

A Participatory Design “Method Story”: The Case of Patients Living With Mild Acquired Cognitive Impairments

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Abstract - This paper presents a story on how patients with Mild Acquired Cognitive Impairment(s) (MACI) could be actively involved in Participatory Design (PD) sessions. A detailed description of what mild acquired cognitive impairments entails is given, followed by an overview of PD and how it might be relevant in the design of new Information and Communication Technology (ICT) solutions for this user group. The story on how we applied the method is presented as a description and reflection by the authors involved in redesigning the layout of a document in a rehabilitation hospital. The paper aims to attract the attention of PD practitioners to the MACI user group and trigger discussion and questions about PD techniques for patients with MACI.

Keywords-Participatory Design; Mild Acquired Cognitive Impairments; Method stories.

I. INTRODUCTION

There is an increase in chronic diseases in our ageing society and ICT is seen as means to cope with the increasing number of these patients. A notable case are individuals with chronic illness affecting cognitive capacities. For this user group, ICT has become a fundamental part of “*their daily lives by providing a wide range of useful services and tools to use at home, work, or anywhere else*” [1]. However, an essential factor for the design of these new ICT solutions is the involvement of users in the design of those solutions that will be used by them in the future. User participation constitutes the core of PD [2], and that is what we will focus on, in this paper.

The user group in focus are people suffering from mild cognitive impairments after an Acquired Brain Injury (ABI). The abbreviation “mild acquired cognitive impairment(s)” (MACI), coined from [1], will be used to refer to the user group further in the paper. Note that this is not an official abbreviation for the clinical condition.

Intensive research is ongoing regarding ICT support for patients with moderate or severe cognitive impairments [3]-[5]. However, less attention has been paid to patients with MACI and their needs, even though mild acquired cognitive impairments are a critical global public health problem and listed among the major causes of permanent impairments [6]-[9]. MACI are usually described as invisible impairments and might include problems with memory, attention, executive functioning, language and fatigue. People suffering from

MACI typically have a very challenging daily life, given the invisible nature of the condition.

This paper aims to first bring the attention of PD researchers and practitioners toward this category of patients, by sharing reflections from a PD research project conducted with this user group. Moreover, as Hendriks et al. [10] state, a good way to go forward on a codesign approach for people suffering from some form of impairments is “*facilitating researchers and designers to share experiences, best practices, lessons learned, and so on is considered very valuable*”. This approach aligns with Lee’s research [11]. She suggests that the design field “*could reflect and re-specify its research direction for design methods, especially for empathic design methods, that is, not by developing new tools or pinning-down practices into recipes, but rather towards empowering designers to be more sensitive and comfortable with the design-led, local approaches that are essential to empathic design methods*”. Thus, she suggests that designers should start presenting rich descriptions of *as it is* – what they actually did with methods in particular circumstances. She calls these descriptions *method stories*. Lee states that method stories help as a reflection tool for designers as the stories do not strip away the rich contextuality of actual use, including method application in and adaption to a specific context. In this paper, we are not aiming to present a new method and give a clear formula of how to actively involve people with MACI in PD sessions. Instead, we will share what Lee [11] calls a method story from a PD project with patients suffering from MACI. Thus, we will give a detailed description of a project that we did with patients with MACI and present some reflections and meta reflections related to that experience. The next section gives a more detailed overview of the user group, followed by a reflective section on why PD might be important for working with this user group. Further, we describe a project done with this user group in a rehabilitation hospital by the use of designer notes and methodological reflections [12], considering the reflections made before, during and after the workshops. The paper concludes with some meta reflections presented as design recommendation for applying PD with MACI patients.

II. MILD ACQUIRED COGNITIVE IMPAIRMENTS AND THE IMPLICATIONS IN PATIENT'S LIFE

In this section, we will initially describe what it means for a patient to live with MACI. Further, we will define what is cognitive rehabilitation and how this service is offered in a rehabilitation hospital in Norway, where we conducted our research.

A. What it means to live with Mild Cognitive Impairments (MCI) after ABI?

Cognition is defined as the individual's capacity to acquire and use information to adapt to environmental demands [13]. Based on Cicerone et al. [14], cognitive impairments may be seen in a) reduced efficiency, b) pace and c) persistence of functioning, d) decreased effectiveness in the performance of routine activities of daily living, and e) failure to adapt to novel or problematic situations. Cognitive impairments may be associated with cognitive decline due to normal ageing, more-serious decline as dementia, or can be the consequence of an ABI. The latest is the category of patients involved in this study.

ABI is brain damage acquired after birth. The causes of ABI can be "from a traumatic brain injury (i.e., accidents, falls, assaults, etc.) and non-traumatic brain injury (i.e., stroke, brain tumours, infection, poisoning, hypoxia, ischemia, metabolic disorders or substance abuse)" [15]. It can affect cognitive, physical, emotional, social or independent functioning. The consequences vary from mild to severe [16]. Thus, the spectrum of patients which have had an ABI is a mixed etiological group, based on the kind of acquired impairment and the severity of it.

The focus of this research is patients suffering from cognitive impairments after an ABI and with mild severity of symptoms. Eghdam et al. [1] and Nilsson et al. [17] use the term mild acquired cognitive impairment for that category of patients. Eghdam et al. [1] states that "MACI is a new term used to describe a subgroup of patients with mild cognitive impairment(s) (MCI) who are expected to reach a stable cognitive level over time. This patient group is generally young and have acquired MCI from a head injury or mild stroke." In this paper, we borrow this terminology.

Cognitive impairments often persist after the ABI, and they can significantly affect an individual's abilities to perform everyday tasks, fulfil former roles and maintain personal-social relationships [17]-[19]. Thus, patient life becomes challenging based on the severity of their injury. Often the reported symptoms are not related to specific problems. Instead, it can be in the form of a headache, tiredness, irritation, anxiety and memory problems. The patient can experience difficulties in cognitive and emotional processing, while having no or limited movement disorders and being independent in self-care [17][20].

Nilsson et al. [17] referring to the clinical definition of mild acquired cognitive impairment, in line with the *Mild Traumatic Brain Injury Committee of the Head Injury Special Interest Group and American Congress of Rehabilitation Medicine (ACRM)* presented in [21] lists these criteria for classifying a person with MACI:

- *Minor motor dysfunction/no motor dysfunction*
- *Appear to function well in social situations occasionally requiring support*
- *May have some different cognitive disabilities, mostly within the area of attention, concentration and memory*
- *May have some concomitant emotional problems*

In this paper, we will use these four points as criteria for including participants in the research.

B. Treatment – Cognitive Rehabilitation

"Cognitive rehabilitation can be defined as a learning experience aimed at either restoring impaired higher cerebral functioning or improving performance in "the real world" using substitution or compensation techniques." [19]. Cognitive rehabilitation is offered in specialised rehabilitation institutions. The case presented in this paper relates to a project that we did with the Cognitive Unit (CU) of a rehabilitation hospital in Norway.

The hospital offers multidisciplinary rehabilitation to people with complex functional impairments following illness or injury. We focused only on the cognitive rehabilitation process. The rehabilitation at the hospital (inpatient) is carried forward by a multidisciplinary team which helps the patient to define realistic and attainable goals for improvement and then define, in collaboration with the patient, a treatment plan based on the predefined rehabilitation goals. This is called the "rehabilitation plan". The rehabilitation plan is imprinted in the "goal plan" document. This "goal plan" document is at the core of the rehabilitation process in the hospital. It coordinates the activities that both the patient and the multidisciplinary team get involved in during the patient's hospitalisation period. In every activity at the hospital both the multidisciplinary team and the patient should refer to the goal plan document. The patient continues with the rehabilitation plan at home and returns to the hospital after 2-6 months for short follow up and further adjustments of rehabilitation goals.

Now that an overview of the patient group symptoms and the rehabilitation process which he/she goes through (specifically the case of the rehabilitation hospital in Norway where we conducted our research), has been presented, we further give a description of PD and how that might be relevant for this user group.

III. PARTICIPATORY DESIGN

PD was established at the end of the 1970s with the aim to democratise both the working life and the design process of new information technologies [15]. PD emphasises the idea that, those who will be affected by the design of new information technologies or digital artefacts, should get involved and have a say during the design process of these technologies [22]. PD considers users as "domain experts" of the realities in which they live, so they must undertake the role of the designers [22].

In *Routledge Handbook of Participatory Design*, Simonsen et al. [2] define PD as:

"a process of investigating, understanding, reflecting upon, establishing, developing and supporting mutual learning

participants in collective “reflection-in-action”. The participants typically undertake the two principal roles of users and designers where the designer strives to learn the realities of users’ situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them.”

At the core of PD is the idea of genuine participation in decision making. Genuine participation stands on a political rationale where the voice of marginalised groups is heard in the decision making that will influence them. Thus, designing technologies for patients with MACI require their participation in the design process. Their marginalised voices in a paternalistic healthcare system where the patient follows what the doctors says, should be raised and heard. By applying PD, patients can have a say and genuinely participate in the design of new ICT solutions which will be used by these patients.

PD is applied as a set of general guidelines which should be adapted to the specifics of the project. Equalising power relations and democratised practices, two main principles of PD, arise due to the commitment that PD has in achieving genuine participation. Another important principle in PD is mutual learning. Mutual learning enables the establishment of a common understanding among different actors by finding common ways of working and exchanging knowledge and value [23]. Only through achieving mutual learning we can have genuine participation.

In PD, a lot of research has been done regarding the active participation of people with disabilities in designing new technologies. Significant research has been done with dementia patients or specific severe clinical conditions affecting cognition (examples [10][24]-[26]). Regarding the mild cognitive impairments, the focus is on old adults or people with intellectual disabilities. Little has been done with patients suffering from MACI. Moreover, we are aware of only one paper which focus on the analysis and reflection on the techniques applied for active participation of patients suffering from mild cognitive impairments in design sessions [27].

However, as also stated in Hendriks et al. [10], researchers are adjusting common PD techniques to involve “fragile” groups in PD sessions with the designers and researchers. This requires new techniques and new PD guidelines to be considered and to emerge in the future. Moreover, as a conclusion in their workshop regarding doing PD with people with disabilities Hendriks et al. [10] suggest the sharing of designers’ experiences through method stories [11] as the best way of moving forward in the crystallisation of design techniques suitable for people suffering from cognitive impairments. Hence, in this paper, we will share the method story of our project, by giving a rich description of our activities. In order to learn from our experience, we will take a reflective practitioner stand and present a set of reflections on our process.

In this paper, we will use Schön’s [28] approach of the reflective practitioner to present some of the reflections-in-action and reflection-on-action of how PD techniques could be applied in the case of patients suffering from MACI.

Reflection-in-action is undertaken in the indeterminate zones of practice. The reflective practitioner *thinks up and tries out new actions intended to explore the newly observed phenomena, test tentative understandings of them, or affirm moves invented to change things for the better. What distinguishes reflection-in-action from other kinds of reflection is its immediate significance for action.* ([28], pp. 28-29). This is also referred to as a reflective conversation with the situation.

Schön’s use of the term reflection-on-action refers to the process of making sense of an action after it has occurred. It serves to extend one’s knowledge base. We will use reflection-on-action in two layers in this paper, the reflections made after each workshop in order to prepare better for the next workshop and reflection-on-action with the whole project as the analytical perspective. We will use the term meta-reflections for the latest.

IV. PROJECT DESCRIPTION

Above we presented the cognitive rehabilitation process in a hospital in Norway. The structure within the hospital which is specialised on cognitive rehabilitation for patients with MACI is the CU. One of the main working documents at the CU as explained above is the “goal plan” document. With the aim of empowering the patient, the CU wanted to redesign the layout of the document so it would fit more patients’ needs and consequently make the patients make more and a better use of the document during their stay at the hospital.

The authors were involved in the project in the role of researchers and designers to investigate patients’ needs and together with the patients redesign a new version of the “goal plan” that would fit those needs. Both authors worked in the preparation phase and the reflective analysis presented in this paper, and the first author participated and facilitated the workshops described below.

In collaboration with a project committee with representatives from the multidisciplinary team at the CU, we prepared and conducted three workshops with the patients. The title of the workshops was: Redesign the “goal plan”: A patient’s perspective. The workshops aim was to get an understanding of what experience the patient has had with the “goal plan” document and discuss ideas on how to redesign that document so that patients can integrate it more in the activities during their rehabilitation period at the hospital. As the document is given to the patient in a paper format, during the workshop we did not put any technological limitations, instead allowing the patient to be free to envision any solution.

A. Preparations

Designing the right workshop for people with mild cognitive impairments has specific challenges and requires thorough preparation. To plan and prepare the workshops, we worked in close collaboration with a multidisciplinary team at the CU. The team was assigned as the leading committee for this project and will be referred hereafter as the multidisciplinary project committee. It consisted of the CU staff members of different professions with high expertise and

longtime experience with the patients with MACI. We will refer to these people as the domain experts.

Before planning the patient's workshop, the first author conducted a PD workshop with the multidisciplinary project committee. The PD workshop aimed to achieve the mutual learning [23] between the researcher designer (the first author) and the multidisciplinary project committee compounded by domain experts. The aim was to trigger a design thinking mindset and make the committee grasp the PD tools and techniques. The designer had expertise on the design methods and the PD approach, but lacked a thorough knowledge of patients' clinical condition, functioning ability, as well as internal procedures and dynamics related to the usage of the "goal plan" in the hospital. On the other side, the domain experts knew the patients and their functioning abilities, but they lacked the knowledge of PD methods and techniques. Indeed, before the authors were involved in the project, the multidisciplinary project committee had planned to do interviews with the patients to map their needs.

It was difficult for the multidisciplinary project committee at the beginning to understand the aim of the workshop, but slowly they started becoming more involved. All the subsequent meetings we had with the committee or specific members of the committee had a PD approach, where everyone was heard, and the common discussion challenged ideas. The domain experts entered a more creative mindset, and the authors in the role of researchers and designers learned more about the patient's group characteristics and the work procedures at the hospital. The participatory meetings were an essential factor in mutual learning.

The multidisciplinary project committee expertise on their patients helped in "designing" better workshops. Among the things discussed in the planning phase were:

1) Timing

Based on the committee expertise the optimal workshop duration would be 1 hour, divided into two parts each of 20-30 minutes with a 5-10 minutes break in between. In this way, it would be possible to have the patient concentrated all the time, without fatiguing him/her.

2) Number of participants

The committee suggested that the maximum number of participants for workshops was 4. In this way, the patients would feel more comfortable and had the right space to share their stories and their opinions.

3) Ethical issues

We decided together with the committee that no personal patient data would be recorded. However, the sessions would be audio recorded so we could analyse the data later. The data collected through recordings are considered not anonymous (they are unidentifiable data), so they need to be stored carefully in safe a location. The project agreement was to store all the digital data for the project in a personalised folder at the hospital servers, and that is what we did. Moreover, a consent form including an invitation to the workshop and a description of the project was given to patients by the CU staff members prior to the workshop. The consent form was written in a very simple language to make it easier for the patient to follow. However, it was a detailed

and consequently long description, to make sure that all the ethical issues were covered. We agreed with the multidisciplinary project committee about the document. We were aware that the description might be excessive for the patient and could make him/her neglect reading it carefully. To make sure that the patient understood the consent form, one of the staff members at CU would spend time with the patient (that had expressed the willingness to participate) before the workshop, going through the document and provide further explanations where needed.

4) Patients abilities

A thorough review of the literature [6][9][13][14][18][29][30] about the patients' clinical condition as well as observing the patients in the unit, made clear that it is a very special user group. The symptoms were almost invisible at first sight. Moreover, this is a very diverse user group. When we discussed this with the committee they suggested to focus on the patients' abilities and how to strengthen those during the workshops. The staff highlighted the patients' willingness to share their stories and express themselves both through words and as visual imagery. Writing and visualisation was further combined in workshops.

5) Facilitators

As the number of participants in a session would be maximum four, we decided that only the first author would participate and facilitate the workshops. Discussing the issue of facilitators with members of the committee we considered an extension of the workshop team by someone from the clinical side that knows how to work with the patient group but is not directly involved with the participating patients. The committee suggested a member from the Learning and Mastering Center at the hospital, which was specialised in providing patient with a deeper insight regarding their health. The member might have met the patients during other activities around the hospital but was not part of the CU staff and not directly involved with the patients. We will refer to this as the knowledgeable third-party. The knowledgeable third-party has the right knowledge and expertise to communicate easily with the patient in case help was needed from the first author. We decided that two facilitators (the first author having design skills and the knowledgeable third-party having domain knowledge) would be sufficient in a workshop with four participants. We used the same knowledgeable third-party representative in the three workshops, so we did not need to explain the goal of the project and the methods in each workshop.

B. Workshops

Three patients' workshops with patients suffering from cognitive impairments and hospitalised at CU were organised. In total, ten patients participated. In the first two workshops, we invited patients that had been at the hospital for more than a week, so they were familiar with the document to be redesigned. Four patients participated in the first two workshops. In the last workshop only two patients

participated, who were back at the hospital for their follow up week, six months after their discharge.

1) *Workshop 1*

The workshop was organized in two parts. The first part was “storytelling”. The title was “Sharing your experience.”. The participants were invited to talk about their experience with the “goal plan” document. They were asked to think and talk about:

- When were they first introduced to the “goal plan” document? How useful was the document in making them better list their goals?
- How had they used the “goal plan” until now, e.g. in a meeting or looking at it in their rooms?
- How had their feelings toward the “goal plan” advanced? How useful was the document to keep them focused on their goals?

The second part was: “What I want my “goal plan” to look like.” The technique chosen was drawing and discussion. We asked the patient to think if they had the chance to have a personal “goal plan” document:

- How would they like that to be?
- Think about the kind of information they would want to have there.
- Think about how they could design it a way that could make them look at the document daily.
- Think about how the new design would help them in meetings with the staff members, nurses or doctors. How could the “goal plan” enhance the collaboration?

For the first part, a whiteboard with a print out of the old “goal plan” document in the middle and sticky notes in different colours were provided. The patients could use those to write down keywords to facilitate remembering what they had to say when their turn would come. For the second part, we removed the “goal plan” document and gave each of the participants a white sheet of paper, where they could design their ideal “goal plan”.

Reflection-in-action: the patients did not use the sticky notes at all in the first part, and once provided the white sheet of paper for designing, they seemed to step back. Realising the hesitation, the designer and the second facilitator abandoned the drawing idea and started bringing up the questions listed above as discussion points to elicit ideas and needs from the patients. None of the patients designed anything. However, they got the white papers back in their rooms to think about.

Reflection-on-action: Opening the workshop by asking the patients to talk about their experience with the goal plan was problematic. It made the patient focus more on their goals and their specific problems rather than the main project aim, the “goal plan” document layout. Thus, we realised that a narrower approach toward the project aim was needed.

The fear of white paper, the blank page syndrome [31]-[32], was made visible in the second half of the workshop. The patients were good at articulating their needs, but they were not able to create a visual image of their needs and consequently design ideas. They got the white paper with them, and only one of the patients came back the next day with a design suggestion and talked personally to the first author. Joyce [33] in her dissertation discusses the role of open option in creativity and finds how the openness of the design space can constrain creativity. Thus, we needed to provide some boundaries in the alternatives in order to increase the chances for creativity from the patients.

The participants had different MACI, which meant they had different levels of articulation abilities and understanding. We noticed that the patients were more focused on discussing personal goals than contributing to the layout of the document. The reflection-on-action in this issue was that more preparatory work from the staff was needed to reinstate the goal of the project to the patient to make sure the patient would have a clearer understanding of the aim of the workshop before entering the room.

After the workshop, project committee representatives met with the designer and the second facilitator and conducted the reflections-on-action as presented above.

2) *Workshop 2*

The reflections on action after the first workshop were taken into consideration before the second workshop. Thus, the nurses talked with the patients again in the morning of the workshop day, to make sure the patient understood the scope of the project. The workshop was divided into three parts. In the first part, the patients got a version of the old goal plan. Next, to each of the fields in the document, we added two icons, thumb up and down. We asked the patients to mark with thumb up those fields that they considered important for their rehabilitation. Then they discussed the choices among each other. To structure the discussion, the knowledgeable third-party facilitator started going from one field to another and asking patients for their choice. Thus, was easier for the participants to follow and contribute to the discussion. In the second part, the patients were asked to try to rewrite the fields that they found important, in a way that they thought would be easier to understand and read. The third part was called “rearrange”. In this part, the patients were asked to rearrange the fields as they wanted, add new fields or, change the structure of the document. At this point, the patient could use the template of the old “goal plan” or get a white sheet and design on it. Colored sticky notes and pens were provided. In the third part, the participants were also provided with some examples of design made by the multidisciplinary project committee in the workshop with the designer. The patient could have a look at those sketches for a short period for inspiration.

Reflection-in-action: The workshop went well. The patients liked the task-oriented approach of the workshop and they got engaged in the discussion with each other and the facilitators. They started building on the ideas of each other. If someone brought up a new idea that would also spark the discussion among other participants. We observed that the patient could focus better on the general task,

marking thumb up and thumb down of the fields in the goal plan and relate their marking to personal stories. The sharing of the stories was very important because it gave the facilitators an opportunity to ask more questions to elucidate meaning of what the patient just said.

Reflection-on-action: One of the lessons learned was that the workshop approach narrowed down to exactly the scope of the project and helped the patient to stay focused on the aim of the project and contribute significantly. While these reflections are not new, they appear very important in the case of patients with MACI. Moreover, the facilitators observed that more work in the pre-workshop phase was beneficial to prepare the patients better for the workshop and enable them to contribute better.

The workshop was organised as a future workshop as presented by [34]. The future workshops have been widely used in PD. The aim is to make people critically discuss a current situation and then envision possible improvements for the issues critiqued in a fantasy phase. After a phase of envisioning any solution, it comes the realisation phase. In the realisation phase, feasible solutions based on what the technology allows are discussed further.

In this workshop, we had a slightly changed version of the future workshop. In the critique phase our rhetoric was not regarding critique but more on what the patient liked or not. Providing both the thumb up and down options enabled the patient to think that some things needs to be improved but at the same time there are others that are extremely relevant that need to be preserved, so the patient did not enter a negative mindset. The second part of the future workshop is the fantasy phase. It was clear from the first workshop that the patient could not produce much information while moving directly to the fantasy phase. Thus, before jumping in the fantasy phase we introduced a transition phase, by asking the patient to rewrite some of the things that they thought could be better. By doing this, patients could start envisioning a better solution but still connected to the things that they knew, to the goal-plan that they had seen many times. That “teaser of future envisioning” made it easier to get involved in design in the “rearrange” part and be able design something new or on top of the goal plan or on a white paper. The white paper syndrome was defeated. Figure 1 shows some of the design suggestions provided by patients.

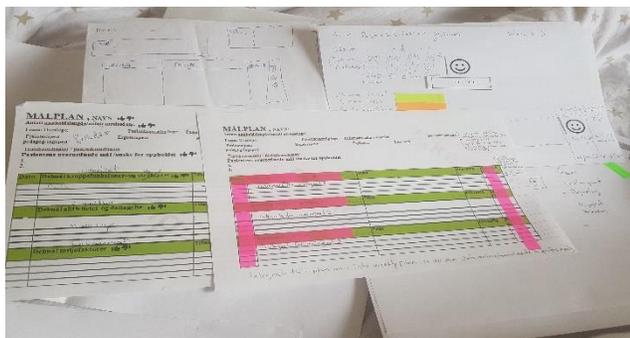


Figure 1. Workshop 2 - Patients' design suggestions

Moreover, the use of exemplars in the “rearrange” part of the workshop, might lead and influence patients’ ideas. We were sceptic about the usage of these exemplars, but we wanted to observe what their influence could be and how the patients would react toward that. However, screening the patients’ designs did not reveal a noticeable influence from the exemplars presented. Some reflections on this: First the exemplars were presented to the patients in the last part of the workshop, and the patients had already built up a mental vision of their goal plan in the previous phases. Second, the exemplars were exposed only for a short period and were a trigger for possible options of how a goal plan could look like. Integrating exemplars was inspired by research through design and Gaver et al. work with the ludic design [35]-[37]. Finally, looking at the amateur designs from the staff inspired the patients to get the colored pens and sticky notes and start designing, overcoming the fear of the white paper. However, this is a very delicate usage and more investigation of the use of exemplars in design sessions should be considered more carefully.

3) Workshop 3

The lessons learned in the second workshop helped in organising the third. As the third workshop had participating patients that were back at the hospital for a follow-up week, their cognition and understanding of the document was more advanced than the previous patients. We chose to focus more on a long perspective of the rehabilitation process and how the goal plan document could assist in that. The structure of the workshop was the same as workshop two, and the outcomes were comparable.

Reflection in-action: The two participants were of different natures. One of them was more expressive, and the other more reserved. Because of this, the facilitator had to make sure that both were getting the same time and attention.

Reflections-on-action on this part where the same as workshop 2.

V. CONCLUSIONS

We will conclude this paper by presenting some meta reflections that we did regarding our experience of doing PD with people suffering from mild cognitive impairments. Through these conclusions we aim to open a discussion in PD regarding the work with this specific user group. Moreover, some of the reflections may also be useful in other contexts.

Based on our reflection-in-action and reflection-on-action in each of the workshops our suggestions are:

- 1) *The role of the multidisciplinary project committee compounded by domain experts* - Working with patients with disabilities can be very demanding. Due to that challenge the patient is typically left out of the design process for technologies aimed for them. While PD promotes the participation of patient in PD sessions the designers and practitioner are aware of the challenges that they might face. Thus, help from domain experts

that know and have a long experience with the patients is vital for the designer. Moreover, the domain experts in most cases lack design knowledge and tends to fall in the trap of surveys as the only method to understand patient's needs. Hence, both designers and domain experts should contribute in preparations of the PD workshops for patients.

- 2) *The role of the knowledgeable third-party facilitators in PD workshops* – We observed that the presence of a domain expert that has the ability to communicate with the patients but is not directly involved with them had a positive effect. First the patient has someone from the hospital in the workshop so that they can feel safer. Moreover, that someone is not a doctor or anybody from the team that the patient is working with at the hospital, which made the patient feel freer to express themselves. Further, the first author felt more comfortable and in control of the situation with a hospital representative that would smooth any kind of situation that could be presented.
- 3) *Short workshop duration and Limited number of participants* – Keeping the workshops in one-hour sessions and with up to four participants had positive results in our case. The patients expressed that they enjoyed the participation without fatiguing him/herself.
- 4) *Avoid the white paper syndrome* – As described by [33], the white paper was a limit in the creativity of the patient. They were not able to envision a new layout. A more task oriented, and creativity evoking technique was needed.
- 5) *Positive rhetoric and the teasers of future envisioning* – Applying future workshop technique in a more task oriented and transitional way than the original version of Jungk et al. [34] made the participants more engaged during the workshop and later able to design their version of the goal plan as presented in Figure 1. We applied two changes in the future workshop technique. First, we used a positive rhetoric in the critical phase and did not only focus on critique. For instance, we used words like good and better and focused on improvement. The other difference was that we presented what we called a teaser of the future envisioning, were the participants could think about a new version of future changes but keeping that still connected with what they knew, and they were familiar with (in connection with the old “goal plan”).
- 6) *Try out the power of exemplars as a way to enhance creativity* – the usage of examples of designs needs more consideration and further study. However, we can state that it was helpful for our participants which had different MACI. It aided their creativity by making them think out of the box. Moreover, we found that the amateur examples presented helped the participants relate more to them and enhanced their ability to break the white paper syndrome and freely draw their ideas.

Finally, in this paper, we aimed to present a story of how we applied PD with MACI. We used the reflective practitioner

approach to present our reflection both in and on action. Moreover, we concluded with some meta-reflections on our process. These meta-reflections can be taken into consideration, discussed and expanded with more insights in other projects in the future.

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