

The Road Less Travelled: Identifying Support Needs in Lewy Body Dementia

Madelaine B. Rañola

Macquarie University Hospital

Abstract

Lewy Body Dementia (LBD) is an umbrella term for two dementia subtypes Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia (PDD) (Armstrong et al., 2020a; Larsson et al., 2019). Despite being the second most common type of dementia after Alzheimer's Disease (AD), 1 in 3 cases of LBD are believed to be missed or misdiagnosed (Armstrong et al., 2020a; Chin et al., 2019). Diagnosis is difficult due to widespread clinical and pathological features that overlap with AD (Tang et al., 2015) consequently, it can take multiple consultations, over many years, before individuals receive an accurate diagnosis. (Galvin et al., 2010a). By then quality of life (QoL) has already been significantly impacted.

LBD differs from AD in that more frequent non-cognitive symptoms, including autonomic dysfunction, motor and neuro-psychiatric symptoms – delusion, anxiety, depression and apathy (van de Beek et al., 2019) can have devastating effects on social engagement and wellbeing (Larsson et al., 2019). Additionally, fluctuations in cognition, wakefulness, attention, visual hallucinations and sleep behaviours (McKeith et al., 2017, as cited in Larsson et al., 2019, p.1) provide distinct challenges for living with LBD (Boot 2015, as cited in Larsson et al., 2019, p.1).

A scoping literature review was conducted to explore support that is available to people with Lewy Body Dementia and family caregivers and to identify gaps in research and service delivery.

Key Words:

Lewy Body Dementia – experience, psychosocial support, caregiver burden

DIAGNOSIS

LBD compared to AD is poorly understood. In a survey of 972 caregivers conducted by the Lewy Body Dementia Association (LBDA), 70% of respondents reported consulting over 3 doctors before a diagnosis of LBD was given (Zweig & Galvin, 2014). 8/10 LBD cases are initially diagnosed as other conditions commonly Parkinson's disease or AD (Taylor & Yardley, 2014). A lack of timely and accurate diagnosis deprives people of the information needed to explain and manage challenging symptoms (Taylor & Yardley, 2014). Despite scientific advances in imaging and biomarkers, LBD remains predominantly a clinical diagnosis requiring skilled assessment from clinicians to make the diagnosis (Zweig & Galvin, 2014). Galvin et al. (2010b) in their landmark survey of caregivers, identified reasons for delays in establishing a diagnosis which included; limited symptom awareness, a lack of consensus criteria and mild symptoms being missed in consulta-

tions. Although informative of key barriers to accurate diagnosis, caregivers were self-reporting, subspecialties of the clinicians were not disclosed and medical records were unavailable to verify symptom severity or diagnosis (Galvin et al., 2010b). To assist in identification and diagnosis of LBD, two assessment toolkits have been created as part of the DIAMOND Lewy Study (Thomas et al., 2018). Instruments were drafted utilising validated assessment tools (Thomas et al., 2016). Patient and Public Involvement panel interviews were conducted for comment on acceptability and feasibility and this was utilised to adjust the tools accordingly (Thomas et al., 2016). Assessments were included for: cognitive fluctuation, rapid-eye movement,

Questions or comments about this article should be directed to Madelaine B. Rañola
Email address: madelaine.ranola@muh.org.au

DOI: 10.21307/ajon-2021-008
Copyright © 2021ANNA

visual hallucinations, motor features of parkinsonism and cognitive impairment (Thomas et al., 2016) The toolkits were piloted in Dementia and Parkinson's services within a single organisation to produce the final tools which proved to be acceptable to clinicians and patients (Thomas et al., 2016). Surendranathan et al. (2021) have since introduced the final versions: "The Assessment Toolkit for Dementia with Lewy Bodies" (for Memory and Dementia clinicians) and "The Assessment Toolkit for Lewy Body Dementia" (for Movement disorders and Geriatric clinicians) (Thomas et al, 2018, p.1) into three movement disorder clinics and four Dementia clinics. This resulted in a compelling increase in the rate of diagnosis of DLB although it is unclear as to whether this was because the clinicians were already confident making the diagnosis (Surendranathan et al., 2021). Although further studies are needed in wider settings, the routine use of these instruments which align with revised consensus criteria should heighten awareness of LBD symptoms and guide less experienced clinicians to elicit key symptoms in clinical practice (Thomas et al., 2018).

TANGIBLE SUPPORT

In 2014, the Lewy Body Society (LBS) hosted a survey of 125 family caregivers of people living with LBD, nearly 50% of respondents reported not having any helpful support or information post-diagnosis (Killen et al., 2016). Although, limited to a survey and a retrospective study, topics for the development of a prospective study were identified which could inform the design of future support interventions specific to LBD (Killen et al., 2016). Following a diagnosis of LBD, families face different education and referral pathways for support, advice and community services (Taylor & Yardley, 2014). People diagnosed in Movement Disorder or Dementia clinics are more inclined to receive LBD resources and referral to support organisations such as Dementia Australia (Taylor & Yardley, 2014). More frequently though, people are diagnosed in secondary care where a broader range of disorders are treated which may reduce the likelihood of receiving LBD-specific information (Taylor & Yardley, 2014). For most people their primary care physician will be responsible for symptom management which highlights the importance of promoting LBD education (Galvin et al., 2010a; Taylor & Yardley, 2014). Specifically, primary care physicians need to be knowledgeable enough to provide patient and caregiver education about symptoms, progression and treatment of LBD as well as prompting anticipatory care (Chin et al.,

2019; Tang et al., 2016). Delivering support that addresses the priority needs of people living with LBD and their family caregivers is likely to enhance the adaptive handling of the more challenging symptoms (Killen et al., 2016).

SELF-PERCEPTION

People with LBD may be vulnerable due to: stigma, ageism, poor public awareness, inadequate means and the utilization of the medical-model of care (Taylor & Yardley, 2014). Fear of disclosing a diagnosis can be isolating and barriers include: worry about being seen differently, fear of the future, worry about being avoided or excluded, not wanting to upset or burden others and shame (Bhatt et al., 2020). In an exploratory study of the subjective experience of men living with LBD, Larrson et al. (2019) identified three themes characterising their experience: "(1) disease impact: (2) self-perception and coping strategies: (3) importance of others" (p.3). Disease impact referred to their experience of cognitive and motor-dysfunction and the restrictions that these placed on social engagement and participation (Larrson et al., 2019). Fear of falling and slowness of articulating speech were barriers that influenced wellbeing (Larrson et al., 2019). Self-perception was influenced by physical and cognitive changes that led to less accountability and responsibility (Larrson et al., 2019.) The importance of others included having support and cooperation from others and respect for those people around them including healthcare professionals (Larrson et al., 2019). Strategies for maintaining a sense of self included: demonstrating own worth, reaching out to others, standing up for yourself and finding new motivations and goals (Larrson et al., 2019). Although only a small sample of 5, the study offers deep insight into the personal reality of living with LBD and demonstrates the usefulness of conducting detailed interviews in the LBD population (Larrson et al., 2019). Similarly, in a longitudinal study of Quality of Life (QoL) in LBD compared to AD, 29 people with LBD and 68 people with AD were followed over 2.5 years and it was suggested that preserving autonomy and maintaining independence in daily living may be just as important as preserving cognition to optimise QoL (van de Beek et al., 2019).

BURDEN OF CARE

Caregivers experience social isolation due to poor community awareness of LBD compared to AD and they may experience a lack of compassion and appreciation from friends

and family (Legett et al., 2011). Worry about performance and whether the care that LBD caregivers are providing is correct is well documented which may reflect the scarcity of resources available regarding care of people with LBD compared to AD (Legett et al., 2011; Tang et al., 2016). Consequently, 80% of caregiver respondents in the LBS survey 2014, requested information about approaches that others in similar positions found beneficial (Killen et al., 2016). High levels of burden are attributable to unique LBD stressors: delusions, depression, apathy, sleep disturbance, hallucinations and high dependency with activities of daily living (Legett, et al., 2011; van de Beek et al., 2021). The prevalence of behavioural and emotional problems (BEPS's) in LBD may contribute to an increase in subjective burden on caregivers over a prolonged period of time (Legett et al., 2011). Lower scores on living well measures: QoL, life satisfaction and wellbeing for patients and caregivers for LBD compared to AD were found in the IDEAL Study which explored living well with dementia in a cohort of 1283 dyads of people with dementia and their caregivers (Wu et al., 2018). In a study of caregiving experiences between adult child and spouse caregivers of LBD, it was suggested that spouses gain benefit from interventions targeting expanding social support whereas adult child caregivers might gain from interventions directed at alleviating responsibility and improving QoL. (Rigby et al., 2019). Vatter et al. (2018), identified 5 burden dimensions following interviews and surveys of 127 life-partners of people with LBD. Psychological and social constraints, "interference with personal life", personal strain, guilt and "concerns about future" were contributors to burden (Vatter et al., 2018, p.1). The common finding of caregiver burden being multi-dimensional in these LBD studies, highlights the need for care interventions to be tailored to address specific types of burden and help maintain the QoL and wellbeing of family caregivers and the dyadic relationship (Vatter et al., 2018; Wu et al., 2018).

ACCESSING SUPPORT

In a study of 32 health care professionals exploring the subjects of their appointments with people with dementia and their caregivers, it was established that the needs of informal caregivers can be challenging to determine where they are unable to privately consult with a professional (Cations et al., 2019). Discussion of caregiver needs could not occur in 22% of cases due to sensitivities with having this conversation with the person with dementia in front of them (Cations et al.,

2019). Although only a selected sample of self-reporting clinicians not fully representative of the dementia workforce, the study identified the following key needs: service navigation, problem solving, responding to BEP's, continence management and advance care planning (Cations et al., 2019). Social Workers could have a role in referral to support services, counselling to improve caregiver confidence and preparing caregivers to plan future care needs (Park et al., 2019). Despite the well documented high burden of care on LBD family caregivers, there are no evidenced based support interventions specific for LBD (Foley et al., 2020). In a study of 10 carers, the "STrAtegies for RelAtives" (START) psychoeducation coping therapy was adapted for LBD symptom focus and piloted to test the acceptability in this caregiver group (Foley et al., 2020). Education regarding: dementia, communication, challenging behaviour, planning for the future, relaxation and self-care were provided and participants felt more supported and confident (Foley et al., 2020). Larger trials of the effectiveness of the LBD adapted START program are needed (Foley et al., 2020).

ADVOCACY

Advocacy groups such as: Lewy Body Society UK, Lewy Body Dementia Association USA and Dementia Australia offer leadership on LBD issues, educational information, emotional support and can provide continuity of contact for caregivers as they negotiate the health and social care system (Chin et al., 2019; Taylor & Yardley, 2014). These organisations are vital in reducing stigma via promoting greater understanding and awareness of the disease among public, care and clinical professions serving the LBD community (Taylor & Yardley, 2014). Becoming part of an LBD support group provides opportunities to access others with new perspectives and understanding about coping with the challenges of the disease and helps caregivers to find meaning and purpose in their role (Park et al., 2019; Taylor & Yardley, 2014). Although Parkinson's and Alzheimer's support groups may assist to a degree, there is a lack of LBD support groups in Australia. LBD caregivers can however access the Dementia Behavior Management Advisory Service and Severe Behavior Response Teams for non-pharmacological crisis interventions (Chin et al., 2019).

FUTURE DIRECTIONS

Advocacy groups can assist by testifying to regulatory agencies about accessing disability services as well as approving safer medi-

cations for LBD symptoms (Killen et al., 2016). Further research into the LBD diagnostic pathway and the practice of primary care clinicians in the diagnosis and management of LBD (Tang et al., 2016) would be helpful to identify education and training needs. The development of LBD specific education resources and psychoeducational support groups to cover diagnosis, progression, therapies, daily function, QoL and caregiving would help to establish a community of people who acknowledge the challenges of living with LBD (Armstrong et al., 2020b; Rigby et al., 2019; Taylor & Yardley, 2014). Research has proven that despite the demands of the disease, people with LBD and their family caregivers have much to contribute to increasing knowledge about the disease (Killen et al., 2016).

CONCLUSION

The provision of person-centred care after a diagnosis of LBD with its complicated features and unpredictable disease trajectory requires an adaptable, multi-faceted approach. The challenge for clinicians is being able to link people with LBD and their caregivers with supports that are suitable for their unique needs and encouraging them to utilise and engage with these resources to maintain their wellbeing and improve their QoL. Further work needs to be done in the areas of research, education, advocacy and service development in order to provide the care and support needed to live well with LBD.

References

- Armstrong, M., Alliance, S., Corsentino, P., Maixner, S., Paulson, H., & Taylor, A. (2020). Caregiver-Reported Barriers to Quality End-of-Life Care in Dementia with Lewy Bodies: A Qualitative Analysis. *American Journal of Hospice and Palliative Medicine*, 37(9), 728-737. <https://doi.org/10.1177/1049909119897241>
- Armstrong, M., Gamez, N., Alliance, S., Majid, T., Taylor, A., & Kurasz, A. et al. (2020). Research priorities of caregivers and individuals with dementia with Lewy bodies: An interview study. *PLOS ONE*, 15(10), e0239279. <https://doi.org/10.1371/journal.pone.0239279>
- Bhatt, J., Ruffell, T., Scior, K., & Charlesworth, G. (2020). "Who to Tell, How and When?": Development and preliminary Feasibility of an Empowerment Intervention for People living with Dementia who are fearful of disclosing their Diagnosis. *Clinical Interventions in Aging*, 15, 1393-1407.
- Cations, M., Radisic, G., de la Perrelle, L., & Laver, K. (2019). Post-diagnostic allied health interventions for people with dementia in Australia: a spotlight on current practice. *BMC Research Notes*, 12(1). <https://doi.org/10.1186/s13104-019-4588-2>
- Chin, K., Teodorczuk, A., & Watson, R. (2019). Dementia with Lewy bodies: Challenges in the diagnosis and management. *Australian & New Zealand Journal of Psychiatry*, 53(4), 291-303. doi.org/10.1177/0004867419835029
- Foley, J., Dore, C., Zarkali, A., Livingston, G., Cipolotti, L., Mummery, C., & Weil, R. (2020). Evaluation of START (STrategies for Relatives) adapted for carers of people with Lewy body dementia. *Future Healthcare Journal*, 7(3), e27-e29. <https://doi.org/10.7861/fhj.2020-0003>
- Galvin, J., Duda, J., Kaufer, D., Lippa, C., Taylor, A., & Zarit, S. (2010). Lewy Body Dementia. *Alzheimer Disease & Associated Disorders*, 24(2), 177-181. <https://doi.org/10.1097/wad.0b013e3181c72b5d>
- Galvin, J., Duda, J., Kaufer, D., Lippa, C., Taylor, A., & Zarit, S. (2010). Lewy body dementia: The caregiver experience of clinical care. *Parkinsonism & Related Disorders*, 16(6), 388-392. <https://doi.org/10.1016/j.parkreldis.2010.03.007>
- Killen, A., Flynn, D., De Brún, A., O'Brien, N., O'Brien, J., & Thomas, A. et al. (2015). Support and information needs following a diagnosis of dementia with Lewy bodies. *International Psychogeriatrics*, 28(3), 495-501. <https://doi.org/10.1017/s1041610215001362>
- Larsson, V., Holmbom-Larsen, A., Torisson, G., Strandberg, E., & Londos, E. (2019). Living with dementia with Lewy bodies: an interpretative phenomenological analysis. *BMJ Open*, 9(1), e024983. <https://doi.org/10.1136/bmjopen-2018-024983>
- Leggett, A., Zarit, S., Taylor, A., & Galvin, J. (2010). Stress and Burden Among Caregivers of Patients with Lewy Body Dementia. *The Gerontologist*, 51(1), 76-85. <https://doi.org/10.1093/geront/gnq055>
- Park, J., Tolea, M., Arcay, V., Lopes, Y., & Galvin, J. (2018). Self-efficacy and social support for psychological well-being of family caregivers of care recipients with dementia with Lewy bodies, Parkinson's disease de-

mentia, or Alzheimer's disease. *Social Work in Mental Health*, 17(3), 253-278. <https://doi.org/10.1080/15332985.2018.1526756>

Rigby, T., Ashwill, R., Johnson, D., & Galvin, J. (2019). Differences in the Experience of Caregiving Between Spouse and Adult Child Caregivers in Dementia with Lewy Bodies. *Innovation in Aging*, 3(3). <https://doi.org/10.1093/geroni/igz027>

Surendranathan, A., Kane, J., Bentley, A., Barker, S., McNally, R., & Bamford, C. et al. (2021). Introduction of an assessment toolkit associated with increased rate of DLB diagnosis. *Alzheimer's Research & Therapy*, 13(1). <https://doi.org/10.1186/s13195-021-00786-8>

Tang, E., Burn, D., Taylor, J., & Robinson, L. (2015). Dementia with Lewy bodies: The emerging role of primary care. *European Journal of General Practice*, 22(1), 53-57. <https://doi.org/10.3109/13814788.2015.1101061>

Taylor, A., & Yardley, C. (2014). Advocacy, education, and the role of not-for-profit organizations in Lewy body dementias. *Alzheimer's Research & Therapy*, 6(5-8). <https://doi.org/10.1186/s13195-014-0059-0>

Thomas, A., Taylor, J., McKeith, I., Bamford, C., Burn, D., Allan, L., & O'Brien, J. (2018). Revision of assessment toolkits for improving the diagnosis of Lewy body dementia: The DIAMOND Lewy study. *International Journal of Geriatric Psychiatry*, 33(10), 1293-1304. <https://doi.org/10.1002/gps.4948>

Thomas, A., Taylor, J., McKeith, I., Bamford, C., Burn, D., Allan, L., & O'Brien, J. (2016). Development of assessment toolkits for improving the diagnosis of the Lewy body dementias: feasibility study within the DIAMOND Lewy study. *International Journal of Geriatric Psychiatry*, 32(12), 1280-1304. <https://doi.org/10.1002/gps.4609>

van de Beek, M., van Steenoven, I., Ramakers, I., Aalten, P., Koek, H., & Olde Rikkert, M. et al. (2019). Trajectories and Determinants of Quality of Life in Dementia with Lewy Bodies and Alzheimer's Disease. *Journal of Alzheimer's Disease*, 70(2), 389-397. <https://doi.org/10.3233/jad-190041>

van de Beek, M., van Steenoven, I., van der Zande, J., Porcelijn, I., Barkhof, F., & Stam, C. et al. (2021). Characterization of symptoms and determinants of disease burden in dementia with Lewy bodies: DEVELOP design and baseline results. *Alzheimer's Re-*

search & Therapy, 13(1). <https://doi.org/10.1186/s13195-021-00792-w>

Vatter, S., McDonald, K., Stanmore, E., Clare, L., & Leroi, I. (2018). Multidimensional Care Burden in Parkinson-Related Dementia. *Journal of Geriatric Psychiatry and Neurology*, 31(6), 319-328. <https://doi.org/10.1177/0891988718802104>

Wu, Y., Clare, L., Hindle, J., Nelis, S., Martyr, A., & Matthews, F. (2018). Dementia subtype and living well: results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study. *BMC Medicine*, 16(1). <https://doi.org/10.1186/s12916-018-1135-2>

Zweig, Y., & Galvin, J. (2014). Lewy body dementia: the impact on patients and caregivers. *Alzheimer's Research & Therapy*, 6(2), 21. <https://doi.org/10.1186/s13195-014-0059-0>

