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Case Title

Whose Research Is This? - Participatory Secondary Data Analysis with People Living with Dementia

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Dr Julie Watson is a Senior Research Fellow at the University of Edinburgh, ECRED. She is currently working on a project, funded by the Alzheimer's Society, developing post-diagnostic support for people affected by dementia. She worked for 10 years in a hospice and has conducted research into palliative care and relationship-centred care in care homes. She is particularly interested in understanding the experiences of people with advanced dementia living in care homes, and how to support carers who work in care homes. She is also a part-time lecturer in Nursing

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Dr Jane Wilcockson is a Senior Research Follow at Edinburgh University, ECRED. Jane is currently working on an Alzheimer's Society funded project, developing post diagnostic support for people affected by dementia. Jane has enjoyed an eclectic research portfolio, ranging from Evaluation of Palliative services, Doctors and Mentoring, Dementia, Risk, Well Being of Older People, Inclusion, and Violent and Challenging Behaviour in Children with Special Education Needs. Jane has a particular interest in how the qualitative software NVivo, can support qualitative researchers working across a range of disciplines and different methodologies.

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Toby Williamson is an independent consultant working in the fields of adult and older people's mental health, dementia, mental capacity. He also works part time as a lecturer and researcher for the Dementia Care Centre at the University of West London. For 14 years Toby worked for the Mental Health Foundation, a UK social research, development, and public affairs charity, where he led its policy work, and its programme of work on mental health in later life, dementia and mental capacity. He has also worked in central government to assist with the implementation of the Mental Capacity Act. Before joining the Foundation, he worked in, managed and delivered training in a variety of community services for people with severe and enduring mental health problems. He has been responsible for research and development projects and authored reports on empowerment and participation of people who use services, disability rights and dementia, dementia friendly communities, personalisation, and truth telling in dementia. He is the co-author of *The Dementia Manifesto: Putting Values-Based Practice to Work* (Cambridge University Press, 2019).

Dr. Heather Wilkinson

Heather Wilkinson is Professor of Dementia Practice and Partnership, and Co-Director of ECRED, University of Edinburgh, and leads a programme of work on the experiences of living with dementia.

Published Articles

Clarke C.L., Wilkinson H., Watson J., Wilcockson J., Kinneard L. & Williamson T. (2018) A seat around the table: participatory data analysis with people living with dementia. *Qualitative Health Research* DOI: 10.1177/1049732318774768

Clarke C.L., Wilcockson J., Watson J., Wilkinson H., Keyes S., Kinneard L. & Williamson T. (2018) Relational Care and Co-Operative Endeavour Reshaping - Dementia Care Through Participatory Secondary Data Analysis. *Dementia: the international journal of social research and practice* DOI: 10.1177/1471301218795353

Abstract

Drawing on our approach and findings from a secondary interrogation of an existing qualitative dataset, this work set out to challenge assumptions of practice through using participatory methods. Our approach brought two key aspects together: applying the theories of Douglas' Cultural Risk Theory and Toronto's Ethic of Care; and a collaboration with people living with dementia as co-analysts in the coproduction (interpretation) of knowledge and representing the experiences within the qualitative dataset. The research generated an understanding of relational care and the subtle ways in which relationships change for someone with dementia.

In this paper we describe the processes we followed and reflect on the demands and challenges, experienced as researchers, in focusing on reflexivity, multiple voicing, literary styling and performance. In our description of how we had to relinquish any sense of a concluding authoritative voice we highlight the innovation in this participatory secondary data analysis and encourage others to engage with this dialogue.

Learning Outcomes

By the end of this case, students should be able to:

1. Critically reflect on the possession of authority and voice in dementia research, and that of other perspectives that are marginalised in society.
2. Consider ways of democratising research voice through participatory and arts-based research methods.
3. Demonstrate knowledge of how to design research which enables the voice of people affected by dementia (and other marginalised groups) to be heard at various stages of the research process.

4. Critically reflect on the barriers to participatory research within the current academic structures which determine the research process.

5. Critically reflect on the dynamics of power in the research process.

Case Study

Background

This study sought to collaborate with people living with dementia in analysis of a large qualitative data set, using the theoretical lenses of Douglas' Cultural Theory of Risk and Tronto's Ethic of Care.

Democratising and participatory research

The democratisation of the research process (Salmon 2007) unsettles the authority of the researcher and the authority of research. One approach to doing this is through participatory research, seeking to re-present 'silent and silenced voices' [a term as authors we use to describe the silence that comes as a result of, for example, sensory and cognitive loss as well as, crucially, the structural silencing by a society that is unhearing of some voices as a result of stigma and societal exclusion] to a range of public, policy and practitioner audiences. Abma et al (2009) claim that participatory research locates people as research partners rather than being the object of research. Bergold and Thomas (2012) describe participatory research as 'a very demanding process that evolves when two spheres of action—science and practice—meet, interact, and develop an understanding for each other' – it is an orientation to research rather than a specific set of research processes (Reason and Bradbury 2008).

Participatory methodologies challenge us to:

- question whether the validity (or confirmability) of research is a property of the teller or the receiver,

- suspend any search for a singular knowledge which is owned by ourselves,

- focus attention on:

    o reflexivity – the juxtaposition of self and subject matter;

    o multiple voicing – the rejection of the integration of multiple voices into a single conclusion;

    o literary styling – the replacement of traditional realist discourse in which language is the medium of communication (Sims-Schouten et al 2007);

    o performance – expanding communities in dialogue and avoiding claims of a dominant knowledge.

The involvement of people living with dementia in research

Wilkinson (2002) and McKillop and Wilkinson (2004) argue that the discrediting of people with dementia because of their cognitive impairment led to the exclusion of their perspective from research – a position that is now changing to include people with dementia not only as research subjects but as co-researchers (Frankham 2009; Tanner 2012; Gove et al 2017). This may involve working with academics as equal partners – identifying questions that need to be asked, collecting data, analysing data, writing reports and knowledge exchange (Swarbrick et al 2016) and producing advice about the involvement of people with dementia in research (Dementia Engagement and Empowerment Project, DEEP, 2013; Scottish Dementia Working Group Research Sub-group 2014). Gillard et al (2012) describe co-research as a marriage of expertise by experience and expertise by profession, and suggest that the presence of different voices in their research team which included mental health service users:

'did not oblige us to choose between alternative perspectives as more or less valid than each other, or that we should understand them as separate, irreconcilable accounts. Rather, we found that those different voices provided our research team with an opportunity to begin bridging the apparent dichotomy of what was conventionally known and what was "radically" known. Our university researchers lost their exclusive status as arbiters of good

science. Instead, we asked ourselves how our respective contributions to the research

process were socially situated, and what that meant for the knowledge that was produced.

(Gillard et al 2012 p.1135)

None-the-less, reports of research that involve people living with dementia at the point of data analysis are extremely rare (one notable exception being Stevenson & Taylor 2017 – and our own research discussed here: Clarke et al 2018a&b). It was to explore ways of blending the 'radical' knowing with 'conventional' knowing to inform the development of empowering support for people living with dementia that we developed the Inciting Dialogue and Disruption study. To achieve this, our objectives were to:

1. Interrogate through secondary data analysis a large qualitative data-set of interviews with people living with dementia using two theoretical frameworks to inform the analytical process: Douglas' cultural Theory of Risk, and Tronto's Ethic of Care.

2. Collaborate with people living with dementia as co-analysts in the co-production (interpretation) of knowledge and re-presenting of experiences within the data set.

Summary

- Participatory research locates people as partners in research processes. It is one way through which research processes can be democratised and through which silent and silenced voices can be heard.

- Increasingly, people living with dementia are being involved in participatory research. However, involvement in data analysis is rare.

The Inciting Dialogue and Disruption Study

We interrogated an existing qualitative dataset, using an approach that set out to challenge assumptions of current practice and to disrupt present understandings of practice. A previous study

known as 'Healthbridge' (Clarke et al 2013; Keyes et al. 2014; Clarke et al. 2014; Clarke et al 2016) had included 155 interviews with 51 people with a diagnosis of dementia and 55 family care partners who were interviewed on up to three occasions. The volume and depth of data made the dataset particularly suitable for secondary data analysis (Corti & Bishop 2005). There were two key aspects to the work – application of theory in analysing the existing dataset, and participation with people living with dementia. Each incites dialogue and disruption and they intertwine with each other, enabling people living with dementia to be part of the process of analysing the data (see Figure 1).

[Insert Figure 1 here]

The secondary data analysis was conducted in participation with 34 co-analysts who had experience of living with dementia (either with a diagnosis of dementia or a family care partner). Everyone lived in their own home or had moved to live with a relative and all co-analysts had capacity to consent to participate. The co-analysts were recruited from four pre-existing groups, two in England and two in Scotland, and therefore, on the whole, people were known to each other.

Here we intertwine an account of the research design with exploration of some of the methodological and practical methods dilemmas of this research:

[Insert Box 1 here]

Key Aspect 1 Step 1 – Preparing and presenting the data ready for secondary data analysis
All the data analysed for the Healthbridge project was stored within the software NVivo 10 and arranged to maximize the potential of the first research project. NVivo is a large electronic database designed to store, manage and retrieve qualitative data in both simple and complex ways irrespective

of the size of the database. A coding framework was set up within NVivo 10 (desktop version) to capture key themes from both Douglas' Cultural Theory of Risk and Tronto's Ethic of Care.

[Insert Box 2 here]

Key Aspect 1 Step 2 – Interpreting the data through theoretical lenses

The secondary analysis used two theoretical frameworks to critique the experiences of people living with dementia, as represented by qualitative data from interviews with people with dementia and carers: Douglas' Cultural Risk Theory (also known as Cultural Theory or Group/Grid Theory) and Tronto's Ethic of Care. These theoretical perspectives created 'lenses' with which to interrogate the qualitative dataset by creating a set of research questions, and asking these of the data in a dialogical manner.

Douglas' Cultural Risk Theory – we applied the Cultural Risk Theory (seeking to understand how the social organisation of communities influence the ways in which members of that community perceive and respond to risk), using Douglas' classic group-grid analysis (Douglas & Wildavsky 1982). The 'grid' refers to regulation and the extent to which members of a community are expected to adopt the rules for personal conduct that the community espouse. The 'group' refers to cohesiveness and is the extent to which individuals within a given community are bounded together and see themselves as a coherent community.

Tronto's Ethic of Care – we used the Ethic of Care (Tronto 1993, Sevenhuijsen 2003) as a lens to understand and explore interpersonal interaction within the data-set, in particular focusing on interactions between people with dementia and those supporting them, including family carers and other significant people as well as within more formal service provision. It provided a framework for considering the complexities of interpersonal relationships within the context of caring relationships.

Tronto (1993) argues that all human beings have needs that others must help them meet; human beings are interdependent beings and Tronto suggests that *'..we need to rethink our conceptions of human nature to shift from the dilemma of autonomy or dependency to a more sophisticated sense of human interdependency'* (Tronto 1993 p.101). Tronto (1993) identified four intertwined ethical principles of care:

- *Attentiveness* – to recognise and be attentive to others, rather than simply focussing on ourselves. To be able to attend to others, our own needs must be adequately met.

- *Responsibility* – to take, or accept responsibility for action.

- *Competence* – caring work should be competently performed.

- *Responsiveness* – the position of care receivers and their responsiveness to the care given should be considered from their perspective. (Tronto 1993, Barnes & Brannelly 2008).

A fifth principle, *'trust'*, was added by Sevenhuijsen (2003) who argues that trust is always interwoven with power and responsibility in conditions of vulnerability.

[Insert Box 3 here]

Early in the analysis, the interconnections between the Ethic of Care principles became apparent e.g. a negative response to the care provided by a support agency could be due to a lack of attention being paid to the needs of specific groups, such as people with early onset dementia or people from minority ethnic communities. Also, with the 'active' role played by people with dementia in the care process, it quickly became apparent and that they were care-givers as well as care-receivers with reciprocity between family members e.g. when a person with dementia recognises that their family also has needs and tries not to put unreasonable expectations on them. As analysis progressed, we explored interconnections between the Ethic of Care and Cultural Risk Theory. For example, the ways in which a 'competent' dementia advisor, by paying attention to the needs of a whole family

affected by dementia and taking responsibility to address those needs, might enable a person with dementia to join and have a sense of belonging in a new group. The Ethic of Care helped to uncover some of the dynamics involved in moving groups, being excluded and becoming included after a diagnosis of dementia. We used the modelling tool in NVivo 10 to analyse how each theory worked within individual cases and also across a range of cases. Creating a model within NVivo generates a visual map of nodes and themes and enables the researcher to incorporate data into the model. Data visualisation can reveal which themes are more prominent and the supportive data automatically embedded within the model enables the researcher to question the underlying data. Models support the detailed refining of analyses and allow this to be illustrated.

Key Aspect 2 Preparation Stage

The project partners, the Mental Health Foundation and Alzheimer Scotland, invited groups of people living with dementia that they worked with to participate in a series of four workshops and, of those who expressed interest, selected two groups in each country (England and Scotland). A total of 34 people (with a diagnosis of dementia or as a care partner) took part in workshops. Most were established groups and, on the whole, people already knew each other within the group. The group sizes varied between two and 12. The workshops took place in the group's normal meeting place and people were supported by the local staff, who were familiar to them. Each workshop commenced with introductions and a discussion about the project's information sheet before signing consent forms. Each lasted for two hours including a refreshment break to ensure that the time was paced appropriately for people who may have tired easily.

Key Aspect 2 Participation Stage 1 - Working with people with dementia as co-analysts

The research questions at this stage included: how do people with experience of dementia understand and interpret the emerging findings from Key Aspect One from within their individual experiences? How does their 'self' act in a reflexive way with the subject matter? And how do we, as researchers, understand their role as 'receivers' in the confirmability of the analysis?

One challenge was to find a way of representing the large original dataset to people participating in the workshops in a way that would be accessible to them and to allow for genuine contributions to analysis – this had to go beyond validating our own ideas and also go beyond the individual perspectives of the workshop participants. Examples of data from the dataset were selected to act as 'triggers' for the discussion – these were frequently occurring experiences of people living with dementia, and were illustrative of both theories (see Table 2 for examples). The selected data extracts were prepared for the workshops by removing non-verbal transcript indicators (e.g. '…' to denote a pause in conversation) and extraneous verbalisations (e.g. 'hmm' and 'err'). Each data extract was printed in Ariel Size 22 font and in black writing on coloured paper to increase visual distinctiveness. Data extracts were discussed at each of the first two workshops with each of the four groups.

[Insert Table 2 here]

In the first two workshops the two theoretical lenses informed the selection of data extracts and, on the whole, workshop participants related to these from the position of their own experiences, frequently expressing a shared or dissimilar personal experience to that in the data extract. In order to enable the workshop participants to engage with the data in a more conceptual way, in the third workshop the two theoretical lenses were discussed. Conceptual thinking can be challenging for people with dementia – indeed, loss of cognitive ability is characteristic of the diagnosis of dementia (Sheehan 2012) – and we approached this by preparing picture and word cards of the five Ethic of Care principles and used a storyboard approach to two data-generated vignettes of people's experiences of changing groups (see Figure 2 for an example). Creative approaches using words and pictures have been identified as a key ingredient within user involvement in research (Read & Maslin-Prothero 2010). The groups discussed in what ways the two theories were helpful in

explaining what was happening within these storyboard examples. Care partners easily adopted this approach as did some people with dementia, while for others it was more difficult.

[Insert Figure 2 here]

Key Aspect 1 Step 3 – Back to the Data!

After each workshop the academic researchers asked the question of themselves 'what difference does this make to our understanding of the original data and how we are using the theories?' There was an increased sensitisation to certain issues that had been discussed in workshops and also awareness that workshop attendees often spoke about their dementia experiences and analysed the data in metaphorical-like language.

Key Aspect 2 Participation Stage 2 – Metaphors of Dementia

For the fourth and final workshop with each group, the metaphors that had been compiled from the previous workshops (Table 3) were presented back to the workshop attendees, both as lists and interwoven into further vignettes of two people (based on Healthbridge data). The aim was to check our understanding of the metaphors by asking what the expressions meant for the co-analysts; what, if anything they brought to mind in relation to their own experience of living with dementia; and to consider whether it would be useful to create stories using these metaphors as an output of the project and a means of sharing findings with policy makers and practitioners.

[Insert Table 3 here]

Key Aspect 1 Step 4 – Blending Theory and Metaphor

The metaphors became a means of blending or drawing together the different strands of the analysis as they were used as heuristic devices to discover new elements in the themes identified by the

theory of Ethic of Care and cultural Theory of Risk, acting as a bridge between the different 'voices'. For example, the Ethic of Care principles were re-coded using the metaphors and the metaphor 'listening on' (meaning 'listen for the meaning even if the actual words used are incorrect' and encapsulated in the broader theme of '*co-operative communication*') led to identifying the theme of '*co-operative action*' as important. The metaphors derived from the workshops increased theoretical sensitivity in further analysis. For example, 'listening on' highlighted a particular style of support offered by a Dementia Advisor and revealed something about the knowledge that was privileged in the interchange (in this case, the experiential knowledge of the care partner rather than the practitioner knowledge of the Dementia Advisor). Similarly, 'co-operative communication' suggests a revision of ways of communicating. The emphasis that Cultural Risk Theory places on the knowledge prioritised to manage decision-making and risky behaviour (Douglas, 1992) made this an illuminating piece of analysis. This is important too in relation to the Ethic of Care in which the notion of solidarity is seen as an important aspect of social justice. Hughes (2011) also emphasises solidarity as a moral imperative for people with dementia, so they are not seen as 'other' and disengaged from society. Within Cultural Risk Theory, weaknesses in solidarity are noted as a possible loss of independence, with Evans (2007, p.5) commenting that "*the greater the solidarity of a group, the weaker the personal liability of any member within it*". The link between solidarity and co-operation led to the development of a third major theme, '*co-operative caring*'. In these ways, metaphors drawn from the workshops with people living with dementia as co-analysts were used to reinterpret the data and integrate it with theory in a novel way.

The co-operative endeavor of living with dementia that this research highlights emphasizes the importance of the relational context in enabling co-operative communication, co-operative action and co-operative care. These broad themes were outcomes of the analysis and, critically, were shaped by both the data analysis using the two theoretical lenses and by the discussions held in the workshops with people living with dementia as co-analysts. In generating these themes, the academic

researchers had to 'let go' of the academic theories of Ethic of Care and Cultural Theory of Risk to a certain extent, shifting them to the background and foregrounding what emerged from the metaphors.

Summary

- There were two key aspects to the study which were intertwined with one another in order to involve people with dementia as co-analysists: (1) application of theory (2) participation with people living with dementia.

- We used a range of methods in working with the data and in working with people with dementia as co-analysists, all of which bridged the gap between theory as knowledge and experience as knowledge.

- From this process, three ideas emerged: co-operative communication (new ways of communicating), co-operative caring (new ways of relating) and co-operative action (linking solidarity and co-operation). Together, these three aspects advance our awareness of care as relational.

Discussion

Data analysis is arguably the most conceptually abstracted stage of a qualitative research study, in which 'voluminous data' is turned 'into understandable and insightful analysis' (Liamputtong 2009). It requires knowledge and skills that are not conventionally attributed to members of the public – they are certainly not conventionally attributed to people living with dementia for whom stigmatising processes have led to a history of exclusion from decision making, presumed lack of mental capacity and social marginalisation (Alzheimer Disease International 2012).

[Insert Box 4 here]

Our purpose in working with people living with dementia was not to generate new data but to work together to analyse existing data. We concur with Tuffrey-Wijine and Butler (2009) that '*the power still lay with the academic researchers*' in that we shaped the discussions through our management of the workshops – selecting particular data extracts and vignettes for discussion and framing questions and discussion points in the workshops – as well as selecting the theories that informed our analysis. Moreover, we controlled the final synthesis of the metaphors and the theoretical lenses to determine the 'final' three themes of co-operative communication, co-operative action and co-operative caring (see Clarke et al, 2018b, for a full account of the findings of this research).

Nierse et al (2012) draw a distinction between responsive methodologies and participative methodologies, with the former emphasising 'dialogue and relational empowerment'. Whilst our study is best described as a move towards participatory research because of the level of control we, as researchers, had over the overall study, it does also share features of responsive methodologies in which we sought to provide a 'space for the exchange of perspectives, opinions and experiences, and for possible controversies, contradictions and ambiguities' (Nierse et al 2012 p.245). Moreover, we were not seeking validation of our established understanding of the dataset. We sought to value the diversity of perspective that the co-analysts brought to the workshops – but had to be open to our own views being disrupted and lose the 'exclusive status as arbiters of good science' (Gillard et al 2012 p.1135) – and in doing so we ourselves were enabled by the co-analysts to find a new understanding of the data.

Cycles of Presentation, Interpretation and Representation

The story of this project is one of multiple voices. In the preceding sections, we have explored the relationship of ourselves as academic researchers with the co-analysts, and the relationship of the data, the theory and the experiences of people living with dementia. But there are many other voices to be considered too and each forms a chain of sometimes singular, sometimes aggregate,

presentations, interpretations and representations. The starting point is beyond defining, but let us here take the starting point as the 106 people living with dementia who individually shared (presented to us) their singular experiences with researchers in the Healthbridge study – who interpreted those experiences as aggregated data and represented it as themes through publications – and who reinterpreted that aggregated data and presented it to 34 people living with dementia as co-analysts – who interpreted those data extracts within the context of their own singular experiences – and represented those analyses back to the researchers – who represent this as the three themes of co-operative communication, co-operative action and co-operative caring.

[Insert Box 5 here]

And so we come to the rejection of single, integrating conclusions and adopt the importance of 'multiple voicing'. And with that we must challenge whether the 'traditional realist discourse' is the right, or perhaps the only, way to communicate such work. If such a discourse means academic publications then this moves the story into an academic environment, to be read by few people other than other academics. It moves the story away from those living with dementia. So we are challenged to find other modes of discourse to keep the story and its cycles of presentation and interpretation alive – to maintain the 'ongoing moral dialogue' described by Denzin and Lincoln (2003) and to keep it in a 'performative' space. This fosters critical reflection and can be effective for addressing social justice by representing the complexities of lived experience in accessible and emotional ways, opening up new ways of seeing, and broadening understanding (Dupuis et al 2016).

The experiences and multiple findings of this project were shared with the artistic director of an arts organization (Skimstone Arts) who, in turn, interpreted them and worked with the researchers to explore, analyse and 'universalise' key themes e.g. rejection of social settings and relationship shifts

to generate a film (*Michael's Map*), which embodies the findings of the research, through character, plot and narrative arch, and allows further stages of presentation and interpretation of the research by the performers and viewers. This film is freely available at

https://vimeo.com/channels/1148563/188113371. In addition, a performance piece which aimed to explore the gradual and complex shifts of 'ethics of care' within sibling and friendship relationships was developed, which toured the UK – *The Ties That Bind*. Collated audience feedback became an on going 'influencer' on how the performance continued to evolve and respected the real narratives that were shared in the post performance Q&A's. We invite you to view the film yourself and play your own part in interpreting the messages from the research and to be part of this ongoing dialogue.

Summary

- Our focus was on involving people with dementia in one of the most "academic" aspects of qualitative research. Our experience was that the overall power remained with us as researchers, however our work represents a shift towards participation of people living with dementia in secondary data analysis.

- There were many cycles of interpretation in this work, perhaps beginning with the experiences of the people living with dementia in the original data set. This has led us to a depth of understanding of 'multiple voicing' in qualitative data.

- We shared the experiences and findings within this work with an arts organisation who developed a short film and theatre production, enabling a wide audience to add their own interpretation to the cycles.

Conclusion

Using a participatory research approach in analysing data has allowed us to re-present otherwise silent and silenced voices to a range of public, policy and practitioner audiences. It has been demanding of us, as researchers, to suspend any search for a singular knowledge that is owned by

ourselves, and instead focus attention on reflexivity, multiple voicing, literary styling and performance. It has demanded of us that we relinquish our own sense of any concluding authoritative voice. As such, the methodology of participatory secondary data analysis developed in this research has been innovative and we hope provides a foundation for further methodological development as well as informing future models of working with and caring alongside people experiencing dementia.

Multiple Choice Quiz Questions

1. Which of the following does Participatory Research endeavour to achieve?

a. Promote the research findings by emphasising the academic voice

b. Locates people as research partners rather than objects of research

c. Seek to promote research findings to policy and practitioner audiences

2. Which of the following does Participatory methodologies seek to avoid?

a. The presentation of multiple, potentially conflicting voices

b. Re-consider the emphasis given to language as the medium of communication

c. Definitively decide where the research validity lies; in the teller or the receiver

3. Which of the following means of communicating the Research results, reflect the ethos of Participatory Research?

a. Publications solely through academic journals to inform other researchers

b. Through a combination of publications, film and performance to keep the story, discussion and interpretation alive and thriving

c. Through archiving the results in a Data Management Bank for future research purposes

Declaration of Conflicting Interests

None

Further readings

Keady, J. Hyden, Lars-Christer, Johnson, A. Swarbrick, C. (eds) (2017) *Social Research Methods in Dementia Studies: Inclusion and Innovation.* Routledge: London.

Dementia Journal: Special Issue: Patient and Public Involvement in Dementia Research: Moving from Proving to Improving Vol 17 Issue 8 Nov 2018
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Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J & Rodriguez, E. (2008) What does participation mean? An insider perspective from people with disabilities. *Disability & Rehabilitation* 30(19):1445-60. doi: 10.1080/09638280701625534.

Web resources

1. https://www.researchgate.net/post/Participatory_action_research-when_is_it_when_is_it_not2

2. https://generic.wordpress.soton.ac.uk/usinggpswithcare/2016/06/28/participatory-research-methods-people-with-dementia-have-a-voice-in-the-research-process-tula-brannelly/

3. https://academic.oup.com/ageing/article/46/4/678/2926037

4. https://www.youtube.com/watch?v=6D492AP9JP4

5. https://vimeo.com/channels/1148563/188113371

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Figure 1 – Two Key Aspects of the Research Design and Flow of Data Analysis

Key Aspect One

Theory from data

Key Aspect Two

Co-production with people living with dementia

Step 1 *Preparing and presenting the data*

Preparation stage

Step 2 *Interpreting the data*

Participation stage 1 *Working with people with dementia as co-analysists (workshops 1 & 2)*

Step 3 *Back to the Data*

Participation stage 2 *Metaphors of Dementia (workshops 3 & 4)*
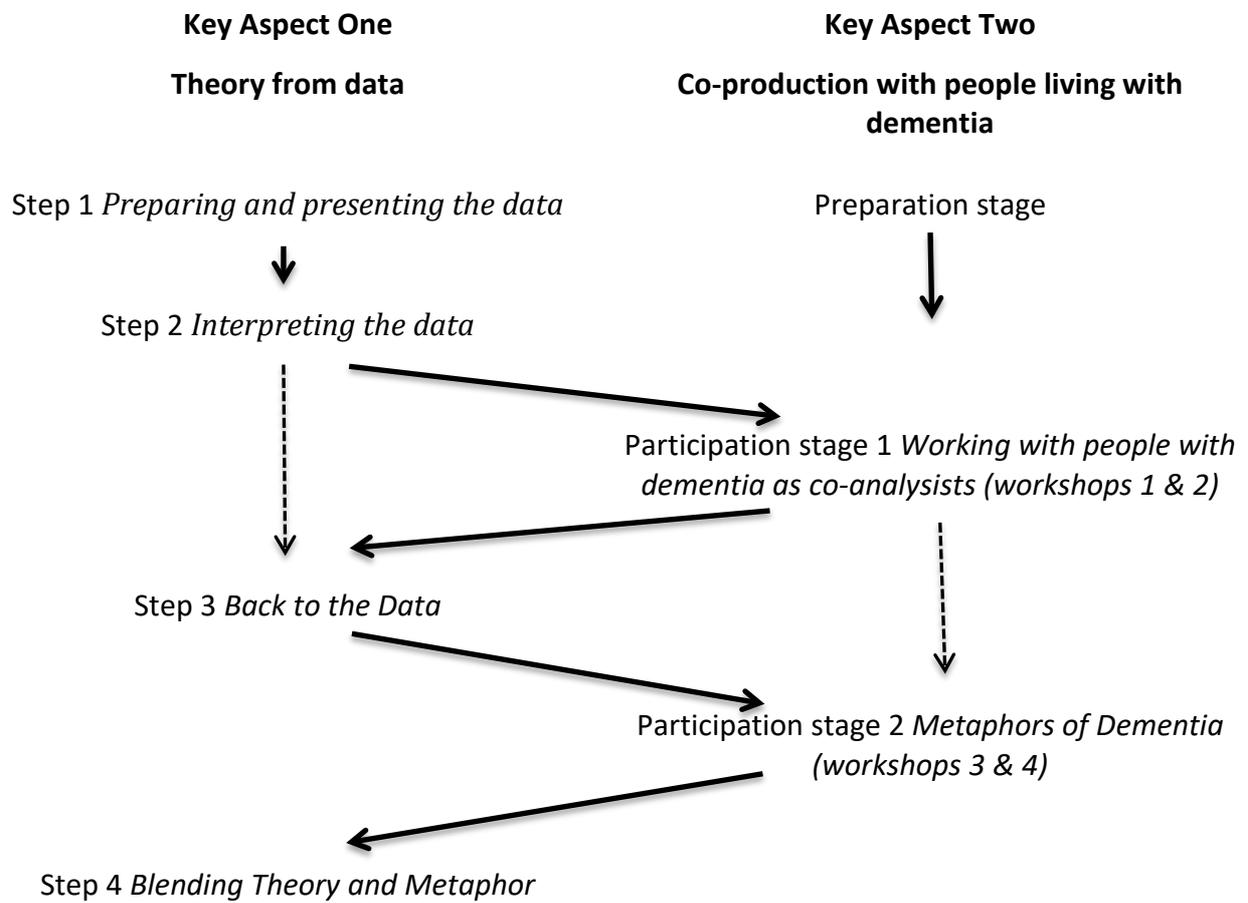
Step 4 *Blending Theory and Metaphor*

Table 1 – Co-analyst Participation in the Key Aspect 2 Workshops

Co-analyst Group	Workshop 1	Workshop 2	Workshop 3	Workshop 4
Group 1 (North-West England)	8 people with dementia 4 care partners	5 people with dementia 4 care partners	6 people with dementia 4 care partners	5 people with dementia 5 care partners
Group 2 (South-West England)	2 people with dementia	5 people with dementia	4 people with dementia	3 people with dementia
Group 3 (East Scotland)	1 person with dementia 1 care partner	2 people with dementia 2 care partners	2 people with dementia 1 care partner	3 people with dementia 2 care partners
Group 4 (North-East Scotland)	3 people with dementia 3 care partners	5 people with dementia 3 care partners	3 people with dementia 3 care partners	2 people with dementia 2 care partners

Table 2 – Examples of Data Quotes Used in Workshop 1 to Elicit Participant Analysis

"When I meet up with people, it's fantastic because we can all talk to each other. We've all got memory problems, and we all help each other and we all listen and talk to each other. And I do feel good when I've been to them."

"When I meet old friends, you can tell straight away they're on a different wavelength to you, and they'll gradually move away because they know I'm not thinking right or saying the right things. So I just keep away."

"I look forward to going out with John. We have the same sense of humour and we enjoy each other's company. He makes me feel we are on the same level. He makes me feel normal. Without John I think I would have been a far lesser person. The way that I am treated by John. I wouldn't have survived. And, here I am".

Table 3 – Metaphor-like Expressions Created by Co-analysts Who Live With Dementia During the Workshops

- 'listening on'
- just give me a minute
- 50/50 communication
- talking eye to eye
- if you are a bit jokey you can cover dementia up so people don't notice
- tell people "openly and without embarrassment"
- trust - "you have to pick the people and hope you have done it right"
- someone will tell you to put your clothes on – but have to be on your guard elsewhere in case you do or say something
- (group has) grown up together
- (group is) same as you feel at home
- here everybody is everybody's concern (but not 'outside')
- we look at each other the same way here
- experience a revelation moment
- I go in with fear and hopefully come out happy
- bars on the windows
- (dementia) turns things around

- the dementia box
- feel outside
- hide under the table
- toxic mix (loneliness and dementia)
- in a fuzz
- dropped like a stone (by friends)
- (friends) checked her out more
- it would be nice if people tried (to understand)
- (relationship) boundaries shift
- reading the signs (in relationship)
- I'm not her gaoler – it's very scary
- if they walk away it is a clue
- mixing with the wrong people
- social watershed
- even if I fall over, I don't want the help
- stuff happens
- no bandages on your head (not obvious you are ill)
- you grow into it, it's not like breaking a leg
- (dementia) not to be shushed up
- poetry not dementia
- I just feel I'm me, I always will be
- people have to admit it to themselves first

Box 1 - Dilemma One – Ethics and positioning of co-analysts

Positioning people as co-analysts establishes a relationship of equals in the endeavour of analysis, whilst positioning people as research participants emphasises the potential of a power differential in which academic researchers lead the research process and participants engage (most commonly as providers of data). Gustafson and Brunger (2014), in relation research with disabled people, found that research ethics committees and their conceptualisation of vulnerability emphasised the positioning of people as research participants rather than co-analysts. This was our experience too, and in order to obtain research ethics approval, those we aspired to position as co-analysts had to be described as 'research participants' and to demonstrate their 'informed consent' to participation. We regarded all of these 'participants' to be co-analysts and no new data was created during the process of secondary data analysis – each person bringing their own knowledge to analysis and to creating an understanding of the Healthbridge data. There was a tension therefore with the requirement that all co-analysts consented to their participation on each occasion of a workshop – at each workshop we provided information sheets, talked through the information sheet and consent form (checking that people understood each point) and the consent forms were signed by all participants present at each workshop.

In England, ethics approval was granted to involve people with and without capacity to consent to participate (Social Care REC Ref: 15-IEC08-0027). In Scotland, the Adults with Incapacity Act precludes the involvement of people without capacity to consent if the research can be conducted with those who can consent, and ethics approval was granted by the University of Edinburgh to involve only those with capacity to consent.

Classroom Discussion Question – How do we regard the relationship between the researcher and research participants in different forms of research? And what are the ethical advantages and disadvantages of involving people 'with experience' as co-analysts?

Box 2 – Dilemma two – data storage and management

Storing data in NVivo software is advantageous as it ensures that it remains accessible, electronic and in one place. However, developing a new project within the original shell of a previous project and using different theories from the original research, presented its own distinct issues and while there is literature available about secondary data analysis in general, there is little to guide researchers undertaking a secondary data analysis within the original NVivo database. Key issues included:

- Deciding how much original data and its particular organisation should be retained.

- Deciding whether retaining clarity and distinctiveness between the two projects was necessary.

- Decisions concerning analysis within existing themes or starting afresh from the transcripts.

Classroom Discussion Question – What are the advantages and disadvantages of re-analyzing data without any reference to the previous analyses undertaken? In the context of participatory research, are there particular challenges for co-analysts engaging with previously analysed data?

Box 3 – Dilemma three – using theory to create research questions

Research questions arising from Douglas' Risk Theory included: What 'groups' and 'grids' are evident and how do these change as dementia is experienced? What dynamics maintain or disrupt former groups and grids? What new groups and grids emerge as dementia is experienced and how are they characterised?

Research questions arising from Tronto's Ethic of Care included: How do accounts of interactions between people with dementia, carers and other significant people portray attentiveness, responsibility, competence, responsiveness and trust? What are the interpersonal and societal dynamics described which promote a positive cycle of the Ethic of Care towards an empowering relationship; or that produce a negative cycle of a disempowering relationship?

Classroom Discussion Question – should research questions always link clearly to theory? Why? What are the implications of using theory in participatory research for the co-researchers?

Box 4 – Dilemma four – bringing the marginal and the radical into centre-stage

People living with dementia can be described as Cotterell's (2008) 'marginal knowers' (because they are so often regarded as marginal in society) and are consequently best placed to speak of experiences of marginalisation and exclusion, or indeed of inclusion (to 'expose oppressive structures', as described by Cotterell 2008). Indeed, Nierse et al (2012) argue that people involved through their lived experiences 'provide a richer more metaphorical interpretation' than conventional analysts. So involving people with dementia as co-analysts demands a radically different approach to analysing data – one that respects the knowledge base and skills that are held and regards them as valuable and contributors of value to the overall process of analysis. It seeks to achieve what Gillard et al (2012) describe as 'bridging the apparent dichotomy of what was conventionally known and what was "radically" known' (p.1135).

Classroom Discussion Question – what other groups could be described as marginal knowers? How might research be conducted to bring their voices to the fore?

Box 5 – Dilemma five – who owns the story?

Let us ask – whose story of dementia is this? Whose data and whose analysis is this? Who has the authority to claim this as their story? Surely, this is not a story that academic researchers can have any singular claim to – it is not theirs to own. It is not one in which they can have any final authoritative voice. It is one in which they play a part and can enable (and be enabled by) those with experience to also have a part in presenting, interpreting and representing their stor(ies).

Classroom Discussion Question – what 'belongs' to researchers and 'belongs' to research participants in conducting research? How do individual participant voices end up being researchers' themes? Is this a process which empowers participants, or does it actually take something away from them?

Figure 2 – Example of Picture and Word Cards Preparing for the Workshops and Using a Storyboard Approach to Data-generated Vignettes of People's Experiences of Changing Groups