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# Stories of Lymphoma Survivors in Early Aftercare

## A Narrative Inquiry

### KEY WORDS

Lymphoma  
Survivorship  
Aftercare  
Nursing  
Narrative inquiry

**Background:** Survivors of lymphoma experience multiple challenges after treatment. However, a lack of knowledge of in-depth experiences of lymphoma survivors in early aftercare persists. **Objective:** To gain an in-depth understanding of the experiences of lymphoma survivors in early aftercare who have received an aftercare consultation based on evidence-based guideline recommendations, with an advanced practice nurse. **Methods:** This study used a narrative design. We recruited lymphoma survivors after a best-practice aftercare consultation with an advanced practice nurse. A total of 22 lymphoma survivors and 9 partners participated. Data were collected through narrative interviews and analyzed according to thematic narrative analysis. **Results:** Six themes emerged: living and dealing with health consequences, coping with work and financial challenges, having a positive outlook and dealing with uncertainty, deriving strength from and experiencing tensions in relationships, getting through tough times in life, and receiving support from healthcare professionals. **Conclusions:** The stories of lymphoma survivors in early aftercare revealed their experiences of how they coped with a range of challenges in their personal lives. Choosing an aftercare trajectory based on an aftercare consultation that encourages patients to think about their issues, goals, and possible aftercare options may be useful

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for their transition from treatment to survivorship. **Implications for practice:** Survivors' social support and self-management capabilities are important aspects to be addressed in cancer care. An aftercare consultation involving shared goal setting and care planning may help nurses provide personalized aftercare.

Lymphomas are a heterogeneous group of hematological malignancies that arise from lymphocytes. Lymphomas are divided into 2 main subtypes: non-Hodgkin lymphoma (NHL) and Hodgkin lymphoma (HL).<sup>1</sup> Treatment options for lymphomas include chemotherapy, radiation therapy, immunotherapy, targeted therapy, and bone marrow transplantation.<sup>1</sup>

Treatment of lymphomas is often associated with fatigue; physical activity deficits; relationship concerns; emotional and cognitive consequences; and financial, employment, and insurance issues.<sup>2-9</sup> Advances in treatment efficacy have improved cure and remission rates, leading to more survivors living after treatment and thus experiencing adverse effects of lymphoma treatment.<sup>10</sup> In addition, the transition period following therapy might cause distress, and lymphoma survivors may have unmet needs. Lingering physical effects of treatment (eg, fatigue), more time to reflect on fear of recurrence, and decreased contact and support from the health team after treatment may all contribute to distress.<sup>11</sup>

Although some research has addressed lymphoma survivors' aftercare needs,<sup>12-14</sup> few in-depth qualitative studies have investigated their experiences in the period after treatment. Moreover, these in-depth qualitative studies<sup>6,14,15</sup> were all conducted more than 3 months after treatment, with average intervals ranging from 14 to 29 months. The experiences of survivors reported in previous qualitative studies<sup>6,14</sup> indicate it might be valuable to support cancer survivors with an aftercare consultation soon after treatment is successfully completed. Evidence-based practice guidelines recommend conducting an aftercare consultation based on shared decision-making in which patients' challenges, goals, and wishes are systematically screened, shared, and integrated into an individualized cancer survivorship care plan to support transition to the survivorship phase.<sup>16-20</sup>

Although qualitative studies concerning the experiences of lymphoma survivors exist, we know little of the experiences of lymphoma survivors in early aftercare who received an aftercare consultation soon after treatment in advanced nursing practice. The aim of the study was to gain an in-depth understanding of the experiences of lymphoma survivors in early aftercare who have received an aftercare consultation based on evidence-based guideline recommendations, with an advanced practice nurse (APN). Exploring patients' experiences of aftercare as well as understanding their needs and the challenges they encounter may enable nurses and other healthcare professionals to deliver personalized and evidence-based aftercare.<sup>19,21</sup> Indeed, oncology nurses and APNs are crucial in providing patients with this aftercare consultation.<sup>22</sup>

## ■ Methods

We used a qualitative narrative inquiry<sup>23</sup> to obtain an in-depth understanding of the experiences of lymphoma survivors and

the meaning they give to these experiences of survivorship in the context of aftercare. We chose to conduct a narrative inquiry because we wanted to understand the real-life experiences of patients with cancer following the completion of their treatment as told through their own stories. Narratives contain rich, detailed, and often personal perspectives and are powerful tools in the sharing of knowledge.<sup>23</sup>

## Setting

The setting was a malignant lymphoma care pathway in a large, urban 980-bed teaching hospital in the south of the Netherlands. On average, 65 patients are treated for malignant lymphoma within this care pathway each year. Three hematologists have the medical responsibility for the patients, and 1 APN supports these patients during their disease trajectory. The APN telephones the patients during the weeks they receive chemotherapy to discuss adverse effects of their treatment and other health-related problems. After treatment, the patients receive long-term medical follow-up care every 3 months to detect recurrences of lymphoma or other malignancies. Aftercare may include education, physical training, and psychosocial support that help patients to deal with the potential challenges following cancer and its treatment. To provide patients with personalized aftercare soon after treatment completion, an aftercare consultation by the APN was implemented.

We developed and pretested this aftercare consultation during an iterative development process for complex interventions in nursing.<sup>24,25</sup> The consultation followed the main recommendations of evidence-based clinical practice guidelines regarding aftercare<sup>16-20</sup> and that are supported by additional published studies.<sup>26-28</sup> The consultation was divided into 4 phases: (1) preparation, (2) goal setting, (3) shared-care planning, and (4) evaluation (see Table 1 for content and process of the aftercare consultation and the Figure for an example of the visual tool "Four Domains of Life"). From March to June 2017, the APN received in-service coaching. After that period, the APN began to conduct the consultations without assistance.

## Recruitment and Participants

A total of 22 patients and 9 partners participated in this study. We applied the following inclusion criteria: (1) having been diagnosed with NHL or HL; (2) having been treated with chemotherapy, whether or not combined with other therapy; (3) being in remission after having been diagnosed for the first time or going through one or several relapses; and (4) having sufficient command of Dutch. We started with a sample of 33 patients who had received an aftercare consultation between June 2017 and March 2018, which occurred 3 and 8 weeks after treatment

**Table 1 • Content and Process of the Aftercare Consultation**

1. Preparation	Patients are invited to complete patient-reported outcome measures (PROMs) to detect health issues.
2. Goal setting	Goals are set collaboratively based on the outcomes of the PROMs facilitated with a visual tool (Figure).
3. Shared-care planning	Care is planned based on shared decision-making of different aftercare interventions (eg, physiotherapy or exercising in a sports club to cope with fatigue) and the impact of these options on lifestyle and financial resources.
4. Evaluation	The process and outcome of the aftercare consultation is evaluated by the nurse and patient.

completion. The APN invited 31 patients who fulfilled the inclusion criteria to participate in the study. Patients who initially agreed to participate when asked by the APN received written information and were contacted by telephone by a researcher (J.H.H.M.F.-S.) 1 week later. Of the 31 patients, 9 patients declined to participate. Reasons were wanting to close the illness period (n = 4); being too busy, for example, because of starting rehabilitation (n = 3); and no reason provided (n = 2). We welcomed partners of patients who agreed to attend the interview with the survivors (self-selection of partners). After having sampled the first 17 consecutive patients and 8 partners, we purposively sampled the next group of patients to guarantee variation in experiences by selecting patients of a younger age or those with a more chronic type of lymphoma and/or with multimorbidity. Data saturation, the point at which no new themes emerged and where the themes across respondents showed a repetition of similar responses in the unique narratives, was reached after 17 interviews.<sup>29</sup> We interviewed 22 patients and 9 partners, first, to confirm saturation,<sup>29</sup> and, second, to obtain additional narrative details within the themes (see Table 2 for patient characteristics).

### Ethical Considerations

The study was reviewed by the Medical Ethical Commission of Zuyderland-Zuyd, and ethical approval was granted (no. 16-N-193). All participants provided verbal and written informed consent prior to their interview. They were advised to contact the APN or a hematologist should the interview cause them distress. Contact information was provided by the interviewer.

### Data and Data Collection

Data collection occurred between June 2017 and March 2018. Participants were interviewed in the second and third week after the aftercare consultation via face-to-face narrative interviewing at the participants' home address. We developed an interview guide with open questions, as suggested in the narrative literature.<sup>23</sup> The interview guide was used flexibly by following the participants' stories to create opportunities for extended narration. First, we invited patients to tell about their experiences of early aftercare in personal stories. Examples of questions asked were as follows: "How are you doing now?" "How did you



**Figure ■ Example of the visual tool "Four Domains of Life."**

**Table 2 • Patient Characteristics**

Patient Characteristics	N = 22
Gender	
Female	8
Male	14
Age, y	
Range	27–74
Median age	65.5
Interquartile range	11
Educational level	
Low	5
Medium	8
High	9
Country of birth	
The Netherlands	19
Germany	1
Turkey	1
Morocco	1
Diagnosis and treatment	
Non-Hodgkin lymphoma	
Chemotherapy	19
Chemotherapy and biological therapy	2
Hodgkin lymphoma	
Chemotherapy and bone marrow transplant	1
Patients with $\geq 2$ recurrences	4

resume your everyday life after you received the diagnosis and treatment?” We then asked questions about their experiences with the care they had received, and we further discussed emerging topics. Partners attending the interviews were invited to add their stories. The interviews tended to last between 45 and 90 minutes.

## Data Analysis

Interviews were audiotaped and transcribed verbatim. A thematic narrative analysis was conducted as described by Riessman<sup>23</sup> using NVivo 11 software (QSR International, Cambridge, Massachusetts). Two researchers (J.H.H.M.F.-S. and J.M.J.H.) read the transcripts several times before and during the analysis to develop an understanding of the stories told. Then, these researchers used the following process steps to analyze the transcripts:

- Step 1: They selected relevant sequences and labeled them inductively with a descriptive code in such a way that the character of the narratives was preserved.
- Step 2: After coding 2 interviews, they discussed the content of the stories and descriptive codes and which codes could be incorporated in which themes. They defined preliminary themes and held a second analytical session after the analysis of the first 5 interviews.
- Step 3: Subsequently, the primary researcher (J.H.H.M.F.-S.) planned 2 analytic sessions with a researcher (A.M.) who is an expert in qualitative research to discuss the provisional themes.
- Step 4: The primary researcher coded all the interviews. During this process, the existing themes were adapted, refined, and merged, and new themes were added. The primary researcher reviewed the themes with the other members of the research team (G.J.J.W.B., A.J.H.M.B., K.-S.G.J., T.W.).

- Step 5: The primary researcher discussed with the expert (A.M.) the breadth and depth of the themes and ways to present them in a way that represented the “wholeness” of the narratives provided by the participants.
- Step 6: The researcher (J.M.J.H.) who had independently coded the first 5 interviews read all remaining interviews, and in an analytic session, she and the primary researcher (J.H.H.M.F.-S.) agreed upon the content and phrasing of the themes. All researchers reviewed and agreed upon the final themes.

## Trustworthiness

We used several strategies to ensure trustworthiness in terms of credibility, transferability, dependability, and confirmability.<sup>30,31</sup> Investigator triangulation was used by involving several researchers in a research team in the data analysis (see above), as well as in addressing the organizational aspects of the study. All researchers discussed the findings several times to capture the essence of the participants’ narratives. We facilitated the transferability of findings to other contexts for readers by providing a “thick description” of the participant, the context, and the research process. To ensure dependability, we followed the narrative thematic analysis process<sup>23</sup> and ensured our study conformed to the standards for reporting qualitative research.<sup>32</sup> To ensure confirmability, the primary researcher (J.H.H.M.F.-S.) discussed and reflected on the study design and analysis with other researchers. In narrative research, utility is often mentioned as a quality criterion.<sup>23</sup> We have formulated recommendations ensuing from our findings, which can further improve early aftercare.

## Findings

We identified 6 relevant themes in the respondents’ narratives: (1) living and dealing with health consequences, (2) coping with work and financial challenges, (3) having a positive outlook and dealing with uncertainty, (4) deriving strength from and experiencing tensions in relationships, (5) getting through tough times in life, and (6) receiving support from healthcare professionals.

### Theme 1: Living and Dealing With Health Consequences

All patients still suffered from fatigue and/or loss of physical condition and strength following treatment. The patients reported that they were gradually expanding their daily activities and improving their physical condition by exercising, often resuming types of exercise they had engaged in before their illness. However, the patients indicated they had not yet regained the exercise capacity they had before their diagnosis.

Yeah, well, have to search a bit to improve fitness a bit, and, yeah, I think I need a strong body. Now I’m still very weak, so my legs are very weak, and so climbing stairs, etc, from the apartment, like, I used to do that, but now I have to take breaks a bit first. (Male, 62 years old, chronic form of NHL, not of native Dutch origin)

Both patients' and partners' stories showed that some activities were meaningful to them, and patients were longing to resume their participation in such activities as walking or cycling in the countryside or working in their garden.

[Wife] Alone. He prefers to cycle on his own, and then it's...

[Patient] Into the woods, and then I can hear the birds singing. That's the best medicine for me.

[Wife] Because if he has to sit inside, it drives him crazy.  
(Male, 73 years old, NHL, partner present)

Some patients still had cognitive problems, including memory loss and an inability to concentrate, and therefore were not able to read a book or follow a television program. This felt like a burden to them, as their partners sometimes had to help them recall information. To ameliorate this, they often played memory training games or trained their memory by working.

Patients were suffering from, albeit to a decreasing degree, hair loss, weight loss, tingling sensations and numbness in their fingers or toes, changes in defecation patterns, dry mouth, fungal infections or blisters in their mouth, dry eyes, or a weak voice. Most patients' hair had grown back, but women were still often wearing a wig or a headscarf. Most patients reported that the hair loss, sometimes including the loss of their beard or pubic hair, had been an emotional burden to them and sometimes also to their families. They felt ashamed of how they looked, as their appearance confronted them and their relatives with their disease.

[Patient] Yeah, I thought it was a bit ugly like that.

[Husband] I know.

[Patient] The way I look. Like a dead person.

[Husband] Our daughter hasn't seen her without her hair yet.

[Patient] No, she didn't want to see me like that. So far.

[Husband] She doesn't want to. (Female, 60 years old, NHL, partner present)

## Theme 2: Coping With Work and Financial Challenges

The stories told by patients regarding employment varied considerably. Some patients worked part-time throughout the treatment period, whereas others stopped working. Some of the patients who stopped had not yet resumed work because of their weak physical condition and strength. Others recently started working part-time as part of occupational reintegration. Only 1 patient was working at the same level as before he became ill. Most patients stated they discussed how they intended to resume their job with their employers and that their employer and/or colleagues were very considerate about their illness.

Yeah, I have a nice job, and I'm also very pleased with the way my employer is currently dealing with my illness. I'm being given all the space, all the freedom I need to arrange

things my way. When I started the chemotherapy, I immediately got an email from the person who took over my work and takes care of my work for me, so that was perfectly arranged. (Male, 58 years old, chronic form of NHL)

Resuming their job was important to the patients in our study; however, in some cases, the illness led to problems with their employment contract, for instance, a temporary contract not being renewed because of their illness or being dismissed after the illness. Patients who had lost their jobs felt worried about finding a new one and were unsure of their legal rights. As one couple remarked, the loss of work negatively affects the family's financial situation:

[Husband] She only thinks about looking for a job because we have a lot of bills, and now we have less income.

[Patient] I did not work enough to get a benefit.\*

[Husband] We do not receive any money, nothing.

[Patient] This case is not closed yet.

[Husband] That woman (from a social security service) said you are entitled to get a benefit, no matter how many hours you have worked. (Female, 60 years old, NHL, partner present)

Some patients reported that additional costs, such as taxi fares to the hospital, made it harder for them to make ends meet. Financial considerations regarding aftercare interventions, such as oncological rehabilitation, discussed during the aftercare consultation included whether the intervention would be reimbursed by their insurance. If an intervention was not reimbursed, some respondents chose another option that was affordable to them, such as physical therapy or joining a sports club.

## Theme 3: Having a Positive Outlook and Dealing With Uncertainty

All patients expressed feelings of having a positive outlook, as well as dealing with uncertainty. Patients who were diagnosed with lymphoma for the first time and had received favorable test results after the treatment were hopeful that the disease would not return. Although they had often gone through a period of uncertainty before the diagnosis, patients courageously underwent their treatment and put their faith in their doctor when they were told their cancer was treatable. Patients expressed they were relieved to be alive, especially because they had known people who had died shortly after being diagnosed with cancer. They also saw the end of their treatment as the conclusion of one period and the start of another, in which they would work on their further recovery. Some patients made new plans for the future, for instance, having children or living with a girlfriend. Some patients also wanted to leave the period of treatment behind and no longer wanted to dwell on it too much.

\*In the Netherlands, patients can receive sick leave or unemployment benefits in the form of money from the state under certain conditions.

Whereas when I meet people I can tell them briefly how I'm doing and then say, "Let's do something enjoyable and fun" and "Let's talk about things that have nothing to do with it," right? Because I don't intend to die yet. Yeah, not thinking about it, that's, that's the main thing. Yeah, not thinking about it. At least that's my view. Anything that stops you from thinking about it increases your quality of life. (Male, 60 years old, NHL)

Patients also described how they learned to set different priorities (eg, women giving less priority to housekeeping). As a patient explained, she tried to live in the moment and take things easier.

Okay, if that's how it is, that's how it is, period. So, then I'm... I must say... I've learned a lot. I've found out that a lot of things can be made a lot easier. Those trousers, do they need to be ironed? Why? Sweater? I've just put it on as it was. I just hang, I just beat out the dust, I put it on a hanger, done. (Female, 66 years old, NHL)

Some patients experienced feelings of "a void," when entering aftercare after the intense period of treatment with chemotherapy and regular check-ups at the hospital in which they were supervised by healthcare professionals. These feelings developed when they were no longer immersed in their treatment routine and had more time to reflect on all that had happened. Some of them also needed to regain trust in their own bodies after the intense treatment.

Well, it's, yeah, I think that's difficult, as I always had something to look forward to, I'd be looking forward eagerly to now, the time I'd have it all behind me, and that everything would be okay, etc. And now I get this feeling like now there's nothing to look forward to, and that's kind of a strange feeling. It also seems as if it's only now, well, as if I'm only now realizing all that's happened. (Female, 27 years old, HL for the second time in 2 years)

Some patients experienced uncertainty if a scan did not decisively show that the disease had resolved, which meant they had to return for a new scan.

Well, it's the uncertainty, isn't it? As I'll have to have another scan in November. Because they know, the latest scan, there was still something there. And well, they'll then compare it with the next scan to see if it's the same or not. That's a bit difficult, yeah. You do carry that around with you to some extent. (Male, 44 years old, NHL)

Patients who had been treated after a recurrence and who had a more chronic form of lymphoma were glad about favorable test results but still worried about the possibility that the disease might recur again. The patients dealt with uncertainty as part of their life, and some respondents received support from a healthcare professional, such as a psychologist, to cope with their feelings. Patients thought about the possibility of recurrence and the way they react to this, ranging from grasping any option and any treatment available to not knowing what to choose. Some patients described not wanting any further treatment or planning euthanasia with their family physician

if the disease returned. Taking control by planning euthanasia made them feel less uncertain. When discussing the possibility of death, patients expressed they did not fear death because of their religious beliefs, they had signed a euthanasia declaration, or they felt they had led a "rich life."

I don't hope so. I don't assume it will, because I actually enjoy life very much. I don't want to keel over tomorrow, but if that should be the case in the end, then, well, I didn't like this chemotherapy, so suppose I was told next, in 2 years' time, another chemotherapy, but 6 times as tough as what you've had, and that might add 6 more months to your life, then yes, I don't know what the answer will be, maybe I'll then say, like, well don't bother, and then I'll keel over tomorrow, so to speak, because I think quality of life is also important, and well, just doing the things you like in life, that keep you on your feet. (Male, 58 years old, chronic form of NHL)

## Theme 4: Deriving Strength From and Experiencing Tensions in Relationships

Many patients expressed deriving strength from relationships, as well as experiencing tensions. Patients derived much strength and support from the assistance they received from relatives, friends, neighbors, or fellow patients. Examples of this assistance came in the form of people being willing to take over tasks, provide emotional support, and listening to their story. Patients reported that it was easier to tell their stories to certain friends than to others, as some people's responses were not helpful such as responses confronting patients with death. Some participants felt overburdened by their social contacts, as they felt they could not say no or they had to do something in return when the other person was also in a difficult situation. Occasionally, people around them failed to understand why they were able to do something one day and not the next.

The disease made some couples realize they could never live without each other, and they expressed how good of a team they were. Although the partner might sometimes have a different way of coping with the disease (eg, by wanting to know all the details of the disease), they remained attentive to the other's wishes. Some stressed the importance of healthcare professionals involving the partner because they can better explain how the patient is doing.

Yeah, that's what I liked very much, too. That at a certain moment, while I was at the physical therapist's, they'd called and my wife had taken the call. And yeah, a partner can, of course, explain much better how the patient is doing than the patient himself, because he tends to make things sound better than they really are. So yeah, it's, of course, important to involve the partner who is sitting beside the patient, right? (Male 72 years old, chronic form of NHL, second relapse)

Sometimes, the disease and its treatment led to tensions between partners and with their children. Family members sometimes had different ways of coping, which also negatively affected the patient's disease process, such as having more feelings of uncertainty. Some

patients reported they had been irritable during the treatment and had often taken it out on their partners. Some had sought counseling from a social worker or psychologist because of the tensions in their relationship, whereas others solved the problems themselves by realizing they needed to understand their partner's views or continued their relationship as it had always been. One couple reported that they had had problems regarding intimacy and sexuality during the treatment and that they were now in the process of rediscovering each other.

[Talking to partner] You've also had a tough time, not just me.

[J.H.H.M.F.-S.] The whole family is involved...

Absolutely. Even after you've had your first chemo, you're not allowed to, so to speak, just kiss each other, you have to sleep in separate beds; sheets and clothes have to be kept separate; you have to go to separate toilets, and all of that is also difficult for them, right, and then if I'm troublesome as well. They would always use the upstairs toilet, and I the downstairs one, those kinds of things, right? But fortunately, it's all over now and we can start to rebuild. (Male, 56 years old, NHL, partner present)

Some patients had lost contact with friends and others who no longer visited them. Although they felt abandoned by them, they tried to understand and accept it. The explanation they gave for this was that people did not know how to deal with the situation and that people often had other things to do during the daytime. However, some patients gained new friends or reconnected with old friends who they felt supported by, and this positively surprised them.

Yeah, I've lost contact with some people... they might send a message now and then, but I'm sitting here alone 24/7, and they never came to see me, so many people have disappeared. But on the other hand, there are also people who I hadn't expected it from and with whom I've developed a stronger bond. (Female, 27 years old, HL first relapse)

## Theme 5: Getting Through Tough Times in Life

Patients and partners said that apart from going through cancer and its treatment, they experienced other tough times, and all were a part of their life stories and influenced how they coped with cancer. Examples included suffering from severe comorbidity, partners or relatives suffering from or dying of various diseases, and problems with a child and coparenting issues, which felt like a heavy additional burden on top of the cancer. This made it harder to cope with cancer.

[Patient] No, not at all, as my brother had just died, 3 weeks before. All I did was cry. They (the nurses) used to ask me why I was crying so much. And I would say, "I'm sad."

[J.H.H.M.F.-S.] So you had that as well.

[Husband] Yeah, that as well. We went to the funeral. All the way from here to there. It was all too much for her. But,

well, there was no cure for him. (Female, 60 years old, NHL, partner present)

Some patients experienced rough times in life, such as immigrating to the Netherlands and trying to earn a living with all kinds of different jobs. These life events made them stronger in dealing with the challenges of cancer (eg, being active as much as possible). Patients said it was important that healthcare professionals knew their life issues and not only of their cancer and that they knew them more personally. This influenced the way they dealt with their cancer and the help they needed from healthcare professionals.

## Theme 6: Receiving Support From Healthcare Professionals

Patients and partners felt supported by care professionals throughout the different stages of their disease. They often placed great trust in their oncologists, and they appreciated it when their family doctor visited them proactively. Patients and their partners mentioned a number of important components of support from healthcare professionals. One aspect was the continuity of care by various doctors or being provided with sufficient information. Personal attention and empathy, similar to what they received from the APN, were greatly valued. Patients and their partners appreciated the aftercare consultation and felt it was useful. Some patients reported that this consultation was different from those during treatment. During treatment, the consultations focused on medical aspects of the disease and its treatment, and the aftercare consultation focused on psychosocial aspects and how to move on after treatment. One patient mentioned that he would have liked more information about the consultation beforehand, as he had not known what to expect. During the consultation, the nurse had discussed challenges experienced by patients based on a self-report questionnaire and a visual tool. The visual tool supported some patients in seeing the connection between challenges they experienced, and the consultation supported them to take action.

Yeah, so that (the aftercare consultation) made me decide to start working on it to become a bit stronger. Yeah. So that's when it all started, with the massages and all. I decided I need to work on it. (Female, 65 years old, NHL, partner present)

During the aftercare consultation, the patients set a variety of goals. One goal that was often mentioned was to regain their strength and to improve their physical condition.

Yeah, I also said my real goal is to improve my fitness to that of a 56-year-old man; I do not need to be as fit as an 18-year-old. (Male, 56 years old, NHL, partner present)

According to the patients, the aftercare consultation frequently resulted in initiatives for interventions, such as oncological rehabilitation or oncological physical therapy, social work, or psychological therapy. Some of the patients were treated by a physical therapist, started an intake procedure for oncological rehabilitation, or visited a psychologist or a social health worker.

Some patients opted to join a fitness center or to work on their physical condition on their own. The arguments patients used to decide whether to choose oncological rehabilitation, a fitness center, or training on their own were discussed during the aftercare consultation. These arguments included financial aspects, the distance to the facility, preferences regarding training in a group or alone, the freedom to attend the intervention or not, and the multidisciplinary approach of rehabilitation.

Just at the end of the street here is the hospital, where they do oncological rehabilitation. So, I opted for the hospital, as that is closest. And I think the care there will be a bit more comprehensive. I got all the forms and so it's been applied for, and I have to inquire at the hospital or at the health insurance to see if it's covered by my insurance or not. (Female, 67 years old, NHL, first relapse)

Those patients who had had few problems or whose problems already had been addressed had perceived the consultation as rounding off the treatment process. The nurse had informed patients about the possible consequences of their disease and the various options for aftercare, such as psychological help or peer support. Even if they did not feel the need for it at that time, at least they knew what was available should they feel the need for it later.

Some said they were glad to have had the aftercare consultation, as it would otherwise have been too abrupt an end to the treatment process.

Yeah, so you get that, and then you go home, and he says I'll see you in 3 months, and then you come home and you think so this was it, and the way it ends. So, you think he does not care about it. But then after a couple of days, XX phoned me, and she said we're going to have an aftercare consultation... I first thought when the doctor said it's over, and then they more or less leave you on your own, that's what it feels like, right, and then when she phoned I thought, "Well, I'll get a talk about what happens now." (Male, 56 years old, NHL, partner present)

The patients differed in terms of whether they still felt the need for more aftercare consultations in the year after their treatment. Some wanted to end the hospital process, indicating that they had other people to fall back on, such as their family doctor. Some explained that their need for further consultation would also depend on whether they would experience any symptoms later, in which case they would like to have consultations over the phone with the nurse. However, patients admitted that they might be more inclined to talk about certain problems in a face-to-face consultation. Other patients preferred to have further consultations at the hospital if they felt their family doctor was not very proactive or might not have the necessary expertise. Also, some patients stated they would appreciate it if problems and goals were followed up in further consultations.

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## ■ Discussion

The aim of the study was to gain an in-depth understanding of the experiences of lymphoma survivors in early aftercare who

have been exposed to an evidence-based aftercare consultation with an APN. We identified 6 themes: the way the lymphoma survivors coped with health consequences, work and financial challenges, optimism and uncertainty, strengths and tensions in relationships, additional difficult experiences in life, and the way they experienced support from healthcare professionals. This study adds to a limited body of in-depth qualitative studies on experiences of lymphoma survivors in early aftercare.

In our study, we found that patients made efforts to self-manage their lives, for example, by resuming activities they used to do before the disease, such as walking, cycling, or occupational activities. However, patients often were dealing with other life events besides the disease, which were also part of their life story. Our findings are in line with those of former studies in which cancer survivors made the best of their lives but with an underlying fear of recurrence.<sup>6,14,33,34</sup> It is important to explore with patients how they cope with uncertainty and if they need support from a healthcare professional.

From the findings of a former study,<sup>6</sup> we learned that moving away from the cancer experience might help patients in the transition from treatment to the survivorship phase. Our study confirmed these findings, as some patients in our study wanted to leave the period of treatment behind them and not dwell on it too much.

Social support from other people, especially their partners, was greatly valued by our patients, although some social relationships had deteriorated during the disease process, and others were not always supportive to the patients. Our study is in line with earlier studies<sup>6,35</sup> in acknowledging the need for healthcare professionals to address relationships (eg, by involving the partner or other people who can provide the survivor with social support in the dialogue with them).

Our findings also indicate that it is important to provide personalized aftercare from a holistic viewpoint and address patients' social support needs and self-management capabilities. This is in line with findings of earlier studies<sup>36-40</sup> and with recommendations in evidence-based clinical aftercare guidelines.<sup>16,18</sup> Personalized care planning based on goal setting and shared decision-making, which is integrated into our aftercare consultation, has been shown to have positive effects on self-management capability.<sup>20</sup>

Findings from other studies concluded that it might be valuable to implement aftercare consultations in routine cancer care,<sup>6,14,34</sup> whereas other studies suggested the need for more structure in consultations,<sup>11,41,42</sup> as patients often felt abandoned or not understood and received little information about aftercare. Our study adds to the knowledge of experiences of lymphoma survivors in early aftercare who received an evidence-based aftercare consultation. In our study, the aftercare consultation allowed patients to talk about the transition from active treatment to the survivorship phase and about their challenges, goals, and the options for aftercare, which frequently led to initiating aftercare interventions. Some patients in our study reported that feelings of abandonment had been prevented by the early aftercare consultation. Our patients varied in regard to their need for further aftercare consultations. Some would prefer to receive further aftercare from their family doctor. Therefore, developing an appropriate aftercare model shared between oncological



hospital care and primary care might be valuable, as suggested in other research.<sup>19,43,44</sup>

## ■ Strengths and Limitations

The narrative design of our study enabled us to obtain an in-depth description of the experiences of lymphoma survivors and some partners regarding the meaning they give to their cancer journey in the context of their lives in early aftercare. We chose this design to support APNs in gaining knowledge and understanding of patient experiences to deliver personalized aftercare. We deliberately included a group of patients who were exposed to an aftercare consultation approach with an APN to provide us with more in-depth insights into patients' experiences within this aftercare trajectory.

A limitation of our study might be a preponderance of older patients, as younger patients might have different experiences. However, the median age of the included patients was 65.5 years, which corresponds with the median age of the reported incidence of NHL.<sup>45</sup> Although the APN purposively sampled younger patients after the first 17 interviews, the only 2 younger patients who fit the criteria during the study period had refused to participate. One of the reasons given was that the patients wanted to leave the period of treatment behind and not dwell on it too much. In addition, we included only 1 person diagnosed with HL. The incidence rate of HL is lower compared to NHL, and the APN provided the aftercare consultation to only 2 patients with HL, of which one declined to participate in the study. Further, interviewing patients with partners might lead to information bias, as patients might give different answers in front of a partner than they would give alone. We, however, chose to welcome partners who agreed to attend the interview with the survivors. Finally, our patients were recruited from 1 lymphoma care pathway in a large urban teaching hospital where only 1 APN conducted the aftercare consultations. Thus, the views of the survivors in our sample represent a specific group. Although our study has revealed the experiences of survivors who were exposed to an evidence-based aftercare consultation, the wider credibility of our findings needs to be established in other settings.

## ■ Implications for Nursing Practice and Further Research

Our study has several implications for practice and research. First, survivors' social support and self-management capabilities are important aspects to be addressed in aftercare, so it can be tailored to their individual needs, preferences, and context. An aftercare consultation involving shared goal setting and shared-care planning may help nurses and other healthcare professionals provide personalized aftercare. Second, it seems important to offer survivors a greater range of aftercare models rather than only 1 aftercare consultation at the hospital, such as models involving both hospital care and primary care. Further research in other cancer aftercare settings in which survivors are provided with an aftercare trajectory

based on the evidence-based aftercare consultation is needed to study its effectiveness.

## ■ Conclusions

The stories of lymphoma survivors and some partners provided us with more in-depth insights into their experiences of coping with various issues in their personal lives during early aftercare. Exploring and addressing their social support and self-management capabilities and knowing the patients as people might help nurses and other healthcare professionals to better tailor the aftercare intervention. Choosing an aftercare trajectory based on a systematic aftercare consultation in which patients are stimulated to think about their challenges, goals, and possible aftercare options may be useful in helping patients with the transition to the survivorship phase and in providing patients with personalized aftercare.

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