

## Original Article

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# Living with a blood cancer in later life: The complex challenges and related support needs of adults aged 75 and older

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**Abstract**

**Objectives.** This study investigated the challenges and support needs of adults aged 75 and older during and after treatment for a blood cancer to aid targeted supportive resource development.

**Methods.** Adults aged 75 and older with a blood cancer participated in in-depth, semi-structured interviews about challenges and unmet support needs. Participants recruited through The Leukemia & Lymphoma Society were (1) in treatment or previously in treatment for a blood cancer at age 75 or older and (2) living in the United States or its territories. A thematic analysis was conducted with findings compared between 2 groups: (1) chronic -living with a chronic blood cancer; (2) acute -living with an acute blood cancer or both an acute and chronic blood cancer.

**Results.** Participants ( $n = 50$ ) ranged from 75 to 91 years old. Both groups described similar experiences and identified 5 challenges and support needs: (1) socioemotional impact, (2) activities of daily living and instrumental activities of daily living (ADLs/iADLs), (3) uncertainty management, (4) treatment-related stressors, and (5) COVID-19-related strain. Properties for these themes illustrate challenges and support needs, with some differences between groups. For instance, those living with a chronic blood cancer highlighted financial strain with treatment-related stressors, while those with an acute blood cancer focused more on iADLs.

**Significance of results.** Findings inform an agenda for targeted resource development for older adults with a blood cancer nearing the end of the life span. Results demonstrate the need for supportive services and family communication interventions to help patients manage iADLs and navigate socioemotional needs and challenges.

**Introduction**

The number of older adults living with cancer is growing rapidly (Berger et al. 2006; Bluethmann et al. 2016; Yancik and Ries 2000). This is especially true among those with a blood cancer, as the incidence of leukemia, non-Hodgkin lymphoma, and myeloma rises substantially in the sixth through ninth decades of life (Howlader et al. 2021). Although older patients with cancer have complex needs that warrant targeted resources (Kadambi et al. 2020), little research has focused on the experiences and needs of the “old–old” (ages 75–85) and “oldest old” (ages 85 and older) (Bluethmann et al. 2016; DeSantis et al. 2019).

Adults aged 75 and older face a complicated cancer care trajectory. They typically concurrently manage preexisting comorbidities, related polypharmacy burden, as well as treatment-related toxicities that can exacerbate comorbidities and linger for years (Burdett et al. 2018; Lees and Chan 2011). Older adults living with an acute or a chronic blood cancer may experience challenges associated with receiving multiple lines of therapy, strenuous treatments and side effects, urgent inpatient treatment, extensive hospital stays, and repeated emergency department visits (Berterö et al. 1997a, 1997b; Bryant et al. 2015; Dionne-Odom et al. 2019; Howell et al. 2022; Zimmermann et al. 2013). Moreover, barriers related to ageist attitudes or time constraints also inhibit older patients’ ability to have their needs met in clinical settings (Fisher and Canzona 2014; Fisher and Fowler 2014; Greene and Adelman 2003; Nussbaum et al. 2008;

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Nussbaum and Fisher 2009). These distressing experiences have been compounded by the COVID-19 pandemic, with blood cancer caregivers and diagnosed loved ones grappling with isolation and disruption to care continuity (Bagautdinova et al. 2023; Fisher et al. 2021; Kastrinos et al. 2022).

Little is documented about the challenges that older adults aged 75 and older face during and after blood cancer treatment and their related support needs. As the aging population grows, so does the need to amplify their voices and prioritize targeted resources that help reduce burden and support healthy blood cancer coping (Berger et al. 2006). We aimed to investigate the challenging experiences that adults aged 75 and older face during treatment for a blood cancer to better characterize their support needs and provide an agenda for targeted resource development.

## Methods

### Participants

Adults aged 75 and older and diagnosed with a blood cancer (hematological malignancy) were recruited through The Leukemia & Lymphoma Society (LLS). Inclusion criteria were patients (1) in treatment or previously in treatment for a blood cancer at the age of 75 or older and (2) living in the United States or its territories.

### Procedure

Following University of Florida Institutional Review Board (IRB) approval (IRB202102120), participants were recruited via email through LLS's constituent database and LLS Community, an online social network for patients. We received over 400 screening eligibility phone calls within 2 weeks in November to December 2021. Two authors (MDM and LAT) screened 255 respondents to maximize comparable representation by gender, race/ethnicity, urban/rural, age, caregiver support, and blood cancer type. Eligible participants were recruited to schedule a phone interview. Two authors (MDM and TBA) conducted in-depth, semi-structured interviews from December 2021 to February 2022. Interviewers obtained verbal consent before each interview and demographic information at the conclusion. Participants were asked about challenges encountered and related support needs in both relational (e.g., family) and clinical contexts (e.g., *What has been challenging for you to manage? How has cancer impacted your family? What has been the most challenging to discuss with your family? When you think about your support needs after your diagnosis and up to the present day, what areas did you lack support and need support with?*). Participants received a \$50 gift card for their time.

### Analysis

Interview data were managed using ATLAS.ti and thematically analyzed using a constant comparative method (CCM) approach (Glaser and Strauss 1967; Strauss and Corbin 1998). Data were initially analyzed separately based on influential variables: race, urban/rural/suburban, and acute/chronic disease type. The sample size was too racially homogeneous to detect meaningful differences, and no location-based differences were found. Thus, before full analysis, to ensure similarities and differences could be identified, we segmented into 2 groups where slight differences were emerging: (1) chronic – living with a chronic blood cancer (e.g., multiple myeloma, chronic lymphocytic leukemia, non-Hodgkin lymphoma) or (2) acute – living with an acute blood cancer

(e.g., acute lymphocytic leukemia, Hodgkin lymphoma), which also included those living with both acute and chronic blood cancers. Data were analyzed separately so that we could identify how experiences converged and diverged in line with a triangulation by perspective approach (Vogl et al. 2019).

CCM analytical steps included (1) open coding to identify concepts and assign codes/labels, (2) collapsing similar concepts to develop themes, and (3) axial coding to identify thematic properties to characterize each challenge and related support needs (Strauss and Corbin 1998). Thematic saturation was guided by Owen's (1984) criteria of repetition, reoccurrence, and forcefulness; all themes were reported by at least 50% of participants. One author (ENW) who did not conduct interviews led the analysis overseen by the senior author (an expert in thematic analysis). To ensure rigor, a third author (DB) used the codebook to validate themes with a subset of data. A fourth author (NDP) analyzed the full dataset to validate themes and properties and refine the typology for presentation, meeting with the senior author to review analysis. To promote translation of findings into resources, results are presented using action statements (Banning 2003; Sandelowski and Leeman 2012).

## Results

Fifty adults participated in the interviews. Ages ranged from 75 to 91 years ( $N = 80.26$ ; median age = 79). The majority represented the “old-old” subgroup aged 75–85 years ( $n = 44$ ). Most respondents identified as white, non-Hispanic ( $n = 44$ , 88%). All but 1 had some caregiver support. Interviews averaged 70 minutes (range, 30–218 minutes). Professional transcriptions resulted in 944 pages of data. See Table 1 for participant demographics and clinical characteristics.

Analyses were conducted and compared based on 2 groups of older adults: (1) those living with a chronic blood cancer and (2) those living with an acute blood cancer or both acute and chronic blood cancers. Both groups described 5 challenges and related support needs: (1) socioemotional impact, (2) activities of daily living/instrumental activities of daily living (ADLs/iADLs), (3) chronic uncertainty, (4) treatment-related stressors, and (5) COVID-19-related strain. Findings also demonstrated slight differences between the 2 groups within each challenge. These are illustrated below along with defining thematic properties (in italics) which help to characterize each challenge and related support needs (see Table 2).

### Socioemotional impact

Older adults described how their socioemotional well-being was affected across the disease trajectory. They highlighted 3 socioemotional needs (*feeling cared about*, *needing a sense of normalcy*, *wanting preservation of self*) and 2 related challenges that arise when needs go unmet (*identity-related challenges*, *relational struggles*). They also identified 3 preferred sources of support (*companionship/family*, *peer*, *professional mental health*) to fulfill these needs.

Older adults identified 3 socioemotional needs. First, they stressed the importance of *feeling cared about*, which they experienced with loved ones showing love, empathy, and concern by keeping in touch: “My number one advice would be [to] call the person. ... Email them, keep in touch, show them you care by contacting them. Ask how they're feeling” (P37: female, age 79, acute). They also described *needing a sense of normalcy*: “One thing I don't

**Table 1.** Participant demographics

	n (%)
Age: mean (SD), [range]	80.3 (4.0) [75–91]
Sex	
Male	24 (48)
Female	26 (52)
Diagnosis <sup>a</sup>	
Leukemia	20 (40)
Lymphoma	14 (28)
Myelodysplastic syndromes (MDS)	1 (2)
Myeloproliferative neoplasms (MPNs)	2 (4)
Myeloma	14 (28)
Diagnosis by Groups	
Chronic/Indolent	33 (66)
Aggressive/Acute	9 (18)
Acute/Combined (both acute and chronic blood cancer type diagnoses)	6 (12)
Unknown	2 (4)
Average Years Since Diagnosis	
Chronic/Indolent (range, 1–31 years)	10
Acute (1–14 years)	5
Acute/Combined (both acute and chronic) (range, 3–24 years)	10
Race <sup>b</sup>	
White	44 (88)
Black/African American	5 (10)
Asian	1 (2)
Native Hawaiian/Pacific Islander	0 (0)
American Indian	2 (4)
Ethnicity	
Hispanic	0 (0)
Non-Hispanic	50 (100)
Education	
High school graduate/GED	8 (16)
Some college	0 (0)
Associate's degree	4 (8)
Bachelor's degree	14 (28)
Post-baccalaureate	1 (2)
Master's degree	19 (38)
Professional degree beyond bachelor's degree	1 (2)
Doctorate degree	2 (4)
No response	1 (2)

(Continued)

**Table 1.** (Continued.)

	n (%)
Employment Status	
Employed full time	0 (0)
Employed part time	1 (2)
Self-employed	2 (4)
Unemployed	1 (2)
Retired	46 (92)
Caregiver Involvement	
Spouse/Partner	26 (7)
Child/Children	4 (8)
Sibling(s)	1 (2)
Receiving occasional help from family member	12 (24)
None	1 (2)
Community Type	
Urban	17 (34)
Suburban	26 (52)
Rural	7 (14)

<sup>a</sup>Some participants specified multiple diagnoses.

<sup>b</sup>Participants were allowed to select more than 1 option.

**Table 2.** Challenges and related support needs

Adults aged 75 and older faced these challenges while coping with a blood cancer	Which are associated with the following support needs
Socioemotional impact	<ul style="list-style-type: none"> <li>▪ Feeling cared about</li> <li>▪ A sense of normalcy<sup>a</sup></li> <li>▪ Preservation of self<sup>a</sup></li> <li>▪ Managing identity threats<sup>a</sup></li> <li>▪ Managing relational struggles</li> <li>▪ Wanting companionship/family support</li> <li>▪ Needing peer support</li> <li>▪ Seeking professional mental health support</li> </ul>
ADLs iADLs <sup>b</sup>	<ul style="list-style-type: none"> <li>▪ Assistance with bathing, meals, and mobility</li> <li>▪ Assistance with medical management, household management, and transportation</li> </ul>
Chronic uncertainty	<ul style="list-style-type: none"> <li>▪ Treatment-related uncertainty</li> <li>▪ Fear of recurrence</li> <li>▪ Future uncertainty</li> <li>▪ Uncertainty related to mortality</li> </ul>
Treatment-related stressors	<ul style="list-style-type: none"> <li>▪ Side effects</li> <li>▪ Financial strain<sup>a</sup></li> </ul>
COVID-19-related Strain	<ul style="list-style-type: none"> <li>▪ Social isolation</li> <li>▪ Loss of activities</li> <li>▪ Family challenges</li> <li>▪ Uncertainty-related distress</li> </ul>

<sup>a</sup>More prevalent with chronic blood cancer group.

<sup>b</sup>More prevalent with acute/acute + chronic group.

appreciate is ... when they call [it's] all about cancer, all about cancer, all about chemo ... You don't want to be talking about it all the time. It just compounds everything" (P5: female, age 79, chronic). Wanting normalcy was heightened for those with a chronic blood cancer (only 1 adult in the acute group reported this need). They also disclosed *wanting preservation of self*, particularly those coping with a chronic blood cancer. The physical effects of treatment contributed to a loss of activities they valued and viewed as a part of their identity:

Side effects of the chemo could be neuropathy in the legs and the hands. I just flat out said to [physician], "I can't have that! I have to play the piano. I have to walk" I said, "Life to me without being able to hike and walk and exercise my dog and ride my bike and play the piano, that's not life. That's just existence." (P47: female, age 90, chronic)

When these socioemotional needs were unmet, older adults encountered 2 related challenges. They experienced *identity-related challenges* when their ability to preserve their sense of self was inhibited: "I saw myself as totally healthy. So, my identity was totally blown. ... I was a swimmer. I was very active. I walked about seven miles every day. Dealing with a loss of that was pretty hard" (P18: female, age 79, chronic). They also described *relational struggles* involving family members not showing concern or empathy by avoiding cancer discussions or diminishing the seriousness of the cancer, which made them feel uncared for: "I don't think that [my children] really were that supportive of my disease or what it meant. ... I think that I expect them to inquire more" (P25: male, age 83, acute). Relational struggles also intersected with loved ones being overprotective or overbearing, which could threaten adults' sense of self, autonomy, and normalcy: "[My family] were overprotective. I'm a very independent person and I kind of bristle when they try to baby me. ... I have to tell them, 'Back off. I can do this for myself'" (P11: female, age 82, chronic).

Older adults further emphasized 3 sources of support that helped fulfill their socioemotional needs and manage related challenges. First, they stressed the importance of *companionship/family support*. Family could enhance their sense of normalcy through consistent, frequent communication:

I had a fair amount of people, friends and that, that would come over and just sit on the lawn chairs out in the driveway and sit around and just chat for 15-20 minutes. It always ended up to be about 2-3 hours, but that was good! (P27: male, age 76, acute)

Also, they reported needing *peer support* from people with shared experiences: "I was in several support groups. ... They were helpful, to hear other people, because very few of my friends had gone through what I went through" (P37: female, age 79, acute). Online peer support was similarly valued: "I'm signed on to the website for lymphoma and leukemia. And probably two or three days a week I go see what they're talking about. ... It's helpful to me to see what other people are going through" (P36: female, age 79, chronic). Finally, they acknowledged the importance of *professional mental health support* to cope with the socioemotional impact: "I went through ... being depressed. ... [My psychiatrist] was wonderful. ... She helped me" (P8: male, age 81, chronic). Similarly, a diagnosed woman shared, "My husband went to the therapist with me, and I don't know how we would have gotten through it without that support" (P1: female, age 79, acute).

## ADLs/iADLs

Older adults shared needing instrumental support for ADLs and iADLs. They needed help with several ADLs, given the physical impact of cancer (*bathing, meals, physical mobility*) but focused more on 3 types of iADLs, particularly adults in the acute group.

For instance, older adults described the complexities of *medical management*, including keeping track of medications, scheduling appointments, maintaining records, and addressing insurance issues: "Trying to track that all and keep it straight, keep it understandable, it's tough" (P38, male, age 79, chronic). They also described functioning as a communication liaison:

I have at least four doctors and I have to call and make sure that they get the information from the other doctors. And one of the problems is that I have to coordinate all of this—all these doctors! ... That gets out of hand for me. That's very difficult. (P43, female, age 86, chronic)

Additionally, they encountered struggles with *household management*: "I want meals, meds, and somebody to help in the house" (P6: female, age 80, acute). At times, they acknowledged not having (and needing) support: "What was hard for me was I couldn't clean the house anymore. I couldn't vacuum. I didn't have the strength," (P6: female, age 80, acute). Likewise, this individual disclosed:

I do wish that I had someone that I could just wake up in the morning and say ... "Would you go to the store for me. Would you get the groceries? I'm just really tired" ... I sometimes wish that I had someone who could walk my dog. ... I wish I had somebody I could count on. (P9: male, age 77, chronic)

Finally, older adults needed help with *transportation*, particularly during treatment including when they didn't need physical care: "I haven't really needed care aside from rides for treatment ... that's mostly just transportation, as opposed to actual care" (P26: male, age 79, chronic).

## Chronic uncertainty

Older adults struggled with persistent uncertainty across the cancer trajectory. They identified 4 types of uncertainty that evolved in relation to variant phases of the cancer trajectory. For instance, they described *treatment uncertainties* based on where they were in the continuum. During "watch-and-wait" period they encountered anticipatory uncertainty: "Who knows what else will come up. I don't know what will come up from now on" (P43: female, age 86, chronic). As they began treatment, they were uncertain of effects, duration, and efficacy: "They give you page after page of all the side effects. ... They just inundate you with all this horrible stuff that can happen. ... They scare the hell out of you when you're starting chemo" (P8: male, age 81, chronic). Likewise, this adult shared:

How long I'm going to have to take the Ibrutinib. How long is it going to work? ... I just need to take it for the rest of my life? If I don't take it, am I going to die? And if I even continue taking it, ... am I going to become tolerant to it or it may become less effective? (P15: male, age 80, chronic)

Post-treatment or during maintenance therapies they coped with *fear of recurrence* or "waiting for the other shoe to drop" and for it to "come back" (P3: female, age 76, chronic):

It can come back in a day, a month, a year. The uncertainty of a relapse or a reoccurrence, it's scary because I think every day now, "Is it going to come back, and how, if I go off all the medicine?" ... You're never really cured in your mind. ... You feel like you're more vulnerable and that's in the back of your mind every day. (P11: female, age 82, chronic)

This fear intersected with *uncertainty about the future*. Anxieties were expressed both about maintaining quality of life and end-of-life planning: “You have anxiety. How long are you going to live with this? And is it going to be a half-way decent life or is it going to be totally miserable?” (P14: male, age 75, chronic). Relatedly, older adults detailed grappling with *uncertainties about mortality*: “We dangled over the abyss for almost a year. It was just terrifying. It was very hard to make friends with death, that was a big challenge. And I am not the same person since” (P1: female, age 79, acute). Mortality uncertainty was also relational in nature: “I have to be more worried about my not being here. What will be the consequences of that for my wife and my children?” (P25: male, age 83, acute).

### Treatment-related stressors

Older adults also described treatment effects. They primarily focused on 2 types of treatment-related challenges.

For instance, older adults struggled to cope with *side effects* that could persist for years like “lack of strength, loss of stamina, [and] lack of stability” (P42: male, age 76, acute). It is noteworthy that those living with a chronic blood cancer also described the long-term *financial strain* of continuing cancer treatments, with only 1 adult in the acute/acute + chronic group addressing it: “My financial situation. I don’t know how long I can go. I don’t know – I just don’t know what will happen with me” (P13: female, age 79, chronic). These adults described the financial strain of medications:

It’s a challenge taking these pills, which believe it or not, cost about \$1,000 each, these Pomalyst pills. So, I have a financial challenge in that even though the majority is paid for by Medicare, ... I’m still supposed to pay 5%. Well, 5% of \$20,000 a month is still \$1,000 a month, which I cannot afford to take the pills. Fortunately, I have a grant from The Lymphoma & Leukemia Society, which helps a lot with that, but it will not cover the cost this year. I’m actually searching for other sources of grant money or whether I can get a discount from the manufacturer of these pills or some way to relieve the financial burden. So, that’s a challenge. (P38: male, age 79, chronic)

### COVID-19-related strain

Adults contextualized their challenges within the realities of living with a blood cancer during a global health crisis. They highlighted 3 types of pandemic-related strain.

Older adults shared how they struggled with *social isolation* due to COVID-19 distancing requirements. This disrupted their ability to be with loved ones and negatively impacted well-being:

I’m alone. ... What’s going on with the United States right now is just the worst and the most depressing and the toughest times that we’ve ever, ever faced in my life. ... It’s the cancer. It’s the COVID. It’s the state of the union, and it’s all of it. ... My kids keep saying, “Well, after your January treatment it’s going to be [a] big celebration,” and blah, blah, blah, blah. ... [I’m] looking toward when my family and I can all be together again. (P5: female, age 79, chronic)

Due to COVID-19 precautions, older adults also struggled with a *loss of activities* (e.g., not traveling or dining out, not attending social events, the movies, or religious services), which intersected with social isolation (i.e., lost time with loved ones): “The risk of going on a plane was too great for us, so we haven’t gone on any visits or vacations involving a plane trip, you know, for years” (P44: male, age 77, chronic). In losing activities they loved or that facilitated time with friends/family, their mental well-being suffered:

“I have had some depression. It’s from being shut up in this building because of COVID” (P12: female, age 82, acute).

The pandemic also contributed to *family challenges*, which centered around older adults’ heightened need for risk-reducing measures. Family members were not always understanding or supportive of their choices:

We had to tell the kids that for a while they couldn’t come [visit us] at all, and I guess that was hard for them sometimes to understand. They thought it was overbearing ... until they each had COVID, and then they understood why. (P45: male, age 78, chronic)

Older adults also described how their relationships became strained when their views on vaccination diverged from family members’: “My other daughter is not vaccinated, so my communication and contact with her is by phone. Now that has impacted me more than the cancer has” (P29: female, age 88, chronic).

Finally, older adults described *uncertainty-related distress* about their immunity and the efficacy of vaccination: “Nobody’s officially said if I have to go back and get two of the COVID [shots] or just a booster. So, this immunity situation’s a little up in the air. I’m concerned about that” (P14: female, age 79, chronic). They also expressed distressing uncertainty not knowing when COVID-19 risk would end: “Just never knowing when it’s all going to end, and everybody’s tired of having to wear masks ... trying to be careful... You just wonder when it’s ending” (P31: female, age 84, acute). They also expressed distress related to COVID-19 mortality and isolation:

I worry about getting COVID and dying all alone in the hospital, with no family members there.... Just the idea that this seems like it’s going on and on and on and on and on, and I’m going to spend the last few years of my life isolated. (P37: female, age 79, acute)

### Discussion

This is the first known study to investigate the needs of the growing population of adults aged 75 and older with a blood cancer. The experiences of the “old–old” (75–85) and “oldest–old” (85 and older) are not prioritized in cancer research or practice (Bluethmann et al. 2016; DeSantis et al. 2019). For those managing a blood cancer, this population is typically merged with adults coping during midlife (e.g., Bergerot et al. 2015; Marte et al. 2022). Findings showcase a complex set of challenges encountered across the disease trajectory that, in turn, provide an agenda for resource development targeting the distinct needs of adults coping with blood cancer at the end of the life span.

Older adults acknowledged the physical and psychological impacts of cancer and highlighted the critical role of social ties in managing these effects. They identified in-home instrumental support needs, including household maintenance or medical information management. Those with a chronic blood cancer struggled with financial strain. Even when adults had some care support, they wanted someone “to count on” for instrumental support if their existing support persons (e.g., adult child) were not co-residing. Emotional concerns were also paramount. They faced concurrent sources of distress (e.g., uncertainty-, identity-, COVID-19-related), and social ties affected their distress management. For example, they wanted to feel cared about by loved ones while maintaining a sense of normalcy and independence – socioemotional needs identified by individuals living with a blood cancer from young to later adulthood (Buchbinder et al. 2009; Darabos et al. 2022).

Findings suggest that resources with instrumental and psychosocial support are needed to reduce burdens among older adults with blood cancer and their families. While some cancer support needs are similar across age (e.g., medical management, ADLs/iADLs, mental health), they are more complex for adults 75 and older (Molassiotis and Wang 2023; Wang et al. 2018). Older adults typically manage cancer with comorbidities, while also having more physical limitations, less in-home care and instrumental support, and increased depression risk (Jones et al. 2015; Kadambi et al. 2020; van Abbema et al. 2017). Our findings show that older adults coping with a blood cancer have a variety of supportive needs to be met, including free transportation, meals, delivery services, home maintenance, and financial assistance. This is especially true for those who live alone, have no family nearby, are on restricted incomes, or reside in remote areas. Furthermore, family communication skills building may help families broach conversations about the needs and preferences for instrumental support in the context of preserving self-identity and feelings of normalcy, especially among families experiencing relational discord. Moreover, access to supportive programs providing peer-led emotional support and mental health interventions is direly needed. Older adults themselves acknowledged encountering both relational strife and emotional distress. Not only is family tension linked to significant psychological distress after a cancer diagnosis (Bergerot et al. 2015) but access to mental healthcare is limited in cancer care. A recent study showed that nearly half of adults coping with aggressive, refractory B-cell lymphomas had elevated levels of distress, but only a quarter received professional mental health treatment (Marte et al. 2022).

A recent systematic review advised blood cancer clinicians to more actively address and assess patients' mental well-being, noting the need to integrate coping skill interventions that are efficacious in reducing anxiety and depression associated with blood cancers (Andersen et al. 2022). Family members can also actively promote diagnosed older loved ones' access to mental health care. However, family members do struggle with discussing mental health in blood cancer caregiving and may avoid the topic (Wright et al. 2022). Communication skills interventions for both clinicians and family caregivers may help both stakeholders broach mental health needs during clinical or familial interactions and reduce barriers to therapy, thereby promoting patients' socioemotional well-being (Bylund et al. 2022; Wittenberg et al. 2019). In doing so, we may further normalize addressing psychological needs in oncology care at home and in clinical settings for all cancer types, at all phases of the life span. Additionally, access and connections to such resources is important as adults typically seek such support on their own, which includes added expenses.

### Study limitations

Our sample was recruited from a population that previously engaged with an advocacy organization and responded to recruitment advertisements via email. Our sample may not represent the perspectives and needs of those with lower engagement or technological literacy. Our patient population also lacked racial diversity. Targeted studies of older adults diverse in race and ethnicity are especially needed to further understand overlap and distinction in support needs. Lastly, our sample also consisted of more adults living with a chronic blood cancer type. Differences between these 2 groups did emerge and exist in other studies (Bergerot et al. 2015; Fisher et al. 2021) and may warrant further examination.

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**Competing interests.** None.

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