret the data and eliminated potential problems.

Another threat to validity is potential researcher bias. As a member of several online support and interest groups, my previous experiences and positive attitudes might have an influence on the interpretation of data. It is also possible that my interpretations of the data could have been influenced by previous research in the field. In order to prevent this potential bias and to increase the trustworthiness of data collection and analyses, I employed several techniques, such as collecting data from multiple sources and peer debriefing. First, I have collected data both from archived email messages and from parent interviews. During parent interviews I had chance to elaborate on the questions that were not easily answered by email data analysis. Second, peer debriefing enabled me share my findings and notes with two colleagues and receive feedback from them. Both peer debriefers were native speakers of Turkish and doctoral students in the U.S.

Lastly, in observation and interview studies the presence of the researcher might have an impact on the participants' behavior (Merriam, 1998). Since email data collection was retrospective in nature and there was no interaction with the study participants this potential threat is not an issue for the current study. However, during the parent interviews, I noticed that interview participants were more focusing on the positive aspects of the support group and telling only success stories. In order to minimize this threat I had to ask different types of interview questions, such as "grand tour" questions and contrast questions.

Despite these threats to validity, the current study attempts to explain the use of online parent support groups by using multiple sources of data and employing different data analysis methods, including descriptive analysis, social network analysis, and qualitative analysis. Future research is needed to further investigate the use of online parent support groups.

### *Implications of the Study*

There are a number of implications that could be drawn from the results of this study. First, the parents' experiences indicate a need to educate both the public in general and the teachers about the nature of autism and the rights of children with autism. In long term, public awareness campaigns could help change the negative attitudes towards individuals with disabilities. Another option is to educate parents of typically developing children by arranging meetings, workshops, sending newsletters or brochures. To accomplish this goal, teachers can collaboratively with other school professionals such as social workers, school psychologists, and parents of children with autism.

The topic of online PSGs could be incorporated into the curriculum of teacher education programs and other social service training programs. This would enable student teachers to get familiar with oPSGs, understand the basics of online support giving and receiving, and their outcomes on parents of children with disabilities. Similarly, through in-service training programs, existing teachers could be provided with information about these groups.

Second, the results of this study highlight the importance of service provider and agency web sites for information dissemination. The information found in some governmental, organizational, educational web sites was cited by parents as inadequate and ambiguous. Update on the content of these web sites could provide parents with detailed information on specific disabilities, available special education services, therapy options, government's financial support, parent rights, and related self-help guides.

Third, professionals play an important role in helping parents in online support groups by providing them with information and referrals. In doing so, professionals in parent-run online support groups, where they are regarded as "guests," should not dominate discussions or argue with each other in an unprofessional way. This type of behavior, rather than helping parents, may discourage their participation in discussions. Instead of providing parents with prescribed information, parents should be given options to choose from and encouraged to participate in the decision-making process. Most importantly, professionals should never impose their ideas. Instead, they should let the parents talk and interfere only when necessary. This would give parents a sense of empowerment and enable parents to control the stressful events around them.

Fourth, this study has several implications for moderators and parent members of online support groups. Moderators or parent members can enforce more strict rules on membership. This would help reduce “unsolicited” participation of non-parent members. New members could be asked to introduce themselves in their first email to the group. This email could contain the following information: The city parents live, child’s diagnosis, child’s age, therapy history, school history, and typical behaviors. This information would help better understand new members and create a sense of community. This could be also a good opportunity to start new discussion topics.

It has been shown that archived email messages are an important feature of online support groups and effective use of these archives could improve the functionality of these groups. New members could be encouraged to check archived emails before posting a new question. In addition, volunteering members could create a Frequently Asked Questions (FAQ) page to help new members find answers to certain questions.

### *Recommendations for Future Studies*

Future research might be conducted with more diverse samples. Studies conducted on both face-to-face and online parent support groups primarily examine parents from Western and/or English-speaking countries. This might be due to the fact that studies published in non-English languages do not reach to international audiences. Future studies should seek ways to include parents from diverse demographic backgrounds. Additionally, including more than one group in the sample or groups that focus on different types of disabilities could help us better understand the effectiveness of online parent support groups for diverse populations.

Longitudinal studies are needed to explore two issues: The first issue is the factors that contribute to the longevity of online parent support groups. Although this study attempted to explain some of these factors, future research is needed to verify the current study findings. The second issue is the change in the nature of support and identity change in parents. Future research should seek answers to the following questions: How does identity change occur in parents of children with disabilities? Why do not all parents change in the same way? What are the factors effecting identity change in parents of children with disabilities? To what extent do online support groups play a role in these identity changes?

Finally, researchers need to become familiar with new interactive communication technologies. Internet is a rapidly growing and changing medium and new interactive communication technologies emerge frequently while some technologies vanish in time. Today, new interactive communication technologies are gaining popularity among Internet users. In addition to text-based communication, these new technologies also support sharing pictures, instant messaging and immediate feedback, voice communication, or both voice- and video-based communication. Also a new concept is blogging. Blogs, (short for weblog) which can be considered as online diaries, allow users to submit entries on a daily basis to a web site. These entries could be accessed publicly or by authorized users and could contain text, picture, audio or video information. Visitors of these blogs may respond to the entries. As educators and social science researchers, we should be familiar with these kinds of new interactive communication technologies. This would help us better understand the users of online support groups and create intervention and support programs to suit their needs.

### *Conclusion*

The results of the current study highlight the importance of online parent support groups in providing support for the Turkish parents of children with autism. A number of conclusions may be drawn from the current study. First, 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.

Second, 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.

Third, 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.

Fourth, 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.

This study used a blend of qualitative data analysis, social network analysis, and descriptive data analysis to examine the use of an online parent support group by the Turkish parents of children with autism. The results of this study have implications for parents, service providers, policy makers, and researchers. As the number of Internet users grow rapidly, it is expected that there will be an increasing demand for online parents support groups. Therefore, it is possible to see more studies conducted on this topic in the near future. It is my hope that this study will contribute to the body of knowledge and inspire future studies.

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# APPENDIX A

Study # 05-9767

## RECRUITMENT SCRIPT

Dear Parent,

I am a doctoral student in the School of Education at the Indiana University at Bloomington, Indiana, researching the use of online parent support groups. I am currently conducting my dissertation research. The purpose of my research is to study the use of online parent support groups by the parents of children with autism in Turkey. The results of this study will help me better understand the factors that affect participation in online parent support groups.

I have found your email address from __________ online parent support group and I would like to conduct a telephone interview with you about your participation in this online parent support group. This interview will last about 30-40 minutes. More information about the study can be found in the attached study information sheet. Sample interview questions are also provided in the attached document.

Your participation in the study is voluntary, and all information will be kept confidential. Your name will not be used in any way, and no one will know about your specific answers except the study researchers. If you agree to participate in this interview please contact me so that I can schedule an interview. Please print and save a copy of the attached study information sheet for your records.

Your participation in this study is appreciated. If you have questions about this study please contact me at alat@indiana.edu.

Sincerely

Kazim Alat

Study # 05-9767

# RECRUITMENT SCRIPT – TURKISH TRANSLATION

Değerli anne-baba,

Indiana Universitesi, School of Education'da doktora eğitimime devam etmekteyim. Su anda doktora tezim üzerinde çalışıyorum ve tez konum otistik çocuğu olan anne-babaların online destek gruplarını kullanımları. Bu araştırmanın sonuçları anne-babaların online destek gruplarını kullanımlarına etki eden faktörlerin daha iyi anlaşılabilmesine olanak sağlayacaktır.

İsminizi ve email adresinizi ____________ online destek gruundan buldum. Bu aratırma için sizinle bir telefon görüşmesi yapmak istiyorum. Bu görüşme yaklaşık olarak 30-40 dakika civarında sürecektir. Araştırma hakkındaki ayrıntılı bilgiyi ekteki "araştırma bilgi sayfasinda" bulabilirsiniz. Ayrıca örnek görüşme sorularını da ekteki dosyada bulabilirsiniz.

Bu araştırmaya katılımınız gizli kalacaktır. Vereceğiniz bilgiler güvenli bir yerde saklanacak ve araştırmacı dışında başka biri tarafından görülmeyecektir. Bu araştırmaya katılmaya karar veririseniz lütfen benimle iletişime geçiniz. Lütfen ekteki araştırma bilgi sayfasının yazıcıdan bir çıktısını alın ve kayıtlarınız için saklayın.

Değerli vaktinizden zaman ayırıp bu araştırmaya katılmayı kabul ettiğiniz icin size çok teşekkür ederim. Araştırma hakkında daha ayrıntılı bilgi isterseniz lütfen benimle alat@indiana.edu adresinden iletişime geçiniz.

Saygılarımla

Kazım Alat

# APPENDIX B

## Sample Interview Questions

*Questions about the characteristics of group members*

- Tell me about the time when you first heard about this group.
- Are you a member of other parent support groups? (online or face-to-face) If so, tell me about the other groups.
- On average how much time in a week do you spend reading or responding to email messages from this support group/other support groups?
- Do you read/write email messages with your spouse? Is she/he also member of the oPSG?

*Questions about Support type/Perceived effectiveness/Perceived satisfaction*

- What were your expectations from this support group?
- What types of support/information you receive from the support group?
- What benefits have you gained from this support group? What drawbacks or costs are there in participating this support group?
    - Can you tell me about an example of a benefit you gained from this support group? / …a drawback you have experienced while participating in this support group?
- Have you changed in any way since you started being part of this group? If so, how?
- Are you satisfied or dissatisfied with the group support? To what extend does the group meet or not meet your needs?
    - Can you tell me about an example of satisfaction/dissatisfaction? Why you felt satisfied/disappointed?

*Question about advantages/disadvantages of online parent support groups*

- Suppose you met a parent who as a child with autism and you want to recommend him/her this online support group. What would you say about it?
    - Tell me about the advantages of participating in this online parent support group.
    - Tell me about the disadvantages of participating in this online parent support group.

# APPENDIX C

## Sample Interview Questions—Turkish Version

*Destek grubu üyeleri ile ilgili sorular*

- Lütfen bu destek grubunu ilk duyduğunuz anı anlatınız.
    - İlk olarak ne zaman bu gruptan haberdar oldunuz?
    - Bu grubu nasıl buldunuz?
- Diğer anne baba gruplarının da üyesi misiniz? (online ya da yüz yüze gruplar) Eğer başka gruplara da üye iseniz kısaca bu gruplar hakkında bilgi verir misiniz?
- Ortalama olarak bir hafta boyunca bu gruptan gelen mesajları okumak ya da cevap yazmak için ne kadar zaman harcıyorsunuz?
- Eşiniz de sizinle birlikte gruptan gelen mesajları okuyor mu? Gruba üye mi?
- Yardıma ihtiyacınız olduğunda bu grup dışında başka kimlere başvuruyorsunuz?

*Destek türü, algılanan etkililik, algılanan memnuniyet*

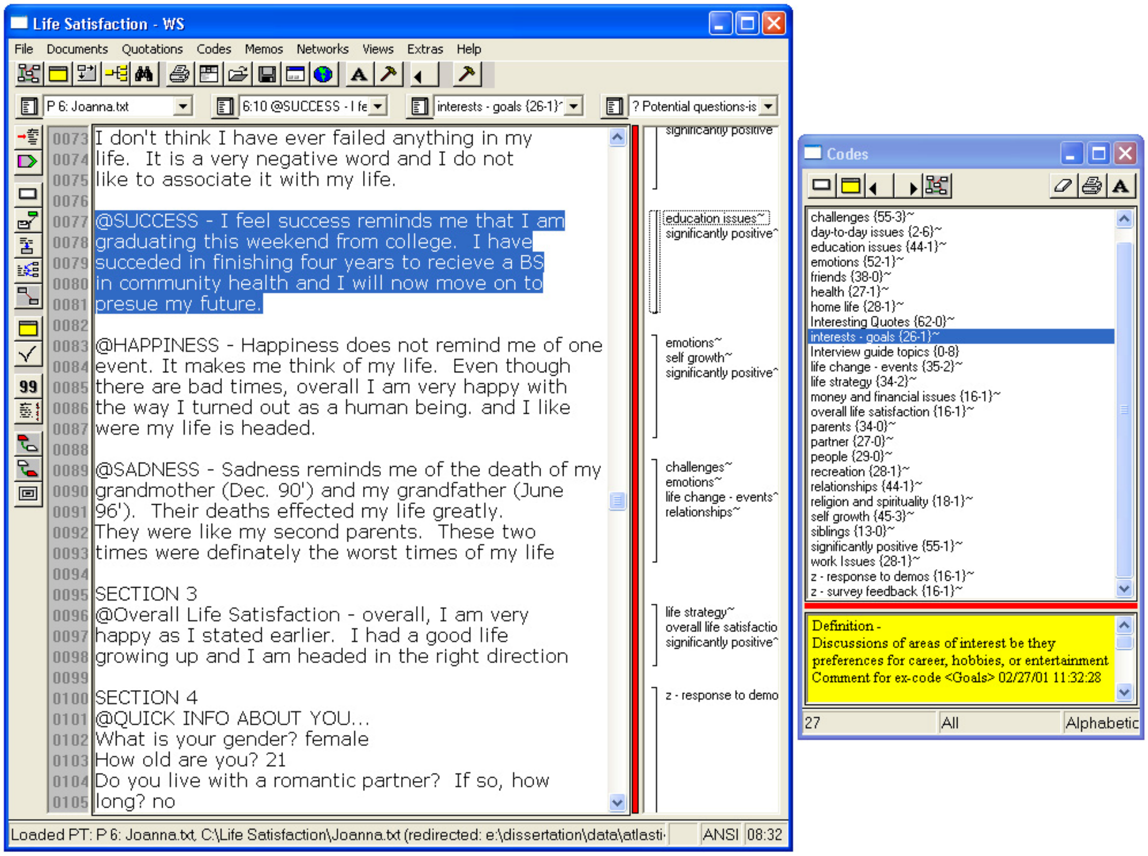
- Bu gruptan beklentileriniz nelerdi?
- Bu gruptan ne türde destek, yardım, ya da bilgi alıyorsunuz?
- Bu grubun size ne gibi faydaları oldu?
- Gruba üyeliğinizden beri sizde herhangi bir tür değişim oldu mu? Eğer olduysa nasıl?
- Grup desteğinden memnun musunuz? Ne dereceye kadar bu grup ihtiyaçlarınızı karşılıyor?
- Bu grubu bir başka kişiye tavsiye edecek olsanız grup hakkında neler söylerdiniz?

*Online anne baba destek grubu faydaları ya da zararları*

- Online anne baba destek grubunun faydaları ya da olumlu yönleri nelerdir?
- Online anne baba destek grubunun zararları ya da olumsuz yönleri nelerdir?

# APPENDIX D

## Sample screenshot for Atlas.ti hermeneutic unit editor



I don't think I have ever failed anything in my life. It is a very negative word and I do not like to associate it with my life.

@SUCCESS - I feel success reminds me that I am graduating this weekend from college. I have succeded in finishing four years to recieve a BS in community health and I will now move on to presue my future.

@HAPPINESS - Happiness does not remind me of one event. It makes me think of my life. Even though there are bad times, overall I am very happy with the way I turned out as a human being. and I like were my life is headed.

@SADNESS - Sadness reminds me of the death of my grandmother (Dec. 90') and my grandfather (June 96'). Their deaths effected my life greatly. They were like my second parents. These two times were definately the worst times of my life

SECTION 3
@Overall Life Satisfaction - overall, I am very happy as I stated earlier. I had a good life growing up and I am headed in the right direction

SECTION 4
@QUICK INFO ABOUT YOU...
What is your gender? female
How old are you? 21
Do you live with a romantic partner? If so, how long? no

Loaded PT: P 6: Joanna.txt, C:\Life Satisfaction\Joanna.txt (redirected: e:\dissertation\data\atlasti·   ANSI   08:32

challenges {55-3}~
day-to-day issues {2-6}~
education issues {44-1}~
emotions {52-1}~
friends {38-0}~
health {27-1}~
home life {28-1}~
Interesting Quotes {62-0}~
interests - goals {26-1}~
Interview guide topics {0-8}
life change - events {35-2}~
life strategy {34-2}~
money and financial issues {16-1}~
overall life satisfaction {16-1}~
parents {34-0}~
partner {27-0}~
people {29-0}~
recreation {28-1}~
relationships {44-1}~
religion and spirituality {18-1}~
self growth {45-3}~
siblings {13-0}~
significantly positive {55-1}~
work Issues {28-1}~
z - response to demos {16-1}~
z - survey feedback {16-1}~

Definition -
Discussions of areas of interest be they preferences for career, hobbies, or entertainment
Comment for ex-code <Goals> 02/27/01 11:32:28

27   All   Alphabetic

# APPENDIX E

Study # 05-9767

## INDIANA UNIVERSITY – BLOOMINGTON
## STUDY INFORMATION SHEET

The Use of Online Parent Support Groups by Turkish Parents of Children with Autism

You are invited to participate in a research study. The purpose of this study is to provide a systematic description of the use of an online parent support group by the parents of children with autism in Turkey.

### INFORMATION

The study involves scheduling a telephone interview with you. You will be interviewed only once and this interview will last about 30-40 minutes. During this interview you will be asked about your experiences as a member of an online parent support group. During our interview your responses will be audio taped. Upon completion of the interview, the tape will be transcribed. You will be emailed a typed transcript of your responses and asked to make any changes you would like. At this time, if needed, follow-up questions may be asked to clarify your responses to interview questions. The audio tapes will be destroyed at the end of the study (by December 31, 2005). The total number of participants in the study will be around eight.

### RISKS

There are no risks associated with participating in this research study.

### BENEFITS

It is anticipated that by participating in this study you will have an opportunity to reflect on your experiences as a member of an online parent support group. Your participation will help me better understand the factors that affect participation in online parent support groups. This information is valuable to the field of special education and will help educators and special education providers to plan better services in the future.

### CONFIDENTIALITY

The information in this study will be kept confidential. Data will be stored securely and will be made available only to the person conducting the study. Names will not be recorded with the data and no reference will be made in oral or written reports which could link you to this study. A code list with your real name and assigned pseudonyms will be used. The code list will be destroyed by December 31, 2005. Every precaution will be taken to protect your confidentiality. However, due to the small sample size of the study there is a possibility that your responses could be linked to you. As a precaution, in the reports, comments will be described only as being “from a northwestern Turkish city,” “a female parent,” “a male parent,” etc.

## CONTACT

If you have any questions at any time about the study or procedures, please contact Kazim Alat at the following addresses:

USA: 120 S Kingston Dr Apt 26, Bloomington In 47403; or call (812) 339-7691; or email: alat@indiana.edu.
Turkey: Cay Mah. 8062. Sk. No: 3 35590, Cigli, Izmir

If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have not been honored during the course of this project, you may contact the office for the Indiana University Bloomington Human Subjects Committee, Carmichael Center L03, 530 E. Kirkwood Ave., Bloomington, IN 47408, 812/855-3067, or by e-mail at iub_hsc@indiana.edu.

## PARTICIPATION

Your participation in this study is voluntary, you may refuse to participate without penalty. If you decide to participate, you may withdraw from the study at anytime without penalty. If you withdraw from the study before data collection is completed your data will be destroyed.

Study Information Sheet Date: 02/22/2005

IRB Approved
Approval Date: FEB 22 2005
Expires: DEC 31 2005

Araştırma Numarası: 05-9767

## INDIANA UNIVERSITY – BLOOMINGTON
## STUDY INFORMATION SHEET – TURKISH TRANSLATION

## INDIANA ÜNİVERSİTESİ – BLOOMINGTON
## ARAŞTIRMA BİLGİ SAYFASI

Otistik Çocuk Anne-Babalarının Online Destek Gruplarını Kullanımları

Bu çalışmanın amacı Türkiye'de otistik çocukların anne-babalarının online destek gruplarını kullanmalarını incelemektir.

### BİLGİ

Bu çalışma sizinle bir telefon görüşmesi yapmayı kapsamaktadır. Sizinle sadece bir kez telefon görüşmesi yapılacak ve bu görüşme yaklaşık 30-40 dakika civarında olacaktır. Bu görüşme esnasında size online anne-baba destek grubu ile ilgili deneyimleriniz hakkında sorular sorulacaktır. Görüşmemiz süresince vereceğiniz cevaplar ses kayıt cihazı ile kaydedilecektir. Görüşme bittikten sonra bu ses kaydı yazılı metne dönüştürülecektir. Bu metin daha sonra size email ile gönderilecek ve üzerinde değişiklikler yapmanıza fırsat tanınacaktır. Bu esnada size bazı yorumlarınıza açıklık getirmek üzere başka sorular sorulabilir. Ses kayıtları çalışma sonunda (31 Aralık 2005) imha edilecektir. Bu araştırmanın toplam katılımcı sayısı 8 kişi civarında olacaktır.

### RİSKLER

Bu araştırmaya katılmak herhangi bir risk içermemektedir.

### FAYDALAR

Bu çalışmaya katılmak size online anne-baba destek grubunda edindiğiniz deneyimleriniz üzerine düşünme fırsatı verecektir. Ayrıca katılımınız biz araştırmacıların online anne baba destek gruplarını daha iyi anlamasına olanak sağlayacaktır. Sizden edineceğimiz bilgiler özel eğitim alanında gelecekte daha iyi hizmetler verilmesi icin büyük önem taşımaktadır.

### GİZLİLİK

Bu araştırmaya katılımınız gizl kalacaktır. Vereceğiniz bilgiler güvenli bir yerde saklanacak ve araştırmacı dışında başka biri tarafından görülmeyecektir. Veri kayıtlarında adınız hiçbir şekilde geçmeyecek, araştırma raporunda da adınız yerine rumuz kullanılacaktır. Kimliğinizi gizlemek için her türlü tedbir alınacaktır. Fakat araştırmanın kapsamı gereği katılımcı sayısının az olması nedeniyle verdiğiniz bazı cevaplar size işaret edebilir. Bunu önlemek amacıyla araştırmanın yazılı raporunda “”bir anne” “bir baba” “Türkiye'nin batı bölgesindeki bir şehirden bir baba” gibi ibareler kullanılacaktır.

## İLETİŞİM

Araştırma hakkında sorularınız için Kazım Alat ile lütfen asağıdaki adreslerden iletişim kurunuz.

USA: 120 S Kingston Dr Apt 26, Bloomington In 47403;
Telefon: 001-812-339-7691; email: alat@indiana.edu.
Türkiye: Çay Mah. 8062. Sk. No: 3 35590, Çiğli, İzmir

Araştırmaya katılımınız esnasında bu belgede yazılandan farklı bir işleme tabi tutulduğunuzu düşünüyorsanız, ya da haklarınızın ihlal edildiğini düşünüyorsanız aşağıdaki adresteki yetkililerle bağlantıya geçebilirsiniz.

Indiana University Bloomington Human Subjects Committee,
Carmichael Center L03, 530 E. Kirkwood Ave., Bloomington, IN 47408 USA
Tel: 001-812-855-3067, e-mail: iub_hsc@indiana.edu.

## ARAŞTIRMAYA KATILIM

Bu araştırmaya katılmak gönüllülük esasına dayalıdır. Şimdi katılmaya karar verseniz bile ileride istediğiniz an araştırmadan çıkabilirsiniz. Bu durumda sizinle ilgili veriler imha edilecektir.

Bilgi Formu Tarihi: 22 Şubat 2005

IRB Approved
Approval Date: FEB 22 2005
Expires: DEC 31 2005

# KAZIM ALAT

e-mail: alat@indiana.edu

## EDUCATIONAL BACKGROUND

| | |
|---|---|
| 2001 - 2006 | Indiana University, School of Education,<br>Department of Curriculum & Instruction<br>Early Childhood Education Doctoral Program<br>*Bloomington, Indiana* |
| 2000 - 2001 | Indiana University, School of Education,<br>Department of Curriculum & Instruction,<br>Early Childhood Education Master's Program<br>*Bloomington, Indiana* |
| 1998 - 1999 | Middle East Technical University, Department of Psychology, Developmental Psychology Master's Program (18 credits taken).<br>*Ankara, Turkey* |
| 1996 | Hacettepe University, Department of Psychology,<br>Psychometrics Master's Program. (9 credits taken)<br>*Ankara, Turkey* |
| 1991 - 1996 | Hacettepe University, Department of Psychology,<br>Bachelor of Arts in Psychology.<br>*Ankara, Turkey* |

## PROFESSIONAL EXPERIENCE

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|---|---|
| 2005 - 2006 | STC Consultant<br>Student Technology Centers, Indiana University,<br>*Bloomington, Indiana* |
| 2003 - 2004 | Technical Consultant and Program Evaluation Assistant<br>Monroe County CAPE Project<br>*Bloomington, Indiana* |
| 2000 - 2003 | Graduate Research Assistant<br>Indiana University, School of Education,<br>*Bloomington, Indiana* |
| 1998 - 2004 | Webmaster<br>Turkish Psychological Association<br>*Ankara, Turkey*<br>Responsible for design and development of TPA's web site |
| 1999 | Research & Teaching Assistant,<br>Middle East Technical University, Department of Psychology,<br>*Ankara, Turkey* |

## PUBLICATIONS & PRESENTATIONS

### Publications

McMullen, M. B., **Alat, K.**, Buldu, M., & Lash, M. (2004). A snapshot of NAEYC’s preschool professionals through the lens of quality. *Young Children*, *59*(2), 87-92.

McMullen, M. B., Buldu, M., Lash, M., **& Alat, K.** (2004). Examining multiple perspectives on quality in preschool professionals with the Early Childhood Professional Questionnaire (ECPQ). *Child Care Information Exchange*, *157*, 31-35.

Alat, K. (2002). Traumatic Events and Children: How Early Childhood Educators Can Help. *Childhood Education, 79*, 2-8.

McMullen, M. B., & **Alat, K.** (2002). Education matters: Preschool teachers' level and type of educational preparation and the adoption of a developmentally appropriate philosophy. *Early Childhood Research & Practice, 4*(2). http://ecrp.uiuc.edu/v4n2/index.html

### Presentations

Alat, K. (June 11, 2005). An Online Community of Parents of Children with Autism: A Turkish Case. Poster presented at the 10th Biennial Conference of Society for Community Research and Action, Urbana-Champaign, IL.

McMullen, M., **Alat, K.**, Lee, S., Yang, H., Elicker, J., Mathers, C., Goetze, G., Huang, H., & Wen, X. (April, 13, 2004). Using mixed methodologies to develop an in-depth picture of factors that impact preschool teachers’ beliefs and practices in the U.S. Paper presented at the annual conference of the American Educational Research Association’s Annual Conference, San Diego, CA.

November, 2003 - McMullen, M. B., & **Alat, K**. Multinational conceptions of quality preschool care and education: A comparison of beliefs and practices in the U.S., China, Taiwan, Korea, and Turkey. Presentation at the National Association for the Education of Young Children’s Annual Conference, Chicago, IL.

McMullen, M., **Alat, K.**, Lin, C., Sun, P., Lee, S., Buldu, M., & Yilmaz. A. (March, 2003). Portraits of ECE professionals in the U.S., Taiwan, Korea, and Turkey. Paper presented at the annual conference of the Indiana Association for the Education of Young Children (IAEYC), Indianapolis, IN

McMullen, M., **Alat, K.**, & Lash, M. (April 21, 2003). Should a four-year degree be required for preschool teachers? Paper presented at the annual conference of the American Educational Research Association, Chicago, IL.

**Alat, K.**, & Alat, Z. (April, 15, 2003). Helping Children Cope with Traumatic Events: Activities for Early Childhood Educators. A workshop presentation for the

Association for Childhood Education International’s Annual International Conference, Phoenix, AZ.

McMullen, M., Wang, J., Elicker, J., Lin, C., Sun, P., Lee, S., Erdiller, Z., **Alat, K.**, Buldu, M., Lash, M., & Yilmaz, A. (August 28, 2002). Differences and Commonalities in Beliefs about Effective Learning and Teaching held by Early Childhood Educators in the United States, China, Taiwan, Korea, and Turkey. Poster symposium presented at the European Early Childhood Education Research Association Annual Conference, Lefkosia, Cyprus

**Alat, K.**, & Alat, Z. (April, 2002). Traumatic Events and Children: How Early Childhood Educators Can Help. A workshop presentation for the Indiana Association for the Education of Young Children’s (IAEYC) Annual Conference, Indianapolis, IN.

Alat, Z., **Alat, K.**, & Peker, D. (April 13, 2001). Are Teachers’ Beliefs Influenced by Their Job Satisfaction? Paper presented at the annual conference of the American Educational Research Association, Seattle, WA.

McMullen, M. B., Lee, S. M., **Alat, K.**, & Buldu, M. (November 10, 2000). From Australia to Zimbabwe: Exploring our global early childhood community. Presentation for the National Association for the Education of Young Children's (NAEYC) Annual Conference, Atlanta, GA.

McMullen, M., **Alat, K.**, Bilgi, S., Connally, J., Erdiller, Z., Ermogenidou, P., Korkmaz, K., Lash, M., Lee, S. M., Lin, C. H., Sahin, V., Sun, P. Y., Tzuo, P. W., Tu, W. Yilmaz, A., & Zachariah, J. (April 15, 2000). Exploring our global early childhood community. Interactive poster session for the Indiana Association for the Education of Young Children’s (IAEYC) Annual Conference, Indianapolis, IN.

## TEACHING EXPERIENCE

- Teaching Assistant in PSY 116 (1999). Statistics for Psychology Department of Psychology, Middle East Technical University
- Teaching Assistant in PSY 414 (1999). Computer Applications in Psychology
  Department of Psychology, Middle East Technical University
- Course Instructor in “Introduction to Computers and Office Package Programs”, Turkish Psychological Association

## PROFESSIONAL AFFILIATIONS

- Member of the Turkish Psychological Association
- Member of the American Educational Research Association (AERA)