

The Preference to Discuss Expected Survival Is Associated with Loss of Meaning and Purpose in Terminally Ill Cancer Patients

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Reference: Vehling Sigrun, Kamphausen Anne, Oechsle Karin, Hroch Swantje, Bokemeyer Carsten, and Mehnert Anja. Journal of Palliative Medicine. November 2015, 18(11): 970-976. doi:10.1089/jpm.2015.0112.

Abstract:

Background: Demoralization is a syndrome of existential distress characterized by loss of meaning and purpose in life, hopelessness, and helplessness. Empirical data on its occurrence and associated factors in terminally ill patients is limited.

Objective: The study objective was to determine the frequency of demoralization and its association with individual and disease-related characteristics and to analyze the association between demoralization and the preference to discuss expected survival.

Methods: We recruited N = 55 terminally ill cancer patients (54% women, mean age 67 years) within 48 hours after admission to a specialized palliative care inpatient ward (55% had a Karnofsky performance status of ≤ 50). Patients completed the Demoralization Scale (DS), the Generalized Anxiety Disorder Scale-7 (GAD-7), the Patient Health Questionnaire-9 (PHQ-9), and a single-item question measuring preferences for discussion of expected survival with a physician.

Results: We found clinically significant demoralization present in 19% and moderate demoralization present in 10% of participants. Better educated patients reported a higher level of demoralization ($d = 0.74$, $p = .010$). Patients with a preference to discuss expected survival reported higher levels in the "loss of meaning and purpose" dimension of demoralization ($d = 0.76$, $p = .010$) and higher levels of anxiety ($d = 0.88$, $p = .003$) compared to those not wanting to discuss survival.

Conclusions: Demoralization is a significant dimension of distress in terminally ill cancer patients. In the end-of-life inpatient care setting, the preference to discuss expected survival with a physician can parallel existential distress and anxiety. Further elucidation of patients' underlying existential needs will inform interventions that sustain meaning and hope in face of a limited life expectancy.

Strengths:

- validated studies/scales (repeatable)
- similar patient population (malignancies)
- include a variety of patients from various sociodemographic groups
- similar unit in terms of patients admitted (significant symptom burden prohibiting further care at home or non-specialized wards)

Weaknesses:

- many patients excluded due to their physical or cognitive impairment
- survey bias (patients declined participation due to lack of interest or distress)
- previous psychosocial support services were not addressed
- no stratification between type of cancer and demoralization rates

Applicability to Palliative Care:

This study strengthens the relevance of demoralization and need for psychosocial support by addressing distress in terminally ill cancer patients. Although the results show that the desire to discuss life expectancy correlates to demoralization, the authors still suggest honest end-of-life discussions. The results of this study can educate healthcare providers as to which patients may have increased psychosocial needs.

TABLE 1. SOCIODEMOGRAPHIC AND MEDIAL SAMPLE CHARACTERISTICS AND MEAN DEMORALIZATION LEVELS

Variable	Sample		Demoralization mean		<i>d</i>	<i>p</i>
	<i>N</i>	%	<i>M</i>	<i>SD</i>		
Total sample	55	100	24.6	14.5		
Age, mean (<i>SD</i>)	67.0 (10.4)				0.24	.40
41–70	33	60.0	23.2	13.9		
71–89	22	40.0	26.7	15.5		
Gender					0.05	.86
Male	25	45.5	24.2	14.8		
Female	30	54.5	24.9	14.4		
Partnership					0.05	.86
Cohabiting	29	52.7	24.2	14.0		
Not cohabiting	26	47.3	24.9	15.1		
Children					0.07	.77
Yes	45	81.8	24.3	14.6		
No	10	18.2	25.9	14.4		
Education					0.74	.01
Less than high school	34	61.8	20.4	13.5		
High school/university degree	21	38.2	30.6	14.0		
Religious affiliation					0.27	.33
Religious	33	60.0	27.1	15.7		
Not religious	22	40.0	23.0	13.7		
WHO-ECOG status					0.06	.83
1–2	27	49.1	25.1	15.1		
3–4	28	50.9	24.2	14.2		
Karnofsky Index, median (range)	50 (20–90)				0.26	.31
90–60	25	45.5	27.0	14.7		
50–10	30	54.5	22.9	14.3		
Disease status					0.14	.73
Partial remission/stable disease	7	13.0	22.8	18.8		
Progressive disease	47	87.0	24.9	14.1		
Current anticancer therapy					0.23	.45
None	39	72.7	23.6	11.8		
Active	16	29.1	27.0	19.8		
Anxiolytics/sedatives					0.11	.69
Yes	34	61.8	23.9	16.2		
No	21	38.2	25.6	11.7		
Antidepressants					0.06	.80
Yes	10	18.2	23.5	17.4		
No	45	81.8	24.8	14.0		
Months since initial diagnosis, median (range)	22 (1–249)				–0.21 ^a	.15
Tumor site						
Lung	20	36.4				
Gastrointestinal	11	20.0				
Urogenital	8	14.5				
Gynecologic	5	9.1				
Breast	3	5.5				
Other	8	14.5				

TABLE 4. PREFERENCE TO DISCUSS EXPECTED SURVIVAL AND MEAN LEVELS IN DEMORALIZATION, ANXIETY, AND DEPRESSION (*N*=55)

	Preference to discuss life expectancy				<i>d</i>	<i>p</i>
	Yes (52%)		No (48%)			
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Demoralization, total scale ^a	28.5	16.2	21.6	12.5	0.45	.12
Loss of meaning and purpose ^b	15.9	7.7	11.0	4.5	0.76	.01
Disheartenment ^c	16.9	6.7	14.1	5.7	0.45	.12
Dysphoria ^d	9.5	3.1	8.2	2.9	0.43	.14
Sense of failure ^e	18.4	3.5	18.1	3.8	0.08	.78
Anxiety ^f	5.7	4.5	2.5	2.5	0.88	.003
Depression ^g	12.9	5.7	12.9	4.3	0.01	.97