

Illustrating Everyday Life: Developing a Series of Zines to Reflect the Meaning of Neighbourhoods for People Living With Dementia

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Abstract

This Beyond the Text submission presents a series of three graphic magazines (zines) as part of a research project about how people living with dementia experience their neighbourhoods and communities of place. The zines were produced through a collaboration of a graphic artist, academics and a small group of people living with dementia and/or family carers. The zines were designed to reflect the wider findings of the research. The idea to produce the zines came from people living with dementia themselves who were keen that the research findings reached beyond at academic audience, while at the same time were not turned into 'yet another leaflet about dementia'. We have published the findings from the research in a number of academic formats, but have not yet had the opportunity to showcase the zines to a wider, and more diverse audience beyond our circle of research supporters, stakeholders and research participants.

Keywords

artwork, co-production, dementia, dissemination, illustration, knowledge exchange

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Contextualising the work

There are 944,000 people living with dementia in the United Kingdom, with numbers estimated to rise to 1.6 million by 2050 (Dementia Statistics Hub, 2024). Symptoms of the condition include memory loss, difficulty concentrating, planning or organising, problems with language and communication, confusion about time or place, and mood changes or difficulty controlling emotions. Many diagnosed with dementia live in their own homes, often supported by family, friends and health and social care services (Keady, 2023). Research has identified associations between living with dementia and social isolation. Those impacted by dementia sometimes experiencing a 'shrinking world' as they find it harder to remain socially connected to others or struggle to get out and about (Duggan et al., 2008). A better understanding how people living with dementia can be supported to engage with the ebb and flow of daily life in local places thus has practical as well as conceptual implications. The lived experience of neighbourhoods for people living with dementia was the focus of an ESRC/NIHR funded research project – Neighbourhoods: Our People Our Places that supported the development of the zines that accompany this commentary.

Developing the work

For 5 years, an interdisciplinary team of researchers worked with people living with dementia and a nominated care partner engaged in participative and experiential methods of data collection in three field sites in England, Scotland and Sweden. The materials presented here were developed by the team and participants at the English site. Alongside more conventional academic activities, some of which we detail below, we developed a collaborative programme of knowledge exchange to engage the wider public in debate about the purposes that neighbourhoods and local communities can and should play to support people living with dementia. Participants living with dementia wanted a mechanism through which they could tell their stories in ways that were less reliant on text or oral communication traditions. In response, the academic researchers worked with a group of people living with dementia, or caring for a person living with dementia and an artist-illustrator to produce a series of zines to promote the research findings in ways that were accessible and visually impactful without rendering the complexities of living with dementia to ways that were patronising or oversimplified (see Campbell and Clark, 2023, for more details).

The idea for a series of zines came directly from people living with dementia who worked with us on the project, but the wider ethos and history of zines also appealed. Zines offer similar benefits to other illustrative or graphic-art based techniques used in research (eg Bartlett, 2013). Zines emerged as a small-scale underground paper-based publishing culture that was most prevalent from the 1970s to the 1990s, though they have since been replaced by Internet self-publishing such as blogs. They are typically produced using low technology, have low print runs and limited (if any) commercial interest. They combine text and illustrations on a specific topic, idea, or interest. Zines are often considered an emancipatory and democratic form of media-making that can be used to express views and experiences rarely featured in mainstream media (Duncombe,

1997). In this sense, Duncombe (1997; 14) describes zines as ‘decidedly amateur’, reflecting the freedoms and resistance of the communities that create and consume them. We were also influenced by other research that had used illustration to convey research messages, and the role of zines as platforms for activism, and generate change among a community of practice. Through a series of three zines, we aimed to retell stories from our research in ways that could perhaps re-energise, or even ‘re-humanise’ the data in a set of vignettes that, we hoped, could reflect the outcomes of our data analysis, as well maintain something of the personhood of those who contributed their individual stories and experiences to the study.

We adopted a broadly constructivist approach to understanding how neighbourhoods, and the social connections that intersected them, were understood and enacted through experiences and practices. At the same time, we were keen that those who took part in the research were able to engage as more than data subjects. While not adopting an explicitly feminist approach, we were influenced by participatory research traditions, and were certainly keen to disrupt power imbalances that are often present in research dynamics (Campbell et al., 2023). We aspired to a participatory ethos, supporting people living with dementia and their care partners to work alongside us at various stages of the research, including input into recruitment, development of methods, production of participant information, and contributing to the emergent analysis. After each meeting, group members received a gratuity for giving their time.

The pieces presented here were developed collaboratively over 2 years alongside 10 people living with dementia or who cared for someone with dementia. Findings from the research were distilled into a series of core messages through analysis and interpretation of the data by the academic researchers before first being presented to a group of people living with dementia and then presented to the artist. We then met regularly to create a series of zines based on these key messages. From our emergent data and analysis we storyboarded a series of new narratives encompassing situations experienced by the research participants. These made use of visual metaphor to highlight key difficulties one could experience while living with dementia. We were encouraged to develop this (at times) surreal imagery as a way of metaphorically reflecting the complexities of participants’ experiences in lieu of more ‘realistic’ representations. Away from the meetings, the artist spent time developing a narrative from the groups’ stories, while the researchers continued to undertake further data analysis and developed indicative text. These were then presented at meetings where drawing and text were amended, sometimes for visual style, other times for key messages. Group members identified stories to feature in each zine from the range of thematic narratives coming from our analysis. They were direct in their instruction that the zines did not look like information leaflets given the preponderance of these, and determined the size, colour ranges used in each zine to reflect this.

The preliminary storyboards were discussed, revised and refined over a series of the meetings. These meetings combined the serious work of developing the materials alongside much time dedicated to getting to know each other to create an environment where group members could feel confident about expressing their views on the work as it unfolded. They responded vitally and sensitively to how the work reflected living with dementia. At each meeting a series of action points were developed, and the artist would attend to changes within the illustrations while the academic researchers attended

to revisions to the text and, on occasion, returned to the data for further analysis. The resulting illustrated stories were accompanied by a brief written account, some information about the wider research, and advice, developed by those living with dementia, for others affected by the condition.

Other outputs (listed below) present the substantive findings from the work and reveal how people living with dementia are not passive observers of neighbourhood life but, instead, engage in the social rhythms of neighbourhoods and, with support, actively shape them as neighbourhoods of choice, though such choices are often restrained by contexts and circumstances. In doing so, the work provides insight into understanding neighbourhoods as relational places; how neighbourhoods might contribute to social health; and how people living with dementia can (with support) engage in the active creation of neighbourhoods (see Clark et al., 2023). The accompanying zines reflect our efforts to develop a more visually orientated mode of representation of these findings, with input from participants.

Depicting a medical condition like dementia is challenging. Sometimes, experiences cannot be easily brought into the visual realm or attempts to do so makes the profoundness of those experiences fall flat. We addressed this through the use of visual metaphor that reflect our attempts to find depictions that brings us to the same emotional experience a person with dementia might feel when sometimes dealing with their symptoms and surroundings. For instance, in one of the zines we let the protagonist's surroundings fade away, making it seem like they lived in an empty box, only for the details to flood back into the picture after they feel a sense of belonging. The depictions we used could be described as surreal in some instances, and in no way attempted to directly depict an experiential reality, though they always stemmed directly from the emotions involved in the story.

Those living with dementia who contributed to the development of the zines told us they felt an immense pride and satisfaction in the work, feeling that their views mattered and that they were working to achieve something, which after a diagnosis of dementia does not always feel possible. The opportunity to be a part of the group allowed them to be valued and have their opinions recognised and to produce a physical output that they could share with their families as evidence of their work and achievements.

The wider research context

The zines form part of the activity at the Greater Manchester fieldsite of work-package 4 of the ESRC/NIHR Neighbourhoods and Dementia Study. Entitled *Neighbourhoods: Our People, Our Places*, the work-package explored how neighbourhoods facilitate, enable or disable support for people living with dementia and their families. Ethical approval was granted for the research across all three settings via the applicable ethical governance systems in each locality, including the NHS Health and Social Care panel (REC reference: 15/IEC08/0007). Informed consent was obtained from all participants to participate. All those who took part in the zine-creation group had capacity to consent. We followed a method of process consent, including ongoing consent monitoring and assessment of group members' choices to continue (Dewing, 2007; Hughes and Castro Romero,

2015). We built breaks into group meetings and individuals were also able to take a step back at any point in each meeting. At times individuals experienced challenges with dementia symptoms including memory, cognitive function, and physical mobility which at times restricted engagement. Not all members could attend every meetings, and one member increasingly relied on an attending spouse (and care partner) to support their involvement. Another participant who engaged in both phases of the research and was active during earlier phases of designing the zines decided to disengage from the work when travel and going out became more challenging. With her permission, we kept in touch to update her on the progress of this and other outputs from the project. While we used pseudonyms in the reporting of findings, we gave group members the option to include their names as authors of the zines since these did not contain directly attributable information. As the group comprised people living with dementia and care partners we did not differentiate (and thereby identify), which members had a diagnosis. We explained the implications of being named as authors, and these were understood by the group with some members electing to remain anonymous.

A number of outputs emerged from the work, including several chapters in Ward et al. (2021). Selected additional outputs include the following:

- Campbell S, Clark A, Keady J, et al. (2023) 'I can see what's going on without being nosy . . .': What matters to people living with dementia about home as revealed through visual home tours. *International Journal of Geriatric Psychiatry* 38(9): e5999.
- Campbell S, Clark A, Keady J et al. (2019) Participatory social network map making with family carers of people living with dementia. *Methodological Innovations* 12(1). DOI: 10.1177/2059799119844445.
- Clark A, Ward R, Campbell S et al. (2023) Experiences and contributions of people living with dementia to the social life of everyday places. In Keady J (ed.) *Reconsidering Neighbourhoods and Living with Dementia: Spaces, places and people*. Maidenhead: Open University Press, pp. 28–49.
- Clark A, Campbell S, Keady J et al. (2020) Neighbourhoods as relational places for people living with dementia. *Social Science and Medicine*, 252: 112927.
- Odzakovic E, Kullberg A, Hellström I, et al. (2019) 'It's our pleasure, we count cars here': An exploration of the 'neighbourhood-based connections' for people living alone with dementia. *Ageing and Society*, 41(3): 645–670.
- Ward R, Rummery K, Odzakovic E, et al. (2021) Beyond the shrinking world: dementia, localisation and neighbourhood. *Ageing and Society* 42(12): 2892–2913.
- Ward R, Clark A, Campbell S, et al. (2018) The lived neighbourhood: Understanding how people with dementia engage with their local environment. *International Psychogeriatrics* 30(6): 867–880.
- Illustrator: Dominique Brouwers (<https://dominiquebrouwers.co.uk>)

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Supplemental material

Supplemental material for this article is available online.

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- Clark A, Ward R, Campbell S, et al. (2023) Experiences and contributions of people living with dementia to the social life of everyday places. In: Keady J (ed.) *Reconsidering Neighbourhoods and Living with Dementia: Spaces, Places and People*. Maidenhead: Open University Press, pp. 28–49.
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Author biographies

Andrew Clark has been Professor in the Institute for Lifecourse Development at the University of Greenwich since autumn 2023, where he also leads the Centre for Inequalities. He previously worked at the University of Salford. Much of his work involves understanding how neighbourhoods and communities of place can support people as they get older, especially those impacted by dementia.

Dr Sarah Campbell is a Senior Lecturer in the Department of Social Care and Social Work at Manchester Metropolitan University. Her research interests include ageing, dementia, gender, social inequalities, relationships to place and approaches to care. Her qualitative research incorporates ethnography, participatory research approaches and creative methods.

Domenique Brouwers is a Belgian illustrator living and working in the north of England. They often find themselves working for sociological and other academic research, using comics and illustration to translate data and meaning for a wider audience. They are interested in exploring the human experience at the intersection of age, sexual and gender identities.

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