



Plan

Draw on data from a recent study to:

- Recognize stigma as an important issue in living well with dementia
- Explore the implications of diagnostic disclosure in relation to stigma

CRPD Centre for Research on
PERSONHOOD IN DEMENTIA



Dementia & Self-management Study: A brief overview

- Purpose of study:
 - Develop and pilot a self-management program for people with dementia;
 - Study the process of conducting collaborative research with different partners
- Theoretical Underpinnings:
 - Social Citizenship Lens (Bartlett & O'Connor, 2010)
- Methodology:
 - 3 site Participatory Action Research (PAR) – E Wiersma, PI
 - Guinine Partnership (Dupuis et al, 2012)

Data Generation Process

- 3 Advisory Hubs created to provide input into content and process of program development
- Vancouver Site:
 - 8 members (2 women and 6 men) all with a diagnosis of dementia
 - Age range 57 – 82
 - Marital status: 2 unmarried, 6 married (1 since diagnosis)
 - Monthly meetings between April 2013 – August 2014;
 - Focus: What do people with dementia need to know to 'live well' with dementia?
 - Audio-taped and meeting notes

Social Citizenship Lens

- ...a relationship, practice or status in which the person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible...
- It requires attention to six rights:
 - Opportunity for **growth**
 - Acknowledgement of multiple **social positions**,
 - Recognition of the importance of a sense of **purpose**,
 - **Participation**,
 - The importance of a sense of **connection and community**, and
 - **Freedom from discrimination**.

(Bartlett and O'Connor, 2010, p. 37)

Analytic Questions

- What does the experience of **discrimination** look like for this group?
 - How did social position impact this experience?
- What fosters and/or challenges:
 - Active **participation**
 - Opportunities for **Growth**
 - Finding/retaining a sense of **Purpose**;
- How does this manifest?
 - Content?
 - Process?

Emerging Analysis

- Content Issues:
 - Stigma as a critical aspect of the experience
 - The significance of the disclosure process
- Process issue
 - Thinking about care partner involvement

Locating Discrimination

- Stigma as a critical part of the experience of dementia
 - emerged from the moment of the first introduction;
 - pervaded all aspects of the dementia experience
- Importantly, if people with dementia were to be taught to self-manage, an important component required 'naming' and addressing it:

Well, the word has to get out there that this is one of the important things, stigma.....So make it so that people understand what dementia is and that's a big part of it – stigma.

Disclosing: To tell or not to tell?

- Considerable time and attention was given to the topic of disclosing one's diagnosis
- Significance of the disclosing process:
 - Self-defense – seeking understanding
 - Set-up for discrimination
 - Act of resistance

Disclosing: Active Self-Defense

- Disclosing to others was raised as a necessary strategy for defending one's self from being considered "mental"
- It was imperative explaining changing or unusual behaviour

And all of a sudden you're starting to do things that you hadn't been doing in the past. There's all sorts of things that come along with having Alzheimer's and I'd rather they know than behind my back saying, "Gee, what's wrong with him?" So that's – I look at it that way, so I let people know.(P5)

Not what... how and to whom

- There were differences in the group regarding 'who' should know... interestingly, most found telling strangers to be important;
- 'How' one told also raised discussion.
- The importance of using humor was raised by several:
I'm of the policy of making it not too significant and mix it up with a little bit of levity too. You can say to someone – it may sound stupid – but they should take it easy with me, I've got Alzheimer's. Everybody laughs. Okay. That's another problem solved. So it all seemed to happen quite naturally and if you handle it with a little bit of levity, it makes it a lot easier (P7)
- It was however also challenged by several, highlighting a **double-bind** between the ability to laugh at one's self while not minimizing the impact or letting others off the hook.

Disclosing: Site for Discrimination?

- For many, things changed when someone found out they had dementia.
- Some found understanding and/or lack of interest;
- But most described some experience of discrimination as a result of the disclosure

My broker – I've been dealing with her for 25 years and she doesn't call me anymore. She calls my wife. For 22 years, she never even talked to my wife once. My wife answered the phone and she always asked for me, even on her investments. As soon as my wife told her – I'm the one who told her, I guess. And the next thing you know, she doesn't – and she doesn't do it on purpose. But she just – that's just the way it is.

Is it me.... Or them?

- Some 'named' their experience as stigma;
- Others laughed it off or tried to be understanding;
- Some took personal responsibility for perhaps setting up responses of other

I think while we're disclosing, we're worried about stigma. I think sometimes we tend to make it a bigger problem than it really is. If we send signals when we're telling people that it's a great big disaster – well, they'll treat it as such.

- There was also a tendency to try to discount the impact:

But stigma shouldn't - at a point shouldn't bother us"

Disclosing, discrimination... and purpose

- The link between disclosing, discrimination and meaningful activity (finding purpose) was raised.
- There was a general belief that *"Once they found out, they're not going to look at you when you tell them you've got Alzheimer's" (P7).*

On the application form they would maybe ask you – is there any medical thing. So it's your choice to put in whatever... So do you want them to know that you have dementia? Not really. That is, you're limited - from a person of experience, if you put something in there that will give them second thoughts, most likely you will not get an answer. So that's the reality of things (P1),

Disclosing: An act of resistance?

- The strategic use of self-disclosure to combat stigma was raised by several members

being able to talk about these things does give you more knowledge, more empowerment to be able to go out and tackle the world with the stigma. I think that's important (p2)

- It had potential to be self-empowering and an opportunity to educate and advocate

...you take control, so you're basically taking control of your diagnosis and in freely talking about it, plus the fact that you get to educate people because part of the stigma is the sort of unknown. (P3)

The importance of disclosure

- As the group progressed, members became increasingly assertive about the importance of self-disclosing their diagnosis;
 - Requirement for self-management participation?
- Within the context of self-management, it was seen as an important part of 'taking control';
- It provided an opportunity for taking on a new role (purpose)– that of teacher, advocate and leader.

A Space to Speak

I can only think that – and it would be in my case and I've seen it over and over and over again – is that when you are just people with dementia together, I think you come out feeling stronger and more confident and able to deal with what's happening to you, rather than having the crutch of your spouse (p2).

- When asked what was empowering to them about the advisory hub process, there was unanimous agreement that the group had been so successful because there were no care partners in it.

“I think if caregivers get into that picture, for me, I think it would be something of an intrusion”

Silencing: The many reasons

- Losing voice
We're patient with each other. But with the caregivers in it as well – they may start, “I'll help you along in conversation” or “What my husband's really meaning to say is –
- Members were afraid of saying something that might hurt their care partner;
- There was also the real recognition that they could not afford to offend their partner because of their dependence on that person:
Sometimes we just clam up because we're afraid that if we say something, then they won't help us (P6).

‘Living well’ with dementia through a social citizenship lens: Key points

- Stigma is a lived experience
 - Felt but not necessarily named
 - Problematic if unnamed because it can be internalized as a personal issue;
- Disclosing diagnosis is an important, albeit complex, issue :
 - Set up understanding and empathy
 - Linked to the experience of discrimination
 - Opportunity to challenge stereotypes and educate
- Inclusion of care-partners can be both supportive and silencing.

Summary

- Social citizenship lens moves beyond individual focus of ‘self-management’ and coping to recognize how societal responses shape the experience.
- Implications for curriculum content include:
 - Foster discussions around the implications associated with disclosing the diagnosis that:
 - Depersonalize/politicize: Name and normalize experiences of discrimination that follow disclosure;
 - Recognize potential of disclosure as an act of resistance/education
- Process:
 - Carefully consider how to address the silencing effect of care partners while also recognizing their importance.



Research Team

- Principle Investigator: Elaine Wiersma (LU)
- Vancouver Research Team:
 - Deborah O'Connor (Lead researcher, Vancouver)
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 - Jim Mann (Dementia Advocate)
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