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Thematic analysis of blog narratives written by people with Alzheimer's disease and other dementias and care partners

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Abstract

Limited research takes a socio-biographical approach to study the experiences and perspectives of individuals affected by Alzheimer's disease and related dementias. The purpose of this study was to thematically analyze blog narratives written by people with Alzheimer's disease and related dementia and care partners in order to increase understanding of their experiences. Nineteen blogs written by people with Alzheimer's disease and related dementia and 44 blogs written by care partners were analyzed. The first two authors utilized line-by-line open coding to analyze five posts from each group for the development of a codebook. Using NVivo software, the first author proceeded to code the remaining blogs for emergent themes and subcategories. Emergent themes included (1) effects of Alzheimer's disease and related dementia on the person with Alzheimer's disease and related dementia and/or the care partner; (2) seeing the positives; (3) feeling out of control; (4) advocacy and empowerment; (5) coping mechanisms and compensatory strategies; and (6) candid descriptions of experiences with Alzheimer's disease and related dementia. These themes also encompassed numerous subcategories that are discussed in this paper. Results from this study provide insights into the experiences of individuals affected by Alzheimer's disease and related dementia. Writers discussed several topics that are consistent with research on illness narratives of individuals with chronic diseases, including loss of identity, strategies for coping, and poignant descriptions of life with the disease. This study provides information in the form of overlapping themes from first-person perspectives of numerous individuals affected by Alzheimer's disease and related dementia. This type of data is crucial to understand the experiences of people who live with ADRD.

Keywords

Alzheimer's disease; writing; narratives; care partner; qualitative analysis

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Introduction

Alzheimer's disease and related dementias (ADRD) are chronic diseases that affect many Americans. As of 2017, an estimated 5.5 million individuals in the United States (US) are living with Alzheimer's disease (Alzheimer's Association, 2017). As the number of individuals aged 65 and older increases, the US will experience an increase in the prevalence of ADRD. The number of Americans in this age range is expected to nearly double from 48 to 88 million by 2050 (Alzheimer's Association, 2017). People with ADRD are often supported by family members or friends (Centers for Disease Control and Prevention, 2016). Those living with ADRD and their care partners may face a number of challenges in managing the physical, emotional, and social effects of ADRD, which can last for extended periods of time, often years or decades (Ressler, Bradshaw, Gualtieri, & Chui, 2012).

Despite the increasing number of individuals affected by ADRD, there is limited research on the perspectives individuals living with a diagnosis of dementia (Beard, 2004). This may be due to the assumption that people with ADRD are poor historians of their own experiences and unable to participate actively in their course of care (Basting, 2003; Beard, 2004; Beard, Knauss, & Moyer, 2009), despite research supporting the claim that individuals with ADRD are able to communicate meaningfully (Cohen-Mansfield, Golander, & Arnhem, 2000; Li & Orleans, 2002). Common stereotypes lead to the perception of those with ADRD as victims of the disease rather than active participants who maintain their status as individuals (Cohen-Mansfield, Parpura-Gill, & Golander, 2006; McColgan, Valentine, & Downs, 2000; Ryan, Bannister, & Anas, 2009). In addition, previous research supports the claim that living with a chronic disease can be isolating as a result of the changes in perceptions about the personhood and societal roles of the individual with the diagnosis (Ressler et al., 2012).

Care partners of those with ADRD often experience changes in identity and social isolation and must find ways to cope (Ivey et al., 2013; Zimmermann, 2013). Research has found, however, that their experiences with care can be both challenging and rewarding through various stages of dementia, attributing to many positive views of self (Ivey et al., 2013). Care partners offer unique perspectives on brain health and make many care decisions based on these perspectives as well as their personal beliefs (Beard, Fetterman, et al., 2009; Raymond et al., 2014). Like blogs, social support groups, including those held virtually online, provide a means for care partners to identify with those with similar experiences, and to better cope through social modeling (Namkoong et al., 2012). Much research that has focused on care partners has been consistent with biomedical or psychological models (Beard, Fetterman, et al., 2009; Downs, 2000; O'Connor et al., 2007), highlighting issues such as financial burden and intervention (Beard, 2004), without attention toward the social aspects of caring for or living as a person with ADRD. This exploratory study aimed to contribute to the limited literature on the social aspects of living with ADRD through the analysis of blog narratives written by individuals with ADRD and care partners.

Exploration of the perspectives of those living with chronic diagnoses is not a new concept (see Frank, 2002, 2013). Individuals living with these conditions have used illness narratives to regain a sense of identity and re-establish societal roles (Hunt, 2000; Ressler et al., 2012; Ryan, 2006; Ryan et al., 2009). Individuals with ADRD, in particular, must face the

difficulty of reconciling their identities before diagnosis with the changes in identity that occur as a result of the illness (Holst & Hallberg, 2003; Pearce, Clare, & Pistrang, 2002). Further, care partners must also cope with the personal and social impact of changes in the perception of the identity of their loved ones, as well as the way they view their own identities as they take on new roles (Zimmermann, 2013). Surr (2006) suggests the use of narratives to formulate a “socio-biographical theory of self” in order to increase knowledge of the experiences of individuals affected by ADRD (p. 1720). Further, illness narratives have been deemed simultaneously social and personal, as these narratives both inform the identity and account for the experiences of the author (Sparkes, 2005), while also positioning them in a broader social context (and identity) through the telling of their narratives to others (Frank, 2013). We aim to utilize narrative analysis in support of these concepts, leaning heavily on thematic analysis (Riessman, 2005), to account for the many shared experiences and social effects of ADRD as expressed in the content of narrative blogs by authors close to the disease.

Previous research has advocated for the use of blog writing in qualitative research for gaining information on the experiences of individuals (Hookway, 2008; Redlich-Amirav & Higginbottom, 2014). Weblogs, also referred to as blogs, are tools that allow individuals to communicate their thoughts and enter into a dialogue with other individuals (Beach Thielst, 2007). Due to their accessibility and readability, blogs and discussion forums are the most popular sources of social networking utilized by individuals with chronic diseases (Fox & Purcell, 2010). Blogs are a unique form of social media and online communication, as they can provide a narrative of the various experiences of the author; when written by a person with an illness diagnosis, they provide a thorough recollection of the perspective of someone living with a disease by narrating various aspects of his or her experience (Gualtieri & Akhtar, 2013).

Numerous studies have explored narratives (both written and verbal) of individuals with chronic diseases and their care partners. Like those with a diagnosis, care partners use narratives to process and reframe their experiences, often allowing them to discover meaning and hope (Williams, Duggleby, & Eby, 2013). Research on bloggers with chronic diseases suggests that individuals with diseases are motivated to write about their experiences for many reasons, including helping others, decreasing the sense of isolation, sharing experiences, and finding a sense of community and authentic voice within an individual’s co-existence with the chronic illness (Ressler et al., 2012). Analyses of blogs written by individuals with cancer have revealed common themes of self-expression and maintaining relationships with others (Gualtieri & Akhtar, 2013; McCosker & Darcy, 2013).

Interviews with people with ADRD have also revealed the importance of using their perceived social roles and relationships with others as a means of maintaining a sense of identity (Surr, 2006). Online surveys directed toward individuals with ADRD have been used to encourage narrative responses to challenging components of living with the disease as well as coping mechanisms used to compensate for these challenges (Beard, Knauss, et al., 2009). One study analyzed the published narratives of individuals with dementia and how these writings combat negative stereotypes about individuals living with the disease (Ryan et al., 2009). While the literature provides valuable information on the experiences of

individuals with various chronic diseases, these studies do not examine the blog writings of people with ADRD or their care partners, who are also experiencing effects of the disease. To our knowledge, there are currently no other studies that analyze blog narratives specific to individuals affected by ADRD. Given that blogs allow for indirect communication through writing, rather than speaking, researchers may be able to gain valuable information about the experiences of these individuals that may not be shared as candidly when sitting face-to-face with a researcher (Clarke & van Amerom, 2008; O'Brien & Clark, 2011; Rodriguez, 2013). Hookway (2008) describes blog analysis as a more naturalistic method of data collection for this reason. Therefore, we believe that blogs serve as an appropriate medium for taking a socio-biographical approach to the analysis of narratives written by our target populations.

Methods

Selection criteria

Relevant blogs were obtained by searching Google. Some of the major search terms utilized were “dementia blog,” “Alzheimer’s disease,” and “Alzheimer’s.” Search terms for other types of dementia in addition to Alzheimer’s, such as “Lewy Body,” were also included. As the purpose of this study was to gain insight into the needs, perspectives, and experiences of individuals living with ADRD and care partners, exclusion criteria were established to eliminate blogs that were not reflective of the focus of the study. Blogs were excluded if they were: written by healthcare professionals who specialize in aging, organized and updated by agencies or foundations (such as the Alzheimer’s Association), written by organizations (such as the Association for Frontotemporal Degeneration), or were solely informational and did not include personal perspectives. While these blogs likely provide useful resources, their primary purpose is not to share perspectives and experiences of individuals living with ADRD.

An objective of this study was to examine emergent themes among the written experiences of the target populations, with an emphasis on highlighting the written personas of these individuals. Therefore, all blogs chosen for this study were “unsolicited,” meaning that the researchers did not provide a request for narratives to be included in the study; this type of request could result in narratives that are skewed toward the perception of what a researcher may want to “hear” or “know” about the disease, rather than the day-to-day experiences of living with ADRD.

Additionally, only blogs with five or more posts were included for analysis to minimize the risk of misinterpretation of content and to achieve a perspective of the writers’ thoughts and experiences. The five most recent posts (as of 22 October 2016) with 10 or more sentences of original content were extracted from each blog for further analysis. The most recent posts were selected in order to maintain continuity in the “storyline” of each blog (rather than choosing posts randomly throughout the course of each blog in its entirety). Additionally, we chose to include posts with 10 or more lines for the purpose of including as much content as possible, while still limiting the number of posts included, given that this study was an initial exploratory study rather than a thorough analysis of each individual blog. In the event that the most recent blog posts were written following the passing of a person with ADRD, the

five most recent posts prior to the individual's death were selected for analysis. If all posts were written after the passing of the person with ADRD (as a means of reflection upon the time spent as a care partner), the five most recent posts were selected. The reason for also including blogs written following the passing of a person with ADRD was to widen the inclusivity of our sample, as this study was meant to be exploratory in nature. Isolated quotations and scriptures were not counted as sentences for the purpose of postselection. Posts written by guest bloggers were excluded unless they contained at least 10 lines of original content from the primary blogger. Furthermore, content posted from outside articles, such as news sources, was not considered as original content for the 10-line minimum but was considered for thematic analysis. All charts, videos, images, and hyperlinks were excluded in this analysis, as the focus of this study was to examine written, rather than visual, material. In the event that the blogger had written original poetry, each line of poetry was counted as one sentence. Only blogs that were written primarily in English were included in order to prevent possible misinterpretation of content through translation.

All blogs chosen for this study were published publically and were easily accessible via Internet search without a password or special access. Names of individuals who either wrote or are featured in these blogs were only utilized if they were a part of selected posts or the overall title of the blog. All excerpts have been italicized and connected with the respective blog title to provide credit to each author.

Coding of themes

Once five posts were selected from each blog, two authors independently proceeded with line-by-line open coding of notable themes from five care partner blogs and five blogs written by individuals with ADRD. Inductive, open coding methods have been used in previous qualitative research in order to highlight overlapping themes from participant data (Bergeron, Friedman, Hilfinger Messias, Spencer, & Miller, 2016a, 2016b; Koskan, Friedman, Hilfinger Messias, Brandt, & Walsemann, 2013). These two authors compared themes in order to establish the initial codebook. Then, the first author utilized NVivo software (© QSR International Party Ltd.) for the organization and continued coding of the five selected posts from the remaining blogs. After all blogs were coded, the first author reviewed all quotations from each thematic category and reassigned quotations to appropriate subcategories to further classify themes. Criteria for development of a subcategory included at least one relevant quotation from a minimum of 10 different blogs (approximately 15.8% of the entire sample). Content that was relevant to more than one category was coded into all appropriate categories. All coded content was included for analysis, and quotes deemed to strongly represent overarching themes are presented as exemplars of selected themes.

Results

Demographic characteristics

A total of 19 blogs written by people with ADRD and 44 blogs written by care partners were included in this study. A list of blog titles can be found in Tables 1 and 2 within Appendix 1. Care partner bloggers were primarily female ($n = 36$) and lived in the United States ($n = 23$).

These bloggers provided support for individuals diagnosed with Alzheimer's disease ($n = 11$), frontotemporal dementia ($n = 14$), Lewy Body dementia ($n = 4$), semantic dementia ($n = 1$), and mixed dementia ($n = 5$). Nine care partner bloggers did not report a specific dementia diagnosis for the individual for whom they were providing support. Most care partners were daughters ($n = 20$) or female spouses/partners ($n = 16$) of people with ADRD.

Writers with ADRD diagnoses were primarily male ($n = 12$) and of unknown regional location ($n = 11$). The bloggers reported diagnoses of Alzheimer's disease ($n = 8$), frontotemporal dementia ($n = 1$), Lewy Body dementia ($n = 1$), mixed dementia ($n = 4$), and misdiagnosed Alzheimer's disease ($n = 1$). Four individuals with ADRD did not report a specific dementia diagnosis. Additional demographic information is displayed in Table 3 of Appendix 1. Additionally, information regarding the relationship of care partners to the respective people with ADRD whom they help support can be found in Table 4 of Appendix 1.

Emergent themes

The qualitative analysis revealed six overarching themes: effects of ADRD on the person with ADRD and/or the care partner, seeing the positives, feeling out of control, advocacy and empowerment, coping mechanisms and compensatory strategies, and candid descriptions of experiences with ADRD. Each overarching theme contained multiple subcategories to further classify themes. A complete list of these subcategories is provided in Table 5 of Appendix 1. As the purpose of this study was to explore overarching themes among the pooled data, verbatim quotations that exemplify each theme and subcategory are taken from groups.

Effects of ADRD on the person with ADRD and/or the care partner

Numerous bloggers reported psychological, physical, emotional, and financial challenges due to ADRD. In particular, several people with ADRD expressed negative feelings regarding loss of independence and personal identity. For example, one blogger stated:

... people wash their cellphones, wallets, electronic car keys, receipts, and many other things not meant to be washed, all the time. Well, I don't and I never have! I have a set routine, a procedure, that I do things by. ... It comes from my Navy training and longtime experience in Weapons!! You either do it right or die. Today, part of me died! (from *Sharing my Life with Lewy Body Dementia*)

This quotation exemplifies this individual's perception of losing his ability to function with complete independence as well as a component of his core identity as a soldier in the Navy.

Both groups expressed a plethora of emotions regarding their experiences with the disease. The most prominent emotions that emerged from the data were: anger/frustration, loneliness, guilt, and sadness/hopelessness. A care partner, frustrated with the responses she received when describing her mother's condition, stated:

My problem starts when people ask questions, and then on getting answers, they show their discomfort by implying I am being "negative" or lacking "faith" ... all I

did was is factually describe my mother's current state in response to your explicit questions. To label statements of facts as "negative" or "complaining" seems unfair to me. (from Swapna Writes)

This quotation describes her frustration toward the reactions of others to ADRD, rather than the direct effects of ADRD itself.

Additionally, numerous bloggers shared their feelings of guilt in regards to the effects of ADRD and their response to these effects. One person with ADRD expressed:

. . . it's my poor family that have [to] stand by and watch their husband, their father, and their grandfather slowly forget, slowly disappear. It shouldn't be my children's job to tell me my pants have fallen down cos [sic] I haven't buttoned them up, or remind me I haven't put my pants on at all. (from Dementia Survivor. . . So Far)

Seeing the positives

The overarching theme of seeing the positives contained the following subcategories: celebrating accomplishments and perseverance, moments of understanding/connection, finding humor in the situation, appreciation of support, increased awareness of simple joys, and positive medical experiences.

Perseverance was noted in blog writings from both groups. For example, a person with ADRD stated:

I am grateful to be doing as well as I am. Still trying to stay active, and keep the brain active as well. I have really had to say "no" a lot this year to give myself some breathing room. Activities wear me out quickly so I have to cut back on some things—but I am still plugging along. (from Dealing with Alzheimer's Blog)

Another subcategory of seeing the positives was moments of understanding/connection. These moments were generally between the primary care partner (and blogger) and the person with ADRD but also included connections between healthcare workers and individuals with ADRD from the perspective of the primary care partner. Numerous care partners reflected upon times when they were confident that the person for whom they were providing support was able to recognize both their presence and the significance of their relationship. For example, a care partner wrote:

I was contemplating leaving for the night when my phone rang. It was a work call and I answered while sitting next to Gary by saying, "Hello, this is Ada." Gary instantly said, "Ada Potata. Ada Potata." He knew I was there. (from Go to your Corners and Come out Loving)

Numerous bloggers used humor when managing the disease. In reference to observed personality changes of a person with ADRD, a care partner stated:

He is a Marxist now. There is not private property in Alex's view of the world, and most of the time, we just deal with it. But when a person pours orange juice into your half-drunk glass of beer—well, that's a line no one should ever cross. Did I lose my composure? You betcha! (from Houlding on Letting Go)

Both groups expressed increases in their awareness and recognition of simple joys. For example, one person with ADRD wrote:

But life here [is] good. I think it [is] good because I made it that way. . . . The flowers are blooming, the leaves are turning, there is a crisp in the air and I can wear a jacket again . . . I keep re-discovering each day and thing . . . like it [was] the first time I ever saw the blue sky, or the red leaf . . . dementia can be kinda cool that way. (from *Still Life with Dementia*)

Feeling out of control

The third overarching theme, feeling out of control, contained three subcategories: uncertainty and fear of the unknown, grief and yearning for what has been lost, and being aware of symptoms but unable to change them. A care partner expressed:

One of the things I hate about Alzheimer's progression is the uncertainty to it all. . . . In most other illnesses there is a path that is followed. In normal situations you can apply logic and be fairly certain of an outcome. With Alzheimer's there is no logic; there is no normal. (from *Younger Onset Dementia from a Spouse's Perspective*)

Expressions of grief were not limited to care partners' reflections following the death of their loved one; both groups also grieved throughout the progression of the disease. An individual with ADRD wrote:

The LBD has been progressing and Linda and I knew it. Today was a big drop off in my mind. I failed a procedure and even though it was a small item, I can no longer trust myself or anyone else to my care. (from *Sharing my Life with Lewy Body Dementia*)

Advocacy and empowerment

Numerous bloggers reflected on their efforts to advocate for individuals with ADRD through promotion of research and awareness. Subcategories within the overarching theme of advocacy and empowerment included: sharing one's story/perspective to educate others, fulfillment of final wishes, desire to contribute to research or funding, conducting one's own research, combatting stereotypes and misconceptions, increasing self-awareness, and engaging in political and social activism.

Some individuals used their experiences with dementia as a means for increasing understanding of the disease. For example, a care partner wrote:

Let me hope sharing this story will provide readers another data point in the spectrum of caregiver lives. That they will "listen", that it will help them understand. That they will glimpse the underlying complexity care situations may have, and next time they meet a caregiver, they will not be hasty in judging, in acting preachy and simplistic. (from *Swapna Writes*)

Care partners were sometimes able to advocate for individuals for whom they were providing support by ensuring the fulfillment of their final wishes in the months before death as well as those after death. A care partner noted:

My mom was quite specific about not wanting to be spoon fed. Telling someone the thing they are doing as an act of care, is not what my mom wishes is painful to both of us in the conversation. While I don't want to have the conversation one more time, I know I will need to because it is what my mom wanted. I need to be her advocate. (from Dealing with Dementia)

Both groups were able to advocate by supporting dementia research and funding and/or conducting their own research on the disease. A care partner reflected upon the contributions of the individual for whom she is providing support to a pharmaceutical trial:

I am absolutely unable to gauge whether the drug has helped Alex or not. . . . But if this drug does benefit some people, then I will be thrilled that we played a part in it and I have started to think of every single blue spot as a little victory for all of us. (from Houlding on Letting Go)

Some bloggers advocated for people with ADRD by combatting stereotypes and misconceptions about the disease. For example, an individual with ADRD wrote:

People often think that anyone in early stage couldn't possibly have dementia because their vision of dementia is only about end stage. . . . The sooner we can change public perception the better it will be for all of us living with dementia. We don't start out at that stage and some of us take a LONG time until we get there. (from Early Young Onset Atypical AD)

Coping mechanisms and compensatory strategies

Bloggers frequently reflected upon tools and strategies they used to manage ADRD and address observed changes in cognition and behavior. Subcategories within this theme included: support groups/online community, finding comfort through faith/spirituality, staying active in body and mind, acknowledgement of one's own needs, use of assistive devices (both high- and low-tech), establishing a routine or planning ahead, eliminating stressors and distractions, providing advice for other care partners, and acceptance of the diagnosis.

Numerous bloggers expressed the benefits of becoming involved in formal or informal support groups with individuals undergoing similar experiences. A person with ADRD expressed:

You cannot hide Dementia. I believe being together, just one hour a week helps us cope with our dementia journey because, for that hour, we do not have to pretend to be "normal" or try to hide the symptoms. Instead we share our journey and gain strength from each other. (from Sharing my Life with Lewy Body Dementia)

Additionally, many bloggers from both groups utilized their faith and spirituality as a coping mechanism for living with ADRD. A care partner wrote:

Dear Lord, I miss the woman that used to live inside my mother's body . . . I thank you for the life that this jewel has shown before her family . . . I know that all of this is in your perfect plan and that our lives are forever engraved in the palms of Your hands as Your Word tells us. (from Porkchops and Pianos)

Some bloggers benefitted from the use of assistive devices to help with management of ADRD. These included both high-tech and low-tech devices. For example, a care partner stated:

I talk with him about not going outside when I am gone or without telling me. I am putting a sign on the doors. Our doors chime when opened so if I am at home, I will hear him I [sic] he opens a door. I have a locked gate on the basement steps which reminds him to not go downstairs without me. (from Lewy Body Journey)

Similarly, many bloggers utilized routines and pre-planning as compensatory strategies when addressing the symptoms of dementia. One care partner shared:

I try to find things we can do together, even if it's just running errands. I don't combine several errands into one trip anymore, but rather make each one separate, so that we can get out of the house more often. . . . We may drive right by the hardware store on the way to the supermarket, but I save that trip for another outing. (from Younger Onset Dementia from a Spouse's Perspective)

Bloggers also took note of stressors and distractions that influenced the person with dementia, resulting in behavior expressions. Both groups expressed awareness of these distractions and took steps to eliminate them. For example, an individual with ADRD wrote:

I used to get a lot of pleasure going to church until this illness started, then I found that I could not remember the Lord's Prayer, something which was horrifying at the time. So I changed services at the church when we lived in Oxford, as it was much quieter, which allowed me to think, and it was more personal. (from Living Well with Lewy Body Dementia and Comorbidities)

Candid descriptions of experiences with ADRD

Numerous bloggers utilized candid statements to express their experiences with the disease. Subcategories of this theme included: end-of-life experiences, experiences with stigma, negative medical experiences, and candid descriptions of symptoms/events related to the disease.

Several care partners provided poignant descriptions of their feelings and experiences as the individual for whom they were caring neared or reached the end of life. For example, a care partner wrote:

I was alone with her when she started the death rattle. . . . I told my mom to wait for my dad, and she did. . . . She was gaunt, probably only 80 pounds, down from her normal 150–160. . . . She stared at the ceiling, eyes unblinking as she labored to breathe. She inhaled, exhaled, and it all stopped. (from The Unlikely Caregiver)

Both groups of bloggers expressed their reactions to negative experiences with stigma associated with the disease. A person with ADRD wrote:

I had and still do have some of those stigmas in my own mind about the word demented especially and was completely mortified recently to see a movie description say a “demented man” and they were using the word in a way as to portray scary or criminally psychotic which is completely the incorrect usage of the word. (from Early Young Onset Atypical AD)

Writers provided descriptions of symptoms or events related to the disease, including changes in executive functioning, changes in memory, changes in reading and/or writing skills, changes in language skills (expressive and receptive), disorientation and confusion, and behavioral expressions of unmet needs. A person with ADRD described the fear of feeling confused and disoriented:

Where am I? What’s throwing me around so roughly? Which way is up? It’s pitch black. Noise as if the world is ending surrounds me. I’m completely disoriented. What’s happening?? (from Watching the Lights go Out)

Overall, these emergent themes support the notion that both groups are capable of clearly communicating their experiences with the disease through narrative blog writing. These perspectives offer an intimate view into the day-to-day lives of people who are living with ADRD. Interestingly, numerous bloggers also offered advice and examples of coping mechanisms to empower others undergoing similar difficulties within their online communities.

Discussion

The results of our narrative analysis paper add to the literature by affirming common themes that have been found through similar studies on the narratives of individuals living with chronic disease (Frank, 2013; Riessman, 2005; Sparkes, 2005). Our study includes the experiences of both individuals with ADRD and care partners in order to maximize the number of perspectives represented in the data.

Self-expression and support

Personal narratives by those with a disability or diagnosis help to break stereotypes, individualizing those who are marginalized and providing them with a voice that speaks to their personal experiences and identity (Ryan, 2006). These poignant descriptions communicate experiences of living with the disease in a manner that is vivid to the reader, which supports findings that the content and style of the writing demonstrate the uniqueness of personality, experience, and selfhood (Ryan et al., 2009). Previous research suggests that individuals with chronic disease (specifically cancer) may feel the need to express these experiences publicly (McCosker & Darcy, 2013). As identity is a social construct, blogging provides the added benefit of validation, as an audience lends attention to the author’s story, affirming their identity as a unique person with a unique story to tell (Clark-McGhee & Castro, 2015; Sabat & Harré, 1992). Furthermore, combatting loneliness and creating connections with others have been identified as purposes of blogging by individuals with chronic diseases (Ressler et al., 2012). Numerous bloggers wrote about participation in either online or in-person support groups and how they benefitted from being a part of these groups. Fox (2011) revealed that approximately 25% of care partners and individuals with a

chronic health condition who use the Internet seek others with similar circumstances. Other studies also revealed the use of support groups as a coping mechanism (Beard, Fetterman, et al., 2009), and it has been argued that participation in these groups may be beneficial to individuals affected by a chronic disease (Harvey, Brown, Crawford, Macfarlane, & MacPherson, 2007; Zufferey & Schulz, 2009).

Sharing experiences and strategies

Additionally, several of our overarching themes align with themes recognized through other studies on the narratives of individuals and care partners affected by chronic diseases. This overlap was particularly noticeable when analyzing the coping mechanisms and compensatory strategies of bloggers in our study. For example, research has shown that care partners and individuals with disease diagnoses create blogs for multiple reasons, including helping others and sharing experiences (Lewis, 2015; Ressler et al., 2012). Both of these purposes formed subcategories of the overarching theme of utilizing coping mechanisms and compensatory strategies in our study. In addition, strategies such as keeping the mind busy, eliminating excessive background noise, seeking support from others, advocating for individuals with the disease, and utilizing external memory aids were represented in our study as well as previous research on the perspectives of individuals affected by chronic diseases (Beard, Fetterman, et al., 2009; Fox, 2011). The repetition of these themes across several studies supports the perceived usefulness of these strategies as well as the ability of individuals who are experiencing the disease to articulate techniques that they have found useful. This ability to communicate with intention and meaning through written word confirms the capabilities of those with dementia, often not obvious due to hindered speech or difficulties with verbal expression (Ryan et al., 2009).

Maintenance of identity

Furthermore, the concern about maintaining identity was prominent in our study as well as in other studies on narratives of individuals with disease diagnoses (Basting, 2003; Beard 2004; Bingley et al., 2006; Frank, 2013). Previous research suggests that despite memory loss or cognitive decline, individuals with dementia can maintain a conscious sense of self (Clark-McGhee & Castro, 2015) and that writers are able to rebuild their identities through the course of their disease by writing about their experiences (Hunt, 2000). The specific experiences chosen by bloggers for narration also help solidify their preferred identity, as they can actively select the memories and experiences that define their unique perspectives (Clark-McGhee & Castro, 2015). For care partner bloggers, the experiences and memories that they choose to share convey both their personal views and desired identities, as well as their view of the identities of their loved ones. The inclusion by bloggers with AD/DRD of memories based on emotional experiences or personal values, which speak to the authors' individual views of life, supports the idea that the central values and emotional attitudes of the individuals are maintained despite cognitive decline (Westius, Andersson, & Kallenberg, 2009). Challenges to identity include factors such as the individual's perceived role in society and relationships with others (Clark-McGhee & Castro, 2015; Mead, 1934; Surr, 2006) as well changes in the physical body and mind that occur as effects of the disease. Several of the blogs analyzed highlighted the frustrations of being aware of decline in cognitive resources over time and mourning the loss of roles and responsibilities that these

individuals once took pride in. In addition, care partners reflected on the changes observed with the individuals for whom they were caring. One care partner expressed her frustration with the changes to her own perceived role in the family, stating “I hate not feeling like a wife anymore—just a caregiver. . .” (from Frontotemporal Degeneration). Recognition of these changes supports the notion that people with ADRD can have a level of awareness of the effects of the disease and are able to reflectively communicate this awareness through writing.

Limitations

While this study offers valuable insights into the experiences of people affected by ADRD, it is not without limitations. Although each of the themes and subcategories represented in our study were identified in a minimum of 10 blogs in the sample, our results cannot be generalized to all individuals who are affected by ADRD. Each individual’s experience is unique; therefore, this is a limitation that is difficult to overcome through any type of qualitative research. Furthermore, although there are many benefits to using blogs in research, the sample is limited to individuals with Internet access (Konovalov, Scotch, Post, & Brandt, 2010; Orzan-Rafferty, Johnson, Shah, & Kursun, 2014) as well as other groups with particular demographic variables, such as those who are literate, and those who have the interest to engage in blog writing (Hookway, 2008). All dementia diagnoses discussed in this study were self-reported, leaving opportunity for deception regarding both diagnoses and reported experiences (Keim-Malpass et al., 2013; Miller & Pole, 2010; Orzan-Rafferty et al., 2014); however, it is also important to recognize that research participants have the opportunity to deceive when being interviewed in person (Hookway, 2008).

Additionally, it should be noted that the sample of blogs reviewed for this study was not necessarily representative of all individuals affected by ADRD. While the authors have tried to include as many blogs as possible that aligned with our criteria, it is unlikely that we were able to find all of them from our search. While we did not specify a particular cut-off in the number of blogs to include, we did begin to taper our search once we were no longer consistently finding blogs that matched our inclusion criteria. Furthermore, we pooled data from people with ADRD and care partners together in our analysis. We were unable to find an equal number of blogs for each group, and therefore, the data presented in this study are more heavily weighted toward the perspectives of care partners. Future research should consider separating data from each group in order to compare and contrast these experiences.

Lastly, the data may be limited by the tendency of individuals to write about the most poignant experiences in their blogs, rather than to report the day-to-day experiences (Entwistle, 2007). This is arguably a limitation of all blog research, yet it is also something that is largely dependent on the individual blogger and cannot be avoided when conducting this type of research.

Implications

Despite these limitations, our study provides information that adds to the current literature by illuminating the experiences of individuals affected by ADRD. Given the personal nature of blogs as well as the number of blogs dedicated to experiences with diseases (Bingley et al., 2006), researchers should consider utilizing blog narratives more frequently in qualitative studies. Future socio-biographical research on the ADRD experience should analyze interactive aspects of blogs, such as commentary from blog readers and hyperlinks to other blogs, social media sites, or health information sites that are provided within blog posts. This study focused solely on blogs of individual authors; however, results may be helpful for medical professionals who work with individuals affected by ADRD to gain a better understanding of their personal experiences.

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Biographies

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Appendix 1

Table 1

Blogs sampled for this study (group 1: people with ADRD, $n = 19$).

Blog title	Hyperlink
1) Sharing my Life with Lewy Body Dementia	http://parkblog-silverfox.blogspot.com
2) Truthful Loving Kindness	https://truthfulkindness.com
3) Dealing with Alzheimer's Blog	http://creatingmemories.blogspot.com
4) George Rook: Living with Dementia as well as I can	https://georgerook51.wordpress.com
5) Dementia Survivor. . .So Far	https://mason4233.wordpress.com/page/2/
6) Living Well with Lewy Body Dementia and Comorbidities	http://ken-kenc2.blogspot.com
7) Living Beyond the Diagnosis	http://lbdlivingbeyonddiagnosis.com/blog.html
8) FTD/Dementia Support Blog	http://earlydementiasupport.blogspot.com
9) Which me am I Today?: One Person's Experience of Living with Dementia	https://whichmeamitoday.wordpress.com/blog/
10) Living with Alzheimer's	http://living-with-alzhiemers.blogspot.com
11) Watching the Lights Go Out	http://davidhilfiker.blogspot.com
12) My Thoughts on Dementia	http://mythoughtsondementia.com/blog.html
13) Maternal Dementia	http://maternal-dementia.com
14) Early (Young) Onset Atypical Alzheimer's Disease	www.earlyonsetatypicalalzheimers.com/blog
15) Wise Words Lost for Words	https://wisewordslostforwords.wordpress.com
16) Welcome to DementiaLand	http://dementialand.chewtor.co.uk/#home
17) While I Still Can	http://phelps2645.blogspot.co.uk
18) Living with the Thief of Dementia	http://dementiathief.blogspot.co.uk
19) Still Life with Dementia	https://stilllifewithdementia.wordpress.com

Table 2

Blogs sampled for this study (group 2: care partners, $n = 44$).

Blog title	Hyperlink
1) Missing Jim: Confessions of an Alzheimer's Wife	http://missingjim.com
2) Livin' in the Shadow of Alzheimer's. . .Goin' Through the Motions	http://sherizeee.blogspot.com
3) "Had a Dad" Alzheimer's Blog	http://alzheimersdad.blogspot.co
4) Michael A Horvich Cares About Alzheimer's Disease	http://mhorvichcares.blogspot.com
5) The Face of Early Onset Alzheimer's Disease	http://mcknowlesabode.blogspot.com
6) Dating Dementia: Alzheimer's, Caregiving, and More	www.datingdementia.com
7) The Diary of an Alzheimer's Caregiver	www.thediaryofanalzheimercaregiver.com/blog.html
8) Early Onset Alzheimer's Blog—L. S. Fisher Encourage, Inspire, and Inform	http://earlyonset.blogspot.com
9) Alzheimer's—My Mom My Hero	http://mommyhero.blogspot.com
10) I am an Alzheimer's Caregiver	http://iamanalzheimercaregiver.blogspot.com
11) Books, Blogs, and Butterflies	http://hwbrycewrites.com/my_blog/
12) Alzheimer's Wife	https://alzheimerswife.wordpress.com
13) My Demented Mom	https://mydementedmom.com
14) Inside Dementia	www.insidedementia.com/blog/
15) Lewy Body Dementia	http://cleaninghousebook.blogspot.com
16) Dementia Diaries: A Journey with Dementia	http://journeywithdementia.blogspot.com
17) Memories from my Life	https://memoriesfrommylife.wordpress.com
18) Dealing with Dementia	http://dealingwithdementia.wordpress.com
19) Porkchops and Pianos: A Dementia Blog	http://porkchopsandpianos.blogspot.com
20) The Lost Kitchen	www.thelostkitchen.org/blog
21) The Dopamine Diaries	https://margaretmassey.wordpress.com
22) Tracey's Caregiver Blog	https://traceycaregiver.wordpress.com
23) Go to your Corners and Come Out Loving	http://gotoyourcorners.blogspot.com
24) The Unlikely Caregiver	http://theunlikelycaregiver.com
25) Lydia's FTD House	https://lydiasftdhouse.com
26) Houlding On—Letting go	http://houldingon.blogspot.com
27) Frontotemporal Degeneration: Tumbling Down the Rabbit Hole	http://ftdtumblingdowntherabbithole.blogspot.com
28) Dementia: Stuck in Between	http://dementiastuckinbetween.blogspot.com
29) Putting One Foot in Front of the Other	http://puttingonefootinfrontoftheother.com/author/nancycarlson/
30) FTD—Aspects and Experiences	https://deborahthelwell.wordpress.com
31) Dr. Patty's Blog	www.patriciabay.com/blog/
32) FTD's Painful Road	http://ftdspainfulroad.blogspot.com
33) The Rookie Caregiver	www.elainesoloway.com/therookiecaregiver
34) FTD Isn't Just Flowers Anymore	https://ftdisntjustflowersanymore.wordpress.com
35) Matt Matherne Support	http://mattmatherne.blogspot.com
36) John Jay Cox (CaringBridge Journal)	www.caringbridge.org/visit/johnjaycox
37) Don's Daughter	http://donsdaughter.blogspot.com

Blog title	Hyperlink
38) Swapna Writes	https://swapnawrites.wordpress.com
39) Living with a Thief Named Lewy Body Dementia	www.thieflewybodydementia.com
40) Younger Onset Dementia from a Spouse's Perspective	http://caregiverscarereceivers4dementia.tumblr.com
41) Dementia Just Ain't Sexy	http://dementiajustaintsexy.blogspot.com
42) Dementia Journey by Deborah Shouse	https://dementiajourney.org
43) Lewy Body Journal	www.lewybodyjournal.org/journal/
44) Lewy Body Journey	https://lewybodyjourney.wordpress.com

Table 3

Demographic characteristics.

	Care partner bloggers (n = 44)		Bloggers with ADRD (n = 19)	
	Number	Percentage	Number	Percentage
Gender				
Male	4	9	12	63
Female	36	82	6	52
Multiple contributors	4	9	0	0
Unknown	0	0	1	5
Location				
United States	23	52	6	32
Canada	1	2	0	0
United Kingdom	1	2	3	11
Israel	1	2	0	0
India	1	2	0	0
Unknown	17	39	11	58
Diagnosis of individual with ADRD				
Alzheimer's disease ^a	11	25	9	47
Fronto-temporal dementia	14	32	1	5
Vascular dementia	0	0	0	0
Lewy body dementia	4	9	1	5
Semantic dementia	1	2	0	0
Mixed dementia	5	11	4	21
Unknown	9	20	4	21

^aOne blogger reported that she had been misdiagnosed as having Alzheimer's disease. Since her posts were written from the perspective of someone who believed she had Alzheimer's, she has been included in this group.

Table 4

Relationship of care partner blogger to individual with ADRD.

	Care partner bloggers (n = 44)	
	Number	Percentage
Relationship to individual with ADRD		

Care partner bloggers (n = 44)		
	Number	Percentage
Male spouse/partner	3	7
Female spouse/partner	16	36
Son	1	2
Daughter	20	45
Multiple contributors	4	9

Table 5

Emergent themes and subcategories.

Overarching themes	Subcategories
Effects of ADRD on the person with ADRD and/or the care partner	<ul style="list-style-type: none"> Psychological <ul style="list-style-type: none"> Loss of identity/independence Physical <ul style="list-style-type: none"> Feeding/swallowing Balance/falls Emotional <ul style="list-style-type: none"> Anger/frustration Loneliness Guilt Sadness/hopelessness Financial
Seeing the positives	<ul style="list-style-type: none"> Celebrating accomplishments and perseverance Moments of Understanding/Connection Finding Humor in the Situation Appreciation of Support Increased Awareness of Simple Joys Positive Medical Experiences
Feeling out of control	<ul style="list-style-type: none"> Uncertainty/fear of the unknown Grief and yearning for what has been lost Being aware of symptoms but unable to change them
Advocacy and empowerment	<ul style="list-style-type: none"> Desire to contribute to research or funding Combatting stereotypes and misconceptions Conducting one's own research Fulfillment of final wishes Sharing one's story/perspective to educate others Increase in self-awareness Engaging in Political and Social Activism

Overarching themes	Subcategories
Coping mechanisms and compensatory strategies	<ul style="list-style-type: none"> • Support groups/online community • Finding comfort through faith/spirituality • Staying active in body and mind • Acknowledgement of one's own needs • Use of assistive devices (both high- and low-tech) • Establishing a routine/planning ahead • Eliminating stressors and distractions • Providing advice for other care partners • Acceptance of the diagnosis
Candid descriptions of experiences with ADRD	<ul style="list-style-type: none"> • Experiences with stigma • Negative medical experiences • End-of-life experiences • Descriptions of symptoms or events related to ADRD <ul style="list-style-type: none"> – Changes in executive functioning – Changes in memory – Changes in reading and/or writing skills – Change in spoken language skills (expressive or receptive) – Disorientation and confusion – Behavioral expressions of unmet needs