The Use of Generative Techniques in Co-design of mHealth Technology and Healthcare Services for COPD Patients

Anita Das[1(✉)], Silje Bøthun[1], Jarl Reitan[1], and Yngve Dahl[2]

[1] SINTEF Technology and Society, Trondheim, Norway
anita.das@sintef.no
[2] SINTEF ICT, Trondheim, Norway

Abstract. People suffering from COPD commonly experience exacerbations leading to hospital admissions. mHealth technologies holds a potential for improved healthcare delivery to this group, with a possible impact on preventing COPD exacerbations. Designing appropriate technology and services for people with COPD requires an in-depth understanding of their needs, values and life situation. Co-design is an approach where users are actively involved in the design process, with democratic participation and empowerment at its center. We involved COPD patients in exploring their perspective on how mHealth technology and appurtenant healthcare services could support them. By the use of generative tools, we identified central aspects that the participants experienced to be of importance related to their health condition and disease. We here report on the main findings using this approach and on reflections on the process.

Keywords: Design thinking · mHealth · Service design · Generative techniques · COPD

1 Introduction

Co-design, also known as participatory design, is an approach where various stakeholders (e.g. end users, employees, customers and citizens) are actively involved in the design process in order to identify, create, and ensure that new solutions are according to their needs. Healthcare is a complex domain with unforeseen incidents, changing contexts, and multiple stakeholders with particular needs, interests, roles, expectations, and power. This requires a particular attention when it comes to design, development, and implementation of technology in the healthcare domain. There are a number of health information systems that have poor usability and which do not consider the contextual aspects [1, 2], due to limited understanding and knowledge about the targeted user groups needs and the products' use context. The need to get insights about user characteristics and preferences, such as insights about users experiences', emotions, dreams, desires, use contexts, and, social and cultural influences are crucial to get a holistic understanding of the targeted user group. Also, the need to explore the diverse contexts surrounding a products' use, are aspects relevant for the design development process.

A. Marcus (Ed.): DUXU 2015, Part III, LNCS 9188, pp. 587–595, 2015.
DOI: 10.1007/978-3-319-20889-3_54

The aim of the current study was to use generative tools in an exploring context, to identify COPD patients' needs, desires, and, aspects related to their health condition and daily life situation, as the first step of the design development process of mHealth technology and appurtenant healthcare service for this patient group. We here report on the main findings using this approach and on reflections on the process.

1.1 Chronic Obstructive Pulmonary Disease

Chronic Obstructive Pulmonary Disease (COPD) is one of the leading causes of mortality and morbidity worldwide (fourth leading cause of death), and incurs significant healthcare and societal costs [3]. People suffering from COPD commonly experience exacerbations leading to hospital admissions [4, 5]. Such admissions are associated with deteriorated health status of the individual and involve considerable costs for the healthcare services [4, 5]. One of the main objectives in COPD management is to improve or preserve the patients' health status. Increasingly, patients with COPD are being managed at home to reduce health-related costs while trying to increase patients' comfort [6, 7].

The use of online health applications has increased the last decade, and people use such applications to search for information, manage their own health and illnesses, and, communicate with peers and healthcare providers [2, 8, 9]. Increasingly, people suffering from chronic diseases, use the Internet and social media as important support tools in their daily life. In the forthcoming future, it is expected that healthcare providers and clinicians increasingly implement communication portals to facilitate and support patients in their daily life, in order to provide quality care services in cost-efficient manners.

A recent systematic review of methodologies and patients' adherence to home tele-monitoring in COPD, recommended future projects to assess patients' needs, characteristics and acceptance of the technology prior to implementation in order to adjust the intervention to the target population [10]. Also, the need for increased considerations to more easy-to-use technology for patients with COPD, and to explore the potential of the technology to change patients' self-management behaviour is required [8, 10].

Online health applications are potential solutions for improved healthcare delivery to this patient group with a possible impact on preventing COPD exacerbations. Finding appropriate solutions for how the new technology and the various elements in the healthcare service should be integrated, are key factors that need to be addressed for service delivery to this patient group.

1.2 Co-design

Co-creation refers to any act of collective creativity, i.e. creativity that is shared by two or more people, and is a broad term ranging from physical to metaphysical, and from the material to the spiritual [11]. Co-design is by Sanders and Stappers (2008) described as a specific instance of co-creation, and is the creativity of designers and lay people working together in the design development process [11]. Usually, the

co-design processes are led by design professionals and are used in development processes of products, services, or organizations [11–13]. During this process, there are various techniques to how to get the participants actively involved. Sanders (2002) distinguish between three approaches of interacting with users during the design process, these being what people do, say, and make [14]. Marketing research have focused on *what people say* (focus groups, interviews, questionnaires), applied anthropology have focused on observational research in *what people do*, and participatory design have focused on *what people make* [15]. According to Stappers and Sanders (2003) generative methods can be used in the design development process together with other methods in a converging perspectives approach that draw simultaneously from these three perspectives [15].

The make tools in design research, (*what people make)*, is focused on what people create from the toolkits designers provide them with, in order to facilitate them in expressing their thoughts, feelings, dreams and desires. In exploring contexts, users are involved in so called generative sessions, which inspires and informs the design team in the early phases of the design process [16]. A generative session is a meeting in which users do generative exercises; the participants are given tools such as illustrations, post-it notes, pictures, or, sets of expressive components, in order to create artifacts that express their thoughts, feelings, and ideas. For instance, this process can involve that the participants are given a "toolkit" of words or picture images, and are requested to make collages expressing good and bad aspects of the particular situation under study. As part of the sessions, the participants present and explain their artifacts and creations, to reveal their insights, anecdotes, and stories related to the topic. The results are then used as inspiration for the design team.

2 Methods

As part of the initial stage of a technology- and service design project, we conducted five separate co-design sessions with COPD patients.

2.1 Participant Inclusion and Procedure

Participants were recruited through the hospital, where a nurse took the initial contact with the patients, and where we later took contact with the participants by phone, informing them about the study and requested participation. The study got approval from the Norwegian Social Science Data Services, and all participants provided written informed consent when participating to the study.

A sample of five subjects with COPD was included in the study, three women and two men, aged 47−76 years. All were diagnosed with COPD and had been admitted to the hospital one time or more due to COPD exacerbations.

Individual co-design sessions were conducted with five participants. Most of these meetings took place in the patients' homes, except from one that took place at our office. A week before the meeting, participants received a workbook consisting of assignments about their current situation. This was to sensitize [16] them to the topic, promote reflection about their current experiences and situation, and prepare them for

the themes that would be addressed in the co-design session. The participants were instructed to fill out the assignments in the workbook and bring it to our meeting (See Fig. 1) .

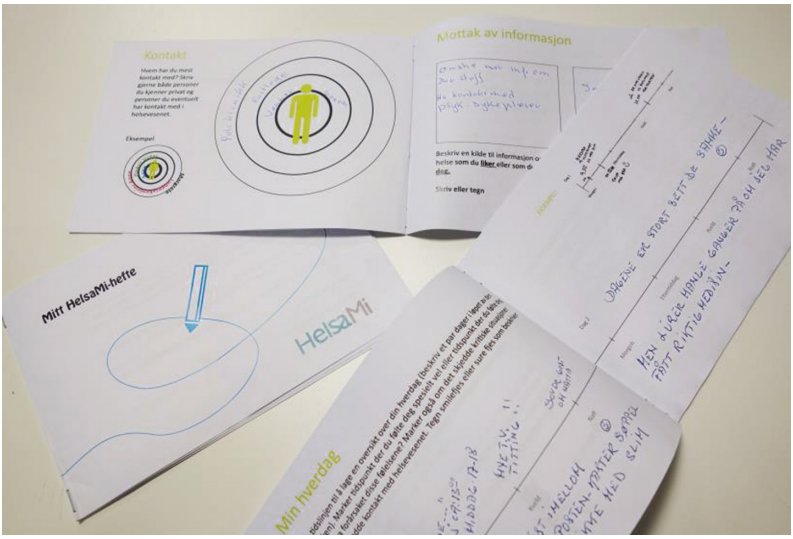

Fig. 1. Workbook that the participants completed before the individual co-design sessions

Two designers/researchers were present during each co-design session, where one had the role as facilitator and the other one as an observer. Standard procedure during each generative session was to go through the workbook before we conducted a semi-structured interview that was facilitated with the use of generative tools and activities, such as illustrations, pictures, and post-it notes. The facilitator guided the process, by asking questions and leading the conversation. The observer had the responsibility of taking notes and pictures. Each meeting typically lasted for 2−3 h each, and audio-recordings were taken during each session.

The overall theme was patients' perspectives regarding the participants' past, present and future daily life situation related to their health condition and healthcare services. More specifically we focused on their experiences, touch points and communication with the healthcare services; their needs and requirements; and technology use. Further on, the participants were to create their future scenario regarding daily life; expectations, ideas, visions, and touch points with various stakeholders and the healthcare service. Activities included: (1) construction of collages to map their feelings and experiences regarding their past and current daily life and healthcare services, e.g. used pictures and post-it notes to show previous health related and life experiences, created timeline regarding daily life, touch points, and stakeholders; (2) Making a future scenario e.g. used pictures, illustrations, and post-it notes; (3) Storytelling activities, where the participants shared their stories (See Figs. 2 and 3) .

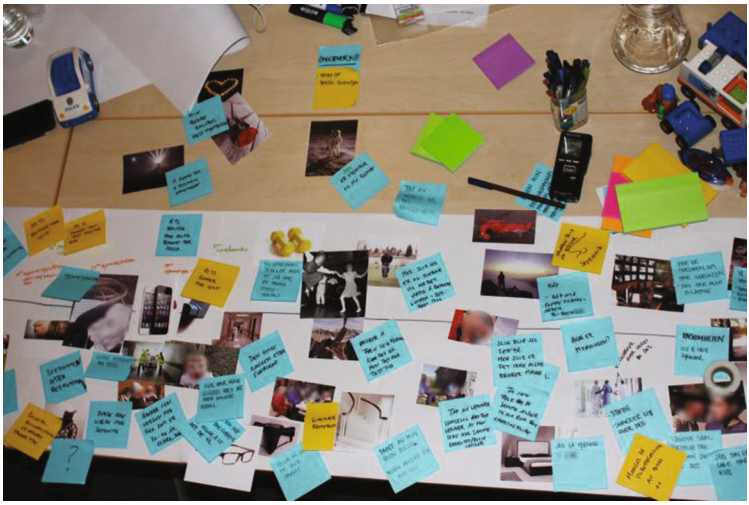

Fig. 2. A collage created in a co-design process during a generative session to map feelings and experiences regarding past and current daily life and health condition of a participant.

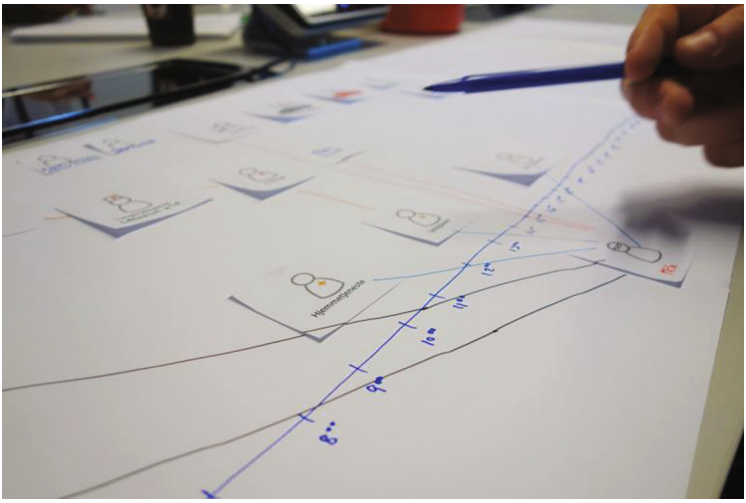

Fig. 3. Participant describing a current daily-life scenario with the use of illustrations and sketches.

3 Results and Discussion

We here report on selected key findings by using generative tools and techniques in a co-design process with COPD patients. Further we reflect on the process of using such tools with this particular user group.

3.1 Key Findings

By using generative tools and techniques we identified that the participants experienced a number of challenges related to their illness, daily life activities, and communication with the healthcare services. The approach provided us with a vast and rich amount of data, and with great details about information that the participants reported that they had not articulated before. With the use of the tools provided, the participants created their past, present and future life scenario. They created collages of current services (focusing on healthcare services) with appurtenant touch points, and, of their desires related to these services, with input on technical solutions.

Selected key factors related to this was (1) the need for information about their illness, diagnose, and about how to cope with their health condition and situation, (2) the requirement to be respected and seen as a whole person (body, mind, spirit), (3) the need to get relief when it comes to organizing health related activities in communication with the healthcare services.

(1) *The patients' need of information about their illness, diagnose, and about how to cope with their health condition and situation.*

The participants expressed the need for more information about their illness, diagnose, and coping strategies related to their health condition and daily life situation. Some of the participants perceived that getting the diagnosis was a "no turn back", with limited possibilities of improved health condition in the future. However, one of the participants had experienced to turn better, and questioned if she really had COPD, as she perceived that this was impossible having the diagnosis. All the participants expressed limited information about COPD, particularly from their primary healthcare providers. The fear of stumbling over unwanted information restricted some of the participants in searching for information themselves. The need for tailor made information according to the illness development was therefore desired, and the possibility to obtain this information whenever it suited the individual was also requested.

(2) *The requirement to be respected and seen as a whole person (body, mind, spirit).*

Some of the participants reported not to be met in a dignified manner during incidents of COPD exacerbation. The desire to be seen holistic, and not merely as the person with COPD diagnosis was underlined to be important. Their personal stories revealed a need to be respected and seen holistic.

(3) *The need to get relief when it comes to organizing health related activities in communication with the healthcare services.*

The participants had various experiences regarding different stakeholders in their daily life. Some had a spouse or a family member that took good care of them, others felt alone and experienced that their illness involved a burden that they barely were capable of carrying. Some experienced that their primary care physician was an important teammate and resource, while others experienced that their physician had limited ability to see their needs. The involved participants had all experienced COPD exacerbations and emergency admittance at the hospital. The requirement of presenting their stories and experiences to each of the healthcare professional during this process

was perceived to be extremely burdensome, as they commonly had breathing problems and anxiety in this situation. Also, having a chronic illness, they were regularly in contact with healthcare professionals, and experienced it as challenging to present their complete stories each and every time. As part of their illness management, the need for a reliable source or coordinator that they could rely on was therefore desired. An mHealth solution where key information about the patients previous medical history, medications etc. Was suggested to be a support tool for this means.

3.2 Reflections on Process

We experienced that the use of generative techniques provided a rich amount of data relevant for designing the future healthcare service and appurtenant technology for patients with COPD. The sensitizing task, the workbook that the participants had received before the meetings, was by most perceived as a good preparation for the meeting. However, one of the participants remarked that she had not understood much of the workbook, and explained that she had tried to complete but did not know if she had understood it correctly.

We found that the participants responded differently towards the use of generative techniques and tools during the sessions. Some were enthusiastic about being given the opportunity and tools to design their own future healthcare service and possible technology. Others were reserved and hesitated in taking part in these activities, but used the generative tools together with the facilitator after overcoming their initial scepticism. We experienced that in some instances it was important that we did not discard the generative tools that were planned, even thought the participants initially showed scepticism, as in most cases the participant just needed information and time to adopt and make use of them. However, in some cases it might be productive to use standard semi-structured interview methods as support, when or if the participant obviously is not capable or willing to use the tools provided.

We experienced that particularly the elderly participants were more skeptic and hesitating towards using the generative tools and techniques. This might have to do with their limited experience of such explorative and interactive approaches. Similar challenges with co-design activities with elderly are reported by Xie et al. [17]. According to the literature, co-designing with users is dependent on the end-users level of expertise, passion, and creativity [11]. The youngest participant that took part used the generative tools with great enthusiasm and also expressed that he enjoyed such approaches, as he had personal experience using such methods from his professional work. This underlines that experience, creativity, and motivation influences participation.

The participants that took part in this study were all diagnosed with COPD, but some were more affected by their illness than others. E.g. one of the participants had to use oxygen-supply during parts of the session due to breathing problems, and had limited ability to interact with the generative tools provided due to her physical limitations, but also that her health condition prohibited her from being able to do more at the same time than focus on the conversation. In these cases the facilitator was required to assist the participant, and write down or sketch what the participant wanted to express, as s/he was not capable of doing it herself/himself. Also, some of the other

participants experienced that they were not able to stand for a long time, interacting with the tools we provided them with, and therefore needed pauses during the process. Therefore, such approaches require that the facilitators are particularly aware of the participants needs, and let the participant set his/her limitations for participation.

Consequently, the sessions took more time than anticipated. We had planned each session to last one to two hours each, but almost all the sessions lasted nearly three hours each. When planning the sessions, we had been aware that we did not want to burden the participants unnecessary, and therefore attempted to make a concise plan for the co-design sessions. However, due to various reasons, such as the fact that the participants needed time and patience to conduct the activities, we had to adjust the procedures according to the participants' health condition and creativity. Also, the participants had a lot on their mind and needed time and space to tell their stories, narrations and perceptions. This required more time than anticipated. We therefore experienced it as more important to be flexible, letting the participant set the standard for how much time and space s/he needed, rather than the need to follow a rigid time schedule.

By using generative techniques in the co-design process with participants with COPD, we could identify a number of central aspects that are crucial for the design of the future mHealth technology and appurtenant healthcare service for this group. The approach provided a rich amount of data and insights about the users' needs, requirements, dreams and desires that would be difficult to capture else way. However, we experienced that enabling generative tools and techniques are not without challenges when co-designing with elderly patients with COPD. Even though we did a number of considerations when planning the generative sessions, the need to adjust and reconsider the planned activities had to be done on site during each session.

Regardless of the challenges with using the generative techniques during co-design activities, it does not imply that the most vulnerable users should be excluded from such activities. Rather, the need to identify what tools and techniques that are the most productive and ethically dynamic for particular vulnerable user groups is still needed in order to design future mHealth technology and healthcare services.

4 Conclusion

By using generative tools and techniques we identified the experiences, needs, dreams, and desires of COPD patients regarding their health condition, daily life, and healthcare services. Selected key factors related to this is the need for information, the requirement to be respected and seen as a holistic person, and the need to get relief when it comes to organizing health related activities in communication with the healthcare services. Participating in co-design activities is resource demanding, and reflections regarding the participants' abilities to make use of the tools and techniques are important to consider when planning and conducting the activities, and the need to adjust and reconsider the planned activities has to be done on site during each session. In conclusion, the most vulnerable participants might not be eligible to enable advanced generative tools during co-design activities, and designers therefore have an important responsibility to plan and create appropriate co-design sessions with particular vulnerable user groups.

Acknowledgements. This project has been a co-operation between the R&D institute SINTEF, Trondheim municipality and St.Olavs Hospital. The project was funded by The Norwegian Research Council.

References

1. Viitanena, J., et al.: National questionnaire study on clinical ICT systems proofs: physicians suffer from poor usability. Int. J. Med. Informatics **80**(10), 708–725 (2011)
2. Jimison, H., et al.: Barriers and drivers of health information technology use for the elderly, chronically III, and underserved. Evidence reports/technology assessments (2008)
3. Mannino, D.M., Kiriz, V.A.: Changing the burden of COPD mortality. Int. J. Chron. Obstruct Pulmon. Dis. **1**(3), 219–233 (2006)
4. Wesseling, G., Vrijhoef, H.J.: Acute exacerbations of COPD: recommendations for integrated care. Expert Rev. Respir. Med. **2**(4), 489–494 (2008)
5. Menn, P., Weber, N., Holle, R.: Health-related quality of life in patients with severe COPD hospitalized for exacerbations - comparing EQ-5D, SF-12 and SGRQ. Health Qual Life Outcomes **8**, 39 (2010)
6. Bolton, C.E., et al.: Insufficient evidence of benefit: a systematic review of home telemonitoring for COPD. J. Eval. Clin. Pract. **17**(6), 1216–1222 (2010)
7. Titova, E., et al.: Long term effects of an integrated care intervention on hospital utilization in patients with severe COPD: a single centre controlled study. Respiratory Research, **16**(8) (2015)
8. Borycki, E.: M-Health: can chronic obstructive pulmonary disease patients use mobile phones and associated software to self-manage their disease. In: Quintana, Y., et al. (eds.) Advancing Cancer Education and Healthy Living in Our Communities. IOS Press, Amsterdam (2012)
9. Das, A., Faxvaag, A.: What Influences Patient Participation in an Online Forum for Weight Loss Surgery? A Qualitative Case Study. Interact. J. Med. Res. **3**(1) (2012)
10. Cruz, J., Brooks, D., Marqies, A.: Home telemonitoring in COPD: a systematic review of methodologies and patients' adherence. Int. J. Med. Informatics **83**, 249–263 (2014)
11. Sanders, E.B.-N., Stappers, P.J.: Co-creation and the new landscapes of design. CoDesign **4** (1), 5–18 (2008)
12. Holmlid, S.: Participative, co-operative, emancipatory: from participatory design to service design. In: First Nordic Conference on Service Design and Service Innovation. Oslo, Norway (2009)
13. Steen, M., Manschot, M., De Koning, N.: Benefits of co-design in service design projects. Int. J. Des. **5**(2), 53–60 (2011)
14. Sanders, E.B.-N.: From user-centered to participatory design approaches. In: Frascara, I.J. (ed.) Design and the Social Sciences: Making Connections. Taylor & Francis, London (2002)
15. Stappers, P.J., Sanders, E.B.-N.: Generative tools for context mapping: tuning the tools. In: Third International Conference on Design and Emotion, Taylor & Francis, Loughborough (2003)
16. Visser, F.S., et al.: Contextmapping: experiences from practice. CoDesign **1**(2), 119–149 (2005)
17. Xie, B., et al.: Connecting generations: developing co-design methods for older adults and children. Behav. Inf. Technol. **31**(4), 413–423 (2012)