


Linking Problems Reported by Care Partners of Individuals With Alzheimer’s Disease and Lewy Body Dementia to the International Classification of Functioning Disability and Health

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Abstract

Aim: This study aims to classify, describe, and compare the problems reported by care partners of adults with Alzheimer’s disease (AD) and Lewy body dementia (LBD) using the International Classification of Functioning Disability and Health (ICF)

Methods: Problems that care partners experience were collected during a problem-solving training intervention. The meaningful concepts were then extracted and linked to the ICF using a standardized linking technique.

Results: 402 meaningful concepts were extracted from 128 problems reported by care partners. 79.4% of the concepts were linkable to the ICF. “Body functions” was most frequently addressed followed by “Activities and participation.” LBD care partners reported more problems ($M = 23.6 \pm 13.4$) on average than AD care partners ($M = 19.4 \pm 12.1$). LBD care partners reported greater relative proportions of problems in mental function (emotional and sleep functions) than AD care partners.

Conclusion: This study suggests that the experience of LBD care partners may include significantly more challenges and may be more emotionally demanding than the care experience of AD care partners. Interventions designed to support care partners of adults with dementia may need to be tailored to meet the needs of care partners based on the care receiver’s type of dementia.

Keywords

International Classification of Functioning, disability and health, dementia care, care partners, caregiving, Alzheimer’s disease, Lewy body dementia

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Transparency statements:

- This study was not formally registered.
- De-identified data from this study will be made available (as allowable according to institutional IRB standards) by emailing the corresponding author.
- There is no analytic code associated with this study.
- Materials used to conduct the study are not publicly available.

Introduction

Caring for someone with dementia is inherently complex, often resting solely on family members or close friends of the person. Care partners usually have little to no experience in dementia care, and caregiving is a risk factor for both psychological and physical ill-health (K. Gilhooly, M. Gilhooly, Sullivan, McIntyre, Wilson, Harding, et al., 2016; Pinquart & Sorensen, 2007; Vitaliano et al., 2003; Xiong et al., 2020). Caregiving demands change as dementia progresses, specifically in the presence of neuropsychiatric symptoms, and as relationship dynamics shift between care partners and care recipients (K. Gilhooly, M. Gilhooly, Sullivan, McIntyre, Wilson, Harding, et al., 2016; Larson & Stroud, 2021). Currently, in dementia care, we assume that assessments, trainings, education material, and outcome measures designed to address the needs of care partners are equally effective across dementia diagnoses without considering the vast variation in care partner experiences. Although AD and LBD are both neurodegenerative diseases that affect memory and learning, they have different disease progression and pathological mechanisms (National Institute of Aging [NIA], 2017). The initial symptoms of AD often include problems with learning, memory, thinking, and planning (NIA, 2017; Koca et al., 2017). By contrast, LBD initially leads to difficulty with problem-solving and reasoning, hallucinations, and sleep disorders (Latimer & Montine, 2018).

A 2016 meta-review of interventions for care recipients and care partners living with dementia found that there is a wide range of intervention types, including psychosocial, psychoeducational, technical, therapy, support groups, and multicomponent programming (K. Gilhooly, M. Gilhooly, Sullivan, McIntyre, Wilson, Harding, et al., 2016). However, the majority of these studies either were in the Alzheimer's disease (AD) population or did not differentiate dementia diagnosis (K. Gilhooly, M. Gilhooly, Sullivan, McIntyre, Wilson, Harding, et al., 2016). Only recently are we able to diagnose and study other dementias, like Lewy body dementia (LBD; the second most common neurodegenerative dementia) due to scientific advances and increased awareness. Despite limited knowledge about the challenges LBD care partners face and how those challenges may differ from those faced by AD care partners, no studies have examined the effectiveness of care partner interventions based on care recipient dementia diagnosis. Furthermore, LBD care

partners report more distress and less ability to cope compared to AD care partners (Zweig & Galvin, 2014), likely because care recipients with LBD have more prominent behavioral and emotional problems, especially in early stages of dementia (Latimer & Montine, 2018; Isik et al., 2019). Thus, little is known about how best to tailor care partner interventions for those who care for individuals with less common, but potentially more disabling, dementias, like LBD (Dauphinot, Delphin-Combe, Mouchoux, Dorey, Bathsavanis, Makaroff, et al., 2015; Galvin et al., 2010).

We propose that these care partner interventions and measures may not be "one-size-fits-all" and that they may need to be tailored to best meet the needs of care partners caring for individuals with dementias other than AD. Therefore, the objective of this study is to characterize and compare the problems that AD and LBD care partners experience, using the International Classification of Functioning, Disability and Health (ICF), to determine if care partner experiences differ based on dementia diagnosis and, if so, how care partner education materials, assessments, and interventions should be tailored.

The ICF, endorsed by World Health Organization (WHO) in 2001, provides a conceptual framework that can be used to understand and describe the lived experience of care partners (WHO, 2001). The ICF is a partner document to the International Classification of Diseases (ICD-10), which classifies diseases, disorders, and other health conditions (WHO, 2001). Since the ICF's conception, the ICF has been applied to numerous health conditions, providing insight into the lived experience of individuals with health conditions and their care partners (Osborne, Kew, Nabsny & Juengst, 2019). A standardized ICF-linking technique, endorsed in 2005 (Cieza et al., 2019), allows investigators to systematically map meaningful concepts to the ICF components, chapters, categories, and/or sub-categories. A meaningful concept is defined as "a single health aspect or an environmental factor with the potential to impact health status" (Offenbacher et al., 2007, p. 692). The technique facilitates the development and tailoring of interventions, education materials, assessments, and outcome measures to best meet individuals' needs. Despite wide application of the ICF in different health conditions, no studies have used the ICF-linking technique to characterize and compare problems experienced by AD versus LBD care partners. Linking AD and LBD care partner problems to the ICF will provide the necessary foundation to best understand their needs.

Methods

This study was conducted during the COVID-19 pandemic. Data were collected as part of a feasibility study of Problem-Solving Training (PST) for care partners of persons with Alzheimer's disease (AD) and related dementias (ADRD). Inclusion criteria were (1) care partner of an individual with ADRD, (2) > 1-year relationship with care recipient, (3)

fluent in English, and (4) able to self-consent. Twenty-six care partners were enrolled in the feasibility study. Care recipients' dementia severity were assessed using the Functional Assessment Staging (FAST) scale based on their ability to perform activities of daily living, scale ranging from stage 1 = normal to 7 = severe dementia (Reisberg, 1988).

PST is a personalized intervention that promotes effective self-management by facilitating active problem-solving; care partners identify and implement possible solutions for self-selected problems in a self-directed manner (D'Zurilla et al., 2004; Juengst, Silva, Goldin, Cicerone, Lengenfelder, Chiaravalloti, Driver, et al., 2019). During the initial PST session, care partners complete a free-text response worksheet designed to help them identify their current or anticipated problems. Problems were defined as "anything that gets in the way of a goal that the care partner wants to achieve." Problems were not limited to caregiving-related problems; that is, they could be separate from caregiving responsibilities or the care recipient's needs. The worksheet had 11 general prompts related to common problem areas for care partners. Problems were discussed in detail during the intervention sessions, and each session was recorded and transcribed. Transcriptions of these sessions were then used to provide context for the problems identified by the care partner on the worksheet to support ICF-linking accuracy.

Linking Concepts to ICF

Care partners' free-text worksheet responses were compiled and linked to the ICF using the refined ICF-linking rules endorsed by the WHO (Cieza et al., 2019). Coders (CK and expert coder CO) identified the meaningful concepts, which were then categorized as care partner (CP) or care recipient (CR) focused based on who the problem directly impacted. An example of a free-text response by a care partner is "changing [my] role—paying bills." This entry contains two meaningful concepts, "changing role" and "paying bills." These concepts were categorized as care partner-focused (CP) as the problem directly impacts the care partner's roles and routines. The following is an example of the linking process of the two concepts. "Changing role" is categorized as "not covered" (*nc*) because it is not covered under the ICF, meaning the ICF does not contain this concept. "Paying bills" is categorized under the Activities and Participation (*d*) component. "Paying bills" falls under Chapter 8 (*d8*): Major life areas and can be further classified into the category: Economic life (*d860-d879*) and sub-category: Basic economic transactions (*d860*). The final codes are *nc* (not covered) and *d860* Basic economic transactions.

In accordance with the most updated ICF-linking rules, coders independently linked the meaningful concepts to one of five components of the ICF: (1) body structures (*s*), (2) body functions (*b*), (3) activities and participation (*d*), (4) environmental factors (*e*), and (5) personal factors (*pf*). Except for personal factors (*pf*), each component is divided into chapters,

and then categories and/or sub-categories (up to four levels). Categories and sub-categories become more detailed with each descending level. Meaningful concepts that were considered too general for linking are either linked at a broader ICF level (i.e., coded at the category level as opposed to sub-categories) or are coded as "unspecified" or "other-specified." Meaningful concepts that were considered too vague or undefinable for linking were coded "not defined" (*nd*) or "not defined-general health" (*nd-gh*, concept relates to health in general). Meaningful concepts that are well-defined but not covered by the ICF were coded as "not covered" (*nc*), and all health conditions or diagnoses were coded as "not covered-health conditions" (*nc-hc*) as they are covered in ICF's partner document, the International Classification of Diseases (ICD).

Reliability

Coders (CK and CO) compared a random 25% of codes to determine inter-rater reliability using Cohen's kappa coefficient. Disagreements were discussed by the coders, and final codes were determined upon consensus.

Statistical Analysis

Demographic variables were analyzed with descriptive statistics. Sample proportions tested differences between the proportions of problems reported by AD versus LBD care partners in each ICF chapter at 95% confidence intervals. Corresponding *p*-values were calculated using either two-sample proportion test or Fisher's exact test, as appropriate. The relative frequency of meaningful concepts linked to each ICF component or chapter was calculated by summing the frequencies of concepts within each component or chapter, as appropriate.

Results

Nineteen care partners ($n = 11$ AD, $n = 8$ LBD) completed the PST problems worksheet. Demographic characteristics are summarized in Table 1. LBD care partners were younger, on average, and their care recipients more often had severe dementia compared to AD care partners.

Care partners reported 128 problems, from which we extracted 402 meaningful concepts. The calculated Cohen's kappa coefficient between both coders was 0.82, considered as *substantial to almost perfect agreement*. Seventy-nine percent of the concepts were linkable to the ICF. The concepts were linked to all four ICF components (Figure 1), across 22 of 30 ICF chapters. On average, AD care partners reported 19.4 (SD = 12.1) problem concepts while LBD care partners reported 23.6 (SD = 13.4) problem concepts.

Sixty of the 402 meaningful concepts were problems of care recipients, 335 were problems of care partners, and 7 were shared problems between both parties. Tables 2 and 3 present summaries of the sample proportions' differences between AD and LBD care partners across the ICF

Table 1. Demographic characteristics of care partners.

	Alzheimer's Disease (AD) Care Partners (n = 11)		Lewy Body Dementia (LBD) Care Partners (n = 8)	
	Mean	Std. Deviation	Mean	Std. Deviation
Age	68.0	12.74	64.9	3.72
Education (years)	17.3	2.20	15.5	3.07
# Family members in house	2.5	1.29	2.1	0.35
	Frequency	Percent	Frequency	Percent
<i>FAST stage of care receiver</i>				
Early dementia	2	18.2	0	0
Mild dementia	6	54.5	4	50
Moderate dementia	3	27.3	0	0
Moderate-severe dementia	0	0	2	25
Severe dementia	0	0	2	25
<i>Gender</i>				
Man	3	27.3	0	0
Woman	8	72.7	8	100
<i>Employment</i>				
Full-time (< 40h/wk)	3	27.3	0	0
Part-time (< 40h/wk)	1	9.1	0	0
Unemployed—currently looking for work	0	0	1	12.5
Unemployed—not looking for work	0	0	1	12.5
Retired (not employed)	7	63.6	6	75
<i>Ethnicity</i>				
Non-hispanic	11	100	7	87.5
Hispanic	0	0	1	12.5
<i>Race</i>				
White	8	72.7	6	75
Black/African American	3	27.3	1	12.5
Unknown	0	0	1	12.5
<i>Marital status</i>				
Single	1	9.1	0	0
Married	10	90.9	8	100
<i>Relationship</i>				
Spouse	8	72.7	7	87.5
Adult child	2	18.2	1	12.5
Sibling	1	9.1	0	0
<i>Duration of relationship</i>				
5–10 years	0	0	1	12.5
> 10 years	11	100	7	87.5
<i>Living together</i>				
Live together	7	63.6	8	100
Live separately	4	36.4	0	0
<i>Depression status</i>				
None to minimal (PHQ-8 score, 0–4)	3	27.3	2	25.0
Mild (PHQ-8 score, 5–9)	6	54.5	4	50.0
Moderate (PHQ-8 score, 10–14)	2	18.2	2	25.0
Moderate to severe (PHQ-8 score, 15–19)	0	0	0	0
Severe (PHQ-8 score >20)	0	0	0	0
<i>Feelings of caregiver burden</i>				
None	0	0	0	0
Mild	1	9.1	0	0
Mild to moderate	9	81.8	6	75.0
Moderate to severe	1	9.1	2	25.0
Severe	0	0	0	0

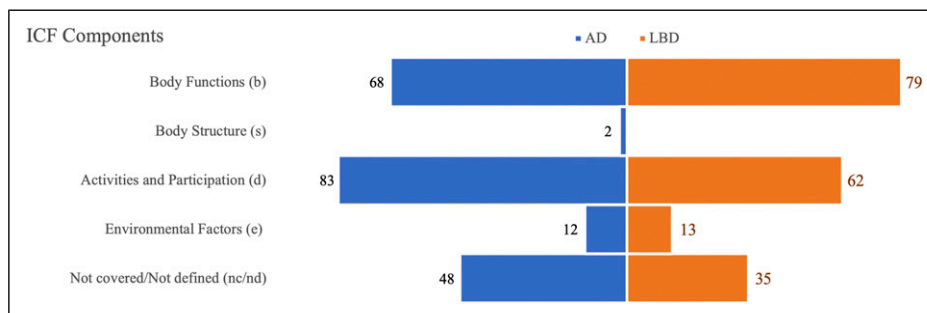


Figure 1. Meaningful concepts by AD and LBD care partners across ICF components. *Numbers in the figures represent count of concepts reported by AD and LBD care partners.

Table 2. Frequency of concepts at the ICF component level between AD and LBD care partners.

ICF Component Level	Frequency		Proportion +/- SD		p-value
	AD	LBD	AD	LBD	
Body functions (b)	68	79	0.319 ± 0.032	0.418 ± 0.036	*0.0402
Activities and participation (d)	83	62	0.390 ± 0.033	0.328 ± 0.034	0.1990
Body structure (s)	2	0	0.009 ± 0.007	0	0.5005
Environmental factors (e)	12	13	0.056 ± 0.016	0.069 ± 0.018	0.6061

Table 3. Frequency of concepts between AD and LBD care partners at the ICF chapter level within the body functions (b) component of the ICF.

ICF Chapter Level	Frequency		Proportion +/- SD		p-value
	AD	LBD	AD	LBD	
b1 mental functions	54	67	0.254 ± 0.030	0.354 ± 0.035	*0.0276
b2 sensory functions and pain	7	3	0.033 ± 0.012	0.016 ± 0.009	0.3465
b3 voice and speech functions	0	1	0	0.005 ± 0.005	0.4701
b4 functions of cardiovascular, hematological, immunological, and respiratory systems	2	2	0.009 ± 0.007	0.011 ± 0.007	1.0000
b5 functions of the digestive, metabolic and endocrine systems	2	2	0.009 ± 0.007	0.011 ± 0.007	1.0000
b6 genitourinary and reproductive functions	0	1	0	0.005 ± 0.005	0.4701
b7 neuromusculoskeletal and movement-related functions	4	3	0.019 ± 0.009	0.016 ± 0.009	1.0000

components and the body functions (b) ICF chapters, respectively.

Body Functions Component

One-hundred-forty-seven (36.6%) meaningful concepts were linked to the body functions component, the most frequently linked component. Body functions are defined as “physiological functions of body systems (including psychological functions)” (WHO, 2001, p. 47). Seven out of eight body functions chapters were linked to problems reported by AD and LBD care partners. This is the only component that differed significantly ($p < 0.05$) in problem concepts reported by AD and LBD care partners ($p = 0.04$); specifically, LBD care partners more frequently reported

problems in *b1 Mental functions* ($p = 0.03$) (Tables 2 and 3).

Figure 2 is a visual summary of the frequencies of problem concepts reported by AD and LBD care partners within ICF chapter *b1 Mental functions*. Both AD and LBD care partners reported the most problems in *b152 Emotional functions*. Emotional functions are “specific mental functions related to feeling and affective components of the processes of the mind”. Concepts such as “stress,” “anger,” “worry,” “anxiety,” “depressed,” “frustrated,” “sadness,” “guilt,” and “grief” are coded in this category. LBD care partners reported more *b152 Emotional functions* problems than AD care partners. AD and LBD care partners reported the same number of problems in *b130 Energy and drive functions*, which includes concepts such as sleep, motivation, and impulse control.

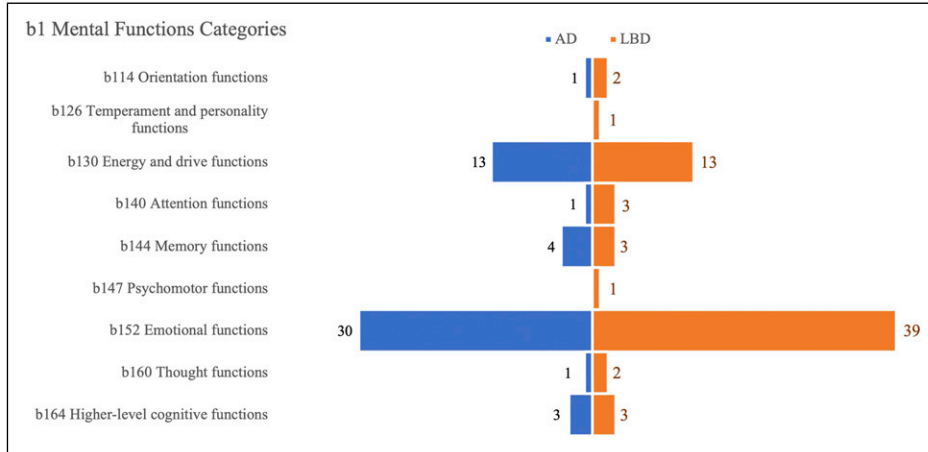


Figure 2. Meaningful concepts by AD and LBD care partners across ICF categories within ICF chapter: b1 Mental functions. *Numbers in the figures represent count of concepts reported by AD and LBD care partners.

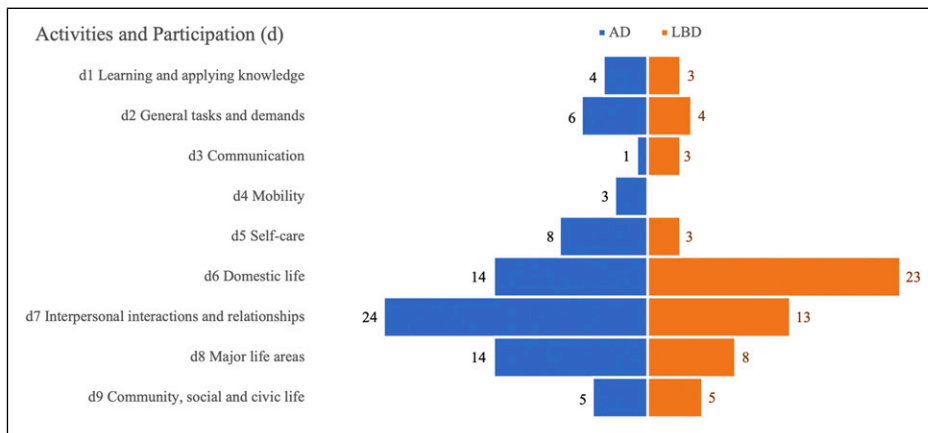


Figure 3. Meaningful concepts by AD and LBD care partners across ICF chapters within the ICF component: Activities and Participation (d). *Numbers in the figures represent count of concepts reported by AD and LBD care partners.

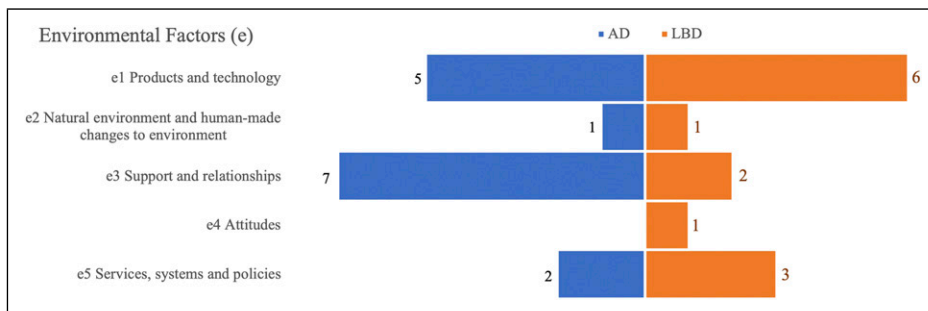


Figure 4. Meaningful concepts reported by AD and LBD care partners across ICF chapters within the ICF component: Environmental Factors (e). *Numbers in the figures represent count of concepts reported by AD and LBD care partners.

Activities and Participation Component

Activity is defined as “the execution of task or action by an individual” and participation is defined as “involvement in a life situation” (WHO, 2001, p. 123). One-hundred-forty-five concepts (36.1%) were linked to the Activities and participation component, making this the second most frequently linked component. All nine Activities and participation chapters were linked to meaningful concepts (Figure 3). Although there were no statistically significant differences in frequency of meaningful concepts between AD and LBD care partners in the Activity and participation chapter (Appendix A), AD care partners reported more problem concepts in *d7 Interpersonal interactions and relationships* and *d8 Major life areas*—concepts related to employment and finances—than LBD care partners. Conversely, LBD care partners reported more problem concepts in *d6 Domestic life*—concepts such as shopping, maintaining vehicles, assisting others with self-care, and mainlining one’s health—than AD care partners.

Environmental Factors Component

Twenty-five (6.2%) concepts were linked to the Environmental factors component, defined as the “physical, social and attitudinal environment in which people live and conduct their lives” (WHO, 2001, p. 171), covering all five chapters (Figure 4). AD care partners most often reported problems in *e3 Support and relationships*. Both groups of care partners also commonly reported problems in *e1 Products and technology*, which includes problems related to drug-use, alcohol-use, smoking cessation, and income.

Not covered/Not Defined

Eighty-three (20.6%) concepts were coded as “not covered” or “not defined.” Nineteen concepts were considered health conditions that can be coded by the ICD, so were coded as “not covered-health condition.” Sixteen concepts were too vague to link to the ICF and were coded as “not defined.” Three concepts were vague concepts of health coded as “not defined-general health,” and 45 concepts were coded as “not covered” (of which 19 were related to behaviors).

Discussion

Our goal was to systematically characterize and compare AD and LBD care partners’ problems, to better understand their lived experiences, using the established ICF linking technique. Consistent with past literature, we found that LBD care partners are more distressed than AD care partners, as they reported significantly more *b152 Emotional functions* concepts compared to AD care partners (Ricci et al., 2009; Zweig & Galvin, 2014). Care recipients with LBD frequently present with neuropsychiatric symptoms, especially in early stages of dementia (Galvin et al., 2010; Latimer & Montine,

2018; Ricci et al., 2009), and presence of these neuropsychiatric symptoms is strongly correlated with high levels of care partner distress and burden (Galvin et al., 2010; Ricci et al., 2009). Also, since functional decline is typically more rapid in LBD than AD (Latimer & Montine, 2018; Ricci et al., 2009), LBD care partners must adapt more quickly to changes in care recipient function. In this study, LBD care partners more often reported help-rejecting behaviors by care recipients, such as care recipients refusing assistance with toileting and/or denying that incontinence problems existed. Lack of quality sleep may also contribute to higher levels of distress. We found that while both groups of care partners reported problems with sleep, LBD care partners were more likely to attribute the cause of sleep interruption to their care recipients’ nighttime behaviors (i.e., wandering at night and acting out their dreams). There is likely a bidirectional relationship between sleep and caregiving, where more caregiving-related stress contributes to interrupted sleep, and poor sleep affects a person’s ability to provide care, contributing to increased caregiving-related stress (Gao et al., 2019). Researchers and clinicians may consider incorporating education materials, outcome measures, and interventions that address sleep problems and nighttime behavior management into LBD care partner interventions.

Over a third (36.1%) of the overall problem concepts were linked to the *Activities and participations (d)* component, only slightly less than the number of concepts linked to *Body functions (b)*. This accentuates the importance of activity participation in care partners’ lives. Activities and participation is an area that most care partners struggle with regardless of the dementia diagnosis (McCabe et al., 2016). This component captured stressors that related to caregiving and to aspects of the care partner’s lives that were separate from their role as a caregiver. The most common categories included domestic life, interpersonal interactions and relationships, major life areas, and self-care. Problems in these areas are well-known risk factors of care partner strain. It appears that AD and LBD care partners’ ability to manage caregiving responsibilities and participate in other life areas (i.e., housework, interpersonal relationships, employment, and self-care) are affected in a similar manner, so interventions and materials that target this area may be transferrable across care partner groups. Of note, this study was conducted during the COVID-19 pandemic, and therefore, care partners’ participation in the community may vary from non-pandemic participation routines.

Dementia care is multidimensional regardless of dementia type, made more complex by preexisting relationship dynamics between the care partner and care recipient. The bidirectional companionship and physical and emotional support that the care partner and care recipient provide for each other will change as dementia progresses (Isik et al., 2019; Larson & Stroud, 2021). Care partners in this study repeatedly expressed concern over the loss of sharing the responsibility of daily tasks and routines. For example, one care partner stated, “Currently, my [care recipient]

drives and I navigate; this may be an issue in the future when [care recipient] can no longer drive.” Another example highlights the emotional strain that both the care partner and care recipient experience, “[care recipient] does not take what I [care partner] say seriously.” Not only do care partners take on responsibilities that were once those of the care recipient, but care partners must also compensate when the support they once received from the care recipient begins to wane. As relationship dynamics change, care partners may also experience a sense loss and/or grief that may further complicate roles, routines, and boundaries. “I [care partner] know I’m still grieving not only the loss of my partner [care recipient], mother, sister, and career within a short time, but also I get depressed about losing the rest of my own life — interests, social engagement, friends, etcetera.” This could occur more rapidly for LBD care partners, and they may have less time to coordinate and organize plans for things such as additional caregivers, end-of-life management, behavioral management, emotional support, and/or home modifications (Galvin et al., 2010; Zweig & Galvin, 2014). Clinicians and researchers who design and implement interventions for LBD care partners should consider these areas and account for the decreased time for planning and preparation due to the rapid onset of disease symptoms.

Limitations

Most of our care partners were non-Hispanic, White, retired, and spouses of their care recipient. Multiple studies report that caregiving experiences are different based on care partners’ ethnicity, race, gender, age, and relationship with their care recipient (Pinquart & Sörensen, 2011; Rigby et al., 2019; Xiong et al., 2020). Therefore, there may be other problems not captured in our study due to our homogeneous study sample. A larger study in the future is warranted to examine differences in problems that care partners face based on demographics and care partner/care recipient relationship dynamics.

Next, the ICF does not currently include the concept of “managing one’s own behavior,” though the ICF Child and Youth (ICF-CY) version does. In the ICF-CY this category is defined as “carrying out simple or complex and coordinated actions in a consistent manner in response to new situations, persons or experiences...” (WHO, 2007). Given that 42% of the “not covered” codes in this study could have been coded under this category, we argue that “managing one’s own behavior” be included in the adult version of the ICF to better characterize both care recipient and care partner experiences.

Conclusion

Our study suggests that AD and LBD care partners experience similar challenges in areas of interpersonal interactions and relationships, domestic life, major life areas, and self-care. Although both AD and LBD care partners experience

challenges in areas of bodily function and mental functions, LBD care partners experience more emotional distress, and their caregiving experience may be more emotionally demanding than the experience of AD care partners. In both AD and LBD, care partners must manage a myriad of additional responsibilities while navigating new relationship dynamics and managing their own daily routine, health, and wellbeing. Given these differences in care partner experiences, existing interventions, measures, and materials designed to support care partners of adults with dementia may need to be tailored to meet the needs of care partners specific to dementia diagnosis.

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Declaration of Conflicting Interests

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Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. IRB Approval was obtained on 2/11/2020 (STU-2020-0300).

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Supplemental Material

Supplemental material for this article is available online.

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