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# Young adult cancer survivors' experiences with a mindful self-compassion (MSC) video-chat intervention: A qualitative analysis

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**ABSTRACT**

Young adult cancer survivors (YACS) are a vulnerable population that reports high anxiety, social isolation, and feelings of inadequacy after cancer treatment completion. Mindful self-compassion (MSC) provides strategies for coping with suffering. We explored how MSC practices addressed the psychosocial needs of a nationally recruited YACS sample ($N = 20$, all female, age $M = 27.00$, various cancer types) that participated in an 8-week MSC video-chat intervention. Descriptive qualitative analysis of the intervention recordings revealed three YACS' psychosocial needs: peer isolation, body concerns, and health-related anxiety. MSC practices addressed these in a number of ways including: self-reliance for emotional support, common humanity within the YACS community, gratitude, self-kindness, and acceptance. Meanwhile, the body scan practice initially triggered distress for some; implications are discussed.

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## Introduction

Each year in the U.S., more than 70,000 adolescent and young adults between the ages 15 to 39 years are diagnosed with cancer (Nass et al., 2015). Receiving cancer diagnosis and treatment in the context of the social, emotional and developmental transitions that occur during this stage of life presents unique and significant challenges (Nass et al., 2015). Indeed, young adult cancer survivors (YACS) report greater distress and worse health-related quality of life compared to healthy age-matched peers (Smith et al., 2013). One year post-diagnosis, nearly one third of YACS report clinically significant distress (Zebrack et al., 2014) and over 40% report post-traumatic stress symptoms (Kwak et al., 2013). Difficulties such as feeling disconnected from peer support, challenges in employment or academic pursuits and body image concerns persist two years post-diagnosis (Mattsson, Ringnér, Ljungman, & von Essen, 2007). Compared to peers without a cancer diagnosis, adolescent and young adult cancer survivors have a significantly elevated risk for suicidal behavior in the year after diagnosis and up to five years thereafter (Lu et al., 2013). Moreover, some studies have indicated female

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YACS are at increased risk for psychosocial challenges compared to male counterparts, such as excessive worry about cancer recurrence, cancer-related infertility concerns (Gorman, Su, Roberts, Dominick, & Malcarne, 2015), and post-cancer sexual wellbeing (Geue, Schmidt, Sender, Sauter, & Friedrich, 2015). Despite these challenges, support for this group has been largely lacking, with many YACS reporting unmet mental health needs (Keegan et al., 2012). Due to this gap, a recent Institute of Medicine panel report prioritized the development of coping skills trainings and stress management programs tailored to YACS needs (Nass et al., 2015).

One program with high potential to increase YACS coping skills is Mindful Self-Compassion (MSC). MSC is an 8-week evidence-based program shown to improve wellbeing in non-clinical (Neff & Germer, 2013) and clinical (Friis, Johnson, Cutfield, & Consedine, 2016) adult populations, with an adapted program demonstrating success in teens (Bluth & Eisenlohr-Moul, 2017; Bluth, Gaylord, Campo, Mullarkey, & Hobbs, 2016). A highly practical skills-based course, MSC focuses on three components: self-kindness, defined as treating oneself with care and compassion in the face of failure or perceived inadequacy; common humanity, defined as recognizing that suffering is not in isolation, but rather part of the shared human experience; and mindfulness, defined as awareness and acceptance of difficult emotions, thoughts or physical sensations.

The three MSC components, which together comprise the definition of self-compassion as described by Neff (2003), may be particularly useful in addressing the common and unique stressors of coping with a life-threatening illness during the developmentally vulnerable adolescent and young adult periods. For example, cancer diagnosis and treatment at a time when self-identity is evolving can negatively impact sexual identity, the establishment of romantic relationships, and body image (Evan, Kaufman, Cook, & Zeltzer, 2006). Likewise, YACS may be forced to live at home longer, require ongoing parental support, be derailed in their educational or career plans, or have substantial difficulty transitioning to school or workforce; thus, leaving some to feel "behind" healthy peers (Parsons et al., 2012). Additionally, the long-term impact of cancer-related fatigue can impose significant physical limitations and negatively impact independence (Spathis et al., 2015). For all of these "inadequacy" issues, the self-kindness component of MSC may be relevant in combating self-criticism that can arise as YACS compare themselves to their healthy counterparts. While these unique YACS issues have not yet been explored in the context of MSC training, mindfulness interventions in other cancer populations have reported a kinder and more accepting response to personal difficulties post-intervention (Kvillemo & Bränström, 2011; L'Estrange, Timulak, Kinsella, & D'Alton, 2016).

Another common stressor for YACS is social isolation, which may be particularly challenging given the rising importance of peer relationships as youth transition to young adulthood. YACS describe the changing or ending of pre-diagnosis friendships, interpersonal difficulties post-diagnosis (Lehmann et al., 2014), and ineffectiveness of peer support systems (Iannarino, Scott, & Shaunfield, 2017). The common humanity focus within MSC training holds potential to reduce feelings of social isolation and encourage feelings of connection and belonging, as has been described in an adult cancer survivor sample post-mindfulness intervention (L'Estrange et al., 2016).

Finally, mindfulness skills may be useful in decreasing excessive worry and rumination that may surround YASCs' fear of cancer recurrence, existential concerns, or attempts to bring life back to normalcy (Desrosiers, Vine, Klemanski, & Nolen-Hoesksema, 2013). Further, by

reducing excessive worry and rumination, anxiety and depression symptoms may be reduced (Desrosiers et al., 2013; Kuyken et al., 2017), an important effect for a population of which a third experiences clinically significant distress.

Moreover, self-compassion as a trait is associated with adaptive responses to life challenges (Allen & Leary, 2010), improved self-care in a variety of chronic illnesses (Dowd & Jung, 2017; Ferrari, Dal Cin, & Steele, 2017), as well as improved psychosocial outcomes in various adult cancer populations. In a study of breast cancer survivors with mastectomy and breast reconstruction, self-compassion moderated the relationship between body image disturbance and psychological distress, such that those with high levels of self-compassion experienced significantly less distress (Sherman, Woon, French, & Elder, 2017). Another study found self-kindness, a main component of self-compassion, mediated the impact of a mindfulness intervention on decreasing depressive symptoms and perceived stress for a group of young breast cancer survivors (Boyle, Stanton, Ganz, Crespi, & Bower, 2017). In a sample of active adult cancer patients with various cancer types, self-compassion was associated with decreased stress, depressive symptoms, and increased quality of life (Pinto-Gouveia, Duarte, Matos, & Fraguas, 2014). However, prior to work by Campo and colleagues from which this paper draws (Campo et al., 2017), no studies have examined the impact of self-compassion training in cancer survivorship, nor the relevance of self-compassion in a young subset of cancer survivors, whose needs may be distinct from older cancer survivors.

Given this gap in knowledge, Campo et al. (2017) explored the feasibility, acceptability, and impact of an 8-week online video-chat MSC intervention with a diverse nationally recruited sample of female YACS. The curriculum, adapted from the evidence-based teen and adult MSC interventions, included didactic content, exercises and meditations, with instructor-facilitated reflection and group discussion. Feasibility (84% of sample attended at least 6 of 8 sessions) and acceptability (average score of 4.69 (SD 0.43) on a 5 point scale regarding satisfaction with the course) were high. Additionally, preliminary exploration of the outcomes revealed statistically significant increases (with moderate to large effects sizes) in participants' mindfulness, self-compassion, and post-traumatic growth, as well as decreases in anxiety, depressive symptoms, social isolation, and body image. Improvements in anxiety, body image, and self-compassion had the largest effect sizes (Campo et al., 2017).

The current study's purpose was to gain insight into why this MSC intervention showed positive impact for YACS participants through a descriptive qualitative analysis of the transcribed intervention sessions. Specifically, our aim was to understand how the MSC curriculum addressed the unique cancer-related psychosocial needs of the YACS participants to inform future full-scale adaptation of this intervention for YACS, other cancer survivor populations, as well as other young chronically ill populations. The semi-structured format of the MSC course curriculum allowed flexibility for open-ended discussion and self-reflection after each meditation or exercise; therefore, the intervention session recordings provided unique "real time" insight into how YACS perceive and utilize the MSC course material over the 8-week period. Furthermore, we use a descriptive approach to allow exploration of the intervention naturalistically without commitment to a particular theory (Sandelowski & Sandelowski, 2000), although some interpretation and a theoretical base are inherently present (Sandelowski, 2010).

This study also fills a gap in the self-compassion intervention literature. While there are some qualitative studies on the topic of self-compassion in non-cancer populations (Pauley

& McPherson, 2010) or self-compassion in the context of mindfulness-based stress reduction training for cancer populations (Kvillemo & Bränström, 2011; L'Estrange et al., 2016), we believe this is the first qualitative exploration of the experience of learning how to cultivate self-compassion through the MSC intervention. Therefore, this study provides valuable information regarding the aspects of the MSC curriculum that are particularly relevant for YACS, and that may be useful when considering use in other cancer populations and in other young chronically ill populations with similar needs.

## Methods

### *Participants*

A nationally recruited sample of YACS with various cancer types (see Campo et al., 2017 for recruitment and screening details) participated in a study examining the feasibility and acceptability of an 8-week MSC videoconference intervention. Eligibility criteria for the intervention study included: Between 18 and 29 years old; cancer diagnosis at ≥ age 15 years; not currently undergoing cancer treatment; access to necessary technology (computer, email, high-speed internet); no participation within six months in a mindfulness- or compassion-based program; no consistent meditation practice (>30 min daily); and English speaking. Respondents who were eligible and interested were consented and enrolled into one of 5 video-chat groups based on their schedule availability (group size ranged from 3 to 7 members). The study groups met online at an assigned evening time and weekday for eight weeks. Participants provided informed consent for their intervention sessions to be recorded and used for research purposes. The study was approved by university Institutional Review Board in the southeast U.S.

Due to one person not consenting to be recorded, one group ($n = 5$) was not included in this analysis, for a final group size of 20. Demographics of the recorded group are shown in Table 1 and the distribution of their cancer diagnoses are displayed in Figure 1. The recorded versus unrecorded groups were similar in age (median age 27.00 vs. 26.60), although the recorded group had more participants of White race (85% vs. 60% white) and less education (85% vs. 100% college degree) than the unrecorded group. Additionally the recorded group had fewer months since treatment completion (median months 23 vs. 36). Of note, the final sample was all female with an average age of 27.00 (SD = 2.2); over half the participants had completed treatment for lymphoma. Group sessions had on average 5 participants per group. Transcripts were available for 27 out of 32 sessions due to technological difficulties (i.e., internet connection).

### *Intervention*

The MSC intervention consisted of 8 weekly 90-min video-chat sessions adapted from the adult MSC program (Neff & Germer, 2013) and the Making Friends with Yourself program for teens (Bluth et al., 2016). Using a Cisco WebEx online platform, a trained and certified MSC instructor led the participants in didactic instruction, experiential exercises (i.e., mindful eating, writing a compassionate letter to oneself), meditations (i.e., compassionate body scan, affectionate breathing) and discussions (i.e., how do you typically respond to yourself in a moment of "failure" vs. how do you respond to a good friend when she "fails"?) designed

**Table 1.** Participants' sociodemographics and medical characteristics ($N = 20$)[1].

| | % (*n*) unless noted otherwise |
|---|---|
| Female | 100% (20) |
| Current age *M* (SD) | 27.00 (2.2) |
| Non-Hispanic Ethnicity | 90% (18) |
| Race | |
| White | 85% (17) |
| Black or African American | 0% (0) |
| Asian | 5% (1) |
| American Indian or Alaska Native | 0% (0) |
| Other race | 10% (2) |
| Marital Status | |
| Married or living as married | 30% (6) |
| Single (never married) | 70% (14) |
| Divorced | 0% (0) |
| Parental Status (yes) | 15% (3) |
| Education level | |
| Some college or vocational training | 15% (3) |
| Associate degree | 5% (1) |
| College degree | 55% (11) |
| Post-graduate | 25% (5) |
| Years since cancer diagnosis *M* (SD) | 3.3 (3.2) |
| Years since treatment completion *M* (SD) | 2.6 (3.3) |

[1]Sample includes participants from the four intervention videoconference groups.

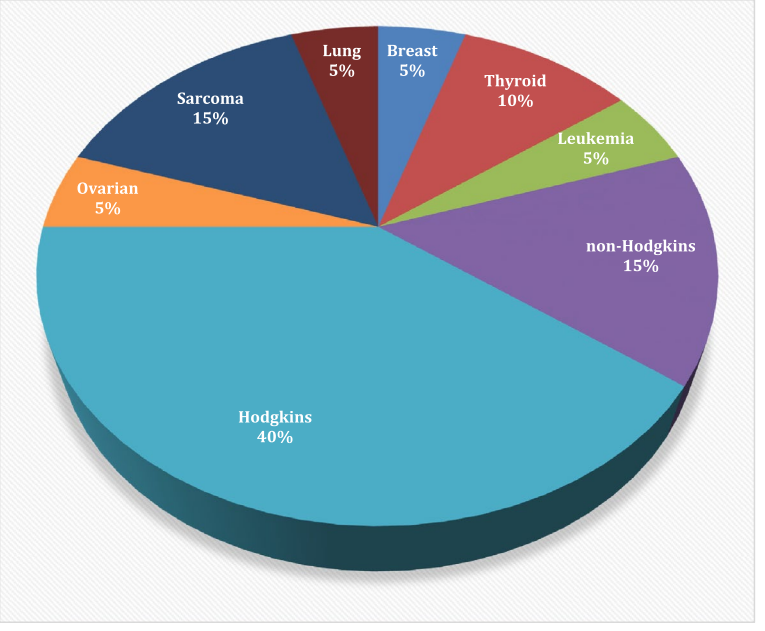


**Figure 1.** Distribution of cancer diagnoses ($n = 20$).

to cultivate self-compassion (see Table 2 and Campo et al., 2017 for further intervention details). Of note, in MSC, practices similar to traditional mindfulness exercises are infused with warmth. For example, during the compassionate body scan, participants are encouraged to notice body parts with a sense of gratitude and appreciation for the support they

**Table 2.** Topics of the mindful self-compassion videoconference intervention.

| Session | Topic |
|---|---|
| 1 | Introduction to mindful self-compassion |
| 2 | Mindfulness Part I: Paying attention on purpose |
| 3 | Mindfulness Part II: Reacting vs. Responding |
| 4 | Self-compassion in depth |
| 5 | Self-esteem vs. Self-compassion |
| 6 | Finding your compassionate voice |
| 7 | Core values & Compassionate strategies for managing difficult emotions |
| 8 | Embracing your life – Gratitude and Self-appreciation |

provide, and to imagine easing any areas of discomfort. Affectionate breathing practice involves placing the hand on the heart or another soothing place, and imagining the waves of the breath as nourishing and life sustaining. Again, an appreciation of the breath is also included in this guided meditation. Additionally, many of the exercises involved bringing to mind an emotionally challenging situation or a current struggle, and then responding to the difficulty with self-kindness and support. Each session began with an open-ended discussion of the challenges and successes of home practice over the previous week, and then moved into the current week's content. The instructor used semi-structured, open-ended prompting questions to generate reflection and discussion among participants after these exercises. For example: "What was this (exercise, meditation, home practice) like for you?"; "What was your reaction to this practice?"; "What did you notice when you did this?" These group discussions provided the content for the current qualitative analyses.

### *Qualitative analysis*

A descriptive qualitative analysis approach was used (Sandelowski, 2010; Sandelowski, 2000). Audio recordings of the sessions were transcribed verbatim and checked for accuracy against the audio recordings. Transcripts were read at least twice prior to coding. One member of the research team coded the transcripts by each study session across the four groups (e.g., coded all groups' session#1) using *in vivo* and descriptive coding. After coding each study session, the results were discussed with a team member present during the sessions to gather feedback and develop consensus. Then, codes were clustered into overarching themes. This step was also reviewed with another team member until consensus was reached.

Authors followed strategies for optimizing trustworthiness in qualitative research (Shenton, 2004). To ensure credibility, transferability, dependability and conformability, authors had extensive experience with MSC and cancer survivor literature, confirmed themes within existing literature, studied a nationally representative sample with four different groups, and reached consensus about findings among multiple team members.

## Results

Participants expressed three categories of psychosocial needs related to their experience as young adult cancer survivors: peer isolation, body concerns, and health-related anxiety. These needs, followed by how MSC addressed (or in some cases, did not initially address) these needs, are described below. Fictional names follow each direct quote.

### *Peer isolation is addressed through self-reliance, common humanity and mindful awareness of positive support*

This theme refers to the perceived difficulties participants expressed in their relationships with peers and others in their lives who had not experienced cancer. Notably, this theme often emerged organically from group discussions at varying points during the 8-week course, rather than being directly elicited from the MSC facilitator. Subthemes relating to peer isolation included: feeling misunderstood, being unsupported, and feeling developmentally "off-track" from peers.

#### *Feeling misunderstood*

Throughout the MSC training, many expressed feeling challenged by the lack of empathy and understanding from peers who could not relate to the experience of cancer, and who at times appeared insensitive. For example, in a group discussion about how to relate to stress, Judy lamented that her stress often did not "line up" with the people around her. She explained that a non-survivor peer's stress might be about making birthday plans, but when she tries to talk about her stressors, her friends "don't even want to go there". Michelle concurred, describing having to console a friend who just broke up with a girlfriend and who said: "God, your life is so easy! You don't know what stress is like!"

In another group, a discussion about accepting body limitations arose after the body scan meditation. Susan described the side effects from cancer and subsequent treatment as being difficult for non-survivor peers to understand:

> It's so hard to explain, especially in our age group. When I say I'm tired, I don't mean the same thing as someone who hasn't had cancer says they're tired, or who hasn't had treatment or surgery says they're tired. Because I'll say I'm tired and they'll be like– oh me too! I'm like, "No you know, you don't get it…"

Similarly, Jessica discussed the ongoing anxiety and stress after cancer treatment has ended as being something that non-survivor peers could not understand:

> I might not have [cancer] anymore but people our age think [once] you're done with your treatment, you're fine. Like "You don't have cancer anymore, what's wrong with you?" And so that's really a hard thing.

#### *Feeling unsupported*

In addition to feeling misunderstood by peers, participants expressed feeling unsupported both emotionally and physically by peers, and this could be a source of sadness. One group discussed how peers often don't use comforting words or are unhelpful in their reactions to their cancer diagnosis. In another group, Susan described lacking the support from peers at school that she needed during treatment.

#### *Feeling developmentally "off-track" from peers*

Finally, several MSC participants described a sense of being at a different stage or maturity than age-matched peers. In a discussion about wisdom being a positive consequence of cancer, Amaya expressed that the cancer experience gave her maturity, but this maturity made her feel isolated:

> Oh I think I'm at least 10 years older than all of my friends that are the same age…. at the very least. But that's also really alienating for me.

MSC course discussions about the pitfalls of self-esteem and comparing oneself to others also illuminated the difficulty of being developmentally different. Melody described the pain of feeling "left behind" as others moved ahead in major life milestones like marriage and children:

> I compare myself a lot. And actually that was one of the issues when I was going through my treatments and afterwards when I was finishing doing my treatments, like I feel like I lost my whole life. And I only did it for six months, my chemo. But I felt like I was a whole year behind my friends. … All my friends are engaged, some of my friends are married and have kids, I'm still living at home -I live part of the time with my boyfriend -….You're like, ugh, I missed out on that, now I'm stuck. And you move two steps forward, and ten steps back. That's how I feel a lot.

To address peer isolation, the MSC curriculum seemed useful and relevant by promoting self-reliance for emotional support, common humanity within the YACS community and mindful awareness of positive support.

### *Self-reliance for emotional support*

MSC curriculum is infused with meditations, exercises and practices designed to cultivate awareness of emotional suffering, followed by responding to these difficulties with words of kindness and compassion. Given the perceived lack of support from peers, this skill was particularly useful for these YACS participants as it empowered them to comfort themselves without relying on others. Mindy had a powerful realization about her ability to support herself emotionally during a discussion after a meditation exercise where participants were instructed to recall a challenging situation, acknowledge their suffering, and then offer themselves comfort in the way they would comfort another:

> Most of the time I'm the person people go to get some advice and some encouragement. So it was really hard when you're on the other side and you don't know who to call. And then you realize you [can be the other person] for yourself. So maybe this is a way to do it, I never realized I'd be able to do this.

Similarly, Kendall, in discussing how her week was going, described how she was able to integrate emotional self-care skills into her daily life by utilizing one of the MSC skills in which you ask yourself in the moment what it is that you need to hear:

> Whenever I'm feeling anything kind of negative, I've been asking myself what would I want to hear–As a way to just sort of interrupt the negative thinking I might otherwise do. And that's definitely helpful.

Participants also found warm self-support useful during medical encounters related to their cancer. For example, Jessica was able to use a lovingkindness practice taught in class the previous week to meet her needs during a check-up:

> And I've actually kind of throughout the week found myself adapting the phrases that I'm using kind of based on how I'm feeling. So, I had an oncology check-up on Friday and so the whole time I was thinking–May I be healthy, may I be healthy–the whole time [laughter].

Related to self-reliance, participants also became aware that they had within themselves their own wisdom, and began trusting themselves for comfort. Amaya noted that while she recognizes that while others in her life may be critical, MSC self-kindness practices helped her to pay more attention to her own more supportive voice: "I'm finding that the mindfulness is helping me more listen to myself than all of the noise."

Thus, MSC provided the opportunity for YACS participants to fill the gaps in their support systems directly through compassionate emotional self-care. It is notable that these skills

took time and practice to develop, and were not without challenges. As is typical for those learning MSC for the first time, some participants noted difficulty both finding and trusting their compassionate voice, or noted that self-kindness seemed uncomfortable. Susan felt that being kind towards herself when struggling was hard, as she needed to "wipe away twenty something years of indoctrination". Others felt challenged to fit in formal self-kindness practices during busy daily life, or to remember to use "in the moment" practices during times of distress. Despite these typical beginner's difficulties, participants were encouraged to practice when they could and were reminded that these struggles were a "normal" part of the process of learning to be kind to ourselves. They were also advised that time and practice help habits stick and make emotional self-care more natural.

### *Common humanity within the YACS community*

The MSC course also addressed YACS peer isolation through the cultivation of "common humanity", or through the strength and comfort gained by recognizing they are not alone in suffering. Not only does the structure of the MSC course create a support-group like atmosphere where common humanity amongst YACS becomes obvious, the MSC curriculum encourages awareness of similarities with others through meditations and exercises designed to highlight human connectedness.

Throughout the course sessions, participants validated one another's experiences and expressed comfort in having others who can relate despite having different cancer types and different treatments. Described as a unique "survivors bond", the common humanity component in the MSC coursework appeared to highlight and strengthen their sense of support and belonging:

Sara spoke about this connection:

> We have this like natural commonality, this natural struggle, which while it's not the same, there are similarities there that bring us together and it gives us a similar mindset for that struggle…

Cancer survivorship carries unique stressors, and although these stressors and their associated feelings can be isolating, in the context of the MSC group, they were unifying:

> …Sometimes there's things that we might experience that are different than what someone who hasn't gone through cancer might experience, like being worried about it coming back or taking every little sickness and thinking it's cancer again. So to remember that those things are common to other cancer survivors too really helps. (Jenny)

This cohesion appeared to diminish the negative impact of the isolation from non-cancer survivor peers; while participants lamented difficulties with peers who were unsupportive, critical, or who lacked the words that would bring them comfort, Susan said: "I feel less alone knowing you guys think this too."

The intimate group of video chat participants became a support group, with positive implications both during the sessions and extending outside of sessions:

> I think our health issues make us feel really alone….it was really nice doing this with you guys and this community because I feel like even when I'm not talking to you, I just know that you're there and that makes me feel a bit stronger. (Amaya)

Similarly, Susan was able to integrate support from the YACS group with an MSC practice to change her from her typical way of reacting to the stress of hospitalization, which involved blaming herself for getting ill. Instead, she was able to adapt the "How would I treat a friend?" MSC practice to feel supported by the group:

> I tried to remind myself that its ok and this happens. I actually kind of enacted in my head "What would [Amaya and Jessica] do? What would I tell them? I would tell them that they're awesome!"

In all, the common bond and support from the MSC group members, as well as feelings of connectedness to the cancer survivor community at large, were highlighted during the MSC sessions and appeared to be a source of relief and strength for participants both in and outside of the video chat session time.

### *Mindful awareness for positive support*

Finally, the MSC course also appeared to highlight positive relationships for some participants. For example, in an exercise where participants were guided in imagining a compassionate friend who speaks comforting words, Mindy became aware of the positive influence a friend had in her life:

> Actually I was thinking about a friend of mine, and she's always said to me like oh these wonderful things, and I just recall all the things that she told me, and I'd never noticed how emotional I get when she tells me these things. So I shed like two or three tears 'cuz like I always listen to her and I know she's really smart and she's always trying to help me, and I just try to think of her. But I never noticed how much impact she had on my emotions.

This exercise sparked similar realizations for others: supportive boyfriends, husbands, mothers all appeared during the exercise and brought comfort and wisdom. Thus, while the MSC experience allowed participants to be with their hurt, disappointment, and anger due to feeling isolated from the mainstream young adult population, it also brought feelings of gratitude for those in their lives who were a source of strength.

## *Body concerns are addressed through self-kindness, gratitude, acceptance, and awareness*

Post-cancer body concerns emerged as a challenge expressed by YACS participants during the MSC course, particularly during the compassionate body scan meditations where participants were instructed to pay close attention to the physical sensations in each region of their bodies. One concern was feelings of anger towards the body for having developed cancer. As Jessica described: "We feel as if our bodies have betrayed us even though we've treated them decently." Other concerns related to changes to the functioning or appearance of their bodies either due to cancer itself or treatment of cancer. MSC addressed these concerns through self-kindness for physical limitations, gratitude for working body parts, and through the gradual cultivation of mindful, non-judgmental acceptance of their post-cancer bodies. MSC practices also elucidated awareness of negative emotions connected to body sensations.

### *Self-kindness when faced with symptoms or limitations*

MSC prompted several participants to meet their own self-care needs with kindness, rather than viewing their body limitations as a sign of weakness, inadequacy or self-indulgence. Amaya, who often criticized herself for or ignored physical symptoms as they were viewed as a "signal of defeat", began "getting better at just recognizing that this is the way it is and being okay with it" and then doing what is best for her, which in this case was seeking medical treatment. Cybil similarly stated she was able to accept her lack of energy and tend to herself

kindly during the week by adapting an MSC practice where participants embraced a difficulty by imagining what a compassionate friend might say.

> [My compassionate friend] told me it was ok to go home [when tired]. And it was ok to be tired. Because you know, I don't like to think that I'm weak or that I have to give up and so, I like using that in like real world experiences… So, it helps. I'm not fighting it, I'm not mad at myself because I can't do something.

These examples and others show how MSC practices had relevance to and became integrated into daily life.

### *Gratitude for working body parts*

The MSC meditations and practices that involved bringing loving attention to body parts evoked a sense of appreciation for many participants. Susan noted the compassionate body scan exercise allowed her to notice and value the working aspects of her body:

> …It was a very different way to see organs and to see parts of your body because I don't think that's something I consciously thought about on a daily basis… I felt really honored to have my legs and I was really honored to have my heart. I felt a lot of gratitude that they work the way that they do and this is nice to take the time to appreciate that.

Similarly, others expressed feeling grateful after the body scan, as in light of all their bodies have been through, there are many parts working well.

### *Acceptance of post-cancer bodies and limitations*

MSC practices, particularly the body scan, encouraged participants to notice sensations and the associated feelings connected to their bodies without judgment. As difficult feelings came up, the MSC facilitator encouraged participants to give themselves kindness and compassion; in other words, provide emotional self-care. Jenny found that the scan helped her feel "centered [with a]…. sense of 'This is the reality of what my body is with its unevenness and the little aches and pains or the parts that don't have as much feeling as other parts.' " Thus, the scan allowed her to be with her body in its current state, as it is in this moment, without harsh judgment.

Susan, who had difficulty with anger towards her body, found observing sensations in her body non-judgmentally during the body scan allowed her to shift to a more accepting perspective and prompted feelings of self-compassion and relief:

> I think that by being mindful – at least when we were on the area where I have my surgical scars – …. I was like oh this is like ridgey…. That's interesting. It's different and it does feel different… That's where my scars are so I think embracing it felt really odd but also relieving. That's usually [what] I see is my area of betrayal and it was really nice to not see it from that perspective.

Later, Susan described how the body scan also brought up mixed feelings of resistance and acceptance for a body part changed by cancer, and acknowledged the exercise as a journey towards gradually becoming more able to accept her body's current reality:

> So when I was doing this I feel like that area [impacted by cancer] is incomplete or hollow. But when I did this [it was like] "That's just what it is now and that's okay." I think there's definitely resistance to the "that's okay" part. Sometimes I get to "okay that's there"- but it isn't always followed by "that's okay." So, I think something like this really helps me get to the "that's okay".

This ambivalence, somewhere between acceptance and resistance, was powerful for one participant, as the body scan of her cancer-affected body part evoked both gratitude ("I'm

lucky to be alive") and sadness for lost abilities ("I can't run anymore which was kind of my thing").

### *Awareness of negative emotions connected to sensations*

Finally, for some participants, the compassionate body scan and other practices that brought attention to the physical self prompted awareness of difficult emotions, as they as they were reminders of cancer treatment side effects like neuropathy, hearing or balance issues, and soft tissue tightness from radiation exposure. However, MSC practices are intended for these very situations, when difficult emotions are present, as they provide a way to cope with emotional pain, provide emotional and physical self-care, and initiate the process of healing through acceptance. In these cases, the MSC facilitator responded to these difficult emotions by encouraging participants to be gentle and patient with their negative emotions, and to be open to the possibility of acceptance and healing without the expectation that it will happen right away.

## *Health-related anxiety addressed through beneficial mindfulness practices and challenging awareness*

Many participants discussed fear of cancer recurrence and general health-related anxiety. Participants described intrusive "what if" thoughts and the challenge to try to live in the now and not worry about tomorrow. Jessica described that she had been "bitten once", or been caught off guard by cancer, and she felt it was difficult to let go of this vigilance, and to trust that her body has healed. Others discussed the anxiety associated with medical scans and the fear that cancer will be found, or the anxiety of transitioning out of treatment and into survivorship phase, where support is less available.

### *Mindfulness practices eased anxiety*

For many, mindfulness practices in MSC appeared very useful in combatting health-related anxiety. For example, Cybil experienced a profound change in perception of sensations during breath meditation; whereas focus on the breath in medical settings was connected to anxiety over health, focus on breath awareness during meditative practice allowed for a separation of physical sensations from this charged emotional state:

> So mine was a little bit anxiety inducing because…when I notice my breath… I get anxious…. And so what I did is what you told [another MSC participant] to do, to just observe it – and not think too much about it and it helped me. I was amazed that when I just observed it, that when I told myself "Just observe it", that anxiety just kind of left. And so it was different for me because every time I think about my breathing I get anxious about it, you know? I just get that fear. So it was different to just breathe without thinking about it you know? Without thinking about the meaning behind it I guess.

Many found "in the moment" mindfulness practices were portable and grounding in everyday life, particularly during doctors' visits and procedures. Participants used music meditation to decrease anxiety during an MRI, discussed how holding the "here-and-now stone" (a stone used as a way of bringing one's attention to the present moment) would have benefited them during treatment procedures, and as Amaya described, used mindfulness techniques to decrease anxiety during medical visits:

> "Name it-and-tame it" got me through my exams…my check-ups. It really works when you just put a name to the knot in your stomach. It starts going away and then you know the soft touch and everything and softening it, that totally worked.

During the last session, participants discussed how the MSC course as a whole impacted them, and several discussed the usefulness of the skills for anxiety. For example:

> I really appreciate having been able to do this. I got a lot out of it and honestly I have tools now that I can use to deal with my anxiety other than popping a pill when I'm having a panic attack kind of thing. I much prefer that and it's given me something I can actually use. (Amaya)

Although not discussed in depth here, many participants also described usefulness of MSC practices in dealing with general daily anxiety and stress unrelated to health concerns (e.g., job related stress, academic stress). Overall, MSC skills, and particularly mindfulness practices that were based in self-compassion, were beneficial to many YACS participants in coping with anxiety.

### *Body awareness triggered health-related anxiety*

On the other hand, for some, MSC practices that brought attention to the body triggered feelings of anxiety or uneasiness regarding physical sensations as possible signs of cancer recurrence or illness. For example, in describing her experience with the compassionate body scan, Sara expressed being "caught in a loophole" of anxiety as sensations led to doubts about her health:

> I've also been hyper aware of my body since the diagnosis, like I'm always kind of wondering, is this pain? Do I need to worry about this? Is that a lump? Is that a bump?…And then if I worry too much, if I fixate too much on wondering if that's a pain I feel, or just something settling, then it becomes a pain or an ache and that takes my focus for a while.

For Michelle, the acknowledgement of the lack of negative body sensations during the practices brought anxiety, as her health meant transition away from the cancer support system she had come to depend on:

> And for me, what's brought me back into therapy is checking with my body and being like, "but nothing hurts!" Like everything's fine, and now that feels so weird … cuz it's like I'm ok now and my oncologist is going to break up with me and I don't know what to do, you know! So for me whenever I do check in it can be sometimes scary, knowing that everything is doing what it's supposed to.

In these cases, the MSC facilitator encouraged bringing awareness back to sensations without connecting to "a storyline", gentleness and self-kindness for their suffering, and tailoring the practices to meet each person's needs (i.e., chose a different body part to focus on if the current one is too activating). However, these issues are important to consider as we gain understanding of the implications of learning MSC for YACS.

## Discussion

This study provided a unique opportunity to explore both the psychosocial challenges facing young people as they navigate cancer survivorship, as well as their reactions to and use of mindfulness and self-compassion practices to address these challenges as they unfolded during the learning process. The three categories of psychosocial needs discussed by participants in this study – peer isolation, body concerns and health-related anxiety – are

prevalent in YACS literature (Barnett et al., 2016; Kent et al., 2012) and highlight the potential relevance and generalizability of these findings to the greater YACS community.

Moreover, these three psychosocial needs, while certainly having their own nuances and unique characteristics within the YACS community, may also have relevance to the larger community of adolescents and young adults who navigate chronic illness. Peer isolation, including marginalization and feelings of being developmentally "off-track", has been described in the young adult chronic illness literature (DiNapoli & Murphy, 2002). Negative body image is also common among young people with chronic illness; a recent meta-analysis showed young people with obesity, cystic fibrosis, scoliosis, asthma, growth hormone deficiency, and spina bifida all had increased body dissatisfaction compared to healthy age-matched peers (Pinquart, 2013). Finally, psychological distress and uncertainty about the future, while somewhat illness-dependent, is also a common characteristic of the adolescent and young adult chronic illness experience (Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012). Thus, the usefulness of MSC practices found in this study may have relevance to other adolescent and young adult populations who have ongoing health concerns and should be explored further.

We found peer isolation and general lack of emotional support to be a source of stress for YACS, with some subthemes bearing similarities to the concept of survivor loneliness as described in adult breast cancer survivors (Rosedale, 2009). While the MSC curriculum seemed to provide several different useful isolation coping strategies, the skill of emotional self-reliance may be particularly pertinent to the YACS experience. As illness and treatment may delay YACS autonomy and independence from families (Wong et al., 2017), being able to give themselves the emotional care they need (i.e., be their own internal support system) may provide a way for YACSs to gain some independence and control.

Moreover, several participants described improved self-care as a result of the MSC course. This involved listening to their bodies' needs, resting and seeking medical care when needed, and generally being more attuned to their physical needs with less self-criticism or judgment. These findings are congruent with other studies in general populations that have linked self-compassion with health-promoting behaviors (Dunne, Sheffield, & Chilcot, 2016; Sirois, Kitner, & Hirsch, 2015). For adults with chronic illness, self-compassion has been linked to better disease management and adherence to treatment regimens (Brion, Leary, & Drabkin, 2014; Dowd & Jung, 2017). The role of MSC practices in promoting self-care for YACS is promising and deserves further exploration.

The challenges of changing physical health, body image disturbances, and fear of recurrence noted by participants are also reflected in cancer survivorship literature (Barnett et al., 2016). In this study, MSC practices, particularly the compassionate body scan practice, evoked gratitude, acceptance for changed body appearance or function, and decreased symptom anxiety for some; these findings mirror that of other studies showing self-compassion's association with decreased body image distress in cancer (Przezdziecki et al., 2012; Sherman et al., 2017). Self-compassion has also been associated with improved outcomes for adults with physically-limiting chronic illnesses (Nery-Hurwit, Yun, & Ebbeck, 2017), as well as beneficial for decreasing body image distress in those suffering from eating disorders, many of whom are in young adulthood (Braun, Park, & Gorin, 2016).

Some participants, however, initially experienced emotional upset when tuning into physical sensations in a compassionate manner, as it reminded them of their imperfections, post-cancer side effects, or worries about cancer recurrence. It is unknown if the emphasis

on bringing gratitude and kindness to body parts in the compassionate version of the body scan, compared to non-judgmental awareness typically encouraged during the MBSR body scan, made this exercise more challenging for some. It appeared, at least for one participant who noted feeling betrayed by the part of her body that had cancer, that cultivation of appreciation was difficult to achieve and added to initial discomfort. Meanwhile, for others, the emphasis on gratitude appeared particularly beneficial. This highlights the importance of qualitative research in understanding varied intervention experiences.

Qualitative literature is sparse, however, regarding difficulty with body awareness practices in mindfulness interventions, and to our knowledge, no other qualitative data are available regarding reactions to the compassionate body scan used during MSC. A recent mixed methods study of mindfulness-based training in women with metastatic breast cancer mentioned one participant's difficulty with the body scan, as it caused her to focus on her illness (Eyles et al., 2015). Similarly, participants in a mindfulness intervention for adults with multiple sclerosis described initial distress associated with the body scan, which triggered unpleasant awareness of disability (Simpson, Byrne, Wood, Mair, & Mercer, 2017). In this instance, the instructors encouraged an accepting, self-compassionate response to these emotions, and these issues subsided and the practice became beneficial.

Given the MSC curriculum is designed to bring awareness to painful emotions as a means of cultivating self-compassion for one's suffering, it is not surprising that the compassionate body scan evoked both positive and negative emotions. These findings highlight several important points. First, MSC facilitators serving YACS should be experienced in handling potential negative emotional reactions to body awareness practices. In addition, curriculum adaptations should be considered for extra emotional support during body scans, with the potential flexibility of beginning with a more traditional body scan and easing into practices that emphasize warmth and gratitude if resistance to the compassionate version is notable. In this study, the facilitator encouraged flexible tailoring of practices (i.e., focusing on a different body part if one part was causing high distress), offering self-kindness when emotional difficulty arises, and focusing on physical sensations rather than the thoughts accompanying the sensations during moments of emotional difficulty. This support appeared beneficial and initial difficulties appeared to ease with practice. Another strategy could include preparing participants ahead of time so as to not be caught off-guard by unpleasant emotions should they arise, and offering pre-body scan instruction on how to "close" or end the practice should negative emotions become overwhelming. Other strategies, and a greater understanding of who is at risk for negative body awareness reactions, should be explored and integrated into future adaptations.

Furthermore, the quantitative findings in this study revealed overall improvement in anxiety and body image distress (Campo et al., 2017); thus, despite the challenges of the body scan, participants reported overall mental health benefits. These benefits are congruent with other mindfulness-based intervention findings and self-compassion correlational studies in cancer populations. Mindfulness-based programs without a self-compassion focus have been shown to decrease anxiety and depressive symptoms (Zhang, 2015), increase overall wellbeing and quality of life, and have small but significant positive impact on biomarkers and physical health in adult cancer populations (Rouleau, Garland, & Carlson, 2015), with a recent single-arm mindfulness-based intervention showing similar promise for adolescent and young adult counterparts (Van der Gucht et al., 2017). Research also supports

that higher levels of self-compassion correlate with lower levels of stress and depression in adult cancer patients (Pinto-Gouveia et al., 2014).

Finally, it is important to note participants' application of the skills they learned during the intervention to difficult situations outside of the course. Whether it be countering negative self-talk with self-compassionate phrases, or using breathing or other grounding techniques to get through a doctor's visit, the participants were able to integrate practices into daily living and appeared to benefit greatly. Meanwhile, the struggles the participants encountered during the MSC course – for example, difficulties finding or trusting their compassionate voice, or finding time to formally practice – are all common in new MSC students, considered part of the learning process, and often decrease with time.

There are a number of important limitations to this work. First, while the study provides a first step in understanding how learning MSC addresses the needs of a heterogeneous group of YACS, the descriptive nature of the study did not allow for larger interpretive leaps with the subject matter, which could be important for generating theory regarding self-compassion in this age group and context. Second, this study provides insight on a brief period of time within survivorship relatively close to treatment completion (2–3 years). As psychosocial issues change over time and as the young person's life situation evolves (Lehmann et al., 2014), it is unknown if MSC practices will remain relevant. Third, the sample was all female, predominately white, and well educated; therefore, these findings may not be generalizable to male cancer survivors or other races or ethnicities, or individuals with less education. Fourth, one group elected not to have their sessions recorded and five transcripts were missing from the recorded groups due to technical difficulties; therefore, it is possible there were themes omitted from this analysis. Moreover, the study did not examine some important contextual elements like whether cancer negatively impacted education, living arrangement, or career goals. Accounting for those variables would enrich the interpretation of the results, so as to illuminate for whom MSC practices are most beneficial. Given that the qualitative analysis was performed at the group level, we were unable to connect specific benefits or difficulties with MSC curriculum to specific demographic variables or cancer history variables. Finally, regarding the quanitative results, the single-arm design of this pilot study is a considerable limitation; future studies with an active control group are needed to confirm the impact of this intervention.

Despite these limitations, this study provides evidence that the MSC curriculum offers practical, relevant coping skills that confer mental health benefits to YACS. Additionally, the skills are potentially relevant to addressing similar challenges in other cancer survivor populations as well as other young chronically ill populations. Given this, we recommend larger randomized controlled trials of the MSC intervention with demographically diverse YACS and adult cancer survivor populations as well as piloting MSC for chronically ill young people. Future MSC interventions should take into consideration the potential sensitivity of YACS to body scans and other practices that call attention to physical sensations. Attending to the expertise and experience of the MSC facilitator and ensuring emotional support for potentially distressing exercises like the compassionate body scan will maximize benefit and minimize distress. Furthermore, studies that include mixed-method case analysis with pre, post and long-term follow-up interviews may elucidate which personal characteristics moderate the relationship between MSC and outcomes and provide guidance on which subpopulations of YACS will be most benefited. By using a variety of approaches to evaluate the impact

of MSC skills for YACS and others, we can ensure the intervention is meeting participants' needs.

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