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## Experiences of healthcare providers of older adults with cancer during the COVID-19 pandemic

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### ARTICLE INFO

#### Article history:

Received 26 June 2020

Received in revised form 31 July 2020

Accepted 16 September 2020

Available online 18 September 2020

#### Keywords:

Older adults

Geriatric oncology

COVID-19

Health care providers

### ABSTRACT

**Objectives:** Care for older adults with cancer became more challenging during the COVID-19 pandemic. We sought to examine healthcare providers' clinical barriers, patient questions, and overall experiences related to care delivery for these patients during the pandemic.

**Materials and methods:** Members of the Advocacy Committee of the Cancer and Aging Research Group along with the Association of Community Cancer Centers developed a 20-question survey for healthcare providers of older adults with cancer. Eligible participants were recruited by email sent through professional organizations' listservs, email blasts, and social media. This manuscript reports the qualitative data from the survey's three open-ended questions. Free text, open-ended survey items were analyzed by two independent coders for identification of common themes using NVivo software. Theme agreement was reached through consensus and count comparisons of participant responses were made.

**Results:** Healthcare system organizational challenges and meeting basic needs and support were commonly reported themes among respondents ( $n = 274$ ). Barriers to care delivery included organizational challenges, patients' access to resources and support, concerns for patients' mental and physical health, and telehealth challenges. Respondents reported older adults were asking about their health and cancer care as well as access to basic needs and supports. Providers described worrying about patients' mental health, fear of personal safety, frustration in multi-level institutions, as well as experiencing positive leadership and communication.

**Conclusion:** Providers are faced with balancing their concerns for personal and patient safety. These findings demand resources and support allocation for older adults with cancer and healthcare providers during the COVID-19 pandemic.

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### 1. Introduction

Older adults (age  $\geq 65$  years) with cancer are a vulnerable population and are at risk for complications related to COVID-19 [1–5]. Recent research has found that older adults with cancer present with increased symptom severity and are more likely to die if diagnosed with COVID-19 than younger adults [2,6,7]. Providing oncologic care to older adults with cancer was already challenging prior COVID-19, largely due to existing geriatric syndromes (e.g., frailty, comorbidity) [5,6,8–10] and lack of evidence-based treatment options and guidelines [11–16].

During the COVID-19 pandemic, healthcare professionals providing care for older adults with cancer are even more challenged by a unique and vulnerable position. Managing the cancer care of an at-risk population for COVID-19 complications requires both internal and external resources from taxed health systems and agencies dealing with an influx of patients. Healthcare providers are coping with the societal shifts and sustained emotional stressors faced by the general population as well as being at greater risk of exposure, moral dilemmas, extreme workloads, and rapidly evolving practice environments (e.g., shifts to telemedicine) [17,18] which may affect the health outcomes of older adults with cancer [19]. Furthermore, as the primary source of medical information for patients, their ability to stay informed and be a consistent trusted resource for patients is hindered by ever-changing institutional and healthcare system guidelines.

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Previous studies have found that healthcare workers, providing care to patients both with and without COVID-19, have higher levels of depressive symptoms, anxiety, burnout, and insomnia since the beginning of the pandemic [20–24]. Recognizing the need to support healthcare providers, Shanafelt and colleagues developed five requests from healthcare professionals to their institutions (“hear me”, “protect me”, “prepare me”, “support me”, and “care for me”) during the COVID-19 pandemic. This research demonstrates a unique opportunity to explore healthcare provider perspectives moving toward the identification of gaps in supporting healthcare providers [25].

The purpose of this exploratory qualitative research was to learn about clinical barriers to care, patient questions, and the overall experiences of oncology healthcare providers of older adults with cancer during the COVID-19 crisis. These findings will help providers and healthcare systems address the reported concerns and barriers of front-line providers. Understanding the experiences of the healthcare providers during this unprecedented time can lead to guidance and support for the team caring for older adults with cancer now and in the future.

## 2. Materials and Methods

Members of the Advocacy Committee of the Cancer and Aging Research Group (CARG) and the Association of Community Cancer Centers (ACCC) developed a Qualtrics survey for providers of direct care of people with cancer. The survey included 20 items, three of which were open-ended questions, focusing on the care for older adults with cancer during the COVID-19 pandemic. The quantitative results of this survey are currently under peer review. The current paper reports the analysis of the qualitative data from the larger survey. The open-ended questions, the focus of this manuscript, asked respondents: 1) to list up to five clinical barriers caused by COVID-19 as they relate to caring for older adults with cancer; 2) the top three questions regarding COVID-19 being asked of providers/colleagues by older adult patients with cancer; and 3) about their experiences as a member of the cancer care team during the COVID-19 pandemic. Information about the provider's professional history (years in providing care to patients with cancer, percentage of older patients, medical profession/specialty, cancer program classification and setting) was collected.

Eligible participants were recruited by emails sent through four professional organizations' listservs and email blasts (ACCC, CARG, Association of Oncology Social Work, and Social Work Hospice and Palliative Care Network) as well as social media messaging (e.g., Twitter, Facebook). The survey was available from April 8, 2020 until May 1, 2020. The median completion time was eleven minutes. The study was determined by the University of Cincinnati Institutional Review Board to not be human research as no identifying information was included in the data used for analysis.

The responses to the three open-ended questions were analyzed using qualitative content analysis by two separate reviewers [26]. Open-ended question answers were reviewed and initially coded independently by the two reviewers (JLKS, JP) using NVivo 12 qualitative software (QSR International, 2018). Themes were then reviewed by co-authors, and discrepancies were resolved through consensus. The reviewers then coded each thought unit (phrase, sentence) into the themes and counted these units in each theme. Unit counts were compared and discrepancies were resolved through consensus. A coding comparison was conducted in NVivo. All Kappa coefficients were > 0.80 and ranged from 0.81–1.00, indicating excellent interrater agreement. The data regarding providers' professional history were analyzed using descriptive statistics (frequencies, percentages) with SPSS 23.

## 3. Results

The professions of respondents ( $n = 274$ ) were social workers (43%), oncologists, geriatricians, and advanced practice providers

(28.3%), other professionals (e.g., case managers, nurse, dietitian, pharmacist) (9.2%), administrator/program leadership (8.1%), navigators (5.1%), and multiple professions or positions (6.3%). The majority of respondents (68%) reported that older adults comprise over 50% of their patient volume. Professional years of caring for people with cancer ranged from over 20 years (26.4%), 11–20 years (28.9%) and 1–4 years (20.5%). Nearly all respondents (92.7%) worked in the United States (Fig. 1). Thirty-six percent of respondents worked in an academic/NCI Comprehensive Cancer Program, 29% in a community cancer program, 16.9% in hospitals, with the remaining working in integrated network cancer programs, physician-owned oncology practices, physician's practices, and other settings. More than half (53.1%) reported working in an urban setting followed by suburban (29.5%) and rural (17.3%) settings (Table 1).

### 3.1. Clinical Barriers During the COVID-19 Pandemic

The first open-ended question asked respondents to share the top five clinical barriers related to caring for older adults with cancer during the COVID-19 pandemic. Numerous clinical barriers were reported. Emergent themes were grouped into five common categories: 1) organizational challenges in care provision; 2) patients' access to resources and support; 3) patients' mental health status; 4) telehealth challenges; and 5) patients' physical health status (Fig. 2). Organizational challenges in care provision included delayed cancer care, low personal protective equipment (PPE) supply, and limited opportunities to educate patients about COVID-19. Providers mentioned “delays in procedures: mammograms, biopsies, scans” and “patients' cancelling appointments” as common institutional barriers. Regarding institutional no-visitor restrictions, one provider said, “I worry about the impact of restricting visitors emotionally and clinically.” Another organizational barrier reported was lack of “PPE to assess patients clinically.” It was also reported that the lack of supplies “increases risk for all.”

Another clinical barrier to care was patients' access to resources and support including transportation issues, limited caregiving support due to stay at home orders and social distancing, and difficulty accessing food and supplies. One healthcare provider stated, “Getting to appointments is huge. We have fewer resources for transportation and the resources that are still in place (like Medicaid transportation) seem to have fewer drivers available and less reliability in terms of pick-up times.” Another provider shared, “Limited transportation and access to caregivers has then impacted access to food and prescriptions even though we are scrambling and getting better at work-arounds including home delivery and mail-order.”

Mental health status was a major clinical barrier due to social isolation and reduced support, fear, and strict visitor policies. Social isolation impacting mental health was a common clinical barrier shared by healthcare providers. For example, one healthcare provider reported that patients are, “feeling isolated with fewer social and practical supports” and “older adults who live alone are just more isolated.” A “lack of awareness and knowledge of cancer and COVID-19 leading to extra high baseline anxiety level” was a patient barrier seen by providers. Lastly, there is, “patient reluctance to come to the hospital or emergency room for fear of contagion.”

Telehealth challenges included access and support issues as well as communication difficulty due to sensory impairment, rurality, and inadequate equipment. One provider stated, “Older adults with cancer are not savvy on the computer and miss the telehealth appointments because the technology is not user friendly for them.” Disparities in access was another reported telehealth challenge. One healthcare provider noted, “patient's tech ability, no internet, no computer, or smart phone availability” while another stated, “rural settings lack internet service.”

The last clinical barrier was concern about physical health status including geriatric syndromes, disease progression, and high-risk status of older adults with cancer. Providers mentioned, “early onset dementia”,

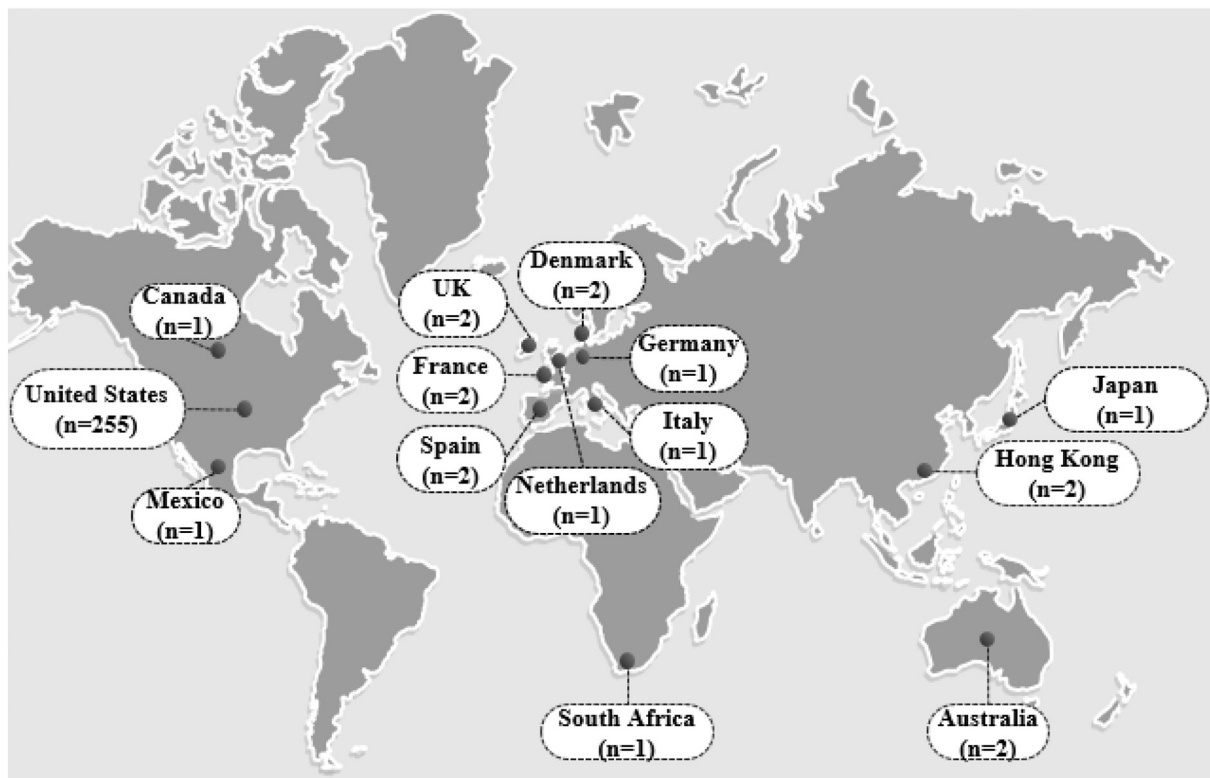


Fig. 1. Distribution map of participants by country.

**Table 1**  
Professional Role, History, and Location of Survey Respondents (n = 274).

Variable	%
<b>Profession</b>	
Social Worker	43.0
MD and APP	28.3
Administrator/Program Leader	8.1
Multiple professions/roles	6.3
Navigator	5.1
Other	9.2
<b>Percentage of patients with cancer older than age 65</b>	
<10%	0.7
10–25%	4.4
25–50%	26.4
50–75%	57.1
>75%	11.4
<b>Years providing care to patients with cancer</b>	
1–4	20.5
5–10	24.2
11–20	28.9
20+	26.4
<b>United States as country of care</b>	
92.0	
<b>Classification of cancer program</b>	
Academic/NCI Comprehensive Cancer Center	36.4
Community cancer program	29.0
Hospital	17.3
Integrated network cancer program	7.0
Physician-owned oncology practice	4.0
Physician practice	0.4
Other	5.9
<b>Location of cancer program/institution</b>	
Urban/city	53.1
Suburban	29.5
Rural	17.3

Other professions include: including dietitians, pharmacists, case managers, medical assistants, pulmonologists, radiation therapists, and research nurses.

“multiple comorbidities and frailty”, and “functional status” as barriers to clinical care. Healthcare providers also noted “potential risks for patients being immune-suppressed”, “safety concerns”, and “this population is at higher risk for complications from COVID-19.”

3.2. Questions Asked of Healthcare Providers by Older Adults with Cancer During COVID-19

The most common themes regarding the questions asked by older adults with cancer were: 1) patients’ health and cancer care; 2) basic needs and support; and 3) future and pandemic timeline (Fig. 3). The most common question was concerning patients’ health and cancer care, particularly regarding the risks and benefits of delays in treatments and procedures as well as how to keep themselves safe. For example, healthcare providers said patients’ questions included, “Do I need to come in to treatment?” and “Is the treatment benefit really worth the risk of being infected?” Similarly, other providers were asked, “If COVID doesn’t kill me, then will the cancer kill me if my treatment plan is altered?” and “What if COVID kills me before my cancer does?”

The second most common question regarded safely accessing basic needs and support including food, supplies, and caregiver presence at appointments. For example, a patient reportedly asked, “How am I supposed to meet my needs when all of my supports are unavailable?” Examples related to visitor restrictions were “Why can’t my family come with me [to the appointment]?” and another, “Why can’t my caregiver join me in the treatment room, when we live together?” One provider was asked, “Can I stay at the hospital after my surgery an extra day because I do not feel safe caring for myself at home?”

The third most common question was regarding estimated timelines of when one can return to the cancer center and restrictions will be lifted. Questions included, “When will this be over and back to ‘normal’?” and, “When will it be safe to be out in public and not shelter in place?” Patients also asked about timelines associated with social

Organizational challenges in care provision	Patient’s access to resources and support	Patient’s mental health status	Telehealth challenges	Patient’s physical health status
<ul style="list-style-type: none"> <li>• Delayed procedures/cancer care services (cancelled appointments, clinics closed, prioritization of resources)</li> <li>• No visitors limiting education and advocacy opportunities</li> <li>• Adherence/compliance with cancer care recommendations</li> <li>• Educating patients on evidence of COVID-19, hygiene, and high-risk status</li> <li>• Safety of home health care delivery</li> <li>• Ageism</li> <li>• PPE supply</li> <li>• Discharge placement options and logistics/insurance contact</li> <li>• Communication within the healthcare team</li> </ul>	<ul style="list-style-type: none"> <li>• Transportation disruptions</li> <li>• Caregiving disruption and challenges</li> <li>• Access to food, meals, basic supplies</li> <li>• Access to prescription refilling</li> <li>• Loss of income including caregivers</li> <li>• Limited home-based services</li> <li>• Long distance transportation/travel lodging</li> </ul>	<ul style="list-style-type: none"> <li>• Anxiety</li> <li>• Fear of contracting COVID-19</li> <li>• Fear of cancer progression due to treatment delay</li> <li>• Fear impacting service receipt</li> <li>• Depression</li> <li>• Social isolation/limited support</li> <li>• Anxiety caused by strict visitor policies</li> <li>• Caregiver distress</li> <li>• Limited leisure time</li> <li>• Frustration and anger with normal life/routine disruption</li> </ul>	<ul style="list-style-type: none"> <li>• Dissatisfaction with limited face to face contact</li> <li>• Communication difficulties (sensory impairments, technology use)</li> <li>• Telehealth access for staff, patients and family/caregivers</li> <li>• Missed appointments due to technology issues</li> <li>• Inadequate IT support</li> <li>• Rural locations with limited technology access</li> </ul>	<ul style="list-style-type: none"> <li>• Geriatric syndromes (frailty, comorbidities, cognitive impairment)</li> <li>• High risk status</li> <li>• Functional status</li> <li>• Risk of exposure vs. delay in treatment</li> <li>• Disease regression</li> <li>• Symptom discernment between COVID-19 and cancer</li> <li>• Side effects of treatment and self-management</li> </ul>

Fig. 2. Top five clinical barriers caused by COVID-19 in caring for older adults with cancer.

distancing and limiting family interactions such as “When will visitors be allowed again?” and, “When can we see our family?”

### 3.3. Experiences as a Cancer Care Team Member During the COVID-19 Pandemic

Participants were candid and thoughtful about their experiences as a member of the cancer care team during the COVID-19 pandemic. Four main themes emerged regarding being a member of the cancer care team during the COVID-19 pandemic: 1) worry about their patients' mental health; 2) feelings of crisis and fear of personal safety; 3) frustration and anger at multi-level institutions; and 4) contrarily positive feelings regarding their healthcare system leadership, colleagues, and communication.

Providers felt that there was an increased prevalence of mental health issues and need for services among patients. One provider stated, “I've seen increased mental health needs throughout the pandemic” while another said, “I feel like the need for mental health/social services is greater than ever right now.” Providers worried about “the toll increased mental health issues (will have)...because it (COVID-19) could negatively impact their physical health.”

Feelings of crisis and fear of personal safety were pervasive. Regarding the stress and emotional toll, a provider stated, “most days feel like 9/11/01.” One provider said, “I am afraid to get sick and die. Afraid to get my patients sick KNOWING that they will likely die.” Another stated, “I think a lot about my older patients and their safety during this pandemic-this keeps me up at night.” Regarding their own well-being, a provider stated, “It (COVID-19) has depleted my energy more than my work typically does.” Similarly, a provider noted that the current situation has “been a recipe for burnout.” Providers noticed that coworkers were experiencing “compassion fatigue” and were “more panicked than our patients.”

Healthcare providers were angry and frustrated at multiple institutions' response to the pandemic. For example, one provider said, “Everyone needs more PPE. The US government has failed its citizens.” Similarly, another declared, “The US federal government response has been a complete disaster in terms of rapid testing and securing adequate PPE.” One provider remarked, “I am so, so saddened at the state of our healthcare system...healthcare employees are not being treated very well.” Another stated, “I am one of the only social workers in the clinic and currently am being asked to follow-up on all 700 patients.”

Despite the constant fear and stress during the COVID-19 pandemic, some providers expressed thankfulness for their coworkers and leaders.

Patient’s health and cancer care	Basic needs and support	Future and pandemic timeline
<ul style="list-style-type: none"> <li>• Personal safety measures</li> <li>• Risk of contracting the virus</li> <li>• Risks vs. benefits of delaying treatments or procedures</li> <li>• COVID-19’s impact on prognosis and overall health outcomes</li> <li>• Safety measures taken by the healthcare facility and providers</li> <li>• Access to health care services during the pandemic</li> <li>• Virus and health information pertaining to older adults with cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Transportation options</li> <li>• Safety regarding care from a caregiver and their attendance during appointments</li> <li>• Social service resources</li> <li>• Access to food and safety of going into the community for necessities</li> <li>• Access to mental health services</li> <li>• Access to medical supplies and medication</li> </ul>	<ul style="list-style-type: none"> <li>• General timeline and what to expect in the future</li> <li>• Returning to normalcy and lifting of restrictions</li> <li>• Safety in the future</li> <li>• Assurance to quell fears of the unknown</li> </ul>

Fig. 3. Questions asked of healthcare providers by older adults with cancer during COVID-19 pandemic.

For example, one provider said, “The teamwork and collaboration needed to problem-solve, support, and encourage from administrative leadership to the hands-on care team has been truly inspiring.” Another stated, “I’ve been tremendously impressed at my institution’s ability to prepare for this pandemic and am now seeing the benefits.” Specific positive multidisciplinary interactions were observed during the crisis, as well. For example, a healthcare provider mentioned, “I appreciate the thoughtful discussion that the healthcare team members are having during our virtual tumor boards.”

#### 4. Discussion

This study sought to explore the clinical barriers to care, patient questions, and the overall experiences of oncology healthcare providers of older adults with cancer during the COVID-19 crisis. Results indicated multiple clinical barriers to care ranging from institutional (e.g., delayed cancer treatment) to individual (e.g., limited access to informal caregivers) difficulties during the COVID-19 pandemic. These findings demonstrate a need to ensure continued flow of care and to improve the infrastructure of patient access. Clinicians should consider simple interventions that are beneficial to all stakeholders (patients, providers, institutions), appropriately based on medical need, and avoid potential exposure to COVID-19 while continuing therapeutic relationships and cancer management [27]. Additional supports for accessing and receiving telemedicine as well as transportation and basic essentials for older adults with cancer need to be established, financially supported, and communicated to healthcare providers and patients. This communication is pertinent, as it will ensure older adults with cancer are not only receiving the cancer care they need, but also the everyday instrumental and emotional support necessary during this uncertain time.

Findings indicated that healthcare providers’ concerns were their patient’s safety and treatment delays and their colleague’s mental health above their own and their family’s safety. This illustrates the devotion these providers have for their older patients. Healthcare providers in geriatric oncology are accustomed to dealing with complex profiles in their patient population [12]. The problem with COVID-19 is that there is no available curative treatment or care guidelines. Given the reported multiple demands and challenges found in this study and others, provider burnout is expected. Healthcare administrators should recognize the importance of self-care and development of psychological intervention services for our healthcare providers [28–31].

The experiences of the healthcare providers were profound and demonstrate the duality of the COVID-19 pandemic. On one hand, there is evidence of the resilience and selflessness of the healthcare providers, the thoughtfulness of clinical teams, and the strong leadership from healthcare administrators. However, respondents also felt that institutions from the local to federal level that are supposed to provide vital resources, such as PPE, to support workers and the general population, are not doing so. At this point in the COVID-19 pandemic, it is clear that healthcare providers as well as older adults with cancer need to have access to support services to minimize the long-term negative outcomes of the difficult choices and psychosocial upheaval they face. This support needs to include information about how the current experience may have long-term effects, access to evidenced-based interventions to address the long-term effects, and explicit appreciation of the care healthcare providers have continued to offer throughout the crisis. Furthermore, leadership needs to acknowledge challenges faced by front-line providers and ensure resources are available and easily accessible [8,32].

#### 5. Limitations

The generalizability of this study is limited because the invitations to participate were highly focused on healthcare providers who care for older adults with cancer. This limitation skews the reported experience

related to older adults with cancer and not people with cancer in general. Another limitation is the uneven distribution of healthcare providers with the largest professional group to respond encompassing oncology social workers followed by MDs and APPs. The majority of respondents are from the United States resulting in reduced generalizability. More than half of the respondents worked in urban areas, which can reduce the application of this study’s findings to suburban and rural settings. Lastly, respondents answered open-ended questions and were not probed for additional information and elaboration (as done in interviews and focus groups) thus possibly limiting the reported scope of barriers and challenges experienced by providers.

#### 6. Conclusion

This study examined the experiences of healthcare providers caring for older adults with cancer during the COVID-19 pandemic. Providers noted several barriers to the treatment of older patients, especially organizational challenges and patients’ access to resources and support. Questions from older adults with cancer focused on their personal health and cancer care (e.g., delayed treatment, risk of infection), their basic needs and support (e.g., caregiving, transportation), as well as general questions about the future and COVID-19 timeline. More research is needed to understand the short- and long-term impact of COVID-19 on the care provision of older adults with cancer. In addition, this research insists upon resource and support allocation for older adults with cancer as well as healthcare providers during the COVID-19 pandemic.

#### Author contributions

Conception and design of the study: KB, JLKS, ARM, BC, EP, LMB, AS.

Data collection: KB, EP, LMB, AK.

Data analysis and interpretation: KB, JLKS, JLP, ARM, EP, AS.

Drafting of manuscript or critical revision: KB, JLKS, JLP, ARM, BC, EP, LMB, AK.

Approval of final article: KB, JLKS, JLP, ARM, BC, EP, LMB, AK.

#### Declaration of Competing Interest

All authors, with the exception of KB, certify that they have no affiliations with or involvement in any organization or entity with any financial interest. KB has a financial relationship with Blue Note Technology, Inc.

#### Acknowledgments

The societies and groups (ACCC, CARG, Association of Oncology Social Work, and Social Work Hospice and Palliative Care Network) who helped distribute the survey to their members. This project was supported in part by the grant No. P30 CA008748 from the National Institute of Health.

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