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Unmet Needs and Health-Related Quality of Life Among Patients With Relapsed/Refractory Indolent Non-Hodgkin Lymphoma: A Mixed-Methods Study

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ABSTRACT

Objective: Patients with relapsed or refractory (r/r) indolent non-Hodgkin lymphoma (iNHL) live with incurable disease for a long-term, experiencing multiple relapses and treatments that impair their health-related quality of life (HRQOL). We aimed to better understand the unmet needs and HRQOL of patients with r/r iNHL.

Methods: This convergent mixed-methods study evaluated patients with r/r iNHL who received treatment. Unmet needs and HRQOL were assessed quantitatively using self-administered questionnaires and analyzed statistically. Qualitative data were collected through face-to-face semi-structured interviews for reflexive thematic analysis. Quantitative and qualitative findings were integrated through narrative discussion and joint display.

Results: Questionnaire respondents (50 participants, mean age: 72.42 years) reported unmet needs in the health system and information and psychological domains and a negative association between unmet needs and HRQOL. Interviews (20 participants, mean age: 72.75 years) identified four themes: "unremarkable symptoms," "anxiety of progression in the near future," "make the best of life," and "means to live with uncertainty." Integration revealed that participants accepted their low HRQOL and attempted to make the best of life, influencing their perception of unmet needs.

Conclusions: Throughout the long course of r/r and repeated treatment, patients with iNHL accepted their low HRQOL, valued their current situations, and endeavored to make the best of life. In this situation, support in the psychological and health system and information domains is crucial. Support for the unmet needs of patients with r/r iNHL is essential as they strive to live their best lives while maintaining a favorable HRQOL.

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1 | Background

Non-Hodgkin lymphoma (NHL) is the most common hematological malignancy [1]. Approximately 40% of newly diagnosed NHL cases are slow-growing indolent NHL (iNHL) [2]. iNHL has a relatively good prognosis, and its 10-year overall survival (OS) rate is 75%–80%, with a median OS > 20 years [3]. However, iNHL is considered incurable and may relapse or progress long-term.

Recently, besides the anti-CD20 monoclonal antibody rituximab, treatment options for relapsed or refractory (r/r) iNHL are expanding, for example, tazemetostat, an oral mutant and wild-type *EZH2* inhibitor, and chimeric antigen receptor T-cell (CAR-T) therapy [4]. While relapse within 2 years of initial treatment or histological transformation is associated with poor prognoses [4, 5], the treatment efficacy after two prior lines of therapy is limited [6]. Patients with iNHL in later treatment lines experience decreased physical, role, and social functioning, as well as worsening fatigue, pain, and dyspnea [7]. Furthermore, patients with relapsed iNHL experience decreased work productivity, high anxiety and depressive symptom levels, and impaired health-related quality of life (HRQOL) [8]. Therefore, even if patients with r/r iNHL survive long-term, they may experience repeated physical, psychological, and social burdens. With a median age at diagnosis of 65 years [4] and a good prognosis, these patients tend to be older and may have comorbidities and frailty [9, 10]. However, these patients live their daily lives with limited opportunities to meet with healthcare providers, and their unmet needs are unknown. As the hematological malignancy incidence increases with age [11], patients may experience difficulties in their daily lives during the long-term course.

Among NHL survivors, unmet needs (needs that were not addressed and additional support was required [12]) are significantly associated with HRQOL [13]. Patients with NHL experience unmet needs in multiple domains [14]. According to quantitative research, common unmet needs are related to treatment and prognosis and keeping mind under control [13], while qualitative research has reported unmet needs regarding tailored care and information to help patients cope with post-treatment experiences [15, 16]. Despite reports on the increasing unmet needs of relapse patients [13, 16], there is a lack of a comprehensive understanding of the unmet needs of patients with r/r iNHL who have received multiple treatments and are surviving longer. Therefore, we used a mixed-methods approach to deepen this understanding for patients with r/r iNHL who continue outpatient monitoring and may be dealing with challenges of daily life long-term. As the global population ages [17], our investigation may also contribute to strategies for supporting older and aging patients living with cancer long-term. Thus, we aimed to quantitatively examine the extent of unmet needs and HRQOL, explore the relationship between these factors, qualitatively investigate the perceptions of patients with r/r iNHL regarding living with the disease and their need for support, and integrate quantitative and qualitative findings to gain a comprehensive understanding of unmet needs and HRQOL.

2 | Methods

2.1 | Design

We used a convergent mixed-methods design [18] to better understand the unmet needs and HRQOL of patients with r/r iNHL. Quantitatively, we performed a cross-sectional study using a questionnaire to determine the extent of unmet needs and HRQOL. Qualitatively, we conducted interviews to identify the patients' perceptions regarding living with iNHL and their need for support. We used the Good Reporting of A Mixed Methods Study reporting guideline [19] for the mixed-methods strand, the Strengthening the Reporting of Observational Studies in Epidemiology checklist for the quantitative strand, and the Consolidated Criteria for Reporting Qualitative Research checklist for the qualitative strand.

2.2 | Ethics and Consent

This study was approved by the institutional review boards of the Keio University School of Medicine (No. 20221190) and Graduate School of Health Management, Keio University (No. 2022-25). Written informed consent was obtained from all enrolled participants.

2.3 | Participants and Recruitment

Participants were recruited from the hematology outpatient clinic of a university hospital in Tokyo, Japan, from May 2023 to March 2024. Eligible participants were patients with iNHL who had relapsed or were refractory to initial treatment, were ≥ 18 years old at diagnosis and were treated for r/r conditions. Patients deemed ineligible by their physicians due to physical or mental conditions were excluded. During scheduled outpatient visits, the physician briefly informed eligible patients concerning the study and asked about their interest in being referred to the study. If interested, the researcher (M.S.) explained the study in writing and verbally.

2.4 | Data Collection and Instruments

2.4.1 | Quantitative Strand

This study only included patients with iNHL treated for r/r disease; due to the small patient population, maximum number of participants was recruited. Consenting participants completed a questionnaire at the hospital's outpatient clinic. Alternatively, they could complete the survey at home and mail it back in a stamped envelope provided by the researcher.

2.4.1.1 | Demographic and Clinical Characteristics. Demographic data were collected via a self-administered questionnaire, whereas clinical characteristics, including disease status, r/r condition, treatment status, diagnosis date, and comorbidities, were extracted from medical records. The

Charlson Comorbidity Index, a comorbidity measure that can predict mortality, was used to assess comorbidities [20, 21].

2.4.1.2 | Unmet Needs.

Unmet needs were assessed using the Supportive Care Needs Survey Questionnaire–short form (SCNS-SF34), Japanese version [22]. The SCNS-SF34 assesses the needs perceived by patients with cancer across five domains (34 items): psychological (10 items), health system and information (11 items), physical and daily living (five items), patient care and support (five items), and sexuality (three items). Participants rated their support needs level regarding having cancer over the past month on a 5-point Likert scale: 1 = no need, not applicable, 2 = no need, satisfied, 3 = low need, 4 = moderate need, and 5 = high need. For each item, responses of 3–5 indicated "some level of needs." [23] Each item's Likert scale scores were summed to calculate the crude domain total, and a standardized Likert summated score was subsequently calculated. Each domain ranged from 0 to 100, with higher scores indicating higher need levels [23]. The reliability and validity of the English and Japanese versions of the scale have been previously confirmed [22, 24].

2.4.1.3 | HRQOL.

HRQOL was assessed using the 42-item Functional Assessment of Cancer Therapy–Lymphoma (FACT-Lym), Japanese version [25], comprising the Functional Assessment of Cancer Therapy–General (FACT-G) [26, 27] and NHL patient-specific concerns and symptoms of lymphoma subscale (Lym-S) (15 items). The FACT-G was used to assess the general quality of life of patients with cancer across five domains (27 items): physical well-being (PWB, seven items), social/family well-being (SWB, seven items), emotional well-being (EWB, six items), and functional well-being (FWB, seven items). The Lym-S is an additional FACT-G subscale measuring lymphoma's impact on HRQOL using 15 items, and its reliability and validity are established [25]. Each FACT-Lym item is rated on a 5-point Likert scale, with total scores ranging from 0 to 168, where higher scores indicate better HRQOL.

2.4.2 | Qualitative Strand

We used purposive sampling [18] based on age, sex, diagnosis, and disease condition. A researcher (M.S.) conducted face-to-face semi-structured interviews following questionnaire completion or at a date convenient for the participant in a private setting at the hospital. Each interview lasted 30–40 min, was digitally recorded with participant consent, and was transcribed verbatim by a professional transcription service. The researcher wrote the field notes after the interview. Data collection continued until saturation was reached.

Interview guide was developed based on a literature review of previous studies on unmet needs [15, 16], the SCNS-SF34 questionnaire [22], and discussions among researchers (M.S. and K.Y.). The interview guide included the following questions: "What lymphoma symptoms and treatment side effects do you have?", "How did lymphoma affect your daily activities and social interactions?", "How do you feel about living with lymphoma?", and "How do you feel about the way medical staff treat you?" After these questions, we inquired regarding the patients' need for support and related reasons. Participants indicating a need for support were asked to specify the type of support required.

2.5 | Data Analysis

2.5.1 | Mixed-Methods Analysis

Integration was performed at the methods, interpretation, and reporting levels [28]. Integration at the methods level occurred by analyzing quantitative and qualitative data separately and then merging. Common concepts across two databases were identified, and results for each concept were compared to determine how they confirmed, disconfirmed, or expanded upon one another [18, 28]. Integration at the interpretation and reporting levels occurred through narrative discussions using a contiguous approach and joint display [18, 28].

2.5.2 | Quantitative Strand

Descriptive statistics were calculated for participant characteristics, unmet needs, and HRQOL: frequencies and percentages for categorical variables and means and standard deviations for continuous variables, depending on the distribution. For missing values on the SCNS-SF34, where < 50% of the items within a domain were incomplete, the mean value of the remaining items in that domain was imputed according to the SCNS scoring guide [23]. Spearman's rank correlation coefficient was used to examine the relationship between the SCNS-SF34 and FACT-Lym subscales. Data were analyzed using SPSS Statistics, version 29 (IBM Corp., Armonk, NY, USA). Statistical significance was set at two-tailed $p < 0.05$.

2.5.3 | Qualitative Strand

Reflexive thematic analysis [29] was used for qualitative analysis: a researcher (M.S.) repeatedly read interview transcripts, extracted research question–related data, and generated initial codes. Codes of similar meaning were clustered, and initial subthemes and themes were created. Candidate themes were subsequently reviewed and developed. Themes were refined, and definitions and names were developed for each theme. Quotations were extracted to provide the results. After 20 interviews, the researcher confirmed that no new information was obtained from the analysis, indicating data saturation [30].

The strategies employed to ensure trustworthiness [31] included credibility through prolonged engagement with participants through interviews and persistent observation by a researcher (M.S.), who generated codes after data collection from five participants. The researcher (M.S.) read, re-read, and analyzed interview data repeatedly and persistently. Moreover, triangulation was conducted by this researcher and another researcher with extensive qualitative research experience (K.Y.), involving regular meetings and repeated themes and subtheme discussion. In interpretation differences among the researchers, data were re-read and refined until no further disagreements were encountered [31]. Recording and transcribing interviews, analyzing data, and quoting patient interviews in detail ensured dependability and confirmability. To ensure transferability, we provided a detailed description of methods and patient context. Regarding reflexivity, the researcher (M.S.) remained conscious of their own subjective views on patients with r/r iNHL and their nursing throughout the study, held discussions with another researcher (K.Y.), and wrote field notes [32].

3 | Results

3.1 | Quantitative Results

3.1.1 | Participants

Fifty-three patients participated, but data from 50 were analyzed (valid response rate: 94.3%). One participant withdrew consent after completing the questionnaire and two did not meet eligibility criteria. Table 1 shows demographic and clinical characteristics of the participants.

3.1.2 | Unmet Needs and HRQOL

Table 2 shows the descriptive statistics for SCNS-SF 34 and FACT-Lym scores. The highest unmet needs were health system and information, followed by psychological domains. The top five most prevalent items, indicating some level of need, were in the psychological and health system and information domains, with the highest item prevalence reaching 40% (Table 3).

The unmet needs in the psychological ($r = -0.410$, $p < 0.01$), health system and information ($r = -0.388$, $p < 0.01$), physical and daily living ($r = -0.539$, $p < 0.001$), and patient care and support ($r = -0.305$, $p < 0.05$) domains were negatively associated with HRQOL (Table 4).

3.2 | Qualitative Results

Twenty-one participants with r/r iNHL were interviewed; one patient withdrew consent and requested data deletion. Finally, 20 participants were included (Table 1). The mean interview time was 36.8 (range: 15–57) min.

Four themes were identified regarding the patients' perceptions of living with r/r iNHL and their needs for support: "unremarkable symptoms," "anxiety of progression in the near future," "make the best of life," and "means to live with uncertainty".

3.2.1 | Unremarkable Symptoms

After undergoing r/r and multiple treatments, the participants understood that iNHL was incurable and that their physical status would not improve. Therefore, they focused on their physical condition, accepted the chronic changes as unavoidable, and recognized the symptoms arising from iNHL, its treatment, and its course as unremarkable within themselves.

3.2.1.1 | Focus on Physical Condition Rather Than Tumor. Participants tended to focus more on the absence of distressing symptoms or interference with their daily lives than on the presence of tumor due to r/r iNHL.

One male who relapsed more than three times and felt a tumor in his armpit considered whether to prioritize reducing tumor size with chemotherapy or maintaining his current good condition and ultimately chose the latter.

> One point is that if I undergo chemotherapy, the damage will be greater. The other point is that I'm not having any problems with my daily life and not feeling unwell at all, so I think it's better to continue as I am now rather than undergoing treatment.

(participant J, male, 60s, watch-and-wait)

One participant, who was treated for an enlarged relapsed gastrointestinal iNHL felt that she was not experiencing any interference caused by iNHL because she had no symptoms.

> This disease, lymphoma, really doesn't hurt or itch. So, in that sense, I can live as usual.

(participant M, female, 70s, remission)

3.2.1.2 | Resigned Acceptance of Chronic Physical Change. Participants continued to experience tumor site-specific symptoms, side effects, and decline in physical strength due to aging over the long-term, which remained post-treatment and did not improve with supportive care. Therefore, they perceived these conditions as inevitable.

> I don't pursue that point (loss of vision) (with the doctor). Even if I want to see it, even if I want to say, what will happen if I say it, it won't help at all.

(participant O, female, 70s, follow-up)

One female, 22 years post-diagnosis, regretted vision loss in her right eye due to intraocular lymphoma; however, she trusted the doctor and believed they did not underestimate her vision loss during treatment, understood that it would not recover, and had no choice but to accept it.

3.2.2 | Anxiety of Progression in the Near Future

Due to their experiences of r/r and multiple treatments, the participants believed that disease progression or death would occur in the near future. The worsening of disease was seen as realistic, and even if anxiety and fear did not dominate their lives, they were always on their minds.

For one female, the repeated relapses in a shorter period than expected were an unpredictable course, and the possibility that future treatment would not be effective caused anxiety.

TABLE 1 | Demographic and clinical characteristics.

	Quantitative data (n = 50)		Qualitative data (n = 20)	
Characteristics	***n***	**%**	***n***	**%**
Sex				
Male	24	48	10	50
Female	26	52	10	50
Age (mean [SD])	72.42 [9.72]		72.75 [7.40]	
Marital status				
Not married	8	16	2	10
Married	42	84	18	90
Living with family or partner				
No	10	20	4	20
Yes	40	80	16	80
Employment status				
Unemployed, retired	37	74	15	75
Employed	13	26	5	25
Diagnosis				
Follicular lymphoma	31	62	11	55
MALT lymphoma	13	26	6	30
Others	6	12	3	15
Time since diagnosis (years) (mean [SD])	14.56 ± 7.37		14.15 ± 8.48	
Relapsed or refractory				
Relapsed	46	92	16	80
Refractory	4	8	4	20
Number of relapses	(n = 46)		(n = 16)	
1	18	39	6	37
2	18	39	3	19
More than 3	10	22	7	44
Disease condition				
Remission	22	44	9	45
Follow-up, watch-and-wait	17	34	6	30
During treatment, scheduled to begin treatment	11	22	5	25
Ever received chemotherapy				
No	1	2	0	0
Yes	49	98	20	100
Ever received radiation				
No	38	76	15	75
Yes	12	24	5	25
Ever received transplant				
No	47	94	18	90
Yes	3	6	2	10
Charlson comorbidity index				
CCI = 0	32	64	15	75
CCI ≥ 1	18	36	5	25

Abbreviations: CCI, Charlson comorbidity index; MALT, mucosa-associated lymphoid tissue; SD, standard deviation.

TABLE 2 | Health-related quality of life and unmet needs in all domains (n = 50).

	Mean	SD	Min	Max
FACT-lymphoma				
FACT-lymphoma total	126.41	19.80	80.50	162.00
FACT-general	78.51	13.73	53.50	107.00
Physical well-being	24.25	3.71	16.00	28.00
Social/family well-being	17.42	6.42	0.00	28.00
Emotional well-being	17.90	4.33	5.00	24.00
Functional well-being	18.94	6.24	0.00	28.00
Lymphoma subscale	47.90	8.06	25.00	59.00
SCNS-SF34				
SCNS psychological	21.83	23.27	0.00	90.00
SCNS health system and information	25.96	23.68	0.00	81.82
SCNS physical and daily living	13.20	17.08	0.00	60.00
SCNS patient care and support	15.08	14.86	0.00	60.00
SCNS sexuality	4.83	11.05	0.00	58.33

Abbreviations: FACT, Functional Assessment of Cancer Therapy; SCNS, Supportive Care Needs Survey; SD, standard deviation.

TABLE 3 | Prevalence of some level of unmet needs (n = 50).

			Prevalence	
Rank	**Domain**	**Item of SCNS-SF34**	***n***	**%**
1	PS	Fears about the cancer spreading	20	40
2	PS	Worry that the results of treatment are beyond your control	18	36
3	PS	Concerns about the worries of those close to you	17	34
4	PS	Anxiety	16	32
5	PS	Feelings about death and dying	15	30
5	H	Being informed about things you can do to help yourself to get well	15	30
5	H	Having access to professional counseling if you, family or friends need it	15	30
5	H	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up	15	30
9	PS	Uncertainty about the future	13	26
10	PH	Not being able to do the things you used to do	12	24
10	H	Being informed about your test results as soon as feasible	12	24
10	H	Being informed about cancer which is under control or diminishing (that is, remission)	12	24
13	PS	Feeling of sadness	11	22
13	PS	Keeping a positive outlook	11	22
13	H	Being adequately informed about the benefits and side-effects of treatments before you choose to have them	11	22
16	PH	Lack of energy/tiredness	10	20
17	PH	Work around home	9	18
18	PS	Feeling down or depressed	9	18
18	PS	Learning to feel in control of your situation	9	18
18	H	Being given explanations of those tests for which you would like explanations	9	18
21	H	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	8	16

(Continues)

TABLE 3 | (Continued)

Rank	Domain	Item of SCNS-SF34	Prevalence *n*	Prevalence %
21	H	Being treated like a person not just another case	8	16
21	H	Being treated in a hospital or clinic that is as physically pleasant as possible	8	16
24	PH	Feeling unwell a lot of the time	6	12
24	PA	Reassurance by medical staff that the way you feel is normal	6	12
26	PA	Hospital staff attending promptly to your physical needs	5	10
26	PA	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	5	10
26	H	Being given written information about the important aspects of your care	5	10
29	PA	More choice about which cancer specialists you see	4	8
30	PH	Pain	3	6
30	S	Changes in sexual feelings	3	6
30	PA	More choice about which hospital you attend	3	6
33	S	Changes in your sexual relationships	1	2
33	S	To be given information about sexual relationships	1	2

Abbreviations: H, health system and information; PA, patient care and support; PH, physical and daily living; PS, psychological; S, sexuality; SCNS-SF34, Supportive Care Needs Survey Questionnaire–short form.

TABLE 4 | Association between health-related quality of life and unmet needs ($n = 50$).

	FACT-lymphoma total	FACT-general	Physical well-being	Social/family well-being	Emotional well-being	Functional well-being	Lymphoma subscale
SCNS psychological	−0.410**	−0.331*	−0.543***	0.075	−0.570***	−0.211	−0.464***
SCNS health system and information	−0.388**	−0.323*	−0.666***	−0.079	−0.490***	−0.103	−0.447**
SCNS physical and daily living	−0.539***	−0.475***	−0.558***	−0.103	−0.470***	−0.389**	−0.542***
SCNS patient care and support	−0.305*	−0.220	−0.579***	0.074	−0.424**	−0.108	−0.457***
SCNS sexuality	0.199	0.217	−0.043	0.135	0.122	0.327*	0.023

Note: Spearman's rank correlation coefficient.
Abbreviations: FACT, Functional Assessment of Cancer Therapy; SCNS, Supportive Care Needs Survey.
*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

> Especially when it (iNHL) came back after the second treatment, I was worried because the effects and the period of effectiveness were getting shorter. I thought, "Why? If it comes back so quickly, what will happen in the future?"
>
> (participant L, female, 50s, remission)

One participant, 20 years post-diagnosis, was aware that his condition would soon worsen and had not experienced any symptoms other than tumor awareness. He was fearful about the uncertainty regarding the distress he would experience from aging and disease progression.

> I imagine that my physical strength will weaken, and as I get older, it (the tumor) will appear more and more, and finally my lymph will become swollen and painful.
>
> (participant F, male, 80s, watch-and-wait)

3.2.3 | Make the Best of Life

Most participants had changed their mindset toward living with r/r iNHL, valuing and cherishing their current life, and made the most of it despite facing a long-term, incurable disease.

3.2.3.1 | Changing Mindset to Live With Disease. Instead of being pessimistic, most participants had changed their mindsets to live with the disease, some of them consciously, and many adopted this mindset after long-term survival despite living with r/r and treatments.

> Eventually, I'm sure there will be times when the condition worsens, but no treatment is given, so I guess there's nothing I can do about that. I've lived for 20 years. When I was first told (diagnosed), me and my wife thought I would die.

(participant E, male, 60s, watch-and-wait)

Participant E, 20 years post-diagnosis and having relapsed more than three times, accepted his disease and what would happen in the future due to its progression, as he lived longer since diagnosis.

3.2.3.2 | Efforts to Continue Now. Most participants were satisfied with their current situation; they were able to survive despite r/r and treatment and were living each day to the fullest. They wanted to maintain their current condition and continued to make efforts to live better.

> Creating my own life. So, it's destiny. So, if you come to pick me up tomorrow (to the afterlife), that would be fine. However, I want to live each day to the fullest.

(participant I, male, 70s, during treatment)

One participant, while thinking that “what will be, will be,” was striving to live a long and healthy life by putting in maximum effort. Another participant appreciated the value of his own life as he was able to continue work and live well into his 70s, despite enduring r/r iNHL and undergoing treatment.

> I am somehow able to work even with this kind of illness. ...do the hobbies... able to move around. So, I guess it is disappointing to have this disease, but I also realized that there is a world of its own.

(participant S, male, 70s, during treatment)

3.2.4 | Means to Live With Uncertainty

Participants recognized that understanding their condition and having access to information that would provide them with the means to help them engage in their autonomous recuperation was important for living better in an uncertain situation.

3.2.4.1 | Grasp Disease Condition to Feel Secure. For participants who recognized that iNHL was incurable, the uncertainty of not being able to grasp their own situation was accompanied by anxiety, and they felt reassured if given an accurate understanding of the condition.

One male scheduled to start a third line of treatment understood that iNHL progresses slowly, but because he had no subjective symptoms and could not grasp his condition, regular check-ups led to a sense of security.

> If it (disease progression) were faster, I would probably worry about it often, but since it is slower, I am relieved to know that I can check it once a year to see how it is doing.

(participant R, male, 70s, scheduled to begin treatment)

3.2.4.2 | Seek Information for Autonomous Recuperation. Many participants recognized the need to make their efforts to enhance their longevity, health, and motivation to combat the disease in a situation where they understood that iNHL is incurable and may progress. They expressed a need for useful information to help access necessary resources and increase what they could do on their own.

The concerns of one male, 24 years post-diagnosis, extended beyond iNHL. He sought a place to discuss future plans, including aging and comorbidities, considering how he would spend the end of his life.

> Since death is gradually approaching... it would be a relief to be able to consult with someone about my condition and treatment, whether I should undergo such treatment, and if not, what kind of place I should go to for care.

(participant N, male, 80s, remission)

3.3 | Integration of Quantitative and Qualitative Results

Quantitative and qualitative results confirmed or expanded on each other (Table 5). Although the participants had low HRQOLs, their acceptance of their situations from living with r/r iNHL long-term and due to aging expanded our understanding of HRQOL. Participants valued and cherished their lives and tried to make the best of them, influencing their perceptions of unmet needs. The fact that the participants were resigned to their symptoms, which they perceived as unremarkable, explained their fewer physical and daily living unmet needs. In contrast, even if participants were changing their mindsets to live with disease, they had psychological unmet needs and were using means to live with uncertainty. The quantitative and qualitative results for the physical and daily living and psychological domains of unmet needs complemented each other and expanded our understanding. Furthermore, confirmation of both results highlighted high unmet needs related to the health system and information, even among patients with iNHL who had long-term experience with r/r and multiple treatments, and low unmet needs in patient care and support and sexuality.

4 | Discussion

This mixed-methods study provides new and comprehensive insights into the unmet needs and HRQOL of patients with r/r iNHL, an understudied patient group. Quantitatively, the findings revealed high unmet needs of patients with r/r iNHL in the

TABLE 5 | Joint display of health-related quality of life and unmet needs.

Domains	Quantitative results	Qualitative results		Meta-inferences
		Themes	Quotes	
Health-related quality of life	FACT-Lym (mean [SD]): 126.41 [19.80]	Make the best of life	“Creating my own life. So, it's destiny. So, if you come to pick me up tomorrow (to the afterlife), that would be fine. However, I want to live each day to the fullest.” (participant I, male, 70s, during treatment)	Expansion: Although HRQOL, FWB, SWB was low, participants were accepting their situation and making the best of life
			“I'm living somehow now. If it doesn't get worse, all the best. It's not going to get better... I do think it will get worse. That's because it's a disease and that's how it is. Many people die from this disease, don't they? I Am fortunate that I have had this disease for more than 20 years. At first, I was told that I would live 7–10 years with this disease. I have lived this long. Isn't that amazing?” (participant O, female, 70s, follow-up)	
			“I think that, after all, I suffered a lot from iNHL for 10 or 15 years. I was in and out of hospital repeatedly, and after I was discharged, I did things like laughing and doing Tai Chi to reduce the side effects of the chemotherapy. I think that the fatigue from all that caused my hearing loss.” (participant Q, female, 70s, remission)	
Functional well-being	FWB (mean [SD]): 18.94 [6.24]		“Right now, I am able to live a normal life, just like everyone else, so I don't think about the things that I don't like.” (participant P, female, 70s, remission)	
			“I am somehow able to work even with this kind of illness. ...do my hobbies ... able to move around. So, I guess it is disappointing to have this disease, but I also realized that there is a world of its own.” (participant S, male, 70s, during treatment)	
Social/family well-being	SWB (mean [SD]): 17.42 [6.42]		“My husband also supports me, and my daughter also comes to see me, and asks me how I was doing. Well, even just that was enough for me, as my daughter was also working, so I was satisfied with that.” (participant B, female, 70s, during treatment)	
			“I was working while taking chemotherapy, but I couldn't say ‘Ugh, I feel sick’ at work, because I don't want people to think I was being weird if I did say something like that.... I never say anything like that at work. Because I don't want to show my weak side to my friends.” (participant K, male, 50s, remission)	

(Continues)

TABLE 5 | (Continued)

Domains	Quantitative results	Qualitative results		Meta-inferences
		Themes	**Quotes**	
Physical well-being	PWB (mean [SD]): 24.25 [3.71]	Unremarkable symptoms	“This disease, lymphoma, really doesn't hurt or itch. So, in that sense, I can live as usual.” (participant M, female, 70s, remission)	Confirmation: PWB was not that low and results of the qualitative result of unremarkable symptom confirmed each other
			“The numbness here (in the face) is still there, ... Now that the lymphoma that was here has cleared up, it's possible that the nerve was damaged that time, so it's a little bit like it (the numbness) remains here.” (participant C, male, 70s, scheduled to begin treatment)	
			“I can manage to get by at work, but I feel like I'm a bit tired and I've probably overdone it a bit. It's not that I'm so tired I can't help but lie down, but I feel like I've done a bit too much work, but it's not really affecting my life in any particular way.” (participant K, male, 50s, remission)	
Emotional well-being	EWB (mean [SD]): 17.90 [4.33]	Anxiety of progression in the near future	“Especially when it (iNHL) came back after the second treatment, I was worried because the effects and the period of effectiveness were getting shorter. I thought, ‘Why? If it comes back so quickly, what will happen in the future?’” (participant L, female, 50s, remission)	Confirmation: Low EWB and qualitative results of participants worried about the progression confirmed each other
			“I imagine that my physical strength will weaken, and as I get older, it (the tumor) will appear more and more, and finally my lymph will become swollen and painful.” (participant F, male, 80s, watch-and-wait)	
			“I'm always worried that ‘as I get older, what if these symptoms get worse and worse again?’” (participant H, female, 60s, follow-up)	
Unmet needs				
Physical and daily living	SCNS PH (mean [SD]):13.20 (17.08) prevalence of items with some level of needs: 6%–24%	Unremarkable symptoms	“I don't pursue (the doctor) that point (loss of vision). Even if I want to see it, even if I want to say, what will happen if I say it, it won't help at all.” (participant O, female, 70s, follow-up)	Expansion: The participants perceive their symptom as unremarkable and trying to make the best of life explains low unmet needs
			“Even if I talked to someone about it, I don't know if my appetite would come back... But I think I'm eating according to my age, so I don't have any desire to do anything about it.” (participant R, male, 70s, scheduled to begin treatment)	
		Make the best of life	“I am receiving regular checkups, information, and treatment, and I am able to manage my daily life on my own, so I guess I need to deal with it. I haven't gotten to the point where I want to ask for help yet.” (participant R, male, 70s, scheduled to begin treatment)	

(Continues)

TABLE 5 | (Continued)

		Qualitative results		
Domains	**Quantitative results**	**Themes**	**Quotes**	**Meta-inferences**
Psychological	SCNS PS (mean [SD]): 21.83 (23.27) prevalence of items with some level of needs: 18%–40%		"Eventually, I'm sure there will be times when the condition worsens but no treatment is given, so I guess there's nothing I can do about that. I've lived for 20 years. When I was first told (diagnosed), me and my wife thought I would die." (participant E, male, 60s, watch-and-wait)	Expansion: Although the participants are making the best of life, the prevalence of unmet needs is high, and the participants are using means to live with uncertainty
			"If I could get better by worrying about it, I would worry as much as I wanted, but that would only make me mentally crazy. Fortunately, I am not in such a difficult situation, so I can say that, but I live my life thinking, 'it doesn't matter if I dwell on it'." (participant T, female, 60s, watch-and-wait)	
		Means to live with uncertainty	"If it (disease progression) were faster, I would probably worry about it often, but since it is slower, I am relieved to know that I can check it once a year to see how it is doing." (participant R, male, 70s, scheduled to begin treatment)	
Health system and information	SCNS H (mean [SD]): 25.96 (23.68) prevalence of items with some level of needs: 10%–30%		"Since death is gradually approaching, ... it would be a relief to be able to consult with someone about my condition and treatment, whether I should undergo such treatment, and if not, what kind of place I should go to for care." (participant N, male, 80s, remission)	Confirmation: High level of unmet needs in the health system and information was confirmed by quantitative and qualitative results
			"I'm still wondering whether new drugs are being developed or not. So, I'd like to know if there's anything that can tell me about that. If I could find out, for example, that a certain drug is at a certain stage of clinical trials, it would give me a lot of energy and I'd feel much more confident." (participant J, male, 60s, watch-and wait)	
			"I'd like to study any useful information to extend my healthy life span. So, I would be happy if a dietitian or someone like that could give me advice on these things again, and... I would be happy if you could give me advice from the same standpoint as I am." (participant I, male, 70s, during treatment)	
Patient care and support	SCNS PA (mean [SD]): 15.08 (14.86) prevalence of items with some level of needs: 6%–12%	No related themes were developed		Confirmation: No related themes developed in qualitative results and the low unmet needs in the quantitative results confirmed each other.
Sexuality	SCNS S (mean [SD]): 4.83 (11.05) prevalence of items with some level of needs: 2%–6%	No related themes were developed		

Note: Confirmation is when the quantitative and qualitative results are similar and confirm each other. Expansion is when quantitative and qualitative results expand insights into a phenomenon by addressing different aspects of the phenomenon, or by explaining complementary aspects of the phenomenon.

Abbreviations: EWB, emotional well-being; FACT-Lym, Functional Assessment of Cancer Therapy–Lymphoma; FWB, functional well-being; H, health system and information; PA, patient care and support; PH, physical and daily living; PS, psychological; PWB, physical well-being; S, sexuality; SCNS, Supportive Care Needs Survey; SD, standard deviation; SWB, social/family well-being.

psychological and health system and information domains and a negative association of unmet needs and HRQOL. Qualitatively, the experience of r/r and undergoing multiple treatments long-term had caused the participants to perceive their physical symptoms as unremarkable; nonetheless, anxieties associated with disease progression remained due to their realistic perceptions of progression in the near future. The participants sought means to live with uncertainty while accepting living with r/r iNHL and aimed to make the best of their lives. The integration of quantitative and qualitative findings revealed that by living with r/r iNHL long-term while aging, participants accepted their low HRQOLs and attempted to make the best of life; this attitude influenced their perception of unmet needs.

The HRQOL of patients with r/r iNHL was lower than that of patients without recurrence [32], but their acceptance of the situation and efforts to make the best of life affected their perception of unmet needs. This finding may be explained by the fact that patients with r/r iNHL were older and had lived longer since diagnosis than previously reported [13, 14]. A qualitative study revealed that older patients with advanced cancer considered their long-term trajectory to be the result of their struggle, so they may feel pressure to continue to fight by showing a good face without complaining; additionally, older age is linked to positive discourse [33]. Furthermore, participants experienced distress that negatively impacted HRQOL, such as fears of progression and persistent physical symptoms [34], and while facing these challenges long-term, they changed their mindset to living for the best, which can be considered posttraumatic growth [35, 36]. This phenomenon is characterized by positive changes that occur from struggling with highly distressing situations, including increased appreciation for life due to a changed sense of what is important, increased sense of personal strength, and recognition of new possibilities and paths in life [35]. Aging and the trajectory of long recuperation for patients with r/r iNHL may lead to a greater appreciation for their current lives and recognition of the need to continue to make efforts to live better, which contributes to the low prevalence of unmet needs.

Additionally, participants' lower unmet physical and daily living needs may be due to 78% of participants not undergoing active treatment, likely leading to fewer distressing symptoms associated with their tumors. Additionally, qualitative findings suggest that participants experienced no improvement in their symptoms and came to view the persistence of these symptoms as inevitable. This finding is supported by a finding in patients with oral cancer who experienced failed expectations regarding symptom recovery, leading to a resigned acceptance [37]. Therefore, participants may have had lower unmet physical and daily living needs.

The participants experienced anxiety and uncertainty regarding disease progression, even when changed their mindset, and had unmet needs related to the health system and information and psychological domains. Patients with cancer recurrence show a low-to-moderate fear of progression that remains stable to some extent due to their acceptance of further progression after recurrence [38]. Furthermore, older patients with advanced cancer have reported that they do not consider their cancer a severe problem, but part of aging that will ultimately lead to death [33]. As the participants had experienced r/r and aging, their anxiety and fear were not severe; however, they were aware about the potential for end-of-life or death in the near future.

The participants' unmet need for means, including information, may stem from their desire to live autonomously in a situation of uncertainty. Patients with cancer recurrence desire to actively participate in the decision-making of treatment plans and obtain a comprehensive understanding of their medical condition as a source to cope with their condition [38]. In addition, older patients with advanced cancer who believe they need to stay active and continue to fight [33] believe it is important to acquire the necessary means and work independently for their disease to make the best of their lives. This is also supported by previous research, which indicated the necessity for clear pathways to access more specific disease-related information [16]. The low level of unmet needs in the sexuality domain aligns with findings from previous studies [39], likely influenced by the older participants, who are beyond the reproductive years.

Herein, higher unmet needs were associated with a lower HRQOL, similar to previous findings on NHL [13]. To help patients with r/r iNHL make the best of life while preserving their HRQOL, it is essential to provide support that addresses their unmet needs, especially in the health system and information and psychological domains.

4.1 | Study Limitations

This study has several limitations. The small sample size, owing to iNHL's low incidence and the inclusion of only patients with r/r conditions, limits the statistical power. Additionally, the recruitment from a single hospital restricts the generalizability of the results, suggesting a need for further multi-center studies. Furthermore, the absence of member checks [31] to validate qualitative data, although intended to reduce participants' physical and psychological burdens, may affect the credibility of the insights gathered; however, peer debriefing with other researchers ensured trustworthiness [40].

4.2 | Clinical Implications

Our findings provide vital insights into the care of patients with r/r iNHL. Healthcare providers should understand that patients with r/r iNHL strive to live autonomously to make the best of their lives. They should offer robust support in the health system and information domains to ensure that patients can access necessary means and receive psychological support. Additionally, patients should be regularly screened to provide timely and appropriate assistance.

4.3 | Conclusion

This study provides comprehensive insights into the unmet needs and HRQOL of patients with r/r iNHL. The long-term process of r/r and repeated treatment and aging led participants to accept their low HRQOL, value their current situations, and make efforts to make the best of their lives. They became resigned to chronic physical change and thought realistically about future progression. To support them, assistance in the health system and information, and psychological domains is essential. This study's results demonstrate that addressing unmet needs is crucial for helping patients with r/r iNHL living with the disease long-term to live their best lives while maintaining a favorable HRQOL.

Author Contributions

Miki Sugimoto conceptualized and designed the study, acquired data, analyzed and interpreted the data, acquired funding, administered the project, and wrote original draft of manuscript. Kaori Yagasaki conceptualized and designed the study, analyzed and interpreted the data, administered the project, and supervised the research. Eri Matsuki, Takayuki Shimizu, Masatoshi Sakurai, and Keisuke Kataoka contributed to the acquisition of data. Ardith Z. Doorenbos designed the study. All the authors involved in revising & editing, and approved the final version of the manuscript.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available upon request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. Transcripts of interviews are not available due to privacy and ethical restrictions.

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