

## This is Me: Evaluation of a boardgame to promote social engagement, wellbeing and agency in people with dementia through mindful life-storytelling

Kristina Niedderer, Vjera Holthoff-Detto, Thomas J.L. van Rompay, Armağan Karahanoğlu, Geke D.S. Ludden, Rosa Almeida, Raquel Losada Durán, Yolanda Bueno Aguado, Jennifer N.W. Lim, Tina Smith, et al.

## ▶ To cite this version:

Kristina Niedderer, Vjera Holthoff-Detto, Thomas J.L. van Rompay, Armağan Karahanoğlu, Geke D.S. Ludden, et al.. This is Me: Evaluation of a boardgame to promote social engagement, wellbeing and agency in people with dementia through mindful life-storytelling. Journal of Aging Studies, 2022, 60, pp.100995. 10.1016/j.jaging.2021.100995. hal-04088346

## HAL Id: hal-04088346 https://hal.science/hal-04088346

Submitted on 11 Apr2024

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers. L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Contents lists available at ScienceDirect

## Journal of Aging Studies



journal homepage: www.elsevier.com/locate/jaging

## *This is Me*: Evaluation of a boardgame to promote social engagement, wellbeing and agency in people with dementia through mindful life-storytelling

Kristina Niedderer<sup>a,\*</sup>, Vjera Holthoff-Detto<sup>b,j</sup>, Thomas J.L. van Rompay<sup>c</sup>,

Armağan Karahanoğlu<sup>d</sup>, Geke D.S. Ludden<sup>d</sup>, Rosa Almeida<sup>e</sup>, Raquel Losada Durán<sup>e</sup>,

Yolanda Bueno Aguado<sup>e</sup>, Jennifer N.W. Lim<sup>f</sup>, Tina Smith<sup>f</sup>, Dew Harrison<sup>g</sup>,

Michael P. Craven<sup>h,i</sup>, Julie Gosling<sup>h</sup>, Laura Orton<sup>a</sup>, Isabelle Tournier<sup>a</sup>

<sup>b</sup> Alexianer Krankenhaus Hedwigshoehe, St. Hedwig Kliniken, Berlin, Germany

<sup>c</sup> Department of Communication Science, University of Twente, the Netherlands

<sup>d</sup> Department of Design, Production and Management, University of Twente, the Netherlands

<sup>g</sup> Wolverhampton School of Art, Faculty of Arts Business and Social Sciences, University of Wolverhampton, UK

<sup>h</sup> Nottinghamshire Healthcare NHS Foundation Trust, Nottingham, UK

<sup>i</sup> NIHR MindTech MedTech Co-operative, Nottingham, UK

<sup>j</sup> Technische Universität Dresden, Germany

#### ARTICLE INFO

Keywords: Design Co-design Dementia Design strategy Psychosocial intervention Life-storytelling Reminiscence Mindfulness

#### ABSTRACT

Receiving a dementia diagnosis is a difficult experience for most people and often affects their wellbeing negatively. To support people's wellbeing, in a therapeutic context, life-storytelling, reminiscence and mind-fulness are used with people with dementia. In an everyday context, traditional games are used as a resource for stimulating memory, cognition and social activity. While an increasing number of creative strategies are available to support people with dementia, the area of board games design and their effect on wellbeing is underexplored.

This paper reports on the evaluation of the *This is Me (TIM)* mindful life-storytelling board game by the European project *MinD*. Using a co-design methodology, *TIM* was developed with and for people with mild to moderate dementia to support their wellbeing by enhancing self-empowerment and social engagement. A focus group methodology was used to evaluate *TIM* with 50 people with dementia and 19 carers across four countries. *TIM* was evaluated with regard to the usability and experience of the design as well as people's emotional wellbeing, social engagement and agency.

The thematic analysis demonstrated that the combination of life-storytelling and mindfulness allowed players to engage in meaningful social interaction and, as a result, they reported enjoyment, learning, more acceptance of the past and present situation, and that they perceived looking forward into the future together with others as helpful. The study demonstrates that design can be a useful means to support people with dementia in aspects of emotional wellbeing, social engagement and a sense of agency.

#### Introduction

Today, dementia is recognised globally as a major public health concern. Almost 10 million people are affected by dementia in Europe, and 50 million people worldwide, with cases set to double by 2050 (Alzheimer Europe, 2019; WHO, 2020). With currently no cure available, receiving a dementia diagnosis is trying for most people. In addition to cognitive decline and dementia-related memory problems (De

https://doi.org/10.1016/j.jaging.2021.100995

Received 21 April 2021; Received in revised form 12 November 2021; Accepted 30 November 2021 Available online 15 December 2021 0890-4065/© 2021 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/).



<sup>&</sup>lt;sup>a</sup> Manchester School of Art, Manchester Metropolitan University, UK

e Fundatión INTRAS, Valladolid, Spain

f Faculty of Education, Health & Wellbeing, University of Wolverhampton, UK

<sup>\*</sup> Corresponding author at: Manchester Metropolitan University, Manchester School of Art, Benzie Building (CH511), Boundary St West, Manchester M15 6BR, UK. *E-mail address:* k.niedderer@mmu.ac.uk (K. Niedderer).

Vugt & Dröes, 2017; Lee, Boltz, Lee, & Algase, 2017), the diagnosis often negatively affects people's wellbeing. It can leave people feeling vulnerable and alone as they struggle with perceptions of self and stigma, practical tasks and reduced independence, making it difficult to imagine a worthwhile future (Low, Swaffer, McGrath, & Brodaty, 2018; Pratt & Wilkinson, 2001). This is compounded by a scarcity of suitable materials and life enhancement strategies available to support people following the diagnosis (Low et al., 2018; Roberts, 2019). In this context, design can play an important role in supporting health and social care through providing life enhancement strategies specifically aimed to support the wellbeing of people with early-stage dementia (Niedderer et al., 2020).

This paper reports on one result of the international, interdisciplinary European MinD project, which has investigated how design can support the wellbeing of people with mild to moderate dementia through enhancing their social engagement and self-empowerment. Working with people with dementia and carers, the MinD team developed the *This is Me (TIM)* board game. *TIM* draws on concepts from positive psychology (Snyder, Lopez, Edwards, & Marques, 2020), including life-storytelling, reminiscence and mindfulness, which are integrated into the game design. It was evaluated with 50 people with dementia and 19 carers across four countries (UK, Germany, Netherlands and Spain).

To facilitate this interdisciplinary and cross-cultural work, MinD adopted an interdisciplinary approach to the development of the study's theoretical underpinnings (Toomey, Markusson, Adams, & Brockett, 2015), combining insights from design, psychology and gerontology. In addition, we have drawn on insights and guidance for interdisciplinary working (Tiainen & Koivunen, 2006) to facilitate its multi-site, multi-lingual and multi-cultural nature. This paper presents a summary of the study's theoretical underpinning and the design's co-development, the methods for the data collection and evaluation, and discussion of the results.

#### Designing for wellbeing

In order to design for wellbeing, we first need to consider what wellbeing means. This is important both for the design process and for the evaluation. For the purposes of this study, we follow Strohmaier and Camic's (2017) understanding of wellbeing as a 'fluctuating subjective state'. This understanding is based on previous discourses that highlight the importance of subjective wellbeing for people with dementia (Kaufmann & Engel, 2016; Kitwood & Bredin, 1992). Definitions variously include the criteria of attachment, comfort, identity, inclusion, occupation and agency (Kaufmann & Engel, 2016) and of a sense of agency, engagement, happiness, feeling well, confidence and optimism (Strohmaier & Camic, 2017). Power (2016) further offers seven domains of wellbeing, including identity, connectedness, security (in the sense of trust rather than safety), autonomy, meaning, growth and joy. While using different terminology, these definitions overlap and can be grouped under three categories: emotional wellbeing (safety/trust, comfort, feeling well, happiness, joy), social engagement (inclusion, engagement, connectedness, attachment) and agency (identity, confidence and optimism, meaningful occupation,<sup>1</sup> autonomy and growth).

Emotional wellbeing is the sense of feeling content, comfortable and coping with life (Stewart-Brown, 1998) and is closely related to social engagement.<sup>2</sup> Having an active and socially engaged life, which includes caring others who empathise with the feelings, thoughts, and behaviours

<sup>1</sup> Occupation is only regarded as a part of agency if it is meaningful and done by the person's choice. Therefore, we add the attribute 'meaningful' here to distinguish it from occupation often used not for their benefit but to keep people with dementia quiet for a time so they don't need 'supervision'. of those affected, is important to wellbeing (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Fernández-Mayoralas et al., 2015). Lee et al. (2017) have shown that social interaction is significantly associated with more positive emotion expressions. In addition to bringing joy and pleasure, social activities can also help people with dementia cope with the losses associated with their condition (Aminzadeh et al., 2007). Social inclusion can also add a sense of agency or autonomy as an important determinant of wellbeing (Ryan & Deci, 2017).

Agency is broadly understood as the idea of meaningful intentional action, such as learning, starting new activities or decision making, and can help with confidence and optimism (Schlosser, 2015; Zeilig, Tischler, van der Byl Williams, West, & Strohmaier, 2019) as well as offering growth (Power, 2016). The construct of autonomy-connectedness underscores the importance of both social engagement and agency. It encompasses the capacity for being on one's own as well as for satisfactorily engaging in interpersonal relationships (Bekker & Van Assen, 2006; Hmel & Pincus, 2002).

For the purposes of this paper, then, we understand wellbeing as a 'fluctuating subjective state' that consists of the three domains of emotional wellbeing, social engagement, and agency. This understanding is useful for our application in the design context and to provide focus for both the design and evaluation processes.

#### Using life-storytelling and mindfulness to enhance wellbeing

When considering means for enhancing wellbeing through social engagement, storytelling - including life-storytelling - is of great relevance for people with dementia. It can bring joy and wellbeing by relying on autobiographic memory content (Ferring & Tournier, 2017). It can further provide a means for reflecting on one's life and for enhancing a sense of identity, often connected to a sense of self and personhood (Kitwood & Bredin, 1992). This is especially the case when the storytelling involves sharing narratives about life events and provides opportunities for connecting with other people who can contribute to stories told (Fels & Astell, 2011; Johnston & Narayanasamy, 2016). Storytelling in social context usually implies a change from the individual storyteller to the interaction with other participants in the storytelling situation (Hydén, 2011, 2013), facilitating social engagement. Additionally, storytelling usually involves the employment of bodily resources like touch and eye contact which strengthen feelings of togetherness (Phinney & Chesla, 2003). These relational aspects as well as reflection on one's life experiences and achievements can help support feelings of identity and confidence, and thus of agency, especially when combined with elements of mindfulness.

Mindfulness has been used in health and dementia contexts in established approaches as well as in relation to storytelling. Mindfulness approaches, both meditation-based and cognitive, include elements such as being in the present moment, non-judgmental acceptance of emotions and events, and reflection on these to help engender new views and perspectives (Kabat-Zinn, 2003a, 2003b; Langer, 1989, 2010; Wells, Kerr, Wolkin, et al., 2013). Langer (1989) has shown that being in the present moment and developing new perspectives can improve physical and mental wellbeing in relation to aging. According to Langer, one way of putting oneself into the present moment is by putting one's mind into the present, such as by speaking in the present tense, even if speaking about the past (p.100-113). When combining mindfulness with storytelling (e.g. mindfulness-based narrative therapy, Rodríguez Vega, Bayón Pérez, PalaoTarrero, & Fernández Liria, 2014), new perspectives can arise through telling about one's own and listening to other's experiences, through self-awareness and reflection on similarities or differences. Developing new perspectives can offer choices (Niedderer, 2014), which afford agency in the sense of meaningful intentional action. Furthermore, being mindfully present in the here and now can provide an alternative road to selfhood. That is, in addition to establishing a sense of identity through reflection on one's life (supported by autobiographic memory content), mindfulness can enhance direct

 $<sup>^{2}</sup>$  We avoid the term 'social wellbeing' here because of its much broader meanings.

awareness of sensory impressions and bodily dynamics (e.g. sensations of pain, tension or relief). This argument corresponds to the notion of embodied selfhood (e.g. Kontos, 2003, 2005), which reflects the idea that fundamental aspects of the self-concept originate from the way the body moves and behaves rather than from the cognitive workings of the mind. This understanding promotes the concept of relational citizenship, recognising "the reciprocal nature of engagement and the centrality of capacities, senses, and experiences of bodies to the exercise of human agency and interconnectedness" (Kontos, Miller, & Kontos, 2017, p.182), which is closely connected with storytelling as a construction of self.

#### Designing for mindful life-storytelling

Although the importance of storytelling is generally acknowledged, there is a need for more research on how to support people with dementia in storytelling: how informal carers (care partners) and formal carers (care professionals) can be involved in co-constructing such stories (Hydén, 2011) and how they can express the relational nature and impact for all involved through various symbolic and sensory means (Baldwin, 2008). In other words, how it is possible to enable narrative citizenship or agency as an opportunity to express oneself through narrative (Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016). For instance, when it comes to initiating social interaction through storytelling, conversation starters are important since spontaneous storytelling is often difficult (Ludden, van Rompay, Niedderer, & Tournier, 2019). Hence, questions arise of how to provide people with dementia a conversation starter for storytelling, how to create an informal and equal setting for such exchanges, and how to offer something concrete to talk about, which is in the present moment, not illness-related, and noninstitutional in character for prompting and supporting informal social interactions (Campo & Chaudhury, 2012; Ludden et al., 2019).

In the MinD project, the design of the TIM board game aimed at invoking narrative and relational citizenship to enhance wellbeing, social engagement and agency through relational life-storytelling and mindful reflection using board game design. Board games are a good vehicle for social interaction, because they can contribute to an informal conversation context and act as a conversation starter for storytelling. Research has shown that board games can help with mental health and social and emotional learning in an engaging and enjoyable manner (Hromek & Roffey, 2009; Kerr, Deane, & Crowe, 2019). In the dementia context, board games are commonly used for preventive or therapeutic purposes related to cognitive health (Dartigues, Foubert-Samier, Le Goff, et al., 2013), whereas the connection with wellbeing is rarely acknowledged and little researched (e.g. Lowrani, Indarwati, & Lestari, 2020), neither is the design of board games acknowledged with regard to supporting people with dementia (e.g. Kerr et al., 2019). The importance of designed objects for initiating social interactions with people with dementia is well-established and storytelling applications have been developed for use in (semi) professional settings (e.g. Gjernes & Måseide, 2015). However, existing products have not capitalised on the power of design to leverage different groups and engage in social interactions to stimulate wellbeing. For example, Cadamuro and Visch (2013) describe a prototype, which uses images collected by care partners to elicit stories from people with dementia in care homes to help formal carers understand residents' behaviour and personalise caregiving. By contrast, TIM was designed to promote interaction between people with dementia themselves and with care partners or formal carers by offering a social context that appeals to the needs and concerns of both and creates an equal playing field.

#### Co-designing TIM

TIM was developed using an iterative user-centered co-design approach (Niedderer et al., 2020, Fig. 1) involving people with mild to moderate dementia living in their own homes.<sup>3</sup> Our co-design and coproduction processes were informed by literature from design (e.g. Rodgers, 2016; Sanders & Stappers, 2008; Treadaway & Kenning, 2016), dementia research (e.g. Gove et al., 2018) as well as direct input from advisors with lived experience of memory problems (Gosling, Craven, Dening, et al., 2019) to create safe spaces, shared roles and responsibilities and provide people with dementia with a voice and a sense of solidarity (Gove, Diaz-Ponce, Georges, Moniz-Cook, Mountain, Chattat, Øksnebjerg, and The European Working Group of People with Dementia, 2018; Wiersma, O'Connor, Loiselle, et al., 2016). In our work, we have distinguished co-production and co-design: co-design refers to the creative process of developing the design together whereas coproduction relates to the setting that surround and facilitate the codesign process (Dening, Gosling, Craven, & Niedderer, 2020).

The design process started with the collection of the experiences of people living with dementia and those supporting them in daily life using interviews (Tournier et al., 2018). Analysis of the results revealed nine key themes, giving insights into difficulties and challenges related to dementia, which informed the design development (Gosling et al., 2019). The design development utilised a co-design and co-production approach (Niedderer et al., 2020) to collectively create and develop suitable ideas and concepts. Multiple co-design sessions were conducted in four countries across Europe in an iterative process, varying in nature dependent on the stage of the project, including:

- developing a mindful analytical framework for the design and codesign development;
- introductions to design ideas, feedback and shared decision making regarding what concepts people wanted to see developed over the course of the project;
- introduction to, exploration of, and feedback and input into selected design concepts in relation to everyday life experiences;
- feedback on and input into the prototype(s) in relation to user experience. Specifically for the development of the *TIM game*, an early prototype was used to play the game with groups of people with dementia in the UK and Spain to elicit feedback and input about the questions and other design details.

The co-design sessions involved the designers, people with dementia, care partners and care professionals, and the insights from these sessions informed which concepts were selected for development, in which way selected concepts were developed, and the prototyping of the game. In order to fully involve people with dementia as co-designers, some social and creative activities were used to overcome common apprehensions and preconceptions and build confidence in working together creatively within multidisciplinary teams. The sessions helped build a safe space where participants were comfortable with each other, felt accepted, valued and able to speak up (Dening et al., 2020; Niedderer et al., 2020).

On completion of the design development, *TIM* was evaluated with regard to its usability, and effectiveness in supporting the wellbeing of people living with dementia. This paper focuses solely on the evaluation of *TIM*. The results of the initial data collection and co-design approach are discussed elsewhere (Niedderer et al., 2020; Tournier et al., 2018). After describing the board game, this paper explains the process of evaluating *TIM* and reports on the results of the evaluation.

#### The TIM design

The TIM board game was designed to support people diagnosed with

<sup>&</sup>lt;sup>3</sup> Including one person in an assisted living community centre.

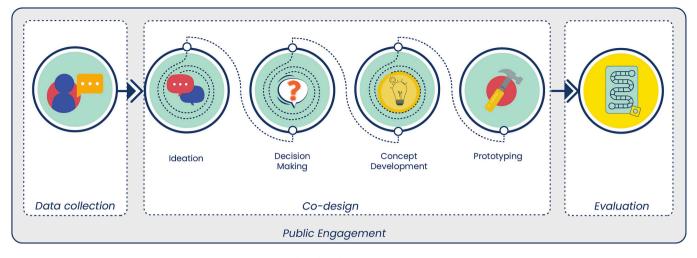


Fig. 1. The research and co-design phases of the MinD project.

dementia to increase wellbeing through mindful life-storytelling in a convivial setting. It is intended to help people adopt a positive outlook on life using mindful questions to enable reflection and seeing new perspectives. The game consists of a game board, 66 question cards, and a dice with six symbols as well as a set of counters (Fig. 2).

The board shows a life-story path, divided into decades from childhood to 100+ years. Each decade is represented by a colour code and has six fields corresponding to six question cards, which are related by means of the symbols and the respective colours. The game is played by 2–4 players with a typical duration of an hour or less. To start playing the game, the first player rolls the dice, moves the counter to the nearest field with the symbol shown, and picks the question card that corresponds to the symbol and colour of the field from the card deck. They then read out and answer the question. The others can answer the same question, or move on to roll the dice anew and pick the next question card. The questions comprise six categories (memories, activities, relationships, experiences, achievements, dreams), are open ended, and are phrased in the present tense to facilitate an in-the-moment experience. For an example of the questions, see Fig. 3.

The questions enable the players to talk and share stories about the different stages of their life. The life-story path leads the players from reminiscing about the past towards what they can and may wish to do in the present and future. The game is not just about occupying people with dementia, or for carers to learn about them, but for every person engaged in the game to share personal experiences, to reflect on and explore their past, present and future life, and so to create a mutually satisfying and enriching experience. It moves away from a problem-focused approach towards one where all players are equal in a safe and convivial atmosphere, where everyone can join in, help and receive help, offering agency to all players.

In terms of its presentation and appearance, the design process has focused on producing a game that is attractive, understandable and usable. Key factors were to make the game look fresh and nonstigmatizing, easy to comprehend cognitively, and to give it good legibility to be inclusive for people with decreasing eyesight. As it can be difficult for designers to assess what the right design decisions may be for the potential players, we involved people with dementia and carers throughout the development of the board game.

#### Method

The *TIM* game was evaluated to understand whether people with dementia and carers were able and willing to use the game (adoption and usability) and what their experience was of using the game. We were interested in whether *TIM* enhanced wellbeing (emotional wellbeing,

social engagement, agency) and experiences of reminiscence and mindfulness.

Prototypes of TIM were produced in four languages (English, Dutch, German, Spanish) for evaluation in a multi-centre study across four countries (UK, The Netherlands, Germany, Spain). Multi-centre studies have many advantages compared to single-centre studies in that they provide a larger and more heterogeneous sample of participants and support pooling of protocols, costs and personnel to improve efficiency (Chung, Song, and WRIST study group, 2010; Johnson, Barach, Vernooij-Dassen, et al., 2012; Kleiderman, Boily, Hasilo, & Knoppers, 2018; Sprague, Matta, Bhandari, et al., 2009). The set-up of the evaluation procedures varied in the four countries according to each care setting: In the UK and Spain, the game was evaluated within day groups, in Germany in a day clinic, and in the Netherlands in participants' own homes. Because of these differences, the study did not aim for comparison between sample populations, but principally sought to gain an understanding of the acceptance and usefulness of the game and its design, and to explore the perceived benefits across different settings.

#### Participants

50 people with mild to moderate dementia participated across the four countries. In addition, 17 formal and informal carers from Spain and the Netherlands participated in the evaluation<sup>4</sup> (Table 1). Participants' ages ranged from their 40's to their 90's (Table 2). Formal carers acted as gate keepers for the recruitment of participants with dementia. All participants were able to give informed consent. In the UK, seven people with dementia were recruited through the Alzheimer's society research partnership scheme. In Germany, 12 people with dementia visiting the day clinic of a psychiatric hospital participated. In Spain, there were three groups: Group 1 included 14 people with dementia visiting a memory clinic for day treatment and six care partners. In Group 2, 14 people with mild cognitive impairment participated. In Group 3, eight care partners from ethnic minority groups participated. In the Netherlands, three people with dementia, two care partners and three care workers participated. There, TIM was brought to people's living environments (own home or assisted living). For all countries, one researcher participated in the game play of each group, a second acted as observer and notetaker during the play and the feedback session (evaluation questionnaire) and did not partake in gameplay.

<sup>&</sup>lt;sup>4</sup> In the Netherlands, the formal carers are called 'case workers'.



Fig. 2. The This is Me game (Dutch version 'Dit ben ik'): a board game with question cards and a special dice (counters not on the photo).

#### Playing TIM

Researchers informed the participants in advance (usually one week) and again at the start of the session about the aim of the study and the general purpose of TIM. Participants were then asked whether they wanted to participate and were given the opportunity to provide consent according to the ethics requirements of each partner organisation.<sup>5</sup> Each session of engagement had careful preparation, including shared icebreaker activities between people with dementia and other participants to create a climate of mutual respect and joint participation. The interviewing researchers then introduced and explained how to play TIM and invited participants to play. Participants were then given the game to set it up within their group. They could play as long as they wanted (or the session allowed) and games generally took 30 min to one hour. During the game, the observing researchers made notes about how the interaction with the game and players unfolded as contextual material. These notes were used during the thematic analysis if clarification was needed with regard to the interpretation of participants' verbal responses. In the UK, Germany and Spain, the interviewing researchers asked the participants about TIM using the evaluation questionnaire immediately after playing the game, and the answers were noted down by the observing researcher(s). In the Netherlands, the same procedure was followed with the exception that participants could provide additional comments on game and gameplay upon collection of TIM one

#### Design of the evaluation questionnaire

A semi-structured questionnaire was developed by researchers from the MinD team, one of whom was the lead for the Public and Patient Involvement group in the UK with whom the questionnaire was piloted before the final evaluation. The questionnaire was designed to elicit aspects of appreciation, usability and adoption of the game as well as of the experience and potential impact of the game. The questionnaire and user elicitation approach was broadly based on the principles of Technology Assessment Models (Davis, 1993) and employed categories of questions similar to those in the User Experience Questionnaire<sup>6</sup> for interactive products (attractiveness, factors contributing to ease of use and feelings engendered) and to those of the AIR activities, internal world, relationships and the positive or negative influences on these) evaluation model that was developed by the MinD consortium (Gosling et al., 2019). The questionnaire instrument (Appendix A) comprised seven sections; section A asking about participants' experiences,

week later. The interview (feedback) sessions took between 15 and 30 min. Most participants were well practiced in group discussions, regularly participating in day group or day clinic discussions, resulting in lively discussions during the game. This means in some cases (e.g. Germany, Netherlands) there was an overlap between gameplay and interview activities, which explains the apparently shorter feedback times.

 $<sup>^5</sup>$  See ethics consent; see also Lim et al. Lim et al., 2019 for an elaboration on the process of gaining informed consent from persons with dementia

<sup>&</sup>lt;sup>6</sup> https://www.ueq-online.org/

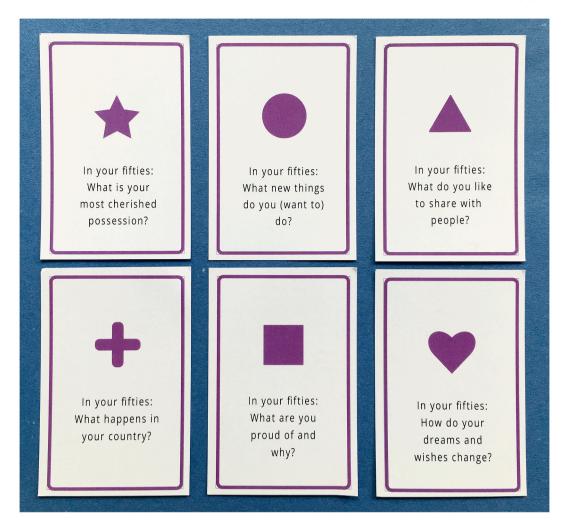


Fig. 3. The *This is Me* (prototpype) game cards (fifties), with an example of each of the six categories of questions in the order of: memories, activities, relationships, experiences, achievements, dreams (left to right, top to bottom).

sections B to D relating to usability and user experience of the game, and sections E to G to people's wellbeing experiences:

A) Personal feelings and details about where This is Me is being used.

The first section elicits personal demographic data and information about personal wellbeing and about prior experience with games.

#### B) Appreciating how This is Me looks and feels to touch and handle

This section is about aesthetic perception, like and dislike of the game's appearance and its feel.

#### C) Ease of use of This is Me

Here, practical information about playing the game is gathered, including ease of using it with regard to ergonomic aspects such as handling and cognition.

#### D) Enjoyment of using This is Me

This section captures personal feelings when playing the game, about any enjoyment and difficulties experienced.

#### E) Feelings experienced when using This is Me

Questions ask about feelings experienced through/during the act of storytelling, regarding self and the benefit, importance or difficulties of sharing personal experiences and emotions.

#### F) Impacts and Outcomes of Using This is Me

This section asks about how the game has helped or may help players with socializing and sharing experiences, mutual appreciation and talking about the future.

#### G) Future Use

This section askss about why, where and with whom people might play the game and whether they would recommend it to anybody.

Each section consisted of two to four main questions, augmented by supplementary questions which the interviewer/focus group lead could use if more detail or prompts were needed. The semi-structured interview questionnaire was developed to enable as much parity as possible across the four different countries and settings. In the delivery, it was effectively used as a conversation guide, to give the flexibility needed when working with people with dementia, and also taking account of the time frame(s) of the different settings. In addition to the questions, a five-point emoji scale, as described by Alismail and Zhang (2018), was included to ask participants to rate satisfaction of the main purpose of each section (e.g. level of enjoyment) and of the game overall. However, these scales proved too difficult and time consuming within the context

#### Table 1

Participants of the TIM evaluation study across the four countries.

UK	SPAIN	GERMANY	NETHERLANDS
7 people with	Group 1:	12 people with	4 people with mild
mild to	14 people with	mild to	dementia and 3 care
moderate	mild to moderate	moderate	partners were
dementia	dementia and 6	dementia	recruited, and 4 case
(4 male, 3	care partners (3	(6 male, 6	workers. 1
female) in 2	tables of 7	female) in 4	participant, their
groups of 4 and	participants)	groups of 3	care partner and
3 participants.	Group 2:	participants.	case worker
	14 people with		withdrew after the
Duration (all	mild cognitive	Duration (all	first visit, leaving 8
sessions):	impairment (3	sessions): 65	participants.
$2 \times 75 \text{ min}$	tables with 4 and 5	min.	People with
Introduction	participants)	Introduction:	dementia, their
(including	Group 3:	ca. 15 min.	respective care
consent): 75	8 formal carers	Gameplay: ca.	partners and case
min.	from Roma and	30 min.	workers met in the
(Lunch)	Gypsy	Feedback: ca.	participants' own
Gameplay:	communities	20 min.	homes (2) or
30-35 min.	(2 tables with 4		community centre
Feedback:	participants)		(1).
30–35 min.	Duration (all		
Debriefing: ca.	sessions): 90-120		Duration (all
10 min.	min		sessions):
	Introduction:		40-60 min.
	15–20 min.		Introduction: ca. 15
	Gameplay: 45–60		min.
	min.		Gameplay: ca. 30
	Coffee break (in		min.
	the middle of the		Feedback: ca. 15
	session): ca. 15		min.
	min.		
	Feedback: ca. 15		
	min.		

#### Table 2

Age distribution of participants of the TIM evaluation across the four countries.

UK	Spain	Germany	Netherlands
Persons with dementia Age 70's-90's <sup>a</sup> Mean 81 <sup>a</sup>	Group1: Persons with dementia Age 61–87 Mean 74 Informal Caregivers Age 64–77 Mean 72 Group 2: Persons with dementia Age 60–88 Mean 74 Group 3 Formal carers No age data collected.	Persons with dementia Age 70s–80s Mean 83	Persons with dementia Age 50's-80's Mean 71 Informal carers Age 48–51 Mean 49.5 Formal carers Age 38–41 Mean 39s

<sup>a</sup> For the UK group, age was collected from participants disclosing their age or by observation, hence the age range for the UK includes some estimates.

of the delivery and were therefore largely disregarded in favour of verbal feedback to the questions, contextualised by researchers' observations.

#### Thematic analysis: Coding and theme development

The analysis of the interview data had two purposes: to assess the performance of the game, and to determine its impact with regard to wellbeing, including immediate and potential longer-term impact as perceived by the players. The analysis thus had both a confirmatory and an exploratory purpose and used a combination of deductive and

inductive analysis that followed Guest, MacQueen, and Namey's (2012) applied approach to thematic analysis. Two principal a priori themes were used for the deductive analysis, which were 'design' and 'wellbeing'. Design had two sub-themes: design/prototype (broadly relating to section B and C) and game (broadly relating to section D). Wellbeing had three sub-themes (relating to sections E, F, G): emotional wellbeing, agency and social engagement. While there is a broad correlation between the sections of the questionnaire and the main themes, this correlation is by no means exclusive since discussions were fluid and could refer back to previous topics. For the exploratory analysis, the main themes were complemented by the additional themes of 'mindfulness' and 'reminiscence' to see whether use of the theoretical underpinnings of the game would be evident. Further themes that offered a more finegrained analysis were added inductively though the coding process as they emerged. They were suggested by the analysts and agreed upon through a process of discussion and consensus. Since not all participants may be familiar with concepts (themes) such as 'agency' or 'mindfulness,' researchers did not ask directly about them. Instead, researchers asked about participants' experiences and feelings of, or elicited through, playing the game. During the exploratory analysis, relevant themes were correlated with these as is evident through the code book (Table 2).

In preparation for the coding process, the data from the four countries were segmented and translated into English by the respective interviewers to ensure translation accuracy. Manual coding was used to enable focusing on the meaning and content of phrases rather than their literal wording. Segments followed individual's contributions, which were generally short (often single sentences) because of the conversational group context. Where longer contributions pertained to different concepts (themes), they were subdivided accordingly (if practical). Segments were then collated in a spreadsheet and organised in four columns by country, and within the columns according to the different sections of the questionnaire, separating affirmative comments, critical comments, and observations which implied no judgment.

In an iterative approach of familiarisation with the data, coding, and defining codes, a code book (Table 3) was created by the lead analyst who had been involved in the data collection in the UK and who was familiar with the aims, setting and data. The code book was then shared with two researchers not part of the *TIM* evaluation events for double coding to provide impartiality. In the process, the themes and subthemes were further defined and clarified until variance in coding of within 10% was achieved.

#### Findings/results

In the following, the findings are reported in relation to the confirmatory aim of the analysis. Then, the insights from the exploratory analysis offer more detail on the wellbeing experiences of participants and their motivations.

#### Confirmatory evaluation

For the confirmatory evaluation of the *TIM* game, the segments were single-coded with no overlap between different themes to provide a clear picture with regard to the appreciation of the game. Of a total of 183 comments (segments), 122 comments were positive and 57 comments were critical of the design, 3 comments were categorised as 'neutral' because they included non-judgmental observations of the design process, and 1 comment was excluded as not applicable because it related to stipulations for the use of the game which were not intended.

The positive comments related to the design of the game, gameplaying as well as to wellbeing, mindfulness and reminiscence, such as: "Good size, no need for any changes, [design is] nice, clear and easy [to understand]" (UK); "The game is entertaining, motivational and involved" (Spain); "A nice means of triggering memories and sharing

the game:

(M+)

Experience/Impact of

mindfulness values

In the present moment

(PM)

#### Table 3

Code book w

able 3 ode book with themes	& descriptions.	
Design of the game:	Design + (D+)	- positive comments/likes of
positives (D+)		the design/appearance of the
	$C_{nmo} + (C +)$	game as a physical entity
	Game + (G+)	<ul> <li>positive comments/likes of the nature and perceived</li> </ul>
		benefit of the game (play)
Design of the game:	Prototype - (P-)	- criticism of, or suggestions
criticisms/negatives		for quality/handling (board,
(D-)		size of counters)
		- criticism of, or suggestions
		for colours, e.g. difficulties
		distinguishing colours (e.g.
		white-yellow: 7) - criticism of, suggestions
		relating to reducing
		cognitive challenge in
		relating colours-symbols-
		organisation etc.
		- criticism of, or reporting or
		observing difficulty/
		challenge with (answering)
		questions
		<ul> <li>suggestions for change to game format</li> </ul>
	Game- (G-)	<ul> <li>dislike of the gameplay</li> </ul>
		design where this is related
		to the game per se and not to
		deficiencies of the prototype
Experience/Impact of	Emotional wellbeing	- Emotion words
the game: wellbeing	(EW)	- Expressions of moods or
(positive) (EW+)		feelings
		- Liking/attraction where
		related to the person's emotions
		- Not: judgments about the
		game if not related to
		emotions
	Agency (A)	- Expressions of optimism/
		confidence in looking into
		the future
		- Expressions of feelings of
		empowerment: feeling
		enabled, confident in doing
		things, incl. Cognition/ cognitive ability
		- Expressions about (the
		importance of) making
		decisions or (forward)
		planning
		- Expressions indicating
		agency/equality in relation
		to playing the game, e.g.
		socially active in the game in their own right
	Social engagement (SE)	their own right - Expressions (direct or
	Joenn engagement (JE)	indirect) that indicate
		interaction, e.g. the
		importance or enjoyment of
		interacting
		<ul> <li>Expressions that indicate the appreciation of sharing and</li> </ul>
		appreciation of sharing and of trust
		<ul> <li>Expressions that indicate</li> </ul>
		mutual consideration and
		respect
Experience/Impact of	Emotions- (E-)	- negative emotions: (no)
the game: wellbeing		motivation for playing
(negative) (EW-)	Agency- (A-)	- relating to lack of
		confidence, optimism, etc.
	Social Engagement-	- negative perceptions of
	(SE-)	social engagement through
Experience (Immed of	In the propert memory	the game
Experience/Impact of	In the present moment	<ul> <li>The person expresses</li> </ul>

		<ul> <li>The person expresses their enjoyment of the present moment implicitly through an exclamation</li> </ul>
	Acceptance/non- judgmental (AJ)	<ul> <li>The person expresses the acceptance of something, or g. something they have con to terms with</li> </ul>
	Paying attention on purpose/awareness/ new perspectives (AP)	<ul> <li>The person expresses an ad of paying attention, e.g. listening</li> <li>The person expresses an ad of (novel) awareness</li> <li>The person expresses (having gained) a new insight or view</li> </ul>
	Reflection (MR)	- The person expresses directly or exhibits indirect an act of reflection
Reminiscence (R)	Reminiscence (R+)	<ul> <li>Expressions of rememberin (facilitated through the game) perceived as positiv even if it included negative emotions</li> </ul>
	Reminiscence (R-)	<ul> <li>Expressions of rememberir (facilitated through the game) where this resulted negative feelings such as frustration</li> </ul>

#### hem" (Netherlands).

The critical comments fell into two categories: the majority (44) vere comments of a formative nature related to deficiencies in the prototype, rather than the gameplay, and offered suggestions for its mprovement, such as: "Don't use yellow + white" (UK) (some participants had difficulties with the lack of contrast); "Better quality of the naterials/more professional looking" (Spain); "Figures could be a bit bigger and heavier" (Germany). Such comments were explicitly invited by the research team to help with further improvement of the game owards its potential future production. They are therefore not counted as critical, because they offer remedial advice which were subsequently used to improve the design.

Actual criticisms of the game were few, comprising a total of 13 comments, 10 by people with dementia (UK: 2, Spain 5, Netherlands 2, Germany 1), 3 by carers (Spain: 1, Netherlands 2). They included intances of dislikes, e.g. due to a lack of motivation or a lack of confidence n playing the game, such as "[I was a] bit nervous at [the] start as [I] lidn't know exactly what to do – [I] needed to be told [I was] doing it ight" (UK); "It does not help me build my confidence and abilities" Spain); "It does not help me think about the life that lies ahead" (Spain).

Overall, the game received a very positive response, with 122 posiive comments opposed to 13 critical comments, indicating a 90% approval rate for this first evaluation.

#### Exploratory evaluation

The exploratory evaluation offers deeper insights into the percepions and experiences of participants during playing the game, especially egarding the different wellbeing aspects, but also regarding the theoetical underpinnings of the design. Participants' feedback is from the nterviewers' transcripts from each of the four sites. Comments someimes reflect the brevity of spoken language or their literal translation nto English, so in the interest of brevity and accuracy, unless indicated otherwise, comments were made by people with dementia.

#### Design

The analysis of the design of TIM was divided into the design (appearance, usability) of the physical entity (prototype) and the game

The person expresses

nov

explicitly the importance of

focusing on the here and

#### K. Niedderer et al.

design relating to the nature of the game and its playability and enjoyment (gameplay).

In terms of the prototype *design*, a significant number of comments related to its appreciation: its aesthetic (look and feel) and that it was clear and easy to use. Participants liked the cards and the shapes that were used on the dice to link the cards to a place on the board. Participants stated, for example, "Shapes on card and dice are good, innovation"; "Text big enough"; "Liked yellow – sunny"; "Good size, no need for any changes, [design is] nice, clear and easy [to understand]" (UK); "Looks inviting" (Netherlands); "The instructions are easy to understand"; "I like the most the questions" (Spain); "Easy to play"; "Questions cover a broad part of people's lives" (Germany).

While largely positive, participants also had criticisms of the design. Being a prototype, the individual parts of the game were not as refined as people are used to from publicly available commercial games, and this was reflected in some of the comments. Criticisms broadly fell into five categories:

- Quality and handling relating to the board, cards and size of counters: "Better quality of the materials/more professional looking"; "Board can be waterproof or easy to clean if it will be manipulated more frequently" (Spain); "Cards [should be] quite strong firm board" (UK); "Figures could be a bit bigger and heavier" (Germany).
- 2. Difficulties in distinguishing colours due to lack of colour contrast: "Colours 40 and 50 are difficult to hold apart" (Germany); "Don't use yellow + white", "wishy-washy" (UK).
- 3. Difficulties related to matching symbols and colours: "The symbols and the written words are confusing" (Spain).
- 4. Criticisms of, and suggestions relating to the questions: "Questions feel sometimes too private, too intimate..."; "Some questions are very basic or too vague. Some questions have a very wide notion, as beliefs or political values. [The] wider the concept is the more difficult to answer, even for a person with no memory problems..." (Spain); "Card 'secret dreams' [was difficult to answer], and about technology"; "One needs a really good memory to locate [events] in different decades. Maybe have more cards for the middle decades" (UK).
- 5. Suggestions for change to game format: "Game can be played just with cards and dice the board and counters make the task more complex for PwD" (Spain, carer).

Both positive and critical comments offered useful insights into how well the game prototype worked, and where perhaps improvements would be needed. Formative comments on the quality of the prototype were expected and were addressed during the professional production of the game, where a higher print and manufacturing quality can be achieved than in the prototype. Comments on colour contrasts were helpful: while participants overall liked the colour scheme and felt it was uplifting (e.g. yellow was perceived as "sunny"), others had problems with the lack of contrast between yellow and white ("wishy-washy"). These are indications for designers to increase colour differentiation and contrast and, in response, the colours were adjusted for the final design to provide better contrast. Surprisingly few people experienced or commented on difficulties relating the colours and symbols, whereas a number of comments related to the phrasing or use of the questions themselves. Some comments were contradictory, an issue encountered in the co-design session in 2018, which led to offering sufficiently generic questions to allow players to choose how to answer questions. The final evaluation appears to indicate that the mix of broadness and specificity of questions provides a suitable balance between remembering and locating specific events in one's life and questions being too broad and unanswerable, even though no design ever can satisfy every individual.

In terms of the *gameplay*, most participants felt positive about the gameplay, both in the present and in the future, especially in the UK and Spain: "The game is entertaining, motivational and involved"; "Curious

game, fun"; "I would play it again with friends"; "I love the game. If it were commercialised, I would buy it" (Spain); "Makes you want to use it"; "Play with Family, use it at centre/dementia café, activity group/at home" (UK); "A nice means of triggering memories and sharing them" (Netherlands).

Only a few participants felt that the game offered no motivation and that there were other games to play: "I can't see the goal of participating in it. I can't see in which ways can this game contribute to our lives, apart from the fact of knowing each other and our interest" (Spain). One of the participants noted that he wasn't very interested in having the kit at his home environment because there were other games to play (Netherlands).

Criticisms here principally related to the non-competitive nature of the game and to the observation that people already had games that they liked to play. These are two valid points, based on participants personal (dis)likes, but which were not shared by the majority of players who recognised and valued the open-ended and relational nature of the game.

#### Wellbeing

The main aim of designing the game was to support the wellbeing of people with dementia and to demonstrate that it is possible to design game(s) specifically for this purpose. Therefore, one important criterion for the evaluation were expressions of wellbeing relating to emotional wellbeing, social engagement and agency.

*Emotional wellbeing* included expressions of moods or feelings, often in the form of emotive words and expressions of liking and attraction related to the person's feelings rather than to a judgment about the game. Participants expressed that they felt comfortable with the game and appreciated the memories and reflection it enabled. Expressions of emotional wellbeing included: "I've felt very comfortable"; "Help[s] to create a trusting atmosphere" (Spain); "A nice means of triggering memories and sharing them" (Netherlands); "It is fun to listen what the others have to say"; "It makes you look back in a very encouraging way" (Germany); "Provoked good memories. Push bad memories to [the] side"; "Gets memories going – everybody gets laughing, which is a good thing" (UK).

Overall, expressions of emotional wellbeing could be seen to relate either to social inclusion and connectedness, such as trust, sharing and laughing together, or aspects of agency, such as feeling encouragement and achievement relating to reminiscence. Instances of negative emotions were rare, but when they did occur, they appear to be based on a perceived lack of agency relating to their condition or unhappy memories: "It confronted [the] participant with her (mild) dementia, which she experienced as frustrating"; "A wide range of memories surfaced, including lighthearted and humorous ones, but also more serious ones (e.g. from war period during which participant and spouse were children). The latter type induced mixed emotions and contributed to the fatigue experienced by the couple as time went by" (Netherlands, both formal carers).

Nevertheless, bringing up negative memories can also lead to processing them and getting over them, as discussed below in relation to agency and mindfulness.

Agency – The notion of agency encompassed both the participants' feelings of enablement and parity within the game, supporting confidence-building, social engagement and thinking about the future. The game was seen to support a sense of being cognitively and socially enabled: "Helping to begin and support dialogue"; "Egalitarian" (Spain); "Smooth, intuitive gameplay with no need for the researcher to help out or to provide additional instructions" (Netherlands).

Being supported and able to do things on their own, so that they felt equal to people not having to contend with the deficits of dementia, helped people with dementia to gain the confidence to interact more freely and to look forward to the future: "Gameplay allows for an informal, non-threatening way of communication and memory sharing" (Netherlands); "Gives people the chance to talk about their experience – they can be reluctant otherwise and withdraw. Helps to get out of isolation"; [All agree that it is important to] "Involve other people in looking to the future" (UK).

While most readily engaged, not all participants felt fully confident. Some felt that they needed support to get started or to keep going: "Bit nervous at start as didn't know exactly what to do – needed to be told doing it right" (UK); "Need somebody to get us started and look after us or stay with us, not all alone" (Germany).

Others felt that it did not help them build either a sense of confidence or future: "It does not help me build my confidence and abilities"; "It does not help me think about the life that lies ahead" (Spain).

There can be a number of reasons the game did not work for some people, including personal preferences (some people do not like playing games, or only like competitive games) or how people felt on the day. No design will work for everyone. The responses highlight the complexities of designing for people in general, and the particular need to include people with dementia in the design process to make the best possible decisions when developing a design.

*Social engagement* was perceived as positive by all involved. Particularly important to participants was the fact that the game enabled social interaction, which they enjoyed, appreciating sharing and trust as well as mutual consideration and respect: "Enjoyed the company who played. Playing it!" (UK); "Meet & learn from the others"; "Helps to create a trusting atmosphere" (Spain); "You talk and listen and people respect that the others don't have to wait too long for their turn" (Germany); "Effortless interaction between family members" (Netherlands, formal carer).

The game helped to establish trust and respect so that people felt able to open up. This was particularly interesting for people who had known each other for some time, and who felt they got to know each other better through the game: "Gets us closer, I didn't know that about you although we have spent 14 days together here" (Germany).

#### Life-storytelling, reminiscence & mindfulness

Essentially, all stories told during the game were related to and part of life-storytelling. When analysing them, it became apparent that a number of these comments related to reminiscence and mindfulness. Mention of these categories emerged as noteworthy instances of the effectiveness of the conceptual underpinning of the game. References to *reminiscence* included: "Trigger[ing] social engagement, memory sharing and storytelling" (Netherlands); "You want to share your memories" (Germany).

Participants further recognised that it was "important to [get to] know others' experiences and memories" (UK).

This reminiscing did not remain fixed in the past and, through the game, reflections on the present and future were also voiced: [All agree that it is important to] "Involve other people in looking to the future" (UK).

While reminiscence was mostly perceived as positive, even where negative memories surfaced, at times "...mixed emotions ... contributed to the fatigue experienced by the couple as time went by" (Netherlands, researcher observation) and it was acknowledged that "...this could hint at the suitability of this game in a care setting in particular where the game could be integrated in social activities supervised by a (formal) caretaker, who can also provide (emotional) support when recalling episodes which might elicit painful memories or feelings" (Netherlands, formal carer).

With regard to *mindfulness*, there were some significant instances of in-the-present-moment experiences, (self-) awareness, acceptance and reflection, and where wellbeing clearly relates to these instances of mindfulness. For example, participants observed that "I like the most, the fact we are playing" (Spain); "[I] enjoyed the company who played. Playing it!" (UK), demonstrating that they were aware of savouring the in-the-moment experience of the game and its social context. Furthermore, they recognised the importance of the moment in relation to their life. For example, one person stated, "[You] forget about bad things.

Trying to live in the now. What to do now" (UK).

This aspect of living in the here and now also helped some participants to recognise the need for acceptance, and generated a sense of positivity for themselves: "[You] learn a lot through life. [I] have had problems [and] got over them..."; "[You] need to accept good and bad" (UK); "It makes you look back in a very encouraging way" (Germany).

Mindful self-awareness was further articulated by one carer, who stated that the "Game makes them aware (mindful) of the different feelings and emotions the game triggered" (Netherlands, care partner).

Besides reflection on one's own emotions, participants also became aware of others, and the importance of listening to them and their differing experiences, but also the benefit of doing so for themselves. The reflexivity also conveyed mutual respect, kindness and demonstrated a growing sense of connection: "While speaking ourself and listening to the other, it kind of gives an order to it again"; "Gets us closer, I didn't know that about you although we have spent 14 days together here" (Germany); "Different people have different opinions and particular opinions – it's important to listen – each individual is individual..."; "Important to [get to] know others' experiences and memories" (UK).

These observations by participants indicated keen awareness and reflexivity in relation to playing the game, associated storytelling and the people they were playing. Their observations in turn conveyed a sense of wellbeing through social connectedness (e.g. knowing more about and appreciating others) and empowerment (e.g. through increased order, feeling encouraged).

#### Discussion

This section reflects on the findings from the evaluation of the *TIM* game. The findings demonstrate a 90% positive response of participants to the *TIM* game and that participants experienced a range of wellbeing benefits playing the game. Participants largely expressed their appreciation of the game and enjoyment of the social interactions as well as a sense of agency. Instances or expressions of reminiscence and mindfulness could also be observed. Positive comments totaled 122, whereas 13 comments conveyed negative experiences or reservations regarding the game including a lack of motivation or confidence in playing the game as well as two instances of negative emotions (frustration, tiredness). A range of formative comments (44) related to the prototype and included aspects of quality of materials (board, cards), size of counters, colour contrast, and some comments regarding the game's improvement to be addressed by the designers before going to production.

With regard to the wellbeing benefits of the game, the exploratory evaluation demonstrated rich findings relating to the three areas of emotional wellbeing, social engagement and agency as set out in the beginning of this paper based on Kaufmann and Engel (2016), Power (2016) and Strohmaier and Camic (2017). Concerning *emotional wellbeing*, participants mentioned feeling comfortable and joyous, in an atmosphere that was non-threatening and allowed opening up for everyone, even those otherwise quiet, to get to know others better. This was observed by both people with dementia and carers. The game thus offered a successful conversation starter (Ludden et al., 2019) as well as a way for connecting with other people through shared storytelling (Fels & Astell, 2011).

With regard to a *sense of agency*, participants enjoyed the intellectual and cognitive stimulation of trying to remember things, telling about them and listening to others telling their stories. Respondents felt that they could learn something through the game, instilling an element of growth (Power, 2016). Participants also felt that it was inviting and inclusive due to the flexibility in the gameplay and the equality between players it engendered. *TIM's* open-ended, flexible rules made it easy to join, without having to observe strict rules that often characterise other popular family games. For instance, they choose whether everyone answered the same question each time and each participant rolled the dice for him/herself. This element of choice and flexibility makes the

#### K. Niedderer et al.

game intuitive and non-demanding in terms of cognitive effort, but also gives the players agency being able to decide what to do, which is important for people with dementia as commented on by participants. This democratising aspect of the game was most important to participants and seemed to work well. Nevertheless, it could potentially lead to peer pressure to speak when perhaps a person might not wish to share, such as where negative memories or connotations surface. While these can be cathartic, participants suggested that it may be useful to have support available through (professional) carers for such a case.

With regard to social interaction, participants engaged in animated and convivial exchanges with effortless interactions between people with dementia as well as in/formal carers and researchers. While this is a general benefit of board games and has been exploited in health and educational contexts (e.g. Chen & Janicki, 2020; Lamey & Bristow, 2015; Olykaynen, 2016), previous research into using board games to support people with dementia has predominantly focused on cognition (Lowrani et al., 2020). Our research has focused on the many differentiated aspects of social interaction and the self-reflective (mindful) awareness of these on the part of the participants. These included: players feeling that the game provided a safe ("non-threatening") atmosphere that allowed them to speak freely; consciously and respectfully listening to others; trusting others to respect them and their experiences; and the joy of sharing experiences and getting to know each other (better), supporting a sense of inclusion, connectedness and attachment (Fernández-Mayoralas et al., 2015).

Storytelling, mindfulness and emotional wellbeing: Playing TIM, there was generally a convivial atmosphere with lots of positive engagement, appreciation, amusement and laughter. TIM turned out to be a successful conversation starter not only because it prompts memory sharing on the part of the person with dementia, but also because it allows others to contribute to the sharing of life events. This sets the stage for a social context in which people empathise with each other and feel free to experience and share emotions ranging from joy and amusement to melancholy and sadness. This richness of (mixed) emotions experienced in a safe, positive context, can be important for coming to terms with the diagnosis of dementia and for mindful reflection on the present (Rodríguez Vega et al., 2014). For instance, during gameplay, sharing life events from days gone by invariably also gave rise to questions such as 'How is this different now?', 'What has changed?', and 'What remains the same'? It is in this sense that TIM enabled the person with dementia and their carers to be (more) mindful of themselves as well as of the issues they face and to reflect on how to confront and shape the things to come. That is, by targeting all periods in life (past, present, and future), TIM invites people with dementia to step up and (in addition to thinking and talking about the past) take an active role in planning, thinking ahead, and (re)considering life goals. The game allowed participants, for example, to reflect on their experiences - both good and bad - and to accept them as they are and to move on. In this regard, a number of participants felt that discussing their future with other people was important, which accords with the acknowledged benefits of lifestorytelling (Fels & Astell, 2011; Johnston & Narayanasamy, 2016).

However, in a small number of cases, thinking about the past was experienced as frustrating when it emphasised things lost and strong emotions could lead to fatigue. In spite of the largely positive impact, reminiscence also bears some risk of negative outcomes since recollections of the past can lead, for example, to experiences of loss (Ferring & Tournier, 2017). In response, some participants suggested that the game could be integrated in other social activities where emotional support from a care professional would be available. While participants in general were very positive about *TIM*, precisely because it triggers a wide spectrum of emotions in a safe setting, these latter findings suggest that depending on who is playing (i.e. the extent to which the person with dementia has come to terms with the diagnosis, types of memories that may be evoked), context of gameplay (e.g. at home or at a care center) and duration are important and should be considered. difference between participants of different countries in the reaction to playing the game. Participants indicated that they could see themselves playing TIM again in various settings, including family, friends, Alzheimer cafes and day groups. Participants aptly observed that it would not be suitable for advanced dementia and that the availability of in/ formal carers might be beneficial to provide (emotional) support if required. Finally, in the Netherlands, where the *TIM* was played at home and the game staved with the three participants for two weeks, the evaluation showed that they had not played it again. While this is a very small sample, this could indicate that the game is best suited for group settings where the game can be integrated into social activities or new "players" may join each time. Another reason for integrating TIM into other social activities related to a (perceived) lack of incentives for playing by a small number of people. Arguably, integrating TIM in a more formal (therapeutic) program, as happened in Germany, could enhance perceived meaningfulness and engagement in playing TIM.

#### Strengths and limitations

This study is the first to evaluate the impact of a board game codesigned with and for people with dementia with regard to their wellbeing based on concepts of life-storytelling, reminiscence and mindfulness. With regard to its implementation, the evaluation was conducted in four Western European countries to enable a larger and more heterogeneous sample of participants than a single-centre study would generally offer. The study included 50 participants with mild dementia or MCI and 17 carers. Settings in the UK, Spain and Germany were similar in that the game was presented in a group setting, including day groups (UK), memory clinic groups (Spain) and therapy groups (Germany) and comments were similar across the three study settings. By contrast, the setting in the Netherlands differed in that the game was played in a home setting where the person with dementia was on their own with the care partner, case worker and researcher(s). While playing the game also elicited positive responses, people did not feel compelled to play it without the researchers' presence, suggesting a longitudinal study would be useful into the suitability of different settings, the longer-term motivation for, and benefits of playing the game.

In terms of the thematic analysis, a codebook and 3 coders were used to ensure impartiality in the analysis. In addition, the use of wellbeing scales (e.g. WEMWBS<sup>7</sup>) was considered, but then abandoned due to complexity and limited time for delivery and in favour of being able to work with a larger sample size. A simplified set of scales was included, using emojis, relating to each of the main questions, but this was also disregarded in the end due to time limits and participant difficulties translating impressions into 'emoji scores'. Follow-up studies could consider including the use of wellbeing scales to allow for more definitive conclusions on the effects of TIM on wellbeing. A comparison with ordinary board or card games could also be useful to determine whether any differences can be observed with regard to the effectiveness of the underpinning concepts (life-storytelling, reminiscence, mindfulness). Also, more detailed and controlled observations could include codingscheme based observations of eye contact, turn-taking (in storytelling), and physical contact as an indicator of social engagement and richness of interaction. For instance, observational techniques such as the Quality of Interactions Scale (QUIS, Dean, Proudfoot, & Lindesay, 1993) and Dementia Care Mapping (Kitwood & Bredin, 1992) could be considered to observe the quality and quantity of social interactions.

These limitations notwithstanding, we feel confident that *TIM* succeeded in enhancing social engagement, agency and emotional wellbeing through life-storytelling, reminiscence and mindful reflection. The study would benefit, however, from follow-up evaluations to provide further insights in contextual and person-related factors shedding light on how to ensure prolonged use by people with dementia and determine

In terms of the setting for playing the game, overall, there was little

<sup>&</sup>lt;sup>7</sup> https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/

its longer-term impact on their wellbeing.

#### Conclusion

This study has demonstrated the successful use of the *TIM* board game, specifically co-designed for engaging people with mild to moderate dementia in meaningful activities of life-storytelling, reminiscence and mindful reflection to enhance their wellbeing, and to take the players beyond a form of reminiscence, which is focused solely on the past, to promote reflection on the present and future. References to storytelling, reminiscence and mindfulness in our findings have demonstrated that the conceptual underpinning of the game was important for the players' wellbeing experience.

While board games have been considered for use with people with dementia before, this has typically been with regard to cognition or other clinical outcomes, and there has been no detailed qualitative study evaluating their role in promoting wellbeing and social engagement. In addition, this study has drawn on concepts from positive psychology for the targeted, theory-based design of *TIM* to demonstrate the usefulness of board game design and extend evidence-based design of games for wider application in a health and wellbeing context.

Finally, further evaluation, both comparative and longitudinal, with the published version of the game would be useful. The game is launched January Januar 2022 under the name *All about Us*<sup>TM</sup>. Its further evaluation would help to determine in more detail the benefits of the positive psychology approach in (board) games, and their potential longitudinal effects not merely on cognition, but also on wellbeing and engagement for people living with mild to moderate dementia.

#### **Ethics** approvals

Ethics approval for the study was obtained by each of the partners in line with national and European regulations and requirements:

UK: University of Wolverhampton and Manchester Metropolitan University ethics boards, ethics reference no. 2018/19:18 (UW) and Ethos 5521 (MMU);

Germany: Krankenshaus Hedwigshöhe ethics reference no. Eth-30/ 16;

The Netherlands: University of Twente, ethics reference no. BFD-BMS/2016-JR.

Spain: INTRAS: Reference letter 26/01/2016.

#### **Funding source**

The 'MinD - Designing for People with Dementia' project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Marie Skłodowska-Curie grant agreement No 691001. This document reflects only the author's view and the Research Executive Agency is not responsible for any use that may be made of the information it contains. The funding body had no

Appendix A. Questionnaire instrument for TIM evaluation

influence on study design; data collection and analysis, writing the article and in the decision to submit the article for publication.

#### Contributors

Kristina Niedderer was the project lead, participated in the design and co-design activities for *This is Me*, led the evaluation in the UK, led the data analysis and drafted the article.

Vjera Holthoff-Detto led the co-design activities and evaluation of *This is Me* in Germany, and contributed to the article (methods).

Thomas van Rompay, Armagan Karahanoglu, Geke Ludden participated in the design and co-design activities for *This is Me*, led the evaluation in the Netherlands, and contributed to the article (concept, methods).

Rosa Almeida, Raquel Losada Durán and Yolanda Bueno Aguado led the co-design activities and evaluation of *This is Me* in Spain, and contributed to the data analysis and the article (methods).

Michael P. Craven and Julie Gosling participated in the co-design activities and contributed to constructing the evaluation protocol.

Jennifer N.W. Lim contributed to construct the evaluation protocol, participated in the co-design activities and the evaluation in the UK, and contributed to the article (methods).

Tina Smith participated in the co-design activities and the evaluation in the UK, and contributed to the article (discussion).

Dew Harrison participated in the design development and contributed to the article.

Laura Orton and Isabelle Tournier contributed to the data analysis and to the article (discussion of results).

#### **Declaration of Competing Interest**

Following completion of the MinD project, the *This is Me* game is published under the name *All about Us*<sup>TM</sup> by Relish, who specialise in products for people with dementia. The MinD project partners will receive a license fee once the game becomes commercially available.

#### Acknowledgements

This article has been developed as part of the MinD project. We wish to thank all project researchers, research participants, external partners, and expert participants involved in the research and design development process for their time and contribution in making it happen. We especially thank: the European Working Group of People with Dementia (EWGPWD), the Group of Experts by Experience at INTRAS, Valladolid, Spain, the Public and Patient Involvement group in Nottingham, and participants recruited through the Alzheimer's Society Research Partnership Scheme, UK, Alexianer St Hedwig Kliniken, Berlin, and Zorggroep Sint Marten, Denekamp.

Further project information: www.designingfordementia.eu

# **THIS IS ME** how well does it work?



A.1. Personal feelings and details about where THIS IS ME is being used

Personal feelings help understand the context. You need only share what you feel comfortable with.

1. Date:	P1-1	P1-2	P1-3	P1-4
2. Time:				
3. Place:				
4. Where and with whom THIS IS ME is being evaluated				
5. Age (observed):				
6. Gender (observed):				
7. Ethnicity (observed):				
8. Common language				
My language of choice:				
9. Self-reported information about problems with memory and/or other mental abilities e.g.	P1-1			1
my diagnosis how my condition impacts on my daily living	P1-2			
how my condition affects my ability to look back on life or forward to the future	P1-3			
	P1-4			
10. Experience of using games, Apps and other technologies: do you play any games?	P1-1			
Examples: I enjoy playing solitaire on my tablet I enjoy board games and cross words	P1-2			
I am not interested in these games. I like games but I find them difficult	P1-3			
	P1-4			

#### A.2. Appreciating how THIS IS ME looks and feels to touch and handle

<ul> <li>1.Likes <sup>(c)</sup></li> <li>Say in your own words <ul> <li>What you like about the materials used (texture / shape / colours)</li> <li>What aspects of the appearance, touch or ease to handle do you like the</li> </ul> </li> </ul>	P1-1 P1-2
most?	P1-3 P1-4
2. Dislikes ☺ Say in your own words - is there anything about the	P1-1
<ul><li>appearance, touch or ease of handling that you do not like?</li><li>is there anything about the appearance, touch or ease of handling</li></ul>	P1-2
that you find difficult?	P1-3
	P1-4
3. Some suggestions for improvement	P1-1
	P1-2
	P1-3
	P1-4
4. Rate your satisfaction with the look, fee	and ease to handle of the game
	gane
awful not too good good	very good

A.3. Ease of Use of THIS IS ME

<ul> <li>1. Usability</li> <li>Say in your own words how easy you have found this game</li> <li>To set up?</li> <li>To use?</li> <li>To put away again?</li> </ul>	P1-1 P1-2 P1-3 P1-4
<ul> <li>2. Clarity of instructions provided: Did you know what to do?</li> <li>Say in your own words how clear the instructions are: <ul> <li>Clear &amp; easy to follow</li> <li>Need support to understand?</li> <li>Simple enough to remember during the game?</li> <li>Helpful if you get lost in the game?</li> </ul> </li> </ul>	P1-1 P1-2 P1-3 P1-4
<ul> <li>3. Playing The Game</li> <li>Say in your own words, how easy it is to play the game:</li> <li>Are the board, counters, cards and dice simple to use?</li> <li>How easy is it to follow the different colours and symbols?</li> </ul>	P1-1 P1-2 P1-3 P1-4
4. Some suggestions for improvement Prompts page 6	P1-1 P1-2 P1-3 P1-4
5. Rate your satisfaction of the look and awful not too good go	

NOTE: Record degree of assistance participants need to play the game or use it independently.

<ol> <li>Enjoyment of playing <sup>(c)</sup> Thinking about the past, present, future, exploring personal thoughts and feelings, say in your own words:</li> <li>What do you enjoy most about playing the game?</li> <li>What you will tell other people you enjoy about it?</li> </ol>	P1-1 P1-2 P1-3 P1-4
2. Not enjoying ☺ Thinking about the past, present, future, exploring personal thoughts and	P1-1
<ul> <li>feelings, say in your own words:</li> <li>If there is anything you do not like or have found difficult?</li> </ul>	P1-2
<ul> <li>What you will tell other people you didn't enjoy about it?</li> </ul>	P1-3
	P1-4
3. Some suggestions for improvement	P1-1
	P1-2
	P1-3
	P1-4
Prompts page 7	
4. Rate your satisfaction with the enjoym	ent of the game
awful not too good good	very good

NOTE: Record reactions while playing game - laughing, impatient, unsure, taking the opportunity for interaction.

<ol> <li>Getting in touch with emotions         <ol> <li>your own words, describe your             feelings when talking about your life:                 <ul> <li>How does it feel to think about yourself</li></ul></li></ol></li></ol>	P1-1 P1-2 P1-3 P1-4
2. Finding it difficult to talk about feelings In your own words, try to explain what is difficult about sharing feelings, if anything?	P1-1 P1-2
<ul> <li>Seems intrusive or over personal?</li> <li>Hard to describe what the feeling is?</li> <li>Rather not think about it?</li> </ul>	P1-3
<b>3. Social aspect</b> Say in your own words how this game could support thinking about your past	P1-1
<ul><li>and future life</li><li>How important is it to share the game with someone?</li></ul>	P1-2
<ul><li>Does it help you identify &amp; share your feelings?</li><li>Connect you to people who listen?</li></ul>	P1-3
	P1-4
4. Some suggestions for improvement	P1-1
(e.g. regarding the questions, time for playing, other)	P1-2

NOTE: People may require support to think backwards or forwards about whole life experiences. NOTE: Struggle and loss are part of life and people may wish to give voice to them.

NOTE: Support for working with distress is found in the relevant ethics guidance document.

### A.6. Impacts and Outcomes of Using THIS IS ME

			P1-3		
			P1-4		
5. Rate yo	our satisfaction with	how the gam	e helps you conne	ct with and understa	and feelings
$\overline{}$		$\overline{}$	$\overline{\mathbf{c}}$	$\bigcirc$	
awful	not too good	good	very good	brilliant	

## F. Impacts and Outcomes of Using THIS IS ME

1. Impacts and Outcomes In your own words say if you think that this	P1-1
<ul><li>game has potential to help</li><li>You talk to and share with other people</li><li>Others appreciate you as a 'whole person'</li></ul>	P1-2
<ul> <li>Others appreciate the life you have lived</li> <li>You appreciate and focus on the lives of others</li> <li>Involve other people in looking to the future</li> <li>you and others make plans to socialise</li> </ul>	P1-3
	P1-4
2. Suggestions for improvement	P1-1
	P1-2
	P1-3
	P1-4
4. Rate the potential impact and life outcomes fro	m engaging with the game
awful not too good good ve	ery good brilliant

#### A.7. Future Use

1. Would you choose to play THIS IS ME again? Why? Where? With Whom?	P1-1 P1-2
	P1-3
	P1-4
	-
2. Would you recommend THIS IS ME to another person? Who? Where? Why?	P1-1
	P1-2
	P1-3
	P1-4

#### A.8. OVERALL SATISFACTION WITH THE GAME



#### References

- Alismail, S., & Zhang, H. (2018). The use of Emoji in electronic user experience questionnaire: An exploratory case study. In Proceedings of the 51st Hawaii International Conference on System Sciences, Kristiansand (pp. 3366–3375). https:// doi.org/10.24251/HICSS.2018.427
- Alzheimer Europe. (2019). Dementia in Europe yearbook 2019. Alzheimer Europe. https ://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks (Accessed on 2 November).
- Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health*, *11*(3), 281–290. https://doi.org/10.1080/ 13607860600963695
- Baldwin, C. (2008). Narrative(,) citizenship and dementia: The personal and the political. *Journal of Aging Studies*, 22(3), 222–228. https://doi.org/10.1016/j. jaging.2007.04.002
- Bekker, M. H. J., & Van Assen, M. A. L. M. (2006). A short form of the autonomy scale: Properties of the autonomy-connectedness scale. *Journal of Personality Assessment, 86* (1), 51–60. https://doi.org/10.1207/s15327752jpa8601\_07 s
- Cadamuro, A., & Visch, V. (2013). 'What remains?': A persuasive story telling game. In B. Schouten, S. Fedtke, T. Bekker, M. Schijven, & A. Gekker (Eds.), *Games for health* (pp. 153–160). Wiesbaden, DE: Springer Vieweg. https://doi.org/10.1007/978-3-658-02897-8\_11.

- Campo, M., & Chaudhury, H. (2012). Informal social interaction among residents with dementia in special care units: Exploring the role of the physical and social environments. *Dementia*, 11(3), 401–423. https://doi.org/10.1177/ 1471301211421189
- Chen, Y., & Janicki, S. (2020). A cognitive-based board game with augmented reality for older adults: Development and usability study. JMIR Serious Games, 8(4), e22007. https://doi.org/10.2196/22007
- Chung, K. C., Song, J. W., & WRIST study group. (2010). A guide on organizing a multicenter clinical trial: The WRIST study group. *Plastic and Reconstructive Surgery*, 126(2), 515–523. https://doi.org/10.1097/PRS.0b013e3181df64fa
- Dartigues, J. F., Foubert-Samier, A., Le Goff, M., et al. (2013). Playing board games, cognitive decline and dementia: A French population-based cohort study. *BMJ Open*, 3, Article e002998. https://doi.org/10.1136/bmjopen-2013-002998
- Davis, F. D. (1993). User acceptance of information technology: System characteristics, user perceptions and behavioral impacts. *International Journal of Man-Machine Studies*, 38(3), 475–487. https://doi.org/10.1006/imms.1993.1022
- De Vugt, M., & Dröes, R.-M. (2017). Social health in dementia. Towards a positive dementia discourse. Milton Park, Oxfordshire: Taylor & Francis.
- Dean, R., Proudfoot, R., & Lindesay, J. (1993). The quality of interactions schedule (QUIS): Development, reliability and use in the evaluation of two domus units. *International Journal of Geriatric Psychiatry*, 8(10), 819–826. https://doi.org/ 10.1002/gps.930081004
- Dening, T., Gosling, J., Craven, M., & Niedderer, K. (2020). Guidelines for designing with and for people with dementia, MinD. https://designingfordementia.eu/wp-content/up loads/2020/02/Design-Guidelines-v3.pdf.

Dupuis, S. L., Kontos, P., Mitchell, G., Jonas-Simpson, C., & Gray, J. (2016). Re-claiming citizenship through the arts. *Dementia*, 15(3), 358–380. https://doi.org/10.1177/ 1471301216637206

- Fels, D. I., & Astell, A. J. (2011). Storytelling as a model of conversation for people with dementia and caregivers. *American Journal of Alzheimer's Disease & Other Dementias*, 26(7), 535–541. https://doi.org/10.1177/1533317511429324
- Fernández-Mayoralas, G., Rojo-Pérez, F., Martínez-Martín, P., Prieto-Flores, M.-E., Rodríguez-Blázquez, C., Martín-García, S., ... Forjaz, M.-J. (2015). Active ageing and quality of life: Factors associated with participation in leisure activities among institutionalized older adults, with and without dementia. Aging & Mental Health, 19 (11), 1031–1041. https://doi.org/10.1080/13607863.2014.996734
- Ferring, D., & Tournier, I. (2017). Autobiographical memory, self-regulation, and wellbeing. In M. D. Robinson, & M. Eid (Eds.), *The happy mind: Cognitive contributions to well-being* (pp. 275–289). Springer International Publishing AG. https://doi.org/ 10.1007/978-3-319-58763-9 15.

Gjernes, T., & Måseide, P. (2015). Dementia, distributed interactional competence and social membership. *Journal of Aging Studies*, 35, 104–110. https://doi.org/10.1016/j. jaging.2015.08.002

Gosling, J., Craven, M. P., Dening, T., et al. (2019). The AIR model (Activities, Internal world, Relationships): A pragmatic framework for evaluating co-design. In K. Niedderer, G. D. S. Ludden, R. Cain, & C. Woelfel (Eds.), Designing with and for People with Dementia: Wellbeing, Empowerment and Happiness. Proceedings of the International MinD Conference 2019. Dresden: MinD & TUD press. ISBN 978-3-95908-183-2. URL: https://tud.qucosa.de/landing-page/?tx\_dlf[id]=https%3A%2P%2Fud. qucosa.de%2Fapi%2Fqucosa%253A36599%2Fmets (accessed 7 April 2021).

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R., ... The European Working Group of People with Dementia. (2018). Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). Aging & Mental Health, 22(6), 723–729. https://doi.org/ 10.1080/13607863.2017.1317334

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). Introduction to applied thematic analysis. In G. Guest, K. M. MacQueen, & E. E. Namey (Eds.), *Applied thematic analysis* (pp. 3–20). London, UK: Sage. https://doi.org/10.4135/9781483384436.n1.

Hmel, B. A., & Pincus, A. L. (2002). The meaning of autonomy: On and beyond the interpersonal circumplex. *Journal of Personality*, 70(3), 277–310. https://doi.org/ 10.1111/1467-6494.05006

Hromek, R., & Roffey, S. (2009). Promoting social and emotional learning with games: "It's fun and we learn things". *Simulation & Gaming*, 40(5), 626–644. https://doi. org/10.1177/1046878109333793

Hydén, L.-C. (2011). Narrative collaboration and scaffolding in dementia. Journal of Aging Studies, 25(4), 339–347.

- Hydén, L.-C. (2013). Storytelling in dementia: Embodiment as a resource. Dementia, 12 (3), 359–367. https://doi.org/10.1177/1471301213476290
- Johnson, J. K., Barach, P., Vernooij-Dassen, M., et al. (2012). Conducting a multicentre and multinational qualitative study on patient transitions. *BMJ Quality & Safety, 21*, i22–i28. https://doi.org/10.1136/bmjqs-2012-001197

Johnston, B., & Narayanasamy, M. (2016). Exploring psychosocial interventions for people with dementia that enhance personhood and relate to legacy-an integrative review. BMC Geriatrics, 16, 77. https://doi.org/10.1186/s12877-016-0250-1

Kabat-Zinn, J. (2003a). Mindfulness-based stress reduction (MBSR). Constructivism in the Human Sciences, 8(2), 73–83.

Kabat-Zinn, J. (2003b). Mindfulness-based interventions in context: Past, present, and future. Clinical Psychology: Science and Practice, 10(2), 144–156. https://doi.org/ 10.1093/clipsy.bpg016

Kaufmann, E. G., & Engel, S. A. (2016). Dementia and well-being: A conceptual framework based on tom Kitwood's model of needs. *Dementia*, 15(4), 774–788. https://doi.org/10.1177/1471301214539690

- Kerr, D., Deane, F. P., & Crowe, T. P. (2019). Narrative identity reconstruction as adaptive growth during mental health recovery: A narrative coaching Boardgame approach. *Frontiers in Psychology*, *10*, 994. https://doi.org/10.3389/ fpsyc.2019.00994
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. Ageing & Society, 12(3), 269–287. https://doi.org/10.1017/ s0144686x0000502x
- Kleiderman, E., Boily, A., Hasilo, C., & Knoppers, B. M. (2018). Overcoming barriers to facilitate the regulation of multi-Centre regenerative medicine clinical trials. *Stem Cell Research & Therapy*, 9(1), 307. https://doi.org/10.1186/s13287-018-1055-2

Kontos, P., Miller, K.-L., & Kontos, A. P. (2017). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. Sociology of Health & Illness, 39(2), 182–198. https://doi.org/10.1111/1467-9566.12453

Kontos, P. C. (2003). 'The painterly hand': Embodied consciousness and Alzheimer's disease. Journal of Aging Studies, 17, 151–170.

Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease: Rethinking personcentred care. Dementia., 4(4), 553–570.

Lamey, B., & Bristow, C. (2015). The game as a talking tool: Using a board game for creative consultation, engagement and inclusion. In G. Brewer, & R. Hogarth (Eds.), *Creative Education, Teaching and Learning.* London: Palgrave Macmillan. https://doi. org/10.1057/9781137402141\_23.

Langer, E. J. (1989). Mindfulness. Wokingham, UK: Addison-Wesley.

Langer, E. J. (2010). Counterclockwise: A proven way to think yourself younger and healthier. London, UK: Hodder & Stoughton.

Lee, K. H., Boltz, M., Lee, H., & Algase, D. L. (2017). Does social interaction matter psychological well-being in persons with dementia? *American Journal of Alzheimer's Disease & Other Dementias*, 32(4), 207–212. https://doi.org/10.1177/ 1533317517704301

- Lim, J. N. W., Almeida, R., Holthoff-Detto, V., Ludden, G. D. S., Smith, T., Niedderer, K., & the MinD Consortium. (2019). What is Needed to Obtain Informed Consent and Monitor Capacity for a Successful Study involving People with Mild Dementia? Our experience in a multi-centre study. In K. Niedderer, G. D. S. Ludden, R. Cain, & C. Woelfel (Eds.), Designing with and for People with Dementia: Wellbeing, Empowerment and Happiness. Proceedings of the International MinD Conference 2019. Dresden: MinD & TUD press. URL: https://tud.qucosa.de/landing-page?tx\_dlf[id]=https%3A%2F% 2Ftud.qucosa.de%2Fapi%2Fqucosa%253A36687%2Fmets (Accessed 21 March 2021).
- Low, L.-F., Swaffer, K., McGrath, M., & Brodaty, H. (2018). Do people with early-stage dementia experience prescribed disengagement®? A systematic review of qualitative studies. International Psychogeriatrics, 30(6), 807–831. https://doi.org/10.1017/ \$1041610217001545
- Lowrani, M., Indarwati, R., & Lestari, P. (2020). Non-pharmacological therapy for the elderly to prevent dementia through cognitive stimulation therapy: A systematic review. Jurnal Ners, 15(2), s221–s229. https://doi.org/10.20473/jn.v15i1Sp.19018a

Ludden, G. D. S., van Rompay, T. J. L., Niedderer, K., & Tournier, I. (2019). Environmental design for dementia care - towards more meaningful experiences through design. *Maturitas*, 128, 10–16. https://doi.org/10.1016/j. maturitas.2019.06.011

Niedderer, K. (2014). Mediating mindful social interactions through design. In A. Ie, C. T. Ngnoumen, & E. Langer (Eds.), Vol. 1. The Wiley Blackwell handbook of mindfulness (pp. 345–366). Chichester, UK: Wiley. https://doi.org/10.1002/ 9781118294895.ch19.

Niedderer, K., Harrison, D., Gosling, J., Craven, M., Blackler, A., Losada, R., & Cid, T. (2020). Working with experts with experience: Charting co-production and codesign in the development of HCI-based design. In R. Brankaert, & G. Kenning (Eds.), HCI and Design in the Context of Dementia (pp. 303–320). Springer. https://doi.org/ 10.1007/978-3-030-32835-1 19.

Olykaynen, D. (2016). Designing a board game for children to enhance well-being and train social skills. (PhD). Joensuu, Finland: Karelia University of Applied Sciences. https://www.theseus.fi/bitstream/handle/10024/117029/Olykaynen\_Darya.pdf?se quence=1 (accessed 13/1/2021).

Phinney, A., & Chesla, C. A. (2003). The lived body in dementia. Journal of Aging Studies, 17(3), 283–299. https://doi.org/10.1016/S0890-4065(03)00029-X

Power, G. A. (2016). Dementia beyond disease: Enhancing well-being. Revised edition (30 Nov. 2016). Health Professions Press.

- Pratt, R., & Wilkinson, H. (2001). The effect of being told the diagnosis of dementia from the perspectives of the person with dementia. In *Final report to the mental Health Foundation. Stirling: CSRD.*
- Roberts, C. (2019). Living with Dementia (Keynote). International MinD Conference 2019: Designing with and for people with Dementia: Wellbeing, Empowerment and Happiness, Dresden, Germany, 19 September 2019. https://designingfordementia. eu/news/mind-events/mind-conference-2019/mind-2019-keynote-presentations/ch ris-roberts-living-with-dementia.
- Rodgers, P. A. (2016). Designing with people living with dementia. Northumbria University (ISBN 978-1-86135-466-2).
- Rodríguez Vega, B., Bayón Pérez, C., PalaoTarrero, A., & Fernández Liria, A. (2014). Mindfulness-based narrative therapy for depression in Cancer patients. *Clinical Psychology & Psychotherapy*, 21(5), 411–419. https://doi.org/10.1002/cpp.1847

Ryan, R. M., & Deci, E. L. (2017). Self-determination theory: Basic psychological needs in motivation, development, and wellness. New York: Guilford Publishing.

Sanders, E. B. N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. Co-design, 4(1), 5–18. https://doi.org/10.1080/15710880701875068

- Schlosser, M. (2015). Agency. The Stanford encyclopedia of philosophy. Online. Stanford University https://plato.stanford.edu/archives/win2019/entries/agency/ (Accessed 11 January 2021).
- Snyder, C. R., Lopez, S. J., Edwards, L. M., & Marques, S. C. (2020). The Oxford handbook of positive psychology. Oxford, UK: Oxford University Press.

Sprague, S., Matta, J. M., Bhandari, M., et al. (2009). Multicenter collaboration in observational research: Improving generalizability and efficiency. *The Journal of Bone and Joint Surgery. American Volume*, 91(S3), 80–86. https://doi.org/10.2106/ JBJS.H.01623

Stewart-Brown, S. (1998). Emotional wellbeing and its relation to health. Physical disease may well result from emotional distress. *BMJ (Clinical research ed.)*, 317 (7173), 1608–1609. https://doi.org/10.1136/bmj.317.7173.1608

Strohmaier, S., & Camic, P. (2017). Conceptualising what we mean by 'wellbeing' in the dementias. In Royal Society for Public Health conference 'Powerful Partners: Advancing Dementia Care through the Arts & Sciences', 24 November 2017, London, UK. https:// repository.canterbury.ac.uk/item/88v33/conceptualising-what-we-mean-by-wellbei ng-in-the-dementias (Accessed 8 April 2021).

Tiainen, T., & Koivunen, E.-R. (2006). Exploring forms of triangulation to facilitate collaborative research practice: Reflections from a multidisciplinary research group. *Journal of research Practice*, 2(2), M2. http://jrp.icaap.org/index.php/jrp/article/v iew/29/61 (Accessed 8 April 2021).

- Toomey, A. H., Markusson, N., Adams, E., & Brockett, B. (2015). Inter-and transdisciplinary research: A critical perspective. In *Brief for GSDR 2015*. United Nations. https://sdgs.un.org/documents/brief-gsdr-2015-inter-and-trans-disciplinar-20682 (Accessed 8 April 2021).
- Tournier, I., et al. (2018). A holistic model of dementia care. Workpackage 3 report, MinD-designing for people with dementia. In H2020 Marie Skłodowska-curie action, research and innovation staff exchange programme, GA 691001.
- Treadaway, C., & Kenning, G. (2016). Sensor e-textiles: Person centered co-design for people with late stage dementia. Working with Older People, 20(2), 76–85. https:// doi.org/10.1108/WWOP-09-2015-0022

#### K. Niedderer et al.

- Wells, R. E., Kerr, C. E., Wolkin, J., et al. (2013). Meditation for adults with mild cognitive impairment: A pilot randomized trial. Journal of the American Geriatrics Society, 61(4), 642-645. https://doi.org/10.1111/jgs.12179 WHO. (2020). Dementia: Situation. Online. World Health Organisation. online https
- ://www.who.int/health-topics/dementia (Accessed on 23 December).
- Wiersma, E. C., O'Connor, D. L., Loiselle, L., et al. (2016). Creating space for citizenship: The impact of group structure on validating the voices of people with dementia.
- Dementia, 15(3), 414-433. https://doi.org/10.1177/1471301216642339 Zeilig, H., Tischler, V., van der Byl Williams, M., West, J., & Strohmaier, S. (2019). Cocreativity, well-being and agency: A case study analysis of a co-creative arts group for people with dementia. Journal of Aging Studies, 49, 16-24. https://doi.org/ 10.1016/j.jaging.2019.03.002