

Challenges for oncologists in discussions about death/ end of life care- a systematic review

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Received: 20.05.2023 • Accepted for publication: 19.07.2023

Abstract

Aim of study: The aim of this systematic review was to identify the influencing factors of discussions about death and end-of-life care, from the oncologists' perspective.

Materials and Method: A systematic research was realised on PubMed, between 12.12.2022 and 13.01.2023, the eligibility criteria being established through exclusion criteria, according to PRISMA diagram.

Results: The results were divided into narrative themes, starting with patients' needs and the benefits of end-of-life discussions. Next, the main fears of oncologists were identified, as well as their underlying mechanisms. All these aspects represent the base of communication barriers, which are related to the doctor, but also to the patient or his family. In this context, a vicious circle appears, in which everyone tries to emotionally protect himself. Regarding the doctors' reluctance, we mention aspects such as: the feeling of guilt, the fear of responsibility, of decision making, of diminishing hope and being in conflict with the families, all these influencing the professional and the personal doctors' life.

Conclusions: Even if there were identified the key-points of the main challenges in discussions about death and end of life care, it is still necessary to deepen the inner experiences of the oncologists, to identify their personal experiences related to death, as well as the socio-cultural or spiritual differences which are the basis of understanding this process.

Keywords: palliative care, end-of-life care, death discussions, end-of-life communication, oncologists.

Rezumat

Scopul: Scopul acestei revizii sistematice este acela de a identifica factorii care influențează discuțiile despre moarte și îngrijirea la finalul vieții, din perspectiva medicilor oncologi.

Materiale și metodă: A fost realizată o căutare sistematică pe PubMed, în perioada 12.12.2022-13.01.2023, criteriile de eligibilitate fiind stabilite prin criterii de excludere, cu ajutorul diagramei PRISMA.

Rezultate: Rezultatele au fost împărțite pe teme narative, pornind de la nevoile pacienților și beneficiile pe care discuțiile de la finalul vieții le aduc. Ulterior, au fost identificate principalele teme ale oncologilor, precum și mecanismele care stau la baza acestora. Toate acestea reprezintă baza barierelor în comunicare, fiind identificate aspecte legate fie de medic, fie de pacient sau familie, existând astfel un cerc vicios în care fiecare încearcă să se protejeze emoțional. În ceea ce privește reținerile medicilor, au fost identificate aspecte precum: teama de responsabilitate, de a lua decizii, teama de a intra în conflict cu familia pacientului sau de a răpi speranța, sentimente de vinovăție, toate acestea având răsunet în viața lor profesională și personală.

Concluzii: Cu toate că au fost identificate punctele-cheie ale provocărilor principale în discuțiile despre moarte și îngrijire la finalul vieții, este necesară aprofundarea trăirilor interioare ale oncologilor, identificarea experiențelor personale legate de moarte, precum și diferențele socio-culturale sau spirituale ce stau la baza înțelegerii acestui proces.

Cuvinte cheie: îngrijiri paliative, îngrijire la finalul vieții, discuții despre moarte, comunicarea la finalul vieții, oncologi.

Introduction

In the current context, medicine has an essential role regarding life prolonging modalities and the continuous attempts to overcome death. However, death is a natural process and it becomes necessary identifying the methods for sustaining the quality of life, especially when curative treatments are excluded. For this, communication between doctor and patient, but also between family and patient, is essential.

Palliative care focuses on one of the most challenging medical topic - end-of-life and death discussions. Even if these can create discomfort and insecurity for both sides, patients and their families, but also for doctors, it still has an important impact on the perception about disease and the way in which the stages of a diagnosis with reserved prognosis are overcome. So, the anticipatory care planning becomes necessary, because it concentrates on the patients' needs (1). This type of approach is addressed to terminal patients and to those with one year or less life expectancy (2). But, in reality, these topics are discussed about a month before death (3).

Communication is the main instrument to integrate aspects about death and end-of-life care in the discussion about oncological disease, which is not an isolated moment, but an entire process that can bring many physical, psycho-emotional, social or

spiritual changes (4). The doctor is often responsible for identifying the right moment to initiate these discussions. Nonetheless, there are data according to which many patients have never discussed such aspects with their doctor (1). Therefore, it is necessary to identify the limiting factors and the facilitating ones in the initiation of end-of-life or death topics among oncologists.

Material and method

Search strategy: A systematic research was realised on PubMed, between 12.12.2022 and 13.01.2023, using the next key words: *palliative care, end-of-life care, death discussions, end of life communication, oncologists*. The searches included only English articles. We screened the articles based on the title and the abstract, then we selected only the full-text articles.

Study selection: According to PRISMA diagram (Fig.1), the full-text of all remaining papers were reviewed for exclusion criteria, such as: studies on paediatric population or non-oncologists professionals, studies on end-of-life communication between patients and their families and some communication guidelines. After this selection, we included only 18 articles.

Data extraction and synthesis: The data from the full-text articles were extracted in a table (Table 1) and systematized according to the authors and the publication year, the study design, the aim of study and the outcomes. Then, we did the thematic synthesis, to clarify the central points of the review.

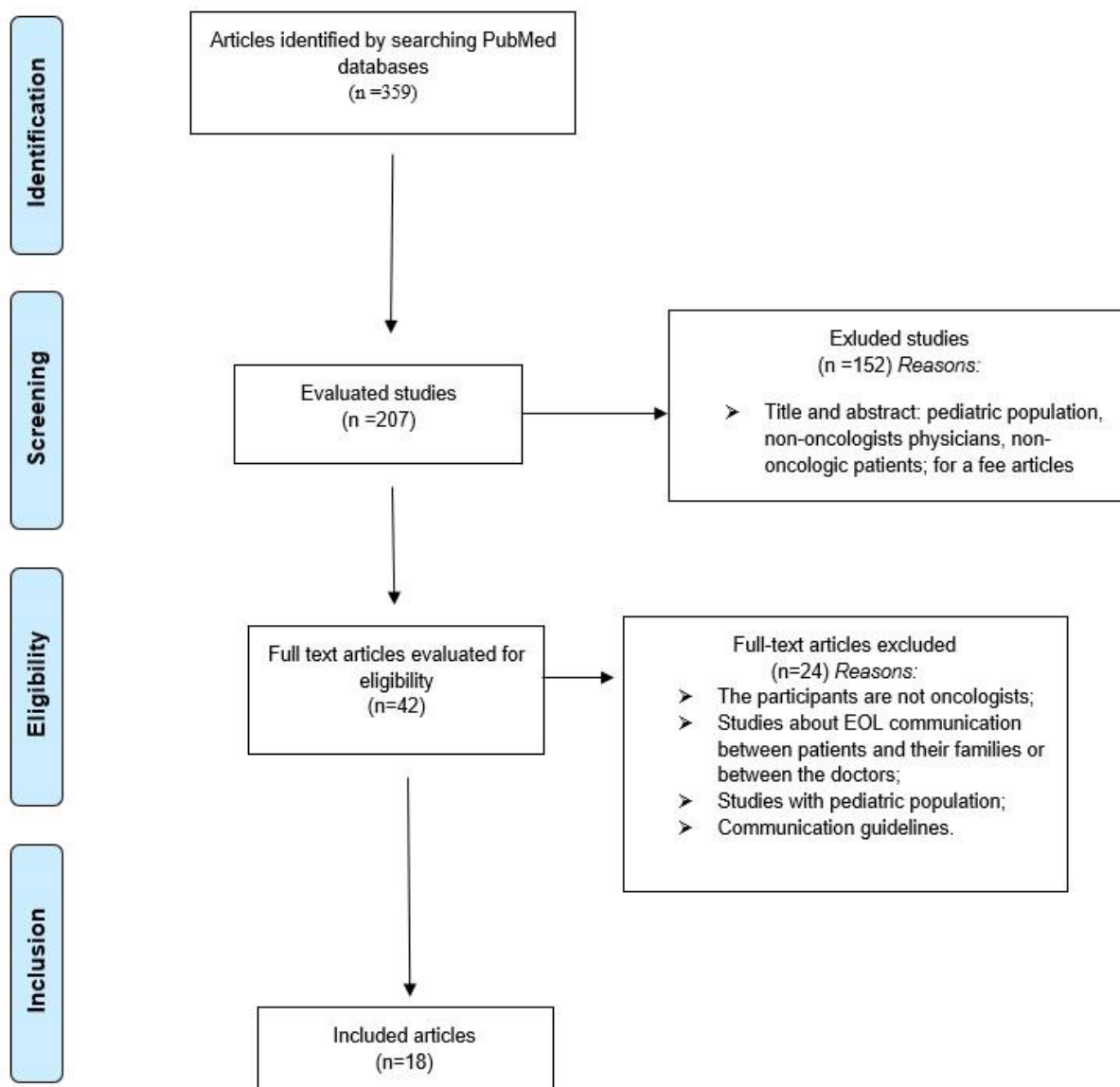


Figure 1 - Study selection on PRISMA diagram

Summary of findings

Table 1 - Summary of findings

Author, publication year	Design of study	Aim of study	Outcomes
Anderson et al., 2019 (5)	Qualitative systematic review	Identifying the characteristics of prognosis and end-of-life communication between health professionals and patients' relatives	6 key-points: highlighting the patients' deterioration, involving the family in decision-making, continuation of care even after curative treatments, individualizing communication, sincerity and clarity, specific methods for providing information and the role of medical team members in communication
Bristowe & Brighton, 2015 (1)	Review	Identifying the main barriers among physicians regarding end-of-life discussions	the uncertain prognosis, the fear of causing distress, difficulty in identifying the opportune moment to initiate discussions
Laor-Maayany et al., 2019 (12)	Questionnaire	Examining the association of Compassion Fatigue and Compassion Satisfaction with the feeling of failure, pain, exposure to suffering and death among oncologists	increased levels of compassion fatigue and grief, moderate levels of failure feeling and lack of association between exposure to suffering/death and compassion fatigue and satisfaction
Piggott et al., 2019 (7)	Cross-sectional study	Identifying barriers on discussing goals of care from the oncologists, residents, and nurses' perspectives	difficulty on accepting an unfavourable prognosis and on understanding the limits of supportive treatments
Luna-Meza et al., 2021(16)	Descriptive-exploratory qualitative study	Analysing the aspects influencing health care professionals' decisions regarding end-of-life care in the Colombian population	the clinical condition of the patient, the socio-cultural context; their own level of training in palliative care
Chan et al., 2022 (6)	Cohort study	Studying the impact of end-of-life discussions on the use of life-sustaining treatments in the last three months of life of cancer patients in Taiwan	less aggressive end-of-life care and better quality of life
Kamau & Medisauskaite, 2017(10)	Systematic review and meta-analysis	Assessing the prevalence of increased levels of distress among oncologists	32%-burnout, 27%-psychiatric morbidity, 42-69%-stress, 12%-depression, 30%-problems with alcohol consumption, 20%-drug use, etc.
Braun et al., 2022 (11)	Questionnaire	Examining how Israeli oncologists Locus of Control influences Compassion Fatigue and Satisfaction	positive association between external sense of control and compassion fatigue and negative association between internal sense of control and compassion fatigue
Otani et al., 2011 (13)	Cross-sectional study	Evaluating the difficulty experienced by oncologists communicating the discontinuation of treatment	47% -burden due to aspects related to time, the fear of causing suffering to patients and their families

Woo, Maytal & Stern, 2006 (8)	Article	Describing the difficulties faced by patients at the end-of-life and the challenges for physicians in approaching their care	Patients: pain, depression, coping mechanisms, sense of dignity, need for control; doctors: fear of therapeutic failure, insufficient communication training, personal discomfort with death-related topics
Marcus & Mott, 2014 (4)	Literature review	Highlighting the importance of breaking bad news	Limitations related to communication training
Granek et al., 2013 (15)	Semi-structured interviews	Evaluation of oncologists experiences in the context of losing a patient, but also of communication barriers in the context of the end-of-life	Physician-related barriers (difficulties related to treatment, personal discomfort with the idea of death, shifting responsibility to colleagues, insufficient experience and focus on healing), patient-related barriers (reluctance to discuss end-of-life, language barriers, young age) and institutional barriers (stigma related to palliative care, lack of protocols and lack of training for oncologists)
Mori et al., 2015 (14)	Cross-sectional study	Identifying factors related to oncologists that contribute to delaying end-of-life discussions in patients with advanced cancer	Physician's previous experiences of end-of-life discussions, their perception of what a 'good death' means
Keating et al., 2010 (2)	Poll	Identifying characteristics about physician and medical practice associated with end-of-life discussions	Most of the doctors would not talk to patients until symptoms appears or until the treatment options have been tried
Sutherland, 2019 (9)	Article	Description of the main issues related to end-of-life discussions	lack of medical training on death issues, the patients' death seen as a therapeutic failure, difficulties in choosing the right moment to discuss
Pfeil et al., 2015 (17)	Qualitative study-interviews	Identifying communication issues related to end-of-life treatments and identifying the roles of oncologists and nurses in preparing patients for end-of-life decisions	Oncologists think that the main barriers are the patients with unrealistic expectations, uncertainty about the appropriate time for discussions, but also difficulties in balancing their degree of emotional involvement and making objective decisions
Koh et al., 2018 (18)	Questionnaire	Identifying how physicians practice end-of-life discussions and their views on how these can improve the quality of end-of-life care	Most participants reported that they were involved in end-of-life care discussions with a low level of satisfaction; the most suitable moment for initiating discussions - when the disease is metastatic or in progression; family members should be involved in discussions

Jackson et al., 2008 (19)	Semi-structured interviews	Understanding how oncologists provide end-of-life care, the emotions they experience, and how caring for dying patients can affect job satisfaction and burnout risk	Differences between doctors who consider that they also have psychosocial duties regarding patient care and those who limit themselves to a medical approach only. The first category: they have a clear method of communication about the end-of-life and skills to positively influence the patient and the family
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Results

The needs of patients and their families, benefits of end-of-life discussions:

In the selected articles, there were identified many modalities to draw attention that the patient is in his last days. Firstly, it is about to emphasize his deteriorate state, observed by the doctor or by the family members. Then, it is about the implication in decision making with the doctor. The continuation of patient's care after finishing curative options is another important aspect to avoid the feeling of abandonment. Discussions can also be held about the quality of communication, because the doctor have to keep in mind the possible previous death experiences of the family, the cultural and religious differences, and also the way the patient would like to receive the information. It is also important offering time to integrate the new aspects about disease and death in the family's life (5).

The initiation of end-of-life discussions brings many benefits. Talking about the therapeutic options or other aspects regarding care in the last days of life is part of ACP (advanced care planning), an approach intended to facilitate the transition through the different stages of the disease, improving the quality of life, but also the quality of death.

One of the evaluated studies emphasizes that patients who discussed end-of-life issues received less sustaining life interventions in their last months, with benefits like: understanding the uselessness of potentially aggressive measures, fulfilment of their own wishes and needs regarding therapeutic measures, avoiding useless costs (6). In the context of late discussions, patients can no longer achieve their expectations - because of the deterioration of cognitive functions- inclusively the ones about place of passing, so many of them die in the hospital, having negative experiences comparing with the ones who die at home or at hospice (7).

The main needs of the patients at the end of life are: control of pain, specialized help for depression and identification of the individual methods of coping, keeping the dignity and the feeling that one can control his own life, but also other individual aspects (8). Therefore, these aspects can be properly evaluated and managed by having early discussions, this also helping the family to have more time with the loved one and to prepare for what is next (9).

The fears of oncologists/ the impact of oncology on oncologist
Oncology has a major impact on the psycho-affective component, because of the limit-experiences and decisions. For the doctors, the feeling of fear, mistrust and helplessness can become overwhelming.

There are many factors involved in distress among oncologists: the responsibility of diagnose and communicate it to the patient, of making the best decision or properly inform

and support him. Also, the doctor can disappoint the patient or the family, he can feel the burden of patient's death with consequences on his personal or professional life, with decrease in the quality of the medical act. There were described many parameters of the distress among the oncologists: burnout, psychiatric morbidity, stress, depression, sleeping disorders, alcohol abuse or other substances (10). An article brings to attention two concepts regarding the inner manifestations of the oncologists: compassion fatigue, as a negative experience, with decrease of empathy and also of professional capacity and a distancing tendency from the dying patient. On the other side, it is the compassion satisfaction, an opposite experience, when the doctor is fulfilled by helping. Also, he may also understand the deterioration or the death of a patient as a failure, a possible cause of this being the medical education focused on cure or prolonging life and less focused on the quality-of-life issues (11,12). According to one of the studies, another difficult task is to communicate the interruption of active oncological treatment, due to the fear of not hurting the patient, of not ruin his hope or not being in conflict with the patient's relatives (13).

Another identified aspect is the *locus of control*, as the way individuals understand the causes of the events and there are two types: the *internal* locus (aspects related to someone's decisions and facts) and the *external* one (aspects related to environmental factors) (11).

The feeling of guilt among oncologists is associated with internal locus of control (the physician makes a connection between his professional results and his degree of involvement and dedication), making the transition to compassion fatigue. On the other side, the helplessness feeling is associated with the external locus (when the doctor is aware of what he cannot control by his own forces) and it can also be associated with compassion fatigue (11). Therefore, it is important to identify the need for psycho-emotional support for doctors and different methods to help normalize the death process, including the literature, many of the literary works having death as a central theme (14).

Barriers in communication

Initiating the discussions about death or end of life care is often difficult. But the doctor is usually the one who has the moral responsibility to discuss these aspects. There have been identified some elements as barriers in communication at the end of life.

Firstly, there are *factors regarding the doctor*, as the difficulty of providing oncological treatment and palliative care concurrently, because of the apparent contradiction between those two. Also, oncologists describe the topic of death as a difficult and painful one. Usually, the greater the discomfort to discuss about death is, the longer the presentation of end-of-

life care options is delayed. Other identified barriers are gaps in communication between specialists or shifting responsibility for discussions from one doctor to another, as well as focus on curative treatments (15).

Even if there is a fear of causing suffering to patients or families, one of the studies mentions that, beyond the limited time until death, there are other sources of hope, such as fulfilling wishes, maintaining quality of life and dignity, or the hope of a peaceful death, which emphasizes that death does not necessarily cancel hope. It is important to have a balance between providing honest information and maintaining hope (1).

There are also data according to which oncologists believe that the main communication barriers are related to the patient or relatives- their inability or fear to accept the prognosis (7). Postponement of discussions by the patient is frequently encountered, as a result of the inability to accept his situation. In this context, the doctor's mission becomes even more difficult, because of the patient's anxieties. This is why the time chosen for discussions requires increased attention to the psycho-emotional stage of the patient. Therefore, a lot of patience and empathy is needed in this process of communication and attention to the human being, not just to the patient, to be able to understand him and to anticipate his reactions (16). This task becomes more difficult the younger the patients are (15).

There are also factors related to the medical system, the environment in which the medical act is carried out, such as the lack of comfortable and intimate spaces, as well as the overloaded schedule (4). Time is essential for patients to understand what is happening to them and for the doctor to observe some reactions and succeed identifying the patient's problems. Also, many misconceptions about palliative care and the inevitable association with death contribute to this reluctance to plan end-of-life care as early as possible, as well as the lack of clear protocols in this regard (15). According to a study, most participating physicians did not discuss end-of-life care issues with their patients until their condition began to deteriorate. There is also a difficulty of estimating the patients' life expectancy. It is interesting to note that younger and female doctors started discussions earlier in the course of the disease (2).

Discussions and conclusions:

The studies included in this review contain, beside communication elements, notions about the patients' needs, because, to identify communication barriers among doctors, it is essential to understand what is the real purpose of effective communication.

Another important topic is the oncologist's impact and the events that can trigger negative feelings, with consequences on personal and professional life and, therefore, impact on patients care.

The majority of the studies are focused on the general identification of the main end of life communication challenges. Although some elements that influence end of life discussions have already been identified in the literature, future research directions are taking into account the thoroughgoing of the inner experiences of the oncologists when they face with death and the ways in which their personal life and previous experiences influence their approach about death. Inter-individual, social, cultural or spiritual differences, which can contribute to the perspective on death are also targeted.

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