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Coping and Social Support for Parents of Children with Autism

Edith H. Luther
San Jose State University

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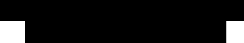
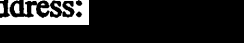
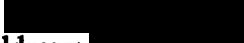
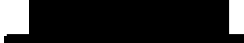

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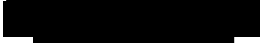
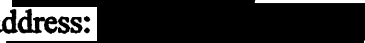
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**COPING AND SOCIAL SUPPORT
FOR PARENTS OF CHILDREN WITH AUTISM**



**Edith H. Luther RN, MS,
Special Education School Nurse
Elementary Education Services,
San Mateo County Office of Education**





Home address:



**Daryl L. Canham, EdD, RN, C
Associate Professor
San Jose State University
School of Nursing
Work Address: One Washington Square
San Jose, CA 95192-0057**



**Virginia Young-Cureton, DrPH, RN
Professor
Work Address: One Washington Square
San Jose, CA 95192-0057**



Coping and Social Support for Parents of Children with Autism

ABSTRACT: The increased incidence of autism in children impacts families, educators, and health professionals. A descriptive survey design was used to obtain responses from parents of autistic children in public schools. Data collection instruments included The Social Support Index, SSI (McCubbin, Patterson, and Glynn, 1982), and The Family Crisis Oriented Personal Evaluation Scale, F-COPES (McCubbin, Olson, and Larsen, 1981). The majority of parents of autistic children perceived that they had support within their families and communities. One half of the families identified serious stressors in addition to autism. Acquiring social support and reframing were the coping strategies used most frequently. The school nurse is in a position to provide support to parents of children with autism and special needs, and integrate coping and social support assessments into practice.

KEY WORDS: autism, parents, social support, coping, school nursing

INTRODUCTION

Autism is a complex developmental disorder that is typically noticed or diagnosed between the ages of 18 months and three years of age. It is one of five disorders known as Pervasive Developmental Disorders (PDD) and is characterized by severe impairment in several areas of functioning including communication, behavior, and socialization. Autism occurs in all social, racial and ethnic groups (Autism Society of America, 2002).

Significance. A major reason for studying autism is its ever-increasing prevalence, recently estimated to be approximately 10-12 per 1,000 individuals. A report by the California Department of Developmental Services (DDS) documented an increase of 273% of reported cases between 1987 and 1998 (Byrd, 2003). From 1998 through 2002, the number of persons with full syndrome autism served by the California DDS had increased from 10,360 to 20,377 according to the Director Allenby (California Department of Developmental Services, 2003). Information from the Gevirtz Graduate School at the University of California, Santa Barbara indicates that as many as 1.5 million Americans are diagnosed with autism and the incidence of autism is increasing by 10-15% annually. The UCSB Autism Center found that parents of autistic children are frustrated with the scarcity of professionals trained to work with their children in specialized programs (J. Zimmer, letter to County Office of Education Superintendent, April 26, 2002). Autism is the fastest growing diagnosed developmental disability with an annual national cost of \$90 billion and the cost is steadily increasing. Autism puts an enormous strain on education resources and takes a tremendous toll on families (Autism Society of America, 2003).

Stressors. When a family has a child with autism, it is stressful and changes the family's life. In a phenomenological study, Werner (2001), isolated themes from in-depth interviews with

parents. Themes were (a) the family's life revolves around dealing with the child's autism and unusual behaviors, (b) family members feel losses because they cannot lead a normal life, and (c) the family experiences only fleeting moments of feeling like a family (Werner). Other stressors common to most parents, but more so in families with an autistic child, are loss of personal freedom and less time for companionship in marriage which can cause difficulties within the family (Miller & Myers-Walls, 1983). Autism affects the family so intensely that families require strong coping skills and utilization of formal and informal support.

Another stressor is the effect on the family's finances. Dobson and Middleton (as cited in Jarbrink, Fombonne, & Knapp, 2003) estimated that the cost of raising a child with a disability is approximately three times greater than the cost of raising a non-disabled child. Jarbrink et al. developed a scale to measure the cost of raising an autistic child. Family costs include difficulties with maintaining employment, especially if both parents need to work, lost leisure time opportunities, and less time available to spend with other children in the family, and difficulty finding or paying for adequate childcare (Jarbrink et al.).

Research studies have shown that being a parent of a child with autism can be more stressful than many chronic illnesses or developmental disabilities such as Down Syndrome (Tunali & Power, 2002, and Sounders, DePaul, Freeman & Levy, 2002). Behavioral problems that commonly occur in children with autism include unpredictable aggressiveness toward self and others, which is a severe problem for parents and teachers (Rapin, 1997). Characteristics of autism such as the child's anxiety, mood swings, resistance to transitions, unusual or absent speech, and ways of relating to people, make raising an autistic child very challenging for parents (Rapin). Parenting is particularly difficult when children do not conform to parental or societal expectations on behavior and academic achievement (Miller & Myers-Walls, 1983).

Research studies have shown that parenting stress and other stressors affecting the family can be a precipitating factor in child abuse and neglect (Fried and Holt as cited in Miller & Myers-Walls, 1983) and parental, especially maternal, depression (Little, 2002; Rousey, Best, and Blancher, 1992). Parents benefit from counseling and parents support groups to help relieve stress. In addition, community agencies can provide respite care and other services which are beneficial to parents and children with autism (Rapin, 1997).

PURPOSE OF THE STUDY

The purpose of the study was to assess the levels of perceived informal and formal social support, and examine ways parents of autistic children cope in this Northern California county, and compare results to other research studies. A demographic questionnaire and two established quantitative surveys were used. The research question was “what are the levels of perceived social support and coping strategies for parents of autistic children?” Parent participants were of various ethnicities, income levels, and lived in geographically and demographically different areas of the county. The Resiliency Model of Family Stress, Adjustment, and Adaptation (as cited in McCubbin, Thompson, & McCubbin, 1996) was the theoretical model selected. This model focuses on the strengths within families, and addresses components of stress, coping, and social support.

The study results have significance for school nurses providing care and services to this population. A component of the school nurse role is to assist parents to connect with support available through the school, from health providers and other professionals, and community organizations. Parents of autistic children need to make difficult decisions about therapy, medications, and various claims for treatments that may or may not have proven efficacy (Rapin, 1997).

Assessing the levels of perceived informal and formal social support and examining coping strategies of parents of autistic children can assist school nurses in providing more knowledgeable care and facilitate more effective utilization of services by the parents.

LITERATURE REVIEW

The impact of stress and social support on families with autistic and special needs children, and children with chronic illnesses has been well documented in the literature. Several studies examined and delineated stressors related to school experiences, coping strategies, and self-efficacy and behavioral control. No studies were found in which a school nurse questioned parents of autistic children about their experiences. In addition, no studies were found relating to parents of autistic children in school settings that used the same instruments selected for this study.

Kasari, Freeman, Bauminger and Alkin (1999) studied parents' perspectives and satisfaction levels with their child's educational placement. The study reported that the parents' satisfaction with the school program, teacher, and the child's fit in the classroom setting is extremely important and can reduce stress. Controlling stress is critical for the families with autistic children.

Tunali and Power (2002) hypothesized that parents have a low level of control in the case of having a child with autism. A group of 58 mothers (half the group had children with autism and half had typically developing children) were interviewed in home visits, during which each participant completed questionnaires on home and career attitudes, a depression scale, and an autism behavior checklist. The study results supported the hypothesis that mothers of autistic children who were the most satisfied with their lives had made cognitive and lifestyle changes

that were congruent with raising a child with autism. In other words, the mothers had adapted or identified strategies to adjust to raising an autistic child.

Additional studies looked at mothers and fathers in relation to raising a child with autism or special needs. Little (2002) examined differences in stress and coping between mothers and fathers of children with Asperger's Syndrome and nonverbal learning disorder. Asperger's Syndrome is a diagnosis on the autism spectrum and similarly, nonverbal learning disorder causes impairment in social interactions, judgement, as well as cognitive and sensory deficits. A comparison was made of how mothers and fathers cope. Little concluded from the study results that because mothers were doing more of the childcare, home maintenance, and school related collaboration, they were more stressed than the fathers. The mothers sought professional help and used anti-depressant medication more frequently than the fathers. This finding was important for professionals working with parents of children with Asperger's Syndrome and autism spectrum disorders.

Another study, Rousey, Best, and Blancher (1992) studied mothers' and fathers' perceptions of stress and coping with children who have severe developmental disabilities and examined the risk of depression with this group. The participants completed the short form (QRS-F) Questionnaire on Resources and Stress by Frederick, Greenberg, and Crnic (as cited in Rousey, et al.). The study results found that both parents indicated they were involved in taking care of the child with a disability. The risk of depression and pessimism was found to be about the same for either parent and higher than normal. The study would indicate that parents of children with autism are at greater risk for depression. These studies reflected the consequences of stress and stressors for the parents of autistic children.

Two studies were reviewed that examined cultural differences in perceptions of social support. Bailey et al. (1999) studied needs and supports of Latino families with developmentally disabled children. The researchers used the Family Support Scale by Dunst, Trivette, & Jenkins (as cited in Bailey et al., 1999) that reflects support from family and friends, informal and formal support. Family support was rated highest but unexpectedly formal support was rated second due to the families perceiving the professional as having the expertise and services to meet their child's needs. They also found that families who were most acculturated into their communities had higher levels of informal support.

The second study (Shin, 2002) compared social support for families of children with mental retardation in the United States and Korea. Shin looked at cultural differences such as Koreans living in a collectivist society that would lead to an assumption that family support would be greater. She found several factors that did not support this assumption. Koreans traditionally had a more negative attitude toward the people with disabilities, some families did not live within close proximity to extended families, and in some cases, because it was considered shameful to have a disabled child, assistance was not sought from family members. Also, Korean women tended to be less educated and assertive than their American counterparts and did not seek professional support as readily. The Korean women scored higher on measures of stress than the American women in the study. The findings of both of these studies assist in providing a broader perspective when working with families of different ethnic groups and anticipating their needs related to caring for a child with disabilities.

Although the previous studies used a variety of tools or questionnaires for data gathering, three studies were identified that utilized research tools applicable for studying stress and coping in families with children with autism. Bristol (1987) studied 45 families with children with

autism or severe communication impairments who had just entered an educational support program for autistic children using the Double ABCX model developed by H. I. McCubbin and Patterson, 1983 (as cited in Bristol, 1987). This model addresses post-crisis adjustment and adaptation over time, active as well as passive coping, and healthy adaptation in response to stress. Bristol found that a "pile-up" of other family stresses made the greatest contribution to maternal depression. In addition, it was found that parents were less stressed after the diagnosis possibly because it ended the uncertainty of the child's problem, and/or the child and family qualified for support and educational services.

Donenberg and Baker (1993) compared (a) parents of preschool children with externalizing behaviors (aggression, hyperactivity, and non-compliance), (b) parents of children with autism, and (c) a control group of parents of typically developing children. The researchers developed the Family Impact Questionnaire-R for use in the study. The Abidin Parent Stress Index (as cited in Donenberg and Baker, 1993) and the Beck Depression Scale (as cited in Donenberg and Baker, 1993) were also used. It was found that the level of stress experienced by parents of children with externalizing behaviors was as high as the stress level for parents of autistic children. They found that more of the children with autism in the study were already receiving support and educational services and this may have helped reduce the parents' stress level.

Gray and Holden (1992) studied psychosocial well-being among parents of children and young adults with autism, ages 3-22 years old. They used the Coping Health Inventory (CHIP) and the Social Support Scale (SSI), both developed by McCubbin and associates (as cited in Gray & Holden, 1992), as well as measures for depression, anger, and anxiety. Results indicated that anger and anxiety were negatively proportional to social support, which was consistent with

previous studies. Mothers reported significantly higher levels of depression and anxiety than fathers. It was also found that anger levels of parents was higher for parents of boys and increased with the age of the child with autism. The increase in anger levels was attributed to control difficulties related to size and strength of the boy as he reached adolescence.

The literature demonstrated the applicability of a variety of data gathering instruments in studying stress and coping issues related to families with autistic children. Recurrent themes reflected in the literature were factors that increased or decreased stress, coping strategies, social support, identification of family members at higher risk, and the complexity of working with this population of families.

Theoretical Perspective/Conceptual Framework. The conceptual framework for this study is The Resiliency Model of Family Stress, Adjustment and Adaptation developed by H. and M. McCubbin and A. and E. Thompson (as cited in Malone, 1998). The Resiliency Model conceptualizes the demands, resources, and developmental issues involved in family life from a holistic perspective (Malone). Family resiliency theory has been used extensively to study families at risk. Having a child with autism can cause extreme stress in a family which may already have other risk factors such as: (a) single-parenting or divorce, (b) child-care needs, (c) care of ill or elderly extended family members, or (d) lack of financial resources (McCubbin, McCubbin, Thompson, Han, & Allen, 1997).

In the Resiliency model there is an adjustment phase during which the diagnosis of an illness, or condition such as autism takes place. In this phase, the family may need or benefit from crisis intervention because their usual coping skills would be insufficient, and the family would reframe their understanding of what has occurred (Malone, 1998).

Next is the adaptation phase, during which the family attempts to meet the demands of the child's disability (Malone, 1998). Protective factors that can help sustain the family are: (a) at the personal level—self-efficacy and self-esteem, (b) at the family level—communication among members, problem solving, and extended family support, and (c) at the community level—the family's social network for informal support, religious and cultural associations, and formal support such as health professionals (Malone).

Families who adapt successfully tend to have traits of resiliency, good coping skills, and informal and formal social support from the community. The Resiliency framework emphasizes positive attributes such as family bonding, flexibility, strength, and problem-solving abilities. This is especially important in times of stress or crisis (McCubbin, et al. 1997).

METHODOLOGY

Design. The purpose of this research study was to answer the question “what are the levels of perceived social support and coping strategies used by parents of autistic children?” The study used a descriptive survey design. Participants self-reported on two Likert-type questionnaires that examined coping strategies and social support and a demographic questionnaire. A feature of the coping scale was an analysis of subscales for different coping strategies. The researcher asked about concurrent stressors present in the family such as health problems as a part of the demographic questionnaire.

Participants, Setting, and Analysis. Participants were parents of children with autism who were enrolled in selected special education classes in a Northern California county. A convenience sample of 72 families was identified from the designated special education classes and 18 families completed and returned the questionnaires. The children

with autism ranged in age from 5 to 13 years and were enrolled in kindergarten through middle school special education classes. Consultation with the statistician resulted in calculating frequencies and percentages for this sample, and comparing the mean scores on the SSI and F-COPES scales and F-COPES subscales (as cited in McCubbin et al. 1996) with a normed sample. The normed sample consisted of university students, parents and other adults for the F-COPES scale and females in military families for the SSI scale. The small sample size of this study did not support more complex statistical analysis.

Procedures. The research study was approved by the Human Subjects--Institutional Review Board (IRB) at San Jose State University and written permission was obtained from the assistant superintendent of the County Special Education Services. The assistant superintendent asked the researcher to send letters asking that parents participate via the classroom teachers rather than contacting parents directly due to confidentiality concerns. Confidentiality was insured by the anonymity of the survey, and by grouping the data. Participation in the survey was entirely voluntary and parents were notified by cover letter that their services and/or relationship with the County Office of Education or the University would not be affected if they decided not to participate.

The surveys were distributed in early to mid-September with a requested date of return by October 3, 2003. The parent who was the primary caretaker was asked to complete the surveys. Participants completed a demographic survey and answered items on the questionnaires. Parents were advised that they could omit any questions that made them feel uncomfortable and were asked to return the completed questionnaires in a pre-addressed, postage paid envelope. The survey results were reviewed only by the researcher and the statistician.

Instrumentation. The Family Crisis Oriented Personal Evaluation Scales (F-COPES) by H. I. McCubbin, Olsen, & Larsen, 1981 and Social Support Index (SSI) by H. I. McCubbin, Patterson, & Glynn, 1982 (both as cited in McCubbin et al. 1996), and a demographic questionnaire developed by the researcher, were the survey instruments used. The F-COPES scale features 30 coping strategies that focus on the two levels of interaction outlined in the Family Resiliency Model: (a) Individual to family systems, and (b) family to social environment, or the ways in which families externally handle problems or demands (McCubbin et al. 1996). The F-COPES scale rates 30 items on a five-point Likert scale with responses ranging from strongly disagree (1) to strongly agree (5). The questions are divided into five subsections: (I) acquiring social support, (II) reframing, (III) seeking spiritual support, (IV) mobilizing family to acquire and accept help, and (V) passive appraisal (as cited in McCubbin et al. 1996).

The Social Support Index (as cited in McCubbin et al. 1996) is a 17-item questionnaire that reflects the degree to which families feel integrated into the community, view the community as a social support and a source of emotional or network support. The SSI uses a five-point Likert scale with responses ranging from strongly disagree (1) to strongly agree (5). Community social support is related to the family's sense of coherence and confidence, and serves as a buffer from various sources of stress. Social support was a predictor of family resiliency in a research study of 500 families (McCubbin, et al. 1996). Permission was obtained from the authors to use the SSI and F-COPES scales. A statistical analysis of perceived levels of informal and formal social support, and coping strategies used by the parents was completed.

RESULTS

Demographic Data. See Table 1 for results of the demographic questionnaire.

Eighteen of 72 surveys were returned, indicating a 25% response rate. Responses indicated that about 3/4 of children lived with both parents, less than 1/4 lived with their mother, one lived part-time with the father, and a grandparent lived with at least two families.

Participants were asked to state their identified ethnic group. The Asian and Filipino groups combined were approximately 1/3 of the total, Hispanics were approximately 1/3, and Caucasian and other were approximately 1/3. There was no response from African-American families who may have had a smaller number number of the autistic children in the county. The ethnic groupings were representative of the population of the county. Parents were asked which language was usually spoken in the home. Of the 11 English-speaking families, 4 were bilingual with Tagalog (Filipino), Arabic, and Spanish the second language spoken in the home. (Ethnicities of the normed group for the F-COPES and SSI instruments are discussed in the Data Analysis section. There was no normed group for the demographic data.)

The mean number of children per family was 2.3 children under 18 years of age. The number of children with autism in the family was 1 (n=16 or 88%), 2 (n=1 or 6%), and 3 (n=1 or 6%). The mean age of the children with autism was 8.3 years old. There are 41 children in the participant's families including the autistic children and their siblings.

Responses on the demographic questionnaire indicated that significant stressors were reported in 50% of the families. Stressors were finances and unemployment (n=2), father living and working in another county (n=2), health conditions in the autistic child such as asthma and eczema (n=1), attention deficit hyperactivity disorder (n=1), diabetes (n=1), busing problems (n=1), and divorce (n=1). Similar conditions, for example single-parent

families, divorced and stepfamilies, and families that have a member with chronic illness are common in normative families also, but difficulties and stressors are compounded in families with a child that has special needs and puts these families at greater risk (McCubbin et al. 1997).

Data Analysis. The results of The Family Crisis Oriented Personal Evaluation scales or F-COPES (as cited in McCubbin et al. 1996) are presented in Figure 1. The mean total score for parents of autistic children was 103.8 as compared with the normed group mean of 93.1 for males and 95.6 for females (McCubbin, et al. 1996). The normative data for the F-COPES scales were drawn from an initial sample of university students (N=119) and a larger sample of parents and adults (N=2740) who were used to test the data and obtain the subscales (McCubbin et al. 1996). This finding suggests that the parents of autistic children have a greater need to develop coping skills and access support services because they had more stressors in their lives compared to the normed group.

The F-COPES Subscales scores are presented in Figure 1. The data for obtaining the normed group is described above. Subscale I, Acquiring Social Support, questions how participants actively engage in acquiring support from relatives, friends, and neighbors. The participants in this study scored similarly (27.5) to the normed group (27.1).

Subscale II, Reframing relates to how the family perceives stressful events and changes. The participants scored slightly higher (31.3) than the normed group (30.4). An example of reframing was that 78% agreed or strongly agreed that they defined family problems in more positive ways to avoid becoming discouraged.

Subscale III, Seeking Spiritual Support, reflects the family's religious ideology, as well as participation in organized religious groups, or seeking advice from clergy. The

participants scored lower (14.3) than the normed group (16.6). However, 83% of the sample strongly agreed with a statement about having faith in God as a way of coping, but fewer than half coped by attending church services or activities or sought advise from a minister (33%).

Subscale IV, Mobilizing to Acquire and Accept Help, refers to the family's ability to seek out community resources including neighborhood agencies and programs, counseling, and health care providers (McCubbin et al. 1996). The participants scored higher (15.6) than the normed group (12.7) in this subscale. 71% of the sample sought professional counseling and help for family difficulties and 67% sought information from the family doctor.

Subscale V, Passive Appraisal refers to accepting problematic issues by reacting less strongly, avoidance, or passivity as a coping strategy. This type of response may be based on a family's lack of confidence in their ability to alter outcomes (McCubbin et al. 1996). Passive appraisal had a mean of 14.6 in this sample as compared with a mean of 8.5 for a normed group. An example of passive appraisal was watching television which 33% of the sample said was used as a way to cope.

The Social Support Index (SSI) scores for the parents of autistic children resulted in a mean of 45.3 as compared with a mean of 43.4 for the normed group. The normative group for the SSI were participants in the development of the SSI scales (N=881), females in military families overseas of primarily Caucasian and African-American ethnicities. The normed group participants were in a unique stressful situation (McCubbin et al. 1996). The participants of this study scored slightly higher than the normed group who were also facing stressors.

The parents responses to individual questions on the SSI scale were ranked from high to low in terms of obtaining social support, as follows. Corresponding data for the normed group were not available.

1. Importance of close friends outside the family, 83% agreed or strongly agreed, 17% were neutral.
2. Family members love them and they feel good about sacrificing for family, 78% agreed or strongly agreed, 12% neither agreed nor disagreed.
3. This is a good community to raise children, 56% agreed or strongly agreed, 39% neither agreed nor disagreed.
4. Can get help from community when in trouble, 50% agreed or strongly agreed, 22% neither agreed nor disagreed, and 27% disagreed or strongly disagreed.

DISCUSSION

Responses to the demographic questionnaire indicated that one participant family had two and another participant family had three autistic children with autism. Although a clear cause for autism has not been determined, there is evidence for genetic predisposition. Families with one autistic child are more likely to have another child with autism than families without autism (Byrd, 2003).

Parent support groups are a means of providing social support within the framework of the educational setting. Several parents indicated on the demographic questionnaire that they were interested in or had attended a support group. The Autism Support Group for county parents had not yet met this school

Results of the F-COPES scale (McCubbin et al. 1996) indicated that social support ranked second highest on the coping scales for families in this study and scores were

comparable to parents in the normed group. This finding would indicate that many parents of autistic children surveyed were familiar with how to obtain the formal and informal social support they needed to educate their autistic child. There were individual differences because of personal beliefs and limitations such as inability to speak English, lack of transportation, or children who have more extreme or unusual needs. There have been many research studies on social support, particularly in the early 1990's. Social support has been correlated with improved coping for parents in a number of studies (Hastings & Brown, 2002).

There have been few studies on other coping strategies for parents of autistic children. The following coping strategies reflect results from the F-COPES subscales (McCubbin et al. 1996). Reframing had the highest score of the subscales for the participants and normed group indicating that the parents outlook or "reframing" can be a factor in how successfully they cope.

Spiritual support was rated lower by the participants in this survey than in the normed group. Most families in this survey strongly agreed that belief in God was a way they cope with stress. However, fewer parents in the study group said they participated in structured religious activities or sought counseling from clergy as a coping strategy as compared to the normed group, possibly reflecting their cultural practices or comfort levels. In some cases, a child with autism may make it difficult to participate.

The participants scored higher than the normed group in the Acquiring and Accepting Help subscale. This finding may be indicative of their need to receive informal and formal support and services for their child. Age of onset of autism is usually at toddler age and ideally children receive services and intervention as early as possible. Most parents continued to seek and accept help as their child grew older.

The participants had a much higher score for the Passive Appraisal subscale than the normed group. This subscale focuses on inactive or passive behaviors the family may use, such as avoidance responses based on a lack of confidence in ability to alter outcomes (McCubbin et al. 1996). This finding may have been due to differences in the severity of stressors for the parents coping with autism as compared with the normed group, and beliefs that problems associated with autism are relatively permanent.

The responses from the Social Support scale (SSI) were consistently high for social support from close friends and family members. Few of the families relied on neighbors for help and support, possibly indicating that most neighbors were casual acquaintances and not consistent sources of support. Responses for obtaining help when needed and feeling comfortable within the community were variable ranging from strongly agree to strongly disagree. These mixed responses concerning community support may have been due to differences in socioeconomic levels and cultures within the communities, and length of time these families have resided in the community or country. Bailey et al. (1999) found that families who were more acculturated into their communities had higher levels of informal support. Similarly families may have had different perceptions or varying experiences with the effectiveness and quality of formal support such as educational or health services.

Balancing multiple role responsibilities is a difficult task for parents (Miller & Myers-Walls, 1983) and has not been examined extensively in research of families of autistic children, with the exception of role differences between mothers and fathers. Parents of children with autism have problems with taking on multiple roles because of the intensive care taking the child with autism requires. Grandparents lived with at least two of the participant families according to the demographic survey and may have influenced the

responses related to acquiring and accepting help. If the grandparent is able to help with childcare, this assistance could be a valuable source of social support that allows the parents greater flexibility in working and meeting the family's financial needs.

The literature review indicated that families of children with autism face many challenges and the school nurse is in a position to identify potential and real problems and assist with appropriate interventions. Assessing the stress levels, coping issues, and social support of this high risk group within a school district can facilitate more effective interventions. The literature supported the need for further exploration of social support issues and coping strategies for parents with children with autism.

Significance. It is significant that these tools, the SSI, F-COPES (as cited in McCubbin et al 1996), and demographic questionnaire have had limited use in special education settings with parents of autistic children. Data were gathered related to parents' coping responses and stressors. The researcher found the F-COPES scale particularly helpful because it differentiated coping strategies used by parents and it had the normed scale of parents for comparison. The SSI scale had less relevance because it did not have a component for formal support that would be the form of support provided in a school setting. However, it did provide information of informal support such as the parent's relationships with family, friends, and their community.

Limitations. The small number of participants was a limitation that prevents generalization of this study to other settings and populations. The low rate of participation in this study (27%) may have been partially due to the indirect method of communication (a letter sent via the teacher) or because parents were busy adjusting to the beginning of a new school year. Sending a follow-up reminder postcard might have been helpful, but was not

done due to time limitations and confidentiality issues. Another limitation was that a convenience sample was used, which limits the application of the study results to a larger population.

IMPLICATIONS FOR SCHOOL NURSING PRACTICE

Results of this study show that one concern that participants had about their children with autism was coexisting medical conditions such as asthma, diabetes or attention deficit hyperactivity disorder (ADHD). The school nurse can be a link between the academic and medical specialties, and can be an effective resource and support person to parents and teachers of autistic children. Finding the optimal treatment approach or interventions for a child with autism can be complex and often requires a team approach, especially when the child with autism has co-existing conditions (Tsai, 2001). The school nurse is an integral part of such a treatment team.

Support groups are a way that parents can communicate with each other and with specialized professionals. In the area where this survey took place, two special education teachers conduct an educational and informational support group for parents of autistic children and a support group for Spanish-speaking parents takes place concurrently. Childcare is provided for the child with autism and siblings to make it more convenient for parents to attend the support group. The school nurse can inform and encourage parents to attend autism support groups that are available in their community or schools, and refer them to numerous resources for parents of children with autism.

Another way to support the parents would be to use a screening tool with parents to determine the parents stress level or coping skills. Little (2002) stated that nurses in schools and in the community are in a "prime position" to assess the levels of stress on caregiving

parents, and to address coping strategies with them. A few questions derived from a tool such as the F-COPES might be sufficient. Also a short demographic questionnaire such as the one used in the study might be modified as an assessment tool to learn more about the family structure and additional stressors.

Further research regarding coping and social support in families with autistic children and application in the school setting is needed. This research would be a worthwhile undertaking for school nurses or graduate nursing student researchers, especially since numerous instruments are available in the areas of stress, coping, and social support. These data from the SSI and F-COPES scales and subscales, may provide initial data to pilot a larger related study for school nurses so that they may improve interventions and anticipate the problems of this population. The information gained by this type of survey can also improve the knowledge base of educators, parents, and other health professionals serving this population.

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Table 1. Demographic Characteristics of Respondents (N=18)

| <u>Characteristic and Group</u> | <i>N</i> | <i>%*</i> |
|---|-----------------|------------------|
| <u>Child lives with</u> | | |
| Mother | 4 | 22 |
| Both parents | 14 | 78 |
| <u>Type of family</u> | | |
| Single parent | 2 | 11 |
| Married-Couple | 15 | 83 |
| Divorced | 1 | 6 |
| <u>Ethnicity of family</u> | | |
| Caucasian | 5 | 28 |
| Hispanic | 5 | 28 |
| Chinese/Asian | 3 | 18 |
| Filipino | 2 | 12 |
| East Indian | 1 | 6 |
| Declined to state | 2 | 12 |
| <u>Language usually spoken at home</u> | | |
| English or English/bilingual | 11 | 61 |
| Spanish | 4 | 22 |
| Cantonese | 2 | 11 |
| Gujarati (E. Indian) | 1 | 6 |
| <u>Estimated family income</u> | | |
| Up to \$30,000/year | 3 | 17 |
| \$30,000-\$50,000 | 11 | 62 |
| \$50,000-\$80,000 | 1 | 6 |
| \$80,000+ | 3 | 17 |
| <u>Number of children under 18 yrs.in family</u> | | |
| 1 | 2 | 11 |
| 2 | 11 | 62 |
| 3+ | 5 | 27 |
| <u>Gender of child with autism</u> | | |
| Female | 4 | 22 |
| Male | 14 | 78 |
| <u>Other significant stressors in family</u> | | |
| Yes | 9 | 50 |
| No | 9 | 50 |

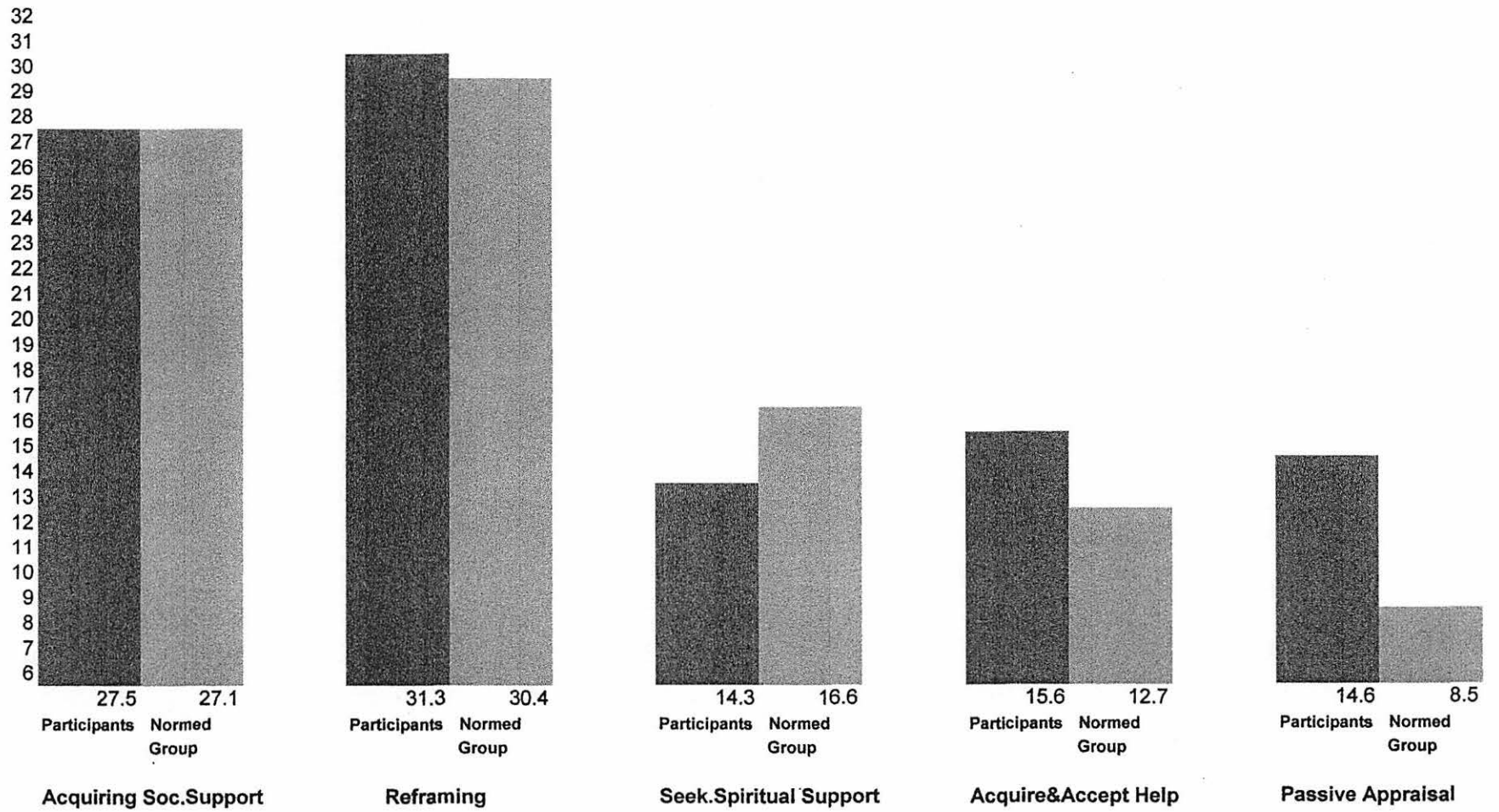
Parent attended autism support group at least 1-2x/year

| | | |
|------------------------------|---|----|
| Yes | 7 | 39 |
| No | 8 | 44 |
| No, but would like to attend | 3 | 17 |

* % rounded to nearest whole number so may not = 100%

Figure Caption: F-Copes Subscales

F-COPES Subscales



UNIVERSITY OF HAWAII AT MANOA

School of Nursing and Dental Hygiene
Department of Nursing

June 30, 2003

Edith Luther
[REDACTED]
[REDACTED]

Dear Ms. Luther:

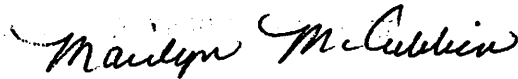
CD ROM #0096-2136-1695

This letter is to give you my written permission to use the F-COPES (Family Crisis Oriented Personal Evaluation Scales) and the SSI (Social Support Index) in your master's thesis study on "Coping and Social Support in Parents of Autistic Children." Please note that because you are now a registered user of the above CD-ROM, you have permission to use any of the other instruments on the CD ROM as well.

We would appreciate receiving an abstract of your research when it is completed for our files. You can mail to me as the address at Kamehameha Schools is no longer valid.

Best wishes to you on your research study.

Sincerely yours,



Marilyn A. McCubbin, PhD, RN, FAAN
Professor & Director
Center for Health Disparities Research
University of Hawaii at Manoa
School of Nursing & Dental Hygiene
[REDACTED]
[REDACTED]
[REDACTED]

Phone: [REDACTED]

FAX: [REDACTED]

e-mail: [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES

The Family Crisis Oriented Personal Evaluation Scales is designed to record problem-solving attitudes and behaviors which families develop to respond to problems or difficulties.

First read the list of "Response Choices" one at a time. Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then darken the oval in the 'Strongly Agree' column indicating that you strongly agree; if the statement does not describe your response at all, then darken the oval in the 'Strongly Disagree' column indicating you strongly disagree, if the statement describes your response to some degree, then select any of the ovals in between to indicate how much you agree or disagree with the statement.

| <i>When we face problems or difficulties in our family, we respond by:</i> | Strongly Disagree | Moderately Disagree | Neither Agree Nor Disagree | Moderately Agree | Strongly Agree |
|--|-----------------------|------------------------|-------------------------------|-----------------------|-----------------------|
| 1. Sharing our difficulties with relatives | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Seeking encouragement and support from friends | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. Knowing we have the power to solve major problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Seeking information and advice from persons in other families who have faced the same or similar problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Seeking advice from relatives (grandparents, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. Seeking assistance from community agencies and programs designed to help families in our situation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. Knowing that we have the strength within our own family to solve our problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. Seeking information from the family doctor | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Asking neighbors for favors and assistance | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Facing problems "head-on" and trying to get solution right away | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Watching television | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. Showing that we are strong | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. Attending church services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. Accepting stressful events as a fact of life | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. Sharing concerns with close friends | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. Knowing luck plays a big part in how well we are able to solve family problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. Exercising with friends to stay fit and reduce tension | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 19. Accepting that difficulties occur unexpectedly | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. Doing things with relatives (get-togethers, dinners, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 21. Seeking professional counseling and help for family difficulties | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 22. Believing we can handle our own problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 23. Participating in church activities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 24. Defining the family problems in a more positive way so that we do not become too discouraged | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 25. Asking relatives how they feel about problems we face | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 26. Feeling that no matter what we do to prepare, we will have difficulty handling problems | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 27. Seeking advice from a minister | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 28. Believing if we wait long enough, the problem will go away | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 29. Sharing problems with neighbors | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 30. Having faith in God | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

-Continue on back-

SOCIAL SUPPORT INDEX

Read the statements below and decide for your family whether you: (1) Strongly Disagree; (2) Disagree; are (3) Neutral; (4) Agree; or (5) Strongly Agree and darken that oval.

Please indicate how much you agree or disagree with each of the following statements about your community and family:

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1. If I had an emergency, even people I do not know in this community would be willing to help. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. I feel good about myself when I sacrifice and give time and energy to members of my family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. The things I do for members of my family and they do for me make me feel part of this very important group. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. People here know they can get help from the community if they are in trouble. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. I have friends who let me know they value who I am and what I can do. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. People can depend on each other in this community. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. Members of my family seldom listen to my problems or concerns; I usually feel criticized. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. My friends in this community are a part of my everyday activities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. There are times when family members do things that make other members unhappy. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. I need to be very careful how much I do for my friends because they take advantage of me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Living in this community gives me a secure feeling. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. The members of my family make an effort to show their love and affection for me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. There is a feeling in this community that people should not get too friendly with each other. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. This is not a very good community to bring children up in. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. I feel secure that I am as important to my friends as they are to me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. I have some very close friends outside the family who I know really care for me and love me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. Member(s) of my family do not seem to understand me; I feel taken for granted. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Thank you for your participation.