

Finding the Right Fit: What Contributes to the Successful? Use of Speech Generating Devices?

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Research Article

Volume 4 Issue 3 Received Date: August 25, 2021 Published Date: September 27, 2021 DOI: 10.23880/aphot-16000209

Abstract

Nearly four million Americans are unable to communicate using natural speech. One intervention utilized by therapists to overcome the problem is through the use of speech generating alternative forms of communication. Though the majority of users benefit from these tools, it is reported that more than one third eventually abandon them. Existing literature suggests a variety of factors that lead to abandonment, yet the phenomenon continues. In an attempt to discover what constitutes successful device use, this qualitative study examined the experiences of self-reported speech generating device users to identify commonalities among them to offer guidance for practitioners prescribing such devices. The data from the study resulted in three themes: user and device attribute match, support from communication partners and engagement in occupations with device use to fulfil roles and routines that resulted in meaningful experiences that provided motivation for continued device use.

Keywords: Augmentative and Alternative Communication; Occupational Therapy; Successful Device Use; Speech Generating Devices

Abbreviations: AAC: Augmentative and Alternative Communication; PEOP: Person Environment Occupation Performance; HAAT: Human Activity Assistive Technology; MPT: Matching Person and Technology; SGD: Speech Generating Devices; MOHO: Model of Human Occupation.

Introduction

Communicative competence is broadly defined as one's ability to express ideas, thoughts and feelings to a variety of listeners across contexts [1,2]. Beukelman and Mirenda estimate that approximately four million Americans are unable to reliably communicate using natural speech to accomplish daily communication needs. One form of assistive technology for these individuals is the use of augmentative and alternative communication (AAC) speech generating devices that generate electronically synthesized speech to approximate a user's natural voice reflective of age, gender and race or ethnicity [3]. AAC interventions,

conducted in part by speech language pathologists, address the development of adequate, functional communication skills to support individuals with complex communication needs to express needs and wants, develop social closeness, exchange information, and participate in social routines [1]. This form of communication is often conducted in conjunction with a communication partner who aids in facilitating communication in social contexts, academic settings, medical settings, vocational settings, etc. [4]. Despite the benefit of using of AAC devices [5]. Schoonover & Argabrite-Grove (2015) note even when AAC systems are well designed and functional, there remains an abandonment rate of one third or more of all users [6]. Johnson, Inglebret, Jones & Ray (2006) define abandonment as the inappropriate discontinuation of an otherwise appropriately designed AAC system [7]. Pape, Kim & Weiner (2002) identified factors such as user frustration, equipment breakdown, rate and frequency of communication and lack of vocabulary as contributing factors to the phenomenon of abandonment.

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There is a need to observe and identify what constitutes the successful use of speech generating devices in the natural environment, although to date there are no reports in the literature of such an undertaking [8].

Occupational therapy is recognized under the profession's scope of practice as a discipline that provides services to address client issues that pertain to the use of adaptive equipment, including AAC devices [9]. Overarching occupation-centered theoretical frameworks such as the Model of Human Occupation (MOHO) and the Person Environment Occupation Performance (PEOP) theories propel intervention [10,11]. Models exist that occupational therapists can utilize in their practice related to assistive technology, in which speech generating devices are categorized. Ones such as the Human Activity Assistive Technology (HAAT) model were developed to describe a process for prescribing a solution, or assistive technology system, optimally suited for a person with a disability: in other words, finding the appropriate fit between user and device [12]. Other models such as the Matching Person and Technology (MPT) assessment process [13] and the Student, Environments, Tasks, and Tools framework (SETT) also exist [14].

Polgar [15] suggests an additional point of view to consider when prescribing any form of assistive technology beyond the current assistive technology models. She posits that the meaning that one derives from assistive devices is as equally an important factor as person and device characteristics in whether an individual will incorporate assistive technology as a useful tool into daily activities or whether it will be discarded. As a result, the purpose of this study was to explore the efficacious use of speech generating devices (SGD), and to identify what constitutes a proper fit between user and device. In doing so, that information can be utilized by practitioners to reduce or eliminate the phenomenon of abandonment. The goal of this study was to answer the question: What contributes to the successful fit between clients and augmentative and alternative communication devices for individuals who have acquired and been trained in their use?

Method

Research Design/Data Collection

In order to gain an understanding of the experiences of speech generating device users and what contributes to their success, the study employed a qualitative, descriptive multiple case study design methodology allowing investigators to explore the subjective experiences of device users, those who prescribe devices, and those who serve as communication partners to the users themselves [16]. Data was collected through semi-structured interviews with device users or their communication partners, semistructured interviews with the speech language pathologists who prescribed the devices for the users, and through observation of selected participants engaging in the use of their devices in a natural community setting. Interviews for clients and communication partners were conducted at a pro bono outpatient therapy clinic utilizing open ended and informal questions (see Appendix A, Appendix B & Appendix C) allowing the participants to describe their experiences with speech generating device use. Interview questions were piloted via internal testing through collaboration with investigators on the research team and with two speech language pathologists currently in practice who utilize speech generating devices with their clients routinely in a clinical setting. The daily activities of participants were identified through the initial interviews, and the researchers observed study participants using their devices in their natural environment in locations of convenience based on participant responses. Triangulation of data was achieved through study design of the three data collection methods [17]. Collected data, field notes and a reflective journal were all examined to check for irregularities. Additionally, peer debriefing with colleagues occurred throughout the study who examined transcripts and field notes. Prior to commencement of the study, institutional review board approval was obtained through both Quinnipiac University and the University of Central Arkansas (see Appendix D, Appendix E & Appendix F).

Data Analysis

Throughout the study, interviews of all participants were audiotaped. Interviews were transcribed via a secure webbased program and stored on a password protected laptop. Confidentiality of participants was maintained by assigning participant codes to each study participant. Field notes from observation sessions were recorded and transcribed following an identical process. At the conclusion of all data collection, electronic transcripts were transferred to an Excel program and coded utilizing a combination of coding for content and in vivo coding, with multiple readings of the data by all study investigators. Themes were generated from the coding process by determining overlapping codes. recurrent topics and patterns within the data. Themes were supported by the data collected as well as observation to represent successful fit of speech generating device users who participated in the study.

Human Participants

Participants for this study were recruited using purposeful selection from a sample of convenience. Prospective participants who are current clients at the pro bono clinic in the Communication Sciences and Disorders Department at the University of Central Arkansas were notified by the staff at the clinic of the nature of the study, and those willing to participate were contacted directly by the coresearcher to obtain informed consent. Client participants and communication partners were selected for the interview based on the following inclusion criteria: (1) report having been prescribed and trained in use of a speech generating AAC device and report weekly use of the tool, (2) and are eighteen and have the legal authority to make decisions regarding their own healthcare. Clinician participants were selected for interview based on the following inclusion criteria: (1) hold a current license to practice as a speech language pathologist in the state of Arkansas, (2) report having participated in the formal assessment and training in the use of AAC devices in the clinical setting. Participants were not excluded based on their race, gender, sexual orientation, religion, or marital status.

Results

A total of ten subjects participated in the study. Two speech generating device users were interviewed and observed, including an 80-year-old male who utilized a Lingraphica device in daily communication labeled Participant 1. The other user, Participant 2, was a 26-yearold female who was prescribed an Accent 1000 device by her speech language pathologist but relied on her iPhone as a communication device based on personal preferences. A third device user, Participant 3, was a 23-year-old female who employed a Tobii Dynavox for routine communication and was not interviewed but was observed with the permission of both of her parents who participated in the study as communication partners. A total of four communication partners participated in the study including at least one from each of the three device users. The three speech language pathologists who participated are currently licensed with an average of 14.3 years of clinical experience. Three major themes that appeared to support successful speech generating device use among all participants emerged from the data. The first theme identified was the match between user and device attributes. The second was the presence of communication partner support. The final theme was the value of occupational roles and routines and the meaning derived from them serving as motivation for device use.

User/Device Attributes: "none of the voices sound like me."

The appropriate match between the human characteristics including physical and cognitive skills and user preferences married with device characteristics including features and programming was a major factor in successful device use. For example, Participant 3 found success with the Tobii Dynavox because of the simplicity of programming and access with a limited vocabulary. As her communication partner noted, "One word. iPad. She loves the iPad and I think that's why she has taken to the Tobii" (CP 3). On the other hand, Participant 1 found the features of the Lingraphica device appeared to suit both his physical abilities, with the loss of use of his dominant hand, and his generational preferences for writing as opposed to simply selecting icons to replicate his voice. In reference to her father's device use, Participant 1's communication partner explained that "he likes the whiteboard [feature on the Lingraphica]" and "He's always just written stuff. He's not a typer or a texter" (CP 2). This was confirmed in the observation of the user at a local restaurant when he engaged with the server and used both pre-programmed words and the whiteboard in tandem to successfully order a meal. One interesting observation in the study was of Participant 2 who demonstrated appropriate use of her Accent 1000 during the interview but routinely relied on her personal iPhone as an alternate speech generating device. She noted, "I use my phone" because the Accent 1000 is "a voice of something that is not normal. Because it's not my voice" and "besides, I use my phone every day for everything anyway" (UP 2).

Communication Partner Support: "I've had fears of the future and it's given me hope."

Communication partners appear to serve a critical role in continued, successful device use. The assistance comes in many forms. Communication partners often play a role in overcoming barriers of the healthcare system and obtaining devices for users. One communication partner noted: "I was like, so how could we get him one? We didn't want to wait for Medicare to pay for it. Not everyone could go and spend \$600 on a machine...we were lucky we could" (CP 2). Another stated, "...and I had some connections with a law firm...and they were sponsoring the device. We were very blessed" (CP 3). Furthermore, communication partners were responsible for acquiring and participating in training in the use of the devices for both themselves and the user. For example, while training is an ongoing process, one participant noted, "slowly over time, you know, we've figured it out" and "I learned a lot just by messing with it myself" (CP 1). But other communication partners took a more proactive approach by actively engaging resources for training. "We email once a month [with speech language pathologist] saying what icons we need to add to the device" (FGP 3). The clinicians that participated in the study suggested that communication partners play a pivotal role in transitioning from device use in the clinic to more generalized use in the community. As one communication partner commented, "every week, we get a little homework assignment" and "I say 'hey, your homework'...and I have the Tobii there" (CP 1). Finally, the data reflects that communication partners appear to be motivated by their counterparts' device use, thus prompting them to facilitate further engagement with the tool. Respondents offered comments such as "just having

him being able to communicate, it was amazing!" (CP 2) and "she's even gotten a little cantankerous, but it's such a change in her demeanor [with device use]" (FGP 2) to "I've had fears of the future for her and it [Tobii] has given me hope" (CP 3).

Meaning and Motivation: "I love you. I miss you. When are you coming to see me?"

The final theme revealed in the study was less tangible but appeared no less important. Successful device use revolved around engagement in occupations in participants' regular routines and roles, and users seemed highly motivated to use the device based on the meaning associated with those activities. In its simplest form, Participant 3 employed her device to satisfy basic wants and needs. For example, her communication partner stated, "just being able to communicate to people in an appropriate way what her needs are" resulted in "helping her with trust" and "just accepting herself in the world" (CP 3). Participant 1 indicated communication related to his role as a husband and his occupations were paramount. He stated throughout the interviews that "I love June" and "I want to take care of her" often gesturing hugs as he spoke through his device (UP 1). His former roles as a member of the Air Force and as a postal worker were also of importance to him and were reflected with pre-programmed pages of his dates and locations of service. His daughter noted it was so he "could tell everyone with pride when he goes to the V.A." (CP 2). During the focus group with speech language pathologists, the clinicians described a wide variety of technical tools and guiding theories used to facilitate competent device use. However, when asked to describe the most successful use of a device with any client, each of the clinician participants spoke not in terms of technical aspects of their clients' use, rather in terms of the occupations in which their clients engaged. One focus group participant defined success in terms of the roles in which her clients engaged while using their devices such as being a "realtor", an "attorney", a "golfer", a "grandparent" and someone who "cared for her pets". The respondent even noted in one particular instance that her client was "more concerned about her dogs than her grandkids" and that she had trained her pets to recognize the voice of the speech generating device to follow commands rather her own which had been lost (FGP 1). She pointed to another example of the "golfer" who "had created his own page for his golf buddies, but I was not allowed on that page!" due the banter the programming afforded him.

Discussion

The problem of abandonment of assistive technology devices like speech generating augmentative and alternative communication devices is an issue that persists for those that prescribe and use them. Many reasons for abandonment have been identified [7], yet rates of abandonment have remained high - at least a third of all users shelve their devices following setup and training in their use [5]. This study moves beyond a reductionist view of abandonment and instead focuses on commonalities of successful device users. The findings of this study have implications for both occupational therapists who prescribe speech generating devices as well as other disciplines who do the same.

Smith [18] reminds practitioners that the profession of occupational therapy should recognize that technology is increasingly becoming inseparable from the day to day lives of the clients we serve. In adopting that perspective, it is incumbent upon occupational therapy practitioners to ensure that any technology we incorporate into our treatment is not discarded, rather becomes an extension of the person and is a facilitator of occupational engagement. While many models exist that guide us in prescribing assistive technology, it appears that the use of those models alone may be insufficient in overcoming abandonment. Models such as HAAT, SETT and MPT are centered largely on the physical and cognitive abilities of the user and the characteristics of the devices prescribed for them. Although they do capture environmental, contextual concerns which could include supports in the form of others who might serve as communication partners, this is not an explicit component of these models. However, as [15] Polgar (2010) posits, the meaning of the assistive technology tool to the user plays an equally important role in contributing to successful use.

The findings from this study suggest that both are true. The data revealed that having a match between the physical and cognitive capabilities of the user and the features of their device contributed to sustained use. Furthermore, when that device served as an extension of the person and facilitated occupational engagement in the person's roles and routines, there was a clear sense of meaning derived from the device use that appeared to serve as motivation for both the user and the communication partners that aided in continued use of the device. This is consistent with Polgar (2010) [15] who suggests that one way that we as therapists can capture occupation and meaning is by initiating our course of treatment that includes assistive technology not from an AT model, but from a larger theoretical perspective just as we would guide our treatment with a non-AT client.

One clear example of this overarching theory is the Model of Human Occupation (MOHO). What distinguishes this theory from others with respect to the findings of this study is that the theory explicitly considers a human as one that engages in roles and routines for occupational pursuits and examines the volitional component of occupational engagement in the client's values, interests and determination of self-efficacy that serves as motivation [10]. Simple, useful tools such as the Role Checklist [19] and the Interest Checklist [20-22] make identifying these factors achievable. In doing so, we can acknowledge that occupation is unique to the individual. As such, clients are the experts in their day to day lives as much as practitioners who are skilled in the technical aspects and use of speech generating devices. If systems are designed for clients that are absent meaning to the them, the risk of abandonment significantly increases [15].

The findings of this study offer several implications related to occupational therapy practice when prescribing augmentative and alternative communication devices to clients. The results suggest engagement in occupation while utilizing a speech generating device facilitates further use. By definition, occupation is a meaningful activity, and incorporating "occupation" into an assistive technology could aid in incorporating the "meaning" that Polgar [15] identifies as essential. One solution could be the practice of prescribing occupational therapists combining overarching themes, such as the Model of Human Occupation (MOHO), with existing AT models to utilize the indispensable features of both when evaluating clients for speech generating device need. Beyond that possibility, occupational therapists should be aware of how others might perceive the profession when prescribing alternate forms of communication as expressed by speech language pathologist focus group respondents who participated in the study. Each perceived occupational therapy as playing a role in "positioning" or "vision" or "accessing the device". That could be achieved by adopting the notion that occupation is central when evaluating and treating our clients and that augmentative forms of communication, such as speech generating devices, are viewed as merely an extension of the client that allows for occupational engagement. Additionally, occupational therapists are trained to consider clients in their context. By accounting for supports in the form of communication partners who could be family members or caregivers, occupational therapists could incorporate those who serve to facilitate communication device use as the data suggests. This too can be accomplished by employing a comprehensive approach through theory and model utilization in tandem.

Limitations of the Study

While this study offers insight into contributors of successful device use, it was not without limitations. Given that users of speech generating devices constitutes a fraction of the overall area of practice of occupational therapists, the participants were selected from a small targeted sample. There is the potential as a result for selection bias in this study. Furthermore, given that the sample of convenience utilized in this study constituted participants only over the age of eighteen, there could exist contributors for successful device use that are inherent in a pediatric population that was not addressed in this study. Additionally, there is little evidence in the existing literature that specifically looks at abandonment with respect to speech generating augmentative and alternative forms of communication. While some causes for abandonment may not have been captured in previous work, the possibility exists that an unidentified reason may not have been uncovered yet which could prove beneficial in overcoming the phenomenon. However, as noted, this study was purposed from an alternate perspective in an attempt to identify success rather than discontinued use. Given the existing gaps in the literature, this study serves to support the idea that there exists a broad range of conditions that afford speech generating devices users' success in employing them, however there is a need for continued research. Research centered on successful speech generating device use that includes further examination of the role of communication partners, pediatric populations and the contribution of the motivating force of occupational engagement stand as prospective areas for future studies.

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