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Book review

Dementia and well-being: possibilities and challenges

Ailsa Cook
Edinburgh: Dunedin Academic Press Ltd, 2008, pp 90,
(Policy and Practice in Health and Social Care series No. 8)
ISBN 978 1 903765 76 0

This book is an insightful critique of the policy agenda in England and Scotland that aims to promote the well-being of users of health and social care services including people with dementia. Based on recent dementia care research, such as ethnographic studies, Ailsa Cook critiques this agenda in meeting the diverse and unique needs of people with dementia and their formal care providers and family caregivers.

The book is structured around four key health and social policy objectives: to promote health, independence, choice, and social inclusion in service users. A review of the empirical evidence reveals the extent to which the health and social care systems are failing people with dementia by not effectively diagnosing, treating and managing dementia. Strategies for promoting health are suggested. For example, shifting from fragmented and responsive care in hospitals to anticipatory, integrated and continuous care in communities; introducing Practice Based Commissioning whereby family physicians pool resources and commission specialized services in the community to prevent admission to hospital, improve management of long-term conditions, and choice and access to services; and implementing an Integrated Care Pathway for dementia that includes a multidisciplinary specialist service team that follows persons with dementia and their caregivers throughout the progression of their condition.

The term interdependence, rather than independence, is a more appropriate objective for people with dementia as total independence is not realistic. Issues preventing the promotion of interdependence in people with dementia are highlighted: an emphasis on risk prevention by restricting behaviours; unavailable low levels of supportive preventive services; and inadequate assessment skills and knowledge needed by dementia care providers to provide quality service. The challenges and strengths of proposed funding models to support care, policies to support family caregivers as partners in care, and telecare initiatives are described.

The lack of choice and control in many care settings and in participating in research has undermined the well-being in people with dementia. Factors impacting on their ability to have choice and some control over their lives are highlighted (e.g. low rate of early diagnosis; conceptualizing cognitive capacity as being incapable of making decisions rather than as fluctuating and requiring ongoing consent; and inflexibility of services and care regimes. Innovative strategies are described that enable people with dementia to express their ideas and for staff and researchers to involve them in decision-making regarding their care and participation in research.

The final objective, social inclusion, is probably the most important in preserving well-being of people with dementia. This chapter examines the processes whereby people with dementia are afforded and denied opportunities to: (i) participate in activities that are important to them, (ii) have a voice in their society and local community, and (iii) have relationships with others. Two key macro processes are elucidated: ‘structural dependency’ (e.g. for-profit sector determining policy to meet the needs of dependent older adults in institutions rather than in their own homes); and the dominance of negative cultural discourses around dementia (e.g. stigmatization of people with dementia). The implementation of the personalization agenda and commissioning innovative services at the local level are key ways to promote people with dementia to remain engaged in relationships with their family, friends, and communities. In addition, the participation of people with dementia in policy, practice, and research that seeks to improve the well-being of this population is a vital step towards decreasing the extent to which they are marginalized and socially excluded.

This book makes an important contribution to dementia care literature as policy and legislation have, to date, not considered the unique needs of this growing population of people with dementia. Although this book examined the policy agenda in England and Scotland, the critique has application for all people with dementia and the suggested strategies may be beneficial to them and their family caregivers in other countries as well.

I would rate Ailsa Cook's book five stars out of five. The book should be recommended to graduate students studying dementia care and gerontology as well as policy makers, administrators, practitioners and those with dementia and their family caregivers.

Dorothy Forbes, RN, PhD,
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Postscript

Readers may be interested to know that, since the publication of this book, the first ever national dementia strategy in England 'Living well with dementia: a National Dementia Strategy'[1] was published after a long period of anticipation on 3rd February 2009. The Strategy sets out an intention to help transform the quality of care to dementia sufferers, their carers and their families by ensuring that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. Integrated working between agencies is an implied theme running throughout the document.

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[1] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058