Designing Connections for Hearing Rehabilitation: Exploring Future Client Journeys with Elderly Hearing Aid Users, Relatives and Healthcare Providers

Anne Marie Kanstrup

Dept. of Communication and Psychology
Aalborg University
Aalborg, Denmark
kanstrup@hum.aau.dk

Sergi Rotger-Griful, Ariane Laplante-Lévesque,

Annette Cleveland Nielsen
Eriksholm Research Centre, Part of Oticon A/S
Snekkersten, Denmark
segr; alni; arll @eriksholm.com

ABSTRACT

Designing technology-mediated connections between patients, relatives and healthcare providers is a main focus of electronic healthcare (eHealth). Involving future users in the innovation and design of eHealth is important for understanding the complex socio-technical challenge of connecting key actors in health management. This paper presents the results of a research project on the design of eHealth solutions for hearing healthcare. We introduce a client journey perspective on hearing rehabilitation and present how we engaged elderly hearing aid users, relatives and healthcare providers in inventing future eHealth-assisted client journeys. Our analysis of this problem space presents a series of boundaries and barriers and possible bridges and connections for future hearing rehabilitation. We synthesise these results by developing an integrated model of the complex interplay between information, communication and learning among key actors in hearing rehabilitation and we outline four implications for design within this framework.

Author Keywords

Connected Health; eHealth; Hearing Rehabilitation; Elderly People; Participatory Design.

ACM Classification Keywords

H.5.2. User Interfaces: User-Centred Design.

INTRODUCTION

Hearing impairment is common and disabling, as it reduces abilities for communication and social participation. It is a non-fatal, age-related illness and the fifth leading cause of years lived with disability [40]. Similar to other chronic diseases and disabilities, people with hearing impairment face demands for daily self-management when they enter

treatment. This places the responsibility for health on the individual, who must confront and live with ongoing health management challenges. Health management encompasses a range of tasks and expectations for the individual, such as learning and following health recommendations, understanding and using health technology, monitoring one's own health, communicating health observations to healthcare providers and cooperating with significant others on daily health [8, 31]. Additionally, an ageing population and increased prevalence of chronic illness pose severe resource challenges for healthcare systems dealing with a global shortage of qualified healthcare providers [42]. The design of interactive systems to support cooperation between patients, relatives and healthcare providers with regard to health management has emerged owing to these challenges, accompanied by increasing digital opportunities to deliver scalable and flexible health services. Furthermore, eHealth has been proposed as a means of improving the cost effectiveness of healthcare [43]. Information and Communication Technology (ICT) provides new opportunities for connected health and has the potential to be a driver for healthcare innovation [41]. The term eHealth is widely used for health delivery via ICT and refers especially to applications aimed at improving communication between individuals and organisations [32]. This includes telemedicine, mobile health solutions, clinical decision support systems, web-based health portals, virtual training environments, electronic health records and computerised physician order entry systems [43].

Despite the digital opportunities of eHealth, researchers call for ongoing studies into how best to support cooperation between health providers and individuals in daily health management. This includes, for example, understanding how people carry out everyday health management [31], understanding communication boundaries between people living with health conditions and healthcare providers [27], understanding information practices for people living with chronic illness and disabilities [33], investigating how to support people with an illness in converting health information into self-management strategies [17] and carefully considering how to share health information between healthcare providers, patients and informal carers [35]. The socio-technical aspects of healthcare systems are

This work is licensed under a Creative Commons Attribution International 4.0 License.

DIS 2017, June 10-14, 2017, Edinburgh, United Kingdom
2017 ACM. ISBN 978-1-4503-4922-2/17/06
DOI: <http://dx.doi.org/10.1145/3064663.3064737>

complex, and eHealth research stresses the importance of engaging key actors in the co-design of future technology to bridge the knowledge gaps in the requirements analysis and design for functional support across actors [4].

In this paper, we contribute to this research need by presenting how we have engaged older adults (≥ 60 years) with hearing impairment (or persons with hearing impairment [PHIs]), their significant others (SOs) and hearing care providers (HCPs) in participatory design of eHealth solutions for hearing impairment. First, we present background information on hearing impairment, eHealth in hearing rehabilitation and hearing healthcare client journeys (CJs). As presented in the subsequent section, numerous hearing applications exist, but few of them are used [7]. On this basis, we engaged in the research challenge of innovating solutions that can bring value for PHIs, SOs and HCPs. We present how we involved these key actors in the design of eHealth solutions for hearing rehabilitation via focus group sessions. Our findings are presented in an analysis synthesising the results, and we develop an integrated framework for the design of eHealth solutions. Finally, we discuss the implications of the results for design, the limitations of the research and suggestions for future research.

BACKGROUND

Hearing impairment

Approximately 5% of the world population has a disabling hearing impairment. Hearing impairment is especially common in older adults (age-related hearing impairment). This condition affects verbal communication and has negative consequences, such as reduced social participation, reduced participation in the workforce and mental health problems [1]. The vast majority of older adults with hearing impairment are candidates for hearing aids, which are ear-level electronic sound amplifiers adjusted to suit an individual's hearing impairment.

Hearing aids improve the quality of life of those who use them [5]. However, they do not restore normal hearing function. Furthermore, the hearing abilities of the elderly typically deteriorate gradually over time. This requires continuous adaptation and acclimatisation to listening situations for the hearing aid user and regular maintenance and fine-tuning of the hearing aids to ensure that they are fitted to the gradual deterioration of the hearing as a consequence of ageing. The target group requires hearing healthcare and self-management to reduce the negative consequences of hearing impairment. Learning to use and live with hearing aids is essential. The learning curve is steep and a significant number of hearing aid users stop using their hearing aids or live with inadequate hearing and the consequences this has for their quality of life [23].

Demographics are changing globally, as the ageing population is growing worldwide. From 2010 to 2015, the number of people aged 60 years and over grew by over

50% [44]. This calls for a paradigm shift within healthcare with responsive care, including the substitution of physical patient visits with online services [15]. Our primary target group, older adults with hearing impairment, is relevant for the research and development of interactive systems, as mobility problems increase with age, making attending physical appointments difficult. Additionally, since memory problems increase as people age, information must be easily accessible at all times, which digital solutions enable [20]. The elderly represent the portion of the population for whom rates of Internet use are increasing most rapidly. In Denmark, where this study was conducted, 79% of Danes aged 65–89 years had Internet access at home in 2016 and reported regular use [10]. Reports from Canada, the UK and Sweden show that elderly people with hearing impairment use the Internet more than their peers with normal hearing [14, 16, 38].

Hearing applications

Numerous applications (apps) exist that are designed to support hearing healthcare. A recent review of such apps identified 203 applications categorised as apps for screening and self-testing, education and information, assistive tools and mobile applications supporting users with easy ways to amplify sound [34]. However, eHealth solutions connecting key actors in hearing healthcare remain a vision, rather than current practice [7]; yet the scenario is presented as ‘a silent and disrupting revolution in the hearing health care practice’ offering opportunities for ‘novel interactions and relationships between actors’ [39]. Challenges in relation to eHealth solutions include adherence, quality, effectiveness and privacy [34]. For example, a study of an online support system connecting HCPs and PHIs presents benefits as well as challenges related to a cumbersome interaction design, lack of personalisation and non-use among some PHIs [2].

eHealth solutions are aimed at empowering people in need of healthcare to self-manage with support from technology-mediated interactions with their healthcare providers. For this reason, the involvement of the key actors – PHIs, SOs and HCPs – in the design of future eHealth solutions for hearing healthcare is strongly recommended to understand how to innovate solutions that fulfil the real needs of the people for whom they are designed [12]. Most eHealth applications are developed on the basis of technological opportunity rather than user needs and are tested in pilot studies, demonstrating technical feasibility, but then stored on a shelf, never to be used again [45]. We worked with this innovative challenge and engaged PHIs, SOs and HCPs in participatory design of future eHealth solutions for hearing rehabilitation.

Hearing healthcare client journeys

Our research is grounded in related work on adult PHIs' perspectives on hearing services. In the results of the previous research, PHIs describe hearing help-seeking and rehabilitation in the context of their daily lives and as a

process of personal adjustment to a health condition, rather than along a healthcare pathway, as many HCPs describe [23]. There is clearly a need for designing CJs that merge healthcare pathways and the psychosocial needs of PHIs and their SOs as they adjust to life with hearing impairment. Furthermore, there is a need for understanding how eHealth can best facilitate such CJs.

Journey has been used as a metaphor for living with chronic illness for many years and can be found in long-established models of health behaviour change, like the transtheoretical model, the health belief model, the self-regulatory model and the self-determination model [9, 29, 30]. Following recommendations for applying theories of health behaviour and change to hearing health research, we combined different models in the CJ used in this study [9].

In general, CJs are used to investigate the experiences of patients and the processes which they undergo during the course of an illness. Despite obvious differences between people and their illnesses, the process which people experience is often similar [29, 30]. To support conversations with PHIs, SOs and HCPs about hearing healthcare, we developed a simple CJ with four phases, presented in Figure 1. This CJ combines aspects of the healthcare journey (fitting and follow-up consultations as anchors) as well as room for the personal journeys of psychosocial adjustment, with attention to concepts such as motivation and readiness, cues to action, severity and maintenance of newly acquired behaviours.

Figure 1. The client journey for hearing healthcare.

The first phase, ‘prepare’, is where the PHIs and SOs become aware of, and acknowledge, the PHI’s hearing problem – that is, taking the first steps into the CJ. The second phase, ‘depart’, is the hearing aid fitting in the consultation room of the HCP resulting in the PHI leaving the clinic with hearing aids. The third phase, ‘explore’, is where the PHI steps into life with hearing aids. In this period, the PHI learns to adjust to amplified sounds, maintain the hearing aids, etc. This learning curve can be steep. The fourth phase, ‘established’, is where the PHI is expected to be on an optimal track with respect to hearing rehabilitation. When facing new problems or needing to be fitted with new hearing aids, the PHI typically starts the CJ again, however with experiences from previous journey(s).

Hearing healthcare has changed very little over the past 30 years. Almost all services are provided through physical meetings between PHIs and HCPs, which is both time- and resource-consuming for all parties. Moreover, people forget 40–80% of the information given during health visits [20]. It is also difficult for SOs to be involved [11]. Thus, it is an HCP-centred journey, where the HCPs provide devices and information to the PHI. The HCPs have very little prior knowledge of the PHI before the fitting and very little

knowledge about how the PHI will use, and benefit from, the hearing aids after they are fitted. Thus, HCPs do not have the opportunity to make full use of their expertise owing to a lack of resources and short time with clients in the clinic – a typical fitting appointment between an HCP and a PHI is 45 minutes, during which the hearing aids need to be adjusted according to objective measures and PHI feedback and the PHI must become confident in self-managing the hearing aids. Future hearing healthcare can benefit from technological opportunities to create connections between PHIs and HCPs in a flexible, scalable and personalised manner, thus offering support to PHIs and SOs in their daily self-management without requiring face-to-face appointments. This brings opportunities for a PHI-centred journey, where PHIs and SOs can also be information providers, and where PHIs and HCPs can share information as part of preparing for the consultation, exploring the new world with hearing aids and self-managing hearing impairment.

In the following, we present how we used the CJ to explore the difficulties faced by PHIs, SOs and HCPs and to develop ideas for future eHealth-assisted CJs.

METHODS

Our three target groups were PHIs, SOs and HCPs, whom we recruited to participate in focus groups to facilitate a participatory approach to the innovation and design of eHealth-assisted CJs for hearing healthcare. The following explains how we staged the focus groups and how we analysed the results of the focus groups. For more details on how to carry out qualitative research in audiology, as conducted in the present study, the reader should refer to [21].

Participants

We conducted 8 focus groups with a total of 42 participants. This comprised four focus group sessions with PHIs, two focus group sessions with SOs and two focus group sessions with HCPs. Although the three key actors were separated into different focus groups, all focus groups followed the same structure.

We targeted an average of five participants per focus group to ensure active participation and, for PHIs, an optimal listening environment. We recruited PHIs through local associations of PHIs, social media (i.e. Facebook) and the research participants in the database of Eriksholm Research Centre as well as their family and friends. We also relied on the database of Eriksholm Research Centre to recruit SOs. Lastly, we recruited HCPs through personal networks and communications with public and private hearing clinics.

We used inclusion criteria developed for user innovation processes and recruited participants experienced in hearing rehabilitation and interested in technology [19]. All participants met the following inclusion/exclusion criteria: (1) Own a smartphone and use apps; (2) Have no direct relation to a hearing aid manufacturer (e.g. through

employment); (3) Have experienced the hearing CJ and would like to contribute to new solutions supporting the CJ; and (4) Have ideas for solutions to improve the hearing CJ. Furthermore, SOs were included if they had never tried or owned hearing aids. To have a varied sample of the three key actor groups, we applied different maximum variation criteria among the participants in the three key actor groups: age, gender, experience with public or private hearing healthcare and length of experience with hearing impairment. Furthermore, we ensured that some HCPs had university training, whilst others did not. PHIs also had different levels of activity: from being employed full-time and living with family members to being retired and living alone. Table 1 describes the participant characteristics.

Target group	Gender ¹		Age ²	Experience ³	Job active ⁴
PHI (n=24)	F	13	67.9 (61-79)	20.4 (0.5-62)	4
	M	11	71.9 (65-81)	7.2 (0.5-12)	3
SO (n=10)	F	9	63.7 (31-76)	17.5 (0.25-54)	N/A
	M	1	76 (76-76)	20 (20-20)	N/A
HCP (n=8)	F	5	N/A	8.5 (1.5-18)	3/2
	M	3	N/A	9.5 (1.5-25)	3/0

¹⁾ F: female; M: male ²⁾ Mean age (range) ³⁾ Mean (range) PHI: Years as a hearing aid user; SO: Years as an SO to a hearing aid user; HCP: Years of practice ⁴⁾ PHI: # of job active; HCP: # in public hearing clinics / # in private hearing clinics

Table 1. Participant characteristics.

All participants received information on the research and provided written informed consent prior to participating in the focus groups. Eriksholm Research Centre has ethical clearance for its research activities from the Committee for Health Research Ethics, Capital Region.

Focus groups activities

To foster communication, our focus groups took place in a quiet meeting room. The chairs of the participants and facilitators were arranged around a table to facilitate lip reading, and hearing assistive technology (e.g. frequency modulation system) was available and its use was encouraged. We worked from a participatory design perspective and endeavoured to engage the participants as partners in the design process, in contrast to their traditional role as testers of products [19, 37]. Related research has documented the quality of engaging older adults in designing for an older target group and reported that most older adults choose to participate in design activities to socialise [25, 36]. For this reason, and to stimulate an atmosphere of trust and creativity, we developed a procedure with ludic activities and a rich opportunity for the participants to share and discuss experiences and

visions. We supported conversation with a series of visual tangible artefacts developed to support turn taking, promote a clear focus and flow in the group conversation and trigger ideas by asking participants to rearrange, sort out and contribute to the design of future CJ. The following materials were developed for the focus group sessions:

- A cardboard CJ was developed and placed on the table. This CJ was the centre of the conversations and activities in all focus groups. The CJ was known to all participants and functioned as a shared frame of reference.
 - Each participant was given a token and was instructed to place the token at the phase in the CJ that they found most important to support. This stimulated reflection on experiences and needs and supported turn taking – each participant could, in turn, present where they had placed their token and why.
 - Following the journey metaphor, a suitcase was placed on the table to represent that the aim of the focus group discussion was to ‘pack a suitcase for future CJs’. We introduced ‘weight restrictions’ for the content of the suitcase to make participants prioritise needs and visions. This restriction stimulated a ludic atmosphere and rich conversation on the relative importance of the proposed solutions.
 - Blank cards for each phase in the CJ were developed to support participants’ reflections on visions for future CJs. For each phase of the CJ, each participant was given a blank card representing the specific stage and two minutes to describe what they found important for that stage in the CJ. There were no restrictions for what to suggest on the blank cards; all visions were valuable, and participants were encouraged to reflect on dreams for future journeys. This activity also supported turn taking as participants read their cards aloud to each other.
 - Red cards (barriers) and green cards (opportunities) for each step in the CJ were developed for card sorting to bring perspectives on needs and visions for future CJs. On average, seven red and green cards were developed for each phase of the CJ. Red and green cards were read aloud clearly and distributed at the table, and participants were asked to choose one to two cards and place them in the suitcase for future CJs.
- The procedure for the focus group sessions was as follows.
1. Introduction: Welcome, introduction of all participants, information about data recording and hearing assistive technology in the room.
 2. The client journey: Presentation of the CJ. Participants places their token at the phase in the CJ that they found most important to support and share their reflections.
 3. The suitcase: Presentation of the suitcase. All participants received one blank card for each step in the CJ, wrote what they found most important for that phase of the

journey, read aloud to the group and placed the card in the suitcase.

4. Red cards: Known difficulties for each step in the CJ were read aloud and placed on the table. Participants discussed the red cards/difficulties and selected one or two for the suitcase for future CJs. Blank cards were available if participants had other priorities.
5. Green cards: Known opportunities for each step in the CJ were read aloud and placed at the table. Participants discussed the green cards/difficulties and selected one or two cards for the suitcase for future CJs. Blank cards were available if participants had other priorities.
6. Check-out: Participants were thanked for their help with preparing the suitcase for future CJs. Opportunities for participants to sign up to follow-up design activities.

Figure 2 displays the cardboard CJ (we placed two on the table so that all participants faced one CJ), the suitcase at the end of the table and how participants distributed tokens in the CJ. Figure 3 depicts the participants in one of the focus groups sorting cards.

Figure 2. Focus group session. The CJ, tokens distributed in the CJ, the suitcase.

Figure 3. Focus group session. Participants sorting cards.

Analysis

The eight focus groups lasted approximately two hours each, were video-recorded and resulted in a rich dataset of cards selected for the suitcase and the participants' shared reflections. We conducted an inductive thematic analysis on the data. Following Braun and Clarke [3], we made a verbatim account of all verbal utterances in the focus group conversations. We went through a reading and coding process starting with the use of initial codes of semantic content. Then we searched for, and identified, key themes that appeared in the focus groups with specific key actors, themes that appeared across all focus groups and themes that captured core elements of the participants' needs and constraints for living with hearing aids. We analysed each theme by coding responses related to the theme. The analysis was an iterative process of moving back and forward between single themes and responses and the entire dataset (cf. [3] p. 86 ff.). We synthesised the results into a comprehensive framework presenting the interplay between the identified themes (cf. Figure 5).

All quotations presented below have been translated from Danish to English.

FINDINGS

Barriers and visions

The analysis of the participants' prioritised barriers and visions for the hearing CJ (activities 4 and 5 in the focus group sessions) identified key themes related to information, communication and learning.

Information barriers identify a lack of information about hearing rehabilitation. This includes difficulties in finding trustworthy information in a complex healthcare system; information that is too general, which is difficult to convert to one's own condition and needs; and delivery of information too late. The participants presented their visions for how to bridge these information barriers as a call for personalised, trustworthy and timely information.

Communication barriers were related mostly to a lack of time to communicate. Difficult communication between PHIs and SOs was additionally expressed, as there was too little communication about hearing rehabilitation in daily life. The participants presented visions for supporting PHIs in the monitoring and sharing of hearing problems and especially visions for more time to communicate with HCPs via easy access and opportunities for on-demand communication.

In terms of learning barriers, PHIs and SOs presented uncertainty about how to explore and adjust to life with hearing loss. HCPs' lack of resources to support clients' exploration of hearing aids in between appointments was presented as a central barrier to learning. The participants' visions for learning were a call for support for the safe exploration of hearing aids in daily life. This included suggestions for digital training tools to support PHIs learning at their own pace and ongoing transition in the CJ

with opportunities to share and collaborate with SOs and HCPs.

Table 2 sums up the analysis of key barriers and key visions.

	Key barriers	Key visions
Information	Too difficult to find information. Too late delivery of information. Too general information.	A place for trustworthy information. Timing information delivery. Personalised information.
Communication	Too difficult to explain hearing problems Too little time to communicate. Too difficult to access communication	Monitoring and sharing hearing problems. More time to communicate. Easy communication on demand.
Learning	Uncertain exploration of hearing aids. Too little time to understand my hearing aid. Too many loops in the CJ – stuck in phases.	Support safe exploration at home. Ongoing self-monitoring. Transition support in the CJ.

Table 2. Key themes, key barriers and key visions identified.

Crossing boundaries – transition and learning

The analysis of the eight focus groups showed that crossing boundaries in the CJ was a key barrier and vision for all actors. There was a broad distribution of tokens in the CJ (activity 2 in the focus group procedure) with variations between the three key actor types and with attention to boundaries between phases (see Figure 4). Most PHIs placed the tokens at the departure and explore phases. SOs had a concentration of tokens in the later phases of the CJ, while HCPs had a concentration of tokens in the early phases of the CJ. As stated above, participants pointed specifically to boundaries, from one phase to another in the CJ, as important. Several participants placed their token in between phases in the CJ and presented transitions as difficult. Nine participants highlighted the boundary between the ‘prepare’ and ‘departure’ phases as the most needed stage for support. Two participants (HCPs) pointed to the boundary between the ‘departure’ and ‘explore’ phases as most critical. Three SOs pointed to the boundary between ‘explore’ and ‘established’ as most important and described unfulfilled ambitions with becoming established.

All participants described progress in the CJ as the overall goal. Journeys that are too long and experiences of being stuck in specific phases were presented as gaps that some PHIs never managed to cross and other PHIs experienced as very problematic. Examples are presentations of too many years to acknowledge hearing loss: *‘to acknowledge hearing loss has been tough (...) the preparing phase was a long and difficult journey for me’*. Other PHIs presented difficult departures: *‘I don’t want to tire you with details, but I have had 45 fittings’*. Other PHIs presented difficulties

with moving from departure to becoming established: *‘It works now, but it has been a long process – 19 years’*. A good CJ was presented as quick and easy movement from the ‘prepare’ phase to the ‘established’ phase. Only 4 of the 24 participating PHIs had experienced an easy CJ.

Thirteen participants pointed to the explore phase as the most difficult phase in the CJ. Similar to boundaries between phases in the CJ, the ‘explore’ phase is a difficult boundary to cross between leaving the clinic with hearing aids and working towards an established life with hearing aids. PHIs presented uncertainty as a dominant feeling at this stage: *‘I don’t know if the sound I hear is right’*; *‘I think that my hearing is fine, but I don’t know. I am very unsure in this phase’*; *‘I have a lot of problems, but I don’t know if it’s normal’*; *‘I am unsure when and how to communicate with providers’*. SOs especially called for information on hearing rehabilitation in order to be able to support their partner: *‘I only have the information that my husband gives to me’*; *‘I don’t know how to help my husband’*. HCPs presented the explore phase as *‘the critical phase’* where PHIs leave the clinic for the first time with hearing aids: *‘There are many frustrations when exploring new hearing aids. This is where I have to keep my clients focused on the goals we have set and help them be patient and understand that this phase takes more than three days (...) this is a fragile stage where many hearing aids end up in the drawer’*.

Figure 4 sums up the distribution of tokens in the CJ.

Figure 4. Distribution of tokens in the client journey.

Connecting key actors – time to communicate

The participants’ suggested ‘luggage’ for future CJs (activity 3 in the focus group procedure) included a series of needs and visions for connecting key actors in the CJ. All groups called for services that can support the connections between PHIs and their SOs. PHIs especially expressed a need for SOs’ help to motivate them in the early stages of the CJ: *‘If my SOs have had tools so that they could say to me, “look, these are the situations where we laugh at you and where it is difficult for you; you need to check up on your hearing”, then, I am sure that my acknowledgement of my hearing problem would have come easier. It is your SOs that affect you most’*; *‘you need your SOs to push you to take this step towards departure’*. PHIs also called for services that could support SOs’ understanding of hearing loss and hearing aids: *‘I really miss information for SOs so that they understand that shouting is not the best way to communicate. It is very important that SOs understand hearing impairment. This also includes the workplace’*; *‘I*

need a course for my wife so that she understands that I cannot hear what she says when she doesn't look at me'.

SOs especially called for services that would include them in the process. Several SOs experienced difficulties in being understanding and supporting in daily life: *'It would be an advantage if SOs were more involved in the process'; 'SOs need to be part of the process and especially get information'*. Similarly, HCPs suggested opportunities for including SOs more, for example, via *'self-management tasks also for SOs'* and *'something that also places responsibility on the SOs'*. Additionally, there were suggestions for connecting PHIs via mentoring arrangements or group consultation.

All participants addressed the problem of too little time for communication between PHIs and HCPs and called for more personalised solutions. PHIs presented that *'there is a need for more time when communicating with the HCP. You need to feel that this conversation is about you'* and *'the communication with the HCP has to be better. It feels like some of them don't see you as a person'*. PHIs especially called for solutions that could give them more time to communicate including services to prepare for communication or follow-up on communication at their own pace: *'I would really like the opportunity to sit at home, quietly, and have time to understand questions and reflect on them and answer them at my own pace'*. Similarly, HCPs called for more opportunities to provide personal feedback and address the problem with current CJs filled with too much and too general paper-based information. As one HCP expressed, *'you have to avoid using the autopilot when you communicate'*. Other HCPs elaborated, *'we need services with personalised information (...) and opportunities to ask quick questions'* and *'we lose people when we give them general information. We need personalised services, like an app with information about my hearing. It could be small videos about how you operate the specific hearing aid you have, like how to change batteries, etc.'* In general, the connection between PHIs and HCPs was presented as crucial. PHIs presented especially a need for *'more feedback between us and the HCPs'* and HCPs stressed a need for *'solutions that establish a good relationship. If they feel that we just talk past them, then we lose them'*.

HCPs also directed attention to the importance of *'timing information'* and of finding new solutions for delivering information with attention to the correct dosage at the right time: *'There is so much information. We need to think about how to break it into smaller pieces and timing delivery, like, for example, this Monday you get this and next Monday you will receive more'*.

Connecting services – timing information

The participants' suggested 'luggage' for future CJs included several services; PHIs especially called for services that could support them in learning about their hearing, for instance, via online hearing tests, monitoring

tools and online services for adjusting hearing aids. Examples are as follows: *'I would really like to be able to perform a simple hearing test at home via my iPad'; 'It would be great if I could do some kind of ongoing adjustment of my hearing aids via an app on my mobile phone. Then I wouldn't have to go to the clinic every time I need an adjustment. It could be a mandatory update and it would be great if there was also information like FAQ so that it was easy to find and I didn't have to do all the web browsing myself'*. Overall, PHIs called for opportunities to connect their hearing experience with opportunities to adjust their hearing aids and suggested several possibilities for monitoring and training tools. This was also supported by HCPs: *'we need something concrete, like a book or an app with daily tasks. It could be tasks like find a spot outside and sit there without hearing aids for 20 minutes and then put on your hearing aids and reflect on your experience'; 'training guides and video guides would be great'*.

All participating PHIs showed a strong interest in understanding and updating hearing technology. They called for opportunities to receive updates about new technologies. This included interests in assistive technology connecting hearing aids to technologies ubiquitous in their daily lives, such as mobile phones, televisions and doorbells.

HCPs emphasised that digital services must be efficient. Examples related to this issue are services that make it easy to deliver information: *'I am thinking that if we should deliver news and updates, etc., then we need something with prefabricated tips and tricks'; 'we need some kind of pool of material that makes it easy for us'; 'I think that one weekly open online counselling [session] would be effective because then you can solve problems quickly. Otherwise we will see them in the clinic for small problems'*. HCPs presented time as an overall constraint for using digital services: *'we all have such busy days, and it is just impossible to answer a flow of electronic messages from clients'*. Thus, HCPs stressed that digital services need to be effective in terms of usefulness for PHIs and time-saving for HCPs.

During the conversations about what to place in the suitcase for future CJs, participants shared several reflections about digital services. These reflections indicate the importance of a broad design perspective that includes future eHealth solutions in the ecology of the CJ. This especially calls attention to a seamless integration of digital services and face-to-face services. Participants often stressed that *'electronic solutions may never replace physical meetings'*. This was found in several conversations in the data. Some HCPs were concerned that too many digital services could result in lost information: *'I am concerned that if you receive information about specific subjects in electronic form, then you forget to talk about these subjects with the patient'; 'you can easily get a wrong picture in written*

information. This does not happen in the face-to-face communication because, here, you can see the person and hear their tone of voice'. A HCP presented her positive experience with Skype sessions and expressed the importance of providing personalised synchronous communication in contrast to general asynchronous information: 'I have tried to present a hearing test via Skype. In principle, I could just send it to the client, but they understand it more when we talk about it'. Another HCP elaborated, 'Yes, we can send and receive a lot via information systems, but when we have a personal conversation, we create this I-see-you-and-your-hearing-impairment, which is so important'. In addition, SOs called for personalised synchronous communication: 'It is the personal meeting with the HCP that is important. This is where you can get personalised support. Online information is too general and not useful'.

A complex interplay – synthesis

We developed an integrated model of our findings as visualised in Figure 5. This model presents a synthesis of our analysis of the problem space of eHealth solutions for hearing rehabilitation. In this synthesis, we included and visualised the complex interplay between the identified themes for future eHealth solutions (information, communication and learning), the visions for future solutions (effective communication, safe exploration, trustworthy information and core attention to personalised services) and the important constraints to be incorporated in future design solutions (transition, time and timing).

Figure 5: Interplay between communication, information and learning – a framework for the design of eHealth solutions.

Learning represents opportunities for conducting safe explorations and transitions in the CJ. This includes personalised tips and tricks, training tools, monitoring tools and, in general, digital services that support PHIs' time to learn. Time is limited in the clinic; thus, learning happens at home, and learning functionality should extend the time in clinic to the home. Personalised learning – that is, understanding one's hearing impairment, communication problems and hearing aids – is fundamental.

Communication represents delivering effective communication. To PHIs, effective communication meant easy access and time to prepare or follow up on communication. To HCPs, effective communication represented communication that works – in other words, that is understandable and valuable to the client and effective to deliver and that is, therefore, not time-consuming but supports efficiency by qualifying time in the clinic. Personalised communication was fundamental to all participants.

Information represents the ability to find (PHIs and SOs) and deliver (HCPs) trustworthy information. Timing is central, and personalised information is fundamental, since too much information and too general information were reported as useless. The right information at the right time to the right person in the right dosage reflects a core vision.

The constraints – time, timing and transition – are critical to future eHealth solutions for hearing rehabilitation. Effective communication that is not used to qualify time for HCPs and PHIs is without value. Trustworthy information is crucial, but if it does not support transition (steps forward in the CJ) and if the timing is wrong, then the value is likely to be low. Safe exploration via training tools and self-monitoring is central to learning, but if there is no time to learn and no transition forward in the CJ, then the conditions and motivation for learning are too difficult.

DISCUSSION

Implications for design

The analysis of the eight focus groups has presented a complex problem space for the design of eHealth solutions for hearing rehabilitation, with several boundaries and barriers, but also opportunities for bridging and connecting people and services, synthesised in Figure 5. On this basis, we outline the following four design implications for future eHealth solutions:

- Design for crossing boundaries along the CJ: Support transitions between phases in the CJ with attention to opportunities for PHIs to explore safely and for HCPs and SOs to follow the progress and provide the right support at the right time for the right situation.
- Design for connecting key actors in hearing rehabilitation: Support effective feedback loops between key actors with attention to tailored services for PHIs and SIs and effective services for HCPs.
- Design for connecting constraints with solutions: Incorporate constraints related to time, timing and transitions in design solutions to support different time needs between various stakeholders (effective time for HCP and more time for moving at one's own pace for PHIs), support different needs for the timing of delivering health information and communication and support transitions via information and learning services that visualise steps and progress in the hearing health journey.

- Design for connected services: Integrate eHealth solutions in the ecology of hearing rehabilitation, with specific attention to the design of connections between digital and physical rehabilitation services.

We are currently exploring concepts for future eHealth solutions in follow-up focus group sessions, with attention to their ability to mediate the complex interplay of connections in hearing rehabilitation. In this ongoing research, we explore visions for cloud clinics to improve information and communication between PHIs, SOs and HCPs especially related to technology-supported monitoring and learning as an ongoing and necessary element of hearing rehabilitation.

Limitations and future research

Using the CJ helped us understand the steps and connections in hearing rehabilitation for the three key actors. However, applying the CJ model also left some issues uncovered. Our study supported related work stressing that the stages in the CJ are far more dynamic and complex than visualised in the progressive CJ models [29, 30]. Hearing rehabilitation is indeed a journey which often does not go smoothly. In our methods and analysis, we applied a holistic perspective on this journey, acknowledging not only the PHIs but also their relatives and HCPs. Future research can benefit from the integration of theoretical concepts that emphasise a holistic and developmental perspective on hearing CJs. For example, the concept of legitimate peripheral participation (LPP) since LPP situates individuals' learning as part of a community of practice in which the individual learns to master knowledge and skills via movements within the community of practice, typically from a peripheral position as a newcomer to full participation [24]. LPP focuses on trajectory, but with attention to non-linear movements foregrounding the complex interactions of people and practices and has been evidenced as valuable for understanding and designing for ongoing health management and health cooperation [18]. In general, theory that brings attention to the development of the complex patterns of interactions in hearing rehabilitation may contribute to future research on technology-mediated hearing healthcare. Reflection on the applied CJ model and our results, in the form of an integrated framework of the complex interplay in hearing rehabilitation, has especially led us to observe a need to supplement future research with theory addressing cooperation. Concepts like 'boundary objects' and 'boundary negotiating artifacts' can be of important value to future research as a theoretical lens to examine in more detail how eHealth solutions facilitate boundary crossing and push boundaries for cooperation among key actors in hearing rehabilitation [6].

With regard to methods, our study could have included participants who were not technology users or who were inexperienced with the hearing health CJ. However, the sample of participants provided us with an in-depth

understanding of the participants' experiences and visions for future CJs. Our approach was not based on specific theory or methods for engaging the elderly in design. Rather, our methods were based on general principles for participatory design [37]. Our overall ambition was to contribute to equalising power relations by giving a voice especially to the elderly and their relatives, who are often not part of technology innovation (predominantly, they take on roles as testers) for hearing applications [7, 33]. We prioritised staging the focus groups sessions so that participants could share experiences and visions for possible futures to support mutual learning. To facilitate this, we developed and used visual tangible artefacts (the CJ, tokens, the suitcase, red cards and green cards) to support all participants to express their thoughts, needs and visions [19]. Our method worked well in engaging the elderly PHIs, the SOs and the HCPs and, overall, we find that the developed toolkit and approach provide a useful structure for future studies.

Several studies have presented valuable insights on the opportunities and challenges of engaging elderly people in technology innovation. Examples are the design of virtual training environments for people with aphasia [22], design of assistive technology [36], design of digital platforms for community development [28], design of robotic pets [25] and design of information systems at community centres [26]. Our developed research approach contributes to this body of design research engaging the elderly as co-designers of future technology. However, we emphasise that technology use and preferences are not only related to age but also to social, economic and cultural factors [13]. Thus, despite our focus on the elderly, it should be noted that our research is anchored in the specific presented situation as well as the dispositions of the participants.

CONCLUSIONS

In this paper, we have described the problem space of eHealth solutions for hearing rehabilitation. The analysis showed that crossing boundaries in the hearing care CJ is a central point of attention, calling for support of PHIs' transition in the CJ. The analysis presented the importance of designing for connecting key actors in the CJ. This involves attention to including SOs more in the CJ, supporting PHIs, especially with more personalised information and time to communicate, and supporting HCPs in effective communication. Moreover, the analysis presented the importance of designing for connecting services. This included a call for services to support PHIs in ongoing monitoring and exploration of hearing and especially a need to integrate future eHealth solutions in the ecology of hearing rehabilitation by connecting digital and physical services. Information, communication and learning were identified as key themes for eHealth solutions. Transition, time and timing were identified as important constraints to be addressed when designing for connections in hearing rehabilitation. The result – an integrated model of the complex interplay between information,

communication and learning among key actors in hearing rehabilitation – provides a useful framework for the future conceptualisation of eHealth solutions. Pursuing our ambition of designing connections for hearing rehabilitation, our design implications point to an integrated perspective on eHealth solutions connecting phases in the CJ, key actors in hearing rehabilitation, constraints with digital solutions and services, with attention to the design of the ecology of hearing rehabilitation.

Although the presented results are only part of a larger design research project, their contribution is fundamental for grounding future innovations of eHealth solutions in the use context of PHIs, SOs and HCPs. Our methods present how we engaged the elderly PHIs, SOs and HCPs in exploring future CJs and can inspire scholars engaged in participatory design with elderly people and multiple stakeholders.

ACKNOWLEDGEMENTS

We thank all the participants in the focus groups for volunteering to take part in this research. Special thanks to Louise Lystrup, research clinician at Eriksholm Research Centre, for her assistance in recruiting participants, conducting hearing tests and supporting the use of hearing assistive technology when needed. Thanks also to Jette Widunok Nissen, secretary at Eriksholm Research Centre, for helping out during the focus group sessions. This research was supported by the Danish Agency for Science and Innovation.

REFERENCES

1. S. Arlinger. 2003. Negative consequences of uncorrected hearing loss: A review. *Int J Audiol*, 42(2): 17-20. Doi: 10.31109/14992020309074639.
2. K. J. Brännström et al. 2016. The initial evaluation of an Internet-based support system for audiologists and first-time hearing aid clients. *Internet Interventions* 4(1): 82-91. Doi: 10.1016/j.invent.2016.01.002.
3. V. Braun and V. Clarke. 2008. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2): 77-101. Doi: 10.1191/1478088706qp0630a.
4. N. Carroll and I. Richardson. 2016. Aligning Healthcare Innovation and Software Requirements through Design Thinking. *SEHS'16*. Doi: 10.1145/2897683.2897687.
5. T. H. Chilsom et al. 2007. A systematic review of health-related quality of life and hearing aids: Final report of the American Academy of Audiology Task Force on the Health-Related Quality of Life Benefits of Amplification in Adults. *J Am Acad Audiol* 18(2): 151-183.
6. C-F Chung et al. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. *CSCW'16*, 770-786. Doi: 10.1145/2818048.2819926.
7. J. L. Clark and D. W. Swanepoel. 2014. Technology for hearing loss – as we know it, and as we dream it. *Disabil Rehabil Assist Technol*, 9(5): 408-413. Doi: 10.3109/17483107.2014.905642.
8. J. Corbin and A. Strauss. 1985. Managing Chronic Illness at Home: Three Lines of Work. *Qualitative Sociology* 8(3): 224 – 247.
9. NS Coulson et al. 2016. Applying theories of health behaviour and change to hearing health research: Time for a new approach. *Int J Audiol*, 55(3): 99-104. Doi: 10.3109/14992027.2016.1161851.
10. Danmarks Statistik. 2016. It-anvendelse i befolkningen 2014 (Statistics Denmark. 2016. IT use in the population 2016). Retrieved March 22, 2016 from <http://www.dst.dk/da/Statistik/Publikationer/VisPub?cid=20738>.
11. K. Ekberg et al. 2015. Family member involvement in audiology appointments with older people with hearing impairment. *Int J Audiol*, 54(2): 70-76. Doi: 10.3109/14992027.2014.948218.
12. M. Ferguson. 2014. Tackling information overload and retention – interactive multimedia videos for first-time hearing aid users. *ENT Audiol News*, 23: 102-104.
13. N. M. Gell et al. 2015. Patterns of Technology Use Among Older Adults With and Without Disabilities. *Gerontologist*, 55(3): 412-421. Doi: 10.1093/geront/gnt166.
14. C. Gonsalves and M. K. Pichora-Fuller. 2008. The effect of hearing loss and hearing aids on the use of Information and Communication Technologies by community-living older adults. *Can j Aging*, 27(2): 145-157. Doi: 10.3138/cja.27.2.145.
15. The Health Research Institute. 2014. *Healthcare Delivery of the Future*. Price Waterhouse Coopers. <http://www.pwc.com/us/technologyandinnovation>.
16. H. Henshaw et al. 2012. Computer skills and internet use in adults aged 50-74 years: influence of hearing difficulties. *J Med Internet Res* 14(4): e113. Doi: 10.2196/jmir.2036.
17. S. K. Johansen and A. M. Kanstrup. 2016. Expanding the Locus of Control: Design of a Mobile Quantified Self-Tracking Application for Whiplash Patients. *NordiCHI'16*, Article No. 59. Doi: 10.1145/2971485.2971497.
18. A. M. Kanstrup. 2014. Design concepts for digital diabetes practice: design to explore, share, and camouflage chronic illness. *International Journal of Design*, 8(3): 49-60.
19. A. M. Kanstrup and E. Christiansen. 2006. Selecting and evoking innovators: combining democracy and creativity. *NordiCHI'06*, 321-330. Doi: 10.1145/1182475.1182509.

20. R. Kessels. 2003. Patients' memory for medical information. *J. R. Soc. Med.* 96: 219-222.
21. L. V. Knudsen et al. 2012. Conducting qualitative research in audiology: A tutorial. *Int J Audiol*, 51(2): 83-92. Doi: 10.3109/14992027.2011.606283.
22. U. Konnerup. 2016. Engaging People with Aphasia in Design of Rehabilitation Through Participatory Design: A Way to Learn what they Really Want. In *Participatory Design & Health Information Technology*, A.M. Kanstrup et al. (Eds.). IOS Press. Doi: 10.3233/978-1-61499-740-5-148.
23. A. Laplante-Lévesque et al. 2012. Hearing help-seeking and rehabilitation: perspectives of adults with hearing impairment. *Int J Audiol*, 51(2): 93102. Doi: 10.3109/14002027.2011.606284.
24. J. Lave and E. Wenger. 1999. *Situated learning: Legitimate peripheral participation*. Cambridge, UK: Cambridge University Press.
25. A. Lazar et al. 2016. Rethinking the Design of Robotic Pets for Older Adults. *DIS'16*, 1034-1046. Doi: 10.1145/2901790.2901811.
26. Y. S. Lee et al. 2012. Active Aging in Community Centers and ICT Design Implications. *DIS'12*, 156-165. Doi: 10.1145/2317956.2317981.
27. C. Lim et al. 2016. "It just seems outside my health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. *DIS'16*, 1172-1184. Doi: 10.1145/2901790.2901866.
28. L. Malmberg et al. 2016. Mobilizing Senior Citizens in CoDesign of Mobile Technology. *International Journal of Mobile Human Compute Interaction*, 8(4): 42-67. Doi: 10.4018/IJMHCI.2016100103.
29. V. Manchaiah, D. Stephens and T. Lunner. 2013. Communication Partners' Journey through Their Partner's Hearing Impairment. *Int J Otolaryngol*. Doi: 10.1155/2013/707110.
30. V. Manchaiah, D. Stephens and R. Meredith. 2011. The patient journey of adults with hearing impairment: the patients' views. *Clin. Otolaryngol* 36(3): 277-234. Doi: 10.1111/j.1749-4486.2011.02320.x.
31. A. Moen and P. F. Brennan. 2005. Health@Home: The Work of Health Information Management in the Household (HIMH): Implications for Consumer Health Informatics (CHI) Innovations. *J Am Med Inform Assoc*, 12(6): 648-656.
32. H. Oh et al. 2005. What Is eHealth (3): A Systematic Review of Published Definitions. *J Med Internet Res*, 7(1): e1. Doi: 10.2196/jmir.7.1.e1.
33. A. O'Kane et al. 2016. Turning to Peers: Integrating Understanding of the Self, the Condition, and Others' Experiences in Making Sense of Complex Chronic Conditions. *CSCW*, 20(6): 477-501. Doi: 10.1007/s10606-016-9260-y.
34. A. Paglialonga et al. 2015. Apps for Hearing Science and Care. *Am J Audiol* 24: 293-298. Doi: 10.1044/2015_AJA-14-0093.
35. C. Pang et al. 2013. Technology Preferences and Routines for Sharing Health Information during Treatment of a Chronic Illness. *CHI'13*, 1759-1768. Doi: 10.1145/2470654.2466232.
36. Y. Rogers et al. 2014. Never too old: Engaging Retired People Inventing the Future with MaKey MaKey. *CHI'14*, 3913-3922. Doi: 10.1145/2556288.2557184.
37. J. Simonsen and T. Robertson (Eds.). 2013. *Routledge International Handbook of Participatory Design*. Routledge.
38. E. S. Thorén et al. 2013. Internet Access and Use in Adults With Hearing Loss. *J Med Internet Res* 15(5): e91. Doi: 10.2196/jmir.2221.
39. G. Tognola et al. 2015. eHealth for Hearing – New Views and Apps Practicalities. *EJBI*, 11(3): en37-en49.
40. T. Vos et al. 2015. Global, regional, and national incidence, prevalence, and years lived with disability from 301 acute and chronic diseases and injuries in 188 countries, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *The Lancet*, 386(9995): 743-800. Doi: 10.1016/S0140-6736(15)60692-4.
41. World Health Organization. 2005. *Connecting for Health: Global Vision, Local Insight*. Report for the World Summit on the Information Society. WHO.
42. World Health Organization. 2006. *The global shortage of healthcare workers and its impact*. Fact sheet No. 302, April 2006. Geneva: WHO.
43. World Health Organization. 2016. *Status of eHealth in the WHO European Region*. Retrieved September 2, 2016, from www.euro.who.int.
44. United Nations, Department of Economic and Social Affairs, population Division. 2015. *World Population Ageing 2015*. ST/ESA/SER.A (390).
45. J. Wyatt. 2005. Carrying out pilot studies on eHealth systems and services: A system that failed. *British Computer Society Health Informatics Forum*, London, UK, July 26. Retrieved from <http://www.bcs.org/upload/pdf/pilotstudies/en>.