



ALLIANCE for SELF CARE RESEARCH
"Enhancing self care"

SELF CARE, DEMENTIA AND SOCIAL MARGINALISATION: ASSESSING THE EVIDENCE GAPS

Background

Dementia, especially age-related forms such as Alzheimer's Disease have received increasing attention from researchers in most Western societies. Moreover, dementia is also emerging as a disabling condition in younger age-groups as a result of life-style choices (obesity as a risk factor of vascular dementia; alcohol-related brain injuries) often with socioeconomic context factors contributing to its manifestation. While health care systems increasingly emphasise service user involvement in decision making, disease prevention, management and rehabilitation it is important to identify those population segments that are currently socially 'excluded' from self care support. Previously, a scoping review of systematic reviews did not find any self care enhancing interventions that were specifically targeted at individuals from social deprivation backgrounds (Jones, MacGillivray, Wyke, Kroll, Zohoor, Baldie & Fleming, 2006).



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"Investigators have largely failed to address socioeconomic context factors in self care and self management research. And they have systematically excluded people from participation in research. We need to remedy this or the evidence base will remain skewed and resource allocations based on premises that don't tell the whole story"

Aims and methods

A combination of methods, including a rapid evidence reviews of the scientific literature (Medline, Cinahl, PsycInfo, AgeLine, Social Work Abstracts, 1996 – 2007) and media content analysis (Nexis™ search, 2000-2007; Major English language newspapers) were used to examine the current evidence base for self care or self management in three 'socially marginalised' population groups: 'homeless individuals'; 'people with immigrant background'; and 'individuals with low socioeconomic status/poverty'.

Key findings

- Social marginalisation of people with dementia is not occurring with regard to service provision but also in the process of research (inappropriate study designs, sampling frames, outcome measures)
- Professional 'stigmatising' attitudes about the individuals' ability to engage in self care are compounded by lack of social and material resources to access services
- Primary study research is mostly 'exploratory', quite heterogeneous in scope, mostly non-intervention research and qualitative (based on 5 studies)
- Media stories (33 homelessness; 17 poverty; 17 immigrant) reveal serious threats to individuals opportunities and capacity for self care based on the ability to afford nursing home services, exposure to violence due to public misperceptions and enhanced vulnerability, linguistic and cultural challenges for migrants, and legal battles over the right for self-determination
- Only 7 media reports focused on self care issues in dementia,

primarily directed towards caregiver support and not service users and not in conjunction with social marginalisation issues.

Recommendations

- Self care support needs and context factors for people with dementia from socially marginalised backgrounds are not well understood and need to be studied further
- Important research priorities can be identified from media stories
- Innovative approaches need to be explored to include people from socially marginalised groups in research studies
- The concept of self care needs to be reviewed for these population groups in terms of deliberate exclusion due to social, physical and economic barriers.



Further information: full report available on www.ascr.ac.uk

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