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**Exploring the Use of the Internet by Caregivers of People with**

**Autism Spectrum Disorders To Obtain Caregiving Information**

Eric C. Twombly, Kristen D. Holtz, & Alison Daub-Sychra

KDH Research & Communication, Inc., Atlanta, GA

Abstract

This paper reports on data from a population of caregivers of people with Autism Spectrum Disorders (ASD) to examine the extent and motivations for their use of the Internet to obtain information on caregiving. We find considerable interest for Web-based information, but a strong bifurcation among respondents on the preferential type of information. The majority of respondents indicate that Web sites that provide factual information about caregiving are most important. Other respondents see the Internet as a vehicle for social exchanges about ASD. Regardless of their preferred method to consume Web-based information, all respondents reported using Web sites to obtain caregiving information.

People who are the primary care providers of those with chronic disorders and diseases often experience multiple sources of stress, which can lead to decreased mental and physical health and quality of life of caregivers and a diminished ability to effectively provide care.[1,2] Those who care for people with autism spectrum disorders (ASD) have particularly high rates of stress.[3] ASDs, which include classic autism, high functioning autism and Asperger's Syndrome, and Pervasive Developmental Disorder, affect more than one in 150 people in the United States.[4] These chronic conditions have no cure[5] and are typically present by three years of age. ASD negatively impacts a person's social relationships, language and communication, and interests and activities[6] and requires a lifetime of care.[7] What is more, when a person with ASD ages, community care resources often become less available, leaving family members responsible for care provision.[8]

A practical question is how can stress-reduction interventions be formulated and implemented in a cost-effective and widely distributed manner for people who care for those with ASD. This paper explores one emerging approach, namely, the use of the Internet to supply and obtain caregiving information. More specifically, the authors use survey data collected from a national population of caregivers of people with ASD to examine the extent and motivations for why and how they use the Internet to obtain information on caregiving. We also assessed the extent to which age, socioeconomic status, and other demographic variables relate to caregivers' preferences to use Web-based resources.

The study finds considerable interest for Web-based information among those who care for people with ASD. However, we find a strong bifurcation among respondents on what the focus of Web-based information should be. For the majority of respondents, Web sites that provide concrete and factual information about caregiving is most important. A smaller set of respondents see the Internet as a vehicle for social exchanges about ASD. In the end, regardless

of their preferred method to consume Web-based information, all respondents reported the use of Web sites and online resources to obtain information about caregiving for persons with ASD.

## Literature on Caregiver Stress

People who care for those with chronic illnesses or disabilities face high rates of stress from two sources. First, they experience an interactive combination of objective factors and subjective feelings that constitutes caregiver burden.[1,2,9,10,11,12] The objective components of caregiver burden include (1) providing daily physical care to the care recipient; (2) responding to the recipient's emotional needs; (3) managing the recipient's behavioral and cognitive problems; (4) disruption to family routines and family interactions due to caregiving demands; (5) limits on the caregiver's ability to engage in leisure activities and outside employment; and (6) the financial costs of caregiving. Subjective aspects of caregiver burden include psychological reactions to the caregiving role, such as feelings of anxiety, anger, guilt, shame, or grief. [2,13,12,14]

Second, caregivers of people with chronic illnesses or disabilities may experience limited social support, which can exacerbate their stress. Limited social support for caregivers may stem from (1) a general ignorance and lack of understanding about the nature of the chronic disorder or illness among the general public; (2) inadequate community sources of support and respite care; and (3) a lack of support and understanding from family and friends.[2,12,15-22]

The effective management of caregiver burden and the strong availability of social support are crucial because of the positive relationship between caregiver stress and negative physical and psychological consequences, such as cardiovascular disease, depression, and anxiety. [2,9,14,23-26]

Caregiving for people with ASD poses special challenges that can markedly increase caregiver stress. Because ASD is a disorder that is present throughout the lifespan, the vast majority of individuals with ASD will require a lifetime of care,[27] which typically and primarily

falls on family caregivers. One particular challenge for caregivers is the early onset and intractable nature of ASD, which causes caregiver perceptions and demands placed on them to evolve. Indeed, Gray found a consistent pattern of changing optimism among parental caregivers of children with ASD.[8] When dependents are young, parents tend to be optimistic about their children's future potential to live semi-independently. However, as children age and enter adolescence and early adulthood, some parents lose hope that their children will develop the skills necessary to live independently.[27,28] Thus, as children with ASD grow into adults, their parents' caregiver burdens change to include place of residence, concerns about their adult children's dependency on them, and what happens to the children if the parents were no longer there to take care of them.[7] Compounding these issues, resources for caregivers typically decrease as children age out of school-based programs,[8] which can have detrimental financial impacts on caregiving parents. This challenge emphasizes the importance of decreasing caregiver burden by providing information to manage the many transitions caregivers face over a lifetime of care.

Despite the specific and documented need, there is little empirically-based information to support caregivers of people with ASD. Much of the recent emphasis on ASD has focused on its early diagnosis and early treatment, which is vitally important to improve the overall life circumstance of those with the disorder. But this emphasis has resulted in a relative lack of program development and evaluation of techniques and strategies to improve caregiving, leaving parents and other care providers who seek methods to reduce their caregiver burden underserved. Because several studies report high levels of depression, anxiety, anger, and stress in caregivers[8,29,30] and concomitant poor physical and mental health outcomes,[2] building effective informational interventions to support caregivers is critical.

The Internet has emerged as a potentially powerful venue for reaching caregivers of those with ASD for several reasons. First, there is a large Internet usage rate in the United States. According to recent reports, roughly 74 percent of the U.S. population uses the Internet.[31,32] Of those users, approximately 75 percent access health information from online sources.[31] Indeed, Mackintosh, Myers, & Goin-Kochel found considerable interest in Web-based information among caregivers of people with ASD.[33] Second, the Internet offers a relatively low-cost means of disseminating information. For example, providing content on Web sites that users can download can be less expensive than creating and shipping the same content in print forms. Third, the Internet can overcome geographic and temporal barriers that restrict caregiver access to needed information and social support. For example, the Internet allows a user to connect with other people through online discussion forums and other means regardless of his or her geographic location. This type of connectivity can be a good source of social support,[34-36] which one may hypothesize can reduce feelings of isolation among caregivers of people with ASD, which in turn may reduce their stress.[27]

Furthermore, the Internet provides caregivers with varied ways to consume information. One may obtain factual and evidence-based information that is designed to improve caregiving, which in turn may lower their caregivers' stress. Or one may enter virtual communities where the caregiver accesses social support by engaging other caregivers. A key question in the development of Web-based resources to reduce caregiver stress is to what extent is there a preferred method among caregivers of how to consume information. This paper attempts to address this question.

## Methodology

To conduct the study, the authors administered an online survey to a national population of caregivers of people with ASD. We worked with the Organization for Autism Research to

recruit study participants. We used an online survey generator to collect and store survey responses over a three-week period, and we addressed possible participant attrition through a series of email reminders to non-respondents. In total, 135 caregivers of people with ASD completed the survey.

Our analysis reveals a caregiver population that is largely female (94 percent) and Caucasian (91 percent). The respondents are generally well educated and live in high income households. In fact, 30 percent of respondents reported having a graduate degree and nearly all noted that they attended some college. Roughly 44 percent reported annual household income of $100,000 or more, and only 22 percent note that their annual household income is less than $50,000.

To explore the extent to which the respondents use Web sites and online resources to get information about caregiving, we asked them three sets of questions. First, we asked about their frequency of using Web sites to obtain information on caregiving. Second, we asked respondents where they find Web sites that contain information about ASDs. Third, we asked the respondents why they use Web sites that provide information about ASDs and caregiving. This third question set contained 10 items. Six of the items focused on the use of a Web site to gain social support, which we define as the provision or consumption of personal information or advice about caregiving, and how it relates to a person's connectivity with others, who, in this context, include friends, family, and other caregivers or people with an interest in ASD.[8,37] The other four items address the use of a Web site to acquire knowledge about caregiving for a person with ASD. The authors define knowledge acquisition as the act of consuming largely empirical or objective information that may directly affect one's provision of care. An example is taking a training seminar on effective caregiving at a local nonprofit or university. Survey participants responded to the items categorically, using a Likert scale. We ran a factor analysis to determine the load

scores of the two groups of items. We analyzed the results of the items individually and used the factors scores for the groups as dependent variables in separate multivariate analyses that included demographic and socioeconomic variables.

In a practical sense, social support and knowledge acquisition are not mutually exclusive concepts. For example, during a training session on caregiving, a participant may be able to share her personal experiences. But there are qualitative differences between them that relate to what the caregiver aims to achieve. Indeed, social support is subjective, emotional, and collective, while knowledge acquisition may have none of those elements. Therefore, for the purpose of this analysis, the methods are sufficiently varied to warrant their separate examination.

The methodological approach used has some limitations. For example, the authors cannot be sure that the demographic composition of the survey respondents resembles the overall population of caregivers of people with ASD in the United States. This is a typical problem with surveys of subpopulations in public health research. The result of this limitation is a potential lack of generalizability of the study findings. What is more, by restricting their analysis to the extent and motivations to use the Internet to obtain information on caregiving, the authors did not assess the empirical relationships among changes in knowledge acquisition, social support, and caregiver stress. While examining these relationships may help to tailor Web-based interventions, it was beyond the scope of this study. Still, the findings allow for an exploratory look into the potential use of the Internet to reduce caregiver stress.

## Findings

Taken together, the data suggest relatively strong Internet usage among respondents. Overall, 37 percent of respondents noted that they use the Internet on a daily basis to obtain information on caregiving. Another 25 percent of respondents use Web sites or online resources on a weekly basis and 18 percent use them roughly once a month. The remainder of respondents

reported relatively infrequent use – less than monthly – but all respondents note at least some use of Web sites to obtain information on caregiving for a person with an ASD. And in order to find Web-based information on caregiving, the majority of respondents indicate that Google is the most commonly used source. Other popular sources are links on Web sites that focus on ASDs and recommendations from other caregivers. Nearly all respondents reported that they view advertisements to find Web sites that support their caregiving.

Although many caregivers use Web-based resources, their reasons for doing so varied widely. For example, survey participants reported relatively low interest in using a Web site to gain social support for caregiving. One-quarter of respondents indicated no interest and 34 percent only some interest in using the Internet to express feelings or frustration about caregiving with other care providers. Roughly 23 percent reported no interest and 30 percent indicated only some interest in using a Web site to meet others who are caregivers of people with ASD. Respondents provided similar results for items on getting advice from other caregivers, sharing experiences, gaining emotional support, and helping others who are coping with caregiving of people with ASD.

Of those caregivers who express interest in using the Web to gain social support, age plays a significant factor. Indeed, using a multivariate approach that controls for the effects of ASD diagnosis, household income, and the educational attainment of the caregiver, we found that the age of the caregiver and the age of the person who has an ASD are significant predictors of interest in pursuing social support through the use of a Web site. Moreover, there is a statistically significant and negative relationship between the age of the caregiver and the person's interest in using the Web to gain social support. In other words, older caregivers are less inclined than younger caregivers to pursue social support through Web sites. Similarly, there is a statistically significant and negative relationship between the age of the person with ASD and the

caregiver's inclination to seek social support through a Web site. Indeed, those who care for older people with ASD are less likely to pursue Web-based social supports and more likely to express interest in knowledge acquisition about caregiving.

In contrast to the desire to use web-based resources for social support, respondents reported relatively high interest in using them to gain knowledge about caregiving for a person with ASD. More than half of respondents indicated a very high interest in using these resources to increase their knowledge of ASD, to learn skills to help with caregiving, or to seek information from experts on ASD, and more than four in ten reported a very high interest in using Web-based resources to obtain recommendations on ASD treatments. What is more, when factoring together the knowledge measures, the data suggest that there is a significant and positive relationship among respondents between age and the use of Web-based resources to obtain information on caregiving, when controlling for other factors. Other factors showed no statistically significant value when predicting the knowledge group.

## Implications

Web-based resources can provide a relatively low-cost, easily disseminated, and real-time environment to supply support to caregivers of people with chronic disorders and disabilities, such as ASD. The issue for public health officials and practitioners is how to develop these resources to effectively reach potential users and provide them with information they want and need. This study suggests that constructing effective Web-based resources for the ASD caregiving population may require the targeting of certain sub-groups to examine interest in Web-based social support and knowledge acquisition separately. Instead of viewing the population of caregivers of people with ASD as homogeneous with identical needs, one should view them categorically with divergent issues that stem from their caregiving roles.

Moreover, the results suggest two important characteristics of ASD caregivers. First, a majority of respondents have insignificant interest in using the Internet to obtain social support for their caregiving, instead viewing the Internet as a source of information. Second, the minority of respondents viewed the Internet as a key vehicle for obtaining the social support they need to buttress their caregiving. In both cases, age plays a key role. Older caregivers sought to use the Internet to obtain information. Younger caregivers and those caring for young children with ASD indicated more interest in Web-based social support.

The relative lack of interest in Web-based social support among the majority of respondents may be the result of many factors. For instance, it may indicate that the caregivers examined had little perceived need for social support. According to Boyd, both caregiver and child characteristics affect the perceived need for social support among ASD caregivers.[38] Moreover, the behavior and cognitive functioning of the person with ASD affect the perceived need for social support more so than the caregiver's identified level of stress.[38]

The study failed to capture the overall level of functioning or behavior of the person with ASD. Thus, it is possible that the majority of caregivers who completed the study had lower perceived need for social support because they care for higher functioning people with ASD who exhibit fewer behavior problems. Caregivers with lower perceived need for social support may be capable of fulfilling their need through family and friends, while those with greater perceived need may be more inclined to seek alternative means of social support acquisition, such as the Internet. Furthermore, this study failed to examine the geographic location of the caregivers. The locality of the caregivers may have dramatically influenced their need and desire for alternative means of social support, as rural caregivers may have fewer support resources.

The results of this study leave unanswered why the ages of the caregiver and the person with ASD significantly relate to a caregiver's inclination to use a Web site to obtain social

support. While several demographic and socioeconomic variables in this study show no

significant explanatory power, one may suspect that other and currently untested factors, such as

the timing of the ASD diagnosis, the caregivers' Internet usage and proficiency, and their degree

of connectedness with other support systems – digital or otherwise – may help to explain these

relationships. These are valuable avenues for research, because they relate to the question of

targeting Web-based supports to those who are most likely to use them.

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