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“Now Everybody Is Thinking About Things Like That.” Young Adult Cancer Survivors Reimagining Work During the COVID-19 Pandemic

Lauren V. Ghazal  ▼ Sheila J. Santacroce  ▼ John D. Merriman  ▼ Victoria Vaughan Dickson 

Background: Diagnosed between ages 20 and 39 years, young adult (YA) cancer survivors have faced disruption to their lives well before the COVID-19 pandemic. Often seen as an at-risk population within cancer survivors, YAs experience the demands of a serious illness, such as cancer, alongside meeting the typical milestones of young adulthood and often have worse quality of life than their noncancer peers. There is a need to further study the effect of the COVID-19 pandemic on specific populations, including YA cancer survivors (YACS), as it relates to work.

Objectives: The aim of this study was to explore working YACS' experiences during the COVID-19 pandemic and identify facets of cancer survivorship that researchers can use to explore COVID-19 survivorship further.

Methods: Secondary thematic analysis of 40 semistructured, qualitative interviews conducted through Zoom audio during the COVID-19 pandemic. YA hematologic cancer survivors were recruited through social media; they were eligible if they had completed active therapy, were within 5 years of their diagnosis, and working at the time of diagnosis. Interviews were transcribed verbatim and subjected to thematic content analysis.

Results: Themes surrounded COVID-19's influence on working YACS' experiences, with the overarching theme: “From solo to shared experience: A change in awareness and understanding.” A subtheme was “Lesson reaffirmed: Reimagining the work environment.”

Discussion: The consequences of COVID-19 on the overall quality of life for YACS are multilevel. Establishing the evidence for effective interventions to support YACS in the workplace, whether physical or virtual, is critically needed. Research is needed on YACS' risk and resilience factors that could ultimately impact future health and quality of life.

Key Words: cancer survivorship • COVID-19 • employment • quality of life • young adults

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The coronavirus disease (COVID-19) pandemic commanded the world's attention, affecting several aspects of everyday life, including work and school (Bowen et al., 2021). The pandemic changed work environments drastically, with remote work in the United States increasing by 250% from 20% prepandemic to 71% in October 2020 (Parker et al., 2020).

For some, the pandemic was not the first time they were subjected to guidelines, including social distancing and mask wearing. Nearly 84,000 young adults (YAs; ages 20–39 at diagnosis)

are diagnosed with cancer each year in the United States (Miller et al., 2020). Even before the pandemic, YA cancer survivors (YACS) faced a “new normal” related to pre- and post-cancer diagnosis; the pandemic brought another experience of uncertainty early in the life course (Donovan et al., 2015; Shay et al., 2021). YAs represent a unique population of cancer survivors, often in-between pediatric and adult oncology care settings (Janardan & Wechsler, 2021; Zebrack et al., 2014), and face a significant health crisis at a time marked by meeting major personal, school, and work milestones (D'Agostino et al., 2011). YAs can be seen as an at-risk population among cancer survivors; they may cope poorly with and be unable to recover from their cancer diagnosis and treatment during a critical period in the life course that affects gaining and losing resources (including employment; Graetz et al., 2019; Spini et al., 2017).

YACS live longer than ever before, with many working throughout cancer therapy or returning following active treatment (American Cancer Society, 2019; Miller et al., 2020).

Lauren V. Ghazal, PhD, FNP-BC, is Postdoctoral Research Fellow, School of Nursing, University of Michigan, Ann Arbor. At the time this research was completed, she was a PhD student, Rory Meyers College of Nursing, New York University, New York.

Sheila J. Santacroce, PhD, CPNP, FAANP, is Associate Professor, College of Nursing, University of North Carolina at Chapel Hill.

John D. Merriman, PhD, RN, is Assistant Professor, Rory Meyers College of Nursing, New York University, New York.

Victoria Vaughan Dickson, PhD, RN, FAAN, FAHA, FHFSA, is Associate Professor, Rory Meyers College of Nursing, New York University, New York.

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Understanding perceptions of work and describing work-related outcomes among the cancer survivorship continuum is critical; work is one of the greatest issues affecting quality of life (QOL) among cancer survivors (Peteet, 2000). We previously reported that hematologic YACS experienced “survivors’ dilemma” when reflecting on their work-related goals (Ghazal, Merriman, et al., 2021). Survivors continuously balanced factors related to changed self-identity, perceived work ability, and new or worse worry about money and difficulty paying for basics, which affected their QOL. Prior to the pandemic, YACS described their work experience as providing them a semblance of normalcy (Leuteritz et al., 2021; Stone et al., 2017). Work brings not just personal fulfillment but financial—through income and additional benefits such as employer-sponsored health insurance coverage.

The pandemic offers an innovative way to examine work and cancer survivorship. We are beginning to see literature comparing return to work post-severe illness, such as cancer, and postpandemic (Shaw et al., 2020). What is needed is a better understanding of the pandemic’s multilevel influence on cancer survivors (Bowen et al., 2021). Science innovation has been described as a “change in thought or practice that leads to improvement in understanding or outcomes” (Pickler, 2021). The COVID-19 pandemic brought many, for the first time, to think about their work and work environment. Innovation postpandemic goes beyond asking, “What can we learn from this experience?” to “How is the pandemic influencing this phenomenon of work accommodations and this experience at every level?” Thus, this brief report explores the experiences of YACS during the COVID-19 pandemic and identifies facets of cancer survivorship that researchers can use to explore COVID-19 survivorship further.

METHODS

Primary Study Overview

The purpose of the primary study was to explore multilevel factors (e.g., individual, microsystem, and mesosystem) influencing QOL in YACS. The study framework, derived from Bronfenbrenner’s (1979) social ecological model and Elder and Rockwell’s (1979) life course perspective, guided the convergent mixed-methods approach to data collection and analysis. The study was approved by the New York University Institutional Review Board (2020-4281). Eligibility, recruitment, and data collection methods of the parent study are described in detail elsewhere (Ghazal, Merriman, et al., 2021). Briefly, participants included YA leukemia and lymphoma survivors who had completed active treatment within 5 years of diagnosis. Participants were recruited through social media platforms and provided written (online) informed consent. The analysis results included work-related goals and work ability profiles and their relationship to QOL (currently under review). The concurrence of the pandemic onset and data

collection period allowed us to undertake secondary analysis to explore multilevel factors affected by the pandemic.

Data Collection

The first author conducted all interviews during the pandemic (April 2020 to August 2020) through Zoom audio conferencing, which has been shown to generate data of comparable quality (Braun & Clarke, 2013). This data set included all instances across the larger study’s data corpus that had some relevance to COVID-19 and work. The interviewer did not ask explicitly about the impact of COVID-19 in the interview, but this topic came up consistently across interviews.

Data Analysis

This brief report is a secondary analysis of qualitative data (interview transcripts from 40 YACS) collected from this primary study, specifically looking at codes related to the COVID-19 pandemic, work accommodations, job flexibility, and so forth. We followed an inductive thematic analysis process (Braun & Clarke, 2006). We employed thematic analysis as the most appropriate method for secondary analysis of qualitative data to identify themes in the data set and patterns of meaning related to the pandemic. It could also interpret various aspects of the research topic (Boyatzis, 1998; Braun & Clarke, 2006). The process was inductive, as it took a “bottom-up” approach, and the overarching research question evolved throughout the coding process (Braun & Clarke, 2006; Patton, 2002).

The first author began the process of fully immersing in the data by listening to audio-recorded interviews and reading through transcripts of the interviews. A qualitative analysis software, MAXQDA, was used to code segments of interviews central to COVID-19-related discussions, generating initial codes. Then, codes were joined together to begin to form potential themes. The study team frequently reviewed developing themes, and a thematic map central to the research question was developed. Lastly, we defined and named the themes, which capture a critical element of how being a YACS during the COVID-19 pandemic provided insight into work-related challenges.

RESULTS

Most participants were female (65%), were White (73%), had a bachelor’s degree or higher (60%), and were primarily employed in a professional type of job (healthcare [22.5%], education or research [17.5%], or a different kind of professional work [37.5%]). The majority received a lymphoma diagnosis (83%). We identified an overarching theme related to working during the pandemic as a YACS, “From solo to shared experience: A change in awareness and understanding.” We describe a “lesson reaffirmed” subtheme under this major theme, “Reimagining the work environment.”

Moving From a Solo to Shared Experience

Participants described the contrast between their solo experiences of a cancer diagnosis and just their own world “stopping” versus the shared experience of the pandemic. The pandemic brought a shared understanding of the “unknown” to not only the participants in this study but to the entire globe. This is unlike their cancer experience, which affected themselves solely; with the pandemic, there was a shared sense of togetherness and mutual understanding, “maybe the fact that there’s more people around you.” That is, throughout their cancer diagnosis and treatment, the rest of the world went on; nothing else stopped. However, with the pandemic, everyone’s life was uprooted. For some participants, this shared experience related to social distancing and isolation that was needed during their treatment period, as this participant described:

....the positive thing I've been able to take away from this is that some people are going through the same thing. I was already isolating myself since December. When people started isolating themselves in March, I was like, “Well, I've been doing it for 3 months.”

Some participants described this move from solo to shared experience to be like they had an advantage, as one participant further explained, “When people say, ‘Oh, how’s the quarantine with you?’ I’m like, ‘Oh, well actually, I just went through cancer treatment, so it’s really not that bad.’” Although others described reliving the trauma of isolation that occurred during their active treatment period: “It’s not awesome being stuck in the house again. It reminds [me] of when I was in treatment, but here we are.”

The shared experience included concepts of the unknown, financial uncertainty, and job instability. Participants described increased awareness of economic uncertainty from others during the pandemic that they had already experienced earlier in their cancer survivorship, “Everyone else is in this situation too, financially.” One participant further explained:

[During treatment], I was coming to this turning point where I realized, like, “Man, I’m struggling to keep my head above water. Maybe I need to apply for financial assistance even in the way of food assistance, or unemployment, or things like that.” This is an interesting time because now everybody is thinking about things like that.

Lesson Reaffirmed: Reimagining the Work Environment
Participants described how flexible work accommodations made during the pandemic should be continued for employees with disabilities, including YACS postpandemic. This lesson learned was something the participants knew before the pandemic but was reaffirmed through the shared experience of the pandemic. One participant compared her time during treatment to time working during the pandemic:

Hopefully, [the pandemic] will help people to make more work adaptations. I tried to join in as much as possible during treatment, but a lot of times, people didn’t know how to use Zoom, and they didn’t know how to figure it out...they just weren’t prepared for it. It was harder. I think this is forcing some organizations and some individuals to figure it out.

Participants also described how showing continued productivity with flexible work arrangements, including telework, could also be a positive, long-term consequence for YACS. Those who could complete their work out of the “office” were offered more flexible work arrangements. As one participant described:

[This has] been around as a topic prior to COVID-19 but been blasted up now—the work from home for everyone to feel more engaged. I really have been able to show my team that working from home can be done. You can be productive. I hope that my organization, as well as others, start to reframe the work-from-home thing as something that will help improve all employees’ engagement and quality of life, and productivity.

DISCUSSION

This article explores YACS’ work experiences that have been illuminated in the COVID-19 pandemic. Participants described how being a cancer survivor unexpectedly prepared them for the pandemic. For example, using resilience methods developed during treatment to cope with the uncertainty and unknown of the pandemic. The central theme of this secondary analysis argues that the pandemic brought a collective consciousness, pushing all vulnerabilities to the forefront—this finding and this analysis challenge researchers and nurses to examine perceptions of workplace support and accommodations postpandemic.

Furthermore, despite the “advantage” participants described having in coping with similar uncertainty in their past, current research conducted during the pandemic reported greater levels of psychological distress for adolescents and YAs (both cancer survivors and noncancer peers) than prepandemic (Košir et al., 2020; Shanahan et al., 2020). For example, Košir et al. (2020) found 62% of their sample of 177 adolescent and YACS reported feeling more anxious than before the pandemic. Potential drivers of observed increases in psychological distress may be related to lifestyle changes, including social isolation, economic disruptions, and uncertainty about the future. For YACS, this may be heightened with the pandemic’s effects on cancer care delivery (e.g., diagnostic or treatment delays, drug shortages, or move to telehealth appointments) and fear of increased susceptibility to severe COVID-19 among cancer survivors (Nekhlyudov et al., 2020; Saini et al., 2020; Shay et al., 2021). Research is needed on

YACS' risk and resilience factors that could ultimately impact future health and QOL.

These findings enhance our previous report of the survivors' dilemma (Ghazal, Merriman, et al., 2021), particularly for questions of "Can I do this work? and "Can I afford to do this work?" because of changes in work environment and job demands. The historic pandemic's consequences on overall QOL for YACS are multilevel; they will likely shape the remainder of their life course, as expressed by the combination of the social ecological model and life course perspective in the study framework. Specifically, significant events in the exosystem and macrosystem resulted in many participants modifying their work environment and changing relationships with their supervisors and colleagues. For individuals in the YACS population, pandemic-related financial pressures worsened preexisting or onset of new financial problems, worries about money, difficulties paying for basics, and meeting existing financial obligations (Baddour et al., 2020; Ghazal, Gormley, et al., 2021). Across and within the multiple levels, factors operate dynamically to affect QOL for cancer populations (Santacroce & Kneipp, 2021). Therefore, future interventions to improve QOL in YACS must be context specific and address the multiple social-ecological levels, not context neutral and focused exclusively on individual-level factors.

Future research should consider how the pandemic may affect results if data were collected during the pandemic and consider pre- and postpandemic effects in data collection and analysis. Furthermore, although this analysis found a "lesson reaffirmed" to reimagine the work environment, it is unknown what effect the transition to remote offerings, or flexibility of workplace setting, had on YACS' work ability and QOL (Brussevich et al., 2020). Establishing the evidence for effective interventions to support YACS in the workplace, whether physical or virtual, is critically needed.

Conversely, we do not know how this dramatic shift in the future workplace environment will affect social support for employees with chronic illness or disabilities, including YACS. Although we are exploring the benefits of a changed work environment, there may be disadvantages lost by a change in the work environment. Compared with older adults, young teleworkers (ages 18–49 years) feel less motivated to do their work (Parker et al., 2020); thus, future research should describe what coworker support looks like postpandemic. As far as resilience-promoting factors described by Roubinov et al. (2020), this analysis argues flexible work can be achieved remotely. Still, it is unclear whether vital employer resources can also be achieved postpandemic. This brief report raises important questions for future occupational health and nursing research, including "Has this historic pandemic offered researchers other ways of envisioning working environments for people with disabilities and/or chronic illnesses?"

Study limitations included a predominantly White and female sample. Strengths of this study included using social

media platforms for recruitment, which allowed for accessing a unique population of YACS where they might be more easily reached than in clinical settings (Gorman et al., 2014). In addition, because of the pandemic, there was no need to shift recruitment efforts to a virtual format or to delay study recruitment because of institutional review board changes to clinical studies.

Conclusion

This report captures the phenomenon of work for cancer survivors in the context of the COVID-19 pandemic. It further details opportunities and challenges for future nursing and occupational health research.

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Corresponding author: Lauren V. Ghazal, PhD, FNP-BC, University of Michigan School of Nursing, 400 North Ingalls St., Ann Arbor, MI 48109 (e-mail: ghazall@umich.edu).

ORCID iDs

Lauren V. Ghazal  <https://orcid.org/0000-0001-5768-5571>
 Sheila J. Santacroce  <https://orcid.org/0000-0001-8713-8069>
 John D. Merriman  <https://orcid.org/0000-0002-7113-5389>
 Victoria Vaughan Dickson  <https://orcid.org/0000-0002-6673-1960>

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