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EDITORS:
Daniela De Sainz Molestina
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Davide Spallazzo

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A systemic perspective on designing for well-being in dementia care: learning from the case of Dementia Friendly Communities

Shen, Xiaolin*[a]; Sangiorgi, Daniela[a]

[a] Politecnico di Milano, Milano, Italy
* xiaolin.shen@polimi.it

This paper aims to analyse the potential contributions of design from a systemic perspective of wellbeing in dementia care and to identify areas for intervention. Specifically, the authors first provide a systemic perspective of well-being in dementia care from three levels: individual, network, and community. Then using Dementia Friendly Communities as a case study, the authors summarise three contributions areas: (1) Involving - shifting the focus from deficits and burdens to remaining capacities and contributions; (2) Connecting - enhancing service inclusivity and building care service network; and (3) Fostering - activating resources within and beyond the community. The authors then explore what we can learn from Dementia Friendly Communities about design for well-being and the potential contribution of service design in promoting well-being for people with dementia, their care partners, and the community as a whole. The paper concludes with future steps for research in service design in this area.

Keywords: service design; well-being; dementia friendly community; community well-being

1   Introduction

As the population ages, it is projected that the number of people with dementia in Europe will increase from 9.95 million in 2010 to 18.65 million in 2050 (WHO, 2017). Due to a cluster of behavioural and psychological symptoms, people with dementia often show high dependent on others, resulting in a wide range of complex care needs for performing normal activities of daily living (WHO, 2017). However, the healthcare system currently focuses mainly on dementia diagnosis rather than care, despite the fact that most people with dementia prefer to live at home and community for as long as possible and rely on their own care partners for support in their daily lives (Burgdorf et al., 2019; Köhler et al., 2021).

In the 20th century, there has been a shift towards promoting the well-being of both people with dementia and their care partners (Burley et al., 2020; Clarke et al., 2020). This highlights the

importance of understanding the interactions and experiences of all actors involved in dementia care, moving beyond the dyadic care relationship to identify additional resources of support such as service networks, community resources, and other social care services (Cho et al., 2016; Watson, 2019; Podgorski et al., 2021; Köhler et al., 2021).

The World Alzheimer Report 2020 highlights the significance of design in promoting well-being for people living with dementia and advocates for the further application and development of design interventions specific to dementia care (Fleming et al., 2020). However, the current design studies are mainly focusing on developing products, interactions or building a better environment for people with dementia (Tsekleves & Keady, 2021; Rodgers, 2022), with little attention paid to the design for dementia care services or communities that consider the complex interactions between people with dementia, their care partners and the broader care network at a collective level.

This paper aims to analyse the potential contributions of design from a systemic perspective of wellbeing in dementia care and to identify areas for intervention. Specifically, the authors provide a definition of well-being from a systemic perspective in dementia care. Then using Dementia Friendly Communities (DFCs) as a case study, the authors summarise what we can learn from DFCs about design for well-being that can inform a design approach, and the potential contribution of service design in promoting well-being for people with dementia, their care partners, and community as a whole. The paper concludes with the authors' future steps of research in service design of this area.

2   Background of dementia care and well-being

The concept of "dementia" has traditionally been viewed as a biological disorder with defined symptoms and stages that lead to loss of function and end-of-life (Sandberg & Ward, 2023). As a result, most dementia research has focused on medical, neurological, or psychosocial interventions in the hope of finding a way to cure or change the state of people with dementia (WHO, 1947; Maddux, 2009). Over the past decade, reports of positive experiences of living with dementia have emerged, coinciding with a re-appraisal of the value of open inquiry into people's lived experiences, based on phenomenological and constructionist perspectives and qualitative research methods (Rahman, 2014). The adoption of the concept of "living well" rather than simply "living with" dementia has also gained traction (Christopher & Hickinbottom, 2008; Clarke et al., 2020). Furthermore, the concept of "social health" has been suggested as a desired framework to shift the focus from individualised, intrapersonal accounts of well-being towards an integrated approach that acknowledges the dynamic balance between opportunities and limitations in the context of social and environmental challenges (Droes et al., 2017; Huber et al., 2011). The perception of social health is also aligned with the developed well-being concept by Dodge, which considers well-being as "the balance point between an individual's resource pool and the challenges faced" (Dodge et al., 2012, p. 230).

Therefore, with the transformational perspective of well-being in dementia, psychologists and psychosocial workers have raised concerns about the biomedical care models that solely focus on deficits when addressing dementia (Kitwood, 1993; Novilla et al., 2006). They have recognized the limitations of the biomedical perspective and the significance of social and psychological factors in the experience of dementia care (Kitwood, 1993; Podgorski et al., 2021). An increasing number of practitioners have started to develop support services for people with dementia to promote their

personal and social strengths, adapt to changes, and mitigate the effects of dementia symptoms on individual well-being (Droes et al., 2017).

However, individual-centric care models can present their own set of challenges, such as being timeconsuming (Gitlin et al., 2010), leading care partners to feel overwhelmed and burnt out (Janssen et al., 2017; Barbosa et al., 2015), or having high costs (Larson & Stroud, 2021). Therefore, to ensure long-term well-being for people with dementia, it is essential to consider social inclusion and inclusive services (Manthorpe & Bowes, 2004). This means not only focusing on the well-being of people with dementia but also taking into account the well-being of other involved actors and broadening wellbeing to include a range of different domains beyond individual subjectivity, to incorporate the family, community, and society as a whole.

3 A systemic perspective of well-being in dementia care

In order to illustrate the dynamic and multi-faceted nature of well-being and its relationship with the border embedded network in dementia care, the authors have developed a systemic perspective of well-being from three levels: individual, network, and community (see Figure 1).
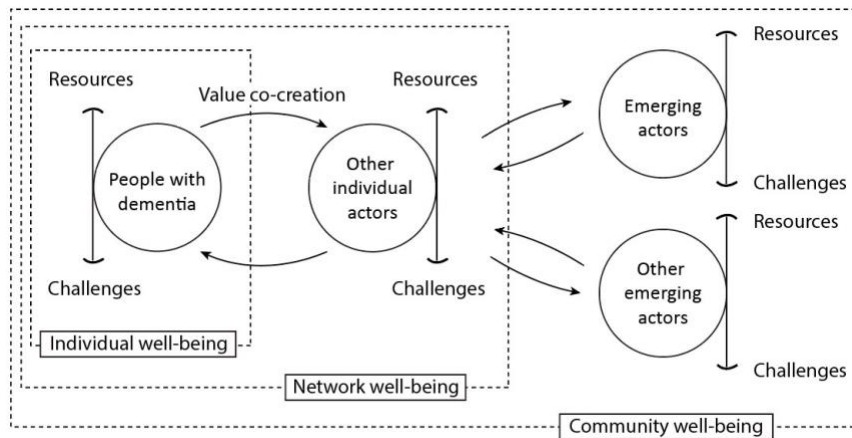
Figure 1. A systemic perspective of well-being. Source: the authors.

Individual well-being is defined as the "balance point between an individual's resource pool and the challenges faced" (Dodge et al., 2012, p. 230). This concept explains the dynamic nature of well-being and how the external context can influence a particular well-being state of an individual, focusing on psychological, physical and social aspects. For example, in the context of dementia care, individual actors can benefit from a range of interventions that support their well-being, such as physical exercise programs, and social activities (Barbosa et al., 2015). These interventions aim to enhance the individuals' resource pool and help them cope with the challenges they face on a daily basis.

Network well-being can be defined as "an aggregated perspective of nested actor's assessment of a system's present conditions in terms of fulfilling its needs and contributing to the betterment of itself" (Leo et al., 2019, p.770). Rooted in service dominant logic, it views value co-creation as "the process through which multiple actors jointly contribute to an actor's well-being" (Vargo & Lusch, 2018, p. 740) as a desired outcome. In dementia care, network well-being can be fostered through the development of supportive networks that aim to enhance the well-being of all actors involved, such as the

relationship centred care (Watson, 2019), which emphasises the importance of enhancing the quality of relationships between care partners and people with dementia to both maintain their well-being.

Community well-being focuses on the dynamic interplay between the context of people's lives and the collective efforts and relationships that influence their well-being (McLeroy et al., 2003; Frow et al., 2016). Community well-being can be defined as "the combination of social, economic, environmental, cultural, and political conditions that individuals and communities identify as essential for flourishing and fulfilling their potential" (Wiseman & Brasher, 2008, p. 358). It takes an asset-based approach that connects with the idea of community development and flourishing, aiming to build on existing strengths and resources within a community (Cassetti et al., 2020). In dementia care, initiatives that involve members of the community, such as educating the public about dementia and reducing stigma, creating dementia-friendly environments, and providing support for caregivers, can promote community well-being (Rahman & Swaffer, 2018).

These three levels of well-being are interconnected, and it is important to consider them together when developing interventions for dementia care, as enhancing the well-being of people with dementia requires a collaborative effort from a range of actors. Therefore, interventions that focus solely on the individual level may not be sufficient to achieve desired outcomes. A more comprehensive approach that considers the network and community levels should be adopted.

Over the past decade, several interventions have been developed to improve the well-being across these three levels, and one of them is the Dementia Friendly Communities (DFCs) initiative. It aims to create "a place or culture in which people with dementia and their caregivers are empowered, supported, and included in society, understand their rights, and recognize their full potential" (ADI, 2016, p.10). Many reports and papers also use the phrase "improve the well-being of people with dementia, their families, informal caregivers, and also the community" to express an ultimate goal (Milton, 2012; Maki et al., 2020; Odzakovic et al., 2021). Therefore, in the following section, the authors use DFCs as a case study to examine how it supports individual and network well-being and contributes towards a better community future together.

4 Learning from the case of Dementia Friendly Communities

The case study process involves three steps, as illustrated in Figure 2. Firstly, the authors reviewed academic papers and published reports of DFCs initiative. The authors then conducted interviews with four DFCs promoters and experts to learn about their understanding of systemic well-being in the DFCs process, as well as the difficulties they faced. Finally, using a systemic perspective of well-being as an analytical lens, the authors summarised their contributions in three key areas: (1) Involving - shifting the focus from deficits and burdens to remaining capacities and contributions; (2) Connecting - enhancing service inclusivity and building care service networks; and (3) Fostering - activating resources within and beyond the community.
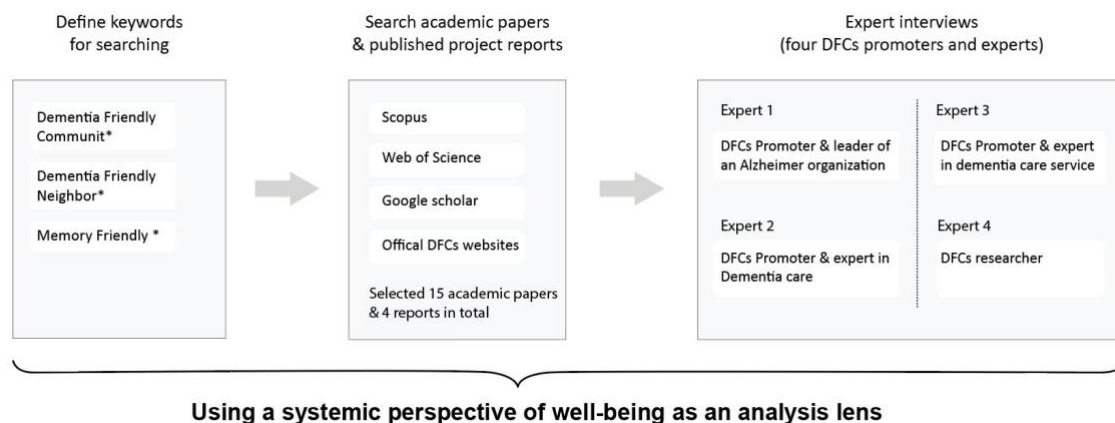
Figure 2. Case study process. Source: the authors.

4.1 Involving: shifting the narrative from deficit and burden to remaining capacities and contribution

Rather than focusing on the symptoms and deficits of dementia, DFCs strive to enhance the lives of people with dementia by empowering them to have "high aspirations and feel confident," and to engage in activities that hold personal meaning (ADI, 2016). By embracing dignity, empowerment, and autonomy, DFCs adopt an optimistic narrative that promotes well-being throughout the lifespan of people with dementia (Hebert & Scales, 2019).

Involving people with dementia, their care partners, and other related stakeholders is an important and crucial process of DFCs in the design and development process (Mathie et al., 2022). Such participation can take various forms, such as morning cafes, memory clubs, or other informal or formal types of meetings (Phillipson et al., 2019). For instance, in Dementia Friendly York, people with dementia and their care partners were invited to participate in a Sounding Board meeting, which was a safe and welcoming space where they could speak and talk with each other freely (Crampton et al., 2012).

To enhance communication and engagement with people who have dementia, it is important to recognize that many of them are accompanied by care partners or psychologists due to their declining cognition and expression ability. Empathy is often required to understand their needs and perspectives, and it is essential to observe their expressions in an inclusive, empathetic, and sensitive manner (Mathie et al., 2022). To encourage their participation in conversations and enable them to express their views about their experiences in the community, various techniques can be used, such as showing photos of places they may be familiar with, like shops, banks, and cafes (Odzakovic et al., 2021). Studies have shown that these approaches are effective in helping those with dementia take an active role in their community and maintain a sense of agency in their daily lives (Downs & Bowers, 2014).

These processes mentioned above can help people with dementia and their care partners no longer view themselves as passive recipients but rather encourage their active participation in the process and co-production of their own well-being. While some people may have limited capacity to participate and provide input, the act of participating in the co-creation of DFCs is itself a form of social activity that helps them identify available social resources.

4.2 Connecting: enhancing service inclusivity and building care service networks

DFCs are based on the fundamental principle of placing people with dementia at the core, recognizing that they should be treated with dignity and respect (ADI, 2016). Different from a single healthcare model, DFCs represent a more socially oriented and community-driven approach that integrates various dimensions (Rahman & Swaffer, 2018; Scher & Greenfield, 2023). This approach can be observed from two specific perspectives: enhancing daily service inclusivity and building care service networks.

People with dementia may encounter difficulties in performing daily activities, such as withdrawing money, shopping, or using public transport. These difficulties can lead to feelings of disconnection from their former social groups, activities, and places. Therefore, a key goal of DFCs is to support people with dementia to live as well and as "normally" as they want. A thorough consideration of available resources within and beyond the community is required, with a focus on service inclusivity and accessibility. This includes promoting dementia-friendly hospitals, transportation, and pathways (Xidous et al., 2020; Riquelme-Galindo & Lillo-Crespo, 2021). Therefore, in designing and developing DFCs, it is important to consider the perspectives of a broad range of stakeholders and to cultivate their awareness of dementia. To achieve this, DFCs use various means, such as focus groups or negotiating meetings, to find possible collaborations with multiple stakeholders (Heward et al., 2017).

In addition, because of the progressive nature of dementia, people with dementia rely more deeply on their care partners or other supportive care facilities. To enable them to live at home and in the community for as long as possible, DFCs encourage the development of a network of services that are adaptable to different situations for people with dementia and their care partners. This involves connecting with health and social care services, as well as specialist dementia services. In Dementia Friendly York, for example, the working group from DFCs collaborated with two organizations to map the dementia pathway, and explored the issues people face at each stage of their dementia journey. After that, they identified specific and appropriate activities for people with dementia and their care partners. In the early stage, people can participate in activities such as Singing for the Brain and New Age Kurling, which provide interactive pleasure and entertainment. In the late stage, there are special care services available for people with housing problems (Crampton et al., 2012).

By enhancing service inclusivity and building care service networks, we can improve the well-being of people with dementia and their care partners. Expanding the scope of dementia care beyond the dyadic relationship to a service network within the community can also strengthen connections between organizations, reaching toward network well-being. However, establishing networks and including profit-driven local businesses and broader public services such as transportation and healthcare can be challenging, as they may have different value propositions, and different service priorities, or it's hard to foster their awareness (Heward et al., 2017).

4.3 Fostering: activating resources within and beyond community

DFCs involve more than just utilising existing resources. It also emphasises the importance of community education to continually increase people's awareness of dementia, with the goal of changing future mindsets and being a precursor to the development of DFCs (Phillipson et al., 2019).

Learning about and raising awareness of dementia can take many forms, such as lectures, social media, or informational brochures. Studies have shown that the most effective way to raise awareness is by

grounding educational programs in the lived experiences of people with dementia, and by incorporating their stories to provide accurate portrayals of situations and events (Davis et al., 2009). Some studies suggest the use of role-playing activities or videos to show the experiences of people with dementia in challenging environments. Or, for example, Dementia Friendly Italia collaborates with primary schools to foster understanding and awareness of dementia from a young age.

The learning and culture change process is ongoing rather than a singular "state." It can identify potential new actors, bringing additional resources and co-creating value in more effective ways. This can improve the well-being of both individual actors and the community.

However, launching activities and expanding impacts can face many challenges. During the implementation process, various problems were encountered, such as a lack of funding, time, staff, and support, inadequate training, and limited community engagement.

5 Discussion

The case of DFCs exemplifies a shift in dementia care, from an individual-centric and healthcare model to a more collaborative and distributed approach, where all stakeholders - including people with dementia, their care partners, public service workers, and other related stakeholders within the community - are actively engaged in the co-creation of well-being. This shift towards a more open and participatory care ecosystem has resulted in the emergence of new service models that are community-based and co-produced.

Reflecting on the process and its main achievements of DFCs, it shows that these three processes (involving, connecting, and fostering) are interconnected and mutually reinforcing (see Figure 3). When people with dementia and their care partners actively voice their concerns or are involved in the design process, they not only identify their own challenges but also recognize their capabilities and discover potential resources that can help them improve their well-being. This process also helps DFCs promoters to recognise barriers and develop more inclusive services by engaging a diverse set of partners and identify more available social resources to promote community development.
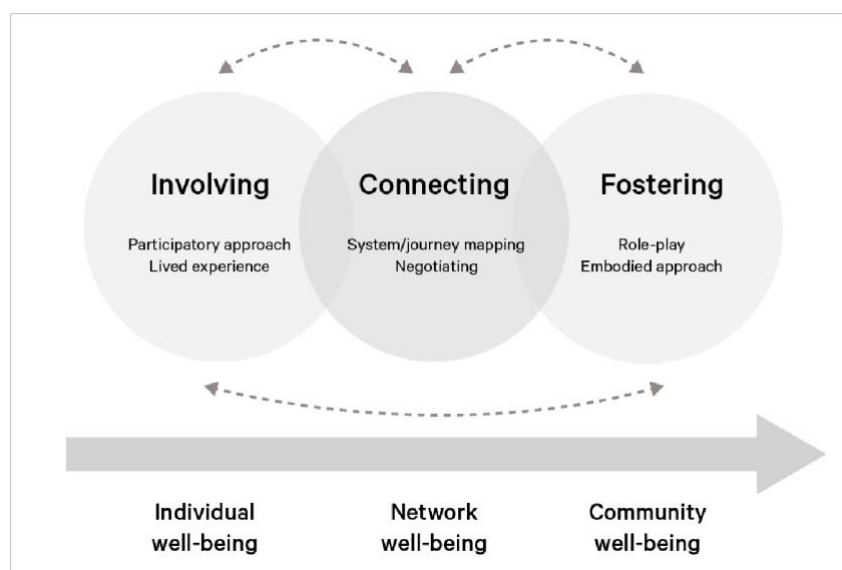

Figure 3. DFC's design and development process. Source: the authors.

In the part of involving, the participatory approach has been widely used to design and develop dementia care (Tsekleves et al., 2020; de Boer et al., 2021). This approach is centred on the belief that people can be creative and seek outlets for that creativity in their lives (Sanders & Simons, 2009; Wang et al., 2019). It aligns with the recent transformative view that people with dementia can still use their remaining capabilities and represents a shift from designing "of" or "for" people to designing "with" them. However, given the decline in cognition and expression ability of people with dementia, empathy and sensitivity are required to understand their needs and perspectives and build personal relationships. By using tools designed to facilitate a safe conversation and relational space, designers can learn from invaluable local knowledge and expertise based on the lived experiences of individuals with dementia and their care partners (Hendriks & Wilkinson, 2020; Hendriks et al., 2020).

Furthermore, connecting care service networks for dementia care and well-being entail more than just providing a one-time co-creation experience or products and interactions. It also requires enhancing external conditions or people's resources collectively. In the case of DFCs, focus groups, journey mapping, or negotiation aids are used to facilitate collaboration among various stakeholders. It is essential to pay attention to the importance of collaboration and involvement of various stakeholders and the value propositions between different parties. This topic has been recently discussed in the field of service design, such as the Service Design for the Value Network approach (Patricio et al., 2018) and pluralistic actor networks (Čaić et al., 2019). The service design approach, including the participatory visual models and tools used across different design stages, can support negotiation among multiple actors (Teixeira et al., 2019; Sangiorgi et al., 2022). However, this approach has limited capacity, especially in situations of unequal power and limited resources. To have a more profound and long-term impact requires wider awareness cultivation, which can be frosted by continuous learning and embodied forms (Wetter-Edman et al., 2018).

While service design has traditionally focused on improving users' experiences and designing touchpoints and service interactions between suppliers and users (Edvardsson et al., 2000; Blomkvist et al., 2010; Meroni & Sangiorgi, 2011), more recent service design research has expanded to focus on designing for multiple interactions and service ecosystems (Patrício et al., 2018; Vink et al., 2021). Service design is no longer seen as the end of the design process but as a means to achieve organizational, community, and social flourishing, leaving the capacity for ongoing change (Sangiorgi, 2011).

While exploring the contributions and possible developments of these different levels and approaches, it would be relevant to study how these three perspectives could coexist and complement each other in a systemic and dynamic service design approach to well-being for dementia care.

6   Limitations and future steps

This paper presents preliminary findings on designing for well-being in dementia care, as part of ongoing research exploring care models and developments in this field. While existing DFCs have achieved some success and advanced a transformational model for dementia care, there are still many challenges and issues to be addressed. However, it should be noted that this short paper also has some limitations.

One limitation of this paper is that the experts and cases come from around the world without a specific region. While the paper offers valuable insights into a systemic perspective of designing for well-being in dementia care, the findings may not be applicable to all regions due to cultural and contextual differences.

The second limitation of this paper is the lack of detailed explanation and interconnection among the three stages in the discussion section, which remains generic. This is due to the fact that data analysis was conducted through already published materials and four expert interviews, without direct contact with people with dementia and their care partners. Therefore, in the next step, the authors plan to collaborate with one of the DFCs in Europe and conduct Research through Design to investigate how service design can contribute to DFCs and promote well-being systemically.

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