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The Online Representation of Palliative Care by Practice, Policy and Advocacy Organizations: Definitional Variations and Discursive Tensions

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ABSTRACT

Negative beliefs and a lack of clarity surrounding the meaning of palliative care have been widely reported as obstacles to its uptake. Information available to the public possibly contributes to this. A descriptive and discourse-theoretical analysis was conducted of information spread online by palliative care policy, advocacy and practice organizations. Discrepancies were found in the way palliative care was defined in relation to curative, end-of-life, terminal and supportive care. Beyond these definitional variations, meaning was generated through the representation of palliative care as a culture, connected to total care, compassion and openness. Tensions arose around the concepts of autonomy, a natural death and an emphasis on the quality of life away from death and dying. Overall, this study showed that the online information of palliative care is a potential source of confusion and might even contribute to its stigmatization. Insights are provided that may help improve clarity towards the public.

1. Introduction

Palliative care is most often defined as an approach to care that aims to improve the quality of life of patients with life-threatening illness and their families, throughout the entire illness trajectory and with a focus on physical, social, psychological and existential needs (Cohen et al., 2014). Related to changes in mortality patterns and the increase of chronic conditions and multimorbidity, the patient population of palliative care has widened and future palliative care needs within the population are estimated to rise significantly (Etkind et al., 2017; Gómez-Batiste et al., 2014; Morin et al., 216). Yet, multiple studies within various local contexts have shown that the awareness and knowledge of palliative care amongst the general public tends to be low and many misunderstandings persist (Benini et al., 2011; Huo et al., 2019; Shalev et al., 2018; Taber et al., 2019; Westerlund et al., 2018). Studies focusing on the views of health care practitioners, patients and their family caregivers have reported similarly worrying results. Particularly for the initiation of palliative care early in the illness trajectory, misperceptions and negative beliefs have been identified as a barrier (Collins et al., 2017; Gott et al., 2012) and this has led many to argue for the necessity of broad education on palliative care (Zimmermann et al., 2016).

However, to develop effective interventions such as public awareness campaigns, an understanding of the context in which public perceptions take shape is needed. A vital part of achieving this, is an examination of the information currently available to the general public. Information that is misleading, conflicting or confusing can, mediated through its effect on beliefs and perceptions, eventually have an impact on the access and use of palliative care, leading to unmet care needs and less than optimal levels of wellbeing and quality of life. Of particular interest is information disseminated online because of the increasingly important role the internet has as a public resource for (health) information (Champlin et al., 2016; Cotten & Gupta, 2004; Huisman et al., 2019). Research furthermore affirmed the internet as

an important source for people searching information on palliative care (Cheng & Hauser, 2019; Huo et al., 2019). Yet, we found relatively few studies with a focus on analyzing this online information and these furthermore all pointed out missed opportunities for organizations to adequately use the internet to disseminate information on palliative care. Some of the reported problems are reading levels that are too high making the information not accessible enough (Claudio et al., 2018), cancer center homepages that rarely even mention palliative care (Vater et al., 2018), a considerable variability in content coverage between palliative care information pages and the absence of information rated by palliative care professionals as important for consumers to know (Kozlov & Carpenter, 2015). A critical consideration to make however is that even if the content is consistent and rated to be of high quality by palliative care experts, this does not tell us anything about the wider systems-of-meaning (discourses) present within the information and how these texts work to construct a certain image of palliative care, serious illness, the end of life, care and society for that matter. Gaining insight into the way meaning is constructed within these texts is a first step towards understanding the multiple ways in which audiences interpret them and this can provide an opportunity to be sensitive to these different systems-of-meaning when informing the public on palliative care.

To reach this deeper understanding, this study was designed to not only look at the online information of palliative care on a descriptive level, focusing on the congruence and discrepancies between the given definitions and descriptions of palliative care, but as well on a discourse-theoretical level, focusing on the way meaning is generated through the discursive organization of the texts. More specifically, we aim to identify the elements of congruence, ambivalence and tension within and between the representations of palliative care in publicly available online information spread by palliative care practice, policy and advocacy

organizations and to identify and interpret the discourses at play.

2. Methods

We conducted a descriptive and discourse-theoretical analysis of the online information of palliative care disseminated by 56 diverse organizations in Flanders, Belgium. Data-collection and analysis took place from December 2019 to July 2020. The authors were not required to obtain ethical approval since all data is freely available in the public domain.

Theoretical framework

We employed a poststructuralist approach to discourse analysis shaped by the theoretical writings of Foucault and Laclau and Mouffe, named discourse-theoretical analysis (Torfing, 1999). Poststructuralist approaches rest on the fundamental position that everything can be studied *as* text and that nothing exists or can be comprehended independent of texts (Dunn & Neumann, 2016, p. 39). Discourses can then be understood as "*systems of meaning-production that fix meaning, however temporarily, and enable actors to make sense of the world and to act within it*" (Shepherd, 2008, p. 20). Importantly, discourses are never fully stable and essentially incomplete by nature (Foucault, 1972, p. 61). Meaning is always only partially fixated and subject to "*contingency at the level of discourse itself*" and at "*the inter-discursive level generated by struggles over meaning between different discourses*" (Van Brussel & Carpentier, 2017, p. 377). This quality of fluidity stands central in discourse-theoretical analysis and its theoretical framework as such provides the necessary tools to gain insight into the way meaning gets (re)produced and/or challenged within specific representational settings, in this case the online information of palliative care. In *box 1* four key theoretical concepts that will be used throughout this article, are briefly explained.

Nodal points: nodal points are what Laclau and Mouffe call "*the privileged discursive points of partial fixation*" (Laclau & Mouffe, 1985, p. 99) and "*every discourse has one or several such nodal points, which together define how this discourse is organized and which meanings it articulates*" (Jacobs, 2019, p. 10).

Articulation: nodal points are constructed through the process of 'articulation', which is "*any practice establishing a relation among elements such that their identity is modified as a result of the articulatory practice*", and discourse is then "*the structured totality resulting from the articulatory practice*" (Laclau & Mouffe, 1985, p. 91).

Floating signifiers: signs that "*different discourses struggle to invest with meaning in their own particular way*" are called floating signifiers. Where nodal points refer to "*points of crystallization within a specific discourse*", floating signifiers refer to "*the ongoing struggle between different discourses to fix the meaning of important signs*" (Jørgensen & Phillips, 2012, p. 28).

Subject positions: relates to "*the positioning of subjects within a discursive structure*" (Carpentier, 2010, p. 253) and is built on the ontological assumption that our individuality is socially constructed: "*one can only ever be what the various discourses make possible, and one's being shifts with the various discourses through which one is spoken into existence*" (Davies, 1991). Subject positions are to be understood relationally since "*what defines a particular subject is the relative relationships that are constructed between it and other subjects*" (Dunn & Neumann, 2016, p. 110).

Empirical material

The data consists of publicly available texts on palliative care disseminated online by palliative care practice, advocacy and policy organizations active in Flanders, Belgium. These include organizations that can be divided into seven different sectors: 1) palliative care field organizations such as local palliative care networks, palliative care day centers and palliative care organizations directed at specific audiences; 2) professional health care organizations such as hospitals and nursing associations; 3) home support services; 4) elderly care facilities; 5) patient and informal care organizations; 6) civil society organizations such as health care funds, volunteer associations and associations for senior citizens and 7) governmental

organizations. These organizations spread information about palliative care for multiple purposes: some provide information on specific palliative care services offered by them, others provide information on palliative care in general directed at multiple audiences such as patients, (informal and/or formal) caregivers and members of the general public. 'Publicly available' implies that the analyzed texts are freely accessible for whomever. Texts that are not made public such as documents that have to be purchased first, were excluded. Social media pages were excluded as well since information shared on these pages is often directly linked to information shared on websites and most of these pages cannot be considered 'publicly available' since you have to 'follow' or subscribe. We further chose to focus on texts written in Dutch since this is the prevailing language spoken in the included region. Images, audio fragments or videos were planned to be included only if online transcripts were available, however, such transcripts were not found.

Search strategy and data extraction

We developed a search strategy based on the purposive sampling principle of maximum variation, meaning that we strategically sampled texts to ensure as wide a variation as possible in terms of our dimension of interest, namely, representations of palliative care. An extensive (but non-exhaustive) inventory of organizations directly or indirectly involved in the policy, advocacy or practice of palliative care in Flanders was made and divided into seven different sectors as described above. Organizations were randomly picked per sector resulting in cycles of 7 diverse organizations. The websites of these organizations were visited and texts on palliative care were searched using the internal search tool (keywords: 'palliatief' and 'palliatieve') or when not available, by scoping through the menu. We extracted all texts containing descriptions and explanations of palliative care, vision or mission statements in relation to palliative care and information on specific regulations and/or activities related to

palliative care. If only a small paragraph on the page was relevant, the whole page was saved and read to ascertain that no important contextual information was missed. Only after all texts within a cycle were analyzed, texts from the following cycle were collected. When theoretical saturation was reached, i.e., the point when emerging concepts were fully explored and no new theoretical insights were generated (Bryman, 2016, p. 697), we continued to collect and analyze texts for one more cycle. As a last step, we performed a Google search for 'palliatieve zorg' (through whatsmyserp.com; a tool that provides location-specific search results and is unbiased by personal search histories) and per sector we analyzed the first organization in the list that we did not analyze yet. This was done as a control measure, to make sure we included all possible representations and that these were not biased by the inventory we made.

Analytical strategy & coding technique

Our analytical strategy contained a descriptive and a discourse-theoretical level of analysis. Each text was first interpreted through a descriptive reading in which the researcher *"submits to the prescribed limits of the discursive terrain, accepting the hierarchical organization of the texts around the implicitly unproblematic presence of the nodal points*" (Shepherd, 2008, p. 28). In this phase we stayed very close to the wording of the texts and focused on the congruence and discrepancies between them. It was then followed by a discourse-theoretical reading, the second level of analysis, in which we focused on the organization of meaning within the discursive context. In this phase, we thus 'turned' to our empirical material to investigate it as a body of articulatory practices; "*what meanings do they establish by positioning elements in particular relationships with one other, and what meaning potentials do they exclude*?" (Jørgensen & Phillips, 2012, p. 29). Leaning on the theoretical concepts explained in *box 1*, this involved identifying and interpreting nodal points, floating signifiers and subject positions to grasp the functioning of the discourses in the empirical material.

This analytical strategy was aided by adopting a coding strategy as described in grounded theory (Corbin & Strauss, 2008) and by using the Nvivo12 software. The texts were first processed through a line-by-line open coding and the simultaneous writing of memos to not lose the context of the codes and to keep track of ideas and thoughts. We then combined the initial codes and memos into higher-order and more abstract codes, reflecting grounded theory's axial and selective coding but done from within the discourse-theoretical framework. By going through more and more cycles, the discourse-theoretical analysis became more solid and we got closer to the theoretical saturation strived for.

Techniques to establish quality and scientific rigor

Transparency was aimed for by being fully explicit about the adopted methods and theoretical framework in the reporting of the study, as well as through the writing of a detailed protocol in preparation of the research and the keeping of an audit trail during the whole research process itself. Further, Marjolein Matthys was aided by a research team of seven members with diverse fields of expertise, established around this study with the aim of systematically guiding and guarding each step. Each member was involved in reviewing the interpretations and results and during two of the eight cycles one of the members, Naomi Dhollander, also took on the role of performing the line-by-line open coding process after which the separately obtained results were compared and discussed. Additionally, two expert meetings were held while developing the research design to discuss discourse-analytical procedures and the methodological coherence with the research aim. Close attention was also paid to reflexivity by properly articulating preconceptions, personal beliefs and ideas that were held prior to the research or which developed during its course and discussing them with the whole research team. This way extra attention could be paid to competing ideas and interpretations during the

analysis of data.

3. Results

Theoretical saturation was achieved after six cycles and two more cycles followed: a seventh cycle drawn again from the inventory and an eight cycle drawn from the obtained Google search results. No new representations emerged, the previously established theoretical saturation remained and therefore data-collection stopped after the analysis of a total of 56 organizations. The online information derived from these organizations provided us with a rich and diverse dataset consisting of brochures, informational webpages, reports, policy letters, opinion pieces and magazines.

3.1 Descriptive reading: congruence and discrepancy

Palliative care was mainly presented through giving definitions (among which two institutionalized ones; the WHO definition and the Belgian legal definition of 2016), statements of its goals and vision, practical information on the organization of palliative care in Flanders and the social policy measures available. Some organizations also presented palliative care in reference to the wider legal framework (zooming in on the evolutions and not only taking over the definition) and an overview of the historical development of palliative care in Belgium and/or internationally.

Within the given definitions and descriptions of palliative care we found a consistent presence of a number of key signifiers that indicates a certain level of congruence between the different presentations of palliative care:

- **Total care** split into different dimensions. There was a certain level of randomness in the exact number of dimensions and terminology used but mostly four were

mentioned and terms were circulating around a physical, a social, a spiritual and a psychological dimension. Psychological needs were sometimes referred to as emotional, mental or psychosocial needs. 'Existential' sometimes was added as the fifth dimension, replaced 'spiritual' or it got 'melted' together (spiritual-existential needs). Some organizations also added 'moral' support/needs to their listing or used this instead of the spiritual or existential dimension. The descriptions of the physical dimension were rather clear and consistently linked to pain- and symptom management, while the descriptions of the other dimensions tended to often remain vague or absent.

- **Multidisciplinary team**: a team of professionals with diverse backgrounds are responsible for the delivery of this total care. Another, interchangeably used, term was 'interdisciplinary'. The exact disciplines named differed depending on the organization, but often they did not only include medical profiles but for instance also spiritual or moral counsellors and social workers. Volunteers were also frequently mentioned as being an invaluable addition to this team.

- Goals of palliative care: **optimizing the quality of life, optimizing comfort and/or relief of suffering**. In general, these were all being presented as important related goals of palliative care although they were not always presented together and sometimes one was emphasized more than the others.

- **Person-centered care**: the delivered care departs from the wishes, choices and needs of the patient and his or her close social environment.

- Palliative care applies to **different settings of care**. Often emphasis was put on the ideal of the home or homeliness of the care environment.

However, we also found discrepancies in the way palliative care was defined in connection to

curative, terminal, end-of-life and supportive care. These discrepancies were encountered not only between organizations but sometimes as well within different texts of just one organization.

- **Palliative care as end-of-life care versus terminal care:**

    Palliative care was often presented as 'more than terminal care' and stating this is a persistent misconception. However, in most of the texts, and sometimes also in the same texts, palliative care stayed dominantly articulated as care at the end of life or during the last stage/phase of life. What this 'end of life' or 'last phase of life' then is, remained rather ambivalent:

    > *The goal of palliative care is not to cure the patient, that is no longer possible. Rather the goal of palliative care is to offer the patient and his or her social environment the highest possible quality of life in the last part of life* [home care organization: webpage] (Thuisverpleging De Lelie, n.d., Palliatieve zorg section).
    >
    > *Palliative care aims for a total care at the end of life, for the sick person and his or her beloved ones* [palliative care field organization: webpage] (Coda, n.d., para. 1).

    Depending on the context, this 'end of life' could have a more broad or narrow meaning and despite being constructed as a demarcated phase, a clear 'starting point' was often lacking. Some texts placed emphasis on the moment when all other treatments had stopped, others merely on underlining it stretches beyond the terminal phase:

    > *Palliative care is often wrongly confused with terminal care (. ...) it better starts earlier to then finally evolve into terminal care* [hospital:

webpage] (Ziekenhuis Oost-Limburg campus Maas en Kempen, n.d.,

Palliatieve zorgen section, para. 2).

In contrast to this, in some texts palliative care was presented as care restricted to the terminal phase or a short life-expectancy. This was also the case within the available social policies:

> *Persons with an incurable illness and a limited life expectancy can rely upon palliative care (. …) to better respond to the physical, psychological and moral needs of the terminally ill patients, as well as their social environment* [governmental organization: webpage] (Federale Overheidsdienst Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu, 2016, para. 1).

Palliative care was furthermore often described in relation to the specialist services that do focus on persons with a limited life-expectancy and it remained ambiguous in those texts how this relates to the definition of palliative care that has a broader focus. Additionally, in many texts a certain amount of background knowledge was implicitly expected from the reader when talking about "the palliative phase", "palliative situations", "palliative patients" or "palliative files". The context of the texts did not always allow to interpret the meaning that was being attached to the adjective "palliative" but often it did seem to imply terminal care:

> *If you are being confronted with a palliative situation, then you can still consult with your loved ones and caregivers about what you want or don't want* [palliative care field organization: webpage] (Netwerken Palliatieve Zorg Oost-Vlaanderen, n.d., "Beslissingen palliatieve fase" section).

- **Palliative care relationship with curative care:**

  Curative care played an important part in the way palliative care was presented, but organizations differed in the way curative care and palliative care were presented as overlapping in time and goals or as strictly separated from each other:

  > *Palliative care is care for patients who can no longer be aided by treatments directed at curing (curative therapy)* [palliative care field organization: webpage] (Netwerk Palliatieve Zorg De Mantel, n.d., para. 1).
  >
  > *Since the transition from the curative phase to the palliative phase in practice mostly does not happen abruptly, it is important to implement this care in the care policy early after diagnosis* [palliative care field organization: webpage] (Palliatieve Hulpverlening Antwerpen, n.d., para. 2).

  When early initiation of palliative care was argued for, it was often not explained or elaborated on. Only a minority of the texts spoke of initiating palliative care from the moment of diagnosis. More common was the statement that palliative treatment could overlap with other active treatments, but here texts then differed if and how these treatments were labelled: stabilizing and/or life-prolonging, or as well curative.

- **Palliative care relationship with supportive care:**

  A small number of texts also mentioned supportive care, but also here there were discrepancies found between texts. Supportive care was used by some organizations as a synonym for palliative care that starts earlier than the terminal phase (directed at incurably ill persons) and others distinguished it from palliative care all together.

In the latter case, palliative care was then equated with care when other treatments had stopped and supportive care was the care at an earlier stage of the illness trajectory, together with curative, life-prolonging or stabilizing treatment.

> *Palliative care is supportive care (. …) we like to use the term 'supportive care' for the palliative support for incurably ill persons, and we reserve the term 'terminal care' for the last weeks, months of the illness* [civil society organization: webpage] (Levenseinde Informatieforum [LEIF], n.d., para. 2).

Adding a layer of complexity to these discrepancies, in some texts 'a palliative treatment' was defined in a strictly biomedical sense, within the differentiations of the possible oncological treatments described on the pages of for instances hospitals or cancer organizations. A 'palliative treatment' did not refer to palliative care as a whole then but to treatments that are aimed at 'slowing down' the disease and the reduction of symptoms and not curing the illness.

The discrepancies were also reflected in the descriptions of "the palliative patient", which were as well characterized by ambiguity. Having an incurable or life-threatening disease were the most frequently used terms in the descriptions (often used interchangeably). Other variations described them as terminal patients, in terms of 'vulnerability', or in relation to the treatment they did not longer receive, want or their illness has been unreceptive to.

3.2 Discourse-theoretical reading; palliative care as a discourse

The fact that we cannot speak of a clear congruence on the level of descriptions and definitions, does not mean that the generation of meaning attached to palliative care is indeterminate in a similar manner. Particularly in the way palliative care was represented

within the online texts as a culture, a philosophy or ideology, we could see the functioning of a discourse, as a (partially) structured system of meaning-production organized around certain 'privileged signs of signification', called nodal points. In what follows we shed light on the palliative care discourse and the discursive elements organizing it. We also look at the 'points of instability' within the discourse itself and under influence of other (competing) discourses present within the online representations of palliative care.

'Total care', 'openness' and 'compassion'

The discourse of palliative care 'as a culture' is organized around the core nodal points of 'total care', 'openness' and 'compassion'.

Total care encompasses a holistic ontology in which an anti-reductionist view and the notion of 'interconnectedness' determine how man, illness, pain, health and care are understood. The division of care, suffering and needs into several different, interconnected 'dimensions' is the clearest articulation of this. The goal of this multidisciplinary total care is then to optimize the comfort and quality of life and to prevent and reduce suffering, not only with a focus on "the palliative patient" but always as well on his or her close social environment.

The other two nodal points, openness and compassion, relate to the values promoted within the discourse and are simultaneously central to the subject position of the palliative caregiver. Openness refers to the open attitude towards death and dying, which was brought as a cornerstone of palliative care identity. Death and dying were articulated as natural facts of life and open conversations about these subjects were argued for. The death-denying thesis, in which Western societies are said to be characterized by a taboo on death and dying, was frequently articulated within the texts mainly by stating it is their task to make this again a

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topic of interest and conversation within society. This also expressed itself in the reference to 'aggressiveness of care':

> *He [a doctor] saw a lot of people die on intensive care. He could not bear this. He always wanted to continue treatment and never give up even if it was pointless (. …) Slowly something changed in him. He started to listen to people who were incurably ill and to old and vulnerable people at the end of their life. He listened to their worries and fears (. …) He started to think differently about death and about dealing with people who have a limited life expectancy. As such, he became a big defender of palliative care* [governmental & palliative care field organization: brochure] (Dienst Welzijn en Gezondheid Provinciebestuur Antwerpen & Netwerken Palliatieve Zorg Antwerpen, 2013, p. 8).

Palliative caregivers were represented as being unique in having embodied this open attitude and not running away from confrontations with serious illness, death and dying:

> *Palliative care wants to leave no one alone in the last period of his or her life. It is the care of people who do not run away from someone who is incurably ill, even if they are confronted with the most difficult human questions* [governmental & palliative care field organization: brochure] (Dienst Welzijn en Gezondheid Provinciebestuur Antwerpen & Netwerken Palliatieve Zorg Antwerpen, 2013, p. 6).

The third nodal point, compassion, refers then to the committed and compassionate attitude of the palliative caregivers. Palliative care as the unique, warm and compassionate care for incurably ill persons, given by empathic and caring professionals and volunteers. Listening and 'just being there' were described as important aspects of this.

"The palliative patient"

In relation to the way the palliative caregiver was represented within the palliative care

discourse we found the representation of the principal care receiver, "the palliative patient", to be an important part of the discourse. In this subject position emphasis was put on 'autonomy' and 'expressiveness', but at the same time it was characterized by a connection to negative signifiers and a passive positioning in relation to the palliative caregiver.

More specifically, having an incurable disease and being in the last phase of life was predominantly connected to negative signifiers such as suffering, pain, unrest, dependency, fear, worries, powerlessness and being a potential burden to family caregivers. The task of palliative caregivers was then to relieve the person of that suffering through the delivery of compassionate and committed total care, to stimulate them to take up their autonomy and to enable going through this last phase of life meaningfully. In other words, in relation to the palliative caregiver "the palliative patient" was often discursively placed in a passive position:

> *A palliative patient is someone who is seriously ill and cannot be cured. Death as a result of the disease is unavoidable. This does not mean that you just have to wait, we can still mean a lot for the patient and his or her environment* [home care organization: webpage] (Carios, n.d., para. 2).

This was reinforced in texts which provided general information on palliative care but were nonetheless directed at the family (the 'you' in the text) and were about the patient. Alternative representations of "the palliative patient" were also found; texts in which he or she was represented as a person that could enjoy life or still have an active role to play, despite having an incurable disease. These were rather exceptional though and palliative care was then still presented as the care that enabled this. Furthermore, these more 'positive' portrayals were mainly limited to texts in which "the palliative patient" was explicitly disconnected from a short life expectancy.

The autonomy of the patient related then to the uniqueness of each individual and that the care departs from his or her needs, wishes, values and choices. Importantly, there are

many different ways in which autonomy can be articulated and in the palliative care discourse this was predominantly done with an emphasis on the interconnectedness and -interdependency of individuals and their social environment:

> *Man seldom chooses and decides things on his own. Agreed, a person often has inner dialogues. But in that self-conversation, echoes from others and the outside world are constantly present. Without the other you will not get clarity in the decision you have to make. The final decision is therefore always the result of a search process. And this always involves at least a few good friends and confidants* [civil society organization: brochure] (Okra, n.d., p. 8).

Expressiveness was then brought forward as the need to communicate, be expressive about one's wishes, fears and thoughts related to the end of life and to make choices to achieve quality care at the end of life and a death as one would have wanted (not excluding however the possibility for this when 'being expressive' is not an option).

'Constitutive outsides'

A last important characteristic of the palliative care -as a culture- discourse, are the role of curative care and the wider society as its 'constitutive outsides'.

Throughout the texts we found how palliative care presented itself as the advocate of people confronted with serious illness and loss and at times it did this through its representation of society as a death denying, isolating or stigmatizing context:

> *In our flashy society there is little room for uncertainty, fear, sadness ... People prefer to keep it cheerful and light-hearted, 'positive'...* [palliative care field organization: brochure] (Federatie Palliatieve Zorg Vlaanderen, 2010, p. 7).

This representation of society, as a 'constitutive other', enabled the representation of itself as an emancipating force.

This was also found in the way that palliative care and the type of care it stands for, was sometimes articulated in opposition to the goals of curative care; to cure and to focus on the quantity of life. The identity of palliative care was then again enforced by a description of that which it is not:

> *Stopping treatments aimed at curing, opens a new road. A road directed at offering maximal comfort. A road that gives the patient the chance to meaningfully spend the time that's left (. ...) Instead of exclusively directing the attention on the treatment and the evolution of the illness, the patient gets the time and opportunity to find him- or herself again, to make the balance of his or her life and to make final arrangements* [hospital: webpage] (Algemeen Ziekenhuis Sint-Lucas Gent, 2018, Vision section, para. 2-3).

However, as has been said earlier, the way that curative care and palliative care were positioned in relation to each other could differ from clear separate phases with distinctive goals to overlapping phases with compatible goals. This integration reflected itself on the level of the discourse; the articulation of palliative care in an antagonistic relation with curative care was rather rare and more common was the articulation of a relationship of difference (meaning that the difference between the two remains an important aspect in the construction of their mutual identity, but this without dichotomizing the discursive structure).

Intra- and interdiscursive elements of instability

Within the logic of discourse dynamics, meaning is always subject to instability from within the discourse itself or under influence of competing discourses. We distinguished three discursive tensions in the palliative care discourse:

1. **The centrality of death and dying:**

   During the analysis we noticed a tension between the open attitude towards death and dying as an important aspect of palliative care identity and the focus away from death and dying in the descriptions of the care itself, definitely when the texts focused on promoting a broad definition of palliative care. In the latter case an emphasis on quality of life could be observed, in the absence of references to goals and tasks at the actual end of life. For instance, in a press release of a recent campaign of one of the organizations to promote palliative care, it was argued that palliative care should not be connected by the public to dying but to the quality of life:

   > *They think it is high time that we look at palliative care with a different gaze. That is why together they want to get rid of the prejudices and uncertainties and send a positive message into the world. No usual associations and connotations such as dying, farewell, sadness and pain, but words such as quality of life, comfort and wellbeing dominate. Because palliative care does not stand for dying but for the quality of life. It wants to stimulate patients and loved ones to get the best out of life, despite the incurable illness* [palliative care field organizations: press release] (Fédération Bruxelloise des Soins Palliatifs et Continus et al., 2020, para. 2).

   Improving the quality of life was put forward as an important goal of palliative care throughout all studied materials but in those texts that defined palliative care independent of life-expectancy and not as care for terminally ill patients, it got a more central position. References to 'a qualitative end-of-life', a serene or dignified death or 'saying goodbye meaningfully' tended to be absent from those texts and would mainly be part of texts where the given descriptions and definitions were more narrow, more closely connected to the process of dying and the 'actual' end of life. The variations in

definitions of palliative care in this sense are not just a matter of changing practices, they also reflect themselves within the discourse and the meanings it produces.

2. **Autonomy as individual choice vs social embeddedness:**

Our analysis identified autonomy as a floating signifier. In the palliative care discourse autonomy is articulated with an emphasis on the social embeddedness of the individual. Alternative articulations, for instance emphasizing "taking control" in the context of advance care planning, are not necessarily conflicting. We did find a tension however when autonomy was articulated as the fundamental value of self-determination and the absence of negative interference. Here we identified the right-to-die discourse in which autonomy functions as a nodal point. The competing articulations of autonomy also resulted in alternative representations of palliative care itself. Within the right-to-die discourse palliative care was articulated as a particular choice the autonomous individual can make regarding the end of life, next to euthanasia. Even though some voices within this discourse affirm that they are not mutually exclusive, they do present it as alternative treatment options in which palliative care can be chosen or refused depending on the will of the person:

> *It is the patient's right, after being properly informed, to accept or refuse treatment. This also applies to palliative care. To invariably want to apply palliative care to all patients could be called palliative obstinacy (sometimes also called 'the palliative filter')* [civil society organization: webpage] (Levenseinde Informatieforum [LEIF], n.d., para. 7).

In contrast to this is the representation of palliative care as the best context in which a request for euthanasia, or other medical-ethical questions, should be approached.

Euthanasia is then not treated as an antagonism nor alternative, but as integrated

within the palliative care pathway:

> *Precisely out of respect for the autonomy and freedom of choice of the patient*
>
> *it is utterly important that patients are assisted according to the principles of*
>
> *palliative care. Our daily involvement with incurably ill patients and their*
>
> *questions has taught us that good palliative care can prevent or even*
>
> *eliminate not all but still the vast majority of requests for euthanasia - the*
>
> *false choices that are actually requests for help* [hospital: webpage]
>
> (Algemeen Ziekenhuis Sint-Lucas Gent, 2017, para. 1).

The articulation of autonomy from its social embeddedness is a crucial part of this

and what is emphasized then is acting respectfully towards the autonomy of the

patient; to listen to their wishes, to interpret them and bring them into a social

dialogue between the different people involved:

> *Our value is 'autonomy' - our norm is 'we approach the patient preferably in*
>
> *his environment' - our belief is 'autonomous decisions that take into account*
>
> *the experience and emotions of the environment are better*' [palliative care
>
> field organization: webpage] (Netwerk Levenseinde, n.d., "Waarden, normen"
>
> section, para. 2).

These articulations also direct at 'care dependency' situations such as severe dementia

in which autonomy cannot be easily connected to the independence of others and self-

determination of the rational and expressive individual.

3. **The ideological articulation of a natural death:**

In contrast to the key role a 'natural death' played within the 'original' hospice

movement discourse, it only played a minor role within the analyzed texts. Medically

assisted dying, end-of-life decision making, advance care planning and as such, the biomedical-ethical context were prominent in the way the event of death and the process of dying were approached. This also resonated in the way "the palliative patient" was at times represented as "the informed care recipient" making choices. Additionally, in many organizations euthanasia was described as an option within palliative care. However, references to a 'natural death' were not completely absent either. The phrases *'affirms life and regards dying as a normal process'* and '*intends neither to hasten or postpone death'* were occasionally found, often when a literal translation of the WHO definition was given without specifying it or without connecting it to a stance in regards to certain end-of-life decisions. A 'natural death' was also present in the way palliative sedation was described as a normal practice within palliative care (with the goal of reducing suffering through lowering consciousness and the event of death being a natural consequence of the illness and not of the sedation). Furthermore, 'a natural death' at times was mentioned in reaction to the perceived 'preference' within society for a timed death through euthanasia and the desire to plan and control the end of life:

> *How to deal with the social representation of dying that is increasingly colored ('framed') by the induced and efficient-sudden death with euthanasia, to that of the 'new dying': well-arranged, clearly timed, not long-lasting and not unexpected. Referring to alleged inhumanity, it is increasingly urged - by the environment, not so much by the patient - to accelerate a natural dying process. It is increasingly important to indicate that people in their final stage of life are not simply 'a burden', but 'may be there', and that natural dying ('slow dying') is not by definition a source of suffering and unworthiness, but in its own way also offers opportunities to experience life 'to the end' and to*

say goodbye, on the rhythm of those involved and with mutual support

[palliative care field organization: vision statement] (Huysmans & Vanden

Berghe, 2014, p. 38).

In this we could see how, even though a 'natural death' was not dominantly framed as

an ideal to be pursued, it was not completely abandoned either.

4. Discussion

Our analysis of online information about palliative care available to the general public

revealed on the one hand, a consistent presence of a number of key signifiers indicating a

certain level of congruence between the given definitions and descriptions of palliative care.

On the other hand, this was seriously limited by the discrepancies found between them (e.g.

its framing as terminal care or not), thereby adding to the lack of clarity. Through a critical

discourse-theoretical lens, a dominant discourse representing palliative care 'as a culture' was

identified, with the concepts of total care, compassion and openness as its nodal points. At the

same time three discursive tensions -i.e. struggle between meanings- could be observed: 1) the

centrality of death and dying vs its removal in defining palliative care, 2) conflicting

articulations of autonomy and 3) the debated role of a natural death.

Strengths and limitations

Empirical strengths of this study lie in the heterogeneity of our research sample and the

integration of a descriptive and a discourse-theoretical level of analysis. Rather than focusing

solely on palliative care field organizations, we turned our gaze to a diverse set of

organizations directly or indirectly involved in palliative care practice, advocacy or policy.

This allowed us to not only grasp a broad range of variations within the online information,

but also to get a better grip on the discursive points of instability.

A limitation of this study was that the data analysis was mostly done by one researcher (Marjolein Matthys). However, transparency, systematic collaboration with other researchers (including recurrent meetings to discuss interpretations) and reflexivity were active strategies during all stages of the research to safeguard the quality and scientific rigor of the study.

What this study adds

While our study focused on information in a specific spatiotemporal context (Flanders, Belgium and sources consulted in 2019-2020), we believe we can make a strong case for theoretical generalizability of our findings to other contexts. The palliative care discourse in Flanders is, as in many jurisdictions, closely entangled with the global 'hospice and palliative care discourse' that has its origins within the UK hospice movement and has now grown and been institutionalized on an international scale. Cicely Saunders was for instance frequently cited, reference was made to the hospice movement when describing the history of palliative care in Flanders and a translation of the WHO palliative care definition was often given. In that sense, the definitional variations and the underlying discursive tensions identified in this study, may be found in many other countries, albeit with their own local particularities. One local particularity in the case of Belgium is the relationship between palliative care and euthanasia. Since 2002 euthanasia has been legalized, together with a law on patient rights and a law to assure generalized access to palliative care (Bernheim & Raus, 2017, p. 490). From in the beginning palliative care played an important role in the debate leading up to the legalization of euthanasia (Gysels et al., 2012, p. 5) and in the Belgian context they are said to have developed side by side (Bernheim et al., 2008). Our results showed how end-of-life decision making in general was brought as an important element of palliative care and in many texts euthanasia specifically was presented as an option within palliative care. However the online information also showed that there are different discourses involved in this and

even though the internal differences between the palliative care discourse and the right-to-die discourse are not always as visible, at some points a conflictual load does becomes overt, nuancing the narrative of a perfect synergy between them.

In light of the described discrepancies and discursive tensions, the online information could definitely be a potential source of confusion for the public and at some points might even contribute to the stigma surrounding palliative care (for instance through the -at times unintended- association of palliative care with care at the very end of life or through the representation of "the palliative patient" in a passive position). As others have pointed out, the information then runs the risk of being an obstacle (rather than an aid) to the equitable and timely access and use of palliative care. An earlier study evaluating USA-based informational webpages on palliative care, for example, found that the majority of information pages are failing to adequately educate the general public and that efforts to improve the quality of the information are essential to stimulate palliative care uptake (Kozlov & Carpenter, 2015, p. 5). The relevance of this becomes even more clear if we take into consideration the projected increase of palliative care needs within the population (Etkind et al., 2017) and the shifts that occur within this widening population. For instance, under influence of novel therapeutic options the courses of numerous cancer trajectories have altered, leading to palliative care needs at different - earlier - stages of the illness in conjunction with oncological care (Ambroggi et al., 2018; Bruera & Hui, 2010). Adequate information on palliative care directed at a wide and diverse audience then plays an important role to stimulate timely access to palliative care for these shifting patient populations.

Our analysis of representations of palliative care in available public information was set up to identify underlying discourses and discursive tensions, but was also intended to provide insights to improve information to the public so that clarity can be enhanced and positive attitudes towards palliative care stimulated. One way through which clarity could be enhanced

is by offering concrete descriptions and avoiding vague or ambiguous statements. Particularly the wide use of constructs such as 'the last phase of life' or 'the end of life' is problematic, not because of the terms themselves but because of the apparent assumption that there is a clear and transparent meaning attached to them. Results of a recent survey of clinicians and members of the public show that the perceived length of the time frame connected to 'the end of life' is susceptible to large differences with almost half of the respondents visualizing it as the last hours or days before death (Cardona et al., 2019, p. 82). In this light, describing palliative care in relation to the last phase of life and simultaneously stating it is more than terminal care only adds to the confusion. We would argue that in terms of clarity, it is above all important that a link is made between the different 'storylines' of palliative care that circulate within the wide range of information available. The fact that palliative care is still presented as terminal care within the communication channels of some organizations makes it highly likely that people will also be confronted with this interpretation of palliative care in the way it is practiced. Clarity then could be improved if it is explained how palliative care evolved in a rather short amount of time from being directed solely at terminal care to a much wider approach of care and how this evolution has influenced palliative care practice and policy within particular local contexts.

Additionally, the existence of a central information point or expertise center carrying some level of knowledge authority on palliative care could help to give direction to organizations searching for ways to inform the public on palliative care. This however explicitly without neglecting the diversity of discourses; striving for one uniform message is neither possible nor desirable.

Another consideration has to do with the focus on 'quality of life' while eliminating a focus on 'a good death'. To break the association of palliative care with terminal care (as a synonym), notions such as 'saying farewell' and 'a dignified death' were sometimes

abandoned in favor for a focus on living well despite having an incurable disease. This finding is consistent with that of Pastrana et al. (2008) who stated that *"whereas the option of palliative care to patients more advanced in the disease trajectory is a great gain, the focus on death and dying should not be lost altogether with this development"*. This in itself could be interpreted as a form of death-denial, a quality that within the palliative care discourse was often subscribed to society at large, regardless of the extensive sociological critique that the concepts of death denial and the taboo of death have gotten (Kellehear, 1984; Tradii & Robert, 2017; Zimmermann & Rodin, 2004).

Connected to this, death itself is then mainly talked about in relation to end-of-life decision making and advanced care planning, strongly influenced by bioethical discourses of patient choice and informed consent. Here different articulations of autonomy are at play and our analysis showed how at some points this can result in a conflict of meaning. Even though the conflict itself is not per definition problematic, there should be a sensitivity to these different articulations of autonomy and the existence of competing discourses surrounding this. Explicit statements that autonomous decisions are to take the social environment into consideration carry the risk of unintentionally polarizing the debate while creating the idea that palliative care neglects the self-determination of individuals. This could then potentially alienate people who strongly identify with discourses such as the right-to-die discourse, definitely in light of the 'weight' these discourses have within the public realm. Previous discourse-theoretical research for instance showed that articulations from within the right-to-die discourse were privileged in analyzed news articles to the disadvantage of the palliative care discourse (Van Brussel & Carpentier, 2012).

Another consideration that emerges from our findings is that, while composing these texts to inform the public about palliative care, one should guard to not limit the agency and diversity of the audiences of the texts. The palliative care discourse for instance stays silent on

people who do not have a social network and it is hard to imagine how people who are alone could feel addressed by a discourse that has such a heavy emphasis on social relationships through which illness, care and quality of life are defined. It can further be argued that the way the "palliative patient" was discursively positioned as being in the last stage of life and on the negative side of the dualism curable/incurable, limits alternative possibilities with which the person can identify with; as someone who is not per definition robbed of a future, can still go through several life stages and enjoy life. Additionally, most patients confronted with the end of life feel a pressing need for recognition as a person, and not as a patient (Drillaud et al., 2020). The widely used term "palliative patient" as such might not be as innocent and replacing it by "a person with palliative care needs" could be a valuable suggestion. Thus, without having the need to romanticize how it is to be confronted with an incurable disease and the end-of-life, texts like these should nonetheless denote the wide range of possibilities in the way that having an incurable illness is experienced and given meaning to. Failing to do this can unintentionally contribute to the stigmatization of palliative care which has been shown to be detrimental to its utilization (Shen & Wellman, 2020). Research can as well play an important role in this, for instance by shedding light on the multiple subjectivities that get generated in the course of serious advanced illness as did Mohammed et al. (2016) who focused on persons with advanced cancer seeking life extension through bio-medical treatments, or, by exploring participant's experiences of palliative care in relation to their understandings of illness and the end of life and the way experiences of self are involved, as did MacArtney et al. (2015).

An important recommendation for further research is the investigation of the audience reception of the online information; how are these texts evaluated and how are the discourses embedded within them recognized, drawn upon, reproduced, negotiated and/or resisted by members of the general population?

Conclusion

This study showed that if we want to employ the information as a vehicle to battle the lack of clarity and stigmatization of palliative care, more is needed than offering a particular consistent definition, we also need to think about the way we want to address people through these wider systems-of-meaning. In any case, the public has to be involved as a partner in this since the way they receive information is not a matter of passive consumption but in itself an active and dynamic process of meaning attribution.

REFERENCES

Algemeen Ziekenhuis Sint-Lucas Gent. (2017, September 4). *Een zorgzaam euthanasiebeleid* [A caring euthanasia policy]. Retrieved January 22, 2020, from https://www.azstlucas.be/euthanasie

Algemeen Ziekenhuis Sint-Lucas Gent. (2018, July). *Palliatieve zorg* [Palliative Care]. Retrieved January 22, 2020, from https://www.azstlucas.be/specialismen/palliatieve-zorg

Ambroggi, M., Biasini, C., Toscani, I., Orlandi, E., Berte, R., Mazzari, M., & Cavanna, L. (2018). Can early palliative care with anticancer treatment improve overall survival and patient-related outcomes in advanced lung cancer patients? A review of the literature. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 26(9), 2945–2953. https://doi.org/10.1007/s00520-018-4184-3

Benini, F., Fabris, M., Pace, D.S., Vernò, V., Negro, V., De Conno, F., Orzalesi, M.M. (2011). Awareness, understanding and attitudes of Italians regarding palliative care. *Annali Dell'Istituto Superiore Di Sanita* 47(3), 253–259. https://doi.org/10.4415/ANN_11_03_03

Bernheim, J. L., Deschepper, R., Distelmans, W., Mullie, A., Bilsen, J., & Deliens, L. (2008). Development of palliative care and legalisation of euthanasia: antagonism or synergy?. *BMJ (Clinical research ed.)*, 336(7649), 864–867. https://doi.org/10.1136/bmj.39497.397257.AD

Bernheim, J. L., & Raus, K. (2017). Euthanasia embedded in palliative care. Responses to essentialistic criticisms of the Belgian model of integral end-of-life care. *Journal of medical ethics*, 43(8), 489–494. https://doi.org/10.1136/medethics-2016-103511

Bruera, E., & Hui, D. (2010). Integrating supportive and palliative care in the trajectory of cancer: establishing goals and models of care. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*, 28(25), 4013–4017. https://doi.org/10.1200/JCO.2010.29.5618

Bryman, A. (2016). *Social research methods* (5th ed.). Oxford University Press.

Cardona, M., Lewis, E., Shanmugam, S., Nicholson, M., Williamson, M., Hanly, L., Hillman, K. (2019). Dissonance on perceptions of end-of-life needs between health-care providers and members of the public: Quantitative cross-sectional surveys. *Australasian Journal on Ageing*, *38*(3), e75–e84. https://doi.org/10.1111/ajag.12630

Carios. (n.d.). *Palliatieve begeleiding* [Palliative support]. Retrieved December 11, 2019, from http://www.carios.be/nl/gespecialiseerde-thuisverpleging/palliatieve-begeleiding/7/

Carpentier, N. (2010). Deploying Discourse Theory. An introduction to Discourse Theory and Discourse Theoretical Analysis. In N. Carpentier, I. T. Trivundza, P. Pruulmann-Vengerfeldt, E. Sundin, T. Olsson, R. Kilborn, H. Nieminen, B. Cammaerts (Eds.), *Media and Communication Studies Intersections and Interventions. The intellectual work of ECREA's 2010 European media and communication doctoral summer school* (pp. 251-265). Tartu University Press.

Champlin, S., Mackert, M., Glowacki, E. M., & Donovan, E. E. (2017). Toward a better understanding of patient health literacy: a focus on the skills patients need to find health information. *Qualitative Health Research*, 27(8), 1160–1176. https://doi.org/10.1177/1049732316646355

Cheng, B.T., & Hauser, J.M. (2019). Adult palliative care in the USA: Information-seeking behaviour patterns. *BMJ Supportive and Palliative Care*, 1–5. https://doi.org/10.1136/bmjspcare-2019-001928

Claudio, C.H., Dizon, Z.B., October, T.W. (2018). Evaluating palliative care resources available to the public using the internet and social media. *American Journal of Hospice and Palliative Medicine*, *35*(9), 1174–1180. https://doi.org/10.1177/1049909118763800

Coda. (n.d.). *Uw verzorging is onze zorg* [Your care is our concern]. Retrieved February 12, 2020,

from http://www.coda.care/about/

Cohen, J., Smets, T., Pardon, K., Deliens, L. 2014. *Palliatieve zorg, meer dan stervensbegeleiding : nood aan integratie en verbreding.* Uitgeverij Lannoo nv.

Collins, A., McLachlan, S.A., Philip, J. (2017). Initial perceptions of palliative care: An exploratory qualitative study of patients with advanced cancer and their family caregivers. *Palliative Medicine*, *31*(9), 825–832. https://doi.org/10.1177/0269216317696420

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Sage Publications.

Cotten, S. R., & Gupta, S. S. (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Social Science and Medicine*, *59*(9), 1795–1806. https://doi.org/10.1016/j.socscimed.2004.02.020

Davies, B. (1991). The concept of agency: a feminist poststructuralist analysis. *Social Analysis: The International Journal of Social and Cultural Practice*, 30, 42-53.

Dienst Welzijn en Gezondheid Provinciebestuur Antwerpen, & Netwerken Palliatieve Zorg Antwerpen. (2013). *Niet alleen: als je niet meer kunt genezen* [Not alone: when you can't get better] [Brochure]. Drukkerij A. Beullens. http://www.palliatief-netwerk-mechelen.be/files/niet-alleen-binnenwerk-definitief-24-7.pdf

Drillaud, F., Saussac, C., Keusch, F., Lafaye, D., Bely, H., Averous, V., Frasca, M., Baudry, P., Burucoa, B. (2020). The existential dimension of palliative care: the mirror effect of death on life. *Omega (United States).* https://doi.org/10.1177/0030222820952187

Dunn, K., & Neumann, I. (2016). *Undertaking discourse analysis for social research*. University of Michigan Press.

Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*, 15(1), 102. https://doi.org/10.1186/s12916-017-0860-2

Federale Overheidsdienst Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu. (2016, January 1). *Structuren voor palliatieve zorg* [Structures for palliative care]. Retrieved February 5, 2020, from https://www.health.belgium.be/nl/gezondheid/zorg-voor-jezelf/patiententhemas/grensoverschrijdende-gezondheidszorg/normen-tav-0

Federatie Palliatieve Zorg Vlaanderen. (2010, November). *Balans in evenwicht: praktische tips voor familieleden van een palliatieve persoon* [Balance in equilibrium: practical tips for relatives of a palliative person]. http://files.palliatieve.org/download/222/brochure_balans_in_evenwicht_2010_v13_definitief.pdf

Fédération Bruxelloise des Soins Palliatifs et Continus, Fédération Wallonne des Soins Palliatifs, Federatie Palliatieve Zorg Vlaanderen. (2020, March). *3 maart 2020: start van nationale sensibiliseringscampagne "Zorg en zoveel meer"* [March 3rd 2020: start of national sensibilisation campaign "Care and so much more"] [Press Release]. https://www.zorgenzoveelmeer.be/wordpress/wp-content/uploads//2020/02/Persbericht_Zorg_en_zoveel_meer_2.pdf

Foucault, M. (1972). *The archaeology of knowledge & the discourse on language*. Pantheon Books.

Gómez-Batiste, X., Martínez-Muñoz, M., Blay, C., Amblàs, J., Vila, L., Costa, X., Espaulella, J., Espinosa, J., Constante, C., & Mitchell, G. K. (2014). Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: A cross-sectional study. *Palliative Medicine*, 28(4), 302–311. https://doi.org/10.1177/0269216313518266

Gott, M., Seymour, J., Ingleton, C., Gardiner, C., Bellamy, G. (2012). "That's part of everybody's job": The perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care. *Palliative Medicine*, 26(3), 232–241. https://doi.org/10.1177/0269216311408993

Huisman, M., Joye, S., Biltereyst, D. (2019). Searching for health: doctor Google and the shifting dynamics of the middle-aged and older adult patient – physician relationship and interaction. *Journal of Aging and Health*, 32(9), 998-1007. https://doi.org/10.1177/0898264319873809

Huo, J., Hong, Y.R., Grewal, R., Yadav, S., Heller, I.W., Bian, J., Wilkie, D.J. (2019). Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey. *Journal of pain and symptom management*, *58*(1), 39–47.e3. https://doi.org/10.1016/j.jpainsymman.2019.03.014

Huysmans, G., & Vanden Berghe P. (2014, February). Visienota Palliatieve Zorg 2020 [Vision statement palliative care 2020]. Federatie Palliatieve Zorg Vlaanderen.

Jacobs, T. (2019). The dislocated universe of Laclau and Mouffe: an introduction to post-structuralist discourse theory. *Critical Review*, *30*(3–4), 294–315. https://doi.org/10.1080/08913811.2018.1565731

Jørgensen, M., & Phillips, L. (2012). *Discourse analysis as theory and method.* Sage.

Kellehear, A. (1984). Are we a "death-denying" society? A sociological review. *Social Science and Medicine*, *18*(9), 713–721. https://doi.org/10.1016/0277-9536(84)90094-7

Kozlov, E., & Carpenter, B.D. (2015). "What is palliative care?": variability in content of palliative care informational web pages. *American Journal of Hospice and Palliative Medicine*, *34*(3), 241–247. https://doi.org/10.1177/1049909115615566

Laclau, E., & Mouffe, C. (1985). *Hegemony and socialist strategy: towards a radical democratic politics.* Verso.

Levenseinde Informatieforum. (n.d.). *Palliatieve zorg is supportieve zorg* [Palliative care is supportive care]. Retrieved June 30, 2020, from https://leif.be/vragen-antwoorden/supportieve-zorg/

MacArtney, J. I., Broom, A., Kirby, E., Good, P., & Wootton, J. (2017). The liminal and the parallax: living and dying at the end of life. *Qualitative Health Research*, 27(5), 623–633. https://doi.org/10.1177/1049732315618938

Mohammed, S., Peter, E., Gastaldo, D., & Howell, D. (2016). The "conflicted dying": the active search for life extension in advanced cancer through biomedical treatment. *Qualitative Health Research*, 26(4), 555–567. https://doi.org/10.1177/1049732315572772

Morin, L., Aubry, R., Frova, L., MacLeod, R., Wilson, D. M., Loucka, M., Csikos, A., Ruiz-Ramos, M., Cardenas-Turanzas, M., Rhee, Y., Teno, J., Öhlén, J., Deliens, L., Houttekier, D., & Cohen, J. (2017). Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliative Medicine*, 31(6), 526–536. https://doi.org/10.1177/0269216316671280

Netwerk Levenseinde. (n.d.). *Onze visie* [Our vision]. Retrieved March 27, 2020, from http://www.netwerklevenseinde.be/index.php/visie

Netwerken Palliatieve Zorg Oost-Vlaanderen. (n.d.). *Beslissingen bij het levenseinde* [Decisions at the end-of-life]. Retrieved February 12, 2020, from http://www.palliatieve.org/patient-familie/beslissingen-bij-het-levenseinde

Netwerk Palliatieve Zorg De Mantel. (n.d.). *Wat is palliatieve zorg?* [What is palliative care?]. Retrieved January 22, 2020, from https://www.demantel.net/content/wat-is-palliatieve-zorg

Okra vzw. (n.d.) *Denk aan later, spreek over later* [Think about later, Talk about later] [Brochure]. https://www.cm.be/media/denk-aan-later_tcm47-13295.pdf

Palliatieve Hulpverlening Antwerpen. (n.d.). *Wanneer start palliatieve zorg?* [When does palliative care start?]. Retrieved March 2, 2020, from https://pha.be/site/site.asp?id=21&lv=2

Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F., Radbruch, L. (2008). A matter of definition-key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*, 22(3), 222–232.

Shalev, A., Phongtankuel, V., Kozlov, E., Shen, M.J., Adelman, R.D., Reid, M.C. (2018). Awareness and misperceptions of hospice and palliative care: a population-based survey study. *American Journal of Hospice and Palliative Medicine*, 35(3), 431–439. https://doi.org/10.1177/1049909117715215

Shen, M. J., & Wellman, J. D. (2019). Evidence of palliative care stigma: The role of negative stereotypes in preventing willingness to use palliative care. *Palliative & Supportive Care*, 17(4), 374–380. https://doi.org/10.1017/S1478951518000834.Evidence

Shepherd, L.J. (2008). *Gender, violence & security: discourse as practice*. Zed Books.

Taber, J.M., Ellis, E.M., Reblin, M., Ellington, L., Ferrer, R.A. (2019). Knowledge of and beliefs about palliative care in a nationally-representative U.S. Sample. *PLoS One,* 14(8), e0219074. https://doi.org/10.1371/journal.pone.0219074

Thuisverpleging De Lelie. (n.d.). *Een greep uit ons zorgaanbod* [A selection of our care services]. Retrieved from https://web.archive.org/web/20200811120912/https://thuisverpleging-delelie.be/ons-zorgaanbod

Torfing, J. (1999). *New theories of discourse: Laclau, Mouffe and Žižek*. Blackwell Publishers.

Tradii, L., & Robert, M. (2017). Do we deny death? II. Critiques of the death-denial thesis. *Mortality* 24(4), 377-388. https://doi.org/10.1080/13576275.2017.1415319

Van Brussel, L., & Carpentier, N. (2012). The discursive construction of the good death and the dying person: a discourse-theoretical analysis of Belgian newspaper articles on medical end-of-life decision making. *Journal of Language and Politics*, 11 (4), 479–499. https://doi.org/10.1075/jlp.11.4.01van

Van Brussel L., & Carpentier N. (2017) Closing the Book of Life: The Hospice Discourse and the Construction of the Dying Role: A Discourse-Theoretical Analysis. In: Parvaresh V., Capone A. (eds) *The Pragmeme of Accommodation: The Case of Interaction around the Event of Death*. Perspectives in Pragmatics, Philosophy & Psychology, (vol 13, pp. 375-401). Springer, Cham. https://doi.org/10.1007/978-3-319-55759-5_19

Vater, L.B., Rebesco, G., Schenker, Y., Torke, A.M., Gramelspacher, G. (2018). Palliative care content on cancer center websites. *Supportive Care in Cancer*, 26(3), 1005–1011. https://doi.org/10.1007/s00520-017-3922-2

Westerlund, C., Tishelman, C., Benkel, I., Fürst, C.J., Molander, U., Rasmussen, B.H., Sauter, S., Lindqvist, O. (2018). Public awareness of palliative care in Sweden. *Scandinavian Journal of Public Health*, 46(4), 478–487. https://doi.org/10.1177/1403494817751329

Ziekenhuis Oost-Limburg campus Maas en Kempen. (n.d.). *Vroegtijdige zorgplanning, een benadering van het levenseinde* [Advance care planning, an approach to the end-of-life]. Retrieved April 3, 2020, from https://www.zmk.be/index/deelsites/etisch_comite/vroegtijdige_zorgplanning.html

Zimmermann, C., & Rodin, G. (2004). The denial of death thesis: Sociological critique and implications for palliative care. *Palliative Medicine*, 18(2), 121–128. https://doi.org/10.1191/0269216304pm858oa

Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., Tannock, I.,

Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, *188*(10), E217–E227. https://doi.org/10.1503/cmaj.151171