

# Perceptions of Hope Among Bereaved Caregivers of Cancer Patients Who Received Early Palliative Care: A Content and Lexicographic Analysis

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## Abstract

**Background:** Oncologists' fear of taking away hope from patients when proposing early palliative care (EPC) is a barrier to the implementation of this model. This study explores hope perceptions among bereaved caregivers of onco-hematologic patients who received EPC.

**Materials and Methods:** Open-ended questionnaires were administered to 36 primary caregivers of patients who received EPC (26 solid and 10 hematologic cancer patients; mean age: 51.4 years, range age: 20-74), at 2 cancer centers, 2 months to 3 years after a patient death. Definitions of hope in the caregivers' narratives were analyzed through a directed approach to content analysis. Results were complemented with automated lexicographic analysis.

**Results:** Caregivers perceived hope mainly as resilience and as expectations based on what they were told about the patients' clinical conditions. Their hope was bolstered by trusting relationships with the healthcare teams. EPC interventions were recalled as the major support for hope, both during the illness and after the death of the patient. The automated quantitative lexical analysis provided deeper insights into the links between hope, truth, and trust.

**Conclusions:** Our findings suggest that telling the truth about an incurable onco-hematologic disease and beginning EPC might be the combination of factors triggering hope in the setting of incurable cancer.

**Key words:** early palliative care; patient; caregiver; qualitative research; hope; bereavement.

## Implications for Practice

Early, truthful discussions between physicians, nurses, patients, and caregivers about goals of care and quality of life that are based on trusting relationships can help to align expectations and support realistic hope. This alignment can support patients and their caregivers in engaging with and benefiting from EPC and prevent burnout in physicians and nurses. Our study findings will inform future research studies on caregiver perceptions, as well as possible interventions to enhance hope in patients and caregivers.

## Introduction

In 1998, Nekolaichuk and Bruera wrote “*Despite its therapeutic value, the concept of hope is neither well understood neither well researched in palliative care*”.<sup>1</sup> Since then, a significant body of research has developed, in the effort to understand hope in different clinical contexts and its role in relation to desired clinical outcomes. However, still in 2005, Hagerty and colleagues considered that “*research is lacking in determining how patients define hope and how health professionals communicate hope to patients*”.<sup>2</sup> Recently, hope has been defined as a “multidimensional construct that might change over time”.<sup>3</sup> Hope in terminally ill patients cannot be considered merely as a coping strategy, nor dismissed simply as wishful thinking.<sup>4</sup> Studies investigating the antecedents of hope have shown that inspiring relationships play a significant role in generating hope and maintaining it, despite adverse circumstances.<sup>3</sup> A critical aspect emerging in all the studies on hope is its connection with truth: on the one hand, healthcare professionals understand the need to sustain hope for their patients; on the other hand, they know they have an obligation to tell them the truth about their condition. This tension is particularly acute when patients must be told they are terminally ill. Under these circumstances, oncologists may fear removing hope from patients by revealing the truth about their condition.<sup>5-6</sup> This tension is amplified because hope remains a concept that is not well understood, due to its complexity and variability through different contexts and because it is difficult to explore using only quantitative methods. Moreover, hope varies depending on who perceives it: patients, their caregivers, and healthcare professionals may hope for different things and in different ways, depending on the situation.<sup>3,7</sup> Unless we understand how hope works for all concerned, it will be difficult to tap into this powerful resource to improve wellbeing.

Existing studies about hope involve mostly patients undergoing delayed palliative care treatments.<sup>8-9</sup> Alam et al have recently proposed the CARES framework to guide care for caregivers in oncology settings. Adverse bereavement outcomes including anxiety and depression may be related to a lack of preparation for the patient’s death.<sup>10</sup> A standardized creation of caregiver records in medical institutions has recently been advocated to positively influence caregivers’ experiences, also to support bereaved caregivers.<sup>11</sup> Early palliative care (EPC) integrated with standard oncologic care has been reported to improve caregivers’ depression.<sup>10</sup> However, qualitative studies are particularly scarce with regard to hope in oncology and existing studies of caregivers of patients undergoing EPC<sup>10,12-14</sup> have not specifically examined hope. Thus, we have addressed the yet neglected issue of hope by primary caregivers of deceased onco-hematologic patients under EPC, by analyzing responses to open-ended questionnaires. The questionnaires were administered to explore if and how these caregivers perceived hope during the illness and after the death of their family members in the context of a long-term established EPC model, in a real-life setting.

## Methods

### Participants

We recruited adult bereaved primary caregivers of deceased onco-hematologic patients treated with EPC. We required

caregivers to have been bereaved no earlier than 2 months before enrollment to avoid acute grief and no later than 2 years to minimize recall bias. The study was performed in accordance with the ethical standards of the 2013 Declaration of Helsinki and was approved by the Departmental Ethics Committee of the University of Modena and Reggio Emilia (N. 0026448/20).

## Materials, Procedures, and Data Analysis

### Study Setting

This study was embedded within the EPC Units of the 2 participating hospitals. The oncology and EPC unit at the Civil Hospital Carpi, USL (Modena, Italy) was established in 2006 while the EPC unit in Azienda Ospedaliera Universitaria Policlinico, University of Modena and Reggio Emilia (Modena, Italy) was established in 2012 within the Section of Hematology. The EPC units integrate primary oncologist and hematology specialists with a palliative care team to provide comprehensive symptom management and psychosocial, spiritual, and emotional support to cancer patients and their families, from the time of diagnosis to advanced/metastatic disease onward, according to general guidelines, to ensure a uniform and reproducible intervention.<sup>15-16</sup> All patients with an advanced/metastatic cancer diagnosis with a high symptom burden were recruited to receive an EPC intervention because of severe cancer pain by both a palliative care physician and an advanced practice nurse. Patients with advanced cancer are defined as those with distant metastases (ie, in case of solid tumors), late-stage disease, and/or with a prognosis of 6-24 months.

### Open-ended Questionnaires

The questionnaires and the study were described to the caregivers during a dedicated encounter and presented by the EPC team, both in Carpi and Modena. At this time, a face-to-face encounter was preferred over an email message in consideration of the long-term relationship established with caregivers during the illness of their relatives and also to offer easier opportunities to ask for clarifications or express concerns regarding the study. After caregivers’ written consent was collected, the participants were given the questionnaire and asked to submit their responses within 1 month. For data collection, a self-administered questionnaire was chosen as the best option to respond with comfort to possibly painful questions and also to minimize the risk of social desirability bias. The questionnaire was composed of 12 questions about caregivers’ experience with EPC. Responses were collected consecutively between July 2020 and June 2021. [Table 1](#) reports the questions we analyzed in this study.

The responses to the questionnaires were analyzed using a directed approach to content analysis,<sup>17</sup> which is among the best-known methods in the medical sciences to conduct qualitative research on textual data as it allows interpretation of texts in the framework of their social uses.<sup>18-21</sup> This kind of approach is generally used when there exists research on a certain phenomenon, but further study is required for it to be fully understood. The existing research is used to formulate the initial coding categories, following a deductive approach. Based on the study by Olsman,<sup>3</sup> we identified the following coding categories, which capture the main functions of hope, as identified in the recent literature on hope in diverse clinical settings:

**Table 1.** Analyzed questions from the questionnaires.

Questions about EPC and hope	
1.	Per quanto tempo il suo caro ha frequentato l'ambulatorio di cure palliative precoci? <i>For how long did your relative come to the EPC Unit?</i>
2.	A suo parere, le cure palliative precoci, cosa hanno significato per il suo caro? <i>What do you think EPC treatments meant for your loved one?</i>
2.1	E per lei come famigliare? <i>And what did they mean to you?</i>
4.1	Come considera il ruolo delle cure palliative precoci per la malattia oncologica? <i>What do you think is EPC's role in the treatment of oncologic illness?</i>
5.	Ritiene che le cure palliative permettano di tenere accesa la speranza? <i>Do you think EPC treatments allow keeping hope alive?</i>
5.1	Che cos'è per lei la speranza? <i>What is hope for you?</i>
5.2	C'è un episodio che desidera condividere con noi di questa esperienza di accompagnamento? <i>Is there an episode you would like to share with us from the period of time when you were caring for your loved one?</i>
6.	Si sente di aggiungere altro? <i>Would you like to add something else?</i>

Abbreviation: EPC, early palliative care.

1. hope as expectation, that is, a positive yet realistic appraisal of an uncertain future outcome;
2. hope as resilience, that is, the strength or a (coping) strategy to endure adversity;
3. hope as desire, that is, the expression of something meaningful embedded in (everyday) life.

As a first step, all responses to each single question were grouped and definitions of hope singled out. Then, preliminary codes were described, tentatively capturing the perception of hope expressed in each definition. This preliminary coding was performed by one researcher (S.B.) in constant dialogue with the researchers responsible for the study design (M.L. and E.B.). The results of the preliminary coding were compared with the 3 categories described above, which were found appropriate to capture the contents emerging from the definitions. Finally, each definition was coded independently by 2 coders (S.B., V.G.) using the 3 categories described above. Every time an uncertain case emerged, this was solved through discussion. After the coding, the responses were further analyzed qualitatively to determine any additional variables that could be relevant to characterize hope in the specific clinical setting of onco-hematologic illness treated with EPC.

Finally, taking up the challenge signaled in the study by Hagerty et al,<sup>2</sup> who point out the “*delicate balance between fostering realistic hope and unethically creating unrealistic expectations of longevity*,” as a complement to the content analysis of the answers to the questionnaires, we conducted a lexical analysis of the words “hope” and “desire” to reconstruct a characterization of these lexemes that would allow comparing primary caregivers' definitions of hope with its meaning in everyday use. We hypothesized that the analysis

of the word “desire” would allow delineating the specific properties of hope by comparison. In this perspective, the combinatorial properties of words extracted from large language corpora can reveal both “intensional”—that is, a technical term in semantics that refers to the properties connoted by a word—and emotional values of the words related to the aims of our study.<sup>22</sup> Relevant combinatorial properties are those connected to the modifiers of a word, that is, adjectives, adverbs, and prepositional phrases. The analysis of modifiers can be revealing of different senses of polysemous words, by showing the semantic context in which a word can occur. This analysis is particularly relevant when performed through automatic tools on large collections of texts representative of the language in use. Empirical combinatorial data were extracted from a large Italian web corpus (ItTenTen16; 5.864.495.700 tokens) using the tool Word Sketch, integrated into the Sketch Engine platform.<sup>23-25</sup>

## Results

The results are described in the following paragraphs, organized in 3 main sections: perceptions regarding hope, perceptions regarding the antecedents of hope, and the results from the lexicographic analysis.

These results are based on the responses of 36 primary caregivers (14 males, 22 females) of deceased onco-hematologic patients treated with EPC at the Oncology and Palliative Care Unit, Civil Hospital Carpi, USL (Modena, Italy) ( $n = 26$ , caregivers of solid tumor patients) and at the Hematology Unit, Azienda Ospedaliera Universitaria Policlinico, University of Modena and Reggio Emilia (Modena, Italy) ( $n = 10$ , caregivers of hematologic tumor patients), who participated in the study. Participant demographics are reported in Table 2. Six caregivers, who had been bereaved for 8-9 months, refused to participate because of feeling uncomfortable or not being interested, resulting in a caregiver response rate of 85.7%.

### Perceptions Regarding Hope

In the questionnaire, hope was explored directly in question 5.1 (Table 1). In the majority of cases, respondents defined hope as resilience, that is, the strength or a (coping) strategy to endure adversity. In these cases, hope was described as allowing caregivers to prepare for the death of their loved one and to endure the difficulties of accompanying a suffering and dying person. This hope allowed them to maintain a positive attitude throughout their loved ones' disease. In Table 3, we report examples of these answers.

The second most frequent answer was hope as an expectation: a positive yet realistic appraisal of an uncertain future outcome. All respondents referred to the time of their relatives' life after they had been informed that there was no possibility of recovery. In this scenario, the expectation the respondents mentioned most frequently was the absence of physical pain, which they related to the possibility of living comfortably until the end of life. There were 3 levels of expectation described by the respondents: absence of physical pain; a peaceful death; and the continuation of life after death. Those who mentioned the third aspect phrased it not as a desire but as an expectation, for example, “Hope is the highest spiritual dimension that reminds us of the fact that we will live forever, that death is but a transition.” The majority of those who expressed this view of death belonged to a religious denomination. Table 4 reports examples of these answers.

**Table 2.** Participant demographics.

Characteristic	Values*
Age at interview, years	
Mean (SD)	52.3 (13.4)
Range	20-74
Sex	
Female	24 (66.7)
Male	12 (33.3)
Education	
Primary school	0 (0)
Secondary school	5 (13.9)
College	11 (30.6)
Bachelor's degree	4 (11.1)
Master's degree	16 (44.4)
Ethnicity	
White	34 (94.4)
Arabian	1 (2.8)
African	1 (2.8)
Religion	
Catholic	21 (58.3)
Muslim	1 (2.8)
Orthodox	2 (5.6)
Animist	2 (5.6)
Atheist/Agnostic	10 (27.8)
Cancer diagnosis of beloved patients	
Solid	26 (72.2)
Lung	7 (26.9)
Gastrointestinal	6 (23.1)
Breast	3 (11.5)
Genitourinary	7 (26.9)
Head and Neck	2 (7.7)
Sarcoma	1 (3.9)
Hematologic	10 (27.8)
Time under early palliative care, months	
Median (SD)	12 (18.2)
Mean (range)	20.1 (2-72)
Time since death, months	
Median (sd)	12.5 (10)
Mean (range)	13.8 (2-36)
Relationship to patient	
Spouse/partner	14 (38.9)
Daughter/son	19 (52.8)
Sister/brother	1 (2.8)
Other family members	2 (5.6)

\*Values are expressed as n (%) unless otherwise indicated.

Finally, only very few answers mentioned hope as desire. In these cases, hope was related to the wish to enjoy the “normal” things of everyday life, such as traveling (01-C-018), seeing a child turn 18 (01-C-024), or going to the restaurant with the rest of the family (01-C-026).

### Perceptions Regarding the Antecedents of Hope

In providing their answers to question 5.1, respondents highlighted factors that supported their hope during the illness

**Table 3.** Descriptions of hope as resilience.

	Hope as resilience
01-C-011	“It is a positive outlook on life, no matter how things might go”
01-C-012	“It has been the trust between patient, caregiver and the doctor, who with truth and without giving us illusions accompanied us along the whole path”
01-C-017	“It has been a light, a path of truth, humanity and love”
01-C-018	“That place and those people are what she used to call, a light of hope”; “It is what has allowed us to be prepared and face what was happening with peace of mind”
01-C-022	“The will to fight because you believe everything will be fine even if there is no reason to believe this”
01-C-026	“These cures give life and shift the focus from a hopeless death to a life without suffering, this has allowed us to slowly accept the thought of death”
01-C-027	“Hope is to believe in yourself, to believe that you can do better and that you can fight and win just because you believed”
0-C-005	“It is that vital energy that allows you to get up every morning and fight, even if everything seems to tell you to stop because it's over”
0-C-008	“Hope is truth...It is finding the strength to stand by each other even in the hardest of times”

of their loved ones. In other words, they described the antecedents of hope. In his review of the literature on hope in the context of healthcare, Olsman identified psycho-socio-spiritual interventions and inspiring relationships as the most frequent antecedents of hope.<sup>3</sup> In the specific clinical context of EPC, other factors also emerged.

### Inspiring Relationships

Inspiring relationships played a central role also for our respondents; in the majority of cases, they mentioned the trusting relationship with the healthcare team. Within this kind of relationship, one crucial factor was truth. The respondents frequently described a direct link between the truth they were told by the doctors about the clinical conditions of their relative and the trust they developed toward them, both of which were indicated as antecedents of their hope. An inspiring and trusting relationship between the healthcare team, the patients, and their caregivers was also what almost all respondents spoke about at the end of the questionnaire when asked if they would like to share a particular episode during the period of caring for their loved one. In this part of the questionnaire, rather than specific episodes, most respondents described the atmosphere they experienced at the palliative care clinic: “peaceful,” “compassionate,” “calm,” “supporting,” “cheerful,” and “comforting.” In a few cases, respondents mentioned the smiles they found at the clinic or the fact that their loved ones used to smile when they knew they were going to the clinic or when they left after their routine encounter. Respondents mentioned this cheerful approach as one of the most important factors that helped them endure the sadness and pain of their loved ones’ illness. [Table 5](#) reports examples of these answers.

### Early Palliative Care Treatments

The adoption of EPC was another important factor participants reported as having an influence on their development of

**Table 4.** Descriptions of hope as expectation.

	Hope as expectation
01-C-003	“It is the absence of suffering, of desperation, of illusion”
0-C-008	“Standing by each other so that memories will be full of emotions, feelings, discussions and words that will accompany you for the rest of your life”
0-C-010	“The highest spiritual dimension that reminds us that we will live forever, that death is only a transition”
01-C-028	“It is the absence of suffering and desperation”
01-C-025	“Hope of feeling well as long as possible and live fully the time that is left”
01-C-032	“Hope is to die peacefully”

hope in this difficult period of their lives. In the questionnaire, there were 3 questions that referred directly to perceptions about EPC: 2, 2.1, and 4.1 (Table 1). The answers to these questions fell into 2 groups: what EPC does, and what it is, for patients and for caregivers.

Regarding what EPC treatments do, the respondents' most frequent answer was that they improved patients' quality of life by removing physical pain, alleviating the sense of isolation faced by patients and their families, and promoting the development of relationships within which to deal with spiritual needs. In the words of the respondents, EPC treatments “have allowed my father to enjoy life as it was before the illness” (01-C002), “are very important because the patient does not feel abandoned and they allow to control pain” (01-C-024), “made my father feel cared for, supported, listened to and understood” (01-C-028), “have allowed my father to feel better physically and spiritually, and to find the love for life he had lost” (0-C-008).

Figurative language (notably metaphors) was often used when respondents spoke about both the effects of EPC treatments, and what they felt EPC was. In these cases, EPC treatments were described as “places”: “an oasis,” “a road,” “a safe haven in the storm of the illness,” “a place where one is listened to, welcomed, cared for.” In other cases, they were described as “a help”: “a blessing,” “salvation,” “an answer to pain,” “a remedy,” “support.”

As for the role of EPC in the treatment of onco-hematologic illness, most respondents described EPC as being fundamental and essential in advanced cancer because it removed physical pain and improved patients' quality of life (QoL). As described above in the questions about hope, these factors appeared to play a crucial role in allowing for a positive, hopeful attitude in both caregivers and patients. Finally, because of these positive effects on patients' wellbeing, many respondents considered EPC to be a valid alternative both to euthanasia and to aggressive medical treatment.

One question specifically asked about the link between EPC and hope (question 5, Table 1): “Do you think EPC treatments allow keeping hope alive?”. All respondents answered affirmatively.

### Lexicographic Analysis

Regarding the connection between supportive relationships, trust, truth, and hope, inspiring insights were suggested by lexical analyses based on natural language processing tools and on the methodologies developed within corpus linguistics. Lexical analysis, the only method allowing the exploration

**Table 5.** Descriptions of inspiring relationships as antecedents of hope.

	Inspiring relationships as antecedents of hope
01-C-012	“When my husband happened to be very troubled he always found a reliable support in the healthcare team; they helped him overcome all his critical moments”
01-C-017	“I remember the beauty of the first encounter with the staff at the clinic. When we finished and left, I can't explain, but we were smiling”
01-C-018	“A small party that my partner organized for her doctors and nurses and a few friends met along the way at the clinic; I remember that time of happiness, smiles, sharing and I thought that everything was perfect and that what scared me so much was something I could face after all”
01-C-022	“The feeling of complete trust my father had in the healthcare team”
01-C-026	“The way he smiled when he knew he had to go to the clinic or when he talked with the doctor or other members of the team on the telephone; he said that just hearing their voices made him feel better”
01-C-029	“All those encounters at the clinic, with a quiet atmosphere of trust, and also cheerful”
0-C-016	“Not just one particular episode, rather a feeling: a pleasant feeling of feeling good and so many smiles every time we left that place of care”

of how individuals actually use words, is based on the exploration of large collections of texts and does not proceed from preconceived assumptions about results. To complement the results of the content analysis performed on the answers to the questionnaires, we analyzed the most common modifiers of the words “speranza” (hope) and “desiderio” (desire). Results show that there is a significant difference in the lexical combinatorial properties of the words, which can be correlated to a difference in the way speakers conceptualize their meanings. On the one hand, “hope” is more frequently modified by words that indicate the existence of reasons; “desire,” on the other hand, is more frequently modified by words that express the degree of the desire. The results of this combinatorial analysis are shown in Table 6.

Modifiers often occurring with both “hope” and “desire” are placed in the center of the table, while words modifying exclusively “hope” are located on the top, and those associated with “desire” on the bottom. Even if there is some combinatorial overlap between “hope” and “desire,” an evident area of specificity in their semantic characterization can be identified. Thus, words such as “well-founded,” “messianic,” “trusting,” “Christian,” “false,” “reasonable,” “concrete,” “placed,” that are preferential modifiers of “hope,” can be explained by assuming that the conceptualization of “hope” entails an orientation toward a specific aim. On the other hand, the more frequent modifiers of “desire” characterize it in terms of its degree (“lively,” “strong,” “deep,” “burning,” “insatiable”) and quality (“pious,” “selfish,” “unconscious,” “erotic,” “carnal,” “sexual”), hinting to a state that arises and is perceived, but is not necessarily grounded on specific reasons.

### Discussion

The results of our study extend the existing literature on hope in the healthcare context. The 3 main functions of hope—resilience, expectation, and desire<sup>3</sup>—were found also in our

**Table 6.** The modifiers of “hope” and “desire.”

		Modifiers of ‘hope’	Modifiers of ‘desire’
The modifiers of ‘hope’	flebile ( <i>feeble</i> )	560	0
	residuo ( <i>remaining</i> )	656	0
	fondato ( <i>well-founded</i> )	348	0
	beato ( <i>blessed</i> )	269	0
	messianico ( <i>messianic</i> )	207	0
	fiducioso ( <i>confident</i> )	187	0
	tenuo ( <i>tenuous</i> )	179	0
	cristiano ( <i>Christian</i> )	1432	14
	falso ( <i>false</i> )	1544	44
	deluso ( <i>unmet</i> )	347	13
	ragionevole ( <i>reasonable</i> )	325	21
	concreto ( <i>concrete</i> )	995	61
	incrollabile ( <i>unshakable</i> )	135	11
	riposto ( <i>placed</i> )	130	13
	vano ( <i>vain</i> )	1698	176
	illusorio ( <i>illusory</i> )	294	36
	perduto ( <i>lost</i> )	236	28
	fermo ( <i>firm</i> )	376	64
	unico ( <i>only</i> )	5029	1369
	vago ( <i>vague</i> )	242	113
	segreto ( <i>secret</i> )	664	480
	recondito ( <i>hidden</i> )	80	336
	legittimo ( <i>legitimate</i> )	122	614
	sincero ( <i>sincere</i> )	107	708
	intimo ( <i>intimate</i> )	79	527
	vivo ( <i>alive</i> )	210	1490
	pio ( <i>pious</i> )	73	600
	forte ( <i>strong</i> )	394	3551
	egoistico ( <i>selfish</i> )	15	270
	inconscio ( <i>unconscious</i> )	36	641
	profondo ( <i>deep</i> )	168	2742
	ardente ( <i>burning</i> )	85	2081
	struggente ( <i>heart wrenching</i> )	11	288
	innato ( <i>innate</i> )	8	328
	espresso ( <i>expressed</i> )	0	322
	inappagato ( <i>unfulfilled</i> )	0	249
insaziabile ( <i>unsatiable</i> )	0	280	
smodato ( <i>excessive</i> )	0	288	
erotico ( <i>erotic</i> )	0	385	
carnale ( <i>carnal</i> )	0	330	
irrefrenabile ( <i>uncontrollable</i> )	0	852	
The modifiers of ‘desire’	sessuale ( <i>sexual</i> )	0	5997

data, with a majority of answers addressing hope as resilience. The critical connection between hope and truth emerged also in the words of our respondents, though not in a problematic

way. Whereas in the literature there seems to be a tension between the professional obligation to tell the truth and the worry of extinguishing patients’ hope if they come to know negative truths, in our data hope and truth were often almost equated (in the words of some respondents, “hope is truth and trust”).

The main difference between our results and those found in the existing literature seems to be the specific clinical context in which our data were collected, that is, an EPC clinic, and the participants involved, that is, caregivers of deceased patients, who have not frequently been the subject of previous studies,<sup>10</sup> but are considered pivotal in the EPC model of care and thus worthy of a specific study. In a study on the effects of early versus delayed initiation of palliative care intervention for family caregivers of patients with advanced cancer, results showed that palliative care for caregivers should be initiated as early as possible.<sup>26</sup> A recent review on the effects of palliative care for family caregivers showed that among the 16 randomized controlled trials, the most promising results showed improvement of depression resulting from EPC interventions.<sup>10</sup>

Eligibility criteria for quantitative clinical studies related to bereavement care are often set to more than 6 months after bereavement.<sup>27</sup> However, prior research engaging bereaved caregivers has demonstrated the stability of responses as early as 3 months after bereavement without any significant safety issues with regards to mental health.<sup>28</sup> In our EPC model, caregivers are considered part of the unit of care with their loved ones and establish a long-term relationship with the EPC team. Thus, caregivers remain in contact with the EPC team even after bereavement.<sup>16</sup> Given this model of care and continued contact with caregivers in the bereavement phase, we thus considered it appropriate to recruit caregivers within 6 months of bereavement for this qualitative study. Moreover, the median and mean time since the death of the patients for this study were 12.5 and 13.8 months, respectively (Table 2).

Our results suggest that the adoption of EPC led to a rapid improvement in patients’ wellbeing (control of pain and other symptoms) and consequently in their overall QoL. The improved conditions of patients have also caused their caregivers to find renewed strength to support them and to accept and endure the pain for the loss of a loved one. The decision to accept EPC appears to have been made after patients and caregivers were told the truth about their situation. The opportunity to experience an unexpected positive turn, under circumstances that appear hopeless, seems to be what triggers trust in the healthcare team and the development of an inspiring relationship, which fosters the perception of hope throughout the end of life. Based on these data, it seems reasonable to infer that caregivers’ hope may be triggered and sustained through the development of an inspiring relationship with the healthcare team and that this relationship begins when patients and caregivers are told the truth about their situation in an empathetic way.<sup>29-30</sup> Of note, years before the recognition of the benefits of EPC interventions,<sup>10,15,31</sup> Hagerty et al, reported that the majority of advanced cancer patients believed hope was not facilitated if the oncologist appeared to be nervous or uncomfortable (91%); if the prognosis was given to the family before the patient (87%); or if euphemisms were used (82%); further, the majority of patients preferred a realistic and individualized approach from the cancer specialist and detailed information when discussing prognosis.<sup>2</sup> In the same study, general

factors influencing hopefulness (in our terms, the antecedents of hope) were family members, religious beliefs or spirituality, friends, a positive attitude, children or grandchildren, partners, and advances in cancer care. In other words, inspiring relationships also emerged as crucial to supporting patients' hopefulness. From the results of our questionnaires and the brief lexicographic analysis, it seems possible to suggest that "realistic hope"<sup>2</sup> is an expectation of positive outcomes that are grounded on concrete evidence. Responses reveal that the positive outcomes implied by hope are not necessarily mutually exclusive extremes (dead – alive), but rather elements that characterize the QoL on a continuum from "healthy" to "dead"; for example, not experiencing physical pain or having the opportunity to discuss psychological or spiritual needs. Finally, the evidence that grounds "realistic hope" is the one offered by the healthcare team when giving the prognosis to patients and their primary caregivers, by calling, often for the first time, an incurable disease by its name, in a way that is truthful and that helps them reconsider the positive outcomes they can *realistically* hope for.

This qualitative study is exploratory in nature and our findings should now be confirmed in a large survey conducted in representative caregivers' samples. Moreover, future research should also focus on caregivers' hope at the time of referral to and during EPC treatment. Another limitation is the extension of the corpus that does not allow for quantitative lexicographic analyses that may allow generalizations. However, the comparison of the meanings of "hope" that emerged in responses to our questionnaire with the analysis of the modifiers in a large corpus of spoken Italian provides a starting point for designing more extended corpus searches.

## Conclusion

This study contributes to current research on hope in healthcare settings, by focusing on hope perceptions by bereaved primary caregivers of cancer patients who received EPC as a standard clinical practice. Contrary to intuitions regarding the scant possibility of hope in the clinical context of incurable onco-hematologic illnesses, the primary caregivers reported developing hope and maintaining it, until the death of their loved ones. They connected the finding of hope to the adoption of EPC treatments and to the inspiring relationships they were able to develop with the healthcare team. A crucial factor in this positive dynamic seems to be the connection between hope, truth, and trust; connections among these fundamental concepts should be further explored. Future studies should also investigate physicians' perceptions of hope in onco-hematologic settings,<sup>3</sup> as the tension described in the literature between hope and truth might be the effect of misaligned expectations, between patients, caregivers, and physicians. Our study findings will inform future research studies on caregiver perceptions, as well as possible interventions to enhance hope in patients and caregivers.

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## Conflict of Interest

The authors indicated no financial relationships.

## Author Contributions

Conception/design: S.B., V.G., E.B., L.P., O.O., C.C., C.A.P., C.Z., F.E., E.B., M.L., E.B. Provision of study material or patients: L.P., F.A., S.E., C.M., L.C., M.C., M.L., E.B. Collection and/or assembly of data: S.B., V.G., E.B., L.P., F.A., S.E., C.M., L.C., M.C., E.B. Data analysis and interpretation: S.B., V.G., E.B., O.O., C.C., C.A.P., C.Z., F.E., E.B., M.L., E.B. Manuscript writing: S.B., V.G., E.B., L.P., F.A., S.E., C.M., L.C., M.C., C.C., O.O., C.A.P., C.Z., F.E., E.B., M.L., E.B. Final approval of the manuscript: All Authors.

## Data Availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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