

# Anticipatory Grief in the Families of Patients with Palliative Requiring Metastatic Cancer

LILIANA SEMENESCU<sup>1</sup>, AMELIA DRĂCEA<sup>2</sup>, DANIEL ZIMȚA<sup>1</sup>, ANDA CRIȘAN<sup>3</sup>

<sup>1</sup>Craiova Municipal Clinical Hospital „Filantropia”, Oncology Clinic

<sup>2</sup>Department of Biophysics, University of Medicine and Pharmacy of Craiova

<sup>3</sup>Department of Oncology, University of Medicine and Pharmacy of Craiova

**ABSTRACT:** Background/Aim. When dealing with metastatic cancer patients, family distortions, such as anticipatory mourning, psychiatric and psychosocial disorders may occur. In the case of anticipatory mourning, there exists the risk of the patient being “given up” as if he is already gone, which will only make the patient feel lonely, with numerous problems occurring in the subsequent period of familial mourning. Currently, the importance of identifying the type of mourning affecting families of cancer patients has become more and more clear, as this allows not only for greater therapeutic success, but also avoids a high number of risks and complications that appear during the critical care period. Our paper aims to identify and assess these risk factors in order to contribute to the optimization and success of palliative therapy. Material and Method: We performed this study on a group of 78 subjects with metastatic cancer. We developed a questionnaire in order to assess the patient-family relationship, family profile and the patient's unique psychological traits, in order to identify potential risk factors. Data processing was performed using Microsoft Excel; the XLSTAT package was used to perform complex statistical tests ( $\chi^2$  test, Spearman correlation coefficient). Results and Conclusions: Women are more prone to fears related to developing cancer themselves. No risk factors leading to the development of significant pathological mourning were identified in our study group. However, the clinician who deals with the treatment of the terminally ill cancer patient will have to include the following objectives related to the relatives in the therapeutic plan: to motivate their involvement, but with the maintenance of a separation in order to maintain the individuality; to keep their realism and to distinguish between normal/pathological mourning.

**KEYWORDS:** Mourning, metastatic cancer, grief.

## Introduction

The shock of being diagnosed with metastatic cancer and the imminence of death on the mental balance of the relatives is highly distinct and represents a major aspect of palliative medicine.

For the family, the terminal phase of relatives' illness (anticipated pain) and the mourning period are defined by high emotional load, caused by changes in family functioning and the problems they face.

Regarding the family as an undivided element and given the turmoil that occurs in the course of assisting the terminally ill patients, the process of palliation is a clinical and ethical challenge for medical staff [1-5].

Relatives may face the patient's deterioration, loss of future plans, and uncertainty about the near future; changes that occur during the course of the disease are most likely to cause pain, and family members in this vulnerable position are highly exposed to the development of psychological disorders during care and after the patient's death [6].

Mourning is a universal experience, characterized by psychological mechanisms that allow the acceptance of the loss of a loved one and the elimination of pain by the progressive transfer of interest in another direction.

While the loss of a loved one affects everyone, cases have shown situations where much more damage than average was incurred, an aspect initially described by Freud in his work "Mourning and Melancholia".

Currently the reaction of mourning is divided into pathological and non-pathological [7,8].

A component of the palliative care system is the delivery of psycho-emotional support to the families of terminally ill patients in the first year after death.

It is estimated that about 12-40% have pathological reactions, with this subset requiring more support than others [9].

Anticipating the loss is a way to prepare for the real trauma-the death of a loved one, easing the suffering [1].

The changes in behavior include an enhancement of closeness, an in strong tendency to bond with the loved ones and an overprotective behavior.

This is accompanied by fears of abandonment, anxiety, despair and helplessness [1].

Studies in literature have shown that the presence of pathological mourning reactions has been associated with increased incidence of mental and organic disease among relatives.

It therefore stands to reason that identifying and assessing the risk of pathological mourning

can help protect these individuals from a future psychological and physical burden [10,11].

The imminence of the death of a close person, the expectation of mourning and the changes that it will produce, are triggers for anticipatory pain; this includes depression, extreme worry for the dying person, preparation for death, and adjustment to the changes caused by death [1,12,13].

Aldrich's definition for anticipatory grief is "pain that occurs before loss, being distinct from that which occurs after loss"; however, the term was first introduced by Lindemann, who, after World War II, observed the case of the soldiers' relatives facing all stages of grief without the death of the soldiers, in some cases resulting in complete rejection of the ones that returned home [13,14,15].

The anticipatory pain of loss differs from the conventional one because:

- It is usually experienced by both the patient and his family;
- It is limited in time, as there is a final moment of death;
- Theoretically, it should increase over time;
- It should be characterized by ambivalence;
- It may include a phase of hope [13].

Acute suffering during mourning is an emotionally and cognitively intense phenomenon, but grief is not a disease similar to major depression or anxiety disorders.

Sadness and mourning aim to reconfigure the individual who has suffered the loss.

From a clinical perspective, mourning is an area of psychological processes, which can be categorized into emotional regulatory processes and learning processes.

When mourning is normal, it involves the transformation and integration of pain, leading to maintaining a feeling of deep connection with the deceased, with their retention in long-term memory and leading also to the imagining of a future in which that person is absent [16].

There are losses that are more likely to lead to complications of the grieving process: the loss of a child, life partner or certain circumstances of death, such as absence or separation from the deceased person at the time of their death, disagreement with said person or uncertainty about health care services [16].

Although the pain of loss is a physiological phenomenon, in 15-25% of cases it cannot be anticipated.

Given the individual particularities and nuances of every individual, the distinction between normality and pathology in terms of

mourning can be difficult, the two being separated by a very fine line [1,17,18].

It is however very important to identify the type of mourning in order to avoid complications and conduct therapy accordingly for those families struggling with the difficulties of having a cancer patient as part of their lives.

This paper aims to identify and assess risk factors for pathological mourning in order to better understand it with the hopes of reducing it and increasing the quality of healthcare services of palliative care patients.

## Materials and Methods

This study was carried out on a group of 78 relatives of metastatic cancer patients, hospitalized between April 15 and May 15, 2018 in the Oncology Department of the "Filantropia" Municipal Hospital in Craiova. The design of the study was observational-recording the perception of the patients' relatives, without influencing them in any way. The study was approved by the Ethics Committee and all the subjects recruited were volunteers, and they have participated to the study following the informed consent.

The research hypothesis was as follows: If elements of pathological grief are present within the family, there is a risk of the patient being "given up", as if he is already gone, which will only make the patient feel lonely, with numerous problems occurring in the subsequent period of familial mourning, and decreasing their treatment compliance.

For this purpose, a specific questionnaire was developed to evaluate the family members' relationship with the patient, the family profile as well as the psychological-individual one, in order to identify potential risk factors.

The questionnaire was composed of 30 questions, evaluating the patient's dependency, the presence of signs and symptoms such as: fatigue, desire for isolation, fear, decreased appetite, presence of guilt [10].

The answers received to these questions scaled from 1 to 5 and were recorded in a database in Microsoft Excel files, and were statistically processed afterwards.

We used the XLSTAT add-on or SPSS in order to perform complex statistical tests ( $\chi^2$  test, Spearman correlation coefficient).

## Results

Analyzing the gender distribution, we found that there is a significant larger percentage of female than male caretakers, 69.23% vs. 30.77% (Table 1).

**Table 1. Gender distribution of the study group.**

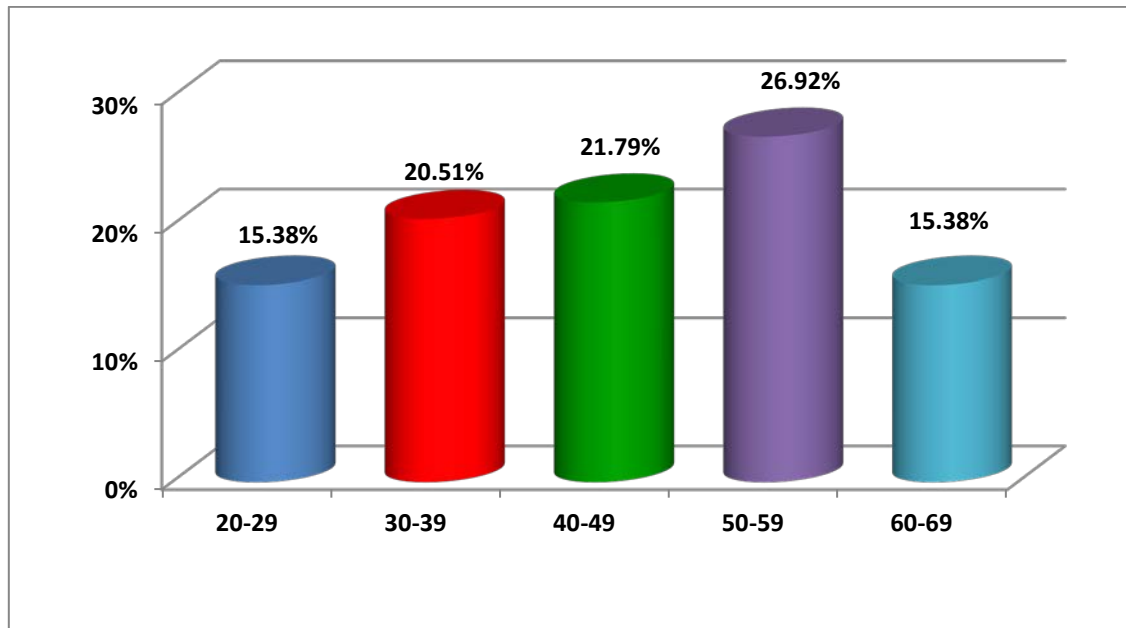
Gender	Number	Percentage
Females	54	69.23%
Males	24	30.77%

Taking into consideration that the national of Romania consists of 48.6% men and 51.4% women [19], we can say that there is a highly significant difference between these percentages

and the gender distribution c in the study group), the p-value calculated for the Z test for proportions being <0.0001.

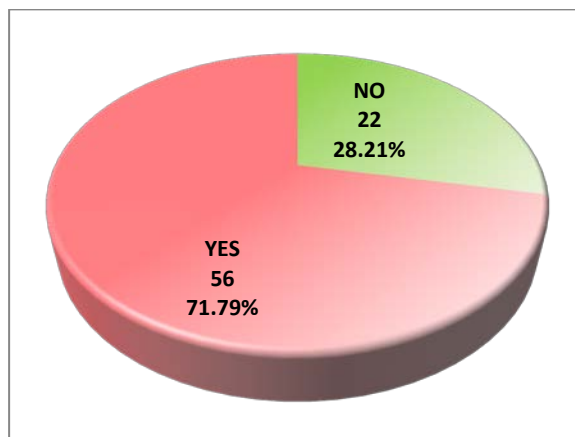
Analyzing the study group, we observed that most relatives of patients with metastatic cancer were in the fourth and fifth decade of life.

This means they were active, employed persons, and the impact of the future loss has an important mark on their social and professional life (Figure 1).



**Figure 1. Age distribution of the study group.**

The majority of the caregivers already experienced the loss of a close person, which makes them more vulnerable to a new exposure to this kind of pain (Figure 2).



**Figure 2. Occurrence of previous loss.**

No significant risk factors (previously documented psychiatric or psychological

conditions) for developing pathological grief were identified in the studied group.

Of the total population of Romania aged 10 and over, 44.2% have a low level of education (primary, secondary or no school), 41.4% have a medium level (high school, professional or technical school) and 14.4% have a higher level of education [19].

In our study, the distribution according to education (Table 2) shows an increased percentage of caretakers with a higher education level compared to the general population, which could be correlated with a higher degree of understanding the medical condition of the oncological patient.

**Table 2. Distribution of the study group according to education level.**

Education level	Number	Percentage
Low/Medium	59	75.64%
High	19	24.36%

Regarding the status of the patient under care, by questioning the relatives, we found out that most patients are assessed as having a

performance status corresponding to an ECOG 3 (Figure 3).

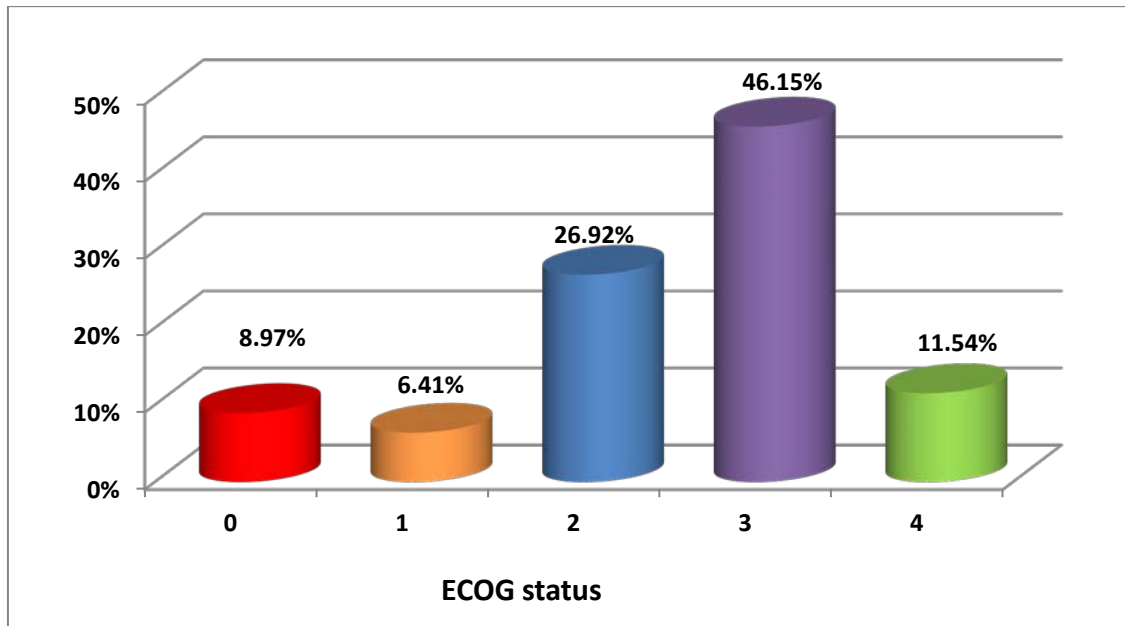


Figure 3. The level of dependence of the patient felt by the relatives.

As the next step, we wanted to observe if the previous loss of relatives can influence the assessment of the ECOG status.

means persons with a previous loss tend to increase the dependency level of the patient (Figure 4).

We highlighted a statistically significant correlation between these two parameters, which

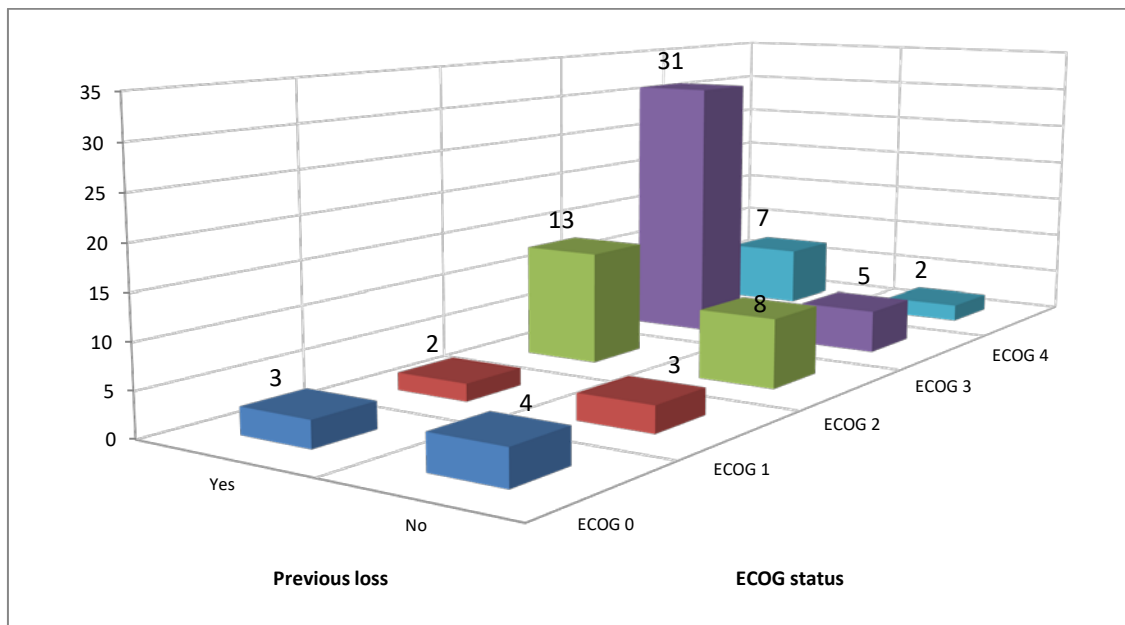


Figure 4. ECOG correlation with previous loss (p-value 0.0371).

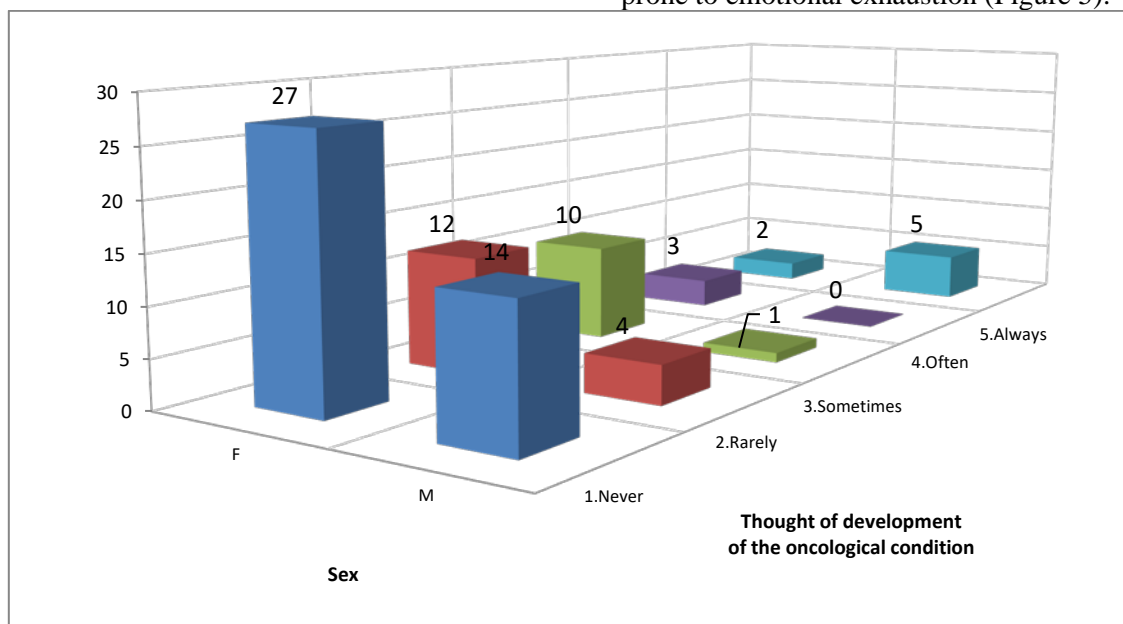
**Table 3. The distribution of the answers to the questionnaire, recorded using a Likert scale.**

Q. no.	Question	1. Never	2. Rarely	3. Sometimes	4. Often	5. Always
Q1	Dependent patient	16.67%	16.67%	21.79%	19.23%	25.64%
Q2	Lack of energy	26.92%	26.92%	35.90%	7.69%	2.56%
Q3	Too many duties	28.21%	23.08%	29.49%	10.26%	8.97%
Q4	Feeling tense	32.05%	23.08%	28.21%	8.97%	7.69%
Q5	Need to isolate yourself	46.15%	23.08%	21.79%	3.85%	5.13%
Q6	Sleep problems	38.46%	24.36%	29.49%	5.13%	2.56%
Q7	Fatigue in the morning	23.08%	32.05%	34.62%	6.41%	3.85%
Q8	Loss of appetite	47.44%	24.36%	16.67%	11.54%	
Q9	Fear of illness	52.56%	20.51%	14.10%	3.85%	8.97%
Q10	Fear of being sick	60.26%	23.08%	8.97%	1.28%	6.41%
Q11	Limited capacity to help	44.87%	19.23%	19.23%	3.85%	12.82%
Q12	Fear of failure to help	38.46%	20.51%	26.92%	8.97%	5.13%
Q13	Feeling guilty	37.18%	24.36%	23.08%	11.54%	3.85%
Q14	Indifference to other things	42.31%	15.38%	29.49%	3.85%	8.97%
Q15	Angry at yourself	73.08%	8.97%	15.38%	1.28%	1.28%
Q16	Angry at others	83.33%	10.26%	5.13%	1.28%	
Q17	Anxiety	58.97%	17.95%	17.95%	3.85%	1.28%
Q18	Providing help affects your social life	62.82%	16.67%	14.10%	5.13%	1.28%
Q19	Feeling fatigued lately	30.77%	37.18%	21.79%	7.69%	2.56%
Q20	Suicidal thoughts	89.74%	1.28%	3.85%	3.85%	1.28%
Q21	How often you offer help	10.26%	10.26%	15.38%	17.95%	46.15%
Q22	Feeling overwhelmed	34.62%	28.21%	17.95%	7.69%	11.54%
Q23	Feeling emotionally drained	44.87%	24.36%	19.23%	10.26%	1.28%
Q24	Denial of patient's diagnosis	33.33%	26.92%	24.36%	3.85%	11.54%
Q25	Curiosity about similar situations	15.38%	20.51%	29.49%	11.54%	23.08%
Q26	Overworking to forget	16.67%	12.82%	29.49%	20.51%	20.51%
Q27	Need for moral support	20.51%	28.21%	30.77%	7.69%	12.82%
Q28	The fate of the patient is unfair	20.51%	12.82%	16.67%	19.23%	30.77%
Q29	Fretfulness	66.67%	16.67%	8.97%	2.56%	5.13%
Q30	Overthinking patient's illness	6.41%	7.69%	19.23%	17.95%	48.72%

By assessing the recorded answers (Table 3) we found that the questions with higher scores 4. Often and 5. Always-are Q1-Dependent patient (44.87%), Q21-How often you offer help (64.10%), Q26-Overworking to forget (41.02%),

Q28-The fate of the patient is unfair (50.00%) and Q30-Overthinking patient's illness (66.61%).

The female gender is more prone to fear of developing cancer themselves when confronted with cancer in a family member and also are more prone to emotional exhaustion (Figure 5).



**Figure 5. The correlation between sex and thought of development of the oncological condition (p-value=0,0465).**

Due to the fact that we noticed a different age distribution than the one of the general populations of Romania, and because other studies [20] suggest an association between younger age and a lower level of complicated grief, we analyzed the relationship between age and pathological mourning.

We found a significant level of correlation between age and fear of illness (Q9-r=0.398) and between age and feeling tense (Q4-r=0.301).

## **Discussions**

The answers recorded in our study do not indicate the presence of a significant level of pathological grief, overall.

The maximum value was 112 of a maximum of 150 points (74.66%), while the average value was  $68.89 \pm 18.48$  points, less than 50% of the maximum score.

Our results point out subjectivity in the perception of the patient's performance as measured using the ECOG scale, influenced by previous losses, the female gender being more prone to it.

This is the only gender-related feature we observed in the study group, though the data in literature suggest female gender is linked to a higher frequency of despair, anger, loss of control, somatization, development of death anxiety [21].

Although the previous reports indicate an association between a young age of the caretakers and a lower level of anticipatory grief, we were not able to prove this hypothesis.

The only significant correlations were between age and fear of illness/feeling tense, respectively, which are normally found in elders.

An interesting finding was the increased percentage of higher educated caregivers, almost 25%, which can be associated to a better understanding of the patient's condition and could explain the lack of pathological mourning elements in the study group.

This finding is consistent with the study of Masferrer [22], which shows that having a better education level is inversely correlated with the development of complicated grief.

Despite not identifying the elements literature describes as preceding a pathological mourning in our present study, the importance of the problem should not be minimized.

The lack of presentation of these elements could easily be explained by the small number of people interviewed in our study.

Due to the fact that most of the relatives of patients with terminal cancer are left without professional support during this period, the doctor who manages the cancer treatment should include the following objectives aimed at the patient's family members into their treatment plan:

- Motivating family members to become involved in the treatment effort while at the same time maintaining some separation in order to maintain individuality between these members and the patient's illness from a psychological standpoint.

- Guiding their expectations and helping them adapt and adjust to a fluid, complex and ever-changing situation.

- Helping the family remain anchored in reality with regards to their expectations and also attempting to distinguish between normal/pathological mourning.

- Encouraging the family to make their peace with the situation and helping them say their goodbyes as the moment of exit us approaches [1,4,7,13,23].

It is clear by this point that the aspects and problems that arise within a family during the terminal phase of cancer when a family member is affected by it (anticipated grief) is extremely important for physicians dealing with palliative care cases [11].

There is a great necessity for adequate, periodic assessment of the emotional status patients and caregivers, in order to develop effective programs aimed at preventing psychological trauma and staging meaningful and supportive intervention to ease grief and help transition the family through this difficult process.

There is no doubt that a better insight in this area is required, to enhance family support, for those families that are confronted with a cancer case, regardless of its stage or possible outcome.

Out of these however, those cases that are confronted with the near possibility of terminal illness and death should be focused on in particular as they represent a more difficult subset to manage, posing more challenges that have to be overcome in order to raise standard of care.

## **Conflict of interests**

None to declare.

**References**

1. Grassi L. Bereavement in families with relatives dying of cancer. *Curr Opin Support Palliat Care*, 2007, 1:43-49
2. Baider L, Cooper CL, De-Nour AK (Eds): *Cancer and the family*, 2nd ed. Wiley, 2000, New York, 212-216
3. McClement SE, Woodgate RL. Research with families in palliative care: conceptual and methodological challenges. *Eur J Cancer Care*, 1998, 7:247-254
4. Kissane DW, Bloch S. Family grief. *Br J Psychiatry*, 1994, 164:720-740
5. Katz L, Chochinov HM. The spectrum of grief in palliative care. In: Bruera E, Portenoy RK, (Eds): *Topics in palliative care*, vol. 2. Oxford University Press, 1998 New York, 295-310.
6. Fasse L, Sultan S, Flahault C, Mackinnon CJ, Dolbeault S, Bredart A. How do researchers conceive of spousal grief after cancer? A systematic review of models used by researchers to study spousal grief in the cancer context. *Psychooncology*, 2014, 23(2):131-142
7. Tomarken A, Holland J, Schachter S, Vanderwerker L, Zuckerman E, Nelson C, Coups E, Ramirez PM, Prigerson H. Factors of complicated grief pre-death in caregivers of cancer patients. *Psychooncology*, 2008, 17(2):105-111
8. Freud S. Mourning and melancholia. In: Frankiel, RV (Ed): *Essential Papers on Object Loss* *Essential Papers in Psychoanalysis*, New York University Press; 1917, New York, 38-51
9. Allen JY, Haley WE, Small BJ, Schonwetter RS, McMillan SC. Bereavement among hospice caregivers of cancer patients one year following loss: predictors of grief, complicated grief, and symptoms of depression. *J Palliat Med*. 2013, 16(7):745-751
10. Prigerson HG, Maciejewski PK, Reynolds CF 3rd, Bierhals AJ, Newsom JT, Fasiczka A, Frank E, Doman J, Miller M. Inventory of Complicated Grief: a scale to measure maladaptive symptoms of loss. *Psychiatry Res*, 1995, 59(1-2):65-79
11. Prigerson HG, Bierhals AJ, Kasl SV, et al. Traumatic grief as a risk factor for mental and physical morbidity. *Am J Psychiatry* 1997;154(5):616-623.
12. Evans AJ. Anticipatory grief: a theoretical challenge. *Palliat Med*, 1994, 8(2):159-165
13. Sweeting HN, Gilhooly ML. Anticipatory grief: a review. *Soc Sci Med*, 1990, 30(10):1073-1080
14. Aldrich C. K. Some dynamics of anticipatory grief. In *Anticipatory Grief* (Edited by Schoenberg B., Carr A. C., Peretz D. and Kutscher A. H.). Columbia University Press, New York, 1974.
15. Lindemann E. Symptomatology and management of acute grief. 1944. *Am J Psychiatry*. 1994 Jun;151(6 Suppl):155-160
16. M. Katherine Shear Grief and mourning gone awry: pathway and course of complicated grief *Dialogues Clin Neurosci*. 2012 Jun; 14(2): 119-128.
17. Vasile DL. Doliul sănătos și doliul patologic. *Revista Paliatia*, 2013, 12:1-3. [online]. Available at: <http://www.paliatia.eu/new/2013/12/healthy-and-pathological-mourning/?lang=ro> [Accessed 06.08.2022].
18. Ciocârlan S. Doliul-între normalitate si patologie. [online]. Available at: <http://www.romedic.ro/doliul-intre-normalitate-si-patologie-0P32784> [Accessed 06.08.2022].
19. INS Romania. Rezultate definitive ale Recensământului Populației și al Locuințelor - 2011 (caracteristici demografice ale populației). Available at: <https://www.recensamantromania.ro/rpl-2011/rezultate-2011/> [Accessed 06.08.2022].
20. Liu NC, Lai EY. Find a way out: bereavement support in Taiwan hospice. *Support Care Cancer*, 2006, 14(1):4-10
21. Gilliland G, Fleming S. A comparison of spousal anticipatory grief and conventional grief. *Death Stud*, 1998, 22(6):541-69
22. Masferrer L, Garre-Olmo J, Caparrós B. Is complicated grief a risk factor for substance use? A comparison of substance-users and normative grievers. *Addiction Research y Theory*, 2017, 25(5), 361-367
23. Varghese M, Kirpekar V, Loganathan S. *Family Interventions: Basic Principles and Techniques*. *Indian J Psychiatry*, 2020, 62(Suppl 2): S192-S200.

---

*Corresponding Author: Amelia Drăcea, Department of Biophysics, University of Medicine and Pharmacy of Craiova, 2, Petru Rareș St, Craiova 200349, e-mail: sanda.amelia.dracea@gmail.com*