Designing with and for People with Dementia: Developing a Mindful Interdisciplinary Co-Design Methodology

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Abstract

This paper reports on the development of a mindful interdisciplinary design methodology in the context of the MinD project research into designing for and with people with dementia, which takes the particular focus on supporting the subjective well-being and self-empowerment of people with early to mid stage dementia in social context.

Existing research is for the most part focussed on functional support and safe-keeping from the perspective of the carer. References to decision-making and empowerment are predominantly related to action planning for dementia care or advance care planning. References to care and social interaction show that caregivers tend to take a deficit-oriented perspective, and occupation of people with dementia is often associated with doing 'something' with little focus on the meaningfulness of the activity. Furthermore, caregivers and people with dementia tend to differ in their perspectives, e.g. on assistive devices, which might offer support.

The MinD project, has therefore developed an interdisciplinary co-design methodology in which the voices to people with dementia contribute to better understanding and developing mindful design solutions that support people with dementia with regard to their the subjective well-being and self-empowerment a well as meaningful and equitable social engagement.

This paper discussed the design methodological framework and methods developed for the data collection and design development phases of the project, and their rationale. It thus makes a contribution to interdisciplinary methodologies in the area of design for health.

Keywords: mindfulness, mindful design, co-design, methodology, public and patient involvement (PPI), interdisciplinary

With ca. 10.9 million people affected by dementia in Europe, with numbers set to double by 2050 (Prince, Guerchet and Prina 2013), with 20 million carers, and with no cure in sight (Alcove 2013: 13), research into dementia is a priority of the European Commission (EC), (OCED 2015: 20). Characterised by progressive memory and cognitive degeneration (Alcove 2013: 13), it is widely recognised that people with dementia experience a range of behavioural and psychological problems subsequent disadvantaged or discriminated status, and reduced social engagement. Therefore, research into care and support to improve the quality of life of people with dementia is essential, to encourage and enable and offer opportunities for them to engage in activities that are in line with their interests and experiences (Alcove 2013: 22; Alzheimer's Society 2013; Alzheimer's Australia 2008, Victorian State Government 2014).

However, currently there is very little research into the quality of life of people with Dementia. Existing studies are largely focussed on functional support and safe- keeping from the perspective of the carer: References to decision-making and empowerment are rare and often related to action planning for dementia care, advance care planning or treatment options (e.g. Fetherstonhaugh 2013:144). Furthermore, caregivers and people with dementia tend to differ in their perspectives, e.g. on assistive devices, which might offer support (Gibson et al., 2015). Initial insights about care and social interaction from our own work[1] indicate that caregivers also tend to take a deficit-oriented perspective, and occupation of people with dementia is often associated with doing 'something', with no focus on meaningful engagement). Some smaller studies which do offer insight into the wellbeing and empowerment of people with dementia, related to exercise programmes (Olsen et al., 2015) or to social eating (Keller et al., 2015), show positive responses and the appreciation of people with dementia of being recognised, respected and socially connected.

The MinD project therefore takes its focus on subjective wellbeing, self- empowerment and meaningful social engagement to recognise the importance and value of meaningful activities and social interactions, and the contribution that people with dementia can make to society. It does so by bringing together and applying both mindful approaches from psychology (Langer 2010, Kabat-Zinn 2003) and design (e.g. Niedderer et al 2014a, b) to put the individual's wellbeing in everyday social life at the centre. Mindful design approaches can offer both, therapeutic practices as well as novel solutions and implementation of mindful approaches into everyday life.

One important aspect in studies about people with dementia is that often they are not included, but data collection is done through cares. In order to enable the voices of people with dementia a voice and increase their level of empowerment also with research processes, it is important to include them as valued participants. Therefore public and patient involvement (PPI) and co-production, especially in an interdisciplinary design and healthcare context, is important to bring together, adapt, adopt, amalgamate and develop suitable methods to facilitate people with dementia as active partners in each step of the research. The MinD project, which develops through three stages (data collection, design development and implementation evaluation), has

[1] Our work includes: 21 interviews with people with dementia and 10 interviews with carers across three countries (Germany, The Netherlands, Spain) conducted between September 2016-January 2017, publication of final results forthcoming.

therefore co-developed an interdisciplinary co-design methodology spanning the three stages to afford a voice to people with dementia. The aim is foll all partners collectively to better understand and develop mindful design solutions that can support people with dementia with regard to their subjective well-being and self- empowerment in social context.

This paper discusses the mindful design development framework and methods developed for the data collection and design development stages, including data collection design tools, analytical mindful design framework, design ideation and co- design activities conducted during the project, and their rationale.

The role of mindfulness and design in dementia care

This section discusses social engagement, self-empowerment and subjective well- being, first in the context of dementia care and support, second in relation to mindfulness, and third the role of design in its implementation.

Dementia and social engagement

People with dementia are regularly affected by behavioural and psychosocial symptoms of dementia (Gautier et al 2010, Manthorpe and Moniz-Cook 2008), either as a cause of Alzheimer's disease, of Stroke (multi-infarct dementia), or other dementias (e.g. Lewy-Body, Pick's or Binswanger's disease), (Barker et al 2002). In addition, they often face various difficulties of engaging in social context, e.g. through difficulties in planning, organizing, thinking strategically, paying attention to and remembering details, managing time and space. They also may have memory impairments, concentration difficulties, and a decreased ability to learn new skills, take initiatives and get motivated (Baddeley, Kopelman, and Wilson 2002).

In social context, this can cause difficulties in recognizing, relating to, and empathising with other people because individuals are struggling with their identity and with coming to terms with their circumstances. These difficulties often lead to social and emotional insecurity, which can e.g. result in aggressive behaviour or in withdrawal, or in being disadvantaged, devalued or discriminated against, posing a challenge for interacting socially and resulting in reduced social engagement. Social contact, however, is central to stimulating mental faculties and emotional balance, and maintaining quality of life (Mendes de Leon et al 2003).While existing research is largely focussed on functional support and safe-keeping as discussed above, our research focuses on the aspects of subjective wellbeing and self- empowerment in social context to encourage more meaningful social engagement. By subjective wellbeing[2], following (Steptoe et al 2015, Deci and Ryan 2008, Waterman, 1993, Seaborn, 2016) we refer to a person's self-perception with regard to both hedonic and eudemonic aspects, i.e. their happiness and self-actualisation, rather than any objective health measures. Subjective well-being, i.e. contentment with one-self, has an important relationship with perceptions of self-empowerment, in that one can see (perceptions of) self-empowerment either as part of and contributing to wellbeing or as a result of well-being. Following Rotter (1990) and Langer (2010), self- empowerment refers to a person's feeling of responsibility and of being in control of one's own life. Both, wellbeing and perceptions of self-empowerment, are important factors that influence and are influenced by social engagement, i.e. by having social contact and interaction with others, in that

[2] In the following simply referred to both as 'subjective wellbeing' or simply as 'wellbeing'

meaningful social engagement can be important for subjective well-being, while feelings of self-empowerment can help build confidence for engaging socially and feeling self-value as one of the constituents of subjective well-being.

Self-empowerment and subjective well-being through mindfulness

Mindfulness is closely related to and can be beneficial in enhancing perceptions of subjective well-being and self-empowerment. The understanding of mindfulness is dominated by two major theoretical approaches.

The first, by Kabat-Zinn (2003), defines mindfulness as 'the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment' (p. 145). Meditation based, it is often used for therapeutic purposes, such as the Stress Reduction and Relaxation Program (SR&RP, see e.g. Winbush et al., 2007; Goyal et al, 2014 for reviews). The aspect of focusing on 'being-in-the-moment', as not requiring memory, also can offer empowerment to people with dementia.

The second understanding is also strongly committed to the notion of being in the present moment. Associated with Ellen Langer's work on mindlessness and choice, this approach presents mindfulness as the process of actively making new distinctions by not relying on automatic categorisations (Ie et al, 2014). With this approach, mindfulness is nurtured by maintaining an orientation in the present, an alertness to distinctions, a sensitivity to different contexts, and an openness to novelty (Langer, 1989, 2010). In addition, Langer has shown that offering people responsibility and choice increases their well-being (Langer 1989: 123).

Mindfulness is therefore increasingly used for therapy in the context of dementia care, both for people with dementia and their carers, and results have indicated reductions of stress and depression in both groups (McBee 2012, Monin and Schulz 2009, Oken et al 2011, Whitebird et al 2012). Mindfulness therapeutic approaches have also begun to be implemented through design with good results (e.g. Chittaro and Vianella, 2013). Cognitive mindful approaches have already been applied successfully in therapeutic and in everyday contexts (Ie et al, 2014: 149-51; Djikic 2014; Manicavasgar et al 2011). In distinction to these approaches, we will look at the use of mindfulness in everyday social contexts and how they can be embedded through design.

Design for dementia

This section reviews the current use of design with regard to dementia care. Currently there are a number of design approaches, which address various aspects of dementia. They can be organised into four categories of non-pharmacological interventions (O'Neil et al 2011):

Cognitive/emotion-oriented interventions: There are a number of interventions and products related to reminiscence therapy that seek to stimulate memory, such as REMPAD, which is a new software tool to create multi-media content that can be used to connect carers and residents with memories from the past (Yang et al, 2013). There are also environmental interventions aimed at helping with orientation, for example, reducing clutter or improving signage and colour contrasts (e.g. Iyendo et al (2016).

Sensory stimulation interventions: Sensory stimulation interventions are mainly of a therapeutic nature. They include for example aromatherapy (e.g. 'ODE' fragrance system, Design Council

2012), light therapy (Thieme et al 2013), tactile pillows and textiles (Pakhchyan, 2013, Treadaway and Kenning, 2016, Ten Bhömer, 2016), or Snoezelen multisensory stimulation (Weert et al, 2005). The various approaches are being used to stimulate tactile or other senses and by doing so to stimulate interest, discussion and/or reminiscence.

Behaviour management techniques: Design interventions available in support of behavioural management include, for example, the above mentioned 'ODE' fragrance system to promote eating. Other interventions address personal safety, such as the personal alarm 'Buddy' (Design Council 2012) or the 'Safe House' sensor system (Kinney et al, 2004) through sensor tracking linked to alerts. Yet others are aimed at enabling independence, e.g. MyLife project (MyLife 2016), COGKNOW (Meiland et al, 2012) or the ReMind Me App (Innovate Dementia, 2015). All three offer different types and levels of software to help people with early stage dementia to keep track of their daily routines and activities and stay connected.

Other psychosocial interventions include various approaches not fitting under the three categories above, such as animal-assisted therapy and exercise, or interventions for more general wellbeing and social engagement. Examples are the 'dementia dog' scheme (Design Council 2012) where trained dogs help people with dementia with orientation when going out, and they act as companions and help e.g. with reminding of eating times; the Alzheimer's cafés (Alzheimer Europe 2013); and the Humanitas scheme in the Netherlands where students are given free accommodation in a care home in return for 30 hours of contact and support time per month with the residents (Jansen 2015).

In summary, there is a large focus on therapy and memory, safety and lately on offering opportunities for social connection and interaction in current non- pharmaceutical design interventions. However, there is a need for attention on the quality and meaningfulness of interaction and the role that people with dementia play within it: much social interaction occurs in everyday context, but may be missed because it is associated with functional aspects of care; also often the role of the person with dementia appears to be reactive rather than pro-active because of negative emotions associated with the diagnosis of the disease.

Designing for mindful social engagement, self-empowerment and subjective wellbeing

To support and enhance self-empowerment and subjective wellbeing for people with dementia within and through meaningful social engagement, our approach extends design approaches to dementia, which have been discussed above, by introducing a mindfulness approach to allow for reflection, choice and responsibility to promote subjective wellbeing, self-empowerment and meaningful social engagement. This mindful design approach for application in the dementia context has been developed in detail elsewhere (Niedderer, Tournier and Coleston-Shields, under review). We therefore summarise here the key points, before moving on to the discussion of its methodological implementation in the next section.

Based on the review of existing approaches to mindful design from various contexts, we have synthesised a framework that comprises five different mindful design approaches as follows:

- Mindful design approach 1: Environment design may be used to improve relaxation and mood through multisensory stimulation (artificial or natural), with or without therapeutic context. For example, multi-sensorial (e.g. sight, sense of smell, taste, touch, etc.) stimulation is

typically found in gardening and through being in contact with nature, but can also be created artificially, such as in the Snoezelen (controlled multisensory environment) approach (Ozdemir and Akdemir, 2009).

- Mindful design approach 2: Design may be used to support mindfulness practices in therapeutic contexts. For example, Thieme et al (2013) have designed an interactive handheld light globe to support mindfulness practice in a mental health/depression therapy context.

- Mindful design approach 3: Design may be used as a tool to deliver mindfulness training. An example is the thought-distancing training delivered via a mobile app: "AEON allows the user to enter his/her thoughts and visualize them as written in ink on a parchment placed under water. By touching the screen, the user can interact with the water and produce waves that progressively dissolve each written thought." (Chittaro and Vianella, 2013).

- Mindful design approach 4: Create self-awareness to initiate mindfulness practice in everyday (or therapy) contexts. A basic application of this idea can be found in the health feature in the Apple watch, which vibrates 'tapping' the user on the wrist every hour to alert them to stand up for a minute, or to prompt them to breathe more deeply.

Mindful design approach 5 embeds mindful choices and reflection in every day actions and social interactions. Drawing on cognitive mindfulness, design can be used to direct awareness to other issues, unrelated of therapeutic purposes, such as social and environ-mental issues, cultural values and beliefs, expectations or preconceptions. It can offer the ability to activate and direct mindful awareness and reflection towards relevant issues or goals within everyday contexts through choices embedded in the design (Niedderer 2014).

This framework of mindful design can help designers as well as people with dementias and their carers to select, develop and apply the most appropriate design interventions within dementia care and support, whether at home or in a formal care context. In order to implement the approach in our project and to develop relevant design interventions, it is further important to make the voices of people with dementia central to all steps of the process. Partners have therefore developed an interdisciplinary co-design methodology, which is discussed in the following section, which includes a discussion about co-producing with people with dementia in the research and design process, and explains the development of the different methods employed during the first and second phases of the project (data collection and design development).

Designing for and with people with dementia

This section discusses the design methodological implications and requirements for the inclusion of participants in the research and design process for the application of the proposed mindful design approach. It reports on the choices and rationale for the development of suitable design methods to support the data collection and to conduct the design development phase in line with the inclusive aims of the study.

Involving people with dementia: Research participation, public and patient involvement and co-production in research and design development

The MinD project seeks to develop designs based on people's real lives and values that are relevant and appropriately designed. Involvement of users in the research and design process is therefore essential. Inclusion for the purposes of our research relates to both, participation in the traditional sense as research subjects, and as co- researchers and designers through public and patient involvement (PPI) and co- production activities throughout the project.

Traditional research participation

Traditional research participation for our purposes includes focus groups, individual interviews and diary probes. They are used to elicit issues and challenges concerning well-being and self-empowerment in everyday and social contexts from the view of the person with dementia. Their aim is to identify situations for design innovation. In this context, focus groups are used to facilitate discussion and elicit different views and arguments through dialogue (Krueger and Casey 2000) while individual semi- structured interviews offer further in depth understandings. These traditional participant-based research tools have been supported and complemented by two design tools: Visual cards have been developed as prompts, memory aids and discussion points for use during the interviews and are discussed further in section 3.2.1; 'Diary probes' have been developed as a complementary tool to focus more strongly on values and feelings, and to collect visual evidence, and they are discussed further in section 3.2.2.

Patient and public involvement (PPI)

PPI in research is defined as research carried out 'with' or 'by' members of the public rather than 'to,' 'about' or 'for' them (INVOLVE, 2017). PPI falls within a spectrum of public engagement from consultation to co-production and is rooted in the civil rights movements of service users and carers, best defined as 'nothing about us without us.' This approach closely aligns with co-design approaches (Sanders and Stappers 2008, Sanders and Westerlund 2011, Sanders, Brandt and Binder 2010), which advocate the inclusion of users into the design process, not just for consultation but for involvement from the beginning to the end. For our research, we merge these two approaches into a 'PPI-based co-design approach', which invites mutual decisions and actions, and aspires to a meaningful and equitable co-creation within the design process of peer researchers and stakeholders, to influence the values, process and content of the research. It thus provides the essential basis for designing outcomes that are both relevant and appropriate for the intended user group with regard to functional, emotional and ergonomic needs and wants. In other words, it aims to ensure that researchers with domain experience and design or clinical expertise and lay participants in the research work equitably, and that preconceptions on both sides are challenged; not only for example, the needs and desires of older people or people with cognitive impairment or their attitudes and capabilities regarding technologies (von Kutzleben et al., 2012) but also service user and carer 'lived experience' perceptions around the authority or capacity of academic 'learned experience.' We use PPI activities throughout the project, in parallel and interspersed with the other methods as further explained below.

In addition, peer researchers have been recruited into the exchange programme, and the values and processes of involvement activities are being documented as in this paper. In working with PPI co-researchers – while it should be recognised that everyone has needs when co-working in

meetings and workshops – the practical challenges that can arise for research engagements with people who have healthcare needs or care responsibilities require organisation to accommodate details such as:

- suitable times of day
- participant travel arrangements where possible
- appropriate and timely reminders if necessary
- flexibility and sensitivity towards health or care requirements.

Organisation by partners of MinD is facilitated by the inclusion of an experienced involvement coordinator, alongside lead involvement personnel, to plan meetings and events through on-going consultation with both researchers with domain experience and participants with lived experience.

Designing mindful data collection tools

For the data collection, two tools have been developed to support and complement the individual and focus group interviews with people with dementia and their carers: Firstly, a set of visual cards depicting daily, leisure and social activities for use in the interviews as prompts or memory aids. Secondly, a visual diary has been developed to complement the interviews to collect visual and written information about personal values and objects used etc.

Visual Cards

The idea to use a set of visual cards (Figure 1) emerged from the discussion about the interviews and focus groups. The question was how best to communicate with participants, how to help them maintain their attention and to remember e.g. tasks and situations of daily living, during the interviews. The aim was to provide support, both, for the interviewer and interviewee during the interview through being

- usable as a prompt and memory aid;
- easy to understand because of offering a visual and written dimension.

Cards to support interviews have already been used successfully by other researchers Hassanzahl & Diefenbach (2010) and Casais, Mugge, Desmet (2016). The team reviewed existing cards as well as approaches of appropriate visualisation. This resulted in a decision to use illustration to visualise the activities in order to reduce them to the key characteristics and keep them visually simple and clear for easy recognition, following guidance for designing web-content for elderly people (Marshall, 2016). The cards were designed to cover four areas of activities and daily life in line with the mindfulness framework of the project, and the focus of the interview schedules, covering:

- activities of daily living
- leisure activities
- social activities
- wellbeing

As part of the development process, different options for the cards were presented to all members of the team as well as potential participants (through dementia outreach groups) to comment on. In this way, the cards were gradually refined in terms of the chosen activities,

figurative representations (concerning age, gender, ethnic diversity, etc.), visual readability, and other criteria.

So far the Visual Cards have been used, and their use observed, in eight interviews with people with dementia, to evaluate their role in supporting the interview process.

They proved to be especially supportive as conversation starters in situations where participants did not directly know what to answer. Additionally, as a physical reminder, they helped the interviewers to cover all of the interview topics in the semi- structured interviews.

Figure 1: MinD Visual Cards, developed to support interviews with people with dementia.

Diary Probes – Do books

As a complement to the interviews and focus groups, a 'diary' probe set in the format of a 'do book' was used to obtain richer contextual information about the life of people with dementia. The 'do book' allowed for more active participation of people with dementia through self-documentation. Probes look at users' personal context, including social, aesthetic and cultural environment as well as needs, feelings and attitudes (Mattelmäki, 2006).

The do books that were developed for the Mind project sought to collect data on two general topics: (1) personal information about e.g., goals, attitudes, experiences, motivation, capabilities, and social context, that could be used to develop rich personas (Figure 2), and (2) information about areas of change and needs for preservation in peoples life with respect to ADL, leisure activities, social engagement and wellbeing, in order to identify areas for design interventions (Figure 3). The design of the do books consisted of a folder and large lose leafs that could be worked on separately in the order of choice. To cater for personal preferences of participants and to generate additional visual information about their life context in addition to the verbal information from the interviews, the activities of the do books allow for various

ways of expression such as writing, drawing, photographing and crafting.
Furthermore, to make the probes accessible for every one of the participants, the activities were of varying difficulty, did not require learning and were designed to be gender neutral. A few of the probes were based on the artful work of Wallace, Wright, et al. who used probes to get insight into personhood in dementia (2013).

15 do books were distributed over three countries, Germany, the Netherlands and Spain. They remained the property of the participants but anonymized pictures were taken of the results for analysis. First results promise valuable insights into decision making and attitudes with respect to future plans of people with dementia.

Figure 2: ‘Do books’ exercise about preserving important moments in people’s lives.

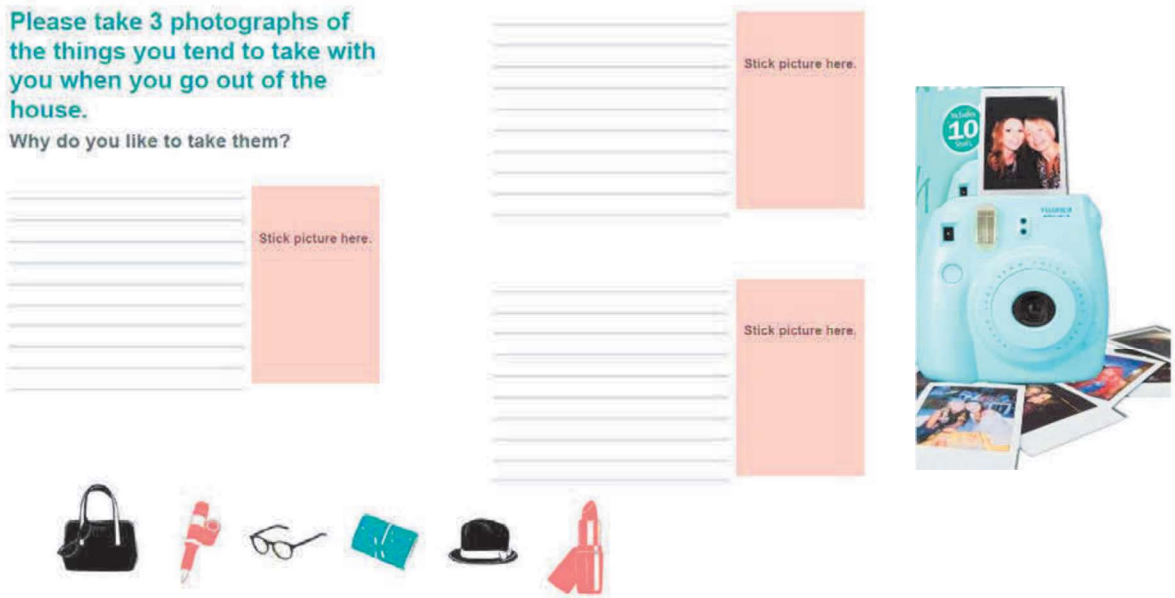

Figure 3: ‘Do books’ exercise about personal things of people with dementia when going out.

Developing Methods for Mindful Design Development

For the actual design development phase of the MinD project, three design methods were defined to enable the design process, which includes the scenario identification, ideation and PPI-based co-design aspects.

Mindful Scenario Task Analysis (MSTA)

Following identification of relevant intervention points from the data collection, the mindful scenario task analysis (MSTA) has the purpose of interrogating potential design opportunities to understand the various opportunities, challenges, and potential mindful strategies and solutions. It is used to analyse real-world scenarios and user stories from persons with lived experience of dementia including individuals living with dementia and care-givers. MSTA as used within MinD draws on and synthesises scenario based design (Carroll, 2000) and hierarchical task-analysis (HTA) (Rogers et al. 2011: 383) with a specific focus on mindfulness. Scenario-based analysis uses the elaboration of scenario cases to take a person centred perspective on design problems:

‘Scenarios are at once concrete and flexible, helping developers manage the fluidity of design situations. Scenarios afford multiple views of an interaction, diverse kinds and amounts of detailing, helping developers manage the many consequences entailed by any given design move.’ (Carroll, 2000:43)

HTA further helps to define individual aspects and steps within any one given scenarios, and which we have further defined for our MSTA through a focus on mindfulness values and characteristics. The mindfulness focus was developed through a test application with initial interview findings.

In the initial stages of MinD, ‘lived experience’ interviews in The Netherlands and focus groups in Germany identified some exemplars in the context of understanding potentially challenging social situations such as going out to a party, family event, group leisure activity or a meeting. (M)STA was used to break down the social going out task into its constituent components (before leaving, en route etc.) from discussion at one of the MinD exchange visits. Three aspects of the scenario were extracted and these were then further developed through UK PPI engagement: 1) Activities (mindful and non-mindful) such as planning or reflecting; 2) Mindful (and non- mindful) states such as experiencing of emotions, sensations, worries, thoughts, reactions and behavioural responses; 3) Mindful (and non-mindful) plans, tactics and strategies that are or could be employed in practice to mitigate the challenges or amplify opportunities. The initial scenario framework was tested in a patient and public involvement (PPI) group session with the addition of one further aspect, incorporated by people with lived experience: 4) Things that help or hinder in the environment or within care-giver and individual’s relationship. The generic MSTA grid is shown in Table 1 below.

Table 1: generic MSTA grid used in MinD

Define and complete for each persona in the chosen scenarios	Task step 1	Task Step 2	Task Step 3	Etc.
Activities (mindful and non- mindful)				
Mindful states				
Mindful strategies				
Things (help or hinder)				

Enhanced processes of engagement during this session between researchers and people with lived experience were co-designed, introduced and evaluated in that real world scenarios detailed from people's lived experience were collaboratively co- created and reflected on in the PPI co-production session to demonstrate the value of the approach. It was concluded that the method was useful in generating understanding, of both need and lived experience potential for involvement and co- production in meeting any such need, that is deep enough to guide requirements to feed into the design process where solutions will be sought. Significantly enhanced understandings were gained furthermore about improved collaborative working partnerships between practitioners with learned experience and people with lived experience. The method and the engagement processes will therefore be used and validated further in future co-design sessions.

Design Brainstorming and Ideation

To create innovative designs, the converging phase of research and data collection is followed by a diverging phase, in which – based upon relevant insights of research and data collection – out-of-the box ideation is stimulated. The design ideation process is complementing and building on the MSTA process through targeted brainstorming of solutions for the identified scenarios based on a model provided by Panton Design. The ideation process as used for MinD is used ideally with a multidisciplinary team of preferably 5-10 participants. It should ideally include participants with creative skills, with knowledge of target groups, their needs and context as well as participants with 'lived experience'.

The first step stars with an explanation of the basic rules of the creative sessions, which are: 1) criticism isn't allowed as it blocks creativity, 2) every participant should try to come up with as many ideas as possible because usually it requires a large quantity of ideas to find that one innovative, outstanding idea and 3) copying from other participants is allowed because someone's ideas can inspire others to come up with even better solutions.

The second step is to define the goals of the creative session and sharing the relevant insights from research and data collection. In the first MinD design workshop, the insights used were four major issues in the context of dementia: a) delivering the diagnosis, b) acceptance (internal and external), c) changing relationship and d) living in a familiar world. In small teams of two participants each of these four issues were explored further by sharing knowledge. Conclusions were noted and shared.

Figure 4: Sharing and discussing brainstorming ideas.

In the third step each team described what the situation would be in a semi-perfect world, in which dementia would still exist, but all imaginable technology and services would be at hand and free. Based upon these descriptions many ideas were created in the fourth step by all participants, both individually and after consulting other participants. In the fifth step each participant detailed his or her top 3 ideas. In the sixth and final step each participant contributed to all top ideas.

So far this process has been used in one 'test' workshop to familiarise all researchers with the process and understand its rules and potential. The process will be used in the forthcoming design development phase.

PPI-based mindful co-design

The MinD project involves people with lived experience of a memory problem including people with a diagnosis of dementia, informal caregivers who are often family relations of a person with dementia, and people with wider lived experience of a mental health condition or a caring role. PPI and co-production are used throughout the project and are arranged through several partners of the consortium, including Alzheimer Europe in Luxembourg and Nottinghamshire Healthcare NHS Foundation Trust (NHT) in the UK.

NHT has for example commissioned a peer researcher as a fee-paid participant with lived experience, along with a team of volunteers recruited based on aptitude and interest, and whose expenses are fully reimbursed. Alzheimer Europe organised a PPI consultation with the members of the European Working Group of People with Dementia (EWGPWD) in Luxembourg on 15 May 2017, at which the MinD researchers presented their findings so far and obtained feedback about issues related to the ongoing development of the project.

Specific examples of PPI co-production in MinD so far include:

- Feedback on the development of design tools such as the visual cards;
- Ideas generation about mindfulness aspects of design, for example, of clothing and accessories prior to one of the project meetings;
- Scenario co-production workshop;
- Feedback on and input into project development and methodology.

Further involvement in the design process will include involvement in the ideation and design development processes over the next year based on the parameters set out in this paper.

Conclusion

In summary, this paper has described the foundations and methodology adopted in the MinD project for designing with and for people with dementia.

The first part of the paper has offered a brief review of the premises of the work in terms of challenges for people with dementia with regard to issues of subjective wellbeing, self-empowerment and social engagement, and available design support. It has introduced and proposed the use of the concept of mindfulness and shown the different possibilities of using design to embed mindfulness both in therapy and everyday contexts. This means our approach looks at opportunities and people's capabilities and flourishing, rather than a deficit oriented approach discussed above.

The second part of the paper has co-developed the design methodology including traditional participant and PPI co-production for the different stages and aspects of the project, and their role and requirements in the process. It has further considered the different design methods for user-centred working, including Mindful Scenario Task Analysis, Design Ideation, and a framework for PPI-based co-design activities.

The contribution and benefit of the proposed framework and methods is in offering a transparent and evidence-based approach and guidance to working proactively with people with early to mid-stage dementia (and their carers) on design research projects to develop real-life interventions that are based on the wishes, wants and needs of people with dementia and their carers.

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