

Original Article

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Prevalence and factors associated with demoralization in palliative care patients: A cross-sectional study from Hong Kong

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Abstract

Objectives. Although demoralization is common among palliative care patients, it has not yet been examined empirically in the Hong Kong Chinese context. This study aims to examine (1) the prevalence of demoralization among community-dwelling palliative care patients in Hong Kong; (2) the percentage of palliative care patients who are demoralized but not depressed and vice versa; and (3) the association of socio-demographic factors, particularly family support, with demoralization.

Method. A cross-sectional study targeting community-living palliative care patients in Hong Kong was conducted. A total of 54 patients were recruited by a local hospice and interviewed for completing a questionnaire which included measures of demoralization, depression, perceived family support, and demographic information.

Results. The prevalence of demoralization was 64.8%. Although there was overlap between demoralization and depression (52.8% meeting the criteria of both), 7.5% of depressed patients were not demoralized, and 13.2% of demoralized patients were not depressed. Participants who were not single and had more depressive symptoms and less family support had a significantly higher demoralization level.

Significance of results. This is the first study which reports the prevalence of demoralization in Hong Kong. Demoralization was found common in community-living palliative care patients receiving medical social work services in Hong Kong. This study provides evidence of the importance of differentiating the constructs between demoralization and depression. It also provides an implication that those who are married, more depressed, and have the least family support could be the most vulnerable group at risk of demoralization. We recommend that early assessment of demoralization among palliative care patients be considered.

Introduction

Globally, an estimated 40 million people need palliative care each year (World Health Organization, 2020). Particularly, the end-of-life stage often brings substantial symptom burden and distress to these patients. Their suffering does not merely include physical pain but is also manifested in psychological, social, and existential dimensions (den Hartogh, 2017). For example, palliative care patients may experience depressive moods in facing the deterioration of physical functioning and in turn the loss of independent living (Woo et al., 2006; Kennedy, 2016). The psychological well-being of these patients may further be challenged by family conflicts (François et al., 2017), financial strain (Hanratty et al., 2007), navigating a complex healthcare system, and making treatment decisions that have life and death implications (Woo et al., 2006). In the existential dimension, it is also common for patients to feel a lack of meaning in life and to have a strong desire for death or loss of the will to live (Chen et al., 2022).

To particularly address the existential distress syndrome that is characterized by hopelessness and loss of meaning or purpose in life, the construct of demoralization has been proposed (Kissane et al., 2001; Clarke and Kissane, 2002; Vehling and Philipp, 2018). According to Kissane et al. (2001), the diagnostic criteria of demoralization includes: (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. Demoralization can negatively affect one's psychological well-being and quality of life (Robinson et al., 2015) and can increase suicidal ideation risk (Xu et al., 2019). In fact, demoralization has been identified as a syndrome commonly found among palliative care patients (Robinson et al., 2015). But compared with other psychological syndromes, such as depression, relatively less attention has been paid to this concept in palliative care. A systematic review conducted on palliative care patients reported a prevalence of 13–18% of clinically relevant cases of demoralization (Robinson

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et al., 2015). Demoralization is more common with increasing proximity to death (Bovero et al., 2018). The prevalence rate can rise to 52.5% among the most advanced care patients who are at the final stage of disease (Vehling and Mehnert, 2014; Julião et al., 2016; Rudilla et al., 2016).

Previous studies have suggested that demoralization and depression correlated with each other but at the same time are two independent distinct concepts (Nanni et al., 2018; Belvederi Murri et al., 2020). The core symptom of major depressive disorder is characterized by anhedonia (general loss of interest) in the present moment. A person with demoralization might not experience anhedonia but is uncertain about the future, and there is an anticipatory loss of hope and life meaning (Jacobsen et al., 2007). Studies indicate that some patients who are demoralized do not experience depression, whereas some patients who suffer from depression do not exhibit symptoms of demoralization (Fang et al., 2014). Additionally, compared with clinical depression, hopelessness in demoralization has a stronger predictive effect on suicidality (Beck et al., 1975; Fang et al., 2014).

Recently, researchers have started to examine the risk and protective factors associated with demoralization. Those who are male, have a partner, and are employed were found to be at lower risk of demoralization among palliative care or cancer patients (Robinson et al., 2015; Tang et al., 2020). Instead, a high level of physical discomfort, pain, and functional dependency predicted demoralization for these patients (Lichtenthal et al., 2009). Studies also show that palliative care patients who received more social support and possessed more social resources are at lower risk of developing demoralization (Robinson et al., 2015). A study conducted on Chinese breast cancer inpatients also showed similar findings (Tang et al., 2020), suggesting that having a positive social support network can ameliorate patients' morale and buffer against demoralization.

Of the sources of social support, family support is of great importance for palliative care patients and is a protective factor against psychological symptoms (Hudson et al., 2012). In the East Asian collectivistic culture, family is one of the most important social ties. When facing the crisis of death and dying, families form a valuable support system which could be helpful in managing distress (Chadda and Deb, 2013). A previous study of palliative care patients in Hong Kong also found that family support is crucial for their psychosocial well-being, yet they also experienced a "support paradox" in which they desire to receive more family support but also worry that this may be a burden to their family members (Chan et al., 2009).

To our knowledge, demoralization has not yet been examined empirically in the Hong Kong Chinese context. In fact, previous studies which examined demoralization in the Chinese context were mainly conducted in mainland China or Taiwan. The targeted participants were cancer patients of various stages, instead of focusing on palliative care patients who are at an advanced stage of illness and are more closely confronted by death and dying. Therefore, this study may help provide empirical findings on the phenomenon of demoralization among Chinese palliative care patients in the Hong Kong context. Based on the literature review conducted, this study aimed to examine the following among Hong Kong Chinese palliative care patients: (1) the prevalence of demoralization among community-dwelling palliative care patients in Hong Kong; (2) the percentage of palliative care patients who are demoralized but not depressed and vice versa; and (3) the association of socio-demographic factors, particularly family support, with demoralization.

Methods

This is a cross-sectional study targeting community-living palliative care patients in Hong Kong.

Participants and recruitment

Inclusion criteria of participants are as follows: (1) Patients were receiving medical follow-up by a palliative care team of a public hospital in Hong Kong; (2) They are Hong Kong Chinese who can understand and communicate in Cantonese; and (3) They were residing in the community. Participants were recruited from community-dwelling palliative care patients 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). The data collection period was shorter than originally planned, due to the COVID-19 pandemic. Patients were first assessed by the referrers (medical social workers) via interviews for confirming the eligibility of participants and determining their appropriateness for joining the study. Medical social workers, based on their professional clinical assessment and patients' clinical records in the palliative care unit, excluded those who are emotionally and cognitively unfit for participating in the research. Of the 286 eligible palliative care patients identified, 151 (53%) declined to participate in this study. Reasons include (a) not interested ($n = 86$), (b) did not want to talk about the topic of demoralization ($n = 63$), and (c) family disagreed ($n = 2$). The remaining 135 patients were further approached by a research assistant by phone; 81 patients did not answer the phone calls, and finally, 54 patients were successfully interviewed to complete a questionnaire which included various measures.

The study was conducted in accordance with the principles of the Declaration of Helsinki. Written consent was obtained from all participants prior to the data collection. No incentive was provided to the participants. Ethical approval was obtained from the ethics committee board of both the PI's affiliated institution and the Hospital Authority of Hong Kong.

Measures

Demoralization scale

The Chinese version of the demoralization scale (DS) (Hung et al., 2010) was used to assess the demoralization of palliative care patients. It is a 24-item scale which assesses demoralization status over the past two 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 (score ranges 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 a previous study (Kissane et al., 2004), a DS-total score of ≥ 30 was used as an indicator of clinically relevant moderate demoralization. The same cut-off point in defining a demoralized population (< 30 : low demoralized; ≥ 30 high demoralized) was used in this study. 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 0.910, 0.773, 0.719, 0.816, 0.710, and 0.452, respectively.

The center for epidemiological studies depression

The 10-item Chinese version of the 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 depressive symptoms over the past week (e.g., restlessness, poor appetite) 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 more 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 cut-off point in identifying patients with depression and those without (Zhang et al., 2012). There is good internal consistency, as evidenced by a Cronbach's alpha of 0.828 we found in this study.

Perceived family support

The Multidimensional Scale of Perceived Social support which was developed and validated in Taiwan was used to measure measured family support (Wang and Chung, 2014). This scale was developed with reference to the multidimensional scale of perceived social support developed by Zimet et al. (1988) but modified to better measure the perceived social support from specific sources in the Chinese context in Taiwan (Zimet et al., 1988). (This scale was used in this study to specifically measure the perceived family support.) The scale includes 13 items, and participants were asked to rate their level of agreement on a 4-point Likert scale (1 = strongly disagree, 4 = strongly agree) for each statement. The total score ranged from 13 to 52, a higher score indicating a higher level of perceived social support from family. We found that the Cronbach's alpha of this scale is 0.939, indicating excellent internal consistency.

Demographic and clinical data of patients

This includes age, gender, type of illness, marital status, education level, religion, the presence of a primary caregiver, and the relationship with the primary caregiver.

Data analysis

IBM SPSS 23.0 software was used for data analysis. To estimate the prevalence of demoralization, we used a cut-off point of 30, which was used in other previous studies (Kissane et al., 2004; Julião et al., 2016; Li et al., 2017). Patients who scored 30 or above were categorized into the "high DS" group, and patients who scored below 30 were categorized into the "low DS group". We performed cross-tabulation to compare high and low DS scores with both depression categories (<10: not depressed vs. ≥ 10 : depressed). The association between different factors (socio-demographics, depression, and perceived family support) and DS (total score and 5 subscale scores) was analyzed using hierarchical regression. Prior to the main regression analyses, bivariate correlations were performed on all socio-demographic variables and DS. Any demographic variables which showed significant association with DS were treated as potential predictor variables. These variables were entered in step 1 of the regression. Other variables (depression, perceived family support) were entered in step 2 and step 3, respectively. All assumptions were examined prior to the analyses. The *P-P* plot suggested normal distribution of residual, and we identified no violation of the assumption of

linearity tested with scatterplots, multi-collinearity, and homoscedasticity.

Results

Participants

Table 1 shows the demographic and clinical characteristics of the patients. Of the participants, 57% ($n = 31$) are male. Their age ranges from 41 to 95, with a mean score of 68.36 (SD = 11.97). The majority (78%) were diagnosed with cancer ($n = 42$). The mean score of the palliative performance scale was 68.14/100 (SD = 10.29; Range: 30–80). Around 70% of participants ($n = 56$) lived with their main caregivers at the time of study enrolment, 42% ($n = 22$) have their spouse as the main caregiver, and 34.6% ($n = 18$) have their daughter(s) or son(s) as their caregivers. In our study, the mean score of perceived family support was 40.81 (SD = 6.38).

Prevalence of demoralization

Table 2 illustrates the descriptive statistics of DS. The mean score of demoralization is 36.02 (SD: 14.03). Using 30 as a cut-off point in determining low and high levels of demoralization, the prevalence of high demoralization was 64.8% ($n = 35$). The subscale mean score of "loss of meaning," "dysphoria," "disheartenment," "helplessness," and "sense of failure" is 7.06 (SD: 3.69), 6.93 (SD: 3.67), 8.28 (SD: 3.94), 5.89 (SD: 3.06), and 7.87 (SD: 2.66), respectively.

Demoralization and depression

Table 3 illustrates the cross-tabulation results between the number of participants who have depression and high demoralization (vs. those who does not have depression and low demoralization). Although there was an overlap between demoralization and depression (52.8% meeting the criteria of both), 7.5% of depressed patients were not demoralized, and 13.2% of demoralized patients were not depressed.

Factors associated with demoralization

Our correlation analyses found that of all the socio-demographic and psychosocial variables we tested, only marital status (single vs. non-single), type of caregiver, depression level, and perceived family support showed significant association with DS scores (total and subscale scores). Therefore, only these variables were treated as potential predictor variables in our regression analyses. Table 4 presents the results of regression analyses. Our results indicate that participants who were not single ($\beta = -0.28$, $p < 0.05$), had more depressive symptoms ($\beta = 0.67$, $p < 0.001$), and had less family support ($\beta = -0.22$, $p < 0.05$) had a significantly higher total DS score. This model explains 59.2% of the variance in the total DS score.

A similar result was found on the subscales DS-helplessness and DS-disheartenment. Participants who were not single (Helplessness: $\beta = -0.25$, $p < 0.05$; Disheartenment: $\beta = -0.43$, $p < 0.001$), had more depressive symptoms (Helplessness: $\beta = 0.60$, $p < 0.001$; Disheartenment: $\beta = 0.48$, $p < 0.001$), and had less family support (Helplessness: $\beta = -0.31$, $p < 0.01$, Disheartenment: $\beta = -0.26$, $p < 0.05$) had a significantly higher DS-helplessness score and DS-Disheartenment score. The two models explain 51% and 49% of the variance in the

Table 1. Demographic and clinical characteristics of participants (*N* = 54)

		<i>n</i>	Valid %
Gender	Female	23	42.6
	Male	31	57.4
Age (M, SD) (Range)		68.36 (11.97) (41–95)	
Marital status	Single	4	7.4
	Married	30	55.6
	Divorced	6	11.1
	Widowed	14	25.9
Educational level	No formal schooling	8	15.1
	Primary or below	23	43.4
	Junior secondary school	12	22.6
	Senior secondary school	6	11.3
	Tertiary education or above	4	7.5
Religion	No religion	24	44.4
	Buddhism	10	18.5
	Taoism	1	1.9
	Christianity	11	20.4
	Ancestor worship	7	13
	Other	1	1.9
Living status with caregivers	Yes	37	69.8
	No	16	30.2
Primary caregivers	Parents	4	7.7
	Husband/Wife	22	42.3
	Daughter/Son	18	34.6
	Sibling(s)	2	3.8
	Other	6	11.5
Types of terminal illness	Cancer	42	77.8
	Kidney failure	10	18.5
	COPD	1	1.9
	MND	1	1.9
PPS score (M, SD) (Range)		68.14 (10.29) (30–80)	
Perceived family support (M, SD) (Range)		40.81 (6.38) (13–52)	
Living status with caregivers	Yes	37	69.8
	No	16	30.2
Primary caregivers	Parents	4	7.7
	Husband/Wife	22	42.3
	Daughter/Son	18	34.6
	Sibling(s)	2	3.8
	Other	6	11.5

Remarks: PPS score is the score of the Palliative Performance Scale. It was used to assess the patient's functional performance and to determine progression toward the end of life. The score ranges from 0 to 100. A lower score indicates a lower level of functional performance and more progression toward the end of life.

DS-helplessness score and DS-disheartenment score, respectively. For the remaining DS-subcales, depression was found as the only factor in predicting DS-sense of failure ($\beta = 0.50$, $p < 0.001$), DS-dysphoria ($\beta = 0.59$, $p < 0.001$), and DS-loss of meaning ($\beta = 0.52$, $p < 0.001$).

Discussion

To our knowledge, this is the first study that solely examined the demoralization of cancer and non-cancer Chinese palliative care patients. In Hong Kong, cancer is still the major type of illness

Table 2. Descriptive statistics of demoralization total and subscale scores ($N = 54$)

	M	SD
DS total score	36.02	14.03
Low demoralized (DS < 30) (N , %)	$(n = 19, 35.2\%)$	
High demoralized (DS \geq 30) (N , %)	$(n = 35, 64.8\%)$	
Loss of meaning	7.06	3.69
Dysphoria	6.93	3.67
Disheartenment	8.28	3.94
Helplessness	5.89	3.06
Sense of failure	7.87	2.66

DS, demoralization score. The DS score ranges from 0 to 96, a higher score indicating a higher demoralization level. The range of the 5 subscale scores of DS is: loss of meaning (ranged from 0 to 20), disheartenment (ranged from 0 to 24), dysphoria (ranged from 0 to 20), helplessness (ranged from 0 to 16), and sense of failure (ranged from 0 to 16).

Table 3. Comparison of demoralization score (DS) with not depressed and depressed (CESD) patients

	Low demoralized (DS < 30)	High demoralized (DS \geq 30)
	N (%)	N (%)
Not depressed (CESD < 10)	14 (26.4%)	7 (13.2%)
Depressed (CESD \geq 10)	4 (7.5%)	28 (52.8%)

in palliative care patients, but similar to the profile of patients in this study, palliative care services have extended to other patients with other life-threatening illnesses, like end-stage renal failure.

Our findings indicate a very high percentage of demoralization among these community-living palliative care patients in Hong Kong (64.8%), which is higher than what was found among terminally ill patients in Portugal (52.5%) (Julião et al., 2016) and advanced cancer patients in Taiwan (27.5%) (Li et al., 2017) (with the same cut-off score of DS). Consistently, we found that the mean DS score (36.2) of our samples is staggeringly high, which is by far the highest mean score reported in the existing literature on demoralization. The mean DS score of cancer patients reported by Western countries (e.g., Australia, Germany, and Ireland) ranged from 20 to 30 (Kissane et al., 2004; Boscaglia and Clarke, 2007; Mehnert et al., 2011; Mehnert-Theuerkauf and Vehling, 2011; Vehling et al., 2013; Costantini et al., 2014).

One reason for our findings may be related to the samples of this study: community-dwelling palliative care patients who were newly referred for receiving medical social work services. In Hong Kong, palliative care services are provided by the hospital-based specialist palliative care teams of public hospitals under the Hospital Authority. In general, these palliative care patients will only be hospitalized in the palliative care wards when they need more intensive symptom control. If not, they usually attend regular follow-up at out-patient palliative care clinics and receive palliative care nurses' visits at homes. When they are referred by nurses or doctors to medical social workers to receive the services, it is likely that they are the most disadvantaged group or have shown psychosocial distress and are in need of professional

support. Therefore, this may explain why the current samples showed a particularly high level of demoralization. Despite this, our findings call for attention to the severity of demoralization among palliative care patients in Hong Kong and reflection on whether palliative care services may provide adequate end-of-life support, particularly to those who are demoralized (Quinn et al., 2021).

Supporting palliative care patients who are demoralized is challenging for both family caregivers and helping professionals. Facing death and dying, which involves experiencing symptom burden and death anxiety, is a problem which may lead to the demoralization of palliative care patients (An et al., 2018). But family caregivers often have great concern about how they may address these existential issues with patients who are confronted by death and dying (Melin-Johansson et al., 2012). The worry of addressing existential issues may be one reason family caregivers often have difficulty and lack confidence in providing care to patients who are approaching the end of life. For example, only 63.8% of Hong Kong family caregivers who are currently providing care to their older family members were found to be willing to continue providing care in the end-of-life care context (Chan, 2021).

Our findings may also highlight the tremendous challenges of palliative care professionals, like medical social workers, in working with patients with a high level of demoralization. Demoralized patients may be preoccupied with feelings of hopelessness and helplessness, which may bring various emotional and existential challenges to palliative care professionals, such as feeling helplessness and questioning life's meaningfulness (Chan and Tin, 2012; Chan et al., 2016). Failure to cope with these challenges may have adverse effects on their professional quality of life, such as experiencing burnout and secondary traumatic stress (Stamm, 2010; Chan and Tin, 2012; Chan et al., 2020). Previous studies suggest that enhancing "self-competence in death work" may help them to cope with these challenges (Chan et al., 2015, 2020). A randomized controlled trial proved that a three-day experiential workshop could effectively enhance helping professionals' self-competence in death work, and the positive effect was sustained 3 months after the workshop (Chan et al., 2017). A previous study also found that a higher level of self-competence in death work was associated with a higher level of hospice self-efficacy (Zheng et al., 2020).

Our findings are consistent with what has been suggested in the literature, highlighting the importance of differentiating the constructs between demoralization and depression (de Figueiredo, 1993; Julião et al., 2016; Nanni et al., 2018; Belvederi Murri et al., 2020). Around 13.2% of participants of this study experienced a high level of demoralization but a low level of depression. In a study conducted in Portugal, patients with a high level of demoralization but not depression were even found to be as high as 42.9% (Julião et al., 2016). Therefore, it is important for palliative care professionals to differentiate between depression and demoralization among palliative care patients, as the latter was found to have a strong predictive effect on suicidality (Beck et al., 1975; Fang et al., 2014). Currently, assessment in the health care setting, including in palliative care, has been focused on depression screening (Payne et al., 2007). Our findings provide further evidence of the importance of assessing demoralization, and not depression only, among palliative care patients. This may help identify patients who are at risk of suicide and require further support.

Our study also suggests that patients who are less depressed, have a higher level of perceived family support, and are single

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

Variable ^{a,b}	B	SE	β	ΔR^2	Statistics of the final model ^c
DV: DS-total score					
Step 1				0.131*	$F(3, 45) = 23.659, R^2 = 0.592^{***}$
Single	-18.985	6.86	-0.361**		
Step 2				0.416***	
Single	-12.408	5.094	-0.236*		
CESD	1.456	0.215	0.657***		
Step 3				0.045*	
Single	-14.702	4.986	-0.28*		
CESD	1.484	0.206	0.67***		
Family support	-0.485	0.21	-0.216*		
DV: DS-Loss of meaning					
Step 1				0.147*	$F(4, 46) = 7.772, R^2 = 0.403^{***}$
Single	-3.314	1.894	-0.246 (ns)		
Caregivers as siblings	-4.209	2.623	-0.226 (ns)		
Step 2				0.253***	
Single	-2.156	1.626	-0.16 (ns)		
Caregivers as siblings	-3.752	2.226	-0.201 (ns)		
CESD	0.314	0.071	0.512***		
Step 3				0.004 (ns)	
Single	-2.35	1.678	-0.174 (ns)		
Caregivers as siblings	-3.644	2.252	-0.195 (ns)		
CESD	0.318	0.072	0.519***		
Family support	-0.036	0.068	-0.063 (ns)		
DV: DS-Dysphoria					
Step 1					$F(4, 46) = 9.611, R^2 = 0.455^{***}$
Single	-2.983	1.876	-0.22 (ns)	0.126*	
Caregivers as daughter/son	1.795	1.055	0.235 (ns)		
Step 2				0.319***	
Single	-1.723	1.53	-0.127 (ns)		
Caregivers as daughter/son	1.338	0.854	0.175 (ns)		
CESD	0.357	0.069	0.578***		
Step 3				0.01 (ns)	
Single	-1.971	1.555	-0.145 (ns)		
Caregiver(s) as daughter(s)/son(s)	1.453	0.864	0.19 (ns)		
CESD	0.363	0.069	0.587***		
Family support	-0.062	0.066	-0.106 (ns)		
DV: DS-Disheartenment					
Step 1					$F(3, 49) = 15.716, R^2 = 0.490^{***}$
Single	-6.857	1.842	-0.462***	0.214***	
Step 2				0.210***	
Single	-5.537	1.622	-0.373**		
CESD	0.292	0.068	0.467***		

(Continued)

Table 4. (Continued.)

Variable ^{a,b}	B	SE	β	ΔR^2	Statistics of the final model ^c
Step 3					
Single	-6.327	1.573	-0.426***	0.066*	
CESD	0.302	0.065	0.482***		
Family support	-0.167	0.066	-0.264*		
DV: DS-Helplessness					
Step 1				0.088 (ns)	$F(3, 49) = 16.749, R^2 = 0.506^{***}$
Single	-3.434	1.545	-0.297*		
Step 2				0.417***	
Single	-2.149	1.271	-0.186 (ns)		
CESD	0.285	0.054	0.584***		
Step 3					
Single	-2.862	1.205	-0.248*		
CESD	0.293	0.05	0.601***		
Family support	-0.151	0.051	-0.306**		
DV: Sense of failure					
Step 1				0.236***	$F(2, 50) = 9.419, R^2 = 0.274^{***}$
CESD	0.204	0.051	0.486***		
Step 2				0.274 (ns)	
CESD	0.212	0.051	0.504***		
Family support	-0.083	0.051	-0.195 (ns)		

CESD, The centre for epidemiological studies depression; DS, demoralization scale.

B, unstandardized regression coefficients; β , standardized regression coefficients; ns, not significant.

^aThe variable single is coded as non-single (coded as 0) and single (coded as 1). Single included those who have a single status/divorced/widowed.

^bThe variables "Caregivers as siblings/caregivers as daughter(s)/son(s)" are coded as "Caregivers are not siblings/daughter(s)/son(s) of the patients" (coded as 0) and "Caregivers are the sibling(s)/daughter(s)/son(s) of the patients".

^cThe final model refers to the model shown at the final step of the regression model.

* $p < 0.05$; ** $p < 0.01$, *** $p < 0.001$.

(single, divorced, widowed) may be at lower risk of demoralization. Our findings are consistent with those of most studies, which found family support (Li et al., 2017) and being less depressed (Julião et al., 2016; Tang et al., 2020) are the protective factor against demoralization. Interestingly, we found that patients who are not single are at increased risk of demoralization. Existing literature in this area has shown mixed results. Some studies found that having a partner is a protective factor against demoralization (Grandi et al., 2011), whereas some did not find any association with that factor (Lee et al., 2012; Fang et al., 2014; Vehling and Mehnert, 2014). A possible explanation is that palliative care patients who are not single could often experience a feeling of being a burden to their spouse, including being a physical burden (physical exhaustion to caregivers), and financial and emotional burden. Studies indicate that self-perceived burden is a common feeling experienced by palliative care patients (De Faye et al., 2006; Gudat et al., 2019). The feeling of being a burden often provokes a feeling of guilt, suicidal ideation, and death-hastening acts (McPherson et al., 2007; Gudat et al., 2019). The presence of a partner may also place a patient at greater risk of experiencing possible family conflicts, such as family disagreements about medical decisions, which may increase their sense of helplessness and hopelessness in the experience of demoralization (Lichtenthal and Kissane, 2008). A growing body of literature has found evidence that perceived support mitigated the negative

effect of being single on well-being (Adamczyk, 2016). This may suggest that whether an individual is single may not be a key factor which affects the demoralization level. Instead, it is the family support the patients perceive that determines their demoralization. We suggest future studies further investigate this by understanding the relationship of marital status and demoralization in the context of family harmony and family support, such as studying whether there is a mediating effect of perceived social support between marital status and demoralization. Our findings highlight the possible positive effects of family support for reducing the demoralization of palliative care patients. Palliative care professionals may focus on how they may help family members to better convey their support to patients with demoralization, like facilitating family members' developing meaningful interactions with patients via legacy activities (Allen et al., 2008; Allen, 2009) and involving family members' participation in activities which aim to enhance patients' dignity in end-of-life care (Wang et al., 2020).

At the same time, palliative care professionals may also need to pay attention to supporting family caregivers of palliative care patients who may be influenced by patients' demoralization and are at risk of demoralization (Hudson et al., 2012). For example, it is important to address the spiritual needs and enhance the spirituality of family caregivers of palliative care patients (Lalani et al., 2018).

Limitations

This study has several limitations. Our sample size is small, and participants were all recruited from one palliative care unit. Our findings may not be representative of the community-living palliative care patients in Hong Kong. Future studies may consider recruiting participants from a larger and more heterogeneous study population. The refusal rate of potential participants was high (53%), and unfortunately data were not available for examining whether there are significant differences in demographics and severity of illnesses between those who refused to participate and those who participated.

Also, this is a cross-sectional study. We are unable to make a causal inference, as both the exposure (factors we examined) and outcome (demoralization) were collected at the same time. No temporality between these variables can be inferred. The reliability of the subscale, sense of failure, was particularly low, and in fact, similar findings were reported in previous studies which may be related to the reverse scoring of items (Hung *et al.*, 2010; Rudilla *et al.*, 2016; Li *et al.*, 2017). Findings using this subscale should be understood with caution. Although our study identified family support as a protective factor against demoralization, it is unclear whether what the family does or conveys could contribute to the protective effect. Future studies may consider examining the effect of other family factors, such as the level of family cohesiveness and family emotional expressiveness on demoralization. Despite the limitations, our study allows us to include the patient group that is difficult to research and examined for the first time the topic of demoralization among palliative care patients in Hong Kong.

Conclusion

This study is the first that reports the prevalence of demoralization among Hong Kong palliative care patients. Our findings indicate that demoralization is common in these community-dwelling palliative care patients. The high prevalence reported in this study calls for attention to how we may better support palliative care patients to cope with demoralization. Early assessment of demoralization among palliative care patients should be considered in the provision of palliative care.

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References

- Adamczyk K (2016) An investigation of loneliness and perceived social support among single and partnered young adults. *Current Psychology* 35(4), 674–689. doi:10.1007/s12144-015-9337-7
- Allen RS (2009) The legacy project intervention to enhance meaningful family interactions: Case examples. *Clinical Gerontology* 32(2), 164–176. doi:10.1080/07317110802677005
- Allen RS, Hilgeman MM, Ege MA, *et al.* (2008) Legacy activities as interventions approaching the end of life. *Journal of Palliative Medicine* 11(7), 1029–1038. doi:10.1089/jpm.2007.0294

- An E, Lo C, Hales S, *et al.* (2018) Demoralization and death anxiety in advanced cancer. *Psycho-Oncology* 27(11), 2566–2572. doi:10.1002/pon.4843
- Beck AT, Kovacs M and Weissman A (1975) Hopelessness and suicidal behavior: An overview. *Journal of the American Medical Association* 234(11), 1146–1149.
- 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
- 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
- Boscaglia N and Clarke D (2007) Sense of coherence as a protective factor for demoralisation in women with a recent diagnosis of gynaecological cancer. *Psycho-Oncology* 16, 189–195. doi:10.1002/pon.1044
- Bovero A, Sedghi NA, Opezzo M, *et al.* (2018) Dignity-related existential distress in end-of-life cancer patients: Prevalence, underlying factors, and associated coping strategies. *Psycho-Oncology* 27(11), 2631–2637. doi:10.1002/pon.4884
- Chadda RK and Deb KS (2013) Indian family systems, collectivistic society and psychotherapy. *Indian Journal of Psychiatry* 55(2), 299–309. doi:10.4103/0019-5545.105555
- Chan WCH (2021) Future provision of home end-of-life care: Family carers' willingness for caregiving and needs for support. *Palliative & Supportive Care* 19(5), 580–586. doi:10.1017/s1478951520001273
- Chan WC and Tin AF (2012) Beyond knowledge and skills: Self-competence in working with death, dying, and bereavement. *Death Studies* 36(10), 899–913. doi:10.1080/07481187.2011.604465
- Chan WC, Epstein I, Reese D, *et al.* (2009) Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the “support paradox”. *Social Work in Health Care* 48(5), 519–532. doi:10.1080/00981380902765824
- Chan WC, Tin AF and Wong KL (2015) Coping with existential and emotional challenges: Development and validation of the self-competence in death work scale. *Journal of Pain and Symptom Management* 50(1), 99–107. doi:10.1016/j.jpainsymman.2015.02.012
- Chan WC, Tin AF, Wong KL, *et al.* (2016) Impact of death work on self: Existential and emotional challenges and coping of palliative care professionals. *Health & Social Work* 41(1), 33–41. doi:10.1093/hsw/hlv077
- Chan WCH, Tin AF and Wong KLY (2017) Effectiveness of an experiential workshop for enhancing helping professionals' self-competence in death work in Hong Kong: A randomized controlled trial. *Health and Social Care in the Community* 25, 1070–1079. doi:10.1111/hsc.12407
- Chan WCH, Tin AF and Yu TK (2020) Professional quality of life, depression, and meaning in life among helping professionals: The moderating role of self-competence in death work. *Death Studies*, 1–11. doi:10.1080/07481187.2020.1793431
- Chen W, Chen Y and Xiao H (2022) Existential distress in cancer patients: A concept analysis. *Cancer Nursing* 45(2), 471–486. doi:10.1097/NCC.0000000000000925
- 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. *Australia-New Zealand Journal of Psychiatry* 36(6), 733–742. doi:10.1046/j.1440-1614.2002.01086.x
- Costantini A, Pompili M, Innamorati M, *et al.* (2014) Psychiatric pathology and suicide risk in patients with cancer. *Journal of Psychosocial Oncology* 32(4), 383–395. doi:10.1080/07347332.2014.917136
- De Faye BJ, Wilson KG, Chater S, *et al.* (2006) Stress and coping with advanced cancer. *Palliative & Supportive Care* 4(3), 239–249. doi:10.1017/s1478951506060317
- 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

- den Hartogh G (2017) Suffering and dying well: On the proper aim of palliative care. *Medicine, Health Care, and Philosophy* 20(3), 413–424. doi:10.1007/s11019-017-9764-3
- 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
- François K, Lobb E, Barclay S, et al. (2017) The nature of conflict in palliative care: A qualitative exploration of the experiences of staff and family members. *Patient Education and Counseling* 100(8), 1459–1465. doi:10.1016/j.pec.2017.02.019
- Grandi S, Sirri L, Tossani E, et al. (2011) Psychological characterization of demoralization in the setting of heart transplantation. *Journal of Clinical Psychiatry* 72(5), 648–654. doi:10.4088/JCP.09m05191blu
- Gudat H, Ohnsorge K, Strecek N, et al. (2019) How palliative care patients' feelings of being a burden to others can motivate a wish to die. Moral challenges in clinics and families. *Bioethics* 33(4), 421–430. doi:10.1111/bio.12590
- Hanratty B, Holland P, Jacoby A, et al. (2007) Review article: Financial stress and strain associated with terminal cancer—A review of the evidence. *Palliative Medicine* 21, 595–607. doi:10.1177/0269216307082476
- Hudson P, Remedios C, Zordan R, et al. (2012) Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *Journal of Palliative Medicine* 15(6), 696–702. doi:10.1089/jpm.2011.0466
- Hung HC, Chen HW, Chang Y-F, 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.
- Jacobsen JC, Maytal G and Stern TA (2007) Demoralization in medical practice. *Primary Care Companion to the Journal of Clinical Psychiatry* 9(2), 139–143. doi:10.4088/pcc.v09n0208
- 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
- Kennedy G (2016) The importance of patient dignity in care at the end of life. *The Ulster Medical Journal* 85(1), 45–48.
- 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.
- 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
- Lee CY, Fang CK, Yang YC, et al. (2012) Demoralization syndrome among cancer outpatients in Taiwan. *Supportive Care in Cancer* 20(10), 2259–2267. doi:10.1007/s00520-011-1332-4
- Li YC, Ho CH and Wang HH (2017) Protective factors of demoralization among cancer patients in Taiwan: An age-matched and gender-matched study. *Asian Nursing Research (Korean Society of Nursing Science)* 11(3), 174–179. doi:10.1016/j.anr.2017.07.001
- Lichtenthal WG and Kissane DW (2008) The management of family conflict in palliative care. *Progress in Palliative Care* 16(1), 39–45. doi:10.1179/096992608(296914
- Lichtenthal WG, Nilsson M, Zhang B, et al. (2009) Do rates of mental disorders and existential distress among advanced stage cancer patients increase as death approaches? *Psycho-Oncology* 18(1), 50–61. doi:10.1002/pon.1371
- McPherson CJ, Wilson KG and Murray MA (2007) Feeling like a burden to others: A systematic review focusing on the end of life. *Palliative Medicine* 21(2), 115–128. doi:10.1177/0269216307076345
- Mehnert A, Vehling S, Höcker A, et al. (2011) Demoralization and depression in patients with advanced cancer: Validation of the German version of the demoralization scale. *Journal of Pain and Symptom Management* 42(5), 768–776. doi:10.1016/j.jpainsymman.2011.02.013
- Mehnert-Theuerkauf A and Vehling S (2011) Cancer patients: Loss of meaning, demoralization and embitterment. In Linden M and Maercker A (eds.), *Embitterment: Societal, Psychological and Clinical Perspectives*, Leipzig: Springer-Verlag Wien, pp. 142–153. doi:10.1007/978-3-211-99741-3_11
- 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. *Open Nursing Journal* 6, 1–12. doi:10.2174/1874434601206010001
- 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
- Payne A, Barry S, Creedon B, et al. (2007) Sensitivity and specificity of a two-question screening tool for depression in a specialist palliative care unit. *Palliative Medicine* 21(3), 193–198. doi:10.1177/0269216307077315
- Quinn KL, Wegier P, Stukel TA, et al. (2021) Comparison of palliative care delivery in the last year of life between adults with terminal noncancer illness or cancer. *JAMA Network Open* 4(3), e210677–e210677. doi:10.1001/jamanetworkopen.2021.0677
- 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
- Rudilla D, Galiana L, Oliver A, et al. (2016) Demoralization scale in Spanish-speaking palliative care patients. *Journal of Pain and Symptom Management* 51(4), 769–775.e761. doi:10.1016/j.jpainsymman.2015.11.019
- Stamm BH (2010) *The Concise ProQOL Manual: The Concise Manual for the Professional Quality of Life Scale*, 2nd ed. Pocatello, ID: ProQOL.org.
- Tang L, Li Z and Pang Y (2020) The differences and the relationship between demoralization and depression in Chinese cancer patients. *Psycho-Oncology* 29(3), 532–538. doi:10.1002/pon.5296
- Vehling S and Mehnert A (2014) Symptom burden, loss of dignity, and demoralization in patients with cancer: A mediation model. *Psycho-Oncology* 23(3), 283–290. doi:10.1002/pon.3417
- 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.
- Vehling S, Oechsle K, Koch U, et al. (2013) Receiving palliative treatment moderates the effect of age and gender on demoralization in patients with cancer. *PLoS One* 8(3), e59417. doi:10.1371/journal.pone.0059417
- Wang K-C and Chung F-C (2014) Psychometric properties of a multidimensional perceived social support scale for adolescents exposed to Typhoon Morakot. *Chinese Journal of Psychology* 56(3), 291–311. doi:10.6129/CJP.20140329
- Wang C, Chen J, Wang Y, et al. (2020) The development of a family participatory dignity therapy programme for patients with haematologic neoplasms and their family caregivers in China: A feasibility study. *European Journal of Cancer Care (England)* 29(2), e13204. doi:10.1111/ecc.13204
- Woo JA, Maytal G and Stern TA (2006) Clinical challenges to the delivery of end-of-life care. *Primary Care Companion to the Journal of Clinical Psychiatry* 8(6), 367–372. doi:10.4088/pcc.v08n0608
- World Health Organization (2020) *Palliative Care*. <https://www.who.int/news-room/fact-sheets/detail/palliative-care#:~:text=Each%20year%2C%20an%20estimated%2040,palliative%20care%20currently%20receive%20it.>
- 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), 326–332.
- 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
- Zheng Z-H, Luo Z-C, Zhang Y, et al. (2020) Hospice care self-efficacy among clinical medical staff working in the coronavirus disease 2019 (COVID-19) isolation wards of designated hospitals: A cross-sectional study. *BMC Palliative Care* 19(1), 188–212. doi:10.1186/s12904-020-00692-0
- Zimet GD, Dahlem NW, Zimet SG, et al. (1988) The multidimensional scale of perceived social support. *Journal of Personality Assessment* 52(1), 30–41. doi:10.1207/s15327752jpa5201_2