

Attitudes and assumptions about people living with dementia and their carers, and their influence on rights to participation, inclusion and access to public spaces.

Carmela Leone, Rachel Winterton, Irene Blackberry

John Richards Centre for Rural Ageing Research, La Trobe Rural Health School, La Trobe University, Australia

Introduction

Public spaces provide opportunities for people living with dementia and carers to create and build social relationships. This is especially important in rural areas where a rural setting and dementia symptoms can lead to further exclusion¹. Attitudinal barriers embedded in institutional practices result in buildings and outdoor environments that exclude people living with dementia². Oppressive public spaces are due to ableist values as well as a neglect of accessibility needs³.

Aim

To identify attitudes, assumptions and influences within the dominant discourses of City of Greater Bendigo's public news media, in relation to people living with dementia, carers and rights to public space.

Methods

Data collection – News stories and letters to the editor were collected from online news media publications. The search terms 'Alzheimer's' and 'dementia' were used, and the date range of 2003 (as far back as texts exist) to June 2020. Texts were read, coded and analysed to identify discursive formations⁴.

Data analysis – A Foucauldian-inspired discourse analysis method^{5,6} was used to identify dominant discourses. Rights to public space were guided by the 'right to the city' framework⁷.



Results

People living with dementia are represented as

- voiceless, helpless and defenceless
- suffering patients and powerless victims
- deficient in skills and abilities
- lacking agency and reliant on others.

Through the voices of others who advocate for the personhood⁸ of people living with dementia, they are also represented as

- persons who retain their identity and can live meaningful lives.

Carers are represented as

- encumbered, suffering individuals.

Rights to public space – through advocacy people living with dementia are represented as

- active and engaged social citizens
- community members
- complex social actors with agency and the ability to live well
- persons who retain their identity, regardless of difference.



Attitudes and assumptions about people living with dementia:

- liminal, non-persons
- incapable of understanding and articulating their own situations.

Through advocacy from others, people living with dementia:

- retain their personhood
- sustain their community membership and social citizenship status
- can live well with dementia, in their communities.

Influences within the discourses:

- a bio-medical model in representations of people living with dementia as helpless and defenceless patients, sufferers and victims who are reliant on others.
- a human rights framework and social model of healthcare/disability in representations of people living with dementia as social citizens with rights to participation, inclusion and access to public spaces.

Conclusion

People living with dementia are negatively represented within most discourses. In relation to rights to public space however, their personhood and social citizenship status are recognised through advocacy. Attitudes and assumptions that influence these positive representations sit within a human rights framework and a social model of healthcare and disability.

Other stages of the study will analyse texts from interviews with community stakeholders, and people living with dementia and their carers. Findings will inform dementia awareness-raising and education programs, towards a rights-based dementia-friendly community in the City of Greater Bendigo.

References

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