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RESEARCH ARTICLE

Quality of Life, Mental Health, and Cancer Care Experiences Among Lymphoma Survivors During the COVID-19 Pandemic: A Cross-Sectional Indonesian Study

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Abstract

Introduction: Lymphoma accounts for a significant share of hematologic cancers globally, including in Indonesia, where the incidence of non-Hodgkin lymphoma (NHL) has been steadily increasing over time. This study seeks to fill existing gaps by exploring lymphoma survivors' lifestyles, perceptions of cancer care, mental health, social support, and quality of life across different phases of the disease. **Materials and Methods:** This cross-sectional study recruited members of the Indonesian Cancer Information and Support Center (CISC) Lymphoma using convenience sampling. All data were collected using an online questionnaire and analyzed using Bonferroni-corrected p-values, effect sizes, 95% confidence intervals, and logistic regression in IBM SPSS version 26.0 for Windows. **Results:** A total of 60 lymphoma survivors participated (response rate 24.7%); most were female (65.0%), married (88.3%), unemployed (48.3%), and in the early or post-early treatment phase (80.0%). No significant differences were found between cancer phases in lifestyles, mental health, social support, and quality of life. Treatment delays were more frequent among relapse/palliative survivors than others (41.7% vs. 14.6%; effect size -0.535, 95% CI: -1.000, -0.378); however, treatment delay was not an independent predictor of cancer phase in multivariate analysis, likely due to a small sample size and limited statistical power. **Conclusion:** This study highlights the challenges lymphoma survivors faced during the COVID-19 pandemic, underscoring the importance of sustained continuity of care and integrated psychosocial support for individuals at greater risk of care disruption or psychological distress.

Keywords: Lymphoma- survivors- lifestyles- mental health- social support- quality of life

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Introduction

Lymphoma represents a major portion of hematologic cancers worldwide, including in Indonesia, where non-Hodgkin lymphoma (NHL) cases have risen steadily over the past 15 years [1]. While advances in treatment have improved survival, many patients face ongoing psychosocial challenges, lifestyle adjustments, and mixed perceptions of care quality.

In low- and middle-income countries (LMICs), survivorship often comes with significant mental health burdens. In Southeast Asia, one year post-diagnosis, cancer survivors report high rates of anxiety (7%) and depression (46%), particularly among those with advanced-stage disease, lower incomes, and aggressive cancers like lymphoma [2]. Although Indonesia-specific data on lymphoma survivors is limited, these trends suggest a vulnerable population.

Lifestyle behaviors are increasingly recognized as contributing to survivors' health-related quality of life (HRQoL) and psychological outcomes among cancer survivors [3]. In the context of hematologic malignancies, lifestyle changes after diagnosis can be constrained by treatment side effects, fatigue, financial burden of

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healthier choices, and social/familial support dynamics [4]. In Indonesia, existing studies have primarily examined general or breast cancer populations, highlighting negative illness perceptions and unmet informational needs, but providing little insight into lymphoma survivors specifically [5, 6].

Important gaps therefore remain, particularly regarding how perceptions of cancer care, mental health, and lifestyle behaviors interact across different phases of lymphoma survivorship within the Indonesian context. This study examined how lymphoma survivors perceive cancer care and how mental health/lifestyle varies by treatment phase.

Materials and Methods

Study Design and Participants

This cross-sectional study involved 60 members of the Indonesian Cancer Information and Support Center (CISC), a non-profit organization established in Jakarta in 2003, and currently has branches in many cities in Indonesia. CISC membership was defined as individuals listed in the CISC lymphoma membership database at the time of data collection. Participants were recruited from the CISC lymphoma membership database using convenience sampling and invited to complete an online survey distributed via Google Forms. Eligibility criteria included being a lymphoma patient, residing in Indonesia, aged ≥18 years, and able to understand and respond to the questionnaire in Indonesian. Participation was voluntary, and informed consent was obtained electronically before data collection.

Data Collection

Data were collected using a structured, self-administered online questionnaire between March 2023 and April 2023. The survey consisted of several validated instruments assessing physical activity, the impact of the COVID-19 pandemic on cancer care, post-traumatic stress disorder (PTSD) symptoms, social support, and quality of life (QoL). The instruments used have not all been formally validated in the Indonesian population; however, they were translated and linguistically adapted into Indonesian and reviewed by bilingual health professionals to ensure accuracy of meaning. Additionally, minor wording adjustments were made to improve cultural comprehensibility. Missing responses from four respondents were resolved through follow-up, resulting in a complete dataset with no exclusions or imputation.

Although we used Google Forms, we ensured strict data privacy. Before accessing the survey, participants were required to read and agree to an informed consent form before accessing any questionnaire items. The consent explicitly stated that no identifying information would be collected, ensuring full anonymity. Although the recruitment was shared through CISC networks, no member lists or personal data were accessed, and CISC had no access to individual responses. All data were stored securely within the password-protected Google Forms platform and accessible only to the research team for academic purposes. The study proposal, including data security procedures, had also been reviewed and approved by CISC. Finally, because some questions related to mental health, we added a note directing participants to contact their healthcare provider or local support personnel if they experienced distress during or after the survey. Together, these measures ensured that participant confidentiality, data protection, and well-being were maintained throughout the study.

Measures

Sociodemographic Characteristics

The sociodemographic characteristics included age, sex, marital status, education, occupation, and living alone or with others.

Body Mass Index and Lifestyles

The self-reported height/weight was used to measure body mass index (BMI). BMI was calculated by dividing body weight in kilograms by the square of height in meters. The BMI was then categorized into four groups, based on the WHO BMI classification for the Asian population: <18.5 (underweight), 18.5-22.9 (normal), 23-24.9 (overweight), and ≥25 (obesity) [7]. Smoking, alcohol consumption, history of working hours, and living alone or with others were also assessed.

Physical activity was measured using a 3-item questionnaire measuring exercise frequency, duration, and intensity. Participants reported the average number of exercise sessions per week, the average duration of each session (in hours), and their perceived intensity. Specifically for intensity, participants were asked: "If you exercise once or more times a week, how hard do you push yourself?" (I take it easy without breaking into a sweat or losing my breath; I push myself so hard that I lose my breath and break into a sweat; I push myself to near exhaustion). Intensity was therefore self-perceived according to the guidance from the Nord-Trøndelag Health Study (HUNT 2), which classifies activity as light, moderate, or vigorous based on exertion level and breathing pattern. While this measure is subjective, it has been widely applied in population-based studies, including the original HUNT 2, and was considered appropriate for our online self-administered format. This instrument has been validated in large population-based studies, including HUNT 2, which classified activity as light, moderate, or vigorous based on exertion level and breathing pattern [8].

Impact of the COVID-19 Pandemic on Cancer Care

The perceived impact of the COVID-19 pandemic on cancer care, QoL, and overall health (OH) was assessed using a modified 18-item questionnaire adapted from a survey developed at a New York City cancer center [9]. Items addressed changes in healthcare access, delays or cancellations of treatment, and perceived changes in health and well-being during the pandemic.

Post-Traumatic Stress Disorder (PTSD)

PTSD symptoms were measured using the PTSD

Checklist for DSM-5 (PCL-5), a 20-item self-report scale assessing the DSM-5 symptom criteria for PTSD. Items are scored on a 5-point Likert scale (0 = "Not at all" to 4 = "Extremely"), yielding a total score ranging from 0 to 80. Higher scores indicate greater symptom severity. Those with scores ≥ 33 were categorized as having PTSD. The PCL-5 can be used for screening, monitoring symptom changes, and making provisional diagnoses [10]. Previous studies have successfully applied the PCL-5 in oncology contexts to assess cancer-related stress and psychological distress [11, 12].

Social Support

Social support was assessed using the Medical Outcomes Study Social Support Survey (MOS-SSS), a 19-item questionnaire covering four domains: emotional/informational support, tangible support, affectionate support, and positive social interaction. Subscale scores and an overall support index were computed, with higher scores indicating greater perceived support [13].

Quality of Life (QoL)

QoL was measured using the Functional Assessment of Cancer Therapy – General – 7 Item Version (FACT-G7). This abbreviated version captures the most relevant symptoms and concerns for cancer patients, with a total score range of 0–28; higher scores reflect better QoL [14].

Data Analyses

Study participants were categorized into two groups: those receiving early treatment, and those receiving post-early treatment, or relapse or palliative care treatment. The continuous variables evaluated in this study included age, BMI, total social support score, the four subscales of social support (emotional, tangible, affectionate, and social interaction), and total quality of life score. Outlier checks identified no extreme values, and no sensitivity analysis was conducted because all data were collected within the same period. The Shapiro-Wilk test for normality showed that age ($p = 0.309$) and BMI ($p = 0.296$) followed normal distribution with homogenous variances; therefore, these variables were summarized as mean ± standard deviation (SD) and analyzed using an independent-samples t-test assuming equal variances. Conversely, total social support ($p = 0.015$) and total quality of life scores ($p = 0.014$) were not normally distributed. Logarithmic, square-root, and inverse transformations were explored, but did not achieve normality; thus, these variables were reported as median and interquartile range (IQR), and analyzed using the Mann-Whitney U test. Moreover, the Hodges-Lehmann estimate and its 95% confidence interval (CI) were reported.

Nominal variables were examined using Cramer's V test, while ordinal variables were evaluated with Kendall's tau-b test. To control the family-wise error rate, Bonferroni-corrected p-values were obtained by multiplying the original p-values by the number of possible pairs (comparisons) and capping values greater than 1 at 1.00, following standard statistical conventions. In addition, the bootstrap method was used to derive a 95% CI.

In the multivariate logistic regression analysis, cancer phase was treated as the dependent variable; whereas age, sex, education, occupation, living arrangement, type of lymphoma, and treatment delay as independent variables. All tests were two-sided with $\alpha = 0.05$ using IBM SPSS version 26.0 for Windows.

Results

Sociodemographic characteristics of lymphoma survivors

Of approximately 243 individuals listed in the CISC lymphoma membership database who were invited to participate, 60 responded. The database served as a valuable recruitment platform and included a broad range of contacts; therefore, the exact number of eligible lymphoma survivors could not be precisely determined. Consequently, the estimated response rate of 24.7% represents an upper-bound estimate. Ongoing enhancements in database management are expected to enable more accurate eligibility and response rate assessment in future studies.

Of the 60 study participants, 48 (80.0%) were in the early or post-early cancer phase, and 12 (20.0%) were in the relapse group of palliative care treatment; the youngest was a 20-year-old, and the oldest was a 76-year-old. Most study participants were females, married, had completed their undergraduate degree, were currently unemployed, and were living with others (Table 1).

BMI and lifestyle characteristics of lymphoma survivors

Overall, there was no significant difference in the average BMI, BMI categories, and lifestyles between the two groups of study participants. Most participants had never smoked or drunk alcohol. The majority had a history of working hours of less than or equal to 40 hours/week, had once/week physical activity, with a duration of 16-60 minutes, and low intensity (Table 2).

Impact of the COVID-19 pandemic on cancer care of lymphoma survivors

Thirty percent of study participants had Hodgkin lymphoma, and 70% had non-Hodgkin lymphoma. Of those in the early or post-early treatment, 11 (22.9%) were diagnosed with Hodgkin lymphoma, and 37 (77.1%) were non-Hodgkin lymphoma ($p=0.017$). The majority of participants reported no delayed control due to COVID-19 and used teleconsultation. There was a significant difference in the delayed treatment due to COVID-19, in which most participants in the early or post-early treatment (85.4%) reported no delayed treatment, while only 58.3% participants in the relapse or palliative care reported the same problem. There was no significant difference in the impact of COVID-19 on increased anxiety, depression, mood swings, negative or positive impact, increased personal anxiety regarding diagnosis, testing for COVID-19 made participants anxious or relieved, and changes in delivering cancer care during the pandemic were in the best interest. Overall health

Table 1. Sociodemographic Characteristics of Lymphoma Survivors

Characteristics	Cancer phase		Bonferroni corrected p-value		
	Mean ± SD, n (%)				
	Early or post-early treatment n = 48	Relapse or palliative care n = 12		Effect size	95% CI
Age	44.04 ±12.69	44.67±17.26	0.888[a]	-0.625	-9.464, 8.214
Sex			0.588[b]	-0.087	-0.357, 0.176
Male	16 (33.3)	5 (41.7)			
Female	32 (66.7)	7 (58.3)			
Marital status			0.546[b]	0.088	-0.162, 0.394
Married	43 (89.6)	10 (83.3)			
Not married	5 (10.4)	2 (16.7)			
Education			1.000[b]	0.09	0.039, 0.441
Junior high school	3 (6.3)	1 (8.3)			
Senior high school	9 (18.8)	3 (25.0)			
University	36 (75.0)	8 (66.7)			
Occupation			1.000[b]	0.131	0.044, 0.382
Civil servant	8 (16.7)	1 (8.3)			
Private sector	16 (33.3)	3 (25.0)			
Unemployed	22 (45.8)	7 (58.3)			
Living arrangement			0.121[b]	-0.283	-0.584, 0.077
Alone	2 (4.2)	2 (16.7)			
With others	46 (95.8)	10 (83.3)			

[a]Independent-samples t-test, [b]Cramer's V, two-sided, $\alpha = 0.05$

and quality of life before the COVID-19 pandemic and the current overall health were not statistically significant between the groups of participants (Table 3).

Mental health, social support, and quality of life

In this study, mental health was assessed based on the questionnaire on PTSD. Even though there was no significant difference in PTSD in both groups of participants, however, the percentage of probable PTSD was higher in the early and post-early cancer phase than in the relapse or palliative care group. Social support index and its components, including emotional, tangible, affectionate, and positive social interaction, did not show a significant difference between the groups. Lastly, the quality of life evaluation based on the functional assessment of cancer therapy, including lack of energy, pain, nausea, worry, sleeping well, enjoying life, and being content with the quality of life, also did not show any significant difference between the groups (Table 4). An additional analysis using Spearman's rank correlation demonstrated a statistically significant relationship between PTSD severity and quality of life ($p < 0.001$, $r = -0.602$, 95% CI: -0.762, -0.393).

In the multivariate logistic regression analysis, none of the examined variables were significantly associated with cancer phase (Table 5). Given the limited sample size and the resulting wide confidence intervals, these findings should be interpreted cautiously, as the analysis may have been underpowered to detect modest or clinically meaningful associations.

Discussion

The first confirmed COVID-19 cases in Indonesia were reported in March 2020, with the most severe waves occurring between 2020 and 2021, followed by gradual improvement through late 2022 and an official transition to endemic status in June 2023 [15]. In March-April 2023, Indonesia's healthcare system was still adapting to the prolonged effects of the COVID-19 pandemic. Persistent workforce and infrastructure limitations, especially outside urban centers, continued to constrain routine and specialized care services. These systemic challenges have been linked to late cancer diagnosis and limited access to oncology care, as health literacy and referral pathways remain uneven across regions [1, 16].

Cancer care, including lymphomas, represents a high demand on the system. Catastrophic cancer cases accounted for nearly 3.9 million service events under the national insurance program in 2023, highlighting the significant healthcare burden [17]. Moreover, lymphoma incidence trends previously showed disruptions during the pandemic, with decreases in hospital presentations in 2020 and fluctuating patient numbers as service utilization changed [1].

In response, national efforts have emphasized strengthening early detection and expanding access to oncology services. Initiatives include the wider distribution of diagnostic tools to primary care facilities and programs to enhance specialist capacity, aiming to improve timely care for patients with hematologic cancers such as lymphoma [18].

Table 2. BMI and Lifestyle Characteristics of Lymphoma Survivors

Characteristics	Cancer phase		Bonferroni corrected p-value	Effect size	95% CI
	Mean ± SD, n (%)				
	Early or post-early treatment	Relapse or palliative care			
	n = 48	n = 12			
BMI	23.19 ±5.02	22.38±3.91	0.604[a]	0.813	-2.305, 3.932
BMI categories			1.000[c]	0.141	0.099, 0.420
Underweight	9 (18.8)	3 (25.0)			
Normal	13 (27.1)	3 (25.0)			
Overweight	7 (14.6)	2 (16.7)			
Obesity	19 (39.6)	4 (33.3)			
Smoking			1.000[b]	0.13	-0.066, 0.394
Never	38 (79.2)	9 (75.0)			
Ever	8 (16.7)	3 (25.0)			
Currently smoking	2 (4.2)	0 (0.0)			
Ever drink alcohol			0.281[b]	-0.148	-0.482, 0.109
Yes	1 (2.1)	1 (8.3)			
No	47 (97.9)	11 (91.7)			
History of working hours/week			0.171[b]	-0.141	-0.360, 0.121
≤ 40 hours	30 (62.5)	10 (83.3)			
> 40 hours	18 (37.5)	2 (16.7)			
Frequency of physical activity			1.000[c]	0.397	0.231, 0.697
Never	6 (12.5)	1 (8.3)			
Once/week	28 (58.3)	5 (41.7)			
2-3 times/week	6 (12.5)	6 (50.0)			
Almost everyday	8 (16.7)	0 (0.0)			
Duration of physical activity			1.000[c]	0.111	0.074, 0.410
< 15 minutes	13 (27.1)	3 (25.0)			
16-30 minutes	16 (33.3)	3 (25.0)			
30-60 minutes	14 (29.2)	5 (41.7)			
>60 minutes	5 (10.4)	1 (8.3)			
Intensity of physical activity			1.000[c]	-0.022	-0.224, 0.248
Low	39 (81.3)	10 (83.3)			
Moderate	9 (18.8)	2 (16.7)			
Strenuous	0 (0.0)	0 (0.0)			

[a]Independent samples t-test, [b]Cramer's V, [c]Kendall's tau-b, two-sided, α = 0.05

In this cross-sectional survey of 60 lymphoma survivors (48 in early/post early treatment and 12 in relapse/palliative care), several key patterns emerged around demographic profiles, lifestyle factors, the impact of the COVID-19 pandemic, and psychosocial outcomes. Our participants were skewed toward females, married, highly educated, unemployed, and living with others. This profile is not uncommon in survivorship studies: many cancer survivors reduce or cease work during or after treatment, leading to a shift in employment status [19, 20]. The predominance of living with other arrangements, including family members or caregivers, may support greater informal social support, which can buffer stress and influence outcomes [21, 22].

The low levels of physical activity and high unemployment rate observed in our study are consistent with global survivorship literature, which highlights persistent functional limitations among lymphoma survivors. Rehabilitation guidelines emphasize structured exercise, fatigue management, and vocational support as key components of survivorship care, suggesting potential areas for future intervention in Indonesian settings [23, 24].

In this study, lymphoma subtype distribution differed by cancer phase, with Hodgkin lymphoma proportionally more common in the relapse or palliative phase and non-Hodgkin lymphoma predominating in the early or post-early treatment phase. Although this association was statistically significant in bivariate analysis, it did not persist after adjustment in the multivariate logistic regression model, where lymphoma subtype was not an independent predictor of cancer phase. This likely reflects limited statistical power, particularly in the relapse/palliative subgroup (n = 12), which constrained

Table 3. Impact of the COVID-19 Pandemic on Cancer Care of Lymphoma Survivors

Characteristics	Cancer phase		Bonferroni corrected	Effect size	95% CI
	n (%)		p-value		
	Early or post-early treatment	Relapse or palliative care			
	n = 48	n = 12			
Lymphoma categories			0.017[b]	-0.134	-0.577, 0.388
Hodgkin	11 (22.9)	7 (58.3)			
Non-Hodgkin	37 (77.1)	5 (41.7)			
Delayed control due to COVID-19			0.082[b]	-0.707	-1.000, -0.378
Yes	15 (31.3)	7 (58.3)			
No	33 (68.8)	5 (41.7)			
Delayed treatment due to COVID-19			0.038[b]	-0.535	-1.000, -0.378
Yes	7 (14.6)	5 (41.7)			
No	41 (85.4)	7 (58.3)			
Teleconsultation during COVID-19			1.000[b]	0.468	0.198, 0.756
Yes	12 (25.0)	3 (25.0)			
No	36 (75.0)	9 (75.0)			
Increased anxiety			0.700[c]	0.575	0.189, 1.000
Not at all	5 (10.4)	3 (25.0)			
To a small extent	10 (20.8)	6 (50.0)			
To some extent	25 (52.1)	1 (8.3)			
To a great extent	5 (10.4)	1 (8.3)			
To a very great extent	3 (6.3)	1 (8.3)			
Increased depression			1.000[c]	0.408	-0.577, 0.661
Not at all	8 (16.7)	2 (16.7)			
To a small extent	19 (39.6)	7 (58.3)			
To some extent	17 (35.4)	2 (16.7)			
To a great extent	2 (4.2)	0 (0.0)			
To a very great extent	2 (4.2)	1 (8.3)			
Increased mood swings			0.305[c]	0.391	0.185, 0.865
Not at all	6 (12.5)	3 (25.0)			
To a small extent	13 (27.1)	6 (50.0)			
To some extent	24 (50.0)	2 (16.7)			
To a great extent	4 (8.3)	1 (8.3)			
To a very great extent	1 (2.1)	0 (0.0)			
Negative impact			1.000[c]	0.443	0.225, 1.000
Strongly agree	6 (12.5)	3 (25.0)			
Somewhat agree	15 (31.3)	0 (0.0)			
Neither agree nor disagree	20 (41.7)	6 (50.0)			
Somewhat disagree	5 (10.4)	2 (16.7)			
Strongly disagree	2 (4.2)	1 (8.3)			
Positive impact			1,000[c]	0.199	0.134, 0.384
Strongly agree	0 (0.0)	0 (0.0)			
Somewhat agree	4 (8.3)	0 (0.0)			
Neither agree nor disagree	25 (52.1)	7 (58.3)			
Somewhat disagree	15 (31.3)	5 (41.7)			
Strongly disagree	4 (8.3)	0 (0.0)			
Increased personal anxiety regarding diagnosis			0.970[c]	0.25	0.173, 0.853
Strongly agree	3 (6.3)	0 (0.0)			
Somewhat agree	16 (33.3)	3 (25.0)			
Neither agree nor disagree	18 (37.5)	3 (25.0)			
Somewhat disagree	9 (18.8)	4 (33.3)			
Strongly disagree	2 (4.2)	2 (16.7)			

Continued Table 3.

Characteristics	Cancer phase		Bonferroni corrected	Effect size	95% CI
	n (%)		p-value		
	Early or post-early treatment	Relapse or palliative care			
	n = 48	n = 12			
Testing for COVID-19 made me anxious			1.000[c]	0.363	0.218, 0.757
Strongly agree	5 (10.4)	0 (0.0)			
Somewhat agree	18 (37.5)	4 (33.3)			
Neither agree nor disagree	17 (35.4)	6 (50.0)			
Somewhat disagree	7 (14.6)	1 (8.3)			
Strongly disagree	1 (2.1)	1 (8.3)			
Testing for COVID-19 made me relieved			0.790[c]	0.363	0.240, 0.784
Strongly agree	1 (2.1)	1 (8.3)			
Somewhat agree	10 (20.8)	5 (41.7)			
Neither agree nor disagree	28 (58.3)	5 (41.7)			
Somewhat disagree	9 (18.8)	1 (8.3)			
Strongly disagree	0 (0.0)	0 (0.0)			
Changes in delivering cancer care during the pandemic were in my best interest					
Strongly agree	5 (10.4)	1 (8.3)	1.000[c]	0.707	0.378, 1.000
Somewhat agree	21 (43.8)	7 (58.3)			
Neither agree nor disagree	18 (37.5)	4 (33.3)			
Somewhat disagree	4 (8.3)	0 (0.0)			
Strongly disagree	0 (0.0)	0 (0.0)			
Overall health before the COVID-19 pandemic			1.000[c]	0.667	0.286, 1.000
Very poor-poor	3 (6.2)	0 (0.0)			
Below average-average	8 (16.7)	1 (8.3)			
Above average-good	25 (52.1)	9 (75.0)			
Excellent	12 (25.0)	2 (16.7)			
Currently overall health			0.192[c]	0.677	0.327, 1.000
Very poor-poor	2 (4.2)	1 (8.3)			
Below average-average	9 (18.8)	2 (16.6)			
Above average-good	20 (41.7)	8 (66.7)			
Excellent	17 (35.4)	1 (8.3)			
Overall quality of life before the COVID-19 pandemic			1.000[c]	0.486	0.286, 1.000
Very poor-poor	2 (4.2)	0 (0.0)			
Below average-average	13 (27.1)	2 (16.7)			
Above average-good	24 (50.0)	8 (66.7)			
Excellent	9 (18.8)	2 (16.7)			
Currently, the overall quality of life			0.294[c]	0.471	0.286, 0.889
Very poor-poor	2 (4.2)	1 (8.3)			
Below average-average	9 (18.8)	2 (16.7)			
Above average-good	20 (41.7)	8 (66.7)			
Excellent	17 (35.4)	1 (8.3)			

[b]Cramer's V, [c]Kendall's tau-b, two-sided, α= 0.05

the ability to detect independent associations while controlling for potential confounders. Importantly, this study was not designed to assess prognosis or survival. The cross-sectional design, small sample size, and lack of detailed clinical variables preclude inference regarding prognostic differences, which are known to be influenced by multiple factors such as disease stage, treatment response, biological characteristics, and timing of diagnosis, rather than lymphoma subtype alone [25, 26].

We found a significant difference in treatment delays during the pandemic between relapse/palliative survivors (41.7%) and others (14.6%); however, the multivariate regression analysis did not identify treatment delay as an independent predictor of cancer phase. This likely reflects limited statistical power, as only approximately five participants in the relapse/palliative subgroup (n = 12) reported treatment delays, resulting in wide confidence intervals and reduced ability to detect

independent associations. Additionally, treatment delays may represent a consequence rather than a cause of disease complexity, introducing potential bidirectional confounding in cross-sectional analysis. Findings should therefore be considered preliminary, and the long-term clinical significance remains uncertain. This suggests that relapsed patients may have been especially vulnerable to disruptions in care continuity, possibly due to greater treatment complexity, frailty, or lower priority in resource-constrained settings [9, 27]. Survivors often experience multifaceted post-treatment challenges that extend beyond traditional clinical outcomes (e.g., psychological distress, fear of recurrence, and fragmented care access) [28, 29]. A comprehensive survivorship care plan should incorporate personalized risk-based follow-up [30], psychosocial support [28], and coordinated multidisciplinary management to improve long-term well-being and quality of life [31].

Our study found no difference in the overall health and QoL before and during the COVID-19 pandemic. In contrast, a longitudinal study of adolescent and young adult cancer survivors (AYACS) found that HRQoL scores improved during the pandemic relative to the pre-pandemic period, especially in domains of social functioning, fatigue, and pain [32]. The results of a prior study indicated that pandemic-induced lifestyle changes (e.g., slower pace of life, more rest, reduced social pressures) may have inadvertently benefited certain survivors [33]. However, this effect is not uniform across cancer types or stages, and must be balanced against known detrimental consequences of disrupted care.

The systematic review by Theofilou et al. (2024) documents that the pandemic has generally impaired the QoL of cancer patients, often via psychological distress, restricted access to care, and social isolation [34]. That said, heterogeneity is substantial: some patients adapt, and "resilience" effects may lead to improvement in subjective QoL over time despite adversities. Unlike the multi-country study, which found paradoxically higher HRQoL among lymphoma patients surveyed during the COVID-19 pandemic [35], our post-pandemic cohort did not exhibit such improvements. A prior study attributed its findings to reduced social pressures, increased time with family, and widespread adoption of virtual communication and support. In contrast, our participants reported persistent anxiety, variability in social support, and HRQoL levels that likely reflect the return of daily stressors and the long-term impact of disrupted cancer care during the pandemic. Additionally, healthcare system limitations in Indonesia may contribute to lower HRQoL in the post-pandemic period. These contrasting results underscore the importance of contextual and temporal differences in interpreting survivorship outcomes [35].

Lymphoma survivors face well-documented psychosocial challenges beyond general cancer survivorship issues. These include high levels of fear of recurrence, fertility concerns, particularly among younger survivors exposed to gonadotoxic chemotherapy, anxiety related to surveillance scans ("scanxiety"), and persistent worry about late effects such as secondary malignancies and cardiotoxicity. Fear of recurrence is one of the most common and distressing psychosocial concerns among lymphoma survivors. Evidence from studies supported the relevance of these lymphoma-specific concerns [36-38]. There was an important caveat that our measure of "overall health before vs during COVID-19" did not show a significant decline ($p = 1.000$). This suggests that participants perceived their health as relatively stable, even in the face of pandemic pressures, and that their reported QoL gains might reflect adaptation [39].

Our findings align with international survivorship guidelines from ASCO (American Society of Clinical Oncology), NCCN (National Comprehensive Cancer Network), and ESMO (European Society for Medical Oncology), which emphasize psychosocial screening, assessment of quality of life, and evaluation of lifestyle behaviors among cancer survivors [40-42]. The observed prevalence of probable PTSD and differences in QoL across cancer phases highlight the importance of integrating mental health and supportive care into survivorship models, particularly in low- and middle-income settings. These frameworks emphasize systematic identification of anxiety, trauma symptoms, and unmet psychosocial needs using validated tools, followed by referral to appropriate mental health and supportive care services [43, 44]. The additional analysis of our study demonstrated a strong negative association between PTSD severity and quality of life. In the lymphoma survivorship literature, post-traumatic stress symptoms (PTSS) and PTSD remain an ongoing concern even long after treatment. For example, a long-term follow-up of non-Hodgkin lymphoma survivors showed that about 37% had persistence or worsening of symptoms over a 5-year interval [38, 45]. Similar rates are found across cancer survivors: in one study of 212 survivor–caregiver dyads, about 20% of survivors had possible PTSS and 11% had probable PTSD [46]. The traumatic stress burden in cancer is influenced by many factors beyond treatment status (e.g., coping, prior psychopathology, social support). Notably, De Padova et al. (2021) found that PTSS severity in survivors correlated with anxious coping, prior psychopathology, and depression [46]. Preliminary evidence suggests that higher PTSD symptoms among early/post-early survivors may reflect the "acute psychological shock" associated with diagnosis and initial treatment. PTSD symptoms often peak early in the cancer trajectory when uncertainty is greatest [47, 48]. In contrast, relapse/palliative patients may have developed coping strategies over time, resulting in lower trauma-related symptoms despite more advanced disease. This pattern is supported by prior studies showing that cancer-related PTSD is typically highest around diagnosis and may decline as patients adapt [49].

Regarding social support, our result of no significant differences between groups contrasts somewhat with the literature showing that perceived social support can buffer distress and improve QoL. A cross-sectional study among cancer patients in Oman found that patients with PTSD had lower perceived social support and worse QoL, and mediation analysis showed that social support mediated the PTSD-QoL pathway [50]. In lymphoma, specifically,

Table 4. Mental Health, Social Support, Quality of Life

Characteristics	Cancer phase Median (IQR), n (%)		Bonferroni corrected p-value	Effect size	95% CI
	Early or post-early treatment n = 48	Relapse or palliative care n = 12			
Post-traumatic stress disorder			0.245[b]	-0.068	-0.492, 0.468
Normal	23 (47.9)	8 (66.7)			
Probable PTSD	25 (52.1)	4 (33.3)			
Social support					
Emotional support	70.31 (21.88)	62.50 (25.00)	0.600[a]	6.25	-6.250, 18.750
Tangible support	75.00 (25.00)	71.88 (25.00)	0.742[a]	6.25	-6.250, 18.750
Affectionate support	62.50 (25.00)	62.50 (25.00)	1.000[a]	0	-12.500, 12.500
Positive social interaction	75.00 (25.00)	58.33 (14.58)	0.162[a]	8.333	0.000, 16.667
Social support index	64.47 (16.78)	61.18 (17.76)	0.488[a]	5.263	-3.947, 15.789
Functional Assessment of Cancer Therapy					
Lack of energy			1.000[c]	0.378	-0.185, 0.853
Very much	2 (4.2)	1 (8.3)			
Quite a bit	6 (12.5)	7 (58.3)			
Somewhat	15 (31.3)	2 (16.7)			
A little bit	15 (31.3)	2 (16.7)			
Not at all	10 (20.8)	2 (16.7)			
Pain			1.000[c]	0.25	0.189, 0.852
Very much	2 (4.2)	0 (0.0)			
Quite a bit	5 (10.4)	1 (8.3)			
Somewhat	11 (22.9)	2 (16.7)			
A little bit	16 (33.3)	4 (33.3)			
Not at all	14 (29.2)	5 (41.7)			
Nausea			1.000[c]	-0.302	-0.426, 0.500
Very much	0 (0.0)	0 (0.0)			
Quite a bit	1 (2.1)	0 (0.0)			
Somewhat	6 (12.5)	0 (0.0)			
A little bit	14 (29.2)	4 (33.3)			
Not at all	27 (56.3)	8 (66.7)			
Worry			1.000[c]	0.535	0.250, 0.865
Very much	2 (4.2)	0 (0.0)			
Quite a bit	9 (18.8)	2 (16.7)			
Somewhat	9 (18.8)	5 (41.7)			
A little bit	10 (20.8)	2 (16.7)			
Not at all	18 (37.5)	3 (25.0)			
Sleeping well			1.000[c]	0.808	0.286, 1.000
Not at all	2 (4.2)	1 (8.3)			
A little bit	7 (14.6)	1 (8.3)			
Somewhat	19 (39.6)	5 (41.7)			
Quite a bit	6 (12.5)	3 (25.0)			
Very much	14 (29.2)	2 (16.7)			
Enjoy life			1.000[c]	0.636	0.189, 1.000
Not at all	0 (0.0)	1 (8.3)			
A little bit	1 (2.1)	1 (8.3)			
Somewhat	19 (39.6)	2 (16.7)			
Quite a bit	14 (29.2)	5 (41.7)			
Very much	14 (29.2)	3 (25.0)			
Content with my QoL			1.000[c]	0.167	0.122, 0.784
Not at all	1 (2.1)	1 (8.3)			
A little bit	5 (10.4)	0 (0.0)			
Somewhat	22 (45.8)	5 (41.7)			
Quite a bit	8 (16.7)	2 (16.7)			
Very much	12 (25.0)	4 (33.3)			
Quality of life	102.8 ± 25.0	102.7±23.2	1.000[a]	0	-2.000, 2.000

[a]Mann-Whitney U, [b]Cramer's V, cKendall's tau-b, two-sided, α = 0.05

Table 5. Logistic Regression

Variables	p-value	Exp (B)	95% CI
Age	0.093	1.06	0.990, 1.134
Sex (1)	0.555	1.822	0.248, 13.364
Education	0.942		
Education (1)	0.783	1.593	0.058, 43.847
Education (2)	0.729	1.779	0.068, 46.444
Occupation	0.45		
Occupation (1)	0.946	1.109	0.057, 21.624
Occupation (2)	0.344	4.088	0.222, 75.327
Living arrangement (1)	0.103	16.565	0.569, 482.345
Lymphoma type (1)	0.058	5.713	0.942, 34.633
Delayed treatment (1)	0.077	5.393	0.834, 34.873
Constant	0.036	0.001	

a study by X et al. (2023) found that patient-centered communication (PCC) partially mediates the relation between social support and mental health outcomes, such as PTSD, and the negative impact of cancer [51]. The absence of significant differences in perceived social support between cancer phases in our study may reflect the high proportion of participants living with family members or partners, which can provide consistent emotional and practical support across disease phases. Additionally, the high level of unemployment in this cohort may have reduced employment-related social disruption, thereby attenuating expected differences in support associated with disease severity.

The lack of difference in domain-specific QoL (symptom, functional, psychosocial) aligns with some survivorship research, which shows that many survivors converge toward similar quality-of-life "baselines" over time, regardless of disease stage at a cross-sectional snapshot. However, the review "Quality of Life and Survivorship in Lymphoma" notes that persistent physical, emotional, and social sequelae often linger, and that patient-reported outcome monitoring can help identify individuals at risk of poorer trajectories [39].

Study limitations

This study has several limitations. Recruitment through CISC membership and associated networks may have introduced selection bias, as these survivors may differ from the broader lymphoma population in health awareness, access to information, or engagement in support activities. Individuals with more severe health conditions or complications may have been less likely or unable to participate, particularly given the challenges posed by the pandemic. The study did not have a priori power calculation. The small sample size, particularly in the relapse/palliative care group (n = 12), limited statistical power and restricted analyses to bivariate comparisons, potentially leaving residual confounding unaddressed. The cross-sectional design precludes causal inference and assessment of changes in HRQoL over time, such as whether any perceived improvement in mental health or lifestyle behaviors is genuine or influenced by recall bias, psychological adaptation, or social desirability bias. The retrospective reporting of pre-COVID-19 overall health and quality of life may have introduced recall bias. Measurement error is also possible because BMI and physical activity intensity were based on self-report rather than objective assessment [52]. This may explain the limited variability in BMI and lifestyle behaviors across clinical groups [53] or selection bias (e.g., participants being those with more stable health behaviors) [54]. Although this limits variability within our sample, it aligns with broader survivorship research showing that healthier lifestyle profiles are commonly observed in cancer survivor cohorts [55], and are associated with better psychosocial outcomes and health-related quality of life (HRQoL) [3]. Moreover, the variation in lymphoma subtypes could introduce confounding. However, because our study used an online self-reported survey to reach survivors throughout Indonesia, we were not able to access medical records for confirmation. Participants had been treated at many different hospitals, both within the country and overseas. In addition, although Indonesia has both hospital-based and population-based cancer registries, data linkage across laboratories and healthcare facilities is still incomplete, and the system is not yet fully comprehensive nationwide [16], making it impossible for us to verify detailed subtype information. Diagnostic capacity also varies widely across regions, and full lymphoma subtyping is not routinely conducted in many areas of Indonesia. Therefore, the findings of this study may not be fully generalizable to all Indonesian lymphoma survivors.

Future studies should employ larger, adequately powered longitudinal designs with broader recruitment and linkage to clinical records or registries to improve causal inference, generalizability, and measurement validity. Mixed-methods, intervention, and health-system research, including qualitative studies, psychosocial intervention trials, telemedicine evaluations, and mechanistic analyses, are needed to clarify long-term trajectories and address unmet needs among relapse/palliative lymphoma survivors. While the use of the abbreviated FACT-G7 was appropriate to minimize participant burden in this online survey, future studies with larger samples may consider employing more comprehensive quality-of-life

instruments, such as the full FACT-G or the EORTC QLQ-C30, to enhance sensitivity in detecting subtle differences across survivorship phases.

In conclusion, this study provides a timely snapshot of how lymphoma survivors experienced survivorship care during a global health crisis. The findings highlight the need for strengthened continuity of care and integrated psychosocial support. Survivorship care models should prioritize clear communication, remote support options, lifestyle promotion, and routine psychosocial screening, particularly for individuals at higher risk of care disruption or psychological distress.

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This study did not receive external funding.

Conflict of Interest

The authors declare no conflict of interest.

Data Availability

The data generated and/or analyzed in this study are not publicly accessible due to legal and ethical considerations. This study was not registered in any official registry.

Ethical Consideration

The authors declare that they have obtained written informed consent from the patient for the clinical information to be reported in the journal. The study protocol was reviewed and approved by the CISC and the Research Ethics Committee, Faculty of Medicine, Hang Tuah University, with certificate number I/024/UHT. KEPK.03/VI/2024.

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