

1. The research

This poster presents findings on an investigation into the lived experience of early-stage dementia, specifically examining people's insight into the presence and consequence of having the illness. The study was undertaken as part of a PhD through the Social Policy and Ageing Research Centre, Trinity College. Taking an Interpretive Phenomenological Analytical approach the person with dementia was placed at the centre of the research enquiry. Awareness was explored using qualitative methods as well as a structured question using a Likert scale.

2. Psychosocial classification of dementia

- **slipping:** initial slips & compensation;
 - **suspecting:** person knows it is serious;
 - **covering up:** actively hiding difficulties;
 - **revealing:** tells family and close friends;
 - **confirming:** open acknowledgement, diagnosis sought;
 - **maximising:** adaptive techniques are implemented;
 - **disorganisation:** losing decision-making abilities;
 - **decline:** relationships less certain and increasingly dependent on others;
 - **death:** the final stage is death.
- (Keady and Nolan, 1994)

*"Interviewer: How would you rate your memory?
Respondent: Not bad anyway, but emm, it's hard to know, I have no problems like really you know. But I get stuck like in conversation I will get stuck for words sometimes" (Fr Hanrahan, 70 years, Alzheimer's disease)*

3. The literature

- ❖ Not accurate to assume people with dementia have no awareness (Phinney, 2002);
- ❖ At least two perspectives on awareness:
 - Biomedical – unawareness is wholly or primarily the result of biological factors of dementia;
 - Bio-psychosocial – unawareness is a product of both neurological changes and psychosocial responses to having dementia.

"To be able to go out and dance would be a great factor because it would be bringing Martin out, he is, I know he is and he never says anything. I know he's missing it because we have friends there, it's great, it was a good, big part of our lives that. And that's a bad thing there" (Mrs Buckley, 79 years, Alzheimer's disease)

4. The methods

- Qualitative, in-depth interviews
 - 17 people with dementia
 - 13 care-partners
 - 6 policy experts
- Theoretical foundation and procedural guide
 - Interpretive Phenomenological Analysis
 - Origins in phenomenology & symbolic interactionism
 - Analytical approach – to give voice' (describe) & 'make sense' (interpret)
- Ethical considerations
 - Including people with dementia in research
 - Role of researcher
 - Capacity & consent
- Process consent method (Dewing, 2007)

5. Levels of awareness

'How would you rate your memory?	Very bad = 2 Bad = 2 Neither good nor bad (Okay) = 8 Good = 4 Very good = 0 No comment = 1
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In the light of these results, obtained using a Likert scale, most respondents appear to be unaware of any significant memory problems. However, the use of open-ended qualitative interviewing produced a different picture.

6. Findings on qualitative investigation

Respondents were aware of one or more of the following:

- Change in relationships
- Change in their social life
- Change in emotional responses
- Change in confidence
- Change in ability to do things
- Affect on loved ones

"I have to have somebody with me when I'm going out. There was a time I'd go to the end of the world on my own, not anymore...I would be afraid I would get lost, not knowing where I was and I'd be afraid I would always take the wrong turn, find myself in trouble" (Mrs Lynch, 87 years, Alzheimer's disease)

7. Responses to awareness

A number of techniques were used to manage awareness of changes:

- covering-up
- pushing it to the back of their mind
- focus on physical health over mental wellbeing
- focus on retained abilities
- withdrawing from social activities

"Interviewer: And have you spoken to anyone about it (her forgetting)? Respondent: No, no, this is something that I would hide (places her hands on her chest)... You see, I'm trying to, I read before about it, I read a lot about it and it said you cover up and let me introduce things themselves and then you might click back, you know. So I cover up" (Mrs. Griffin, 75 years, Alzheimer's disease)

8. Conclusion

- Focus on narrative: how people talk about their lives can provide insight into levels of awareness;
- Unawareness of dementia does not equate with unawareness of nature and symptoms of dementia;
- Need to distinguish covering-up and genuine unawareness;
- Assumption of unawareness may lead to exclusion from discussions about their care;
- Need for further research on qualitative investigations into awareness



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