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Experiences of Family Caregivers of Individuals with ID and Dementia

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Abstract

Introduction: Dementia poses a number of impairments in cognitive functioning impacting everyday operational tasks and functions. Individuals with intellectual disability (ID) may experience dementia earlier and at a greater rate than the general population. Dementia can pose complex challenges for individuals with ID and their caregivers.

Aim: A qualitative phenomenological study was used to examine the lived experiences of caregivers of individuals diagnosed with both ID and dementia.

Method: Individual interviews were conducted among six participants, who were all family caregivers of individuals diagnosed with both ID and dementia.

Results: Based on the results from the content analysis of interview responses, four themes emerged: (a) difficulty getting a dementia diagnosis, (b) barriers to obtaining services, (c) caregiving realities and challenges, and (d) rewards of caregiving.

Implications for Practice: To support caregivers, practitioners should be adequately trained on this dual diagnosis to assess the support needs in helping caregivers obtain adequate services.

Conclusion: As individuals with ID continue to live longer and age, many will experience dementia. Caregivers of individuals with ID and dementia are often an overlooked, vulnerable population. Practitioners should be aware of their needs in order to provide adequate support to this caregiving population and individuals with ID and dementia.

Key words: *caregiving, dementia, intellectual disability, developmental disabilities*

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1. Introduction

Caregivers of loved ones with dementia and intellectual disability (ID) are understudied in the literature. Dementia and ID can be debilitating conditions when experienced separately, but can be especially overwhelming when occurring simultaneously. Individuals with ID are at increased risk of developing dementia (Heller et al., 2018; Keator et al., 2020; McGlinchey et al., 2019). Shooshtari et al. (2011) indicated an increased prevalence of dementia 4 to 5 times greater among those with ID compared to the comparison group. Likewise, Strydom et al. (2013) found there is an increased propensity for older adults with ID to develop dementia, with these individuals being five times more likely to develop dementia than the general population. Given prevalence studies from the UK, Ireland, Australia, and the US, consensus could not be reached regarding the percentage of individuals diagnosed with both ID and dementia as known studies produced inconsistent results (Shooshtari et al., 2011).

The Diagnostic Statistical Manual-5, as outlined in the American Psychiatric Association (2016) defined dementia as a category of symptoms of cognitive and functional decline, such as diminishing abilities in attention, memory, executive functioning, and motor functioning. Globally, the World Health Organization (WHO) estimates that there are 50 million cases of dementia worldwide (Alzheimer's Disease International, 2015; Dementia, 2020). A recent study of the prevalence of dementia in the U.S. estimated that 5.8 million Americans age 65 and older have dementia, a number which continues to grow as the U.S. population ages (Alzheimer's Association, 2020). Among individuals with ID in the US, 22% of adults (40-60 years) and 56% (over 60 years) have a dual diagnosis of ID and dementia (McMunn & Tolisano, 2015).

Intellectual disabilities refer to a range of disabilities that impact an individual's intellectual functioning and adaptive behavior (American Psychiatric Association, 2013; Wehmeyer & Thompson, 2016). Down syndrome (DS) is an ID that has been associated with early onset dementia (Lott & Head, 2019). DS occurs when a person has an extra 21st chromosome (Dierssen, 2012). Even at younger ages (e.g. adolescent years and young adulthood) individuals with DS can experience acute regression, which is a rapid loss of function (Mircher et al., 2017). The comorbid conditions of ID and dementia can be par-

ticularly challenging for caregivers (Janicki et al., 2019).

A review of literature for professional caregivers of individuals with ID and dementia detailed a number of challenges these caregivers face (Cleary & Duddy, 2017). Professional caregivers expressed mealtime difficulties (e.g., swallowing concerns), behavioral issues, and pain management challenges regarding the progression of dementia comorbid with ID. Professional caregivers also reported they lacked knowledge about working with a collaborative team to provide services needed to respond to their health challenges.

Caregivers of people with dementia who were recently surveyed by the World Health Organization (World Alzheimer Report, 2019) indicated that their health, work, and social lives were impacted by caring for their family members with dementia. In a literature review specific to caregivers in the US, Grossman and Webb (2016) found that family caregivers of people with dementia tended to report higher levels of caregiver burden when compared to caregivers of those with other disabilities. Likewise, Heller et al. (2018) noted that in instances where family members who were already providing caregiving for a loved one with an ID, the increased level of needs that dementia brings may add to the preexisting caregiving responsibilities.

Recent information from the US National Task Group on Intellectual Disabilities and Dementia Practices suggested that some individuals with ID may experience dementia earlier and at greater rates than the general public (Heller et al., 2018). Individuals with ID are living longer, and many are affected by dementia. The majority of adults (71%) with ID live with family caregivers (Braddock et al., 2015) who have been providing care for extended periods of time. Additional complications from dementia can be challenging for these caregivers. For example, Heller et al. (2018) noted that these caregivers are susceptible to poor health, stress, depression, and financial hardship, which adds to caregiver burden.

Recent studies have rated dementia as the sixth most burdensome disease in the US for both individuals and their caregivers. Family members who are caregiving for loved ones with dementia often stated that the most difficult part of caring for their loved one is the personality and behavioral changes that occur with dementia (Alzheimer's Association, 2020). Factors that may compound the stress associated with

carings for a loved one with dementia include gender (women prone to increased stress levels) and lower income levels (Papastavrou et al., 2007). Thus, caregiver burden may be exacerbated when providing care for loved ones with both ID and dementia (Heller et al., 2018).

Similar to the emotional strain of caregivers of individuals with dementia, researchers also noted that caregivers of aging adults with ID experience unique stressors (Heller et al., 2014; Williamson & Perkins, 2014). Williamson and Perkins (2014) found that the physical health of caregivers of people with ID often was directly proportional to the health of their loved one with ID. This finding indicated that caregivers were likely to experience poorer health if their loved one with ID had poor health.

Caregivers of individuals with ID and dementia may experience challenges related to obtaining a diagnosis, as well as finding and securing services. Janicki and Dalton (1998) described dementia as a diagnosis of exclusion that should be applied only when functional decline cannot be attributed to any other cause. These researchers stress the importance of thorough psychosocial and medical evaluations before adding the label of dementia to an individual with DS or another ID. Follow-up assessments to document changes in symptoms and behaviors are needed to confirm the dual diagnosis of ID and dementia (Dodd et al., 2018; Keller et al., 2016). Obtaining a dementia diagnosis can be difficult and further complicated due to diagnostic overshadowing, which can happen when healthcare professionals overlook symptoms of dementia due to an individual's preexisting diagnosis of ID (McHale & Silverman, 2014; Silverman et al., 2013). In this way, diagnostic overshadowing can contribute to complications associated with the diagnostic process for individuals with ID and dementia (Silverman et al., 2013).

Even when caregivers are able to obtain a diagnosis for their loved ones, finding and securing appropriate services can be difficult. These difficulties arise as services often do not exist to support the unique needs of individuals with ID and dementia (Heller et al., 2018; Jokinen et al., 2018). Service delivery models exist to support those with dementia and those with ID; however, it is rare to find a system that comprehensively supports individuals with these dual diagnoses (Heller et al., 2018; Watchman & Janicki, 2019).

2. Aim of the Study

Innes et al (2012) conducted a review of literature focusing on individuals with ID who were aging. Findings were categorized using three themes, including studies relevant to users' perceptions of services, caregivers of individuals with ID, and service provision among older individuals with ID. The authors' review indicated a lack of research on older adults with ID, highlighting the need to conduct research that directly engaged older adults with ID and their caregivers. Previous research has examined either the impact of caregiving for an aging family member with ID (e.g., Grossman & Webb, 2016; Williamson & Perkins, 2014) or the impact of providing care for a family member with dementia (e.g., Grossman & Webb, 2016; Papastavrou et al., 2007). However, limited research has focused on the effects of caring for an adult with a dual diagnosis of ID and dementia (Janicki et al., 2010). This paper is unique in using a vulnerable population of caregivers in the US to examine their lived experiences associated with caring for adults with ID and dementia. The research question addressed in this study was:

What are the experiences faced by caregivers of adults with IDs and dementia?

3. Methods

3.1 Research Design

This phenomenological study is a companion to a pilot study that used a web-based survey to examine the lived experiences and quality of life of caregivers of individuals with both ID and dementia. According to Creswell and Poth (2018), a phenomenological study is used to describe the lived experiences of a group of individuals who have experienced a common phenomenon. In the present study, the common phenomenon is providing care for an adult with a dual diagnosis of ID and dementia.

3.2 Recruitment

Following approval from XXX University's Institutional Review Board to conduct a pilot study of caregivers of individuals with ID and dementia, the principal investigator (PI) contacted professionals and organizations that supported individuals diagnosed with both ID and dementia. Professionals and organizations (e.g. Alzheimer's organizations) shared information and the survey link with their constituents via email, websites, and organization-specific newsletters.

The US National Task Group on Intellectual Disabilities and Dementia Practices, as well as a Facebook support group for caregivers of individuals with DS and Alzheimer's disease assisted in disseminating information and the survey to their participants. Snowball sampling efforts were used to reach this population of caregivers. Caregivers of individuals with both ID and dementia shared study information with their contacts (e.g. friends and acquaintances). The survey was accessible through the link for Qualtrics that was available on social media and organizational websites.

3.3 Procedure

The final question on the online survey asked participants if they were interested in participating in an individual interview to provide more information regarding their experiences of caring for a loved one with both ID and dementia. Six of the 13 caregivers in the pilot study were interested in participating in the interviews and included their email addresses to allow the PI to contact them. The PI contacted caregivers via email to assure they met inclusion criteria and schedule a convenient time for the interviews. Individual, semi-structured interviews were conducted via phone with participants. The interviews focused on the use of formal and informal dementia-related supports and services, along with the lived experiences of caregivers of individuals with ID and dementia. (See Appendix A for interview questions.) Interviews lasted approximately one hour, with a range from 45 to 75 minutes.

After obtaining participant consent, all interviews were audio-recorded. Interviews were transcribed by paid transcriptionists with all personal identifiers omitted from the transcripts. The PI read and verified each of the transcripts to ensure accuracy, making corrections where necessary. Following individual interviews, each participant received a US\$ 20 gift card in appreciation for their time and involvement in the study.

3.4 Participants

Thirteen participants, who were caregivers of individuals with ID and dementia met the criteria for inclusion, completed the pilot study (Blinded for Review, under review). The inclusion criteria included unpaid caregivers who were either parents or siblings of adults with ID and dementia. Table 1 outlines the demographics for the six caregivers who participated in the individual interviews who were all

living in the United States (US) at the time of the study, representing four regions in the US (North Atlantic, North West Central, East North Central, and South Atlantic). Two caregivers, Sharon and Joe, were married and supporting their adult son. The remaining four caregivers were in discrete households. Among the five families, four were parent-child dyads and one was a sibling dyad. Three care-recipients were female and two were male; their ages ranged from 39 to 58 years, with a median age of 48 years. The majority ($n = 4$) of family caregivers in the present study were caring for loved ones with DS and dementia. Of this number one caregiver (Kelley) was caring for her son (Tim) who was diagnosed with dementia, as well as both DS and autism spectrum disorder. Only one care-recipient (Max) in this study did not have DS. Max experienced a traumatic brain injury at the age of 10. Four of the five care-recipients lived outside of the family home with one care-recipient living with a sibling caregiver. Regardless of living arrangement, all six caregivers were providing extensive, unpaid support to their loved ones. Names for both caregivers and care recipients are pseudonyms to assure confidentiality.

3.4.1 Data analysis

The two authors coded all interviews separately and developed the initial codes using open coding. In this phase, the data were routinely examined and segmented into discrete parts to expose similarities and differences (Charmaz, 2014; Cohen & Crabtree, 2006; Saldaña, 2015). The coders used line-by-line coding with continual memoing to identify processes, trends, and patterns (Charmaz, 2014; Saldaña, 2015). Peer debriefing meetings were held frequently to validate and strengthen the study (Whittemore et al., 2001). To minimize the risk of imposing pre-conceived codes or categories (Charmaz, 2014), the initial codes were generated without referring to an existing list of predetermined codes.

Following open coding, axial coding was used to collapse and consolidate the related codes into broader categories and to remove redundant codes, allowing only the most representative codes to remain (Cohen & Crabtree, 2006; Saldaña, 2015). In the subsequent rounds of analysis, the researchers used a constant comparative approach. Using this method, the data were systematically analyzed to compare codes across the interview data, clustering and condensing codes into relevant themes (Cohen & Crabtree, 2006; Coyle et al, 2014; Saldaña, 2015).

The researchers met on multiple occasions to discuss the axial coding process and the resulting themes (Patton, 1999, 2015). During these meetings, through comparing their axial codes, the two researchers came to consensus on the themes that emerged from the data.

4. Results

Six participants from the pilot study were interviewed, and their responses were analyzed to address the purpose of the study. Four themes that emerged from the interview responses include the following (a) difficulty getting a dementia diagnosis, (b) barriers to obtaining services, (c) caregiving realities and challenges, and (d) rewards of caregiving.

4.1 Difficulty Getting a Dementia Diagnosis

All caregivers mentioned the challenges they encountered with getting an initial diagnosis of dementia. These caregivers stated that it took them several years and visiting many doctors before their loved ones were officially diagnosed with dementia. For example, Carrie stated that when her daughter was in her 30s, she suspected she had early-onset dementia. Getting a diagnosis was difficult because “I kept calling places and nobody would take her because of her age. They have a big thing here where the mindset is that people don’t get dementia until they’re in their sixties.” Likewise, Kelly stated, “It’s hard finding medical professionals who deal with adults with Down syndrome and intellectual disability. Finding someone [medical professional] who understands the whole ID and dementia stuff . . . it almost never happens.”

A common sentiment that caregivers shared was the challenge of finding a doctor who would acknowledge that their loved one’s symptoms were not due to their *IDDs*. For example, Angela noted that when she discussed her sister’s (Beth) possible dementia symptoms with Beth’s doctor, he assumed these challenges were due to Beth’s *DS* and did not take Angela’s concerns seriously. Kelly further expanded on this dilemma: “I mean, I’m finding that I have to – that is, if they’re open to listening to me—I’m having to educate Tim’s [son] medical providers.”

Carrie noted that when her daughter [Mary] was in her 30s and first started showing symptoms of dementia, “all they [doctors] wanted to do was drug her, ‘cause they don’t know anything about people with developmental disabilities, at all, they don’t

even know about people with dementia.” Eventually, through Carrie’s advocacy, she was able to get an accurate diagnosis of dementia for her daughter, Mary. These examples highlight how medical professionals’ lack knowledge about the unique combination of *ID* and dementia resulted in delayed diagnoses of dementia, and thereby delayed additional support needed by caregivers and their care-recipients.

4.2 Barriers to Obtaining Services

Caregivers identified several barriers to obtaining services. As shown in Table 1, the extent of caregiving support provided from organizations varied greatly. For example, Beth did not receive any outside organization caregiving, whereas others lived in group homes (Mary, Deanna) or their own apartments (Tim, Max) and received caregiving from organizational staff. Similar to the challenge of finding a doctor who was knowledgeable in both *ID* and dementia, caregivers also stated that it was difficult to find service providers who were knowledgeable in helping individuals with these co-occurring disabilities. Carrie described the biggest challenge of caring for her daughter, Mary, as “not having anybody who really understands what’s going on with them. You know, that’s why I’ve had to seek assistance elsewhere . . . because I just don’t feel like very many people understand this disease very well. . . .”

Participants identified that another barrier to services was inadequate staff provided by an organization. Joe described that he and his wife had to fire many in-home caregivers who were incompetent in providing support for their son, Max, whose challenging behaviors increased since the onset of his dementia. In one extreme situation, a direct support person lost patience with Max and pushed him, resulting in this person being fired on the spot by his parents. This is an example of the many negative situations that family caregivers experience with staff who lack appropriate training for working with this specialized population. In Joe’s case, despite working through an organization, he had to manage the staff in this case requiring him to dismiss the staff support person.

Another barrier that participants identified was the apprehension about current and future agencies and supports for their loved ones with *ID* and dementia. Carrie noted that her greatest barrier was “actually finding some place that you have the confidence in,” an attitude echoed by Sharon and Joe. Others stated a

major barrier was managing the ever-changing service delivery system (Kelly and Joe). Kelly explained the challenges that came with trying to fight for additional services due to her adult child's increasing needs.

All participants shared this view, indicating the need to continually advocate for their loved ones with dementia and ID due to continual budget cuts and/or organizational changes. Sharon stated that "certainly, the barriers are... what the systems require." She went on to specify that these barriers included age requirements, funding requirements, and the limited level of training for staff who work with individuals with disabilities. Sharon also shared a story of getting a letter in the mail stating that her son's funding had been terminated. After calling various offices, Sharon was informed the letter was sent in error and funding would continue. This organization's communication error posed a potential barrier to services that added undue stress for this caregiver.

Other participants discussed difficulties associated with understanding requirements of the service system, a challenge that was compounded when participants and/or their loved ones with dementia and ID moved to a different state in the US. Caregivers mentioned that extensive research was needed to find services and/or plan for their loved one's future. For example, Angela noted that she was in the process of researching types of residential facilities that were available to support her sister's unique needs. Likewise, Joe referenced consulting extensively with a lawyer to plan for his son's financial needs after he and his wife passed away. These examples highlighted barriers to obtaining services that required caregivers to do additional research and seek legal consultation.

4.3 Caregiving Realities and Challenges

Each caregiver explained challenges that were unique to caring for their loved one with ID and dementia. Participants mentioned challenges faced by caregivers included managing their loved one's new behaviors (Joe), the pain of seeing their loved one regress in skills (Darla, Kelly, Sharon, and Joe), and apprehension of planning for the future, such as worrying about who would be a back-up guardian (Darla). Sharon mentioned that Max's dementia caused him to start touching women inappropriately and becoming less talkative. She described how Max's loss of language abilities led him to start watching television on mute because it was too much effort for

him to try to process what the people on the television were saying. Max's loss of abilities impacted his quality of life and was emotionally difficult for Sharon.

Similar to how Max's decline in abilities impacted his interactions with his parents, Kelly also mentioned that her son, Tim, lost a lot of language abilities, making communication more difficult. Prior to his dementia, Tim was nonverbal and used a lot of signs to communicate, but now he uses fewer signs. She stated, "with ID and no spoken language, just not knowing if he's upset, we don't know why... you know, it's even more of the guessing game... than it was prior to the dementia setting in." Angela also shared this sentiment of the pain of watching her sister, Beth, lose abilities. She described how Beth used to write down facts from *Sports Illustrated* magazine in a notebook, but then she began tearing up the pages from the notebook. Angela stated she was greatly affected by Beth's regression.

Max was previously able to live in his own apartment with support from organizational workers. Sharon mentioned Max's decline in independence increased day-to-day caregiving responsibilities for her and her husband. Darla revealed that the emotional strain that comes from caring for her daughter, Deanna: "... I think that emotional involvement is the most difficult." Similar to Sharon, Darla expressed the sadness felt by watching Deanna's independence decrease and losing abilities, such as no longer being able to cook simple meals for herself.

4.4 Rewards of Caregiving

Even though each caregiver indicated unique challenges faced due to their loved one's diagnosis of dementia, they also shared rewarding aspects of caring for their family members. Most rewards associated with caregiving for their loved ones with ID and dementia were linked to their loved one's personality and close relationship. For example, Darla shared that her daughter, Deanna, is "a unique individual and you just have to appreciate her personality... she loves people." Likewise, Angela shared that some of the most rewarding aspects of caring for her sister, Beth, occurred when Beth recognized her and gave her a hug.

Joe mentioned his deep appreciation for Max's personality, which he described as being both friendly and joyful. Joe described Max as a "gift," highlighting the intrinsic, relational bond between caregiver and care recipient. Likewise, Kelly specifically stated

how Tim's dementia caused her to "appreciate the small stuff... knowing that he [Tim] has something that's terminal and however long it's going to take, it just makes me appreciate more, even more, every moment I get to spend with him." Similarly, Carrie shared her joy in the fact that her daughter, Mary, was well cared for and happy. The caregivers shared a deep satisfaction in the relationships they had with their loved one with dementia and ID, as well as contentment in seeing their care recipients happy.

5. Discussion

The purpose of this study was to examine the experiences of caregivers of adults with ID and dementia. After analyzing interview responses from six caregivers, four themes emerged: (a) difficulty getting a dementia diagnosis, (b) barriers to obtaining services, (c) caregiving realities and challenges, and (d) rewards of caregiving.

Similar to other research findings (Silverman, et al., 2013; Lautarescu et al., 2017), caregivers of individuals with ID faced challenges obtaining an accurate dementia diagnosis for their loved ones. For example, all participants in this pilot study mentioned delays in an initial dementia diagnosis due to diagnostic overshadowing, which other studies have noted (e.g., Krinsky-McHale & Silverman, 2013; Lautarescu et al., 2017; Silverman et al., 2013). Four caregivers had difficulty finding a doctor who was knowledgeable about individuals with ID. The remaining two caregivers indicated their loved one was excluded from receiving an assessment for dementia due to age (being too young). In many ways, caregivers felt their concerns were not being heard, and they could not get an accurate diagnosis for their care recipients.

Just as participants experienced challenges in getting a diagnosis for their loved one, they also experienced several challenges in navigating the service system. As caregivers work to support their loved ones, they often experience a number of barriers in obtaining services. Barriers included lack of confidence in the services and/or support providers, not knowing what the systems require, what supports are even available, or being promised certain services but waiting for long periods of time without receiving the services.

Consistent with previous literature among other caregiver populations (Grossman & Webb, 2016; Marsack-Topolewski & Weisz, 2019; Macleod et

al., 2017; Polvere et al., 2018), the present study indicated barriers caregivers experienced in trying to obtain services. While the needs may differ for individuals with other types of disabilities, obtaining the services is a challenging part of caregiving that is shared by many caregivers of people with various disabilities (Grossman & Webb, 2016). Caregivers of individuals with comorbid ID and dementia may face greater challenges locating services as specific services do not exist in many areas. Caregivers in the present study shared sentiments and illustrated examples regarding perceived lack of knowledge from healthcare professionals about adults with ID and dementia. Similar to literature on professional caregivers of individuals with dementia and ID (Cleary & Doody, 2017), family caregivers also experienced difficulties finding staff who were competent and knowledgeable about the dual diagnosis of ID and dementia.

Similar to other study findings (Alzheimer's Association, 2020; Heller et al., 2018), caregivers of individuals with ID and dementia faced additional challenges associated with noticeable declines in communication and behavior. With the signs of dementia, both professional and family caregivers recounted additional challenges in managing behavioral difficulties and declines in communication ability (Cleary & Doody, 2017). For example, both family and professional caregivers expressed concerns regarding the lack of knowledge of the progression of the condition among professional staff regarding ID and dementia (Cleary & Doody, 2017). All caregivers expressed challenges associated with declines in their loved ones' daily independence levels, placing additional strain on their abilities to balance her day-to-day caregiving responsibilities.

Despite the many challenges experienced by caregivers, the participants in this study also discussed the rewards associated with caring for their family members. These findings were aligned with previous studies among other caregiver populations (Doris et al., 2018; Grossman & Webb, 2016; Pope et al., 2018; Quinn et al., 2019). In the present study, all caregivers shared rewards related to their loved one's personality and the close relationship they had with him or her. To others, the rewards may seem small, but to the caregiver, a hug or smile was a huge reward. These rewards were meaningful for caregivers and helped put the challenges and difficulties associated with caregiving in a new context.

If a greater number of participants had been available for the individual interviews, additional themes may have emerged to explain the lived experiences of caregivers of individuals with ID and dementia. These themes may have reflected quality of life, personal impacts on caregiver health, and failure to meet caregiver milestones (e.g. retirement, grandchildren, typical social life). Future research is needed with a larger sample to fill this gap.

6. Implications for Practice

This study yields many important practice implications. Based on the first thematic finding, difficulty obtaining a dementia diagnosis, health care professionals and service providers should be aware of the challenges that caregivers face when they recognize something is not right or suspect signs of dementia. Professionals should receive specialized training to be knowledgeable about the signs and symptoms associated with cognitive decline experienced by individuals with ID regardless of their age and preexisting disability (e.g., ID). This implication for practice aligns with recommendations provided by the Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities (Heller et al., 2018) advocating to increase the frequency and extent of dementia screening and raise awareness for the need to integrate aging and disability networks.

Awareness of diagnostic overshadowing should be reinforced in healthcare professionals and efforts should be made to mitigate the threat of diagnostic overshadowing. Rather than simply using prescription drugs to remediate signs and behaviors exhibited by a loved one with ID and dementia, caregivers should be supported in the journey of getting an accurate diagnosis and having the appropriate support to navigate changes that occur with this dual diagnosis. Training staff to understand the varied needs of individuals impacted by this dual diagnosis is paramount.

Support should be provided to caregivers given the many barriers reported in obtaining services. Supports, such as educational programs for family and professional caregivers, behavior management consultations, resource guides and information, and diagnostic clinics with specifically trained staff (for ID and dementia), would be helpful to have accessible to caregivers of individuals with ID and dementia (Personal Communication with Kate Pierce, May 28, 2020). Training practitioners to assess support

needs and creating streamlined systems to access services could be helpful in providing support for caregivers as they juggle the day-to-day caregiving responsibilities and seek the most appropriate services (e.g. specific supports for caregivers and individuals with ID and dementia available through Alzheimer's organizations) for their loved ones. Adjusting age-related services often is difficult, with caregivers required to spend excessive time when advocating for their care recipient, which adds to the stress associated with caregiving.

Caregivers discussed declines in behavior and communication of their loved ones. As such, caregivers and individuals with this dual diagnosis should be supported throughout the decline associated with dementia. Caregivers faced the pain and heartache of witnessing their loved ones decline from symptoms associated with dementia. Physicians and other healthcare professionals caring for the individual with the dual diagnosis should inform the caregiver and care-recipient regarding available support and services. Practitioners should be cognizant of the pragmatic changes affecting everyday life, while attending to the emotional needs that will manifest in varied ways when such losses occur.

7. Study Limitations and Directions for Further Research

Despite the novelty of the present study, some limitations should be acknowledged. The sample size of this study was six participants from the United States who volunteered to be interviewed. While this number may not have been sufficient to reach data saturation, much of the information obtained from the participants was consistent across the interviews. Additional interviews may not have yielded novel information. The recruitment methods (e.g., through organizations for dementia) may have resulted in a homogeneous sample, as some overwhelmed family caregivers may not have time to participate in support organizations. Future researchers should seek to diversify their recruitment methods to recruit a heterogeneous sample. Policies related to supports for caregivers of individuals with ID and dementia differ across the 50 states in the United States. Because of the diversity in policies, some services and supports may not be available to meet needs of caregivers and care-recipients in each state. Further research is needed to examine possible relationships between available support needs of individuals with dementia

and ID using validated methods, such as the Waisman Activities of Daily Living (W-ADL) Scale (Esbensen, Johnson, Amaral, Tan, & Macks, 2016; Maenner et al., 2013).

8. Conclusion

Caregivers of adults with ID and dementia experience many challenges in providing care for their loved ones. Practitioners should be aware of their needs and the needs of their care recipients to provide positive outcomes in complex caregiving situations. Providing access to obtaining a diagnosis, helping ease the path to needed services, and balancing challenges with rewards is important for maintaining equilibrium in the lives of caregivers.

Conflict of Interest

Authors declare no conflicts of interest.

Compliance with Ethical Standards

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. All procedures performed in this study involving human participants were in accordance with the ethical standards of the XXX Institutional Review Board.

Informed consent: For the web-based study, the use of an electronic survey program precluded the use of an informed consent form. In its place an information sheet that required the participant to indicate that he/she agreed to participate was used. At the end of this web-based survey, participants were informed that a follow up interview would be conducted with interested participants. Participants could indicate whether they would be interested in sharing more information regarding their experiences. For participants interested in sharing more information, they were asked to select “yes” and leave their name and contact information. An email was sent to participants that indicated interest in participating in the follow up interview. In the email sent, participants were notified that interviews could be recorded and that the recorder could be stopped at any time.

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