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743. Evaluation or 'anecdote'? Understanding the impact of design

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ABSTRACT *Designers are increasingly engaging in participatory co-design approaches to understand the needs and wants of the people who will engage with the artefacts produced. These approaches are particularly relevant for design that focuses on social change, work undertaken with vulnerable groups who may not be articulate, and for designers working across disciplines, engaging with, for example, health related issues. While these projects may have clear goals in terms of outputs, often outcomes are not as clearly defined. So, how do we measure, evaluate and understand what has taken place, and reflect and report the findings?*

This paper reports on a UK-funded research project designing for people living with advanced dementia using mixed methodology research and evaluation. It explores issues around how designers self-evaluate and report on outputs and outcomes, and how robust evaluation can be undertaken throughout projects that use design research and thinking, or action research approaches. While, informal feedback in design projects can sometimes be dismissed as 'anecdotal', it suggests that unsolicited responses provide rich and valuable data to inform the overall evaluation and findings of a project. While designers may resist evaluation, feel that evaluation is imposed on them, or are not sure how to evaluate their projects, this paper suggests that by evaluating appropriately they can produce evidence to show the value and importance of their work.

Keywords: design for dementia, evaluation, participatory design

Introduction

As design is reconceptualized as a professional practice, as a growing area of research, is an activity that is 'constitutive of human beings', and increasingly aims to engage meaningfully with users and stakeholders by focusing, for example, on improving quality of life for individuals, changing behaviour, or bringing about social change, so the mechanisms used to assess and evaluate and help us understand how design impacts also need to adapt and change (Krippendorff 2006). In designing for individual benefits or for social impact, design, designers, and design researchers are working across fields and disciplines and are introducing and being introduced to new methods, approaches and procedures. They include new ways to assess, evaluate, measure and understand the impact of design.

Designing in areas such as health is complex and impacts a wide range of stakeholders, that may include, for example, scientific, clinical, and medical professionals and practitioners, nursing and care staff, people receiving care, family members, informal carers, and care organisations and advocacy groups. Design in healthcare may range from the technological to the pharmaceutical, include preventative approaches, or support lifestyle decisions, quality of life, and impact general wellbeing. Therefore, no single approach can be used in design and there is no simple 'one size fits all' approach to the assessment, measurement and evaluation of the impact of design.

This paper will discuss the evaluation processes undertaken in relation to the LAUGH (Ludic Artefacts Using Gesture and Haptic) project. The UK Arts and Humanities Research Council funded project designed objects and activities to promote pleasure and joy, to stimulate sensory engagement and contribute to the quality of life and subjective wellbeing of people living with advanced dementia. As the project's aims extended beyond the development of, and engagement with artefacts, and was intended to have social impact, a range of evaluation methods were used to ensure that the project was thoroughly assessed.

Background

As design research and projects focus on bringing about behavioural or social change or impacting quality of life through design, it is necessary to understand the needs and wants of people who will potentially engage with the artefacts (objects, products, activities or services) produced, and what impact the artefacts will have. This means not only focusing on the 'users', but also the wide range of stakeholders invested in or impacted by the design process and outcomes. To this end designers are employing co-design methods that enable them to design 'with' rather than 'for', that suit projects which require understandings beyond a single discipline, and that facilitate high degrees of personalisation and customisation. In projects, such as those that aim to contribute to health and wellbeing or work with people living with dementia, participatory approaches need to be adapted to ensure inclusivity for those with specific access needs or compromised communication abilities (Hendriks et al. 2014; Maldonado Branco, Quental, and Ribeiro 2017).

Design research projects using participatory approaches often have clear goals in terms of the artefacts to be produced. However, outcomes—what is the greater goal beyond what the artefact is to achieve in context—are not always made explicit. This can make evaluation difficult. Furthermore, even if the overall outcomes are expressed, they may occur over an extended period of time, and long after the project has been concluded. So, how then do we measure, evaluate, reflect on and effectively report the findings so that we can show the impact of a design research project that aims to bring about change?

Measurement and evaluation used in relation to projects that aim to impact change must account for not only how design artefacts are placed within a context and responded to, but also what change takes place as a result of the overall design process, outputs, and outcomes. It is, therefore, useful to understand measurement and evaluation frameworks developed in other fields and disciplines, to assess programs designed to bring about individual or social change. Program evaluation has an established history in the social sciences, in public policy making, epidemiology, in communication strategies, and in exploring how policy, decisions, and interventions impact people. Many of the approaches used can be applied to co-design projects to create an evaluation framework to enable quantitative and qualitative data to be triangulated and provide robust evidence-based findings (Calidoni-Lundberg 2006).

Confusion can arise in establishing evaluation frameworks because the terms evaluation and measurement are used interchangeably—even though they talk about different things. We might think about measurement as a means of matching an object, process, or response to a preconceived scale where it is processed as *units* (most often numbers), whereas an evaluation is an exploration of values assessed against *criteria* which may be tangible or intangible, and may remain as language¹. All too often at the borderline of disciplines, for example when design comes up against clinical, medical, economics or business, the robustness and validity of data evaluated and expressed in language is questioned. This can arise because the rich and valuable data of unsolicited feedback, so important to design projects, may not be sufficiently put into context as evidence, and so dismissed as ‘anecdotal’. This paper discusses the use of qualitative interpretive data that aims to provide evidence rather than ‘anecdote’.

The study

The LAUGH design research project ‘intersected’ with the health and wellbeing of people living with advanced dementia (Vogelpoel and Gattenhof 2012). Stakeholders included people living with dementia, family members, carers, professional care staff, directors, the management of the partner care organisation, designers, and the funding body. The project aims were varied and included participation with stakeholders, enhancing subjective wellbeing, personalisation and the development of hand-held objects that promoted pleasure and enjoyment in the moment. It used inclusive **participatory** design approaches in a three-year research study to inform the development of playful artefacts to support the **wellbeing** of those for whom quality of life has been compromised by memory loss, or cognitive and physical impairment. The research investigated ways of **integrating digital technology** into designs to supplement physical and

material properties, providing opportunities to **personalize** the experience (for example by including family photographs or favourite music), and making it possible for people living with dementia to interact with the devices either independently or socially. A toolkit for designing playful devices for people living with dementia was produced based on the findings from the research, in order to inform the design community and care professionals working in the sector (Treadaway et al. 2018).

The study used a participatory approach engaging in design research within a compassionate design framework (Treadaway, Taylor, and Fennell 2018) and interpretative qualitative research methods, working within a realist context and paradigm. The project employed summative and formative research and evaluation approaches which included questionnaires; ethnographic methods (real-time and post-event observation); structured and semi-structured interviews; journaling; and recording of designer/researcher reflections and reflexivity. Narrative, thematic, and text analyses of the data were carried out. The findings show the richness of the data collected and provides insights into the variety of experiences of participants in the study and the outcomes for stakeholders.

A wide range of data was collected however it is not possible to discuss it in the context of this paper. It included demographic, social and cultural data about participants living with dementia; attendee data from the workshops; notes from the advisory group and research team; interview and case study data; photographs, and audio and video recordings of the workshops and artefacts in context; real-time observation schedules of the artefacts in context; and questionnaire booklets. Data was analysed in Excel and Nvivo 11 with case study notes transcribed verbatim and all other data transcribed to note form. Audio and video recordings were coded by up to four coders. Qualitative data was subject to thematic analysis and case study data to text analysis.

Findings and discussion

This paper will focus on two related data sets to show how they inform our understanding of the design research project. Further analysis of other data collected and the findings will be published in due course.

Questionnaires

A questionnaire was prepared as a colourful easy-to-read A5 booklet, to minimize formality and reduce potential impact on participants' mood which may influence research findings. To ensure face validity it was based on the work of Lawton, Van Haitsma, and Klapper (1996), Logsdon et al. (2005) and Kenning (2017b) and was adapted to suit proxy completion and cultural differences (Kenning 2017b, a). The number of questions, adapted from mood scales, self-esteem questionnaires and quality of life surveys, was reduced to avoid tiring participants and to account for staff workloads. Each questionnaire was completed immediately before people living with advanced dementia were introduced to the design prototypes developed personally for them. But,

due to time constraints and shortages of staff, all forms were completed by proxy with the person living with dementia, when possible, in close proximity to answer questions.

The questionnaire began by asking 'How do you [they] feel today?' In the twenty questionnaires completed over four separate visits only one response suggested 'Very unhappy'. The majority of responses were 'Happy' or 'Very Happy' (65%). In response to questions about quality of life, 90% of replies to 'Do you think your memory is ...' were 'Poor' or 'Fair'. Similarly, to 'Do you think your [their] physical health is ...' 80% suggested 'Poor' or 'Fair' and to questions about energy levels 75% said 'Poor' or 'Fair'. However, when asked about mood most suggested that their mood was 'Good' or 'Excellent' (65%) and no one suggested their mood was poor. Responses to the self-esteem questions were divided. Responses to 'I can do things as well as most other people' were overwhelmingly negative with 70% suggesting they disagreed with this statement. However, all responses to 'I take a positive attitude toward myself' and 'I am satisfied with myself' suggested that they 'agree' or 'strongly agree' with the statement.

The care staff completing the questionnaire often provided important insights by offering both verbal and written unsolicited information. For example, suggesting that one person living with dementia '... is currently unwell, would not respond to any questions today'. Care staff often added their own perspective to the few words offered by the person living with dementia — still replying in the first person — by suggesting, for example, that participants had an understanding of their condition; 'I have dementia and need support and encouragement on (sic) times', and 'I have dementia, I sometimes forget things and forget where I am, I need lots of encouragement and reassurance'. Another suggested 'I have dementia but can remember certain (sic) things when I want to - I don't like noise, I make people laugh and I can make them cry', and another; 'I have dementia so have problems completing and understanding some verbal questionnaires. I depend on staff to guide me through this'. Care staff also made observations as shown by the remarks about a particularly well-dressed participant, adorned with jewellery; 'I live on an EMI unit. I have always took (sic) pride in my appearance, my house and my children. I was always a strong character within my family'.

There were limitations in that questionnaires were completed by proxy, and not all in close proximity to the person with dementia; time restrictions meant some people could not be asked the questions directly and not all questionnaires were completed for each person on each visit. However, they provide valuable data by providing glimpses of a social or shared understanding of individuals' quality of life and self-esteem. This was further reinforced when data was cross referenced with data from real-time observation and analysis of the video and audio recordings.

It was also noted that most care staff answered questionnaires generically, comparing abilities across the group, rather than answering inter subjectively for a particular person at a specific date and time. These generic responses provided insights into group dynamics—including staff interactions—valuable for assessing the observation data.

Observation

Researchers observed the interaction of people living with dementia with the prototypes and artefacts made for them. To record their observation they were given an observation schedule adapted from design research projects carried out in Australia with similar populations of participants (Kenning 2016; Kenning 2017b). The schedule, based on the work of Kinney and Rentz (2005) focussed on the seven domains of wellbeing: interest, sustained attention, pleasure, negative affect, sadness, self-esteem, normalcy. These domains of wellbeing can be observed through bodily responses such as making eye contact; attention to activity for sustained period; verbal or physical expression; closed body language; weeping; expression of pride or satisfaction; or connection or group engagement. To support the observation by researchers, care staff and family members with an intimate knowledge of the participant were asked, prior to the observation, to provide information about person-specific responses. They were provided with suggestions of bodily responses to emotions and asked to indicate how their participant showed, for example, interest, disinterest, or annoyance, and asked to identify any other responses not listed. This provided valuable insights for researchers undertaking the observation who became aware, for example, that when David moved his hand to his abdomen this was a sign of discomfort or pain, and suggested he wanted to withdraw. Researchers were also made aware that Thelma often sat relaxing with her eyes closed, and this was not because of disinterest or because she was sleeping.

Observation notes were made about body or verbal responses to researchers, care staff, and the objects and activities given to each of the participants to engage with. Researchers particularly focused on levels of intensity and frequency of responses, marking the observation schedule accordingly and adding descriptive notes, such as 'reaches out and touches the *Hug*' and 'Thelma said "don't touch him"' as she holds Hug tightly.

Concluding comments

It is not possible, in this paper, to discuss the nuanced findings that arise as a result of the triangulation of the range of data available, these details will be published in the near future. However, the examples of data analysed here, show how different types of data can provide different perspectives and robust evidence with regard to what took place in an engagement between people, an interaction with an artefact, individual's embodied or verbal response, and group dynamics. This approach allows for the data to be interpreted and for the findings to be validated and considered trustworthy because of the range of data available that allowed for the same conclusions to be drawn from various sources. Working through the data in this way and understanding what happened and the types of engagement that occurred produced reliable findings which can inform future research and development, point to new possibilities, and future outcomes. The LAUGH project not only created a series of objects and activities that impacted the wellbeing of people living with advanced dementia, it produced artefacts with the potential to become products, and impacted a wide range of stakeholders in dementia care.

References

- Calidoni-Lundberg, Federica. 2006. Evaluation: definitions, methods and models. edited by Swedish Institute for Growth Policy Studies ITPS. Sweden: Swedish Institute for Growth Policy Studies.
- Hendriks, Niels, Liesbeth Huybrechts, Andrea Wilkinson, and Karin Slegers. 2014. "Challenges in doing participatory design with people with dementia." Proceedings of the 13th Participatory Design Conference on Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - PDC '14 2:33-36.
- Kenning, Gail. 2016. Arts engagement for people with dementia: Independent evaluation of the art access program. Sydney: University of Technology Sydney and Art Gallery of New South Wales
- Kenning, Gail. 2017a. "Evaluating Art and Design projects for Dementia." Dementia Lab.
- Kenning, Gail. 2017b. Making It Together: Reciprocal design to promote positive wellbeing for people living with dementia. Sydney: University of Technology Sydney.
- Kinney, Jennifer M., and Clarissa A. Rentz. 2005. "Observed well-being among individuals with dementia: Memories in the making, and art program, versus other structured activity." *American Journal of Alzheimer's Disease and other Dementias* 20 (4):220-227.
- Krippendorff, Klaus. 2006. The semantic turn: a new foundation for design. Boca Raton: CRC/Taylor & Francis.
- Lawton, M. Powell, Kimberley Van Haitsma, and Jennifer Klapper. 1996. "Observed affect in nursing home residents with Alzheimer's disease." *Journal of Gerontology* 51B (1):3-14.
- Logsdon, R.G, L.E Gibbons, S.M McCurry, and L Teri. 2005. "Assessing changes in quality of life in Alzheimer's disease." In *Research and Practice in Alzheimer's Disease*, edited by B. Vellas, M Grundman, H Feldman, L.J Fitten, B Winblad and E Giacobini, 221-225. Paris: Serdi Publisher.
- Maldonado Branco, Rita, Joana Quental, and Óscar Ribeiro. 2017. "Personalized participation: an approach to involve people with dementia and their families in a participatory design project " *CoDesign* 13 (2):127-143. doi: 10.1080/15710882.2017.1310903.
- Treadaway, Cathy, Jac Fennell, David Prytherch, Gail Kenning, Amie Prior, Andy Walters, and Aiden Taylor. 2018. *Compassionate Design: How to Design for Advanced Dementia – a toolkit for designers*. Cardiff: Cardiff Met Press.
- Treadaway, Cathy, Aiden Taylor, and Jac Fennell. 2018. "Compassionate design for dementia care." *International Journal of Design Creativity and Innovation*. doi: DOI: 10.1080/21650349.2018.1501280.
- Vogelpoel, Nicholas, and Sandra Gattenhof. 2012. "Arts-Health intersections: A model of practice for consistency in the arts-health sector." *Journal of Applied Arts and Health* 3 (3):259-274.

¹ For an example of this see Krippendorff's comparison between colour expressed in digital form as numbers, and as an individual's perception expressed in language (2006 pp 20-23).