

Designing experiences to foster empathy

Dear research council,

I am applying for artistic development funding to conduct research into how I could use design to improve emotional care for dementia patients.

Introduction

In an ageing society, managing and providing care for people with dementia is one of the great challenges of today. Worldwide, 47.5 million people have dementia and there are 7.7 million new cases every year. The total number of people with dementia is projected to 75.6 million in 2030 and almost triple by 2050 to 135.5 million. Much of this increase is attributable to the rising numbers of people with dementia living in low- and middle-income countries. (WHO, 2015). These numbers do not include families and carers, who are also affected emotionally and economically by their condition (Prince et al, 2011).

“Design is still an under explored aspect of the care and support of people with dementia” (Bowman as quoted in Timlin and Rysenbry, 2010, p4).

Motivation

I would like to create a meaningful (positive) change using design; I would like to investigate what I can do – as a designer – to enhance the communication between care-givers and care-receivers in a dementia setting.

Borne out of frustration in looking after my mother, who died of Alzheimer’s disease in 2015, I observed a number of areas that I thought could be improved upon using design, particularly I found the area around the early stages of the disease most in need of help.

I was frustrated with a couple of specific areas:

- The diagnosis of Dementia / Alzheimer’s, and
- Respectful management of the declining mental capacity of the patient.

Which could lead to the following areas of study:

- Design of diagnostic tools
- Designing empathy

Method

The initial method of research will use various design experiments to explore if I can enhance communication between care-receiver and care-giver;

- Using information design to create a better diagnostic toolset.
- Designing an “experience” to foster empathy; creating understanding on what the patient is experiencing to enhance the care-giving possibilities of non-professional carers.

I will quantitatively, but mostly qualitatively 'measure' these experiments, through form feedback, conversations, observations and a co-creation session with care-givers (both professional and lay people). I will use the outcomes to gain further understanding on how I could enhance the communication between care-givers and dementia patients.

Expected results

The design experiments will be results in themselves, but the further analysis and testing of these experiments will yield further outcomes that could be discussed in a paper which could potentially be presented at a conference or be published in design and/or dementia related media. I will also aim to present this project in a research seminar at UID. Additionally, I also hope to create an exhibition to explore the notion of the 'experience to foster empathy'.

The outcomes from these design experiments and the reflection materials will also – hopefully – lead to a more in-depth study into the problems surrounding dementia care.

Planning

Ethical groundings

My primary focus will be on working for and with care-givers. Naturally some of the design experiments that I will make will be used by and tested on dementia patients themselves, but almost always indirectly, through their care-givers. My aim is to try and collaborate with xxx project (anna croon?), and their selected group of patients. Additionally I will ask my personal network of care-givers in the Netherlands for permission to work with them.

Creating an inter-disciplinary team

Meetings with Anna Croon Fors and trying to collaborate with a big nationally funded project related to dementia care.

Meetings with Per Olof Sandberg, Professor of Nursing at the Department of Neurobiology, Care Sciences and Society.

Diagnostics

Studying current methods

Design phase 1

User testing

Design iterations

Design presentation

Experience

Set up collaboration partners (partly in place already)

Design phase 1

User testing

Design iterations

Design presentation (mock-up)

> apply for separate funding to make the experience a reality in case of positive user feedback

Exploration

Two student projects around the subject matter that would feed into my research.

- Cognitive design course at UID
- Dementia and design Master course at the Industrial Design department TU/e Eindhoven in collaboration with Swedish ICT and Caroline Hummels (professor), Jorge Alves Lino (designer), Sietske Klooster (design choreographer)

Support and feedback

In order to gain support within the field of research and feedback on the many aspects of this project, I will plan three seminars with the research group at Umeå Institute of Design. One to take place in the early stages, the second sometime in the middle, and the third towards the end of the project period.

Additionally I would want to learn some basic programming skills, and will sign up to Rickard's introductory course.

Budget

Time allocation

I would want to spend 50% of my time for a duration of 6 months starting as soon as possible, which would leave 30% of my time for teaching. Of the teaching time I'd like to run the Single Subject course for the Cognitive Science students about Designing for Dementia (brief to be developed with Linda Bogren).

Marije's time: 6 x (34.700/2)	104.100
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Materials

Paper	100
Printing	250
Lo-fi prototypes	200
Medium-fi prototypes	1.000
Camera hire	0
Learning arduino, and building simple sensory mock-ups	0

Exhibition/experience

Note: This budget is a rough estimation based on an idea that would be further developed and may change considerably during the funded period. The experience would be location based; mimicking a normal home setting where a visitor would experience the home from a dementia patient's perspective.

Guest house@Floda	0
Props	2.000
Printing / signage	2.000

Travel

2 x return trip to Eindhoven ± 3.500 sek per trip	7.000
Accommodation for ±8 nights in Eindhoven ± 800 sek per night (tbc, may be provided?)	6.400

Total	123.050
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