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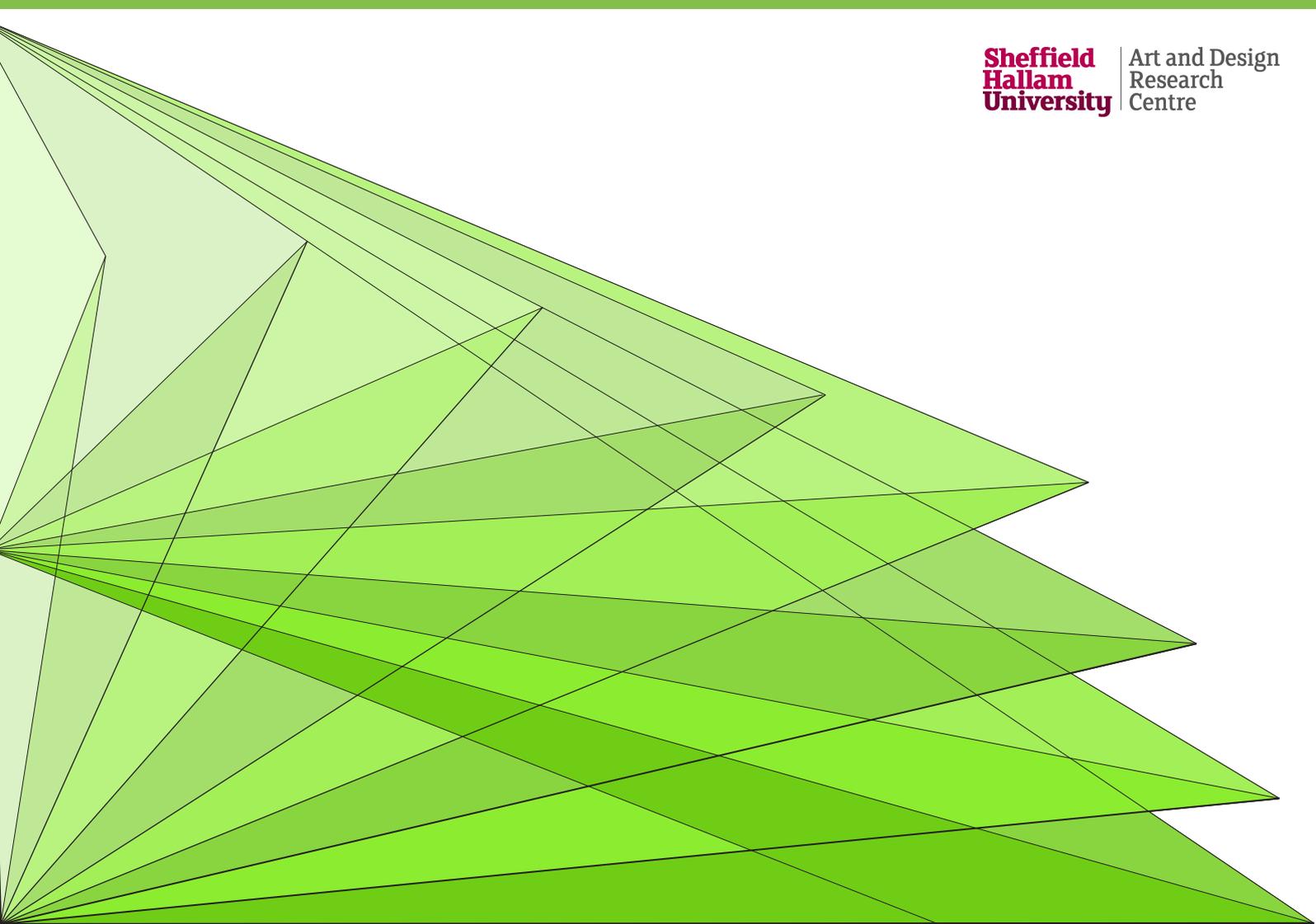
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Drawing Memories: An empowering and enjoyable aged care activity promoting confidence, independence and engagement.

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Abstract

It is well documented that active participation in creative activities improves quality of life and clinical outcomes in aged care services. (Cohen, 2006; Gottlieb-Tanaka, 2006; McNiff, 1992). With the population growth in aged care, particularly in dementia care, there is an increased demand for systematic, rigorous research into the health benefits of non-pharmacological interventions such as creative expression activities (Rusted et al, 2006).

Drawing is a visual communicator and a vehicle of creative expression. As Moon (2010) argues, this is where materials and media play a central role, by acting as an intermediary between thought, communication and the physical experience of creating. This paper presents the outcomes from the "Drawing Memories" program, developed and implemented with the aim of promoting quality of life indicators for elderly people in aged care. Appropriate drawing material and media choices, with their role in providing experimentation and enjoyment, was a key aspect of the professionally designed program. As a pilot study, the "Drawing Memories" program was conducted across two aged care services, both residential and community, in NSW Australia. The research questioned the useability, practicalities and therapeutic potential of various drawing media and activities designed for elderly people with diverse physical and cognitive impairments.

Taking an artist/educator/practitioner approach, the study is set in the context of art as therapy. To address the cross-disciplinary nature of the research, a phenomenology/heuristic framework was used in conjunction with quantitative evaluation measures, to form a mixed methods enquiry into the lived experiences of the participants.

The focus of this paper is on the choice of activities, materials and media and how the participants responded to them. Through the exploration of various media it was found that the participants' confidence, independence and engagement improved while undertaking the drawing activities. An interesting outcome was the Apple iPad rating highly in useability and enjoyment. Further research is needed to address the issues that have emerged from this study.

Keywords: aged care, dementia, drawing, communication, visual language, health and well-being, non-pharmacological intervention, creative expression

Introduction

Dementia cases are rising rapidly. It was revealed in the Summary of Dementia Statistics in Australia (Alzheimer's Australia, 2013) that 1,700 new cases of dementia are diagnosed in Australia each week. They predict this number will increase to 7,400 per week by 2050. With more people living longer, greater resources are needed for end-of-life care. This means that the population growth in both aged care and dementia care services internationally, will generate a greater strain on the economies for the provision of the necessary clinical and medicinal care (Castora-Binkley et al, 2010; Cohen, 2009). These forecasts have sparked an increased interest in, and demand for research into, the health benefits of non-pharmacological interventions, such as creative expression activities. (Cohen, 2006; Gottlieb-Tanaka, 2006; Rusted et al, 2006). A review of current literature, conducted by Castora-Binkley et al, reveals few studies showing systematic research into the impact on health outcomes through the therapeutic use of the arts conducted by professional artists, in the field of ageing.

Creative expression activities encompass diverse art forms that include music, performance, writing and the visual arts; the latter being the area explored in this study. Dissanayake (1988) affirms that art is both "pleasurable and advantageous because it is therapeutic" and this concept forms the theoretical framework of this research. Drawing is a fundamental human activity and underpins all art making. As a communicative tool, drawing is a visual language used to 'express our experience of the natural world' (Ramm, 2005) and is inherent in all of us. Because of its primacy, drawing was chosen for this study as a vehicle of exploration into creative expression.

The outcomes from the participation in creative expression activities studied in this paper, is distinct from art therapy, a form of psychotherapy. As Castora-Binkley explains, "art therapies are typically provided in clinical settings such as hospitals and hospices by trained health care professionals to heal...the effects of disease and disability" (p. 353). Set in the context of art as therapy, this study was approached from an artist/educator/practitioner perspective. This posits art making purely as an activity rather than a clinical therapy tool, and aligns with the view of Casson (1994) that creativity is therapeutic in itself. In this way, the pleasurable and therapeutic benefits from art making are considered as an alternative/complementary treatment to medicinal intervention; assisting in the prevention of psychological symptoms such as depression, often experienced by people in aged care (Australian Institute of Health and Welfare, 2013). This research explored the cross-disciplinary connection between drawing, memory and health with its application in an aged care setting, through the "Drawing Memories" program.

The program, developed and facilitated by the researcher, aimed at promoting quality of life for the elderly and people with dementia (PWD). Various drawing materials and media were explored using drawing as the vehicle of inquiry. Moon (2010) argues materials and media play a central role in these activities, by acting as an intermediary between thought, communication and the physical experience of creating. Malchiodi (2012) agrees, but observes that little research has been conducted on the effects and qualities of art materials and media during arts participation. A tacit understanding of this, as a practising artist/designer and educator, stresses the importance of careful consideration when choosing materials and media. Poor media choices often result in poor outcomes and bad experiences. Therefore, it is argued that drawing with appropriate materials

fosters self-esteem and dignity. The study questioned the useability, practicalities and therapeutic potential of various media and activities designed for elderly people with diverse physical and cognitive impairments.

This paper focuses on drawing material and media choices and how the participants responded to them. At the time of writing, the preliminary statistical and observational data has been collated. In-depth descriptions, analyses and conclusions will come in a future paper. Through the exploration of various media, it was found that participants’ overall confidence, independence and engagement improved while undertaking the drawing activities.

Program Overview

Scope

The “Drawing Memories” program was a pilot study; conducted over 12 weeks across two UnitingCare Ageing (UCA) aged care services, in NSW Australia. These services included residential care and community care. A total of sixteen people participated in the study. Small numbers limit the generalisability of the findings for the whole population in aged care, but were appropriate for a pilot study.

Participants

Distribution of participants

Three groups of participants were distributed across two facilities as follows:

1) Residential

Group A: Low care and high care residents.

Group B: Dementia care unit.

2) Community

Group C: PWD and non PWD attending a weekly day therapy program.

The following table identifies the total participants and PWD distribution per groups/facilities.

			NON PWD	PWD
Residential	Group A	High care and low care	3	1
	Group B	Dementia care	0	3
Community	Group C	Combination incl. PWD	7	2
TOTAL NON PWD			10	
TOTAL PWD				6
TOTAL PARTICIPANTS				16

Figure 1: Participant Distribution

Cognitive and physical limitations

All three groups had people with a range of cognitive and physical impairments, which were disclosed by the clinical care team for the purposes of data analysis. All PWD were medically diagnosed, with the level of severity, based on clinical judgement, as early stage dementia. However, quite diverse levels of symptoms (e.g. behavioural patterns and memory loss) were apparent among the PWD.

Physical and sensory limitations included stroke, arthritic, sight and hearing impairments. One participant was medically diagnosed with profound hearing and sight loss. Out of the sixteen participants, there were only three who were mobility independent.

Program structure

ACTIVITY	DESCRIPTION	DURATION
1 Intro	Each session began with a 'cuppa' and general chit-chat followed by a discussion of the reminiscence topic of the week. Visual imagery/tactile objects/sensory items were used as props.	15 mins
2 Warm-ups	The topic of the day led into 'warm-up' drawing exercises, which were designed to stimulate memory, thinking and problem solving. The focus was on drawing with traditional media, such as pens/markers. These sometimes went longer if the participants were fully engaged and interested.	5-10 mins
3 Main Activity	The main activity was structured to allow flexibility in delivery. A different medium was introduced each week and demonstrated by the facilitator, but alternate activities/materials were available if it necessitated. Emphasis was on exploration of media without concern for representational description of subject material. The art making was either based on the topic of the day or something randomly chosen by the participant.	30 mins

Figure 2: Program Session Structure

Materials and media

Many materials were researched and tested prior to data collection, keeping in mind the health and safety issues and tools/aids for useability. Although very important, the details are not discussed in this paper. From personal experience it has been found that poor quality materials produce disappointing results. Particularly with the elderly, this may set a scenario of loss of self-esteem and confidence in their ability, promoting discouragement from further engagement. Providing quality materials to people with physical impairment and little or no knowledge in drawing techniques lays a good foundation of mutual respect between the participants, the researcher and the materials. The drawing paper for instance, was chosen because of its weight being 245gsm (grams per sq. metre) (Photocopier paper is about 90gsm). A heavier paper doesn't crumple as easily, and it was proven, in this study, to withstand many repetitive drawing strokes, which seemed common in the patients with dementia. They were quite impressed and felt honoured to use quality materials. Their ingrained thriftiness was often revealed through their concern for wastefulness and expense of such media. When offered additional sheets of paper, one PWD remarked "Oh dear, can we afford this?"

A total of twelve different drawing media were explored over the 12 weeks. Ten were introduced as the 'medium of the day', one of which is not included in the statistical data. In the anticipation of rejection due to personal preferences or physical limitations, gel pens, graphite sticks and markers were on standby each week (Fig 3).

	MEDIUM/ MATERIALS	BRAND	DESCRIPTION	TESTING DURATION
Dry Media	Charcoal	Winsor & Newton	Willow sticks - medium	1 week
		Gallery	Compressed blocks	
		Generals	Pencil Kit	
	Clay	Staedtler Fimo AIR	Air drying soft modelling	1 week
	Pastels Chalk	Jasart Deluxe	Soft compressed – set 24 asstd. colours	1 week
	Pastels Oil	Mungyo	Oil – compressed sticks – asst set 24	3 weeks
Wet Media	Acrylic Paint	A2 Artists	Water based – 250ml x10 colours	3 weeks
	Aquarelle Coloured Pencils	Jasart	Water soluble. Option to use dry/wet.	1 week
	Food Colouring	Queen	Water soluble – set 6 mini, asst colours	1 week
	Ink	Art Spectrum	Water soluble, pigmented x 3 colours	1 week
	Marker Pens	Posca	Water based. 7 colours	1 week + standby
New Media	Computer Tablet	Apple iPad3	Brushes app V.3	2 weeks
			ArtRage app V.1.4.7	
Standby	Graphite	Jasart	Sketch Pencils – 12 asst grades	2 weeks standby
		Lyra	Graphite crayons – 2B, 6B & 9B	
	Gel Grip Pens	Hybrid	1mm	All weeks standby
Surface Media	Paper	Jasart Sketch	110gsm A3 White	All weeks
		X-Press Aqua	200gsm A3 White	3 weeks
		Rising Stonehenge	245gsm A3 Warm White	2 weeks
		Cansen	110gsm A4 Coloured	1 week
	Canvas	Fredrix	100% woven cotton 30cmx40cm	2 week
Misc. Tools	Brushes	Jasart	#4; #8	5 weeks
		Reeves WC	Set 12ML; 22ML	
	Clay Modelling Kit	Mungyo	Plastic asst modelling tools	1 week

Figure 3: Materials and Media Overview

Methodology

Systematic testing and evaluation of the outcomes required a mixed methods approach, utilising quantitative evaluation tools and qualitative methods commonly associated with a phenomenological/heuristic inquiry. The ethnographic method of participant observation was used to enable the researcher-as-facilitator to become fully immersed in the phenomena – in this case, the “Drawing Memories” program. During each drawing session, the behaviours and emotional responses were observed by three people – the *researcher*, a *UCA staff member* and a *UCA volunteer*. Three specific techniques were used to collect and record the experiential data from each participant per weekly session – 1) *Participant Questionnaire* 2) *Measured Experience Scale* and 3) *Observation Notes*. To test the effectiveness of the program, *t* tests were used for a comparison of results between the first and last weeks of the program (Figure 8). The following is a detailed description of methods used in the study:

Participant questionnaire – self evaluation

After each session, the participants were invited to answer a set of four questions. The answers were compiled of a series of five emoticons ranging from very unhappy to very happy to which they circled the one that best described their thoughts and feelings about the session. Participants rated their response to 1) the overall session 2) the activity 3) using the materials 4) creating their artwork. The questions and emoticons were designed and developed by the researcher specifically to assist with the evaluation of the “Drawing Memories” program. The answers were entered into a formulated matrix scoring between zero – 4 for each answer. The total score ranged from zero to 16, higher scores indicating a more positive experience (Figure 4).

Measured experience scale – facilitator evaluation

Immediately following the sessions, time was allowed for the observers to reflect upon each participant while addressing specific criteria. The tool developed for this evaluation was based on the Non-Pharmacological Therapy Experience Scale (NPT-ES), which was designed by Muñiz *et al* (2011) ‘..to measure the experience of people with dementia (PWD) while undergoing non-pharmacological interventions’ (p.1). Not all of the criteria fully addressed the Drawing Memories objectives. For an in-depth evaluation of their experience of the program the tool was modified to include two additional criteria – ‘engagement’ and ‘self-confidence’. Subsequently the NPT-ES was renamed as the Post-Activity Observation Measurement Tool (PAOMT) for use in this project. The PAOMT consists of a list of seven behavioural criteria with check boxes relating to the frequency of the respective behaviour displayed. Each criteria attracts a score between zero – 3, results from which being tallied to one overall score ranging from zero to 21, higher scores indicating a more positive experience (Figure 4).

QUESTIONNAIRE

Name..... Date.....

**POST-ACTIVITY QUESTIONNAIRE
'DRAWING MEMORIES'**

Please circle the icon that best describes your thoughts and feelings.

Q1. How did you feel about the workshop session overall?

Q2. How did you feel about the activity?

Q3. How did you feel using the materials?

Q4. How did you feel about the artwork you created?

Question designed by Margaret Kelly BSC

PAOMT

Staff Volunteer Facilitator (Please tick)

Date 15/12

**POST-ACTIVITY OBSERVATION MEASUREMENT TOOL
for the 'DRAWING MEMORIES' WORKSHOP SESSIONS**

INDIVIDUAL PARTICIPANTS' EXPERIENCE SCALE *

Participant name: **STAN** Activity:

ITEMS	NEVER	SOMETIMES	FREQUENTLY	ALWAYS	NOT ASSESSABLE
1. ENGAGEMENT			<input checked="" type="checkbox"/>		
2. FOCUSING		<input checked="" type="checkbox"/>			
3. FLEXIBILITY			<input checked="" type="checkbox"/>		
4. CONFIDENCE			<input checked="" type="checkbox"/>		
5. SOCIAL INTERACTION			<input checked="" type="checkbox"/>		
6. EMPATHY		<input checked="" type="checkbox"/>			
7. REACTION		<input checked="" type="checkbox"/>			

INSTRUCTIONS

The above experience scale aims to measure aspects of each participant's experience during the 'Drawing Memories' workshop sessions. Experience or observation of the present moment, conditioned by position of each participant. Some of the observable components of an experience are measured through behaviour and action responses.

The scale consists of five items, which must be filled in prior to the questions included below:

- The evaluation must be for the entire period of each session, from greeting to closure/feedback.
- The observer will be observed at the end of the observation.
- The item may possibly observe the closing of another (or instance, if a participant has abandoned the session, any time that further spent out of the room will be counted as "absent" as well as "non-participant" though not necessary as "absent" as "non-participant" will be indicated unless information is not available for the rest of the session.

SCORING

Observable consequences of an experience are expressed through posture, looks, gestures, words or actions.

- ENGAGEMENT:** eye attention and response either spontaneously or to the facilitator's indications to the art activity. Should the participant not understand the graphical words or actions (facial, body) reference assistance will be needed especially for writing purposes. N/A. Participant does not necessarily mean engagement or pleasure.
- FOCUSING:** consistent focus on the activity, able to sustain attention.
- FLEXIBILITY:** shows signs of flexibility and pleasure/interest and enthusiasm.
- CONFIDENCE:** makes clear decisions and choices, can initiate and complete a task with limited coaching or external prompting, appears thoughtful about.
- SOCIAL INTERACTION:** communicates positively (nonverbal, or a friendly manner) and/or verbally with other participants in the room or with the facilitator either spontaneously or at the facilitator's indication.
- EMPATHY:** displays positive feelings, such as compassion, empathy, sadness, discomfort, shame, hostility, hostile actions will only be scored as "negative" if accompanied by some other indication of negative mood (e.g., high forehead accompanied by tense posture or hostile expression of anger), or disarming of the target accompanied by hostile expression of hostility (stare, actions of rejection (turning) will only be included here if accompanied by signs of hostility).
- REACTION:** patient actively reacts to the facilitator's indications (in activity). This includes gestures (e.g., making/holding head, touching, holding, etc.) or using the hand, words, verbal actions (e.g., saying words or showing objects) and more complex actions (e.g., using objects, reaching, handling). Should the patient touch the length of the handle in out of the room it also counts as "reaction". N/A. Touching the handle, there is no negative expression to the process. If the participant touches the art activity but chooses to remain for the entire session, they may still show signs of pleasure and positive accommodation.

* Based on the Non-Verbal Interaction Therapy Success Scale (NVTSS) developed by Ruffalo, Charlini, Frenkel, and Pyle (2008).

Figure 4: Evaluation Measurement Tools

Observation notes

The researcher's immersion in the project was an important part of the process of evaluation by contributing a personal reflection on the phenomena, a reality not captured in statistical data. This took place immediately following the completion of the PAOMT.

Prior to each session, the researcher "checked-in" with the clinical care staff for any relevant issues relating to the participants e.g. emotional upsets or health concerns that could affect their reaction to the activities. Notes were also taken in relation to any visitor or staff intrusions. Notes on visitor or staff intrusions and anecdotal conversations between the participants, myself and other observers were entered into a journal as additional data.

Observational Findings

Through observation it was found that reduced agitation, greater social interaction and improved confidence, mood and attention span was evident. Selected observations are presented as individual case studies as follows:

Observation 1: Introduction of technology embraced better than expected

Outcome: Improved mood and self – confidence

Using the Apple iPad3 proved mentally challenging to all, with one PWD rejecting it. With assistance, they were able to follow instructions, becoming accustomed the interface. Some chose the stylus; most chose their fingers to produce explorative drawings. All showed a sense of pride in their ability

to use new technology. One participant with stroke impairments could only use her non-dominant hand in all drawing activities. She commented that the drawing she produced on the iPad “..is my best yet!” The iPad is not reliant on firm pressure unlike other drawing media and she found this to be pleasurable for her.

Observation 2: Interesting phenomena experienced through observational drawing exercise

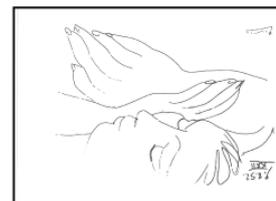
Outcome: Increased concentration and attention span, reduced agitation

Based on Betty Edwards’ upside-down drawing exercise (Edwards, 1999). Aimed at improving observation skills, the original drawing should be viewed upside-down and re-drawn in this orientation. The theory is that when turned right way up, the drawing should display better proportion and spatial identification. Few participants showed this outcome. However, one PWD who had previously shown agitation and reluctance in commencing tasks became fully engaged, producing a close replica of the original Picasso upside-down drawing (Figure 5). Another interesting outcome was observed of a participant diagnosed with dyslexia; while viewing the original in its vertically reversed state, he not only interpreted it in its correct orientation but in its horizontal reversal also, producing a mirror-image of the original (Figure 5). This outcome amazed everyone but the participant; he could not see the phenomenon.

1. PICASSO ORIGINAL IN CORRECT ORIENTATION



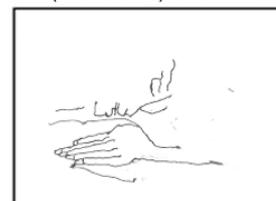
2. PICASSO ORIGINAL IN REVERSED ORIENTATION



1b. PWD DRAWING VIEWED IN CORRECT ORIENTATION



2b. DYSLEXIA (NON-PWD) DRAWN AS MIRROR IMAGE



Picasso, Pablo, (1952). *Sleeping Woman*

Figure 5: Observational Exercise – Upside Down

Observation 3: Creative expression and problem solving through group activity

Outcome: Increased concentration and attention span, improved mood and confidence

This activity spanned the final two weeks of the program and culminated in a canvas wall hanging. The “Forget-Me-Not” mural is currently hanging in the boardroom of the head office UnitingCare Ageing, Hunter, Central Coast and New England, NSW. This activity differed from the others because

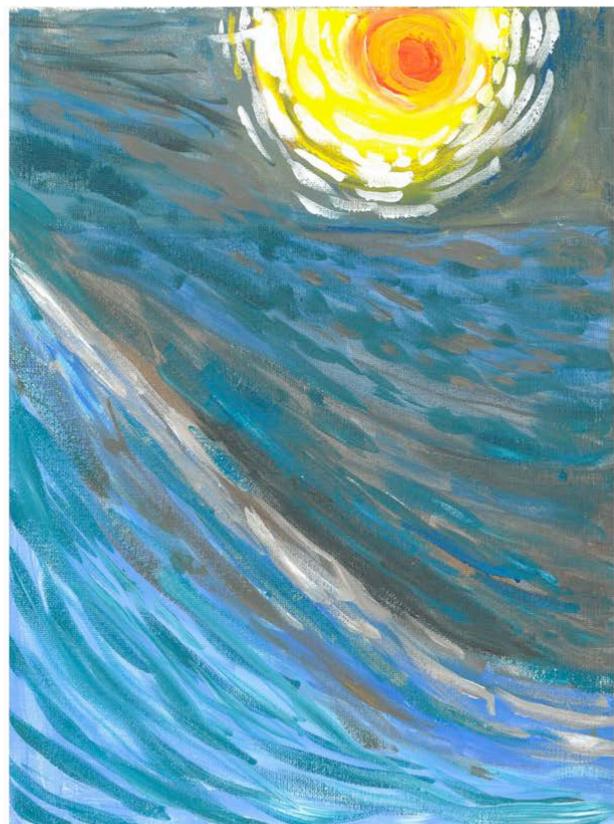
it involved all groups across both facilities. Each participant was given an A4 section of Van Gogh's famous "Starry Night" (Figure 6) to interpret onto an A3 size canvas. These pieces were stitched together to form the complete image before attaching a rod ready for hanging. Amazingly, pieces constructed randomly across the different groups appeared to match up in many areas. Many participants showed dislike for their 'piece' at the completion of the first week. They were struggling with the concept of 'work in progress' and could not foresee the goal or the 'whole picture'. They endeavoured to copy their given section in the best way possible; one drawing an outline of shapes first, some visually measuring distances and sizes of shapes, while others plunged in with wild abandon. The second week proved better for their morale when they saw their individual groups' completed artworks displaying dazzling compositions full of vibrancy and colour. Each was a complete artwork in its own right. The full effect of the assembled mural was not envisaged until seeing it at the grand finale where it was unveiled a month later (Figure 6). The sense of pride and achievement in the room was palpable. Family, carers, staff and participants stood hushed and in awe of the magnitude of this accomplishment. This observation cannot be measured statistically.

Van Gogh Original



Vincent van Gogh, (1883). *Starry Night*.

Single piece - PWD



"Forget-Me-Not" Mural



Figure 6: Final activity showing the process and completed mural

Statistical Findings

The findings from statistical data are presented as overall outcomes and are not based on individual responses. Week 6 evaluation of 'inks' has been discarded from this data due to questionnaires being completed in only one facility. The evaluation tools each had a different rating. One had a

maximum score of 16 and the other had a maximum score of 21. Therefore the scores were adjusted by the factor 16/21 (meaning the /21 score was scaled down to equate to /16 for equal comparisons (Figure 7).

Weekly Evaluation of Overall Responses showing overall scores from the questionnaires/self evaluation (SE) and PAOMT /facilitator evaluation (FE)

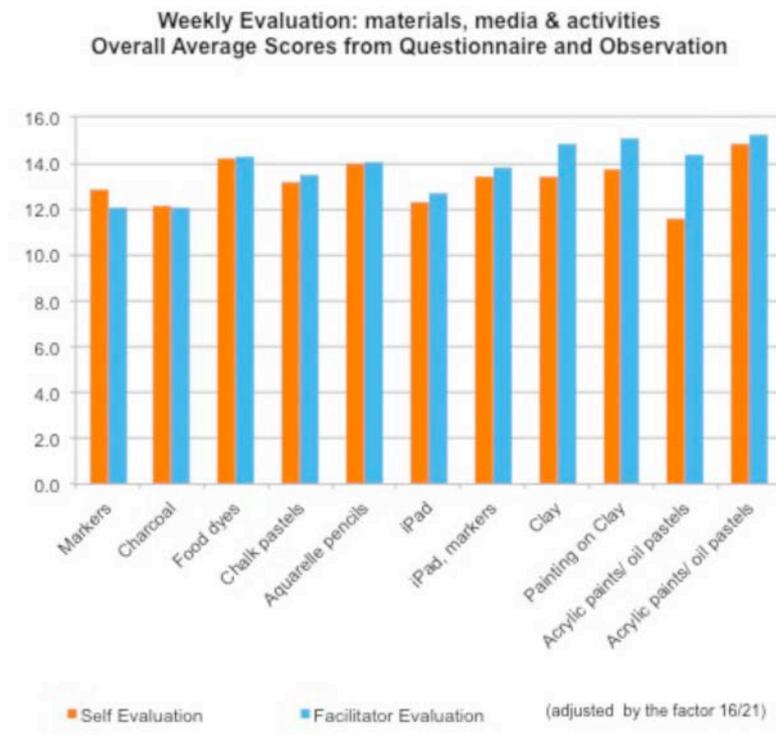


Figure 7: Weekly Evaluation Overall Scores

Comparison of week 1 and 12 – SE and FE scores - *t* test Results (*p* -value)

Statistical significance refers to whether any differences observed between groups being studied are "real" or whether they are simply due to chance. To be statistically significant *t* test results must yield a *p* - value of .05 or less (Campbell and Swinscow, 2009).

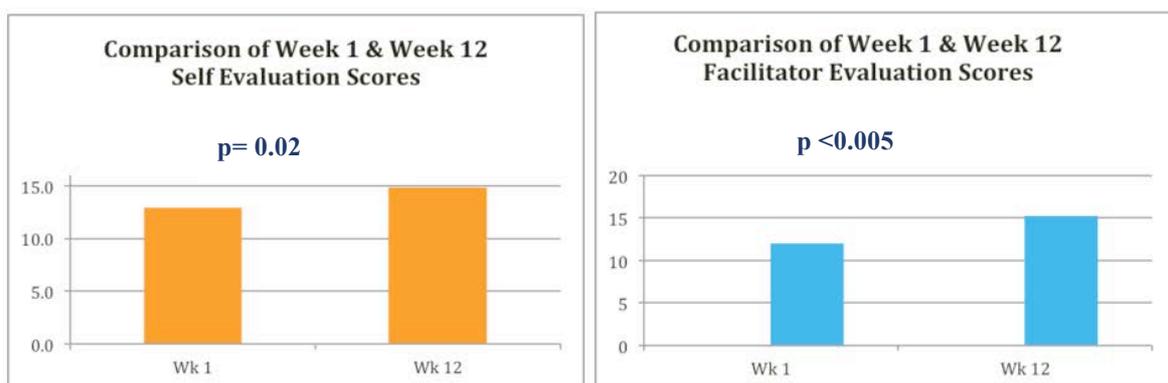


Figure 8: SE and FE *t* tests comparison

Paired student *t* tests were utilised to determine differences between the first and last week scores for both SE and FE evaluations.

Both SE and FE results show a rise in positive outcomes from week 1 to week 12. Both *t*-test results yield a *p* - value of <0.05. This means there is a high probability (more than 95 per cent chance) that these responses would NOT be observed if the “Drawing Memories” program was ineffective. This difference could either mean that participants felt better about the sessions and finished artwork at the end than they did at the beginning, or it could mean that they enjoyed the activities/materials used in the last sessions more than the activities/materials used in the early sessions. To isolate specific trends the data will require further analysis, or a larger scale study.

Limitations, discussion and conclusion

The paper recognises that the study has limitations. When research involves the study of people it is difficult to quantify human behaviour and emotions. When reducing it to a rigid set of statistics, the full appreciation and ‘human’ components of the experience may be disregarded. One of the major limitations of measurement tools in this study is of the validity of the questionnaire, which has not been established for people with dementia. However, the simple illustrative design proved effective in that minimal words were used, thus enabling easier processing of the questions by PWD.

As demonstrated in the case of the participant with stroke impairments, with use in only her non-dominant arm, the Apple iPad was shown to be more effective in useability. Art making outcomes improved because less pressure was needed to receive desirable results. Through observation and conversations, the introduction of new media was a success beyond our hopes. While not the highest in positive responses, it was higher than expected considering the non-technological abilities of this generation. In spite of both cognitive and physical limitations, most participants adapted to the newest technology. This is an area where further research may be conducted, to address the issue of the forecast growth of population in aged care. Future generations are more technology literate and will expect this to be age-friendly and accessible to them.

Although the results are not conclusive, the observational data show that agitation levels were visibly reduced. These are all indicative of a better quality of life. Unfortunately this study does not provide evidence that these results have long-term impacts on their health and well-being. However, it seems problem solving and reminiscence can stimulate the mind, which the outcomes from the program suggest. Moreover, if healthy memory relies on its practice, particularly in creative pursuits, as Minichiello (2012) revealed in his recent exploration of the role drawing plays in memory stimulation, it is reasonable to consider that regular participation in reminiscence based drawing activities, may assist in cognitive function of the elderly and people with dementia. It is argued then, if participation in creative activities has such a positive effect, then regular implementation of these activities, as a companion treatment, could reduce the reliance on medicinal intervention.

In conclusion, the mixed methods results imply that the Drawing Memories program had a positive effect on the well-being of the participants, at least during the sessions. Through the exploration of the useability and practicalities of various drawing media and activities, it was found that participants’ confidence, independence and engagement improved while undertaking the activities.

It can therefore be argued that drawing with appropriate materials and media, can be effective in promoting quality of life for people in aged care.

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Please resuscitate! How to share a project concerning self-management in diabetes to enable participants to elaborate on it after project completion

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Abstract

This paper discusses how we developed and shared documentation of a participatory design project 'Bespoke design', in which three personalised self-management tools are designed for three participants with type 1 diabetes. To generate a larger impact and prevent the project from fading out after its completion, the design team aims to enable other interested parties (designers, developers, people with diabetes, et cetera) to elaborate on the project, e.g. rework or alter the tools and ideas for new contexts. We refer to this objective as 'generativity' (Erikson, 1950; Zittrain, 2008; Van Osch & Avital, 2009). Documenting and sharing practices in the context of generativity is predominantly concentrated on the material aspects of a design, enabling others to remake it (Huybrechts, Storni & Schoffelen, 2014; Schoffelen & Huybrechts, 2013). However, the inclusion of immaterial aspects, in the form of meanings and viewpoints of participants on the project's process and results (e.g. Dix, 2007; Avital, 2011; Kanstrup, 2012), can generate an additional impact. It supports an interpretative and generative discourse that can result into a wider range of variations on concepts and meanings involved, instead of merely concentrating on developing (new) self-management tools. This approach better fits the complexity of design projects in the field of health care. In this paper we evaluate Make-and-tell, a toolkit developed to support design teams to specifically document and share these immaterial viewpoints and material aspects, as used in the project 'Bespoke Design'.

Keywords: diabetes, self-management, documentation, participation, fabrication lab

Introduction of key concepts, question and context

The design of self-care and self-management systems that are better integrated in people's lives is receiving increased attention, also in the fields of design (see e.g. a workshop concerning Designing self-care for everyday life: Verdezoto *et al*, 2014). The project 'Bespoke Design' deals with the participatory (re)design of self-management tools for people with type 1 diabetes. Since diabetes is to a large extent self-managed, the tools are very personal (Funnel & Anderson, 2004; Bauer en Ringel, 1999; Wootton, 2000). Therefore we believe that "universal" tools may only superficially answer to the needs of many people and aim to collaboratively develop bespoke designs, personalised to an individual's needs and wishes. However, since the design research project aims to have a broader impact, we look for ways in which these personalised designs can also 'generate' solutions for others dealing with similar issues. Generativity (Van Osch & Avital, 2009; Zittrain, 2008) refers to a project's ability to generate on-going participation by a variety of parties (e.g. end-users, designers, developers, at home or in organisations) that are interested in using, contributing to or reworking the project after its completion. The term generativity is introduced by Erikson (1950, p. 231) as an 'interest to establish a next generation'. In recent literature the concept is referred to by terms like metadesign or infrastructuring (see e.g. in HCI and Participatory Design, Fisher *et al*, 2004; Ehn, 2008; for an elaborated study, see Huybrechts, Storni & Schoffelen, 2014). Although designers cannot ensure or control this process of generativity, previous research shows that they can stimulate it by sharing documentation of the participatory design process. However, documenting this process often does not transcend the mere material aspects of the design process (see e.g. Schoffelen & Huybrechts, 2013; *Ibid*, 2014). For example, documentation in FabLabs¹ is often approached via sharing source codes or blueprints (similar to platforms like instructables.com; thingiverse.com; knowable.org). This helps to make the functionalities of a design transparent but is limited when it comes to sharing complex design matters - such as design in healthcare contexts - wherein different viewpoints and meanings are at stake (Kanstrup, 2008). Since the viewpoints of different stakeholders concerning diabetes (e.g. the participant with diabetes, his/her social network, the designers, the caregivers) aren't always compatible (Storni, 2011), it is interesting to document these diverse viewpoints as well (see e.g. Dix, 2007; Van Osch & Avital, 2009; Kanstrup, 2012), offering diverse paths for (re)design (e.g. the functionalities or concepts developed during the research).

This paper further discusses how we can support designers and participants to document the viewpoints of stakeholders to enable generativity in the context of the Bespoke Design project (taking place in Fablab Genk, www.fablabgenk.be) via using various methods, toolkits and moderators. In this paper we will especially focus on the use of the 'Make-and-tell' documentation toolkit that we developed. Hence, in 'Bespoke Design' we question: How can we support designers and participants in documenting both material and immaterial aspects of their – rather personalised - design research process of self-management tools for diabetes in order to enable generativity?

¹ Neil Gershenfeld was involved in conceptualising these so-called Fabrication (or Fabulous) Laboratories for making production tools, developed by MIT, available to students, see Gershenfeld, Neil. (2005). *FAB: The Coming Revolution on Your Desktop: From Personal Computer to Personal Fabrication*, Basic Book, New York.

Documentation in 'Bespoke Design'

In 'Bespoke Design', the Make-and-tell toolkit was used to design and document during the *first workshop* in the design research process. The design team, five participants² with diabetes and an endocrinologist introduced three challenges related to self-management tools: (1) How can I carry my tools with me? (2) Which rituals can support using my tools in public environments? (3) How can we make smart tools that react when needed in different situations (e.g. forgetting them, restocking food, and providing sugar when having a "hypo"³)? Make-and-tell - consisting of dice, game rules and hexagonal shaped documentation cards (Figures 1 and 2) - was used to support designing and documenting the participatory design process conducted for answering these three questions.

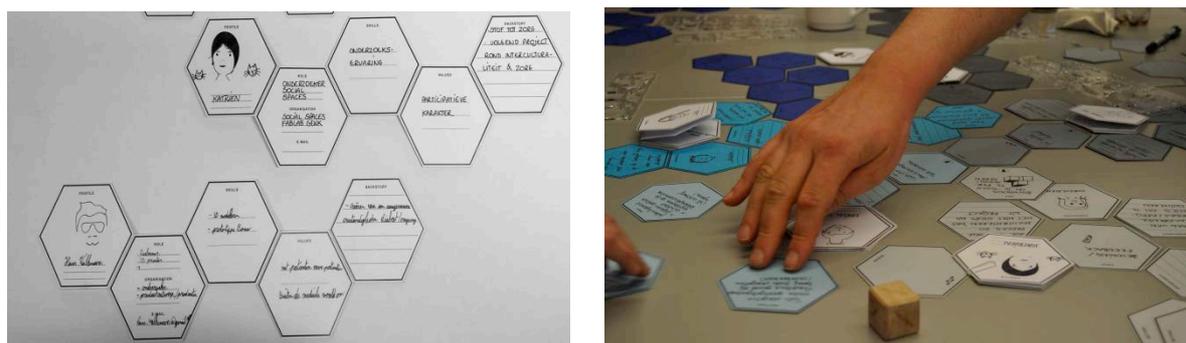


Figure 1: Profile cards document roles and viewpoints. Figure 2: Participants map viewpoints and ideas

First, participants *map* their profile cards and viewpoints concerning self-management tools for diabetes (Figures 1 and 2) in the form of actors, goals, settings and artefacts. Via a set of game rules, dices and 'bridging cards', they relate their individual viewpoints to those of others to form smaller design teams. This format leads to interesting confrontations of viewpoints and expressions of very personal ideas. For example, participant M. indicated in her video that she did not feel the same hesitance other participants experience when using their tools in public. Also, participant B. indicated during a concluding interview, that the toolkit made him express elements that he normally wouldn't share, e.g. how he particularly approached specific ways of handling his tools during sport. Second, stepwise participants translate their individual viewpoints into collaborative *scenarios* (Figure 3). They define a goal, reuse components from the mapping, provide more contextual elements (i.e. actors, artefacts and settings) and define their own role in the scenario. Finally, the scenarios are enacted by each team and *video documented*.

Make-and-tell supports design teams to document immaterial aspects of the project, e.g. their personal viewpoints or concepts, next to material aspects by guiding them through these three stages of mapping, building scenarios and enacting in video. These videos were used as briefing for a second workshop, where a different group of designers collaboratively designed prototypes for these scenarios. While most participants found the documentation of the immaterial aspects of the project inspiring for future social uses, one participant found that the documentation

² Participants were gathered through an 'open call' that was distributed via the blog of our research group, the Facebook account of the members of the design team, and via direct e-mailing to a group of athletes with diabetes (introduced to us by an endocrinologist). After the first exploratory phase, three participants were selected to develop prototypes for, based on the issues they found valuable and on their possibilities to participate in the project for a longer period. We selected issues that were different in nature because we wanted to explore different contexts and develop different types of tools. Since participation happened voluntarily, no ethical committee was involved.

³ A hypo or hypoglycaemia is when the blood glucose level has dropped too low, resulting in symptoms like weakness, trembling or shaking, hunger, et cetera.

about the sugar dispenser as part of a larger system for a person with diabetes and the idea of parametric designs to enable the redesign of this dispenser in a FabLab.

- The second scenario and video representing the viewpoints of the design team and participant S. deals with S's experience of using her glucometer and insulin pen e.g. during a professional lunch meeting: she doesn't always feel like explaining her diabetes. Building on the rituals taking place during a lunch, a social researcher, an interaction/graphic designer and a jewellery designer together developed the concept of a napkin that entails the different steps of measuring the glucose concentration in the blood: disinfecting the finger; pricking; capturing the drop of blood; and cleaning off the blood. Instead of hiding, this act is made more comfortable and familiar, like a ritual. In the video, this team explains the origin of the concept, alternative ideas, possible elaborations and a Q&A with the workshop participants. During this Q&A, they discussed the concept's meaning and how it could make the self-care act discussable in a different way than S. is used to. As workshop participant B. mentioned: "by making it less medical you would still suspect an 'oh my'-reaction from bystanders..." and another designer O. (part of the core team) finishes his sentence: "...but she would find this type of conversation more pleasant".
- The third scenario and video created by the design team and participant B. represent B's wish to carry his self-care tools on his body during sports. Based on this, a product designer and product developer created a concept for carrying a glucometer. In their video documentation these makers explain their ideas concerning the prototype's functionalities. It also includes a small discussion between the makers and the other teams about the design of this 'holder' that makes you carry the glucometer in a very prominent way (i.e. on the outside of your clothes). The design team and B. redeveloped the prototype into a range of new 3D-printed prototypes with the same functionalities.

Evaluation of documentation in 'Bespoke Design'

The documentation approaches in 'Bespoke Design' were evaluated via an action research process. This means that the design research team brought together *action and reflection* in a process wherein academic and practical knowledge was developed in participatory ways (Reason & Bradbury, 2001a, p. 1). In 'Bespoke Design' we researched iteratively through action how to enable generativity of the project's process and outcome, by documenting its material and immaterial aspects. As described and presented in figure 5, three iterations of making and sharing video documentation among groups took place. Combined, all videos are a montage of the different viewpoints on the design project (and the prototypes) and illustrate diverse possibilities for elaborations. Including these documentation phases in the project allows evaluating the making⁴ as well as the sharing of this type of documentation (focussing on how it was perceived by its viewers/users). In a later research phase, we will elaborate our research and evaluate how sharing video documentation supports the sustaining of a generative cycle.

⁴ All documentation - i.e. the scenarios, video messages, prototype descriptions, blueprints, et cetera - are shared on the project blog (In Dutch: <http://www.designopmaat.be>)

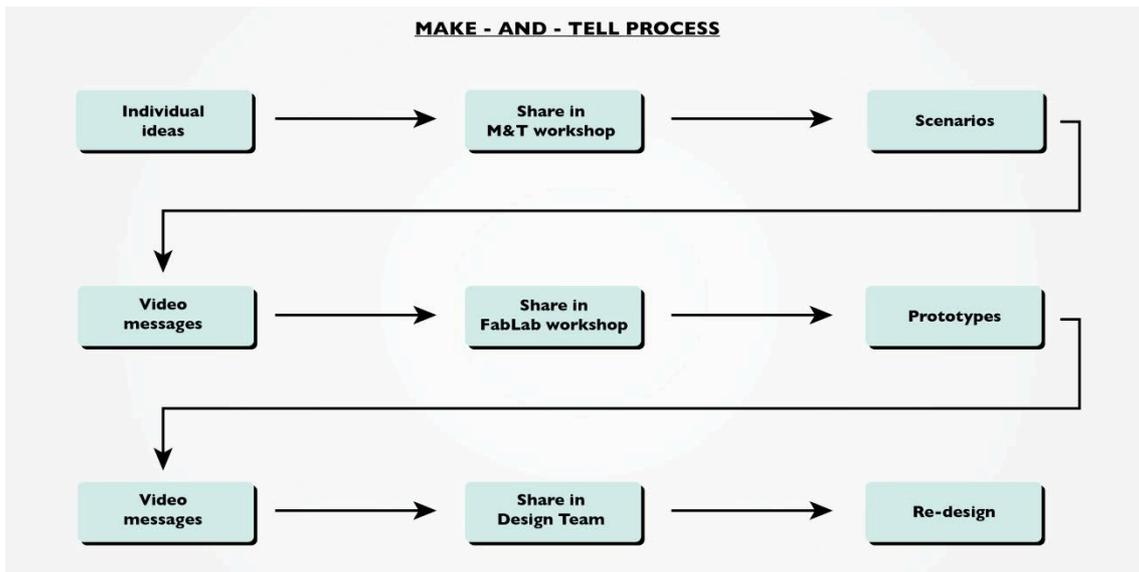


Figure 5: Three iterations of making and sharing video documentation

Since video documentation is used throughout different project phases, evaluations took place on different times, settings and using various methods by one design researcher, involved in a Phd on the role of documentation for generativity ends. To prevent bias this evaluation was further discussed with the three other members of the design research team and with another external researcher having expertise in documentation. We can cluster our reflections in three aspects.

First, Make-and-tell supports designers and participants to explore and confront each other's viewpoints. Make-and-tell includes a stepwise format by first mapping individual viewpoints and later collaboratively translating these into scenarios and video documentation. The use of Make-and-tell in Bespoke Design illustrates the value of this format: the design team was able to explore and discuss hypotheses about the experience of using self-management tools and design ideas with the participants. It also facilitated participants and designers to disagree. Taking into account the use of playful formats in other research (Brandt, 2006; Dreessen *et al*, 2011), we conclude that the playful format allows dissensus in sharing each other's viewpoints on a project, which is valuable in relation to documenting immaterial aspects of participants on a design project.

Second, Make-and-tell facilitated documenting the - sometimes contradicting - viewpoints of the participants in a readable way through a scenario. While it is interesting to share the - often kept hidden - viewpoints and exchanges that take place throughout a design process (Visser, 2010; Dix, 2007; Kanstrup, 2012), empirical research pointed out that these subjective backstories are difficult to document in a comprehensible way (Schoffelen & Huybrechts, 2013). The video documentation made with the toolkit and displaying the viewpoints of participants, however, proved useful as a briefing for the following workshop. Participants of this workshop could comprehend the videos and express their own viewpoints on them, which allowed teams to be formed spontaneously based on interests. Nevertheless, one participant found that the documentation overemphasised subjective information, while he found an exchange about technical information more useful. However, the design research team also observed that the videos communicating about material and immaterial (subjective) perspectives on the prototype led to more in-depth discussion between participants. We conclude that Make-and-tell offers participants and the design team a tool to easily create a

comprehensible scenario incorporating an exchange of immaterial viewpoints on a project, facilitating an easy transformation into a readable video message, leading to in-depth discussions.

Third, it is necessary to structurally support the documentation of viewpoints on both material and immaterial aspects of a design project. The first workshop demonstrated that Make-and-tell stepwise supports documenting viewpoints in scenarios and video documentation. However, the design team experienced limited support for translating this 2D form into video. While the videos enabled interesting elaborations in the FabLab workshop, we believe they can be made more engaging when the toolkit also structures making video documentation. In the second workshop a moderator supported the teams to produce video documentation. While this was of great value, not using the toolkit led to creating video documentation without a predefined scenario and insufficient attention to documenting both immaterial and material aspects. For the videos that were produced according to the Make-and-tell format, viewpoints on material and immaterial aspects were documented on paper cards before translating them into well-thought out paper scenarios for the video documentation. We should further explore how to integrate this stepwise format for documenting and sharing material as well as immaterial aspects through video documentation, without being too time-consuming. This latter brings us to our final result of the evaluation.

Last, the method stimulates designers and participants to take the necessary time to document.

This is at the same time the method's main weakness. The participants with diabetes indicated that they valued the method to collaboratively explore the complexity of using self-management tools but also stated that the process of documenting is time-consuming and sometimes felt as disturbing the workflow of the workshop, e.g. making video messages to explain their viewpoints more in-depth.

The project is still in the phase of developing a first series of prototypes and does not yet include redesigns by new designers or for new participants with diabetes. Consequently we could not empirically reflect on how the used documentation formats - i.e. structured via Make-and-tell versus a more freely making of video documentation - support the generative qualities of a design project. However, we observed that paying attention to the immaterial aspects of documentation, gives room to generate various scenarios for social use of these tools (e.g. the napkin), next to technical redesigns (e.g. redesign of sugar dispenser). These contextual explorations are necessary in design projects that engage with socially complex issues such as health. Also, it allows discussing the very personal aspects of a design (e.g. the importance of intimacy versus openness in using tools) with a variety of people (e.g. the more in depth discussion in the Q&A of the napkin project), and thus has potential for generating solutions on a larger scale. In the next phases of 'Bespoke Design' additional prototypes will be developed during new iterative Make-and-tell workshops, creating new stories for the prototypes and more insight can be gained in its generative qualities.

Note

The project Bespoke Design is a collaboration between Social Spaces and FabLab Genk and was made possible by OPAK funding of LUCA School of Arts (Catholic University of Leuven). More information can be found on the project blog www.designopmaat.be (in Dutch).

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Exploring the potential of touch-screen computer technology in the facilitation of enjoyable activity with people living with dementia: A visual ethnography

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Abstract

One of the most frequently identified unmet needs for the person with dementia is something enjoyable to do during the day (Smits et al 2007). It is increasingly considered that enabling technologies may contribute to this need by positively influencing the dementia experience (Topo, 2008). Although researchers have recognised the potential of developing technologies that assist the individual to navigate their day successfully, few have recognised the potential of existing technologies to support enjoyable activity. This multidisciplinary project focusses on the potential of touch-screen computer technology as a facilitator of enjoyable activity. Twelve participants in the moderate to later stages of the condition agreed to participate. This visual ethnography (Pink, 2001) utilised video-based participant observations as the main data collection method. Data analysis was multimodal, drawing on concepts derived from an interactional multimodal perspective (Norris, 2004) enabling both the audible and visual aspects of behaviour to be explored. The main findings suggest that people with dementia can enjoy preferred activities promoted through touch-screen computer technology when appropriately supported.

Key words: Touch-screen computers, dementia, video methods, participant observation, enjoyable activity

Introduction

Dementia is a chronic, degenerative brain disease that typically presents itself through the gradual but irreversible decline of short term memory. The progression of the condition results in other cognitive domains becoming affected including language, comprehension and attention (Alzheimer's Society, 2012).

Activities that may be enjoyed during leisure time have been considered one of the most frequently identified unmet needs for people living with dementia (Smits *et al*, 2007). Yet, Dementia can lessen a person's ability to continue creating their own enjoyable activities which in consequence may lead to social isolation and disquiet (Topo, 2008). Evidence suggests that opportunities to be involved in enjoyable, meaningful activities may enable continued engagement in life (Genoe & Dupuis, 2012). Nevertheless, it is observed that many people with a diagnosis of dementia are consistently bored and are sitting at home with nothing to do (Phinney and Moody, 2011).

Technology can take many forms and, in common with the general population, can also play an important role in the lives of people living with dementia. In particular, technology can provide capacity to allow for continuous adaptation to changing circumstances. Many interventions have focused on impairment and loss of function associated with the condition. Research is limited on all that is retained and the potential of technology to promote enjoyable activity preventing people from becoming socially isolated and under-stimulated (Smith & Mountain, 2012).

There is increasing evidence that stresses the importance of giving the person with dementia a 'voice' in the research process (Genoe & Dupuis, 2012; MacRae, 2011; Phinney and Moody, 2011). Dementia can impair verbal communication, consequently non-verbal behaviour should be considered of equal importance when undertaking research in this area. It is therefore necessary to exploit appropriate methods that may attend to both the verbal and non-verbal behaviours when eliciting the perspectives of people living with dementia.

This multidisciplinary project drew on existing theories and models from Sociology, Psychology and Occupational Therapy to aid understanding of the findings. Specifically, The Zone of Proximal Development (Vygotsky, 1978), Actor Network Theory (Latour, 1987) and The Model of Human Occupation (Kielhofner 1980).

Methodology

Visual ethnography is being increasingly utilised in contemporary research and describes a process of creating and representing new knowledge based on the researcher's own experiences within the research setting (Pink, 2001).

Data collection methods

Video recorded participant observations are a preferred method for visual ethnographers intending to document the actual 'doing' of activities rather than the 'saying', as they are played out in the social context (Pink, 2004). This method enables the capture and retention of participants'

interactions with each other and the technology as well as allowing the researcher to participate in the event and facilitate engagement with the device. Video-based participant observation has been selected as appropriate to meet the aims of the project as this well established method has been considered effective in overcoming challenges that can be encountered when researching in the field of dementia (Nygård, 2006).

For example, dementia can impair verbal communication which can significantly impact how researchers obtain insight through verbal reporting, as to an individual's subjective experience. Thus, attending to non-verbal communicative behaviour including gestures, body language, facial expression and posture becomes paramount. This non-verbal behaviour cannot be effectively captured using audio recorders or field notes alone (Rose, 2012). It is vital that people with dementia are faithfully represented in research and any benefits to their participation are made clear. Video based participant observation is key to this representation as meaning is amplified and supported by written text as well as visual evidence.

Sixteen hours of video footage was captured during two, one hour sessions per week over a period of four weeks. Two discrete video recorders stood on tripods, each positioned at opposite ends of a large table around which the group gathered for each session. Based on previous observations of the group, the devices were uploaded with familiar activities already enjoyed by members that were considered to transfer effectively. These included dominos, solitaire and jigsaws as well as new interactive applications including virtual fish ponds and firework displays and the use of the camera app to enjoy photographs of the group.

Participants and research context

Twelve participants, nine women and three men, in the moderate to later stages of dementia consented to take part in the study. Participants were between the ages of seventy and ninety two, living locally within the catchment area of the group enabling community transport for those that required it. Eleven participants had no experience of touch-screen computer technology and one participant had used touch-screens in his job pre-retirement. The research context was a charity based organisation that provides a meeting place three days per week for people with dementia who live in the community. Attending the group also provides respite for informal caregivers. The aim of the group is to promote opportunities to increase wellbeing, develop friendships and maintain existing skills.

Ethics and consent

The Mental Capacity Act (2005) states that a person must be assumed to have capacity to make informed decisions unless all practical steps to enable that person have been unsuccessful. The goal was for the person with dementia to consent with a full understanding of the nature and purpose of the research project. Written informed consent was obtained from all participants, informal carers as well as staff and volunteers involved with the group. A process of continuous consent checking was adopted in order to reaffirm that all group members remained happy to continue with their participation.

Consent included the use of video equipment in the collection, analysis and dissemination of the data. Visual research methods can be problematic as recognisable images of the individual are produced which makes it difficult to guarantee confidentiality and anonymity. Thus, each image used during research dissemination required the individual's prior approval. Providing the person has given their consent and is aware of their freedom to withdraw, there should be no ethical concern.

Data analysis

Data analysis has drawn on the methodological framework referred to as 'multimodal interactional analysis' (Norris, 2004). This technique is appropriate when non-verbal behaviour plays an equally fundamental role alongside verbal behaviour when analysing video based participant observations. Challenges arose when representing the non-verbal dimension of behaviour as meaning was lost when transcribing the data into text. An analytic technique was required that could translate the data effectively. It was decided to extract images taken from the video footage that when incorporated in combination with text could describe the gradual unfolding of a specific event. The ultimate aim was to illustrate how important aspects of social behaviour may go unarticulated when data is transcribed verbatim. Yet, when supported by images that depict non-verbal behaviour, knowledge is gained, meaning is evoked and understanding increases. An example transcript using this analytic technique can be viewed in figure 1.

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal	Mode 4 – Researchers reflexive diary	Mode 5 – research context
<p>Researcher: Have you done this before? Participant: I don't know whether I have or not love....you tell me! Researcher: You seem to keep winning Participant: Maybe I'm not as thick as I thought I was.</p>	<p>Participant turns to the researcher with her hands raised and an expression of accomplishment on her face. The researcher turns to the participant in amazement.</p>		<p>I felt her sense of achievement. I wonder how often she has considered herself as 'thick'. She had no difficulty interacting with the technology and was looking forward to telling her great-grandsons.</p>	<p>This is a day care centre held in a church hall. Group members, staff and volunteers sit around a large table chatting and interacting with various activities. Support is on a one-to-one basis within a group context.</p>

Figure 1: Example transcript

Findings

Overall, participants were receptive to the technology and their participation with enjoyable activities. Some chose not to engage with the devices for extended periods of time yet were observed participating in increased social interaction and conversation enabled by the technology. Engagement with the technology was not necessarily consistent across sessions for each person as individual differences play a large part in explaining the ways people may experience dementia. Three recurring 'types' of behaviour became obvious during data analysis and are described here as

scaffolding, technology interaction and observed gains. The typology depicted in **figure 2** below illustrates the main findings from the study.

Typology depicting individual technology use

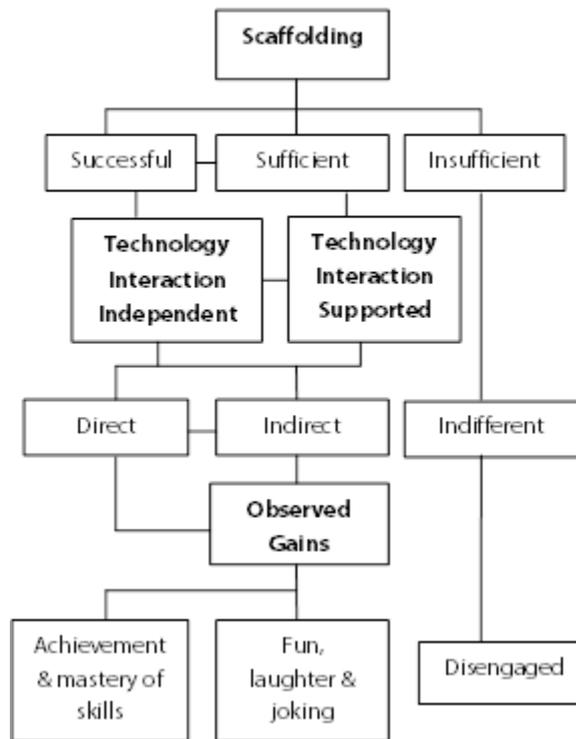


Figure 2: Typology

Scaffolding describes a structure of suitable encouragement and support based on consideration of the individual’s capabilities (Vygotsky (1978)). Scaffolding has been divided into three types; successful, sufficient and insufficient. Successful scaffolding may lead to no required support and the participant maintaining independent technology use. Sufficient scaffolding describes the presence of support as sufficient for the individual to interact with the technology. Insufficient scaffolding describes the situation whereby technology interaction fails to be maintained by anyone, including those in a supporting role. Each type of scaffolding impacts the technology interaction that the individual experiences.



Figure 3: Scaffolding

Technology interaction was observed to be influenced by the type or quality of scaffolding received as well as having an impact on any observed gains experienced by the individual. Technology interaction has been divided into three types; direct, indirect and indifferent. Direct technology interaction was observed to involve serious tactical and competitive strategies and ultimately the aim appears to be the mastery of certain applications. Indirect technology interaction is far more relaxed and informal whereby the interaction is an indirect consequence of the technology. The technology or an application on the screen may act as a prompt for a certain conversation or interesting anecdote but there is no ultimate goal here, just interacting for enjoyment's sake. Indifferent interaction describes the reality of technology use as some people have no desire to interact with ICT, irrespective of dementia.



Figure 4: Technology Interaction

Observed gains are influenced by the type of technology interaction that has been experienced in addition to the type and quality of the scaffolding in place. Observed gains have been divided into two types, achievement and mastery of skills, and fun, laughter and joking. A third type has been labelled disengaged for those interactions that were not maintained. The achievement and mastery of skills was observed to be a product of direct technology interaction that has been successfully scaffolded. The fun, laughter and joking type is characteristic of indirect technology interaction that has been sufficiently scaffolded. Finally, the disengaged type appears to be a consequence of indifference to ICT that has been poorly supported.



Figure 5: Observed gains

Discussion

The findings indicate that touch-screen computer technology has the potential to facilitate enjoyable activity with people living with a diagnosis of dementia. Positive experiences such as these have the

potential to support function in the person with dementia overcoming some of the obstacles that accompany the impairment (Clare *et al*, 2013).

Few acknowledged that there may be a place for touch-screen technology in their day-to-day life. This suggests a need to increase knowledge as to the possibilities presented by such technologies, rather than a reluctance to participate in technology interaction. This is supported by the suggestion that people with dementia lack knowledge of available technologies and how they may be beneficial but they do not lack the desire to interact with them (Nygard & Starkhammar, 2007).

It was observed that the type of technology interaction can be dependent on the quality of support or scaffolding that is available. Likewise, the observed gains are characteristic of the type of interaction that took place. Each 'type' depicted in the typology will be discussed in turn.

Scaffolding

The term scaffolding (Vygotsky, 1978) has been used mainly in educational settings as a teaching method that provides the tools to those beings taught as they learn new concepts. The 'scaffolding' is gradually reduced as confidence in the task increases until such time as the behaviour becomes independent and the support may be withdrawn completely. Rather than merely the delivery of information, scaffolding requires the demonstration of information which is a vital factor in the success of the method. In this study context, it is the joint attention and the social interaction between the researcher and participant that also plays a key role and promotes this scaffolding behaviour (Astell *et al*, 2010). Not all participants received the same quality of scaffolding and equally not all participants would have behaved the same had they received the same quality of scaffolding support. Although the concept of scaffolding is useful in explaining how certain behaviours may be supportive, a comprehensive understanding is not achieved without the contribution from additional established theories.

Technology interaction

Traditional explanations considered social interaction to be akin to a theatrical performance carried out by actors (humans) using props (non-humans) in front of their audiences (Goffman, 1959). Contemporary theorists consider both humans and non-humans to contribute to social interaction. Actor Network Theory (Latour, 1987) proposes a society consisting of people, objects, ideas and concepts, collectively referred to as actors. An actor may only perform within the network in combination with other actors whether it be another human (other people with dementia, staff members, and group volunteers) or a non-human (touch-screen device, video camera). An actor is considered the source of an action irrespective of whether they are human or non-human, thus, not defined by 'humanness' but rather the potential to initiate an action that causes a reaction. A good example is provided by Turkle (2007), who explored human-robot interactions using Paro Therapeutic Robot. Results indicated that robots had the potential to diminish anxiety for people with dementia. It was concluded that those who felt socially isolated from friends and family were most likely to engage robots (non-humans) in social interaction. In the context of the present study it is suggested that the technology acts as an additional person during social interaction. Participants were observed initiating conversation that had been instigated by the device and, in contrast,

participants were observed physically turning away from the device as you might if you didn't wish to converse with a person.

Observed gains

The Model of Human Occupation (Kielhofner 1980) also suggests the environment is a form of network by proposing that behaviour is the product of both information and action within this network. Action yields new information which in turns enables new action and the cycle continues. The person (referred to as a system) operates in the physical, social and cultural environment by way of a process of input, output, throughput and feedback. This process is in constant interaction with the environment and seen as a *'dynamic network of inseparable relationships'* (Kielhofner, 1980 p. 573). The model suggests that the activities a person participates in and with is a result of combining motivation, past experience, ability and environment. This is interesting as it suggests that a person's unique characteristics interact with the context to create a network of ideal conditions. These conditions influence a person's motivation, what activities that person does and how they perform that activity within a given environment. This deepens our understanding of how different people accomplish different goals even when participating in the same activity, within the same context. An awareness of individual differences is vital when undertaking any research project but more importantly, we need to acknowledge the aspect of 'self' that is retained in dementia (Sabat, 2010). People with dementia are not one homogenous group with the same likes and dislikes, capabilities and preferences merely because they share the same condition.

The three 'types' discussed above illustrate that future research with people with dementia and touch-screen technology needs to be based on three key findings. First, the interactions between the researcher and the participant must be scaffolded successfully to encourage optimum enjoyable interaction. Second, technology participates in the negotiation of social relationships, almost as though it were a third person (Pink, 2004). Third, the technology needs to be personalised to meet the unique needs and requirements of the individual.

Conclusion and future research

Familiarity of the technology and mastery of certain applications by particular individuals was observed within sessions. Limited familiarity of the devices or applications was observed between sessions for people in the moderate to later stages of the condition. Dementia is a degenerative condition, thus it can be assumed that the opportunity for new learning also reduces over time. Published evidence of new learning in the field of Dementia is limited although the trajectory of the condition could be considered as *'malleable....where change, adaption and improvement is possible'* (Spector & Orrell, 2010 p.959).

A subsequent study intends to focus on individuals who have received a recent diagnosis, thus possibly, but not categorically, in the earlier stages of the condition. The aim is to create opportunities that exploit retained skills thereby promoting possible new learning through personalised technology use. Encouraging such behaviours may enable and empower the person in the present as well as the future as they adapt to their changing circumstances.

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Affective Information Design for Patients

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Abstract

This paper deals with the subject of affective or emotion-centred information design for patients. The issue of emotion in information design for patients is currently under-researched and there are no existing models to account for how it might work or the components of it. This paper discusses two existing models of product emotion design (Norman, 2004; Desmet & Hekkert, 2002) to raise the question – ‘can existing models help the designer create information for patients that is both informative and emotionally appropriate?’. The paper finds much relevancy for the models and demonstrates their applications based on examples of designs currently in use with patients. Aspects of Norman’s (2004) design affects, particularly visceral and behavioural affects, map well onto the area of information design. Reflective design was found more problematic. Desmet & Hekkert’s (2002) model is applied and then expanded with ‘health as object’ and ‘information as object’ added as phases. The study explains how specific patient experiences can inform thinking about the movement between these proposed phases (the impact of self-efficacy) and other impacts on patient concern (such as health environment).

Keywords: Emotion, Healthcare, Information Design

Introduction

This paper deals with the subject of affective information design for patients. Affective information design for patients involves selecting and presenting information to patients with the aim of encouraging an appropriate emotion. The term 'appropriate' is used instead of positive, to allow for flexibility as to the type of emotion that needs to be elicited.

Research into patient information design has tended to mostly deal with issues of attention, comprehension, recall and behavioural change (Dixon Woods, 2001; Houts *et al*, 2006). The issue of affection in information design for patients is currently under-researched and there are no existing models to account for how it might work or the components of it. This paper discusses two existing models of product emotion design (Norman, 2004; Desmet & Hekkert, 2002) raising the question – 'can existing models help the designer create information for patients that is both informative and emotionally appropriate?'

This is a position paper calling for an adoption of models from different design disciplines, using a method of applied examples. It contributes evidence for the usefulness of these models and hopes to instil detailed future research as a result.

'Patient' as a term is used loosely in this paper to describe a person either using a particular health service or seeking advice due to a health problem prior to possible treatment. Information here refers to any form of content - in this context related to health issues - distributed on-line, on paper or in an environment. Healthcare information encompasses an enormous range of subjects including symptoms, treatments, results, helpful techniques and service information. The three short case studies included here focus on particular examples of information: survival rate charts, hospital displays and chronic pain information leaflets and there is much scope for a wider examination in the future.

Why is Emotion important in Health Communications?

Levanthal's (1970) parallel processing model describes how patients can process information both cognitively and affectively. These two types of information processing interact with each other and both require the designer's equal attention. It is clear, when reviewing research on emotion and cognition that positive emotion may impact positively cognition and decision making (Um *et al*, 2007). Positive emotion may also enhance motivation (Erez & Isen, 2002), and may lead to more positive opinion-forming (Petty *et al*, 1993). Peters *et al* (2006, p.147) demonstrated the need to "tailor our communication approaches to a person's emotions". Shrank and Choudhry (2012) concluded, echoing views of Peters *et al* (2006) that we need to find ways to make doing the right thing 'feel good' to patients. How do we achieve this as designers?

Identifying Existing Models

Current Emotion Models in Information Design

Emotion is not a term usually associated with information design. Information design has associations with neutrality (Levie & Lentz;1982) though according to Kinross (1985) neutrality is a problematic term. His work opens up our sense of what can be analysed with respect to emotion, including seemingly neutral diagrams. The information design community, however, lacks an 'emotional' model when working in the sensitive area of health. By far the largest amount of work in terms of design and emotion has been in the field of product design.

Current Emotion Models in Product Design

There are two influential models for analysing user emotions in product design (Ho & Siu, 2012). The first model examined (Norman, 2004) consists of the Visceral, Behavioural and Reflective Affects of Design. The second model examined is the basic model of product emotions (Desmet & Hekkert, 2002).

Visceral, Behavioural and Reflective Affect Design

Visceral Affect Design

Visceral design is an important function of products. It triggers an immediate reaction and it relates to the perception of a design (Norman 2004). Visual appeal within information design is already a recognised characteristic (Lankow, Ritchie and Crooks, 2012) and thus can easily be seen as relevant. However, this aspect of design raises particular questions for patient information design.

There is a glut of research that examines the use of pictures versus text in the design of patient information (reviewed in Houts *et al*, 2006). However there is a lack of research attempting to record patient preference in terms of visual appeal. By raising visceral design as a theme the model enables the designers of patient information to interrogate the role visual appeal plays in patient emotion.

Does visual appeal simply make a patient more likely to choose or use material or could it also help elicit a measurable positive affect such as inducing calm or feeling re-assured? What do patients currently find appealing in terms of picture use? Can, singularly, a layout, colour scheme, picture or typeface support or even induce a positive emotion? Whilst there are studies that examine the potential emotional meaning of typography (Tsonos & Kouroupetroglou, 2008) or colour (Simmons, 2011) to non-patients, it is unclear what role they play to patients. For instance, there is a difference between emotions connoted by certain colours or typefaces and an emotion actually triggered by seeing the typeface or colour.

Visceral design therefore is a potentially useful component of information design for patients but research is currently lacking in this area in order to provide designers with more conclusive guidelines about the relationship between visual appeal and emotion.

Behavioural Affect Design

Behavioural design relates to the functionality of an object (Norman, 2004). The mapping of behavioural design onto information design is straightforward as information needs to be used, read, interpreted and understood. If this is not achievable it can lead to negative emotion.

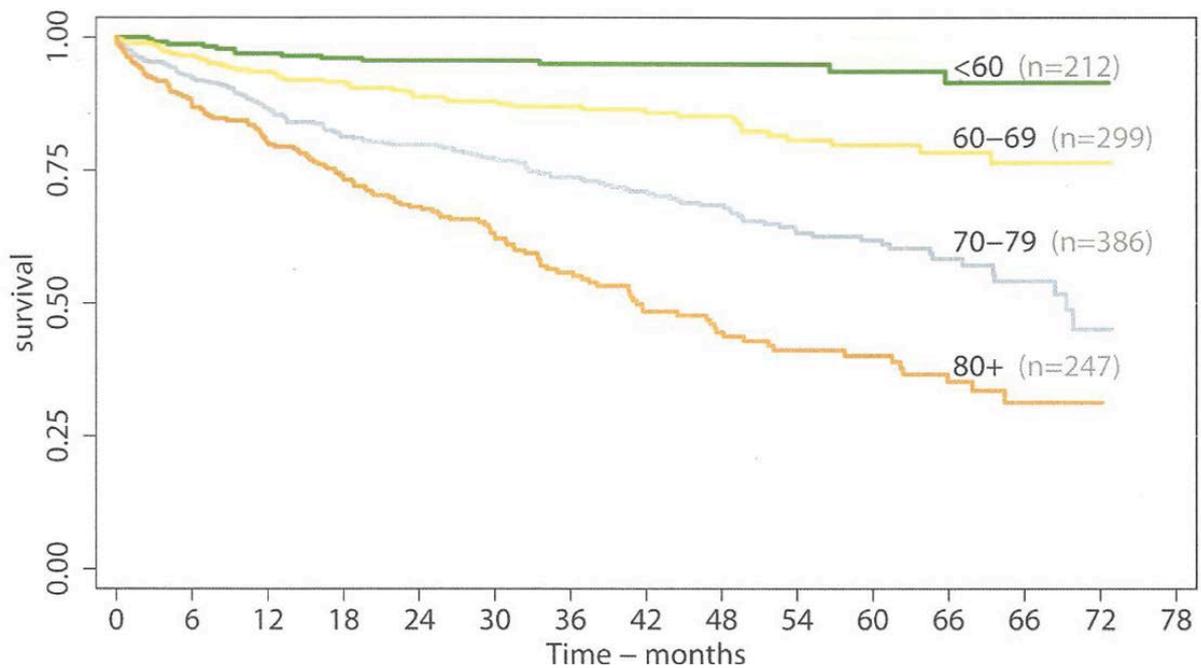


Figure 1: MGUS survival chart recently in use with patients

Clarity of information is vital. In a brief case study, we can examine a real-case example where a redesign of information was required. During consultations with cancer patients, a survival chart (fig 1) had been in use. It had not been designed specifically for patients. There are at least four reasons why usability fails in this chart. Alongside the possible frustrations of usage, there is also a clear emotional concern. Those who are 80 or over in age may be alarmed to see how poor their 'chances' are in relation to someone younger. Whilst the news the patient receives is potentially very alarming, the redundant content should not exacerbate the situation.

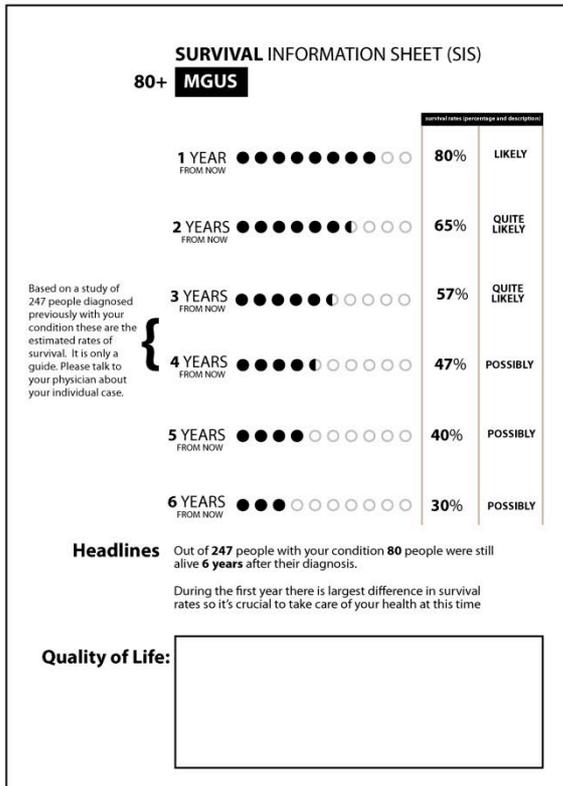


Figure 2: MGUS survival chart redesigned prototype - black and white version

In figure 2 we see a redesigned survival chart produced by the author. A bespoke set of statistics per age group (+80 is featured here) is now featured. Issues of clarity and ease have been improved according to design principles. Once behavioural design principles are applied the design can then be re-tested with patients.

Reflective Affect Design

The Reflective aspect of a design is the aspect that controls higher-level and intellectual powers of the user. In relation to products this is classed as those concerns that relate to prestige, brand and self-identity. Patient information may not, at first glance, be readily owned as a form of self-identity or prestige but is there a reason why it couldn't be? The key argument against this is that it says that the owner has a health problem and this usually would be negative connotation for the self-image. The second argument against this is the issue of ownership - without ownership can there be brand attachment? Payne (2002) cited a small scale qualitative study of patient views on leaflets, stating that patient leaflets tend to be viewed as ephemeral. Reflective design seems difficult to apply to the health area.

Taking a broader view, however, on the issue of high levels of intellectual power, information design of course may facilitate this, allowing the patient to grapple with complex issues. However, this intellectual power embeds itself more in behavioural design at this current time. Reflective design may very well play a part in certain aspects of information design for patients in the future but it is difficult to apply an example from current information design practice.

In summary then, Norman's (2004) work appears most relevant for information designers in terms of visceral and behavioural affect design. Reflective design requires further consideration if it is to play a role in future models.

Appraisal Theory and the Basic Model of Product Emotions

Desmet and Hekkert (2002) presented an appraisal-based model of emotion in design, stating that the user's appraisal (Frijda, 1986) is a key factor in determining if and how a product design evokes emotion. Their model is shown in figure 3.

The 'Object' within the model is broken down into three components: product, interaction and consequence. In addition the model comprises of 'Concerns' made up of Attitudes (enduring, strong beliefs), Goals (achievements to be met) and Standards (a set of ideals).

This basic model on first view is sufficient and flexible for modeling many user encounters with a design but what are the specific differences between an average user and a patient in terms of concern?

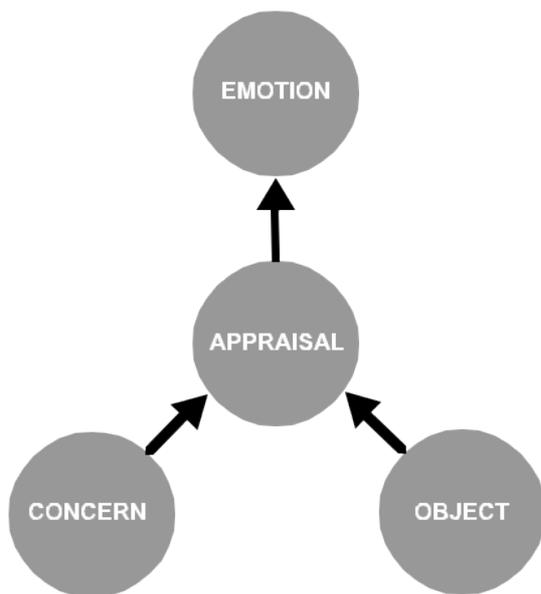


Figure 3: A Basic Model of Product Emotions (Desmet & Hekkert, 2002) taking the form of the diagram developed by Desmet & Hekkert (2008)

For patients, the health condition is the first stimuli (object) for appraisal, the precursor to seeking information. To accommodate this added complexity we propose firstly, a two-tiered expansion of the Desmet and Hekkert (2002) model (shown in Figure 4). This includes a 'Health as Object' phase that occurs first, followed by an 'Information as Object' phase.

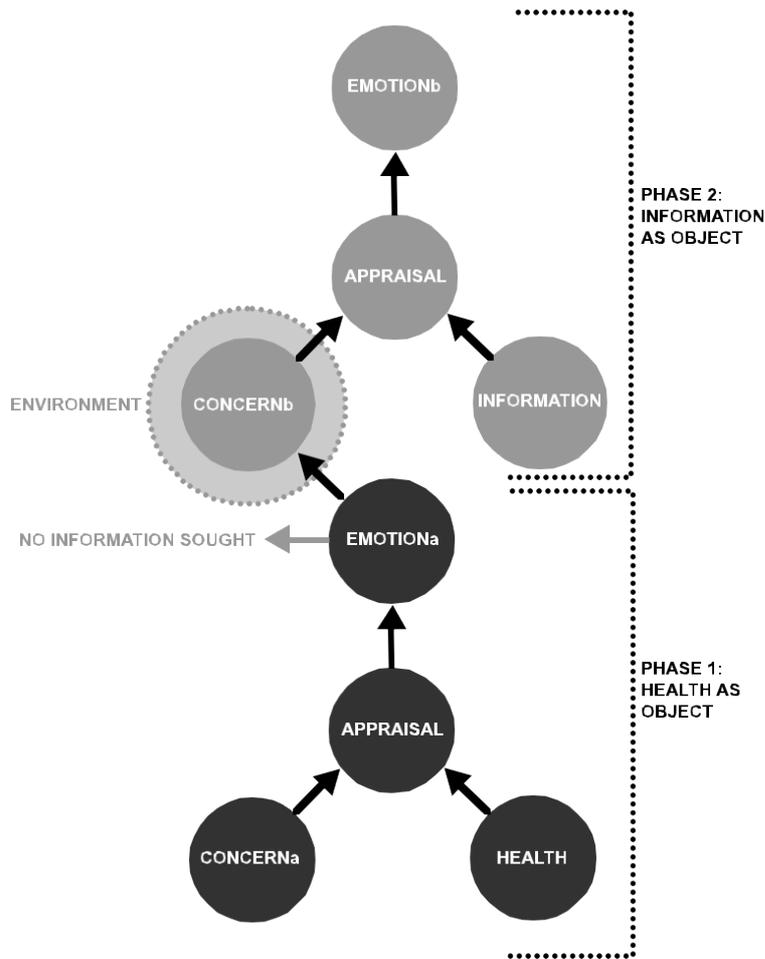


Figure 4: A new model of affective information design for patients (based on Desmet & Hekkert, 2008).

'Health as Object' - Phase 1

The object components (product, interaction and consequence) map strongly onto the 'Health as Object' phase - a diagnosed health condition has an identity (the product), the condition interacts with the patient (interaction), and a condition has a consequence. Typical concerns at this phase are very broad e.g. the expectations that a person stays healthy (standard), can improve fitness (goal), and their ability to cope (attitude).

Whether patients push past their 'appraisal of health' to their 'appraisal of information' is concerning. One reason for failing to progress may be lack of self-efficacy (Rimal, 2006; Bass *et al*, 2006). Therefore the 'Information as object' phase may not even begin if the patient appraises their own ability to cope as being too low. Though just one example, this highlights the problematic nature of appraisal of health. It leads us to question whether information design can tackle the issue of self-efficacy itself. The model in figure 4 includes a potential 'exit' from Phase 1 to highlight the issue.

'Information as Object' - Phase 2

The object components (product, interaction and consequence) also map strongly onto the 'Information as Object' phase and designers often focus their attention on the information design artefact, user interaction and end result.

The attitudes, goals and standards of 'concerns' map neatly onto the model. Attitudes are likely to impact upon engagement with information: for example, high self-efficacy could mean greater engagement with more pages of information.

Goals are likely to dictate what the patient wants the information to do for him/her. Particular goal concerns may well have already been discussed in academic research. Equipped with this knowledge, the designer should be able to prioritise this information, enabling it to be more dominant both on the page and within the overall structure of the pages. One of the challenges in this area, however, is the diversity of the two domains - healthcare and design - and the designer's access to the healthcare information.

Standards could be employed to guide the patient to select materials that look 'professional' and materials that appear trustworthy and reliable.

The model, then, seems very useful and appropriate. But are there further adjustments to be made? Two examples below will make the case for just one more additional expansion.

Environment as a crucial concern

An example of information design for patients that directly attempts to affect emotion is The 'Reducing violence and aggression in A&E' project, an initiative funded by the British Government's Department for Health and organised by the Design Council, UK (Design Council, 2011). Its aim is to reduce levels of high abuse and violence and hence curb a particularly strong type of negative emotion - one of anger and frustration. One of the key insights identified during the research phase was that lack of information and growing uncertainty was often the trigger to frustration and then aggression. Considering this in the light of the 'Information as Object' model concerns, whilst the initial goal of the patient was to be seen quickly, the environment of the A&E department itself was not only making that difficult but was also obscuring the goal itself, making it difficult to know when or even if, the patient would be seen. The solution was to devise a series of design interventions in the hospital environment, including maps of the A&E department and a number-based queuing system. What is interesting about this project is that the design does not say 'calm down' explicitly but instead intends to calm through giving the patient increased knowledge about the reason for the wait. What this example highlights is that goals must be facilitated by information and indeed should not be hindered by the health environment. The health environment can significantly impact upon patient goals and thus needs to be considered as a key element of 'concern'.



Figure 5: Screen designs from The Design Council's 'Reducing Aggression in A&E Departments' Project, 2011

For the second example we may examine a leaflet developed by the author to help patients reflect on the impact pain has on their lives and to encourage positive change. The paper-based tool aimed to positively show that life can be rich with or without pain. The tool is currently in use in the NHS as part of a pain management programme. However, it is vital that the place of distribution of the tool is sensitive to the goals of the patient. When this 'goes wrong' the induced emotion is undesirable. When a patient was given the tool after attending a physiotherapy clinic by a clinician, her goals at that time were related to having the pain lessened. This caused a mismatch between the object and the goal at that time. The result was the triggering of a negative response, in her case, anger directed at the clinician. This could have been easily avoided by ensuring that the information object complemented the environment-led concerns.

In both these cases environment has played a role in concern - either impacting and changing concern or causing a mismatch between concern and the object. Thus 'Environment' has been included in the model, surrounding concern in the 'Information as Object' phase, to acknowledge the role it could play in the formation of concerns.

Conclusion

It appears that both the work of Norman (2004) and Desmet and Hekkert (2002) can be very usefully applied in the area of affective information design for patients.

It was suggested that the first two design affects of Norman (2004) - Visceral and Behavioural - are particularly appropriate to information design for patients. However, many questions stem from the role that visceral design plays in eliciting emotion and this paper seeks to raise a research agenda for this area. The final reflective design affect is more problematic to apply to this field though challenges of attachment were raised which enables design thinking to occur outside the usual parameters of information design. Is this possible in our field and what are the implications of it?

Desmet and Hekkert's (2002) basic model of product emotions appears helpful when considering information design for patients. It allows the designer to consider and understand three states of patient concern and the appraisal model makes sense in the context of health. Here we have proposed an expansion of the model to accommodate some specifics of the patient experience. The model also now highlights the possible failure to move from one phase to another. Though just one example of what can provoke the patient to turn away from the 'Information as object' stage, it highlights again, the complexity of the patient as audience, and points to the need for the designer

to take account of blockages not just to reception of a particular design, but also to information in general. It also leads to questions such as 'how do we design to promote self-efficacy?'. We have also presented real examples of information design projects, raising other aspects of potential impact for 'concerns'.

This paper leaves many areas yet to be explored. Clearly a research agenda is required that examines the role of visual appeal in emotion for patients. Can visual appeal make a measurable difference to patient emotion? The differences in EMOTION_a and EMOTION_b of the model in Figure 4 depend enormously on the design and content engaged with. More information can lead to greater levels of distress or reduce stress and whilst this is beyond the scope of this paper, it is flagged up here as an area in need of much investigation.

This paper has demonstrated the usefulness of considering information design in the light of existing emotion design models and has shown how, even applying a few examples, models can be usefully applied and then adjusted. Since the model has been expanded in a reactive though reflective manner, drawn from experience and existing literature, more expansion will be needed over time.

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MS Outpatient Future Groups; Designing Tools of Interaction in Health Service Improvement Activities

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Abstract

*The National Health Service (NHS) has put great effort into service redesign, improving information provision and the patient experience for people with long-term conditions (Department of Health, 2009). Despite this, little has changed in multiple sclerosis (MS) services in England and Wales (Wade et al, 2011). The MS Outpatient Future Group study aims to improve the experience for people with multiple sclerosis (PwMS) when attending the outpatient department at The Royal London Hospital (RLH). **Aim:** To explore how speculating through design can be used to develop service improvements for PwMS who attend the outpatient department at the RLH. We will use a future group approach to explore how analogies and props can be used as tools to develop service improvements. **Methodology:** Qualitative explorative study using 'future groups,' a reinterpretation of the recognised focus groups method directed towards exploring future alternatives through employing analogies and physical props to engage participants to speculate about future health experiences and interactions, recording their feelings as contours on an Ordinance Survey (OS) map of the patient journey. Participants were PwMS and outpatient staff: staff nurses, nursing assistants, junior sisters and reception staff. **Results:** Use of future groups enabled PwMS and outpatient staff to envisage alternative health care scenarios. The analogy of an ideal journey and the accompanying props encouraged participants to invest their own ideas and feelings in the service improvement activity. The combination of participants in the groups with their diverse perspectives and knowledge of the service led to a collaborative approach in which staff highlighted potential practical problems and patients ensured ideas were holistic. **Conclusion:** Engagement of service users increased validity of the design proposals emerging from the future groups and encouraged adoption of the improvements. The analogy enabled participants to remove themselves from current financial, organisational and physical constraints, enabling them to suggest improvements for the outpatient clinic.*

Keywords: Outpatient experience, multiple sclerosis, focus groups, design

Introduction

Improving the patient experience through service redesign and greater information provision is at the heart of current health policy (Cayton, 2006; Department of Health, 2009). However in 2011, an MS Trust audit reported that little has changed in terms of enhancing the patient experience for PwMS (Wade *et al*, 2011). Various initiatives started to address this need although it was quickly realised that achieving this ambitious goal would depend on the active engagement of all staff in direct contact with patients to improve the quality of patient and staff interactions (Coulter, 2009). According to Parker *et al* (2007) this would involve changing people's behaviour. With this in mind, researchers, designers and health professionals have responded by involving patients and staff in service design activities (Bate and Robert, 2007).

Co-design is a participatory approach involving the public as partner designers of their own services (Cayton, 2006; Sanders and Stappers, 2008). By introducing a variety of design-based methods, co-design allows people who do not consider themselves as designers to carry out the design activity. This approach has been developed into toolkits to deploy design-based methods within service improvement activities (The Kings Fund, 2011). These toolkits are available for health care teams to conduct themselves within their professional teams. A popular toolkit is Experience Based Design (EBD), introduced into the NHS by the NHS Institute for Innovation (Freire and Sangiorgi, 2010), bringing staff and patients together in service design activities. Its core principles include partnership working with an emphasis on sharing experiences rather than opinions and storytelling to identify service touch points. By identifying areas in the care pathway where user experiences are critical, it is believed that service users can work together with staff to redesign their experiences. Tools and techniques employed within the toolkit include post-it notes, service diagrams, prototyping and scenario building (Bate and Robert, 2007).

Freire and Sangiorgi (2010) presented a review of service design innovation projects and their long-term impacts. They noted that although these techniques are seen as successful in the service improvement discipline, there was a lack of evaluation of the methods success in improving health services (Freire and Sangiorgi, 2010). Additionally, little is known about how the toolkits are used in practice and whether the toolkit approach is successful as a method for delivering design-based activities amongst non-designers (Kimbell, 2013).

This paper examines how speculation through the use of analogies can be used as a design tool by non-designers in a service improvement project. The notion of speculating to imagine alternative futures is influenced by the speculative design discipline (Malpass, 2013). In this specific field, speculation is used to imagine alternative ways of living for the purpose of reflecting and developing discussions on current issues.

For any individual patient, each episode of care is a complex series of interactions that make up the processes of care and is commonly likened to a journey (Layton *et al*, 1998). A crucial aspect of the MS Outpatient Future Group study was likening this journey through the health service to that of an ideal journey, the example that was used was of travelling on holiday. Through speculating, the study aimed to discuss service interactions that evoke ideal feelings of pleasure, excitement and enjoyment then imagine these as service interactions in a future health service. Although, at first

unrealistic, this aims to act as a catalyst for discussion and to create an opportunity for participants to think innovatively and re-imagine the outpatient service.

Methods

Setting

The MS Outpatient Future Group study was developed as part of a larger service improvement project. The outpatient clinic was chosen as it is a key access point for relevant medical knowledge and specialist services for PwMS. It is in the outpatient clinic where PwMS have regular consultations with their Neurologist and MS Specialist Nurse, get access to disease modifying therapies and receive access to wider care services.

Recruitment

The research team consisted of a Design Researcher, Medical Sociologist, Matron of Outpatients and Professor of Neurology at Queen Mary, University of London. The study successfully received National Research Ethics Service ethical approval in July 2012.

Patients were initially approached in clinic by a member of the clinical team, before meeting the Design Researcher. The patient sample was purposefully selected from the MS outpatient clinic at RLH. Patient participants required experience of being treated in this clinic. Two male and three female patients were successfully recruited alongside eight female members of staff. The sampling procedure for the outpatient staff group was naturally occurring (Kitzinger, 1994) i.e. the nurses were already working together in the MS clinic. The outpatient management team arranged the opportunity for outpatient staff to be relieved of their nursing duties for a morning and an afternoon to take part in the study. Full written informed consent was given by all participants.

Ideal Journey, OS Maps and Props

The study explored the group dynamics of focus groups to elicit feedback and discussion from participants (Morgan, 1998; Bowling, 2009). Although the interaction aspect of the methodology is pivotal (Bender and Ewbank, 1994; Kitzinger, 1995) and open to analysis (Lehoux *et al*, 2006), there have been few attempts to examine the impact of these interactions on the focus group participants or outcomes (Crossley, 2002). This study considers the method of interactional events and social spaces where participants can share and acquire knowledge from other participants while also co-constructing ideas.

Future group procedure

There were three stages to the study, each stage consisting of either one or two future group sessions. Each participant attended three future groups, one in each stage. Figure 1 displays how these worked. Every future group session was sound recorded, then transcribed by the Design Researcher and analysed using NVivo Version 8. Data was extracted and themes developed using

grounded theory (Glaser and Strauss, 2012) which are discussed in a separate paper (Thomson *et al*, (Submitted for publication)).

Stage One	Future group A: Patient participants (n=5)	Future group B: Staff participants; staff nurses, nursing assistants, junior sisters and reception staff (n=8)
Stage Two	Future group C - Patient and staff participants combined	
Stage Three	Future group E: Patient participants	Future group F: Staff participants

Figure 1: Future group procedure

Stage one – mapping the staff and patient journey

In the first stage, the Design Researcher asked both participant groups to reflect on their own experience of the outpatient department in response to probing questions from a topic guide developed by the two field researchers from looking at Appreciative Inquiry discovery interviews (Dewar *et al*, 2009). The questions centered around six stages of the outpatient journey; (1) preparation for appointment, (2) reception, (3) the waiting experience, (4) consultation, (5) leaving the appointment, (6) returning home and lasting memories. For staff participants, the questions dealt with their experience of working in the MS clinic; (1) preparing for clinic, (2) reception area, (3) interacting with patients while they wait, (4) consultation rooms (6) the close of clinic.

This journey map was in the form of an information diagram, compiled from conversations with the Professor of Neurology. People use maps in various forms to navigate the world, the maps for this study were designed to metaphorically navigate the outpatient service. The journey maps were designed to give the impression of an OS map (Figure 2) with a colour scheme and layout mimicking this, so that patients could immerse themselves in the analogy. In the maps, orange coloured roads relate to the individuals journey through the outpatient department and blue grid lines represent the journey structure.

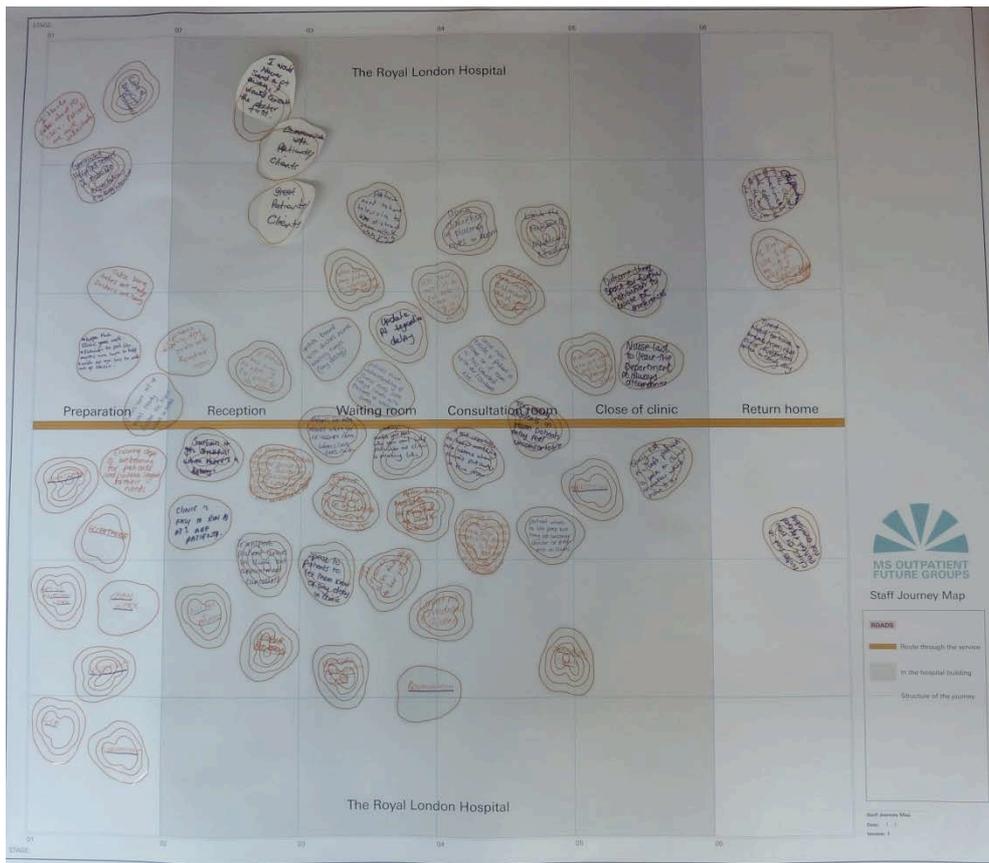


Figure 2: Outpatient journey map complete with contours after discussions in the staff future group, stage 1.

Stickers that looked like the contours on a map were provided for the participants to represent their feelings (Figure 3 and 4). For example a one contour line sticker represented a calm feeling, whereas the more contours (traditionally meaning a hill) the greater the feeling such as being scared, or anxious, or happy. When replying to the questions, participants were encouraged to write their feelings on a sticker and stick them onto the map at the relevant place. This visually linked the feelings of the participants to specific stages within the service. Over time the layers of contours built up, giving a 3-dimensional representation of the 'landscape' of their journey. The areas of intense feelings became immediately obvious.

Stage two – combing maps and discussing an ideal journey

The second stage combined the groups of patients and staff. The Design Researcher encouraged discussion around the journey maps from stage one, considering each interaction from both staff and patient perspectives. Sharing the feelings on the maps allowed the participants to understand how the other group perceived the service and experience interactions.

The participants were then encouraged to use an analogy for communicating the nature of the lived experience (Manen, 2007). The idea of going on holiday, an ideal (pleasurable) journey, was used as the analogy to best illustrate the different stages of a desired patient journey. This artistic approach served as a foundation to understand the participant's world (Janesick, 1994), and encouraged non-formulaic discussion.



Figure 5: Set of props given to every participant

Each participant was given a set of props to prompt thinking about the interactions they have throughout their ideal journey and their feelings associated with them (Figure 5). The props were used to encourage participants to engage in the analogy, record thinking and increase the interaction of participant in the session (Stewart and Shamdasani, 1990). Each prop related to each of the six stages that was being discussed: (1) luggage tag: for preparation, (2) passport: for checking-in, (3) departure clock: for waiting, (4) book on translation: to use at the destination, (5) return ticket: for departure booking, (6) postcard: for lasting memories.

Again the group was asked open questions about their feelings, as done in the first stage, to start the discussion then the participants wrote the interaction that they would carry out. The Ideal Journey Map's six stages were labelled similarly to the previous two journey map but with titles relating to traveling on holiday; for example instead of 'preparation' 'packing', instead of 'reception' 'check-in' and instead of 'consultation' 'destination'. Participants were able to consider the behaviours around ideal interactions, for example how they research new holiday locations, how they order from a

foreign menu and how they plan to travel to the airport. At each of the six stages, the participants were able to suggest how their service interaction on holiday could become a future interaction in the outpatient service. This activity encouraged participants to suggest new interactions and improvements that could be provided for future patients and staff throughout the outpatient journey. This included receiving more information or interacting with staff in new ways, in order to achieve their ideal feelings.

One of the participants read out the comments on the props and allowed the rest of the group to assign these to the proposed improvement ideas. It was crucial that this came from the participants to enhance the interpretation and validity of research findings.

Stage three – developing service improvements

In the third and final stage, the staff and patient participants met separately. The service improvement ideas were presented back to participants in the form of prototypes that were visualised and presented through a series of conference style posters that the Design Researcher developed. The aim of the final stage was to discuss how to implement the new service improvements in the clinic. Senior nursing staff management, the Barts Health NHS Trust volunteer service, an MS Specialist Nurse and the Professor of Neurology attended the staff group to endorse and strengthen the transition of the improvements into clinic procedure.

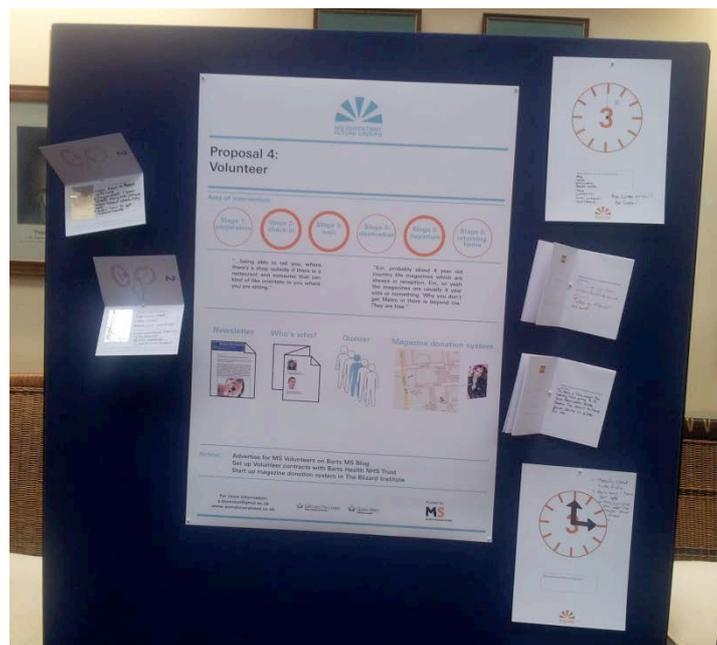


Figure 5: Example of one presentation board to presenting service proposals back to participants in stage 3

Findings

Use of the analogy

Participants responded to using the analogy of an ideal journey in different ways. One patient participant, right at the outset of the activity, stated that they understood how the props and the analogy were to be used to think differently about the outpatient service.

(Patient 4); I suppose with all these things, as much the same way you go the doctors or to the hospital, I can see that there's a good correlation between the two things. It's quite good, it's a good way of doing it, looking at it from a slightly different angle.

Six participants shared their experience of holidaying and three of these were able to make direct suggestions for service improvements. For example, one participant describes how she researches the holiday location before she travels then relates to how this would be useful behaviour for the outpatient clinic.

(Patient 5); ...So I suppose what is there, slightly different is em, where, what is the destination, what the nice restaurants what is the nice places for the kids, still related to MS, but just beaches, woods or whatever, but em, in relation to hospital I think, there is never ever a map with em, or there is never ever a eh 'drinks are over there,' never, and I think that would be really useful.

After the initial analogy was successfully adopted by the participants it then brought about a further seven analogies of service experiences. Three participants used other analogies of non-health related service experiences such as barbers, airports, travel companies, and car services. Four participants referred to service experiences of other health clinics such as maternity, diabetes and cancer services. The example below demonstrates how staff describe the volunteer in the epilepsy clinic to the patient participants.

(Staff 1); ...you've got epilepsy patients and they have volunteers that come in and they have a stand with that information stand and the volunteer the patients can come and chat to. [And they give them leaflets and things liked that.]

(Staff 2); [It's in the coffee room, its in the photocopy room.]

(Patient 5); Really?

(Staff 2); There's a stand

(Patient 1); [We talked about that before]

(Staff 1); [You can chat to them while you are waiting]

(Staff 1); [A little more information]

(Patient 5); [Yup yup]

(Staff 2); You can take it with you.

(Patient 4); That's usually a lay person isn't it

(Staff 1); Yeah it's usually a volunteers that can have epilepsy themselves [so they are speaking about experience]

(Patient 5); [That's perfect that's perfect, you know]

Possible limitations of this methodology were that some patient participants found it difficult to engage with the analogy of thinking of their hospital visit as 'ideal' or like 'going on a holiday'. Three participants did not refer to any analogy at all. One patient stated that she had not been on holiday in a long time so can't remember what it is like. One participant described how she felt initially the idea of 'going on holiday' to be 'silly' and found it hard to relate attending outpatients to going on holiday.

Use of the props to suggest improvements

The props were used by participants throughout the sessions to make notes and think about the questions posed by the facilitator and the groups discussion. When the translation book was introduced to the group, participants discussed how they translate foreign languages on holiday and were able to relate this to the idea in health.

- (Patient 5); I learn a little bit of the language, yeah I do, just to orientate myself.
(Facilitator); How do you do that?
(Patient 5): Learn the basics. Bonjour, Oui, you know the absolute basics to get me through. Knowing that I won't have, I can't master all of it. So I can understand some of the very simple communication, very simple, almost child like actually. You know, very quite basic
(Staff 2); The basic, please, thank you
...
(Patient 5); Yes because in your case [going to] France when you did its pretty alienating and you shut yourself away which is awful.
(Staff 2); [Yeah yeah] I was completely cause I was already in this country, two, just two years and I was scared me to death I didn't want to go there
(Patient 5); It's pretty alienating, in fact the experience, coming to close to medical jargon etc can be really really alienating.

When the passport was introduced to the group, discussions then revolved around patient notes. Staff were able to suggest how the maternity services deals with notes.

- (Staff 3); I'm straying from the subject now but...I see why they want to say their notes as they do it elsewhere like midwifery.
(Staff 2); Yes
(Patient 5); Why is it like that in midwifery?
(Staff 2); Cause they can have a baby anywhere, that's why. That why, you have to carry.
(Staff 3); So the same format should be eh eh you know,
(Patient 3); Because following that theme you could become ill anywhere
(Staff 3); [Ofcourse]
(Staff 2); [Yes. And also]...this is why we get so many.
(Staff 3); If patient comes to hospital the first thing they should hand over is the passport, the notes!

The physical props in conjunction with the visual mapping supported the use of the analogy and engaged participants to discuss possible future health interactions. Participants were cognitively engaged by spending time choosing the contour, organising them on the relevant position on the

map and relating to how they could use the props. These actions promoted a deeper learning (Moreno and Valdez, 2005). The use of the verbal and non-verbal platforms involved a variety of cognitive processes in making sense of the presented information. There was also the risk that the physical objects – the contours, the OS Maps and the props could have overshadowed the discussion but as the group was large it worked well, as some participants took a lot of time thinking and writing on the props whereas others immediately responded when the props were distributed. One participant specially commented on the attention to the detail and craft of the props. This participant commented on how the highly emotive contours made her feel that her ideas and thoughts were valued.

Use of speculation

The inclusion of the Design Researcher as the main facilitator explored the nature of developing service improvements in health service co-design activities. In this study it was not the designer's role to design the service improvements, but to facilitate the participants' creative process and produce their ideas, which were then reviewed in the final future group. The Design Researcher was able to encourage participants in their discussion, while also highlighting innovative ideas that had potential for implementation.

Sharing results with research participants in stage three acknowledged their contributions to the research study and was an essential component of knowledge transfer (Crosswaite and Curtice, 1994). This feedback session was crucial in the way that the Design Researcher ensured that the staff could make sense of the new improvements and discuss what the changes would mean for them (Brown *et al*, 2006). The presence of senior members of staff ensured the improvements would be implemented and especially for staff, their contributions to the project acknowledged. Discussions between participants and senior members of staff centered around the projected scenarios of staff and patient interactions allowing participants to discuss the implications of the idea before its use.

A number of ideas for service improvements were developed within the study and are being implemented; the introduction of expert patient volunteers into the outpatient department waiting room, a system where popular magazines are donated from the University Research Institute then delivered to the RLH on a weekly basis. An information resource was created which collates learnings from expert patients of the service including how to change your appointment, where is the best place to get a coffee in the local area, how to get the most out of your appointment, who's who in the clinic and how to contact them alongside prompt cards to prepare patients for their appointment while waiting.

Conclusion

The use of the analogy of an ideal journey successfully engaged both the patient and staff participants to think imaginatively about service experiences, both from within and out with health services. This freed up their thinking and led them to suggest future service improvements for the outpatient clinic. The analogy also enabled participants to remove themselves from current financial, organisational and physical constraints encouraging affective talk freeing participants from the rut of formulaic responses about resource pressures.

The physical props clearly enhanced the interaction between PwMS and staff provoking responses from participants. Feedback from participants in the collected data showed the success in uptake of the props was due to the design and attention to detail in crafting the analogy of an ideal journey. This contributed to the participants valuing the activity and investing their own ideas and feelings in the service improvement activity.

The MS OP Future Group study showed that the focus group approach can facilitate speculating as a design tool within service improvement activities, contributing to the vast research into the material environment and spatial arrangements of focus group research (Stewart and Shamdasani, 1990). Speculation alongside the use of props can be used to support non-designers in being creative. The interactive element of the methodology can structure and support a combined group of staff and patients to share experiences and collaboratively discuss their ideas and hopes for the future.

The approach described in this paper differs from existing toolkits and methods of service improvement through tailoring the focus group method to include speculation as a tool to engage participants to explore alternative service interactions. Further differences not addressed in this paper include the consideration of the limitations of time as a resource in design projects opposed to time attributed to research studies (Bruseberg and McDonagh-Philp, 2002) and differing perspectives of design.

To conclude, the purpose of this paper was not to argue that speculating should be enough to create action, but rather that it can be harnessed as a design tool within structured activities to inspire people into action, creating stimuli for creativity. Building and sharing a vision of what the outpatient service could be can ignite both personal agency and collective aspirations to produce an energy to drive change and implement service improvements.

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Evidence based design of single-bed patient rooms - Exploring the processes behind two successful stories

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Abstract

Evidence Based Design (EBD) is a promising approach in reducing the prevailing quality gap and pursuing new quality goals (Gesler, et al., 2004). The ultimate aim of the EBD is to increase the use of rigorous evidence. However, project level actual procedures of EBD can be neither self-prescriptive nor unique at every application. The process can be facilitated in a range of ways for collecting and applying evidence during the design process (Wanigarathna et al., 2012). The nature of EBD has opened up many prospects to implement it at project level. However, these tailored procedures and their relative merits in different contexts are less reported.

The aim of this paper is to contribute to this knowledge gap by responding to two main questions. Firstly, how the principles of EBD are applied by different project organisations, in different project contexts. Secondly, how these different approaches to EBD might ensure success in the ultimate design of the hospital. In the paper, the evidence based design process of a single-bed patient room was selected as an example to respond to the two questions. The EBD processes used during designing were explored through interviews with representatives of the design team, hospital trust and through documented evidence. Further interviews with representatives of the hospital trust and hospital staff revealed the performance of the design. Two project organisations have taken different approaches to design. Interviews confirmed both designs as successful, in terms of performance at the operational phase. EBD approaches implemented during designing have been influenced by opportunities to access the rigorous evidence of how properly designed buildings can improve health outcomes. Project teams have ensured the success of the design through different approaches to collect, evaluate and apply evidence. The processes have also been influenced by project unique circumstances and requirements. Success of the design has not, largely, been dependent on the design approach, but corresponding and appropriate activities.

Keywords: Evidence-based design, healthcare, single-bed patient room

Introduction

Following the practice of EBM, the concept of Evidence-based Design (EBD) emerged in the healthcare built environment design practice nearly three decades ago. Therefore, EBD is often termed as the ‘architectural parallel and analogue to Evidence-based Medicine’ (Hamilton, 2003; Pati, 2010). Not until the concept of evidence-based design, has design literature frequently used the term ‘evidence’. Instead, commonly used terms have been ‘design information’ (Emmitt, 2007, Austin et al., 1999; Austin et al., 2000 & 2001), ‘design knowledge’ (Lawson, 2004; Demian and Fruchter, 2009, Heylighen, et al., 1999; Heylighen, 2000; Cross, 2001) and ‘design inputs’ in the design process models. The Oxford dictionary defines ‘evidence’ as:

“the available body of facts or information indicating whether a belief or proposition is true or valid” (Oxford dictionary, 2013).

In this sense, ‘evidence for design’ is the available body of facts, or information, indicating whether a design proposition is true or valid. However, within the concept and practice of EBD, not all fact or information is evidence for EBD. ‘Evidence’ in EBD is frequently tagged with the attribute ‘best’ and or ‘credible’. What is ‘best’ or ‘credible’ is an ongoing debate in the EBD literature. Thus, for the research reported in this paper, evidence is defined as any research based evidence derived by academia, or practitioners, which proves how built environments can impact health outcomes. In the same way Moore and Geboy (2010) define evidence as:

“.....credible research conducted according to the highest standards of rigour appropriate for that given research approach....” (Moore and Geboy, 2010)

According to this definition, both scientific researches as well as interpretive researches, generated by both academia and practitioners in the industry, are considered as generators of evidence.

The strategy of single-bed patient room can be considered as a key design strategy that has emerged from the EBD approach. There is a considerable amount of literature which reviews evidence as to how single-bed patient rooms could improve health outcomes. Systematic literature reviews relating to this evidence have been conducted by previous scholars (van-de-Glind, et al., 2007; Habib, et al., 2005; Ulrich, 2006; Lawson and Phiri, 2004) but this paper does not intend to review these scholarly writings. This paper reviews how practitioners used evidence during the design process, based on data from two case studies of newly built hospitals with successfully designed single-bed patient rooms.

Case studies

As stated above, this paper presents results from two case studies. This section presents details of the selected two cases studies and research methods used in data collection and data analysis.

Description of cases

Case study A is one phase of a redevelopment programme of a children’s hospital located in London. The main purpose of the redevelopment is to improve the quality of the NHS estate to ensure that

the clinical quality is not compromised by the quality of the estate. The project has been funded mainly by the charity supporting the hospital, and partly by the NHS. The hospital delivers speciality care for children from the UK and around the world. The particular phase studied within this case study is a nine floored building with a 18,000m² floor area. The scope of the project is to procure a new building with the provision of 92 new beds. Case study B is a newly built hospital in Wales. It is a 'pathfinder' project which was delivered through the 'Designed for Life: Building for Wales' scheme. The project has been funded by the Welsh Government. The hospital has been built under a new health service strategy of the health board. Previously, the Health Board has provided both critical and non-critical care healthcare in several district hospitals. As the existing building stock is old a considerable amount of money has been spent maintaining them. In this new strategy, the Health Board has procured three new non-critical care hospitals and one specialist and critical care hospital to replace several of the existing district hospitals. The hospital selected for Case B is one of the three non-critical care hospitals which provide non- critical elderly care and a mental health service. It is a 100% single-bed room hospital.

Interviews with representatives from the client, designer, and engineers were conducted, together with a document analysis to gather additional supportive data. All interviews were face-to-face, except for the interview with the representative of the engineers in case study A, which conducted over the telephone. All interviews were voice recorded with the consent of interviewees, and were then transcribed into word documents. First, the process of designing a single-bed patient room was identified within the data as a narrative. This data were then further analysed, based on inductive thematic analysis principles to identify evidence use (sources of evidence) during the design process of the two hospitals.

Results

Approach to designing

The approaches to the designing of single-bed patient rooms in the two case studies have been notably different.

During the design of Case Study A, the practitioners engaged in the design process initially devised a single-bed patient room based on the evidence gathered through several sources (see Table 1 of the next section for more details). Design consideration specific to the particular hospital has been considered at this step of the designing (for instance extra storage for patients and family). This initial design was then improved, based on internal reviews by project team members, through a series of iterative evaluation steps. Internally evaluated design was then physically mocked-up by the constructor on site for further evaluation. The physical mock-up of the single-bed patient room was built when the basic design detail had been completed. However, further detailing and technical design continued during and after the physical mock up evaluation.

Members of the project team have then been able to evaluate the design in the as-built condition, thereby identify improvement opportunities. Further, representatives from the hospital staff, other users and interested parties were then invited to visit and evaluate the physical mock-up of the room. All evaluations have been conducted using a structured evaluation form. All comments

received through this evaluation step have then been assessed to identify important improvement steps.

As stated above, the physical mock-up has been built on the actual hospital site and has been preserved for subsequent uses by project team and the client. More importantly, sub-contractors who were later involved in the project have used this physical-mock-up to test and evaluate their fittings to be used during construction. This physical mock-up has also been used to train clinical and other hospital staff. Figure 1 summarises the approach taken in the designing of the single-bed patient room in Case Study A.

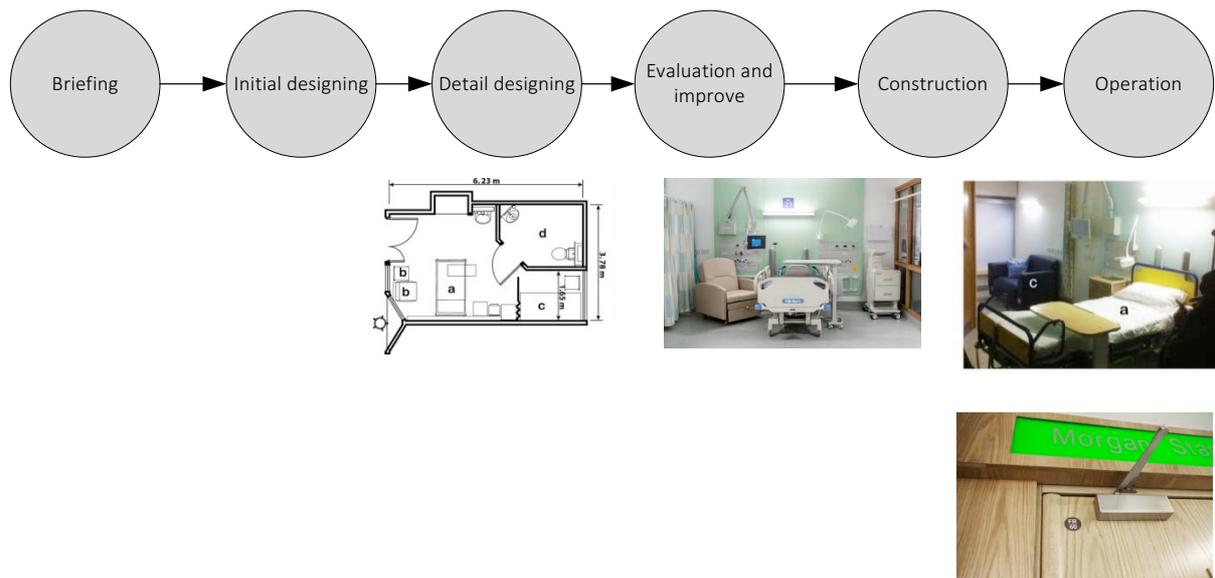


Figure 1: Design development approach of Case Study A

Case Study B has taken a different approach to that of Case Study A. Practitioners engaged in the project team of Case Study B first identified the design criteria that needed to be considered during the design of a single-bed patient room. These criteria were then articulated in the 'Terms of Reference (ToR)' which was then used to evaluate subsequent designs. Evidence gathered through many sources by all the stakeholders (see Table 1 in the next section) were used to devise these criteria. The project team, initially, spent a considerable amount of time to identify these criteria and the preparation of ToR was an iterative process of articulation and review. The final version of the ToR contained 26 design evaluation criteria related to functionality, infection control, observation of patients by staff, staff and patient environment, and other factors. The weight of each criterion during the design evolution was also identified alongside the criteria.

The design team then devised a series of single-bed patient room designs (during schematic design phase). These designs were evaluated against the criteria stated in the ToR. The three best suited design options were shortlisted. The selected three design options were then physically mocked up for further evaluation (Phase II mock-up). Physical mock-ups have been built on the site rather than in an existing hospital, or on the site of the intended hospital. Free transportation was, therefore, provided for the staff, public and other interested parties to visit the physical mock-ups in order to evaluate them. Key organisations involved in the project team (designer, healthcare planners,

engineers) produced evaluation reports of the three mock-ups and suggested the best suited design option. Other visitors also evaluated the three mock-ups, based on the criteria stated in the ToR.

One design option was selected during this initial mock-up evaluation process and was then developed further, in terms of detail and technical design. The mock-up of the selected design option was then improved to incorporate further details in the design through another phase of mock-up (Phase II mock-up). Phase II mock-up was evaluated based on the comments from the members of the project team.

The Figure 2 summarises the approach taken to the designing of the single-bed patient room in Case Study B.

ToR

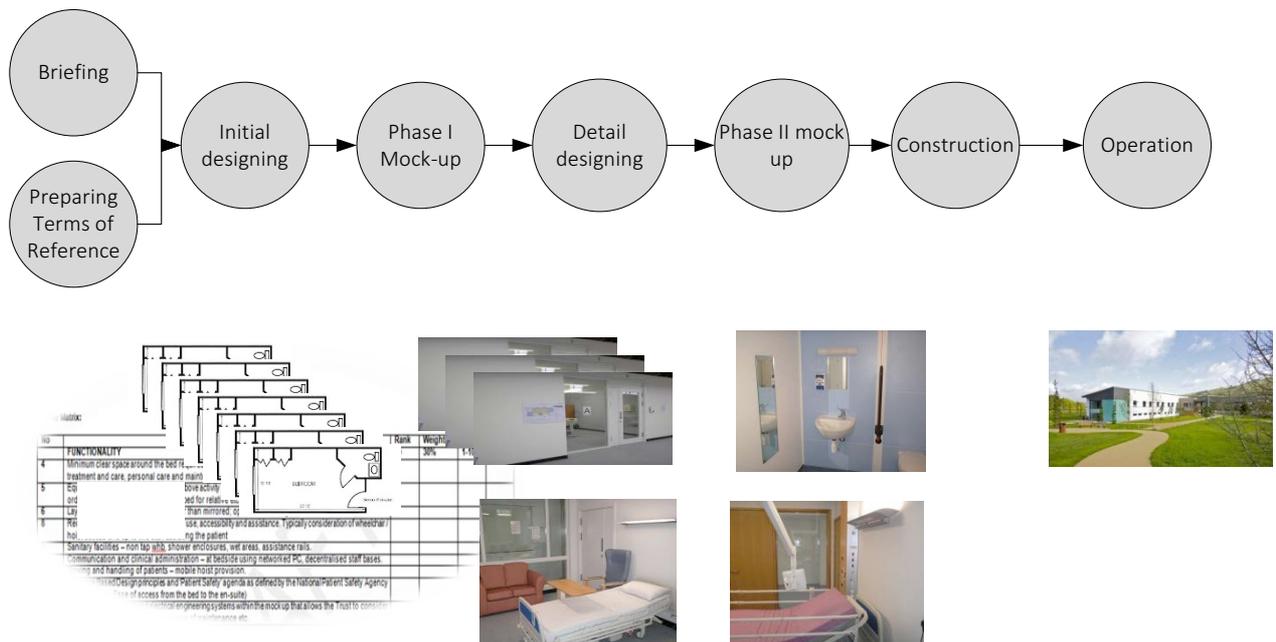


Figure 2: Design development approach of Case Study B

In summary, Case Study A has taken a problem driven approach to designing, where the design team have developed the design to solve the structured design problem, based on evidence. On the other hand, Case Study B has taken a solution driven approach to designing, where the design team has developed alternative design solutions and evaluated them against a set of performance criteria, identified through evidence.

Alternatively, the role of evidence has been contrasted with the approach to designing. In Case Study A, evidence has been used to identify prescriptive solutions to the design problems. For instance, the design team decided to use only the movable furniture whilst not using any carpets in responding to the problem of infection control through furniture. On the other hand, during the design of Case Study B, evidence has been used primarily in the form of performance specification to set performance criteria to review subsequent design solutions. For instance, one of the

performance criterion set for the design of the single rooms is 'bed head to be viewed from screen / observation window'. Subsequent design solutions have then been evaluated against these performance criteria formed, based on evidence.

Evidence use

Evidence use by practitioners during the designing of single-bed patient rooms in the two case studies was identified.

Both A and B cases have accessed research and other evidence through the sources listed below.

- Research (accessed through practitioners' engagement in research, newly generated evidence during the particular project and published research)
- Knowledge and experience
- Visits to other facilities
- User consultation
- Evidence from the industry
- Standards and guidance

The two cases have utilised the above sources of evidence through different means and to different extents (see Table 1).

In terms of operating performance, both hospital designs have shown improved functioning in many aspects. Case Study A has received positive feedback from the patients and families. Staff have commented that the design is positive and help to provide service better. The redevelopment team, through an initial observational process, has identified that the design has achieved most of its intentions, irrespective of minor snags. A formal Post-occupancy Evaluation (POE) for Case Study A is being carried out. For Case Study B, through a formal POE, it has been identified that the new hospital performs well in relation to: better sleep for patients, major reductions in infection and MRSA, increased patient and staff satisfaction and greater privacy and dignity. Few minor snags have been identified for Case Study B as well.

Examining the results, it is evident that the two case studies have adopted different activities in gathering, evaluating and applying evidence. The reason for this was associated with differences in circumstances of the two case studies. Case A has been in a favourable position to visit international facilities and gather evidence, due to the availability of resources. They have also been invited by other hospitals around the world for medical purposes due to the clinical expertise they have in-house. In addition Case Study A was in the second phase of a redevelopment programme. The client and the design team have gathered evidence and incorporated them into in-house standards for subsequent use. Further, the building in concern has been built on the site of the existing hospital as part of an expansion programme. The hospital had operational procedures in place and single-bed rooms have been used in a part of the existing hospital. All these have impacted positively on EBD activities in Case Study A. On the other hand, in Case Study B, the project has been a pilot project for the 'design for life' scheme started by Welsh Health of Estates (WHE), and the first 100% single bed room hospital in the UK. Therefore, the design team have had access to research activities conducted by the WHE (Welsh Health Estates) regarding single bed room hospitals. Second, the hospital has been built to support a new care model for the health board in order to treat non-

critical elderly and mental health patients. Therefore, hospital staff were not fixed at the time of development and the staff of the health-board had no prior experience of this type of hospital.

Table 1 – Means of accessing evidence by Case Studies A and B

Case Study A	Case Study B
Research – through practitioners engagement in research	
<ul style="list-style-type: none"> - Clinical staff engage in research - Facility management staff engage in research (infection control) - Partners of design team engage in research - Support research institutions to carry out research 	<ul style="list-style-type: none"> - Clinicians and designers engage in the research undertaken by Welsh Health Estates (WHE) - Clinical staff engage in research - Support research institutions to carry out research
Research – new evidence generation	
<ul style="list-style-type: none"> - Single stage mock-up - Test products and materials through enabling works - Modelling performance 	<ul style="list-style-type: none"> - Two stage mock-up (Free transportation has been provided for the public and other parties visiting the mock-up)
Published research	
<ul style="list-style-type: none"> - Access to medical journals by clinical staff - Pebble project evidence - Research reports by DH and other research institutions 	<ul style="list-style-type: none"> - Access to medical journals by clinical staff - Professor Roger Ulrich’s visit to share knowledge - Healthcare related conferences - Research reports by DH and WHE
Knowledge and experience	
<ul style="list-style-type: none"> - Knowledge and experience of design team - Knowledge and experience of client - Experience gained through previous phase of the redevelopment - In-house standards, guidance and tools developed through previous phase of the redevelopment 	<ul style="list-style-type: none"> - Knowledge and experience of design team - Expert opinion (Welsh Health Estates, National Patient Safety Agency, Community Health Council, Environmental Authority) - Expert opinion from Professor Roger Ulrich invited by the Welsh Health Estates <i>(knowledge and experience of client has been limited since this was the first large scale hospital for the client)</i>
Visits to other facilities	
<ul style="list-style-type: none"> - National and international hospitals including major paediatric hospitals in the world <i>(International visits have been video recorded to pass to the design team)</i> - Other places of interest to children (museums) 	<ul style="list-style-type: none"> - National and some international hospitals - Web searches for international best practice hospitals <i>(Many local hospitals visited have been converted into the single bed room hospitals and any newly constructed single bed room hospital or elderly care specific single bed room hospital has not been available to visit)</i>
User consultation	
<ul style="list-style-type: none"> - Patients and families <i>(Redevelopment team has developed a tool to identify patient needs, based on existing patients of the hospital since the hospital serves international patients as well)</i> - Staff consultation <i>(Consultation of clinical staff and other users has mainly been done through physical mock up evaluation and staff representative groups have been formed for involvement throughout the design review process.)</i> - In-house experts (play specialists, infection control specialists) have been directly involved in guiding some parts of the design 	<ul style="list-style-type: none"> - General public - Staff consultation - Physical mock up evaluation (by selected clinical staff and health board staff) <i>(This evidence has mainly been gathered through physical mock up evaluation)</i>
Evidence from the industry	
<ul style="list-style-type: none"> - Brought by Architects through tradeshows, conferences (eg. smart glass) - Brought by clinicians through visits to other facilities (eg. ceiling mounted patient hoists) <i>(Due to expertise available within the hospital staff of Case Study A have visited many hospitals around the world for medical purposes)</i> 	<ul style="list-style-type: none"> - Brought by Architects through tradeshows, conferences (eg. Whiterock) - Design teams’ experience from non-healthcare projects - Brought by clinicians through visiting to other facilities (eg. Vistamatic panels)
Standards and guidance	
<ul style="list-style-type: none"> - DH standards and guidance - Own standards and guidance 	<ul style="list-style-type: none"> - DH and WHE standards and guidance <i>(This evidence has mainly been used as a starting point and</i>

<i>(This evidence has been mainly used as a starting point and solutions are been improved through other evidence, for instance room layout, en-suite position to overcome deficiencies of standards and guidance and to support case specific needs)</i>	<i>solutions have been modified to improve based on other evidence, for instance room layout, en-suite position to overcome deficiencies of standards and guidance and to support case specific needs)</i>
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In addition, the Health Board has not procured a new built hospital of this scale in the recent past. The impact of these circumstances has been evident during the design process. Some of these circumstances in Case Study B have not been favourable when gathering, evaluating and applying evidence during the design stage. However, Case Study B has taken actions and alternative activities that mitigate the impact of negative circumstances (for instance the consultation of several external expertise to evaluate the design, attending conferences, the provision of free facilities for the public to visit the physical mock-up) to improve the EBD process.

In summary, the circumstances of the two case studies have been different and they have adopted different approaches in applying the principles of EBD. Yet both approaches have resulted in successful designs which showed increased performance during the operation.

Discussion and conclusions

This paper has given an account of evidence based design approaches taken by two successful hospitals built in the UK. The aim of this paper has been to identify how the principles of EBD are applied by different project organisations, in different project contexts and how different approaches to EBD ensure the success of ultimate design of the hospital.

The following conclusions can be drawn from the part of the research presented in this paper. First, there is no universal approach to evidence-based design. In other words, success of the design has not largely been dependent on the design approach, but on corresponding and appropriate activities conducted based on project circumstances. Practitioners engaged in designing could adopt the principles of evidence-based designing to suit their designing styles and project circumstances. Second, identification of weaknesses of the process, and the incorporation of alternative activities to mitigate negative impacts of the weaknesses, has been an important element of the EBD approach. Third, a considerable amount of research evidence (gathered through published research and generated by practitioners engaged in the industry) has been used during designing, and these have always been used in combination with evidence from other sources. Physical mock-up of the design has been used to evaluate the validity of this evidence (and evidence gleaned through other sources) before actual implementation.

The results of this study suggest that evidence could be incorporated into the design process in the form of prescriptive solutions, as well as performance specifications. Further work needs to be done to establish effective ways of articulating evidence into these two types of specifications.

This work contributes to existing knowledge by identifying a variety of sources practitioners use to gather and apply evidence, and by establishing how EBD is applied to projects with different circumstances. The conclusions drawn are limited as only two case studies have been examined. In order to gain stronger insights, this study needs to be expanded further by examining additional projects where design approaches have been successful, and comparing and contrasting them with those that have less successful.

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Ethnography in Designing for Older People

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Abstract

As the global population rapidly gets older, designers are continually seeking means to gaining understanding and eliciting true user insights into older people's design, health and wellbeing needs. Comprehensive field studies that are both empathic and sensitive are cited as essential in this regard, with ethnographies predominantly heralded for achieving this (Seidel, 2009; Newell et al, 2010). However, it has been identified that Ethnography, because of its roots in Anthropology, has not been fully elucidated for the purposes of designing, particularly for older people (White, 2013). This paper will outline the stages and methods of design ethnography required when designing for older people.

Keywords: Design for older people, Ethnography, Design Methodology

Introduction

It is now well recognised that the world's population is ageing. It is projected that by 2050 two billion older people are projected to be alive (United Nations, 2013); this will account for one in five persons in the world (World Health Organisation, 2000). As the percentage of older people grows, demand will also grow to meet and understand their specific design needs. With this, the methods in which we approach design and the individuals we are designing for will change. Designing appropriate products and services for older people requires deep unbiased understanding of their health and wellbeing needs. In achieving this, person centric methodologies are becoming increasingly important. Methodologies particularly with empathy and sensitivity as a core are essential in this regard and Ethnography has been heralded in accomplishing this (Seidel, 2009; Newell *et al*, 2010).

The marriage between anthropology and design has evolved through the 20th century in its earliest incarnation through studies in material culture, consumerism, and the anthropological study of object in culture. Ethnography has been used within Design Industry since the early 1980's. Parc Xerox pioneered this for design interaction between people and computer software in the workplace using it in Computer Supported Cooperative Work. However it has been noted that Ethnography has not been fully elucidated for the purposes of designing, particularly when designing for older people (White, 2013)

This paper discusses and outlines the process of Design Ethnography specific to older people. It will reflect on the role of the design ethnographer and inform future practice; detailing the key stages and considerations of the process. This paper will firstly outline the early stages of design ethnography prior to fieldwork; noting the construction of a participant sample and the ethical considerations required. It will outline means of conducting field research and further to analysing ethnographic data for the purposes of designing. Finally the practical output of a design ethnographic study will be discussed through the creation of older adult personas.

Constructing a Sample of Older Adult Participants

Ethnographic studies require participants that are "information rich" and that provide a trade-off between 'breadth' and 'depth' in a study (Patton, 2002 p.242). To best construct an information rich sample of older adult participants. it is proposed to recruit both prior to and during fieldwork. The sampling selection for this needs to be sufficiently broad, so as to facilitate the development of emerging theories, however allowing for appropriate movement between participants as fieldwork progresses. To achieve this, purposive sampling generates necessary boundaries and a representative sample. Coupled with this, chain or snowball sampling affords the design ethnographer the freedom to move with developing theories and to choose suitable participants to interview as they occur. This process of recruitment is very beneficial in developing a sample of older adults particularly for example, in retirement home settings, by gradually building the trust and confidence of a community.

Gatekeepers are essential in developing a sample of older adults. Gatekeepers for older people can be found amongst occupational therapists, managers within care homes, carers, community leaders,

and community board members. In the first instance, formal written letters of consent sent to gatekeepers outlining the scope, intent, and details of the research are helpful. However in addition to this a concise and easy to read information flyer can be more effective. This can quickly communicate the intent of the research in an informal way to older people. Recruitment through older adult communities can develop greatly through 'word of mouth'; in this regard it should be noted that within these communities another type of gatekeeper is present, these have been noted as "sub-gatekeepers" (White, 2013). Sub-gatekeepers assume the role of a spokesperson, representative or organiser and someone held in high regard within a community. Sub-gatekeepers were usually the first participant to be interviewed within the community. Once an interview is successfully completed with a sub-gatekeeper, trust is built and referral can be put to a number of friends or neighbours.

Methodology

Interviewing

Ethnographic interviews with older people should be informal and conversational in nature. Agar states that informality relies on semi-structured questioning, suggesting that researchers:

" [do not have] a list of written questions. Rather have a repertoire of question- asking strategies from which you draw as the moment seems appropriate.... not taking on the formal role of interrogator" (Agar, 1980, p.90).

To avoid an interrogatory approach to interviewing, it is firstly important to ease the participant into relaxed discussion. This allows for comfortable dialogue and for understanding to develop through deep and personal viewpoints. Interview questioning can mainly be achieved by semi-structured open ended enquiry, extracting information from participants whilst not interfering with natural flow of insight.

'Information-giving sessions' should be conducted before interview commences. This involves explaining the process of design ethnographic fieldwork, reviewing and signing consent forms, and showing the participant the equipment used in documenting the study. The interview can commence with broad informal conversation. This initial conversation could be in relation to a topical news story to increase confidence and informality, and this would be continued until exhausted. Following this, conversation can be steered more directly depending on conversation flow, maintaining informality whilst interspersing direct questioning when required. More direct questioning could be firstly used to help build a profile of the participant and gain a deep sense of personal and a cultural background. Spradley divides ethnographic questioning into descriptive, structural, and contrast questioning (1979). Throughout questioning, these techniques should be used in a casual sense, used when and if required rather than strictly adhered to in interview. In interview the researcher should adopt the role of listener rather than talker, ensuring conversation flow without interruption. Continually listening and understanding the participant's point of view, and reading the body language of the participant to interpret the flow of conversation.

Further informality can be added to interviewing by encouraging stories, storytelling and "oral histories" (Plowman, 2003, p.33) within interview content. This allows older participants to express individual and cultural experiences, nostalgic or otherwise, in a relaxed personal and narrative

fashion. This format was used successfully in an ethnographic study conducted by Sheehan *et al*, on Irish older adults and their experiences of falls in the domestic environment (2008).

Observation

Observation forms an extremely important function in design ethnography. It is used to visually collect data relating to the material world of people. Participant and artefact observation can construct a holistic and true visual repertoire of the older adult culture, their surroundings, and artefacts. To obtain rich and descriptive data in observation, Spradley (1980) cites nine dimensions to be considered: Space, Actors, Activities, Objects, Acts, Events, Time, Goals and Feelings. These dimensions, according to Robson (2002), describe the setting, the people and the events that are taking place.

Observing all nine of these dimensions is important to design ethnographies, specifically Actors, Objects and their acts between. In design research observation of *objects* is important in understanding the arrangement and schematic together with the real and “perceived affordances” (Norman, 1988; Norman, 2004) of artefacts. In observation of older people “cultural inventories” (Collier and Collier, 1986: 45) can be collected and constructed by the use of photography. Examples of cultural inventories are: the style of the environment, aesthetic of the décor, activities of the household, the character of order of the household, and signs of hospitality and relaxation (Collier and Collier, 1986). Collecting these cultural inventories is very much of interest in design ethnography as they help visually construct rich observational snapshots of cultural and artefact activity. Observation extends to the *activities* older people have in usability and interactions with the *objects* within their *space*. Of particular interest is the observation and understanding of *acts* within these *objects* and the *goals* participants are attempting to achieve.

Developing descriptive scenes through observation requires an awareness of Spradley’s ‘structured’ nine dimensions. However, ultimately, observation should be conducted unstructured, freely, and openly. Observational data can be effectively collected and collated by photography. In anthropology Collier and Collier promotes the use of a camera in the ethnographic process to record patterns, relationships, and specific evidence relating to the goals of the research (1986). In using methods of observation in a design ethnography for older people it must be noted the obtrusiveness of this. Whilst the researcher is trying to observe what is naturally occurring, temptation can occur in “surreptitious observations” (Wolcott, 1995 p.152) or observation by stealth. Curiosity can lead a researcher to come in contact with data of confidential nature. In using observation with older people, it is important to continually reinforce and reiterate ethical consideration. An example of this was used in an ethnographic observation study of older people and beauty therapy; here Paulson (2008: 258) used what she cites as “Open ethnography”. In open ethnography the researcher reaffirms that “the research subjects were continually aware of the purpose of the study for which they were being observed and gave their verbal consent” (Paulson, 2008: 258). This requires the researcher to be conscious of when the participant does not want to be photographed.

Participatory Techniques

A design ethnographic enquiry relies heavily on understanding artefact and human relationships, and it is essential to experience this relationship first hand. This can be achieved through active participation and the use of participatory techniques. Used primarily in product design research, participatory techniques are employed to gather data by using artefacts in context during interview. Participation should be used to observe interaction within the true context of use, to gain insight and empathy into usability acts. Furthermore, participation can be used to offer rich description to physical acts that could not be communicated by any other means. Participation and participatory techniques allow for the construction of thicker descriptions of occurrences, ones that cannot be achieved without physically participating with or interacting with objects.

Participatory techniques are used to observe artefacts, activities and acts between these. Furthermore to document theories in relation to how older adult participants perceive artefacts and the researcher's perception as an observer. For participatory techniques in ethnography and design, Sperschneider and Bagger (2003) utilise three methods. These are: "acting out", "researcher acting as apprentice" and "shadowing" :

Acting out

'Acting Out' involves the use of scenarios, allowing the participant to demonstrate the 'normal procedures' in use of products. Allowing the participant to act out or re-enact normal routines or scenarios within the natural setting while being observed and recorded. For example, White (2013) investigated the barriers in which older adult users experienced difficulty or failure in thermostat operation. In this study participants was firstly allowed to give personal verbal understanding of what was occurring followed by operating the thermostat or 'talking aloud' so as to describe how it was operated (See Figure 1.)

The Researcher Acting as Apprentice

This method involves the participant adopting a role of 'teacher' and the researcher of 'apprentice' to the participant. The researchers steps into the role of the participant (or user) and delves into the older adult perspective. It involves the researcher 'doing it themselves'. This method can be coupled with 'speaking out loud' the operation steps or thoughts involved in operation. During this method co design or participatory design sessions can also be introduced by questioning and collaborating with the participant into how artefacts could be hypothetically redesigned.

Shadowing

Shadowing can be used freely throughout design ethnographic fieldwork, allowing the researcher to walk with the older adult participant and broadly observe their daily routine.

'Acting Out' 'Researcher Acting as Apprentice' and 'Shadowing' adapted from: (Sperschneider and Bagger, 2003)



Figure 1: Fieldwork Data Collection: Observation and Acting out

Analysing Ethnographic Data for the Purposes of Designing

White (2013) suggests that design ethnographers should use traditional qualitative methods of analysis combined with design visualisation methods in order to execute analysis of data for optimum effect. In design ethnography for older people, it is important to visualise analysed data in a person-centric means, ensuring that data remains 'humanistic' and representative of participant's true requirements. Creating 'personas' of older people can satisfy the functions required for visualising data. Using the persona approach to collate and represent data for analysis is advantageous to designers for many reasons:

1. **Human centrality:** Developing and displaying hypothetical users preserves the human centrality of the data. Representing them in a true, personal, and humanistic format.
2. **Making sense of complexity:** Personas convey complex cultural archetypes with deep idiosyncrasies in a succinct manner.
3. **Maintaining focus:** To create theory from observations it is important that data is reduced to actionable insights. It is important to maintain focus on actual insights and people/end users rather than digressing off topic. Goodman *et al* (2006), suggest that presenting end users as personas helps a designer to focus attention directly on end users and thus creates empathy with them.
4. **Transition steps to designing:** It is appropriate to see the creation of personas as the first step in the act of designing. In a way, 'designing' the end user before designing for them.
5. **Validity and Reliability:** It is important for the purposes of validity and reliability in analysis to share finding and gain other interpretations and points of view from the data. Using personas in this regard focus's other viewers to understand and interpret collected data, this includes older adult interpretations.
6. **Confidentiality:** Creating fictional personas from data conceals actual individual identities.

"This is the airing cupboard and the water-tank with the boiler"
"In the winter when I want heating and hot water I can get it on the clock"
"I'm not a great man for the central heating it's nice to have it on in the morning...you
'm lucky 'cos I'm in the middle room. It's very warm in here"
"The bills don't cost me too much as account of the pension, but maybe a bit more with
broadband"



us other stages of the design process.
of inspiration and grounding in design phases such as
nd marketing.
to be organised, coded and analysed. Using colour to
ble for design ethnography. As distinct from other
lear visualisation and illustration to help develop
Coding data in colour is an iterative process (Figure.
developing new themes and categories as coding
progresses. This is achieved by reading, re-reading, highlighting, assigning and reassigning
appropriate colours to patterns and themes in the data. These patterns and themes can be used in
the development of realistic personas (Figure. 3).

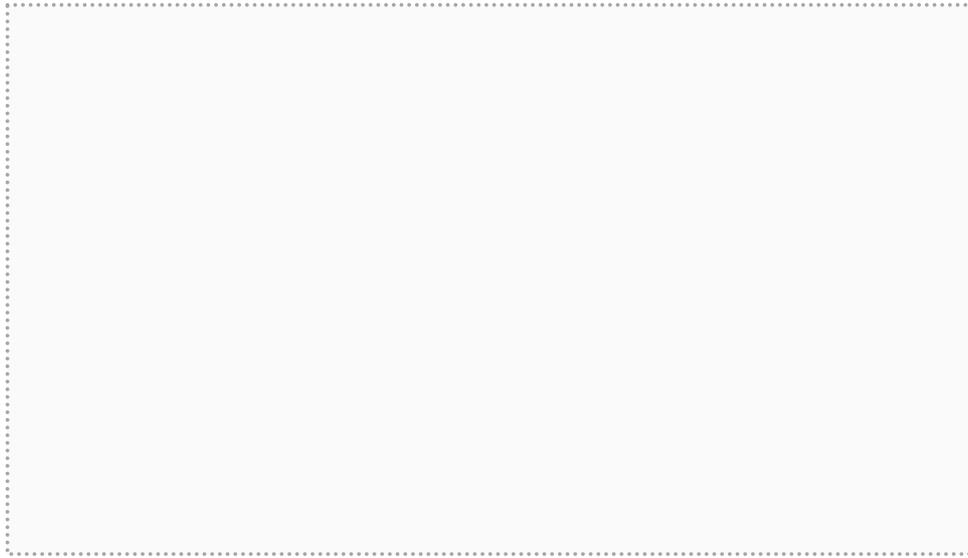


Figure 2: Colour Coding of data in process



Figure 3: Personas of Older adult participants developed from Colour Coding

Finally, when designing from design ethnographic data, it is important to describe the form of conceptual output that it creates. There is a vast quantity of implicit meaning derived from design ethnography whereby many abstract ideas can be created by this meaning. As a result, concepts can be critical and abstract in nature. Therefore it is important to maintain focus on the persona's requirements and, in staying true to person centric methodologies, triangulate design output with older people. This is where Co-Designing with older people can be useful, in reinforcing the data and in interpreting design output correctly.

Conclusion

As the world's population rapidly gets older, designers are required to be more empathic and sensitive in their approaches to design. Considering that ethnographic methods have been cited in achieving these approaches, this paper has outlined the stages and methods of design ethnography required for older people. It considers methodologies from early stage research to the intermediate stages of fieldwork and through to creating designed output from design ethnography. Even though many of these approaches are not restricted to designing for older people alone, it highlights the care and attention designers require in investigating this emerging population. Further research is required to continue merging ethnography and design for older people's health and wellbeing needs. With this future research, reflection and practice are essential in its continual development. Only by reflecting on the acts of ethnography and the practice of designing from these methods can we truly develop empathic and meaningful results.

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Understanding the influence of user context in persuasive self-management systems for diabetes control: The example of Chinese adults

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Abstract

Self-management is a tedious task for diabetes patients since it requires high motivation which is challenging. Persuasive systems have been found to help with diabetes management. However, many persuasive technologies treat users as a homogeneous group and ignore the user context. This study employed two different persuasive systems with the web-based system focused on narrative and affective approach whereas the mobile application systems were mainly used graphical and cognitive approach. The results revealed that although the web-based self-management system provided higher motivation for system use, there were considerable user context factors affecting the effectiveness of the persuasion and motivation. This study demonstrated that understanding the user context from the patient perspective can help to design more effective monitoring and self-management systems to improve health and well-being. This paper further discusses the implications of these findings for the design and future direction of research and persuasive technology.

Keywords: chronic disease, diabetes, motivation, persuasive technologies, self-management, user context, user experience

Introduction

Self-management is important for diabetes patients since it can reduce hospital readmissions, decrease the risks of developing complications, and achieve healthier outcomes while improving quality of life (Lorig et al, 2001; Bodenheimer et al, 2002; Holman and Lorig, 2004). However, self-management is also very challenging since patients need to change their lifestyles in many aspects over a long period of time; it causes adherence and motivation problems (Delamater, 2006).

Persuasive technology, as “an interactive technology that attempts to change attitudes or behaviours in some way” (Fogg, 1998), has been used in studies for weight control (Purpura *et al*, 2011) and diabetes self-management (Nachman *et al*, 2010) to motivate behaviour change. However, many of the persuasive systems were criticized providing only limited benefits and failing to sustain behaviour change in the longer term (Lustria *et al*, 2009; Neville *et al*, 2009). One of the problems is that many of these systems see users as a homogeneous group with the same motivations and use patterns. Many of these systems also lack an in-depth understanding of the connection between the users, the technologies, and the context of the system use, which results in high attrition rate over a period of time (van Gemert-Pijnen *et al*, 2011).

User context in persuasive self-management systems

User context, according to Oinas-Kukkonen and Harjumaa (2008a; 2008b), refers to a larger context of the users such as their needs, attitudes, motivations, abilities and cultural factors. They contend that understanding of use context and user context are important for the design of persuasive systems since they affect the effectiveness of the persuasion and system use. From the literature, there are at least three reasons why user contexts are important in diabetes persuasive systems:

- People differ in their reception of persuasive message.

According to the Elaboration Likelihood Model (ELM), people differ in their receptions of persuasive message (Petty and Cacioppo, 1986). The theory states that persuasion occurs through two routes of messages - the *central* and *peripheral* route. People with high involvement are most likely to be influenced by the central-route of persuasive message such as fact and figures, critical argument and claims, whereas people with low involvement are affected by the peripheral-route of the message which mainly relies on contextual cues such as attractive images.

Petty and Cacioppo (1986) claim that since central-route processing requires the individual to make cognitive efforts to evaluate the claim by comparing the information and considering the arguments, this leads to more persistent attitude change than the peripheral-route processing (Borchers, 2013). However, Petty and Cacioppo (1986) contend that the persuasion is successful only to satisfy two factors: motivation and ability. The individual should have adequate motivation such as personal relevance and need for understanding, and the ability to understand the message. They suggest that the persuasive message should be tailored to the individuals in their route of processing to be more effective.

- Patients differ in their self-management integration.

Adobe et al (2012) identify that individuals go through four phases in self-management integration. The individual's unique context, such as resources available, social supports, etc., affects their engagement in self-management (Audulv, Asplund, and Norbergh, 2012). The research recognizes the stages of change in self-management and how patients cope with the disease according to individual situations.

- Patients differ in their health beliefs and personal role in health care.

Some studies found differences between genders, ages, culture, health literacy, financial situations, lifestyles, and diabetes duration in self-management. For example, culture has a significant influence on diabetes management and the perception of health, including the individual characteristics, repertoire of skills, goals and motives, coping resources, diet, as well as exercise (Chun and Chesla, 2004; Chun, Chesla, and Kwan, 2011).

Since studies about user context in diabetes persuasive systems, especially in Asian context, are limited, the research is aimed at answering the following questions :

- Does user context affect the effectiveness of these systems?
- If yes, what kind of user context mostly affects the motivation and persuasive effects?
- Do the above mentioned user contexts affect the motivation and persuasive effects of the systems?
- Do cultural factors matter?

Research methods

This research was exploratory in nature, and used a mixed method approach including questionnaire, semi-structured interviews, diaries, and observations. To understand the user experience of diabetes systems in more depth, the research was composed of four phases: introduction to the systems, using the systems, post-use evaluation and discussion of the design prototype. Due to the length limitation, this paper is focused only on the results of the user context factors from the post-use evaluation and the design prototype interviews.

Process

The research involved two persuasive systems with distinct persuasive strategies; one was a narrative which focused on affective mode of persuasion; the others were graphical and didactic format which focused mostly on the cognitive mode of persuasion. The purpose was to understand how user contexts affect the effectiveness of different persuasive systems.

The participants were divided into two groups with one group using a web-based system, and the other group using two mobile application systems. They used the systems for about six to ten weeks in their own environment and a semi-structured interview was conducted individually to understand their experience and any problems they encountered in using the systems. The contextual factors

and the social aspects of using these systems were also examined in the interview. All the interview was audiotape recorded and the Chinese transcripts were translated into English for content analysis. The deductive qualitative analysis approach was used since it aims to validate or extend the theoretical framework or theory (Hsieh and Shannon, 2005).

The two systems

In persuasive technologies, the use of entertainment education and logbook type in the form of graphics and statistic format are the most common forms. Entertainment education refers to “the intentional placement of educational content in entertainment messages” (Singhal and Rogers, 1997, p. 117). EE can be in various formats such as games and narratives and, it is said to be especially useful in situations where the involvement of the receivers is low (Kreuter *et al*, 2007). Hence, it should be more effective for peripheral-route processing since it can increase engagement and reduce resistance.

On the other hand, the visual displays of graphics or statistics can assist in presentation of risk. The use of graphics and statistics can help the individuals to view and interpret certain information such as the comparative risks than just numerical information (Lipkus and Hollands, 1999). Moreover, the visualization of personal data such as physiological data and behaviour could help people to be more aware of their own behaviour and enhance decision making (Li, Dey and Forlizzi, 2011). The graphs and statistics can be seen as objective proof of progress so to enhance motivation (Goodman and Foucault, 2006). However, it requires certain numerical literacy to understand it so more cognitive efforts are needed to process the information.

These two kinds of diabetes systems were employed in this study. Both systems included information about diabetes, and/or diet and exercises, but they were in different formats and persuasive strategies: *narrative based* or *statistical based*. They were currently in the market so that the participants could use them on their device in their own environment and the problems could be truly identified than using a prototype.





Figure 1: Multimedia Web-based Diabetes Management System

Web-based system was a kind of entertainment-education including multi-media, multi-modal and multi-formats. It mainly used a narrative format consisting of games, case scenarios, quizzes, questions and answers, etc. It was served as education and training in self-management. It also provided different online forms for self-management recording. This web-based system was mainly employed an affective approach of persuasion. (Figure 1)

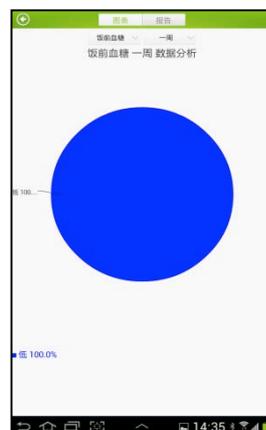
Mobile application systems were largely logbook types of systems for recording health, diet and exercise data; they also included information about diabetes, food as well as exercises. The users needed to record their health data manually in the systems and the data were presented in numerical and graphical format and could be retrieved when needed. These systems primarily used

a cognitive approach of persuasion with figures, numbers and statistics to communicate about risks and progress. (Figure 2 & 3)

Figure 2: Diabetes Management System



Figure 3: Weight Management System



Target participants

The participants were Chinese adults aged 40 to 70 with Type 2 diabetes who had been diagnosed the disease for three years to more than 10 years. Their educational levels were from secondary level to university level with diverse social and occupation backgrounds. They were randomly assigned into two groups depending on the device they were using in order to eliminate the problem in device use. In the pre-use phase, eighteen patients were recruited but later five female patients were withdrawn so the total number of patients in the post-use evaluation was thirteen, with five patients in the mobile group and eight patients in the website group.

Findings and discussion

The research discovers several user contexts affecting the persuasive effects and motivation in diabetes persuasive systems. Many of them are consistent with the literature review discussed above. Specifically, two types of patients with different *health literacy*, *level of involvement*, as well as *stages of the disease* were identified with distinct needs and motivations in system use, although individual differences were also found. *Cultural factors* also affected the motivation in system use mainly in relation to food issues. Other user contexts include *demographics* and *perception*; however, due to the limitation of length, this paper is only focused on discussing the former findings.

Health literacy, level of involvement and stage of the disease

Health literacy (HL) refers to the knowledge of the disease and self-management. The level of involvement (LI) refers to the motivation in self-management. It was found that the motivation in system use and information needs of the patients with higher HL and higher LI were different from patients with lower HL and lower LI.

For example, although most participants in the website group regarded the website as fun and interesting, a higher HL participant viewed it was boring: "*It is not useful to me since I have known the knowledge about diabetes before. I think this website is good for somebody who doesn't know much about diabetes.*" She mainly read the information about medication and food converter "*because it helps me to know more about these things*". In contrast, a lower HL and LI participant was mainly attracted by the games and quizzes on the website. He said, "*The games will enhance your memory, since if you make mistakes, it'll scold you!*" and he "*felt happy when using it*". He also demanded more information about food and restaurants.

In the mobile group, a participant with high HL and LI criticized the systems, saying they did not provide enough information in the graphs. He demanded suggestions to assist him to understand his health situation and how to solve it when needed. In contrast, a lower HL and LI participant did not care about the graphs it showed since he did "*not understand its meaning*" and thought that the blood sugar level will come down eventually, so he "*pretended nothing happened*". While he and another lower HL and LI participant regarded that using games and rewards made them more motivated to use the systems, the higher HL and LI participants did not. One participant even said he would not use it if it were a game-like system.

For high HL and LI patients, they required information and features that are more detailed, especially related to the treatments of the disease to aid them in controlling their disease - hedonic features were not their major concerns, whereas for low HL and LI patients, they were more motivated by simpler information and hedonic features. Hence, goals and needs are different in different types of patients .

Patients in different stages of disease were also found to have different needs in information and the features of the systems. Newly diagnosed patients seemed more concerned on how their activities related to the health situations. They checked their blood sugar more often; however, once they discovered the patterns, they checked their blood sugar less frequently. On the contrary, longer diagnosed patients checked their blood sugar less frequently; they checked it only a few times per week, or when they felt a change in their health situation, or they wanted to find new information such as the effects on their blood sugar levels when they tried a new kind of food.

The longer diagnosed diabetic patients were also more concerned about updated information regarding medication and new treatments of the disease. For example, two participants who had diabetes for over ten years strongly demanded updated information on diabetes medication and treatments in the systems. In fact, many participants who have higher HL and LI from the two groups were also concerned about the medication information. By contrast, one participant with around three years of diabetes confessed that she did not comply with diabetes medication since she thought that she could control the disease herself.

The research is in line with the study by Li *et al* (2011) that people experienced two phases in personal informatics: *discovery* and *maintenance*. The goals for newly diagnosed patients were to discover the relationship of their behaviour and health outcomes by collecting data for self-knowledge, whereas the goals for patients with longer years of disease were to maintain their health and control their disease, but they would go back to the discovery phase if their health condition changes.

This finding is also in line with the ELM (Petty and Cacioppo, 1986) that high involvement individuals are more affected by cognitive processing persuasion whereas low involvement individuals are more motivated by affective processing persuasion. These kinds of user contexts affect their goals and needs, as well as motivations in diabetes systems.

Cultural factors

The problems of cultural factors include food culture and lifestyles. Most of the participants liked to read food information and thought it was important, but they found difficulty in food counts. One of the problems is that Chinese food culture is different from the Western counterpart in terms of the food itself, the cooking methods, and how dishes and meals are served (Newman, 2004, p. 105). For example, Chinese people usually share a meal with other family members and each meal is usually composed of different dishes. This eating habit makes the diet very difficult to count and leads to accuracy problems. For instance, some participants mentioned it was difficult when they have social gatherings in Chinese restaurants or away from home since there were no information about the nutrition of the food and they found difficult to remember the food afterwards. These kind of obstacles affected their motivation to use the logbook systems. In fact, all the participants, except for one in the mobile group, resisted the idea of using the logbook system. As one participant stated:

LA: "It has to spend a lot of time to do so. How do you count how much you eat? You also need to convert it back, then to register it. It makes the whole process from start to end very difficult."

Furthermore, the participants in the mobile group were also asked for English version and more variety of food including western and Chinese food since "*Hong Kong is an International city*".

Interestingly, many participants in the website group preferred to use a mobile phone in self-management since it was more convenient for them as they were always on the go. However, one participant refused to use mobile management system since he thought it was a burden and that it seemed as if somebody was controlling his life.

Implications for design

The findings have identified that there is diversity in user needs due to different user contexts. Some implications for the design of these kinds of systems are suggested:

- Rather than designing one system to fit all, the use of persuasive strategies should be tailored for different users to be more effective. For example, for newly diagnosed patients and low involvement patients, using games and narrative strategies may be more effective in helping them to develop reflection and self-efficacy, whereas for longer diagnosed and high involvement patients, providing more updated information about treatments and facilitating easy monitoring of their health data is more important.
- It is necessary to develop a more comprehensive user profile for persuasive self-management systems to tailor for different user needs, not only demographic, but also health conditions, level of involvement, stages of disease, capabilities and lifestyles.

- Providing training and adequate information for chronic disease patients is also helpful in increasing patients' health literacy and self-efficacy and increasing their motivation to engage in self-management. However, in order to meet their motivations and abilities, and enhance the effectiveness of the persuasion, information should be delivered in appropriate formats such as narrative or graphs, and through appropriate channels such as website or booklet.
- The logbook systems were shown to create barriers rather than to assist in self-management and most of the patients refused to use them. Many patients actually developed self-regulation in food consumption if they understood the risks of diabetes. Simpler and more creative ways of managing diabetes are therefore needed.
- Multidisciplinary research and development of these systems is essential for self-management. It is complex and involves specialist information, knowledge and expertise from different disciplines.

Conclusions

In diabetes management, it is essential for patients to understand why changing lifestyle is needed and how to accomplish the tasks, so effective persuasive strategies is important. However, many diabetes systems employ a one system for all approach and ignore the context of use and user contexts. By using two types of persuasive systems, this research demonstrates that there are diverse user needs and goals based on different user contexts, which can significantly affect the effectiveness of the persuasive effects and motivations in the diabetes systems.

It also finds that diabetes and self-management is very complex, including personal, social, cultural and environmental influences. Although advanced technologies can assist in self-management, they will not yield success by themselves. The future design of these systems needs to have in-depth understanding of the user needs and contexts to create more user-centric design to help improving health and well-being.

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Warning! Packaging Can Damage Your Health

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Abstract

Previous work by the authors has shown that access to packaging in hospitals can influence the nutritional status of patients. This work indicated that five particular pack forms performed badly and that the issue surrounding poor access was linked to both strength and dexterity.

The study presented here looks at initial work undertaken to examine the dexterity needed to access this problematic packaging and examine methods for measuring users' dexterity. To that end a Purdue Pegboard, questionnaires, HSV and task analysis were used.

This work showed that there was a direct link between the reduction in dexterity and the time taken to open a pack. Further, packs that required multiple stages and complex actions were more likely to be ranked as problematic and cause problems for patients and staff.

Significantly, even users with poor dexterity were, however, able to open the packs. This is consistent with work undertaken by Sangar (2011) that showed users who had very poor dexterity and who had their medication decanted could, with some effort, open their medication. This leads to the conclusion that inability to open the packs is a function of dexterity, time taken and motivation. In a hospital setting the 'wellness' and posture of the patient may affect dexterity and hence increase time. The degree of 'wellness' is also likely to contribute to reduced motivation.

Keywords: Packaging, openability, nutrition

Introduction

Society is ageing; in 1950 the population of over 65s Worldwide was estimated at 200 million, increasing to 486 million by 2006 and to over 1.5 billion by 2050 (UN, 2008). Natural ageing results in a loss of strength, dexterity and cognition whilst the likelihood of living with some form of chronic illness is significant. The prevalence of disability from the US Census in 2005 demonstrates

that for individuals over 75, the proportion of people who need assistance is 55.9% rising to 71% for those 80 and over (US Census Bureau, 2010).

This significant demographic change creates a major public health problem for government, health practitioners and other stakeholders. Further, many of the illnesses previously associated with old age have more recently been attributed to poor diets (Sharkey, 2008).

The significance of these observations becomes clear with the recognition that nutritional status influences the age-related rate of functional decline in some organ systems. Hence there is undisputed evidence that diet and nutrition are directly linked to many of the chronic diseases afflicting older adults (Committee on Diet and Health, Food and Nutrition Board, Commission on Life Sciences, National Research Council, 1989).

A consumer's contact with food occurs across a wide range of scenarios, from meals in canteens, restaurants and takeaways to cooking at home with family or friends. Work by Yoxall (2012) showed that as people age, this interaction with food becomes more complex. Factors such as weight of packaging, accessibility of packaging, familiarity of brand and the environment such as isolation, the weather or access to transport affected purchase decisions (see Figure 1). The packaging of the food was seen to play a prominent role in older people's purchase decisions and their ability to access and prepare their food.

Figure 1: Influences on purchase of older consumers over 70 years old (Yoxall, 2012)

Packaging accessibility, whether for food, medicines or other products, has been found to cause difficulties for the aged or disabled consumer. A survey of 2000 people over the age of 50 by 'Yours' magazine (McConnell, 2004, Figure2) found that 91% of respondents have had to ask for help in opening a package, whilst 71% of respondents had injured themselves trying to open packaging. The 'openability' of packaging is therefore a huge issue for the aged and those with disabilities.

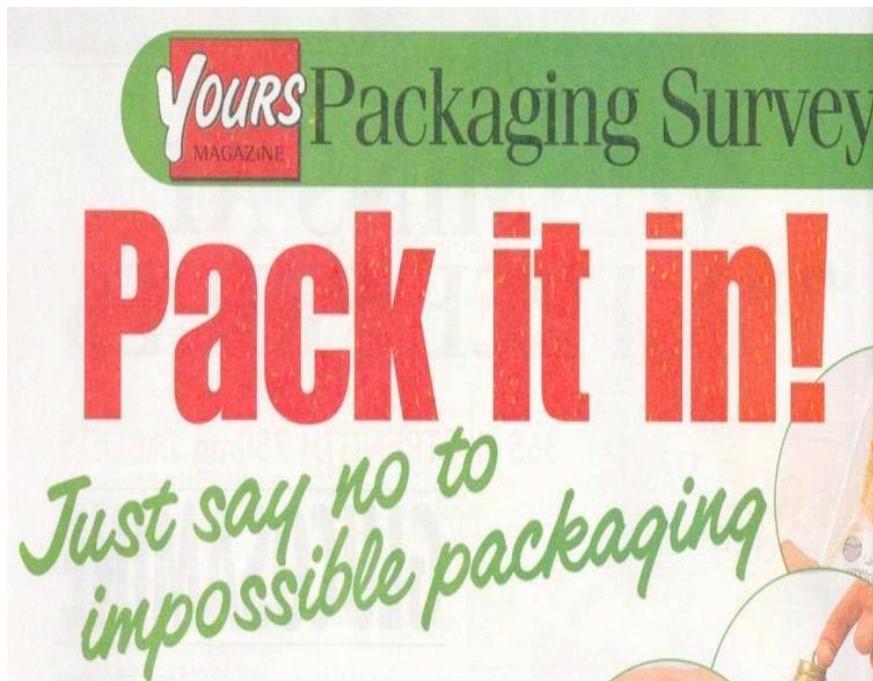


Figure 2: 'Yours' magazine survey

Previous Research

A significant amount of work has been undertaken by numerous researchers to understand the issues surrounding packaging and use by older people including the study by Rholes *et al* (1983), The Department of Trade and Industry (1999), Voorbij and Steenbekkers (2002) and more recently by Su *et al* (2009) and Kuo *et al* (2009). The majority of this work has attempted to understand the accessibility of glass jars with a vacuum lug closure. This type of packaging is commonly used for sauces, preserves and pickles and in the survey outlined earlier (McConnell, 2004) jars were ranked as the second most difficult item to open after bleach bottles.

However, whilst this previous work studied accessibility of packaging amongst the 'well-elderly', less research has been undertaken on the use of packaging within hospitals and care environments.

Schenker (2003) in their review paper estimated 40% of UK hospital patients were malnourished with 60% of patients at risk, whilst further studies have shown that elderly patients are five times more likely to be at risk of malnutrition than younger patients (Lazarus & Hamlyn, 2005; Banks, Ash, Bauer, & Gaskill, 2007; Vivanti *et al*, 2008).

Significantly, work by Mathews, Bartlett, & Hall, (2007) conducted a 1-day malnutrition prevalence audit across hospital sites in NSW, Australia and showed 51% (n = 777) to have some degree of

The work showed that for water bottles, the accessibility issue was related to strength, whereas for the cereal packages and tatra packs the issue appeared to be a problem of both dexterity and strength.

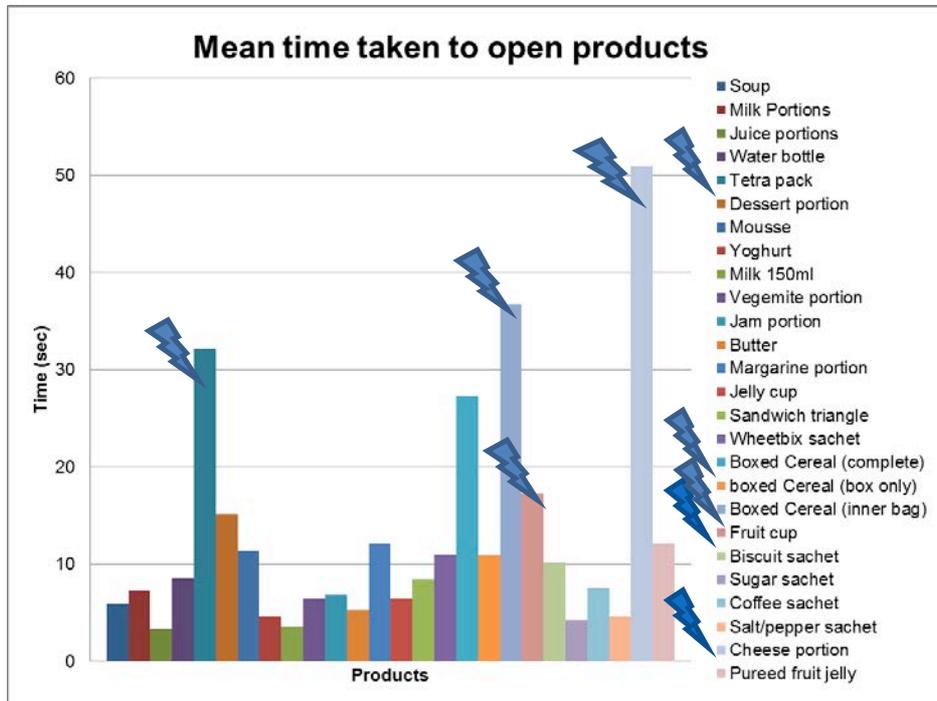


Figure 4: Time taken to open packaging items

New Study

Dexterity Testing

Hence, it was proposed to studying the issue surrounding what patients and staff had termed 'fiddly' packaging by analysing the issue around accessing these problematic items in more detail. Several approaches to this work were undertaken, most notably studying the relationship between packaging use and dexterity.

Dexterity of participants was analysed using the Purdue Pegboard Test first proposed by Tiffin in 1948 (Tiffin et al). The Purdue Pegboard Test can be used for numerous purposes including testing for the presence and/or extent of brain damage, learning disabilities and dyslexia. There are four individual tests that are carried out when using the Purdue Pegboard. For all of these tests, the participant sits at a table that is at comfortable height (see Figure 5).



Figure 5: Participant undergoing Purdue Pegboard test

Test One (Dominant Hand): The first test involves the participant using their dominant hand to pick up a pin from the cup that is on the same side as the hand that is being used. The pin is then placed in the topmost hole that is also on the same side. This action is repeated and the pin is placed in the next hole down. The aim is to see how many pins the participant can place in thirty seconds.

Test Two (Non-Dominant Hand): The second test is similar to the first, except the task is performed with the non-dominant hand. The participant takes the pins from the cup on their non-dominant side and places the pins down this side as well.

Test Three (Both Hands): The third test involves a repeat of the previous two tests; however, both hands are working simultaneously. In this test, only the number of pairs of pins is recorded.

The sum of these three tests, Right + Left + Both (R+L+B), gives the overall Macro dexterity score for the participant.

Assembly Test: The final test performed is the assembly test. The assembly test involves picking a pin up from the dominant hand side of the board and then placing it in the hole at the top of the dominant hand side of the board. Meanwhile, the other hand picks up a washer and places it over the pin the dominant hand has just placed. The dominant hand now places a collar on top of this washer, followed by another washer placed by the non-dominant hand. The final assembly consists of a pin running through the centre of a washer, collar and another washer. This process is repeated down the dominant hand side of the board. The time limit for this test is one minute and the score is determined by the number of individual components the participant is able to place in that time. This score gives the participant's Micro dexterity score.

Hence, 31 participants were asked to open three of the five problematic packaging types. The time taken to open and the dexterity of each participant was measured. The water bottle was excluded as the previous research had shown that inability to access this pack type was mainly due to insufficient grip strength. The milk carton was chosen as it was easily available and had a similar opening tab to the cheese and jam portions. Participants were chosen across the age spectrum with the oldest being 83 and the youngest 19 years of age with the mean age of all participants was 40 years. This enabled the researchers to study the differences between older and younger participants.

Video Analyses

Video Observation

Video ethnography is the video recording of subjects performing actions in their natural setting, in order to gain an understanding of a certain cultural phenomenon of interest. Other research has suggested that more natural settings are needed for studies exploring these areas, rather than solely using lab experiments which might over simplify what is being tested. As this is the case, video ethnography, which monitors subjects performing a task in their natural setting, could prove to be a method of expanding these experimental paradigms. The participants were asked to open two of each of the three types of packaging. They were asked to open two of each in order to help eliminate the cognition element of opening packaging. A series of studies were undertaken including interviewing people with their experiences in using the problematic packaging including dexterity analysis and video testing.

High Speed Video Analysis

Participants were also analysed using High Speed Video (HSV) analysis to study finger motion in greater detail. This method enables filming at speeds significantly higher than a standard video camera (60 thousand frames a second, a standard camera films at 25 frames per second) using a 'Phantom' SA3 camera (Photron.com). Five participants with low dexterity scores were selected from the previous analyses and their hands filmed both undertaking the Purdue Pegboard test and the subsequent video analysed. Analyses were undertaken at a range of speeds from 60 frames per second (fps) to 200fps.



Figure 6: High speed video analysis



Figure 7: Still frame from HSV of participant opening problematic packaging

Timing

Each participant was timed from the video recordings outlined earlier. This was done so that the timings could be repeated if there was doubt as to when to start the timing. The ability to do this is one of the key advantages of using video ethnography as identified by Joseph Schaeffer.

Each participant opened two of each type of packaging and the fastest time taken was the time used in further analysis. The fastest time was used, as opposed to an average time, because the first attempt to open the packaging was meant to remove the cognition element of accessing packaging. This effectively gave the participants a practice run at opening the packaging to remove learning effects.

Task Analysis

The three types of packaging were segmented into tasks based on the participants' actions and different objectives that must be achieved for the packaging to be opened. Each task consisted of a few actions made by the participant which achieved the objectives. For example, the cereal box requires the outer cardboard box to be opened (task one) and then the inner plastic bag to be opened (task two). Each of these tasks is composed of smaller actions made by the participant. Where the tasks for each object usually remain the same for all participants, the smaller, detailed actions that allow each participant to complete these tasks can often change.

The Task Analysis was performed in order to determine if a link exists between the numbers of tasks, or the type of actions required to complete a task, and dexterity. Where participants struggled with the packaging was also noted in this part of the analysis. Where participants found difficulties are the areas that receive design suggestion for improvements.

Results and Discussion

Significant analysis was undertaken as to the most relevant way to show the dexterity results. It was found, for example, that dexterity change is very sensitive to age, a result consistent with that found by other researchers (Michimata, 2008). No significant difference was found in younger (under 60 year old) participants but significant decline (also matching that of other researchers) was found for the over 60 participants.

Using the HSV analysis and studying the high-definition images produced, it was seen that accessibility of the packaging was likely be related to macro-dexterity, due to the significant amount of wrist, arm and finger pinch gripping used during accessing these items. It was also shown that in accessing the Tetra Pak and cereal box, participants had to undertake far more complex tasks and even multiple tasks to successfully access the contents than the milk carton.

It was decided that the most appropriate way of showing the results was by plotting Macro dexterity versus time for the cereal, juice and milk cartons (a technique first published by Rowson *et al*, 2013). This enables us to assess the influence of dexterity upon the pack performance. A pack uninfluenced by dexterity will produce a horizontal line, a pack with a strong correlation to dexterity will have a steeper gradient.

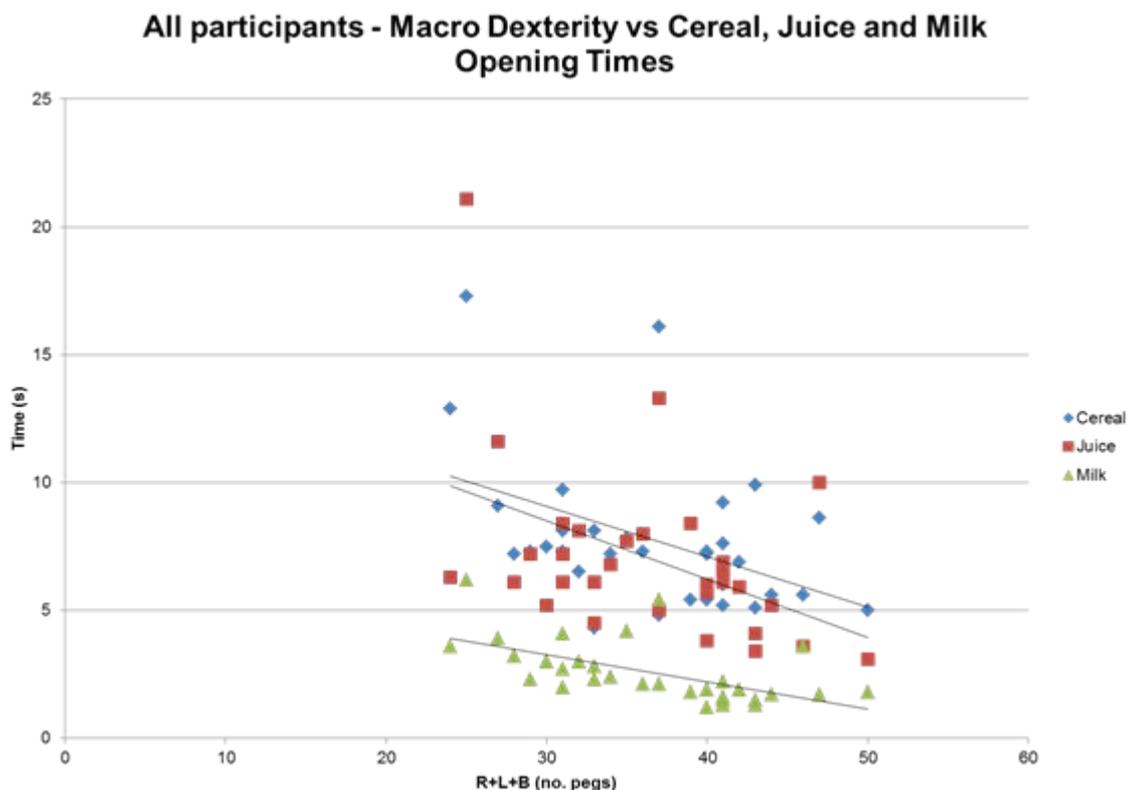


Figure 8: Dexterity versus time for three problematic packaging types

The milk carton was found to be the least susceptible to dexterity; this is largely due to the simplicity of the task when compared to the other items that require multiple tasks and significant dexterity, as seen from the HSV analysis.

In our study all the participants were able to access the packs. This indicates there may be issues around 'context of use' between the study conducted here and users experiences' in hospitals. For example hospital patients may be in a different posture when using the packaging.

Further, and most of obviously, the user is unwell and in hospital; it is therefore likely that energy and motivation levels will be reduced when compared to the 'well elderly'. Further work is needed to study these differences along with a more detailed analysis on the dexterity.

Conclusions

In the original study by the authors, emphasis was placed on the strength needed to access problematic packaging and identify what that problematic packaging was. It showed that there were five packages with the main problem being what participants termed 'fidliness'. In this subsequent work we have looked at a way of identifying what this 'fidliness' might be by examining ways of understanding dexterity and packaging. To that end Purdue Pegboard tes, questionnaires, HSV and task analysis were used.

This work showed that there was a direct link between the reduction in dexterity and the time taken to open a pack. Further, packs that required multiple stages and complex actions were more likely to be ranked as problematic and cause problems for patients and staff.

Significantly, even users with poor dexterity were able to open the packs. This is consistent with work undertaken by Sangar (2011) that showed that users who had very poor dexterity and who had their medication decanted could, with some effort, open their medication. This leads to the conclusion that inability to open the packs is a function of the dexterity, time taken and motivation. In a hospital setting the 'wellness' and posture of the patient may affect dexterity and hence increase time. The degree of 'wellness' is also likely to contribute to reduced motivation.

Future Work

Future work is to examine the effects of posture on dexterity and determine effective and reliable methods to analyse people in context. It is also desirable to understand the similarities and differences between the packaging used in NSW, Australia and that in used with the UK and elsewhere.

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Effect on Frequency Changing of Tactile Feedback on Touchscreen Devices

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Abstract

As people get older their senses deteriorate, yet many electronic touchscreen devices rely on people's senses for interactions; one example of this is tactile feedback. This paper describes a study of how finger sensibility changes with respect to age for the differentiation of tactile effects. The study focused on two frequency bases, 125Hz and 250Hz, presenting a pair of vibrations to participants for discrimination. At each frequency base (125Hz and 250Hz) 11 pairs were tested. In total, 33 people were included in the test, 17 participants between 20 to 40 years and 16 between 60 to 90 years split between genders. The greater discriminating change in frequency at 250Hz base led to a better performance in older participants. However, there is no significant influence in the younger group. The threshold of correct responses at 125Hz was 60% in younger group and 35% in older group. To compare, at 250Hz, the threshold was 65% in younger group and 55% in older group. The sensibility of discrimination improved almost 60% in older group; while in younger group it increased by 8%. The recommended threshold of discriminating frequency is 60% at high frequency for all adults. Further work is necessary to explore how adults can discriminate vibrations at different frequency bases, especially for older populations.

Keywords: frequency discrimination, tactile feedback, human perception, touchscreen devices.

Introduction

As technology is being developed and expanded, people are becoming more reliant on it for communication, information and everyday activities, for instance, the usage of smartphones. A UK statistic revealed that 66% of people aged between 16 to 24 years old and 60% of 25 to 34 years old have a smartphone, compared to 3% of people over 65 (OFCOM, 2012). Similar results are found in the usage of tablets. It can be predicted that smartphones and tablets will dominate the future market of electronic touchscreen devices. For older populations, they are too complicated to use. Becker and Webbe (2006) found that the barriers to the usability of handheld devices for older users are caused by impairments of vision, hearing and motor skills; literacy-age and technology skills; cognition and other psychological factors. Another reason is that older people were educated when technical devices were less complex than current ones. On the other hand, Czaja and Lee (2007) argued that the designers do not consider age-related changes due to the fact that the older group is not active and have less understanding of how to accommodate older people's needs. Nevertheless, the usability of current smartphones is not well-designed for the older generation. However, the next generation who are reaching retirement are largely happy using technology (ONS, 2011), but the problem is that if the devices are not sufficiently well designed with their projected abilities in mind, they will not be able to continue using smart devices.

Many electronic touchscreen devices rely on people's senses for interaction. Tactile feedback, such as a vibration, uses a person's sense of touch to enhance the user-device interaction. As people get older their senses deteriorate (Wickremaratchi and Llewelyn, 2006). Psychologists reported that pacinian corpuscle (PC) mechanoreceptors are sensitive to vibrations at the frequency of 40-400Hz and the sensibility has a progressive decrease with age (Wolfe *et al*, 2006). Verrillo (1980) pointed out that the threshold of finger sensation has a duplex model with low- and high-frequency limbs in the range of 0-1000Hz frequency within different populations. Furthermore, he found out that the sensibility of very low frequency (<40Hz) has no changes in populations of all ages. For mid-frequency (80 Hz), the loss of sensibility gradually decreases by 3dB per decade of age. However, for higher frequency (100-1000Hz), the sensibility is dramatically reduced over 50 years old and the loss continues to accelerate over 65 years old.

A current trend for designing touchscreen devices is to include additional tactile feedback in conjunction with the visual and audio cues (Pathak and Kumazawa, 2012). Most tactile feedback is generated by a linear resonance actuator (LRA) on current smartphones. Vibrations range in frequency between 100-300Hz. It was first introduced in PDAs by Fukumoto and Sugimura (2001). They attached motor actuators to the body of a PDA and evaluated the tactile feedback under four different environments. Their study demonstrated that tactile feedback could improve the usability of touch panels, especially in a noisy environment. Hoggan *et al* (2008) compared the effects of tactile feedback between a physical keyboard phone and a touchscreen device. The results showed that tactile feedback could benefit the performance of text entry in a touchscreen device in comparison with the users' errors with a physical keyboard phone. Another study also confirmed that adding tactile feedback to touchscreen interactions makes the whole process seem more natural with the user able to really feel what they are interacting with (Pathak and Kumazawa, 2012). This could also make touchscreen mobile devices also accessible for visual impaired and blind people.

In summary, it is clear that there is a lack of knowledge about how to design a 'natural feel' tactile feedback on touchscreen devices with the respect to the ability of finger sensibility. Hence, the aim of this paper is to investigate the ability to perceive vibration tactile feedback, also called vibrotactile feedback, in relation to age. This paper will focus on studying the ability of finger perception with tactile feedback on touchscreen devices, investigating the fingers perception threshold and discrimination.

Experiment: Vibration Discrimination of Frequency Changing

Method

An explorative study was carried out where tactile vibration stimuli were evaluated with the criteria of discrimination and user preference. BS ISO 13091-1:2001 standard (Standard, 2001) recommends the stimuli of 125Hz, or equivalent 100Hz or 160Hz, to measure vibrotactile perception threshold (VPT) for PC mechanoreceptors. Hence, in this experiment, two frequency bases were designed at 125Hz and 250Hz for comparison purposes.

Participants included 17 younger adults (aged between 20 and 40 years old, of which there were 11 males and 6 females) and 16 older adults (aged between 60 and 90 years, of which there were 5 males and 11 females).

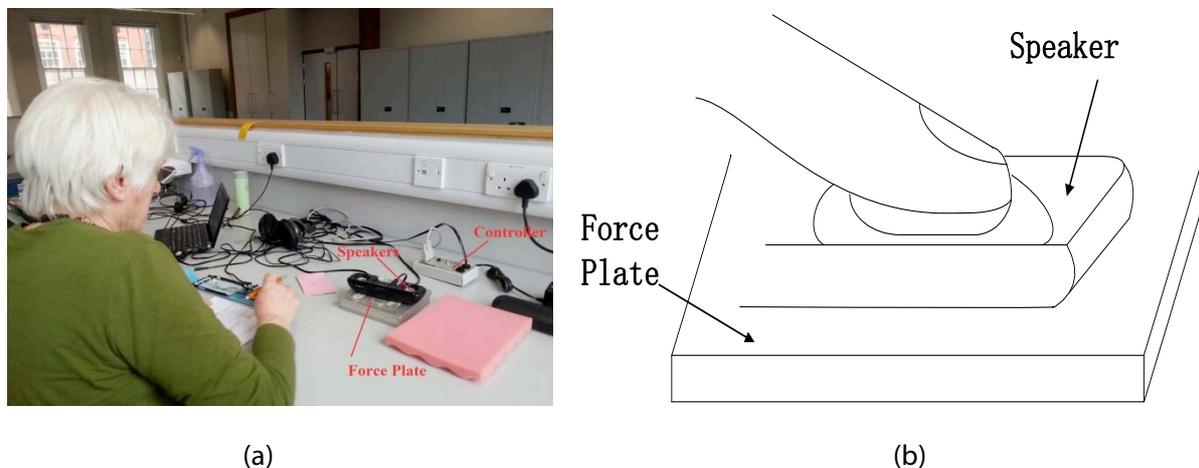


Figure 1: (a) Set-up used for analysis of tactile sensibility. (b) Close-up of finger in contact with speaker during testing.

The experiment set up is shown in figure 1; the vibrator used is a speaker. Its vibration mechanism uses enhanced voice-coil actuators with added mass for stronger output, which is widely used in smartphones (e.g. LRA). Audacity software (version 2.0.2) was used to generate different vibration signals through the small speaker. The room temperature was controlled between 24-27°C. A thermometer was used to measure the participants' index finger temperature, which ranged between 28-33°C. The pressing force has a huge influence on the finger perception (Lederman and Taylor, 1972). Thus, a force plate, shown in figure 1, was used to measure the force and ensure was kept between 0.5N and 1.0N. A key factor of touchscreen devices is the contact area, as this

significantly affects the performance of user interactions. Jin *et al* (2007) proposed an area between 16.51 to 19.05mm square for older adults. Moreover, Kobayashi *et al* (2011) suggested that icon size on touchscreen devices should be larger than 8mm square and the same size of the spacing between two icons in order to design an ageing friendly smartphone. In this test, the contact area available for the finger was circular with a diameter of 18mm.

Tests were carried out at two frequency bases, 125Hz and 250Hz, each using a pair of vibrations to test participants for discrimination. The exposure time of each sine wave was 1.0 second. The amplitude of all the sinuous waves was the same at 54dB calibrated by the Audacity software.

Table 1: Vibration pairs tested

	125 Hz Base (Hz) pairings		250 Hz Base (Hz) pairings	
	Vibration A	Vibration B	Vibration A	Vibration B
(1)	100	125	125	250
(2)	105	125	150	250
(3)	110	125	175	250
(4)	115	125	200	250
(5)	120	125	225	250
(6)	125	125	250	250
(7)	130	125	275	250
(8)	135	125	300	250
(9)	140	125	325	250
(10)	145	125	350	250
(11)	150	125	375	250

11 pairs were tested as listed in table 1 at frequency base 125Hz with discriminating changes between 5Hz and 25Hz. Each pair first presented the vibration A and then vibration B on the same finger. Participants were asked if the vibration sensation was the same or different and scored according to table 2 (Likert *et al*, 1993). A flexible time was left for them to make decisions. All the pairs were repeated in order to reduce human error. The same test was carried out at frequency base 250Hz with a discriminating change of between 25Hz and 125Hz.

Table 2: Subjective Criteria

	Correctly identified same or different signals	Scores
Correct	2 out of 2 times	1
Moderate	1 out 2 times	0.5
False	0 out 2 times	0

Results

The results from the discrimination tests showed that for 125Hz base younger group outperform older people in figure 2 (a). It could be seen that at 125Hz frequency base, the best discrimination occurs at the point of 125Hz -25 for all ages, but at 250Hz frequency base in figure 2 (b), it happened at the point of 250Hz +125. Particularly the performance at 125Hz+25 and 250Hz +25 improved from 40% to 60% in older group. However, the ability of discrimination in younger group had no big changes.

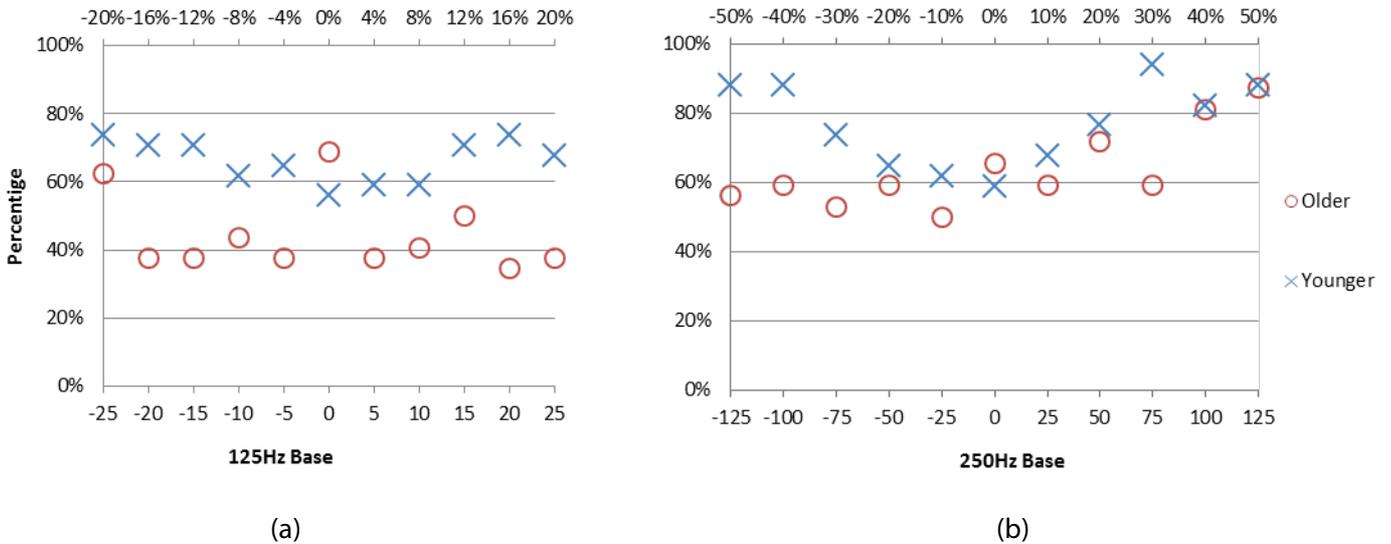
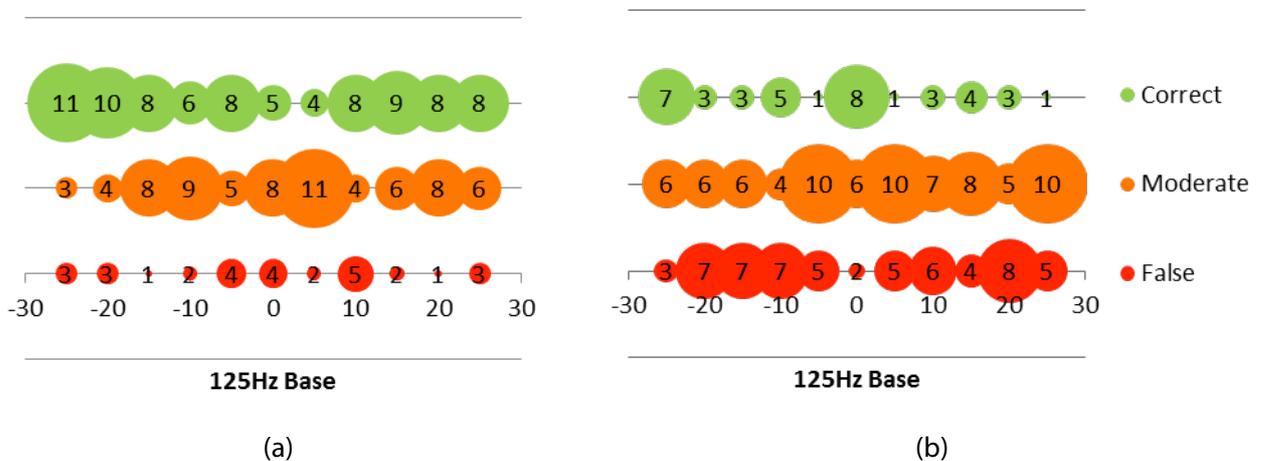


Figure 2: (a) Number of correct responses at frequency base 125Hz. (b) Number of correct responses at frequency base 250Hz.

After generally examining the ratio of correct responses, the data could be also analyzed based on participant scores shown in figure 3. It was shown that 250Hz frequency base got more correct responses overall. The number of moderate responses decreased in both groups. The significant change occurred in older group from 125Hz to 250Hz frequency base, but the younger group showed no significant improvements.



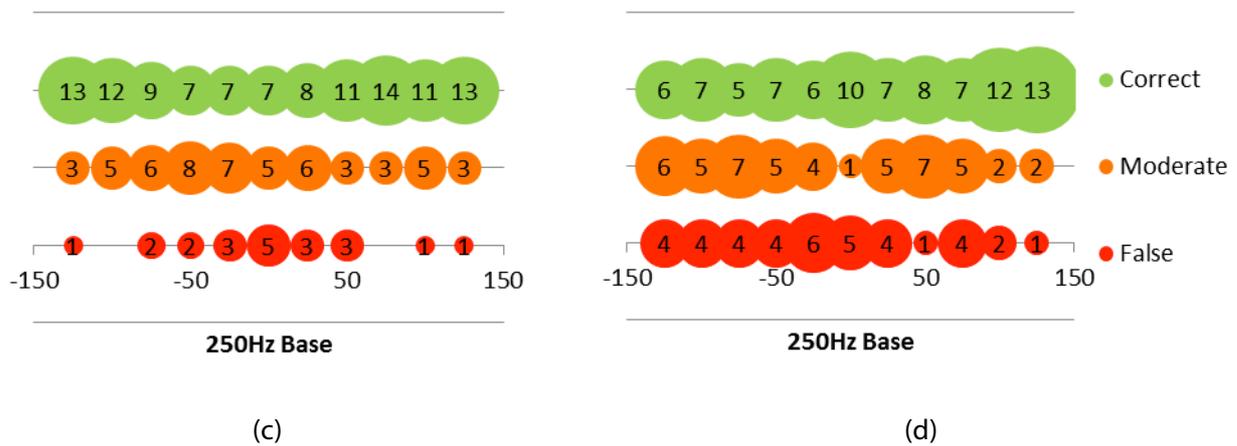


Figure 3: (a) Discrimination results at 125Hz base for younger (20-40 years old). (b) Discrimination results at base for younger and older group (60-90 years old). (c) Discrimination results at 250Hz base for younger group (20-40 years old). (d) Discrimination results at 250Hz base for younger group (60-90 years old)

Discussion

This experiment showed that all adults can discriminate the frequency changing with the same amplitude. At higher frequency base people perform better, but there is no evidence to show that older people have worse sensibility than younger adults. At lower frequency base, the best perception occurred at 125Hz-100 for younger and older group. However, at the higher frequency base, it occurred at 250Hz+125. Specially, performance at 125Hz+25 and 250Hz +25 improved from 40% to 60% in older group while no significant improvements in younger group. The sensibility of discrimination improved almost 60% in older group; while in younger group it increased by 8%.

Conclusions

This paper investigated the tactile feedback of finger perception with the respect to discriminating a change in frequency. The greater discriminating change in frequency led to a better performance in older participants. However, there is no significant influence in the younger group. The threshold of correct responses at 125Hz was 60% in the younger group and 35% in the older group. To compare, at 250Hz, the threshold was 65% in the younger group and 55% in the older group. The sensibility of discrimination improved almost 60% in the older group; while in the younger group it increased by 8%. The recommended threshold of discriminating frequency is 60% at high frequency for all adults.

In the future, it is necessary to explore how accurately people can discriminate vibrations at a variety of frequency bases, especially focusing on older users. The recommended discrimination map of frequency base should be at 125Hz, 150Hz, 175Hz, 200Hz, 225Hz, 250Hz and 275Hz utilising a minimum change at 5Hz. This can lead to design a variety of tactile feedback that can provide 'natural real' perceptions for all ages.

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Design of a Caregiver Collaboration Tool Using Subtle Group Awareness

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Abstract

Caregiving for seniors with mild cognitive impairments (MCI) brings the challenge to provide the right care task at the right time, thus requiring highly cooperative collaboration among caregivers. Meanwhile, caregivers experience stress caused by concerns regarding MCI patients' progressive disorientation and wandering, which results in 'Caregiver burden'. This paper presents a design case study on the development of a collaboration tool to support formal and informal caregivers. The design was informed by user research on caregivers' group awareness with a particular focus on caregivers' emotional experience. A conceptual prototype supporting care experience through reporting and sharing care activities and whereabouts of seniors was developed and tested with the caregivers. The concept describes how social network and mobile technology help minimize miscommunication between caregivers by inviting caregivers to articulate their activities in an enjoyable collaboration. For future work, participants suggested to explore how the application could be further tailored to address the needs of different care parties and the needs of the senior.

Keywords: communication tool design, caregiving collaboration, caregiver burden, group awareness

Introduction

Seniors with mild cognitive impairments (MCI) suffer from time and space disorientation. MCI is early dementia, more than half of which progress to dementia as the illness deteriorates (Gauthier *et al*, 2006; Petersen *et al*, 2001). Worries of family caregivers and professional caregivers increase in providing constant care to the affected senior, provoking anxiety at the moments when the senior is by herself. This result of an emotional and physical drain on time leads to a 'caregiver burden' (Pollard, 2008). Computer-supported coordinated care (CSCC) (Consolvo *et al*, 2004) uses technology to aid the network of people who support an elder living at home. This is a meaningful focus for pervasive computing, computer supported cooperative work (CSCW) (Mark, 2000) and human-computer interaction (HCI) communities.

Two early examples of CSCC, CareNet Display (Consolvo, Roessler and Shelton, 2004) and Solar Model (Morris, 2005) have focused on raising group awareness through sharing different information regarding functional aspects of the situation of the elderly person and his social connectivity (Vastenburg and Vroegindewei, 2009). Recent studies, Augmented Binder and Press To Talk (Christensen and Gronvall, 2011), explored opportunities of improving the communication efficiency of care collaboration by facilitating message notifications and supporting voice messages. However, the experience of caregivers in communicating with other caregivers has been, to the best of our knowledge, rarely considered in these developments.

The care experience is strongly related to the awareness of seniors' condition, whereabouts (Schoenmakers, Buntinx and Lepeleire, 2009), and the communication between caregivers. Also broadly, it involves societal factors, like caregivers' education, social class and financial resources etc. (Kitwood, 1997). To raise awareness of the broader context of dementia care, it is important to reduce the caregiver's existing negative feelings and raise the subtle group awareness on positive attitudes toward this stressful situation. Lack of positive awareness, however, increased unnecessary worries and concerns; miscommunication leads to unclear task distribution and lack of knowledge regarding care involvement.

This design case aims at improving the subtle group awareness in caregiving, which refers not only to increasing information exchange but also improving affective experience in taking care of the seniors with MCI. By designing a digital communication tool that aims to reduce the 'caregiver burden', mentally increase caregivers' peace of mind and support the care network, it will ultimately impact seniors' wellbeing.

Scope

The focused user group in this project was the caregivers who are closely related to the patients, including case managers, home care nurses and family members, as they are mostly involved and play the key roles in the care system. The case manager works like a spider's web connecting and coordinating different care members, while the home nurse visits the seniors every day and deals with their daily basic routines. Among family caregivers, sons or daughters take the most responsibility, and are considered as contact persons for the seniors.

Additionally, age groups in the caregivers' system, which vary from 20 to more than 70 years old, imply a wide range of digital literacy. The target users for this study were those with low-moderate experience of using digital devices, as they are the majority of the system.

Challenges

In the design of a collaborative tool that is based on sharing information, there is a fine line between providing sufficient information to be able to make well informed decisions as well as timely and relevant information, to avoid overload information that has little value. Also in the case of a situation that involves sensitivity and critical data, it requires a careful balance to trigger positive and active feelings and avoid negative and passive ones, as it may raise unnecessary concerns undermining caregiver's peace of mind. The key is, hence, to understand the balance in delivering the different information, which would not only ease the caregiver burden but also raise people's subtle awareness and light up their life.

The Concept

The design of the communication tool was conducted based on an extensive research of the current caregiving situation. Figure 1 depicts the research process throughout which design artefacts and interventions were used. The insights collected in the first three steps were used to guide development of a concept and test and evaluation.

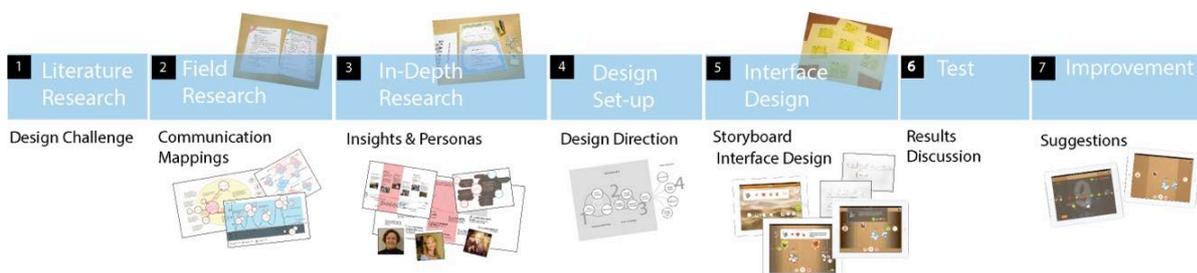


Figure1: Design Steps

A. Research and Insights

Research

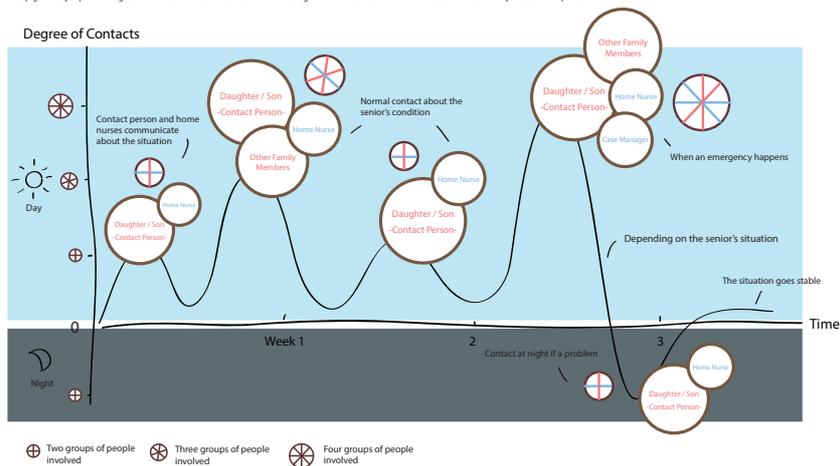
By visiting care institutions and joining care activities in seven Dutch cities, the field research resulted in describing communication maps that represent how care parties work together (Figure 2). Then, through conducting sensitizing studies and interviews with users, the in-depth research examined caregivers' needs, preferences and difficulties in taking care of the senior. The in-depth research involved four female family caregivers, two home nurses, two case managers, a family of four generations and a family of three brothers. Based on the acquired context knowledge, the interview questions were prepared on the sheets with stickers and pens, which were used to help the participating caregivers feel at ease in thinking aloud (Figure 3).

Insights

Generally, the caregivers have good communication with their team members. They contact each other mainly by phone and email (Figure 2 (1)). Most family contact persons are actively present in the communication interaction. The home care nurses have the latest information about the situation, and function as proxies to deliver information to other members. In addition, the case managers are periodically involved in checking care process and renewing plans (Figure 2 (2)).

Communication Mapping (1)

The communication between families, home nurses and case managers frequently changes according to seniors' situations. Since memories gradually decline, seniors become easy to forget things of a few minutes ago and get hard to recognize people. As the conditions get worse, seniors do not know day and night. Ten percentage of them will get lost when moving outdoors. The in-between contacts become very busy as a problem happens but meanwhile it becomes very less as the situation goes stable. The following communication map generally depicts a diagram of the current communication. More caregivers are involved in the communication when they encounter a problem.



Communication Mapping (2)

Families take the most responsibility in taking care of the seniors. They work with professional caregivers as a team but play different roles in the system. There is usually one contact person responsible for connecting other family members, who delivers information and communicate with the professional caregivers about the patient's situation. Besides home nurses take care of daily basis for seniors and communicate with families through a notebook every day. Meanwhile case managers are responsible for the care progress and contact with families at a period of one month or even longer. Whenever there is a situation or an emergency, the one first knows will spread the information in the system, which mainly starts from the contact person and home nurses. The rest younger family members (grandchildren and great grandchildren) are less involved in the communication. Also families live together or close to the senior are involved more than those from a distance.

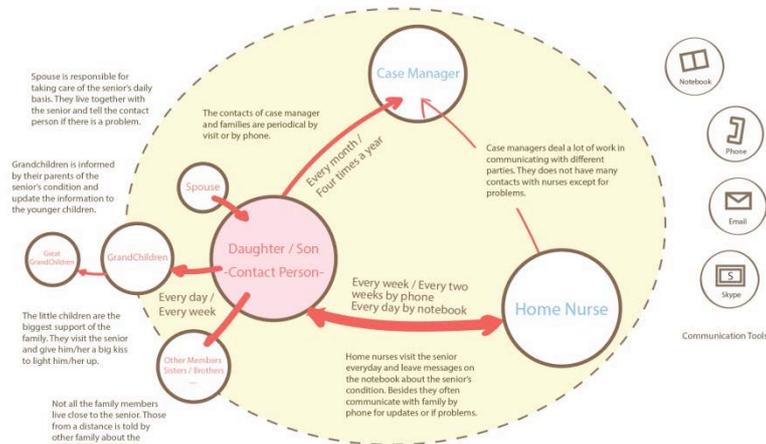


Figure 3: Interview Tools

Moreover, one of the identified problems reflected by family caregivers in the interview is that the information shared in the current communication protocol (via a physical notebook) is not adequate in providing relevant and frequent information from professional caregivers.

- Caregivers worry about unstable situations when they are away from the senior. The communication protocol between caregivers frequently changes (Figure 2 (1)). Therefore, caregivers like to be more frequently updated about the real situation, including the seniors' weight, mood and mobility location.
- There is miscommunication between caregivers on who is responsible for specific care tasks or when a special situation has emerged. This is especially the case between family and nurses. E.g. who is responsible for medication today?
- Family caregivers are unaware of the involvement of other caregivers. Family would like to be informed about their visits to the senior, since they feel supported as knowing other members' contribution in caregiving.

In addition to these information problems, in the interviews caregivers were asked to reflect on questions regarding their care experience like: "What do you like and what don't you like about caregiving? And what do you expect in the care collaboration?" Learning from the care difficulties, the following subtle awareness is commonly agreed by caregivers in maintaining the peace of mind in the face of this aging issue.

- a) The caregivers like to be in control of the situation. Since they deal with many difficulties in taking care of the patient, feeling in control is important and helps them get all the information needed in time.
- b) As previously mentioned, burden is a negative feeling that increases as illness progresses. Finding the right balance of information sharing and creating an interesting informative environment is conducive to their awareness of being in a positive state.
- c) It is observed that all the care parties want to work together in supporting each other. But families feel that they are not as involved in the current communication as they could be. So enhancing enjoyment is good to get caregivers positively involved in the care activity.

B. Design Goal

To improve inadequate and inconvenient communication and to avoid negative emotion caused by miscommunication between the caregivers, the design goal is defined as: To design an easy to use communication tool for caregivers to instantly update seniors' conditions and inform other caregivers about the caregiving activities. The design will be implemented as an iPad application, in which this information can be fully presented. Based on the subtle awareness described above, the design vision is defined as feeling in control, informative and enjoyable, which were used to guide the design development.

C. Technology Support

To facilitate the sharing of information, a technological platform will mediate the input, processing, delivering and output of information. Two types of inputs are considered: manual input by caregivers of seniors' condition and care activities; automatic information of the outdoor location of

seniors. In addition notifications of recent updated information will be automatically provided by the platform. Regarding location, privacy is implemented by defining fixed points in the neighbourhood where the senior normally walks around (e.g. the bakery, supermarket, park, etc.). With the help of GPS, senior's whereabouts can be approximated to these points.

D. Interface Design

The interface design consists of four different screens conveying different layers of information: the main screen were updated information of caregiving activity and seniors' situation; an input screen where caregivers add information about their visits; a history screen to provide week overviews of past information shared, and the notification screen that provides notifications of senior's emergency situation. The application can be used on caregiver's own iPad or by a public iPad placed at senior's home. And the users log on every time using their created accounts.

Main screen design

The visualization of the app's main screen includes four information lines extracted from the research: a time line in the middle presenting events in chronological order with an update of the caregiving activities (Figure 4, ⑥-⑩) on the top and the senior's locations underneath (⑪), a visit line presenting information of the caregivers' visits to the senior by informing their care work by leaving a message (⑦) or indicating the preset icons (⑨), or report the senior's weight (⑧). A location line providing the landmarks (⑪ e.g. bookstore, park and supermarket etc.) that the senior passed by when they wondering around and a mood line reporting seniors' emotional state (⑩) by using a pictorial mood instrument, Pick A Mood (Desmet, *et al*, 2012). A creative process led to the result of seven ideas for the main interface which, after discussion and validation with experts, were combined and finalized into one concept. Acknowledging the relevant impact of the visual design on user experience, a number of iterations were planned to design icons and colour scheme for the interface. Icons are designed to create a playful and accessible tool to provide input as well as obtain relevant information. A colour scheme of light warm orange was chosen to reinforce a feeling of enjoyment in caregiving.

In addition to the main screen, the three other interfaces are presented.

Input screen

The users update their visit using the add button on the main interface (⑬). As most of the home nurses have limited literacy, it is time saving for them to indicate their work and the senior's conditions by simply touching the corresponding icons, which efficiently improves the articulation of the caregivers' communication. Also a small open area was offered for them to exchange the necessary messages.

History screen

The history interface shows a weeklong care condition, which could be accessed by the history button on the main menu (⑭). The red and green represent good (everything goes normal) and not

good days (get notification of the abnormal). Additionally, the exact problems were indicated under the date circle. By scrolling the timeline, the older records could be checked ahead.

Notification screen

According to settings, a pop out screen can provide emergency situation messages regarding, for example, the senior’s locations. The instant notification will be sent to the related caregivers. It shows the problem and the map with the most recent positions senior has been to in chronological order. It enables the caregivers to give the in-time action in case the senior is lost. An exclamation sign will be marked on the timeline of the main interface to represent that a notification was flagged.



Figure 4: Main Screen and Design Captions

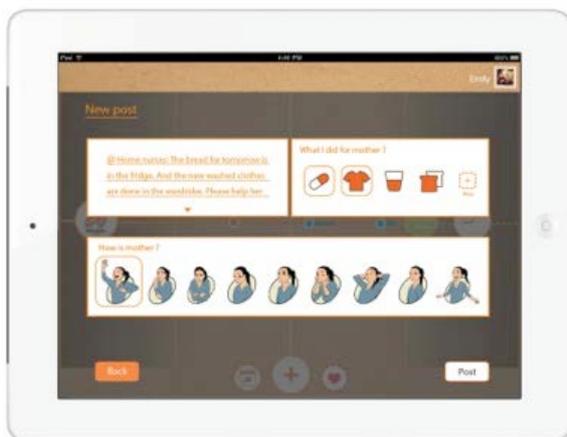


Figure 5: Input screen



Figure 6: History screen

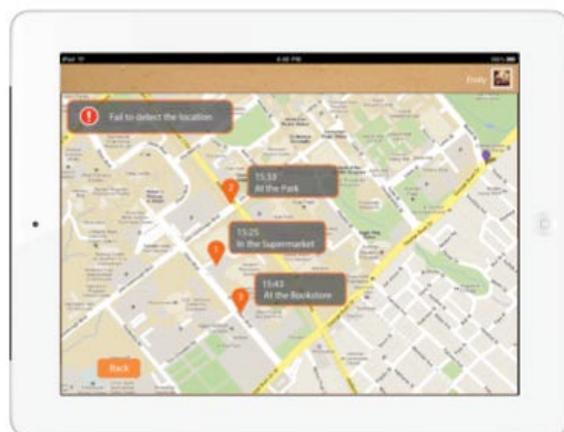


Figure 7: Notification screen

Evaluation

To examine whether the concept is understandable and the design is clear and easy to use, a Wizard of Oz prototype was developed, in which the subject interacted with a computer with the simulated autonomous system. Roughly 70% of the functions from the final concept were implemented by PowerPoint with animations and links, which were shown on a laptop simulating a tablet app. A study with seven caregivers was carried out, who were recruited from caregivers who have previously participated in the former research, including five family caregivers, one case manager and one home nurse. The test was conducted in several individual sessions, each of which started with a brief introduction on the design purpose, the app functions and the prototype operation.

A. Method

The test consisted of two parts: 'understand the interface' and 'situations tasks'. In the first part, the main app interface was displayed on an iPad and the participant was required to answer questions: *Which part of the interface first comes to your sight? What do you think it means? What else attract your attention? Anything else in the interface you do not understand?* For the second part, three assignments were given asking participants to complete the corresponding tasks within a specific scenario by operating the prototype on the laptop.

1st Check history Scenario: You want to have a look at the senior's records of the past three days.
Question: how to do it?

2nd Add a visit Scenario: You visit the senior at home and help him take the medicine and get dressed. Now you want to inform other caregivers of these. Question: How to do it?

3rd Emergency situation Scenario: You are in the office. Suddenly you get a notification on the iPad informing that the senior has been for some time outside. Question: What information can you see on this page? How useful do you think it is? What do you think you need to do?

B. Analysis

Positive feedback

The result of the test showed that both the family and the professional caregivers liked the caregiving support to easily fill in what they did for the senior and also to be aware of what others have done. Also they liked to be informed of the locations when the senior moves around. Particularly, the family caregivers reported the useful notification function, which provides in time information that could prevent senior's getting lost. Besides, in line with the three design visions, both the professional and family caregivers liked the enjoyable style of the interface. They all said in the test that they would like to have it. Regarding requirements of feeling in control and being informative, the concept was perceived as providing relevant and meaningful information.

Possible improvements

Based on the test insights, two main aspects require special attention for further developing this collaboration tool: How to involve an extended community of care? And how to develop a trustful location based technology with accurate but privacy information of seniors' whereabouts?

The caregivers like adding other family members like grandchildren, friends and neighbours of seniors, but it is challenging to customize information for different care parties. Some private information needs to be blocked to keep the senior's privacy. And family caregivers reported being doubtful about the accuracy of GPS technology, as it is uncertain when the seniors are right at the location or merely passed by. Also the locations where the senior usually moves around should be preset at the start to activate the notification, which requires an extra investment. The research emphasis should be laid on the technical accuracy in distinguishing the exact position of the senior and the senior's general behaviour when wandering around, e.g. how long she usually goes out for shopping, how long it usually takes her to go to bookstore. Therefore an extensive test should be conducted to validate the concept in a realistic setting, and to further improve the application.

Conclusion

This paper described contributes to the design community developing supportive tools for caregivers in need of care to strengthen the power of the care network. With a deep concern for humanity, this practical design attempted to apply social knowledge in the study of CHI. With the use of mobile devices, instant communication among caregivers can be facilitated at any time. Also, with respect to providing information in the format that best communicates to the viewer, this design increases user experience by visualizing data in icons and graphics that are easy to process and are pleasant to see. The design idea was inspired by the subtle awareness from humanistic care: to be in a state of peace of mind, enjoyment and order in experiencing dementia, which keeps caregivers from suffering too much that is unnecessary. The evaluation of the concept was conducted with seven participating caregivers to examine if the concept is understandable and the design is useful. Roughly 70% of all functions were implemented in a PowerPoint animation and presented on a laptop. The result showed that the participants appreciated the awareness gained by engaging with the interface design and expressed that they would like to use it to manage their care work.

Particularly, the solution could minimize miscommunication between caregivers by inviting caregivers to articulate their activities in collaboration. For future work, participants suggested to explore how the application could be further tailored to address the needs of the different caregivers and the senior.

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