

**UNIVERSITY OF MARYLAND SCHOOL OF NURSING  
CURRICULUM VITAE**

**Date Prepared:** October 21, 2025

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College	Howard University Washington, DC	May (2013)	BSN
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**Certifications:**

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2021-present Sigma Theta Tau International Honor Society of Nursing  
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**Professional training and academic career:**

2008-2013 Clinical Research Coordinator II, Children's National Hospital,  
Washington, DC  
2013-2017 Acute Care Float Pool Registered Nurse II, Children's National Hospital,  
Washington, DC  
2016-2018 Staff Civilian Registered Nurse, Walter Reed National Military Medical Center,  
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2017-present Research Nurse Coordinator/Registered Nurse, Children's National Hospital,  
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2020-present Respecting Choices Advance Care Planning Instructor/Consultant, Children's  
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## Publications:

1. Younge T, Moore H, **Thompkins JD**, Lyon ME. Parental Goals of Care for Children With Rare Diseases: A Content Analysis of Pediatric Advance Care Planning Conversations. *Am J Hosp Palliat Care*. 2025 Jul 2;10499091251356237. doi: 10.1177/10499091251356237. Epub ahead of print. PMID: 40601301.
2. Friebert S, Trujillo Rivera EA, Baker JN, **Thompkins J**, Needle J, Lyon ME. Pediatric Advance Care Planning and Adolescent Preparedness and Quality of Life: An RCT. *Pediatrics*. 2025;155(2):e2024068699 doi: 10.1542/peds.2024-068699. PMID: 39821687; PMCID: PMC11993244.
3. Lyon ME, Fraser JL, **Thompkins JD**, Clark H, Brodie N, Detwiler K, Torres C, Guerrero MF, Younge T, Aoun S, Trujillo Rivera EA. Advance Care Planning for Children With Rare Diseases: A Pilot RCT. *Pediatrics*. 2024 Jun 1;153(6):e2023064557. doi: 10.1542/peds.2023-064557. PMID: 38699801 .
4. Needle JS, Friebert S, **Thompkins JD**, Grossoehme DH, Baker JN, Jiang J, Wang J, Lyon ME. Effect of the Family-Centered Advance Care Planning for Teens with Cancer Intervention on Sustainability of Congruence About End-of-Life Treatment Preferences: A Randomized Clinical Trial. *JAMA Netw Open*. 2022 Jul 1;5(7):e2220696. doi: 10.1001/jamanetworkopen.2022.20696. PMID: 35819787; PMCID: PMC9277499.
5. Lyon, M., Friebert, S., Needle, J., **Thompkins, J.**, Grossoehme, D., & Baker, J. (2022). 18-Month Sustainability of FACE®-TC Pediatric Advance Care Planning for Teens with Cancer: A Longitudinal Randomized Clinical Trial. *Journal of Pain & Symptom Management*, 63(5), 850. <https://doi-org.proxy-hs.researchport.umd.edu/10.1016/j.jpainsymman.2022.02.027>
6. Bedoya, S. Z., Fry, A., Gordon, M., Lyon, M. E., **Thompkins, J.**, Fasciano, K., Malinowski, P., Heath, C., Sender, L., Zabokrtsky, K., Pao, M., Wiener, L. (2022). Adolescent and Young Adult Initiated Discussions of Advance Care Planning: Family Member, Friend and Health Care Provider Perspectives. *Frontiers in Psychology*, 2409.
7. **Thompkins, J. D.** (2021). Thompkins' Response to Morrison: Advance Directives/Care Planning: Clear, Simple, and Wrong (DOI: 10.1089/jpm.2020.0272) Morrison RS. Advance directives/care planning: Clear, simple, and wrong. *J Palliat Med*. 2020;23:878–879. *Journal of Palliative Medicine*, 24(1), 7. <https://doi-org.proxy-hs.researchport.umd.edu/10.1089/jpm.2020.0488>
8. **Thompkins J**, Needle J, Baker JN, Briggs L, Cheng YI, Wang J, Friebert S, Lyon ME. Pediatric Advance Care Planning and Families' Positive Caregiving Appraisals: An RCT. *Pediatrics*, 147(6), 1–10. <https://doi-org.proxy-hs.researchport.umd.edu/10.1542/peds.2020-029330>
9. Livingston, J., Cheng, Y. I., Wang, J., Tweddle, M., Friebert, S., Baker, J. N., **Thompkins, J.**, Lyon, M. E. (2020). Shared spiritual beliefs between adolescents with cancer and their families. *Pediatric Blood & Cancer*, 67(12), 1–9. <https://doi-org.proxy-hs.researchport.umd.edu/10.1002/pbc.28696>
10. Friebert, S., Needle, J., **Thompkins, J.**, Baker, J., Cheng, Y., Wang, J., & Lyon, M. (2020). Intersectionality of Gender and Poverty on Symptom Suffering Among Adolescents with Cancer (RP423). *Journal of Pain & Symptom Management*, 60(1), 227–228. <https://doi-org.proxy-hs.researchport.umd.edu/10.1016/j.jpainsymman.2020.04.091>
11. Grossoehme DH, Friebert S, Baker JN, Tweddle M, Needle J, Chrastek J, **Thompkins J**, Wang J, Cheng YI, Lyon ME. Association of Religiosity and Spirituality Factors with Patient-Reported Outcomes of Anxiety, Depressive Symptoms, Fatigue, and Pain Interference among Adolescents with Cancer. *JAMA*

- Netw Open*. 2020;3(6):e206696. doi:10.1001/jamanetworkopen.2020.6696
12. Friebert S, Grossoehme DH, Baker JN, Needle J, **Thompkins J**, Cheng YI, Wang J, Lyon ME. Congruence Gaps between Adolescents with Cancer and their Families Regarding, Values, Goals, and Beliefs in End-of-Life Care. *JAMA Netw Open*. 2020;3(5):e205424. doi:10.1001/jamanetworkopen.2020.5424
  13. V Lyon ME, **Thompkins J**, Fratantoni Karen, Fraser J, Schellinger S, Briggs L, Friebert S, Aoun S, Cheng Yao, Wang J. Family Caregivers of Children and Adolescents with Rare Diseases: A Novel Palliative Care Intervention. *BMJ Supportive & Palliative Care*. (July) 2019;0:1-10:10. doi:10.1136/bmjspcare-0019-001766.

#### **Selected Abstracts / Poster Presentations:**

1. Younge T, **Thompkins J (presenter)**, Moore H, Lyon, ME. Goals of Care and Treatment Preferences for Parents of Children with Rare Diseases, a Content Analysis of Pediatric Advance Care Planning Conversations. 17th International Family Nursing Conference. ID 163. Oral Presentation. June 18, 2025. Perth, Australia. (Accepted)
2. Younge T, Moore H, Wolfe K, Mahmood K, **Thompkins J**, Lyon M. Family Centered Pediatric Advance Care Planning for NICU and Palliative Care Providers: Training and Self-Efficacy. (April 2, 2025). Family Centered Pediatric Advance Care Planning for NICU and Palliative Care Providers: Training and Self-Efficacy. Poster Presentation. Research, Education and Innovation Week, Children's National Hospital, Washington, DC.
3. Younge T, **Thompkins J**, Moore H, Lyon ME. FACE-Rare: Goals of Care and Treatment Preferences for Parents of Children with Rare Diseases: A Content Analysis of Pediatric Advance Care Planning Conversations. (April 2, 2025). Poster Presentation. Research, Education and Innovation Week, Children's National Hospital, Washington, DC. #332.
4. Lyon ME, Baker J, Friebert S, Needle JS, **Thompkins JD**, Grossoehme D, Jiang J, Wang J. (April 19, 2023). Effect of FACE®-TC on Adolescents' Decisional Support, Preparedness, and Symptoms at 3- and 12- Months Post-Intervention. 12th Annual Research, Education and Innovation Week, Children's National Hospital, Washington, DC. ID#314.
5. **Thompkins J (Presenter)**, Ulrika Kreicbergs, Camila Udo, Charlotte Handberg. Symposium: Lesson's Learned During the COVID-19 and Beyond Pandemic For Children Living with Rare Diseases, Their Siblings and Families. 7<sup>th</sup> Public Health Palliative Care International Conference September 20-23, 2022.
6. Lyon ME, Needle J, Friebert S, **Thompkins JD**, Grossoehme D, Baker J, Jiang J, Wang J. (April 6, 2022). Sustainability of FACE®-TC pediatric Advance Care Planning for Teens with Cancer at 18 Months Post-Intervention. 11th Annual Research, Education and Innovation Week, Children's National Hospital, Washington, DC. Dr. Lyon was recipient of the Recognition Poster Award for Clinical Faculty Research (i.e. best abstract in its category, Clinical and Translational Research and career level, Faculty).
7. Lyon ME, Baker J, Friebert S, Needle J, **Thompkins JD**, Grossoehme D, Jiang J, Wang J. (April 6, 2022). Effect of FACE®-TC Advance Care Planning on Congruence in End-of-Life Treatment Preferences: RCT. 11th Annual Research, Education and Innovation Week, Children's National Hospital, Washington, DC
8. Lyon ME (presenter), Friebert S, Baker JN, Jennifer S. Needle JS, **Thompkins JD**, Iris Y. Cheng IY, Jichuan Wang J. The Effect of Family CEntered pediatric Advance Care Planning for Teens with Cancer (FACE-TC) on Congruence in Treatment

- Preferences between Teens and their Families: A Multi-Site Randomized Clinical Trial. Session # 020\_5-1. **Oral Presentation.** International Psycho-Oncology Society (IPOS) 2020 World Congress (August 12-15, 2020). Kyoto, Japan. Rescheduled to May 27-29, 2021.
9. Friebert S, Needle J, **Thompkins JD**, Baker J, Cheng I, Wang J, Lyon ME. (April 13, 2021). Intersectionality of Gender and Poverty on Symptom Suffering Among Adolescents with Cancer. Virtual presentation at the 10th Annual Research, Education and Innovation Week, Children's National Hospital, Washington, DC. Dr. Lyon was recipient of Award for Clinical Faculty Research (i.e. best abstract in its category and career level).
  10. Friebert S, Needle J, **Thompkins JD**, Baker JN (Presenter), Cheng YI, Wang J, Lyon ME. Intersectionality of gender and poverty on symptom suffering among adolescents with cancer. **Poster.** SIOP-20-742 52<sup>nd</sup> Congress of the International Society of Paediatric Oncologists (SIOP) Virtual Meeting October 14-17, 2020.
  11. Lyon ME, Friebert S, **Thompkins J**, Baker J (Presenter), Needle J, Cheng YI, Wang J. Let's Talk: quality of facilitator communication as a determinant of satisfaction with Family Centered pediatric Advance Care Planning for Teens with Cancer (FACE-TC pACP). Accepted as **Oral Presentation, presented as Virtual Poster.** SIOP-20-#755. 52<sup>nd</sup> Congress of the International Society of Paediatric Oncologists (SIOP) Virtual Meeting October 14-17, 2020.
  12. **Thompkins J**, Baker JN, Friebert S, Needle J, Wang J, Cheng YI, Lyon ME. Effect of FAMILY CENTERED (FACE) advance care planning (ACP) on families' appraisals of caregiving for their teen with cancer. 2020 American Society of Clinical Oncology (ASCO) Annual Meeting. (ASCO Virtual Scientific Program). J Clin Oncol 38: 2020 (suppl; abstr e22533) DOI:10.1200/JCO.2020.38.15\_suppl.e2253
  13. Friebert S, Needle J, **Thompkins J D**, Baker JN, Cheng Y, Wang J, Lyon ME. Intersectionality of Gender and Poverty on Symptom Suffering among Adolescents with Cancer. **Poster.** 2020 State of the Science in Hospice and Palliative Care March 20-22, 2020.
  14. Livingston L, Cheng YI, Wang J, Friebert S, Baker JN, Needle J, **Thompkins J**, Lyon ME. (March 18, 2020) Shared Spiritual Beliefs Between Adolescents with Cancer and Their Families: An Exploration of Social Determinants of Spiritual Well-Being. **Poster.** SRA Pre-conference on Adolescent Religious and Spiritual Development. Bi-Annual Meeting of the Society for Research on Adolescence. San Diego, CA. Remote presentation being scheduled.
  15. Grosseohme DH, Friebert S, Baker JN, Tweddle M, Needle J, Chrastek J, **Thompkins J**, Wang J, Cheng YI, Lyon ME. (March 18, 2020) The Importance of Religiousness through Meaning/Peace for the Physical and Mental Well-Being of Adolescents with Cancer. **Poster.** Society for Research in Adolescence (SRA). Pre-conference on Adolescent Religious and Spiritual Development. Bi-Annual Meeting of the Society for Research on Adolescence. San Diego, CA. Remote presentation being scheduled.
  16. **Thompkins J**, Cheng YI, Baker JN, Needle J, Friebert S, Wang J, Lyon ME. (March 18, 2020) Is My Cancer a Punishment From God? The Association of Religiousness/Spirituality on Physical and Psychological Symptoms among Adolescents with Cancer. **Poster.** SRA Pre-conference on Adolescent Religious and Spiritual Development. Bi-Annual Meeting of the Society for Research on Adolescence. San Diego, CA. Remote presentation being scheduled.
  17. Lyon ME, **Thompkins J**, Baker JN, Needle J, Cheng YI, Friebert S. Is it safe? Is it worthwhile? A multi-site randomized clinical trial of FAMILY CENTERED (FACE) pediatric advance care planning for adolescents with cancer and their families.2020

- American Society of Clinical Oncology (ASCO) Annual Meeting. ASCO20 Virtual Scientific Program. Poster Presentation & Abstract #10557. Remote presentation approximately May 29, 2020. *J Clin Oncol* 38: 2020 (suppl; abstr 10557)
18. Lyon ME, Friebert S, **Thompkins J**, Baker JN, Needle J, Cheng I, Wang J. (2020) Let's Talk: Quality of Facilitator Communication as a Determinant of Satisfaction with FAmily CEntered (FACE<sup>®</sup>) pediatric Advance Care Planning (FACE-TC pACP). Poster presentation cancelled due to COVID. *Journal of Adolescent Health*. In press.
  19. Lyon ME, Grosseohme DH, Baker JN, Friebert S, Cheng Y, Chrastek J, **Thompkins J**, Tweddle M, Wang J, Needle J. Relationship of spiritual constructs to mental health PROs in adolescents with cancer. DOI: 10.1200/JCO.2019.37.31\_suppl.136 *Journal of Clinical Oncology* 37, no. 31\_suppl (November 01, 2019) 136-136. Published online November 25, 2019.
  20. **Gaines Thompkins J**, Friebert S, Baker JN, Needle J, Cheng Y, Lyon ME. Effect of FAmily CEntered (FACE) advance care planning (ACP) on families' appraisals of caregiving for their teens with cancer. *J Pain Symptom Manage* 2019;57(2):446-447. PMID:30267845. Concurrent session 2019 Annual Assembly of Hospice and Palliative Care (AAHPM). Orlando, FL. Rated 4.7 on scale of 5 with 5 being best score (N=18 participants).
  21. Friebert S, Fratantoni K, Wiener L, Needle J, Fraser J, **Gaines (Thompkins) J**, Alderfer M, Lyon M. Introduction to a novel palliative care intervention for family caregivers of children and adolescents living with rare diseases. *J Pain Symptom Manage* 2019;57(2):366-367. 2019 Annual Assembly of Hospice and Palliative Care concurrent session with CME credit. Orlando, FL.
  22. Lyon ME, Grosseohme DH, Baker JN, Friebert S, Cheng Y, Chrastek J, **Thompkins J**, Tweddle M, Wang J, Needle J. Relationship of spiritual constructs to mental health PROs in adolescents with cancer. DOI: 10.1200/JCO.2019.37.31\_suppl.136 *Journal of Clinical Oncology* 37, no. 31\_suppl (November 01, 2019) 136-136. Published online November 25, 2019.
  23. Livingston J, Cheng Y, Wang J, Tweddle M, Friebert S, Baker JN (Presenter), Needle J, **Thompkins J**, Greenberg I, Lyon ME. Shared Spiritual Beliefs between Adolescents with Cancer and their Families: An Exploration of Social Determinants of Spiritual Well-Being. **Oral Presentation** SIOP19-1630. (October 25, 2019). 51<sup>st</sup> Congress of the International Society of Paediatric Oncologists. Lyon, France.
  24. **Thompkins J**, Greenberg I, Cheng Y, Baker JN (Presenter), Needle J, Friebert S, Tweddle M, J Wang J, Lyon ME. The influence of religious beliefs on symptoms of anxiety and depression among adolescents with cancer. **Oral Presentation** SIOP19-1630. (October 25, 2019). 51<sup>st</sup> Congress of the International Society of Paediatric Oncologists. Lyon, France.
  25. **Thompkins J (Presenter)**, Greenberg I, Cheng Y, Baker JN, Needle J, Friebert S, Tweddle M, J Wang J, Lyon ME. Religiousness/Spirituality among Adolescents with Cancer. (August 13-16, 2019). **Oral/Podium Presentation**. 14<sup>th</sup> International Family Nursing Conference. Washington, DC.
  26. Livingston J (Presenter), Cheng Y, Wang J, Tweddle M, Friebert S, Baker JN, **Thompkins J**, Greenberg I, Lyon ME. Shared Spiritual Beliefs between Adolescents with Cancer and their Families: An Exploration of Social Determinants of Spiritual Well-Being. (August 13-16, 2019). **Oral/Podium Presentation**. 14<sup>th</sup> International Family Nursing Conference. Washington, DC.
  27. **Thompkins (Gaines) J**, Cheng Y, Baker J, Needle J, Friebert S, Lyon ME. (March 13-16, 2019). Oral Presentation. Effect of FAmily CEntered (FACE) Advance Care

- Planning (ACP) on Families' Appraisals of Caregiving for their Teens with Cancer. Poster presentation at the 2019 Annual Pediatric Academic Societies (PAS) Meeting. Baltimore, MD.
28. Friebert S (presenter), Baker J, Needle J, **Thompkins J**, Cheng Y, Lyon ME. (March 14, 2019). **Oral Presentation.** What Do Adolescents Want? Values, Goals and Beliefs of Teens with Cancer. 2019 Annual Assembly of Hospice and Palliative Care. Orlando, FL. Abstract *J Pain Symptom Manage* 2019;57(2):378.
  29. Friebert S, Baker J, Needle J, **Thompkins J**, Cheng Y, Lyon ME (presenter). (April 27, 2019). Oral Presentation. *What Do Adolescents Want? Values, Goals and Beliefs of Teens with Cancer.* Platform/oral presentation at the 2019 Annual Pediatric Academic Societies (PAS) Meeting. Baltimore, MD. Rated 4.6 on scale of 5 with 5 being best score (N=71 participants).
  30. Livingston J, Cheng Y, Wang J, Tweddle M, Friebert S, Baker JN, **Thompkins J**, Greenberg I, Lyon ME. Shared Spiritual Beliefs between Adolescents with Cancer and their Families: An Exploration of Social Determinants of Spiritual Well-Being. (May 2, 2019). Poster #465, Dr. Baker presenting. Publication in *Pediatric Blood & Cancer*. 2019 ASPHO Conference of the American Society of Pediatric Hematology/Oncology. New Orleans, LA.
  31. Friebert S (presenter), Baker J, Needle J, **Thompkins J**, Cheng Y, Lyon ME. (March 14, 2019). **Oral Presentation.** What Do Adolescents Want? Values, Goals and Beliefs of Teens with Cancer. 2019 Annual Assembly of Hospice and Palliative Care. Orlando, FL. Abstract *J Pain Symptom Manage* 2019;57(2):378.
  32. Lyon ME, Wang J, Fratantoni K, Detwiler K, Cheng YI, **Thompkins JD**, Schellinger S, Summar M. (April 2, 2019). Poster. Living on the Precipice: The Journey of Children with Rare Diseases and their Families. Poster presentation at the 9th Annual Research and Education Week, Children's National, Washington, DC. #296.
  33. Lyon ME, Wang J, Fratantoni K, Detwiler K, Cheng YI, **Thompkins JD**, Schellinger S, Summar M. (October 15, 16, 2018). Living on the Precipice: The Journey of Children with Rare Diseases and their Families. *NORD 2018 Rare Diseases and Orphan Products Breakthrough Summit.* Washington, DC.
  34. **Gaines, J**, Wang J, Cheng YI, Lyon ME. (March 23, 2014) Does Spirituality or Religion Hinder or Help Adherence to Highly Active Antiretroviral Therapy Among Adolescents Living with HIV? Poster Presentation Society for Adolescent Health and Medicine Annual Meeting, Austin, TX How Are You Feeling? Abstract ID#113.
  35. **Gaines J**, Lere J, Jacobs SS, Greenberg J, Perez J, Lyon M. (March 5, 2012) Overcoming Barriers to Recruitment in a Dyadic Study of Adolescents with Cancer. Presented at Society for Adolescent Health and Medicine Conference. New Orleans, LA.
  36. Jacobs SS, Perez J, Briggs L, **Gaines J**, Lyon M. (August 11, 2011). Advocating for Adolescents: Family CEntered (FACE) Advance Care Planning. Poster presented at The Science of Compassion: Future Directions in End-of-Life and Palliative Care. National Institute of Nursing Research/NIH. Bethesda, MD
  37. **Gaines J**, Lere J, Jacobs SS, Greenberg J, Perez J, Lyon M. (August 11, 2011). Overcoming Barriers to Recruitment in a Dyadic Study of Adolescents with Cancer. Peer reviewed poster presented at The Science of Compassion: Future Directions in End-of-Life and Palliative Care. National Institute of Nursing Research/NIH. Bethesda, MD
  38. **Gaines J**, LaGrange R, Lewis M. (April 2010). Health Protective Behaviors of Adolescents Living with HIV/AIDS. Children's National Medical Center Washington D.C. Research Day. This work won Honorable Mention.
  39. LaGrange R, **Gaines J**, Marschall D, Lewis M. (August 2010). Self-Report vs.

Clinical Diagnostic Screening for Mental Health Needs in young people living with HIV. International Congress of Behavioral Medicine Washington D.C

**Professional awards and special recognitions:**

Ho Chiang Grant Pediatric Palliative Care Book Bundle for Hospice and Palliative Nurses  
Association Certification Exam

**Teaching responsibilities including continuing education:**

2023-present Adjunct Faculty, School of Nursing, The Catholic University, Washington DC  
2023 Adjunct Faculty, School of Nursing, George Mason University,  
Washington DC  
2022 Adjunct Faculty, School of Nursing, Howard University, Washington DC  
2021-2022 Adjunct Faculty, School of Nursing, Stratford University-Tysons Corner  
Campus, VA  
2020 Certified Advance Care Planning Instructor, Respecting Choices, A Division of  
CTAC Innovations, Washington DC

**Areas of research interests (basic and applied) - list:**

1. To find ways to alleviate suffering and provide support for children with life threatening illness
2. To advance our understanding of pediatric advanced care planning and the psychosocial impact of these important conversations

**External support - gifts, grants, and contracts:**

Past:

*Conway Nursing Scholarship*- Full tuition coverage for PhD in Nursing at the University of Maryland Baltimore

*The Suzanne Feetham Research Award*-\$1,000 to support the actual conduct of an IRB-approved study that was previously reviewed and approved by the Nursing Research Advisory Committee (NRAC) at Children's National Hospital

## **Abstract**

**Title of Dissertation:** Take a Moment to Breathe: A Multi-Methods Study to Build Supportive Interventions for the Psychosocial and Overall Well-Being of Adolescents and Young Adults with Cancer

**Jessica Denise Gaines Thompkins, Doctor of Philosophy, 2025**

### **Dissertation Directed by:**

Kim E. Mooney-Doyle, PhD, RN, CPNP-AC, FAAN, Associate Professor, Department of Family and Community Health, University of Maryland, Baltimore School of Nursing

**Background:** Adolescents and young adults (AYA) with cancer face significant physical and psychological challenges due to the nature of their diagnosis and treatment. High rates of psychosocial distress and post-traumatic stress can persist into survivorship, often exacerbated by adverse childhood experiences (ACEs) and social determinants of health (SDoH). This distress may lead to disengagement from treatment and poorer health outcomes. Despite its impact, there is limited research describing the nuanced psychosocial experiences of AYA with cancer and few tailored interventions exist to support their mental health needs especially considering the compounding effects of SDoH and ACEs.

**Purpose:** This study aims to describe the psychosocial well-being and distress experienced by AYA with cancer (ages 12–21) and to identify perceived barriers and facilitators to managing that distress. The findings are intended to inform the development of targeted, developmentally appropriate psychosocial interventions that support resilience and reduce suffering.

**Methods:** The dissertation includes three manuscripts. The first is a scoping review using Arksey and O'Malley's framework and PRISMA-ScR guidelines to examine the scope and effectiveness of mindfulness-based interventions (MBIs) for adolescents with cancer. The second is a multi-methods pilot study assessing anxiety, depression, ACEs, SDoH, and mindfulness traits among 25 AYA with qualitative interviews exploring lived experiences and coping strategies. The third manuscript describes the use of community-based participatory research (CBPR) to co-develop components for a supportive care toolkit with input from a community advisory board (CAB) of AYA with cancer.

**Results:** The scoping review identified 27 studies showing MBIs are feasible and well-received, especially in digital formats. The pilot study found that increased anxiety and depression were significantly associated with lower mindfulness scores. CAB members helped refine study tools and co-designed a flexible, engaging toolkit that included individualized mindfulness sessions, video game-based coping strategies, and portable resources adaptable to treatment settings.

**Conclusion:** This dissertation highlights the psychosocial challenges AYAs face and the promise of MBIs and participatory approaches in addressing their needs. Findings support the development of flexible, culturally responsive, and developmentally appropriate interventions to promote resilience and improve quality of life.

Take a Moment to Breathe: A Multi-Methods Study to Build Supportive Interventions for  
the Psychosocial and Overall Well-Being of Adolescents and Young Adults with Cancer

By: Jessica Denise Gaines Thompkins

Dissertation submitted to the Faculty of the Graduate School of the  
University of Maryland, Baltimore in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
2025

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## **DEDICATION**

To my mother, Cynthia

For your endless love, encouragement, and belief in my dreams

We've walked this road together, and we've made it through hand in hand.

## ACKNOWLEDGMENTS

I am profoundly grateful to my advisor and dissertation chair, Dr. Kim Mooney-Doyle, for your invaluable guidance and for reminding me to “not let the perfect get in the way of the good.” Your professional and personal support has been instrumental throughout my PhD journey. I also extend heartfelt thanks to my dissertation committee, Dr. Debra Scrandis, Dr. Kristen Rawlett, Dr. Vicki Freedenberg, Dr. Erika Friedmann, and Dr. Maureen Lyon for your dedication and commitment to my success. Dr. Kirsten Corazzini, who was the dean of the school during my admission, I am immensely grateful for your belief in me, I truly thank you.

To my mentors through my work at Children’s National Hospital, Dr. Maureen Lyon, Dr. Pamela Hinds, and Dr. Hemant Sharma, your wisdom, encouragement and stellar examples of leadership have inspired me to persevere and reach beyond what I thought possible. Your continuous support made the completion of this work possible. Dr. Lyon, thank you for all the experience in research you have shared with me over the past 17 years, as this foundation made this work possible. I am also deeply appreciative of Dr. Shana Jacobs and Dr. Catriona Mowbray for your consultation and assistance with study recruitment at Children’s National Hematology and Oncology Clinic, and to Ricki Weisbrot and Holly Deluca for your support with recruitment at the University of Maryland Pediatric Hematology/Oncology unit.

A sincere thank you to my mentor, Dr. Suzanne Feetham, for the research award that funded this study and consistent guidance you provided along the journey. Your generosity, words of wisdom, and belief in my work provided the opportunity and

resources necessary to pursue and complete my PhD in Nursing. Thank you for paving the way in Nursing Research.

I extend my deepest gratitude to my children, parents, siblings, and close friends, whose steadfast love and support have been the foundation of this journey. To my mother Cynthia Jackson, without you and Pop-William Jackson, Sr., this achievement would not have been possible. Thank you for your consistent belief in me and for taking this journey with me daily. Your devoted care and daily love during my own adolescent cancer experience instilled in me the resilience and compassion that have guided me through every step of this work. Mom, my role as your caregiver during your own cancer diagnosis while completing this dissertation was both humbling and deeply grounding. It offered me invaluable reminders of the lived cancer experience and reaffirmed the importance of this work in supporting those facing life-threatening illness. To my brother Gregory, your daily motivational calls and constant encouragement sustained me through the most challenging moments. Your strength and unwavering commitment to supporting our family has been a powerful example of love in action, and I am deeply grateful to both you and my sister Alexandra.

To my beloved children, Eian and Nia thank you for your patience and understanding as I worked late nights and weekends, often during our cherished time together. Your companionship as we sat side by side, each immersed in our own work, was a profound source of motivation. I love you both deeply and with all of my heart.

To my “village”, your enduring support and unconditional love have been my guiding light. To my friends, thank you for being pillars of strength and sources of joy. Brehanna, my sister-friend, thank you for being a compassionate listener and a source of

strength throughout this process; your presence has meant more than words can express. To Tamara and Deondra, thank you for the laughter, light, and the safe space you provided for me to simply be myself especially during moments when I needed to pause, breathe, and reconnect amidst the demands of this journey. To my friend, Dr. Brennan DuBose, thank you for your in-the-moment coaching and unwavering encouragement from the very start as your “no excuses” approach helped me stay focused and committed to making this PhD a reality.

To my classmates, your fellowship, resilience, and shared determination especially as we navigated the challenges of doctoral study during a global pandemic have been a source of inspiration and solidarity. Learning and growing alongside you has enriched this journey in immeasurable ways. And to all who believed in me, especially during moments of self-doubt, this work stands as a testament to your faith and a tribute to your patience and kindness.

Finally, I offer my deepest respect and gratitude to the courageous adolescents and young adults with cancer who participated in this study, and to the members of the community advisory board. Your voices and experiences are the heart of this work, and I am honored to have had the opportunity to learn from you.

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## LIST OF ABBREVIATIONS

<b>Abbreviation</b>	<b>Terms</b>
AYA	Adolescent and Young Adults
ACEs	Adverse Childhood Experiences
BCR	Building Community Resilience
CAB	Community Advisory Board
CAMM	Child And Adolescent Mindfulness Measure
CBPR	Community Based Participatory Research
MAAS	The Mindful Attention Awareness Scale
MBCT	Mindfulness-Based Cognitive Therapy
MBCT-C	Mindfulness-Based Cognitive Therapy for Children
MBI	Mindfulness-Based Interventions
MBSR	Mindfulness Based Stress Reduction
RCT	Randomized Controlled Trials
SDoH	Social Determinants of Health

## **CHAPTER 1: Background and Significance**

Recent estimates suggest 85,480 Adolescents and Young Adults (AYA) will be diagnosed with cancer in the United States this year and 9,380 will die (National Cancer Institute SEER Program, 2023). This number is only 5% of all cancer, making this population unique for building effective supportive care interventions that are driven based upon their own identified needs. AYA with cancer experience significant physical and psychological challenges due to the impact of living with life threat and treatment symptom burden (Wiener, Alderfer, & Hersh, 2011).

The impact of psychological and physical challenges can be experienced even more intensely for adolescents and young adults. Adolescence is a period of establishing self-identity and reliance on social supports from peer groups (Orben, Tomova, & Blakemore, 2020). The diagnosis of cancer during adolescence places a barrier on these critical life milestones. The COVID-19 pandemic exacerbated these psychosocial challenges due to the fear and anxiety surrounding living with a life-threatening illness while being immunocompromised and remaining in strict social isolation (Tran et al., 2023). In the post-pandemic context, families continue to experience financial instability and systemic barriers, which may significantly influence the implementation and sustainability of psychosocial interventions. Social Determinants of Health (SDoH) are likely to shape both the uptake and overall impact of such interventions among adolescents and young adults with cancer, underscoring the need for contextually responsive and equity-informed approaches.

Emotional distress such as anxiety and depression is an indicator of negative health outcomes as well as decreased quality of life in AYA with cancer (Sawyer,

Antoniou, Toogood, & Rice, 1997; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). In a study of cancer patients 7-21 years old, 37.4% of patients met the DSM-5 criteria for depressive and/or anxiety disorders (Yardeni et al., 2020). The first year of a cancer diagnosis is the most prevalent time for a diagnosis of anxiety and depression disorders with 48% for children and adolescents in a study that utilized self-report measures. Symptoms that contribute to this emotional distress reported by AYA were feeling tired, concern with appearance, decreased energy, pain, nausea, and lack of appetite (Hinds, Quargnenti, & Wentz, 1992; Collins et al., 2000). Feelings of alienation, changes in appearance and wanting to get back to school or work during the initial diagnosis period have been reported as significant issues related to the initial diagnosis period (Hedström, Haglund, Skolin, & von Essen, 2003; Decker, Phillips, & Haase, 2004). There is a deeper understanding of living with cancer as an AYA post pandemic and the psychosocial implications that warrant further exploration.

The Adverse Childhood Experience's (ACE) study suggests 61% of Americans experience at least one ACE such as neglect or abuse (Felitti et al., 2019). Recent research indicates more than half of adolescents with medical complexity, including cancer, have experienced two or more ACEs (Mooney-Doyle, Ventura Castellon, & Lindley, 2024). ACEs are well known to contribute to long-term negative mental and physical health from adolescence to adulthood (Chapman et al., 2004). Increased ACE exposure has been linked to increased difficulties in psychosocial adjustment (Sharkey et al., 2020). An investigation of a supportive care intervention promoting resilience in AYA with cancer found that 60% of the study sample had experienced one or more ACE, however this sample still found the resilience intervention effective (Healthy People 2030

Framework, 2023). We need to understand the prevalence of ACEs and their potential role in the life of AYA with cancer to implement effective supportive care interventions.

In addition to ACEs, we must consider the social determinants of health (SDoH) that our AYA with cancer are facing. Post-pandemic household incomes and inflation have placed families at a disadvantage across the globe. Families from low socioeconomic status with neighborhood and school safety concerns are further burdened psychosocially (Asare et al., 2018). Among racial and ethnic minorities, economic stability, access to health care, neighborhood environment, education and social context are all underlying factors that contribute to health disparities and health care outcomes (Asare et al., 2019; Phillips & Davis, 2015). Latinx or Spanish speaking families face additional difficulties due to language barriers, so to advance health care equity clinicians must address their specific needs as well. Structural barriers of school and neighborhood safety concerns combined with low socioeconomic status should be considered when offering effective sources of psychosocial support to AYA with cancer of all racial and ethnic backgrounds. Such intersections are not fully reported in the literature to date.

While there are several options to support AYA with cancer during an active diagnosis of cancer, clinicians can learn from their lived experience and what they deem as helpful from a supportive care intervention. Mindfulness Based Stress Reduction (MBSR) teaches AYA how to redirect attention to the present moment and remain non-judgmental towards one's thoughts and emotions (Hoge et al., 2020). Techniques taught with MBSR include yoga, deep breathing, meditation, and discussion of stressors (Hoge et al., 2020). MBSR has been shown to be clinically as effective as standard antidepressant medication in a sample of adult white females in a large multi-site

randomized trial (Hoge et al., 2020). MBSR is used in adult oncology patients with promising improvements in psycho-social well-being. Adults with advanced cancer benefited from mindfulness at any stage post-diagnosis (Zimmermann, Burrell, & Jordan, 2020). Feasibility and acceptability using a structured 8-week group intervention program was demonstrated within AYA who have cardiac disease using an AYA-tailored MBSR intervention (Freedenberg, Hinds, & Friedmann, 2017). Mindfulness has been studied in adolescents with cardiac diagnoses and with at-risk adolescents living at boarding school (Freedenberg, Hinds, & Friedmann, 2017; Rawlett, Friedmann, & Thomas, 2019).

Findings from these clinical trials suggest increased positive effect and decreased anxiety and depression levels amongst adolescents. While feasibility was demonstrated with the cardiac population, the at-risk youth sample demonstrated issues with retention due to disease severity and symptom burden. Most of these studies yielded similar results of reduced psychosocial distress post mindfulness, except one trial in which issues related to intervention design may have increased participant burden and led to decreased retention. As adolescents with cancer live longer into survivorship, the traumatic psychosocial impact can follow. Exploration of the experience of psychosocial distress, well-being and sources of support AYA with cancer face should be studied further to address some of the root causes and shared experiences.

A promising approach to building an AYA-driven supportive care intervention tailored to the individual needs of the population, especially racial and ethnic minorities, is to use a community-engaged approach. Community-engaged research privileges partnership between community stakeholders (AYA with cancer) and researchers in an equitable partnership designed to deconstruct the power differentials that typically exist

in academic-community relationships (Minkler, 2010; Betancourt et al., 2015).

Partnership engages the research team and community stakeholders in all aspects of the research process, beginning with identifying problems that need to be further evaluated to dissemination of results to the stakeholders and then the broader audience (Betancourt et al., 2015; Wallerstein & Duran, 2006). Community-engaged research focuses on respecting the understanding of the experiences of the individuals within the situational context and those with the knowledge from daily experiences with the phenomenon to be studied. Community-engaged research is well suited for eliminating health disparities among marginalized groups as it highlights their “unique language” (Wallerstein & Duran, 2006; Israel et al., 2010; Berge, Mendenhall, & Doherty, 2009; Stacciarini, Shattell, Coady, & Wiens, 2011). This study will utilize these methods to better understand the psychosocial wellbeing and sources of support AYA with cancer deem as helpful during an active diagnosis of cancer.

### **Significance**

AYA with cancer are a heterogenous population due to variances in cognitive and social development, differences in cancer diagnosis and disease severity. Yet AYA with cancer are all facing a tremendous burden of distress derived from their life-threatening diagnosis and existential experiences. This population has reached a developmental phase that seeks social interaction and support from peers. Unfortunately, this is not as attainable due to their diagnosis, treatment plan, symptom burden, and immunocompromised state which limits the typical social interaction achieved during adolescence. Compounded with the extensive social isolation driven by the COVID-19 pandemic, mental health has been severely impacted for all Americans and warrants

tailored interventions. Other considerations when finding a tailored approach to dealing with these issues are whether the child has exposure to ACEs and/or SDoH (Scott et al., 2021).

Without addressing these important variables and integrating their lived experience into intervention development, we may use an intervention that is not fully effective and miss opportunities to support AYA with cancer. This study will help advance the field by describing AYA experiences of psychosocial distress and perceived barriers and facilitators to their relief. Using this information, investigators will create an intervention that will help ameliorate their distress. For our AYA oncology care to be trauma-informed and a source of healing, we need this information so interventions can be targeted to different levels of risk among AYA. Results from this study may inform clinical practice to include supportive care interventions for this population to ultimately relieve the stress and burden AYA with cancer face as they journey through their diagnosis and beyond to survivorship. This is an upstream approach to intervene and help early in diagnosis to avoid long lasting turmoil for AYA with cancer.

The overarching goal of this study, guided by the transactional stress and coping theory, is to describe the experience of psychosocial well-being and distress among adolescents with cancer (ages 12-21 years), as well as the perceived barriers and facilitators to help their distress (Lazarus & Folkman, 1984). This evidence is critical to ensuring psychosocial interventions can be targeted to AYA levels of risk and resilience and more likely to alleviate psychosocial distress. Kazak and colleagues' Pediatric Psychosocial Preventative Health Model suggests that chronically ill children and their families need psychosocial support based upon their level of need and risk (Kazak, 2006).

The research team will use a community-engaged approach, partnering with an advisory board of adolescents who have cancer, using the evidence we gather to create targets for a supportive care toolkit grounded in the perspectives of AYA with cancer

**Aim 1. To quantify and explore relationships among anxiety, depression, adverse childhood events, social determinants of health, and mindfulness qualities.**

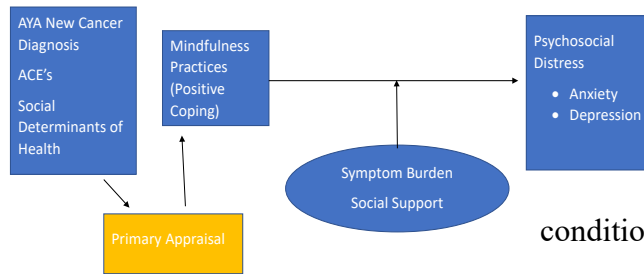
We will collect data (N=25) using validated measures in REDCap to describe these outcomes.

**Aim 2. To explore the psychosocial health, well-being, and distress of AYA with cancer during active treatment and sources of support AYA perceive as helpful.** We will conduct individual qualitative interviews with N=5 AYA to describe the experience of psychosocial wellbeing and distress of AYA with cancer, preferences for support, and challenges to psychosocial health and accessing supports.

**Aim 3. Determine targets and preferences for delivery and format of an AYA-focused intervention or supportive toolkit.** We will utilize qualitative and quantitative data from aims 1 and 2 along with our partnership with an adolescent patient community advisory board (N=10), comprised of AYA with cancer. We will elicit feedback from the community advisory board on aggregate findings to identify targets they deem important, modes of delivery, core components, and factors that enhance acceptability and feasibility of an AYA-focused intervention or toolbox to alleviate psychosocial distress and enhance psychosocial health and well-being. This content is vital in developing AYA-informed and focused interventions or tools that align with their preferences, address what is important to them, and potentially travel with AYA across settings of care.

## Theoretical Premise

**Figure 1.** Transactional Stress and Coping Theory-Adapted for Mindfulness Model for AYA with Cancer



Lazarus and Folkman's

transactional stress and coping

theory informs this study (See

Figure 1). It posits under

conditions of chronic and severe stress (e.g.

new cancer diagnosis) positive coping (psychosocial supportive intervention) facilitates positive reappraisals of the difficult situation, which help to support positive psychological states (Lazarus & Folkman, 1984). Interventions that can reduce the stress burden of cancer treatment may have the potential to improve both psychosocial distress and symptom burden AYA experience by practicing MBSR skills such as deep muscle relaxation, breath awareness, and yoga in the context of peer support (potentially an adapted MBSR intervention) while they are receiving treatment. We must learn from the experience of the AYA with cancer to find out what sources of support they deem helpful. There will be the exploration of MBSR and other supportive care interventions as we learn what AYA deem helpful. In addition, such intervention could have the added benefit of increasing engagement with the treatment plan and improving health outcomes. Once the cancer diagnosis is introduced, AYA immediately go into primary appraisal of this new life-threatening stressor and can experience intense distress. Intervening at this early stage can enhance positive coping by shifting appraisal of the situation. In this model, we acknowledge AYA may experience ACEs and may have an impact to SDoH; thus, we include these in the model to explore them as predictive

factors. Finally, once the positive coping mechanisms are in place, study outcomes should suggest lower psychosocial distress and enhanced coping.

### **Manuscript Methods**

The first manuscript (Chapter 2) presents a scoping review designed to identify key concepts, highlight gaps in the existing literature, and inform the future direction of this research (Munn, Stern, Aromataris, Lockwood, & Jordan, 2018). The findings from this review will be integrated with the empirical results of the current study to support Aim 3, which focuses on the development of a supportive care intervention toolkit tailored to the needs of adolescents and young adults with cancer. The research question guiding this scoping review is “What is known about the effects of mindfulness techniques (yoga, meditation, breathing) on suffering (anxiety, depression) in adolescents undergoing cancer treatment?” The scoping review explored the existing literature on what is known about the effects of mindfulness techniques on psychosocial suffering in adolescents undergoing cancer treatment. Using the JBI Methodological framework, our team searched PubMed, Embase, CINAHL, PsychINFO, Scopus, and Google Scholar, from 2010 to 2025.

The screening process to review abstracts and full text was completed using Covidence. Two authors (Jessica Thompkins and Susan Keller) screened all texts and conflicts were resolved by a third author (Kim Mooney-Doyle). Data will be presented in table format and synthesized in text. The following were key data points that were extracted from the text to be included in reporting:

- Author(s)/year of publication/participants (sample size)
- Study setting

- Study design (intervention)
- Main Findings

The second manuscript (Chapter 3) presents the findings of the pilot study, encompassing both quantitative and qualitative data. Eligible participants were adolescents and young adults (AYA) aged 12 to 21 years who were either undergoing active cancer treatment or within six months post-treatment. Additional inclusion criteria required participants to be at least two weeks post-diagnosis and proficient in either English or Spanish. This manuscript focuses on the characterization of anxiety, depression, ACEs, SDoH, and mindfulness traits among AYA diagnosed with cancer. Qualitative findings (Aim 2) are also reported, derived from in-depth individual interviews with AYA on active treatment or within six months post cancer treatment. All qualitative data have been de-identified to protect participant confidentiality.

The manuscript provides a comprehensive account of the psychosocial challenges experienced by AYA during cancer diagnosis and treatment. Results from the content analysis are presented in detail, highlighting key themes and patterns. Additionally, the study explores the types of social support that AYA identified as most beneficial during their cancer journey.

The third manuscript (Chapter 4) presents the methodological framework for the third aim of the study, emphasizing the innovation of engaging an AYA with cancer Community Advisory Board (CAB), both prior to and following data collection to co-create a responsive and contextually grounded intervention toolkit. The study design process included the development of eligibility criteria, recruitment strategies tailored to

the AYA population, and the selection of validated instruments to assess psychosocial, clinical, and demographic variables. Emphasis was placed on ensuring ethical rigor, feasibility for recruitment within clinical settings, and sensitivity to the unique developmental and emotional needs of AYA. This paper details the rationale behind key study design decisions, the targets for a supportive care toolkit as identified by AYA with cancer, and considerations for future research involving this vulnerable and understudied population. Finally, the manuscript incorporates feedback from the AYA community advisory board regarding the study findings and their preferences for the design, delivery, and format of a future AYA-centered intervention or supportive resource toolkit.

### **Summary**

This chapter presented the background, significance, and focus of this dissertation. Three interrelated manuscripts were prepared that collectively contribute to a deeper understanding of the psychosocial experiences of AYA with cancer and inform the development of a supportive care toolkit. The first manuscript, a scoping review, synthesizes existing literature on mindfulness-based interventions such as yoga, meditation, and breathing techniques and their effects on anxiety and depression in AYA undergoing cancer treatment. By identifying key concepts and gaps in the literature, this review provides a critical foundation for future research and directly informs the design of a developmentally appropriate support toolkit. The second manuscript reported findings from a multi-methods pilot study that examined the psychosocial burden experienced by AYA, including anxiety, depression, ACEs, and SDoH. Qualitative data from interviews further illuminated the types of support AYA find most meaningful during their cancer journey.

The third manuscript detailed the process of delineating the intervention targets, preferred delivery modalities, and format specifications for an AYA-focused supportive care toolkit, informed by empirical data, shaped through a multi-methodological research design, and guided by structured input from a CAB. This study emphasized ethical rigor, feasibility within clinical settings, and sensitivity to the unique developmental and emotional needs of this population. Together, these three manuscripts offer a comprehensive, evidence-informed perspective on the psychosocial challenges faced by AYA with cancer. They also underscore the importance of integrating both empirical findings and community voices into the design of future interventions. The insights gained from this body of work will directly inform the creation of a culturally responsive, patient-centered toolkit aimed at enhancing psychosocial support and improving quality of life for AYA navigating the cancer experience. Chapter 5, the final manuscript concludes this dissertation with a synthesis of chapters 2 through 4, application of the results of this research to nursing practice, and implications for future directions for further research based on the results of this pilot study.

## **CHAPTER 2: Mindfulness in Relation to Adolescent and Young Adults with Cancer Psycho-Social Suffering: A Scoping Review**

### **Background**

Cancer prevalence among Adolescents and Young Adults (AYA), defined as individuals aged 15–39, has significantly increased over the past three decades, with an estimated 85,480 new cases and 9,380 deaths projected in the United States for 2025 alone (National Cancer Institute, 2025). Although AYA represent only 4.2% of all new cancer diagnoses, cancer remains the leading cause of disease-related death in this age group (Howlader et al., 2019; Friebert & Williams, 2015). Despite improvements in five-year survival rates, the psychosocial toll of cancer during this critical developmental period is profound. AYA face unique challenges due to their transitional life stage, which includes identity formation, pursuit of independence, and establishment of social and romantic relationships. A cancer diagnosis during this time can severely disrupt these trajectories, leading to profound emotional, social, and psychological consequences (Zebrack & Butler, 2012; Clinton-McHarg et al., 2010).

Psychosocial distress among AYA cancer survivors is conceptualized in varied and often inconsistent ways across the literature, encompassing emotional distress, mood disturbances, trauma, stress, and overall well-being. This lack of a unified framework complicates both assessment and intervention. Moreover, psychosocial and physical health symptoms are deeply interrelated. Fatigue, nausea, pain, and cognitive impairments stemming from aggressive treatments like chemotherapy, radiation, and surgery not only disrupt daily functioning but also intensify emotional distress (Wolfe et al., 2000). The burden of these overlapping challenges is heavy for AYA to carry. Adding

to the complexity, research efforts continue to struggle with establishing a consistent conceptualization of psychosocial distress, which further hinders progress in care standards. This underscores the importance of examining psychosocial standards to guide more coherent and comprehensive approaches to support.

Psychosocial symptoms commonly experienced by AYA with cancer include anxiety, depression, sleep disturbances, social withdrawal, and post-traumatic stress (Osmani, V., et.al 2023; Weiner et al., 2011; Lee, 2006). The emotional toll of “missing out” on life milestones such as graduations, college experiences, travel, and family planning during a cancer diagnosis can lead to long-term psychological effects, including identity crises and existential distress. Cognitive impairments from cancer treatment therapies, such as memory loss and difficulty concentrating can affect educational and occupational performance, likewise social isolation while undergoing therapy may result from physical limitations, emotional withdrawal, or stigma associated with illness (Husson et al., 2018). Financial toxicity is another major concern, as AYA with cancer are often in the early stages of their careers or education and may lack adequate insurance coverage, leading to economic hardship and increased dependency on family (Cheung et al., 2023).

Fertility and reproductive health concerns are also prominent, with many AYA reporting inadequate information and support regarding fertility preservation. This uncertainty can affect romantic relationships and long-term life planning. Moreover, AYA from marginalized communities including racial minorities, LGBTQIA+ individuals, and those from rural areas face compounded psychosocial challenges due to systemic barriers such as limited access to care, mistrust in medical institutions, and

cultural stigma (Cheung et al., 2023). The psychosocial burden also extends to caregivers, who may experience stress, anxiety, and burnout, underscoring the need for family-centered interventions and peer support networks (Reuvers et al., 2023).

As survivorship rates increase, these psychosocial issues often persist beyond treatment, affecting quality of life and long-term adjustment. Therefore, interventions that address both the acute and chronic psychosocial needs of AYA are essential. One promising approach is mindfulness, which has emerged as a mind-body intervention to mitigate psychosocial distress in cancer populations.

Mindfulness is defined by the *Merriam-Webster Dictionary* as “the practice of maintaining a non-judgmental state of heightened or complete awareness of one’s thoughts, emotions, or experiences on a moment-to-moment basis.” Originating from Buddhist philosophy over 2,000 years ago, mindfulness was developed to alleviate human suffering. It encourages individuals to focus attention on the present moment while cultivating a non-judgmental awareness of their internal experiences (Matchim et al., 2011). Jon Kabat-Zinn operationalized this ancient practice into a clinical intervention Mindfulness-Based Stress Reduction (MBSR) in 1979 at the University of Massachusetts Medical School, targeting adults with chronic illness (Kabat-Zinn & Hanh, 2009).

MBSR incorporates meditation, body scanning, and gentle yoga to cultivate present-moment awareness and emotional regulation. It has demonstrated efficacy in reducing anxiety, depression, and stress in adult cancer patients and is increasingly adapted for pediatric and adolescent oncology populations. Preliminary studies suggest that MBSR is feasible and acceptable among AYA with cardiac conditions and with at-risk adolescents living in boarding school, with benefits including improved mood, sleep, self-esteem, and

coping capacity (Freedenberg et al. 2017; Rawlett et al. 2019). Moreover, national guidelines from the Society for Integrative Oncology and the American Society of Clinical Oncology now recommend mindfulness-based interventions as evidence-based strategies for managing anxiety and depression in adult cancer patients (Carlson et al., 2023).

Given the high symptom burden and persistent psychosocial challenges faced by AYA with cancer, further investigation into the application and outcomes of mindfulness-based interventions in this population is warranted. This scoping review aims to map existing research on mind-body interventions for pediatric and adolescent oncology populations, summarize intervention characteristics, and identify knowledge gaps to inform future clinical practice and research.

## **Methods**

### ***Scoping Review Protocol***

This scoping review was conducted using the methodological framework outlined by Arksey and O'Malley (Arksey & O'Malley, 2005; Levac et al., 2010) and guided by the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines (Tricco et al., 2018). The five-stage process for this framework included identifying the research question, identifying relevant studies, study selection, charting the data, collating, summarizing, and reporting results. The review protocol was registered at the Open Science Framework (Center for Open Science, 2023).

The research question for this scoping review was “*What is the scope and nature of existing mindfulness-based stress reduction (MBSR) interventions aimed at reducing*

*psychosocial suffering among adolescents aged 14–18 years diagnosed with cancer?”.*

This question was derived using the theoretical perspective of Lazarus and Folkman’s transactional stress and coping theory. The transactional stress and coping theory posits under conditions of chronic and severe stress (cancer diagnosis), positive coping (mindfulness techniques) facilitates positive reappraisals of the difficult situation, which help to support positive psychological states (Lazarus & Folkman, 1984).

### ***Search Strategies***

A structured literature search was conducted in collaboration with a health services librarian to identify studies evaluating mindfulness-based interventions designed to reduce psychosocial distress among adolescents diagnosed with cancer. The search strategy was developed iteratively to ensure comprehensive coverage. Citations were screened for cancers commonly affecting adolescents, including leukemia, lymphoma, sarcomas, and brain tumors. A detailed list of mindfulness-related practices such as meditation, yoga, deep breathing, and body scan techniques was compiled to guide the identification of relevant interventions. Studies were further filtered to include only those that implemented these practices as part of a formal intervention. To distinguish adolescent-specific research from pediatric and adult populations, the search was restricted to studies involving individuals aged 14 to 18 years. Intervention components or study “key ingredients” were defined as a set of activities or techniques that are utilized to get to a common goal (Sidani & Braden, 2021).

Databases utilized for this scoping review were PubMed, Embase, CINAHL, PsychINFO, Scopus, Google Scholar, Ovid, and Medline using keywords related to mind-body therapies, adolescents, and various cancer diagnosis. The search strategy

included terms related to “adolescents and young adults,” “cancer,” “psychosocial distress,” and “mindfulness.” Boolean operators (AND, OR) and truncation were used to refine results. Additionally, reference lists of included articles were hand-searched to identify any relevant studies not captured in the initial search.

### ***Eligibility***

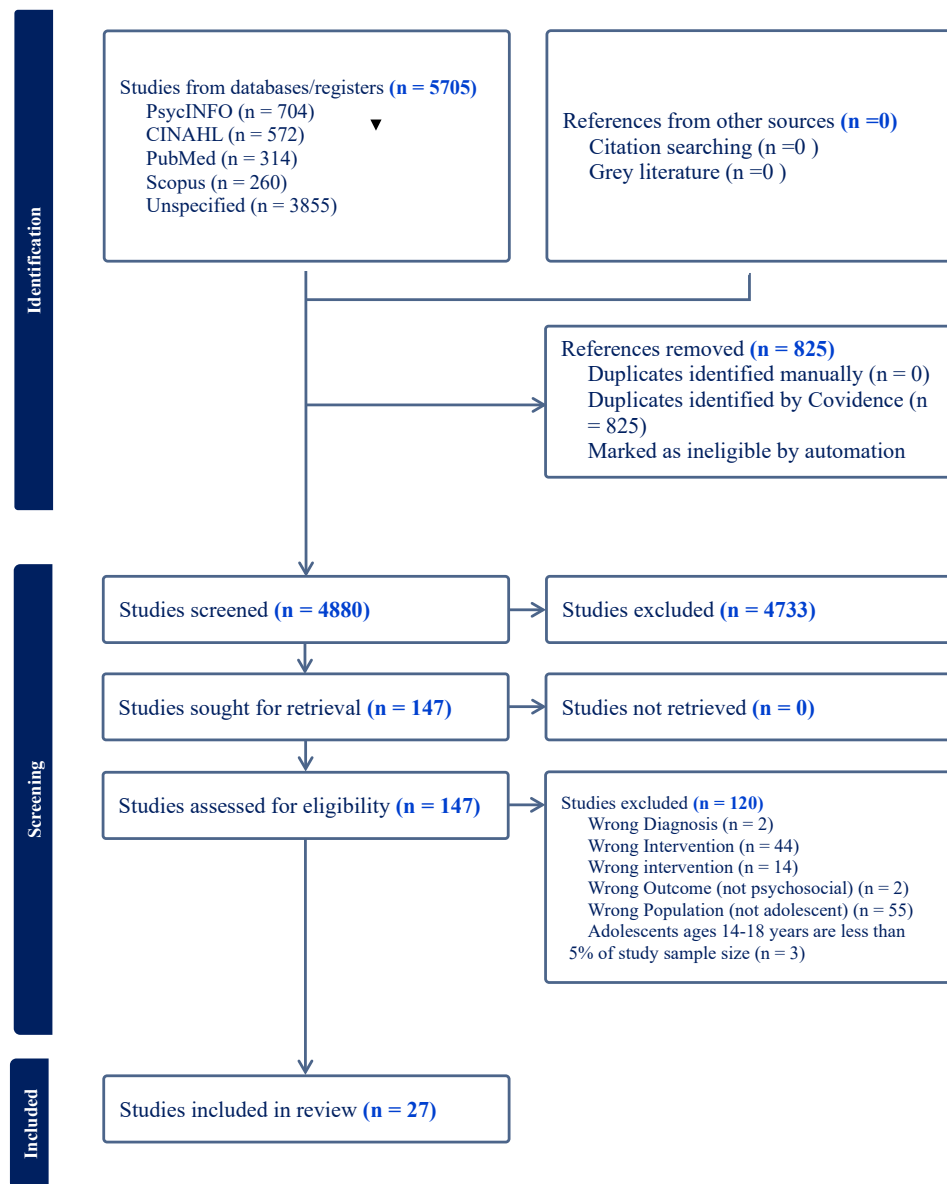
Studies that were peer-reviewed, published in English between 2010-2025, and reported on Mind-body intervention studies were considered for inclusion. Full text review articles and intervention studies were included. Several studies were excluded from this scoping review due to misalignment with the defined inclusion criteria. Specifically, studies that focused on populations outside the adolescent age range (14–18 years) were excluded, particularly when adolescents comprised less than 5% of the total sample size, thereby limiting the relevance of findings to this target group. Additionally, studies that did not involve participants diagnosed with any form of cancer were excluded, as the review is centered on cancer-related psychosocial outcomes. Furthermore, interventions that did not align with the operational definition of mindfulness were excluded. This includes studies that examined non-pharmacologic therapy modalities such as aromatherapy, music therapy, art therapy, walking exercises, writing, or journaling as a primary intervention. While these approaches may offer psychosocial benefits, they fall outside the scope of mindfulness-based interventions as defined (meditation, yoga, deep breathing, body scanning) for this review.

### ***Data Extraction and Charting***

Prior to initiating the study selection process, two authors convened to collaboratively develop the inclusion and exclusion criteria, as well as to establish a

scoping review protocol. Following the completion of database searches, all retrieved citations were imported into Covidence, a systematic review management platform, to facilitate organized screening and data extraction. Title and abstract screening was conducted independently by two reviewers, each assessing eligibility for progression to full-text review. In the subsequent phase, the same two reviewers independently evaluated the full-text articles for inclusion in the scoping review. Any discrepancies arising during either stage of screening were resolved through consensus meetings between the reviewers, with no unresolved conflicts reported. The screening process is visually represented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Figure 2). Each publication included in the final review was read in full, and key data were systematically extracted, including title, author(s), year of publication, methodology, study sample characteristics, and intervention outcomes (Appendix A). The resulting data matrix provided a structured framework for cross-study comparison and facilitated the identification and synthesis of emergent themes.

**Figure 2.** Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram



## Results

This scoping review identified a diverse range of studies examining mindfulness-based interventions (MBIs) in pediatric and adolescent oncology populations. The initial search identified 5,705 publications. After removal of 825 duplicates, 4,880 abstracts and titles were reviewed for relevance. A total of 147 studies were further evaluated for

inclusion/exclusion criteria. Finally, a total of 27 studies met inclusion criteria, encompassing randomized controlled trials (RCT), pilot feasibility studies, mixed-methods designs, and systematic reviews. The studies varied in geographic location, sample size, intervention format, and outcome measures. Studies varied in design, delivery format, offering a broad overview of current practices and gaps in the literature.

### ***Population***

Most studies targeted pediatric oncology patients that ranged from age 11–18 years, with some extending into the young adult range (up to age 25). Sample sizes were small, often fewer than 20 participants. There were few studies with quasi-experimental designs and larger sample sizes (n=60+). Notably, adolescents aged 14–18 years were underrepresented in many studies, often comprising less than 5% of the total sample, which frequently led to their exclusion based on predefined eligibility criteria.

Participants were typically in active treatment phases, though some studies included survivors or mixed-stage populations (Hehr et al., 2022; Walker et al., 2016). Settings included inpatient hospital units (Diorio et al., 2015), outpatient clinics (Stein et al., 2019), and community-based environments (Wurz et al., 2014). Digital interventions were often self-guided and accessed remotely, increasing feasibility for geographically dispersed populations (Donovan et al., 2019; Lau et al., 2024).

### ***Intervention Characteristics***

Mindfulness-based interventions (MBIs) were delivered through diverse modalities including in-person group sessions (Malboeuf-Hurtubise et al., 2013), individualized bedside programs (Abedini et al., 2020), mobile applications (Donovan et al., 2019; Lau

et al., 2024), and interactive e-books (Perumbil Pathrose et al., 2021). Several studies met the inclusion criteria for this scoping review by incorporating mindfulness practices alongside other therapeutic modalities, such as yoga (Wurz et al., 2014; Spector, 2021), music therapy (Knoerl et al., 2022; Liu et al., 2019), and complementary approaches like prayer and aromatherapy (Apriany et al., 2025). Core mindfulness components included breath awareness, body scans, meditation, and emotion regulation strategies.

Some interventions were adapted from established protocols such as Mindfulness-Based Stress Reduction (MBSR) or Mindfulness-Based Cognitive Therapy for Children (MBCT-C), while others integrated complementary elements to these established protocols. Intervention duration ranged from single sessions (Thygeson et al., 2025) to multi-week programs lasting up to 12 weeks (Wurz et al., 2014). Session frequency and length varied widely, with some studies offering daily sessions (Jacobs et al., 2021) and others weekly or biweekly formats. Adaptations were common to accommodate medical constraints, such as removing physical components like yoga in inpatient settings (Abedini et al., 2020). While all MBIs showed benefits, online MBIs with guided support and those integrated with other therapeutic modalities (ex. music therapy) demonstrated the most substantial effects on psychological outcomes. These findings suggest that delivery format and integration with expressive therapies may enhance effectiveness.

### ***Feasibility and Acceptability***

Across studies, MBIs were consistently reported as feasible and well-received, even in high-acuity inpatient settings. Adherence rates varied, with higher engagement observed in interventions tailored to developmental needs and delivered in flexible formats. Mobile-based interventions demonstrated particular promise for adolescents and

young adults, offering privacy, convenience, and scalability. Barriers to participation included treatment fatigue, scheduling conflicts, and travel distance, especially for in-person formats. Others demonstrated feasibility and acceptability without significant changes in outcomes, often due to small sample sizes or short intervention durations (Malboeuf-Hurtubise et al., 2015; Stein et al., 2019).

### ***Outcomes and Measures***

Psychosocial outcomes assessed across the reviewed studies included anxiety, depression, attention problems, stress, fatigue, and overall quality of life. Several interventions demonstrated statistically and clinically significant improvements in internalizing symptoms and attention regulation. For instance, Abedini et al. (2020) reported that a modified MBCT-C led to sustained reductions in anxiety and attention problems, with effects maintained at a two-month follow-up. Similarly, Liu et al. (2019) found that a combined mindfulness-based stress reduction and music therapy intervention significantly improved pain, anxiety, and sleep quality in adolescents with osteosarcoma.

Measurement tools varied across studies, with commonly used instruments including the Pediatric Quality of Life Inventory (PedsQL), PROMIS measures, and the Hospital Anxiety and Depression Scale (HADS). However, inconsistencies in outcome measures and a lack of standardized intervention protocols limited cross-study comparability and synthesis (Walker et al., 2016; Perumbil Pathrose et al., 2021).

Mindfulness-based interventions (MBIs) were generally associated with reductions in anxiety, depression, attention problems, and perceived stress. Improvements in emotional regulation and quality of life were also noted in several studies (Donovan et al., 2019; Knoerl et al., 2022). Notably, neuroimaging data from a pilot study by Hehr et

al. (2022) revealed decreased activity in the default mode network (DMN) during meditation, suggesting a potential neurological mechanism underlying the observed psychosocial benefits.

## **Discussion**

This scoping review synthesized findings from a diverse set of studies examining mindfulness-based and mind-body interventions in pediatric and adolescent oncology populations. The interventions varied in format, duration, and delivery method, including in-person sessions, mobile applications, and interactive e-books. Studies that were mobile-based, flexible in format to accommodate symptom burden (e.g., removing physical components like yoga when necessary), and integrated with other non-pharmacological modalities such as art therapy or music therapy demonstrated the greatest feasibility and psychosocial benefit.

These findings are corroborated by research in other clinical populations, such as adolescents with cardiac conditions, where similar interventions have shown promise. For example, Freedenberg et al. (2017) conducted a randomized controlled trial comparing a modified MBSR program to a clinician-led video support group for adolescents with congenital heart disease, cardiac devices, or postural orthostatic tachycardia syndrome. Both groups demonstrated significant reductions in illness-related stress, anxiety, and depression, with the MBSR group reporting additional benefits from learning specific mindfulness techniques that were applied in real-life situations to manage distress. Importantly, the study highlighted the feasibility and acceptability of delivering these interventions remotely via videoconferencing platforms, which is particularly relevant for

adolescents facing barriers to in-person participation due to illness, treatment schedules, or geographic limitations (Freedenberg et al., 2017).

In the broader oncology literature, MBIs including MBSR and MBCT are associated with reductions in anxiety, depression, fatigue, and improvements in quality of life and emotion regulation (Carlson et al., 2016; Piet et al., 2012). While most studies focus on older adult samples, these findings demonstrate underlying mechanisms and potential effectiveness that are relevant for AYA. Neuroimaging findings from Hehr et al. (2022) revealed decreased activity in the default mode network (DMN), suggesting a neurological basis for mindfulness effects. However, variability in outcomes was noted, often influenced by sample size, intervention fidelity, and measurement tools.

Modified MBSR interventions that incorporated adaptable modalities, such as music therapy and flexible session structures to accommodate symptom burden, demonstrated notable efficacy in AYA oncology populations. The significant improvements in anxiety, attention regulation, and sleep quality reported in studies by Abedini et al. (2020) and Liu et al. (2019) represent key therapeutic outcomes that can inform the design of future mindfulness-based interventions (MBIs) for adolescents and young adults (AYA) with cancer. These findings underscore the importance of tailoring MBIs to the unique physical and emotional needs of this population, suggesting that symptom-responsive and developmentally appropriate adaptations may enhance both engagement and clinical effectiveness.

Digital platforms, such as those utilized by Donovan et al. (2019) and Lau et al. (2024), demonstrate considerable promise for the scalable and acceptable delivery of MBIs in AYA oncology populations. These interventions were designed to be mobile-

accessible, asynchronous, and user-centered, allowing participants to engage with mindfulness content flexibly and independently. This format is particularly advantageous for AYAs undergoing intensive treatment, managing fluctuating symptom burdens, or facing logistical barriers such as transportation, immunosuppression, or scheduling conflicts.

Compared to traditional in-person formats, digital MBIs offer several distinct advantages. In-person interventions, while often more immersive and relational, require consistent attendance, physical presence, and access to trained facilitators, factors that may limit participation among AYA with complex medical needs. Studies such as Malboeuf-Hurtubise et al. (2015) demonstrated feasibility in clinical settings; however, they also noted challenges related to scheduling, fatigue, and attrition. In contrast, digital interventions can be accessed remotely, repeated as needed, and tailored to individual preferences, thereby enhancing both reach and adherence.

Moreover, digital platforms align with the technological fluency of AYA and can incorporate interactive features such as guided meditations, mood tracking, journaling prompts, and peer support forums. These elements not only foster engagement but also allow for real-time feedback and personalization. Importantly, studies reported high levels of user satisfaction and perceived benefit, suggesting that digital MBIs are not only feasible but also well-received by this population (Donovan et al., 2019; Lau et al., 2024). In a 2024 single-arm pilot study, 25 survivors aged 18–29 years used the *Ten Percent Happier* mindfulness app over six weeks, achieving an 84% retention rate and showing medium to large improvements in mindfulness, negative emotion, stress, mental health,

meaning and purpose, and sleep disturbance (Kwok, Sharma, Mandato, & Devine, 2024). This platform is a promising digital delivery modality to utilize for AYA with cancer.

Recent innovations in virtual reality (VR) and video game-based interventions further expand the potential of digital platforms in supporting psychosocial health among adolescents. VR-based mindfulness exercises have demonstrated significant reductions in anxiety and physiological stress markers, such as heart rate and electrodermal activity, while also enhancing engagement through immersive environments that promote a flow state and altered time perception which are factors known to improve therapeutic adherence (Olasz, Erdős, & Horváth, 2024). Interactive VR environments, as evaluated by Hanna et al. (2025), have shown to increase mindfulness scores and foster deeper emotional regulation and motivation among young users, particularly when users can personalize their experience and interact with calming virtual elements.

In clinical oncology settings, VR has also been used effectively as a distraction tool during painful procedures. For example, Wint et al. (2002) found that adolescents undergoing lumbar punctures who used VR glasses reported lower pain scores and described the experience as less distressing, with 77% indicating that the VR helped distract them from the procedure. These findings support the feasibility of VR as a non-pharmacologic adjunct to conventional care and highlight its potential to reduce procedural anxiety and improve patient experience.

Collectively, these studies suggest that integrating VR and gaming technologies into MBIs may enhance both scalability and acceptability by offering engaging, immersive, and developmentally appropriate interventions. Such approaches are particularly well-suited to the AYA population, who are digitally literate and often prefer self-directed,

interactive formats. Future research should explore the integration of VR and gamified mindfulness platforms in pediatric oncology to optimize therapeutic outcomes and broaden access to psychosocial support.

Perumbil Pathrose et al. (2022) described the co-development of a trauma-informed, user-centered mindfulness eBook, designed collaboratively with young people and healthcare providers. This digital intervention offered simplified, experiential content with modular, interactive features, demonstrating both feasibility and high content acceptability among adolescents and young adults (AYAs) with cancer. The trauma-informed design was particularly significant, as it acknowledged the psychological impact of cancer diagnosis and treatment, which can often result in post-traumatic stress symptoms and emotional dysregulation. By incorporating principles such as choice, transparency, and emotional safety, the eBook aligned with best practices in trauma-informed care, ensuring that mindfulness practices were accessible and non-triggering for participants.

Trauma-informed digital delivery appears especially well-suited to AYA, who often prefer technology-based formats that offer flexibility, autonomy, and privacy. This preference is further supported by the broader literature on trauma-informed mindfulness, which emphasizes the importance of adaptable, developmentally appropriate interventions that can be personalized to meet the unique needs of youth with complex medical and psychological experiences (Murphy, Muttillio, & Galletta, 2022). The eBook's design featuring options for engagement, simplified language, and non-directive guidance reflects a growing recognition that trauma-informed mindfulness must move beyond traditional protocols to accommodate the lived realities of AYA with cancer.

Together, these findings suggest that trauma-informed digital mindfulness interventions, particularly those co-designed with end users, hold significant promise for enhancing psychosocial support in pediatric oncology. They offer a scalable, acceptable, and psychologically safe modality that can be integrated into survivorship care and active treatment settings, potentially improving emotional regulation, resilience, and overall well-being.

A key finding across intervention studies in this scoping review was that adverse childhood experiences (ACEs) and social determinants of health (SDoH) were not consistently assessed or incorporated into the development of mindfulness-based interventions (MBIs). These contextual factors are critically important, as they shape the psychological vulnerability and coping capacity of AYAs with cancer. Exposure to ACEs, including abuse, neglect, and household dysfunction has been linked to increased risk of anxiety, depression, and post-traumatic stress symptoms, which may be exacerbated by the trauma of a cancer diagnosis and treatment. Similarly, SDoH such as socioeconomic status, access to care, housing instability, and systemic inequities can influence treatment adherence, emotional well-being, and engagement with psychosocial interventions.

Trauma-informed mindfulness practices, as described by Murphy et al. (2022), emphasize the need for psychological safety, choice, and transparency in intervention design. These principles are particularly relevant for AYAs with cancer, who may experience heightened emotional sensitivity and medical trauma. Given this landscape, further research quantifying relationships among mindfulness qualities, anxiety, depression, ACEs, and SDoH in AYAs with cancer is well grounded in both clinical need

and emerging evidence. The high acceptability of digital MBIs, feasibility signals, and the importance of tailored content support the inclusion of trauma-informed design principles, mindfulness-related constructs, and usability assessments as central to future intervention development. Despite promising findings, not all studies demonstrated statistically significant changes, highlighting the need for larger, more rigorously designed trials with standardized outcome measures, longer follow-up periods, and explicit consideration of contextual factors that influence psychosocial outcomes.

### **Strengths and Limitations**

This scoping review offers several notable strengths. First, it was conducted using a rigorous and transparent methodological framework, guided by the Arksey and O'Malley (2005) approach and enhanced by recommendations from Levac et al. (2010), ensuring a systematic and replicable process. The use of the PRISMA-ScR guidelines (Tricco et al., 2018) further strengthened the reporting quality and transparency of the review. The protocol was registered with the Open Science Framework (Center for Open Science, 2023), promoting methodological accountability and reproducibility.

A second strength lies in the comprehensive and librarian-assisted search strategy, which spanned multiple databases and included hand-searching of reference lists to maximize coverage. The inclusion of diverse study designs, ranging from randomized controlled trials and feasibility studies allowed for a broad understanding of the current landscape of MBIs in adolescent oncology. Additionally, the use of a structured data extraction matrix facilitated cross-study comparisons and thematic synthesis, enabling the identification of key intervention characteristics, feasibility indicators, and psychosocial outcomes.

Despite these strengths, several limitations must be acknowledged. One primary limitation is the underrepresentation of adolescents aged 14–18 years in the included studies. Although this age range was the focus of the review, many studies featured broader pediatric or young adult samples, with adolescents comprising less than 5% of participants in some cases. This limited the ability to draw age-specific conclusions and may have excluded potentially relevant findings due to strict eligibility criteria.

Another limitation pertains to the heterogeneity of intervention designs and outcome measures. The lack of standardized protocols and variability in the use of validated instruments (e.g., PedsQL, PROMIS, HADS) hindered direct comparisons and synthesis across studies. Furthermore, while the review focused on mindfulness-based interventions, many included studies integrated additional modalities such as music therapy, yoga, or prayer, complicating the attribution of outcomes solely to mindfulness practices. Additionally, few studies explicitly considered trauma-informed principles or assessed contextual factors such as ACEs and SDoH, despite their known influence on psychosocial outcomes in AYA cancer populations. This gap limits the generalizability and equity of current intervention models and underscores the need for future research to incorporate these critical dimensions.

Finally, while digital MBIs demonstrated high acceptability and feasibility, the evidence base remains limited by small sample sizes, short follow-up periods, and a lack of randomized controlled trials. These methodological constraints highlight the need for more robust, longitudinal studies to evaluate the sustained impact of MBIs and to inform best practices for intervention design and implementation in pediatric oncology settings.

## **Implications**

The findings support the integration of MBIs into pediatric oncology care as a non-pharmacologic strategy to address psychosocial distress. Future research should prioritize larger, multicenter RCT with standardized protocols, longer follow-up periods, and culturally tailored content. Digital delivery platforms, such as mobile apps, offer promising avenues for expanding access and engagement, particularly among adolescents. There is also a need to explore the impact of MBIs on specific cancer types, treatment modalities, and developmental stages to optimize intervention design and implementation.

## **Conclusions**

The emerging concept of mindfulness practices for AYA cancer patients is a promising approach to reduce psycho-social suffering. This is a critical step to building empirical knowledge to address the lack of interventions to alleviate psycho-social issues for AYA with cancer. High symptom burden as a result of being on active treatment causes stress to AYA. The use of mindfulness to cope with being on active treatment could significantly impact the health of AYA with cancer during active treatment and into survivorship.

## **CHAPTER 3 “Cancer Can’t Rob You of Yourself” Adolescent and Young Adults Experience with Their Cancer Diagnosis: A Pilot Multi-Methods Study**

### **Background**

Adolescents and young adults (AYA), occupy a unique developmental stage. These individuals, as defined by the National Cancer Institute (2025), are first diagnosed with cancer between the ages of 15 and 39. During this period of life AYA experience critical life transitions, including identity formation, pursuit of independence, exploration of relationships, education, and career paths (Zebrack & Isaacson, 2012). A cancer diagnosis during this period can be particularly disruptive, compounding the psychological and social challenges that AYA experience. Compared to younger pediatric and older adult populations, AYA face distinctive medical, psychosocial, and survivorship challenges that often remain under-recognized in clinical settings (Bleyer et al., 2017; Zebrack et al., 2014).

Psychological distress is notably prevalent among AYA cancer patients and survivors, with many experiencing symptoms of anxiety, depression, and post-traumatic stress, both during treatment and in survivorship (Hoey et al., 2018; Seitz et al., 2010). These mental health outcomes are often intensified by pre-existing vulnerabilities, including adverse childhood experiences (ACEs) such as abuse, neglect, or household dysfunction, which have been shown to negatively affect emotional regulation, health behaviors, and stress response systems (Felitti et al., 1998; Hughes et al., 2017). When ACEs intersect with the trauma of a cancer diagnosis, they may further heighten psychological risk and impair recovery trajectories (Lanctôt et al., 2016).

In addition, social determinants of health (SDoH) such as socioeconomic status, access to healthcare, housing stability, and social support play a critical role in shaping

both the cancer experience and overall health outcomes for AYA (Maya et al., 2021; Singh et al., 2020). Disparities in access to timely diagnosis, high-quality treatment, and supportive care are well documented, particularly among racially and economically marginalized groups (Kirtane et al., 2019; Miller et al., 2019). These structural inequities contribute to poorer physical and mental health outcomes and often compound the challenges of navigating a cancer diagnosis in young adulthood (Asare et al., 2019). Thus, we need supportive tools for AYA with cancer that are effective, feasible to use across settings, low-cost, and can be readily implemented by AYA themselves.

Mindfulness may address this need and fill this critical gap. It is most commonly defined as “paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally” (Kabat-Zinn, 1994, p. 4), and is both a state and a practice that cultivates awareness and acceptance of one’s thoughts, emotions, and bodily sensations. Mindfulness-based interventions (MBIs), such as Mindfulness-Based Stress Reduction (MBSR) and Mindfulness-Based Cognitive Therapy (MBCT), have been shown to reduce psychological distress, improve emotion regulation, and enhance quality of life in individuals facing serious illness, including cancer (Carlson et al., 2016; Piet et al., 2012). Among AYA with cancer, mindfulness may provide accessible and adaptable coping tools to manage uncertainty, mitigate anxiety and depression, and foster resilience, even in the context of pre-existing trauma or adverse social conditions (Perumbil Pathrose et al., 2022).

Lazarus and Folkman’s transactional stress and coping theory informs this study. It posits under conditions of chronic and severe stress (e.g. new cancer diagnosis) positive coping (psychosocial support) facilitates positive reappraisals of the difficult

situation, which help to support positive psychological states (Lazarus & Folkman, 1984). The aims of this pilot study were (1) to quantify and explore relationships among anxiety, depression, adverse childhood events, social determinants of health, and mindfulness qualities in AYA with cancer and (2) to explore the psychosocial health, well-being, and distress of AYA with cancer during active treatment and the sources of support they perceive as helpful.

## **Methods**

### ***Study Design***

This multi-site pilot study employs a community-engaged, descriptive, cross-sectional, multi-method design to examine the psychosocial well-being and distress experienced by adolescents and young adults (AYA) undergoing active cancer treatment. Participants were recruited from oncology clinics at Children's National Hospital in Washington, D.C., and the University of Maryland Greenebaum Comprehensive Cancer Center in Baltimore. A community-based patient advisory board comprised of AYA with cancer, provided input on the research questions and study procedures through in-person consultations at Children's National Hospital. Using a quantitative descriptive approach in Aim 1, quantitative data were collected from AYA to measure key psychosocial variables and explore potential relationships among them. In Aim 2, a qualitative descriptive approach was used to gain deeper insight from AYA about their experiences of psychosocial health, well-being, and distress, as well as to identify supportive interventions perceived as beneficial, through individual semi-structured interviews.

### ***Participant Recruitment and Setting***

**Table 1.** Inclusion/Exclusion Criteria for AYA with Cancer Pilot Study

Inclusion	Exclusion
English/ Spanish speaking	Inability to read or write English or Spanish.
AYA 12-21 years old	AYA less than 12 years or greater than 21 years
Active treatment for a diagnosis of cancer or 6 months post treatment.	Non-malignant or deemed not to be on active treatment or within 6 months post treatment by medical provider.
At least two weeks post diagnosis	Within two-week period of diagnosis
	AYA whose primary oncologist or advanced practice provider note the AYA will not be able to complete study procedures.

Inclusion and exclusion criteria are listed in Table 1. We used a patient-centered and inclusive recruitment

approach to enroll AYA if they were at least 2 weeks from diagnosis, had an “active diagnosis” (defined as receiving cancer-directed therapy, not yet transitioned into survivorship), or were within six months of completing treatment; and were Spanish or English speaking. Such inclusion helped to ensure the AYA experiences described were reflective of the active treatment phase and the ongoing psychological impact of a life-threatening illness.

To support patient-centered and inclusive recruitment, a minimum two-week interval was observed between diagnosis and study approach, allowing patients time to initiate their treatment plans. Eligible participants were undergoing chemotherapy, surgical interventions, maintenance therapy, or radiation at the time of recruitment. Enrollment was capped at age 21, consistent with institutional policies at participating pediatric centers, which transition patients to adult oncology care at that age. Recruitment and enrollment procedures were guided by principles of inclusivity, ensuring representation across sex, sexual orientation, race, age, and socioeconomic status. Participants may be English or Spanish speaking; a native Spanish speaking research

intern or medical translator was utilized through existing Translation Services team embedded at the study sites.

A convenience sample of eligible AYA was recruited for quantitative data collection from inpatient and outpatient Hematology/Oncology clinics across participating study sites. For the qualitative component, a purposive sampling strategy was employed to recruit a subset of five AYA participants who met the study's inclusion criteria. Following completion of the quantitative measures, participants were invited to indicate their interest in participating in a qualitative interview. This invitation was embedded within the study electronic data capture system, allowing participants to opt in to the qualitative phase immediately after completing the quantitative assessments.

### ***Measures***

A comprehensive set of validated instruments in both English and Spanish were utilized to assess demographic characteristics, psychosocial functioning, SDoH, ACE's and mindfulness traits among AYA participants (Table 2). All study visits were conducted in private rooms with a team member present to assist as needed. Demographic and medical history data were collected and entered directly into the REDCap database by the participant. The study team ensured participant privacy and performed data completeness checks post-measure completion in real time.

**Table 2.** Study Measures and Operational Definition

Measures	Description	Operational Definition
Demographic Data Interview (Parent Report)	Demographic data collection	Demographic data, diagnosis, inpatient/outpatient treatment, and staging, education level, etc.
Protocol for Responding to & Assessing Patients' Assets, Risks & Experience (PRAPARE) (Parent Report)	21 item measure that is a national standardized patient risk assessment protocol designed to engage patients in assessing & addressing social determinants of health.	Social Determinants of Health-the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.
Adverse Childhood Experiences (ACEs) Questionnaire	10-item measure used to measure childhood trauma. The questionnaire assesses 5 types of childhood trauma-physical abuse, verbal abuse, sexual abuse, physical neglect, and emotional neglect.	ACE's-potentially traumatic events that occur in childhood (0-17 years) and will be assessing 5 types of childhood trauma-physical abuse, verbal abuse, sexual abuse, physical neglect, and emotional neglect.
PROMIS Short Forms	Valid and reliable measure of child and adolescent Emotional Distress-Anxiety; Emotional Distress-Depressive Symptoms. 16 items total.	Depression and anxiety- Measured by the number of depressive and anxiety related symptoms the participant is experiencing using the PROMIS measures.
Child and Adolescent Mindfulness Measure (CAMM)	Designed to assess acceptance and mindfulness using a 5-point Likert scale. 10 items.	Measurement of purposefully focusing attention on one's present experience and remaining non-judgmental. Cronbach's alpha for CAMM responses was .87 indicating adequate levels of internal consistency.
The Mindful Attention Awareness Scale (MAAS)	15-item measure of dispositional mindfulness traits.	core characteristic of dispositional mindfulness, namely, open or receptive awareness of and attention to what is taking place in the present. The internal consistency (Cronbach's alpha) of the scale was .87.

Demographic data were collected via patient-report, capturing variables such as diagnosis, treatment setting (inpatient/outpatient), cancer staging, and educational background. Social determinants of health were evaluated using the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE), a 21-item standardized tool designed to assess environmental and social factors influencing health outcomes. This measure utilizes a cumulative risk tally approach, wherein each

identified social determinant of health risk is assigned a score of one, resulting in a total score that reflects the number of distinct social risks reported by the patient.

Childhood trauma was measured using the Adverse Childhood Experiences Questionnaire (Cronbach's  $\alpha = .87$ ), which includes 10 items assessing five domains of early trauma: physical abuse, verbal abuse, sexual abuse, physical neglect, and emotional neglect reported by participant directly into Red Cap database. The Adverse Childhood Experiences Questionnaire is scored by summing affirmative responses to ten items, each representing a distinct category of childhood trauma, yielding a total score ranging from 0 to 10 that reflects the cumulative exposure to adverse experiences before age 18. A score of 4 or more is often used as a threshold indicating elevated risk for long-term health impacts (Murphy et al., 2014; Meinck, Cosma, Mikton, & Baban, 2017). A higher score indicates a higher exposure to ACEs.

Emotional distress, specifically symptoms of anxiety and depression, was assessed using the PROMIS Short Forms, a reliable 8-item measure for depression (Cronbach's  $\alpha = .95$ ) and anxiety (Cronbach's  $\alpha = .93$ ) validated for pediatric populations (Schalet et al., 2016, Hinds et al., 2013). The PROMIS Depression and Anxiety Short Forms are scored by summing responses on a 5-point Likert scale and converting the raw scores into standardized T-scores, with higher T-scores indicating greater symptom severity. While anxiety and depression are both internalizing disorders and share overlapping psychological and neurobiological features, measuring them separately in AYA with cancer is critical because each condition contributes uniquely to emotional distress, functional impairment, and suicide risk, and their high comorbidity can obscure differential diagnosis and treatment needs (Kalin, 2020).

Mindfulness was evaluated using two instruments: the Child and Adolescent Mindfulness Measure (CAMM), a 10-item scale assessing present-moment awareness and non-judgmental acceptance (Cronbach's  $\alpha = .87$ ), and the Mindful Attention Awareness Scale (MAAS), a 15-item measure of dispositional mindfulness (Cronbach's  $\alpha = .87$ ), which captures open and receptive awareness of present experiences (Greco, Baer, & Smith, 2011; Brown & Ryan, 2003). The CAMM is rated on a 5-point Likert scale, with reverse scoring applied to select items; total scores range from 0 to 40, with higher scores reflecting greater trait mindfulness, particularly in the domains of present-moment awareness and nonjudgmental acceptance. The MAAS is scored by averaging all 15 item responses on a 6-point Likert scale; all items are negatively worded to reflect mindless states, with higher mean scores indicating greater mindfulness and attentional awareness in daily life; total scores range from 1 to 6. Collectively, these measures provided a multidimensional assessment of psychosocial health and mindfulness in AYA with cancer.

### ***Data Collection***

Eligible patients receiving care in outpatient or inpatient settings were screened by the oncology provider and a study team member prior to recruitment to ensure appropriateness and sensitivity to recent changes in care or stressors. All study visits were conducted in private rooms and study team performed data completeness checks post-measure completion. Parent/guardian and AYA participants were approached using a standardized recruitment script. Interested participants received an IRB-approved Information Sheet with HIPAA disclosures. A study team member provided the electronic Information Sheet and study measures via Red Cap link during clinic visit/inpatient downtime. Materials were available in English and Spanish. The Institutional Review

Board of record was Children’s National Hospital (STUDY00000751 approved 10/30/2023) and a Waiver of Documentation of Consent/Assent were approved for this minimal risk study (see Appendix B). A reliance agreement was established with the Institutional Review Board at University of Maryland Baltimore (HP-00108985 approved 1/5/2024) as recruitment occurred at the Hematology/Oncology clinic.

AYA participants completed validated, standardized questionnaires assessing study outcomes, requiring approximately 20 minutes for completion. Parents/caregivers were available to assist if needed to complete demographic and PRAPARE measures. AYA aged 12–21 completed self-report measures on their own devices with research team nearby for assistance.

To qualitatively explore psychosocial health, well-being, and distress, semi-structured interviews were conducted individually with participants by author (JT) using a guide informed by the theoretical model, see Figure 1 (Lazarus & Folkman, 1984). Using a qualitative descriptive approach, interviews began with open-ended questions about diagnosis and support, followed by discussions on psychosocial experiences and awareness of supportive interventions (e.g., mindfulness). Interviews were audio-recorded, transcribed verbatim, and conducted in participants’ preferred settings (phone, Zoom, or in-person). Hospital based translation services supported interactions with Spanish-speaking parents to inform them about study procedures and review elements of informed consent for their children to participate. The research team, experienced in qualitative methods, monitored participant distress and offered breaks as needed. Interviews lasted approximately 30–60 minutes.

#### *Data Analysis*

Quantitative data were checked for completeness following each participant's entry and no missing data were reported. All statistical analyses were conducted using R statistical programming. Descriptive statistics (frequency, percentage, means, standard deviations, and ranges) were computed for study variables, including measures of psychosocial health (CAMM and MAAS), adverse childhood experiences (ACE), PROMIS Anxiety and Depression T-scores, PRAPARE (SDoH measure) and demographic variables (gender, race/ethnicity).

Given the modest sample size ( $N = 25$ ), univariate regression models were employed to examine associations between individual variables and the continuous outcome variables (CAMM and MAAS). This analytic approach allowed each variable to be evaluated independently while reducing model complexity and minimizing the potential for overfitting. Bivariate correlations were not conducted, as the univariate models provided comparable information regarding the direction and strength of associations. For categorical variables (gender and race/ethnicity), group differences in outcome measures were assessed using independent-samples  $t$  tests and one-way ANOVA, as appropriate. This approach was intended to identify preliminary relationships among study variables that may warrant further investigation in future research with larger, more diverse samples. Statistical significance was determined at  $p < .05$ .

Race/ethnicity was coded as a categorical variable and recoded into a series of dummy variables for inclusion in regression analyses. Black or African American participants represented the largest racial group in the sample and were therefore designated as the reference category to facilitate interpretation of regression coefficients. This recoding procedure produced three dummy variables representing participants who

identified as Asian, Hispanic or American Indian, and White. The reference category was excluded from the regression models to prevent multicollinearity among variables. For regression analyses, all race/ethnicity dummy variables were entered simultaneously within a single univariate model, treating the overall set of dummy variables as one categorical variable to assess group differences relative to the reference group.

Qualitative data from the transcribed interviews were reviewed for accuracy against audio recordings. Conventional content analysis was used to identify themes, appropriate for exploring under-researched phenomena (Creswell & Poth, 2024). An initial code list, informed by the theoretical model, guided analysis of participants' experiences with diagnosis and sources of support. Transcripts and field notes were linked in Atlas.ti and analyzed iteratively by two reviewers (Jesssica Thompkins and Kim Mooney-Doyle). The first three transcripts were reviewed to identify latent and manifest content, informing the development of a codebook with definitions, application guidance, and examples by both reviewers. Codes were grouped into categories through constant comparison. Subsequent transcripts were coded, and categories refined to identify patterns and overarching themes. Relationships among themes were explored, with ongoing refinement discussed in weekly team meetings until consensus was achieved.

Qualitative rigor was ensured through multiple analysts, prolonged engagement with data, member checks, expert consultation to mitigate bias, audit trail maintenance, and reflexivity journaling.

## **Results**

### ***Sample Characteristics***

The final sample consisted of 25 AYA aged 12 to 21 years, each with an active cancer diagnosis or within six months of completing treatment (Table 3). This sample size was selected to capture variability in age, cancer type, and disease severity, which are critical factors in assessing psychosocial outcomes in this population. Participants had a mean age of 16.2 years (SD = 1.8; range = 12–21), and the majority were male (76%). The sample was racially and ethnically diverse, with 36% identifying as Black or African American, 24% as White, 20% as Asian, and the remainder identifying with other racial/ethnic backgrounds. In terms of medical characteristics, 56% of participants had a diagnosis of leukemia and 20% were diagnosed with solid tumor. 92% were actively receiving treatment and 88% had never had a relapse. See Table 3 for remaining demographic and sample characteristics.

**Table 3.** Demographic and Clinical Characteristics of AYA with Cancer Full Study (n=25)

<b>Variable</b>	<b>Mean (SD) [range]</b>
<b>Age</b>	16.2 (1.8) [12-21]
<b>Sex</b>	<b>N (%)</b>
Female	6 (24)
Male	19 (76)
<b>Race</b>	
Asian	5 (20)
Black or African American	9 (36)
White	6 (24)
American Indian	1 (4)
Declined to answer	0 (0)
<b>Ethnicity</b>	
Hispanic or Latino	4 (16)
<b>Housing Situation</b>	
I have housing	24 (96)
I do not have housing	1 (4)
I worry about losing my home	2 (8)
<b>Transportation</b>	
Lack of transportation to medical appointments	1 (4)

**Table 3.** Continued

Lack of transportation for getting things I need	2 (8)
<b>Unable to Obtain When Needed</b>	
Phone	1 (4)
Food	2 (8)
Clothing	1 (4)
<b>Cancer diagnosis</b>	
Leukemia	14 (56)
Solid tumors	5 (20)
Brain Tumor	0 (0)
Lymphoma	2 (8)
Other	4 (16)
<b>ACE Score</b>	<b>N (%)</b>
0	14 (56%)
1	5 (20%)
4	4 (16%)
5	2 (8%)
	<b>Mean (SD) [range]</b>
CAMM Score	30 (10) [12-40]
MAAS Score	4.69 (1.17) [2.2-6]
PDS T-Score	50 (13) [35.2-75.1]
PAS T-Score	46 (11) [33.5-64.5]

### ***Quantitative Findings***

Indicators of social determinants of health (SDoH) revealed that 4% of participants did not have stable housing, 12% reported transportation challenges in accessing daily needs or medical appointments, and 16% reported being unable to obtain essential resources such as a phone, food, or clothing when needed (Table 3). Nearly half of the sample (44%) reported at least one adverse childhood experience (ACE) and those with an ACE score of 4 or above (elevated risk for long-term health impacts) represented nearly a quarter of the sample (24%). In this sample, the mean T-score on the PROMIS Depression Short Form was 50 (SD = 13, Range 35-75) and on the PROMIS Anxiety Short Form was 46 (SD = 11, Range 33-64), indicating symptom levels within normal

limits when compared to the general population reference scores of 50 (SD=10). 36% of the sample had a T-score with mild to moderate symptoms of anxiety and depression.

In contrast, the mean score on the MAAS was 4.69 (SD = 1.17, Range 2-6), which is comparable to scores reported among adolescents and young adults (AYA) with cancer, suggesting similar levels of dispositional mindfulness (Brown, West, Loverich, & Biegel, 2011). The mean CAMM score was 30 (SD=10, Range 12-40) for this sample which was lower than normative scores in the general adolescent population, suggesting reduced trait mindfulness (Greco et al., 2011).

Univariate regression analyses (Table 4 and 5) were conducted to examine whether significant independent variables of demographics (gender, age, race), psychosocial (ACE score), and psychological distress variables (anxiety, depression) predicted mindfulness qualities (outcome variables), as measured by the Child and Adolescent Mindfulness Measure (CAMM) and the Mindful Attention Awareness Scale (MAAS). CAMM is a measurement purposefully focusing attention on one’s present experience and remaining non-judgmental. MAAS measures core characteristics of dispositional mindfulness, namely, open or receptive awareness of and attention to what is taking place in the present.

**Table 4.** Univariate Regression Model Predicting Child Adolescent Mindfulness Measure (CAMM) Scores (N=25)

<b>Predictor Variable</b>	<b>Beta</b>	<b>95% CI'</b>	<b>p-value</b>
Male (ref= Female)	7.1	-1.9, 16	0.12
Age	-1.1	-2.5, 0.35	0.13
<b>Race/Ethnicity</b>			
White (ref= Black/AA)	-1.5	-10, 7.1	0.7
Hispanic/American Indian (ref= Black/AA)	-15	-24, -5.6	0.003
Asian (ref=Black/AA)	3.2	-6.7, 13	0.5
ACE Score	-1.9	-4.0, 0.15	0.067

**Table 4.** Continued

Depression (PROMIS T-Score)	-0.58	-0.77, -0.40	<0.001
Anxiety (PROMIS T-Score)	-0.65	-0.88, -0.42	<0.001

**Table 5.** Univariate Regression Model Predicting Mindful Attention Awareness Scale (MAAS) Scores (N=25)

Predictor Variable	Beta	95% CI'	p-value
Male (ref=Female)	1.2	0.19, 2.3	0.022
Age	-0.16	-0.33, 0.02	0.073
Race/Ethnicity			
White (ref=Black/AA)	-0.17	-1.4, 1.1	0.8
Hispanic/American Indian (ref=Black/AA)	-1.3	-2.6, -0.01	0.049
Asian (ref=Black/AA)	-0.63	-1.9, 0.69	0.3
ACE Score	-0.25	-0.50, 0.01	0.055
Anxiety (PAS T-Score)	-0.10	-0.11, -0.08	<0.001
Depression (PDS T-Score)	-0.08	-0.10, -0.06	<0.001

***Child and Adolescent Mindfulness Measure (CAMM)***

The univariate regression model for CAMM scores showed several significant associations (Table 5). Higher anxiety (PAS T-score) was strongly associated with lower CAMM scores,  $\beta = -0.65$ , 95% CI [-0.88, -0.42],  $p < .001$ . Similarly, higher depression (PDS T-score) was negatively associated with CAMM scores,  $\beta = -0.58$ , 95% CI [-0.77, -0.40],  $p < .001$ . Having a Hispanic/Latino or American Indian background, compared with Black participants, was also significantly associated with lower CAMM scores,  $\beta = -15.0$ , 95% CI [-24.0, -5.6],  $p = .003$ . Univariate analysis showed that each one-point increase in ACE score was associated with a 1.9-point decrease in CAMM score ( $\beta = -1.90$ ), this negative association did not reach statistical significance (95% CI [-4.0, 0.15],  $p = .067$ ). Gender, age, and other racial/ethnic groups were not significantly associated. In this model, participant sex, age, and identifying as White or Asian, were not significantly

associated. Univariate linear regression analysis also revealed that for each additional year of age, CAMM scores decreased by an average of 1.1 points ( $\beta = -1.10$ ), indicating a negative association between age and mindfulness in adolescents.

#### *Mindful Attention Awareness Scale (MAAS).*

The univariate regression model for MAAS scores also identified significant associations (Table 6). Both higher depression and higher anxiety were significantly associated with lower MAAS scores (anxiety:  $\beta = -0.10$ , 95% CI  $[-0.11, -0.08]$ ,  $p < .001$ ; depression:  $\beta = -0.08$ , 95% CI  $[-0.10, -0.06]$ ,  $p < .001$ ). Male participants reported significantly higher MAAS scores than females,  $\beta = 1.2$ , 95% CI  $[0.19, 2.3]$ ,  $p = .022$ . ACE scores showed a negative association at a trend level,  $\beta = -0.25$ , 95% CI  $[-0.50, 0.01]$ ,  $p = .055$ . Age and race/ethnicity were not significantly associated in this model.

Across both measures, depression and anxiety consistently were associated with lower mindfulness qualities, highlighting the strong inverse relationship between psychological distress and mindful awareness. ACE exposure trended toward negative associations with mindfulness but did not reach statistical significance. Demographic variables had limited effects in the model, aside from gender was associated with higher MAAS scores in males. Hispanic/Latino or American Indian identity was associated with lower CAMM scores.

#### ***Qualitative Findings***

Qualitative analysis was completed (N=5) from participants who completed the quantitative measures. The qualitative analysis yielded three central themes: (1) Emotional dynamics of being diagnosed with cancer as an AYA (2) facilitators for well-

being at interpersonal (deep breathing etc.) and intrapersonal (family, medical staff, friends) levels (3) challenges faced along the cancer journey (Table 6).

**Table 6. Qualitative Analysis Thematic Analysis**

Theme	Description of Theme	Codes Included	Number of Occurrences	Related Insights
Emotional dynamics of being diagnosed with cancer as an AYA	Initial emotional response to being diagnosed	<ul style="list-style-type: none"> <li>a. Shock</li> <li>b. Fear</li> <li>c. Uncertainty</li> <li>d. Distress</li> <li>e. Acceptance</li> <li>a. Self-criticism</li> <li>b. Guilt</li> <li>c. Shame</li> <li>d. Embarrassment</li> <li>e. Regret</li> <li>f. Lowered self-esteem</li> <li>g. Anger</li> <li>h. Self-blame</li> <li>i. Disgust</li> <li>j. Depression</li> <li>k. Anxiety</li> </ul>	18	Key findings: This experience is not a "one size" fits all or cookie cutter experience. Emotions to being diagnosed can range with positive and negative undertones. Acceptance and peace can occur sometimes simultaneously with frustrations of a major life-threatening diagnosis.
	Feelings surrounding diagnosis and therapy	<ul style="list-style-type: none"> <li>a. Family</li> <li>b. Doctors</li> <li>c. Nurses</li> <li>d. Child life</li> <li>e. Friends</li> <li>f. Humor</li> <li>g. Staying Active/Normalcy</li> </ul>	36	Key findings: dynamics surrounding feelings to each individual loved ones, angry this has restricted life and social engagements.
Facilitators for well-being as expressed by AYA with cancer at interpersonal (deep breathing etc) and intrapersonal (family, medical staff, friends) levels.	Helpful Sources of support/Ways to Cope with Diagnosis	<ul style="list-style-type: none"> <li>a. Mindfulness Group</li> <li>b. Mindfulness Alone</li> <li>c. Art Therapy</li> <li>d. Deep breathing</li> <li>e. Yoga</li> </ul>	22	Key findings: AYA did leverage strengths in different ways. Relationships with parents and families were key to support and well-being. Most AYA describe the closeness they felt with parents during diagnosis. AYA describe health care providers as helping make the process understandable and therefore reducing stress felt surrounding diagnosis. Humor, staying active, finding "normalcy" in a period of abnormality was deemed helpful by AYA
	Mindfulness Activities	<ul style="list-style-type: none"> <li>a. Mindful walking</li> <li>g. Helpful or not</li> <li>h. In person at hospital or home</li> </ul>	20	Key Findings: All AYA were open to the idea of MBSR. While the majority were not familiar with the term of "mindfulness", they all experienced some form of it as beneficial during treatment. This was experienced by deep breathing, mindful walking, music therapy, and distraction techniques. All preferred one on one session and not a group setting. Using an app and having someone come in person were preferred methods of support for MBSR. All AYA were open to additional techniques that they had not already participated in such as yoga.
Distressing events, barriers, and relationship changes AYA experience during cancer diagnosis.	Distress during illness	<ul style="list-style-type: none"> <li>a. Distress r/t Treatment/Symptoms</li> <li>b. Distress r/t School</li> <li>c. Distress r/t Work</li> <li>d. Distress r/t Stress</li> <li>e. Distress r/t Friends</li> </ul>	20	Key Findings: multifaceted impact of medical treatment, encompassing physical suffering, emotional strain, social isolation, and disruption of daily life, significant hardship and loss of normalcy.

*Theme 1: Emotional dynamics of being diagnosed with cancer as an AYA*

Adolescents and young adults (AYAs) described their experiences with illness as highly individualized, emphasizing that it does not conform to a "one-size-fits-all" or "cookie-cutter" model. Emotional responses to diagnosis varied widely, encompassing both positive and negative dimensions. One participant reflected on their initial response to being diagnosed, *"At the end of the day you are still you so you might as well keep going like before this all ever happened. I mean cancer can't rob you of yourself,"* highlighting a resilient sense of identity and continuity despite the diagnosis. Others described the overwhelming pace of events at diagnosis, as one AYA shared, *"It took me a couple days; like once my hair started falling out, which was probably three days after I got diagnosed because they did the chemo as soon as possible, but, yeah, I didn't really understand because I just... everything happened so fast."* These accounts illustrate how the emotional landscape evolved throughout the illness trajectory, revealing shifts in perception and coping mechanisms over time. Feelings of sadness and confusion were also present, as another participant noted, *"I was definitely sad in the beginning and I wasn't told much else all I was told was I had some type of cancer, and I would have to go to the ER and that would make me feel bad."* Common themes included feelings of being a burden to loved ones, anger over limitations imposed on daily life and social engagement, and a sense of isolation. These insights underscore the complexity and fluidity of emotional experiences among AYA navigating serious health challenges. One participant shared, *"Well, right now it's gotten better because I don't have like chemo every week. I get it like not a lot, but I'm still taking like pills and stuff. But when we were at the clinic I would get a water treatment. I just felt like a burden to my family because*

*they had to take me to get my treatments and then I just would always feel sick all the time.”*

*Theme 2: Facilitators for well-being as expressed by AYA with cancer at interpersonal (deep breathing, etc.) and intrapersonal (family, medical staff, friends) levels.*

AYA demonstrated varied approaches to leveraging personal strengths throughout their treatment experiences. Supportive relationships with parents and family members emerged as central to emotional well-being, with many participants describing increased closeness with their parents following diagnosis. Across interviews, AYA consistently emphasized the importance of familial and peer support in mitigating the psychological burden of cancer and its treatment. Emotional presence, companionship, and consistent support were identified as protective factors against isolation and distress. As one participant noted, parents were an important source of support and assistance, even in adolescence when youth might be expecting to separate from parents:

*"I would say that for my mom. She helped me the most through it. She tried her best. Making sure that I was set up for everything when she was away or for when I was stuck at home and in bed or if I needed help in the bathroom with my soap or anything. Also, with doctors' appointments and understanding things as well."  
-AYA reported helpful sources of support/ways to cope with diagnosis*

Healthcare providers were also recognized as instrumental in reducing stress by helping AYA understand the diagnostic and treatment processes. Participants noted that clear communication and empathetic care contributed to a greater sense of control and reduced anxiety.

AYA identified humor, physical activity, and efforts to maintain a sense of normalcy during treatment as effective coping strategies. Although most were unfamiliar

with the formal concept of Mindfulness-Based Stress Reduction (MBSR), all participants expressed openness to its techniques and acknowledged engaging in similar practices such as deep breathing, mindful walking, music therapy, and distraction methods as beneficial. For example, one young person noted, *"Like you're kind of breathing it out. I mean it won't get rid of like the underlying problem, but I guess it makes you feel a little better for the moment."* -AYA exploring mindfulness activities. A wide range of current coping mechanisms were described, including nature-based mindfulness, video games, and other hobbies. Additionally, AYA expressed interest in exploring new techniques, including yoga. Despite their diversity, these activities shared a common function: redirecting attention away from illness and fostering moments of calm, enjoyment, and psychological relief during active treatment. Participants viewed these practices as accessible and meaningful tools for managing stress and medical uncertainty.

Youth also shared their preferences for receiving or using supportive strategies, emphasizing the importance of flexibility and personalization. The participants in this study leaned toward individualized support, with one-on-one sessions and app-based or in-person delivery methods favored over group formats. One AYA explained, *"I would probably say online for the convenience and everything. And then with online you can take it all places with them. Whereas in person you have to commit to a place, a time. Sometimes during the treatment when you don't feel as well you don't have to worry as much about the pace,"* highlighting the value of accessibility and autonomy in managing their care. Another participant shared a positive experience with a mindfulness app, stating, *"My mom used this app for a bit, and you can play like meditations and stuff, and like I don't know, there are... one thing was like pretend you're an ocean, all of your*

*muscles like relaxed, and I don't know, but it's like an app where you just play meditations, like you can play them, just as you're sitting around or as you're sleeping.*" These reflections underscore the importance of offering diverse, adaptable tools that meet youth where they are emotionally, physically, and logistically, especially during periods of treatment when energy and motivation may fluctuate.

### *Theme 3: Challenges faced along the cancer journey*

This theme explored the multifaceted impact of medical treatment, encompassing physical suffering, emotional strain, social isolation, and disruption of daily life, significant hardship and loss of normalcy. Narratives reveal a complex interplay of physical, emotional, and social challenges associated with undergoing intensive medical treatment. The physical toll of surgeries and repeated procedures, such as lumbar punctures, was described as particularly burdensome, with side effects including extreme fatigue, nausea, spinal headaches, and general weakness that significantly impaired daily functioning. One young person shared, *"I was extremely weak afterwards. I could barely eat anything, I slept through basically a week after my treatments. I could barely leave the bed or walk the dog. That was one of the hardest parts for me because I couldn't barely do anything."* -AYA exploring distress during illness

The cyclical nature of treatment and recovery disrupted school/work routines and necessitated extended leave from school/work, contributing to a sense of lost autonomy. Emotionally, AYA grappled with the unpredictability of treatment outcomes and the disconnect between the body's adverse reactions.

Socially, the illness led to missed developmental milestones, such as participation in sports and school activities, and fostered feelings of jealousy and isolation as peers and siblings continued with their lives. Relationships with friends and family were strained, with reduced communication and physical absence contributing to a sense of social withdrawal. Despite some efforts to maintain contact through scheduled interactions, AYA noted a decline in closeness, particularly with siblings and previously close friends. Anxiety surrounding medical procedures and the lack of consistent emotional support further compounded the psychological burden. Collectively, these themes underscore the multifaceted impact of serious illness on adolescents and young adults, highlighting the need for integrated support systems that address both medical and psychosocial dimensions of care.

## **Discussion**

This multi-method pilot study explored psychosocial associations with mindfulness qualities among adolescents and young adults (AYA) with cancer. Using two validated mindfulness measures, the Child and Adolescent Mindfulness Measure (CAMM) and the Mindful Attention Awareness Scale (MAAS), we found that the psychological distress variables of depression and anxiety were the most consistently associated with lower mindfulness. Specifically, higher depressive symptoms and higher anxiety were predictive of lower scores on both the CAMM and the MAAS. These findings align with prior research demonstrating the inverse relationship between psychological distress and mindfulness skills across both general populations (Creswell, 2017) and individuals with cancer (Carlson et al., 2016; Piet et al., 2012). They extend this work by confirming similar patterns in an AYA cohort, a group historically

underrepresented in mindfulness and psycho-oncology research (Perumbil Pathrose et al., 2022).

Adverse childhood experiences (ACEs) trended toward negative associations with mindfulness across both measures, though results did not reach statistical significance. This suggests that early-life adversity may contribute to reduced capacity for mindful awareness, consistent with prior work linking ACEs to difficulties in emotion regulation and stress reactivity (Hughes et al., 2017; Lanctôt et al., 2016). However, the small sample size has limited statistical power to detect these effects, warranting further investigation into larger, more diverse AYA samples. Demographic variables played a limited role, although notable patterns emerged: male participants reported higher MAAS scores than females, and Hispanic/Latino or American Indian participants reported lower CAMM scores. These findings from the CAMM scores emphasize the need for MBIs to be culturally responsive and inclusive, recognizing that mindfulness is not a one-size-fits-all construct. The validation of CAMM in racially diverse, low-income adolescent populations (Prenoveau et al., 2018) supports its use in underrepresented groups but also highlights the importance of ensuring that intervention content and delivery resonate with the lived experiences of participants. For example, cultural norms around emotional expression, attentional focus, and coping strategies may influence how mindfulness is practiced and perceived, which in turn affects engagement and outcomes.

The MAAS measures the frequency of present-moment awareness and attentiveness, emphasizing experiential mindfulness rather than emotional dimensions such as regulation or nonjudgment. This distinction is important when considering gender differences in mindfulness. A longitudinal study by Cao et al. (2025) found that males

scored higher on facets such as awareness, non-reactivity, and nonjudgment traits linked to attentional control, while females scored higher on observing and describing, which relate to emotional sensitivity and expression. Although this study was conducted in a general adolescent population, these findings offer insights relevant to AYA oncology, where emotional and physical stress is heightened. Understanding these gender-specific mindfulness traits can inform the tailoring of MBIs to better support coping and psychological resilience.

For male AYAs, interventions might emphasize practices that cultivate attentional stability and non-reactivity, such as focused attention meditation, body scan exercises, and mindful walking, which promote sustained attention and reduce impulsive emotional responses. For female AYAs, MBIs may benefit from incorporating practices that support emotional processing and sensory grounding, including loving-kindness meditation, mindful journaling, and sensory awareness exercises. These gender-responsive approaches can enhance engagement and therapeutic outcomes by aligning with the distinct ways in which adolescents experience and utilize mindfulness.

While the experience of a cancer diagnosis during adolescence or young adulthood is highly individual and shaped by each person's developmental stage, medical context, social constructs, and life trajectory, our qualitative findings revealed important commonalities across participants. Many AYA emphasized the critical role of social support from parents, siblings, close family and friends in coping with their diagnosis and treatment. These relationships provided not only practical help but also emotional grounding, contributing to a sense of security and belonging. Participants often described that knowing loved ones were "present" and "standing with them" made the cancer

experience more manageable. This finding is consistent with prior research identifying social support as a robust protective factor against distress in AYA cancer populations (Zebrack et al., 2014).

Participants also identified the value of intentional distractions as a coping strategy, including mindful walking, spending time in nature, and engaging in hobbies such as video games. While these activities varied in formality and mindfulness orientation, they shared the common function of shifting attention away from illness-related stress and fostering being present in moments of enjoyment or peace. These strategies align with evidence suggesting that both formal mindfulness practices and informal mindful activities such as nature immersion can enhance emotional regulation and promote psychological recovery (Creswell, 2017; Nisbet et al., 2011). Integrating these types of personalized, low-barrier activities into supportive care programming could provide additional tools for AYA to navigate the challenges of treatment and survivorship (Perumbil Pathrose et al., 2022; Kwok, Sharma, Mandato, & Devine, 2024).

The implications of these findings for clinical practice are substantial. First, psychosocial care for AYA should intentionally incorporate mechanisms to strengthen or maintain close social connections during treatment, including facilitated family communication, peer-to-peer programs, and technology-based support networks (Kwok, Sharma, Mandato, & Devine, 2024). Second, intervention design may benefit from a hybrid approach that combines structured mindfulness-based interventions (MBIs) with opportunities for personalized, preferred activities that promote mindful engagement and emotional respite (Carlson et al., 2016; Piet et al., 2012). This flexibility could improve

uptake, sustain engagement, and enhance perceived relevance for AYA with diverse backgrounds and needs (Khanna et al., 2024).

### **Strengths and Limitations**

A key strength of this study is its multi-methods design, which combined rigorous conventional content analysis with quantitative data collection from two pediatric tertiary care hospitals. This approach allowed for a more comprehensive understanding of the psychosocial experiences of AYA with cancer by integrating rich narrative accounts with measurable indicators of distress, mindfulness, and social determinants of health. The qualitative strand benefited from a systematic analytic process that ensured trustworthiness and depth, while the quantitative data provided opportunities to examine patterns and relationships across variables. Additionally, the study was conducted by a nurse investigator with extensive training and experience in both qualitative and quantitative research methodologies, ensuring methodological rigor, credibility, and nuanced interpretation of findings.

Several limitations should be acknowledged. While recognizing the developmental heterogeneity inherent in the 12–21 age range, future research should aim to tailor psychosocial interventions to specific stages of adolescence, while also attending to the shared experience of navigating cancer treatment during this critical period of identity formation and emotional vulnerability. The pilot nature of the study and relatively small sample size limit generalizability, and the cross-sectional design precludes conclusions about causality. Self-reported measures of mindfulness and distress may be subject to bias, and the qualitative data, while rich, reflect the perspectives of a self-selected group who may differ from AYA less inclined to engage in research.

Additionally, while the sample included participants with diverse social determinants of health (SDoH) profiles, further work is needed to understand how structural inequities intersect with intervention accessibility and effectiveness in broader AYA populations (Abdullah, Liu, & Molinari, 2025).

Importantly, this sample was primarily male, as the majority of female participants were experiencing increased pain and symptom burden and were therefore not identified as appropriate to approach by the medical team. This recruitment limitation reflects broader trends in the literature, where female AYA have been shown to report higher levels of pain, fatigue, and emotional distress compared to their male counterparts (Lyon et al., 2021). These disparities are further compounded by intersecting factors such as poverty and systemic inequities, which can exacerbate symptom suffering and reduce access to supportive care. The underrepresentation of female AYA in psychosocial intervention research highlights a critical gap and underscores the need for gender-sensitive approaches to supportive care interventions that account for differential symptom experiences and barriers to participation.

Nonetheless, this study builds on the shared experiences of AYA navigating cancer treatment during adolescence and young adulthood and contributes to the growing evidence base supporting the feasibility and relevance of mindfulness-based interventions in this population.

### **Implications and Applications**

Future research should build on these findings by testing developmentally tailored, trauma-informed mindfulness interventions that integrate both formal practices and participant-preferred mindful activities (Creswell, 2017). Randomized controlled or

programmatic trials with diverse and adequately powered samples could assess both clinical outcomes and implementation feasibility. Given the strong role of social support identified here, future interventions should also explore ways to embed mindfulness within social contexts such as family-based sessions, peer group formats, or app-based communities to strengthen relational buffers against distress (Zebrack et al., 2014).

Further research that explores the multidimensional experience of cancer in AYA populations through the lens of psychological distress, ACEs, and SDoH is critical. By examining the interplay between these factors, we will better inform a more holistic and accessible approach to care that addresses not only the biological but also the psychosocial and structural dimensions of cancer in young people.

## **Conclusion**

This pilot study provides preliminary evidence that lower mindfulness qualities are associated with higher symptoms of anxiety and depression in adolescents and young adults with cancer, even in the presence of adverse childhood experiences and challenging social determinants of health. Qualitative findings underscore the importance of social support from close family and friends and the utility of both formal mindfulness practices and personally meaningful distractions such as mindful walking, spending time in nature, or engaging in hobbies in coping with the cancer experience. The multi-methods approach, incorporating rigorous qualitative content analysis and quantitative data from two pediatric tertiary hospitals, offers a nuanced understanding of the psychosocial needs of this population.

Taken together, these findings highlight the potential for developmentally tailored, trauma-informed, and socially embedded mindfulness-based interventions to support psychological well-being in AYA with cancer. By integrating flexible delivery formats and leveraging both formal and informal mindfulness strategies, supportive care programs can be made more accessible and relevant to young people navigating cancer during a pivotal stage of life. Future research should explore these approaches in larger, more diverse samples to further evaluate their feasibility, acceptability, and impact on long-term psychosocial outcomes.

## CHAPTER 4 Empowering AYA Voices: A Community-Based Approach to Supportive Cancer Care

### Background

Adolescents and young adults (AYA) diagnosed with cancer experience substantial psychosocial challenges that extend beyond the burden of medical treatment. Rates of psychological distress in this group are consistently higher than in their healthy peers and older adults with cancer. For instance, a meta-analysis by Osmani et al. (2023) reported that approximately one in three AYA cancer survivors experience elevated psychological distress or anxiety, and nearly one in four experience depression. Duan et al. (2021) similarly found that 83.4% of AYA in active treatment in China reported psychological distress, with strong associations with anxiety and depression. Data from the BRIGHTLIGHT cohort, which incorporated perspectives from a Young Advisory Panel, revealed rates of anxiety among AYA with cancer ranging from 8% to 55% and depressive symptoms ranging from 13% to 47% (Korenblum, Taylor, Fern, Hough, & Wickramasinghe, 2025). Compared to peers without cancer, AYA with a cancer history report nearly double the rates of psychological distress (11.5% vs. 5.8%), alongside increased healthcare utilization and costs (Abdelhadi et al., 2022). These findings underscore the urgency of developing supportive care interventions that address the psychosocial burden of cancer during this developmental stage.

An important lens for understanding such psychosocial burdens is provided by the Building Community Resilience (BCR) model proposed by Ellis and Dietz (2017). The BCR model emphasizes that adverse childhood experiences (ACEs) do not occur in isolation: rather, they co-exist with adverse community environments, (e.g., poverty,

discrimination, poor housing, lack of opportunity) what the model terms the “Pair of ACEs” which amplify risk and toxic stress. The framework further highlights that addressing toxic stress effectively requires action across social determinants of health, multisector collaboration, and continuous quality improvement in community and clinical systems (Ellis & Dietz, 2017). In the context of AYA with cancer, the dual impact of individual early adversities (such as ACEs) and current social determinants (e.g., financial insecurity, unstable housing, limited social supports) likely contribute to symptom burden, psychosocial distress, and quality of life.

Recent data underscore the urgency of addressing these intersecting challenges. A national registry analysis by Muffly, Tardif, and de Souza (2023) revealed that 92% of the financial burden experienced by pediatric and AYA cancer patients stems from non-medical costs, with rent and mortgage alone accounting for 62% of these expenses. This financial toxicity is compounded by reduced access to social supports and housing instability, particularly among families from low-income and racially marginalized communities. Ruiz et al. (2023) further emphasized that childhood cancer survivors and their families face persistent economic hardship, including decreased wages and limited insurance coverage, which can exacerbate psychological stress and impede recovery. These findings highlight the critical need for integrated, equity-focused interventions that address not only clinical care but also the broader social and economic contexts shaping the lived experiences of AYA with cancer.

Despite the well-documented prevalence of distress, few interventions are tailored specifically to AYA. Traditional approaches often fail to consider fluctuating symptom burden, evolving developmental needs, or the importance of patient preference. One

promising approach for responding to these psychosocial needs is the use of intervention toolkits. Toolkits are increasingly recognized in healthcare as adaptable, multi-component resources that package evidence-based strategies in a way that is practical, flexible, and scalable (Gagliardi et al., 2015). Within oncology and psychosocial care, toolkits have been shown to enhance accessibility, promote self-management, and provide continuity of support across diverse care settings (Devine, Viola, Coups, & Wu, 2018). Importantly, when toolkits are co-developed with end-users, they are more likely to reflect authentic needs, be perceived as acceptable, and demonstrate greater feasibility for real-world implementation (Hannon et al., 2017). For AYA specifically, whose psychosocial needs are highly individualized and often fluctuate with treatment intensity, toolkits offer the potential for tailored interventions that can travel with patients across settings of care and adapt to changing developmental and clinical contexts. The objective of this manuscript is to delineate the intervention targets, preferred delivery modalities, and format specifications for an AYA-focused supportive care toolkit, informed by empirical data, shaped through a multi-methodological research design, and guided by structured input from a Community Advisory Board (CAB).

The involvement of AYA themselves in the design of toolkits is crucial. Community-based participatory research (CBPR) offers an alternative model of intervention toolkit development by directly engaging the population of interest in all stages of research, from study planning and measure selection to interpretation of findings and intervention development (Israel, Eng, Schulz, & Parker, 2013; Simonds, Wallerstein, Duran, & Villegas, 2013). CBPR emphasizes co-learning, power sharing, and mutual benefit, making it particularly well suited for work with AYA with cancer, whose

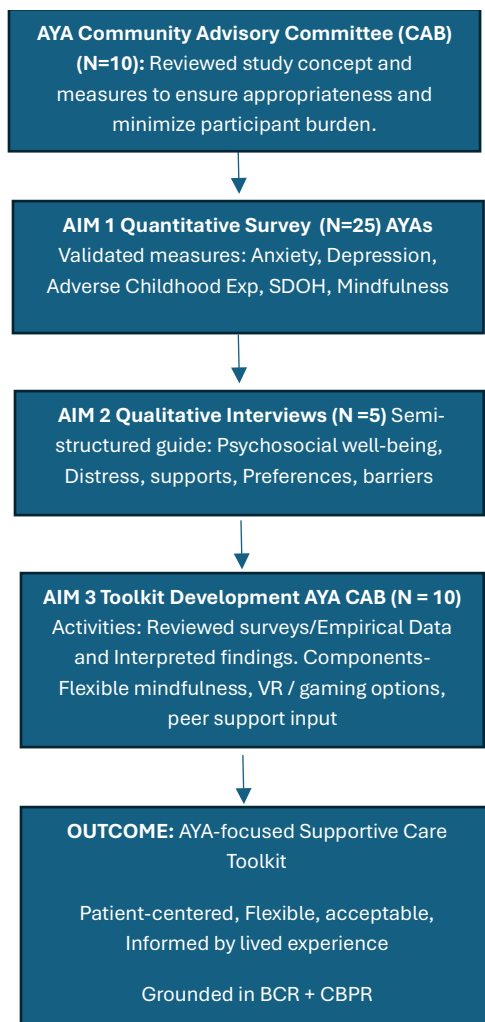
perspectives are often underrepresented in research. Evidence from participatory oncology research supports this approach; for example, Casillas, Ganz, Kahn, and colleagues (2021) used community-partnered participatory methods with Latino AYA and community organizations to co-develop survivorship interventions, ensuring cultural relevance and feasibility. Likewise, the BRIGHTLIGHT study included AYA from the outset, with advisory members contributing to study naming, outcome selection, and interpretation of results (Korenblum et al., 2025). In the present study, AYA CAB members were involved both prior to data collection reviewing measures for appropriateness and burden and after data collection, where they reviewed findings and co-created intervention strategies. This iterative feedback process directly shaped the development components of a supportive care intervention toolkit tailored to AYA with cancer.

Building on a foundational understanding of AYA cancer experiences, the present study employed a sequential multi-methods design to investigate psychosocial outcomes and inform the development of a supportive care intervention toolkit through a participatory framework. The integration of pilot study quantitative and qualitative findings (described in Chapter 3) was further enriched by the involvement of an AYA CAB, which contributed critical insights into intervention targets, preferred delivery formats, and features that would enhance the acceptability and feasibility of the proposed toolkit. This paper focuses on the third aim of the study, emphasizing the methodological innovation of engaging the AYA CAB both prior to and following data collection to co-create a responsive and contextually grounded intervention toolkit.

## Methods

This study utilized a sequential multi-methods design embedded within a CBPR framework (Israel, Eng, Schulz, & Parker, 2013; see Figure 3). The multi-methods approach enabled integration of quantitative and qualitative data to comprehensively examine psychosocial health, well-being, and distress among AYA with cancer. The CBPR framework ensured that AYAs were active collaborators in all stages of the research process, from design through interpretation and dissemination.

**Figure 3.** Study Design & Community Based Participatory Research Process Flowchart



The CAB consisting of 10 AYA diagnosed with cancer at varying stages of treatment and survivorship was established through referrals from the medical team at Children's National Hospital. Inclusion criteria for CAB participation included being between the ages of 12 and 21 years at diagnosis, ability to communicate in English or Spanish, and willingness to engage in multiple consultation meetings (both group and individual meetings were offered) throughout the study. CAB members represented diverse demographic and diagnostic backgrounds to ensure that a broad range of lived experiences and perspectives were reflected in the research.

Following CAB formation, the lead investigator conducted an initial orientation and review meeting to introduce the study objectives, review proposed data collection procedures, and collaboratively refine study materials. This included a structured review of all quantitative measures to ensure their relevance, developmental appropriateness, and ability to minimize participant burden and emotional distress. The semi-structured interview guide for qualitative data collection was also reviewed by the CAB to ensure sensitivity to participants' experiences and appropriateness of question tone, content, and sequencing. Revisions were made through an iterative process until the CAB reached acceptance on all study materials. This process reflected key CBPR principles of shared ownership, co-learning, and respect for participant expertise as partners in research.

Upon final approval of study materials, CAB members were invited to formally enroll in the study and complete quantitative assessments. All study participants were subsequently offered the opportunity to participate in qualitative interviews, with five individuals electing to do so from the total sample using self-selection to indicate they

would like to participate. Not all CAB members chose to participate in the qualitative interviews.

These findings were then summarized and reviewed in partnership with the same AYA CAB post data collection to inform components for a supportive care intervention toolkit tailored to the unique needs of this population. This approach was consistent with CBPR principles of shared decision-making, mutual benefit, and co-learning (Simonds, Wallerstein, Duran, & Villegas, 2013), ensuring that AYA perspectives guided the intervention development process at every stage.

CAB feedback was documented and analyzed targeting the key items that were priorities in supporting the psychosocial well-being of AYA with cancer alongside empirical findings from Chapter 2 Scoping Review findings. Across all phases, methodological rigor was ensured using validated instruments, credibility and reflexivity in qualitative analysis, and transparent documentation of CAB contributions.

The study was approved by the Institutional Review Board of record at Children's National Hospital (STUDY00000751 approved 10/30/2023) and a Waiver of Documentation of Consent/Assent and a Waiver for Alteration of Health Insurance Portability and Accountability Act were approved, given the study's minimal risk classification. A reliance agreement was established with the Institutional Review Board at University of Maryland Baltimore (HP-00108985 approved 1/5/2024) as recruitment occurred at the Hematology/Oncology clinic (Appendix B).

## Results

A total of 10 AYA participated in the community advisory board (CAB). CAB members were primarily male (90%), diagnosed with Leukemia (80%) and Lymphoma (20%) with a mean age of 17.1 and were racially diverse (Table 7). Members engaged in two phases of consultation: before data collection to review study questionnaires and following data collection to review aggregate findings and guide intervention development.

**Table 7.** Community Advisory Board Demographics

<b>Variable</b>	<b>(N=10)</b>
<b>Age, mean (SD) [range]</b>	17.1 (2.6) [12-21]
<b>Sex, n (%)</b>	
Female	1 (10)
Male	9 (90)
<b>Race<sup>a</sup>, n (%)</b>	
Asian	2 (20)
Black or African American	3 (30)
White	4 (40)
American Indian	1 (10)
Declined to answer	0 (0)
<b>Ethnicity, n (%)</b>	
Hispanic or Latino	2 (20)
<b>Cancer diagnosis, n (%)</b>	
Leukemia	8 (80)
Lymphoma	2 (20)

Pre-data collection feedback focused on the importance of minimizing participant burden, both in terms of time commitment and emotional strain. CAB members recommended shortening redundant measures (Quality of Life measures removed), using plain language for sensitive items, and incorporating flexible survey completion options (REDCap electronic completion) to accommodate fatigue or treatment schedules. All

members of the CAB agreed that the inclusion of the Adverse Childhood Experiences measure was both necessary and appropriate for assessing psychosocial risk among AYA with cancer. They also emphasized the importance of timing in administering all measures, noting that responses may vary depending on the clinical context for example, anxiety levels may be elevated during hospitalization compared to post-discharge. Additionally, CAB members recommended expanding the assessment to include questions about secondary diagnoses, such as Attention-deficit/hyperactivity disorder, which may influence how adolescents perceive and report their well-being and emotional responses to their cancer diagnosis and treatment. Their feedback resulted in streamlining the assessment battery and restructuring items order to reduce distress, consistent with CBPR principles of participant relevance and feasibility (Israel et al., 2013).

Post-data collection consultations centered on interpreting findings from quantitative and qualitative data (Chapter 3) and identifying intervention priorities. Preliminary evidence that was presented to the CAB showed that lower mindfulness qualities are associated with higher symptoms of anxiety and depression in adolescents and young adults with cancer, even in the presence of adverse childhood experiences and challenging social determinants of health. Male participants reported higher Mindful Attention Awareness Scale scores than females, and Hispanic/Latino or American Indian participants reported lower Child and Adolescent Mindfulness Measure scores.

Qualitative findings that were shared with the CAB highlight the critical role of close family and peer support, as well as the therapeutic value of both structured mindfulness practices and personally meaningful activities such as mindful walking, time in nature, and engaging in hobbies, in helping AYA cope with the cancer experience.

CAB members affirmed the salience of psychosocial distress, particularly anxiety and depression, while also emphasizing practical stressors such as social isolation, financial challenges, and disruptions to education and employment. Members noted that traditional support models often failed to adapt to the fluctuating symptom burden associated with treatment and highlighted the need for interventions that were flexible, accessible, and engaging.

From these discussions, several key toolkit components were prioritized. Empirical data from Chapter 2 Scoping Review were shared with the CAB alongside the quantitative and qualitative data. Identified components were (1) individualized and one-on-one mindfulness sessions were endorsed, with an emphasis on flexible delivery that could be adapted on days when treatment side effects or fatigue may limit participation; (2) CAB members recommended the incorporation of video game-based coping strategies, including virtual reality experiences, building games, and farming games, as effective forms of distraction from daily challenges; (3) members identified adaptable delivery formats designed to remain accessible across care settings and treatment phases; (4) opportunities to connect with other AYA in supportive and flexible formats (i.e. virtual). Collectively, these inputs informed the development of components for a supportive care intervention toolkit designed to enhance psychosocial well-being while remaining responsive to the lived experiences of AYA (Table 8).

**Table 8.** Supportive Care Toolkit Components with CAB Input

<b>Toolkit Component</b>	<b>Description</b>	<b>CAB Input/Feedback</b>	<b>Intended Purpose</b>	<b>Participant Quote</b>
<b>Flexible Mindfulness Sessions</b>	One-on-one sessions tailored to AYA needs and symptom burden.	Requested flexibility in timing, length, and format.	Promote coping, reduce anxiety, fit within treatment schedules.	“I would probably say online for the convenience and everything. And then with online you can take it all places with you. Where as in person you have to commit to a place a time. Sometimes during the treatment when you don’t feel as well you don’t have to worry as much about the pace.”
<b>Virtual Reality (VR) Games</b>	Immersive experiences for distraction and stress reduction.	Preferred VR for pain and distress during treatment.	Provide engaging escape from cancer-related stress.	“What this VR app is called, my mom used this app for a bit, and you can play like meditations and stuff, and like I don’t know, there are... one thing was like pretend you’re at the ocean, all of your muscles like relaxed, and I don’t know, you just play meditations, like you can play them, just as you’re sitting around”
<b>Building / Farming Games</b>	Low-stress, interactive games accessible across platforms.	Identified as comforting, easy to use during fatigue or treatment downtime.	Encourage relaxation and sense of normalcy.	“My farming game helps me to relax. Helps me not to focus on feeling bad from my chemo. It’s a nice distraction. Minecraft helps to just focus on building and playing”
<b>Peer Support Integration</b>	Opportunities to connect with other AYA in supportive formats.	Emphasized value of shared lived experience and peer validation.	Reduce isolation, foster community, normalize experiences.	“Well, most of my friends, our friendships have like kind of disappeared because we don’t talk as much and they never really reach out, so I don’t really have any good friends right now... I see them less than I would if I was at school. Having the ability to connect with other teens going through cancer would make me feel better”
<b>Toolkit Flexibility</b>	Options tailored to individual preference and symptom variability.	Highlighted need for customizable resources to reflect diverse AYA needs.	Increase acceptability, sustainability, and real-world use.	I personally like it on my own. I think it may help other people to do it with others but personally I would like to do it on my own. Sometimes I just don’t know when I will feel nauseous and I don’t like to be around people when that happens”

## **Discussion**

This study's findings and procedural innovations align closely with the Building Community Resilience (BCR) framework described by Ellis and Dietz (2017). The CAB's input regarding adverse childhood experiences (ACEs), social determinants of health, and resilience reflects the "Pair of ACEs" concept, which recognizes that early life adversity and community-level challenges such as poverty, discrimination, or housing instability interact to shape health trajectories. By highlighting both individual psychosocial distress and broader structural challenges, the CAB echoed the BCR model's emphasis on addressing toxic stress through interventions that target both personal coping and systemic barriers. Pre-study feedback from the CAB emphasized the importance of assessing ACEs, leading to their inclusion in the study measures. However, post-study feedback revealed that ACEs were not a prominent topic of discussion among participants, which may reflect either the lack of statistically significant findings due to the small sample size or a greater salience of other psychosocial outcome variables during qualitative interviews.

This study highlights the value of integrating AYA as active partners in intervention development through a CBPR framework. By engaging an AYA CAB both prior to and following data collection, the research team ensured that study measures were developmentally appropriate and that intervention priorities were directly informed by those with lived experience. This approach aligns with existing literature demonstrating that CBPR enhances cultural and contextual relevance, fosters trust, and improves feasibility of interventions in oncology settings (Casillas et al., 2021; Israel et al., 2013; Simonds et al., 2013).

Methodologically, the use of a CAB facilitated both rigor and relevance. Pre-data collection feedback minimized participant burden while preserving measurement validity, addressing a common barrier to psychosocial research with medically vulnerable populations. Post-data collection consultations functioned not only as a mechanism for validating findings but also as a structured process for co-creating intervention components. This dual role of the CAB demonstrates how participatory models can move beyond advisory consultation to genuine collaboration, ensuring that interventions are anchored in the preferences and priorities of the intended population (Korenblum et al., 2025).

The development of the supportive care toolkit also reflects growing evidence on the value of toolkits as vehicles for translating evidence into practice. Toolkits are widely used in healthcare to package evidence-based resources into accessible, adaptable formats that can be implemented across diverse settings (Gagliardi et al., 2015). In psychosocial oncology, toolkits support self-management, reduce barriers to access, and facilitate continuity of care (Devine, Viola, Coups, & Wu, 2018). When toolkits are co-created with the intended population, they are more likely to be perceived as relevant, acceptable, and feasible in real-world contexts (Hannon et al., 2017). In this study, CAB members directly shaped toolkit components, prioritizing flexible mindfulness sessions that could adapt to fluctuating symptom burden and recommending engaging distraction strategies such as virtual reality and building games. These features not only align with the CAB's lived experience but also exemplify how co-design enhances feasibility and sustainability.

By integrating the BCR model with participatory toolkit development, this study contributes to a growing methodological literature on psychosocial intervention design in AYA oncology. The BCR framework situates individual-level outcomes such as anxiety and depression within the broader context of social determinants of health, providing a rationale for interventions that address both coping skills and systemic inequities. Meanwhile, the toolkit model emphasizes flexibility and adaptability, ensuring that interventions can meet AYA where they are, across settings of care and stages of treatment. Together, these approaches underscore that sustainable psychosocial interventions must be both evidence-based and community-informed.

The development of the supportive care toolkit illustrates the potential of this participatory process. By integrating mindfulness practices with video game-based distraction strategies, the toolkit reflects both evidence-based psychosocial approaches and innovative modalities that resonate with AYA. Importantly, the emphasis on flexibility and portability addresses the unique challenges of cancer care during adolescence and young adulthood, when treatment intensity, symptom burden, and developmental transitions can vary widely. These findings echo prior work underscoring the importance of adaptability in supportive interventions for AYA (Abdelhadi et al., 2022; Osmani et al., 2023).

In addition to these empirical and theoretical considerations, the lead investigator's positionality shaped the design and implementation of this work. The lead investigator is an experienced nurse researcher whose professional expertise lies in oncology care and psychosocial health. Importantly, she was also diagnosed with cancer as an adolescent more than 20 years prior to this study. This dual perspective as both a

clinician and former patient provided unique insight into the challenges AYA encounter, from managing treatment side effects and symptom burden to navigating the developmental disruption that accompanies a cancer diagnosis during adolescence or young adulthood. Drawing on this lived experience informed the process of fieldwork, particularly in the selection of measures, the framing of interview questions, and the prioritization of participant well-being. It also reinforced the central importance of partnering with AYA themselves through the community advisory board to ensure that the study authentically represented their voices, preferences, and needs.

Overall, the results demonstrate that CBPR offers a feasible and effective framework for developing psychosocial interventions tailored to AYA with cancer. By centering youth voices in the design process and integrating both evidence-based and innovative strategies, the study advances the field of AYA psycho-oncology and provides a replicable model for participatory intervention development. Future directions include the application of evidence-based implementation strategies to operationalize the components of the intervention toolkit and to evaluate the feasibility and acceptability of the model among AYA with cancer.

### **Strengths and Limitations**

This study demonstrates several methodological strengths. It employed a CBPR framework to ensure AYA with cancer were active partners in shaping the research process. Engagement with the CAB throughout the study enhanced its developmental relevance and feasibility, while the integration of quantitative, qualitative, and advisory data strengthened the rigor of the mixed-methods design. The positionality of the lead investigator further strengthened the methodological approach. As both a nurse researcher

and a former adolescent with cancer, she was able to anticipate areas of potential participant burden, facilitate empathetic engagement during interviews, and prioritize the authenticity of AYA voices throughout the study. This reflexive stance aligns with emerging calls in qualitative and mixed-methods research to acknowledge the influence of researcher positionality on study design and interpretation (Berger, 2015).

Nonetheless, several limitations must be acknowledged. The sample size was small, particularly for the qualitative interviews, which may limit the transferability of findings across diverse AYA populations. CAB membership, while diverse in treatment and demographic background, was drawn from an institution in a single geographic region (Eastern United States) and may not fully capture the heterogeneity of AYA cancer experiences across geographic or cultural contexts. Additionally, although the intervention toolkit reflects the expressed preferences of participants and advisory members, its acceptability and efficacy have not yet been empirically tested. Future research should evaluate the implementation of the toolkit in larger and more diverse AYA populations, with attention to feasibility, cultural tailoring, and long-term outcomes. Despite these limitations, the methodological innovations and participatory processes described here provide a strong foundation for future intervention development in AYA psycho-oncology.

### **Clinical Implications**

The findings of this study underscore the importance of embedding psychosocial interventions for AYA with cancer within a participatory and resilience-focused framework. Involving AYA directly through community advisory boards ensures that supportive care resources are aligned with patient-identified priorities and reduces the

risk of mismatch between clinical offerings and lived needs. In practice, clinicians can draw on these methods to co-create interventions that reflect the voices of those most affected by cancer. Equally important is the flexibility of supportive care delivery. Intervention components such as individualized mindfulness sessions and distraction-based strategies, including virtual reality and gaming platforms, must be adaptable to the fluctuating symptom burden, treatment schedules, and psychosocial stressors that AYA encounter. Finally, this work highlights the need to address broader determinants of health in psychosocial care. Recognizing the influence of adverse childhood experiences and social determinants of health can guide clinicians toward holistic care models that combine individual-level coping support with system-level advocacy and resource navigation. Together, these clinical implications call for a shift away from standardized, one-size-fits-all approaches toward strategies that are co-designed, adaptable, and situated within a resilience-building framework. This approach offers a pathway to delivering more equitable and patient-centered psychosocial oncology care for AYA.

## **Conclusions**

Through the sustained involvement of an AYA community advisory board, we co-designed a supportive care toolkit that reflects patient-identified priorities. Toolkits such as this have been shown to improve uptake, adaptability, and sustainability when they are built with the direct input of end-users (Gagliardi et al., 2015; Hannon et al., 2017). By incorporating both evidence-based components and lived-experience feedback, the toolkit offers a model for addressing psychosocial distress that is both responsive and equitable. The methods and processes described here provide a replicable pathway for future

intervention development efforts seeking to address the psychosocial needs of vulnerable populations across diverse healthcare settings utilizing evidence-based delivery formats.

## **CHAPTER 5 Lessons Learned from Building a Supportive Care Intervention Toolkit for AYA with Cancer**

*Take a Moment to Breathe: A Multi-Methods Study to Build Supportive Interventions for the Psychosocial and Overall Well-Being of AYA with Cancer* explores the urgent need for holistic, developmentally sensitive interventions to address the profound psychosocial suffering experienced by Adolescents and Young Adults (AYA) diagnosed with cancer. The purpose of this dissertation was to (Aim 1) quantify and explore relationships among anxiety, depression, adverse childhood events, social determinants of health, and mindfulness qualities; (Aim 2) to explore the psychosocial health, well-being, and distress of AYA with cancer during active treatment and sources of support they perceive as helpful; and (Aim 3) Determine targets and preferences for delivery and format of an AYA-focused intervention or supportive toolbox. The three manuscripts are presented in Chapters 2, 3 and 4. This chapter summarizes major findings, examines strengths and limitations, underlines implications for clinical practice and policy and recommendations for future nursing research.

### **Summary of Study Findings**

#### **Chapter 2 Mindfulness in Relation to Psycho-Social Suffering: A Scoping Review**

In this chapter, I conducted a systematic, librarian-assisted scoping review (Arksey & O'Malley, 2005) to determine the scope and nature of existing mindfulness-based interventions (MBIs) for adolescents with cancer. Across the 27 studies that met inclusion criteria, I found most studies targeted pediatric oncology patients aged 11–18, though adolescents 14–18 were often underrepresented. MBIs were delivered through group sessions, individualized bedside programs, mobile apps, and interactive e-books,

with core components like breath awareness, body scans, and meditation. Feasibility and acceptability were consistently high, especially for digital intervention which offer scalability and accessibility. Barriers included treatment fatigue and scheduling conflicts. Psychosocial outcomes measured included anxiety, depression, stress, fatigue, and quality of life, with several studies reporting significant improvements in these domains. Limitations included small sample sizes, lack of control groups, short follow-up durations, and reliance on self-report measures. Heterogeneity in intervention content and outcome measures limited cross-study comparability. Cultural and gender representation was often lacking, and few studies rigorously evaluated digital engagement or long-term effects.

The findings support integrating MBIs into pediatric oncology care as non-pharmacologic strategies to address psychosocial distress. Digital delivery platforms are promising for expanding access, especially among adolescents. Mindfulness practices offer a critical step toward addressing the lack of interventions for psychosocial suffering in AYA cancer patients and impact health and quality of life during active treatment and survivorship, but further research is needed to optimize intervention design and implementation.

### **Chapter 3 “Cancer Can’t Rob You of Yourself” Adolescent and Young Adults’ Experiences with Their Cancer Diagnosis: A pilot multi-methods study**

In chapter 3, I describe the results of a multi-method, community-engaged pilot study at two pediatric oncology centers. This pilot study employed a multi-method, community-engaged design across two pediatric oncology centers. Quantitative data were collected from 25 AYA aged 12–21 years, using validated measures for anxiety,

depression, ACEs, SDoH, and mindfulness qualities (CAMM and MAAS). Qualitative data were obtained through semi-structured interviews with a subset of five AYA, exploring their psychosocial experiences, sources of support, and preferences for intervention delivery. Recruitment emphasized inclusivity across demographic variables, and data collection was conducted in both English and Spanish. The study also involved a patient advisory board to guide research questions and the co-development of AYA friendly research procedures. AYA.

Quantitative analyses revealed that higher levels of anxiety and depression were strongly associated with lower mindfulness scores on both Child and Adolescent Mindfulness Measure (CAMM) and The Mindful Attention Awareness Scale (MAAS). ACE exposure trended toward negative associations with mindfulness but did not reach statistical significance. Demographic factors had limited effects, though males reported higher MAAS scores compared to females and Hispanic/Latino or American Indian participants reported lower CAMM scores compared to Black peers. From the qualitative data, I identified three central themes: (1) the emotional dynamics of cancer diagnosis, (2) facilitators of well-being at interpersonal and intrapersonal levels, and (3) challenges faced during the cancer journey. AYA described their experiences as highly individualized, with emotional responses ranging from shock and sadness to resilience and acceptance. Support from family, healthcare providers, and peers was crucial, and AYA expressed openness to mindfulness practices such as deep breathing, mindful walking, and app-based meditation.

Through this multi-method analysis, I learned psychological distress was associated with lower mindfulness qualities among AYA with cancer, aligning with

previous research in both general and cancer populations (Van der Gucht et al., 2017; Prentice, Rees, & Finlay-Jones, 2021). Social support emerged as a robust protective factor, with participants emphasizing the importance of close relationships in coping with diagnosis and treatment. AYA valued intentional distractions and personalized coping strategies, including both formal mindfulness practices and informal activities like nature immersion and hobbies. The findings suggest that psychosocial care for AYA should integrate mechanisms to strengthen social connections and offer flexible, developmentally tailored interventions that combine structured MBIs with participant-preferred activities. Hybrid delivery formats, including app-based and in-person options, may enhance accessibility and engagement.

#### **Chapter 4 Empowering AYA Voices: A Community-Based Approach to Supportive Cancer Care**

In chapter 4, I brought the findings of the scoping review together with the empirical findings described in chapter 3 to create a mindfulness toolkit, using a community engaged approach. I worked with the same AYA community advisory board (CAB) from chapter 3, of 10 AYA and sought their feedback about the study findings and effective intervention components gleaned from the scoping review through individual discussions. This partnership culminated in co-creation of the supportive care toolkit that includes AYA flexible, individualized mindfulness sessions; video game-based coping strategies (e.g., virtual reality, building and farming games); and adaptable delivery formats to accommodate fluctuating symptom burden and treatment schedules. Peer support integration and customizable resources were emphasized to foster community and increase acceptability. The toolkit was designed to be portable and responsive to AYA' changing needs across care settings.

The participatory approach allowed for the creation of a toolkit that responds to both individual coping and systemic barriers to well-being. Centering AYA voices in toolkit design allows for developmental appropriateness, cultural relevance, and feasibility. Toolkits co-created with AYA are more likely to be perceived as acceptable and sustainable in real-world contexts (Hannon et al., 2017). Clinical implications include the need for flexible, patient-centered psychosocial interventions that integrate mindfulness, distraction-based strategies, and peer support, while also addressing broader determinants of health. This approach moves away from standardized, one-size-fits-all models toward strategies that are co-designed, adaptable, and resilience-focused.

### **Study Strengths and Limitations**

The collective strengths of Chapters 2, 3, and 4 reflect a rigorous, multi-methodological approach to understanding and addressing psychosocial distress among AYA with cancer. The strengths of chapter 2 include adherence to the Arksey and O'Malley framework and PRISMA-ScR guidelines, with a registered protocol and a librarian-assisted comprehensive search strategy that enhances transparency and reproducibility. It synthesizes a diverse body of literature on mindfulness-based interventions (MBIs), identifying core components, delivery formats, and psychosocial outcomes relevant to pediatric oncology. The strengths of chapter 3 include the use of a multi-methods approach to capture both quantitative description through validated quantitative measures and nuance through qualitative interviews; guidance by and AYA CAB to ensure research procedures were feasible and developmentally sensitive; and the use of multiple analysts in the qualitative analysis. The strengths of chapter 4 include the use of a community-based participatory research (CBPR) framework, actively engaging

AYA in the co-design of a supportive care toolkit. The integration of advisory board input throughout the research process ensured developmental relevance, feasibility, and authenticity of AYA voices, while description of the investigator's reflexive positionality contributed to empathetic and context-sensitive methodological choices.

Despite these strengths, several limitations are evident across chapters. Chapter 2 is constrained by the underrepresentation of the target age group (14–18 years), heterogeneity in intervention designs, and limited attention to trauma-informed and equity-based factors such as ACEs and SDoH. The small sample size and cross-sectional design of the study outlined in chapter 3 limit generalizability and causal inference, while self-reported measures may introduce bias. The qualitative findings, though rich, reflect the perspectives of a self-selected group from two urban hospital institutions, which can limit transferability. Further research is needed to explore structural inequities in intervention accessibility. Chapter 4, while methodologically innovative, draws its CAB membership from an institution within a single geographic region, potentially limiting cultural and geographic diversity. Across all chapters, the broad age range (12–21 years) presents challenges for developmental specificity, suggesting future research should tailor interventions to distinct stages of adolescence and young adulthood. Nonetheless, the integration of empirical evidence, stakeholder engagement, and reflexive practice across these chapters provides a strong foundation for advancing psychosocial care in AYA oncology.

## **Implications for Clinical Practice**

Based on the findings and recommendations across all chapters and included studies, several key clinical practice recommendations emerge for supporting adolescents and young adults (AYA) with cancer. First, clinicians should routinely screen for psychosocial distress, including symptoms of anxiety and depression, using validated measures at regular intervals throughout the cancer care continuum. This screening should also encompass adverse childhood experiences (ACEs) and social determinants of health (SDoH), such as housing instability, financial stress, and access to care, to identify AYA at heightened risk for poor psychosocial outcomes. Second, the integration of MBI into supportive care for AYA with cancer is recommended. The AYA in this study endorsed mindfulness practices including meditation, deep breathing, and yoga and other research supports feasibility and acceptability among AYA, with evidence supporting their role in reducing psychological distress. Clinicians should offer both formal mindfulness programs and informal, accessible options, such as app-based exercises or brief guided practices, to accommodate varying preferences and energy levels.

Third, providing flexible, individualized support toolkits created by and with AYA is recommended. Such collaboration ensures that programs reflect authentic patient voices and preferences, and increases the relevance, acceptability, and sustainability of supportive care resources. AYA Psychosocial support should be age-appropriate, flexible, and sensitive to the unique challenges of adolescence and young adulthood, including identity formation, independence, and peer relationships. Recognizing these developmental factors is essential for designing interventions that resonate with AYA and foster engagement.

Based on the findings of this dissertation, supportive care toolkits should include mechanisms to facilitate support across the systems in which the AYA resides. At the individual AYA levels, supportive tool kits should offer a menu of supportive care options including mindfulness sessions, gaming or distraction strategies that can be portable, tailored to each AYA's needs and symptom burden, and adaptable across care settings and treatment phases to ensure continuity and relevance. At the peer and family relationship level, supportive tool kits should facilitate connection among AYA and peers, family, and supportive networks to mitigate isolation and enhance coping. These social supports are robust protective factors against distress and should be integrated into care plans. Leveraging technology to make such connections possible through mobile applications, virtual reality experiences, and online peer support is warranted. Finally, supportive tool kits can support AYA as they encounter and address practical barriers and social needs. For example, given the impact of SDoH on treatment adherence and psychosocial outcomes, AYA and their families could be connected to resources for financial counseling, transportation, housing, and educational supports in their local communities.

### **Implications for Nursing Research**

Future research should examine AYA psychosocial well-being, mindfulness, and quality-of-life outcomes longitudinally using validated measures to refine interventions and ensure their ongoing relevance and effectiveness. Further testing of supportive care toolkits and their impact on larger samples of AYA with cancer is needed and may be accomplished using pragmatic or multi-center trials. Additional research is required to more comprehensively describe the influence of ACEs, SDoH, and other structural factors on the psychosocial well-being of AYA with cancer. The role of technology, such

as virtual reality and artificial intelligence, among this population also warrants further investigation on safety and efficacy, as these tools may augment engagement, coping, and self-management.

Equally important, nursing research should advance understanding of family systems and social support as central determinants of AYA psychosocial health and recovery. Adolescence and young adulthood represent periods of growing independence, yet family remains an enduring and powerful influence on coping, emotional regulation, and health behaviors throughout the cancer continuum. Research demonstrates that family functioning, communication, and perceived support are significantly associated with psychosocial adjustment, treatment adherence, and quality of life among AYA (Wiener et al., 2015; Harper et al., 2021). Families often experience their own distress and uncertainty, which can in turn affect the patient's emotional well-being and engagement in care. Therefore, understanding the bidirectional dynamics between AYAs and their families is essential to developing interventions that support both autonomy and connectedness.

Nurse-led, family-based interventions represent a promising avenue for promoting resilience and holistic well-being. Nurses are uniquely positioned to facilitate open communication within families, identify unmet psychosocial needs, and provide ongoing education and emotional support. Interventions that integrate family-centered mindfulness, psychoeducation, and coping strategies can help families navigate role changes, manage uncertainty, and build collective resilience. Nurse researchers should also explore dyadic and triadic designs for example, AYA-caregiver or AYA-sibling studies to better capture the interdependence of emotional experiences within family

systems. Families often provide insights into barriers to care, transitions between treatment and survivorship, and the feasibility of implementing psychosocial supports in home environments. Integrating these perspectives enhances the ecological validity and sustainability of interventions developed for AYAs.

Finally, further research of supportive care for AYAs and their families should be analyzed within a resilience-building framework that acknowledges both individual coping and systemic challenges. Clinicians should advocate for holistic care models that combine individualized psychological support with system-level advocacy, equitable access to mental health services, and family resource navigation. Nursing research and practice grounded in this integrative, resilience-oriented approach can contribute to reducing psychosocial disparities and strengthening the continuity of care across the AYA cancer trajectory.

## **Conclusion**

This dissertation advances understanding of psychosocial suffering and resilience among AYA with cancer through a multi-method, community-engaged approach. Chapter 2's scoping review revealed that MBI are feasible and acceptable in pediatric oncology, particularly when delivered digitally, yet highlighted gaps in cultural representation, long-term evaluation, and developmental tailoring. Chapter 3's pilot study demonstrated that psychological distress is inversely related to mindfulness qualities, and that AYA value personalized coping strategies and social support. Chapter 4 built upon these insights by engaging AYA directly in the co-design of a supportive care toolkit, emphasizing flexibility, relevance, and accessibility through mindfulness sessions, video game-based coping, and peer support.

Together, these findings underscore the importance of integrating trauma-aware, developmentally sensitive, and culturally responsive interventions into AYA cancer care. By centering AYA voices and leveraging CBPR, this work contributes a replicable model for designing psychosocial supports that are both evidence-informed and grounded in lived experience. Future research should continue to refine and evaluate these interventions across diverse populations and care settings, with the goal of promoting resilience, reducing distress, and improving quality of life for AYA navigating cancer.

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**APPENDIX A**

**1. A Randomized Clinical Trial of a Modified Mindfulness-Based Cognitive Therapy for Children Hospitalized with Cancer**

<b>Reference/Citation</b>	<p>Abedini, S., Habibi, M., Abedini, N., Achenbach, T. M., &amp; Semple, R. J. (2020). A Randomized Clinical Trial of a Modified Mindfulness-Based Cognitive Therapy for Children Hospitalized with Cancer. <i>Mindfulness</i>, 12(1), 141–151.  <a href="https://doi.org/10.1007/s12671-020-01506-3">https://doi.org/10.1007/s12671-020-01506-3</a></p>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Study conducted from August 2013 to June 2014 at the Mahak Hospital and Rehabilitation Complex - a public pediatric cancer research and hospital center</li> <li>● Located in Tehran, Iran</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● 40 pediatric oncology patients</li> <li>● Age: 11–13</li> <li>● 21 boys and 19 girls</li> <li>● All were receiving some form of cancer treatment             <ul style="list-style-type: none"> <li>○ 27.3% received chemotherapy, 66.7% received radiation treatment, and 6.1% received both chemotherapy and radiation</li> </ul> </li> <li>● Time that had passed since diagnosis ranged from 3 days to 1 month</li> <li>● Had to have the following to participate:             <ul style="list-style-type: none"> <li>○ Average fluency in Persian</li> <li>○ A first diagnosis of any type of cancer, excluding brain cancer</li> <li>○ Be undergoing radiation therapy and/or chemotherapy through the hospital’s oncology division</li> <li>○ Not received any psychological interventions or psychiatric meds in the 6 months preceding study</li> <li>○ Screened to have internalizing (<math>T \geq 60</math>) and attention problems (<math>T \geq 57</math>) on CBCL/YSR.</li> </ul> </li> <li>● Exclusions: Patients with brain cancer, developmental disabilities, major cognitive dysfunctions, terminal prognosis (&lt; 6 months), prior psychological interventions or psychiatric medications within 6 months.</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Early diagnosis (3 days to 1 month post-diagnosis); all were receiving active treatment; no terminal illness cases included</li> </ul>

<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Quantitative, randomized clinical trial (RCT)</li> <li>● Participants randomly assigned to Modified Mindfulness-Based Cognitive Therapy for Children (MBCT-C) (n=20) or Treatment as Usual (TAU) (n=20).</li> <li>● Longitudinal, with 3 assessment points: baseline, post-intervention, and 2-month follow-up.</li> <li>● Measures used: <ul style="list-style-type: none"> <li>○ Child Behavior Checklist (CBCL; parent-reported)</li> <li>○ Youth Self-Report (YSR; child self-reported)</li> </ul> </li> <li>● Clinically meaningful change evaluated via Reliable Change Index (RCI)</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Modified MBCT-C adapted from original MBCT-C manual <ul style="list-style-type: none"> <li>○ Hospitalization ranged from 40-60 days</li> <li>○ Duration reduced to 4 weeks (from standard 12-week program).</li> <li>○ Total of 20 sessions, each lasting 45 minutes, conducted 5 times weekly.</li> <li>○ Adaptations to hospital constraints: Removed yoga, mindful eating due to physical fatigue and medical limitations.</li> <li>○ Groups consisted of 2-4 participants, smaller than typical due to scheduling constraints and medical status.</li> <li>○ Conducted by trained therapist, supervised for fidelity.</li> <li>○ Each child received a workbook for assignments and practices.</li> </ul> </li> <li>● Control Group (TAU): Standard medical treatments with limited psychosocial support, including information and optional unstructured play activities.</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Primary Outcomes: <ul style="list-style-type: none"> <li>○ Significant reductions in internalizing (anxiety, depression, somatic complaints) and attention problems in the MBCT-C group compared to TAU <ul style="list-style-type: none"> <li>■ Post-treatment, ~94.7% of subjects in MBCT-C group were categorized in normal T-score range for internalizing problems on both CBCL and YSR</li> <li>■ 89.5% (CBCL) and 73.7% (YSR) categorized in normal T-score range for attention problems</li> </ul> </li> <li>○ Improvements were maintained at 2-month follow-up <ul style="list-style-type: none"> <li>■ 94.1% were categorized in normal T-score range on both CBCL and YSR</li> </ul> </li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ No significant improvement observed in TAU group</li> <li>● Statistical Outcomes (Key details): <ul style="list-style-type: none"> <li>○ Internalizing Problems (CBCL): MBCT-C group showed marked decrease post-intervention (69.31→50.60; p&lt;.0001), maintained at follow-up (50.36). TAU remained stable (68.42→69.41)</li> <li>○ Internalizing Problems (YSR): MBCT-C group significantly reduced (70.22→51.25; p&lt;.0001), maintained at follow-up (50.52). TAU no significant change (69.57→69.02)</li> <li>○ Attention Problems (CBCL): MBCT-C group showed significant improvement (65.91→51.17; p&lt;.0001), maintained at follow-up (50.05). TAU no significant change (68.00→68.44)</li> <li>○ Attention Problems (YSR): Significant improvement in MBCT-C group (69.19→50.00; p&lt;.0001), maintained (50.29). TAU worsened slightly (67.66→71.03)</li> </ul> </li> </ul>
<p><b>Discussion/Key Takeaways</b></p>	<ul style="list-style-type: none"> <li>● Clinical Significance: <ul style="list-style-type: none"> <li>○ Reliable Change Index scores indicated clinically meaningful and stable changes for MBCT-C group across all measures</li> <li>○ At post-intervention and again at the 2-month follow up assessment, no child in the MBCT-C group had clinically elevated symptoms for either internalizing or attention problems</li> <li>○ “By contrast, no significant changes were found for the TAU group either post-intervention or at the 2-month follow-up,” supporting the effectiveness of the program</li> </ul> </li> <li>● Novelty: <ul style="list-style-type: none"> <li>○ This study is one of the few to adapt MBCT-C specifically for inpatient pediatric oncology, addressing a population often excluded from mindfulness research <ul style="list-style-type: none"> <li>■ “The MBCT-C program flexibly attends to the concerns that are present within each individual group”</li> <li>■ The program was flexibly tailored to the unique needs of children with cancer, allowing space to explore real experiences (e.g., hair loss or being examined by doctors) in a safe, group setting.</li> </ul> </li> <li>○ Therapist training and supervision helped maintain consistency and quality in how the program was</li> </ul> </li> </ul>

	<p>delivered</p> <ul style="list-style-type: none"> <li>● Mechanisms highlighted: <ul style="list-style-type: none"> <li>○ Mindfulness helped children become more aware of their thoughts, emotions, and physical sensations, especially those tied to illness and treatment, without judgment. <ul style="list-style-type: none"> <li>■ This awareness allowed them to talk about difficult experiences, such as missing school, feeling pain or fatigue, or noticing family stress.</li> </ul> </li> <li>○ The intervention promoted self-acceptance and taught that others may interpret the same situation differently, which can reduce social and emotional reactivity.</li> <li>○ Exercises focused on breath, body, and senses gave children tools to respond differently to distressing thoughts, improving emotional control</li> <li>○ Attention problems, often worsened by anxiety and cognitive avoidance, were addressed through mindfulness strategies that retrained attention away from threat cues</li> </ul> </li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>● No active control group (TAU only)</li> <li>● Highly adapted protocol limits generalizability to standard MBCT-C</li> <li>● No long-term follow-up beyond 2 months; potential variability post-discharge</li> <li>● No formal fidelity assessment measure used, though therapist supervised</li> <li>● Adaptations of the protocol constrain direct comparison to standard MBCT-C studies</li> <li>● Brain cancers excluded based on research suggesting they may affect attention (key outcome variable)</li> <li>● Patients who had a major cognitive dysfunction or developmental disability, or were diagnosed with a terminal illness were excluded</li> <li>● Adaptations of the protocol constrain direct comparison to standard MBCT-C studies</li> </ul>
<p><b>Implications and Future Directions</b></p>	<ul style="list-style-type: none"> <li>● Demonstrates feasibility and efficacy of MBCT-C in reducing psychosocial distress among hospitalized pediatric oncology patients receiving cancer treatment</li> <li>● Suggests MBCT-C may promote resilience by reducing bias in attention and ruminative thinking.</li> <li>● Future studies recommended: <ul style="list-style-type: none"> <li>○ Larger samples</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Inclusion of more diverse diagnoses (e.g., brain tumors)</li> <li>○ Longer follow-up periods</li> <li>○ Behavioral and physiological outcome measures to supplement self-report</li> <li>○ Exploration of specific cancer types or treatment modalities' influences on attention and engagement</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● This RCT revealed that a significantly modified version of MBCT-C can be successfully adapted to a hospital context, showing substantial reductions in anxiety, depression, and attention issues in newly diagnosed pediatric oncology patients</li> <li>● The intervention was both statistically and clinically effective, offering strong support for MBIs in similar clinical settings and populations</li> </ul>

## **2. A pilot study to evaluate the feasibility of individualized yoga for inpatient children receiving intensive chemotherapy**

<b>Reference/Citation</b>	Diorio, C., Schechter, T., Lee, M., O'Sullivan, C., Hesser, T., Tomlinson, D., Piscione, J., Armstrong, C., Tomlinson, G., & Sung, L. (2015). A pilot study to evaluate the feasibility of individualized yoga for inpatient children receiving intensive chemotherapy. <i>BMC Complementary and Alternative Medicine</i> , 15(1). <a href="https://doi.org/10.1186/s12906-015-0529-3">https://doi.org/10.1186/s12906-015-0529-3</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Toronto, Ontario, Canada</li> <li>● Study conducted at The Hospital for Sick Children (SickKids)</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Pediatric oncology patients aged 7–18</li> <li>● Diagnoses included acute myeloid leukemia (AML), relapsed acute lymphoblastic leukemia (ALL), Burkitt's lymphoma, solid tumors, brain tumors, and aplastic anemia</li> <li>● Participants were receiving intensive chemotherapy or hematopoietic stem cell transplant (HSCT); specifically, 6 children (55%) underwent HSCT</li> <li>● 11 patients enrolled (8 completed the full yoga intervention)</li> <li>● All participants were hospitalized for at least 3 weeks</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Intensive treatment phase</li> <li>● All participants were inpatients undergoing high-intensity</li> </ul>

	<p>chemotherapy</p> <ul style="list-style-type: none"> <li>○ Acutely ill inpatient population</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Prospective single-arm pilot study (non-randomized)</li> <li>● Feasibility-focused</li> <li>● No control group</li> <li>● Mixed-methods (quantitative session tracking and qualitative feedback)</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Individualized yoga program tailored to the patient's physical ability, interest, and energy level <ul style="list-style-type: none"> <li>○ For example, based on child's medical schedule and condition</li> </ul> </li> <li>● Targeted 3 sessions per week for 3 weeks (later increased to 4–5 sessions/week excluding weekends)</li> <li>● Yoga sessions included breath work, guided relaxation, physical postures, and sensory exercises <ul style="list-style-type: none"> <li>○ Structured intensity levels (low/moderate/high)</li> </ul> </li> <li>● Led by trained/certified yoga instructors with pediatric experience</li> <li>● Sessions lasted approximately 30 minutes and were conducted bedside or in a playroom</li> <li>● Family members could participate</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Yoga was feasible: 10/11 participants met the threshold of at least 60% delivery of planned sessions</li> <li>● Median yoga sessions = 9 sessions; range = 3–13</li> <li>● “Mean ± standard deviation for the day 21 proxy-reported PedsQL general fatigue scores was 55.6 ± 15.5”</li> <li>● No adverse events were reported</li> <li>● Proxy-reported fatigue and QoL data collected; only 3 children self-reported</li> <li>● All children, caregivers, and nurses expressed positive impressions of the yoga program</li> <li>● Reported benefits included reduced anxiety, improved mood and sleep, decreased nausea, and greater energy</li> <li>● Engagement was high despite treatment intensity</li> <li>● Qualitative data suggested both physical (e.g., more energy, less nausea, reduced pain meds) and psychological benefits (e.g., better mood, sleep, relaxation) <ul style="list-style-type: none"> <li>○ Parents reported reduced fatigue, anxiety, agitation, and better overall mood and restfulness</li> </ul> </li> <li>● 3/3 children asked said they would participate in a future RCT</li> </ul>
<b>Discussion/Key</b>	<ul style="list-style-type: none"> <li>● Yoga was shown to be safe, acceptable, and feasible even in</li> </ul>

<p><b>Takeaways</b></p>	<p>a severely ill pediatric inpatient population undergoing intensive treatments</p> <ul style="list-style-type: none"> <li>● Novel aspects: <ul style="list-style-type: none"> <li>○ This is the first study to assess near-daily individualized yoga in such a high-acuity setting</li> <li>○ Aligns with prior feasibility studies but uniquely targets HSCT and chemotherapy inpatient children</li> <li>○ Supports the design of future RCT that reduce the burden of outcome measures and increase yoga exposure</li> </ul> </li> <li>● Tricky aspects: <ul style="list-style-type: none"> <li>○ Lack of randomization, single-site design, low threshold for feasibility, and limited child self-reporting</li> </ul> </li> <li>● Modifications to the original intervention protocol were necessary for this context (e.g., increasing session frequency, reducing session duration, eliminating weekend sessions)</li> <li>● Researchers emphasized the value of tailoring activities to patient energy levels and preferences</li> <li>● Study encourages use of parent proxy-reporting due to low child participation in surveys</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>● Small sample size (N=11)</li> <li>● No control group for comparison</li> <li>● Some patients were too unwell to participate fully or complete outcome questionnaires</li> <li>● Limited generalizability due to single-site setting</li> <li>● Many self-report scales were difficult to complete due to patient fatigue; proxy reporting was often needed</li> </ul>
<p><b>Implications and Future Directions</b></p>	<ul style="list-style-type: none"> <li>● Supports the feasibility of conducting a full RCT to test yoga’s effectiveness in reducing fatigue and psychological distress in pediatric oncology</li> <li>● Future studies should: <ul style="list-style-type: none"> <li>○ Reduce measurement burden and exclude unnecessary scales</li> <li>○ Use daily yoga (excluding weekends)</li> <li>○ Train multiple instructors to ensure consistency</li> <li>○ Consider use of child-centered outcome tools suitable for inpatient settings</li> </ul> </li> </ul>
<p><b>Additional Key Observations</b></p>	<ul style="list-style-type: none"> <li>● Children found yoga provided a welcome break from the hospital routine</li> <li>● Family involvement was frequent and appreciated</li> <li>● Some measures (e.g., school/social function items) were poorly suited to the inpatient setting</li> </ul>

	<ul style="list-style-type: none"> <li>● Strong anecdotal support for physical and emotional benefits, even though this study was not powered to assess efficacy</li> </ul>
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### 3. A Mobile-Based Mindfulness and Social Support Program for Adolescents and Young Adults With Sarcoma: Development and Pilot Testing

<b>Reference/Citation</b>	Donovan, E., Martin, S. R., Seidman, L. C., Zeltzer, L. K., Cousineau, T. M., Payne, L. A., Trant, M., Weiman, M., Knoll, M., & Federman, N. C. (2019). A Mobile-Based Mindfulness and Social Support Program for Adolescents and Young Adults With Sarcoma: Development and Pilot Testing. <i>JMIR MHealth and UHealth</i> , 7(3), e10921. <a href="https://doi.org/10.2196/10921">https://doi.org/10.2196/10921</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Participants were recruited from a pediatric sarcoma clinic in Los Angeles, California</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Adolescents and Young Adults (AYAs) with sarcoma <ul style="list-style-type: none"> <li>○ Ages 13–25</li> </ul> </li> <li>● 14 participants total; 8 females, 6 males (mixed gender)</li> <li>● All undergoing or had recently completed cancer treatment</li> <li>● Included participants in various stages of treatment or survivorship (specific breakdown not detailed)</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Mixed: Some participants were undergoing treatment, others had completed treatment <ul style="list-style-type: none"> <li>○ Not clearly specified; included AYAs either currently in treatment or survivors</li> </ul> </li> <li>● Not limited to early diagnosis, relapse, or survivorship exclusively</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Mixed methods pilot study</li> <li>● Feasibility and acceptability testing; not an RCT</li> <li>● Qualitative feedback collected post-intervention</li> <li>● Quantitative pre/post measures (self-report scales)</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● 28-day mobile-based intervention combining mindfulness and social support <ul style="list-style-type: none"> <li>○ 4-week mobile-based intervention: Mindfulness for Resilience in Illness (MiRI)</li> </ul> </li> <li>● Mindfulness delivered via the Mindful Powers app (designed for adolescents, includes audio-guided sessions, breathwork,</li> </ul>

	<p>emotion tracking)</p> <ul style="list-style-type: none"> <li>● Social support provided through a private Facebook group moderated by a psychologist</li> <li>● Participants encouraged to engage with both components daily</li> <li>● No control group (single-arm pilot)</li> <li>● Weekly email reminders and brief check-ins from study staff</li> <li>● Daily content delivered via text or email links to audio/video materials (2–4 minutes)</li> <li>● Topics included: breath awareness, body scan, acceptance, compassion, gratitude</li> <li>● Also included anonymous peer support features (messaging + feedback icons)</li> <li>● Optional participation by parents (access to their own parent-tailored content)</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Average adherence: 13.6 mindfulness sessions completed per participant (range: 3–28)</li> <li>● All participants engaged with the Facebook group at least once; average of 12.6 posts/comments per participant</li> <li>● Qualitative feedback indicated participants valued flexibility, peer connection, and emotional validation</li> <li>● Common themes included improved coping, reduced loneliness, and enjoyment of mindfulness practices</li> <li>● Participants recommended app improvements, such as older voice actors and tailored content for AYAs with cancer</li> <li>● High acceptability and usability; daily engagement varied, ~2–3 interactions per day</li> <li>● Perceived benefits included reduced stress, improved mood, greater self-awareness</li> <li>● Parent feedback suggested the parent module was helpful but less essential for all participants</li> <li>● No adverse events reported</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Novelty: <ul style="list-style-type: none"> <li>○ This was one of the first mobile interventions designed specifically for AYAs with sarcoma, integrating both mindfulness and social support</li> <li>○ Highlighted the potential of tech-based platforms to reach a dispersed, vulnerable population during and after treatment</li> </ul> </li> <li>● The flexibility, privacy, and brevity of content likely contributed to feasibility/acceptability and seen as helpful for youth managing cancer-related stress</li> <li>● Anonymous peer support via Facebook was especially valued as an outlet for shared experiences, reducing feelings</li> </ul>

	<p>of isolation</p> <ul style="list-style-type: none"> <li>● Some technical limitations and suggestions for improvement noted (e.g., app usability, message interface)</li> <li>● AYAs emphasized importance of relatable, non-patronizing tone in content delivery</li> <li>● Data suggest mobile-based delivery is a promising platform for psychological support during cancer treatment</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>● Small sample size, limiting generalizability</li> <li>● No control group; cannot assess intervention efficacy</li> <li>● Self-selection bias may have favored participants already open to mindfulness</li> <li>● Short duration (4 weeks)</li> <li>● Reliance on self-report data for engagement and outcomes</li> <li>● Lack of diversity in cancer type (focused only on sarcoma)</li> <li>● Challenges included technical limitations of the app and variation in engagement across participants</li> <li>● App not originally designed for cancer patients, limiting content relevance</li> </ul>
<p><b>Implications and Future Directions</b></p>	<ul style="list-style-type: none"> <li>● Indicates feasibility of mobile mindfulness and social support interventions for AYAs with cancer</li> <li>● Future work should include randomized controlled trials to evaluate effectiveness</li> <li>● Tailoring app content specifically for oncology populations may improve engagement and outcomes</li> <li>● Incorporating structured reminders or incentives may help increase adherence <ul style="list-style-type: none"> <li>○ May consider longer intervention duration and more interactive features</li> </ul> </li> <li>● Parent module could be expanded or tailored based on individual family needs</li> <li>● Strong potential for mobile-based psychosocial interventions in pediatric/AYA oncology</li> <li>● Further research needed to assess long-term impact on psychosocial outcomes such as anxiety, depression, and quality of life</li> </ul>
<p><b>Additional Key Observations</b></p>	<ul style="list-style-type: none"> <li>● Theoretical basis: Program design grounded in mindfulness-based stress reduction (MBSR) and peer support theory</li> <li>● Engagement strategies included weekly staff check-ins and peer encouragement within the Facebook group</li> <li>● Data collected through exit interviews, online surveys, and app usage logs</li> <li>● Participants suggested features such as age-relevant content and better customization for medical context No fidelity</li> </ul>

	<p>assessment for mindfulness practices (e.g., whether participants followed guided meditations as intended)</p> <ul style="list-style-type: none"> <li>● Study emphasizes need for accessible, age-appropriate mental health tools for AYA cancer patients</li> </ul>
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#### 4. Yoga as a Complementary and Alternative Therapy in Children with Hematologic and Oncologic Disease

<b>Reference/Citation</b>	<p>Fukuhara, J. S., O’Haver, J., Proudfoot, J. A., Spies, J. M., &amp; Kuo, D. J. (2020). Yoga as a Complementary and Alternative Therapy in Children with Hematologic and Oncologic Disease. <i>Journal of Pediatric Oncology Nursing</i>, 37(4), 278–283.  <a href="https://doi.org/10.1177/1043454220909787">https://doi.org/10.1177/1043454220909787</a></p>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● N/A; summarizes findings from multiple studies</li> <li>● Includes studies conducted in various locations</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Pediatric population (children with hematologic and oncologic diseases)</li> <li>● Specific ages varied based on study - general reference to children and adolescents undergoing cancer treatment</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Not explicitly categorized by stage (e.g., early diagnosis, relapse)</li> <li>● Applies broadly to pediatric patients undergoing cancer treatment</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Narrative review and conceptual discussion</li> <li>● Not an empirical study or clinical trial.</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Yoga is described as a multimodal mind-body practice involving breathing techniques, physical postures, and meditation/relaxation</li> <li>● Theoretical integration of yoga into pediatric cancer care is discussed</li> <li>● Focuses on yoga’s ability to affect physical, psychological, and emotional functioning</li> <li>● No specific protocol or formal intervention study described</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● No original data presented</li> <li>● Describes potential benefits of yoga based on adult studies and extrapolated pediatric experiences: <ul style="list-style-type: none"> <li>○ Enhanced relaxation</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Reduced anxiety</li> <li>○ Improved mood and coping</li> <li>○ Potential immune and endocrine system modulation</li> <li>● Anecdotal reports suggest benefits in managing stress, pain, and treatment-related anxiety in pediatric oncology settings.</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Yoga may serve as a useful complementary therapy in pediatric oncology by addressing psychological and emotional dimensions of illness</li> <li>● The authors propose yoga could help mitigate the trauma of medical interventions, support emotional expression, and promote resilience</li> <li>● Highlights the potential for yoga to be tailored to developmental stages and physical limitations of pediatric patients</li> <li>● Emphasis on the importance of qualified instructors and integrative care planning</li> <li>● Advocates for future research and pilot testing of yoga in pediatric oncology populations.</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● No empirical evidence or formal study conducted</li> <li>● Relies on extrapolation from adult studies and anecdotal reports</li> <li>● No standardized intervention design, dose, or delivery model described</li> <li>● No data on feasibility, safety, or outcomes in pediatric oncology patients.</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Suggests a strong rationale for conducting pilot studies and clinical trials of yoga in children with cancer</li> <li>● Recommends integration of yoga into comprehensive psychosocial care models</li> <li>● Calls for systematic assessment of yoga’s impact on quality of life, symptom management, and psychological well-being</li> <li>● Points to need for child-specific yoga protocols and outcome measures.</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Frames yoga within the broader context of complementary and alternative medicine (CAM)</li> <li>● Mentions previous research linking stress reduction to improved immune function</li> <li>● Discusses theoretical pathways through which yoga may impact pain, anxiety, and treatment burden</li> <li>● Describes potential role of yoga in providing children with “internal locus of control” and a “non-invasive tool” for coping</li> </ul>

	<ul style="list-style-type: none"> <li>● Encourages multidisciplinary collaboration between medical teams, psychologists, and certified yoga instructors.</li> </ul>
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## 5. Effect of yoga on the symptom response in pediatric brain tumor in-patients undergoing chemo and radiotherapy

<b>Reference/Citation</b>	<p>HB, G., Nelson, N., Khaleel, I., Kumar, A., Roy, M., SJ, D., KR, H., Hegde, A., KR, A., Vasana, H., Mathewa, S. M., Sanny, S., Kashyapa, R., &amp; B, K. (2019). Effect of yoga on the symptoms response in pediatric brain tumor in-patients undergoing chemo and radiotherapy. <i>Oncology and Radiotherapy</i>, 1(46), 34–38.  <a href="https://www.oncologyradiotherapy.com/articles/effect-of-yoga-on-symptom-response-in-paediatric-brain-tumour-inpatients-undergoing-chemo-and-radio-therapy.pdf">https://www.oncologyradiotherapy.com/articles/effect-of-yoga-on-symptom-response-in-paediatric-brain-tumour-inpatients-undergoing-chemo-and-radio-therapy.pdf</a></p>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Kidwai Cancer Institute, Bangalore, Karnataka, India</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Pediatric inpatients (n = 18), aged 6–18 years (mean age = 9.8 years)</li> <li>● Diagnosed with brain tumors (e.g., anaplastic ependymoma, medulloblastoma, glioma)</li> <li>● All were undergoing chemotherapy and/or radiotherapy</li> <li>● Parents were involved as proxy respondents and attended every yoga session</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Active treatment phase (radiotherapy and/or chemotherapy)</li> <li>● Included patients with prior tumor excision but excluded those with metastasis or advanced disease</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Single-arm prospective feasibility study (not an RCT)</li> <li>● Pre-post intervention design using paired t-tests for analysis</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Yoga sessions held 5 days/week for 4 weeks; participants required to attend a minimum of 3 sessions/week</li> <li>● Each session lasted 1 hour and included chanting, loosening, breathing, postures, relaxation, and meditation</li> <li>● Conducted individually after medical treatment, with parental presence required</li> <li>● Yoga was adapted per participant needs (props used for support)</li> <li>● Delivered within the hospital setting by trained instructors</li> <li>● Orientation session held before program start</li> </ul>

	<ul style="list-style-type: none"> <li>● Feedback was collected using a customized 4-point Likert scale symptom questionnaire (administered pre- and post-intervention)</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Feasibility confirmed: All 18 participants met minimum attendance; median sessions attended = 16 (range: 12–20)</li> <li>● All participants agreed to continue yoga post-discharge</li> <li>● Significant symptom improvements (p-values listed): <ul style="list-style-type: none"> <li>○ Pain reduction (p = 0.0001)</li> <li>○ Relief in headache (p = 0.0005)</li> <li>○ Increased appetite (p = 0.0005)</li> <li>○ Better sleep (p = 0.0003)</li> <li>○ Reduced fatigue (p = 0.007)</li> <li>○ Improved daily activity (p = 0.0018)</li> </ul> </li> <li>● No adverse events linked to the yoga practice</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Yoga was feasible and well-accepted among pediatric brain tumor inpatients undergoing intensive treatment</li> <li>● Notably, children looked forward to sessions and perceived them as opportunities to relax</li> <li>● Use of props (ropes, cushions) increased comfort and engagement, especially among those with neurological/physical deficits</li> <li>● Stress levels did not show significant improvement - possibly due to repeated medical procedures during hospitalization</li> <li>● The study highlights the potential for yoga to address pain, appetite, fatigue, and sleep issues, even in a short 4-week period</li> <li>● Suggests a future RCT with larger sample and standardized symptom/QoL measures</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Single-arm, no control group</li> <li>● Small sample size (n = 18)</li> <li>● Reliance on parent-proxy reports; child responses were not formally measured due to reliability concerns</li> <li>● No standardized pediatric QOL instruments used (translation issues and school-related content deemed inapplicable)</li> <li>● Stress outcomes may have been confounded by daily medical procedures</li> <li>● Weekly assessments recommended but not used in this study</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Findings support yoga as a safe, feasible, and potentially beneficial supportive therapy during active cancer treatment in children</li> <li>● An RCT with a control group and standardized</li> </ul>

	<p>symptom/QOL tools is needed to validate effects</p> <ul style="list-style-type: none"> <li>● Tailoring interventions to include play/yoga games and stress-reduction strategies may further improve stress outcomes</li> <li>● Differentiating groups with and without neurological impairments could help refine delivery and assess targeted benefits</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Yoga was individualized per patient comfort and functional status</li> <li>● Parents played a dual role as caregivers and facilitators of at-home continuation post-discharge</li> <li>● Custom symptom questionnaire focused on key domains: pain, appetite, fatigue, sleep, activity, headache, etc.</li> <li>● No prior yoga experience in any participant</li> <li>● Data analysis conducted using GraphPad (paired sample t-tests)</li> </ul>

**6. Efficacy of Progressive Muscle Relaxation Training on Anxiety, Depression and Quality of Life in Cancer Patients Undergoing Chemotherapy at Tabriz Hematology and Oncology Research Center, Iran in 2010**

<b>Reference/Citation</b>	Herizchi, S., Asvadi, I., Piri, I., Golchin, M., Shabanlui, R., Sanaat, Z., Road, E., & Hospital, R. (2012). Efficacy of Progressive Muscle Relaxation Training on Anxiety, Depression and Quality of Life in Cancer Patients Undergoing Chemotherapy at Tabriz Hematology and Oncology Research Center, Iran in 2010. <i>Middle East Journal of Cancer</i> , 3(1), 9–13.
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Tabriz, Iran</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Adult cancer patients aged 15–65 years</li> <li>● Sample size: 60 patients, randomized into intervention and control groups</li> <li>● No pediatric population involved</li> <li>● No family members included in the intervention</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Undergoing chemotherapy</li> <li>● Specific stage of cancer not stated</li> <li>● Patients had received at least two rounds of chemotherapy prior to enrollment</li> </ul>

<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Randomized clinical trial</li> <li>● Controlled design with intervention and control groups</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Progressive Muscle Relaxation (PMR) training</li> <li>● Delivered in small groups of 3–6 patients during inpatient stay</li> <li>● Patients instructed to practice PMR 2–3 times daily, including after discharge</li> <li>● Follow-up reminders were provided post-discharge</li> <li>● Control group received no intervention</li> <li>● Duration: Outcomes assessed at 1 month and 3 months post-intervention</li> <li>● Tools used: HADS (Hospital Anxiety and Depression Scale) and EORTC QLQ-C30 (Quality of Life)</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● No significant changes in anxiety, depression, or QOL at 1-month follow-up in either group (<math>P &gt; 0.05</math>)</li> <li>● Significant improvement in anxiety and depression in intervention group after 3 months (HADS, <math>P = 0.004</math>)</li> <li>● Significant improvement in QOL after 3 months in intervention group (<math>P = 0.045</math>)</li> <li>● No significant improvements in control group at either time point</li> <li>● HADS and QOL scale scores both showed time-dependent positive effects in the intervention group only</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● PMR was found effective in reducing anxiety and depression and improving QOL, but only after sustained practice over 3 months</li> <li>● The lack of significant improvement at 1 month may be due to patients' limited initial practice or difficulty concentrating due to chemotherapy side effects (e.g., pain, vomiting, fatigue)</li> <li>● The results align with previous international studies showing PMR's benefits in reducing distress in cancer patients</li> <li>● Anxiety had a stronger relationship to QOL than depression in this study</li> <li>● PMR is a practical, low-cost self-help method suitable for integration into supportive cancer care, especially when drug-free alternatives are needed</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Short duration of follow-up (only up to 3 months; no data at 6 months)</li> <li>● Heterogeneous cancer diagnoses; stage/type of cancer not standardized</li> <li>● Dropout due to illness severity limited longer-term follow-</li> </ul>

	<p>up</p> <ul style="list-style-type: none"> <li>● Results may not generalize to those with severe psychiatric comorbidities (patients with history of mania, psychosis, substance abuse, etc. were excluded)</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● PMR may be incorporated as a supportive care strategy to manage psychological distress and improve QOL in cancer patients</li> <li>● Future research should include longer-term follow-up (e.g., 6 months or more) and potentially standardize cancer type/stage for more targeted findings</li> <li>● Investigations into PMR's effect in pediatric or adolescent populations could be valuable for expanding its applicability</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Measurement tools: <ul style="list-style-type: none"> <li>○ HADS (validated Persian version): Depression (HADS-D) and Anxiety (HADS-A)</li> <li>○ EORTC QLQ-C30: Assesses 5 functional domains and 9 symptom domains related to QOL</li> </ul> </li> <li>● Cut-off scores: <ul style="list-style-type: none"> <li>○ HADS-D: <math>\geq 8</math></li> <li>○ HADS-A: <math>\geq 5</math></li> <li>○ HADS-T (total): <math>\geq 11</math></li> </ul> </li> <li>● Participants had to be literate and previously received <math>\geq 2</math> chemotherapy rounds</li> <li>● Exclusion criteria included prior psychiatric treatment, radiotherapy, serious comorbidities, or low baseline distress scores</li> <li>● PMR involved group-based instruction followed by individual practice with follow-up encouragement</li> </ul>

## 7. Challenges of Implementing Multicenter Studies of Yoga for Pediatric Cancer and Hematopoietic Stem Cell Transplantation Recipients

<b>Reference/Citation</b>	Jacobs, S., Plenert, E., Stein, E., Mowbray, C., Stewart, R., Schechter, T., Diorio, C., & Sung, L. (2021). Challenges of Implementing Multicenter Studies of Yoga for Pediatric Cancer and Hematopoietic Stem Cell Transplantation Recipients. <i>International Journal of Yoga Therapy</i> , 31(1). <a href="https://doi.org/10.17761/2021-d-19-00060">https://doi.org/10.17761/2021-d-19-00060</a>
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<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● The Hospital for Sick Children (SickKids), in Toronto, Canada</li> <li>● Second site: Children’s National Health (CNH), in Washington, D.C</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Pediatric oncology patients aged 8–18</li> <li>● Diagnoses included acute myeloid leukemia, relapsed acute lymphoblastic leukemia, stage III/IV Burkitt or diffuse large B-cell lymphoma/leukemia, or receiving myeloablative autologous/allogeneic HSCT</li> <li>● Participants were expected to be hospitalized for at least 3 weeks</li> <li>● Guardians were required to understand English or Spanish (after amendment)</li> <li>● Family members were optionally involved in sessions</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Active treatment phase (during intensive chemotherapy or HSCT)</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Feasibility randomized controlled trial</li> <li>● Multicenter (two sites)</li> <li>● Descriptive analysis only</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Yoga Group: <ul style="list-style-type: none"> <li>○ Individualized yoga sessions, daily (excluding weekends/holidays) for 21 days</li> <li>○ Delivered by certified yoga instructors (200+ hours of training)</li> <li>○ Sessions ranged 15–45 minutes and included relaxation, breathing, strength, flexibility, and balance poses at adjustable intensity levels</li> <li>○ Family member participation encouraged</li> <li>○ Same instructor intended to follow child throughout if possible</li> </ul> </li> <li>● Control Group: <ul style="list-style-type: none"> <li>○ Also met daily for 21 days with instructors offering iPad-based engagement (games, books, music)</li> <li>○ Same session duration as yoga arm</li> <li>○ Same yoga instructors administered both conditions</li> </ul> </li> <li>● Cross-over offered on day 21 for 1 week to improve enrollment/retention</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Total participants enrolled: 6 (3 yoga, 3 iPad)</li> <li>● Median age: 12 (range 8–15); 2 were boys</li> <li>● Yoga sessions completed: 22/36; iPad sessions completed: 14/32</li> <li>● Only 1 participant met the adherence threshold (<math>\geq 9</math> sessions)</li> </ul>

	<ul style="list-style-type: none"> <li>● Dropout: 1 in each group</li> <li>● Primary quantitative outcomes: <ul style="list-style-type: none"> <li>○ PedsQL Multidimensional</li> <li>○ Fatigue (general fatigue): Mean <math>52.2 \pm 22.2</math> (yoga: <math>58.3 \pm 24.3</math>, iPad: <math>45.2 \pm 18.7</math>) Fatigue Scale–Parent: <math>49.0 \pm 10.0</math></li> <li>○ PedsQL 3.0 Acute Cancer Module: <math>62.4 \pm 19.2</math></li> </ul> </li> <li>● Crossover preference: 2 preferred yoga, 1 liked both equally</li> </ul>
<p><b>Discussion/Key Takeaways</b></p>	<ul style="list-style-type: none"> <li>● Expansion beyond a single site revealed significant feasibility challenges</li> <li>● Hiring external yoga instructors (not embedded in research team) created barriers including scheduling, fidelity, communication, and safety</li> <li>● Protocol deviations (e.g., exceeding session durations, unapproved poses) occurred in over half of yoga sessions</li> <li>● Lack of safety auditing (e.g., no video recordings completed) hindered protocol oversight</li> <li>● One instructor conducted a prohibited headstand pose; no injury occurred but the study was stopped</li> <li>● A multicenter approach is essential to establish feasibility when specialized personnel are required</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>● Limited training and engagement in research procedures by yoga instructors reduced data quality and protocol compliance</li> <li>● Very small sample size (N=6)</li> <li>● Only one site (CNHS) evaluated for multicenter feasibility</li> <li>● Poor adherence and incomplete documentation</li> <li>● No safety auditing conducted due to participant withdrawal of consent</li> <li>● Study prematurely closed due to protocol safety breach</li> <li>● Results may not generalize due to staffing model limitations</li> </ul>
<p><b>Implications and Future Directions</b></p>	<ul style="list-style-type: none"> <li>● Future studies should integrate instructors into research teams or utilize centralized, trained therapy programs to ensure protocol fidelity and minimize risks</li> <li>● Emphasize integrating therapeutic instructors within research infrastructure</li> <li>● Require training on research procedures and consistent safety monitoring</li> <li>● Improve documentation standards and session tracking protocols</li> <li>● Consider centralized hiring or partnership with integrative therapy organizations</li> <li>● Future multicenter trials should anticipate and address</li> </ul>

	<p>logistical barriers early on</p> <ul style="list-style-type: none"> <li>● Ensure fidelity monitoring mechanisms are practical and enforced</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Fidelity issues: Only 8 of 68 case-report forms completed correctly</li> <li>● Safety: One protocol violation (headstand pose), no adverse event occurred</li> <li>● Instructors' availability limited due to external employment</li> <li>● iPad control condition had lower engagement, raising bias concerns</li> </ul>

## 8. Exploring the Feasibility of a Mindfulness-Music Therapy Intervention to Improve Anxiety and Stress in Adolescents and Young Adults with Cancer

<b>Reference/Citation</b>	<p>Knoerl, R., Mazzola, E., Woods, H., Buchbinder, E., Frazier, L., LaCasce, A., Li, B. T., Luskin, M. R., Phillips, C. S., Thornton, K., Berry, D. L., &amp; Ligibel, J. A. (2022). Exploring the Feasibility of a Mindfulness-Music Therapy Intervention to Improve Anxiety and Stress in Adolescents and Young Adults with Cancer. <i>Journal of Pain and Symptom Management</i>, 63(4), e357–e363. <a href="https://doi.org/10.1016/j.jpainsymman.2021.11.013">https://doi.org/10.1016/j.jpainsymman.2021.11.013</a></p>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Dana-Farber Cancer Institute</li> <li>● Music therapy conducted in person and via Zoom</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Adolescents and young adults (AYAs), ages 15–39</li> <li>● Receiving cancer treatment for ≥8 weeks</li> <li>● Recruited from pediatric, melanoma, sarcoma, breast, lymphoma, and leukemia outpatient centers</li> <li>● No family members included</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Active treatment phase (not limited to early diagnosis or relapse)</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Single arm, longitudinal, pilot study</li> <li>● Mixed methods (quantitative pre-post comparison and participant satisfaction)</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Mindfulness-based music therapy (MBMT) intervention</li> <li>● Four individual sessions delivered over 12 weeks</li> <li>● Conducted in person or via Zoom</li> </ul>

	<ul style="list-style-type: none"> <li>● Facilitated by a board-certified music therapist trained in mindfulness</li> <li>● Sessions included mindfulness (breathing/body awareness), live or recorded music, and verbal processing</li> <li>● Participants received recorded music for home use</li> <li>● No control group included</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● 93 eligible; 37 enrolled (39.8% consent rate)</li> <li>● 27/37 participants (73%) completed at least two sessions and both baseline and post-study measures</li> <li>● Median age = 32; 56.8% female</li> <li>● Perceived Stress Scale: significant reduction (median change: -4.0, P = 0.013)</li> <li>● PROMIS Anxiety 4a: non-significant reduction (median change: -1.9, P = 0.20)</li> <li>● Average reduction in anxiety: from 55.3 to 49.8</li> <li>● Average reduction in stress: from 59.0 to 53.2</li> <li>● Retention rate was strong for this population (73%)</li> <li>● High participant satisfaction and acceptability <ul style="list-style-type: none"> <li>○ Participants reported the intervention was enjoyable, relaxing, and helped them cope with stress</li> </ul> </li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● MBMT was feasible and well-received among AYAs receiving outpatient cancer treatment <ul style="list-style-type: none"> <li>○ Feasibility was supported by reasonable recruitment, retention, and adherence rates</li> </ul> </li> <li>● Intervention led to statistically significant reduction in perceived stress, but anxiety reduction was not statistically significant</li> <li>● Participants responded positively to combining music with mindfulness</li> <li>● Remote and in-person delivery models were both viable</li> <li>● Supports growing interest in psychosocial and mind-body interventions tailored for the AYA cancer population</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Generalizability is limited due to single-site design and a predominantly Caucasian, non-Hispanic, young adult sample</li> <li>● No control group was used, limiting conclusions about intervention effectiveness</li> <li>● Findings related to anxiety and stress are exploratory and should be interpreted with caution</li> <li>● High levels of missing data on participants' use of daily mindfulness-music practices</li> <li>● Potential that anxiety and stress levels naturally declined over time, independent of the intervention</li> <li>● Many participants had already received several</li> </ul>

	<p>chemotherapy cycles before enrolling, which could have influenced outcomes</p> <ul style="list-style-type: none"> <li>● Study was underpowered to detect statistically significant pre-to-post differences in anxiety or stress</li> <li>● No adjustment made for multiple comparisons, increasing risk of Type I error</li> <li>● Variation in frequency and timing of music therapy sessions due to differences in treatment schedules and delivery format</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Findings warrant replication in a randomized controlled trial</li> <li>● Future research should evaluate long-term effects and include larger, diverse samples</li> <li>● Potential to integrate MBMT into standard AYA oncology supportive care</li> <li>● Digital delivery methods like Zoom increase accessibility and scalability</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Enrollment occurred over ~14 months</li> <li>● Demonstrated flexibility in delivery format (virtual/in-person)</li> <li>● No adverse events or safety concerns reported</li> <li>● Satisfaction data support intervention acceptability and relevance</li> </ul>

### 9. Effects of mindfulness-based stress reduction combined with music therapy on pain, anxiety, and sleep quality in patients with osteosarcoma

<b>Reference/Citation</b>	Liu, H., Gao, X., & Hou, Y. (2019). Effects of mindfulness-based stress reduction combined with music therapy on pain, anxiety, and sleep quality in patients with osteosarcoma. <i>Brazilian Journal of Psychiatry</i> , 41(6), 540–545. <a href="https://doi.org/10.1590/1516-4446-2018-0346">https://doi.org/10.1590/1516-4446-2018-0346</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Liaocheng People’s Hospital, Shandong, China</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Patients aged 10 to 21 years</li> <li>● Diagnosed with osteosarcoma</li> <li>● Pediatric/AYA population</li> <li>● Most had undergone surgery; stage of illness not otherwise</li> </ul>

	specified
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Not explicitly categorized, but all were undergoing treatment for osteosarcoma</li> <li>● Inclusion required capacity to follow instructions and complete assessments</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Randomized controlled trial (RCT) <ul style="list-style-type: none"> <li>○ Random allocation of participants into intervention (MBSR + MT) and control (usual care) groups</li> </ul> </li> <li>● Single-center</li> <li>● Per-protocol analysis (not intention-to-treat), excluding those who dropped out</li> <li>● Pre- and post-intervention assessments of pain, anxiety, and sleep quality</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Intervention group: 8 sessions of combined MBSR + music therapy <ul style="list-style-type: none"> <li>○ Each session included 30 minutes of music therapy, followed by MBSR guided by a trained psychologist, then an additional 30 minutes of music</li> <li>○ MBSR components included breathwork, yoga, body scans, meditation, walking meditation</li> <li>○ Music components included various types of music (lyrical, cheerful, elegant, hopeful)</li> </ul> </li> <li>● Control group: Routine care only (no psychological intervention)</li> <li>● Outcomes assessed: pain (WBRS), anxiety (HAM-A), and sleep quality (PSQI), pre- and post-intervention</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Pain: <ul style="list-style-type: none"> <li>○ No difference between groups at baseline (<math>p = 0.659</math>)</li> <li>○ Post-intervention: significant reduction in pain scores in intervention group (<math>p = 0.000</math>), no change in control group</li> </ul> </li> <li>● Anxiety: <ul style="list-style-type: none"> <li>○ Baseline: no difference (<math>p = 0.510</math>)</li> <li>○ Post-intervention: significant decrease in anxiety in intervention group (<math>p = 0.000</math>); no change in control group</li> </ul> </li> <li>● Sleep Quality: <ul style="list-style-type: none"> <li>○ Baseline: no difference (<math>p = 0.869</math>)</li> <li>○ Post-intervention: PSQI scores improved significantly in intervention group (<math>p = 0.000</math>); no change in control group</li> </ul> </li> </ul>
<b>Discussion/Key</b>	<ul style="list-style-type: none"> <li>● The MBSR + MT intervention significantly reduced pain</li> </ul>

<b>Takeaways</b>	<p>and anxiety and improved sleep quality</p> <ul style="list-style-type: none"> <li>● Supports the therapeutic benefit of non-pharmacological interventions in osteosarcoma care</li> <li>● Reinforces existing literature on MBSR and MT in cancer care (especially breast cancer)</li> <li>● Suggests feasibility of this combined approach in clinical settings for pediatric and AYA cancer populations</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Conducted at a single hospital; limits generalizability</li> <li>● Small sample size</li> <li>● No MBSR-only or MT-only groups, making it difficult to isolate effects</li> <li>● Focused only on osteosarcoma patients; findings not applicable to other cancers</li> <li>● Did not include mechanistic observations</li> <li>● Only assessed three symptoms (pain, anxiety, sleep); other relevant outcomes not evaluated</li> <li>● Participants were not blinded; potential bias</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Combined MBSR and MT is promising as an adjunctive intervention in pediatric/AYA oncology</li> <li>● Future research should include multi-arm designs (MBSR only, MT only)</li> <li>● Broader symptom assessment and mechanistic studies recommended</li> <li>● Multi-site studies with larger, more diverse samples are needed to confirm findings</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● High adherence to intervention protocol</li> <li>● Session structure was detailed and standardized</li> <li>● Study used validated tools appropriate for pediatric/AYA populations (e.g., WBRs, HAM-A, PSQI)</li> <li>● Post-study, control participants were offered the same intervention to ensure ethical fairness</li> </ul>

**10. Mindfulness-based intervention for teenagers with cancer:  
study protocol for a randomized controlled trial**

<b>Reference/Citation</b>	<p>Malboeuf-Hurtubise, C., Achille, M., Sultan, S., &amp; Vadnais, M. (2013). Mindfulness-based intervention for teenagers with cancer: study protocol for a randomized controlled trial. <i>Trials</i>, 14(1), 135. <a href="https://doi.org/10.1186/1745-6215-14-135">https://doi.org/10.1186/1745-6215-14-135</a></p>
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<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● N/A</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Adolescents aged 11–18 years</li> <li>● Diagnosed with any type or stage of cancer</li> <li>● No specific exclusion criteria related to cancer trajectory</li> <li>● Patients recruited from pediatric oncology departments in Canada</li> <li>● Family members not included in the intervention</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Any stage (diagnosis, treatment, or remission)</li> <li>● Study includes patients across various points in their illness trajectory</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Prospective, longitudinal, experimental design <ul style="list-style-type: none"> <li>○ Three time points (baseline, post-intervention, and follow-up)</li> </ul> </li> <li>● Two groups (experimental and control) <ul style="list-style-type: none"> <li>○ Wait-list control group</li> </ul> </li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Experimental group: 8-week mindfulness-based meditation intervention</li> <li>● Weekly 90-minute group sessions led by two trained therapists</li> <li>● Content includes body awareness, breathing, meditation, and group sharing</li> <li>● Delivered in a hospital setting</li> <li>● Control group placed on a wait-list; offered the intervention after follow-up</li> <li>● Both groups complete assessments at baseline, immediately post-intervention, and follow-up</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Protocol article - no results reported yet (trial design only)</li> <li>● Outcomes to be measured: <ul style="list-style-type: none"> <li>○ Quality of life (PedsQL)</li> <li>○ Sleep (Adolescent Sleep–Wake Scale)</li> <li>○ Mood (Child Depression Inventory, Multidimensional Anxiety Scale for Children)</li> </ul> </li> <li>● Quantitative analyses will evaluate intra-group (pre-post) and inter-group differences</li> <li>● Target sample size: 28 participants</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Project addresses an important gap in adolescent psycho-oncology by evaluating mindfulness meditation’s impact on psychological and physical well-being</li> <li>● Design allows examination of both short-term and sustained effects of the intervention</li> </ul>

	<ul style="list-style-type: none"> <li>● One of the few studies targeting quality of life, sleep, and mood together in adolescent cancer populations</li> <li>● Intervention is designed to be developmentally appropriate for teens, emphasizing experiential learning and peer support</li> <li>● Feasibility of group delivery in clinical settings is also being assessed indirectly</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Small sample size may limit statistical power</li> <li>● Risk of attrition among adolescent cancer patients</li> <li>● Voluntary participation may lead to selection bias</li> <li>● Protocol acknowledges logistical challenges of implementation and follow-up in this population</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Study aims to provide foundational evidence for integrating mindfulness into pediatric cancer care</li> <li>● Results could inform development of hospital-based or virtual mindfulness programs tailored for adolescents</li> <li>● May contribute to standardizing non-pharmacologic interventions for symptom management</li> <li>● Future studies could expand on this framework with larger samples and longer follow-up periods</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Measures chosen are validated for adolescent populations</li> <li>● Intervention grounded in established mindfulness protocols but tailored to teenagers</li> <li>● No active control or placebo; reliance on wait-list design</li> <li>● Ethical consideration: control participants are eventually offered the intervention</li> </ul>

### **11. A Mindfulness-Based Meditation Pilot Study: Lessons Learned on Acceptability and Feasibility in Adolescents with Cancer**

<b>Reference/Citation</b>	Malboeuf-Hurtubise, C., Achille, M., Muise, L., Beauregard-Lacroix, R., Vadnais, M., & Lacourse, É. (2015). A Mindfulness-Based Meditation Pilot Study: Lessons Learned on Acceptability and Feasibility in Adolescents with Cancer. <i>Journal of Child and Family Studies</i> , 25(4), 1168–1177. <a href="https://doi.org/10.1007/s10826-015-0299-z">https://doi.org/10.1007/s10826-015-0299-z</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● N/A</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Adolescents aged 11–18 years with a history of cancer</li> <li>● Total screened: 481</li> </ul>

	<ul style="list-style-type: none"> <li>● Contacted: 63</li> <li>● Final sample: 14 (7 in MBI intervention, 7 in no-treatment comparison group)</li> <li>● No family or caregiver involvement</li> <li>● Participants were not necessarily in active treatment; current treatment status not specified</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Not explicitly stated</li> <li>● Participants had a history of cancer; may include survivorship or post-treatment phase</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Prospective, quasi-experimental pilot study</li> <li>● Pretest–posttest design with two groups: MBI intervention (n=7) and no-treatment comparison (n=7)</li> <li>● Only MBI group (intervention group) completed 6-month follow-up</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Mindfulness-Based Intervention (MBI) using 8 weekly sessions, 90 minutes each</li> <li>● Delivered in-person by two trained therapists</li> <li>● Techniques included: breathing meditation, body scan meditation, heartfulness meditation, mountain meditation, walking meditation, and group sharing</li> <li>● No digital/home practice tools provided</li> <li>● No adaptations for remote access</li> <li>● Location of delivery was a barrier due to travel distance</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● No statistically significant changes in sleep, mood, or quality of life were found between or within groups at post-test or follow-up</li> <li>● High barriers to participation: <ul style="list-style-type: none"> <li>○ 418 of 481 excluded due to travel distance or ineligibility</li> <li>○ 1.4% of eligible contacted participants (7/63) enrolled and completed baseline</li> </ul> </li> <li>● MBI participants completed the intervention and follow-up measures</li> <li>● Participants qualitatively reported program as helpful and enjoyable</li> <li>● Findings are exploratory only, due to extremely small sample size</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Recruitment and retention of adolescents with cancer into in-person MBIs is feasible only for a narrow subset</li> <li>● Major logistical barriers (travel time, scheduling conflicts) limit scalability of traditional in-person formats</li> <li>● Adolescents who participated found the MBI acceptable and</li> </ul>

	<p>meaningful</p> <ul style="list-style-type: none"> <li>● The study was not powered to detect significant differences, and results should be interpreted with caution</li> <li>● Authors emphasize the need for adapted delivery formats, including online options and flexible scheduling</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Very small final sample (n=14) regarding those who provided complete dataset</li> <li>● Extremely low participation rate (1.4% of those contacted)</li> <li>● No randomization or active control group</li> <li>● Self-report measures only</li> <li>● Follow-up data collected only for the MBI group</li> <li>● Generalizability limited by narrow demographic and small sample</li> <li>● No data on fidelity of intervention delivery</li> <li>● In-person format and travel distance were substantial participation barriers</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Larger, randomized controlled trials are necessary</li> <li>● Remote or telehealth-based MBI formats may improve accessibility</li> <li>● Recruitment strategies should address barriers specific to adolescents (e.g., school schedules, treatment fatigue)</li> <li>● Interventions should be tailored for flexibility and potentially integrated with outpatient or survivorship care</li> <li>● Findings highlight logistical challenges more than clinical outcomes, offering key insights for future program design</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● No adverse effects reported</li> <li>● Participants appeared motivated once enrolled, suggesting the issue lies primarily in access, not engagement</li> </ul>

## 12. User-friendly mindfulness-based interventions (MBI) for children and adolescents with childhood cancer

<b>Reference/Citation</b>	<p>Mele, C., Hulett, J., &amp; Goldschmidt, K. (2022). User-friendly mindfulness-based interventions (MBI) for children and adolescents with childhood cancer. <i>Journal of Pediatric Nursing</i>, 63, 168–170. <a href="https://doi.org/10.1016/j.pedn.2021.12.017">https://doi.org/10.1016/j.pedn.2021.12.017</a></p>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● United States</li> </ul>

<b>Population</b>	<ul style="list-style-type: none"> <li>● Children and adolescents with cancer</li> <li>● Includes both acute care and survivorship populations</li> <li>● No specific cancer type or stage delineated in primary focus</li> <li>● Emphasizes those experiencing psychological distress, chronic pain, sleep disturbances, anxiety, or PTSD-like symptoms</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● All stages (acute treatment and survivorship)</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Narrative review and commentary</li> <li>● Includes references to pilot studies, scoping reviews, and feasibility studies</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Overview of MBIs tailored for pediatric cancer patients, especially adolescents</li> <li>● Descriptions of: <ul style="list-style-type: none"> <li>○ Guided imagery, meditation, tension release, breath-focused practices, mantram meditation</li> <li>○ Technology-assisted options (e.g., virtual reality via Samsung Gear VR, mindfulness apps like Calm, Headspace)</li> <li>○ Portable options like the Mantram Repetition Program (MRP) using sacred phrases for stress reduction</li> </ul> </li> <li>● Not a controlled trial, but provides synthesized information from various cited studies and clinical examples</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Describes evidence from other studies supporting benefits of MBIs on: <ul style="list-style-type: none"> <li>○ Pain management</li> <li>○ Stress and anxiety reduction</li> <li>○ Sleep improvement</li> <li>○ Improved physiological markers (e.g., blood pressure, cortisol, inflammation)</li> </ul> </li> <li>● Reports from pilot programs suggest acceptability and feasibility in pediatric settings</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Emphasizes the need for developmentally appropriate and flexible MBIs tailored to pediatric oncology</li> <li>● Highlights virtual reality and mobile app-based MBIs as promising, scalable options</li> <li>● Advocates for integration into brief clinical visits and for nurses to support their delivery</li> <li>● Mantram repetition uniquely offers spiritual and cultural flexibility, which may meet unaddressed patient needs</li> </ul>

<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Not an empirical study; synthesizes findings from other pilot trials and reviews</li> <li>● Notes that pediatric MBI research is still in its early stages</li> <li>● Most evidence comes from adult studies or small pediatric pilot samples</li> <li>● Barriers include time constraints, emotional readiness, session inflexibility, and technology access</li> <li>● Lack of large-scale RCT in pediatric cancer populations</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Encourages nurse-led delivery of MBIs during short visits</li> <li>● Calls for future studies with larger sample sizes and more rigorous designs (e.g., RCT)</li> <li>● Recommends validating mobile and virtual MBI formats in pediatric oncology</li> <li>● Suggests that incorporating spirituality (e.g., MRP) could enhance patient-centered care</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Includes a clinical vignette of a 14-year-old male brain tumor patient using the Apple Mindfulness app</li> <li>● Supports use of brief MBIs to overcome logistical barriers and patient fatigue</li> <li>● AAP endorses mind-body therapies as safe and potentially effective for pediatric patients</li> </ul>

### 13. Results of a Pilot Yoga Intervention to Improve Pediatric Cancer Patients' Quality of Life and Physical Activity and Parents' Well-being

<b>Reference/Citation</b>	Orsey, A. D., Park, C. L., Pulaski, R., Shankar, N. L., Popp, J. M., & Wakefield, D. (2017). Results of a Pilot Yoga Intervention to Improve Pediatric Cancer Patients' Quality of Life and Physical Activity and Parents' Well-being. <i>Rehabilitation Oncology</i> , 35(1), 15–23. <a href="https://doi.org/10.1097/01.reo.0000000000000052">https://doi.org/10.1097/01.reo.0000000000000052</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● N/A</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Pediatric cancer patients (ages 6–13) receiving active treatment</li> <li>● Their family members (primarily parents)</li> <li>● Patients had varied cancer diagnoses; all were on active treatment</li> <li>● Inclusion: cleared for physical activity by treating physicians</li> </ul>

	<ul style="list-style-type: none"> <li>● Exclusion: physical impairments preventing participation, medical contraindications</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Active cancer treatment (not survivorship or relapse)</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Mixed methods <ul style="list-style-type: none"> <li>○ Study 1: Survey (preferences, expectations, and perceived barriers)</li> <li>○ Study 2: Single-arm, 8-week pilot clinical trial (pre-post design)</li> </ul> </li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● 8-week yoga intervention</li> <li>● Weekly 60-minute group yoga sessions led by a certified instructor held at a pediatric medical center</li> <li>● Content: breathing, stretching, relaxation, guided imagery, gentle movement</li> <li>● Delivered to both patients and their family members</li> <li>● Measures collected: <ul style="list-style-type: none"> <li>○ Pediatric: PedsQL, Fatigue Scale, Physical Activity Questionnaire for Children</li> <li>○ Parents: PedsQL (Parent), Caregiver Strain Index</li> </ul> </li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Study 1 (Survey; n=20 patients and parents) <ul style="list-style-type: none"> <li>○ 85% of parents and children expressed interest in yoga during treatment</li> <li>○ Barriers included scheduling, treatment fatigue, travel</li> </ul> </li> <li>● Study 2 (Intervention; n=10 children and their family members) <ul style="list-style-type: none"> <li>○ 8 of 10 families completed all 8 weeks</li> <li>○ Pediatric outcomes (pre to post): <ul style="list-style-type: none"> <li>■ Improved PedsQL total score (mean: 68.6 → 74.2)</li> <li>■ Reduced fatigue (mean: 41.7 → 49.4)</li> <li>■ Increased physical activity (mean: 2.3 → 2.6)</li> </ul> </li> <li>○ Parent outcomes: <ul style="list-style-type: none"> <li>■ Improved PedsQL (mean: 73.4 → 78.9)</li> <li>■ Decreased caregiver strain (mean: 7.3 → 6.4)</li> </ul> </li> </ul> </li> <li>● No formal statistical testing due to small sample size</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Yoga during active treatment is novel in pediatric oncology research</li> <li>● Inclusion of parents as participants alongside patients enhanced support and feasibility</li> <li>● The intervention showed early promise for improving QOL, fatigue, and physical activity in children, and QOL and strain in parents</li> </ul>

	<ul style="list-style-type: none"> <li>● Challenges included timing yoga around clinical care and managing patient fatigue</li> <li>● Despite small sample size, consistent trends indicated feasibility and potential benefit</li> <li>● Authors suggest yoga could be a valuable supportive care component for children during cancer treatment</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Small sample size (n=10 families in pilot; n=20 for survey)</li> <li>● No control group (non-comparative single-arm design)</li> <li>● No inferential statistical testing due to limited power</li> <li>● Generalizability limited (volunteer sample, possibly more motivated families)</li> <li>● Self-report measures only; no objective fitness or activity data</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Larger, randomized controlled trials are needed to confirm preliminary findings</li> <li>● Potential for integrating yoga into pediatric cancer care settings</li> <li>● Future research should explore delivery modifications to improve accessibility</li> <li>● Need for assessing long-term effects, cost-effectiveness, and implementation fidelity</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Intervention was well-received; no adverse events reported</li> <li>● Data collection tools were standardized and appropriate for pediatric use</li> <li>● The study supports the whole-family approach to mind-body interventions</li> <li>● Demonstrates a foundational step toward scalable yoga programs in pediatric oncology</li> </ul>

## 14. Mindfulness-Based Interventions for Young People With Cancer

<b>Reference/Citation</b>	<p>Perumbil Pathrose, S., Everett, B., Patterson, P., Ussher, J., Salamonson, Y., McDonald, F., Biegel, G., &amp; Ramjan, L. (2021). Mindfulness-Based Interventions for Young People With Cancer. <i>Cancer Nursing</i>, 44(5), 349–360.  <a href="https://doi.org/10.1097/ncc.0000000000000821">https://doi.org/10.1097/ncc.0000000000000821</a></p>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● The review includes studies from multiple countries: Canada, Australia, the United States, and the United Kingdom</li> </ul>

	<ul style="list-style-type: none"> <li>○ Location varied by individual study reviewed</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Adolescents and young adults (AYAs) with cancer</li> <li>● Age range: 10 to 29 years</li> <li>● Cancer stage varied; most studies included young people during or after treatment</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Mixed: studies included patients during active treatment, post-treatment, and in survivorship phase</li> <li>● Specific stage was often not clearly defined in individual studies</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Total of 6 studies included in the review</li> <li>● Integrative literature review including: <ul style="list-style-type: none"> <li>○ 3 pre-post studies (without control)</li> <li>○ 1 randomized controlled trial (RCT)</li> <li>○ 1 pilot feasibility study</li> <li>○ 1 qualitative interview study</li> </ul> </li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Most interventions were adapted from standard MBSR or MBCT frameworks</li> <li>● Delivery formats included group sessions (in-person or virtual), mobile-based applications, and individual delivery</li> <li>● Some interventions were adapted for AYA developmental needs (e.g., shorter sessions, inclusion of multimedia or interactive components)</li> <li>● Modifications included: <ul style="list-style-type: none"> <li>○ Shortened session durations</li> <li>○ Delivery via online platforms (e.g., Zoom)</li> <li>○ Inclusion of psychoeducational content</li> <li>○ Use of metaphors, age-appropriate language, and interactive components</li> </ul> </li> <li>● Content included meditation, body scan, breathing techniques, informal practices</li> <li>● One study incorporated yoga alongside mindfulness</li> <li>● Duration ranged from 4 to 8 weeks; sessions ranged from 30 to 120 minutes</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Acceptability: <ul style="list-style-type: none"> <li>○ Participants generally found MBIs acceptable and feasible Benefits included increased awareness, relaxation, and sense of connection</li> </ul> </li> <li>● Psychosocial outcomes (inconsistent across studies): <ul style="list-style-type: none"> <li>○ Improvements noted in mindfulness, anxiety, stress, and social isolation</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ One study found reduced anxiety and improved sleep</li> <li>○ Another showed no significant change in mood or stress</li> <li>○ Engagement varied; attrition was a concern in some cases</li> <li>● Qualitative feedback: <ul style="list-style-type: none"> <li>○ Participants reported that the interventions helped with “noticing feelings,” coping with uncertainty, and improved mood</li> </ul> </li> <li>● Preliminary evidence suggests mindfulness-based interventions may reduce anxiety, depression, and stress in AYA with cancer</li> <li>● Improvements in emotional regulation and coping strategies were noted across multiple studies</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● This is the first integrative literature review focused specifically on MBIs in AYAs with cancer</li> <li>● MBI adaptations (e.g., length, modality, content) were necessary to suit the developmental needs and cancer-related experiences of young people</li> <li>● Engagement was influenced by age, treatment status, and logistical barriers (e.g., fatigue, distance, schedules)</li> <li>● MBIs show promise for reducing psychosocial burden, but current evidence is limited and inconclusive due to small sample sizes and varied methodology</li> <li>● Review highlighted the lack of standardization in delivery and measurement tools across studies</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Only 6 studies met the inclusion criteria</li> <li>● Most studies had small sample sizes and lacked control groups</li> <li>● High variability in intervention type, delivery format, and outcome measures</li> <li>● Differences in study populations (age, cancer type, stage) limited generalizability</li> <li>● Most studies had short follow-up periods; long-term effects unknown</li> <li>● Potential publication bias; only peer-reviewed studies in English were included</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Need for well-designed RCT with adequate power to determine MBI effectiveness</li> <li>● Emphasis on standardizing protocols and outcome measures to allow comparisons</li> <li>● Encouragement for culturally appropriate and developmentally tailored MBI content</li> </ul>

	<ul style="list-style-type: none"> <li>● Future research should explore technology-based delivery (e.g., mobile apps)</li> <li>● Healthcare providers, including nurses, can play a key role in promoting MBIs, especially if programs are validated and do not require advanced training for delivery</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Review used Joanna Briggs Institute critical appraisal tools to assess study quality</li> <li>● Despite limitations, all included studies showed some level of benefit or acceptability</li> <li>● Authors emphasized the need for greater youth engagement during design and delivery</li> <li>● This review provides a foundational synthesis for advancing MBI research and practice in pediatric/AYA oncology</li> </ul>

### 15. Effectiveness of Regular Breathing Technique (Hey-Hu) on Reduction of Intrathecal Injection Pain in Leukemic Children: A Randomized Clinical Trial

<b>Reference/Citation</b>	Pourmovahed, Z., Dehghani, K., & Sherafat, A. (2013). Effectiveness of Regular Breathing Technique (Hey-Hu) on Reduction of Intrathecal Injection Pain in Leukemic Children: A Randomized Clinical Trial. <i>Iranian Journal of Pediatrics</i> , 23(5), 564–568. <a href="https://pmc.ncbi.nlm.nih.gov/articles/PMC4006507/">https://pmc.ncbi.nlm.nih.gov/articles/PMC4006507/</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Yazd, Iran - Shahid Sadoughi University of Medical Sciences</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Pediatric leukemia patients</li> <li>● Ages 6–15 years</li> <li>● 100 children total (50 in the intervention group, 50 in control)</li> <li>● Undergoing intrathecal injections</li> <li>● No family members present during procedure</li> <li>● Excluded children with severe anxiety, use of sedatives, hearing/speech/cognitive disorders, or prior pain training</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● During treatment for leukemia</li> <li>● Undergoing regular intrathecal chemotherapy injections</li> </ul>

<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Single-blind Randomized Clinical Trial (RCT)</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Intervention: Regular breathing technique (“Hey-Hu” method) <ul style="list-style-type: none"> <li>○ Children were taught to inhale (“Hey”) and exhale (“Hu”) slowly and regularly</li> <li>○ Training provided by a nurse before injection</li> <li>○ Breathing began before the injection and continued throughout</li> </ul> </li> <li>● Control Group: Received routine care without the breathing intervention</li> <li>● Pain assessment tools: <ul style="list-style-type: none"> <li>○ Wong-Baker FACES Pain Rating Scale and researcher-observed behavioral checklist</li> <li>○ Pain measured immediately after injection</li> </ul> </li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Pain scores: <ul style="list-style-type: none"> <li>○ Intervention group: <math>2.98 \pm 1.68</math></li> <li>○ Control group: <math>3.80 \pm 1.30</math></li> <li>○ Difference was statistically significant (<math>P = 0.01</math>)</li> </ul> </li> <li>● No significant difference in pain based on sex</li> <li>● Significant age-related effect: Children <math>&gt;10</math> years in the intervention group reported significantly lower pain than younger children</li> <li>● Observed behaviors (restlessness, crying, body movement) were reduced in the intervention group</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Regular breathing (Hey-Hu) is a simple, effective non-pharmacologic technique to reduce injection-related pain in children with leukemia</li> <li>● Particularly effective in older children (<math>&gt;10</math> years) who may better understand and implement the technique</li> <li>● Highlights the potential for nurses to implement this strategy in routine pediatric oncology care</li> <li>● Emphasized that distraction techniques like breathing are underutilized in clinical nursing practice despite being cost-effective</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Single-center study (limited generalizability)</li> <li>● Did not evaluate long-term impact or repeated use of the technique</li> <li>● Behavioral checklist was not a standardized validated scale</li> <li>● No follow-up to determine whether pain reduction persisted in subsequent injections</li> </ul>

<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Breathing techniques should be more widely taught to nurses in pediatric oncology units</li> <li>● Larger, multi-center studies could enhance generalizability</li> <li>● Future studies could compare breathing with other distraction techniques</li> <li>● Development of standardized behavioral assessment tools recommended</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Randomization method was computer-generated</li> <li>● Parents were not present during injections, reducing external influence</li> <li>● Pain was assessed immediately post-procedure by both self-report and observation</li> <li>● Cultural context: Breathing technique is a culturally adapted, cost-effective approach feasible in low-resource settings</li> </ul>

## **16. Preprocedural Distress in Children With Cancer: An Intervention Using Biofeedback and Relaxation**

<b>Reference/Citation</b>	Shockey, D. P., Menzies, V., Glick, D. F., Taylor, A. G., Boitnott, A., & Rovnyak, V. (2013). Preprocedural Distress in Children With Cancer. <i>Journal of Pediatric Oncology Nursing</i> , 30(3), 129–138. <a href="https://doi.org/10.1177/1043454213479035">https://doi.org/10.1177/1043454213479035</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● N/A</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Pediatric oncology patients ages 6 to 12</li> <li>● Actively undergoing treatment (stage not specified)</li> <li>● Diagnosed with cancer and undergoing repeated invasive procedures</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Actively in treatment</li> <li>● Procedures included central line placement, bone marrow aspirations, lumbar punctures, etc.</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Feasibility study</li> <li>● Single-group, pre-post intervention design</li> <li>● Mixed methods (quantitative and qualitative feedback)</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● 4-session intervention combining progressive muscle relaxation (PMR), guided imagery, and biofeedback</li> <li>● Biofeedback used heart rate variability (HRV) via emWave PC software</li> </ul>

	<ul style="list-style-type: none"> <li>● Sessions lasted 45 minutes and occurred over four weeks</li> <li>● Conducted in an outpatient clinic setting before procedures</li> <li>● Caregivers also received education on relaxation to support reinforcement at home</li> <li>● Measures used: <ul style="list-style-type: none"> <li>○ Procedure Behavior Checklist (PCS)</li> <li>○ HRV biofeedback via emWave PC</li> </ul> </li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Children demonstrated a decrease in procedural distress from session 1 to session 4 (mean PCS scores declined)</li> <li>● Mean PCS (Procedure Behavior Checklist) scores: <ul style="list-style-type: none"> <li>○ Session 1: 11.58 (SD = 4.85)</li> <li>○ Session 4: 7.08 (SD = 3.79)</li> <li>○ Decline was statistically significant (<math>p = .01</math>)</li> </ul> </li> <li>● Participants described increased confidence and feelings of control</li> <li>● Anecdotal feedback from children indicated feelings of calmness, use of breathing techniques, and reduced fear</li> <li>● Parents reported improved coping behaviors in children during medical procedures</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Novel combination of biofeedback and relaxation within a pediatric framework showed promise</li> <li>● Children responded positively to learning about physiological stress responses (HRV visualization)</li> <li>● Intervention allowed children to develop self-regulatory coping skills for managing distress</li> <li>● The study suggests that brief, structured interventions can be feasible and meaningful in clinical pediatric oncology settings</li> <li>● Reinforcement from caregivers may have enhanced retention and practice of techniques</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Small sample size (<math>n = 12</math>) limits generalizability</li> <li>● No control group</li> <li>● Conducted at a single site, further limiting external validity</li> <li>● Not all participants completed the full intervention due to scheduling conflicts and illness</li> <li>● Reliance on behavioral checklist limits subjective insight into distress (though qualitative data helped supplement)</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Supports the feasibility of integrating non-pharmacologic distress interventions into pediatric oncology care</li> <li>● Encourages future studies with larger, randomized samples to establish efficacy</li> <li>● Suggests training caregivers may improve practice fidelity</li> </ul>

	<p>and generalization outside of clinic</p> <ul style="list-style-type: none"> <li>● Future work could compare intervention with standard care or other distraction/relaxation techniques</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Participant adherence: 9 of 12 completed all 4 sessions</li> <li>● Children showed engagement with visual HRV feedback and relaxation tasks</li> <li>● Strong emphasis on child empowerment and autonomy during procedures</li> <li>● All sessions conducted by an advanced practice nurse trained in the techniques</li> </ul>

## 17. Yoga in the Pediatric Oncology Population: A Review of the Literature

<b>Reference/Citation</b>	Spector, D. (2021). Yoga in the Pediatric Oncology Population: A Review of the Literature. <i>Journal of Pediatric Oncology Nursing</i> , 38(6), 410–419. <a href="https://doi.org/10.1177/10434542211011065">https://doi.org/10.1177/10434542211011065</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● N/A</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Children and adolescents diagnosed with cancer</li> <li>● Ages: Not explicitly defined across all studies, but generally includes pediatric and adolescent age groups</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Not consistently specified; participants were generally in or post-treatment for cancer, with varied diagnoses and cancer trajectories.</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Integrative literature review</li> <li>● Included studies: <ul style="list-style-type: none"> <li>○ 8 non-randomized, single-arm designs</li> <li>○ 5 of the studies designed as feasibility studies</li> </ul> </li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● All studies focused on yoga interventions</li> <li>● Sessions varied in length and frequency</li> <li>● Yoga practices typically included breathing, physical postures, and relaxation techniques</li> <li>● Interventions were adapted for pediatric oncology</li> </ul>

	<p>populations where reported</p> <ul style="list-style-type: none"> <li>● No randomized controlled trials were identified</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● All reviewed studies reported high feasibility and acceptability of yoga among pediatric oncology participants</li> <li>● Retention rates were around 70% across studies</li> <li>● Recruitment rates varied (34%–55%)</li> <li>● Improvements were noted in certain HRQL domains: <ul style="list-style-type: none"> <li>○ Decreased anxiety</li> <li>○ Reduced pain</li> <li>○ Improved physical functioning</li> </ul> </li> <li>● Qualitative feedback from children and families was overwhelmingly positive</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● The existing body of literature is small and lacks rigorous randomized controlled trials</li> <li>● Despite this, preliminary findings support that yoga is a feasible and safe intervention for pediatric cancer patients</li> <li>● Reported benefits spanned both psychological and physical domains</li> <li>● Positive themes emerged from participant feedback, including improved well-being and emotional coping</li> <li>● There is significant potential for yoga to address common cancer- and treatment-related symptoms in youth</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Lack of RCT; all studies were non-randomized and single-arm in design</li> <li>● Small sample sizes</li> <li>● Variability in yoga intervention protocols and outcome measures</li> <li>● Inconsistent reporting of cancer types, stages, and treatment contexts</li> <li>● Short follow-up durations, limiting long-term efficacy evaluation</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Strong need for well-powered RCT to establish efficacy</li> <li>● Future research should include standardized intervention protocols and validated outcome measures</li> <li>● Considerations should be made for tailoring yoga programs to individual developmental levels and cancer trajectories</li> <li>● Exploring barriers to recruitment and retention could improve study implementation</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Safety of yoga interventions was consistently affirmed across studies</li> <li>● None of the included studies reported adverse events</li> <li>● Yoga may serve as a complementary therapy to enhance</li> </ul>

	quality of life and symptom management during and after cancer treatment in youth
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**18. A feasibility study examining the impact of yoga on psychosocial health and symptoms in pediatric outpatients receiving chemotherapy**

<b>Reference/Citation</b>	Stein, E., Rayar, M., Krishnadev, U., Gupta, A., Hyslop, S., Plenert, E., Schechter-Finkelstein, T., & Sung, L. (2019). A feasibility study examining the impact of yoga on psychosocial health and symptoms in pediatric outpatients receiving chemotherapy. <i>Supportive Care in Cancer</i> , 27(10), 3769–3776. <a href="https://doi.org/10.1007/s00520-019-04673-9">https://doi.org/10.1007/s00520-019-04673-9</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Toronto, Canada (The Hospital for Sick Children)</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Pediatric oncology patients receiving outpatient chemotherapy</li> <li>● Age: 10–18 years</li> <li>● English-speaking</li> <li>● Mixed cancer types, not disease-specific</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Undergoing active outpatient chemotherapy (treatment phase)</li> <li>● Not specific to relapse or survivorship</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Feasibility study</li> <li>● Single-arm, prospective design</li> <li>● Quantitative assessments (psychosocial and symptom measures)</li> <li>● Descriptive outcome reporting (no control group)</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● 10-week yoga intervention</li> <li>● Weekly individualized yoga sessions <ul style="list-style-type: none"> <li>○ Week 1, 5, and 10 held in-hospital</li> <li>○ Remaining sessions delivered remotely via Skype</li> </ul> </li> <li>● Twice-weekly assigned homework between sessions</li> <li>● Tailored to participant's needs and physical limitations</li> <li>● Delivered one-on-one by a certified yoga therapist</li> <li>● In-person and remote hybrid model</li> <li>● Home practice was encouraged but not mandatory</li> <li>● Measures used:</li> </ul>

	<ul style="list-style-type: none"> <li>○ PROMIS Pediatric Fatigue, Anxiety, Depression, and Anger scales</li> <li>○ PedsQL (Pediatric Quality of Life Inventory)</li> <li>○ SSPedi (Symptom Screening in Pediatrics Tool)</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Primary outcome (feasibility): <ul style="list-style-type: none"> <li>○ Only 6 out of 10 participants completed <math>\geq 60\%</math> of yoga sessions</li> <li>○ Study did not meet predefined feasibility threshold (80% completion of 60% sessions)</li> </ul> </li> <li>● Homework compliance: <ul style="list-style-type: none"> <li>○ Very low; only one homework session completed across all participants</li> </ul> </li> <li>● Psychosocial outcomes (exploratory): <ul style="list-style-type: none"> <li>○ No formal statistical analysis reported due to small sample</li> <li>○ Individual variations observed in symptoms (anxiety, fatigue, etc.), but overall trends not reported</li> <li>○ Some participants reported perceived improvements</li> </ul> </li> <li>● Retention: <ul style="list-style-type: none"> <li>○ 2 participants dropped out early</li> <li>○ 8 participants completed end-of-study assessments</li> </ul> </li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● A 10-week individualized yoga intervention combining in-person and Skype delivery was not feasible in this population</li> <li>● Barriers included low participation in remote sessions and poor homework adherence</li> <li>● Challenges may be due to scheduling, physical condition during treatment, and competing demands</li> <li>● Despite feasibility limitations, individualized yoga remains a potentially valuable intervention and warrants further testing with adjusted formats</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Small sample size (n = 10), limiting generalizability</li> <li>● High attrition and low adherence to intervention protocol</li> <li>● Lack of control group</li> <li>● Inadequate data on session fidelity or qualitative feedback</li> <li>● Homework engagement extremely low, reducing total exposure to intervention</li> <li>● No statistical analysis conducted due to underpowered sample</li> <li>● Selection bias possible due to inclusion of only English-speaking patients</li> </ul>
<b>Implications and</b>	<ul style="list-style-type: none"> <li>● Future studies should explore alternative delivery models to</li> </ul>

<b>Future Directions</b>	<p>improve feasibility, such as:</p> <ul style="list-style-type: none"> <li>○ Shorter duration programs</li> <li>○ Fully in-person or better-supported virtual sessions</li> <li>○ Use of group-based formats to increase engagement</li> </ul> <ul style="list-style-type: none"> <li>● Strategies to enhance homework compliance are necessary</li> <li>● Larger randomized controlled trials needed to determine efficacy</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● No major adverse events reported</li> <li>● Yoga was tailored by therapist based on patient feedback and symptoms</li> <li>● Despite limited feasibility, participants still expressed interest in yoga intervention</li> </ul>

### 19. Yoga, Meditation and Mindfulness in pediatric oncology – A review of literature

<b>Reference/Citation</b>	Stritter, W., Everding, J., Luchte, J., Eggert, A., & Seifert, G. (2021). Yoga, Meditation and Mindfulness in pediatric oncology – A review of literature. <i>Complementary Therapies in Medicine</i> , 63, 102791. <a href="https://doi.org/10.1016/j.ctim.2021.102791">https://doi.org/10.1016/j.ctim.2021.102791</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● N/A</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Children and adolescents with cancer</li> <li>● Exact ages vary by study; typically includes school-aged children to late adolescence</li> <li>● Family involvement is not a central focus of the review, though some studies may have included parent feedback</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Varied across included studies: during treatment, post-treatment, and palliative stages</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Literature review of 11 studies: <ul style="list-style-type: none"> <li>○ 8 studies on yoga (most were feasibility or pilot studies)</li> <li>○ 3 studies on mindfulness</li> <li>○ Predominantly non-randomized, single-arm studies; no meta-analyses or large RCT</li> </ul> </li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Yoga: Varied in structure (group or individual, duration, frequency)</li> <li>● Mindfulness: Based on MBSR principles in some cases</li> </ul>

	<ul style="list-style-type: none"> <li>● Delivery settings: hospital, outpatient clinics, or home</li> <li>● Most studies lacked a standardized intervention protocol; adaptations were often based on patient needs or treatment setting</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Yoga and mindfulness interventions were feasible and well accepted across various settings</li> <li>● Reported benefits included: <ul style="list-style-type: none"> <li>○ Improved quality of life (QOL)</li> <li>○ Reduced fatigue</li> <li>○ Better sleep quality</li> <li>○ Decreased anxiety</li> <li>○ Improved physical activity, flexibility, and fitness</li> <li>○ Increased appetite (in some yoga studies)</li> </ul> </li> <li>● Psychological well-being showed positive changes in several cases</li> <li>● Recruitment and retention varied; overall acceptability was high</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Interventions are safe and feasible for pediatric oncology patients</li> <li>● Despite variability in interventions and outcome measures, yoga and mindfulness show promise in supporting well-being during or after cancer treatment</li> <li>● Authors emphasize the importance of tailoring interventions to the pediatric population and their specific needs</li> <li>● Research designs need improvement to draw firmer conclusions about efficacy</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Small sample sizes across most included studies</li> <li>● Lack of randomized controlled trials (RCT)</li> <li>● Heterogeneity in outcome measures, intervention content, and delivery settings</li> <li>● Inconsistent reporting on session adherence, fidelity, and long-term follow-up</li> <li>● Limited generalizability due to underrepresentation of diverse pediatric oncology populations</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Need for well-designed, adequately powered RCT</li> <li>● Standardization of intervention protocols and outcome measures</li> <li>● Integration of objective physiological outcomes (e.g., biomarkers)</li> <li>● Exploration of long-term benefits and implementation feasibility in clinical settings</li> <li>● Increased focus on culturally sensitive, age-appropriate</li> </ul>

	adaptations
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>• Some studies used validated measures (e.g., fatigue, anxiety scales), while others relied on qualitative feedback</li> <li>• Interventions were mostly short-term; limited evidence on sustained effects</li> <li>• The review calls for interdisciplinary collaboration in future research, including input from oncology, psychology, and complementary medicine experts</li> </ul>

## 20. Peaceful Play Yoga: Serenity and Balance for Children With Cancer and Their Parents

<b>Reference/Citation</b>	Thygeson, M. V., Hooke, M. C., Clapsaddle, J., Robbins, A., & Moquist, K. (2025). Peaceful play yoga: serenity and balance for children with cancer and their parents. <i>Journal of Pediatric Oncology Nursing</i> , 27(5), 276–284. <a href="https://doi.org/10.1177/1043454210363478">https://doi.org/10.1177/1043454210363478</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>• Pediatric patients aged 6 to 18 years diagnosed with cancer <ul style="list-style-type: none"> <li>○ 11 children aged 6–12 years</li> <li>○ 5 adolescents aged 13–18 years</li> </ul> </li> <li>• 33 parents of the pediatric patients also participated</li> <li>• Study included both patients and family members</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>• Not explicitly stated; implied to be in active treatment due to inpatient hospital setting on a hematology/oncology unit</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>• Single-session, feasibility intervention study</li> <li>• Pre–post design using quantitative anxiety measures</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>• Anxiety was measured using the Spielberger State Anxiety Scale</li> <li>• A single Peaceful Play Yoga session tailored to the physical and emotional needs of patients and parents</li> <li>• Conducted in the inpatient hematology/oncology unit</li> <li>• Designed with consideration for patients' medical conditions</li> </ul>

	<p>(e.g., intravenous lines, surgical wounds)</p> <ul style="list-style-type: none"> <li>● Focus on poses, breathing, and relaxation.</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Children (ages 6–12): <ul style="list-style-type: none"> <li>○ No significant change in anxiety scores (baseline anxiety already within normal range).</li> </ul> </li> <li>● Adolescents (ages 13–18): <ul style="list-style-type: none"> <li>○ Significant reduction in anxiety scores post-session.</li> </ul> </li> <li>● Parents: <ul style="list-style-type: none"> <li>○ Significant reduction in anxiety scores post-session.</li> </ul> </li> <li>● Feedback: <ul style="list-style-type: none"> <li>○ All cohorts (children, adolescents, and parents) provided positive feedback</li> <li>○ Described as a “welcomed break” and “restorative”</li> </ul> </li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Yoga was found to be a feasible and well-received complementary intervention in the pediatric oncology inpatient setting</li> <li>● The greatest benefit was seen in adolescents and parents, who had significant anxiety reduction</li> <li>● Children had baseline normal anxiety, suggesting limited room for measurable improvement in this group</li> <li>● Tailoring the session to participant physical limitations (e.g., fatigue, devices, illness burden) was critical to its success</li> <li>● Interdisciplinary collaboration between yoga instructors and medical staff enhanced feasibility and safety.</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Single session only; unable to assess sustained effects</li> <li>● Small sample size, especially among adolescents (n=5)</li> <li>● Lack of control group; no comparison condition</li> <li>● Potential bias due to participant self-selection and positive expectancy.</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Supports integration of yoga into pediatric oncology care as a non-pharmacologic strategy for reducing anxiety</li> <li>● Suggests that tailored, patient-centered complementary interventions are acceptable and feasible in inpatient settings</li> <li>● Recommends further research using larger samples, repeated sessions, and control comparisons to assess long-term impact and clinical efficacy.</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Sessions were led by certified yoga instructors with pediatric experience</li> <li>● Collaboration with medical team ensured yoga was safely adapted to each patient</li> <li>● Positive emotional language (e.g., “serenity,” “balance,” “play”) was intentionally used in the intervention branding</li> </ul>

to be child-friendly and reduce intimidation.

## 21. Mind-Body Therapies in Childhood Cancer

<b>Reference/Citation</b>	Velez-Florez, G., Velez-Florez, M. C., Mantilla-Rivas, J. O., Patarroyo-Rodríguez, L., Borrero-León, R., & Rodríguez-León, S. (2018). Mind-Body Therapies in Childhood Cancer. <i>Current Psychiatry Reports</i> , 20(8). <a href="https://doi.org/10.1007/s11920-018-0927-6">https://doi.org/10.1007/s11920-018-0927-6</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>• Pediatric oncology population</li> <li>• No specific age range provided</li> <li>• Studies including use of MBTs in children and/or adolescents up to 19 years old and youth up to 24 if diagnosis and intervention occurred in childhood</li> <li>• Multiple interventions discussed directly involve parents and siblings, reflecting a family-centered approach.</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>• All stages included (diagnosis, treatment, survivorship)</li> <li>• Also includes end-of-life care and bereavement period in some studies cited</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>• Narrative literature review (targeted search from 2008–2018)</li> <li>• No pooled statistical analysis or meta-analysis conducted</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>• Interventions reviewed include: <ul style="list-style-type: none"> <li>○ Art Therapy: Expressive tool for self-regulation and externalization of emotions (drawing, origami, dreamcatchers, PPAT drawings)</li> <li>○ Music Therapy: Useful for reducing anxiety and pain, enhances emotional expression (lyric writing, live music, recorded songs)</li> <li>○ Meditation and mindfulness: Calming effect; helps regulate attention and stress (focused attention, breath work, guided imagery)</li> <li>○ Prayer and Spirituality: Source of comfort, especially in religious communities (including centering prayer, transcendental meditation)</li> <li>○ Hypnosis: Described as effective in pain management and coping with procedures (procedure-</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ related and chronic pain, anxiety, nausea)</li> <li>○ Relaxation Techniques: Progressive muscle relaxation; often combined with guided imagery (beach visualization with sensory cues) and breathing techniques</li> <li>● Most interventions are tailored, non-standardized, and adapted to age, developmental level, and individual preferences.</li> <li>● Includes both individual and family-based formats.</li> <li>● Some sessions led by licensed professionals (e.g., music therapists), others by trained staff or students using internal manuals</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Art therapy: <ul style="list-style-type: none"> <li>○ Improved communication, reduced anxiety, enhanced mood, decreased perception of pain, and increased emotional expression</li> <li>○ Some quantitative evidence cited (e.g., <math>p = 0.03</math> for pain; <math>p = 0.0061</math> for nausea).</li> </ul> </li> <li>● Hypnosis: <ul style="list-style-type: none"> <li>○ Effective in procedure-related pain and anxiety</li> <li>○ Stronger effects in highly hypnotizable patients</li> <li>○ 12 RCT in pediatric oncology reviewed</li> </ul> </li> <li>● Meditation: <ul style="list-style-type: none"> <li>○ Decreased anxiety, distress, and analgesic use</li> <li>○ Moderate effect sizes for quality of life, mood, and sleep</li> </ul> </li> <li>● Prayer/Spirituality: <ul style="list-style-type: none"> <li>○ Improved meaning-making and family resilience; most used CAM reported by caregivers (62.3%)</li> </ul> </li> <li>● Music interventions: <ul style="list-style-type: none"> <li>○ Lower anxiety and pain during procedures; improved family adaptation and coping in video therapy trials</li> </ul> </li> <li>● Progressive muscle relaxation &amp; guided imagery: <ul style="list-style-type: none"> <li>○ Reduced heart rate, sadness, tension, and anxiety in both patients and parents</li> </ul> </li> <li>● Family involvement: <ul style="list-style-type: none"> <li>○ Associated with better child adjustment, coping, cohesion, and communication. MBTs often help families regulate emotions and cope with uncertainty</li> </ul> </li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● MBTs serve as important supportive care modalities in pediatric cancer</li> <li>● Highlighted the benefit of relationship-based, longitudinal care</li> <li>● Emphasized multimodal MBTs tailored to the unique</li> </ul>

	<p>emotional, spiritual, and physical needs of each child</p> <ul style="list-style-type: none"> <li>● Mind-body strategies helped build trust, enhance emotion regulation, and improve therapeutic alliance</li> <li>● Institutional experience supports their feasibility and benefit</li> <li>● Some therapies (e.g., hypnosis, music therapy) show reduced anxiety, pain, and improved coping</li> <li>● Diaphragmatic breathing and guided imagery were particularly well received and effective</li> <li>● Studies cited show improvement in patient mental health and family well-being</li> <li>● Effects described qualitatively; no pooled statistical outcomes</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Lack of standardization across intervention types limits generalizability</li> <li>● Many studies have small sample sizes, no control groups, and lack long-term follow-up</li> <li>● Cultural differences may influence acceptability and relevance of therapies.</li> <li>● Limited comparative data between therapies</li> <li>● Another limitation is the “perception of MBT as a non-essential aspect of oncologic care in the medical setting”</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● MBTs show promise but require further study through well-designed RCT</li> <li>● Need for protocol standardization and outcome tracking</li> <li>● Importance of training non-specialist staff (e.g., medical students) to implement basic MBTs</li> <li>● Institutions should develop integrative manuals and invest in family-oriented care models</li> <li>● Emphasis on early and continuous involvement of psychosocial teams in pediatric oncology</li> <li>● Call for greater integration of MBTs into conventional pediatric oncology care, not as “extras,” but as essential tools</li> <li>● Use of technology (apps, telehealth) is suggested for expanding access</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Clear evidence that emotional well-being is tied to clinical outcomes in pediatric cancer</li> <li>● Article emphasizes a biopsychosocial model of care</li> <li>● Notes that MBTs can be adapted to developmental stage and cultural context</li> <li>● Encourages using MBTs alongside pharmacologic treatments to enhance holistic care and promotes early intervention across illness trajectory (diagnosis to</li> </ul>

	<p>survivorship)</p> <ul style="list-style-type: none"> <li>● Institution uses creative arts (e.g., dreamcatchers, song composition) to promote healing.</li> <li>● Some therapies (e.g., hypnosis) require trained specialists; others (e.g., art therapy) more flexible</li> </ul>
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## 22. Psychosocial Interventions for Adolescents and Young Adults Diagnosed with Cancer During Adolescence: A Critical Review

<b>Reference/Citation</b>	Walker, E., Martins, A., Aldiss, S., Gibson, F., & Taylor, R. M. (2016). Psychosocial Interventions for Adolescents and Young Adults Diagnosed with Cancer During Adolescence: A Critical Review. <i>Journal of Adolescent and Young Adult Oncology</i> , 5(4), 310–321. <a href="https://doi.org/10.1089/jayao.2016.0025">https://doi.org/10.1089/jayao.2016.0025</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Studies mostly conducted in the U.S. (13 of 18), others in Hungary, Taiwan, Canada, New Zealand, and Israel</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Adolescents and Young Adults (AYA), ages 10–30 years</li> <li>● All participants had cancer; many studies included multiple diagnoses (e.g., leukemia, lymphoma, CNS tumors)</li> <li>● Included both on-treatment and off-treatment AYAs</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● 9 studies included AYAs on-treatment</li> <li>● 4 studies focused on AYAs off-treatment</li> <li>● 2 studies included both on- and off-treatment participants</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● 8 RCT</li> <li>● 10 non-randomized designs (e.g., pre-post, quasi-experimental)</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Wide variation: skills training, counseling, physical activity, music therapy, family-based care, yoga, video games, online CBT, etc.</li> <li>● Delivery: individual, group-based, or family-based; face-to-face, computer-mediated, or hybrid</li> <li>● Length: ranged from single session to 16 weeks</li> </ul>

<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● All but two interventions showed a positive effect on at least one measure of psychosocial well-being</li> <li>● Greater improvements seen in off-treatment AYAs than on-treatment ones</li> <li>● Off-treatment groups saw more consistent improvements in QOL, anxiety, and body image</li> <li>● On-treatment interventions often failed to improve symptom distress, resilience, or QOL</li> <li>● Only one study showed improvements across all psychosocial measures</li> <li>● Multiple studies used inconsistent or poorly aligned outcome measures, limiting comparability</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Evidence for psychosocial interventions is growing, but still limited</li> <li>● Greater psychological needs may emerge after treatment ends, yet most interventions target on-treatment AYAs</li> <li>● Studies lacked consistency in outcomes, use of validated tools, and rarely specified primary outcomes</li> <li>● No study assessed long-term effects beyond 1 year; cost-effectiveness largely ignored</li> <li>● Different approaches may be needed for on- vs off-treatment AYAs</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Small sample sizes, short follow-up periods, and poor retention in many studies</li> <li>● Wide variation in outcome measures; few used validated tools for AYAs Short follow-up periods (mostly 3 months)</li> <li>● Few studies clearly identified primary outcomes</li> <li>● Limited economic evaluations or theoretical frameworks</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● More theory-based, age-appropriate, and validated psychosocial interventions are needed</li> <li>● Interventions should consider timing (on- vs off-treatment), delivery format, and sustainability</li> <li>● Long-term follow-up and cost-effectiveness must be integrated into future research</li> <li>● Better alignment of intervention aims and psychosocial outcome measures is critical</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Administering too many outcome measures may reduce acceptability and increase dropout</li> <li>● Even when QOL was measured across studies, only off-treatment groups showed improvements</li> </ul>

### 23. The Feasibility and Benefits of a 12-Week Yoga Intervention for Pediatric Cancer Out-Patients

<b>Reference/Citation</b>	Wurz, A., Chamorro-Vina, C., Guilcher, G. M. T., Schulte, F., & Culos-Reed, S. N. (2014). The feasibility and benefits of a 12-week yoga intervention for pediatric cancer out-patients. <i>Pediatric Blood &amp; Cancer</i> , 61(10), 1828–1834. <a href="https://doi.org/10.1002/pbc.25096">https://doi.org/10.1002/pbc.25096</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Canada; participants recruited from the Alberta Children’s Hospital in Calgary</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● 8 pediatric cancer out-patients (4 male, 4 female)</li> <li>● Actively receiving or recently completed treatment</li> <li>● Diagnoses included leukemia, brain tumors, and lymphoma</li> <li>● Inclusion criteria: age 5–18, physician approval, able to participate in yoga, English fluency</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Mixed: all participants were outpatients; some on active treatment, some post-treatment</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Quantitative, single-group pre-post design</li> <li>● Pilot feasibility and intervention study</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● 12-week community-based yoga intervention</li> <li>● Supervised sessions: twice per week</li> <li>● Each session: 45 minutes (30 min yoga + 15 min relaxation)</li> <li>● Yoga included stretching, breathing, and relaxation tailored for pediatric cancer patients</li> <li>● No control group</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Feasibility confirmed: <ul style="list-style-type: none"> <li>○ Recruitment rate: 40%</li> <li>○ Retention: 100% (no dropouts)</li> <li>○ Attendance: average 70% of sessions attended</li> </ul> </li> <li>● Statistically significant improvements (Wilcoxon Signed Rank tests): <ul style="list-style-type: none"> <li>○ Patient-reported HRQL (P = 0.02)</li> <li>○ Parent-proxy HRQL (P = 0.03)</li> <li>○ Functional mobility (Timed Up and Go test) (P = 0.01)</li> <li>○ Hamstring flexibility: <ul style="list-style-type: none"> <li>■ Left leg (P = 0.01)</li> <li>■ Right leg (P = 0.02)</li> </ul> </li> </ul> </li> <li>● Total physical activity level (PAL) (P = 0.02; measured by</li> </ul>

	accelerometers)
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● Novel: <ul style="list-style-type: none"> <li>○ This is one of the first studies examining community-based yoga as a supportive care intervention in pediatric oncology outpatients.</li> </ul> </li> <li>● Tricky: <ul style="list-style-type: none"> <li>○ Small sample size limits generalizability; lack of control group prevents attribution of improvements solely to the yoga intervention</li> </ul> </li> <li>● Yoga was found to be not only feasible and safe but also effective in improving physical and psychosocial functioning</li> <li>● Included both self-report and parent proxy measures for HRQL; used objective physical activity data (accelerometry)</li> <li>● Parents and children reported positive subjective experiences and emotional benefits from participating</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>● Small sample (N=8), limits statistical power and generalizability</li> <li>● Lack of randomization and control group; without a randomly assigned control condition, the study cannot determine whether improvements were due to the yoga intervention or other confounding variables.</li> <li>● Possible response bias (selection bias): <ul style="list-style-type: none"> <li>○ Participants who volunteered may differ systematically from the broader population of pediatric cancer outpatients, possibly being more motivated or open to interventions like yoga.</li> </ul> </li> <li>● Stringent inclusion criteria: <ul style="list-style-type: none"> <li>○ Only patients with low physical activity and limited prior yoga experience were eligible, which further narrows generalizability.</li> </ul> </li> <li>● Larger, randomized controlled trials are necessary to clarify yoga's specific effects in pediatric oncology populations</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Encouraging findings support expanding yoga programs for pediatric cancer populations</li> <li>● Larger, randomized controlled trials are warranted</li> <li>● Consider testing yoga across treatment phases (e.g., active, maintenance, survivorship)</li> <li>● More diverse samples and longer follow-up needed to assess long-term benefit</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Yoga may help offset sedentary behavior trends among pediatric oncology populations</li> <li>● Flexibility in session structure and instructor adaptation were</li> </ul>

crucial for engagement

## 24. Feasibility, Acceptability, and Psychosocial Outcomes of a Mindfulness-Based Interactive e-Book for Young People with Cancer

<b>Reference/Citation</b>	Perumbil Pathrose, S., Patterson, P., Ussher, J., Everett, B., Salamonson, Y., McDonald, F., Biegel, G. M., He, S., & Ramjan, L. (2021). Feasibility, Acceptability, and Psychosocial Outcomes of a Mindfulness-Based Interactive e-Book for Young People with Cancer. <i>Journal of Adolescent and Young Adult Oncology</i> , 11(1), 27–34. <a href="https://doi.org/10.1089/jayao.2020.0185">https://doi.org/10.1089/jayao.2020.0185</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Australia <ul style="list-style-type: none"> <li>○ From August to December 2019</li> <li>○ Recruitment through flyer distribution on Canteen (Australian Organization for Young People Living with Cancer 12–25 years) website, emails, and social media advertisements</li> </ul> </li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Intervention aimed toward young people aged 15–24 years, but eligibility criteria included those aged 14-29</li> <li>● Included both: <ul style="list-style-type: none"> <li>○ Those undergoing active treatment</li> <li>○ Survivors of cancer</li> </ul> </li> <li>● Mixed diagnoses and stages of cancer (not limited to a single type or stage) <ul style="list-style-type: none"> <li>○ Majority were survivors (80.6% off active treatment)</li> </ul> </li> <li>● 61.3% were female</li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Mixed: includes both active treatment and post-treatment (survivorship)</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Concurrent mixed methods <ul style="list-style-type: none"> <li>○ Quantitative: pre- and post-intervention surveys</li> <li>○ Qualitative: semi-structured interviews</li> </ul> </li> <li>● Feasibility and acceptability study</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Mindfulness-Based Intervention (MBI) delivered as a self-guided, interactive e-Book <ul style="list-style-type: none"> <li>○ Based on “Be Mindful and Stress Less” workbook</li> </ul> </li> <li>● Duration: 6 weeks</li> <li>● Modules: Focused on each sense (sight, sound, smell, touch,</li> </ul>

	<p>taste) + self-care</p> <ul style="list-style-type: none"> <li>● Features: Audios, reflection activities, quizzes, mindfulness practices</li> <li>● Content also included: <ul style="list-style-type: none"> <li>○ Educational information on mindfulness</li> <li>○ Exercises and audio-visual content</li> <li>○ Activities based on mindfulness-based stress reduction and mindfulness-based cognitive therapy</li> </ul> </li> <li>● No control group</li> <li>● Participants encouraged to engage with the e-Book 2–3 times per week</li> <li>● Participants received \$60 Australian voucher for time and internet costs</li> <li>● Data collected at baseline and post-intervention</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● 31 participants enrolled; 20 completed post-intervention survey (64.5% retention)</li> <li>● Participation: 90% of completers accessed &gt;50% of the e-Book</li> <li>● Statistically significant improvements: <ul style="list-style-type: none"> <li>○ Depressive symptoms: reduced from 2.35 to 1.25 (p = 0.03)</li> <li>○ Psychological distress: reduced from 23.63 to 19.79 (p = 0.03)</li> </ul> </li> <li>● Non-significant but positive improvements : <ul style="list-style-type: none"> <li>○ Mindfulness: increased from 20.05 to 22.9 (p = 0.08)</li> <li>○ Quality of Life (QOL): improved from 62.0 to 69.1 (p = 0.13)</li> </ul> </li> <li>● Three participants participated in follow-up interviews confirming intervention acceptability</li> </ul>
<b>Discussion/Key Takeaways</b>	<ul style="list-style-type: none"> <li>● The intervention utilizing the e-book format largely was feasible and acceptable</li> <li>● Retention rate exceeded typical digital health interventions for this group</li> <li>● Self-directed format was convenient, private, and flexible</li> <li>● Participants appreciated accessibility and content but suggested improvements: <ul style="list-style-type: none"> <li>○ More tailored content to cancer-specific stressors and real-life examples</li> <li>○ Inclusion of peer interaction features (e.g., chat or online discussion options), as some participants desired face-to-face or real-time interactions</li> </ul> </li> <li>● The flexibility and self-guided structure supported user engagement</li> <li>● Recruitment and retention were noted challenges</li> </ul>

<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>● The study included self-selected participants, introducing potential selection bias; those with an interest in mindfulness or with better baseline coping skills may have been more likely to participate</li> <li>● The majority of participants were survivors (off active treatment), which limits the generalizability of findings to those undergoing active treatment</li> <li>● There was a gender imbalance, with most participants being female, so results cannot be generalized to male adolescents and young adults with cancer</li> <li>● Small sample size with high attrition (11 of 31 did not complete post-intervention) <ul style="list-style-type: none"> <li>○ Since only three participants completed post-intervention interviews, it limited the depth and diversity of qualitative feedback</li> </ul> </li> <li>● Lack of control group restricts the ability to attribute psychosocial changes directly to the intervention</li> <li>● Reliance on self-report data</li> <li>● The study did not assess key contributing variables, such as: <ul style="list-style-type: none"> <li>○ Adherence to using the e-Book (e.g., how often it was accessed)</li> <li>○ Duration and consistency of mindfulness practice</li> <li>○ Long-term impacts of the intervention</li> </ul> </li> <li>● The interactive e-Book was not cancer-specific; it was designed for general youth populations, which may have reduced its relevance or emotional resonance for those coping with cancer-specific stressors.</li> </ul>
<p><b>Implications and Future Directions</b></p>	<ul style="list-style-type: none"> <li>● The intervention shows promise as a scalable and accessible support tool for young people with cancer <ul style="list-style-type: none"> <li>○ E-Book MBIs are a promising, low-cost, accessible strategy for psychosocial support</li> </ul> </li> <li>● Future research should: <ul style="list-style-type: none"> <li>○ Cancer-specific tailoring</li> <li>○ Optional interactive/peer support features</li> </ul> </li> <li>● Further research should: <ul style="list-style-type: none"> <li>○ Incorporate control groups</li> <li>○ Include cancer-specific mindfulness content</li> <li>○ Assess adherence and long-term outcomes of digital mindfulness interventions</li> <li>○ Consider gender-specific engagement strategies</li> <li>○ Explore blended delivery (e.g., synchronous orientation sessions)</li> <li>○ Use larger sample sizes</li> <li>○ Identify strategies to improve retention and engagement</li> </ul> </li> </ul>

<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● The study builds on a limited body of evidence for self-administered MBIs in adolescent and young adult oncology populations</li> <li>● Demonstrates feasibility of using digital, self-guided mindfulness tools as alternatives to face-to-face formats <ul style="list-style-type: none"> <li>○ e-Book format successfully addressed some common barriers to MBI accessibility (time, privacy, location)</li> </ul> </li> </ul>
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## 25. Meditation reduces brain activity in the default mode network in children with active cancer and survivors

<b>Reference/Citation</b>	<p>Hehr, A., Iadipaolo, A. S., Morales, A., Cohen, C., Taub, J. W., Harper, F. W. K., Goldberg, E., Bluth, M. H., Rabinak, C. A., &amp; Marusak, H. A. (2022). Meditation reduces brain activity in the default mode network in children with active cancer and survivors. <i>Pediatric Blood &amp; Cancer</i>, 69(10).  <a href="https://doi.org/10.1002/pbc.29917">https://doi.org/10.1002/pbc.29917</a></p>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Recruited from Children’s Hospital of Michigan Hematology/Oncology clinic (Detroit, MI) and local cancer support groups and organizations (e.g., Kids Kicking Cancer, Gilda’s Club of Metro Detroit)</li> <li>● Data collected from August 2017 to January 2019</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● 12 children with a current or past diagnosis of cancer <ul style="list-style-type: none"> <li>○ 5 females</li> <li>○ 5 actively undergoing cancer treatment, including chemotherapy, surgery, radiation, blood transfusion, or bone marrow transplant</li> </ul> </li> <li>● Participants cancer diagnoses: <ul style="list-style-type: none"> <li>○ Acute lymphoblastic leukemia (ALL): n = 8 (67%)</li> <li>○ Acute promyelocytic leukemia (APML): n = 1 (8%)</li> <li>○ Neuroblastoma: n = 1 (8%)</li> <li>○ Wilms Tumor: n = 1 (8%)</li> <li>○ Juvenile myelomonocytic leukemia 1 (8%)</li> </ul> </li> <li>● Eligible participants were 5-17, English speaking, and previously diagnosed with any type of pediatric cancer</li> <li>● Participants excluded for CNS impacting cancers, MRI contraindications (e.g., claustrophobia, braces, non-MRI compatible port), major sensory impairments (e.g., severe vision loss), comorbid neurological disorders (e.g., epilepsy), gross neuropathologies (e.g., ventriculomegaly), pervasive</li> </ul>

	developmental disorders, or other severe psychopathology (e.g., schizophrenia)
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Mixed: Active treatment and survivorship</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Prospective pilot study</li> <li>● Experimental within-subjects design</li> <li>● Neuroimaging/Functional MRI-based</li> <li>● Non-randomized</li> <li>● Quantitative</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● All participants underwent 4 hours of meditation training prior to fMRI</li> <li>● Martial arts-based meditation: focused attention and mindful acceptance (delivered via guided instructions)</li> <li>● Within-subjects design comparing 4 conditions while viewing distressing videos: <ul style="list-style-type: none"> <li>○ LOOK: Passive viewing (control)</li> <li>○ DISTRACT: Counting backward from 10 and two meditation emotion regulation techniques (non-meditation distraction technique)</li> <li>○ BREATH: Focused attention on the breath (mindful awareness)</li> <li>○ ACCEPT: Mindful attention toward/acceptance of emotions</li> </ul> </li> <li>● 20 total trials (5 per condition), each with instruction, video (30s), and distress rating</li> <li>● Distress-inducing videos depicted realistic clinical scenarios (e.g., child getting an injection)</li> <li>● MRI scans were taken during each condition to measure neural activation</li> <li>● Emotion ratings collected after each clip using a visual analog scale (1–6)</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● Wilcoxon Signed-Ranks tests revealed no significant differences in distress ratings between the conditions</li> <li>● Focused attention (BREATH) resulted in significantly reduced DMN activity, especially in the precuneus and posterior cingulate cortex, compared to LOOK and DISTRACT</li> <li>● Mindful acceptance (ACCEPT) also associated with reduced activity in the medial frontal cortex (MFC) compared to DISTRACT</li> <li>● Distraction (DISTRACT) showed no significant reduction in</li> </ul>

	<p>DMN activity</p> <ul style="list-style-type: none"> <li>● BREATH showed greater reductions in DMN activity than ACCEPT, particularly in MFC</li> <li>● Exploratory analyses: <ul style="list-style-type: none"> <li>○ Older participants had lower activation in DMN regions during meditation</li> <li>○ Trait mindfulness and anxiety levels were not significantly correlated with brain activity</li> <li>○ Age at diagnosis was associated with less distress during distraction condition</li> </ul> </li> <li>● Findings suggest that meditation modulates brain regions involved in self-referential processing even in children with cancer</li> <li>● Supports the idea that meditation techniques may be effective regardless of age, since they do not rely on top-down prefrontal mechanisms</li> </ul>
<p><b>Discussion/Key Takeaways</b></p>	<ul style="list-style-type: none"> <li>● First pediatric fMRI study showing real-time neural changes during active meditation in children with cancer</li> <li>● Meditation (especially focused attention) may suppress self-referential processing in the DMN, potentially reducing depressive rumination</li> <li>● Meditation was more effective than distraction in reducing DMN activity - important since distraction is commonly used in pediatric care but may not be as neurologically effective</li> <li>● The DMN is implicated in depressive symptoms, so reducing its activity may offer long-term emotional benefits</li> <li>● Simple meditation forms (e.g., breath focus) are developmentally appropriate and neurologically effective even in children with minimal training</li> <li>● No evidence of increased activation in the central executive network (CEN), consistent with the hypothesis that meditation does not require prefrontal-based control</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>● Very small sample size limits generalizability and statistical power</li> <li>● Wider age range introduces developmental variability in brain function</li> <li>● Sample included both survivors and actively treated patients, limiting clarity of subgroup effects</li> <li>● No long-term follow-up or outcome data</li> <li>● Only two forms of meditation (focused attention and mindful acceptance) and one non-meditation strategy (distraction) were tested - may not reflect the full range of emotion regulation techniques</li> </ul>

	<ul style="list-style-type: none"> <li>● No non-distressing (e.g., positively valenced) video condition was included, limiting interpretation of whether neural responses were specific to negative emotion regulation</li> <li>● The study did not integrate assessments of state and trait mindfulness, which could have clarified individual differences in neural responses</li> <li>● Brief meditation training may have influenced brain activity even during non-meditative conditions like distraction</li> </ul>
<p><b>Implications and Future Directions</b></p>	<ul style="list-style-type: none"> <li>● Meditation may serve as a developmentally appropriate, neurobiologically effective intervention for distress in pediatric oncology</li> <li>● Reducing DMN activity may protect against depressive rumination and emotion dysregulation</li> <li>● Supports integrating brief meditation strategies into pediatric healthcare (e.g., during painful procedures)</li> <li>● Could inform development of brief, accessible interventions (e.g., pre-surgical, inpatient support)</li> <li>● Future work should: <ul style="list-style-type: none"> <li>○ Include larger and more diverse sample sizes</li> <li>○ Explore longitudinal outcomes</li> <li>○ Investigate different forms of meditation and their impact</li> <li>○ Examine dose-response and training effects</li> <li>○ Integrate measures of both state and trait mindfulness</li> <li>○ Consider including positive/neutral stimuli and additional regulation strategies</li> </ul> </li> </ul>
<p><b>Additional Key Observations</b></p>	<ul style="list-style-type: none"> <li>● Children as young as 5 years old successfully engaged in meditation in an fMRI setting</li> <li>● BREATH was more effective than ACCEPT - possibly due to simplicity and developmental suitability of focusing on the breath</li> <li>● Findings align with adult fMRI literature but uniquely extend insights to a pediatric cancer population</li> <li>● Intervention program (Kids Kicking Cancer) emphasizes martial arts-based breathing and meditation techniques</li> </ul>

**26. The Effect of The Mindfulness-Based Relaxation, Aromatherapy, and Prayer (RADO) Intervention on Anxiety and Quality of Life Among Children With Cancer**

<b>Reference/Citation</b>	Apriany, D., Rakhmawati, W., Iskandarsyah, A., & Hilmanto, D. (2025). The Effect of The Mindfulness-Based Relaxation, Aromatherapy, and Prayer (RADO) Intervention on Anxiety and Quality of Life Among Children With Cancer. <i>Journal of Multidisciplinary Healthcare</i> , 18, 1381–1392. <a href="https://doi.org/10.2147/jmdh.s507759">https://doi.org/10.2147/jmdh.s507759</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Participants recruited from three hospitals in Bandung, Indonesia <ul style="list-style-type: none"> <li>○ Dr. Hasan Sadikin Hospital in Bandung, Al Islam Hospital, and Al Ikhsan General Hospital</li> </ul> </li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Children with cancer, ages 10–17</li> <li>● Inclusion criteria: <ul style="list-style-type: none"> <li>○ Diagnosed with cancer for <math>\geq 3</math> months</li> <li>○ Actively undergoing treatment</li> <li>○ Able to communicate verbally</li> <li>○ In grades 4 of elementary school through 11 of high school</li> </ul> </li> <li>● Sample size: 66 total <ul style="list-style-type: none"> <li>○ Initially calculated to be 25 for each group, but after accounting for potential dropout, 33 participants were enrolled for each group (33 intervention, 33 control)</li> </ul> </li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● All participants were in active treatment (no focus on survivorship or relapse)</li> <li>● Children who had cancer for at least 3 months</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Quasi-experimental design</li> <li>● Pre- and post-test control group</li> <li>● Repeated ANOVA and independent t-tests used for statistical analysis of quantitative data</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Data collected at baseline (T0), day three (T1), and day seven (T3)</li> <li>● Anxiety and QoL measured using the Hamilton Rating Scale for Anxiety (HRS-A) and Pediatric Quality of Life Inventory (PEDQL 3.0)</li> <li>● 7 consecutive days, 20 minutes daily</li> <li>● Delivery: Conducted daily by a nurse or facilitator</li> <li>● RADO intervention group: <ul style="list-style-type: none"> <li>○ Pre-Assessment: <ul style="list-style-type: none"> <li>■ Baseline evaluation of mindfulness and QoL to determine intervention impact.</li> </ul> </li> <li>○ Introduction to the Intervention:</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>■ Participants were briefed on the purpose and process of RADO</li> <li>■ Explained the benefits of mindfulness, deep breathing, aromatherapy, and prayer components</li> </ul> </li> <li>○ Deep Breathing Relaxation Techniques: <ul style="list-style-type: none"> <li>■ Each session began with slow, mindful breathing (inhale through nose, hold, exhale through mouth)</li> <li>■ Verbal guidance was provided to enhance present-moment awareness and relaxation</li> </ul> </li> <li>○ Aromatherapy: <ul style="list-style-type: none"> <li>■ Introduced after breathing exercises</li> <li>■ Participants selected essential oils (e.g., lavender for calm, citrus for uplift) to personalize the session</li> <li>■ Oils were diffused in the room to create a relaxing environment.</li> </ul> </li> <li>○ Prayer Component: <ul style="list-style-type: none"> <li>■ Session ended with a prayer tailored to participants' beliefs</li> <li>■ Could be led by a nurse or parent, promoting comfort and spiritual support</li> <li>■ Participants engaged at their comfort level (listening or active participation).</li> </ul> </li> <li>○ Daily Sessions: <ul style="list-style-type: none"> <li>■ Repeated daily for 7 days with the same structure to build familiarity and reinforce practice</li> </ul> </li> <li>○ Post-Assessment: <ul style="list-style-type: none"> <li>■ Mindfulness and QoL reassessed post-intervention using the same tools as baseline</li> </ul> </li> <li>● Control Group: <ul style="list-style-type: none"> <li>○ Received standard care only with no RADO intervention</li> </ul> </li> </ul>
<p><b>Findings/Results</b></p>	<ul style="list-style-type: none"> <li>● Anxiety: <ul style="list-style-type: none"> <li>○ Significant reduction in anxiety in the intervention group from T0 (pre) to T3 (day 7)</li> <li>○ <math>p &lt; 0.001</math> (between-group difference)</li> <li>○ No significant change in control group over time</li> </ul> </li> <li>● Quality of Life (QoL): <ul style="list-style-type: none"> <li>○ Significant improvement in PedsQL scores by T3 day 7 in the intervention group (<math>p = 0.001</math>) compared to the control group</li> </ul> </li> <li>● Repeated measures ANOVA showed significant within-</li> </ul>

	<p>group effects in intervention group across all time points</p> <ul style="list-style-type: none"> <li>● Subgroup Findings: <ul style="list-style-type: none"> <li>○ Children diagnosed with Acute Lymphoblastic Leukemia (ALL) and male participants experienced slightly greater improvements in outcomes, indicating possible moderating effects of gender and diagnosis.</li> <li>○ Children with &lt;10 chemotherapy cycles showed greater anxiety reduction and QoL improvement compared to those with ≥10 cycles</li> </ul> </li> </ul>
<p><b>Discussion/Key Takeaways</b></p>	<ul style="list-style-type: none"> <li>● RADO is a feasible, non-invasive, low-cost, and culturally appropriate intervention</li> <li>● Intervention effectively reduced anxiety and improved QoL in a short 7-day span <ul style="list-style-type: none"> <li>○ Significant short-term improvements in psychological and quality-of-life outcomes</li> </ul> </li> <li>● Cultural integration (e.g., incorporating prayer) may enhance relevance and acceptability</li> <li>● Strengths included ease of delivery in a clinical setting and strong effect sizes on primary outcomes <ul style="list-style-type: none"> <li>○ Intervention requires minimal equipment and can be administered in a short amount of time, even in busy hospital settings</li> </ul> </li> <li>● Mechanisms of benefit include parasympathetic activation (relaxation), limbic calming (aromatherapy), and emotional resilience (prayer/spiritual coping)</li> <li>● Holistic format (mind-body-spirit) helped address both emotional distress and physiological arousal</li> <li>● Participants acquired lifelong emotion regulation tools that extend beyond cancer care</li> <li>● Novelty lies in combining multiple therapeutic elements (relaxation, aromatherapy, prayer) into a culturally grounded, brief pediatric MBI</li> <li>● May be especially beneficial for use in religious or spiritual cultural contexts</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>● Short duration of intervention (7 days) limits insight into long-term efficacy</li> <li>● Relatively small sample size, potentially limited generalizability of findings</li> <li>● Lack of randomization (quasi-experimental design)</li> <li>● No blinding of researchers or participants</li> <li>● No long-term follow-up to assess sustained effects</li> <li>● Study conducted in a single cultural setting (Indonesia), which may limit applicability to populations from different</li> </ul>

	<p>cultural backgrounds</p> <ul style="list-style-type: none"> <li>● No physiological or behavioral measures included to validate self-reported data</li> </ul>
<b>Implications and Future Directions</b>	<ul style="list-style-type: none"> <li>● Demonstrates clinical potential of mindfulness-based RADO as a culturally adapted complementary intervention to reduce anxiety and enhance QoL in pediatric oncology</li> <li>● Highlights importance of integrating culturally sensitive mindfulness practices to increase patient engagement and therapeutic benefit</li> <li>● Recommends tailoring psychosocial interventions to address individual and gender-specific needs for optimized outcomes</li> <li>● Suggests prioritization of psychosocial resources for children undergoing prolonged chemotherapy or with rarer cancer types</li> <li>● Advocates for integration of routine mental health assessments and family-centered counseling into pediatric oncology care</li> <li>● Calls for future studies with larger, more diverse samples, longer follow-up periods, and cross-cultural comparisons to better evaluate efficacy and adaptability of MBIs in global contexts</li> </ul>
<b>Additional Key Observations</b>	<ul style="list-style-type: none"> <li>● Children were encouraged to choose their preferred essential oils, promoting autonomy and personalization within the relaxation process</li> <li>● Structured consistency across the 7-day intervention (same time, format, and length) helped deepen mindfulness practice and routine familiarity</li> <li>● Participants with fewer chemotherapy cycles (&lt;10) had better outcomes in anxiety and QoL than those with ≥10 cycles, suggesting treatment intensity may influence psychosocial responsiveness.</li> </ul>

**27. Mobile App Promoting Resilience in Stress Management for Adolescents and Young Adults With Cancer: Protocol for a Pilot Randomized Controlled Trial**

<b>Reference/Citation</b>	Lau, N., Palermo, T. M., Zhou, C., Badillo, I., Hong, S., Aalfs, H., Yi-Frazier, J. P., McCauley, E., Chow, E. J., Weiner, B. J., Ben-Zeev, D., & Rosenberg, A. R. (2024). Mobile App Promoting Resilience in Stress Management for Adolescents and Young Adults With
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	Cancer: Protocol for a Pilot Randomized Controlled Trial. <i>JMIR Research Protocols</i> , 13. <a href="https://doi.org/10.2196/57950">https://doi.org/10.2196/57950</a>
<b>Geographic Location</b>	<ul style="list-style-type: none"> <li>● Seattle Children’s Hospital</li> </ul>
<b>Population</b>	<ul style="list-style-type: none"> <li>● Adolescents and young adults (AYAs) - peds oncology patients</li> <li>● Eligible participants: <ul style="list-style-type: none"> <li>○ 12-25 years old</li> <li>○ Within 12 months of new cancer diagnosis</li> <li>○ Receiving chemotherapy or radiation therapy at Seattle Children’s Hospital</li> <li>○ Speak, read, or write English</li> <li>○ Have no cognitive limitations that’d complicate participation</li> </ul> </li> <li>● Exclusion criteria: <ul style="list-style-type: none"> <li>○ Patient refusal to participate</li> <li>○ Parental refusal to participate (for patients under 18 years old)</li> <li>○ Cancer diagnosis received more than 12 months prior</li> <li>○ Diagnosis of relapsed or refractory cancer</li> <li>○ Patient has not received any chemotherapy or radiation therapy as part of cancer treatment</li> <li>○ Cognitive or physical inability to participate</li> <li>○ Prior participation in any PRISM-based studies</li> </ul> </li> </ul>
<b>Stage of Illness</b>	<ul style="list-style-type: none"> <li>● Patients were in active treatment phase (chemotherapy or radiation)</li> <li>● Recruited within the first year post-diagnosis</li> </ul>
<b>Study Type(s)</b>	<ul style="list-style-type: none"> <li>● Pilot randomized controlled trial (RCT)</li> <li>● Parallel, two-arm, single-site, with waitlist control design</li> <li>● Quantitative, exploratory analysis included</li> </ul>
<b>Intervention Components</b>	<ul style="list-style-type: none"> <li>● Design: <ul style="list-style-type: none"> <li>○ 2-arm, parallel, single-site pilot RCT with a waitlist control design (N = 80)</li> <li>○ Participants randomized 1:1 to (1) Usual Care (UC) or (2) UC + mPRISM</li> <li>○ The UC group receives delayed access to mPRISM after 3-month follow-up to enhance retention</li> </ul> </li> <li>● Duration: <ul style="list-style-type: none"> <li>○ mPRISM intervention lasts 8 weeks; surveys conducted at baseline, posttreatment (8 weeks), and 3-month follow-up (20 weeks)</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>● Usual Care (UC): <ul style="list-style-type: none"> <li>○ Standard ad hoc psychosocial support including assigned social workers</li> <li>○ Optional referrals available for mental health, chaplaincy, palliative care, child life, pain medicine, art/music therapy</li> <li>○ Control Group receives UC and later receives mPRISM after 3-month follow-up</li> </ul> </li> <li>● mPRISM Intervention: <ul style="list-style-type: none"> <li>○ A mobile app adaptation of the in-person PRISM (Promoting Resilience in Stress Management) intervention</li> <li>○ Retains 4 core PRISM skills: <ul style="list-style-type: none"> <li>■ Stress Management: deep breathing, relaxation, mindfulness</li> <li>■ Goal Setting: SMART goal creation with planning around barriers</li> <li>■ Cognitive Reframing: identify and reframe negative thinking patterns</li> <li>■ Meaning-Making: identify purpose and benefits from cancer experience</li> </ul> </li> <li>○ Co-designed with AYA input and iteratively refined based on stakeholder feedback</li> </ul> </li> <li>● Measurement Tools: <ul style="list-style-type: none"> <li>○ All surveys administered electronically through REDCap.</li> <li>○ Measures include feasibility, acceptability, appropriateness (FIM, AIM, IAM), usability (SUS), quality of life (PedsQL), resilience (CD-RISC), distress (K6), and anxiety/depression (HADS)</li> <li>○ mPRISM usage behavior tracked with Mixpanel analytics (e.g., frequency of use, duration)</li> </ul> </li> <li>● Data and Consent: <ul style="list-style-type: none"> <li>○ All data stored securely in HIPAA-compliant REDCap servers</li> <li>○ eConsent obtained through REDCap framework; assent required for minors</li> <li>○ Participants compensated \$25 per completed survey</li> </ul> </li> <li>● Participants not blinded due to waitlist design, but outcome measures are self-reported to minimize bias</li> </ul>
<b>Findings/Results</b>	<ul style="list-style-type: none"> <li>● 20 participants enrolled since September 2023; 25 enrolled as of July 2024 - recruitment ongoing <ul style="list-style-type: none"> <li>○ Complete data collection expected in 2027</li> </ul> </li> <li>● Expected primary outcome measures: <ul style="list-style-type: none"> <li>○ Feasibility (≥60% enrollment, ≥70% retention)</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Acceptability and appropriateness (score <math>\geq 4/5</math> on 3 validated implementation measures: FIM, AIM, IAM)</li> <li>● Expected secondary/exploratory outcomes: <ul style="list-style-type: none"> <li>○ Usability (SUS <math>\geq 70</math>), HRQoL (PedsQL), resilience (CD-RISC), psychological distress (K6), anxiety/depression (HADS), digital usage metrics (Mixpanel data tracking user engagement)</li> </ul> </li> <li>● Digital usage metrics will also be analyzed</li> </ul>
<p><b>Discussion/Key Takeaways</b></p>	<ul style="list-style-type: none"> <li>● This is the first evidence-based psychosocial mHealth intervention specifically designed for AYAs with cancer, addressing a critical gap despite the existence of hundreds of thousands of health-related apps</li> <li>● mPRISM demonstrates potential to extend evidence-based supportive care to underserved and remote populations by leveraging mobile technology</li> <li>● Additional novelty lies in its digital, scalable, and self-directed delivery format, which improves accessibility for AYAs</li> <li>● The study contributes to translational innovation by adapting an in-person resilience program (PRISM) into a digital format, aligning with WHO's recommendations for mHealth to transform access and care equity</li> <li>● mPRISM's digital delivery model reduces reliance on clinical personnel and infrastructure, enhancing cost-effectiveness and scalability in real-world settings</li> <li>● Backend analytics will yield insights on user engagement patterns, offering data that can optimize future intervention delivery and personalization</li> <li>● Future analyses will inform scalability and broader implementation</li> <li>● Findings from this pilot will inform the design of a future multisite, hybrid effectiveness-implementation trial powered to evaluate clinical efficacy outcomes on a larger scale</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>● Protocol article; therefore, efficacy outcomes are not yet available</li> <li>● Single-site recruitment may limit generalizability beyond the study setting</li> <li>● Higher attrition or lower adherence is a common issue in smartphone-based interventions; although the research team has experience mitigating this, engagement will still require close monitoring</li> <li>● As a pilot feasibility trial using a waitlist control, causal inferences about efficacy are limited; exploratory trends will</li> </ul>

	<p>be used to inform future trials</p> <ul style="list-style-type: none"> <li>● Participants receive no formal instruction on how to engage with mPRISM beyond suggested module order, which may influence consistency in app use.</li> <li>● Participants are not blinded to intervention condition, introducing potential bias in outcome reporting</li> </ul>
<p><b>Implications and Future Directions</b></p>	<ul style="list-style-type: none"> <li>● Findings will inform the design of future larger-scale RCT powered for efficacy, moving beyond feasibility</li> <li>● Future studies will include active treatment comparisons, such as testing mPRISM against other behavioral health apps</li> <li>● Results may not be applicable to non-English speakers or other cultural groups; thus, future trials aim to adapt mPRISM for diverse populations, including non-English languages, varied cultures, and different patient groups</li> <li>● Could be integrated into routine psychosocial oncology care</li> <li>● Offers potential to bridge gaps in mental health support for geographically and socially underserved populations</li> <li>● Could serve as a template for other chronic illness contexts beyond cancer</li> </ul>
<p><b>Additional Key Observations</b></p>	<ul style="list-style-type: none"> <li>● mHealth platforms are uniquely suited to AYAs given their high smartphone usage, digital fluency, and preference for privacy/anonymity in mental health support</li> <li>● Economic implications: digital psychosocial interventions may reduce medical costs associated with psychological distress in AYAs</li> <li>● Digital tools integrated into routine oncology psychosocial care represent an expanding and essential healthcare trend, accelerated by pandemic-driven demand for remotely delivered interventions</li> <li>● Study emphasizes the urgent need for evidence-based psychosocial mHealth interventions in pediatric oncology settings, highlighting a significant gap in current clinical practice and digital health research</li> </ul>

## APPENDIX B



### APPROVAL

October 30, 2023

Jessica Thompkins  
111 Michigan Avenue  
Washington, DC 20010

JGaines@childrensnational.org

Dear Jessica Thompkins:

On 10/30/2023, the IRB reviewed the following submission:

Protocol Information	Submission Details
Type of Review:	Initial Study
Title:	Take a Moment to Breathe: A Multi-Methods Study to Build Supportive Interventions for the Psychosocial and Overall Well-Being of AYA with Cancer
Investigator:	Jessica Thompkins
IRB ID:	STUDY00000751
Funding:	None
Grant Title:	None
Grant ID:	None
IND, IDE or HDE:	None
Device:	None
Risk:	Minimal Risk
Pediatric Risk:	46.404
Documents Reviewed:	<ul style="list-style-type: none"> <li>• JThompkins Dissertation Proposal FINAL 10302023.docx, Category: IRB Protocol;</li> <li>• Take a Moment HIPAA Waiver of Authorization Request Form_01 24 2022 (2).docx, Category: Other;</li> <li>• Take a Moment Information Sheet Template_10-23-2023 revised w HIPAA FINAL.pdf, Category: Consent Form;</li> </ul>

The IRB approved the protocol on 10/30/2023. This study was approved per Expedited Category 6 and 7. A Waiver of Documentation of Consent and a Waiver for Alteration of HIPAA to eliminate the need for a signature are approved for this study.

To obtain consent, use the consent documents that were approved and stamped by the IRB. Go to the Documents tab to download them.

Investigators are required to continue to meet all institutional requirements for conducting research with human subjects as outlined in [HRP-103 – INVESTIGATOR MANUAL](#).

FWA00004487

For questions contact Children's National Hospital OPHS at 301-565-8447 or [ophs@childrensnational.org](mailto:ophs@childrensnational.org).  
Children's National Hospital IRB is in full compliance with U.S. Department of Health and Human Services (HHS) Regulations and U.S. Food and Drug Administration (FDA) Regulations.



- Modifications to this study must be approved by the IRB in advance of implementing changes to the research.
- New information related to this study must be reported to the IRB in accordance with institutional reporting requirements.
- Annual Continuing Review is not required for this study; however, an Annual Progress Update will be requested.
- Close this study by submitting a Continuing Review report once all research activities are complete.

Sincerely,  
Office for the Protection of Human Subjects

#### Terms of Approval

The Principal Investigator is responsible for the following (as applicable to the study referenced above):

1. Informing the IRB of any and all changes to this study. Submit a modification for the review of any and all changes. IRB approval must be obtained prior to the implementation of any changes. Examples include changes to the protocol, number of subjects, recruitment materials, consent forms, assent forms, etc.
2. Submitting any and all Reportable New Information (e.g. unanticipated problems involving risks to subjects or others) that occur during the course of this study.
3. Use of IRB approved copies of the consent forms, assent forms, surveys, questionnaires, letters, advertisements, etc., in the research. **Do not use expired consent documents.**
4. Ensuring that the Continuing Review Report is submitted to the IRB in a timely manner. There is no grace period extending the conduct of the research beyond the expiration date of IRB approval. If IRB approval expires investigators must cease all research activities including: recruitment, screening and enrollment, intervention and interaction, follow-up, and data analysis.



University of Maryland, Baltimore  
 Institutional Review Board (IRB)  
 Phone: (410) 706-5037  
 Email: [hrpo@umaryland.edu](mailto:hrpo@umaryland.edu)

**APPROVAL OF RESEARCH NOTIFICATION**

The IRB and the HRPO, as part of the Office of Accountability and Compliance is committed to excellence and customer service. Please take a moment to tell us how we are doing: [HRPO/IRB/OAC Customer Feedback Survey](#)

Date: January 5, 2024

To: Kim Mooney-Doyle  
 RE: HP-00108985  
 Type of Submission: Initial Review  
 Type of IRB Review: Expedited

Approval for this project was granted on 1/5/2024.

This is to certify that the University of Maryland, Baltimore (UMB) Institutional Review Board (IRB) approved the above referenced protocol entitled, *“Take a Moment to Breathe: A Multi-Methods Study to Build Supportive Interventions for the Psychosocial and Overall Well-Being of AYA with Cancer”*.

The IRB has determined that this protocol qualifies for expedited review pursuant to Federal regulations 45 CFR 46.110, 21 CFR 56.110, & 38 CRF 16.110 category(ies):  
 (7) - Research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

- The IRB made the following determinations regarding this submission:
- Subpart D Determination for research involving children: 45 CFR 46.404/21CFR 50.51.
  - Permission of one parent is sufficient even if the other parent is alive, known, competent, reasonably available, and shares legal responsibility for the care and custody of the child.
  - A waiver of assent has been approved per 45 CFR 46.116(f) / 21 CFR 50.55(d)
  - A waiver of documentation of consent has been approved per 45 CFR 46.117(c)(2) / 21 CFR 56.109(c)(1).

This study is approved to enroll 50 local participants.

This study is approved to enroll 50 worldwide participants.

Below is a list of the documents attached to your application that have been approved:  
 Eligibility Checklist for HP-00108985 v12-4-2023-1701726322526  
 JThompkins Dissertation Proposal FINAL 10302023.docx  
 JThompkins Dissertation Proposal FINAL 10302023.docx

STUDY00000751.pdf  
Study Measures from JThompkins Dissertation Proposal FINAL 10302023.pdf  
Study Measures from JThompkins Dissertation Proposal FINAL 10302023.pdf  
Take a Moment Information Sheet Template\_12-27-2023 revised w HIPAA FINAL (1).docx  
Take a Moment HIPAA Waiver of Authorization Request Form\_01 24 2022 (2).docx  
Correspondence\_for\_STUDY00000751.doc.pdf

In conducting this research you are required to follow the requirements listed in the INVESTIGATOR MANUAL. Investigators are reminded that the IRB must be notified of any changes in the study. In addition, the PI is responsible for ensuring prompt reporting to the IRB of proposed changes in a research activity, and for ensuring that such changes in approved research, during the period for which IRB approval has already been given, may not be initiated without IRB review and approval except when necessary to eliminate apparent immediate hazards to the subject (45 CFR 46.103(4)(iii)). The PI must also inform the IRB of any new and significant information that may impact a research participant's safety or willingness to continue in the study and any unanticipated problems involving risks to participants or others.

DHHS regulations at 45 CFR 46.109 (f)(1) Unless an IRB determines otherwise, continuing review of research is not required in the following circumstances: (i) Research eligible for expedited review in accordance with §110; (ii) Research that has progressed to the point that it involves only one or both of the following, which are part of the IRB-approved study:  
(A) Data analysis, including analysis of identifiable private information, or  
(B) Accessing follow-up clinical data from procedures that subjects would undergo as part of standard care for their medical condition; or (iii) Research reviewed by the IRB in accordance with the limited IRB review procedure described in §111(a)(9).

(2) The IRB must receive confirmation every two years that the research is still ongoing and that no changes have been made to the research that would require the IRB to conduct continuing review of the research.

You will receive an email reminder notice to submit your update every two years. Investigators should submit updates via CICERO.

Research activity in which the VA Maryland Healthcare System (VAMHCS) is a recruitment site or in which VA resources (i.e., space, equipment, personnel, funding, data) are otherwise involved, must also be approved by the VAMHCS Research and Development Committee prior to initiation at the VAMHCS. Contact the VA Research Office at 410-605-7000 ext. 6568 for assistance.

The UMB IRB is organized and operated according to guidelines of the International Council on Harmonization, the United States Office for Human Research Protections and the United States Code of Federal Regulations and operates under Federal Wide Assurance No. FWA00007145.

If you have any questions about this review or questions, concerns, and/or suggestions regarding the Human Research Protection Program (HRPP), please do not hesitate to contact the Human Research Protections Office (HRPO) at (410) 706-5037 or [HRPO@umaryland.edu](mailto:HRPO@umaryland.edu).