

Reviews

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Julia Botsford and Karen Harrison Denning, *Dementia, Culture and Ethnicity: Issues for All*, Jessica Kingsley Publishers, London, 2015, 328 pp., pbk £29.99, ISBN 13: 978 1 849054 867.

This is a timely and necessary book that reviews the evidence base in the United Kingdom (UK) and draws on expert practitioners' experiences to expound how culture and ethnicity inform the experience of dementia and the support that people with dementia and their families receive. In 2013, the All-Party Parliamentary Group on Dementia (2013) launched an inquiry into services and support for people living with dementia in the UK within minority ethnic groups that helped to focus attention on the significant unmet need among this population. Serving as an important counterpart, *Dementia, Culture and Ethnicity* is a level-headed book that nevertheless confronts the challenge of how dementia care services will need to develop to ensure that provision is culturally appropriate for an increasingly diverse older population.

Section One sets the scene, outlining the progressive ageing of the minority ethnic population before presenting dementia projections among black and minority ethnic (BME) groups in the UK that are far higher than in the majority population. This is juxtaposed against evidence that older adults from BME groups are under-represented in the use of dementia services in comparison with the white British population. While it is true that the evidence base on dementia and ethnicity is considerably less established in the UK than the United States of America, the authors present findings from an accumulation of qualitative studies that prioritise the perspective of BME carers and older people and form a strong foundation for future research. It becomes clear that we now have a good understanding of the different barriers to accessing dementia services that can exist among BME groups, such as a propensity to attribute symptoms to normal ageing, concerns about stigma, strong family expectations to provide care, and a belief that little or nothing can be done to help people with dementia or their families.

In Chapter 6, Karen Jutla illustrates these themes further with a fascinating account of how migration experiences and cultural norms associated with family roles can determine how care is negotiated within South Asian families. It is noteworthy that attention is also given to the barriers that can exist at the provider and system level, for instance a lack of clinical experience and diagnostic skills among general practitioners to diagnose dementia in BME older people and a failure among mainstream dementia services to reflect cultural requirements such as dietary, linguistic or religious needs. It is suggested that strategies are needed both to address the

specific information and awareness needs of BME groups *and* to develop culturally sensitive services.

This is a practical and constructive book and Section Two responds to the challenges outlined in Section One by focusing on positive approaches to engaging and working with people with dementia and their families. Chapters 7 and 8 discuss, respectively, the complexities of assessing cultural needs and communicating with people with dementia and families who speak different languages, before offering practical guidance on undertaking culturally sensitive assessments and working with interpreters in the dementia care setting. In Chapter 9, Julia Botsford and Karen Harrison Denning present a range of examples of innovative practice that have responded to the needs of individual communities. These include a Connecting Communities project aimed at promoting awareness in minority ethnic communities in London, a project to develop dementia-friendly Sikh Temples, and a community organisation providing information, a crisis line and a support group to the African Caribbean community. The book does not dwell on the contentious topic of whether culturally appropriate care can and should be achieved through attending to individual needs within mainstream services or whether 'specialist' services targeted at people from minority backgrounds are required. However, strong themes emerge, such as the importance of working in partnership with ethnic community groups and of raising awareness and exploring understandings of dementia within the community itself. I would have welcomed a fuller discussion of the shared strengths of these initiatives, but appreciate that few have been subject to independent evaluation. The need for further research is a recurring theme in the book that is stressed in the subsequent chapters on ethnicity and care homes (Chapter 10) and end-of-life care in BME groups (Chapter 11). The discussion of dementia and care homes is particularly interesting not only as it addresses a profoundly neglected area, but because it helps us to understand what culturally competent care might actually look like in practice.

This leads to Chapter 12 in which 11 family members provide short portraits of their relative and their experience of dementia. Described as the heart of the book, these are moving and penetrating accounts. Here we begin to truly understand how differences in culture and language can contribute to a profound sense of isolation among people with dementia and their families. Equally powerful are the examples of where culture has been celebrated and shared, where assumptions have been avoided and care providers from diverse cultural backgrounds have sought to understand the values of the individual. We hear about the comfort that can be found in familiar food and rituals and the bonds that can be formed in the face of cultural differences. In the final chapter, Jill Manthorpe reminds us that dementia care will only succeed in respecting cultural diversity if supported by policies and strategies, both at a local and national level. An accessible review of age-, dementia- and equality-focused policies contributes to what is an essential read for those supporting families affected by dementia.

Reference

All-Party Parliamentary Group on Dementia 2013. *Dementia Does Not Discriminate: The Experiences of Black, Asian and Minority Ethnic Communities*. Alzheimer's Society, London.

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Shibley Rahman, *Living Well with Dementia. The Importance of the Person and the Environment for Wellbeing*, Radcliffe Publishing, London, 2014, 321 pp., pbk £29.99, ISBN 13: 978190891 197 1.

Rahman aims to provide an introduction to what it means to live well with dementia. He highlights in his introduction to this text that living well with dementia is a complex and challenging issue for our society. This challenge extends to the undertaking of writing a book on this topic, which must necessarily address a diverse range of issues and attempt to make it accessible to a wide audience.

This ambitious book includes 17 chapters that address various aspects of the importance of the person and the environment for wellbeing. The earlier chapters deal with theoretical perspectives that underpin the book, such as what it means to live well and how this can be measured, and socio-economic arguments for promoting living well with dementia. The next chapters focus on social, psychological and neurological factors associated with living well, including leisure activities, end-of-life care, the impact of different types of dementia, decision-making and communication. The latter chapters focus on the physical environment and living well, including home and hospital ward design, assistive technologies, ambient assisted living, built environments and dementia-friendly communities. One of the strengths of this book is that all of these topics are underpinned by the philosophy and principles of person-centred care. Thus, the perspective and needs of the person with dementia and their family are considered throughout and there is a focus on retained abilities and understanding what people can do, rather than what they cannot.

The challenge of covering such a diverse range of topics is no better demonstrated than in the early theoretical chapters of the book, where vast and complex areas such as what it means to live well and the measurement of wellbeing and quality of life in dementia are covered within the confines of 20 or so pages. One limitation of this book is that the depth of coverage of these topics may be too superficial for those with some familiarity of the issues, but at the same time lack sufficient explanation for readers coming to them for the first time. Other chapters, however, such as those addressing the debate around dementia screening and case