



OPEN ACCESS

# Early palliative care perceptions by patients with cancer and primary caregivers: metaphorical language

Elena Bandieri,<sup>1</sup> Sarah Bigi ,<sup>2</sup> Melissa Nava,<sup>2</sup> Eleonora Borelli ,<sup>3</sup> Carlo Adolfo Porro,<sup>4,5</sup> Erio Castellucci,<sup>6</sup> Fabio Efficace ,<sup>7</sup> Eduardo Bruera ,<sup>8</sup> Orefofe Odejide,<sup>9</sup> Camilla Zimmermann ,<sup>10,11</sup> Leonardo Potenza ,<sup>3</sup> Mario Luppi

► Additional supplemental material is published online only. To view, please visit the journal online (<https://doi.org/10.1136/spcare-2024-004842>).

For numbered affiliations see end of article.

## Correspondence to

Dr Sarah Bigi, Department of Linguistic Sciences and Foreign Literatures, Catholic University of the Sacred Heart, Milan 20123, Italy; [sarah.bigi@unicatt.it](mailto:sarah.bigi@unicatt.it)

EB, SB and MN contributed equally.

CZ, LP and ML contributed equally.

Received 22 February 2024

Accepted 29 April 2024



© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

**To cite:** Bandieri E, Bigi S, Nava M, et al. *BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/spcare-2024-004842

## ABSTRACT

**Objective** This article reports on the results of an analysis of metaphorical language used by patients diagnosed with advanced cancer and their caregivers receiving early palliative care (EPC).

**Methods** Data were collected through a pen-and-paper questionnaire on respondents' perceptions of the disease, its treatment and their idea of death, before and after receiving EPC. The data were analysed by identifying all metaphorical uses of language, following the 'metaphor identification procedure' proposed by the Praggljaz Group.

**Results** Metaphors were used from a variety of semantic fields. EPC was described using spiritual terms, to indicate that this approach was instrumental in 'restoring life', 'producing hope' and making patients feel 'accompanied'. The most recurrent metaphors were those referring to light and salvation; spatial metaphors were used to describe the treatment and the hospital as a 'safe haven' and 'an oasis of peace'. Patients and caregivers were overall consistent in the aforementioned ways of referring to illness and treatment; caregivers were more likely than patients to use war metaphors, although their use overall was rare.

**Conclusions** Our results suggest that EPC is perceived positively by patients and their caregivers and provide insights regarding the manner in which EPC could be presented to patients, caregivers and the public.

## INTRODUCTION

Metaphor involves 'talking and, potentially, thinking, about one thing in terms of another, where the two things are different, but some similarities or correspondences can be perceived between them'.<sup>1</sup> Metaphors have important functions as cognitive and communicative

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The use of metaphor in cancer treatment has focused on the use of language by professionals or on descriptions of the disease by patients. Our study is based on data from patients and caregivers undergoing early palliative care, who describe the disease and its treatment.

## WHAT THIS STUDY ADDS

⇒ Patients and caregivers describe early palliative care as a treatment that has 'brought them back to life', 'saved' them, given them 'hope', representing a 'safe place' in the 'storm of illness', accompanied and supported them physically and spiritually, helping them cope with the idea of death.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ These results demonstrate the favourable impact of early palliative care on patients and caregivers and support early referrals to the palliative care team by oncologists. This study also provides insights into the ways in which early palliative care could be presented to patients, caregivers and citizens in public discourse.

tools. The use of metaphor allows for discussion about an incurable disease and the future in a way that may be more acceptable to patients and their families.<sup>2</sup> Hutchings elaborates on this concept and compares the metaphor to a dance of many veils, describing it as follows: 'In language we want to dance with many veils, veils that allow our patients to peek at their prognosis without being blinded. We want to share a truth without the reflection of reality.'<sup>3</sup>

Several studies have investigated the role and usefulness of metaphor in the context

of palliative care, showing how its use may improve communication and understanding of poor prognosis, encouraging new coping strategies.<sup>4</sup> However, these studies have tended to examine metaphor among patients with cancer receiving palliative care near the end of life. The use of metaphor in patients receiving early palliative care (EPC) has not been previously examined.

EPC has been shown to produce several benefits in patients with advanced solid tumour or haematological malignancies.<sup>5</sup> However, patients with a cancer diagnosis and their caregivers often misperceive palliative care as being associated with the end of life.<sup>6</sup> Although there have been qualitative studies describing patients' and caregivers' perceptions of palliative care, most of these have interviewed patients before they received palliative care, or late in the course of illness, rather than while receiving EPC.<sup>7,8</sup>

In this article, we present the results of a qualitative study in which we specifically explored how patients with advanced cancer and their caregivers undergoing EPC treatment use figurative language to describe their past and present clinical story in light of their experience with EPC. Interviews focused on patients' and caregivers' experiences of the disease, and their perceptions of EPC.

## METHODS

We consecutively enrolled patients with advanced cancer who were treated with EPC at the Outpatient Palliative Care Unit, USL Modena, and the Outpatient Palliative Care Unit, Hematology Section, University Hospital of Modena, Italy,<sup>9</sup> between July 2020 and December 2023. Other eligibility criteria included being a patient at the EPC clinic for at least 2 weeks, age  $\geq 18$  years and willingness to complete an interview. Patients were asked to identify one or more primary caregivers, who were then invited to take part in the study (eligibility criteria: age  $\geq 18$  years); if caregivers declined, this did not prevent patient participation. Bereaved caregivers, who are followed up after the passing of the patient and frequently maintain contact with the EPC team thereafter via occasional calls, visits or holiday greetings, were also included, if they were bereaved for at least 2 months before enrolment (to avoid acute grief) and no later than 2 years (to minimise recall bias). All participants provided written informed consent prior to data collection.

Patients completed a self-administered pen-and-paper open-text questionnaire at one point during their appointments at the EPC clinics. Caregivers completed the same questionnaire at home. When both the patient and caregiver(s) participated in the study, their questionnaires were completed within the same month. To reduce the risk of social desirability bias, the questionnaires and collection procedure were anonymised. Participants were asked to report in their own words their perceptions regarding: (1) their

experience with the disease before receiving EPC; (2) their experience with the disease during EPC; and (3) possible changes in the perception and expectations of their future following exposure to EPC, including regarding the end of life. The questionnaire ended with a question regarding their idea of death (list of questions in online supplemental table 1).

Once data collection was completed, each questionnaire was analysed by two investigators (SB and MN), who read it closely to identify figurative language and themes. Differences in coding were resolved by discussion during research meetings. To identify metaphors, we followed the 'metaphor identification procedure' (MIP),<sup>10</sup> according to which words used metaphorically can be marked as such 'if the chosen lexical unit has a more basic contemporary meaning in other contexts than the one in the given context'.<sup>10</sup> Based on MIP, the concept of metaphorical language encompasses a broader spectrum of rhetorical figures than what is referred to in the literature as metaphor. The most common rhetorical devices were then classified<sup>11</sup>: metonymy, which represents the act of referring to something using a word that describes one of its qualities or features; synecdoche, which indicates a word or phrase in which a part is used to refer to the whole (eg, 'a pair of hands' for 'a worker'), or the whole is used to refer to a part (eg, 'the law' for 'a police officer'); personification, which gives human characteristics to inanimate objects or situations; and simile, which establishes an explicit comparison between two things using words such as 'like' or 'as'.

Conventional metaphors can be considered part of everyday language and are generally understood and accepted by members of the same cultural group, to the point of not even being considered as metaphors. Creative metaphors require a communicative effort, such as finding the right words to explain a concept that would otherwise be too complex to understand or describe. While both types of metaphor provide a deeper understanding of a person's perception of some specific experience, creative metaphors that nonetheless have a common cultural component can help each party in the interaction to acquire new knowledge and promote linguistic alignment for more effective communication.

## RESULTS

Of 244 eligible patients, 49 declined to participate because of feeling uncomfortable or not being interested, resulting in a patient response rate of about 80%. Of 221 caregivers identified by patients, 66 declined to participate because of feeling uncomfortable or not being interested, resulting in a caregiver response rate of 70%. This study included 350 participants, of which 195 were patients and 155 were caregivers. The demographics and clinical features of study participants are presented in [table 1](#).

**Table 1** Demographic and clinical/caregiving characteristics of the sample (n=350)

Characteristics	Patients (n= 195)	Caregivers (n= 155)
Age at interview, years		
Mean (SD)	68.8 (10.7)	57.2 (14.1)
Range	35–87	20–87
Sex, n (%)		
Female	89 (45.6)	104 (67.0)
Male	106 (54.3)	51 (32.9)
Education, n (%)		
Primary school	44 (22.6)	14 (9.0)
Secondary school	59 (30.3)	31 (20.0)
College	75 (38.5)	61 (39.4)
Bachelor's/graduate degree	13 (6.7)	41 (26.5)
Missing data	4 (2.1)	8 (5.2)
Ethnicity, n (%)		
Caucasian	184 (94.4)	142 (91.6)
Arab	3 (1.5)	2 (1.3)
African	0 (0)	1 (0.6)
Missing data	8 (4.1)	9 (5.8)
Religion, n (%)		
Christian		
Catholic	148 (75.9)	115 (74.2)
Orthodox	4 (2.1)	3 (1.9)
Evangelical	1 (0.5)	1 (0.6)
Jehovah's Witness	2 (1)	1 (0.6)
Muslim	3 (1.5)	2 (1.3)
Agnostic	31 (15.9)	23 (14.8)
Missing data	6 (3.1)	8 (5.2)
Cancer diagnosis, n (%)		
Solid		126 (81.3)
Head, neck, larynx	8 (4.1)	—
Rectum, sigma	5 (2.6)	—
Colon	22 (11.3)	—
Gastric	23 (11.8)	—
Pancreas	14 (7.2)	—
Breast	31 (15.9)	—
Lung	28 (14.4)	—
Genitourinary (kidney, testis, prostate, ovary)	36 (18.5)	—
Skin	2 (1.0)	—
Sarcoma	5 (2.6)	—
Missing data	3 (9.2)	—
Haematological	18 (1.5)	29 (18.7)
Time since first EPC consult, months		
Mean (SD)	9.5 (12.3)	13.6 (14.2)
Range	0.5–96	0.5–72
KPS score at first EPC consult, median (IQR)		
0–100	60 (50–60)	—
NRS pain score at first EPC consult, median (IQR)		
0–10	7 (6–8)	—
Active CT at first EPC consult, n (%)	143 (73.3)	—

Continued

**Table 1** Continued

Characteristics	Patients (n= 195)	Caregivers (n= 155)
Relationship to patient, n (%)		
Parent	—	1 (0.6)
Spouse/partner	—	71 (45.8)
Daughter/son	—	69 (44.5)
Sister/brother	—	4 (2.6)
Other family	—	5 (3.2)
Missing data	—	5 (3.2)

—, no data; CT, chemotherapy; EPC, early palliative care; KPS, Karnofsky Performance Status; NRS, Numerical Rating Scale.

The results are presented by first discussing the figurative language used by patients, and then the language used by caregivers. Patients and caregivers provided answers to the questionnaires in Italian. The examples in the following sections are presented in English translation, followed by the italicised original in parentheses.

### Patients

#### Light and salvation

Figurative language belonging to the religious conceptual domain mostly fell into the category of conventional metaphors. When describing palliative care treatment, patients often used figures of speech such as 'heaven-sent' (*manna dal cielo*) to describe palliative care and 'angels' (*angeli*) to refer to palliative doctors and nurses. Along these lines, the most common metaphor used to describe palliative care was 'salvation' (*salvezza*). Most patients claimed that they were saved by this type of treatment:

This clinic is our salvation. (*Questo ambulatorio è la nostra salvezza.*) (002-P-011)

A lifesaver. For me it has been salvation from a life-nonlife. (*Un salvavita. Per me una vera salvezza da una vita-non vita.*) (002-P-038)

I was lucky to come here. For me it has been my salvation. (*Per me è stata una fortuna arrivare qua. Per me è stata la mia salvezza.*) (002-P-023)

In addition, palliative care treatment was often associated with the imagery of light. Sometimes, the word itself appeared as metaphor and in other instances, it was implied:

For me it is a light in a dark tunnel. (*Per me sono una luce dentro ad un tunnel buio.*) (002-P-041)

For me it has been a panacea, a light. (*Per me sono state un toccasana, una luce.*) (002-P-107)

Life is splendid and it shines even brighter with this ward. (*La vita è splendida e con questo reparto splende di più.*) (002-P-011)

#### Metaphors using opposites

Another relevant feature of participants' responses was the use of the antithetical structure of give and take or increase and decrease to create a parallel between the

pain that was taken away from them and the quality of life that was given back to them. In these cases, palliative care treatment was represented as an agent performing the action of giving something positive to patients (eg, life, trust, hope). A few examples follow:

As the pain receded, my desire to live became greater and greater. (*Calando il dolore, la voglia di vivere è stata sempre più grossa.*) (002-P-009)

Not only have they taken away the pain, but they gave me trust. (*Non mi hanno solo tolto il dolore, ma mi hanno dato fiducia.*) (002-P-054)

By taking away the pain, they brought me back to life. (*Togliendomi il dolore mi hanno fatto rinascere.*) (002-P-069)

They gave me hope to live. [...] They took away my suffering. (*Mi hanno dato la speranza di vivere [...] Mi hanno tolto la sofferenza.*) (002-P-005)

The most common ‘thing’ that seemed to have been taken away from patients by the illness and given back to them by EPC treatments was dignity. Because of their illness, patients felt as if they were already dead or were not considered as people anymore. Phrases like ‘I was basically nothing’ (*ero un nulla*) and ‘I was a dead person’ (*ero una persona morta*) were quite common, reiterating the idea of a life that was totally deprived of its meaning until patients started EPC treatment:

I couldn’t take it anymore; I was basically nothing. (*Non ce la facevo più, ero praticamente un nulla.*) (002-P-008)

I was a dead man. (*Ero un uomo morto.*) (002-P-055)

I couldn’t live with that pain; it was already as if I had been dead. (*Con i dolori non vivo, ero già come morto.*) (002-P-079)

In this regard, the use of metonymy and synecdoche was widespread. These literary devices were used to indicate that patients stopped identifying or being identified with their illness and were once again considered as people with their own stories, feelings and lives outside the hospital. For example, palliative care was described as having helped patients stop feeling like ‘an organ’, ‘a tumour’, ‘an illness’ or ‘a number’. In the first two examples below, patients resort to synecdoche, which highlights how one part of the patient’s identity is overshadowing their being as a whole. In the last two instances, patients use metaphors, which indicate that their whole identity has been replaced:

I feel like a person and not a number. (*Mi sento una persona e non un numero.*) (002-P-071)

I felt like a number, a tumor, not a person. (*Mi sentivo un numero, un tumore, non una persona.*) (002-P-093)

I feel like a person and not an ill organ. (*Mi sento una persona e non un organo malato.*) (002-P-057)

They never made me feel like an ill organ. (*Non mi hanno mai fatto sentire come un organo malato.*) (002-P-057)

Feeling like a number can be considered a conventional metaphor, because it is often used in various circumstances when individuals feel like they are not being seen or considered. However, the term ‘ill organs’ may be considered a creative metaphor: it is only in a clinical setting and in the words of patients that persons refer to themselves as ‘ill organs’. Thus, we must recognise a certain level of originality in these metaphors, which contribute to making patients’ perceptions explicit.

Oasis of peace, safe haven

When referring to the effects of EPC, patients described them as ‘an oasis of peace in the storm of illness’ (*un’oasi di pace nella tempesta della malattia*) or ‘a safe haven in the storm of illness’ (*un porto sicuro nella tempesta della malattia*). Both metaphors recall a delimited protected space, characterised by safety and stability, as opposed to the storm that surrounds it and indicates confusion, loss of direction and danger. One patient even described their mind as full of ‘black clouds’ (*nubi nere*), which dissolved after starting to receive EPC. In this case, the image of light returned, though not explicitly, but as the natural consequence of a clear sky. The choice of a spatial metaphor creates a comparison between the oasis or the haven and the hospital where palliative care is delivered. The sense of stability was reinforced by another conventional metaphor, namely ‘lifeline’ (*ancora di salvezza*). EPC was therefore compared to a place that was able to give shelter and a tool to save lost patients.

Doctors who work in this safe haven were often referred to as ‘angels’ (*angeli*). Similarly, doctors were also defined by the synecdoche ‘safe hands’ (*mani sicure*), which indicates a sense of security and protection. A more predictable idiom including hands would have been ‘to be in good hands’ (*essere in buone mani*); therefore, its originality lies in the choice of a different adjective, namely ‘safe’ (*sicure*). By operating this change, a greater emotional involvement of the person can be perceived through their words, since ‘good hands’ can be perceived as ‘skilled, qualified hands’, whereas ‘safe hands’ are able to convey a sense of warmth which is lacking in the first fixed expression. Hands were also mentioned by a patient who felt ‘taken by the hand’ (*presa per mano*), which introduced another essential element related to palliative care: the feeling of being accompanied.

I’m grateful for this treatment that is accompanying me humanely and spiritually. (*Sono grato a queste cure che mi stanno accompagnando umanamente e spiritualmente.*) (002-P-030)

I know I am and will be accompanied by people I trust. (*So che sono e sarò accompagnato da persone di cui mi fido.*) (002-P-098)

It makes me feel accompanied in the right way. (*Mi fa sentire accompagnato nel modo giusto.*) (002-P-062)

The verb ‘accompany’ can be used figuratively in these instances, since its most basic meaning involves physical movement towards the same place. This definition allows us to assume that patients have a vivid sense of doctors in palliative care sharing their own experience, in which the common goal is to increase the quality of life that remains.

#### Life

Palliative care was indeed often referred to by patients as ‘treatment for life’ as opposed to standard treatments:

Oncology is pain. It’s a lot of pain. (*L’oncologia è dolore. È tanto dolore.*) (002-P-003)

I hope that [...] this doctor will assist me to continue this life path. (*Spero che [...] la dottoressa mi segua per andare avanti in questo percorso di vita.*) (002-P-004)

I went from death to life. (*Sono passato dalla morte alla vita.*) (002-P-005)

For me it has been like coming back to life. (*Per me è stato come tornare a vivere.*) (002-P-102)

I would define this treatment as treatment for life. (*Definirei queste cure le cure della vita.*) (002-P-038)

This treatment is a declared battle against pain, suffering, and in doing so it has been a hymn to life for me. (*Queste cure sono una lotta dichiarata contro il dolore, la sofferenza, e così facendo sono state per me un inno alla vita.*) (002-P-038)

The last transcription is rich in metaphors that describe palliative care, and it is interesting to observe how the patient starts from a place of violence, choosing a term that refers to war (‘battle’), to then transition to a more peaceful state of mind, selecting a term belonging to the conceptual domain of music (‘hymn’). The choice of words referring to war can be considered as conventional when associated with cancer. Especially in health campaigns for cancer awareness, ‘battle’ (*lotta*, in Italian) is a very common term. However, in our data, the term ‘battle’ only occurred twice: in the last example mentioned above and in the following instance to indicate a struggle to control the pain the patient was feeling before receiving EPC:

I struggled a lot at home because of the pain. (*A casa ho lottato molto per il male.*) (002-P-004)

These examples show that in patients’ words, prevention or treatment was not associated with war, rather it was associated with acceptance, or simply a different life path.

#### Caregivers

##### Light and salvation

There was also interesting use of figurative language by caregivers. Most caregivers used the same metaphors

as patients, for example, the words ‘light’ and ‘salvation’ were widely employed to describe palliative care and the sense of hope caregivers experienced:

That place and those people were what she defined as a light of hope. (*Quel luogo e quelle persone erano ciò che lei definiva una luce di speranza.*) (01-C-018)

For me, hope has been a light in this path. (*La speranza per me in questo mio percorso è stata una luce.*) (01-C-017)

These cures have been like real salvation in the first place for my father and then also for me. (*Queste cure sono state prima per mio padre e poi anche per me una vera salvezza.*) (01-C-002)

[...] these cures, which have been salvation for all of us. ([...] *queste cure, che sono state la salvezza per tutti noi.*) (01-C-006)

##### Victory

The most noticeable difference in comparison with patients’ responses lay in the fact that the conceptual domain of war was used more frequently by caregivers and was often associated with a sense of hope provided by palliative care:

I finally saw a strength in my brother that he had never expressed before and for me this was what we had to count on, his emotional state, the only strong point to start the fight and win. (*Ho visto finalmente in mio fratello una forza che mai prima aveva espresso e per me questo era l’aspetto su cui contare, il suo stato emotivo, unico punto di forza per iniziare la lotta e vincerla.*) (01-C-027)

[...] to be able to fight to reach victory anyway. ([...] *di poter lottare per raggiungere in ogni caso una vittoria.*) (01-C-027)

The feeling of hope is a victory over illness. (*Il sentimento di speranza è [...] una vittoria al male.*) (01-C-027)

Hope is that vital energy that allows us to get up every morning and fight. (*La speranza è quell’energia vitale che ci permette di alzarci ogni mattina e combattere.*) (01-C-005)

##### Linguistic alignment

The second phenomenon we observed was linguistic alignment: caregivers often used the same expressions and metaphors as their relatives. At times, caregivers referred explicitly to their relative, as in the following extracts:

Palliative care is, using my father’s words, an ‘actual caress’ that every human being needs to receive in such a delicate moment in life. A caress that cures, that’s what my father used to say. (*Le cure palliative sono, usando un’espressione di mio padre, una ‘coccia vera e propria’ che ogni essere umano ha bisogno di ricevere in un momento così delicato della propria vita. Una carezza che cura, così diceva mio padre.*) (01-C-029)

Early palliative care is, as he used to say, ‘the opposite of the end of life’, it is life. (*Le cure palliative precoci*

*sono come diceva lui 'il contrario del fine vita', sono la vita.* (01-C-026)

The same happened with the use of metaphors and similes to describe the sense of protection and safety, as well as community, produced by palliative care: caregivers reported patients saying that they felt 'hugged' (*abbracciati*). At other times, despite the anonymity of the questionnaires, both patients and caregivers used the same creative metaphor, for example, 'storm of illness'.

## DISCUSSION

In this qualitative linguistic analysis, patients with advanced cancer and caregivers described EPC using metaphors of light, salvation, safe haven and life. Caregivers also used the metaphor of victory. Metaphors were often used to express opposites, with EPC represented as the positive aspect versus standard treatments and the illness. Metonymy and synecdoche were often used, and there was linguistic alignment between the reports of patients and caregivers. These results are in contrast with previous reports of patients' and caregivers' perceptions of palliative care and indicate how patients' and caregivers' views of palliative care may be influenced by their experience of receiving EPC.

In metaphor studies, patients with cancer and caregivers described their illness by drawing on many different conceptual domains, for example, chaos, a natural disaster, an animated being or something that divides.<sup>1</sup> While cancer was framed by our patients as a dark, chaotic, dangerous place, palliative care was framed as a bright, peaceful, safe place, where no one is left alone. All the metaphors used have in common a strong sense of security and community, which is what remains in the memory of the caregivers who participated in the survey, after losing their relative. In clear antithesis to the common perception of end-of-life palliative care being synonymous with death and the absence of hope, EPC interventions have instead been described as an intervention that effectively counteracts pain and suffering, supports hope and dignity of life, and promotes the elaboration of the meaning of one's illness and the acceptance of death. The need for a search for meaning is also demonstrated by the prevalent presence of spiritual metaphors in the responses of patients and caregivers.

Metaphors have been explored as ways to more effectively present EPC or as ways to assess patients' perceptions of EPC.<sup>4 12</sup> For example, a recent study identified deep metaphors associated with palliative care through qualitative interviews with eight patients with serious illness and eight caregivers receiving palliative care.<sup>4</sup> Like this study, which found that a deep metaphor was the concept of the illness 'taking' and palliative care 'giving', our analysis demonstrates that metaphors were often used to express opposites, in which palliative care was noted to give hope and

restore quality of life. Despite the similarities in our findings, it is important to note that our study focused exclusively on an oncology population, while two out of the eight patients in the aforementioned study had cancer. Moreover, our patients were undergoing EPC for advanced/symptomatic oncological disease with prognosis >6–24 months (table 1) allowing for long-term conversations on the topics of suffering and death.<sup>13</sup>

The metaphors identified in our study were spontaneously reported by patients and caregivers to describe their disease and the first EPC encounter, which is relevant to understand the experience and perceptions of patients and caregivers undergoing EPC. More specifically, regarding the conceptual domain of light and salvation, so often used to describe EPC, it is noteworthy that these terms were used despite patients being aware of the non-curability of the metastatic/advanced disease. This suggests that EPC can enable patients and caregivers to hold the concept of hope while facing the reality of incurable disease. Similarly, when asked about their perceptions of the future, including the end of life after exposure to EPC, study subjects largely expressed feelings of gratitude. The interviewees reported feeling saved from the severe physical and spiritual pain suffered before their referral to EPC unit and relieved and grateful for the 'restored' possibility of an almost pain-free life.

Palliative care remains synonymous with end-of-life care due to late referrals, when oncologists feel there is 'nothing left to offer' or when patients' goals are seen as 'giving up the fight'.<sup>14</sup> Such winning and losing language is destined to inevitably worsen patients' perception of palliative care and the subsequent cancer trajectory after exposure to palliative care. In clear antithesis to the prevailing oncology language, which adopts war metaphors, our study shows how in the EPC setting, militaristic metaphors are almost completely absent, leaving instead space for metaphors of light and hope, security and community. Although caregivers used the metaphor of 'victory', this was used to represent not the cure for cancer, but the hope provided by EPC.

Another noteworthy aspect is the frequent use of expressions in which patients and caregivers describe EPC as allowing them to move from death to life, although being aware of the advanced stage of the disease; this contrasts with perceptions that link palliative care to end of life and death. Finally, we found very similar uses of figurative language in caregivers and patients, almost as if the former echoed the latter in an effort to find linguistic alignment, reinforcing the need to include caregivers early in palliative care interventions.

Analysis of metaphor use among patients with advanced cancer has potential implications beyond assessment of EPC. Given the need for oncologists to monitor the degree to which patients and caregivers

integrate prognostic information, in the context of prevailing high level of clinician–patient prognostic discordance, analysis of metaphors could serve to qualitatively assess prognostic understanding. Indeed, analysis of metaphors could be used as a complementary tool in combination with quantitative measures of prognostic understanding and awareness.<sup>15</sup>

We acknowledge limitations to this study. First, although our analyses allow in-depth assessments of participants' perceptions, the inherent qualitative nature of the work limits broad generalisations. Second, the fact that this study was conducted in one country and participants all spoke the same language may restrict its applicability to other settings and cultures. Finally, the population studied had relative homogeneity with respect to religion, with approximately 75% of participants being of Catholic faith.

## CONCLUSION

Our study expands upon existing literature on the use of metaphorical language in advanced cancer care settings, focusing on data regarding disease and treatment descriptions by patients and caregivers undergoing EPC. In contrast to some studies in which patients and caregivers had negative perceptions of palliative care, we found that patients and caregivers described EPC using metaphors of light, salvation, safe haven and life. These metaphors may be useful when communicating with patients and caregivers about the benefits of EPC.

### Author affiliations

<sup>1</sup>Oncology and Palliative Care Units, Civil Hospital Carpi, Local Health Agency (USL), Carpi (MO), Italy

<sup>2</sup>Department of Linguistic Sciences and Foreign Literatures, Catholic University of the Sacred Heart, Milan, Italy

<sup>3</sup>Hematology Unit and Chair, Azienda Ospedaliera Universitaria di Modena and Department of Medical and Surgical Sciences, University of Modena and Reggio Emilia, Modena, Italy

<sup>4</sup>Department of Biomedical, Metabolic and Neural Sciences, University of Modena and Reggio Emilia, Modena, Italy

<sup>5</sup>Center for Neuroscience and Neurotechnology, University of Modena and Reggio Emilia, Modena, Italy

<sup>6</sup>Archbishop Abbot of Modena-Nonantola, Bishop of Carpi, Italy; Vice President of the Italian Episcopal Conference, Modena, Italy

<sup>7</sup>Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy

<sup>8</sup>Palliative Care & Rehabilitation Medicine, UT M D Anderson Cancer Center, Houston, Texas, USA

<sup>9</sup>Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, Massachusetts, USA

<sup>10</sup>Department of Supportive Care, Princess Margaret Cancer Centre, University Health Network, Toronto, Ontario, Canada

<sup>11</sup>University of Toronto Faculty of Medicine, Toronto, Ontario, Canada

**Contributors** EBa and ML are responsible for the overall content as guarantors. EBa, LP and ML have full access to all the data used in the study and take the responsibility for the integrity of the data and the accuracy of the data analysis. EBa, SB, MN and EBo have contributed to the acquisition, analysis and interpretation of data. EBa, SB, MN, EBo, CAP, EC, FE, OO, CZ, EBr, LP and ML have commented on manuscript draft and final version and approved the submitted manuscript. SB and MN performed qualitative linguistic analysis.

**Funding** This research was supported by PNRR CN3 Terapia Genica-Spoke 2 (ML), the 'Charity Dinner Initiative' in memory of Dr A Fontana for Associazione Italiana Lotta alle Leucemie, Linfoma e Mieloma (AIL OdV)–Sezione 'Luciano Pavarotti'.

**Competing interests** EBa—consultancy for Sandoz and Viatrix, outside the submitted work. SB—consultancy for Biomarin, Roche and Viatrix, outside the submitted work. FE—consultancy or advisory role for AbbVie, Incyte, Syros and Novartis, outside the submitted work. EBr—grants from Helsinn Healthcare, outside the submitted work. ML—advisory board of AbbVie, Novartis, Gilead Science, Jazz Pharmaceuticals, Sanofi, MSD, Daiichi-Sankyo, Grifols and Incyte; and travel grant from Gilead Science, outside the submitted work.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by the Modena Ethics Committee (no. 0026448/20). The data collection was carried out in accordance with the ethical standards of the 2013 Declaration of Helsinki. Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available upon reasonable request. Data used in the study can be made available upon reasonable request.

**Supplemental material** This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

### ORCID iDs

Sarah Bigi <http://orcid.org/0000-0003-0506-6140>

Eleonora Borelli <http://orcid.org/0000-0002-3391-4437>

Fabio Efficace <http://orcid.org/0000-0002-5065-5166>

Eduardo Bruera <http://orcid.org/0000-0002-8745-0412>

Camilla Zimmermann <http://orcid.org/0000-0003-4889-0244>

Leonardo Potenza <http://orcid.org/0000-0002-2738-6105>

Mario Luppi <http://orcid.org/0000-0002-0373-1154>

## REFERENCES

- 1 Semino E, Demjén Z, Demmen J. An integrated approach to metaphor and framing in cognition, discourse, and practice, with an application to metaphors for cancer. *Applied Linguistics* 2018;39:amw028.
- 2 Sontag S. *Illness as metaphor*. New York: Farrar, 1978.
- 3 Hutchings D. Communicating with metaphor: A dance with many veils. *Am J Hosp Palliat Care* 1998;15:282–4.
- 4 Back AL, Wax JS, Rossi RD, *et al*. What patients and caregivers experience when they receive palliative care: a study eliciting

- metaphors that could shape public messaging. *J Palliat Med* 2023;26:751–6.
- 5 Hui D, Bruera E. Models of palliative care delivery for patients with cancer. *J Clin Oncol* 2020;38:852–65.
  - 6 Zimmermann C, Swami N, Krzyzanowska M, *et al.* Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ* 2016;188:E217–27.
  - 7 Formagini T, Poague C, O’Neal A, *et al.* "When I heard the word palliative": obscuring and clarifying factors affecting the stigma around palliative care referral in oncology. *JCO Oncol Pract* 2022;18:e72–9.
  - 8 Collins A, McLachlan SA, Philip J. Initial perceptions of palliative care: an exploratory qualitative study of patients with advanced cancer and their family Caregivers. *Palliat Med* 2017;31:825–32.
  - 9 Bandieri E, Banchelli F, Artioli F, *et al.* Early versus delayed palliative/supportive care in advanced cancer: an observational study. *BMJ Support Palliat Care* 2020;10:e32.
  - 10 Group P. MIP: A method for identifying metaphorically used words in discourse. *Metaphor and Symbol* 2007;22:1–39.
  - 11 Barlow J. Training manual for identifying figurative language. Tennessee Metaphor Research Group; 1971.
  - 12 Zimmermann C, Mathews J. Palliative care is the umbrella, not the rain. A metaphor to guide conversations in advanced cancer. *JAMA Oncol* 2022;8:681–2.
  - 13 Bigi S, Ganfi V, Borelli E, *et al.* Perceptions of death among patients with advanced cancer receiving early palliative care and their caregivers: results from a mixed-method analysis. *Oncologist* 2023;28:e54–62.
  - 14 Alcalde J, Zimmermann C. Stigma about palliative care: origins and solutions. *Ecancermedicalscience* 2022;16:1377.
  - 15 Brenner K, Greer JA, Jackson V, *et al.* Development of a prognostic awareness impact scale for patients with advanced cancer. *Journal of Palliative Medicine* 2022;25:445–54.



## Supplemental material

Table 1. SUPPLEMENTAL Questions of the semi structured interviews for patients and caregivers.

---

### PATIENTS

---

Discuss your disease experience prior to EPC.

Discuss your disease experience during EPC.

Discuss your perception and expectations of the future and your thoughts and feelings about the end of life. How has your way of conceiving the idea of life and death changed, if it has changed at all?

Is there anything more that you would like to say about the idea of death?

---

### CAREGIVERS

---

For how long did your relative come to the EPC Unit?

What do you think EPC treatments meant for your loved one? And what did they mean to you?

Is there an episode you would like to share with us from the period when you were caring for your loved one?

Would you like to add something else about the idea of death?

---