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Discourse Analysis as a Tool for Uncovering the Lived Experience of Dementia: Metaphor

Framing and Well-Being in Early-Onset Dementia Narratives

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Metaphors for Well-being in Early-onset Dementia Narratives

Abstract

The aim of this paper is to explore how metaphor is mobilized to frame and describe the lived experience of dementia in a corpus of illness narratives compiled from ten blogs initiated and maintained by individuals diagnosed with early-onset dementia. The paper is set against the background of contemporary healthcare practices and discourse around chronic illness, and focuses on the metaphors that patients use to communicate about their dementia experience in relation to three basic psychological needs: autonomy, competence and relatedness, which are essential for human well-being and are heavily challenged in complex medical situations. Results are discussed in terms of the framing metaphors provide of the emotional, psychological impact of dementia and their implications for patient-centered care. This study expands prior work by researching metaphors used for a condition that has been scarcely explored from this point of view and by focusing on the patient's perspective exclusively.

Key words

Bionote

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1. Introduction

People rely on metaphor as a primary cognitive mechanism for understanding and reasoning about complex experiences as well as for communicating those experiences to others (Lakoff and Johnson, 1980, 1999). By relating a complex, abstract, or unfamiliar notion (target domain) to another that is perceived as more concrete, well-structured, simple or familiar (source domain), metaphor makes abstract, complex experiences more imaginable, comprehensible and easier to communicate about (Gibbs, 2008; Lakoff and Johnson, 1980, 1999). Metaphor, therefore, is more than a stylistic device. It is conceived of as a cognitive mechanism that allows understanding and talking about one kind of thing in terms of another – e.g., talking about illness in terms of war: *the virus has attacked the immune system–* (Lakoff and Johnson, 1980, 1999). Moreover, metaphor is also a powerful framing device able to shape the way a situation or event is perceived. Metaphors evoke particular worldviews highlighting certain aspects of a situation while downplaying others. (Lakoff and Johnson, 1980, 1999; Lakoff, 2008; Charteris-Black, 2005; Ritchie, 2013).Thus, metaphor choices are not trivial, they reveal particular ways of thinking about a topic and stress the aspects of that topic that the speaker considers most important. This property of metaphor transcends language by helping "to promote a particular problem definition, causal interpretation, moral evaluation and/or treatment recommendation for the item described" (Entman, 1993: 52). Metaphorical expressions, therefore, can be seen as a window into the way individuals experience and understand the world, including highly sensitive experiences such as illness and health.

1.1 The illness experience

Metaphors figure particularly strongly in illness discourse and it comes as no surprise since illness is an especially subjective domain of experience with strong emotional, psychological and social

implications (Semino et al., 2018). In the case of chronic diseases such as dementia, diagnosis often has consequences that go far beyond its pathophysiological effects and partly derive from the patient's illness experience, that is, from the way individuals perceive their disease and live with it (Larsen, 2013). Among those consequences, which dementia shares with other chronic diseases, experts list: stress; changes in the patients' self-image and self-esteem; feelings of loss, dependence, powerlessness (i.e. the inability to have agency in one's own life (Miller, 2000) and lack of control as well as difficulty maintaining social roles and relationships (Alzheimer Europe, 2009; Hummel, 2013). These constructs are closely related to the needs for autonomy (a perception of volition, freedom, and choice in our actions), competence (a sense of control and success in achieving desired outcomes) and relatedness (the feeling of being cared for and connected to others) that self-determination theory poses to be essential for human well-being (Deci and Ryan, 2000; Ryan and Deci, 2000) and that patient-centered care practices in dementia try to promote (Kauffmann and Engle, 2014; Kitwood, 1997; Stechl, 2006). These needs refer to highly subjective and complex experiences, as such they belong to the type of notions that people tend to conceptualize and describe in metaphorical terms. Owing to this fact, tracking the metaphor choices that individuals make to communicate about them can help to uncover how they frame their dementia experience in relation to these needs and the implications that it has for their general psychological well-being and coping responses. Moreover, it can also be useful to identify strategies that help to reframe their experiences in a more positive light and foster their well-being.

1.2 Metaphors and illness discourse

The analysis of illness discourse from the point of view of metaphor has a long tradition. Since the publication of *Illness as Metaphor* (Sontag, 1977), a wealth of studies have analyzed illness-related discourse from a metaphorical point of view. Some of those studies have

investigated the metaphorical portrayal of diseases such as HIV, cancer and dementia in public

discourse and how it has influenced social perceptions and attitudes toward those diseases

(Williams Camus, 2009; George, 2010; Hanne and Hawken, 2007; Van Gorp and Vercruysse,

2011). Other studies have analyzed the role of metaphors in healthcare professional-patient

communication with mixed results. While some of those studies have proven that metaphors aid

comprehension and retention of illness information, foster well-being, empower patients, and

help to achieve consensual communication (Appleton and Flynn, 2014; Gallagher, McAuley and

Moseley, 2013), others have concluded that metaphors may not always be effective in illness

communication, especially if conversational partners do not share the same conceptualization of

the situation. The use of violence metaphors in cancer discourse, for example, has been

criticized by a number of scholars, patients and medical practitioners who argue that violence

metaphor can inhibit patients from expressing their emotions as well as offend, victimize and

disempower them (Rojas and Fernández, 2015; Reisfield and Wilson, 2004). All in all, these

studies have shown that metaphors can be interpreted differently depending on individuals'

experience, attitude and conceptualization of the situation.

Finally, a third major strand of research into illness metaphors has focused on the study

of patients' lived experience of complex medical conditions like cancer, motor neuron disease,

diabetes, infertility, or mental health, among others (Fullagar and O'Brien, 2012; Gibbs and

Franks, 2002; Locock, Manzanderani, and Powell, 2012; Palmer-Wackerly, and Krieger, 2015;

Youngson, Cole, Wilby, and Cox, 2015). These studies have shown that patients use metaphors

to describe their symptoms, emotions, and the impact of illness on their expectations and

psychological well-being. In the case of dementia, only a few studies have explored the patient'

perspective from a metaphorical point of view. Zimmermann (2017a, 2017b) provides the major

contribution to the analysis of Alzheimer's disease metaphors on literary representations of the Alzheimer's experience. Her analysis of how people diagnosed with Alzheimer's write about their condition shows that they perceive their illness as an enriching journey and, despite their awareness of the degenerative and incurable effects of a disease that constrains their future prospects, they assert themselves as individuals and alive.

In this context, the present study aims to expand upon previous research on metaphor and illness as a means to explore patients' subjectivity. To this end, an analysis of the metaphorical expressions that people diagnosed with early-onset dementia use in their blogs to communicate about their needs for autonomy, competence, and relatedness (Deci and Ryan, 2000) has been conducted using self-determination theory (SDT) as an overarching organizational framework.

Having defined the theoretical framework of the current study, the following sections will discuss the methodology, data and results.

2. Materials and Method

Traditionally, research on the illness experience has focused on the analysis of interviews, autobiographical narratives, press reports, letters, or diaries (for a review see O'Brien and Clark, 2012), Nowadays, the use of the internet to search and share health-related information has contributed to the proliferation of publicly accessible illness narratives that provide a comprehensive view of individuals' lived experience of disease beyond patient-doctor interactions in clinical settings (Gualtieri and Akhtar, 2013). Despite this fact, the study of illness blogs to understand the patient's experience is still an emerging area of research (Keim-Malpass, Steeves, and Kennedy, 2014). In the particular case of dementia, only a couple of studies have resorted to internet blogs or forums to explore patients' perspective, either through a thematic analysis of blog narratives aiming at investigating the social aspects of living with Alzheimer's (Kannaley, Mehta,

Yelton, and Friedman, 2018), or through the study of how patients use illness narratives to connect

and establish a sense of community in online forum interactions (Rodriquez, 2013). To the best of

our knowledge, however, no study to date has approached the analysis of these type of blogs from

a metaphorical perspective.

      This study provides a descriptive qualitative analysis of the metaphorical expressions

found in a corpus of dementia illness blogs written by men (5) and women (5) diagnosed with

early-onset dementia. Blog sampling was based on an established set of criteria, which included

demographic, linguistic, and content factors. Only blogs self-initiated by people diagnosed with

an early form of dementia, which contained personal demographic details about the author (e.g.,

age at time of diagnosis and dementia type), were written in English, and focused on their

personal experiences of living with this disease, were included in the study. Moreover, the

sampling criteria also required that blogs were regularly updated and spanned several years after

diagnosis. Likewise, following the Principles and Code of Conduct approved by the American

Psychological Association (2003, with 2010 amendments) and adopting the ethical

considerations laid out by O'Brien and Clark (2012), and Eastham (2011), it was also required

that the blogs included in the analysis were publicly accessible without a password, offered an

RSS feed, and had clear advocacy or educational purposes. On the basis of these criteria, a

modified snowball technique was used to identify relevant blogs. The search resulted in a data

set of ten blogs with more than 2,500 potentially relevant entries, which covered an average

period of five years. In order to determine the eligibility of the posts for inclusion, they were

skimmed for content and only those posts that were clearly related to the bloggers' illness

experience were selected[1]. The final corpus of blog entries comprised a total of 622 posts

(252.466 words) which ranged in length from 150 words to 2440 words.

2.1 Data Analysis

The Metaphor Identification Procedure (Pragglejaz Group 2007; Steen et al., 2010), which despite its limitations is widely acknowledged as appropriate for the identification and analysis of metaphors in natural discourse (Gibbs, 2017), was used to identify the most salient metaphorical expressions used by the bloggers. All possible metaphors connected to dementia were identified, as we did not have an a priori list of potential source domains. In this paper, however, we just focus on those metaphors that referred to the bloggers' perception of the impact of dementia on their freedom of choice, sense of control over their disease, self-efficacy and personal relationships, factors tightly linked to human well-being (Deci and Ryan, 2000). Posts were analyzed chronologically so that potential changes in the participants' lived experience of dementia over time could be detected.

First, texts were read to establish a general understanding of their meaning; then the lexical units in the text were identified and their meaning in context was determined[2]. In a third step, the possibility that those lexical units could have a more basic, physical, concrete meaning in other contexts and that their contextual meaning could be understood via a comparison with that basic meaning was evaluated. Finally, if that was the case, the lexical units were marked as metaphorical (e.g. The verb *to fight* was marked as metaphorical in *We all know Alzheimer's disease doesn't go away. No matter how hard we <u>fight</u> against it* because its meaning in context, dealing with the disease, is understood in terms of a physical fight that cannot be won). This analysis resulted in the identification of 439 metaphorical expressions related to the notions of autonomy, competence and relatedness that were subsumed under 12 major types of metaphors (See table 1).

METAPHOR GROUPS	EXAMPLES	PROPORTION
Death sentence	I thought I was given a <u>death sentence</u>.	6,3%
Journey	It's a <u>one-way journey</u> and you know what's probably coming toward the end.	10,2%
Game	You have to accept the <u>cards</u> you are <u>dealt.</u>	5,9%
War/combat	Every day is a <u>battle</u>. My <u>battle</u> is to be the best "me" that I can be.	11,8%
Robbery	This disease is a <u>stealthy robber</u> that <u>makes off with</u> people's memory.	10,9%
Loss	I am continuously mourning the <u>loss </u>of my memories.	14,3%
Loss of the self	I will slowly, subtly <u>lose</u> me.	8,2%
Transformation	I'm still me, or at least a <u>version</u> of me.	6,3%
Roller coaster	This disease is the worse emotional <u>roller coaster</u> ever.	5,2%
Secret	My skills are still good enough, so most of the time I <u>hide</u> this disease well.	7,2%
Infantilization	We become very quickly <u>infantilized</u>.	6,1%
Traveling companion	We can <u>sign-post</u> the dangers as we <u>go</u>, for those <u>fellow travelers</u> <u>following</u> behind.	7,8%

Table 1. Results of metaphor analysis

The following section provides a detailed analysis of the results. To ensure participants'
anonymity, their identity has been masked and selected words, including proper names and some
pronouns has been changed. Moreover, the examples used to illustrate our results have been

searched in Google to discard the possibility that they could be traced back to the original blogs and compromise the anonymity of bloggers.

3. Results

3.1 Autonomy

People's need for autonomy can be severely challenged by disease, given that illness often represents a biographical disruption (Bury, 1982) in which the taken-for-granted course of a person's life is unexpectedly altered through no choice of fault of their own. Our analysis shows that dementia is not an exception and that bloggers often resorted to metaphorical expressions that described diagnosis as a 'death sentence', disease as part of the 'life game', and dementia as a 'one-way journey' or as 'war' to frame diagnosis and its aftermath as a biographical turning point that challenged their sense of freedom of choice.

3.1.1 Death sentence metaphors

For most of the blog authors included in this study, the diagnosis of dementia arrived after a long period of tests and visits to specialists. Even though most of them were bracing themselves for this diagnosis, its confirmation was often compared to *being given a <u>death sentence</u>* (Karl). A verdict that threatened to end their life at any time: *I accepted the <u>verdict</u>. I gave up and began to prepare for the inevitable* (Jane). This metaphor, which is also part of other illness narratives such as, for example, motor neuron disease (Locock et al., 2012) or HIV/AIDS in the 1980s (Couser, 1997), shows a certain conformity in the way people think and talk about irreversible diseases (Zimmermann, 2017a), at least in the period immediately following diagnosis. Indeed, data show that individuals progressively drifted away from this conceptualization of dementia once they realized that the threat was not as imminent as they first thought and found acceptance with their diagnosis (1):

(1) I thought I was given a <u>death sentence</u> but it does not have to be, many people

live for a long time with their diagnosis. I went through denial and anger. I finally

found acceptance with my diagnosis. (Peter)

3.1.2 Game metaphors

In discussing the life-changing effect of their diagnosis, participants sometimes turned to

'game' metaphors to emphasize their lack of choice and control over the situation. Thus, for

instance, Joseph said: *This is not the life I wanted to live, however, you have to accept the <u>cards</u>*

you are <u>dealt</u> and make the most of it. By resorting to these metaphorical expressions,

participants framed life as a gambling game and life events, such as being diagnosed with a

disease, as the circumstances that an individual is dealt and has to accept (Gibbs and Franks,

2002; Lakoff and Johnson, 1980). Some bloggers elaborated on this metaphor to show their

awareness that, given the degenerative effects of dementia, once diagnosis is confirmed there is

no turning back: *a <u>waiting game</u> begins* (Karl). *You don't <u>play the what if game</u> anymore, you*

<u>play the when game</u> (Peter).

3.1.3 Journey metaphors

Our analysis also shows that participants repeatedly described diagnosis confirmation as

the beginning of a metaphorical journey that abruptly diverted the course their lives and

dismantled their expectations: *After diagnosis you have to put your dreams away and let life <u>take</u>*

you <u>where</u> it wants (Peter). These metaphorical expressions illustrate the use of the metaphor

LIFE IS A JOURNEY (Lakoff and Johnson, 1980, 1999) as a vehicle to show individuals' awareness

of the restrictive effects of dementia on their freedom of choice. This feeling also resonates in the

narratives of other bloggers who, following the metaphorical entailment that in life, like in

journeys, the path to follow is not always voluntarily chosen, claimed in reference to dementia:

Life's pathway is different for each of us. So, pathways may be our own or those imposed on us (Patrick). Taken together, these data evidence that people diagnosed with dementia share with other patients a conceptualization of diagnosis and illness that evokes the imagery of a journey (Semino, Demjen, Hardie, Payne, and Rayson, 2018; Zimmemann, 2017a). However, in the case of dementia (as opposed to other diseases), the possibility that patients will recover and resume their lives at the end of their journey is prevented by the very nature of their disease. Hence, dementia patients, far from using the 'journey' metaphors to describe their healing process, often employed these metaphors to describe what they defined as *a one-way journey*, elsewhere defined as *a journey of no return*, (Zimmermann, 2017a). Thus, for instance, one of the bloggers said: *I can't return to whatever was interrupted because there is no returning to what was* (Joseph). This statement clearly shows that, in our data, 'journey' metaphors served as an instrument for patients to show understanding of their prognosis and express their powerlessness and lack of control over the situation. Nevertheless, blog narratives also show that when participants moved their focus from future expectations to everyday life – even though their illness experience was still framed by the 'one-way journey' metaphor – they were able to experience a sense of choice and purpose that comes across in sentences such as this: *It's a one-way journey and you know what's probably coming toward the end. But that doesn't prevent you from choosing to do things that make you happy* (Samuel). All in all, individuals mainly used the 'journey' metaphor to frame dementia as a disruptive life event and emphasize the irreversible effects of the disease. Nonetheless, as people adjusted to their diagnosis, this metaphor was also coupled with an appreciation that living with dementia does not mean to relinquish a life of choice and purpose.

3.1.4 War metaphors

In our data, it was common for participants to describe themselves as being at war with dementia, both individually and collectively, while they simultaneously acknowledged that, given its current lack of treatment, fighting dementia is a winless battle (2). One of the bloggers, for example, stated:

(2) The time will come when I <u>lose</u> my <u>battle</u> (…) but I want to leave the memory

that I <u>fought</u>. (Peter)

The 'war' metaphors that patients used in their blogs evidence that after diagnosis they made the choice not to give in. However, this decision came with a caveat of the need to accept the outcome of their disease, as reflected by the words of one of the bloggers: *I won't ever <u>give in</u>, but I accept that, as the dementia <u>takes over</u>, my abilities will decline* (Lisa). Patients' words show awareness that, at some point, the battle will be inevitably lost but, up to then, they *want to live and are willing <u>to fight</u> to do so* (Peter). Their choice is to fight every day to be the best version of themselves that they can possibly be (3).

(3) Every day is a <u>battle</u>. My <u>battle</u> is to be the best "me" that I can be. This <u>war</u> will

cost my memories and connections, eventually it will cost my life. I could <u>give up</u>

but the <u>battle </u>is worth <u>fighting</u> and the <u>warriors</u> are honorable. (Emma)

Across their narratives, blog authors also drew on 'war' metaphors to describe their joint efforts to raise social awareness, achieve equality, and get administrative recognition and support. Thus, for example, they talked about, *<u>soldiering on </u>for Alzheimer's awareness and education* (Joseph); *<u>fighting </u>for equalities for people with dementia*; or *<u>fighting on</u> until dementia has its own tick box on forms and we can apply for certain benefits and help that we need and are entitled to* (Lisa). As pointed out by Palmer-Wackerly and Krieger (2015) in

relation to infertility, by using this metaphor, bloggers expressed their choice to assume the

identity of a "fighter", a "warrior" while facing the effects of disease or advocating for a joint

cause. This reflects their determination to take an active role against their disease as long as they

can. Nonetheless, data also show that, for some participants, the incurable nature of dementia

deemed the idea of fighting an unfeasible strategy. In that case, bloggers often resorted to direct

comparisons between dementia and other diseases, such as cancer or HIV/AIDS: *If it were*

cancer, I'd have a chance of beating it. Dementia? No chance (Samuel). Finally, our analysis

also evidences that some bloggers progressively retreated from the active fight. In some cases,

this happened because they reframed their illness experience and adopted new coping strategies

over time. For instance, one of the bloggers stated, *I don't fight my illness anymore. I just try to*

find ways not to be punched (Peter). In other cases, the overwhelming effects of the disease as it

progressed limited the patient's capacity to fight back (4):

>   (4) I have fought back hard all these years from over many admissions, this last one,
>
>   I haven't been able to get my fight back. (Sophie)

In short, the analysis reported here shows that bloggers' narratives portrayed dementia as

an unquestionable threat to their autonomy. However, it also shows that, after the initial shock of

diagnosis, most of the patients were determined to fight and that, in adopting the role of a fighter,

they seemed to gain a sense of perceived autonomy that made them feel volitional and

empowered in their actions.

3.2 Competence

In expressing their need for competence, blog authors mostly relied on metaphors that

portrayed their inability to inhibit the effects and progression of dementia as the 'robbery', the

'loss' or the 'transformation' of their cognitive abilities and selves, and their lack of control over their emotions as a 'roller coaster'.

3.2.1 Loss and robbery metaphors

Blog narratives show that metaphors grounded in folk theories of cognition, which conceive of memories, knowledge and ideas as objects that are stored in a mind space and that can be organized, searched, found, and lost (Roediger, 1980), helped bloggers to depict their inability to control the cognitive effects of dementia. In this context, cognitive decline was commonly described as an uncontrollable loss of memories, skills, and abilities, which rendered dementia *a gradual, slow loss process* (Sophie). In this respect, one of the bloggers said in reference to his memory problems: *The worst is when I am asked about a memory and I can't recall it. It is gone. I am continuously mourning the loss of my memories* (Peter). Some bloggers also grieved over the negative impact of dementia on their writing skills: *I have lost the ability to find words that a normal adult would use in their writing* (Lisa). Others, however, focused on the undermining effects of the disease on their ability to read, *after various attempts to understand what I had written the day before, I just broke down. I realized that I had lost that much ability in 24 hours* (Emma). These statements conveyed a sense of loss of control over the disease that also became apparent when dementia was personified as a thief (5), a *stealthy robber that makes off with people's memory*" (Samuel).

> (5) This disease robs people of their most precious memories. It takes away our ability to reminisce, to memorize, and recognize our loved ones. It even takes away our ability to recognize ourselves. (Peter)

3.2.2 Loss and transformation metaphors

Blogs also show that, for those living with dementia, the loss or robbery of their memories and abilities represents a serious threat to their identity: *I am what I know, remember and feel. I am the pictures and sensations <u>stored</u> in my brain. When I <u>lose</u> them, who will I be?* (Joseph). Thus, as their disease progressed, blog authors often showed their concern about losing themselves (6) or being undergoing an undesired transformation that was turning them into a different person (7).

(6) I face <u>losing</u> what makes me me in the coming years. I will slowly, subtly <u>lose</u>

me. (Samuel)

(7) I'm losing control and I can't stop it. I am <u>changing</u>. This is not me. I want to

be me again! I miss me! I am a <u>stranger</u> to myself! (Mary)

In this context, most of the bloggers wrote about initiating a struggle to adjust to their new selves, while revendicating the continuity of their old selves: *Maybe I will have some scattered better days, but this is essentially my new normal. I grieve, accept and go on with the abilities I still have trying to settle in this new <u>version</u> of me* (Emma). *I know I'm not as sharp as I used to be. I can't remember too much from my recent past but in my mind, I'm still me, or at least a <u>version</u> of me* (Joseph).

3.2.3 The Roller coaster metaphor

The 'roller coaster' metaphor, conventionally used in everyday language and present in the narratives of other complex medical situations such as infertility (Palmer-Wackerly and Krieger, 2015) and cancer (Semino et al., 2018), helped participants to express their failure to control the course and intensity of their emotional reactions, which ranged from anger and anxiety to hope, guilt, frustration and sadness. One of the bloggers, for instance, claimed: *This disease is the worse*

emotional <u>roller coaster</u> ever (Mary), a feeling that other bloggers described as *the highs and the lows*, *ups and down* , or *the peaks and valleys* of a disease characterized by a fluctuation in good and bad days (8).

> (8) Some days are filled with light and others with darkness. That is the <u>roller coaster</u> we call dementia. It goes on forever and you are not able <u>to get off</u> of it. (Peter)

The findings reported above show that participants drew on metaphors to describe how their need for competence was threatened through the course of their illness experience. Their inability to control the course of their disease and its effects on their cognitive and emotional responses renders their lived experience of dementia too challenging for them to feel effective enough in controlling what they perceived as identity changes. Despite this situation, blogs also show that, when participants framed cognitive decline as a transformation rather than as the loss of their old selves and accepted that new reality their need for competence was fostered.

3. 3 Relatedness

Bloggers' need for relatedness was mainly communicated through metaphors that described dementia as a 'secret', overprotective relationships as 'infantilizing' or 'disempowering' relationships and people affected with dementia as 'fellow travelers in the dementia journey'. These metaphors show how living with dementia constrains or fulfills the need for close and intimate relationships with others.

3.3.1 Secret metaphors

Bloggers' narratives make it clear that one of the first dilemmas that most of them faced right after the confirmation of their diagnosis was *whether <u>to come out of the closet</u> or not* (Sophie) because they were afraid that their condition would influence people's attitude toward them.

Since dementia is not an immediately perceptible condition, at least in the first stages, for some participants deciding not to disclose their diagnosis became a strategy of self-preservation (Beard, 2004; Rodriquez, 2013) against the stigmatization and denial that many find when people either do not believe they have dementia or minimize the problem (9):

> (9) My skills are still good enough, so most of the time I <u>hide</u> this disease well. When you say the word dementia, people shrink back in horror and then they deny the possibility. (Emma)

Our analysis also evidences that, when participants finally decided to share their diagnosis, they carefully chose who to tell. For instance, one of the bloggers said: *I did not <u>blast</u> it <u>out</u> on Facebook for the world to see. I chose who I wanted to share my diagnosis with* (Joseph).

Despite participants' reservations about disclosing their diagnosis, some of them agreed on the fact that being open about it has benefits to them and their families and that open awareness was necessary to change social perceptions of dementia, so people see the person and not the label: *We should <u>brought</u> dementia <u>out of the cupboard</u>. I tell people openly that I have it to challenge the stereotype* (Samuel).

3.3.2 Infantilization metaphors

The relationship between bloggers and caregivers was also discussed in the blogs, where the use of metaphorical expressions that characterized overprotection in terms of 'infantilization' and 'disempowerment' helped participants to emphasize the thin red line that lies between feeling supported and feeling deprived of control over your life in a relationship. Even though bloggers openly acknowledged the invaluable role that family carers play in maintaining their overall physical and emotional well-being through the course of their disease, some of their narratives also showed their concern about the fact that carers may sometimes slide into an overprotective

behavior that transforms the egalitarian relationship of two adults into a relationship where the patient feels treated as a child (10):

> (10) In many occasions people with dementia never get to finish their sentences because their caregivers jump in. They choose the drink or cake, on the grounds that she always has this. We become very quickly <u>disempowered</u> and <u>infantilized</u>. (Samuel)

In this context, participants claimed the control of their lives for as long as possible, which, to them, meant to establish relationships that foster their autonomy and prevent the disempowering effects of overprotection (11):

> (11) It is essential to make sure that other people don't <u>take over</u> your life when you can still <u>manage</u> it. You need to make your own choices for as long as you can and feel able to <u>control</u> your life and retain your dignity and confidence. (Patrick)

3.3.3 The travelling companion metaphor

With their social and family relationships often conditioned by dementia, some of the bloggers acknowledged that coming into contact with other *<u>fellow travelers</u> in the dementia journey* (Mary) was an important source of socialization. They represented a community whose members understood and supported each other. In the dementia journey, some of those fellow travelers are considered *guides* (Peter) who share their experiences with other patients to help them to deal with the changes and challenges that dementia brings about (12):

> (12) I discovered online peer groups and blogs […] one of the bloggers was <u>leading the way </u>on this <u>trail</u> when I arrived. The Dementia <u>path</u> is <u>full of bumps</u>. Through our blogs we can <u>sign-post</u> the dangers as we go, for those <u>fellow travelers</u> <u>following</u> behind. (Emma)

This metaphor helped participants to express a sense of belonging to a group whose members are bonded with one another by their shared experience of living with dementia. In fact, most of them said that thanks to peer support groups, blogs, and virtual forums, they felt they were not alone. They found in their traveling companions the social contact and well-being that they much needed.

3.4 Discussion and Conclusion

The aim of this study on dementia metaphors was to analyze the metaphorical expressions that individuals diagnosed with early-onset dementia used to describe their lived experience of the disease, paying especial attention to those metaphors that helped bloggers to frame and communicate the impact of dementia on their psychological well-being.

3.4.1 Implications for metaphor research

From the point of view of metaphor research, our findings build on the previous literature on metaphor and illness discourse by providing new evidence that metaphors are essential to the way people make sense and communicate about their illness experience, including their emotional and psychological implications (Gibbs and Frank, 2002; Semino et al., 2018). Results also show that in the case of dementia, just like in the case of many other diseases, individuals share a relatively stable set of conceptual metaphors to describe the impact of their disease on their lives and that most of those metaphors are conventional metaphors commonly used in everyday language (Gibbs and Frank, 2002). Our research also adds to the literature by showing that the connotations associated to metaphors are not stable, they rather vary as a function of contextual factors such as the disease at hand or patients' attitude. Thus, for instance, our data supports the claim that, even though 'war' metaphors and the victor-victim frame that they evoke can be detrimental for patients (Miller, 2010; Sontag, 1977), violence metaphors are not

necessarily negative. Patients can also use these metaphors in empowering ways (Demjén and Semino, 2017; Semino et al., 2015; Magaña and Matlock, 2018). In our corpus, bloggers resorted to them to show determination or to praise themselves or others for their tenacity and effort. Likewise, the blogs analyzed in this study also evidence that 'journey' metaphors are not by default more positive than 'war' metaphors if, as in the case of dementia, patients' prognosis leads to conceive of the journey as a 'one-way journey' marked by a progressive and unavoidable decline of people's physical and cognitive abilities. In this case, as shown above, 'journey' metaphors are mainly used to explain the difficulties that patients face in their everyday life, express uncertainty and emphasize their awareness of the disease prognosis rather than to describe their path to recovery. Our analysis also expands what is known about the use of metaphors to convey the impact of complex medical situations on patients' psychological well-being (Palmer-Wackerly and Krieger, 2015; Peterson and Sterling, 2009) and shows that bloggers used the 'death sentence' metaphor to frame dementia as a biographical disruption that they did not willingly choose. The 'loss of the old self' metaphor served participants to describe their inability to control cognitive decline, and the 'secret' metaphor to convey their fear of being reduced to a label and being treated differently. Likewise, our findings also show that metaphors helped bloggers to convey a certain sense of choice and control in coping with their condition. 'War 'metaphors, as stated above, often appeared as an expression of patient's autonomy. Bloggers used them to show that, even though they could not escape their condition, they still had the option to choose the attitude they wanted to have against their disease. They could have surrendered but they chose to fight. In the same vein, by framing cognitive decline as a 'transformation of the old self', bloggers not only acknowledged the uncontrollable nature of their disease and voiced the tension between continuity and change of identity that patients in the

early stage of dementia experience (Caddell and Clare, 2011), they also took control over dementia discourse and argued against the mind-body dualistic perspective that conceives of those living with dementia as 'empty shells' or 'zombies' – i.e., physically present but mentally absent (Behuniak, 2011; Devlin, MacAskill, and Stead, 2007). Claiming that despite their illness and the changes that it brings about they were still themselves might have helped bloggers to meet their need for competence, since they could effectively describe what cognitive decline means to them and challenge the well-established metaphor of the 'empty shell'. In this respect, patients' narratives went beyond the mere description of their experiences, they also tried to raise awareness and defy stereotypical views of dementia.

3.4.2 Practical implications for healthcare

The metaphorical expressions in our study provide an insight into the in-group language choices that bloggers made to communicate about their experience with dementia. Given their stability, consistency and coherence and taking into account the framing power of metaphor, such lexical choices and patterns in metaphor can be taken as evidence of the way they understand and reason about their disease, which can have important implications for healthcare practices. While the biomedical paradigm of healthcare disregards illness experience and focus instead on the anatomic, physiologic and biochemical dimensions of disease, there is increasing recognition that understanding the psychosocial and emotional consequences of chronic illness is an essential aspect of healthcare (Carr, Loeser, and Morris, 2005) In fact, over the last decades healthcare practices have progressively shifted away from a purely biomedical conception of disease in favor of a more bio-psychosocial view (Williams, 2001; Engel, 1977). In the case of dementia, this translates into healthcare practices that try to support individuals' personhood and well-being (Kitwood, 1997). Considering metaphorical expressions from an SDT perspective can be useful

to inform those practices. It can contribute to improving patient-doctor communication, including how diagnosis and prognosis are discussed, as well as to eliciting more effective coping strategies for patients (Palmer-Wackerly and Krieger, 2015; Peterson and Sterling, 2009). Moreover, analyzing the metaphors that patients use to talk about the psychosocial aspects of their experiences may serve as instrument to identify the needs that they emphasize as most important to their well-being and to renegotiate or reframe patients' metaphorical conceptualizations in a more positive light (Beard, Knauss and Moyer, 2009). Thus, for instance, reframing patients and family carers' conceptualization of cognitive decline as a process of transformation rather than of disappearance can help to equate it to the many transformation processes a person goes through in a lifetime, so the initial view of diagnosis as a 'death sentence' can be renegotiated and attention can be drawn to the need of making adjustments and developing coping strategies to deal with that transformation. Likewise, by raising carers' awareness of the 'infantilization' metaphor, overcompensating behaviors could be controlled, which can help to strengthen patients' sense of competence and autonomy. Moreover, the 'guide' metaphor can also be used to foster their need for competence and relatedness. By making patients aware that their experiences can be valuable to others, patients can be encouraged not to withdraw from social activities and feel useful. All in all, our results support the statement that analyzing how people affected with dementia naturally communicate about their condition and its different aspects can lead to a better understanding of the disease and serve as a tool to inform the psychosocial dimensions of healthcare.

3.4.3 Study limitations and further research

One of the potential limitations of this study is that the sample analyzed here might not be taken as representative of a wider population of people affected with dementia. It is likely that bloggers

differ in a number of ways from the wider population. Moreover, bloggers may have censored or

embellished what they said being aware that they were publicly exposed (Nardi et al., 2004). On

the other hand, the relatively small number of participants also limits the analytic power of this

article, even though using a small number of blogs allowed an in-depth analysis of a large

number of posts contributed over an extended period, 5 years on average.

To gain a better understanding of the use of metaphors in dementia communication and test its

efficacy as an instrument to foster patients' well-being, future research should explore how

metaphor is used across contexts and languages and evaluate its impact on individuals' coping

response to the emotional, psychological consequences of disease. Thus, on the one hand, it

should be analyzed whether or not the use of metaphors differs when illness narratives are

communicated through different media (e.g., in face to face interpersonal communication) and

to different interlocutors (i.e., family, friends, and doctors). Likewise, register and gender

differences (e.g. do males and females communicate differently?) should be studied and the

effectiveness of metaphors in facilitating coping for individuals experiencing complex medical

situations such as dementia should be tested. Moreover, it would also be important to analyze

how speakers of languages other than English use metaphor to communicate about their illness

experience and how and why they struggle with one or all needs for well-being because every

culture has its own idiosyncrasies when it comes to what metaphor are used and how they are

used (Kövecses, 2015) and because cultural factors such as religious beliefs may influence our

understanding of illness. Finally, critical discourse analysis (Van Dijk, 2008, 2009) should be

applied to analyze patients' counter-discourse against the cultural mainstream dementia

narrative.

Acknowledgements

Notes

1.   The post included in the study dealt with the following topics: the experience of being diagnosed and its aftermath, the challenges that they face in their everyday life, their symptoms, feelings, hopes and expectations for the future and the impact of dementia on their social relationships.

2.   The word was taken as one lexical unit for the purpose of metaphor identification and analysis. However, whenever a phrasal verb (e.g. make off with), a compound (e.g. death sentence) or a phrase (e.g. come out of the closet, play the waiting game), as identified by its labelling in the Macmillan dictionary for Advanced Learners (Rundell and Fox, 2002), conveyed a metaphor, it was coded as one instance of metaphor (Cameron et al., 2009; Magaña and Matlock, 2018). Novel phrases (e.g. play the when game, play the what if game) were also counted as one unit. Finally, delexicalized verbs such as make, have or do and prepositions were excluded from the analysis, as suggested by Demjén et al. (2016).

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