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Cancer during a pandemic: A psychosocial telehealth intervention for young adults

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ABSTRACT

The SARS-II COVID-19 pandemic has posed pronounced global health threats and prompted assorted transformations in societal engagement and clinical service delivery. For cancer survivors, many of whom are immune-compromised, these pandemic-related health threats pose greater challenges, warranting extra precautions within everyday living. Young adult (YA) cancer survivors already confront many unique physical and emotional challenges specific to their demographic. Already comfortable with assorted technologies, the pandemic presented an opportunity to provide telehealth intervention that targeted social isolation and distress in an effort to facilitate healthy coping. Within this context, we created an 8-week telehealth intervention for YAs (age 18-39) comprised of 60-minute sessions with interventions derived from Acceptance and Commitment Therapy and Meaning-Centered Psychotherapy. Participants reported a reduction in anxious preoccupation, helplessness/hopelessness, and psychological inflexibility and provided rich qualitative feedback on their experiences. Findings contribute new insight for an underinvestigated population navigating the dual health threats of cancer and COVID-19, provide practice recommendations with attention to the value of qualitative data capturing in group settings, and underscore participants' preference for flexible group structure and age-related connections.

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Introduction

Cancer poses challenges to one's physical, emotional, and social well-being. Health anxiety, depression, reduced social connectivity, and acute stress, often in the form of trauma, thread across all diagnostic groups and can negatively impact quality of life. Young adult (YA) cancer survivors (18-39) in active and post-treatment remain underrepresented in the oncology literature.¹ One year postdiagnosis, approximately 25% of YA survivors report significant clinical distress.² Body image concerns, unpleasant emotions, social isolation, and problems at school or work are common 2 years after diagnosis.³ Flexibility in care and age-appropriate psychoeducational materials have been found to increase autonomy and improve physical and psychological outcomes in YAs through survivorship.⁴

The COVID-19 pandemic, with more than 79 million cases and over 964,000 deaths in the United States as of March 2022,⁵ exacerbated cancer survivors' existing distress and disrupted oncology services. For YAs, the pandemic impacted many important developmental milestones involving work, school, and socialization. Navigating cancer survivorship amid a pandemic further complicates coping processes and normal avenues of support.

Cancer survivors commonly contend with reduced immune functioning, placing many at higher risk for viral contagion and/or comorbidities. Survivors presenting with COVID-19 face a higher risk of being admitted to an ICU, being placed on a ventilator, or dying compared to noncancer patients with COVID-19.⁶ In addition to physical concerns, cancer survivors navigating disease survivorship and dynamic pandemic conditions may be at even higher risk for emotional distress and trauma as they confront dual health threats. Commonly reported mental health concerns during a pandemic include anxiety, depression, and posttraumatic stress disorder.⁷ Consistent with these findings, many YAs endorse anxious and depressive symptoms, hopelessness, and loneliness related to the COVID-19 pandemic.⁸ The need exists for tailored mental health interventions to help YA cancer survivors navigate the psychological impacts of survivorship amid the ongoing pandemic.

As pandemic-era mental health visits usually take place online, equitable access to telehealth opportunities is imperative. Cancer survivors, including YAs, rural or geographically distant, and economically distressed individuals, may find this modality inviting due to familiarity or enhanced access to care.⁹⁻¹² For YAs, acceptance of the modality was common even prior to COVID-19.¹³ Similar treatment outcomes exist for telehealth and in-person groups.^{14,15} Successful outpatient telehealth services with YAs throughout the pandemic have been reported.¹⁶

We conducted a mixed methods pilot study of an 8-week telehealth support group for YA cancer survivors that targeted the constructs of health anxiety, depression, trauma, and social connectivity. Our aims were to: (1) replace avoidance coping skills with acceptance skills; (2) reduce helplessness and hopelessness with purposeful life choices; (3) reduce depression and anxiety levels through meaning-making; and (4) provide an outlet for meaningful social connection.

Material and methods*Recruitment*

Participants were recruited by asking oncologists, advanced practice providers, and other multidisciplinary clinicians for direct referrals; contacting YAs who participated in former clini-

Table 1

Inclusion and exclusion criteria.

Inclusion	Exclusion
1. Documented cancer diagnosis within the medical record	1. Active inpatient hospitalization
2. Outpatient Cancer Survivor (new diagnosis, in treatment, or post-treatment)	2. Major cognitive impairment, marked concerns with working memory, concentration, or word finding difficulties that significantly impairs daily functioning documented in most recent clinic note or self-reported
3. Aged 18-39	3. Recent suicide attempt(s), psychiatric hospitalization, or psychotic processing (last 3 years)
4. Must speak English	4. Bipolar disorder (I or II) diagnosis, as evidenced by an International Classification of Diseases (ICD)-10 code within the past year or revealed during subject interview
5. Must have computer with audio and visual capabilities	5. Moderate to severe alcohol or drug abuse; as evidenced by an ICD-10 codes related to alcohol or illicit substance abuse in the medical record within the past year or revealed during subject interview
6. Must live within North Carolina	6. Severe eating disorders; as evidenced by an ICD-10 code in the medical record such as anorexia nervosa or bulimia within the past year or revealed during patient interview
7. Must have experienced health-related anxiety and/or distress in last 3 months	7. Repeated "acute" crises for example: marked psychological distress that impairs function and warrants clinician intervention (eg, occurring once a month or more frequently)

cal or research offerings (existing databases from Psychosocial Oncology and Public Health Sciences); advertising through hospital channels (clinic flyers, waiting room TVs, intranet); and reviewing existing Psychosocial Oncology staff members' clinical caseloads. Following the closing of a 3-month recruitment window, researchers called individuals who met general inclusion criteria during a 4-week period in February/March 2021, offered a study introduction, and asked specified screening questions (reference Measures). Researchers entered participant information into a secure institution-wide clinical trials database. Psychotherapy groups are typically comprised of 7-10 participants.¹⁷ The recruitment goal of 15 was established to account for attrition after the initial session. Each participant was compensated with a \$50 gift card after completion of the first session. The study was approved by the institutional review board.

Participants

YA North Carolina residents who had a cancer diagnosis and were in active treatment or transitioning into long-term survivorship, including those in remission, were eligible to participate. Additional inclusion and exclusion criteria are listed in Table 1. If participants were deemed ineligible at any point, they were offered the opportunity to participate in a nonprotocolized support group or individual therapy.

Intervention

The intervention was created using elements from Acceptance and Commitment Therapy (ACT) for Group¹⁸ and Meaning-Centered Group Psychotherapy (MCP).¹⁹ Content included coping strategies that enable positive psychosocial outcomes: acceptance of cancer-related distress, reduction of cancer-related avoidance, identification of personal values, a commitment to making meaningful behavior changes, and identification of meaning in life.^{20,21} Intervention developers and telehealth facilitators were trained in therapy approaches. The intervention consisted of

Table 2

Session topics and example content.

Session	Title	Content
1	Making Meaning Out of Anxiety: "How can mindfulness settle my worry?"	Introduction to group, health anxiety, 4 sources of meaning, here and now mindfulness practice
2	Finding Meaning through Cancer & COVID: "How can I let go of things I cannot control?"	Control and avoidance, identity and cancer, manatee mindfulness practice
3	Accepting Cancer & COVID: "How can embracing my identity lead to life meaning?"	Personal and medical check-ins, avatars as metaphors, polar bear and open mind mindfulness practices
4	Self-Observation, Legacy & Values: "How can acting on life serve my values?"	Personal and medical check-ins, valued activities that give meaning, the inner self mindfulness practice
5	Control, Willingness, and Acceptance: "How can I make room for my cancer?"	Personal and medical check-ins, connecting with life through experiences, defusion mindfulness practice
6	Wellness, Mindfulness & Legacy: "How can I create a vision board reflective of my identity & values?"	Personal and medical check-ins, sources of meaning and legacy, Wellness Wheel
7	Observing the Self with Willingness: "How can I create distance from my thoughts through mindfulness practice?"	Personal and medical check-ins, connecting to the observing self, inner peace mindfulness practice
8	Commitment, Mindfulness & Legacy: "How I will integrate group participation into my life."	Participants share Legacy Projects, summation of group experience

Adapted from Eilenberg, Frosthalm, & Kronstrand (2014) with elements on meaning making from Breitbart & Poppito (2005, rev. 2011).

eight 60-minute sessions and included a combination of psychoeducation, ACT and MCP concepts and skills, experiential activities, and reflection. See [Table 2](#) for session topics and example activities.

Measures

The 17-question investigator-created initial screening assessed group suitability with attention to inclusion and exclusion criteria and was administered verbally during first phone contact with prospective participants. Enrolled participants completed the following validated psychosocial measures at 3 time points: pre- (T1), mid- (T2), and post- (T3) intervention: Cancer Acceptance and Action Questionnaire, AAQ-C²⁰; The Mini-Mental Adjustment to Cancer, Mini-MAC²²; The Impact of Events Scale – Revised, IES-R²³; Coronavirus Anxiety Scale, CAS²⁴; The Cancer Behaviour Inventory-brief version, CBI-B²⁵; UCLA Loneliness Scale, version 3²⁶; and The Purpose in Life Test.²⁷ Details about these measures are provided in [Table 3](#). The 15-question investigator-created group evaluation assessed satisfaction and solicited feedback from participants at mid- and postintervention: (1) Eleven free response questions asked participants about the most and least helpful parts of the group (eg, What aspects of being part of this group have been most helpful to you?), psychoeducation and coping skills (eg, What information or skills learned throughout this group are you most confident you will apply within your life?), and outside engagement (eg, Do you keep in touch with any members outside the group?); (2) Four questions using a 10-point Likert scale assessed how likely members would recommend the group to others, how confident they feel in coping with cancer and the pandemic, and their subjective level of loneliness.

Procedures

Eligible participants provided verbal consent via phone and were required to sign a hard copy sent via USPS. Participants kept one informed consent packet for reference and returned the

Table 3

Psychosocial measures assessed at baseline, mid-point, and postintervention.

Measure	Description & Scoring	Subscales
Cancer Acceptance and Action Questionnaire (AAQ-C; Arch & Mitchell, 2016) eg. 8. <i>I try to avoid reminders of my cancer</i>	<ul style="list-style-type: none"> • 18-item, 7-point Likert scale examining one's psychological flexibility from 1 (Never True) to 7 (Always True), total sum score, higher numbers indicate greater inflexibility. 	
The Mini-Mental Adjustment to Cancer (Mini-MAC; Watson et al., 1994) eg. <i>I feel that life is hopeless</i>	<ul style="list-style-type: none"> • 29-item, 4-point Likert scale for rapid assessment of present coping style from 1 (Definitely Does Not Apply to Me) to 4 (Definitely Apply to Me), higher score represents higher endorsement of the adjustment response. 	<ul style="list-style-type: none"> • Helplessness-hopelessness (8 items), anxious preoccupation (8 items), fighting spirit (4 items), cognitive avoidance (4 items), and fatalism (5 items)
The Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1996) eg. 9. <i>Pictures about it popped into my mind</i>	<ul style="list-style-type: none"> • 22-item, 5-point Likert scale to assess subjective distress during the past 7 days caused by traumatic events from 0 ("Not at All") to 4 ("Extremely"), total score is calculated with higher scores indicating greater distress with indications based on specific cut-offs. 	<ul style="list-style-type: none"> • Intrusion (8 items), Avoidance (8 items), and Hyperarousal (6 items)
Coronavirus Anxiety Scale (CAS; Lee, 2020) eg. 1. <i>I felt dizzy, lightheaded, or faint, when I read or listened to news about the coronavirus</i>	<ul style="list-style-type: none"> • 5-item, 5-point Likert scale to reflect frequency of symptom endorsement, ranging from 0 (Not at All) to 4 (Nearly Every Day) over the preceding 2 weeks, CAS total score of ≥ 9 indicates probable dysfunctional coronavirus-related anxiety. 	
The Cancer Behaviour Inventory-brief version (CBI-B; Heitzmann et al., 2011) eg. 9. <i>Seeking consolation (support)</i>	<ul style="list-style-type: none"> • 12-item, 9-point Likert scale measuring self-efficacy for coping with cancer from 1 (Not at all Confident) to 9 (Totally Confident), higher sum scores equal greater self-efficacy. 	
UCLA Loneliness Scale, version 3 (Russell, 1996) eg. 3. <i>I have nobody to talk to</i>	<ul style="list-style-type: none"> • 20-item, 4-point Likert scale to assess one's subjective feelings of loneliness and social isolation from 1 (Never) to 4 (Often), positively worded items are reverse-code and scores are summed and higher scores indicate greater loneliness. 	
The Purpose in Life Test (PIL; Crumbaugh & Maholick, 1964) eg. 9. <i>My life is: 1 2 3 4 5 empty, filled only with despair running over with exciting things</i>	<ul style="list-style-type: none"> • 20-item, 7-point Likert scale designed to measure the extent to which a respondent perceives a general sense of meaning and purpose in life using varying scale labels, scores are aggregated with a minimum score of 20 (lowest purpose) and a maximum score of 140 (highest purpose). 	

signed copy using a prepaid, addressed envelope. They were e-mailed a REDCap link to complete a set of 7 preassessment questionnaires prior to the start of the intervention.

The day before each scheduled session, an e-mail reminder was sent to all enrolled participants including the date, time, and video platform log in information. Telehealth sessions were scheduled at 12:00 pm lunchtime to accommodate school and work schedules. Headphones were purchased and offered to all participants to ensure confidentiality and eliminate

background noise. Mid-point and postassessments were sent after session 4 and 8, respectively. At the conclusion, participants received a list of YA local and national resources.

Theory

The use of ACT¹⁸ and MCP¹⁹ with cancer survivorship groups has demonstrated promising results, including the reduction of anxiety, depression, fatigue, fear of cancer recurrence, physical pain, and trauma-related symptoms, while also increasing meaning and purpose and a feeling of regaining some control over one's life. In line with the guiding principles of ACT and MCP, the group focused heavily on coping strategies that enable positive psychosocial outcomes: Acceptance of cancer-related distress, reduction of cancer-related avoidance, identification of personal values, a commitment to making meaningful changes in one's behavior, and identifying meaning and purpose in life.^{18,19}

Results

Recruitment and enrollment

Among the eligible recruitment pool, direct staff member referrals were most common. The final group was comprised primarily of referrals from existing databases. The most common exclusion reasons were being from outside the health system, patients/missing information or deceased prior to medical record review and non-North Carolina resident status. Of the 55 individuals who met basic study criteria, 42% cited no specific reason for declining interest or participation. A total of 14 individuals (25%) were both eligible and interested in participating. Two people verbally consented and/or returned written forms but did not participate. Four individuals never formally consented. See the flow chart (Figure 1) for accrual information.

Participant characteristics

Eight YAs ages 19-37 years ($M = 26$) agreed to participate. The majority were not newly diagnosed or in active treatment. There were an equal number of males and females. All participants identified as Caucasian and non-Hispanic. Sixty-three percent were single. Education levels ranged from high school graduates, undergraduates, a master's level professional, and a physician. All but 2 participants worked and/or studied from home due to state-mandated COVID-19 requirements. Diagnoses were heterogeneous including sarcoma, lymphoma, and multiple myeloma.

Psychosocial outcomes

Seven participants completed instruments at T1, 6 at T2 and T3. The longitudinal data were modeled using a repeated measures analysis of variance to assess changes in scores for psychosocial measures between visits (ie, assessment time). For consistency within these exploratory analyses, all statistical tests were performed with a significance level of 0.05. As these analyses are exploratory, the scores were tested over time (longitudinally, using all 3 visits) and also in pairwise fashion between visits. Given the exploratory nature of these data, pairwise comparisons are tested and reported, even in the absence of a significant overall test. This approach provides a better understanding of where significant changes between visits might occur, regardless of the overall effect.

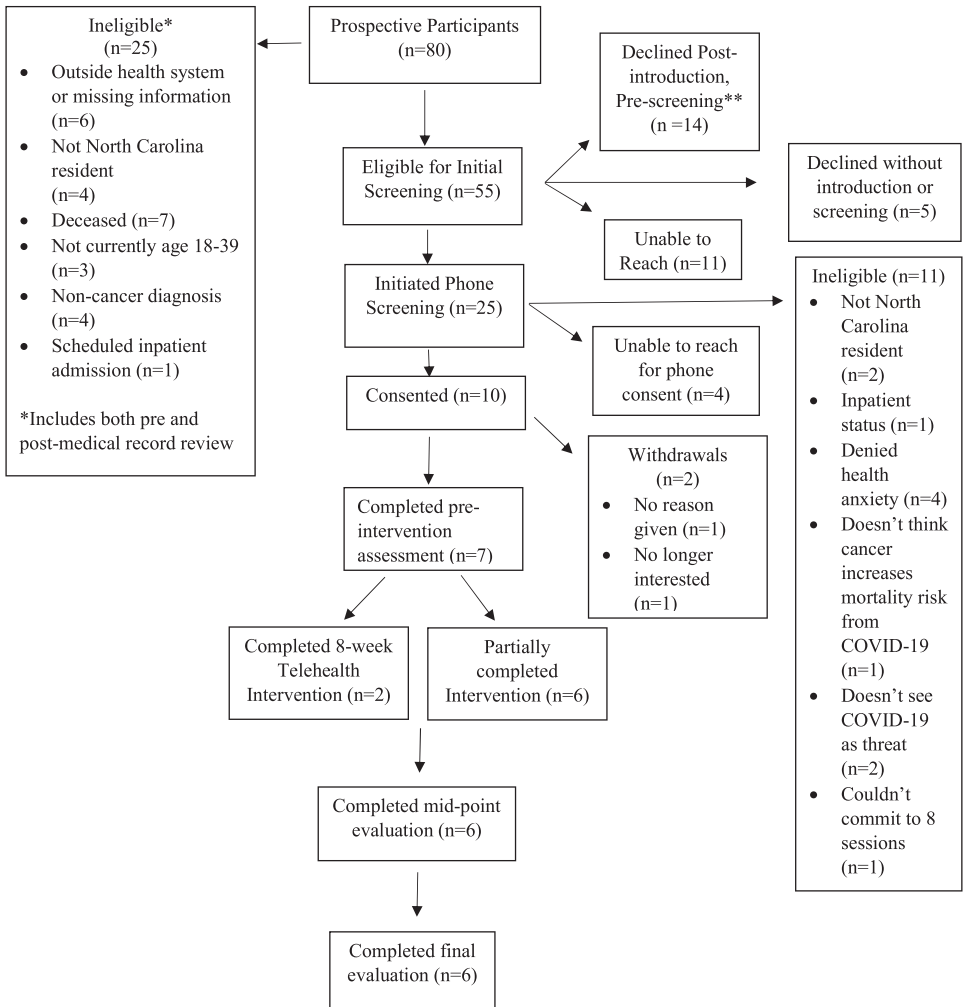


Figure 1. Flowchart outlining accrual information. **Reasons for decline: Adequate support (n = 3); Too busy (n = 2); Poor health (n = 2); Couldn't commit (n = 1); Unrelated concerns (n = 1); No reason (n = 5).

Overall effect and pairwise effect(s) significant:

- The overall effect for the Cancer Acceptance and Action Questionnaire (AAQ-C) was significant [F(2, 6)= 7.45, $P = 0.02$] with a significant decrease found from T1 to T3 [t(6)= 2.70, $P = 0.04$], indicating an increase in psychological flexibility.
- The overall effect for the Anxious Preoccupation subscale of the Mini-Mental Adjustment to Cancer (Mini-MAC) was significant [F(2, 6)= 16.05, $P = <0.01$]. There was a significant decrease in scores from T1 to T3 [t(6)= 3.58, $P = 0.01$] as well as T2 to T3 [t(6)= 5.66, $P = <0.01$], showing a movement towards less anxiety measured compared to baseline.
- The overall effect for the Helplessness/Hopelessness subscale of the Mini-MAC was significant [F(2, 6)= 6.09, $P = 0.04$] with a significant decrease in scores from T1 to T3 [t(6)= 2.66, $P = 0.04$], indicating a drop in a sense of helplessness/hopelessness from baseline to the last visit.

Table 4

Qualitative themes with examples.

Themes	Mid-	Post-
Support and Connection	008: Just being able to be in the presence of folks similar in age and similar in cancer experiences. I feel there is a natural bond between those in our group.	008: Being able to connect with and relate to people my age and with similar experiences.
Mindfulness skills	005: I will continue the mindfulness exercises.	005: Mindfulness exercises geared more towards adults/ more practical methods.
Homework	006: I don't like having weekly homework, as most of us are too busy to add that into our lives.	006: No homework

Overall effect not significant but pairwise effect(s) significant, or vice versa:

- The overall effect for the Cognitive Avoidance subscale of the Mini-MAC was not significant [$F(2, 6) = 3.94, P = 0.08$]; however, the score dropped significantly from T1 to T2 [$t(6) = 2.72, P = 0.03$], indicating a decrease in using this strategy of coping with cancer.
- The overall effect for the Fighting Spirit subscale of the Mini-MAC was significant [$F(2, 6) = 11.66, P = 0.01$], but no pairwise comparisons were significant.
- The overall effect for the Impact of Events Scale (IES-R) was not significant [$F(2, 6) = 3.93, P = 0.08$]. However, there was a significant decrease in T1 vs T3 scores [$t(6) = 2.76, P = 0.03$], meaning that the stress level measured within patients had dropped.

Neither overall effect nor pairwise effect(s) significant:

- Coronavirus Anxiety Scale (CAS) [$F(2, 10) = 2.01, P = 0.18$]
- Cancer Behavior Inventory- brief version (CBI-B) [$F(2, 6) = 3.86, P = 0.08$]
- Fatalism subscale of the Mini-MAC [$F(2, 6) = 4.48, P = 0.06$]
- UCLA Loneliness Scale [$F(2, 6) = 1.73, P = 0.26$]
- Purpose in Life Test (PIL) [$F(2, 6) = 0.15, P = 0.87$]

When asked if they would recommend the group, YAs averaged 7.5/10 at midpoint and 7.8/10 at final evaluation. YAs reported feeling confident that they could cope with cancer (8.2/10 at midpoint; 8.6/10 final evaluation) and the pandemic (10/10 at both time points).

Participant feedback and facilitator observations

Investigators used thematic analysis to identify themes within the qualitative data, adhering to Braun & Clarke's²⁸ systematic framework of analysis.²⁹ This process entails generating codes, searching for themes, and refining themes (Reference Table 4 for themes and example quotes). Participants found the Intervention helpful in offering support, facilitating connection, and learning mindfulness skills. They also expressed their dislike of homework.

Many participants shared the most powerful aspects of the group via narrative feedback (eg, "It's reassuring to hear others discuss their cancer stories in relation to the pandemic, and I have lost the majority of my teenage years to either cancer or COVID"; "[Group was] life-changing for me. I can't express how important it is for me to be able to talk to people who went through things like I did, as I never got to meet anyone while I was in the hospital and always felt so isolated"; "Because of this group, I was able to let go of the emotional weight I was carrying with me, and finally, after 3 years I got my first haircut, and I feel like myself again. I feel like I am free to make my own decisions. I am so incredibly grateful for this group.") This data substantiates the importance of age-related connections amongst YAs.⁴ Group participants also referred to specific aspects of the intervention they found useful, including mindfulness practices, guided

meditations, and a self-care legacy project. YAs expressed interest in co-creating future offerings and took initiative to create a shared music file for the group after technological difficulties occurred during one session.

Regarding group process, facilitators were appropriately trained in the ethics, technological, and logistical issues related to providing telehealth interventions but were limited in their ability to assess nonverbal cues on a telehealth platform. Facilitators experienced tension between planned content and participants' desire to deviate into salient experiences.

Although many participants were open to conversation prompts, coping strategies, and mindfulness practices, they expressed interest in connecting over shared experiences and other developmentally appropriate topics of interest. The group provided a forum and collaborative structure; however, participants actively worked to make the structure their own (rather than clinician-guided). Facilitators worked to balance fidelity to the intervention with the opportunity for members to co-construct the experience.

The social connection and shared meaning making pieces were key, exhibited by questions from present members about the health status of absent members. Group members continued to reinforce that the pandemic was a nuisance; yet cancer remained their biggest stressor. Accustomed to social isolation and delays in developmental milestones, many YAs expressed that they had already learned to isolate to protect themselves pre-pandemic; hence their self-reported confidence in navigating the pandemic.

Discussion

Our findings provide comparative data for YAs navigating the duality of cancer care and the COVID pandemic, with attention to key concepts such as anxious preoccupation, cognitive avoidance, and hopelessness/helplessness. Data on YAs are sparse, particularly related to these constructs, thereby limiting comparisons. However, participants exhibited similar behaviors noted in the literature, indicating that YAs want to connect socially, albeit in an unstructured, nonsupport group format.³⁰ The statistically significant improvement in anxious avoidance and decrease in helplessness/hopelessness suggests participants benefited from group experience and exercises.

This study provides new knowledge about effective interventions for YAs that can be translated into best practices. First, YA programming should reflect the needs of survivorship: newly diagnosed, those in treatment, and those in remission. Providers should consider conducting a needs assessment to identify actual needs and interests in their YA population. Second, telehealth modalities work well with this population but introduce new challenges to facilitation, such as lack of nonverbal cues. Third, group content and structure should be flexible to encourage maximum participation and therefore, clinicians must consider carefully how to measure outcomes. Fourth, psychosocial providers should partner with other North Carolina oncological YA advocates, including those from their own and sister organizations, to enhance recruitment efforts and participation. Finally, conducting this YA telehealth group highlighted the need for licensure portability. United States psychosocial providers should partner with their respective professional associations working at the federal and state levels to secure licensure portability to reach and provide YA telehealth interventions across state lines.

Limitations

Recruitment

Recruitment relied heavily on direct provider referrals. Reaching YAs via phone posed challenges for a variety of reasons: school/work balance, parenting; and messaging preferences of this demographic. Choosing a time for the group that would accommodate most, given school and/or work demands, created additional commitment and attendance challenges. Once enrolled, we experienced mailing delays due to COVID-19 (at minimum, one week to send and one week

to return), thereby slowing both the consent and enrollment processes and connection with the intervention. Our group reflected a lack of racial and ethnic diversity as well, limiting generalizability.

Study design

Participants' emphasis and interest consistently focused on obtaining social support from others who had experienced similar challenges, rather than adherence to more structured material. The different phases of survivorship within the group likely affected the dynamics of the conversation and relationship of the content discussed. We captured quantitative data with validated instruments, but our approach was problematic for several reasons. First, achieving large sample sizes in YA psychosocial oncology is difficult.³¹ Second, COVID-19 precautions at the time of the study reduced our already small clinical team from 6 to 4 clinicians, creating longer hours and larger caseloads than prepandemic figures for the facilitators. Third, some of the most meaningful aspects of the group experience, such as intimate social connectivity, were absent from quantitative data. In short, this study's attempt to co-construct a safe space to process, share, and mutually learn new skills was not adequately captured by these outcome measures even though we noted statistically significant movement in several constructs.

Conclusions

In summary, our findings offer guidance on how to establish future telehealth groups for YAs navigating the dual health threats of cancer and COVID-19. They also highlight the limitations of strictly quantitative analysis, when qualitative data provide rich understanding of individual experiences and growth. Consistently, YAs shared that their concerns related to cancer are predominant. There is great interest on the part of YAs to engage in collective experiences; yet they desire loose structure and the ability to co-construct those experiences. It is our hope that these practice recommendations will be useful for enhanced recruitment, and YAs will benefit from such undertakings.

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