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Original Article

Perceptions of Death Among Patients with Advanced Cancer Receiving Early Palliative Care and Their Caregivers: Results from a Mixed-Method Analysis

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Abstract

Background: Oncologists are often concerned that talking about death with patients may hinder their relationship. However, the views of death held by patients have not been thoroughly investigated. This study aimed to describe the perception of death among patients with advanced cancer receiving early palliative care (EPC) and their caregivers.

Material and Methods: Qualitative and quantitative analyses were performed on 2 databases: (a) transcripts of open-ended questionnaires administered to 130 cancer patients receiving EPC with a mean age of 68.4 years and to 115 primary caregivers of patients on EPC with a mean age of 56.8; (b) texts collected from an Italian forum, containing instances of web-mediated interactions between patients and their caregivers.

Results: Quantitative analysis shows that: (a) patients and caregivers are not afraid of speaking about death; (b) patients and caregivers on EPC use the word "death" significantly more than patients on standard oncology care (SOC) and their caregivers ($P < .0001$). For both participants on EPC and SOC, the adjectives and verbs associated with the word "death" have positive connotations; however, these associations are significantly more frequent for participants on EPC (verbs, Ps $< .0001$; adjectives, Ps $< .003$). Qualitative analysis reveals that these positive connotations refer to an actual, positive experience of the end of life in the EPC group and a wish or a negated event in the SOC group.

Conclusions: EPC interventions, along with proper physician-patient communication, may be associated with an increased acceptance of death in patients with advanced cancer and their caregivers.

Key words: early palliative care; qualitative research; advanced cancer; communication; death; terminal care.

Implications for Practice

The realistic description of patients' prognoses, through the support of a multidisciplinary EPC team, could contribute to help patients with cancer accept their death and prepare for it. This study also suggests that speaking about death in a meaningful way may prove to be highly beneficial to patients' primary caregivers.

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Introduction

Integration of early palliative care (EPC) with standard oncology care (SOC) results in multiple benefits for patients with cancer and their caregivers.[1] For example, EPC is associated with improved quality of life and reduced physical and psychological symptoms burden. In addition, EPC contributes to improved prognostic awareness, timely hospice use, and lower rates of intensive health care utilization near death.[2,3] Although a key aspect of EPC is honest prognostic communication with patients and their caregivers and psychological preparation for death,[4,5] and in spite of a growing interest in this particular aspect of cancer care,[6,7] studies focusing on the perception of death by patients with cancer receiving EPC are lacking.[1]

Understanding people's attitudes toward death are fundamental to inform public policies about end-of-life care. Nevertheless, discussions about death are, by nature, disturbing and hard to deal with.[8,9] A recent study conducted by the American Society of Clinical Oncology examined patients' and caregivers' thoughts about end-of-life care. Respondents agreed that it is important to communicate with one's doctor about the end of life, but only 26% of respondents reported having discussed it with their doctor.[10] Although physicians themselves recognize the importance of these conversations, their implementation is often neglected.[11] End-of-life communication skills are generally lacking in medical schools and care providers experience barriers to serious conversations, at many levels.[12,13] Dying people need to talk about death to normalize and demystify this topic but are denied access to these conversations by both physicians and the rest of society.[14,15]

Acceptance of death is also a fundamental precondition of palliative treatments;[16,17] several studies show that it facilitates the process of caring for the dying.[18,19] In this respect, the need to assess perceptions about death in different cultural settings has been highlighted.[20]

Relative to the Italian situation, literature is scarce on this topic. A recent paper about palliative care and the narrative surrounding the end of life as they are represented in Italian public television programming[21] states that the difficulty in accepting death is a constant that goes beyond differences of time and place, apparently similar in many countries. Thus, we have no reason to believe that the Italian situation should diverge from the aforementioned scenario.

This work aims to describe the way in which patients and caregivers facing oncological diseases conceptualize death. More specifically, we hypothesize that receiving EPC can be associated with positive perceptions of death as expressed through individuals' linguistic choices, based on the assumption that what people say reflects their physical, psychological, and social condition.[22,23] For this purpose, original linguistic data are studied, combining quantitative and qualitative[24,25] corpus-based methods, commonly adopted in linguistic research.[26]

Materials and Methods

Participants

This study was conducted within the outpatient Oncology and Palliative Care Unit, Civil Hospital Carpi, USL, and the outpatient Palliative Care Unit, Section of Hematology, Azienda Ospedaliera Universitaria di Modena, Italy. The primary study data were collected within these 2 outpatient units, where the EPC teams follow on average 20-30 patients/week, and each patient on a regular basis, 1-2 times/week.[24,27,28] Outpatient EPC interventions are integrated with both specialized nurse home care services and hospices, as recommended.[24,27-30] The main reason for referral is pain beyond an acceptable threshold.[24] We consecutively enrolled patients with advanced cancer receiving EPC at the study institutions between July 2020 and February 2022. Other eligibility criteria included being a patient at the clinic for at least 1 month (corresponding to 4 visits), age ≥18 years, and willingness to complete an interview. Patients were asked to identify their primary caregiver/s, who was/were then also invited to take part in the study (eligibility criteria: age ≥18 years); caregiver refusal did not prevent patient participation. To include death perception in the bereavement period, a sample of bereaved caregivers was also included. In this case, we required caregivers to have been bereaved no earlier than 2 months before enrolment to avoid acute grief and no later than 2 years to minimize recall bias. All participants provided written informed consent prior to data collection.

Data Collection

Two different collections of linguistic data (corpora) were created for the analysis: the "EPC Corpus" and the "Forum corpus".

The "EPC Corpus" (henceforth, EPCC) is a collection of transcripts of interviews, consisting of 53 308 tokens (ie, the overall numbers of words).[24] Patients completed a self-administered pen-and-paper semi-structured interview, during their appointments at the Units. Caregivers completed the same task at home. When both the patient and his/her caregiver/s participated in the study, their interviews were completed within the same month. To reduce the risk of a social desirability bias, the questionnaires and the collection procedure have been anonymized. Participants were asked to report their thoughts and feelings about their experience with the disease: (1) prior to the EPC intervention; (2) during the EPC intervention; (3) and about possible changes in the perception and expectations of their future, including at the end of life, following the exposure to EPC, with an explicit mention on death. The semi-structured interview ended with an open question (see Supplementary Table S1 for the complete list of questions included in the interview). To perform linguistic analysis, transcriptions of the interviews were collected in a corpus through the Sketch Engine platform. The collection of data was performed in accordance with the ethical standards of the 2013 Declaration of Helsinki and was approved by the Ethics Committee of Modena (N. 0026448/20).

The "Forum Corpus" (henceforth, FC), consisting of 3 163 910 tokens, was automatically collected, gathering texts from the forum website of AIMAC (*Associazione Italiana Malati di Cancro, Parenti, Amici*, Italian Association of Cancer Patients, Relatives, Friends; https://forumtumore.aimac.it/) through the corpus building software embedded in the Sketch Engine platform. This website contains many instances of web-mediated interactions between users, who are mainly oncological patients or their caregivers, dealing with practical and emotional issues related to oncological diseases; thus, we hypothesize that it could be considered a good example of oncological discourse among individuals receiving SOC only.

Data Analysis

To know (a) how death is perceived by patients and caregivers dealing with oncological diseases and undergoing EPC, and (b) if these perceptions may be influenced by the EPC setting, we performed various analyses on our corpora. First, we evaluated the combinatorial properties of the word "death." By "combinatorial properties," we mean the most frequent combinations in which the word "death" appeared. Generally, the semantic potential of a word "*x*" is specified and restricted within discourse by the words it is combined with. This is a phenomenon that allows mutual understanding by reducing ambiguity; at the analytical level, it can be considered as a clue, indicating the sense of "*x*" that is probably the most relevant for the individuals who are using that word.[31] Since the word indicating death in our corpora is a noun, we focused on the syntactic contexts that usually modulate the meaning of nouns, ie, verbs and adjectives.[32] The meaning of nouns can be modulated by the verbs they are objects of, or by the modifying adjectives, as can be seen in the following examples, where the noun "book" appears first as the object of different verbs: in "to enjoy a book", the noun refers to the story; in "to buy a book", it refers to the object. Similarly, when the noun appears with adjectives: in "an interesting book", it refers to the content; in "a thick book", it refers to the whole object; in "a red book", it refers to the cover. The combinations of the word "death" were found by using Sketch Engine, a platform commonly used by linguists, translators, and lexicographers to analyze the meaning of lexical entities through text mining functions.[33] Sketch Engine allows us (a) to store our corpora; (b) to linguistically annotate stored corpora; and (c) to describe meanings of words. Once adjectives and verbs modulating the noun "death" were identified, N-1 chi-squared tests were performed to compare their frequencies in the 2 corpora.

To provide context for the interpretation of these results, the second level of analysis involved a qualitative approach, which considered segments larger than the phrase, usually a sentence. This part of the analysis was performed by 2 of the co-authors independently (SB and VG); every time an uncertain case emerged, this was solved through discussion. Through qualitative analysis, we observed markers of modality and evaluative expressions. Markers of modality are linguistic strategies that indicate events or situations that cannot take place at the time when the sentences are uttered.[34,35] Modal expressions can be lexicalized as adverbs (ie, "perhaps"), or, more commonly, as modal verbs (ie, "must", "can") or modal periphrasis (ie, "I would like", "I hope that"). Speakers use these constructions to indicate possible, desirable, or hypothetical events. Thus, they are important to understand utterances such as, for example, "a good death": if someone said, "I wish my father could have a good death", it would be very different from the case of, "I am grateful because my father had a good death".

Results

Study Population

For EPCC data, 130 patients with advanced cancer under EPC were consecutively enrolled between July 2020 and February 2022. A total of 115 caregivers of both living and deceased patients were also involved in the study in the same period. Of the 130 patients enrolled, 60 (46.2%) were female and 70 (53.8%) were male. Their mean age was 68.4 years (ranging from 35 to 87). One-hundred-fifteen (88.5%) were diagnosed with solid cancer, while 15 (11.5%) had a hematologic malignancy. The mean time receiving EPC at the time of study registration was 9.9 months. Of the one-hundred-fifteen caregivers enrolled, 77 (67%) were female and 38 (33%) were male. Their mean age was 56.8 years (ranging from 20 to 82). Seventy-eight (67.8%) were taking care of an alive patient, while 37 (32.2%) took care of a patient who was dead at the time of the interview. The mean time their beloved ones received EPC or were receiving EPC at the time of the interview was 14.1 months (additional details are reported in Supplementary Table S2).

For FC, instead, demographic and clinical information about patients and caregivers is not available. The AIMAC forum is a growing community that counts 9311 users. First users were activated in February 2010 and new users are constantly signing in; users' demographic data and clinical information are not automatically recorded. Thus, we have collected demographic information spontaneously provided by a random sample of users who have indicated at least their age in the forum section "Raccontiamoci" (Let's introduce ourselves), where people may introduce themselves to the community (Supplementary Table S3). Linguistic interactions collected in FC cover a time span ranging from February 2010 to July 2021.

Quantitative Use of the Word "Death" and Its Combinatorial Properties in Phrases

The use of the word "death" both in the EPCC and in the FC was very common. It represents the fourth most frequent noun among the nouns used in the EPCC and the 78 most frequent noun among those of the corpus FC.

In terms of occurrences, the word "death" occurs 185 times on a total of 15 287 nouns in the EPCC (1.21%) and 1134 times on a total of 568 754 in the FC (0.2%). The proportion of the word "death" is significantly higher in the EPCC than in the FC, 95% CI, 0.85–1.2, $P < .0001$.

The frequency of verbs associated with death was significantly higher in the EPCC compared to the FC (Table 1). For both corpora, most of the verbs (80%) associated with death had a positive connotation (eg, "I learned to accept death"). In instances where a verb associated with death was present in the FC, but not in the EPCC, the difference between both corpora was not statistically significant.

In Table 1, the percentage of the total of the verbs for the 2 corpora is reported in brackets. For each verb, 95% CI and *P*-values are also reported.

The analysis of the adjectives modifying the word "death" in the 2 corpora is shown in Table 2.

In Table 2, the percentage of the total of the adjectives for the 2 corpora is reported in brackets. For each adjective, 95% CI and *P*-values are also reported. We found multiple adjectives (both positive and negative) modifying "death" in the study data. Interestingly, adjectives modifying "death" in the EPCC had positive meanings such as *peaceful* ("*sereno*") and *enviable* ("*invidiabile*"). The frequency of adjectives with positive meanings modifying "death" was significantly higher in the EPCC. In the FC, the adjectives modifying "death" showed more varied semantic characterizations than those in the EPCC. Adjectives found in the FC but not in the EPCC had frequencies not high enough to result in a significant difference between both corpora.

Table 1. Occurrences of verbs with "death as object" in the EPCC and FC.

Verbs	Translation	Total occurrences		95% CI	*P*-value	Connotation
		EPCC	FC			
Accettare	To accept	7 (0.05%)	12 (0.002%)	[0.02, 0.09]	<.0001	Positive
Affrontare	To face	7 (0.05%)	7 (0.001%)	[0.02, 0.09]	<.0001	Positive
Concepire	To conceive	2 (0.013%)	0 (0%)	[0.004, 0.05]	<.0001	Positive
Vivere	To live	2 (0.013%)	4 (0.0008%)	[0.003, 0.05]	<.0001	Positive
Attendere	To wait	1 (0.007%)	0 (0%)	[0.001, 0.04]	<.0001	Positive
Assimilare	To assimilate	1 (0.007%)	0 (0%)	[0.001, 0.04]	<.0001	Positive
Contemplare	To contemplate	1 (0.007%)	0 (0%)	[0.001, 0.04]	<.0001	Positive
Percepire	To perceive	1 (0.007%)	0 (0%)	[0.001, 0.04]	<.0001	Positive
Arrivare	To arrive	1 (0.007%)	0 (0%)	[0.001, 0.04]	<.0001	Positive
Capire	To understand	1 (0.007%)	0 (0%)	[0.001, 0.04]	<.0001	Positive
Accompagnare	To accompany	1 (0.007%)	0 (0%)	[0.001, 0.04]	<.0001	Positive
Considerare	To consider	1 (0.007%)	0 (0%)	[0.001, 0.04]	<.0001	Positive
Aspettare	To wait	0 (0%)	11 (0.002%)	[-0.02, 0.004]	.577	Positive
Augurare	To wish	0 (0%)	5 (0.0009%)	[-0.02, 0.002]	.707	Positive
Accelerare	To speed up	0 (0%)	3 (0.0006%)	[-0.03, 0.007]	.771	Negative
Piangere	To cry	0 (0%)	2 (0.0004%)	[-0.03, 0.001]	.812	Negative
Spiegare	To explain	0 (0%)	2 (0.0004%)	[-0.03, 0.001]	.812	Positive
Immaginare	To imagine	0 (0%)	2 (0.0004%)	[-0.03, 0.001]	.812	Positive
Subire	To suffer	0 (0%)	2 (0.0004%)	[-0.03, 0.001]	.812	Negative
Vedere	To see	0 (0%)	2 (0.0004%)	[-0.03, 0.001]	.812	Negative

Qualitative Use of the Word "Death" and Its Combinatorial Properties in Sentences

Tables 3 and 4 respectively demonstrate the use of the word "death" when it is the object of a verb or modified by an adjective but in the broader context of the sentences in which the words occur. These tables qualitatively expand on Tables 1 and 2 that capture the combinatorial properties of the word "death" only in the context of phrases.

As for the perception of death in sentences including verbs with "death", in the EPCC the meaning of most of the verbs identified expresses the acceptance or rationalization of death. This is the case, for instance, of *to accept death* ("*accettare la morte*"), *to face death* ("*affrontare la morte*"), *to understand death* ("*capire la morte*"), and *to consider death* ("*considerare la morte*"). There are cases in which verb-object combinations unveil the expectation or nearness of death, as shown in *I am waiting for death* ("*attendo la morte*") and *death arrives* ("*la morte arriva*"). Even if syntactically the combination *death arrives* is a subject-verb structure, we decided to include it in our sample for the importance that the expression has for our analysis.

In contrast to the EPCC, in the FC verbs associated with the noun "death" can designate either the acceptance or the facing of the end of life, as in *to accept* ("*accettare*"), *to face* ("*affrontare*") and *to suffer* ("*subire*"). In the last example, death is depicted as an unfair event that is experienced passively. There are cases in which the verbs describe the experience of death as something that has already happened, as in *to experience* ("*vivere*"), *to see* ("*vedere*"), or as a future event, *to imagine* ("*immaginare*"). As for future representations of death, the data show several examples in which uses of "death" are associated with a feeling of relief, since the event of death can relieve patients from pain: eg, *to wait* ("*aspettare*"), in which the subject is waiting for the end of life, or *to wish* ("*augurare*"), ie, wishing someone to die. On the other hand, and in clear contrast with the data from the EPCC, verb phrases containing existential expressions or verbs denoting acceptance of death are characterized by negative polarity, as in examples (1)-(4):

(1) *Think of this wonderful house, where death does not exist, where we will drink together with intense passion at the unending fountain of love and happiness ("Pensa a questa meravigliosa casa, dove non esiste la morte, dove ci disseteremo insieme, nel trasporto più intenso alla fonte inesauribile dell'amore e della felicità").*
(2) *Maybe it's because I have not accepted his death. ("Forse perché non ho accettato la sua morte").*
(3) *I haven't yet accepted the death of my parents. ("Non ho accettato ancora la morte dei miei genitori").*
(4) *I haven't yet been able to come to terms with the death of my own father. ("Io ancora non riesco a metabolizzare la morte del mio [padre]")*

In other sentences, caregivers represent "death" as a desirable event, because it is the only thing that can relieve patients from pain, as in examples (5) and (6):

(5) *I would have never thought I could come so far as to wish my father would die. ("Non avrei mai pensato di poter arrivare ad augurare la morte al mio babbo . . .")*
(6) *By the way, we should always be thinking about the death we will all have to face one day. ("Tra l'altro sempre si dovrebbe pensare alla morte a cui tutti noi andiamo incontro").*

Table 2. Occurrences of adjectives coupled with "death" in the EPCC and FC.

Adjectives	Translation	Total occurrences		95% CI	*P*-value
		EPCC	FC		
Fisico	Physical	1 (0.02%)	0 (0%)	[0.003, 0.09]	<.0001
Sereno	Peaceful	1 (0.02%)	2 (0.001%)	[0.002, 0.09]	.003
Invidiabile	Enviable	1 (0.02%)	0 (0%)	[0.003, 0.09]	<.0001
Sicuro	Sure	0 (0%)	12 (0.007%)	[−0.06, 0.01]	.527
Dignitoso	Decent	0 (0%)	8 (0.004%)	[−0.06, 0.009]	.605
Certo	Sure	0 (0%)	6 (0.003%)	[−0.06, 0.007]	.655
Improvviso	Sudden	0 (0%)	5 (0.003%)	[−0.06, 0.007]	.683
Imminente	Imminent	0 (0%)	4 (0.002%)	[−0.06, 0.006]	.715
Dolce	Sweet	0 (0%)	3 (0.002%)	[−0.06, 0.005]	.752
Naturale	Natural	0 (0%)	2 (0.001%)	[−0.06, 0.004]	.797
Brutto	Bad	0 (0%)	2 (0.001%)	[−0.06, 0.004]	.797
Buona	Good	0 (0%)	2 (0.001%)	[−0.06, 0.004]	.797

Furthermore, some sentences in FC openly refer to death as a very tormented experience, as in example (7):

(7) *She did not deserve all this suffering, none of your parents deserved this ugly death. And we, as children, we also did not deserve it ("Non meritava tanta sofferenza, nessuno dei vostri genitori meritava questa morte brutta. E noi figli pure non ce lo meritavamo").*

Markers of modality clearly entail the representation of a "good death" as something that cannot really be experienced by either patients or caregivers, as in examples (8) and (9):

(8) *But you must try and accept his death as something painful ("Ma devi provare ad accettare la sua morte come una cosa dolorosa").*
(9) *The hope of someone who cannot accept death. ("La speranza di chi non riesce ad accettare la morte").*

Taking the same qualitative approach, we observed the adjectives modifying the noun "death" in their discursive context (Table 4).

As for perceptions of death in sentences including adjectives modifying "death" in the EPCC, all the adjectives occur once. The comparison again shows meaningful differences. In all instances where adjectives were used to modify death in the EPCC, they expressed positive connotations of death, experienced by patients and/or their caregivers. For example, bereaved caregivers described the dying process of their loved ones as serene or enviable (Table 4).

As for perceptions of death in sentences including adjectives modifying "death" in the FC, although positive connotations of death were present in the FC, these appeared in sentences expressing more the desire than the experience of a "good death". Caregivers in the FC often expressed that the patients deserved a "better death" than what they actually experienced, as shown in examples (10-12):

(10) *I was only asking for a sweeter death for my father. ("Chiedevo solo una morte più dolce per mio padre")*
(11) *I was hoping for a peaceful death for her. ("Speravo per lei una morte serena")*
(12) *I would have hoped, for him and for us, a peaceful death in old age for our sweet dad. But this is not what happened . . . ("Avrei desiderato per lui e per noi, una serena morte di vecchiaia per il nostro dolcissimo papà. Ma così non è stato . . .")*

In conclusion, qualitative analysis of data obtained through the quantitative approach shows a situation in which patients and caregivers in oncological settings are not afraid of speaking about death and of expressing their hopes and perceptions about it. However, the ones undergoing EPC seem to perceive death in a more positive way; more significantly, "good death" is for them a reality, an actual experience. In the data from the FC, instead, when participants refer to a "good death" it is generally to express regret that it did not happen or hope that it might happen.

Discussion

When referring to conversations about death, common sense has it that they should be avoided. In society, it is a sound interpersonal practice to avoid death as a topic of conversation among those who are not directly facing it and this assumption is commonly applied also to clinical settings where individuals are facing the end of life.[36-42] This study shows that, contrary to previous assumptions,[36] patients/caregivers facing hemato-oncological cancers tend to commonly use words referring to death, as the comparison with a general Italian corpus shows. Indeed, in the general corpus itTenTen16,[43] an Italian web corpus embedded in Sketch Engine platform collecting web-extracted data (5 864 495 700 tokens), "death" reaches only the 260-fourth position among the most frequent nouns (0.02%).

In our study data, the linguistic contexts in which the word "death" is used, largely reveal positive connotations of the end of life, although these are significantly more common in the EPCC than in the FC. As shown in a previous study on a subsample of these same reports, in the case of the EPCC, positive connotations were not attributed to the idea of death prior to the EPC referral but emerged following the EPC intervention.[24] Importantly, we found a key difference in the concept of a "good death" between the 2 corpora. Caregivers

Table 3. Verbs with "death" as object in EPCC and FC and illustrative quotations.

Verbs	Translation	Examples	English translation
Accettare	To accept	Ho imparato ad accettare la morte	I learned to accept death
Affrontare	To face	Non si è mai pronti ad affrontare la morte della persona cara	You are never prepared to face the death of your loved one
Concepire	To conceive	Ho iniziato a concepire la morte come qualcosa di più vicino e reale	I began to conceive of death as something closer and more real
Vivere	To live	Prima vivevo la morte come distacco, come fine di tutto, perdita insanabile	Before, I lived death as a detachment, as the end of everything, an irremediable loss
Attendere	To wait	Attendo la morte come un incontro	I await death as an encounter
Assimilare	To assimilate	Ti aiuta anche ad assimilare la morte	It also helps you integrate death
Contemplare	To contemplate	Ho sempre contemplato la morte	I have always contemplated death
Percepire	To perceive	Dopo questo percorso è cambiato il mio modo di percepire la morte	After this journey, my way of perceiving death has changed
Arrivare	To arrive	Può arrivare la morte perché è naturale	Death can come because it is natural
Capire	To understand	Ti dà il tempo di capire la morte e di accettarla	It gives you time to understand death and accept it
Accompagnare	To accompany	La morte in solitudine non è accettabile, la morte accompagnata lo può diventare	Death in solitude is not acceptable, accompanied death can become acceptable
Considerare	To consider	Ora considero la morte un passaggio che non mi spaventa	Now I consider death a passage that does not frighten me
Accettare	To accept	È difficile accettare una morte prematura	It is difficult to accept an untimely death
Aspettare	To wait	Chiusi in casa ad aspettare la morte	Locked in the house waiting for death
Affrontare	To face	Non stavano affrontando la morte con superficialità	They were not facing death superficially
Augurare	To wish	Poter arrivare ad augurare la morte al mio babbo	To be able to wish death to my father
Vivere	To live	Io vivevo la morte del mio più caro amico	I was experiencing the death of my dearest friend
Accelerare	To speed up	Il sedativo non accelera la morte	The sedative does not speed up death
Piangere	To cry	Oggi piango la morte della speranza.	Today I mourn the death of hope
Spiegare	To explain	Dover spiegare la morte a tuo figlio così piccolo	Having to explain death to your son so young
Immaginare	To imagine	Noi ci immaginiamo la morte come il distacco definitivo	We imagine death as the final parting
Subire	To suffer	Ho subito la morte di mia madre	I suffered the death of my mother
Vedere	To see	Pensi di vedere la morte in faccia...	You think you see death face to face . . . .

of people receiving EPC reported that their loved ones experienced a "good death", while, for caregivers of people receiving SOC, a "good death" for their loved ones was depicted as hope that was, regrettably, not attained.

The linguistic differences observed among EPCC and FC can be explained by external (ie, extra-linguistic) factors such as clinical experiences fostering acceptance of death and a more positive connotation of the end of life. EPC provides expert symptom management, which contributes to improvement in patients' wellbeing (control of pain and other symptoms) and, consequently, improved symptom burden and quality of life.[3,7] Moreover, EPC promotes honest and empathetic end-of-life communication, as well as physical and psychological support for the dying experience. These underpinnings of EPC likely lead to a more positive representation of death, which may promote increased acceptance and a positive view of the end-of-life phase among patients. In addition, the improved conditions of patients may have a downstream impact on their caregivers' perceptions of the end-of-life phase and death. In this respect, our linguistic analysis corroborates the systematic review of Haun and colleagues,[44] showing that "early palliative care interventions may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone."

The frequency of modal expressions, embedding references to a gap between the desire for a good death and the actual experience of patients in FC, demonstrates the important need for improved end-of-life care and preparation for the dying process for patients with cancer and their caregivers.

Our data reinforce the importance of effective communication strategies between physicians and patients/caregivers regarding illness, understanding, realistic expectations, and planning for the future.[1,45] This strategy can disclose patients' preferences about therapy and outcome, ensuring the possibility to solve doubts or questions regarding either palliative or disease-directed treatment options.[46] In this respect, the communication of death should be viewed as one of the central topics of physicians'/patients' discourse, in line with patients' and relatives' readiness and preferences.[47] This study suggests that engaging in clear and empathetic communication about the end of life, along with support from EPC, could be a way to begin bridging the gap between desired and experienced end-of-life for patients and their caregivers.[6,45]

This study has limitations, the main one being the lack of systematically-provided demographic and clinical data on the FC group, potentially questioning the legitimacy of its comparability with the EPCC group. Thus, caution typically used when generalizing results of quasi-experiments should be used in this case. For the same reason, we cannot

Table 4. Adjectives occurring with "death" in EPCC and FC and illustrative quotations.

Adjectives	Translation	Examples	English translation
Fisico	Physical	Non ho avuto alcun sentimento di paura o rifiuto su questo suo nuovo stato di morte fisica	I did not have any feeling of fear or rejection about this new state of his physical death
Sereno	Serene	Permettendoci di arrivare alla morte più sereni e preparati	Allowing us to arrive at the time of death more serene and prepared
Invidiabile	Enviable	Abbiamo avuto la "fortuna" di vivere un'esperienza di morte invidiabile	We had the "luck" to live an enviable dying experience
Sicuro	Safe	Il tumore non è più sinonimo di morte sicura	Cancer is no longer synonym with certain death
Dignitoso	Dignified	Io capii che aveva diritto a una morte dignitosa.	I understood that he was entitled to a dignified death.
Certo	Sure	Tumore prostatico, non significa a priori che sia preludio di morte certa	Prostate cancer does not mean a priori that it is a prelude to certain death
Improvviso	Sudden	Il dolore per la morte improvvisa di mio papà senza una diagnosi	The pain of the sudden death of my father without a diagnosis
Imminente	Imminent	I parametri vitali non danno segni di una morte imminente.	The vital parameters do not show signs of imminent death.
Dolce	Sweet	Chiedevo solo una morte più dolce per mio padre	I was only asking for a sweeter death for my father
Naturale	Natural	Sperando di non avere più noie fino alla morte naturale	Hoping to have no more troubles until his natural death
Sereno	Serene	Speravo per lei una morte serena	I hoped for a peaceful death for her
Brutto	Ugly	Purtroppo quella del mio papà è stata una morte bruttissima	Unfortunately, that of my father was a terrible death
Buona	Good	Si, è stata una buona morte	Yes, it was a good death

speak of an "actual" control group of patients/caregivers not receiving EPC intervention. However, based on the linguistic analysis of both corpora (Supplementary Table S4), we can infer that the FC group differed from EPCC group for the type of care received and may be considered a representative sample of patients receiving SOC only. In spite of these limitations, our results might still suggest a direction to follow when implementing strategies to improve death acceptance in the oncological population. Indeed, while the adjectives "palliative"/"palliativist" are significantly more frequent in the EPCC, the nouns "chemo"/"chemotherapy" is significantly more frequent in the FC. This is also consistent with the limits of implementation of EPC in Italy, with few exceptions,[48] as reported in the 2 most recent national and regional surveys, respectively.[49,50] Another limitation is represented by the type of data since spontaneous interactions could have strengthened the generalizations we have made. Finally, the individual frequency in the use of the word "death" among participants (an information not provided by the forum) would have been a more reliable type of information than the overall frequency in the 2 groups. The difference in data collection period between the EPCC (19 months) and the FC (12 years) may have biased the data. In fact, in a 12-year time frame more than one cultural representation of death and dying could be represented, while this is less likely over a 19-month time frame. Based on literature (eg,[51]), cultural attitudes toward death may take several decades or even centuries to change. Thus, we believe that in the current cultural context, data collection periods of 19 months and 12 years may be comparable, for the purpose of this study. Strengths of the study include access to large samples and the integrated use of qualitative and quantitative analyses of language used by patients and caregivers.

By integrating clinical, psychological, and linguistic methods, we can shed new light on several aspects concerning EPC treatments and, more generally, oncological discourse, unveiling recurrent correlations between clinical practices, emotional repercussions, and language choices of people experiencing oncological diseases. Such interdisciplinary approach allows scholars to highlight still neglected correspondences between phenomena, ascribed to various research areas.

Conclusion

This study indicates that talking about death is by no means a taboo for both patients receiving EPC and their caregivers. In both our corpora "death" was referred to very frequently, as compared to a non-specialist corpus of Italian,[43] demonstrating that for patients/caregivers talking about death can be considered a common practice in interactions with physicians or with other patients/caregivers.

In addition, results from the quantitative analysis do not support the expectation that death would be mainly characterized by negative connotations. Indeed, in both corpora words explicitly designating the experience of death are often combined with words expressing its rationalization or acceptance. However, qualitative analysis has revealed that, while in the EPCC positive representations of death are embedded in syntactic constructions designating an actual, positive experience of the end of life, in the FC patients/caregivers seem to lack a real experience of good death. This linguistic evidence hints at the fact that a positive experience of death may indeed be favoured in EPC settings.[19,52]

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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., U.F., L.L., K.C., A.P., V.F., I.B., 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., U.F., L.L., K.C., A.P., V.F., I.B., 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: All authors. Final approval of manuscript: All authors.

Data Availability

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

Supplementary Material

Supplementary material is available at *The Oncologist* online.

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