

Title: Characterizing Negative Communication Experiences at the End of Life for Adolescent and Young Adult Cancer Patients Living in Poverty

PI: Bryan A. Sisk, MD, MSCI

Research Plan: Cancer is the leading cause of disease-related death for adolescents and young adults (AYA) in the United States.^{1, 2} High quality, open communication is a standard of palliative care for these AYA patients at the end of life.³⁻⁵ However, clinicians might have difficulty identifying the unique communication needs and preferences of each patient, which can lead to communication breakdowns and less effective care. Exploring negative communication experiences near the end of life is an important first step in understanding how to best individualize communication to meet each patient's unique needs. In this proposed secondary analysis, we will explore the content and context of negative communication experiences for AYA patients with cancer at the end of life.

My research team recently performed an analysis of negative communication experiences from the perspectives of parents in pediatric oncology (manuscript under review). We found that parents reported 12 personal consequences of communication breakdowns, including emotional distress, poor understanding, decreased trust, and decreased hope. Additionally, we learned that many of these negative experiences were personal and based on individual preferences rather than a single "right" approach to communication. In other words, the same communication behavior can lead to positive or negative experiences depending on the parent's preferences, values, and expectations. For example, one parent in our study described the importance of honest prognostic disclosure in supporting her hope. Another parent explained how disclosing the poor prognosis would have diminished her hope.

To provide adaptive care and communication, clinicians must be able to identify and solicit cues from patients. Analyzing negative experiences of AYA patients at the end of life is an important next step towards helping clinicians to identify these unique communication needs. In a study deposited in the PCRC repository, Mack et al. performed 28 semi-structured interviews with caregivers of AYA patients who died of cancer. The interview guide explored several themes pertinent to our proposed analysis, including prognostic awareness, decisions about location of death, barriers to care, and quality of care. Dr. Mack's research team has published one analysis from this study that identified 3 categories of barriers to optimal care, including "delayed or absent communication about prognosis, which in turn delayed care focused on comfort and quality of life."⁶ I discussed our proposed secondary analysis with Dr. Mack, and she indicated that this dataset contains several instances of negative communication experiences. She was supportive of the feasibility and importance of this analysis.

Feasibility: Our research team is uniquely qualified to complete this analysis in the allotted time. Dr. Sisk has extensive training and experience in qualitative analysis.⁷⁻¹³ Additionally, Dr. Sisk has trained two graduate research assistants (GRAs) in qualitative analysis. These GRAs will be able to focus on the completion of this project as of March 15, 2021.

Future Grants: I am currently developing an R21 proposal focused on developing and refining a communication intervention for children and AYAs with cancer at the end of life. The negative experiences identified in our proposed secondary analysis will inform intervention development and bolster an R21 proposal to NINR next year.

Research Aim: To explore characteristics of negative care and communication experiences for AYA decedents from the perspective of caregivers.

Analysis Plan: We will employ thematic analysis¹⁴ by reading transcripts to form ideas, developing initial codes, and refining codes around themes. We will develop a codebook

through iterative consensus coding until we reach thematic saturation for primary themes. We will define “negative care and communication experiences” as encounters that caregivers described as creating difficulties or undesirable outcomes. Upon finalizing the codebook, we will apply the codes to the full set of transcripts. In iterative cycles, coders will independently code 5 to 10 transcripts, review the other coder’s application of codes, mark disagreements, then resolve all disagreements through discussion. To ensure agreement and consistency, we will follow this consensus coding process for all transcripts using Dedoose qualitative software.

Data Set: Barriers to Hospice and Palliative Care Utilization among Adolescent and Young Adult Cancer Patients Living in Poverty; PI: Jennifer W. Mack, MD, MPH

Budget:

<u>Category</u>	<u>Item</u>	<u>Period 1</u>
Personnel Costs - Salaries	Bryan Anthony Sisk, PI, 10%	5,265
	Research Asst TBN (57%)	7,434
	Subtotal Personnel:	12,699
	Total Sponsor Direct Costs:	12,699
	Sponsor F&A:	7,301
	Total Sponsor Costs:	20,000

Timeline: On March 15, 2021, Dr. Sisk will submit an expedited IRB proposal. We anticipate approval within 1 to 2 weeks. Upon disbursement of funds, Dr. Sisk will redirect the effort of 2 currently hired GRAs to this analysis. The research team will collaboratively develop the initial codebook by May 1, 2021. The team will then apply the codes to the full dataset, with completion of final coding by June 30, 2021. Upon completion of this coding, Dr. Sisk will draft the manuscript.

PI Biosketch (Appended below)

References

1. Bleyer A. The adolescent and young adult gap in cancer care and outcome. *Current problems in pediatric and adolescent health care*. May-Jun 2005;35(5):182-217. doi:10.1016/j.cppeds.2005.02.001
2. *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. vol Pub. No. 06-5767. National Cancer Institute, NIH; 2006.
3. Weaver MS, Heinze KE, Bell CJ, et al. Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliat Med*. Mar 2016;30(3):212-23. doi:10.1177/0269216315583446
4. Sansom-Daly UM, Wakefield CE, Patterson P, et al. End-of-Life Communication Needs for Adolescents and Young Adults with Cancer: Recommendations for Research and Practice. *Journal of adolescent and young adult oncology*. Oct 29 2019;doi:10.1089/jayao.2019.0084
5. Weaver MS, Heinze KE, Kelly KP, et al. Palliative Care as a Standard of Care in Pediatric Oncology. *Pediatr Blood Cancer*. Dec 2015;62 Suppl 5:S829-33. doi:10.1002/pbc.25695
6. Mack JW, Currie ER, Martello V, et al. Barriers to Optimal End-of-Life Care for Adolescents and Young Adults With Cancer: Bereaved Caregiver Perspectives. *Journal of the National Comprehensive Cancer Network : JNCCN*. Feb 11 2021;1-6. doi:10.6004/jnccn.2020.7645
7. Sisk BA, Zavadil JA, Blazin LJ, Baker JN, Mack JW, DuBois JM. "Assume It Will Break": Negative Communication Experiences in Pediatric Oncology. 2020 (Under Review);
8. Sisk BA, Schulz GL, Blazin LJ, Baker JN, Mack JW, DuBois JM. Parental views on communication between children and clinicians in pediatric oncology: a qualitative study. *Support Care Cancer*. Feb 10 2021;doi:10.1007/s00520-021-06047-6
9. Sisk BA, Friedrich AB, Mozersky J, Walsh H, DuBois J. Core functions of communication in pediatric medicine: an exploratory analysis of parent and patient narratives. *Journal of cancer education : the official journal of the American Association for Cancer Education*. Dec 18 2018;35(2):256-263. doi:10.1007/s13187-018-1458-x
10. Sisk BA, Friedrich AB, DuBois J, Mack JW. Emotional Communication in Advanced Pediatric Cancer Conversations. *J Pain Symptom Manage*. 2019:S0885-3924(19)30652-9. doi:10.1016/j.jpainsymman.2019.11.005
11. Sisk BA, Friedrich AB, DuBois J, Mack JW. Characteristics of uncertainty in advanced pediatric cancer conversations. *Patient Educ Couns*. Oct 17 2020;doi:10.1016/j.pec.2020.10.006
12. Sisk BA, Friedrich A, Kaye E, Baker JN, Mack JW, DuBois JM. Multilevel Barriers to Communication in Pediatric Oncology: Clinicians' Perspectives. *Cancer*. 2021 (*In Press*);
13. Sisk BA, Friedrich A, Blazin LJ, Baker JN, Mack JW, DuBois J. Communication in Pediatric Oncology: A Qualitative Study. *Pediatrics*. Aug 20 2020;146(3):e20201193. doi:10.1542/peds.2020-1193
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BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.

Follow this format for each person. DO NOT EXCEED FIVE PAGES.

NAME: Sisk, Bryan

eRA COMMONS USER NAME (credential, e.g., agency login): siskba

POSITION TITLE: Assistant Professor

EDUCATION/TRAINING (*Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.*)

INSTITUTION AND LOCATION	DEGREE (if applicable)	END DATE MM/YYYY	FIELD OF STUDY
University of Missouri - Columbia, Columbia, MO	BS	05/2007	Biochemistry
Cleveland Clinic Lerner College of Medicine of Case Western Reserve University, Cleveland, OH	MD	05/2013	Medicine
Washington University School of Medicine, St. Louis, MO	MS	05/2020	Clinical Investigation with Emphasis in Bioethics Research
St. Louis Children's Hospital, St. Louis, MO	Resident	06/2016	Pediatrics Internship and Residency
St. Louis Children's Hospital, St. Louis, MO	Other training	06/2018	Chief Residency
Washington University School of Medicine, SAINT LOUIS, MO	Other training	05/2020	Mentored Training Program in Clinical Investigation
Washington University School of Medicine, St. Louis, MO	Fellow	06/2020	Pediatric Hematology and Oncology

A. Personal Statement

My research focuses on social and ethical issues in the care of seriously ill children and adults. I am on faculty at Washington University School of Medicine in the division of pediatric hematology and oncology on the investigator track. To date, I have served as PI on 2 qualitative studies and I have published more than 40 peer-reviewed manuscripts related to ethics or communication. I have also completed a Master's of Science in Clinical Investigation with special emphasis on bioethics research and social science skills, and I have completed a Mentored Training Program in Clinical Investigation through Washington University. Through this training, I have completed coursework on qualitative methods, survey design, shared decision-making, biostatistics, and clinical trial design.

B. Positions and Honors**Positions and Employment**

2020 - Assistant Professor, Washington University School of Medicine, St. Louis, MO

Other Experience and Professional Memberships

2012 - 2014 Deputy Editor for "The Living Hand", Journal of General Internal Medicine – Web Edition
 2013 - Member, American Academy of Pediatrics
 2014 - 2015 Assistant Section Editor for "In the Moment", Academic Pediatrics
 2014 - 2017 Section Editor - Pediatric Trainees Monthly Feature, Pediatrics
 2016 - 2017 Editorial Fellowship, Pediatrics
 2017 - Member, Children's Oncology Group

Honors

2019 Commissioner, Lancet Commission on the Value of Life
 2019 Young Investigator Award - Pediatric Palliative Oncology Symposium, St. Jude Children's Research Hospital

C. Contribution to Science

1. Healthcare and Research Ethics: I have contributed to the ethics literature related to informed consent, communication and decision making. Additionally, my work has argued for the important role of implementation science in ethics to support ethical practice.
 - a. Sisk BA, Mozersky J, Antes AL, DuBois JM. The "Ought-Is" Problem: An Implementation Science Framework for Translating Ethical Norms Into Practice. *Am J Bioeth.* 2020 May;20(4):62-70. PubMed Central PMCID: [PMC7164659](#).
 - b. Sisk BA, Dubois J, Hobbs BP, Kodish E. Reprioritizing Risk and Benefit: The Future of Study Design in Early-Phase Cancer Research. *Ethics Hum Res.* 2019 Nov;41(6):2-11. PubMed Central PMCID: [PMC7418216](#).
 - c. Sisk BA, Baker JN. Microethics of Communication-Hidden Roles of Bias and Heuristics in the Words We Choose. *JAMA Pediatr.* 2018 Dec 1;172(12):1115-1116. PubMed PMID: [30357382](#).
 - d. Sisk BA, Kodish E. Therapeutic Misperceptions in Early-Phase Cancer Trials: From Categorical to Continuous. *IRB.* 2018 Jul-Aug;40(4):13-20. PubMed PMID: [30387976](#).
2. Communication Practices in Pediatric Oncology: I have studied the historical norms of communication in medicine and pediatrics, as well as current communication practices in pediatric oncology. These studies have identified unmet parental information needs regarding prognosis and late effects, disparities in support for decision making, and negative psychosocial outcomes of ineffective communication. Additionally, I have explored prognostic communication with adolescent and young adult patients. Together, these studies have provided an important understanding of how clinicians and patients' families communicate in pediatric oncology.
 - a. Sisk BA, Friedrich AB, DuBois J, Mack JW. Characteristics of uncertainty in advanced pediatric cancer conversations. *Patient Educ Couns.* 2020 Oct 17; PubMed PMID: [33109428](#).
 - b. Sisk BA, Friedrich AB, DuBois J, Mack JW. Emotional Communication in Advanced Pediatric Cancer Conversations. *J Pain Symptom Manage.* 2020 Apr;59(4):808-817.e2. PubMed Central PMCID: [PMC7096262](#).
 - c. Sisk BA, Fasciano K, Block SD, Mack JW. Longitudinal prognostic communication needs of adolescents and young adults with cancer. *Cancer.* 2020 Jan 15;126(2):400-407. PubMed Central PMCID: [PMC7010331](#).
 - d. Sisk BA, Kang TI, Mack JW. How Parents of Children With Cancer Learn About Their Children's Prognosis. *Pediatrics.* 2018 Jan;141(1) PubMed PMID: [29208726](#).
3. Functional Model of Communication: Building on this communication work, I have developed a functional model of communication in pediatric oncology. While prior work has focused on individual components of communication, further progress in this field necessitates a complete understanding of the functions that communication fulfills for patients and families. Through reviews, pilot studies, and an ongoing multi-institutional qualitative study, we have identified 8 distinct functions of communication. This functional model will inform the development of robust communication measures and targeted communication interventions.
 - a. Sisk BA, Friedrich A, Blazin LJ, Baker JN, Mack JW, DuBois J. Communication in Pediatric Oncology: A Qualitative Study. *Pediatrics.* 2020 Sep;146(3) PubMed Central PMCID: [PMC7461134](#).
 - b. Sisk BA, Friedrich AB, Mozersky J, Walsh H, DuBois J. Core Functions of Communication in Pediatric Medicine: an Exploratory Analysis of Parent and Patient Narratives. *J Cancer Educ.* 2020 Apr;35(2):256-263. PubMed Central PMCID: [PMC6581646](#).
 - c. Sisk BA, Schulz GL, Mack JW, Yaeger L, DuBois J. Communication interventions in adult and pediatric oncology: A scoping review and analysis of behavioral targets. *PLoS One.* 2019;14(8):e0221536. PubMed Central PMCID: [PMC6705762](#).

- d. Sisk BA, Mack JW, Ashworth R, DuBois J. Communication in pediatric oncology: State of the field and research agenda. *Pediatr Blood Cancer*. 2018 Jan;65(1) PubMed Central PMCID: [PMC6902431](https://pubmed.ncbi.nlm.nih.gov/30404441/).

D. Additional Information: Research Support and/or Scholastic Performance

Ongoing Research Support

R01 R01AG05825403, NIH/NIA

DuBois (PI)

04/01/20-04/01/21

Implementing Evidence-Based Informed Consent Practices To Address The Risk of Alzheimer's Dementia Administrative Supplement - Understanding and addressing challenges to informed consent and research compliance during Covid-19 research

Role: Co-Investigator

Completed Research Support

Young Investigator Award, American Society for Clinical Oncology – Conquer Cancer Foundation

Sisk (PI)

07/01/19-12/01/20

Quality of Communication in Pediatric Oncology (QCOM): Advancing Understanding and Measurement of Communication Functions and Quality in Pediatric Oncology

The goal of this study was to identify the core functions of communication in pediatric oncology from the perspectives of parents and clinicians.

Role: PI

ICTS-RF, Institute for Clinical and Translational Sciences Seed Funding at Washington University

Sisk (PI)

03/01/19-02/29/20

Quality of Communication in Pediatric Oncology (QCOM): Advancing Understanding and Measurement of Communication Functions and Quality in Pediatric Oncology

The goal of this study was to identify the core functions of communication from the perspectives of parents and clinicians. Also, we explored the impact of advanced medical technology on clinical relationships in pediatrics.

Role: PI

LRP, NIH Loan Repayment Program

Sisk (PI)

01/01/18-01/01/20

Quality of Communication in Pediatric Oncology (QCOM): Advancing Understanding and Measurement of Communication Functions and Quality in Pediatric Oncology

Role: PI