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Expressing negative emotions as a key to living with and coping with dementia



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1. Introduction

Given the impairments at a cognitive and emotional level caused by dementia as a 'disease', focused on the measurement of symptoms (Ames et al., 2017), biomedical research tends to describe individuals living with dementia's (ILWD) emotional life in terms of deficits, including affective symptoms, like apathy and depression (Verdelho & Gonçalves-Pereira, 2017). Accordingly, less attention was dedicated to clarifying the different circumstances that cause ILWD's emotional distress (see Petty et al., 2018). This aspect has been investigated more broadly by research focusing on dementia as an 'illness', that is, the internal, lived experience of ILWD and their family (De Boer et al., 2007; Larsen, 2013). This branch of research, for example, showed that challenging negative emotions is a key factor in making sense of the illness and developing coping strategies – especially within supportive environments (Lishman et al., 2014; Francis et al., 2020).

In this article, we aim to offer a broad investigation of ILWD's negative emotions in their daily lives. We want to highlight aspects of ILWD's experience with their illness that may reveal a positive mirror image of the deficit view of negative emotions in dementia as a disease. This positive psychology approach to dementia shows ILWD's potential to evolve, or how ILWD can flourish despite adverse personal and environmental conditions (Clarke & Wolverson, 2016).

1.1. Negative emotions and dementia research

Negative emotions, like sadness and fear, reflect subjectively experienced unpleasant and undesirable feelings. It has been well documented that negative (vs. positive) emotions generally have stronger effects in people's lives (e.g., Baumeister et al., 2001). In addition, negative emotions take part in self-regulation, or how people can manage their behaviour toward beneficial outcomes (Baumeister, 2018). Negative emotions, thus, are not strictly 'negative'.

In dementia research, various authors have described and referred to the Need-driven Dementia-compromised Behaviour model (NDB) (Algase et al., 1996) which allows to better understand the role of negative emotions. In the NDB, behavioural symptoms of dementia can be interpreted as signs of individuals' needs that are not being fulfilled (unmet needs). The NDB model includes emotions within the proximal personal factors that trigger behaviours in ILWD that in the eyes of the others are interpreted as *deficits* (Verdelho & Gonçalves-Pereira, 2017). Research, for example, showed that agitating behaviour was associated with lack of social intimacy, anxiety and loneliness could induce screaming, and frustration could cause aggression (see Algase et al., 1996; Verdelho & Gonçalves-Pereira, 2017). In line with the NDB model, psychosocial research in dementia has emphasized that these symptoms/signs of unmet needs must be recognized and used to improve

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ILWD's wellbeing (Verdelho & Gonçalves-Pereira, 2017; Dröes et al., 2016).

1.2. Negative emotions and sensemaking of dementia

Coping responses to illness are influenced by individual illness perceptions and social-psychological factors (Larsen, 2013). One of the achievements of psychosocial studies of dementia is clarifying the role of negative emotions in making sense of and coping with dementia (Perach et al., 2020). A fundamental aspect of coping is emotion regulation or how people experience, express and manage their emotions. Research showed that negative emotions can work in opposing ways for ILWD: as exacerbating factors in demanding situations (e.g., Benbow & Kingston, 2016) and as potential factors in developing coping strategies (e.g., Lishman et al., 2014). Benbow and Kingston (2016) in their analysis of narrative production with ILWD and their carers, for example, highlighted that negative emotions, such as feeling ashamed, frustrated and without hope, can be factors exacerbating ILWD's coping potential. Lishman and colleagues' (Lishman et al., 2014) analysis of ILWD's affective responses to diagnosis emphasized a more positive role of emotions. They showed that ILWD who could manage their negative emotions, like anxiety, fear and sadness, and felt supported in doing so, could make sense of the diagnosis, assimilate it into their lives and positively adjust to illness.

The aim of this article is to further examine the *complex* role of negative emotions in ILWD. In line with previous research (e.g., Francis et al., 2020), we argue that investigating ILWD's expression of negative emotions serves several theoretical and application purposes. First, it helps shedding light on the role of negative emotions as affective signs, rather than symptoms, showing what ILWD's unmet needs may be. Second, it clarifies ILWD's emotion regulation process in making sense of illness. Third, shedding light on the *complexity* of ILWD's negative emotional states carries practical implications. Supporting ILWD to get in touch with their negative emotions can serve as a basis for tailored support interventions, based on individual preferences, instead of programmes that should fit all ILWD (Kelly et al., 2021). For these purposes, investigating the internal, lived perspective of ILWD is key to understand which factors can help improving ILWD's wellbeing (Clare et al., 2019).

1.3. Online resources and diary research with ILWD

Personal perspectives of ILWD have been investigated in different ways by dementia research. For example, qualitative analyses have mostly focused on informant analysis (like interviews and focus groups; see De Boer et al., 2007). However, more recently, dementia research is increasingly using online resources, like health forums and blogs (e.g., Castaño, 2019; Rodriguez, 2013). This approach clarified that, online, ILWD can share their subjective experiences in a free, unfiltered, and informal way (Mehta et al., 2020). The freedom expressed by ILWD online contrasts with the restrictions of other research's sources. For example, in informant analysis, questions and relevant topics are typically prompted to ILWD by the interviewers' interest and not by the participants themselves (Mehta et al., 2020). Investigations conducted through these types of online sources, therefore, can more likely be compared to diary searches carried out with ILWD. In diary research, individuals, under guidance, are asked to keep a diary with their thoughts and feelings (Bartlett, 2012). Bartlett showed that, by using this method, the diarists, instead of the researcher, were more in control. Both in terms of the topics they considered relevant and of the most suitable time to share them. For these reasons, we conducted our study on ILWD's own reports shared in the Dementia Diaries online platform (see Section 2). Our study focuses on two main questions:

- RQ1) Which types of experiences spark negative emotions in the daily lives of ILWD?

- RQ2) How do ILWD refer to their negative emotions in relation to making sense of dementia?

The following sections explain the set up and the development of the analysis including design, setting, data collection, data analysis and ethics.

2. Methods

2.1. Data collection

We used ILWD's narratives gathered online through the platform Dementia Diaries (DD; <https://dementiadiaries.org>, see the Appendix for details). DD is a project based in the United Kingdom (UK) that is part of the *Dementia Voices Programme* (<https://www.dementiavoices.org.uk>). The DD project gathered a varied group of ILWD, henceforth the diarists, with distinct types of dementia, including individuals with early-onset dementia. Since 2015, on the DD's platform, the diarists, share their audio recordings on different topics, such as personal issues and their experiences with the illness (see Woodall et al., 2016). The total number of diarists who authored the texts in our corpus is 94, including 43 women and 51 men from all over the UK. DD is a project not designed for research, e.g., privacy-sensitive information is not stored. Nevertheless, through correspondence and meetings with DD's director and collaborators, the PI gained a better understanding of DD's setting and development (for details see the Appendix).

The diarists' audio records are transcribed and become publicly available in the DD site, from where we retrieved them. We downloaded a corpus of texts including all messages published on the DD website from the starting date to the date we began our analysis (28-01-2015 until 01-12-2020). This yielded a total of 2717 texts and 719,058 words. The number of texts per diarist ranged between 1 and 245 with an average of 28.9 (SD = 45.9). Then, to select our material, we referred to Vine and colleagues' (Vine et al., 2020) 94 negative emotions words (see Appendix) as keywords to search in the DD corpus for excerpts related to the diarists' expression of negative emotions. To confine results to our goal –the role of negative emotions in the diarists' illness trajectories– we only selected excerpts where the diarists talked about their own experience of living with dementia. For example, when they talked about their symptoms or how they were experiencing changes and challenges in their lives because of dementia (see Table 1).

2.2. Data analysis

Comparable to other studies (e.g., Johnson, 2014), our qualitative research included a discourse analysis (DA) guided by the principles of the Grounded Theory Methodology (GTM) (Glaser & Strauss, 1968). The combination of GTM and DA allows a flexible research design best used to track progress from an explorative to a more focused qualitative analysis. Both methodologies consist of iterative levels of analysis and ongoing comparison of emerging themes and discourses, allowing for deepening and narrowing of the research focus (Johnson, 2014). In addition, both approaches are embedded in a critical theoretical perspective with which we addressed the issue of ILWD's negative emotions.

GTM (Glaser & Strauss, 1968) is one of the first guiding method to focus on the patients' experience of their illness instead of focusing on the disease (Larsen, 2013). GTM's principles (e.g., Bryant & Charmaz, 2019) include initial open coding, keeping memos, then the creation of more focused codes in categories and in themes. Eventually, through theoretical sampling and constant comparison the emerging themes are linked to relevant literature. The aim of GTM is letting the theory emerge from data rather than imposing a theory on data. DA analyses texts and language use in their social contexts (Gee, 2011). We used DA for our qualitative text analysis because of the value DA places on both individual and dominant discourses (see Gee, 2011). Through DA, we

Table 1

The diarists' negative emotions. Main discourses, themes and subthemes found per research question.

RQ1: Experiences sparking ILWD's negative emotions			
Discourse	Theme	Subtheme	Illustrative paraphrased example
<i>Social Neglect</i>			
	External Circumstances		Depression worsens with winter. It is something that we may get
	Lack of Support		Though I am a whole individual, health professionals do not see it and this makes me sad
RQ2: Making sense of illness			
<i>Living with dementia</i>			
	Dementia-Related Symptoms	Complex emotions	My mood swings with anxiety and loneliness
		Symptom description	I have holes in my memory. It is not just forgetfulness but loss
		Depression	When I am depressed it is difficult to get back on my feet
	Acknowledging Dementia	Diagnosis	I panicked: I focused on the end and no one tells you that there is also a beginning and a middle
		Declining	I am aware that I become clumsy and forget things. It is so upsetting and frustrating
		Individual trajectories	I feel sad looking back at who I was
<i>Empowerment</i>			
	Challenging Negative Emotions	Social activities	By sharing your story, you learn that you are not alone
		Support from family and HP	Their love, support, and care make me feel less scared
		Positive attitudes	Try to use your inner power to manage your fears

* RQ: Research Question; ILWD: Individuals Living with Dementia; HP: Health Professionals.

compared our findings across the diarists' texts highlighting their emerging discourses. As dementia discourse tends to be limited by (negative) cultural stereotypes and discrimination (Hillman & Latimer, 2017), through DA we brought the more silent discourses of ILWD to the foreground.

Using Atlas. ti (version 8.4.5), we coded and then categorized all instances of Vine and colleagues' (Vine et al., 2020) 94 negative emotions words in the DD corpus until saturation of the main themes was reached (Bryant & Charmaz, 2019). Throughout the analysis, the authors had open discussions on the PI's analysis on completeness and clarity of the codes and categories until full agreement was reached.

2.3. Ethics and privacy concerns

This study follows the ethical requirements of the national Code of Conduct for Research Integrity of the country of the first author and with the Ethics Committee's (EC) guidelines for conducting online research of the country and faculty of the first author. In addition, the study was formally approved by DD's director. To increase understanding of the aims of the study, an accessibly written message and a video describing the purpose of the research, as well as the outcomes, were channelled to the diarists via the DD's director. DD's texts are publicly available online. The diarists can withdraw their consent anytime. Upon consultation with the EC and DD's director, to avoid making content personally traceable we paraphrased all quotes. We agreed that protecting the diarists' privacy

was more important than providing the reader with a quotation. Therefore, the words extracted from the diarists' texts will be shown in *italics*, and all the examples will be paraphrased (see Table 1).

3. Findings

3.1. Experiences sparking negative emotions in ILWD

RQ1 asked which types of experiences spark negative emotions in ILWD. In response to this RQ, one overarching discourse emerged from the data focusing on *Social Neglect*. In relation to this discourse, two distinct themes emerged: *External circumstances* and *Lack of support* (see Table 1).

3.1.1. External Circumstances

Many circumstances sparked negative emotions in the diarists, such as anger, fear and sadness. Some circumstances were consequences of dementia, like being obliged to *stop working* and *changing daily routines*. Other circumstances related to what the diarists missed in their lives, like *social relationships*, *cuddles*, *gardening* and *travelling*. Besides, there were circumstances raising issues in the diarists' everyday life. Issues with transportation, like *missing a train*, or *getting lost*, could cause anxiety, especially for diarists with impaired mobility. Issues with *technology*, like difficulties with call centres, could be frustrating too. The diarists pointed out the importance of new *more hospitable* and *people friendly* technological advances helping ILWD in their use of technology.

External environmental circumstances, like winter, could make ILWD annoyed and depressed; and with *Christmas* those feelings could get worse. Being surrounded by noise and frenetic sociality could make the diarists feel even more *lonely*. Other sensitive circumstances, like *people dying*, and *isolation* could also hit the diarists with sadness and depression.

In 2020, the Covid-19 pandemic generally increased the diarists' fears, worries and anxieties: because of the risk of *contracting the virus*, *self-isolation*, *feeling limited in freedom* and *space* and for the *delayed contacts* with *family* and *doctors*. Besides, the lack of aid and information from the government in the management of the pandemic in the UK generated anger. The diarists felt both *panic* and a sort of *apathy* for the prolonged lockdown; they also worried that long-lasting non-activity and withdrawal, on the long run, could impair ILWD's skills and independence, for instance, being able to travel again. These findings highlighted three main events sparking negative emotions in the diarists (RQ1): 1) their change in social status after diagnosis, e.g., being forced to stop working and social isolation; 2) challenges in daily life, e.g., transportation and technology; and 3) sensitive issues, e.g., people dying, and the Covid-19 pandemic.

3.1.2. Lack of Support

Another source of negative emotions for the diarists was perceiving people's lack of sensitivity in dealing with ILWD. Among these we highlighted healthcare professionals, the media, and other stakeholders. To start with, the diarists' communication and relationships with healthcare professionals could go wrong because of *time pressure*, and because some health professionals did not provide enough *empathy*, *caring attitude* and the *emotional* support needed for ILWD to deal with dementia. Some diarists, moreover, reported being sad because they had not been treated as *whole persons* by the medical professions, in that the individual's encompassing story had not been acknowledged.

Secondly, according to the diarists, the *media* have a responsibility to fight ignorance and enrich public opinion about dementia. However, the diarists often reported being disappointed by the media. On the one hand, the diarists find that the media portrayal of dementia lacks balance. For example, the images proposed by the media tend to emphasize sadness and depressing portrayals of ILWD. These images, according to the diarists, perpetuate persistent negative stereotypes about living with dementia. On the other hand, newspapers seem to recur to exaggerate promises in their headlines, for example of new therapies, that are not

kept in the article.

Thirdly, other stakeholders could also spark disappointment and distress in the diarists. For example, interaction with families may generate frustration at not being able to maintain independence (see 3.2.2), as well as interaction with *politicians*, who showed interest about ILWD, making hopeful promises to take part in dementia gatherings, and eventually did not show up. The diarists also noted people's lack of sensitivity during daily activities (like *shopping* or *queuing at the post office*) such as *rushing* ILWD or *talking too fast*. *Public fears* and *stigma* of dementia sparked negative emotions like *loneliness* and *sadness* in the diarists. Some diarists belonging to minority ethnic backgrounds in the UK (like the Turkish and the Asian-Indian communities) reported cultural stigmas associated with dementia causing their fears and isolation.

Organizers of dementia initiatives may also show a lack of sensitivity towards ILWD when designing activities. Bringing ILWD together at various stages of dementia, according to some diarists, can generate discomfort in ILWD in the first stages of the disease. Furthermore, the diarists reported last-minute changes without informing them in advance and presentations showing disrespectful images which could be confusing and disturbing. The diarists suggested always testing events for ILWD in advance with a group of peers with dementia.

The diarists' discourses on the lack of societal support towards ILWD brought to light that a relevant social factor causing ILWD's negative emotions is not being acknowledged socially. We highlighted *Social Neglect* as the main overarching discourse that emerged from the first part of our analysis (RQ1).

3.2. Making sense of illness

RQ2 asked how ILWD refer to their negative emotions in relation to sensemaking of their illness. For this RQ, we found two overarching discourses emerging from the data: *Living with dementia* and *Empowerment*. The *Living with dementia* discourse consisted of two themes: *Dementia-Related Symptoms and Acknowledging Dementia*. The *Empowerment* discourse consisted of one theme: *Challenging Negative Emotions*.

3.2.1. Dementia-Related Symptoms

Three subthemes belonged to *Dementia-Related Symptoms*: *Complex Emotions*, *Symptom Description*, and *Depression* (see Table 1).

3.2.1.1. Complex emotions. The diarists reported mood swings, like a sudden shift from *extreme sadness* to *happiness*. Moreover, they reported several emotions that got triggered simultaneously. For example, anxiety could be triggered along with confusion and the feeling of insecurity, making it necessary to double-check and plan everything in advance, such as *driving* only in daylight and *avoiding* crowded risky areas. These activities, in turn, could trigger stress and anxiety again.

Our analysis showed that explaining *Complex Emotions* could be challenging for the diarists. To this end, the diarists seemed to use figurative language such as metaphors. The most suitable definition of metaphor in the context of health communication is that of Semino et al. (2018, p. 5): 'Metaphor in verbal communication involves talking, and, potentially, thinking about one thing in terms of another, where the two things are different, but some form of similarity can be perceived between them' (see also Semino et al., 2018, p. 29). Metaphors and other figurative devices can help sense making and framing thoughts (Burgers et al., 2016; Lakoff & Johnson, 1980/2003; Semino et al., 2018) in that they can help reasoning on a topic, by foregrounding a particular problem definition, cause, evaluation and/or solution (Entman, 1993). For example, a diarist described their depression, by evaluating it as '*really bad*' and '*hard to explain*'. To elaborate on that, they framed the complex issue of depression with the metaphor of the '*light at the end of the tunnel*'. This metaphor shows their expectation and hope (*the light*) that they will be able to come out of depression (*the tunnel*). According to Conceptual

Metaphor Theory (CMT; Lakoff & Johnson, 1980/2003), this metaphor can be referred to the conceptual metaphors *HAPPINESS IS LIGHT* and *EMOTIONAL STATES ARE CONTAINERS*. Our findings suggest that in making sense of illness (RQ2), ILWD could expect to become more susceptible to *Complex Emotions* which can challenge ILWD and can be difficult to share.

3.2.1.2. Symptom Description. Explaining to others how an emotion feels can be difficult, especially when it concerns negative life events (Armstrong et al., 2011). The diarists reported that ILWD are even more challenged to *articulate* their emotions because of cognitive impairments and because they may experience new, unusual emotions. The negative emotion of loss explains quite well this challenging experience for ILWD. The noun 'loss' has at least two meanings in English. It can refer to both a symptom such as the deterioration or absence of a physical capability or function and to a sense/feeling of loss (like distress). In the diarists' reports, 'loss' was associated to both symptoms (like loss of *sight*, *hearing*, *balance*) and emotions (like distress). According to CMT (Lakoff & Johnson, 1980/2003), the use of the term loss to refer to memory issues linked to dementia can be understood as a linguistic manifestation of the conceptual metaphors *THE MIND IS A CONTAINER* and *IDEAS ARE OBJECTS*. In this metaphoric frame, memory can be viewed as a 'warehouse' where memories are 'objects' that can be stored and lost.

It is not surprising that, for the diarists, acknowledging and describing these new symptoms and emotions could be difficult. A diarist reported a complex emotion of grief troubling them. The quality (*not feeling down* but *sad*) and the intensity of the feeling (*achingly sad*) were clear. By contrast, the diarist could not explain the cause of this emotion. Our analysis revealed that to talk about such complex symptoms and emotional states the diarists may use figurative expressions such as metaphors and metonymy (i.e., describing one thing through another of which it is a part or with which it is associated). For example, a diarist explained a *bad* day with dementia and their tiredness through the *BODY FOR PERSON* metonymy where 'the body' is described as screaming when referring to the person. Another diarist, moreover, compared metaphorically losing memory with *holes*: as if memory were a tissue that deteriorates due to cognitive impairment. These findings suggest that experiencing and explaining their symptoms (like *somatic* and *cognitive loss*), although they may be difficult, are important elements of making sense of illness (RQ2).

3.2.1.3. Depression. The diarists often reported *feeling depressed* –with a peak in winter. They also argued that dementia diagnosis by itself could be overwhelming and could cause depression. According to the diarists, *negative* (stereotypical) public images and *stigma* related to dementia could be devastating and deepen the depression of recently diagnosed people. Besides, they suggested, this could lead, in a minority of cases, to dramatic backlashes like suicidal wishes. Some diarists pointed out that media portrayals of ILWD that do not highlight coping strategies (i.e., not mentioning medication and support groups) are insensitive and potentially harmful. These findings show that *Depression* is involved in the emotional process of making sense of illness (RQ2) for two main reasons: 1) as part of dementia symptoms, and 2) because receiving a diagnosis can contribute to a depressive state, amplified by the negative stereotypes of dementia circulating in society.

The discourses of the diarists about the complex symptoms and emotions generated by dementia outlined a first level of the making sense of illness process (RQ2). The second level of this process concerned acknowledging the illness.

3.2.2. Acknowledging dementia

This theme focused on the gradual change from shock and frustration after receiving the diagnosis to accepting the illness. We found three subthemes: *Diagnosis*, *Declining*, and *Individual Trajectories* (see Table 1).

3.2.2.1. Diagnosis. Receiving a diagnosis of dementia is shocking and complex. Our analysis showed that the diagnosis triggered varied individual responses in the diarists. These could range from a state of *relief*, for being able to explain the cognitive and behavioural symptoms that they perceived, to *panic*, because of *feeling alone* and *not knowing what to expect*. According to the diarists, a related fear for newly diagnosed people is to end up in nursing homes. This fear was enhanced by *negative images* of nursing centres spread by the media, which, in the eyes of the diarists, are generally accepted by society. Receiving a diagnosis, thus, could be so heavy and alienating, that some diarists compared it figuratively to a *'blow'* and to an *'invasion'*. The diarists' further reactions to the first shock varied too. With a metaphor, a diarist explained that at the beginning they withdrew at home for months feeling *'imprisoned'*. Later, the diarist acknowledged the need to either keep *grieving* or *reacting*. The analysis showed that the diarists could more positively acknowledge their diagnosis when they felt supported by their network. These findings indicate that, in the emotional process of making sense of illness (RQ2), the diagnosis is a sensitive topic and that ILWD's responses to it are extremely varied, ranging from *relief* to *panic*.

3.2.2.2. Declining. We outlined a feeling of *Declining* that can be upsetting and frightening for ILWD. A point often remarked by the diarists is that acknowledging dementia requires much more than facing memory loss – as the public stereotype assumes. The diarists noticed that ILWD can feel attacked by their illness on many fronts including cognitive (like memory loss), physical (like feeling clumsy), and sensorial (like hearing loss). Moreover, the diarists felt *frustrated* on a social level, as with dementia, both the expectations of others and their own may become *harder* to fulfil. The analysis of *Declining* at a social level revealed a tension between the feeling of *losing control* and that of *maintaining independence* from others in decisions and actions. The diarists emphasized the importance for ILWD to remain *active* and *independent* given the tendency of others to act *for* them. Besides, they emphasized the need of feeling *reassured* and supported by their carers in coping with dementia. These findings suggest that in making sense of illness (RQ2) ILWD need to get in touch with their sense of *Declining* and its social repercussions.

3.2.2.3. Individual Trajectories. Both acknowledging dementia and slowly adapting to it are complex cognitive and emotional processes. Our analysis showed that each diarist's trajectory was different because it is based on their characters, biographies, and needs. The strong sense of self of the diarists emerged. For example, when affirming their need to be publicly *distinguished from their disease*. At the same time, some diarists described a discontinuity in their sense of self. This discontinuity seemed to appear from the comparison of two *kinds of self*. On the one hand the person they were before the illness, and on the other hand, the person they have become after the illness, who, for example, is no longer able to *cook* or *travel*. At the social level, e.g., with their families and carers, this discontinuity seemed to cause tension in the diarists, who were torn between *asking for help* and *independence*.

The diarists described *individualized* strategies that helped them coping with the disease. These included little steps in setting up new cognitive and emotional assessments: adapting to do things that are no longer easy, such as *travelling* and fine-tuning *social relationships*, as well as *keeping busy* and developing new habits. However not all activities work for every individual. For example, a diarist enjoyed *travelling*. By contrast, others preferred to be *quiet* and do *gardening*.

The crucial advice from the diarists in making sense of illness (RQ2) seems to find the right emotional balance between recognizing the negative side of illness and continuing to see the positive side of life. A diarist called this *inevitable* mix the *bittersweet* of dementia and another diarist compared it to the *variability of the weather*. For example, they advise ILWD to pay attention to their *future*, which is unknown, uncertain, and, yet should be dealt with (such as with *care planning* and wishes for one's own *funeral*). Another diarist noted how important it is to

overcome the fear of dementia which led them to a general *liberation* from fears. Setting the right coping strategies could make the diarist pass from feeling *hopeless* to be *hopeful*. The subtheme *Individual Trajectories* outlined that making sense of illness (RQ2) is a highly individualized process. The diarists affirmed the need to keep a sense of self both personally and socially that helps them distinguishing themselves from their illness and being positive despite the challenges of dementia.

The diarists' discourses about *Dementia-Related Symptoms* and *Acknowledging Dementia* focused on the need to consider dementia in its complexity. We synthesized this view in the overarching discourse *Living with dementia* that focuses on the negatives and positives sides of living with dementia daily. The experience of dementia as a disease can be *'bitter'* for ILWD and their associates. It poses challenges to ILWD in their daily lives: in the sense of self, in considering things that were possible before the disease and are no longer possible, and in the sense of confidence vs. the sense of limitation in social relationships. These bitter aspects can be offset by a more positive side with the help of social integration, support in daily activities, and through interaction with peers.

3.2.3. Challenging negative emotions

An overarching discourse emerged from the data that focused on ILWD's *Empowerment*. In relation to this discourse, one main theme emerged, *Challenging Negative Emotions* along with three subthemes: *Social Activities*, *Support from Family and Health Professionals*, and *Positive Attitudes*.

3.2.3.1. Social activities. The diarists emphasized the importance of finding reference points and taking part in *Social activities* for ILWD like Dementia Diaries (DD). These activities are beneficial, according to the diarists, for three main reasons. First, they allow them to share their feelings in a safe, respectful and authentic environment. The diarists, for example, could *mirror* the experience of other diarists, feeling heard and legitimized. DD was compared by a diarist to an *extended family*. Second, with their own stories of living with dementia, the diarists contribute to raising awareness by helping to challenge negative stereotypes and strengthen the public image of ILWD. Third, such initiatives keep the diarists socially connected and prevent their further isolation.

The diarists highlighted that joining social media could be helpful too. They considered keeping contact via *Zoom* a positive way to avoid loneliness. *Twitter* was considered reassuring by a diarist because it allowed for contact *during night and day*. However, the diarists noted the duplicity of these new AI technologies including *Alexa*: while on the one hand they allow virtual contact, on the other they lack *human touch*. These findings point out that, during the process of making sense of illness (RQ2), live and online *social activities* together are valuable resources: they contribute to social contact, support, advice, and fulfilment for helping other ILWD.

3.2.3.2. Support from Family and Health Professionals. A life with dementia, compared by a diarist to a *rollercoaster (without seatbelts)* because of the sudden changes and stress it generates, can be experienced by ILWD as a *lonely journey*. To make the journey less lonely, the support of family members can be an invaluable resource in *Challenging Negative Emotions*. For instance, family members, the diarists argued, could help ILWD managing new routines and practical matters and keeping their worries under control.

Healthcare professionals and assistants could make the diarists feel heard and supported. For example, *listening* carefully, being patient, showing *empathy* and being ready to help ILWD with *mobility* issues. *Facilitators* involved in activities with ILWD also could help creating an environment that the diarists perceived as *safe*: for example, feeling comfortable to *talk in a group*. The diarists reported that similar consideration from care providers in dementia care centres can help ILWD *flourishing* and meeting individual needs. For example, seeing an ILWD

participating in a *painting* course encourages people to see them not as a *sad* person, but as an *artist*. These findings suggest that family and professionals caring for ILWD, who are empathetic and supportive, are an essential element in helping ILWD making sense of illness.

3.2.3.3. Positive attitudes. The last aspect of the theme *Challenging negative emotions* that we observed is the potential for ILWD to develop positive attitudes which make them feel empowered (i.e., to grant someone more control over their life). The diarists mentioned cognitive, practical, and emotional strategies that made them feel more in control. Among the cognitive strategies, the diarists reported relativizing *problems* and *worries*, being *focused* and assertive, such as being aware of their needs and making them heard by society. A diarist illustrated this point with the example of a *dementia friendly* shop where there was *no music*, there were soft *lights*, and *helpful* people around, all things that reassured the diarists. Starting new activities like *crafting* also awakened positive emotions, such as *joy*, in the diarists together with a *sense of achievement*.

The diarists emphasized the importance of managing their emotion regulation process, especially in the delicate post-diagnosis phase. The diarists noted that ILWD need advice and support from professionals to overcome the shock and the complex emotions raised by a recent diagnosis. Nevertheless, they remarked, this emotional support is often lacking. As a result, the diarists themselves offer advice to encourage and support each other. Our analysis showed that a whole category of negative emotion words is used by the diarists to support each other. However, here, the reference to a negative emotion word, such as 'alone', instead of indicating a negative emotional state is used to suggest a reaction to that state or a contrast, such as in '*You are not alone*'. A distinct category of the diarists' expression of negative emotions involves a change in the valence of the emotion *from negative to positive* (You are *not* alone). This is the attitude with which the diarists warmly invited ILWD to spread new empowering *messages to the next generation* such as not to be afraid of dementia. We highlighted many diarists' discourses concerning how they can stay active, express themselves, joining dementia-friendly environments, receive support, as well as support other ILWD. We linked these discourses together within the overall discourse of *Empowerment* of ILWD with which the second part of our analysis concludes.

4. Discussion

4.1. NDB and social neglect

In our analysis, we investigated the role of negative emotions in ILWD's lives. We had two goals: analysing the experiences sparking negative emotions in the diarists' lives (RQ1) and investigating how the diarists referred to their negative emotions in relation to making sense of illness (RQ2). Overall, the diarists, who are a group of ILWD engaging in social activities such as DD, showed a rich emotional life. The analysis related to RQ1 brought to light the general discourse of *Social neglect* of ILWD and revealed two main themes that may cause ILWD's negative emotions as reported by the diarists: *External Circumstances* and *Lack of support*.

Our findings extended the investigation of ILWD's negative emotions in two main directions. First, despite the literature tends to focus on the study of depression among the symptoms of dementia (see van der Linde et al., 2016), our analysis revealed that the diarists experienced many negative emotions including *fear*, *anger*, *distress*, *panic*, and *loneliness*. All these emotions are worth exploring. Our findings, thus, support what was highlighted by other researchers: the internal view of dementia provided by ILWD's own account is richer than that provided by the external accounts (Gerritsen et al., 2016). Second, trying to understand ILWD's negative emotions by focusing mainly on the symptoms of dementia as a disease seems a limited approach. Rather, we propose to interpret part of the findings within the NDB model (Algase et al., 1996). In this way,

rather than as deficits, negative emotions can be explained as the expression of *unmet needs* provoking negative reactions in ILWD.

Our analysis highlighted three main factors that can upset the daily life of ILWD according to the diarists: 1) *change of social status* (like stop working and driving, and isolation), 2) *challenges in daily life* (like technology and transportation) and 3) *sensitive issues* (like people dying and Covid-19). These results were in line with a British study on the Covid-19 pandemic and prolonged isolation of ILWD by Talbot and Briggs (2021). The diarists' fears and isolation increased during the pandemic. In particular, the diarists revealed their concern about the negative consequences of prolonged isolation when they would return to normal life.

The second theme emerging from our analysis, the societal *Lack of Support* of ILWD, reinforced this insight. Within the psychosocial view of dementia (Dröes et al., 2016), our work brought to the foreground the discourse of *Social neglect* of ILWD and the resulting responsibilities for society at large. This discourse emphasized what was brought to public attention by the World Alzheimer Reports (Alzheimer's Disease International, 2012; 2019): the media and public discourse spread negative stereotypes (such as equating dementia with ageing) and disturbing images that conflate all ILWD to the end stage of the condition. These views can increase stigmatizing and discriminatory attitudes towards ILWD – with related isolation and depression. Our findings, for example, suggested the need to seek support for minority groups in communities where stigma may be enhanced. We therefore endorse the call for public reflection on the ethical consequences of these stigmatizing attitudes and the dominant representations of end-stage dementia (Gerritsen et al., 2016).

The discourse of *Social neglect* of ILWD raises urgent practical considerations for improving the wellbeing of ILWD (Livingston et al., 2020). For example, the diarists highlighted that it was not technology itself, but *how* it was used with them that cause their worries. The lack of sensitivity towards ILWD that the diarists perceive as widespread in society suggests that changing the dominant negative attitudes towards ILWD is a priority (Alzheimer's Disease International, 2019).

4.2. Acknowledging dementia in its complexity

The analysis related to making sense of illness (RQ2) brought to light the general discourse *Living with dementia*, which involves recognizing dementia in its complexity. Three themes belong to this discourse: *Dementia-Related Symptoms*, *Acknowledging Dementia* and *Challenging Negative Emotions*. *Living with Dementia* provides a more inclusive view of dementia, emphasizing the importance of balancing the negatives and positives aspects of a daily life with dementia.

Petty and colleagues (Petty et al., 2018) expressed their concern that dementia research tends to pay attention to ILWD's negative emotions, like anxiety and depression, exclusively as mood disorders. That is why they suggested to deepen research into the causes and the complexity of ILWD's emotions.

Emotion regulation, or how people manage their emotions, in ILWD is especially complex (Perach et al., 2020). Several of our themes align with themes recognized by previous research on emotion regulation (e.g., Zhang et al., 2015). For example, we highlighted contextual factors affecting the complexity of the diarists' emotion regulation, such as mood swings caused by several types of dementia (Kazui et al., 2016). Furthermore, the diarists have clarified how ILWD can be expected to become more sensitive to certain emotions such as anxiety and depression as noted in previous research on psychological distress and self-beliefs in dementia (Sutin et al., 2018). Finally, we found that some symptoms of dementia (such as memory loss and incontinence), in turn, may trigger new worries, anxiety, and fears in ILWD.

Assessing and expressing these complex emotions proved to be a challenge for the diarists, e.g., dealing with the general sense of *loss*, which involves physical, cognitive, and social levels. The diarists expressed the need to receive specific emotional support from professionals – which, however, they often felt was lacking. The insight

obtained from our analysis is that diarists used figurative language to explain some of these complex emotions, such as *'seeing the light at the end of the tunnel'*. Our findings corroborate previous analyses in fields such as cancer and psychotherapy, showing that metaphors can be useful for talking about symptoms and emotions and for making sense of illness (Del Piccolo et al., 2012; Semino et al., 2018). In the field of dementia, Castaño's study of ILWD's blogs Castaño (2019) highlighted that metaphors play a role in emotion regulation. For example, the 'roller coaster' metaphor tended to be associated to the expression of conflicting emotional states in a challenging situation. However, Castaño (2019, pp. 123–124) noted that when ILWD re-framed the illness as 'transformation' it became more acceptable to them. This power of transformation resonates with our analysis of the diarists' emotional appraisal, where the emotional balance between negative and positive sides of life with dementia was instrumental to develop individualized coping strategies.

The second aspect of complexity in ILWD emotion regulation that we found is the ability to adapt to living with dementia. We highlighted three main contextual factors affecting this aspect: 1) *Diagnosis*; 2) *Decline*; and 3) *Individual Trajectories*. Other studies investigating coping patterns in the experience of ILWD also revealed that emotions play a role in all these aspects (e.g., Górska et al., 2018).

In short, the process of making sense of illness, as experienced by the diarists, is complex also because it involves a constant evaluation that we found in the discourse *Living with dementia*. For example, assessing each other's boundaries, maintaining independence from families and carers, as well as going through moments of shame, frustration, and sadness. Like in Lishman and colleagues' findings (Lishman et al., 2014), this complexity is portrayed by the diarists as an ambivalent, *bittersweet* feeling: that implies a balance between the bad and the good sides of the illness. Caddell and Clare (2011) explained this double feeling as a state of flux between 'maintaining' and 'adjusting' the self throughout illness. Within this framework, the diarists, and each one in their own way, needed to acknowledge those things that kept them being the same person ('self-maintaining'), but they needed to accept that, with the illness, some things changed and needed to be integrated differently ('self-adjusting'). This could also generate a tension with their families and caregivers between the sense of *loss of control* vs. *maintaining independence*. Therefore, as previous research showed (Caddell & Clare, 2010; 2011) acknowledging dementia and adjusting to live with it, are complex processes, context dependent and can vary between individuals and within the experience of one individual.

4.3. Empowerment

Our analysis of how the diarists could make sense of their illness converged towards the potential of emotion regulation in ILWD (see Perach et al., 2020). Many diarists who have gone through the *'roller-coaster'* of emotions related to their illness were also able to turn the valence of their emotion *from negative to positive* and develop a sense of empowerment. The ability to overcome their negative emotions was prominent in our study as well as in the emotion regulation literature (e.g., Baumeister, 2018). This fundamental ability, as shown by other research on ILWD's subjective experience, affects acceptance, subjective well-being, and the ability to live well with dementia (Clare et al., 2019; Lishman et al., 2014).

Social support proved to be an invaluable resource of emotion regulation and well-being for the diarists as also previous studies on ILWD's use of social media showed (Rodríguez, 2013; Talbot et al., 2021). The value of illness narrative of ILWD to construct community and generating solidarity was highlighted by other research as well as in our analysis (Rodríguez, 2013). DD proved to be a network of personal and social resources, where the diarists could also learn of helpful strategies to cope with their illness. Sharing their problems but, equally importantly, bringing help to others allowed the diarists to reach out and find support and comfort when they needed it. The repetition of similar findings on ILWD's use of social media confirms the value of these new social

networks for use with ILWD. Despite limitations in the accessibility of this type of technology, as they tell stories and share opinions online, ILWD can express their sense of self and experience a rich sense of contribution to society (Rodríguez, 2013; Talbot et al., 2021).

In conclusion, all the main aspects involved in making sense of illness highlighted by other researchers –self-preservation, coping strategies, and supportive environment (e.g., Lishman et al., 2014)– were also found in our analysis. In addition, our study highlights that ILWD can develop a sense of empowerment. The notion of empowerment in dementia has recently been defined by van Corven et al. (2021) along four main aspects: personal identity, sense of choice and control, feeling useful, and sense of worth. All these aspects emerged from the diarists' discourses that emphasize the importance of ILWD's empowerment: using their talents, feeling in control, fulfilled and valued by society. This image contrasts sharply with the traditional stereotype of dementia as a general loss of self (Gerritsen et al., 2016).

4.4. Limitations and further research

The diarists have been trained to connect and interact with social media. These tools and resources are not accessible for every individual with dementia. Moreover, they may be less feasible for individuals in the later stages of dementia. DD makes no claims to being representative of a general population of ILWD, though they are making a lot of effort to include and support diarists with more advanced dementia. Researchers, thus, should be cautious in extrapolating our findings to a general population of ILWD. Moreover, some diarists have early-onset dementia. For this specific group of people, results about the emotional impact of dementia might have been affected in two ways. A systematic review showed that early-onset ILWD are more impacted by dementia in their lives than other ILWD (Greenwood & Smith, 2016). First, as they would not expect a diagnosis at their age. Second, as their life is overturned by events, like being obliged to stop working and driving. Our setting, furthermore, included ILWD living in the UK who were taking part in at least a group activity like DD and in advocacy campaigns for dementia. This may have increased our chances to find the discourse of *Empowerment* with the theme *Challenging Negative Emotions*. In addition, because of their advocacy activities some diarists' opinions could also gather the experience of other ILWD whose voices were not directly reported in the diaries. As in previous research on ILWD's narratives online, the ecological validity of online dementia sources is high because the diarists reported their own real experiences with dementia; however, extrapolation to other populations with dementia should be investigated at length (see Rodríguez, 2013).

We have limited ourselves to discussing metaphor use as a by-product of our main analysis on negative emotions. Our findings suggest that metaphor is a tool that can be used by ILWD to express complex emotions. A refined metaphor study on this topic, for example, combining quantitative and qualitative approaches, could deepen this insight. Given that DD is not a project designed for research (privacy-sensitive information is not stored) when we conducted our study there was no available information on the diarists' demographic factors and their specific illness trajectories. However, our analysis pointed to individualized strategies with which ILWD made sense of their emotions and illness. Future research on ILWD's emotional balance may profit from conducting systematic analyses of ILWD's trajectories distinguished per type of dementia, gender and other demographic factors, to show potential patterns in ILWD's emotion regulation.

5. Conclusion

This study presented a broad analysis of how ILWD acknowledge, express and react to their negative emotional life. We have shown that to increase understanding of the (positive) role of negative emotions in dementia, it is crucial to broaden the range of the emotions studied (Petty et al., 2018), but also to focus on the internal perspective of ILWD in their

social and daily life. In line with the psychosocial framework (Dröes et al., 2016), the discourse of *Social neglect* of ILWD showed that ILWD's negative emotions can be interpreted, in part, as signs of individuals' needs that are not being fulfilled (Algase et al., 1996). We have shown that negative emotions play a dual role in the diarists' emotion regulation: 1) to deal with demanding situations and social relationships in everyday life and 2) to develop coping strategies. The key emotional strategy that the diarists shared to support ILWD is to find a balance between the negative and positive sides of their life with dementia. According to our findings, in this process it is possible to support and empower ILWD in at least two ways. First, by addressing social neglect and stigmatizing views about ILWD, which are also prevalent in the media (Gerritsen et al., 2016). Second, by designing new environments, such as 'dementia friendly' shops, and social contexts where ILWD feel safe to share their emotions and concerns. Initiatives such as DD can make ILWD feel part of society and valued rather than marginalised (van Corven et al., 2021). The *Lancet* Commission suggested tailoring well-being intervention to ILWD's unique needs (Livingston et al., 2020). The more we understand individual perspectives on living with dementia the more it would be possible to tailor intervention to ILWD's preferences and address personalized care (Kelly et al., 2021).

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Ethical statement

All authors declare that their research fully complies with the 'Duties of authors' described in the Journal SSM - QUALITATIVE RESEARCH IN HEALTH's Ethics in publishing page (<https://www.elsevier.com/about/policies/publishing-ethics#Authors>).

Authorship is limited to those who have made a significant contribution to the conception, design, execution, or interpretation of the reported study. All those who have made substantial contributions are listed as co-authors.

Appropriate consent, and permission was obtained to conduct the study. For details, we refer to the 'ethics' and 'privacy concerns' parts extensively described in the manuscript.

Declaration of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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