

Can you remember? Leaving and returning to the field in longitudinal research with people living with dementia

Andrew Clark and Sarah Campbell

Introduction

This chapter draws on our experiences of leaving and returning to the field in an investigation of the neighbourhood experiences of people living with dementia. Between 2014 and 2019 we engaged in a five-year longitudinal study of the neighbourhood experiences of people living with dementia and their families, friends and care partners (Ward et al. 2018). We deployed a range of approaches and methods that are rooted in ethnographic practice, placing fieldwork and the sustained, repeated engagement with participants in particular places over a period time at the centre of our approach. The 'field' we were concerned with was not simply a geographically bounded location (such as the neighbourhoods where participants lived), but also temporal (incorporating change over time) and social (incorporating relational ties with other people regardless of their location). The 'field' thus emerged from ongoing relations between us and participants nurtured over time (Caretta and Cheptum 2017). It was also constructed through intellectual inquiry and engagement with research material during periods of data collection, analysis and dissemination (Amit 2000).

Through repeated interactions with participants, and their associated networks of friends, family members and acquaintances, in the places they visited or where they lived prompted a messy process of entering, 'leaving', and re-engaging with what we came to recognise as the field. The presence of dementia further also heightens some of the challenges for understanding what it means to leave and return to the field at regular intervals. Our intention in this chapter is not to provide a confessional tale or how-to guide for engaging and disengaging with the field in a dementia context. Rather, by focusing on fieldwork designed to better understand the lives of individuals living with dementia, we intend to question and recast what it means to leave and return to the field.

Dementia is associated with a range of symptoms including cognitive change such as memory loss, declining physical abilities, and communication difficulties. Over time it can become difficult for participants living with dementia to cognitively and physically access, recognise, or locate themselves in the fields we were researching in the ways that they may might have done earlier in the research. Some may might also be unable to remember previous interactions with the research team or the experiences they previously have narrated to us. So, it is tempting to reduce what is was happening here to a somewhat pithy perspective that it is was the participants, rather than the researchers, who are were 'leaving the field'. In practice this is was considerably more nuanced and requires careful reflection, and in this chapter we on reflect on what it means to leave, return, and remember the field as a cognitive as well as a physical and temporal location. We consider how researchers might plan for and respond to the possibility that participants will experience cognitive decline or memory loss over the course of research, the ethical implications that might arise from this, and the impact on what we might come to recognise as 'the field'.

Introducing the wider research context

Dementia is a progressive condition that has become a global health priority. The worldwide prevalence of dementia is set to increase from 54 million to around 130 million by 2050 (Alzheimer's Society 2021). It is estimated that 850,000 people in the UK live with a diagnosis of dementia

(Alzheimer's Society 2021^{ibid}), many of whom will continue to live in their own homes with the support assistance of family, friends and support services.

It was within this context that we sought to understand how people living with dementia, and their care partners, understood local places with which they associate. We were interested in how they made sense of the places where they lived and experienced the intersection of people, activities, history and biography when going about 'neighbourhood life'. The work was completed in three locations in England, Scotland and Sweden, with ethical approval obtained for the research across all three settings including the relevant National Health Service (NHS) Health and Social Care panel in England. This chapter is based on activities in England.

We encouraged participants to reveal their experiences through three methods;: walking interviews in which people living with dementia and occasionally a supporter took us on a 'neighbourhood walk' to show us around their local area; a filmed tour around their home; and a participatory social network mapping technique to explore relationships and social connections. In total, 127 participants people took part, completing 108 network maps, 100 walks and 59 home tours. All names reported here are pseudonyms.

Leaving the field in dementia studies

There has been considerable attention paid to designing research that can better engage with those living with dementia and enable them to document or record their own lived experiences (Novek and Wilkinson 2019), including adapting research methods to better 'fit' a dementia context and enabling those living with dementia to participate as fully as possible in research (Keady et al. 2018). Nonetheless, a recent review of dementia literature noted that 'relatively little has been written about how researchers and research practice must adapt in preparation for and during data collection, so that people living with dementia can be involved in research' (Webb et al. 2020: p2; our emphasis). So, while dementia studies may have started to pay attention to issues of research design and access to participants and entering the research field, the later stages of research, after data collection is completed, are largely absent from debate. That said, this is not to suggest that withdrawal from the field has been ignored in dementia studies. For instance, there has been discussion of risks around role confusion when boundaries between researcher and research-participant might become blurred, and of the importance of 'signposting' participants who display signs of distress (McKeown et al. 2010; Novak and Wilkinson 2019).

Yet, such accounts arguably focus on the practical implications of withdrawing from the field, offering limited reflection of how leaving, and returning to, might influence knowledge production. Indeed, recent guidance from the UK Health Research Authority (which protects and promotes the interests of patients and the public in health and social care research) advises that:

the definition of the end of the study should be documented in [research] protocol. In most cases, this will be the date of the last visit of the last participant or the completion of any follow-up monitoring and data collection described in the protocol. (HRA 2021).

This implies both a linear and a researcher- determined process of how and when withdrawal should happen, as well as a geographically and temporally fixed notion of where, when and what constitutes 'the field'. It also belies both the ease with which leaving the field can be achieved, and offers a somewhat deterministic construction, bounded by visits to or interactions with participants. For , because designing research around a series of exits and re-entries, particularly with participants

living with a fluctuating and complex cognitive and physical condition, can make locating end-points difficult. In the remainder of this chapter then, we explore what it means to leave and return through three broad issues: how we (re)engaged with participants at multiple re-entries to the field; supporting participants to return with us to the field; and the implications these might have for how the field is constructed in situations when participants might struggle to engage with, or easily recognise, the social worlds researchers are seeking to understand.

Remembering and being reminded of the field

Throughout the research we repeatedly returned to participants, sometimes in short succession such as after a few days, other times up to a year later, each time becoming reacquainted with the people and places we were researching. Each time, we were conscious that the lives we were returning to may be quite different to the ones we had been introduced to on earlier visits. This was compounded by an awareness that some participants living with dementia may not be able to easily remember taking part in the research or may have only vague recollections of doing so. Mindful that it might not be possible for some participants' memories to be 'jogged', we engaged in a process of 'active reminding' about their participation – a process that is common to other longitudinal research contexts. This included regular contact through postal and electronic mail communicating study updates so as to aid the continuation of engagement, though these could not be relied upon to always enable ongoing remembering. Where possible, we also worked with a friend or family member who could support this reminding, drawing on the trust between them and participants to secure ongoing involvement. This was not intended to manipulate the process of proxy consent to ensure ongoing involvement, but was about adopting a relational approach to participation in ways that we hoped were sensitive and appropriate.

Consequently, reminding was reliant on the relationship with each participant. We asked questions about their lives on topics they had previously shared, or might remind participants of the activity we had carried out together, such as the walk we had gone on, or met them at places we knew to be familiar. This active reminding helped to refamiliarise participants with us and our connection to them and, arguably supported the re-establishing of trust with participants, as well as with family members and friends, through demonstrable familiarity. Crucially, this required being attentive to risks of ascent or even coercion, as well as avoiding, as best we could, appearing to be over-familiar or even of 'faking friendship' (Dunscombe and Jessop 2002).

Supporting participants to 'return to the field' consensually, especially in the absence of easy recollection, placed significant emphasis on the relationships we developed with participants, the knowledge we held about them, and what we in turn did to maintain those relationships. This included deciding if, when, and why it was appropriate to return to participants, and careful justification and articulation of our reasons for wanting to do so. It also placed importance on the processes and procedures we established to ensure these relationships remained fair and accommodating of changes in individual and well as relational dynamics.

Attempts to keep in touch through research updates, active reminding, and requests to revisit participants may all be part of the toolbox of re-engagement but they are not neutral. For instance, when embarking on a return walk with Roger we reminded him of a previous interaction with us, repeating one of the stories he had shared:

SC: We've been on one walk, haven't we? We walked down to the bowling club.

Roger: Have we?

SC: Yes. Yes, we did.

Roger: Right.

SC: And walked around so we'll do the same kind of walk again and just have a talk about ... if anything's different since the last walk we went on.

Roger: Yes. Yes.

Beyond a dementia contact, this might appear a banal and inconsequential effort of reminding, but in Roger's case we cannot be certain that he does remember our previous visits. Nor can we really know how he felt about our return and our efforts to initiate re-engagement with the research. However, this does not mean that Roger does not understand the purpose of this new exchange. Soon into the walk Roger asked again who the researcher worked for and where she lived as he attempted to place her and the context for us our being with him. Roger was also confident in directing the walk and sharing stories about his local area, despite not necessarily remembering these previous encounters and requiring regular reminders about the purpose of our time together. There is an imbalance here, present perhaps in all longitudinal research (Miller 2015), but brought to the fore in the context of cognitive impairment, about when and how much to what extent existing information we should re-share existing information with participants to support them to remember past encounters. In thinking through what sorts of information to re-share with participants, we are not seeking to deny people living with dementia the right to own and be reminded of their pasts, but, rather, drawing attention to the ways and the contexts within which this might, or might not, be done. The re-introduction of 'snippets' of the participant's life through active reminding also reflected attempts on our part to redress some of the power imbalance between us and participants, presenting back to them in anticipation that they might regain ownership of those stories. On our returning to conduct a home tour, Anna did not appear to remember our previous interactions, which had included visiting her at a dementia support group, going on a walk and a car journey, and a trip to her local public house. We drew on these moments to invite Anna back to the field, arguably regardless of whether she wanted, or indeed was able, to offer any further comment on these previous interactions. In such ways, returning to the field was as much about facilitating participants' re-entries into their realm of experience, as it was about us our wanting to return to a point in participants' lives where we had previously left off.

Returning to different fields

For some participants, their dementia had changed to a point at which they struggled to participate in ways that we might have hoped. In such circumstances, the fields we were returning to were notably different socially, physically and cognitively, to those initially constructed. This is not to conflate the field with each participant, nor to make a point about difficulties in recognising how the field might have changed. Rather, it is to remark on how our intention to co-construct the field of experience for participants proved an ontologically, as much as an analytically, daunting task because participants were no longer able to recognise the previous lives and experiences or how they might have changed.

For instance, Dennis had previously walked with us for over an hour and talked in depth about his experiences of living with dementia. In between research encounters, Dennis experienced a health setback which meant he could no longer manage taking part in the dementia activism which had been a central part of his life. Although he was able to take us on a walk, this was much shorter, terminating at the end of his street:

Dennis: As I say, it's like ... you know, when I went out with the dog ... we'd go miles. But all that's gone. There's no point getting uppity about it because the reality is that's what it's got to be, you know. I would say as well, I'm walking down here and I'm just thinking ... [I've been] going up and down here for years. But now this all seems different to me.

SC: Does it? It doesn't feel recognisable?

Dennis: It's not the same, no. I still can see some of it ... but there always seems to be something different now than what it used to be. Especially if I wanted to go into [town] or anything like that, I wouldn't have a ... any chance at all.

For Dennis, the field has shifted in geographical and social scope and scale. There has been a reduction in the places he might be able to go to, or the contacts and relationships he can maintain. Although we were aware of these changes, we held back from pursuing them because of the potential to cause distress to Dennis that we had limited ability to redress, and which could potentially cause more harm to him, than benefit for 'our' research.

Returning to other participants, we found some to be less mobile or not as sociable as they had been, though this was not necessarily always due to dementia. Celia, for example, had developed an illness that limited her physical abilities, which, combined with dementia made it difficult for her to walk and talk. She was no longer keen to participate in the research, and although her husband, Malcolm, continued to participate, the experiences and stories were no longer co-constructed, as they once had been, between the couple and the researcher. At one point, Malcolm shared his experiences of dealing with the changing situation:

Malcolm: "Lots of things can change, you know. I mean, ... I was getting no sleep at all and you lose all your focus. So eventually, you know, I put the bed down[stairs] ... just so I can get [some sleep]. It was when [Celia] was up all the time".

With some faltering, Malcolm described a period where Celia's health was precarious and had deteriorated significantly, and the impact this was having on him. The construction of the field here has shifted our view from one developed through our relationship with Celia, to that with Malcolm's, and created a very different viewpoint from which we tried to understand something of Celia's experiences.

Changes in the symptoms of dementia mean that participants may no longer access the worlds that they used to, finding that their lives had become more restricting. This was emotionally challenging for participants to reflect upon, as well as for us to navigate. We wanted to ensure that we were 'doing the right thing' by maintaining, reducing, or even ending participants' involvement. We were coming to understand about changes that, at times, some participants may struggle to identify, while being privy to private problems that in other circumstances may not have been revealed to a relative stranger outside the research context. This sense of invasion was particularly acute when participants had moved from the family home into care settings and when family members sometimes accounted for decisions in ways that inferred a desire to justify them. Some shared their sense of reaching 'breaking point' to explain why they were no longer able to

support a loved one at home. Frank, for instance, described a decision about the care- needs of partner Florrie:

‘[The social worker] decided that I couldn’t carry on the way I was. And he just said, ‘it’s just common sense, you’re running yourself into the ground, and you can’t keep going the way you are’. So he said, ‘we’re gonna have to do something about it’ ... she was going to need permanent care. So, the social worker, and the mental health visitor, between them, they decided that Florrie was going to need full time care’.

Frank explained the changed circumstances that we found him and Florrie in, that which were very different to those we had previously encountered. Indeed, our return visits to Celia, Malcolm, Frank, and Florrie laid bare the emotionality of encounters and provoked consideration of whether participants might, or even could, continue to be involved in research in the context of deteriorating health. Returning to the field thus required assessing the extent to which individuals could participate in what might ostensibly be repeated phases of data collection but which were also processes that (re)created the field in emotionally complex ways. We sometimes got a sense of change ahead of any discussion, such as by visiting participants in new homes, but this did not offer much insight into the lived experiences we were seeking, aside from rather superficial observations of changed, and changing, scenes. It could also be difficult to facilitate ongoing engagement using the methods we hoped to deploy, especially if participants were no longer able to take us on a walk outdoors or show us around their homes. For them, while we had hoped that our absence from the field might have been temporary, and despite their apparent eagerness for us to return, their situations were so significantly changed as to make previous fields out of our reach.

Extending the field

Our final set of reflections involve the ending of relationships with participants and our engagement with the field. At times this was stark, such as when participants became unwell, or, for a small number, had died. Despite seemingly clear termination points, such participants do not simply vanish (Thorneycroft Thorneycroft 2020). Relationships continued through our custodianship of, and analytical engagement with, their stories, and some participants returned to centre stage through the dissemination activities. Following our interactions for the purposes of data collection, a smaller number of participants joined us in dissemination activities, advising on activities, contributing to outputs, and commenting on themes emerging from analysis. Their involvement in these stages extended the field in a somewhat different configuration. A group worked with us to develop several visual guides summarising the research, and we continued to have discussions about emerging findings, sharing of our analytical ideas, and collectively reconstructing the fields we had all engaged in. We continued to encounter issues with memory, cognitive function, and physical mobility which at times restricted engagement. Some participants stepped away from these activities because of changes to their symptoms. One participant had engaged in both phases of the research and was very active during early dissemination activities but decided to disengage from the work when travel and going out became more challenging. Her presence continued through the stories she had shared, such that her involvement was kept lively through an ongoing association with the research endeavour, such that and she never fully left, at least not in our fieldwork imaginations. We are not suggesting that our experiences of engaging participants in dissemination here are novel, nor trying to reveal something new about where the field might be located. Rather, they force us to ask what it means, for participants and researchers, to leave the field indefinitely. For if the field is an intellectual

endeavour, then, perhaps, we can never really identify the precise point at which we leave, any more than we can really locate the field that we are entering, returning to, and leaving.

Discussion

Researchers can access plenty of advice about how to negotiate entry to and exit from the field and navigate relationships with others during research (e.g., Fox, 2008; Gallaher 2011; LeCompte 2008). Oftentimes, accounts of leaving the field can seem somewhat unproblematic, or at least 'manageable', reduced to a case of getting in, getting data, and getting out (Feldman et al. 2003). Yet the seemingly innocuous phrase of 'leaving the field' is a messy endeavour invoking much emotional toil (McGarrol 2017; Thorneycroft 2020). To leave the field erroneously implies, erroneously, a linear process at the end of which researchers and participants go back to their respective lives and carry on 'as normal', with the research act a temporary blip. Researchers and participants alike cannot simply put aside the emotions and histories that developed through previous interactions and then expect to 'pick up where they left off' at re-encounters.

The exits and re-entries we have described here are imperfect, not least because the field is as much a moveable idea as it is a location in time and space. So too is returning is a relational act that it is not always obvious how to accomplish. In the context of dementia research, participants may have difficulties in recollecting previous interactions, even with support or prompting that meant our own exiting and returning was dependent on the layering of the relationships through each interaction. We acted and responded differently with different participants but remained imperfectly attuned to the situations to which we returned, not only because of the changes we may witness or be told about, but also because of the ongoing influence of these previous encounters, and the status and form of the relationships with each participant that we had left off and perhaps naively hoped to simply pick back up. We worked hard to 'tread carefully' (Miller 2015), but still stumbled through the relationships and situations as we all, participants and researchers alike, tried to reacclimatise.

Leaving and returning to the field has inevitable implications for how data is collated, ordered and analysed to ensure its authentic recreation at the end of the research process. Used uncritically, they also suggest that researchers and participants can recognise when we are in the field, when we enter and leave it, and that researchers are adept at navigating the complexity of socio-spatial relations that constitute the field, in the quest for knowledge. The field though, is less a geographical and temporal location and more 'a set of relations nurtured, contested and developed during the course of several months' (Caretta and Chetum 2017: 415). It emerges through the nexus of power in a collaborative, but not wholly equal, process of co-constructing (Gupta and Fergusson 1997). This is particularly apparent when it is researchers who drive the desire to re-engage with the field and, as in our case, might find themselves better equipped to drive its reconstruction.

Exiting and returning demands ethical attentiveness, most obviously perhaps around consent, but also to the avoidance of emotional discomfort or a candidness that might be too revealing (Duncombe and Jessop 2012). In the case of dementia, Hyden (2013) has argued for a shift in focus, in narratives, from their textual aspects as products to be created and analysed, to relational and embodied processes. Our return to the field creates a scaffold to encourage people living with dementia to tell new stories, reflect on past stories in new contexts, and recast once-told tales in a different light. We re-engaged with this scaffolding, rather than with the specifics or 'realities' of what may have changed or may not have changed in the intervening period between our visits, in

order to remake relationships with participants, creating new moments of familiarity and connection, and ultimately recasting what, where, and how we came to construct the field.

Conclusion

We are certainly not the first to worry about the issues we have discussed here. Others have agonised over how to avoid being (mis)interpreted as having exploited unequal relationships in a hunger to extract as much data possible from individuals considered by some to be vulnerable (Miller 2015). Nor are we alone in expressing caution in our engagement with those with whom we hope to establish longer- term research relationships. We find some reassurance in Oakley's (2016;: 208) view of research materials as having been (cautiously) 'gifted' to us rather than 'somehow forced' into being disclosure through faked friendships. Nonetheless, dementia adds another facet to how we might go about returning to the field and, to what we might do with the stories bestowed on us while we are there. The negotiation of roles, interactions and relationships with participants, as well as emotions, ethics and expectations, are all important in the context of leaving and returning. Perhaps, our experiences working in a dementia context bring these to the fore in ways that emphasise the complexity of what it means to depart from, return, to and, ultimately, terminate, the field. Consequently, we finish with consideration of three implications that emerge from our discussion.

First, it is worth restating that researchers should continue to recognise the field as more than a geographical and temporal location to be moved into and out of. It is constructed in moments of interaction with participants, through reflection on those interactions, and during dissemination activities (Burrell 2009; Gupta and Ferguson 1997). Researchers are certainly familiar with reflecting on their own role in constructing the field, but perhaps should give a little more consideration to how they move on from the field in ways that remain sensitive to the experiences and intentions of research participants. This is not so much in terms of more careful articulation and negotiation of relationships, but, rather, in recognising the different ways that participants may also leave the field and return to the field.

Second, leaving and returning to the field raises inevitable ethical implications. These includes consideration of consent in cases when ongoing involvement may be assumed, or when participants are less able to consent to further engagement. Thought should be given to possible social and emotional attachment to the field for both participants and researchers (Duncombe and Jessop 2012). Returning to the field is an emotional process for both participants and researchers. Participants reveal experiences and views that they may subsequently not remember, in doing so creating dilemmas about what researchers should in turn re-share. Reminding, or not reminding, people of things they might have forgotten is a messy but unavoidable business. Each research engagement may start afresh, with the notable difference that we as researchers may well know more about participants than they are able to remember or than what they can make understood.

Finally, researchers should remain aware of the importance of renegotiating relationships and the ways in which the field itself is constructed through them. The field is no longer uncritically accepted as bounded spaces (Burrell 2009; Marcus 1998). As researchers engage and disengage with the field they are validating and narrating an experiential and cognitive rather than a physical movement (Amit 2000). Here, Rapport's (2000) focus on narrative awareness to clarify where and when to locate the field takes on a particular complexity in the context of dementia, though the wider point remains about how, and by whom, the field gets constructed. For leaving and re-entering the field is

a relational act, dependent on interactional and cognitive as well as a physical and embodied conditions that are performed in moments of unequal understanding. Doing this alongside participants living with dementia might bring this into sharper focus, but it is arguably always part of how 'the field' gets understood and articulated.

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