Supportive Care in Cancer (2025) 33:1110
https://doi.org/10.1007/s00520-025-10144-1

RESEARCH

Exploring the link between unmet needs and quality of life in lymphoma survivors: a cross-sectional study

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Received: 25 April 2025 / Accepted: 1 November 2025 / Published online: 21 November 2025

Abstract

Purpose Lymphoma survivors face long-term treatment-related side effects that impact their quality of life (QOL) and needs. Yet, evidence on their specific challenges in the five years following diagnosis remains limited. Existing research has often examined unmet needs and QOL separately or within broader cancer populations, lacking a comprehensive analysis of their interconnections. This study explored the link between lymphoma survivors' unmet needs and quality of life.

Methods A cross-sectional survey study recruited lymphoma survivors from the outpatient haematology-oncology services of five hospitals. The questionnaire comprised validated instruments for unmet needs (Short-Form Survivor Unmet Needs) and QOL (FACT-LYM and EQ 5D-5L). Descriptive statistics, hierarchical multiple regression and canonical correlation analyses were performed to analyse the data.

Results A survey was completed by 205 lymphoma survivors one to five years post-diagnosis. An increase in QOL was significantly associated with decreased unmet needs. Female and younger survivors were more likely to report higher unmet needs. The top two most frequently unmet needs items were 'dealing with feeling tired' (72.5%, $n=145$) and 'coping with having a bad memory or lack of focus' (67.2%, $n=135$).

Conclusion The relationship between unmet needs and QOL among lymphoma survivors is complex, highlighting the need to address specific unmet needs and well-being dimensions to improve longer-term outcomes. This study supports the use of instruments to measure unmet needs, which help to identify survivors who may benefit from clinical attention or enhanced supportive care. The study findings suggest that interventions targeting unmet needs could improve survivors' QOL.

Keywords Cancer survivorship · Lymphoma · Quality of life · Unmet needs

Introduction

Many lymphoma survivors have extended life expectancies but often face treatment-related side effects [1–4], increasing their risk of unmet needs and compromised quality of life. In 2022, there were over 600,000 estimated new lymphoma cases, with 157,000 deaths worldwide [5]. Continuous improvement in long-term survival for Hodgkin lymphoma (HL) has resulted in 5-year survival of around 90% in Western countries; this is lower for non-Hodgkin lymphoma (NHL) at 74% in the United States and 71% in Ireland [6, 7]. Gains in survival have been especially rapid for lymphoma because of improvements in treatment protocols, including the development of targeted therapies [8]. The incidence of NHL increases with age, while HL is more common in younger patients, resulting in significant differences in patient needs and quality of life outcomes [9].

Plain English Summary Lymphoma survivors often deal with long-term side effects from their treatment that impact their quality of life. However, there is not much research on the specific challenges they face, particularly in the first five years after diagnosis, which is a critical time for them. Understanding these challenges can help improve the care and support provided to lymphoma survivors.

This study looks at how unmet needs affect the quality of life of lymphoma survivors. It also explores which factors contribute to these unmet needs and how they influence survivors' well-being.

The findings show that survivors with a better quality of life tend to have fewer unmet needs. Factors such as younger age, or being female were linked to having more unmet needs. The most common unmet needs involved feeling tired and experiencing memory or focus problems. The study suggests that addressing unmet needs, particularly fatigue and cognitive issues, could help improve the quality of life for lymphoma survivors.

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Lymphoma shares challenges with other cancers but also presents unique difficulties due to its systemic impact and heterogeneity. Diagnosis is often complex, with prolonged delays between symptom onset, help-seeking, and referral to secondary care, sometimes leading to emergency admission [10–14]. Unlike cancers with distinct early symptoms, lymphoma often presents with varied, nonspecific symptoms that overlap with common illnesses [15, 16], complicating diagnosis and often resulting in referrals to non-cancer specialities before haematology-oncology [11, 17].

The treatment for lymphoma varies considerably depending on various clinical factors and individual patient factors, such as age, symptom status and performance status [15]. Treatment modalities for lymphoma can require in-patient hospital stays for several weeks and lifelong medical follow-up care [18, 19]. Advances in chemo-immunotherapy have improved outcomes in several lymphoma subtypes; however, the prognosis for many patients with relapsed and refractory disease remains poor [20]. The pathology and the treatment for lymphoma induce several side effects long after therapy for survivors has ended, such as secondary malignancies, infertility, and increased susceptibility to infection [21, 22]. The complications following treatment are variable depending on the type of treatment used. Previously, treating lymphoma was focused on merely achieving survival; now, there is a necessary interest in treatment which is less tolerant of high-risk toxicities.

A clear and consistent definition of unmet needs remains scarce in patient-reported research addressing this topic. An individual is categorised as having unmet needs if they are unable to access quality care when required [23, 24]. Directly assessing an individual's perceived need for help provides insight into required resources, the extent of the need, and those most at risk and vulnerable [25, 26]. Similarly, quality of life (QOL) is often assessed and reported but is rarely accompanied by a definition [27]. QOL is a multidimensional concept that involves an individual's perception of their position in life, which is context-bound to their culture, values, and way of life [28]. The term extends not only to the impact of cancer and its treatment but also to the recognition of the individual living with or beyond the diagnosis.

With the growing number of lymphoma survivors, raising awareness to enhance survivorship care is essential [29]. There is broad recognition that cancer survivorship begins at diagnosis and continues until the end of life, involving the health and well-being of the individual with cancer [30–32]. While survivorship is recognised as a critical and distinct phase of the cancer care continuum [33, 34], this period can encompass different experiences for survivors, which differ by the timing or phase of survivorship [35]. Understanding how a lymphoma diagnosis and its management impact an individual's needs and quality of life at each stage is critical for optimising cancer care [9]. The one-to-five-year period post-diagnosis marks a transition from completing treatment or ongoing maintenance to managing fears of recurrence and striving to resume 'normal' life [35–38]. Although this group has a high five-year survival rate and is increasing in number, there is limited evidence on the unmet needs and quality of life outcomes of lymphoma survivors during the one-to-five-year period post-diagnosis [39].

This study aims to explore the relationship between lymphoma survivors' unmet needs and their quality of life by:

(i) Identifying the unmet needs of lymphoma survivors, including the most frequently endorsed 'high/very high' unmet needs and those reporting none.
(ii) Identifying the factors that influence lymphoma survivors' unmet needs.
(iii) Exploring the link between unmet needs and quality of life with the hypothesis that improved lymphoma survivors' quality of life is associated with a significant decrease in unmet needs.

Method

Study design and participants

This cross-sectional descriptive survey study forms phase one of a larger sequential explanatory mixed methods study. Lymphoma survivors one to five years post-diagnosis were recruited from the outpatient haematology-oncology services from five hospitals across Ireland (two cancer centres and three regional hospitals). Recruitment commenced at the first site in December 2020 and continued until September 2021 at the final site. Six months of recruitment was carried out at each site or until sufficiency was achieved (i.e., no new eligible participants were found). Inclusion criteria included individuals with (i) a lymphoma diagnosis (inclusive of all subtypes but specific to one to five years post-diagnosis), (ii) adults aged 18 years or older, (iii) who received their cancer care in Ireland, and (iv) can speak, read and write in English. Ethical approval was secured from the university (Trinity College Dublin Faculty Research Ethics Committee Ref: 210,605) and hospital ethics committees (Beaumont Hospital Ethics (Medical Research) Committee Ref: 20/89; HSE Northeast Area Research Ethics Committee Ref: 17,821; St James's Hospital/Tallaght University Hospital Joint Research and Ethics Committee Ref: 2021–09 Chairman's Action (05); and Connolly Hospital Research Ethics Committee: CHB004/21).

Patient and public involvement in research was considered valuable for this research. Eight experts with lived experience (lymphoma survivors) or clinical experience of lymphoma (nursing, medicine, pharmacy) reviewed the

questionnaire for clarity, relevance and representativeness of the selected instruments' items to lymphoma. The experts rated the questionnaire as clear (S-CVI/Ave = 0.94 excellent), relevant (S-CVI/Ave = 0.96 excellent) and representative (S-CVI/Ave = 0.94 excellent) [40–42] (Supplementary File 1).

Instruments

A systematic review conducted by the authors guided the selection of valid and reliable instruments suitable for use in this cohort [43]. Relevant sociodemographic characteristics were captured i.e. age, gender, and time since diagnosis. In Ireland, a medical card provides means-tested entitlement to free public health services, including GP visits, hospital care, and prescription medicines (with a small per-item charge). In contrast, private health insurance is purchased independently and provides faster access to consultants and hospital services, in a system where public waiting lists can be lengthy. These distinctions affect both financial burden and access to services and are therefore important contextual factors for interpreting survivors' unmet needs in an international context.

Short-Form Survivor Unmet Needs (SF-SUNS): The 30-item SF-SUNS assesses unmet needs among cancer survivors at a specific time point using four domains: information needs (INF, 3 items), work/financial needs (FIN, 8 items), access/continuity of care needs (ACC, 6 items), and coping/sharing/emotional needs (COP, 13 items). Participants rate their needs on a Likert scale from 0 (no unmet need) to 4 (very high unmet need), with domain scores calculated as the mean of item scores. Derived from the original 89-item SUNS [44], SF-SUNS is validated for survivors one to five years post-diagnosis, including HL and NHL populations [45, 46]. Reliability testing showed strong internal consistency (Cronbach's alpha > 0.85), high intra-class correlations (ICC > 0.9), and mixed test–retest reliability (0.45–0.74). Discriminant validity successfully differentiated groups with varying unmet needs. Cronbach's alphas in this present study were 0.84 for INF, 0.91 for FIN, 0.92 for ACC and 0.95 for COP.

Functional Assessment of Cancer Therapy – Lymphoma (FACT-LYM): The FACT-LYM is a 42-item lymphoma-specific tool for assessing quality of life and symptoms over the past week, using a Likert scale from 0 (not at all) to 4 (very much) [47]. It comprises the FACT-G general component with four subscales: Physical Well-being (PWB, 7 items), Social/Family well-being (SWB, 7 items), Emotional Well-being (EWB, 6 items), and Functional Well-being (FWB, 7 items), along with a lymphoma-specific subscale (LYM, 15 items). Developed with input from NHL participants ($n = 84$), expert interviews, and a literature review, the tool demonstrates strong internal consistency ($\alpha > 0.70$) and validity. Cronbach's alphas in this present study were 0.81 for PWB, 0.82 for SWB. 0.75 for EWB, 0.89 for FWB, and 0.86 for LYM.

EuroQol Five Dimension Five Level (EQ-5D-5L): The EQ-5D-5L is an instrument for describing and valuing health, featuring a visual analogue scale (VAS) ranging from 0 (worst imaginable health) to 100 (best imaginable health) and a descriptive system with five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression [48, 49]. Psychometric testing shows strong reliability (ICC = > 0.7), face and content validity, and significant convergent validity with other instruments. Designed for self-administration and brevity, it complements measures like FACT-LYM and SF-SUNS for cancer-related outcomes.

Study procedure

Patients meeting the study inclusion criteria were approached by a gatekeeper and invited to participate. Participants provided informed consent. A supplementary online recruitment was used to maximise the study's reach for potential participants. Social media platforms (Facebook, X, and Instagram) were targeted with study posters and descriptive text to reach a broad age range of lymphoma survivors. Thirty-two cancer support groups in Ireland also promoted the study via newsletters and social media, enhancing awareness among potential participants. To accommodate the diverse age range of lymphoma survivors, paper and electronic survey formats were offered based on participant preference. Paper surveys were returned via prepaid envelopes, while online surveys were accessed through a survey link or QR code.

Data analysis

Survey data was collected in Qualtrics and imported into SPSS v27.0 for analysis. Descriptive statistical analysis involved subscale and total scores that were calculated for responses to the SF-SUNS, FACT-LYM and EQ-5D-5L, following manual scoring templates provided by the corresponding authors for each standardised instrument. In addition, the authors of the FACT-LYM provided a syntax for use in SPSS. Descriptive statistics, such as percentages, means or medians, ranges, and standard deviations were used to summarise and describe the dataset. This process identified patterns and relationships for subsequent inferential statistical analysis.

Hierarchical multiple regression (HMR) was used to assess whether adding specific blocks of variables increased

the model's ability to explain unmet needs [50]. Variables were introduced sequentially in blocks, allowing for the evaluation of each block's unique contribution while controlling for others [51]. Three exploratory hierarchical multiple regression analyses were conducted to describe the relative contribution of patient demographics, clinical factors, and QOL attributes as assessed by patient responses measured by the SF-SUNS, FACT-LYM and EQ-5D-5L VAS. This approach provides a systematic understanding of factors influencing unmet needs in lymphoma survivors. Independent variables were selected and entered in blocks based on prior research, the aims of this research, and adjusted R^2 values. The four subscales of unmet needs (SF-SUNS, i.e., INF, FIN, ACC, COP), the five quality of life subscales (FACT-LYM, i.e., PWB, SWB, EWB, FWB, LYMS), the VAS of the EQ-5D-5L, sociodemographic and clinical characteristics formed the variables of interest in evaluating the explanatory factors influencing lymphoma survivors' unmet needs. Therefore, participant sociodemographic details were entered in the first step (model one); clinical characteristics were added for the second step (model two); and quality of life attributes were entered in step three (model three) after centring on offsetting possible multicollinear effects. The hierarchical multiple regression analysis assumptions were fulfilled by inspecting scatterplots, p-p plots and correlation tables to ensure normality, linearity, multicollinearity (no tolerance values were greater than 0.7), and homoscedasticity was not violated.

Canonical correlation analysis (CCA) examines the relationships between multiple dependent and independent variables, expanding on the HMR, which focuses on a single dependent variable [52–54]. The number of canonical functions equals the number of variables in the smaller set [55]; for this study, the unmet needs variate is the smaller set with four variables (CV1, CV2, CV3 and CV4). The FACT-LYM scale (using variables PWB, SWB, EWB, FWB and LYMS) measures the QOL variate, and the SF-SUNS scale (using variates INF, FIN, ACC, and COP) measures the Unmet Needs variate (Fig. 1). The canonical correlation (Rc) can be viewed as a measure of the overall strength of association between two sets of variables, with the squared value (Rc^2) indicating the proportion of variance they share. For example, Rc of 0.50 corresponds to Rc^2 of 0.25, meaning that 25% of the variance is shared between the two sets. Canonical loadings highlight which specific variables drive this association, offering insight into the most clinically relevant relationships. Assumptions of linearity and homoscedasticity were evaluated using scatter plots. Normality was checked for each subscale variable using p-p plots. Multicollinearity was assessed using the Variance Inflation Factor (VIF); a cut-off of 0.45 was used to identify meaningful coefficient correlations or loadings [54].

Results

Sociodemographic characteristics

A total of 205 lymphoma survivors participated in this study. Participants' sociodemographic and clinical information are detailed in Table 1. Gender distribution was almost equal, with 51% female participants. The age range of participants was 19–88 years. Participants resided across Ireland (urban 67.3%, $n = 136$ and rural 32.7%, $n = 66$). One hundred and forty-four participants (71.3%) had a diagnosis of non-Hodgkin lymphoma (NHL), and fifty-one (25.2%) had Hodgkin

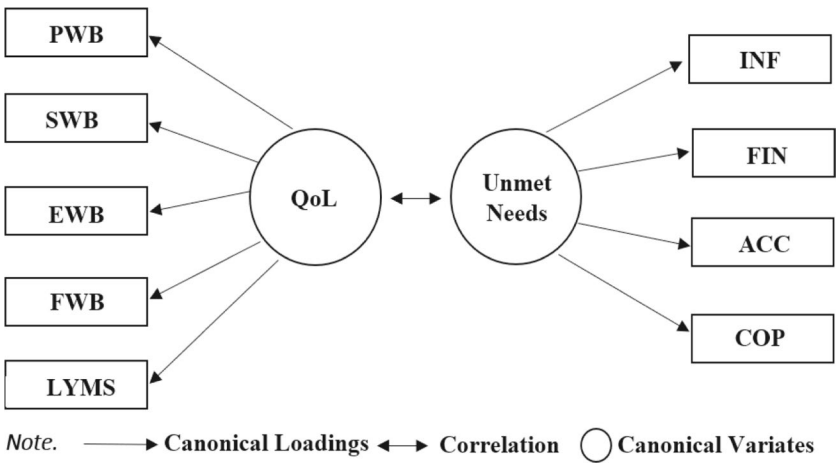

Fig. 1 Conceptual Model of Proposed Canonical Correlation Analysis of the Relationship Between Unmet Needs and Quality of Life

Table 1 Sociodemographic Characteristics of the Sample by Lymphoma Subtype

	HL $n=51$	NHL $n=144$	Total $N=195$
Age, mean (*SD*)			
	41.7 (18.8)	57.5 (15.6)	53.7 (17.9)
Age categories %			
18–39	56.0	15.8	26.5
40–69	30.0	58.3	50.8
70 or older	14.0	25.9	22.8
Gender %			
Female	51.0	50.0	50.3
Male	49.0	50.0	49.7
Residence %			
Rural	25.5	36.1	33.3
Urban	74.5	63.9	66.7
Living status %			
Living with others	84.3	77.8	79.5
Living alone	15.7	22.2	20.5
Ethnicity %			
Irish	80.4	92.4	89.2
Other	19.6	7.6	10.8
Employment status %			
Full-time/Part-time	60.8	52.8	54.9
Retired/Homemaker	17.6	42.4	35.9
Student	13.7	2.1	5.1
Unemployed	7.8	2.8	4.1
Employment hours %			
Working less hours than before	26.7	35.5	33.0
Working usual hours	63.3	53.9	56.6
Working more hours than before	10.0	3.9	5.7
Not working	0.0	6.6	4.7
Time since diagnosis %			
1 to 3 years	51.0	60.4	57.9
3 to 5 years	49.0	39.6	42.1
Sites %			
Cancer centre	65.2	57.4	59.4
Regional	34.8	42.6	40.6
Medical card %			
	51.0	43.4	45.4
Private health insurance %			
	49.0	58.7	56.2
Chemotherapy	92.2	91.7	91.8
Immunotherapy	11.8	35.4	29.2
Radiotherapy	45.1	20.1	26.7
Surgery	29.4	15.4	19.1
Other cellular therapy	2.0	0.0	0.5
Stem Cell Transplant	5.9	3.5	4.1
Arthritis	11.8	18.1	16.4
Respiratory conditions	5.9	4.9	5.1
Diabetes	0.0	4.2	3.1
Epilepsy	0.0	2.1	1.5
Kidney disease	2.0	3.5	3.1
Liver disease	0.0	2.1	1.5
Cardiac conditions	9.8	29.9	24.6
Hearing or visual impairments	5.9	10.4	9.2
Other chronic conditions	17.6	23.6	22.1
Cognitive conditions	3.9	2.8	3.1
None of these conditions	58.8	38.9	44.1

Key: HL = Hodgkin lymphoma; NHL = non-Hodgkin lymphoma

lymphoma (HL). Fifty-one per cent of participants were one to three years post-diagnosis and forty-nine per cent were three to five years post-diagnosis.

Unmet needs

The top two most frequently unmet needs items reported by lymphoma survivors were 'dealing with feeling tired' (72.5%, $n=145$) and 'coping with having a bad memory or lack of focus' (67.2%, $n=135$). By consolidating the participants' responses for "high unmet needs" and "very high unmet needs," a comprehensive understanding of unmet needs categorised by higher levels of severity can be provided. The most frequently endorsed 'high/very high' unmet need for the sample ($N=202$) was 'coping with having a bad memory or lack of focus' (21.4%, $n=43$) (Supplementary File 2). The following most endorsed items involved dealing with: 'feeling tired' (19.0%, $n=38$), 'people who expect me to be 'back to normal' (17.9%, $n=36$), 'changes in how my body appears' (16.9%, $n=34$), 'feeling stressed' (16.4%, $n=33$) and 'paying household bills or other payments' (16.0%, $n=32$).

There were few significant sociodemographic or clinical differences between the subgroups, HL and NHL (Supplementary File 3). HL survivors were more likely to report 'dealing with not being able to feel normal' compared to NHL survivors ($z=4.03$, $p<0.001$). Similarly, HL survivors were more likely to have higher unmet needs for 'having access to cancer services close to my home' ($z=2.60$, $p=0.009$), 'dealing with feeling lonely' ($z=3.20$, $p=0.001$) and 'dealing with people who expect me to be back to normal' ($z=2.04$, $p=0.04$) compared with NHL survivors. Thirteen per cent of the sample reported 'no unmet needs' across all thirty items ($n=26$). The mean age for these participants was 58.2 years (range 38–88 years). Almost ninety per cent of those participants

Table 2 The Hierarchical Regression Models for Unmet Information Needs (INF)

Unmet Information Needs (INF)	Model 1		Model 2		Model 3	
	β	*p*	**β**	*p*	**β**	*p*
Gender						
Female	-	-	-	-	-	-
Male	−0.210	0.008**	−0.183	0.016*	−0.132	0.047*
Age						
18—39 years	-	-	-	-	-	-
40—69 years	−0.124	0.202	−0.062	0.550	0.035	0.691
70 + years	−0.289	0.022*	−0.217	0.107	−0.075	0.506
Residence						
Rural	-	-	-	-	-	-
Urban	0.019	0.797	0.017	0.822	0.008	0.900
Employment status						
Full-time/Part-time	-	-	-	-	-	-
Retired/Homemaker	0.160	0.130	0.244	0.024*	0.185	0.040*
Student	−0.121	0.142	−0.116	0.155	−0.093	0.177
Unemployed	−0.017	0.823	0.009	0.902	−0.097	0.139
Medical Card						
No	-	-	-	-	-	-
Yes	0.113	0.184	−0.110	0.192	−0.048	0.502
Private Health Insurance						
No	-	-	-	-	-	-
Yes	−0.208	0.013*	−0.215	0.010*	−0.109	0.125
Lymphoma Type						
Hodgkin Lymphoma			-	-	-	-
Non-Hodgkin Lymphoma			−0.086	0.310	−0.107	0.132
Time Since Diagnosis						
1 to 3 years			-	-	-	-
3 to 5 years			−0.178	0.021*	−0.138	0.036*
Site						
Regional Hospital			-	-	-	-
Cancer Centre			0.078	0.290	−0.002	0.972
Chemotherapy						
No			-	-	-	-
Yes			−0.062	0.393	−0.060	0.330
Immunotherapy						
No			-	-	-	-
Yes			−0.001	0.989	−0.046	0.476
Radiotherapy						
No			-	-	-	-
Yes			−0.005	0.952	0.020	0.755
Surgery						
No			-	-	-	-
Yes			−0.183	0.015*	−0.154	0.014*
No Conditions						
No			-	-	-	-
Yes			0.097	0.271	0.128	0.084
Quality of Life Subscales						
PWB			0.254	0.009*	0.209	0.034*
SWB			−0.011	0.882	0.004	0.957
EWB			−0.248	0.006*	−0.319	0.001*

Table 2 (continued)

Unmet Information Needs (INF)	Model 1		Model 2		Model 3	
	β	*p*	**β**	*p*	**β**	*p*
FWB			−0.223	0.038*	−0.197	0.070
LYMS			−0.192	0.095	−0.198	0.080
VAS			−0.182	0.048*	−0.140	0.125
	Model 1		Model 2		Model 3	
R^2	0.119		0.212		0.479	
Adjusted R^2	0.073		0.119		0.395	
ΔR^2	0.119		0.093		0.267	
ΔF	2.578*		1.911*		13.297*	

*significant, $p < 0.05$

**highly significant, $p < 0.001$

β = Standardised coefficient (reference level). PWB = Physical Well-being; SWB = Social/Family Well-being; EWB = Emotional Wellbeing; FWB = Functional Well-being; LYMS = Lymphoma-specific; VAS = Visual Analogue Scale

reporting no unmet needs across all items had a diagnosis of NHL (88.5%, $n = 23$), and a large portion were male (65.4%, $n = 17$) or lived in an urban setting (61.5%, $n = 16$).The mean subscale scores for the SFSUNS were 0.79 ($SD = 0.88$) for INF, 0.85 ($SD = 0.92$) for FIN, 0.67 ($SD = 0.86$) for ACC and 1.07 ($SD = 0.93$) for COP.

Explanatory factors influencing survivors' unmet needs

The hierarchical multiple regression identified several factors which influence lymphoma survivors' unmet needs.

Unmet Information Needs: Being female, not having private health insurance, having a recent lymphoma diagnosis (1–3 years post-diagnosis), being retired or a homemaker and having better physical well-being influenced unmet information needs (Table 2). The variable that contributes most to an increase in unmet information needs was physical well-being (PWB) with a beta coefficient of 0.254 and a *p*-value of 0.009. In other words, PWB has the most decisive influence on the extent to which individuals experience unmet information needs. Interestingly, an increase in EWB, FWB and VAS scores led to a significant reduction in unmet information needs ($\beta = -0.248$, $p = 0.006$, $\beta = -0.233$, $p = 0.038$, $\beta = -0.182$, $p = 0.048$), respectively, after adjusting for sociodemographic and clinical characteristics.

Unmet Financial and Work Needs: Being female, not having private health insurance, being younger, and being in employment (full-time or part-time) were all factors that contributed to higher unmet financial and work needs (Table 3). Participants with better functional well-being or fewer lymphoma-specific concerns were associated with lower unmet financial and work needs. An increase in the lymphoma-specific (LYMS) variable scores made the most significant contribution ($\beta = -0.377$, $p < 0.001$) to a decrease in unmet work and financial needs, followed by an increase in FWB scores ($\beta = -0.251$, $p = 0.012$), after adjusting for sociodemographic and clinical characteristics.

Unmet Access and Continuity of Care Needs: Participants who had surgery, a hearing or visual impairment, a diagnosis of non-Hodgkin lymphoma or better emotional well-being were associated with lower unmet access and continuity of care needs (Table 4). An increase in EWB made the most significant contribution ($\beta = -0.352$, $p < 0.001$) to decreased unmet needs for access and continuity of care after adjusting for sociodemographic and clinical characteristics.

Unmet Coping, Sharing and Emotional Needs: Higher unmet coping, sharing and emotional needs were found in female participants, younger participants, those without private health insurance or those with one or more conditions (Table 5). Better social well-being ($\beta = -0.148$, $p < 0.001$), emotional well-being ($\beta = -0.335$, $p < 0.001$), or fewer lymphoma-specific problems ($\beta = -0.363$, $p < 0.001$) were associated with lower unmet coping, sharing and emotional needs.

Relationship between unmet needs and quality of life

The canonical correlation analysis identified which specific QOL characteristics were significantly associated with attributes of unmet needs. The CCA supports the hypothesis of a significant association between QOL and patients'

Table 3 The Hierarchical Regression Models for Unmet Work and Financial Needs (FIN)

Unmet Work and Financial Needs (FIN)	Model 1		Model 2		Model 3	
	β	***p***	**β**	***p***	**β**	***p***
Gender						
Female	-	-	-	-	-	-
Male	−0.157	0.033*	−0.120	0.113	0.013	0.825
Age						
18—39 years	-	-	-	-	-	-
40—69 years	−0.130	0.169	−0.166	0.113	−0.106	0.198
70 + years	−0.299	0.016*	−0.281	0.038*	−0.187	0.076
Residence						
Rural	-	-	-	-	-	-
Urban	0.005	0.947	0.028	0.710	0.026	0.656
Employment status						
Full-time/Part-time	-	-	-	-	-	-
Retired/Homemaker	−0.029	0.776	−0.033	0.761	−0.076	0.359
Student	−0.115	0.152	−0.138	0.091	−0.141	0.029*
Unemployed	0.138	0.064	0.131	0.088	−0.007	0.908
Medical Card						
No	-	-	-	-	-	-
Yes	−0.125	0.133	−0.120	0.157	−0.077	0.246
Private Health Insurance						
No	-	-	-	-	-	-
Yes	−0.166	0.042*	−0.179	0.032*	−0.042	0.528
Lymphoma Type						
Hodgkin Lymphoma			-	-	-	-
Non-Hodgkin Lymphoma			−0.032	0.710	−0.052	0.434
Time Since Diagnosis						
1 to 3 years			-	-	-	-
3 to 5 years			−0.081	0.282	−0.005	0.935
Site						
Regional Hospital			-	-	-	-
Cancer Centre			0.101	0.171	−0.033	0.581
Chemotherapy						
No			-	-	-	-
Yes			−0.102	0.158	−0.104	0.071
Immunotherapy						
No			-	-	-	-
Yes			0.090	0.237	0.025	0.671
Radiotherapy						
No			-	-	-	-
Yes			−0.102	0.191	−0.060	0.326
Surgery						
No			-	-	-	-
Yes			−0.005	0.943	0.032	0.581
No Conditions						
No			-	-	-	-
Yes			−0.092	0.293	−0.029	0.670
Quality of Life Subscales						
PWB			−0.061	0.495	−0.051	0.581
SWB			0.127	0.073	0.113	0.114
EWB			−0.091	0.275	−0.067	0.445

Table 3 (continued)

Unmet Work and Financial Needs (FIN)	Model 1		Model 2		Model 3	
	β	***p***	**β**	***p***	**β**	***p***
FWB			−0.251	0.012*	−0.234	0.024*
LYMS			−0.377	< 0.001*	−0.370	0.001*
VAS			−0.036	0.670	−0.049	0.573
	Model 1		Model 2		Model 3	
R^2	0.159		0.212		0.550	
Adjusted R^2	0.115		0.119		0.478	
ΔR^2	0.159		0.053		0.339	
ΔF	3.605*		1.086		19.571*	

Key: ***significant, $p < 0.05$**. β = Standardised coefficient (reference level). PWB = Physical Well-being; SWB = Social/Family Well-being; EWB = Emotional Well-being; FWB = Functional Well-being; LYMS = Lymphoma-specific; VAS = Visual Analogue Scale

unmet needs. Table 6 shows descriptive statistics for the SF-SUNS and FACT-LYM scales used for this sample.

CCA resulted in four canonical functions with squared correlations R_c^2 of 0.587, 0.159, 0.060 and 0.022. Two of the four canonical functions (CV1 and CV2) are significant, and these measures of the overall model fit with correlations shown in Table 7. The relationship between QOL and unmet needs variates was statistically significant, using Wilk's $\lambda = 0.320$, $F(20, 627.79) = 12.873$, $p < 0.001$. Functions 2 to 4 and 3 to 4 were also statistically significant, $F(12, 502.98) = 4.275$, $p < 0.001$ and $F(6, 382.00) = 2.718$, $p = 0.013$, respectively. Function 4 was not statistically significant. The four functions yielded a full model effect size of $1 - \lambda = 0.68$, indicating that the full model explained about 68% of the variance shared by the two variates.

The R_c^2 effects for each variate indicate that only the first two functions (CV1 and CV2) should be considered, showing that approximately 58.7% (CV1) and 15.9% (CV2) of the variance is shared between the combined set of quality of life variables and unmet needs variables. This represents a moderate to large effect size, suggesting a meaningful relationship between the two sets of variables. The other two functions (CV3 and CV4) contributed only 6% and 2.2% shared variance and were not considered for further analysis. The first relationship, canonical variate CV1 ($p < 0.001$), indicated that participants with an increased QoL across all the variables (except (SWB) were more likely to experience significantly lower unmet needs across all outcome variables with unmet work and financial needs (FIN) and unmet coping, sharing and emotional needs (COP) being particularly strong, followed by ACC. The second relationship, CV2 ($p < 0.001$), revealed that none of the variables exceeded the significant threshold of 0.45 (Table 8).

The findings indicate that patients with lymphoma who maintain better emotional health and achieve effective symptom control report fewer financial, occupational, and psychosocial difficulties. The first significant canonical variate demonstrated that those participants with increased scores in LYMS (0.615) and EWB (0.369) were significantly associated with lower unmet work and financial needs (FIN) (−0.380) and lower unmet coping, sharing and emotional needs (COP) (−0.649). However, both PWB (−0.014) and SWB (0.022) had a reduced impact across all the unmet needs variables. The second significant canonical variate showed a large decrease in the FWB score (−1.375), resulting in a significant increase in unmet work and financial needs (FIN) (0.971), but a large significant reduction in unmet coping, sharing and emotional needs (COP) (−0.953).

Discussion

This study enhances understanding of the relationship between unmet needs and quality of life among lymphoma survivors. An increase in the quality of life of lymphoma survivors is associated with a statistically significant decrease in unmet needs. Physical, emotional, functional, and lymphoma-specific concerns were each related to unmet needs, underscoring the importance of comprehensive survivorship care. Routine screening of quality of life and unmet needs can help guide the provision of timely psychosocial, informational, and practical support.

The results of the hierarchical multiple regression analyses provide clinically relevant insights. Survivors with better physical well-being nonetheless reported higher unmet information needs, indicating that physical recovery does not equate to informational satisfaction. Structured survivorship

Table 4 The Hierarchical Regression Models for Unmet Access and Continuity of Care Needs (ACC)

Unmet Access and Continuity of Care Needs (ACC)	Model 1		Model 2		Model 3	
	β	*p*	β	*p*	β	*p*
Gender						
Female	-	-	-	-	-	-
Male	−0.086	0.274	−0.027	0.743	0.035	0.647
Age						
18—39 years	-	-	-	-	-	-
40—69 years	−0.054	0.591	−0.013	0.908	0.044	0.667
70 + years	−0.225	0.088	−0.132	0.352	−0.064	0.624
Residence						
Rural	-	-	-	-	-	-
Urban	−0.034	0.651	−0.056	0.475	−0.052	0.468
Employment status						
Full-time/Part-time	-	-	-	-	-	-
Retired/Homemaker	0.119	0.283	0.169	0.134	0.131	0.208
Student	−0.036	0.677	−0.074	0.388	−0.064	0.420
Unemployed	0.003	0.971	0.008	0.918	−0.084	0.267
Medical Card						
No	-	-	-	-	-	-
Yes	−0.033	0.715	−0.057	0.520	−0.050	0.549
Private Health Insurance						
No	-	-	-	-	-	-
Yes	−0.085	0.331	−0.105	0.230	−0.017	0.833
Lymphoma Type						
Hodgkin Lymphoma			-	-	-	-
Non-Hodgkin Lymphoma			−0.174	0.053	−0.165	0.045*
Time Since Diagnosis						
1 to 3 years			-	-	-	-
3 to 5 years			−0.043	0.590	0.025	0.741
Site						
Regional Hospital			-	-	-	-
Cancer Centre			0.051	0.509	−0.033	0.653
Chemotherapy						
No			-	-	-	-
Yes			−0.133	0.080	−0.110	0.126
Immunotherapy						
No			-	-	-	-
Yes			0.012	0.879	0.003	0.964
Radiotherapy						
No			-	-	-	-
Yes			−0.067	0.411	−0.055	0.463
Surgery						
No			-	-	-	-
Yes			−0.163	0.038*	−0.121	0.092
No Conditions						
No			-	-	-	-
Yes			−0.066	0.478	0.003	0.976
Quality of Life Subscales						
PWB			−0.086	0.442	−0.129	0.253
SWB			0.006	0.949	0.031	0.717
EWB			−0.352	0.001*	−0.436	< 0.001*

Table 4 (continued)

Unmet Access and Continuity of Care Needs (ACC)	Model 1		Model 2		Model 3	
	β	*p*	β	*p*	β	*p*
FWB			0.013	0.916	0.007	0.952
LYMS			−0.082	0.532	−0.092	0.478
VAS			−0.008	0.941	0.044	0.675
	Model 1		Model 2		Model 3	
R^2	0.036		0.128		0.303	
Adjusted R^2	0.015		0.026		0.192	
ΔR^2	0.036		0.092		0.175	
ΔF	0.709		1.718		6.542*	

Key: ***significant, $p < 0.05$**.. β = Standardised coefficient (reference level). PWB = Physical Well-being; SWB = Social/Family Well-being; EWB = Emotional Well-being; FWB = Functional Well-being; LYMS = Lymphoma-specific; VAS = Visual Analogue Scale

education and tailored information provision remain essential, particularly within the first three years post-diagnosis. Lymphoma-specific concerns were strongly associated with financial/work needs, suggesting that addressing disease-specific worries through specialist nurses, social workers, or survivorship programs may help mitigate broader vocational and financial challenges. These results underscore the importance of proactive, multidisciplinary care, particularly for younger survivors and those in active employment.

Cancer-related fatigue and impaired cognitive functioning were reaffirmed as the most burdensome symptoms for lymphoma survivors [56–59]. Notably, unmet information needs are the most prevalent domain among myeloma patients (mean = 1.43) [59], whereas lymphoma survivors report a lower mean of 0.79. This suggests that lymphoma survivors have different unmet needs than other cancers, including haematological cancers. The persistent fatigue and cognition issues for lymphoma survivors mirror earlier research and highlight the value of targeted supportive interventions such as fatigue management programs (including tailored exercise, symptom management, rehabilitation, and psychoeducation) and cognitive rehabilitation approaches (e.g., memory training and attention exercises) [60–62]. Embedding such interventions into survivorship pathways would directly address some of the most frequently reported concerns in this cohort.

When compared internationally, our results align with studies from Western contexts such as Australia, the US, France, and the UK, where unmet emotional and financial/work needs consistently emerge as predominant challenges for cancer survivors [39, 63, 64]. Quality of life has also been shown to be influenced by female gender, younger age, psychological distress, and a more recent diagnosis [65, 66], while minimal differences in unmet needs were reported across Western European countries for mixed haematological survivors [67]. Although the patterns of unmet needs are broadly consistent across Western settings, the underlying drivers differ, being shaped more by healthcare financing in the US and by access to coordinated survivorship care or cultural expectations of support in European contexts. In contrast, research from Eastern countries, such as Singapore, South Korea, and Thailand, reports greater emphasis on existential and social functioning, with family roles and access to comprehensive care being more central [58, 68–70]. These differences reflect variations in healthcare systems, cultural norms, and social support structures. Collectively, this evidence underscores that while unmet needs are universal, their domains of priority differ across regions, reinforcing the importance of culturally and systemically tailored survivorship care.

Our findings are also consistent with prior SUNS and SFSUNS research, in which emotional and financial/work needs were the most frequently reported domains [56, 57, 71]. Being female, younger, and having a more recent diagnosis were key predictors of higher unmet needs, echoing evidence across haematological cancer populations [69, 72]. Previous evidence shows that higher distress, depression, poorer coping and younger age are independent factors associated with higher unmet needs for indolent haematology patients during watch-and-wait [73]. These findings indicate that the first five years after diagnosis represent a critical juncture for survivorship support, with some studies suggesting that high unmet needs may persist for a decade or more [70].

A strength of this study lies in its use of validated, lymphoma-specific instruments specifically suited for one to five years post-diagnosis. By selecting measures with strong psychometric properties, the study ensured an accurate and meaningful assessment of unmet needs and quality of life. This study offers a comprehensive statistical examination of quality of life outcomes and unmet needs, considering their interrelated nature rather than treating them as separate constructs. Offering both paper and electronic formats enhanced feasibility, reduced burden, and improved response

Table 5 The Hierarchical Regression Models for Unmet Coping, Sharing and Emotional Needs (COP)

Unmet Coping, Sharing and Emotional Needs (COP)	Model 1		Model 2		Model 3	
	β	*p*	β	*p*	β	*p*
Gender						
Female	-	-	-	-	-	-
Male	–.185	.014*	–.174	.025*	-.047	.397
Age						
18 – 39 years	-	-	-	-	-	-
40 – 69 years	–.126	.193	–.118	.267	–.057	.448
70+ years	–.281	.026*	–.275	.046*	–.164	.088
Residence						
Rural	-	-	-	-	-	-
Urban	.028	.699	.060	.427	.081	.123
Employment status						
Full-time/Part-time	-	-	-	-	-	-
Retired/Homemaker	.079	.455	.060	.581	–.004	.956
Student	–.027	.740	–.046	.578	–.082	.159
Unemployed	.128	.091	.097	.215	–.060	.273
Medical Card						
No	-	-	-	-	-	-
Yes	–.039	.647	–.037	.666	.013	.827
Private Health Insurance						
No	-	-	-	-	-	-
Yes	–.184	.027*	–.171	.044*	.009	.878
Lymphoma Type						
Hodgkin Lymphoma			-	-	-	-
Non-Hodgkin Lymphoma			–.111	.200	–.090	.136
Time Since Diagnosis						
1 to 3 years			-	-	-	-
3 to 5 years			–.098	.209	–.027	.618
Site						
Regional Hospital			-	-	-	-
Cancer Centre			.135	.073	–.047	.383
Chemotherapy						
No			-	-	-	-
Yes			.004	.959	.063	.233
Immunotherapy						
No			-	-	-	-
Yes			–.009	.903	–.038	.484
Radiotherapy						
No			-	-	-	-
Yes			–.016	.838	.004	.942
Surgery						
No			-	-	-	-
Yes			–.020	.795	.055	.299
No Conditions						
No			-	-	-	-
Yes			–.183	.043*	-.078	.214
Quality of Life Subscales						
PWB			–.115	.160	–.123	.146
SWB			–.148	.022*	–.140	.033*
EWB			–.335	.000*	–.348	.000*

Table 5 (Continued)

Unmet Coping, Sharing and Emotional Needs (COP)	Model 1		Model 2		Model 3	
	β	*p*	β	*p*	β	*p*
FWB			–.050	.583	–.056	.552
LYMS			–.363	.000*	–.367	.000*
VAS			.131	.090	.137	.084
	Model 1		Model 2		Model 3	
R^2	.123		.178		.627	
Adjusted R^2	.077		.082		.567	
ΔR^2	.056		.056		.449	
ΔF	**2.671***		1.095		31.316*	

*significant, $p < .05$. β Standardised coefficient (reference level). *PWB* Physical Well-being; *SWB* Social/Family Well-being; *EWB* Emotional Well-being; *FWB* Functional Well-being; *LYMS* Lymphoma-specific; *VAS* Visual Analogue Scale

Table 6 Descriptive Statistics for Quality of Life (FACT-LYM) and Unmet Needs (SFSUNS) Subscales

Subscales	*N*	Score Range	Mean	*SD*
Quality of Life				
Physical Well-being (PWB)	205	0–28	22.5	4.5
Social Well-being (SWB)	205	0–28	21.8	5.3
Emotional Well-being (EWB)	202	0–24	18.2	4.4
Functional Well-being (FWB)	204	0–28	19.4	6.3
Lymphoma-Specific Subscale (LYMS)	205	0–60	41.0	10.0
Unmet Needs				
Unmet Information Needs (INF)	202	0–12	2.4	7.4
Unmet Financial and Work Needs (FIN)	201	0–32	6.8	7.4
Unmet Needs for Access and Continuity of Care (ACC)	201	0–24	4.0	5.1
Unmet Coping, Sharing and Emotional Needs (COP)	201	0–52	13.9	12.1

Table 7 Measures of Overall Model Fit for Canonical Correlation Analysis for the Hypothesis of Interest

Canonical Function	Canonical Correlation (Rc)	Canonical (Rc^2)	Wilk's	*F* Statistic	*p*
1	0.766	0.587	0.320	12.873	**< 0.001***
2	0.399	0.159	0.773	4.275	**< 0.001***

Key: *$p < 0.05$

rates. This study was conducted at five hospital sites across Ireland, supplemented by relevant cancer networks, which enhances the generalisability of study findings.

Limitations

The self-report design limits the addition of further clinical details of participants; for example, differences in treatment regimens could not be explored within this current study. However, previous evidence found no differences in chemotherapy regimens on quality of life among HL and NHL survivors [74]. Chemotherapy and immunotherapy are the primary treatments for lymphoma, and previous reviews have confirmed their links to reduced quality of life and unmet patient needs [39, 74]. However, the therapeutic landscape is constantly changing. The study's timeline did not allow for the recruitment of patients receiving chimeric antigen receptor (CAR) T-cell therapy, as this is newly available in Ireland. A recent qualitative paper was the first to report on how patients (including lymphoma survivors, $N = 14$) experience this novel treatment, aptly referred to as 'the last bridge'; the findings show that the patient experience of CAR-T therapy differs from those of other cancer patients [75]. To advance the development of survivorship services for lymphoma survivors and address the heterogeneity among them, insights into novel treatment experiences require investigation. Interventions to enhance quality of life and reduce unmet needs are necessary to advance lymphoma survivorship, particularly in targeting tiredness and cognitive impairment.

Table 8 Canonical correlations and standardised variate coefficients for the first and second canonical variates

Subscales	CV1		CV2	
	COR	COE	COR	COE
Quality of Life				
Physical Well-being (PWB)	**0.728***	−0.014	0.184	0.702
Social Well-being (SWB)	**0.4**18	0.022	0.218	0.774
Emotional Well-being (EWB)	**0.874***	0.369	0.178	0.608
Functional Well-being (FWB)	**0.720***	0.126	−0.426	−1.375
Lymphoma-Specific Subscale (LYMS)	**0.955***	0.615	−0.023	−0.393
Unmet Needs				
Unmet Information Needs (INF)	**−0.687***	−0.160	0.279	0.690
Unmet Financial and Work Needs (FIN)	**−0.837***	−0.380	0.386	0.971
Unmet Needs for Access and Continuity of Care (ACC)	**−0.558***	0.068	−0.189	−0.702
Unmet Coping, Sharing and Emotional Needs (COP)	**−0.939***	−0.649	−0.315	−0.953

Key: ***Significant correlations ≥ 0.45**; COR = canonical loadings; COE = standardised canonical loadings variate coefficient; CV1 = canonical variate 1; CV2 = canonical variate 2

Conclusion

This study examined the relationship between the unmet needs of lymphoma survivors and their quality of life, addressing a key gap in survivorship research. Unmet emotional and financial/work needs were the most frequently endorsed. Younger age, female gender, and a more recent diagnosis were significant explanatory factors associated with higher unmet needs. A higher quality of life was consistently associated with fewer unmet needs, particularly in terms of functional, emotional, and social well-being, as well as lymphoma-specific concerns, which were closely linked to multiple unmet need domains. These findings identify clear priorities for survivorship care: structured information provision, financial and vocational counselling for younger survivors and those in employment, and targeted programs to address lymphoma-specific concerns. Embedding fatigue management and cognitive support interventions into routine care could provide immediate, practical benefits. Together, these results offer clinicians a roadmap for prioritising interventions based on patient-reported outcomes. Looking ahead, as novel therapies such as CAR-T become more widely available, further research should examine their impact on survivors' unmet needs and long-term quality of life. This study contributes to the global evidence base by providing the largest investigation of unmet needs among Irish lymphoma survivors, offering insights to inform cross-cultural survivorship care.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s00520-025-10144-1.

Acknowledgements Statistical guidance provided by Dr. Joshua Tobin is gratefully acknowledged.

Author contributions V.B., A.D., and A.M.B. contributed to the conception and design of the work. V.B. wrote the main manuscript. V.B. and M.O.D. prepared Tables 1–8 and Fig. 1. All authors critically reviewed the drafts and the final version of the manuscript.

Funding This work was supported by the School of Nursing and Midwifery, Trinity College Dublin, PhD Scholarship, awarded to Vanessa Boland.

Data availability No datasets were generated or analysed during the current study.

Declarations

Ethical approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committees of five hospitals (Beaumont Hospital Ethics (Medical Research) Committee Ref: 20/89; HSE Northeast Area Research Ethics Committee Ref: 17821; St James's Hospital/Tallaght University Hospital Joint Research and Ethics Committee Ref: 2021–09 Chairman's Action (05); and Connolly Hospital Research Ethics Committee: CHB004/21) and one university (Trinity College Dublin Faculty Research Ethics Committee Ref: 210605).

Consent to participate Informed consent was obtained from all individual participants included in the study.

Competing interests The authors declare no competing interests.

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