Positive experiences whilst living with dementia:
A qualitative exploration of growth in older adults

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Positive experiences in spite of dementia?

Are we missing a key part of the story?

- 58% “living well” with dementia
- Interview accounts of hope, coping, quality of life, etc.

Importance of supporting positive experiences, not just reducing symptoms

\(^1\) Alzheimer’s Society (2014)
Positive experiences because of dementia?

“In a way I’d be a better Samaritan now than I was...In some ways I could be grateful for what’s happened...you learn a lot in the process” ²

Growth

• Positive change in psychological well-being ³
• Development beyond a previous level of ourselves ⁴

Positive experiences because of dementia?

1. A consequence of a struggle: Post-traumatic-growth
   • Cancer, HIV/AIDS, spinal injuries, brain tumours etc.
   • Dementia caregivers – e.g. opportunity to give back, become closer, find new strengths

2. Growth through the life course: Gerotranscendence
   • Appreciation of life, open-mindedness, focus in relationships, spirituality

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Research questions

1. In what ways might positive changes be experienced in individuals living with dementia?

2. How have these individuals made sense of these changes?

3. What things are thought to support or prevent positive changes, according to people with dementia?

4. What is it like for people with dementia to have a conversation about positive changes?
Methods

Design

Qualitative approach – in-depth interviews

Participants

8-10 people (65+) living with dementia

Analysis

IPA – exploring how people make sense of experiences

• Stage 1: Highlighting and describing key thoughts and experiences
• Stage 2: Drawing out themes and making connections
“Michael”

“when you've been on the stroke ward, you see the state of some of them there, it’s - I think I'm very very lucky...That I can, you know, get about and do things”

“you slow down and, you know, you enjoy the telly more and sitting down and reading and what have you...it makes you realise, shall we say, to be satisfied with what you've got”

“it learns you to enjoy things more - what you've got, you know”
“Christine”

“I can remember the year after, when I had stepped down from everything...I can remember walking round thinking, oh! [laughs] I don't have to. You know, I don't have to be here or anything...But I was still enjoying being there, but not having to be there”

“I have been thinking about this – this past few months – the difference growing old makes. You don’t – you don’t want to waste time on things you can’t do anything about, and also you don’t want to be unhappy too much”
What might we take from this?

• The possibility of positive changes as a consequence of living with dementia?

• Considering the impact of our own assumptions

• Considering the ethics of talking positives and negatives
Your thoughts or questions?
References


Clare, L. (2002). We’ll fight it as long as we can: coping with the onset of Alzheimer’s disease. *Aging & Mental Health, 6*(2), 139-148.


