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Discourse and Dementia

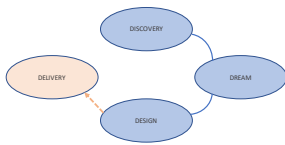
People living with dementia using Appreciative Inquiry to challenge discourse

Ian Davies-Abbott, Jaci C. Huws, Sion Williams (2022)

Background and Aims: People living with dementia experience stigma and fear about their condition which can marginalise them within society. A novel Appreciative Inquiry approach was used by people living with dementia to inform a mechanism of change to positively influence the discourse of family members/carers, healthcare workers and lay people. The inquiry aimed to instigate change in people outside of the initial inquiry, reconfiguring the approach to change.

Methods: A cohort of four people living with young onset dementia worked through three phases of an Appreciative Inquiry (Discovery, Dream and Design) and the outcome was presented (the Delivery phase) to three natural discussion groups (Healthcare workers, Family members/carers and Lay people). Discourse data was analysed using positioning theory and thematic analysis to assess whether desirable change had occurred.

Adapted from: Cooperrider, D. L. & Whitney, D. (2005)



Discovery: The group considered real life situations when they had been treated with respect and positioned by others in a manner they agreed with. Whilst all the participants were able to recall situations when this had occurred, some felt that this had only happened before their diagnosis of dementia. From the narratives, 16 factors were identified which contributed to positive positioning. Factors from the Discovery phase have been described as 'life giving' (Cooperrider, Whitney & Stavros, 2008) as it is these experiences that require nourishment and growth if positive experiences are to become regular occurrences.

Dream: The group developed six conceptual themes to envisage a world without negative positioning: **A change in understanding (about dementia and me)** leads to an acceptance of the emotional consequences of living with dementia. **Acceptance** of the person's beliefs and motivation. Focussing on **what I can** do results in people being positioned due to their retained rather than lost abilities. Respecting the individual characteristics of **who I am**. Ensuring that dementia friendly **language** has meaning rather than swapping one label for another. People living with dementia have increased positive regard for **ourselves**.

Design: The group drew on what they had Discovered and their Dream to create a short film. In the film, each participant shared their experience when they had been positively positioned and the groups vision for change.

The results of the three phases were analysed using positioning theory and thematic analysis. Four themes and eight sub-themes were identified to highlight the discourse advocated by the group:

Theme	Belonging	Able	Supported	Dementia Unseen
Sub-themes	Respect	Capable	Purpose	Doesn't matter
	No blame	Superior	Encourage	No dementia

A positioning theory framework (the Balancing Framework) was developed as a mechanism to visually display whether discourse met the requirements of positive verbal positioning advocated by the people living with dementia in the group. Discourse which positively (+) positions people living with dementia is located in the centre of the Balancing Framework whilst non-positive (-) positions are indicated by a line on the edge of the framework. The Balancing Framework was used to visually display the results of the Delivery phase (see right hand column).



Results: People living with dementia were empowered to identify the requirements for positive verbal positioning using three phases of Appreciative Inquiry. An original positioning theory framework was developed for the analysis of discrete discourse in relation to this 'ideal' positioning. Other societal groups were directly influenced by the outcomes of the Appreciative Inquiry, resulting in more positive discourse concerning people living with dementia. However, the influence of the outcome varied across different groups, with the emotional and practical experience of group members remaining a key influence on the overall positioning of people living with dementia.

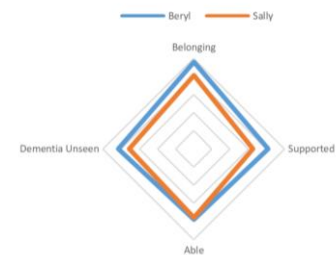
Conclusions: Appreciative Inquiry can be reconfigured to involve different participants across phases, retaining its generative and transformative potential, without foregoing its underpinning principles. People living with dementia can successfully complete an Appreciative Inquiry exercise with outcomes that have the power to transform the discourse of other members of society. Social action can be influenced by people living with dementia using this adaptation of the Appreciative Inquiry methodology.

References:
Cooperrider, D. L. & Whitney, D. (2005) *Appreciative Inquiry: A Positive Revolution In Change*. Berrett-Koehler Publishers Inc.
Cooperrider, D. L., Whitney, D. & Stavros, J. M. (2008). *Appreciative inquiry handbook for leaders of change*. Berrett-Koehler Publishers, Inc

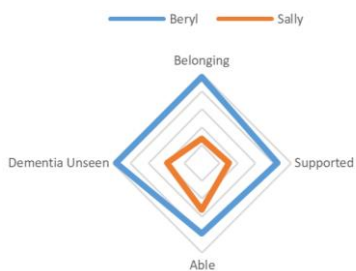
DELIVERY

The discourse of the natural discussion groups was analysed using the Balancing Framework. The first group discourse involved a case study (Beryl). Following this, the groups viewed the film created through the Appreciative Inquiry by people living with dementia. Their discourse was then analysed regarding a further case study (Sally) to ascertain whether their language had become more aligned to the positive positions advocated by the film.

Whilst the healthcare worker group did offer more positive positions for people living with dementia following the film, their vocational discourse was often a barrier to fully embracing the positions advocated by the people living with dementia.



Overall, the lay people group were able to adopt the positive positioning advocated by the people living with dementia, suggesting that this discursive change was easier for those without an emotional or practical connection to a person living with dementia.



The family member/carer group were able to adopt the positive positioning of people living with dementia regarding their abilities and the need for purpose. Less positive changes were observed regarding being able to position the person beyond their dementia diagnosis.

