Palliative Care in the Public Eye:

Insights & Strategies to Enhance Understanding & Engagement

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**Both authors contributed equally to this work*

A word of gratitude…

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Chapter I

General introduction

1. Background

Noncommunicable diseases such as cancer, diabetes, cardiovascular and chronic respiratory diseases are the leading global cause of death[1] and, tied to strong increases in life expectancy and population growth, increasing in most countries[2]. Consequently, the global burden of serious health-related suffering is projected to nearly double by 2060[3]. As more and more people experience prolonged periods of physical, psychological and cognitive decline, there is a growing demand for comprehensive care that goes beyond merely managing the disease, including a focus on diverse, multifaceted needs and supporting (family) caregivers[4]. Palliative care has become a crucial part of this comprehensive care, as reflected in the public health strategy for palliative care of the World Health Organization (WHO)[5] and its articulation and recognition of palliative care as a human right[6]. In Box 1 the most widely recognized official definition of palliative care[7,8], issued by the WHO in 2002, is given. However, despite what any singular definition might suggest, to understand what palliative care is (and what it might mean for the general public), a brief look at its history, evolutions and ongoing debates is warranted.

Box 1 .

Palliative care according to the WHO[9]

Palliative care is an approach that improves the quality of life of patients – adults and children – and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during a patient’s illness and their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

1.1. Palliative care: origins and evolutions

The origins of palliative care are mostly attributed to the pioneering work of Cicely Saunders who founded the first modern hospice in 1967 in the UK[6,10]. Yet, the defining ideas and strategies that led to the opening of this hospice had already been developing for over a decade, originating the international hospice movement[11]. This movement emerged as a critical response to the perceived neglect of dying people by the dominant biomedical model of health care during the post-war period[12]. Medical technology and therapeutic possibilities had evolved drastically, causing the experience and meaning of dying to lose its social embeddedness in daily life and become primarily a physiological and highly technological event[13,14]. By the late 1950s, dying of cancer in particular symbolized a modern, medicalized death shaped by the heroic struggles of science against illness[11]. A new way to care for the dying, based on holistic care, comfort, compassion and understanding was strived for and put into practice in St. Christopher's hospice, serving as a source of inspiration around the world[15]. Even though in origin the hospice movement and St. Christopher's hospice were fueled by a commitment to religious principles, it gradually and pragmatically moved away from being framed as a religious community, facilitating a strengthening of its professional efforts around terminal cancer care[11].

From this hospice movement, the practice of palliative care[i] as we know it today has grown and to some extent it continues as a critique of highly medicalized care practices surrounding serious advanced, incurable illness[16]. Yet, much has also changed. Firstly, palliative care gradually evolved to a broader care approach applicable much earlier in a disease trajectory and in combination with curative or disease-modifying treatment from the time of diagnosis[17,18]. Secondly, while palliative care was initially mainly focused on patients with cancer, it is now being integrated into treatment of all life-threatening health conditions[19]. Thirdly, pioneered by the WHO in 1990, a public health strategy of palliative care was developed and promoted[5], which greatly impacted palliative care provision on a global scale. This strategy urged countries to develop proper palliative care policies, adopt minimum standards for pain relief and ensure adequate drug availability, provide training and education to health professionals, promote public awareness and implement palliative care services at all societal levels[5,20]. In a parallel movement, palliative care also became increasingly articulated as a fundamental human right[20]. Framed as a human right and a public health concern, efforts of international palliative care alliances alongside global organizations such as the WHO[21], led to an increasing number of

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[i] The term 'palliative care' comes from Balfour Mount who established a hospice service in Montreal around 1973, modelled after St. Christopher's hospice. He named it 'palliative care' over 'hospice' to distance it from nursing homes for the destitute, as the latter term was understood in French-speaking contexts, and later 'palliative care' became the preferred term worldwide for programs that were based on the hospice philosophy[36]. This new term helped to avoid the associations commonly linked with 'hospice' at the time, such as charity, religion, and 'homes for the dying[44].

countries that now have national palliative care policy recognition. However, despite these emerging narratives of global palliative care[22], palliative care provision is still mostly confined to high-income countries and far from universal[23].

Additionally, as palliative care evolved from being a 'rebellious' countermovement to being gradually integrated into mainstream health care systems[24], it was argued to increasingly operate from within clinical and institutional paradigms of care, echoing the medical emphasis on the importance of direct clinical interventions[25]. A fourth evolution within the international landscape of palliative is therefore connected to a resistance against the so-called bureaucratization, routinization and medicalization of mainstreamed palliative care practices[16]. Critics argue that, as a consequence, palliative care progressively abandoned the social context of dying while simultaneously de-emphasizing psychological, social and spiritual care over physical care[14]. Under the name of 'health promoting palliative care', a renewed interest in underdeveloped holistic and social aspects of conventional palliative care developed[22]. Gradually, this grew into a field now predominantly known as 'public health palliative care', with several international networks and research projects dedicated to its further development[26]. Starting from the recognition that serious illness, the end of life, loss, grief and caregiving are contextual social experiences that affect everyone, the core emphasis within this field is on the strengthening of social networks around people with serious illness through partnerships with local communities and civic sectors[27]. This includes active strategies to influence policy and preventive efforts to empower people and communities to address concerns related to serious illness and end-of-life issues in the future.

1.2. Palliative care in Belgium

In the beginning of the 1980s efforts were made to introduce and organize the hospice movement in Belgium and in 1985 the first specialized home care service was initiated[28,29]. Also here the dehumanization of medicine was the steering reason for the development of palliative care and from its inception onwards, the goal was to integrate palliative care into the general health care system[28]. Yet, during these initial years, the first autonomously developed specialist palliative care services were still isolated from the rest of the health care system in the absence of policy organization[30]. In the 1990s, this changed when palliative care got enshrined in Belgian legislation and a strong structural framework was set up[30,31]. Palliative care has grown substantially since then and a diverse set of specialist structures and services spread over different settings of care can now be found[32]. In addition, aside from specialist services, 'generalist palliative care' is provided by professional caregivers such as general practitioners, employees of residential care facilities, and regular hospital specialists and nurses[33]. Palliative care networks, divided over different regions (25 in total of which 15 in Flanders), are responsible for the coordination and support of palliative care provision in their specific region. Additionally, Belgium has three federations of palliative care which together represent all the organizations and institutions involved in palliative care[33].

The legislation around palliative care further advanced in 2002 when, in one legislative move, a law to assure generalized access to palliative care, a law on patients rights and a law on euthanasia were passed[34]. In 2016 the legal definition of palliative care was changed to better reflect the broader articulation put forward by the WHO. However, the actual translation into new policies and new forms of practices has not been as straightforward as can for instance be seen in the fact that (most of) the financial support available for people with palliative care needs is still dependent on having a limited life-expectancy. Important changes are however forthcoming, with the Flemish government -in collaboration with diverse stakeholders from the field- having initiated a broad reform of the current palliative care landscape. Central elements within this reform are improving patient-centered care, public awareness and accessibility, timely initiation and care continuity[35].

1.3. Defining palliative care today

As described above, since its origins palliative care moved from institutional end-stage care for terminal cancer patients to a timely, community- and population-based care approach[6]. However, a clear challenge remains in sharply divergent views and continuous debates about the definition, scope and meaning of palliative care[36–38], with tensions found across global and local contexts. Over two decades ago, Cairns already wrote that *"no other area of health care seems to have gone to such lengths to write definitions of itself as has palliative care"*[37(p187)] and this continues to this day. Although the 2002 official palliative care definition from the WHO (see Box 1 on page 6) is most frequently referenced[8,39], this definition is also often criticized for being too vague[40] or too limiting in terms of patient populations[41], and not adequate for low- and middle-income settings with limited resources[7]. Several attempts to improve this definition or formulate new ones have been made but consensus so far has not been reached, resulting in a rather large number of circulating definitions[7].

While across sources, relief and prevention of suffering and the improvement of quality of life are described as the main goals of palliative care[38], confusion and debates remain about several other fundamental concepts and practical aspects. One of the largest and most fiercely debated aspects, for instance, concerns the relationship between palliative care and medical assistance in dying, with perspectives - and practices - ranging from normative opposition to viewing them as integrative and synergistic[42]. In addition, the association between the fields of palliative care, on the one hand, and public health and health promotion, on the other, has not gone undebated. In the literature many different articulations and interpretations of this association are found, with 'public health' and 'health promotion' frequently being used interchangeably and often with little definitional foregrounding[43]. From there the association has been argued to be actively constructed to achieve specific objectives, particularly to enhance policy positions of palliative care, resulting in an asymmetrical relationship where palliative care needs public health (or health promotion) more than the reverse[43]. Critique has also been expressed at the mere endeavor of searching for one universal definition, privileging a particular perspective on the practice and future of palliative care over the vast diversity between and within countries in terms of past and present local problems and issues relating to care for serious advanced illness and the end of life[22,44]. Moreover, these ongoing debates and negotiations about its meaning are not just discussions about definitions and different opinions about the practicalities of care delivery; they also reflect the fundamental ideological nature of palliative care which at its core is driven by moral principles and concepts[16]. Even the WHO definition of palliative care can be argued to carry not simply the function to descriptively state what palliative care is about, but rather to fulfil a normative function in stating the way things ought to be, i.e. a statement about how health care professionals ought to care for people whose illness is incurable and progressive to the point of death[45]. This illustrates how palliative care as a practice is actively and dynamically (re)produced out of the negotiation of divergent philosophical, theoretical and moral views embedded in particular sociohistorical and cultural contexts. Inevitably, gaining insight into public perceptions of palliative care also requires an analytical orientation towards this broader context and complex interactions within.

1.4. Public perceptions of palliative care: what does the international literature tell us?

In general, international research has shown that within the various local contexts being studied, the knowledge of palliative care among the general public tends to be low and negative beliefs and misperceptions persist[46–54]. Studies focusing on the views of health care practitioners, patients and 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 described to function as a potential barrier[51,55,56]. For instance, a study on the perceptions of palliative care among patients with advanced cancer and their caregivers[57] showed how palliative care carried a negative stigma associated with death and with care at the very end of life, provoking fear and avoidance. Furthermore, this was enforced through interactions with health care professionals who had presented palliative care to patients “as an option of last resort”, as an alternative to further treatment or had delayed it since “they were not there yet”[57]. Personal experiences involving friends, family or acquaintances needing palliative care, in this sense, potentially not only shape awareness of palliative care, but also introduce or reinforce misconceptions[49]. The existence of a stigma surrounding the term palliative care was also pointed out in a study on the implementation of primary palliative care in five Belgian regions which reported a resistance to use the word ‘palliative care’, fearing it would provoke distress in patients and would distract them from the intended focus on their care[58].

A somewhat more encouraging observation within the international literature revolves around increasing levels of awareness of palliative care. For instance, results from a comparative study using internet search query surveillance reported a significant increase in the relative popularity of the internet search-term ‘palliative care’ in the USA, interpreted as a rise in public awareness of palliative care[59]. A study focusing similarly on Google search activity on palliative care in Austria, Germany, and Switzerland demonstrated likewise an increasing interest and connected this to the simultaneous realization of palliative care services, laws and policies to promote palliative care[60]. Survey studies in The Netherlands[61] and the UK[62] reported high levels of awareness of palliative care among the general public as well. Nonetheless, these and other studies also show that despite having more public awareness of palliative care, misperceptions and differences between self-proclaimed levels of knowledge and actual knowledge persist[49,63–65].

Differences between social groups have also been reported. Most commonly observed sociodemographic characteristics associated with higher levels of knowledge and/or awareness of palliative care in the general public are: being a woman, of older age (40+), having a higher educational background, experience with a close friend and/or relative requiring palliative care and lastly, working in health-care and/or palliative care[54]. However, the existing research on this is rather limited and inconclusive[66]. Gender for instance has frequently been reported as an important factor with men having less knowledge of palliative care[48,49,67] while other studies failed to find a significant effect of gender[51,68,69] or only within certain subpopulations[70].

From these research observations and from practice experiences, the need for public health initiatives to raise awareness and improve knowledge of palliative care has been extensively argued[48,50,71]. Besides being a serious obstacle to the timely access and uptake of palliative care[55], limited understandings and negative beliefs have been identified as an important barrier to the further development of palliative care across the Western European region[72] and on a global scale[73]. As argued by Alcalde and Zimmerman, societal recognition of palliative care is a necessary condition to build enough political pressure to create better palliative care policies and structures[74]. Additionally, public awareness and knowledge on palliative care are needed to stimulate the development and uptake of new public health initiatives in palliative care, aiming to involve the wider community in the care and support for people confronted with illness or loss[62].

1.5. Public information, communication and education regarding palliative care

Research has shown that people with better understanding of the contemporary palliative care approach show greater receptivity and less negative emotions towards palliative care[65,75]. Public information, communication and education about palliative care thus play a crucial role in achieving these better understandings.

In general, people actively as well as passively 'consume' health information across a wide array of sources going from traditional, more easily accessible sources to high tech, new media sources[76]. However, with the emergence of health literacy in various policy agendas[77], and related, the changing role of the patient who has become more engaged, in charge and accepting higher levels of responsibility in his or her own care[78], more and more people are expected to actively search for health information[79]. The question on the nature and quality of this information is thus essential. In the field of palliative care, research on this is limited but studies that have been done unfortunately show that the publicly available information and communication leaves much to be desired. For instance, a discourse-analytical study of mission statements of Australian palliative care services demonstrated there was little consistency between the statements and the use of exclusive language made the statements less understandable for the public[80]. Previous studies on online sources, all conducted in the USA, furthermore reported cancer center homepages that rarely even mention palliative care services[81], and a considerable variability in content coverage between palliative care information pages as well as the absence of vital information[82]. Conversely, a descriptive study that compared the most popular websites on palliative care found through Google reported consistent definitions of palliative care (with several of the 13 websites linking back to the same source), while required reading levels were too high making the information not accessible to a wide audience[83].

Studies focusing on traditional communication channels are likewise sparse but show the need to improve coverage. Studies on news coverage in written media in Spain between 2009 and 2014 for instance demonstrated an ongoing presence of palliative care in the media, but this was mainly connected to socio-political debates concerning how to address end of life care, rather than accurately reflecting the nature, practice and contributions of palliative care[84]. Messages on palliative care were entangled in ideological debates, controversies and political and religious meanings unrelated to its definition[85]. A study on the portrayal of palliative care in the Australian print media, occurring in the context of debate surrounding the Victorian Voluntary Assisted Dying legislation, also showed that palliative care was frequently discussed but not with a focus on its potential benefits and the exposure rather seemed to contribute to negative public views and misconceptions[86]. Even though similar studies have not been done in Belgium, a quantitative content analysis of the Belgian (Dutch language) media coverage of medical end-of-life decision-making showed that media sources tended to overreport on euthanasia at the expense of the wide spectrum of possible palliative care decisions[87]. A discourse-theoretical study on the print media coverage of three euthanasia cases in the year 2008 further demonstrated how articulations from within the right-to-die discourse were clearly privileged over the palliative care discourse which was either silenced or explicitly discredited[88].

Next to the daily communication and dissemination of information of palliative care, public awareness and education on palliative care can also be achieved through the development and implementation of educational interventions. Previous studies have shown that palliative care education programs are effective in improving knowledge, attitudes and confidence in palliative care, but these are mostly directed at health care professionals[89]. In addition, research among patients has shown that improving knowledge of palliative care positively influences the intention to enroll oneself or a family member in palliative care should the need arise[90,91], and that it can stimulate patients to engage in timely conversations about palliative care with health care providers[92]. However, scientific attention to the development, implementation and evaluation of strategies and initiatives to positively influence public perceptions of palliative care is limited[93–95].

Public awareness campaigns, understood as organized communication activities designed to raise awareness, induce behavior change, and improve quality outcomes for individuals and populations[96,97], have been one instrument implemented by palliative care policy, practice and/or advocacy organizations[96]. It has been suggested that these campaigns, which include broad multimedia campaigns but are not limited to them, among others can improve the visibility of palliative care within the public domain, as a vital factor for public understanding and engagement towards palliative care[98]. However, most public campaigns surrounding palliative care focus on normalizing death and dying, and broad educational campaigns or interventions focusing on the relevance and benefits of early integration of palliative care have been rather limited[65]. Moreover, although sound research is recognized as essential for developing effective interventions[99], it is often unclear how public palliative care campaigns have been developed and whether researchers, research findings, and evidence-based change methods have been involved. While in some cases it might be that research efforts and techniques were part of the development process and it is more a matter of underreporting (definitely within the international scientific literature[94]), in most cases it is more likely that research was sidelined or omitted, coinciding with a lack of evaluative activities demonstrating effectiveness[96].

There are a few international exceptions, including an interdisciplinary and creative design strategy which was co-creatively developed with students in a local university context[95], as well as a multi-faceted community intervention in Japan[100]. While not all intervention elements of the Japanese intervention proved to be successful, providing palliative care information via flyers, booklets, posters, as well as lectures in the community was effective in improving palliative care perceptions[100]. Another promising concept, developed through international collaboration and regularly adapted to the current state of knowledge, is called ‘Last Aid Courses’[93,101]. These short courses (4 hours max) are directed at school pupils as well as the general public, and organized around four different modules (care at the end of life; advance care planning and decision making; symptom management; and cultural aspects of death and bereavement)[93]. While the global delivery of Last Aid courses is growing rapidly[102], detailed research on its implementation and effectiveness is however still underway in various countries[101]. Currently, it remains for instance unclear which people are being reached by this initiative and if this aligns with those who might need it the most.

1.6. Knowledge gaps this dissertation seeks to address

In contrast to the growing amount of international research on public perceptions of palliative care, research on this in Belgium is absent and therefore highly warranted for palliative care practice, policy and advocacy organizations to be able to estimate the need and direction of future educational interventions. Furthermore, the existing research base often fails to gain a deeper understanding of the wider personal and sociocultural contexts in which perceptions of palliative care are embedded. In addition, there is a need for more scientific attention to public communication on palliative care in its various forms and the deeper contextually bound processes of meaning attribution and negotiation involved. For instance, observing potential inconsistencies between the publicly available information on palliative care is important, but it is also not enough to fully understand in what direction this information might be improved. Like any text, informational texts activate certain discourses, which are interpreted by meaning-making audiences[103]. Gaining insight into these deeper systems-of-meaning and the way they are interpreted and responded to by diverse audiences, can provide opportunities to improve public communication and education on palliative care in a direction that might not only reach a wider audience but also have a more profound and positive impact on them. Currently, there is a clear lack of evidence-based strategies and initiatives aimed at enhancing public knowledge, receptivity, and engagement with palliative care. Overall, this project is designed to address this shortfall.

2. Dissertation aims and objectives

The project described in this dissertation was driven by two main research aims:

Research aim 1: to gain a deeper understanding of public perceptions of palliative care within the sociocultural context of Flanders.

Specific objectives to reach this aim were:

<u>Objective 1:</u> To examine the public knowledge of palliative care and its different aspects, and assess which personal characteristics and experiences are associated with better palliative care knowledge (Chapter two).

<u>Objective 2:</u> To explore patterns of shared meaning across personal narratives surrounding experiences with palliative care, serious illness, and the end of life (Chapter three).

<u>Objective 3:</u> To examine representations of palliative care within the online information spread by palliative care policy, advocacy and practice organizations in Flanders, to detect elements of congruence, ambivalence and tension within and between these representations and to identify and interpret the discourses at play (Chapter four).

<u>Objective 4:</u> To investigate how members of the general public interpret, evaluate and engage with public awareness campaigns on palliative care (Chapter five).

Research aim 2: to co-creatively design a broad public campaign strategy to tackle unknown, misunderstood and stigmatized aspects of palliative care in Flanders (Chapter six).

3. Methodological approach

To achieve our research aims and objectives, five different studies were conducted. Each of these studies strived to achieve different objectives and can be considered as a separate study. Research aim one is obtained by integrating the findings of the first four studies, while research aim two is achieved through the development of a campaign strategy that further builds on these integrated findings. Overall, our approach brings together multiple methodologies, predominantly interpretative qualitative research, and is driven by social constructionist ontology and epistemology.

Social constructionism, tied to postmodernism and poststructuralism[104], argues that the human world is not as simple and obvious as it seems but rather is continuously, dynamically and actively being constructed through social interactions[105]. It emphasizes how meanings attributed to phenomena arise from social processes and contexts rather than being intrinsic to the phenomena[106]. Similarly, human subjects are viewed as being constituted in and through discourses and social practices which all have complex histories[104]. There are many different traditions within social constructionism, making some rather speak of constructionisms, but they all nonetheless share some general characteristics (i.e., fundamental theoretical principles) and functions (i.e., what constructionism offers following these characteristics)[105] which are shown in Table 2.

Table 2.

General characteristics and functions within social constructionism (table derived from Hjelm T., 2014)

Characteristics:		
1.	**Contingency**	The human world is a human product
2.	**Liberation**	Categories and definitions can be changed
3.	**Process**	Construction is an interactive and historical achievement
Functions		
1.	**Ontological**	A view on what the human world [and our being in that world] consists of ■ *Example: race is not biologically fixed but rather contingent upon social, historical, and political processes*
2.	**Epistemological**	A view on how knowledge of the human world is produced ■ *Example: knowledge of gender is produced among others through socialization, language use, institutional structures and daily social interactions and recognizing this offers potential for destabilizing socially constructed binaries, allowing for more fluid and diverse understandings of gender.*
3.	**Critical**	How to [challenge and] change the human world by thinking and communicating differently ■ *Example: shifting stigmatizing medical labelling practices, such as "persons living with dementia" having replaced the term "demented persons," which was commonly used before the turn of the century.*
4.	**Methodological**	How to study the processes of construction ■ *Example: understanding psychiatric diagnostic categories as contingent products of specific sociohistorical contexts places methodological emphasis on examining the broader systems of meaning that reproduce, dispute, or negotiate them, for instance through discourse analysis.*

From within this theoretical paradigm, the biological realities of serious illness, dying and death are not called into question[104]. Rather, social constructionism emphasizes how they are socially defined, i.e. how our perceptions and experiences of them in everyday life are actively shaped by social interactions within historical and cultural contexts[107]. Social constructionism moreover views language, communication and speech as central to the interactive process through which we understand the world and ourselves[108]. As will become clear further in the dissertation, narrative, discourse and audience reception theory and analysis (particularly the strands that we engage with) are all intertwined with social constructionist principles[105,109–111].

In the following we briefly describe the methods of each study. Ethical approval was obtained for each of these studies from the Medical Ethics Committee of Ghent University (Hospital) or Vrije Universiteit Brussel (Hospital), except study three since the data for this study is freely available in the public domain.

3.1. Methods used to address the objectives of research aim 1

Study 1: A cross-sectional population-based survey to examine the public knowledge of palliative care and differences between subgroups among the general public of Flanders (objective 1 – Chapter two).

In this study we conducted a cross-sectional population-based survey in two urban and two semi-urban cities in Flanders. In all four purposely selected cities, a city official drew a random sample from the population registry, targeting citizens over 16 years old. During the timeframe January–June 2021, a total of 4400 persons (1100 in each city) were invited to partake in our survey study, either by filling in the provided paper version or by completing it online. The survey questionnaire consisted of several validated scales as well as self-constructed questions, measuring in total eight different concepts. In keeping with the aim of our study, we focused on questions surrounding the knowledge of palliative care as well as questions tapping into socio-demographical information and personal experiences surrounding serious illness, the end of life and loss. The validated Palliative Care Knowledge Scale (PaCKS)[112] was used to assess what our respondents knew about palliative care and its different aspects. A more detailed overview of the method can be found in Chapter two.

Study 2: Narrative inquiry using reflexive thematic analysis to explore patterns of shared meaning across personal narratives concerning experiences with palliative care, serious illness, and the end of life (objective 2 – Chapter three).

A narrative inquiry study was conducted during which we collected and analyzed lay people's personal narratives surrounding palliative care, serious illness, and the end of life. Narrative inquiry research involves the analysis of stories about life experiences to gain insight into the way people understand and make meaning of their lives within a broader social context[111]. We collected personal narratives from citizens who took part in a broad public engagement initiative on palliative care, called 'The Palliative Debate', organized during the period March 2020 to March 2021 by a well-known NGO in Belgium (Kom op tegen Kanker). Aside ‘prototypical narratives’ understood as stories on personal, past experiences of non-shared events[113], the collected personal narratives also including so-called ‘small stories’ (i.e. ‘a-typical’ narrative activities often of a fragmented, complex, diffuse and interwoven nature)[114]. Reflexive thematic analysis[115] was used to explore patterns of shared meaning across narratives. A more detailed overview of our methodological approach can be found in Chapter three.

Study 3: Descriptive and discourse-theoretical analysis of online information on palliative care disseminated by practice, policy and advocacy organizations (objective 3 – Chapter four).

A descriptive and discourse-theoretical analysis of online information on palliative care disseminated by 56 diverse organizations in Flanders was conducted from December 2019 to July 2020. Specifically, we employed a poststructuralist approach to discourse analysis shaped by the theoretical writings of Foucault, Laclau and Mouffe[116–121]. This theoretical framework provides conceptual tools to gain insight into the way meaning gets (re)produced and/or challenged within specific representational settings, in this case the online information on palliative care.

We collected publicly available online information by applying a purposive maximum variation search strategy. An extensive -yet not exhaustive- inventory of organizations was made, which included: (1) palliative care field organizations, (2) professional health care organizations such as hospitals, (3) home support services, (4) elderly care facilities, (5) patient and informal care organizations, (6) civil society organizations, and (7) governmental organizations. Starting from this inventory, organizations were randomly picked per sector resulting each time in a cycle of 7 diverse organizations. We visited the websites of these organizations and 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. Only after all texts within a cycle were analyzed, texts from the following cycle were collected until theoretical saturation. To guard against any bias in our results from the inventory we made, we also performed a Google search for ‘palliatieve zorg’ after which another cycle of seven organizations was analyzed from the Google search results pages. The analysis itself applied a ‘double reading’ approach[117], encompassing two different levels. On a descriptive level, we focused on congruence and discrepancies in the definitions and descriptions of palliative care, and on a discourse-theoretical level we focused on identifying and interpreting the discourses at play. A more detailed overview of our methodological approach in this study can be found in Chapter four.

Study 4: Audience reception research of public awareness campaigns on palliative care using the Multidimensional Audience Reception model (objective 4 – Chapter five).

We conducted a qualitative audience reception study, using a focus group design, to explore the diverse ways in which members of the general public interpret, evaluate and engage with public awareness campaigns on palliative care. A maximum variation sampling strategy was adopted, combining natural and constructed focus groups, to fuel the inclusion of a wide range of voices, backgrounds and experiences. Participants had to be adults (18+), not professionally involved or volunteering in chronic care or palliative care settings and residing in Flanders. In addition, since all campaign materials were in Dutch, participants would ideally possess a basic understanding and conversational skills in Dutch. Yet, in the absence of this they could still participate in the study if their mother tongue was shared by one or more of the other participants in the focus group (who would help translate) and if they had a basic understanding and conversational skills in French and/or English.

Ten focus groups were held from October to December 2023, mainly in the region of Ghent. In these focus groups three public campaigns, previously disseminated in the Netherlands or Belgium, were shown and discussed guided by a limited number of open-ended questions. The transcripts of the focus group conversations were analyzed using the Multidimensional Audience Reception model developed by Schrøder [122] which offers conceptual tools to account for the complex processes through which audiences engage, understand, criticize and respond to media messages. Data collection and analysis followed an iterative process and, adopting a pragmatic approach to saturation[123], until findings reflected sufficient analytical depth, conceptual clarity and insight regarding our research question. More details on the methods we used in this study can be found in Chapter five.

3.2. Methods used to address research aim 2

Study 5: Integrative approach of co-creation & Intervention Mapping to develop a broad campaign strategy to tackle unknown, misunderstood and stigmatized aspects of palliative care in Flanders (Chapter six).

For the last study in this dissertation, encompassing the development of a broad public campaign strategy on palliative care, we combined a co-creative approach with Intervention Mapping. Co-creation enables various stakeholders, including the target audience, to become active campaign designers[124], facilitating an overall commitment to their needs and to the collaborative nature of innovative, creative processes[125]. Intervention Mapping is an evidence-based, socio-ecological planning approach to develop health promotion programs[126]. As our project focused on the design of a multifaceted public campaign and not on the production, implementation and evaluation of its included components, only the first three steps of Intervention Mapping were applied: (1) the completion of a needs assessment and the creation of a logic model of the problem; (2) the specification of change objectives and the creation of a logic model of change; and (3) the design of the campaign strategy using theory- and evidence-based change methods and practical applications. At the beginning of this process, two planning groups were formed consisting of a diverse group of 22 citizen stakeholders, and a group of 8 professional stakeholders active in the field of policy, practice and/or advocacy surrounding palliative care and health promotion. Additionally, two communication professionals were involved who, depending on their individual expertise, advised on techniques to facilitate the co-creative design process and/or contributed to copywriting and prototyping posters, based on the planning group members' input. A detailed description of the whole process can be found in Chapter six.

4. Dissertation outline

After this introduction, the dissertation consists of three parts which together describe our studies, followed by a general concluding discussion.

In part I, we focus on the public perceptions of palliative care in Flanders. In Chapter two we take a closer look at what exactly is known and unknown about palliative care among the general public in Flanders, as well as what the differences are between subgroups. In Chapter three we aim to reach a deeper, contextualized understanding of the way people perceive and give meaning to palliative care through an exploration of patterns of shared meaning across personal narratives surrounding experiences with palliative care, serious illness, and the end of life.

In part II, we take a closer look at public communication on palliative care and its reception. Chapter four describes the descriptive and discourse-theoretical analysis of representations of palliative care within the online information spread by palliative care policy, advocacy and practice organizations in Flanders. In Chapter five, we examine the diverse ways in which existing public awareness campaigns on palliative care are interpreted, evaluated and engaged with by members of the general public.

In part III, Chapter six, the focus is on the co-creative development of a public campaign to address unknown, misunderstood and stigmatized aspects of palliative care in Flanders.

The final section, Chapter seven, concludes this dissertation with a summary of our main results, methodological considerations, a deeper discussion of the relevance and interpretations of our findings in relation to the broader research literature and lastly, some recommendations for practice, policy and research.

Chapters two to five present original research articles which have either been published or submitted to A1 peer-reviewed journals. Chapter six presents the methods and results section of an original research article which is currently being finalized for submission. All of these chapters can be read independently.

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Part I

Public perceptions of palliative care

Chapter II

What does the general public know about palliative care? A population-based survey

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Abstract

Objectives: The need for public education on palliative care has been widely argued for. To develop effective educational strategies, a stronger evidence base is needed on what exactly is known and unknown about palliative care as well as what the differences are between subgroups.

Methods: We conducted a cross-sectional population-based survey. Mail questionnaires were sent to a random sample of 4400 citizens (aged ≥16 years) within 4 municipalities in Flanders, Belgium. The Palliative Care Knowledge Scale (PaCKS) was used to measure knowledge. Associations between knowledge and sociodemographics and various experiential factors were tested, as well as the congruence between actual and self-perceived knowledge scores.

Results: Response was obtained from 2008 (45.6%) citizens, of which 1852 (92.2%) filled in at least 11 of the 13 PaCKS items and were included in the further analyses. The mean PaCKS score was 7.87 (SD 3.41; range 0-13) with the highest proportion (84.7%) correctly answering that palliative care is not specifically for older adults and the lowest (32.1%) correctly answering that improving the ability to participate in daily life is a palliative care goal. Being aged between 30 and 59, non-religious, more highly educated, having professional healthcare experience and knowing palliative care through personal experience were significantly associated with higher knowledge, while sex and informal caregiving experience were not. 52.4% self-perceived their knowledge as lower than it actually was.

Conclusions: While the general public seems to be familiar with some basic concepts of palliative care, several key aspects remain unknown. Educational strategies, with suggested potential for community- and experience-based approaches, may need to focus specifically on these aspects and not just on the broader palliative care concept.

1. Introduction

Previous studies have often demonstrated low levels of public awareness and knowledge, persistent misperceptions and negative beliefs about palliative care[1–6]. Overall, these observations can be identified as serious obstacles to a timely and equitable use of palliative care[1], potentially leading to unnecessary suffering, inappropriate treatments, suboptimal levels of wellbeing and quality of life and other negative end-of-life outcomes such as dying in non-preferred locations[7]. This lack of public awareness and recognition of palliative care has also been recognized as an important barrier to the further development of palliative care across the Western European region[8] and on a global scale[9]. As argued by Alcalde and Zimmerman, societal awareness is a necessary condition to build enough political pressure to create better palliative care policies and structures[10]. Additionally, public awareness and knowledge on palliative care are needed to stimulate the development and uptake of new public health initiatives in palliative care, aiming to involve the wider community in the care and support for people confronted with serious illness, dying or loss[11]. Educational initiatives can help in this regard[12,13] but for those to be effective, it is important to have an assessment within the local context they are targeting, of what precisely is unknown or misunderstood and what the differences in knowledge are between subgroups. While the international literature on public perceptions of palliative care is slowly emerging, there remains an ongoing need for more research since public perceptions of palliative care are - just like the field itself - constantly evolving and because gaining a broader view on similarities and differences across regions and timespans can help to inform global efforts to improve the access, delivery and uptake of palliative care. Moreover, there is a need for more clarity and a stronger evidence base towards factors associated with palliative care knowledge, since the existing research on this is rather limited and inconclusive[14]. This study therefore set out to investigate knowledge about palliative care and differences between subgroups among the general public in two urban and two semi-urban cities in Flanders, Belgium. The research question guiding this research is: '*How well does the general public know palliative care and its different aspects?'.* Secondary research questions are:

1: Which personal characteristics and experiences are associated with better palliative care knowledge?

2: How congruent is the actual knowledge score of citizens with their self-estimated knowledge of palliative care?

3: Through what information sources did persons with low levels of palliative care knowledge learn about palliative care and do these sources differ from the sources reported by people with average to high levels of palliative care knowledge?

2. Methods

Design

We applied a cross-sectional population-based survey study-design in two urban and two semi-urban cities in Flanders, Belgium.

Population, sampling and data collection procedures

The target population was all citizens aged 16 and older. A random sample was drawn from the population registry by a city official in all four cities. In three of the four cities a simple random sampling procedure was drawn, in one a disproportionally stratified random sample (with an oversampling of registered informal caregivers in the only city which kept such a register; see published protocol for more details[15]). To strive for optimal response rates, the Total Design Method[16] was applied and a total of 4400 individuals (1100 in each city; corresponding to an anticipated response rate of 35%, determined by applying a conservative approach[17]) were invited by mail to partake in the survey-study during January – June 2021. Questionnaires were accompanied by a pre-paid return envelope and an information letter indicating among others the goal of the study, reasons to participate and its voluntary and anonymous nature. Individuals were sent a maximum of three reminders at set time intervals in case of continuing non-response. We also provided the opportunity for respondents to complete the questionnaire online.

Survey instrument

The survey questionnaire (see Appendix 1) consisted of several validated scales as well as self-constructed questions measuring in total eight different concepts. We focused on (1) the Palliative Care Knowledge Scale (PaCKS), a validated scale to measure the knowledge and knowledge gaps of palliative care[18], (2) self-constructed questions regarding personal experience with serious advanced illness, the end of life and loss, sources through which information on palliative care was obtained and self-perceived knowledge of palliative care, and (3) sociodemographic information. The PaCKS consists of 13 different statements about palliative care with answer options ‘correct’, ‘incorrect’ and ‘don’t know’ and was translated using the forward-backward translation technique. The total score has a range of 0 (no knowledge) to 13 (perfect knowledge) and is calculated by the sum of correctly assessed items (incorrectly assessed items or ‘don’t know’ are given a score of 0).

Statistical analysis

For the descriptive analyses, data were weighted to correct for the disproportional stratification (in one city), for sampling error and for differential nonresponse by age. To deal with missing values in the calculation of the total PaCKS score, we chose to only include respondents who completed at least 11 of the 13 items (see Appendix 2 for sensitivity analysis). To study the relationship between self-perceived and actual knowledge of palliative care, a ‘congruence variable’ was created linking the seven possible values of self-estimation to the fourteen possible values of the total PaCKS score according to a symmetrical scheme (see Appendix 3). For the multivariable analysis, missing data of all relevant variables were explored starting from the unweighted dataset. Incomplete data of the total PaCKS score and estimated predictors (sex, professional health care experience, informal caregiver experience, personal experience with palliative care, age, educational level and religion) were multiply imputed using the fully conditional specification method (number of imputations = 15, number of iterations = 20). Missing values for all (categorical) predictors for the multivariable model were imputed using logistic regression. As required, the imputation model was congenial with the analysis model. Potential predictors for the knowledge of palliative care were identified based on literature and, conform recommendations from the ‘table 2 fallacy’ literature[19], directed acyclic graphs were drawn to hypothesize causal relations (see Appendix 4) so that models would each time be adjusted for possible confounders of the predictor-outcome association, but not for variables identified as mediators. Since the data distribution of the dependent variable, the total PaCKS score, showed an excess of zero’s, we applied a hurdle model to investigate associations. For each predictor of interest, the analysis involved two parts: the fitting of a binary logistic model for the zero values and the fitting of a linear regression model for the non-zero values. A sensitivity analysis was performed by running complete case analyses on the original observed data which operates under the stricter assumption of missing completely at random (see Appendix 5). All analyses were carried out using SPSS, version 27 and the significance level was set at $p < 0.05$.

3. Results

Of 4400 questionnaires sent, 2135 were returned. After removing unusable questionnaires 2008 remained, resulting in a response rate of 45.6% (2008/4400)[20]. Characteristics of respondents are found in Table 1.

Table 1. Characteristics of respondents (n=2008).

		Unweighted data		Weighted data[a]	
Sociodemographics[b]		n	%[c]	n	%
Age					
16-29		246	12.4%	306	15.4%
30-44		322	16.2%	362	18.3%
45-59		541	27.3%	536	27.0%
60-74		564	28.5%	505	25.5%
75 and older		309	15.6%	273	13.8%
Sex					
Male		958	48.2%	951	47.9%
Female		1027	51.7%	1034	52.1%
Other		1	0.1%	1	0.1%
Highest level of education					
Lower educational level		525	26.7%	506	25.8%
Medium educational level		655	33.4%	666	33.9%
Higher educational level		741	37.7%	748	38.1%
Other		43	2.2%	43	2.2%
Professional status					
Working		985	49.9%	1038	52.6%
Retired		745	37.7%	658	33.4%
Other (student, unemployed, unfit to work, other)		244	12.4%	277	14.0%
Religion					
Not religious		647	33.1%	675	34.6%
Catholicism		1161	59.4%	1128	57.8%
Islam		89	4.6%	92	4.7%
Other		56	2.9%	58	3.0%
Residence of respondents					
Brugge		561	27.9%	561	27.9%
Sint-Niklaas		515	25.6%	515	25.6%
Herzele		441	22.0%	441	22.0%
Gavere		491	24.5%	491	24.5%
Personal experiences with serious advanced illness, death, dying and loss					
Informal caregiver (currently or in the past)	**Yes**	739	36.8%	700	34.9%
	No	1269	63.2%	1308	65.1%
Having a chronic illness	**Yes**	234	11.7%	220	11.0%
	No	1774	88.3%	1787	89.0%
Currently mourning for someone	**Yes**	447	22.3%	441	22.0%
	No	1561	77.7%	1567	78.0%
Ever work(ed) in health care	**Yes**	271	13.5%	278	13.8%

	No	1737	86.5%	1730	86.2%
Ever talked with a dying person about his or her death	Yes	602	32.1%	600	31.9%
	No	1274	67.9%	1280	68.1%
Ever kept somebody company who was close to death	Yes	1120	59.6%	1107	58.8%
	No	759	40.4%	774	41.2%

[a] *weighting coefficients: 0.58, 0.70, 0.94, 0.98, 1.00, 1.36, 2.26, 2.42.*
[b] *Missing data (unweighted): n= 26 (1.3%) for age, n=22 (1.1%) for sex, n=44 (2.2%) for educational level, n=34 (1.7%) for professional status, n=55 (2.7%) for religious beliefs, n=132 (6.6%) for 'talked with a dying person about his or her death', n= 129 (6.4%) for 'kept somebody company who was close to death'. No missing values for residence of respondents, having a chronic illness, mourning for someone, work(ed) in health care, and, informal caregiver (currently or in the past).*
[c] *Valid percentages are given, that is, not including missing values.*

Public knowledge of palliative care

The total PaCKS score was calculated for 1852 respondents (92.2% of total cases). A mean score of 7.87 and median of 8 was obtained (range 0 - 13). 24.1% answered correctly on at least eleven of the thirteen items and 19.8% gave the correct answer on less than six items. The data further showed a zero-inflated pattern with zero-scorers (6.6%) consisting mainly of respondents who filled in 'I don't know' (6.1%) on all items (see Figure 1). Items with strikingly high as well as strikingly low total scores were observed (see Table 2). Less than half of respondents correctly knew that 'stress from serious illness can be addressed by palliative care' (35.6%) and that 'a goal of palliative care is to improve a person's ability to participate in daily activities' (32.1%). Likewise, less than half of respondents correctly knew that the statement 'palliative care is exclusively for people who are in the last 6 months of life' is incorrect (44.2%). However, the majority of respondents knew that the statements 'palliative care is specifically for people with cancer' (82%), 'people must be in the hospital to receive palliative care' (78.2%) and 'palliative care is designed specifically for older adults' (84.7%) are wrong and that 'palliative care helps the whole family cope with a serious illness' (76.1%) is correct. On all but one PaCKS item (item five) the % of people responding 'I don't know' exceeded the % of persons giving the incorrect answer.

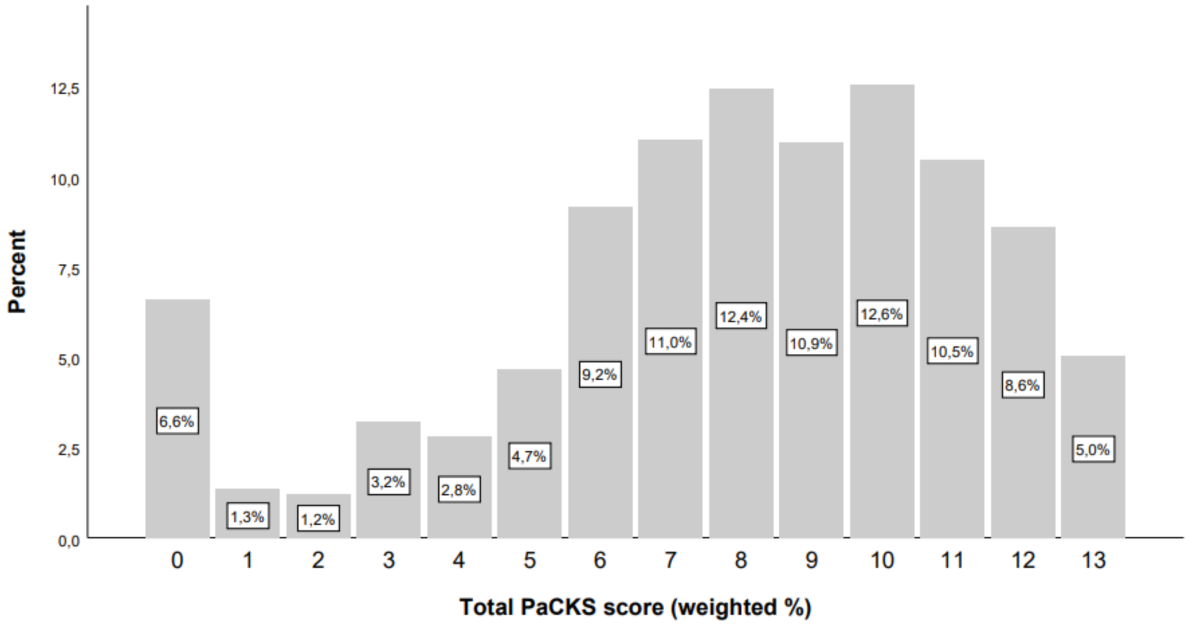

Figure 1. Division of total scores on Palliative Care Knowledge Scale.

Table 2. Knowledge on different aspects of palliative care (weighted data)

PaCKS

	True n (%)	False n (%)	'Don't know' n (%)	Missings n (%)
1. A goal of palliative care is to address any psychological issues brought up by serious illness.	**969 (51.7%)**	367 (19.6%)	538 (28.7%)	133 (6.6%)
2. Stress from serious illness can be addressed by palliative care.	**667 (35.6%)**	554 (29.6%)	652 (34.8%)	135 (6.7%)
3. Palliative care can help people manage the side effects of their medical treatments.	**916 (49.3%)**	432 (23.3%)	509 (27.4%)	151 (7.5%)
4. When people receive palliative care, they must give up their other doctors.	87 (4.6%)	**1357 (72.1%)**	438 (23.3%)	126 (6.3%)
5. Palliative care is exclusively for people who are in the last 6 months of life.	535 (28.7%)	**824 (44.2%)**	507 (27.2%)	141 (7%)
6. Palliative care is specifically for people with cancer.	96 (5.1%)	**1545 (82%)**	244 (12.9%)	123 (6.1%)
7. People must be in the hospital to receive palliative care.	108 (5.7%)	**1480 (78.2%)**	305 (16.1%)	115 (5.7%)
8. Palliative care is designed specifically for older adults.	58 (3.1%)	**1594 (84.7%)**	231 (12.3%)	124 (6.2%)
9. Palliative care is a team-based approach to care.	**1274 (68.8%)**	109 (5.9%)	468 (25.3%)	156 (7.8%)
10. A goal of palliative care is to help people better understand their treatment options.	**999 (53.9%)**	293 (15.8%)	561 (30.3%)	155 (7.7%)
11. Palliative care encourages people to stop treatments aimed at curing their illness.	170 (9.1%)	**1251 (66.7%)**	455 (24.3%)	132 (6.6%)
12. A goal of palliative care is to improve a person's ability to participate in daily activities.	**594 (32.1%)**	526 (28.4%)	733 (39.6%)	155 (7.7%)
13. Palliative care helps the whole family cope with a serious illness.	**1442 (76.1%)**	89 (4.7%)	364 (19.2%)	113 (5.6%)

Bold numbers represent the correct answers.

Congruence with self-perceived knowledge

36.9% rated their knowledge as very low to rather low (score of less than 4 on a scale from 1 'I don't know anything about it' to 7 'I know a lot about it'), 21.4% situated their knowledge at the midpoint of four and 41.6% rated their knowledge as rather high to very high (score of more than 4). Comparison of self-estimation and actual knowledge scores showed that 52.4% of respondents underestimated their knowledge compared to 22.7% who overestimated their knowledge (see Figure 2). One-quarter (25%) estimated their knowledge accurately.

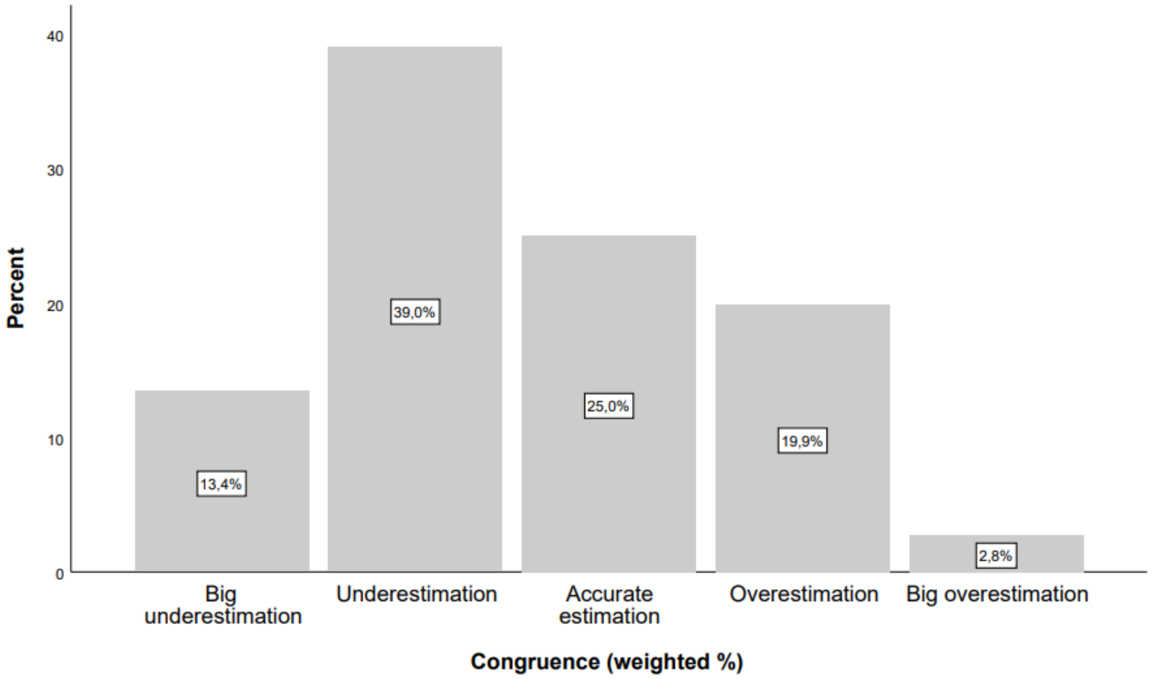

Figure 2. Congruence between self-perceived knowledge and actual knowledge on palliative care.

Associated factors

Our analysis (see Table 3 for condensed results and Appendix 6 for full results) showed that those with lower educational attainment and of younger age (16-29) were less likely to have a knowledge score above 0 and (of those who did score higher than 0) had significantly lower mean PaCKS scores than their counterparts with higher educational attainment and older age (see specific age ranges in table). Non-religious people were significantly more likely to score better than 0 compared with those indicating their beliefs as Islamic or 'other' and had higher average above-zero knowledge scores than those subscribing to Catholicism or Islam. Having professional experience in health care and knowing palliative care through personal experience were also associated with better knowledge (i.e. non-zero scores and higher average scores). For sex we only found a significantly higher chance of men to score 0 but the average scores above 0 did not significantly differ between men and women. No significant associations were found with having informal caregiving experience. Our sensitivity (complete case) analysis confirmed all significant associations and achieved similar estimates (see Appendix 5).

Table 3. Associated factors with knowledge of palliative care

	PART 1: binary logistic models for zero values		PART 2: linear regression models for non-zero values	
	OR (95% CI)	Sign.	B (95% CI)	Sign.
Model 1 (no confounders)				
Sex*			Sex	
Female	Reference			
Male	0.59 (0.37 – 0.95)	p=0.032	-0.17(-0.44 – 0.11)	p=0.232
Model 2 (no confounders)				
Age*			Age*	
16-29	Reference			
30-44	1.21 (0.66 – 2.22)	p=0.542	0.56 (0.06 – 1.05)	p=0.028
45-59	2.08 (1.14 – 3.78)	p=0.017	0.73 (0.26 – 1.19)	p=0.002
60-74	2.45 (1.11 – 5.37)	p=0.027	0.34 (-0.14 – 0.82)	p=0.166
75+	1.06 (0.56 – 1.99)	p=0.864	0.07 (-0.50 – 0.63)	p=0.815
Model 3 (confounders: sex and age)				
Educational level*			Educational level*	
Low	Reference			
Medium	3.37 (1.99 – 5.71)	p<0.001	0.85 (0.47 – 1,23)	p<0.001
High	10.18 (5.38 – 19.26)	p<0.001	1.69 (1.31 – 2.07)	p<0.001
Other	0.71 (0.30 – 1.70)	p=0.442	0.06 (-0.94 – 1.07)	p=0.900
Model 4 (confounders: sex, age and educational level)				
Religion*			Religion*	
Not religious	Reference			
Catholicism	0.72 (0.42 – 1.22)	p=0.221	-0.36 (-0.65 – -0.08)	p=0.013
Islam	0.10 (0.05 – 0.19)	p<0.001	-2.24 (-3.05 – -1.42)	p<0.001
Other	0.36 (0.13 – 0.97)	p=0.043	-0.46 (-1.24 – 0.33)	p=0.252
Model 5 (confounders: sex, age and educational level)				
Professional experience in health care*			Professional experience in health care*	
No	Reference			
Yes	5.83 (1.35 – 25.19)	p=0.018	1.08 (0.71 – 1.46)	p<0.001
Model 6 (confounders: sex, age and professional experience in health care)				
Informal caregiving experience			Informal caregiving experience	
No	Reference			
Yes	1.35 (0.82 – 2.20)	p=0.233	0.13 (-0.18 – 0.44)	p=0.426
Model 7 (confounders: sex, age, professional experience in health care and informal caregiving experience)				
Knowing palliative care through personal experience*			Knowing palliative care through personal experience*	
No	Reference			
Yes	9.15 (4.00 – 20.95)	p<0.001	0.66 (0.38 – 0.95)	p<0.001

**significant with p<0.05 in all 15 imputed datasets*

Information sources

Informal sources, personal experience and traditional media were the most important sources through which people with low levels of knowledge of palliative care (operationalized as scoring less than the mean PaCKS score) reported having heard of palliative care (see Table 4). Looking only at people with average to high knowledge levels (scoring higher than the mean PaCKS score), the same three information sources were most frequently reported although the relative order differed (personal experience > informal source and traditional media) and the importance of 'formal sources' was relatively higher in this group.

Table 4. Information sources through which people have heard of palliative care (weighted data)

	People with low levels of palliative care knowledge (n=726)		**People with average to high levels of palliative care knowledge** (n=1110)	
	n	%	n	%
Informal source[a]	313	**43.2%**	487	**43.9%**
Formal source[b]	66	9.1%	265	23.8%
Traditional media[c]	237	**32.6%**	479	**43.2%**
New media[d]	90	12.4%	183	16.5%
Personal experience[e]	260	**35.8%**	594	**53.5%**
Other source[f]	12	1.7%	43	3.9%
'Never heard from it'	88	12.1%	11	1%
'I don't remember'	49	6.7%	31	2.8%

Bold numbers represent the highest percentages.

[a] through an acquaintance, friend or family member who talked about palliative care and/or works in the field.

[b] through schooling and/or work as a professional or volunteer.

[c] newspapers, magazines, television or radio.

[d] the internet or social media.

[e] person receives, or, a friend, family member or acquaintance receives or received palliative care.

[f] includes among others: health promotion & health literature, through health care providers and settings.

4. Discussion

Main findings

Our cross-sectional population-based survey showed that palliative care is generally well known among a substantial portion of the general public but remains an unknown or misunderstood concept for many others. Within a range from 0 (minimum knowledge) to 13 (maximum knowledge), a mean total PaCKS score of 7.87

was found. Some specific aspects of palliative care were very well known such as the facts that palliative care is not only for older adults nor just persons with cancer, yet clear gaps in knowledge were also found with the largest one being that palliative care aims to improve a person's ability to participate in daily activities. Being aged between 30 and 59, non-religious, more highly educated, having professional experience in health care and knowing palliative care through personal experience were significantly associated with higher mean knowledge scores.

Strengths and limitations

One of the strengths of this study lies in the random sampling and the statistical generalizability for the city populations. However, the selection of the four cities might not be enough to argue for theoretical generalizability to the whole of Flanders. Another strength comes from the use of the validated PaCKS scale, facilitating comparisons with other studies and contexts. It can still be argued though that the PaCKS scale's items are too limited and do not capture the broader meaning of palliative care as a vital public health and human rights issue, going beyond being a pure health service.

What this study adds

While the 2015 Quality of Death Index ranked Belgium as the highest scoring country on public awareness and understanding of palliative care services[21], our results paint a more nuanced picture and show - at the very least - that there is much room for improvement. Our obtained mean PaCKS score (7.87) was lower than the mean found in studies among young adults (aged 18-29) in the UK[11] (8.87) and adults in Northern Ireland[2] (8.31) but higher in comparison to three studies done among various samples in the USA (mean scores ranging between 4.38 and 5.25)[22–24]. The differences between these scores may be seen as partly reflecting the diversity in structural conditions and broader socio-cultural settings in which the knowledge on palliative care is embedded (although these differences have to be interpreted cautiously in light of the differences in sample characteristics and potential divergencies in the use of the PaCKS scale between studies). Importantly though, while palliative care is historically anchored the longest in the UK and this might partly explain the higher mean scores, the studies there still report widespread misunderstandings on palliative care, leading to similar conclusions as the studies with much lower mean scores in the USA.

Considering the gaps in knowledge found in our sample, many of those seem to reflect a belief that palliative care is synonymous with terminal care or care at the very end of life. Across studies, this persistent view has been reported, often directly linked to the stigma surrounding palliative care[25,26]. Given the prevailing practice of late referrals[27] and the fact that most palliative care services still focus their interventions strongly at the end of life, it is not surprising that a substantial portion of the population sees palliative care as purely terminal care. Understood within this context it also deserves a more nuanced interpretation than merely being a 'misconception' or 'negative belief' as is often done in the literature. However, contrasting to what is often presented as myths or persistent misconceptions of palliative care[28,29] but resonating with findings of two other relatively recent studies[11,30], high proportions of our respondents were familiar with the facts that palliative care is not only for persons who have cancer nor only for older adults, is not given exclusively in hospital settings and has a focus on the whole family. Although minimal improvements over time in public awareness and knowledge of palliative care have been reported[4], other studies have argued differently[11,31]. The results of our study also seem to suggest that the historical developments of palliative care have at least partly seeped through into the public knowledge about palliative care.

With the exception of sex, most of the knowledge associated factors that are frequently brought forward (education, gender/sex, age, personal experience and professional health care experience[4]) were confirmed as relevant to palliative care knowledge in our study. The fact that no significant difference was found between people with or without informal caregiving experience might be explained by the broad range of possible chronic conditions that require or benefit from informal caregiving support, also outside the broad scope of palliative care. Additionally, being religious proved to be a factor related to poorer palliative care knowledge and this differs from earlier studies finding no associations among young adults in the UK[11] or among Asian populations in the USA[23]. Lower knowledge scores among Muslims and Catholics might be influenced by a variety of factors such as individual religious beliefs and practices and access to information and services, but further research (preferably in-depth qualitative research) is needed to fully understand the relation between palliative care knowledge and religion.

Our findings furthermore show the importance of experience within the personal social context on obtaining knowledge of palliative care. This finding emerges consistently across various studies and points to the potential value of community-based educational approaches[32], centered around peer advisors and experience-based knowledge exchange. Efforts to stimulate talking about death, dying and loss, the sharing of personal narratives surrounding these topics, can serve as a vehicle to spread more awareness on the different care options at the end of life. Our results are also in line with previous research showing the unfulfilled potential to promote palliative care through new media such as websites and YouTube channels[33–35] and urges further investigation of the quality of information offered through traditional media channels (which has been shown to be limited in scope and potentially contributing to negative or inaccurate perceptions[36,37]).

In terms of implications for practice and policy, our findings indicate a clear need for educational efforts to improve the public knowledge on palliative care. Previous research has shown that educational initiatives on palliative care are effective in improving knowledge and attitudes towards palliative care[12,24,38]. Importantly though, since many people seem to be already familiar with some of the basic concepts, these educational efforts may need to focus primarily on specific unknown or misunderstood aspects of palliative care rather than (only) on the broad concept of palliative care and its contributions. The implications of the specific understanding of palliative care as terminal care for instance go beyond the conceptualizations of the field itself but also translate into the image it (re)produces of the person with palliative care needs, for example as someone who is ‘losing the battle’[39] or in a passive, dependent position[33]. Efforts to promote (early) palliative care should therefore pay proper attention to underscore palliative care as care directed at persons who can still have other active treatments and who can still have active roles in life, a life that can last for years. This way not only more knowledge on palliative care can be aimed for but also a reduction in the stigma surrounding it[3]. Public education initiatives are however only part of the puzzle; they will also need to be accompanied by shifts in policy and actual practices that currently perpetuate misconceptions such as late referrals and financial support systems restricted to limited life expectancy.

Building on the findings from this research and addressing a scarcity of in-depth qualitative research regarding public perceptions of palliative care, our next steps include a reflexive thematic analysis of personal narratives surrounding experiences with palliative care, serious illness, and the end of life. This analysis aims to achieve a more profound and contextualized understanding of perceptions of palliative care. Furthermore, to enhance the effectiveness of forthcoming public campaigns on palliative care, a focus group study will be undertaken to investigate how past (both national and international) educational initiatives on palliative care are received and evaluated by diverse members of the public.

5. Conclusion

Improving public knowledge on palliative care is a crucial part of improving a timely and equitable access to palliative care and stimulating political and community engagement with palliative care. The results of this study highlight this need and show that even though the general public seems to have a relatively good understanding of some of the basic concepts of palliative care, several of its key aspects remain unknown or misunderstood. As long as the general public remains unaware that palliative care is not limited to the last six months of life or that it aims to improve one's ability to participate in daily activities despite serious illness, a stigmatized perception of palliative care as terminal care can persist, thus obstructing timely initiation of palliative care to fully benefit patients and their families.

Strategies to improve the public knowledge on palliative care will need to be locally grounded, collaborative and adaptable to fully serve the diversity within our societies. This means that to reach all who could benefit from palliative care, now or in the future, educational strategies directed to the general public need to be tailored to the needs and resources of different social groups to ensure existing inequalities in access and use of palliative care are not unintentionally exaggerated. This necessitates actively listening to and involving people from diverse backgrounds in the development of these initiatives. Additionally, global discourses on palliative care, for instance considering compassionate communities, should be effectively translated into the local context. One way to do this is through the existence of durable local partnerships between palliative care practitioners, policy makers, researchers and citizens. By implementing these strategies, we can reduce gaps in knowledge, battle stigmatization, and enhance public receptivity towards palliative care, ultimately leading to improved care and quality of life for individuals facing serious illnesses.

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Ethics approval

This study was approved by the Medical Ethics Committee of the University Hospital Brussels with reference B1432020000186 on 16 September 2020. The study was conducted in an ethical manner, adhering to principles of informed consent and confidentiality. Each questionnaire was accompanied by an information letter indicating among others the goal of the study, potential reasons to participate and the voluntary and anonymous nature of it. People's response to the questionnaire was regarded as informed consent.

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Chapter III

Patterns of shared meaning across personal narratives surrounding experiences with palliative care, serious illness, and the end of life

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Abstract

Prior observations of persistent public misconceptions and negative beliefs surrounding palliative care have led to extensive calls for public education on palliative care. Yet, the development of effective initiatives to improve public perceptions of palliative care is still hindered by a lack of research providing a deeper, contextualized understanding of the way people perceive and give meaning to palliative care. This study therefore set out to explore patterns of shared meaning across personal narratives surrounding experiences with palliative care, serious illness, and the end of life. These narratives were collected during a broad public engagement initiative on palliative care in Flanders, Belgium which included a call to share personal stories surrounding palliative care (which 72 persons did) as well as a Citizens' Forum in which 24 persons engaged in live conversations on palliative care. Reflexive thematic analysis was used to analyze the personal narratives and yielded four axes of meaning: 1) 'Sense of Support', describing feeling supported or abandoned on multiple levels with key elements of open and empathetic communication, being informed and listened to; 2) 'Being-in-Time', incorporating a renewed sense of temporality and the weight of uncertain prognosis; 3) 'Constituting a Sense of Self while Coping with Life-Threatening Illness', involving concerns surrounding role adjustments and posthumous reputation; and 4) 'Going Through the Process of Dying', unique to bereaved individuals' narratives, highlighting the importance of being informed during the dying process and honoring the wishes of the dying person. Together, these axes illuminate how both positive and stigmatized views on palliative care are shaped by broader patterns of meaning attribution, deeply ingrained in personal and social contexts. The identified narrative elements can play a crucial role in improving the content, reach, and impact of future public communication and education on palliative care, effectively enhancing public receptivity and engagement.

1. Introduction

Palliative care improves the quality of life of patients and their families facing physical, psychological, social or spiritual challenges associated with life-threatening illness[1]. Under the impulse of the World Health Organization and several international palliative care alliances[2], palliative care has gradually become more integrated into mainstream health care systems and has significantly broadened its scope since its origins. Today, palliative care is recognized as applicable from the moment of diagnosis, in combination with curative or disease-modifying treatments, and for all types of life-threatening health conditions[3]. Furthermore, a new field within palliative care has emerged, called 'public health palliative care'. This field developed in response to the mainstreaming of palliative care and a narrowing focus on health services and clinical symptom management[4]. Spurred by a renewed interest into the social context of serious illness, dying and death, 'public health palliative care' broadens the palliative care approach further to also encompass civic participation and (non-medical) provision within palliative care[5].

Yet, despite calls for universal access to palliative care, early integration within care trajectories and its development with and within communities, many people still die without the (timely) support of palliative care[6]. Aside structural reasons such as resource availability, various studies have shown that public receptivity and engagement with palliative care is also impeded by limited public knowledge, persistent misperceptions and negative attitudes towards palliative care[7–10]. Depending on the local contexts of these studies, different levels of awareness and different gaps in knowledge of palliative care have been identified. Yet, one common finding is that palliative care is dominantly understood by the general public as care at the very end of life. This perception, propagated by misinformation and late referrals, contributes to what is described in the literature as a stigma surrounding palliative care, i.e., the association of palliative care with cessation of treatment and imminent death resulting in fear and avoidance[11,12]. Often references are also made to a wider societal taboo surrounding death and dying, despite the wide range of literature debunking this so-called societal climate of death-denial[13,14]. In general, there is a remarkable paucity in the literature in regard to shedding light on the specific meaning of this stigma, as well as, more broadly, offering a deeper, multilayered, contextualized understanding of public perceptions of palliative care. Palliative care is a distinct mode of care shaped by specific values and norms[15]. It is deeply embedded in sociohistorical, economic, political and cultural contexts that shape how serious illness, death, dying, loss and grief are experienced and approached[16]. Thus, perceptions of palliative care cannot be viewed as static or isolated from these broader influences and contexts.

For instance, in Belgium, where this study took place, palliative care and euthanasia do not exist as contradictory practices, even though their relationship is often portrayed as antagonistic in the international literature[17]. Palliative care played an important role in the public debates preceding the legalization of euthanasia in 2002, highlighting good palliative care as a prerequisite for a justified practice of euthanasia[18]. Today, palliative care services are often involved in the decision-making process and the actual performance of euthanasia[19]. However, differences in practice exist, among others due to divergent interpretations of the euthanasia law within the guidelines of Catholic and non-Catholic health care institutions[20]. Additionally, tensions between the right-to-die movement and palliative care discourses have been found within Belgian newspaper articles[21], as well as in the online information of palliative care disseminated by diverse Flemish organizations[22]. Importantly, it remains unclear how these public debates, in which palliative care and euthanasia are closely intertwined, affect public perceptions of palliative care.

While exceptions exist, prior research on public perceptions has mainly focused on measuring and describing palliative care knowledge and attitudes, mostly through survey designs. In general, as argued elsewhere, palliative care research tends to be dominated by empiricist frameworks focused on quantification, partly under influence of the biomedical positivist paradigm towards which palliative care as a clinical specialist subdiscipline is orientated[23]. However, a deeper understanding of the meanings attributed to palliative care within broader personal and sociocultural contexts is crucial, especially since, based on the observation of limited public perceptions and fueled by increasing evidence of the ample benefits of early integrated palliative care[11], calls for broad public education on palliative care are repeatedly made[9,10]. To accurately estimate the direction and content of comprehensive and effective public education on palliative care, a better understanding of the complex, multilayered, context-bound, and interconnected meaning-making aspects of serious illness, the end of life, and palliative care is essential. Additionally, it has been pointed out that public messaging about palliative care often lacks insights from people's lived experiences, which could enhance the appeal and impact of these messages[24]. As argued by Boyd[25] positive communication about palliative care is needed to counteract limited and stigmatized perceptions, and this means finding out what matters to patients and people within the social circles around them. In other words, changing perceptions requires first understanding them, and research opportunities and designs need to be sought that can achieve this.

In alignment with the ‘public health palliative care’ approach, this study views palliative care as extending beyond service provision and encompassing the whole social context in which individuals experience and make sense of serious illness and the end of life. The study aims to address the discussed research gaps by collecting and analyzing personal narratives surrounding experiences with palliative care, serious illness, and the end of life. Personal narratives are understood as culturally mediated practices of sense-making, involving the interpretation and presentation of someone's experiences[26]. While personal narratives are born out of experience, they simultaneously give shape to experience and are intricately linked to tellers' (and listeners') concerns about their present and their future lives[27]. An exploration of personal narratives surrounding palliative care, serious illness, and the end of life can, on the one hand, provide a deeper understanding of the wider context and processes of meaning-making in which perceptions towards palliative care have to be understood. On the other hand, the identified narrative elements can serve as valuable tools to touch upon the life worlds of a broader audience in future efforts to improve public awareness, receptivity and engagement with palliative care. The research objective guiding this study is to explore patterns of shared meaning across personal narratives surrounding experiences with palliative care, serious illness, and the end of life. The results of this analysis are then discussed to further explore their theoretical relevance and how insights into these patterns of shared meaning can inform strategies for public communication and education on palliative care.

2. Methodology

Methodologically this qualitative study situates itself under the umbrella of narrative inquiry research which involves the analysis of stories about life experiences to gain insight into the way people understand and make meaning of their lives within a broader social context[28]. Leaning on the ontological and epistemological premises coming from narrative hermeneutics, narratives are understood as interpretative practices, i.e. not only as an object of interpretation but also as a mode of interpretation and life as such is a process of constant narrative reinterpretation[26]. Narratives are thus not seen as a transparent window into people's lives, but rather as an ongoing and constitutive part of our realities and modes of being[29]. People attribute meaning to life experiences through stories while stories also preserve memories, trigger reflections, and connect us - tellers and listeners - to our past, present, and imagined future lifeworlds[27,28].

Materials & context of data-collection

This research focuses specifically on autobiographical narratives surrounding experiences with palliative care, serious illness, and the end of life. These personal narratives were gathered from data collected during a broad public engagement initiative on palliative care, called 'The Palliative Debate', organized by a well-known NGO in Belgium (Kom op tegen Kanker) during the period March 2020-March 2021. This public engagement initiative consisted of several parts. One part involved a wide public call, through several media channels, to share ideas or personal stories surrounding palliative care on the public campaign website. The ideas and stories were collected and organized separately from each other on the website and, in line with our research objective, we only included the 72 publicly shared stories in our study. The majority of stories were lengthy, detailed accounts, describing the moment of diagnosis, progression of treatment and illness and - depending on the narrator - the moment of dying and death. Other stories were short and mainly focused on sharing particular sentiments or giving a certain advice to others.

Another part of this public engagement initiative was a Citizens' Forum in which 24 citizens (none with professional palliative care experience) engaged in conversations on palliative care. Participants were found through an online call on the initiative's website, and through an independent online citizen panel that collaborates in societal research. Out of 90 respondents, 24 citizens were purposively selected by the organizers, aiming for a diverse division of age, gender, social background, personal experiences and reasons for participation. During three full weekends participants talked about their personal experiences and thoughts related to serious illness, loss, dying and death, and their perspectives on the future organization of palliative care in Belgium. Our research team was initially invited as external observers for the Citizens' Forum. During the observations we developed the idea to explore the personal narratives further to gain a better understanding of the different elements that potentially influence palliative care perceptions. All conversations within the formal setup of the Citizens' Forum were audio-recorded. During the last weekend, we addressed participants about our intention to analyze these recordings and our observations for scientific purposes. We informed them about the study aim and asked for their permission, both orally and in writing (by means of an information letter and written informed consent forms). After obtaining participants' informed consent and ethical approval, all audio-recordings were listened to. Recordings that contained personal narratives of participants were transcribed in full and true verbatim. In addition, fieldnotes (including notes on the process, participants and context, as well as stories told directly to the researcher) were included in the analysis. The public initiative also encompassed other components, such as small-scale 'table conversations' on palliative care and consultations with experts and stakeholders. However, these were not relevant to our research objective.

Considering the type of narratives, it is important to mention that not all gathered narratives neatly fit in the category of what is predominantly called "big stories" or "prototypical narratives", i.e. personal, past experience stories of non-shared events[30] containing an element of narrative reflection[31]. Narratives often are of a fragmented, complex, diffuse and interwoven nature[32], making it in this sense a futile and reductionist practice to try to chop them into separate bounded entities. This is particularly relevant to the narratives collected in the interactive context of the Citizens' Forum. While some narratives involved detailed accounts of particular personal experiences, many others were shorter and shared intermittently: at different times during the conversations, people would share parts of their stories. Given this fragmented, interwoven nature, we refrain from providing an exact count of collected narratives.

In terms of narrators' voice, most stories were told from the perspective of a family caregiver or loved one, while others were told from the perspective of a person with a serious illness. Palliative care was mentioned explicitly in the wide majority of the stories, typically when the stories navigated towards the end of life, while others talked about needs and care connected to serious illness or the end of life without explicitly naming palliative care.

Analytical strategy

Narrative inquiry research encompasses a wide range of different approaches and techniques and following the distinction of Polkinghorne[33], we conducted an inductive analysis of narratives which covers the collection of stories as data, followed by 'paradigmatic' analysis that results in descriptions of themes that hold across the stories. For this, we applied reflexive thematic analysis[34], as suggested by Sharp et al.[28]. After familiarization with the data, coding was done inductively by MM (who also participated as the external observer to the Citizens' Forum) using NVivo 12. Additionally, ND coded 1/3 of the data, and codes were then compared and discussed, not to reach consensus or intercoder reliability, but to develop a richer and more nuanced understanding of the data[34]. After coding all individual data-items, the relationships between the different codes and broader patterns of meaning were explored. As a result, themes, which we label axes of meaning, were construed and further developed, reviewed and refined. The analytical process, results and reflections were regularly discussed within a project group of seven members with diverse expertise. This, in combination with keeping a reflexive journal, helped to look critically at interpretations, stimulated the process of continuously going back to the data and coding and overall, strengthened analytical engagement and scientific rigor.

Further ethical considerations

The online narratives were posted without names or contact information attached, and therefore, direct consent for scientific use was unobtainable. However, after consulting with the initiative's organizers, thoroughly discussing the ethical implications within our research group, and reviewing the critical literature on the scientific use of online personal data[35], we deemed it ethically acceptable to include these publicly shared narratives. We ensured that all narratives were stripped of any potentially identifying information to guarantee confidentiality and the unobtrusive nature of our research. Additionally, we emphasized to the Citizens' Forum participants that participation in the initiative did not obligate them to agree to the use of their personal data for our research. We made it clear that participants could refuse without providing reasons, face no consequences, and could revoke consent at any time. Ethical approval for this study was obtained in June 2021 from the Medical Ethics Committee of Ghent University Hospital.

3. Results

Four axes of meaning were construed as a result of the analysis: three common across narratives, and one specific to narratives from bereaved individuals. An overview of these four axes and key elements within can be found in Table 1.

Table 1. Axes of Meaning

Sense of Support: Feeling Supported versus Abandoned on Multiple Levels	Being-in-Time: Shifts in the Subjective Experience of Time	Constituting a Sense of Self while Coping with Life-Threatening Illness	Between a Good and a Bad Death: Going Through the Process of Dying*
▪ Open and empathetic communication with health care practitioners ▪ Being listened to and taken seriously ▪ Embeddedness in social networks ▪ Being informed and guided while maintaining a sense of control ▪ Feelings of gratitude versus powerlessness, anger, disappointment and/or sadness	▪ Renewed sense of time and temporality as horizon through which life is given meaning: viewing life as (un)completed, adopting attitude of gratitude, setting goals ▪ Time as limited resource: weight of uncertain prognosis	▪ Underscoring personal traits: being positive, being courageous, a fighter while balancing between hope, anxiety and acceptance ▪ Maintaining a sense of self in light of changes in physical capabilities or roles: rearticulating the meaning of being a 'palliative patient' ▪ Investing in post-self (posthumous reputation): role of memory objects	▪ Importance of being informed about the process, particularly in the context of palliative sedation: witnessing suffering and pain of loved one ▪ Fulfillment of wishes of dying person (frequently centered around euthanasia) and communication surrounding the end of life ▪ Dying process as moment of intensity, beauty and connection: meaning of being there, caring and 'at ease' until the last moment

**Dark grey column: unique to bereaved individuals' narratives*

Axis 1 – Sense of support: Feeling supported versus abandoned on multiple levels

Many narrators spoke of fluctuations in physical and mental status, sequences of treatment failures and successes, and pivotal moments requiring difficult choices. During the analysis it became clear though that the way these aspects were experienced seemed less tied to the severity of the issues, than to the sense of support people felt during the whole process. Often stories were characterized by a recurring thread of 'feeling abandoned', or conversely, 'feeling supported' on multiple levels: by health care practitioners, family, neighbors, government institutions, or society at large.

Key elements of this sense of support were being seen and listened to by the personal as well as professional health care environment, and, having open, empathetic conversations with health care providers:

> *"For two years, I tried to convince her doctor and my own family members that something was going wrong. [...] Months went by, no one listened..."* (bereaved daughter – shared online).

This was also closely connected to the trust people expressed towards their doctors: *"my doctor really listens to me, I could almost call him a friend after all this time*" (Citizens' Forum participant with incurable cancer). Another key element within this axis centered around the meaning of having a social network to lean on and this was touched upon in different forms across stories: while some reflected back on the invaluable support they or family members receive(d) from these networks, others expressed worries for themselves or others because of limited networks. Some stories also conveyed the significance of professional caregivers being attentive to the (limited) social networks people have. In the quote below, a person who lost his mother at the age of 16, reflects on this relational focus and the sense of support derived from it:

> *"The first evening and night after her death, I was, of course, alone at home and realized that this was now my new situation, without family members and without any idea of what my future would hold. [...] I decided to go to the palliative care unit since I had felt the genuine care there that I needed. The entire team present at the time took fantastic care of me, talked to me, and eventually made a bed for me in an available room where I spent the night."*

Being informed and guided throughout the process, without losing a sense of being in control, was another key element of the sense of support emphasized in the narratives:

> *"The value of how we experienced the palliative process when we went through it as a young family, that was actually... the support. So maybe that word is sufficient. They stood beside us and they stood behind us, but we remained at the steering wheel."* (Citizens' Forum participant who lost her husband)

Conversely, many stories emphasized a lack of guidance on a practical and/or emotional level, by having to find out everything themselves, through the absence of the previously mentioned relational focus (e.g. focus on the patient and not his or her loved ones), by not fitting the ‘patient profile’ of organizations, or not being ‘sick or inactive enough’ to be offered support:

> *"As a caregiver, I received absolutely no support, everything was for the patient. I still haven't processed that trauma because what you go through when your husband is dying is no small thing. Also after his death, all the help suddenly disappeared, and it was like: 'you're on your own'."* (family caregiver – shared online)

> *"So now I am not being treated for cancer... and not for anything else either. I don't know if I have 1 year left or maybe 15 years. I can't make any future plans. [...] I also have no idea what I should do to leave my partner as well off as possible, both financially and emotionally. In short... I am palliative and could use some care and guidance, but as long as I'm walking upright, working, and putting on a grin, I don't get any care offered."* (person with incurable cancer – shared online)

When people narrated on these negative experiences, they often -explicitly or implicitly- emphasized feelings of powerlessness, desolation, anger and/or sadness that they themselves or their loved ones do/did not receive proper care and have/had to suffer needlessly. On the other hand, when the stories were focused on the support one feels or has felt, people often expressed immense gratitude.

Axis 2 - Being-in-time: Shifts in the subjective experience of time

The second axis of meaning revolves around shifts in the way time was experienced, as said literally by one of the (online) narrators: "*Time takes on a different dimension at the end of life. Every day of delay feels like a year*". On the one hand, this involves a (renewed) sense of time as a limited, most valuable resource and not knowing how much time one has/had was frequently mentioned as a continuous burden:

> *"The difficult part, as I've said before, is that uncertainty. So yes, I'm still doing relatively well now, sometimes better than others, but for how long... [emotionally:] When will they bring bad news?"* (Citizens’ Forum participant with incurable cancer)

Time in this sense was not just about the quantity of life left but just as much connected to the quality of life, to enjoying life as much as possible. Bereaved narrators often reflected back with gratitude for the time that was spent meaningfully with each other, and conversely, with regret when they did not have these moments or time was taken away from them because of unnecessary treatments or bureaucratic procedures.

On the other hand, the stories also reflected a (renewed) sense of time and temporality in a more abstract sense: as the horizon through which life was given meaning, particularly in the way people (persons with serious illness as well as family/friends of seriously ill persons) adopted an attitude of gratitude, set meaningful goals (often surrounding helping others), or judged life as completed or uncompleted:

> *"[My husband] frequently said how happy he was to have so much luck in his life. It may sound strange for someone who is afflicted with such a serious illness, but he had a whole array of evidence where he had come out as a 'lucky guy' time and time again."* (shared online)

When life was judged as uncompleted, allusions were sometimes indirectly made to the unfairness of this person becoming seriously ill in relation to age or the way somebody had lived:

> *"I am 45 years old and have an incurable illness, so palliative. I have two children aged 9 and 13. These should be the most beautiful years of my life, and I am dying?"* (shared online)

Axis 3 – Constituting a sense of self while coping with life-threatening illness

When persons with serious life-threatening illness described in their narratives how they chose to deal with their illness, or likewise when family caregivers reflected back on how they or their sick loved ones coped, very often this was connected to implicit or explicit reflections on who they are/were as a person. Being positive for instance was often mentioned not only as the way somebody dealt with the illness but as well as an innate, defining characteristic that served as a continuous source of strength.

> *"I can deal with this in two ways. Either I choose the negative path, curl up in a corner, and slowly wither away, or I choose to face it in a positive way, a way that appeals to me because I've always had a positive outlook on life and never shied away from any challenge."* (person with incurable cancer – shared online)

The majority of stories showed the difficulty of acceptance and rather accentuated an attitude or desire to *"keep on fighting*", connected to bravery and courage. Even when people stated they had accepted the illness of themselves or their loved one, expressions of hope were still present, indicating the complexity and continuous struggle of dealing with serious illness and the prospect of demise. Additionally, expressions of anxiety were paramount in the stories of seriously ill persons. Some spoke of a continuous anxiety, while others specifically centered around fears for having to suffer at the end of life, becoming care dependent or being a burden to others:

> *"I can't accept that I'm sick. I've had 22 rounds of chemotherapy now and I've crashed. [...] Dealing with this as a relatively young family is very tough and confusing. I live in constant fear. Fighting, trembling, and hoping."* (person with incurable cancer – shared online)

The narratives also portrayed the drive to constitute a sense of self in light of changes in physical capabilities or social roles. A desire for a continuity of identity and keeping a certain image of oneself intact often became palpable:

> *"I learned a year ago that I will be blind within 2 to 4 years. I live for my family, gardening, playing music, and light. I have led a very fulfilling life as an engineer, active in multiple parts of the world. [...] Now, I am growing into a dependent man who will have too little time to embrace life as a blind person. My life will be lived, and my wife, children, and grandchildren will witness their husband, father, and grandfather transition from an independent rock to a needy soul."* (person with incurable illness – shared online)

Connected to this, reference was sometimes made to people not recognizing themselves in the image of a 'palliative patient', as touched upon in the quote below:

> *"I am also palliative, but I am sure no one will call me that. Should this term change? Isn't palliative care just that bit closer to the end? Do cancer patients want to be reminded of that?"* (person with incurable illness – shared online)

The emphasizing of certain defining characteristics and the desire to keep a certain image intact, can also be seen as reflecting the way in which people, persons with serious illness themselves as well as their loved ones, work towards creating and investing in a certain image of the person to survive after death (post-self). Memory objects also play a role in this: in awareness of imminent death/loss, people wrote books or collected personalized objects to give to their loved ones. These memory objects kept someone's image 'alive' and were a big source of comfort for the bereaved.

Axis 4 - Specific to the stories told from the perspective of a bereaved person - Between a good and bad death: Going through the process of dying

Within the narratives of people who lost a loved one, the impact of witnessing the process of dying became clear. Several recurring elements emerged that appeared to influence how the dying process was experienced and given meaning. The first one was a very clear need for information about what to expect during the process. Uncertainty or not knowing what was happening with their loved one, was experienced as highly disturbing. This was often mentioned in the context of palliative sedation. For instance, a participant of the Citizens' Forum reflected on the felt powerlessness of seeing the bodily changes of her dying grandmother and not knowing how to interpret them:

> *"Once the palliative sedation was happening, it was like, 'What's happening now?' and 'Is it normal that she's still doing this?' [...] like when her feet became cold, and she started getting thinner and thinner [...] you stand there looking at it and thinking, 'I can't do anything', 'I can only wait until her body gives up on its own.' You feel a bit powerless."*

The same person also narrated on the luck they had of having a befriended nurse join the process to explain what was going to happen and guide them through it, contributing greatly to it being in the end -considering- a rather positive experience. Bereaved narrators clearly found it difficult to cope with the perception their loved one had experienced pain and suffering and in some cases it seemed that better guidance and being informed about the process could have been at least part of the solution.

> *"I was informed that they were going to implement 'comfort end-of-life care.' [...] My mother passed away after 5 days and 5 nights without eating or drinking. This is now one year ago, and I cannot come to terms with the way she died, namely, 'letting her starve and dehydrate'."* (bereaved daughter – shared online)

Another important element in the experiences of the bereaved was whether the wishes of the deceased were fulfilled or not. When this was the case, bereaved family members felt reassurance, which helped to make the loss more bearable, even when the wishes of their loved one were conflicting with their own.

> *"My husband absolutely did not want to go back to the hospital. He died at home with me and the children there and he had not chosen euthanasia. Unfortunately, he became very ill towards the end and so there was no peaceful and gentle end of life. I know how tough it is to experience this up close. But it was his choice, and I can't be angry with him or myself for it."* (shared online)

When it was clear wishes were not fulfilled, this was an important source of regret and guilt or sometimes anger towards the persons deemed responsible for not being able to fulfill the wishes. The unfulfilled wishes most often revolved around euthanasia and repeatedly palliative care was perceived and/or experienced as being in opposition to it, with or without explicitly connecting it to Christian or Catholic values:

> *"After a brave battle but above all, an intense period of suffering, he asked for euthanasia. It was promised but instead, he was transferred to the palliative care unit. I believe the hospital's Catholic approach did not allow for euthanasia; that's how it felt to me. I knew nothing about palliative care,*

> *and to me, this sounded the same as 'going somewhere to die with a Catholic sermon every day about resurrection and life after death."* (bereaved wife – shared online)

Linked to this, a strong association of palliative care with palliative sedation or the administration of medication (most named is morphine) to induce death was present across many stories and while for some these were rather positive experiences, others spoke of "*controlled suffocation*", a "*horrible long death struggle*", or palliative care being the ones to "*bring death closer*".

> *"In the Christian environment where he was cared for, in the palliative care unit, euthanasia was rather a taboo, and constrainedly the path of palliative sedation was taken. For me, it was witnessing a horrible long death struggle that is forever etched in my mind."* (bereaved daughter – shared online)

> *"A while later, my wife said that she had requested euthanasia. She didn't know what it meant, but she had heard about it there. Next day, the palliative [care team] was already there ey! Very friendly and all but they slowly guided her toward death. They administered morphine through a pump until the moment…"* (bereaved spouse – shared online)

This last quote illustrates how experiences and interpretations of palliative care were impacted by confused understandings of medical end-of-life practices, with the death of his wife, in his experience and interpretation, being 'delivered' by the palliative care team. The quote also shows how the wishes of dying individuals weren't always clear and bereaved persons sometimes expressed doubts about whether they had made the right choice concerning medical end-of-life decisions. In this context, the need to talk about the end of life for family and loved ones became clear: on the one hand, to know about wishes people have and one the other hand, to share thoughts, feelings and fears about the end of life:

> *"The fact that there could be communication about what was going to happen and what ultimately did happen made it much, much more beautiful…beautiful is a difficult word in this context but…it made it somehow softer."* (Citizens' Forum participant looking back at the death of his nephew)

For some this not having talked about the end of life, "*the elephant in the room*", was directly connected to regret, having a more difficult time to process it, and expressing a need for guidance during these moments:

> *"I am left with this question: what did our mother think, what did our father think, what did my brother think? We never reached a point of communication. And then you stand in the hallway and… your brother has died, your father has died, your mother has died. They are gone, you can't say another word to them."* (Citizens' Forum participant)

Others rather emphasized that by not talking about it, they respected the wishes of the deceased who had 'the right to not talk about it'.

In sharp contrast with the negative stories of bereaved narrators, the moment of dying was at times also articulated as a moment of intense connection and even beauty. The dying of a loved one in those cases was brought as a positive memory while people looked back on the warmth and connection felt between everyone involved and the intensity of going through it together. Caring for a loved one up to the last moment of life, was several times expressed as meaningful and an aid in processing the loss (whether or not articulated as well as burdensome). Feeling at home, at ease in the place somebody died (not necessarily the personal home) was another important aspect and palliative care teams were repeatedly praised and offered words of gratitude for enabling this through their commitment:

> *"The affection we experienced there, both herself and us, was like a warm bath, a warm nest we found ourselves in. Attention to so many little things, like an extra Virgin Mary statue in her room, preparing what she liked, a Duvel [beer] instead of water, … It only lasted a few days, but those few days became very beautiful days. Days in which gratitude took over from sorrow."* (bereaved daughter – shared online)

4. Discussion

Summary of main findings

This narrative inquiry study involved the analysis of personal narratives surrounding experiences with palliative care, serious illness, and the end of life, collected in the context of a public engagement initiative on palliative care in Flanders, Belgium. Our reflexive thematic analysis generated four axes of meaning: 1) 'Sense of Support', describing feeling supported or abandoned on multiple levels with key elements of open and empathetic communication, being informed and listened to; 2) 'Being-in-Time', incorporating a renewed sense of temporality and the weight of uncertain prognosis; 3) 'Constituting a Sense of Self while Coping with Life-Threatening Illness', involving concerns surrounding role adjustments and posthumous reputation; and 4) 'Going Through the Process of Dying', highlighting the importance of being informed during the process and honoring the wishes of the dying person. Together these four axes of meaning provide a deeper, contextualized insight into the way palliative care is perceived and given meaning.

What this study adds

While our findings resonate with several themes previously identified in the literature surrounding personal experiences with serious illness and the end of life, our study contributes to this literature in several ways. Firstly, within the wider literature, emphasis is often put on psychosocial experiences of loss, including the suffering connected to a 'loss of self' and increasing social isolation[36–39]. While many of the narrators in our study struggled with changes in social roles, capabilities and limited support networks, overall the emphasis was not on loss and the consequential suffering derived from it. In particular, our findings surrounding the various strategies to foster a sense of self reflect what has been called "lived multiplicity", that is: rather than being nested in-between states of being well or sick, or living and dying (which typically is coined under the term liminality), people can experience different understandings of their situation concurrently, while their experience of the self is still characterized by continuity[40]. Within the narratives, articulations of hope or positivity often coincided with articulations of acceptance or fear, and narrators who actively negotiated the meaning of being 'a palliative patient' explored these various positions from within a seemingly coherent sense of self. The active and dynamic work to constitute oneself in the face of experienced challenges, in this sense, does not necessarily imply the loss, or coping with the loss, of the self as a coherently experienced 'entity'.

Secondly, many of the key elements within the axes of meaning can be theoretically interpreted as ways to establish and position oneself more firmly as a moral subject into the social fabric of life. For instance, the adaptation of an attitude of gratitude and the emphasis on positivity not only reflect a search for and/or discovery of new (existential) meaning[41], but can also be understood as ways to continue to engage in relations of reciprocity[42,43]. In her article on two ethnographic studies among adults with life-threatening illnesses and home-dwelling frail elders and their caregivers in Japan, Long[43] argues that changing temporal experiences constitute 'moral timelines' in which attitudes of gratitude and positivity demonstrate "*a continued desire to live in society as a full human being [...] These attitudes contribute not only to their relations with others, but give their own lives continued purpose when the future of life is short*"[43(p39)].

Thirdly, our findings highlight the co-constructed, relational nature of these meaning-making strategies, going beyond being mere individual coping mechanisms dominated by a "language of loss" and a heightened self-concern as Charmaz[37] had found in her classic study with patients with chronic "debilitating" illnesses. Aspects such as gratitude, positivity and viewing life as fulfilled or not were not just emphasized in narratives of patients but also in those of family caregivers and loved ones. By bringing together these various narrator perspectives, our results illustrate how meaning-making in the face of serious illness and the end of life is relationally constructed, and continues to resonate within the lived experiences of those who stay behind after the seriously ill person has died.

Thus, rather than highlighting the suffering from a loss of self and social connectivity, the narratives primarily reflected narrators' agency and resilience in response to the challenges of serious illness and the end of life. Importantly, this also needs to be understood within the unique context of our data collection. Instead of being shared in the private, intimate setting of a one-on-one interview, the narratives were shared in the highly public context of the public engagement initiative ("The Palliative Debate"). By being recognized as experts through their lived experiences, and by being able to shape the public debate surrounding palliative care, we suggest that the sharing of personal stories -often containing intimate, personal, and emotional details- also fostered a sense of purpose and self-empowerment. Many explicitly expressed a hope that their stories would help others. Labov (in Ochs & Capps[27(p26)]) stressed that narratives about personal experiences have a point to make and in the context of the public debate, this may be understood more explicitly than the sole implicit realization through narrative plots. This aligns with findings from Metzger[44], who noted similar strategies of self-empowerment and the striving for community connection in the ways severely ill and dying individuals engaged in 'expressive endeavors' such as blogging, writing and sharing of photographs. Through the public sharing of their experiences and struggles, Metzger's interlocutors influenced the emotional style and tone of the public debate about serious illness, just as - we believe - the narrators in this study aimed to do.

Against this background, the findings of this study also foster a richer understanding of the wider personal as well as sociocultural context in which meaning is attributed to palliative care. Gratitude was evident in stories that reflected positive views on palliative care which, in line with our axes, were built on experiences of feeling supported, being guided through difficult times, being informed and listened to and receiving the time, space and liberty to say goodbye in the way one wants. Conversely, stories that reflected negative perceptions of palliative care often narrated an experienced lack of access, support, information, guidance and/or not honoring end-of-life choices. Particularly in relation to the latter, negative perceptions towards palliative care were often connected to the view that palliative care is in conflict with the practice and principles behind euthanasia, as well as confused understandings surrounding palliative sedation. Views on palliative care were then also fueled by (conflicting) perceptions of the practice of palliative care with the norms and values the narrators adhered to (for instance surrounding the right to self-determination) and the broader societal discourses these belong to. Prior research has shown how the values of choice, autonomy and control play an important role within public discourses surrounding a good death in Belgium as well as the Netherlands[21,45,46].

Our study adds to this literature by highlighting how people differ in the way they connect these to palliative care, particularly concerning medical end-of-life practices.

In relation to this, our results offer an important nuance on the assumptions about stigma surrounding palliative care. Within the literature this stigma is often described as a consequence of the reduction of palliative care to terminal care and the induced fear and anxiety connected to death and dying[11,12]. Yet, even though palliative care was clearly connected to the end of life within the narratives, this was rarely (in itself) negatively charged. Our study suggests that, instead of merely embodying a broad negative perception linked to the idea of palliative care as exclusively terminal care, stigmatized attitudes towards palliative care may also be connected to, or at least be influenced by, public views on end-of-life practices. A Dutch study on the public perceptions of palliative sedation also found that, even though most of the Dutch general public accepts the use of palliative sedation, confusion exists about what palliative sedation represents, sometimes equating it with euthanasia or describing it as starvation[47]. In addition, despite the fact that palliative care and euthanasia do not exist as contradictory practices in Belgium[19], the findings of this study highlight that the relationship between palliative care and euthanasia is often still perceived as contentious and in need of clarification to the public. This need is particularly significant given the differences in interpretation and implementation of the euthanasia law depending on the religious affiliations of healthcare institutions[20]. Mitigating the public ambiguity regarding end-of-life practices, might also go a long way in reducing the stigmatization of palliative care.

Importantly, this implies going against the emerging tendency to try to conceal the end-of-life component of palliative care despite its continued importance[3]. Rather than leaning on the assumption that we are living in death-denying societies, it might prove more fruitful to explore contemporary narratives of death and dying[48] and to engage with more nuanced concepts, such as Paul's concept of 'death ambivalence'[49], to understand our socioculturally influenced relationship with death and dying. The context in which we were able to collect these narratives also hints more at "*an expressive culture of dying and death which values expression of and talk about feelings*"[44(p5)], rather than to a broader culture dominated by death-denial. As stated before, consistent, positive language surrounding palliative care is needed to break its stigmatization[25] but this does not necessarily mean avoiding or disguising death and dying as essential components. On the contrary, as also found in other studies, our study showed the importance of being guided and informed during the process of dying[50,51] and making people feel at ease, at home during the process[52]. The indispensable role palliative caregivers had played in this was often emphasized within the narratives. By tapping into the generated axes of meaning and highlighting the multifaceted nature of support derived from palliative care, public communication on palliative care has the potential to contribute to a more nuanced and positive public understanding of palliative care, while resonating with the inner worlds and experiential spheres of a wider audience, including those who may not have direct experiences with serious illness and palliative care.

Moreover, as an additional recommendation for public communication on palliative care, we suggest incorporating the importance of relationality within lived experiences, which emerged clearly across all four axes of meaning. People among others narrated on the impact of interpersonal relationships with caregivers, their needs in facilitating conversations with loved ones, or the importance of care being oriented towards persons' social embeddedness (e.g. offering care not only to persons with serious illness but as well their loved ones and recognizing when someone has limited social networks). A previous study on family carers' experiences with palliative care home services likewise found the relational component emerging as an underlying key aspect of those experiences[53]. By highlighting and visually portraying palliative care's fundamental relational focus, its building of supportive social environments[54], public education efforts might effectively reach and engage a wider audience through the reflection of the interconnected nature of their own lives.

In addition to the above-mentioned recommendations, the findings of this study also underscore the need to enhance existing support systems. Reflecting findings from the wider literature[55,56], our exploration of personal narratives illuminated a broad range of support needs in people confronted with serious illness and the end of life, many of them being unmet. As argued in the Report of the Lancet Commission on the Value of Death, healthcare systems have become the central context in which many encounter serious advanced illness, dying and death while family and community settings have been pushed to the margins[6]. Yet, healthcare systems are under major pressure globally[57] and in urgent need for strategic health system changes at the macro-, meso- and micro-level to address pressing challenges such as inequity in access[58]. Reflecting on the broad range of support needs and the meaning of having social networks to lean on, both elucidated in the narratives, it would thus seem desirable that support systems also be enhanced through the creation and cultivation of meaningful partnerships with diverse actors and organizations from the wider society. Importantly, this also involves exploring already existing resources and initiatives, such as online support forums where people facing death and bereavement resist the medicalization of dying and grief, finding support for needs unmet by formal healthcare systems[59], and learning from these ongoing efforts.

Strengths and limitations

A considerable strength of this study comes from the combination of various narrator perspectives and various sources of material. This significantly enhanced the depth of our study, with the convergence of axes and key elements across diverse data underscoring their weight within people's interpretations of experiences. The study also has some limitations. Because we only conceptualized the research aim and design during the public engagement initiative, our initial focus was not only on stories specifically but also on citizens' ideas on the future organization of palliative care. Because of this, the researcher present at the Citizens' Forum had a very general, open observational focus and might have missed specific elements that could underscore or challenge the meaning attribution and interpretation within stories (body language cues for instance). Also, more direct questions about personal narratives could have been asked to participants. In addition, persons responding to the public engagements initiative's call for participation may not represent the full diversity of Flemish society. Varying digital literacy skills, for instance, could have impacted inclusion of a more diverse range of narratives. Lastly, our chosen approach of the analysis of narratives also comes with a limitation. In the process of generating the axes of meaning across stories, unique aspects within stories are necessarily downplayed. Additional narrative inquiry studies employing alternative approaches would therefore be valuable.

5. Conclusion

Personal narratives count as a valuable source to gain insight into dynamic processes of sensemaking and our human efforts to strike *"a balance between being an actor and being acted-upon*"[60(p182)]. The axes of meaning derived from analyzing narratives surrounding palliative care, serious illness, and the end of life, aid a deeper understanding of perceptions of palliative care, by situating them within a broader personal and social context. Together, these insights can play a crucial role in shaping effective initiatives to enhance public awareness, receptivity, and engagement with palliative care, ultimately reducing unnecessary suffering and improving wellbeing throughout the illness trajectory and bereavement.

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Part II

Public communication on palliative care and its reception

Chapter IV

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 toward 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[1]. 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[2–4]. Yet, multiple studies within various local contexts have shown that the awareness and knowledge of palliative care among the general public tends to be low and many misunderstandings persist[5–9]. 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[10,11] and this has led many to argue for the necessity of broad education on palliative care[12].

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[13–15]. Research furthermore affirmed the internet as an important source for people searching information on palliative care[6,16]. 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[17], cancer center homepages that rarely even mention palliative care[18], 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[19]. 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 toward 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 online information on palliative care disseminated by 56 diverse organizations in Flanders. 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[20]. 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[21]. 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*"[22(p20)]. Importantly, discourses are never fully stable and essentially incomplete by nature[23]. 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*"[24(p377)]. 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.

Box 1. Discourse-theoretical concepts

Nodal points: nodal points are what Laclau and Mouffe call "the privileged discursive points of partial fixation"[25] and "every discourse has one or several such nodal points, which together define how this discourse is organized and which meanings it articulates"[26(p10)].

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"[25(p91)].

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"[27(p28)].

Subject positions: relates to "the positioning of subjects within a discursive structure"[28(p253)] 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"[29]. 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"[21(p110)].

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. 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[30], 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*"[22(p28)]. 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 another, and what meaning potentials do they exclude*?"[27(p29)]. 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[31] and by using the NVivo 12 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. Furthermore, MM 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, ND, 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. A table listing all analyzed organizations, their websites, and the included documents found on these websites, is provided as Appendix 7.

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 indicating 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 support service, webpage].
  >
  > *“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].

  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].

  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:

  > *“Incurable ill persons with 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 for public health, webpage].

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].

- **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].
  >
  > *“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].

  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 labeled: 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].

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 instance, 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 no longer receive, want or to which their illness has been unreceptive.

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 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 toward 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-denial 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 topic of interest and conversation within society. This was also expressed in 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 [...] 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].

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].

The third nodal point, compassion, refers then to the committed and compassionate attitude of 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’ were 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].

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, information brochure].

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].

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].

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 toward 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 incurable illness"* [palliative care field organization, press release].

   Improving 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].

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, policy text on euthanasia].

The articulation of autonomy from its social embeddedness is a crucial part of this and what is emphasized then is acting respectfully toward 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].

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 the 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].

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 potential limitation of this study was that the data analysis was mostly done by the first author of this article. 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 (Flemish 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[32]. From in the beginning palliative care played an important role in the debate leading up to the legalization of euthanasia[33] and in the Belgian context they are said to have developed side by side[34]. 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[19]. The relevance of this becomes even more clear if we take into consideration the projected increase of palliative care needs within the population[35] 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[36,37]. 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 toward 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[38]. 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[39(p229)] 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[40–42].

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[43].

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[44]. 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[45]. 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)[46] who focused on persons with advanced cancer seeking life extension through bio-medical treatments, or, by exploring participants' 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)[47].

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?

5. 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.

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Chapter V

Public awareness campaigns on palliative care: applying a multidimensional model to understand the reception by the general public

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Abstract

Public awareness campaigns on palliative care aim to tackle limited public knowledge and negative perceptions of palliative care. However, little is known about their public reception. This study examined how existing campaigns are interpreted, evaluated and engaged with by members of the general public. Three public campaigns, launched in Flanders or the Netherlands between 2020-2023, were discussed in ten focus groups (total of 65 participants). The analysis was guided by the Multidimensional Audience Reception model. Our results show that campaigns were interpreted, evaluated and engaged with in highly divergent ways. People with personal experiences surrounding serious illness were generally more open toward campaign messages, while a sense of personal relevance was lacking for others. Campaigns that centered on the perspectives of seriously ill individuals while portraying them in active and resilient positions were more positively evaluated. Moreover, they were more successful in broadening perceptions of palliative care beyond being hospital-based end-of-life care for severely ill and care-dependent persons. Conversely, materials that neglected the patient's voice while framing palliative care as enabling moments of joy 'despite serious illness' generally fortified prior perceptions and were often rejected. Additionally, a preference for highlighting the social context surrounding the patient was repeatedly expressed. We conclude that diversified strategies, optimizing a sense of personal relevance, are needed to more effectively influence public understanding and engagement toward palliative care. Destigmatizing palliative care also involves destigmatizing persons with serious illness and representing them with an emphasis on their agency and strength is vital to this.

1. Introduction

The global burden of serious health-related suffering is projected to nearly double by 2060 due to ageing populations and the rise in non-communicable diseases[1]. This trend underscores the growing necessity for palliative care, which has evolved from focusing primarily on end-of-life cancer care to encompassing early integration into the treatment of all life-threatening health conditions[2]. Moreover, next to a focus on health services, palliative care emphasizes community development, i.e. the strengthening of social networks around people with serious illness through partnerships with local communities and civic sectors[3].

Despite these advances, a lack of awareness, understanding and recognition of the meaning and scope of the palliative care approach challenges its further development and integration into societies and health care systems[4,5]. One of the most persistent perceptions, as shown across studies involving the general public, patients, informal, and formal caregivers[6–10], lies within the conflation of palliative care with end-of-life or terminal care. This conflation creates a cycle wherein referrals to palliative care occur too late, perpetuating the perception that palliative care is synonymous with end-of-life care[11]. Additionally, palliative care tends to be perceived as something people passively resign to, instead of actively choose[10,12]. These perceptions of palliative care may lead to fear, hesitation, or reluctance among patients and/or family members to discuss, consider, and accept such support, alongside the belief that it is not relevant or beneficial for them, thereby presenting a substantial barrier to timely access and uptake.

Given these observations, there has been extensive advocacy for broad public education initiatives on palliative care[13,14], including public awareness campaigns as one promising approach[15]. Public awareness campaigns are understood as organized communication activities directed at the general public (often taking the form of mass media campaigns but not limited to this), aiming to create awareness, behavioral change and better outcomes surrounding a particular topic[16]. On an international scale there has been a wide range of public campaigns on topics surrounding palliative care[15]; however, the predominant focus tends to be on end-of-life care and normalizing death and dying, rather than promoting a broader perspective and early integration of palliative care[17]. Furthermore, while education programs for health care providers have proven effective in improving knowledge, attitudes and confidence in palliative care[18], the limited initiatives directed at the general public remain understudied[19].

This study aims to fill this gap by examining how members of the general public interpret, evaluate, and engage with public awareness campaigns on palliative care. Investigating the diverse ways in which individuals with various backgrounds, beliefs, and values understand and respond to public campaigns on palliative care can provide valuable insights and tools to advance the development of effective and accessible communication strategies.

2. Methods

We conducted a qualitative audience reception study, using a semi-structured focus group design. Leaning on theoretical premises of audience reception research, the audience is understood not as passive receivers of the message, but as actively engaging and making sense of it from within societal and situational contexts[20]. Polysemy, and the broader, related concept of meaning multiplicity, i.e. the phenomenon of a text invoking multiple interpretations[21], form a central theoretical point of departure in this. Rather than assuming the absence of interpretive divergence, our interest lies in shedding light on the range of possible audience readings' and understanding the sociocultural patterns within. Additionally, audience reception (and our interest) goes beyond interpretive repertoires and also encompasses facets such as motivational aspects, attitudinal responses, engagement with textual construction, and the influence of the 'textual encounter' on the daily life of its readers.

Sampling and recruitment

To fuel the inclusion of a wide range of voices and experiences, we aimed for a combination of natural groups (involving participants who know each other) with constructed groups (relative strangers) and adopted a maximum variation sampling strategy[22]. As recommended in the literature[23], our recruitment technique consisted of three stages (prepare, contact and follow-up) and a multi-layered strategy, combining an 'active fieldwork approach' (collaborating with gatekeepers of diverse sociocultural organizations as well as directly engaging people at local libraries and markets) with a more 'standard approach' (widespread call for participants through posters and channels of stakeholder organizations). Participants had to be adults (18+), residing in Flanders and not professionally involved or volunteering in chronic care or palliative care settings. Additionally, a basic understanding and conversational skills in Dutch were needed since all campaigns were in Dutch. However, in the absence of this, participants could still participate if their native language was shared by one or more other participants in the focus group (who could assist with translation) and if they had a basic understanding and conversational skills in French and/or English.

Data collection

Focus groups were held from October through December 2023, mainly in the region of Ghent, Flanders. Groups were not divided by age, gender or other sociodemographic characteristics since the actual evidence that homogenous group composition facilitates comfort and disclosure is rather limited and often based on stereotypical assumptions of group dynamics[24,25]. The focus groups followed a semi-structured format covering a limited number of open-ended questions (see topic guide as Appendix 8). Data collection and analysis followed an iterative process and, following a pragmatic approach to saturation[26], until findings thoroughly reflected analytical depth, conceptual clarity and insight regarding our research question.

Campaign materials

We reached out to the two main umbrella organizations for palliative care, one in Flanders and one in the Netherlands, both actively involved in raising public awareness about palliative care in Dutch. We inquired about any recent public campaigns and requested their willingness to share related materials for our research purposes. Three campaigns were subsequently shared, which were all included in the study. A concise overview of these campaigns can be found in Figure 1. A more extensive overview of the materials, as well as our researchers' reading (interpretation) of them, is provided as Appendix 9. All campaign materials, except websites, were shown in each focus group, with the order of campaigns and materials varying.

Figure 1. Overview of the three public campaigns used in this study.

C1: 'Care and so much more' (Dutch: 'Zorg en zoveel meer')

- Launched in 2020, in Flanders and Brussels, Belgium.
- Consists of 3 radio spots, 3 posters and 1 information folder, all referring to a campaign website.
- Main slogan (with variations): "*Erik loves how relaxed his dog is. Thanks to palliative care he can enjoy this, despite his illness.*"
- Researchers' reading of main concept: All materials visualize or audibly represent specific things loved by different (imagined) persons with serious illness. Through this, the campaign emphasizes the vital role palliative care has in creating the conditions in which persons with serious illness can still enjoy the things they love.

C2: 'When you are no longer getting better' (Dutch: 'Als je niet meer beter wordt')

- Launched in 2022, in the Netherlands.
- Consists of 2 video spots and 3 information folders, all referring to a campaign website.
- Emphasis is put on personal quotes and the campaign as such does not have one prominent slogan, although the sentence "*Palliative care offers quality of life when you are incurably ill.*" is featured in all materials.
- Researchers' reading of main concept: Materials are all anchored in the personal testimonies of 3 persons with different incurable illnesses. The main emphasized message differs depending on the protoganist (autonomy; enjoying the small things in life; coping with the broad impact of illness), but all protagonists point out that palliative care helps to achieve those aspects.

C3: 'Beyond cure. Not beyond care' (Dutch: 'Ongeneeslijk. Niet uitbehandeld.')

- Launched in 2023, in the Netherlands.
- Consists of 6 posters, connected to a previously launched website.
- Main slogan: same as title.
- Researchers' reading of main concept: The six posters contain portrait pictures of persons with serious illnesses, all looking straight into the camera, with their name and age included. The main emphasized message is that incurable illness does not imply people are left without support or care and that palliative care is dedicated to providing this.

Analytical strategy

Focus groups were audio-recorded, transcribed ad verbatim and analyzed with NVivo 14. Analysis was done by MM who regularly discussed interpretations and findings with seven members of an interdisciplinary project group established around this study. The analysis consisted of a combination of an inductive (data-driven) & deductive (theory-driven) approach. On the deductive level, we leaned on the Multidimensional Audience

Reception model developed by Schrøder[27] which offers conceptual tools to account for the complex processes through which audiences engage, understand, criticize and respond to media messages. A short description of this model, and the slight adaptation to our subject of public campaigns, can be found in Table 1. Although originally developed with mass-media texts in mind, its conceptual tools have proven fruitful in relation to different genres and materials beyond media communication[28]. The original model contained an extra dimension ('evaluation') which was later removed[29] and, following Schrøder's reasoning for this, is also omitted in our analytical approach.

After familiarizing with the data, the data was processed through a line-by-line open coding and the simultaneous writing of memos. Next, the multidimensional model was applied to organize and interpret the data and inductively produced codes, along the dimensions of motivation, comprehension, position, discrimination and implementation.

Before the analysis, we descriptively summarized the content of campaign materials and its intended messages as we comprehend it from within our researchers' perspectives (see Appendix 9). In line with the epistemological groundings of the Multidimensional Audience Reception model[27], our reading is considered not as a 'privileged master interpretation' of the texts but as one of many possible readings. During the analysis, audience readings were primarily analyzed in relation to the readings produced by the other participants and in a secondary manner, in relation to our researchers' reading of the campaign materials.

Table 1. Summary of the Multidimensional Audience Reception model developed by Schrøder.

Multidimensional Audience Reception Model[20,27,29]	
Dimension	**Description**
Motivation	This dimension encompasses motivational aspects triggering persons to pay attention and actively make sense of texts. It deals with the 'link of relevance' between a reader's personal universe and the textual universe perceived to be presented by the text, extending beyond the text into the whole situation of consumption. It can be based on various aspects such as personal interest in the subject, something in the message reminding the reader of certain experiences, gaining new insights, feeling attached to a character in the text or feeling a sense of belonging in the textual universe. This dimension covers a continuum from strong to weak involvement on which readers may occupy a sustained position or 'commute' between degrees of involvement.
Comprehension	Comprehension is understood as a decoding continuum from complete divergence from to complete correspondence with the readings produced by other recipients (participants' readings as well as researchers' readings of the campaign materials). Theoretically, this leans on the notion that signs are inherently polysemic but meaning is simultaneously stabilized through the workings

	of interpretative communities, which are what make communication possible and which manifest itself in the analysis as socially patterned readings. In alignment with our research subject, this dimension also involves a closer look at the relationship between the audience readings and (prior) perceptions of palliative care.
Position	This dimension encompasses a continuum of subjective attitudinal responses, from acceptance to rejection of the perceived textual position and the various textual elements perceived to make up that position. This liking or disliking of texts is often based on properties stemming from the other dimensions. Importantly, it involves not the acceptance or rejection of a certain intended message but instead, the readers' attitudinal response of what they perceive to be the message. Acceptance of perceived textual meaning happens mostly unaware while rejecting responses are always consciously recognized by readers because the very recognition of attitudinal difference produces an awareness of the existence and struggle of conflicting perceptions of social and cultural phenomena.
Discrimination	In the original model, the central question of this dimension was: are audience readings characterized by an awareness of 'constructedness', i.e., do they recognize the text as a product of human production and creativity (typically taking the form of a 'genre awareness') or do they treat it as a direct portrayal of social reality? In the context of this specific study, we rather presume the audience's awareness of the constructed nature of campaign materials and focus on exploring how they critically engage with the way messages are produced, communicated and disseminated. This includes as well exploring their considerations for future palliative care campaigns.
Implementation	This dimension involves a focus on the consequences of the 'textual encounter' for one's everyday life. This encompasses the relationship between audience readings and (small or big) social and/or behavioral change, going - for instance - from checking more information online to starting a conversation with loved ones about palliative care. This also encompasses changes in knowledge, opinions and beliefs but in our slight adaptation of the model we mainly look at these under 'comprehension'.

Ethical considerations

The public campaigns discussed in our focus groups seek to promote palliative care to those who are unfamiliar with it or hold incomplete or negative beliefs about it. Therefore, it was crucial to capture a wide range of interpretations and evaluations in our study, not limited to participants already familiar with palliative care or with positive perceptions of it. After thoroughly discussing this issue within our project group, we decided not to use the specific term 'palliative care' on the recruitment posters and flyers. Instead, we opted for the more general description of 'care for serious illness' to avoid discouraging participation due to existing unfamiliarity and misconceptions (i.e., overly narrow interpretations) around 'palliative care'[30]. With this choice, we stayed close to the general re-framing of palliative care as 'serious-illness care', prevalent in international literature. We submitted our chosen approach to the Medical Ethics Committee of Ghent University (Hospital) for further consideration. The Medical Ethics Committee agreed with our approach and approved the study on 04/07/2023 with reference number B6702023000405.

While we did not use the specific term 'palliative care' during recruitment, in our in-person contact with potential participants and key contact persons of sociocultural organizations, we made it clear that the topic would be about serious, life-threatening illness and could be potentially sensitive. We emphasized that participation was voluntary, could be stopped at any time without the need for explanation or consequences, and that psychological support would be available if needed. Additionally, potential participants were made aware of some ethical considerations specific to the nature of focus groups (e.g., unpredictability of conversations and issues of confidentiality and anonymity[31]) so they could consider them before giving consent. All participants provided written informed consent prior to enrollment in the study.

During the focus groups, conversations quickly turned to palliative care since all campaign materials explicitly mention the term. Only after participants shared their interpretations did we ourselves name 'palliative care', not just the general description of 'care for serious illness'. We always ensured that all participants were comfortable with the setting and topic, and in none of the ten focus groups was the topic of palliative care an issue for any of the participants.

3. Results

Ten focus groups were conducted, including three ‘natural’ groups (a local women’s group and two groups with participants that knew each other from two different social organizations dedicated to supporting people in structurally vulnerable positions) and seven ‘constructed’ groups. The total number of participants was 65, with focus group sizes varying between 5 to 9 participants. Participants were aged between 19 and 88 years old (mean age 53) and were predominantly female (44 identified as female, 20 as male, and 1 as other). Regarding religious beliefs, Catholicism and Islam were most adhered to (19 and 14 participants, respectively), but the majority (21) were not religious. At least seven different self-identified ethnicities were reported, with most participants identifying as Belgian and/or Flemish (40) or Turkish/Turkish-Belgian (12). Most participants (42) reported personal experience with serious illness and/or bereavement, while 21 had no such experience and 2 preferred not to answer. Educational levels varied greatly. An overview of characteristics across and within focus groups can be found as Appendix 10.

Our analysis revealed large differences between campaigns and campaign materials concerning overall appeal, interpretations, attitudinal responses toward the perceived message, influence on prior perceptions and ability to stimulate further action. In the following we give an overview of our most important findings in relation to each of the five dimensions described in Table 1. An extensive table with more detailed results can be found as Appendix 11.

Motivation

Motivational aspects triggering participants to pay attention and actively make sense of campaign materials, varied widely. In general, across campaigns, whether participants had personal experience with frailty, serious illness, the end of life, and/or palliative care greatly influenced interest and receptivity toward campaign materials. This interest out of personal experience was further strengthened by broader aspects such as the cultural significance of caring for parents, as commented and agreed upon in one focus group:

> *"We all have older parents. I also lost my mom. And especially in our culture [Turkish-Belgian Muslims], caring for the elderly runs very deep. So yeah, I think, whoever has had something to do with it, they will immediately pay attention"* (P55).

Conversely, not being personally confronted with serious illness or palliative care, was very often iterated as a reason why campaign materials failed to appeal. Because of this perceived lack of personal relevance, participants said they would not pay attention to or engage with campaign materials if they encountered them in daily life:

> *"Personally, as someone who isn't sick, who doesn't know anyone who is sick, I don't have much interest in it. That might be selfish, but I can't do much with that message"* (P18).

In addition, participants were more inclined to pay attention to materials when they could recognize or identify with certain elements, while a lack of recognition or identification with campaign elements was often cited as a reason for the materials not being appealing or engaging:

> *"So, I think with these posters... it's all outside of my age category, which also makes me feel a bit less engaged. If the combination were to happen with a teenager or a young adult, then it would be much more relatable or something. Much more representative"* (P46).

A priori negative attitudes toward what was framed as 'advertising' also affected receptivity. Some participants responded with a clear resistance to what they perceived as trying to sell something or "*do something to me"*. Further, the emotional weight or perceived negativity in some materials also played a role and while for some this was a factor pulling them in, other participants immediately disengaged because of it:

> *"It's also not really a topic that [sighs] … yeah, when you're just working and you're already quite deep into your energy, then it's actually not very nice"* (P19).

Lastly, the (hypothetical) context in which campaign materials are received was mentioned to be important, with contextual influence differing depending on personal characteristics and the type of campaign material. For instance: participants differed greatly in typical level of attention directed toward posters in public places, with some participants stating navigating traffic does not allow it, others stating they tend to only glance, and only a few stating that they usually actively pay attention to them. When placed at public transport stops the chance was generally higher that posters would be noticed. The posters of the two campaigns also differed in the sense of connection they created with the audience, with the portraits of individuals making direct eye contact (C3) proving much more successful to gain focused attention than those featuring a dog or bath tub (C1). Various participants also said they would be more inclined to engage with the campaigns if presented to them in a social and conversational setting, among others because of the potential to foster social connections.

Comprehension

When looking at the way participants understood and interpreted the different campaigns, divergent readings were encountered for all three campaigns. Participants at times struggled to understand what the campaigns were trying to accomplish and who they were trying to reach:

> *"I'm still searching a bit for what exactly they want to achieve. It's not that they say: we're collecting money or anything like that… It remains a bit unclear to me"* (P18).

The posters of C1 and C3 were the campaign materials which were met with the most confusion, but the source of confusion differed for both. Because of the chosen images the C1 posters were very often interpreted as being commercials for other things than palliative care, such as day care facilities (image of a child), bath products (image of feet popping out of a bath tub) or dog food or an animal asylum (image of a dog, likewise for the flyer). Also the sentence 'Because of palliative care, he/she can enjoy this, despite his/her illness.' was not always understood. Within the C3 posters, the slogan was the greatest obstacle. The Dutch word "uitbehandeld" (literal meaning 'treatment exhausted'), preceded by the negation 'not' was for many difficult to interpret and to connect to palliative care:

> *"Even though I understand that palliative care is more than just the ultimate last phase of life, I don't understand how this matches with this slogan"* (P38).

In the discussion it then became clear that people often understood 'uitbehandeld' in a purely medical sense, involving only curative treatments. However, for several other participants the C3 posters were immediately clear. Among those the dominant reading was (congruent with our researchers' reading): 'people might be incurably ill, they still need treatment and care, and palliative care gives this to them'. Other people placed less emphasis on palliative care within their reading and more on the persons themselves who were expressing that they could still do things, and still make something of their lives, despite their illness. A few participants discerned several layers of meaning within the posters, including the above ones and saw them as an attempt to destigmatize seriously ill persons among others by portraying them as people that do not necessarily look severely ill. Other, more divergent readings were from participants who interpreted the posters as showing seriously ill persons who were refusing to accept that they were no longer receiving treatment (opinions differed in agreeing with them or not), or somebody who guessed that they were trying to recruit study participants.

In general, there was a discrepancy between participants who did not understand the campaigns because the images or sounds were too far removed from their understanding of what palliative care is, and participants for whom these images were likewise perceived as non-typical, but were nonetheless interpreted as being a part of palliative care and were thus effective in changing their image of palliative care. Interpretations of materials were thus, not surprisingly, closely linked to prior perceptions of palliative care. Conversations surrounding campaign materials revealed that, for most participants, palliative care was clearly connected to the last weeks or days of life, directed at severely ill and care-dependent individuals, and mainly confined to hospital settings:

> *"Palliative is usually, yes, the last step. The last thing you have to go through. Getting sicker, becoming bedridden, having to be admitted"* (P62).

Following our researcher's reading, C1 and C2 most explicitly aim to alter these typical (mis)perceptions. However, while readings were divergent, C1 mainly seemed to reinforce prior perceptions of palliative care, regardless of it being interpreted in a positive or negative way:

> *"It gives me again the image of palliative care as care for the seriously ill, death rattling patient"* (P8).

> *"It's about how she wants to spend her last days, in her garden, hearing bird sounds, while palliative care maybe provided her a customized chair to enable this"* (P62).

On the other hand, C2 was much more successful in challenging prior perceptions. The three most recurring readings were: (1) showing that seriously ill persons can still do things and maintain control over their lives, (2) the value of discussing end-of-life matters and preferences and (3) emphasizing that seriously ill persons are not alone, still belong and palliative care is there for them and their loved ones. Through these readings, participants developed a new understanding of palliative care, and, of persons who might need palliative care:

> *"The core message is that you shouldn't think that someone who is incurably ill, is lying in bed crying all day, so to speak, but they can still make something beautiful of it. That's the essence for me. And then you automatically start thinking further… Your perception of incurably ill people changes a bit"* (P36).

Nonetheless, divergent from these more dominant readings, in two of the ten focus groups, participants struggled to understand the essence of the campaign in relation to palliative care:

> *"They did mention palliative care, but what do they do? What does it mean? […] You don't really get any information on that"* (P44).

Also the specific, abbreviated illness conditions were for some participants a source of confusion, especially COPD (Chronic Obstructive Pulmonary Disease) and to a lesser extent ALS (Amyotrophic Lateral Sclerosis). Several participants asked others what COPD is and a couple of times it was then explained as a *"smoking disease"*.

Position

In general, attitudinal reactions toward public campaigns on palliative care varied between and within focus groups. Positive attitudes were centred around supporting that the campaigns broaden the public perception of palliative care away from purely end-of-life care and offer hope of still having a good life even when seriously ill. Additionally, people found it important to bring themes such as serious illness and the end of life beyond the private confines of family and medical settings, challenging a perceived prevailing societal attitude of indifference. Negative attitudes were twofold: 1) in relation to the target audience and its effectiveness; and 2) doubting the veracity.

1) Participants, mostly those without personal experience, regardless of age, reacted often dismissive toward the fact that these campaigns are directed at the general public:

> *"It is not something you should be concerned about if you are not confronted with it. My husband is fine, my daughter is fine. I shouldn't start worrying about everything that could happen… (laughing) If you have to start living like that, it just won't work"* (P6).

The effectiveness of targeting the general public was doubted, and for some, it was considered a waste of money, suggesting that resources would be much better spent going to the people who actually need palliative care or are responsible for delivering it:

> *"A lot of time, money, and energy is being invested in these campaigns. But what if hospitals would actually pay attention to the people who need it, and inform them properly, wouldn't that be better than all that paper and those people staring you in the face [C3] and then people not even reading it?"* (P10).

In connection with this, participants often pointed out their belief that it is primarily the responsibility of doctors to inform patients about palliative care, especially in advanced stages of illness. Therefore, campaigns should primarily be directed at healthcare providers. However, other participants debated this and, speaking mostly from personal experience, emphasized the importance of empowering citizens and patients themselves, rather than blindly relying on healthcare practitioners to provide information.

2) Several participants received the campaigns with skepticism, not believing that what is shown and promised in the campaigns is what most seriously ill persons actually experience: *"they only show the nice stories"* (P33); is actually possible within our current health care system: *"the problem is you call and then you hear 'ah we'll put you on a waiting list' and then your whole world falls apart again"* (P41); or is only available for affluent people:

> *"They come with a beautiful poster, but then I'm going to dig a bit, and what will I find? That it's actually an empty box. If you're rich and using your own money, you can pay for palliative care. But if you're not wealthy, there will be fundamental obstacles. And then it becomes like a hollow slogan… Well, like a hollow campaign… That is my fear"* (P20).

Many of those people were speaking from their own (negative) personal experiences with the health care system, such as long waiting lists and having to find out everything themselves.

Across focus groups, the Dutch campaigns (C2 and C3) were received much more positively than the Flemish campaign (C1), although some participants expressed a preference for specific C1 materials. Following what has been described under 'comprehension', divergent interpretations of materials were accompanied by divergent attitudinal responses, resulting in a complex picture in which people's responses to campaigns would cross on multiple levels. As an example, while many participants did not understand the C1 radio spots and posters, others interpreted them in line with our researchers' reading, as highlighting the role of palliative care in enabling incurably ill persons to enjoy the little things of life. For some of these participants this was an inviting, positive message, showing it isn't *"all about hardship and misery"* (P14). Many others though rejected it for several reasons. Firstly, the focus on 'enjoyment' was found to be unrealistic, limiting and/or condescending. Participants felt it was painting an untruthful, deceiving *"velvet glove"* picture of palliative care, demonstrating *"a lack of courage to name things as they are"* (P37). Secondly, the choice of objects and sounds (e.g. the rustling sound of wrapping paper or eating a sandwich) caused rejection, often framed as being 'banal'. One participant expressed this recurring sentiment when summarizing the campaign message as:

> *"'Yes, you can still do the bare minimum, but you can't do it alone, you need care for it'. I find this a very strange message to send to people who need care, and I think it also creates a very high barrier because you are telling them 'okay I have to be really low and deep, and then I'll get care'"* (P46).

Several participants also commented on the absence of (the voice of) persons with serious illness themselves, while for others it was not the absence but rather the passive, victimized representation of seriously ill persons that was rejected. The emphasis within this campaign was found to be on serious illness, rather than on the agency of the person and on what he or she still wants or does. Some other participants rather accepted (implicit at first, later explicit in response to others) the implied care-dependency and sidelined agency as neutral and not as something to have negative connotations: *"that's just how it is"* (P47). Regardless, the C1 posters evoked the strongest negative responses of all campaign materials. Conversely, the strongest positive reactions were evoked by the C2 videos. These videos were generally seen as clear, touching and beautiful. Particularly liked was that the perspective of the person with serious illness stood central and that they were portrayed in an active and resilient way, still wanting things from life and making something beautiful of it. Yet, two participants explicitly stated they did not really want to know about any of these persons' personal lives but instead would be interested to hear more about palliative care or the illness itself. Additionally, participants often had different reactions to the two videos but it was consistently noted as positive that the campaign included distinct stories with different emphases. For different reasons, the videos also elicited anger from some participants. For instance, while one person reacted angrily from within his interpretation that the protagonists were denouncing a lack of proper care, agreeing with their stance, another person's anger was connected to not wanting to see content that was thought to be personally irrelevant: *"it's just another one of many; it has nothing to do with me"* (P44).

Lastly, the (dis)liking of campaign materials was also influenced by visual characteristics of portrayed individuals. The inclusion of different age groups for instance was positively valued by several participants. Even so, many of the older participants explicitly appreciated the fact that *"none of them are really old"* (P28):

> *"It doesn't specifically feature an old man or an old lady anywhere. I find that positive because you can be in palliative care at 50 too. So in that sense, I think it's positive, because now palliative care is very often associated with old people"* (P4).

Additionally, many participants considered it credible and positive that the portrayed individuals did not look severely ill or bedridden. For some this effectively changed their image of palliative care and it was believed to convey a strong message that such conditions can affect anyone and positively contribute to destigmatizing people with incurable illnesses. However, for others, this portrayal made it less credible. Those participants often preferred to see images of *"a hospital bed on the palliative care unit"* (P17) or a person *"without hair because of chemo"* (P58), which was then countered by the other participants who asserted that is exactly what they do not want to see. Comprehension and position clearly cross here; with visual cues tapping into common societal images being preferred by some for reasons of clarity, while being rejected by others for being reductive and stigmatizing.

Discrimination

Focusing on the critical engagement of participants with the textual constructedness of campaign materials and their mode of communication and dissemination, the radio spots were mostly considered too fast and too fleeting for messages surrounding palliative care and most participants clearly preferred the other mediums. Regarding the manner of dissemination, in general, it was deemed important to not only disseminate materials in medical settings such as waiting rooms of healthcare practitioners and health insurance funds, but to also disseminate them in public, non-medical locations with suggestions spanning from cultural centers and libraries to hairdressers and bakeries. However, materials and messages should be customized to suit these diverse contexts as the information folders presented in the focus groups were frequently deemed unsuitable for non-medical settings. Further, regarding the C2 videos, some participants expressed a preference for showcasing them as television commercials or public service announcements during regular programming while others preferred seeing them as a topic on a serious talk show or debate, but not as a television commercial.

Many participants also commented on ways to improve the comprehensibility and accessibility of materials, for instance by reducing the amount of text in the C1 posters and C2 folders, shortening sentences and adding pictograms to the C1 folders which were judged as *"too intellectual"* or by adding QR-codes to posters that link to translations. Participants also observed that all campaigns relied heavily on digital skills of people and it was deemed crucial to not only provide a website but also phone numbers and concrete settings where people could go to for more information. Some participants also stressed the importance of adding cost-related information:

> *"The only thing I miss in those brochures... When you're sick, it costs money. You get help, fantastic, but it always costs money. That's never mentioned anywhere..."* (P41).

Opinions further varied regarding the general tone of the campaigns. While some participants emphasized the importance of keeping it positive, light, and cheerful, others preferred a more direct, confrontational and/or emotional approach.

As described under position and comprehension, the way persons with serious illness were represented influenced (divergent) interpretations and evaluations of materials, and this also came back in the reflections relating to visual objects/subjects that participants would place central in future campaigns. Many participants reiterated they preferred hearing about palliative care from persons with serious illness themselves, outside of hospital settings, and shown in an active, empowering manner and not as people to be pitied. Portraying different age groups (although for some there was hesitancy regarding the portrayal of seriously ill young children, as well as the very old), different health conditions and needs, and different social contexts was also encouraged. Regarding the latter, many participants, across focus groups, commented on the absence of a more social gaze within the materials:

> *"In all images and campaigns we've seen, it's only about the patient, but there's much more than just the patient. There is also an environment, there are children, there are parents, there are brothers and sisters, which would certainly be an enriching element in a campaign"* (P38).

Suggestions were therefore given to also show, for instance, friends and neighbors supporting each other, how palliative care can help people participate in social activities in the neighborhood, and how families differ in dealing with serious illness and the end of life, and how palliative care can assist with this. Some participants also wanted to see health care practitioners as part of the social connections around the seriously ill person:

"Not with their stethoscope and white coat… But as humans too" (P37).

In addition, a recurrent suggestion centered around organizing 'conversations moments' in social service centers, mosques, neighborhood health centers, women's groups or cultural centers. At the end of the focus groups several persons stressed the value of the full focus group conversation (and not only, or for some more than, the campaign materials) in having developed a different view of palliative care. One participant for instance commented that the story shared by another participant had significantly broadened her perspective and instilled a sense of hope, surpassing the impact of any materials presented.

Implementation

In half of the focus groups, participants stated at the end that particular campaigns or materials, the conversations or the focus group as a whole had given them a broader view of palliative care and/or would keep them more alert, aware of palliative care in the future. The most recurring new insights being shared were that palliative care is not only limited to the very end and can start early, persons with palliative care needs can still be active and have a good life, and that palliative care can also be offered at home. Other new insights included that palliative care also involves social non-professional support, is not only for older persons, and is not against euthanasia. Most participants stated that the campaigns would stimulate them to search for more information if they were being confronted with serious illness themselves or in their environment. However, when not being personally confronted, participants were a lot more hesitant to state they would act upon the campaigns. Of all three campaigns C2 was said to have the most impact in terms of potentially influencing behavior. For instance, one participant who has a chronic illness and was drawn to one of the protagonist's message of self-determination and having control, would consider palliative care for herself now, while before she had rather negative views on it:

> *"I also had the image of palliative care as being in a hospital room and nothing beyond that. Just painkillers and maybe a nice wallpaper on the wall, but that's it… I used to be against it a bit. It was just prolonging life because they are against euthanasia. But when I hear this now… I'm quite pro-euthanasia. If the end is approaching anyway, then preferably as soon as possible for me. But maybe now I'm starting to doubt"* (P9).

For others the C2 videos trigger further thought on the subject, among others on what it means to be seriously ill, as well as further conversations about the videos themselves.

4. Discussion

Summary of main findings

Our study revealed large differences between participants as well as between campaigns in terms of interpretations, evaluations and engagement with campaign materials. Participants often struggled to connect certain images and slogans with palliative care, leading to confusion and varied understandings of the materials. Many participants also expressed doubts about the relevance, impact and credibility of the campaigns. In general, personal experiences surrounding serious illness, whether direct or involving loved ones, greatly influenced participants' receptivity to the materials, with those having such experiences being more inclined to pay attention and actively make sense of campaign messages.

Our study also highlighted the importance of presenting palliative care primarily from the perspectives of persons facing serious illness while representing them with an emphasis on their agency and strength, since these elements greatly affected participants' attitudes toward campaign materials as well as palliative care perceptions. Connected to this, two of the three campaigns (particularly C2 and to a somewhat lesser extent C3) had a positive impact on perceptions of palliative care, while a third campaign (C1) mainly reinforced prior (mis)perceptions. Additionally, there was a widely shared preference for including a focus on the social context surrounding the patient. Moreover, the importance of having meaningful dialogues in fostering understanding and openness toward palliative care was shown.

Interpretations of main findings

Looking at the divergence in audience readings of all three campaigns, our findings on the one hand shed light on the macro-social factors active in decoding but on the other hand also on the micro-social situational factors as present in the focus group set up. More specifically, readings of materials were intrinsically interwoven with prior (stereotypical) perceptions of palliative care (mainly shown within comprehension), but also on a broader level with views on the meaning of having a serious incurable illness within the context of the Belgian health care system (mainly shown under position). In case of negative views this was often accompanied by emotions such as anger, frustration and sadness, mainly resulting in skepticism and distrust toward what was portrayed and promised in the messages. This was most dominantly present in one of the three 'natural' focus groups, involving participants that knew each other from a sociocultural organization dedicated to people within structurally vulnerable positions of poverty. On a micro-social level, participants in this focus group clearly reinforced each other in their opinions, which relates to what Kitzinger described as complementary interactions toward consensus[32], leading -in this case- to less divergent readings and a rejection of most materials. As has been argued before, distrust in health systems can result in resistance toward health campaigns[33,34], and while it was most clearly present within this focus group, it was encountered across focus groups and across participants characteristics. Moreover, even when group dynamics obscure certain viewpoints (e.g., due to hesitancy to go against a perceived group norm), this in itself provides valuable insights into the social processes and the wider societal context that influence audience reception[32]. Ultimately, these findings show that to be effective, public campaigns cannot be seen in isolation of broader societal structures and conditions leading to inequities in access and a general sense of distrust in underserved populations.

Our findings also show how audience identification and representation intersect with broader societal discourses, in this case particularly surrounding palliative care and ageing, and thus involve more than just seeing oneself in images. While the youngest participants in our study were often not drawn to campaign materials because they could not identify with the portrayed individuals outside of their age-range (dimension of motivation), many of the oldest participants in our study appreciated these materials (dimension of position) for not depicting elderly persons, which based on objective age (yet, not subjective experience) would be their peers. Research on representations of older people in media and advertisement has shown that despite a shift toward more positive portrayals in the 21st century, older individuals remain under-represented, with their depictions often restricted to limited roles, specific products, and common stereotypes[35]. Being a patient in clinical palliative care settings, counts as one of these stereotypical representations. A recent analysis of palliative care stock photos for instance demonstrated how these images typically involve older persons (or their hands) being cared for by younger caregivers[36]. Images shape perceptions of what it means to grow older, and by extension, the treatment older people tend to receive[37]. Against this background, readings of the campaign materials among the oldest participants can reasonably be argued to have been shaped by a rejection of conventional representations connecting old age with disease, decline and dependency, especially combined with a stereotypical, hegemonic understanding of palliative care as clinical end-of-life care for severely ill care-dependent individuals.

Our findings furthermore indicate that public campaigns on palliative care mostly fail to engage or attract focused attention of individuals without personal experience with serious illness, frailty, and/or palliative care. Given the wide call for broad public education on palliative care, spanning beyond those who are immediately affected, this urges further reflection. Understood from within the Elaboration Likelihood Model - a theoretical framework for organizing and understanding the basic processes underlying the effectiveness of persuasive communications[38] - low levels of motivation, fueled by the lack of personal relevance, translate into messages being (peripherally) processed without careful consideration, making potential changes in attitudes and judgements among others more easily affected by emotions, as well as less durable[39]. Stimulating the personal relevance of campaign messages is thus considered an important task within this model[40]. This however is not evident, with previous research highlighting a prevailing perception of palliative care as not being of interest to those who are not directly affected by illness, death or grief and (perceived) social norms dictating that conversations surrounding palliative care belong to the private, intimate sphere of the inner social circle[12].

How can developers of public campaigns then proceed to stimulate the personal relevance to a broader audience? One potential way to do this is by primarily emphasizing social relationships instead of serious illness and its consequences and by tailoring campaign messages to the needs and interests of various broader social circles surrounding persons with serious illness. For instance, following suggestions of participants in our study, by visualizing how people can support their friends, colleagues or classmates going through bereavement or by showing how different families respond to a diagnosis of incurable serious illness and referrals to palliative care. Moreover, seeing the essential role of social connection and relational identity in the way serious illness and care are experienced and responded to[41], a relational focus in campaigns may also enable them to resonate more deeply with individuals currently facing serious illness. In addition, entertainment-education, i.e. a distinct theoretical, practice, and evidence-based communication subdiscipline with at its heart the merging of entertainment and education to engender individual and social change[42], can be considered. Serendipitous learning from entertainment-oriented sources such as television drama series, can effectively serve to change perceived social norms and be a primary form of health information gathering[43].

We further recommend incorporating opportunities for meaningful dialogue about palliative care into campaign strategies. Previous research demonstrated that the effects of campaign exposure are mediated by interpersonal communication and campaign developers are advised to design campaign messages that stimulate interpersonal communication to increase persuasiveness[44]. Organizing conversations with and within local communities, for instance by adopting a World Café approach to conversations surrounding serious illness, the end of life, grief and care[45], are a more direct approach to achieve these dialogues and have the advantage that facilitators can help ensure that correct information is shared or reinforced[40]. These events can serve as inclusive platforms fostering social connections and new understandings through the sharing of experiences and perspectives. Moreover, as shown in our results, developers and implementers should recognize varying levels of (dis)trust as an important element influencing health information-effectiveness[46] and community conversations on palliative care can be an approach to simultaneously rebuild trust where it is most eroded.

Lastly, our findings imply that destigmatizing palliative care also involves destigmatizing persons with serious illness, and that it is important to represent them in active, resilient positions. However, in line with arguments that have been made against the binary opposition of 'heroes of ageing' versus 'unsuccessfully ageing bodies' within media and advertisement representations of older people[37,47], we advise to seek alternatives between polarized constructions of positive palliative care images containing happy, smiling, active persons who are seemingly unimpeded by serious illness, versus negative images of isolated, bedbound, generally frail, visually close to death patients. Instead, the focus should be on representing the various, potentially ambiguous, lived experiences and processes of meaning attribution of persons with serious illness, as well as the persons around them. This way images and messages remain credible, representative of real life experiences and daily practices, inspirational to its audience who (as argued in modelling theory) needs realistic examples and, lastly, do not have the unintended detrimental consequence of reinforcing stigmatized views on people with serious incurable illness who do not fulfil these idealized representations.

Strengths and limitations

A considerable strength of our study is the diversity of participants in terms of age, ethnicity, socio-economic positions, educational background, religion, and personal experience with serious illness, grief and palliative care. Even if the obtained diversity still represents just a fraction of societal diversity, our strong efforts to obtain diverse audiences have enabled a deeper understanding of the way audience readings are also shaped by wider societal discourses and practices.

A potential limitation of our study is connected to the fact that the majority of our focus groups (nine out of ten) were conducted in the region of Ghent, which is centrally situated in Flanders, the northern Dutch-speaking region of Belgium. This concentration in one region might limit the transferability of our findings to the whole of Flanders. However, this choice was deliberate, as prior familiarity with local sociocultural organizations and their functioning within the region greatly facilitated access to these organizations, which was crucial for our study.

Another limitation is linked to the focus group design. Despite its many advantages, getting a group of people together to discuss a particular topic invites them to consciously and critically reflect and verbalize thoughts regarding objects and processes that produces results that might not be representative of their reactions and interpretations in real life. While we do not view all explicit (linear linguistic) knowledge as problematic, i.e. as probably remote from knowledge employed in practical activities under normal circumstances[48], additional research encompassing different methods such as participant observation could further benefit insight into the audience reception of campaign materials and the non-explicit interpretive practices behind this.

5. Conclusion

This study shed light on the audience reception of public awareness campaigns on palliative care and spurred a number of implications and recommendations for the development of future evidence-informed campaigns. In general, it is clear that diversified strategies are needed to improve public understanding and involvement in palliative care. As shown in our study, the challenge for developers of future campaigns goes far beyond finding a catchy slogan and also encompasses a need to, collaboratively, develop strategies that enhance personal relevance and incorporate elements of trust, our relational being-in-the-world and the broader societal discourses at play.

Acknowledgements

The authors would like to sincerely thank all research participants for their time and input. They also extend their gratitude to everyone who helped connect them with potential participants and groups for their trust and collaboration. Lastly, the authors thank Indra Albrecht from the End-of-Life Care Research Group at the Vrije Universiteit Brussel and Ghent University for her invaluable assistance during the data collection.

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Part III

The development of a public campaign on palliative care

Chapter VI

Shifting public perceptions of palliative care: a co-creative design to address unknown, misunderstood and stigmatized aspects

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Abstract

Background: Despite the growing global need for palliative care, access and uptake are often hindered by limited public knowledge, misconceptions, and stigma.

Aims: To co-creatively design a comprehensive public campaign strategy to tackle unknown, misunderstood and stigmatized aspects of palliative care in Flanders.

Methods: Using an integrated approach of co-creation and Intervention Mapping, this project involved twenty-two citizen stakeholders, eight professional stakeholders, two communication professionals, and four researchers. Starting from a needs assessment and logic model of the problem, change objectives were formulated and a logic model of change created. The campaign strategy was then designed using theory and evidence-based methods.

Results: The co-created strategy includes six communication principles and six conceptual components. The former include naming palliative care while broadening interpretations through language and imagery; representing persons in active positions, i.e. in control, in the midst of society, fulfilling social roles; and to also name death and dying as core components of palliative care from within the broader narrative of palliative care. The six components are: (1) a strong, diverse network focused on raising societal awareness of palliative care; (2) a structurally embedded, interactive website with an informative, supportive and connecting function; (3) initiatives to encourage professional caregivers to inform patients correctly and timely about palliative care options; (4) a multimedia campaign which seeks to reshape public understanding of palliative care and of those living with life-threatening illness through the use of positive language and imagery; (5) a palliative care ambassadors program for community-based outreach; and (6) low-threshold community conversations on key themes within palliative care across sociocultural settings.

Discussion: Complex problems require comprehensive, multilayered answers. The co-created strategy offers both general direction and concrete tools to enhance public understanding and engagement with palliative care, while fully recognizing and addressing societal diversity.

1. Introduction

This project was initiated to co-creatively design a versatile, sustainable and comprehensive public campaign strategy to combat unknown, misunderstood, and stigmatized aspects of palliative care in Flanders. Public campaigns are understood as organized communication activities directed at the general public aiming to create awareness, behavioral change and better outcomes surrounding a particular topic[1]. Public campaigns are thus not limited to mass media campaigns, even though they can take this form[1] or include them as a component within an overall strategy. By focusing on broadening existing perceptions about palliative care and combating the stigma around it, public openness and engagement with palliative care can be encouraged, enabling more people to become aware of the possibilities of palliative care and subsequently make informed decisions about it.

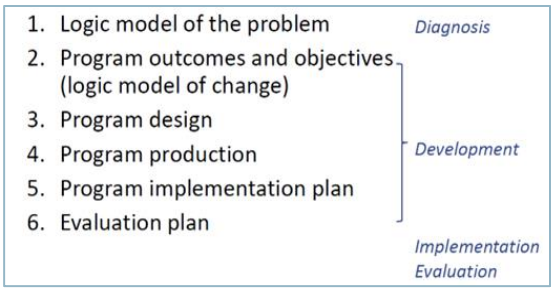
2. Methods

This project combines a co-creative approach with Intervention Mapping. Ethical approval for this study was obtained in January 2024 from the Medical Ethics Committee of UZ Brussel/VUB, reference EC-2023-38.

In general, co-creation is used with various meanings across multiple disciplines[2], but in the context of our study we define it as *"a collaborative public health intervention development by academics working alongside other stakeholders"*[3(p2)]. Co-creation enables various stakeholders, including the target audience, to become actively involved in the design of the program[4]. This involvement has the potential to ensure that key shared priorities are addressed within the developed programs and that they are not being developed in isolation from broader societal developments and needs[5,6]. It further enhances the collaborative nature of innovative, creative processes[7] and may increase the likelihood of producing sustainable change[8]. The process of co-creation allows all participants, both academics and non-academics, to exchange perspectives, derive valuable insights from mutual engagement, enhance skills in various areas, and foster a commitment to ongoing interaction[3,7].

The co-creative development was further guided by the Intervention Mapping framework. Intervention mapping is a detailed, evidence-based, socio-ecological planning approach to develop health promotion programs[6]. Conducting such an intervention development process heightens the chance of developing effective and durable interventions. As our project focused only on the design of a multifaceted public campaign strategy and not on the production, implementation and evaluation of its included components, only the first three steps of Intervention Mapping were applied (see Figure 1 for an overview of all Intervention Mapping steps).

Figure 1. Intervention Mapping Steps.



1. Logic model of the problem
2. Program outcomes and objectives (logic model of change)
3. Program design
4. Program production
5. Program implementation plan
6. Evaluation plan

Diagnosis
Development
Implementation
Evaluation

Below, Figure 2 contains a detailed schematic representation of the co-creative trajectory guided by the three Intervention Mapping steps. In the rest of this method section, we will outline the purpose, approach, and intermediate outcomes of each step in the Intervention Mapping process, before detailing the final design in the results section.

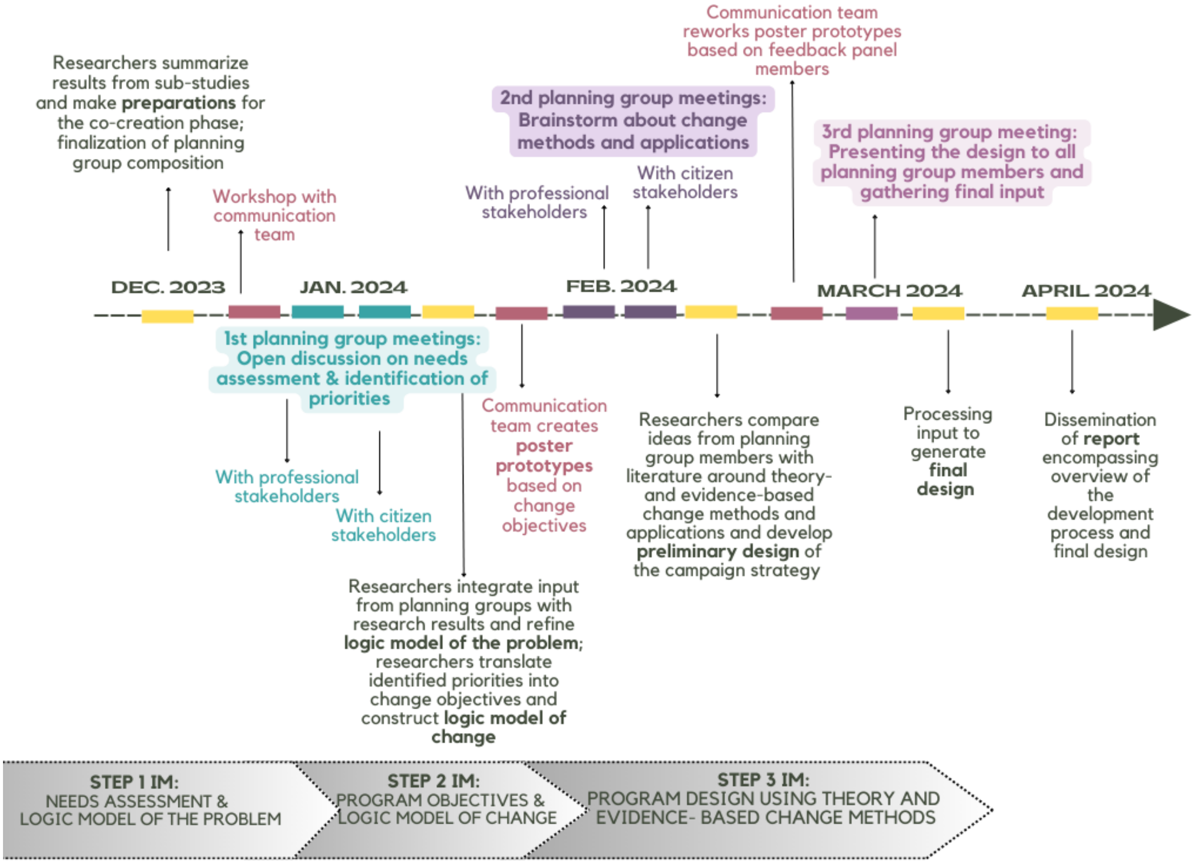


Figure 2. Overview of the co-creative process (IM = Intervention Mapping).

2.1. Step 1 Intervention Mapping: needs assessment and creation of a logic model of the problem

The goal of the first Intervention Mapping step is to come to a detailed overview of the problem the intervention is addressing. This includes an understanding of the behavioral and environmental factors involved, determinants of these factors and the impact of the problem on the quality of life and health of the target population. Research results and findings from the broader literature are an important part of this, but importantly, also need to be integrated with the knowledge from community members, professional stakeholders and the potential intervention beneficiaries[3,6]. A first task therefore is the establishment of one or more planning groups. In this project, a diverse group of citizens, professional stakeholders and communication professionals were engaged as co-creators.

2.1.1. Recruitment and composition of planning groups

During the course of the project, we initiated our search for planning group members with whom to co-create a comprehensive public campaign strategy. Two planning groups were formed:

> 1) A professional stakeholder planning group consisting of 8 persons active in the field of policy, practice and/or advocacy surrounding palliative care (not necessarily limited to it), as well as health promotion. These persons were found after conducting a stakeholder mapping exercise and holding preliminary meetings to probe for their interest, availability and expectations. An overview of the planning group members' organizations, and the roles they hold within them, can be found in Table 1.
>
> 2) A citizen stakeholder planning group consisting of a diverse group of 22 individuals with no direct professional involvement in palliative care. Members were recruited through various ways:
> - Most planning group members (14) had participated in the audience reception study described in Chapter five after which they had been invited to participate in this project (ethical approval for this study, including the invitation of participants for the next study, obtained on 04/07/2023 under reference ONZ-2023-0267).
> - Three members were recruited through a Patient Advisory Board for scientific studies connected to the Ghent University Hospital.
> - Others members were recruited through reaching out to some of the previous participants of the Citizens' Forum described in Chapter three (1), through contacts made during the recruitment phase of the audience reception study (1), and, through the personal networks of researcher-colleagues not

involved in this study (1).

- Lastly, two members were brought along by another planning group member.

See Table 2 for an overview of all planning group members characteristics.

The role of the planning group members was to engage in the development process as co-creators, i.e. to actively reflect and work on the formulation of campaign goals as well as the design of a comprehensive campaign strategy. To stimulate a sense of ownership, a key dimension within co-creation[3], we affirmed the equal status of all planning group members in regard to their contributions, knowledge and responsibilities and adhered to an open approach, allowing feedback from co-creators and the possibility to make amendments to the process. Repeated open discussions were engaged in to facilitate the sharing of knowledge between all co-creators.

In addition, two communication experts were involved during the whole trajectory. In line with their individual expertise, one person did a workshop with the researchers in which he provided advice on the campaign design process by shedding light on theoretical frameworks within behavioral and communication science, as well as practicing certain co-creative facilitation techniques with the researchers which they could then apply during the planning group meetings (techniques to elicit planning group members' ideas and reflections through a creative process instead of a purely verbal exchange). This person was also involved in the copywriting of some of the poster slogans (see results section), based on the input of the planning group members and researchers, as well as giving input (from a copywriter perspective) on the language use in the recommendation card (see results section). The other person, an expert in audiovisual production, was mainly involved in the creative process of making poster prototypes, based likewise on the input of the planning group members and researchers. She also actively participated in the last planning group meeting.

Co-creation also necessitates facilitation in order to operate and progress productively over time[9]. Researchers MM and ND primarily took on this role. Their facilitation, guided by the available literature[2,9], mainly involved fostering trust and creating a safe and comfortable environment for sharing potentially conflicting views, communicating objectives recurrently to keep the planning group focused and motivated, synthesizing ideas and information while respecting diverse perspectives, and continuously evaluating the process and redirecting the conversations when necessary.

The co-creative process was practically organized around three subsequent meetings which all planning members were planned to attend (one in January 2024, one in February 2024, and one in March 2024). To accommodate different work and life schedules, we organized a total of seven meetings, allowing citizen stakeholders to choose between early afternoon or evening sessions. An overview of this can be found in Figure 3. Except for one meeting, all meetings were organized in-person, as this was estimated to greatly improve senses of commitment, trust, and ownership, and to generate richer discussions. Only the second meeting of the professional stakeholders was organized online due to practical reasons. The citizen stakeholders and the professional stakeholders met separately the first two times and together during the third session. We did this to make sure that each person had sufficient space and time to comfortably express personal views, without being potentially discouraged because of perceived power differences ("I'm not a professional, so I don't know"). However, it was also deemed important to move beyond having separate groups of stakeholders operating in parallel and ensuring that all stakeholders could have open discussions with each other. The third session therefore brought everyone together in one room, contributing to a sense of collective commitment. During the joint discussions, diverse stakeholders could not only negotiate potential differences in views but also get a more clear grasp on commonalities and shared values in their engagement. This alternation between separate and joint meetings was designed to ultimately lead to a more comprehensive and inclusive campaign strategy.

Table 1. Overview professional stakeholder planning group members' organizations and roles.

Name organization	Short description of organization	Role of planning group member in that organization
Kom op tegen Kanker - Fight against Cancer	A Flemish umbrella organization which advocates for cancer patients' interests through advocacy, psychological and social support services, awareness campaigns, research funding, and policy influence.	- Expert on cancer care
MOPA - Migration and Palliative Support	Organization dedicated to the provision of low-threshold, high-quality palliative support for Muslim patients and their relatives in Flanders.	- Coordinator
VIVEL - The Flemish institute for primary care	VIVEL serves as the central contact point and platform for dialogue between primary care providers – including health and welfare actors, care councils, representatives of people in need of care and support, caregivers, local governments, knowledge and expertise centers and hospitals - and the government and each other in Flanders.	- Coordinator Support for Care Councils and Governance
Palliatieve Zorg Vlaanderen – Palliative Care Flanders (two planning group members)	Umbrella and network organization that supports caregivers, organizations, and family caregivers who provide daily palliative care.	- Director - Communication manager
Vlaamse Ouderenraad – Flemish Council of Older Persons	As the official advisory body for the Flemish ageing policy, the Flemish Council of Older	- Communication manager

	Persons voices the needs, concerns and proposals of older people in Flanders, Belgium.	
Team Eerstelijnszorg binnen Departement Zorg – Primary Care Team of the Governmental Department of Care	The team coordinates primary care in Flanders by recognizing and funding care councils, general practitioner circles, palliative care, and VIVEL. The team develops digital tools and concepts such as care coordination and case management to enable integrated collaboration between healthcare providers and citizens.	- Policy officer
Vlaams Instituut Gezond Leven - Flanders Institute for Healthy Living	Independent Flemish expertise center on health promotion that aims to help people in an accessible way to live healthier lives, and to create healthier living environments together with them and with policy makers.	- Senior staff member for health inequality and behavioral insights

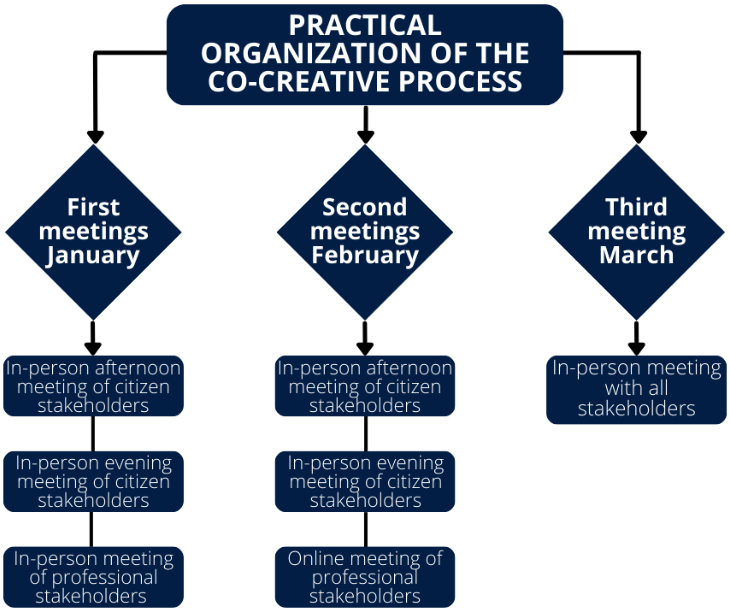
Table 2. Characteristics of planning group members.

Sociodemographics		**Total (n=30)**	**Citizen stakeholder planning group (n=22)**	**Professional stakeholder planning group (n=8)**
Age	18-25	1	1	/
	26-44	13	7	6
	45-59	6	5	1
	60-75	10	9	1
Gender	Female	24	17	7
	Male	6	5	1
Ethnicity*	Belgian and/or Flemish	18	12	6
	Turkish	2	2	/
	Western-European, or, Belgian and Western-European	3	3	/
	Luxembourger	1	1	/
	Turkish and Dutch	1	1	/
	Belgian and LGBTQIA+	1	/	1
	World citizen	2	2	/
	Prefer not to say	1	1	/
	Missing	1	/	1
Education	Higher secondary education	6	5	1
	College	6	5	1
	University or higher	18	12	6
Life stance and/or religious beliefs	Catholic	10	8	2
	Muslim	4	3	1
	Secular humanism	3	1	2
	Not religious	10	8	2
	Other	1	1	/
	Missing	2	1	1

Personal Experience with serious illness and/or bereavement	Yes	24	18	6
	No	6	4	2

**Ethnicity was self-identified through an open question; all other items, except age, had predefined answer options.*

Figure 3: overview of the practical organization of the co-creative process.



2.1.2. Needs assessment and creating the logic model of the problem

An integral part of the needs assessment had already been done prior to the first planning group meetings, namely through the four conducted substudies (described in the previous chapters of this dissertation) and through reviewing the literature. Yet, as already stated above, this needed to be integrated and refined with the knowledge provided by the non-academic co-creators[3].

The first goal of the first planning group meetings therefore was to generate input from the planning members on the needs assessment. The separate meetings (for professional and citizen stakeholders) began with a short presentation of the broad definition of palliative care, our assessment of the problem based on results from our research and the literature, and listening to the planning group members' thoughts on this through an open discussion. Based on the input of planning group members a (previously made) schematic overview of the problem that we want to address with the campaign (= outcome step 1 Intervention Mapping – see Figure 4) was refined.

2.2. Step 2 Intervention Mapping: formulation of change objectives and the creation of a logic model of change

The second goal of the first planning group meetings was to identify key priorities for the campaign. The biggest part of the session was therefore dedicated to eliciting views and reflections on what is important to the planning group members and what they would want the campaign to achieve (building further on the priorly discussed needs assessment). We did this by engaging in a creative exercise in which planning group members were asked to make their own campaign poster(s) and think about the slogan(s) and images they would use. Drawing in this sense was used as a method to help people conceptualize, allowing them to express and perceive through different senses and tapping into the many ways of knowing and intuiting[2]. Participants were aware of this purpose and that the posters by no means were meant to reduce the campaign strategy to the single medium of posters. Each created poster was discussed and reflected on in group.

After the planning group meetings, the creations and the (recorded and transcribed) conversations were analyzed by researcher MM (using a descriptive qualitative approach) to identify key campaign priorities from the planning group members' perspectives (see Figure 5 for an overview of these priorities, accompanied by digital images, slogans and key elements that represent some of the poster ideas of the co-creators).

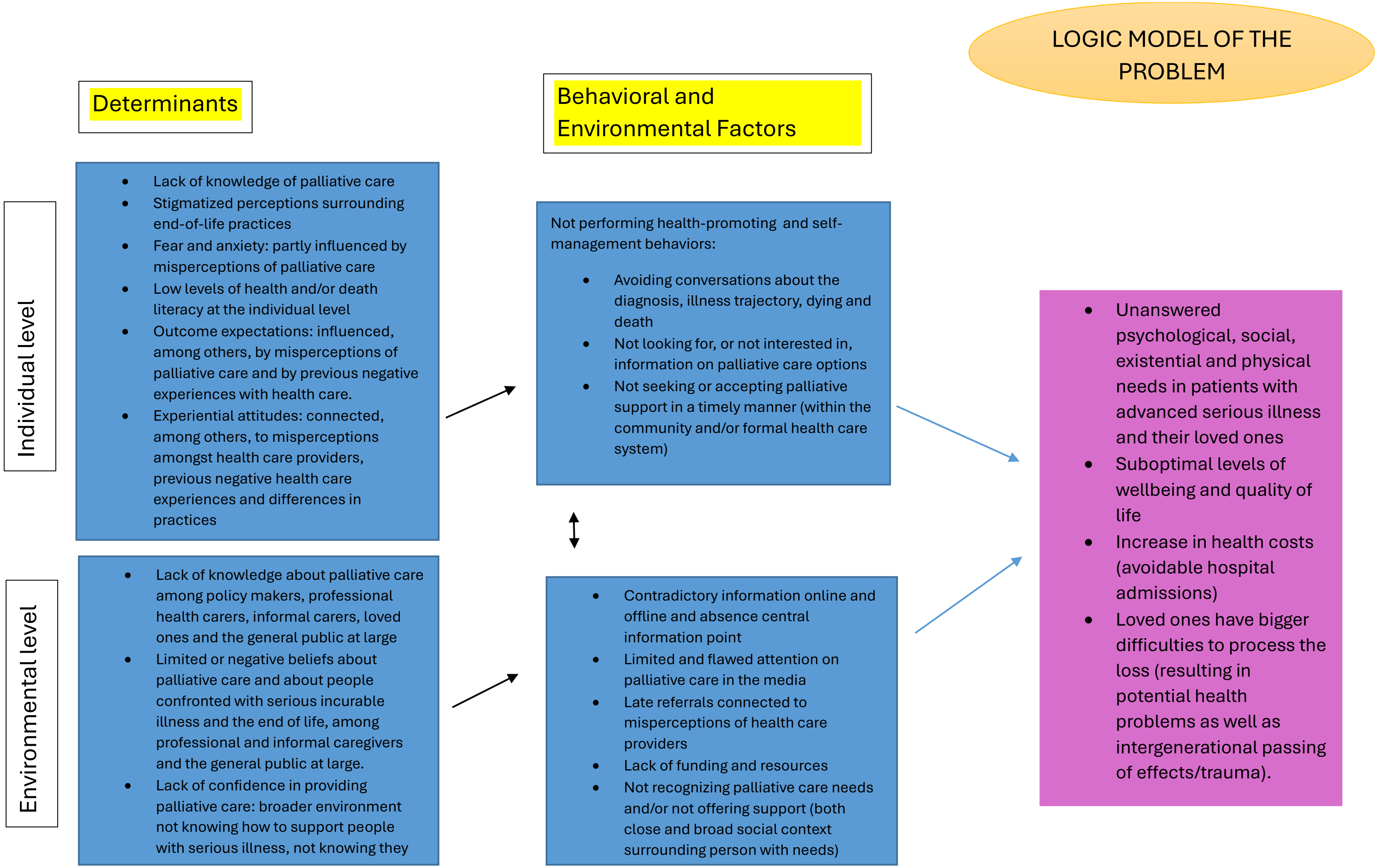
Based on the identified priorities, the following Intervention Mapping tasks were conducted:

1) specification of campaign goals and the construction of matrices of change objectives (= part of step 2 Intervention Mapping - see Table 3 for an overview of campaign goals and change objectives).
2) creation of a schematic overview of the intended change (= outcome step 2 Intervention Mapping - see Figure 6).

In accordance with Intervention Mapping guidelines, the change objectives are articulated using action verbs to specify the intended changes in determinants necessary to meet performance objectives[6]. Despite their precise wording, these objectives are not rigid behavioral prescriptions. Instead, they are meant as directional tools within the development process, facilitating rather than dictating outcomes. The overarching campaign goals were nonetheless articulated with an emphasis on empowerment (we used the Dutch word 'versterken' for this) instead of behavior, because this resonated well with the planning group members and encouraged a comprehensive view to change, encompassing not only individual factors but also interpersonal and societal ones, throughout the co-creative process.

The audiovisual production expert additionally made a diverse range of preliminary poster prototypes (11 in total), based on the change objectives and on some of the planning group members' creative ideas. During this phase of the design process, the preliminary posters primarily served the purpose of facilitating further the decision-making processes involved in designing a campaign[2]. By visualizing various concepts, styles and emphases, the poster prototypes stimulated discussions about what works and what does not work, for whom and for what reasons. The insights gained from these discussions could then inform the further development of the campaign strategy (not limited to posters).

Figure 4. Logic model of the problem.



LOGIC MODEL OF THE PROBLEM

Determinants

Behavioral and Environmental Factors

Individual level

- Lack of knowledge of palliative care
- Stigmatized perceptions surrounding end-of-life practices
- Fear and anxiety: partly influenced by misperceptions of palliative care
- Low levels of health and/or death literacy at the individual level
- Outcome expectations: influenced, among others, by misperceptions of palliative care and by previous negative experiences with health care.
- Experiential attitudes: connected, among others, to misperceptions amongst health care providers, previous negative health care experiences and differences in practices

Not performing health-promoting and self-management behaviors:

- Avoiding conversations about the diagnosis, illness trajectory, dying and death
- Not looking for, or not interested in, information on palliative care options
- Not seeking or accepting palliative support in a timely manner (within the community and/or formal health care system)

Environmental level

- Lack of knowledge about palliative care among policy makers, professional health carers, informal carers, loved ones and the general public at large
- Limited or negative beliefs about palliative care and about people confronted with serious incurable illness and the end of life, among professional and informal caregivers and the general public at large.
- Lack of confidence in providing palliative care: broader environment not knowing how to support people with serious illness, not knowing they

- Contradictory information online and offline and absence central information point
- Limited and flawed attention on palliative care in the media
- Late referrals connected to misperceptions of health care providers
- Lack of funding and resources
- Not recognizing palliative care needs and/or not offering support (both close and broad social context surrounding person with needs)

- Unanswered psychological, social, existential and physical needs in patients with advanced serious illness and their loved ones
- Suboptimal levels of wellbeing and quality of life
- Increase in health costs (avoidable hospital admissions)
- Loved ones have bigger difficulties to process the loss (resulting in potential health problems as well as intergenerational passing of effects/trauma).

Figure 5. Identified Priorities.

PRIORITIES

CAMPAIGN

Time for quality

Seek palliative support in a timely manner

Make palliative care discussable

Encourage to engage in conversation

Feel comfortable to interact

Broaden the image of palliative care

Just being yourself

You can still be active

Can happen to anyone

At the helm, in control

Broaden the image of a person with a severe incurable illness

Provide basic information about palliative care

What, by whom, for whom, where, how, and is it affordable?

Encourage support from the wider community

Positive experience

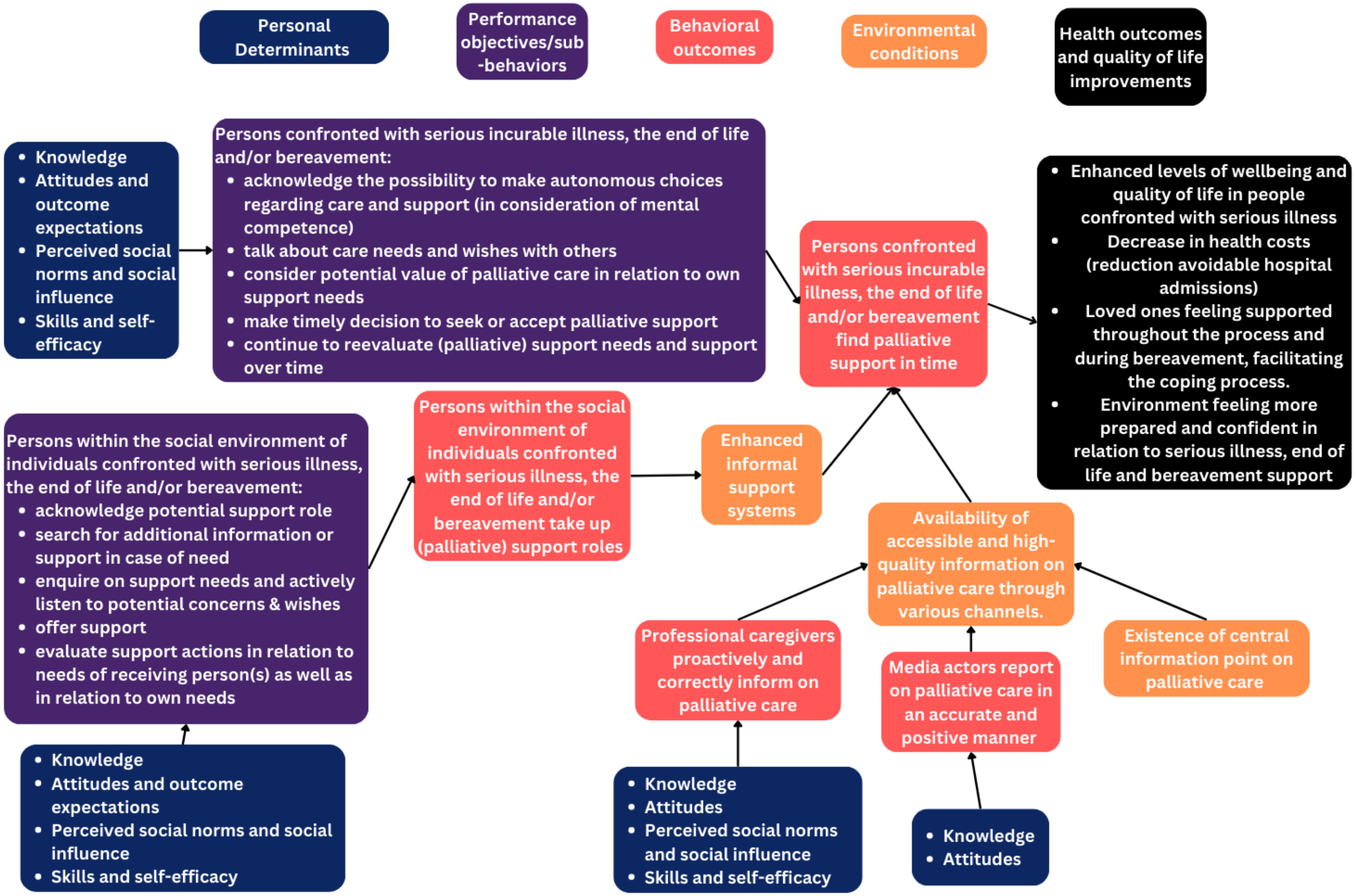
Small things matter

Building towards the future

Table 3: Campaign Goals.

<table>
<tr><td colspan="2"><u>Campaign goal 1:</u>
Individuals confronted with serious illness, the end of life, and/or grief are empowered to find palliative support in time (in relation to their support needs).</td></tr>
<tr><td>Determinant</td><td>Change objectives</td></tr>
<tr><td>Knowledge</td><td>● The target group explains that they can make choices regarding care and support.
● The target group is familiar with the broad approach of palliative care: in other words, explains that palliative care is not only medical, professional care for (inactive) individuals at the end of life, that optimizing quality of life in relation to individual wishes and needs is central, and that they can seek palliative care from the diagnosis onward for physical, psychological, social, existential/spiritual, and also practical needs.
● The target group explains that palliative care always starts from the individual's wishes and needs, and in that sense, is not in conflict with philosophical or religious beliefs.
● The target group explains where to find timely information and support regarding palliative care.</td></tr>
<tr><td>Attitudes & outcome expectations</td><td>● The target group expects that discussing wishes and needs contributes to finding the right care and support.
● The target group expresses positive views about palliative care and the importance of starting it early.</td></tr>
<tr><td>Social Norms & Influences</td><td>● The target group recognizes that others in similar situations receive palliative support at different stages of serious illness and/or grief, and they positively assess this support regarding autonomy, quality of life, and the well-being of themselves and their loved ones.</td></tr>
<tr><td>Skills and Self-efficacy</td><td>● The target group demonstrates how to initiate conversations with others about needs and wishes.
● The target group demonstrates how to seek and accept suitable support in a timely manner.</td></tr>
<tr><td colspan="2"><u>Campaign goal 2:</u>
Individuals within the (close or distant) social context of those confronted with serious, incurable illness, the end of life, and/or grief are empowered to take on (palliative) support roles.</td></tr>
<tr><td>Determinant</td><td>Change objectives</td></tr>
<tr><td>Knowledge</td><td>● The target group explains that support needs extend beyond professional healthcare and include not only physical needs but also psychological, social, practical, and existential/spiritual needs, and that they can play a potential role in this.
● The target group lists where additional information and support can be found regarding providing support to those confronted with serious illness, the end of life, and/or grief.</td></tr>
<tr><td>Attitudes & Expectations</td><td>● The target group expresses positive attitudes toward taking on support roles.
● The target group has positive expectations about seeking additional information or support when needed.</td></tr>
<tr><td>Social Norms & Influences</td><td>● The target group acknowledges that others in similar situations provide (palliative) support at different stages of serious illness and/or grief, and that this support is experienced positively in relation to social connectedness and well-being.</td></tr>
<tr><td>Skills and Self-efficacy</td><td>● The target group shows how they can find additional support or information.
● The target group expresses confidence in identifying support needs and offering support.</td></tr>
</table>

Figure 6. Logic model of change.



Personal Determinants

Performance objectives/sub-behaviors

Behavioral outcomes

Environmental conditions

Health outcomes and quality of life improvements

- Knowledge
- Attitudes and outcome expectations
- Perceived social norms and social influence
- Skills and self-efficacy

Persons confronted with serious incurable illness, the end of life and/or bereavement:

- acknowledge the possibility to make autonomous choices regarding care and support (in consideration of mental competence)
- talk about care needs and wishes with others
- consider potential value of palliative care in relation to own support needs
- make timely decision to seek or accept palliative support
- continue to reevaluate (palliative) support needs and support over time

Persons confronted with serious incurable illness, the end of life and/or bereavement find palliative support in time

- Enhanced levels of wellbeing and quality of life in people confronted with serious illness
- Decrease in health costs (reduction avoidable hospital admissions)
- Loved ones feeling supported throughout the process and during bereavement, facilitating the coping process.
- Environment feeling more prepared and confident in relation to serious illness, end of life and bereavement support

Persons within the social environment of individuals confronted with serious illness, the end of life and/or bereavement:

- acknowledge potential support role
- search for additional information or support in case of need
- enquire on support needs and actively listen to potential concerns & wishes
- offer support
- evaluate support actions in relation to needs of receiving person(s) as well as in relation to own needs

Persons within the social environment of individuals confronted with serious illness, the end of life and/or bereavement take up (palliative) support roles

Enhanced informal support systems

Availability of accessible and high-quality information on palliative care through various channels.

Professional caregivers proactively and correctly inform on palliative care

Media actors report on palliative care in an accurate and positive manner

Existence of central information point on palliative care

- Knowledge
- Attitudes and outcome expectations
- Perceived social norms and social influence
- Skills and self-efficacy

- Knowledge
- Attitudes
- Perceived social norms and social influence
- Skills and self-efficacy

- Knowledge
- Attitudes

2.3. Step 3 Intervention Mapping: the design of the campaign

The purpose of the third Intervention Mapping step was to conceptualize and design the campaign strategy using theory- and evidence-based change methods and practical applications. Two planning group meetings were organized for this purpose. During the first of these meetings (organized again separately for professional stakeholders and citizen stakeholders), we gathered input from planning group members on campaign themes, components, and scope. We first presented the campaign goals and change objectives and listened to planning group members' reflections on this (all agreed on the defined objectives). Following this, we presented the preliminary poster prototypes and discussed what worked and what did not work for the planning group members, focusing on the chosen images and language. Afterward, we engaged in a creative brainstorm to think about and discuss other campaign components, besides posters, needed to reach our change objectives. Planning group members were challenged to think broadly and also consider the prerequisite changes needed in environmental conditions (as reflected in the logic model of change) in order to achieve our objectives. For instance, in both the citizen and professional stakeholder planning groups, the informational role of professional caregivers and traditional media channels had been highlighted and ideas to target them were thus also discussed and included within the strategy.

All planning group members' ideas were looked at from within the existing literature around theory- and evidence-based change methods and practical applications, and processed into a coherent design (see Table 4 for an overview). Ideas that were not supported by the literature, or that in practice would not meet the parameters for effectiveness of the involved methods[10], were left out, but most of the planning group members' ideas were incorporated into the final design (after being refined as necessary).

In addition, new poster prototypes were made based on the extensive feedback on the preliminary versions. Researcher MM synthesized the planning group members' feedback into a new conceptual poster idea, which was subsequently refined by the copywriting work of one of the communication experts. The final poster prototypes were then crafted by the audiovisual production expert in collaboration with MM, ensuring that the planning group members' preferences remained at the forefront throughout the process.

During the last planning group meeting, the co-creative design was presented to all planning group members together. After going over the process and presenting the communication principles and the different components incorporated in the design, a world café approach was adopted to elicit final input and thoughts of the planning group members. Based on their input, the design was afterwards refined into the final version described in the results section.

Table 4: Components as practical applications of theory- and evidence-based methods.

Components	Short Description	Theoretical methods*	Intended change (based on determinants)
1. **Building a Network**	Establish a network with the mission to stimulate societal awareness of palliative care, comprising tasks like media plan creation, inventorying existing materials and initiatives and developing new materials and initiatives to positively influence public perceptions of palliative care, public perception monitoring, actively contributing to related initiatives, and policy influencing.	○ Coalition formation ○ Advocacy & lobbying ○ Agenda setting ○ Mobilization of social networks ○ Increasing stakeholder influence ○ Media plan: mass media-role modelling, advocacy, and educational entertainment.	Creating change in environmental conditions: changing policies, communities, social networks, available social support, social norms, and organizations
2. **Building a Website**	Develop a user-friendly, reliable online information source about palliative care that includes basic information based on testimonials and Q&A, resources, an interactive forum to share experiences with other people and a chat function to ask questions and/or talk with volunteers about palliative care related subjects.	○ Basic information: modelling, persuasive communication, selection of beliefs, elaboration, shifting perspective, information about approval (positive attitude towards the theme) from others, promoting social support within existing relationships, verbal persuasion (targeted at skills of the target group) ○ Resources: facilitation, technical assistance, tailoring ○ Interactive section/chat: individualization (personalized communication in response to individual needs and questions) ○ Interactive section/forum: developing new social network ties, mobilizing social networks	Creating change with respect to individual behavioural determinants: knowledge, attitudes, perception of social norms and social influence, skills & self-efficacy. Additionally, changing the environment: the website as a structurally embedded, reliable, and accessible source of information.
3. Sensitize and activate healthcare providers as an information channel	Sensitization of healthcare providers so that they have a complete understanding of palliative care and can pass on accurate information. This involves infographics and e-learning modules tailored to specific care disciplines; the wider promotion of an existing, reliable website with information about palliative care aimed at healthcare providers; an inventory of existing materials and initiatives so that promising materials	○ Persuasive communication, modelling, tailoring, information about approval (positive attitude towards the topic) from others, verbal persuasion (focused on skills), facilitation (information brochures), mobilizing social networks, shifting perspective.	Creating change with respect to knowledge, attitudes, perceived social norms & influence, skills, and self-efficacy of healthcare providers. As a result, change in the available support and information (environmental condition) for individuals facing serious illness, end-of-life, and bereavement

	can be re-implemented or spread more efficiently; the widespread distribution of an accessible information brochure to be given to patients during or after a discussion about palliative care (newly developed or existing: depending on the inventory).		
4. Multimedia campaign	Starting from personal stories of both individuals confronted with serious, incurable diseases, as well as people from their close or wider surroundings (colleagues or teachers, for example), posters and videos are distributed via social media, public places, public broadcasting, and network partner channels. Slogans aim to broaden existing perceptions of palliative care, among individuals who, now or in the future, might benefit from this care and those who, now or in the future, can potentially take on support roles, to thereby encourage timely seeking and providing of support.	○ Elaboration, selection of beliefs, mass media role-modelling, repeated exposure, shifting perspectives, mobilizing social networks.	Knowledge, attitudes, perceived social norms & social influence.
5. Palliative Care Ambassador Program (PAZAP)	Peer educator program that mobilizes individuals with personal experiences surrounding serious incurable illness and palliative care to act as pioneers and sources of information and support within their own diverse communities. Ambassadors are trained, compensated, and are a cornerstone in the dual process of social integration and societal awareness of palliative care.	○ Peer educators, community health workers, strengthening existing social support ties ○ Mobilizing social networks ○ Cultural similarity	Strengthening social support and social networks, changing social norms and attitudes.
6. Community conversations	Conversation moments within various socio-cultural organizations and centers with a focus on dialogue in an accessible, open, informal atmosphere. Palliative care ambassadors and/or PAZAP coordinators, individuals with serious incurable illnesses from the target group, and other members of the target audience (attendees) engage in discussions about one or more themes related to palliative care. A thematic blueprint is available but can be adapted according to the needs and wishes of the target group.	○ Discussion ○ Persuasive communication & argumentation ○ Tailoring ○ Cultural similarity	Knowledge, attitudes & outcome expectations, perceived social norms & influence.

**For descriptions, conditions (parameters), and theoretical foundations of methods, see references* [6,10]

3. Results: the co-created campaign

By applying Intervention Mapping, the integrated results from the preliminary research and planning group discussions produced a comprehensive strategy based on six communication principles and six components. The six communication principles also serve, more broadly than this project, as general recommendations for more effective public communication about palliative care. The six components include: (1) building a strong network focused on improving societal awareness of palliative care (aligned with practice and policy); (2) the development of an accessible interactive website; (3) a component directed at professional caregivers; (4) a multimedia public campaign; and (5)-(6) two components that strongly focus on community-oriented efforts. These components mainly involve conceptual ideas. The more detailed and practical development of the components will occur in a later phase, once the implementers are identified and the available resources are determined. It is important to again involve patients, citizens, and professionals at that stage to ensure that their perspectives, needs, and experiences are continuously considered throughout the process. Below, we first briefly describe the six communication principles, and then, in detail, the six components.

3.1. How do we communicate about palliative care?: 6 principles

1. **We name palliative care, without stigma:**

   Research shows that educational interventions can effectively broaden and improve knowledge and perceptions about palliative care. Having positive experiences and sharing these experiences also contribute to a broader understanding of palliative care. Therefore, we consciously choose to name palliative care (instead of using another term or description) while immediately putting emphasis on broadening interpretations through imagery and language. In addition, we avoid deterministic language, particularly labeling individuals or life stages as ‘palliative’. People are more than their illness and wish to be recognized as such. Thus, we talk about palliative care, but not about ‘being palliative’.

2. **We emphasize the beginning: "When cure is no longer possible" [in Dutch: “Wanneer genezen niet meer kan”]:**

   The dominant perception of palliative care is that it is terminal or end-of-life care. To break this perception, it is important to avoid vague terms or descriptions that reinforce the (exclusive) association with end-of-life care, such as "care in the final phase" or "when the end is near". Using concrete examples, we clarify who can benefit from palliative care, for what, and from when. We particularly emphasize the onset of care: when (it becomes likely that) curing is no longer possible. We also highlight the aspects that palliative care adds to the already provided care, the additional support and expertise, without necessarily stopping other treatments.

3. **We represent persons in active positions:**

Here, active means: in control, in the midst of society, and fulfilling social roles; both in images and in language. We avoid depicting people as passive recipients of care, isolated from the broader society. This image already exists today and is what we aim to broaden. We use words with positive connotations, such as strengthen, enable, can, be part of, participate and collaborate.

4. **We involve friends, family, and other social relationships in our narrative:**

We not only say that the social context is important in palliative care, we also show it by discussing palliative care from the perspectives of individuals from both close and distant social networks. In this way, a much broader audience can feel addressed and involved through the reflection of their own social connectedness.

5. **We always start from diversity, in all its layers:**

Making communication about palliative care accessible and relevant for as many target groups as possible requires: 1) recognition of the broad diversity in personal and sociocultural meaning attached to serious illness, the end of life, and mourning; 2) active participation and representation of people from diverse demographic and sociocultural backgrounds; 3) varied strategies which direct messages at every one but simultaneously vary the offering based on the needs and possibilities of different target groups (=proportionate universalism) and 4) testing of materials.

6. **We also talk about death and dying:**

It is important to also name death and dying as core components of palliative care but at the right time (not as an ‘entry point’) and always within the broader narrative of palliative care. Clear communication is particularly crucial regarding end-of-life practices such as euthanasia and palliative sedation, since research shows that stigmatized views about palliative care are also linked to these practices.

We incorporated these six communication principles into a 'recommendation card', provided as Appendix 12.

3.2. What is our strategy?: 6 components

01.

Building a network

The first vital step is to build a **strong and diverse network of engaged partners** who are willing and able to play an active role in **raising public awareness of palliative care**. This network should include a wide range of organizations and actors so that initiatives aimed at raising public awareness are always aligned with the current (shortcomings in) practice and policy surrounding palliative care and accessible to a broad audience. Organizations that are not directly involved in palliative care but have an interest in raising public awareness of it (such as poverty organizations, various patient associations, etc.) are also important partners in this regard. The network should have a transparent, accessible, open structure so that it can continue to grow organically. In addition, there should be a formal core team responsible for efficiently pursuing and overseeing the implementation of the tasks defined below, as well as guarding the communication and agreements within the network. Clear communication with partners about the roles they would like to and can take on (and the periodical reassessment of this) is important for successful collaboration. The minimum contribution of partners is the dissemination of campaign materials and adapting their own public communication about palliative care (see also Appendix 12). Organizations and actors that can take on a larger role also actively participate in the development, implementation, and evaluation of (new) initiatives to address unknown, misunderstood, or stigmatized aspects of palliative care.

Tasks:

Within its main assignment of raising public awareness of palliative care, the network has several clearly defined tasks:

1. **Media relations**: Developing a media plan that includes maintaining good relationships with journalists and continuously facilitating accurate portrayal of palliative care in popular programs (such as "Thuis," "Like me," etc.), as well as topics or segments in reports, talk shows, etc. The network positions itself as the primary contact for journalists (as well as other inquiring parties) who have

substantive questions about palliative care and people with serious, incurable illnesses, thereby – as much as possible - monitoring the language, images, and messages used around palliative care.

2. **Public education initiatives**: Making an inventory of all existing initiatives and materials, and developing and implementing (new) public campaigns and educational materials about palliative care suitable for different target groups, such as patients, families, caregivers, the general public and groups within.
3. **Monitoring and evaluation**: Changes in public perceptions, the reach of campaigns, and the level of engagement of stakeholders are continuously monitored, and based on this data, strategies can be adjusted and improved.
4. **Collaborations**: Actively engaging in collaborations, whether with partners within the network or beyond the network, contributing actively to related initiatives such as compassionate schools, learning networks, compassionate/caring communities, etc.
5. **Policy influence**: Since the network closely monitors developments in public perceptions, receptivity, and engagement regarding palliative care, it can also provide meaningful input into the development of palliative care policy.

02.

Building a website

The construction of the **website Leefmee.be** is the second step. The purpose of the website is to provide a **user-friendly, reliable online information source** with up-to-date, accessible information on palliative care and all its facets. The overall management of the website is handled by the core team of the network described above, in collaboration with an external expert in web development. However, the content of the website is actively supplied and updated by all network partners. The website, available in multiple languages, primarily targets individuals who, themselves or within their close or extended circle (such as a teacher of, colleague of, etc.), are faced with serious illness, end-of-life issues, and bereavement. Within this website, there is no separate section for professional caregivers but rather an easily identifiable link to a separate website (see third component).

The website provides **basic information** about palliative care (as a broad approach): what it is, for whom, when, where, affordability, etc. Additionally, it offers concrete **tools and resources** to help people provide support to those in their social circle facing serious illness, end-of-life issues or bereavement, and, to find support for their own needs. The website, among others, gathers current evidence, testimonials, and materials around end-of-life choices, dealing with existential questions, conversation cards linked to advance care planning, podcasts about themes related to palliative care, apps to connect care recipients and providers (Give-a-day, Hoplr, etc.), a guide to transforming your school into a 'compassionate school' (currently in development), and more. Here, you can also find a **social map** of palliative care. As described in the policy vision document on the reform of palliative care in Flanders[11], the social map provides an overview of all formal and informal support and care providers, organizations, and initiatives around palliative care, with the option to search by theme and region.

Additionally, the website features an **interactive section** consisting of a chat service where individuals can engage in discussions and ask questions about palliative care, daily at set times (for example, from 4 PM to 9 PM). The chat service serves an informative, supportive, and connecting function and to achieve this, a sufficient number of committed individuals must be hired and trained. The 0800 number, which is simultaneously launched with the public campaign (see below), would also fall under their responsibility. Moreover, research has shown that adding an online forum, where individuals can share experiences and discuss issues surrounding serious illness and palliative care, provides an added value[12]. However, since it is crucial that this forum is moderated, its inclusion will depend on the availability of staff. To further develop the interactive section of the website, partnerships can be sought with organizations such as 'Steunpunt Mens en Samenleving' (SAM), which assists other organizations in using information and communication technology efficiently and critically to support and inform diverse target groups.

Finally, it is important that the website is structurally embedded. Optimized technical aspects such as a logical and intuitive navigation structure, a design accessible on various devices and screen sizes, and the use of SEO tools are essential. Moreover, partners must be involved and activated to routinely refer to the website and continuously provide content to keep the website up-to-date.

The website wireframe is provided as Appendix 13.

03.

Targeting professional caregivers

Healthcare providers are one of the primary information channels about palliative care, making it vital that diverse care providers, especially those who potentially take on palliative information and support roles, are also involved in the campaign. Currently, palliative care is increasingly being integrated into the formal education of caregivers, but this remains a long-term endeavor, the effects of which will not be immediately noticeable. In the first phase, healthcare providers are therefore also themselves a target group. The aim is to **enhance healthcare providers' perceptions of palliative care and to encourage them to inform patients correctly and timely about palliative care options** (by focusing on caregivers' knowledge, attitudes, skills, and perceptions of social norms). Since there is already a vast amount of resources available, it is important to first inventory existing resources and from there identify the best initiatives and materials that could be re-implemented or distributed more efficiently. Warranted materials to be developed and/or implemented include:

1. An **infographic**, adapted to different healthcare disciplines, succinctly covering 'what is palliative care?'; 'where can one turn, and when'; and, 'what can I do and with whom can I collaborate?'. Within a consistent general style and layout, the images and the answer to the last question vary depending on the healthcare discipline (general practitioners, psychologists, pharmacists, physiotherapists, home nurses, oncologists, etc.). This ensures that healthcare providers feel more directly addressed in their specific roles and are more likely to absorb the information and actively engage with it. The tailored infographics will be widely distributed among various healthcare provider organizations and their members.

2. **E-learning module** on palliative care, again adapted to specific healthcare disciplines, and with the possibility for accreditation. The module briefly discusses the developments in the palliative care landscape, the diversity and dynamic nature of patient needs, the potential palliative care roles that healthcare providers can take on within their specific discipline, and whom they can collaborate with. Testimonials from both patients and fellow healthcare providers are a central theme in the module.

These testimonials highlight both the benefits of providing and receiving palliative support, as well as the challenges and doubts experienced by the provider (identification, relatability, and credibility increase the effectiveness).

3. It is also important that healthcare providers have access to **information brochures with clear, concise, easily understandable information about palliative care that they can give to patients** during or after a conversation about palliative care. To ensure consistency and recognizability (in relation to the overall campaign strategy), a new brochure could be developed. This brochure would use the same language and visuals as the public campaign described in component four and would also refer to the public website developed in component two (see Appendix 14 for an example for inspiration). However, an already developed, positively received brochure could also be used if it reflects the six communication principles described above.

The infographic and e-learning modules would refer to and also be accessible via a **website for healthcare providers**. On this website, healthcare providers can find more information, documentation, tools, and training offerings. The existing Palliative Care Flanders [Palliatieve Zorg Vlaanderen] website already does this, and one could opt to continue working with it and incorporate the campaign component. Additionally, the ‘CureNaarCare’ website (vancurenaarcare.be) could serve perfectly for this purpose. Finally, healthcare providers must also be made aware of the public components within the campaign strategy so that they can also respond appropriately when individuals ask questions after being exposed to, for example, the website, multimedia campaign, or community conversations.

04.

Multimedia campaign

The **"Leef Mee" multimedia campaign** aims to broaden public perceptions of palliative care as well as public perceptions of individuals with serious, incurable illness through **positive language use and powerful images** (see also the communication principles about this). The campaign additionally aims to address the close and broad environment surrounding people faced with serious illness and show them (in a non-patronizing and non-coercive way) how they too can play a role in palliative care. The campaign includes **various aspects**:

- **Posters:** these are displayed in public areas and on public transport, featuring individuals with serious incurable illnesses and persons from within their social networks, accompanied by one of the three campaign slogans described below.
- **Website** Leefmee.be
- **TV spots**: short testimonies from the individuals featured on the posters, broadcasted on public television, accompanied by one of the three slogans
- **Social media**: distribution of videos and banners across various online channels as well as the involvement of influencers to broaden reach and impact.
- **Network partners' channels:** newsletters, social media pages, etc.

The protagonists of this campaign are individuals of diverse ages, genders, ethnicities, and socio-economic backgrounds who are personally confronted, or have someone in their environment confronted, with serious, incurable illness, and who are willing to represent the campaign messages. Through their authentic personal stories, a realistic and positive image of palliative care is brought. Three core elements of palliative care are encapsulated in three slogans (with variations):

1. "Continue doing what you have always been doing for as long as possible. Also when cure is no longer possible." - [Zolang mogelijk doen wat je altijd al deed. Ook wanneer genezen niet meer kan.]
   → Emphasizes the core element of 'time': palliative care can play an important role in relation to your quality of life especially when integrated early into your care.
2. "The best team. Also when cure is no longer possible." - [Het beste team. Ook wanneer genezen niet meer kan.]. This slogan varies with "The best crew", or "The best friends".
   → Emphasizes the core element of 'relationality': the value of palliative care to maintain or strengthen social networks around persons confronted with serious illness, the end of life or bereavement.
3. "Staying yourself. Also when cure is no longer possible." – [Jezelf blijven. Ook wanneer genezen niet meer kan]
   → Emphasizes the core element of 'control': palliative care empowers persons to maintain control over their lives and care.

The call to action is consistently, "Find everything about palliative care at LeefMee.be or call us at 0800/000 00." [Alles over palliatieve zorg vind je op...]. In the second version, this is preceded by "Supporting your best friend?", "Supporting your colleague?", etc. Together the posters form a series in which the third slogan always features the image of one person with serious illness and the other slogans always feature images of more than one person. The posters also vary in how visibly ill the person(s) appears, aiming to reflect diversity in this and to also appeal to a broader audience.

Prototypes of these posters (with a basic layout) are provided as Appendix 15.

05.

Palliative care ambassadors

Patients, families, and community members are typically engaged as the target audience of community-oriented projects in care and health, rather than as full partners[13]. The Palliative Care Ambassador Program (working title, abbreviated as PAZAP), however, fully invests in the proven value of peer support & community health ambassadors. The program **mobilizes individuals with personal experiences around serious, incurable illnesses and palliative care to act as pioneers [kwartiermakers] and sources of information and support within their own, diverse communities.** From research and practical experience, we know that not everyone easily finds their way to palliative care, and the purpose of PAZAP is to bring palliative care closer to various social communities in Flanders through outreach work. To find ambassadors, an active fieldwork approach should be applied. This involves identifying various sociocultural organizations (linked to the communities one wants to reach), contacting key individuals within these organizations, and from there, building on established trust relationships, further engaging in conversations with potential candidates. This is a process that requires time, flexibility, and above all, a respectful, open attitude. Ambassadors are trained, compensated, and are a cornerstone in the **dual process of socialization [vermaatschappelijking] and societal awareness of palliative care**. In their continuous training, coordinated by network partners and possibly partly based on existing programs, they learn, among other things, to explain complex topics about palliative care in an accessible way to others and become familiar with the broad range of support available. Specifically, the ambassadors fulfill three tasks in cooperation with a (local) PAZAP coordinator:

1. Actively disseminating correct and accessible information about palliative care by, among other things:
   - proactively approaching individuals in their own community and/or neighborhood who are confronted with serious, incurable illness, end-of-life issues, and/or grief, and, if they are open to it, informing them about palliative support options;
   - helping to distribute (campaign) materials;
   - taking the first step towards local organizations, associations, and actors that can play a possible role;
   - being available as the first point of contact to help people on their way.
2. Identifying initiatives and places in a community or neighborhood where one can find support around serious illness, end-of-life issues, and grief, and where necessary and desired, helping to develop them.
3. (Co-)organizing conversation moments about themes related to palliative care in sociocultural organizations and settings within their own neighborhood or community (see component below). From the trust relationships the ambassadors have built, conversation events can be organized that directly respond to the needs and preferences of the target populations and thus have a greater chance of success.

Potential ambassadors must have an empathetic attitude and a genuine interest in supporting others in their community. They must be willing to participate in training and workshops offered as part of the PAZAP program, as well as activities and events within their community. Finally, ambassadors are core partners within the network described under component 1 and are supported at all times by the coordinator and each other (regularly scheduled intervision moments are one vital aspect of this).

06.

Community conversations

This component involves organizing conversation sessions within **sociocultural organizations** such as women's associations, houses of prayer, local service centers, and youth clubs. The emphasis is on **dialogue in an accessible, open, and safe atmosphere**. Palliative Care Ambassadors and/or PAZAP coordinators, individuals with serious incurable illnesses from the target group, and other audience members participate in conversations on one or more **themes connected to palliative care**. The PAZAP coordinator or ambassador act as facilitators, ensuring that discussions are conducted respectfully and constructively, and that accurate information about palliative care is reinforced. They are also trained in empathetic, intercultural, and facilitative communication skills to effectively fulfill this role. A thematic blueprint, based on our preliminary research and discussions with planning group members, is available. It has been designed to allow groups to choose themes and discussion methods that align with their own interests, needs, and preferences. The proposed themes are:

1. Support needs for serious, incurable illnesses and making them discussable:
    - Identifying the practical, emotional, spiritual/existential, and social needs of individuals confronted with serious, incurable illness.
    - Exploring ways to make these needs discussable, including different viewpoints and potential challenges.
    - Sharing personal experiences and offering mutual support.

2. Comprehensive care & support options and accessibility:
    - Informing participants about the broad, integrated range of palliative support options and resources available in the community, primary care, and specialized care.
    - Exploring the various roles that people in close and extended social circles can take on, and considering available resources and support for caregivers and others involved.
    - Discussing potential barriers or challenges in accessing palliative care and identifying possible solutions.

   - Encouraging participants to spread awareness of available resources and support those in need.

3. End-of-life choices & practices:
   - Discussing the different options and choices available regarding end-of-life care.
   - Exploring questions, doubts, and desires related to palliative care, end-of-life decisions, and advance care planning.
   - Creating a safe space for open conversations about potentially sensitive topics such as treatment limitations, euthanasia, and palliative sedation.

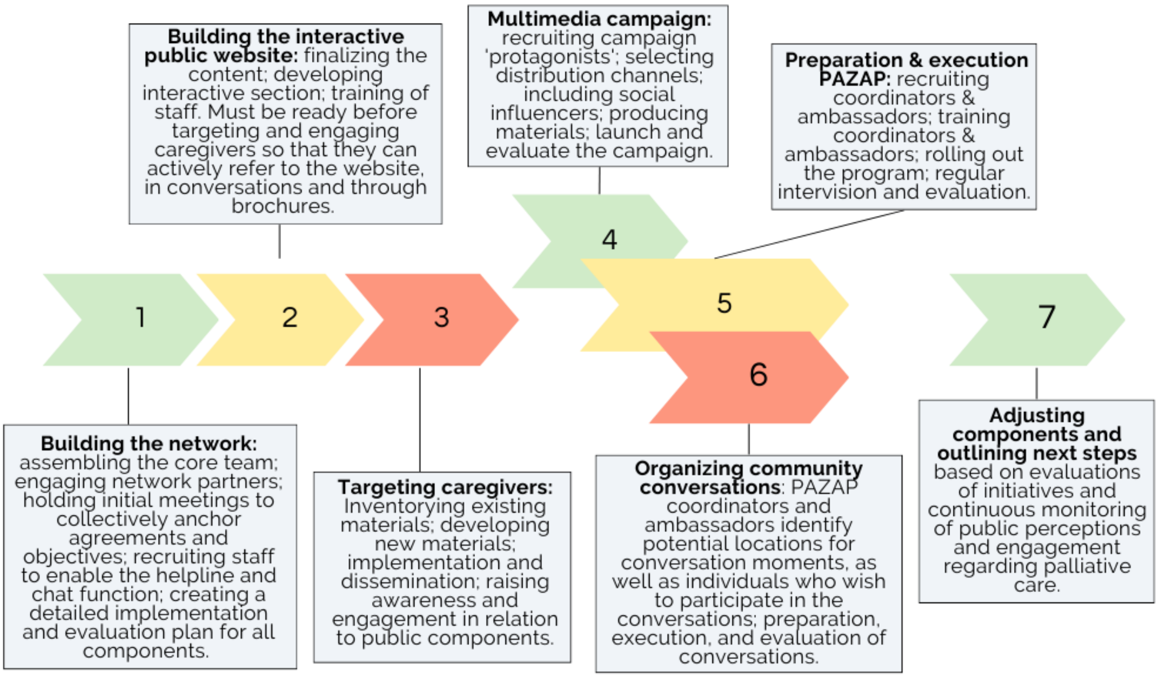
4. Grief experiences and support:
   - Exploring the various aspects of grief and sharing personal experiences of loss and sorrow.
   - Providing information and resources about grief processing, grief support, and self-care during the grieving process.
   - Encouraging open communication and creating a supportive community for those mourning a loved one.

After gathering experiences from the initial series of community conversations, the impact can also be extended to other societal domains, such as organizing conversations within employers' organizations or workplaces. This approach aims to raise societal awareness of palliative care and expand support capacity at various levels within society.

3.3. Sequence

The six components were described above in the order in which they need to be implemented. The last three overlap with each other in time. Below, the order is shown schematically.

Figure 7: implementation sequence.



Building the network: assembling the core team; engaging network partners; holding initial meetings to collectively anchor agreements and objectives; recruiting staff to enable the helpline and chat function; creating a detailed implementation and evaluation plan for all components.

Building the interactive public website: finalizing the content; developing interactive section; training of staff. Must be ready before targeting and engaging caregivers so that they can actively refer to the website, in conversations and through brochures.

Targeting caregivers: Inventorying existing materials; developing new materials; implementation and dissemination; raising awareness and engagement in relation to public components.

Multimedia campaign: recruiting campaign 'protagonists'; selecting distribution channels, including social influencers; producing materials; launch and evaluate the campaign.

Preparation & execution PAZAP: recruiting coordinators & ambassadors; training coordinators & ambassadors; rolling out the program; regular intervision and evaluation.

Organizing community conversations: PAZAP coordinators and ambassadors identify potential locations for conversation moments, as well as individuals who wish to participate in the conversations; preparation, execution, and evaluation of conversations.

Adjusting components and outlining next steps based on evaluations of initiatives and continuous monitoring of public perceptions and engagement regarding palliative care.

4. CONCLUSION

This project resulted in a comprehensive strategic design to address unknown, misunderstood and stigmatized aspects within public perceptions of palliative care. From a socio-ecological perspective, building blocks were designed to interact at various levels—from individual to broad societal—and to effect real change in public perceptions of palliative care. The co-creative design also includes concrete, tangible materials (such as the recommendation card) that organizations can use immediately to improve their communication about palliative care.

Changing public perceptions of palliative care requires time, effort, and especially collaboration. This project brought together a diverse group of individuals and organizations, illustrating the great potential of such collaborations. Initially, the merging of diverse perspectives and expertise is accompanied by a complex web of ideas and opinions, where contradictions are also inherently present. However, this complex web is an indispensable breeding ground for developing a sustainable, new narrative about palliative care, so that eventually more people can find timely, appropriate care and support when they face serious, incurable illness, end-of-life issues, and/or grief.

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Their valuable contributions not only made the drafting of this broad public campaign strategy possible but will also continue to resonate in ongoing efforts to promote societal awareness and engagement with palliative care.

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Chapter VII

General discussion and recommendations

1. Introduction

This dissertation focuses on the public perceptions of palliative care in Flanders and the co-creative development of a broad public campaign strategy to address unknown, misunderstood and stigmatized aspects of palliative care. In the final chapter of this dissertation, an overview is given of our main results in relation to the overall research aims, which is then followed by a discussion of methodological considerations. Next, our results are elaborated on by reflecting deeper on some of our interpretations and their implications from within the broader literature. Finally, recommendations are offered for practice, policy and research.

2. Summary of main findings

2.1. Research aim 1: to gain a deeper understanding of public perceptions of palliative care within the sociocultural context of Flanders

To address our first research aim, four substudies were conducted which each addressed a different objective.

Cross-sectional population-based survey to examine the public knowledge of palliative care and differences between subgroups among the general public of Flanders

In Chapter two, we examined the public knowledge of palliative care in Flanders and the associated personal characteristics and experiences by applying a population-based survey design. Within a range of 0 (minimum knowledge) to 13 (maximum knowledge), a mean total score of 7.87 was found on the Palliative Care Knowledge Scale [PaCKS]. The majority of respondents knew that palliative care: (1) is not only for older adults (84.7%); (2) nor just for persons with cancer (82%); (3) is not restricted to hospital-settings (78.2%); and (4) helps the whole family cope with a serious illness (76.1%). Conversely, a minority of respondents knew that palliative care: (1) has the goal to improve a person's ability to participate in daily activities (32.1%); (2) addresses stress from serious illness (35.6%); (3) is not exclusively for people in the last 6 months of life (44.2%); and (4) can help people manage the side effects of their medical treatments (49.3%).

In addition, we found that being aged between 30 and 59, nonreligious, highly educated, having professional experience in healthcare and knowing palliative care through personal experience were all significantly associated with higher mean knowledge scores. The most important information sources through which people with low levels of palliative care knowledge reported having heard of palliative care were informal sources (43.2%), personal experience (35.8%), and traditional media (32.6%). People with average to high knowledge levels most frequently reported the same three information sources, although the relative order differed: personal experience (53.5%), informal sources (43.9%), and traditional media (43.2%). Additionally, the importance of formal sources was relatively higher in this group (23.8% compared to 9.1%).

In general, our cross-sectional population-based survey showed that even though the general public seems to have a relatively good understanding of some of the basic concepts of palliative care, several of its key aspects remain unknown or misunderstood.

Narrative inquiry using reflexive thematic analysis to explore patterns of shared meaning across personal narratives concerning experiences with palliative care, serious illness, and the end of life

In Chapter three, patterns of shared meaning were explored across personal narratives surrounding experiences with palliative care, serious illness, and the end of life, as told by persons with serious illness, as well as (bereaved) family caregivers and loved ones. Our reflexive thematic analysis yielded four ‘axes of meaning’:

1) ‘Sense of Support’: involving a recurring thread of feeling supported or abandoned on multiple levels. Key elements included being seen and listened to by the personal as well as professional health care environment, and having open, empathetic conversations with health care providers. Additionally, the meaning of having a social network to lean on was stressed, as well as being informed and guided throughout the illness trajectory, without losing a sense of being in control.

2) ‘Being-in-Time’: revolving around shifts in the way time was experienced. On the one hand, this included a (renewed) sense of time as a limited, most valuable resource and not knowing how much time one has/had was frequently described as a continuous burden. On the other hand, a (renewed) sense of time and temporality was present in the narratives in a more abstract sense; as the horizon through which life was given meaning, particularly in the way people adopted an attitude of gratitude, set meaningful goals or judged life as completed or uncompleted.

3) ‘Constituting a Sense of Self while Coping with Life-Threatening Illness’: the narratives also served to constitute a sense of self in the way people described they were coping with their situations. Being positive and having an attitude or desire to ‘keep on fighting’, connected to bravery and courage, were not just mere descriptions of how people had dealt or were dealing with illness but were simultaneously underscoring who

they are/were as a person. This axis also included a desire for a continuity of identity and keeping a certain image of oneself intact, both when physical abilities or roles evolve and beyond death, in the memories of others.

4) 'Going Through the Process of Dying' – unique to the narratives of bereaved individuals: involving the impact of the process of dying and showing a sharp contrast between 'negative stories' emphasizing regret, doubts and/or emotional distress and 'positive stories' emphasizing gratitude, connection and warmth. Being informed and guided during the dying process was central to the way these experiences were narrated on and given meaning, particularly regarding the uncertainty about its physical aspects and witnessing the potential suffering of a loved one. In addition, whether the wishes of the deceased were fulfilled or not played an important role. Often this revolved around euthanasia and palliative sedation, and divergent perceptions and practices surrounding them manifested themselves in the narratives as a source of conflict and distress.

The organization of the data along these four axes concomitantly enabled a deeper insight into the multilayered, relational and context-bound nature of the way palliative care is perceived and given meaning. In line with our axes, positive views on palliative care were built on experiences of feeling supported, being guided through difficult times, being informed and listened to and receiving the time, space and liberty to say goodbye in the way one wants. Conversely, stories reflecting negative perceptions of palliative care often narrated on an experienced lack of access, support, information, guidance and/or not being able to honor the wishes of dying loved ones. Particularly in relation to the latter, negative perceptions toward palliative care were often informed by confused understandings of palliative sedation, and/or the view that palliative care is in conflict with the practice and principles behind euthanasia (often connected to Catholicism). In this light, perceptions of palliative care were also fueled by (conflicting) perceptions of the practice of palliative care with the norms and values the narrators adhered to (for instance surrounding the right to self-determination) and the broader social discourses these belong to.

Descriptive and discourse-theoretical analysis of online information on palliative care disseminated by practice, policy and advocacy organizations

In Chapter four, we examined the online information of palliative care spread by palliative care policy, advocacy and practice organizations in Flanders, to detect elements of congruence, ambivalence and tension within and between these representations and to identify and interpret the discourses at play. Our descriptive analysis showed a certain level of congruence between the given definitions and descriptions of palliative care through the consistent presence of a number of key signifiers. These include: person-centered care; total care comprising different dimensions; practiced by multidisciplinary teams; applicability in diverse care settings; and goals aimed at optimizing quality of life, comfort, and/or relief of suffering. On the other hand, this level of congruence was seriously limited by discrepancies in the way palliative care was defined in connection to curative, terminal, end-of-life, and supportive care, thereby adding to the lack of clarity. More specifically, despite the fact that palliative care was often presented as “more than terminal care”, overall it 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 ambivalent. The texts also differed in the way curative care and palliative care were presented as overlapping in time and goals or as strictly separated from each other. In some texts supportive care was also mentioned but likewise with divergent descriptions connected to it.

Next, through a critical discourse-theoretical lens, we identified a dominant discourse representing palliative care ‘as a culture’, with the concepts of total care, compassion and openness as its nodal points. The function of total care within the discourse lies within the articulation of 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 other two nodal points, openness and compassion, relate to the values promoted within the discourse which were simultaneously central to the subject position of the palliative caregiver. Further, we found that “the palliative patient” was represented in a passive position in relation to palliative caregivers and ‘having an incurable disease’ and ‘being in the last phase of life’ were predominantly connected to negative signifiers such as suffering, dependency, fear and powerlessness (discursively enabling the compassionate and open subject positioning of the caregivers). Curative care and the wider society at times also functioned as discursive ‘constitutive outsides’, meaning that through the articulation of society as death-denying or isolating, and curative care as focused only on cure and quantity of life, the representation of palliative care as an emancipating force was enabled. Moreover, three intra- and interdiscursive tensions, that is, struggle between meanings, could be observed across texts, involving: (1) a tension between the open attitude toward 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; (2) conflicting articulations of autonomy between the right-to-die discourse (emphasizing individual choice) and the palliative care discourse (emphasizing social embeddedness); and (3) the debated (ideological) role of a natural death.

In general, based on the findings of this study, we concluded that the online information contributes to the lack of clarity and potentially even stigmatization of palliative care.

Audience reception research of public awareness campaigns on palliative care using the Multidimensional Audience Reception model

Chapter five encompassed a multidimensional audience reception study to examine how the public interprets, evaluates and engages with public awareness campaigns on palliative care. Our study revealed large differences between participants as well as between campaigns concerning their overall appeal, clarity of communication, attitudinal responses toward the perceived message, as well as efficacy in stimulating further thought or action. The motivation to actively make sense of campaign messages was impacted by a number of elements but most prominent was the role of personal experience surrounding serious illness, frailty, the end of life and/or palliative care. Those who had these experiences generally showed more interest and motivation to pay focused attention. Prior (negative) attitudes to what is perceived as advertising and the situational conditions in which the campaigns would be encountered also impacted motivation and interest. In addition, being able to recognize or identify with certain elements within campaign materials played a role, but our study demonstrated that this is not a one-on-one relation, but instead interacts with broader societal discourses (most clearly illustrated by the fact that the oldest participants were often appreciative that the campaign materials did not portray older persons which arguably would reinforce stereotypical representations of both palliative care and older persons). In terms of comprehension, participants often struggled to connect certain images and slogans with palliative care, leading to confusion and varied understandings of the materials. Conversations surrounding the campaigns revealed that palliative care is commonly associated with end-of-life care in hospitals, provided to severely ill, bedridden persons. Two of the campaigns had a stronger influence in positively changing those perceptions, while a third one mainly reinforced them. In connection to this, our study showed the importance of informing on palliative care primarily through the perspectives of persons confronted with serious illness and to represent them in active and resilient positions, since these elements greatly impacted participants attitudes towards campaign materials as well as palliative care perceptions. Additionally, our results suggested that visualizing the meaning of palliative care through the broader social context surrounding the person with serious illness would appeal to a wider audience (tapping into a sense of personal relevance amongst others) and might prove valuable to stimulate further public engagement with palliative care. In general, many participants expressed doubts about the relevance, impact and credibility of the campaigns, while others supported the campaigns for broadening perceptions of palliative care and bringing the themes of serious illness and the end of life into the public sphere. Moreover, the importance of not relying solely on the digital proficiency of the intended audience was highlighted, as well as the value of having meaningful dialogues in shaping understanding of palliative care.

Overall, this study showed that public campaigns on palliative care are interpreted, evaluated and engaged with in highly divergent ways, and that diversified strategies are needed to improve public understanding and involvement in palliative care.

2.2. Research aim 2: to co-creatively design a broad public campaign strategy to tackle unknown, misunderstood and stigmatized aspects of palliative care in Flanders

In Chapter six, we reported on an integrative approach combining co-creation and Intervention Mapping to develop a broad public campaign strategy to tackle unknown, misunderstood and stigmatized aspects of palliative care.

Within the co-creative process the specific campaign goals were defined as follows: (1) Individuals confronted with severe incurable illness, the end of life, and/or grief are empowered to find palliative support in time (in relation to their support needs); (2) Individuals within the (close or distant) social context of those confronted with serious, incurable illness, the end of life, and/or grief are empowered to take on (palliative) support roles. From there, the co-created campaign strategy was built on six communication principles and consisted of six conceptual components.

The six communication principles were: (1) to name palliative care, without stigma, i.e. emphasis on broadening interpretations through imagery and language while avoiding deterministic language such as labeling persons or life stages as ‘palliative’; (2) to emphasize the onset of care by giving concrete examples that clarify who can benefit from palliative care, for what and from when while avoiding vague terms or descriptions that reinforce the (exclusive) association with end-of-life care; (3) to represent persons, both in images as in language, in active positions, i.e. in control, in the midst of society, fulfilling social roles and avoiding depictions of people as passive recipients of care, isolated from the broader society; (4) to also highlight the importance of the social context within palliative care by showing palliative care from the perspectives of various individuals from within both close and distant social networks; (5) to recognize and work with the broad diversity across society and within meaning attribution surrounding serious illness and the end of life, in order to make communication about palliative care accessible and relevant for as many people as possible; (6) to also name death and dying as core components of palliative care but at the right time (not as an ‘entry point’) and always within the broader narrative of palliative care.

The six components were:

(1) Building a Network: Develop a strong and diverse network of engaged partners who are willing and able to play an active role in raising societal awareness of palliative care. This network fulfills several clear, well-defined tasks such as lobbying for positive and correct media representation of palliative care, monitoring changes in public perceptions, and influencing policy. Next to a formal core team who oversees the effective pursuing of goals and division of tasks, the network has a low-threshold and open structure so that it can continue to grow organically.

(2) Building a Website: To optimize and centralize online information about palliative care, a website needs to be built with general information, campaign materials, and above all, many accessible tools and resources that people can use. The website ideally also contains an interactive section (consisting of a chat service, and if sufficient moderation can be achieved also a forum) fulfilling an informative, supportive, and connecting function, and run by a sufficient number of committed and trained individuals.

(3) Targeting Professional Caregivers: Starting from an inventory of existing resources, initiatives need to be implemented that can enhance healthcare providers' knowledge of palliative care and encourage them to inform patients correctly and timely about palliative care options. Valuable materials to develop or reimplement (depending on outcome of inventory) are: infographics and e-learning modules adapted to different health care professions, and information brochures caregivers can give to patients during discussions about palliative care.

(4) Multimedia Campaign called “Leef Mee”: Seeks to reshape public understanding of palliative care and of those living with serious, incurable illnesses through the use of positive language and imagery. The campaign's messages, encapsulated in three main slogans, are embodied by individuals from diverse backgrounds who share their authentic stories, in different forms and across different channels, to present a realistic, positive view of palliative care.

(5) Palliative Care Ambassadors: A program that mobilizes individuals with personal experiences around palliative care to act as pioneers and sources of information and support within their own communities. Ambassadors are core pillars within the dual process of societal integration and societal awareness of palliative care.

(6) Community conversations: Organizing discussion moments within various socio-cultural settings and organizations such as women's associations, places of worship, libraries and local community centers. The focus is on dialogue about important themes surrounding palliative care in a low-threshold, open atmosphere.

3. Methodological considerations

3.1. Methodological considerations regarding the overall approach

To achieve our research aims and specific objectives we applied multiple methodologies and methods. Overall, our methodological approach was dominated by qualitative, interpretative research leaning on theoretical principles of social constructionism. The main focus was thus on enhancing understanding while recognizing subjective meaning as a critical component of knowledge building[1]. However, research methods and practices do not count as straightforward practical translations of certain philosophical positions[2], which means that epistemological assumptions and values are not inherently tied to certain methods and per definition incommensurable with others[3]. In this project, a deterministic view on qualitative versus quantitative methods was thus rejected and instead, a pluralist, pragmatic approach[4] was taken endorsing the value of both in relation to the different objectives within our overall research aim. The integration of the qualitative findings (Chapter three – five), and the quantitative findings from the population-based survey (Chapter two) significantly enhanced our understanding of the topic at hand, regardless of the fact that as a quantitative method the latter typically operates under different epistemological principles than the ones adhered to in this project.

In addition to the survey, also Intervention Mapping (Chapter six) is not typically associated with social constructionist principles and mostly operates from within different academic discourses, focusing on the generation of empirically-sound logic models and behavioral change (be it from a systemic, socio-ecological perspective). Within the field of health promotion, which Intervention Mapping belongs to, health promotion programs have been argued to be often implicitly conceptualized from an empirical realist ontology, i.e. as objective solutions to objectively defined problems, in which a critical perspective on the subjective production of knowledge in program planning, implementation and evaluation is sidelined[5,6]. Furthermore, as argued by Mantoura & Potvin[7], health promotion (and thus also Intervention Mapping) leans heavily on the values of empowerment and participation, but these tend to be brought as normative issues guiding methodology rather than as (part of) an epistemological research posture. Nonetheless, Intervention Mapping in itself does not impose any epistemological or ontological perspectives and the implicit references to them (mainly stemming from the fact that the original Intervention Mapping protocol was written by authors who are all closely tied to the field of behavioral psychology), are in no sense preventing its adaptation to (the language of) other theoretical frameworks. On the contrary, the distinctive key principles of health promotion, i.e.

empowerment, participation and a positive, socio-ecological conception of health, even invite these theoretical, epistemological and methodological expansions and adaptations, to advance its development as a discipline[8]. Therefore, any initial theoretical tension felt – even though we were never pursuing a 'purist' overall design – was automatically resolved during the process.

3.2. Strengths and limitations of the overall approach

The variety of methods and angles counts as a first strength of our overall research approach since it greatly enhanced insight into the contextually influenced public perceptions of palliative care, thereby enabling the development of a comprehensive campaign strategy.

In addition, as a logical consequence of the social constructionist epistemology, a critical interrogation of our own (researchers') understanding of palliative care and how this is shaped by dominant discourses within academics, palliative care practice and the wider societal context, was engaged in throughout the project. This reflexive attitude, fueled by our theoretical commitments, fostered a critical awareness of potential blind spots and taken-for-granted notions and enabled a deeper and more nuanced understanding of our topic.

Further, the project was built on the recognition of the inherent diversity of the 'general public' and the necessity to reflect this diversity within research designs. Active, multilayered strategies were thus sought to recruit participants from diverse backgrounds (in terms of gender, age, ethnicity and socio-economic position among others), in regard to the audience reception study as well as the composition of the planning groups. These efforts led to the inclusion of a wide variety of voices, ultimately enhancing the richness of our data and the insights we could derive from them.

Another overall strength is connected to the fact that this project was guided by a project group consisting of seven members with diverse academic backgrounds and expertise. Every six weeks meetings were held to critically discuss methods, findings, interpretations and doubts. Conceptually, this form of collaboration overlaps with a well-known technique to increase the credibility of studies, called 'peer review or peer debriefing'[9]. As described by Lincoln and Guba[10], peer reviewers *"provide support, play devil's advocate, challenge the researchers' assumptions, push the researchers to the next step methodologically, and ask hard questions about methods and interpretations".* Each project group member took on this role of peer reviewer, but depending on the point in the project course, their specific 'tasks' could differ from one another. Overall, the systematically received input from project group members amplified reflexivity and scientific rigor, proving invaluable for the progress and results of the project.

Our overall methodological approach nonetheless also has some limitations. A first limitation relates to the potential lack of transferability or theoretical generalizability of some of our research findings to the whole of Flanders. While the narrative inquiry study involved narratives of people from all over Flanders, the survey study was conducted in only four cities, the audience reception focus group study mainly in the region of Ghent and the majority of citizen co-creators were likewise residents of the Ghent region. Within the overall design, the possibility to shed light on and gain access to regional differences in the public perceptions of palliative care was therefore limited. Even though generally speaking palliative care practice does not differ widely across Flemish regions, local contextual factors can still be expected to play a role and potentially interact with the way (information of) palliative care is perceived and given meaning. For instance, in our research a tension between systems-of-meaning surrounding palliative care and euthanasia was encountered, often also connected to a perceived relationship with Catholic or Christian values. Depending on the division of ideological and religious beliefs across regions, it is possible that the tension between the two may be perceived as more or less antagonistic in some places and insight into these potential regional differences would thus foster a more nuanced insight into the public perceptions of palliative care in Flanders. In addition, seeing the local context the studies were conducted in, the value of our findings could also be questioned in relation to palliative care research and practice in an international context. Nonetheless, we believe that the results of our different sub-studies substantially enhance insight into the multilayered nature of the public perceptions of palliative care and in this sense can also be of value for international researchers and palliative care practitioners interested in this topic, regardless of the specific regions they are operating from. Furthermore, in qualitative research, transferability or (theoretical) generalizability are mostly seen as a shared responsibility between the researcher, who needs to embed interpretations within sufficient contextual information, and the reader, who then determines the usefulness and applicability of the reported *"interpretations-in-context"*[11] to other contexts. In this sense, even though we do estimate that our findings are to a large degree reflective of the whole of Flanders and that they are in fact responding to a research need resonating on an international scale, we leave it to the reader to make the final judgement.

A second limitation connected to the overall design is the absence of a sub-study on the representation of palliative care within popular, mass media sources. This sub-study was initially planned but due to practical time constraints, left out of the final project design. Yet, our survey study (Chapter two) showed that, next to personal experience and informal information sources, traditional information sources (such as radio, television, newspapers and magazines) play an important role in the way people obtain knowledge on palliative care. A decade ago some interesting work was done showing the tension between the right-to-die discourse and the palliative care discourse within popular media sources[12,13], but since then there has been no further attention to the representation of palliative care within these sources. Seeing the rapid evolutions within the palliative care practice and policy landscape, and seeing the nature of our research aims, the absence of a sub-study on this could arguably count as a limitation.

A third limitation of the overall design revolves around the limited attention given to the concept of health literacy. Although health literacy is included as an individual level-determinant within the logic model of the problem (page 136), we did not directly research it, nor did I engage with the extensive literature on the subject in this dissertation. Incorporating a more explicit focus on health literacy could have enriched the methodological and theoretical depth of the project. Nonetheless, the concept of health literacy is implicitly recognized within the comprehensive co-created campaign strategy, as it acknowledges that not everyone has the same tools, competencies, or resources to find, comprehend, evaluate, and apply palliative care information. To address these varying needs, the campaign incorporates outreach efforts, such as the Palliative Care Ambassador Program and community conversations. Additionally, an interactive function was added to the website, allowing users to engage in discussions and ask questions directly to trained volunteers. While still conceptual at this point, once implemented, volunteers should be trained to recognize potential (non-static) differences in health literacy.

In addition to these overall strengths and limitations, each study reported on in this dissertation also has its own specific strength and limitations. For all studies, except the co-creative campaign development, these have already been described within their dedicated chapters and will thus not be repeated here. However, a further consideration connected to the survey study that was not described in the published article and is rather the result of progressive insight, will be elaborated on below. After, we will describe the strengths and limitations of the co-creative development of the broad public campaign strategy since these were not included in Chapter six.

3.3. Evaluating the Palliative Care Knowledge Scale

In Chapter two, the use of the validated Palliative Care Knowledge Scale (PaCKS) to measure the public knowledge of palliative care was described as a strength of our survey study, although its predominantly service-oriented conceptualization of palliative care was recognized as a potential limitation. However, in retrospect, a more critical perspective towards this scale and, in particular the wording or framing of the separate items could have been taken. More specifically, there is a possibility that an underlying pattern in the specific wording of the 13 PaCKS items influenced responses. The pattern that can be discerned is the following: all PaCKS items that contain the words ‘onder meer’ (n=3) - which translates as ‘among other’ - are correct statements, while all items that contain the words ‘exclusively’ or ‘specifically’ (n=3) are false statements. Additionally, all items that contain the word ‘can’ (n=2) are correct, while all items that contain the word ‘must’ (n=2) are false. Most of these potential wording issues were already present in the original English scale, others were introduced after applying the forward-backward translation technique (specifically: ‘onder meer’ which translates as ‘among other’ is not included in the original English version). Overall, this means that responses on 10 out of 13 items might have been partly influenced by the item wording itself, which counts as a threat to the internal validity of our study. However, the results of the validation process of the PaCKS showed that the scale meets or exceeds all standards for psychometric scale development[14]. Moreover, research has shown that question wording effects are unpredictable[15] and the actual effect of the wording of the items on the response behavior might as well be very limited. We therefore believe that the more important limitation to report here is connected to the fact that the (translated) scale was not tested rigorously beforehand with a small group of Flemish respondents, definitely seeing the importance it has within our survey study as the only measurement tool used to assess the actual knowledge of palliative care. Qualitative pilot interviews in which persons are asked to think out loud when answering survey questions, offering the option to criticize wording and ask to repeat the meaning of the question in their own words, for instance, could have been used to estimate and avoid bias caused by the wording or framing of questions[16].

A further point regarding the potential wording effect is that it might offer a partial explanation for the observation that 52.4% of respondents underestimated their knowledge when comparing the congruence between self-perceived and actual knowledge scores. This underestimation could be attributed to the influence of item wording on responses, which might have led to higher PaCKS knowledge scores. In addition, it might partly explain a discrepancy that we found between our studies. Namely, in our survey study we found that most of our respondents knew that the statement ‘people must be in the hospital to receive palliative care’ is false. However in our audience reception focus group study, conversations surrounding the campaign materials showed that participants were very often not aware of the possibility of palliative care being provided outside of hospital settings. The use of the word ‘must’ in the particular PaCKS item, and the overall wording pattern it belongs to, might have led respondents to interpret the question as ‘false’ regardless of the actual knowledge on this aspect of palliative care.

3.4. Strengths and limitations of the co-creative development of the broad public campaign strategy

The last step taken as part of this doctoral project was the development of a broad public campaign strategy to tackle misunderstood, unknown and stigmatized aspects of palliative care, in close collaboration with diverse citizen and professional stakeholders. There are several strengths as well as limitations connected to this co-creative development. A first strength lies fully within the commitment and capacities of all co-creators. Throughout the process almost all 30 planning group members as well as the two communication professionals, exhibited great motivation and enthusiasm to give input and collectively create an effective campaign strategy. Conversations were rich, purposeful and critical and, from within an open, respectful atmosphere in which divergent opinions and ideas were shared, led to a comprehensive design that resonated with the whole group. Through this collaboration, a campaign strategy was designed that could never have been achieved if the work had been carried out by academics alone. Moreover, the diversity in backgrounds, perspectives and expertise also strengthened the inclusion of campaign components that are specifically needed to reach people and groups that are too often too easily dismissed as being ‘hard to reach’. Another strength of this project is its use of Intervention Mapping. Co-creative processes can quickly become ‘messy’ and although there is creative potential within that messiness, having a robust and clearly defined step-by-step plan was invaluable. It facilitated the integration of theory, research findings and participants’ input, and helped to maintain a clear sense of direction throughout the process.

Aside these strengths, there are also some limitations to report. A first limitation is that the practical set-up of the different meetings was limited in scope (planning group members were asked to join three meetings, one each month between January and March, resulting in a total time investment of 6 hours). We took this approach to make participation feasible and manageable for the planning group members alongside their other responsibilities. While this strategy offered advantages, it also led to a fast-paced process. Consequently, discussions were sometimes cut short when it would have been beneficial to have more time to continue them. Additional time would also have been good to elaborate further on certain decisions that were made out of divergent opinions, for instance with regard to the choice to explicitly name palliative care or not in the multimedia campaign, or with regard to the type of images chosen. In fact, each campaign component could have easily merited its own full session. However, this would have been near impossible to organize in practice - let alone, still have planning group members left with that much available time. Another potential limitation, partly connected to the practical set-up, is that the process did not allow sufficient space and time for the professional stakeholders and citizen stakeholders to get to know each other. There was only one joint meeting and the time allocated for introductions was limited. Separate, mixed groups were formed during this meeting to discuss the different campaign components and two of the citizen stakeholders afterwards (separate from each other) shared to the doctoral researcher that at times they did not really understand some of the jargon or 'insider' language being used during the conversations by the professional stakeholders. This sporadic lack of mutual understanding and an apparent hesitation to ask for clarification by at least some of the citizen stakeholders, could to a certain level have been prevented, which then could have further enhanced the richness of the input received during this last meeting. On the one hand, moderators (researchers in this case) could have been more sensitive to these potential differences in language use by rephrasing comments or questions where needed to foster mutual understanding. On the other hand, if more time would have been available to (informally) get to know each other's backgrounds and experiences, planning group members would have also familiarized more and been more attuned to each other's communication styles and reference frames, potentially facilitating the effective, open sharing of ideas as well as the interpretation of them.

4. Interpretation and discussion of the main findings of this dissertation

In this section, we will discuss the main findings of this dissertation in relation to the broader literature. Overall, the conducted studies confirmed the relevance of addressing public perceptions of palliative care by pointing out the existence of unknown, misunderstood and stigmatized aspects of palliative care in the Flemish context. During the course of the project, vital elements to focus on to enhance understanding and engagement became progressively tangible, before ultimately being concretized within the co-creation of the campaign strategy.

4.1. Stigma and (de)stigmatization of palliative care

Within the broader literature, the public stigma or the stigmatization of palliative care are often discussed[17–21]. While the former refers to the phenomenon of palliative care evoking fear, avoidance and/or aversion due to the close association of palliative care with end-of-life care, death, hopelessness and dependency[20–22], the latter refers to the acts and processes, occurring on - interconnected - individual, interpersonal and societal levels[23], that (re)produce this phenomenon. As an example, health care practitioners that persistently frame palliative care in the context of ‘treatment withdrawal’ or ‘ceiling of care’ strengthen the impression that persons are being handed over to palliative care while being denied potentially helpful interventions, thus reinforcing stigmatized perceptions[24]. Distinguishing stigma as an outcome from stigmatization as a process, facilitates a deeper understanding of its essentially dynamic, multilayered and contextually dependent nature. To gain a more nuanced understanding of this perceived stigma, it is important to look at the elements with which negative perceptions are connected and the contexts in which these are embedded. Based on the findings of this project, we can confirm a dominant perception of palliative care as end-of-life or terminal care in Flanders, yet importantly, in itself this did not necessarily carry negative (attitudinal) connotations. Rather, among the participants of our various studies, we found a wide range of negative, neutral and positive perceptions of palliative care (not mutually exclusive), fueled by prior knowledge, beliefs and past experiences. Moreover, we found that negative perceptions of palliative care were often connected to beliefs, opinions or confused understandings surrounding medical end-of-life practices, more specifically, the practices of palliative sedation and euthanasia. Within both the narrative inquiry study (Chapter three) and the focus group study (Chapter five), palliative care was repeatedly framed as being in opposition to euthanasia, whether linked to Catholicism and based on concrete experiences or not, often conflicting with the ideals of choice and self-determination that people adhered to. Additionally, palliative care was seen as closely associated with palliative sedation, with much confusion surrounding its practice. As also found in a Dutch survey study on public views of palliative sedation[25], misunderstandings include ideas that it is a form of ‘controlled suffocation’, ‘letting people dehydrate and starve to death’ or being euthanasia in disguise (albeit without personal choice). A first important nuance that this project therefore brings is that, while the conflation of palliative care with terminal care surely plays a role, stigmatized perceptions might be more connected to, or at least be also partly influenced by, public (mis)perceptions surrounding medical end-of-life care practices. A second important nuance has already been written about in the literature but is nonetheless often lost in discussions surrounding the stigma of palliative care. More specifically, this concerns the connection between negative (stigmatized) perceptions of palliative care and the idea that it is care one has to succumb to, passively resign to and undergo as a form of disempowered dying[22,26,27]. This stands in a stark contrast with the key signifiers (nodal points) of choice, autonomy and control that have been shown to be dominant within the public discourses surrounding a good death[13,28,29]. Furthermore, our discourse-theoretical analysis (Chapter four) showed how in the online information of palliative care “the palliative patient” was often represented in a passive position in relation to the subject position of the palliative caregiver, and ‘having an incurable disease’ and ‘being in the last phase of life’ were predominantly connected to negative signifiers such as suffering, dependency, fear and powerlessness. Based on these findings we suggested this could potentially reinforce stigmatized perceptions of palliative care. This was later confirmed in our focus group study as we observed that many participants picked up and strongly rejected the passive positioning of the person with serious illness in one of the campaigns, while 'palliative care' was being represented as the 'enablers', the active agents. Some people interpreted and evaluated this particular campaign in a more accepting, neutral or positive way, with one person for instance explicitly stating in response to the others *"that's just how it is*". However, with the risk of pseudo quantifying this study, this was a clear minority and in almost all ten different focus groups, the campaign was predominantly rejected. Stigmatized perceptions of palliative care are thus also closely connected to stigmatizing representations of persons with palliative care needs.

Our suggestion that the stigma surrounding palliative care is not just the mere natural consequence of its close association with terminal or end-of life care, of course does not exclude the possibility of death and dying evoking fear and anxiety. Here it is important to distinguish ideas and discussions surrounding societal discourses and attitudes towards death and dying, from individual responses of persons, patients and their loved ones, in particular when confronted with a diagnosis of serious incurable illness. On the individual level, death anxiety has been described as a normal, universal psychological quandary for humans[30], despite the possibility of maladaptive consequences. The practical confrontation with one's own imminent death or that of a loved one is seen as a naturally upsetting experience and subject of conversation, not as a sign that we deny its existence[31]. It has also been argued that the fears that people have are mainly surrounding the process of dying and the impact of death upon close others, rather than death itself[32,33]. On the societal level, death anxiety and a taboo on death and dying are often highlighted as inherent to Western culture[34,35], despite the abundance of literature rejecting this greatly popularized assumption[36–38]. The existence of a stigma of palliative care is often seen as a partial consequence of this perceived quality of modern Western societies being death-denying[39–41]. The death-denial thesis in this sense has a double function. Firstly, historically up to this day, it is part of the discursive machinery legitimizing the existence of palliative care (with palliative care rejecting the societal taboo and death-denying attitudes exemplified in medicalized practices). Secondly, it serves as the backbone in the explanations of the perceived stigma of palliative care, as an obstacle which is deterring its uptake and growth[36]. Both 'functions' were also present within the online information that we analyzed. Society (as well as curative care) was at times discursively represented as a constitutive outside, as that which denies death and secludes serious illness and the end-of-life from the public sphere, constructively enabling palliative care to be the emancipating death-facing compassionate 'other'. Additionally, death and dying were often sidelined or omitted in the actual descriptions of the practice of palliative care, as has also been found in a discourse-analysis of palliative care definitions in the specialist literature[42], which we interpret here as the result of the second function of the death-denial thesis. The idea of a societal taboo on death is a very persistent one, even when thirty years ago Walter already wrote *"the announcement that death is taboo and that our society denies death continues, yet death is more and more talked of [...] what we find today is not a taboo but a babel of voices proclaiming various good deaths"*[43(p1-2)]. Without repeating the full body of literature on this here, we believe the results of our studies show the importance of adopting a more nuanced perspective on the stigma surrounding palliative care and the stigmatizing processes that enable and reinforce it, in order to develop effective destigmatizing strategies. As stated by Zimmermann & Rodin, the emphasis of palliative care should not be on changing the so-called death-denying contemporary western attitude but on creating supportive environments for anyone who might benefit from this type of care[31]. Moreover, omitting death and dying from its descriptions based on ungrounded assumptions might not only hinder public understanding of the full scope of palliative care, but it might also bypass the importance that caring and committed end-of-life care have within the public eye.

4.2. Addressing gaps in the public knowledge of palliative care, while closing social gaps across society

In Chapter two we highlighted that several key aspects of palliative care remain unknown or misunderstood across the general public. Gaps in knowledge on palliative care have been reported in numerous international studies[44–53], and while there are variations specific to different locations, there is considerable overlap in unknown aspects connected to the dominant understanding of palliative care as care at the very end of life. This persistent perception is linked to the historical origins of palliative care as total care for those dying from malignancies[54] and the observation that palliative care is often not practiced as it is defined (for instance in relation to late referrals)[52]. Seeing that this perception hinders the involvement of palliative care early in the disease course, which has been shown to improve symptom management, quality of life, mood, and satisfaction with care for patients and their loved ones[55,56], broad educational initiatives to improve the knowledge of palliative care are warranted.

However, while specific gaps in knowledge of palliative care are found across society, knowledge on palliative care in general is not equally distributed across society. Our survey study showed that knowledge levels differed depending on age, educational background, religious beliefs or life stance, knowing palliative care through personal experience, and having professional caregiver experience, thereby confirming most of the characteristics - except gender - reported in the literature[53] in the context of Flanders. A recognition and understanding of knowledge differences between individuals and social groups is important when developing educational initiatives such as health communication campaigns to avoid the risk of unintentionally reproducing or reinforcing existing social distributions of knowledge, attitudes, and behaviors[57,58]. The results of our audience reception study for instance clearly show that the public communication and education on palliative care has a substantial risk to only reach and persuade those who are already knowledgeable and interested. Active strategies are thus needed to make sure that social knowledge gaps are not exaggerated as an unintended consequence of educational efforts.

Moreover, while people living in socioeconomical structural positions of vulnerability have been shown to have a higher burden of disease and lower life-expectancy[59], a social gradient in the access and provision of palliative and end-of-life care has been repeatedly reported[60,61]. In this light, the need for educational initiatives to incorporate strategies that recognize societal diversity and actively work towards closing knowledge gaps between individuals and groups, becomes even more pressing. Also in Belgium considerable socio-economic inequalities in health outcomes and behaviors exist with for instance a strong negative income gradient in relation to mortality patterns[62]. Even though in general the healthcare system has been reported to perform rather well in providing accessible care[63], serious inequities exist, also in relation to palliative care. A Belgian study looking at the uptake of supportive measures for palliative home care, for instance, showed differences in uptake related to socio-economic position, suggesting the existence of a social gradient in the use of these measures[64]. Education has been argued (for both fundamental as well as pragmatic reasons) to be a crucial indicator of socioeconomic status[62] and the significant influence of educational attainment on the knowledge of palliative care, as shown in our survey study (Chapter three), in this sense likewise points to the risk that those who might need it the most, are less likely to easily find access to palliative care. Socioeconomic position however cannot be divorced from the wider society in which people live[60], and a comprehensive understanding of the extent and nature of socioeconomic inequities is critical to any equity-promoting effort.

Furthermore, previously demonstrated differences in the access and uptake of palliative care across (intersecting) sociodemographic factors[60,65–70] are only partly a reflection of differences in awareness and knowledge across individuals and groups. Rather than implying any simple relationship, it points to a complex reality in which various personal and structural factors intersect with wider systems-of-meanings through which serious illness, the end of life and different care approaches are experienced. Improving knowledge of palliative care alone, for instance by directing interventions at those with lower educational attainment or specific cultural or religious backgrounds, without fully recognizing the broader structural, sociohistorical and cultural factors influencing the access and uptake of palliative care, most likely will fail to achieve positive change. On the contrary, they risk becoming part of the symbolic violence that maintains middle- and upper-class privilege and advantage[71], by failing to respond to actual needs and preferences of underprivileged and underserved societal groups. Mistrust in the medical establishment for instance needs to be taken into account. Findings from our audience reception study (Chapter five) clearly demonstrated how repeated negative experiences with health care services (mostly shared in one of the natural focus groups with persons in structurally vulnerable positions of poverty but definitely not limited to participants of this focus group) negatively affected the reception of public campaign messages on palliative care and, supported by the literature[72], we recognized trust as an import aspect of the effectiveness of health information. As stated by French[73(p2)]: *"health inequities can manifest across someone's lifetime, meaning that by the time people are nearing the end of life they may have already experienced multiple forms of inequity throughout their live*s". These experiences affect the reception of palliative care information. Therefore, strategies that simultaneously work on rebuilding trust while informing on palliative care are needed. In particular, two of the six components of the co-created campaign strategy, namely the Palliative Care Ambassador Program and the community conversations, can be promising means to achieve this.

In sum, educational initiatives to enhance understanding and engagement with palliative care also bear part in the collective responsibility to reduce inequities in palliative care access and uptake. In line with the principle of proportionate universalism, we argue that public campaign strategies should be universal, i.e. directed at the whole population and not exclusively targeted at some, while simultaneously recognizing that under particular circumstances different standards, resources and methods need to be applied to ensure that diverging societal (information) needs and structural disadvantages are adequately being met[74]. Complex problems need complex solutions[75] and we believe that the diverse components of the co-creatively developed campaign strategy offer both general direction as well as concrete tools to enhance understanding and engagement with palliative care while fully recognizing and addressing societal diversity.

4.3. Promoting palliative care through emphasizing social connection

In Chapter four we showed how palliative care was consistently defined in the online information as not only being directed at the patient but also at the patient's family or inner circle. In addition, autonomy (as a floating signifier) was articulated with an emphasis on the social interconnectedness of the individual within (our analytical interpretation of) the palliative care discourse. Based on these findings, we questioned how people who are alone could feel appealed to a discourse that has such a heavy emphasis on social relationships through which illness, care, and quality of life are approached. Yet, in Chapter five we reported that participants of the audience reception study often expressed a preference for a more social gaze beyond the individual and individualistic angle. Combined with the findings of the narrative inquiry study (Chapter three), which emphasized the relational nature of the way meaning was given to experiences with palliative care, serious illness, and the end of life, these studies suggested the potential of public communication and education initiatives on palliative care to reach a broader audience by showing palliative care through the broader circles surrounding the patient and the social connections it fosters. This might seem conflicting at first with the conclusions made based on the findings of the discourse-theoretical study. In this section we therefore shed some more light on this to resolve this potential tension.

Firstly, the importance (or ontological necessity) of relationality for our being-in-the-world is of course hardly a new thought and there is a vast amount of literature across disciplines and historical time frames in which the interpersonal realm is shown or argued to be fundamental for the experience and interpretation of our personal existence. While this dissertation does not seek to explore the full scope of historical and contemporary discussions about relationality across the human sciences[76], we understand the self as inherently relational[76], and relations as preeminently dynamic, unfolding, ongoing processes rather than as static ties among inert substances[77]. This ontological understanding of relationality clarifies why arguing for a more deeply ingrained social gaze within the public communication and education on palliative care does not imply the further (discursive) exclusion of people without social networks. On the contrary, rather it urges for the application of an anti-categorical approach of relationality[76], thus going beyond the conventional relationships captured in the prototypical categories of 'the family' or even 'friends' and beyond social capital or networks as fixed characteristics. Relationality encompasses the dynamic nature of people's connectivity with others[78], including the constant 'unfolding transactions'[77] of diverse relationships which may be more or less bonded, constricting or enabling[79]. In line with what we argued in the previous section, the diversity of people with palliative care needs across characteristics, experiences as well as available support networks (dynamically understood) needs to be incorporated in public communication and education strategies. This is even more so seeing the cumulative evidence associating social disconnection as a risk factor for morbidity and mortality[80], and that the absence of strong support networks to lean on can be tied to structural vulnerability that hinders the access and uptake of palliative care[64,81]. Additionally, interpersonal relationship quality has been reported as a primary factor influencing people's awareness of and attitudes towards palliative care, with people who had more stable interpersonal relationships showing greater awareness of the actual goals of palliative care and more favorable attitudes[82]. Communication on palliative care thus needs to also speak to people living without strong support networks. For this purpose we advise going beyond the 'traditional relational categories' and to articulate them not as predetermined, bounded entities, but rather as what they are in *"a state of becoming within a wider set of relational processes"*[76(p149)]. Aside the various, dynamic relational processes people engage in with people they work with, receive classes from, buy food from, chat with in real-life or online, and so on, the relationships that people build with professional caregivers matter[83]. Additionally, our relational-being does not necessitate the co-presence of other beings[84] and, as an example particularly relevant in this context, the conversations with deceased loved ones and remembrance rituals bereaved individuals engage in, are all part of our relational mode of being. Highlighting these various lived relational experiences in the context of palliative care can aid to resonate with audiences who lack close family ties, friends and/or neighbors but nonetheless live their lives and experience illness as relational beings and through relational processes.

Moreover, it is important to take into account that meaning is not only constructed through written or verbal language but also through the interplay of various other resources such as images and gestures[85]. Therefore, when the online information emphasized relationality, it mainly did this through the connection of verbal signifiers. In the same vein, many of the analyzed public campaigns on palliative care explicitly mentioned social relationships, yet participants still missed seeing (and feeling one might argue) the social connections through which palliative care defines itself. This clearly shows how the meaning of a text is not fixed or predetermined but actively interpreted by its recipients and the significance of messages for their audiences cannot be known from an analysis of the message alone[86]. Within broader sociocultural contexts, audiences actively allocate meaning to the discourses activated in the texts[87]. Discourses, as partially fixated systems-of-meaning[88], can thus be recognized, drawn upon, reproduced, negotiated, and/or resisted by its audience. The emphasis within the palliative care discourse on relationality and interconnectedness as we identified it in the online information, in any case was not dominantly reflected within the audience readings of the public campaign materials. Here the discourse-theoretical concepts of 'subject position', i.e. the positioning of subjects within a discursive structure[89] and the 'logic of identification', i.e. the way people invest in the activated discourses and embedded subject positions[87], aid to shed light on the signifying mechanisms behind this possibility. Discourses can succeed in getting a hold on its audience by providing individuals with subject positions with which they can identify[87]. Of course, as stated by Jacobs[90(p9)]: *"there is no juncture where a subject picks his or her preferred subject positions from the available batch: he or she is always already part of the structure, 'thrown' into it at birth so to speak"*. Yet, discourses are activated within (media, public campaign, policy, …) texts and recipients of texts or audiences, invest in *"bits and pieces from potentially different, sometimes conflicting discourses […] discourses that provide audiences with subject positions to identify (or dis-identify) with and which in turn allow them to 'speak'"*[87(p385)]. The subject positions we identified within the palliative care discourse as present within the online information were limited to "the palliative patient" and the palliative caregiver, and the social circles around the patient were 'discursively underrepresented' in this sense. Seeing the importance of relationality within the axes of meaning surrounding personal experiences with (care for) serious illness and the end of life, and seeing the reported value of palliative care to foster social connections[82,91], we argue that the main task for improvement within the communication and education on palliative care is to not just talk about relationality and the importance of social connections, but to articulate their meaning and importance through the full representational mechanisms available within the textual domain. In particular, this means really showing, visualizing the social connections through which palliative care is enacted, interpreted and given meaning, and, giving a voice to the various persons within the close and broad social circles surrounding the patients, in order to enable the possibility of a logic of identification within the audience reading of materials.

5. Recommendations for practice, policy and research

In the last section of this general discussion, several recommendations based on the findings and interpretations of this dissertation are formulated. One general suggestion, of course, is to work with the broad public campaign strategy that we developed based on the fruits of five years of research and the active participation of a diverse group of citizen and professional stakeholders. The specific recommendations for practice and policy below highlight key aspects to improve public communication and education on palliative care. Additionally, the specific recommendations for research identify important areas of inquiry to further enhance our understanding of public perceptions of palliative care.

5.1. Recommendations for practice and policy

Show palliative care through the eyes of persons confronted with serious illness, including not only the patient but as well their broader social surroundings, and represent them in active positions.

To address limited understandings and stigmatized perceptions of palliative care, more is needed than just promoting a broad definition of palliative care. Efforts should also focus on a different representation of persons with palliative care needs. Throughout this dissertation, the importance of representing persons with palliative care needs in active and resilient positions was shown as a requisite to any effort aiming to destigmatize and promote palliative care. Active in this means: shown with an emphasis on people's strengths, agency and social value. The focus should be first and foremost on those who the care is directed at and from there, spoken from within a diversity of voices, on what palliative care is about. This includes persons confronted with serious illness as well as persons from within the close and broad social circles around them. As already touched upon above, fostering social connections and supportive environments is an important aspect in the practice of palliative care. Highlighting this within the public communication on palliative care, not as a factual statement but again, through the eyes and voices of those involved, can have several beneficial effects. On the one hand messages might resonate on a deeper level with persons confronted with serious illness because of the role of social connections and social identity in the way people experience, approach and give meaning to serious illness, treatment and care[92]. On the other hand, a broader audience can feel personally addressed by these messages and motivated to actively make sense of them from within the recognition of the relational embeddedness of their own lives.

The recommendation that the central focus of public information on palliative care should be on the people who potentially benefit from it, while representing them in active positions, also comes with a word of caution as has already been elaborated on in Chapter five. To repeat, we argued that emphasis should be on showing a wide range of, potentially ambiguous, lived experiences and stories, without falling into the trap of promoting certain ideal-types, i.e., idealized images of persons who despite serious illness go unimpeded through life, with zero dependency, pain or physical signs of their deteriorating condition. These idealized depictions create normative expectations that risk perpetuating stigmatization of those who fall short of these idealized standards. A previous study on palliative care stock photos for instance showed that the depicted patients in the images, typically older persons, seemed to exemplify more the ideals of successful and healthy aging, rather than the realities of severe illness[93]. Importantly, not everybody in need of palliative care is able to meet these expectations because of unequal access to the biomedical and social resources needed to maintain 'successful aging'[94], and, by extension, successful coping with serious life-threatening illness. In this sense, the discourses activated within public communication on palliative care, in this case to promote palliative care, would risk unintentionally perpetuating social structures that exclude, include, and/or embed certain groups within the medical establishment[94].

Build sustainable partnerships to promote societal awareness and engagement with palliative care

Optimizing public information and developing new educational initiatives on palliative care are crucial for addressing unknown, misunderstood and stigmatized aspects; however, these efforts alone are insufficient. Changes in practice and policy are also necessary to ensure the widespread availability and accessibility of the support services and networks being promoted[95], and to eliminate practices and policies that perpetuate misconceptions[18]. Public communication and education on palliative care ideally should thus be intertwined and substantively aligned with the practice and policy context and developments. For this, sustainable partnerships are necessary. Building a strong and diverse network of engaged partners who are willing and able to play an active role in raising public awareness of palliative care was therefore taken up as the first, essential component within the co-creatively developed campaign. As stated in Chapter six, the network should include a wide range of organizations and actors so that initiatives aimed at raising public awareness are always aligned with the current (shortcomings in) practice and policy surrounding palliative care and have a higher chance to be accessible to a broad audience. Aside organizations involved in policy, practice and advocacy of palliative care, organizations that are not directly involved in palliative care but have an interest in raising public awareness of it (such as poverty organizations, various patient associations, etc.) are also important potential partners. Within this network, partnerships should also be sought with the citizens and communities that initiatives aim to serve. This participatory approach ensures that the programs are relevant and sensitive to the specific needs and cultural contexts of diverse social groups, enhancing the accessibility and effectiveness of public education efforts about palliative care across society. Another vital chain within this network are researchers from diverse fields such as communication science, health promotion as well as palliative care. Ideally, public campaigns and other educational initiatives should be developed using a scientific framework that incorporates sufficient consideration of available theory, as well as findings from formative research on the topic and target audience[95,96]. As seen in Chapters four and five, and tapping into a typology of unintended effects made by Cho and Salmon[57], previous efforts of public communication and education on palliative care ran into the unintended consequences of obfuscation, i.e. the creation of confusion and misunderstanding; a boomerang effect, i.e. audiences having opposite reactions than what was intended to be achieved by the persuasion messages, and risk social reproduction, i.e. reinforce existing social distributions of knowledge, attitudes, and behaviors. Building educational initiatives on the findings from sound research can actively help to prevent these negative unintended effects. Furthermore, researchers can apply methodological skills and expertise before, during and after implementation to adequately test the effectiveness of educational initiatives, both in pilot and outcome evaluation phases[97]. In sum, public education on palliative care counts as a continuous task and the reach and impact of educational initiatives depend on the scope and quality of the relationships they are built upon.

5.2. Recommendations for research

Public communication about palliative care must be able to address the wide diversity of meanings attributed to serious illness and the end of life, and this requires more in-depth research.

Barriers to the access and uptake of palliative care are reinforced by 'one-size fits all' policies which fail to recognize diversity[60]. In a similar manner, educational interventions on palliative care that fail to actively recognize and work from within this diversity, are bound to exacerbate social inequities in palliative care. Research has an essential role in this. Across this dissertation we have argued that insight into the wider sociocultural contexts and processes of meaning attribution is crucial to any effort trying to improve palliative care perceptions and ultimately, access and involvement. Palliative care is not a neutral concept but one embedded within particular sociohistorical and cultural contexts through which certain values and perspectives are emphasized and others silenced, negotiated or rejected[98]. It is therefore important to research how people with diverse intersecting characteristics and backgrounds perceive and give meaning to it. While we believe that we have made some valuable contributions in this direction in this dissertation, we also recognize that it is far from enough and encourage more research on this. In particular, interpretative, qualitative research is needed to gain a better understanding of the complex social interactions that shape understanding and receptivity towards palliative care. Immersive ethnographic fieldwork is particularly suited to gain a better understanding of the social dynamics through which care and its associated values are negotiated within particular local contexts[99].

Moreover, researchers should actively work to develop strategies to enhance inclusivity in palliative care research for diverse individuals and social groups. As described in the literature, 'hard to reach' populations are often more accurately framed as 'easy to ignore'[100,101], moving the emphasis away from a characteristic ascribed to particular social groups toward the conduct and responsibility of the researcher. Researchers have to be prepared to be flexible, move out of their comfort zones and find strategies that work to reach and include diverse participants. In any case, the priority should be on fostering relationships based on trust, irrespective of the outcome being participation in the research or not.

Engage in further in-depth research on (de)stigmatization of palliative care, including analyses of embodied dispositions, institutional practices and public discourses

Stigma in the context of palliative care is described as one of the reasons why patients are being deprived of care[17] as well as one of the reasons why people are reluctant to engage with it[18]. Insight into stigma and stigmatization surrounding palliative care was arrived at in our study as the ‘indirect’ consequence of the broader focus on public perceptions and public communication, information and education on palliative care. Our research was not guided by research questions explicitly aiming to enhance insight into stigma and stigmatization, nor by the rich and extensive theoretical landscape surrounding the concept of stigma. Yet, the more research can enhance understanding of a certain phenomenon, the more the possibility of positive change can be envisioned and effectively strived for. We therefore believe it would be valuable to further investigate the existence of palliative care stigma, the processes and practices that it entails, and the consequences it has on the actual lives of those who provide and receive it. Theoretical conceptualizations of stigma (such as the four dimensions described by Pryor & Reeder[102] or the application of Bourdieu’s social practice theory to stigma[103]) can aid this research process.

Furthermore, a multilayered approach needs to be taken, including explorations of embodied dispositions, institutional practices and public discourses. Regarding the public discourses, the representations of palliative care within traditional media sources are particularly important to explore since these were not taken up in this dissertation but nonetheless are expected to play an important role. Further, the existence, legitimatization and perpetuation of palliative care stigma can be examined at the institutional level[23]. Building upon our findings about public perceptions, research attention can, for instance, be directed at exploring how various medical as well as non-medical organizations frame and practice palliative care in relation to medical end-of-life practices. Ideally research should also succeed in shedding light on the dynamic interplay of institutional practices, public discourses and individual embodied dispositions or stigma habitus. The latter refers to the individual every day experiences of stigma, from positions of both ‘stigmatized’, potentially relating to the person receiving palliative care as well as providing, and ‘stigmatizer’ situated within particular social contexts[103]. As a methodological approach, discourse analysis seems particularly suited seeing its potential to transform *“the delineated taken-for-granted understandings into potential objects for discussion and criticism and, thus, open to change”*[104(p178)]. Through the analysis of the different ways palliative care gets presented to the world, and the different subject positions these discourses open up, a better understanding of the structural dynamics of meaning attribution and change can be achieved. Insights like these also further strengthen the adaptation of critical perspectives in the development of public education initiatives on palliative care.

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English summary

1. Background

While the need for palliative care is growing on a global scale, its access and uptake are hindered by limited levels of public knowledge, misconceptions and negative beliefs surrounding palliative care. These are found across society: among the general public, patients and informal caregivers, as well as among professional caregivers. A call for broad educational initiatives on palliative care, directed at the whole population and not only at those currently receiving care, has therefore often been made. However, for educational initiatives to be effective, they need to be built on a thorough understanding of the public perceptions within the sociocultural contexts they are embedded in. Furthermore, important lessons can be drawn from investigating the quality and the discursive organization of meaning within publicly available information and communication on palliative care, as well as exploring how the public receives, interprets and evaluates these various sources. Research on all of these aspects was lacking and this dissertation set out to fill this gap.

2. Research aims

The project described in this dissertation was driven by two main research aims:

> **Research aim 1: To gain a deeper understanding of public perceptions of palliative care within the sociocultural context of Flanders.**
> Specific objectives to reach this aim were:
>
> > Objective 1: To examine the public knowledge of palliative care and its different aspects, and to identify which personal characteristics and experiences are associated with better palliative care knowledge (Chapter two).
> >
> > Objective 2: To explore patterns of shared meaning across personal narratives surrounding experiences with palliative care, serious illness, and the end of life (Chapter three).
> >
> > Objective 3: To examine representations of palliative care within the online information spread by palliative care policy, advocacy and practice organizations in Flanders, to detect elements of congruence, ambivalence and tension within and between these representations and to identify and interpret the discourses at play (Chapter four).
> >
> > Objective 4: To investigate how members of the general public interpret, evaluate and engage with public awareness campaigns on palliative care (Chapter five).

Research aim 2: To co-creatively design a broad public campaign strategy to tackle unknown, misunderstood and stigmatized aspects of palliative care in Flanders (Chapter six).

3. Methods

To achieve our research aims and objectives, five different studies were conducted. A quantitative population-based and cross-sectional survey design was adopted to examine the public knowledge of palliative care and its different aspects. A narrative inquiry study employing reflexive thematic analysis was conducted to explore patterns of shared meaning within personal narratives surrounding palliative care, serious illness, and the end of life. Further, a descriptive and discourse-theoretical analysis was undertaken to examine the online information on palliative care spread by palliative care policy, advocacy and practice organizations in Flanders. Additionally, a focus group design was adopted to assess the multidimensional audience reception of public awareness campaigns on palliative care. Lastly, an integrated approach of co-creation and Intervention Mapping guided the development of a broad public campaign strategy on palliative care. Overall, our approach brought together multiple methodologies, predominantly interpretative qualitative research, and was driven by theoretical principles of social constructionism.

4. Main findings

Cross-sectional population-based survey to examine public knowledge of palliative care and differences between subgroups among the general public of Flanders

Our assessment of the public knowledge of palliative care and its different aspects showed that, even though the general public seems to have a relatively good understanding of some of the basic elements of palliative care, several of its key aspects remain unknown or misunderstood. More specifically, the majority of respondents knew that palliative care: (1) is not only for older adults (84.7%); (2) nor just for persons with cancer (82%); (3) is not restricted to hospital settings (78.2%); and (4) helps the whole family cope with a serious illness (76.1%). Conversely, a minority of respondents knew that palliative care: (1) has the goal of improving a person's ability to participate in daily activities (32.1%); (2) addresses stress from serious illness (35.6%); (3) is not exclusively for people in the last 6 months of life (44.2%); and (4) can help people manage the side effects of their medical treatments (49.3%). Focusing on the association between personal characteristics and experiences and palliative care knowledge scores, we found that being aged between 30 and 59, nonreligious, more highly educated, having professional experience in healthcare and knowing palliative care through personal experience were all significantly associated with higher mean knowledge scores. In addition, informal sources, personal experience and traditional media were the most important information sources through which people reported having heard of palliative care.

Narrative inquiry using reflexive thematic analysis to explore patterns of shared meaning across personal narratives surrounding palliative care, serious illness, and the end of life

Our reflexive thematic analysis yielded four 'axes of meaning' across personal narratives of persons with serious illness, (bereaved) family caregivers or loved ones. These axes were: (1) 'Sense of Support', describing feeling supported or abandoned on multiple levels with key elements of open and empathetic communication, being informed and listened to; (2) 'Being-in-Time', incorporating a renewed sense of temporality and the weight of uncertain prognosis; (3) 'Constituting a Sense of Self while Coping with Life-Threatening Illness', involving concerns surrounding role adjustments and posthumous reputation; and (4) 'Going Through the Process of Dying', unique to bereaved individuals' narratives, highlighting the importance of being informed during the dying process and honoring the wishes of the dying person. The organization of the data along these four axes concomitantly enabled a deeper insight into the multilayered, relational and context-bound nature of the way palliative care is perceived and given meaning. For instance, negative perceptions towards palliative care were often informed by confused understandings of palliative sedation, and/or the view that palliative care is in conflict with the practice and principles behind euthanasia (often connected to Catholicism). Perceptions of palliative care were then also fueled by (conflicting) perceptions of the practice of palliative care with the norms and values the narrators adhered to (for instance surrounding the right to self-determination) and the broader social discourses these belong to.

Descriptive and discourse-theoretical analysis of online information on palliative care disseminated by palliative care practice, policy and advocacy organizations

Our descriptive analysis of the online information on palliative care showed a certain level of congruence between the given definitions and descriptions of palliative care through the consistent presence of a number of key signifiers. However, this congruence was seriously limited by discrepancies in the way palliative care was defined in connection to curative, terminal, end-of-life, and supportive care, thereby adding to the lack of clarity. For instance, despite the fact that palliative care was often presented as 'more than terminal care', overall it stayed dominantly articulated as care at the end of life or during the last stage/phase of life. In addition, through a critical discourse-theoretical lens, we identified a dominant discourse representing palliative care 'as a culture', with the concepts of total care, compassion, and openness as its nodal points. We found that "the palliative patient" was represented in a passive position in relation to palliative caregivers and 'having an incurable disease' and 'being in the last phase of life' were predominantly connected to negative signifiers such as suffering, dependency, fear and powerlessness. Curative care and the wider society at times also functioned as 'constitutive outsides' within the palliative care discourse, meaning that through the articulation of society as death-denying or isolating, and curative care as focused only on cure and quantity of life, the representation of palliative care as an emancipating force was enabled. Moreover, three intra- and interdiscursive tensions, that is, struggle between meanings, could be observed across the texts, involving: (1) a tension between the open attitude toward 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; (2) conflicting articulations of autonomy between the right-to-die discourse (emphasizing individual choice) and the palliative care discourse (emphasizing social embeddedness); and (3) the debated (ideological) role of a natural death. Overall, we concluded that the online information contributes to the lack of clarity and potentially even the stigmatization of palliative care.

Audience reception research of public awareness campaigns on palliative care using the Multidimensional Audience Reception model

Our multidimensional audience reception study revealed large differences between participants as well as between campaigns concerning their overall appeal, clarity of communication, attitudinal responses towards the perceived message, as well as efficacy in stimulating further thought or action. The motivation to actively make sense of campaign messages was impacted by a number of elements but most prominent was the role of personal experience surrounding serious illness, frailty, the end of life and/or palliative care. In addition, being able to recognize or identify with certain elements within campaign materials played a role, but our study demonstrated that this is not a one-on-one relation, but instead interacts with broader societal discourses (most clearly illustrated by the fact that the oldest participants were often appreciative that the palliative care campaign materials did not portray older persons, which arguably would reinforce stereotypical representations of both palliative care and older persons). In terms of comprehension, participants often struggled to connect certain images and slogans with palliative care, leading to confusion and varied understandings of the materials. Conversations surrounding the campaigns revealed that palliative care is commonly associated with end-of-life care in hospitals, provided to severely ill, bedridden persons. Two of the campaigns had a stronger influence in positively changing those perceptions, while a third one mainly reinforced them. In connection to this, our study showed the importance of informing the public on palliative care primarily through the perspectives of persons confronted with serious illness and to represent them in active and resilient positions, since these elements greatly impacted participants' attitudes towards campaign materials as well as palliative care perceptions. Additionally, our results suggested that visualizing the meaning of palliative care through the broader social context surrounding the person with serious illness would appeal to a broader audience and might prove valuable to stimulate further public engagement with palliative care. Moreover, the importance of not relying solely on the digital proficiency of the intended audience was highlighted, as well as the value of having meaningful dialogues in shaping understanding of palliative care.

The co-creative design of a broad public campaign strategy to tackle unknown, misunderstood and stigmatized aspects of palliative care in Flanders

Within the co-creative process, the specific campaign goals were defined as follows: (1) Individuals confronted with serious, incurable illness, the end of life, and/or grief are empowered to find palliative support in time (in relation to their support needs); (2) Individuals within the (close or distant) social context of those confronted with serious, incurable illness, the end of life, and/or grief are empowered to take on (palliative) support roles. From there, the developed co-created campaign was built on six communication principles and consisted of six conceptual components.

The 6 communication principles are: (1) to name palliative care, but with an emphasis on broadening interpretations through imagery and language while avoiding deterministic language such as labeling persons or life stages as 'palliative'; (2) to emphasize the onset of care by giving concrete examples that clarify who can benefit from palliative care, for what and from when while avoiding vague terms or descriptions that reinforce the (exclusive) association with end-of-life care; (3) to represent persons, both in images as in language, in active positions, i.e. in control, in the midst of society, fulfilling social roles; (4) to highlight the importance of the social context within palliative care; (5) to recognize and work with the broad diversity across society and within meaning attribution surrounding serious illness and the end of life; (6) to also name death and dying as core components of palliative care but at the right time and always within the broader narrative of palliative care.

The six components are: (1) the development of a strong and diverse network of engaged partners who are willing and able to play an active role in raising societal awareness of palliative care; (2) the development of a high-quality, reliable, structurally embedded website that, aside from general information on palliative care, contains campaign materials, many accessible tools and resources, as well as an interactive section run by trained and dedicated volunteers that fulfills an informative, supportive and connecting function; (3) initiatives (going from infographics to e-learning modules) targeting professional caregivers, and aiming to enhance their knowledge of palliative care and encourage them to inform patients correctly and timely about palliative care options; (4) implementation of a multimedia campaign called LeefMee.be which seeks to reshape public understanding of palliative care and of those living with serious, incurable illnesses through the use of positive language and imagery; (5) development and implementation of the Palliative Care Ambassadors program that mobilizes individuals with personal experiences around palliative care to act as pioneers and sources of information and support within their own communities; (6) organizing community conversations within various sociocultural settings and organizations such as women's associations, places of worship, libraries, and local community centers. The focus is on dialogue in a low-threshold, open atmosphere on important themes surrounding palliative care.

5. General discussion

Overall, the conducted studies confirmed the relevance of addressing public perceptions of palliative care by pointing out the existence of unknown, misunderstood and stigmatized aspects of palliative care in the Flemish context. During the course of the project, vital elements to focus on to enhance understanding and engagement became progressively tangible, before ultimately being concretized within the co-creation of the campaign strategy. The general discussion further explored the literature on the stigma of palliative care and its connection to the broader societal belief in a death taboo. It was argued that it is vital to adopt a more nuanced and multilayered understanding of the stigma and processes of stigmatization of palliative care, by focusing, among others, on the role of the representation of persons with palliative care needs as well as public perceptions of medical end-of-life practices.

In addition, the importance of addressing specific gaps in the public knowledge of palliative care was elaborated on. Leaning on our findings as well as the broader literature, we argued that developers of educational initiatives need to simultaneously acknowledge knowledge differences between individuals and social groups. Failing to do so creates the risk of unintentionally reproducing or reinforcing existing social distributions of knowledge, attitudes, and behaviors. Moreover, limited knowledge is only one part of the puzzle; educational initiatives also need to take into account the broader structural, sociohistorical and cultural factors that influence the access and uptake of palliative care for different groups within society.

Mistrust in the medical establishment, for instance, affects the reception of palliative care information. Therefore, strategies that simultaneously work on rebuilding trust while informing on palliative care are needed.

Lastly, the significance of incorporating a more social gaze in communicating, informing, and educating about palliative care was discussed. By visualizing the social connections through which palliative care is enacted, interpreted and given meaning, and, by giving a voice to the various persons within the close and broad social circles surrounding the patients, a wider audience may feel addressed and engaged. Importantly, relationality and social connectivity in this context are understood as dynamic instead of fixed, and as going beyond predefined categories of 'family' and 'friends'. The argument thus made is to highlight the various lived relational experiences in the context of palliative care and thereby also speak to persons potentially living without strong support networks, especially in light of the research evidence indicating potentially higher (palliative) care needs among this group.

6. Recommendations

Several recommendations were made based on the findings and interpretations of this dissertation.

In terms of recommendations for practice and policy, it was firstly advised to show palliative care through the eyes of persons confronted with serious illness, including not only the patient but as well their broader social surroundings, and to represent them in active positions. Importantly, the emphasis should be on showing a wide range of, potentially ambiguous, lived experiences and stories, without falling into the trap of promoting certain ideal-types that risk perpetuating stigmatization of those who fall short of these idealized standards. Secondly, building sustainable partnerships was strongly recommended as a first strategic step in any effort to promote societal awareness and engagement with palliative care.

Next, research recommendations were made, including the need to enhance research inclusivity and the need for further interpretative, qualitative research to gain a better understanding of the complex social interactions that shape understanding and receptivity towards palliative care. In addition, more in-depth research on the (de)stigmatization of palliative care is needed, including analyses of embodied dispositions, institutional practices and public discourses.

Nederlandse samenvatting

1. Situering

Terwijl de behoefte aan palliatieve zorg wereldwijd toeneemt, worden de toegang en het gebruik ervan belemmerd door beperkte publieke kennis, misvattingen en negatieve overtuigingen rond palliatieve zorg. Deze worden gevonden in de hele samenleving: onder het algemene publiek, patiënten en informele zorgverleners, evenals onder professionele zorgverleners. Er wordt daarom vaak opgeroepen om brede educatieve initiatieven te ontwikkelen over palliatieve zorg, gericht op de hele bevolking en niet alleen op degenen die momenteel zorg ontvangen. Echter, om effectief te zijn, moeten educatieve initiatieven ontwikkeld worden vanuit een grondig begrip van publieke percepties binnen de sociaal-culturele context waarin ze zijn ingebed. Bovendien kunnen belangrijke lessen worden getrokken uit het onderzoeken van de kwaliteit en de discursieve organisatie van de publiekelijk beschikbare informatie en communicatie over palliatieve zorg, evenals uit het bestuderen van hoe het publiek deze verschillende bronnen ontvangt, interpreteert en evalueert. Studies naar al deze aspecten ontbraken, en het in deze dissertatie beschreven onderzoek beoogde deze lacune op te vullen.

2. Onderzoeksdoelen

Het project werd gedreven door twee hoofdonderzoeksdoelen. Het eerste hoofdonderzoeksdoel was om dieper inzicht te krijgen in publieke percepties van palliatieve zorg binnen de sociaal-culturele context van Vlaanderen. Specifieke subdoelstellingen om dit doel te bereiken waren: (1) het onderzoeken van de publieke kennis van palliatieve zorg en welke persoonlijke kenmerken en ervaringen geassocieerd zijn met betere kennis over palliatieve zorg (Hoofdstuk 2); (2) het exploreren van patronen in betekenisgeving binnen persoonlijke verhalen rond palliatieve zorg en palliatieve zorgnoden (Hoofdstuk 3); (3) het onderzoeken van representaties van palliatieve zorg binnen de online informatie verspreid door palliatieve zorg praktijk-, belangenbehartigings- en beleidsorganisaties in Vlaanderen (Hoofdstuk 4); en (4) het onderzoeken hoe leden van het algemene publiek publiekscampagnes over palliatieve zorg interpreteren, evalueren en er gevolg aan geven (Hoofdstuk 5). Het tweede hoofdonderzoeksdoel van dit project was de co-creatieve ontwikkeling van een brede publiekscampagnestrategie om onbekende, misbegrepen en gestigmatiseerde aspecten van palliatieve zorg in Vlaanderen aan te pakken (Hoofdstuk 6).

3. Methoden

Om onze hoofdonderzoeksdoelen en subdoelstellingen te bereiken, werden vijf verschillende studies uitgevoerd. Een kwantitatieve, cross-sectionele, populatiegerichte survey studie werd uitgevoerd om de publieke kennis van palliatieve zorg te onderzoeken. Een narratief onderzoek met toepassing van reflexieve thematische analyse werd uitgevoerd om patronen van gedeelde betekenis binnen persoonlijke verhalen rond palliatieve zorg en palliatieve zorgnoden te verkennen. Daarnaast werd een beschrijvende en discours-theoretische analyse ondernomen om de online informatie over palliatieve zorg, verspreid door beleids-, belangenbehartigings- en praktijkorganisaties in Vlaanderen, te onderzoeken. Verder werd een focusgroepstudie uitgevoerd om de multidimensionale publieksreceptie van publiekscampagnes over palliatieve zorg te onderzoeken. Ten slotte leidde een geïntegreerde benadering van co-creatie en Intervention Mapping tot de ontwikkeling van een brede publiekscampagnestrategie over palliatieve zorg. Over het algemeen bracht onze aanpak meerdere methodologieën samen, voornamelijk interpretatief kwalitatief onderzoek, en werd het gedreven door theoretische principes van sociaal constructionisme.

4. Belangrijkste bevindingen

Survey-onderzoek om de publieke kennis van palliatieve zorg en verschillen tussen subgroepen onder het algemene publiek van Vlaanderen te onderzoeken

Onze studie over de publieke kennis van palliatieve zorg en de verschillende aspecten ervan toonde aan dat, hoewel het algemene publiek een relatief goed begrip lijkt te hebben van enkele basiselementen van palliatieve zorg, verschillende kernaspecten onbekend of misbegrepen blijven. Meer specifiek wist de meerderheid van de respondenten dat palliatieve zorg: (1) niet alleen voor oudere volwassenen is (84,7%); (2) noch alleen voor personen met kanker (82%); (3) niet beperkt is tot ziekenhuisinstellingen (78,2%); en (4) de hele familie helpt om te gaan met een ernstige ziekte (76,1%). Daarentegen wist een minderheid van de respondenten dat palliatieve zorg: (1) als doel heeft om de mogelijkheid van een persoon te verbeteren om deel te nemen aan dagelijkse activiteiten (32,1%); (2) stress van ernstige ziekte aanpakt (35,6%); (3) niet uitsluitend is voor mensen in de laatste 6 maanden van het leven (44,2%); en (4) mensen kan helpen bij het onder controle krijgen van bijwerkingen van hun medische behandelingen (49,3%). Bij het focussen op de associatie tussen persoonlijke kenmerken en ervaringen, en kennis over palliatieve zorg, vonden we dat een leeftijd hebben tussen de 30 en 59 jaar, niet-religieus zijn, hoger opgeleid zijn, professionele ervaring hebben in de gezondheidszorg en palliatieve zorg kennen door persoonlijke ervaring, allemaal significant geassocieerd waren met hogere gemiddelde kennisscores. Daarnaast waren informele bronnen, persoonlijke ervaring en traditionele media de belangrijkste informatiebronnen waarlangs mensen kennis over palliatieve zorg hadden vergaard.

Narratief onderzoek om patronen in betekenisgeving binnen persoonlijke verhalen rond palliatieve zorg en palliatieve zorgnoden te verkennen

De reflexieve thematische analyse leverde vier 'assen van betekenis' op: (1) ‘Gevoel van Ondersteuning’, zich ondersteund of verlaten voelen op meerdere niveaus met sleutelaspecten van open en empathische communicatie, geïnformeerd en gehoord worden; (2) ‘Being-in-Time’, een hernieuwde ervaring van de tijd en de last van onzekere prognose; (3) ‘Percepties van het Zelf tijdens het Omgaan met Levensbedreigende Ziekte’, betreft bezorgdheden rondom veranderende rollen en postume reputatie; en (4) ‘Het Proces van Sterven Doormaken’, uniek voor de verhalen van nabestaanden, waarin het belang van begeleid en geïnformeerd worden tijdens het stervensproces werd benadrukt, evenals het eerbiedigen van de wensen van de stervende persoon. Het organiseren van de data langs deze vier assen stelde ons in staat om een dieper inzicht te krijgen in de gelaagde, relationele en contextgebonden aard van de manier waarop palliatieve zorg wordt waargenomen en betekenis krijgt. Eén aspect daarvan was bijvoorbeeld dat negatieve percepties ten aanzien van palliatieve zorg vaak werden geïnformeerd door verwarde opvattingen over palliatieve sedatie en/of het idee dat palliatieve zorg in strijd is met de praktijk en principes achter euthanasie (al dan niet gekoppeld aan katholicisme). Percepties van palliatieve zorg werden vervolgens ook gevoed door persoonlijke normen en waarden hieromtrent en de bredere sociale discoursen waartoe deze behoren.

Beschrijvende en discours-theoretische analyse van online informatie over palliatieve zorg verspreid door praktijk-, beleids- en belangenbehartigingsorganisaties

De beschrijvende analyse van de online informatie over palliatieve zorg toonde een zeker niveau van congruentie tussen de gegeven definities en beschrijvingen van palliatieve zorg door een consistente aanwezigheid van een aantal belangrijke betekenaars. Echter, deze congruentie werd ernstig beperkt door discrepanties in de manier waarop palliatieve zorg werd gedefinieerd in verband met curatieve, terminale, levenseinde- en supportieve zorg, wat bijdroeg aan de onduidelijkheid van de informatie. Bijvoorbeeld: ondanks het feit dat palliatieve zorg vaak werd gepresenteerd als 'meer dan terminale zorg', bleef het over het algemeen dominant gearticuleerd als zorg aan het einde van het leven of tijdens de laatste fase van het leven. Daarnaast identificeerden we, doorheen een kritische discours-theoretische lens, een palliatieve zorgdiscours georganiseerd rond de ‘nodal points’ (kernbetekenaars) van totaalzorg, openheid en betrokkenheid en de subject posities van de “palliatieve patiënt” en palliatieve zorgverlener. De “palliatieve patiënt" werd daarbij in een passieve positie gerepresenteerd in relatie tot palliatieve zorgverleners en 'het hebben van een ongeneeslijke ziekte' en ‘het zijn in de laatste levensfase' werden voornamelijk verbonden aan negatieve betekenaars zoals lijden, afhankelijkheid, angst en machteloosheid. Curatieve zorg en de bredere samenleving functioneerden soms ook als 'constitutive outsides' binnen het palliatieve zorgdiscours, wat betekent dat door de articulatie van de samenleving als dood-ontkennend of isolerend, en curatieve zorg als alleen gericht op genezing en levensduur, de representatie van palliatieve zorg als een emanciperende kracht werd mogelijk gemaakt. Bovendien konden drie intra- en interdiscursieve spanningen, dat wil zeggen, spanningen tussen betekenissen, worden waargenomen overheen de teksten: (1) een spanning tussen de open houding ten opzichte van dood en sterven als een belangrijk aspect van de identiteit van palliatieve zorg en de focus weg van dood en sterven in de beschrijvingen van de zorg zelf; (2) conflicterende articulaties van autonomie tussen het recht-op-waardig-sterven discours (dat individuele keuze benadrukt) en het palliatieve zorgdiscours (dat sociale inbedding benadrukt); en (3) de betwiste (ideologische) rol van een natuurlijke dood. In het algemeen concludeerden we dat de online informatie kan bijdragen aan een gebrek aan duidelijkheid en mogelijk zelfs aan de stigmatisering van palliatieve zorg.

Onderzoek naar multidimensionale publieksreceptie van publiekscampagnes over palliatieve zorg

Deze studie onthulde grote verschillen tussen deelnemers en tussen campagnes met betrekking tot hun algehele aantrekkingskracht, duidelijkheid van communicatie, attitudereacties op de waargenomen boodschap, evenals effectiviteit in het stimuleren van verdere gesprekken of acties. Motivatie om actief aandacht te besteden aan campagneboodschappen werd beïnvloed door een aantal elementen, maar het meest prominent was de rol van persoonlijke ervaring rond ernstige ziekte, kwetsbaarheid, het einde van het leven en/of palliatieve zorg. Daarnaast speelde het kunnen herkennen, of zich kunnen identificeren met bepaalde elementen binnen campagnematerialen een rol, maar onze studie toonde aan dat dit geen een-op-een-relatie is, maar in plaats daarvan interageert met bredere maatschappelijke discoursen (het duidelijkst geïllustreerd door het feit dat de oudste deelnemers vaak waardeerden dat de campagnematerialen geen oudere personen afbeeldden, wat stereotiepe voorstellingen van zowel palliatieve zorg als oudere personen zou versterken). Wat het begrijpen van campagnematerialen betreft, worstelden deelnemers vaak om bepaalde afbeeldingen en slogans met palliatieve zorg te verbinden, wat leidde tot verwarring en uiteenlopende opvattingen over de materialen. Gesprekken rond de campagnes onthulden verder dat palliatieve zorg vaak wordt geassocieerd met zorg aan het einde van het leven in ziekenhuizen, gegeven aan ernstig zieke, vaak bedlegerige personen. Twee van de campagnes hadden een sterkere invloed om die percepties positief te veranderen, terwijl een derde ze voornamelijk versterkte. Daaraan gekoppeld toonde onze studie het belang aan van het informeren over palliatieve zorg vanuit de perspectieven van personen die geconfronteerd worden met ernstige ziekte, terwijl zij gerepresenteerd worden in actieve en veerkrachtige posities. Deze elementen hadden tezamen een grote invloed op zowel de attitude van deelnemers ten opzichte van campagnematerialen, als ook op hun percepties van palliatieve zorg. Daarnaast suggereerden onze resultaten dat het visualiseren van de betekenis van palliatieve zorg vanuit de bredere sociale context rondom de persoon met ernstige ziekte waardevol zou zijn om een breder publiek aan te spreken en verdere publieke betrokkenheid bij palliatieve zorg te stimuleren. Bovendien belichte deze studie het belang van het niet alleen vertrouwen op de digitale vaardigheden van het beoogde publiek, evenals de waarde van het voeren van betekenisvolle dialogen bij het vormgeven van het begrip van palliatieve zorg.

De co-creatieve ontwikkeling van een brede publiekscampagnestrategie om onbekende, misbegrepen en gestigmatiseerde aspecten van palliatieve zorg in Vlaanderen aan te pakken

Binnen het co-creatieve proces werden de specifieke campagnedoelen als volgt gedefinieerd: (1) Individuen die geconfronteerd worden met ernstige ongeneeslijke ziekte, het einde van het leven en/of rouw worden versterkt om tijdig palliatieve ondersteuning te vinden (in relatie tot hun ondersteuningsbehoeften); (2) Individuen binnen de (nabije of brede) sociale context van degenen die geconfronteerd worden met ernstige, ongeneeslijke ziekte, het einde van het leven en/of rouw worden versterkt om (palliatieve) ondersteuningsrollen op zich te nemen. Van daaruit werd de co-creatief ontwikkelde campagne gebouwd, leunend op zes communicatieprincipes en bestaande uit zes conceptuele componenten.

De 6 communicatieprincipes zijn: (1) palliatieve zorg benoemen, maar met nadruk op het verbreden van interpretaties door beeld- en taalgebruik terwijl deterministische taal zoals het labelen van personen of levensfasen als ‘palliatief’ wordt vermeden; (2) het begin van de zorg benadrukken door concrete voorbeelden te geven die verduidelijken wie kan profiteren van palliatieve zorg, waarvoor en vanaf wanneer, terwijl vage termen of beschrijvingen die de (exclusieve) associatie met zorg aan het einde van het leven versterken, worden vermeden; (3) personen, zowel in beelden als in taal, in actieve posities vertegenwoordigen, d.w.z. in controle, midden in de samenleving, sociale rollen vervullend; (4) het belang van de sociale context binnen palliatieve zorg benadrukken; (5) de brede diversiteit binnen de samenleving en binnen betekenisgeving rond ernstige ziekte en het einde van het leven erkennen en vandaaruit werken; (6) ook dood en sterven benoemen als kerncomponenten van palliatieve zorg maar op het juiste moment en altijd binnen het bredere verhaal van palliatieve zorg.

De zes componenten zijn: (1) de ontwikkeling van een sterk en divers netwerk van betrokken partners die bereid en in staat zijn om een actieve rol te spelen in het verhogen van maatschappelijk bewustzijn van palliatieve zorg; (2) de ontwikkeling van een betrouwbare, structureel ingebedde website met algemene informatie over palliatieve zorg, campagnematerialen en veel toegankelijke hulpmiddelen en bronnen. Daarnaast bevat de website ook een interactief gedeelte met een informatieve, verbindende en ondersteunende functie, beheerd door getrainde en toegewijde vrijwilligers; (3) initiatieven (variërend van infographics tot e-learningmodules) gericht op professionele zorgverleners, met de doelstelling om hun kennis van palliatieve zorg te verbeteren en hen aan te moedigen patiënten correct en tijdig te informeren over palliatieve zorgopties; (4) implementatie van de multimediale campagne genaamd LeefMee.be die streeft naar het herdefiniëren van het publieke begrip van palliatieve zorg en van personen die leven met een ernstige, ongeneeslijke ziekte door middel van positieve taal en beeldtaal; (5) ontwikkeling en implementatie van het Palliatieve Zorg Ambassadeurs-programma dat individuen met persoonlijke ervaringen rond palliatieve zorg mobiliseert om als pioniers en informatie- en ondersteuningsbronnen te fungeren binnen hun eigen gemeenschappen; (6) het organiseren van gespreksmomenten binnen verschillende sociaal-culturele organisaties zoals vrouwenverenigingen, gebedshuizen, bibliotheken en lokale gemeenschapscentra. De focus ligt op dialoog in een laagdrempelige, open sfeer over belangrijke thema's rond palliatieve zorg.

5. Bespreking van de bevindingen

Over het algemeen bevestigden de uitgevoerde studies het belang van het adresseren van publieke percepties van palliatieve zorg door te wijzen op het bestaan van onbekende, misbegrepen en gestigmatiseerde aspecten van palliatieve zorg in de Vlaamse context. Gedurende het verloop van het project werden essentiële elementen om het begrip en de betrokkenheid te verhogen geleidelijk tastbaar, voordat ze uiteindelijk werden geconcretiseerd binnen de co-creatie van de campagnestrategie. De algemene discussie verkende verder de literatuur over de stigmatisering van palliatieve zorg en de assumptie van het bestaan van een maatschappelijk taboe rond dood en sterven. Er werd betoogd dat het van essentieel belang is om te vertrekken van een meer genuanceerd en gelaagd begrip van het stigma en de processen van stigmatisering van palliatieve zorg, door onder andere te focussen op de rol van de representatie van personen met palliatieve zorgnoden, evenals de rol van publieke percepties van medische praktijken rond het levenseinde.

Daarnaast werd de noodzaak om specifieke lacunes in de publieke kennis van palliatieve zorg aan te pakken besproken. Steunend op onze bevindingen en de bredere literatuur, beargumenteerden we dat ontwikkelaars van educatieve initiatieven tegelijkertijd verschillen in kennis tussen individuen en sociale groepen moeten erkennen. Dit veronachtzamen creëert het risico op het onbedoeld reproduceren of versterken van de bestaande sociale distributie van kennis, attitudes en gedragingen. Bovendien is beperkte kennis slechts een deel van de puzzel en moeten educatieve initiatieven ook rekening houden met de bredere structurele, sociaalhistorische en culturele factoren die de toegang en het gebruik van palliatieve zorg voor verschillende groepen binnen de samenleving beïnvloeden. Wantrouwen in het medisch zorgsysteem, bijvoorbeeld, beïnvloedt de receptie van informatie over palliatieve zorg. Strategieën zijn daarom nodig die tegelijkertijd vertrouwen opbouwen en informeren over palliatieve zorg.

Tot slot werd het belang besproken van het incorporeren van een meer sociale blik in het communiceren en informeren over palliatieve zorg. Door het visualiseren van de sociale connecties waarlangs palliatieve zorg wordt uitgevoerd, geïnterpreteerd en betekenis krijgt, en door een stem te geven aan de verschillende personen binnen de dichte en brede sociale kringen rondom patiënten, kan een breder publiek zich aangesproken en betrokken voelen. Belangrijk is dat relationaliteit en sociale connectiviteit in deze context worden begrepen als dynamische in plaats van vaste begrippen, en daarnaast nauw gedefinieerde klassieke categorieën van ‘familie’ en ‘vrienden’ overstijgen. Het argument dat wordt gemaakt is zodoende om verschillende relationele ervaringen en belevingen in de context van palliatieve zorg te benadrukken. Daardoor kunnen ook personen aangesproken worden die mogelijk leven zonder sterke sociale (steun)netwerken, wat belangrijk is aangezien onderzoek wijst op potentieel hogere (palliatieve) zorgnoden in deze groep.

6. Aanbevelingen

Meerdere aanbevelingen werden gedaan op basis van de bevindingen en interpretaties van deze dissertatie. Wat betreft aanbevelingen voor praktijk en beleid, werd in de eerste plaats geadviseerd om palliatieve zorg te tonen door de ogen van personen die geconfronteerd worden met ernstige ziekte, inclusief niet alleen de patiënt maar ook hun bredere sociale omgeving, en hen in actieve posities te vertegenwoordigen. Belangrijk daarbij is dat de nadruk moet liggen op het tonen van een breed en divers scala aan *lived experiences* en verhalen, zonder in de val te trappen van het promoten van bepaalde ideaaltypes die het risico lopen om stigmatisering in de hand te werken van degenen die niet aan deze geïdealiseerde normen voldoen.

Ten tweede werd het opbouwen van duurzame partnerschappen sterk aanbevolen als een eerste strategische stap in elke inspanning om maatschappelijk bewustzijn en betrokkenheid bij palliatieve zorg te bevorderen.

Vervolgens werden aanbevelingen voor onderzoek geformuleerd, waaronder de nood aan inclusieve onderzoeksdesigns, alsook meer interpretatief, kwalitatief onderzoek om verder inzicht te krijgen in de complexe sociale interacties die het begrip en de ontvankelijkheid voor palliatieve zorg vormgeven. Daarnaast is er meer diepgaand onderzoek nodig naar de processen van (de)stigmatisering van palliatieve zorg, inclusief analyses van belichaamde disposities, institutionele praktijken en publieke discoursen.

Appendices

Appendix 1. Survey questionnaire (study 1 – Chapter two)

**Gemarkeerde vragen zijn vragen die geïncludeerd werden in onze studie.*

Vragenlijst inwoners *stad x*

UW BETROKKENHEID IN DE LOKALE GEMEENSCHAP

We stellen u enkele vragen over uw activiteiten in uw lokale gemeenschap. Indien we spreken over lokale gemeenschap, bedoelen we elke plaats waar u binnen de 20 minuten geraakt. Zowel te voet als met de auto, fiets, bus,…

1 Antwoord op de volgende vragen.

A	Helpt u bij in een lokale groep als vrijwilliger?	**Nee, helemaal niet**			**Ja vaak (minstens 1x per week)**
		1	**2**	**3**	**4**
B	Heeft u in de 6 maanden voor de coronacrisis een evenement in uw lokale gemeenschap bijgewoond? (bv. Parochiefeest, schoolconcert, hobbybeurs).	**Nee, helemaal niet**			**Ja, meerdere (minstens 3)**
		1	**2**	**3**	**4**
C	Bent u een actief lid van een organisatie of club in uw lokale gemeenschap (bv. sportclub, hobbyclub, praatclub)?	**Nee, helemaal niet**			**Ja, erg actief**
		1	**2**	**3**	**4**
D	Zit u in een beheers- of organisatiecomité voor een groep of organisatie in uw lokale gemeenschap?	**Nee, helemaal niet**			**Ja, verschillende (minstens 3)**
		1	**2**	**3**	**4**
E	Heeft u in de afgelopen 3 jaar voor de coronacrisis ooit meegedaan aan een actie in uw lokale gemeenschap om een noodtoestand op te vangen? (helpen bij een verkeersongeval, een zieke buur naar spoed brengen,…).	**Nee, helemaal niet**			**Ja, frequent (minsten 5x)**
		1	**2**	**3**	**4**
F	Heeft u in de afgelopen 3 jaar ooit deelgenomen aan een gemeenschapsproject of liefdadigheidsactie in uw lokale gemeenschap? (buurttuin, straatfeest, een festival voorbereiden,…).	**Nee, helemaal niet**			**Ja, zeer veel**
		1	**2**	**3**	**4**
G	Heeft u ooit deelgenomen aan een project om een nieuwe dienst in uw lokale gemeenschap te organiseren? (bv. nieuwe jeugdclub, bouw scoutslokaal, opstarten kinderopvang, ontwikkelen van recreatie voor mensen met een handicap).	**Nee, helemaal niet**			**Ja, verschillende (minstens 3)**
		1	**2**	**3**	**4**

H	Hoeveel evenementen/activiteiten heeft u in het jaar voor de corona-crisis in uw stad bijgewoond die betrekking hadden op thema’s rond ernstige ziekte, overlijden, sterven of rouw (bv. kunsttentoonstelling, theater, toneel, film, een getuigenis bijwonen)?	**Geen enkel**	**Één of twee**	**Drie of vier**	**5 of meer**
		1	**2**	**3**	**4**
I	Hoe dikwijls heeft u in het jaar voor de corona-crisis vrijwilligerswerk gedaan bij een organisatie die zich inzet rond onder andere ernstige ziekte, overlijden, sterven of rouw?	**Nooit**	**1 keer**	**2 tot 5 keer**	**Meer dan 5 keer**
		1	**2**	**3**	**4**

2 Als u ziek zou worden en naar het ziekenhuis moet, krijgt u dan hulp om naar de winkel te gaan, het gras af te rijden, voor uw huisdieren te zorgen van de mensen hieronder?

		Zeker niet			**Zeker wel**	**Ik weet het niet**
A	Familie of mensen met wie u veel contact hebt	**1**	**2**	**3**	**4**	**0**
B	Vrienden of kennissen uit uw lokale gemeenschap	**1**	**2**	**3**	**4**	**0**
C	Vrienden of kennissen buiten uw lokale gemeenschap	**1**	**2**	**3**	**4**	**0**
D	Mensen uit uw buurt die u niet (zo goed) kent: vrijwilligers uit de buurt, Whatsapp-buurtgroepen, een pastoor …	**1**	**2**	**3**	**4**	**0**

E	Stel: u woont samen met iemand die hulp nodig heeft. U moet even weg. Zou u iemand uit uw lokale gemeenschap vragen om even bij die persoon te blijven?	**Nee, helemaal niet**		**Ja, meerdere personen**	
		1	**2**	**3**	**4**
F	Hebt u de voorbije week iemand uit uw lokale gemeenschap bezocht die het moeilijk heeft? Bijvoorbeeld omdat die iemand heeft verloren, voor iemand moet zorgen, een burn-out heeft ….	**Nee, helemaal niet**		**Ja, vaak**	
		1	**2**	**3**	**4**
G	Als u gaat winkelen in uw lokale gemeenschap, komt u dan vrienden of kennissen tegen?	**Nee, helemaal niet**		**Ja, bijna altijd**	
		1	**2**	**3**	**4**
H	Hebt u iemand uit uw lokale gemeenschap geholpen in het jaar voor de coronacrisis? Bijvoorbeeld: door een bezoek te brengen, eten te maken, te helpen met poetsen, de hond uit te laten,…?	**Nee, nooit**		**5 keer of meer**	
		1	**2**	**3**	**4**

3 Hieronder ziet u drie situaties die in uw lokale gemeenschap kunnen voorkomen. Omcirkel telkens wat u denkt dat u zou doen.

			Zeker niet	**Waarschijnlijk niet**	**Niet zeker**	**Waarschijnlijk wel**	**Zeker wel**
A	In uw straat woont een oudere vrouw. Haar echtgenoot is enkele jaren geleden gestorven. Ze heeft een goed contact met haar zoon, maar die woont in het buitenland. U hebt nog nooit met haar gepraat. Op een dag vertelt uw buur dat de dame van de trap is gevallen. Ze moet enkele weken zoveel mogelijk rusten. Zou u haar met deze zaken willen helpen als u kon?	Het gras afrijden	**1**	**2**	**3**	**4**	**5**
		Naar de winkel gaan	**1**	**2**	**3**	**4**	**5**
		Koken	**1**	**2**	**3**	**4**	**5**
		Gezelschap houden	**1**	**2**	**3**	**4**	**5**
B	Uw buur van een paar huizen verder zorgt voor zijn vrouw, die waarschijnlijk niet meer lang zal leven. Hij vertelt dat hij het heel zwaar heeft. Een verpleegkundige helpt hem thuis, maar hij wil zijn vrouw liever niet alleen laten als hij naar de winkel of de apotheek moet. Zou u uw buren willen helpen met volgende zaken als u kon?	Naar de winkel gaan	**1**	**2**	**3**	**4**	**5**
		Op bezoek gaan	**1**	**2**	**3**	**4**	**5**
		Haar gezelschap houden	**1**	**2**	**3**	**4**	**5**
		Met uw buurman praten over de toestand van zijn vrouw	**1**	**2**	**3**	**4**	**5**
C	In uw straat is pas een eenzaam persoon gestorven. U en de andere mensen in de straat wisten het pas na de begrafenis. Uw buren organiseren een straatfeest om de mensen beter te leren kennen en om eenzaamheid tegen te gaan. Zou u deze zaken doen als u kon?	Naar het straatfeest gaan	**1**	**2**	**3**	**4**	**5**
		Mee het straatfeest organiseren	**1**	**2**	**3**	**4**	**5**

Bij de volgende vragen willen we graag meer weten over uw kennis over palliatieve zorg. Het is geen probleem indien u er weinig of geen kennis over hebt.

4 Omcirkel het getal dat het best bij u past.

A	Hoe goed kent u het begrip 'palliatieve zorg'?	**Totaal niet** **1**	**2**	**3**	**4**	**5**	**6**	**Zeer goed** **7**
B	Hoeveel denkt u dat u weet over palliatieve zorg?	**Ik weet er niets over** **1**	**2**	**3**	**4**	**5**	**6**	**Ik weet er erg veel over** **7**
C	Hoe goed kan u aan iemand uitleggen wat palliatieve zorg is?	**Ik kan het niet uitleggen** **1**	**2**	**3**	**4**	**5**	**6**	**Ik kan het zeker correct uitleggen** **7**

5 Hoe hebt u over palliatieve zorg gehoord? U mag meer dan één antwoord kiezen.

A	☐ Een kennis of vriend sprak erover	G	☐ Ik hoorde erover in mijn opleiding (verpleegkunde, psychologie, bij het Rode Kruis …)
B	☐ Een familielid sprak erover	H	☐ Via mijn werk als vrijwilliger
C	☐ Ik ken het via internet of sociale media (Facebook, Twitter, Instagram …)	I	☐ Via radio of televisie
D	☐ Ik heb er nog nooit over gehoord	J	☐ Via kranten of tijdschriften (ook online)
E	☐ Ik heb zelf palliatieve zorg gekregen	K	☐ Ik weet het niet meer
F	☐ Een kennis, vriend of familielid heeft palliatieve zorg gekregen	L	☐ Andere:………………………………………

Hebt u meer dan 1 antwoord aangekruist? Beantwoord deze vraag:
Wat was voor u de belangrijkste manier om informatie over palliatieve zorg te krijgen?

……………………………………………………………

6 Hoe zou u het liefst informatie willen krijgen over palliatieve zorg? Duid maximaal 3 antwoorden aan.

A	☐ Via de huisarts of andere hulpverleners	E	☐ Via vrienden, familie of collega's
B	☐ Via sociale media (Facebook, Twitter, Instagram …)	F	☐ Via posters op straat, in bushaltes, in de metro …
C	☐ Via activiteiten in de buurt, georganiseerd door bijvoorbeeld een lokaal dienstencentrum of een regionaal netwerk palliatieve zorg	G	☐ Via radio
		H	☐ Via televisie
D	☐ Via één website waarop u alle info vindt over palliatieve zorg in Vlaanderen	I	☐ Via kranten of tijdschriften (ook online)
		J	☐ Andere:………………………………………

7 Wij zijn geïnteresseerd in culturele ervaringen in verband met de dood en sterven. Kruis ja of nee aan.

		Ja	Nee			Ja	Nee
A	Ik heb een boek over de dood, doodgaan of het verlies van een dierbare gelezen of besproken	☐	☐	E	Ik heb een kunsttentoonstelling gezien met werken over sterven, de dood of rouw	☐	☐
B	Ik heb een autobiografisch verhaal over iemands	☐	☐	F	Ik ben naar een toneelvoorstelling of film geweest die het doodgaan, de dood of rouw uitvoerig behandelde	☐	☐

	stervensproces of verlies gelezen						
C	Ik heb op school geleerd over levenseindekwesties (waaronder de dood, sterven en rouw)	☐	☐	G	Ik heb een gesprek gehad met iemand die op sterven lag over zijn/haar dood	☐	☐
D	Ik heb deelgenomen aan gemeenschapsevenementen of activiteiten die verband houden met de dood of sterven	☐	☐				

8 **Duid aan of volgens u de volgende uitspraken juist of fout zijn of dat u het niet weet, gelieve niet te gokken.**

		Juist	Fout	Weet niet
A	Palliatieve zorg heeft onder meer tot doel psychologische problemen aan te pakken die ontstaan bij een ernstige ziekte	☐	☐	☐
B	Stress ten gevolge van een ernstige ziekte kan aangepakt worden door palliatieve zorg	☐	☐	☐
C	Palliatieve zorg kan mensen helpen om de bijwerkingen van hun medische behandelingen onder controle te krijgen	☐	☐	☐
D	Wanneer mensen palliatieve zorg krijgen, moeten ze hun andere dokters opgeven	☐	☐	☐
E	Palliatieve zorg is uitsluitend voor mensen die in de laatste zes maanden van hun leven zijn	☐	☐	☐
F	Palliatieve zorg is specifiek voor mensen met kanker	☐	☐	☐
G	Mensen moeten in het ziekenhuis zijn om palliatieve zorg te krijgen	☐	☐	☐
H	Palliatieve zorg is specifiek bedoeld voor oudere volwassenen	☐	☐	☐
I	Palliatieve zorg is een teambenadering van zorg	☐	☐	☐
J	Palliatieve zorg heeft onder meer tot doel mensen te helpen hun behandelingsopties beter te begrijpen	☐	☐	☐
K	Palliatieve zorg stimuleert mensen om de behandelingen gericht op de genezing van hun ziekte stop te zetten	☐	☐	☐
L	Palliatieve zorg heeft onder meer tot doel mensen beter in staat te stellen om deel te nemen aan dagelijkse activiteiten	☐	☐	☐
M	Palliatieve zorg helpt de hele familie om met een ernstige ziekte om te gaan	☐	☐	☐

Hier stellen we u enkele vragen over wat u reeds gedaan hebt en of u weet waar u informatie kan vinden over aspecten die te maken hebben met het levenseinde.

9 **Welke zaken hebt u al gedaan rond het einde van uw leven?** U mag meer dan één antwoord kiezen.

A	☐ Een testament opgemaakt	F	☐ Een schriftelijke wilsverklaring voor euthanasie opgemaakt
B	☐ Een verklaring opgemaakt dat u uw organen wil doneren	G	☐ In een document een vertegenwoordiger aangeduid, die persoon kan dan beslissen over uw gezondheid als u dat zelf niet meer kan
C	☐ Een negatieve wilsverklaring opgemaakt: daarin staat welke medische zorgen u **niet** meer wil als u het niet meer kan zeggen, bijvoorbeeld omdat u in coma bent	H	☐ Met een professionele hulpverlener besproken wat u op het einde van uw leven wenst
		I	☐ Met vrienden, familie of andere mensen met wie u vaak contact hebt, besproken wat u op het einde van uw leven wenst
D	☐ Een positieve wilsverklaring opgemaakt: daarin staat welke medische zorgen u **wel** wil als u het niet meer kan zeggen	J	☐ Ik heb deze zaken nog niet gedaan, omdat: ……………………………………………………………………
E	☐ Een wilsbeschikking opgemaakt: daarin staat wat er met uw lichaam moet gebeuren als u overlijdt, bijvoorbeeld: begraven, cremeren of doneren aan de wetenschap	K	☐ Andere zaken rond het levenseinde: ……………………………………………………………………

10 **We zijn geïnteresseerd in uw ervaringen met het ondersteunen van een mantelzorger.** Antwoord met ja of nee op de volgende uitspraken.

	Ik heb iemand die een stervende persoon bijstaat (mantelzorger) geholpen door:	**Ja**	**Nee**	
A	Contact op te nemen om te tonen dat ik bezorgd ben	☐	☐	Ik heb andere zaken gedaan voor iemand die zorgt voor een stervende persoon (mantelzorger), namelijk:
B	Emotionele ondersteuning te geven	☐	☐	……………………………………………………………………
C	Hem/haar te ondersteunen	☐	☐	……………………………………………………………………

	bij het verdriet en verlies			
D	Beschikbaar te zijn om te praten	☐	☐	

11 **We zijn geïnteresseerd in uw ervaring van bij iemand te zijn op het moment van zijn/haar overlijden.** Antwoord met ja of nee op de volgende uitspraken.

		Ja	**Nee**			**Ja**	**Nee**
A	Ik heb iemand gezelschap gehouden die dicht bij de dood stond	☐	☐	C	Ik heb tijd doorgebracht met een persoon na zijn/haar overlijden (bijvoorbeeld een groet uitbrengen)	☐	☐
B	Ik ben getuige geweest van het overlijden van een andere persoon	☐	☐	D	Ik heb geholpen bij het verzorgen van het lichaam van een overledene	☐	☐

12 **Hoezeer gaat u akkoord met deze zinnen?** Omcirkel**.**

	Ik weet waar ik informatie of hulp kan vinden over:	**Helemaal niet akkoord**				**Helemaal akkoord**
A	Rouw of de ervaring om iemand te verliezen	**1**	**2**	**3**	**4**	**5**
B	Mantelzorg: zorgen voor iemand die hulp nodig heeft	**1**	**2**	**3**	**4**	**5**
C	Sterven	**1**	**2**	**3**	**4**	**5**

De volgende vragen gaan over hoe u zich zou voelen in bepaalde situaties die te maken hebben met het levenseinde.

13 **Hoe ongemakkelijk zou u zich voelen bij deze situaties?** Omcirkel**.**

		Niet ongemakkelijk	**Een beetje ongemakkelijk**	**Neutraal**	**Ongemakkelijk**	**Heel erg ongemakkelijk**
A	U bent bij iemand die aan het sterven is.	**1**	**2**	**3**	**4**	**5**
B	Een persoon die gaat sterven, wil met u praten over de dood.	**1**	**2**	**3**	**4**	**5**
C	U ziet een stervende persoon pijn lijden.	**1**	**2**	**3**	**4**	**5**

D	U moet aan iemand vertellen dat die gaat sterven.	**1**	**2**	**3**	**4**	**5**
E	U ziet iemand die gaat sterven lichamelijk achteruitgaan.	**1**	**2**	**3**	**4**	**5**
F	U bent bij iemand die gaat sterven en die heeft verdriet.	**1**	**2**	**3**	**4**	**5**
G	U ziet iemand die gaat sterven mentaal achteruitgaan.	**1**	**2**	**3**	**4**	**5**
H	U beseft dat ook u ooit kan sterven op deze manier.	**1**	**2**	**3**	**4**	**5**

14 **Hoezeer gaat u akkoord met deze zinnen?** Omcirkel.

	Ik denk dat ik deze zaken kan:	**Helemaal niet akkoord**						**Helemaal akkoord**
A	omgaan met mijn verdriet als een vriend of familielid gaat sterven	**1**	**2**	**3**	**4**	**5**	**6**	**7**
B	bij vrienden of familieleden zijn die gaan sterven	**1**	**2**	**3**	**4**	**5**	**6**	**7**
C	praten over sterven en dood met een stervende vriend of familielid	**1**	**2**	**3**	**4**	**5**	**6**	**7**
D	vrienden of familie steunen bij het overlijden van hun dierbare	**1**	**2**	**3**	**4**	**5**	**6**	**7**
E	een stervende vriend of familielid steunen	**1**	**2**	**3**	**4**	**5**	**6**	**7**

De volgende vragen gaan over de praktische of emotionele steun die u zou kunnen ontvangen in situaties rond het levenseinde.

15 **Stel: u rouwt om iemand die overleden is. U hebt praktische hulp nodig, zoals uw kind ophalen van de crèche, de begrafenis voorbereiden … Bij wie zou u die hulp zoeken?** U mag meer dan één antwoord kiezen.

A	☐ Familie	D	☐ Professionele hulpverleners, zoals een huisarts, verpleegkundige, psycholoog …

B	☐ Vrienden of kennissen	E	☐ Ik zoek geen hulp
C	☐ Mensen uit mijn omgeving die ik niet (goed) ken, zoals vrijwilligers, buren, Whatsapp-buurtgroepen, een pastoor …		

16 **Stel: iemand in uw omgeving wordt ernstig ziek of sterft. U hebt praktische hulp nodig, bijvoorbeeld bij de boodschappen, om de hond uit te laten, te koken … Bij wie zou u die hulp zoeken?** U mag meer dan één antwoord kiezen.

A	☐ Familie	D	☐ Professionele hulpverleners, zoals een huisarts, verpleegkundige, psycholoog …
B	☐ Vrienden of kennissen	E	☐ Ik zoek geen hulp
C	☐ Mensen uit mijn omgeving die ik niet (goed) ken, zoals vrijwilligers, buren, Whatsapp-buurtgroepen, een pastoor …		

17 **Stel: iemand in uw omgeving wordt ernstig ziek of sterft. U hebt emotionele steun nodig, bijvoorbeeld om erover te kunnen praten, raad te vragen… Bij wie zou u die hulp zoeken?** U mag meer dan één antwoord kiezen.

A	☐ Familie	D	☐ Professionele hulpverleners, zoals een huisarts, verpleegkundige, psycholoog …
B	☐ Vrienden of kennissen	E	☐ Ik zoek geen hulp
C	☐ Mensen uit mijn omgeving die ik niet (goed) ken, zoals vrijwilligers, buren, Whatsapp-buurtgroepen, een pastoor …		

UW DEMOGRAFISCHE GEGEVENS

18 **Bent u de afgelopen 10 jaar verhuisd?**

Ja	Nee
☐	☐

19 **Hoe oud bent u?**

………….. **jaar**

20 **Welk geslacht heeft u?**

Man	Vrouw	X
☐	☐	☐

21 **Wat is uw hoogst behaalde diploma?**

Lager onderwijs of minder	Lager middelbaar onderwijs (eerste 3 jaren)	Hoger middelbaar onderwijs (middelbaar afgerond)	Hogeschool	Universiteit of hoger	Andere:
☐	☐	☐	☐	☐	……………………

22 **Wat is uw professioneel statuut?**

Student	Werkzoekend	Arbeids-ongeschikt	Werkend	Gepensioneerd	Huisvrouw/ -man	Andere:
☐	☐	☐	☐	☐	☐	……………………

23 **Wat is uw religieuze/ levensbeschouwelijke overtuiging?**

Katholiek	Islam	Joods	Vrijzinnig humanisme	Niet gelovig	Andere:
☐	☐	☐	☐	☐	……………………

24

Om een betere interpretatie van de resultaten te verkrijgen willen we van u vernemen of een van de volgende stellingen bij u past. Meerdere antwoorden mogelijk.

A	☐ Ik neem de zorg op mij voor een zorgbehoevend persoon (mantelzorger)	D	☐ Ik heb een chronische ziekte
B	☐ Ik nam vroeger de zorg op mij voor een zorgbehoevend persoon (mantelzorger)	E	☐ Ik rouw om iemand die ik verloren heb
C	☐ Ik verblijf in een verzorgingscentrum (woonzorgcentrum, serviceflat, instelling,…)	F	☐ Ik werk(te) in de gezondheidszorg en mijn beroep is/was: ………………………………………..

Heeft u opmerkingen of bedenkingen na het invullen van deze vragenlijst? Dan kan u dat hier delen.

Hartelijk dank voor uw medewerking!

Appendix 2. Sensitivity analysis calculation PaCKS score (study 1 – Chapter 2)

- *Table 1: Exploration of different options to calculate the total PaCKS score*
- *Figures 1 to 3: Division of total PaCKS scores according to different options*

Table 1. Exploration of different options to calculate the total PaCKS score

	Total PaCKS score Restrictive[1]	Total PaCKS score Lenient[2]	Total PaCKS score Inclusive[3]
N valid	1658	1852	1934
N Missing	350	156	74
Mean	7.92	7.87	7.71
Median	8.00	8.00	8.00
Standard deviation	3.460	3.411	3.478
Total score values	**valid %**		
0	7.1	6.6	6.9
1	1.3	1.3	2.0
2	1.2	1.2	1.4
3	2.8	3.2	3.5
4	2.6	2.8	3.1
5	4.6	4.7	4.7
6	8.7	9.2	9.3
7	11.1	11.0	10.8
8	12.2	12.4	12.5
9	11.0	10.9	10.7
10	12.2	12.6	12.0
11	10.7	10.5	10.0
12	8.9	8.6	8.2
13	5.6	5.0	4.8
Total %	100.0	100.0	100.0

[1] ‘restrictive’ option: includes only respondents who filled in all 13 items

[2] ‘lenient’ option: includes only respondents who completed at least 11 of the 13 items

[3] ‘inclusive’ option: includes respondents as soon as one of the 13 items is answered

Figure 1. Division of total PaCKS scores among respondents who filled in all 13 items

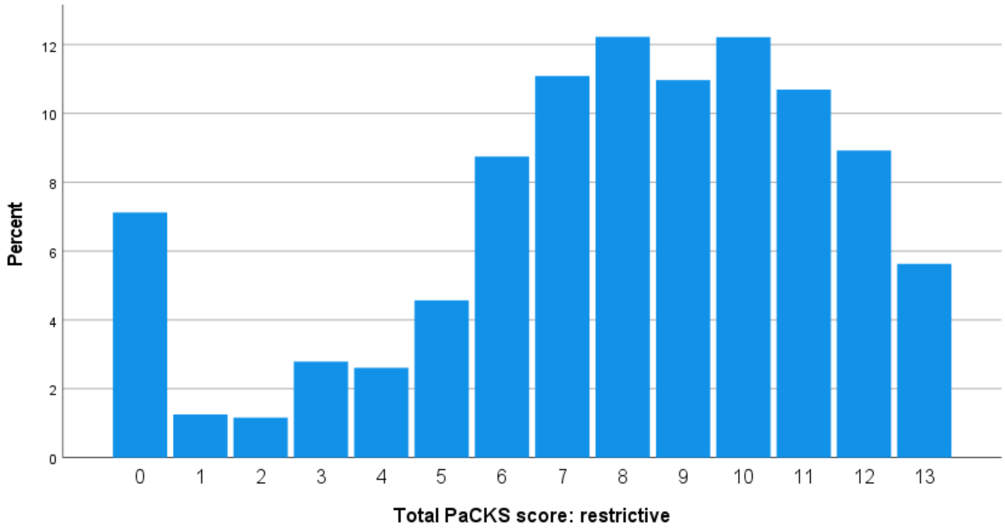


Figure 2. Division of total PaCKS scores among respondents who completed at least 11 of 13 items

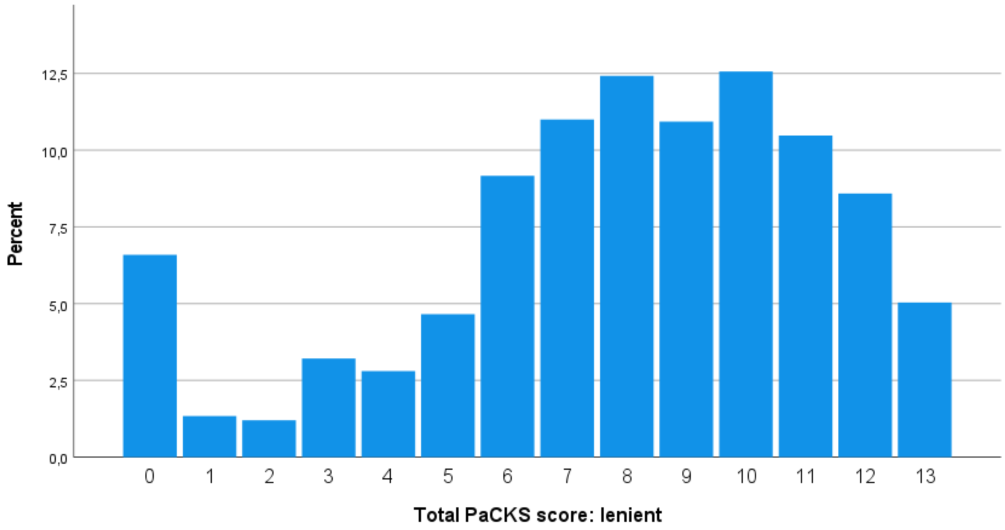
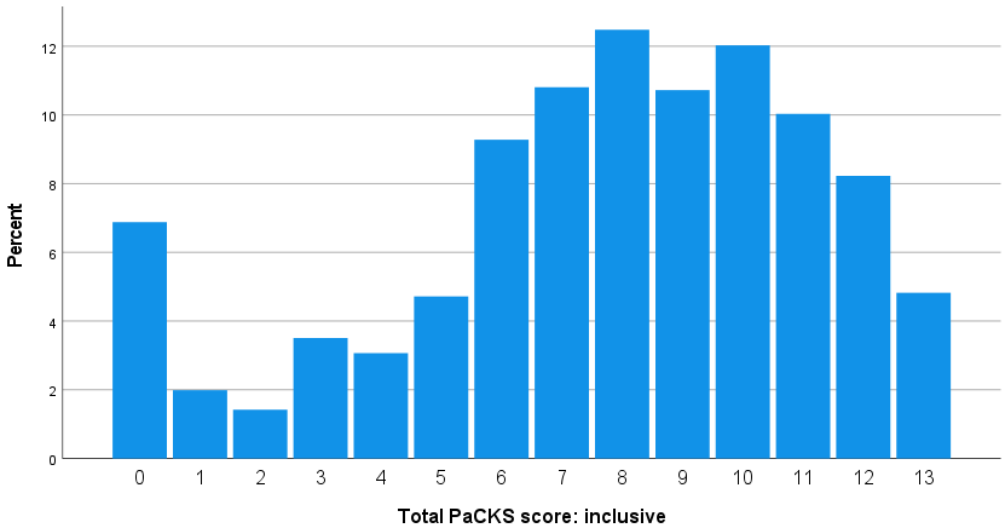
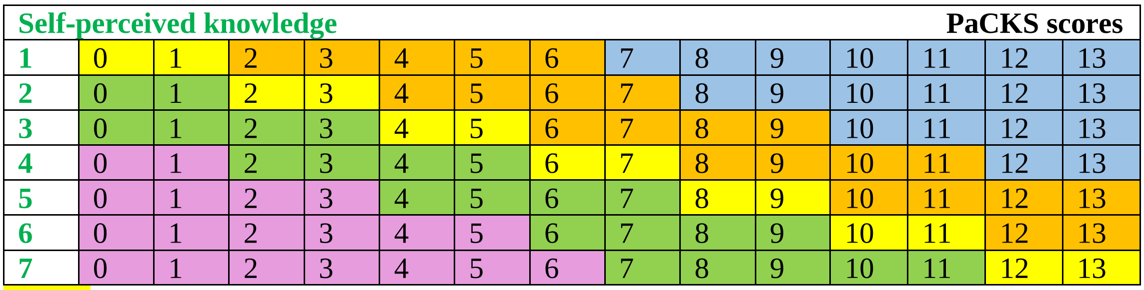


Figure 3. Division of total PaCKS scores among respondents who filled in at least one of 13 items



Appendix 3. Scheme to determine the congruence between self-perceived and actual knowledge of palliative care (study 1 – Chapter 2)

CONGRUENCE

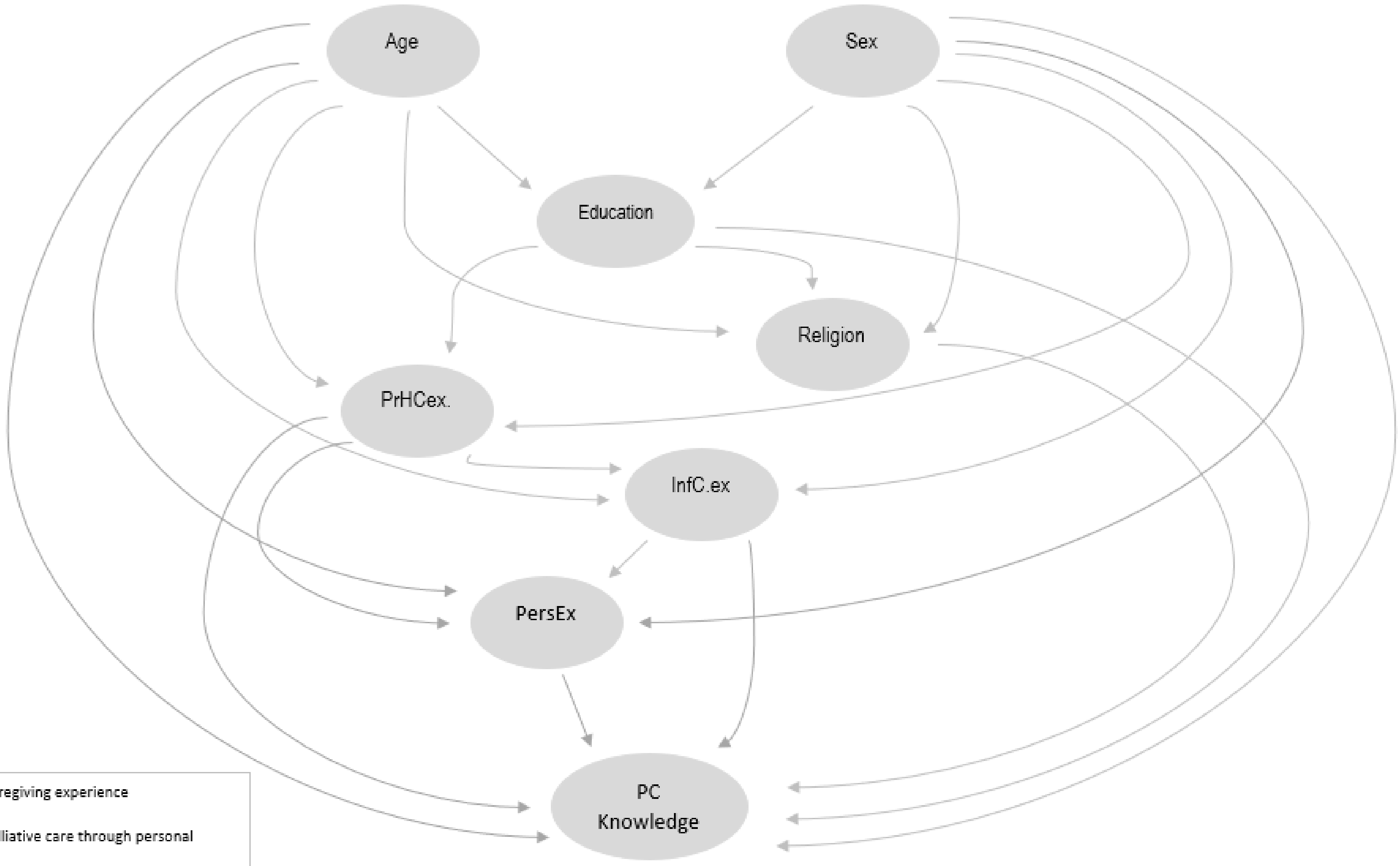


Self-perceived knowledge														**PaCKS scores**
1	0	1	2	3	4	5	6	7	8	9	10	11	12	13
2	0	1	2	3	4	5	6	7	8	9	10	11	12	13
3	0	1	2	3	4	5	6	7	8	9	10	11	12	13
4	0	1	2	3	4	5	6	7	8	9	10	11	12	13
5	0	1	2	3	4	5	6	7	8	9	10	11	12	13
6	0	1	2	3	4	5	6	7	8	9	10	11	12	13
7	0	1	2	3	4	5	6	7	8	9	10	11	12	13

Yellow = accurate estimation
Orange = underestimation
Green = overestimation
Blue = big underestimation
Purple = big overestimation

Appendix 4. models by Directed Acyclic Graphs (study 1 - Chapter 2)

Figure 1. Integrated Directed Acyclic Graph model



InfC.ex=informal caregiving experience
PC=palliative care
PersEx=knowing palliative care through personal experience
PrHCex=professional experience in health care
yellow=predictor
green=outcome
blue=confounders

Figure 2. Model 1: predictor age

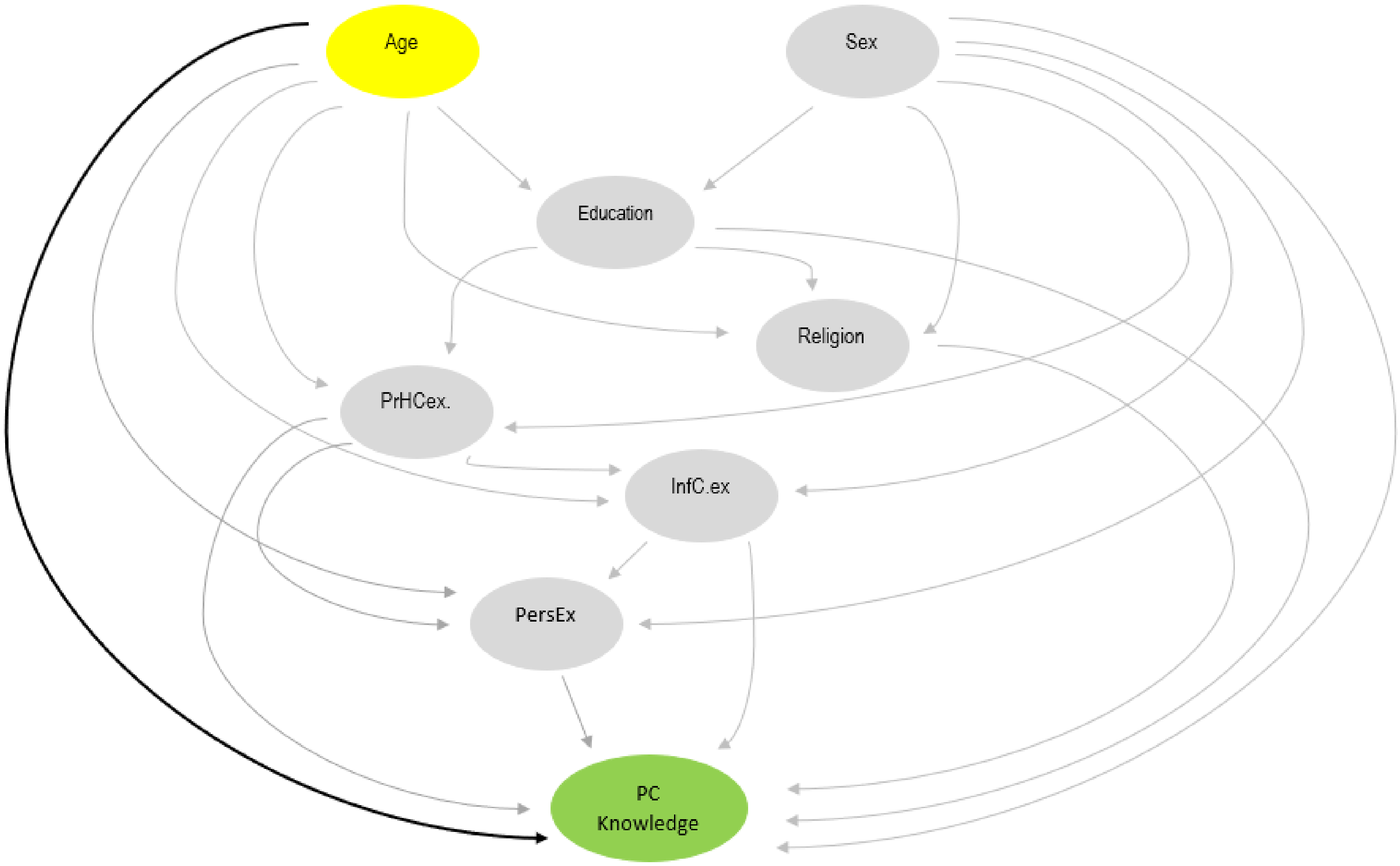


Figure 3. Model 2: predictor sex

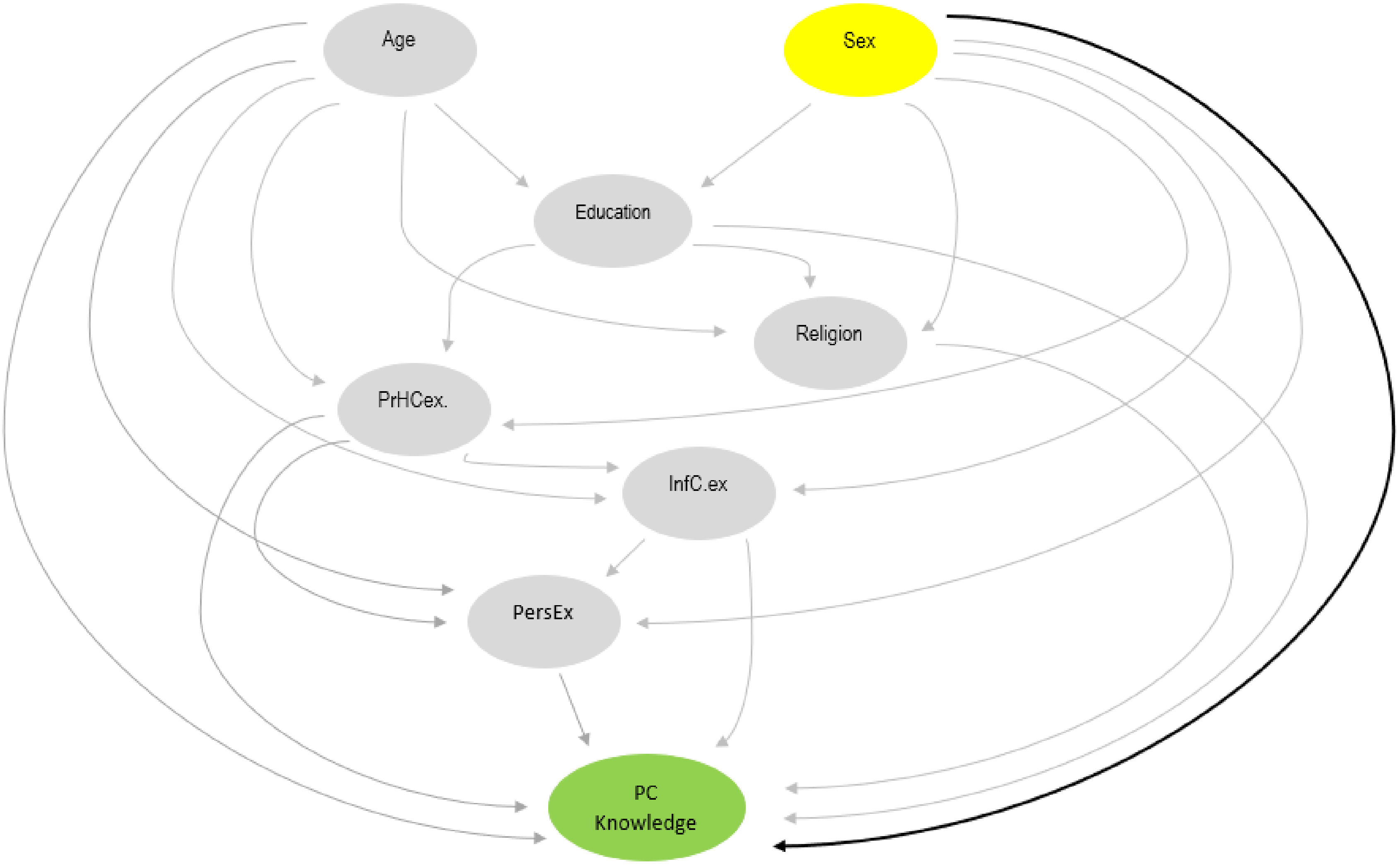


Figure 4. Model 3: predictor educational attainment

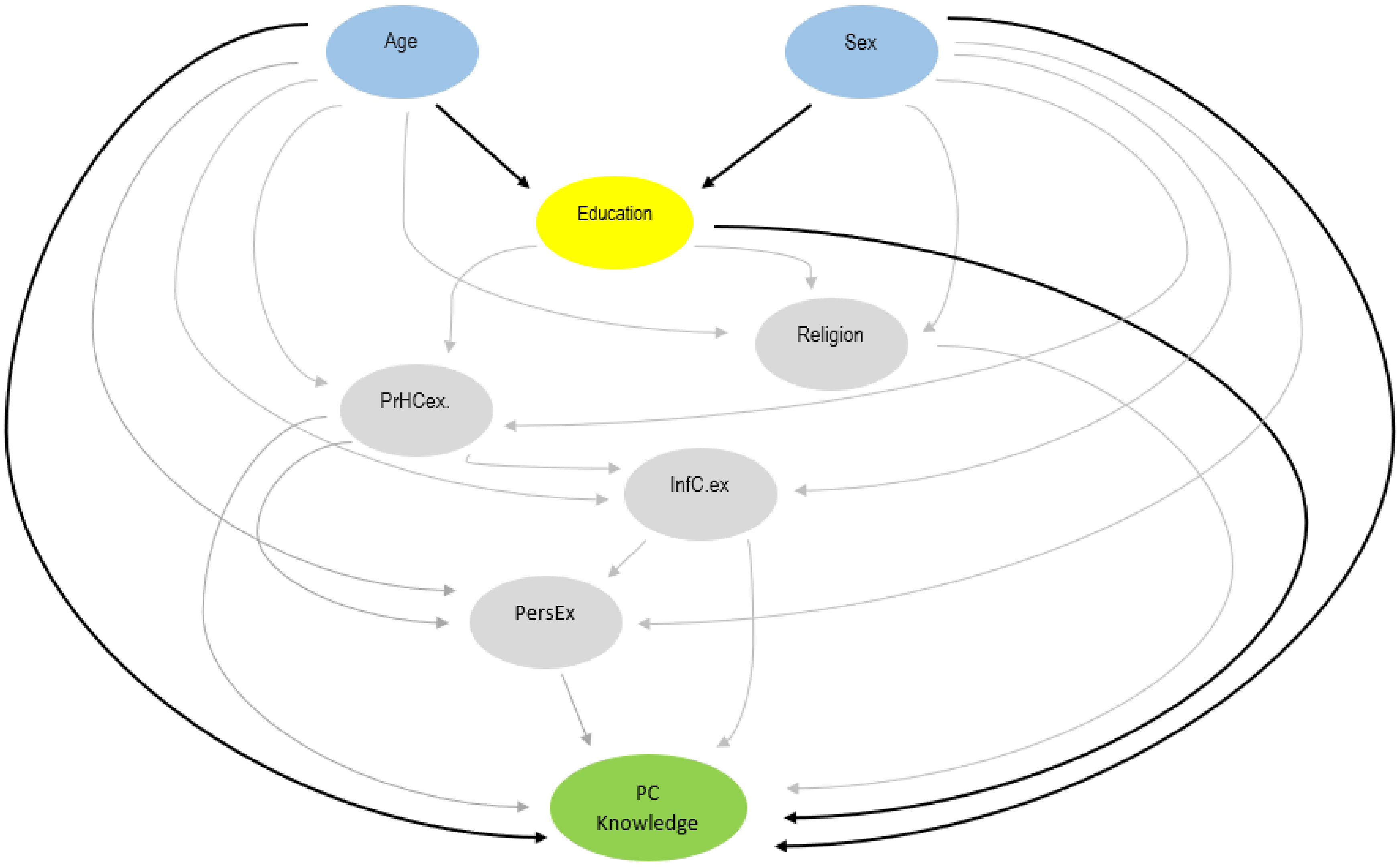


Figure 5. Model 4: predictor religious beliefs

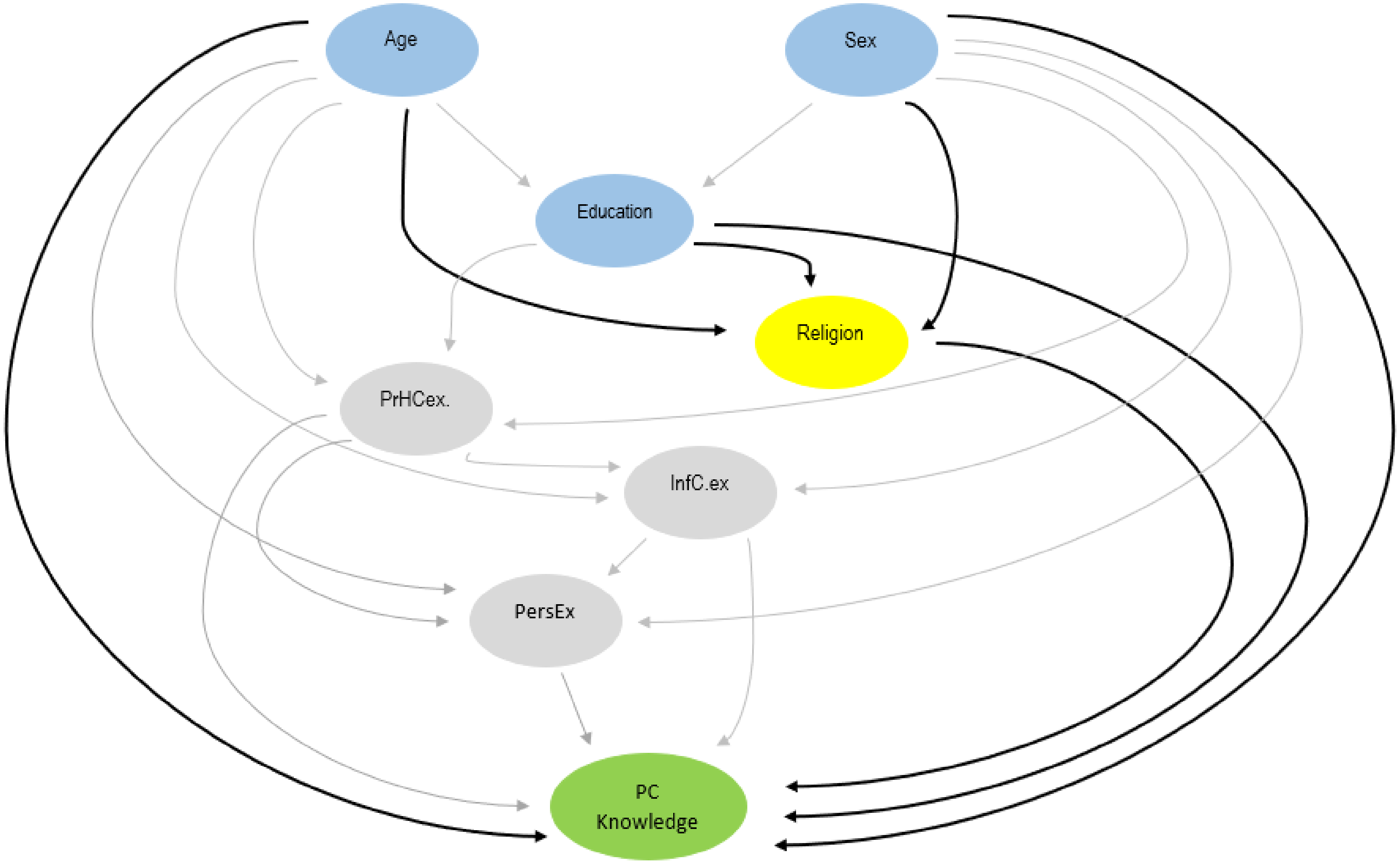


Figure 6. Model 5: predictor professional experience in health care

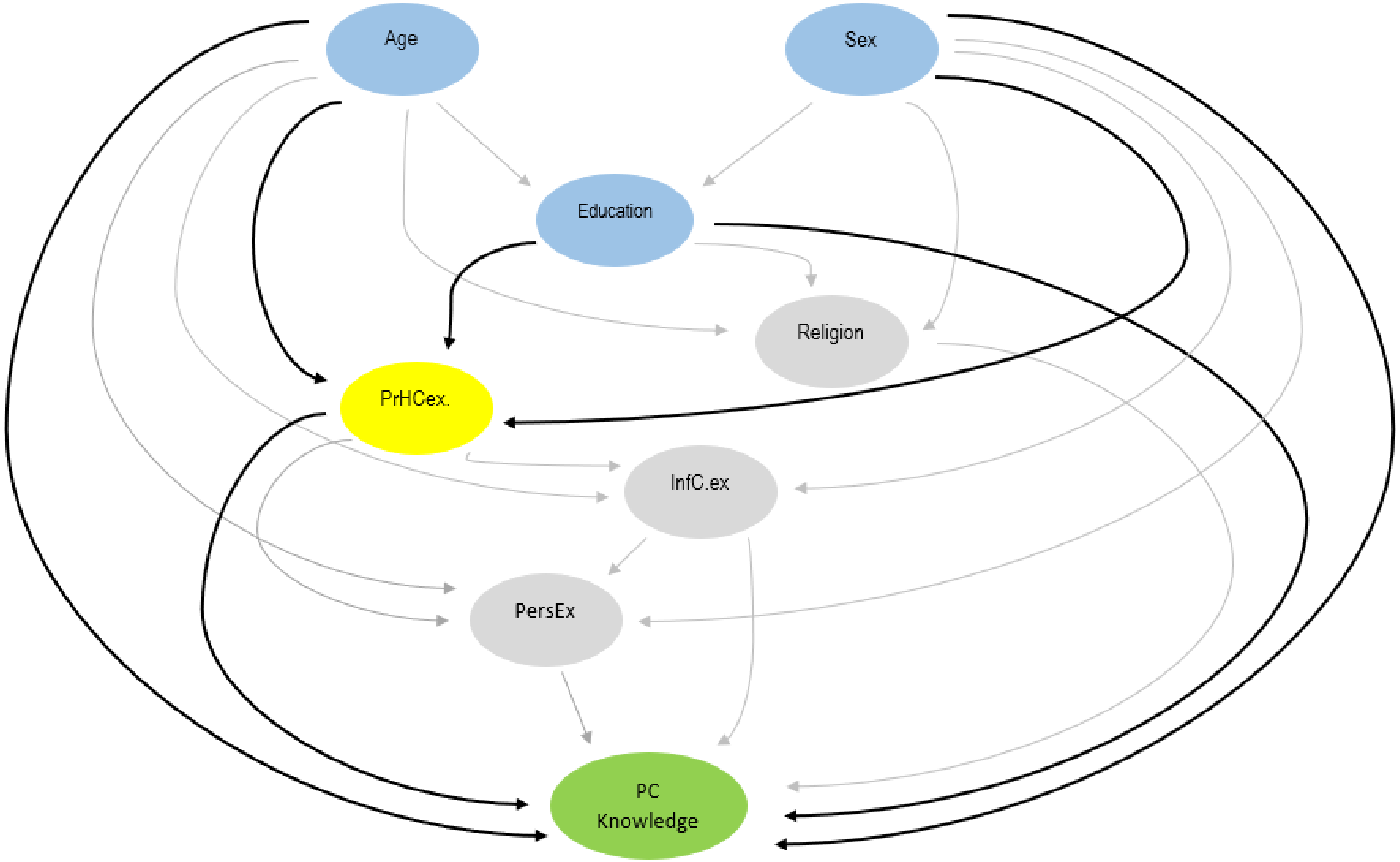


Figure 7. Model 6: predictor informal caregiver experience

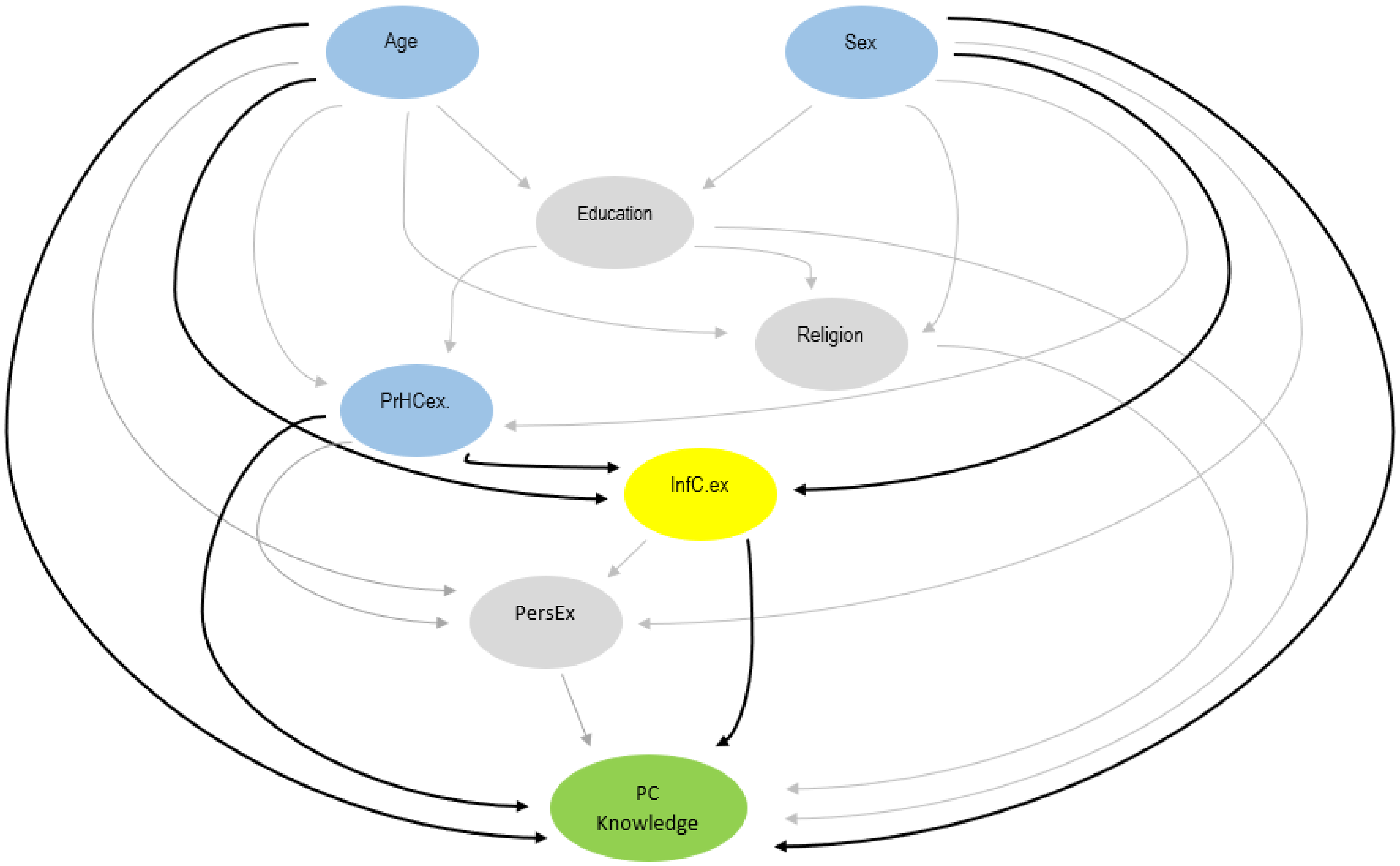
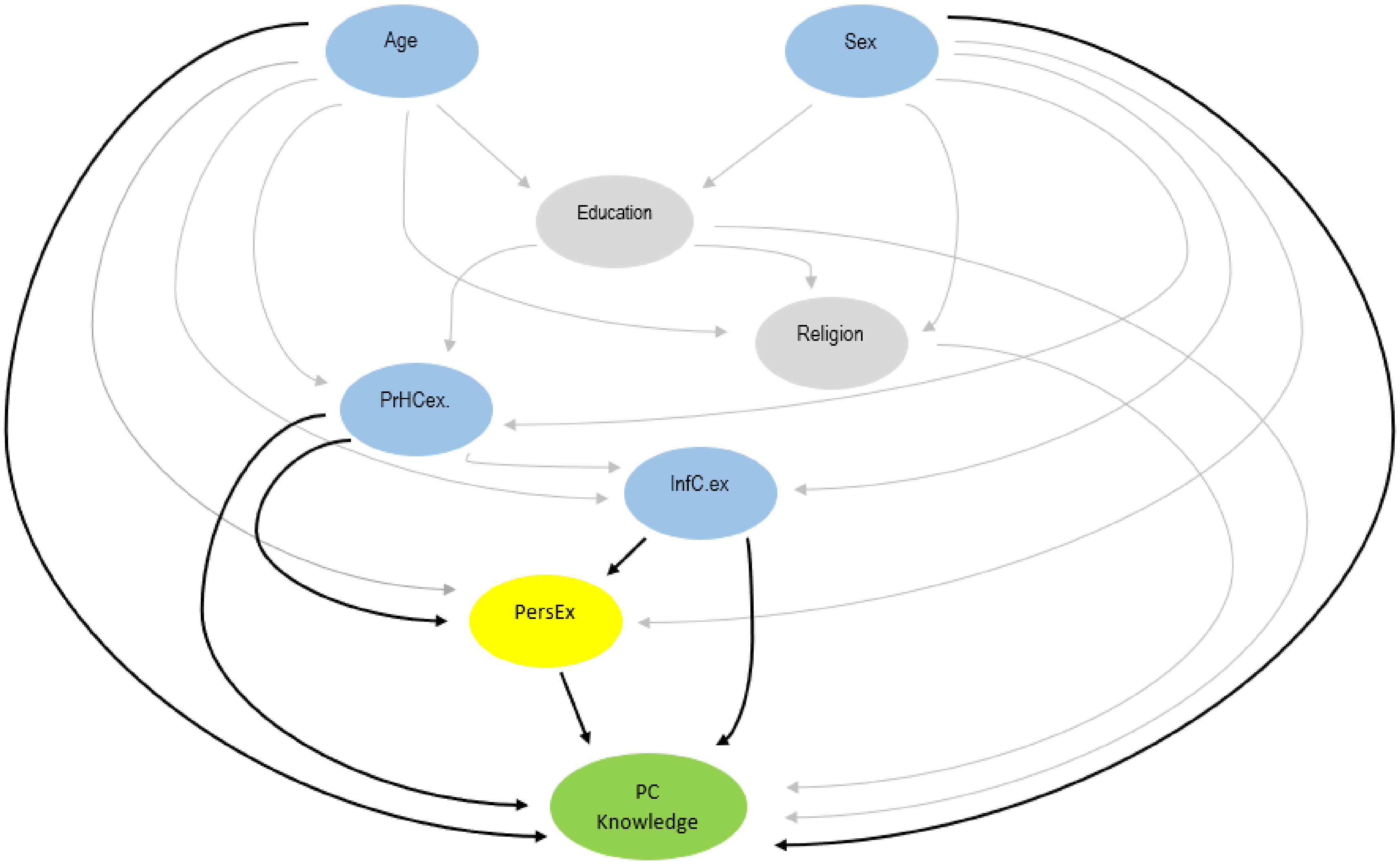


Figure 8. Model 7: predictor knowing palliative care through personal experience



Appendix 5. Complete case analysis hurdle model – sensitivity analysis (study 1 – Chapter 2)

Hurdle model (complete case analysis)									
PART 1: Binary logistic models for zero values					**PART 2: linear regression model for non-zero values**				
		95% CI for Exp (β)					**95% Confidence Interval**		
	Exp (β)	Lower	upper	**Sign.**		**B**	lower	upper	**Sign.**
Model 1:									
Constant	21.38			p<0.001	**Constant**	8.55	8.37	8.73	p<0.001
Sex[a]*					**Sex[a]**				
Male	0.51	0.35	0.76	p<0.001	**Male**	-0.20	-0.46	0.07	p=0.140
Model 2:									
Constant	9.50			p<0.001	**Constant**	8.06	7.69	8.44	p<0.001
Age[b]*					**Age[b]***				
30-44	1.20	0.66	2.18	p=0.559	30-44	0.52	0.03	1.02	p=0.038
45-59	1.99	1.10	3.60	p=0.022	45-59	0.69	0.25	1.14	p=0.002
60-74	2.89	1.52	5.50	p=0.001	60-74	0.37	-0.08	0.82	p=0.106
75+	0.98	0.54	1.77	p=0.936	75+	0.09	-0.42	0.60	p=0.727
Model 3:									
Constant	4.46			p<0.001	**Constant**	7.08	6.61	7.55	p<0.001
Educational level[c]*					**Educational level[c]***				
Medium	3.47	2.15	5.59	p<0.001	Medium	0.82	0.46	1.18	p<0.001
High	9.93	5.29	18.63	p<0.001	High	1.66	1.30	2.01	p<0.001
Other	0.69	0.29	1.63	p=0.395	Other	0.06	-0.93	1.05	p=0.909
Sex[a]*					**Sex[a]**				
Male	0.50	0.33	0.75	p<0.001	Male	-0.16	-0.42	0.10	p=0.224
Age[b]*					**Age[b]***				
30-44	0.95	0.50	1.80	p=0.862	30-44	0.35	-0.13	0.84	p=0.152
45-59	2.08	1.11	3.88	p=0.022	45-59	0.66	0.23	1.10	p=0.003
60-74	4.25	2.15	8.39	p<0.001	60-74	0.54	0.10	0.99	p=0.015
75+	1.86	0.97	3.55	p=0.061	75+	0.57	0.05	1.08	p=0.031
Model 4:									
Constant	11.01			p<0.001	**Constant**	7.55	7.04	8.05	p<0.001
Religion[d]*					**Religion[d]***				
Catholicism	0.74	0.43	1.26	p=0.266	**Catholicism**	-0.38	-0.66	-0.10	p=0.009
Islam	0.09	0.05	0.17	p<0.001	**Islam**	-2.22	-3.04	-1.41	p<0.001
Other	0.33	0.12	0.91	p=0.031	**Other**	-0.28	-1.07	0.52	p=0.497
Sex[a]*					**Sex[a]**				
Male	0.51	0.33	0.78	p=0.002	**Male**	-0.22	-0.48	0.04	p=0.096
Age[b]*					**Age[b]**				
30-44	0.88	0.44	1.78	p=0.728	**30-44**	0.35	-0.14	0.83	p=0.161
45-59	1.46	0.74	2.91	p=0.279	**45-59**	0.60	0.15	1.04	p=0.008
60-74	2.52	1.19	5.35	p=0.016	**60-74**	0.46	0.02	0.91	p=0.042
75+	1.04	0.50	2.18	p=0.910	**75+**	0.47	-0.06	1.00	p=0.079
Educational level[c]*					**Educational level[c]***				
Medium	2.90	1.76	4.78	p<0.001	**Medium**	0.74	0.38	1.10	p<0.001
High	7.45	3.91	14.22	p<0.001	**High**	1.53	1.18	1.89	p<0.001

Other	0.61	0.25	1.48	p=0.270	**Other**	0.30	-0.70	1.30	p=0.556
Model 5:									
Constant	3.96			p<0.001	**Constant**	6.95	6.48	7.42	p<0.001
Professional experience in health care[e]*					**Professional experience in health care[e]***				
yes	6.00	1.43	25.10	p=0.014	**yes**	1.09	0.72	1.46	p<0.001
Sex[a]*					**Sex[a]**				
Male	0.55	0.36	0.83	p=0.004	**Male**	-0.03	-0.29	0.23	p=0.835
Age[b]*					**Age[b]***				
30-44	0.94	0.49	1.79	p=0.841	**30-44**	0.33	-0.15	0.81	p=0.176
45-59	2.13	1.14	4.00	p=0.018	**45-59**	0.66	0.22	1.09	p=0.003
60-74	4.37	2.21	8.65	p<0.001	**60-74**	0.57	0.13	1.00	p=0.011
75+	1.98	1.03	3.78	p=0.040	**75+**	0.65	0.14	1.16	p=0.013
Educational level[c]*					**Educational level[c]***				
Medium	3.29	2.04	5.31	p<0.001	**Medium**	0.75	0.39	1.11	p<0.001
High	8.70	4.62	16.37	p<0.001	**High**	1.48	1.12	1.83	p<0.001
Other	0.60	0.25	1.44	p=0.253	**Other**	-0.15	-1.13	0.84	p=0.771
Model 6:									
Constant	9.96			p<0.001	**Constant**	7.82	7.42	8.21	p<0.001
Informal caregiving experience[f]					**Informal caregiving experience[f]**				
yes	1.43	0.91	2.25	p=0.116	**yes**	0.11	-0.17	0.39	p=0.438
Sex[a]*					**Sex[a]**				
Male	0.57	0.38	0.85	p=0.006	**Male**	-0.03	-0.29	0.24	p=0.846
Age[b]*					**Age[b]***				
30-44	1.22	0.66	2.23	p=0.532	**30-44**	0.48	-0.01	0.97	p=0.054
45-59	2.05	1.12	3.75	p=0.020	**45-59**	0.68	0.23	1.13	p=0.003
60-74	2.91	1.50	5.67	p=0.002	**60-74**	0.39	-0.07	0.84	p=0.097
75+	1.03	0.55	1.92	p=0.939	**75+**	0.22	-0.30	0.74	p=0.403
Professional experience in health care[e]*					**Professional experience in health care[e]***				
yes	8.53	2.08	35.02	p=0.003	**yes**	1.36	0.99	1.73	p<0.001
Model 7:									
Constant	7.47			p<0.001	**Constant**	7.60	7.19	8.00	p<0.001
Knowing PC through personal experience[g]*					**Knowing PC through personal experience[g]***				
yes	14.21	6.52	30.93	p<0.001	**yes**	0.65	0.39	0.91	p<0.001
Sex[a]*					**Sex[a]**				
Male	0.56	0.37	0.85	p=0.007	**Male**	-0.02	-0.28	0.25	p=0.904
Age[b]*					**Age[b]**				
30-44	1.09	0.57	2.07	p=0.802	**30-44**	0.42	-0.07	0.90	p=0.091
45-59	1.59	0.85	2.98	p=0.149	**45-59**	0.61	0.16	1.05	p=0.007
60-74	2.24	1.12	4.48	p=0.023	**60-74**	0.30	-0.16	0.75	p=0.201
75+	0.91	0.47	1.76	p=0.772	**75+**	0.18	-0.34	0.70	p=0.495
Professional experience in health care[e]*					**Professional experience in health care[e]***				
yes	8.93	2.17	36.84	p=0.002	**yes**	1.40	1.03	1.77	p<0.001
Informal caregiving experience[f]					**Informal caregiving experience[f]**				
yes	1.05	0.65	1.68	p=0.845	**yes**	-0.01	-0.29	0.28	p=0.954

[a] 'Female' is reference category
[b] '16-29' is reference category
[c] 'low educational level' is reference category
[d] 'not religious' is reference category
[e] 'no professional experience in health care' is reference category
[f] 'no informal caregiving experience' is reference category
[g] 'not knowing palliative care through personal experience' is reference category
*significant with P<0.05

Appendix 6. Full results hurdle model-analysis (study 1 – Chapter 2)

Hurdle model (imputed data)									
PART 1: Binary logistic models for zero values					**PART 2: linear regression model for non-zero values**				
		95% CI for Exp (β)					**95% Confidence Interval**		
	Exp (β)	Lower	upper	**Sign.**		**B**	lower	upper	**Sign.**
Model 1:									
Constant	18.19	12.23	27.06	p<0.001	**Constant**	8.50	8.30	8.69	p<0.001
Sex[a]*					**Sex[a]**				
Male	0.59	0.37	0.95	p=0.032	Male	-0.17	-0.44	0.11	p=0.232
Model 2:									
Constant	8.93	5.78	13.79	p<0.001	**Constant**	8.02	7.63	8.40	p<0.001
Age[b]*					**Age[b]***				
30-44	1.21	0.66	2.22	p=0.542	30-44	0.56	0.06	1.05	p=0.028
45-59	2.08	1.14	3.78	p=0.017	45-59	0.73	0.26	1.19	p=0.002
60-74	2.45	1.11	5.37	p=0.027	60-74	0.34	-0.14	0.82	p=0.166
75+	1.06	0.56	1.99	p=0.864	75+	0.07	-0.50	0.63	p=0.815
Model 3:									
Constant	3.83	2.06	7.11	p<0.001	**Constant**	7.02	6.53	7.51	p<0.001
Educational level[c]*					**Educational level[c]***				
Medium	3.37	1.99	5.71	p<0.001	Medium	0.85	0.47	1.23	p<0.001
High	10.18	5.38	19.26	p<0.001	High	1.69	1.31	2.07	p<0.001
Other	0.71	0.30	1.70	p=0.442	Other	0.06	-0.94	1.07	p=0.900
Sex[a]**					**Sex[a]**				
Male	0.59	0.36	0.97	p=0.039	**Male**	-0.15	-0.42	0.12	p=0.269
Age[b]*					**Age[b]*****				
30-44	1.00	0.53	1.89	p=0.997	30-44	0.39	-0.10	0.88	p=0.119
45-59	2.17	1.17	4.05	p=0.015	45-59	0.69	0.23	1.15	p=0.003
60-74	3.73	1.65	8.39	p=0.002	60-74	0.57	0.09	1.04	p=0.019
75+	2.14	1.09	4.20	p=0.027	75+	0.59	0.04	1.15	P=0.036
Model 4:									
Constant	9.23	4.35	19.58	p<0.001	**Constant**	7.47	6.95	7.99	p<0.001
Religion[d]*					**Religion[d]***				
Catholicism	0.72	0.42	1.22	p=0.221	**Catholicism**	-0.36	-0.65	-0.08	p=0.013
Islam	0.10	0.05	0.19	p<0.001	**Islam**	-2.24	-3.05	-1.42	p<0.001
Other	0.36	0.13	0.97	P=0.043	**Other**	-0.46	-1.24	0.33	p=0.252
Sex[a]***					**Sex[a]**				
Male	0.60	0.35	1.01	p=0.052	**Male**	-0.21	-0.48	0.06	p=0.126
Age[b]					**Age[b]**				
30-44	1.00	0.50	1.99	p=1.000	**30-44**	0.36	-0.13	0.84	p=0.146
45-59	1.61	0.82	3.17	p=0.164	**45-59**	0.63	0.17	1.08	p=0.007
60-74	2.27	0.97	5.33	p=0.059	**60-74**	0.47	-0.01	0.95	p=0.053
75+	1.26	0.59	2.72	p=0.552	**75+**	0.51	-0.04	1.06	p=0.070
Educational level[c]*					**Educational level[c]***				
Medium	2.87	1.65	4.98	p<0.001	**Medium**	0.79	0.41	1.17	p<0.001
High	7.76	4.04	14.92	p<0.001	**High**	1.59	1.21	1.97	p<0.001
Other	0.69	0.28	1.72	p=0.429	**Other**	0.13	-0.86	1.12	p=0.799
Model 5:									

Constant	3.44	1.86	6.35	p<0.001	**Constant**	6.89	6.40	7.38	p<0.001
Professional experience in health care[e]*					**Professional experience in health care[e]***				
Yes	5.83	1.35	25.19	p=0.018	**Yes**	1.08	0.71	1.46	p<0.001
Sex[a]****					**Sex[a]**				
Male	0.65	0.39	1.06	p=0.085	**Male**	-0.02	-0.29	0.25	p=0.878
Age[b]*					**Age[b]****				
30-44	0.98	0.52	1.86	p=0.950	**30-44**	0.36	-,122	,847	p=0.019
45-59	2.21	1.18	4.13	p=0.014	**45-59**	0.68	,224	1,132	p=0.003
60-74	3.80	1.68	8.62	p=0.002	**60-74**	0.58	0.11	1.05	p=0.015
75+	2.24	1.14	4.40	p=0.020	**75+**	0.66	0.11	1.21	p=0.143
Educational level[c]*					**Educational level[c]***				
Medium	3.20	1.88	5.43	p<0.001	**Medium**	0.78	0.40	1.16	p<0.001
High	8.88	4.68	16.85	p<0.001	**High**	1.51	1.13	1.90	p<0.001
Other	0.62	0.25	1.50	p=0.289	**Other**	-0.15	-1.15	0.85	p=0.775
Model 6:									
Constant	8.92	5.30	15.01	p<0.001	**Constant**	7.77	7.36	8.17	p<0.001
Informal caregiving experience[f]					**Informal caregiving experience[f]**				
yes	1.35	0.82	2.20	p=0.233	**yes**	0.13	-0.18	0.44	p=0.426
Sex[a]					**Sex[a]**				
Male	0.66	0.40	1.08	p=0.094	**Male**	0.00	-0.28	0.28	p=0.999
Age[b]**					**Age[b]§**				
30-44	1.20	0.65	2.22	p=0.552	**30-44**	0.51	0.01	1.00	p=0.044
45-59	2.08	1.14	3,82	p=0.018	**45-59**	0.69	0.22	1.17	p=0.004
60-74	2.44	1.04	5.72	p=0.041	**60-74**	0.36	-0.15	0.86	p=0.166
75+	1.11	0.57	2.13	p=0.765	**75+**	0.19	-0.40	0.77	p=0.526
Professional experience in health care[e]*					**Professional experience in health care[e]***				
yes	8.28	1.98	34.68	p=0.004	**yes**	1.37	0.99	1.74	p<0.001
Model 7:									
Constant	6.48	3.82	11.01	p<0.001	**Constant**	7.55	7.14	7.96	p<0.001
Knowing PC through personal experience[g]*					**Knowing PC through personal experience[g]***				
yes	9.15	4.00	20.95	p<0.001	**yes**	0.66	0.38	0.95	p<0.001
Sex[a]					**Sex[a]**				
Male	0.66	0.40	1.09	p=0.104	**Male**	0.00	-0.28	0.28	p=0.985
Age[b]					**Age[b]****				
30-44	1.04	0.56	1.96	p=0.892	**30-44**	0.44	-0.05	0.93	p=0.080
45-59	1.67	0.90	3.09	p=0.106	**45-59**	0.61	0.14	1.08	p=0.012
60-74	1.88	0.80	4.41	p=0.145	**60-74**	0.25	-0.25	0.76	p=0.326
75+	0.92	0.47	1.79	p=0.798	**75+**	0.11	-0.48	0.69	p=0.714
Professional experience in health care[e]*					**Professional experience in health care[e]***				
yes	9.16	2.18	38.48	p=0.003	**yes**	1.41	1.04	1.78	p<0.001
Informal caregiving experience[f]					**Informal caregiving experience[f]**				
yes	1.03	0.63	1.69	P=0.917	**yes**	0.02	-0.29	0.32	p=0.920

[a] 'Female' is reference category
[b] '16-29' is reference category
[c] 'low educational level' is reference category
[d] 'not religious' is reference category
[e] 'no professional experience in health care' is reference category
[f] 'no informal caregiving experience' is reference category
[g] 'not knowing palliative care through personal experience' is reference category
*significant with P<0.05 in all 15 imputed datasets
§significant with P<0.05 in all but one of 15 imputed datasets
**significant with P<0.05 in all but two of 15 imputed datasets
***significant with P<0.05 in all but three of 15 imputed datasets
****significant with P<0.05 in all but four of 15 imputed datasets
variables that had non-significant coefficients in five or more than five of 15 imputed datasets are reported as non-significant

Appendix 7. Overview of analyzed materials and organizations (study 3 – Chapter 4)

Analyzed organizations

Type of Organization	**Organization**	**URL and Date Accessed**	**Additional documents found on the organization's website(s) included in the analysis**
Palliative Care Field Organizations	1. Coda	www.coda.care Accessed December 2, 2019.	
	2. Netwerk Palliatieve Zorg De Mantel	www.demantel.net/ Accessed January 22, 2020.	*Information brochures:* - Netwerk Palliatieve Zorg De Mantel. (n.d.) *Netwerk palliatieve zorg De Mantel vzw* [Network palliative care De Mantel vzw]. https://www.demantel.net/assets/websitedata/Palliatieve%20zorgen%20-%20Main/Files/de%20mantel/Folders/Netwerk%20De%20Mantel%202018.pdf - Netwerk Palliatieve Zorg De Mantel. (n.d.). *Palliatieve thuiszorg De Mantel vzw* [Palliative home care service De Mantel vzw]. https://www.demantel.net/assets/websitedata/Palliatieve%20zorgen%20-%20Main/Files/de%20mantel/Folders/Thuiszorg%20De%20Mantel%202018.pdf
	3. Het Heidehuis	http://www.heidehuis.be/ Accessed January 31, 2020.	
	4. Netwerk Palliatieve Zorg Oost-Vlaanderen	http://www.palliatieve.org/ Accessed February 12, 2020.	*Information brochures:* - 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 - Federatie Palliatieve Zorg Vlaanderen vzw. (2012, May). *Palliatieve sedatie* [Palliative sedation]. http://files.palliatieve.org/download/210/Folder_PalliatieveSedatie_mei2012.pdf - Netwerken Palliatieve Zorg Oost-Vlaanderen. (n.d.). *Rol en betekenis van de kinesitherapeut in de palliatieve zorg* [Role and significance of the physiotherapist in palliative care]. http://files.palliatieve.org/download/61/kinebrochure0208.pdf

	5. Palliatieve Hulpverlening Antwerpen	https://www.pha.be Accessed March 2, 2020.	*Information brochures:* - Palliatieve Hulpverlening Antwerpen. (n.d.). *Uw eerste aanspreekpunt voor palliatieve zorg* [Your first contact for palliative care]. - Craps, Bruno. (2013). *Niet alleen: als je niet meer kunt genezen* [Not alone: when you can't get better]. Drukkerij A. Beullens. *Magazines:* Analyzed issues (five randomly chosen from the list with all issues: https://pha.be/info-pha/): - Palliatieve Hulpverlening Antwerpen. (2010). Info PHA. 16(1). https://pha.be/wp-content/uploads/2020/02/Info-PHA-J16-N1.pdf - Palliatieve Hulpverlening Antwerpen. (2016). Info PHA. 22(2). https://pha.be/wp-content/uploads/2020/02/Info-PHA-J22-N2.pdf - Palliatieve Hulpverlening Antwerpen. (2018). Info PHA. 24(3). https://pha.be/wp-content/uploads/2020/02/Info-PHA-J24-N3.pdf - Palliatieve Hulpverlening Antwerpen. (2019). *Info PHA*. 25(1). https://pha.be/wp-content/uploads/2020/02/Info-PHA-J25-N1.pdf - Palliatieve Hulpverlening Antwerpen. (2019). Info PHA. 25(4). https://pha.be/wp-content/uploads/2020/02/Info-PHA-J25-N4.pdf
	6. Netwerk Levenseinde vzw	http://www.netwerklevenseinde.be Accessed March 27, 2020.	
	7. Federatie Palliatieve Zorg Vlaanderen	http://www.palliatief.be/template.asp?f=links.htm Accessed June 9, 2020. [archived homepage: https://web.archive.org/web/20200707190222/http://www.palliatief.be/template.asp?f=index.htm]	*Information Brochures:* - Federatie Palliatieve Zorg Vlaanderen. (2017, October). *Palliatieve thuiszorg…en nu?* [Palliative home-care…what now?]. http://mailsystem.palliatief.be/accounts/143/attachments/Brochures/flyer_palliatieve_zorg_2017_oktober.pdf - Federatie Palliatieve Zorg Vlaanderen. (2020, January). *Medisch begeleid sterven: een begrippenkader* [Medically assisted dying: a conceptual framework]. - Palliatief Support Team UZ Leuven. (2017, March). *Mijn wensen voor mijn gezondheidszorg: traject vroegtijdige zorgplanning (VZP). Informatie voor zorgverleners* [My wishes for my healthcare: trajectory advance care planning

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	30. Site Mariahuis	http://sitemariahuis.be/ Accessed April 7, 2020.	
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Appendix 8. Topic guide focus groups (study 4 – Chapter 5)

Topic Guide - translated from Dutch

Estimated Duration: About 1 hour 30 minutes (including a 5-minute buffer).
Semi-structured approach

Introduction (approx. 10 min):

Brief (re)introduction of ourselves, our roles, some 'ground rules', purpose and general course of the focus group. Participants also introduce themselves briefly (after being assured that they are free to share as much or as little as they like).

Main Session (approx. 60 min):

Focus on the reception of campaign materials on palliative care and how the information is interpreted, evaluated and engaged with.

We aim to show all three campaigns to the participants, alternating the order in each focus group. After viewing the first campaign materials (posters, videos, flyers or radio spots), we will discuss their perspectives on these materials with the following questions:

- What do you think this is about?
- How do you feel about it?
- Would you pay attention to it in your regular daily activities?

If it does not naturally arise in the discussion, participants will be asked to clarify what comes to mind when they read or hear the term 'palliative care'. When all three campaigns have been shown and discussed, we will ask:

- Which of the campaigns or materials appealed most to you?
- Is there anything you would change about the campaigns to make them more appealing to you and if so, how?

Only if necessary, for example, if participants request it or struggle to interpret the materials, will we explain our interpretation of the campaign messages at the end of the conversation. This will be followed by the question: 'What do you think about these messages?

Closing (approx. 15 min):

- Do participants have any final reflections or thoughts they would like to share?
- Has participation in this focus group changed views on palliative care in any way?

We will briefly mention the opportunity to stay involved in the broader research project (as a planning group member during the development of a public campaign on palliative care) and express our interest in keeping them informed about the results of this study (participants can leave their email address on a provided form).

Appendix 9. Public awareness campaigns and researchers' reading (study 4 – Chapter 5)

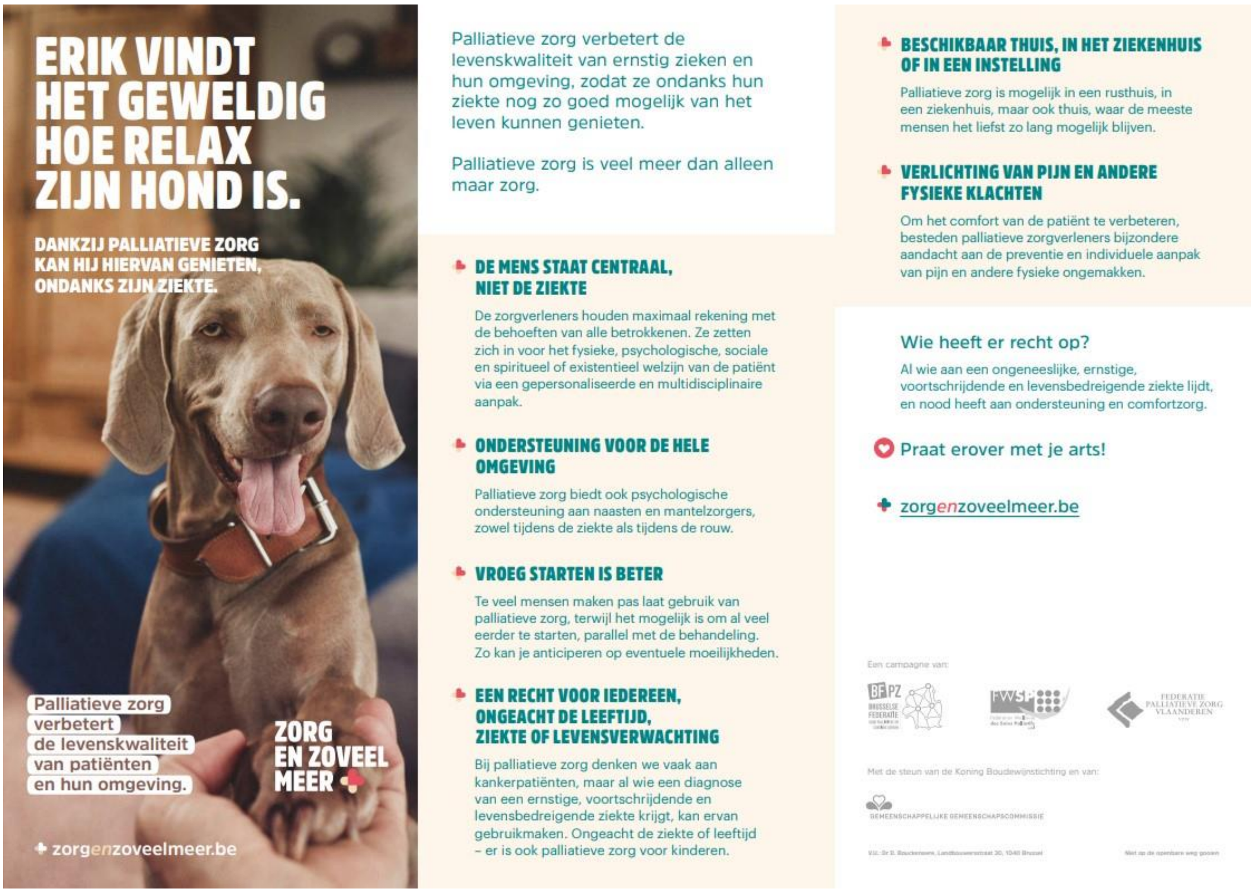
- *Overview of campaigns and materials*
- *Researchers' reading: table*

Overview public campaigns

C1: "Care and so Much More"

Link to campaign page: https://www.zorgenzoveelmeer.be/

Link to all materials, including radio spots: https://www.zorgenzoveelmeer.be/toolkit/



Palliatieve zorg verbetert de levenskwaliteit van ernstig zieken en hun omgeving, zodat ze ondanks hun ziekte nog zo goed mogelijk van het leven kunnen genieten.

Palliatieve zorg is veel meer dan alleen maar zorg.

DE MENS STAAT CENTRAAL, NIET DE ZIEKTE

De zorgverleners houden maximaal rekening met de behoeften van alle betrokkenen. Ze zetten zich in voor het fysieke, psychologische, sociale en spiritueel of existentieel welzijn van de patiënt via een gepersonaliseerde en multidisciplinaire aanpak.

ONDERSTEUNING VOOR DE HELE OMGEVING

Palliatieve zorg biedt ook psychologische ondersteuning aan naasten en mantelzorgers, zowel tijdens de ziekte als tijdens de rouw.

VROEG STARTEN IS BETER

Te veel mensen maken pas laat gebruik van palliatieve zorg, terwijl het mogelijk is om al veel eerder te starten, parallel met de behandeling. Zo kan je anticiperen op eventuele moeilijkheden.

EEN RECHT VOOR IEDEREEN, ONGEACHT DE LEEFTIJD, ZIEKTE OF LEVENSVERWACHTING

Bij palliatieve zorg denken we vaak aan kankerpatiënten, maar al wie een diagnose van een ernstige, voortschrijdende en levensbedreigende ziekte krijgt, kan ervan gebruikmaken. Ongeacht de ziekte of leeftijd – er is ook palliatieve zorg voor kinderen.

BESCHIKBAAR THUIS, IN HET ZIEKENHUIS OF IN EEN INSTELLING

Palliatieve zorg is mogelijk in een rusthuis, in een ziekenhuis, maar ook thuis, waar de meeste mensen het liefst zo lang mogelijk blijven.

VERLICHTING VAN PIJN EN ANDERE FYSIEKE KLACHTEN

Om het comfort van de patiënt te verbeteren, besteden palliatieve zorgverleners bijzondere aandacht aan de preventie en individuele aanpak van pijn en andere fysieke ongemakken.

Wie heeft er recht op?

Al wie aan een ongeneeslijke, ernstige, voortschrijdende en levensbedreigende ziekte lijdt, en nood heeft aan ondersteuning en comfortzorg.

Praat erover met je arts!

zorgenzoveelmeer.be

Een campagne van:

Met de steun van de Koning Boudewijnstichting en van:

ERIK VINDT HET GEWELDIG HOE ZEN ZIJN HOND IS.

DANKZIJ PALLIATIEVE ZORG KAN HIJ HIERVAN GENIETEN, ONDANKS ZIJN ZIEKTE.

Palliatieve zorg verbetert de levenskwaliteit van patiënten en hun omgeving.

ZORG EN ZOVEEL MEER

zorgenzoveelmeer.be

Een campagne van:

Met de steun van de Koning Boudewijnstichting en van:

GEMEENSCHAPPELIJKE GEMEENSCHAPSCOMMISSIE

GERDA IS DOL OP HAAR CREATIEVE KLEINDOCHTER.

DANKZIJ PALLIATIEVE ZORG KAN ZE HIERVAN GENIETEN, ONDANKS HAAR ZIEKTE.

Palliatieve zorg verbetert de levenskwaliteit van patiënten en hun omgeving.

ZORG EN ZOVEEL MEER

zorgenzoveelmeer.be

Een campagne van:

Met de steun van de Koning Boudewijnstichting en van:

GEMEENSCHAPPELIJKE GEMEENSCHAPSCOMMISSIE

NADIA HOUDT VAN ZACHT BADSCHUIM.

DANKZIJ PALLIATIEVE ZORG KAN ZE HIERVAN GENIETEN, ONDANKS HAAR ZIEKTE.

Palliatieve zorg verbetert de levenskwaliteit van patiënten en hun omgeving.

ZORG EN ZOVEEL MEER

zorgenzoveelmeer.be

Een campagne van:

Met de steun van de Koning Boudewijnstichting en van:

GEMEENSCHAPPELIJKE GEMEENSCHAPSCOMMISSIE

C2. “When you are no longer getting better”

Link to campaign page and to all materials, including videos:
news.pressmailings.com/hvdm/toolkit-palliatieve-zorg

“Ik omarm het leven, maar alles draait ook om ziek zijn. Palliatieve zorg helpt mij om hiermee om te gaan.”

Jannie (68 jaar) heeft uitgezaaide borstkanker.

“Na de diagnose had ik een aantal gesprekken met een verpleegkundige van de thuiszorg. Mijn man was daar ook bij. Dat was prettig. Een geestelijk verzorger begreep goed in welke achtbaan ik zat en hielp mij weer richting aan mijn leven te geven.”

Ministerie van Volksgezondheid,
Welzijn en Sport

Palliatieve zorg gaat over kwaliteit van leven als je niet meer beter wordt.

Er komt veel op jou en jouw naasten af als je hoort dat je niet meer beter wordt. Palliatieve zorg kan helpen om deze periode nog te doen wat jij belangrijk vindt.

Praten over je wensen en grenzen met je familie en arts of verpleegkundige kan rust geven. Als zorgverleners weten wat jij belangrijk vindt, krijg je de zorg die bij je past.

Lees meer over lichamelijke, psychische, sociale zorg, zingeving en andere mogelijkheden op overpalliatievezorg.nl/kwaliteit

over
Palliatieve
zorg

"Het zijn de kleine dingen: kunnen genieten met je gezin en met je vrienden. Dat is wat palliatieve zorg mij oplevert."

Michiel (63 jaar) heeft ALS.

"Voor mij is goede palliatieve zorg onder andere de psychische begeleiding. Nadenken, en praten met je vrouw en kinderen over als je er niet meer bent, maakt het accepteren dat ik niet meer beter word makkelijker."

Ministerie van Volksgezondheid, Welzijn en Sport

Palliatieve zorg gaat over kwaliteit van leven als je niet meer beter wordt.

Er komt veel op jou en jouw naasten af als je hoort dat je niet meer beter wordt. Palliatieve zorg kan helpen om deze periode nog te doen wat jij belangrijk vindt.

Praten over je wensen en grenzen met je familie en arts of verpleegkundige kan rust geven. Als zorgverleners weten wat jij belangrijk vindt, krijg je de zorg die bij je past.

Lees meer over lichamelijke, psychische, sociale zorg, zingeving en andere mogelijkheden op overpalliatievezorg.nl/kwaliteit

over Palliatieve zorg

"Je hebt regie over je eigen leven en palliatieve zorg ondersteunt mij om mijn leven zo leuk mogelijk te houden."

Jolanda (49 jaar) heeft COPD.

"Het is belangrijk om aan te geven wat je wil. Dan krijg je de palliatieve zorg die bij je past. Ik heb goed contact met mijn longarts en longverpleegkundige. Dat betekent heel veel voor mij."

Ministerie van Volksgezondheid, Welzijn en Sport

Palliatieve zorg gaat over kwaliteit van leven als je niet meer beter wordt.

Er komt veel op jou en jouw naasten af als je hoort dat je niet meer beter wordt. Palliatieve zorg kan helpen om deze periode nog te doen wat jij belangrijk vindt.

Praten over je wensen en grenzen met je familie en arts of verpleegkundige kan rust geven. Als zorgverleners weten wat jij belangrijk vindt, krijg je de zorg die bij je past.

Lees meer over lichamelijke, psychische, sociale zorg, zingeving en andere mogelijkheden op overpalliatievezorg.nl/kwaliteit

over Palliatieve zorg

C3. “Beyond cure. Not beyond care”

Link to campaign page: https://overpalliatievezorg.nl/over-de-campagne

Link to all materials: https://overpalliatievezorg.nl/toolkit-ongeneeslijk-niet-uitbehandeld

Researchers’ reading of campaign materials

Care and so Much More (Belgium)		
	Description of content	**Researchers’ interpretation**
Radio spots (3)	All three radio spots (30”) have the same voice-over, are connected to one of three personas and share the same structure: - Voice-over actor starts by saying one of the three different names and what this persona loves (for instance: “*Erik loves how his grandson laughs when he tickles him, how his cat softly spins and how the wrapping paper rustles when he opens a gift*”), while the listener simultaneously hears the sounds of these specific things - Followed by the sentence “*Thanks to palliative care, he can continue to enjoy this, despite his illness, and it does him an incredible amount of good”.* - Ends with the sentences: “*Palliative care improves the quality of life of seriously ill persons and the persons around them. Do you have another image of palliative care? Go to zorgenzoveelmeer.be* [name of website connected to the campaign]”	- Message emphasizes the vital role palliative care plays to create the conditions in which persons with serious illnesses can still enjoy the things they love - Reflects the active-passive subject positioning as previously found in the analysis of online information of palliative care* - Through the sentence “*Do you have another image of palliative care?”,* the radio spots allude to supposed misperceptions people have of palliative care (of it being predominantly focused on dying & death for instance)
Information brochures (1)	Three fold flyer containing: - On the front side the image of a dog with on top the text “*Erik loves how relaxed his dog is – thanks to palliative care he can enjoy this, despite his illness*” and on the bottom the sentence “*Palliative care improves the quality of life of seriously ill persons and the persons around them*”, the logo of the campaign and the website. - The two middle pages offer more information on key pillars of palliative care starting with the main sentences: "*Palliative care improves the quality of life for seriously ill individuals and their surroundings, enabling them to continue enjoying life as best as possible, despite their illness. Palliative care is much more than just care*". Key pillars that follow (each with a small block of text – only summary given here): “*The individual takes center stage, not the illness*”; “*Support for the entire surroundings*”, “*Early initiation is better*”,	- Main emphasized message (front side and main text of middle side) is the same as the one from the radio spots (see comments above). - Middle, informational, part on the one hand reflects some of the ‘typically’ emphasized core aspects of palliative care (holistic view of persons within their environment for instance) and on the other hand, alludes on some of the typically assumed ‘myths’ surrounding palliative care (for instance, palliative care being only for older people or people with cancer). - People are explicitly encouraged to start a conversation about palliative care with their doctor while the website is

	"A right for everyone, regardless of age, illness, or life expectancy", *"Available at home, in the hospital, or in an institution"*, *"Relief from pain and other physical complaints"*. - The key pillars are followed by "*Who is eligible? Anyone suffering from an incurable, severe, progressive, and life-threatening disease, and in need of support and comfort care*", and the imperative: "*Discuss it with your doctor!*" - The website is mentioned at the end with below, low-key in small letter cases and grey colours, the logos of the palliative care organizations and the funders behind the campaign.	mentioned without explicit encouragement to visit for more information. - The sentence "*Palliative care is a lot more than care*" is quite ambiguous and unclear (a lot more than medical care or a lot more than care through the effects it has?) - Throughout the text, the articulated subject positioning reflects the ones found in prior analysis (passive positioning of persons with serious illness, use of negatively charged words such as suffering illness, etc.)* - The brochure places emphasis on professional-driven medical care
Posters (3)	Three posters that have the same lay-out and content, except for the central image and quote on top, both of which are connected to one of the three personas. - One poster is identical to the front side of the information brochure ("*Erik loves…*" and the image of a dog) - Second poster has the image of a young, happy and dressed-up child and the text "*Gerda loves her creative granddaughter*" - Third poster is an image of (relatively young) nail-polished feet popping up from a bath tub with the text "*Nadia loves soft bath foam*" Aside these differing elements all posters have the same content as the front side of the information brochure described above.	- Main emphasized message is the same as the one from the radio spots and front side of the information brochure (see comments above). - Aside a pair of feet, the persons with serious illness themselves are not visualized which seems to demand more focused attention of recipients in order to grasp the message of the campaign and might be confusing at first sight.
When You Are No Longer Getting Better (the Netherlands)		
Video spots (2)	In both videos (1') a person with a serious incurable illness is shown narrating on their experience of illness and palliative care. In both videos the name of the campaign ("*When you are no longer getting better*") is shown at the beginning and the viewer also later sees a second person who is painting a portrait of the protagonist while they talk. In the end the viewer sees the results of the painting and the reactions of the protagonist	- Main emphasized message differs slightly depending on each video. In the video of Jolanda autonomy and self-determination are central. In the video of Michiel it is more the support to facilitate conversations and acceptance of the illness, as well as the quality of life

	to the portrait, all while the voice of the protagonist narrating on their experience stays the dominant element. - In the first video ‘Jolanda’ (49) talks about the rich social life she used to have before she got sick and received the diagnosis of COPD. She states “*You have control over your own life and care services can support you to keep it as fun as possible. So that part where I’m already a little bit in, the palliative care towards the end of life... You yourself must be assertive enough to bring up what is important to you. Yes, I’m quite proud of that.*” - In the second video ‘Michiel’ (63) starts by saying he has a wife and two daughters and that he was quite athletic before, biking a lot and loved skiing and riding horse, until he got the diagnosis of ALS. He then states: *“Palliative care for me mainly means the mental support. That you have to think about when you’ll no longer be here. And when you talk about it more often, with your wife or your children, it makes the acceptation also easier. And this you don’t do alone. You also do this under the support of the ALS-treatment team. It are the small things: enjoying with your family, your friends...and that is what palliative care delivers*.” Both videos end with a white screen that in the middle has the sentence “*Palliative care offers quality of life when you are incurably ill*”, followed by a second white screen with “*Read more about the possibilities on overpalliativezorg.nl*” and the logo of the campaign.	derived from being able to enjoy ‘the little things of life’. Both underscore that palliative care helps them to achieve those aspects. - The person narrating while simultaneously being painted emphasizes the person-centeredness, symbolically underscoring its importance within palliative care
Flyers (3)	- Frontside contains unique image of person with serious incurable illness holding a painted portrait of themselves in their home. Each flyer contains the name of the person, age, diagnosis and two personal quotes (big one on top and smaller one at the bottom of the flyer). Big quotes are: - *"I embrace life, but everything also revolves around being ill. Palliative care helps me cope with this."* - *"You have control over your own life,*	- The main aspects emphasized vary depending on the flyer—autonomy, enjoying the small things in life, coping with the broad impact of illness—but palliative care is consistently presented as playing a role in these areas - The backside emphasizes quality of life, the importance of

	and palliative care supports me in keeping my life as enjoyable as possible." - *"It are the small things: being able to enjoy time with your family and friends. That's what palliative care brings to me."* - Backside (identical for all three flyers): "*Palliative care is about the quality of life when you are no longer getting better. A lot comes your way, and that of your loved ones, when you hear that you won't recover. Palliative care can help you to still do what is important to you during this period. Talking about your wishes and boundaries with your family and healthcare professionals can bring peace. When caregivers know what is important to you, you receive the care that suits you. Learn more about physical, psychological, social care, existential support, and other possibilities at overpalliatievezorg.nl/kwaliteit*". Also contains logo of campaign.	communication and the holistic nature of palliative care - Central emphasis on voice of the patient and his or her needs
Beyond Cure. Not Beyond Care. (the Netherlands)		
Posters (6)	Six posters featuring portrait pictures of people with incurable illnesses. Except for the unique image, name and age (at the right bottom corner) the posters all have the same content: -The slogan (at the top) "*Beyond cure. Not beyond care.*" ["*uitbehandeld*" in Dutch with the closest literal translation being "treatment exhausted"] -Followed (at the bottom) by "*look at the possibilities: overpalliatievezorg.nl*"	- Main emphasized message is that incurable illness does not imply people are left without support or care and that palliative care is dedicated to delivering this - "uitbehandeld" in Dutch is a strong but commonly used word to describe people who have come to the end of curative medical treatment possibilities and the slogan thus evokes the societal image of incurably ill persons who have no other options left than to wait for death. By adding "not" before "beyond care" [uitbehandeld], the messages implies palliative care actively goes against this societal discourse.

**See: Matthys M, Dhollander N, Van Brussel L, Beernaert K, Deforche B, Cohen J, Deliens L, Chambaere K. The Online Representation of Palliative Care by Practice, Policy, and Advocacy Organizations: Definitional Variations and Discursive Tensions. Qualitative Health Research 2021; 31: 2743-2756.*

Appendix 10. Overview focus group participants (study 4 - Chapter 5)

		Total (n=65)	**F1 (n=6)**	**F2 (n=5)**	**F3 (n=6)**	**F4 (n=9)**	**F5 (n=6)**	**F6 (n=6)**	**F7 (n=6)**	**F8 (n=6)**	**F9 (n=9)**	**F10 (n=6)**
Age	18-25	6			2	3				1		
	26-44	14		1	2	5		3		3		
	45-59	17		1		1	1	1	1	1	8	3
	60-75	21	4	3	2		3	1	4	1	1	2
	75+	7	2				2	1	1			1
Gender	Female	44	5	4	4	3	4	4	3	2	9	6
	Male	20	1	1	2	5	2	2	3	4		
	Other	1				1						
Ethnicity*	Belgian and/or Flemish	40	5	4	3	7	4	4	5	5		3
	Turkish-Belgian	9			1						8	
	Turkish	3			1						1	1
	Western-European	1		1								
	Luxembourger	1						1				
	Indonesian-Chinese	1								1		
	Tunisian-Belgian	2										2
	Other (world citizen, human, no idea)	3			1	2						
	Prefer not to say	1							1			
	Missing	4	1				2	1				
Educational attainment	Primary education or less	9					2		3		2	2
	Lower secondary education	8	1				2		3		1	1
	Higher secondary education	16	1	1	2	2				5	2	3
	College	12	1	2	2	3		1			3	
	University	16	1	2	1	4	2	5		1		
	Other	1			1							
	Missing	3	2								1	
Life stance and/or religious beliefs	Catholic	19	3	1	1	3	2	2	5			2
	Muslim	14			2						9	3
	Secular humanism	5	1	1		1		1		1		
	Not religious	21	2	2	2	4	4	2		4		1
	Buddhism	1				1						
	Prefer not to say	1							1			
	Other	4		1	1			1		1		
Personal Experience with serious illness and/or Bereavement	Yes	42	5	3	3	4	3	5	5	3	6	5
	No	21	1	2	3	5	2	1	1	3	3	
	Prefer not to say	2					1					1

Ethnicity was self-identified through an open question; all other items, except age, had predefined answer options.

Appendix 11. detailed multidimensional audience reception table (study 4 – Chapter 5)

<table>
<tr><th colspan="2">Multidimensional Audience Reception Model</th></tr>
<tr><td colspan="2">MOTIVATION
The motivation dimension deals with the ‘link of relevance’ between readers personal universe and the textual universe perceived to be presented by the text, extending beyond the text into the whole situation of consumption. Can be based on various aspects such as personal interest in the subject, something in the message reminding the reader of certain experiences or feeling some kind of attachment to a character in the text, etc.</td></tr>
<tr><td>General (across campaigns & materials):</td><td>❖ Having **personal experience** with serious illness, the end of life and mourning was an important reason why people said they are interested and have an open attitude towards public communication messages on palliative care. Two participants additionally also mentioned that **being of older age and having a frail health** made them more attuned to these kinds of messages. One person also mentioned that the **cultural significance of caring for aging parents** also contributed to attention to these campaigns and this was widely agreed upon by the other participants in this group (consisting of Turkish-Belgian Muslim women).
❖ The main reasons why participants cited a **lack of interest or generally not having an open attitude** towards these messages were: a lack of personal experience with these themes, and, a reluctance or a lack of understanding about why they should engage with such messages when not directly confronted with serious illness, either personally or within their immediate environment. Many of those participants indicated that they would be more attentive to these campaigns and likely be stimulated to take action by them once they or a loved one received a diagnosis of a serious illness.
❖ Some participants had **a priori negative motivational attitudes towards what they frame as “advertising**”, “*trying to sell me something*”; when campaign materials were perceived as such they were met with resistance by them.
❖ Various participants also said they would be more inclined to engage with the campaigns if presented to them in a **social, more conversational, setting** such as an information night at a local service centre or women’s group, amongst others because of **the social connection** these moments offer as well as a preference to **hear information directly from persons with personal experience**.
❖ Another element that would make some of the participants engage more with the materials is based on **trust derived from clearly seeing the initiating source of the campaign**, with two participants favouring government-led initiatives.</td></tr>
<tr><td>Material specific</td><td>➢ **Radio spots (C1)**
- Across focus groups participants mainly stated (or agreed with others) they would **not (actively) listen to the radio spots** because they never listen to radio and definitely not commercials, or, radio serves as background sound to them and the campaign spot would most likely not be noticed.
- The few participants that stated they would pay attention to it would do this because of the **appealing, recognizable** sounds, or, identifying as a patient with the persons described in the messages (one person).
➢ **Posters (C1 & C3)**
- Participants differ greatly in typical level of attention directed towards posters in the street scene. While **most tend to quickly glance at posters, others claim they seldom or never notice them**. Some of the</td></tr>
</table>

elderly participants for instance said they prioritize focusing all their attention on navigating through traffic. Only a few individuals asserted that they consistently pay attention to posters, for instance to stay informed about upcoming cultural events. Posters at public transportation stops had the highest chance to be read.

- The posters of the two campaigns (C1&C3) differed in the way they would hypothetically draw attention and appeal to people within the street scene:
    - ▪ The C3 posters were found by many participants to be powerful posters that would draw attention for one of several mentioned reasons: the view that the **portrayed persons do not look sick and this surprises**, the **confronting, triggering slogan** (even though frequently not understood-see ‘comprehension’) and the fact that the portrayed persons are looking straight in the camera, creating **a feeling of connection and being directly addressed** (“*They are really speaking to you*”). Conversely, other participants said that they wouldn’t engage with the posters or not be impacted by them during their daily routine, because the images were considered too dark (“*reminding of memorial cards*”, “*do not appeal on a rainy, grey day*”), **not identifying with the portrayed persons** (stated by younger participants), rather **avoiding emotionally heavy subjects**, and immediate **disengagement after reading the slogan** judged as too negative.
    - ▪ Across focus groups, most participants stated they would not be drawn to the C1 posters, mainly because the posters were judged as **superficial** (“saying very little”), the images of a dog, child, and feet in a bathtub were found to be **not personally appealing and/or interpreted as being commercials for other subjects** than palliative care. Conversely, a few people were very much appealed by (some of) the images, for instance because they considered themselves “dog lovers” or just because of the fact that it are **not images you typically associate with palliative care** and for this reason it intrigues and would draw their attention.

➢ **Information folders/flyers (C1 & C2)**

- While some participants expressed a general aversion to flyers or folders, irrespective of layout or topic, others were disinterested either because the topic did not personally concern them at this point in their lives or the specific layout failed to appeal to them.
    - ▪ C2 flyer: not many participants indicated they would spontaneously pick up this flyer, mostly due to its **unappealing lay-out or perceived lack of personal relevance**. One participant mentioned being attracted to the "meta-image" of a person holding a painting of themselves, finding it interesting and wanting to examine it closely. Two other participants stated that the back of the flyer was more appealing to them than the front, and if seen first, they might consider picking it up.
    - ▪ Several participants stated they would **not pick up the C1 information folder**, because they would not notice it, the unappealing image of the dog, the idea that it is trying to sell something or not at all feeling personally addressed by the image and/or by the written information.
- The **context** in which the flyer or information folder would be offered also plays a crucial role in determining whether they would be noticed and read. While participants suggested to also offer flyers within **public contexts** such as libraries and cultural centres (see more under ‘discrimination’), these particular materials were predominantly perceived as **unsuitable** for such locations. Instead they were deemed

	more fitting for **medical settings**, such as the waiting room of the family physician, where, according to several participants, they would most likely or surely be read. Both materials were suggested to work best if given directly by the physician when a diagnosis of serious illness had been given. ➢ **Videos (C2)** - The short videos, in general, across focus groups, were appealing and would **capture the attention** of many participants. Participants mentioned the following reasons why they would actively watch them: the mere fact that something like this would be shown on television, the **personal perspective** that stands central, the triggering message at the beginning '*When you are no longer getting better*', identifying with the protagonists, the emotional nature of it "*It plays on your emotions, you really feel it*", the dramatic effect created by the music, and other technical-aesthetic aspects such as use of light in the videos. - Nonetheless, some participants also stated they would **not pay attention to it** ("*I would go get me a sandwich*"). Expressed reasons being: not identifying with the protagonists, it not appealing to them because its does not concern them personally, its message being too vague, being saturated with the typical format of a personal story with dramatic background music, already seeing enough misery every day and not wanting to see more, it being shown as one of the commercials between programmes (contrasting with other participants who said this should be repeatedly shown on television between breaks or as a public service announcement-see 'discrimination').
COMPREHENSION ***Comprehension is understood as a decoding continuum from complete divergence from to complete correspondence to the readings produced by other recipients (focus group participants, as well as researchers' readings of the materials). Is also looked at in relation to prior perceptions of palliative care.***	
General	- Participants at times **struggled to understand what the campaigns were trying to achieve and who exactly they were trying to reach**. - There was a general **discrepancy between participants who did not understand the campaigns because the images or sounds were too far removed from their interpretations of what palliative care is; and participants for whom these likewise as non-typical experienced elements, were nonetheless interpreted as being a part of palliative care and were thus effective in changing their image of palliative care** (for instance, not knowing beforehand that palliative care can also be offered at home) and/or persons that need palliative care (for instance, not necessarily being bedridden). The former 'group' often expressed a preference for more images that they considered as typical, such as "*a hospital bed on the palliative care unit*" or "*a person without hair because of the chemo",* to enable them to immediately understand the campaign subject and message.
Campaign and material specific	**C1** - Two participants commented on the campaign as a whole with one of them understanding it as informing about available support for seriously ill persons and their loved ones, and the other one as showing that palliative care can still sheer people up a bit. All other readings were connected to particular materials. ➢ **Radio spots**

	- For some the radio spots were **too abstract or too rushed** to understand what it was about. Some participants were also confused by the question '*Do you have another image of palliative care?'*. - For other participants the radio spots were very clear, but interpretations were quite diverging. Some of the participants interpreted the message as follows: that seriously ill persons are still able to **enjoy "*small joys*" in life,** indicated by the concrete sounds of for instance, a door bell, someone eating a sandwich or the laughter of a child. One of these participants then concluded that palliative care can also be something positive, which was a new insight for her. Another person understood the main message as: "D*espite my illness, I matter to people and society, and palliative care helps them with this*". However, other participants read the message in a more negative manner: "*it gives me again the image of palliative care as care for the seriously ill, death rattling [reutelende] patient*". In general, interpretations seemed to **emphasize the end of life**, regardless of being viewed negatively or positively, focusing on how persons want to spend their last days: "*in her garden, hearing bird sounds, while palliative care perhaps provided her a customized chair to enable this"*. ➢ **Posters** - The C1 posters were generally **unclear for most** participants across focus groups. If seen as the first material in the focus groups or when participants imagined seeing them in the streets, all three posters were interpreted as being **commercials for other things than palliative care**, such as day care facilities (image of the child), bath products (image of the feet popping out of the bath tub) or dog food or an animal asylum (image of the dog). Also the sentence 'because of palliative care, he/she can enjoy this, despite his/her illness' was sometimes met with confusion: "*why she enjoys her grandchild because of palliative care*?". Only some participants found the posters clear and interpreted its message as 'keeping comfort as high as possible', 'serious illness aftercare such as massages' or, rather uniquely, 'reflecting the awareness of imminent death of a grandmother while she watches her creative granddaughter'. ➢ **Information folders** - Just as with the posters, the front cover of the C1 flyer (portraying a dog) was generally met with **confusion**, connecting it rather to information about an animal asylum or dog hotel. Some participants also interpreted it as the dog being seriously ill and needing care. The inside of the brochure was often only rapidly glanced at (time was provided to look at the flyers, and read if wanted, but without the explicit instruction to carefully read all the information) or selectively read. The message that palliative care can be offered early in the illness trajectory stood out for some participants for whom this was also new information, a new insight provided by the folder. One participants found the information unclear because it was to general and not concrete enough. **C2** - The C2 campaign was often interpreted as a whole but with **more emphasis on the videos**. There were three recurrent readings: 1) showing that seriously ill persons can still do things and maintain control over their lives, 2) the value of discussing end-of-life matters and preferences, 3) emphasizing that seriously ill persons are not alone, still belong and palliative care is there for them and their loves ones. Some participants stated **this campaign had profoundly**

changed their prior perspectives. Firstly, on seriously ill persons: "*they are not just laying in bed crying each day and still make something beautiful from life*". Another new insight was that self-determination is also important in palliative care and palliative care is not just care directed at "*prolonging life because they are against euthanasia*". Additionally, one participant gained clarity that the peer support groups he organizes for seriously ill individuals—focused on what people can do rather than what they can't—are also a form of palliative care.

- The specific illness conditions were for some participant a source of confusion, especially COPD and to a lesser extent ALS. One person found it rather puzzling who the target group of palliative care is because of the very specific illnesses shown in the campaign. Several participants asked others what COPD is and sometimes it was then explained as a "*smoking disease*".

- **C2 videos**
  - A number of participants (in two out of ten focus groups) found the **essence of the films unclear**, mainly because the role and possibilities of palliative care remained too vague: "*sure, nice film and too bad for her but…what is palliative care? What can they do for me? What can I do? You don't hear about that*", or because the persons did not look sick enough to connect it to palliative care. Related to this, once person said she realized too late its about palliative care and because of that she felt she had missed the essence of the video. Additionally, Michiel's speech was hard to understand for some, making it also more difficult to understand its message.
  - Most participants however found the videos **very clear** and different readings were provided for each video. Many participants read the main message of Jolanda's story to be about self determination and taking control of your own life and care. One participant commented that seeing Jolanda 'swollen face' frightened him for all the suffering she will still have to endure on which two other persons countered that the emphasis was rather on Jolanda, depicted with nice clothes and makeup on, **being still actively engaged in life despite being seriously ill.** This latter reading was a recurring one across focus groups. The readings of Michiel's story varied more but what was mostly picked up was that palliative care offers mental support for him and his family, with some specifying around worries Michiel has about what will happen with his beloves ones after his death and making sure all necessary arrangements are made. One person also stated Michiel's story **effectively broadens his image of palliative care as being more than pain control at the end of life** since he is still active and explicitly states in the movie that he contacted palliative care as soon as he got the diagnosis.
  - After seeing both videos, people interpreted the videos as: showing that palliative care is individually adapted care that extends beyond medical care, that everyone can benefit from palliative care, that palliative care will help you if you need it and you won't be on your own and that seriously ill persons can still do things. Two rather unique interpretations were that the videos show how palliative care also involves a creative connection between caregiver and care recipient, and, that it are videos from insurance companies that offer palliative care to seriously ill persons, who are shown in the video denouncing a lack of proper care.
- **C2 flyers**

The C2-flyers were often showed after the C2 videos and interpretations were then often directed at the campaign in a whole and not only the flyer. It was also commented on that **the flyers by themselves would not work** and you need the videos to understand them. Some participants did however comment specifically on how they understood the main message of the flyer and these readings centred around '*taking the step to talk about your condition and the end of life with your surroundings'*. For two persons it wasn't really clear and at first sight they would think its something about a painting course.

C3

- **Posters**
    - The C3 posters were **unclear for many** participants across focus groups, with the greatest **source of confusion being the slogan**. The Dutch word "uitbehandeld" (closest literal meaning is 'treatment exhausted'), preceded by the negation 'not' was for many **difficult to interpret and to connect to palliative care**: "*it's about palliative care, but what about this 'uitbehandeld'? It's like they won't do nothing no more and the seriously ill persons will just need to live with it*", "*even though I understand that palliative care is more than just the last phase of life, I don't understand how this matches up with this slogan*". In the discussion it then often became clear that people understood 'uitbehandeld' in a purely medical sense, involving curative treatments. Aside the slogan, also the **intention, the aim of these posters and who they were directed at was found to be unclear** for some, while for others it was clear they were trying to reach people who might benefit from palliative care, or to the whole population so that as many people as possible can pass on the information to whomever might need it. Two persons also did not understood the bottom text as the (informational) website.
    - On the other hand, for several other participants the C3 posters were **immediately clear.** Among those the dominant reading was 'people might be incurably ill, they still need treatment and care, and palliative care gives this to them'. Other people placed **less emphasis on palliative care within their reading and more on the persons themselves** who were expressing that they could still do things, and still make something of their lives, despite their illness. A couple of participants discerned **several layers of meaning** within the posters, including the above ones and saw them as an attempt to **destigmatize seriously ill persons** by portraying them as people that don't look seriously ill and can still do things. There were also more divergent readings. Two participants interpreted the posters as showing seriously ill persons who were not receiving the care they should rightfully receive, resulting in feelings of anger for one and feelings of sadness for the other. A third participant interpreted the posters as patients who were demanding care from their doctors, even though there was really nothing else they could do and the persons should just accept their condition. A fourth person was not sure but guessed that they were searching study participants.

POSITION

Continuum of attitudinal responses, from acceptance to rejection of the perceived textual position and the various textual elements perceived to make up that position. Involves not the acceptance of intended message but the readers agreement of what he or she perceives to be the message of the text.

General	- Attitudinal responses towards public campaigns on palliative care in general varied between and within focus groups. While many participants had positive attitudes, others were more negative or sceptical. - Positive attitudes were centred around finding it **positive that the campaigns broadens the public perceptions of palliative** care away from purely ‘end-of-life care’, offering hope on still having a good life even when seriously ill. Additionally, people found it very **important to bring themes such as serious illness and the end of life into broader society**, going against the ‘not my concern’-mentality and outside of the private sphere of the family and/or hospital. - Several participants also positively valued the inclusion of **diverse age groups** in all three campaigns. Yet, many of the elderly participants explicitly appreciated that “*none of them are really old*”. - **Negative attitudes** were twofold: **1) in relation to the target audience and its effectivity and 2) doubting the veracity**. 1) Participants, mostly those without personal experience regardless of age, often reacted dismissive towards the fact that these campaigns are directed at the general public: "*I personally don't have much to do with that, being not sick myself, not knowing someone who is sick. That may be selfish, but I can't do much with that message. And then I think: the only thing that can happen is that I feel bad for those people"*. The **effectiveness of targeting the general public was doubted**, and for some, it was considered a waste of money, suggesting that resources would be much better spent going to the people who actually need palliative care or are responsible for delivering it. In connection with this, participants of all ages often pointed out their belief that it is primarily the responsibility of doctors to inform patients about palliative care, especially in advanced stages of illness. Therefore, campaigns **should primarily be directed at healthcare providers**. However, other participants debated this and, speaking mostly from personal experience, emphasized **the importance of empowering citizens and patients themselves**, rather than blindly relying on healthcare providers to provide information. 2) Several participants received the campaigns with scepticism, **not believing that what is shown and promised in the campaigns**: - is what most seriously ill persons actually experience; “*they only show the nice stories*” - is actually possible within our current health care system; “*the problem is you call and then you hear ‘ah we’ll put you on a waiting list’ and then your whole world falls apart again*” - or only available for affluent people; "*They come with a beautiful poster, but then I'm going to dig a bit, and what will I find? That's actually an empty box. If you're rich and using your own money, you can pay for palliative care. But if you're not wealthy, there will be fundamental obstacles. And then it becomes like a hollow slogan... Well, like a hollow campaign... That is my fear*". Many of those people were speaking from their own (negative) personal experiences with the health care system, such as long waiting lists and having to find out everything yourself. - Across focus groups, the **Dutch campaigns (C2 and C3) were received much more positively than the Flemish C1 campaign**, although some participants expressed a preference for specific C1 materials (mainly radio spot or information folder – never the posters) over all others, finding them more effective, informative or appealing. These participants were

	often persons who found the focus on individual persons within the Dutch campaigns confusing and/or limited, as it did not provide enough factual information on palliative care for them, or, too confronting and instead preferring the softer, "*less heavy and more inviting*" approach of the C1 campaign. - Preferences between the two Dutch campaigns were less outspoken, but some stated they preferred C2 in comparison to C3 because it offered a more complete picture of palliative care (through the perspective of the seriously ill person). Others preferred the C3 posters over all other materials because they were found to be the most powerful to reach the broad population, or in the words of one of the participants, "*to wake up as many people as possible"*. - The strongest reactions, most emotional also, were evoked by the C2 videos (positive) and the C1 posters (negative).
Campaign and material specific	**C1** - The C1 campaign as a whole was generally not well-received, although reactions to particular materials were more varied. Only a minority of participants had positive reactions towards the whole campaign. One person for instance found the campaign's approach and slogan "care and so much more" **inviting**, another person liked the overall **positive focus on 'enjoyment'** and showing it isn't *"all about hardship and misery*", and another found it a good campaign because it was **informative** enough. - However, **many readings of the campaign were met with rejection** of participants. To begin with the **focus on "enjoyment" was found to be unrealistic, limiting and condescending**. Participants felt it was painting an untruthful, "*velvet glove*" picture of palliative care, demonstrating "*a lack of courage*" to name things as they are. Additionally, also the choice of objects and sounds caused rejection, often framed as being **'banal'**, and "*why would I need palliative care for that?"*. One participant expressed this recurring sentiment when summarizing the campaigns' message as: "*'Yes, you can still do the bare minimum, but you can't do it alone, you need care for it.' I find this a very strange message to send to people who need care, and I think it also creates a very high barrier because you are telling them 'okay I have to be really low and deep, and then I'll get care.' Whereas I think that's a very wrong and even **further stigmatizing image***." - Several participants also commented on the absence of (the voice of) the persons with serious illness themselves: "*On the one hand, it's about making palliative care discussable, yet on the other hand, it's a advertising campaign with **a concept marked by shame**. By not addressing it after all. We are now going to let people get the idea of what it's about, but we are nonetheless not going to show anyone who is ill*". For still others it wasn't the absence but rather the **passive, victimized representation of seriously ill persons** that was rejected. The emphasis within this campaign was found to be on serious illness, rather than on the agency of the person and what he or she still wants or does, summarized by participants as: "*poor thing [ocharme], you're written off, you don't belong anymore…but we'll still give you something*". Related to this, also the 'despite her illness', was met with resistance. - One participant also reacted specifically to the reference to grandchildren in the campaign, finding it distressing for those without grandchildren *"who not only have to cope with the news of their illness but then also with the reminder of this additional absence"*. ➢ **Radio spots** - Most negative attitudes towards the radio spots were also present with regards to the other materials (and thus discussed above and not

repeated here: rejection of focus on enjoyment, banality of 'objects of enjoyment', stigmatising representation, etc).

- Other attitudinal responses, uniquely tied to the radio spots, involved the question asked at the end of the radio spot 'do you have another image of palliative care? Go to ...': while several participants thought this was a **strong and triggering ending, effectively making them think longer about the message, for just as many other participants its was evaluated as condescending, passive-aggressive or unclear**.
- Other criticisms of the radio spots were that they were too long, experiencing the radio voice listing things as very impersonal and unappealing sounds that are too distant from palliative care and thus uninformative. Regarding the latter, amidst negative reactions, two participants expressed a positive reaction to one specific sound -the doorbell- (which they associated with the arrival of friends), while disliking all other sounds.
- Several participants particularly liked the radio spots because of the *"recognizable, cheerful sounds", "the warm voice",* finding it **positive** that *"it offers tools to help other people",* not making recipients feel powerless, that it pulls palliative care out of the hospital spheres, *and,* a (rather divergent) positive reading that the radio spot shows that people still matter to others, even though they are seriously ill.

➢ **Posters**

- Of all generally not well-received C1 materials, the **posters were rejected the most**. Those who expressed positive sentiments toward the posters often appreciated the departure from typical images associated with palliative care or that it gives a more positive outlook on palliative care. Most other participants however rejected the "*strange", "superficial*" or "*unclear*" message and the random, banal images (the posters with the dog and the bathtub received the most negative comments). Additionally, two participants from different focus groups expressed **a feeling of being deceived**, being "*lured in with a beautiful image*". The posters were also considered as **not credible**: "*they have tried to make it personal but I believe even less that those are really Nadia's toes*".
- While disliking the posters in general, the phrase 'palliative care improves quality of life of the patient and their surroundings', was found valuable by one of the participants.

➢ **Information folders**

- While the front cover was generally dismissed across focus groups, the overall inside content was often thought to be **informative and valuable**. However, some participants reacted with **scepticism** to it: finding the phrase 'the person stands central, not the illness' not realistic, not believing that everything that is promised in the flyer is possible in our healthcare system, or being sceptical about the possibility to organize palliative care at home. Others thought it lacked "*the warmth of palliative care*", as well as more concrete information on financial aspects "*how much will it cost me*". The folders were also considered ***"too intellectual"*** to reach the people who might need it the most and the phrase 'palliative care is more than just care' was considered nonsensical.

C2

- The C2 campaign in general was received very positive in all focus groups, except two where reactions were more mixed. One aspect that was repeatedly praised was that **persons with serious illness were shown in their strength and the information really comes from them**. The double

focus on self determination as well as care was thought to be a strength of the campaign.
  - A number of participants did not find it credible though, asserting that it **portrayed a more idealized image than the reality experienced by the majority** of individuals dealing with serious illness.
  - The videos elicited more, and also stronger, attitudinal reactions than the flyers.

- **Videos**
  - The videos were generally seen as **clear, touching and beautiful**, offering a great way to inform people about palliative care. Particularly liked was that the perspective of the **person with serious illness stood central** and that they were portrayed in an **active and resilient** way, still wanting things from life and making something beautiful of it. Only two persons explicitly stated they did not really want to know about any of these persons' personal lives but instead would be interested to hear more about the illness or palliative care itself.
  - Participants often had **different reactions** to the video featuring Michiel compared to the one featuring Jolanda. The video of Jolanda (containing the message of self-determination, taking control of your life) was most picked up and appealing to participants. In Michiel's video it was mainly the emphasis on his family life and mental support which was positively received. Michiel's video was evaluated as harder, less uplifting than Jolanda's, which made it less appealing to some. However, it was also considered more informative about what palliative care entails, making it the preferred choice for others. Nevertheless, it was consistently noted as **positive that the campaign included distinct stories with different emphases**.
  - Most participants also found it **credible and positive** that Jolanda and Michiel were **not bedridden** and did not look severely ill, for some effectively changing their image of palliative care. For others, this made it less credible. In one focus group for instance, a person preferred to see someone in a hospital bed or in a wheel chair when its about palliative care which was countered by the other participants who asserted that is exactly what they don't want to see.
  - Participants also reacted positively to the **creative aspect of painting** portraits, for some because they are personally interested in visual arts, for others because it showed the creative potential of the persons with serious illness as well as, for one person, the creative connection between caregiver and care recipient.
  - The videos also **elicited anger** from some persons. For one person this came from within his interpretation that the protagonists were denouncing a lack of proper care, agreeing with their stance. Another person's anger was connected to perceiving it as a deceptive commercial, and for another to not wanting to see content that was thought to be personally irrelevant: "*it's just another one of many; it has nothing to do with me*." A fourth person reacted angrily from within a very negative view on COPD, stating amongst others that it was her own fault (Jolanda). Finally, one person reacted with a mixture of sadness and anger, drawing parallels with his own experience as a seriously ill patient and deeming it unfair that he was not receiving this type of care.

- **Flyers**
  - The flyers were mostly received positive, although also evaluated as less appealing (mainly the front cover) and more passive than the videos. Particularly liked were that the written text was informative, accessible, positive and "*offering* ***humane advice instead of a dry enumeration of services***". Specific messages that were positively highlighted by participants include the importance of talking about the end of life, the

	emphasis on quality of life over the end of life, the focus on doing what still matters to the individual and that it also is about his or her loved ones. **C3** - The attitudinal responses to the C3 posters varied strongly both within and between focus groups, **ranging from immediate enthusiasm to more pronounced reservations**. The slogan, in particular, evoked opposing reactions. While it resonated strongly with some, serving as a triggering message that "*hits the nail on the head*", others disliked it because they found it challenging to interpret and/or too negative or too heavy [heftig]. - Many participants considered it **credible and positive that the portrayed individuals did not look very sick**. It was believed to convey a strong message that such conditions can affect anyone and contribute to destigmatizing people with incurable illnesses. However, some participants found specific portraits (such as Mike) less credible. - Additionally, the age range (38-75) was positively evaluated by several participants, for older participants specifically that "*none of them are really old*", and thus **changing the stereotypical image of palliative care.** However, two younger participants (19 and 21) remarked that younger age groups were still lacking and the portraits actually fortified the image that palliative care is mainly for older people (relating to the dimension of comprehension). - The posters also **triggered various emotional reactions** among participants: for one it was gratitude for being healthy, for two others pity and compassion [medeleven/medelijden] and a connected feeling of powerlessness, not knowing what they could possible do to help (general message of poster unclear for both participants). - Some portraits tended to evoke stronger (positive) reactions, mainly Chrisje and Renee.
DISCRIMINATION ***Departs from the audience's awareness of the constructed nature of campaign materials and their critical engagements with the way the messages are produced. Involves also ideas and reflections on future campaigns on palliative care.***	
General: reflections on future campaigns	Across focus groups, participants put forth various ideas regarding the development and dissemination of future campaign materials: - Many participants spontaneously suggested that sensibilization around palliative care should also target **schools and younger populations,** although a couple of participants opiniated that children and young people should not yet have to dwell on these topics. - Related to this, some participants viewed public communication campaigns on palliative care as positive, but emphasized the importance of **not insisting or pressuring individuals for whom it is not personally relevant**. Some participants also felt its important to be clear on the intention and target audience behind the campaign. - At the end of the focus groups several persons expressed the value of the full focus group conversation (and not only the campaign materials) for having now a different view of palliative care, underscoring **the importance of having meaningful dialogues in shaping their understanding of the subject**. A recurrent suggestion therefore centred around organizing '**conversations moments'** for instance in social service centres, mosques, neighbourhood health centres, women's groups or cultural centres. In addition, these events serve as platforms for

social connections and the sharing of experiences, which adds to their appeal (see ‘motivation’).
- Related, several participants preferred **hearing stories directly from people with lived experience**, being most ‘affected’ by hearing these personal stories. For instance, at the end of one of the focus groups, one participant commented that the story shared by another participant had significantly broadened her perspective and instilled a sense of hope, surpassing the impact of any materials presented.
- Aside distributing campaign materials in waiting areas of healthcare practitioners and health insurance funds, it was also deemed important to **disseminate materials in public, non-medical locations** with suggestions spanning from cultural centres and libraries to hair dressers and bakeries. However, materials and messages should be customized to suit these diverse contexts as the information folder and flyer presented in the focus groups were frequently deemed unsuitable for non-medical settings.
- A **broader framework** to launch the campaign in was considered important. For instance, organizing a Week of Palliative Care and ensuring simultaneous coverage in newspapers and talk shows to enhance awareness and impact.
- Opinions varied regarding the **general tone** of the campaign. While some participants emphasized the importance of **keeping it positive, light, and cheerful, others preferred a more direct and confrontational approach**. There were also differing views on the most effective way to engage people without personal experience: some believed that short campaigns with a strong slogan (such as C3) would work best, while others argued that this approach would have minimal impact, and a more informational strategy would be more effective.
- Some participants, particularly dealing with serious illness themselves, pointed out that the discussed campaigns could be improved by providing **more information on where and how to seek support, along with financial details** to estimate the affordability of palliative care.
- Participants observed that **all campaigns relied heavily on digital skills** of people and it was deemed crucial to not only provide a website but also **phone numbers and concrete settings** where people could go to for more information. Related, disseminating campaign messages through social media was advised by some participants, but the idea was not widely endorsed or actively put forward.
- The suggestion was also made to introduce palliative care as a **theme in fictional programs**.

Key messages that resonated most with participants and that they would prioritize in future public campaigns on palliative care were:

- **That palliative care also supports friends and family of patients** and can help them to support their loved ones who are dealing with serious illness, the end of life and/or bereavement.
- That despite serious illness, you can **still have a good life and you are not written off** from society.
- That palliative care is for every one and **not only about the end of life.** Palliative care can already help much earlier.

Reflections and comments of participants relating to visual objects/subjects they would place central in campaign materials:

- **Persons with serious illness** should stand central for many participants and, importantly, shown in an **active, empowering manner** and not as victims or people to feel pity for. Hearing about palliative care through their perspective was thought to be much more appealing than a dry

	explanation on palliative care, and to stimulate more the further sharing of information. Portrayed persons should also **represent different age groups.** However, during the focus groups, the absence of "*very old*" individuals was often viewed as positive (by the elderly participants) and there was also some hesitancy regarding the portrayal of seriously ill young children. To **create personal connection between the audience and the depicted persons**, subtle elements could be added that connect to their home (the C3 poster of Chrisje for instance was thought to be particularly powerful because it was the only one that showed a closet on the background, creating a more personal, direct appeal). One participant remarked though that showing 'a veranda' (such as in the C2 flyers) might appeal to a middle class audience but not broader. - The **social context surrounding the person with serious illness**: a recurring remark made by various participants across focus groups was that they wanted to see social connections visualized in the campaign: "*There is a pattern in all three campaigns that it is very individualistically designed. So here again, this man [Michiel] talks about still spending time with his wife and children. But they don't show them and there is not really a moment of viewing a more social context*". It was thought important to really **visualize that palliative care is also about them** and different suggestions were given to for instance show how friends and neighbours support each other, how palliative care can help to participate in social activities in the neighbourhood and how families differ in dealing with serious illness and the end of life and how palliative care can help with this. Some participants suggested also showing health care practitioners as part of the social connections around the seriously ill individual: "*not with their stethoscope and white coat... But as humans too*". - **Palliative care at home**: many participants were not aware of this possibility and had a perception of palliative care as (end of life) care restricted to hospitals. - Even though for various persons the materials weren't always clear because they did not have the typical images they associated with palliative care or depicted persons did not look very ill, very few actually preferred visualizations of a person confined to a hospital bed, or professional service settings as visual cues to immediately understand the subject of the campaign. For the majority, these images would be met with rejection, reinforcing negative perceptions of palliative care or being too emotionally confronting (triggering fear, or unpleasant memories). - In one focus group, the importance of **religion** when dealing with serious illness and the end of life was brought up and they suggested this would really appeal to them if shown in relation to palliative care.
Campaign & material specific	**C1** ➢ **Radio spots** - Most participants considered radio spots too fast and too fleeting for this type of message. - A couple of participants commented on the structure of the radio message (noticing that the sounds serve to trigger attention, etc) and suggestion was given to turn it around and to start with the informational part on palliative and the nuancing examples after. ➢ **Posters** - Participants commented that the posters have too much information on them and priority should be given to the sentences about palliative care. If not, you only read 'Nadia likes bath foam' and most readers at that point disengage. - One participant thought the poster with the girl combined with the C3 slogan and the C1 short sentence on quality of life, would work.

- **Information folders**
  - Several participants stated the information is not accessible to a broad audience: sentences are too long, “*too intellectual*” and more broadly accessible contact information (not only website) is lacking. A suggestion was made to add pictograms as well.
  - The sentence in the middle part ‘the person stands central and not the illness’ was thought to be a much better slogan, and in contradiction with the ‘despite his illness’ that is now on the front cover.
  - Some participants found this type of folded flyer more appealing compared to a one-page (double-sided) flyer.

C2

- **Videos**
  - Although most participants supported the idea of publicly sharing these videos, there were **varying opinions on the method of dissemination**. Some individuals expressed a preference for showcasing them as television commercials or public service announcements during regular programming. Others preferred seeing these videos as a topic on a serious talk show or debate, but not as a television commercial. Conversely, some participants cautioned against associating the content with "*elitist*" programs and instead recommended utilizing channels and programs with the widest audience reach. Some also suggested spreading them on social media.
  - One of the strengths of these videos was considered to be the fact that it entails different stories with different emphases, and this should definitely be kept in future campaigns.
  - Two participants from different focus groups shared the opinion that the videos should delve even further into experienced pain and emotions to get people to engage with the videos, but this viewpoint was not commonly shared.
  - Some participants also commented on the general format of having somebody tell their story with slightly sad music on the background but opinions conflicted in terms of finding this appealing or not:
    “It is mainly a cliché, I think. I think that in the long run it comes down to habituation of such types of message. You can already feel it coming at the first tune or with the choice of colour palette or whatever, and eventually it just passes you by. I don’t know if being completely positive, if that is going to help, I don’t know that either. But I think from the moment you can do something that just steps outside of that cliché, then it's going to stand out much more”.
  - For one participant, seeing somebody talk (Jolanda) worked better than only hearing a voice-over (Michiel).
  - Another person linked the way of lighting and aesthetics in the videos to a constructed message of hope and connection.
- **Flyer**
  - Even though, in terms of aesthetic-technical aspects, the front page lay-out was not generally liked, some participants did like it because it showed personal homes, a layered image of individuals holding a painting of themselves, or was less stylistically clean than some of the other materials. These latter two elements were disliked by others (not strong photographically, pictures too dark, two levels don’t work).
  - Several participants commented on the layout and suggested that it could be improved by reducing the amount of text or guiding the reader to the most important pieces of text through variations in font sizes, etc.
  - Only a website was considered insufficient; a phone number to call for more information should be added.

C3

	➢ **Posters** - Some participants found the website not clearly discernible and the ‘look at the possibilities’ should be highlighted more. - Participants frequently commented on the aesthetic aspects of the posters. Some found them technically excellent, while others considered them too dark. There were also occasional doubts about whether the portraits truly depicted individuals with illnesses. It was generally considered good that the name and age of the person was given and opinions differed whether the illness should also be added. For some, the posters should be made even more personal, for instance by adding more text on what palliative care has meant to the individuals portrayed. - One person suggested this poster would also work well as a flyer with the backside information of the C2 flyer added. - Doubts were articulated about the effectiveness of the slogan and one participant suggested that more people would be triggered to go to the website if the latter part of the slogan, [niet uitbehandeld], was replaced with ‘living with quality’ [kwalitatief leven]. - A suggestion was also made to add **QR codes that link to translations** of the materials.
IMPLEMENTATION ***Involves a focus on the consequences of the ‘textual encounter’ for one’s everyday life. Looks at the relationship between audience readings and (small or big) social and/or behavioural change; for instance, do the campaign materials stimulate participants to start conversations with their loved ones about palliative care or search for more information on palliative care?***	
General: reflections on future campaigns	- In half of the focus groups, participants stated at the end that particular campaigns or materials, the conversations or the focus group as a whole had given them a **broader view of palliative care and/or would keep them more alert, aware of palliative care** in the future. - The most recurring **new insights** being shared were that palliative care is not only limited to the very end and can start early, persons with palliative care needs can still be active and have a good life, and that palliative care can also be offered at home. Other new insights included palliative care as also involving social non-professional support, not being only for older persons, and not being against euthanasia. - Most participants stated that the campaigns would be effective for them to search for more information, if they were being confronted with serious illness themselves or in their environment. However, **when not being personally confronted, participants were a lot more hesitant to state they would act upon the campaigns**.
Campaign and material specific	➢ **C1** - None of the C1 materials seemed to motivate to action. Three participants did say that the radio spots would stimulate them to pass on the information to others who might need it, yet four persons stated that the radio spots would definitely **not stimulate them to search for more information**. - One person even explicitly asserted that the **campaign rather stimulated a rejection of palliative care** and several others indirectly implied it. ➢ **C2** - The videos **did motivate to action** for several participants. One participant, who has a chronic illness and was greatly appealed by Jolanda’s message of self determination and having control, would consider palliative care for herself now, while before she had rather negative views on palliative care. For others, the videos trigger further thought on the subject, among others on what it means to be seriously ill, as well as stimulating further conversations about the videos themselves.

	- Some participants stated that the flyer would be a good accessible option to **facilitate conversations with a physician after a diagnosis** had already been given. One person, with incurable cancer and insufficient psychological support, said that if a phone number was provided, he would definitely call and ask for somebody to come to his home. - Lastly, one participant thought the campaign in general could help patients to get over the potential difficulty of **starting conversations** and asking for help. ➢ **C3** - Three people said the posters would trigger them to **go to the mentioned website** to find out more, because of loved ones who are seriously ill or because the posters are intriguing and you want to find out more.

Appendix 12. Recommendation card (study 5 – Chapter 6)

Tijd voor een nieuw verhaal.

Praten over palliatieve zorg is niet eenvoudig. De redenen? Een gebrek aan kennis, negatieve connotaties en het ontbreken van een gemakkelijk te vertellen en motiverend verhaal rond zorg, waneer genezen niet meer kan.

Het is de hoogste tijd om dat nieuwe verhaal samen te schrijven én te vertellen. In dit document vind je zes - wetenschappelijk onderbouwde - tips waarmee je meteen aan de slag kan.

6 PRAKTISCHE TIPS VOOR EEN EFFECTIEVERE PUBLIEKSCOMMUNICATIE ROND PALLIATIEVE ZORG

1 **Benoem palliatieve zorg, zonder stigma**

- Benoem palliatieve zorg maar leg meteen de focus op het verbreden van interpretaties, o.a. via persoonlijke verhalen die dat breder beeld illustreren.
- Vermijd deterministisch taalgebruik, met name het labellen van personen of levensfases als 'palliatief'.

2 **Benadruk het begin: "Wanneer genezen niet meer kan."**

- Vermijd vage termen of beschrijvingen, zeker wanneer die de (exclusieve) associatie met levenseindezorg kunnen versterken, zoals "zorg in de laatste fase" of "wanneer het einde nadert".
- Benadruk vooral het begin van de zorg aan de hand van concrete voorbeelden.

3 **Representeer personen in actieve posities**

- Actief betekent hierbij: aan het roer, midden in de samenleving, sociale rollen vervullend (in plaats van iemand die passieve ontvanger is van zorg, afgezonderd van de bredere samenleving).
- Zowel in beelden (bijvoorbeeld iemand aan het werk in plaats van in een ziekenhuisbed) als in taal (bijvoorbeeld nadruk op 'versterken' in plaats van 'verzachten').

4 **Betrek vrienden, familie en andere relaties mee in het verhaal**

- De sociale omgeving speelt een belangrijke rol in palliatieve zorg. Praat daarom ook over palliatieve zorg vanuit het perspectief van personen uit de (dichte en verre) sociale omgeving.
- Spreek mensen in de omgeving aan in hun rol van vriend, familielid, collega, ... en vergroot op die manier de persoonlijke relevantie voor een breder publiek.

5 **Vertrek altijd van diversiteit, in al zijn lagen**

- De manier waarop mensen van verschillende leeftijden, culturen en gemeenschappen omgaan met ziekte en verlies verschilt.
- De communicatie over palliatieve zorg toegankelijk en relevant maken voor zoveel mogelijk doelgroepen vraagt erkenning, actieve participatie, variërende strategieën, representatie en het testen van materialen.

6 **Spreek ook over dood en sterven**

- Benoem dood en sterven maar op het juiste moment en altijd binnen het bredere verhaal van palliatieve zorg.
- Heldere communicatie over levenseindepraktijken zoals euthanasie en palliatieve sedatie is belangrijk, aangezien gestigmatiseerde opvattingen over palliatieve zorg hier grotendeels aan gekoppeld zijn.

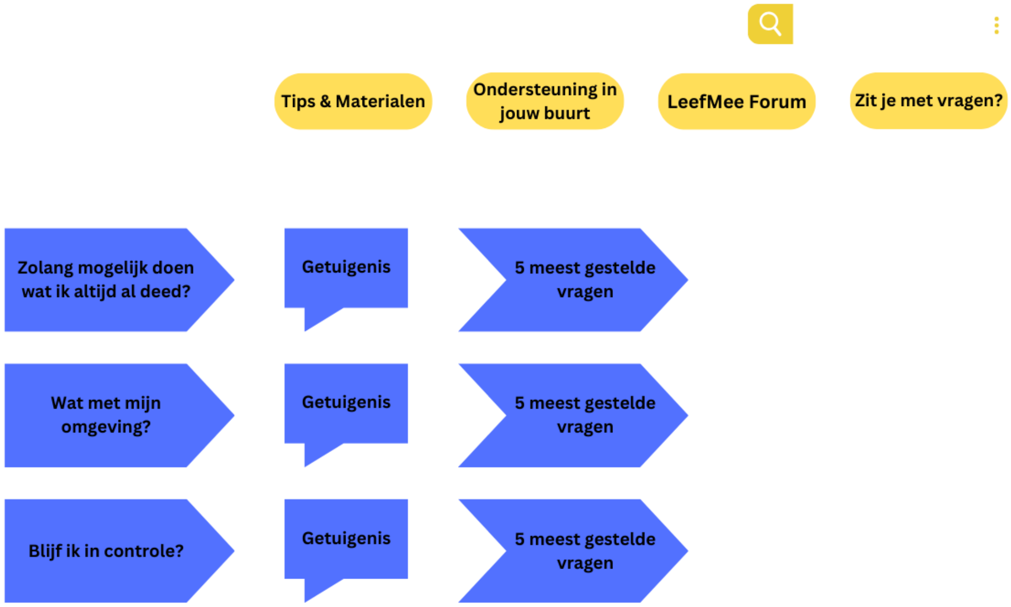
Appendix 13. Wireframe website (study 5 – Chapter 6)

Ik kreeg te horen dat ik niet meer kan genezen

Iemand in mijn omgeving kreeg te horen dat genezen niet meer kan

Ik kreeg te horen dat ik niet meer kan genezen

Iemand in mijn omgeving kreeg te horen dat genezen niet meer kan


Tips & Materialen
Ondersteuning in jouw buurt
LeefMee Forum
Zit je met vragen?
Zolang mogelijk doen wat ik altijd al deed?
Getuigenis
5 meest gestelde vragen
Wat met mijn omgeving?
Getuigenis
5 meest gestelde vragen
Blijf ik in controle?
Getuigenis
5 meest gestelde vragen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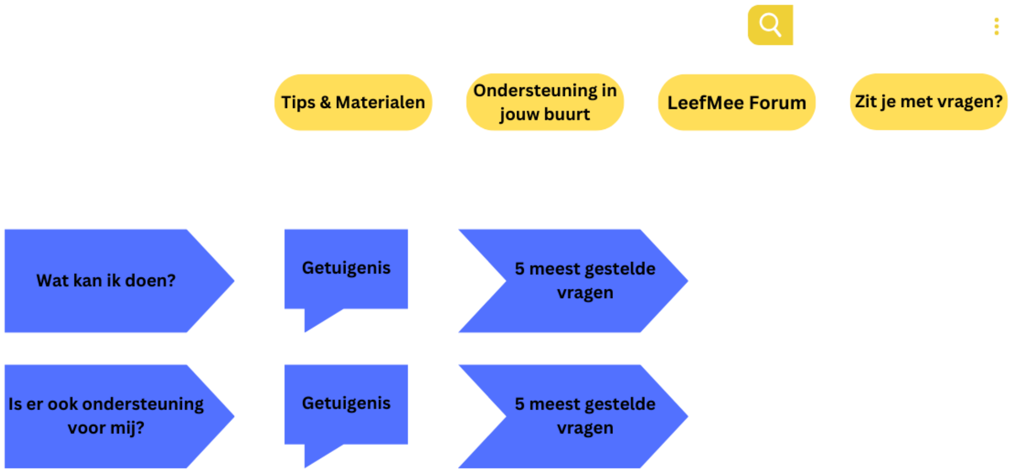
LeefMee Forum
Zit je met vragen?
Ik kreeg te horen dat ik niet meer kan genezen
Iemand in mijn omgeving kreeg te horen dat genezen niet meer kan



Tips & Materialen

Ondersteuning in jouw buurt

LeefMee Forum

Zit je met vragen?

Wat kan ik doen?

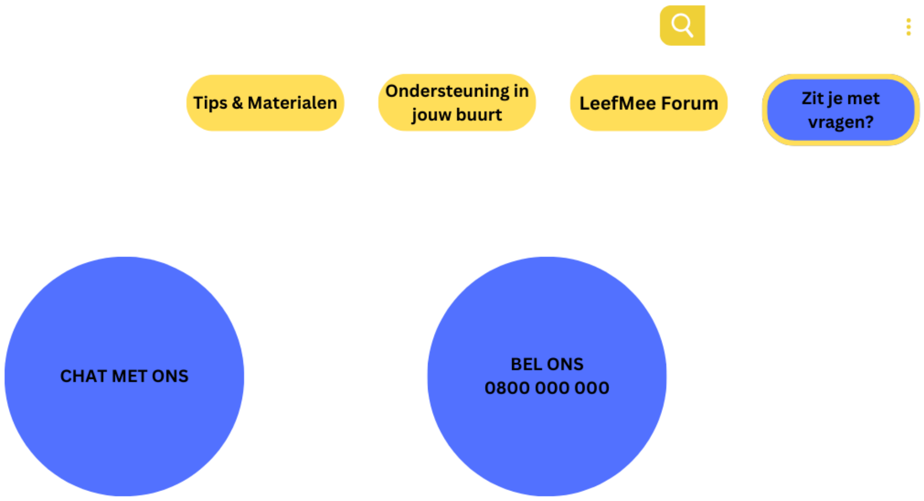
Getuigenis

5 meest gestelde vragen

Is er ook ondersteuning voor mij?

Getuigenis

5 meest gestelde vragen



Tips & Materialen

Ondersteuning in jouw buurt

LeefMee Forum

Zit je met vragen?

CHAT MET ONS

BEL ONS
0800 000 000

Appendix 14. Inspirational information folder (study 5 – Chapter 6)

Doen wat ik graag doe, wat ik altijd al deed. Daar helpt palliatieve zorg mij bij. Nu weet ik waar ik hulp kan vinden als het nodig is, en dat maakt echt een verschil. Soms is een simpel gesprek al voldoende en dan kan ik weer verder, voluit mijn leven leiden.

PALLIATIEVE
ZORG

MEER INFORMATIE :

☎ **0800-000-000**

✉ Info@leefmee.be

LEEFMEE.BE

Blijven wie je bent.

Ook wanneer genezen niet meer kan.

Waar kies je voor?

Zorg, ondersteuning en begeleiding voor jou en je omgeving, op de manier die jij wil.

Toen mijn papa, mijn allereerste superheld, te horen kreeg dat hij niet meer ging genezen stond de wereld even stil. Niemand had op dat moment gedacht dat hij nog jaren ging leven, goed leven bovenal. De ondersteuning die we kregen was zo waardevol. Ook nu nog.

Palliatieve ondersteuning vind je ook bij jou in buurt

Er zijn veel verschillende organisaties, initiatieven en mogelijkheden rond palliatieve zorg. Denk bijvoorbeeld aan een gesprek met een psycholoog, lotgenotengroepen, jouw huisarts, of gespecialiseerde zorgequipes die aan huis komen.

Ontdek het aanbod op LEEFMEE.BE

Tijd & Kwaliteit

Palliatieve zorg begint meestal wanneer het waarschijnlijker wordt dat genezen niet meer kan. Hoeveel weken, maanden of zelfs jaren je palliatieve zorg krijgt, verschilt van persoon tot persoon. Alles draait in de eerste plaats om het vasthouden van de goede dingen, het maximaliseren van de kwaliteit van jouw leven.

Verbondenheid

Palliatieve zorg gaat ook over verbondenheid met vrienden, familie, zorgverleners en andere mensen in je omgeving. Dezelfde zorg, ondersteuning en begeleiding is er ook voor hun.

In controle

Ondanks de uitdagingen van een ongeneeslijke ziekte, heb je nog steeds de controle over je leven. Palliatieve zorg versterkt jou daarin. Jouw wensen, de dingen die voor jou belangrijk zijn, staan centraal.

Appendix 15. Prototype posters (study 5 – Chapter 6)

BLIJVEN WIE JE BENT

OOK WANNEER GENEZEN NIET MEER KAN

ALLES OVER PALLIATIEVE ZORG

VIND JE OP LEEFMEE.BE

OF BEL ONS OP 0800 000 00

DE BESTE VRIENDEN

OOK WANNEER GENEZEN NIET MEER KAN

JE BESTE VRIEND ONDERSTEUNEN?

ALLES OVER PALLIATIEVE ZORG

VIND JE OP LEEFMEE.BE

OF BEL ONS OP 0800 000 00

DE BESTE VRIENDEN.

OOK WANNEER GENEZEN NIET MEER KAN.

JOUW BESTE VRIEND ONDERSTEUNEN?

Alles over palliatieve zorg vind je op LEEFMEE.BE of bel ons op 0800 000 000

JEZELF BLIJVEN.

Ook wanneer genezen niet meer kan.

ALLES OVER PALLIATIEVE ZORG
VIND JE OP **LEEFMEE.BE**
OF BEL ONS OP 0800 000 000

Academic curriculum vitae

1. About the author

Marjolein Matthys, born January 11, 1987, has a Bachelor's degree in Clinical Psychology obtained at the University of Ghent (2008) and Bachelor's and Master's degrees in Cultural and Social Anthropology obtained at the University of Amsterdam (2010 and 2012 respectively, the latter cum laude). In the context of her Master's research, she studied death confrontations as existential-dynamic conflicts in the lives of non-religious adults in the Netherlands. For this work, she was awarded the Annual Thesis Competition Award of the University of Amsterdam, Department of Anthropology. In May 2019, she joined the End-of-Life Care Research Group to work as a doctoral researcher on the CAPACITY consortium project that aimed to develop capacity in palliative care across society. Her project focused on public perceptions surrounding palliative care and the development of a public awareness campaign to promote its benefits in Flanders. After completion of her doctoral studies, Marjolein Matthys will join a FWO project of Prof. dr. Kenneth Chambaere as a postdoctoral researcher. She will conduct ethnographic research to explore the complexities and challenges at the intersection of palliative care and assisted dying within Flemish end-of-life practices. Marjolein's main research interests encompass narrative & discourse theory, anthropology of ethics, existential anthropology, and all aspects of interdisciplinary and qualitative research that contribute to our understanding of the dynamics of meaning-making surrounding the end of life.

2. Research presentations at (inter)national conferences

November, 2020	*'The representation of palliative care by practice, policy and advocacy organizations; definitional variations and discursive tensions'.* Oral presentation given at the seminar "EAPC Public Health Research in Palliative Care: Towards Solutions for Global Challenges", online
April, 2022	*'De online representatie van palliatieve zorg door praktijk-, beleids- en belangenorganisaties: variaties in definities en discursieve spanningen'.* Oral presentation given at the Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg, in Tiel, the Netherlands
September, 2022	*'What does the public know about palliative care? A population-based survey in two urban and two semi-urban cities'.* Oral presentation given at the Public Health Palliative Care International Conference, in Bruges, Belgium

September, 2022	‘*Using a health promotion approach in palliative care research’*. Workshop presented together with Luc Deliens, Anne-Lore Scherrens, Marjolein Matthys, Malin Eneslätt at the Public Health Palliative Care International Conference, in Bruges, Belgium
May, 2023	*‘What does the public know about palliative care? A population-based survey in two urban and two semi-urban cities’*. Oral presentation given at ‘Dag van de Sociologie, in Ghent, Belgium
June, 2023	*‘What does the public know about palliative care? A population-based survey in two urban and two semi-urban cities’*. Oral presentation given at EAPC world congress, in Rotterdam, the Netherlands
November, 2023	‘*Shared meaning across lay people’s personal narratives of serious illness, palliative care, and the end of life*’*. Oral presentation at the 3rd International Research Seminar of the European Association for Palliative Care Reference Group on Public Health and Palliative Care, in Belfast, Northern Ireland *awarded the prize of Best Abstract
May, 2023	*‘Integrating health promotion and palliative care’*. Workshop presented together with Anne-Lore Scherrens & Leen Van Brussel during the International Conference on Integrated Care, in Antwerp, Belgium
October, 2024	*‘Public awareness campaigns on palliative care: applying a multidimensional model to understand the reception by the general public’*. Oral presentation at the 8th Public Health Palliative Care Conference, in Bern, Switzerland

3. List of publications

Published

Matthys, M., Chambaere, K., Beernaert, K., Cohen, J., Van Brussel, L., Deforche, B., Quintiens, B., Deliens, L., Dhollander, N. What does the general public know about palliative care? A population-based survey. *BMJ Supportive & Palliative Care* 2024; 14: 335-344.

Matthys, M., Dhollander, N., Van Brussel, L., Beernaert, K., Deforche, B., Cohen, J., Deliens, L., Chambaere, K. The online representation of palliative care by practice, policy, and advocacy organizations: definitional variations and discursive tensions. *Qualitative Health Research* 2021; 31:2743-2756.

Pivodic, L., Jennings, N., & **Matthys, M**. The problems of using migration background as a conceptual framework in palliative care research. *Palliative Medicine* 2021; 35: 2028–2029.

Matthys, M. *De dood en het goddeloze subject: een antropologisch onderzoek naar doodsconfrontaties als existentieel-dynamisch conflict en de invloed op morele subjectiviteiten in Nederland.* AMB, 2013.

Accepted for publication

Matthys, M., Deforche, B., Deliens, L., Cohen, J., Beernaert, K., Van Brussel, L., Chambaere, K.*, Dhollander, N.*
Public awareness campaigns on palliative care: applying a multidimensional model to understand the reception by the general public.
*both authors contributed equally to this work
- Accepted on the 25th of October to be published in *Qualitative Health Research*

Submitted

Matthys, M., Chambaere, K., Deforche, B., Cohen, J., Deliens, L., Beernaert, K., van Brussel, L., & Dhollander, N.
Patterns of shared meaning across personal narratives surrounding experiences with palliative care, serious illness, and the end of life.
- Currently in review in *Social Science & Medicine*

Being prepared for submission

Matthys, M., Van Brussel, L., Deforche, B., Cohen, J., Beernaert, K., Deliens, L., Chambaere, K.*, Dhollander, N.*
Shifting public perceptions of palliative care: a co-creative design to address unknown, misunderstood and stigmatized aspects.
*both authors contributed equally to this work
- to be submitted to *BMC Palliative Care*