Revolutionizing a cancer care and support ecosystem in British Columbia unique to adolescents and young adults

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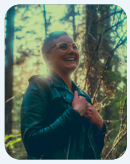
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Globally, the incidence of cancer in adolescents and young adults (AYAs) is rising significantly and cancer care systems often fail to meet their unique life-stage needs. For many AYAs, dying from or surviving cancer is influenced by their intersecting social identities alongside health system factors, resulting in significant inequities in AYA cancer care. Further, AYAs want to contribute to improvements in their care, yet have few opportunities to do so. In this article, we argue that to develop AYA-focused programmes there are important guiding principles for consideration to revolutionize AYA cancer care and support and respond to the holistic needs of AYAs.

Globally, over 1.3 million adolescents and young adults (AYAs), between the ages of 15 to 39 are diagnosed with cancer each year *(1–3)*, and the incidence of cancer in AYAs is on the rise *(1,4–6)*. AYAs have distinct medical and psychosocial needs that differ from children and older adults *(1,4–8)*; yet, cancer care systems often have limited capacity to respond *(5)*. This gap widens in lesser-resourced countries and is further amplified by an AYA's intersectionality (e.g., race, age, sex, gender, culture, socio-economics, geography, family) and access to healthcare *(2,9–11)*.

In this article, we, a group of participatory, arts-based researchers and people with lived experience with cancer as AYAs, share important guiding principles to help revolutionize AYA cancer care and support ("AYA care") and respond to the holistic needs of AYAs. We begin with an orientation to the distinct realities of AYAs globally. We then briefly share about our work to transform AYA care, before advocating for the adoption of guiding principles to shape and inform AYA care globally in research and praxis.

Adolescent and young adult cancer care and support

By definition, AYAs are classified as anyone diagnosed with cancer between the ages of 15 to 39 *(6)*. AYAs with cancer face unique clinical and life stage challenges compared to children and older adults (1,4–8). A cancer diagnosis thrusts AYAs into a medical environment misaligned with their life stage and coincides with major life transitions such as entrance to post-secondary education or employment, independent living, marriage and partnerships, parenthood, or caring for ageing relatives *(1,4–8)*. Further, it brings added anxieties and psychosocial impacts *(12,13)* including fear of early death *(12,13)*, infertility *(14)*, social and financial disruptions *(15,16)*, social isolation *(7,12,16,17)*, and fear for the future *(12,16–19)*.

Despite the distinct needs and realities of AYAs, cancer care and support for AYAs is often inconsistent and fails to respond to their needs *(1,4–8)*. Further, the annual diagnoses of cancer in AYAs are markedly rising *(20,21)*. AYA cancers are poorly understood *(5)*, pathways to diagnosis are generally prolonged meaning AYAs frequently present with advanced disease *(1,4–7)*, and AYAs continue to have limited access to clinical trials *(22)*. Although most AYAs are expected to survive, AYA survivorship outcomes have not seen similar improvements compared to other populations *(23)*, and in survivorship, AYAs often face physical and psychosocial challenges impacting quality of life and healthcare systems *(5,7)*. There is urgency for AYA-specific care that responds to the unique needs of AYAs

and supports them to survive and flourish.

Globally, there is an increased interest in AYA care *(6,24–26)*. For example, the American Society of Clinical Oncology recommends comprehensive and coordinated care and support for AYAs alongside specialized training for clinicians working with AYAs *(24,25)* and, in several higher resourced countries (e.g., United Kingdom, Australia), AYA care is standard practice *(25,26)*.

Despite global movements to advance AYA care, significant inequities remain *(1,2)*. In lesser-resourced countries, AYA cancers are more likely to be advanced and fatal *(2)*, and specialized AYA care is often non-existent *(2)*. These inequities are amplified by an AYA's intersectionality and access to healthcare. There is an urgent need to address global health disparities and improve cancer care for AYAs who consistently "have been under-recognized, under-diagnosed, and under-served" *(2)*.

Lastly, evidence suggests AYAs want to play an active role in contributing to change and have tangible recommendations to facilitate improvements *(27–29)*. Yet, AYAs rarely have opportunities to share their insights and this lack of engagement is further pronounced in non-curative contexts *(27)*.

"AYA cancers are poorly understood, and AYAs face unique challenges navigating cancer in their lives. More needs to be done to understand and address cancer for AYAs. I've lost too many friends and want to be part of the change." – AYA with cancer

To address the issues identified above and revolutionize AYA care, a new approach is required. We call for an approach that places AYAs at the heart of the process, which draws on their unique and diverse experiences, provides them opportunities to exercise their agency to shape and influence practice, and draws on the power of creativity and partnerships to facilitate change.

Our commitment to create change in AYA care

Over the last five years, we have been working together with AYAs and knowledge users (healthcare providers, decision makers, researchers, community organizations, funders, supporters) in British Columbia, Canada, to better understand the cancer care and support experiences, needs, priorities, and capacities of AYAs and knowledge users; build awareness, understanding, and support amongst knowledge users; and co-design comprehensive AYA care in research and programming.

Through engagements with AYAs and knowledge users, we have intentionally used arts-based and creative practices to generate knowledge, build understanding, and create conditions for change. For example, we used drawing, poetry, and video with AYAs to support them in sharing their experiences and perspectives about cancer care and support *(30–32)*, and worked with AYAs to co-design immersive theatre experiences for healthcare providers, decision makers, and other knowledge users to get a felt sense of what it means to navigate cancer as an AYA *(33)*. This work informed and shaped collaborations with AYAs and knowledge users to co-design initiatives and resources to improve AYA care, including the establishment of an AYA counselling pilot, AYA-specific resources, and an oncofertility programme that includes resources for both AYAs and healthcare providers, a care pathway, and a prompt in the electronic medical record *(34–36)*. We are now witnessing strengthened collaborations amongst AYAs and interdisciplinary knowledge users and building momentum to revolutionize and reimagine AYA care.

As we seek to apply our learning more broadly, we believe it is vital to draw on interdisciplinary research and expertise in innovative, creative, holistic, and inclusive ways to respond to the unique experiences, needs, priorities, and capacities of AYAs, and nurture their health and wellbeing across contexts. We highlight the following principles for consideration.

Guiding principles for revolutionizing AYA cancer care and support

Value the wisdom of AYAs and knowledge users. Research indicates AYAs have a clear understanding of how their cancer experiences can be improved and want to play an active role in doing so *(28,37)*. Yet, historically, AYAs have had little opportunity to share their insights with cancer care systems and contribute to transformative change *(29)*. Of the AYA programmes developed in Canada, AYAs had have limited engagement in programme co-design *(29)*. Yet, literature from patient-oriented research and knowledge translation (KT) demonstrates that relevant patient and stakeholder engagement can improve research quality, healthcare practice, KT efforts, informed health decision-making, and patient reported outcomes *(29,38–46)*. Further, engagement of AYAs with an uncertain future can develop new skills and insights, build networks, promote self-confidence, and contributes to legacy building *(27)*. To create meaningful change in AYA care, it is essential that AYAs and knowledge users are meaningfully engaged as partners and collaborators to co-design, implement, monitor, and evaluate initiatives and programmes. This includes being at the heart of arts-based approaches that challenge conventional paradigms of health research.

Address inequities and enhances representation. Within research and healthcare practice generally, and in AYA-focused cancer care and support specifically, there remains a limited focus on understanding and improving care for AYAs with diverse intersectional identities *(47–50)*. Evidence suggests that AYAs with certain facets of identity are particularly

underrepresented and underserved in research and practice, i.e., younger AYAs *(4)*, AYAs who live rurally and remotely *(51,52)*, AYAs who identify as 2SLGBTQIA+ *(53,54)*, AYAs who identify as Indigenous *(55,56)*, racialized AYAs *(30,31,56)*, and AYAs with advanced cancer *(57,58)*. Further, as Kimberlé Crenshaw explains in her theory of intersectionality, the overlapping, intersecting nature of identities (e.g., age, sex, gender, race, class, geography, disability) and how they intersect and reflect social structures of oppression and privilege amplify inequities *(59–61)*. In addition, healthcare systems and practices have a longstanding history of being discriminatory, oppressive, and in some cases harmful to individuals with diverse intersectional identities

In our work, we intentionally work with AYAs who have been historically and systematically excluded, marginalized, and underserved because of their identities *(30,31,47–51,53–61)* to better understand their lived experiences; interrogate health systems and practices; and co-design programmes, initiatives, and systems that better respond to the needs and realities of AYAs with diverse intersectional identities. For example, we engaged racialized AYAs to use arts and creative processes to explore their experiences with cancer care and support and identify solutions to improve their care *(30,31)*, and we are working with AYAs living in rural and remote communities to explore how to better respond to their distinct needs in both research and practice. In all our research efforts, we work intentionally to engage AYAs with diverse experiences and intersectional identities, and we strive to ensure that members of our research teams are from communities who are historically excluded or underrepresented in research and practice. As we approach research and programming, we must commit to meaningfully engage AYAs with diverse intersectional identities to understand their experiences, needs, priorities, and capacities; interrogate the systems that provide care and support; and co-design equitable solutions. We must recognize the crucial importance of building a care system where AYAs with diverse intersectional identities see their identities are valued and represented in the people, services, cultures, practices, and systems.

Extend along the continuum of cancer care. In theory, cancer care and support extends along the continuum of cancer including prevention and screening, diagnosis, treatment, post-treatment care and survivorship, and end-of-life care. Yet, AYA programming and research tends to focus on active treatment phases, with limited focus on the other phases of care and on the continuity of care across phases *(62)*. There is a need to provide cancer care and support to AYAs across the continuum of cancer.

Span across geographies and organizations. The AYA care landscape is vast and diverse and involves many organizations and players. Simultaneously, AYA care often straddles both pediatric and adult care. Amidst this landscape, there is often limited integration and coordination across organizations (including community organizations) while healthcare systems are under pressure and strain. Further, pilot projects and specialized services (e.g., fertility services) tend to focus on AYAs in urban settings *(52)*; however, digital health innovations offer opportunities to expand access to care. As we develop AYA programmes globally, it is critical that we focus on partnerships to overcome borders (e.g., geographical and organizational) to reach all AYAs.

Include a focus on creative health. Cancer care and support efforts, and healthcare efforts more generally, often focus on medical interventions and treating disease rather than adopting a more holistic conceptualization aligned with the World Health Organization *(63)*. Adopting the orientation of creative health currently popularized in the United Kingdom shows promise, where creative health refers to creative approaches and activities that benefit health and wellbeing alongside more medicalized approaches *(64–66)*. This includes prescribing arts and creativity through social prescribing; exploring the role of the arts and creativity in the provision of care; considering the role and function of arts and creativity in research and professional development; and leveraging creative partnerships and community collaborations to improve health and wellbeing *(64–66)*. Broadening our perspectives to include a focus on creative health opens possibilities for innovation in AYA care and supporting the health and wellbeing of AYAs.

Apply creative approaches. Aligned with a creative health orientation, we argue for creative, arts-based approaches in health research, KT, and clinical practice. Arts-based and creative approaches use any form of art or creativity to collect, interpret, and/or share new knowledge *(67,68)*, and they can support meaningful participation by valuing the perspectives and insights of participants, provide opportunities for participants to exercise their agency and contribute in ways that feel meaningful and important to them, share perspectives that may be new or overlooked, and move beyond power imbalances that may exist *(67–71)*. In the context of health research, arts-based research practices are considered emancipatory or even radical in that they seek to amplify perspectives that are typically silenced or repressed *(69)*, can challenge injustices and inequities *(72)*, and challenge dominant research paradigms *(67)*. Through our work using arts-based and creative approaches with AYAs and knowledge users, we witnessed the capacity of arts and creativity to disrupt power imbalances and create changes in AYA care. There are unique opportunities to leverage creative approaches to envision a novel and revolutionary approach to AYA care that does not yet exist and to inspire interdisciplinary actors and cancer

care systems to respond to the unique experiences, needs, priorities, and capacities of AYAs.

Leverage medical knowledge and expertise alongside qualitative research. Research indicates that some cancers in AYAs are biologically distinct; however, research on AYA cancer remains sparse. For example, in Canada, only 0.4% of all cancer research focuses on AYA cancer *(73)* and AYAs often have limited access to clinical trials *(22)*. Further, clinician and patient reported outcomes suggest that AYAs can present with unique symptoms and respond to treatment differently compared to the average adult or paediatric patients *(1,5,6,74)*. There is an urgent need to leverage the specialized knowledge and expertise of genomic research, clinical trials, population-based studies, and biomedical research to explore and extend how to best tailor and target cancer care and support for AYAs while simultaneously engaging in qualitative, participatory research studies to understand the lived and living experiences of AYAs and identify patient-centred priorities and solutions for AYA care.

Leverage digital health innovations. Advances in technology – and digital health specifically – are rapidly transforming possibilities for cancer care and support *(75,76)*, and AYA's technical savviness and comfort position AYAs to access, develop, and leverage technology innovations along the cancer care continuum *(77,78)*. Opportunities for digital health innovations in oncology are vast and have the potential to improve patient experience and safety; facilitate patient engagement and empowerment; enhance patient interactions with clinicians and peers; streamline diagnoses and ongoing monitoring; improve clinical workflows, documentation and resource allocations; provide decision support for AYAs and clinicians; improve clinical trial access and monitoring; and enhance equitable clinical and supportive care, particularly for underserved AYAs and those who live in rural and remote locations *(75–79)*. Further, digital health and technology innovations offer creative ways to engage in research, improve cancer care, and facilitate KT *(80)*. It is important to explore and leverage technology and digital health innovations to revolutionize AYA care, while also recognizing the associated challenges and ethical considerations around privacy, equitable access, and responsible data *(77)*.

Adopt an ethic of care. As we seek to revolutionize AYA care, we recognize we have a responsibility to care for the wellbeing of AYAs in research and practice, and commit to applying an ethic of care to our work *(81,82)*. Based on our previous research projects, adopting an ethic of care means building AYA specific counselling support (or other culturally relevant supports) into all research budgets, ensuring participants have the means to access the supports they need throughout the research process; providing food in all group gatherings (e.g., grocery or food delivery cards for virtual gatherings, catered meals for in-person gatherings that meet participants' dietary and cultural food needs); providing compensation to AYAs for their time and expertise *(83)*; offering both virtual and in-person research opportunities to support more equitable access; ensuring venues are accessible; providing a secure internet connection; not scheduling events during cultural days and times of significance; building in time and space for prayer; offering child and family care; and ensuring participants do not incur out-of-pocket expenses. Adopting an ethic of care also involves providing opportunities to AYAs to showcase or extend existing capacities and develop new capacities. For example, we seek to leverage and build the existing knowledge, skills, and capacities of AYAs to create change (e.g., catering, graphic recording, professional communications, and counselling) and we are committed to hiring AYAs with the required project skills to effectively support projects. As leaders, researchers, and practitioners, we must commit to building knowledge, skills, and capacities of knowledge users and AYAs to develop the next generation of researchers able to address complex challenges in innovative, interdisciplinary, and novel ways and improve AYA care. As we seek to revolutionize AYA care, a commitment to adopting an ethic of care remains at the forefront.

Conclusion

In summary, as awareness about AYA cancer care and support grows and incidence of AYA cancer rises, we have a distinct opportunity to reimagine AYA care. These principles provide a strategic framework that can be responsive to local contexts and set a new agenda for global change in AYA cancer care and support in research and praxis. ■

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Alice O'Grady, PhD, is a professor of applied performance at the University of Leeds, United Kingdom. She is a member of the Creative Arts and Health Research Laboratory which explores inclusive arts-based and digital methodological innovation in healthcare and is leading the establishment of a creative health strategy in West Yorkshire. O'Grady's expertise in applied theatre lies in exploring performance as a means of facilitating social

agency, engagement, and expression. Her research explores participation across a range of health contexts and investigates how participatory practices are mobilized as embodied tools for engaging with and problematizing processes of research, resistance and representation.

Tiffany T Hill, MA, is a queer of colour interdisciplinary researcher, educator, and artist from the Pilipino diaspora. She is associate faculty in the Faculty of Interdisciplinary Studies at Royal Roads University. Her work builds and convenes critical knowledge about health and wellness, with particular attention to grief, social and racial justice, and systems change. Hill's research brings together critical grief studies, participatory action research, visual and arts-based methods, and indigenous feminist ethics to explore lived experiences of grief and possibilities for more just and responsive systems of care.

Jennifer Wolfe, BA, is research program coordinator for the Anew Research Collaborative supporting all projects to move forward in an effective and timely manner and contributing communications expertise. She holds a degree in communications and worked extensively with BC Cancer's Primary Care Program developing and delivering education to improve cancer care at the community level throughout BC/Yukon.

Kat Dornian, MSc, is a research assistant at Anew. They have led community-engaged, educational projects in museums, universities, and local communities to increase involvement in sustainability, science, and engineering among groups that have been historically excluded from formalized participation in those fields. For their master's programme in engineering, they investigated the role of mentorship for diverse students in engineering outreach programmes. Now, as a young adult living with cancer, they bring their design, communication, and facilitation expertise to support change in AYA cancer care and support.

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