Autism spectrum disorders in the era of mobile technologies: Impact on caregivers

Anna A. Allen & Howard C. Shane

Department of Communication Sciences and Disorders, MGH Institute of Health Professions, Charlestown Navy Yard, Boston, MA, USA and Center for Communication Enhancement, Boston Children’s Hospital, Waltham, MA, USA

Abstract

Objective: This paper explores possible connections among existing literature on parental stress, augmentative and alternative communication (AAC), and use of mobile technology for persons with autism spectrum disorder (ASD). Methods: A narrative review of the literature. Results: Parental support contributes to positive outcomes for children who use AAC. Parents identify communication as a high priority, but describe the process as challenging. AAC is often used with children with ASD, a population in which parental stress is especially high. Though there is research evidence that mobile technology is a promising tool for individuals with ASD, potentially misleading media anecdotes exist, and the effects on parental expectations and stress remain unstudied questions. Conclusion: Increased understanding of the connections in these research areas should help clarify the potential impact of mobile technologies on parental stress level, help to define appropriate future research directions, and contribute to development of appropriate caregiver training.

Keywords

AAC, autism, mobile technology, parents, stress

Introduction

The arrival of mobile technology in the mainstream, with the release of the first iPhone in 2007 [1], has led to changes not only in society at large [2], but also in evaluation and treatment of individuals with communication disorders [3]. In particular, mobile technologies have become extremely popular tools for individuals with autism spectrum disorders (ASD). Little is known about the impacts of the mobile technology revolution on these individuals and their caregivers. In this paper, we review the literature on stress in parents of children with ASD, as well as the literature on caregiver involvement, and attitudes toward, augmentative/alternative communication (AAC) strategies. We conclude with a discussion of existing research on mobile technologies, and explore possible connections to caregiver stress.

Methods

A review of existing literature was conducted focusing on stress in parents of children with ASD; caregiver training and parental attitudes toward AAC; and use of mobile technologies as tools for persons with disabilities.
behavior, with considerable variation between and within individuals [17]; however, research suggests that communication is a particular source of concern for parents. Parents rank social and communication skills as among their top priorities for treatment targets [18]; furthermore, deficits in children’s social relatedness are associated with overall parenting stress and distress for mothers and fathers [19].

Searching for information is one way that parents cope with the stress of an ASD diagnosis in the family [20]; searching for solutions may restore hopeful feelings and lead to a sense of increased confidence [21]. As parents seek information amid the emotional intensity of the coping process, the seemingly continuous appearance of new treatments, many of which have not been evaluated objectively, might complicate the process of considering various treatment options [17]. The Internet has increased the number of first-hand reports available, but inaccurate information is at least as easily disseminated as evidence-based reliable forms of information [22]. Personal experiences and anecdotes are often more compelling to both caregivers and clinicians than other more rigorous forms of evidence [23]. Indeed, in a survey regarding decision-making, ‘other parents of children with ASD’ were reported as sources of information more often than any group of professionals [24]. Adding further complexity, advertising and Internet use continue to become increasingly widespread [22, 25]. Consider the following recent headlines regarding autism treatment: ‘Some with autism diagnosis can overcome symptoms, study finds’ [26]; ‘Early therapy can change brains of kids with autism’ [27]; ‘Treating autism: There’s an app for that’ [28]. Messages such as these could conceivably lead to unrealistic expectations, and if these are not met, additional stress.

**Augmentative and alternative communication**

In their search for information, parents of individuals with ASD will no doubt come across information on AAC strategies. AAC is increasingly incorporated into recommendations for children with ASD, and findings regarding outcomes of these methods are largely promising [29–33]. Evidence suggests that parent and family support contributes to positive outcomes for individuals who use AAC. Choosing appropriate skills to teach communication partners can improve outcomes [34, 35]. Adding an AAC intervention can increase parent responsiveness to their child’s communicative behaviors [36]. When strategies such as use of expectant delay, use of open-ended questions, and modeling of AAC system use are employed, positive changes (e.g., improved social-pragmatic skills, increased participation in conversations, and better range of communicative functions) happen in both the partner and the individual using the AAC device [37]. However, the successful integration of an AAC system into a child’s life requires commitment and constant support from parents and other family members [38]. Findings from interviews with families of children with ASD who are AAC users reveal several themes. Parents note the complexity of AAC devices as communication tools [39]. They view the ability to communicate via AAC device as a key measure of their child’s success [40], yet communicating with the child, and the child’s communication with others, is experienced by parents as effortful and time-consuming [41]. The ability to communicate wants and needs is parents’ most frequently mentioned priority for skill development in their children who use AAC [42]. It is not yet known whether parent priorities and expectations have shifted as a result of the ever-increasing involvement of mobile technologies in AAC.

**Mobile technologies**

The iPad was released in January 2010 – just four years ago, yet it has had a seismic influence. In the past few years, with the release of the iPad and other mobile technologies, the landscape of care has changed considerably for individuals with AAC needs. The revolution in this area is fostering several shifts: increased social acceptance of AAC in the mainstream, greater consumer empowerment, increased adoption of AAC technologies, and greater functionality and connectivity of AAC devices [3]. But there is a lack of research on parent expectations of, and attitudes toward, mobile technologies. Consider some of the media messages that exist about iOS mobile devices: ‘Tapping this app gives special-needs users a voice’, proclaims CNET.com [43]. ABC News announces, ‘iPhone app opens world to boy with rare syndrome’ [44]. The iPad is described as a ‘near-miracle’ [45] and a ‘life-changer’ [46, 47] for individuals with special needs, including those with ASD. Research has not yet explored whether the increased presence of mobile technologies, along with the prevalence of these messages, influences parental stress.

Given that children with ASD have a predilection for visual media, this population tends to find mobile technologies engaging and motivating [48, 49]. It may be that having a mobile device to occupy their child, particularly in situations that would otherwise be challenging, mitigates day-to-day stress in parents of children with ASD. Additionally, one can imagine that, because of how ubiquitous mobile devices have become among the general public, use of an AAC device is no longer as noticeable or stigmatizing; this could also conceivably reduce parent stress levels in families using AAC. Research suggests that reduced parent stress leads to improved outcomes for children; for instance, Dyches et al. [50] found a moderate association between parenting attributes and child outcomes. Lowering parental stress may maximize the efficacy of parent training interventions and behavioral programs for parents of children with intellectual disabilities [51].

Being able to express needs and make choices has been identified as a top priority for parents of children using AAC [41]; presumably improved communication skills would decrease parental stress. Studies published to date suggest enormous potential variety of possible applications for mobile technologies for individuals with special needs. Flores et al. [52] conducted a comparison of requesting using the iPad and a picture exchange system. They found that, when using the iPad as compared to picture cards, communication behaviors either increased or remained the same. Lorah et al. [53] found that the iPad, functioning as a speech-generating device, produced higher rates of independent responding than a picture exchange system. Use of mobile technology for
several specific functions has been investigated. With minimal training, caregivers can successfully create video models on an iPad, and implement Video Modeling Imitation Training, resulting in gains in imitation skills during caregiver-implemented treatment [54]. Video self-modeling (VSM) intervention delivered via iPad was effective for increased frequency of correct, unprompted responding of an adolescent with ASD and intellectual disability in the classroom [55]. Use of the iPad as a means of instructional delivery may decrease escape-maintained behavior for some children with ASD [56]. The results of a recently published systematic review [57] suggest that, with the use of instructional procedures based on the principles of applied behavioral analysis (ABA), iPads and related iOS devices can be used successfully in educational programs to target communication, academic, leisure, and employment skills for individuals with developmental disabilities.

Still, it must be kept in mind that research on the use of mobile technology with individuals with developmental disabilities is in the early stages, and several limitations exist. Published studies to date involve relatively small sample sizes, with broad age ranges and variable degrees of intellectual disabilities; furthermore, studies thus far address limited communicative functions (i.e., naming and requesting), and do not specifically target social skills [57]. Despite high frequencies of use of mobile technologies, children with ASD spend little time using social media or playing video games with other people [49]. Overall, the boom in mobile device availability and use raises many challenges, including (i) the tendency to focus on the technology instead of on communication; (ii) the adoption of mobile technologies without input of knowledgeable professionals (causing a lack of development in innovative approaches to AAC assessment and intervention); and (iii) there being limited options for alternative access (and thus, marginalization of individuals with complex communication needs) [42]. Though there is some evidence that computer-based interventions can improve socio-emotional and communication skills in individuals with ASD [32, 58, 59], more evidence is needed to determine whether this finding extends to mobile technologies.

**Discussion**

The effect of the mobile technology revolution on stress in parents of children with ASD is yet unexplored. Perhaps the shift toward a more consumer-oriented model of accessing AAC solutions [42] fosters greater feelings of empowerment in parents, or perhaps the vast array of choices is overwhelming. After all, there is no reliable way to predict the outcomes of young children with ASD [60], and research suggests that parental uncertainty about their child’s needs leads to feelings of loss of control in their role as parents [20, 61]. A mismatch between expectations and reality could conceivably lead to increased stress once mobile technology has been obtained. Furthermore, concerns have been raised about the lack of capitalization on the increased functionality provided by mobile technologies [42].

ASD is one of the more prevalent as well as mysterious developmental disorders of our time. Many factors, such as the range of behavioral presentations in ASD, both within and across individuals, and the preponderance of co-morbid disorders and multiple treatments happening simultaneously, make it challenging to conduct research with this population. There is a lack of evidence on which to base treatment decisions, and best practice guidelines are not clear.

Any parenting is stressful, but research suggests that it is even more so for parents of children with disabilities, and yet more so for parents of children with ASD [8–10]. When a child is first diagnosed, parents typically go through a coping and adjustment process that includes a variety of intense emotions [19]. A common initial response is to begin seeking information, and in an era when exposure to media is drastically and rapidly increasing, parents seeking explanations and advice can be met with a veritable bombardment [20, 21]. Research indicates that they tend to rely on the testimonials and anecdotes of other families, rather than on empirical evidence [16]. It seems likely that, amidst the complex emotional landscape of a new diagnosis in the family, parents may be more prone to common errors of thinking that can lead to adoption of pseudoscientific approaches [22].

The recent advent of mobile technologies, particularly the iPad, has added complexity to the implementation of AAC strategies for this population. Recent research has yielded evidence that iPads can be used to foster gains in imitation and unprompted responding for individuals with ASD [53, 57]. The literature also suggests that the iPad and related mobile devices can be used successfully to target a variety of skill areas, including communication and leisure [57]. However, strong media attention can have the effect of it leading to unrealistic (miracles) outcomes [28, 43–47]. This may give parents – particularly parents in the emotionally intense process of coping with a new ASD diagnosis, and thus potentially more prone to errors of thinking – the idea that a mobile device will enable their child to talk. This possibility and its implications have yet to be addressed in the research literature.

There is much research on parenting stress in parents of children with ASD, and much empirical evidence that AAC strategies can improve communication in individuals with ASD; furthermore, the literature suggests that parents can be successfully trained to use AAC strategies, resulting in improved communicative interactions with their children [33–36]. Though research evidence is appearing on applications of mobile technologies in individuals with ASD, and on parental attitudes toward AAC in general, the actual effect of the arrival of these technologies on caregivers remains unclear. Thus far, research on parenting stress, parental attitudes towards AAC, and the use of mobile technologies represents a disparate literature with little overlap in relation to aims or methodologies that might enable any conclusions to be drawn about the relationship between these areas of investigation. Further research on the overlapping territories of these research areas is required to inform clinicians in the development of appropriate supports and training for caregivers, and provide unique insights into the relationship of parental stress and AAC device abandonment.
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Declaration of interest

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