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Desire for hastened death in advanced cancer: cross-sectional study in China

Feng Liu, Wanglian Peng, Ran Zhou, Xufen Huang, Hui Yang, Minni Wen, Lemeng zhang, Fei Tong, Desong Yang, Ling Jiang, Lili Yi, Xiaohong Liu

Hunan Cancer Hospital and The Affiliated Cancer Hospital of Xiangya School of Medicine, Central South University, Changsha, Hunan, People's Republic of China

Correspondence to
Xiaohong Liu, Hunan Cancer Hospital and The Affiliated Cancer Hospital of Xiangya School of Medicine, Central South University, Changsha, Hunan, People's Republic of China; 415723796@qq.com

FL and WP contributed equally.

FL and WP are joint first authors.

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ABSTRACT

Objective To evaluate the incidence of desire for hastened death (DHD) among patients with advanced cancer and to identify factors associated with DHD.

Methods This was a cross-sectional study of 227 patients with advanced cancer in Hunan Cancer Hospital. The patients were assessed using Chinese version of the Schedule of Attitudes toward Hastened Death, Karnofsky Performance Scale, Quality of Life (QOL), MD Anderson Symptom Inventory and Patient Health Questionnaire Depression Module-9.

Results The number of patients with or without DHD were 71 (31.3%) and 156 (68.7%), respectively. Follow-up visits and average and high QOL were protective factors for DHD; severely disturbed sleep, symptoms that severely interfered with mood, and symptoms that severely interfered with relations with other people were risk factors for DHD.

Conclusions The incidence of the DHD in patients with advanced cancer at home is high. Those who have low QOL, severely disturbed sleep, symptoms that severely interfered with mood, or symptoms that severely interfered with relations with other people should be paid attention to. These data provide a theoretical basis for the early detection and diagnosis of the desire to accelerate death of patients with advanced cancer.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Studies have shown that 11%–45% of patients with advanced cancer had a short-term desire for hastened death (DHD).

WHAT THIS STUDY ADDS

⇒ Our study shows that physical and psychological impairment are associated with DHD in patients with advanced cancer of mainland China.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study highlights the need to explore an implicit DHD and to ensure patients receive the care required to minimise associated suffering.

BACKGROUND

Patients with advanced cancer sometimes express the desire for hastened death (DHD; also referred to as 'wish to hasten death').[1] DHD refers to the expectation for death faster than natural death.[2] It is usually evaluated by the Schedule of Attitudes toward Hastened Death (SAHD), developed by Rosenfeld *et al*.[3]

The assessment of DHD could help early detection and could contribute to the development of more effective healthcare plans for these patients. Research on the factors associated with the emergence of DHD in these patients has highlighted the importance of considering the combined influence of factors related to different domains including physical (pain and physical symptoms, impaired functionality, etc), psychological (depression, hopelessness, despair), existential/spiritual (loss of meaning in life, loss of purpose) and social (feeling like a burden to others, loss of social role).[4 5]

There are limited studies with large samples of DHD in patients with advanced cancer. Furthermore, no such research has been carried out in mainland China. Hence, we decided to study DHD and assess the association between DHD and physical and psychosocial factors in patients with advanced cancer. Our team has revised the SAHD scale in Chinese, and Rosenfeld's study confirmed that SAHD has high reliability and validity.[3] This study aimed to: (A) evaluate the incidence of DHD in patients with advanced cancer and (B) explore the correlations between SAHD scores and physical and psychosocial factors.

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METHODS

Study design and participants

We enrolled patients with advanced cancer admitted to the Department of Hospice Unit of Hunan Cancer Hospital, which provides free, home-based holistic care for low-income patients with advanced cancers with pain. Recruitment took place between January 2017 and January 2018. The eligibility criteria of this study were as follows: (A) patients in the advanced stage of cancer, (B) expected survival period no more than 6 months, (C) full understanding of their cancer diagnosis, (D) age from 18 to 70, (E) able to communicate effectively and (F) able to provide informed consent. The exclusion criterion was cognitive impairment, indicated by a score >5 on the Short Portable Mental Status Questionnaire.

A total of 851 patients were invited to participate in this descriptive cross-sectional study, and a total of 227 patients were enrolled and completed survey. The desire of patients to accelerate death was measured by the Chinese version of the Schedule of Attitudes towards Hastened Death (SAHD-CV). SAHD-CV was developed using the translation and back-translation procedure, as recommended by the Scientific Advisory Committee of the Medical Outcomes Trust. SAHD[3] includes 20 dichotomous (true/false) items that are scored as either 0 or 1; the higher the score, the greater the desire to hasten death. Functional (physical) status was assessed by the Karnofsky Performance Scale.[6] Quality of life (QOL) was assessed using the QOL assessment.[7] The Patient Health Questionnaire Depression Module (PHQ-9)[8] was used to evaluate depression. Finally, the severity of cancer-related symptoms was assessed using the Chinese version of the M. D. Anderson Symptom Inventory (PHQ-9).[9]

Statistical analysis

This was an exploratory, cross-sectional study. Categorical variables are presented with frequencies and percentages, while continuous variables are expressed by either mean and SD, when normally distributed, or the median and IQR (IQR1–IQR3) when the distribution was skewed. A 95% CI was used to define continuous variables. The demographic variables and clinical characteristics and symptoms in MD Anderson Symptom Inventory (MDASI) that showed statistical differences in univariate analysis were then used as independent variables in binary logistic regression analysis. The level of significance was set at $p<0.05$.

Table 1 Binary logistic regression analysis of factors related to the DHD

Factors	B	SE,	Wals	P value	OR	95% CI Lower limits	95% CI Upper limits
QOL score (<30 vs ≥31)	1.439	0.505	8.116	0.004	4.218	1.567	11.354
Part I of MDASI: Symptoms							
Pain (<7 vs ≥7)	0.219	0.554	0.157	0.692	1.245	0.421	3.687
Fatigue (<7 vs ≥7)	0.327	0.747	0.191	0.662	1.386	0.321	5.995
Disturbed sleep (<7 vs ≥7)	−1.045	0.509	4.216	0.040	0.352	0.130	0.954
Feeling of being distressed (<7 vs ≥7)	−0.524	0.642	0.668	0.414	0.592	0.168	2.082
Shortness of breath (<7 vs ≥7)	−0.145	0.566	0.066	0.798	0.865	0.285	2.625
Lack of appetite (<7 vs ≥7)	−0.261	0.512	0.261	0.610	0.770	0.282	2.099
Feeling Drowsy(<7 vs ≥7)	−0.625	0.608	1.056	0.304	0.535	0.162	1.763
Dry mouth (<7 vs ≥7)	−0.653	0.678	0.927	0.336	0.521	0.138	1.966
Feeling sad (<7 vs ≥7)	−0.031	0.593	0.003	0.958	0.969	0.303	3.101
Part II of MDASI: How have the symptoms interfered with life?							
General activity (<7 vs ≥7)	−0.560	0.824	0.463	0.496	0.571	0.114	2.869
Mood (<7 vs. ≥7)	−2.083	0.769	7.329	0.007	0.125	0.028	0.563
Work (including work around the house) (<7 vs ≥7)	0.471	1.092	0.186	0.666	1.601	0.188	13.611
Relations with other people (<7 vs ≥7)	−1.973	0.802	6.058	0.014	0.118	0.026	1.343
Walking (<7 vs ≥7)	0.178	0.780	0.052	0.819	1.195	0.259	5.517
Enjoyment of life (<7 vs ≥7)	−1.098	0.738	2.215	0.137	0.333	0.079	1.416
First visit or follow-up visit	1.906	0.696	7.498	0.006	6.725	1.719	26.308
Understanding of the disease	0.740	0.754	0.964	0.326	2.097	0.478	9.197
Understanding of current treatment	1.564	1.050	2.219	0.136	4.779	0.610	37.413
PHQ-9 score (<10 vs ≥10)	1.506	0.919	2.687	0.101	4.507	0.745	27.272
KPS (<50 vs ≥50)	−0.101	0.769	0.017	0.896	0.904	0.200	4.078
Constant	−3.725	1.601	5.416	0.020	0.024	–	–

DHD, desire for hastened death; KPS, Karnofsky Performance Scale; MDASI, MD Anderson Symptom Inventory; PHQ-9, atient Health Questionnaire-9; QOL, quality of life.

All statistical analyses were performed using SPSS V.25.0 for Windows (SPSS).

RESULTS

Among the 227 patients, the mean score on SAHD in this sample of patients with advanced cancer was 5.70 (SD=5.90; range 0–20), with 48.9% of patients scoring 3 or less, 19.8% scoring between 4 and 9, and the remaining 31.3% scoring over 10.

Characteristics significantly different ($p<0.05$) in the distribution of with DHD and without DHD groups were used as independent variables in binary logistic regression analysis. We found the following to be independent factors of DHD: the first visit or follow-up visit, QOL score, disturbed sleep, symptoms that interfered with mood and symptoms that interfered with relations with other people. Among them, follow-up visits and average and high QOL were protective factors for DHD, while severely disturbed sleep, symptoms that severely interfered with mood, and symptoms that severely interfered with relations with other people were risk factors (table 1).

DISCUSSION

A number of previous studies[10 11] have shown that among patients with advanced cancer, at least 11%–45% patients have a short-term DHD, and 3%–20% of patients experience persistent DHD.[12] The mean SAHD score for this sample can be considered high (5.70, SD=5.90), which is higher than the figure reported by Rosenfeld *et al* with patients with cancer in New York (4.7, SD=4.3)[3]; it is consistent with Wang *et al*'s[13] study with terminally ill patients with cancer in Taiwan, China (5.56, SD=5.19). This could be due to the nature of the sample, patients with advanced cancer admitted to the hospice unit due to acute worsening of their symptoms. In our study, all patients came from low-income families, and 77.1% did not receive professional inpatient or day or home palliative care services, which might have a negative impact on DHD.

Some authors have highlighted the relationship between DHD and depression. Studies reported the prevalence of depression in patients with cancer who wished to hasten their death as being between 8.5% and 17%.[10 14] The study by Breitbart *et al*[10] found that DHD was significantly associated with a clinical diagnosis of depression in patients with advanced cancer. Our study found that PHQ-9 scores were significantly different in the distribution of patients with or without DHD. While symptoms that severely interfered with mood is a risk factor for DHD, depression is not. It could be that home-bound patients with the most advanced cancer have physical discomfort, which leads to psychological distress.

Symptom severity experienced by terminally ill patients with cancer negatively affects their overall QOL and increases their levels of DHD.[13] Our study found that average and high QOL were protective factors for DHD. The severity of cancer-related symptoms (pain, fatigue, disturbed sleep, etc) and symptoms that interfered with general activity, mood, work, walking, etc, assessed by the MDASI were significantly different in the distribution of the patients with or without DHD. Disturbed sleep, symptoms that interfered with mood, and symptoms that interfered with relations with other people were independent influencing factors of DHD. Mystakidou's study also found sleep is an independent variable of DHD.[15] Wang *et al* used the MDASI to assess the severity of the cancer-related symptoms of 85 terminally ill patients with cancer. Their study showed that spiritual well-being was significantly negatively correlated with symptom severity. Spiritual care addressing meaning to enhance spiritual well-being may have a profound effect on improving QOL and preventing DHD in terminally ill patients with cancer.[13]

STUDY LIMITATIONS

This study has some limitations that need to be considered. First, it was a single institution study, and the sample collection was from the Department of Hospice Unit in Changsha. Second, the cross-sectional observational design means that causal relationships cannot be established between the study variables. Further large-scale, multicentre, longitudinal clinical studies are needed for a more robust examination of the phenomenon studied here.

CLINICAL IMPLICATIONS

Our results show both physical and psychological impairment to be associated with DHD, and this supports the idea that such a desire emerges in response to overall suffering. This highlights the need, in clinical settings, to explore the possibility of an implicit DHD in those patients with serious impairment of this kind and to ensure that they receive the care required to minimise any associated suffering.

CONCLUSIONS

In summary, the incidence of DHD in patients with advanced cancer is high. The follow-up visits and average and high QOL were protective factors for DHD, and severely disturbed sleep, symptoms that severely interfered with mood, and symptoms that severely interfered with relations with other people were risk factors for DHD. Our findings have identified the demographic, physical and psychological factors that can affect DHD, providing a theoretical basis for the early detection and diagnosis of the desire to accelerate death of patients with advanced cancer.

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is the corresponding authors). FT and WP developed the study design and aims, designed data collection tools, completed data collection for the whole study, analysed the data, and drafted and revised the paper. RZ, XH, HY, MW and FT developed the study design and aims, designed data collection tools, and completed data collection for the whole study. LZ, DY, LJ and LY designed data collection tools and completed data collection for the whole study. All authors read and approved the final version of the manuscript.

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ORCID iDs
Feng Liu http://orcid.org/0000-0002-7708-9475
Lemeng zhang http://orcid.org/0000-0002-2239-7307

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