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ORIGINAL ARTICLE

Quality of life in survivors of adult haematological malignancy

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Abstract

Background: Survivors of haematological malignancies endure long-term effects of both treatment and disease. This paper examines factors that influence their quality of life through reporting on the results of a survey.

Methods: Survey using previously validated quality of life questionnaires for use in cancer management. Participants were adults aged 18 and over who had completed treatment for a haematological malignancy and were between 1 and 5 years post-treatment.

Findings: A total of 131 participants, median age of 66, completed questionnaires (66% response rate). Significant associations were found between age, global quality of life, physical and role functioning. Men reported better physical functioning and lower symptom scores than women. Employed participants reported better quality of life. Increasing age was associated with lowest quality of life. Best role functioning was also noted in participants who lived beyond 2.5 years following treatment completion. The survey suggested a gender difference with men reporting better physical functioning, fewer symptoms of pain and less loss of sleep compared with women.

Conclusion: This study contributes to the underdeveloped area of care for and research into adult haematological cancer survivors. Knowledge and understanding of the factors that affect the quality of life of such adults may provide an insight into implementation measures.

KEYWORDS

cancer survivors, EORTC QLQ-C30, EQ 5D-3L, haematological malignancies, quality of life, quantitative research

1 | INTRODUCTION

There has been a steady increase in survival rates of all patients with cancer in the UK when compared with the United States and Europe with 50% of patients surviving for ten years and beyond (Cancer Research UK, 2014). Overall, the approximated two million cancer survivors in the UK will increase by 3% per year as the population ages (Maddams et al., 2009) and by 2030 the number of cancer survivors in the UK is estimated to be four million (Maher & McConnell, 2011).

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Haematological malignancies are the fourth most frequent cancer type in the developed world, and incidence rates are increasing, in part, secondary to our ageing population (Chihara et al., 2014; Howlader et al., 2014; Smith, Howell, Patmore, Jack, & Roman, 2011). B-cell malignancies such as chronic lymphocytic leukaemia (CLL), lymphoma and multiple myeloma (MM) are some of the most common haematological malignancies, and this study focused on patients who were treated for these conditions. In 2011, the numbers of new cases registered in the UK were 12,783 with non-Hodgkin's lymphoma (NHL), 1,845 with Hodgkin's lymphoma (HL), 3,233 with CLL and 4,792 with MM (Office for National Statistics [ONS], 2015). Although many of these malignancies are not curable, the routine use of novel and targeted therapies has led to a steady improvement in survival rates (Hall, Lynagh, Bryant, & Sanson-Fisher, 2013; Sant et al., 2014). Individuals treated for a B-cell malignancy are no longer viewed as victims but as survivors who go on to live for many years following diagnosis (Aziz & Rowland, 2003).

In England, the 5-year overall survival for men diagnosed with HL during 2011–2015 and followed up until 2016 was over 80%, 64.9% for NHL, 53.3% for all leukaemia and 51.9% for survivors of MM. During the same period, women showed survival rates of 83% for HL, 69.4% for NHL, 52.4% for all types of leukaemia and 50.8% for survivors of MM (ONS, 2018). The 5-year survival for a patient treated for CLL is 67.0% for men and 73.0% for women in England (De Angelis, Sant, & Coleman, 2014). These figures show improvement in survival rates compared to previous years.

Contrary to other malignant diseases, chemotherapy treatment regimens for B-cell malignancies are often more complex and intense. Hence, they can be more physically and psychologically burdensome with prolonged, intensive treatments (De Vita, Lawrence, & Rosenburg, 2008; Junlen et al., 2015; Mounier et al., 2015; Pulte, Jansen, Castro, & Brenner, 2016). These treatments have also led to significant improvements in survival rates (Mounier et al., 2015; Pulte et al., 2016). When a patient is diagnosed with a B-cell malignancy, the treatment not only affects clinical outcomes, but also it can influence their quality of life (QoL) (van de Poll-Franse et al., 2018). The physical difficulties (e.g. fatigue, decreased physical capacity) and psychosocial problems (e.g. anxiety, depression, stress, insecurity, grief, decreased self-esteem, hindered job reintegration, social isolation) experienced by these survivors may lead to diminished QoL (Gotay, Holup, & Pagano, 2002; Tomich & Helgeson, 2002).

The intense treatment received, especially in patients with haematological malignancies, can cause deficits in one or more QoL domains (Hassan & Abdi-Valugerdi, 2014). Studies investigating the long-term adverse effects of treatment for haematological malignancies have identified problems with the eye, endocrine function, neurosensory and cardiopulmonary impairments (Aleman & van Leeuwen, 2007; Hess et al., 2011; Hodgson, Grunfeld, Gunraj, & Giudice, 2010; Punnett, Tsang, & Hodgson, 2010; Walsh, 2010). Treatment-related toxicities such as acute confusion and sometimes metabolic disturbances have been reported (Hallek et al., 2010; Hassan & Abdi-Valugerdi, 2014). Those who survive adverse effects of treatment and go on to experience prolonged remission, often continue to live with decreased functioning and reduced QoL (Efficace, Novik, Vignetti, Mandelli, & Cleeland, 2007), because they continue to deal with the daily challenges of living with the late- and long-term adverse effects of treatment and fear of disease recurrence. QoL has, thus, been incorporated as an important outcome parameter in clinical trials and in daily clinical practice, enabling haematologists to assess the effectiveness of a treatment and guide in making tailored treatment decisions (Lopez-Herce, Rollon-Mayordomo, Lozano-Rosado, Salazar-Fernandez, & Gallana, 2009).

During the acute phase, most patients interact with nursing staff on haematology day units for emotional and psychological support (Swanson & Koch, 2010). Most haematology departments have access to social workers if required. Therefore, issues that affect physical, social or emotional functioning, thereby having an impact on the QoL of patients during this phase, are mostly addressed and dealt with (Lobb et al., 2009). It is following completion of treatment when patients feel the lack of such support measures in place (Lobb et al., 2009) as they move into long-term follow-up in an outpatient setting and lose interaction with the healthcare providers. Patients have many needs that emerge which can influence their QoL during this time. In Dorset, cancer care centres employ social workers who provide services to both inpatients and outpatients departments.

This study sought to examine the QoL of adult survivors treated for a B-cell malignancy, and this cohort appears to be largely an older group, which represents the majority of patients in Dorset. Dorset is a unique county in the UK as it has the largest population of older adults with 28.3% being 65 years and older which is significantly higher than the 18% average for England and Wales (ONS, 2016). The high proportion of older cancer survivors in this cohort and factors that influence their QoL will provide insight into the future ageing UK cancer survivors' population as a whole. This may, in turn, inform future healthcare planning strategies.

2 | METHODS

A cross-sectional design was used in this study, which was part of a wider mixed-methods study in a population of patients who were treated for a haematological malignancy. This paper only reports the first quantitative survey data collected between July 2013 and May 2014.

2.1 | Recruitment

Potential participants were identified by treating haematologists at three hospital sites. They were contacted by mail and in the outpatient clinics by their clinicians, and/or they were directly approached by the first author in outpatient clinics following confirmation of eligibility by the clinicians.

Eligible participants were mailed an invitation letter detailing the purpose of the study, a demographic questionnaire designed specifically for this study, QoL questionnaires namely, the EORTC QLQ-C30, the EQ-5D and a postage-paid reply envelope. Those participants approached in outpatient clinics were given the same by hand. To enhance the response rate, a reminder letter and pack were sent out after 2 weeks to all the participants who had initially received the pack either by hand or by post.

Inclusion criteria were >18 years of age, in clinical remission, as determined by treating clinicians. They must have completed treatment for a B-cell malignancy (CLL, all lymphomas, MM) 1–5 years prior to the commencement of the study, lived within the catchment area and/or attended one of the three hospitals. Exclusion criteria included cognitive impairment or a history of major psychiatric illness and those who lacked the capacity to provide informed consent. Participants determined by treating clinicians to be too unwell to complete questionnaires were also excluded from the study. Basic proficiency in the English language was expected, as there were no resources for translation. The study received ethical approval from the National Research Ethics Committee South Central—Southampton A (12/SC/0708). All participation was voluntary, and people returning questionnaires were perceived to have implied consent.

2.2 | Demographic data and variables

The demographic questionnaire captured socio-demographic data such as age, gender, marital status, living arrangements, educational status, employment status, health status and ethnic origin of the participants. Clinical information about diagnosis and time of treatment completion was extracted from the medical records or hospital database and recorded on an Excel spreadsheet and later transferred onto SPSS. Data were electronically stored securely on a hospital shared drive which was password protected.

2.3 | The EORTC QLQ-C30 questionnaire

EORTC QLQ-C30 is a health-related QoL questionnaire developed by the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Study Group to assess the QoL of patients with cancer (Aaronson et al., 1993; Sprangers, Cull, Bjordal, Groenvold, & Aaronson, 1993). The validity and reliability of this questionnaire have been verified in several studies (Groenvold, Klee, Sprangers, & Aaronson, 1997; Luckett et al., 2011), and the instrument is available in several languages (Fayers et al., 2001).

The questionnaire comprises 15 scales with 30 questions in total, including physical, emotional, cognitive, social and role functioning, fatigue, pain, nausea/vomiting, dyspnoea, insomnia, appetite loss, constipation, diarrhoea, financial difficulties and global health status. The questions were rated from 1 to 4 with scores corresponding from “not at all” to “very much.” Questions 29 and 30 were rated from 1 to 7 (very poor to excellent) (Aaronson et al., 1993). Each rated scale was used to compute a score ranging from 0 to 100 according to the scoring manual of Fayers et al. (2001).

2.4 | EQ-5D quality of life questionnaire

The EQ-5D, validated by the European QoL group, measures generic health-related QoL. This questionnaire has been used to measure the QoL of individuals with long-term health conditions. It consists of five domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Participants were requested to choose from one of the three options (levels) which best described how they feel day to day ranging from “no problems” to “extreme problems.” The EQ-5D VAS (visual analogue scale) a part of this questionnaire ranges from 0 to 100 the latter being the best imaginable health state. Participants were requested to mark their health status on the scale, and this was used as a quantitative measure to report their health outcomes. Data from the questionnaires were analysed descriptively in accordance with the European Quality of Life Group User Guide (Williams, 1990). The three options (levels) were combined into dichotomous variables in SPSS version 19—option 1 (no

TABLE 1 Characteristics of survivors of a B-cell malignancy in Dorset, UK

Characteristics	*N* (%)
Median age in years (interquartile range)	66 (21–95)
Gender	
Female	53 (40.5)
Male	78 (59.5)
Marital status	
Single/divorced/separated	27 (20.6)
Married/cohabitating	92 (70.2)
Widowed	12 (9.2)
Children	
Have children	104 (79.4)
Do not have children	27 (20.6)
Educational status	
Up to college	81 (61.8)
Graduate and above	44 (33.6
Employment status	
Employed	39 (29.8)
Not employed	80 (61.1)
Living status	
Living alone	39 (29.8)
Not living alone	92 (70.2)
Ethnic origin (White)	131 (100)
Diagnosis	
Leukaemia	14 (10.7)
Lymphoma	102 (77.9)
Myeloma	14 (10.7)
Time since completion of treatment	
≤2.5 years	55 (41.9)
>2.5 years	76 (58.1)
Health status	
Good	74 (59.6)
Average	35 (28.2)
Poor	15 (12.2)

TABLE 2 Associations between Quality of Life domains and socio-demographic characteristics of survivors of a B-cell malignancy in Dorset, UK (EORTC QLQ C-30)

Factor	QoL	Physical Functioning	Role Functioning	Emotional Functioning	Cognitive Functioning	Social Functioning	Fatigue	Financial Difficulties	Pain	Dyspnoea	Sleep Loss	Appetite	Constipation	Diarrhoea
Age*														
Z	−0.139	−0.277	−0.218	0.136	−0.048	−0.065	0.105	−0.163	0.150	0.188	0.020	−0.025	0.093	−0.119
p Value	0.032	0.000	0.002	0.039	0.489	0.341	0.108	0.023	0.030	0.007	0.741	0.727	0.188	0.102
Gender														
Male	65.94	52.67	61.99	64.01	67.11	62.80	62.65	63.57	55.80	65.51	57.61	63.19	65.20	62.32
Female	61.20	41.29	59.59	62.75	59.52	64.53	64.75	64.52	74.80	66.72	76.96	68.86	65.93	66.51
Z	−0.724	−2.039	−0.408	−0.195	−1.213	−0.286	−0.324	−0.209	−3.210	−0.202	−3.190	−1.228	−0.135	−1.065
p Value	0.469	0.041	0.683	0.846	0.225	0.777	0.746	0.834	0.000	0.840	0.001	0.219	0.893	0.287
Living arrangements														
Living alone	60.64	53.34	64.96	62.68	70.28	71.84	60.23	65.46	60.70	63.85	69.85	70.62	59.32	60.76
Not living alone	65.38	45.65	59.19	63.84	61.42	60.03	64.86	63.40	64.60	66.91	63.64	63.31	68.15	65.33
Z	−0.671	−1.291	−0.925	−0.168	−1.310	−1.808	−0.659	−0.382	−0.620	−0.480	−0.950	−1.476	−1.512	−1.078
p Value	0.502	0.197	0.355	0.866	0.190	0.071	0.510	0.703	0.540	0.631	0.340	0.140	0.131	0.281
Education														
Upto college level	61.29	44.62	58.19	61.32	59.75	62.68	60.36	61.46	59.90	65.14	65.24	63.35	61.51	61.54
Graduate and above	60.48	47.18	57.63	60.42	63.27	56.59	60.76	60.17	61.70	59.07	57.52	60.95	64.30	61.42
Z	−0.124	−0.456	−0.094	−0.139	−0.562	0.999	−0.062	−0.261	−0.300	−1.017	−1.270	−0.525	−0.510	−0.031
p Value	0.901	0.649	0.925	0.889	0.574	0.318	0.951	0.794	0.760	0.309	0.205	0.600	0.610	0.975
Employment														
Employed	73.61	58.88	73.10	63.21	71.38	69.03	40.34	56.05	43.30	48.32	46.38	51.84	51.54	58.07
Not employed	51.14	33.86	46.08	55.43	52.22	52.56	66.38	59.69	65.30	65.69	65.73	63.14	63.28	58.71
Z	0.732	−4.591	−4.590	−1.214	−3.055	−2.714	−3.979	−0.732	−3.670	−2.941	−3.190	−2.157	−2.157	−0.162
p Value	0.464	0.000	0.000	0.225	0.000	0.007	0.000	0.464	0.000	0.003	0.001	0.031	0.031	0.464
Time since completion of treatment														
≤2.5 years	55.85	45.46	52.08	56.13	54.84	52.20	59.68	52.83	58.20	61.37	61.86	60.68	58.93	58.92
>2.5 years	56.98	47.23	63.36	56.78	57.74	58.79	53.20	59.25	54.30	56.33	55.03	55.94	57.28	55.58
Z	−0.186	−0.323	−1.977	−0.109	−0.498	−1.184	−1.069	−1.368	−0.710	−0.904	−1.220	−1.104	−0.323	−0.907
p Value	0.853	0.747	0.048	0.913	0.619	0.236	0.285	0.171	0.480	0.366	0.224	0.270	0.747	0.364

Note. *Kendall's Tau correlation coefficient used for age and Mann–Whitney U test used for other variables. For functioning scales: higher the scores, better the functioning.For symptom scales: higher the scores, higher the magnitude of the symptoms.

problems) was relabelled as “no problems” and option 2 (some problems) and option 3 (extreme problems) together as “problems.”

2.5 | EORTC QLQ-C30 scores and analysis

Descriptive statistics were first calculated; numerical data were described using median and interquartile range when skewed. Here, age was the only continuous variable that was skewed. Non-parametric Kendall's tau correlation coefficient was used to determine associations between age and QoL subscales with a two-tailed significance test ($p < 0.05$) to assess the strength of the dependence of two variables (Bland, 2000) and data collected from the EORTC QLQ-C30 questionnaires were considered ordinal, and QoL measurement was considered nominal ordered. The associations between socio-demographic, clinical factors and QoL subscales were determined using the Mann–Whitney U test. This test is used when two independent random samples are compared and when data are ordinal as in this sample (Bland, 2000). Raw scores of this questionnaire were transformed to a linear scale ranging from 0 to 100. Higher scores represent higher functioning and QoL and a higher level of symptoms. Scoring was undertaken using directions from the EORTC scoring manual (Kaasa et al., 1995; Groenvold et al., 1997; Gulbrandsen, Hjermstad, Wisloff, & Nordic Myeloma Study Group, 2004).

2.6 | EQ-5D scoring and analysis

The independent samples *t* test was used to determine associations between age and the EQ-5D dimensions. This test was used as it identifies statistical differences between the means of two groups of reasonable size (Petrie & Sabin, 2009). The independent sample *t* test requires the assumption of homogeneity of variance. The test that is used for this assumption is Levene's test. The associations between age and the EQ-5D VAS were determined using Spearman's rank correlation coefficient as age was considered non-normal. This test is a non-parametric test and has been used to measure the strength and direction of two variables (Petrie & Sabin, 2009). Associations between the socio-demographic variables and the dichotomised EQ-5D dimensions were determined using cross-tabulations. Row percentages were chosen as they were more useful and appropriate in answering the research question. If one cell had an expected count of <5, then Fisher's exact test was used (Foster, Jefferies, & Foster, 2014).

3 | RESULTS

3.1 | Patient and clinical characteristics

A total of 200 participants were invited to take part resulting in 131 completed questionnaires with a response rate of 66%. The median (interquartile range) age of participants was 66.0 years (21.0–95.0) reflecting the prevalence of these types of haematological malignancies in an older population. Demographic and clinical characteristics of participants are summarised in Table 1.

The proportion of men (59.5%) was more than women in the sample enrolled in the study. More than 70% of the sample was married or cohabitating but nearly one-third (29.8%) of participants were living alone at the time of data collection; the majority (79.4%) had children. Almost two-thirds (61.8%) of the sample had been educated to graduate level, and nearly two-thirds (61.1%) of the enrolled participants were not in employment and/or retired. All the participants were Caucasian. The main disease type represented in the sample enrolled was NHL and HD (78%); nearly 11% of the respondents reported having been treated for MM, and similarly, a tenth of them was treated for CLL (10.7%). More than half of the people enrolled (58%) had completed treatment for a B-cell malignancy more than two and a half years previously. Less than two-thirds (59.6%) and almost 30% of the respondents rated their general health status as good and average, respectively, whereas 12.2% of participants rated their general health status as poor. All the enrolled participants were in remission at the time of data collection.

3.2 | EORTC QLQ-C30 questionnaire

The correlation between the QoL domains in the EORTC QLQ-C30 questionnaire and the socio-demographic characteristics are presented in Table 2. Age showed a significant negative correlation with global QoL, physical functioning and role functioning. Significant QoL differences were observed by gender with men reporting better physical functioning ($p = 0.041$) when compared to women. In addition, men reported fewer symptoms of pain ($p = 0.000$) and less sleep loss ($p = 0.001$) compared with women. Employed participants experienced better physical functioning ($p = 0.000$), role functioning ($p = 0.000$) and cognitive functioning ($p = 0.000$), social function ($p = 0.0007$) compared to those who were not employed (as above). Unemployed participants experienced more fatigue ($p = 0.000$), more symptoms of pain ($p = 0.000$), dyspnoea ($p = 0.003$), sleep

TABLE 3 Survivors treated for a B-cell malignancy who reported any problems in Dorset, UK (EQ-5D)

	No problems		Problems	
Dimension	Number	Percentage	Number	Percentage
Mobility	84	64.6	46	35.4
Self-care	116	89.9	13	10.1
Usual activity	82	64.1	46	35.9
Pain/discomfort	80	61.5	50	38.5
Anxiety/depression	96	73.8	34	26.2

TABLE 4 Associations between socio-demographic characteristics, EQ-5D-3L and VAS of survivors of a B-cell malignancy

	Mobility				**Self-care**			
	No problem % [*n*]	**Problem % [*n*]**	**Total % [*n*]**	***p* Value**	**No problem % [*n*]**	**Problem % [*n*]**	**Total % [*n*]**	***p* Value**
Gender								
Male	66.2 [51]	33.8 [26]	100.0 [77]	0.642	90.8 [69]	9.2 [7]	100.0 [76]	0.695
Female	62.3 [33]	37.7 [20]	100.0 [53]		88.7 [47]	11.3 [6]	100.0 [53]	
Treatment Compl[a]								
≤2.5 years	56.0 [28]	44.0 [22]	100.0 [50]	0.690	86.0 [43]	14.0 [7]	100.0 [50]	0.102[b]
>2.5 years	72.3 [47]	27.7 [18]	100.0 [65]		95.3 [61]	4.7 [3]	100.0 [64]	
Living								
Living alone	69.2 [27]	30.8 [12]	100.0 [39]	0.471	92.3 [36]	7.7 [3]	100.0 [39]	0.753[b]
Not living alone	62.6 [57]	37.4 [34]	100.0 [91]		88.9 [80]	11.1 [10]	100.0 [90]	
Children								
Yes	60.0 [63]	40.0 [42]	100.0 [105]	**0.024***	88.5 [92]	11.5 [12]	100.0 [104]	0.461[b]
No	84.0 [21]	16.0 [4]	100.0 [25]		96.0 [24]	4.0 [1]	100.0 [25]	
Education								
Up to College	62.5 [50]	37.5 [30]	100.0 [80]	0.373	91.1 [72]	8.9 [7]	100.0 [79]	0.754[b]
Graduate and above	70.5 [31]	29.5 [13]	100.0 [44]		88.6 [39]	11.4 [5]	100.0 [44]	
Employment								
Employed	89.5 [34]	10.5 [4]	100.0 [38]	**<0.001**	100.0 [38]	0.0 [0]	100.0 [38]	**0.009**[b]
Not employed	50.0 [40]	50.0 [40]	100.0 [80]		84.8 [67]	15.2 [12]	100.0 [79]	
Health								
Good	100.0 [25]	0.00 [0]	100.0 [25]	**<0.001**	100.0 [25]	0.0 [0]	100.0 [25]	**<0.001**
Average	100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	
Poor	100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	

Bold values represent statistically significant difference with a $p < 0.001$.
[a]Duration of completion of treatment. [b]Fisher's exact test. *Statistically significant.

loss ($p = 0.001$), appetite ($p = 0.031$) and constipation ($p = 0.031$) compared with those employed. Other variables such as “time since completion of treatment”, “living arrangements” and “educational status” did not have a significant impact on other QoL domains.

3.3 | EQ-5D QoL questionnaire

Associations between the QoL domains and the socio-demographic characteristics are presented in Table 3. Amongst the five dimensions, fewest problems were reported for self-care (10.1%) and the most for pain/discomfort (38.5%), followed by usual activity (35.9%). Almost two-thirds (61.5%) of participants reported being problem-free.

The proportion of participants reporting any/no problems in the five dimensions of the EQ-5D descriptive system is shown in Table 4. According to the EQ-5D-3L questionnaire, most participants did not report problems with self-care or anxiety/depression. However, a high proportion of participants reported problems with mobility (35.4%), usual activities (35.9%) and pain/discomfort (38.5%).

There was little difference by gender in mobility, self-care, usual activities and anxiety/depression, and two-thirds (66.2%) of men and 62.3% of women reported no problems with mobility. Most (90.8% of men/88.7% of women) reported no problems with self-care activities, and 68% of men and 58.5% of women had no problems in continuing with usual activities. However, there were significant gender differences in reporting of pain/discomfort. The proportion of men who reported no problems with pain/discomfort (70.1%) was higher than the proportion of women (49.1%) who reported no problems with the same symptom. This difference was statistically significant with a p-value of 0.015. All participants reported the lowest proportion of problems in the self-care dimension (10%). Participants with children were more likely to report problems with mobility (40.0%) than those without children (16.0%). A statistically significant difference was observed here with a p-value of 0.024. Participants with children were less likely to report no problems with usual activities (59.2%) than those without children (84.0%) with a p-value of 0.021. The variable that was significant for all dimensions was employment. Employed participants reported no problems with

Usual activities				Pain/Discomfort				Anxiety/Depression			
No problem % [*n*]	Problem % [*n*]	Total % [*n*]	*p* Value	No problem % [*n*]	Problem % [*n*]	Total % [*n*]	*p* Value	No problem % [*n*]	Problem % [*n*]	Total % [*n*]	*p* Value
68.0 [51]	32.0 [24]	100.0 [75]	0.269	70.1 [54]	29.9 [23]	100.0 [77]	**0.015***	76.6 [59]	23.4 [18]	100.0 [77]	0.385
58.5 [31]	41.5 [22]	100.0 [53]		49.1 [26]	50.9 [27]	100.0 [53]		69.8 [37]	30.2 [16]	100.0 [53]	
58.0 [29]	42.0 [21]	100.0 [50]	0.154	62.0 [31]	38.0 [19]	100.0 [50]	0.906	72.0 [36]	28.0 [14]	100.0[50]	0.547
70.8 [46]	29.2 [19]	100.0 [65]		63.1 [41]	36.9 [24]	100.0 [65]		76.9 [50]	23.1 [15]	100.0 [65]	
69.2 [27]	30.8 [12]	100.0 [39]	0.420	69.2 [27]	30.8 [12]	100.0 [39]	0.238	74.4 [29]	25.6 [10]	100.0 [39]	0.931
61.8 [55]	38.2 [34]	100.0 [89]		58.2 [53]	41.8 [38]	100.0 [91]		73.6 [67]	26.4 [24]	100.0 [91]	
59.2 [61]	40.8 [42]	100.0 [103]	**0.021***	58.1 [61]	41.9 [44]	100.0 [105]	0.098	71.4 [75]	28.6 [30]	100.0 [105]	0.199
84.0 [21]	16.0 [4]	100.0 [25]		76.0 [19]	24.0 [6]	100.0 [25]		84.0 [21]	16.0 [4]	100.0 [25]	
64.1 [50]	35.9 [28]	100.0 [78]	0.841	60.0 [48]	40.0 [32]	100.0 [80]	0.516	75.0 [60]	25.0 [20]	100.0 [80]	1.000
65.9 [29]	34.1 [15]	100.0 [44]		65.9 [29]	34.1 [15]	100.0 [44]		75.0 [33]	25.0 [11]	100.0 [44]	
92.1 [35]	7.9 [3]	100.0 [38]	**<0.001***	78.9 [30]	21.1 [8]	100.0 [38]	**0.004***	86.8 [33]	13.2 [5]	100.0 [38]	**0.035***
48.7 [38]	51.3 [40]	100.0 [78]		51.3 [41]	48.8 [39]	100.0 [80]		68.8 [55]	31.3 [25]	100.0 [80]	
100.0 [25]	0.0 [0]	100.0 [25]	**<0.001**	100.0 [25]	0.0 [0]	100.0 [25]	**<0.001**	96.0 [24]	4.0 [1]	100.2[5]	**<0.001**
100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	
100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]		100.0 [25]	0.00 [0]	100.0 [25]	

mobility (*p*-value < 0.001) when compared to unemployed or retired participants. All employed participants reported no problems with self-care. Most (92.1%) employed participants reported no problems with carrying out usual activities with the differences being statistically significant (*p*-value < 0.001). Most (78.9%) employed participants did not report any pain/discomfort (*p* = 0.004). Anxiety/depression was not a problem reported in 86.8% of participants who were employed (*p* = 0.035).

4 | DISCUSSION

4.1 | EORTC QLQ C30

The key findings of the importance of gender for pain, having children for mobility and usual activities, employment status and health status for all dimensions are presented. This study addressed issues that were predominant amongst the survivors. It explored the impact of selected socio-demographic variables on the QoL of survivors of B-cell malignancies. Increasing age was associated with lower QoL. These findings support those of Priscilla et al. (2011) who reported reduced QoL with impaired physical and role functioning in older patients with a haematological cancer. A similar trend is seen in the study conducted by SlovacekSlovackova, Pavlik, and Jebavy (2007).

Men reported lower pain scores and less loss of sleep than did women. Studies by Mellon, Northouse, and Weiss (2006) and Matthews, Tejeda, Johnson, Berbaum, and Manfredi (2012) add support to these findings where women reported lower QoL than men. However, these findings were not specific to survivors of a haematological malignancy but encompassed all cancer survivors. A significant difference was seen in the domain of physical functioning with men reporting higher levels of physical functioning (*p* < 0.05) in these studies.

Employed survivors reported significantly better physical functioning and social functioning and fewer role limitations and symptoms than those who were not employed. In general, employed participants, therefore, reported a much better QoL than those who were not employed. To add, most of the participants with more symptoms of fatigue, pain, sleep loss, appetite loss and constipation were unemployed or retired (Table 2). Participants who lived beyond two and a half years following completion of treatment for haematological malignancy reported better role functioning than those who completed treatment less than 2.5 years previously (*p*=<0.048). Other QoL dimensions did not show significant associations with time since completion of treatment. No significant associations were found between the QoL dimensions and the marital status and/or living arrangements of participants.

The correlation between the QoL domains in the EORTC QLQ-C30 questionnaire and the socio-demographic characteristics are presented in Table 2. Age showed a significant negative correlation with global QoL, physical functioning and role functioning. Significant QoL differences were observed in gender with men reporting better physical functioning ($p = 0.041$) compared with women. In addition, men reported fewer symptoms of pain ($p = 0.000$) and less sleep loss ($p = 0.001$) compared with women. Employed participants experienced better physical functioning ($p = 0.000$), role functioning ($p = 0.000$) and cognitive functioning ($p = 0.000$) compared with those who were not employed/retired. Unemployed participants experienced more fatigue ($p = 0.000$), more symptoms of pain ($p = 0.000$), dyspnoea ($p = 0.003$), sleep loss ($p = 0.001$), appetite ($p = 0.031$) and constipation ($p = 0.031$). Other variables such as “time since completion of treatment,” “living arrangements” and “educational status” did not have a significant impact on the other QoL domains. Overall, younger participants, men and those in employment reported better quality of life.

4.2 | EQ-5D questionnaire

Less than 30% of participants reported problems with self-care and anxiety/depression. The present findings seem to be consistent with other studies amongst patients with lymphoma who had received chemotherapy (Cull et al., 1996) and patients with acute leukaemia with anxiety and depression showing an improvement towards the end of treatment and after (Zittoun, Achard, & Ruszniewski, 1999). Another study by Heinonen et al. (2001) suggested that the level of anxiety and depression was lower in the post-treatment follow-up phase than in the active treatment phase for peripheral stem cell transplant recipients. However, over 35% of participants reported having problems with mobility, usual activity and pain or discomfort. A study of cervical cancer survivors showed comparable results (Lang, Chuang, Shun, Hsieh, & Lan, 2010) for the self-care dimension; however, only <10% of participants had problems with mobility.

Pain or discomfort was the most frequently reported symptom amongst all the other dimensions in this group of survivors of haematological malignancy with 38.5% of survivors reporting moderate or severe pain or discomfort. Women reported more pain or discomfort when compared to men with >50% of women reporting moderate or severe levels of pain/discomfort, whereas <30% of men reported moderate/severe problems with pain/discomfort. These findings were consistent with the findings of earlier studies (Baker, Haffer, & Denniston, 2003; Matalqah, Radaideh, Yusoff, & Awaisu, 2011; Oh, Han, Park, Park, & Chung, 2014).

Performing usual activity was the second most frequently reported problem in this group of survivors (35.9%) followed by mobility dimension which was the next frequently reported dimension where participants reported moderate or severe problems (35.4%). A study by Oh et al. (2014) also showed similar results with self-care being the lowest reported dimension with moderate to severe problems. These symptoms may also be attributed to a predominantly older population. This indicates that even if the survivors are disease free, they may experience debilitating symptoms of pain/discomfort and other issues such as mobility and performing a usual activity to a certain degree which can have a significant impact on their quality of life. These factors can also be attributed to an ageing population as in Dorset. It is therefore very important as healthcare providers to pay attention to and address these needs.

The main strength of the study was that it was representative of an ageing population with haematological malignancies of the whole UK. A high completion and return rate of the questionnaires was also strength of this study. The use of a combination of validated generic and disease-specific questionnaires that enabled capturing of data in greater detail was also strength of this study. However, it is important to address some limitations here. Due to the cross-sectional nature of the study, it has not been possible to explore the changes in QoL over time as in longitudinal studies. The participants’ mental status at the time of completion of questionnaires may have influenced their answers and the EQ-VAS scores. Based on the sample of 131 in total, the number of participants with a diagnosis of MM and CLL was relatively small, and it did not allow for comparison of the QoL amongst the groups. The number of participants with MM and CLL was 15 each. Those with a diagnosis of any type of lymphoma were predominant in this population, which may not be representative of the quality of life assessment of the smaller groups (CLL and MM). The limitation of the EORTC QLQ-C30 questionnaire is that it provides an overview of health-related QoL in general and not a greater understanding of the different aspects of QoL that may affect patients who have completed treatment for a haematological malignancy. As it gathers the subjective experience of the patient about their symptoms and functions, it can be interpreted in various ways; pain may be due to malignant disease or another co-morbid condition. A validated questionnaire that explores in greater detail specific issues pertinent to survivors may have been immensely useful but none was available at the start of the study. Another consideration is the multiple significance tests and that differences have been found by chance.

5 | CONCLUSION

Men and those in employment who have completed treatment for haematological malignancy reported better QoL in this study. Women reported lower physical functioning, more pain and less sleep when compared to men. Age had a significant negative correlation with global QoL, physical and role functioning. These issues need to be addressed when planning long-term survivorship care as it must be tailored to suit individual needs. With the gender differences in QoL identified, different clinical approaches are warranted in male and female survivors. These different approaches may enable healthcare providers to provide tailored treatment modalities to optimise outcomes and improve QoL. In order to provide ongoing support and set up robust systems in the cancer care pathway, it is very important to understand the experiences of these survivors and the possible long-term effects, the malignancy and its treatment entails. Assessment at an early stage will prepare healthcare providers to determine the level of support each patient may require in the survivorship phase. To optimise QoL for these survivors, healthcare services must focus and target on the disease and treatment associated sequelae that may influence a patient in the survivorship phase. Structured survivorship care models can be implemented to further enhance the quality of lives of these survivors. It is evident that patients' needs and concerns may change along their cancer spectrum. It is important to utilise assessment tools that report concerns of survivors and enable conversations with healthcare providers with "care planning," continued communication between primary care physicians and haematologists, access to health and well-being services is recommended as the optimal approach in delivering personalised survivor care. A further validated questionnaire that specifically addresses needs pertinent to survivors of a haematological malignancy is required. These questionnaires will facilitate the capturing of such needs and may enable the development of care models. This study warrants the investigation of a systematic long-term follow-up care model in larger studies.

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