A Seat Around the Table: Participatory Data Analysis with People Living With Dementia

Abstract

The involvement of 'people with experience' in research has developed considerably in the last decade. However, involvement as co-analysts at the point of data analysis and synthesis has received very little attention – in particular, there is very little work that involves people living with dementia as co-analysts. In this qualitative secondary data analysis project, we (1) analysed data through two theoretical lenses: Douglas' cultural theory of risk and Tronto's Ethic of Care, and (2) analysed data in workshops with people living with dementia. The design involved cycles of presenting, interpreting, representing and reinterpreting the data and findings between multiple stakeholders. We explore ways of involving people with experience as co-analysts and explore the role of reflexivity, multiple voicing, literary styling and performance in participatory data analysis.

Key Words Dementia**,** Co-analysis**,** Secondary Data Analysis**,** Participatory Research**,** Ethic of Care**,** Risk Theory

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Background

Participatory research

Participatory research seeks to re-present otherwise silent and silenced voices to a range of public, policy and practitioner audiences and creates a shift from people being the object of research to a research partner (Abma et al 2009). It is seen as a way of democratizing the research process

(Salmon 2007). However, these laudable aspirations present a challenge to conventional social science research paradigms - challenges that unsettle the authority of the researcher and the authority 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) that, argue Reason and Bradbury (2008), denote research as participatory.

We argue that, firstly, participatory methodologies challenge us to question whether the validity (or confirmability) of research is a property of the teller or the receiver. Secondly, for researchers, it demands that we suspend any search for a singular knowledge which is owned by ourselves, and instead focus attention on: reflexivity – the juxtaposition of self and subject matter; multiple voicing – the rejection of single, integrating conclusions; literary styling – the replacement of traditional realist discourse in which language is the medium of communication (Sims-Schouten et al 2007); and performance – expanding communities in dialogue and avoiding claims of a dominant knowledge. These are issues that we explore in this article through the example of a project to undertake secondary data analysis of a qualitative dataset in partnership with people living with dementia (those diagnosed with dementia and their family care partners). Secondary data analysis is beginning to be recognised as an opportunity to maximise the value of data, especially for difficult to access groups, such as people with dementia (Yardley et al 2014).

The involvement of people living with dementia in research

The last two decades have witnessed a major shift towards involving people with dementia in research, where previously their views were discredited because of their cognitive impairment (Wilkinson 2002, McKillop & Wilkinson 2004). This has extended to including people with dementia

in research, not only as research subjects but as co-researchers (Frankham 2009, Tanner 2012, Gove et al 2017). As well as being a way for people with dementia to embrace a positive dementia identity, utilising their diagnosis in constructive ways and challenging negative social stereotypes (Tanner 2012), it can enhance the relevance of research and its impact on the day to day lives of people with dementia. Specifically, this may involve working with academics as equal partners, from identifying the questions that need to be asked, collecting data, analysing data, writing reports and knowledge exchange (Swarbrick et al 2016) and producing advice involving people with dementia in research (Dementia Engagement and Empowerment Project, DEEP, 2013; Scottish Dementia Working Group, SDWG, Research Sub-group 2014).

People with dementia are experts in their own lives: they are 'agents' of knowledge in that they have knowledge that comes from personal experience and are using a different form of knowledge than that which is used by professionals or is derived from academic theory (Cottrell 2008). Gillard et al (2012) describe co-research as a marriage of expertise by experience and expertise by profession, and suggested 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 doing so in a way that relinquishes the authority of the 'academic' researcher being even more challenging. In undertaking co-analysis with people with learning difficulties, which involved reading transcripts and content analysis, Tuffrey-Wijne and Butler (2009) reflected that the academic researcher still had the task of integrating themes into theory and thus the power still lay with the academic researchers.

The Inciting Dialogue and Disruption Study

To inform the development of empowering support for people living with dementia, we interrogated an existing qualitative dataset, using an approach that set out to challenge assumptions of current practice (and in so doing disrupt present understandings of practice). 'Healthbridge', the national evaluation of innovative and empowering services recommended by the National Dementia Strategy for England (DH 2009) had generated a large volume of data from people living with dementia (Clarke et al 2013). In total, 155 interviews were completed (lasting 45-120 minutes) with 51 people with a diagnosis of dementia and 55 family care partners interviewed on up to three occasions. The analysis that took place for Healthbridge focused on the role and impact of the Dementia Adviser and Peer Support Network Services (Keyes et al. 2014; Clarke et al. 2014; Clarke et al 2016). The volume and depth of data made the dataset particularly suitable for secondary data analysis (Corti & Bishop 2005). In comparison with datasets of interviews with people with dementia and care partners identified in a search of ASSAI, Medline, PsychInfo and Medline databases, the Healthbridge data set is one of the largest set of qualitative interviews with people with dementia and carers - exceeding previous largest datasets (Boyle 2013 - 21 couples; Johannessen et al 2013 - 20 people with dementia).

One of the early dilemmas faced in implementing this participatory secondary data analysis study concerned the positioning of the co-analysts as people with dementia – whether to be positioned as co-workers or as research participants. The former position establishes a relationship of equals in the endeavour of analysis; the latter emphasises the potential of a power differential with academic researchers leading the research process and participants engaged more commonly as providers of data. Previous studies aspiring to a participatory approach with disabled people have found the structures within ethical approval boards and their conceptualisation of vulnerability challenging (Gustafson & Brunger 2014). On the advice of NHS Research Ethics Committees in both England and Scotland, the latter position took precedence, forcing those we aspired to position as co-analysts who lived with dementia 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. All participant co-analysts consented to their participation on each occasion of a workshop, and 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.

Aims and objectives

We aimed to inform the development of support for people living with dementia that they experienced as empowering.

To achieve this aim, 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 experiences within the data set.

In identifying the suitability of the dataset for secondary data analysis, we considered the five questions that Long-Sutehall et al (2010) suggest should be addressed prior to undertaking a reuse of data (ethics, ability to answer the questions, assessment of the primary dataset, symmetry between data collection and analysis, and the role of context in the data). The assumption in the literature is that other researchers' data is being used (Kelder 2005) or that methodological approaches are being compared (van den Berg 2005) so our familiarity with the data as its originators was advantageous (but an advantage denied to those people living with dementia who were co-analysts).

There are 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). The findings at each stage are presented only in sufficient detail to allow an understanding of stage of the research.

[Insert Figure 1 here]

Profile of Co-analysts

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. Recruitment was coordinated by the organisers of the pre-existing groups (the Alzheimer's Society in England and Alzheimer Scotland in Scotland). Each of the four groups met on four occasions at monthly intervals for each group and on the whole the same people participated on each occasion (with some being absent occasionally through ill-health or holidays) – see Table 1. Overall, approximately 60% of participants were female, and care partners sometimes came alone or were sometimes with the person they care for e.g. in Group 4 workshop 3, there were two couples (a husband and his wife with dementia, and a wife and her husband with dementia), a woman with dementia (who was unaccompanied and living with her adult son) and an unaccompanied bereaved care partner (whose parents had had dementia).

[Insert Table 1 around here]

Stages of the Participatory Analytical Process

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. 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 - all the data was retained except for inapplicable content that could not inform or be relied upon for the new project, e.g. some memos, empty theme nodes, redundant queries.
- Whether retaining clarity and distinctiveness between the two projects was necessary - original 'working' themes were retained and new themes were positioned 'cheek by jowl' so to avoid muddying the footprints of earlier work.
- Decisions concerning analysis within existing themes or starting afresh from the transcripts - a new audit trail of our thinking and actions was started using the Memo tool, enabling us to revisit our research movements.

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. Care was taken to organise the NVivo themes to facilitate team working as the desktop version of NVivo requires each researcher to work

on individual copies of the database, and later merge them together. This enables the researchers to work with updated analyses as all work was correctly stored and commentary shared while avoiding confusing duplication or loss of findings when copies of the project were merged. This process of merging and copying the database for further individual work took place 12 times throughout the duration of the eighteen-month project.

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: 'risk and resilience' and 'ethic of care'. These theoretical perspectives created 'lenses' with which to interrogate the qualitative interview dataset by creating a set of research questions, and asking these of the data in a dialogical manner. Hammersley (2010) refers to data as a 'sign-vehicle' (something that conveys a perceptible sign) and the theoretical perspectives we adopted enabled us to identify and locate the meaning and effect of those signs (e.g. evidence of the meaning and effect of trust in relationships).

Theoretical Lens 1 - Risk and Resilience

Risk and resilience theory in relation to people living with dementia has been a central focus of work of the authors (e.g. Clarke et al 2011; Bailey et al 2013). Risk theories are complex and lack homogeneity (Althaus 2005), but they do offer a high level of explanatory power for the interpersonal dynamics that were central to this analysis. Our approach to risk was dominated, firstly, by sociological constructions in which the concept of risk is politicised through differing cultural perspectives and regarded as a moral and ethical concept (Tansey & O'Riordan 1999) and

secondly, by understanding risk management as central to professional care practice (e.g. Alaszewski et al 1998).

Specifically, the analysis applied the cultural theory of risk (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 that 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.

Research questions arising from risk and resilience 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?

A section of the analytic framework was created to reflect the five broad themes and subthemes indicative of the features of groups and peoples' movement between them. The main theme nodes and a selection of subthemes are:

- *Grid/Group Changes* - this node held data quotations referring to changes that occurred while experiencing movement (or not) between groups, such as a premature end to employment, seeking and receiving information leading to a diagnosis, or the lack of interest other people may demonstrate towards those with difficulties.

- *Grids or Criteria or Rules for Groups* - capturing characteristics of the groups that were valued or not enjoyed by people living with dementia. These included the nature of activities undertaken or those activities unavailable, the ethos of people who ran the groups or the attributes of those who attended them, how the group made them feel and practical elements of the group such as ease of access both in timing and geographical location, or whether they could afford to go (travel costs).
- *Dynamic* - holding data illustrative of the event, thing or person that appeared to initiate the shift from one group to another. This could include receiving a diagnosis, other people being the instigator for change or not, the person with dementia's actions or their reluctance to move.
- *Transition* - storing illustrative data of the events or happenings that were influential in peoples' movement between groups or not. This included coming to terms with symptoms and diagnosis, experiences of isolation and exclusion, discouraging service experiences and non-dementia related aspects influencing transitions such as other diagnoses. Data coded at Transition held quotations reflecting something of the nature of the movement between change and dynamic and where appropriate vice versa.
- *Groups* - captured data referring to the social networks that people are involved in or attached to or moving between. These included a range of dementia or ageing related groups, hospital groups, and family or friendship groups.

Theoretical Lens 2 - Ethic of Care

We used an 'ethic of care' framework (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).

In this sense, care cannot be contained within the private sphere of the family but is a political as well as a private issue (Barnes 2012). By drawing attention to the need all human beings have for care, an Ethic of Care approach challenges the stigmatisation experienced by people who are dependent on help from others to live well. 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. This highlights the importance of considering care-givers' needs as well as care-receivers. Attentiveness can be considered at a political level but also on the face-to-face level.
- *Responsibility* – to take, or accept responsibility for action. Again, this can be considered at a political level but also at a face-to-face level.
- *Competence* – caring work should be competently performed. At an individual level and a political level, attending to care needs and taking responsibility for them but failing to address the need to deliver it competently, leads to the need for care not being met.
- *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, and that power should be used in a positive and creative manner (Barnes & Brannelly 2008).

An 'ethic of care' shifts the focus away from traditional perceptions of care as one way and patronizing, acknowledging the complexities of relationships and positioning care as political and moral, promoting citizenship in the context of interdependent relationships (Barnes 2012). Applied to people with dementia, an ethic of care also balances the tension between independence, control and choice and the need of many people accessing services for care. It values the participation of all people involved, thus promoting citizenship in the context of care, acknowledging that some people with dementia are unable to 'care' for themselves, but that an ethic of care approach can enable voices to be heard, leading to participation (Brannelly 2011).

Research questions arising from the theory of the 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?

We created a section of the coding framework to capture both positive examples of where the ethic of care principles were in operation, and examples of where they were absent e.g. where there was a negative response to the care given or where attention was not paid to a need.

Early in the analysis, the interconnections between the ethics 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, the 'active' role played by people with dementia in the care process 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. The ethics of care principles can be assigned to any member of the caring relationship, whether the person with dementia, a professional or family carer, and responsibility is not assigned only to a care giver but also a care receiver, which may require negotiation and a recognition that, for example, refusing care, for whatever reason, has a knock-on effect on other family members, impacting on their health and well-being.

Connecting the Theoretical Perspectives

As analysis progressed, we explored interconnections between ethic of care and cultural theory of risk. 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 theory helped to uncover some of the dynamics involved in moving groups, being excluded and becoming included after a diagnosis of dementia.

Within interviews, comments from people with dementia also highlighted limitations in the ethic of care principles. For example, in one interview, a person with dementia spoke of how she found it hard to know at memory cafes "who is 'like me' (i.e. has dementia) or who is a helper". At these points, cultural theory of risk may augment ethic of care theory in terms of understanding the experiences of people with dementia and their position in 'groups'. In desiring to ascertain "who is

like me", the participant could be searching for information indicative of the expectations of behaviour acceptable to the group. For some people living with dementia, these expectations or criteria appear easily recognisable even if they are unspoken. For example, having found a new group to join, participants used language that reflected that sense of recognition, feeling at home with their new group because "they welcome you as if you're one of them". However, in another example, a man describes his wife with dementia as "not being the woman he married" - within an ethic of care perspective this could be seen as a lack of attention to the person who remains but a cultural theory of risk perspective allows us to recognise the view that she no longer conforms to the expectations (the grid criteria) that have up until now held them connected together in their relationship.

Ethic of care may also augment risk theory in terms of understanding the relational nature of care and risk: human beings are interdependent rather than independent. Negotiating risk can be an emotionally fraught experience for people with dementia, families and communities. For example, keeping people with dementia safe may help families cope and prevent a person with dementia getting lost or physically harmed. Conversely, it maybe compromise the health and happiness of the person with dementia and inflict silent harms (Clarke et al 2011). However, enabling a person with dementia to take risks may negatively impact families, compromising their emotional and mental health and threaten their ability to maintain their caring role. In an example from the Healthbridge data, a daughter considered giving up her job, and thus putting her at risk of financial hardship, in order to enable her mother to take risks and remain living alone. In grid / group terms, the previous criteria (grid) of their family relationship was shifting, challenging the daughter's employment because of the mother's changing health needs which risked the breakdown of their relationship. The principles of ethic of care may provide a framework for open communication and

decision-making about risk whereby the goal is to reduce the risk of relationship breakdown by balancing the needs of those in the relationship through paying attention, taking responsibility, attending to the response and maintaining trust of all parties. In this sense, an ethic of care framework may enable the family group to shift in tandem, adjusting their 'criteria', and thus retaining their group cohesiveness, avoiding separation and the accompanying isolation of both.

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 (in England and Scotland respectively) to participate in a series of four workshops and, of those who expressed interest, selected two groups in each country. 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-analysists

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 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 that 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') and 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 ethics 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]

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 things 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 cultural theory of risk 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 ethic of care theory 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 theory of risk, 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.

Discussion - Voice and Authority in Participatory Data Analysis

Designing A Seat Around the Table

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). They are, as Cotterell (2008) describes, '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).

Our purpose in working with people living with dementia was not to generate new data but to work together to analyse existing data. We considered in what ways the workshop participants engaged with the data extracts and identified three facets of engagement – here we use the word facet to denote a non-hierarchical level of analysis as we no not wish to imply that any one facet is superior to another:

- Facet 1 - Describing personal experiences with no reference to the data extracts or theories. In this facet, the discussion has proximity to personal experience and is distant from theory.
- Facet 2 - Relating the data extracts and theories to personal experiences and providing insight through these first-hand lived experiences. In this facet, the discussion uses a mix of personal experience and theory to illuminate each other.

- Facet 3 - Discussing the data extracts and theories without reference to personal experiences. In this facet, the discussion has proximity to theory and the data extracts but is distant from personal experience. This is also the facet that the academic researchers largely operated from.

The majority of discussion in the first two workshops with each group was in facet 1 and 2. There were a few examples of engagement in facet 3 in one of the groups who were 'ambassadors' for people with dementia (for example, advocating for people with dementia at the town hall) and it may be that they had more of an overview of issues facing people with dementia and familiarity with presenting other people's views.

However, co-analysis required a shift in how we, as researchers, 'ask' questions. Normally researchers are trying to understand something of the participant's lived experience through asking questions and probing to clarify or open up the conversation more. Using this same approach when the purpose is co-analysis is less effective as it perpetuates engagement in facet 1. We found that we had to 'disrupt' this usual approach and as we refined our way of approaching the workshops (and as people became more accustomed to working together with us), engagement in facet 2 became more prevalent. And perhaps the stage of analysis through metaphors was a critical point at which the co-analysts living with dementia were able, in their own words and expressions, to highlight Cottrell's (2008) 'oppressive structures' that led them to feel, at times, 'dropped like a stone' or want to 'hide under the table' or feel that there were 'bars on the windows'.

We concur with Tuffrey-Wijine and Butler (2009), however, 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.

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). Nor were we seeking validation of our established understanding of the dataset, but 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.

Beyond Analysis? – Cycles of Presentation, Interpretation and Representation

The story of this project is one of multiple voices. In the preceding section, 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 three themes of co-operative communication, co-operative action and co-operative caring. But let us stop this cycle at any point and 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).

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 is 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 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. Dupuis et al (2016) suggest that the arts can create transformative spaces which foster 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.

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 generate a film (*Michael's Map*), which embodies the findings of the research 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 has been developed which is touring the UK – *The Ties That Bind*. We are assessing the impact that such plays and films may have on their audiences, but here simply 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.

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.

The core principles for involving people with dementia in research developed with the SDWG Research Working Group (2014) highlights the importance of 'dementia time' which is totally at

odds with the faster pace of 'academic time'. Maybe we need to ask 'What needs to be done differently to truly work in partnership with people with dementia in research?' – what structures within funding calls, proposals, data collection and analysis need to change and how do we as researchers need to change? The guidance on co-production within disability research appears to assume capacity and the issue of doing research *with* people with a disability, when their disability is cognitive, requires much further consideration within ethics committees and legal frameworks to ensure that people with dementia are not excluded.

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

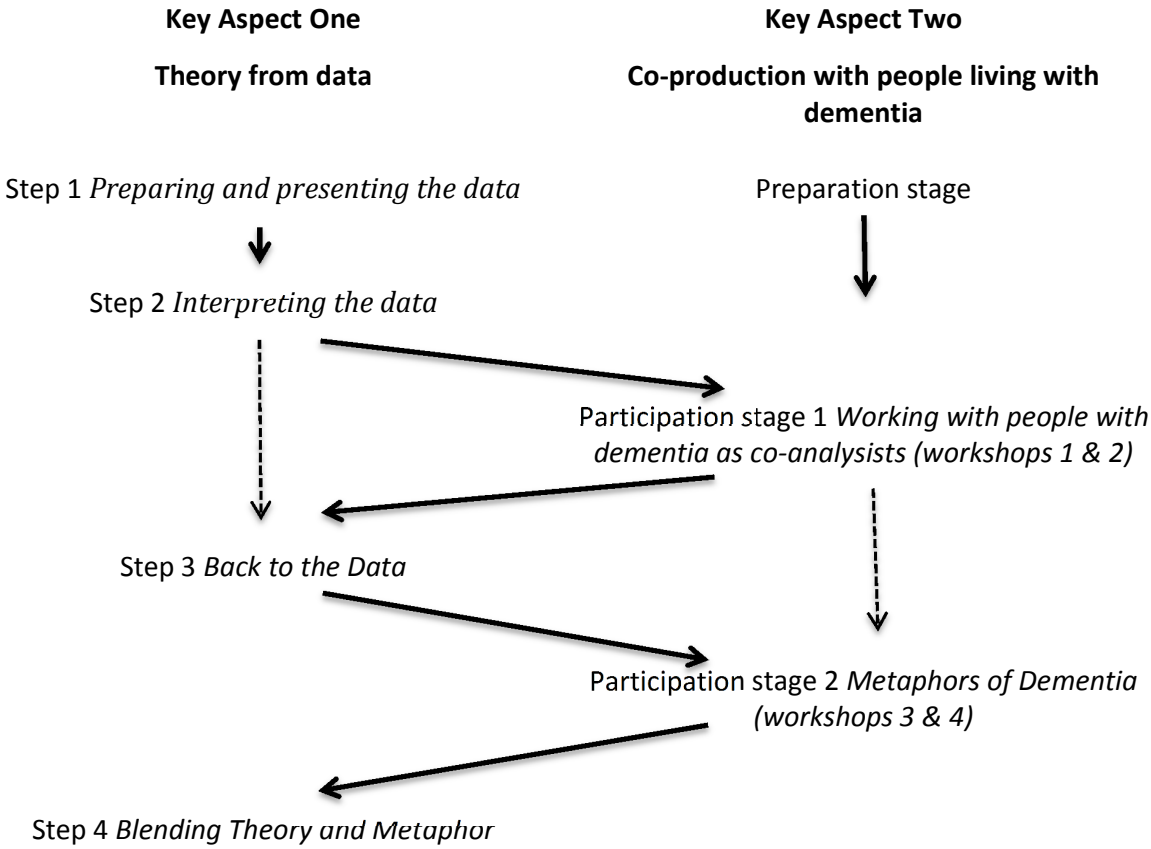

Table 1 – Co-analyst Participation in the Key Aspect 2 Workshops

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 partners	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

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