The Person I Used To Be: Employment Experiences of Young Adults with Cancer

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Abstract

**Purpose:** Adults can experience employment-related hardships after a cancer diagnosis but young adults at the beginning of their careers may face unique challenges. This study explored the impact of cancer on young adults’ employment experiences.

**Methods:** The authors conducted 27 qualitative semi-structured interviews with young adults who had received a cancer diagnosis.

**Results:** Participants encountered mixed workplace support. Many reported that they did not have the benefits, such as time off or short-term disability insurance, that would have ameliorated some challenges encountered during treatment. They also shared that many workplaces do not do an adequate job of informing people with cancer about federal laws that protect people with disabilities. Most participants reported that the cancer diagnosis and treatment caused them to rethink their career trajectory.

**Conclusions:** Cancer affects young adults in ways that present distinct struggles attributable to less access to resources. Career choices and the consequent opportunities for on-the-job training can have lifelong import.

**Implications for Cancer Survivors:** Disability and discrimination laws do not protect all employees. Young adult cancer survivors may need to conduct their own research into these protections so they can receive entitled benefits. They and employers may also benefit from workplace interventions or trainings to lessen the employment consequences of cancer.

Introduction

Receiving a cancer diagnosis and treatment can upend people’s careers. Adults diagnosed with cancer can experience work-related hardships such as taking time off for treatment and/or experiencing treatment-related symptoms. Even after treatment concludes, side effects such as fatigue, pain, and confusion can linger for months and even years [1]. Individuals who continue or return to work may find that they can no longer engage in the required tasks at the same level of effort [2]. These barriers pose unique challenges to young adults just beginning their careers [3]. Young adults may have comparatively fewer financial resources or workplace status. The structural nature of work in the United States (US), where benefits and status accrue over time, may leave young adults with cancer with fewer workplace options than their peers who do not have cancer [4].

The Family Medical Leave Act (FMLA) and Americans with Disabilities Act (ADA) require certain employers to provide unpaid leave or modifications to the job or workplace environment to address the worker’s disability. When employees know to request benefits and/or reasonable accommodations, they can pursue this option. However, these protections do not guarantee continued employment [5]. Considering the burden that cancer causes, it is likely that having cancer shapes young adults’ career
choices [6]. Each year in the United States, more than 60,000 young adults aged 20 to 39 receive a cancer diagnosis [7]. Assuming a retirement age of 67, these young adults may expect to spend several decades in the workforce after cancer treatment. The purpose of this article is to describe the employment experiences of young adults who have been diagnosed with cancer and their perceptions on how it influenced their career choices. By better understanding precisely how cancer intersects with employment for this age group and the role reasonable accommodations may or may not play, we can better develop interventions and supports to address this population’s needs.

Researchers have explored the dynamics of work for adults diagnosed with cancer in adolescence or early adulthood. Parsons and colleagues (2012) found that, while 72% of these individuals returned to work or school 15 to 35 months post-diagnosis, over half reported barriers to accomplishing educational or employment goals [8]. These authors also noted that young adults who developed severe side effects or lacked insurance were more likely to report negative school or work outcomes.

A 2017 systematic review of young adult cancer survivors and work provides a comprehensive snapshot of this population [9]. Across the 23 eligible studies, researchers found that most individuals eventually return to work but it is often not the same type of job. Cancer treatment and its side effects frequently affected the survivor’s physical and/or cognitive functional ability [10, 11, 12]. These effects, in turn, influenced what the individual could accomplish at the same job. These young adults also struggled with economic and mental distress. One study found that 67% of participants lost income because of their diagnosis and course of treatment [13]. Another found that career path interruptions caused distress [14]. Job type (white collar or nonwhite collar) can also predict who returns to work [15]. Participants often had a different relationship to their workplace post-diagnosis and consequently rethought their career path [16, 17, 18]. However in some cases work can ameliorate some of this cancer-related distress. In one study, participants engaged in full-time employment during treatment reported lower levels of stress than those employed part-time [19].

In 2015, Strauser and colleagues developed a conceptual model around young adults with cancer and their career development [20]. They identify three factors: individual awareness, education/employment acquisition, and education/employment maintenance. These separate spheres interreact, shaping career develop and what types of supports may be necessary. Critical to the first domain is self-reflection about one’s interests and limitations for optimal career development.

Taken together, this body of literature suggests that young adults with cancer may have an ambivalent relationship to work, and that cancer might inhibit the perception which careers are possible and appealing. One the one hand, the treatment regime and aftermath can have a negative impact on ability to work in a particular job. On the other, being employed full-time may help blunt some financial and emotional stress. The degree to which employers provided reasonable accommodations likely moderates workplace experience. Connecting these disparate experiences is the idea of self-reflection, that these young adults are constantly negotiating their career development and deliberating on what kinds of employment may be meaningful to the people they have become.
Methods

The qualitative methods outlined here adhere to all domains outlined in the consolidated criteria for reporting qualitative research (COREQ). [21] Two research team members conducted semi-structured interviews with young adults who had been diagnosed with cancer about the employment-related effects of cancer and who had completed an online survey developed by the study authors. To be eligible to participate in either study component, the person had to have received any cancer diagnosis except nonmelanoma skin cancer) between the ages of 18 and 39 and live in the United States or a U.S. territory. Interviewers received a written copy of the informed consent and prior to the interview, the researcher discussed any concerns or questions the potential participant raised. Participants had to verbally agree to participate before the interview commenced.

Participant recruitment for the study was performed online and in-person by members of the research team. Recruitment strategies included requesting cancer advocacy and service organizations to share outreach with their audiences, invitations through social media, and publicizing the study in organizational newsletters. Information shared with participants explained that the information gathered from the research will help the researchers 1) understand what people know about the non-discrimination laws that protect them in employment after a cancer diagnosis; and 2) to develop and improve the information, support and guidance needed to help manage their work-related concerns. These findings will also influence further research on cancer and its impact on work. Additionally, participants who completed the online survey were invited to participate in a subsequent 60-minute phone-based interview. Ultimately, the team conducted 27 qualitative semi-structured interviews. Participants received one gift card for completing the survey and another gift card for completing the interview.

The interview guide contained questions about workplace accommodations, side effects of their cancer treatment, disclosing their cancer diagnosis at work, and knowledge about resources such as vocational rehabilitation. Two white female PhD-level social scientists, authors on this manuscript, conducted the interviews over the phone and developed their own follow-up questions based on participant responses. Interviews were recorded, transcribed, and the team members coded them using the qualitative software NVivo™. Inter-coder reliability—the percentage of text segments that two different team members coded the same way—was 96 percent. Table 1 outlines the codes.
| Main Code | Subcodes |
|-----------|----------|
| Cancer Side Effects | Anxiety |
| | Depression |
| | Fatigue |
| | Loss of concentration |
| | Mobility impairment |
| | Nausea |
| | Other treatment-related sickness |
| | Pain |
| | Physical changes |
| Effect at Work | Asked to resign |
| | Demotion |
| | Fired |
| | Passed up for promotion or projects |
| | Pressure to stop working |
| | Pressure to continue working |
| | Received negative performance reviews |
| | Stigmatized or left out of social events |
| | Treated as incompetent |
| | Other change in job responsibilities |
| | No change occurred |
| | Positive change occurred |

*How cancer diagnosis, treatment and remission affected the participant’s daily life*

*Job-related events in the workplace that occurred because of cancer diagnosis, treatment, or remission status*
| Main Code                                      | Subcodes                                                                 |
|-----------------------------------------------|--------------------------------------------------------------------------|
| **Effect of Cancer Disclosure**               | **Could not tell coworkers**                                             |
| *Informing people at work about cancer diagnosis, treatment or status of remission and the consequences* | **Could not tell employer**                                             |
|                                               | **Disclosing to coworkers**                                              |
|                                               | **Disclosing to employer**                                               |
|                                               | **Job demands (physical)**                                               |
|                                               | **Job demands (stress and emotional)**                                   |
|                                               | **Satisfaction with general work relationships**                         |
|                                               | **Satisfaction with supervisor**                                         |
| **Career Trajectory**                         | **Revaluate priorities**                                                 |
| *General discussion about how cancer has influenced the way in which the participant’s career has evolved over time* | **Change in career**                                                     |
|                                               | **Loyalty to a workplace**                                               |
|                                               | **Role of workplace benefits**                                           |
|                                               | **Expectations after treatment**                                         |
| **Knowledge about Employment-Related Federal Legislation or Program** | **American with Disabilities Act**                                      |
| *General discussion around employment-related federal legislations or programs; the judiciary system; and protections or lack of protections for people with cancer* | **Other federal laws**                                                   |
| **Reasonable Accommodations**                 | **Accessibility of IT**                                                   |
| *Adjustments made in the workplace to enable the participant to continue working at the same place of employment* | **Assistive technology**                                                 |
|                                               | **Change in job duties**                                                 |
|                                               | **Flexible work schedule**                                               |
|                                               | **Physical mods of workspace**                                           |
|                                               | **Reduced work hours**                                                   |
|                                               | **Telecommuting**                                                        |
|                                               | **Time Off**                                                             |
| **Vocational rehabilitation services**        |                                                                          |
| *State-level agencies dedicated to supporting people with disabilities* |                                                                          |
Modified grounded theory guided coding and analysis. This approach, rooted in social constructionism, accounts for both \textit{a priori} theories about the phenomena being studied as well as sensemaking narratives and new concepts conveyed by the participants [22–23]. The transcripts were first coded with “deductive codes” that corresponded to topics directly addressed in the interviews. Next, the interviews were coded with “inductive codes” that related to themes arising from the data during the first round of coding. For example, the team added the code “loyal to workplace” for cases where the participants felt indebted to employers after their cancer diagnosis. In NVivo™, the team did a series of text retrievals to observe how different codes overlapped, which highlighted participants’ reports in relation to certain topics. The goal of the analysis was to capture the themes that emerged across most of the interviews as well as capturing the diversity of workplace experiences. No new themes emerged related to the research question after approximately 22 interviews, indicating saturation. However, due to the homogeneity around certain sample demographics such as gender, type of occupation and type of cancer, some workplace experiences may not have arisen so saturation should not extend to all young adults who had a cancer diagnosis. In the finding section, quotes are taken verbatim from transcripts and used to illustrate a larger theme. Ellipses in quote refer mean that word or short phrase was deleted to clarify or improve comprehensibility of the participants’ thoughts, not to indicate the speaker is pausing or hesitating.

Almost 89 percent (88.9%) of the interview participants were female. About half (48.1%) had received a diagnosis and underwent treatment for breast cancer. The mean age at the time of the interview was 35.2 years old and the mean age of diagnosis was 29.9. All but three were employed, part- or full-time, at the time of the interview. Most positions were white collar jobs such as lawyer, management or education.
| Participant |  |
|-------------|-------------|
| **N = 27**  | **n (%)**   |
| **Sex**     |            |
| Male        | 3 (11.1%)  |
| Female      | 24 (88.9%) |
| **Age at Diagnosis, in years** |            |
| Mean        | 29.9       |
| Range       | 18–39      |
| **Age at Interview, in years** |            |
| Mean        | 35.2       |
| Range       | 27–46      |
| **Type of Cancer:** |            |
| Breast cancer| 13 (48.1%) |
| Leukemia     | 2 (7.4%)   |
| Lymphoma     | 4 (14.8%)  |
| Melanoma     | 1 (3.7%)   |
| Myxoid liposarcoma | 1 (3.7%) |
| Ovarian      | 2 (7.4%)   |
| Sarcoma of the liver | 1 (3.7%) |
| Testicular   | 1 (3.7%)   |
| Thyroid      | 1 (3.7%)   |
| Other        | 1 (3.7%)   |
| **Current Occupation:** |            |
| Cancer Activism | 2 (7.4%) |
| Education    | 2 (7.4%)   |
| Engineer     | 2 (7.4%)   |
| Government   | 4 (14.8%)  |
| Healthcare   | 5 (18.5%)  |
In this section, we outline how participants’ experiences in the workplace and their perceptions about careers were and were not changed by having cancer. First, we describe what happened while participants underwent treatment, including the perceived tenor of their workplace environment, access to reasonable accommodations, and how these experiences may have been shaped by their relatively early tenure as working adults. Next, we outline how the workplace did and did not change after they finished treatment. Finally, we discuss how experiencing cancer influenced how many of these young adults imagined their career trajectories.

Influences on career while undergoing treatment

Workplace Environment

Almost all participants (N = 24) disclosed their cancer diagnosis to a supervisor or someone in position of authority at their workplace. The ADA and FMLA both require the employer to receive notice of the disability or serious medical condition before providing leave or other job accommodations to the employee. The most cited reason for disclosing was to explain why they would be missing work—doctor’s appointment or surgery—so that their superiors would not interpret their absence as a lack of commitment to their job or a lackadaisical work ethic. Once their diagnosis had been disclosed to at least a small circle, workplace experiences generally fell into one of three categories. Six participants had overwhelmingly positive experiences, one in which they received the accommodations they needed along with strong support from colleagues that buoyed their health and career.

A woman who was diagnosed with breast cancer at age 31 explained that her colleagues at her government job offered unequivocal support.

*It didn’t cross my mind that they were going to fire me or cut my pay or anything because I had got cancer. They actually gave me a raise when I got cancer. I was going through treatment and they said, “You’ve got a lot of bad news so we’re going to give you a raise and hopefully this will make things a little bit better.”* (Participant No. 13)
Another woman who was diagnosed with breast cancer at 39 found that the positive work environment ameliorated some of her medical anguish.

*My work was a wonderful, wonderful distraction from this horrific diagnosis at such a young age. It was like I could come here and for eight to nine hours forget about it. And that’s what I did—and it was beautiful.* (Participant No. 4)

In these cases, where work played a supportive role, each participant had a well-placed advocate who either buffered them from other negative workplace influences or had the authority and desire to craft a flexible (and often informal) solution that fit the needs of the particular participant. The story of a woman who, at age 25, was diagnosed with non-Hodgkin's lymphoma, illustrates this dynamic: *“I think it also helped to have my direct manager be someone who was very compassionate and, for lack of a better word, just liked me. So that probably worked in my favor.”* (Participant No. 3)

Seventeen participants fell into a second group: colleagues offered support but also engaged in subtle acts that made the participant feel uncertain about their employment future. In these cases, participants were ultimately able to receive most if not all of the accommodations requested, but they did encounter some barriers from their employers in the process. For example, a woman diagnosed with melanoma at 22 recalled a meeting with her supervisor.

*I remember telling [my supervisor] when I went for the appointment with the surgeon, [that] they’re going to call me with a date, and it’s not flexible at all. And I said, “Once I know, I’m pretty much just going to tell you—this is when I need off from this time until, whatever.” And she’s like, “Well, I might need you to work around that time a couple days before…. maybe you’re going to have to try to switch with people so that you’re not taking PTO [paid time off].” And I was like, “I shouldn’t have to be emailing people to switch to get PTO time off for this.”* (Participant No. 2)

Participants most often viewed these actions as insensitive or thoughtless, not discriminatory. Even when they did believe that legal intervention may be warranted, the other demands in their lives made this option less viable. A woman who worked as a hairstylist when diagnosed with breast cancer at 37 commented:

*I had to cover my head when I lost my hair. I wasn’t allowed to be bald. I needed to either have a scarf, or a hat, or something on. I couldn’t wear a wig because my head is giant and my wig didn’t fit well. And it was hideous. Seriously, it was like the worst wig ever. Legally, I know that that’s a lot of things that [the supervisor] is not really supposed to say. But it wasn’t, at the time, anything that I really felt like pursuing because I had enough on my plate. My staff sometimes would be great. And then sometimes, I would walk in the back room and I would hear them saying, “Well, she can’t do that because she has cancer.” And I’m talking about things like I can’t scrub the toilet that 45 other people have used today. I have had so much muscle wasting that carrying this giant bag of trash 100 yards to the dumpster, I can’t do. I didn’t ask for a whole lot of accommodations, but people get tired of hearing about it after a while.* (Participant No. 22)
The third category, experienced by four participants, is characterized by overt hostile at work after disclosing cancer. These participants’ employers refused to offer accommodations. Here, participants encountered open hostility or refusal to offer accommodations. For example, a female participant described her work environment after she received her second breast cancer diagnosis at 42.

*I was living under such an umbrella of fear that I went back to work less than two weeks after a complete mastectomy. I was at my desk. My husband was like, “Are you kidding?” And I said, “She'll fire me.” So I tried really hard—excessively so—to make sure that there were no accommodations or requests made, period.*

Later, she recounts a particular exchange with her boss.

*[My boss's comments] were more focused on the physical. So, a perfect example, when I was heading out the door to go to my complete mastectomy. My husband was out in the car waiting for me because I worked in the morning, and then we were going to drive down to the surgical center. She said to me, “Hey, before you leave I want you to stand against this wall and turn sideways so I can take a picture of you because I think the before and after will be funny.” (Participant No. 14)*

In another case, a participant diagnosed with breast cancer at 29, took legal action. After being fired from her job as an administrative assistant after asking for reasonable accommodations, she led a lawsuit. However, she settled in arbitration because she lacked the funds to proceed with the court case. She explained her situation.

*Participant No. 12: It did go to arbitration and lawsuits were filed. Basically, I asked to be accommodated for my treatment. My doctors provided notes and everything, and they weren’t. At the time I worked in a title department. I was having to file the titles into very heavy drawers that, going through with this, I was having a hard time with it. I’m tired all the time, these drawers are really heavy. And my doc even signed a thing, do not have her pushing, lifting or anything over 10 pounds. They didn’t even follow it. So no matter what I did they didn’t. They ended up firing me. It was like an uphill battle. I tried going to HR. My boss, she wasn’t nice at all. You could not go to her about anything. So it was just a lot of that. They weren’t very accommodating and a lot was put on me and I’m like, OK, I’m done here. Once I got fired it's like, OK, I'm hiring an attorney over the documents they gave me.*

*INTERVIEWER: What did the attorneys or others explain to you were your rights and that you have as an employee?*

*Participant No. 12: They had to accommodate me. That’s a part of the ADA act, they were supposed to accommodate me, which they didn’t do. That was something that they violated. But I only had so much money to go on legal stuff, that’s where everything was settled in arbitration. Yeah, they said a lot of my rights had been violated because of that. And it didn’t go to trial because [I didn’t have] the money.*

**Reasonable Accommodations**
The most frequent type of reasonable accommodation was requesting time off for treatments or doctor’s visits. Over 77 percent of participants explicitly asked their employer about taking time away from the workplace during business hours. About half (55.6%) asked for flexible hours or work schedules to accommodate their treatment regime. Other types of accommodations included changing job duties, establishing or increasing a telework schedule, and/or reduced or flexible work hours. For some, asking for time off was not viewed as an accommodation per se because the participant was using his or her paid leave, which was a benefit that any employee at their company could enjoy regardless of the reason. That said, many of these workers needed more time off than they had available, and those who worked retail or nursing did not have as much flexibility or autonomy around their schedule.

Office culture and one’s immediate supervisor influenced response to a request for reasonable accommodations. Some supervisors “probably looked the other way” as one participant put it, or developed their own informal processes for taking paid leave. In other situations, participants found that their requesting time off was viewed as lacking commitment to the job.

In general, while participants had heard of the American with Disabilities Act (ADA) only four knew that employers could not discriminate people with cancer. Of those who knew they had rights they did not specifically know what those rights were or how to exercise them. They often did not know in practice what that looked like. One participant who had done research on the ADA noted that many employers, includes hers, were not adept at communicating workers’ rights.

*My job did a really terrible job of telling me what I needed to do, and what my rights were, and what my benefits were. I knew my job was protected, but I also knew that it was only protected for a short period of time. And my doctor had to be very specific about how long they had anticipated me being out.* (Participant No. 22)

About half of participants knew about the Family Medical Leave Act (FMLA) with many noting that they had taken that leave. A few who talked about the process shared that they were too sick to fill out the necessary paperwork and had family members or coworkers do much of it for them. No one interviewed accessed vocational rehabilitation services or knew that these services could help people with cancer.

**Resources As A Young Adult**

In addition to the support—or lack of support—they encountered, about half of participants noted that they lacked certain resources because they were early in their careers. Several mentioned that they had not accrued enough Paid Time Off (PTO) to adhere to the time-consuming schedule that treatment demanded. Some participants devised a workable plan either by taking a leave of absence (formal or informal), working a reduced work week, or accepting donated leave from fellow employees. However, participants who discussed needing time off shared that these restrictions changed how they handled treatment. A social worker, aged 33 when diagnosed with ovarian cancer shared: “I went back to work as fast as I did because I only had about a month and a half worth of sick leave saved up. So I knew I was running out. If I don’t have sick leave, I don’t get paid, so I had to go back.” (Participant No. 16)
Five participants said that because this was their first job, they did not pay attention to employee benefits. Others reported that their job did not offer disability benefits but this did not concern them initially. Still others did not sign up for such benefits to avoid paycheck deductions. A male participant who was diagnosed with testicular cancer at 23 explained his situation:

*I had not signed up for short-term or long-term disability. So after I used my paid time off, which went through in about three weeks. I wasn’t paid at all from the company. So I ended up having to be on Social Security, which [meant] I actually didn’t get the check for eight months.* (Participant No. 17)

Several participants recommended that young adults look at benefits like insurance and leave policies when on the job market and not make career decisions based on salary alone. They noted that most young adults, themselves included, can be more focused on take-home pay than benefits that may not seem relevant because of their age.

**Influences on career after treatment**

**Expectations After Treatment:** Almost all participants noted that their colleagues assumed that, once active treatment stopped, work life would return to normal, which turned out not to be the case for most participants. Some experienced bouts of debilitating fatigue because of chemotherapy and/or radiation. Others felt they lost cognitive skills due to “chemo brain” and could not resume the level of activity they once did. Even when support was initially present, it often waned over time. A female participant diagnosed with Hodgkin’s lymphoma at 32 summarized it this way: “At first, you have everybody’s support, and of course, it dies down towards the end.” (Participant No. 24)

The duration of the treatment side effects surprised even those going through treatments. A male participant who had Hodgkin’s lymphoma at 27 contrasted the expectations young adults have with the realities of cancer:

*I had zero idea that shingles could be a byproduct of cancer treatment and things like that. So knowing those kinds of things, like, okay yeah, your treatment’s done, but you’re not out of the woods. You need to be very careful of how you pace yourself and what you take on and your stress levels and things like that. Especially for 20 and 30-year-olds, that’s a pretty foreign concept too.* (Participant No. 10)

In other cases, treatment timelines kept changing as new surgeries or medication options were added. Diagnosed with acute myeloblastic leukemia at 24, one female participant explained how she and her workplace did not understand originally how long she would be unable to work. “I definitely didn’t understand that it was going to be 11 months, I thought that it was maybe going to be a few months, and then I’d be able to start again. I remember getting texts from colleagues being like, ‘I can’t believe you’re still not back.’” (Participant No. 19)

**Change in Job Responsibilities:** Cancer treatment and its side effects frequently affected the participant’s job responsibilities. For some, a flexible work schedule ameliorated some issues and they could resume their responsibilities in time. For others, receiving a cancer diagnosis and undergoing treatments directly
changed their career trajectory. In some cases, the employer demoted or changed the person's job responsibilities. One participant diagnosed with ovarian cancer at 33 reported back to work, ready to resume her job, and was told by another employee that she had taken over those duties. Another participant, who earlier discussed how she was on leave for 11 months, was demoted once she returned.

*I felt like they were going to be really supportive because they kept saying it. But then once I was actually ready to come back, unfortunately, [my] position had been filled. Legally they couldn't tell me that I was fired; they kept it at the same pay. But professionally I was really upset because I had worked really hard for that promotion.* (Participant No. 19)

Some participants, particularly those who were on track to obtaining leadership positions in their organization, decided that the high stress and multiple responsibilities that come with these positions made this path no longer viable. A female participant, diagnosed at 33 with breast cancer while working for a large corporation, illustrated this dilemma:

*I just really found out I couldn't hack the hours and the demands of that senior program management job. As you go up the chain, you have more responsibility, more things fall on your head to make decisions. And if my brain's a little foggy or doesn't work all the time, that probably wouldn't lead me to be successful in one of those jobs.* (Participant No. 20)

**Influences on future career choices**

**Physical and Mental Side Effects:** About three in four participants expressed that treatment left them with physical or cognitive challenges that influenced the viability of certain careers. A few stayed in their current career with the help of accommodations. A hairdresser was able to stay employed in her chosen profession once she able to acquire certain type of seating and arrange to have regular breaks. Others changed career paths completely. A former social worker transitioned into teaching so she could have regular vacations. A high-end gardener left that field because she no longer had the physical endurance needed to complete the tasks. The psychological trauma of facing cancer also influenced a few participants’ career tracks. One participant was a nurse in a hospital before she was diagnosed with Hodgkin's lymphoma at age 32. Here, she explained her decision to leave the healthcare field.

*I think that my empathy kind of just isn't 100% there. And I think that I need to have 100% empathy to be working with [patients]. The smell of saline makes me nauseous to the point where I want to puke. I don't know. I think that it's something that I can go back to, but I don't want to do it right now. I mean, if I wasn't home sick, then I was at the hospital sick. So don't want to [go back]. I'm not ready for it yet.* (Participant No. 24)

**Desire to Stay with Current Employer:** About a third of the participants remained employed by the same company at which they experienced their cancer diagnosis and treatment. A few remained because they liked their jobs, but most of these participants explicitly tied their decision to remain with the same employer to their medical history. They felt unsure what would happen with their health insurance and other benefits if they left and it was not a risk some were willing to take. Many of these participants also
felt loyal or indebted to their employers for superb handling of their illness. As one participant noted: “This is just the most loyal place and that’s why I’m so loyal to them.” For the most part, these participants felt ambivalent about their position, grateful for employment but also “felt stuck” or believed that they have “settled” for a less optimal career. One participant, diagnosed breast cancer at 28, conveys that ambivalence in her story.

[My colleagues have] been very generous to me. This is not exactly what I imagined doing for the rest of my life, and I do feel stuck in that regard. I went back to get my master’s in public health because I’m really interested in health issues, having been exposed now to this whole system. So I’m interested in health policy, all of these things that I would really love to explore. But, at this point in my life, there’s no way that I could make a career change or have that level of flexibility. So it’s frustrating in that regard because I do feel trapped. At the same time, I feel like a jerk saying that because it’s the gilded bird cage. I have it better than, I’m sure, 99% of people do who would be in my situation. (Participant No. 27)

**Reevaluating priorities:** Facing cancer at a young age caused most participants to reevaluate their priorities in life. For those that stayed with the current job, they often sought ways to improve the work/life balance or to make their job more meaningful. A woman working in finance when her non-Hodgkin’s lymphoma was diagnosed commented

*When you get close to death—which, I was pretty close—you’re looking for meaningful work. There’s this balance between that realization that, oh, I don’t want to just work to work, but I want to do something more meaningful and try to incorporate things to make me happy. (Participant No. 18)*

For over half of the participants in this study, this contemplation prompted a change in career path. For some, their experience motivated them to help others with cancer. Four participants currently work with or advocate for people with cancer. Other participants left their careers in search of more meaningful employment or a better work/life balance. A female participant, diagnosed with breast cancer at 26, believed her experiences could benefit others. “I feel like my continued diagnosis and medical issues and my experience through the cancer and being a young woman, that I feel like this all of this helps me to be able to counsel other families and other women that are going to through similar situations.” Another participant explains his story this way:

*I think the biggest thing for me was the emotional aspects, that the person who you are before you’re diagnosed at work is—for me—a very different person from one who I came back. In a way it’s a good thing. It just doesn’t get you up the corporate ladder as fast. I wanted to spend more time with my family after, and I wanted to have other passions in life that did not involve my job. And I just felt like I feel sometimes when I came back, this overwhelming feeling I need to make the most out of my life. Oh my God, I don’t know how much longer I have, I need to make sure that I’m living the best possible way for me. And if this is not the job then I need to get out. (Participant No. 19)*

For many participants, one of the larger challenges they faced post-retreatment were fears about employment, and very few participants felt adequately supported in the process of working after a cancer
Conclusion

Some of these obstacles, such as having colleagues expect that everything is “back to normal” once treatment ends, are not unique to young adults [24]. In other ways, however, this study sheds light on the specific ways that cancer affects young adults in the workplace. These young adults with cancer have distinct struggles: they have less access to resources than do more established workers and are at a time in their lives when career choices and the consequent opportunities for on-the-job training can have lifelong impact. In addition to dealing with the shock of receiving a diagnosis, they navigated workplaces where they have neither the tenure nor resources of their older colleagues. For instance, several participants in this study noted that, at the time of treatment, they had not accrued enough time off to cover their absences. Others had declined employer-provided disability insurances, thinking they were too young to need it, while others did not have access to that benefit.

Notably, for most participants, their experiences caused them to rethink how they wanted to move forward in their careers. Almost all talked about how their cancer diagnosis and treatment affected how they wanted to earn a living. For a few, it pushed them toward working directly with people with cancer in some advocacy role. For others, it caused them to reevaluate how they want to allocate their work-life balance and strive for a job that felt more meaningful. Importantly, several participants discussed how cancer shaped—and in many cases limited—their career options. Some believed that they needed to stay with a supportive employer. Others felt that high status, higher paying management jobs were no longer an option. Presumably, a decision to seek nonmanagerial jobs has differential effects on pay. To determine the impact of cancer on sustained professional achievement, future research could examine systematically how earnings change after a cancer diagnosis. Young adults who may be opting out of more lucrative jobs even before hitting their peak earning years.

Implications For Cancer Survivors

As seen in these stories, disability and discrimination laws do not protect all employees. However, experiences are not uniform. Some participants report ideal arrangements and support. Others were harassed and/or fired. One finding consistent with prior research is the role of immediate supervisors and their disposition to their staff [25]. This suggests that managers, not just Human Resource departments, may benefit from training about the ADA and cancer.

About three in four participants were in white collar jobs when diagnosed, many working for companies offering FMLA. These participants had structural advantages over service industry employees or whose jobs require physical labor. Many participants were able to utilize these benefits—from paid time off to telecommuting to formal leave policies—that enabled them to devise arrangements where they could maintain their job while pursing treatment. This supports previous research, including Blinder et al. (2011) that found that job type (white collar or nonwhite collar) is a significant predictor of who can return to
work [26]. Still, even some participants in white collar professions experienced negative consequences because of cancer. Workplace and job composition may buffer but do not guarantee protection from some of the negative workplace consequences of cancer. Given that young adults presumably have decades left in the workforce, future research could explore how these cohorts do over time as compared with those young adults who do not have a history with cancer. That many young adults who participated in this study explicitly acknowledge how cancer has changed their career trajectory suggests that young adults with cancer may need resources or interventions specifically tailored to support these adjustments and improve their future prospects. Young adult cancer survivors may need to conduct their own research into disability and discrimination laws so they can hopefully receive the benefits to which they are entitled.

**Declarations**

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**Compliance with Ethical Standards**

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**Disclosure of potential conflicts of interest**

The authors declare that they have no conflicts of interest.

**Research involving Human Participants**

The institutional review board governing research at TIRR Memorial Hermann Hospital, housed at the University of Texas Health Science Center, (IRB number HSC-GEN-15-0657) reviewed this study and declared it exempt under category 2. In addition, the IRB at the University of Texas MD Anderson Cancer Center (PA16-0271) reviewed and approved this study’s protocol. The study was performed in accordance with the ethical standards as laid down by the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.
Informed Consent

Informed consent was obtained from all individuals participants included in this study.

Consent to publish

The informed consent stated that the information gathered during the interview would be used influence further research on cancer and work. No personally identifiable information was included in the article. Certain identifiable information has been excluded from the study.

Data availability

The data that support the findings of this study are not publicly available. The transcripts contain information that could compromise research participant privacy.

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