LISTENING TO THE PERSON LIVING ALONE WITH DEMENTIA

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Overview

• Research Study
• Narrowing Environment
• Maintaining Environment
• External Environment
• Conclusion
Exploration of the underlying causal mechanisms and the interplay of factors which attribute to a loss of agency in a person living alone with dementia.
Why is Agency important?

- Definition:
  
  “Human agency is the capacity of an individual to act independently and to exercise choice.” (Kontos et al 2010)

- Bandura (2001) states that:
  
  “the capacity to exercise control over the nature of one’s life is the essence of humaness”.

Why is Agency important?

- Dementia causes impairment of brain functions, including language, memory, perception, personality and cognitive skills (Australian Institute of Health & Welfare 2007).

- Dementia diminishes the capacity of an individual to act and over time, results in a complete loss of agency.
Why is Agency important?

- Involving and supporting a person with dementia in their own decisions increases their feelings of autonomy, identity, and quality of life. (Church et al. 2002; Whitlatch & Menne 2009).

- Few studies have been conducted on the perspectives of people living alone, although one-third of persons with dementia live alone in the community. (Ebly, Hogan & Rockwood 1999; Edwards & Morris 2007; Webber, Fox & Burnette 1994)
Research Methodology

Critical Realist theoretical framework

- Focuses on the relationship between social structures and human agency (Angus et al 2006)
- Social structures are the conditions or contexts of a person’s life which provide resources that may enable or constrain an individual to act (Angus 2006, Wand 2009)
- Semi-structured interviews were conducted with nine individuals (4 females and 5 males, ages 48 – 86)
• Almost all participants interviewed realised and experienced a loss of agency.
• This loss in agency resulted in a contraction of their social environment. Some of the factors impacted by their diminished capacity which contributed to their narrowing environment included:
  – Driving
  – Employment
  – Leaving home
  – Legal responsibilities
Driving

**Michael:** “I have no car, so I can’t do all the things I like to do because I don’t have a car.”

**Mary:** “I couldn’t drive the car. The most frustrating thing was not to be able to get out and get in the car, and go down the shop, and get a loaf of bread and a pint of milk, or whatever might be, and it’s frustrating. I couldn’t go and see anyone.”
Employment

Jane: “There’s no way I could function anymore. And I knew that. I knew that that was part, that was very distressing as well because I knew that I had to give up work so I kept stretching it along and I thought I can’t do this anymore.”
Leaving home

Paul: “I’m scared to walk off down the road and then I worry about getting back because I tend to go too far and find I couldn’t get back.”

Adam: “I don’t go out.”

Interviewer: “Is there a reason why you don’t go out?”

Adam: “Because when I leave Moore Street I am lost. And I’m scared.”
Legal responsibilities

• Managing paperwork posed a real difficulty and it tended to be found in large piles.

Mary: “I’ve got to get out of this muddle. You know I can’t get that table cleared. I keep trying, and it’s been a misery really.”

Ann: “There’s a lot of things I would like to tidy up. But the things that aren’t tidy need a healthy brain to fix them.”
Although participants were losing agency they were striving to find ways to retain it. Maintaining their current environment, particularly their home, emerged as a significant factor in retaining control as:

- Owning their home enabled them to stay there
- One can do as one pleases
- A familiar environment assists in coping with their memory loss
Owning their own home

When asked what do you think of your current living situation or life as a whole?

Jane: “I like where I live. This is my house. My unit. So no one’s going to kick me out.”

Ann: “I would say for one thing I’m lucky I’m in my home, nobody can force me out of it. I can’t consent to being shoved into a something or other. And I won’t consent to it.”
When asked would they ever think of living in a community residence?

Mary: “I mean why would I want anything else. I mean I can still have friends and you can still have company, but I can listen to whatever music I like to listen to.”
Mary: “And I can’t just give it up, and the thought of packing it up, I can’t find anything now. I mean what would I do? It would be a nightmare. Absolute nightmare, and I can’t do it.”
• “The core features of agency enable people to play a part in their self-development, adaptation and self-renewal with changing times.” (Bandura 2001)

• Some participants have taken steps within their own homes to minimise risk to themselves thus enabling them to remain living independently.
Ann: “And of course I went to walk down the back steps the other day for something, not even thinking, and I got to the second step and I thought oh shit I’m not allowed to go down the back steps. I quietly turned around, came back and around the driveway.”

Jane: “I put everything in the oven basically rather than on the top of the stove.”
Two participants use a third party to monitor their ability to perform and manage specific tasks.

Jane: “I keep an eye on things to make sure everything’s alright, and I get other people to check. You know make sure I’m doing the right thing, that sort of thing.”
There was an acceptance that they will have to enter residential care in the future. But as long as the participants were capable of managing at home they wanted to remain there.

Sally: “I’m quite capable of doing things for myself. I’m not going to go into a nursing home unless I really have to.”

Ann: “If I am that bad that there is no alternative, I will face that when it comes. If I have to go, then, I’ll have to go.”
• But there was a fear that others in positions of power will judge these individuals based on their mistakes.

Ann: “But is that any reason to put me into a home or something? I don’t think so. I think that any mistakes I make, I usually find out before anyone else, and apologise. I don’t know how elderly people go, or how they’re treated, but sometimes I think it’s very unfair.”
The external environment, particularly family members and/or friends, were found to play an important role in the enabling or disabling of a participant’s agency.

The disabling mechanism often resulted from disagreements on the level of agency between both parties. The consequences of such resulted in others;

- Speaking on their behalf
- Excluding them from decisions around their own life
Mary and Betty were friends for 38 years. Mary: “It’s a bit spoilt with that little blue that we had, but she [Betty] was sort of taking over, and people come in like Polly [the advocate] and different ones, and she was doing all the answering. It left me – I wasn’t part of it you know. And in the end I hit the roof. So did she.”

Mary: “It got too much with everybody talking as if I was a nincompoop. Perhaps I was but they didn’t have to let me know.”

Interviewer: “And do you feel more in control of your life now?”

Mary: “Yes. Because I’m not being dominated over. And I was treated as if I was an idiot.”
Excluding them

Sally’s was completely removed from the decision-making process by her partners children.

**Sally:** “he couldn’t live here no more because he wasn’t capable, and they said I wasn’t capable of looking after him because I was too frail.”

**Interviewer:** “And how did you feel about that? Did you agree with their decision?”

**Sally:** “You can’t do anything else but agree. No you can’t do nothing. You’ve got to go along with it.”

**Interviewer:** “Why did you feel you had to go along with it?”

**Sally:** “I didn’t feel very happy about it, but what’s the point? You can’t do nothing.”
• This disabling mechanism created tensions between parties and invoked feelings and behaviours such as;
  – Feeling they cannot say anything as they will be dependent on the family in the future or will not be listened to.
  – Family member tends to take over and both are very different in personality. He would prefer not to live like this.
  – Fear of exclusion and misrepresented thus resulting in confrontational behaviour.
Interviewer: “How does it make you feel when they start suggesting things, or making decisions?”

Jane: “Pissed off?”

Interviewer: “Do you tell them?”

Jane: “No I don’t because I respect the fact they are looking out for me. But yeah perhaps I need to start telling them sometimes.”

Interviewer: “How do you deal with that feeling?”

Jane: “I get a bit upset about it, but I try not – well I don’t do that in front of the kids. I try not to. And I know they’re not kids anymore, but you know that’s ... I mean I guess in a way you know I’m going to be quite dependent upon them you know, so I’ve got to...”
Taking over

**Michael:** “He will take over and say what I should say, So he’s sort of - but he does try, he look after for me.”

**Michael:** “He would look after, but I don’t want to live like this.”
**Fear of Exclusion**

**Paul:** “People say you can’t go to New Zealand in your condition and I say why the hell can’t I? They won’t let you go. Who’s they? And that’s a lot of hooey. I can’t be stopped doing anything I want to do.”

**Paul:** “I worry about sort of you always turning up here, or girls saying ‘But you can’t do that’. And I say who the hell says I can’t do that.”

**Interviewer:** “So that’s a real worry?”

**Paul:** “But then they have no conception about what my life has been like.”
Family members, under the correct circumstances, were also found to be an enabling mechanism of human agency by acting as proxy agents.

Individuals who do not have the capacity to make all their own decisions may seek their well-being, security and valued outcomes through the use of proxy agents. They get others to act on their behalf to secure the outcomes they want (Bandura 2001).
External Environment

• Individuals were happy to appoint proxy agents in certain situations/decisions. The circumstances which facilitated this were:
  – Responsibilities which were very stressful
  – Having individuals they could trust in and could reply upon
  – Being able to chose the situations where they require involvement of another
**Jane:** “I haven’t got all the control anymore. In a way that’s a relief because I don’t have to worry about it, or think about it really, you know.”

**Peter:** “I rely on my son certainly more than I used to but he doesn’t sort of press himself on me and I can go to him and he’s been terrific.”

**Ann:** I’ve got no worries. I mean, whatever is happening I get the bill and pay it because I have got that trust in Jack, to know that person that did it is a reliable person and that Jack’s sort of given his okay to anything to be done.”
Conclusion

• People living alone with dementia are losing agency and the struggle to maintain it often creates tensions between family members and/or service providers.

• The importance of agency to these individuals with dementia needs to be considered by those involved in their care.

• Ways to promote the involvement of these individuals in decisions regarding their own lives should be sought.

• Involving people in decisions about their own life improves the quality of life of these individuals.
Conclusion

• Unless people believe they have agency they have little incentive to act or to persevere in the face of difficulties. (Bandura 2001)
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References


