

Review Article

Carers' narratives: Finding dementia with Lewy bodies experiences

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Carers' narratives provide a unique insight into the caring experience. From a human interest perspective they have appeal to the general population; however, they also target and are read by niche audiences – families striving to understand the challenges of the caring role. This article examines four carer narratives and their relevance to particular niche audiences; three classified from the information provided on their book covers as pertaining to Alzheimer's disease and one to Parkinson's disease. It explores the impact of care on the caregivers and reviews the promoted diagnoses in light of the current understanding of dementia with Lewy bodies. The author argues that the information provided in the titles, in good faith, may not reflect the content of the narratives and that three of these narratives may provide carers of people who have dementia with Lewy bodies with insights into the challenges that this disease presents.

Key words: Alzheimer's disease, caregivers, dementia – Lewy body, Parkinson disease, personal narratives.

Introduction

Carers' narratives are as diverse and as individual as the presentations and courses of the illnesses themselves. A mantra espoused by health professionals and support services is that everyone experiences illness, especially chronic and progressive illness in their own way. Holland posits that the same can be said for carers:

It is important to recognise that no two carers share identical experiences. Carers like people they care for and like other members of society, are unique individuals. This means that each carer will understand their experience of caring and the experiences of carers generally in different ways. ([1], p. 58)

That being said, guiding carers in their quest for information and understanding is central to an ethos of empowerment and informed choice. There is a raft of literature available to carers, part of which is the carer narrative. Narratives are often promoted through the popular press and recommended

by support services. So does it matter what texts carers read to gain some understanding of their journey?

This question is explored through a content analysis and discussion of four carer narratives. The information provided on their dust jackets indicates that they address the caring experience associated with Alzheimer's disease (AD) and Parkinson's disease (PD) and consequently it could be assumed that they could have relevance for people caring in the presence of those illnesses. However, there is an argument to suggest that three of the narratives may better inform and educate those caring for people with dementia with Lewy bodies (DLB).

What is dementia with Lewy bodies?

Dementia with Lewy bodies is a progressive neurodegenerative disease of ageing and is thought to be the second most prevalent dementia [2,3]; AD being the most prevalent. DLB has only recently been formally established as a form of dementia within medical communities. At present, there is little psychosocial research on the effects of caring for a person with DLB and limited community awareness.

Since 1995 there have been three consensus meetings of the International Consortium establishing the criteria for the clinical diagnosis of DLB [4]. The criteria are presented as follows:

1. The central feature is dementia: defined as progressive cognitive decline of sufficient magnitude to interfere with normal social or occupational function. The Consortium emphasises that prominent or persistent memory impairment may not be an early feature of the disease; probably the earliest and most significant differential between DLB and AD, and that fronto-subcortical (attention and executive function) and visuo-perceptual symptoms are more prominent.
2. Three core features are fluctuations, visual hallucinations and parkinsonism. At least one of these core features must be present with dementia to support a diagnosis of DLB.
3. The suggestive features raise the likelihood of a DLB diagnosis if they are present in a person at assessment. They are REM (rapid eye movement) sleep behaviour disorder (active nightmares), severe neuroleptic sensitivity (particularly to psychotropic drugs) and low dopamine transporter uptake demonstrated by neuroimaging.
4. The Consortium [4] lists 10 features commonly present in people with DLB which support a diagnosis but are not proven to have diagnostic specificity. Two of these

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The author has reported no conflicts of interest.

can have significant impact on a person's quality of life [5]. The first is syncope or a loss of the body's ability to regulate postural tone and the second is autonomic dysfunction – bladder, bowel and sexual dysfunction.

Even with this extensive range of signs and symptoms to provoke the possibility of an initial diagnosis of DLB, it is often a secondary diagnosis to that of AD, or PD because the motor signs are more prominent. Frequently it is the carers who request further assessments because of their difficulties in providing ongoing care and a sense that the range of issues confronting them are different to those faced by carers of people with PD or AD. It is acknowledged that a diagnosis of atypical AD may be given because of restrictive Pharmaceutical Benefit Scheme regulations in Australia associated with the prescribing of cholinesterase inhibitors, the medications currently available for the treatment of dementia.

Methodological approach

This article is drawn from the literature review of a doctoral thesis – a qualitative, heuristic [6] inquiry into the experience of caring for people with DLB. Having engaged with the research topic, heuristic methodology requires the researcher to become immersed in all aspects of it so that understandings can incubate and then be brought to light through analysis and discussion.

As there is scant psychosocial research into caring and DLB and as an adjunct to a review of the research literature, carers' narratives were read to gain insights from carers' perspectives. Narratives which promoted AD and PD in either the title or promotional bylines on the dust jackets, were selected because texts specifically addressing caring for a person with DLB could not be located.

Of those read, four texts; three '*A matter of timing*' [7], '*Daddyboy: A Memoir*' [8] and '*The Long Good Night*' [9], selected from the Alzheimer's Australia Victoria library; and one '*Take Me Home: Parkinson's, My Father, Myself*' [10] purchased over the internet, had particular resonance. Content analysis of the texts revealed that the first was true to its extended title: '*Alzheimer's – a carer's journey*' however the other three highlighted aspects of the AD, PD, DLB conundrum.

Review findings

In '*A matter of timing*' [7], '*Daddyboy: A Memoir*' [8] and '*The Long Good Night: My father's journey into Alzheimer's*' [9], three female academics explore the experience of AD in the context of family life. All interweave continuing family life through the ravages of progressive illness. Narratives of life's expectations and dreams are shaped by the deterioration of a husband or father. Significant milestones and happy times sit beside confusion, frustration and loss. Loss encompasses the deaths of other family members, the person for whom they cared and their own sense of selves. Each writes with poignancy and insight into

the emotional toll that physical caring for a person exacts and all are recommended by the reviewers as providing valuable insights for carers of people with AD.

In the first narrative '*A matter of timing*', Brown, as the carer of her husband Stan who was diagnosed with AD at the age of 57, gives a cogent picture of the insidious onset of this disease. Her husband's enforced redundancy triggers her to heed her intuition of being '*certain that something was very wrong*'. Stan's confusion, loss of short-term memory, loss of learnt skills, getting lost and wandering off would resonate with many carers of people with AD as would Brown's enforced early retirement and her lament that '*somehow I would just have to take over the reins and try to keep things going as smoothly as I could*'. Brown chronicles the progression of Stan's illness by highlighting the good times while providing insight into the difficult decisions pertaining to relinquishing care, incontinence and the difficulties of hospitalising a person without autonomy. Of her own grief and healing she writes:

I am aware that for many years I have been living a sort of bereavement but I have no idea at all about how I will cope with a real one. Everything that lies ahead is unknown and all I can do is what I have been doing for so many years – live a day at a time and fill every minute as usefully and pleasantly as I can. I cannot help my emotions – bitterness, despair, anger, remorse, guilt, self-pity. They are awful, negative ones. But there must be room for happy thoughts – I try to brush aside the sadness and think of making every moment as happy as possible. ([7], p. 134)

The other texts by Wolfe-Konek [8] and Simpkins [9] present narratives of their families' journeys with dementia. Interspersed with reminiscence of their relationships with their ailing fathers and within their families, they differ in the philosophical journeys – Wolfe-Konek and her family contemplate issues surrounding the meaning of the quality of life and euthanasia, while Simpkins explores her belief system and the deep spiritual comfort it offers.

The jackets of both books highlight AD, however analysis of the texts and the fathers' journeys suggest that, in light of current understanding, a focus on DLB rather than AD may be more informative to the contemporary reader.

'*Daddyboy: A Memoir*' is about Leonard Konek who was diagnosed with PD, and subsequently, in 1980, with PD dementia syndrome, which together with DLB are now considered the spectrum of Lewy body disease [11–13]. The diagnosis was sought because of Leonard's cognitive difficulties (he recognised deficiencies in his business acumen), his parkinsonism and his wife's increasing concern about his active nightmares including an episode where he acted out protecting her from a tiger attack.

Within the text, but not specifically dated, is mention of hallucinations, fluctuations, incontinence, delusions and

aggression. Addressing the fluctuations Wolfe-Konek writes that Leonard was at times lucid, able to speak in meaningful sentences and able to recognise people, pain and pleasure; the latter in the last days or weeks of his life.

Although diagnosed with variants of Lewy body disease, the family appears to have taken on the alternate diagnosis of AD because of the increasing recognition and profile of AD in the early 1980s in medical circles, in the media and in emerging carer support networks. In a similar vein to Brown, Wolfe-Konek structures images of isolation, denial, guilt, loss of personhood, rejection, acceptance and moving on through conversations shared with others at Alzheimer's carer support meetings rather than through her family's own journey.

'*The Long Good Night*' is about Jerry Simpkins, an early 50s recently retired civil engineer, who, in 1985, experienced an episode of cardiac arrhythmia. Controlled by reversion and medication he continued in his retirement buying and on-selling land. From the text it is difficult to be precise, suffice to say that in her narrative Simpkins, who ultimately became his carer, describes a decade of her father's paranoid delusions of kidnapping, loss and robbery as well as his inattention, dizzy spells and behaviour that resulted in the alienation of family.

Jerry's reaction (denial, confabulation and hallucinations) to his wife's sudden death resulted in a psychiatric assessment. He was admitted to hospital and administered anti-psychotics which caused a severe adverse reaction resulting in a coma. He regained consciousness 5 days later. While convalescing he paced, was agitated and aggressive and, to his daughter's dismay, he misinterpreted her affection as sexual advances from '*a nice lady who says she loves me*'. Formally diagnosed with depression and AD, he was discharged home to her care for the last 3 years of his life.

Simpkins indicates that his palliative care, initiated because of his inability to swallow, was brief yet prior to his last days he was still ambulant, at times lucid and articulate as illustrated by the following vignette:

Three weeks ago we found him unconscious on the floor. By ambulance we took him to hospital. While the nurse and I were appraising him in his semi conscious state, his clothes soiled, bruises surfacing on his face from having landed on it when he fell, and she was asking me if I wanted extraordinary measures employed to keep him alive, I replied, 'this man can get up and walk out of here any time he wants'.

I was the only person who thought that ending was possible. Everyone else was predicting the end of his life. I stood in front of Daddy, immobile in his hospital bed, and I asked, 'Are you ready to go home?'

He got right up. People backed away from the mystery of his return to life by simply being offered the refuge of home. ([9], p. 178)

Simpkins juxtaposes her loss of self and her deepening faith with descriptions of 'exploding' incontinence, life in an hallucinatory world, and the physicality of caring and exhaustion. She acknowledges the support gained through sharing her father's care with her sisters and an occasional community carer.

The final narrative, promoted through its title as focussing on PD, has much in common with the narratives of Wolfe-Konek and Simpkins. In '*Take me home: Parkinson's, My Father, Myself*' Taylor [10], also an academic, provides a retrospective that commences in 1983 and spans 18 years of caring for his father, John. In 1988, 60-year-old John's parkinsonism, poor driving skills, nightmares, hallucinations and depression were diagnosed as PD. Taylor's narrative is multifaceted. It is the story of his teen and early adult life, through which he chronicles his father's illness, the increasing burden of care and its impact on the immediate family. It is also a quest to understand his father and finally, after his father's death, Taylor seeks to discover meaning in his father's symptoms, specifically John's illusion that his son is someone else – someone to fear and reject – his nemesis in his decision to retire early.

Taylor writes that John was still ambulant in early 2001, the year of his death; a year complicated by surgery, time in intensive care, and a lengthy convalescence during which time he was able to lucidly, albeit briefly, communicate. Following a difficult and demeaning convalescence John's wife took him home and later wrote to her son recalling the last weeks of his life:

In those last days, we were close. He was loving again. He caught hold of my arm one afternoon and 'proposed'. At least what he actually said was 'I want us to be married'. It is a special memory. ([10], p. 232)

Discussion

The narratives all reinforce the uniqueness of each experience. All provide valuable insights into the caring journey and sensitively raise questions of personhood, quality of life, loss, grief and moving on. However from the disease perspective, one narrative stands alone. If it is possible to describe a typical experience of caring in the presence of AD then Brown's narrative '*A matter of timing*' provides a cogent insight.

Leonard Konek's initial diagnosis suggests DLB, John Taylor's records indicate DLB and, from the information provided, Jerry Simpkins' adverse drug reaction, together with many other symptoms, also points in that direction. Their carers vividly explore the complexities of a multitude of significant behavioural and psychological symptoms of dementia – symptoms which are a feature of DLB and well recognised as contributing significantly to carer burden [14–16].

None of the narratives are diminished nor negated by potential inconsistencies in the diagnostic labelling or this retrospective attempt to infer an alternative diagnosis. All four narratives provide powerful insights into the highs and lows of the caring experience, strategies to rise above the difficulties of caregiving and sensitively address the difficult, and often thought but unvoiced, life and death questions of many carers. Perhaps the significant inference is that Leonard, Jerry and John, the men who exhibited the signs and symptoms of DLB, are presented throughout as existing in the world [17]. The experience of caring for a person who retains a sense of personhood, to which the carer can relate and recognise, contrasts significantly with the loss experienced by Brown:

Somewhere along the journey, probably many years ago, I lost him. . . . He registers no recognition when I visit him. There are no remaining memories. ([7], pp. 139–141)

All are unique interpretations of individuals, singly and collectively impacted by a progressive, debilitating disease; but what resonance do they have for today's carers seeking understanding and information?

Although medical understanding of dementia has progressed significantly in the last three decades, there is little psychosocial research about the impact of DLB and limited awareness in the community about this condition. More qualitative work is needed to better understand the experience of caring for a person with DLB. Wolfe-Konek published in 1991 with her caring experience spanning the 1980s – a decade where the focus was on the 'epidemic' of AD and before the emergence of DLB as a disease entity. Through her narrative there is an intuitive undercurrent that places her father in a different experience to those with AD.

It could be argued that Simpkins and Taylor, publishing in 2001 and 2007 respectively, could have used their experiences to raise an awareness of DLB. That they did not is through no fault or omission of theirs. Asked, in personal correspondence in 2008, if DLB was considered as an alternative diagnosis, Simpkins replied 'no fancy name other than Alzheimer's was ever mentioned'. Taylor, whose understanding of DLB is emergent, said: 'I went with the Parkinson's label because that was the label we, as a family, were given all along' even although he writes in his narrative that a diagnosis of DLB had been made but not shared with the family during his father's life.

Conclusion

These narratives certainly elucidate the complexities of providing care for a partner or parents confronted with progressive degenerative diseases. A content analysis of the narratives discussed suggests that, with an informed understanding of the criteria for the diagnosis of DLB, three provide powerful observations about living with, and caring for, people with the symptoms of this devastating yet poorly recognised or understood dementia.

Appropriate carer information and education can ameliorate carer burden [18] and provide carers with points of reference in their own caring journeys. Unfortunately for the contemporary reader these narratives are promoted as insights into life with AD and PD. Perhaps, from a human interest perspective that is irrelevant; however, in most instances carers' narratives are viewed as an educational resource. If carers of people with 'typical' AD or PD without dementia select these narratives to gain an understanding of those diseases, they may find themselves more confused than informed.

This review is a timely reminder that all resources should be evaluated in light of current knowledge and promoted accordingly. In an environment where there is scant psychosocial research associated with caring for people with DLB, these narratives make a significant contribution to the resources that are available to carers.

Acknowledgements

Thanks to Professor David Ames and Dr Pamela St Leger for their review of this manuscript. This project has been supported by Alzheimer's Australia Research, the Dementia Collaborative Research Centre – Consumers and Carers and the Australian Government.

Key Points

- Carers' narratives provide valuable insights into the caring journey.
- Caring for a person with dementia with Lewy bodies presents unique challenges.
- Promoted diagnoses in narratives may be at odds with current understandings.
- Carers should be guided in their selection of educational resources.

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