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Demoralization in End-of-Life Cancer Patients' Family Caregivers: A Cross-Sectional Study

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Demoralization in end-of-life cancer patients' family caregivers: A cross-sectional study

Short title

Demoralization in cancer patients' family caregivers

Abstract

Objectives: The aims of this study were to evaluate the prevalence of demoralization in a sample of end-of-life cancer patients' family caregivers and investigate the association between demoralization and different factors, such as distress, hope, quality of life, and caregiver burden.

Methods: The study used a cross-sectional design and 142 participants were sampled. Family caregivers were included if they were caring for a cancer patient in palliative care with a limited life expectancy.

Socio-demographic data were gathered, and Italian versions of the following scales were administered: Demoralization Scale (DS), **Herth Hope Index** (HHI), Caregiver Reaction Assessment (CRA), Short Form-36 Health Survey (SF-36), and Distress Thermometer (DT).

Results: The average total demoralization score was 29.04 (SD = 13.62). **19.50% of caregivers was the low scorers at DS (0-25th percentile), 27.50% was the middle scorers (25th-75th percentile), and 39.00% was the high scorers (75th-100 percentile).** ~~19.50% of the caregivers showed mild demoralization, 27.50% moderate demoralization, and 39.00% showed severe demoralization.~~ **Strong Moderate** correlations were found between the total DS score and the *Temporality and Future* HHI subscale ($\rho = .520$); the HHI total score ($\rho = .528$); the *Social functioning* ($\rho = .536$) and *Mental health* ($\rho = .675$) SF-36 subscales.

The HHI total score and the *Mental health* SF-36 subscale emerged as the main predictors of demoralization.

Conclusions: The results show that not only end-of-life patients but also family caregivers may experience demoralization. This demoralization seems to be more associated to spiritual and psychological suffering rather than difficulties relating to caregivers' personal time, social roles, physical states, and financial resources.

Keywords

Cancer, caregivers, demoralization, end-of-life, family caregivers, palliative care.

Introduction

Family caregivers are often a vital source of social and emotional support for cancer patients.

¹ Nevertheless, they frequently show various problems such as physical pain and fatigue and various mental health concerns such as depression, anxiety and sleeping issues due to caregiver burden.^{2,3}

It has been shown that existential distress is a substantial part of the burden faced by caregivers assisting cancer patients.^{4,5} Caregivers may experience their own existential challenges as they observe the suffering and anticipate the loss of their loved one.⁶ In this observational cross-sectional study, the focus is on a particular expression of existential distress, namely demoralization. Demoralization is an existential distress syndrome presented by subjects suffering from a mental or physical illness who feel that their existence or integrity is threatened.⁷

Kissane⁸ defines demoralization syndrome as a persistent mental state deriving from failing in functionally coping with a stressful event. If demoralization lasts for two or more weeks, the patient: reports a loss of meaning and purpose; struggles with facing the stressor and therefore feels trapped, helpless, and unable to control or change the situation; experiences a profound sense of failure linked to his/her and others' expectations.

Few studies have analyzed demoralization in family caregivers assisting patients with medical illnesses. One of the first studies on the topic was conducted in a sample of spouses of patients with Alzheimer's disease.⁹ The most interesting results emerged in this research were the association of demoralization with health problems, the quality of social support, and financial status. In a later study,¹⁰ demoralization among caregivers of patients suffering from dementia was investigated. The research evidenced that the burden of care was a

predictor of the demoralization in all groups, except for the sons of patients.

To our knowledge, only one study¹¹ has assessed demoralization in patient's caregivers in the oncological setting, and more specifically in the palliative one. The results showed that a percentage of the caregivers (10%) had medium or high levels of demoralization. The demoralization levels appeared to be positively associated with insomnia and serious financial problems but negatively correlated with optimism. The authors suggested to further investigate demoralization syndrome in caregivers, since research in the palliative care context has focused almost entirely on the patients themselves.

In addition to the variables considered in the above-mentioned studies, this study also examined quality of life, hope, and distress, to investigate in patients' caregivers the correlation between demoralization and psychological, social, and existential variables less closely linked to the burden of care.

Therefore, the aims of the present study were to evaluate the prevalence of demoralization in a sample of end-of-life cancer patients' family caregivers and to investigate its association with variables such as distress, hope, quality of life, and caregiver burden.

Methods

Study design and participants

The participants of this cross-sectional study were recruited from May 2018 to May 2019 at the "Città della Salute e della Scienza" Hospital of Turin.

The participants were identified among the caregivers of palliative care patients admitted to one of the seven clinical settings involved in this study. This included three Medical Oncology units, two Hematology units, a Neurology unit, and an Intensive Care Cardiology

unit. The inclusion criterion was being a family caregiver of a cancer patient who met the criteria for palliative care. The latter are regulated in Piedmont by the Regional Legislative Decree n.45/2002 and the National Law on palliative care and pain treatment (n. 38/2010). The criteria are the presence of a progressive disease, for which curative treatment is not possible or appropriate, unfavorable/poor prognosis, a presumed life expectancy of four months or less, and a Karnofsky Performance Status (KPS) of 50 or lower.¹² The exclusion criteria for caregivers included not speaking Italian fluently, a diagnosis of any severe psychiatric disorder, or a score of 23 or less on the Mini Mental State Examination (MMSE),¹³ implying the inability to provide valid answers and/or informed consent.

One hundred ninety-three caregivers were initially identified as possible candidates. However, 15 did not meet the inclusion criteria as three were unable to speak Italian fluently and 12 had a previous diagnosis of a severe psychiatric disorder. Furthermore, 36 did not want to take part in the study. The final sample consisted of 142 end-of-life cancer patients' family caregivers (**Figure 1**). [insert Figure 1]

Once the caregivers meeting the inclusion criteria were identified, ~~they were a study~~ **investigator** asked **them** to participate and complete a form with questions collecting socio-demographic information and a set of validated rating scales (see Measures section). The socio-demographic information gathered were sex, age, marital status, number of children, level of education, employment, previous experience as a caregiver, the patient's age, kind of caregiver (who they were to patients, i.e. relatives and type of kinship, friends, etc.), psychotropic drug use, whether they were receiving psychological support, religious affiliations, information concerning the patient's condition, and clinical information related to the terminal phase, such as the prediction of survival and prognostic information.

The forms were compiled by caregivers in one of the seven clinic units mentioned above with the help of a study investigator, while the cancer patient was engaged in bedside counseling with a psychotherapist. **Therefore, the study investigator and the psychotherapist were two different people and the caregivers' compilation of the questionnaire and patients' psychotherapy were conducted at the same time in different locations. The caregivers were asked to fill in the questionnaire in a visit room to avoid that the patient's presence could influence the caregiver's responses, preventing him from expressing his emotions, and consequently the results of the study.**

Written informed consent was obtained from all the participants. All the procedures performed in this study were done in accordance with the ethical standards of the “Comitato Etico Interaziendale A.O.U. San Giovanni Battista di Torino A.O.C.T.O./Maria Adelaide di Torino”: protocol number 0034403, procedure number CS2/1178, date of approval 22/04/18 and with the 1964 Helsinki Declaration (Code of Ethics of the World Medical Association)¹⁴ and its later amendments.

Measures

The Italian versions of several validated rating scales were used. The Demoralization Scale (DS-IT)¹⁵ is a 24-item self-report questionnaire that evaluates the presence of demoralization syndrome. The items are scored using a 5-point Likert scale, ranging from 0 (Never) to 4 (Always). The cut-offs used in this study were below the 25th percentile for mild demoralization, between the 25th-75th percentile for moderate demoralization and severe demoralization for scores above the 75th percentile.¹⁶ The five DS subscales were also investigated separately. These scales consist of *Loss of Meaning*, *Dysphoria*,

Disheartenment, Helplessness and Sense of Failure.^{17,18}

The Herth Hope Index (HHI-IT)¹⁹ is composed of 12 items, rated from 1 (Strongly Disagree) to 4 (Strongly Agree). The items are divided across three subscales²⁰: *Temporality and Future; Positive Readiness and Expectancy; Interconnectedness with Self and Others*. This self-report rating scale was created to define hope in cancer patients in the palliative care context and to identify the strategies that encourage the experience of hope.

The Caregiver Reaction Assessment (CRA)²¹ is a 24-item rating scale that assesses the burden experienced by caregivers. The items are divided into five subscales: *Impact on schedule, Impact on Finances, Lack of Family Support, Impact on Health, Caregiver's Esteem.*²² The items are scored on a 5-point Likert scale, ranging from 1 (Strongly Disagree) to 5 (Strongly Agree).

The Short Form-36 Health Survey (SF-36)²³ is a self-report quality of life measure. It includes eight subscales with multiple-answer questions: *Vitality, Physical Functioning, Bodily Pain, General Health, Role Physical, Role Emotional, Social Functioning, and Mental Health.*

The Distress Thermometer (DT-IT)²⁴ is a quantitative instrument, measuring levels of distress through a visual analogue scale, ranging from 0 to 10. The DT cut-off score is 4. To help identify the source of the indicated distress, it also includes a 34-item Problem List divided into five categories: *Practical Problems, Family Problems, Emotional Problems, Spiritual/Religious Problems, and Physical Problems.*²⁵

Statistical analysis

Descriptive statistics were used to analyze the socio-demographic features of the sample.

~~The associations between demoralization and socio-demographic variables, hope, caregiver burden, quality of life and distress were explored through a Multivariate Analysis of Variance (MANOVA), t-test and Pearson's correlations, considering p values < .05 as statistically significant.~~ **The association between DS and HHI, CRA, SF-36 and the quantitative score of the DT was explored with Pearson's correlations. The associations between DS and the qualitative part of the DT (the Problems List) and the socio-demographic variables were explored through Multivariate Analysis of Variance (MANOVA) and t test. *p* values < .05 were considered as statistically significant.**

Since many variables have been analyzed, to prevent the discovery of any correlations by chance, a multiple linear forced-entry regression model was performed to determinate with more certainty the variables associated with demoralization. Then, after selecting the predictors with the highest β coefficients, a standard linear block-wise regression model followed to further analyze the predictive ability of the variables. Statistical analysis was executed using the software SPSS Statistics Version 24.0 (IBM Corp. Armonk, NY, USA).

Results

Socio-demographic and clinical characteristics of the sample

The final sample consisted of 142 caregivers. The average age of the participants was 56 years. Most of the ~~patients~~ **caregivers** were female (78.2%, N = 111) and married (66.2%, N = 93). Most commonly caregivers had children (71.8%, N=102), a high-school diploma (42.3%, N=60) and only 10.6% (N = 15) had a degree. Most of them were employed (47.2%, N = 67) and, at the time of the data collection, were taking care either of their spouse (39.4%, N = 56) or a relative (43.0%, N = 61). Almost all the caregivers were religious (81.7%,

N=116) and approximately half of the sample was a non-practicing Catholic (51.4%, N = 73).

Only a small part of the sample used psychotropic drugs (22.5%, N = 34) and even less regularly attended psychotherapy sessions (4.2%, N = 6). Most of the caregivers were aware of both the diagnosis and of the prognosis of the patient receiving their care (78.2%, N = 111). See Table 1 [insert Table 1].

Demoralization, distress, hope, quality of life, and care burden prevalence

The average total demoralization score was 29.04 (SD \pm 13.62). It emerged that ~~19.50% (N = 28) of the caregivers was mildly demoralized, 27.50% (N = 39) was moderately demoralized, and 39.00% (N = 55) severely demoralized~~ **19.50% of caregivers (N = 28) was the low scorers at DS (0-25th percentile), 27.50% of caregivers (N = 39) was the middle scorers (25th-75th percentile), and 39.00% of caregivers (N = 55) was the high scorers (75th-100 percentile).**

The average DS, DT, HHI, SF-36, and CRA scores are reported in Table 2. [insert Table 2]

Associations between demoralization and the other variables

Correlations between the scores on the demoralization DT, HHI, SF-36, and CRA scales are shown in Table 3. [insert Table 3]

With regard to the total DS score, ~~strong~~ **moderate** correlations were found between the latter and: *Temporality and Future* HHI subscale ($\rho = .520$); the HHI total score ($\rho = .528$); the *Social functioning* ($\rho = .536$) and *Mental health* ($\rho = .675$) SF-36 subscales.

Other significant results were the associations between *Disheartenment* DS subscale and:

DT ($\rho = .526$); *Temporality and Future* HHI subscale ($\rho = .506$); HHI total score ($\rho = **-.534**$); *Vitality* ($\rho = .584$), *Social functioning* ($\rho = .505$) and *Mental health* ($\rho = .675$) SF-36 subscales.

Moreover, an association emerged between demoralization and *emotional* ($t = 3.78$; $p = .002$) and *spiritual problems* ($t = 12.43$; $p = .001$), assessed through the DT.

There was no evidence of an association between demoralization and the considered socio-demographic variables.

Predictors of demoralization

By performing the multiple linear forced-entry regression, three significant demoralization predictors were identified: DT, HHI, and the *Mental health* SF-36 subscale. This was followed up with a standard linear block-wise regression in which HHI and the *Mental health* SF-36 subscale were found to significantly predict demoralization scores (See Table 4). [insert Table 4]

Discussion

The majority of the sample reported being moderately or severely demoralized. This result indicates that not only end-of-life cancer patients can experience existential distress syndrome but also their family caregivers. In particular, the average score on the *Disheartenment* subscale of the DS was higher than the other scales, suggesting that the demoralized caregivers **suffer mainly from** ~~because of pervasive feelings of~~ discouragement and isolation. This is probably due to the assistance given to loved ones

during the last days of their lives. Caregivers seem to feel trapped by what is happening to them and feel alone, discouraged, and sad. This could be because being a caregiver requires a significant amount of time and resources and therefore may have a major impact on well-being and quality of life.²⁶

In the study conducted by Hudson,¹¹ only 10% of the subjects ~~was~~ **were** moderately or severely demoralized. The difference between our and Hudson's study in terms of prevalence, might be due to discrepancy in the cut-off scores used in the studies. Indeed, Hudson and colleagues used a cut-off score of 50 to outline a moderate to severe demoralization. In our study, instead, Robinson's cut-off scores were applied. Finally, the average expectancy of life of the sample of this study was about 27 days, ranging from less than 24 hours to 120 days. This could determine higher levels of demoralization.¹⁸

The *Mental health* SF-36 subscale was shown to be a predictive factor for demoralization for caregivers. **This scale is composed by five items that measures how much the caregiver has felt nervous, down in dumps, peaceful, sad and happy in the last four weeks.** Being able to implement adaptive **emotional** strategies to deal with a beloved's illness can protect caregivers from demoralization syndrome, which can be defined as a perceived inability to cope.²⁷

Moreover, data analysis highlighted that hope represents a predictive factor of demoralization: the presence of future goals, a positive outlook on life, the ability to see new possibilities every day, and the lack of excessive fear regarding the future ~~seem to~~ **can** help caregivers in facing demoralization. Hope can be sustained by six key strategies implemented by caregivers themselves: sustaining relationships, cognitive reframing, time refocusing, attainable expectations, spiritual beliefs, and uplifting energy.²⁸ These strategies

might represent efficient coping strategies for the caregivers and would alleviate the risk of developing demoralization syndrome.

The results from this research ~~seem to highlight that caregivers' demoralization was less related to their care burden but rather to other variables such as mental health and hope~~ **highlight that caregivers' demoralization was more related to variables such as mental health and hope than to the care burden. However, caregiver's burden may play a more indirect role respect to demoralization, causing psychological and spiritual suffering, from which the demoralization could generate itself.**

Considering these results, it might be useful to implement psychosocial interventions that are effective at the end of life for both patients and their caregivers, such as the Meaning-Centered Psychotherapy for Cancer Caregivers.²⁹ This kind of psychotherapy can help cancer caregivers in finding or improving their personal sense of meaning and purpose.

Regarding associations, caregivers' physical and psychological well-being were negatively associated with the *Dysphoria* and *Disheartenment* DS subscales. Caregivers with reduced psychological well-being and physical ailments could be unable to comply with the care requests and could develop greater difficulties in facing the terminal disease of the loved one by feeling helpless and incapable of controlling or changing the situation, and a sense of failure and isolation.

~~Strong~~ **Moderate** correlations were found between the demoralization and the *Vitality*, *Social functioning*, and *Mental health* SF-36 subscales. The least demoralized caregivers appear to be the ones able to conserve their energy and avoid excessive fatigue, who do not restrict their social lives and maintain low levels of distress and high levels of well-being. Moreover, demoralization was positively correlated with distress. Thus, caregivers are at

greater risk of developing a demoralization syndrome if they experience greater difficulties in adapting to various stressful aspects of the situation, i.e. the terminal oncological disease, the burden of care, the uncertainty about the future, compared to those who use effective coping strategies. Regarding the Problem List of the DT, an association between demoralization and emotional and spiritual problems assessed through the DT, emerged. Once again, the results seem to suggest, as already evidenced by the HHI results, that demoralization is more linked to spiritual and psychological suffering rather than assistance related factors, such as relative to caregivers' personal time, social roles, physical states, and financial resources.

The greatest limitation of this research is its cross-sectional design, as it did not allow us to assess the caregivers' burden over time in the sample and the patient's history of disease. Another limitation concerns the role of awareness. Whether or not most patients were aware of both their diagnosis and their prognosis was not assessed. Future research could investigate the demoralization of caregivers in relation to the role held by the caregiver (e.g. parent, spouse, or in-home nurse) and the stages of the disease.

Conclusions

Not only terminal cancer patients but also their caregivers can experience demoralization. The results of this research ~~seem to highlight that caregivers' demoralization is less related to the burden of care but rather to other variables such as mental health and hope~~ **was more related to variables such as mental health and hope than to the care burden.** Therefore, it seems that in end-of-life cancer patients' caregivers, demoralization syndrome is more

associated to a dimension of spiritual and psychological suffering rather than caregivers' personal time, social roles, physical states, and financial resources. **However, caregiver's burden may play a more indirect role respect to demoralization, causing psychological and spiritual suffering, from which the demoralization could generate itself.**

In order to reduce and prevent demoralization, **on the one hand clinicians could help caregivers to explore and improve personal resources (e.g. coping strategies and social support) and recognize and legitimize their needs; on the other, when personal resources are not enough,** psychotherapies aimed at working on the concepts of meaning and purpose, such as the Meaning Centered Psychotherapy for Cancer Caregiver, ~~should~~ **could** be used with caregivers.

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