

Using Cultural Probes to Inform the Design of Assistive Technologies

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Abstract. This paper discusses the practical implications of applying cultural probes to drive the design of assistive technologies. Specifically we describe a study in which a probe was deployed with home-based carers of people with dementia in order to capture critical data and gain insights of integrating the technologies into this sensitive and socially complex design space. To represent and utilise the insights gained from the cultural probes, we created narratives based on the probe data to enhance the design of assistive technologies.

Keywords: Cultural probes, Assistive technology, Dementia, Design.

1 Introduction

‘Cultural Probes’ were first developed by Gaver et al [2] as a research method to design technologies for the home. It is a technique that is used to inspire ideas in a design process and serves as a means of gathering inspirational data about people’s lives, values and thoughts. There are several ways in which cultural probes can be implemented and interpreted. In the case of design teams, they can be seen as a tool to help build a rich picture of the lives and experiences of potential users of products.

Cultural Probe investigations involve giving participants a package of artefacts (such as a map, postcard, camera or diary) along with instructions to perform tasks such as recording specific events, feelings or interactions. The packages are designed to provoke responses to help designers better understand participants’ culture, thoughts and values. There are several common features in cultural probes [1]: The process is inherently participatory as participants are the active data contributors, rather than passive study subjects; probes can make details of familiar events noticeable by capturing the significant aspects of everyday actions, places, objects and people; the artefacts which can be used, such as cameras, maps, diagrams and postcards, are engaging tools that allow participants to capture image-rich responses;

probes document people's lives by merging diary narratives with photographs to elaborate stories of people's lives and daily routines in an autobiographical format; wishes, desires, emotions and motives can be aggregated as personal meaning and connotation to the data; probes can facilitate dialogues between researcher and participant by reducing the power imbalance between them [3].

Cultural probes can be effective as they elicit evocative responses from participants during the data gathering phase. Traditional approaches of data gathering that rely on methods such as observations, focus groups, interviews and questionnaires contribute meaningful knowledge only focused on the design team's perspectives, which do not always adequately reflect participants' concerns. This informational gap can be resolved by utilising cultural probes as a research method to allow participants to determine the focus of some of the elicitation activities, and help designers gain a deeper insight into people's lives that may not otherwise be considered [2].

When carrying out an investigation using cultural probes, it is imperative to keep the focus open to encourage participants to highlight issues from their own viewpoints without being directed by the objectives of researchers. It is an approach that values uncertainty and ambiguity, and detects inconspicuous data in the studies. Furthermore, the collected stories can often lead to unexpected insights, which can inspire designers to think differently about the problem and drive new ways to design.

While they generally share the characteristics described above, cultural probes have been appropriated and reformulated in HCI research [7]. This adaptability is a strength, as an exploratory method that can be widely applied to different concerns, but it also brings with it a need to describe and reflect upon the detailed use of the method in different contexts. Therefore, this paper describes and reflects upon the details of our application of cultural probes, the insights that resulted, and how these insights can be utilised.

Assistive Technology can be defined as any piece of equipment, object, or product system to help individuals with disabilities improve and maintain functional capabilities. Through the appropriate use of Assistive Technologies, people with disabilities can have better control over themselves and their environment, resulting in greater freedom of movement, exploration, and participation alongside their peers at home and workplaces, thereby improving their quality of life [4].

Assistive Technology has been increasingly adapted to enhance the facilitation of healthcare services for many years [8]. The revolution of Smart Homes, equipped with responsive sensor networks and monitoring solution is also making an impact on the development of Assistive Technology. It is now greatly evolved and has the expediency to provide effective support to people with cognitive impairment, such as dementia, so that they can remain independent in their own home. However, while the importance of Assistive Technology is increasingly recognised across the world, the biggest challenge is how to find ways to adjust the context of the technology properly in order to obtain sufficient outcomes for the end users.

2 Project Background

This paper reports on the development and use of cultural probes in the AHRC-funded project *Stories of User Appropriation*, where they have been applied to support the development of design-drama techniques for use in the process of designing assistive technologies for people with Dementia and their carers. The aim of the project is to transfer knowledge about creative innovation processes from the creative economy to a wider economy, healthcare domain in particular, by combining design-drama techniques with digital-enabled open innovation platforms to engage users in the design process. The project was devised to tackle barriers that healthcare manufacturers face when considering how, where, and why their products will be used. In particular, the following issues have been identified:

1. Without overcoming significant practical and ethical difficulties, the current research methods used by the medical device manufacturers were inappropriate and unlikely to collect the type of data that is needed to inform design.
2. A number of barriers show the results of user research cannot be fully integrated into the development of new medical devices. User data that fed back to manufacturers was not effective in conveying the range, depth and importance of the information.

In this project, we focus on the healthcare domain as a particularly appropriate area for innovation in knowledge exchange practices, to be achieved through the co-development of digital platforms that make user-centred design techniques accessible. Through this process, information exchange can be stimulated between research from user-centred design, human-computer interaction, drama and film, and small-medium sized medical device manufacturers. These SMEs do not generally have the resources to conduct user-centred research, and as such they lack a grounded understanding of their potential customers, and other stakeholders, that could be key to effective innovation and success.

The key challenges in new medical device development will underpin the development of our digital platforms, framed by a specific case study: the range and variety of the obstacles that face people living with dementia, and the opportunities for assistive technology intervention to support independent living at home. In the context of this project cultural probes were deployed to create exemplar narratives describing issues faced by people with dementia and the people that care for them in the home. Examples from seven research investigations are presented in this paper to showcase how cultural probes support data collection in the home environment with people who take care of family members with dementia in different stages.

3 Methodology

3.1 Design of the Probes

The content of the cultural probes was based on a series of rich and engaging tasks that people could partake by choice and over time. Cultural probes should be designed to ensure the process is intuitive, and open to interpretation. The open-ended activities

included in the probes allow the participants to spend their own time producing narratives to illustrate their lives for researchers and designers. By implementing this uncontrolled approach, data in the opposite direction of the researcher's knowledge and patterns might be discovered.

The creation process of a probe needs to be carefully evaluated to avoid bias and subjective expectations and it usually involves many hours of preparation. Since this research is dealing with vulnerable people, the probe is also implemented at a level of sensitivity which allows data to be collected on participants which provides an understanding of their lives through a typical day without being intrusive.

3.2 Objectives of the Probe

Currently, there is no cure for dementia. It is a complex medical condition, and for those who have been diagnosed, it involves a life-long process fighting with the illness. There is no one way to care for someone with dementia; however, it's important to know that the key to care is to help the person maintain mental function, manage behaviour symptoms and sustain his/her independence in life.

There are a variety of factors that can influence the quality of dementia care as well as the condition changes of the person with dementia. The design of our probe was based on this notion and intentionally structured to capture as many of these variables as possible. To look after someone with dementia it is imperative to perform a Person-Centred Care approach since no two are the same, and different things mean different context to different people. Therefore, before investigating one's living space and finding opportunities for assistive technology interventions, one's identity, personhood and his/her relation with the specific items and elements in the space will need to be examined first.

The content of our probe is focussing on several subjects about the life of the person with dementia from the perspectives of psychological, physical and social. In order to help researchers and designers dissect the inherent causes of issues and phenomenon, the probes were deployed to the family carers to record, observe and help us build a realistic picture of the user. Our cultural probes contain two parts:

3.3 Activity Booklet 1 – Life Background Narratives

Several short interviews with the participants who expressed interest in taking part in the research project were conducted before the cultural probe content was formulated. From the interviews we learned that individuals' conditions are relatively diverse and often attributed by the changes of personhood development and situation of care to a certain degree. We took this into account and structured questionnaires in a way to learn about everyone better as individuals. The first booklet from the cultural probe pack is designed to gain an overview of the carer's role, the illness progression of the person with dementia as well as the condition of care in the home. Scale charts and diagrams were frequently used in this booklet as a prompt to encourage participants to evaluate the questionnaire items subjectively. They were asked to mark the scale charts related to the subjects and given further detail about the decision of their

selections. Information such as family carer's care management plans and support channels as well as symptoms of cognitive/mental impairment of the person with dementia is acquired here.

Because personhood is critical to the progression of dementia, important aspects from the life, background and social network of the person with dementia were also comprised to encourage the participants to reflect their own experience whether or not it is positive or negative, in which to help build a preliminary picture about their lives for researchers and designers during the cultural probe investigation process.



Fig. 1. A cultural probe pack

3.4 Polaroid Camera + Activity Booklet 2 – Life and Daily Recording

Many items and commodities that a person would use and keep around the living space have profound meanings to his/her life background history and personhood development. For people with dementia, these things represent an important part of their remained memory in the world, and constantly remind them who they are. The second part of the cultural probe was designed to document this unique aspect of one's life, from the owned items, favourite tastes in music and sound.

A life recording and a daily recording activity were formulated with the use of another booklet and a Polaroid camera. In the beginning of booklet 2, the family carer is asked to point out key activities that the person with dementia does in typical weekdays to allow the researchers and designers to gain some acquaintance with critical dimensions of the life of the person with dementia and see an even more completed picture about that individual's daily routine.

Entering the life recording activity in booklet 2, participants are invited to use the provided Polaroid camera from the probe pack to capture events and commodities from the living space of the person with dementia and double-sided tape the developed photographs in the booklet with writing description on each one of them. This activity was included to encourage family carers to think about aspects of living space that are important to the persons that they are looking after. It was specified that

the participants could take any pictures they wanted but not directly to the sufferers' faces in order to protect their identities. The participants were given the choice of taking photographs related to the following themes:

- Living space of the person with dementia
- Objects that the person with dementia frequently uses in his/her living space
- Objects that have been around the longest in the living space of the person with dementia
- Things (taste, smell, visuals, etc) that prompt the person with dementia from the living space

In addition to performing the tasks of capturing photographs and adding descriptions, in booklet 2's daily recording activity, participants are also asked to evaluate their own experience by using the provided emotion scale to add another layer of data to the information they record. Everyday situations such as the moment that brings either positive or negative feelings to participants' care giving experience are reported here. A page of a short daily reflection questionnaire is included in the end of every daily recording section such as "what would be the one (or two) things that would make it easier for you to care for this person today?" and "what is the biggest (or worry) that you have about the person you care for, or in your care giving process?" to let family carers summarise other significances that they want to address relevant to their everyday care giving management.

3.5 Recruitment of Participants

A group of participants were recruited at a "Carers's Circle" meeting held at Brunel University, UK as well as through the recruitment posting on the university's intranet system. This group of participants were all family carers who are caring for loved ones who have been diagnosed with a form of dementia or have acquired syndromes that are similar to dementia. We received responses from ten university staffs that were interested in taking part, and seven of them were willing to participate after meeting with our researchers for more information about the project.

The majority of the caring subjects that this group of family carers are looking after are women in their 80's, who are in the mid stage of dementia, and are situated in either care homes or in senior housing near the homes of the family carers. The criteria of our recruitment were fairly open, aspects such as social-economic and cultural backgrounds are not strictly considered. However, the recruited participants' situations presented a range of health conditions and care needs, including mobile-disability, memory loss, cognitive impairment, mental health problems and social engagement issues to allow us to discover a greater spectrum of design opportunity.

3.6 Delivery of the Probe Packs

We gave the probes to the family carers of the people with dementia in a series of short, casual meetings in the university, and show them how to operate a Polaroid

camera for the tasks that they need to perform in the research. Ethical concerns were explained to them during the meetings and the participant signed a sheet of ethical agreement form after he/she has agreed to take part in the program. The original intention for the probe deployment was to let the participants bring it home and doing the recording for one week then returning to us. However, it became apparent that there were a variety of caring relationships, and as such, contact could be irregular. In response we decided to extend the timeframe and let the participants to take as much time as they need to complete the probe pack.

4 Insights into Living with Dementia

4.1 Content Analysis

Content analysis provides an established and systematic research methodology, looking at quantitative and qualitative materials gathered by research participants through a variety of data collecting methods [5]. It presumes that repeating keywords and groups of words can refer to underlying themes and allows the researcher to reflect people's cognitive schema [6]. Combining qualitative probe data generated by questionnaires with a life recording activity (inviting participants to use a Polaroid camera to document daily life), content analysis provides a tool to systematically describe written and visual material. Using a deductive approach, categories have been formulated prior to analysis deriving from the project's theoretical framework. The aim of the research project is to 1) generate findings for design guideline to integrate articulations of smart home sensors and 2) to generate findings to address key points for constructing re-enact scenarios for co-design purpose.

Four main categories were identified: two categories focusing on the family carers experiences; and the condition of care and emotion. On the other hand, two categories observed the effects of dementia on patients' daily life. They include observations of daily patterns and condition changes due to dementia.

4.2 Results and Analysis

The qualitative research approach using cultural probes has provided a rich data set, giving insight into both of the challenges of living with the illness and day-to-day experiences of dementia care. The family carers filled in the probe packs with a different range of accuracy. Some chose to use the Polaroid camera to visualise the living environment of the person in care, others preferred to fill in the diary with writings only instead, following daily routines and providing information about the conditions of care. In relation to the objectives formulated in the probe design.

5 Life Background Narratives

5.1 Carer's Role

The probes highlighted, that for people who care for family members with dementia, time management and organisation of care resources are imperative for them to

maintain the balance between the quality of care and their personal wellbeing. Most family carers are employed, at least on a part-time basis. Therefore, care arrangements can be an additional and quite stressful responsibility to be taken on top of the daily or weekly agenda. Participants usually visit their loved-ones after work, or on weekends. In rare cases they are taking on a full-time care responsibility.

Our first recruited participant is in her late 50s and cares for her father. Working in a full-time position, she visits her father twice a week for a few hours in his care home. She is worried about the care home situation, as her father gets anxious with the staff and had to change already three care homes due to her father's "unacceptable behaviours". She said to have visited 60 care homes in the past three years, which illustrates how difficult it can be to find an appropriate care home for a relative with significant character changes during the progression of the illness.

- *Illness progression of the person with dementia*

As conditions of dementia start to differ, emotional instability of people with dementia will increase. For people with dementia, the ability to express themselves and reasoning can affect the quality of their social relations, whereas their family carers can significantly experience more difficulties engaging interaction with them. From one of our most significant cases in the probe data collection, the increasing impairments of reasoning pose a threat to the participant's loved one's wellbeing. During a regular visit, the participant found that her mother had diligently gone around the house switching all the sockets off, including the storage heater. To guarantee independence of people living with dementia and to enable them to stay in their homes alone safe, aids need to be intervened i.e. in situations as the example mentioned above. Nevertheless, even though family carers try to integrate social activities into the weekly schedule, interaction with others is worsening as the illness progresses for the person with dementia, and the person with dementia will become less responsive to the surrounding situation.

- *Condition of care in the home space*

The cultural probes identified how the emotional condition of family carers is strongly connected to the situation of care. It is important to ensure that the family carers are comfortable with a care plan through good cooperation within their support network is necessary in order to alleviate the stress of their duty. The support from family members, friends and other healthcare professionals plays an important role during a care responsibility. Knowledge exchange among carers is critical to prevent the feeling of being left alone or isolated in the situation of care. Our research participants have also addressed that shared visiting responsibilities among family members as a way to reduce stress. In addition, professional healthcare authorities dealing with questions of dementia providing information and knowledge play an important role in training and supporting family carers.

Concerning the condition of care, one of the participants was very fearful about the care approach performed in the care home. According to her observations, staff do not follow the recommendations of the physiotherapist in handling seat transfers. The photographs she has taken for the activity booklet 2 help to visualise her father's daily life activity and his living environment. Photographs are an insightful tool to understand and highlight commodities, as well as D.I.Y. solutions family carers

develop to adapt to certain needs in a care situation. For example, to alleviate struggles during the transfer from his main chair to the wheelchair, the legs of the chair have been raised.

Good communication between other carers involved, or the care home staff, is crucial to the personal wellbeing and stress-reduction of the family carer. Many participants pointed out their worries about their loved ones while not being with them in their home, or care home. Especially the decline of cognitive and physical abilities, i.e. handling of devices such as a mobile phone, has challenging implications. Carers describe the situation of not being able to reach their relative, as a very stressful and worrying experience.

6 Life and Daily Recording

6.1 -Living Space of the Person with Dementia

Most family carers point out, that they would prefer to enable their relatives to stay in their homes for as long as possible. Available care time and the ability of the person with dementia to live independently, are determining factors. Especially, older generations have often lived in their homes for decades and the home environment is strongly connected with memories and family history. With increasing symptoms of dementia, the living space of the patient has to be adapted accordingly. As for example long ways in the home can start to be a challenge for the person with dementia and orientation abilities decrease, new arrangements in the house have to be made. One participant, for instance, moved her mother's bedroom to the ground floor to shorten her routes within the home. Some interventions do not succeed unfortunately, as her mother still had difficulties to find the rooms even though they have been labelled with descriptions.

Another family carer described how her mother started to forget how to handle commodities that are part of her daily routine. With the increasing progress of dementia, she was not able to use the microwave anymore without burning her food, even though her daughter attached instructions to the front of the microwave. Assistive technologies play an important role to enable people with dementia to stay longer in their homes. Responsive sensor networks could provide technical interventions to maintain functional capabilities and to create a safe living environment.

- *Objects that the person with dementia frequently use in his/her living space*

People with dementia have different capacities of independence. In order to maintain personal identity and wellbeing, their motivation to keep up daily routines is essential; this can provide cognitive stimulation and help sustain their self-management ability. Daily routines that have been part of the patient's life for decades have been pointed out as being crucial to the wellbeing of the person with dementia, e.g., fixed hours for enjoying a cup of tea, the morning programme on the radio, as well as reading the newspaper. With the progression of the illness, there is an increasing need for assistance in the handling of commodities in daily life of the person with dementia, i.e., remote control, mobile phone, lighting, heating system, etc.

Referring back to the father of the first recruited participant, to fight the increasing memory loss the family created a family tree with photographs and attached it to the wall in his room. Whenever they talk about a family member he cannot remember; they point at the image to stimulate his memory. Other visual stimulations, such as family photographs, birthday cards and paintings from his old house are placed within his field of vision. Participants also mention activities such as Sudoku and crosswords as a way to keep their relatives active and thereby avoiding a quicker deterioration of cognitive abilities.

- *Objects that have been around the longest in the living space of the person with dementia*

Objects mentioned to have been around for a long time in the living space, are often referred to as paintings and photographs. They are main reference points to the person's private life and memories. Paintings of places where the person has been born, or lived for a long time of his/her life, as well as travel souvenirs and pictures taken with loved ones. As physical performance is often very limited, items connected with intimate memories seem to play an important role in the person with dementia's life. Family carers point out an increasing limitation of the perceptual field of the person they are caring for. Therefore, they arrange items close to the person's field of action, such as the table in front of the chair (where most patients spent their day, especially in later stages of dementia).

- *Things (taste, smell, visuals, etc) that prompt the person with dementia from the living space*

As mentioned previously, people often stick rigidly to daily routines that have been part of their lives for years. Things that prompt people with dementia are for instance the radio, TV, crosswords and Sudoku, newspaper and books. Family carers are very creative to position stimulating items in the main living areas. As said before, photographs play a crucial role and one carer created a family tree to stimulate her father's memory. Calendars have been placed in the side of field to prompt the patient's time awareness and to memorise for instance weekly appointments, or activities. Crosswords and Sudoku seem to be popular, especially among patients in the early stage of dementia. A carer refers to her mother saying, that it might help her to slow down the decline of her cognitive ability. Some carers recommended the people they are looking after to use To-Do lists, to structure their days and minimise the chance of forgetting things. Overall, family carers are very creative to adjust the patient's house and to respond to the needs of people living with dementia, often based on their own observations and care experience.

7 Building Design Narratives

While the data created from these probes is interesting and insightful, it can also be unwieldy and difficult to interpret, thus we used the information from them to create a series of design narratives, providing a set of accessible, rich and grounded design resources to inspire design implications of assistive technologies.



Fig. 2. Example storyboard developed from Probe Data

There's a unique aspect to this project, using design narratives to bring picture and the understanding of dementia. This approach was selected as it can avoid the ethical difficulties by using scripts and storyboards to represent the living condition of the vulnerable populations in order to present the data to a wider audience. Design narratives has the advantage of supporting collaborative design to drive creativity and dialogue among different groups of stakeholders, as it can be an open and accessible medium. The scripts and storyboards are informed by the cultural probes and therefore able to point out different challenges people living with dementia can face. It can serve as an inspiration and profound research information for designers, healthcare professionals and family carers. This approach supports the project's ultimate focus on developing co-design methods for producing assistive technologies for people with dementia.

8 Implications

This work has provided specific insight to support the design of assistive technology - specifically to build a social-media based co-design digital platform that will enable users to be engaged in the design process with SMEs in the healthcare sector. We envisage producing re-enactments of narratives from the probes using actors that will serve as a repository of user experiences. We envisage that our platform will comprise: 1. A system for delivering scripted narratives in the home which will deliver and collect user responses, in order to understand patients' requirements in context, and evaluate future technologies through the use of narratives. 2. A prototype platform for web based co-design, which will bring together script-writers, designers

and users to collaboratively design storyboards to inform design and the products/services themselves. The tools that will enable this will include tools for communicating the data produced by technology to stakeholders; forum for discussion of data, scripts and storyboards; tools for scriptwriters/designers to quickly and meaningfully interpret the large volumes of text generated during the forum discussions.

Acknowledgements. This work was supported by the Arts and Humanities Research Council (AH/K00266X/1) and RCUK through the Horizon Digital Economy Research grant (EP/G065802/1).

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