Blogging through Dementia: Reworking Mainstream Discourse through Metaphor in Online Early-onset Dementia Narratives.

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Abstract:	Drawing on Conceptual Metaphor Theory, this article analyzes whether and how mainstream discourse on dementia is reworked in a corpus of illness blogs written by people diagnosed with early-onset dementia. The findings demonstrate that across blogs no single metaphor alone is capable of capturing the complexity of the dementia experience; instead multiple metaphors are deployed to provide a characterization of the multiple faces of this condition. In this way blogs transcend and reshape the reductionist view of dementia that emerges from the either/or dichotomy of the tragedy vs living well with dementia discourses that dominate in media representations (McParland et al., 2017; Peel, 2014). By reshaping some of the metaphors used in mainstream discourse and introducing new ones, blog narratives draw attention to the complex nature of the experience of dementia, acknowledging both the suffering and social and functional losses that the condition brings, while also claiming recognition for personhood, agency, validation, and the aspiration to grow beyond the diagnosis and live a valued life as part of a family and community. Overall, this study demonstrates that metaphor is a useful tool for providing insights into people's experience of dementia and that blogs are a platform where stereotypes may be defied and mainstream representations of dementia reworked offering a more holistic view of the condition and granting narrative agency to those who live with dementia.

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1. Introduction

More than 55 million people currently live with dementia worldwide. With an estimated prevalence of 139 million in 2050 (WHO, 2021), dementia is one of the most feared conditions in Western societies (Van Gorp & Vercruysse, 2012). This is primarily because it embodies deeply entrenched cultural anxieties about aging, illness, and death (Lock, 2014) that spring from long-standing cultural, philosophical, and theological precepts such as: (a) the Cartesian body-mind dichotomy and the identification of the self with the mind rather than the body (Descartes, 1984); (b) hypercognitivism and its emphasis on rational thinking and memory to the detriment of other human abilities (Post, 2000); and (c) the successful aging paradigm with its emphasis on agency, control, and the importance of staying physically and cognitively active as one grows older (Lamb, 2014). All have contributed to building a cultural representation of dementia as the epitome of decline, frailty, dependence, and passiveness (Low & Purwaningrum, 2020; McParland et al., 2017; Post, 2000; Van Gorp & Vercruysse, 2012).

Furthermore, the media reinforce and legitimize this view of the condition (Basting, 2009) thanks to their power to frame discourses and influence beliefs and attitudes toward health and illness (Doyle et al., 2012; Seale, 2003). This, along with the fact that sociocultural narratives of dementia are primarily constructed from the point of view of the scientific community and caregivers (Villar et al., 2019), with the voice of those living with the condition usually underrepresented or absent (Clarke, 2006; Kirkman, 2006; Siiner, 2019; Van Gorp & Vercruysse, 2012), may result in a biased representation of dementia that dispossesses people with dementia of narrative agency (Villar et al., 2019).

In this context, this article presents a metaphorical analysis of a corpus of blogs written by individuals living with early-onset dementia to explore whether and how dementia narratives, as represented in the news and popular culture, are reworked in first-person accounts of the disease online. The article focuses on the analysis of the metaphors used to describe dementia and the consequences that it has on people's perceptions of themselves and their relationships with others[1] as these are the topics most extensively discussed in the media. The data and methodology employed for the current study were selected for two reasons. The first is that blogs offer an insight into the experience of chronic disease that is inherently patient driven and centered (O'Brien & Clark, 2012). The second reason is that metaphor is well known to be a linguistic and cognitive mechanism used to reason and talk about sensitive and complex experiences such as illness (Lakoff & Johnson, 1999).

1.1 Metaphor and Illness Discourse

Conceptual Metaphor Theory conceives of metaphor as a cognitive mechanism by which we conceptualize, reason, and talk about an abstract, complex, unfamiliar, or subjective experience (target domain) in terms of another (source domain), which is more tangible, or familiar so that the former becomes more imaginable, comprehensible, and easier to communicate (Lakoff & Johnson, 1980, 1999). For example, people sometimes talk about illness in terms of war, as in *I am going to fight this disease.* This metaphor builds on perceived resemblances between the domains of war and illness such as that "both are difficult and dangerous enterprises that require effort and concentration, and both involve

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[1] In this paper only those metaphors that are under discussion are underlined.

harm to people, and, in some cases, death" (Semino, 2021, p. 50) and entails the mapping of attributes from the source domain of war (e.g., enemy, weapons, soldiers, victims, etc.) onto the target domain of illness. In this way illness can be seen as an enemy, treatments as weapons, and patients as soldiers or victims and so on. These mappings allow us to call upon our knowledge of the source domain (i.e., war) to reason and also talk about the target domain (i.e., illness).

Metaphors pervade language to the extent that they are estimated to comprise as much as 20% of natural discourse (Steen et al., 2010), where they serve different functions, being the most general one to make communication more efficient and aid understanding (Ortony, 1975; Semino, 2008). Moreover, given the potential of metaphors to evoke different conceptualizations of the exact same situation by foregrounding certain aspects while downplaying others (Charteris-Black, 2005; Lakoff & Johnson, 1980, 1999), they also work as framing tools able to "promote a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation for the item described" (Entman, 1993, p. 53).

In the context of illness discourse, given the subjective, sensitive and complex nature of illness experience, metaphors figure particularly strongly. They have been found to frame descriptions of the lived experience of conditions such as depression (Charteris-Black, 2012), cancer (Gibbs & Franks, 2002; Semino et al., 2018), mental health (Wilson & Lindy, 2013), or addiction (Shinebourne & Smith, 2010). Likewise, metaphors hasve also proven instrumental in shaping how illness –e.g., HIV or Cancer (George, 2010; Hanne & Hawken, 2007; Sontag, 1977)– is depicted in public discourse and how it is socially perceived (George, 2010; Hanne & Hawken, 2007; Sontag, 1977). Dementia is not an exception; as shown in the following section, evidence indicates that a most notable characteristic of dementia public discourse is that it is rich in figurative language (Frezza, 2018).

1.2 Metaphorical Frames of Dementia in the Media

Previous studies have shown that the depiction of dementia in public discourse tends to operate on two levels: the *tragedy* discourse or *the living well with dementia* discourse (McParland et al., 2017; Peel, 2014).

1.2.1 The tragedy discourse

Biomedical and media narratives largely depict dementia as a tragedy by emphasizing the irreversible decline that it causes, linking it to the notions of loss and death, and describing it as an uncontrollable personal and societal threat (Behuniak, 2011; Johnstone, 2013; McParland et al., 2017; Van Gorp & Vercruysse, 2012). Most of the studies that have approached the analysis of the so called *tragedy* discourse draw attention to the role of language in the construction of dementia as fearful, negative and tragic condition (Mitchell et al., 2013; McParland et al., 2017) and point out that metaphors abound in it (Behuniak, 2011; Mitchell et al., 2013; Peel, 2014; Zeilig, 2013, among others).

1.2.1.1 Metaphors in the tragedy discourse

Previous research has shown that the conceptualization of dementia as a 'natural force' pervades news media, novels, and poems where dementia is depicted as a 'rising tide', 'a flood', or a 'silent tsunami' to emphasize its uncontrollable nature and increasing prevalence, which evokes a sinister image of the condition (Peel, 2014; Zeilig, 2013). This metaphor coexists with a conceptualization of dementia that evokes the image of an 'epidemic' through expressions such as 'dementia is a silent epidemic that sneaks up on victims' or 'dementia is a plague' which are repeated in print media, films, and on the radio (Johnstone, 2013; Peel, 2014; Zeilig, 2013). Such a metaphor views dementia as a contagious, infectious, and rapidly spreading condition, which evokes fears of death (Johnstone, 2013).

Previous studies have also found that dementia is often characterized as a destructive ‘agent’ that deprives people of normal cognitive functioning and causes harm and suffering (Behuniak, 2011; Brookes et al., 2018; Johnstone, 2013; Zeilig 2013). This imagery is evident in expressions such as ‘the millennium demon’; ‘a monster that steals lives’; ‘a physical disease which kills brain cells’; or ‘an invader that creeps up on people’, where dementia is conceptualized as a ‘monster’, a ‘killer’, an ‘invader’, and a ‘thief’. The conceptualization of dementia as an assailant or enemy has been found to work in tandem with the use of ‘war’ metaphors that, on the one hand, depict the brain/body as a ‘battleground’ upon which practitioners ‘combat’ the disease and, on the other, describe scientific and administrative actions to deal with dementia as a ‘battle’ or ‘crusade’ (Bailey et al., 2019; Gerritsen et al., 2014; Johnstone, 2013; Lane et al., 2013;Van Gorp & Vercruysse, 2012; Zeilig, 2013). In this context, those who live with dementia are seen as ‘sufferers’ of a ‘cruel disease that is coming for its victims’ (Bailey et al., 2019; Kirkman, 2006).

A number of studies have also shown that the concept of ‘victim’ is sometimes reformulated in the media where, on the basis of the philosophical assumption that identity is tied to memory and intellect, those living with dementia are characterized as ‘nonpersons’: ‘vegetables’, ‘empty shells’, or ‘zombies’ (Behuniak, 2011; Clarke, 2006; George, 2010; Kirkman, 2006). Finally, there is also evidence that in mainstream representations, dementia is conceptualized as a ‘burden of care’ not only on caregivers but also on societies because of the economic ‘load’ implied by care and productivity loss (Van Gorp & Vercruysse, 2012). All these metaphors share a negative, threatening view of dementia that contributes to the stigmatization of the disease (Gerritsen et al., 2016).

1.2.2 Living well with dementia discourse

Although the *tragedy* discourse remains dominant, in recent times a shift in the way dementia is represented in public discourse has been identified (McParland et al., 2017; Peel, 2014). The *living well with dementia* discourse has emerged as an alternative to the *tragedy* discourse thanks to the work of campaigning organizations and the increasingly prominent emphasis on the vascular aspects of the disease and the potential for reducing the risk of developing it by adopting a healthy lifestyle and exercising the mind (McParland et al., 2017; Peel, 2014). An essential aspect of the *living well with dementia* discourse is that it argues for the enduring selfhood of those who live with dementia (McParland et al., 2017) and presents dementia as a manageable disability (Hillman et al., 2018), emphasizing the role of brain training and healthy habits in fighting the condition back.

1.2.2.1 Metaphors in the living well with dementia discourse

Recent research has suggested that the *living well with dementia* narrative and particularly its focus on the concepts of neural plasticity, recovery and resilience partly depends on the metaphorical conceptualization of the brain as ‘malleable’ and able to ‘rewire’ through ‘training’ (Frezza, 2018). These notions, which are strongly implanted in people’s reasoning (Leibing, 2015), find their way into public discourse through the metaphorical description of the brain as ‘plastic’ or the use of expressions such as ‘cognitive reserve’, ‘mental exercise’, ‘brain training’ or ‘use it or lose it’, among other metaphorical expressions, (Frezza, 2018). These metaphors draw attention to brain’s resilience and the possibility of halting deterioration, which contributes to enhancing hope.

In sum, these studies show that language, particularly metaphor, decisively contributes to the representation of dementia in public discourse. Because metaphor choices reflect different ways of understanding and evaluating our experiences (Semino et al., 2018), exploring how metaphors are mobilized to describe the overall experience of dementia in first-person narratives compared to mainstream discourse may uncover alternative frames that reflect the voices of those with dementia and support their narrative agency. In this respect, the analysis of illness blogs (i.e., personal online websites initiated by people diagnosed with a condition to describe their experience), which has been proven a valid method of research in other conditions (Keim-Malpass et al., 2014), may be enlightening.

In the case of dementia, only a handful of studies have examined internet blogs and forums to explore the perspectives of patients. For instance, Rodriquez (2013) analyzed how people diagnosed with dementia use online forums to connect and establish a sense of community with those experiencing similar situations. Kannaley et al. (2019) conducted a thematic analysis of the content of a corpus of blogs to examine the social aspects of living with Alzheimer's. Finally, Castaño (2020) investigated the impact of dementia on people's subjective well-being by analyzing online descriptions of the effects of this condition on three basic psychological needs: autonomy, competence, and relatedness.

In this context, the aim of this paper is to analyze a corpus of illness blogs on dementia from a metaphorical point of view to shed light on the following questions: do online first-person narratives of dementia rework or provide alternative metaphorical frames to those exhibited in mainstream narratives? If so, how are those frames reshaped? And what attitudes and assumptions about dementia do they reflect and/or defy?

Subsequent sections describe the material and methods employed in this study and present the main findings and conclusions.

2. Methodology

2.1 Materials

Research on the illness experience has traditionally been conducted through the analysis of interviews, focus group transcripts, diaries and memoirs (O'Brien & Clark, 2012). At present, the potential of illness blogs to analyze people's experiences with specific conditions is increasingly acknowledged. This is because illness blogs grant a voice to those who live with a disease and afford them the chance to share their insider's knowledge of the condition with others (Keim-Malpass et al., 2014). Moreover, they are a naturalistic and unobstructive method of data collection (Hookway, 2008).

The present study comprised an analysis of a corpus of blogs self-initiated by 10 people (5 men and 5 women) diagnosed with early-onset dementia. Blogs were sampled on the basis of demographic, linguistic, content, temporal, and educational criteria. Only blogs that provided demographic information about their authors (i.e., age of diagnosis and dementia type), were written in English, described people's lived experience of the disease, were regularly updated and covered at least 5 years after diagnosis (the average lifespan of blogs was $M = 7.1$, $SD = 1.37$, considering the time passed from the first post to the most recent post analyzed in this study) were included. Moreover, for ethical purposes (APA, 2010; Eastham, 2011; O'Brien & Clark, 2012), an important prerequisite was that blogs were publicly accessible, had clear advocacy or educational purposes, offered an RSS feed, and no login was required. Prior to initiation of the study, it was submitted to the Institutional Review Board and need for approval was exempted due to the public nature of the blog sites and because a passive analysis was going to be conducted.

Blogs were then skimmed for content and a dataset of 622 posts was selected (see Table 1). The number of posts per blog included in the corpus ranged from 44 to 77 (M = 62.2, SD = 9.11), which amounted to a total of 252,466 words.

Table 1. Corpus description. Number of posts, words and years of blogging per blogger.

BLOG	POSTS PER BLOG	WORDS PER BLOG	YEAR OF THE FIRST POST	YEAR OF THE MOST RECENT POST ANALYZED
DLE-B1	67	28,637	2014	2020
DLE-B2	58	29,720	2012	2016
DLE-B3	52	22,054	2015	2020
DLE-B4	77	23,728	2013	2020
DLE-B5	48	28,228	2015	2019
DLE-B6	69	24,637	2012	2018
DLE-B7	52	21,272	2011	2018
DLE-B8	44	25,410	2013	2019
DLE-B9	85	26,501	2014	2020
DLE-B10	70	24,279	2011	2020

2.2 Metaphor Identification

Metaphor identification was based on the PRAGGLEJAZ (2007) metaphor identification procedure (MIP) which is widely acknowledged as appropriate for the analysis of metaphors in natural discourse. In this study, a metaphorical expression is to be understood as one word or multi-word unit (e.g. compounds (dead sentence); fixed collocations (go on holidays); phrases (come out of the closet)) that describes a notion in terms of another by means of comparison. For example, ‘eat’ in *dementia eats your brain* describes the degenerative neurological effects of dementia via a comparison with the basic meaning of the verb ‘to eat’. The analysis was conducted in 3 steps. First, texts were read to establish a general understanding of their meaning; candidate metaphorical expressions were then identified and their contextual meanings established. Finally, it was determined whether those linguistic units had more basic meanings in other contexts, and whether their contextual meanings within the blogs could be understood in comparison with these. In that case, they were marked as metaphorical. The online version of the *Macmillan Dictionary for Advanced Learners* (Rundell & Fox, 2002) was used as a point of reference to identify the basic meanings of the lexical units under analysis. For our purposes, the basic meanings were more concrete or related to bodily action.

Each metaphorical expression was then allocated to a semantic field on the basis of its basic meaning (e.g., war, journey, etc.), following which the aspects of dementia they described (e.g., life with dementia, impact on identity, social and family relationships, expectations, hopes, etc.) were established. Metaphor identification and classification were not based on any assumptions about conceptual metaphor or source domains, therefore some of the metaphors discussed in this paper cannot be found in established metaphor lists (e.g., Lakoff & Johnson, 1980).

Table 2. Metaphorical frames in blog narratives.

TOPIC	METAPHOR GROUPS	EXAMPLE	PROPORTION
Depiction of dementia	Assailant agent	It is a torturous thief, slowly and meticulously robbing individuals until there is nothing left.	8,5%
	Annoying visitor	I equate it to the obnoxious relative that comes for a visit.	2,2%
	Companion	Dementia has been my companion rather than my enemy.	3,3 %
	War/battle	I continue my battle with dementia. I live life to the full, as best I can.	12.6,%
	Journey	I will travel this path with honor and integrity.	10.4%
The body, the mind, the disease and the self	Divided-self metaphor (Loss of the self)	I will slowly, grindingly lose me. My body will be here, but I will be gone	9,1%
	Divided-self metaphor (Continuity of the self)	Brain -self separation My brain is out to thwart me.	3,6%
		Mind-self separation Is my mind playing tricks with me or are these memories really true?	1,7%
		Different world/ inside I am still the same person inside	3,6%
	Transformation	I'm still me, or at least a version of me.	6.8%
	Brain training	I need to exercise my brain in order to keep it functioning	4,2%
Social and relational aspects of dementia	Label	I am me not the illness. I am not a label.	2,7%
	Deprivation	I had a career I worked so hard to obtain, to just have it taken away from me in a moment.	5,3%
	Distance	Some friends may back off or even walk away	3,2%
	Secret	Most of the time I hide this disease well	5,4%
	Infantilization	We become very quickly disempowered and infantilized	5,5%
	Fellow travelers / guides	Dementia is a trail with tangles of thistles. We can sign-post the dangers for those following behind.	8,7%
	Lifeline	Support groups are a lifeline for those who live with dementia	3,2%

3. Results

3.1 The Metaphorical Depiction of Dementia

In the blogs, dementia was personified as a (a) ‘stealthy, equal opportunity thief’ (1); (b) a captor that ‘kidnaps you in your fifties or sixties’; (c) a ravenous agent that ‘likes to eat brain and eats at you slowly’; and (d) as ‘a brain gremlin invading your life’ (DLE-B1, DLE-B3, DLE-B6, DLE-B8)[2]. These metaphors conveyed the image of being acted upon by an external force, and were used to convey two main notions: (a) that dementia alters people’s lives indiscriminately, unexpectedly, and through no fault of their own and (b) that its effects spread without control.

> (1) You’re a thief of the worst kind. You go as far as taking away people’s ability to recognize themselves […] but we will settle for a way to prevent you from robbing others. (DLE-B2)

Along with these metaphors, bloggers also employed other personifications of dementia that depicted it as an ‘annoying visitor’ (2) or ‘companion’ rather than ‘an enemy’ (DLE-B3; DLE-B5). These metaphors highlighted the need to learn to live with the condition and retain as much control over the situation as possible (3).

> (2) Living with the Disease. I equate it to the obnoxious relative that comes for a visit and winds up staying only to get more annoying as times goes on!
>
> (3) One of the things about my companion, Mr. D, is that it likes to play with me for its own entertainment […] Following my diagnosis I made the decision to show it who’s boss.

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[2] To safeguard the anonymity of bloggers, the quotes used to illustrate the analysis have been searched on Google to ensure they cannot be traced back to the original blogs and personal information have been removed.

‘War’ metaphors also occupied a remarkable place in the description of dementia among bloggers. In their narratives, military metaphors served two main functions. First, ‘war’ metaphors echoed an effort to raise social awareness and ensure the rights of people with dementia were recognized (4). Second, warfare imagery was used as a symbol of agency and self-determination that showed that, although fighting dementia is a ‘winless battle’ (5), their choice was to maintain an active role in managing their condition.

(4) I am so passionate about fighting for our rights and raising awareness of dementia. (DLE-B4)

(5) I am well aware that each of us will lose the battle because that is the known outcome of this war but only when I give up will the battle be over. The battle is worth it and the warriors are honorable. (DLE-B3)

The data also indicate that dementia was repeatedly conceptualized as the beginning of a metaphorical journey, ‘the dementia journey’ (DLE-B2). This metaphor is not exclusive to dementia, it is also evoked by people affected by other conditions to describe their illness experience and healing process (Semino et al., 2018). However, in the case of dementia, this metaphor was used to foreground the fact that the absence of a cure precludes people from recovering, which leads to ‘a journey of no return’ (6). Expressions such as ‘dementia is an uncharted territory’ or ‘dementia is a path full of pitfalls and highs and lows’ demonstrate that bloggers also used this metaphor to evoke the idea that living with dementia involves uncertainty and experiencing constant difficulties.

(6) Dementia is a terminal illness […] so we know where we are going. I can’t retrace my steps to that other life I once lived […]I am alone and wandering down this dementia road. (DLE-B1)

Notwithstanding the negative connotations this metaphor brings, blog narratives also indicate that the ‘journey’ metaphor served to describe disease acceptance (7), and to shift the focus from future prospects to everyday life. In the latter case, the ‘journey’ metaphor emphasized that from diagnosis and throughout the course of the illness people can have a fulfilling life despite the difficulties that may be encountered (8).

(7) The hardest step to take on the road of dementia is to accept your disease. Once you take that hardest step your new life begins to look a lot better. (DLE-B4)

(8) It is a bumpy road but there are special moments of joy. A diagnosis of dementia does not mean your life is over. (DLE-B3)

3.2 The Body, the Mind, the Disease, and the Self

In the blogs, the use of metaphors connected with the themes of ‘loss’ and ‘disappearance’ to express concern about the impact of dementia on the bloggers’ sense of self and identity (9, 10) echoed the dualistic concept of Person that characterizes Western philosophy and theology and reflected their fear of losing themselves as their memory and cognitive abilities began to fade.

(9) If we lose our mind, who the hell are we? (DLE-B4).

(10) I still do well but in some ways that is even worse, it gives me time to see how I am fading away. (DLE-B9).

Nonetheless, understanding the mind and the body as two separate substances also permitted the otherization and personification of the brain found in some of the narratives, where the brain was perceived as having taken on an agency of its own and acting independently of the self (11). Through this ‘divided-self’ metaphor, body-mind dualism was reinterpreted and employed to put some distance between the self and the diseased brain (12), which could be made responsible for the situation.

(11) My brain is on holiday today... I'm unable to explain myself. Hard as I try. (DLE-B2).

(12) My brain may have given up but I never did. (DLE-B3)

In some cases, bloggers not only conceptualized the self and the body as separate but also perceived their minds as separate from their primary identities (13). In this case, the 'divided-self' metaphor served as a strategy to claim the continuity of the self throughout dementia by establishing a demarcation line between their brains/minds and themselves. Through this dissociation, bloggers expressed a determination to hold control over their minds and not give in to the disease.

(13) I can let my mind shape me or I can shape my mind. (DLE-B8).

The separation of the brain and the self also allowed the latter to be conceptualized as an entity that inhabits a different world, 'the dementia world' (14), or lives 'inside the body' and becomes less perceptible to others over time (15). These metaphors contributed to establishing a dichotomy between the world of those who live with the disease and the rest of the world, as well as between their inside and their outside. This dichotomy foregrounds the idea that cognitive decline may conceal people's identity or make it difficult to reach but it does not erase it, which is ultimately a claim for the continuity of the self.

(14) I let my mind escape into the world where people living with dementia go. What people with healthy brains cannot understand is how to get into our hidden world. (DLE-B5).

(15) Don't give up on me. What you can see on the outside can often be a poor representation of the "me" that is on the inside. (DLE-B7).

The "divided-self" metaphor also showed another variant in the blog narratives. In this case, the split in the self was connected to the notion of "transformation" (see Emmott, 2002) and the view that dementia inevitably changes those who live with it. Sometimes it makes them feel like a completely different person because their old selves and new selves are irreconcilable (16). In other cases, the transformation was seen as the development of a 'new version' of the same self (17) that granted continuity and coherence to the self in the face of the changes brought about by dementia.

(16) With our constantly changing cognitive dis-abilities, we do not feel like the same person. This is not me. I am a stranger to myself! (DLE-B2).

(17) We all change but we do not become a different person […] I'm still me, or at least a version of me. (DLE-B1).

Finally, in a context in which cognitive decline either threatens or transforms the self, biomedical and cultural discourses on the importance of individual engagement and brain stimulation to prevent or delay cognitive decline were also integrated into the bloggers' narratives. The "brain training" metaphor was used to convey commitment to self-care as a strategy to resist 'be[ing] consumed' by the disease, and ensure a better quality of life (18)

(18) I am in a race with my disease. It is trying to consume me and I refuse to let […] I need to exercise my brain in order to keep it functioning. No magic pill, just work on my part. (DLE-B5).

3.3 Social and Relational Aspects of Dementia

Blogs showed that being given a diagnosis of dementia generates important emotional and relational challenges associated with the stigma attached to the disease. Through the “label” metaphor, bloggers conveyed their fear of being reduced to a collection of cognitive symptoms and being treated differently (19). In connection with this idea, the use of the “deprivation” metaphor became especially relevant in descriptions of how a diagnosis of dementia undermines opportunities to retain former roles (20).

(19) We are not defined by the disease but rather our abilities are affected by it. I am me, not the illness. I am not a label. (DLE-B9)

(20) I felt I was stripped as a person. I said to my daughter: “Don’t strip me of being a mom. I’m still your mom”. (DLE-B3)

Narratives also showed an awareness that maintaining or building new social connections may be difficult because of the stereotypical images of the disease that many people possess (Birt et al., 2020; Villar et al., 2019). This situation was metaphorically described through metaphorical expressions connected to the theme ‘setting distance’ such as ‘back off’, ‘walk away’ or ‘shrink back’, which were used to describe people’s reactions to the disease (21).

(21) One of the hardest lessons I needed to learn was how people react. Some friends have backed off or even walked away because they do not understand the condition or because they are afraid of it. (DLE-B6)

In this context, bloggers resorted to the ‘secret’ metaphor to explain that because there are no visible signs of the disease in its early stages, ‘masking’ dementia becomes a strategy of self-preservation (22, 23) (Beard, 2004; Rodriquez, 2013). Despite this, 'coming out of the closet' (DLE-B3) was described as necessary to raise awareness and change social perceptions.

(22) Watching us, a stranger would not guess our secret. But there is a curious shame within me; a sense of incompleteness. (DLE-B1)

(23) We learn to hide our symptoms so well that people around us do not suspect what we are going through. (DLE-B4)

Bloggers also dealt with family relationships in their narratives. They acknowledged that their caregivers, who were metaphorically defined as 'travel companions' (24), played a key role in fostering their wellbeing and described their attempts to lessen the 'burden' some of them felt they had become by means of the 'secret' metaphor (25).

(24) I am fortunate to have two travel companions coming along with me on this journey. (DLE-B7)

(25) I am just another burden. So I pretend I am alright. I hide my inner and outer pain. (DLE-B10)

Blog narratives also provided evidence that the overprotective behavior caregivers and even practitioners may exhibit was sometimes interpreted as paternalistic and thwarting the individual's autonomy. In this context, the 'infantilization' metaphor was used to describe feelings of being treated as children with a lack of control over their lives (26).

(26) We become very quickly disempowered and infantilized. We need time to get our thoughts out. We might choose to wear some wacky clothes, but what is the harm? What matters is that we live as we choose. (DLE-B9)

Finally, the blogs also made it clear that connecting and establishing a sense of community with other people with dementia, ‘fellow travelers on the path of dementia’, either through peer support groups, blogs, or forums, became a ‘lifeline’ (27) for most of the bloggers. Through these metaphors (i.e., the ‘fellow traveler’ and ‘salvation’ metaphors), bloggers conveyed a sense of belonging to a group whose members may serve as ‘guides’ or ‘leaders’ (28) to others by helping them face the disease through their advice.

(27) I started a secret support group of only people with dementia. It is a lifeline for us to voice fears, struggles, frustrations … (DLE-B6)

(28) Coaches and onlookers can assist but we have a unique perspective. Thank you, [blogger’s name], for shining the light on your path, in order for us to better see ours. (DLE-B1)

4. Discussion

Results show that bloggers drew on several metaphorical domains when conceptualizing dementia. Some of the metaphorical frames they employed were in line with mainstream discourse where dementia is also conceptualized as an ‘invader’ or a ‘thief’ (Behuniak, 2011; Van Gorp & Vercruysse, 2012; Zeilig, 2013). However, bloggers also opted for alternative metaphorical frames such as the ‘companion’ or ‘annoying visitor’ which, as helped to downplay the menacing characterization of dementia evoked by other personifications of the disease (Gorp and Vercruysse (2012).

In contrast to media representations, blogs did not portray dementia as ‘a natural force’, ‘an epidemic’, or a ‘social/economic burden’, although bloggers demonstrated awareness of such conceptualizations and the implications these may have for social attitudes toward dementia. For instance, in reference to the epidemic metaphor, some of the bloggers argued that “people are afraid of the condition. Some of them illogically think they can catch it” (DLE-B2). Others showed their rejection of the conceptualization of dementia as ‘a burden’ by comparing dementia to other conditions such as cancer and wondering why in that case the cost was not considered ‘a waste’ or an ‘intolerable burden’ to conclude that the cause is “the fear that the media perpetuate of dementia. Demented, mad, idiot, it is still there” (DLE-B5).

Likewise, ‘war’ metaphors were used in a way that differs from their conventional use in public discourse where they describe the quest for a cure (Low & Purwaningrum, 2020). Understanding dementia as a ‘winless battle’ in the short term led bloggers to shift their expectations from a “cure” to the need of supporting people with dementia to optimize their quality of life. This is evident in the following quotation (29).

> (29) Experts are fighting the war for us, but I believe sometimes on the wrong front. They are shocked to hear that a cure would be nice but a better way to live with dementia is better. (DLE-B7).

The ‘war’ metaphors also served as a tool to confer to the bloggers the active role of a fighter instead of the passive role of a victim, and to describe them as volitional in their actions to control their disease.

Although conceptualizing dementia as ‘a winless battle’ or ‘a journey of no return’ evokes a hopeless view of dementia that profiles the terminal stages of the condition, in the blogs, unlike mainstream discourse (Van Gorp & Vercruysse, 2012), the terminal stages of dementia were not representative of the entire course of the condition. Viewing dementia as a ‘war’ or ‘journey’ contributed to conveying the idea that, despite the uncertainty and difficulties a person with dementia may experience, a meaningful life is still possible, which foregrounds resilience over decline (McParland et al., 2017).

Results also indicate that, in blog narratives, dementia also appears inextricably bound up with cultural beliefs about the relationship between the body, the mind, and the self that converge in the 'divided-self' metaphor and the fear of losing the self as the disease progresses. However, blog narratives, as opposed to mainstream discourse (Behuniak, 2011; Clarke, 2006; George, 2010; Kirkman, 2006), drew attention to the dehumanizing view of dementia that body-mind dualism brings by demanding recognition of their personhood and condemning the demeaning connotations of the language used in the media to characterize people with dementia (30, 31).

(30) It requires remembering that it is still a whole human being inside that <u>shell</u>, one with a soul and one with feelings even though they may not show outwardly very much anymore.

(31) There is no alternate language for <u>victim</u>. Just do not use it. <u>Empty shell</u>, <u>Fading away</u>, etc. There are no alternatives. Discard these demeaning terms.

Moreover, in blog narratives, the 'divided-self' metaphor was reformulated and used to dissociate the self from the disease and its effects, a strategy that has also been observed in the case of pregnancy loss (Littlemore & Turner, 2019) or cancer (Gustafsson et al., 2020) and that serves to draw strict boundaries around incompatible parts of life or the self and preserve the self intact (Gustafsson et al., 2020). In the case at hand, it validated the continuity of the self and challenged the conceptualization of those living with dementia as 'living bodies without a mind' (Gerritsen et al., 2016).

In the same line, the ‘training’ metaphor was used to describe the struggle to resist a progressive loss of abilities that will potentially lead to the loss of the self as it is understood within the cultural framework of a hypercognitive society that has a capacity-based view of personhood.

Finally, as for the social and relational aspects of dementia, the ‘deprivation’ and ‘infantilization’ metaphors drew attention to the patronizing and disempowering consequences of what Brody (1971) terms ‘excess disability’ (i.e., to be treated as incapacitated to a greater extent than the condition warrants) and helped bloggers to assert their autonomy and reshape the ‘burden of care’ discourse that is enshrined in media representations of people with dementia and their relationships with their families (Low & Puwaningrum, 2020). Moreover, the ‘fellow traveler’ and ‘guide’ metaphors functioned as a claim for their need to stay connected to other people, maintain meaningful relationships and reciprocate and served to counter the view of people with dementia as experiencing a ‘social death’. A notion which signifies their cessation as social actors (Brannelly, 2011; Lyman, 1993).

All things considered, this study offers new evidence that metaphors are an integral part of the way people understand and communicate about their illness experiences (Gibbs & Franks, 2002; Semino et al., 2018) and that metaphors may serve different purposes in the context of illness discourse including emotional disclosure, self-empowerment and reframing. Although bloggers drew on some of the same metaphors used in the media (e.g., the ‘invader’, the ‘thief’, the ‘divided-self’ metaphors), they often reformulated them and introduced others to foreground different aspects of the experience of living with dementia, counter the stereotypes and stigmas attached to the disease and highlight the complexity and, in some cases, conflicting facets of dementia. In this way, blog narratives escaped reductionism and reworked the either/ or dichotomy constructed in mainstream *tragedy* vs *living well with dementia* discourses (Peel, 2014; McParland et al., 2017), constructing a delicate balance between an acknowledgement that living a fulfilling life after diagnosis is possible and the recognition that it does not preclude people from experiencing a range of functional and social losses and negative emotions.

Nonetheless, these findings should be read with caution in terms of generalizability since the sample is limited to the views of a very specific demographic group: people with early-onset dementia, who are literate, are engaged in blogging for advocacy or educational purposes and live in a Western cultural context (USA and UK). Future research should consider this aspect and also the possibility of conducting a cross-cultural analysis of dementia metaphors in illness blogs to detect possible differences between Western and non-Western countries.

5. Conclusions

Overall, this study provides evidence that blogs may serve as a vehicle for those voices that are absent or underrepresented in mainstream discourse and function as a platform where more nuanced and encompassing views of dementia surface. In this way illness blogs contribute to revealing and challenging the assumptions that underline cultural understandings of dementia and provide valuable insights into the lived experience of dementia that might help to inform media representations and promote a more open, less partial and stereotyped frame of thinking about this condition and those who live with it.

Declaration of Interest Statement

The authors report there are no competing interests to declare.

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