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MAKING GRAPHIC MAGAZINES WITH PEOPLE LIVING WITH DEMENTIA

The case for participatory dissemination

Sarah Campbell and Andrew Clark

Introduction

The social sciences have witnessed a burgeoning interest in creative and arts-based approaches to knowledge creation, data collection, and dissemination. As Boydell et al., 2012, para.1 remarks, "arts-based knowledge creation and dissemination strategies is driving an important shift in our understanding of what counts as evidence, as well as an appreciation for the complexity and multidimensionality involved in creating new knowledge". Such developments have coincided with efforts to engage more participatory approaches to research and to considerations around legacy and impact (Facer and Pahl, 2017). These include the involvement of participants and stakeholders advising on research processes, contributing to design and development, and engaging in data collection. Arguably, the result is not just a more emancipatory and transparent approach to the undertaking of research, but also the formulation of alternative, perhaps more authentic, types of knowledge about the social world. While participation in research formulation, design, and data collection has become widespread, we contend that participatory approaches to dissemination and knowledge translation are less well developed, or at least less frequently reported or appraised (Boydell et al., 2012). In response, this chapter contributes to how arts-based methods can enable a more participatory approach to this stage of the research process and a consideration of impact and legacy.

We report on the collaborative development of graphic 'magazines', herein described as 'zines', as part of a participatory and creative approach to disseminate findings from a longitudinal, international research project investigating what neighbourhoods mean for people living with dementia. The wider research revealed insight into how neighbourhoods might enable or restrict opportunities for informal and semi-formal support, as well as their potential to facilitate people living with dementia to live independently in the community. Primary findings emphasise the benefits of remaining connected, acts of kindness, reciprocity, and maintaining routines and habits among familiar people and places (Clark et al., 2020). Throughout the process, we aspired to a collaborative approach to the research, working alongside people living with dementia and their care partners. People living with

dementia were involved at various stages of the research, including input into recruitment, development of methods, production of participant information, and contributing to the emergent analysis. Alongside more conventional academic activities such as conferences and written outputs, 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. These included events aimed at the general public to widen the sphere and scope of influence and impact of the research using a creative blend of audio and visual approaches. For instance, we staged exhibitions that engaged visitors in challenging and dispelling some popular myths and stereotypes about living with dementia. Many participants and wider collaborators in the research, especially those living with dementia, wanted a mechanism through which they could tell their stories in ways that were less reliant on textual or oral traditions. Hence, we worked with a group of people living with dementia or caring for a person living with dementia alongside an artist, to produce a series of zines to promote the research findings.

This chapter outlines the process of developing the zines and our reflections on working as part of a team of academics, artists, and people living with dementia and their care partners. We consider zines as a useful format for disseminating and translating knowledge from research and outline methodological and practical implications of engaging in such a practice. We detail the process to develop and produce the zines as well as the opportunities and challenges of using zines in research, drawing on our experiences as researchers, artists, and participants. We end with reflections on how more participatory approaches to dissemination might contribute to a more transparent, potentially impactful, research practice. By way of conclusion, we do not claim that zines are necessarily truer or more representative, or meaningful than other research outputs. Rather, we suggest that their collaborative production helped us to more closely understand the sorts of experiences that comprise our data and to present analytical ideas that resonate with those whose lives the research purports to understand.

The research context

The zines and the collaborative process we describe emerged from an ESRC/NIHR-funded research project investigating the neighbourhood experiences of people living with dementia. There are 944,000 people living with dementia in the UK, with numbers estimated to rise to over one million by 2030 (Luengo-Fernandez & Landeiro, n/d). Many of these individuals will live in their own homes, supported by family, friends, and health and social care services. Thus, there is a pressing need to understand how those affected by dementia experience their local neighbourhoods; and explore the ways in which local places might better support people living with dementia and their care partners. Particularly as there are associations between living with dementia and social isolation and those affected by dementia may experience a 'shrinking world' as they find it harder to remain socially connected to others to get out and about (Duggan et al., 2008). The research that forms the context for our discussion here was undertaken to understand first-hand, what neighbourhoods mean for people living with dementia. Data was collected and analysed about how neighbourhoods can support people living with dementia to remain socially and physically active. People living with dementia and a nominated care partner engaged in three methods of data collection (walking interviews, participatory social network mapping, and home

tours)[1] over a period of two years as a way of articulating and/or demonstrating the places where they lived and the people, organisations, and institutions that featured in their lives. We involved 56 participants from Greater Manchester in the research, 29 of whom were living with dementia and 27 were care partners. They came from a variety of backgrounds, were aged between 57 and 88, and lived with different types of dementia.

A more detailed discussion of the findings is available elsewhere (Clark et al., 2020; Odzakovic et al., 2020; Ward et al. 2018). For many participants, 'staying connected' represented the importance of interactions both in terms of ongoing communications, but also as a way of being seen by, and seeing others. Familiarity in local shops, cafes, and even on the street was considered important as a way of feeling a sense of belonging to, and welcome in, a wider community. Great value was highlighted through 'acts of kindness' carried out by neighbours unbidden but as routine acts that support people to continue to live independently. These ranged from putting out a neighbour's rubbish bins each week to providing support in times of emergency or distress. These acts were not unidirectional, and people living with dementia were carrying out acts of support in the neighbourhood too, such as 'keeping an eye out' for anything unusual, taking in parcels, and caring for grandchildren. Such reciprocity illustrates the valuable role that people living with dementia continue to play in their neighbourhoods, as active local citizens, looking out for others and engaging in the social life of everyday places. 'Routines and habit' are an essential part of everyday life in connecting people to their neighbourhoods by using the same routes to walk the dog, visiting the same café, or attending dementia peer support groups. Such activities are important to enabling recognition, which in turn facilitates staying connected, and more readily can prompt acts of support. Finally, for some participants, getting out and about had become more difficult and this increased the value of home, and of 'staying in'. In these cases, connections that link the home to a wider neighbourhood are particularly valued and include receiving visitors, telephone and Skype calls, chats over the garden fence with neighbours, and being able to sit by a window and see the comings and goings of the neighbourhood. It was these core messages that we were keen to promote to a wider public through a series of zines.

Our approach to zine-making

As a mode of predominantly visual representation and communication, zines offer similar sorts of benefits as other visual-arts-based techniques used in research. Colantonio et al. (2008) for instance suggest that knowledge conceptualised in this way is more accessible to diverse stakeholders. Arts-based research is thought to enhance general or public knowledge of relevant issues as well as foster a sense of community among the general public (Vaughn et al., 2008). By developing an explicitly visual approach to disseminating findings from research we are following an emergent tradition that makes use of comic-type media to inform others. Bartlett (2013: 216) for example has drawn on the widespread and playful position occupied by cartoons in popular culture, providing "light relief from the written word, they can illustrate and open up debate about serious and/or sensitive topics". She discusses the development of a series of cartoons to disseminate findings from a research project that explored how higher-functioning people living with dementia campaign for social change. Bartlett (2013) drew inspiration from work in health care research that used cartoons to enable participants to feel freer to discuss sensitive topics (Peterson et al., 2006), to make serious research more accessible (Lea, 2012), and offer a "visual

experience and open up other (non-linguistic) ways of knowing that cannot be achieved with the written word" (Bartlett, 2013: 219). In recent years, the use of graphic illustrations be it in the form of 'zines', 'comics' or even sketching has begun to capture social scientists' methodological imaginations (e.g. Heath and Chapman, 2018; Mickwitz, 2016; Priego, 2016; Wang, 2016).

Zines are typically produced using low technology and have limited (if any) commercial interest. They tend to be print-based and comprise a combination of text and illustrations, and as their initial popularity as 'fanzines' implies, focus on a specific topic, idea, or interest (Duncombe, 1997). In most cases, they will have limited distribution and are subject to small print runs. So, zines have long been considered an emancipatory and democratic form of DIY media making (Cameron, 2016), acting as a vehicle for voices rarely featured in mainstream media, produced by and often for, more marginalised lifestyle groups, that have little or no affiliation to a formal organisation and, almost certainly, no plans to generate profit for their producers (Weddel, 2018).

The idea to produce something akin to a zine came from a group of participants who had been working alongside us to engage in more participatory forms of dissemination. They were keen that the key findings and recommendations arising from the research were promoted to core stakeholders. Although the group saw the value of a collection of more conventional findings leaflets and briefing papers, they also wanted to produce something that was more readily digestible, could appeal to different generations, and was accessible to a wider public as well as people living with dementia. They wanted something they could imagine someone picking up in their local GP surgery. As outlined in the introduction, the academic team wanted to engage with participants as we took the work forward, where possible sharing the research journey, adopting a more equitable stance on the ownership and sharing of findings, and contributing to an open approach about who is able to retell research findings to others. In this way, we hoped to avoid some of the criticism that academics frequently claim ownership of research findings and the data that comprise them, to the neglect of the individuals whose experiences make up that data in the first place (Beresford, 2009). As a frequently overlooked collection of voices, we also wanted people living with dementia to engage in more prominent ways in the research, especially in those stages where participants have been less involved, such as dissemination and knowledge translation (Keady et al., 2017; Swarbrick, 2015). Finally, we wanted to present findings in ways that were less abstract or de-sensitised to the lived experiences they seek to explain, as well as remain consciously respectful and inclusive of the voices, and the owners of, the stories our analysis was based upon. Consequently, we aspired to remain as faithful as possible to the experiences of those people living with dementia who had contributed their time and experiences to us during data collection. The history of zine-making aligned well with how our substantive findings work to dispel some of the stigmatising discourses around dementia. These include an emphasis on recognising personhood and encouraging a sense of citizenship and active participation in society (Bartlett, 2014). Such work has also been seen in the mental health survivor movement through the work of 'Mad Pride' and organisations such as Southwark Mind, which created a monthly zine newsletter and published zine-type works finding alternative forms to share survivor stories (Dellar, 2014).

Producing the zines was a collaborative effort between two academics, a varying group of up to ten participants living with, or supporting someone with dementia, and an artist experienced in zine-making. The zine-making project took place between 2016 and 2019, after the fieldwork phase was completed, and ended at the end of the project in May 2019,

culminating also in the production of the third and final zine. During the zine-making project, membership fluctuated in response to ongoing changes in the members' personal lives. For instance, two participants withdrew due to health issues, and one couple contributed to only one of the zines and did not attend group meetings, preferring instead to meet individually with the academics. As such, the project was undertaken with a degree of flexibility, often required for participatory research (Liamputtong and Higginbottom, 2015).

Three group members with dementia lived alone, and three lived with their spouses. Four group members living with dementia were female, and two were male and there were two male spouses and one female spouse who took part in the zine-making. We did not ask participants to disclose their type of dementia, and we did not undertake any assessment of their dementia, nor did we consider what 'stage' participants were in their experience of dementia. We took care, though, to ensure all those who engaged in the process were able to fully consent to their involvement themselves and understood the purpose of the group.

The zines took shape through a series of meetings held on University premises where group members attended a series of regular two-hour meetings where progress was shared, feedback sought, and crucially, new ideas were discussed. Group members were recompensed for their time through high street vouchers. Certainly, improving methods of payment for co-researchers and the contributions of those with lived experience should be explored further to find more equitable ways of valuing contributions (McLaughlin, 2021); and we recognise that the project was fortunate to have funding available to provide this kind of support.

Outside of the meetings, the graphic artist spent time developing a narrative from the stories that he had been told, and a way to metaphorically and visually present the stories, while the researchers continued to undertake further data analysis. The graphic artist produced content while the researchers led the development of indicative text and engaged in ongoing analysis to identify further topics for possible inclusion in the zines. Meetings themselves were facilitated to create an enjoyable and inclusive atmosphere. We would start with lunch and a general catch-up. The group members brought different skills to the group and were all able to contribute opinions throughout the sessions. Sometimes less confident members of the group were supported by others, to provide space for them to share their own experiences in relation to the images and the narrative devised within the storyboard. As the zines developed, the group commented on storylines became more confident about offering ideas for key messages as the series unfolded, provided written content and details of specific illustrations and drawing frames, and offered their views on various formatting, stylistic, and presentational options. Those living with a diagnosis of dementia also reflected further on their own experiences. They had already shared some of these with the researchers during the formal data collection process, but they also offered new, additional insights prompted or elicited directly from engaging with the stories emerging in the zines.

The outcome:- zines as products

A series of three zines were produced in total between 2016 and 2019. Each zine is A4 in size and has a simple linear story told through comic frames. Group members requested an item that did not look like an information-giving piece, even though they were keen that was to be the primary purpose of the zine. The group felt A4 pages were easier for people living with dementia to hold and read, and enabled easier reproduction of the text in larger font size. The group also suggested the greyscale colour for the images was easier

to read and had more visual clarity than some of the alternative colour combinations that were considered. We were mindful of how dementia was represented in the zines, both in the illustrations and the stories that they told. The amateurish or comic-book-type nature of some zine styles could arguably give a childlike illusion which we were keen to avoid given some of the infantilising discourses around dementia that imply that those diagnosed regress to a childlike state of being. We believe we achieved a balance that means that while the products are comic-like in appearance, and evocative of participants' childhoods, they are not childish. Indeed, graphic novels have had a resurgence that has seen them move beyond superhero-type stories and have been found particularly useful and compelling for telling difficult stories (see: Alison Bechell's [2006] memoir 'Fun Home' or Joe Sacco's [2003] 'Palestine').

The first zine tells the story of 'Lily', a composite character who encapsulates the experiences of several participants through a series of vignettes (Figure 17.1). The zine presents key messages relating to three analytical themes outlined earlier; 'staying connected', 'routines', and 'reciprocity'. Through a series of short episodes over the course of a trip to the shops, the zine presents examples of experiences shared by several participants. Lily was diagnosed with vascular dementia five years ago. Now in her early 80s, a social person who enjoys 'looking out' for others. She strives to lead a busy social life and has become involved in different dementia support and campaigning groups. Several times a week she uses her local shops that are a short walk from her home. She is now recognised by, and recognises, shopkeepers and other local residents as she goes about her regular walks. On her trips to the shops, she often collects a newspaper for another older neighbour in her flats who is less able to get out. Lily's access to her neighbourhood is supported through the relationships she has built over the years with her neighbours, local shopkeepers, dog walkers, and other familiar strangers who she stops to chat with on her walks to the shops. Of course, living with dementia brings challenges, sometimes it can be difficult to be out and about when living with dementia. Some days, familiar places may look unfamiliar. It can be difficult to get on with everyday activities such as dealing with money or visiting a shop. These are also depicted in the zine, alongside a clear message arising from the research that positive connections and acts of kindness by others can make these challenges less difficult.

The first zine offers a simple but important message about the ways in which people living with dementia continue to play an active role in their neighbourhoods and are able to support others and offer kindness. It demonstrates how familiarity and connections with others can help someone feel orientated and a little safer. So too, can people living with dementia play a role in maintaining the social life of local places, undertaking small acts of kindness themselves for neighbours and friends. The zines make use of visual metaphors to represent aspects of life for those living with dementia. For instance, in our attempt to demonstrate how the environment can become disorientating, the images depict a disrupted landscape, such as when using an elevator (Figure 17.2).

We were keen that the zines not only raised awareness of some of the challenging aspects of the environment but also presented ways in which these could be lessened through ordinary encounters. In one instance Lily bumps into a dogwalker she knows, and they stop for a chat, and the second is in the newsagents where she is recognised as a regular shopper and greeted by the employee. We also sought to counter a sense that the individual becomes disorientated and 'lost' to the world with a view that the individual remains present and complete, and that it is the environment (be that social or physical) that needs to change, or at least better accommodate people living with dementia such that they might retain a sense
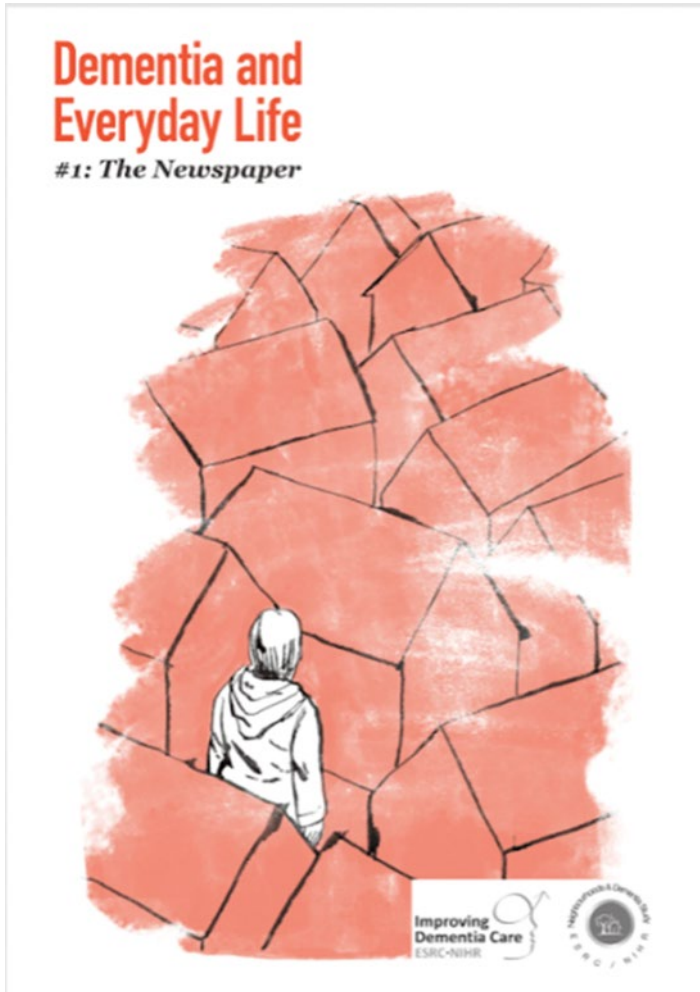
Figure 17.1   Dementia and everyday life, #1: The Newspaper.

of who they are as an individual who happens to be living with a diagnosis of dementia (Thomas and Milligan, 2018) (Figure 17.3).

It was important to find ways to create storylines where the central characters retain a sense of personhood but we did not want to focus on the experiences of one or two individuals who took part in the research. Instead, we created composite characters who portrayed many of the characteristics, or with similar experiences to a range of participants. In this way, we were able to maintain a direct link with the first-hand accounts that we did not want to lose sight of and to enable participants to recognise their own stories rather than struggle to identify themselves with the more generalised or abstracted outputs associated with some forms of research outputs. At the same time, this meant that no one individual became the 'protagonist' of the story, potentially alienating other participants or disrupting the rigour of the analysis process by focusing too much on a small number of cases or

Figure 17.2   Zine example of living with dementia (1).

an individual. It allows us to sidestep the somewhat thorny issue of whether the stories we present in the zines are 'true' in how far they might accord with a specific set of life experiences, or objectively depict 'real' or evidence-based events or experiences in the images.

The value of the zine-making process

At a time when alternative forms of dissemination from research are gaining attention, alongside growing expectations about achieving impact from research we believe the zines offer a useful way of accessing diverse audiences. We hope they stand out from the more typical resources arising from research, especially regarding dementia, where leaflets and research findings briefing papers are arguably prolific. At the same time, and as others who engage in creative and artistic modes of data collection and analysis have also argued, the process of producing the zine has been as impactful as the final products. This contributes to a notion of creating legacy from the research, both materially through the zine object and

Figure 17.3   Zine example of living with dementia (2).

for those involved in the process of production (Facer and Pahl, 2017). Indeed, one member of the zine-making group noted 'I felt really proud; especially seeing the comics. I feel like we are part of history – and my granddaughter can say my nana was part of that'.

Participatory work is understood to require time and resources to ensure that it is meaningful (Boyce et al., 2009). We were mindful to consider the practicalities of the work and ensuring enough time was a crucial part of the process. The process of zine-making was arguably slower than some other types of output. Each zine required four half-day meetings with the group. We had to take into consideration the availability of everyone involved, and while all the meetings ran to a predetermined agenda, catch-up time was essential to enable all members of the group to feel confident and secure within the group to be able to express views and work together.

The group did not always agree on the direction, shape, or form the zine should take. Though not wanting to downplay the significance for those with firm views on matters, for

the most part, concerns and changes were relatively minor, such as issues of colour choice. On some occasions, however, the group pointed to ways in which research findings might be reinterpreted by others. For instance, such as the way, a particular scene was illustrated and had the potential to be misinterpreted by readers of the zine. At other times disagreement might be over how the episodes were depicted, such as the potential confusion that arises from entering a lift, or when making purchases from a local store, which did not accord with their own experiences. Addressing such dissonance goes beyond a question or assessment of the amount of resonance or quality of the authenticity of the stories we thought might represent our research findings and speaks to issues of generalisability and representativeness in qualitative methodology, as well as ways in which cases from a data set can come to stand in for a wider collection of experiences through the identification or formation of an analytic theme. It was also important to reflect on how particular instances or experiences became central to the construction of 'overriding narratives' that are told from the research findings. We were able to discuss with the group how we came to develop such instances that, while not representing the entirety of the experiences of those who participated in the research, come to stand in as useful exemplars of themes that, in this example, show concern around becoming geographically disorientated or dealing with money, and explore how help might be offered or sought in cases of possible disorientation.

In resolving disagreement we were able to collectively sense-check the interpretations we offered from more formal data analysis, with an admittedly small group of participants. They, in turn, offered unprompted affirmations or alternative perspectives, which enabled us to reconsider our data analysis, or offer further recollections of their own experiences of living with dementia, or recast previous interpretations in a new light. In this way, the zine-making opened the analysis process to greater scrutiny as participants questioned where our ideas came from, and furthermore offered their own suggestions about how the analytical themes we had identified resonated with their own experiences. Ultimately, the researchers needed to ensure that the stories told reflected, as authentically as possible, the themes that emerged from the analysis of the full data set. Finally, there was a further layer of analysis undertaken by the artist who also reinterpreted the findings to create images and develop a series of metaphors that represented an idea or story with narrative coherence.

While differences in the direction of a storyline were resolved with recourse to what our analysis of the wider dataset was revealing, there were also differences of opinion about the aesthetic qualities of the zines. Given the subjective nature of such decisions, we tried wherever possible to reach a consensus within the group, usually on the basis of what might be best in terms of enabling legibility for someone living with dementia. In such instances, we were guided by the expertise of the artist who offered his work up for ongoing critique. At the end of each meeting, we summarised the issues that had been discussed and the decisions that had been agreed upon, with actions for the artist to undertake whatever revisions were proposed.

The zine-making progressed as a process of layering of analytical and experiential interpretations onto technical and aesthetic processes of artistic production. In doing, so, the work becomes the product of collective decisions and actions which, while not perhaps achieving the status of a work of a community of interest that other zine makers might aspire to (Bryant, 2014), was certainly the result of more than individual effort or the mere visual depiction of the fruits of academic labour. At the outset, we discussed with the artist how we hoped the work would develop in this way, and some of the resultant implications for formal (viz. legal) as well as more socially positioned understandings of ownership.

Like other forms of dissemination, we were conscious that the stories told through the zines did not depict individual experiences, but reflected composite experiences that, we hoped, would resonate with many participants, and others living with dementia. We have already described how we worked to ensure participants kept some sort of control over their own stories, but we also wanted the artist to maintain a sense of ownership of the process. As a result, the final zines are presented as joint authorship between the academic team, the artist, and the participants involved.

Zine-making and questions of empowerment and community voice

Our decision to produce a series of zines draws on a long history of zine-making as a potentially empowering process (Bryant, 2014; Duncombe, 1997). Feedback suggested that those who participated in the process felt their opinions were valued and acted upon, and a sense of engagement and shared ownership of the zine-making process was achieved. However, we are cautious to declare greater impact, at least in terms of how those we worked with might feel more empowered as part of the process. The final zines generated a sense of pride among the group and were well received outside of it. Nonetheless, it is not clear beyond the confines of the research and the zine-making process itself, whether participants feel better equipped to have their voices heard or to achieve positive outcomes in other walks of life.

Equally though, and as alluded to above, the academic team ultimately made final production decisions. In part, this was because we were privileged with an analytical understanding drawn from across the data which, for better or worse, might outweigh individual lived experiences that were brought to the group. Second, there is something of an imbalance in that the academic team and the artist were responsible for delivering the product, which meant that further decisions occasionally had to be made outside of the group meetings to advance the work. Although we repeatedly took the resultant work to the group for discussion, we would have liked to have been involved in all decisions. We were also fortunate to be well-resourced to bring the group together and recompense for their time. Given such resourcing came from a successful research grant, in the end, accountability and final responsibility, at least where funders were concerned, lay with the grant holders and those employed to deliver on the funding. Some may argue that, by drawing on the benefits of the institutional resources at hand, we appropriated methods used by subcultures and historically marginalised groups to further our own research successes (Radway, 2011).

Literature detailing the history of zines draws on conceptual debates about the nature of community, identity, and the coming together of people to share ideas and/or common interests as part of a 'community of practice' (Wenger, 1998). Indeed, the construction of an idea of community built around shared goals, beliefs, and practices, reproduces some of those ideals and beliefs in material form, and is at the heart of much work on how communities can be understood (Anderson, 2006). Bryant (2014: 81) surmises that zines enable community formation wherein zine makers form "their own communities or ha[ve] a community coalesce around them, either intentionally or incidentally as a result of making a zine". An alternative perspective considers zine-making itself to be constitutive of community such that "the zine is made as part of a process of community information, identification or analysis" (ibid). We cannot declare that the process produced a community among participants akin to the making of community (Boellstorff, 2004; Collins, 1999). The academic team brought the group together, and while the group were actively supportive of

our ambitions, and indeed proposed the ideas that drove the design process, the academic team maintained 'control' of the process. Nonetheless, through the production of the zine, we were able to bring individuals together with a shared commitment to understanding and articulating the experiences of those living with dementia as a collective, or at least as a grouping with potentially similar experiences of a shared condition (Eichhorn, 2001; Schilt, 2004; Zobl, 2004). While the group expressed the value in being amongst others who shared their experiences, the key for them was the purposeful nature of the production of the zines (Hagan and Campbell, 2021), and the final product as a material legacy (Facer and Pahl, 2017).

Conclusion

In this chapter, we have outlined a participatory method of dissemination and representation of findings using a visual medium. While engaging with stakeholders and ensuring impactful research is important, we wanted to do more. As qualitative researchers interested in understanding the lived experiences of people with dementia, we were also influenced by the need for more engaged, and engaging, ways of doing research. Additionally, we hoped to better enable that the outputs from the research remained authentic to the voices of those whose experiences we strive to understand. We were also aware of the need for greater reflexivity in how research findings are communicated, and of how in many research outputs those who contribute their experiences to research remain absent from the process of dissemination, save for their occasional appearance via an anonymised quotation (Alcoff, 1991).

The series of zines we produced represent a process as well as a product that enabled a more participatory involvement in research, albeit with constraints. The zines offer a sense of shared ownership and active engagement in the retelling of participant stories. Key here is less the aesthetic appeal of the zine, the more the social context and interactions that produced them. We contend that it is still rare for those who participate in research as the objects of and for data collection to engage in the wider spectrum of activities such as dissemination. In the case of those living with dementia, we suggest this is rarer still, despite many attempts and good intentions, to include participants in the production of research outputs or the co-production of the stories that are told from the work (Swarbrick, 2015). We hope our attempts to engage some participants in a more transparent process of dissemination hold true to the wider principles of participatory research we subscribe to. There is certainly much work to be done on this front, but this chapter presents a contribution to the ongoing debate about the politics of display and representation of other voices, even if this falls short of a truly equal approach to the owning and telling of stories about life with dementia. And in this respect, perhaps we are not too far removed from the efforts of other zine makers who strive to create meaning from the stories of those outside of the mainstream.

Acknowledgements

Note

1 Walking interviews were used as a mechanism to ask people living with dementia and sometimes their family carers to take us on a 'neighbourhood walk' and to show us around their local area. Participants tell us about their memories of living there, and we ask about their different connections to the place. We also asked what people did or did not like about where they lived. In addition, participants living with dementia took us on a 'video tour' or 'photography tour' around their home, telling us about how they spend time at home, and what is important to them about their home. Finally, we asked family carers and sometimes people living with dementia to tell us about the relationships they have in their everyday lives. We asked them to 'map' and describe these relationships and tell us about any support they give and receive.

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