


Please cite the Published Version

Niedderer, Kristina  and Fung, Pui Ling (2023) Living the life: evidence-based design and evaluation of psychosocial interventions with people with dementia. In: IASDR 2023: Life-Changing Design, 09 October 2023 - 13 October 2023, Milan, Italy.

DOI: <https://doi.org/10.21606/iasdr.2023.644>

Publisher: Design Research Society

Version: Published Version

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Additional Information: This is an open access conference paper which was originally presented as IASDR 2023: Life-Changing Design

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Living the Life: evidence-based design and evaluation of psychosocial interventions with people with dementia

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doi.org/10.21606/iasdr.2023.644

Design is increasingly recognised as an important means to create and deliver psychosocial interventions for people living with early to mid-stage dementia to help manage impacts on cognitive and psychosocial health. Managing them is important, especially for people with a recent diagnosis, who may live 10 or more years and who want to live well. However, interventions often lack a sound evidence base, both in terms of designing as well as evaluation. This paper argues for the need to promote and further evidence-based designing and evaluation, using the example of the Living the Life mindful-reflective booklet, an evidence-based, self-administered psychosocial intervention, co-designed during the MinD project. The booklet was designed to help people with early-stage dementia to adjust to their everyday living, including relieving stress and maintaining social connections. This paper reflects on the evidence-based approach for its design and the methodology for its evaluation.

Keywords: *dementia; evidence-based design; co-design; evaluation*

1 Introduction

Dementia is a common neurological degenerative disease among older adults. About 55 million people are living with dementia currently worldwide and this figure is expected to increase to 132 million by 2050 (World Health Organization, 2023). The impact of dementia is not only affecting individuals and their families but also society with global costs of US\$ 818 billion in 2015 and an expected rise to US\$ 2 trillion by 2030 (World Health Organization, 2017).

People living with different types of dementia experience similar symptoms such as memory loss, language problems and mood change, and which affect their wellbeing. At present, there is no medical cure for dementia and the aim of current medical treatments is to slow down disease progression. People can live with dementia for more than 15 years after being diagnosed (Wolters et al., 2018). More than 85% of population with dementia in United Kingdom are living with early to mid-stage dementia and 61% of people with dementia live in the community (Prince, 2014).



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Getting a dementia diagnosis is a stressful moment for most. People often feel helpless, anxious and alone, struggling with self-identity and stigma, with maintaining independence and how to view the future, leading to depression and even suicidal thoughts (Low et al., 2018; Roberts, 2019). The Alzheimer's Society found that peer support and social contact after being diagnosed were rated as "extremely" or "very" important, while insufficient peer support and help to maintain social connections were also reported (Arblaster & Brennan, 2022). However, currently, much of the support offered is targeted at the later stages of dementia, with activities not suited to the needs of people with early-stage dementia.

Therefore, it is important to provide post diagnostic interventions for people at the early stage to adapt to living well with dementia in everyday life, promote wellbeing and quality of life. In our understanding of wellbeing, wellbeing is seen to include emotional wellbeing, social engagement and a sense of self and agency (Niedderer et al., 2022). With regard to living well in the community, Oyeboode and Parveen (2019) observe the need to develop psychosocial interventions that focus less on control of behaviours and more on wider aspects of life for people with dementia. Psychosocial intervention that help people to maintain an active lifestyle and to stay socially connected have shown to improve wellbeing (Fernández-Mayoralas et al., 2015). The National Institute for Health and Care Excellence (2018) further suggests that activities which are based on individual's preferences are beneficial for promoting wellbeing.

Psychosocial interventions which support the wellbeing of people following their diagnosis further need to be designed, developed and evaluated based on sound evidence in order to ensure their appropriateness and their effectiveness (Oyeboode & Parveen, 2019). In this paper, we discuss the meaning and implications of evidence-based research, both in terms of developing and evaluating psychosocial interventions. We use the Living the Life booklet (MinD project team, 2020), which was designed as part of the MinD project (2016-2022) to support people with a dementia diagnosis to adjust to living with dementia, as a case study to explore these aspects. By design, we mean here the creative conception and development of relevant products and services. Design is particularly useful because it is used in, and can influence every part of human life, and it can be used by people living at home to support their daily and social lives (Niedderer et al., 2017; Niedderer et al., 2022). We explore the idea of evidence-based working, and what this means in the design process with and for people living with dementia as well as in valuating psychosocial interventions. In particular, we look at tensions relating to evidence-based working in relation to inclusive co-design approaches recommended in the context of working with people with dementia. We will summarise the insights regarding the methodology of designing and evaluating psychosocial interventions with people in the conclusion.

2 Designing and evaluating evidence-based psychosocial interventions

In order to support people's wellbeing following the diagnosis better, we propose a holistic, evidence-based approach (Zengul & O'Connor, 2013) to developing and evaluating psychosocial design interventions. By holistic, we mean taking a broader view of the person and their circumstances, feelings and aspirations to support wellbeing (Low et al., 2018; Oyeboode & Parveen, 2019), including emotional wellbeing, social engagement and a sense of agency (Niedderer et al., 2022; Zeilig et al., 2019). A person's feeling can strongly influence their confidence and level of social engagement, and

vice versa, and reduce feelings of loneliness. Confidence also affects agency, as the ability to act in an independent capacity, and therefore people's motivations and perceptions of their quality of life.

To enable such an approach, this needs to be reflected in the methodology. With regard to providing an evidence-base, Oyeboode and Parveen (2019) suggest that a sound theoretical underpinning can provide both, guidance for the (design) development as well as for the later evaluation. In addition, Pati (2011) provides a useful framework for drawing on different kinds of knowledge base to establish the evidence base and argues that connecting the design and evaluation methodologies allows to create a strong foundation and rigour (Pati, 2011). Drawing on the existing evidence base and integrating theories within design concepts and solutions and, by extension, in people's lives can help enhance a design's effectiveness. An example of how such concepts and theories can be integrated and used within and through design is demonstrated by the use of mindfulness to improve mental health is discussed by Chittaro and Vianello (2016) with a digital app to deliver thought distancing training into everyday life. This example shows that a clear theoretical approach can offer clear guidance towards defining the underpinning aim and concept of an intervention.

A second evidence-base can be found in people's experiences, which can help to translate such a concept into an actual design through user experience and user input to ensure the resulting design is relevant and appropriate. Involving stakeholders through co-design processes to obtain their views and input can help to achieve this. Therefore, co-designing with end-users, in this case people with early to mid-stage dementia, their care partners, formal carers and care professionals is vital. It brings user experience to bear on the development process to ensure that design solutions are informed by real-life needs, wants and experiences and thus helps to create solutions that are both relevant and fit for purpose for the people who will use them. At the same time, the process gives agency to the persons involved, which can in itself have a wellbeing effect (Denning et al., 2020; Kristina Niedderer et al., 2020; Rodgers, 2018; Winton & Rodgers, 2019). In the following, we discuss the two approaches in more detail, including considerations on their combination and integration.

Co-design is by now a well-established methodology. It includes stakeholders in the design process to enable the development of design products and services to be both relevant to the target group and appropriate with regard to ergonomics, semantics, emotional aspects, etc. (Sanders & Stappers, 2008; Zeilig et al., 2019). Its use in the health sector is becoming more common, also with people with dementia. Best practice examples include the Kilt pattern project (Rodgers, 2018) where people with dementia participated in the design of a kilt pattern to be used as a signature product by the Alzheimer's Society, or the design of memory blankets by Treadaway and Kenning (2016) to facilitate social engagement and closeness between people with late stage dementia and their familial carers (spouses). Our approach adds to these approaches through a model that includes people with early to mid-stage dementia in the full cycle of the design and decision-making process. Our approach is based on the premise that, when working with people with early to mid-stage dementia, co-design should seek to include people in a meaningful way, from beginning to end, to enable them to say what the issues are for them, to help make decisions about what products and services would be most suitable, and to help with the concept and prototype development (Denning et al., 2020; K. Niedderer et al., 2020).

Once developed, it is important to evaluate psychosocial interventions rigorously (Oyeboode & Parveen, 2019). This evaluation needs to mirror the ethos of the design development, both in relation to the

theories used and the ethos of the methodology, as shown in the example by Chittaro and Vianello (2016). For example, an intervention which has been developed on the basis of mindfulness theories to promote wellbeing, is likely to be matched by an evaluation theory that incorporates mindfulness and wellbeing, such as a wellbeing and/or mindfulness scale. The methodology also should be sensitive to the nature of the intervention and the capabilities of the participants, and preserve the ethos of inclusion and respect (Denning et al., 2020).

3 Case study: the Living the Life mindful-reflective booklet

This section summarises the methodology for the design development and the considerations for evaluation of the Living the Life booklet to draw out and illustrate the evidence base in both parts and how they interlink.

3.1 Developing Living the Life

In the development of Living the Life (MinD project team, 2020), four types of evidence were utilised: First, testimony from people with dementia and carers informed the initial idea generation; second, co-design with people with dementia, informal carers and care professionals was used to identify their wants and wishes as well as potential ideas for the design; third, theories from positive psychology were used to develop the design concept; and fourth, expert knowledge and guidelines were used to support the final design development as set out in the following.

The Living the Life booklet was conceived to help people shift away from the deficit-oriented nature of the dementia diagnosis and towards adopting a positive attitude to managing everyday life to improve agency and quality of life. This focus was identified from people with dementia and supporting literature (Ziebuhr et al., 2023). In particular, concerns were raised by people with dementia and their care partners regarding the negative impact of the diagnosis on the person and the lack of helpful information and support (Roberts, 2019; Ziebuhr et al., 2023).

The co-design process went through several iterations of idea generation and decision-making in four countries (Germany, Netherlands, Spain, UK). The co-design process with people with dementia, explored different ideas, including advice on dementia, on areas and tasks of daily life as well as a diary style physical and interactive presentation. During the process, it became clear from feedback from people with dementia that it was more important for the design to offer positive (non-deficit orientated) advice to manage life after the diagnosis and for the design's appearance to be fresh, relaxing and non-stigmatising rather than to offer factual information on dementia, services etc. and a diary style presentation. Such information and services are already available, but it seems that people may not be able to take in or accept the information due to the 'trauma' of the diagnosis. Therefore, it became paramount to offer help with supporting people's confidence, for them to feel enabled and in charge of their lives, if they are to cope well with the situation.

To address issues of confidence and empowerment and to promote a positive attitude, the team drew on theories from positive psychology. They introduced the concept of mindfulness to engender relaxation, reflection on and acceptance of oneself as well as changes within one's life and one's relationships. Mindfulness can help with wellbeing through living in the moment, which can further relaxation, reflection and acceptance (Ie et al., 2014; Kabat-Zinn, 2003; Langer, 2010; Langer, 1989; Rodakowski et al., 2015). Mindfulness principles, including reflective statements and simple

mindfulness exercises, were used to construct the Living the Life reflective booklet. In addition, the visual design was informed by an understanding of the benefits of nature imagery in supporting relaxation (Ludden et al., 2019).

The final design of Living the Life booklet consists of two parts: 'Making the Most of It' which is the actual reflective booklet (Figure 1) and 'A Walk Around Myself' which is an interactive card with mindfulness exercises to complement the booklet (Figure 2). 'Making the Most of It' comprises advice for adjusting to everyday living with dementia, grouped into five categories of reflective statements relating to memory loss, health, wellbeing, relationships, and asking for help. Each section contains one question and several corresponding statements for reflection. The questions represent common situations that people with a recent diagnosis of dementia encounter. The statements serve to guide the user's reflection on how they want to manage and adapt to the changes in their daily life. They are supported by complimentary images from nature to help with relaxation and reflection (Ludden et al., 2019). 'A Walk Around Myself' is a card with six simple mindfulness exercises relating to relaxation (breathing), safety (imagining a safe space), awareness (walking, listening), compassion (hug, smile). Each exercise is represented by a symbol which is also used to associate the exercises with the reflective statements. The users can choose the exercise either according to the statements in the booklet or by spinning the arrow on the card. The exercises are designed to help the users relax and reflect on their feelings, thoughts and experiences. They were developed specifically for the booklet by members of the team who have experience of working with people with dementia in care and clinical settings. The objective was for the exercises to be accessible for people without regular practice, easy to understand and quick to implement (1-3 min. per exercise), and to offer a varied experience when paying attention to different senses. The layout, including colours, font and font size, was informed by relevant guidelines (DEEP, 2013).

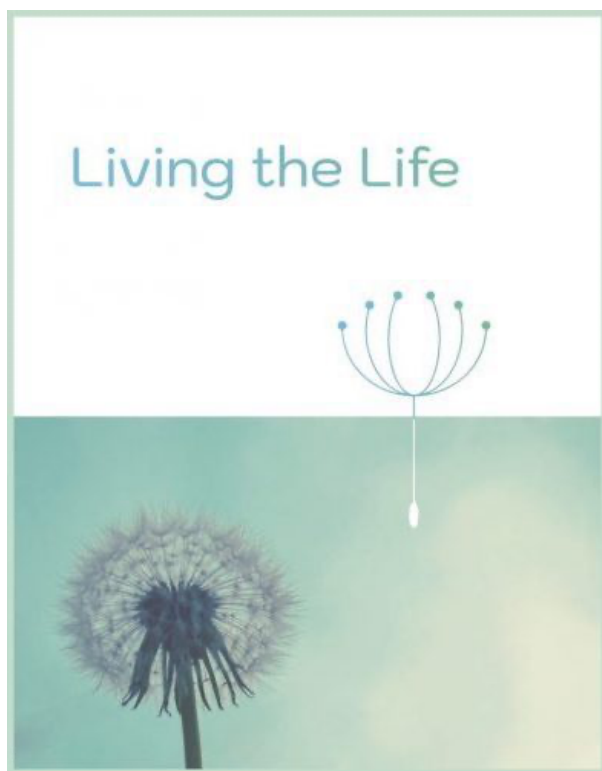


Figure 1. Living the Life reflective booklet.



Figure 2. A walk around Myself - interactive card with mindfulness exercises.

This example demonstrates that several different methods were used to gain different types of data to provide the holistic evidence base for the development of the Living the Life design. These include:

1. Literature Review to identify contextual data based on previous research to inform the initial design focus and identify suitable theoretical frameworks.
2. Co-design to draw on user experience to interrogate and refine the design focus and develop the concept.
3. Concept development: Apply theoretical frameworks (mindfulness, nature imagery) to provide a further evidence-base to the design decisions.
4. Concept realisation: Draw on expert knowledge and design guidelines (mindfulness practises, accessibility guidance) to embed key aspects of the theoretical framework within the design and to ensure its accessibility.

3.2 Methodology for evaluating Living the Life

Rigorous evaluation is recommended to evaluate the effectiveness of any psychosocial intervention after its development (Moniz-Cook et al., 2011). In terms of effectiveness, the evaluation should focus on various aspects including outcomes measurement, assessing cost and value, and gaining insight for widespread implementation (Oyebode & Parveen, 2019). As Living the Life is a newly developed post-diagnostic, self-help psychosocial intervention, the priority of its evaluation is on outcome measurement and gaining insight for its widespread implementation. For the outcome measurement, we first need to know if there is any impact towards the wellbeing after using the booklet. Regarding widespread implementation, we need to know about the user experience and the opinion on the design of the booklet.

Choosing an appropriate methodology is essential for us to learn about the effectiveness of the intervention. There is no golden standard that suggests the best methodology in the evaluation of

design-based psychosocial interventions. Randomised control trial (RCT) is one of the common methodologies adopted in evaluating psychological interventions due to its rigorous characteristics (Hariton & Locascio, 2018; Moniz-Cook et al., 2011; Oyeboode & Parveen, 2019). However, before an RCT can be conducted, certain parameters must be known. As a newly developed psychosocial intervention, we have as yet little knowledge about its application parameters. Hence, it is most appropriate to conduct a small-scale pilot study at this stage, before attempting an RCT. Another reason of not choosing an RCT is that validity of an RCT relies on a significant sample size, ideally at multiple sites. Moniz-Cook et al. (2011) reported that having enough participants to use the psychosocial intervention and gaining access to the sites are the common challenges encountered. In addition, a small-scale pilot study can be helpful to further refine the initial design of Living the Life booklet and to explore the feasibility of its wider application in a cost-effective way (Polit & Beck, 2017) before moving on to a larger scale of trial.

For the evaluation, we adopt a concurrent triangulation mixed study design. This approach triangulates quantitative and qualitative data to offset the bias and limitation of both methods (Greene et al., 1989). Both types of data together provide a more holistic view about the use of Living the Life from the users' perspective (Creswell & Clark, 2011). For the outcome measurement, we propose measuring the wellbeing of the participants before and after the use of the booklet through a quantitative survey. The benefit of using a pre-test and post-test design is to allow us to conduct a within-subject comparison that compensates for not having a control group (Polit & Beck, 2017). With consideration of the participants' perceptual and language skills, use of a simple, well-structured and validated questionnaire, 7-items Warwick Edinburg Mental Wellbeing Scale is proposed to measure the wellbeing of the participants (Shah et al., 2021). This provides an overview of the wellbeing of the participants through descriptive statistics and we will adopt Fisher's Exact test to investigate the relationship between changes in their wellbeing and the use of the booklet, which is appropriate for the small size of the participant group (Bland, 2015). We further use focus group discussion to allow participants to share their user experience and their view on the design of the booklet. Thematic analysis is adopted in data analysis to capture the abstract meaning and in-depth understanding of the users' experience and opinion on the design (Braun & Clarke, 2022).

Additional considerations are taken into account when planning the data collection with people with dementia. People with dementia can be influenced by the environment, and their perceptual and language ability. Several strategies are adopted to reduce stress and minimise the impact of an unfamiliar environment on the data collection and therefore will enhance the validity of the evaluation (Guruge et al., 2021). These strategies include arranging data collection in a setting which participants are familiar with, allowing longer response time, reading questionnaires for them, and avoiding abstract notions (van Baalen et al., 2011). By adopting these strategies, we aim to enhance the rigour of the evaluation study.

4 Conclusion

This article illustrates the use of an evidence-based approach (Oyeboode & Parveen, 2019; Pati, 2011; Zengul & O'Connor, 2013) to the design and evaluation of a psychosocial intervention—Living the Life—to empower people with a recent diagnosis of dementia to live better for longer. We use the development of Living the Life to elucidate how we apply evidence-based design and evaluation in

practice. Following Oyeboode and Parveen (2019) and Pati's framework (2011), the evidence-based design of Living the Life has built on the foundations formed by theory and by empirical data collected in interviews with research participants to derive the design's starting point. This foundation was complemented by practical knowledge through co-design with people with lived experience and expert knowledge by design and health professionals using an iterative process.

In the second step, we illustrate how to choose an appropriate methodology for evaluating Living the Life to complete the cycle of evidence. In this regard, the choice of methodology for evaluation should be flexible and based on, and appropriate to, what is to be evaluated, such as the size and characteristics of the target population as well as the type of information sought (Pati, 2011). In the case of Living the Life, this information is two-fold: firstly information on the wellbeing impact of using the intervention on the target group is sought through an appropriate wellbeing measure; and secondly feedback on the design is sought to understand how well it is working from a user-experience point of view, and whether further improvements can and should be made, which might further improve the designs impact and benefit. This means an iterative cycle of design and evaluation is required until an optimum state is achieved.

In conclusion, this research has offered a practical case study and discussion of how to develop and evaluate an evidence-based design intervention with the aim to advance the development and methodology of evidence-based psychosocial intervention design.

Acknowledgements

This article builds on the outcomes of the 'MinD - Designing for People with Dementia' project (2016-2020), which received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Marie Skłodowska-Curie grant agreement No 691001.

We wish to thank all project researchers, external partners, and especially participants of several Groups of Experts by Experience (GEE), including the European Working Group of People with Dementia (EWGPWD), the patient group at Alexianer Hospital, Berlin, the GEE participants at INTRAS, Valladolid, and the Public and Patient Involvement (PPI) group in Nottingham, for their excellent contributions to the MinD project.

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

Further project information: www.designingfordementia.eu

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