Northumbria Research Link

Relational Care and Co-Operative Endeavour – Reshaping Dementia Care Through Participatory Secondary Data Analysis

Abstract

Dementia is emerging from the shadows of societal exclusion and stigma. The engagement within society for people who are marginalised is co-constructed through the everyday practices that take place between them and those around them. However, this is inherently political, positioning people as active and activist in the relationship of their lives with their communities. The research aimed to interrogate an existing qualitative dataset in partnership with people living with dementia to inform the development of a way of working with people with dementia that is empowering. 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) co-analysed the data together with people living with dementia during 16 workshops. The design involved cycles of presenting, interpreting, representing and reinterpreting the data and findings between multiple stakeholders. We identified a granular understanding of the way relationships change for people with dementia and how subtle factors and nuanced behaviour contribute to social exclusion, or support social inclusion. The results support relational care through the co-operative endeavour (of co-operative communication, co-operative action and co-operative care) in promoting the inclusion of people living with dementia.

Relational Care and Co-Operative Endeavour – Reshaping Dementia Care Through Participatory Secondary Data Analysis

Background

Dementia is emerging from the shadows of societal exclusion and stigma. This article reports on research that informs the continuing development of support by and for people living with dementia that is experienced as empowering. It achieves this through an exploration of the dynamics of social relationships. In collaboration with people living with dementia, we interrogated an existing qualitative dataset, using an approach to secondary data analysis that set out to challenge assumptions. Our intention was to disrupt present understandings of the inclusion and involvement of people with a diagnosis of dementia and their care partners in society.

Bartlett and O'Connor (2010) challenge traditional, exclusionary notions of the involvement of people with dementia in society that are based on narrow notions of personal rights and responsibilities. They expand this to include 'social practice'. This approach is based on Prior et al's work in which 'individuals relate to other people, their communities and the state' (Prior et al 1995) and Barnes et al's (2004) notion of 'everyday talk and actions'. Thus, understanding the engagement within society of people who are marginalised is co-constructed through the everyday practices that take place between them and those around them. However, this is inherently political, positioning people as active and activist in the relationship of their lives with their communities and seeking to uphold their human rights (Clarke et al. 2016a).

People with dementia, however, may be perceived to be vulnerable (Austin et al. 2016) and this impacts on perceptions of their welfare, decision-making and ability to develop, maintain or achieve the interdependency of relationships that they wish for. To be perceived to be vulnerable, and consequently at risk, (whether by the individual, professional services, family or members of the public) can result in profound consequences - for example, these consequences may include heightened surveillance, restriction of freedoms, and alterations to a physical and social / family environment. These actions may be perceived as safer and more protective of well-being yet also incur some detriment, such as prevention people from going outside. The acknowledgement and recognition of risk by individuals then becomes part of the

appraisal of their perceived capacity and independence (Clarke et al. 2016a). This informed our choice of Douglas' (1982) Cultural Theory of Risk for exploring these complex relationships.

Exploring relationships between disabled people and services, Keyes et al. (2014) create dialogue between the social model of disability and an Ethic of Care, suggesting that empowerment can be achieved *through* care, when care is conceptualised within an Ethic of Care framework. This challenges the positioning of 'care' as necessarily one-way, oppressive and leading to dependence in interactions (see for example Morris 1997). It points to the limits of relationships between disabled people and those supporting them, which seek to promote empowerment through independence without acknowledging the significance of relationships in facilitating empowerment. This stance also positions people with dementia and care partners as engaged in *interdependent* (as opposed to independent or dependent), caring relationships (Keyes et al. forthcoming). When conceptualised in this way, an Ethic of Care positions empowerment in the context of interdependent relationships.

Hutcheon and Lashewicz (2014) highlight the need to move away from a focus on ability to more relationship focused approaches – this being a critical shift from arguments that older people are diminished by a society that values productivity and self-management (Powell et al 2007; Hicks & Conner 2014). It also reminds us of Lupton's (2013) argument that the experiences of an individual are fundamentally shaped by the relationship between individuals, institutions and society, and is critical to the theoretical premise of the analysis reported here. An Ethic of Care is a theoretical approach that draws attention to the need we all have for care and integrates practical, moral and political aspects about the place of care in society (Tronto 1993). Tronto (1993) suggests that there are four levels: caring about (the macro level of policy); taking care of (public health measures, community development, service provision); care giving (the micro-level, requiring face to face contact); and care receiving (the micro-level of the experience of care receivers). These levels serve as 'an ideal to describe an integrated, well accomplished act of care' (Tronto 1993 p.109). Disruptions at any of these levels can impact on the integrity of the caring process. Thus analysis at the micro-level (both disruptions and what works) can feed back into the macro level.

This intersects with the emerging public health focus on prevention through promoting resilience in individuals (Garcia-Dia et al 2013). The emerging narrative, focusing on the strengths and abilities of people is an uneasy companion with the narrative of vulnerability and protection, as well as presenting a concern with litigation. For family members and professionals there can be real tension between wanting to avoid harm and wishing to uphold a person's autonomy (Robinson et al. 2007; Clarke et al. 2009, 2010).

Contemporary policies (e.g. Department of Health 2016, Scottish Government 2017), which aim to empower people with choices and resources, represent a move away from earlier ideas in which risk was understood as something to be controlled and limited (and residing with the individual) towards understanding risk as offering the opportunity to be beneficial to the individual (and residing in the context and circumstances surrounding the individual) (Adams 2010). This move from managing 'vulnerable people' (through an emphasis on safety and loss) to managing vulnerable situations is evident in the contemporary language used such as 'risk enablement', 'positive risk taking', 'reasonable risk', and positive risk in practice models. Relationships with family, friends and wider social networks form a central part of people's lives. For example, friendships provide comfort, support and meaning in life and are an important part of the human experience (Harris 2012). Experiencing dementia can, however, result in relationship changes such as withdrawal from (or by) former friendship groups (Harris 2013; Ward et al 2012) resulting in social isolation.

The 'ethic of care' (Tronto 1993; Sevenhuijsen 2003) identifies five ethical principles (attentiveness, responsibility, competence, responsiveness and trust), which provide a framework for considering the complexities of interpersonal relationships within the context of caring relationships. An 'ethic of care' shifts the focus away from traditional perceptions of care as one way and patronising (by acknowledging the complexities of relationships and positioning care as political and moral) and promotes citizenship in the context of interdependent relationships (Barnes 2012; Brannelly 2016). Applied to people with dementia, an ethic of care also balances the tension between independence, control and choice with the need of many people accessing services for care. It values the participation of all people involved, thus promoting citizenship in the context of caring relationships (Brannelly 2011).

Methodology

Research aim: To interrogate an existing qualitative dataset in partnership with people living with dementia to inform the development of a way of working with people with dementia that is empowering. Consequently, our objectives were to:

1. Interrogate through secondary data analysis a large qualitative dataset 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 (outlined below).

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

We hoped to achieve a more detailed understanding of how dementia is experienced by people living with dementia and what approach could be used to enhance their experience of living within the community.

The dataset originated from the 'Healthbridge' study, the pan-national evaluation of the role and impact of Dementia Adviser and Peer Support Network Services advocated in the National Dementia Strategy for England (Department of Health 2009). In total, 155 interviews were completed (lasting 45-120 minutes) with 51 people with a diagnosis of dementia and 55 carers interviewed on up to three occasions (Keyes et al. 2014; Clarke et al. 2014; Clarke et al 2016b). Ethical approval for the secondary data analysis was granted by the Social Care Research Ethics Committee in England (Ref: 15-IEC08-0027) and gave permission to involve people with and without capacity (with consent from a consultee). In Scotland approval was granted by University of Edinburgh Ethics Committee to involved people with dementia with capacity to consent. A more detailed account of the methodology can be found in Clarke et al (in press).

Cultural Theory of Risk

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. Grids may be understood as the 'terms of engagement' with a group. The 'group' refers to cohesiveness and is the extent to which individuals within a given community are bounded together and see

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themselves as a coherent community. Group-grid analysis has been applied to several fields (e.g. public health, Langford et al. 2000) but this is the first time it has been applied to analysing relational dynamics in dementia.

Research questions arising from group-grid analysis 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?

Ethic of Care

The research also used an 'ethic of care' framework (Tronto 1993, Sevenhuijsen 2003) as an analytical lens to understand and explore interpersonal interaction within the dataset, 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 and understands care as something that everyone is involved in. Tronto (1993) identified four intertwined ethical principles of care: attentiveness, responsibility, competence and responsiveness. A fifth principle, 'trust', was added by Sevenhuijsen (2003) who argued 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). Ethic of care has had some application in the field of disability (Keyes et al 2015) and of dementia previously (Branelly, 2006; Barnes & Branelly 2008; Barnes & Henwood 2015).

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?

Stages of the Analytical Process

All the data analysed for the research was stored within the software NVivo 10 and prepared for secondary data analysis. This included discarding irrelevant content from the primary research, such as unrelated memos, and redundant coding, which were not applicable to the new project. The process of analysis involved two interactive key aspects, each with multiple stages within them.

Key aspect 1 - Interpreting the data through theoretical lenses

A coding framework was set up within NVivo 10 to capture key themes from the analysis that were stored as 'nodes' (codes) in NVivo. In relation to Douglas' cultural theory, the following nodes were included: grid/group changes, grids or criteria or rules for groups, dynamics of group shifts, transitions, and types of groups. In relation to Tronto's ethic of care, nodes captured examples of where the ethic of care principles were evident or absent. As an example, Figure 1 illustrates the modelling of nodes in relation to the ethic of care principle of (in)attentiveness.

[Insert Figure 1 here]

Through the coding process and merging of codes from within each theory, the interconnections between the two theoretical frameworks became apparent. For example, disengagement with the care provided by a support agency could be due to a lack of attention being paid to people's specific needs. The model tool in NVivo 10 was used to assist analysis in how each theoretical framework worked within a selection of individual cases and also across a range of cases.

Key aspect 2 - Working with people with dementia as co-analysts

The project partners (the Mental Health Foundation and Alzheimer Scotland) recruited four dementia peer support groups in England and Scotland to each participate in a series of four workshops. A total of 34 people (with a diagnosis of dementia or a care partner) took part in a total of 16 workshops (see Table 1). The groups sizes varied between 2 and 12. The workshops took place in the group's normal meeting place and people were supported by local staff who were known to them. Each lasted for two hours including a refreshment break to ensure that the time was paced appropriately for people who may have tired easily.

In workshops 1 and 2, samples of data from the Healthbridge dataset were selected to act as 'triggers' for discussion and were presented as quotes – these were frequently occurring experiences of people living with dementia, and were illustrative of both theoretical frameworks. Each was printed in Ariel Size 22 font and in black writing on coloured paper to increase visual distinctiveness. Workshop 3 involved presenting picture and word cards depicting the two theoretical frameworks and used a storyboard approach to two data-generated vignettes. The groups discussed in what ways the two theoretical frameworks were helpful in explaining what was happening within these storyboard examples.

[Insert Table 1]

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 theoretical frameworks?' There was an increased sensitisation to certain issues that had been discussed in workshops. In particular, we developed an awareness that workshop participants sometimes spoke about the data and their dementia experiences in metaphorical-like language. A list of these metaphorical-like terms was compiled from written notes kept during workshops 1-3 (see Table 2).

[Insert Table 2]

For the fourth and final workshop with each group, the metaphor-like terms were presented back to the workshop members, both as lists and interwoven into vignettes of two people (drawn from the Healthbridge dataset). The aim was to: reflect the metaphors back to workshop members to check our understanding; identify 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.

The metaphors became a means of synthesising the two aspects of the analysis. They were used as heuristic devices (Ricoeur 2003) to discover new things in the data and acted as a bridge between the different 'voices'.

Findings

The analytical framework of cultural theory of risk, with its emphasis on groups and grids, allowed for a granular understanding of the way relationships change for people with dementia and how subtle factors and nuanced behaviour contribute to social exclusion, or support social inclusion. The analytical framework of ethic of care guided an explanation for these changing relationships, as highlighted below in describing the research findings of relational networks of care and co-operative endeavour.

Relational Networks of Care

The Healthbridge study participants spoke extensively about losing friends and becoming socially excluded – but they also spoke of gaining friends and restoring their sense of social inclusion through accessing new peer support networks. These processes were underpinned by gaining (or losing) horizontal trust from peers and vertical trust from health and social care professionals, and these allowed for the creating of relationship-based (relational) networks of care.

People with dementia were attuned to the subtle ways that they were excluded from community, social, civic, and public life or gradually withdrew themselves from social situations in which they felt uncomfortable. For example:

1. People sensed others withdrawing from them during conversations – in the following quote, Albert feels that other people think that he is no longer socially competent: *"Whether they get bored with... I'm taking my time telling them, or they just lose interest"* (Albert, a person with dementia).

2. People with dementia recognised that, at times, they were not able to do things that previously they could: *"I can't write, write things, I can't do it, can I?"* (Connie, a person with dementia).

3. People were very conscious of social expectations about 'doing the right things': *"It puts the fear up you. Whether you're doing the right thing or not...whether you're capable"* (Fred, a person with dementia).

Care partners too felt that they would be become cut off from society when their relative has dementia, for example:

> *All I could envisage for life was struggling and struggling …and (now) I have met five different women from my [peer support] group …and we're just really good friends. We've got some more friends that understand how we feel, whereas I felt one day we'll come to shutting ourselves away from society and this is going to be it, you know, if things get worse.* (Ellen, care partner)

In contrast to these experiences of increasing social exclusion, the participants (who were all involved with peer support networks and/or work with a dementia advisor) spoke of the understanding and acceptance that comes from being with people in a similar situation. There were five aspects to this:

1. Mutual trust and confidence in each other among peers with dementia:

> *We all get on together and help each other… if… somebody is doing something wrong, we can tell them. Or if I'm doing something wrong they'll tell me… We've all, sort of, become friends now.* (Frank, a person with dementia)

2. Restoration of a sense of competence and hope:

> *And it's helping to keep him perhaps… He's thinking, "Well I'm not as bad as perhaps I thought I was." So it may be giving him a bit of hope… knowing he still can go and be with other people.* (Sarah, Paul's care partner)

3. Restoration of a sense of confidence to reconnect socially. Matt described his peer support group as *"A stepping stone for me to go to other places like the library and so forth"* (Matt, a person living with dementia) and Denise too talked of her widening engagement with her community:

Since I've been to the (dementia) cafe and got more confidence, I tend to chat to people more...people on the bus or people you see in town. Whereas I wouldn't do that before. (Denise, a person with dementia)

4. Taking responsibility to care for each other and sometimes advocating for each other:

    We have one gentleman who is more advanced. He's a lovely chap. I kicked up merry hell when they took him off our course (memory café) because of the mere fact that he dropped a point [on an assessment measure] below what he was supposed to achieve. (Ross, a person with dementia)

5. A sense of solidarity with those in the later stages of dementia and support for them to keep coming to groups: *"We too could be someone like that"* (Alice, a person with dementia).

Using the ethic of care principle of trust as an analytical lens to examine the data drew attention to the different ways that trust operates within peer support groups. The 'horizontal' trust that develops between peers was characterized by equality, reciprocity and voluntariness (Barnes et al 2015), with people paying attention to each other and sharing responsibility for each other, recognising that interdependency through care-giving, care-receiving and caring-with was critical to the success of the group.

The vertical trust between people living with dementia and dementia advisors and peer support network facilitators was, however, critical in initiating and facilitating horizontal trust to develop. For example, Sally (John's care partner) spoke of how their dementia advisor *"was able to, sort of, persuade, cajole, encourage, ...where we would have a battle [to join a peer group]"* and that facilitation of peer groups contributed to their success. Competence and 'vertical trust' created the conditions for 'horizontal' trust to develop.

I feel now that they're part of a family, and [peer support network facilitator] as well, you know. The advice and help for John and everything. So we're not stuck here on our own. (Sally, John's care partner)

Professionals needed to earn trust and the skill of achieving these conditions that foster vertical and horizontal trust is not to be underestimated. A lack of competence by facilitators, linked with a lack of paying attention or of taking responsibility, could lead to negative experiences in peer support groups, indicating the importance of understanding care as a practice and not simply a disposition. Tronto (1993) argues that 'Care as practice involves more than good intentions. It requires a deep and thoughtful knowledge of the situation and of all the actors' situations, needs and competencies……and a knowledge of the context of the care process' (p.136/137).

> *[dementia cafe network facilitator] is a lovely person, but sometimes she doesn't realise we are a higher level. And the [craft activity at the dementia café, which was perceived to be too simple] did, sort of, get me.* (Ross, person living with dementia)

The relational nature of care was highlighted, in contrast to care as a commodity to be chosen and delivered, or as an oppressive practice to be resisted (Barnes & Henwood 2015): "*I think she [dementia advisor / facilitator] genuinely cares. You know, it's not just a job, it's more than that to her*" (Suzanne, Jim's care partner).

There is a complex and dynamic nature to the day-to-day lives and changing relationships of people living with dementia that creates tensions because of the relational nature and interdependency of people - and to negotiate this complexity, a network of care with people in which the principles of the ethic of care are exercised (such as trust) is advantageous, as is captured in the following quote:

> *You might be able to walk the tightrope but you might walk it better with a safety net underneath.* (Suzanne, care partner)

The ethic of care principle of responsiveness highlighted that peer support groups are not universally appropriate, with some choosing to limit social contact:

> *Well sometimes it's too much. You know, they sort of try and… Because Matt sometimes feels he's being pushed into things. And you just want a bit of peace and quiet just to do nothing, sometimes. And yet they're very supportive. You can't say, "Oh well, just leave us alone." Because they are good. And then he does enjoy himself anyway. It's just… I think we're both*

tired. And we're both a bit low, at times, as well. So that doesn't, sort of, help. (Christine, care partner for her husband Matt)

A 'collective' approach to care, within a network of relationships, contributed to the overall experience of living with dementia and being socially included. Peer support is just one part of this complex relational network of care. It also includes family/friends, the neighbourhood and various communities to which people belong, and professional carers. The analysis revealed that the person with dementia remains active within their relationships in this network, and not simply a passive recipient of care, through:

<u>Paying attention to needs in themselves and others</u> by recognising there is a problem, such as losing independence, and being open to suggestions as to how take responsibility to address this:

> *(Dementia Advisor) says…you might be able to get back some independence that way….by going to these, erm, these various outlets, like that Stroke Society place, I might go there, erm, find my independence, even if its only limited, it might be better than what it is at the moment…. I mean I still go out and I like to meet people, erm, but I, erm, you know I definitely have noticed my independence has been curtailed a lot because of the situation that I find myself in.* (Richard, person living with dementia)

The example below shows a person with dementia paying attention to the needs of his wife:

It happens to both of you, sort of thing, you know…it (support group) should have been a little bit more how your carer feels. Like the wife and stuff like that, you know. Because, I mean, they go through it just as much as we do, you know. And I think they don't really look after the spouse as much. It's all… Like me having dementia, it seems to be all me, you know. And I don't want it all me. And I want to be able to say, "She's okay" like, sort of thing, you know. (Luke, person living with dementia)

<u>Taking responsibility for others</u> such as family or peers and also themselves by 'delegating competency' when they need support with certain things:

> Suzanne (care partner): *I think you're more open to help now than you were a short while ago.*

> Jim (person living with dementia): *Yeah, alright.*

Suzanne: *Because you, we had both a conversation didn't we after Christmas, sometime after Christmas, erm, where you actually said to me 'I do actually understand you are helping me, now I didn't at one time' this is what he's saying 'I didn't, I realise now that you are trying to help me even though its maybe not what I want to hear'. So that was a breakthrough.*

Jim: *Oh yeah. I know I've not always been nice to her, I know that, but, the way I've been feeling, you know, then. I mean now I feel a lot better, but you know a couple of months ago I was feeling down, down and out sort of thing really. I felt like disappearing off the earth. Erm, and I know I wasn't fair to(Suzanne half the time. But that's just something I couldn't help with, you know, at the time. Now, I'm not likely to, am I? …. I feel much better now anyway, I really do …. I mean, I owe her a lot, you know, for what she's doing for me. You know, I've got no argument over that. You know, she's looking after me as much as she can and as much as, maybe I should say it, but I let her at times. Sometimes I don't, do I, love?*

<u>Choosing to trust others</u> who have earned their trust or entrusting aspects of their lives to others:

PWD - [Dementia Adviser] knows me. And she has an understanding of the… My behavioural problems, if you want to put it that way. But the most important help I've had is definitely the fact that I trust [Dementia Adviser] and that [Dementia Adviser] is able to get me to do things in the past and in the future if it comes up, that nobody else would get me to do. So I think it's trust. (John, person living with dementia)

<u>Communicating their response to care</u>, either verbally or non-verbally:

And there's quite a few people there that I haven't known for long, but now there's others there that I've known for quite a while. And also had a couple of young chaps come down from other places, you know, that, I don't know where they're living or anything like that, but they come in there and they enjoy the singing as well, so, its quite good, yeah…. Well as soon as you walk in there there's a cup of coffee given to you, or a cup of tea, or whatever you want, and some biscuits and its nice. You know, that's all very nice. It sounds silly but it isn't, its really nice. (Jim, person living with dementia)

We're in this together – a co-operative endeavour

During the collaborative analysis workshops, people with dementia and their care partners discussed how co-operation in relationships is required to ensure they do not become socially isolated. Responding to the data being discussed, and referring to their own experiences, they spoke of situations where they adjusted their communication or actions to meet each other's needs, to demonstrate care and to nurture solidarity within the relationship. The metaphor-like terms used by people living with dementia during the workshops provided a route into talking and understanding the experience of living with dementia and dementia care in a different way with the workshop groups – as an heuristic device for discovering more in a secondary data analysis.

When the researchers returned to the data with the metaphor-like terms as another lens alongside the notion of co-operation, further analysis revealed subtleties in communication and behaviour that relate to: Co-operative Communication, Co-operative Action, and Co-operative Care.

Co-operative Communication

Co-operative communication addresses the importance of engaging with the meaning behind the words that someone uses. For example, rather than assuming that a person with dementia is confused because their words don't immediately make sense, it is essential to 'listen-on' - to keep on listening and not lose patience or assume that the person is speaking nonsense, because the person is often saying something meaningful behind the words. In the following example, Eve demonstrates how her 'paying attention' to her mother's conversation is underpinned by an assumption that she is trying to communicate something:

> *We were coming home from the café yesterday and they were building flats up the road and she said "oh look, they are burning those flats". So I said "I don't think you mean burning, do you. But what word did you mean?" and she said "um, you know that word that begins with B". And she meant to say building but she said burning instead.* (Eve, care partner for her mother Marjorie)

Examples of where 'listening-on' did not happen were also identified, with consequent distress and strain on relationships.

She then starts arguing with me. And that's where I lose it and I think, "If you can't trust me to tell you that you're wrong, or you're mistaken, or that isn't the way it is". So that's when I go crazy. It's when you're not listening to what I'm saying. And there's been many a bust up where I turn around and say to her, "You have got to trust me in saying, [Person with Dementia], that wasn't right. You've got to accept it." (Simon, care partner for his wife Alice)

Evidence of dementia advisors listening in a co-operative way was apparent, which helped ensure that support which suited the family and their particular situation was provided, as in the following example:

"Some of the suggestions [dementia advisor] gave us …. because, having got to know us a little bit, and sort of seeing how things worked and learnt a bit about the characters involved, it meant that her suggestions were personal rather than just giving a whole load of information but with no qualification between the different options" (Annie, care partner for her father)

Co-operative communication also means taking a '50:50' approach - for example, being in a restaurant and helping the person prepare in advance what they are going to say to the waiter. This enables people with dementia to remain actively involved in social situations, and to be seen as being actively involved, drawing on their continued capabilities, rather than passively present.

Co-operative Action

There were examples in the data where the importance of working with people with dementia, drawing out their continuing abilities in a form of cooperative action, was seen. The quote below illustrates some of the fine texture in having remaining abilities recognised and supported through co-operative action, within the context of a helping relationship which supports interdependence, rather than aiming for independence.

And they might get him to peel a couple of carrots and you think, you know, if it takes him a while to do it, so be it. But, you see, I don't have time for that at home. It's... You know, it's totally different, but if somebody can do it on a one-to-one with him, he will. (Nina, care partner)

Co-operative action is consistent with the ideas proposed by Hyden (2014) in advocating for a framework that focuses on what people can do together rather than focusing on individual abilities – recognising that cognitive and communicative resources are not exclusively individual but part of a collaborative and communicative context. Co-operative action predicates on an awareness of one's own and the other person's competence. Competence is one of the Ethic of Care principles and cannot be assumed to be present (it is a practice rather than an attribute, Tronto 1993). While some examples within the data did demonstrate the level of competence to enable them to take co-operative action with people with dementia, others did not.

The problem that I've found with a lot of the memory cafes is the volunteers are lovely people, but the big problem they have is they have a tendency to talk to you if it's your mentally... You mention the word dementia and they think you're a child. They talk to you not as an adult. (Ross, person with dementia)

Doing things *with* people, as opposed to *on* them or *for* them leads to the idea of co-operative caring and solidarity with people with dementia.

Co-operative Care

Recognising relational networks of care, in which we are all beneficiaries as well as providers of care, helps to highlight the relational nature of human beings, the collective nature of care, and that we all need various degrees of help. It breaks down polarizing distinctions between care-givers and care-receivers as we are all both. Shona, in the following quote, describes this merging of care roles, illustrating how encouraging her mother to speak is beneficial to both of them:

I don't know if it's right or wrong, but I do encourage my mum to do the talking, you know... like sometimes I can't be there when (the dementia advisor) comes, other times I think, it's good for my mum to speak up for herself and you know, I say to her before (the dementia advisor) comes "have a think about things, perhaps write down a few things" and you know

for her to sort of take more ownership in it because, you know, I don't want to. It's a funny thing life, isn't it, you keep changing roles don't you. (Shona, care partner of her mother)

Recognising the duality that can exist between care giver / receiver roles reduces the sense of 'otherness' that people with dementia often experience due to the effects of dementia, which can contribute to their social exclusion. Instead, it promotes a sense of solidarity with people with dementia and acknowledgement of the reciprocal way they continue to contribute to relationships in positive ways, 'caring with' family and friends as well as peers.

This research reveals the sometimes 'unspoken' expectations of citizenship through social networks and engagement, which are frequently taken for granted but are disrupted by dementia. The opportunity to retain solidarity with people with dementia can be facilitated by recognizing the obstructions that some social expectations can create, and acting flexibly within them to create possibilities to maximize peoples' abilities, participation, and social inclusion. In the following quote, Albert brings together in a single description many of the aspects of relational networks of care and co-operative endeavour that have been highlighted in this work:

But within going (to the dementia café), it was just so friendly. Just so... as though I knew everybody straight away. And nothing is too much trouble for them. It really isn't. And they just sit and listen and then help. And that's brilliant. Like I say, I've never stopped talking... You know, I've come back from each class – because it's... It's got me out of sitting there and just... You know, I've never been a real telly watcher, but I have to be now because... I don't know where to go. I've joined a gym. My wife, she joined me to a local gym and I go there twice a week. But, I know it sounds awful, I feel uncomfortable sometimes. And I keep myself to myself, in a way, because... And I try and talk to people, but as soon as I start talking to people it's like, "Yeah, okay". And you can see them wanting to go on another machine. And I think "Crikey, I never used to be like that when I was... You know, I used to talk to people and". No matter what I thought of whoever, we were all equal. But, you don't seem to get that now. Or I don't, with what people... I won't say normal people, because it's wrong to say I'm not normal, but, you know, people that's basically working and that. They know that you're a little bit different. But, yeah, these groups are great, yeah. (Albert, person with dementia)

Ethic of care has a transformative ambition (Barnes et al 2015) and a practical application of these findings could be to consider co-operative action within advice and guidance for carers, both family and paid carers. This could help empower both carers and people with dementia within the context of interdependent relationships – empowerment through care (Keyes et al 2015). Co-operative action, as this quote shows, also takes time. Since care is more than a private issue for families but also a political issue (Barnes et al 2015), the time it takes to act co-operatively with people with dementia needs to be considered within policy and practice in health and social care for people with dementia.

Discussion

At the outset of this participatory secondary data analysis, we sought to address a number of research questions, derived from the theoretical frameworks of Douglas' cultural theory of risk (Douglas & Wildavsky 1982) and Tronto's ethic of care (Tonto 1993):

- What 'groups' and 'grids' are evident and how do these change as dementia is experienced? What new groups and grids emerge as dementia is experienced and how are they characterised?
    - We found many examples, in the data and that were shared during the workshops with people living with dementia, of situations in which people felt excluded by their former friendship and social groupings (as Albert, above, describes) or chose to withdraw themselves from family and other social gatherings. We also found many examples of people forming new groupings with people with whom they found a shared identity (as Ellen describes above, and as identified by Keyes et al 2014). Since the data originated from a study of peer support networks and their facilitation, and the co-analysts with dementia were largely familiar with a peer dementia group, it is important to note that it is likely that our study identified more frequent peer identification than may be found in the general population.

- How do accounts of interactions between people with dementia, carers and other significant people portray attentiveness, responsibility, competence, responsiveness and trust?
    - We also identified many accounts, in the data and shared in the workshops, of people experiencing these characteristics of the ethic of care failing to be upheld, but also

examples where they were. Above, for example, Connie questions her competence to write and Sarah highlights how her husband comes to realise he has more competency than he had perceived, and Frank talks of benefiting from all of these characteristics within his peer group.

- What dynamics maintain or disrupt former groups and grids?
  - What we found was that the dynamics that maintained or disrupted former groups were situations in which the grids (the 'terms of engagement' with a group) were upheld or were compromised. Invariably, these dynamics were of the characteristics of ethic of care. For example, this is illustrated in Figure 2 in relation to transitions between groups.

[Insert Figure 2 around here]

- What are the interpersonal and societal dynamics described that promote a positive cycle of the ethic of care towards an empowering relationship; or that produce a negative cycle of a disempowering relationship?
  - What we found was evidence of subtle mechanisms that alter how people with dementia experience social exclusion and inclusion. This led us to identify three 'co-operatives' as critical to promoting empowering relationships that allow for the inclusion of people living with dementia: Co-operative communication, Co-operative action and Co-operative care.

Solidarity and Cultural Theory

This research indicates that solidarity in the form of co-operative communication, co-operative action and co-operative care are key aspects of inclusion and citizenship for people living with dementia. Let us return here to the cultural theory of risk to explore how it informs and is informed by this research. Evans (2007) describes cultural theory as a 'classification system' in which grids can be seen as the 'constraints' of the structure / group. Although a group is a collective, Evans highlights the individual's importance in influencing the group and how it functions, so the relationship of individual to the group remains important irrespective of the

nature of the group (indeed, it is critical to it since people are active agents in the group). Albeit in relation to corporations, Evans (2007) writes that:

> 'explicit rules and orders determine social opportunities, and (the individual's) relative ranking within the group defines their status. Therefore the more that a member of a group feels bound by a collective decision, the higher they are on the "Group" dimension. The greater the degree to which the member follows imposed rules, the higher they are on the "Grid" distinction. This blend of "Group" vs. "Grid", of integration vs. regulation, of solidarity vs. constraint, provides the framework upon which a comparative Cultural Theory can be created."' (Evans 2007 p.4).

Thus, integration and solidarity are more evident in social organisations that have a high group dimension combined with a low grid distinction. This group / grid blend results in an egalitarian social organisation in which the group is maintained by strong relationships between group members, where there is little role differentiation between members and where the group is bounded by a shared opposition or sense of difference to the world outside the group. It is, therefore, the very things that alienate and exclude people with dementia from society which lead to their sense of peer solidarity – indeed Douglas herself felt that this societal form would appropriately describe a group of dissidents! Ironically of course, the contemporary movement of activism by people with dementia (Bartlett & O'Connor 2007, Bartlett 2014) reflects this social positioning and associated terminology of dissidents; those who are no longer part of the 'mainstream' in society and who campaign against their exclusion.

What is evident in this research is that within the strong relationships between peer members, people are able to expose their vulnerability (for example, one person spoke of what would happen if they took their clothes off in a peer group meeting), trusting in the knowledge that others in the group will 'look out' for them – and they make the distinction that this would not be possible 'outside'. In so doing, the risk of exposing an 'inappropriate' behaviour by an individual is negated by the group capacity to be responsive – the solidarity of the group ensures that the risk of doing something potentially harmful to yourself (whether that is physical harm or harm to your dignity) is minimised. Evans (2007, p. 5) also observes that 'the greater the solidarity of a group, the weaker the personal liability of any member within it'. This accords with 'collective care' - or 'caring with' that Tronto (2013) has recently added to the ethic of care theory as a means of adding solidarity to care thinking, and with component 5 of the Nuffield Council on Bioethics for people with dementia (the requirement to act in accordance with solidarity), which

implies the need to recognise the citizenship of people with dementia: 'we are mutually interdependent, so have responsibilities within families as well as in society as a whole' (Nuffield Council on Bioethics 2009 p29-30).

To be in solidarity requires a rejection of exclusion, and the findings of this research reflect a large body of evidence on the stigma associated with a dementia diagnosis which both causes and reflects the reality of some people's experiences – loss of status and family and friends, social exclusion (Williamson 2008), compounded by the effect of self-stigmatisation in which people with dementia may view themselves as 'lesser' people. Our findings go further in revealing more of the underlying mechanisms that contribute to this, as well as offering solutions, given the damaging effect of exclusion on psycho-social well-being and quality of life (Williamson 2008). The Scottish Social Attitudes Survey (Reid et al 2014) showed evidence of a persistent prejudice and fear, as well as stigmatising attitudes among a small minority of people. For example, 19% said 'I would find it hard to talk to someone with dementia' and 12% said 'I would feel ashamed' if given a diagnosis of dementia. Two in five people (39%) said they would not want their employer to know if they were diagnosed with dementia. Indeed, the social positioning of people with dementia by others (without dementia) is implicated in social exclusion as much as the neuro-physiological effects on the brain of dementia (Sabat & Lee 2011).

Inclusion Through Relational Care

The co-operative endeavor of living with dementia that this research highlights emphasizes the importance of the relational context in enabling co-operative listening, co-operative action and co-operative care. Pozzebon et al (2016) also argue that sustaining relationships is central to the human experience and so support for relationships is 'warranted'. We would state this more emphatically – this research argues that sustaining relationships and forging new ones is essential for the welfare of people living with dementia.

Globally, dementia policies are recognising that support for social inclusion, which is a fundamental human right, is core to enabling people to live well with dementia (e.g. Alzheimer's Disease International 2016). Providing post-diagnostic support and developing dementia friendly communities are key parts of this. However, while many people with dementia are being empowered to live well (Clarke et al 2016b), a gap remains between policy

and people's everyday experiences of living with dementia - as identified in this research, marginalisation within neighbourhoods and communities and, at times, in families is still experienced. This research highlights the very subtle social interactions that lead to exclusion and sustain the inclusion of people with dementia and care partners, and argues for the need for more people knowing how to communicate and act in co-operative ways that draw on the remaining capabilities of people with dementia. It also highlights the needs of those who do not consider themselves to be 'joiners' and for whom dementia peer support groups do not meet their needs. While many people benefit from 'services' such as peer support groups, or self-organising grassroots groups, these do not suit everyone and indeed access to them is predicated on meeting 'grid rules' that differentiate someone as somehow different from others. What is required is more attention to establishing dementia inclusive social expectations of co-operative endeavour, and in so doing enabling co-operative communication, co-operative action and co-operative care at both the micro-interpersonal level of relationships and within our neighbourhoods.

There are challenges in achieving this since co-operative endeavour disrupts the current dominance of individual responsibility and autonomy – demanding attention to responsibility and autonomy in a more relational and inter-dependent way. It highlights the tensions between the societal mandate to protect vulnerable citizens (as individuals) and the right to be protected, and the right to have freedoms of agency protected within a relational approach of collective (mutual and reciprocal) care. This challenge to the ways in which we perceive and organize care in our societies is important. As Tronto (2013) and Barnes et al (2015) argue, care is political and without it we can't function as a society – and it is what we need to attend to in order to develop more inclusive ways of living with people with dementia.

Critique of the Research

The data in this research derives from participants who were involved in peer support - an artefact of the sampling process and original research focus. Cultural theory requires us to be open to those who engage with less structured groups and there were indications in our data of people who described themselves as 'not joiners'. This warrants further research that focuses on people living with dementia who do not participate in groups, whether through choice or lack of access. The sampling process and original research focus also meant that the dataset we analysed included people with dementia who were able to participate in a supported research

interview, as was the case for those contributing to the data analysis workshops. Consequently, the findings of this research may be less pertinent to those who are more impaired by dementia. The process that we developed of secondary data analysis in collaboration with people living with dementia is novel and has stretched the boundaries of both secondary data analysis methods and involvement and collaboration in research in the field of dementia. As such, we look forward to further advances in this area as other researchers build on our approach and tackle the methodological challenges this brings.

Conclusion

These findings add to our understanding of how the usual 'social expectations' within relationships and within communities are disrupted by dementia, and how adopting co-operative endeavour in the form of co-operative communication, co-operative action and co-operative care can help people living with dementia to remain socially included.

References

Adams, T. (2010) The social construction of risk by community psychiatric nurses and family carers for people with dementia. *Health, Risk & Society*, 3,*3*, 307-319.

Alzheimer's Disease International (2016) Improving healthcare for people living with dementia: Coverage, quality and costs now and in the future.
URL: https://www.alz.co.uk/research/worldalzheimerreport2016sheet.pdf
Accessed 16/11/2017.

Austin, A., O'Neill, J. & Skevington, S. (2016) Dementia, Vulnerability and Well-being: Living Well With Dementia Together. University of Manchester for Age UK and the Manchester Institute of Collaborative Research on Ageing. Manchester, UK, March 2016.

Barnes, R., Auburn, T., & Lea, S. (2004). Citizenship in Practice. *British Journal of Social Psychology,* 43, *2,* 187-206.

Barnes, M. & Brannelly, T. (2008) Achieving care and social justice for people with dementia *Dementia* 15(3) 384-395

Barnes, M. (2012) *Care in Everyday Life. An ethic of care in practice*. Policy Press, Bristol.

Barnes, M. Brannelly, T. Ward, L. Ward, N. (eds) (2015) *Ethics of Care: Critical advanced in International Perspectives Policy* Press: Bristol

Barnes, M. & Henwood, F. (2015) Inform with Care: Ethics and Information in care for people with dementia *Ethics and Social Welfare* 9(2) 147-163

Bartlett, R. & O'Connor, D. (2007) From personhood to citizenship: Broadening the lens for dementia practice and research *Journal of Ageing Studies* 21 107-118.

Bartlett, R. & O'Connor, D. (2010) *Broadening the Dementia Debate: Towards Social Citizenship.* Policy Press: Bristol.

Bartlett, R. (2014) The emergent modes of dementia activism *Ageing and Society* 34(4) 623-644.

Brannelly T. (2006) Negotiating ethics in dementia care: an analysis of an ethic of care in practice *Dementia* 5(2) 197-212.

Brannelly, T. (2011) That others matter: the moral achievement – care ethics and citizenship in practice with people with dementia. *Ethics and Social Welfare*, 5,*2*, 210-216.

Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia*, 15(3), 304-314.

Clarke C.L., Gibb C., Keady J., Luce A., Wilkinson H., Williams L. & Cook A. (2009) Risk management dilemmas in dementia care: An organisational survey in three UK countries. *International Journal of Older People Nursing* 4:89-96.

Clarke C.L., Keady J., Wilkinson, H., Gibb C., Luce A., Cook A. & Williams L. (2010) Dementia and risk: contested territories of everyday life. *Journal of Nursing and Healthcare in Chronic Illness* 2:2;102-112.

Clarke, C.L., Keyes, S.E., Wilkinson, H., Alexjuk, J., Wilcockson, J., Robinson, L., Corner, L. & Cattan, M. (2014) Organisational Space for Partnership and Sustainability: Lessons from the Implementation of the National Dementia Strategy for England. *Health & Social Care in the Community*. Published online: 22 SEP 2014 | DOI: 10.1111/hsc.12134

Clarke C.L., Rhynas S., Schwannauer M. & Taylor J. (2016a) Advancing Risk and Resilience – Why is it so Important? In: Clarke C.L., Rhynas S., Schwannauer M. & Taylor J. (eds) *Risk and Resilience: Global learning across the age span.* Dunedin Press, Edinburgh.

Clarke, C.L., Keyes, S.E., Wilkinson, H., Alexjuk, J., Wilcockson, J., Robinson, L., Reynolds J., McClelland S., Hodgson P., Corner, L. & Cattan, M. (2016b) 'I just want to get on with my life' – A mixed methods study of active management of quality of life in living with dementia. *Ageing & Society.* DOI: https://doi.org/10.1017/S0144686X16001069

BLIND et al (in press) A seat around the table: participatory data analysis with people living with dementia. *Qualitative Health Research*

Department of Health (2009) *Living well with dementia: A National Dementia Strategy*. London: Department of Health.

Department of Health (2016) *Prime Minister's Challenge on Dementia 2020 Implementation Plan*. London: Department of Health

Douglas, M., & Wildavsky, A. (1982). *Risk and culture: An essay on the selection of technical and environmental dangers*. Berkeley. Cal.: University of California Press.

Evans, A.J. (2007) Towards a Corporate Cultural Theory; ESCP-EAP European School of Management

Garcia-Dia M.J., DiNapoli J.M., Garcia-Ona L., Jakubowski R., O'Flaherty D., (2013) Concept Analysis: Resilience, *Archives of Psychiatric Nursing* 27 pp264-70.

Harris, P. B. (2012). Maintaining friendships in early stage dementia: Factors to consider. *Dementia*, 11(3), 305-314.

Harris, P. B. (2013). Dementia and friendship: the quality and nature of the relationships that remain. *The International Journal of Aging and Human Development*, 76(2), 141-164.

Hicks M. & Conner N.E. (2014) Resilient ageing: a concept analysis, *Journal of Advanced Nursing* 70 (4) pp744-55.

Hutcheon E. & Lashewicz B. (2014) Theorizing resilience: critiquing and unbounding a marginalizing concept *Disability and Society* 29 (9) pp1383-97

Hyden, LC. (2014) Cutting brussel sprouts: collaboration involving persons with dementia *Journal of Ageing Studies* 29, 115-123.

Keyes S.E., Clarke C.L., Wilkinson, H., Alexjuk, J., Wilcockson, J., Robinson, L., Reynolds, J., McClelland, S., Corner, L. & Cattan, M. (2014) 'We're all thrown in the same boat…' A qualitative analysis of peer support in dementia care. *Dementia* Published online 17/4/14 DOI: 10.1177/1471301214529575

Keyes, S. Webber, S. & Beveridge, K. (2015) Empowerment through care: Using dialogue between the social model of disability and an ethic of care to redraw boundaries of independence and partnership between disabled people and services *European Journal of Disability Research* 9, 236-248.

Langford, I. H., Georgiou, S., Bateman, I. J., Day, R. J., & Turner, R. K. (2000). Public perceptions of health risks from polluted coastal bathing waters: A mixed methodological analysis using Cultural Theory. *Risk Analysis*, 20(5), 691–704.

Lupton D. (2013) *Risk* (2nd edn). Routledge: London.

Nuffield Council on Bioethics (2009) *Dementia: ethical issues*. London: Nuffield Council on Bioethics.

Powell, J., Wahidin A. & Zinn, J. (2007) Understanding risk and old age in western society. *International Journal of Sociology and Social Policy* 27, 65–76.

Pozzebon, M. Douglas, J. Ames, D (2016) Spouses' experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research *International Psychogeriatrics* 28(4) 537-556.

Prior, D., Stewart, J. & Walsh, K., (1995).*'Opening up Government'*. Chapter 8 of *Citizenship: Rights, Community and Participation*. London: Pitman.

Reid, S., Waterton, J. & Wild, A. (2014) *Attitudes to Dementia: Scottish Social Attitudes Survey.*

Ricoeur P. (2003) *The Rule of Metaphor: The Creation of Meaning in Language*. Routledge, London.

Robinson, L., Hutchings, D., Corner, L, Fitch, T., Hughes, J., Brittain, K. & Bond, J. (2007) Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health, Risk and Society* 9(4):389- 406.

Sabat, S.R. & Lee, J. M. (2011) Relatedness among people diagnosed with dementia: Social Cognition and the possibility of friendship *Dementia* 11(3) 315-327.

Scottish Government (2017) *Scotland's National Dementia Strategy 2017-2020*. Edinburgh: Scottish Government.

Sevenhuijsen, S. (2003) The place of care: the relevance of the feminist ethic of care for social policy. *Feminist Theory*. 4:2;179-197.

Tronto, J. (1993) *Moral Boundaries. A Political Argument for an Ethic of Care*. Routledge, London.

Tronto, J. C. (2013). *Caring democracy: Markets, equality, and justice*. NYU Press.

Ward, R., Howorth, M., Wilkinson, H., Campbell, S., & Keady, J. (2012). Supporting the friendships of people with dementia. *Dementia*, 11(3), 287-303.

Williamson, T. (2008). *Dementia: Out of the shadows*. Alzheimer's Society.

Acknowledgements

Figure 1 - The data analysis model of nodes that related to the ethic of care principle of attentiveness

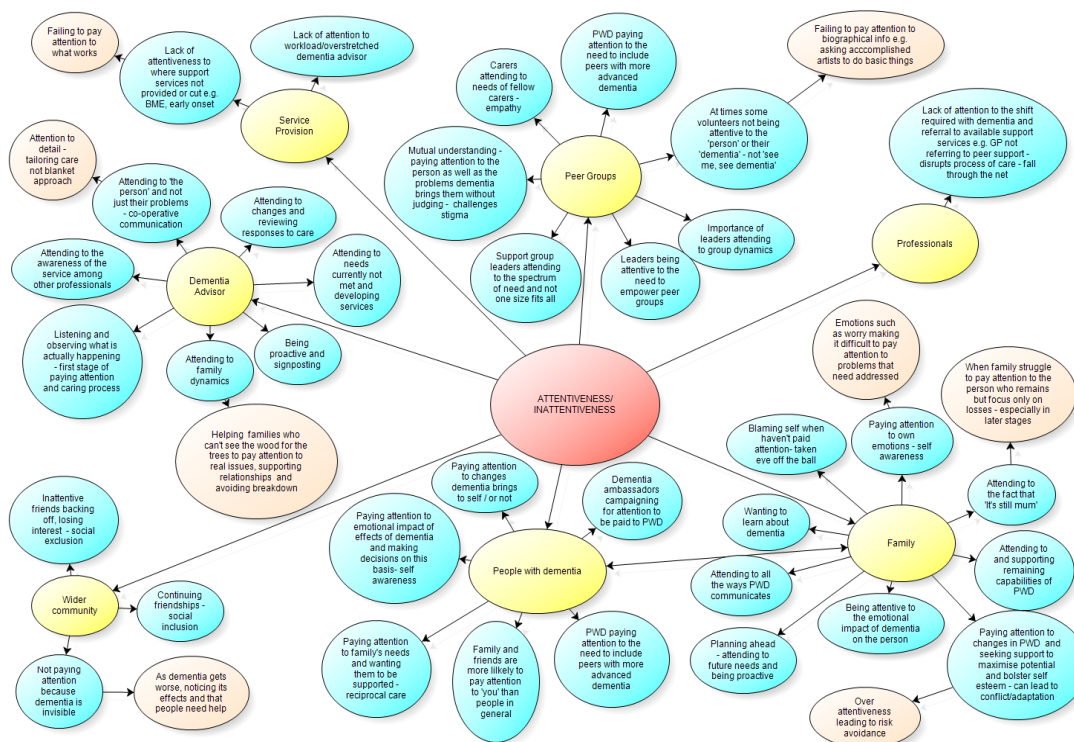**Table 1 – Co-analyst Participation in the Key Aspect 2 Workshops**

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 – Metaphor-like expressions elicited in co-analysis workshop

- '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: A developmental model of analysis illustrating the moments of transition when people move between one group and another. Features of the Ethic of Care theory that influence the process of making this transition are included where demonstrable.