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Social Networking Site Use among Caregivers of Children With Autism Spectrum Disorders

Research-in-Progress

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Abstract

Caregivers of children with autism spectrum disorder (ASD) experience higher levels of stress relative to those of children with other developmental disabilities and typical development. To date, little research has empirically examined the relationship between social supports, social networking site (SNS) use, and stress among caregivers of children with ASD. Using the resiliency model of family stress, adjustment, and adaptation as a theoretical framework, we explore the links between perceived social supports, SNS use, and stress among caregivers of children with ASD. We do this by conducting a cross-sectional research design and using a structural equation modeling statistical approach. Practical and theoretical implications will be revealed by this study.

Keywords: Social networking site, stress, caregiver, strain, social support, coping strategies, Partial Least Squares.

Introduction

Research consistently demonstrates that stress among caregivers is linked with several negative outcomes, including anxiety, depression, and disease (Dyson 1997; Mausbach et al. 2012). Evidence also shows, however, that perceived social support mitigates caregiver stress (Luther et al. 2005), and can contribute to more positive outcomes for caregivers of individuals with various conditions including dementia (Kaufman et al. 2010), Alzheimer (Mausbach et al. 2012), and mental health (Mackay and Pakenham 2012). While traditional, face-to-face support groups have been shown to provide caregivers with social support thereby decreasing stress, the recent availability of social networking sites has broadened the ways in which caregivers connect with one another. For example, social media is used by patients to seek healthcare information and social support through support groups (Hamm et al. 2013).

A major reason for studying the antecedents of stress among caregivers of children with autism spectrum disorders (ASD) is the rapidly growing prevalence of the disorder. The growing prevalence of ASD in recent years has increased the interest among researchers to investigate the effect of caring for children with ASD on caregivers. Autism is arguably the fastest growing developmental disability since estimates show the number of American children diagnosed with ASD will increase by 10 to 15 percent annually (Luther et al. 2005). Recent estimates suggest that 1 in 68 children in the U.S. will be diagnosed with an ASD by the age of 8 years (CDC, 2014). Studies consistently show that caregivers of children with ASD report higher levels of stress than those of children with other developmental disabilities as well as typical development (Dykens et al. 2014; Emerson 2003; Estes et al. 2009; Harper et al. 2013). Among caregivers of children with developmental disabilities, similarly to research on caregivers of others with other disabilities, research suggests that formal social support groups partially mitigate the immense stress

associated with caregiving (Cousino and Hazen 2013; Dyson 1997; Myers et al. 2009). However, caregivers of children with ASD are less likely to utilize traditional, face-to-face support groups (Zimmerman 2013) due to the difficulty of finding care for their children (Kolb 2007) as well as their children's difficult behaviors (Twyo et al. 2007). Autism impacts caregivers so intensely that caregivers need resilience and informal and formal social support. Most studies have looked at counseling, support groups, respite care through community agencies, and other services that require face-to-face contact to reduce stress among caregivers of children with ASD (Dyson 1997; Luther et al. 2005), but there is a lack of research on identifying mechanisms that can suit the situation of this particular group which experiences a higher level of social isolation. Therefore, investigating the role of the use of SNS among caregivers of children with ASD as a source of social support will fill this gap in the literature.

Recently Hamm et al. (2013) conducted a meta-analysis studying the social media use among caregivers and concluded that empirical rather than descriptive research is needed on specific caregiver populations of specific conditions in order to guide the use and implementation of social media. Therefore, our study answers this call for empirical research on the use of SNS among caregivers by exploring the links between perceived social supports, SNS use, and stress among caregivers of children with ASD. In doing so, our study addresses the following questions:

- (1) To what extent does SNS use (i.e., Facebook) among caregivers of children with ASD impact stress?
- (2) To what extent does social support mediate the relationship between SNS use and stress among caregivers of children with ASD?

Drawing on the resiliency model of family stress, adjustment, and adaptation as a theoretical framework, we postulate that a caregiver's resilience, adjustment, and adaptation (McCubbin 2001) to the stress resulted from the diagnosis of a child with ASD is alleviated by SNS use, a major source of social support in this socially isolated population. We also investigate the role of social support as a mediator in the relationship between SNS use and stress and postulate that SNS influences caregivers' stress through social support. We answer the research questions related to the antecedents of a caregiver's stress using data collected through a survey of caregivers of children with ASD with diverse backgrounds.

The paper is organized as follows. The next section presents a brief review of the related literature and sheds lights on the unique contributions of our study, while the third part lays out the theoretical basis of our research model and the hypotheses to be tested. We then summarize our research methods. Finally, we discuss and conclude with the implications and limitations of our study.

Literature Review

Caregivers of children with ASD experience remarkable financial, social, and emotional stress due to caregiving demands (Estes et al. 2009; Montes and Halterman 2008; Stuart and McGrew 2009). The annual income of families of children with ASD is significantly less than families of children with typical development (Montes and Halterman 2008). The Center for Disease Control (CDC) estimated that it costs families \$17,000 more per year to care for a child with ASD as compared to a child without ASD. Caring for children with ASD can also impact caregivers' other aspects of life such as leisure time, spending quality time with other children in the family, and most importantly maintaining employment (Järbrink et al. 2003).

The higher level of stress among caregivers of children with ASD has been associated with the caregivers' feelings of social isolation (Myers et al. 2009) due to external sources such as society's lack of understanding (Woodgate et al. 2008), and also because they want to escape awkward meetings with those that do not understand their child's condition (Gray 1997). For example, caregivers of children with ASD suffer from the burden of bystanders in public lacking the understanding of the child's extreme and strange behaviors such as aggression, screaming, staring, and making strange sounds. Caregivers most of the times get judged by others for spoiling their children, lacking control over their children, and their inability to instill discipline without being given the chance to explain the circumstances (Gerber 2014). What aggravates these assumptions and lack of empathy from the public is the absence of any obvious direct signs of disability on the child with ASD (Gray 1997). Therefore, caring for a child with autism brings enormous stress on caregivers. Although these are significant drivers of stress among caregivers of children with ASD, research consistently reports that the primary source of stress in this group is the lack

of social support (Boyd 2002; Luther et al. 2005). Internet-based peer support tends to provide informational and emotional support (Niela-Vilén et al. 2014), two main subscales of social support (Sherbourne and Stewart 1991).

Social supports for caregivers of children with ASD include face-to-face support groups, community supports, family members, and friends. However, research suggests that due to the distinct symptoms of ASD (e.g., problem behavior, elopement) as well as society's lack of understanding, caregivers of children with ASD utilize fewer face-to-face social supports (Siklos and Kerns 2006; Weiss 2002). Caregivers of children with ASD, then, resort to SNS such as Facebook as an alternative form of social support that does not require physical presence (Hamm et al. 2013). In fact, adults accounted for 71% of Facebook use in 2013 (Duggan and Smith 2013), and there has been a growing focus on the ways in which individuals are integrating social media into their daily lives to impact health (Chou et al. 2009; Ziebland and Wyke 2012). Facebook has been used as an intervention platform to address health issues, such as increasing physical activity in obesity (Napolitano et al. 2013), problem drinking in posttraumatic stress disorder (Brief et al. 2013), and stress reduction in anxiety disorders (Drozd et al. 2013). Clearly, Facebook is being used as an intervention tool for clinical populations not only for its use popularity among all age groups, but also for it, unlike other sites such as LinkedIn which is more for professional networking searching for jobs and Twitter which is more of a mini-blog, encompasses all of the above and still is informal and enables users to socialize and share information with others. Although a myriad of antecedents exist to address caregiver stress in ASD (Hastings and Johnson 2001; Keen et al. 2010), studies to date have not utilized a Facebook platform to do so. Given that there are over 1,000 Facebook groups dedicated to providing social support for caregivers of children with ASD, research on the ways in which the use of social networking site impacts stress in this specific group is warranted (Hamm et al. 2013).

There is a plethora of research on SNS use in recent years due to the exponential growth of use (Boyd and Ellison 2007; Ellison et al. 2014). Approximately seven out of ten individuals used social media in the U.S. in 2012 (Morris 2014). This use is not confined to teenagers as it is commonly stereotyped by many, but it also includes adults. Adults account for 73% of SNS use in general and for 71% in Facebook use in 2013 (Duggan and Smith 2013). Evidence shows that the effect of SNS use on behavior is controversial; some argue that it can have positive impact while others posit it can have negative ones (Ellison et al. 2007; Jelenchick et al. 2013; Moqbel et al. 2013; Steinfield et al. 2008). There is evidence that SNS use improves self-esteem and satisfaction with life among teenagers (Steinfield et al. 2008) enhances job performance by inducing work-life balance (Moqbel et al. 2013), leads to more satisfied workers and better job performance (Charoensukmongkol 2014), has significant association with work performance (Leftheriotis and Giannakos 2014), and elicits organizational commitment (Eren and Vardarlier 2013). More recently, SNS (e.g., Facebook) is arguably a gold mine for social resources especially informational resources through networks of friends (Ellison et al. 2014). No evidence were found that SNS use leads to depression among children and adolescents (Jelenchick et al. 2013). On the other hand, there is a stream of research that claims that people who continuously use SNS (e.g., Facebook) tend to make comparisons of their lives and assume that others are better off (Chou and Edge 2012). Several studies have been conducted on SNS use in healthcare (Hamm et al. 2013; Niela-Vilén et al. 2014). SNS is a major platform for health information sharing (Scanfeld et al. 2010) and for health research data collection (Alshaikh et al. 2014). SNS use in the healthcare sector has been prominent for seeking support whether in the form of awareness, fundraising, or patient and caregiver support (Bender et al. 2011). Although numerous studies have looked at SNS use in healthcare (Bender et al. 2011; Hamm et al. 2013; Niela-Vilén et al. 2014; Scanfeld et al. 2010) no study has yet researched the role of SNS use by caregivers of children with ASD as a tool for mitigating stress.

Theoretical Framework and Hypotheses Development

The rationale of the hypotheses delineated below is framed in the context of resiliency model of family stress, adjustment, and adaptation (McCubbin et al. 1996; McCubbin 2001) a strength-based and competency-oriented model that was derived from the family stress theory. The resiliency model allows a great understanding of how individuals can adapt, adjust, and overcome stressors arising from adversities and changes (McCubbin 2001). The resiliency model has been used by several studies of caregivers' stress and outcomes in family life changes such as loss, strain, and chronic ailments (Twoy et al. 2007).

Caregiver stress is alleviated mainly by caregivers' resiliency and strengths when introduced with a stressor such as a diagnosis of ASD of a child. Family resilience is contingent on caregivers' utilization of social supports and is strongly influenced by the ways in which parents cope with the demands of caregiving. When caregivers of children with developmental disabilities including ASD, utilize social supports, their problem-solving skills increase. This leads to increased family strength and resilience over time. We argue that Facebook use including support pages are integral to the social support networks of families of children with ASD. The shared problem solving that occurs on Facebook support sites likely perpetuates support resources in caregivers. For example, one mother that belongs to a Facebook support group site recently posted: "I think this group is a God send for us parents. No matter what bizarre crazy, thing your child does, there is absolutely NO JUDGING and a handful of people who have been in your shoes. So nice to know we don't have to walk the rough road alone." Clearly, families are drawing social support from online groups, which potentially increase family resilience.

Caregivers of children with ASD tend to keep themselves isolated from other contacts in the community because of the lack of understanding of the child's behavior by family, teachers, friends, and the society in general (Twyo et al. 2007). For this reason among other, caregivers of children with ASD report higher levels of stress than those of children with other developmental disabilities as well as typical development (Dykens et al. 2014; Emerson 2003; Estes et al. 2009; Harper et al. 2013). However, caregivers mitigate this social isolation by resorting to online social support communities (Sarkadi and Bremberg 2005). Social networking sites have been increasingly used by caregivers to gain health information and social support (Hamm et al. 2013). Caregivers of children with ASD can employ SNS support groups as a platform to discuss their difficulties, achievements, and to meet other caregivers in a similar situation. SNS use arguably offers an economical and wide-reaching platform for caregivers to attain resiliency especially because the nature of caregiving of children with ASD makes in-person meetings difficult (Hamm et al. 2013). Before the advent of the Internet and social media, social support among caregivers has been successfully provided via telephone and in person (Ahmed et al. 2010). It is important to acknowledge that SNS use by caregivers of children with ASD may increase stress by making comparisons (Chou and Edge 2012) of their children with children of others especially if they find other's children are making more progress than their children.

To attain resiliency, caregivers need social support in the form of informational support by receiving information and sharing their experiences with other caregivers. Social support among caregivers in the form of emotional support by understanding another's similar situation is an important source of resiliency (Rossman 2007). Social support from friends, family members, and social network circles is key for managing stress (Chao 2011). SNS's friends and communities with similar interests can be great sources for social support (Koch et al. 2012). SNS such as Facebook plays an important role in providing caregivers with a platform to gain informational support by sharing their experiences with other caregivers in an understanding and safe environment (Ahmed et al. 2010) and learning from each other how to adjust and adapt to the changes came along their child's diagnosis of ASD (Luther et al. 2005; Niela-Vilén et al. 2014). SNS use anecdotally provides informational and emotional support to caregivers despite physical and time constraints (Niela-Vilén et al. 2014). Therefore, we argue that SNS use—Facebook—can elicit social support that broadens individual's arsenal of resources in alleviating stress by providing informational, tangible, and emotional supports. This leads to the following hypotheses.

H1: *SNS use by caregivers negatively affects perceived stress.*

H2.1: *SNS use by caregivers positively affects social support.*

The mediating role of social support on the relationship between SNS use and stress can be explained by the buffering hypothesis theory which posits that social support buffers the level of stress (Lin et al. 1985). According to the buffering hypothesis, social groups (e.g., SNS) do not have a direct impact on stress but rather they moderate stress by affecting social support (Schafer and Schafer 2000). This leads the following hypothesis:

H2: *The effect of SNS use on stress is mediated by social support.*

The main source of resiliency and strength among caregivers with ASD is arguably social support (Luther et al. 2005). Social support can be in several different forms, e.g., informational support by giving advice, guidance, feedback or information; emotional support by expressing empathetic understanding and positive emotions, and encouraging expressions of feelings; tangible support by providing material aid or behavioral help (Sherbourne and Stewart 1991). Social support in the form of accessibility to support resources such as individuals a person feels they can be counted on for tangible and intangible help (Grant et al. 2001) plays a significant role in achieving adjustment to caregiving. In the same token, to successfully attain adaptation, caregivers need to employ external social support from social networks and internal social support from family and close friends (Lavee et al. 1985). Caregivers of children with ASD with higher perceived social support tend to report less negative outcomes such as depression, anger, and anxiety (Gray and Holden 1992). In fact, social support is a major resiliency factor in overcoming and alleviating caregivers' stress (Corcoran and Fischer 2013). This leads us to the following hypothesis:

H2.2: Social support will negatively affect perceived stress.

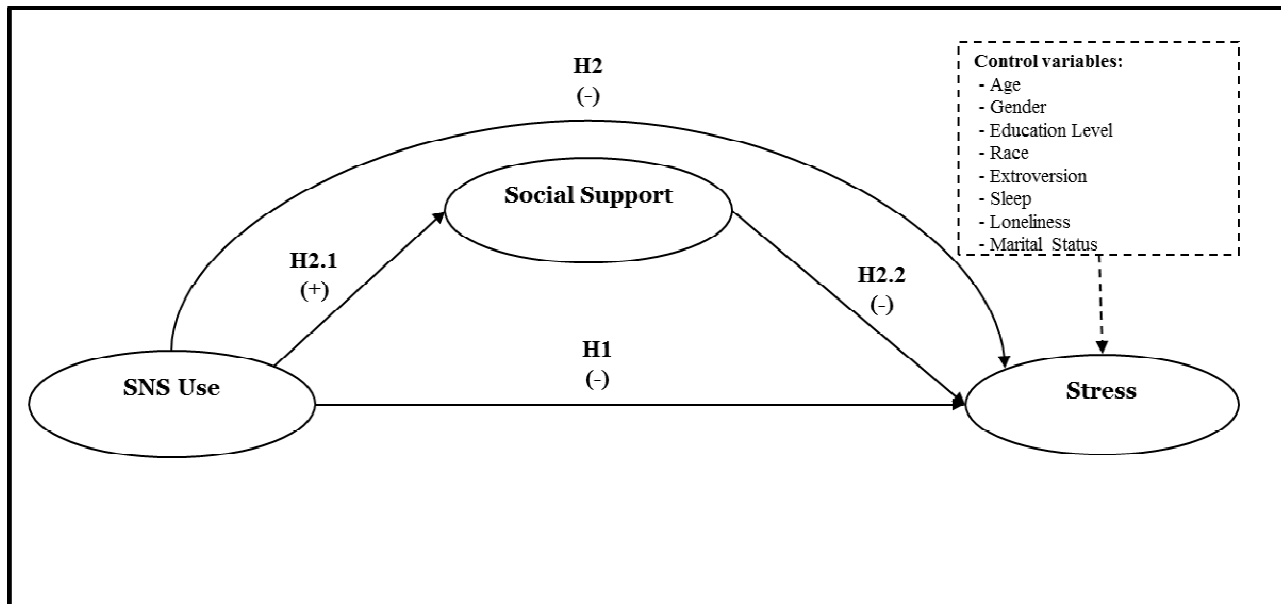


Figure 1. Model with Related Hypotheses

Research Methods

This is a cross-sectional survey study in which data will be collected from at least 200 caregivers via questionnaires at one time point. We are using both paper and electronic formats to collect data through mailings and email to account for that not all caregivers have access to the Internet and, thereof, email.

Measures

In order to address our specific aims, we are measuring the following latent variables: SNS use, caregiver stress, and social support. All of our measures are based on validated measures published in literature. We have operationalized our measures as latent variables in order to reduce measurement error from perception-based questions, and to reduce collinearity among variables (Gefen et al. 2000; Schumacker and Lomax 2004). The items used in the latent variables were written as statements with which the respondents were to report their perceptions of agreement or disagreement using Likert scale. A five-point Likert scale (i.e., 1 = strongly disagree to 5 = strongly agree; never = 1 to Always = 5) will be used for

all latent variables in the research instrument. We will measure the following through multiple items to tap each latent variable.

SNS use. SNS use will be measured using a multi-item scale informed by prior studies (Chen 2013; Kwon and Wen 2010; Venkatesh et al. 2008). These items ask caregivers to report the frequency, regularity, amount of time, and the intensity of their use of SNS specifically for caregiving purposes, e.g., seeking health information. This latent variable is measured by four items. Examples of items include: *I regularly use Facebook to find information about health and medical issues about my child.*

Caregiver Strain Questionnaire (Brannan et al. 1997). This 21-item questionnaire asks parents about the stress in the past 6 months specifically related to caregiving, and has a validated factor structure for caregivers of children with ASD (Khanna et al. 2012).

Social support. A multi-indicator scale adopted from Burg et al. (2005) and Sherbourne and Stewart (1991) will be used to measure social support. Examples of items include: *How often is each of the following kinds of support available to you through your social networking site (Facebook) community? Someone you can count on to listen to you when you need to talk, someone to turn to for suggestions about how to deal with a personal problem.*

We are also collecting **demographic information** (e.g., gender, parent age, child age, the number of years they have had a Facebook account), although not confidential or identifying information, in order to characterize our sample and control for socioeconomic status and maternal education.

Statistical Analysis

In order to address our specific aims, our research model will be analyzed using structural equation modeling (SEM), a second generation multivariate statistical technique, variance-based SEM—partial least squared (PLS) to be specific which is a robust technique for analyzing both the measurement and the structural models simultaneously (Chin 1998; Haenlein and Kaplan 2004; Kock 2010). SEM has been widely employed by researchers because it considers measurement errors when analyzing data. The software WarpPLS 4.0 will be used to generate estimates for validity and reliability of the measurement instrument, confirmatory factor analysis, and the structural equation modeling analysis (Kock 2010). WarpPLS is a nonlinear variance-based structural equation modeling software tool that uses a PLS regression algorithm. PLS is recommended for analysis of mixed construct models (Chin, 1998; Fornell & Bookstein, 1982; Petter et al., 2007). PLS-based structural equation modeling is popular among researchers because it has flexible requirements and does not require normality, homogeneity, and large sample size (Gefen and Straub 2005; Hair et al. 2010). The reason for using PLS-based structural equation modeling is because it is appropriate for exploratory studies (Gefen et al. 2000) like this study. In this paper, we will use the linear PLS regression algorithm in WarpPLS 4.0 (Kock 2014) rather than the nonlinear algorithm. Data will be reported as standardized beta coefficients along with their significance level (p) as well as r-squared values that assess the variance explained in endogenous variable by the exogenous variables.

Measurement Model

In the first phase of data analysis, the measurement model should be evaluated. In the measurement model, reliability and convergent/discriminant validity will be examined. Internal consistency of latent variables will be assessed using composite reliability and Cronbach's alpha. Values should be greater than the recommended threshold of 0.70 (Nunnally & Bernstein, 1994).

In order to assess the convergent and discriminant validity of the scales, a confirmatory factor analysis will be conducted on all of the items of latent variables used in this study. The loadings of all indicators should be greater or equal to 0.50 in order to claim that the instrument has acceptable convergent validity (Hair et al., 2010). The goal behind the discriminant validity is to evaluate whether the latent variables differ from each other (Bollen, 1989; Chin, Marcolin, & Newsted, 2003; Fornell & Larcker, 1981). Discriminant validity will be evaluated by comparing the square roots of the average variance extracted (AVE) (representing the average association of each latent variable to its measures) with the correlations among latent variables which indicates that each latent variable is more closely related to its own measures than to those of other latent variables. We are going to test for mediation (Baron and Kenny 1986; Hayes and Preacher 2010; Preacher and Hayes 2004).

Model fit indices including the explained variance by the independent latent variables, the strength and magnitude of the paths will be assessed through the following stringent measures: Tenenhaus GoF (GoF), average path coefficient (APC), average R-squared (ARS), average adjusted R-squared (ARS), and average variance inflation factor (AVIF). It is recommended that the values for both the APC, AARS and ARS be significant at least at the 0.05 level, while the AVIF should be less than 5 (Hair et al. 2011; Kock 2011).

Discussion and Conclusion

Limitation

The current study is limited by its sole use of caregiver report; future research should utilize behavioral measures of children's functioning to determine if there are differences in SNS use among caregivers of children based on child characteristics (e.g., IQ, autism severity). Moreover, caregivers that utilize SNS will likely be biased to respond to the mailed questionnaires. We may be missing a group of individuals that do not use SNS sites and are using differing methods to address stress. It is important to acknowledge that SNS use may not lead to positive outcomes. For example, SNS use among caregivers of children with ASD may increase rather than decrease stress by making comparisons (Chou and Edge 2012) of their children with children of others especially if they find other's children are making more progress than their children. Lastly, we may be more likely to gain participants that have higher socioeconomic status and are increasingly using SNS to connect with other caregivers of children with ASD. Another limitation is that super-stressed people probably won't take the time to fill out a survey which can cause a self-selection bias in the sample. As a cross-sectional study, this research cannot determine causality and therefore, longitudinal design will be better but not feasible at this point.

Implications

Our long term goal is to understand how to incorporate SNS use into interventions to decrease stress among caregivers with ASD. Specifically, intervention approaches aimed at educating caregivers about evaluating the quality of information on social networking sites as well as using social support available through this method will be pursued. The overall objective of this study, which is the next step to this goal, is to understand the extent to which SNS impacts stress among caregivers of children with ASD, as well as the mediating effect of caregiver characteristics (social support) on this relationship. The rationale for the proposed research is that if we can gain an understanding of the impact of SNS use, we can design targeted intervention approaches aimed at educating caregivers of children with ASD about the use of SNS to decrease stress and increase social support.

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