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Résumé de l'article

In this paper we share key insights from an 18-month participatory research project exploring the lived experiences and realities of cancer among racialized adolescents and young adults (AYAs). Written collaboratively with adolescent and young adult co-thinkers, we discuss the creative methodologies used in the study, critical and imaginative frameworks within Indigenous, Black and queer of colour theorizing, and the value of an interdisciplinary approach for understanding the cancer care experiences of racialized adolescents and young adults. The analysis explores five core research themes, which highlight what the project offered to the adolescents and young adults who participated: a place to meaningfully participate, to be understood in their complexity, to create and be creative, to be in community, and to imagine their desired futures. We argue for a meaningful and inclusive engagement of AYAs in cancer care systems and research, urging healthcare practitioners and researchers to recognize the complexities of AYAs' lives and experiences. Ultimately, we advocate for transformative changes in cancer care research and practice, with the goal of supporting AYAs as active agents in their own care and futures.

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Imagining Futures Amidst the Uncertainty of Living: A Critical Participatory Action Research Project with Adolescents and Young Adults with Lived Experiences with Cancer

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Abstract: In this paper we share key insights from an 18-month participatory research project exploring the lived experiences and realities of cancer among racialized adolescents and young adults (AYAs). Written collaboratively with adolescent and young adult co-thinkers, we discuss the creative methodologies used in the study, critical and imaginative frameworks within Indigenous, Black and queer of colour theorizing, and the value of an interdisciplinary approach for understanding the cancer care experiences of racialized adolescents and young adults. The analysis explores five core research themes, which highlight what the project offered to the adolescents and young adults who participated: a place to meaningfully participate, to be understood in their complexity, to create and be creative, to be in community, and to imagine their desired futures. We argue for a meaningful and inclusive engagement of AYAs in cancer care systems and research, urging healthcare practitioners and researchers to recognize the complexities of AYAs' lives and experiences. Ultimately, we advocate for transformative changes in cancer care research and practice, with the goal of supporting AYAs as active agents in their own care and futures.

Keywords: *Critical Participatory Action Research; Creative Methods; Adolescents and Young Adults; Cancer Care; Black, Indigenous and Queer of Colour Futures*

Imagine this: sitting in front of a brightly lit screen, participating in a research project over Zoom—an extraordinary advancement in connectivity, but also a notably impersonal medium. After two hours of sharing virtual space, the session draws to a close with music softly playing in the background. Despite the goodbyes, no one seems eager to disconnect; smiles linger on faces as they remain on the screen. Amidst humming and swaying across time and space, Tracy Chapman's lyrics resonate deeply: "Don't you know, they're talking about a revolution? It sounds like a whisper." Against all odds and amidst apprehension, grief, and frustration, a community is forged.

In this paper we describe an 18-month participatory research project led by Anew Research Collaborative—a collective working toward reshaping cancer care for all young adults. The project explores the lived experiences and realities of cancer among racialized adolescents and young adults (AYAs). The first phase, detailed in previous work (Hill et al., 2024), focused on interviews with racialized AYAs that revealed a call for transformation within health and cancer care systems. The second phase, which is the focus of this paper, engaged AYAs through participatory creative processes (Cammarota & Fine, 2008; Cox et al., 2021; Gaventa & Cornwall, 2006; Hall, 1981; Mitchell, 2011) to expand upon and deepen these findings. Written collaboratively by three researchers (Tiffany, Ian, and Cheryl) and three AYA co-thinkers (Rabi, Vinesha, and Nellie), we argue for meaningful engagement of AYAs in cancer care systems. We call upon researchers and healthcare practitioners to recognize the complexities of AYA's lives, with the goal of fostering transformative changes in cancer care research and practice.

In the sections that follow, we begin by discussing the influence of biomedical research on social science inquiries, with a focus on the lived experiences and realities of cancer and cancer care systems. We argue that interdisciplinary approaches are better suited to understanding AYA experiences and introduce our approach to an 18-month study with racialized AYAs. Specifically, we discuss the methodologies and methods we engaged, as well as the theoretical frameworks that guide us. Then, we discuss five research themes emerging from this work, which highlight what the project offered to AYA participants: a place to meaningfully participate, to be understood with complexity, to create and be creative, to be in community, and to imagine desired futures. To conclude, we argue that this research can inform the transformation of cancer care spaces to better support racialized AYAs.

Biomedical Research and Social Science Approaches to Health

Historically deemed the most “credible” form of knowledge production, biomedical research continues to dominate scholarship within the health sciences (Albert et al., 2008). Biomedical research is often considered superior to social science research because it is perceived as rigorous, reliable, reproducible, and transparent (Albert et al., 2008; Leung, 2015). In recent decades, social science research has gained credibility within the health sciences (Albert et al., 2008), but it remains marginal within a research environment that is largely experimental (Clarke, 2013). As such, the biomedical principles of “rigorous scientific inquiry” have shaped the design of social science research in the health sciences. With notable exceptions (e.g., Wright, 2023), social science research in medical contexts, including cancer care, has tended to focus on the use of structured, replicable methods such as surveys, interviews, and focus groups. It is often intervention focused rather than exploratory or interdisciplinary in nature.

While we appreciate the potential benefits of this research for medical and clinical care, we firmly believe social science research can offer greater nuance. Reductionist approaches to medical thinking often fail to consider the social, cultural, and personal dimensions of what it means to be human, and they do not address the complex, interdisciplinary challenges present in the health sciences (Clarke et al., 2019). This is especially disconcerting when we consider the violence and harm biomedical research has caused—and continues to cause—to Indigenous and racialized communities (Wilson et al., 2024). Rabi—a survivor of childhood and young-adulthood cancers, who has described herself as often being the poster child for various survivorship support initiatives, programs, and organizations—writes:

> The word “research” normally meant that someone had come to me looking for evidence of something specific they had already identified, or they came for an element of my experience which they wished to isolate, break-down, and salvage for usable parts. Whether it was a questionnaire on a screen, an interview, or a program designed to prompt corralled responses from cancer survivors, it always felt like I was being scavenged. I knew I wasn’t alone in this feeling. In group settings, I could see others tailoring their responses and filtering their experiences to fit into a report we would never see. We automatically looked for nonverbal cues, whether in the frown lines of a questioning face or between the serif font on a screen where word choice and repetition would reveal thinly veiled agendas and sweep us into tidy corners of a cancer hypothesis.

Given our collective opposition to the harm that can be caused by biomedical inquiry (Brody, 1998; White, 2020), the researchers on this project imagined other possibilities—possibilities where AYAs like Rabi engage in research designed with care, the same kind of care that AYAs in this study yearn for from cancer care systems.

An Interdisciplinary Approach to Social Science Health Research

This project draws from interdisciplinary approaches to social science research that often have limited application in cancer care research. Specifically, we drew upon person-centred and creative approaches to research including Participatory Action Research (PAR) (Cox et al., 2021; Gaventa & Cornwall, 2006; Hall, 1981), patient-oriented research (Gould et al., 2009; Government of Canada, 2014), arts-based research (Barone & Eisner, 2012; Hinsliff-Smith et al., 2022) and trauma-informed research practice (Edelman, 2023), all of which shaped and informed Cheryl's past work. This approach was further developed and refined by Tiffany to include critical PAR (Fine & Torre, 2021), visual research (Mitchell, 2011), and a deep reading of Indigenous, Black, feminist, and queer of colour scholarship and theory.

The researchers in this study acknowledge our participants as co-thinkers. Throughout the paper, we write alongside them and, in some instances, highlight their individual theorizing and writing. As researchers, we felt it was our responsibility to adopt a relational approach at every stage of the research (Wilson, 2008). Learning from Opaskwayak Cree scholar Shawn Wilson (2008), we challenge conventional Western research paradigms and emphasize the significance of honouring and nurturing relationships throughout the research process, recognizing them as foundational to knowledge creation and understanding. In line with Indigenous epistemologies that view knowledge as collaboratively generated and not individually created or discovered (Chilisa, 2012; Collins, 1990; Smith, 2000), we question how we could truly come to know something in its fullest sense, without knowing—or, in this case, writing—together. Throughout the paper, we bring AYAs' spoken or written words into conversation with scholarly literature. As an act of resistance (or perhaps revolution), we uphold AYA voices as equally valuable as academic scholarship, challenging who gets to decide what is knowledge.

Similarly, we draw from Cammarota & Fine (2008), who examine how social inequalities shape who has the privilege or power to conduct research, and for whose benefit. As a collective, we embrace research as resistance and, specifically, lean into the ways in which participation and arts-based methods can be utilized to develop better research practices. We value participants as active agents and contributors to change (Gaventa & Cornwall, 2006; Hall, 1981; Kemmis & McTaggart, 2005) and see the arts and arts-based research as vital—perhaps even radical—ways to support participants in exercising their individual and collective agency. These methods help adolescents and young adults to contribute and engage in ways that feel meaningful and important, often sharing perspectives and narratives that are new, overlooked or stifled (Barone & Eisner, 2012; Bird, 2022).

Learning from critical and imaginative frameworks such as Indigenous World-Making (Kimmerer, 2013; Simpson, 2017; Tuck, 2009), Afrofuturism (Butler, 1979), and Queer Futurity (Muñoz, 2009), we look to the future. Rather than focusing on the pain and harm done to Black, Indigenous, and communities of colour, we position our work to reimagine the wants, hopes, and desires of racialized AYAs, offering new ways to think about possibilities and liberation from systems that otherwise constrain them.

Study Design and Methods

In the first phase of this 18-month project, we interviewed 18 AYAs who identified as racialized, had lived experiences of cancer, and were treated by the cancer care system in what is colonially known as Canada. After an extensive multi-coder thematic analysis of the interview transcripts, we identified five core themes (read Hill et al., 2024 for a more detailed account of this process). In the second phase of the project, AYAs who had been interviewed were invited to partake in a participatory creative process where they explored themes in greater depth. We called this process a creative series. It took place online over Zoom from July 12-August 16, 2023, with nine racialized AYAs participating in facilitated two-hour sessions each week for a total of six weeks. While eight AYAs participated in all six weeks, one AYA joined the project in the third week. In the creative series, AYAs engaged in a variety of activities, including poetry creation (Tkaronto CIRCLE Lab, 2023), participatory photography (Mitchell, 2011), postcard and canvas making (Mitchell et al., 2018), free writing, and found poetry (Hill, 2019). Alongside creating, AYAs participated in open discussions, building on each other's ideas and making connections across their experiences. Throughout this paper, creative artefacts are presented with rich descriptions, and quotes from AYAs are included alongside intentional pseudonyms, which emerged from their discussions and creative works, such as poetry. At the end of the series, Tiffany and Ian transcribed audio recordings from the sessions, and, alongside the creative artefacts and their descriptions, coded for values, attitudes, and beliefs using Dedoose, a qualitative data analysis platform (Saldaña, 2016). Then, they engaged in another round of coding for stories and connections. Codes and ideas were presented to Rabi, Nellie, and Vinesha—three AYAs who participated in the creative series and who are the co-authors of this paper. In this exchange, which resembled processes such as enhanced member checking (Chase, 2017) and participatory analysis (Jackson, 2008), they validated and expanded our learnings. These learnings are outlined as headings and explored in detail throughout the remaining sections of the paper.

As we have reflected on this project through numerous conversations, reflections, and writing, some of what we present here was unanticipated at the outset. Through this process, we learned that racialized AYAs want to participate meaningfully, be understood in all their complexity, express themselves creatively, build community, and imagine their desired futures. Below, we build a more comprehensive understanding of what we learned and describe how our approach to the research aimed to address the needs that AYAs deemed lacking in cancer care systems.

To Meaningfully Participate

AYAs want to have active and meaningful participation in all aspects of their care (Hawkins, 2018). To do so in a generative way, they need to feel heard and not dismissed—something that directly contradicts their experiences in the cancer care system (Hill et al., 2024). The responses and creations generated through the creative series focused on this need, as pictured below (Barone & Eisner, 2012; Hinsliff-Smith et al., 2022).

Figure 1. Unprofessional

This creative artefact was created by Rainforest, who shared that the image represented the feeling of being ignored by their doctor and receiving solutions in the form of prescriptions and medication, rather than being listened to. While it serves as a powerful visual depiction of Rainforest's need to meaningfully participate in their own care, the intention and meaning behind the choice of image also offers significant value. In response to an activity where AYAs were asked to create a physical postcard to their oncologist using scrapbook materials provided to them, Rainforest generated this image by engaging artificial intelligence. Some may interpret this as breaking the rules, but what we learn from this is that meaningful participation means allowing AYAs to engage in ways they want and choose. This concept applies not only to their autonomy over their cancer care but also to their participation in research about their cancer. Rabi illustrates this further:

> Someone should try to approach research from a place of intuition. Lean into the parts of human connection and experiences that we don't have clear understandings of. To try and understand it with us, not in spite of our inferior intellect or understanding, as many others will have us believe. This may seem harsh but the same classist culture that has surgeons and other healthcare workers treating patients like cattle who need herding or like children that need to be spoken to in simple terms and with largely omitted chunks of information, is what I encounter with most researchers. The "us/them" mentality. When you are brought in as an equal, and the whole process is seamless, it becomes evinced in the candid answers the researchers offer you at every turn. That genuine openness and inclusivity, the dignity and respect of including the people you are trying to help (or at the very least are trying to use for your own means) will come through glaringly in contrast to what has been normalized between scientists, healthcare professionals, and the rest of "us." Science is held back by its sanitization of the human experience. On the rare occasion that someone will make space for us to communicate beyond a "yes sir, thank you sir," we'll stumble through our limited vocabularies and try to explain that we desperately feel the need for a form of healthcare that is not being provided, only to be met with a smug face asking for more details and proposed solutions and having none to offer.

At its core, PAR is about research *with* people that seeks to meaningfully engage participants as experts of their own lived experiences (Gaventa & Cornwall, 2006; Kemmis & McTaggart, 2005). Further, PAR is designed as a co-learning process that can help mitigate power imbalances (Hall, 1981) and focus on the issues that participants deem significant (Kemmis & McTaggart, 2005). Within this project, it was critical that participants had opportunities and agency to participate in ways that felt appropriate and meaningful to them, acknowledging them as active agents of change (Gaventa & Cornwall, 2006). In this way, we aimed to advance patient-oriented research (Government of Canada, 2014) and ensure that patient engagement was not tokenistic, but truly meaningful.

In addition, given the emphasis on participation in this project and what critical youth scholars Cammarota and Fine (2008) define as true and meaningful participation, participants were invited not only to co-theorize during the study, but also to co-write this paper. Studies that interrogate how research is typically conducted and how knowledge is mobilised in mainstream health research have shifted toward variations of this inclusion, advocating for participants to be "participators in authorship" (Fursova, 2023). As AYA co-thinkers, we recognize researchers trying to break the mould. Vinesha writes:

> I cried tears of joy receiving the email about co-writing this paper. It finally felt validated that I had a voice and that I was an expert in my care…I was not going to be extracted and then cut out of the conversation. I could truly be the author of my own story.

We learn from AYAs in this study that they desire to meaningfully and actively participate in their cancer care plans and the research related to their cancer. In particular, they emphasize the need for systems to treat them as autonomous, agentic beings with choices, inherent value, and wisdom worth learning from.

To Be Understood with Complexity

AYAs, and specifically racialized AYAs in the context of this study, clearly articulated their need to be understood with complexity. While many AYAs initially introduced themselves in the creative series through their identity as cancer patients, the "We Are From" poems (see Appendix) created as part of the series highlight the complex identities that extend beyond their cancer diagnosis. Vinesha articulates her growing understanding of this complex identity:

> These are the questions that grappled me from at least when I was 15 as this question has lived in me and in my bones, layered throughout my days, wrapped through my DNA, intertwined all the way back through my ancestral line. You see, I was born into an Indigenous, oppressed peoples from Tamil Eelam in a time in history our peoples were not afforded self-determination. While still a child, encountering genocidal war and forced to flee from Sri Lanka, we came to Turtle Island, now known as Canada, through this pipeline. A handful of years later I was diagnosed with cancer as a teenager.

In this study, we reexamine the traditions that biomedical research has introduced to social science and question the practice of collecting demographic data solely to enhance generalizability and validity (Leung, 2015). This customary practice often involves researchers posing intrusive questions about participants' identities, affections, and preferences, yet without genuine concern for the responses, reducing participants to mere statistics. While we recognize the potential value of collecting demographic data in research to promote equity (Varcoe et al., 2009), we favour practices that tell fuller stories of people, and more importantly, stories they want to tell (Tuck, 2009). The extraction of stories and intimate details from participants is a dominant theme in the lived experiences of AYAs navigating cancer care systems. Rabi writes:

> I'm taking liberties. I'm not a statistician, a scientist, or a researcher… but I am human. I'm part of the research. I'm the source of the data and this puts me in the position to be able to see what's being neglected, and intuitively causes me anxiety because I can tell these missing pieces are important and, the data will then inform incomplete, inefficient, or flawed conclusions/programming/policy/what-have-you. But I have no way to communicate this view in previous contexts. So when we started this creative series, I was hesitant. I couldn't grasp the notion of someone not having a predetermined agenda. They didn't select me to participate within the ticked boxes, and only in the capacity which made sense to them.

In this project, we collected minimal demographic information and instead used practices that encouraged participants to tell fuller stories of themselves, helping them move beyond boxes they are typically confined to. For example, in the introductory session of the creative series, participants engaged in an activity where they created poems inspired by sounds, smells, tastes, and feelings from the places they come from (Tkaronto CIRCLE Lab, 2023). This activity was learned by Tiffany from her mentor, Unangax̂ scholar Eve Tuck, through their work together in the Tkaronto CIRCLE Lab. On this activity, Vinesha writes:

> Having provided many talks and biography profiles in the past in which I touch on my cancer journey and identity as an equity-denied person, I was ready to write the similar tropes to get through this exercise. Tiffany then gave us a sample that she had written. I was stunned. She was speaking of her roots, her skin in beautiful language and not medical terminology, and talked about her people and how revered they are. I saw so much of myself in Tiffany's words, sentiments, her ancestral cadence. All of a sudden, this activity was no longer about my cancer identity, but about all of me—the major parts of me—that I don't easily share or speak. I was shaken that I had found myself in this space I intimately needed that I perhaps couldn't even fathom could exist because of my pre-existing experiences with the cancer support world.

Vinesha's sentiments are echoed by participants in the creative series. Some found the activity resonate with them because it gave them the opportunity to describe themselves as "a Little Mix of everything and everywhere" (Waterfall), echoing Vinesha's sentiments about the challenges of oversimplifying categories and identities. Others felt "homesick writing" (Fiddlehead), emotional because they were and continue to be displaced from the places they call home. While yearning for the lands and waters they wrote about, many shared sweet and nostalgic memories through smiles. This sharing fostered moments of connection. As Ian writes:

> Growing up, I visited the Maritimes as some of my family grew up there. Hearing [Fiddlehead] describe where they were from in this way was breathtaking to me. I could see those fields and the faces of my family around me. I also could taste and smell the comfort of fiddleheads fried in butter and the feelings of home it evokes.

These connections to the natural world echo the teachings of Potawatomi botanist and scholar Robin Wall Kimmerer. In her book *Braiding Sweetgrass*, she explores the interconnectedness between all humans and more-than-human beings, emphasizing the importance of nurturing these relations. This creative activity provided AYAs with an opportunity to recognize their relationships with more-than-human beings, describing these relations as integral to their identity and humanity. For instance, one AYA wrote that they were “from rushing rivers, aromatic soils, and jutting mountains of a motherland whose memory is as shrouded in fog as are its valleys” (Stardust). Another wrote that they were from “tiger lilies” (Fiddlehead), “beautiful waterfalls and where water falls” (Waterfall), and from “mosquitoes and sandflies. Itchy skin. Red welts.” (Wildflower). To read a shortened and collective version of the “We Are From” poems, see the Appendix.

While the activity gave AYAs a means to express themselves beyond the confines of race and helped them to gradually release the hold of identifying solely as cancer patients, it also inspired a more creative approach to respecting anonymity in written and visual forms of research. As such, key words from participant poems are used as pseudonyms, serving as false names to maintain confidentiality while ensuring AYAs are recognized as individuals, not just numbers or statistics.

To Create and Be Creative

AYAs, specifically racialized AYAs in the context of this study, emphasized the importance of creativity and the creative process in supporting meaningful participation, facilitating meaning-making, and translating ideas that may be difficult to express in words. Reflecting on the role of creativity throughout the process, AYAs shared that it helped foster deeper thinking and understanding of their experiences. As Nellie highlights:

> One of the reasons why the creative series helped in my process of reflecting on race in cancer care is that we were allowed to express ourselves freely in colour, found poetry, collage, free association writing. There were hardly any limits to what we could create, and it became easier to unearth feelings and experiences that are hard to articulate in a rational way.

Similarly, Rabi describes the benefits of creative expression for communicating the human experience with others: “When I think of creative modes of communication like freewriting, poetry, and art, I think it's like speaking a new language, unique to one soul, but large and small bits will overlap with and be understood by other souls.”

Generally, arts-based research refers to the use of any art form to collect, interpret, and/or share new knowledge (Barone & Eisner, 2012), and arts-based approaches are typically participatory in nature (Matarasso, 2019). Further, arts-based methods, like participatory methods, are often considered emancipatory or radical in that they seek to amplify perspectives and narratives that are typically silenced or repressed (Bird, 2022) and challenge dominant research paradigms (Hinsliff-Smith et al., 2022). In the context of this study, arts-based, participatory processes were used to support AYAs who identify as racialized in sharing their perspectives on a system in which they are often silenced and within a healthcare research context where arts-based approaches are not the norm. As such, our approach to research may also be considered radical.

In addition to providing opportunities for participants to share their perspectives, variations of arts-based (Barone & Eisner, 2012), visual (Mitchell, 2011), and creative participatory action research (Cox et al., 2021) generally offer common benefits. These benefits allow participants to express themselves beyond words and recognize different ways of knowing. For instance, Rabi writes:

> Have you ever wondered how many of your own feelings you may have dismissed because you didn't have the vocabulary to define them? Did the feelings go away? Or did you notice them become a wordless, shapeless ache/discomfort, pressing out from within you, demanding to be felt whether or not someone had bothered to label them in your language? The pain of aching and having no words to describe what is happening to you is something most everyone knows. The more complex the experience gets, the more pressure the pain builds. The longer you carry it, the heavier it feels. To live a life built on layers of unvalidated experiences is to be so deeply disconnected within, that you never truly connect with anyone or anything, without. So you can understand that the logical thing to bridge this gap in human connection is to use modes of communication outside of language. Clay, charcoal, or calcite on a wall, a chant, a hum, a wail, a song, acrylic on canvas, oil on napkin, a prompt for an AI image generator, an extra cookie in your lunchbox, a shared moment of silence whilst listening to Tracy Chapman.

Barone and Eisner (2012) suggest that engaging art in research is "an effort to extend beyond the limiting constraints of discursive communication in order to express meanings that otherwise would be ineffable" (p. 1). Instead of endorsing a singular interpretation of reality, arts-based researchers encourage both the audience and participants to reconsider the world from multiple perspectives, urging them to look beyond the surface of what is familiar (Barone & Eisner, 2012).

Building from the idea that creativity provides AYAs with different ways to share their experiences, art and the creative process also offer them new ways to understand those experiences. As Vinesha writes:

> White society has conditioned us to believe that expression must be intelligent, intellectualized, credentialed, articulated verbally or in writing, often stripped of human creativity and vulnerability. White gaze and its approval are the pinnacle. Our creative process reiterated over and over again that cultural and Indigenous modes of communication and creativity go far beyond the words and are done in communion–the body language, a glance, a shift in posture, the feelings and emotions, the shared silence, the sounds, noises, chants and music, the eating together, the relationship with land, water and other beings. White supremacy with its colonizing and violent roots is death-dealing; while our ways of creativity, communication, and community are life-giving and healing as we experienced in the

> series. Creating together, the act of creation, elevating, adding benefit to and giving to the world and each other, rather than destruction, destroyers and deaths—the suppression of [all of these:] creativity, co-creation, expression and communication we often see in white-dominant systems.

Many critical scholars share Vinesha's perspective on the power of expressing truths beyond words (van der Kolk, 2015). For instance, in *The Body Keeps the Score*, psychologist van der Kolk (2015) explores the intricate ways in which bodies hold both wisdom and trauma. Nellie writes:

> Maybe the experience was too raw, or we didn't have the words to describe it. In this way, we could bypass our rational minds to access this deeper wisdom and/or trauma that is held in our bodies. I found it helpful to also examine the process of creating a piece. For example, if I was tentative in putting colour to the page, did that reflect a tentativeness in my commitment to my healthcare, or voicing a complaint to my oncologist? Many times, the creative process mirrored the way an event unveiled itself in real life and allowed me to explore my relationship to these events, and these insights were available to me because I had created something during this creative series.

This is especially true for experiences related to cancer, where AYAs are thrust into a cancer care system that is not designed with them in mind (Chisholm et al., 2018), particularly for racialized AYAs (Hill et al., 2024). The cancer care system rarely reflects on the emotional and psychological processes that patients go through, and AYAs often speak about the trauma of the experience (Chisholm et al., 2018; Zebrack et al., 2014). They also report having few opportunities to reflect on or process their experiences (Hawkins, 2018), a challenge further compounded by the pressure to be a "good" patient and avoid saying or doing the "wrong" thing (Hill et al., 2024). Nellie continues:

> Besides, how many times have I tried to explain systemic racism to someone (often a "devil's advocate") and my words are used against me, or argued with so that my experience is reduced to a rejected pile of words? Another reason could be that I am a person that wants to dismantle systemic racism in our world, and yet, I can admit that I have not really analyzed how I show up in this world as a racialized person. It's easy to be outraged at acts of violence that happen to other people, and I consider myself lucky that I have never had physical harm come to me, but it's also easy to lean into being a Chinese Canadian who can benefit from being quiet, outwardly complacent and a super pleasant cancer patient. I remember when my GP referred me to an obstetrician years ago, she called me "delightful and pleasant". It's hard to give up this positive regard, but I think it might be worth it to examine race more closely in my life.

For AYAs involved in this study, the creative process enabled them to share perspectives and insights that may be difficult to express otherwise, offering opportunities they may not have had before. Additionally, the creative process provided a space for reflecting on lived experiences in ways that challenge traditional research paradigms in health sciences, supporting a more process-oriented approach focused on the needs of AYAs involved.

To Be in Community

A throughline throughout every phase of this study was the need to be in community. In previous work, we explored how community spaces for AYAs are places they where can relate to, look out for, and support each other (Hill et al., 2024). While these ideas held true in the creative series, what became more explicit was the desire to be in community with other racialized AYAs. For instance, in the first session, one AYA shared that "it's nice to be able to see people and talk about it, that feels more like a community to me. And not to put [AYA] on the spot, but it's nice to see other Black [people] as well" (Waterfall). In addition to being in community with other Black, Indigenous, and racialized people, AYAs emphasized the importance of collectively unpacking and critiquing systems of power. This idea is frequently highlighted by critical youth scholars, who advocate for young people—especially those of colour—to have access to spaces that foster an analysis of systems of oppression (Cammarota & Fine, 2008). For AYAs, a key aspect of community was the opportunity to engage in this kind of critical thinking together.

In this study, the contrast between how race and racism are discussed in isolation (during interviews) versus how they can be understood within a collective community (in the creative series) emerged as a significant theme. For example, in the initial interviews, racialized AYAs shared that the spaces within the cancer care system where they sought support were often predominantly white, including other AYAs and healthcare providers, who often ignored their seemingly obvious difference (Hill et al., 2024). AYAs expressed both positive and negative affects about these encounters. Some found it difficult to recall experiences of blatant racism, with a few even commending others for not treating them differently. Others, however, offered a more nuanced perspective, recognizing the challenges of speaking about racism. In the creative series, we witnessed AYAs discussing this issue among themselves, identifying their fear of repercussions for being honest about their experiences or questioning whether their treatment could be anything but life-saving. In a collaboratively authored creative piece, they write:

> There is no way to know, but we carry with us a lifetime of microaggressions and major and minor harms directed at us directly and the skin tone we are born with. We flinch, but we do not engage, hardly ever. What good does it do? We take it in, we receive it, we do not make waves. Not in the doctor's office, or in the cancer clinic, or the support group. We already feel othered. And now we question whether our otherness is going to politely do us in. (Whisper)

Rabi further elaborates on this idea, offering deeper insight into the complexities of discussing race and racism in these spaces:

> It's a long road to rewiring a self-lobotomizing brain that has identified that survival through acceptance into community is a much more emergent need than the ability to identify what parts of that same community may be indirectly killing you at a slower rate. It takes some very blatant venting about white supremacy and patriarchy, and explicit statements acknowledging that people of colour walk through a different, much less friendly world than our white counterparts, for me to feel I can safely talk to a group or person about how much race plays into my experience and everyday life.

AYAs discussed their need to have these conversations in spaces where they don't feel the need to "defend" (Whisper) or "justify" (Auntie) their experiences—something they encountered in the creative series. Nellie writes:

> Taking part in the creative series came at an interesting time for me. I would say that I have spent most of my life dimly aware of race, as in I do not want my racial identity to be an issue or a problem. So I did not spend much time thinking about it. This changed for me with the public murders of George Floyd, Breonna Taylor and many others in the US, along with the COVID-motivated racial attacks on Asian Americans and Canadians. It was like: I can no longer ignore this. It dawned on me that racial injustice has always been a part of my life, and I want to be able to think critically about it. I want to be able to walk in the world as an anti-racist (Kendi, 2020), and use my Chinese Canadian identity to dismantle rather than uphold white supremacy (Oluo, 2019). So with a new lens on society, I was ready to turn my focus on the cancer healthcare system and my role within it, I just needed people to do it with.

The unique space created for racialized AYAs in this study is captured in a photo taken by Whisper during one of the creative series activities. They described the photo as follows:

> I took this picture of fibre (that I had blended) ready to be spun into yarn. Looking at it again, I appreciate how the colours in the fibre are both varied and subdued, how their cloud-like forms are full-bodied but look light as air, and how the length of this cloud looks like it is transformed so easily into a compact thread. The cloud bundles form a circle like they have come together to gather, much as I imagine we have. We share many things in common, but we are each unique, stunning, and vital. (Whisper)

Figure 2. Wool for the Tapestry

In this study, racialized AYAs expressed a deep desire to build community with one another. What stood out as particularly significant was that this sense of togetherness was meaningful because it allowed them to openly critique the unjust systems they were navigating.

To Imagine Desired Futures

For young people diagnosed with cancer, the idea of a future is fraught with complexity. Questions arise about the quality of the futures they may have, or if they will have a future at all (Chisholm et al., 2018; Jones et al., 2020; Lane et al., 2019). For instance, AYAs worry about cancer recurrence (Lane et al., 2019) and how their lives may compare to those without a cancer diagnosis—especially in terms of having a family, home, partner, financial security, and more (Young Adult Cancer Canada, 2023). Moreover, it is well-documented that AYAs are at high risk for long-term physical and psycho-social consequences (Jones et al., 2020). While futures remain uncertain and, based on what is known, may seem undesirable, AYAs in this study emphasise the importance of imagining the futures they do desire. This act resonates with queer scholar José Muñoz's concept of queer futurity (Muñoz, 2009). In his book *Cruising Utopia: The Then and There of Queer Futurity*, Muñoz argues that queer futurity involves an aspirational and imaginative engagement with the future, where queers envision and strive for a world that transcends the limitations and exclusions of the present (Muñoz, 2009). Relevant to this study, Muñoz emphasizes that performing or imagining utopian possibilities can have real-world implications, inspiring change and creating spaces where identities and desires can flourish.

When describing their desired futures, AYAs imagine them as vibrant and filled with joy, imagining themselves as whole and complete. Nellie writes:

> I imagine that I can be affirmed in who we are and celebrate the joy in being ourselves. We can be joyful and also ask for more from our healthcare system, not to mention the world at large. We can reflect on our experiences together and come away with a deeper understanding. We can heal our spiritual selves maybe. We can centre our own experiences, and get to know how that feels. Not feeling like that is asking too much, that it is just right. We can lift each other up. We create the space and define the parameters. I'm not sure how to manufacture this, but the creative series community felt so good to be a part of. I want every racialized young adult to have that same uplifting experience. There's nothing wrong with who we are or with taking up the space that others enjoy. We can share in our happiness, in our dreams, in our anger, and our hope.

In cancer care systems that might treat racialized AYAs as disposable, Muñoz helps us think about how we might imagine otherwise. The work of queer futurities (Muñoz, 2009), read alongside Indigenous feminist theorizing of worlding or world-making (Kimmerer, 2013; Simpson, 2017) and Black theorizing of Afrofuturism (Dery, 1994; Kaler-Jones, 2022) deepens our understanding of the significance of imagining futures for racialized young people. This theorizing emphasizes the need to create futures that are not only meaningful but also affirming, allowing communities to reclaim agency and envision transformative paths forward.

In the creative series, AYAs discussed what *care* could look and feel like, and how, through their time together, they lived it: "a people-centred care system. One starkly different, centred in love and radical empathy" (Gold). As Vinesha reminds:

> We can create our own circles of true care and love, as illustrated in the last 6 weeks. Cancer has already decimated our lives almost ten times over, and yet here we gather, in the middle of summer, busy finding that true, glorious light and community we really needed via our online screens and in the comfort of our homes.

Building from ideas of queer futurity and radical care, Black scholar Cierra Kaler-Jones (2022) affirms what she calls future dreaming. She and her co-researchers argue that Black girls—and in our work, we extend to racialized young people—deserve futures where joy, creativity, equity, and love are at the center (Kaler-Jones, 2022). Nellie writes:

> What I'm envisioning for the ideal future in cancer care is clear communication and validation. I don't want our identities to be a burden, too heavy to wield, or to be simply ignored. I want our existence to be validated, immediately and without question. I want us to feel like we can speak up, like we can use our voice, like we can take up space. We deserve care.

Like Nellie, racialized AYAs emphasize the significance of imagining futures filled with radical care, empathy, and joy.

Conclusion

In this paper, we argue that to improve how cancer care systems and research processes serve racialized AYAs, healthcare practitioners and researchers must examine how they invite meaningful participation from those who have long been excluded. We urge healthcare practitioners and researchers to understand AYAs with complexity, not merely as statistics, and to do so in care-filled and careful ways. Under such conditions—surrounded by community and given space for easeful creation—racialized AYAs will be better positioned to imagine the futures they desire, even amidst uncertainty. This study teaches us that, within the context of cancer care research and practice, racialized AYAs want to be acknowledged as experts and agents of change in their own complex lives. When invited to contribute in creative and caring ways, they offer valuable insights that can improve cancer care and support for racialized AYAs and AYAs more generally. Amidst the complexities of navigating cancer as a racialized AYA, they seek meaningful opportunities to create change.

Declarations

The authors have no competing interests to declare.

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Appendix: "We Are From" Poems

We are from a Little Mix of everything and everywhere.
We are from the Carribean and also the ones who colonized them.
We are from the land of fish and chips but also fried dumplings.
We are from beautiful **waterfall**s and where water falls.
We are from beautiful, sunny days were you want to lay out, as well as, grey, rainy days where you want to curl up.

We are from Pakistan—India… or maybe Kashmir…
We are from jasmine blossom garlands
heavy with the hopes of our futures
permeating blood/brain barriers with their intoxicating scent.
We are from rushing rivers, aromatic soils, and jutting mountains of a motherland whose memory is as shrouded in fog as are its valleys.
We are of the healing spices of haaldi dood
a cultural staple we could only appreciate
once it was appropriated and reintroduced to us as "golden milk".
We are from maple syrup sweetening that golden milk
cradled in our hands
warming us with the knowledge that we belong to each other
more than any land could belong to us.
We are from each other
and we are **stardust**
and we are children
and we are aching
and we are healers
and we are each others liturgies for a life worth living.

We are from dirt roads, hot, dusty **wildflower**s.
We are from mosquitoes and sandflies. Itchy skin. Red welts.
We are from Pow Wow. Matching clothes. Bubble gum ice cream.
We are from water fights. Red rose tea. Warm summer nights.

We are from loving hands. Sisters. Brother.
We are from cigarette smoke. Motor oil and my dad's sweat.
We are from George Jones singing and my mom who works so hard.

We are from a place of stories
told in hushed tones.
We are from a place I have experience only in **whisper**s.
We are from a place my ancestors were physically beaten
they fled in the middle of the night
and we are never going back.

We are from fiery sunlight baptizing the land with a touch of brilliance, mirroring that
we are from people forged by oppression into **gold**. (Tamil peoples).

We are from the lands of trees and water.
We are from a place of ancient artifacts.
We are from where fields of crab apples grow wild.
We are from where the sky is full of night stars.
We are from the River Valley where **fiddlehead**s grow.
We are from where the train soothes the night.
We are from the land of tiger lillies.

Note: 2 AYAs were not present to engage in this activity and 1 AYA chose not to include their poem in the research.