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Innovation through Participatory Design: Collaborative Qualitative Methods in the
Development of Speech and Language Pathology Technology

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Abstract

Speech-Language Pathologists (SLPs) have embraced many aspects of technology in their practice, from telehealth to tablet device applications (apps) that support intervention practice. In this article, we consider the design, development, and implementation of technology. We discuss how some processes of technology development in Speech and Language Pathology (SLP) tend to follow research pathways which centre clinicians and researchers as designers of the intervention. This approach side-lines user involvement. We propose that a Participatory Design framework is a suitable way to reconceptualise design and development of these technological innovations in a client-centred way. Further, we explore how Participatory Design approaches utilise methods from and have much in common with qualitative research. We explore this overlap and propose that technology design teams take up the challenge of innovation in technology by engaging in a participatory rather than clinician-driven process for future technology design. Implications for both research and clinical practice are explored.

Keywords: Participatory Design, Qualitative Methods, SLP, Telehealth, Technology

Introduction

Speech-Language Pathologists (SLPs) have a long history of using technologies for assessment (e.g. computer-based speech assessments, (Telage, 1980)) and intervention (e.g. computer-based language therapy (Katz & Nagy, 1982)). This includes the design and use of computer-based and online programs, apps and telehealth platforms and interventions (See Mata et al., 2018 for examples). In this paper, we introduce the reader to Participatory Design, used in the field of Human-Computer Interaction (HCI), and increasingly applied to the innovation of medical and health care technologies. Participatory Design was born in the

1960s to 1980s in what was to become the field of Human-Computer Interaction. It grew from the idea of democratising design processes, ensuring that the person most concerned with the use of the designed object (e.g. the new technology) was cooperatively involved in the design (Sanders et al., 2010). Participatory Design emphasises the centrality of the user in the design process and provides a mandate for embedding consumer (including patient/client and health care professional) participation into the development of new technology from the beginning of the process. Participatory Design is one of many approaches that emphasise collaboration with users/consumers, including co-creation, co-design, interaction design and many more. These terms are sometimes used interchangeably, without a clear framework. We've adopted Participatory Design as the basis for discussion in this paper because it is well articulated as an approach. The first author of this paper has extensive experience in Human-Computer-Interaction, and in particular, Participatory Design. The second author has substantial experience in qualitative research methods. We draw on our experience in discussing the relationship of qualitative research to the Participatory Design of SLP technology. Whilst we draw examples from digital technology in this paper, it is worth noting that the methods explored could also be used for the development of low tech and other intervention approaches. The aim of this paper is to 1) highlight the role qualitative methods can play in Participatory Design, and 2) to call for the design of new SLP technology in line with Participatory Design approaches, engaging with qualitative research methods.

Pathways for technology design and development

Participatory Design provides a contrast to how technology for intervention in health care settings is often designed. A common approach might entail the expert clinician and/or researcher assuming full responsibility for devising and developing an intervention. This may be based on theory, evidence, and their own clinical knowledge and experience. As evidence

of this, Croot et al (2019) systematically examined interventions designed to improve health, mapping studies between 2015 and 2019 to understand how they were developed. Many of the interventions, of which over one third were digital, were developed without using a published development framework. None used a user experience approach and only 10 of the 87 reviewed studies included partnership (e.g. community engagement, co-design) in the development of the intervention.

Once developed, at least to a pilot level, researchers often assess an intervention for efficacy before consulting end users as part of understanding feasibility and acceptability of the intervention. While this information may have some role in informing the further development of the intervention, the onus for design is on the clinician-researcher. Thus, a common model of intervention development could be summarised by a sequence of *develop intervention* → *assess efficacy* → *consult end-users*. Of course, this is a simplification of what is often a multidisciplinary, collaborative effort. SLP technology design involves multiple parties including software designers and researchers from other disciplines such as occupational therapy. The key feature of this trajectory, however, is that the user consulted only toward the end of the process, providing feedback on what has already been developed.

We see examples of this sequence of *develop* → *assess* → *consult* in the development of telehealth technologies in speech-language pathology. Telehealth has existed since at least the 1960s, and has included SLP services since at least the mid-1970s (Park, 1974). By this time, several sites in the United States of America had telehealth links between two or more centres providing SLP services. For example, SLPs at one hospital site used an “interactive television” (a closed circuit linked system) to interact with clients at another site, providing intervention (both group and individual) for patients with aphasia,

apraxia, dysarthria, dysphonia, stuttering and post-laryngectomy (Park, 1974). At another site, local school children attended a hospital telemedicine suite to receive SLP intervention services (Park, 1974). Clinical needs and technological feasibility were the main drivers for development of these services and researchers sought user views only after the fact. That is, researchers invited clients to provide feedback on the established telehealth service, with a focus on “user satisfaction”. An early example of this comes from analysis of interviews with nine parents school children who accessed SLP telehealth. Park (1974, p. 134) reports the results as follows:

...all felt the experience was as satisfactory as an "in person" one would have been and none felt his or her child was intimidated in any way; one felt her child showed less shyness than would have been the case in a face-to-face transaction; and if the television therapy had not been available, four parents would have been unable to get any help, two would have tried to help the child themselves, two were prepared to seek professional help elsewhere, and one didn't know what she would have done.

As telehealth was a new way of providing services, clinicians, managers, and funders were keen to understand what the public thought. However, research and development into telehealth became “dominated by efficacy trials” (Greenhalgh et al, 2013, p. 86). There was little focus on developing a sophisticated understanding of user needs and their interaction with technologies. While telehealth technology has developed over time and been put to many uses, there has not been concurrent investment in understanding how people want to use this technology (Greenhalgh et al., 2012). Taking publications between 1966 and 1998, Mair and Witten (2000) identified 32 studies across all of healthcare that had explored client views of

telehealth. They noted that only one had used qualitative methods to engage in rich exploration of client experiences or views of this technology.

Development of SLP telehealth technologies has followed this *develop* → *assess* → *consult* pattern. Researchers often undertake examination of client views of established telehealth systems either directly through surveys, interviews or focus groups (e.g. Carey et al., 2012; Theodoros et al., 2006) or indirectly, through data around home use of the telehealth technology (Choi, Park, & Paik, 2016; Mortley, Wade, Davies, & Enderby, 2003), or attendance at telehealth sessions (Sicotte, Lehoux, Fortier-Blanc, & Leblanc, 2003). However, there are examples of researchers and clinicians centring users in the development of new telehealth technologies that illustrate the value of this approach. Siden (1998) included focus groups with doctors, allied health professionals and parents (of children with disabilities) as part of a “needs assessment” for a proposed new telehealth service. These user groups proposed elements of the design of the technology that the research group had not previously considered. Siden describes users “trying to forecast uses” for the telehealth technology with suggestions that included innovative ideas, such as “a mobile head camera” (p. 231). Siden argues that this needs assessment approach allowed participants, perhaps for the first time, to hypothesise, predict and “fantasise” about what telehealth technology could look like. Their suggestions also “implied new approaches to health care systems” (Siden, 1998, p. 231). Wentink et al (2019) used focus groups of patients, carers and health professionals involved in stroke rehabilitation to identify “end user requirements” for online rehabilitation interventions. Using content analysis, they identified user requirements relating to the content, usability, and accessibility of these interventions. They particularly highlighted the difference in perspectives of patients/carers and health professionals with respect to some of these areas, arguing that both groups need to be involved in this type of development to meet all needs.

Hill and Breslin (2016) used semi-structured interviews with people with aphasia and SLPs to refine the development of an asynchronous SLP intervention telehealth platform, eSALT. After using the eSALT platform for a period of intervention, researchers interviewed both groups and used content analysis to explore themes around usability in order to improve the final eSALT product. Refinements included improvements to interfaces and increased variety in feedback options.

Participatory Design pathways for technology design and development

In contrast to some of the *develop* → *assess* → *consult* approaches explored above, “the heart of Participatory Design is participation” (Sanders et al, 2010, p. 147). This participation is of users; to understand user needs, to design, and to examine feasibility and acceptability (Sanders et al, 2010). Muller and Druin (2012) define Participatory Design as a set of processes which involve “end-users *as full participants* [emphasis ours] in activities leading to software and hardware computer products and computer-based activities” (p. 1125). Participatory Design processes require development of a shared understanding between end-users and developers (including researchers), bringing together individual knowledges into a mutual design space.

The role of qualitative methods within Participatory Design

The growth of qualitative research in health care has unlocked huge potential for the meaningful engagement of clients in the design and evaluation of health care innovations. Qualitative methods centre the client voice (Locock & Boaz, 2019), focus on the meanings, understandings, and experiences of clients, and thus support design that is truly client-centred. Researchers and clinicians can use qualitative methods in ways that are genuinely

participatory, establishing shared spaces for knowledge creation and sharing between users and researchers.

There is already a recognised overlap between qualitative research and patient and public involvement (PPI) methods in the development of health care interventions and services (Locock & Boaz, 2019). A similar overlap between Participatory Design and qualitative methods is not as well described in the literature but is evident when one looks at the techniques used for Participatory Design in various fields. For example, Nielsen et al (2019) used interviews, observations, and focus groups to understand client needs, taking a phenomenological-hermeneutic approach when developing a telehealth tool. Muller and Druin (2012), in their summary of “methods, techniques and practices in Participatory Design” (p. 2) describe ethnographic techniques commonly used by researchers in Participatory Design including the use of narrative structures such as stories, drama, and videos to present/represent knowledge. They also describe the use of games, such as pictures of scenarios that end-users describe and discuss, to allow “hands-on, highly conversational approaches” to design (p. 36). Interactive workshops including both clients and service providers are often key to Participatory Design, and can include any of the techniques above, with the aim of interpreting user needs and proposing solutions (Nielsen et al., 2020).

These techniques that have obvious potential for substantial qualitative data generation. Further, Muller and Druin (2012) discuss the idea of Participatory Design approaches creating “the third space”. This is a conceptual space for design created by the involvement of technology developers and researchers on the one hand, and end-users on the other. The shared space brings together the knowledge of both groups into a design that is not owned by either group but is shared and co-created by both. Creating a third space requires dialogue

across and between groups, an emphasis on interpretivism, iteration, and an understanding of heterogeneity as the norm (Muller & Druin, 2012). These are all concepts that fit well with qualitative research.

The “third space” discussed by Muller and Druin (2012) requires viewing end-users (e.g. clients) as *partners* in design, not as *participants* in research. Nielson et al (2020) state: “the intention [of Participatory Design] is to equalise the power between designers and users, using participation to facilitate mutual learning” (p. 1239). Designing within the third space requires more than recording and interpreting what clients say about technology or interventions and using this information to design an intervention. Rather it requires sharing of power, and of information between both parties, to create a shared perspective and product. This requires an iterative conversation between designers and clients about why they need the technology intervention, how a technology might meet their needs, what features will best support those needs, and so on.

Participatory Design in SLP

There are several examples of Participatory Design approaches for SLP technologies that provide evidence that these approaches are valuable in the development of these technologies. Hudson et al (2020) describe HCI researchers using Participatory Design to co-design SLP digital tools appropriate to local needs for clinicians and student clinicians working in Ghana. Methods implemented to collaboratively develop knowledge and ideas for relevant digital tools included semi-structured interviews, co-design workshops and a week-long design probe study. Students documented details of their SLP journey, support network, SLP practice, “creative self” and their “future me”. Researchers undertook inductive thematic analysis of the data using the Braun and Clarke (2006) model to extract themes and develop empirical

insights for consideration within the design of future digital tools. The authors identified the potential for the creation of an online community of practice within the Ghanaian SLP context. This space would be used to support community members to learn and share across a wide variety of settings through an inter-connected digital environment.

S. Wilson et al (2015) similarly adapted Participatory Design approaches to support participation of people with aphasia in design. They describe two interdisciplinary projects involving researchers from SLP and HCI. These projects both used Participatory Design methods for co-design of technologies for people with aphasia, one to support gesture therapy practice (GeST), and one to develop an online space for conversational practice (EVA Park). Use of techniques to engage and allow participation of people with aphasia in co-design of technology included ice breaker games, photo diaries and scenarios exploration, story grid creation and the creation of tangible avatars. Photo diaries, for example, were used by people with aphasia to document situations where they experienced communication challenges in their lives. In workshops, the same people reflected on their photographs and discussed the communication and challenges experienced. Researchers also used a “story grid” to propose environments or scenarios that were categorised per the challenge they presented in terms of communication. The researchers note that this process “generated a lot of discussion about peoples’ daily lives, what they found difficult and why” (p. 29). The authors emphasise the use of interaction and collaborative and iterative engagement throughout the design process from conceptualisation to exploring early acceptability.

While the above two studies are examples of collaborative HCI and SLP led research, HCI-led examples that engage SLPs within participatory design processes are also relevant.

Participatory Design often includes components that are heavily reliant on verbal

communication, such as interviews or workshops. Thus, HCI-led research that engages people with communication disability can provide important insights to the Participatory Design process for SLPs. C. Wilson et al (2019) adapted existing co-design methods for use with 10 children, aged from five to eight years old, within an autism-specific primary school in Australia. Over a period of 20 weeks, school students, who were minimally verbal worked alongside participant teachers, SLPs and an occupational therapist on a series of child-led activities to establish the children's interests and to develop low fidelity prototypes. The authors used qualitative methods to analyse videos, photographs, field notes and interviews with teachers and therapists. They applied an approach based on "the pillars of communication" and described in Greenspan, Wieder, & Simons (1998). The iterative Participatory Design process resulted in a "playful prototype, the TangiBall" (p.1) which aimed to support engagement, interaction, and expression.

O'Connor et al (2006) also engaged SLPs as co-designers alongside a person with severe physical and communication disabilities in order to develop video-editing tools. The design process included qualitative analysis of video recordings of interactions between co-designers and prototype technologies. The researchers used these in-depth data to identify key features of interaction, communication, and use, using methods similar to coding in qualitative research.

The imperative for Participatory Design in SLP

The Participatory Design principles of including all end-users in the design of technology align with the principles of the disability rights movement expressed in the phrase "Nothing About Us Without Us" (as discussed in Charlton, 1998). Participation in design of technology is undeniably important when users are people with health conditions or disabilities. This is

not just about the usability of the end-design. For example, Alami et al (2018) highlights that involving clients in the development of telehealth is important to understand variable digital literacy, the impact on patient privacy and data protection, and the potential for “medicalization of the living space” (p. 2). There is also a need to identify what such a use of technology symbolises for some people and communities (Alami et al, 2018). People with communication disabilities have unique needs that make their direct involvement imperative (Hill & Breslin, 2016). There is evidence that technology developers often do not fully recognise or understand the preferences and abilities of users with communication disabilities (Roper et al., 2019) leading to common instances of digital exclusion (Menger et al., 2016). Participatory Design offers a potential means of addressing such issues.

We believe there is a strong case for SLP technology design to use the iterative cycles of development supported within a Participatory Design approach. SLP interventions and client groups are complex. A simple develop, test, implement design is unlikely to meet the real world needs for technology design from either client or clinician perspectives. Taking a user-centred Participatory Design approach and harnessing qualitative methods in the design of new SLP technologies can not only support the development of more useable technologies, but also promotes innovation. Clients bring perspectives on things clinician-researchers would not have thought about (e.g. Siden, 1998; C. Wilson et al, 2019). Participatory Design seeks to harmonise multiple stakeholder perspectives throughout the design process. For example, it introduces the knowledge and understanding of clients regarding their daily lives, needs and lived experience. It creates a space to combine this with knowledge of the clinical evidence base, experience of work with a range of client needs, and an understanding of the limitations and possibilities of practice. Factor in expertise in qualitative research methods and human-computer interaction design and you establish a fertile and novel context in which to develop

meaningful innovation in SLP technology. As demonstrated within the interdisciplinary work by S. Wilson et al (2015) and C. Wilson et al (2019), SLPs have the skills to implement and operationalise Participatory Design principles, modify Participatory Design approaches to allow people with communication disorders to participate, and to create co-designed technologies. Further, people with communication disabilities can meaningfully collaborate in these processes.

Challenges in undertaking Participatory Design

A critical step to take in the adoption of Participatory Design relates to the relinquishment of power by healthcare professionals, researchers and technology developers when working collaboratively with people with communication disabilities. The shift between participant and partner, mentioned earlier, may seem straightforward, but can require considerable active work to achieve. The first author of this paper is an SLP and has developed extensive experience of Participatory Design in SLP technology development through several years of practice in the HCI domain. Her reflections on this experience indicate that such a shift requires greater agency to be assigned to co-designers with communication disabilities than might be the case in traditional qualitative research, health care design or indeed clinical practice (Roper, 2013). The International Association for Public Participation (IAP2) highlights the difference between surface-level ‘consultative’ engagement, versus ‘collaboration’, where health care professionals and design teams would “partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution” (IAP2, 2014). This shift requires a willingness to acknowledge the bounds of professional knowledge and release the responsibilities of coming up with all the solutions to each challenge. In return, professionals engaged in the Participatory Design process benefit and learn from the wider set of skills and perspectives

brought by co-designers with communication disabilities. This can richly enhance the patient voice not only in objective observation and analysis, but also in dialogue. C. Wilson et al (2019) argue that the Participatory Design process itself is an opportunity for unique interaction opportunities between clinician-researchers and clients, providing a space to create novel methods to reveal interests and competencies. We suggest that such space offers room for innovation both in terms of methods and of design.

Conclusions and implications

It is imperative that SLP technologies are developed with greater involvement of clients at the very beginning. This involvement ensures that the end product meets the user's needs. It also allows unique opportunities for innovation, bringing in perspectives and ideas that would not otherwise have been fore fronted. Participatory Design includes many principles and practices with which qualitative researchers would be familiar, and which should apply as best practice within design of new SLP technologies. SLPs themselves bring established expertise enabling them to provide a space for others to communicate, which is vital to the Participatory Design process. Through this, SLPs can effectively collaborate with group members with communication disabilities and HCI researchers to work towards a consensus design with a shared understanding of both the process and the goal. Similarly, as health care professionals consider, evaluate and integrate new technologies into practice, there is a need to be aware of how these technologies have been developed. While not all technology will have been developed using a full Participatory Design approach, engagement with end users throughout the design process should be considered best practice. When appraising SLP technologies for intervention, for example, professionals should look for evidence that end users have collaborated throughout the design, development, assessment, and real-world implementation.

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