

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 towards campaign messages, while a sense of personal relevance was lacking for others. Campaigns that centred 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 towards 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.

Key words: palliative care, audience reception, public awareness campaigns, destigmatisation, focus groups, qualitative methods

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 (Sleeman et al., 2019). 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 (Clark et al., 2015). 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 (Abel & Kellehear, 2022).

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 (Lynch et al., 2010; Pettus & De Lima, 2020). One of the most persistent perceptions, as shown across studies involving the general public, patients, informal, and formal caregivers (Dionne-Odom et al., 2019; Fliedner et al., 2021; Grant et al., 2021; McIlpatrick et al., 2021; Patel & Lyons, 2020; Zimmermann et al., 2016), 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 (Alcalde & Zimmermann, 2022).

Additionally, palliative care tends to be perceived as something people passively resign to, instead of actively choose (Mallon et al., 2021; Zimmermann et al., 2016). 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 (Collins et al., 2020; Lane et al., 2019), including public awareness campaigns as one promising approach (Seymour, 2018). 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, behavioural change and better outcomes surrounding a particular topic (Masiulienė et al., 2015). On an international scale there has been a wide range of public campaigns on topics surrounding palliative care (Seymour, 2018); 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 (Zimmermann et al., 2021). Furthermore, while education programs for health care providers have proven effective in improving knowledge, attitudes and confidence in palliative care (Li et al., 2021), the limited initiatives directed at the general public remain understudied (Bollig & Heller, 2016; Bollig & Bauer, 2021).

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.

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 presented messages, but as actively engaging and making sense of it from within societal and situational contexts (Schröder, 2018b). Polysemy,

and the broader, related concept of meaning multiplicity, i.e. the phenomenon of a text invoking multiple - at times conflicting - interpretations (Boxman-Shabtai, 2020), 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 (Holloway & Galvin, 2017). As recommended in the literature (MacDougall & Fudge, 2001), 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 (languages mastered by the moderator).

Data collection

Focus groups were held from October through December 2023, mainly in the region of Ghent, Flanders. Two trained, experienced researchers conducted each focus group, with one moderating the discussion and the other primarily focusing on observation. 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 (Greenwood et al., 2014; Hollander, 2004). The focus groups followed a semi-structured format covering a limited number of open-ended questions (see topic guide in the supplementary file, section 1). Data collection and analysis followed an iterative process and, following a pragmatic approach to saturation (Low, 2019), 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 in the supplementary file (sections 2 and 3). 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.



Analytical strategy

Focus groups were audio-recorded, transcribed ad verbatim and analysed with NVivo 14.

Analysis was done by M.M. 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 Schröder (2000) 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 (Almlund et al., 2020). The original model contained an extra dimension ('evaluation') which was later removed (Schröder, 2018a) and, following Schröder'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 supplementary file, section 3). In line with the epistemological groundings of the multidimensional audience reception model (Schröder, 2000), 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 analysed 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 multidimensional audience reception model developed by Schröder.

Multidimensional audience reception model (Schröder, 2000, 2018a, 2018b)	
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 behavioural 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'. 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 for further consideration to the Medical Ethics Committee of Ghent University (Hospital) with the following explanation:

- To improve chances that we do not only reach and include research participants that are highly knowledgeable about palliative care and mainly have positive attitudes towards it, we will introduce the topic of the study (during recruitment and in the information letter) in a general way, i.e. as follows: "examining the different ways in which public communication campaigns about care for serious illness are interpreted and evaluated" (in Dutch: "het onderzoeken van de verschillende manieren waarop deelnemers publieke informatiecampaagnes over zorg bij ernstige ziekte interpreteren en evalueren"). The term "palliative care" will thus be purposively avoided since on the one hand research has shown that significant stigma remains associated with the term "palliative care" and on the other hand since many people have no knowledge about palliative care and are thus not familiar with this term. We believe providing this broad yet clear description improves the chance of inclusivity in our research

while simultaneously not deterring potential participants to make an informed decision about participating in our study or not.

- In general, the risks associated with participation in this study are minimal and based on our experience from previous research around palliative care, we do not expect the focus groups to have a negative impact on participants. However, as the topic of palliative care may be sensitive for some participants, we will take extra care to emphasize the potentially sensitive nature of the subject during recruitment as well as ensure their well-being throughout the study. One of the researchers conducting the focus groups is a licensed grief and loss consultant who can help to safeguard that emotional cues are not missed and reacted to appropriately. We will make sure that the participants know before the start of the focus group that they can stop their participation at any time and that support is available if needed. Should participants appear to experience stress or other negative emotions during the focus group, we will make sure to repeat this message in a discrete (directed to all participants) manner. We will additionally provide contact details of a clinical psychologist (working in the same research group) who the participants can contact after their participation, in case of need.

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; Sim & Waterfield, 2019) so they could consider them before giving consent. All participants provided written informed consent prior to enrolment 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.

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 in the supplementary file (section 4).

Our analysis revealed large differences between campaigns and campaign materials concerning overall appeal, interpretations, attitudinal responses towards 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 – motivation, comprehension, position, discrimination and implementation - described in Table 1. An extensive table with more detailed results can be found in the supplementary file (section 5).

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 towards 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 towards 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 towards 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 towards 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 towards the fact that these campaigns are directed at the general public:

It's not something you should be concerned about if you're 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 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*” (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 is actually an empty box. If you are rich and using your own money, you can pay for palliative care. But if you are 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 oldest 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 centres 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 neighbours supporting each other, how palliative care can help people 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 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 centred around organizing ‘conversations moments’ in social service centres, mosques, neighbourhood health centres, women’s groups or cultural centres. 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 behaviour. For instance, one participant who has a chronic illness and was drawn to one of the protagonists' 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 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.

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 the messages.

Our study also highlights 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 towards 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 towards 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 scepticism and distrust towards 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 organisation 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 towards consensus (Kitzinger, 1994), 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 towards health campaigns (Crossley, 2002; Thompson & Kumar, 2011), and while this was most clearly present within this focus group, it was encountered across focus groups and across participant 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 (Kitzinger, 1994). Ultimately, these findings show that to be effective, public campaigns cannot be seen in isolation from 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 towards 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 (Ylänne, 2015). 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 (Metzger & Braun, 2023). Images shape perceptions of what it means to grow older, and by extension, the treatment older people tend to receive (Featherstone & Hepworth, 2009). 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 (Petty & Cacioppo, 1986) - low levels of motivation, fuelled 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 (Petty & Briñol, 2015).

Stimulating the personal relevance of campaign messages is thus considered an important task within this model (Bartholomew Eldredge et al., 2016). 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 (Mallon et al., 2021).

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 (Galick et al., 2015), 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 (Sood et al., 2017), can be considered. Serendipitous learning from entertainment-oriented sources can effectively serve to change perceived social norms and be a primary form of health information gathering (Dutta-Bergman, 2004). Entertainment-education programs on palliative care can be newly created, such as developing a podcast series that follows a family confronting a serious life-threatening illness. Additionally, educational content on palliative

care can be embedded into existing entertainment programs, such as popular television drama series. In the latter case, it is essential to understand the program's audience and integrate the content organically and authentically, ensuring the educational goal aligns with compelling storytelling, which requires collaboration and complementary expertise (Hursting & Comello, 2021).

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 (Solovei & Van Den Putte, 2020). Campaign-generated interpersonal conversations, for instance fostered through explicit discussion prompts within campaign messages, can broaden the campaign's reach and help achieve the desired outcomes (Jeong & Bae, 2017). For example, palliative care campaign messages can be shared on social media platforms, notably by popular content creators (Kostygina et al., 2020), while encouraging users to share their personal stories. 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 (McLoughlin et al., 2016), 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 (Bartholomew Eldredge et al., 2016). 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 (Thiede, 2005) and community conversations on palliative care can be an approach to simultaneously rebuild trust where it is most eroded.

Moreover, future efforts to broaden public perceptions of palliative care should carefully consider how and when to introduce the term, given the associated stigma, misconceptions, and potential disengagement due to perceived personal irrelevance. Rather than avoiding the term altogether, we recommend being strategic about its use within broader communication efforts. In certain contexts, such as a multimedia campaign specifically aimed at destigmatizing palliative care, it will likely be necessary to clearly communicate the term upfront in order to directly confront misconceptions. In other cases, a more subtle introduction may be more effective. For example, as suggested by Reigada et al. (2019), short film festivals or other art-based public events covering a range of topics related to serious illness can help raise awareness, foster a deeper understanding, and reduce stigmas surrounding palliative care, without necessarily promoting these events explicitly as palliative care-focused.

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 (Featherstone & Hepworth, 2009; Richards et al., 2012), we advise to seek alternatives between polarised 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. Nonetheless, it should be noted that teenagers were not included in the study, and their perspectives could provide additional insights, especially as future caregivers and decision-makers, warranting further research.

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 (Bloch, 1991), 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.

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.

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