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**Distress and unmet needs during treatment and quality of life in early cancer survivorship: a longitudinal study of haematological cancer patients**

**Short title: Distress unmet needs and quality of life**

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## **Abstract**

### **Objective**

To examine the influence of anxiety, depression and unmet supportive care needs on future quality of life (QoL) in multiple myeloma (MM) and diffuse large B cell lymphoma (DLBCL) patients.

### **Methods**

MM and DLBCL patients recruited through the population-based Victorian Cancer Registry. Data was collected through two telephone interviews: T1) on average 7 months post diagnosis, T2) average 8 months later. QoL was examined at T2 using the Functional Assessment of Cancer Therapy (FACT-G) scale. The Hospital Anxiety and Depression Scale measured anxiety and depression and the Supportive Care Needs Survey measured unmet needs at T1. Multivariate linear regression examined associations between QoL subscales (physical, emotional, social, and functional wellbeing and overall QoL) and T1 anxiety, depression and unmet needs.

## Results

Except physical wellbeing, all other QoL subscales and overall QoL were significantly associated with T1 anxiety. All QoL subscales and overall QoL were significantly associated with T1 depression. Only patient-care needs were associated with physical and social wellbeing and overall QoL.

## Conclusion

Anxiety, depression and patient-care unmet needs during treatment are associated with diminished physical and emotional well-being in the following months. Psychological distress and unmet supportive care needs experienced during treatment should be addressed to maximise future QoL.

Key words: Haematological cancer, multiple myeloma, Diffuse large B-cell Lymphoma, distress, unmet needs, Quality of Life.

## Background

Haematological cancers account for around 9% of all cancers and are the fourth most frequently diagnosed cancer in men and women in economically developed countries[1]. Diffuse large B-cell lymphoma (DLBCL) and multiple myeloma (MM) are the two most common types of haematological cancers, and for both cancers the median age of diagnosis is 71 years [1]. Treatment of these cancers most commonly includes chemotherapy, with some patients also receiving radiotherapy. Younger MM patients in particular may also receive bone marrow transplant and supportive care (transfusion of red blood cells and platelets) which are complimentary to traditional chemotherapy and radiotherapy [2, 3].

Health-related quality of life (QoL) has become one of the main patient reported outcome measures in cancer treatment [4] and is a multi-dimensional measure of psychological, physical, role, cognitive and social well-being. It can provide insight into the effect of an illness and its therapy on a patients' well-being [5], considering their coping strategies and social support [6-9]. A high proportion of haematological cancer survivors have a diminished QoL [10-12], with MM and lymphoma patients experiencing worse QoL across multiple domains compared to survivors of other hematological cancer especially during and soon after treatment[11].

Many haematological cancer patients particularly lymphoma and MM patients, experience psychological distress and poor QoL at the beginning of their illness and during treatment [13-15]. This is partly related to fear and uncertainties towards cancer and its treatment, side effects of the treatment, fear of cancer relapse and uncertain prognoses [16]. Past studies of cancer patients have shown that higher levels of anxiety, depression [12, 14, 17, 18] and unmet supportive care needs [19, 20], particularly those related to social support and information [12, 21] are associated with decreased QoL. In a systematic review of 14 studies, Allart et al. [15] reported that the QoL in haematological cancer patients was inversely related to emotional distress, information needs, social support and general health perceptions. However, most studies in the review were cross-sectional. Although cross-sectional associations between QoL and unmet needs and between QoL and anxiety and depression in hematological cancers have been studied [7] we could not find any study examining these relationships using a longitudinal design. Further, as unmet supportive care needs are associated with anxiety and depression in cancer patients, at least at the cross-sectional level [7, 22, 23], it is of interest to determine their independent effects on future QoL. However, again we could not find any published study that has examined the relative influence of anxiety, depression and unmet needs on QoL in hematological cancer survivors, using a longitudinal design.

Cancer survivors who experience anxiety and depression symptoms, can experience a deterioration in their psychological well-being as well as their QoL in the following months [24]. However, little is known about the role of psychological distress and unmet needs during treatment on future HRQoL in hematological cancer patients. Improved understanding of the role of anxiety, depression and unmet needs during cancer treatment, in influencing future HRQoL, would enable healthcare professionals to identify patients potentially at risk for increased distress post end of treatment allowing them to assist patients in addressing problems at an early stage. The current study aims to fill this gap in the literature and seeks to evaluate the relative influence of anxiety, depression and unmet supportive care needs experienced by haematological cancer patients during the late treatment phase on their future QoL. The late treatment phase represents an important point in cancer care for this population as patients transition to follow-up care and may still experience treatment related side-effects. We predicted that negative emotional states (anxiety and depression), and high levels of unmet needs at this time would be associated with poorer QoL in the future.

## Methods

### *Design*

A longitudinal study design was used to collect data by self-report questionnaire at two time points (T1 and T2).

### *Sample and procedure*

The sample was recruited through the population-based Cancer Registry (CR) in Victoria, Australia's second most populous state. Eligible patients were aged between 18 and 85 years, within 5-months of their diagnosis of DLBCL or MM when recruitment commenced, had a prognosis greater than 2 years and were cognitively and physically able to participate in the study as determined by their clinician.

After confirming patients' eligibility with their clinician, the CR approached patients by letter to inform them of the study and seek their consent for the researchers to contact them. Researchers contacted consenting patients by letter to invite them to participate in telephone interviews at two time-points approximately 8 months apart (T1 and T2). Respondents who completed their T1 interview more than 12-months post-diagnosis were also excluded from analysis.

### *Ethics*

The study was approved by the Cancer Council Victoria's Human Research Ethics Committee and the recruitment of patients took place between July 2010 and July 2014.

### *Measures*

*Quality of life* was assessed using the general Functional Assessment of Cancer Therapy (FACT-G) scale at T2. The primary goal of the FACT [25] is to assess the effects of cancer therapy on patients in four major areas: physical well-being, social/family well-being, emotional well-being, and functional well-being. All items in the scale are responded to on a Likert-type scale ranging from 4 (0 = not at all; 1 = a little bit; 2 = somewhat, 3 = quite a bit; and 4 = very much) (Higher scores indicate better QOL). The FACT-G is scored by summing the five subscales yielding a composite quality of life score for each individual. The QoL subscales and the overall FACT-G scale, which were the outcome variables, were measured on continuous scale with score ranges for PWB, SWB and FWB: 0-28, for EWB: 0-24, and for overall FACT-G: 0-108.

*Anxiety and depression* were assessed at T1 using the 14-item Hospital Anxiety and Depression Scale (HADS) [26], a self-assessment tool with demonstrated validity in assessing anxiety and depression [27, 28]. HADS classifies anxiety (7 items) and depression (7 items) scores as normal (0 to 7), mild (8 to 10), moderate (11-14) and severe (15-21). Scores between 8-10 are considered elevated and between 11-21 are considered clinically significant [26]. In this study, scores on each subscale were dichotomised to indicate elevated anxiety (HADS-A  $\geq 8$ ) and depression (HADS-D  $\geq 8$ ).

*Unmet needs* were measured at T1 using the Supportive Care Needs Survey (SCNS-SF34) [29], a 34-item self-reported questionnaire assessing current psychological (10 items), information (11 items), sexuality (3 items), physical and daily living (5 items), and patient care and support (5 items) needs. For each item, participants indicated their level of need over the past month on a five-point scale (1 = no need, not applicable; 2 = need satisfied; 3 = low need; 4 = moderate need; 5 = high need). The responses for the unmet needs items were recoded with 0 indicating *no need or need satisfied* and 1 indicating *low need* and 2 indicating a *moderate or high need*. The total number of *moderate or high needs* for each domain was determined on a continuous scale.

At T1, respondents rated their perceived state of health on a 5-point scale ranging from excellent to poor. Socio-demographic characteristics including education, and marital status were collected. Patients were also asked if they had any co-morbidity before their cancer diagnosis (yes/no). Information about participants' age at diagnosis and sex was obtained through the CR.

### *Sample Size*

Sample size calculations were based upon detection of medium effect sizes (power = 0.8) with an *a priori* estimation of 15–20 predictor variables: a sample size of 150 was required [30]. Data were analysed using SPSS (v.20).

### *Analysis*

Differences in baseline characteristics between respondents participating in both interviews, and those participating only at T1 were compared with chi-square or t-tests. Descriptive statistics were used to characterise participants by demographic and clinical characteristics. Correlation assessed the strength of associations between T1 unmet needs and T1 anxiety and depression rule out multicollinearity in the multivariate regression model.

Multivariate associations between each T2 outcome variable (Overall FACT-G, PWB, SWB, EWB and FWB subscales) and T1 anxiety, depression and unmet needs domains were

examined using multiple linear regressions. The multivariable models controlled for potential confounders of age, sex, time since diagnosis, region of residence, cancer type, perceived health at T1 and chemotherapy received as past studies, have been found associations between these variables and QoL in haematological cancer [9, 14, 31-33].

## Results

### *Participants*

The details of the recruitment process and response rates are reported elsewhere [34]. In brief, the number of eligible cases approached was 983 for DLBCL and 791 for MM, of which, 36% of MM patients and 36% of DLBCL patients responded to the first survey and of these 76% of MM and 73% of DLBCL patients responded to the T2 survey. Thirty patients, who were more than 12-months post-diagnosis when they completed their T1 survey, were considered ineligible and excluded from this study. The sample was aged on average 63.82 (SD:  $\pm 11.08$ ) years at diagnosis. Mean (SD) time since diagnosis at T1 was 6.71 ( $\pm 1.98$ ) months and time between T1 and T2 was 8.38 ( $\pm 0.89$ ) months, which did not differ by cancer type. Participants completing both interviews did not differ significantly from those not completing the T2 interview in terms of their clinical or demographic characteristics ( $p > 0.05$ ). Reflecting the patient population, slightly more males than females participated in the study and nearly 2/3<sup>rd</sup> of participants were aged  $> 60$  years (Table 1). Seventy-five percent of participants were in a relationship (married or *de facto*) (Table 1). Reflecting the distribution of residents in the state of Victoria around 33% of study participants lived in regional areas. At T1, 91% of the sample had received chemotherapy and 17% had had a SCT (Table 1). Patients reported the following comorbidities at the time of cancer diagnosis: hypertension (14%), arthritis (11%), angina/ischemic heart disease (11%), hypocholesteremia (8%), diabetes mellitus type 2 (8%), chronic pain (4.3%) and asthma (2%).

### *Anxiety, depression and unmet needs*

At T1, 15% of participants had elevated anxiety and 18% had elevated depression scores. Also, 30% of respondents reported at least 1 moderate to high unmet need in the *psychological and emotional needs* and the *physical and daily living needs* domains each, 24% reported at least one moderate to high *information need* with 8.5% reporting at least one *sexuality need* and 11% reporting a *patient care need*.

### *Levels of QoL*

Means (SD) for the QoL subscales and the overall FACT-G scale are reported in Table 1. There was some variation in mean scores across subscales with highest scores found for SWB and lowest score found for EWB (Table 1). While demographic factors were not related to QoL scores, perceived health status was, with participants reporting their health as poor having lower scores on all QoL subscales and overall FACT-G (Table 1). Patients receiving chemotherapy (22.16 vs. 24.81,  $p < 0.01$ ) or SCT (21.25 vs. 22.64,  $p = 0.03$ ) had significantly lower mean scores for PWB than those not having these treatments (Table 1).

### *Correlations*

While most unmet needs domains had weak to moderate correlations with anxiety and depression, T1 physical needs were strongly correlated with T1 depression ( $r = 0.51$ ) (Table 2).

### *Prediction of T2 QoL*

#### *Bivariate associations*

PWB, EWB, SWB and FWB were significantly associated with all T1 unmet needs domains as well as with T1 anxiety and depression.

#### *Multivariate associations*

Except for PWB, all other QoL subscales, and overall FACT-G were significantly associated with T1 anxiety (Table 3). All QoL subscales and the overall FACT-G were significantly associated with T1 depression. Of the unmet needs domains, only patient care needs and daily living needs were associated with future HRQoL domains. Patient care needs were inversely associated with PWB, SWB and the overall FACTG, while daily living needs were inversely associated with PWB (Table 3).

## **Discussion**

To our knowledge, this is the first study to use a longitudinal design to examine the independent effects of anxiety, depression and unmet needs nearing or at the end of treatment (T1) on QoL of haematological cancer patients in their second year post diagnosis (T2). At T2, the participants reported diminished physical and emotional wellbeing. At T1, 15% of participants experienced symptoms of anxiety and 18% experienced depression symptoms. Anxiety and depression at this time point predicted lower QoL in the future (T2). Although just 11% of the patients reported physical and daily living needs at T1, these needs predicted diminished physical wellbeing and social wellbeing at T2. The findings indicate that QoL in the second year of diagnosis is influenced by anxiety, depression and some unmet

supportive care needs experienced at the end of treatment, highlighting the importance of addressing these health problems for haematological patients during their transition to follow-up care.

We demonstrated that anxiety and depression during later stages of treatment were independently predictive of QoL in the following months. Anxiety and depression at T1 predicted diminished emotional, social and functional wellbeing as well as overall QoL at T2. In addition, T1 depression also predicted diminished physical wellbeing at T2. Our results are consistent with past studies that have advocated for improvement in QoL of cancer patients by addressing symptoms of psychological distress and offering social support to patients including satisfactory interaction with family and friends [18, 21, 35]. As both anxiety and depression were associated with most QoL domains and overall QoL, our results demonstrate the independent effects of these variables on QoL.

Approximately 1 in 7 MM and DLBCL patients in our study reported symptoms of anxiety and 1 in 6 reported symptoms of depression towards the end of their treatment. While these levels are lower than those reported for haematological patients at the beginning of their treatment [36] our findings suggests that if not addressed at the end of treatment, anxiety and depression can contribute to diminished QoL in the second year of diagnosis. Rates of unmet needs were higher than that for anxiety and depression, with 1 in 3 patients reporting *psychological and emotional needs* and *physical and daily living needs* and 1 in 4 *information needs*. The proportion of patients with unmet needs in the different need domains in our study was consistent with those reported in other studies of mixed haematological cancer patients [16, 37, 38].

Our QoL scores can be compared with those of the general population in Queensland Australia. While our scores for overall QoL and functional QoL were similar to those obtained for the general population, scores for PWB [22.4 (SD=4.9) vs. 25.1 (SD=3.7)] and EWB subscales [20.7 (SD=3.5) vs. 21.2 (SD=3.7)] in our study were significantly lower than in the general population [39]. This pattern of results is consistent with other studies [8, 40]. Additionally social QoL in our study was higher than levels found in the general population. This could be because cancer patients often receive high level of social support from family and friends particular during diagnosis and treatment [41]. Our findings about reduced physical functioning compares with Sherman et al's study [14], which examined MM patients, on average 3 months after diagnosis, albeit using a different QoL measure - the SF 12. Sherman et al reported that physical functioning and energy were affected far more than the mental health functioning. The results also compare with Pulgar et al.'s study [40] that reported diminished QoL outcomes on all subscales such as physical, and emotional

functioning although their sample consisted of mixed haematological cancer patients including myeloma, leukaemia and lymphoma who and were between < 1 year and > 2 years post diagnosis. In another study of haematological patients approximately 5 years post diagnosis, Molassiotis et al [7] reported lower physical and social functioning, but higher emotional functioning compared to healthy adults. QoL was assessed using EORTC QLQ-C30 and patients were assessed on average 68 months after their diagnosis. However, in our study we found that patients experienced reduced emotional QoL. It is plausible that emotional functioning improves in the late cancer survivorship, while physical and social functioning decline. Additionally, our measure for QoL, the FACT-G, was different to that used in Molassiotis' study [7], which makes comparison across studies challenging.

Not only are our results consistent with other studies, they also suggest a longitudinal association between psychological distress and QoL in a large population based sample of DLBCL and MM, the two most common haematological cancers. Most studies have examined the cross-sectional association between QoL and anxiety and depression in this cancer cohort [7, 12, 14, 42]; only few studies have explored the longitudinal association in either leukaemia [43], or mixed haematological cancer patients [17, 44]. We also demonstrated independent effects of patient care needs during treatment on future QoL. These needs were mostly related to the responsiveness and sensitivity of hospital staff to patients' physical needs and emotional needs, as well as reassurance from hospital staff that the way patients feel about their condition is normal.

The strength of our study is the cancer-registry based sample, ensuring that eligible patients were drawn from a wide range of treatment centres and regional and metropolitan areas and the prospective study design. As the patients were interviewed on telephone, there was minimal missing data. There were minimal variations in time since diagnoses at both assessments, ensuring participants were reporting on their anxiety, depression, unmet needs and QoL at similar times in the course of their disease. In addition, in our study, comparisons were made with data from a reference general population in Australia. The study focused on the two most commonly occurring hematological cancers mostly affecting the elderly. Thus, it cannot be assumed that QoL of cancer survivors is similar across the different hematological cancer types, particularly those that require less intensive treatments or occur in younger individuals. Additionally, we found no difference in the demographic characteristics of the study sample with those of all eligible patients, suggesting that the sample was generally representative of the larger population of patients.

There are a few methodological limitations of our study that also need to be noted. We used a general measure of QoL rather than a measure specific to haematological patients.

However a recent study has demonstrated that the FACTG is valid measure for monitoring QoL in haematological cancers Yost, Thompson [45]. A key limitation was the relatively low response rate which may have implications on the generalizability of the findings although our response rates are comparable to several other psychosocial surveys utilizing population-based cancer registries in Australia and internationally [46-48].

The findings of this longitudinal study suggest that anxiety, depression and the patient care related needs experienced by DLBCL and MM patients during the later stages of treatment are associated with diminished physical and emotional well-being in the following months. Our study suggests that addressing patient's psychological distress alone is not sufficient to ensure improved QoL in future. Unmet supportive care needs, particularly the patient care needs and physical and daily living needs, during treatment need to be addressed for potentially improved QoL in the follow-up care phase. However, as the majority of interventions designed to reduce unmet needs among cancer patients have not been found to be effective and there is little evidence to favour any particular approach for reducing unmet need [49] currently evidence-based strategies for addressing unmet needs cannot be recommended. Clinicians aiming to prioritize health services to improve survivors' HRQoL should be guided by an understanding of their cancer patients' and survivors' anxiety and depression levels as well as their unmet needs with any interventions aimed at addressing all three factors developed in consultation with their patient. Further research is needed to identify effective strategies for intervening on unmet needs to improve haematological cancer survivors HRQoL.

### **Conflict of Interest and Sources of Funding**

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There are no conflicts of interests to declare for any author.

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**Table 1: Sample characteristics and Quality of Life scores (means and Standard Deviation (SD)) overall and for the different demographic and treatment variables**

Characteristic	QoL scores [Mean (SD)]					
	PWB	EWB	SWB	FWB	FACTG	
	22.4 (4.9)	20.7 (3.5)	23.2 (4.5)	21.1 (5.84)	87.4 (15.0)	
<b>Gender</b>						
Males	234 (56.5%)	22.34 (5.05)	20.76 (3.36)	23.32 (4.13)	21.1 (5.98)	87.56 (15.12)
Females	180 (43.5%)	22.40 (4.880)	20.55 (3.61)	23.18 (5.02)	21.20 (5.67)	87.26 (14.93)
		p=0.90	p=0.60	p=0.50	p=0.86	p=0.84
<b>Age at diagnosis (years)</b>						
≤60	157 (37.9%)	22.23 (4.79)	20.32 (2.97)	23.03 (4.55)	21.20 (5.53)	86.78 (13.950)
> 60	257 (62.1%)	22.46 (5.08)	20.88 (3.73)	23.40 (4.52)	21.11(6.03)	87.83 (15.66)
		p=0.36	p=0.09	p=0.42	p=0.86	p=0.48
<b>Marital status</b>						
Married/ de-facto	309 (74.6%)	22.36 (4.96)	22.36 (4.96)	23.55 (3.99)	21.13 (5.89)	87.66 (14.62)
Not in a relationship (Single/ separated/ divorced)	105 (25.4%)	22.37 (5.02)	22.37 (5.02)	22.37 (5.80)	21.19 (5.72)	86.73 (16.19)
		p=0.99	p=0.99	p=0.06	p=0.92	p=0.60
<b>Perceived health at T1</b>						
Good to excellent	299 (73.1 %)	23.67 (4.07)	21.46 (2.73)	24.06 (3.92)	22.68 (4.90)	91.89 (11.66)

Poor to fair	110 (26.9%)	18.96 (5.52)	18.71 (4.14)	21.15 (5.32)	17.18 (6.24)	75.99 (16.43)
		p<0.01	p<0.01	p<0.01	p<0.01	p<0.01
<b>Received following treatments by Time 2</b>						
Chemotherapy						
Yes	377 (91.3)	22.16 (4.99)	20.73 (3.40)	23.34 (4.36)	21.07 (5.83)	87.32 (14.73)
No	36 (8.7)	24.81 (3.83)	20.55 (3.32)	22.68 (5.94)	22.13 (5.65)	89.90 (16.19)
		p<0.01	p=0.77	P=0.53	P=0.29	P=0.37
Radiotherapy						
Yes	109 (26.4)	22.85 (4.90)	20.61 (3.45)	23.69 (4.66)	21.23 (5.80)	88.75 (14.73)
No	304 (73.4)	22.22 (4.97)	21.00 (3.19)	23.14 (4.45)	21.15 (5.84)	87.13 (14.90)
		p=0.25	p=0.28	P=0.29	P=0.90	P=0.34
*SCT						
Yes	72 (17.4)	21.25 (4.95)	20.46 (3.20)	23.41 (4.51)	20.40 (5.65)	85.53 (14.53)
No	105 (59.0)	22.64 (4.92)	20.76 (3.43)	23.25 ( 4.51)	21.33 (5.85)	87.98 (14.91)
		p=0.03	p=0.47	P=0.78	P=0.21	P=0.19

\*SCT: (Stem cell transplant ) was received only by MM patients . PWB: Physical well being, EWB: Emotional well being, SWB: Social well being, FWB: Functional well being, FACTG: Functional assessment of cancer therapy-general.

**Table 2: Correlations between T1 anxiety and depression and T1 unmet needs subscales**

	HADS Anxiety (T1)	HADS depression (T1)
Psychological needs (T1)	.475	.461
Information needs (T1)	.343	.376
Patient care needs (T1)	.168	.244
Physical needs (T1)	.388	.510
Sexuality needs (T1)	.245	.230
HADS Anxiety (T1)	-	.528

HADS: Hospital anxiety and depression scale dichotomised into normal or elevated anxiety or depression.

**Table 3: Results of multiple linear regression analysis for each QoL subscales and overall FACT-G<sup>^</sup>**

	Time 2									
	PWB		EWB		SWB		FWB		FACTG	
R <sup>2</sup>	0.33		0.32		0.32		0.31		0.43	
Time 1	Beta <sup>^</sup>	<i>p</i>	beta	<i>p</i>	beta	<i>p</i>	beta	<i>p</i>	beta	<i>p</i>
Anxiety (binary)	-.079	.150	-.214	.000	-.174	.001	-.155	.001	-.190	.000
Depression (binary)	-.10	.001	-.125	.013	-.153	.005	-.227	.000	-.220	.000
Psychological needs	.027	.661	-.098	.121	-.024	.719	-.037	.558	-.038	.513
Information needs	.027	.675	-.111	.088	-.049	.489	.001	.993	-.031	.602

Patient care needs	-.120	<b>.040</b>	-.038	.522	-.189	<b>.003</b>	-.041	.483	-.125	<b>.020</b>
Physical and daily living needs	-.164	<b>.007</b>	.005	.940	.074	.260	-.059	.331	-.049	.376
Sexuality needs	-.077	.092	-.074	.104	.013	.788	-.065	.153	-.065	.115

PWB: Physical well being, EWB: Emotional well being, SWB: Social well being, FWB: Functional well being, FACTG: Functional assessment of cancer therapy-general.

^ beta= Standardized coefficient

All models are adjusted for age, sex, time since diagnosis, region of residence, cancer type, perceived health and chemotherapy.

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