

Experiences of Young Adults With Lymphoma During the COVID-19 Pandemic

Joseph A. Vena, PhD, RN

PURPOSE: To investigate the experiences of young adults with lymphoma during the COVID-19 pandemic.

PARTICIPANTS & SETTING: 8 young adults with Hodgkin or non-Hodgkin lymphoma from one National Cancer Institute–designated cancer center in the northeastern United States.

METHODOLOGIC APPROACH: Secondary data analysis of a study that investigated the experiences of young adults with lymphoma during acute survivorship was used. Thematic analysis was chosen for the secondary data analysis methodology.

FINDINGS: Three themes define the experiences of young adults with lymphoma during the COVID-19 pandemic: susceptibility and threats of COVID-19, isolation and confronting cancer alone, and healthcare provider supportive care.

IMPLICATIONS FOR NURSING: Nurse-led survivorship care and education of young adults with cancer may mitigate COVID-19–related anxiety and threats.

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and the resulting illness, COVID-19, rapidly developed into a global pandemic, with more than 44 million known cases and more than 700,000 deaths in the United States as of mid-October 2021 (Centers for Disease Control and Prevention, 2021; Fauci et al., 2020). Cancer survivors are at an increased risk of contracting SARS-CoV-2 and developing COVID-19 because of acute treatment with antineoplastic and immunosuppressive medications, susceptible immune system risk to bacterial and viral infections, comorbidities, increased contact with sick individuals in healthcare systems, and heightened immune response because of treatment with certain types of immunomodulatory therapies (Dai et al., 2020; Kuderer et al., 2020). In addition, the COVID-19 pandemic has fundamentally altered cancer management and treatment, such as the move from face-to-face to virtual encounters, the demands of oncology healthcare providers aside from caring for patients with cancer, the adherence of healthcare providers to COVID-19 guidelines while fulfilling the supportive care needs of patients with cancer, the social isolation of patients with cancer because of nursing workforce restrictions, and the balance of essential and nonessential medical treatment (Broom et al., 2020; Butler et al., 2020; Paterson et al., 2020; Ueda et al., 2020).

The transition of oncology healthcare providers from face-to-face to virtual care has successfully mitigated the risk of vulnerable patients with cancer contracting SARS-CoV-2 (Curigliano et al., 2020; Ohannessian et al., 2020). However, the increased use of telemedicine and other related COVID-19 changes have caused unintended consequences, such as diminishing the emotional aspect of the clinician–patient encounter and producing unintentional effects on populations with fewer digital resources, including certain racial and socioeconomic groups (Elkaddoum et al., 2020; Royce et al., 2020; Yoon et al., 2020). Although

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the described guidelines and strategies inhibit exposure to SARS-CoV-2, the unintended consequences on the quality of life and experiences of patients with cancer are still under investigation.

Young adults with cancer are a unique population because of the distinctive biologic features of cancer diagnosed in this group, the prevalence of certain types of cancers during this age period, various developmental changes during young adulthood, the psychological and social effects of cancer as a young adult, and the range of adverse health outcomes, including the socioeconomic and racial disparities affecting their diagnosis, treatment, and overall survival (American Cancer Society, 2020; Anderson et al., 2019; Bleyer et al., 2008; Close et al., 2019; National Cancer Institute, 2006; Zembrack, 2011). Hodgkin and non-Hodgkin lymphoma are hematologic malignancies of the immune system with increased prevalence in young adults (Bray et al., 2018; James et al., 2018). In young adults, lymphoma is most often treated systemically with a combination of chemotherapy, radiation therapy, immunotherapy, and stem cell transplantation, among other novel approaches (Cairo & Beishuizen, 2019; Neelapu et al., 2017; Rashidi et al., 2016). The types and length of treatment for lymphoma vary based on the stage at diagnosis, risk stratification, and histologic subtype; however, most patients are treated for several months or longer, followed by years of maintenance therapy and observation (Evens et al., 2008; Kahn et al., 2017). Researchers have described numerous and varied physical, psychological, and social effects and outcomes of cancer, treatment, and survivorship among young adults with lymphoma (Leak et al., 2011; Linendoll et al., 2016; Smith et al., 2013). Given the prevalence of lymphoma among young adults with cancer, the length and severity of treatment and management, and the varied survivorship and quality-of-life outcomes, this study sought to report the experiences of young adults with lymphoma during the COVID-19 pandemic.

Methods

Secondary data analysis of qualitative research is an effective method to answer new questions beyond those addressed in the primary qualitative research study (Hinds et al., 1997; Ruggiano & Perry, 2019; Szabo & Strang, 1997; Thome, 1998). The primary study used interpretive phenomenology to explore the lived experience of young adults with lymphoma during acute survivorship. That study aimed to address the limited body of research in the young adult lymphoma population during acute survivorship, defined as the

period of cancer survivorship at diagnosis, relapse, or remission when a patient is actively receiving acute treatment or intervention (Arden-Close et al., 2010; Leak et al., 2011; Linendoll et al., 2016; Surbone & Tralongo, 2016). This secondary data analysis is intended to explore the experiences of young adults with lymphoma in the context of the COVID-19 pandemic. This study used thematic analysis as detailed by Braun and Clarke (2006). Thematic analysis was chosen because it is a rigorous yet reasonably straightforward and inductive approach to quickly and efficiently code, analyze, and report qualitative data.

Ethical approval was considered before completing this secondary data analysis (Irwin, 2013; Thome, 1998). In the primary study, permission was granted from the institutional review boards affiliated with the primary study investigators and the recruiting academic medical center. Primary study participants provided written informed consent, which included a provision that allowed for future use of the research data in subsequent research studies, presentations, or publications if in a deidentified manner. The primary study used purposive sampling to recruit young adults with lymphoma aged 18–39 years at the time of lymphoma diagnosis and study enrollment from one National Cancer Institute–designated cancer center in the northeastern United States. Young adult patients with Hodgkin or non-Hodgkin lymphoma were eligible to participate in the primary study. The primary study enrolled young adults with lymphoma during acute survivorship, defined as actively receiving acute treatment for lymphoma or having received acute treatment for lymphoma within 90 days of study enrollment. Acute treatment was any type of treatment specific to lymphoma, including chemotherapy, immunotherapy, radiation therapy, targeted therapy, stem cell transplantation, surgery, and treatment on a clinical trial. Patients with concurrent cancer were excluded; in addition, patients who could not complete the study requirements in full were not eligible for the study.

In the primary study, eligible patients were recruited and enrolled until data saturation was achieved (Patton, 2002; Sandelowski, 1986), as determined by the primary study investigators. The primary study data were collected from October 2020 through February 2021, several months of the highest number of new infections and deaths from COVID-19 in the United States (Pan American Health Organization, 2020). Enrolled participants completed three study procedures: a study demographic form, a recorded telephone interview,

TABLE 1. Sample Characteristics (N = 8)

Characteristic	n
Employment status^a	
Full-time	4
Part-time	2
Student	2
Disabled	1
Not employed	1
Gender	
Female	6
Male	2
Highest level of education	
College graduate	3
Graduate or postgraduate education	5
Lymphoma stage at diagnosis	
I	1
II	2
III	1
IV	4
Lymphoma type	
Classical Hodgkin lymphoma, nodular sclerosis	3
Classical Hodgkin lymphoma, primary refractory	2
Chronic lymphocytic lymphoma	1
Diffuse large B-cell lymphoma	1
Follicular B-cell lymphoma	1
Marital status	
Married	3
Not married or partnered	3
Partnered	2
Race^a	
White	7
Asian	1
Black	1
Treatment to date^a	
Immunotherapy	8
Chemotherapy	6
Surgery	2
Clinical trial ^b	1
Radiation therapy	1
Stem cell transplantation	1
Targeted therapy	1

^a Participants could select more than 1 response.
^b Consists of treatment not approved by the U.S. Food and Drug Administration

and a study validation form. The demographic form collected participant and cancer-related information, including age, gender, race, education level, diagnosis date, lymphoma type and subtype, lymphoma stage at diagnosis, treatment type, and time since last treatment. During the telephone interviews, the researchers employed various questions to collect data on the participants' lived experience of having lymphoma during acute survivorship; the telephone interviews were audio recorded and transcribed verbatim. The validation form returned a summary of the transcribed data to the study participants for additional comments or feedback.

The purpose of this secondary data analysis was to answer the following question: What is the experience of young adults with lymphoma during the COVID-19 pandemic? Trustworthiness criteria established by Nowell et al. (2017) were implemented to ensure that this secondary analysis reached an acceptable level of rigor and integrity. First, the current author refamiliarized himself with the primary study data. The primary study data consisted of demographic data, recorded interviews, transcriptions of the recorded interviews, journal entries following each interview, and participant responses to the study validation form. Second, the author created an initial set of codes from the data. Both descriptive and pattern coding were conducted to analyze the data more broadly across the participants and then examine the text and data units precisely (Creswell, 2014; Miles & Huberman, 1984); ATLAS.ti, version 9.0, was used for data management. Next, the author inductively generated themes from the coded data without preconceptions or prior knowledge concerning the research topic. The fourth phase consisted of reviewing and refining the themes in the context of the coded data. In addition, the author focused on the essence of each theme by writing a short analysis with regard to the research question, the primary research data, and the generated themes. The final phase involved writing a comprehensive and cohesive description of the analysis.

Results

Data from eight young adults with lymphoma were reanalyzed in this secondary data analysis (see Table 1). Two participants were male and six were female; most participants were White, non-Hispanic, and college graduates. The mean age of participants was 31.63 years (SD = 5.29), with a median of 31 years and a range of 24–39 years. Participants had been diagnosed an average of 22.5 months (SD = 29.41) ago, with a median of 7 months and a range of 4–73 months. In

total, five participants had Hodgkin lymphoma, and three participants had non-Hodgkin lymphoma; most participants were diagnosed at an advanced stage and were receiving systemic treatment. Participants reported an average of 14.88 days (SD = 16.48) since their last treatment, with a median of 11 days and a range of 1–50 days.

Three themes were constructed to describe the experiences of young adults with lymphoma during the COVID-19 pandemic: susceptibility and threats of COVID-19, isolation and confronting cancer alone, and healthcare provider supportive care.

Susceptibility and Threats of COVID-19

The first theme defined participants' sense of susceptibility, threats, and vulnerability to COVID-19. The participants described how the heightened risk of COVID-19 intensified threats and fears as vulnerable young adult cancer survivors. Several participants diagnosed with lymphoma during the COVID-19 pandemic described their increased anxieties and prolonged uncertainties leading to a diagnosis and during the acute treatment experience:

Nobody taught you how to prepare for this [being diagnosed with cancer]. Nobody, you know. You're not sitting around practicing, "Would you like cancer?" So, it's been a nightmare at times, most of the time, especially with COVID, because you're just fumbling through it as it happens.

The participants were well educated by healthcare providers on their specific lymphoma diagnosis and the personalized treatment plan. However, their insightful knowledge of lymphoma, the cancer treatment regimen, and immune-related side effects instilled within participants a deeper susceptibility to COVID-19. One participant explained that "COVID affected me hard. Being that basically, you know, with lymphoma, it's my immune system that's kind of trying to kill me, and that was being suppressed. And so obviously, that doesn't play well with [COVID-19] hanging around outside." Another participant explained further, saying, "Yeah, I mean, it's scary knowing that the treatment is suppressing the immune system and that if I would come into contact with COVID, I might not be able to fight it."

When defining their increased susceptibility to COVID-19, some participants reported frustration with others for not following or mocking widely accepted public health COVID-19 guidelines. One participant found it particularly challenging when others in

community settings, such as grocery stores or pharmacies, refused to wear a face covering or face mask:

You have a chronic illness, and you're living in a world where there are literally people who just don't care. They don't care about people like me. They don't care about anybody besides themselves. And what I mean by this is people who refuse to wear masks.

Some participants described the internal struggle in the lead-up to medical appointments, treatment infusions, or other visits to healthcare centers:

It's like, "OK, you know you need to leave the house." That's another layer. Like, I'd rather not leave the house if I don't have to. Leaving the house and being around people that are potential [COVID-19] patients is, like, that's a little bit scary.

However, most participants accepted their precarious position: Although their susceptibility to COVID-19 remained great, they acknowledged the need to meet treatment guidelines, schedules, and timelines set forth by the medical team:

And it's [COVID-19] just really scary. But at the same time, I can't get around going to the hospital for appointments from time to time, although trying to avoid the physical appointments is ideal just because of the risks. You've got to give your blood or be looked at and everything.

Isolation and Confronting Cancer Alone

The second theme described the social isolation faced by young adults with lymphoma during their acute treatment experience. The COVID-19 guidelines at medical centers resulted in most participants attending medical appointments and infusion treatments alone. This social isolation brought forth prevailing anxieties and worries to the participants during acute survivorship:

I wasn't allowed to bring anybody with me [to the infusion suite] because they were only allowing, you know, a companion if you needed it. And so, I pretty much did the whole thing, the whole six months, on my own.

Although participants in the primary study detailed numerous challenges with being diagnosed and receiving acute treatment for lymphoma, several acknowledged the restrictions from the COVID-19

pandemic as being equally daunting and compounding the stresses of cancer during young adulthood. One participant noted, “I think the biggest part that has affected me as far as, you know, being a cancer patient, having lymphoma, has been like going in by myself. I think that’s been the hardest thing because of my anxiety.” Some of the participants in the primary study were diagnosed before the COVID-19 pandemic. Having a spouse, partner, family member, or friend join them for medical visits created a support system that provided stability and structure to the acute treatment experience. Without this support system, several participants described severe nervousness and isolation. One participant said, “I wouldn’t be able to, like, absorb anything [during medical appointments] because it’s just kind of an anxiety-like trigger. So, I would always bring somebody with me.” A second participant agreed, stating,

For me, anyway, it was much more like the idea of feeling like I have to do this by myself now. Because it was always comforting just having someone there to, I don’t know, to keep me calm, to keep me from spiraling.

Some participants noted increased stressors on healthcare systems and healthcare providers, in addition to a reprioritization of medical care because of the COVID-19 pandemic: “You definitely became a back seat [to COVID-19], but not on purpose. Just because of overload and then just the infusion experience or going to doctors. It definitely added to everything, which is something that is understated.”

Healthcare Provider Supportive Care

The third theme characterized how healthcare providers, particularly advanced practice nurses and RNs, instinctively and efficiently met the supportive care needs of young adults with lymphoma during the COVID-19 pandemic. Although participants heavily underscored the social isolation of COVID-19, they described how nurses strived to meet their physical and emotional needs during the acute treatment experience:

The nurses were very, I want to say they were overly compassionate with me because we couldn’t have someone else there. So, I mean, they were very willing to just sit down and talk to you if you needed it and stuff like that. They were extra helpful in, like, being that person to be the “there with you” kind of thing.

Nurses allotted the necessary time and presence to provide supportive care to participants at all treatment stages: “Every time we talked, she [an RN] would ask me how I’m feeling emotionally, if there’s anything I wanted to talk about. So, I definitely got that from her for sure.” Another participant described the sense of community and presence among nurses during prolonged treatment infusions:

And I have, you know, I guess a second out with the nurses, with, you know, making things feel a little bit normal. I mean, it’s hard to avoid. We’re all wearing masks. So, obviously, it’s the elephant in the room, but we’re still able to, like, just talk like normal people and have conversations . . . things like that.

Nurses were highlighted by several participants as the healthcare providers most adept at following the mandated COVID-19 guidelines, as well as the most resourceful and efficient in care delivery:

I think they’ve [the treatment team] done a really good job of, especially at kind of limiting exposure. And instead of sending me out [for] blood work or sending me to somewhere to get something done, the nurse often comes here [to the participant’s home] and does it, which is great. And the nurses, they sanitize, they wear masks, they take their shoes off. They do everything right.

Several participants described the difference that nursing staff made given the restrictions created by the COVID-19 pandemic: “You know, I would say, look, my nurses are amazing across the board, like, I ended up getting readmitted and no visitors were allowed [due to COVID-19], and they were, like, so incredible.”

Discussion

This study aimed to explore the experiences of young adults with lymphoma during the COVID-19 pandemic. This article adds to the limited body of research concerning the quality-of-life and cancer survivorship outcomes of young adults with cancer during the COVID-19 pandemic and is the first study of young adults with lymphoma throughout the COVID-19 pandemic. Participants detailed how the COVID-19 pandemic deepened their fears as cancer survivors during cancer diagnosis, acute treatment, and post-treatment follow-up. Research has demonstrated that young adult cancer survivors experience

psychological distress from diagnosis through treatment and long-term survivorship and less frequently pursue psychological supportive care services than older adult cancer survivors (Nass et al., 2015; Zebrack et al., 2014). In the current study, young adults with lymphoma described increased psychological distress regarding their susceptibility and isolation because of the COVID-19 pandemic.

Other researchers have reported similar findings regarding the susceptibility and isolation concerns of patients with cancer during the COVID-19 pandemic (Casanova et al., 2020; Košir et al., 2020; Moran et al., 2020; Romito et al., 2020; Staehler et al., 2020). Casanova et al. (2020) explored the perception of risk and the stress level of adolescents and young adults with cancer who were receiving treatment, who were receiving follow-up care post-treatment, or had completed treatment from one pediatric oncology unit in Italy. They found that healthy study participants did not feel affected by the COVID-19 pandemic; however, those receiving acute treatment reported being individually susceptible. In another study, Košir et al. (2020) explored the predictors of psychological well-being and holistic recovery of young adult cancer survivors during the COVID-19 pandemic using a global cross-sectional survey. In that study, almost half of the young adult participants reported an impact on their treatment and care, and more than half requested additional information on coping strategies. In the current study, young adults with lymphoma were found to experience social isolation and anxiety secondary to receiving acute treatment during the COVID-19 pandemic and discussed elevated feelings of susceptibility and seclusion, in addition to apprehension and fears of COVID-19. The participants held both positive and negative views on their general outlook following acute treatment for lymphoma during the COVID-19 pandemic.

Although some participants regarded COVID-19 as one of many complications in their acute treatment experience, others were more burdened by the pandemic and the effects on themselves and their support system. Several participants noted the benefit of healthcare providers as they immediately and efficiently met their supportive care needs. Provided with the support system of advanced practice nurses and RNs, several participants reported the physical and emotional encouragement to undertake and complete their acute treatment regimen. Future research is needed on the experiences of young adults with cancer during the COVID-19 pandemic to create recommendations for management and supportive care.

KNOWLEDGE TRANSLATION

- Young adults receiving acute treatment for lymphoma described heightened susceptibility and social isolation because of the COVID-19 pandemic.
 - Nurses offered young adults with lymphoma a safeguard during acute survivorship through physical and emotional presence and comprehensive supportive care.
 - Additional research is necessary to create comprehensive survivorship care for young adults with cancer during public health crises.
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Limitations

This study has several limitations. Although four authors completed the primary study, only one author reanalyzed the data in this secondary data analysis. The sample population in this study consisted of eight young adults with lymphoma, and more study participants may have contributed additional information. Because most participants in this study were female, White, non-Hispanic, and well educated, additional sample demographic concerns were raised. A supplementary research study might examine the experiences of ethnic and racial minority patients with cancer and, more specifically, ethnic and racial minority young adult patients with cancer in the United States during the COVID-19 pandemic. In addition, the primary study participants were treated at a National Cancer Institute–designated cancer center by healthcare providers specializing in hematologic malignancies, including lymphoma. Therefore, participants' medical and supportive care may not represent that received by young adult patients with cancer treated in the community or rural oncology settings.

Implications for Nursing

Researchers have recognized the distinguished adaptability and unique contributions of oncology nurses during the COVID-19 pandemic (Jackson et al., 2020; Paterson et al., 2020). In addition, oncology nurses have been identified for their compassionate delivery of supportive nursing care to patients with and without COVID-19, as well as for strengthening and maintaining healthcare systems through the COVID-19 pandemic (Young et al., 2020). In the current study, nurses were regarded for their strict adherence to COVID-19 guidelines concerning the safety of young adults with lymphoma while maintaining high levels of physical, emotional, and social support throughout diagnosis, acute treatment, and post-treatment

survivorship. Providing young adult patients with cancer with the necessary physical and emotional care by being with patients, meeting their supportive care needs, and creating an open dialogue and shared communication may help alleviate concerns related to the COVID-19 pandemic (Fingeld-Connett, 2008; Olsen & Harder, 2011; Richardson, 2004). Oncology nurses should continue to strengthen partnerships with other interprofessional team members to create tailored survivorship guidelines, treatment pathways, and post-treatment care plans for young adults with cancer throughout future related public health crises (Clark-Snow & Rittenberg, 2021).

Conclusion

This study adds to the limited body of research exploring the experiences of cancer survivors during the COVID-19 pandemic in the United States. Future research should explore the experiences of young adults with cancer during and after the COVID-19 pandemic, including those from urban and rural areas and academic and community hospitals. Supplementary studies might assess nurse-led survivorship programs previously implemented with young adult cancer survivors and execute those strategies to increase support for young adult patients with cancer during public health crises. Additional studies that pilot strategies with young adult patients with cancer during public health crises may discover additional channels or methods to alleviate the shared survivorship burden among healthcare providers and cancer survivors. Given the range of COVID-19 severity in different regions globally and across the United States, more research is needed to create specific guidelines for young adults with cancer.

Joseph A. Vena, PhD, RN, is a graduate of the PhD in nursing program in the M. Louise Fitzpatrick College of Nursing at Villanova University in Pennsylvania. Vena can be reached at jvena@villanova.edu, with copy to ONFEditor@ons.org. (Submitted April 2021. Accepted June 3, 2021.)

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QUESTION GUIDE FOR A JOURNAL CLUB

Journal clubs can help to increase and translate findings to clinical practice, education, administration, and research. Use the following questions to start discussion at your next journal club meeting. Then, take time to recap the discussion and make plans to proceed with suggested strategies.

1. What issues were identified by young adults with lymphoma that were compounded by the COVID-19 pandemic?
2. How do you think nurses could contribute to enhancing well-being in situations like this?
3. Do you think that individuals with cancer have specific pandemic-related health needs that oncology providers need to attend to at this stage of the pandemic?

Visit <https://bit.ly/1vUqbVj> for details on creating and participating in a journal club. Contact pubONF@ons.org for assistance or feedback. Photocopying of the article for discussion purposes is permitted.