



## Physical, Emotional and Spiritual Well-Being, Dignity and Hope in Adult Patients with Solid and Hematologic Malignancies, on Cure or Follow-Up

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### Abstract

**Introduction:** In oncological setting, the assessment of physical/emotional symptoms and above all of existential/religious needs and resources, hope and dignity are rarely performed in the routine clinical practice. Moreover, comparative assessments of patients with Solid Cancers (SC) vs. those with Haematological Malignancies (HM) are lacking.

**Patients and Methods:** We analyzed data collected in 2 similar cross-sectional studies of consecutive patients with SC or HM on cure or follow-up regarding the presence and intensity of physical/emotional symptoms, religious needs and resources, level of hope and dignity-related distress. We used the Edmonton Symptom Assessment System (ESAS), System of Beliefs Inventory (SBI\_15R), Hert Hope Index (HHI) and Patient Dignity Inventory (PDI).

**Results:** 289 patients with SC and 169 with HM were involved with a mean age of 61 and 58 years respectively ( $p=.012$ ); 56% of patients with HM vs. 43% with SC were male ( $p=.009$ ). KPS  $\geq 80$  was above 90% in both groups, and 49% of the HM as well as the SC patients were on active treatments; 18% of the HM patients had received psychological support vs. 29% SC patients ( $p=.007$ ). No significant differences were observed between the two groups regarding physical/emotional symptoms, dignity – related distress and the presence of hope, whereas religious resources were higher among patients with solid cancer ( $p=.036$ ). Among HM patients, in comparison with the phase of diagnosis hope score was significantly lower during the treatment phase ( $-3.3$ ; 95% CI:  $-5.6$ ;  $-1.0$ ), and in case of relapse/metastases ( $-6.6$ ; 95% CI:  $-11.6$ ;  $-1.6$ ).

**Conclusion:** SC and HM patients don't differ much in their physical, emotional and spiritual needs, even if HM patients seem to be more vulnerable to losing hope as the disease progresses. More important, HM patients may lack sufficient patient support.

**Keywords:** Physical/emotional symptoms; Existential/religious needs/resources; hope; Dignity related distress; Solid cancer; Haematological malignancies

### Introduction

The World Health Organization suggests the Health Care Professional to perform multidimensional evaluations of the presence and intensity of emotional and physical symptoms in cancer patients starting from the diagnosis [1], because early identification of suffering due to cancer and its treatments can be addressed at the earliest opportunity and when necessary referred to specialists. The psychosocial domain should be integrated into the routine cancer care to improve the possibility of cognitive and emotional processing for the patients and also for their families [2]. Scientific evidence exists to recommend supportive psychotherapy as a valid therapeutic intervention [3]. It is often recommended a two-phase process for the assessment of the psychological unmet needs, as a case at the screening through standardized tools identifies the level of symptoms (above a certain cutoff) without providing a diagnosis [4]. Although data of the literature have demonstrated the utility of simple screening tools to assess the symptoms and to activate the specific services, as support therapies to manage pain and toxicities, psychological support [4,5] and group therapy

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Received Date: 06 Mar 2017

Accepted Date: 04 Apr 2017

Published Date: 26 Apr 2017

#### Citation:

Ripamonti CI, Buonaccorso L, Maruelli A, Miccinesi G. Physical, Emotional and Spiritual Well-Being, Dignity and Hope in Adult Patients with Solid and Hematologic Malignancies, on Cure or Follow-Up. *Clin Oncol.* 2017; 2: 1268.

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**Table 1:** Demographic and clinical characteristic of patients with Solid Cancer (SC) and Haematological Malignancies (HM). Mean value and (DS), or N and (column %).

	SC N=289 (%)	HM N=169 (%)	p-value	All N=458 (%)
<b>Age</b>	61.1 (13.2)	57.8 (14.1)	<b>.012</b>	59.9 (13.6)
<b>Gender</b>				
Male	124 (43.2)	94 (55.9)	<b>.009</b>	218 (47.9)
<b>Civil status</b>			.718	
With partner	200 (69.4)	120 (72.2)		320 (70.3)
Widowed	32 (11.1)	14 (8.4)		46 (10.1)
Separated/divorced	21 (7.3)	10 (6.0)		31 (6.8)
Single	35 (12.1)	23 (13.8)		58 (12.7)
<b>Education</b>			.546	
University degree	58 (20.1)	29 (17.2)		87 (19.0)
High School	129 (44.6)	81 (47.9)		210 (45.9)
Middle school	81 (28.0)	42 (24.8)		123 (26.9)
Primary school	21 (7.3)	17 (10.1)		38 (8.3)
<b>Occupation</b>			<b>.043</b>	
Retired	146 (50.7)	70 (41.4)		216 (47.3)
Employed	77 (26.7)	39 (23.1)		116 (25.4)
Self-employed	33 (11.5)	26 (15.4)		59 (12.9)
Housewife	19 (6.6)	19 (11.2)		38 (8.3)
Other	13 (4.5)	15 (8.9)		28 (6.1)
<b>Religiousness</b>			.096	
Churchgoer	133 (46.2)	71 (42.0)		204 (44.6)
Believer non-churchgoer	123 (42.7)	67 (39.6)		190 (41.6)
Non-believer	32 (11.1)	31 (18.3)		63 (13.8)
<b>Karnofsky Performance Status</b>			.243	
<80 = 70	10 (3.5)	10 (6.0)		20 (4.5)
<b>Phase of disease</b>			.329	
Diagnosis	56 (19.4)	39 (23.2)		95 (20.8)
Treatment	142 (49.1)	83 (49.4)		225 (49.2)
Follow up	67 (23.2)	39 (23.2)		106 (23.2)
Relapse/Metastasis	24 (8.3)	7 (4.2)		31 (6.8)
<b>Psychological Support</b>				
Yes	81 (29.1)	29 (17.7)	<b>.007</b>	110 (24.9)

[6,7], the routinely assessment of the symptoms and the needs, the dignity-related distress, the resources (religiosity, hope) of the patients undergoing oncological therapies with curative or palliative intent or during follow-up period both in patients with solid cancer or with hematological malignancy is still few. One possible explanation is the lack of proper education in symptom assessment and management and the lack of simple, not time consuming, validated in the own language, assessment tools to use in the daily clinical practice in a context of a structured conversation. Further difficulties come from the lack of adequate training in communication skills and processes for health professionals [8,9]. A recent Italian study showed that the cancer patients that used complementary therapies reported more unmet needs about the quality of the relationships with health professionals [10].

A revision of the literature extracted from 21 multi-national studies in a pooled sample of 4,067 patients with solid or

haematological malignancies undergoing active cancer treatments and assessed by means of different assessment tools, showed that the most prevalent symptoms were fatigue, irritability, disturbed sleep, outlook, unspecified pain, dry mouth, anorexia/appetite changes, dyspnea, difficulties in concentration/remember, numbness tingling, bowel changes, nausea, dizziness, dysphagia, sexual dysfunction, nocturia [11]. Contrary to data reported in the past literature, also the haematological patients refer physical and emotional distress during all phases of disease [12-14]. In particular leukemia patients may suffer from moderate and sever physical pain and emotional distress, depression and hopelessness during all clinical phases [15,16]. However comparative data are not available on the differences between the presence and intensity of the symptoms in the two groups of patients with SC or HM. The aim of this study is to compare the patients with solid and haematological malignancies on cure or on follow-up, in order to investigate the differences in prevalence of the patients reported physical and emotional symptoms, dignity-related

**Table 2:** Physical and emotional symptoms (moderate/severe), and religious needs/resources in patients with Solid Cancer (SC) or Haematological Malignancies (HM). Mean value and (DS), or N and (column %).

	SC N=289 (63%)	HM N=169 (37%)	p-value	All N=458(%)
<b>Pain</b>			.393	
<i>moderate</i>	56 (19.9)	26 (15.9)		82 (18.4)
<i>severe</i>	24 (8.5)	11 (6.7)		35 (7.9)
<b>Fatigue</b>			.863	
<i>moderate</i>	80 (28.4)	43 (26.2)		123 (27.6)
<i>severe</i>	71 (25.2)	41 (25.0)		112 (25.1)
<b>Nausea</b>			.984	
<i>moderate</i>	21 (7.5)	12 (7.3)		33 (7.4)
<i>severe</i>	16 (5.7)	10 (6.1)		26 (5.8)
<b>Depression</b>			.543	
<i>moderate</i>	30 (10.6)	23 (14.1)		53 (11.9)
<i>severe</i>	14 (4.9)	8 (4.9)		22 (4.9)
<b>Anxiety</b>			.990	
<i>moderate</i>	50 (17.8)	28 (17.3)		78 (17.6)
<i>severe</i>	21 (7.5)	12 (7.4)		33 (7.4)
<b>Drowsiness</b>			.533	
<i>moderate</i>	55 (19.4)	39 (23.8)		94 (21.0)
<i>severe</i>	41 (14.5)	21 (12.8)		62 (13.9)
<b>Anorexia</b>			.621	
<i>moderate</i>	39 (13.8)	25 (15.2)		64 (14.3)
<i>severe</i>	32 (11.3)	14 (8.5)		46 (10.3)
<b>Feeling of not well-being</b>			.127	
<i>moderate</i>	62 (22.0)	27 (16.6)		89 (20.0)
<i>severe</i>	21 (7.4)	20 (12.3)		41 (9.2)
<b>Dyspnoea</b>			.721	
<i>moderate</i>	18 (6.4)	11 (6.7)		29 (6.5)
<i>severe</i>	13 (4.6)	5 (3.1)		18 (4.0)
<b>SBI_15R</b>				
total	25.4 (13.5)	22.4 (14.8)	<b>.036</b>	24.3 (14.0)
<b>HHI</b>				
total	36.8 (5.6)	37.4 (6.3)	.367	37.0 (5.8)
<b>PDI'</b>				
Total	51.5 (20.5)	46.0 (18.0)	.105	49.9 (19.9)

\*Patient Dignity Inventory was filled in by a subsample only, N=159 (SC 112, HM 47)

distress, religious needs and resources such as hope.

## Patients and Methods

### Patient population

In this study we report a secondary analysis of two different cross-sectional studies, conducted in 2012 and 2014 respectively, with the same methodology. The patients enrolled were cared for by Supportive Care in Cancer Unit of Fondazione IRCCS, Istituto Nazionale dei Tumori of Milan, and Centre of Oncological Rehabilitation-LILT, CERION of Florence. The inclusion criteria were: 1. Age >18 years; 2. Ability to read and speak Italian; 3. On active oncological treatments or in follow-up; 4. Life expectancy >6 months; 5. Karnofsky Performance Status (KPS) ≥70; 6. No severe symptoms which could cause discomfort during the compilation of

questionnaires; 7. Outpatients; 8. Written informed consent. Patients with signs/symptoms of cognitive impairment were excluded from the study.

By means of a questionnaire *ad hoc*, basic information was collected comprising of age, gender, civil status, education, employment, religiousness (churchgoer, believer non churchgoer, non-believer), Karnofsky Performance Status (KPS), clinical variables including phase of the disease (diagnosis/treatment, follow up/rehabilitation, metastasis/relapse), primary tumour, oncological treatment received in the last 3 months, previous referral to a psychologist. Approval was obtained from the ethics committees of the participating centers. Measures Of all patients, we analyzed the presence and intensity of physical and emotional symptoms, the religious needs/resources, the hope and dignity related distress,

**Table 3:** Crude and adjusted association, obtained through simple and multiple linear regression models, between hope (HHI score) and phase of disease, religious needs/resources (SBI score), problems with dignity (PDI score), psychological support, sex and age class; stratified by type of cancer: Haematologic Malignancies (HM) or Solid Cancer (SC). Regression coefficient and (95% C.I.).

	HM		SC	
	crude	adjusted	crude	adjusted
<i>Phase of disease</i>				
Diagnosis	1	1	1	1
Treatment	<b>-3.5 (-5.6; -1.2)</b>	<b>-3.3 (-5.6; -1.0)</b>	<b>2.4 (.6; 4.1)</b>	1.1 (-.8; 3.0)
Follow up	-2.4 (-5.2; .3)	-2.0 (-4.7; .6)	1.6 (-.3; 3.6)	.2 (-1.9; 2.4)
Relapse/Metastasis	<b>-7.2 (-12.4; -1.9)</b>	<b>-6.6 (-11.6; -1.6)</b>	1.3 (-1.4; 4.0)	1.0 (-1.8; 3.8)
<i>SBI score</i>	<b>.11 (.05; .18)</b>	<b>.11 (.05; .18)</b>	<b>.13 (.08; .18)</b>	<b>.13 (.07; .18)</b>
<i>PDI score</i>	<b>-.09 (-.17; -.01)</b>	-	<b>-.06 (-.10; -.01)</b>	-
<i>Psychological support</i>	<b>-3.4 (-5.9; -.8)</b>	-2.5 (-5.1; .13)	<b>-2.6 (-4.1; -1.2)</b>	-1.7 (-3.4; .06)
<i>Age</i>				
≤50	1		1	1
51-65	-1.3 (-3.7; 1.2)	-1.9 (-4.3; .5)	-.9 (-2.8; .9)	-1.2 (-3.0; .6)
66-75	-.4 (-3.2; 2.4)	-.8 (-3.5; 1.9)	-1.1 (-3.0; .8)	<b>-2.0 (-3.9; -.06)</b>
>75	-.4 (-4.0; 3.1)	-.04 (-3.5; 3.4)	<b>-2.5 (-5.0; -.1)</b>	<b>-3.1 (-5.7; -.5)</b>
<i>Sex</i>				
Female	1	1	1	1
Male	1.1 (-.8; 3.1)	.8 (-1.7; 2.8)	1 (-.4; 2.3)	.6 (-.9; 2.0)

The adjusted model included all the variables reported in table except problems with dignity (PDI score) which was collected on a subsample only. Statistically significant results are in bold.

through the following questionnaires validated in Italian language.

### Edmonton symptom assessment scale

(ESAS) [17] validated in the Italian language [18]. We considered the intensity of physical symptoms as moderate when the intensity was from 4 to 6 of the numerical scale and severe when the intensity was from 7 to 10 [18]. Moreover, moderate anxiety or depression reported through the corresponding ESAS items (cutoff=4) has been used as a screening tool for anxiety and depression [19].

### System of belief inventory

(SBI-15R), developed by Holland [20], an instrument of self-compilation, consisting of 15 questions (items) which are grouped in 2 sizes: the first consists of 10 items relating to religious beliefs and practices, the second consists of 5 items, relating to the social support provided by the religious community. The score of each item consists of a four-level verbal scale ranging from "strongly disagree" to "strongly agree" or "Never" to "Always". The SB-15R total score ranges from 0 to 45, with higher values indicating higher levels of religiousness. It was recently validated in the Italian version [21].

### Herth hope index

(HHI) developed by Herth is a tool used to measure the cognitive, affective, behavioral, temporal, and contextual dimensions of patients' level of hope in a hospital setting [22]. HHI consists of 12 items on a 4-point Likert Scale (strongly disagree, disagree, agree and strongly agree). The scale has three subscales: inner sense of temporality and future, inner positive readiness, and interconnectedness with self and others. A high score on the HHI suggests that patients have subsequently higher levels of hope. The HHI Italian version has been validated with 266 patients, which had either solid or hematologic

cancer during active oncological treatment and supportive care [23]. The results of the validation show the unidimensionality and the good reliability indexes of the Italian version of HHI, and the practicality of its use with cancer patients at non-advanced stages.

### Patient dignity inventory (PDI)

Composed of 25 items to assess the dignity-related distress. Each item was rated on a five-point scale (1. Not a problem; 2. A slight problem; 3. A problem; 4. A major problem; 5. An overwhelming problem). Five-point scales of this nature have been reported most reliable on 6 measurements of attitude-judgment, with response categories above five not yielding significant additional discrimination. High PDI score is related to high dignity related distress [24]. The Italian validation of PDI showed the one-dimensionality of the instrument [25].

### Statistical analysis

Usual univariate descriptive statistics are presented. To test the differences between solid and haematologic cancer patients, chi square or unpaired t test, according to the nature of the variable considered, were performed. P-values <0.05 were considered significant. The association of hope with the other collected variables, such as age, sex, spirituality, psychological support, problems with dignity and phase of disease was studied separately in the two groups of SC and HM, through simple and multiple regression models. All the analyses were performed using the statistical package STATA 12.1.

### Results

Table 1 shows clinical characteristics of patients with solid (N=289) and haematological (N=169) malignancies in different phases of diseases. The patients had a mean age of 60 years (range 19-

89), 47.9% were male. Most of the hematological patients were male (55.9% vs. 43.2%;  $p$ -value=.009), and on average they were younger than SC patients (57.8 vs. 61.1 years old,  $p$ =.012). The 70% of the patients lived with the partner, 19% had a high level education. Most of the patients were retired (47%), more often among SC patients (50.7% vs. 41.4%,  $p$ =.043). Regarding religiousness, the 14% were non believer, 45% believer and churchgoer, the rest believer non churchgoer. In respect to patients with HM, SC patients received more psychological support (29% vs. 18%,  $p$ =.007). Most of the patients had KPS  $\geq$ 80 (only 4.5% had KPS = 70). Half of the patients were on active treatments (49%). Only 6.8% of all patients presented relapse or metastases. Table 2 shows the percentage of patients with physical and emotional symptoms of moderate to severe intensity and the average score of religiosity, hope, and dignity related distress. The 53% of the patients reported fatigue, 35% drowsiness, 26% pain, 25% anorexia, 13% nausea, 10% dyspnoea, 25% anxiety and 17% depression, 29% sense of not well-being. We didn't find any significant differences between the two groups of patients about physical/emotional symptoms. As concerns the religious resources, the SBI score was higher in our sample among SC patients than among HM patients (25.4 vs. 22.4 respectively,  $p$  =.036; max score=45), whereas the levels of hope and dignity related distress (this last measured on 159 subjects only) were not significantly different in the two groups, with an average score of 37 for hope (max score=48) and 50 for dignity problems (max score=125). Table 3 Simple linear regression models, fitted separately among SC or HM patients to show the association between hope and selected covariates (phase of disease, age class, sex, religious needs/resources score, problems with dignity, psychological support), show interesting similarities between the two groups, and some differential results. Whereas SC patients had higher hope score (+2.4) at the entry in a treatment phase than at diagnosis, the opposite (-3.5) occurred among HM patients. After adjustment for the other covariates presented in table but PDI (due to collinearity), the result was no more statistically significant among SC patients, whereas among HM patients hope score was still significantly lower (-3.3) during the treatment phase than at diagnosis, and in case of relapse/metastases (-6.6). Age showed significant association with hope among SC patients: people older than 65 years had a statistically significant lower level of hope than those younger than 51 after adjustments. Sex did show any association with hope neither at the crude analysis nor after adjustment.

Religious needs/resources were positively associated with hope in both groups of patients even after adjustment; the opposite (negative association) was true for dignity related distress and psychological support at the crude analysis only.

## Discussion

Our study shows that fatigue, drowsiness, the sense of not well-being, anorexia and pain of moderate to severe intensity were present and overlapped in patients with solid cancer as well as in those with hematological malignancies. Also the emotional symptoms like anxiety and depression were similar among the two groups of patients. However data of literature shows that the relief of pain and other symptoms as psychological and spiritual suffering were frequently under-recognized in patients with haematological malignancies [26-28]. A recent review on psychosocial needs among patients who received a diagnosis of cancer revealed that these aspects of suffering were underestimated among HM patients in comparison with SC patients [29]. HM patients fear of relapse, fear of death in a curative

regimen, show specific social needs due to the change occurred in the familiar system after the occurrence of the disease and information needs as much as SC patients [28,29]. Preoccupation with death is a predictor of psychological distress in patients with HM [30]. Among HM survivors it has been shown high level of psychological distress and financial worries, together with the perception of having their own needs underestimated by health professionals [31]. The higher psychological support received in our sample by SC patients may be due also to the higher prevalence of female and of retired people, given that women are more able to feel psychological needs and retired people have more mental space to feel psychological needs and more time to look for psychological support [32,33]. This result strengthens the importance of giving more access to psychological support for everyone after a cancer diagnosis and more attention to communication processes in medical-patient relationships [34]. Patients who feel to be supported by good relationships with health professionals tend to feel less need of specific psychological support, as it has been shown in a recent study conducted in a Supportive Care Unit [35]. We suggest that the decreased level of hope registered among HM patients only, since diagnosis through the successive phases of disease, might be due to the awareness of having a disease spread all over the body, whereas SC patients after diagnosis more easily feel that the disease is centered somewhere in their body, so more controllable through targeted treatment. Anyway, these results show again the importance of careful monitoring the psycho-social needs among these patients. Depression and Hopelessness was reported in leukaemia patients [15]. Moreover, in patients with acute leukaemia (a highly fatal condition characterized by a sudden onset and a fluctuating disease course) depression was associated with greater physical burden while hopelessness, measured by Beck Hopelessness Scale, was present in 8.5% of the patients and was associated with older age and lower self-esteem. Both were associated with poorer spiritual wellbeing [16]. SC patients had higher level of spiritual/religious resources according to SBI. This might be related to the smaller percentage (borderline statistically significant) of SC patients that were non-believer and maybe also to the higher proportion of SC patients who received psychological support. Religiosity was positively associated with hope, with a similar force, in the two groups of patients. Only few data are available on the hope of patients with SC and HM on cure or follow-up, during supportive care therapies to manage toxicities due to oncologic therapies, and they confirm the positive association between religiosity and hope [35]. Among SC patients older age was negatively associated with hope. It has been shown that having long-term projects influences positively hope [22], therefore it may be that older patients have lower level of hope when facing a cancer disease just due to the feeling of can no more have long-term projects in any way, both for the old age and for the disease, whereas younger patients can still use the longer life-expectation to keep having long-term projects and hope [27,30]. No data of the literature are available on the dignity-related distress in patients on cure or follow-up during supportive care to manage toxicities-related to oncologic treatments. In our study dignity-related distress was negatively associated with hope in a similar way in the two groups. The clinicians can use standardized questionnaires to assess the dignity related distress [22] and the sense of hope [24] in cancer patients during all phase the disease [23,25]. No cut-off is indicated to the correct use of these questionnaires: the questions want more to open a dialogue useful to make the patient feel safe and to trust health professionals who know better what is really important for him/her [36]. Indeed critical passages in the course of the disease can be dealt

with better if this dialogue on important personal preferences and values has already been opened. The multidimensional assessment of cancer patients, on physical, psychological, social and spiritual (including hope and dignity) dimensions, in any phase of the disease, made by well-trained health professionals, gives them the possibility to understand and to facilitate the dynamic process of coping with the disease, and to find out which ways are still viable for wellbeing, even in the presence of a life-threatening disease, by controlling symptoms and giving relevance to personal hope and personal dignity issues [37,38]. A number of studies indeed showed that patients involved in decision-making processes on care have higher compliance with the suggested treatments and better coping with the disease, resulting in higher level of wellbeing [6,34,39,40]. The main limitation of this study is its cross-sectional design which provides only weak support to the hypothesized direction of the described association. Moreover the differing setting of care of SC and HM patients makes the comparisons open to different interpretations, and the national size of the study makes its results to be confirmed in other health systems.

Overall the results of our study suggest the need for early assessment and management of physical and emotional symptoms, spiritual/religious needs, level of hope and dignity-related distress, psychosocial support, also for cancer patients who are on cure or follow-up [41]. SC and HM patients have overlapping physical and emotional symptoms. However it is possible that HM patients need to be more supported in order to encourage hope during the phase of cure and relapse. According the data of literature, in comparison with other kind of cancer HM seem to be less supported, for instance there is a lack of self-help materials and of systematic provision of information and support groups for patients, which may be associated with lower empowerment among these patients [34]. The early multidimensional assessment and the related early psychosocial support can improve the skills of coping among patients and their families, in order to manage the emotional reactions to disease and treatments, and to integrate the disease's experience into the life plan both during active therapy and when the patient enters into follow-up or rehabilitation settings of care [33,41].

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