Development of Educational Resources Regarding Lewy Body Dementia for Nurses in Long-term Care

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Abstract

Background: Due to an aging population, rates of dementia are rising in Canada increasing the incidence of Lewy body dementia. To provide quality care to individuals with this disease, nursing staff need to be aware of evidence-based practices to ensure resident-centered care. Within Eastern Health, nursing staff in long-term care are well versed in dementia care, but there is no training specific to Lewy body dementia.

Purpose: To develop educational resources related to nursing care of individuals with Lewy body dementia, to be used by nursing staff in long-term care settings to enhance resident-centered care.

Methods: 1) An integrative literature review was conducted to assess relevant evidence-based information related to the nursing care of individuals with Lewy body dementia; 2) Key stakeholders, both locally and provincially, were consulted to determine relevant strategies and perspectives on nursing care of individuals with Lewy body dementia; 3) Educational resources related to Lewy body dementia were developed for nursing staff in long-term care.

Results: The findings from the literature review and the consultation process guided the development of a presentation and resource manual for nursing staff in long-term care focusing specifically on Lewy body dementia.

Conclusion: The proposed educational resources regarding Lewy body dementia will address the lack of awareness regarding LBD among nursing staff in LTC to improve quality of care and positively influence quality of life for residents with LBD.

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Due to the population advancing in age, dementia is a growing global concern. Worldwide in 2015, 47.5 million people were living with dementia (Alzheimer Society of Canada, 2015a). This number is expected to triple within the next 35 years (Alzheimer Society of Canada, 2015a). Globally, the most common dementias in ranked order are Alzheimer's disease which affects 60-80% of people diagnosed with dementia; vascular dementia which affects 20% of people diagnosed; and Lewy body dementia (LBD) which affects 15-20% of people diagnosed (Alzheimer Society of Canada, 2015b). Parkinson's disease dementia occurs in about 50-80% of people diagnosed with Parkinson's disease (Alzheimer Association, 2016a). In Canada, Alzheimer's disease (AD) accounts for 64% of dementia cases while vascular dementia accounts for 20% and Lewy body dementia accounts for 5-15% of cases (Alzheimer Society of Canada, 2015b). As a result of this global increase in dementia diagnoses, nursing staff will encounter more residents diagnosed with LBD in long-term care (LTC) settings in the future. Education regarding LBD is needed for nursing staff to develop interventions that are resident-centered and improve quality of life of residents with LBD in LTC.

There is considerable overlap of clinical manifestations between LBD, AD, and Parkinson's disease (PD) which impacts diagnosis and care delivery. Appropriate staff training is needed so that nursing staff can differentiate between LBD, AD, and PD which will lead to improved care practices. LBD education should be a priority area for healthcare to increase understanding of the disease process and care practices, as a result, improving quality of life for individuals diagnosed with LBD in LTC.

The following report will include an overview of the practicum objectives and the methods used to accomplish these objectives. Full reports of the integrative literature review and the consultation process, as well as the developed educational resources are also included. A discussion of the advanced nursing practice competencies (Canadian Nurses Association [CNA], 2008) demonstrated throughout the practicum is also included.

Objectives

The objectives of the practicum were:

1. Conduct a thorough literature review to assess relevant evidence-based information and clinical practice guidelines related to the nursing care of individuals with LBD.
2. Conduct consultations with key stakeholders to determine relevant strategies and perspectives on nursing care of individuals with LBD.
3. Develop a resource manual outlining information related to nursing care of individuals with LBD.
4. Disseminate information related to nursing care of individuals with LBD, along with dissemination of the completed resource manual to improve care of individuals with LBD.
5. Demonstrate advanced nurse practice competencies such as clinical practice, researcher, leadership, and consultation/collaboration.

Objectives three and four did change once the consultation results were determined. Instead of developing a resource manual alone, the new objectives were to develop a presentation and a resource manual for nursing staff related to LBD.

Methods

Summary of Literature Review

An integrative literature review was conducted (see Appendix A) using the following databases: CINAHL, PubMed, Cochrane Library, and Google Scholar with the following search terms to identify articles relevant to the care of individuals with LBD: Lewy body dementia and non-pharmacological treatment, pharmacological treatment, signs and symptoms, quality of life, and nursing care. A hand search of article reference lists was also conducted to retrieve additional information. Articles were not limited to a specific geographic location, clinical setting, or year of publication in an effort to maximize search results. Nine relevant research articles were identified and were critically appraised according to the Public Health Agency of Canada [PHAC] Infection Prevention and Control Guidelines Critical Appraisal Toolkit (2014). There were two randomized control trial studies (Culo et al., 2010; Larsson et al., 2011); a cohort and respective cohort study (Auning et al., 2011; Ballard et al., 2001); and five cross-sectional studies (Bostrom, Jonsson, Minthon, Londos, 2007; Galvin et al., 2010a; Galvin et al., 2010b; Leggett, Zarit, Taylor, & Galvin, 2010; McKeith et al., 2006). The grey literature was also searched and had useful information related to LBD that better summarized evidence that was found to be contradictory in the research.

After the literature review it was determined that there is a lack of strong research design and nursing research regarding LBD. Many of the articles addressed LBD in comparison to AD or PD. These articles are relevant as they portray the overlap of symptoms in dementia and what distinguishes LBD from other types of dementia. The predominant themes depicted in the research included the overlapping symptoms of LBD, AD, and PD, quality of life of individuals living with LBD, managing LBD symptoms, and the challenge of providing a differential diagnosis of LBD.

LBD is an umbrella term for two related diagnoses: dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD) (Lewy Body Dementia Association [LBDA], 2016a). The central feature in each diagnosis is dementia and the time frame of the dementia will determine the exact diagnosis (LBDA, 2016a). Individuals can have three clinical presentations: 1) If a person presents with a movement disorder, they are diagnosed with Parkinson's disease. If dementia develops a year or more later, then the person is diagnosed with PDD (LBDA, 2016a); 2) If a person presents with a cognitive disorder before or within one year of Parkinson's symptoms, then it is diagnosed as dementia with Lewy bodies (DLB) (LBDA, 2016a); 3) If a person presents with neuropsychiatric symptoms, such as hallucinations, behavioral problems, and issues with complex activities, the diagnosis is DLB (LBDA, 2016a). The three clinical presentations have different symptoms initially, but over time will develop similar cognitive, physical, sleep, and behavioral problems (LBDA, 2016a).

Overlapping Symptoms of LBD, AD, and PD

There are two diagnostic tools used to diagnose LBD: the Diagnostic and Statistic Manual of Mental Health Disorders, fifth edition (DSM-5) and the Consortium on Dementia with Lewy Bodies Consensus Guidelines (McKeith et al., 2005; Walter, Edwards, Griggs, & Yehle, 2014). Both diagnostic tools have the same criteria for diagnosing LBD, and the literature does not indicate which tool is more valid and reliable for diagnosing LBD. The Lewy Body Dementia Association (LBDA) uses the four categories of symptoms as specified by the Consortium on Dementia Consensus Guidelines to diagnosis LBD (LBDA, 2016a): 1) Central features include dementia with problems in the areas of planning, judgment, processing, and understanding information. Memory impairment is usually not present upon diagnosis; 2) Core (hallmark) symptoms include fluctuating cognition with variations in attention and alertness with short-term memory intact in early stages. Recurrent, vivid visual hallucinations that are well-formed and detailed and spontaneous features of Parkinsonism such as tremors, stiffness, slowness, and difficulty walking; 3) Suggestive features include rapid eye movement (REM) sleep behavior disorder that involves talking and acting out dreams while asleep, severe sensitivity to neuroleptics, and low levels of dopamine reuptake on brain imaging that can cause depression, apathy, anxiety, and agitation; 4) Supportive features include repeated falls and fainting, short-term unexplained loss of consciousness, autonomic dysfunction such as blood pressure control, temperature regulation, and bowel and bladder control; hallucinations that involve touch or hearing; problems processing and

interpreting visual information such as the ability to orient oneself in the environment, and other psychiatric disturbances such as delusions and paranoia.

There are concerns with the Consortium Guidelines because, although it has high specificity in identifying those who do not have LBD, it has a low sensitivity in correctly detecting those who have LBD. This could lead to misdiagnosis and underdiagnosis of LBD. Both diagnostic tools are being used in practice, and this could be creating issues with receiving a definitive diagnosis of LBD. As well, healthcare providers may lack clinical familiarity with the diagnostic tools for LBD which could be contributing to the two year lag between onset of symptoms and diagnosis (LBDA, 2016c).

The research indicated that the common presenting symptoms of LBD and AD have similar characteristics but the symptoms occur at different stages of the disease continuum (Auning et al., 2011; Ballard et al., 2001; Walter et a., 2014). In LBD, the deficits in cognitive reaction time, slowing of cognitive processing, and fluctuations of attention are significantly more prominent than in AD. The attentional deficits that occur early in LBD do not occur until advanced stages of AD. Combined with their awareness of this, quality of life of individuals with LBD is considerably impacted early in the disease course.

There are similar symptoms between LBD, AD, and PD, further increasing misdiagnosis and underdiagnosis of LBD (Barber, Panikkar, & McKeith, 2001; McKeith, Perry, & Perry, 1999; Oliveria, Sampaio, Chen, & Bertolucci, 2015). Therefore, nursing

staff need educational resources that clearly distinguish the clinical manifestations of LBD to improve resident-centered care and quality of life in LTC settings.

Quality of Life and LBD

Research indicates that individuals with LBD have more impaired quality of life, and more severe functional impairments than AD (Bostrom et al., 2007; McKeith et al., 2006). Neurological and psychiatric symptoms, and functional impairments related to daily living were more debilitating in LBD than in AD. Early in the LBD disease trajectory, dependence on others is high because of extrapyramidal symptoms such as bradykinesia, tremors, and gait disturbances along with cognitive symptoms which severely impact basic care needs and mobility (McKeith et al., 2006). Individuals with LBD require earlier admission to nursing homes, have increased mortality, and die earlier in comparison to other types of dementia (Khotianov, Singh, & Singh, 2002; Zupancic, Mahajan, & Handa, 2011; Zweig & Galvin, 2014). Evidence gathered from individuals with LBD and caregivers indicate that quality of life is significantly lower in those with LBD than AD (Bostrom et al., 2007). As a result of a lowered quality of life, individuals with LBD and their families have an increased use of healthcare services (Bostrom et al., 2007). Therefore, prompt, resident-centered care for individuals with LBD to manage symptoms effectively can promote optimal outcomes (Bostrom et al., 2007).

Managing LBD Symptoms

There was limited information regarding the use of non-pharmacological approaches to manage LBD specifically, but research did indicate approaches are similar

to those used with other types of dementia such as, behavioral and communication strategies, reminiscence, doll therapy, aromatherapy, and music therapy (Neef & Walling, 2006; McKeith, 2004; McKeith et al., 2005; Yuhas, McGowan, Fontaine, Czech & Gambrell-Jones, 2006; Zupancic et al., 2011). As well, studies analyzing quality of life and pharmacological interventions in LBD are limited.

There are limited pharmacological options for those diagnosed with LBD due to lack of approved medications to treat the disease (Larsson et al., 2011). As a result, medications are generally used off label in the treatment of LBD (LBDA, 2016b). The greatest concern with pharmacological management is best course of treatment of symptoms and control of side effects (Culo et al., 2010; Larsson et al., 2011). Research indicates the recommended medications for management of LBD are cholinesterase inhibitors, N-Methyl-D-receptor antagonists (NMDA), Levodopa-carbidopa, benzodiazepines, and atypical antipsychotics (Culo et al., 2010; Larsson et al., 2011; LBDA, 2016b; Lewy Body Dementia Society, 2015).

Cognitive symptoms are more severe earlier in LBD when compared to AD, therefore proper management is crucial to improve quality of life (Culo et al., 2010). Cholinesterase inhibitors, such as Aricept (donepezil HCl), are the recommended first course of treatment for the cognitive symptoms of LBD (LBDA, 2016b; Lewy Body Dementia Society, 2015). These medications decrease the loss of acetylcholine in mild to moderate dementia which will help decrease problems with memory, thinking, and alertness (LBDA, 2016b; Lewy Body Dementia Society, 2015).

A more recent pharmacological intervention for LBD is the use of N-methyl-D-receptor antagonists that are commonly used in AD and PDD (Larsson et al., 2011; Shagham, 2009). NMDA for example, Ebixa (Memantine HCl) is used in moderate to severe stages of dementia when cholinesterase inhibitors are ineffective or the person has a sensitivity to them (LBDA, 2016b; Shagham, 2009). These medications may slow the loss of learning and memory skills such as, toileting and dressing, improving overall quality of life and functional capacity of individuals with LBD (Larsson et al., 2011; Shagham, 2009).

Levodopa-carbidopa, such as Sinemet, is a combination medication that is commonly used with LBD (LBDA, 2016b; Lewy Body Dementia Society, 2015). The carbidopa increases the uptake of levodopa to improve motor symptoms such as restless leg syndrome, rigidity, and tremors (LBDA, 2016b; Lewy Body Dementia Society, 2015). This medication is the initial treatment protocol for PD and is beneficial for management of Parkinson symptoms in LBD (LBDA, 2016b; Lewy Body Dementia Society, 2015). Levodopa-carbidopa should be started at the lowest dose and titrated slowly to allow for close monitoring of adverse effects (LBDA, 2016b; Lewy Body Dementia Society, 2015).

Benzodiazepines for example, Clonazepam (Klonopin) are used to treat REM sleep disorder and restless leg syndrome (Vallerand & Sanoski, 2015). These medications produce a sedative effect in the central nervous system (Vallearand & Sanoski, 2015).

Typical antipsychotics are often used to manage the behavioral and psychological features demonstrated in other types of dementia, but with LBD these medications are never used because they produce severe and fatal side effects known as neuroleptic sensitivity and neuroleptic malignant syndrome (Culo et al., 2010; LBDA, 2016b; McKeith et al., 2005; Walter et al., 2014). Neuroleptic sensitivity results in worsening of cognitive symptoms, hallucinations, and Parkinsonism and occurs in up to 50% of LBD patients treated with atypical antipsychotics (LBDA, 2016b). Neuroleptic malignant syndrome is a rare life-threatening adverse effect that produces symptoms of fever, generalized rigidity, and breakdown of muscle tissue that can result in kidney failure and death (LBDA, 2016b).

Atypical antipsychotics can be used to treat hallucinations and/or delusions that occur in LBD (Culo et al., 2010; LBDA, 2016b; Lewy Body Dementia Society, 2015). Extreme caution and close monitoring is required when atypical antipsychotics are prescribed because neuroleptic sensitivity and neuroleptic malignant syndrome are possible (LBDA, 2016b; Lewy Body Dementia Society, 2015). The recommended atypical antipsychotics to be prescribed are Quetiapine and Clozapine, in this order (LBDA, 2016b; Lewy Body Dementia Society, 2015; McKeith et al., 2005; Walter et al., 2014).These medications are only used if long-term cholinesterase inhibitors have been ineffective or better behavioral control is warranted (LBDA, 2016b; Lewy Body Dementia Society, 2015; McKeith et al., 2005; Walter et al., 2014). When atypical antipsychotics are prescribed, the lowest dose should be used for the shortest amount of time (LBDA, 2016b; Lewy Body Dementia Society, 2015; McKeith et al., 2005; Walter

et al., 2014). Atypical antipsychotics are safer than typical antipsychotics, but there is no antipsychotic medication that is absolutely safe for the management of LBD behavioral symptoms since all antipsychotics increase the chance of death in people with dementia (LBDA, 2016b; Lewy Body Dementia Society, 2015).

Certain medications should also be avoided in the management of LBD. Atypical antipsychotics Risperidone and Olanzapine, should be avoided as they have an increased likelihood of increasing side effects such as increased Parkinson symptoms, sedation, and orthostatic hypotension (LBDA, 2016b). As well, the following medications used with Parkinson's disease should be avoided as they worsen cognitive impairment: Amantadine, Catechol-O-methyltransferase (COMT) inhibitors (ex: Entacapone), Monoamine oxidase (MAO) inhibitors (ex: Selegiline), and anticholinergics (ex: Benztropine). Dopamine agonists such as Pramipexole and Bromocriptine should also be avoided because they cause excessive daytime sleepiness and swelling of the legs (LBDA, 2016b). It is important to also avoid over-the-counter sleep agents such as Tylenol or Advil PM, and bladder control medications as they may cause agitation (LBDA, 2016b).

It is evident that LBD symptom management requires a complex and different pharmacological approach than with other dementias to effectively manage the symptoms of the disease and improve quality of life.

Non-pharmacological interventions such as behavioral and communication strategies, music therapy, doll therapy, aromatherapy, and reminiscence aid in the

management of behavioral and psychological symptoms by lessen disruptive behaviors for example agitation, anxiety and aggression (Azcurra, 2012; Bisiani & Angus, 2012; Forrester et al., 2014; Haslem et al., 2014; Lin et al., 2011; Raglio et al., 2008; Subramaniam, Woods, & Whitaker, 2014; Sung, Lee, Li, & Watson, 2012; Van Bogaert et al., 2013; Yuhas et al., 2006). The non-pharmacological interventions improve quality of life by calming residents and promoting relaxation, sleep, memory recall, and attachment needs (Azcurra, 2012; Bisiani & Angus, 2012; Forrester et al., 2014; Haslem et al., 2014; Lin et al., 2011; Raglio et al., 2008; Subramaniam et al., 2014; Sung et al., 2012; Van Bogaert et al., 2013; Yuhas et al., 2006)

The Challenge of Providing a Differential Diagnosis of LBD

Healthcare professionals lack awareness regarding LBD (Galvin et al., 2010a; Galvin et al., 2010b; Leggett et al., 2010). Families have described the challenge of having a loved one correctly diagnosed with LBD and in a timely manner (Galvin et al., 2010a; Galvin et al., 2010b; Leggett et al., 2010). Research consistently demonstrated that there was a two year lag between onset of symptoms and a LBD diagnosis which could be due to the lack of clinical familiarity among primary care providers regarding LBD diagnostic criteria (Galvin et al., 2010a; Galvin et al., 2010b; Leggett et al., 2010).

Studies that utilized input from family experiences of the LBD journey can be used to influence the direction of educational needs and resources for healthcare professionals. The literature suggests there are few educational programs and other resources for healthcare professionals regarding LBD (Galvin et al., 2010a; Galvin et al.,

2010b; Leggett et al., 2010). Increasing awareness of LBD among health care providers will most likely lead to earlier diagnosis, enhanced care for individuals living with LBD, and better support for family members. As a result, quality of life for individuals with LBD will improve.

Summary of Consultations

Consultations were conducted with 15 nursing leaders and front-line nurses. Nursing leaders from the following LTC sites agreed to participate: one site in Edmonton, Alberta; one in Vancouver, British Columbia; one in Waterloo, Ontario; one in Halifax, Nova Scotia; and three within rural Avalon Eastern Health authority. As well, front-line nurses from the dementia unit at Harbour Lodge Nursing Home (one senior and one junior RN, two senior and one junior LPN, and one senior and one junior PCA) participated. Also, a physician from urban Eastern Health Authority who specializes in neurocognitive disorders in geriatrics participated. Purposive sampling was used to recruit participants. An information letter was sent via email to each potential participant outlining the purpose of the consultation process and full disclosure of how the data collected would be utilized to develop the LBD educational resources. Interviews were completed with the participants after an email confirming agreement to participate was received by the MN student. Verbal agreement was also obtained at the time of the interview. Notes were taken during each interview and analyzed for themes. There were five major themes that emerged from the consultation process: lack of education resources specific to LBD in LTC, knowledge gaps of nursing staff in LTC regarding

LBD, lack of clinical knowledge regarding diagnosis and care specific to individuals living with LBD, preferred learning styles of nursing staff related to LBD in LTC, and impact of LBD education on care delivery in LTC (see Appendix B). The findings of the consultations were consistent with those of the literature review.

Lack of Education Resources Specific to LBD in LTC

The consultations demonstrate that the majority of staff orientation is based on dementia in general, with a focus on AD. Very limited information is provided regarding LBD. Findings indicate that most LTC sites focus on programs geared toward AD specifically. For example, in Eastern Health, nursing staff complete a Gentle Persuasive Approaches (GPA) course and Dementia Care Orientation course related to responsive behaviors in AD. Both these programs focus mainly on AD with little information regarding LBD.

Education related to dementias other than AD is self-initiated by nursing staff through internet websites such as the Alzheimer Society of Canada. Some facilities have handbooks covering dementia in general for families which nursing staff use as well to increase their knowledge base regarding dementia. All participants stated there was a need for resources specific to LBD for nursing staff.

Knowledge Gaps of Nursing Staff in LTC Regarding LBD

Numerous areas of knowledge deficits among nursing staff in LTC were evident in the consultation process. The main learning needs identified focused on the following

areas: What is LBD? What are the signs and symptoms of LBD that distinguish it from other dementia types? What are the risks for being diagnosed with LBD? What are the pharmacological and behavioral management options? What are some Canadian resources related to LBD? Many members of the nursing staff were only aware of care approaches to be used with AD residents and not for residents with LBD which impacts resident-centered care for these individuals. A major issue with pharmacological management of LBD is knowing when to use particular classes of medications, what classes of medication not to use or with great caution, and when behavioral approaches are more appropriate to manage signs and symptoms. Nursing staff need to be aware of current and relevant alternatives to antipsychotic use due to their severe side effects. With more education nursing staff will be better able to differentiate the clinical manifestations of LBD from other dementia types and provide interventions that are appropriate and safe for LBD to promote optimal care.

Lack of Clinical Knowledge Regarding Diagnosis and Care Specific to Individuals Living with LBD

It was deemed by nursing leaders and nursing staff that not many residents in LTC are definitively or appropriately diagnosed with LBD; they are generally given an umbrella diagnosis of dementia. This impacts the ability of nursing staff to provide resident-centered care in LTC settings. Nurses expressed frustration in managing hallucinations and behavioral symptoms of LBD using general dementia approaches. Nursing staff also indicated that the pharmacological interventions used with AD are not

effective in managing hallucinations and behavioral symptoms in LBD. By not being properly informed regarding LBD, nursing staff cannot effectively provide individualized care which negatively impacts quality of life. As a result, nursing staff feel specialized plans of care should be put into place for LBD residents based on current, evidence-based practices which will also help nurses relay pertinent information regarding LBD to families to help with the coping process of LBD diagnosis.

Preferred Learning Styles of Nursing Staff Related to LBD in LTC

Nursing leaders and nursing staff identified that educational resources were needed to enhance knowledge regarding LBD so that staff can be more confident and competent in delivering resident-centered care to LBD residents thus improving quality of life and well-being for residents. The preferred types of educational resources were a presentation related to key areas of concern identified in the consultations and a detailed resource manual to remain on the dementia unit. As well, nursing leaders and nursing staff indicated the importance of videos and case studies to apply new knowledge and to use problem-solving skills which would enhance retention of the new information.

Impact of LBD Education on Care Delivery in LTC

The nursing leaders and nursing staff agreed that the presentation and resource manual regarding LBD will increase the knowledge base of nursing staff and improve resident-centered care for LBD residents, resulting in enhanced well-being and quality of life. Nursing staff will be more attuned to identifying symptoms of LBD and use effective

interventions to manage disease symptoms. Better management of the symptoms will promote positive changes on the dementia unit for residents, families, and staff.

Theoretical Framework

After identifying the common themes in the literature review and the concerns identified by staff in the consultation process, it was determined that the principles of Knowle's Adult Learning Theory would be incorporated into the development of the educational resources for nursing staff in LTC (Chesbro, 2002; Milligan, 1997; Mitchell & Courtney, 2005). The six principles of Knowle's Adult Learning Theory include self-concept, experience, readiness to learn, orientation to learning, motivation to learn, and relevance (Chesbro, 2002; Milligan, 1997; Mitchell & Courtney, 2005). Self-concept of the nursing staff was maintained as they were involved in the planning and evaluation of the presentation and resource manual. The educational resources build upon the knowledge and experience of the nursing staff regarding dementia care. The content of the educational resources was determined by the nursing staff and is pertinent to their work environment, therefore learning will occur. The new knowledge related to LBD will be readily applied with the use of case studies, interactive questions during the presentation, and pre-post tests as well as in clinical practice, upholding the principle of orientation to learning. Knowing there was a lack of educational resources regarding LBD and being self-aware of their learning needs will motivate the nurses to learn about LBD. The nursing staff are aware that with the increased aging population a diagnosis of LBD is more likely and there will inevitably be more residents with LBD on the unit. As

a result, being informed of LBD will enhance care delivery and better meet the needs of residents with LBD.

In order to know if the manual has enhanced the knowledge of nursing staff regarding LBD, evaluation must occur. Kirkpatrick's Four-Level Model of Evaluation will be used to evaluate the educational resources (Kirkpatrick, 1996; Kirkpatrick & Kirkpatrick, 2006; Smidt, Balandin, Sigafoos, & Reed, 2009). Level one is concerned with how participants felt about the learning experience. At the end of the presentation and resource manual, an evaluation survey will be completed by participants to determine satisfaction and to offer comments for improvements to the educational resources. Level two will assess if there is an increase in knowledge and/or skill among the nursing staff as a result of the LBD resource manual. A pre-test and post-test will be given to nursing staff to assess the extent of advancement in knowledge levels regarding LBD. Level three, behavior or transfer, assesses the ability of the nursing staff to apply what they have learned from the LBD educational resources. On a small scale, this will be assessed among nursing staff using case studies in both educational resources to enhance problem-solving abilities that are relevant in the care of residents with LBD. On a larger scale, informal discussions with the Resident Care Manager and nursing staff will determine a change in confidence and competency regarding the care and assessment of LBD residents. As well, a survey of nursing staff could be conducted to determine changes in confidence levels. Level four, results, looks beyond the educational resources on a larger scale to determine the effectiveness and impact of the program on the care of residents with LBD and staff performance. This will occur in an informal manner through a

discussion with the Resident Care Manager on the dementia unit to assess the outcomes of comparing quality of life indicators of residents with LBD before and a specified time period after the completion of the LBD training. As well, the Resident Care Manager can assess changes in performance indicators for nursing staff such as assessment skills of LBD residents, before and a specified time period after the training to note if there is improvement in staff performance regarding the care of residents with LBD and track quality of care indicators.

Summary of Materials Developed

LBD Presentation

A 45 minute presentation was developed that will introduce the basic information related to LBD. It will be given to the Clinical Nurse Specialist to use in orientation training of new staff to LTC and continuing education for current staff (see Appendix C). The topics covered are: dementia information in general, LBD clinical presentations and categories, pharmacological and non-pharmacological management, importance of resident-centered care with LBD, topics to be addressed in the resource manual, and a LBD case study. A video is used to illustrate the life of an individual with LBD and links to other relevant LBD videos and relevant organizations are provided. The presentation is practical for nursing staff in that it is short in nature, visibly appealing with colored fonts, and images to keep them interested. As well, the slides are written in active voice, in short sentences, in bulleted format, and an easy reading level to promote understanding and enhance learning.

LBD Resource Manual

The resource manual provides extensive detail regarding LBD and is readily available to nursing staff during work hours so they can set the learning pace (see Appendix D). The manual is practical in that it has a table of contents that can direct nursing staff to a particular topic and an overview that informs the nursing staff about the rationale of the manual and how it will help them in their nursing practice. As well, the manual contains color, graphics, ample white space, headings, and subheadings with short sentences in bulleted format to keep the reader focused and promote comprehension. The resource manual is composed of five chapters that cover the following topics: Chapter 1 – Dementia; Chapter 2 – Clinical Manifestations of Lewy Body Dementia, Alzheimer's Disease and Parkinson's Disease; Chapter 3 – Pharmacological Management of Lewy Body Dementia; Chapter 4 – Non-pharmacological Management of Lewy Body Dementia; Chapter 5 – LBD Resources. There is also a pre-post test, two case studies, and an evaluation survey.

Advanced Nursing Practice Competencies

Advanced Nursing Practice refers to a higher level of nursing knowledge that is derived from graduate preparation, critical thinking, expert nursing knowledge, and expertise in meeting the health needs of others (CNA, 2008). Distinct to advanced nursing practice are core competencies which are based on nursing knowledge, theory, research, and clinical experience. The advanced nurse practice competencies include

clinical, research, leadership, and consultation/collaboration. Throughout the practicum I have demonstrated and become proficient in the following competencies:

Clinical Practice

Through the process of critical appraisal, data gathering, analysis, and dissemination during the development of the LBD educational resources, I have a better understanding of this disease and strengthened my knowledge base. As a result, I can be a resource person and leader for nursing staff in LTC in accordance with my position as an Advanced Practice Nurse. Through interactions with various levels of healthcare providers, I have developed resources that are based on evidence-based practices and research to promote holistic care for residents with LBD.

Researcher

During the literature review and consultation process, I interpreted research results and incorporated the findings into the LBD educational resources that will be used to assist in care delivery in LTC. The analysis and interpretation of the research findings used in the educational resources will increase the knowledge base of nursing staff and improve nursing care for residents with LBD in LTC.

Leadership

Both residents and the Eastern Health organization will benefit from my knowledge as an educational leader related to LBD. As a leader, I can enhance nursing staff knowledge to improve care delivery to LBD residents in LTC. The lack of

educational resources and policies in LBD care practice in rural Avalon LTC facilities drives the need for a leader in this area.

Consultation/Collaboration

I consulted with nursing staff, Resident Care Managers, the Clinical Nurse Specialist, and the Program Manager of rural Avalon Eastern Health, along with nursing leaders in other regional health authorities, both locally and provincially, to enhance current dementia care practices in LTC. I also consulted with professional associations, organizations, and other experts in the field of LBD provincially, nationally, and internationally. By doing this I am effectively enhancing nursing knowledge and benefiting my professional practice as a LBD resource person for nursing staff.

Next Steps

The next step is to implement the LBD educational resources on the dementia unit of Harbour Lodge Nursing Home. The Clinical Nurse Specialist will use the presentation and resource manual as part of orientation for new nursing staff and continuing education for current staff in rural Avalon Eastern Health LTC sites and has taken the responsibility of updating the resource manual and presentation as necessary. Furthermore, the results of the evaluation process for both the presentation and resource manual will aid the revision process to ensure the LBD educational resources meet the needs of the nursing staff.

Conclusion

LBD is likely to become a more common diagnosis in the future due to an aging population. As a result of the challenging symptoms and complex care needs of this diagnosis, admission to LTC sites is probable. Therefore, nursing staff in LTC need to be informed regarding LBD and effective care interventions. Review of the literature and the consultation process provided information to guide the development of the LBD educational resources for nursing staff in LTC to improve nursing care and enhance quality of life for residents with LBD. The LBD educational resources were developed in accordance with Knowle's Adult Learning Theory to meet the needs of the nursing staff. Evaluation using Kirkpatrick's Four-Level Model of Evaluation will be ongoing and will allow for revisions in both the presentation and resource manual to determine their impact on nursing care for residents with LBD in LTC. These LBD educational resources will improve resident-centered care for individuals with LBD in LTC as well as improve quality of life and well-being.

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Appendix A – Literature Review and Summary Tables

Lewy Body Dementia: An Integrated Literature Review

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Table of Contents

Abstract

Lewy body dementia is a growing concern in the aging population. The literature indicates that there is a lack of knowledge among health care professionals about this type of dementia, which greatly impacts quality of life for individuals diagnosed. This is further complicated by an overlap of symptoms between Lewy body dementia, Alzheimer's disease, and Parkinson's disease which increases the difficulty for nursing staff differentiating one disease from the other. No literature specifically exists related to nursing knowledge of Lewy body dementia in long-term care or the quality of care for individuals with Lewy body dementia in this setting. Therefore, it is reasonable to assume that nursing staff in LTC settings have limited knowledge related to Lewy body dementia. The literature indicates that a diagnosis of Lewy body dementia is challenging, quality of life is more significantly impacted in Lewy body dementia and management of the disease is different than with other types of dementia. Therefore, an educational resource manual related to Lewy body dementia is a beneficial resource that can be utilized by nursing staff in long-term care to promote resident-centered care and quality of life for individuals diagnosed with this disease. The resource manual will be designed using Knowles' Adult Learning Theory and will aim to enhance care to individuals diagnosed with Lewy body dementia in long-term care settings. Furthermore, the resource manual will contain information related to evidence-based practices that were revealed through the literature review and consultation process.

Rates of Lewy body dementia (LBD) are rising because of an aging population (Lewy Body Dementia Association [LBDA], 2016a). Nursing staff are encountering more patients diagnosed with LBD in long-term care (LTC) facilities as a result. Informational resources are lacking in LTC facilities related to LBD, hence relevant education is needed to enhance nursing care for individuals diagnosed with this disease (S. Hawco, personal communication, September 15, 2015). Evidence-based practices related to LBD in LTC will improve care delivery to individuals with this diagnosis. Continued nursing education related to LBD is needed for nursing staff to develop therapeutic nursing interventions that better meet the needs of residents with LBD in LTC.

LBD is an umbrella term for two related diagnoses: dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD) (LBDA, 2016b). Dementia is the main feature in each diagnosis and the time frame of the dementia will determine the exact type (LBDA, 2016b). Individuals can have three clinical presentations (LBDA, 2016b): 1) a diagnosis of Parkinson's disease is given when a person has symptoms of a movement disorder. If dementia develops a year or more later, then the person is diagnosed with PDD; 2) A diagnosis of DLB is given when a person has symptoms of a cognitive disorder before or within one year of Parkinson's symptoms; 3) A diagnosis of DLB is also given when a person presents with neuropsychiatric symptoms, such as hallucinations, behavioral problems, and issues with complex activities (LBDA, 2016b). Initially, the three clinical presentations have different symptoms, but eventually affected persons will develop similar cognitive, physical, sleep and behavioral problems (LBDA,

2016b). LBD is a challenging and complex multisystem disease to manage effectively (LBDA, 2016c).

Individuals with LBD require LTC services earlier, have increased mortality, and die earlier in comparison to other types of dementia (Khotianov, Singh, & Singh, 2002; Zupancic, Mahajan, & Handa, 2011; Zweig & Galvin, 2014). It is believed the greatest risk factor for LBD is advanced age, but contradictory evidence exists that risk may or may not increase with a family history of the disease (LBDA, 2015a; Neef & Walling, 2006; Walter, Edwards, Griggs, & Yehle, 2014).

Appropriate staff training is needed so that nursing staff will be able to more effectively differentiate between LBD, Alzheimer's disease (AD), and Parkinson's disease (PD) which will lead to improved caregiving practices. Evidently, LBD education should be a priority to increase understanding of the disease process and care guidelines for nursing staff and, as a result, improve quality of life for individuals diagnosed with LBD in LTC.

Epidemiological Information

There are several types of dementia, but AD and LBD are two of the most common. AD occurs in 10 per 100 people commonly over 65-69yers old and accounts for 60-80% of dementia cases worldwide (Alzheimer Association, 2016a; Walter et al., 2014). LBD occurs in 7 out of 1000 people over 75 years of age and older and accounts for 15-20% of dementia cases worldwide (LBDA, 2016a; Walter et al., 2014). Parkinson's disease occurs in 8 per 1000 people over 80 years of age and 50-80% of

people with this disease will develop Parkinson's disease dementia (PDD) (Alzheimer Association, 2016b; Walter et al., 2014). Globally, the total healthcare costs of dementia amount to 1% of the gross domestic product (Alzheimer Society of Canada, 2015a).

The World Health Organization estimates there were 35.6 million cases of dementia worldwide in 2010 and this number is expected to double by 2030 and triple by 2050 (Public Health Agency of Canada [PHAC], 2014c; Walter et al., 2014). In Canada, LBD accounts for 5 – 15% of dementia diagnoses while AD accounts for 64% (Alzheimer Society of Canada, 2015b; Alzheimer Society of Canada, 2015c). Therefore, AD is the most common form of dementia in Canada and LBD ranks third (Alzheimer Society of Canada, 2015b; Alzheimer Society of Canada, 2016c). It was estimated that the number of Canadians over 65 years of age experiencing various types of dementia will double from 310, 000 in 2011 to 639, 700 by 2031 (PHAC, 2014b; PHAC, 2014c). In this same time, the number of new cases for all types of dementia in Canada will increase by 90% (360 to 530 cases per 100, 000 population) (PHAC, 2014b). This increase in prevalence and incidence rates will result in a large percentage of the senior population living with dementia. Furthermore, in 2011 men were diagnosed at an earlier age with LBD and have an earlier onset of symptoms than women (PHAC, 2014b). On average, men are diagnosed with LBD at 72.2 years of age and women at 73.6 years of age (PHAC, 2014b). However, it is possible for LBD to occur as early as 50 years of age but it is most common after 60 years of age (Lewy Body Dementia Society, 2015; Walter et al., 2014). For both sexes there is a two year lag between onset of symptoms and a confirmed diagnosis of LBD (PHAC, 2014b). Generally, individuals with LBD will die

5-7 years after diagnosis (LBDA, 2015a). In 2011 approximately 11% of deaths in the general population occurred because of dementia-related complications (Statistics Canada, 2014).

As is evident, the number of Canadians affected by dementia is vast and incidence will increase as the population advances in age. In 2011, 3-5% of the population in LTC facilities had a dementia diagnosis (PHAC, 2014b). There were no statistics for prevalence of LBD in LTC noted in the literature. The complex care needs that coincide with a dementia diagnosis are best managed in LTC facilities; therefore as the aging population increases, these facilities will experience great demands in the future (PHAC, 2014c).

Diagnostic Tools for LBD

There are two diagnostic tools used to diagnose LBD, the Diagnostic and Statistic Manual of Mental Health Disorders, Fifth Edition (DSM-5) and the Consortium on Dementia with Lewy Bodies Consensus Guidelines (McKeith et al., 2005; Walter et al., 2014).

The Consortium on Dementia Consensus Guidelines specifies four categories of symptoms (LBDA, 2016b; McKeith et al., 2005). The first category, central feature, is dementia with problems noted in planning, judgment, processing and understanding information. At this early stage of LBD, memory impairment is usually not present. The second category, core (hallmark) symptoms includes fluctuating cognition with variations in attention and alertness and short-term memory is intact. Also there are recurrent, vivid

visual hallucinations that are well-formed and detailed along with spontaneous features of Parkinsonism such as tremors, stiffness, slowness, and difficulty walking. The third category, suggestive features includes rapid eye movement (REM) sleep behavior disorder that involves talking and acting out dreams while asleep, severe sensitivity to neuroleptics, low levels of dopamine reuptake on brain imaging that can cause depression, apathy, anxiety, and agitation. The final category, supportive features includes repeated falls and fainting, short-term unexplained loss of consciousness, autonomic dysfunction such as blood pressure control, temperature regulation, and bowel and bladder control; auditory and tactile hallucinations; problems processing and interpreting visual information such as the ability to orient oneself in the environment, and other psychiatric disturbances such as delusions and paranoia. The Lewy Body Dementia Association follows these guidelines.

The DSM-5 criteria, which is based on more recent research, incorporates the Consortium Guidelines into its diagnostic tool but identifies the similarities and differences between LBD, AD, and PD (Walter et al., 2014). The use of both diagnostic tools may well be contributing to the two year lag between onset of symptoms and diagnosis (PHAC, 2014b).

Both diagnostic tools are being used in practice but the literature does not indicate which is more valid and reliable. The literature does indicate there is a lack of awareness among health care professionals of when exactly symptoms occur at each stage in LBD, AD, and PD (Auning et al., 2011; Ballard et al., 2001). However, the most recent

Consensus Guidelines have high specificity in identifying those who do not have LBD but it has low sensitivity in correctly detecting those who have LBD (McKeith, Perry, & Perry, 1999). This may lead to issues with misdiagnosis and underdiagnosis that are alluded to in the literature (Barber, Panikkar, & McKeith, 2001; McKeith, Perry, & Perry, 1999; Oliveria, Sampaio, Chen, & McKeith, 2001). The aim of this integrated literature review is to explore and critically appraise the literature on LBD (see Tables 1-9 in Appendix 1). Specific objectives are to provide a synthesis of the literature and identify common themes in the literature. As well, the literature review will identify the gaps in knowledge among health care professionals related to LBD, and justify the need for a LBD resource manual as an educational tool for nursing staff to improve care delivery in LTC settings for individuals with LBD.

Literature Review

An online search was conducted in the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Cochrane Library, and Google Scholar using the following search terms to identify articles relevant to the care of individuals with LBD: Lewy body dementia and non-pharmacological treatment, pharmacological treatment, signs and symptoms, quality of life, and nursing care. Key questions to guide the search were: What is LBD? How is quality of life impacted by LBD? What is the nursing role in providing care to individuals with LBD? What are the current treatment options for LBD? What are the knowledge gaps of nurses regarding LBD? A hand search of article reference lists was also conducted to retrieve additional information. Articles were not

limited to a specific geographic location, clinical setting, or year of publication in an effort to maximize search results. The grey literature was also searched and had useful information related to LBD that better summarized evidence that was found to be contradictory in the research.

Nine relevant research articles were identified and were critically appraised according to the Public Health Agency of Canada [PHAC] Infection Prevention and Control Guidelines Critical Appraisal Toolkit (2014a). There is a lack of qualitative research regarding LBD, but numerous articles of a clinical nature exist to assist healthcare professionals in care delivery. There are two randomized control trial studies with small samples that evaluate the effectiveness of pharmacological therapy in managing LBD symptoms (Culo et al., 2010; Larsson et al., 2011). Culo et al., (2010) used the following instruments to assess neuropsychiatric symptoms: Neuropsychiatric Inventory (NPI) scale and the Empirical Behavioral Pathology in Alzheimer's disease (E-BEHAVE-AD) scale. As well, cognitive status was assessed using the Mini Mental Status Exam (MMSE). Larsson et al., (2011) utilized the Quality of Life Alzheimer Disease (QOL-AD) scale to assess quality of life during pharmacological management of LBD.

Ballard et al., (2001) conducted a cohort study with a small sample that examined attention and fluctuating attention in LBD and AD. Auning et al., (2011) conducted a retrospective cohort study of small sample size that examined the early and presenting symptoms of LBD using the Neuropsychiatric Inventory (NPI) scale.

There are five cross-sectional American studies with moderately large samples that examined quality of life, functional impairments, and caregiver experiences related to LBD (Bostrom, Jonsson, Minthon, Londos, 2007; Galvin et al., 2010a; Galvin et al., 2010b; Leggett, Zarit, Taylor, & Galvin, 2010; McKeith et al., 2006;). Bostrom et al., (2007) examined quality of life in a small sample, using the EuroQol-5D (EQ-5D) instrument and Quality of Life- Alzheimer disease (QOL-AD) instrument as well as the Neuropsychiatric Inventory (NPI) scale to evaluate behavioral disturbance, the Mini Mental Status Exam (MMSE) to assess cognitive function, and the Disability Assessment for Dementia scale to assess dependency in instrumental activities of daily living (I-ADL). McKeith et al., (2006) examined functional impairments in LBD and AD in a small sample. The following instruments were used: the Neuropsychiatric Inventory (NPI) scale to assess neuropsychiatric symptoms, the Bristol Activities of Daily Living Scale (BADLS) to assess functional impairment, the United Parkinson's Disease Rating Scale part III motor examination (UPDRS-III) to assess extrapyramidal motor symptoms, and the Mini Mental Status Exam to assess global cognitive function. Galvin et al., (2010a), Galvin et al., (2010b) and Leggett et al., (2010) used the same survey with the same moderately large population to examine different aspects of caregiver experiences in LBD. The Zarit Burden Interview was used as a data collection instrument. These three cross-sectional studies also used the same sample of participants that completed one survey from which three publications arose, which is a major limitation.

Different data collection instruments were used in all the studies to assess the impact of LBD on individuals, and this could be considered a limit of the research.

Several of the research studies demonstrated selection bias because they did not utilize randomization techniques (Auning et al., 2011; Ballard et al., 2001; Galvin et al., 2010a; Galvin et al., 2010b; Leggett et al., 2010; McKeith et al., 2006). The studies by Bostrom et al., (2007), Auning et al., (2011), Galvin et al., (2010a), Galvin et al., (2010b) and Leggett et al., (2010) also demonstrated recall bias because they relied on information sought from past experiences which may have led to inaccuracies and incomplete data collection.

As is evident, there is a lack of strong research design and nursing research regarding LBD. Many of the articles addressed LBD in comparison to AD or PD. These articles are relevant as they portray the overlap of symptoms in dementia and what distinguishes LBD from other types of dementia. The predominant themes depicted in the research included the overlapping symptoms of LBD, AD, and PD, quality of life in LBD, managing symptoms of LBD, and the challenge of providing a differential diagnosis of LBD.

Overlapping Symptoms of LBD, AD, and PD

Two studies of moderate quality have confirmed that the common presenting symptoms of LBD are slowing of cognitive processing, fluctuating attention, and visual hallucinations (Auning et al., 2011; Ballard et al., 2001). As well, these studies concluded that the most common early symptom of AD is impaired memory. These results are consistent with the clinical article by Walker et al., (2014) that distinguishes the hallmark symptoms between LBD, AD, and PD. Ballard et al., (2001) strongly suggests that LBD

patients experience immense difficulty maintaining attention which severely impacts every day activities and quality of life. This study concluded that while LBD and AD may have similar clinical manifestations, the manifestations occur at different points along the disease trajectory. Deficits of cognitive reaction time, slowing of cognitive processing, and fluctuations of attention are significantly more pronounced in LBD than in AD. Attentional deficits that occur early in LBD do not occur until advanced stages of AD, therefore individuals with LBD experience a significant impact on quality of life early in the disease trajectory (see Table 3 in Appendix 1).

Caregivers play a central role in gathering information related to a diagnosis of LBD. Auning et al., (2011) questioned caregivers regarding early and presenting symptoms of LBD. This study agrees with the Consortium on Dementia with Lewy Bodies Consensus Guidelines and the DSM-5 criteria that visual hallucinations are a common early symptom of LBD and impaired memory is the common early symptom of AD. However, this study indicates that memory impairment is also a common presenting symptom of LBD which is in contrast to the Consensus Guidelines and the DSM-5 criteria (McKeith et al., 2004; Walter et al., 2014). All dementias have cognitive impairments but visual hallucinations and fluctuating attention in LBD cognitive states occur specifically in early stages of the disease, which is in contrast to other types of dementia (see Table 4 in Appendix 1).

Lewy body dementia.

With LBD fluctuating cognition may cause the person to have a vacant stare, be extremely drowsy, and have disorganized thoughts but at other times to be alert, competent in activities of daily living and logical conversation (Auning et al., 2011; Ballard et al., 2001; Lewy Body Dementia Society, 2015; Walter et al., 2014). This is the complex symptom of LBD because short-term memory is still intact in the early stages and individuals are aware of their changes in cognition. The hallucinations that occur with LBD can be severely distressing for the person and can result in agitation and aggression (Lewy Body Dementia Society, 2015). The symptoms of fluctuating cognition and visual hallucinations do not often occur during examination by a physician which can make an accurate diagnosis difficult (Lewy Body Dementia Society, 2015)

The motor symptoms that occur during LBD may be subtle at first but become more pronounced in later stages of the disease (Auning et al., 2011; Ballard et al., 2001; Lewy Body Dementia Society, 2015; Walter et al., 2014). Individuals experiencing LBD may demonstrate many symptoms of Parkinson's disease such as muscle rigidity or stiffness, shuffling gait, slow movement, freezing of movements, tremor of the hands even at rest, balance problems resulting in falls, issues with handwriting, difficulties with facial expressions and swallowing, and decreased strength of voice. These symptoms severely impact independence and quality of life early in the disease course of LBD (Bostrom et al., 2007; McKeith et al., 2006).

Behavioral changes also occur in LBD. Individuals with LBD can experience apathy, anxiety and agitation (LBDA, 2016b; Lewy Body Dementia Society, 2015).

Anxiety and agitation can be a result of the confusion and visual hallucinations but can also be present in the absence of hallucinations.

Sleep problems are also very common in individuals with LBD (LBDA, 2016b; Lewy Body Dementia Society, 2015). REM sleep behavior disorder involves acting out vivid dreams while asleep through talking and violent movements. Even though individuals with LBD may get sufficient sleep at night they often experience excessive day time sleepiness as well. Some individuals with LBD may experience insomnia where they cannot fall asleep or stay asleep at night. Restless leg syndrome may occur in people with LBD so that their legs are constantly twitching and moving in an attempt to decrease unusual sensations and discomfort in the legs.

Involuntary activities are affected in individuals with LBD due to autonomic dysfunction (LBDA, 2016b; Lewy Body Dementia Society, 2015). Variations may occur in the following areas: Body temperature, blood pressure, dizziness, fainting, sensitivity to temperature changes, falls, problems with sexual functioning, constipation, and changes to the sense of smell (LBDA, 2016b; Lewy Body Dementia Society, 2015).

Alzheimer's disease.

The hallmark symptoms of AD are problems with short-term memory loss and early symptoms of recall, learning, and orientation deficits (Walter et al., 2014). AD progresses at a much slower rate than LBD (Alzheimer Society of Canada, 2015c). Early in the AD course the symptoms are similar to the late stages of LBD such as problems

with planning, problem-solving, and judgment along with disorientation to person, place, and time (Walter et al., 2014). As AD progresses, psychiatric symptoms such as hallucinations and delusions are common, along with problems with movement, speech, activities of daily living (ADL's), and long-term memory(Walter et al., 2014). Once individuals with AD reach this point there is no intact memory (Dementia Care Central, 2016).

Parkinson's disease.

The symptoms of Parkinson's disease are the result of Lewy bodies found in the midbrain and this disease is most common in individuals over the age of 70 years (Walter et al., 2014). Most individuals with PD will progress to LBD (Alzheimer Association, 2016b). The risk of males developing PD is 1.5 times greater than females (Walter et al., 2014). The hallmark symptom of PD is tremors and the early symptoms of PD are movement problems such as stiffness, difficulty with balance, and coordination (Walter et al., 2014). As well, cognition, problem-solving, planning, and memory dysfunctions can also occur early in the disease (Walter et al., 2014). As the disease progresses, the motor symptoms become severe resulting in safety issues for those diagnosed such as swallowing, bathing, and falls.

Because similar symptoms occur in LBD, AD, and PD there is often misdiagnosis or underdiagnosis of LBD (Barber et al., 2001; McKeith et al., 1999; Oliveria et al., 2015). As a result, information related to distinguishing clinical manifestations is needed

to increase nursing staff awareness of LBD and to improve resident-centered care and quality of life in LTC settings.

Qualify of Life and LBD

Two studies of low and moderate quality respectively, indicate that individuals with LBD have more impaired quality of life and more severe functional impairments than AD (Bostrom et al., 2007; McKeith et al., 2006). Data demonstrates that neurological and psychiatric symptoms, and functional impairments related to daily living, were more severe in LBD than AD (see Tables 5, 6 in Appendix 1). McKeith et al., (2006) attributes higher levels of dependency for individuals in early LBD to extrapyramidal symptoms such as bradykinesia, tremors, and gait disturbances. These symptoms have a major impact on activities of daily living, such as basic care needs and mobility. It is evident from the research that LBD and AD affect individuals differently and care needs are quite different as well (McKeith et al., 2006). Regardless of whether quality of life was assessed directly from individuals with LBD or their caregivers, evidence indicates that quality of life is significantly lower in those with LBD compared to AD (Bostrom et al., 2007). Lowered quality of life is associated with increased use of healthcare services by individuals with LBD and their families (Bostrom et al., 2007). The more severe clinical manifestations of LBD require prompt, resident-centered care that promotes optimal outcomes (Bostrom et al., 2007). Prompt and effective management of LBD symptoms will preserve quality of life for both residents and families (Bostrom et al., 2007).

It must be noted that the studies by Bostrom et al., (2007) and McKeith et al., (2006) are limited by the use of self-reported and proxy-reported data collection instruments which may contribute to recall bias. Accordingly, the results should be used cautiously but support the need for more research related to LBD.

Managing LBD Symptoms

There was limited information regarding the use of non-pharmacologlical approaches to manage LBD specifically, but research did indicate approaches are similar to those used with other types of dementia such as, behavioral and communication strategies, reminiscence, doll therapy, aromatherapy, and music therapy (Neef & Walling, 2006; McKeith, 2004; McKeith et al., 2005; Yuhas, McGowan, Fontaine, Czech & Gambrell-Jones, 2006; Zupancic et al., 2011). As well, studies analyzing quality of life and pharmacological interventions in LBD are limited.

Pharmacological management targets the loss of the neurotransmitters acetylcholine and dopamine as the disease progresses (LBDA, 2016c; Lewy Body Dementia Society, 2015; Walter et al., 2014). Pharmacological treatment is different depending on what symptoms present first. Cognitive symptoms are initially treated with cholinesterase inhibitors, motor symptoms are initially treated with levodopa-carbidopa and neuropsychiatric symptoms are initially treated with atypical antipsychotics (LBDA, 2016c). The medications can improve some symptoms but worsen others so caution should be exercised and residents monitored closely for adverse reactions during the medication regimen.

The greatest concern with pharmacological management is proper treatment of symptoms and control of side effects (Culo et al., 2010; Larsson et al., 2011). There are limited pharmacological options for those diagnosed with LBD due to lack of approved medications to treat the disease (Larsson et al., 2011). As a result, medications are generally used off label in the treatment of LBD (LBDA, 2016c). Research indicates the recommended medications for management of LBD are cholinesterase inhibitors, N-Methyl-D-receptor antagonists (NMDA), levodopa-carbidopa, benzodiazepines, and atypical antipsychotics (Culo et al., 2010; Larsson et al., 2011; LBDA, 2016c).

In LBD cognitive symptoms are more severe earlier in the disease when compared to AD, therefore proper management is crucial to improve quality of life (Culo et al., 2010) (see Table 1 in Appendix 1). Cholinesterase inhibitors, such as Aricept (donepezil HCl) are the recommended first course of treatment for mild to moderate LBD (LBDA, 2016c; Lewy Body Dementia Society, 2015). These medications help decrease problems with memory, thinking, and alertness (LBDA, 2016c; Lewy Body Dementia Society, 2015). Cholinesterase inhibitors are long-term drugs so it may take time to see improvements in symptoms. These medications are safe and tolerated well in individuals with LBD (LBDA, 2016c; Lewy Body Dementia Society, 2015). Cholinesterase inhibitors should be discontinued if cognitive improvement is not possible due to progressing severity of dementia or if side effects are intolerable.

A more recent pharmacological intervention for LBD is the use of N-methyl-D-receptor antagonists that is commonly used in AD and PD (Larsson et al., 2011;

Shagham, 2009). NMDA for example, Ebixa (Memantine HCl), is used in moderate to severe stages of dementia (Shagham, 2009). These medications can be used when cholinesterase inhibitors are ineffective or the person has a sensitivity to them (LBDA, 2016c). NMDA medications may slow the loss of learning and memory skills such as toileting and dressing, improving overall quality of life and functional capacity of individuals with LBD (Larsson et al., 2011; Shagham, 2009). Discontinue when there is no longer any potential to preserve cognitive functioning or side effects become intolerable (see Table 2 in Appendix 2).

Levodpa-carbidopa, such as Sinemet is a combination medication that is commonly used with LBD (LBDA, 2016c; Lewy Body Dementia Society, 2015). The carbidopa increases the uptake of levodopa to improve motor symptoms such as restless leg syndrome, rigidity, and tremors (Lewy Body Dementia Society, 2015). Carbidopa controls Parkinsonism with lower doses of levodopa. The low doses of levodopa decreases the incidence of nausea and vomiting experienced with levodopa alone, allows for more rapid titration and a better response to levodopa. This medication is the initial treatment protocol for PD and is beneficial for management of Parkinson symptoms in LBD (LBDA, 2016c; Lewy Body Dementia Society, 2015). Medications containing levodopa can cause increased hallucinations so they may not be recommended if motor symptoms are mild (LBDA, 2016c). Levodopa-carbidopa should be started at the lowest dose and titrated slowly to allow for close monitoring of adverse effects (LBDA, 2016c; Lewy Body Dementia Society, 2015). Dosing should be kept at the lowest effective level to control symptoms and adverse effects (LBDA, 2016c; Lewy Body Dementia Society,

2015). Dosage depends on whether the person is presently taking levodopa. The dosage of levodopa should be decreased if involuntary movements occur, as this should be regarded as a sign of levodopa toxicity and an indicator of overdosing. Discontinue if Parkinson symptoms are not controlled and/or neuropsychiatric symptoms and confusion worsen.

Benzodiazepines for example, Clonazepam (Klonopin) are used to treat REM sleep disorder and restless leg syndrome (Vallerand & Sanoski, 2015). The individual may have paradoxical episodes of sedation and agitation that may result in discontinuation (LBDA, 2016c). Discontinue if there is worsening of cognitive symptoms, anxiety, paradoxical agitation and sedation, falls, and impulsive behavior.

Typical antipsychotics are often used to manage the behavioral and psychological features demonstrated in other types of dementia, but with LBD these medications are never used because they produce severe and fatal side effects known as neuroleptic sensitivity and neuroleptic malignant syndrome (Culo et al., 2010; LBDA, 2016c; McKeith et al., 2005; Walter et al., 2014). Neuroleptic sensitivity results in worsening of cognitive symptoms, hallucinations, and Parkinsonism and occurs in up to 50% of LBD patients treated with atypical antipsychotics (LBDA, 2016c). Neuroleptic malignant syndrome is a rare life-threatening adverse effect that produces symptoms of fever, generalized rigidity, and breakdown of muscle tissue that can result in kidney failure and death (LBDA, 2016c).

Atypical antipsychotics can be used to treat hallucinations and/or delusions that occur in LBD (Culo et al., 2010; LBDA, 2016c; Lewy Body Dementia Society, 2015). Extreme caution and close monitoring is required when atypical antipsychotics are prescribed because neuroleptic sensitivity and neuroleptic malignant syndrome are possible (LBDA, 2016c; Lewy Body Dementia Society, 2015). The recommended atypical antipsychotics to be prescribed are Quetiapine and Clozapine in this order (LBDA, 2016c; Lewy Body Dementia Society, 2015; McKeith et al., 2005; Walter et al., 2014).With quetiapine, changes can occur to blood glucose, therefore regular blood sugar checks should be ordered to monitor sugar levels. With clozapine blood monitoring for agranulocytosis is required. Atypical antipsychotics are discontinued if there is worsening of Parkinson and cognitive symptoms and increased sedation is noted. These medications are only used if long-term cholinesterase inhibitors have been ineffective or better behavioral control is warranted (LBDA, 2016c; Lewy Body Dementia Society, 2015; McKeith et al., 2005; Walter et al., 2014). When atypical antipsychotics are prescribed, the lowest dose should be used for the shortest amount of time (LBDA, 2016c; Lewy Body Dementia Society, 2015; McKeith et al., 2005; Walter et al., 2014). Atypical antipsychotics are safer than typical antipsychotics, but there is no antipsychotic medication that is absolutely safe for the management of LBD behavioral symptoms since all antipsychotics increase the chance of death in people with dementia (LBDA, 2016c; Lewy Body Dementia Society, 2015).

Certain medications should also be avoided in the management of LBD. If cholinesterase inhibitors are effective, atypical antipsychotics are not prescribed because

they have serious side effects including death (LBDA, 2016c). Atypical antipsychotics Risperidone and Olanzapine, should be avoided as they have an increased likelihood of increasing side effects such as increased Parkinson symptoms, sedation, and orthostatic hypotension (LBDA, 2016c). As well, the following medications used with Parkinson's disease should be avoided: Amantadine, Catechol-O-methyltransferase (COMT) inhibitors (ex: Entacapone), Monoamine oxidase (MAO) inhibitors (ex: Selegiline), and anticholinergics (ex: Benztropine) because they worsen cognitive impairment. Dopamine agonists such as Pramipexole and Bromocriptine should also be avoided because they cause excessive daytime sleepiness and swelling of the legs (LBDA, 2016c). It is important to also avoid over-the-counter sleep agents such as Tylenol or Advil PM and bladder control medications may cause agitation (LBDA, 2016c).

It is evident that LBD symptom management requires a complex and different pharmacological approach than with other dementias to effectively manage the symptoms of the disease and improve quality of life.

The studies by Culo et al., (2010) and Larsson et al., (2011) have strong randomized control design and quality which is not a common finding in LBD research. Even though sample sizes are small, the results are beneficial because they confirm that not all types of dementia can be pharmacologically managed the same. Pharmacological treatments used in AD have the potential to cause neuroleptic sensitivity in LBD resulting in worsening of disease symptoms.

The lack of evidence regarding pharmacological and non-pharmacological management of LBD is problematic as this can lead to problems with care delivery and quality of life. Specific education concerning pharmacological and non-pharmacological management of LBD symptoms is of utmost importance to ensure that interventions do not negatively impact quality of life.

The Challenge of Providing a Differential Diagnosis of LBD

A lack of awareness among health care professionals regarding LBD is a common theme in the research (Galvin et al., 2010a; Galvin et al., 2010b; Leggett et al., 2010). Families have described the challenge of getting a diagnosis of LBD for a loved one (Galvin et al., 2010a; Galvin et al., 2010b; Leggett et al., 2010). Therefore, it is reasonable to assume that the difficulty of getting a diagnosis is indicative of a lack of awareness regarding LBD among health care professionals. The research consistently demonstrated that there was a two year lag between onset of symptoms and a LBD diagnosis which could have been the result of physicians lacking clinical familiarity with LBD diagnostic criteria (Galvin et al., 2010b; Leggett et al., 2010). There is no information in the literature related to nurses' knowledge of LBD; however, information does exist regarding nurses' knowledge and general dementia care (Broughton et al., 2011; Crater & Hughes, 2012; Furaker & Nilsson, 2009; Page & Hope, 2013; Robinson et al., 2014). Furthermore, based on an analysis of the literature there is no research to demonstrate quality care of LBD residents in LTC facilities.

The overlapping symptoms between LBD, AD, and PD complicate the diagnosis and care delivery process. There is little research regarding when the symptoms of LBD and AD specifically occur in the disease trajectory, consensus on diagnostic criteria for LBD, and healthcare provider knowledge of the disease. Health care professionals have trouble diagnosing LBD, and nursing care provided to these individuals in LTC is compromised by lack of awareness among nursing staff related to LBD.

Walter et al., (2014) identifies the common characteristics between LBD, AD, and PD according to the DSM-5. LBD occurs more commonly in men over 60 years of age with no family history of the disease. The issue of family history is contradicted in the research (LBDA, 2015a). The hallmark symptom of LBD is fluctuating cognition, specifically attention and alertness, along with early stage symptoms of recurrent and vivid visual hallucinations, and Parkinsonism within one year of diagnosis. In contrast, AD occurs equally in men and women over 60 years of age and is more likely with a family history of the disease. AD does not have fluctuating cognition; the hallmark symptom is short-term memory loss and early stage symptoms consist of recall and learning deficits and recent orientation deficits. Furthermore, the hallmark symptom of PD is tremors and early symptoms consist of motor dysfunction, visual hallucinations, and executive dysfunction. In late stages of LBD, AD, and PD the following symptoms are common: agitation, aggression, memory loss, apraxia, dependency for ADLs, and executive and visuospatial deficits.

Pathologically, LBD and PD are characterized by Lewy body protein deposits in various areas of the brain and a lack of acetylcholine and dopamine neurotransmitters. In LBD, the sequence of changes in neurotransmitters determines the type: DLB or PDD (LBDA, 2016b). In DLB, the neurotransmitter acetylcholine is decreased first which produces the fluctuations in alertness and confusion (Walter et al., 2014). This is followed by a decrease in dopamine, which produces the Parkinsonian symptoms (Walter et al., 2014). In PDD, the neurotransmitter dopamine is affected first which produces the movement symptoms. This is followed by a decrease in acetylcholine, resulting in cognitive changes (Walter et al., 2014). Pathologically, in AD neuronal plaques and neurofibrillary tangles occur throughout the brain with deficits of the neurotransmitter acetylcholine (Alzheimer Society of Canada, 2015c).

It must be noted that the studies by Galvin et al., (2010a), Galvin et al., (2010b) and Leggett et al., (2010) were of weak design but moderate quality and were all based on a national internet survey from the Lewy Body Dementia Association. Each study used the results of a survey with the same population to examine different aspects of the caregiver experience, which is a major limitation. The respective studies had large sample sizes, but self-reported data collection instruments were also a limitation of the studies. However, these studies exhibit relevant findings regarding the lack of awareness in health care professionals related to LBD and highlight the need for additional informational resources on the disease (Galvin et al., 2010a; Galvin et al,. 2010b; Leggett et al., 2010).

Understanding the experiences of families as they progress along the LBD continuum could be an important influence directing education needs and resources for healthcare professionals (see Tables 7, 8, 9 in Appendix 1). The studies by Galvin et al., (2010a); Galvin et al., (2010b), and Leggett et al., (2010) further explained that the lack of communication and resources surrounding LBD is also a challenge for families. Increasing awareness will lead to early diagnosis of LBD and appropriate management of the disease and better care when placed in LTC facilities. As well, increased awareness among nursing staff in LTC will provide more support to caregivers of individuals with LBD. Receiving adequate support from health care professionals will help to enhance quality of life for individuals with LBD. LBD is beginning to be recognized as a separate entity from other types of dementia especially AD, therefore it is essential to increase awareness of nurses in LTC to ensure adequate and efficient management of the disease (Galvin et al., 2010b; Leggett et al., 2010).

A LBD resource manual addressing specific clinical manifestations, non-pharmacological and pharmacological treatment options, as well as other relevant evidence-based information has the potential to improve resident-centered care and quality of life for individuals with LBD. The manual will increase awareness of LBD among nursing staff in LTC facilities so that care needs will be holistic, individualized, and based on evidence-based practices.

Theoretical Framework

The LBD resource manual for nursing staff in LTC will be developed in accordance with Knowles' Adult Learning Theory so that learning is self-directed, practical, and relevant (Chesbro, 2002; Milligan, 1997; Mitchell & Courtney, 2005). Eastern Health defines nursing staff as Registered Nurses, Licensed Practical Nurses, and Personal Care Attendants. The resource manual will be developed through an interactive consultation process with nursing staff and management at rural Avalon Eastern Health. The newly acquired knowledge from the manual will increase nursing staff knowledge related to LBD care. As adult learning is the primary focus of the resource manual, the Adult Learning Theory is the most appropriate to use to guide the development of the manual and to promote knowledge enhancement.

The six basic principles of Adult Learning Theory will be adhered to in the development of the manual (Chesbro, 2002; Milligan, 1997; Mitchell & Courtney, 2005). The six principles include self-concept, experience, readiness to learn, orientation to learning, motivation to learn, and relevance. The first principle, self-concept, requires the learner to be involved in the planning and evaluation of the resource manual so that learning is self-directed. The second principle, experience, indicates that life experiences provide a basis for adult learning. The third principle, readiness to learn, indicates that learning is more likely to occur if the content is relevant and realistic to job performance and constructed so that it coincides with the learners' readiness to progress. The fourth principle, orientation to learning, specifies that immediate application of new knowledge and problem-solving are central to learning. The fifth principle, motivation to learn, assumes that internal factors promote learning for adults. The sixth principle, relevance,

specifies that adults need to know why they need to learn something new. Consultation and collaboration with nursing staff and management using a pre-survey to discover what the staff know, what they need to know, and how they want the information presented, and explaining to nursing staff the importance of this information to dementia care practice, along with a post-evaluation of the material presented in the manual will address the following principles of Adult Learning Theory: self-concept, readiness to learn, motivation to learn, and relevance. The Adult Learning Theory principles of experience and orientation to learning will be addressed through the use of case studies and pre- and post-tests which will build upon staff experiences and knowledge base through active learning and problem solving.

Benefits of a Resource Manual

A resource manual is a form of self-directed learning that correlates to the principles of Adult Learning Theory. Carcich and Rafti (2007) and Sparling (2001) are in agreement that there are many advantages of a resource manual. As nurses are expected to be committed to life-long learning, a resource manual is a useful tool for continued competency (Carcich & Rafti, 2007; Sparling, 2001). The LBD resource manual will be easily accessible and can be reviewed at the convenience of the staff, thereby promoting flexibility and portability of the manual as a learning tool (Carcich & Rafti, 2007; Sparling, 2001). As well, the nursing staff will be assuming responsibility for their learning by using the resource manual when time permits and progressing through the contents of the manual at their own pace (Carcich & Rafti, 2007; Sparling, 2001).

Overall, the resource manual is less costly than other forms of educational delivery and can reach many members of nursing staff, thereby promoting high rates of participation in the learning process (Sparling, 2001). Likewise, the use of the resource manual is well supported by research and is the most common chosen method of continued education for nurses (Sparling, 2001). The LBD resource manual will be maintained and updated by the Clinical Nurse Specialist in rural Avalon Eastern Health as this is her specialty area and she is responsible for nursing staff education in LTC settings.

The LBD resource manual will be beneficial to Eastern Health because it will increase knowledge among nursing staff in LTC regarding LBD to improve care delivery. Improving knowledge of nursing staff related to LBD will reduce health care costs because nursing staff in LTC will be more informed therefore, immediate care needs of residents will be addressed and managed more effectively (PHAC, 2014b). As well, better resident-centered care will positively impact quality of life for residents, families, and nurses because the disease symptoms will be more effectively managed. Additionally, nursing staff can transfer their knowledge regarding LBD to other healthcare professionals and families to increase disease awareness (Galvin et al., 2010a; Galvin et al., 2010b; Leggett et al., 2010).

Conclusion

The literature review reveals that LBD has a significant impact on quality of life, and there is a gap in disease-related knowledge in health care professionals. As evidenced in the literature, there is a lack of awareness concerning diagnosis and management of

LBD among health care professionals in general (Galvin et al., 2010a; Galvin et al., 2010b; Leggett et al., 2010). Furthermore, there is a lack of literature related to nursing knowledge of LBD in LTC specifically and the quality of care for these residents in LTC. The literature also demonstrates that there is an apparent overlap of symptoms between LBD, AD, and PD which may lead to misdiagnosis or underdiagnosis of LBD (Barber, Panikkar, & McKeith, 2001; McKeith, Perry, & Perry, 1999; Oliveria, Sampaio, Chen, & McKeith, 2001). Furthermore, it was acknowledged that the use of pharmacological options appropriate to AD has the potential to negatively impact quality of life in individuals with LBD (Culo et al., 2010; Larsson et al., 2011; McKeith, 2004). The literature strengthens the need for more educational resources for nursing staff related to LBD to lessen the knowledge gap regarding the disease in clinical practice in LTC. Developing a LBD resource manual for nursing staff in LTC based on evidence-based practices will be the first step toward improving resident-centered care for individuals with LBD. It is hoped that quality of care will be improved by addressing this lack of awareness in nursing staff. As a result, nursing staff will broaden their knowledge base and positively influence quality of life for individuals diagnosed with LBD in LTC. As the aging population is increasing and rates of LBD are expected to increase, it is imperative that nurses in LTC endeavor to incorporate evidence-based practices regarding LBD into care delivery. The LBD resource manual will be a fundamental tool in the care of individuals with LBD in LTC.

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Appendix

Table 1: Study Examining Neuropsychiatric Symptoms in DLB

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
• "Treating neuropsychiatric symptoms in dementia with Lewy bodies" by Culo et al., (2010) • **Objective:** To investigate the tolerability and efficacy of citalopram and risperidone in the treatment of behavioral and psychotic symptoms in patients with DLB and AD.	• n=31 DLB, n=66 AD • Psychiatric Institute, PA, 2000-2004 • **Inclusion criteria:** dementia and moderate-severe behavioral/psychotic symptoms, 3 or > on agitation or psychosis item Neurobehavioral Rating Scale • **Exclusion: criteria:** extensive exclusion criteria	• Prospective, randomized double-blind, parallel treatment design • 1 capsule bedtime x 3 days, increased to 2 a day • After 2 wks, 2 more increases up to 4 a day • Increases separated by 2 wks. • Assessed at randomization, q2 wks and at termination. • NPI, E-BEHAVE-AD, MMSE	• DLB patients poorer outcome, 67.7% DLB and 50% AD dropout rate due to intolerability • Dropout between groups or between DLB patients treated with citalopram or risperidone did not differ significantly. • DLB patients had minimal improvement or worsening. • Total side effect burden significantly higher in DLB	Strengths: • Ethics approval • Informed consent • Stratified randomization of patients • Trained raters • Appropriate statistical tests for level of data • *P*= 0.05, two tailed **Limitations:** • Small sample size • Reliance on clinical diagnosis rather than autopsy confirmation of cases. • Loss to follow up • Conflicts of interest declared	• Strong design • Strong quality • Extrapolation of evidence • Moderate generalizability • Patients with DLB and neuropsychiatric disturbances show minimal benefit when treated with atypical antipsychotic or SSRI antidepressant. • Future studies should identify other treatments that are tolerable and efficacious.

Table 2: Study Examining Quality of Life and Memantine in DLB and PDD

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
• "Quality of life and the effect of memantine in dementia with Lewy bodies and Parkinson's disease dementia" by Larsson et al., (2011) • **Objective:** To investigate QOL and the effect of memantine treatment in patients with LBDs.	• n=36 placebo • n=35 memantine • Sweden, Norway, UK, 2005-2008 • Random assignment to memantine and placebo • Assessed at baseline, 12 wks and 24 wks • QOL-AD given to patients and caregivers • Inclusion criteria: DLB or Parkinson's diagnosis; MMSE score of 12 or >	• Secondary analysis of randomized controlled, double blind, placebo controlled study design • Memantine 5mg in morning then up to 20 mg by week 4. • Cholinesterase inhibitors, antiparkinsonia antidepressants, anxiolytics, antipsychotics meds were allowed to be taken by participants during study	• Caregiver-rated QOL improved significantly when treated with memantine particularly aspects of body functions. • DLB and PDD might benefit globally from using Memantine.	**Strengths:** • Ethical approval • Informed consent • Valid and reliable instruments • Appropriate statistical tests for level of data • $P < 0.05$, two tailed • First study of how pharmacological intervention may impact QOL in DLB and PDD **Limitations:** • Small sample • Reduced statistical power • Several patients lost to follow-up • Response shift phenomenon where QOL perception changes with health • Polypharmacy	• Strong design • Moderate quality • Extrapolation of evidence • Moderate generalizability • No conflict of interest declared • Memantine can improve QOL for patients with DLB and PDD. • Future studies should have larger samples and additional instruments, and intervention studies using QOL as primary outcome measure

Table 3: Study Examining Attention and Fluctuating Attention in LBD and AD

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristic)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
• "Attention and fluctuating attention in patients with dementia with Lewy bodies and Alzheimer disease" by Ballard et al., (2001) • **Objective:** To investigate attention and fluctuating attention in DLB and AD patients.	• n=85 DLB, n= 80 AD, 35 spouse controls • dementia care registry, England • patients matched on MMSE scores • **Inclusion criteria:** LBD, AD	• Cohort analytic design • Cognitive Drug Research Computerized Assessment System for Dementia Patients Computerized Neuropsychological Battery Informed consent • Ethics approval • Descriptive statistics	• DLB significantly more cognitively impaired than AD on all tests • Neuropsychological and clinical observations strongly suggest DLB patients experience great difficulty in sustaining attention • Both groups significantly more impaired than controls for all comparisons other than cognitive reaction time • deficits of attention worsened with severe dementia for both groups	**Strengths:** • Statistical tests appropriate for data collected • Significance $P <$ .001 • Use of control group • Groups well matched on severity of cognitive impairment **Limitations:** • More females in AD group • Small sample • No random sampling • Selection bias	• Moderate design • Moderate quality • Moderate generalizability • Extrapolation of evidence • Findings indicate that the slowing of cognitive processing, attention and fluctuating attention are significantly more pronounced in DLB than AD

Table 4: Study Examining Early and Presenting Symptoms of Dementia with Lewy Bodies

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
• "Early and presenting symptoms of dementia with Lewy bodies" by Auning et al., (2011) • **Objective:** To explore the presenting and early and presenting symptoms of dementia with Lewy bodies (DLB).	• n = 61 DLB • n = 109 AD • 5 outpatient dementia clinics, Western Norway 2005 – 2007 • **Inclusion criteria:** DLB and AD , MMSE >20 • **Exclusion criteria:** acute delirium or confusion, terminal illness, recently diagnosed major somatic illness, previous bipolar or psychotic disorder.	• Retrospective cohort analytic design • NPI tool • Clinical Assessment of Cognitive Function or Mayo Fluctuation Scale assessed cognition • Standardized carer survey • Diagnosed by two clinicians	• Memory impairment (57%), visual hallucinations (44%), depression (34%), and problem-solving difficulties (33%) most common presenting DLB symptoms • Visual hallucinations (77%), parkinsonism (60%),delirium/ fluctuating cognition (43%), most common prior to first assessment	**Strengths:** • Ethical approval • Informed consent • Validated instruments • Significance $P < 0.05$ • Statistical tests appropriate for level of data **Limitations:** • Recall bias • Selection bias • No random sampling • Sensitivity/specificity of identifying presenting symptoms not assessed with a tool • No blinding or control • Small sample size	• Moderate design • Medium quality • Moderate generalizability • Extrapolation of evidence • DLB should be suspected in pre-dementia cases with visual hallucinations • Future studies should include broader range of participants. • Authors noted funding for some aspects of study i.e. manuscript preparation and travel.

Table 5: Study Examining Quality of Life and Determinants of Quality of Life

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
• "Patients with dementia with Lewy bodies have more impaired quality of life than patients with Alzheimer disease" by Bostrom et al., (2007). • **Objective:** To compare quality of life in patients with DLB and patients with AD; to investigate determinants of quality of life in DLB.	• n = 34 DLB, n = 34 AD • participants were matched on sex, age and cognitive function • Patients selected from 6 memory clinics in Sweden, Finland , Norway • **Inclusion criteria:** DLB, AD	• Prospective cross-sectional descriptive design • QOL assessed EQ-5D instrument and QOL-AD • Administered to patients and caregivers • Examined at home/memory clinic with primary caregiver • MMSE for cognitive function • NPI for behavioral disturbances • DLB patients examined for ADL needs	• Caregiver-reported QOL significantly lower than patient-reported QOL. • DLB patients significantly lower QOL. • 24% caregiver-rated EQ-5D scores corresponded to below zero values, thus LBD state worse than death. • NPI score, I-ADL, apathy, delusions, and living with caregiver were significant determinants of QOL in DLB.	**Strengths:** • Validity and reliability of instruments reported. • $P < 0.01$ • Same investigational protocol used with both groups • Appropriate statistical tests for level of data. • First study to describe QOL with DLB **Limitations:** • Recall bias • Selection bias • DLB and AD patients not selected from same population. • Small sample	• Weak design • Low quality • Low generalizability • Extrapolation of evidence • Consequences of DLB and AD differ greatly. • DLB diagnosis predicts an almost 3-fold increase in resource use and significantly lower QOL than AD. • Future studies should examine caregiver QOL , use intervention studies of QOL outcome

Table 6: Study Examining Functional Impairments in LBD and AD

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
• "More severe functional impairment in dementia with Lewy bodies than Alzheimer disease Is related to extrapyramidal motor dysfunction" by McKeith et al., (2006) • **Objective:** To compare functional impairments in DLB and AD and their relationship with motor and neuropsychiatric symptoms.	• n = 41 DLB n = 43 AD • Recruited from old age and psychological units, England. • **Inclusion criteria:** DLB, AD	• Cross-sectional descriptive design • NPI assessed neuropsychiatric symptoms • BADLS assessed functional impairment (caregiver rated tool) • UPDRS-III assessed extrapyramidal motor symptoms • MMSE assessed global cognitive function	• Greater overall functional impairment in patients with DLB • Total UPDRS III and total NPI scores significantly higher in DLB. • The highly significant correlation between total BADLS and total UPDRS III scores in DLB suggests that extrapyramidal motor dysfunction is a key factor	**Strengths:** • *P* <0.01 • Statistical tests appropriate for level of data • Informed consent • Study was funded **Limitations:** • Small sample • Little information on case selection and assessment as was previously described in another study. • No evidence of caregiver training to complete BADLS • Selection bias • No control	• Weak design • Moderate quality • Moderate generalizability • Extrapolation of evidence • Extrapyramidal motor dysfunction may lead to greater functional impairment in DLB. • Treating extrapyramidal motor symptoms may help to improve patient function and caregiver well-being.

Table 7: Study Examining Caregiver Burden and LBD

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitation	Conclusion and Rating
• "Lewy body dementia: caregiver burden and unmet needs" by Galvin et al., (2010a) • **Objective:** To ascertain the unmet needs of LBD caregivers and collect data to inform educational programming and enhance caregiver support.	• Used data from LBDA generated survey • 6 month period, Dec 2007-Apr 2008 • 962 caregivers • 83% of respondents completed entire survey	• Cross-sectional descriptive design • Internet-based survey • Zarit Burden Interview used to measure caregiver burden. • Asked to describe the first symptoms of LBD they noticed.	• Early symptoms: cognitive (48%), motor (39%) or both (13%) • Initial symptoms: memory (67%), gait (47%), attention/alertness (43%), hallucinations (43%), driving (42%), tremor/abnormal movements (38%) or depression (37%) • Increased dependence of patients early in disease, high burden levels • Lacking support from family, friends, health care providers.	**Strengths:** • Ethical approval • Met HIPAA requirements • Appropriate statistical tests used for level of data • Large sample size • High response rate **Limitations:** • 88% of respondents female • Validity and reliability of instrument not discussed. • No *P* value stated • No comparison • Selection bias • Recall bias	• Weak design • Moderate generalizability & quality • Extrapolation of evidence • Information and supports needed for caregivers and healthcare professionals. • Significant unmet needs for patients/caregivers • Improve education & social supports, so caregiver burden will decrease & outcomes improve for patients/caregivers

Table 8: Study Examining Caregiver Experience When Seeking LBD Diagnosis.

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
• "Lewy body dementia: The caregiver experience of clinical care" by Galvin et al., (2015b) • **Objective:** To explore caregiver perceptions of the difficulty obtaining a diagnosis for the patient and their experience with health care providers.	• Used data from LBDA generated survey • 6 month period, Dec 2007- Apr 2008 • 962 caregivers • 83% of respondents completed entire survey • Volunteer survey • Posted for 6 months online	• Cross-sectional descriptive design • Internet-based survey • Zarit Burden Interview used to measure caregiver burden. • Analysis focused on experiences with obtaining a LBD diagnosis, experiences after diagnosis, and perceptions of physician knowledge.	• Obtaining a LBD diagnosis often required multiple visits to multiple physicians causing delay in treatment • Over 40% reported it took more than 18 mths to get LBD diagnosis. • Alternate diagnosis were given first in 78% of cases • Reported physicians lacked knowledge on disease course, prognosis, and community resources.	**Strengths:** • Ethical approval • Met HIPAA requirements • Appropriate statistical tests for level of data • Large sample size • High response rate **Limitations:** • No validity and reliability of instruments noted • No *P* value stated • No comparison group • No data on hours/wk of care giving • Selection/recall bias • 88% respondents female	• Weak design • Moderate quality • Moderate generalizability • Extrapolation of evidence • LBD less likely to be recognized in primary care settings, more commonly diagnosed AD. • Early diagnosis gives caregivers and families access to more therapeutic interventions, time to plan for patient decline and access resources.

Table 9: Study Examining Caregiver Stress and Burden.

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
• "Stress and burden among caregivers of patients with Lewy body dementia" by Leggett et al., (2010) • **Objective:** To assess if disease and caregiving-related issues in LBD add to explanations of subjective burden more than stressors in other types of dementia; assess structure/predictors of burden and if similar to other dementias	• Used data from LBDA generated survey • 6 month period, Dec 2007- Apr 2008 • 982 caregivers responded to survey but 611 cases were eligible for this study • 83% of respondents completed entire survey • Volunteer survey • Posted for 6 months online	• Cross-sectional descriptive design • Internet-based survey • Zarit Burden Interview used to measure caregiver burden. • Analysis of experiences of behavioral and emotional problems, ADLs and mobility, isolation, difficulty finding/evaluating a physician, help received, and burden.	• Higher scores for LBD subjective burden • Dimensions of burden: role strain, personal strain, worry of performance. • Burden related to poorer health, LBD caregivers need adequate help and services. • Predictors of burden: behavioral/ emotional problems ADL assistance, isolation due to lack of awareness in public and MD.	**Strengths:** • Ethical approval • Met HIPAA requirements • Appropriate statistical tests for level of data • Large sample size • High response rate • Valid and reliable instruments • $P < .001$ **Limitations:** • No comparison group • No data on hours/wk that caregivers provide care • Voluntary sample • Selection bias • Recall bias • 88% respondents were female	• Weak design • Moderate quality • Moderate generalizability • Extrapolation of evidence • Caregivers of LBD patients have significant burden increased by noted predictors of burden. • Future interventions should consider predictors. • Increased public awareness of LBD needed

Appendix B – Consultation Report

Lewy Body Dementia: Consultation Report

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Table of Contents

Abstract

Purpose: To determine the objectives and content that will be included in an educational resource regarding Lewy body dementia (LBD) to be used by nursing staff in long-term care (LTC) to enhance resident-centered care.

Participants and Methods: Purposive sampling was utilized to include nursing staff from Harbour Lodge Nursing Home in rural Avalon Eastern Health as well as nursing leaders in Ontario, Alberta, and Nova Scotia. These participants have been interviewed regarding LBD education at the LTC facilities where they are employed. These individuals are key informants because they have experience working with residents with LBD in LTC settings.

Data Management and Analysis: The data obtained was coded into categories and comparisons made to create common themes. The data collected then created the foundation for this consultation report.

Ethical Considerations: An information letter was sent to each participant outlining the purpose of the consultation and full disclosure of how the data collected would be utilized to develop the LBD educational resource. Verbal permission to participate was obtained and confidentiality was ensured. Ethical approval was not needed for these consultations.

Findings: Nursing leaders and nursing staff indicate that there is a lack of awareness and a lack of educational resources regarding LBD in LTC settings. Nursing staff in LTC believe that current and relevant LBD educational resources based on evidence-based

practices will improve resident centered care and quality of life for residents with LBD in LTC. Through the consultation process it has been determined that the best type of educational resource to present the LBD information to nursing staff in LTC will be a brief presentation and a resource manual.

Lewy body dementia (LBD) is ranked as the second most common type of dementia in Canada (Alzheimer Society of Canada, 2015a). As the population ages in Canada, it is estimated that those diagnosed with dementia over 65 years of age will double from 310,000 in 2011 to 639,000 by 2013 (Public Health Agency of Canada [PHAC], 2014a, p.66). It can be concluded that there will be a 90% increase in the number of new dementia cases in Canada (360 to 530 cases per 100,000; PHAC, 2014a, p.68).

Living with LBD is challenging due to the early onset and rapid progression of symptoms, especially fluctuating cognition, hallucinations and aggression (McKeith et al., 2005; Walter, Edwards, Griggs, & Yehle, 2014). Diagnosis of LBD is challenged by the overlapping symptoms with other forms of dementia, especially AD and PD (Walter, Edwards, Griggs, & Yehle, 2014). Early admission to LTC often occurs in individuals with LBD because they become dependent at an early stage and the hallucinations and behavioral symptoms are better managed in this setting (PHAC, 2014b, p.8). Managing LBD is challenging because pharmacological interventions used with other types of dementia are often ineffective with LBD (Larsson et al., 2011). As well, there is limited literature available regarding non-pharmacological interventions to manage LBD.

Therefore, education on both non-pharmacological and pharmacological interventions as well as diagnosis is needed to better manage the clinical symptoms of LBD. Controversy exists surrounding the use of antipsychotics because these drugs can cause worsening of disease symptoms in individuals with LBD (Culo et al., 2010).

In Eastern Health LTC facilities, nursing staff receive general dementia education but nothing specific to LBD. Nursing staff in LTC need to acquire new knowledge on this disease as one can only conclude that staff have been and will continue to be caring for LBD residents on a regular basis in the future. Presently, nursing staff feel care is compromised in LTC settings for residents with LBD because nursing staff lack awareness and understanding of the disease, thus care is not effectively resident-centered. Developing educational resources specific to LBD will promote effective differentiation between LBD, Alzheimer's disease (AD), and Parkinson's disease (PD) which will result in more resident-centered care and better resident outcomes. As a result, it is expected quality of life for LBD residents in LTC will improve.

The literature review indicated that there are numerous issues related to the diagnosis and care of individuals living with LBD: lack of awareness about LBD among healthcare professionals; problems differentiating between LBD, AD, and PD due to overlapping symptoms, which impacts resident-centered care; comparatively reduced quality of life for LBD residents, due to early dependency because of the rapid progression of neurological and psychiatric symptoms and functional impairments; little research on the non-pharmacological interventions to manage LBD, but current evidence

suggests that similar interventions used with other types of dementia, such as music therapy and reminiscence, are effective; and pharmacological interventions such as antipsychotics versus other medications are controversial (Auning et al., 2011; Ballard et al., 2001; Culo et al., 2010; Galvin et al., 2010a; Galvin et al., 2010b; Larsson et al., 2011; Leggett, Zarit, Taylor, & Galvin, 2010; McKeith, 2004; McKeith et al., 2005; McKeith et al., 2006; Neef & Walling, 2006; Yuhas, McGowan, Fontaine, Czech, & Gambrell-Jones, 2006; Zupancic, Mahajan, & Handa, 2011)

The consultation process was formulated based on the results of the literature review. The consultation findings correlate to those of the literature review. The consultations helped identify areas of concern for nursing staff in LTC regarding LBD and will guide the development of the proposed LBD educational resources. The proposed 30 minute presentation and resource manual related to LBD will allow nursing staff in LTC to receive education that pertains to current and relevant evidence-based practices for care delivery to residents with LBD. Eastern Health defines nursing staff as Registered Nurses, Licensed Practical Nurses, and Personal Care Attendants. The hope is that the educational resource will enhance resident-centered care for individuals with a diagnosis of LBD. Key stakeholders at rural Avalon Eastern Health and Harbour Lodge Nursing Home will be invited to participate in the 30 minute presentation and review the manual for content and general satisfaction. There will also be a variety of problem-solving tools utilized in the LBD educational resources, such as pre-post tests and case studies, to determine knowledge acquisition. The stakeholders will evaluate both the presentation and the resource manual so that revisions can be made accordingly.

Purpose of Consultations

(1) To determine the information needs of nurses related to LBD that should be included in the educational resource.

(2) To determine the existence of educational resources specific to LBD for nursing staff in LTC settings.

(3) To determine the content related to LBD that should be included in the educational resource.

(4) To determine how education related to LBD should be provided to nursing staff in LTC.

(5) To determine if educational materials from other Health Authorities in Canada are applicable to the care of LBD residents in LTC facilities in Newfoundland.

(6) To determine the approval of Eastern Health to incorporate a LBD educational resource into staff training into LTC settings.

Setting and Sample

Consultations occurred with nursing leaders and front-line nurses. It was planned that one leader from at least one LTC facility in two regions of Canada (Western and Atlantic) were going to be consulted. Leaders from two LTC sites in Ontario were going to be consulted because this province has a large population and a vast number of LTC facilities. As the consultations with nursing leaders progressed, one site in Edmonton, Alberta, one in Vancouver, British Columbia, one in Ontario (Waterloo), one in Halifax, Nova Scotia, and one within the rural Eastern Health Authority (Harbour Lodge Nursing

Home) were contacted to participate. In addition, nursing leaders were contacted in multiple sites throughout Ontario, but only one agreed to participate. A physician from urban Eastern Health Authority who specializes in neurocognitive disorders in geriatrics participated. As well, nursing staff on the dementia unit of Harbour Lodge Nursing Home (one senior and one junior RN, two senior and one junior LPN, and one senior and one junior PCA) were consulted because these individuals care for residents with LBD in LTC and will be involved in the implementation and evaluation of the practicum project, therefore their input is vital and practical. As well, a nurse leader at the largest Eastern Health LTC site in St. John's was contacted but did not participate. Another well-known physician who specializes in geriatric medicine and neurology in Nova Scotia was also contacted but did not participate.

Data Collection

An introductory email was sent to each potential participant outlining the project purpose, contact information of the MN student, and a request for their participation in the consultations. A different information letter was sent to local and out of province nurses (Appendices A and B). These individuals were requested to respond to the email in order to set up a convenient time for a telephone interview, or face-to-face interview for local participants only. A total of three local nursing leaders responded to the email in order to set up a time to conduct the interviews. An additional four leaders at out of province LTC sites responded and agreed to set up an interview time. There were seven

members of the nursing staff at a local LTC site that responded to the email and agreed to an interview time.

At the initiation of the interviews, participants were informed of the purpose of the interview and how the data collected would be utilized in the development of the LBD educational resource. Based on the literature review and my experience in LTC settings, two different sets of interview questions were developed to meet the needs of the key informants. One set of interview questions was for local and out of province nursing leaders (Appendix C) and another was developed for use with local nursing staff (Appendix D). The interviews were scheduled in 30 minute intervals and contained a series of open and closed ended questions. Notes were taken during the interviews and analyzed for content to identify exclusive categories and common themes. Member checking was used to ensure the data collected was accurate (Streubert and Carpenter, 2011). At the end of each question during the interview, a quick summary was done with the participant to ensure accuracy and validity of the data provided (Streubert & Carpenter, 2011). Alphabetic coding was assigned to each interview to ensure privacy and confidentiality, and the data may be shared with Dr. Anne Kearney, MN supervisor, in the final consultation report.

Data Management and Analysis

There were no interviews conducted in a face-to-face manner as all participants preferred the format of a telephone interview. At the initiation of the interview, verbal permission was sought and all questions or concerns of the participants were addressed.

Detailed notes were taken during the interviews, typed, and organized according to question response. These notes were summarized briefly with the participant after each question response to ensure validity and accuracy. The notes from the interviews were coded into mutually exclusive categories and comparisons were made on the basis of common themes (Streubert & Carpenter, 2011). This content analysis ensured that the most important points were identified and included in the consultation report. All participants were aware that the data would be analyzed and incorporated into the development of a LBD educational resource.

Ethical Considerations

The Health Research Ethics Review (HREA) Board screening tool was completed prior to the consultation process (Appendix E). The tool determined that the sole purpose of the consultations was for program development quality and evaluation, therefore review by an Ethics Board was not needed. Consent to participate was implied when informants responded to the email containing the information letter to arrange a convenient interview time. Full disclosure concerning privacy, confidentiality, and the use of data in the development of the LBD educational resource was outlined for participants. All interviews were conducted via telephone in a private office with the door closed to ensure confidentiality. All participants were alphabetically coded to protect their identity and interview details. The data was kept in a locked filing cabinet in the locked office of the MN student. At the end of the practicum project, all data will be shredded. There are no risks to participants during the consultation process, and all

participants were aware the process was voluntary. They were aware they could discontinue the interview at any time.

Key Findings

A total of 15 participants were interviewed. Two participants were in management roles within Eastern Health and one was a Clinical Nurse Specialist. One participant was a physician who is well known for his work in geriatrics and dementia in Eastern Health. Four participants were nurses who were either managers, directors of care, or educators in LTC facilities throughout Canada that cared for dementia residents. The remaining seven were a mixture of nursing staff in rural Avalon Eastern Health. Data analysis identified five major themes: (a) Lack of education resources specific to LBD in LTC; (b) Knowledge gaps of nursing staff in LTC regarding LBD; (c) Lack of diagnosis and care specific to individuals living with LBD; (d) Preferred learning styles of nursing staff related to LBD in LTC, and (e) Impact of LBD education on care delivery in LTC.

Lack of Education Resources Specific to LBD in LTC

The interview results across Canada indicate there is a lack of educational resources in LTC that focus specifically on LBD. Generally, the topic of LBD is covered briefly in staff orientation to LTC sites upon hiring. Out of province sites focus mainly on programs known as Supportive Pathways related to individualized care for AD, with only a brief discussion on definitions of other dementia types. The LTC site in Nova Scotia trains everyone employed there using a three day program called PIECES, which was derived from the Alzheimer Society of Ontario. The PIECES program is an initiative that

promotes understanding and enhancing care for individuals with AD with physical, cognitive and behavioral needs (Alzheimer Society of Ontario, 2015). In Eastern Health, nursing staff in LTC sites complete a 7.5 hour course in Gentle Persuasive Approaches (GPA) and a 6 hour Dementia Care Orientation related to responsive behaviors in Alzheimer's disease (AD), under the direction of the Clinical Nurse Specialist. Education related to dementias other than AD is mainly self-initiated online by nursing staff through internet websites. The physician referenced a resource called First Link created by the Alzheimer Society of Canada that he often talks to nursing staff informally about to better inform them of dementia care services. The First Link program is a referral system that enables individuals diagnosed with dementia and their families to make informed choices through receiving support and education regarding dementia (Alzheimer Society of Canada, 2015b). Nursing staff noted that within Eastern Health there is a family handbook often utilized by staff to increase their knowledge base of dementia but, yet again, this handbook very generally discusses dementia, not the specific types.

There were no resources in Newfoundland or most of Canada to be shared, as the nursing leaders indicated that well known dementia organization websites such as the Alzheimer Society of Newfoundland and Canada were the tools accessed to aid discussions with nursing staff. The only site that offered to send a resource used in LBD education was the facility in Nova Scotia. The resources that are to be sent are related to the PIECES program. All participants stated there was a need for further resources specific to LBD to enhance staff knowledge regarding the disease because more residents with LBD may be seen in LTC settings in the future.

Knowledge Gaps of Nursing Staff in LTC Regarding LBD

There were numerous areas of knowledge deficits related to LBD evident in the interview findings. The main learning needs identified by the participants focus on the following areas: What is LBD? What are the signs and symptoms of LBD that distinguish it from other dementia types? What are the risks for being diagnosed with LBD? What are the pharmacological and behavioral interventions to manage symptoms? A need for a directory for, and quick access to, Canadian resources on LBD was also identified. All participants stated there was a lack of awareness, knowledge, and understanding of LBD among nursing staff, which prevents effective nursing interventions related to resident-centered care. Members of the nursing staff were only aware of care approaches to be used with residents with AD rather than specific interventions for LBD. Both nursing leaders and nursing staff believe these knowledge deficits lead to frustrations for care providers in LTC and ineffective plans of care for residents.

With respect to pharmacological and behavioral management of LBD symptoms, a key concern is when to choose appropriate antipsychotics versus behavioral approaches to manage signs and symptoms. Nursing leaders indicated that non-pharmacological management is safer than antipsychotic use due to the negative effects from the medications, such as toxicity and worsening of cognitive symptoms. The nursing leaders feel that nursing staff need to be abreast of current and relevant alternatives to antipsychotic use, such as music therapy and aromatherapy, to better manage LBD residents' symptoms. The physician reported that most nursing staff are routinely trying

to manage LBD symptoms using pharmaceutical interventions meant for general dementia care, which are proving ineffective, especially the use of atypical antipsychotics to treat hallucinations. The physician reports that atypical antipsychotics such as clozapine and risperidone can worsen the behavioral symptoms of LBD but cholinesterase inhibitors are more effective. He cites experiences of nursing staff suggesting higher doses of atypical antipsychotics or alternative antipsychotics when caring for residents with LBD in LTC, which he feels also exacerbate the already challenging behaviors. With more education, nursing staff will be better able to differentiate the clinical manifestations of LBD from other types of dementia and provide appropriate interventions, thus encouraging resident and care plan re-evaluation to promote optimal care.

Lack of Diagnosis and Care Specific to Individuals Living with LBD

This theme is closely tied to lack of educational resources in LTC related to LBD and knowledge gaps among nursing staff related to LBD in LTC. The general consensus from nursing leaders and nursing staff is that not many residents in LTC are definitively diagnosed with LBD; they more or less are given a general umbrella diagnosis of dementia. As a result, this impacts the ability of nursing staff to provide resident-centered care to individuals in LTC. The key issue experienced by nurses was frustration with handling the hallucinations and behavioral symptoms, such as aggression, experienced by residents with LBD. Nursing staff feel that they are not adequately informed on the LBD disease process, therefore care is not individualized and quality of life is negatively

affected. The physician suggested that nursing staff are not aware of the subtle features of Parkinsonism in LBD and that a high incidence of falls early in dementia could be indicative of a LBD diagnosis. If nursing staff are more aware of the clinical manifestations of the disease, they will be more alert to subtle changes in the residents' disease state and notice the autonomic dysfunctions that happen early in LBD, which will aid diagnosis and promote more resident-centered care plans.

With experience, nursing staff become aware that the pharmacological interventions utilized with AD to manage hallucinations and behavioral symptoms are not as effective with those suffering with LBD. Nursing staff also explained that they notice a much faster physical progression of decline and more cognitive fluctuations in residents with LBD in LTC. Therefore, specialized care plans must be put into place containing relevant evidence-based information so that care approaches are current and effective. As well, the participants indicated that the lack of understanding experienced by nursing staff means that accurate and pertinent information related to a LBD diagnosis cannot be relayed successfully to families to aid in the coping process.

Preferred Learning Styles of Nursing Staff Related to LBD in LTC

During the interview participants stated that by addressing their needs in an educational resource, nursing staff will have enhanced knowledge of LBD, be more confident and competent in care delivery to residents with LBD in LTC and, as a result, care will be more resident-centered. In addition, it was indicated that quality of life and well-being for residents with LBD in LTC will improve. Nursing staff and leaders stated

that a presentation and resource manual was the preferred educational resource because it addressed many learning styles and best promoted retention of new material. A webinar was also suggested by a few members of the nursing staff, but others felt webinars were not interactive and did not promote learning. The only educational program that was discussed during the interview with local nursing staff was the GPA training which uses presentation, videos, and case studies to promote knowledge development. Nursing staff felt this same approach would work best with LBD educational resources as they were interactive, informative, and promoted retention of new information. Different approaches were not suggested for RNs versus LPNs versus PCAs in the development of the presentation and resource manual.

The main type of LBD educational resource identified by the participants is a 45 minute presentation addressing the key areas of concern, and a resource manual to be left on the units for easy access by staff. Participants stressed the importance of easy, quick reading educational resources with minimal medical terminology because time is so limited on the LTC units and not all members of the nursing staff have high levels of educational training, such as the PCAs. The PCAs do not have university level education; therefore medical based information must be kept simple and clear so that all nursing staff benefit from the LBD educational resources. As well, many participants suggested the idea of using case studies and videos during the presentation and in the resource manual to allow participants to apply new knowledge and problem-solve, which would promote retention of the new information.

Impact of LBD Education on Care Delivery in LTC

The participants were extremely pleased with the idea of a LBD educational resource for LTC settings as there is such a lack of awareness amongst nursing staff and a lack of resources on the disease in LTC. By increasing the knowledge base of nursing staff, participants believe that care delivery to LBD residents should improve and be more resident-centered, resulting in enhanced well-being and quality of life. As indicated by the physician, with increased knowledge of LBD, nursing staff will be more in tune to the accurate symptoms of LBD and use effective behavioral interventions, especially to control hallucinations. Furthermore, better management of the challenging behaviors related to LBD, such as hallucinations and behavioral symptoms, will improve the overall atmosphere of the dementia unit. Being better able to meet the specific needs of LBD residents will promote positive change on the LTC units, and over time these interventions will become regular practice on dementia units. Easy access to relevant LBD resources will permit nursing staff in LTC to tailor interventions to meet resident needs, therefore allowing nursing staff to see the resident beyond the diagnosis. Preliminary discussions with the Clinical Nurse Specialist indicate that she is supportive of using the LBD resource manual during nursing staff orientation within LTC facilities in rural Avalon Eastern Health. It was indicated the CNS would do periodic updates of the resource manual as necessary. Further discussions with the CNS will occur in the development phase of the project.

Conclusion

The findings of the consultation process are consistent with the literature regarding LBD. The consultation process demonstrated that nursing leaders, nursing staff, and physicians feel that there is a need for education specific to LBD in LTC settings. Several areas of concern were identified that negatively impact dementia care delivery and thus quality of life for individuals with LBD in LTC. These concerns are consistent with the literature review related to LBD. The information from both the literature review and consultation process revealed that further education is needed in LTC regarding LBD disease processes, diagnostic criteria, and clinical manifestations, as well as behavioral and pharmacological approaches to promote more resident-centered care plans for residents with LBD. Canadian resources were recommended to be included in the LBD resource manual.

The proposed 30 minute presentation and resource manual will address selected needs determined by the literature review and consultation process. Currently, the presentation and the resource manual will be delivered to nursing staff on the locked dementia unit at Harbour Lodge Nursing Home as this is where the majority of dementia residents reside. The hope is that the presentation will introduce the basic information related to LBD, and the manual will be more extensive and readily available to staff at all times during work hours. The manual and presentation can also be utilized and updated by the Clinical Nurse Specialist for rural Avalon Eastern Health to use in training sessions for nurses in LTC as well as other health care settings.

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Appendix A

Information Letter for Leaders Outside of NL

To Whom It May Concern;

My name is Stephanie Hawco and I am currently completing my final practicum for the Master of Nursing degree at Memorial University. My supervisor is Dr. Anne Kearney, Associate Professor at the School of Nursing, Memorial University. The goal of my practicum is to develop an educational resource regarding the care of residents with Lewy body dementia (LBD) to be used by nursing staff in long-term care (LTC) facilities throughout Eastern Health Regional Authority. Effective resident-centered care will help improve quality of life for residents with LBD in LTC facilities.

As part of this practicum, I am conducting consultations with representatives from LTC facilities to determine the necessary information needed by nursing staff to promote knowledge development regarding LBD so that symptoms can be managed with resident-centered care interventions that will improve quality of life. I am requesting your input because you and your facility have been identified as leading edge in the development of programs related to LBD. A 20-30 minute telephone interview will be conducted to assist in the development of a LBD educational resource. The privacy of all individuals will be protected. There will be no identifying information provided that will link participants to the interview responses provided.

It is my hope that you will be willing to share your knowledge, and/or any other relevant material related to LBD that is utilized at your facility. The information collected through the consultation process along with a comprehensive literature review will be the basis of the LBD educational resource.

Participation in this project is voluntary. Please respond to the e-mail address below and indicate if you are willing to participate in the consultation process. If you agree to participate I will contact you to arrange a convenient time to conduct a short interview. If you do not feel you can contribute but know of someone with expertise in the area of LBD who may, then please share this email with them and invite them to contact me. I greatly appreciate your assistance and would be more than willing to share the results of the practicum project upon completion.

Thank you for your time and consideration.

Stephanie Hawco
Master of Nursing Student
Memorial University of Newfoundland
Email: steph@persona.ca

Appendix B

Information Letter for Local Nurses

To Whom It May Concern;

My name is Stephanie Hawco and I am currently completing my final practicum for the Master of Nursing degree at Memorial University. My supervisor is Dr. Anne Kearney, Associate Professor at the School of Nursing, Memorial University. The goal of my practicum is to develop a Lewy Body Dementia (LBD) educational resource regarding the care of residents with Lewy body dementia (LBD) to be used by nursing staff in long-term care (LTC) facilities throughout Eastern Health Regional Authority. Effective resident-centered care will help improve quality of life for residents with LBD in LTC facilities.

As part of this practicum, I am conducting consultations with representatives from LTC facilities to determine the necessary information needed by nursing staff to promote knowledge development regarding LBD so that symptoms can be managed with resident-centered care interventions that will improve quality of life. I am requesting your input because of your experience in providing care and/or education to residents living with dementia. A 20-30 minute telephone interview will be conducted to assist in the development of a LBD educational resource. The privacy of all individuals will be protected. There will be no identifying information provided that will link participants to the interview responses provided.

It is my hope that you will be willing to share your knowledge, and/or any other relevant material related to LBD that is utilized at your facility. The information collected through the consultation process along with a comprehensive literature review will be the basis of the LBD educational resource.

Participation in this project is voluntary. Please respond to the e-mail address below and indicate if you are willing to participate in the consultation process. If you agree to participate I will contact you to arrange a convenient time to conduct a short interview. If you do not feel you can contribute but know of someone with expertise in the area of LBD who may, then please share this email with them and invite them to contact me. I greatly appreciate your assistance and would be more than willing to share the results of the practicum project upon completion.

Thank you for your time and consideration.

Stephanie Hawco
Master of Nursing Student
Memorial University of Newfoundland
Email: steph@persona.ca

Appendix C

Interview Questions for Local and Out of Province LTC Leaders

1. a) What current training is required in your facility for nursing staff who work with LBD residents (if any)?

   b) What types of educational resources (i.e. pamphlets, presentations, etc.) are available?

   c) How effective are these educational resources?

   d) How would you change these educational resources?

   e) Are you willing to share these educational resources?

2. What are the current issues experienced by individuals with LBD in your LTC facility?

3. What are the experiences of nurses caring for individuals with LBD in LTC?

4. What do you think are the knowledge gaps/concerns of nurses regarding care delivery to individuals with LBD in LTC?
5. What would be important components to include in a LBD educational resource for nursing staff in LTC to improve care delivery?
6. How should information/education be provided to nursing staff?
7. How do you think education related to LBD can improve quality of life for individuals with LBD in LTC?

8. Is there anything else you would like to share to help develop an educational resource for nurses in LTC?
9. Can you recommend any cutting edge LTC facilities, or nursing leaders in LTC, that I should contact to help inform the development of an educational resource for LBD?

Appendix D

Interview Questions for Nursing Staff

1. a).What has been your experience of the special needs of individuals with LBD?

   b) What has been your experience of nurses' knowledge of LBD?

   c) What has been your experience of nurses' ability to care for individuals with LBD?

2. Do you have training specific to LBD at your facility? Or is the care related to this disease covered in general dementia care education?
3. Do you have resources available on the nursing units for staff to refer to regarding care delivery to LBD residents?
4. How are nursing staff kept current regarding changes to dementia care delivery to ensure care is resident-centered?
5. Do you feel there is a need for more specific education among the nursing staff regarding LBD?
6. How do you think specific education for nursing staff on LBD can impact care delivery?
7. What form of educational tool do you find to be most effective with nursing staff (i.e. pamphlets, presentation, etc.)? Do you think this would work for LBD?
8. What do you think are the key components to be included in a LBD educational resource for LTC?
9. Is there anything else you would like to add?

Appendix E

Health Research Ethics Authority Screening Tool

	Question	**Yes**	**No**
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review	□	■
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?	□	■
	IF YES to either of the above, the project should be submitted to a Research Ethics Board. **IF NO** to both questions, continue to complete the checklist.	□	□
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	■	□
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	□	■
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?	□	■
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?	□	■
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?	□	■

LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)		**1**	**6**
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	■ □	□
9.	Is the project intended to define a best practice within your organization or practice?	■ □	□
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	■ □	□
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	■ □	□
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?		**no**
LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)		**4**	**0**
	SUMMARY **See Interpretation Below**		

Interpretation:

- If the sum of Line A is greater than Line B, the most probable purpose is **research**. The project should be submitted to an REB.
- If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).

- If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at: http://www.hrea.ca/Ethics-Review-Required.aspx.

Appendix C – Lewy Body Dementia Resources for Nursing Staff in Long-term Care

Lewy Body Dementia:

A Resource Manual for Nursing Staff

In Long-term Care Settings

Prepared for Eastern Health

Harbour Lodge Nursing Home

August 30, 2016

Developed by:

© Stephanie Hawco BN RN

&

Dr. Anne Kearney

School of Nursing, Memorial University of Newfoundland

If you wish to make revisions to the resource manual, contact the primary author at the following email address steph@persona.ca. Revisions can be made but authorship must remain as Stephanie Hawco and Dr. Anne Kearney. Ensure that the primary authors are credited and the revised work is noted as being adapted from the original resource manual. The primary author may request a copy of revisions completed.

Table of Contents

b) Communication Strategies
c) Music Therapy
d) Reminiscence
e) Doll Therapy
f) Aromatherapy

Chapter 5: Resources: Organizational Websites

a) Resource descriptions

Appendix A – Case Studies

Appendix B – Test Your Knowledge – Post-test

Appendix C – Evaluation Survey

Appendix D – Presentation for Nursing Staff

References

Who Can Use the Resource Manual and Why?

This resource manual was developed following a review of the literature and from consultations with nursing management, Registered Nurses, Licensed Practical Nurses, and Personal Care Attendants in long-term care settings. The consultation process and literature review demonstrated there is a lack of awareness regarding Lewy Body Dementia (LBD) among nursing staff.[31, 32, 40, 45, 66]

This resource manual is designed to help nursing staff deliver care to residents who are diagnosed with LBD and residing in long-term care. It is a comprehensive and current resource that provides evidence-based information about dementia in general, LBD, pharmacological and non-pharmacological interventions, as well as professional resources related to LBD. The rationale of the resource manual is to enhance nursing knowledge regarding LBD to improve resident-centered care and quality of life for those diagnosed with the disease and living in long-term care.

How Can You Use This Resource Manual?

This resource manual is divided into five chapters which will provide detailed information on LBD. The manual can be used as an educational tool and as a reference tool in long-term care to help problem-solve when providing care to residents living with LBD. It can also be used by other staff at Eastern Health who collaborate in the care of residents with LBD to heighten understanding of the disease and its management.

The results of the consultation process indicated that nursing staff wanted two educational resources developed regarding LBD: a short presentation providing an overview of LBD and interventions for disease management; and a resource manual that provided more in-depth detail related to LBD, pharmacological and non-pharmacological interventions and useful resources to access additional information. As well, the nursing staff suggested the use of videos and case studies regarding LBD to promote problem-solving skills and enhance learning.

TEST YOUR KNOWLEDGE

BEFORE READING THE MANUAL, COMPLETE THE PRE-TEST ON THE NEXT PAGE TO DETERMINE YOUR KNOWLEDGE REGARDING LBD.

Test Your Knowledge – Pre-Test

Select True or False for each of the following statements:

1. Lewy body dementia (LBD) is more common in men. □ True □ False

2. The greatest risk for Lewy body dementia (LBD) is advanced age.
   □ True □ False

3. Lewy body dementia (LBD) is the second common type of dementia.
   □ True □ False

4. Lewy body dementia (LBD) can be dementia with Lewy bodies or Parkinson's disease dementia. □ True □ False

5. The hallmark symptoms of Lewy body dementia (LBD) are fluctuating alertness and confusion, visual hallucinations, and Parkinson motor symptoms.
   □ True □ False

6. An early symptom of Lewy body dementia (LBD) is delusions.
   □ True □ False

7. Acetylcholine is the only neurotransmitter affected in Lewy body dementia (LBD). □ True □ False

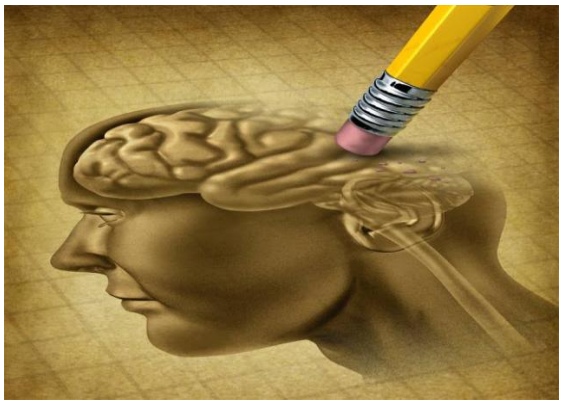
8. Amyloid plaques are found in the brain of individuals of Lewy body dementia.
   □ True □ False

9. The first line of treatment for the cognitive symptoms in Lewy body dementia is cholinesterase inhibitors. □ True □ False

10. Typical antipsychotics are safe to use in the management of LBD behavioral symptoms. □ True □ False

Answers can be found on page 75.

Chapter 1: Dementia



1a).What is Dementia?

Dementia is a disorder that affects the brain, especially cognitive abilities such as thinking, problem-solving and language.[4] It usually occurs in individuals over 65 years of age.[4, 74] Physical changes occur in the brain resulting in progressively worsening symptoms overtime.[10] There is no single known cause for dementia and the rate of disease progression varies among affected individuals. Usually, dementia will severely impact activities of daily living as the disease progresses.[4]

1b). Dementia Statistics

- Worldwide in 2015, 47.5 million people were living with dementia.[57]
- This number will triple within the next 35 years as the population advances in age.[57]
- In 2011, 747, 000 Canadians over the age of 65 years were living with dementia.[7]
- By the year 2031, it is expected there will be 1.4 million cases of dementia in Canada.[7]
- The risk for dementia doubles every five years after the age of 65 years.[7]
- $33 billion dollars a year is spent on dementia care in Canada.[7]

1c). Risk Factors for Dementia

- Risk factors are characteristics that increase the likelihood of developing dementia.
- There are modifiable and non-modifiable risk factors for dementia.[12]
- Modifiable risk factors can be changed but non-modifiable risk factors cannot.[12]
- Many of the modifiable risk factors such as smoking, high blood pressure, diabetes, and high cholesterol affect blood vessels which reduces blood flow to the brain.

Modifiable risk factors

1) **Smoking** – Quitting smoking can reduce the risk for dementia. Smokers have a 45% greater risk of developing AD.[12]
2) **High blood pressure** – Elevated blood pressure affects the cardiovascular system, therefore increasing the risk for dementia, especially vascular dementia.[12]
3) **Diabetes** – Individuals with type 2 diabetes are twice as likely to develop dementia.[12]
4) **High cholesterol** – Individuals with higher levels of total cholesterol are at increased risk for dementia. Treating high cholesterol levels will decrease dementia risk.[12]
5) **Obesity & physical inactivity –** Both factors increase the likelihood of developing high cholesterol, high blood pressure, and diabetes which elevates risk.[12]
6) **Alcohol –** Individuals who drink excessively (more than 3-4 drinks a day) have the highest risk of developing dementia due to toxic effects of alcohol on brain tissue.[12]

Those who drink moderate amounts of alcohol (1-2 drinks a day) have the lowest risk of developing dementia.[12] Not drinking alcohol at all puts one at a slightly higher risk of developing dementia because of the absence of the benefits of alcohol for a healthy heart.[12] However, the literature is controversial on the positive effects of alcohol on the cardiovascular system.

7) **Depression –** May be a risk factor or an early symptom of dementia. The literature is controversial on this topic.[12]
8) **Head injuries –** Individuals who experience severe or repeated head injuries are at increased risk for dementia because plaques and tangles can form in the brain.[12]
9) **Lower education** – Formal education is believed to lower the risk of dementia because higher educated individuals are more cognitively stimulated and are more likely to have healthy lifestyle practices. However, the amount and quality of education that lowers dementia risk is not clarified.[12]

Non- modifiable risk factors

1) **Age** – The risk of developing dementia increases with age, particularly after 65 years of age. Aging impairs the body's ability to repair itself which greatly impacts brain functioning. As well, modifiable risk factors increase with age which also leads to increased dementia risk.[12]
2) **Family history and genetics –** Some forms of dementia are believed to have a familial link, especially AD.[12]
3) **Gender –** An association with gender has been noted with certain types of dementia. Studies are still investigating this factor.[12]

1d). Clinical Manifestations of Dementia

Generally, most types of dementia have the same characteristic symptoms:

- Memory loss.
- Problems with thinking, problem-solving and language abilities.
- In early stages, individuals cannot recall recent events or conversations.
- As dementia progresses, affected individuals will not recognize or be able to recall names of people and things.
- Errors in conversation will occur due to forgetting words.
- Eventually, managing money, personal care, and nutrition require assistance.
- Other symptoms may include changes in mood, personality, and behavior:[2, 4, 9]
    - Emotional distress.
    - Restlessness, pacing, shredding things, wandering.
    - Aggression, agitation, anxiety, depression, anger, irritability, paranoia.
    - Confusion – Disorientation to person, place, and time.
    - Compulsion – A repeated act or ritual such as checking doors, repeating words, or hoarding items.
    - Resistant behavior.
    - Hallucinations and delusions.
    - Sleeplessness.

- Sundowning – When symptoms of confusion and agitation occur late in the evening hours.
    - This could actually be delirium but not recognized as such.
- Delirium – A short-term state of confusion affecting thinking and behavior including changes in attention, mood, and activity level.
    - People with dementia are at increased risk for delirium.

Most often the early symptoms of dementia are not noticed by the individual themselves but by family members.[27] Usually the symptoms progress to the point that home and family life are impacted resulting in admission to long-term care for management of complex care needs.[27]

1e). Stages of Dementia

Research indicates there are seven stages of dementia that a person may experience as the disease progresses.[27]

Stage 1: No cognitive impairment	The person functions normally. There are no notable changes.
Stage 2: Very mild cognitive decline	The person experiences normal forgetfulness that occurs with the aging process but it is not noticeable to others.
Stage 3: Mild cognitive decline	The person experiences increased forgetfulness, minor issues with concentration, and errors in conversation. The person gets lost in familiar places and others begin to notice the dementia symptoms.
Stage 4: Moderate cognitive decline	The person has increased problems with concentration, recall of events/words, and handling money. The person generally is in denial and isolates themselves from others. At this point, the primary care provider will notice the cognitive changes in the individual upon examination.
Stage 5: Moderately severe cognitive decline	The person experiences significant memory loss and requires moderate help with hygiene and nutrition.
Stage 6: Severe cognitive decline	The person requires extensive help with daily living as little long-term memory remains. Family members are forgotten and there are issues with incontinence, muteness, delusions, compulsions, agitation, and anxiety.
Stage 7: Very severe cognitive decline	The person does not speak or communicate in other ways. Around the clock care is needed. All meaningful movement is lost.

1f). Reversible and Irreversible Forms of Dementia

There are reversible and irreversible forms of dementia that have many overlapping symptoms.[5] With reversible forms of dementia, once the cause is treated, the dementia may be cured or controlled.[5] Some common causes of reversible dementias are:[3]

- Depression.
- Medications.
- Alcohol and drug abuse.
- Lack of vitamins/minerals.
- Trauma.
- Hormonal changes.
- Infections.
- Uncontrolled medical conditions.

Irreversible forms of dementia result in deterioration of the brain and normal functioning.[6] There is no cure for irreversible dementias, but symptoms can be managed with appropriate interventions. The common forms of irreversible dementia are:[6]

- Alzheimer's disease.
- Vascular dementia (Multi-infarct).
- Frontotemporal dementia (Pick's disease).
- Lewy body dementia.

Alzheimer's Disease

- AD is the most common dementia.[11]
- Worldwide, it affects approximately 60-80% of those with dementia.[1]
- Worldwide, AD occurs in 10 per 100 people.[74]
- In Canada, AD accounts for 64% of dementia diagnoses.[7]
- Commonly occurs between the ages of 65-69 years.[74]
- AD affects both men and women equally.[74]
- It is believed that risk for AD increases 30% if an immediate family member is diagnosed with the disease.[74]
- Familial AD accounts for less than 5% of AD cases.[12]
- Short-term memory loss is present upon diagnosis.[6]
- Individuals affected will experience changes in cognition, functional abilities, emotions, mood, behavior, and physical abilities.[11]
- Beta amyloid plaques and neurofibrillary tangles made of tau protein are scattered throughout the brain.[1]
- These deposits in the brain and a lack of the neurotransmitter acetylcholine produce symptoms characteristic of the disease.[1]

Vascular Dementia

- Vascular dementia is also known as multi-infarct dementia.[6]
- Vascular dementia is the second most common dementia in Canada.[6]
- Up to 20% of all dementia cases in Canada are diagnosed as vascular dementia.[6]
- Vascular dementia commonly occurs as a result of a stroke when brain cells do not get proper oxygen.[6]
- With this type of dementia, there are sudden impairments in cognition, emotion, motor, and autonomic functioning.[6]
- Risk is increased in individuals over 65 years of age, those with heart disease, high blood pressure, and diabetes.[6]
- These risk factors can be controlled by reducing the risk for stroke and therefore vascular dementia.[6]

Frontotemporal Dementia

- Frontotemporal dementia is also known as Pick's disease.[6]
- Accounts for 2-5% of all dementia cases worldwide.[6]
- It affects only the frontal and temporal lobes of the brain which control personality and behavior.[6]
- In some cases, brain cells in the frontal and temporal lobes shrink or die. In other cases, the brain cells in the frontal and temporal lobes get larger and contain round, silver Pick's bodies which are a build-up of tau protein.[6]
- There is little known about the risk factors for frontotemporal dementia in the literature.
- Presenting symptoms include sudden onset of memory loss, behavior changes, or difficulty with speech and movement.[6]

Lewy Body Dementia

- Accounts for 15-20% of dementia diagnoses worldwide.[41]
- Globally, LBD occurs in 7 out of 1000 people over 75 years of age and older.[74]
- In Canada, LBD accounts for 5-15% of dementia cases.[8]
- LBD is the third most common dementia in Canada.[6]
- LBD is an umbrella term for two related diagnoses:[42]
    - Dementia with lewy bodies (DLB)
    - Parkinson's disease dementia (PDD)
- The central feature in each diagnosis is dementia. The timeframe of the dementia will determine the diagnosis.[42]
- Individuals can have three clinical presentations:[42]
    - If a person presents with a movement disorder, they are diagnosed with Parkinson's disease. If dementia develops a year or more later, then the person is diagnosed with PDD.
    - If a person presents with a cognitive disorder before or within one year of Parkinson's symptoms, then it is diagnosed as DLB.
    - If a person presents with neuropsychiatric symptoms, such as hallucinations, behavioral problems, and issues with complex activities, the diagnosis is DLB (this presentation is less common).
    - The 12 month cut off is somewhat arbitrary.

- The three clinical presentations have different symptoms initially, but over time will develop similar cognitive, physical, sleep, and behavioral problems.[42]
- Individuals diagnosed with LBD will have deposits of Lewy bodies in the midbrain, brainstem, temporal, and frontal lobes of the brain which contain the protein alpha-synuclein.[41]
- Affected individuals experience the hallmark symptoms of fluctuating alertness and confusion, recurrent vivid visual hallucinations, and Parkinson motor symptoms.[74]
- LBD is a multi-system disease affecting thinking and movement, thus producing symptoms similar to AD and PD.[8]
- LBD is often misdiagnosed as AD because of the cognitive symptoms, or misdiagnosed as PD because of the motor symptoms.[74]
- Generally, there is a two year lag between onset of symptoms and diagnosis, possibly due to lack of awareness among healthcare professionals regarding LBD and the issue of overlapping symptoms with other forms of dementia, particularly AD and PD. [46]
- Affects more men than women.[45, 74]
- LBD can occur as early as 50 years of age but is most common after 60 years of age.[48, 74]
- On average, men are diagnosed at 72.2 years of age and women at 73.6 years of age, which is earlier than other forms of dementia.[74]
- Advanced age is the greatest risk factor for LBD.[43]

- Controversy exists in the literature regarding a familial link for LBD.[45, 74]
- 80% of cases have visual hallucinations.[48]
- 25-50% of LBD cases have Parkinsonism upon diagnosis.[55]
- Individuals with LBD require earlier admission to nursing homes than those with other types of dementia because this multi-system disease impacts independence early in the disease course.[77]
- LBD is a rapidly progressing form of dementia.[6,42]
- Death usually occurs 5-7 years after diagnosis.[46]
- LBD has a higher mortality and earlier death than other dementias.[77, 78]

Chapter 2: Clinical Manifestations of LBD, AD, and PD

2a). Common Diagnostic Tools for LBD

There are two diagnostic tools used to diagnose LBD:[56, 74]

- The Diagnostic and Statistical Manual of Mental Health Disorders, Fifth Edition (DSM-5).
- Consortium on Dementia with Lewy Bodies Consensus Guidelines.

Both diagnostic tools have the same criteria for diagnosing LBD and both diagnostic tools are being used in practice.

The DSM-5 criteria are based on more recent research and incorporate the Consensus Guidelines into its diagnostic tool; as well, it identifies the similarities and differences between LBD, AD, and PD.[74]

Two issues may contribute to the issue of the two year lag from onset of symptoms to receiving a definitive diagnosis of LBD as well as to misdiagnosis and underdiagnosis:[46, 62]

- Primary care providers may lack clinical familiarity with the LBD diagnostic criteria; and
- Many healthcare professionals lack awareness of when symptoms occur at each stage in LBD, AD, and PD.[13, 15]

The DSM-5 provides clear guidelines for dementia and dementia subtypes under the category of neurocognitive disorders.

- The DSM-5 diagnoses of a neurocognitive disorder requires evidence of decreased cognitive decline and decline on standardized testing such as the Mini Mental Status Exam (MMSE) in one of the following areas:[74]
    - Attention.
    - Decision-making and working memory.
    - Learning and short/long-term memory.
    - Visual, auditory, and fine/gross motor skills.
    - Attitude.
    - Behavior.
- Furthermore, clinical manifestations are assessed in detail with neurological and physical examinations.
- The DSM-5 identifies the clinical manifestations of LBD, AD, and PD so that these diseases can be clearly differentiated from one another which can result in faster diagnosis and earlier treatment.[74]

The criteria set forth by the Consortium on Dementia with Lewy Bodies Consensus Guidelines use categories of features to diagnose LBD.[56]

The criteria examine symptoms in relation to central, core, suggestive, and supportive features of LBD.

According to the Consensus Guidelines, the following core features must be present for a definitive diagnosis of LBD:[56]

- Fluctuating cognition with prominent variations in attention and alertness.
- Recurrent, vivid visual hallucinations which are detailed and well-formed.
- Spontaneous Parkinsonism.
- The criteria require that physicians be suspicious of LBD when screening for any type of dementia.
- Recent modifications to Consensus Guidelines have resulted in a high specificity in identifying those who do not have LBD but low sensitivity in correctly detecting those who have LBD; therefore, errors in diagnosis are possible, including misdiagnosis and underdiagnosis.[56, 74]

2b). Learning How to Differentiate between LBD, AD, and PD

There are at least two biological processes underlying dementia:

- Foreign bodies.
- Neurotransmitters.

Foreign bodies:

- With AD, plaques and neurofibrillary tangles affect the brain.[1]
- In DLB and PDD, Lewy bodies affect the brain.[6, 74]
- The foreign bodies impact the structures of the brain which disrupt the brain's normal functioning.
- Definitive diagnosis of dementia type can only be determined through autopsy.[45]

Neurotransmitters:

The symptoms of AD, PD, and LBD are the result of decreased neurotransmitters in the brain including acetylcholine and dopamine. [43, 48, 74]

- Acetylcholine is responsible for cognition including, learning and memory functioning.
- Dopamine is responsible for motor functioning, or movement.

- In AD, only acetylcholine is decreased producing the cognitive symptom of memory loss.

- In PD, only dopamine is affected.
- In LBD, the sequence of changes in neurotransmitters determines the type: DLB or PDD.
    - In DLB, the neurotransmitter acetylcholine is decreased first which produces the fluctuations in alertness and confusion. This is followed by a decrease in dopamine, which produces the later parkinsonian symptoms.
    - In PDD, the neurotransmitter dopamine is affected first which produces the movement symptoms. This is followed by a decrease in acetylcholine, resulting in the later cognitive changes.
- Pharmacological management targets the loss of these neurotransmitters as the disease progresses.[44, 4, 8, 74]

Lewy Body Dementia

The Lewy Body Dementia Association (LBDA) follows the categories of symptoms as specified by the Consortium on Dementia Consensus Guidelines:[42]

- Central feature:
  - Dementia with problems in the areas of planning, judgment, processing, and understanding information.

- Core (Hallmark) symptoms:
  - Fluctuating cognition with variations in attention and alertness.
    - Short-term memory is intact in early stages.
  - Recurrent vivid visual hallucinations which are well-formed and detailed.
  - Spontaneous features of Parkinsonism such as tremors, stiffness, slowness, and difficulty walking.

- Suggestive features:
  - Rapid eye movement (REM) sleep behavior disorder that involves talking and acting out dreams while asleep.
  - Severe sensitivity to neuroleptics such as atypical and typical antipsychotics.
  - Low dopamine transporter uptake that can cause depression, apathy, anxiety, and agitation.

- Supportive features:
  - Repeated falls and fainting.
  - Short-term unexplained loss of consciousness.
  - Autonomic dysfunction such as blood pressure control, temperature regulation, and bowel and bladder control.
  - Hallucinations that involve touch or hearing.
  - Problems processing and interpreting visual information such as the ability to orient oneself in the environment.
  - Other psychiatric disturbances such as delusions and paranoia.

Fluctuating cognition may cause the person with LBD to have: [13, 15, 48, 52, 74]

- A blank stare, be very sleepy, and have scattered ideas.
- At other times to be alert, capable of self-care, and logical conversation.

- Fluctuating cognition is a challenging and difficult aspect of LBD because short-term memory is still intact in the early stages and individuals are aware of their changes in cognition.
- The hallucinations that occur with LBD can be severely distressing for the person and can result in agitation and aggression.[48]

- The symptoms of fluctuating cognition and visual hallucinations do not often occur during examination by a physician which can make an accurate diagnosis difficult.[48]

The motor symptoms that occur during LBD can be subtle at first then become more prominent in later stages of the disease.[13, 15, 48, 52, 74] Individuals experiencing LBD may have the following Parkinsonian symptoms:[48]

- Muscle rigidity or stiffness.
- Shuffling gait.
- Slow movement.
- Freezing of movements.
- Tremor of the hands even at rest.
- Balance problems resulting in falls.
- Issues with handwriting.
- Difficulties with facial expressions and swallowing.
- Decreased strength of voice.

These symptoms in combination with the cognition symptoms greatly impact functional abilities and quality of life early in the disease course of LBD.[19, 54]

Behavioral changes also occur in LBD:

- It is possible for individuals with LBD to experience a lack of interest in things they previously enjoyed, as well as anxiety and agitation. [48]
- Anxiety and agitation can be a result of the confusion and visual hallucinations but can also be present in the absence of hallucinations.

Common sleep problems experienced by individuals with LBD are:[42, 48]

  - Rapid Eye Movement (REM) sleep behavior disorder.
  - Excessive daytime sleeping.
  - Insomnia.
  - Restless leg syndrome.

- REM sleep behavior disorder involves acting out vivid dreams while asleep through talking and violent movements.[48]
- Even though individuals with LBD may get sufficient sleep at night they often experience excessive day time sleepiness as well.[42, 48]
- Some individuals with LBD may experience insomnia where they cannot fall asleep or stay asleep at night.[48]

- Restless leg syndrome may occur in people with LBD in which their legs are constantly twitching and moving in an attempt to decrease unusual sensations and discomfort in the legs.[42, 48]

Autonomic dysfunction may also occur in individuals with LBD which affects the involuntary activities within the body.[42, 48] Such symptoms may consist of variations in the following:[42, 48]

- Body temperature.
- Changes in blood pressure.
- Dizziness.
- Fainting.
- Sensitivity to temperature changes.
- Falls.
- Problems with sexual functioning.
- Constipation.
- Changes to the sense of smell.

Alzheimer's Disease

The hallmark symptoms of AD are:[74]

- Problems with short-term memory loss.
- Early symptoms of recall, learning, and orientation deficits.

- AD is progressive but at a much slower rate than LBD.[11]
- Early in the AD course the symptoms are similar to the late stages of LBD:[74]
  - Problems with planning, problem-solving, and judgment.
  - Disorientation to person, place, and time.
- As AD advances to the later stages:[74]
  - Psychiatric symptoms such as hallucinations and delusions are common.
  - Problems with movement, speech, activities of daily living (ADL's), and long-term memory.
  - At this late stage there is no intact memory.[27]

Parkinson's Disease

- The symptoms of Parkinson's disease are the result of Lewy bodies found in the midbrain. [74]
- Parkinson's disease is most common in individuals over the age of 70 years.[74]
- Globally, PD occurs in 8 per 1000 people commonly over 80 years old.[74]
- Parkinson's disease dementia will occur in 50-80% of those with PD; as a result, most individuals with PD will progress to LBD.[3]
- The risk of males developing PD is 1.5 times greater than females.[74]
- The hallmark symptom of PD is tremors.[74]
- The early symptoms of PD are movement problems such as stiffness, difficulty with balance, and coordination.[74]
- Cognition, problem-solving, planning, and memory dysfunction can also occur early in the disease.[74]
- As PD progresses, the motor symptoms become severe resulting in safety issues for those diagnosed such as swallowing, bathing, and falls.

2c). Table 1: Similarities and Differences among LBD, AD, and PD

Table 1 below summarizes the similarities and differences among LBD, AD, and PD.[74]

	LBD	AD	PD
Age of Onset	**Generally > 60 years old, but can be as young as 50.**	**> 60 years old**	**> 70 years old**
Gender	**More men**	**Men=women**	**Risk is 1.5 times higher in men**
Family history	**Possible**	**Yes**	**No**
Hallmark symptoms	**Fluctuating alertness and confusion. Recurrent and vivid visual hallucinations in 80% of cases, spontaneous Parkinsonism.**	**Short-term memory loss.**	**Tremor**
Early symptoms	**Depending on the clinical presentation: Motor, dementia, or neuropsychiatric symptoms.**	**Difficulty with person, place, time, and planning.**	**Rigidity, difficulty with movement, balance, and coordination. Problems with planning, problem-solving, and functioning.**
Late symptoms	**Agitation, aggression, hallucinations, memory loss, parkinsonism.**	**Hallucinations, delusions, problems with movement, speech, ADL's, long-term memory, planning,**	**Worsened problems with planning, problem-solving, judgment, slowed thinking, rigidity,**

		judgment, and relationship among objects.	movement, and coordination.
Pathology	Lewy bodies containing alpha-synuclein protein.	Beta amyloid neural plaques and neurofibrillary tangles composed of tau protein.	Lewy bodies containing alpha-synuclein protein.
Affected neurotransmitter	Dopamine & acetylcholine. Usually acetylcholine first.	Acetylcholine	Dopamine & acetylcholine. Usually dopamine first.
Medications	Cholinesterase inhibitors, NMDA, levodopa-carbidopa, benzodiazepines, atypical antipsychotics.	Cholinesterase inhibitors, NMDA.	Levodopa-carbidopa, cholinesterase inhibitors, antipsychotics cautiously.

Chapter 3: Pharmacological Management of LBD

- Pharmacological management of LBD is complex because the commonly used medications were initially developed for use with AD and PD and are used off label in the management of LBD.[44]
- As well, the medications may improve some symptoms of the disease but also have the potential to worsen others.[48]
- There are no medications to cure LBD so the disease will inevitably progress, but medications can reduce symptoms of the disease.[48]
- A combination of medications is generally the course of action to treat LBD.[44, 48, 74]
- Residents should be monitored closely during the medication regimen for adverse reactions.[44, 48, 55]
- **Certain medications must also be avoided in the management of LBD.**[44]

3a). Things to Know about Pharmacological Management of LBD

The medications commonly used are [44, 48, 55, 56, 58, 65, 74, 77]

- Cholinesterase inhibitors.
    - N-methyl-D-aspartate receptor antagonists (NMDA).
- Levodopa-carbidopa.
- Benzodiazepines.
- Atypical antipsychotics.

3b). Cholinesterase Inhibitors

- Ex: Aricept (donepezil HCl)[24]
- Cholinesterase inhibitors are the recommended first course of treatment for mild to moderate LBD.[44, 48]
- These medications decrease the loss of acetylcholine in mild to moderate dementia which will help decrease problems with memory, thinking, and alertness.[44, 48]
- These medications are long-term drugs so it may take time to see improvements in symptoms.

- These medications are generally safe and tolerated well in individuals with LBD.[44, 48]
- **Recommended dose:**[24]
    - 5 mg daily for 4-6 weeks then increased to maximum dose of 10 mg daily.
    - Recommended to be given either in the morning or evening.
- **Side effects:** [24, 44]
    - Nausea, vomiting, diarrhea
    - Insomnia
    - Muscle cramps
    - Fatigue
    - Anorexia
- Discontinue if cognitive improvement is not possible due to progressing severity of dementia or if side effects are intolerable.

N-Methyl-D-Aspartate Receptor Antagonists

- Example: Ebixa (Memantine HCl)[24]
- Used in moderate to severe stages of dementia.[24, 65]
- Can be used when cholinesterase inhibitors are ineffective or the person has a sensitivity to them.[44]
- Inhibits activation of the excitatory neurotransmitter glutamate in the brain that is involved with learning and memory.[70]
- These medications may slow the loss of learning and memory skills such as toileting and dressing.[65]
- **Recommended dose:**
    - 5 mg daily then titrated slowly over weekly intervals to maximum dose of 20 mg per day.
    - The10 mg to 20 mg doses are given as divided daily doses.[24]
- **Side effects:**[24]
    - Headache.
    - Sleepiness.
    - Constipation.
    - Tiredness.
    - Confusion.
    - Hallucinations.
    - Vomiting.

    - Loss of appetite.
    - Dizziness.
    - Sleep disturbances.
    - Anxiety.
    - Elevated blood pressure.
    - Changes in urinary frequency.
- Discontinue when there is no longer any potential to preserve cognitive functioning or side effects become intolerable.[24]

3c). Levodopa-Carbidopa

- Example: Sinemet.[24]
- This medication is the initial treatment protocol for PD and is beneficial for management of Parkinson symptoms in LBD.[44, 48]
- A levodopa-carbidopa combination medication is commonly used. [44, 48]
- The carbidopa increases the uptake of levodopa to improve motor symptoms such as rigidity, tremors, and restless leg syndrome.[44, 48]
    - Carbidopa enables better control of Parkinsonism with lower doses of levodopa.[24]
- Should be started at the lowest dose and titrated slowly to allow for close monitoring of adverse effects.[44, 48]
- Dosing should be kept at the lowest effective level to control symptoms and adverse effects.[44, 48]
- Adverse effects include:
    - Increased hallucinations so may not be recommended if motor symptoms are mild.[44]
    - Abnormal movements and nausea.[24]
- The low doses of levodopa decreases the incidence of nausea and vomiting and allows for more rapid titration.[24]

- **Dosing practices may vary for levodopa-carbidopa and nurses should ascertain agency policy/practice guidelines.**
- Levodopa-carbidopa is available in the following ratios:[24]
    - 4:1 (100/25 – 100 mg of Levodopa and 25 mg of Carbidopa)
        - This dosage is available in immediate release and controlled release tablets.
    - 10:1 (100/10 – 100 mg of Levodopa and 10 mg of Carbidopa or 250/25 – 250 mg of Levodopa and 25 mg of Carbidopa or 200/50 – 200 mg of Levodopa and 50 mg of Carbidopa).
        - The 100/10 and 250/25 doses are immediate release tablets.
        - The 200/50 dose is a controlled release tablet.
- Dosage depends on whether the person is presently taking levodopa.[24]

- **Recommended dose if the person is not currently taking levodopa**: [24]
    - A ratio of 4:1 (100/25 tabs) TID is given.
    - This can be titrated up by a tablet every three days to reach 300/75 – 300 mg of Levodopa and 75 mg of Carbidopa.
    - Normally a resident would not receive more than 1500 mg/day of Levodopa, but if they need to receive above 1800 mg/day then follow the instructions below.

- If further titration is necessary after a daily dose of 6 tablets of 4:1 (100/25) ratio, then additional tablets of 10:1 ratio (100/10 or 250/25) may be used to reach the optimal dose.

- **Recommended dose if the person is currently taking levodopa alone:** [24]
  - Discontinue the levodopa 12 hours before beginning levodpa-carbidopa.
  - Start the levodopa-carbidopa the morning after levodopa is discontinued.
  - The dose of levodopa-carbidopa should be enough to provide 20% of the previous daily dose of levodopa.
  - 4:1 ratio is the tablet of choice to reach desired dosage.

- **Side effects:**[24]
  - Worsening of hallucinations.
  - More pronounced abnormal movements such as chorea and dystonia.
    - Chorea – involuntary movements of the shoulders, hips, and face.
    - Dystonia – muscle spasms and abnormal posture.
  - Nausea
- Decrease the dosage of levodopa if worsening or new involuntary movements occur, as this should be regarded as a sign of levodopa toxicity and an indicator of overdosing.[24]
- Plasma levels of levodopa should be monitored to prevent toxicity.
- Discontinue if Parkinson symptoms are not controlled and/or neuropsychiatric symptoms and confusion worsen.

3d). Benzodiazepines

- Example: Clonazepam (Klonopin)[24]
- Used to treat REM sleep disorder and restless leg syndrome.[70]
- Produces a sedative effect in the central nervous system.[70]
- The individual may have paradoxical episodes of sedation and agitation that may result in discontinuation.[24, 44]
- **Recommended Dose**:
    - 0.5 mg TID that can be increased by a 0.5-1 mg every three days.
    - Not to exceed 20 mg daily.[24]
- **Side effects**:[24]
    - Drowsiness.
    - Behavioral changes.
    - Lack of coordination.
    - Increased confusion.
- Discontinue if there is worsening of cognitive symptoms, anxiety, paradoxical agitation and sedation, falls, and impulsive behavior.

3e). Atypical Antipsychotics

Typical antipsychotics, such as haloperidol, should NEVER be used to manage LBD because they affect the brain differently in LBD and can produce neuroleptic sensitivity and neuroleptic malignant syndrome which can be fatal. [44, 48, 56, 74]

- **All antipsychotics increase the chance of death in people with dementia.**[44, 48]
- Atypical antipsychotics can be used to treat hallucinations and/or delusions that occur in LBD.[44, 48]
- These medications are only used if long-term cholinesterase inhibitors have been ineffective or better behavioral control is warranted.[44, 48, 56, 74]
- When atypical antipsychotics are prescribed, the lowest dose should be used for the shortest amount of time.[44, 48, 56, 74]
- The recommended atypical antipsychotics to be prescribed are Quetiapine and Clozapine in this order.[44, 48, 56, 74]
- Extreme caution and close monitoring is required when atypical antipsychotics are prescribed because neuroleptic sensitivity and neuroleptic malignant syndrome are possible.[44, 48]

- ***Neuroleptic sensitivity*** results in worsening of cognitive symptoms, hallucinations, and Parkinsonism. Occurs in up to 50% of LBD patients treated with atypical antipsychotics.[44]
- ***Neuroleptic malignant syndrome*** is a rare life-threatening adverse effect that produces symptoms of fever, generalized rigidity, and breakdown of muscle tissue that can result in kidney failure and death.[44]
- Antipsychotics stabilize mood and behavior by interfering with serotonin and dopamine to increase binding in the brain.[70]
- Atypical antipsychotics are safer than typical antipsychotics, but there is no antipsychotic medication that is absolutely safe for the management of LBD behavioral symptoms.
- Atypical antipsychotics are discontinued if there is worsening of Parkinson and cognitive symptoms and increased sedation is noted.

- **Quetiapine (Seroquel):**[24]
    - **Recommended dose:**
        - 25 mg BID which can be titrated with increases of 25-50 mg BID per day to a maximum dose of 300 mg/day.
        - Dosage adjustments should be at intervals no less than 2 days apart.

- **Side effects:**
  - Increased blood sugar.
  - Light headedness.
  - Dizziness.
  - Drowsiness.
  - Falls.
  - Dry mouth.
  - Weight gain.
- Regular blood sugar checks should be ordered to monitor sugar levels.

- **Clozapine (Clozaril):**[24]
  - **Recommended dose:**
    - 12.5 mg once or twice daily initially, then can be increased over a 2 week period by 25-50 mg up to a maximum dose of 300-450 mg/day.
  - **Side effects:**
    - Drowsiness.
    - Dizziness.
    - Weakness.
    - Fainting.
    - Low blood pressure.

        - Rapid heartbeat.
        - Constipation.
        - Increased saliva.
        - Weight gain.
        - Urinary retention.
    - Blood monitoring for agranulocytosis is required with this medication as residents are at increased risk of frequent bacterial infections.

3f). Medications That Should Be Avoided With LBD

- If cholinesterase inhibitors are effective, atypical antipsychotics are not prescribed because they have serious side effects including death.[44]
- Avoid the atypical antipsychotics Risperidone and Olanzapine, as they have an increased likelihood of increasing side effects such as increased Parkinson symptoms, sedation, and orthostatic hypotension.[44]
- Avoid the following medications used with Parkinson's disease because they worsen cognitive impairment:[44]
    - Amantadine.
    - Catechol-O-methyltransferase (COMT) inhibitors (ex: Entacapone).
    - Monoamine oxidase (MAO) inhibitors (ex: Selegiline).
    - Anticholinergics (ex: Benztropine).
- Avoid dopamine agonists such as Pramipexole and Bromocriptine because they cause excessive daytime sleepiness and swelling of the legs.[44]
- Avoid over-the-counter sleep agents such as Tylenol or Advil PM and bladder control medications may cause agitation.[44]

Chapter 4: Non-pharmacological Management of LBD



Little research exists regarding non-pharmacological approaches that are specific to managing the behavioral challenges of LBD.

Much of the literature indicates that the approaches used with other types of dementia, such as behavioral and communication strategies, reminiscence, music therapy, doll therapy, and aromatherapy, are beneficial in the management of behavioral challenges that occur in LBD.[18, 29, 49, 54, 55, 56, 58, 76, 77]

Using a combination of comprehensive approaches that are individualized to the resident is the best course of action.[44]

Resident-centered care focuses on the whole resident and their active participation in the care process.

Resident preferences and ideals guide care decisions so that care specifically meets the needs of the resident and clinical manifestations are better managed. Resident-centered care will maintain the individual's self-identity, lead to more positive outcomes, and promote quality of life.

4a). Behavioral Strategies

- Effective behavioral strategies can help to lessen disruptive behaviors.[76]
- Here are some tips for managing behaviors associated with dementia generally [47, 76]:
    - Keep a consistent schedule on the unit.
    - Read the admission history of the resident and ask family members about the jobs or activities residents liked in former years so these can be used to provide resident-centered care; for example, knowing a resident was a farmer and talking about farm animals during care delivery may decrease the resident's challenging behavior.
    - Cue residents to participate in activities of daily living. For example, imitate for them what you would do with a comb.
    - Be flexible in the schedule to be able to deal with the unexpected.
    - Schedule meal and toileting to ensure needs are met.
    - Encourage regular exercise to decrease wandering and sundowning.
    - Use easy-to-use clothing to lessen disruptive behaviors during ADL's.
    - Encourage adequate nutrition and fluids to decrease sundowning.
    - Limit caffeine as this can heighten disruptive behaviors.
    - Limit napping so that residents will sleep more at night.
    - Ensure adequate nighttime sleep so that residents are not drowsy in the daytime.

4b). Communication Strategies

- Effective communication strategies can lessen disruptive behavior.[76]
- Here are tips for communicating with a resident with dementia[47, 65, 76]:
    - Address residents by name for orientation purposes.
    - Use eye contact during conversations.
    - Do not argue with residents when they are confused or hallucinating as this can increase agitation.
    - Avoid quizzing the person or trying to teach them to remember as this is frustrating for them.
    - Do not try to orient the person to reality, instead provide reassurance and comfort.
    - Encourage reminiscence to promote positive emotions.
    - Step away from aggressive behavior and approach the resident later.
    - Give one step instructions in clear short phrases to avoid further confusion.
    - Break tasks down into steps so it is easier for them to accomplish.
    - Use a respectful tone of voice with low volume.
    - Be aware of your facial expressions.
    - Limit distractions and noise in the environment to prevent overstimulation.
    - Repeat information using the same wording to avoid confusion.

- Ask one question at a time to lessen confusion.
- Try to use only questions that require yes/no answers to promote communication.
- Do not give residents too many choices as this heightens confusion.
- Use cuing or visual examples when trying to encourage their participation in activities.

4c). Music Therapy

- Music therapy involves the use of music either, individualized or in a group setting.[49, 68, 75]
- Listening to music chosen by the resident is the most common type of music therapy.[49, 68, 69, 75]
- Music therapy can also involve the active use of instruments.
- The therapy can be monitored by a music therapist or trained nursing staff.
- The use of music therapy helps to bring back memories of happier times thus helping the person relax.
- The positive outcomes of music therapy have the potential to decrease medication usage to manage agitation and aggression.[17, 64]
- Music therapy can be used in all stages of dementia because it does not require alertness to be a meaningful form of treatment [49, 64, 73]
- The nervous system is activated during music therapy releasing stress reduction hormones.[49, 64, 73]
- The stress reduction hormones lessen the behavioral and psychological symptoms of dementia such as agitation, aggression, and hallucinations, which can improve quality of life.[49, 63, 64, 73]
- There are no documented negative side effects with music therapy.[72]

- Music therapy is a relatively new complementary therapy in the management of dementia but it does support the concept of resident-centered care.[73]

4d). Reminiscence

- Reminiscence involves the discussion of past experiences and memories with the help of such tools as music, photos, memory boxes, and life story books.[14, 21, 22, 23, 28, 33, 36, 38, 39, 51, 52, 59, 61, 67]
- Reminiscence as a form of resident-centered care has demonstrated significant improvement in quality of life for people with dementia.[35]
- Individuals in all stages of dementia can participate in reminiscence.[22]
- Reminiscence can be done in a group setting or one-on-one with nursing staff and/or family members.
- Individualized reminiscence is best for those people who do not want to participate in group activities.[71]
- Reminiscence has been used in dementia care since the 1980s.[26]
- This complementary therapy stimulates the person with dementia to engage in their surroundings, promotes communication, and enhances physical and mental functioning to improve well-being and quality of life.[38, 71]
- Reminiscence enhances resident-centered care as it allows insight and understanding into another's life.[35]

4e). Doll Therapy

- This complementary therapy involves the use of dolls to reduce anxiety and agitation and promote attachment in individuals with dementia.[18]
- Doll therapy can be used in all stages of dementia but the resident should choose if they want to participate or not so that they do not feel like a child.[34]
- Caring for a doll allows the person with dementia to feel as if they are useful and needed.[18]
- Doll therapy reduces behavioral symptoms and improves social interaction and communication.[18]
- It has been noted that doll therapy reduces anxiety, wandering, and drug usage as well as increases happiness, activity levels, interactions with nursing staff, and ease of care – all contributing to improved well-being.[20, 34]
- Doll therapy is a growing practice in dementia care.[57]

4f). Aromatherapy

- Aromatherapy involves the use of essential oils, such as lavender, that can be absorbed directly into the bloodstream when applied to the skin or inhaled.[29, 30]
- The oils interact with hormones and enzymes to produce a physical reaction similar to the mood regulating neurotransmitter serotonin.[29, 30]
- Lavender is often used as it has a calming effect, decreases wandering, and promotes sleep. [29, 30, 37]
- Residents can be more alert and in better moods during the daytime allowing better social functioning and engagement.[29, 30, 37]
- It is the fastest growing complementary therapy and has few adverse effects.[50]

Chapter 5: Resources

5a). Resource Description

1. Alzheimer Society of Canada. (http://www.alzheimer.ca/en)
    - This is a not-for-profit organization that works to improve the quality of life for Canadians experiencing dementia, their families and caregivers.
    - The website provides information related to the types of dementia, causes and risk factors, statistics, living with dementia issues such as care, communication, understanding behaviors, and preparing for the future.
    - The website provides details on how to get involved with the Alzheimer Society, recent research and news events.

2. Alzheimer Society of Newfoundland. (http://www.alzheimer.ca/en/nl)
    - This organization is a provincial branch of the Alzheimer Society of Canada. The website will provide you with the same details as those listed above.

3. Alzheimer Association Canada (http://www.alz.org/ca/dementia-alzheimers-canada.asp)
    - This organization is committed to dementia care, support and research in hopes to improve quality of life for those with Alzheimer's disease and other dementias.

- The website will provide you with information related to research funded by the organization, educational resources, awareness campaigns, and government initiatives.

4. Lewy Body Dementia Association (United States) (http://www.lbda.org/)

    - This association is a nonprofit organization that is geared toward raising awareness of LBD as well as supporting individuals diagnosed with LBD, their families and caregivers.
    - The website offers a vast amount of educational information on LBD and the latest details regarding LBD research.

5. Lewy Body Society (United Kingdom) (http://lewybody.org/)

    - The mission of this organization is to increase awareness of DLB in both the public and the medical profession.
    - The link to the resource *Information about Lewy body dementia* is very beneficial.

6. Parkinson Canada (http://www.parkinson.ca/site/c.kgLNIWODKpF/b.8647145/k.6D4A/Diffuse_Lewy_Body_Disease.htm)

    - This organization provides support and education to individuals diagnosed with Parkinson's disease, their families, caregivers and healthcare providers.
    - Information can be found on the website related to education, advocacy efforts and support services as well as research.

7. Dementia Care Central(United States) (http://www.dementiacarecentral.com/)

    - This website is a resource center for dementia caregivers.
    - Links are provided to up-to-date dementia information that is applicable to practice.

Videos

- The video links below provide information related to the various behavioral challenges associated with LBD as well as possible reasons as to why these behaviors occur and ways to manage them.
- These videos are great resources that can be used during orientation to the dementia unit for new nursing staff or with students on clinical placements to summarize the various behavioral challenges that individuals with LBD experience.

Mayo Clinic. (2011, August 22). *Living with Lewy Body Dementia [*Video file*]*. (2 min 58 sec). Retrieved May 28, 2016 from: https://www.youtube.com/watch?v=RSRbR1R4mz_0 (2min 58sec)

Lewy Body Dementia Association. (2006, June 08). *Behavioral Challenges in Dementia with Lewy Bodies [*Video file*]*. Retrieved July 06, 2016 from:

Part 1: https://www.youtube.com/watch?v=3nJQncMlneI ((8 min 30 sec)

Part 2: https://www.youtube.com/watch?v=Ks12t8niET8 (6 min 17 sec)

Part 3: https://www.youtube.com/watch?v=I4iBJazhNQY (6 min 13 sec)

Part 4: https://www.youtube.com/watch?v=I4iBJazhNQY (7 min 35 sec)

Part 5: https://www.youtube.com/watch?v=egRxkTRp9-c (5 min 43 sec)

Part 6: https://www.youtube.com/watch?v=ApL_ZazuYVU (7 min 26 sec)

Part 7: https://www.youtube.com/watch?v=9uay245oOr0 (9 min 22sec)

Appendix A

Case Study A

A 78 year old gentleman is newly admitted to a long-term care facility with a diagnosis of Lewy body dementia. During morning care, he becomes aggressive during a tub bath. After speaking with the nursing team and reading the resident's history on his chart, you know the gentleman was a farmer and becomes increasingly agitated when his stuffed animals are rearranged in his room. You also notice that he occasionally becomes very agitated and confused, picking at items that are not there. He sometimes appears frightened. The resident displays appropriate emotions, for example, he appears upset when discussing sad things but when asked about his work as a farmer he quickly reverses his emotions and becomes content and happy.

1. How would you provide resident-centered care to this resident?
2. What are the possible causes of his behavior?
3. What are possible medications that can be recommended to the primary care provider?
4. What are some non-pharmacological strategies that can be used to meet the needs of the resident?

Adapted from: (Hamilton, P, Harris, D., Le Clair, K., & Collins, J. (2008). Putting the P.I.E.C.E.S. Together: A model for collaborative care and changing practice. A learning resource for professionals providing long-term care to older adults with complex physical and cognitive/mental health changes. (6th ed.). Retrieved July 27, 2016 from: http://pieceslearning.com/model/)

Answers to Case Study A Questions

1. Resident-centered care can be provided by learning about the life history of this resident from his or her family member, by documenting it on his chart, and using this information in care delivery to encourage participation and ensure his needs are met. For example: asking what types of animals were on the farm and the names of the animals may distract the resident during care delivery and lessen agitation.

2. The resident may be having visual hallucinations that are causing him to be frightened, aggressive, agitated, and uncooperative.

3. If the patient is experiencing visual hallucinations that are disturbing and affecting his quality of life, then a cholestinerase inhibitor may be prescribed initially. If these are ineffective after long-term use or better behavioral control is warranted, a cautious course of atypical antipsychotics may be used starting with Quetiapine then Clozapine. Close monitoring is required when atypical antipsychotics are prescribed to monitor for adverse effects.

4. Non-pharmacological strategies:

    - Reminiscence may help to provide care to this resident.

    - Knowledge of the resident's life history as a farmer and his love of animals can be used to carry on conversation and elicit positive emotions during care.
    - Music therapy may also be an option if staff are aware of the resident's music preferences or if he played an instrument.
    - Behavioral approaches such as calm, low tone of voice with eye contact can also be helpful.
    - When agitated or aggressive, leave the resident to safely calm down and then try again later when his emotions and mood are more positive.
    - Communication strategies such as reassurance, breaking tasks into steps, sticking to a regular routine, and ensuring basic nutritional needs are met can lessen episodes of agitation.

Case Study B

A 69 year old woman was being seen by a neurologist for questionable Parkinson's disease. After further examination a referral was made to a geriatric psychiatrist.

Medical history:

- 2 year history of hand tremor for which patient was prescribed Levodopa.
- 14 month history of progressive short-term memory loss and mild cognitive problems
- 8 months ago the Levodopa was discontinued because it caused the patient severe nausea and she began to experience distressing visual hallucinations.
- High blood pressure
- Query history of mini stroke
- Younger sister with potential AD, not yet diagnosed

Assessment findings:

- Fluctuating cognition
- Responding appropriately to questions
- Soft, slow speech with mild slurring
- Bilateral tremor at all times in hands/arms
- Mild degree of mask-like facial expression
- Shuffling gait that required assistance due to fall risk

Plan:

- Aricept was prescribed for the mild cognitive changes.
- Quetiapine was prescribed for the distressing visual hallucinations.
- Levodopa-carbidopa prescribed for motor symptoms.

1 month follow-up:

- Patient began acting out dreams in her sleep and experiencing restless leg syndrome.

1. What type of dementia does this woman most likely have?

2. What 3 symptoms are indicative of LBD?

3. What medications can be recommended to the physician to control the acting out of dreams and restless leg syndrome? Why should the patient be monitored closely when taking this medication?

4. What non-pharmacological interventions could be used to assist in the care of this individual to manage motor symptoms and memory loss?

Adapted from: (Kaufer, D. I. (2004). A case study in the treatment of dementia with Lewy bodies. *Acta Psychiatrica Scandinavica, 110*(1), 73-76. doi: 10.1111/j.1600-0447.2004.00323.x)

Answers to Case Study B Questions

1. LBD

2. The three symptoms indicative of LBD are: fluctuating cognition, recurrent vivid visual hallucinations, and Parkinson symptoms.

3. Medications that can be prescribed to control the acting out of dreams and restless leg syndrome are benzodiazepines. The patient should be monitored closely for paradoxical sedation and agitation as well as worsening cognitive symptoms which may require discontinuing the medication.

4. Non-pharmacological approaches that can be used to manage the motor symptoms:
    - Suggest the use of clothing that is easy to take on and off
    - Encourage the use of walkers/wheelchairs/bed rails/ and easy to use eating utensils
    - Aromatherapy and music therapy for relaxation

    Non-pharmacological approaches that can be used to help with memory loss:

    - Always use your name and the patient's name.
    - Break tasks down into steps.
    - Keep a consistent schedule.
    - Cue residents to trigger their memory - for example, role play for them what a fork is used for.
    - Reorient residents – for example, tell them the day, month and year
    - Use clocks, calendars, pictures for orientation
    - Reminiscence – for example, talk about their families or past jobs.
    - Use music therapy if acceptable to the resident
    - Use doll therapy if acceptable to the resident.

TEST YOUR KNOWLEDGE!

NOW THAT YOU HAVE READ THE MANUAL, COMPLETE THE POST-TEST ON THE NEXT PAGE TO DETERMINE WHAT YOU HAVE LEARNED REGARDNG LBD.

Appendix B

Test Your Knowledge – Post-Test

Select True or False for each of the following statements:

1. Lewy body dementia (LBD) is more common in men. □ True □ False

2. The greatest risk for Lewy body dementia (LBD) is advanced age.
   □ True □ False

3. Lewy body dementia (LBD) is the second common type of dementia.
   □ True □ False

4. Lewy body dementia (LBD) can be dementia with Lewy bodies or Parkinson's disease dementia. □ True □ False

5. The hallmark symptom of Lewy body dementia (LBD) is fluctuating alertness and confusion, vivid visual hallucinations and Parkinson motor symptoms.
   □ True □ False

6. An early symptom of Lewy body dementia (LBD) is delusions.
   □ True □ False

7. Acetylcholine is the only neurotransmitter affected in Lewy body dementia (LBD). □ True □ False

8. Amyloid plaques are found in the brain of individuals of Lewy body dementia.
   □ True □ False

9. The first line of treatment for cognitive symptoms in Lewy body dementia is cholinesterase inhibitors. □ True □ False

10. Typical antipsychotics are safe to use in the management of LBD behavioral symptoms. □ True □ False

Answers to Test your knowledge - Pre and Post Tests (page 7 and page 74).

1. T
2. T
3. T
4. T
5. T
6. F
7. F
8. F
9. T
10. F

If you answered any of the questions incorrectly, please go back and review the appropriate chapter of this resource manual.

Appendix C

Evaluation Survey

Age: _____ Gender: _____ Are you an RN, LPN or PCA? _____

How long have you been working in long-term care? _____

Please complete the following survey using the 5 point Likert scale for each question.

1-Strongly disagree 2- Disagree 3- Undecided 4- Agree 5- Strongly agree

1. The resource manual was easy to understand.

1 2 3 4 5

2. The resource manual will help me care for residents with LBD.

1 2 3 4 5

3. I understand the symptoms of LBD.

1 2 3 4 5

4. I understand that LBD can look like AD and PD.

1 2 3 4 5

5. I understand the medications used to manage LBD.

1 2 3 4 5

6. I understand that strategies other than medications can be used to manage LBD.

1 2 3 4 5

7. The case studies were helpful to apply new knowledge about LBD.

1 2 3 4 5

8. The information provided about LBD resources was helpful.

1 2 3 4 5

9. The pre-post tests were helpful in determining if new knowledge was gained about LBD.

1 2 3 4 5

10. What did you like best about the resource manual?

_____
_____
_____
_____

11. What did you like least about the resource manual?

_____
_____
_____
_____

12. Do you have any suggestions to improve the resource manual?

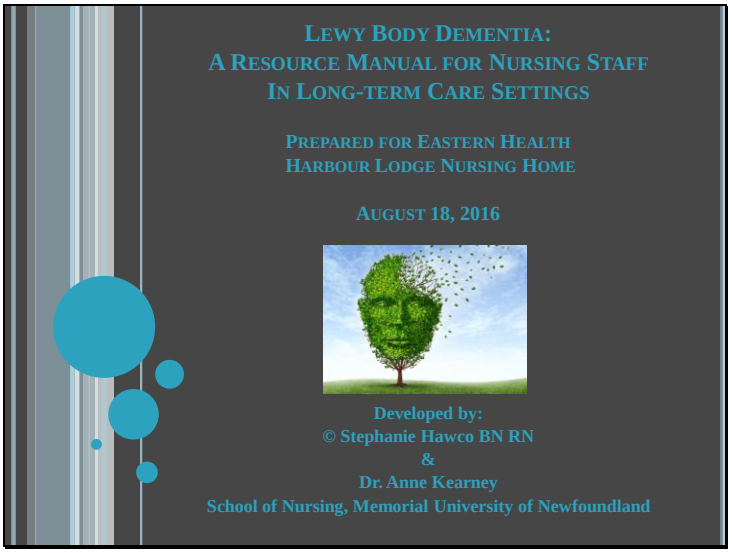
_____
_____
_____
_____

Thank you for taking the time to complete this survey ☺

Appendix D

LBD Nursing Presentation

Slide 1

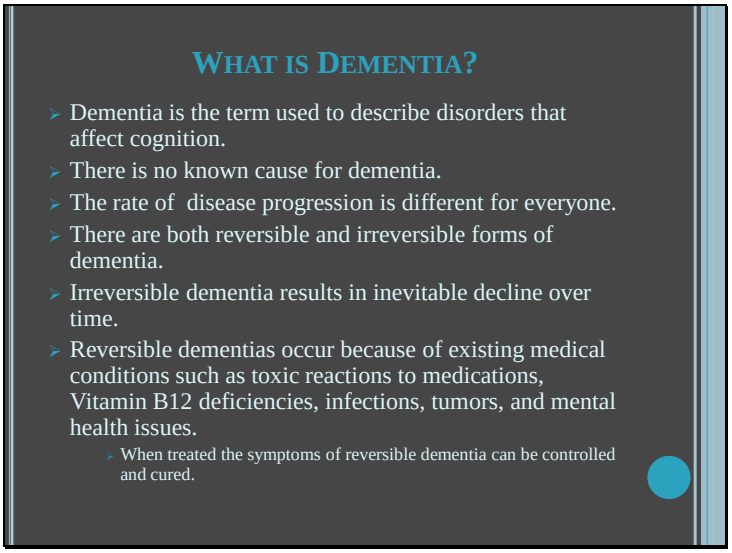


Slide 2

OBJECTIVES

- Define Lewy Body Dementia (LBD).
- Identify the cause and risks of LBD.
- Identify the clinical manifestations of LBD, Alzheimer's disease (AD), and Parkinson's disease (PD).
- Identify various non-pharmacological and pharmacological management approaches.
- Identify why resident-centered care is important in the management of LBD.
- Identify the contents of the LBD Resource Manual.
- Enhance new knowledge of LBD using a case study.
- Demonstrate the clinical manifestations of LBD through the use of a video.

Slide 3



Alzheimer Society of Canada, 2015a
Alzheimer Society of Canada, 2015b

Slide 4

DEMENTIA STATISTICS

Global

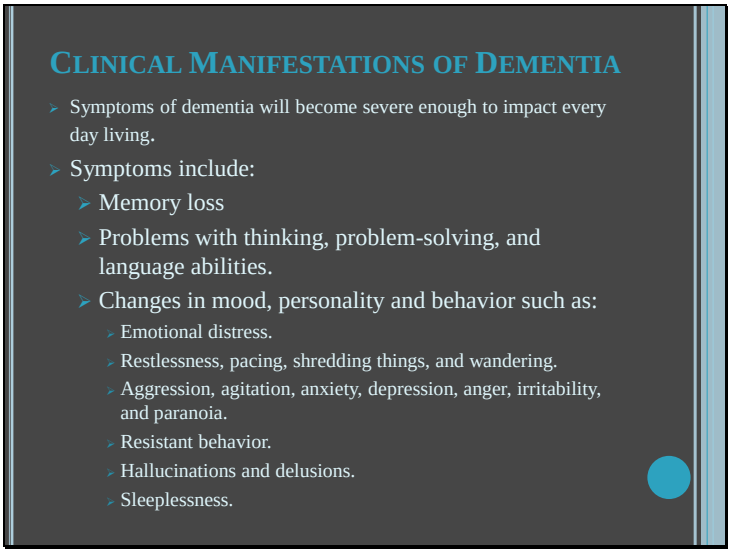
- In 2015, 47.5 million people worldwide were living with dementia.
- This number will triple within in the next 35 years as the population advances in age.
- The risk for dementia doubles every 5 years after 65 years of age.
- Alzheimer's disease (AD) occurs in 10 per 100 people commonly over 65-69 years old.
- Parkinson's disease (PD) occurs in 8 per 1000 people over 80 years old.
- Parkinson's disease dementia (PDD) will occur in 50 – 80% of those with Parkinson's disease.

Canada

- In 2011 – 747, 000 Canadians over 65 had some form of dementia.
- $33 billion dollars a year is spent on dementia care in Canada.

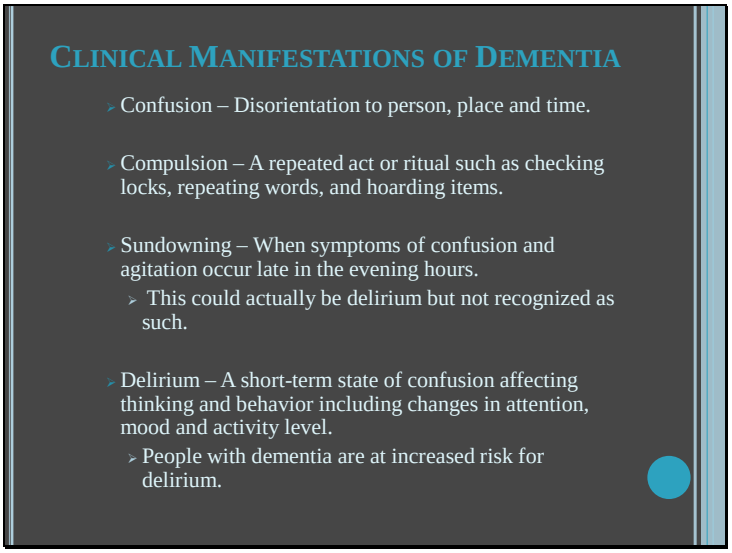
Alzheimer Association, 2016c
Alzheimer Society of Canada, 2015d
Walter et al., 2014

Slide 5



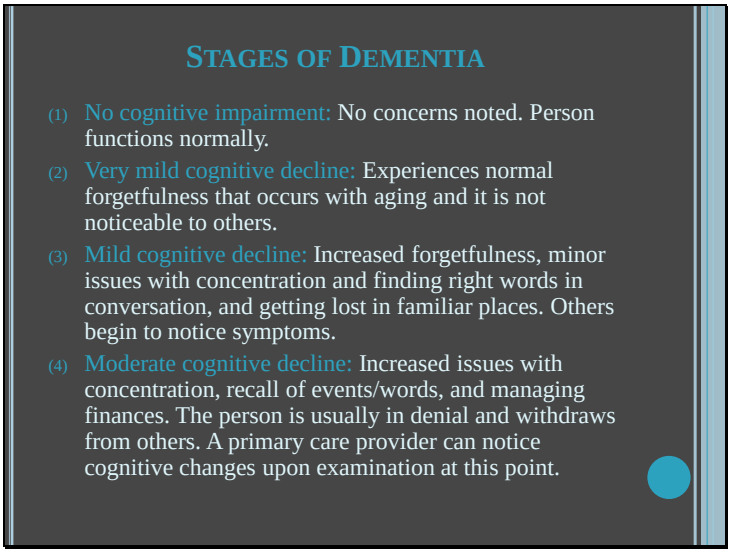
Alzheimer Society of Canada, 2015f
Lewy Body Dementia Association, 2016f

Slide 6



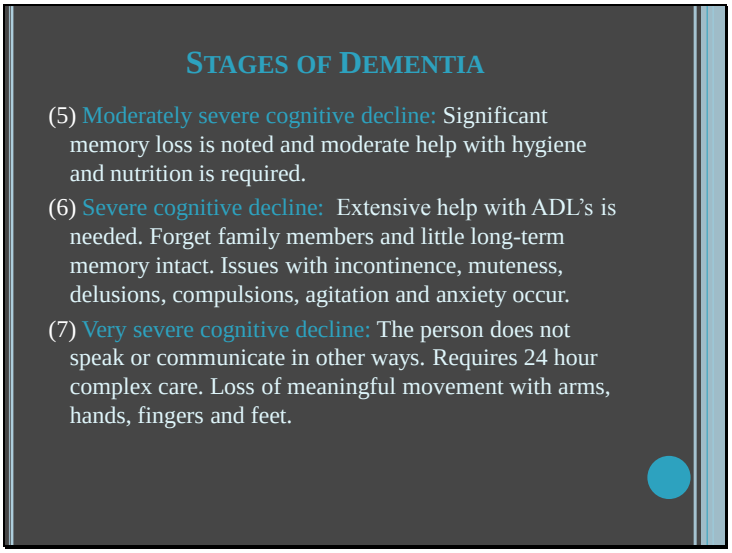
Alzheimer Association, 2016b

Slide 7



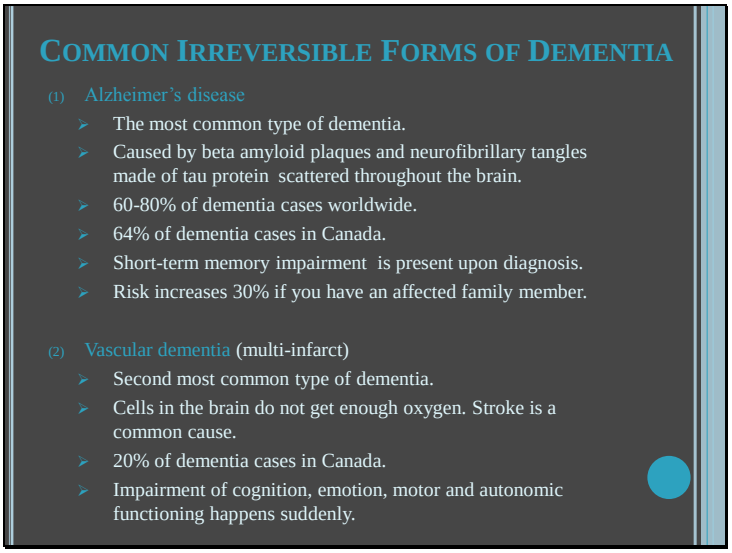
Dementia Care Central, 2016

Slide 8



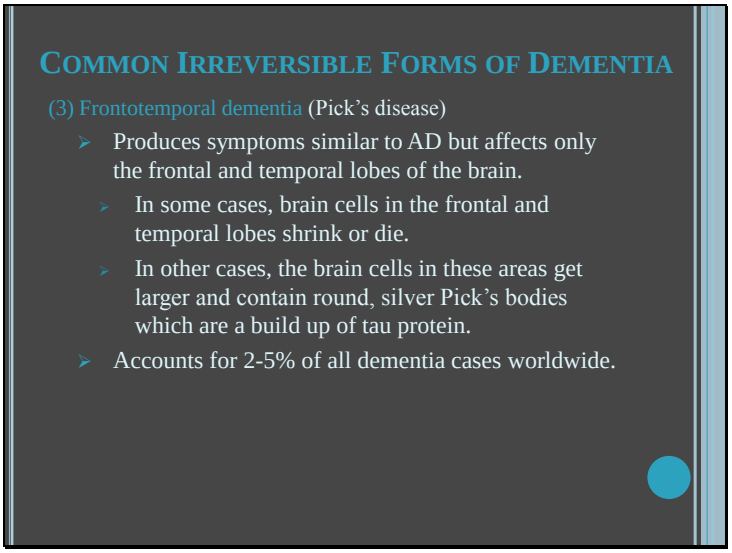
Dementia Care Central, 2016

Slide 9



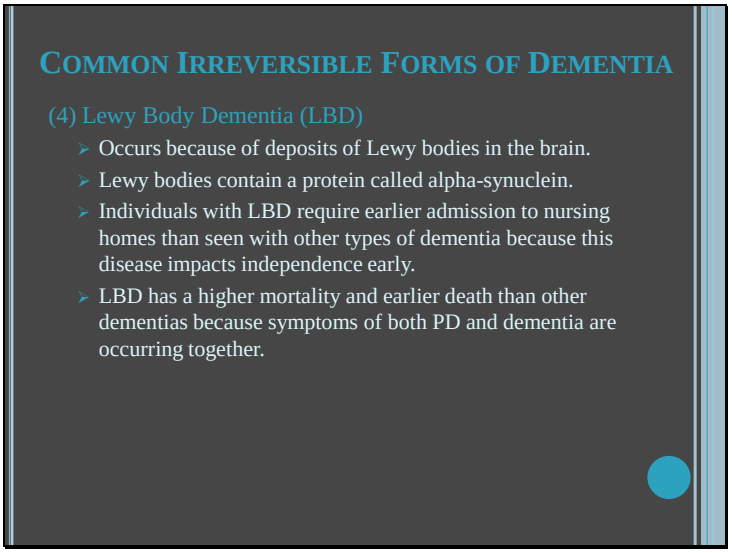
Alzheimer Society of Canada, 2015c
Lewy Body Dementia Association, 2016g

Slide 10



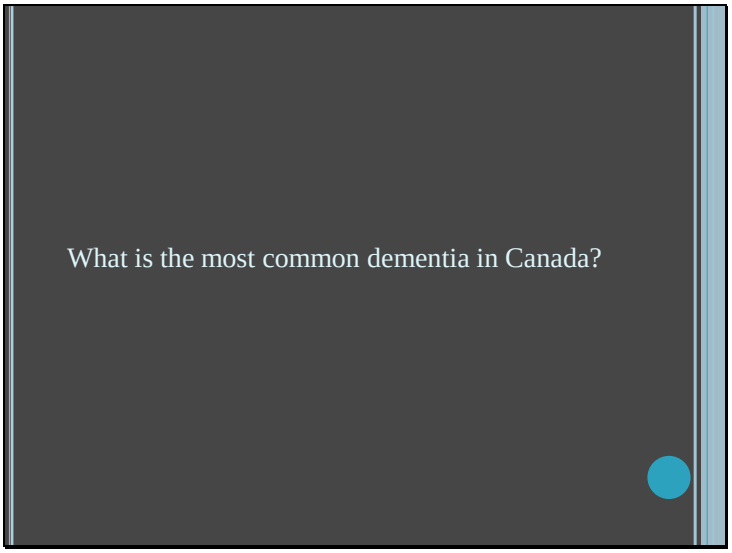
Alzheimer Society of Canada, 2015c
Lewy Body Dementia Association, 2016g

Slide 11



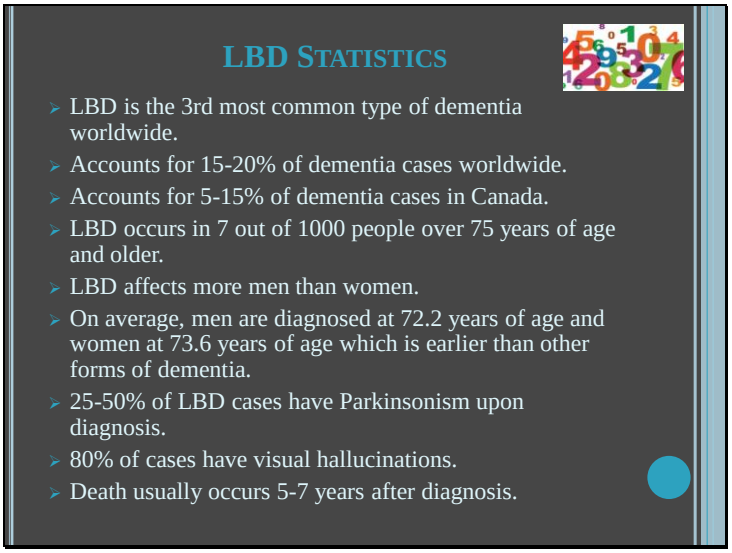
Alzheimer Society of Canada, 2015e
Lewy Body Dementia Association, 2016a

Slide 12



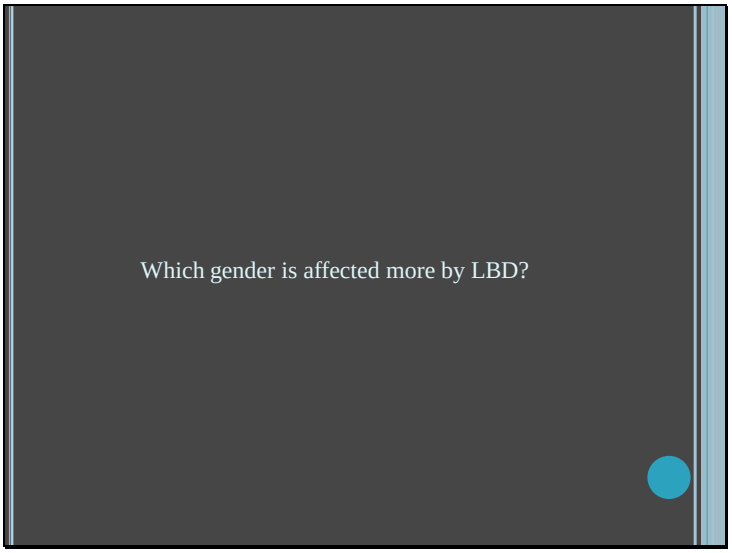
Ans: Alzheimer's disease

Slide 13



Lewy Body Dementia Association, 2016
Lewy Body Dementia Society, 2016e
Walter et al., 2014

Slide 14



Ans: Male

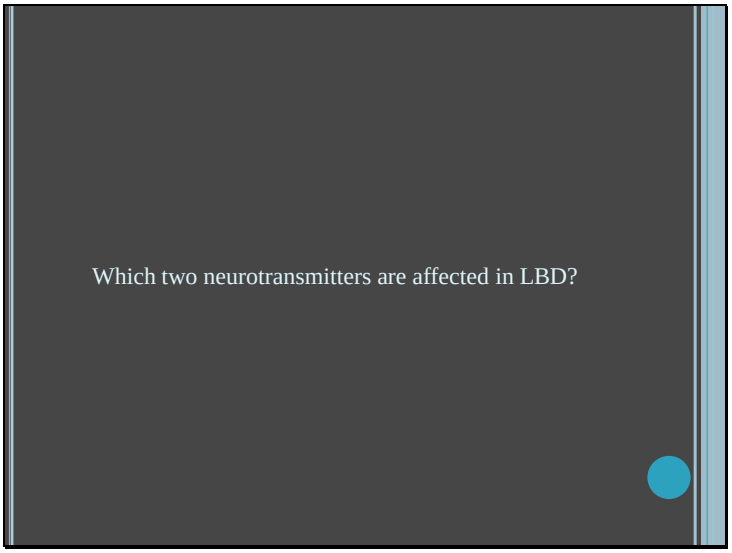
Slide 15

AFFECTED NEUROTRANSMITTERS & RISK OF LBD

- Decreased levels of the neurotransmitters acetylcholine and dopamine result in difficulties with cognition and movement noted in LBD.
  - Acetylcholine – cognition
  - Dopamine - movement
- Controversy exists in the literature regarding a familial link for LBD.
- Advanced age (50 – 85 years) increases risk for LBD.

Lewy Body Dementia Association, 2016c
Walter et al., 2014

Slide 16



Ans: Acetylcholine & dopamine

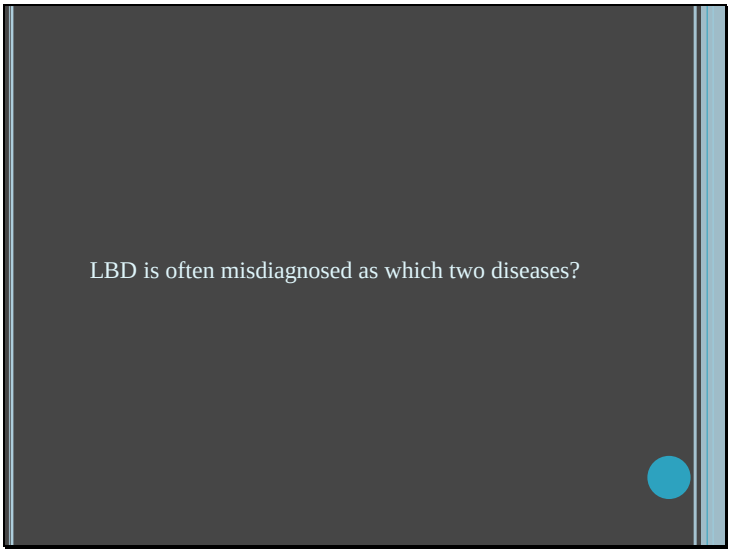
Slide 17

LEWY BODY DEMENTIA

- LBD is often misdiagnosed as AD or PD.
  - AD because of the cognitive symptoms.
  - PD because of the motor symptoms.
- Generally there is a two year lag between onset of symptoms and diagnosis due to lack of awareness among health care professionals regarding LBD and the issue of overlapping symptoms with other forms of dementia.
- LBD is a complex and challenging disease to manage.

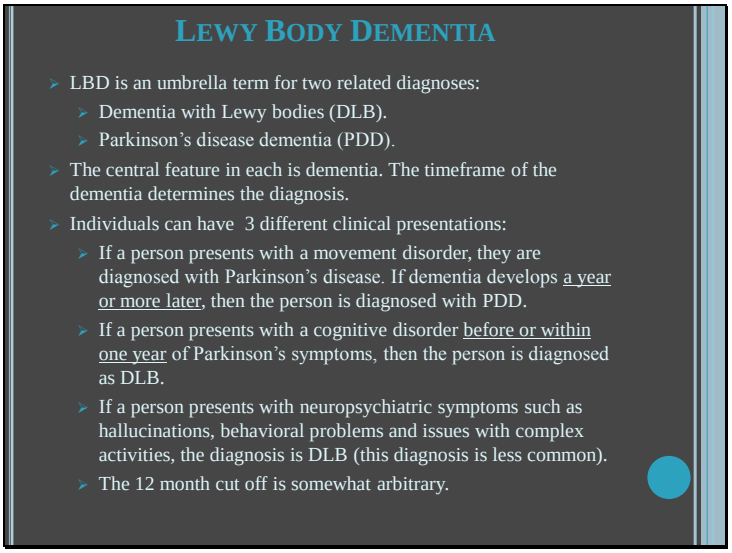
Lewy Body Dementia Association, 2016a

Slide 18



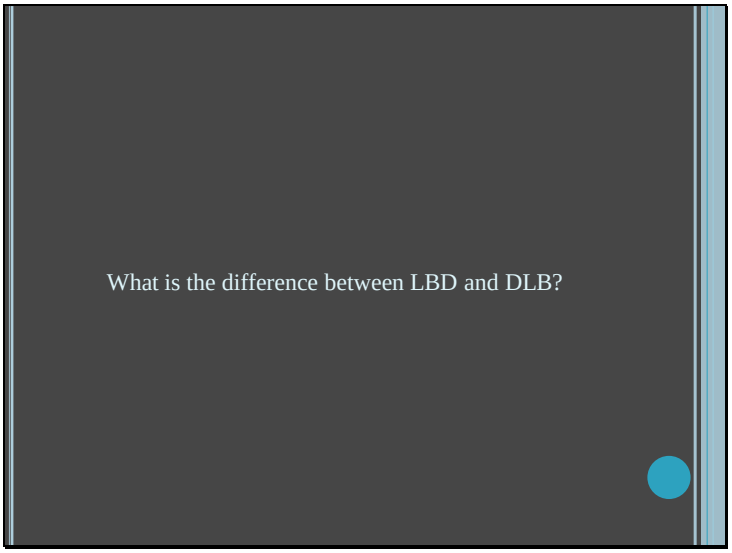
Ans: AD & PD

Slide 19



Alzheimer Society of Canada, 2015e
Lewy Body Dementia Association, 2016h
Lewy Body Dementia Society, 2015

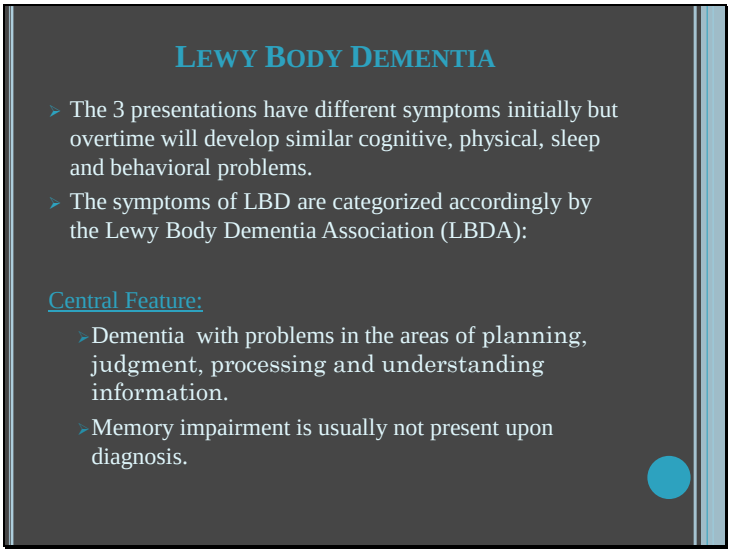
Slide 20



Ans: LBD includes both DLB and PDD diagnoses.

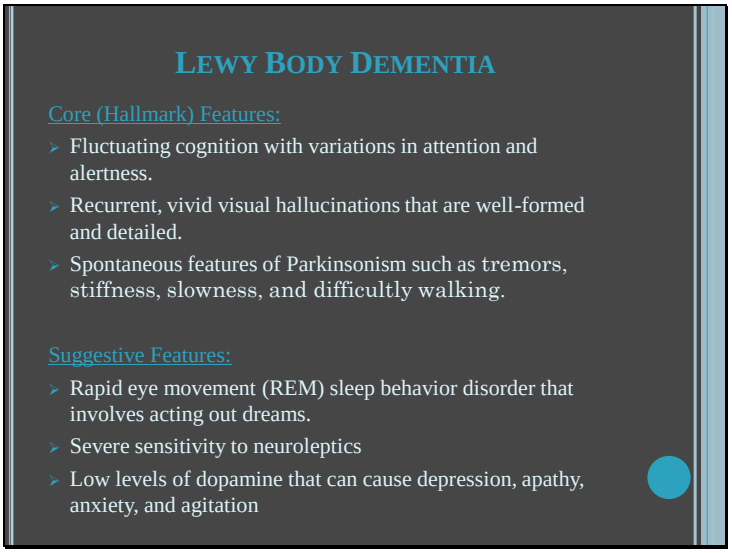
DLB: Cognition affected first, then movement and could also be neuropsychiatric features.

Slide 21



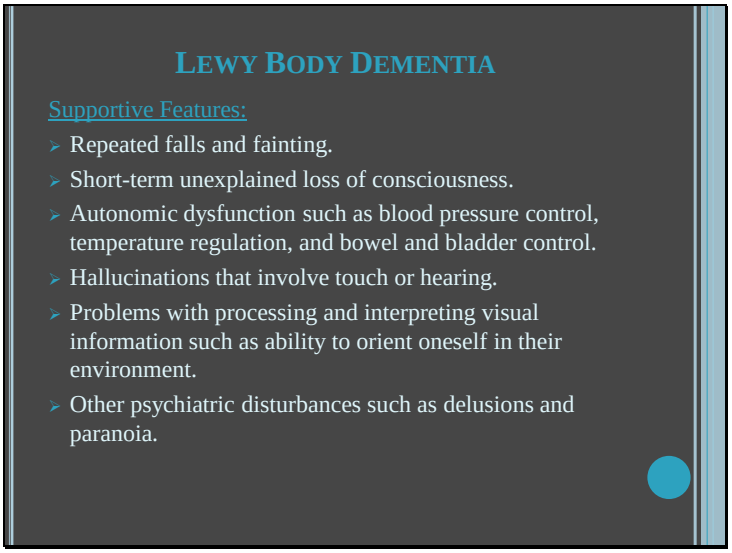
Lewy Body Dementia Association, 2016b
Lewy Body Dementia Association, 2016h

Slide 22

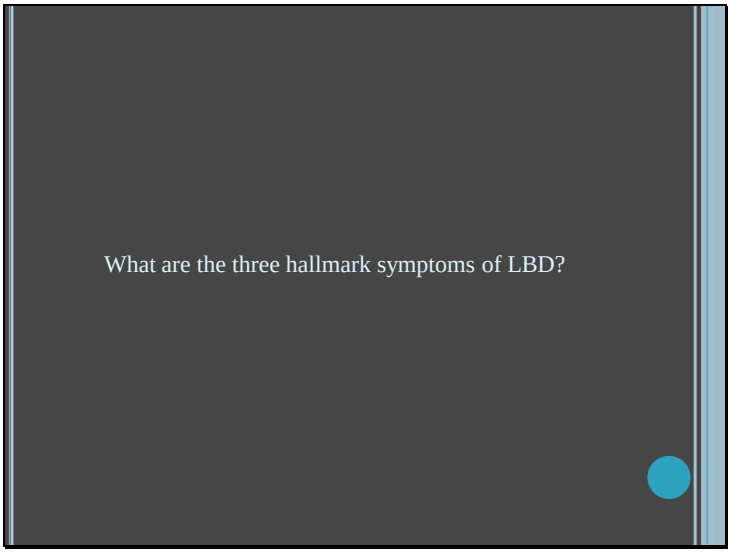


Lewy Body Dementia Association, 2016b

Slide 23

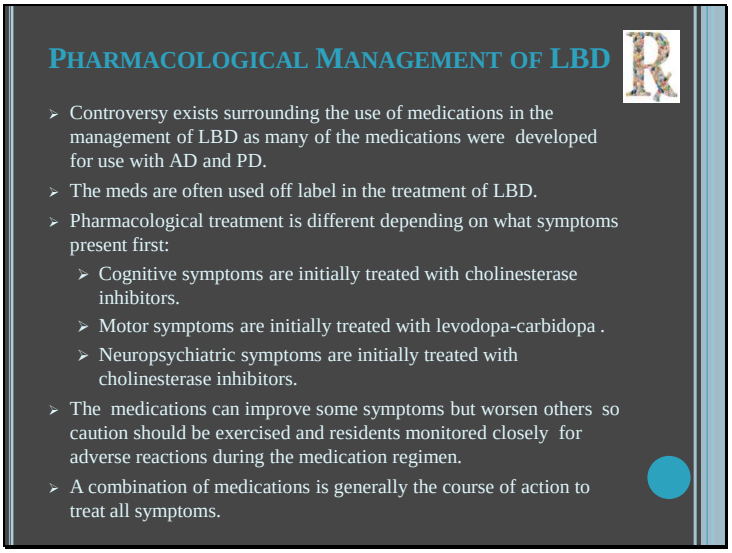

LEWY BODY DEMENTIA
Supportive Features:
Repeated falls and fainting.
Short-term unexplained loss of consciousness.
Autonomic dysfunction such as blood pressure control, temperature regulation, and bowel and bladder control.
Hallucinations that involve touch or hearing.
Problems with processing and interpreting visual information such as ability to orient oneself in their environment.
Other psychiatric disturbances such as delusions and paranoia.

Slide 24



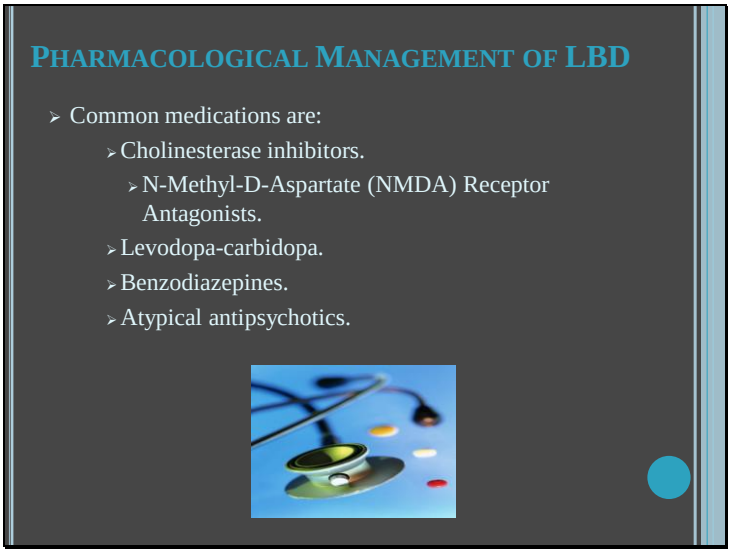
Ans: Fluctuating attention and alertness, vivid visual hallucinations, and spontaneous parkinsonism

Slide 25



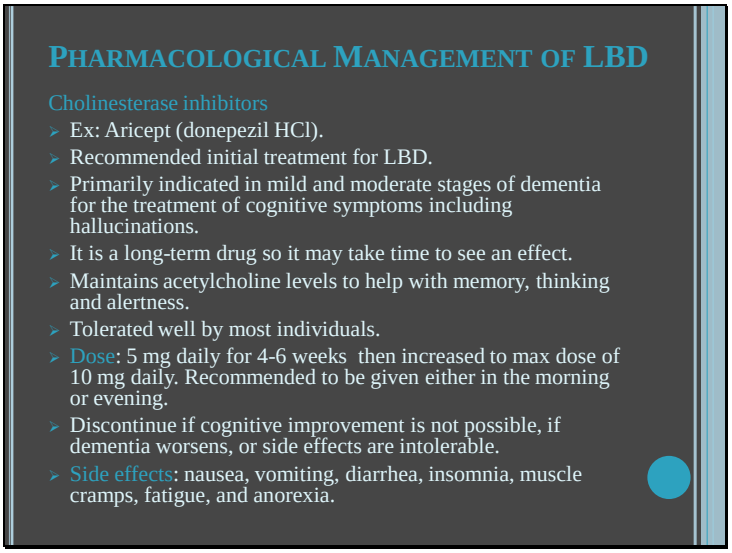
Lewy Body Dementia Association, 2016d
Lewy Body Dementia Society, 2015
McKeith, 2004; Walter et al., 2014

Slide 26



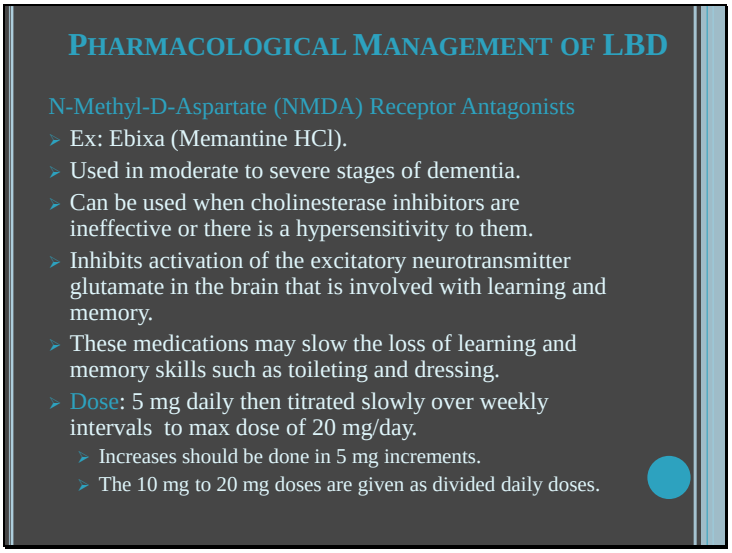
Lewy Body Dementia Association, 2016d
Lewy Body Dementia Society, 2015
McKeith, 2004; Walter et al., 2014

Slide 27



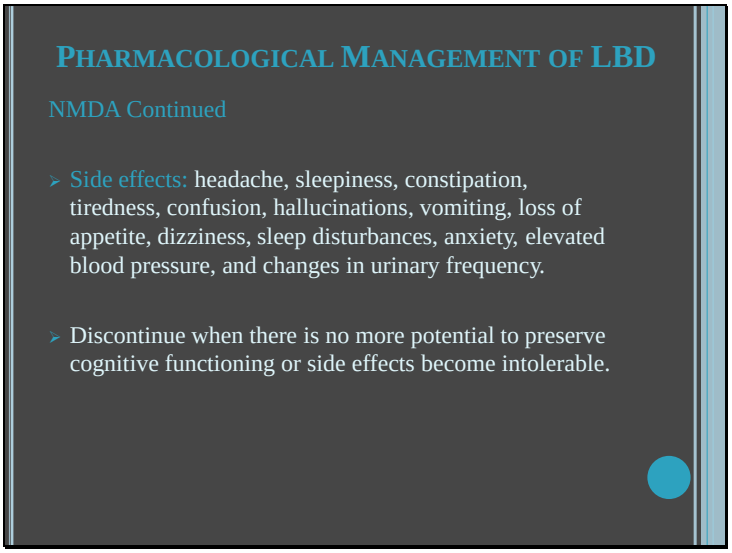
Lewy Body Dementia Association, 2016d
Lewy Body Dementia Society, 2015
Walters et al., 2015
McKeith, 2004
McKeith et al., 2005
Vallerand & Sanoski, 2015
Canadian Pharmaceutical Association, 2015

Slide 28

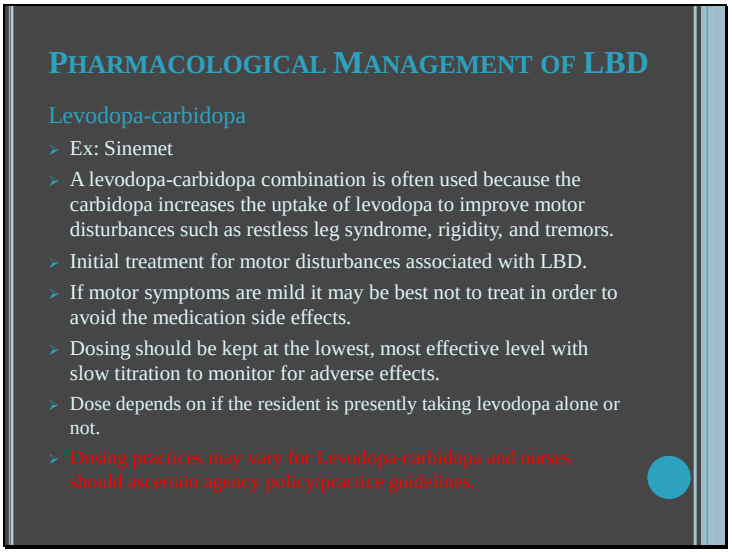


Lewy Body Dementia Association, 2016d
Vallerand & Sanoski, 2015

Slide 29

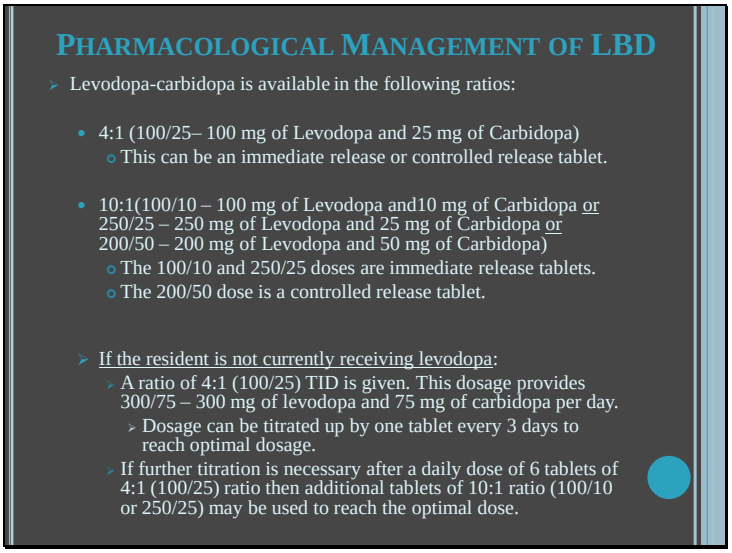

PHARMACOLOGICAL MANAGEMENT OF LBD
NMDA Continued
Side effects: headache, sleepiness, constipation, tiredness, confusion, hallucinations, vomiting, loss of appetite, dizziness, sleep disturbances, anxiety, elevated blood pressure, and changes in urinary frequency.
Discontinue when there is no more potential to preserve cognitive functioning or side effects become intolerable.

Slide 30



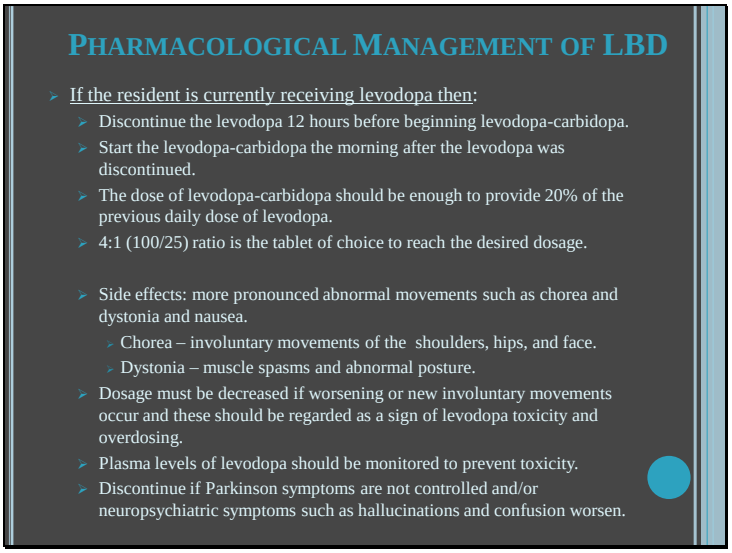
Lewy Body Dementia Association, 2016d
Lewy Body Dementia Society, 2015
McKeith, 2004
McKeith et al., 2005
Walter et al., 2014
Zupancic et al., 2011
Vallerand & Sanoski, 2015.

Slide 31



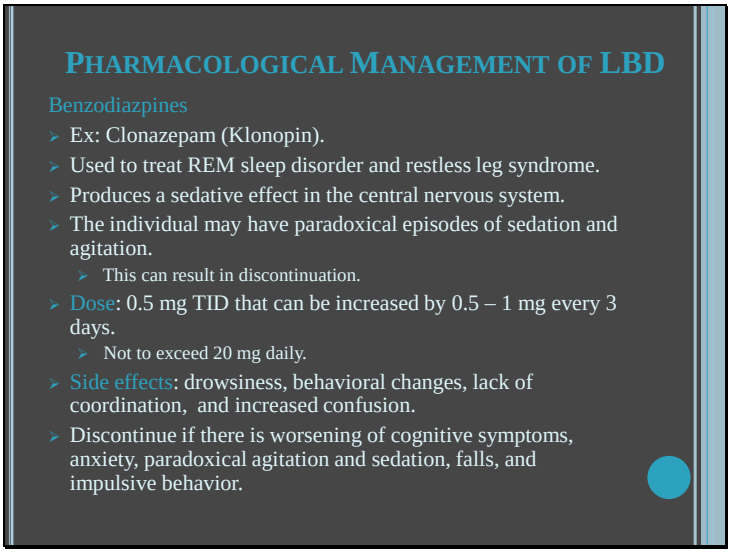
Note: Normally a resident would not receive more than1500 mg/day of levodopa, but if they need to receive above 1800 mg/day then follow the above instructions.

Slide 32



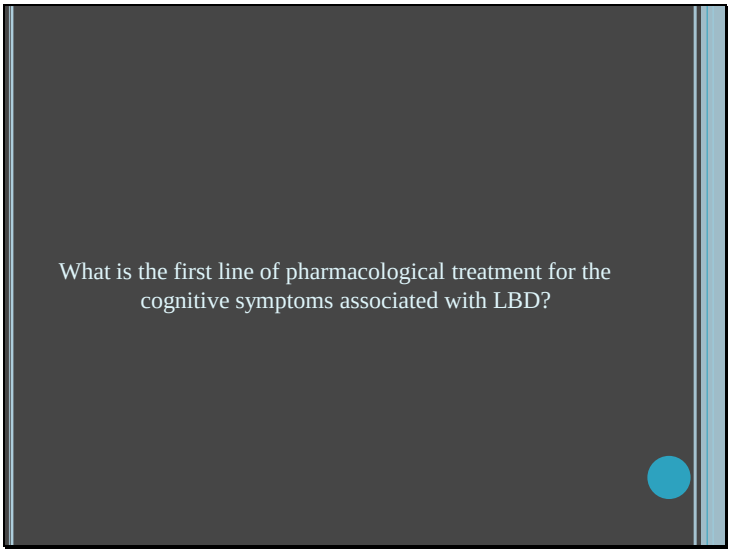
dyskinesia – difficulty or distortion in performing voluntary movement that worsens in PD due to longterm use of levodopa. Chorea and dystonia are the most common.

Slide 33



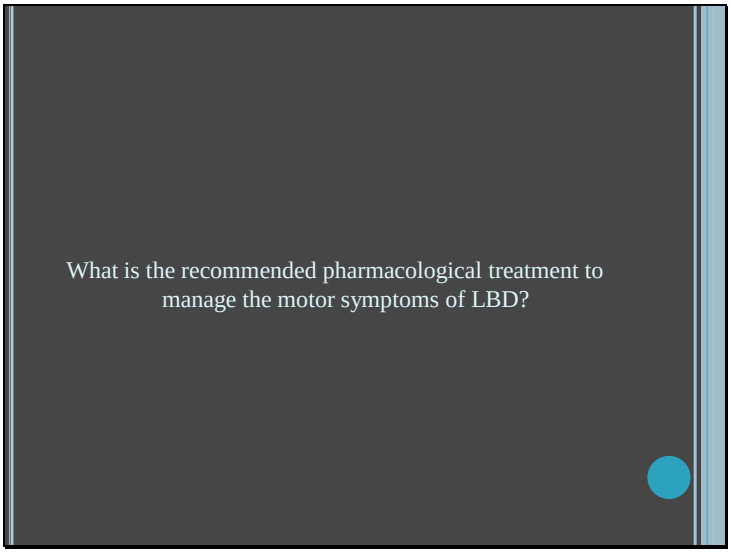
Lewy Body Society, 2015
Vallerand & Sanoski, 2015

Slide 34



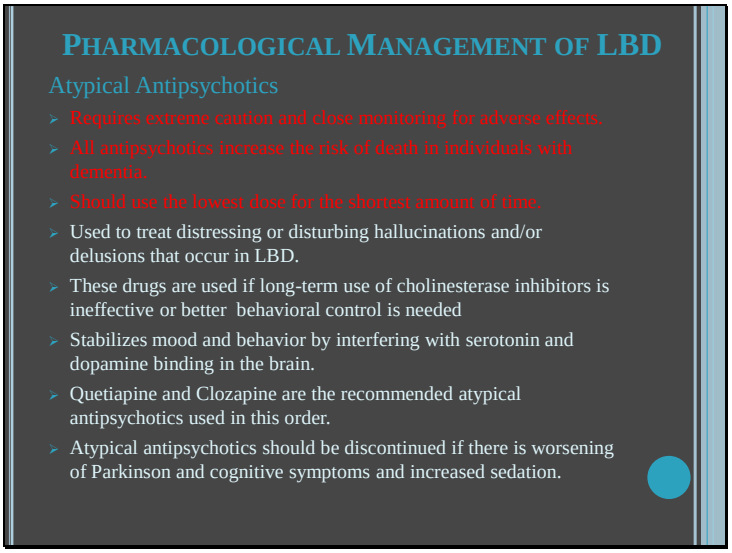
Ans: Cholinesterase inhibitors

Slide 35



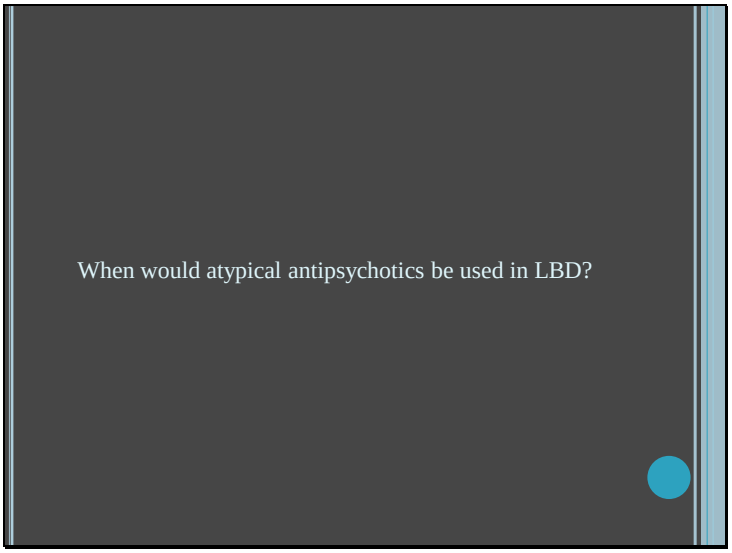
Ans: Levodopa-carbidopa

Slide 36



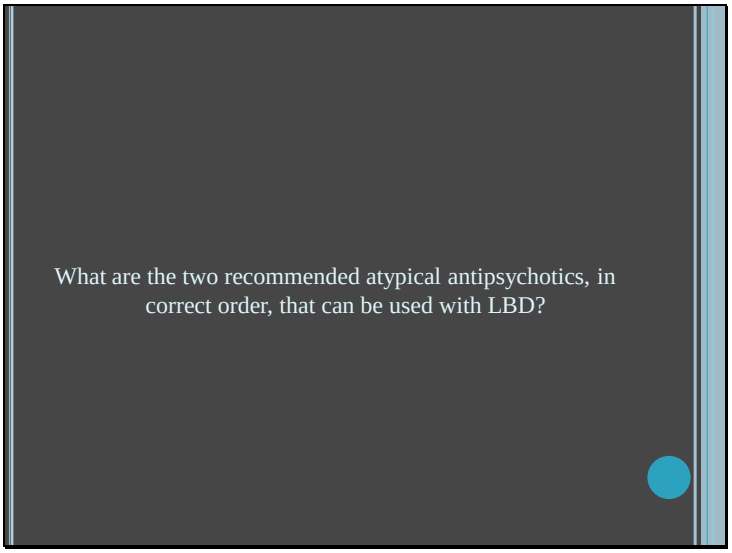
Lewy Body Dementia Association, 2016d
Lewy Body Dementia Society, 2015
McKeith et al., 2005
Walter et al., 2014

Slide 37



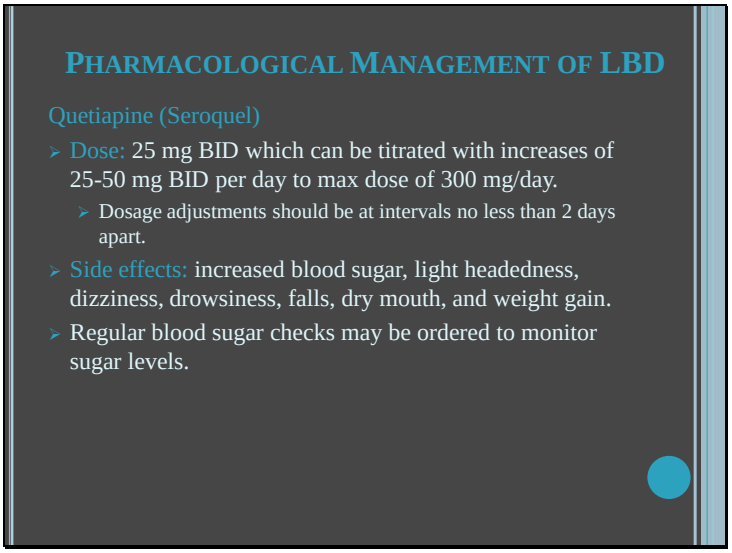
Ans: When long-term use of cholinesterase inhibitors are ineffective or better behavioral control is warranted.

Slide 38



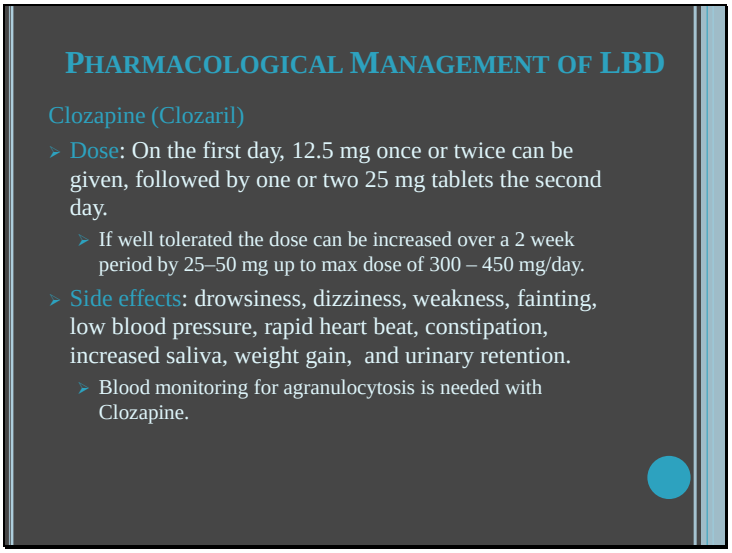
Ans: Quetiapine & clozapine

Slide 39

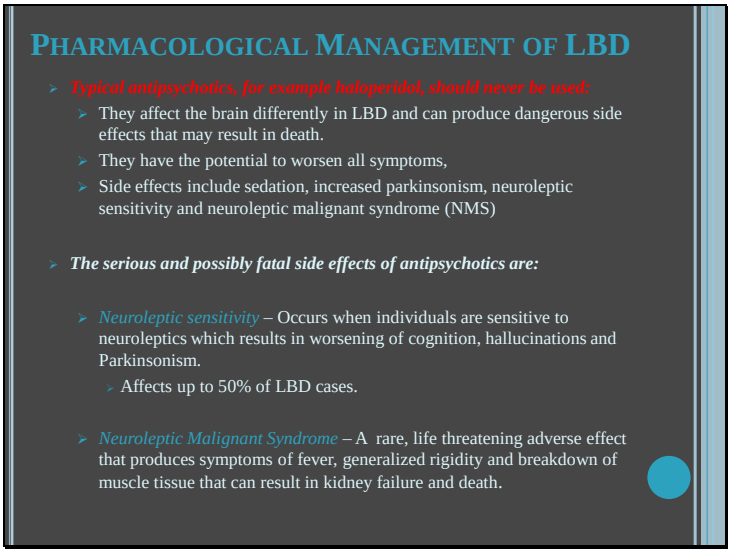


Canadian Pharmaceutical Association, 2015

Slide 40

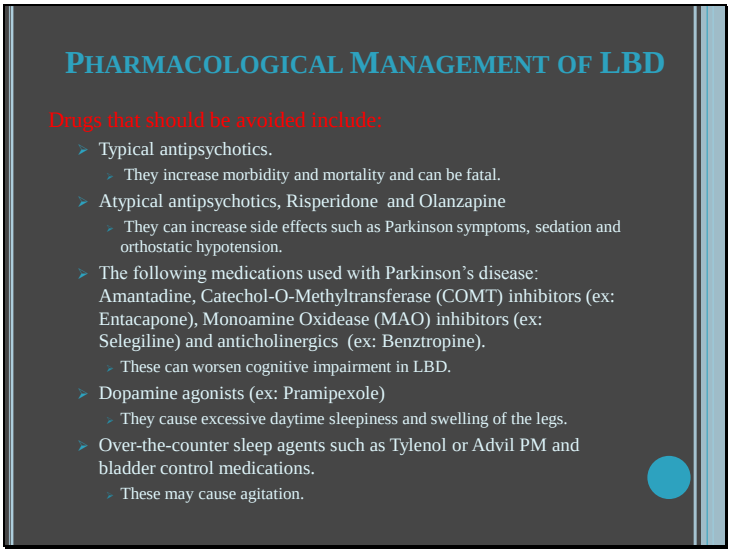

PHARMACOLOGICAL MANAGEMENT OF LBD
Clozapine (Clozaril)
Dose: On the first day, 12.5 mg once or twice can be given, followed by one or two 25 mg tablets the second day.
If well tolerated the dose can be increased over a 2 week period by 25–50 mg up to max dose of 300 – 450 mg/day.
Side effects: drowsiness, dizziness, weakness, fainting, low blood pressure, rapid heart beat, constipation, increased saliva, weight gain, and urinary retention.
Blood monitoring for agranulocytosis is needed with Clozapine.

Slide 41



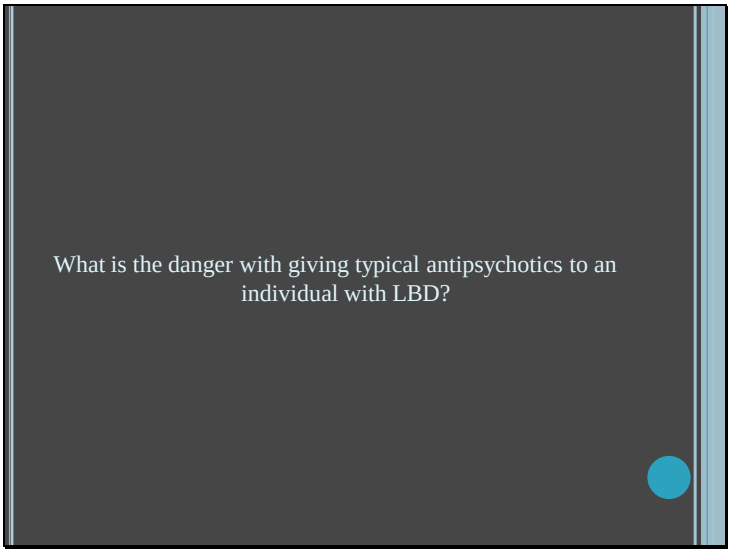
Lewy Body Dementia Association, 2016d

Slide 42



Lewy Body Dementia Association, 2016d
Lewy Body Society, 2015

Slide 43



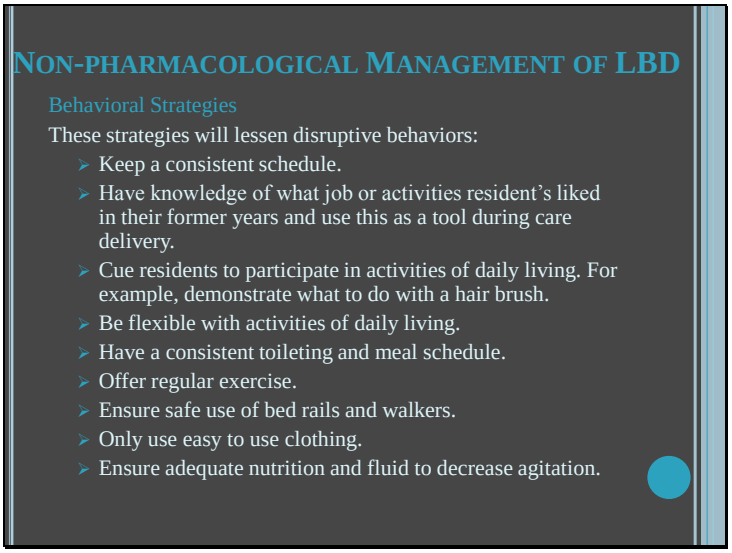
Ans: Neuroleptic sensitivity and neuroleptic malignant syndrome both which can be fatal.

Slide 44

Bullet 1: No literature exists on non-pharmacological interventions specific to LBD but many research articles demonstrate evidence that techniques used with other types of dementia are beneficial for LBD as well (Neef & Walling, 2006; McKeith, 2004; McKeith et al., 2005; Yuhas et al., 2006; Zupancic et al., 2011).

Lewy Body Dementia Association, 2016f

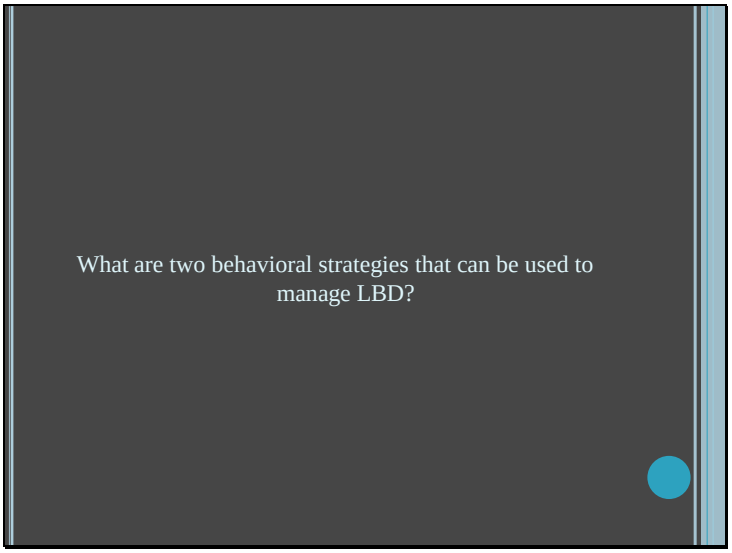
Slide 45



Yuhas et al., 2006

Bullet 2: If a resident was a fisherman all his/her life, then conversations about fishing and the ocean may calm a resident that is agitated so that care can be provided.

Slide 46



Ans: Any listed on prior slide.

Slide 47

NON-PHARMACOLOGICAL MANAGEMENT OF LBD

Communication Strategies

The following communication strategies can lessen disruptive behaviors:

- Address residents by name.
- Use eye contact.
- Give one step instructions in clear short phrases.
- Break tasks down into steps so individuals do not become overwhelmed.
- Use nonverbal cues to lessen agitation and anxiety:
  - smile.
  - low, gentle tone of voice.
  - hand holding.

Yuhas et al., 2006

Slide 48

Ans: Any on prior slide

Slide 49

Lin et al., 2011; Raglio et al., 2008; Sung, Lee, Li, & Watson, 2012

Slide 50

Azcurra, 2012; Haslem et al., 2014; Subramaniam, Woods & Whitaker, 2014; Van Bogaert et al., 2013).

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NON-PHARMACOLOGICAL MANAGEMENT OF LBD

Doll therapy

- Involves the use of dolls to reduce anxiety and agitation as well as meeting attachment needs.
- Allows the person to mimic caring for a child and can increase their feelings of being useful and needed.
- Behavioral issues of dementia are reduced and social interaction and communication improve as a result.
- Can be used in all stages of dementia.

Bisiani & Angus, 2015

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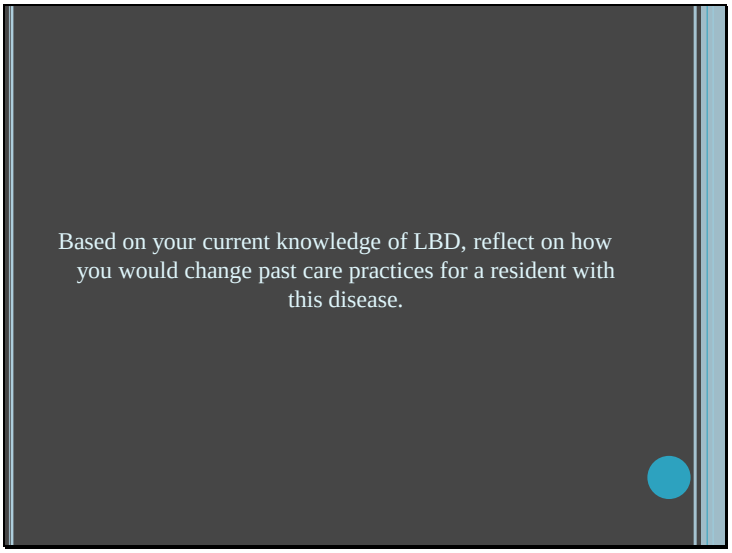
NON-PHARMACOLOGICAL MANAGEMENT OF LBD

Aromatherapy

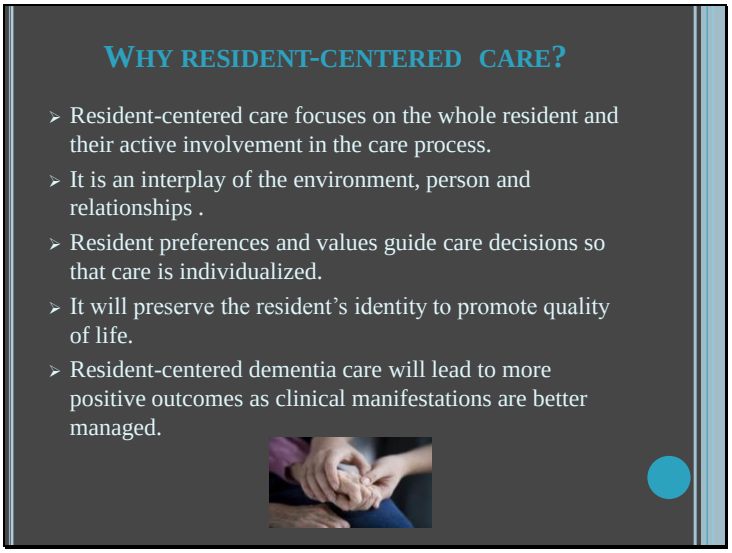
- Involves the use of essential oils such as lavender either absorbed directly on the skin or inhaled.
- Lavender acts as an antidepressant, has a calming effect, reduces agitation and promotes sleep.
- It is a fairly new treatment option so research is limited.
- Can be used in all stages of dementia.

Forrester et al., 2014

Slide 53


Based on your current knowledge of LBD, reflect on how you would change past care practices for a resident with this disease.

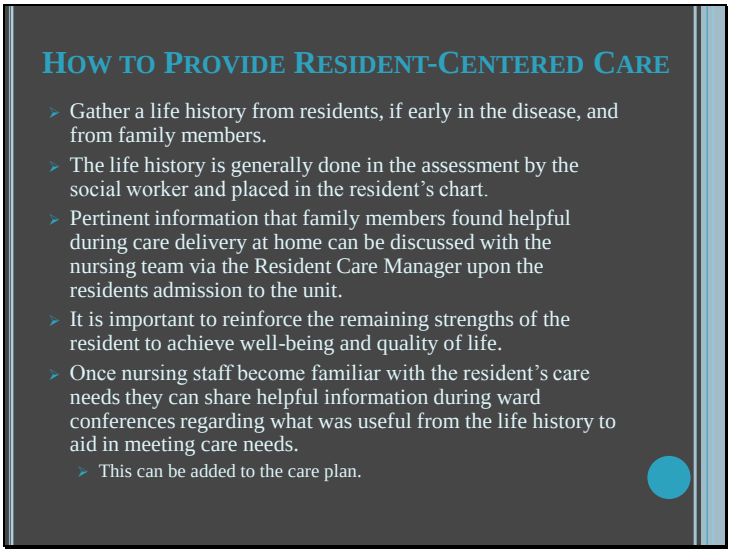
Slide 54



Bullet 1: Holism will preserve a sense of self (Chenoweth et al., 2009).

Bullet 2: All aspects of a clients life including clinical, social and functional history, along with preferences and needs are important to individualized care (Stein-Parbury et al., 2012)

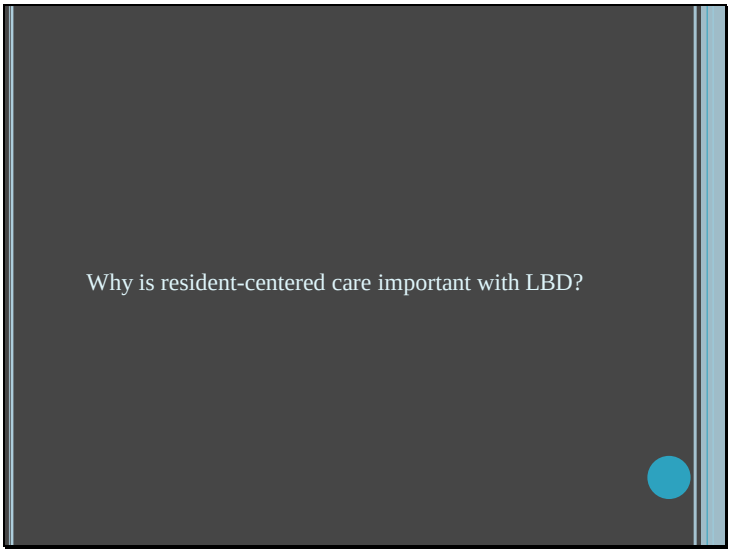
Slide 55



Stein-Parbury et al., 2012
Hoe & Thompson, 2010

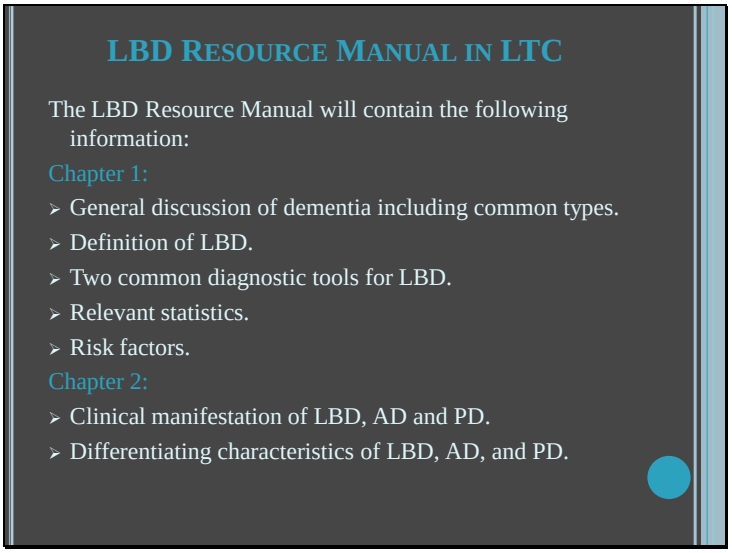
Through empathetic interactions between the nurse and client in dementia care, the client will have a better sense of self and nursing staff will have an increased understanding of the importance of life history to preserve the client's identity, well-being and overall quality of life (Kitwood & Bredin, 1992; Stein-Parbury et al., 2012).

Slide 56



Ans: To ensure resident needs to maintain well-being and quality of life.

Slide 57


LBD Resource Manual in LTC
The LBD Resource Manual will contain the following information:
Chapter 1:
General discussion of dementia including common types.
Definition of LBD.
Two common diagnostic tools for LBD.
Relevant statistics.
Risk factors.
Chapter 2:
Clinical manifestation of LBD, AD and PD.
Differentiating characteristics of LBD, AD, and PD.

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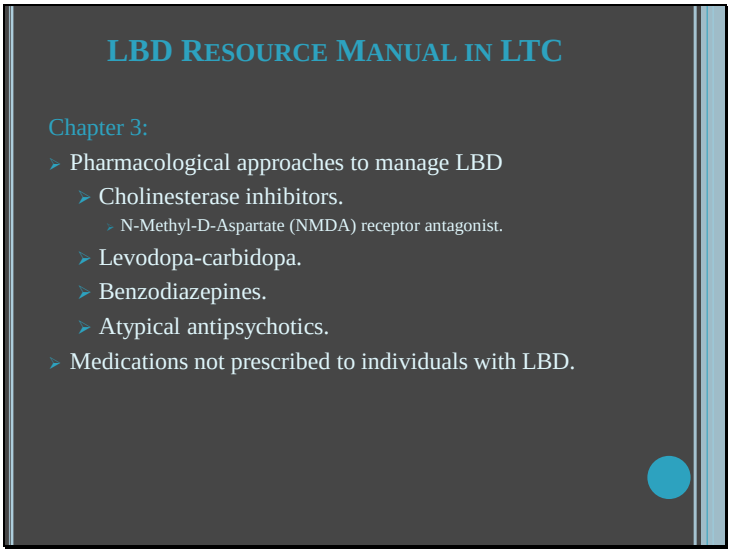
LBD Resource Manual in LTC
Chapter 3:
Pharmacological approaches to manage LBD
Cholinesterase inhibitors.
N-Methyl-D-Aspartate (NMDA) receptor antagonist.
Levodopa-carbidopa.
Benzodiazepines.
Atypical antipsychotics.
Medications not prescribed to individuals with LBD.

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-The enhanced knowledge regarding LBD will improve care practices and hopefully improve quality of life.

-Treatment options that are resident-centered to specifically meet each residents needs will enhance quality of life and patient outcomes.

-If nursing staff are better informed on the disease process of LBD then they are more prepared to communicate with families and physicians regarding the disease trajectory and care options.

- the resource manual can be used at the learner's own pace when time permits and is deemed to be a good education tool in the literature to enhance learning and knowledge for nurses (Sparling, 2001).

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LBD Resource Manual in LTC

The manual will also contain:

- Pre-post tests to assess knowledge levels regarding LBD before and after reading the manual.
- 2 Case studies to promote problem-solving abilities using newly acquired knowledge.
- Evaluation survey to assess satisfaction with the resource manual.

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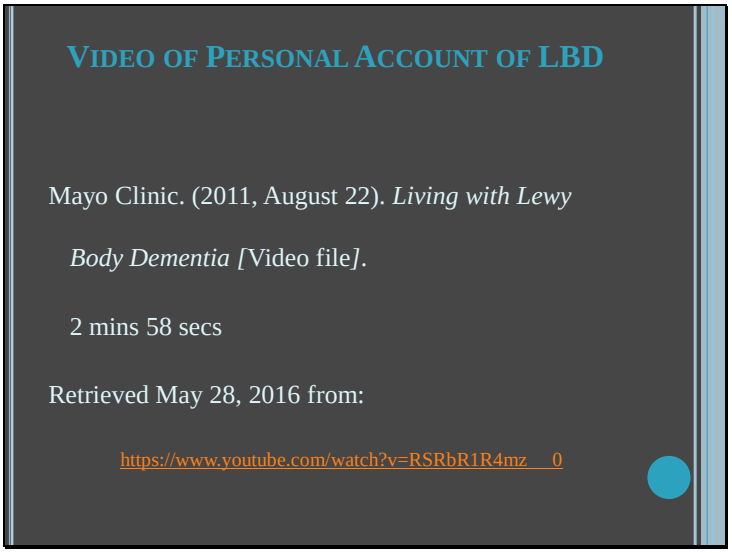
SUMMARY

- LBD progresses very rapidly.
- LBD greatly impacts quality of life.
- LBD has 3 clinical presentations with the timeframe of the dementia determining the diagnosis.
- The presenting symptom determines the pharmacological course of treatment.
- A combination of individualized non-pharmacological and pharmacological interventions is most effective for the management of LBD.
- Resident-centered care as a result of enhanced nursing knowledge will enhance quality of life.
- Enhanced knowledge of nursing staff regarding LBD is necessary because the aging population is increasing, and more individuals will be diagnosed with LBD and need care.

Slide 62

Slide 63


VIDEO OF PERSONAL ACCOUNT OF LBD
Mayo Clinic. (2011, August 22). *Living with Lewy Body Dementia* [Video file].
2 mins 58 secs
Retrieved May 28, 2016 from:
https://www.youtube.com/watch?v=RSRbR1R4mz__0

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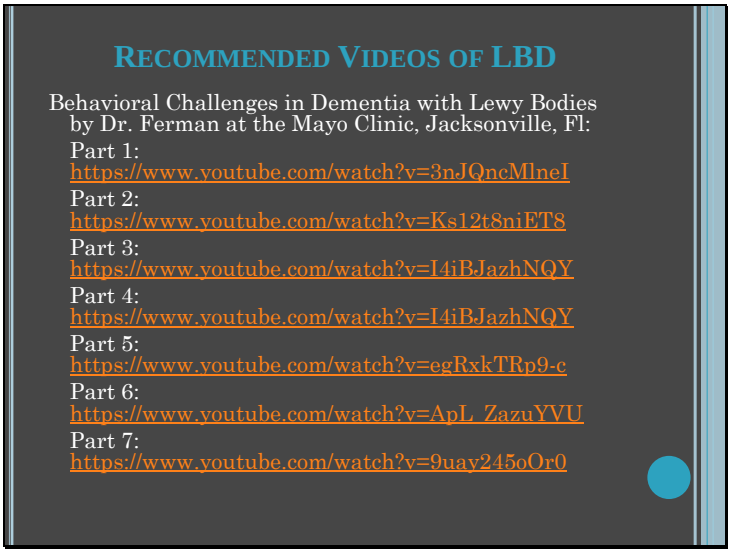
RECOMMENDED VIDEOS OF LBD
Behavioral Challenges in Dementia with Lewy Bodies by Dr. Ferman at the Mayo Clinic, Jacksonville, Fl:
Part 1: https://www.youtube.com/watch?v=3nJQncMlneI
Part 2: https://www.youtube.com/watch?v=Ks12t8niET8
Part 3: https://www.youtube.com/watch?v=I4iBJazhNQY
Part 4: https://www.youtube.com/watch?v=I4iBJazhNQY
Part 5: https://www.youtube.com/watch?v=egRxkTRp9-c
Part 6: https://www.youtube.com/watch?v=ApL_ZazuYVU
Part 7: https://www.youtube.com/watch?v=9uay245oOr0

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Case Study

See hand-out for case study.

Adapted from:

Khotianov, N., Singh, R., & Singh, S. (2002). Lewy body dementia: Case report and discussion. *The Journal of the American Board of Family Practice*, *15*(1), 50-4. Retrieved from: http://www.jabfm.org

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Alzheimer Society of Canada. (2015a). What is dementia? Retrieved May 30, 2016 from: http://www.alzheimer.ca/en/About-dementia/What-is-dementia

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Alzheimer Society of Canada. (2015e). *Lewy body dementia*: Retrieved February 01, 2016 from: http://www.alzheimer.ca/en/About-dementia/Dementias/Lewy-Body-Dementia

Alzheimer Society of Canada. (2015f). *Normal aging vs dementia*. Retrieved May 30, 2016 from: http://www.alzheimer.ca/en/About-dementia/What-is-dementia/Normal-aging-vs-dementia

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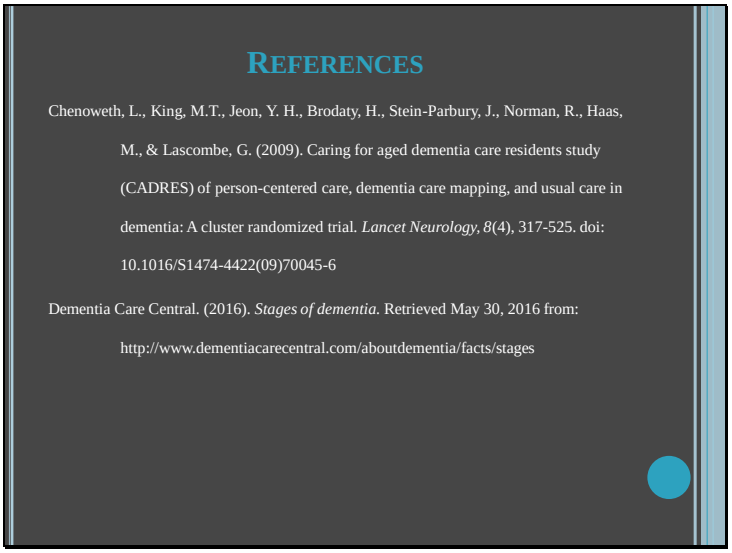
Bisiani, L. & Angus, J. (2012). Doll Therapy: A therapeutic means to meet past attachment needs and diminish behaviors of concern in a person living with dementia – a case study. *Dementia*, *12*(4), 447-462. doi: 10.1177/1471301211431362

Canadian Pharmaceutical Association. (2015). *Compendium of Pharmaceuticals and Specialties*. Retrieved July 05, 2016 from: https://www.etherapeutics.ca/search

Slide 70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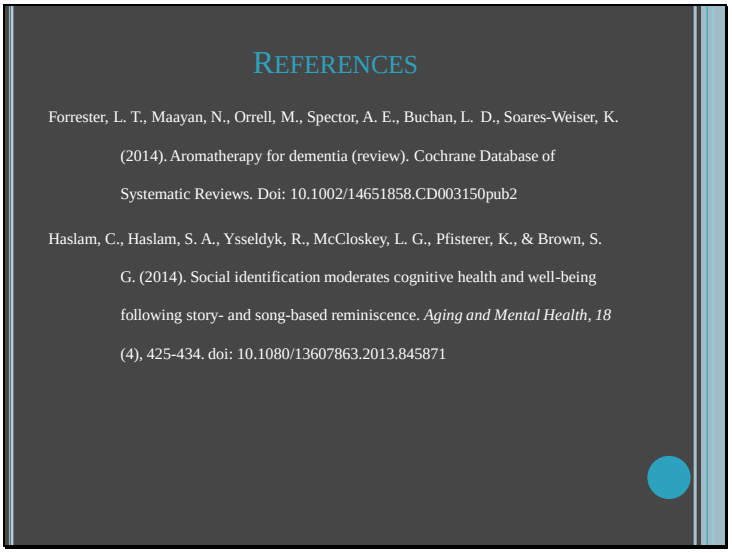
Chenoweth, L., King, M.T., Jeon, Y. H., Brodaty, H., Stein-Parbury, J., Norman, R., Haas, M., & Lascombe, G. (2009). Caring for aged dementia care residents study (CADRES) of person-centered care, dementia care mapping, and usual care in dementia: A cluster randomized trial. Lancet Neurology, 8(4), 317-525. doi: 10.1016/S1474-4422(09)70045-6
Dementia Care Central. (2016). Stages of dementia. Retrieved May 30, 2016 from: http://www.dementiacarecentral.com/aboutdementia/facts/stages

Slide 71


REFERENCES
Forrester, L. T., Maayan, N., Orrell, M., Spector, A. E., Buchan, L. D., Soares-Weiser, K. (2014). Aromatherapy for dementia (review). Cochrane Database of Systematic Reviews. Doi: 10.1002/14651858.CD003150pub2
Haslam, C., Haslam, S. A., Ysseldyk, R., McCloskey, L. G., Pfisterer, K., & Brown, S. G. (2014). Social identification moderates cognitive health and well-being following story- and song-based reminiscence. Aging and Mental Health, 18 (4), 425-434. doi: 10.1080/13607863.2013.845871

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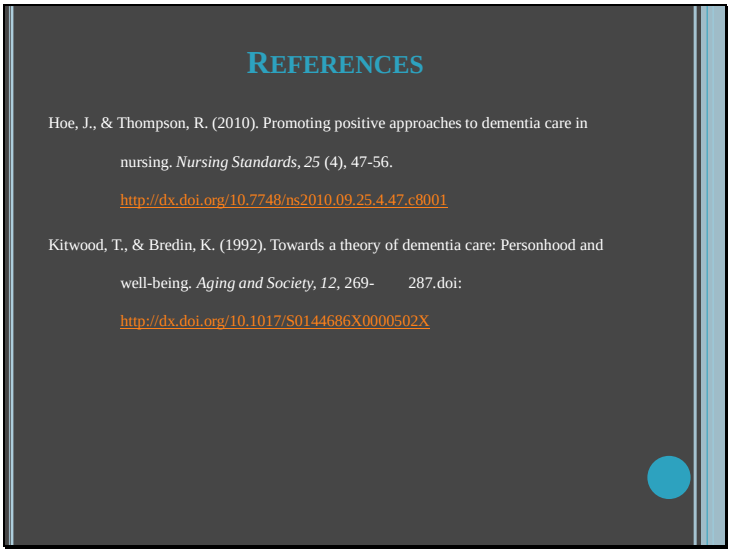
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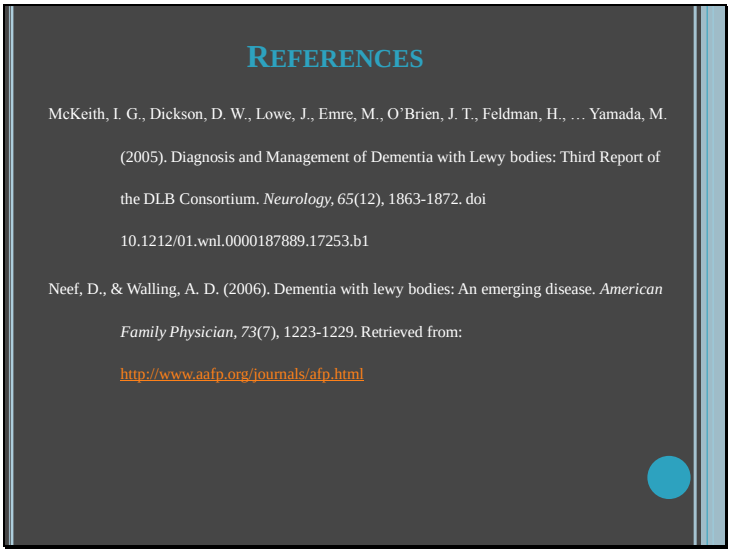
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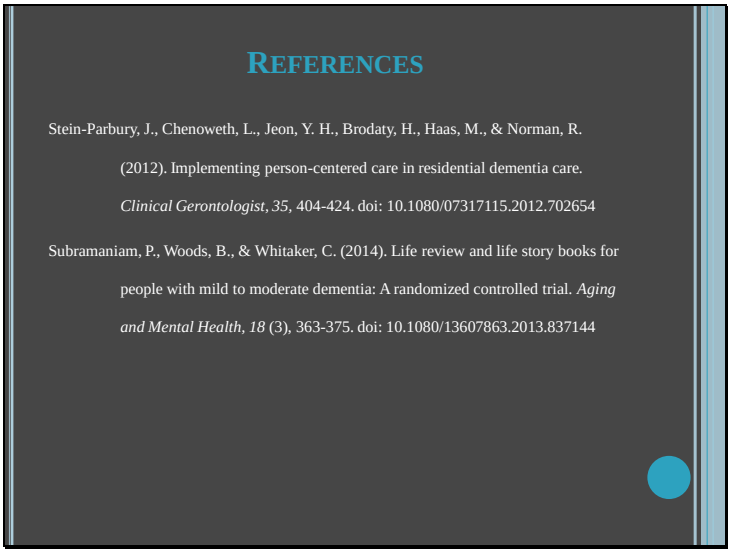
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