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Management model of caregiver's grief in a tertiary oncological center Hospice, from anticipatory mourning to condolence conversation: preliminary observations

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Abstract

Background Bereavement is a crucial physiological process in palliative care; grief-processing disorders can be diagnosed at least 6 months after death and can have severe clinical or psychological consequences. This study aims to verify how adequate management of anticipatory mourning and condolence conversations can be protective in the early stages of grief.

Methods Patients and caregivers are supported by a multidisciplinary team through semi-structured interviews. In condolence conversations within one month of the death, we identify signs of psychological fragility that require support for adequate processing of the loss.

Results From the condolence conversations, only 2–4% of caregivers who had received psychological support during the hospital stay and showed a good level of acceptance of their relative's end of life exhibited grief problems within 1 month of death; none showed excessive avoidance of memories, difficulties with trust, or feelings of emotional loneliness.

Conclusions Despite the limitations, the preliminary data of our study clearly suggest the protective potential of multidisciplinary support, particularly in reducing the risk of developing grief processing disorders. These considerations encourage us to implement our model of clinical and psychological support systems and develop pathways dedicated to caregivers experiencing greater difficulty.

Simple summary

Bereavement is a crucial psychological process, indeed processing the loss of a relative is a complex and painful experience, which can sometimes become complicated, with the appearance of grief processing disorders.
In palliative care and particularly in Hospice a progressive path is possible to protect patients and caregivers, identifying their vulnerabilities. This leads to correct management of anticipatory grief, taking advantage of all the skills of the multidisciplinary team involved in taking charge. Furthermore, scheduling an interview within a month

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of the death ("condolence conversation") allows the team to identify those most at risk for complicated grief and suggest strengthening strategies, directing the caregivers most in difficulty towards a dedicated psychological path.

Keywords Palliative care; multidisciplinary, Grief, Anticipatory mourning, Hospice care, Psychological support

Background

Palliative care is an "*approach that improves the quality of life (QoL) of patients and their families, address the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and smart assessment and treatment of pain and other problems, physical, psychosocial and spiritual*" [1, 2]. Global palliative care for terminal cancer patients can be managed at home or in Hospice, which is dedicated to patients with poor prognosis, according to litterature and national and local regulations: admission to Hospice allows greater support for the caregiver, who can also dedicate themselves to the processing of anticipatory grief, supported by the palliative care team [3–5].

Grief processing a matter that the palliative care team deals with every day: in fact, mourning is a natural response to the loss of a loved one and for most people, the symptoms of grief begin to decrease over time. Despite most individuals having sufficient personal resources to adapt to this transition phase, there are more vulnerable subjects who are at risk of complicated bereavement [6–8].

Classically, according to Elizabeth Kübler Ross, the mourning process is divided into 5 phases: rejection and denial, anger, negotiation, depression, and acceptance [9, 10]. The acceptance phase represents a crucial moment in the mourning process. During this phase, the grieving person begins to gradually integrate the awareness of the loss into their reality and find a new emotional balance. Acceptance of death requires time and energy as an individual goes through the various stages of processing the loss and must be correctly supported in case of need [10].

Contemporary theories on grief processing have evolved beyond Elisabeth Kübler Ross's pioneering model, which outlined five stages of grief. While Kübler-Ross's model provided a valuable framework, modern research and clinical practice have recognized the complexity and individuality of the grieving process. Current theories acknowledge that grief is non-linear and multifaceted, influenced by various factors such as culture, personal beliefs, and social support. Models like the Dual Process Model by Margaret Stroebe and Henk Schut, or the Meaning Reconstruction Model by Robert Neimeyer, emphasize the dynamic nature of grieving, incorporating elements of oscillation, meaning-making, and coping strategies. These contemporary approaches offer a more nuanced understanding of grief and provide valuable insights for supporting individuals through their bereavement journey [11–15].

The literature clearly shows how, even in palliative care settings, guaranteeing a universal bereavement service is neither necessary nor beneficial, and can sometimes be counterproductive in individuals with adequate individual resources [16–23]. Indeed, prolonged grief disorder (PGD) is characterized by this intense and persistent grief that causes problems and interferes with daily life, and an estimated 7-10% of bereaved adults will experience the persistent symptoms of prolonged grief disorder 19. The PGD is included in the International Classification of Diseases, 11th Revision (ICD-11), with diagnostic criteria also accepted for inclusion in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5 TR) (identity disruption, such as feeling as though part of oneself has died; marked sense of disbelief about the death; avoidance of reminders that the person is dead; intense emotional pain related to the death; difficulty with reintegration, such as problems engaging with friends, pursuing interests, planning for the future; emotional numbness; feeling that life is meaningless or intense loneliness) [24–31]. To be significant, symptoms must be present nearly every day during the prior month and the relative's death had to have occurred for at least 6 months. The bereavement lasts longer than might be expected based on social, cultural, or religious norms. Factors that may increase the likelihood of developing PGD include the high burden of care on the part of the caregiver, social isolation, advanced age, the nature of the death, the number of losses, and psychiatric comorbidity [24, 31].

Anticipatory grief refers to the process of mourning and psychological adjustment that occurs before the actual loss of a loved one, typically when death is expected due to a terminal illness or a significant decline in health. It involves feelings of sadness, and anxiety, and preparing emotionally for the impending loss, allowing individuals and families to begin the grieving process before the death occurs. The notion that addressing grief before the actual loss has not been consistently substantiated [32]. Despite the skepticism surrounding the concept of anticipatory grief, it was found that well-prepared caregivers experienced better outcomes. Therefore, caregivers experiencing pre-loss grief and low preparedness levels should receive additional support [33]. Many studies support that adequate management of the anticipatory grief phases could significantly reduce the risk of developing PGD, especially in hospice care settings [17, 33], so monitoring for signs of severe grief in caregivers could be fundamental to increasing preparation for death and reduce caregiver burden [17, 33–36].

The issue of grief management is a reality that palliative care professionals face every day. Sharing experiences, within the limits of our study, is the cornerstone of improving care. Our study aims to assess whether, within a multidisciplinary management context, offering semi-structured psychological support from the early stages of hospitalization in Hospice, continuing through the condolence conversation, may be helpful and protective in the development of mourning disorders. The care model we propose aims to facilitate proper and gradual processing of anticipatory grief by the caregiver. Our observations and data refer to the initial stages of our small Hospice (6 beds), but we believe that, situated within the reality of a tertiary oncology center, where patients arrive after long illness trajectories and with still very high expectations of care, they could be indeed useful.

Methods

We considered the patients admitted to our Tertiary Oncological Center Hospice in the period 2021–2023: 144 patients admitted to the Veneto Institute of Oncology (IOV) Hospice from November 2022 to November 2023; of the 144 patients, 30 were discharged with home care, while 114 died in Hospice. Our hospice primarily receives patients from the Oncology Institute where it is located and accommodates 6 patients.

The decision of Hospice admission was formulated by the attending physician (oncologist, palliative care doctor, general practitioner) and approved by the palliative care team: according to the procedure in use, before entering the Hospice, the patient and caregiver are involved in a multidisciplinary interview (the pre-entry interview) to define the objectives of hospitalization and share decisions. The pre-entry interview involves the palliative care team composed of a palliative physician, psychologist, and nurse. As part of the caretaking process for patients admitted to our Hospice, a psycho-oncological assessment and possibly management of the patient, caregiver, and family members is envisaged. The psychologist, starting from the pre-entry interview and based on the clinical evaluation of the physician and the analysis of the family's needs during the entry interview, proceeds with a specialized assessment of the patient and the family members who take care of him for a more in-depth analysis of any emerging problems and needs. This evaluation will allow the setting up of a specific psychological-therapeutic intervention program for the family unit evaluated. Participation in the interview by the caregiver is desirable but not mandatory. In our experience, in many cases, participation in this interview has been limited by the inability to freely access the facility due to COVID pandemic restrictions or the personal commitments of the caregivers themselves who have declined to participate in the interview, postponing the sharing of objectives to subsequent evaluation.

During hospitalization, the patients and caregivers are supported by the multidisciplinary team and some semi-structured psychological interviews are offered to identify any critical issues and vulnerabilities, in the management of anticipatory grief. During the psycho-oncological interviews, the levels of awareness of diagnosis and prognosis (of the patient, caregiver, and family members), the type of functioning of the family, and any fragility of the family context are assessed. All those elements that allow the team to understand whether a good job of anticipatory mourning processing is underway are also explored. The interview used in our study was developed for this study.

For all caregivers of patients who died in Hospice, a condolence interview is planned within 1 month of the death, which can be performed in person or remotely based on the needs of the subjects. The timing and contents of the condolence interview are evaluated on the findings made thanks to the use of "observation grids", as well as on the quality and necessity of the interventions carried out during hospitalization.

The team warns the family members that they will receive a condolence phone call from the psychologist and/or palliative care doctor every few weeks to evaluate their emotional state and the emergence of any needs/frailties related to the loss. Alternatively, a condolence conversation in person with the entire palliative care team is agreed upon immediately.

Through a semi-structured interview, defined as a "condolence interview", we try to identify early elements of suspicion of psychological fragility that require support for adequate processing of the loss. If the need for a therapeutic path is identified, family members are helped to activate competent local services in an appropriate manner (Fig. 1).

In particular, the semi-structured psychological interview is based first of all on the clinical and demographic data shared with the palliative care doctor, who plays a fundamental role in the all-round management: the origin of the patient (home vs. hospital or other structure), the reporting methods and the figures involved in the interview before the proposal to enter the Hospice.

The interviews were performed according to Table 1.

As part of the condolence conversation, the timing of which is evaluated with the team based on the work done and the problems that have emerged, the presence of disorders that may indicate a difficulty in processing is assessed, partly borrowed from the item indicative of PGD of DSM V.

All patients and caregivers gave their consent to the collection of clinical and psychological data emerging

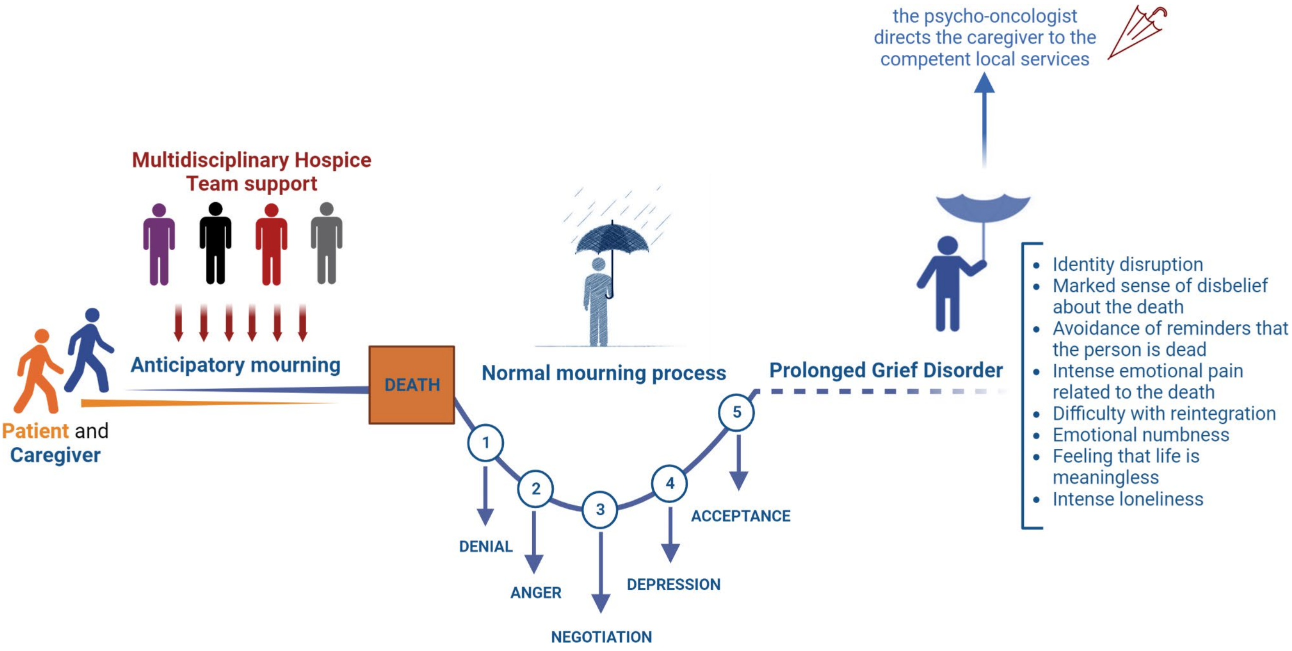

Fig. 1 The figure shows the mourning process, starting from the anticipatory mourning phases up to the management of any mourning disorders. In the phases of anticipatory mourning, the support of the multidisciplinary palliative care team is essential for both the patient and the caregiver, to provide the appropriate tools also for the management of actual mourning. The mourning process is divided into 5 phases, not necessarily consequential but all indispensable: denial, anger, negotiation, depression, and acceptance. The diagnosis of mourning disorder occurs at least 6 months after the loss of a loved one, in the presence of disturbing and persistent symptoms, which compromise the normal functioning of daily life. Condolence conversations, a natural continuation of taking charge of palliative care during the hospice stay, can make it possible to identify elements of vulnerability early and direct people to competent local services for a targeted psychological path

during hospitalization; the study was conducted under the principles of the Declaration of Helsinki. The Ethics Committee of IOV approved the study and the virtual consultation. Clinical data reported in eCRF were collected anonymously.

Proportions and rates were calculated for categorical data. Groups were compared with the chi-square test for categorical variables (the raw p values were adjusted with the Bonferroni method for multiple comparisons, Fisher exact test was applied in selected cases). The SPSS 24 software package for Windows (SPSS, Inc., Chicago, IL, USA) was used to manage the database and perform the statistical analysis. The significance level was set at $p<0.05$ for all tests.

Results

In the period November 2022-November 2023, our Hospice welcomed 144 patients, of which 30 were discharged home with the activation of an exclusive home palliative care program.

Of the 114 patients followed until death in our Hospice, 60% were male and 40% female. Table 2 describes the patients: malignancies of admission, age and the length of stay in the Hospice.

Regarding caregivers, the majority were female (66%) moreover the 34% were male. The Fig. 2 shows their distribution based on role in the family unit: most caregivers were sons (51%) or spouses (31%). Only 9% were not first-degree relatives or did not belong to the nuclear family (2%). No significant differences in mourning emerge in relation to the family role or the gender of the caregiver.

None of the caregivers who had not participated in the pre-entry multidisciplinary interview subsequently demonstrated difficulties in grieving during the condolence interview carried out within 1 month of the death of the relative. Instead, the 29% (6 of 20) of caregivers who had participated in the pre-entry interview showed difficulties in grieving, more easily highlighted perhaps also due to the better relationship of trust established in early care. Particularly, by evaluating the pathological mourning items according to the DSM V, significant correlations emerge with pervasive nostalgia and disbelief.

From the analysis of the condolence conversation, as shown in Fig. 3, among the caregivers who had been psychologically supported during the hospital stay and demonstrated a good level of acceptance of their relative's end of life, a small minority showed problems in grieving (3%) within 1 month of death. The 4% (2 of 49) expressed pervasive nostalgia, intense emotional pain, disbelief, 2% (1 of 49) perplexity about the circumstances of the death, lack of positive memories, feeling of an empty

Table 1 Description of the items and definitions evaluated during the psychological interview

PSYCHO-ONCOLOGICAL ASSESSMENT IN HOSPICE	
PRE-ENTRY INTERVIEW WITH PATIENT AND CAREGIVER	
AWARENESS LEVEL	
DIAGNOSIS	**PROGNOSIS**
Partial	Partial
Full	Full
ACCEPTANCE LEVEL	
DIAGNOSIS	**PROGNOSIS**
Absent	Absent
Partial	Partial
Full	Full
PSYCHO-EMOTIONAL ASSESSMENT	
Adaptation difficulties:	
difficulties in accepting and dealing with the changes associated with illness,	
alterations in behaviour and relationships due to the illness,	
problems relating to the state of information on the diagnosis,	
problems relating to the state of information on the prognosis,	
Unrealistic expectations.	
Emotional fatigue	
ASSESSMENT OF SOCIAL-RELATIONAL SUPPORT NETWORKS	
Family functioning	
functional, i.e. elastic in its internal organization, good adaptation skills;	
mute or frozen: use of silence as a defence mechanism; asks not to inform the patient of his condition; tendency towards relational isolation;	
rigid: unable to express emotions; also controlling the therapies administered; poor tendency to adapt; asks for continuous explanations and reassurances;	
conflictual: aggression internal and external to the family context; difficulty relating and expressing requests;	
broken up: weak intra-family ties; puts the needs of individuals before those of family members and the patient; absent in providing assistance and company to the patient);	
rejecting: not cohesive; distrustful; devaluing the professionalism of the treatment team.	
ANTICIPATORY MOURNING	
PATIENT'S INTERVIEW	
FEARS	**ACCEPTANCE OF YOUR OWN END OF LIFE**
Physical pain	Choice of the Hospice as a place for end-of-life management
Unknown	Acceptance and sharing of the treatment path
Judgment	Consent to deep palliative sedation to control refractory symptoms
Separation from loved ones	Provisions regarding the post-mortem (e.g. body management...)
Dependence	Special expressions of wishes for family members
Feeling like a burden to the others	

Table 1 (continued)

PSYCHO-ONCOLOGICAL ASSESSMENT IN HOSPICE	
Disfigurement	
Loneliness	
To be forgotten	
Sense of fragility	
Sense of helplessness	
Emotional loneliness	
CAREGIVER'S INTERVIEW	
FEARS AND ATTITUDES	**ACCEPTANCE OF LOVED ONE'S END OF LIFE**
"Premature abandonment" actions, delegating all care and care to healthcare personnel [defensive action ≠ indifference]	Choice of the Hospice as a place for end-of-life management
Symbiotic attitude (try to grab every moment still available)	Acceptance and sharing of the treatment path
Denial of the reality of death (patient treated as if he were in the past) e.g.: behaviours or feelings incompatible with his illness are required of him; ≠ cynicism/indifference, rather an attempt to avoid the reality of loss and pain	consent to deep palliative sedation to control refractory symptoms
Hope in the patient's death (+ feelings of guilt) - to be understood as the end of suffering for the patient and/or the end of the family member's suffering from anticipatory mourning	Sharing of body management
	Awareness that everything possible has been done to accompany your loved one
	Sharing the signs and physiological changes that precede death
CONDOLENCE CONVERSATION	
Persistent longing/pervasive nostalgia for the deceased person	
Sadness and intense emotional pain	
Concern about the circumstances of the death	
Marked difficulty accepting death	
Feel disbelief	
Difficulty in indulging in positive memories regarding the deceased	
Bitterness or anger	
Negative self-evaluation	
Excessive avoidance of memories of the loss	
Desire to die to remain close to the deceased	
Difficulty trusting others	
Feeling of being alone or detached	
Feeling that life is empty or meaningless without the deceased	
Confusion about one's role in life, or a diminished sense of one's identity	
Difficulty or reluctance in pursuing one's interests or making plans for the future	
Impairment in occupational, social, or other important areas of functioning.	

Table 2 Neoplastic conditions of patients that died during Hospice recovery, their age class and duration of stay in Hospice. CNS: Central Nervous System

	%
CANCER (n)	
CNS (7)	6,1
Lung (21)	18,4
Genitourinary (12)	10,5
Female genital system (5)	4,4
Gastrointestinal (31)	27,2
Pancreas (11)	9,6
Skin (3)	2,6
Breast (6)	5,3
Blood (11)	9,6
AGE range (n)	
31–40 years (1)	0,9
41–50 years (6)	5,3
51–60 years (12)	10,5
61–70 years (18)	15,8
71–80 years (37)	32,5
> 81 years (40)	35,1
DURATION OF STAY (n)	
< 7 days (51)	44,7
8–10 days (19)	16,7
11–15 days (14)	12,3
16–20 days (10)	8,8
> 21 days (20)	17,5

life, confusion about their role in life, maintaining their interests or identifying their role in the community. None showed excessive avoidance of memories, difficulties with trust, and feelings of emotional loneliness.

Discussion

Processing the loss of a loved one is a complex experience and always represents a moment of great fragility. Although everyone can count on their own personal resources and on the support of their own family, the risk of developing a mourning disorder must always be considered [3, 5, 24, 33].

The model that we propose emphasizes the importance of a multidisciplinary approach: the palliative care physician and the psycho-oncologist co-participate in taking charge of the patient himself and his family unit, actively involving the other assistance figures (nurses and social-health workers). Especially in Hospice, the caregiver, in fact, can count on multidisciplinary support in the processing of anticipatory grief, regardless of the length of hospitalization. Our data support the notion that, while the opportunity to say goodbye to relatives is a privilege denied to those experiencing sudden death, everyone's personal resources can still be exhausted in the effort to provide as much support as possible to the patient while they are alive [37, 38]. Specific staff training, in a delicate and multifaceted context such as exclusive palliative care, represents the key to adequately taking care of the patient.

Our preliminary data indeed, highlights how a specialized psychological support allows the team to focus on the problems of anticipatory mourning, significantly minimizing the caregivers' risk of pathological mourning. It will then be the team intervention that allows the patient and family to feel welcomed and listened to; furthermore, the possibility of interfacing with multiple professional figures allows us to highlight different facets and grasp a greater number of symptoms, taking advantage of different specific skills.

The proposal of a condolence conversation within a month of death, borrowing a more classically used model in the management of sudden death, allows us to identify those most at risk and direct them toward specialist support. On the other hand, as evident for the caregivers who did not participate in the pre-entry interview without showing acceptance problems, psychological support must not be offered to everyone without distinction, but only to those who demonstrate the need for it.

In summary, our model was created to evaluate the protective potential of psycho-oncological caregiver's care from the early stages of hospitalization in the Hospice concerning the risk of pathological bereavement. As suggested by our data, thanks to the support received from the entire team during hospitalization, many families show excellent coping strategies at the time of death. We then proceed with reinforcement and, if necessary, a review of skills or anything else necessary to face the first days in the absence of your loved one.

In the model we tested, each caregiver is offered psychological support through semi-structured interviews during the hospitalization of their family member, without however making the interview an obligatory moment or in which the family member must feel obliged to share their feelings and problems. This engagement system, which where possible starts before entering the Hospice with the pre-entry interview, allows coping skills to be assessed and greater support to be offered to those in greater difficulty. Furthermore, the analysis of the problems inherent to anticipatory mourning, conducted with evaluation interviews but without the use of predetermined scales, makes the interview perceived as more informal and therefore more spontaneous.

Although the assessment with a condolence conversation within 1 month is not in itself sufficient to diagnose mourning disorder, it allows family members to maintain a channel of communication with the staff who assisted them in a delicate period such as that of the end life of their loved one. It also allows the team to identify the greatest difficulties or vulnerabilities, directing those at risk to competent external psychological support.

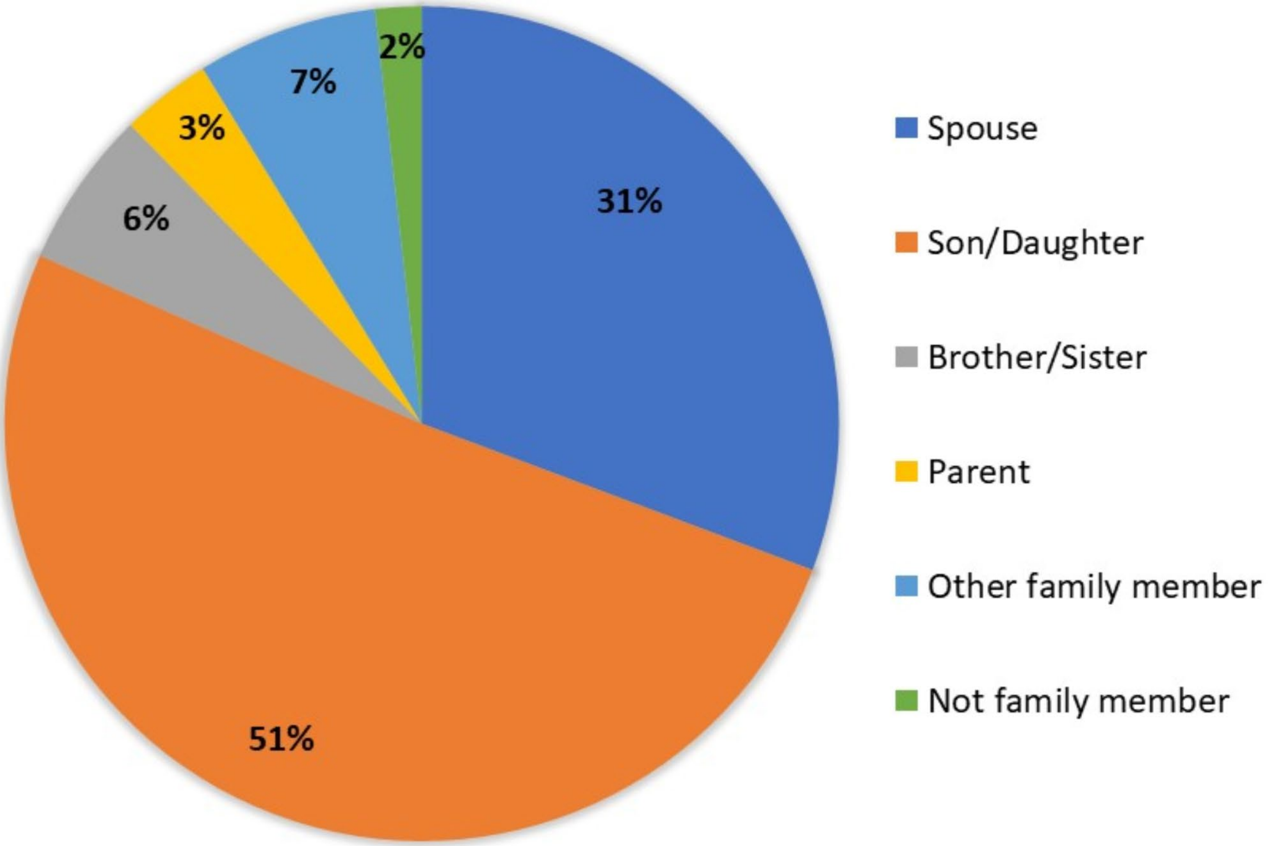

Fig. 2 Distribution of the role in the family unit: most caregivers were sons (51%) or spouses (31%). Only 9% were not first-degree relatives or did not belong to the family (2%)

As evident in our sample, the difficulty in formulating the prognosis explains why nearly 30% of hospice patients die in 7 days or less, so a fundamental step is certainly involvement in the care path right from the phases of life-prolonging therapies, with early palliative care. From the perspective of early palliative care, in line with international literature [39–41], we hope to be able to expand this model of care to patients in active care, also with the difficulty of formulating the prognosis and the care burden growing of the caregiver. Our institute already offers dedicated support to family members, but is not strictly connected to the outpatient palliative care unit, a context in which it would be desirable to have a dedicated psycho-oncologist.

The involvement of the caregiver in the pre-entry interview is certainly an important step to allow an adequate process of anticipatory mourning [36, 42]. Although our Hospice procedure, in the pandemic and post-pandemic period many factors may have contributed to reducing these possibilities, by national and international regulations for the prevention of COVID. Following the demographic distribution [43] the majority of patients of our Hospice are over 70 years old and the caregivers are in most cases the patients' sons, often with an active job and heavily burdened by assistance in the patient care process. This is a factor that could partly explain the greater difficulty in participating in pre-entry interviews.

Moreover, given the heterogeneous basic training of physicians who deal with palliative care (oncologists, general practitioners, internal medicine specialists, geriatricians, neurologists and others), it is also worth considering the possibility that different basic trainings, despite the targeted specialist training, underlie different sensitivities and attitudes which may or may not lead to the valorization of the interview as a moment of care and therefore to push for the interviews to be as multidisciplinary as possible and involve the caregiver, even in the face of the organizational difficulties that may arise.

The heterogeneity of the outcomes of the procedures based on specialist training is a fact already known in other settings, which would also be interesting to study in palliative care [44].

Surely, the objective of our working group is to make the care of the patient and his family as homogeneous as possible, to guarantee adequate support for everyone.

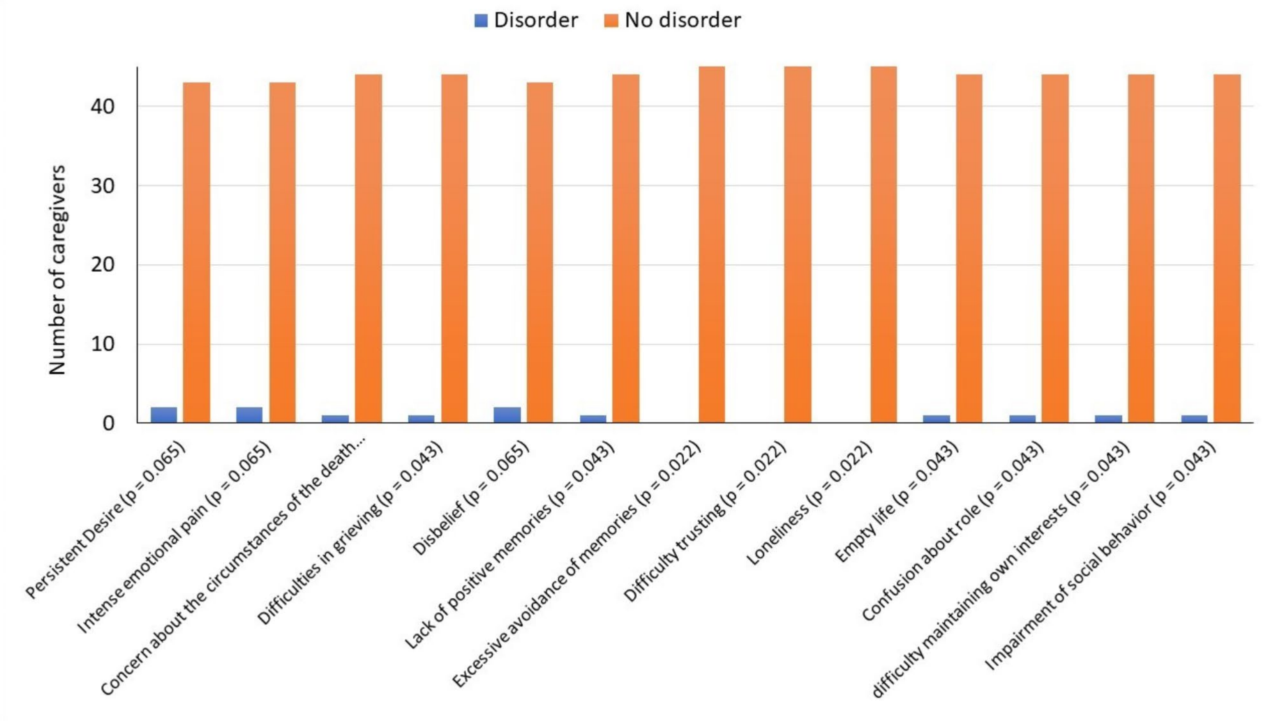

Fig. 3 Presence (blue columns) or absence (orange columns) of potentially prolonged grief disorders in caregivers with good acceptance of relative's end-of-life phase, investigated one month after the death with the condolence conversation

Conclusions

Despite the numerous limitations (such as the small sample, the reduced involvement of caregivers in the pre-entry interview, and the percentage of patients with hospital stays of less than a week) the preliminary data of our study suggests the protective potential of multidisciplinary support, particularly in the risk of developing grief processing disorders. These considerations encourage us to implement our model of clinical and psychological support system and develop paths dedicated to caregivers in greater difficulty.

The major limitations of the present study are its retrospective design, the absence of a control group and the presence of personal response elements that are not quantifiable, as well as the variability of the therapeutic paths that lead patients to admission to the Hospice.

On the other hand, one of the major challenges of research in palliative care, which is both demanding and ethically delicate, is putting together rigorous research protocols with adequate methodologies without risking compromising the care that patients and caregivers need and must be guaranteed. Further studies are underway to create an ad hoc form for psycho-oncological management in Hospice and we hope there will be the possibility of implementing this model by also extending it to management in simultaneous palliative care, adequately preparing patients and their caregivers in the perspective of a shared path.

Supplementary Information

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Supplementary Material 1

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Author contributions

Conceptualization, I.G. and M.L; methodology, I.G, M.L, A.F.; software, M.L.; validation, M.L, A.F.; formal analysis, M.M.; investigation, I.G, M.L. M.M, C.M.; data curation, M.L and E.R; writing—original draft preparation, E.R, I.G, M.L.; writing—review and editing, E.R, A.F F.F; visualization, I.G, M.M, C.M, M.P.; supervision F.F.; project administration, E.R.; funding acquisition, M.P. All authors reviewed the manuscript.

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Data availability

Data are available to all those requiring them, upon a reasonable request to the corresponding author elena.ruggiero@iov.veneto.it and with the permission of IOV.

Declarations

Ethics approval and consent to partecipate

The study was conducted in accordance with the Declaration of Helsinki, and approved by the Institutional Review Board (or Ethics Committee) of Veneto Institute of Oncology IOV–IRCCS, Padua, Italy (L04P10 - cod. int. CET ANV 2024-19). Informed consent was obtained from all subjects and/or their legal guardian(s).

Competing interests

The authors declare no competing interests.

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