DEVELOPMENT OF A DESIGN PROCESS TO DESIGN FOR PEOPLE WITH DEMENTIA AND THEIR EXTENDED CARE NETWORK - LEARNING FROM A CASE STUDY

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ABSTRACT

In Europe we face an aging society with a growing number of people suffering from dementia. This challenge we face as a society, because current healthcare systems are not ready for such an increase.

In this paper we propose a new design process to find new opportunity areas using an interactive experience flow based on the dementia care chain. This overview is based on multiple perspectives in the care chain, and reflects the different experiences people have in the process.

Design for dementia is difficult as user-driven techniques are challenging to apply with the impaired user group, surrounded by an extended network. The methodology proposed shows how we can include the shared perspective of all the people involved (including users). And in this way develop a design proposition together iteratively.

In the case study, about the design of a physical activity reminder, the methodology is illustrated and explored. It shows the overall design process is promising, arguing to use the methodology for future design projects as well. Eventually we aim to improve the quality of life for people living with dementia and keep them at home longer to unburden healthcare systems.

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1   INTRODUCTION

1.1   Global challenge

In this paper we develop and portray a design process to contribute to the lives of people living with dementia, which includes both patients and caregivers. Dementia is a progressive cognitive disease, which gradually deteriorates the brain. Dementia is often seen in older adults, and there is currently no cure available.

The number of people with dementia is globally increasing, which proposes one of the main societal challenges of the near future (Alzheimer's disease international, 2009). The number of people with dementia is expected to double by 2050 (Kinsella et al, 2009). New solutions to keep people living with dementia at home are needed, as current healthcare systems are not ready for this increase (Prince et al, 2010). The challenge is to create solutions that enable extended living at home while maintaining a high quality of life. Design plays an important role in providing an answer to such challenges; designers are able to identify new opportunities and create new design propositions (Martin, 2009). These are skills that complement those of the traditional players in the dementia health care domain.

1.2 Problem context

Dementia has a different impact on every individual; a design proposition has to take this into account (Wey, 2006). Over the course of the disease people with dementia loose basic cognitive abilities like social interaction and learning. Therefore, design proposals for a person with dementia have to be simple and need a minimal learning curve.

Current design solutions for people living with dementia often focus on moderate to advanced dementia, while studies seldom involve people with onset dementia (Topo, 2009). Design for early-onset dementia provides an opportunity, as the deterioration of the mind is still manageable, and they can still learn new things (Germano and Kinsella, 2005). Supporting the early stages of dementia might help to extend the time they can live at home while the disease progresses.

An example approach is context-awareness (Vogt et al., 2012) in which intelligence is put in the environment, unburdening a person with dementia. Yet such a solution is only focused on the person with the disease. Typically solutions for people living with dementia are different from regular products and services, as they need to be used not just by the people suffering from dementia themselves, but also by their caregivers. Over the course of the progressive disease the amount of people involved in the care process increases. In order to achieve higher-level goals like keeping people with dementia within their home environment, design propositions need to be supported by this extended group of caregivers (Pol and Ville, 2009).

1.3   Study objectives

This paper contributes to the design process of usable and accepted products or services, from identified opportunities, for an impaired user group. This is done while considering and including the extended care network in the design process. In this paper the design process is developed and illustrated through a case study of the design of the PhysiCAL, an activity reminder calendar. The approach in this paper is explorative and gathers qualitative insights and learning on whether such a design process is feasible and desirable.

In this paper we apply a research through design approach in which we step-by-step propose new prototypes and models through design iterations, by this we are also looking at the *how to* of the design approach.

In the iterative design process we use a user centered design approach. Dealing with a cognitively impaired user creates a need to adapt the design process. Such approaches often only include the user (or in the case of dementia, patients suffering from dementia), in the complex environment of dementia many more indirect users can be identified, which should also be addressed to make the design appropriate and acceptable. The most important, often forgotten user, is the caregiver providing full time care (often the partner), yet other members of the care network, such as the care institute and the local municipality are affected by new interventions as well. In the case study we deal with these factors, the impaired user and their care network. We propose a design process in which they influence the design process and thus the resulting design.

2   METHODOLOGY

2.1 Research-Through-Design approach
In this project we use a research-through-design approach (Zimmerman et al, 2007). We intend to generate knowledge through a process in which both the act of designing and the act of evaluating designs play an important role (Hoven, et al., 2007). Through this we aim at both exploring the practical application of the proposed theory (an assembled and adapted design process), as well as to generalize the knowledge to develop the theory.

2.2 Development of a new design process
The proposed design process is illustrated in figure 1. The process, building on existing design approaches and methods, contains three phases:
1.   Translating an opportunity frame into a design scope.
2.   The iterative design of a proposition including the user and the extended care network.
3.   Development and evaluation of the resulting design scope and design in real-life.
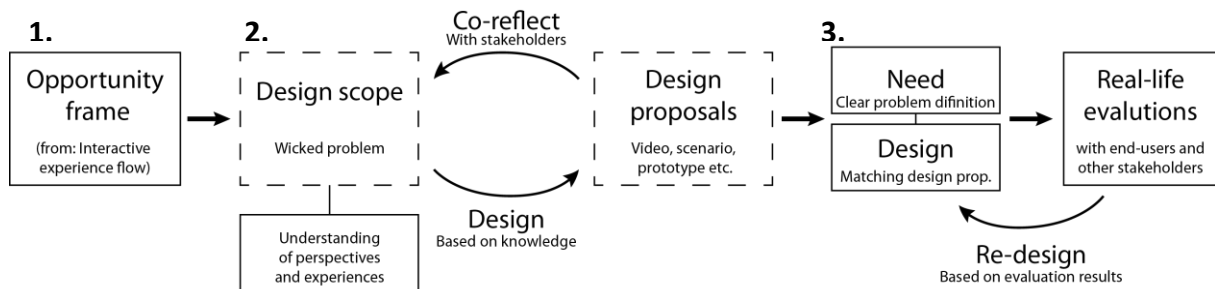

Figure 1: Visual overview of the proposed design process methodology.

Phase 1: Translating an opportunity frame into a design scope
The aim of this phase is to define a first design scope as starting point for the design process. To find an opportunity frame, proven research techniques used to identify personas and customer journeys (a.o. Zaltman, 2003) have been extended to an Interactive Experience Flow (IEF). The IEF provides an overview of the multiple perspectives in the different phases of the dementia care chain that was derived from user and expert interviews (Alblas et al, 2011). The IEF contains different personas that represent typical groups of patients, as well as the different people involved in the care for the patients. Personas are fictional characters that represent a (user) group, creating a shared understanding of the needs and goals of this persona (Markopoulos et al., 2008). The IEF also contains the stages of the progressive disease and highlights transitions between the different stages and the resulting impact on the care network. The overview allows for an exploration of the different stages in the dementia journey and provides insight in the unmet needs and context in the specific stages. In the overview the stages of dementia and a fictional path personas go through can be followed. The focus is on experience of the various people involved in each of these stages. The IEF allows designers and researchers to explore the dementia care process and network, and based on this have their own interpretation. Designers' insights are combined in an opportunity layer, which show, mapped on the overview, the unanswered opportunities and new challenges for the future. For design or research in this area, a single perspective research tool will only lead to single perspective solutions. The IEF enables a multi-perspective view and therefore reveals new opportunity areas. This approach enables a focus on achieving need-driven innovation bypassing incremental improvements (Verganti, 2008).
The IEF is used to define the design scope by selecting an unmet need. It also provides a context for the design by not only providing insight in the particular stage of the need but also of the subsequent stages of the dementia journey, which is relevant when aiming for solutions to extend living at home with a high quality of life.

Phase 2: The iterative design of a proposition including the user and care network
In this phase the design scope (design incentive or need) is defined and iteratively developed through design proposals. The design scope has the characteristics of a "wicked problem" (Martin, 2009) a marginally defined problem, which requires extra attention to the problem understanding. To address

the "wicked problem" apparent in design for dementia, the design process is based on a user-centered design approach, realized through constant dialogue with potential end-users (including members of the care network) during an iterative design process (Markopoulos, 2008). Often only target users are involved in such processes, involving other stakeholders is vital, especially in the complex field of dementia healthcare. The goal of the design process is a potentially viable and accepted design. Acceptance can be researched through user evaluations (see also Phase 3). For an indication of the viability of the proposition the impact and realization process have to be analyzed together with experts from the field and the extended care network. Therefore they have to be able to influence the design process, already from the beginning.

A co-reflection methodology (Tomico, 2009) is chosen as a method to have this dialogue with potential users and members of the care network, continuously through the design process, to achieve this user-centered design process. The design proposals are used to explore and develop the understanding of this problem context (Cross, 2006) through evaluations with the users and care network. The reflections steer the design iterations, an increase in the appraisal of the concept in the evaluation indicates the end of this phase.

User-driven methods require participation of the end-users in cognitive intensive sessions, which is difficult for people diagnosed with dementia. Some recommend professional caregivers as spokespersons for people suffering from dementia in the challenge of designing assistive technology (Orpwood et al., 2004). This is a valid approach for medium to progressed dementia, as in these more advanced phases professional interventions are more frequent. In early-onset dementia people don't have many interaction with professional care, and the caregiver (often the partner or close family) becomes an optional spokesperson. Baker et al. (2003) recommend using the caregiver as proxies for the people suffering from dementia, to decrease the burden while maintaining a representative output. Other research (Ettema et al., 2005) state people with early-onset dementia are perfectly capable to express in situ experiences and opinions. For this reason we choose to include both. This is what we call the shared perspective, to combine the first and second perspective, in the co-reflection sessions, as well as the design evaluation in Phase 3.

Phase 3: Evaluation of the resulting design scope and design in real-life
The aim of this phase is to evaluate and reflect on the proposed design in real-life. In the development of assistive technology for people with dementia there is a need to evaluate new concepts in a real-life setting (Bharucha et al, 2009). Therefore the resulting design proposition is evaluated within the home environment of people living with dementia. This improves the ecological validity of the final design (Koskinen, 2011). The evaluation is used to verify the resulted design scope and design proposition. The evaluation phase contains three steps: 1) A need assessment with people living with dementia, to find the specific needs in the household, 2) Experiencing the proposed design (through a prototype) and 3) Reflection sessions to both find indicators for redesign and other opportunities.

The results are used to evaluate the effect of a design in comparison to the needs evident. In these sessions we can find out to what extend the design is fulfilling needs, and whether the design is relevant and usable. This reflects on the design process, and gives indicators for development.

3 CASE STUDY: DESIGN AND EVALUATION OF THE "PHYSICAL"

A case study is presented to concretize the approach of the above described design process, and show a practical application. This case study illustrates the application of the explorative approach, but is also used to further develop the proposed design process based on the results.

3.1 Phase I: Interactive Experience Flow to design scope

The choice for using the IEF tool arose from struggles in finding appropriate insights in the dementia process, as information is scattered and no overviews providing an integral perspective are available. Especially in design for dementia there is a need for a helicopter view involving all the different people involved in the care of dementia.

From the IEF an opportunity was chosen within the early phase of dementia; assistive tools in this area are rare while there are evident needs (Rasquin et al., 2007). In the chosen "arrange" phase (Table 1) people struggle with accepting the disease, and have a desire to maintain their independence as long as possible. In our design approach this collection of issues, among others provides the opportunity frame (Brankaert, 2012/13-1-2013).

Through qualitative sessions with professional care providers and people living with dementia a design scope was defined based on this opportunity frame (see also Table 1). Several issues become apparent in the sessions, where the most recurring are: Safety for the person with dementia (reassurance for the caregiver), independence for the caregiver and the person with dementia and a need for activities for the person with dementia. This shows the design scope is the translation of an experienced issue into a design incentive.

Table 1. Opportunity frame in the interactive experience flow for dementia.

	Opportunity
Arrange phase	…. A person with dementia changes in role from somebody of the same level, to a person who has to be cared for. This is psychological load for both caregiver and patient. Arranging a plan for living and other basic needs. The dementia is mildly progressed and small issues (at first sight) rise. The first memory problems are evident, and for people with dementia the loss of independence is a struggle. The caregiver worries about safety and difficulties to find suitable activities in the home environment becomes a problem …

3.3 Phase II: Co-reflection with multiple stakeholders

The goal of the co-reflection sessions is developing the design and the design scope, through design iterations of developing representations (videos, scenarios, prototypes etc.). Eventually the goal is to achieve a defined design scope and a fitting design concept, which have been co-developed through the iterations. Within the design process different members of the care network, relevant in the "arrange" phase, are integrated in the sessions. The involved members all have their specific relation to dementia. Table 2 shows their role (from the IEF) and their perspective on the specific phase. As we aim for a user driven approach, we limit the selection of stakeholders to potential users of the product or service, and those directly influenced by it. In the case of dementia these are not only the people diagnosed with dementia themselves, but also informal and formal caregivers. For the business viability of the concepts a much wider network of stakeholders would have to be included (e.g. including insurance companies, regulatory bodies).

Table 2. An overview of involved members of the care network and their perspective (summarized)

Members of the care network	Involvement	Perspective in this phase
People with dementia	Target group	Maintain independence
Informal caregivers	Extended target group	Safety, care effort, planning and activities
Professional caregivers	Providing (daily) care	Efficient care, wellbeing of patients
Care institution	Organizing care	Efficient care process, regional networked support
City municipality	Community support	Community wellbeing, Community support services

In several iterations (Table 3) the stakeholders participated in co-reflection sessions on specific design representations, matching the design scope. For example in the first iteration the design proposition, an explorative video prototype, shows how assistive technology could be integrated in currently available hardware (smartphones, tablets etc.). The results showed that touch screen interfaces were difficult and confusing for elderly with dementia, as recent research confirms (Armstrong et al, 2013). It also reveals that people suffering from dementia experience a difficulty to interact with unfamiliar things. Based on these qualitative results, the design scope evolves. This specific iteration teaches us that concepts should be embracing a physical part and that including reminiscence, the theory of recalling memory by sensorial input (Woods et al, 1992), could support the design. The other iterations, visible in Table 3, narrow the design scope and design propositions further down. Over three iterations the final design scope was found with an interesting design proposition.
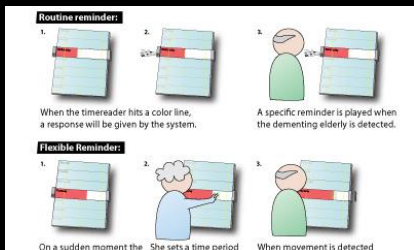
	Starting Design scope	Design proposition format	Design proposition	Shared perspective	Second perspective	Third perspective
Iteration I	Design fulfilling the most urgent needs in the opportunity frame: Safety, activity and independence	Video Prototype	Monitoring of elderly and suitable activities provided through tablet and phone interfaces	Tablet or phone interactions are too difficult. Idea of continues monitoring not desirable.	Useful to be able to monitor person with dementia, interface provided are still difficult to use.	Smartphones and tablets are not integrated in the target group (yet). Difficult to create a business model.
Iteration II	Achieve the goals, set earlier, through a specific action our goal to integrate the goal in daily routines of people living with dementia.	Scenario sketches	Physical activities, tools to stay in control of daily tasks with a focus on safety and independence	If they do not see the use of interacting with an object they will not do it. There is a need for focus.	Even in early phase there is agitation and room for design. Simpler design is better.	Realizable if product is for sale in a store, and fulfills a specific need.
Iteration III	Focus on activity and independence in a redesign in the context of the white boards already available at homes.	Working Prototype	Physical scheduling system inspired by schedule white boards to remind of activities	Promises to be a reminder for important things needed. Interaction has to be as simple as possible!	Neat tool for patient, and usable but not necessary by caregivers. Should not put burden on professional care.	Effects of system have to be proven for insurance support. If for sale in store numbers have to be high to enable affordable product price.

Table 3. Summary of results during the design iterations co-reflecting on the different design propositions

3.4 Design proposition: The PhysiCAL concept

The resulting design proposition is the PhysiCAL, an activity calendar (see figure 3), which provides a memory cue in the home environment for crucial activities and tasks at home.

Figure 3. A picture of the PhysiCAL proposition being used in the home environment.

The PhysiCAL calendar shows an entire week with the weekdays clearly visible in a schedule (E). On this calendar activity tags (B) can be placed, representing things to remember. An arm bar (C) moves vertically to indicate the current day. Time is represented by a time indicator (A), which moves from left to right. When it passes an activity tag, a signal is given. The time indicator lights up, and an audio signal is played through the speakers (F). The system notices when somebody is in front of the system, with a sonar sensor (D). In this way the device knows when somebody is in front of it, and stops providing a signal if so. The design introduces a familiar shape, based on the regular whiteboards already used, and adds technology. Without taking over control, it provides a tool to maintain independence. The system works as a platform, and the people living with dementia can decide for themselves for what purpose they would like to use it.

Overall, the PhysiCAL calendar is a design reflecting apparent needs in the context of people living with dementia. It can be used to provide more independence, be a time reference and acts as a physical time management tool for both people with dementia and their caregivers.

3.4   Phase III: Design evaluation in real-life

For the evaluations in real-life of the PhysiCAL, a prototype was made. In the evaluation sessions (n=4) a qualitative approach was used to generate results in context of people living at home with dementia. As a test group, couples living at home independently are asked to participate, from which one person is diagnosed with dementia. All couples signed a consent form. All the people diagnosed with dementia were in an early stage of the disease, and thus able to discuss. Allowing for a shared perspective reflection.

Step 1: *Introduction to evaluation process and need assessment*
In this step the evaluation phase was explained as well as the prototype. The need assessment showed regular problems that occur in the early-phases of dementia at all four couples. Which are forgetfulness, struggle with accepting the disease and worries about the near future concerning safety and planning. Other needs that were found related mostly to individual physical problems related to general aging, for example impaired sight and hearing.

Step 2: *Experiencing the prototype in the home environment*

For the evaluation of the prototype in these home sessions, the couples were asked to use the product at home as they desired. All couples participated, however the number of days using the prototype varied. The caregiver was asked to conduct a daily questionnaire to capture the shared perspective. The daily questionnaire was short and focused on usability and desirability.

The most important results of these daily questionnaires were in two categories. One on the functional attributes of the prototype, and two on the concept in general. The prototype was for all participants (except one) to big, and the quality of the sound was too bad for all users. These are elements that have to be improved in future iterations. On the concept in general the remarks were more positive as all couples expect one could imagine they could use such a device in the near future.

Step 3: *Reflective session to evaluate the design.*

As the tests were of an explorative nature this reflective session allows for an open conversation with both people suffering from dementia and their caregivers. In this open semi-structured interview a questionnaire was used to support the researcher to capture insights. This questionnaire contained three sections: General innovation, re-design opportunities for the PhysiCAL and a final reflection on the overall evaluation process.

In general all couples liked participating in the study and wanted to contribute to innovations for dementia in general. For the redesign opportunities the results were similar to the daily evaluation focused on size and sound quality, but also on the precise positioning of the tags. Most couples stated they don't need it in their current situation, as they could still manage. The overall process and prototype was assessed positively.

3.5 Ethical considerations

During the case study, the researchers cooperated with a care institution. The care professionals supervised the early explorations, provided expert input and supervised the home evaluation sessions to make sure no harm was done to the integrity of the participants.

4   DISCUSSION

4.1 Interactive Experience flow to define an opportunity frame

The IEF revealed new opportunities that would not have been discovered by focusing solely on the disease or a single perspective tool. Moreover, it provided a common ground for the extended care network to create a shared perspective on opportunities, potentially resulting in products based on shared values (Ballantyne et al., 2010).

As the IEF is specifically focused on the Dutch dementia care chain, the resulting design scope and proposition might only be appropriate in this context. The user-driven needs might be depending on cultural values or practical issues, and thus might reveal different results. It might be useful to make IEF's for other countries, also to be able to identify common opportunities.

4.2 Co-reflection with users and other stakeholders

Next to choosing an opportunity frame, the IEF supports identifying the relevant parties to be incorporated in the co-reflection sessions, which provide different perspectives. The sketches and early design propositions support the process of considering, revising, developing and rejecting with different stakeholders (Cross, 2006), in this process the designer found unmet needs (Alblas et al., 2011). The designer also functions as an integrator of these perspectives in a design proposition, allowing progressing insights and experience from the involved parties to be included in the design. Thus contributing to the process of 'making sense together' (Thompson Klein, 2004). Progressively shared meanings, diagnoses and objectives emerge, individual interests and needs are seen in a different perspective.

While it is evident the different parties had influence on the design process, this doesn't reveal the viability of the design and therefore the design process from this perspective. A good indicator for viability could be the commitment of the different parties in the care network, or the willingness to support new services in a trail. Currently we cannot exemplify such a viable business case, and thus a continuation of the research is necessary.

4.3 Design process – learning and development

Designing from an opportunity frame reveals a new approach to design for people living with dementia, and contribute with meaningful solutions to the global challenge of a growing dementia population. The results of the evaluation show the design is relevant for the user group. Even while the evaluation was conducted with a limited number of participants, we succeeded in exploring the potential. In design for an impaired user-group such results over three design iterations are promising, and show potential for a user-centered design approach, including multiple groups. More evaluations are needed to verify the design proposition, and with it we can argue stronger for the design approach. After a validation from the user, other design tracks are necessary to find out what the application area of the design process is. Currently the tool is only used to design a product, in future trails we might find out how the IEF based process works for service design. Currently we propose a combined design process, linking existing methodologies, and creating a new one. The explorations show, as mentioned earlier, the potential of this combined design process. Yet the separate parts need to be investigated further as well to reveal how all the design phases contributed individually, and see how they jointly generated the outcome.

5   FURTHER RESEARCH

The project will continue with three objectives; Firstly, we want to further validate the design of the PhysiCAL through more evaluation sessions; by this we can make a stronger argument for the design and the design process. Secondly, we want to include more potential business stakeholders in the evaluation process. In this way we are going to explore if this design process can be developed to design viable products ready for the market. Finally, we want to pursue more design tracks based on other opportunity frames in the IEF, and generalize the theoretical model of the proposed design process. Other new design scopes with matching propositions might reveal more strengths and weaknesses, making a stronger case for the design approach.

Extending the IEF tool might improve the tool for design and research. A rating system, based on the need-assessments might provide a priority overview of the opportunities. Making it easier for the people using the IEF to choose an opportunity frame.

Also adding different business models that are viable for different type of products and services could enrich the tool to create an efficient design approach. A continues growth of insights in the care network, and deeper knowledge on the disease will increase the quality of the tool. And eventually the approach might be used for other diseases and global challenges as well.

In summary, the project's aim is to continue real-life evaluations and co-reflection sessions within the extended care network to develop products and services to be able to judge their desirability and viability. By developing such a design process we can accelerate the innovation process and design for global challenges like the growing number of people living with dementia.

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