CLINICAL CORRESPONDENCE

Photographs of meaning: A novel social media intervention for adolescent and young adult cancer patients

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1 | BACKGROUND

Adolescents and young adults with cancer (AYAs) have distinct psychosocial needs due to the interaction between the cancer experience and their developmental stage. They are at risk for a variety of negative psychological outcomes, including depression, posttraumatic stress, and fears of recurrence. AYAs have consistently reported unmet psychosocial needs, both during and after treatment; however, AYAs underutilize psychological support services that may be due to differences in AYAs' developmental life stage and the associated preferences (social outings with other survivors and refusal to return to cancer center).

Social media (SM) provides a promising platform for engaging AYAs. Individuals ages 18 to 29 are more likely than 50- to 64-year-olds to use SM (88% vs 64%). Given their familiarity with SM as a communication tool, supportive interventions utilizing SM may be more appealing and less stigmatizing than traditional psychotherapeutic interventions.

The aim of this study was to assess the feasibility of a novel intervention called photographs of meaning (POM). POM-AYA was designed to provide AYAs an opportunity to reflect on and process themes in a nonconventional manner, using a SM application to facilitate engagement. Meaning-centered psychotherapy (MCP) in individual and group contexts has been shown to be an effective treatment in adult cancer populations in reducing psychological and spiritual distress. Meaning-based approaches have promise in AYA populations given their focus on identity, social connectedness, and hope, which are all salient developmental themes associated with this population. Photovoice is a participatory research method in which participants take pictures to illustrate their situations. POM-AYA was developed based on MCP and photovoice and is introduced to AYA cancer survivors here.

2 | METHODS

2.1 | Design

This exploratory study assessed the feasibility of POM-AYA, a 10-week meaning-based intervention for AYA survivors. Participant enrollment, retention, and satisfaction data were used to assess the feasibility and engagement rates of the intervention.

2.2 | Participants

One-hundred four eligible participants were identified through the cancer center’s Clinical Data Network (patient and tumor registry) based on the following study inclusion criteria: (1) ages 15 to 24 at the time of diagnosis, (2) diagnosed within the last 3 years, and (3) English language comprehension in oral and written form. Exclusion criteria were a diagnosis of mental retardation, severe or untreated psychopathology, or dementia. Identified participants were then recruited through a direct mailing that explained the purpose and...
nature of the study, and follow-up phone call to screen participants for study interest and confirm eligibility. Eligible participants were scheduled for a one-time consent session, where they were given navigation instructions for the SM application, Pixstori. Participant recruitment and consent occurred over approximate 3 months. In effort to reduce dropouts during the wait time, two study update e-mails were sent during this timeframe.

This study was approved by the local institutional review board.

2.3 | SM application

Participants had access to a closed study portal on the PixStori mobile and website application. Unlike most mainstream SM applications, PixStori enables participants to upload photographs along with audio or text narratives. Pixstori was chosen over other SM platforms due to its secure portal and ability for participants to maintain anonymity throughout the study intervention. Participants’ “pixstories” were shared among the cohort, and the study portal enabled participants to view, “like,” and comment on other’s posts. Pixstori developers managed the closed portal that is not a ready available feature to Pixstori users and provided the research team with useful information such as how many times was a post viewed and how much time was spent on a post.

2.4 | Intervention

The POM-AYA intervention was derived from MCP, an empirically supported manualized psychotherapy for advanced cancer patients.7 Content areas were adapted for an AYA population and converted into nine weekly themes. All participants started the intervention at the same time. Participants were instructed to upload a minimum of two pictures with accompanying text or audio narration each week based on their interpretation of the weekly theme. Instructions regarding the narrative content of the themes were adapted from photovoice methods (“Tell us about the picture and what’s going on” and “Tell us the story about why it’s important”).8,9

Weekly themes were “Who am I?”; “Living with cancer”; “What matters most?”; “Understanding my roots”; “What makes me proud?”; “Coping with bad days”; “Living life to the fullest”; “Experiencing the moment”; “My story of uncertainty and hope”; and a review week. Themes were introduced every Sunday and via e-mail and text message from the study coordinator and student research assistant. Each participant who did not complete the theme by mid-week received an additional prompt. To encourage interaction among the cohort, one member of the research team anonymously “liked” each post made by participants. Research team members monitored the study portal daily for inappropriate or graphic content.

Participants completed a satisfaction questionnaire and follow-up interview at the end of the intervention.

3 | RESULTS

3.1 | Participant characteristics

Thirteen participants were recruited ranging in age from 17 to 26 \(M_{\text{age}} = 23.15; \text{SD}_{\text{age}} = 2.76\), and 83% were female. Fifty-four percent were leukemia/lymphoma survivors, along with papillary thyroid carcinoma (23%) and melanoma (15%) survivors. Three participants (23%) did not participate, while five participants (38%) completed at least 9 of 10 weeks. Remaining participants partially completed the 10 weeks. Excerpts narratives are shown in Table 1. Of the five participants who actively participated, three lived between 22.8 and 504 miles from the cancer center. Forty-seven percent lived beyond 15 miles from the cancer center.

Overall, results of the satisfaction questionnaire indicate positive reactions with 100%, indicating they would recommend the POM-AYA intervention to others. Fifty percent expressed discomfort with the audio narrative, and all participants felt the number of assigned photos each week was appropriate. Thirty-three percent indicated their preference for a larger cohort size, while 67% found the cohort size appropriate.

Qualitative responses in the follow-up interview were also positive. Feedback statements included terms such as ‘pretty awesome, I was really happy to be a part of it’ and expressed an appreciation for the opportunity to connect and share experiences with others.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Weekly themes and sample narratives</th>
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</thead>
<tbody>
<tr>
<td>Week</td>
<td>Paraphrased quotes</td>
</tr>
<tr>
<td>Week 1: Who am I?</td>
<td>Pp004: “Happy ... I wasn’t going to let cancer define me. I was going to continue to be happy.”</td>
</tr>
<tr>
<td>Week 2: Living with cancer, how has cancer changed who I am?</td>
<td>Pp002: “... my scars from melanoma and it’s a daily reminder of what I went through ...”</td>
</tr>
<tr>
<td>Week 3: What matters most?</td>
<td>Pp008: “... just being happy. Waking up and being happy every day ... I choose this picture because I was extremely happy. I left all of my problems at the shore.”</td>
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</table>
The only negative feedback came from frustration associated with technical problems recording their narratives.

4 | DISCUSSION

In this study, an exploratory method to engage AYA cancer patients and survivors was introduced. Based on MCP and photovoice, POM-AYA is an innovative and feasible program, which may be a promising SM intervention to enhance psychological well-being among AYAs.

The strengths of POM-AYA include its flexible time commitment and its ability to be offered remotely. Indeed, the majority of participants lived over 15 miles from the cancer center and two of the most active participants lived 75 and 504 miles away. Feedback from participants confirm the POM-AYA tasks are neither difficult to complete nor too long in duration of intervention. The posting of photographs and narratives based on themes facilitated AYAs to share their thoughts in ways conventional psychosocial tactics may not, and it also encouraged social connectedness with the other participants.

Our results reflect the difficulty in engaging AYA cancer patients in psychosocial interventions despite extensive outreach efforts, as it has been previously described. Only 12% of eligible participants were recruited. Of these, under 50% of participants regularly participated. Feedback from participants identified how a remote consent process, and a less “clunky” SM application would enhance the POM intervention experience. Surprisingly, our participants expressed appreciation for the small study size. This information may help design other AYA projects whereby bigger sample size may not attract this population.

Overall, participants responded positively to the size, structure, and content of the intervention. Given this positive feedback, the POM intervention has significant promise for further investigation as a support mechanism for AYA cancer patients. An additional cohort study is underway, and indeed, an upgrade to the application along with a more streamlined remote consent process has been included.

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REFERENCES


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