Palliative and Supportive Care

cambridge.org/pax

Prevalence of and factors associated with demoralization among family caregivers of palliative care patients in Hong Kong

Wallace Chi Ho Chan, PH.D., R.S.W., F.T.[1], Clare Tsz Kiu Yu, B.SOC.SC, M.SC.[2], Denis Ka-Shaw Kwok, B.SOC.SC., M.A.[2] and Jamie Kit Ming Wan B.S.W., R.S.W.[3]

[1]Department of Social Work, Education, Community Wellbeing, Northumbria University, Newcastle Upon Tyne, UK; [2]Department of Social Work, The Chinese University of Hong Kong, Shatin, Hong Kong and [3]Medical Social Work Department, Bradbury Hospice, Hospital Authority, Shatin, Hong Kong

Original Article

Cite this article: Chan WCH, Yu CTK, Kwok DKS, Wan JKM (2024) Prevalence of and factors associated with demoralization among family caregivers of palliative care patients in Hong Kong. *Palliative and Supportive Care* **22**(5), 1125–1135. https://doi.org/10.1017/S1478951523000950

Received: 31 January 2023
Revised: 04 May 2023
Accepted: 17 June 2023

Keywords:
Demoralization; Family caregivers; Palliative care; Depression; End of life

Corresponding author: Wallace Chi Ho Chan; Email: wallace.chan@northumbria.ac.uk

Abstract

Objectives. This study aims to examine (1) the prevalence of demoralization among family caregivers of palliative care patients (PCP) in Hong Kong, (2) the percentage of caregivers who are demoralized but not depressed, (3) the factors associated with demoralization, and (4) the differences in caregivers' support needs between high and low levels of demoralization groups.

Methods. Ninety-four family caregivers were recruited and completed a questionnaire that included measures of demoralization, depression and caregiving strain, caregivers' support needs, and demographic information.

Results. The prevalence of demoralization among family caregivers of PCP was found to be 12.8% (cutoff score = 50) and 51.1% (cutoff score = 30). Although 27.7% of caregivers met the criteria of depression and demoralization, 12.8% of demoralized caregivers were not depressed. Depression and caregiving strain were identified as the predictors of demoralization. Caregivers with a poorer subjective physical status and a lower education level are more prone to demoralization. The three major caregivers' needs for support reported were (1) knowing what to expect in the future (77.7%); (2) knowing who to contact (74.5%); and (3) understanding your relative's illness (73.4%). Those who experienced a high level of demoralization often reported more need for support in end-of-life caregiving.

Significance of results. This is the first study that focused on the demoralization of family caregivers of PCP in the East Asian context. Demoralization is prevalent among these caregivers. We recommend that early assessment of demoralization among family caregivers of PCP be considered, especially for those who are more depressed and have a higher level of caregiving stress.

Introduction

Family caregivers play a key role in the care of palliative care patients (PCP). For example, around 2.3 million family caregivers provided care to older patients aged 65 or above in the last year before their death in the United States (Ornstein et al. 2017). The caregiving of PCP is undeniably a physically and psychologically demanding task. Family caregivers not only often need to take care of patients' activities of daily living but also provide emotional support to patients in facing death and dying (Morris et al. 2015; Wong et al. 2022). Compared to non-end-of-life caregivers, these caregivers often report more care-related challenges (e.g., physical difficulty) and higher caregiver strain (Ornstein et al. 2017). It is well documented that this population is at a higher risk of physical complications such as higher mortality, and psychological complications such as depression and anxiety (Götze et al. 2018; Sklenarova et al. 2015).

Apart from these physical and psychological burdens, family caregivers of PCP may be vulnerable to existential distress. Around 20% of caregivers reported identity-related existential concerns during the end-of-life stage of their relatives (Applebaum et al. 2014). The impending death of their loved ones could lead caregivers to experience hopelessness and helplessness and feeling fearful about the need to continue life after the patients die (Lowers et al. 2020; Mok et al. 2003). Some might even feel trapped and experience a pervasive feeling of isolation. Studies indicate that these distresses can be especially high for family caregivers of PCP in the home setting, as they receive fewer social supports (Rumpold et al. 2016; Sklenarova et al. 2015). The unmet existential and spiritual needs of family caregivers can be extended to the post-loss period, which may further complicate their adjustment to bereavement (Benites et al. 2023).

Demoralization can be one of the existential distress syndromes that family caregivers of PCP experience. Demoralization can also be understood as a failure of coping with a stressful event – leading to their loss of morale and hope (Kissane 2014 as cited in Bovero et al. 2022). Demoralization is thus often manifested by incapacity to cope, feeling helpless and hopeless, experiencing a loss of meaning and purpose, and impaired self-esteem (Clarke and Kissane 2002; Kissane et al. 2001; Vehling and Philipp 2018). The diagnostic criteria of demoralization include (1) the experience of emotional distress (e.g., hopelessness and losing life meaning); (2) attitudes of helplessness, failure, pessimism, and lack of a worthwhile future; (3) reduced coping to respond differently; and (4) social isolation and deficiencies in social support (Kissane et al. 2001). Demoralization can negatively affect one's psychological well-being and quality of life (Robinson et al. 2015) and increase suicidal ideation risk (Xu et al. 2019).

To date, the majority of demoralization studies in palliative care have focused on patients (Robinson et al. 2015; Tang et al. 2015). But the fact is that taking care of demoralized patients may be so stressful that it may also induce demoralization of both professional caregivers (e.g., health-care professionals) and family caregivers. For example, little is known about demoralization of family caregivers; to our knowledge, only 2 studies have examined the demoralization of family caregivers of PCP. In these studies, the mean score of demoralization was found to range from 26 to 29 (Bovero et al. 2022; Hudson et al. 2011). The prevalence of demoralization among family caregivers of PCP reported in these 2 studies varied and could not be directly compared, as different cutoff scores were used. The studies found that a more severe disruption of caregivers' schedule and poorer family functioning could lead to higher demoralization (Hudson et al. 2011), whereas optimism, self-perceived caregiving competency (Hudson et al. 2011), and spiritual and mental health (Bovero et al. 2022) were found to be protective factors against demoralization. However, many issues on demoralization can be further examined among family caregivers of PCP, such as prevalence using different cutoff scores, in a different sample and in a different sociocultural context, as well as other caregiving factors which may be associated with demoralization.

Previous studies show that demoralization is a distinct construct from depression (Costanza et al. 2020; Tecuta et al. 2015) although they are highly correlated (Bobevski et al. 2022; Robinson et al. 2015). Anhedonia is a key symptom of depression, but a demoralized person might not experience anhedonia (Robinson et al. 2015). For example, some patients who were highly demoralized were found not to experience depression, and those who were depressed might not be demoralized (Fang et al. 2014). A study from Hong Kong found that 52.8% of PCP met the criteria of both demoralization and depression, 7.5% of patients were depressed but not demoralized, and 13.2% of patients were demoralized but not depressed (Chan et al. 2022). Previous findings have focused on patient samples, but the situation among family caregivers of PCP remains under-explored.

Caregiving stress and burden are often experienced by family caregivers of PCP (Hebert and Schulz 2006). A global review found that family caregivers of PCP were often overburdened, and stress was associated with poor physical and mental health and with the development of complications in the grieving process (Mayra et al. 2015). In Hong Kong, 1 study found a higher level of caregiver burden is associated with depression and anxiety symptomatology among family caregivers of patients with advanced cancer (Chan and Ng 2022). Family caregivers may particularly feel more stressed when they are not able to perceive the meaning in their caregiving (Funk et al. 2010; Lalani et al. 2018). Meaning in life of family caregivers may also be associated with their caregiving strain and burden (Chan 2017; Chan et al. 2013). Therefore, caregiving stress and burden could also be an important factor associated with demoralization of family caregivers.

To minimize caregiving stress and burden, in recent years, the carer support needs of family caregivers of PCP have been highlighted (Diffin et al. 2018; Ewing et al. 2016; Ewing and Grande 2013). In Hong Kong, 1 study indicated that family caregivers' willingness to take care of family members in end of life increased from 63.8% to 78.5% if their support needs were met (Chan 2021). This study also highlighted that caregivers' support needs could be different for family caregivers with different psychological conditions. Family caregivers in the psychological distress group experienced a significantly greater need for support in "dealing with your feelings and worries" and "looking after your own health" (Chan 2021). Along this line, demoralization could also be an important condition which may differentiate the support needs of family caregivers of PCP. Yet, no previous study has examined this.

Because of all these research gaps, it is important to conduct an empirical study which focuses on demoralization of family caregivers. Findings may also help inform earlier intervention for managing demoralization among family caregivers of PCP (Kissane et al. 2001). Therefore, this study aimed to (1) examine the prevalence of demoralization among family caregivers of PCP in Hong Kong using different cutoff scores; (2) determine the percentage of caregivers who are demoralized but not depressed; (3) determine the relationship among depression, caregiving stress, and demoralization; and (4) determine the differences in support needs of family caregivers of PCP between high and low levels of demoralization groups.

Method

Participants and recruitment

Participants were family caregivers of PCP in Hong Kong. To be eligible for this study, participants had to be (1) family caregivers of community-dwelling patients who were receiving medical follow-up by a palliative care team of a public hospital in Hong Kong, and (2) able to understand and communicate in Cantonese. All participants were recruited from PCP who were newly referred to medical social workers in a palliative care unit of a public hospital in Hong Kong during the data collection period (October 2019 to February 2020). Participants who were assessed by the referrers (medical social workers) as emotionally unfit for participating in the research were excluded. The medial social workers contacted potential participants (the family caregivers). Those who were interested in participating in the study were referred to the research team for follow-up. Participants were then contacted by a research assistant for a more detailed briefing about the study procedure. No incentive was provided to the participants. Before conducting the study, ethical approval was obtained from the ethics committee board of both the principal investigator's affiliated institution at the time of study and the Hospital Authority of Hong Kong.

Study procedure

Data collection was at the caregiver's home or hospital, depending on the preference of participants. Written consent was obtained from all participants before data collection. The data collection was

https://doi.org/10.1017/S1478951523000950 Published online by Cambridge University Press

face-to-face assessment, orally administered by a trained research assistant. The entire questionnaire assessment takes approximately 20 minutes to complete. The assessment consists of the following outcome measurements and demographic information:

Demoralization Scale

The Chinese version of the demoralization scale (DS) was used to assess demoralization (Hung et al. 2010). This is a 24-item scale which assesses demoralization status over the previous 2 weeks. Participants were asked to rate their level of agreement on a 5-point Likert scale (0 = strongly disagree to 4 = strongly agree) for each statement. DS demonstrated satisfactory validity and reliability in Chinese cancer patients (Hung et al. 2010). DS generates a total score (from 0 to 96) and 5 subscale scores: loss of meaning (5 items; score ranges from 0 to 20), disheartenment (6 items; score ranges from 0 to 24), dysphoria (5 items; score ranges from 0 to 20), helplessness (4 items; score ranges from 0 to 16), and sense of failure (4 items; score ranges from 0 to 16). A higher score indicates a higher level of demoralization. In our study, we found that Cronbach's alpha of DS-total, DS-loss of meaning, DS-dysphoria, DS-disheartenment, DS-helplessness, and DS-sense of failure are 0.939, 0.851, 0.826, 0.875, 0.778, and 0.714, respectively, indicating acceptable to excellent internal consistency.

The Center for Epidemiological Studies Depression

The Chinese version of the 10-item Center for Epidemiological Studies Depression (CESD) was used to assess depression symptom severity in this study (Boey 1999). Participants were asked how often they experienced depression symptoms over the previous week, on a 4-point Likert scale (from 0 = rarely to 3 = most or all the time). The total score ranges from 0 to 60, a higher score indicating a higher level of depressive severity. The Chinese version of CESD demonstrated satisfactory validity and reliability among Hong Kong Chinese elderly people (Boey 1999; Cheng and Chan 2005). We used a score of 10 as the cutoff point in identifying patients with depression and those without (Andresen et al. 1994; Zhang et al. 2012). In our study, we found that Cronbach's alpha was 0.837, indicating good internal consistency.

The Chinese version of Modified Caregivers' Strain Index

Caregiving stress and burden were measured by the Chinese version of Modified Caregivers' Strain Index C-M-CSI (Chan et al. 2013). This is a 13-item scale that measures the caregiving strain in financial, physical, psychological, social, and personal domains. Participants were asked if they experienced the situation as described in each item (0 = no, 1 = yes, sometimes, 2 = yes, regularly). The total score of caregiving strain ranges from 0 to 26. The higher the score, the higher the level of caregiver strain. This is a valid and reliable tool for Chinese caregivers of patients in Hong Kong (Chan et al. 2013). In our study, we found that Cronbach's alpha was 0.874, indicating good internal consistency.

The Chinese version of Caregivers' Support Needs Assessment tool

The Chinese version of Caregivers' Support Needs Assessment tool (CSNAT) was originally developed by Ewing et al. (2013) to measure carers' support needs in providing palliative and end-of-life care at home. This is valid tool used in both research and palliative care service settings (Ewing et al. 2013). CSNAT contains 14 items which assess caregivers' need for more support in different aspects, such as support for taking care of family members in end of life (e.g., understanding your relative's illness) and personal support for themselves (e.g., looking after your own health). Items were scored from 0 (none) to 3 (very much more). As CSNAT is not a scale, the rating of items could not be summed up to form a total score. The Chinese version of CSNAT (C-CSNAT) was developed, following the procedure of direct and back-translations of the English version and with the permission of the corresponding author of CSNAT (Dr. Gail Ewing). C-CSNAT was used in a previous study of family caregivers in Hong Kong and was found to be a useful tool for exploring the support needs of caregivers (Chan 2021). For details of CSNAT, refer to http://csnat.org.

Demographic information including age, gender, marital status, education status, employment status, relationship with the patient, living status with patient, average hours of care provided to the patient per week, number of medical conditions, and subjective health status (1 item using a 5-point Likert scale, from very bad to very good) were obtained.

Statistical analyses

IBM SPSS 23.0 software was used for data analysis. In this study, the cutoff score of 30 in DS was used in all major analyses. Family caregivers who indicated a DS total score $\geq$30 were categorized to a high demoralization group, and those who indicated a total score $<$30 were categorized to a low demoralization group. This cutoff score was used in the original scale development and validation study (Kissane et al. 2004). It was also used in a recent study for demoralization of PCP in Hong Kong (Chan et al. 2022). However, for the purpose of comparison with previous studies (Bovero et al. 2022; Hudson et al. 2011), apart from using this cutoff score for computing the prevalence of demoralization, we also used the cutoff score of 50 and categorized the level of demoralization by percentiles ($<$25%, between 25% and 75%, and $>$75%) in this study. Moreover, we performed cross-tabulation between the above 2 DS groups and 2 depression groups ($<$10: not depressed versus $\geq$10: depressed) and computed the percentage among the 4 groups. The associations between factors (sociodemographics, depression and caregiving stress) and DS (total score and 5 subscale scores) were analyzed using hierarchical regression. Before the main regression analyses, bivariate correlations were performed on all sociodemographic variables and DS. Any sociodemographic variables which showed significant association with DS were treated as potential predictor variables. These variables were entered in step 1 of the regression. Depression and caregiving stress were entered in step 2 and step 3, respectively. All assumptions were examined before the analyses. The P-P plot suggests normal distribution of residual, and we identified no violation of the assumption of linearity tested with scatterplots, multicollinearity, and homoscedasticity. Descriptive statistics were reported for all CSNAT items by groups (high and low demoralized groups). The Mann–Whitney U-test was also conducted to examine the difference in CSNAT items between participants of the low and high demoralized groups. The percentage of participants who expressed a need for more support in each CSNAT item was computed according to the number of participants who rated the CSNAT item other than 0.

Results

Participants

A total of 94 caregivers participated in this study. Table 1 illustrates the demographic characteristics of participants. Of all participants, 72% are female. The mean age is 53 years, ranging from 25 to

https://doi.org/10.1017/S1478951523000950 Published online by Cambridge University Press

80 years. Most (73%) were married and received education at primary level or above (79%). The majority do not have a religious belief (58%). Around 36% classified themselves as full-time caregivers. About one-fifth (20.7%) reported having 1 chronic disease. Around 16.4% had 2 or more chronic diseases. Only 2.2% of participants indicated they have a bad or very bad health status. Regarding the psychological health of our participants, the mean score of depression (measured by CESD) is 10.23 (SD = 5.94). If a cutoff point of 10 is used for classification (Zhang et al. 2012), 43% of caregivers showed depression symptoms. The mean score of caregiving strain is 9.55 (SD = 5.63). Adult children/children-in-law caregivers and spousal caregivers constituted 56% and 30% of the samples, respectively. More than half (56%) were living in the same household with the patient. On average, they provided 41 hours of care each week.

Mean scores and prevalence of demoralization

Table 2 gives the descriptive statistics of DS. The mean score of demoralization is 31.03 (SD = 14.88). The mean score of subscales, "loss of meaning," "dysphoria," "disheartenment," "helplessness' and' sense of failure" are 4.64 (SD = 3.62), 7.17 (SD = 3.92), 7.45 (SD = 4.23), 4.86 (SD = 2.93), and 6.91 (SD = 2.98), respectively. Using 30 as a cutoff point, the prevalence of demoralization is 51.1% (n = 48). But when a cutoff of 50 was used, the prevalence became 12.8%. When categorizing the level of demoralization into mild (below the 25th percentile), moderate (between the 25th and 75th percentiles), and severe (above the 75th percentile), the percentage was 23.4, 52.1, and 24.5, respectively.

Demoralization and depression

About 27.7% of participants experienced both depressive mood and demoralization, whereas 10.6% of participants experienced a low level of demoralization and were found to be depressed. Another 12.8% experienced a high level of demoralization but were not depressed (see Table 3).

Factors associated with demoralization

Our findings indicate that participants with a higher level of depression ($\beta = 0.569$, $p < .001$) and caregiving strain ($\beta = 0.23$, $p < .05$) had a significantly higher level of demoralization (the DS total score), when controlled with the demographic covariate (full-time caregivers versus non-full-time caregivers). This model explains 56% of the variance in the DS total score. Comparable results were found on DS-dysphoria and DS-disheartenment. When controlled for the effects of their corresponding demographic covariates, participants with a higher depression level (for dysphoria: $\beta = 0.358$, $p < .01$; for disheartenment: $\beta = 0.491$, $p < .001$) and caregiving strain (for dysphoria: $\beta = 0.294$, $p < .01$; for disheartenment: $\beta = 0.275$, $p < .01$) had a significantly higher level of DS-dysphoria and DS-disheartenment. The 2 models explain 38% and 56% of the variance in the DS-dysphoria and DS-disheartenment, respectively. For DS-loss of meaning, participants with a lower educational level ($\beta = -0.208$, $p < .05$) and a higher depression level ($\beta = 0.508$, $p < .001$) had a significantly higher level of DS-loss of meaning. The model explains 43% of the variance. For DS-sense of failure, participants with a poorer perceived health status ($\beta = -0.227$, $p < .05$) and a higher depression level ($\beta = 0.489$, $p < .001$) had a significantly higher level of DS-sense of

Table 1. Demographic and clinical characteristics of caregivers (N = 94)

	n	Valid %
Gender		
Female	67	72
Male	26	28
Age (M, SD) (Range)	52.96 (13.21) (25–80)	
Marital status		
Single	18	19.6
Married	67	72.8
Divorced	6	6.5
Widow	1	1.1
Educational level		
No formal schooling	1	1.1
Primary or below	18	19.6
Junior secondary school	25	27.2
Senior secondary school	27	29.3
Tertiary education or above	21	22.8
Religion		
No religion	52	57.8
Buddhism	12	13.3
Taoism	1	1.1
Catholic	2	2.2
Protestant	13	14.4
Ancestor worship	9	10
Other	0	0
Employment		
Full-time employee	31	34.4
Half-time employee	6	6.7
Part-time employee	4	4.4
Full-time caregiver	32	35.6
Unemployed	5	5.6
Other	12	13.3
Relationship with the patient		
Children/Children-in-law	50	55.5
Spouse	27	30
Parents	6	6.7
Siblings	4	4.4
Paternal/Maternal grandchildren	2	2.2
Other	1	1.1
Living status with patient		
Yes	51	56
No	40	44
CESD (using cutoff points as classification)		

(*Continued*)

https://doi.org/10.1017/S1478951523000950 Published online by Cambridge University Press

Table 1. (*Continued.*)

	n	Valid %
Without depressive symptoms (<10)	54	57.4
With depressive symptoms (≥10)	40	42.6
CESD (M, SD) (Range)	10.23 (5.94) (0–26)	
C-M-CSI (M, SD) (Range)	9.55 (5.63) (0–23)	
Average hours of care provided each week (M, SD) (Range)	41.02 (48.50) (0–168)	
Subjective health status		
Very bad	0	0
Bad	2	2.2
Moderate	56	60.9
Good	28	30.4
Very good	6	6.5

CESD = The Centre for Epidemiological Studies Depression, C-M-CSI = The Chinese version of Modified Caregivers' Strain Index.

Table 2. Descriptive statistics of demoralization total and subscale scores (N = 94)

	M	SD
DS total score	31.03	14.88
Low demoralized (DS < 30) (*N*, %)	46, 48.93	
High demoralized (DS ≥ 30) (N, %)	48, 51.1	
Loss of meaning	4.64	3.62
Dysphoria	7.17	3.92
Disheartenment	7.45	4.23
Helplessness	4.86	2.93
Sense of failure	6.91	2.98

DS = demoralization scale. For the DS total score, the score ranges from 0 to 96, a higher score indicating a higher demoralization level. For the 5 subscale scores of DS, the range of subscale score is stated as follows: loss of meaning (from 0 to 20), disheartenment (from 0 to 24), dysphoria (from 0 to 20), helplessness (from 0 to 16), and sense of failure (from 0 to 16).

Table 3. Comparison of demoralization score (DS) with non-depressed and depressed (CESD) caregivers

	Low demoralized (DS < 30) *N* (%)	High demoralized (DS ≥ 30) *N* (%)
Not depressed (CESD < 10)	36 (38.3)	12 (12.8)
Depressed (CESD ≥ 10)	10 (10.6)	26 (27.7)

failure. The model explains 31% of the variance. Details are shown in Table 4.

Caregivers' support needs between low and high levels of demoralization groups

Overall, 3 items that call for the greatest need for support in end-of-life caregiving among participants are: (1) knowing what to expect in the future (77.7%), (2) knowing who to contact (74.5%), and (3) understanding your relative's illness (73.4%). (Full details are available upon request.) But our analyses show that participants in the high level of demoralization group expressed a higher level of need for support in 8 aspects than did participants in the low level of demoralization group: "providing personal care for the relative"; "own financial, legal, and work issues"; "own belief and spiritual concerns"; "equipment to help care for the relative"; "managing your relative's symptoms"; "dealing with your feelings and worries"; "knowing who to contact"; and "knowing who to contact in future" (see Table 5). Figure 1 shows the percentages of need for support among the high level of demoralization group, the low level of demoralization group, and all participants. Participants in the high level of demoralization group indicated a higher percentage of need for support in these 8 items than did participants in the low level of demoralization group.

Discussion

This study provides empirical findings on the demoralization of family caregivers of PCP in Hong Kong. More than half the family caregivers in this study (51%) indicated demoralization using the cutoff score of 30. Using the same cutoff score, a previous study reported 64.8% of PCP in Hong Kong experienced demoralization (Chan et al. 2022). Our findings reveal that not only do PCP experience demoralization but also the family caregivers do. In a previous study of family caregivers of patients who were newly referred to palliative care services in Australia, a cutoff score of 50 was used to indicate moderate-to-severe demoralization; the percentage was found to be 9.6% (Hudson et al. 2011). Using this cutoff, our findings indicate a greater percentage – about 12.8% of family caregivers of PCP in this study – reported moderate-to-severe demoralization. Another study of family caregivers of PCP in Italy showed that about 32% experienced moderate demoralization (25th to75th percentiles) and 45.1% experienced severe demoralization (75th to100th percentiles) (Bovero et al. 2022). Using the same percentile classification, our study reports a smaller percentage of severe demoralization (24.5%). Yet, the total percentage of moderate-to-severe demoralization in our study (76.6%) is almost the same as in Bovero et al.'s (2022) study (77.04%).

Caution is required for these comparisons, as the research methods varied in these studies. For example, the prevalence of demoralization found in these studies may be affected by the source of participants and the prognosis of patients of the family caregivers. This study and that of Hudson et al. (2011) recruited family caregivers of PCP who had just commenced the services, but participants in our study came from those who were referred for medical social work services. As described in a previous study (Chan et al. 2022), these patients are often more psychosocially disadvantaged and experience a high level of demoralization. It is likely that the demoralization of patients and their family caregivers are interdependent (Jacobs et al. 2017). When caring for a demoralized patient who is frustrated by death and dying, caregivers may also struggle with how they can address their existential distress (Melin-Johansson et al. 2012). The distress of addressing the patients' existential frustration may contribute to a further sense of helplessness, hopelessness, and sense of failure and in turn the demoralization of family caregivers. This may help explain why our study reported a higher prevalence of demoralization than that in the study of Hudson et al. (2011). The prevalence of severe demoralization found in this study is lower than what was found in Bovero et al. (2022). One possible reason is that participants in the latter study included family caregivers of patients who had a poorer

https://doi.org/10.1017/S1478951523000950 Published online by Cambridge University Press

Table 4. Hierarchical regression analyses for demoralization (total score and 4 subscale scores)

	Variable[b]	*B*	SE	*B*	ΔR^2	Statistics of the final model[a]
DV: DS-Total score						
Step 1	Full-time CG	6.492	3.114	0.221*	0.049*	$F(3, 83) = 35.62$, $R^2 = 0.56$***
Step 2	Full-time CG	4.623	2.218	0.157*	0.478***	
	CESD	1.677	0.182	0.695***		
Step 3	Full-time CG	3.779	2.17	0.128 (ns)	0.036*	
	CESD	1.375	0.211	0.569***		
	CG strain	0.595	0.228	0.23*		
DV: DS-Loss of meaning						
Step 1	Full-time CG	0.98	0.796	0.136 (ns)	0.084*	$F(4,82) = 15.19$, $R^2 = 0.43$***
	Education level	−0.704	0.359	−0.216(ns)		
Step 2	Full-time CG	0.645	0.642	0.089 (ns)	0.331***	
	Education level	−0.637	0.289	−0.195*		
	CESD	0.343	0.05	0.578***		
Step 3	Full-time CG	0.498	0.651	0.069 (ns)	0.011	
	Education level	−0.681	0.29	−0.209*		
	CESD	0.301	0.06	0.508***		
	CG strain	0.081	0.065	0.128 (ns)		
DV: DS-Dysphoria						
Step 1	Unemployed	4.178	1.932	0.228***	0.052*	$F(3,83) = 16.61$, $R^2 = 0.38$***
Step 2	Unemployed	3.033	1.662	0.166 (ns)	0.264***	
	CESD	0.337	0.059	0.518***		
Step 3	Unemployed	2.526	1.609	0.138 (ns)	0.059**	
	CESD	0.233	0.068	0.358**		
	CG strain	0.205	0.073	0.294**		
DV: DS-Disheartenment						
Step 1	Living with patient	1.026	0.952	0.123 (ns)	0.154**	$F(6,79) = 16.58$, $R^2 = 0.557$***
	Full-time CG	0.965	0.916	0.112 (ns)		
	Relationship to patient: Child(ren)	−1.149	1.114	−0.139 (ns)		
	Relationship to patient: Spouse	1.67	1.324	0.181 (ns)		
Step 2	Living with patient	0.61	0.734	0.073 (ns)	0.353***	
	Full-time CG	0.923	0.704	0.107 (ns)		
	Relationship to patient: Child(ren)	−0.942	0.856	−0.114 (ns)		
	Relationship to patient: Spouse	−0.226	1.048	−0.025 (ns)		
	CESD	0.45	0.06	0.643***		
Step 3	Living with patient	0.453	0.702	0.054 (ns)	0.051**	
	Full-time CG	0.692	0.676	0.08 (ns)		
	Relationship to patient: Child(ren)	−0.744	0.819	−0.09 (ns)		
	Relationship to patient: Spouse	0.053	1.003	0.006 (ns)		
	CESD	0.344	0.067	0.491***		
	CG Strain	0.208	0.069	0.275**		

(*Continued*)

https://doi.org/10.1017/S1478951523000950 Published online by Cambridge University Press

Table 4. (*Continued.*)

	Variable[b]	*B*	SE	*B*	ΔR^2	Statistics of the final model[a]
DV: DS-Helplessness						
Step 1					0.053*	$F(3, 83) = 16.34$, $R^2 = 0.37$***
	Full-time CG	1.363	0.623	0.231*		
Step 2					0.306***	
	Full-time CG	1.064	0.518	0.18*		
	CESD	0.269	0.042	0.56***		
Step 3					0.012(ns)	
	Full-time CG	0.964	0.522	0.163 (ns)		
	CESD	0.233	0.051	0.481***		
	CG strain	0.07	0.055	0.136 (ns)		
DV: Sense of Failure						
Step 1	CG's subjective health status	1.068	0.461	0.24*	0.057*	$F(3, 86) = 12.730$, $R^2 = 0.308$***
Step 2	CG's subjective health status	1.025	0.398	0.23*	0.025***	
	CESD	0.245	0.044	0.5***		
Step 3	CG's subjective health status	1.013	0.406	−0.227*	0.000(ns)	
	CESD	0.24	0.054	0.489***		
	CG strain	0.01	0.058	0.02 (ns)		

CESD = The Center for Epidemiological Studies Depression; DS: demoralization scale.
B = unstandardized regression coefficients, β = standardized regression coefficients.
[a]The final model refers to the model shown at the final step of the regression model.
[b]The variable "full-time caregiver" is coded as "not a full-time caregiver" (coded as 0) and "full-time caregiver" (coded as 1). The variable "unemployed" is coded as employed (coded as 0) and unemployed (coded as 1). The variable "religion status" is coded as no religion (coded as 0) and have religious belief (coded as 1). The variable "patient as parents/patient as spouse" is coded as parents not as parent/spouse (coded as 0) and patient as parent/spouse (code as 1). The variable "are you currently living with the patient" is coded as "not living with the patient" (coded as 0) and "living with the patient" (coded as 1). The variable "subjective health status" is a continuous variable. Scores ranged from 0 to 5, a higher score indicating a better perceived health status. The variable "educational level" is an ordinal variable. Scores ranged from 1 to 5, a higher score indicating higher education level.
*$p < 0.05$; **$p < 0.01$, ***$p < 0.001$

prognosis – life expectancy of 4 months or less – and a Karnofsky Performance Status ≤50. It is likely that these family members may be even more confronted by the distress in facing the death and dying of patients. Despite the percentage of severe demoralization found in this study being lower than that of Bovero et al. (2022), our study found the highest mean demoralization scores (mean = 31) when compared with the studies of Hudson et al. (2011) (mean = 25) and Bovero et al. (2022) (mean = 29). The impending death of the loved one may lead to feelings of hopelessness, helplessness, and guilt among caregivers (Lowers et al. 2020; Mok et al. 2003). It is also challenging for caregivers to discuss these feelings with others, as they often feel disconnected to society (Benites et al. 2023, 2022b). Therefore, our findings call for greater attention to the demoralization of family caregivers of PCP in Hong Kong, especially those in which patients and caregivers are more psychosocially deprived.

Our study also shows that 27.7% of family caregivers met the criteria of both depression and demoralization. But 12.8% of demoralized caregivers did not experience depression, and 10.6% of depressed caregivers were not demoralized. These findings show that, among caregivers of PCP, demoralization and depression are 2 distinct constructs despite the similarity. This finding is consistent with previous findings on demoralization and depression on PCP (Belvederi Murri et al. 2020; de Figueiredo 1993; Julião et al. 2016; Nanni et al. 2018). However, to the best of our knowledge, there are no existing studies which investigated this difference among family caregivers. Our findings suggest the importance of assessing demoralization and not only depression among family caregivers of PCP; otherwise, the need for support among some demoralized but not depressed family caregivers may be ignored. Attention should be given to the conceptualization and measurement of depression and its possible overlapping of contents with demoralization. For example, 1 item of CES-D in this study measures whether the participant feels hopeful about the future, and this may confound the relationships between depression and demoralization.

The current study also determined the factors associated with demoralization. Depression was identified as the strongest predictor of the total score and all subscales of demoralization. Although caregiving strain was also found to be significantly associated with the total score of demoralization, and the subscales of dysphoria and disheartenment, the strength of association is much weaker than is depression. A previous study also reported that demoralization was more associated with mental health well-being than with caregiving burden (Bovero et al. 2022). Despite these findings, caregiving stress and burden could be potential factors that may lead to demoralization directly and indirectly, considering the close relationship between depression and caregiving stress among family caregivers (Given et al. 2004; Govina et al. 2019). Future studies may also examine the role of caregiving stress for the relationship between depression and demoralization. Our findings also show that poorer subjective physical status is significantly

https://doi.org/10.1017/S1478951523000950 Published online by Cambridge University Press

Table 5. Results of Wilcoxon Signed-Rank test comparing CSNAT items between the low and high demoralized groups

	Low demoralized (<30)				High demoralized (≥30)				Between-group difference	
	M	SD	Mean ranks	Sum of ranks	M	SD	Mean ranks	Sum of ranks	*U* value	*p*-Value
1. Understanding your relative's illness	2.18	0.912	43.76	1969	2.36	1.031	49.13	2309	934	0.313
2. Having time to yourself in the day	1.84	0.928	43.23	1945.5	2.06	0.919	49.63	2332.5	910.5	0.225
3. Managing your relative's symptoms (e.g., medication)	1.53	0.842	38.18	1718	2.16	1.086	52.82	2377	683	0.004
4. Your financial, legal, or work issues	1.73	1.031	39.68	1785.5	2.11	0.959	51.32	2309.5	750.5	0.024
5. Providing personal care for your relative (e.g., dressing, washing, toilet)	1.48	0.792	37.67	1657.5	2.09	1.05	52.99	2437.5	667.5	0.002
6. Dealing with your feelings and worries	1.41	0.583	37.09	1632	1.94	0.763	54.34	2554	642	0.001
7. Knowing who to contact	1.82	0.724	37.02	1629	2.41	0.933	53.61	2466	639	0.001
8. Looking after your own health	1.41	0.693	41.69	1834.5	1.72	0.935	49.14	2260.5	844.5	0.115
9. Equipment to help care	1.65	0.813	36.58	1573	2.28	0.981	52.87	2432	627	0.002
10. Your beliefs and spiritual concerns	1.2	0.509	38.45	1692	1.67	0.871	52.24	2403	702	0.002
11.Talking with your relative about his/her illness	1.73	0.758	41.32	1818	2.04	0.942	49.5	2277	828	0.113
12. Practical help in the home	1.49	0.798	36.31	1561.5	2.15	1.032	53.12	2443.5	615.5	0.001
13. Knowing what to expect in the future	2.07	0.846	40.75	1793	2.43	1.025	50.04	2302	803	0.076
14.Getting a break from caring overnight	1.48	0.773	40.3	1692.5	1.73	0.889	47.46	2135.5	789.5	0.135

For all the CSNAT items, the score ranged from 0 to 4 (1 = no, 2 = a little more, no; 3 = quite a bit more; 4 = and very much more).

associated with a higher sense of failure (a subscale of the DS). Findings may suggest that family caregivers who are depressed and have a poorer physical health condition could be more prone to demoralization. Similarly, family caregivers with a higher education level were found to be associated with a lower level of loss of meaning (a subscale of the DS). All these findings may reflect the needs for supporting the more deprived and disadvantaged family caregivers who may be more at risk of experiencing demoralization.

Our findings also show that family caregivers who experienced a high level of demoralization reported more need for support in different issues in end-of-life caregiving, which covered both need for supporting them to take care of the patients and themselves. As mentioned, apart from understanding demoralization as an existential distress, demoralization could be understood as a failure of coping with a stressful event. Our findings seem to support this definition. Our findings highlight the significance of identifying caregivers who experience a high level of demoralization: they could be the most vulnerable who require extensive support in end-of-life caregiving. Not only will the well-being of caregivers be affected if adequate support is not provided to them, but it may also lead to serious caregiving issues which will also influence the quality of care provided to the PCP (Hansen et al. 2020; Litzelman et al. 2016). Alternatively, if their needs are met, a previous study has shown that family caregivers will be more willing to provide end-of-life caregiving to their family members (Chan 2021).

Limitations

The small sample size of our study may decrease the statistical power in the analyses, and it is more difficult to detect statistically significant findings. Also, limited by the cross-sectional research design, causality between factors could not be established. Despite these limitations, this is the first empirical study which focused the demoralization of family caregivers of PCP, not only in Hong Kong but also in the East Asian context.

Caution is required for interpreting the relatively high level of demoralization among family caregivers of PCP in this study. First, our samples came from the more deprived family caregivers who were referred for medical social workers' follow-up and may not represent the situation of family caregivers in general. Also, this study has no intention to pathologize the family caregiving of palliative and end-of-life care. In fact, family caregivers may still have positive experience in end-of-life caregiving despite experiencing demoralization at the same time (Peacock et al. 2014). Future studies may help examine this complicating and paradoxical experience in caregiving.

https://doi.org/10.1017/S1478951523000950 Published online by Cambridge University Press

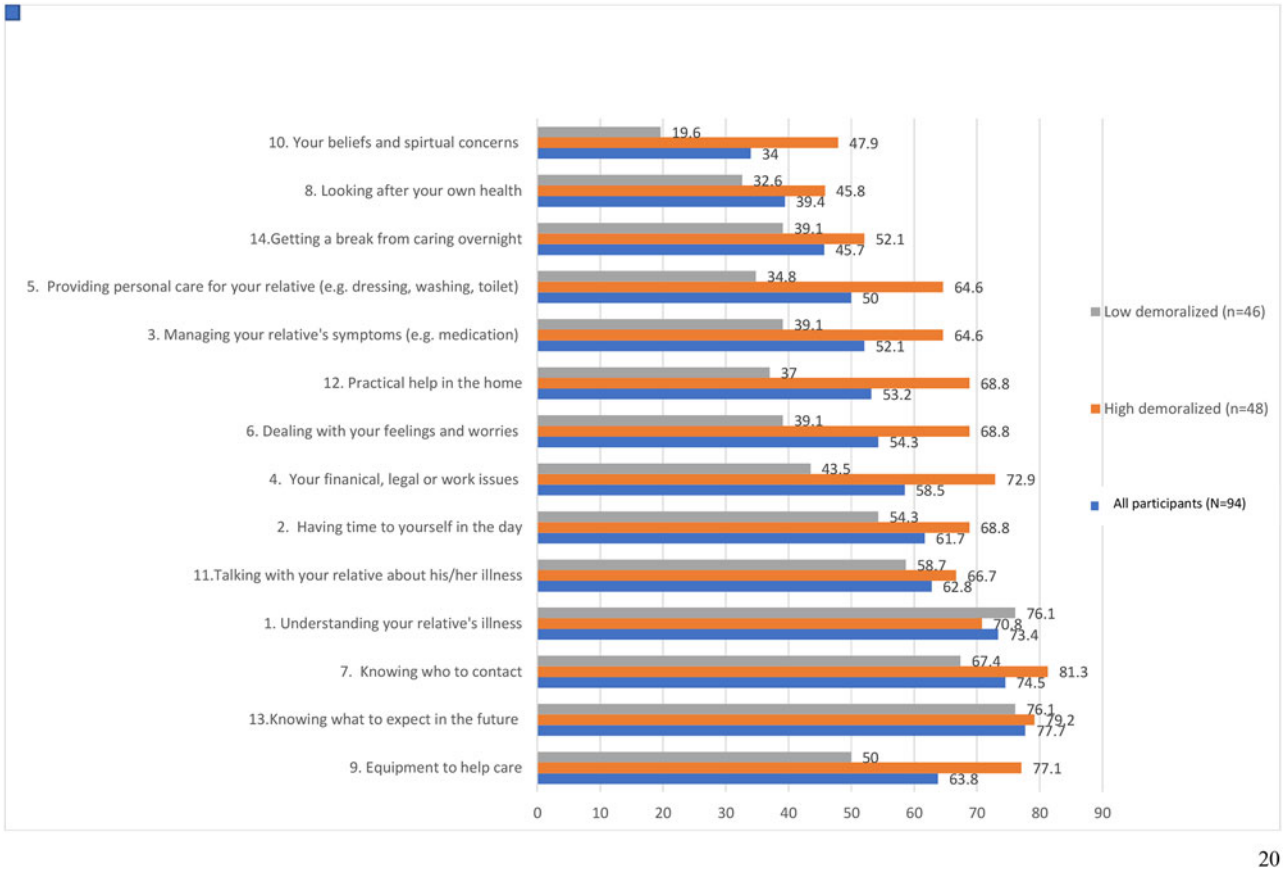

Figure 1. Percentage of caregivers expressing need for more support with each carer support needs assessment tool domain at baseline and follow-up ($N = 94$).

Limited by the research design, we could not compare the demoralization between PCP and their family caregivers directly in this study. Future studies could recruit dyads of patients and family caregivers, or even palliative care professionals who provide support to these families, to further examine the reciprocal relationships among the demoralization of PCP, their family caregivers and palliative care professionals.

Conclusion

This study shows that demoralization does exist among family caregivers of PCP in Hong Kong. The prevalence of demoralization could be high among the more disadvantaged family caregivers. At the practice level, demoralization should be assessed and differentiated from depression though depression may often co-exist with demoralization. Caregiving stress may also be associated with demoralization, and more attention should be given to demoralized family caregivers who are likely to report more need for support in end-of-life caregiving. Demoralization among family caregivers is worth further attention in the provision of palliative care.

Acknowledgments. We would like to express our gratitude to the social workers from the Medial Social Work Department, Bradbury Hospice, who assisted with the recruitment of participants in this study. Also, special thanks are given to all family caregivers who were willing to share their situations with us.

Funding. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Competing interests. None.

References

Andresen EM, Malmgren JA, Carter WB, *et al.* (1994) Screening for depression in well older adults: Evaluation of a short form of the CES-D. *American Journal of Preventive Medicine* **10**(2), 77–84. doi:10.1016/S0749-3797(18)30622-6

Applebaum AJ, Farran CJ, Marziliano AM, *et al.* (2014) Preliminary study of themes of meaning and psychosocial service use among informal cancer caregivers. *Palliative and Supportive Care* **12**(2), 139–148. doi:10.1017/S1478951513000084

Belvederi Murri M, Caruso R, Ounalli H, *et al.* (2020) The relationship between demoralization and depressive symptoms among patients from the general hospital: Network and exploratory graph analysis. *Journal of Affective Disorders* **276**, 137–146. doi:10.1016/j.jad.2020.06.074

Benites AC, Arantes de Oliveira-cardoso É and Dos Santos MA (2023) Spirituality in Brazilian family caregivers of patients with cancer from the end-of-life care to bereavement. *Death Studies* **47**(3), 249–258. doi:10.1080/07481187.2022.2051095

Benites AC, Rodin G, de Oliveira-cardoso ÉA, *et al.* (2022b) You begin to give more value in life, in minutes, in seconds: Spiritual and existential experiences of family caregivers of patients with advanced cancer receiving end-of-life care in Brazil. *Supportive Care in Cancer* **30**(3), 2631–2638. doi:10.1007/s00520-021-06712-w

Bobevski I, Kissane DW, Vehling S, *et al.* (2022) Demoralisation and its link with depression, psychological adjustment and suicidality among cancer patients: A network psychometrics approach. *Cancer Medicine* **11**(3), 815–825. doi:10.1002/cam4.4406

Boey KW (1999) Cross-validation of a short form of the CES-D in Chinese elderly. *International Journal of Geriatric Psychiatry* **14**(8), 608–617. doi:10.1002/(SICI)1099-1166(199908)14:8<608::AID-GPS991>3.0.CO;2-Z

Bovero A, Vitiello LP, Botto R, ***et al.*** (2022) Demoralization in end-of-life cancer patients' family caregivers: A cross-sectional study. *American Journal of Hospice and Palliative Care* **39**(3), 332–339. doi:10.1177/10499091211023482

Chan WCH (2017) Assessing meaning in life in social work practice: Validation of the Meaning in Life Questionnaire among clinical samples. *The British Journal of Social Work* **47**(1), 9–27. doi:10.1093/bjsw/bcv144

Chan WCH (2021) Future provision of home end-of-life care: Family carers' willingness for caregiving and needs for support. *Palliative and Supportive Care* **19**(5), 580–586. doi:10.1017/s1478951520001273

Chan WCH, Chan CLF and Suen M (2013) Validation of the Chinese version of the Modified Caregivers Strain Index among Hong Kong caregivers: An initiative of medical social workers. *Health & Social Work* **38**(4), 214–221. doi:10.1093/hsw/hlt021

Chan LM and Ng SCJ (2022) Prevalence and correlates of caregiver anxiety in family caregivers of patients with advanced cancer: A cross-sectional study in a palliative care unit in Hong Kong. *East Asian Archives of Psychiatry* **32**(2), 27–33. doi:10.12809/eaap2171

Chan WC, Yu C, Kwok D, ***et al.*** (2022) Prevalence and factors associated with demoralization in palliative care patients: A cross-sectional study from Hong Kong. *Palliative and Supportive Care*, 1–9. doi:10.1017/s1478951522001171

Cheng ST and Chan AC (2005) The Center for Epidemiologic Studies Depression Scale in older Chinese: Thresholds for long and short forms. *International Journal of Geriatric Psychiatry* **20**(5), 465–470. doi:10.1002/gps.1314

Clarke DM and Kissane DW (2002) Demoralization: Its phenomenology and importance. *Australian and New Zealand Journal of Psychiatry* **36**(6), 733–742. doi:10.1046/j.1440-1614.2002.01086.x

Costanza A, Baertschi M, Richard-Lepouriel H, ***et al.*** (2020) Demoralization and its relationship with depression and hopelessness in suicidal patients attending an emergency department. *International Journal of Environmental Research and Public Health* **17**(7), 2232. doi:10.3390/ijerph17072232

de Figueiredo JM (1993) Depression and demoralization: Phenomenologic differences and research perspectives. *Comprehensive Psychiatry* **34**(5), 308–311. doi:10.1016/0010-440x(93)90016-w

Diffin J, Ewing G, Harvey G, ***et al.*** (2018) Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: A qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention. *BMC Palliative Care* **17**(1), 129. doi:10.1186/s12904-018-0382-5

Ewing G, Austin L and Grande G (2016) The role of the Carer Support Needs Assessment Tool in palliative home care: A qualitative study of practitioners' perspectives of its impact and mechanisms of action. *Palliative Medicine* **30**(4), 392–400. doi:10.1177/0269216315596662

Ewing G, Brundle C, Payne S, ***et al.*** (2013) The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study. *Journal of Pain and Symptom Management* **46**(3), 395–405. doi:10.1016/j.jpainsymman.2012.09.008

Ewing G and Grande G (2013) Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. *Palliative Medicine* **27**(3), 244–256. doi:10.1177/0269216312440607

Fang CK, Chang MC, Chen PJ, ***et al.*** (2014) A correlational study of suicidal ideation with psychological distress, depression, and demoralization in patients with cancer. *Supportive Care in Cancer* **22**(12), 3165–3174. doi:10.1007/s00520-014-2290-4

Funk L, Stajduhar K, Toye C, ***et al.*** (2010) Part 2: Home-based family caregiving at the end of life: A comprehensive review of published qualitative research (1998–2008). *Palliative Medicine* **24**(6), 594–607. doi:10.1177/0269216310371411

Given B, Wyatt G, Given C, ***et al.*** (2004) Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum* **31**(6), 1105–1117. doi:10.1188/04.Onf.1105-1117

Götze H, Brähler E, Gansera L, ***et al.*** (2018) Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *European Journal of Cancer Care (English Language Edition)* **27**(2), e12606. doi:10.1111/ecc.12606

Govina O, Vlachou E, Kalemikerakis I, ***et al.*** (2019) Factors associated with anxiety and depression among family caregivers of patients undergoing palliative radiotherapy. *Asia Pacific Journal of Oncology Nursing* **6**(3), 283–291. doi:10.4103/apjon.apjon_74_18

Hansen MIT, Haugen DF, Sigurdardottir KR, ***et al.*** **The, ERANet-LAC CODE Project Group** (2020) Factors affecting quality of end-of-life hospital care—a qualitative analysis of free text comments from the i-CODE survey in Norway. *BMC Palliative Care* **19**(1), 98. doi:10.1186/s12904-020-00609-x

Hebert RS and Schulz R (2006) Caregiving at the end of life. *Journal of Palliative Medicine* **9**(5), 1174–1187. doi:10.1089/jpm.2006.9.1174

Hudson PL, Thomas K, Trauer T, ***et al.*** (2011) Psychological and social profile of family caregivers on commencement of palliative care. *Journal of Pain and Symptom Management* **41**(3), 522–534. doi:10.1016/j.jpainsymman.2010.05.006

Hung HC, Chen HW, Chang YF, ***et al.*** (2010) Evaluation of the reliability and validity of the Mandarin version of demoralization scale for cancer patients. *Journal of Internal Medicine of Taiwan* **21**, 427–435.

Jacobs JM, Shaffer KM, Nipp RD, ***et al.*** (2017) Distress is interdependent in patients and caregivers with newly diagnosed incurable cancers. *Annals of Behavioral Medicine* **51**(4), 519–531. doi:10.1007/s12160-017-9875-3

Julião M, Nunes B and Barbosa A (2016) Prevalence and factors associated with demoralization syndrome in patients with advanced disease: Results from a cross-sectional Portuguese study. *Palliative and Supportive Care* **14**(5), 468–473. doi:10.1017/S1478951515001364

Kissane DW (2014) Demoralization: A life-preserving diagnosis to make for the severely medically ill. *Journal of Palliative Care* **30**(4), 255–258. doi:10.1177/082585971403000402

Kissane DW, Clarke DM and Street AF (2001) Demoralization syndrome—a relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care* **17**(1), 12–21. doi:10.1177/082585970101700103

Kissane DW, Wein S, Love A *et al.* (2004) The Demoralization Scale: A report of its development and preliminary validation. *Journal of Palliative Care* **20**(4), 269–276.

Lalani N, Duggleby W and Olson J (2018) Spirituality among family caregivers in palliative care: An integrative literature review. *International Journal of Palliative Nursing* **24**(2), 80–91. doi:10.12968/ijpn.2018.24.2.80

Litzelman K, Kent EE, Mollica M, ***et al.*** (2016) How does caregiver well-being relate to perceived quality of care in patients with cancer? Exploring associations and pathways. *Journal of Clinical Oncology* **34**(29), 3554–3561. doi:10.1200/jco.2016.67.3434

Lowers J, Scardaville M, Hughes S, ***et al.*** (2020) Comparison of the experience of caregiving at end of life or in hastened death: A narrative synthesis review. *BMC Palliative Care* **19**(1), 154. doi:10.1186/s12904-020-00660-8

Mayra D, Joana P, António B, ***et al.*** (2015) Burden of caregiving and its repercussions on caregivers of end-of-life patients: A systematic review of the literature. *Ciência & Saude Coletiva* **20**(9), 2731. doi:10.1590/1413-81232015209.09562014

Melin-Johansson C, Henoch I, Strang S, ***et al.*** (2012) Living in the presence of death: An integrative literature review of relatives' important existential concerns when caring for a severely ill family member. *The Open Nursing Journal* **6**, 1–12. doi:10.2174/1874434601206010001

Mok E, Chan F, Chan V, ***et al.*** (2003) Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nursing* **26**(4). doi:10.1097/00002820-200308000-00003

Morris SM, King C, Turner M, ***et al.*** (2015) Family carers providing support to a person dying in the home setting: A narrative literature review. *Palliative Medicine* **29**(6), 487–495. doi:10.1177/0269216314565706

Nanni MG, Caruso R, Travado L, ***et al.*** (2018) Relationship of demoralization with anxiety, depression, and quality of life: A Southern European study of Italian and Portuguese cancer patients. *Psycho-Oncology* **27**(11), 2616–2622. doi:10.1002/pon.4824

Ornstein KA, Kelley AS, Bollens-Lund E, ***et al.*** (2017) A national profile of end-of-life caregiving in the United States. *Health Affairs (Project Hope)* **36**(7), 1184–1192. doi:10.1377/hlthaff.2017.0134

Peacock S, Duggleby W and Koop P (2014) The lived experience of family caregivers who provided end-of-life care to persons with advanced

dementia. *Palliative and Supportive Care* **12**(2), 117–126. doi:10.1017/S1478951512001034

Robinson S, Kissane DW, Brooker J, ***et al.*** (2015) A systematic review of the demoralization syndrome in individuals with progressive disease and cancer: A decade of research. *Journal of Pain and Symptom Management* **49**(3), 595–610. doi:10.1016/j.jpainsymman.2014.07.008

Rumpold T, Schur S, Amering M, ***et al.*** (2016) Informal caregivers of advanced-stage cancer patients: Every second is at risk for psychiatric morbidity. *Supportive Care in Cancer* **24**(5), 1975–1982. doi:10.1007/s00520-015-2987-z

Sklenarova H, Krümpelmann A, Haun MW, ***et al.*** (2015) When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer* **121**(9), 1513–1519. doi:10.1002/cncr.29223

Tang PL, Wang HH and Chou FH (2015) A systematic review and meta-analysis of demoralization and depression in patients with cancer. *Psychosomatics* **56**(6), 634–643. doi:10.1016/j.psym.2015.06.005

Tecuta L, Tomba E, Grandi S, ***et al.*** (2015) Demoralization: A systematic review on its clinical characterization. *Psychological Medicine* **45**(4), 673–691. doi:10.1017/s0033291714001597

Vehling S and Philipp R (2018) Existential distress and meaning-focused interventions in cancer survivorship. *Current Opinion in Supportive and Palliative Care* **12**(1), 46–51. doi:10.1097/SPC.0000000000000324

Wong EL, Lau JY, Chau PY, ***et al.*** (2022) Caregivers' experience of end-of-life stage elderly patients: Longitudinal qualitative interview. *International Journal of Environmental Research and Public Health* **19**(4). doi:10.3390/ijerph19042101

Xu K, Hu D, Liu Y, ***et al.*** (2019) Relationship of suicidal ideation with demoralization, depression, and anxiety: A study of cancer patients in mainland China. *The Journal of Nervous and Mental Disease* **207**(5). doi:10.1097/NMD.0000000000000974

Zhang W, O'Brien N, Forrest JI, ***et al.*** (2012) Validating a shortened depression scale (10 item CES-D) among HIV-positive people in British Columbia, Canada. *PLoS One* **7**(7), e40793–e40793. doi:10.1371/journal.pone.0040793