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Creating Space for Citizenship: The Impact of Group Structure on Validating the Voices of People with Dementia

ABSTRACT

Recently, there has been increasing attention given to finding ways to help people diagnosed with dementia “live well” with their condition. Frequently however, the attention has been placed on the family care partner as the foundation for creating a context that supports the person with dementia to live well. A recent participatory action research (PAR) study highlighted the importance of beginning to challenge some of the assumptions around how best to include family, especially within a context of supporting citizenship. Three advisory groups consisting of 20 people with dementia, 16 care partners, and 3 service providers, were set up in three locations across Canada to help develop a self-management program for people with dementia. The hubs met monthly for up to two years. One of the topics that emerged as extremely important to consider in the structuring of the program revolved around whether or not these groups should be segregated to include only people with dementia. A thematic analysis of these ongoing discussions coalesced around five inter-related themes: *creating safe spaces*; *maintaining voice and being heard*; *managing the balancing act*; and *the importance of solidarity*. Underpinning these discussions was the fifth theme, recognition that ‘*one size doesn’t fit all*’. Overall an important finding was that the presence of family care-partners could have unintended consequences in relation to creating the space for active citizenship to occur in small groups of people with dementia although it could also offer some opportunities. The involvement of care partners in groups with people with dementia is clearly one that is complex without an obvious answer and dependent on a variety of factors to inform a solution, which can and should be questioned and revisited.

KEY WORDS: dementia, citizenship, group, family care, participatory action research

INTRODUCTION

With an emphasis upon earlier diagnosis, and the development of pharmacological treatments for slowing the progression, people with dementia can expect to live longer post-diagnosis. This changing picture is challenging a tendency to focus on accepting and preparing for the inevitable deterioration and total dependency that was seen as accompanying a diagnosis of dementia, to recognize dementia as a chronic health condition that is mediated, at least in part, by how one is treated within a broader interactional and societal context (O'Connor et al., 2007). Within this context, the notion of "living well" with dementia is gaining currency and self-management is being considered as one way of achieving this.

Self-management programs can be effective in assisting people with chronic conditions to learn new skills, organize their lives, and create a sense of order as they deal with the transitions and responses to illness (Kralik et al., 2004). While very popular in responding to some chronic health issues such as arthritis and diabetes, these programs have been slow to be adopted in dementia care although the few attempts to adapt them to dementia demonstrate their potential applicability (ie., Martin et al., 2013; Mountain, 2006). This is despite increasing research demonstrating the continuing abilities of people with dementia to find effective ways of coping, to live well, and to even become self-advocates (Bartlett, 2014a; 2014b; Clare, 2002; Harman & Clare, 2006).

At least part of the reluctance to apply ideas of self-management to dementia may be related to the stigma that accompanies a diagnosis of dementia. A diagnosis of dementia can supersede all other aspects of one's identity (Milne, 2010) and people with dementia often feel that they are treated with less respect once a diagnosis is acknowledged (Burgener et al., 2014a; Burgener et al., 2014b, Mitchell et al., 2013). In short, stigma labels people with dementia by their diagnosis, with negative stereotypes of a loss of self and capabilities (Behuniak, 2011) and a tendency to feel 'less than' (Swaffer, 2014). Behaviours and actions become interpreted through this lens, and people with dementia are often presumed to lack capacity to oversee their own lives.

Assumptions about the degenerating abilities and behaviours associated with dementia shape our understandings of the ways in which families are involved with people with dementia. Research has outlined the changes that can occur within family relationships, particularly marital or intimate partnerships, as family members take on increasing responsibility for overseeing the needs of the person with dementia. For example, some research suggests an important shift in the relationship, as partners begin to see themselves as 'carers' rather than within their relational role of husband or wife (Vernooij-Dassen et al., 2006; O'Connor, 2007) – at least some of this shift is societally imposed as others increasingly position the family member as a 'care-giver' (O'Connor, 2007). The dominant understanding of the relationship between the person with dementia and his or her care-partner positions the person with dementia as 'dependent' and potentially a 'burden' (Davies & Gregory, 2007; McGovern, 2011; Vernooij-Dassen et al., 2006) although there is research that challenges the notions that the experience is simply about loss, dependency and negative change and a small but growing body of research is exploring meaning making in couplehood and strategies to sustain couplehood (Davies & Gregory, 2007; Hellström et al., 2005; McGovern, 2011). Ultimately however, despite some refocusing, there is an assumption underpinning much of the general understanding of the family role in the dementia experience that positions the family member as a vital 'co-partner' at a minimum, responsible for providing protection and care.

Recognizing the importance of the family in the care of the person with dementia, services in many western countries have historically been geared towards family care partners, rather than people with dementia. This began to shift about ten years ago in some countries (for example, Canada) with the development of services – for example, education, support groups, leisure programs and health care services - that were geared specifically for people with dementia, or for both people with dementia and their care partners (e.g., Zarit et al , 2004). Little research, however, has explored the implications - including advantages or disadvantages - of separate or conjoint participation and why these decisions might be important.

The need to question how family are involved as supports for persons with dementia becomes more pressing when attention shifts to the importance of citizenship within the context of living well with dementia. Specifically, countering the tendency to focus on dependency and family care, a citizenship lens promotes a more active and political understanding of the dementia experience. Social citizenship as a concept is directly related to the stigma that people with dementia experience, in that the experiences of dementia are shaped and constrained by social and cultural structures in our society (Bartlett & O'Connor, 2010). Personhood and person-centred care has been described as a way to address stigma (Milne, 2010) because it promotes a lens that sees the person behind the dementia. Social citizenship extends the notion of personhood, suggesting that "...the debate about dementia is not just about seeing a person; it is about seeing a person as an active social agent" (Bartlett & O'Connor, 2010, p. 5). A social citizenship framework posits a rights-based – as opposed to needs-based – lens that draws attention to six basic components of living well as a social citizen: 1) opportunities for growth, change and development; 2) a power analysis that recognizes how one's social locations help shape one's experiences of the world; 3) respect for personal meaning-making and finding purpose; 4) promoting active participation (as opposed to simply being included); 5) the importance of building community and solidarity as both a social and political goal; and 6) creating a context that challenges stigma and discrimination (Bartlett & O'Connor, 2010). With its focus on the person with dementia, a citizenship lens implicitly fosters questions as to how family involvement may promote, or stymie, the experiences of someone with dementia to practice full citizenship.

Interrogating the role of the family within the context of living well with dementia, querying it as de facto supportive, constitutes a wicked question: It gets at the very heart of our assumptions about family care. Wicked questions or problems are those questions which are complex in nature, and do not have an obvious answer (Ritchey, 2011; Tamarack, n.d.). As defined by Ritchey (2011), wicked problems are:

...ill-defined, ambiguous and associated with strong moral, political, and professional issues. They are *subjective* and strongly stakeholder dependent: there is often little consensus about what the problem actually *is*, let alone how to resolve it. Above all, WPs won't keep still: they are sets of complex, interacting issues evolving in a dynamic social context. Often, new forms of wicked problems emerge *as a result* of trying to understand and solve one of them. (p. 20).

The questions of the involvement of care partners and people with dementia together are complex, value-laden, encompassing family and relational dynamics with group dynamics and the context of dementia. The purpose of this paper is to begin to explicitly address this 'wicked'

question –acknowledging that the assumptions and practices surrounding inclusion of care partners in groups with people with dementia need to be further interrogated.

Methodology

Data for this paper was generated through a larger study titled “Developing a Self-Management Program for People with dementia” led by the first author (E. Wiersma) in partnership with the Alzheimer Society of Ontario (D. Harvey) using a participatory action research approach (PAR). PAR is a reflexive process as participants are engaged in critically reflecting on current practice collaboratively, to challenge assumptions and work towards social justice and transformation, and where lived experiences are privileged and valued (Kemmis & McTaggart, 2000). The purpose of the larger study was two-fold: 1) to translate knowledge about living well with dementia into a self-management program for people with dementia, and 2) to examine the process whereby people with dementia and other knowledge users are engaged meaningfully in program development. A research team involving 10 academic researchers, 3 people with dementia (who also chose to refer to themselves as personal advocates because of their other advocacy work), and 5 service providers, were involved in this project. Three main sites in two provinces (Ontario and BC), were involved in this project. The project was approved by the Research Ethics Boards at four organizations, and informed consent was obtained from all participants in the advisory hubs.

At each of the three main sites, advisory hubs were set up and facilitated by individuals from the research team. Participants were recruited through existing connections with the researchers and the Alzheimer’s Society. The purpose of the advisory hubs was to provide input and feedback on the development of the self-management program. Each advisory hub had a different structure. Group One (G1), co-facilitated by two research team members (a researcher and service provider), consisted only of people with dementia and included 6 men and 2 women. Group Two (G2), co-facilitated by a research team member and project staff, consisted of 6 men with dementia and 6 female care partners (all spouses) who separated for discussions every meeting. Two service providers who had experience with people with dementia and familiarity with the group also participated. Group Three (G3) consisted of 6 people with dementia (5 female and 1 male), 7 care partners (5 male and 2 female), and 1 service provider. This group participated together for discussions, although occasionally had sessions where they were separated. In total, 20 people with dementia participated in the advisory hubs, along with 13 family care partners and 3 service providers. Support was also provided by project staff, and each group had one or two individuals to assist with note-taking and other data collection tasks.

The advisory hubs met for between one to two years on a monthly basis for an hour and a half to two hours each. The meetings were tape-recorded and transcribed. The first meetings were spent exploring what self-management meant to the group members. Conversations were then structured around a number of themes which emerged from these initial discussions as well as ideas generated from a literature review. These themes included, for example, maintaining a positive attitude, staying connected, accepting a diagnosis, staying well physically, communication, and adapting to change.

An important topic that generated discussion revolved around the inclusion of care-partners in the self-management program. Some of these discussions were initiated by questions brought specifically to the advisory hubs for discussion from the research team, but this was also a topic that generated spontaneous discussion by advisory hub members. The focus of this paper

is to discuss the data that emerged in relation to the question of care partner involvement in groups for people with dementia. All transcripts were reviewed and any data related to this topic was abstracted for further, detailed thematic analysis. Analysis focused around two questions: 1) What issues need to be considered when deciding whether or not to include care partners in a group program for people with dementia? and 2) How does the involvement of care partners facilitate or hinder the enactment of citizenship by people with dementia? The data that was abstracted was then coded, keeping in mind the above two questions. Quotes were grouped according to themes, and the themes were revised and revisited by the authors through meetings and discussion.

Through an iterative process of reviewing the transcripts and quotes, and discussions among the research team, several themes emerged. The three co-authors on this paper (B. Heibein, B. Hounam, and J. Mann), personal advocates, who also participated in the advisory hubs and research team, were then given an opportunity to reflect on their experiences and the themes emerging from the data: their reflections are incorporated into each of the themes. Quotes from the advisory hub members are identified through group number and role in the group, while the three co-authors' self-advocate reflections are attributed directly to them and are italicized.

Findings

The discussion of group composition, especially in relation to the involvement of care partners, emerged as a vital consideration in the development of a self-management program. Both within the research team and in advisory hub discussions, the involvement of care partners was discussed and questioned. Specifically, group composition as a site of tension in relation to concepts of voice, empowerment, advocacy, caring, and support emerged as a dominant issue. Discussion around group composition coalesced around four inter-related themes: *creating safe spaces; maintaining voice and being heard; managing the balancing act; and the importance of solidarity*. Underpinning these discussions was a fifth theme, the recognition that *'one size doesn't fit all'* – in other words, there are no absolutes in offering guidance around group composition, rather, there are important considerations to having care partners involved. Each of the themes is presented below.

Creating Safe Spaces

Although the advisory groups were formed to provide direction, and not primarily as support for participants, the importance of creating safe spaces for discussions was identified as critical. These safe spaces ensured that participants – especially those with dementia – felt comfortable and confident expressing their ideas and feelings. Creating safe spaces reflected the respect that people had for others' experiences and personal meaning-making in living with dementia. Bill described the importance of this within his group:

We can say anything that we want to each other. We know each other. And we know that we can say anything we want and we won't get laughed at. Everyone is tolerant of each other. This type of group where you have people together builds individual confidence. And that builds people to come out, get involved, and open up. [Bill Heibein]

A variety of factors helped create this context of safety. Brenda for example, identifies the importance of a good facilitator:

Safety is huge. Because we had a great facilitator, we started to trust each other. And once your trust level builds, feeling safe follows. We did some social things that worked well to establish trust. We decided to always sit in the same seats, and there's a certain comfort in that too. It gave you the opportunity to talk to people on your left or right, so you weren't always sitting by someone new and having to start over. People developed relationships with those people sitting beside them. We had large name plates at the table for easy visibility. Our facilitator was a great listener and showed interest in all the conversations. Starting with two or three questions helped to guide conversation. She never put preconceived ideas in our heads and always summarized and clarified what we said. You were allowed to pass if you didn't have anything to share. Humour and laughter was also really important. We had one person in the group who had a great sense of humour, and this became contagious. [Brenda Hounam]

While a focus on safety is not surprising, and the role of the facilitator (who were the same at every meeting) was clear, what was less anticipated was the clear sense that for many, safety was more likely when the group composition consisted only of those with dementia. As one person with dementia (G2) stated,

“But I think meeting in the separate groups here – I think you're more free to talk. You're not – I don't know - not having an audience of people that are involved alright; but they're not the individual that has it.... I found that right from the start, being in the separate group, that I can get up and feel free to talk...”

Creating safe spaces emphasized that respect for personal meaning-making in living with dementia occurred when others understood their experiences in a personal way. One person with dementia (G2) equated his interactions within the segregated group as akin to creating a sense of family, clearly a place of safety for him: “I think with our group anyway, that we have the feeling that we're family and we're one for all, all for one.” Another person with dementia who participated in the same group stated,

“You know you can say just about anything... This has developed into a real family group that can pretty well say – I know myself, and I'm not much for opening my mouth for talking – and I feel comfortable and I feel that if I have a question to ask that I'm going to ask it. And I think you have that feeling when there's a group like this together and not with other – the other [family care partners].” (G2)

As one person with dementia described, “It's a feeling of trust more than anything else” (G2). And this sense of trust contributed to a sense of safety. Jim's thoughts bring together the importance of both good facilitation and a separate group within a context of solidarity: *We were sitting in a room with the door closed and the conversation seemed to just flow. Yes, we had a good facilitator but we were all persons with dementia. We were common in many respects, which gave us comfort in our confidence. [Jim Mann]*. As Jim commented, safe spaces enhanced people's self-confidence.

At least some of the participants with dementia expressed concern that the participation of care partners in their group inhibited the sense of safety. For example, one person with dementia noted: “I don’t want my wife telling everybody what I do. Other things are okay, but not everything. She might get too carried away and I’d crawl under the table” (G1). Safe spaces meant that people were able to choose what they wanted to share with the group, and not have someone else speaking about them. As a person with dementia stated,

I feel very much that sitting down with the group that you’re in without sort of outside help, other than the facilitator. I’m talking about the monthly things. I think that frees you up to talk about a lot of things, some with respect to our dementia and others talking about something else, and laughter and so forth. And I think if care partners get into that picture, for me – I think it would be something of an intrusion. (G1)

Part of creating a safe space was to be able to discuss topics that people with dementia felt might be distressing or offensive to their partner. Talking about death for example was one of these:

Interviewer: Are there any particular topics that you think are important to be able to discuss, but you definitely would not want to discuss them with care partners in the room?

Person with Dementia: Death.... Well, let’s face it. In the new world that we have now, euthanasia is a very active – I shouldn’t say active – but it has been resurrected. So you won’t want to discuss that because it would upset your partner, definitely; so you don’t want to discuss that. (G1)

The need for a safe space was not just identified by people with dementia. Family care partners also recognized that sometimes they felt safer and less inhibited talking when the person with dementia wasn’t in the room. Noted one G3 care partner: “There are some things you’re not comfortable sharing. So that’s the place where I see the need to sometimes go your separate ways.” Having a safe space created opportunities for power dynamics to be balanced, and for both groups to share experiences openly.

Maintaining Voice and Being Heard

At the heart of feeling safe was creating the space to maintain voice and be heard. This theme refers to two things: first, being heard meant that not only did people feel they were safe to share thoughts and feelings within their groups, but that they were listened to by others; and second, maintaining voice meant that people had something specific to contribute within the group, whether it be through giving advice or collective problem solving. Being heard and maintaining voice moves beyond just being included in the group to actively participating and contributing. Sharing common experiences was important in being heard. But beyond sharing common experiences, it was knowing that others heard and valued what one had to say.

Sometimes that’s all the person needs. It doesn’t even need to go to the next level. They just have one person who knows somebody else that they can open up and discuss that with and just – it’s like a burden lifted once you’re able to communicate with somebody.

So sometimes you don't even need to go to the next level. To have that opportunity to be able to release your innermost feelings that have been penning up and maybe causing you a little bit of stress, once you tell one person you just feel that weight has been lifted and you may not need it to go any further. So just to have the avenue of being able to do that, I think is extremely beneficial. (G3 member with dementia)

According to advisory members' comments, part of sharing experiences also included sharing strategies for coping with various symptoms of dementia. But this sharing was seen as only occurring within environments where people were confident that their ideas would be appreciated by others who were also experiencing similar things, that one's contributions were valued by others in the group. For example, one person with dementia stated, "... I thought there were some real opportunities for making it interesting than just hearing each other's stories, but how we could help each other give ideas to help other people" (G3). Another person with dementia stated, "Because maybe you could get some help from somebody else – that others are maybe having the same problem" (G2).

Brenda's reflections on her experiences in the advisory hub recognizes the importance of feeling empowered through the process of sharing expertise:

Validation is so important. People don't have to agree with you, but they have to acknowledge what you've said. It took the group a while to really grasp what they were doing and achieving, and that they were contributing to helping other people with dementia in the future. The feelings you get by still being able to be involved in a project that is going to benefit someone else when you have this feeling of being written off when you have a diagnosis, that's huge. It wasn't just us sitting there. It wasn't just us as a group. It was for future people being diagnosed. We got more out of it than we gave. For the group, it's a factor that resonated--once they knew that someone was listening and that their opinions counted. [Brenda Hounam]

In this way, being heard meant having an impact both within the group, as well as beyond the scope of the group. The conversations and activities of the group were having an impact at a larger level beyond the group. In the context of dementia, where one's opinions can be easily discounted, contributing and being heard, is captured by Jim: *We were all one with our diagnosis: a group of people with dementia, no care partners. That was how we started and was certainly my preference. We listened to each other, offered opinions, thoughts and ideas. Through it all we all listened and learned.* [Jim Mann] As another person with dementia stated, "But if I got in a room with just my peers, I've got a voice..." (G3).

While being heard and valued was pivotal to the success of the advisory hubs, several also acknowledged that maintaining one's voice could be a challenge, and this was more challenging in a mixed group. A majority of the people with dementia across all three groups acknowledged the potential to feel silenced when in the presence of their care partners.

Not one person spoke pejoratively about their care partner – in or outside of segregated groups – but several reasons to account for potential silencing were identified. One reason included the perception that care partners could have a tendency to speak for, or over, the person with dementia. While this was often motivated by best intentions to protect, one common result was that both care partners and those with dementia recognized the potential for those with dementia to feel, as one care partner described it "overshadowed" by the care partner when the groups met together (G3) Again, often this was motivated by good intentions to protect:

You can look and you'll see that you're not going to get an answer. They'll struggle with it, so you speak for them.... A lot of times I don't know if it's something not comfortable or something they don't want to talk about, if they have something to say about it. And you know from conversations you have at home and that, that they have an opinion on it." (G3 -care partner)

A conversation with two people with dementia in the advisory hub also captured this:

Participant 1: We're patient with each other. But with the care partners in it as well – they may start, "I'll help you along in conversation" or "What my husband's really meaning to say is – “.

Participant 2: Paraphrasing. Yeah.

Participant 1: And I don't think that's helpful. (G1)

Bill shed further light on this:

Sometimes people are afraid to say something not knowing how others would respond. There are benefits to having care partners in their own group. I was hearing things from the guys that I wouldn't have heard otherwise. When people are together, care partners can take over and assume the person has nothing important to say, or that what they have to say is more important than the person with dementia. But being apart, we can be open. [Bill Heibein]

Echoing his perspective, a care partner, also in a conjoined group, voiced his concern that:

Some of the other meetings we go to and you're there with your spouse, it seems a lot of the care partners do a lot of talking for the spouses when they're in a group like that. So I really think – this is my own personal feeling because I'm not involved in the other side of it – that when some of the people with dementia are in their own little group, it's a chance for them to say something too without their care partner talking or speaking for them. (G3)

To emphasize the importance of being heard and having a voice, one person with dementia stated,

Just because we've been diagnosed with dementia doesn't mean you're no longer part of society. You still want to feel like you count. What you say matters and what you do matters.... So even after you've been diagnosed, you still count. What you have to say still matters. (G3)

A Balancing Act

A tension emerged between the desire to speak on one's own behalf and the recognition of the importance of the care partner in one's life. While those with dementia could feel inadvertently silenced by their care partner, a number of people with dementia also talked about self-silencing in groups with care partners. Specifically, people with dementia clearly

recognized the importance of care partners in supporting them, and did not always wish to express their feelings for fear of inadvertently alienating or hurting: Several participants acknowledged both the importance of speaking on their own behalf *and* the strong motivation to avoid doing anything that might hurt their care-partner or challenge their relationship. This concern about inadvertently hurting or making a partner uncomfortable, was expressed by both members with dementia and care partners . Brenda elaborated on the importance of safe space where there was no potential for recrimination or hurt to the care partners:

There's a certain amount of filtering that happens when people with dementia and care partners are together. It can't be totally eliminated. That's just human nature. To have time to be separated, to have the freedom to voice things and get it off your chest is good. There's a freeing to that process. Your peers become your friends. They become like family. [Brenda Hounam]

Another person with dementia expressed how it might be difficult for care partners to also participate in groups with people with dementia for fear of hurting feelings: “And you may also have a care partner who is a little reluctant to say certain things because they don’t want to upset the person with the diagnosis. So there are definite benefits to separation at times” (Group Two). Another person with dementia talked about how he and his wife didn’t always talk about things that were shared in groups, and as such, if his wife were participating in the group with him, he might say things that she would be surprised about. Capturing the importance of this in a non-pejorative way, one of the people with dementia notes: “I love my son. I almost – 98%, I tell him everything. There’s always a small percentage of something, but I don’t want to hurt his feelings and he’s so awesome that I don’t want to say those” (G3).

In addition to avoiding doing harm, some people with dementia also identified concerns about unintended repercussions in an integrated group. For example, one participant identified some trepidation that this could invoke a discussion with his partner that he had not intended:

Well, I know myself. I’m liable to say some things that she will be flabbergasted about and vice versa. I mean, because you don’t talk about all the things you should sometimes. So I’ll get home and say – you never told me that – and vice versa or whatever. We don’t have a real conversation... I’m not saying it’s bad, but I know there’s lots of things that I don’t talk to her about. And she doesn’t tell me all the things she thinks about, even though we’ve been married all those years. (G1)

Others expressed concern about being misunderstood: “In some cases the care partner may be a little concerned about what they say and that – oh, I think it’s the same thing basically, isn’t it – but going in the other direction?” (G2)

Importantly, there was also some recognition of the precariousness of one’s situation and the associated fear of inadvertently alienating the person to whom they were closest and most dependent. There was some recognition that this could potentially have serious ramifications. As one person with dementia noted: “Sometimes we just clam up because we’re afraid that if we say something, then they won’t help us” (G1).

Integrated groups then, can potentially lead to people with dementia being silenced, not only because there is a tendency for carers to speak on their behalf, but also because people with

dementia may self-silence because they do not want to say something that might hurt or be misunderstood by their care partners. Hence, a number of participants with dementia indicated that they felt freer to express themselves in a context where they did not need to worry about doing harm. As Bill stated: *We feel open to talk about things. What we say in the group stays in the group, and someone is not going to tell someone else outside of the group what happened. That's also part of safety. [Bill Heibein]*

Solidarity: "You're Not Alone"

The advisory groups were not designed as 'therapeutic' or support groups. However, a sense of solidarity emerged quickly among the advisory group members. Solidarity -a sense of being a unique and similarly-aligned community - emerged where people felt connected because they shared common experiences. Capturing this notion, one person with dementia stated, "I find that groups like this are very helpful. Just having an opportunity to discuss it with other people with similar experiences I think is very useful" (G1). This sense of not being alone and knowing that others shared the same issues was identified as helpful to both those with dementia as well as family care partners. Hence, the importance of a sense of community and connection based on shared experiences was identified as important. Brenda describes her experiences:

Peer support is one of the most valuable things to me, even to this day 15 years after diagnosis. It is THE most important thing in any part of our journey. In our advisory hub, it took a while for this sense of solidarity to develop. We had a breakout session close to the beginning. If we didn't have that, I'm not convinced we would have bonded as quickly as we did. I was absolutely for separation at the beginning because the benefits of being together as peers are immeasurable. But what I learned in this whole process was the importance of a good facilitator. If we didn't have an excellent facilitator, the group could have been completely different. [Brenda Hounam]

She goes on to identify the importance of group facilitation for overcoming some barriers when everyone is not starting from the same experience. Interestingly, the focus on shared understanding and not being alone also began to reveal the importance of recognizing that care partners and persons with dementia were having different experiences. It was this recognition of 'difference' that led to considerable discussion and debate around the need to segregate the groups in order to create a context of solidarity. The importance of segregation came across in all three advisory hubs, but with different degrees of commitment and passion. Specifically in the advisory hub that consisted only of people with dementia, there was a clear consensus that much of the strength and solidarity of their group had been obtained *because* they had not included family members in the group. The other two groups also identified the importance of separate groups, but were less stringent, recognizing that at least during some parts of any group, people with dementia and family care partners could participate together.

Moreover, while feeling that "one was not alone" was comforting, when people with dementia and care partners separated for discussion, this sense of mutual aid and comfort was taken a step further and seemed to create a sense of solidarity that was empowering. This was reflected in Bill's sentiments about how "not being alone" translated beyond the group structure, where the members provided emotional and practical support for each other outside of the group.

We're unique because we knew each other before this project started. The group of us can say anything to anyone of us, whether in joke or serious form. We know we're all living with the same thing, and we're not alone. When one of our members wasn't feeling well and needed help to get his wood chopped and split, we helped him. Everyone's available to help someone if they need it. Nobody's alone in this. [Bill Heibein]

Solidarity within the groups wasn't solely an emotional feeling of "not being alone", but validated people's experiences as "normal" because others described similar experiences. This moved people beyond merely providing emotional support within the group, to action where they became involved in helping others outside of the group, as described by Bill above. In this way, the context of solidarity created opportunities for the practice of citizenship beyond the group structure, as members stepped up to help each other when needed. In a dementia context where people are recipients of support, stepping up to give support was a departure from traditional expectations.

In one of the advisory groups, composed entirely of people with dementia, the importance of stigma as a shared experience emerged almost immediately. Jim's reflections on his experiences in his advisory hub capture this sentiment:

Our final meeting showed the power of that phrase, you are not alone. Our group members were from differing parts of the city and none of us knew all members. We also approached our dementia diagnosis differently; however, by the end, our approach had been forever changed. Those who had chosen to 'hide' their diagnosis later were decidedly more open in public while those who were already public about their dementia were more aware of some of the challenges faced when a person receives a diagnosis of dementia. We learned first-hand about the stigma and the sting of dementia!

This group became increasingly political in their understanding of their issues as the group progressed: joining political rallies, speaking out at educational events, and challenging discriminatory practices including recognizing the importance of owning one's diagnosis of dementia as a political statement. The degree that this was related to being only people with dementia was raised repeatedly as an important contributing factor.

One size doesn't fit all: Thoughts on structure and the need for flexibility

While strong benefits were associated with segregated groups – especially in relation to self-management – almost everyone recognized that there were times when integration was important and hence, a one-size fits all approach was not considered appropriate. Most participants felt that there were many benefits to participating in groups together. One particular benefit was consistent messages and communication. Picking up on this point, one person with dementia recognized both the practicalities associated with joint attendance – travelling for example – as well as the usefulness of having support: "...considering that some of us forget, it's best that somebody would take notes of what's in there and it's also a good reminder or a good point in the discussion" (G1 – person with dementia). Others also expressed openness to having care partners participate in groups to ensure full communication. Specifically in relation to the self-management program being developed, one person with dementia commented on the need to engage care partners:

I regard that as putting up barriers to full communication. I don't want to put any barriers to full communication, so I would opt for the care partners being present throughout. But I don't think there's anything I wouldn't talk about or not want my care partner to talk about in a general session. (G1)

In addition to promoting full communication, joint participation could facilitate more effective problem solving:

I mean, maybe having the individuals or the spouses together, that you have a better chance of solving the problem. Because sometimes you don't see – you don't see what you're doing and you're thinking that your wife is seeing things there that are not there. But in reality, they are. (G2 – person with dementia)

This ability to 'see' the problem within a broader context could work both ways: care-partners also derived benefit from recognizing that they were not alone and from opportunities to position their care-partners behaviours as expectable or 'normal'. This was recognized by one person with dementia:

So when a care partner is present, I think it helps if they understand a common problem. So when they are in a group with other people with illnesses, she may acknowledge that – oh, my husband or whoever is not the only one suffering this; and it may become a little bit more bearable for them to understand that – hey, I just have to put up with this because he's not being cranky or being difficult. It's just that it's the illness that causes these issues. That's my take on that... (G1)

As such, it would appear that the purpose of the group would be an important consideration in whether or not people with dementia participated on their own. The tension appeared to be between fostering a sense of self as still capable, relevant and autonomous despite one's diagnosis, with teaching and learning opportunities for and with care partners.. As one person with dementia stated, "...the learning aspect you can have from together and separate is invaluable. There's no other place you can get it unless you have those two sessions" (Group Three). Another person with dementia felt that separating the groups would be important, but then bringing information back anonymously or in aggregate form would be helpful for learning.

But if I got in a room with just my peers, I've got a voice and then we bring it back to the table and we're all sitting there; and that's brought up, but nobody knows who said it, then it's a great learning tool for everybody at the table. (G3)

Coming together to share experiences could sensitize care partners to better understand what it was like to live with dementia. Jim also reflected on his experiences:

"As with most things in life, nothing stays the same. What worked this time doesn't necessarily mean it will again. Flexibility is the key word accompanied by the need to adapt. Having said that, I contend our group was always in a good place and finished

with a good outcome principally because we were a group of only individuals with a diagnosis of dementia.” [Jim Mann]

Others were less inclined to state as definitive of an opinion. Rather, much discussion focused on trying to be accommodating to both needs for segregated time and time together. Suggestions from those with dementia included: “What about having – I don’t know what dates or anything like that – but having the group together at one meeting and then, say, maybe one or several other meetings just the [people with dementia]?” (G2) Another suggested: I think they should meet separately; but at times I think they should get together and kind of recap what was agreed upon, said, or some major items that were important and brought up. I think the care partner needs to know how the other half lives and vice versa. (G3 – person with dementia)

Ultimately, there was wide-spread agreement that a ‘one size doesn’t fit all’ and that there was high need for flexibility because it would be difficult to determine in advance with any certainty what might work. Bill also echoed those sentiments:

What we might recommend would be beneficial to one individual might not be beneficial to another individual. We’re all individuals. What works for one person might not work for another, so it’s hard to tell ahead of time. Much depends on the relationship between the care partner and person with dementia. There are times when we should be together. [Bill Heibein]

Brenda translated this into a statement that recognizes that perhaps fundamentally, the issue is about the importance of having choice for people with dementia.:

It’s important for flexibility—that groups can be together or separate sometimes. But it’s important that groups have the choice if they want to separate, that this is asked separately of people, and that people can change their minds as they become more comfortable. To have care partners participate in the program together with people with dementia has benefits. It strengthens the opportunity to work together with the same goal in mind. And care partners can get more insight into what it’s actually like for more than one person with dementia. But even with the best of intentions, some care partners can be gatekeepers and protect their loved ones, not realizing they are disabling them. Many people don’t have a significant other, so the care partner who would come to a group may be someone other than a significant other. People can feel uncomfortable when they don’t fit the “norm” of a couple. So it’s important to consider that as well. Some people with dementia may want their care partners there with them, and others may not. It’s important to consider all the possibilities. [Brenda Hounam]

In conclusion, capturing the complexity of the discussion around group structure, one person with dementia summed up the discussions accurately:

You have to be very careful not to lay down hard and fast rules because you’re dealing with two very highly complex relationships—one, the relationship of the husband and wife; and the other relationship is a group like this. And I think my preference would

be—as with most of the rest of you—would be to exclude care partners. But I wouldn't make it a hard and fast rule. I think there may be lots of exceptions. (G1)

Discussion

In this study, using participatory action research to develop a self-management program for people with dementia that was grounded by a citizenship lens, the importance of considering group structure emerged as a critical consideration. The involvement of care partners in groups with people with dementia is clearly a wicked question—one that is complex without an obvious answer and dependent on a variety of factors to inform a solution, which can and should always be questioned and revisited. Through our work, both people with dementia and care partners felt strongly that at least some time for separation were needed. While this is perhaps not surprising, the potential for social citizenship to be undermined for people with dementia when care partners were involved is remarkable, and has not been addressed in previous literature. Specifically, clear benefits emerged regarding the potential of segregated groups to foster safer spaces where a sense of one's self as a contributing member of society with something important to say could emerge in a context of solidarity. While important benefits were also identified for maintaining a mixed group structure, the data suggests that this is a decision that needs to explicitly and thoughtfully be considered in light of potential ramifications.

Bringing social citizenship together with our understandings of family dynamics and groups for people with dementia, a few important considerations emerge which coalesce around key components of social citizenship. First, a social citizenship lens outlines power relations, and the power imbalances which occur (Bartlett & O'Connor, 2010). Assuming that people with dementia need care partners with them in programs, particularly in a program focused on self-management, implies that people with dementia cannot themselves take action to live well, that they are not active social agents, but must rely on a care partner. This study suggests that there are important benefits to segregated groups, particularly related to maintaining voice as a strategy for maintaining a sense of power. Because stigma is so prevalent in dementia and many assumptions are made about the capabilities of people with dementia, it is vitally important, if we are to move towards social citizenship, that we continually interrogate power relations among people with dementia and care partners.

Second, in a societal context where the stigma of dementia can be all encompassing, group participation can provide contexts to challenge stigma and discrimination (Bartlett & O'Connor, 2010). This study then supports findings by Clare et al (2008) that when people with dementia participate in groups and other activities which challenge the stigma associated with dementia that they are simply recipients with declining capabilities, they can shift and change perceptions and assumptions in significant ways. Within the advisory hubs, members described helping and supporting each other. In addition, they discussed how it was important to be participating, knowing their opinions counted and that they were contributing to potential future opportunities for other people with dementia. Dementia is a site of discrimination, and participants in the study made it clear that talking with others in a similar situation was affirming and empowering – fostering a sense of competence, connection and recognition that one has something offer while simultaneously naming the many ways that these same competencies can be undermined unintentionally through discriminatory societal practices. Social citizenship can

be achieved through everyday talk and practice, as the power dynamics of being dependent and receiving of support are challenged (Bartlett & O'Connor, 2010).

Participating in groups with other people with dementia then can be liberating, empowering, and build confidence (Keyes et al., 2014; Mason et al, 2005; Snyder et al., 2007; Ward et al., 2012), providing opportunities for growth, change, and development (Bartlett & O'Connor, 2010). When the focus is on “living well” and “self-management”, feeling a sense of solidarity with others can be transformative.

Creating space for maintaining voice, as groups for only people with dementia can do, is a vital part of providing opportunities to practice citizenship. Safe spaces can create opportunities for personal meaning making, finding purpose, and promoting active participation (Bartlett & O'Connor, 2010). Participants in the advisory hubs discussed the importance of sharing experiences and making sense of those experiences with others, and safe spaces ensured that people with dementia and care partners were able to actively participate in conversation without being silenced. Baldwin (2008) suggests that the stories we tell have political meaning, as the storyteller becomes someone with agency. “The making of stories deals with the strategies that are employed in order to tell one’s own narrative and to silence others” (Baldwin, 2008, p. 224). Clearly, it is easy for people with dementia to lose their voice, particularly in contexts where safety is not ensured, and where others speak for, or over, them. Sometimes participating in groups with care partners can have unintended consequences. As people with dementia described in our advisory hubs, the need for opportunities to participate in groups only for people with dementia was extremely important to maintain voice. Safe spaces to share stories and experiences, without being silenced or self-silencing, positions people with dementia as agentic.

What is also clear to us is that the lack of attention to the participation of care partners indicates some strongly held implicit assumptions of the need for care partner involvement. To support social citizenship of people with dementia, we must pay attention to these dynamics between people with dementia and care partners, and understand the implications of groups participating separately or together. The structure of the group must be clearly aligned with the purpose of the group, as participants described. A learning/education group might in fact have a different structure than a support or advocacy group. Within an integrated group, there are real potentials for people with dementia to act as educators and provide learning opportunities for care partners from those with dementia, and that they would take on a “teacher” or “educator” role within those groups. Recognizing that people with dementia can take on a teacher or educator role not just for others with dementia, but to help to sensitize and educate those who support people with dementia positions them in roles that challenge the stigma and assumptions of dementia. Indeed, it moves people with dementia beyond a recipient or dependency role into a contributor role, recognizing the expertise and contributions that they can make (Clare, Rowlands, & Quin, 2008). People with dementia are placed in the role of “expert” with important contributions in shaping the knowledge and perceptions of others, whether in groups only for people with dementia or mixed groups.

There are clear implications of this work for practice. First, important considerations need to be made when designing groups for people with dementia. The purpose of the group is significantly important, and should determine whether or not care partners become involved in the group. Second, consulting people with dementia before the group takes place for direction on the structure of the group can provide important insights into the needs of people with dementia, and ensure that groups are empowering for people with dementia. This needs to be done with caution, however, since the default position can be to unquestionably involve family members--

to suggest otherwise might be seen as demonstrating lack of gratitude or a suggestion that something is wrong with the relationship, rather than a legitimate need for individual space. Third, the facilitation of the group needs to be taken into account. If care partners are involved in the group, the facilitator needs to understand that people with dementia may feel inadvertently threatened and/or silenced and will need to take proactive steps to insure that the voices of people with dementia are not marginalized or over-shadowed. While this can occur with care partners participating together, a skilled facilitator will have to pay attention to group dynamics to ensure that people with dementia can maintain voice. Fourth, the composition and structure of the group should be revisited, and at any point in time, people with dementia should be consulted about their wishes and desires in relation to the structure of the group on a regular basis. This needs to be done in a way that is sensitive to potential power imbalances. For example, this would include having this discussion outside the presence of family care partners and normalizing needs for separation as legitimate and not reflective of individual relationships with care partners. Structure and composition of the group should be revisited on a regular basis. Fifth, it is important for group facilitators to avoid making assumptions about either the need for care partners to be involved in groups for people with dementia or the importance of care partners not participating. As was clearly demonstrated in our work, one size does not fit all, and we should continually be reflecting on and questioning our implicit values and assumptions when working with people with dementia, and ensuring that we are consulting with people with dementia regularly.

Further research in this area is needed. Our findings raise interesting questions about the importance of considering group structure in relation to empowerment and claiming full citizenship but there is need to develop this understanding more fully. In particular, how might family members inadvertently contribute to the stigmatizing and silencing of people with dementia despite their love and caring? How can group experiences be used proactively to support full citizenship? Further exploring these issues can help to provide important understandings about how to better empower people with dementia and how to possibly work with care partners for them to empower and support people with dementia in social citizenship.

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