

Living positively with dementia:

Findings and implications of a systematic review and synthesis of the qualitative literature.

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Living positively with dementia: a systematic review and synthesis of the qualitative literature

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Objective: Little is known about how and to what extent people with dementia live positively with their condition. This study aimed to review and carry out a synthesis of qualitative studies where accounts of the subjective experiences of people with dementia contained evidence of positive states, experiences or attributes.

Methods: A meta-synthesis was undertaken to generate an integrated and interpretive account of the ability of people with dementia to have positive experiences. A methodological quality assessment was undertaken to maximize the reliability and validity of this synthesis and to contextualize the findings with regard to methodological constraints and epistemological concepts.

Findings: Twenty-seven papers were included. Three super-ordinate themes relating to positive experiences and attributes were identified, each with varying and complementing sub-themes. The first super-ordinate theme related to the experience of engaging with life in ageing rather than explicitly to living with dementia. The second theme related to engaging with dementia itself and comprised the strengths that people can utilize in facing and fighting the condition. The third theme captured how people with dementia might transcend the condition and seek ways to maintain identity and even achieve personal growth.

Conclusions: This review provides a first step towards understanding what conceptual domains might be important in defining positive outcomes for people who live with dementia. Highlighting the potential for people to have positive experiences in spite of or even because of their dementia has important implications for de-stigmatizing dementia and will enhance person-centred approaches to care.

Keywords: dementia; Alzheimer's disease; positive psychology; lived experience; systematic review

Discourses Surrounding Dementia

Assumptions -> language -> care practices and policy

Dominant 'Frames'

- Loss/deficit – pathology focused; 'victim/sufferer'
- Othering / depersonalising; 'living death'
- Military metaphors; 'defeat' dementia.

Emergent 'Counter-Frames'

- Living *well* with dementia
- Dementia friendly communities
- Self-advocacy and empowerment, e.g. *DEEP*
- Ageing successfully in subjective terms?

Van Gorp, B., & Vercruyssen, T. (2012). Frames and counter-frames giving meaning to dementia: A framing analysis of media content. *Social Science and Medicine*, 74(8), 1274-1281.

Lived Experiences

- Personal accounts indicate that some people are able to live positively in relation to dementia (e.g. Christine Bryden, *Dancing with Dementia*)
- Subjective experiences may not involve degree of suffering that is assumed (De Boer, et al. 2007).
- People *actively* adjust to and cope with dementia in ways protective of identity and well-being (e.g. Clare, 2002).
- ‘Shifting Perspectives’ accounts of living with chronic illness (Paterson, 2001) potentially applicable to living with dementia

Positive Psychology



- PP - 'Flourishing / optimal functioning of people, groups, and institutions' (Gable & Haidt, 2005, p. 104).
- Non-pathologising perspective – focused on assets and what makes life 'good'.
- Provides conceptual models for understanding positive strengths, experiences and outcomes (e.g. Character Strengths and Virtues, 5 Domains of Positive Functioning).
- Applications in ageing (e.g. gerotranscendence) and living with chronic illness (e.g. optimism, benefit finding – Aspinwall & Tedeschi, 2010).
- Dementia should be linked with positive images and concepts, e.g. resilience, wisdom, hope to challenge negative stereotypes and stigma (Harris & Keady, 2008).

Systematic Review: Objectives

“No one should be criticized for not finding positive aspects of this disease [Alzheimer’s Disease], but no one should be overlooked who has found gifts amid such loss”

(Stuckey, Post, Ollerton, FallCreek and Whitehouse, 2002, p 206)

- To establish the range and extent of current findings relating to positive experiences and attributes reported or demonstrated by people living with dementia.
- To use PP alongside person- and self-hood approaches to living with dementia to help conceptualise positive experiences and strengths.
- To inform knowledge and the measurement of psycho-social outcomes in dementia.

Methodology

A systematic search from 1990 - March 2015

3 databases: MEDLINE, CINAHL and PsychINFO.

Key search terms - 'dementia' and 'Alzheimer's' combined with:

- (1) Terms relating to the lived experience literature in dementia, e.g. 'experience', 'adjustment', 'coping', 'meaning'.
- (2) Terms relating to possible positive experiences and personal attributes that might be present in the experience of dementia, e.g. 'happiness', 'hope', 'optimism', 'resilience' and 'faith' (Peterson & Seligman, 2004).

Analysis: qualitative thematic synthesis (Thomas & Harden, 2008) and meta-data analysis (Paterson et al. 2001; Zimmer, 2006).

Key Findings

- 27 papers included in the synthesis
- 2 studies focused explicitly on positive experiences (hope and spirituality)
- Majority of studies (n=20) conducted in the community
- The sample sizes ranged from 2 to 81, totalling 439 people with dementia
- Studies from a variety of countries including, Canada, China, Denmark, Sweden, UK and USA.
- Studies varied considerably in methodological quality – most were only satisfactory in relation to sampling, data collection and rigour.

Key Findings

3 overarching themes:

Living Positively



Engaging with life in ageing

Active engagement and appreciation of life & relationships with awareness of challenges of ageing

Engaging with dementia

Positive experiences and resources in the context of living with dementia

Identity and Growth

Conservation of self with a focus on meaning and transcendence

Theme 1 - Engaging with life in ageing

Sub-themes & Illustrative Extracts:

Seeking Pleasure and Enjoyment

“I do all the cleaning of the house...that keeps me going” (From the theme ‘Pride and Enjoyment’; Macquarrie, 2005, p. 437)

Keeping Going

“All the while I’m well enough to keep going I’ll keep going. And that’s it.” (From the theme ‘I’m alright, I’ll manage’; Clare et al., 2008, p. 716)

Love and Support

“If my husband wasn’t here, my daughter’s there, and if she wasn’t, her husband would be there, you know what I mean?...”

(From the theme ‘Interactions with friends and family’; Roger, 2006, p. 189)

Theme 2 - Engaging with life in dementia

Sub-themes & Illustrative Extracts:

Facing It and Fighting It

“Then you decide,
well OK, we’ll fight it
as long as we can.”

(From the theme
‘Developing a fighting
spirit’; Clare, 2002, p.
144)

Humour

“I’ve got into the habit
of making a joke about
it otherwise it would
take over my life”.

(From the theme
‘Normal vs. abnormal
memory loss-putting
it into context’;
Langdon et al., 2007,
p. 995)

Hope

“If at first you don’t
succeed, there is no
use giving up if you
don’t hope for things
you don’t get them.”

(From the theme ‘Self
activating hope’;
Wolverson et al.,
2010, p. 454)

Theme 3 – Identity and Growth

Sub-themes & Illustrative Extracts:

Giving Thanks

I've had a lovely life and I feel satisfied.

(From the theme 'Coping strategies recounting the life story'; Sorensen et al., 2008, p. 294)

Still Being Me

You've lost your memory but you haven't lost your mind. And you're still the same person.

(From the theme 'Seeing self as the same person';

Werzak & Stewart, 2002, p. 81)

Growing & Transcending

I've learned an awful lot in this curious reaction thing... you understand about yourself...in some ways I could be grateful for what's happened.

(From the theme 'Learned from it/positive aspects'; Clare, Goater, & Woods, 2006, p. 756)

Implications (1)

- Some people live positively in spite of dementia
- Some people may 'find gifts'
- Has previous research overlooked these possibilities?
- Acceptance, agency (self-determination) and relatedness appear as core themes underpinning positive experiences.
- People's positive lived experiences not necessarily defined in relation to dementia: shifting perspectives account?
- How far is it possible to age 'successfully' AND live with dementia?

Implications (2)

- Personal strengths, hope and humour potentially key resources that uphold wellbeing in dementia.
- What role might gratitude play in wellbeing in dementia?
- Implications for outcome measurement in dementia research; beyond health-related QoL?
- Personal growth – could it be possible to live well *because of* not just *in spite of* dementia?

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Thank you!

Any questions?

