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Explaining social exclusion in alcohol-related dementia: a literature review

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Explaining social exclusion in alcohol-related dementia: a literature review

Abstract

Background: The purpose of our project is to explore the lived experience of people with alcohol-related dementia and their carers to explain the impact of social exclusion. The literature review has been completed. The empirical study will be a qualitative study using narrative storylines (Keady et al., 2009) to understand the Australian experience of alcohol-related dementia. **Methods:** Academic and publishers' databases (CINAHL, ScienceDirect, Wiley Interscience and SAGE) were searched using the terms: 'alcohol-related dementia', 'diagnosis', 'carer', 'services', 'treatment' and 'stigma'. Snowballing techniques were also used to source papers and Google Scholar for grey literature. **Findings:** A total of 35 articles were retrieved and reviewed. An overall theme of social exclusion was found to explain the experience of people with alcohol-related dementia and their carers. There were 7 sub-themes discovered to explain this social exclusion: (1) stigma; (2) homelessness; (3) under-recognition and lack of timely diagnosis; (4) inappropriate service provision; (5) carer education needs; (6) carer needs ignored and (7) recovery pathways. **Conclusion and Implications for Practice:** The findings from the literature review illustrate that before people with alcohol-related dementia and their carers can have an opportunity to adequately live with alcohol-related dementia the issue of social exclusion must be addressed. Our proposed empirical study will provide a voice for those with alcohol-related dementia and their carers and understand how social exclusion can be addressed to improve the quality of life for people with an alcohol-related dementia and their carers.

Keywords

exclusion, alcohol, related, dementia, literature, review, social, explaining

Disciplines

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Explaining Social Exclusion in Alcohol-Related Dementia: A Literature Review

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and

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Why research this?

- People 'fall through the net' – do not meet with 'criteria' for majority of services
- Inexperienced staff & unsuitable services do not take into account the complexities that surround people with alcohol-related dementia
- Remains the 'hidden dementia' in current clinical practice and the literature



What is alcohol-related dementia?

- Alcohol intrinsic to Australian culture, but large proportion population drink at levels that place them at risk of alcohol-related harm
- NHMRC (peak body who develops alcohol guidelines) found ¼ Australians at risk of alcohol-related harm
- Harms include cognitive & neurological impairment, structural brain changes = alcohol-related dementia, but degree of recovery possible
- Over 10% younger people have dementia that is alcohol-related, some research even states over 20%



What was found in the literature?

- 35 articles retrieved - quantitative and qualitative studies, systematic reviews and government reports
- Research had to be with those with a definite diagnosis of alcohol-related brain condition and/or their carers
- **6 key themes** evident in the research



Case study

- Darcy, artist, divorced 52 year-old gentleman with a 25+ year history alcoholism
- 12 year contact D&A services, over last 9 years worsening cognitive impairment noted on each contact
- Symptoms included: memory loss, difficulties mobilising, slowed thought processes, poor judgement, changes in personality, perception & behaviours
- Also experienced mild liver problems & nutritional deficits



First theme

- **Under recognition & lack of timely diagnosis**
 - Darcy experienced 8 years of significant cognitive impairment, but diagnosed at 45 with clinical depression
 - No alcohol-related brain diagnosis given until age 49, when Darcy needed constant supervision & could not adequately maintain independent living



Second theme

- **Service provision (or lack there of...)**
 - Darcy treated for at least 3 years by both D&A and mental health services, without either knowing about one another
 - No fixed abode for approximately 5 years, used up 'quota' of emergency accommodation
 - Did not meet criteria for drug and alcohol residential rehabilitation



Third theme

- **Stigma**

- Darcy's family/former friends would have 'nothing to do with him', related to poor behaviours from persistent alcohol abuse
- Health care workers & others called him 'sub-human', not deserving of love and care, due to 'self-inflicted' nature of his illness
- Resulted in damaging self-stigma, 'alcoholic creep', 'worthless human being', 'did not deserve to live'



Fourth theme

- **Homelessness**

- Darcy homeless for 5 years, no money, no family or friends to take him in
- Difficulty for Darcy to distinguish between right & wrong, short-term memory problems – difficulties caring for himself
- Darcy left in an extremely vulnerable state with others taking advantage of him, loss of identity and 'broken' life



Fifth theme

- **Carer needs (not being addressed)**
 - Darcy's friends found difficulty accessing services, treatment, support & any information about alcohol-related dementia
 - Friends 'fed up' with lack support/information and Darcy's worsening cognitive symptoms & behavioural problems – Darcy 'kicked out' and homeless for at least 5 years



Sixth theme

- **Recovery pathways (also lack there of...)**
 - Lack of coordinated services for Darcy = no chance of recovery
 - No one person/organisation coordinating care = no opportunity to stop drinking and to slow down or stop cognitive impairment
 - Darcy sadly died alone just short of his 53rd Birthday



Social Exclusion

- Wider marginalisation and social exclusion occurs for the majority of those with alcohol-related dementia
- The need to heal the 'broken lives' of these people needs to be prioritised before a reduction in this social exclusion will be seen



Specialist rehabilitation unit

- **Key principles of treatment:**
 - Staff are experienced in complexities of alcohol-related dementia - coordinate care, provide safe and therapeutic environment
 - Support for abstinence from alcohol, so that recovery a possibility
 - A rehabilitative approach to assist with independence in everyday living
 - Active family involvement, as support networks improve treatment outcomes



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