

Reconnecting with Past and Present

Personalizing Sensory Stimulated Reminiscence Through Immersive Technologies – Developing a Multidisciplinary Perspective on the SENSE-GARDEN Room

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Abstract: Dementia is a degenerative disease affecting the cognitive abilities in a serious way among the persons living with it. Through different kinds of sensory stimulation, one may slow down the deterioration processes among persons with dementia. The use of personal photographs, storytelling and familiar question-and-answers in an informal setting and with informal caregivers may be very valuable. Several national health services around the world have established sensory stimulation gardens (sense-gardens), as well as sensory stimulation rooms (Snøezelen rooms). In the SENSE-GARDEN room, we build on these concepts to develop and implement immersive technologies that create multisensory stimulation – sound, sights, smells, movements. We propose technology-based tools that link the stimulation experience directly to the personal history of persons with dementia to help them reconnect with their past and present. The professional participants in the project come from different fields and have different expectations and views on the various aspects of the project. This may have affect on elements such as goals, strategies, and tasks. In this paper, we sum up our work to build a common understanding and definition of these elements. By using a qualitative approach, we have mapped the different perspectives among representatives of the professional groups involved in the SENSE-GARDEN room. The methods used for mapping and analysing these differences are described. We have discovered some *a priori* differences that mainly seem to be related to the professional groups. To some extent, this may be due to each group's tasks and responsibilities within the project, but most likely also to different professional cultures. However, through the process we have found a strong commitment to define a common ground from where the project can progress. The differences we are left with are complementary, not contradictory, and will be valuable as they allow to shape synergies within the development of various aspects of the project.

1 INTRODUCTION

1.1 The Challenge

One of the main characteristics of dementia is the deterioration of memory capabilities. This represents practical challenges in everyday life for diagnosed individuals, with capabilities in remembering how to perform daily activities becoming progressively impaired.

The ability to perform these activities on an efficient level is a prerequisite for an independent life.

When the ability to do so is restricted the person's independence will also gradually be reduced. (Holthe et al., 2017, Dooley and Hinojosa, 2004))

Dementia is a serious problem, both on a personal and on a societal level. On an individual level, it affects the ability to take an active part in one's own personal life (Nguyen et al., 2017). For society, it places pressure on resources, both on human resources within the health services, and on economic resources. The demographic changes in Europe most likely implicate that the prevalence of dementia will grow in the years to come. Both on personal and

societal levels every serious effort to meet these challenges should be regarded as important contributions.

Our lives are lived in a complex context. Our reality is not purely social or cultural, nor material or biological. Our health issues relates to social relations, genetics, biology, chemistry, psychology, economy, climate, and more.

One might say that technology is the link in this complex weave: All technology – ideally, and in its core – is designed to help people meeting different challenges. This may be done through extending, strengthen or improving the individual's capacities and competences, by replacing or compensate for capacities that are not present, available, or sufficient, or by reducing the effects of unwanted individual characteristics.

We want to explore whether – and how - we through careful use of different technologies within a SENSE-GARDEN room may be able to stimulate the memory capacities among persons with dementia so that they more easily may reconnect with their own lives. If this is shown to be the case, one might expect significant positive effects on life quality, social participation and communication with others.

1.2 Project's Aim

Several health organizations and national health services around the world – for instance in Canada, Denmark, Germany, Norway, Sweden, UK, and many more - have established sensory stimulation gardens (sense-gardens), as well as sensory stimulation rooms (Snoezelen rooms) (Cox et al., 2004, Berentsen et al., 2007). Most of the sensory stimulation gardens, however, have been gardens in a horticultural sense.

Systematic use of different stimuli has of course been used extensively through the years, and has a central place in dementia care. This goes for both photographs (Yasuda et al., 2009), videos (Capstick and Ludwin, 2017), music (Onieva-Zafra et al., 2018). However, the potential in the various technologies has not yet been fully exploited (Bejan et al., 2018; Lorentz et al., 2017, Lazar et al., 2014; Westphal et al., 2010).

The SENSE-GARDEN room proposes an innovative approach to the care of individuals living with dementia. Within the project, we will develop a therapeutic environment through blending technology together with architectural, social, emotional, and physical elements. Through this, we will provide a platform and means for creating

individually adjustable visual and sound stimuli, as well as stimuli for tactile and olfactory senses.

In the SENSE-GARDEN room, we build on these concepts, but take it further by creating a mixture of natural and technological environments, which are linked to the individual memories of the user, and automatically adapt to them. To actually design a technical solutions with the ability to adapt automatically to the users' individual preferences and capacities is one of the ambitious aims of the project, and one that calls for a creative and ground-breaking multidisciplinary approach.

SENSE-GARDEN rooms are filled with familiar music, videos and photos from known places and with known people. Pictures and videos are combined with music – such as a large image of mountains together with singing birds, for example. Smells - for example, the odour of a pine forest - are dispersed with a scent delivery system. This provides an immersive space that is automatically adjusted to each visitor, the person with dementia, creating a connection to the more active areas of the memory. Relatives will have a key role in providing information regarding the users' past life.

By stimulating the senses, we hope to create reminiscence activity in the minds of persons with dementia, which may help them to reconnect with reality – both with their own personal history and with the present moment. The underlying idea is that this will benefit not only the persons with dementia, but also their close and loved ones, as well as the health services (Macdonald et al., 2017). Most of all, our ambition is to improve quality of life and sense of wellbeing among the persons with dementia.

1.3 The Task at Hand

The project includes public and private partners in Belgium, Norway, Portugal, and Romania. Its multidisciplinary team comprises elements from a wide range of professional activities such as care-giving, medical aid, technical, law, architecture, business, research, etc. With this wide range of competencies, there also comes a wide range of perspectives on what *should* be achieved, what *may* be achieved – and *how* to achieve it.

The most important questions in establishing a common ground for the development of the technological solutions, including the technological framework, are the familiar what, how, and who.

What is this project really about? What should be the outcome? What are the key success factors? What is needed to achieve the – hopefully – common goals?

What is the new vision we can bring into the treatment of dementia?

How can a technical framework be of help to the persons with dementia and their caregivers? How shall we define and develop the right technological solutions? How can the solutions proposed be turned into real innovations? How can we be sure that all relevant competences and groups – engineers, designers, health professionals, architects, economists, informal caregivers – are represented and their competences used within the project? And how can we ensure that the voice of the persons with dementia are integrated in the project?

Then the ‘whos’: Who defines which technology is needed? Who defines which technology is the best? Who does what in the project? Who defines what is needed throughout the different stages?

And maybe more important than any other question: How can we be sure that our achievements actually will benefit persons with dementia?

The project is carried out by a wide range of professionals, within medicine, health sciences, care, architecture, technology, economy and administration, social science and more. Most important, we have been able to open up a discussion by ‘exploiting’ the different professional approaches. In this paper we describe how the basic ideas in the project has been established as a collective property within the project group. To create this kind of common platform we have conceived as important especially with reference to the multiprofessional background among the participants. From this platform, we also will describe the initial stages of the project so far.

2 THEORY AND CONCEPTS

2.1 Artefacts – and More

One should notice that our point-of-departure is a relatively broad understanding of the term ‘technology’. Any given technical artefact is part of what may be called a sociotechnical network (cf. 1.3) (Bijker and Pinch, 1987).

Within STS studies (Science, Technology and Society) the term *sociotechnical network* is used to describe technological artefacts within their relevant context, a context that can be viewed upon as a heterogeneous network where humans and non-humans are mixed together in a dynamic co-play (Latour, 1992).

This leads to the notion that one needs to take both technical and social elements into consideration to

fully understand technology, why it may or not may function in a proper way, and therefore also the prerequisites for technical development. These ‘additional elements’ are ‘everyone and everything’; they may be human actors such as designers and constructors, users on different levels and different users’ competences, other artefacts, necessary knowledge and skills, a variety of stakeholders, and so on.

In our case – the immersive sense-garden – the architecture, the different sensors and devices for distributing stimuli, computers that control the system, formal and informal caregivers, technical aid and support, health authorities, the users’ needs and competencies and more must all be brought together in a functioning collaboration to make the technology work.

This is what we have tried to take into account when we organised a seminar with the project team defining an early challenge to create a common ground. This process is described in the Method section.

2.2 Script and Program

Actor Network Theory, influenced by semiotic analysis, points out that any artefact can be said to contain a script. The artefact can be viewed as a form of text, and through narrative analysis, this text can be read. Through this narrative analysis one can extract the meaning and so it may be ‘de-scripted’ (Akrich, 1992).

The script tells us about the designer’s/ constructor’s intentions with the technology, his or her visions of what it can do, and how it should be used. This can be interpreted as guidelines for how the technology should be used – a program.

This description, this reading of the technology, this identifying of a program, is not something that we do in our everyday life. Still, on an unconscious level, maybe this is what we do after all: Facing a given technology we interpret what it can do for us, what we have to do in order for it to do what we like, and what we need to achieve this. We will find ourselves facing three options:

- We may accept the program – in the way that we can and will use it according to the designer’s intention, to achieve what we are told that we can achieve (i.e. subscribing to the program)
- We may reject the program, by just refusing to use the technology, or by being prevented from using it, not able to meet the demand of necessary resources and competencies

- We may reject the program as it is presented to us, but by redefining the program and/or reshaping the technology we may use it for another purpose or in another way according to our own needs, goals, and capabilities (i.e. creating an anti-program).

Why is this important for our project? As we want to create and implement technology that will prove to be to the end-users' benefit, we need to establish a good relationship between all relevant social groups *within* the sociotechnical network (Bijker and Pinch, 1987).

3 METHODS AND TECHNIQUES

3.1 Reflections upon Methodology

Throughout the project, we will apply a variety of methods, both in order to gather and analyse data needed for the development/construction process, and also for the analysis of effects and outcomes of the technology we implement.

Both qualitative and quantitative data is needed. To gather these data we will include tools such as surveys/questionnaires, different measuring devices, demographic and economic statistics, observations, semi-structured interviews, and through sessions of group interviews and discussions. During the project, we will gather interview data from all relevant groups within the project as well as with end-users, informal caregivers and professionals within formal health care not participating directly in the project.

Likewise, the analysis of these data obviously has to span over a wide range of analytical tools – from statistics to narrative analysis.

The overall methodological framework may be described as action research: We are introducing certain stimuli during the project. Not only as stimuli as part of the SENSE-GARDEN experience in itself, but also by introducing a new service within health care. The project aims to have an effect and an influence on the field studied, and as the project moves forward the object of our study will change, partly due to our interventions.

In the same way, since we are studying the processes as they take place, the development of the project, and the changes within it, will affect our study. The development and implementation of technology, the reconstruction of the social and sociotechnical setting, and the research project should be seen as interdependent, and as constantly influencing each other. From a research point of view, this means that the research design will have to change during the project – not only by taking into

account the changes that occur in what we study, but also by considering how the research itself may affect what is going on in the project. (Creswell, 2007)

3.2 'The Yellow Sticker Approach'; Finding a Common Ground

We now describe an initial qualitative study performed with the aim to build a common understanding between the project members. For our purpose, the qualitative approach has two main advantages: Firstly, qualitative methods are well suited to map attitudes and values so that one can get a broad picture of the actual variations in the field studied. Secondly, a qualitative approach may open, as we saw above, possibilities to initiate changes throughout the process. Whether this is the case depends on which method one has chosen.

The methodology we chose included a group session with the various professionals represented in the project team. The method was organized in two stages.

Initially we collected information using yellow stickers on the participants' views on certain aspects of the SENSE-GARDEN room, its basic concepts and strategies. This was done on an individual level, and provided us with information on the thoughts and ideas that each participant was bringing into the project. This stage may be described as a process of *opening up the width in perspectives*.

In the second stage, the group discussed the content from the yellow stickers. The individual perspectives were processed collectively, and this stage may be described as *consensus-seeking*.

4 THE FINDINGS; VARIATIONS AND ESSENCE

4.1 Findings

An initial analysis of the yellow stickers show that different views may be identified and classified: usefulness, ethical judgement, feasibility.

Through our analysis, we could see that the participants – quite loosely – clustered into three groups or personas: 1) formal caregivers and other staff from social care institutions, 2) representatives of specialised medical services and medical doctors, and 3) researchers/technologists/designers. This is reflected also through an underlying view on the relation between the user and the project itself.

4.1.1 Variations

As we went through the keywords that were given on the yellow stickers, we saw that they could be seen as positions along a continuum from ‘the active’ patient to ‘the passive’ patient. Many of the keywords referred specifically to what the project can ‘deliver’: ‘Help’, ‘give support’, ‘provide better health’ – implicating that the project itself can be seen as a provider and the person with dementia as the recipient.

On the other hand, we found keywords on how the project may affect the patients so that they can be active participants in improving their lives. These keywords contained, for example, terms such ‘empower’ and ‘stimulate’, terms which imply that a central goal within the project is to support and encourage the user to be a more active participant, to provide them with opportunities to use their own resources to improve wellbeing and life quality – to be an *active patient*.

It should be noted that these differences were more of a complementary character rather than contradictory, but still with some different notions of the relation between the project and the patient.

We understand this mostly as an effect of the different tasks these groups are expected to take care of in society. The medical doctors, for instance, possess some highly specialised competences – these are primarily meant to be used on behalf of or in the service of the sick person, rather than to be spread to and adopted by the patient. For the professional caregivers, the interaction with the patient and his/her primary network is essential – to establish a close, although not private, relation with the person that is in need of care. Finally, technology developers and designers focus on creating something for the user. Doing so, they know that one needs to take the user’s perspective into account, to be sure that the solutions will work for him or her.

4.1.2 The Essence

The process led to identifying common keywords: “emotions”; “reconnected”; “their social relations/their life”. In the end a common essence, an expression capturing the goal of the project with a consensual agreement, was achieved: “Emotions reconnect us”. We therefore could see how the professional groups were able to define a common ground, instead of letting unnecessary controversies dominate the collaboration throughout the project period.

The arrival on a common platform grew out from the group discussions. Through the discussions, the



Figure 1: Word-cloud extracted from the brainstorming.

various views and ideas were presented and elaborated, for then to be validated by the group. In this way we achieved two things: We became able to construct a common understanding, and achieved a kind of collective ownership to the final findings and conclusions.

4.1.3 Sociotechnical Networks

Through our analysis, we confirmed that the perspective of sociotechnical networks, with the conception of how different artefacts and social elements together form a functional technical solution, seems very fruitful. This was an overall understanding among the professionals, however different their basic tasks and views were. The concept highlights the importance of bringing together all the relevant social groups within the network so that they may be able to reach a common understanding.

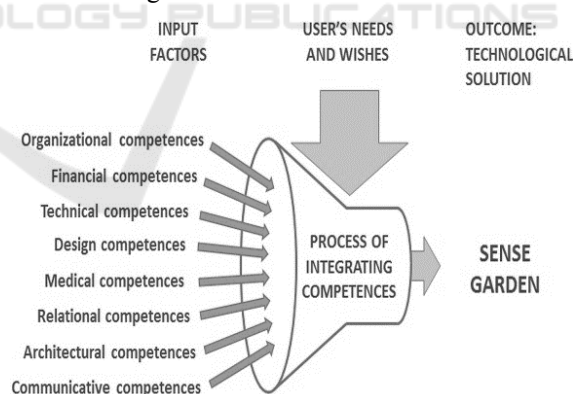


Figure 2: Translating different competences into one unified solution (inspired by Latour, 1988).

The process of reaching a common understanding can, with reference to Actor Network Theory, be described as a process of *negotiation* and *translation* (Bijker and Law, 1992). Different competences and basic views from the different professionals are negotiated between the participants, and translated accordingly to fit into an emerging common platform.

The overall ‘negotiation guideline’ is the reference to the user’s perspective. How the competences are to be translated to form the basis for the further work has to take this into account. In the end, the critical factor for evaluating a given technical solution is whether it will function *for* the user within his or her context.

5 DISCUSSION

The project challenges the way we look at dementia – an innovative view on dementia treatment, one that engages the patient and reconnects her or him to reality. In the SENSE-GARDEN room, we will develop and implement immersive technologies that create multisensory stimulation – sound, sights, smells, movements. By doing so, we go from standardized designs to personalized solutions. By linking the stimulatory experience directly to the person’s own history, we may have an even stronger tool for helping persons with dementia to reconnect with their past – and through this their present life as well: Activities, values, family, loved ones, etc.

In projects like this, the different groups of participants will typically have somewhat differing expectations and views on the foundation of the project. This will affect perspectives on elements such as goals, strategies, and tasks. To achieve success in the project, it is necessary to reach a common understanding of its basic concepts. We have attempted at building a common understanding and definition of these elements. By using a qualitative approach, we have mapped the different perspectives among representatives of the professional groups involved in the SENSE-GARDEN room. In this process, we have discovered some *a priori* differences that mainly seem to be related to the professional groups. To some extent, this may be due to each group’s tasks and responsibilities within the project, but most likely also to different professional cultures.

The user-perspective is crucial when developing and shaping technology in general, but even more so when it is a strong emphasis on personalization or individualization of the technical solutions. You can’t personalize without knowledge about, and from, the persons in focus.

6 ACHIEVEMENTS AND FURTHER WORK

What has been achieved? Within the project we have developed a common understanding, but still managed to take care of the complementary differences between the participants. In this respect, we have a very good platform for our further work.

Users and informal caregivers have been included in the project, and 50 interviews have been carried out. This number will be extended, and we will follow the user’s experiences with the SENSE-GARDENS as they unfold. This will be important data, and supplemented with other types of information as well. This variety of datatypes will help us to continuously develop the project further.

We have developed and built the first virtual SENSE-GARDEN prototype in Belgium. More are in progress, and will be taken into use as they are completed.

As mentioned above we have an ambitious project with respect to develop a method for individualized stimulation of senses, where possibilities for this is built directly into the technology. To further develop these solutions are the main task in the further progress of the project.

We have also an ambitious task with reference to how we shall measure the outcomes of this project. This is a challenge not only in our project but in most projects dealing with health, well-being and quality of life. To further develop these methods of measuring are therefore also an important tasks to be addressed. It seems clear that no single datatype or no single research method will be sufficient to provide a full picture of the knowledge generated in the project.

To develop and implement welfare or assistive technology is a truly multidisciplinary task. It depends on a wide range of professionals with different backgrounds, and therefore different perspectives and expectations. However, these differences are more of a complementary character rather than contradictory, and can help in the creative process. In the SENSE-GARDEN the fundament of the work is not only to develop the technical solutions, but also to lay the foundation for the technology to be taken into use.

In addition to the professionals directly involved in the project, there is a vital necessity to establish a close collaboration with both the persons with dementia and their informal caregivers. This process is known as users’ co-design, and is also being used in SENSE-GARDEN. This will be the focus of another paper. Inclusion of the users’ perspective is essential to ensure that the outcome of the project will

actually benefit them. In the end, it is the users that may define the outcome as a success or not – depending on whether the solutions can and will be used, and whether they actually improve the users' sense of wellbeing, their reconnection with and participation in their own lives, and their quality of life.

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