



1-12-2018

An Exploration of the Impact of Social Support on the Parents of Children with Autism Disorder

Elizabeth McDevitt

[How does access to this work benefit you? Let us know!](#)

Follow this and additional works at: <https://commons.und.edu/nurs-capstones>



Part of the [Nursing Commons](#)

Recommended Citation

McDevitt, Elizabeth, "An Exploration of the Impact of Social Support on the Parents of Children with Autism Disorder" (2018). *Nursing Capstones*. 256.

<https://commons.und.edu/nurs-capstones/256>

This Independent Study is brought to you for free and open access by the Department of Nursing at UND Scholarly Commons. It has been accepted for inclusion in Nursing Capstones by an authorized administrator of UND Scholarly Commons. For more information, please contact und.common@library.und.edu.

AN EXPLORATION OF THE IMPACT OF
SOCIAL SUPPORT ON THE PARENTS OF
CHILDREN WITH AUTISM DISORDER

By

Elizabeth McDevitt

Post-baccalaureate Program in Nursing, St. Catherine University, 2006

An Independent Study

Submitted to the Graduate Faculty

Of the

University of North Dakota

In partial fulfillment of the requirements

For the degree of

Master of Science

Grand Forks, North Dakota

August

2017

ABSTRACT

The impact of social support on parents of children with autism disorder is not fully understood. There can be multiple difficulties with communication and behaviors that autism disorder brings to individuals and caregivers . Parents of children with autism disorder experience a range of psychosocial phenomena in their role as a result of the challenges their children experience. The objective of this literature review is to review existing literature on current understanding of how social support impacts many aspects of parents' psychosocial experience. The literature reviewed demonstrated that experiencing social support provides positive outcomes with aspects of psychosocial well-being and resilience while having negative outcomes related to parental stress, depression and anxiety. This literature review highlights the need for further study to understand any relationship between social support and psychosocial phenomena that parents of children with autism disorder experience. These findings emphasize the need for the advance practice psychiatric nurse (APPN) to investigate the currently available formal social support options available to their patients and families in their communities. APRNs can collaborate with other health professionals, social service and public health agencies as appropriate to further develop and implement social support resources to assist the parents of children with autism disorder.

Introduction

The prevalence of autism disorder has increased over the last decade. According to the Centers for Disease Control (CDC) (2016), 1 in 68 children in America or 1.5% of children have an autism diagnosis. Autism disorder's impact goes beyond the individual with the condition to include family members especially the individual's parents. As a neurodevelopmental disorder, autism disorder impacts the individual's functioning particularly in the areas of fine and gross motor skills, communication and social interaction. These effects can be particularly challenging for parents to manage.

The impact of autism disorder on individuals varies immensely. Some with autism are able to learn to perform their activities of daily living without assistance as children and go on as adults to work and live independently (United States Department of Health and Human Services, 2015). However, most children with autism disorder require additional interventions and therapies from educational and rehabilitation specialists to manage their symptoms and many adults go on to require at least some support to work and live in the community (National Institute of Neurological Disorders and Stroke, 2015). Parents are often quite challenged to manage their child's range of symptoms and behaviors.

Parents of children with autism disorder face many challenges in their attempts to manage and intervene in their child's behaviors and communication deficits (Zablotsky, Bradshaw, & Stuart, 2013). Parents often describe the situations they experience as difficult and stressful (Barker et al., 2010). Children with autism disorder often exhibit unusual behaviors, maladaptive communication traits and social deficits which require frequent and intense intervention on the part of parents (Zablotsky et al., 2013). Parents often report feeling distinct

distress and, at times, depression and anxiety. The ability of parents to cope in a positive manner with these behaviors and situations, which are often daily and intense, can often be challenging (Whitehead, Dorstyn, & Ward, 2015). Interventions to help the parents in their role, benefit not only the parent's well-being but the child with autism disorder and the other family members.

When a parent is experiencing mental health challenges and increased distress, their ability to care give effectively is impacted with negative consequences at least temporarily for themselves and their families (Barker et al., 2010). Among a range of interventions available to parents of children with autism disorder, social support is one that is uniquely available in a range of formats and styles, whether it is emotional, instrumental or has aspects of both. This paper will explore the impact of social support on the parents of children with autism disorder.

Understanding the role of social support for these individuals will aid agencies and healthcare providers in their efforts to provide assistance in manners that are the most beneficial to these parents and by extension, their children with autism disorder.

Purpose

Much of the focus in the review of literature of children with autism disorder and their parents has been directed at interventions to support the needs of the child related to the symptoms and challenges they experience as a result of autism disorder. Over the last several years, it has been noted that the parents of children with autism disorder experience significant distress as they take on a role managing and guiding their child who has a disorder that can impact significantly how they interact with people in their environment. Beyond the stress experienced, these parents have an increased incidence of depression and anxiety (Siman-Tov & Kaniel, 2011). Additionally, the unique challenges that children with autism disorder create in the areas of communication and interaction can be particularly stressful for parents, in turn, this

can lead to a sense of isolation as parents may be reluctant to engage in the community with their child whose behaviors are often not well understood or accepted by others (Pottie, Cohen, & Ingram, 2009).

Social support encompasses a wide range of behaviors and resources that may be of benefit to the parent of a child with autism disorder. The nature of the social supports that are beneficial to these parents will be identified and discussed in this literature review. The evidence from this literature review will elicit proposed strategies to meet the needs of the parents related to social support.

Significance

It has been established that parents of children with autism disorder have higher stress levels than, parents of normal developing children (Bonis & Sawin, 2016). The often unpredictable behaviors that are frequently a manifestation of autism disorder can be challenging for parents to manage (Bonis & Sawin, 2016). With an increased incidence of autism diagnosed in the U.S., up from 1 in 150 in 2000 to 1 in 68 in 2012 (CDC, 2016), the need for interventions to support parents has become more apparent.

It has been shown that parents do seek the support of family and friends for informal social support and as well as seeking social support from professionals to meet their own child's needs (Troy, Connolly, & Novak, 2007). Social support has been shown to benefit the parents of children with disabilities (Ozbay et al., 2007). With this knowledge in hand, this paper will review the role of social support and its impact on parents of children with autism disorder.

A greater understanding of how social support impacts the parents of children with autism disorder will positively impact the practice of psychiatric nurses and specifically APPNs

allowing the provision of care that is evidence based, family-centered, and compassionate. This paper aims to bring greater understanding of how social support impacts parents.

Theoretical Framework

The Stuart Stress Adaptation Model of Psychiatric Nursing Care is the theory that underpins this review of literature. The first assumption of this model acknowledges the social hierarchy that is the grounding for the environment in which individuals interact. Within this hierarchy, all individuals exist as one part, but more importantly, as members of other entities such as families, communities, societies and finally the biosphere (Stuart, 2013). Parents of children with autism disorder are individuals at the core and have their own unique needs, strengths and experiences. However, in this literature review, their role in the social hierarchy as a member of a family, particularly as a parent, is integral. Not only is the parent a member of the family, they are also a part of many communities. These communities include extended families, neighborhoods, faith groups, and any other institution or organization with which they find some commonality. The parent influences those around themselves in all these groups and the members of the groups, either individually or collectively, influence the parent with experience, information, and materials (Stuart, 2013).

A second assumption that Stuart's model incorporates is the many-faceted role that nursing plays in a wide range of contexts. These contexts include the biological, sociocultural, legal, ethical, policy and advocacy (Stuart, 2013). The population of interest in this literature review, the parent of a child with autism disorder, has needs in all these areas. The parent has their own health concerns yet is also caring for a child with a condition that may present many challenges to the parent. The parent operates in many roles, and manages complex demands.

Psychiatric nurses are called upon to understand the range of contexts the individual operates in and to provide competent, holistic care. (Stuart, 2013).

The illness/health continuum and maladaptation/adaptation continuum exist separately in the Stuart Stress Adaptation Model of Psychiatric Nursing Care (Stuart, 2013). They are a concepts that is particularly well-suited to the population being reviewed here. Autism is a disorder which is life-long. Autism disorder's symptoms and impact on the individual and their family may vary over time, but the disorder persists. In Stuart's model, it is understood that one can live, thrive, and have a child with an illness such as autism disorder. The existence of this disorder need not determine that the individual will cope in a maladaptive manner. From the nursing perspective, it is understood that one can develop an adaptive response to a chronic disorder and its challenges. For the purposes of this literature review, the use of social support as an adaptive response to parenting a child with autism disorder is explored.

Parents of children with autism disorder need different types of care from a psychiatric advanced practice nurse (APPN) over time. The Stuart Stress Adaptation Model recognizes these stages as crisis, acute, health maintenance and health promotion (Stuart, 2013). In each of these stages, parents could benefit from different interventions. Social support interventions may impact a parent in each of these stages.

The definitions and understanding of mental health and illness as described by Stuart (2013), reflect an understanding that individuals respond to their environments. As an APPN, it is incumbent to analyze behavior in relation to particular experiences. The parent exists on a continuum of health and illness. Depending upon the circumstances, they may find themselves at different locations on that continuum. What is important to understand, is how the parent is responding to the relative health or illness of their child. Are they adapting to the situation in a

manner that benefits their mental health or are choices being made that are maladaptive and have a negative impact on their own health? This literature review explores how a parent accesses social supports as an adaptive force to benefit their health.

Components of mental health highlighted in the Stuart Stress Adaptation Model, which are of particular relevance to the issue investigated in this literature review are resilience, integration, autonomy, and environmental mastery (Stuart, 2013). This review explores the impact, if any, social support has on the resiliency or the ability to regain a baseline sense of health and functioning. (Stuart, 2013). Similarly, whether social support has any impact on the parent and their ability to withstand the stresses and challenges of life experiences or integrate these experiences into their concept of themselves as an individual and member of their communities is reviewed (Stuart, 2013). A particularly interesting concept as it relates to social support and the population of interest in this literature review is environmental mastery. Stuart (2013) discusses this as the ability of the individual to manage the challenges one inevitably encounters in life without being overwhelmed and still be able to find satisfaction with their life. How one's sense of environmental mastery is impacted by social support will be explored in this review.

Definitions

Social support refers to the various types of support (i.e., assistance/help) that people receive from others and is generally classified into two (sometimes three) major categories: emotional, instrumental (and sometimes informational) support.

Emotional support refers to the things that people do that make us feel loved and cared for, that bolster our sense of self-worth (e.g., talking over a problem, providing

encouragement/positive feedback); such support frequently takes the form of non-tangible types of assistance.

Instrumental support refers to the various types of tangible help that others may provide (e.g., help with childcare/housekeeping, provision of transportation or money).

Informational support represents a third type of social support (one that is sometimes included within the instrumental support category) and refers to the help that others may offer through the provision of information. (MacArthur Foundation Research Network on SES & Health, Psychosocial notebook, 2008, para 1)

Autism disorder is defined as a complex neurodevelopmental disorder which impacts social communication and interaction and is characterized by repetitive patterns of behavior. The symptoms often impact daily living. The condition typically presents in early childhood and persists throughout life (U.S. Department of Health and Human Services, 2016).

Resilience is defined as “a process of adapting well in the face of adversity” (Ozbay et al., 2007, p. 3).

Process

Literature search strategies were used to find evidence to explore the impact of social support on parents of children with autism disorder. The literature search was conducted through the Harley E. French Library of the Health Sciences at the University of North Dakota. Based on the subject matter of the study topic, the literature search engines used include CINAHL, PUBMED, PsycINFO, and the Cochrane Database of Systematic Reviews.

PUBMED was the first search engine to be engaged in this search. The literature search terms used were “autism” AND “autism spectrum disorder” AND “parent” AND “social support”. The following filters were also used to further focus the results: date range limited to

the last ten years, articles written in the English language, and that are peer-reviewed. This search returned 78 articles. Of these articles, three articles were determined to be relevant.

The CINAHL database was next used in this literature search. Search terms include “autism” AND “autism spectrum disorder” AND “parent” AND “social support”. The search was then limited to articles in the English language, those that are peer reviewed, and those written in the last ten years. This search yielded 81 articles, of which six were determined to be relevant to the study question.

The PsycINFO database was also searched. Again, the terms searched were “autism” AND “autism spectrum disorder” AND “parent” AND “social support”. The search was also limited to articles published in the last ten years, in the English language, and peer reviewed. This search returned 231 articles. Of these articles, six were determined to be relevant to the study question.

The Cochrane Database of Systematic Reviews was searched with terms used in other searches. This revealed four articles. Of those it was determined that none were relevant to the question being studied.

Articles which were considered but not included in this review were discarded due to an older publication date, lower reliability of the measurement tools for social support or not being sufficiently related to the study question

A total of 15 articles were found to be relevant to the investigation of this study question. The articles were retrieved in full text format from the search engines.

The information from this literature review will be used to share the findings through a poster presentation with peers as well as professionals and agencies who serve or are in contact with families of children with autism disorder. This information will highlight how

social support impacts parents and by extension the needs of families that have a child with autism disorder. This writer's faculty advisor and fellow classmates will provide input on the summary of the findings. The presentation will offer strategies to APPNs that they may want to individualize or fine-tune to meet the needs of families within their care. After the presentation information is reviewed, it may also aid primary care providers and agencies as they proactively create social support resources and services to offer to parents. This informational resource may be shared with primary care health care providers including pediatricians and family nurse practitioners as well as with agencies that serve children with autism disorder and their parents.

Review of Literature

Overall, the findings from the literature reviewed show that social support is associated with positive impact on the well-being of parents of children with autism disorder. A more detailed review of the literature shows some variation of specific results based both on the type of social support investigated as well as the particular parent variables measured. By and large, the evidence presented in the studies reviewed was cross-sectional. 13 of 15 articles reviewed here discuss studies where data is gathered at a single point in time, either in total or in part, as the result of self-report, either by questionnaires completed by the study subjects or in interviews with the study authors. Of those studies, three of them included a control group for comparison. An additional study was conducted longitudinally over a period of ten years with data collected on five separate occasions (Barker et al., 2010). Data was captured over eight days using a daily diary in one study, and included a control group for comparison.

The evidence gleaned from these studies is Level III, based on an evaluation using the Johns Hopkins Nursing Evidence Based Practice (JHNEBP) Research Evidence Appraisal Tool

(Johns Hopkins Medicine Center for Evidence-Based Practice, n.d.). Level III is the lowest level strength of evidence.

Social Support and Stress

Six studies reviewed in this paper explore the impact of emotional and/or instrumental forms of social support on the parents' perception of stress. One area that was widely covered was the parents' perceptions of stress and how social support may impacts stress. Stressors for these parents may be defined as demands on and/or constraints upon the individual (Siman-Tov & Kaniel, 2011). How the individual perceives the stressors as well as how they believe they can cope with the stressors, in large part, determines the impact of the stressor on the individual (Siman-Tov & Kaniel, 2011).

Siman-Tov and Kaniel (2011) studied the parents' stress or ability to cope with a child with autism disorder as measured by several independent variables including social support. Both instrumental and emotional forms of social support were measured as perceived by the parents. Eighty- eight pairs of parents, 176 subjects in all, participated in the study. Of note, this study took place in Israel. This was a cross- sectional study in which each of the subjects completed a series of self-reported questionnaires designed to assess their perception of each variable being studied (Siman-Tov & Kaniel, 2011). Social support was measured using the Social Support Scale with an internal reliability considered high (Cronbach alpha = 0.86). All subjects had at least one child on the autism spectrum who was aged six to sixteen years of age. The study found that social support was negatively correlated with parental stress, with a slightly stronger correlation for fathers than for mothers.

Weiss et al., (2013) explored how several independent variables including social support predicted stress in the parents of children with autism disorder in a cross-sectional study. In

particular, the authors were looking at how these variables may individually mediate between the hardiness of families and the levels of parental stress. Hardiness is described as the family's ability to have an adequate level of control over their lives as well as how they perceive their ability to positively accommodate to the elements which may be challenging (Weiss et al., 2013). Subjects were recruited online through agencies that serve the parents of children with autism disorder. This was a cross-sectional study which included 138 mothers who had a child on the autism spectrum. The ages of the children were 4 to 41 years of age. The Family Support Scale was used to assess the mother's perception of social support with a Cronbach's alpha of 0.67(Weiss, et al., 2013). The questions asked about the helpfulness included family and social circles (including spouses, extended family, friends and co-workers) (Weiss, et al., 2013). The results of this study showed that social support was a variable that mediates a sense of family hardiness and the stress experienced by the parents of children with autism (Weiss et al., 2013). In particular, it found that social support helped to mitigate the stressors associated with aggressive child behaviors to allow the family to experience a greater level of hardiness than they might otherwise have experienced (Weiss et al., 2013).

Studies which investigated the links between parental stress and aspects of mental health functioning and social support were also reviewed by this author. Zablotsky, Bradshaw, and Stuart (2013) investigated the links between mental health and stress in parents of children with autism disorder and social supports. This cross-sectional study was a part of a much larger National Survey of Children's Health (NSCH) which interviewed mothers. 667 mothers of children age 18 and younger with an autism diagnosis were queried by telephone in the U.S. (Zablotsky et al., 2013). This study looked at two forms of social support; emotional social support which refers to people who can be relied upon daily for assistance and neighborhood

support which was described as people in the neighborhood who can be depended upon for assistance as needed (Zablotsk et al., 2013). Negative correlations were found between less favorable mental health and having emotional and neighborhood social support (Zablotsky et al., 2013). Similarly, mothers with higher stress levels were found to report lower levels of social support when compared to mothers who had lower levels of stress (Zablotsky et al., 2013).

Falk, Norris, and Quinn (2014) conducted a study investigating a correlation among parental stress, depression and anxiety, and independent variables including emotional social support and economic social support. Emotional social support was further delineated between family and non-family (Falk, Norris, & Quinn, 2014). Social and economic support were discussed separately in the literature but were combined in the results of the study. 280 mothers and 229 fathers with children age four to seventeen years completed questionnaires in this cross-sectional study (Falk et al., 2014). Participants were recruited internationally via Facebook (Falk et al., 2014). The results of the study found that social support was negatively correlated with depression in both mothers and fathers while it was negatively correlated with anxiety in fathers only (Falk et al., 2014). Regarding stress, social support was found to be negatively associated for both mothers and fathers (Falk et al., 2014). This study provided important information from a somewhat larger sample size of both mothers and fathers with results analyzed by gender. While social support had similar negative correlations with depression and levels of stress, it was interesting to find that it had an impact on anxiety for fathers but not mothers.

Kissel and Nelson (2016) conducted a study which looked at the impact of social support and other variables on the stress level of mothers who have children with autism disorder. It further delineated the results based on the severity of autistic behaviors. This study employed a small number of subjects, 64 total, which included 33 mothers whose children have more severe

autistic behaviors, 15 whose children had less severe autistic behaviors, and 16 in a normal control group (Kissel & Nelson, 2016). Emotional social support was measured in this cross-sectional study. Social support was measured using the Family Support Scale, a validated measurement tool (Kissel & Nelson, 2016). The results of the study showed social support was negatively correlated with stress across all three groups studied (Kissel & Nelson, 2016).

Ekas, Lickenbrock, and Whitman (2010) conducted a study which looked at the impact of informal social support on aspects of maternal outcomes including depression, psychological well-being, life satisfaction, stress as well as negative and positive effect. Additionally, one of the study's other goals was to look at the potential mediating effect of social support on optimism and the variables representing maternal outcomes. Social support was defined by the study's authors as informal support which is explained as support one would receive from a partner or spouse, family, and friends (Ekas, Lickenbrock, & Whitman, 2010). Subjects were asked specifically about informal support from partner, friends, and family separately (Ekas, et al., 2010). Previous studies have shown that the questions asked have good internal consistency with Cronbach's alpha for friend of .89, partner of .92 and family .89 (Ekas et al., 2010). 119 mothers of children under age eighteen with autism were queried in a paper questionnaire in this cross-sectional study. Results of this study found that informal social support from partner, friends, and family negatively correlate with depression and stress (Ekas et al., 2010). The strongest negative correlation with depression was found with support from a partner (Ekas et al., 2010). The strongest negative correlation with stress was found with support from friends (Ekas, et al., 2010). Similarly, the informal social supports from friend, family, and partner all had a positive correlation with positive effect, life satisfaction, optimism, and psychological well-being (Ekas et al., 2010). The strongest positive correlations with positive effect was from the

informal support of friends while the strongest positive correlation with life satisfaction and psychological well-being is found with the informal support of a partner. None of the forms of social support were found to mediate the relationship between optimism and maternal outcomes yet optimism was found to mediate the relationship between informal social support and maternal outcomes (Ekas et al., 2010).

As noted here, the literature reviewed (Ekas et al., 2010; Falk et al., 2014; Kissel & Nelson, 2016; Siman-Tov & Kaniel, 2010; Weiss et al., 2013; Zablotsky et al., 2013) discussed a range of social supports. These social supports include informal emotional support (Ekas et al, 2010), neighborhood support (Zablotsky et al, 2013), and economic support (Falk et al., 2014). Additionally, Simon-Tov and Kaniel (2011) detected greater negative correlation between stress and social support for parents than mothers which wasn't a finding noted in other studies discussed. Uniquely, Kissel and Nelson (2016) delineated the results of the impact of social support on the stress levels of mothers of children with autism disorder which showed that stress was negatively correlated with social support for mothers whose children have both severe and more mild autistic behaviors. Weiss et al., (2013), in particular, found that social support helped mitigate the impact of a child with autism disorder's aggressive behaviors on the parent's perceived level of stress. All literature reviewed revealed a negative correlation between stress and social support.

Social Support and Depression

It has been well established that the parents of children with autism disorder are at increased risk for depression, depressive symptoms, anxiety, and symptoms of anxiety (Barker et al., 2010). What is further known is that depression in parents has a negative impact on the functioning of the family (Bonis & Sawin, 2016). Several studies were reviewed which look at

the association between social support, depression, and anxiety in the parents of children with autism disorder.

Cantwell, Muldoon, and Gallagher (2015) conducted a study which looked at the role of social support, both emotional (someone to talk to about problems) and practical (providing care for your child when needed). This study also looked at the impact on the incidence of depressive symptomology, and a mediator between the stigma of caregivers and depressive symptomology through self-esteem. Stigma here refers to the perception that one experiences based on the negative attitudes and behaviors related from the public (Cantwell, Muldoon, & Gallagher, 2015). Subjects were the parents of children under age 18 with an intellectual disability; 56% of the 115 parents with children with disabilities had a child with autism spectrum disorder, the remainder with Down's Syndrome and mixed disabilities (Cantwell et al., 2015). Additionally, 58 parents were queried as a control group for this study (Cantwell et al., 2015). Both groups of parents were matched based on socioeconomic status as well as age and marital status (Cantwell et al., 2015). Of note, this cross-sectional study took place in the Republic of Ireland. The support was measured using the Support Functions Scale, a tool whose reliability has been validated with previous studies and whose internal consistency reliability measured .85 for emotional support and .86 for practical support (Cantwell et al., 2015). The results of this study showed that social support was negatively associated with stigma and depressive symptomology with practical support more strongly correlated with stigma and emotional support more closely associated with symptoms of depression (Cantwell et al., 2015). Further, just emotional support was found to mediate the relationship between stigma and depressive symptoms through self-esteem but only when self-esteem was measured as low or moderate (Cantwell et al., 2015).

Benson (2012) conducted a cross-sectional study investigating, among other phenomena, correlations between social support, including emotional and instrumental aspects, as measured by the size of a social network, and depressed mood and well-being among mothers of children (mean age 8.6, SD 1.5) with autism. 106 mothers were queried using questionnaires and in-home interviews (Benson, 2012). Social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS) with a reliability measure for this study of 0.89 (Benson, 2012). According to Benson (2012), this study found that social support was positively correlated with maternal well-being and negatively correlated with depressed mood. (Benson, 2012).

Barker et al. (2010) discussed a ten-year longitudinal study of mothers of adolescents and adults with autism disorder. The study looked at depressive symptoms, anxiety, and how several variables including social support impacted those two variables over time. The authors reviewed associations among the variables as those ranged over time (Barker et al., 2010). 379 mothers from Massachusetts and Wisconsin with children 10 years or older at the start of the study participated from 1998-2008 by completing self-administered questionnaires and in home interviews five times over the study period (Barker et al., 2010). The social support scale measured the number of people in the mother's social support network as an indicator of the strength of social support (Barker et al., 2010). Results of this study showed that at the start of the study, larger social support networks were positively associated with fewer depressive symptoms and lower levels of anxiety (Barker et al., 2010). Interestingly, over the years of the study, the relationship between depressive symptoms and the size or strength of the social support network did correlate (Barker et al., 2010). Regardless of the size of social support network, over time, depression remained stable or slightly worsened related to stressful life

events (Barker et al., 2010). Anxiety, on the other hand, is negatively associated with the size of the social support network over time (Barker et al., 2010). In summary the level of depression experienced by mothers of children with autism disorder was not impacted by the size of a social support network while a larger social network was negatively associated with anxiety for mothers in this study.

Several other studies that have been reviewed explore the impact of social support on symptoms of depression and anxiety (Cantwell et al., 2015; Ekas et al., 2010; Falk et al., 2014). Social support is found to be negatively associated with depression in four of the five studies reviewed (Benson, 2012; Cantwell et al., 2015; Ekas et al., 2010; Falk et al., 2014). A fifth study (Barker et al., 2010) showed a negative association between depression and indicators of social support at the initiation of the study but this correlation didn't continue over the length of the study. In terms of anxiety, the correlation with social support is a bit more mixed. Anxiety was addressed in two studies (Barker et al., 2010; Falk et al., 2014). Barker et al. (2010) noted an increase in maternal anxiety associated with a smaller social support network while Falk, et al. (2014) noted a significant negative association between paternal anxiety and social support with no significant correlation between these two variables for mothers.

Social Support and Well-Being/Resilience

The association between social support and a parent's well-being or quality of life is investigated in several studies which are reviewed in this paper. Whitehead, Dorstyn, and Ward (2015) conducted a study of parents of children under 18 years of age with autism disorder. The study looked at how protective factors such as social support may influence caregiver adjustment, as well as, how it may contribute to caregiver resilience (Whitehead, Dorstyn, & Ward, 2015). This cross-sectional study took place in Australia and included 438 female

subjects (Whitehead et al., 2015). Social support was measured using the Social Support Index (SSI) whose Cronbach alpha in this study had good reliability at .82 (Whitehead et al., 2015). Results showed a positive correlation between social support and caregiver resilience while dissatisfaction with social supports was positively associated with signs of psychological distress such as depression, anxiety, and stress (Whitehead et al., 2015).

Marsack and Samuel (2017) conducted a study which investigated the impact of social support, both formal and informal on the quality of life of parents of adult children (over age 18) with autism disorder. This study looked at how social support mediates the relationship between the parents' quality of life and their burden of caregiving (Marsack & Samuel, 2017). Formal support was defined as professional services such as social work, respite care, and financial support while informal support was interpreted as emotional support from friends, family and a partner (Marsack & Samuel, 2017). 320 subjects age 50-70 completed a web based survey which included items from Enhancing Recovery in Coronary Heart Disease (ENRICHD) Social Support Index (ESSI) whose Cronbach alpha was .89. Formal social support was measured using an author created checklist (Marsack & Samuel, 2017). Results of this study showed that informal social support was found to be positively correlated with the caregiver's quality of life (QOL) while formal support showed no such association (Marsack & Samuel, 2017). Secondly, informal social support mediated the negative effects of caregiver burden on QOL while formal social support had no such impact (Marsack

Pottie, Cohen, and Ingram (2009) conducted a study which took place over a twenty four week period of time. This study investigated links between daily emotional and instrumental social support and the caregivers' reports of positive and negative mood (Pottie, Cohen, & Ingram, 2009). Subjects included 93 parents of children with autism disorder age four to twelve,

who completed biweekly measures over two 12-week periods of time (Pottie et al., 2009). These measures included questions related to seven elements of emotional and instrumental social support. The tool used at 12 weeks and 24 weeks had Cronbach alpha of .86 and .82 for instrumental social support and .78 and .80 for emotional social support (Pottie et al., 2009). Both instrumental and emotional social support that were received daily were positively associated with higher levels of positive mood (Pottie et al., 2009). Secondly, higher levels of daily received emotional social support were predictive of lower levels of negative mood, however these results were not found when looking at daily received instrumental social support (Pottie et al., 2009).

Ruiz-Robledillo, Andres-Garcia, Perez-Blasco, Gonzalez-Bono, and Moya-Albiol (2013) conducted a study which evaluated the correlation between social support and resilience. 67 parents of children with autism disorder with mean ages between 13-14 years participated in this cross-sectional study (Ruiz-Robledillo, et al., 2013). Social support including items related to emotional/informational and instrumental support were measured using the tool Medical Outcomes Study Social Support Survey (MOS-SSS) whose reliability coefficients are over .91 (Ruiz- Robledillo et al., 2013). Higher levels of resilience were found to be correlated with higher levels of emotional and instrumental support (Ruiz- Robledillo et al., 2013).

Smith et al. (2010) conducted a study of 96 mothers of co-residing adolescents and adults with autism disorder utilizing an eight-day diary to report their experiences daily. A comparison group of mothers with adult and adolescent children who co-reside and don't have autism disorder also completed this same diary which included a daily 15-25 minute-long telephone interview (Smith et al., 2010). The purpose of the study was to determine the impact of daily experiences including the receipt of social support on positive and negative emotions (Smith et

al., 2010). Results showed that receiving social support is positively correlated with positive emotions among the subjects who have children with autism disorder, while the receipt of this support was negatively associated with positive emotions for parents in the control group (Smith et al., 2010).

Khanna et al. (2011) conducted a cross-sectional study which investigated the connection among social support, the Health-Related Quality of Life (HRQOL), and caregiver burden among 304 parents of children who have autism disorder age 18 years and younger. Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS) whose Cronbach's alpha was .95 (Khanna et al., 2011). The subjects were queried using mailed questionnaires (Khanna et al., 2011). Social support was found to positively correlate with both physical and mental HRQOL of the parents and negatively correlate with the level of caregiver burden as reported by the parents (Khanna et al., 2011).

Overall, the studies related to social support and resilience (Ruiz- Robledillo et al., 2014 and Whitehead, et al., 2015) showed agreement in the positive association between social support and caregiver resiliency. Additionally, studies looking at associations between social support and caregiver quality of life (Khanna et al., 2011 & Marsack & Samuel, 2017) also showed unanimity in finding a positive correlation between social support and caregiver quality of life.

Studies that explored the impact of social support on the parents of adolescents and adults with autism disorder (Barker et al., 2010; Marsack & Samuel, 2017) provided information on how social support impacts caregiver burden and quality of life (Marsack & Samuel, 2017) as well as depression and anxiety (Barker et al., 2010). Interestingly, as it relates to social support, parents of adolescents and adults in this study experienced similar correlations between quality

of life and social support with parents of younger children (Khanna et al., 2011). While Barker et al. (2010) found a negative correlation between anxiety and social support in mothers of adolescents and adults, this was not replicated in a study (Falk et al., 2014) examining depression and anxiety and its connection in mothers and fathers. Falk et al. (2014) found a negative correlation between anxiety and social support for fathers but not for mothers. Barker et al. (2010) did find a negative association between social support and depression at the start of its ten-year study but it didn't persist over time among the mothers of adolescents and adults with autism disorder. Falk et al. (2014), on the other hand, found a negative correlation between depression and social support in mothers of younger children with autism disorder. In summary, studies that investigated the association between social support and quality of life and anxiety in parents of adolescents with autism disorder showed a negative correlation (Barker et al., 2010; Falk et al., 2014). However, studies that investigated the correlation between depression and social support in parents of adolescents and adults with autism disorder were mixed, showing both negative correlation (Barker et al., 2010) and a lack of correlation (Falk et al., 2014).

All studies reviewed here included input from parents of children with autism disorder that were self-reported. This may be a limitation to the validity of the findings of the studies as the subjects could be vulnerable to recall biases as well as self-serving and social-desirability factors (Whitehead et al., 2015). As all studies, with the exception of two (Barker et al., 2010; Smith, et al., 2010), were cross-sectional in nature, it wasn't possible to determine causality between social support and any of the other variables measured (Khanna et al., 2011). Finally, most studies had a small sample size which also put into question the generalizability of the findings discussed here.

Interpretation

The evidence discussed in this paper point consistently to the positive association between social support and several different aspects of well-being of parents of children with autism disorder. Studies reviewed here have shown the negative association between social support and the negative states of depression, stress and anxiety. [06]The findings discussed here point consistently to the benefit of social support for parents of children with autism disorder in terms of hardiness, positive sense of well-being, and HRQOL. Other research has shown positive associations between social support and parental well-being among parents who have children with a range of disabilities (Benson, 2012). Additionally, research on the impact of social support, in general, found that it has many positive psychosocial impacts for parents including enhancing resilience to stress as well as protecting against mental illness (Ozbay et al., 2007).

With the understanding that social support has been shown to have positive correlation with positive psychosocial effect in other similar groups, as well as, the consistent results showing associations between social support and parental well-being in the studies with low-quality evidence. It seems reasonable to follow a path that will develop initial strategies to promote effective social support opportunities for parents of children with autism disorder. At the same time, efforts must be made to move beyond the cross-sectional study types such as reviewed in this literature review. It will be important for clinicians to develop studies which are quantitative in nature and employ random assignment or random selection to investigate the role of social support as it relates to positive and negative psychosocial factors and determine any causality (Mateo & Foreman, 2014). Additionally, it will be important to have an understanding of the most effective tools for providing social support, be it emotional, instrumental and/or informational. Literature reviewed here consistently report that each of those forms of support

offers some benefit to parents of children with autism disorder. Understanding how to make social support available to parents of children with autism disorder will be valuable. It will be important to understand more clearly how to most effectively to offer social support whether in-person or virtually. Additionally, it will take further research to understand how to most effectively inform parents of children with autism disorder of the forms of social support available to them.

To help ensure that social support as in intervention is accessible and appropriate to the needs and preferences of a diverse range of families who are impacted by autism disorder, a diverse group of subjects needs to be studied. This diversity should include ethnic, racial and socioeconomic factors. The subjects in the studies discussed in this paper were overwhelmingly Caucasian and a disproportionate number with higher socioeconomic status. While the results of these studies show the correlation between social support and positive effect for parents, more needs to be known and understood about the impact of social support on parents whose demographics are not reflected in studies investigated here. Specifically, it will be important to understand the association between social support and positive effect for parents of children with autism disorder who are from ethnic minority groups, lower socioeconomic groups with limited health care access and are non-English speaking. More needs to be understood about the impact of social support on fathers and their psychosocial needs as their needs was examined in just four (Falk, et al., 2014; Pottie et al., 2009; Ruiz-Robledillo et al., 2014; Siman-Tov & Kaniel, 2011) of the fifteen studies reviewed here. Results from studies from outside North America (Cantwell et al., 2015; Falk et al., 2014; Ruiz-Robledillo et al., 2014; Siman-Tov & Kaniel, 2011; Whitehead et al., 2015) demonstrate consistency with results from U.S. studies showing that social support is associated with positive psychosocial effect among the populations investigated

internationally. These factors support the need to make diverse study populations a priority in future studies.

The needs of both those with autism disorder and their parents often change with aging (Marsack & Samuel, 2017). It is crucial that parents of adults with autism disorder be studied experimentally to understand how their needs and preferences for social support may alter over time in accordance with their own aging. Studies have shown that social support is helpful for parents of people with autism disorder and this literature review has found the need for additional high-quality experimental studies to gain a more comprehensive perspective of what social support strategies are effective. Since the benefits of social support offerings are most effective, it is critical that health care professionals who serve these populations gain an understanding of what options are currently available and share this information with the parents of individuals with autism disorder. Reaching out to other healthcare professionals, social service agencies, disease specific organizations and public health providers to learn more about the opportunities for social support currently available and sharing this information is a critical component of the care APPNs provide to their patients with autism disorder and their parents.

Outcome and Dissemination

A poster outlining the key findings and recommendations from this paper with references is attached as appendix 1&2. The poster provides an overview of the purpose and methods included in this paper. In addition, the theoretical framework which is the conceptual basis for this study as well as the findings of the literature review are highlighted. Finally, recommendations and clinical practice implications that were determined from the review of literature are included in the content of the poster. The poster is designed as a tool to share with APPNs as well as other healthcare professionals, social service, public health agencies and

school districts who serve and interact with people with autism disorder and their parents. It is expected that the dissemination of these findings will enrich the understanding these individuals and organizations have of how social support impacts parents of children with autism disorder. Additionally, with this improved understanding, it is expected that these individuals and entities will implement these recommendations and/or develop high quality studies to gain additional knowledge to determine what causality may exist among social support and elements of parental well-being and mental health concerns.

Implications for Nursing

The question investigated in this paper has ramifications on nursing practice in the clinical understanding of how the presence of autism disorder in a member of a family can impact the entire family (Barker et al., 2010). Consideration of the impact of autism disorder on the family and particularly the parents of a child with autism disorder is important in all aspects of nursing practice including assessment, diagnosis, and treatment. Understanding the substantial ramifications that this condition can have on the parents and their ability to cope can guide the APPN in her interactions with families as they relate to these challenges. Social support is one intervention that APPNs may integrate into their practice and provide education to families.

Given that autism is a disorder which impacts the individual and those close to him or her most often over a lifetime, it is critical that the nurse is actively involved in education with the individual and his or her parents or guardians as appropriate. Autism disorder's impact can be felt developmentally and behaviorally across many environments. When the person with autism disorder is young, it is imperative to engage the parents in a discussion about available resources for both the patient and the child's developmental needs. Resources need to be provided to about

services available in communities. Studies of parents of adolescents and adults with autism disorder reviewed here point to the importance of ongoing education for both the person with autism disorder and their parents. Most often a child with autism disorder has needs that will continue throughout their life (Barker et al., 2010).

As autism disorder is lifelong developmental condition whose impact is growing with its more recent increased incidence (CDC, 2016), it is imperative that public policy continue to develop which recognizes this phenomenon and the impact that it will have from several perspectives. While children with autism disorder will achieve a level of independence that will allow them to live on their own as they grow up and be employed competitively, 58% of people in their 20s with autism disorder are unemployed (NPR, 4/21/15). This is significant in the impact that this will have on their caregivers (Barker et al., 2010). One must advocate for public policy to meet psychosocial needs by creating educational, training, housing, and social support services for those with autism disorder, parents, and caregivers.

Conclusion

Autism disorder is a neurodevelopmental condition whose incidence has increased significantly over the last decade. The CDC (2016) estimates that 1 in 68 children are diagnosed with autism disorder. The great majority of these individuals have parents who manage the often complex developmental and social needs. Parents of children with autism disorder experience increased stress as well are at increased risk for developing depression and experiencing symptoms of anxiety (Russa, et al., 2015). When parents experience mental health concerns and increased distress, their parenting ability is negatively impacted (Bonis & Sawin, 2016). In particular, parents experiencing increased distress are less able to focus on the physical and emotional needs of themselves as well as the physical, emotional and developmental needs of

their children (Bonis & Sawin, 2016). With the challenges presented by autism disorder, parents need many effective tools to help guide their children with autism disorder to reach their potential (Benson, 2012). The results of the studies investigated here show parents benefit from social supports designed to meet their psychosocial needs (Russa et al., 2015). Experimental studies need to be done to gain an understanding of any causal relationship between social support and positive effect on parents. As the evidence presented in this paper shows, having social supports made available to parents provides needed assistance that benefits them and, by extension, their children with autism disorder.

References

- Barker, E. T., Hartley, S. L., Seltzer, M.M., Greenberg, J.S., Floyd, F. J., & Orsmond, G.I. (2010). Trajectories of Emotional Well-Being in Mothers of Adolescents and Adults with Autism. *Developmental Psychology*, 47, 551-561. doi: 10.1037/a0021268
- Benson, P.R. (2012). Network Characteristics, Perceived Social Support, and Psychological Adjustment in Mothers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 42, 2597-2610. doi: 10.1007/s10803-012-1517-9
- Bonis, S.A., & Sawin, K.J. (2016). Risks and Protective Factors for Stress Self-Management in Parents with Autism Spectrum Disorder: An Integrated Review of the Literature. *Journal of Pediatric Nursing*, 31, 567-579. doi: 10.1016/j.pedn.2016.08.006
- Cantwell, J., Muldoon, O., & Gallagher, S. (2015). The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. *Journal of Disability Research*, 59, 948-957. doi: 10.1111/jir.12205
- Centers for Disease Control and Prevention. (2016). *Identified Prevalence of Autism Spectrum Disorder*. Retrieved from: <https://www.cdc.gov/ncbddd/autism/data.html>
- Ekas, N.V., Lickenbrock, D.M., & Whitman, T.L. (2010). Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 40, 1274-1284. doi: 10.1007/s10803-010-0986-y
- Falk, N.H., Norris, K., & Quinn, M.G. (2014). The Factors Predicting Stress, Anxiety, and Depression in the Parents of Children with Autism. *Journal of Autism and Developmental Disorders*, 44, 3185-3203. doi: 10.1007/s10803-014-2189-4

- Irwin, M. (2014). Quantitative Research Design for Nursing Practice. In Mateo, M.A., & Foreman, M.D.(Eds.), *Research for Advanced Practice Nurses* (2nd ed.). (129-160). New York: Springer Publishing Company, LLC.
- Johns Hopkins Medicine Center for Evidence-Based Practice. John Hopkins Nursing Evidence-Based Practice Model. Retrieved from:
http://www.hopkinsmedicine.org/evidence-based-practice/jhn_ebp.html on 7/14/17.
- Khanna, R., Madhavan, S.S., Smith, M.J., Patrick, J.H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of Health-Related Quality of Life Among Primary Caregivers of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 41, 1214-1227. doi: 10.1007/s10803-010-1140-6
- Kissel, S.D., & Nelson, W.M. (2016). Parents' Perceptions of the Severity of Their Child's Autistic Behaviors and Differences in Parental Stress, Family Functioning, and Social Support. *Hamilton Institute on Disabilities Focus on Autism and Developmental Disabilities*, 3, 152-160. doi: 10.1177/1088357614537352
- MacArthur Research Network on SES & Health. (2008). *Psychosocial notebook*, para.1. Retrieved from: <http://www.macses.ucsf.edu/research/psychosocial/socsupp.php> on 7/14/17
- Marsack, C.N., & Samuel, P.S. (2017). Mediating Effects of Social Support on Quality of Life for Parents of Adults with Autism. *Journal of Autism and Developmental Disorders*, doi: 10.1007/s10803-017-3157-6
- National Public Radio (2015). Young Adults with Autism More Likely To Be Unemployed, Isolated. Retrieved from: <http://www.npr.org/sections/health-shots/2015/04/21/401243060/young-adults-with-autism-more-likely-to-be-unemployed->

isolated

Ozbay, F., Johnson, D.C., Dimoulas, E., Morgan, C.A., Charney, D., & Southwick, S. (2007).

Social Support and Resilience to Stress From Neurobiology to Clinical Practice.

Psychiatry, 4, 35-40. Retrieved from:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2921311/>

Pottie, C.G., Cohen, J., & Ingram, K.M. (2009). Parenting a Child with Autism: Contextual

Factors Associated with Enhanced Daily Parental Mood. *Journal of Pediatric*

Psychology, 34, 419-429. doi: 10.1093/jpepsy/jsn094

Ruiz-Robledillo, N., De Andres-Garcia, S., Perez-Blasco, J., Gonzalez-Bono, E., &

Moya-Albiol, L. (2014). Highly resilient coping entails better perceived health, high

social support and low morning cortisol levels in parents of children with autism

spectrum disorder. *Research in Developmental Disabilities*, 35, 686-695.

doi: 10.1016/j.ridd.2013.12.007

Russa, M.B., Matthews, A.L., & Owen-DeSchryver, J.S. (2015). Expanding Supports to

Improve the Lives of Families of Children with Autism Spectrum Disorder. .

Hamilton Institute on Disabilities Journal of Positive Behavior Intervention, 17,

95-104. doi: 10.1177/1098300714532134

Siman-Tov, A., & Kaniel, S. (2011). Stress and Personal Resource as Predictors of the

Adjustment of Parents to Autistic Children: A Multivariate Model. *Journal of*

Autism and Developmental Disorders, 41, 879-890.

doi: 10.1007/s10803-010-1112-x

Smith, L.E., Hong, J., Seltzer, M.M., Greenberg, J.S., Almeida, D.M., & Bishop, S.L.

(2010). Daily Experiences Among Mothers of Adolescents and Adults with Autism

Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 40, 167-178.

doi: 1007/s10803-009-0844-y

Stuart, G.W. (2013). The Stuart Stress Adaptation Model of Psychiatric Nursing Care, Chapter

3. Retrieved from:

<https://nursekey.com/the-stuart-stress-adaptation-model-of-psychiatric-nursing-care/>

Twoy, R., Connolly, P.M., & Novak, J.M. (2007). Coping Strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners*, 19, 251-260.

U.S. Department of Health and Human Services, National Institutes of Health, National

Institute of Neurological Disorders and Stroke. (2016). Autism Spectrum Disorder Fact

Sheet. Retrieved from: [https://www.ninds.nih.gov/Disorders/Patient-Caregiver-](https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet)

[Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet](https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet)

Weiss, J.A., Robinson, S., Fung, S., Tint, A., Chalmers, P., & Lunsy, Y. (2013). Family hardiness, social support, and self-efficacy in mothers of individuals with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 7, 1310-1317.

doi: 10.1016/j.rasd.2013.07.016

Whitehead, K., Dorstyn, D., & Ward, L. (2015). Psychological Adjustment in Families Affected Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities*, 27,

703-717. doi: 10.1007/s10882-015-9446-0

Zablotsky, B., Bradshaw, C.P., & Stuart, E.A. (2013). The Association Between Mental Health, Stress, and Coping Supports in Mothers of Children with Autism Spectrum Disorders.

Journal of Autism and Developmental Disorders, 43, 1380-1393.

doi: 10.1007/s10803-012-1693-7

Appendix 1: Poster titled: An Exploration of the Impact of Social Support on the Parents
of Children with Autism

Appendix 2:

Reference list for Poster titled: An Exploration of the Impact of Social Support on the Parents of Children with Autism:

Centers for Disease Control and Prevention. (2016). *Identified Prevalence of Autism Spectrum*

Disorder. Retrieved from: <https://www.cdc.gov/ncbddd/autism/data.html>

Pottie, C.G., Cohen, J., & Ingram, K.M. (2009). Parenting a Child with Autism: Contextual

Factors Associated with Enhanced Daily Parental Mood. *Journal of Pediatric*

Psychology, 34, 419-429. doi: 10.1093/jpepsy/jsn094

Siman-Tov, A., & Kaniel, S. (2011). Stress and Personal Resource as Predictors of the

Adjustment of Parents to Autistic Children: A Multivariate Model. *Journal of*

Autism and Developmental Disorders, 41, 879-890.

doi: 10.1007/s10803-010-1112-x

Stuart, G.W. (2013). The Stuart Stress Adaptation Model of Psychiatric Nursing Care, Chapter

3. Retrieved from:

<https://nursekey.com/the-stuart-stress-adaptation-model-of-psychiatric-nursing-care/>

U.S. Department of Health and Human Services, National Institutes of Health, National

Institute of Neurological Disorders and Stroke. (2016). Autism Spectrum Disorder Fact

Sheet. Retrieved from: [https://www.ninds.nih.gov/Disorders/Patient-Caregiver-](https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet)

[Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet](https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet)

Zablotsky, B., Bradshaw, C.P., & Stuart, E.A. (2013). The Association Between Mental Health,

Stress, and Coping Supports in Mothers of Children with Autism Spectrum Disorders.

Journal of Autism and Developmental Disorders, 43, 1380-1393.

doi: 10.1007/s10803-012-1693-7