

Reviews

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Heather Wilkinson (ed.), *The Perspectives of People with Dementia: Research Methods and Motivations*, Jessica Kingsley, London and Philadelphia, 2002, 256 pp., pbk \$23.95 (£15.95), ISBN 1 84310 0010.

The aim of this book is to inform readers, whether students, researchers or practitioners, of how important it is for researchers to engage directly with people with dementia. The contributing authors write about some of the issues that arise, how they have tackled them and the lessons they have learned. The 13 chapters are based largely on a number of research projects but also draw on the published literature, and two helpful chapters have been written by individuals with dementia (although curiously their names do not appear in the list of contributors at the end of the book). The main gains to the reader are to learn from various projects how researchers went about their sensitive inquiries, how they negotiated some of the difficulties, and in the tips they pass on. The chapters that I found most useful were by Gill Hubbard, Murna Downs and Sue Tester, on ‘Including the perspectives of older people in institutional care during the consent process’, by Kate Downs on ‘Working with staff to include people in dementia research’, and by Alison Bowes and Heather Wilkinson, on ‘South Asian people with dementia: research issues’. There are also many helpful points in other chapters, notably on ethical issues in dementia care research (Helen Bartlett and Wendy Martin), and on successes and challenges in using focus groups with older people with dementia (Claire Bamford and Errollyn Bruce).

There is however a disappointing side to the book. The editor, Heather Wilkinson, has done little more than commission the various chapters. There is repetition and the thrust of the book is descriptive rather than analytical. Three particular weaknesses struck me. First, with small exceptions, the book does not guide the reader to the essential research literature. There is a maddening lack of cross-referencing, notably in the discussion of ethical issues, so that in only a few cases do the same references appear in different chapters, even though the authors are discussing the same issue. Secondly, the book is weak in its analysis of the key methodological issues, like reliability and validity, and it fails to examine in a hard-edged way the aims, costs and benefits of research with dementia sufferers. This may sound churlish, but the book inevitably raises questions, not about the worthiness of the endeavour to involve dementia sufferers in research, but also about the nature and quality of the resulting gains to knowledge and understanding. Finally, the authors generally brush over the process of research ethics committee approval, a hurdle that is increasingly challenging. It would have been very helpful to have had more attention to these issues with examples, for instance, of consent forms. A focus on users in all contexts is part of the contemporary research ‘must-do’. If you are about to embark on a piece of research that involves people with dementia in any way, this book,

despite its limitations, would provide helpful signposts, warnings and practical advice.

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Renée Rose Shield and Stanley M. Aronson, *Aging in Today's World: Conversations Between an Anthropologist and a Physician*, Bergen, New York, 2003, 248 pp., hbk \$29.95 (£20.00), ISBN 1 57181 420 5.

This book presents a sequence of dialogue exchanges between a middle-aged social anthropologist, who specialises in ageing, and an ageing physician, who happened to have served on her dissertation committee, and thereby straddles academic and personal perspectives in various ways. It is a cross-generational encounter, an inter-professional commentary and, above all, a confrontation between two distinct age-related worldviews that emanate from different consciousness. The genre of dialogical texts constitutes a discourse whose flow and liveliness is capable of embracing all these levels as a dynamic story that interweaves scientific knowledge with individual experience. The dramatic plot of this discourse moves from the conventionally acknowledged, in the form of some essential facts and figures on old age, to the morally debated ethical issues of relocating and stigmatising older people. The poetics of this theatre of voices is conversationally engineered through the interjection of a third imaginary voice – that of an 87-year-old nursing home resident who offers a wry commentary on the thoughts and observations of the primary speakers. This gimmick, while adding to the literary flair of the book, is injurious to its credibility and spells out the self-conceived inadequacy of both writers to represent authentically the object of their joint inquiry: ‘old people’.

The fictitious intervention introduces the assumed natives’ point of view, thus challenging the limits of the two disciplines as insightful and instructive gazes into the state of being old. This casts doubt on the worth and usefulness of the dialectic between anthropology and medicine – as neither captures the gist of the experience at stake. Conversely, such induced reflection attenuates the potentially mounting tension between the two apparently discrepant discourses of the body-social and the body-physical. In the interplay between these conflicting approaches, the book conjures up an intriguing reversal of disciplinary fortunes, for the anthropologist engages with the medical, and the physician is preoccupied with the cultural.

The tale of ageing according to our protagonists begins with a run-of-the-mill drafting of the gerontological map. Thus the territory of the book expounds some basic facts concerning the socio-historical demography of ageing around the globe and its implications for population profiles and the economy of health and welfare. Both anthropologist and physician are informed in their discussion of the processes of ageing. This common scholarly orientation depersonalises the conversations and renders the text scientifically tenable. However, professional mutual respect bifurcates into almost opposite stances by virtue of the age-contingent

differences between the two. Here, cohort effect, imbued with present position and outlook, over-rides the façade of academic discourse and throws into relief a subtext of irreconcilable personal perspectives on the meaning of ageing. The anthropologist, captured by the relativistic model of human diversity, expresses heightened awareness of her own biological ageing, in terms of a prospective deterioration in mental and physiological functioning. The physician, perhaps unexpectedly, does not ponder over geriatric ailments, is troubled by culturally-ingrained ageist attitudes and embarks on a detailed search for the pejorative vocabulary, that disparagingly excludes ‘the old’.

This reversal of professional concerns resonates in an interesting twist to the protagonists’ respective interpretations of ageing. The anthropologist, following her disciplinary ethos and convictions, maintains that, despite obvious age-linked changes, older people are no different from younger humans in their prime; whereas the physician, reflecting upon his own frame of mind, muses the fundamental transformation besetting him in his older years. This transformation is marked by a gradual distancing from the pursuit of attainment and recognition and by an acquiescence with impending death and other losses. Notwithstanding these alternations, both authors partake in the game of brinkmanship with the otherness of the old. As no distinction is made between old persons and old age, cultural idioms and myths are embodied in older people who in turn become icons of otherness and strangeness. In a line of argument that is reminiscent of the much maligned theory of disengagement, the phenomena of retirement, dementia and life in a nursing home are discussed and described as uncharted territories of exclusion and withdrawal. The socio-anthropological literature has plenty to offer to the understanding of such social impasses and their inhabitants – the stranger, the other and the outcast – yet none of that is employed to suggest a comparative framing of the concept of the old within the available analytic parameters, such as taboo areas, liminality, boundary maintenance, colonisation and disembodiment.

It is perhaps the in-built quest for mutually intelligible communication based on the broadest common denominator that compromises the anthropologist’s fine-tuning of their disciplinary knowledge. Reflexivity and inter-subjectivity, which used to be the hub of autobiographical anthropology, endows the book with its literary and testimonial merits but simultaneously reduces its contribution to the much needed conceptualisation and legitimisation of the study of ageing in the socio-cultural discourse. Under the guise of a sketchy portrayal of ageing in today’s world, the two learned interlocutors, haunted by a third fictional commentator, present a reading of their own ‘map of life’, as drawn by their American heritage, their generational sentiments and their professional identities. This is a telling document of a three-phase process on the course of ageing among relatively affluent and highly educated Americans; but their experience is no cue to the fate of their contemporaries worldwide. Read and understood within such ethnocentric terms, the book offers a fresh hearing of voices pleading with the biologically inevitable, and argues a strong case for cultural variability.

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Carol L. Jenkins (ed.), *Widows and Divorcees in Later Life: On Their Own Again*, Haworth, New York, 2003, 202 pp., pbk \$24.95, ISBN 0 7890 2192 7. Co-published simultaneously in *Journal of Women and Aging*, 15, 2/3.

This edited volume presents a wide range of scholarship on older women who live alone in their latter years and addresses some important 21st century issues, such as changing family and marital dynamics and ethnic diversity. It offers a nicely balanced collection of analytical and theoretical work. Despite its prominence in the title, I was, however, disappointed by the minimal attention given to *divorced* older women, whose prevalence while still low is increasing, especially in the developed world. Of the nine chapters, six are devoted to widowhood and only one, by Barbara Butrica and Howard Iams, exclusively to divorcees. Even their chapter focuses on future baby-boomer divorcees (and their projected retirement income) rather than current divorcees. A chapter by Karen Glaser, Emily Grundy and Kevin Lynch discusses the predisposing and precipitating factors in the transition to supported environments for widowed and divorced women. The longitudinal data on which it is based cover the inter-census changes during 1971–1981 and 1981–1991 and has information on ‘ever married’ elderly women – so widowed and divorced are treated as a single category. As a result, neither of these chapters examines the lived experience of current older divorcees, surely a missed opportunity. The final chapter, by Dorothy Ruiz, Carolyn Zhu and Martha Crowther, reports research on African-American custodial grandmothers of all marital categories, only a quarter of whom were over the age of 65 years. This last chapter, despite its interesting findings, is probably not best placed in this book because its remit is much wider than suggested by the book’s title.

Despite these reservations, the chapters on widowed women offer excellent insights into their experience. James Laditka and Sarah Laditka report on the increased hospitalisation risk for recently widowed older women and examine the protective effects of social contacts. They found that recently widowed women had just under a 40 per cent higher risk of hospitalisation than women not recently widowed. The risk is higher for socially-isolated older widows. Their findings support other studies which have shown that women who have been widowed for more than two years demonstrate a similar pattern of hospital admission to married women. A chapter by the editor examines care-arrangement choices for older widows, and demonstrates interesting diversity in the meanings of ‘independence’, as viewed from older women’s, adult children’s and professionals’ perspectives. She concludes that independence for older women is best understood as a flexible concept, so that choices of care and responses to changes in condition are readily adapted to need. This observation has policy implications, particularly in relation to hospital discharge, when professionals are often less optimistic about the capacity for self-care than older people and their relatives. Michael Scott, Martha Crowther, Bettina Schmid and Rebecca Allen investigate spirituality and responses to bereavement. They conclude that older widows use religious coping as well as religious and spiritual beliefs and behaviour to facilitate positive adjustment to their loss. They recognise the limitation of focusing on ‘Christian’ religiosity and suggest a wider remit that includes non-Christian and

supreme being spiritual practices. They also suggest that more research should be carried out on same-sex partnership bereavement and the place of spirituality in coping strategies.

The remaining chapters on widowhood examine the experience of older women from different ethnic backgrounds. James McNally compares health, widowhood and family support in the North and South Pacific, using the Philippines and Fiji as examples. Maria Catell writes about sub-Saharan Africa, and Jacqueline Angel, Nora Douglas and Ronald Angel discuss their research on older Mexican-American widows and widowers. Maria Catell's chapter is particularly thought-provoking, because it challenges Eurocentric definitions of widowhood. For example, it illustrates the diversity in cultural and social norms which determine what property and possessions a widow may retain, and who she may be obliged to remarry, as by leviratic customs whereby she marries one of her late husband's kin, or which stipulate who she should live with after the loss of her spouse, (e.g. return to her kin fold, live with her son). Interestingly, the Rukuba and Irgwe tribes of Nigeria are polyandrous which begs the question: is she a widow if only one husband dies?

As the volume unfolds, the authors demonstrate that most widows and divorcees live in social and cultural networks from which they receive substantial support. The title is therefore a little misleading in another way, for most of the women under discussion were living without a spouse but were not really 'on their own'. For this cohort of women, the loss of a spouse, either through bereavement or divorce, may mean that they are living alone for the first time in their lives. Indeed, for some widows and divorcees, the apt title might be 'on their own at last'. To a large extent the positive aspects of widowhood and divorce are missing from this book, although exceptions are in the chapters by McNally, who concludes that the situation of elder widows in the Pacific islands is generally far from dire, and by Catell, who argues that for many African women, widowhood and the independence it bestows are preferable to remarriage. Catell supplies a wonderful quote from a Nigerian woman who says, 'I have had so much of this bossing by men. ... I have my house, my garden, I grow my vegetables, I sell in the market. ... Why should I have a man take it from me? ... I am the boss now' (p. 59). This collection will be especially useful for those conducting research on older women who live alone and I recommend it for the library and as a recommended text on gender and later life.

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Susan H. McFadden, Mark Brennan and Julie Hicks Patrick (eds), *New Directions in the Study of Late Life Religiousness and Spirituality*, Haworth Pastoral, New York, 2003, 243 pp., hbk \$39.95, ISBN 0 7890 2038 6, pbk \$24.95, ISBN 0 7890 2039 4.

While religion remains a domain of constructs which defy simple explanations (Levin and Tobin 1995), it is clear that one of the core functions of religion is to

provide meaning. The editors have selected 12 papers presented at various symposia on religion and spirituality at the annual meeting of the *Gerontological Society of America* in 2001. They illuminate various meanings, practices and beliefs attributed to religiousness and spirituality in late life. Although most of the chapters have an empirical foundation, the book contains something for everyone interested in this field. A drawback is that only one of the chapters reflects a European perspective: there is a considerable paucity of comparable research in Britain (but see Coleman, Ivani-Chalian and Robinson 2004).

The book has three parts: a brief introduction and a useful overview of succeeding chapters by the editors. Part 1 is concerned with research methodology and data analysis. Brennan and Mroczek bravely lead the way, by arguing for more sophisticated methods of analysing longitudinal data, but those less familiar with complex statistics will not be overwhelmed. Their explanations are accessible and should benefit students entering this area of research. Next is a well described qualitative study and an exemplar of good practice. The chapter on the 'Spirited Scotland' project is well written and timely for a British audience.

Part 2 grapples with the thorny problems of definitions of religiousness and spirituality. All the chapters in this section repay close attention and offer very useful advice to researchers in the field. Nelson-Becker asked older people for their own definitions. Although these had many similarities, they could still be clearly differentiated. Wink's metaphors of 'religious dwelling' and 'spiritual seeking' suggest that these two distinct constructs are useful in understanding successful ways for psychosocial functioning in later life. Thompson and co-authors' study of recently bereaved widows asked if they began to engage in reflective dialogues and had begun a spiritual journey. The findings indicate that the journey itself was both 'controlling and comforting'. Religious involvement led to good adjustment, and belief and prayer encouraged a sense of meaning and purpose. Chatters and Taylor focus on current research into religion and its association with wellbeing. They conceptualise and examine social contexts by offering worldview, ecological and social location perspectives. They suggest that different denominations have unique experiences which require diverse methods to capture these differences, particularly with regard to wellbeing outcomes.

Part 3 examines broader aspects of the influence of religion and spirituality on wellbeing in later life, with Hicks, Patrick and McKinney asking what effects religion has on emotional wellbeing for younger and older people. Kinney and colleagues discuss Pargament's concepts of general and religious coping and apply them to care-givers whose partners have dementia. The discussion is intriguing, particularly concerning the care-giver's depressive symptoms. Bonner and co-authors also look at depression and religion in later life, but argue that 'subjective spirituality' can apply to both public and private belief practices with interesting gender differences. The final chapter focuses on the way in which religiousness is influenced by spousal bereavement, including sudden and violent death.

Susan McFadden's many contributions to religious research are well known and this book will be no exception. In spite of its heavy United States focus, it should be useful to a wide range of readers including researchers and practitioners. Indeed, the final comments by the editors argue for closer co-operation

between the two. This book also adds to a substantial body of literature which indicates that having religious or spiritual beliefs encourages physical and mental wellbeing in later life. It should therefore be of particular interest to those working in health and social care settings.

References

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Margaret P. Norris, Victor Molinari and Suzann Ogland-Hand (eds), *Emerging Trends in Psychological Practice in Long-Term Care*, Haworth, New York, 2003, 303 pp., hbk \$69.95, ISBN 0 7890 2004 1, pbk \$39.95, ISBN 0 7890 2005 X. Co-published simultaneously as *Clinical Gerontologist*, **25**, 1/2 and 3/4, 2003.

This book examines the contribution that consultants, clinical and counselling psychologists can make to the lives of residents in long-term care settings. As such it provides a welcome focus on a neglected group as far as psychological practice is concerned. The book has 12 contributions that are organised in three sections. The first section of five chapters is concerned with ‘Modifications of traditional psychotherapy techniques’. Molinari leads with an overview of various types of group therapy and their potential uses. It is unfortunate that his discussion of Yalom’s seminal work is referenced to the first edition of 1975, for by 1995 the book was in its fourth edition and Yalom, not surprisingly, had changed what he considered to be the key therapeutic factors. A reference to ‘inter-personal living’ (p. 17) should surely be to ‘inter-personal learning’? Carpenter and colleagues then describe Restore-Empower-Mobilise (R-E-M) psychotherapy. Although this seems highly relevant, the trial describes interventions with only three residents. Clearly, larger trials are needed to assess its potential. Hyer, Sohnle, Mehan and Ragan review memory work and then describe their own approach – 12 group-work sessions that focused on ‘Positive core memories’. An appendix contains their manual. Briefly, the group leaders aimed to elicit three positive core memories from each group member and then to link them to their current experiences. The sketchy results are positive, but as these authors and others in this book point out, the clinical research paradigm does not transfer easily into the long-term care setting. I found Duffy’s chapter on ‘Disruptive behavior: systemic and strategic management’ particularly stimulating. His interesting focus is on a systemic

understanding of the long-term care unit and on counter-intuitive interventions, such as being sympathetic and attentive to the hypochondriacal client's insistence that they have physical troubles. He also uses this approach in dealing with the troublesome behaviours that can arise when a person is confused. It has parallels with Jay Haley's work on 'paradoxical intention' (although it is not referenced).

The second section is about multi-disciplinary and systemic approaches to therapy. Ogland-Hill and Florsheim discuss the difficulties of carrying out family work in long-term care settings. Meeks and Depp advocate increasing the number of positive events in a depressed person's life. I found their discussion of negative and positive events confusing and thought that they failed to acknowledge sufficiently the contribution that a devalued status (being an older person in western society) can make to lowered mood. Nonetheless, their idea that an intervention can be aimed at any link in the chain of events-perceptions-mood is useful. Parr and Green describe a survey of how residents and staff saw their facility. Unfortunately, while the residents were asked about how they *as individuals* valued various aspects of their lives, staff were asked how the residents *as a whole* valued the same aspects: the two sets of questions were not therefore equivalent. The study, limited as it was to one unit, is weak and its focus on pure (as opposed to applied) research means that it does not fit well in a book on clinical practice. The issue of practice is returned to, however, in Slone's chapter, which emphasises the need for teamwork in the treatment of depression and describes ways of creating teams that involve all staff in various roles. This chapter will be a good *vade-mecum* for anyone doing consultancy work. But the final chapter on training in this section by Hyer and Ragan will be of limited use to a non-American reader: for one thing, it contains many acronyms. This same comment is even more applicable to the third section of the book, which is concerned with ethical and confidentiality issues as laid down by US federal and state laws, although the issues raised have a trans-national relevance and are thought-provoking.

This book has several shortcomings. The cover has the all too common stereotypical photo of a middle-aged carer intruding into the personal space of an older person who is valiantly smiling – or is it grimacing? The book is published without love: it has narrow margins, variable print size and unaccountable changes in font style. It is limited to the US academic scene – no European work is mentioned at all, which is a pity because it might have contributed a missing philosophical dimension. For example, I cannot agree with Hyer and Ragan that it is 'the person' that disintegrates as a result of dementia, or that 'insight' or 'personality' could be key indicators of a new 'psycho-philosophy' (p. 218). Finally, the authors most referred to in this collection, such as Camp, Lawton, Lichtenberg and Teri, are all conspicuous by their absence. Those with ready access to the *Clinical Gerontologist* probably would not buy the book. It will be useful, however, to those who do not have ready access to academic journals. Written, as it is, by practitioners who have 'been there', it should be particularly useful for those undertaking psychological work in residential units with people with dementia or depression. The range of topics, and the emphases on systems and on various groups and their differing needs are admirable. There is an air of optimism: 'key people in this area now believe that restorative change can occur for many (and) that the caregiver is the only game in town' (p. 229). While this might

be prescriptive hope masquerading as description maybe, without hope and determination, this kind of work will not succeed.

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Bethel Ann Powers, *Nursing Home Ethics: Everyday Issues Affecting Residents with Dementia*, Springer Publishing Company, 2003, 215 pp., pbk \$35.95, ISBN 0 8261 1964 6.

Some moral philosophers balk at the idea of medical ethics; some medical ethicists balk at the idea of nursing ethics. What would either of the above, or a nursing ethicist, make of the idea of nursing-home ethics? None of the above, however, need panic at the concept, as this book is about the application of ethics in nursing homes where people with dementia live, and does not promote any particular ethical framework. Rather, it promotes the idea that there is a wide range of situations in such homes where the use of an ethical, indeed, an ethics committee, approach can lead to resolutions which provide the best conditions for people with dementia. The book is written from a North American perspective and provides information about some aspects of the care of people with dementia which must be particular to its settings. For example, I had not previously heard of 'safe return' programmes for people with dementia who wander from home. The issue of advance directives is also covered: they are taken more seriously in the United States of America, but there are differences between the States and there are implications for paramedical staff, such as ambulance staff, who may encounter a person with dementia.

The book has four chapters and a substantial appendix. The first two chapters are general, with the first dedicated to living with dementia and the second to the nursing-home experience. Both chapters are excellent and could be papers in their own right. The data for the chapters were gathered using qualitative anthropological methods and each gives a very full description, supported by copious and lengthy quotes from relevant informants, such as people with dementia, relatives and carers. Chapter 1 addresses the problems of living with dementia and is refreshingly free of the politically-correct jargon that surrounds much contemporary writing on dementia. Dementia is not pleasant to watch and clearly not pleasant to suffer from; the picture painted of it here, while not entirely negative, constitutes a self-contained piece which could be handed with confidence to anyone who asks 'what is dementia?'

Chapter 2 is concerned with the various circumstances which lead to nursing-home admission for people with dementia and the consequences. Again, the material is copiously supported by first-hand quotes. The issues arising will be familiar outside the USA. The material on the nursing-home experience draws on the feelings that arise in people who have had to 'conspire' in the admission of a loved-one to a nursing home, and covers issues such as advocating for a person with dementia in a nursing home, dealing with the desire in the person with dementia who wants to go home, evidence of poor care, institutionalisation, and

threats to the dignity of the person with dementia. Ethics in action and case examples constitute the material of the second two chapters. Having described life with dementia and life with dementia in a nursing home, Chapter 4 puts these in an ethical context. It is based on the premise that many nurses working in nursing homes with people with dementia become habituated to certain problems and to dealing with them in isolation – to the extent that they never stop to think; they do not see that ethics are relevant. Judging from some of the poor practice that is exposed in nursing homes on both sides of the Atlantic, this may be a valid premise. Several ethical approaches and principles are reviewed in Chapter 2, the emphasis being on applied, everyday ethics which the following chapters ground in very practical examples. The work of Kitwood is drawn upon in relation to personhood; surely a central concern of an ethical approach to living in a nursing home. The author's own taxonomy of everyday ethical issues is presented as a framework for approaching nursing-home ethics and is explained in terms of positive and negative valences: the right to have something done and the right not to have something done, respectively.

Twelve case examples are provided, and anyone who has worked with people with dementia in an institutional environment will recognise the situations (although the applicability of the book extends beyond nursing homes). Each case example is analysed in terms of the ethical issues, the potential solutions and the compounding factors associated with the individuals and the resources in the nursing home. The overall approach to nursing home ethics is the establishment in nursing homes of ethics committees to review the problems which arise. The appendix, which is presented in a question-and-answer format, suggests how resistance amongst staff can be approached and what the composition of such a committee might be. This is an excellent book which should find its way into the hands of nursing-home managers and head nurses, and which could form the basis of an educational module for nurses working in nursing homes. The sooner, the better.

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