

**WE CHATT: A Pilot Study to Improve Physician-Youth
Communication and Medical Decision Making**

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BACKGROUND

Prevalence and Impact of Pediatric Heart Failure. Congenital heart disease (CHD), the most common birth defect, impact 1 in every 100 live births.^{36,37} Due to significant medical advancements, many children born with CHD now survive into adolescence and beyond. In 1985, CHD patients were on average 11 years old. In 2000, the mean age had increased to 17 years old.³⁸ For the growing population of adolescents and young adults (AYAs; 12-24 years) with congenital and acquired heart diseases, survival comes at a cost. Common complications, including heart failure and arrhythmias, require intensive, long-term medical care which has a significant financial impact on society. An estimated 6 billion dollars are spent each year on CHD-related acute care costs,³⁹ accounting for some of the highest resource utilization among all hospitalized children. Approximately 14,000 children experience heart-failure related hospitalizations annually in the US, and the average length of admission has increased over the past two decades. Among this group, 7% die during their hospitalization – a mortality rate nearly 20 times greater than that among children without heart failure and approximately double that in adult heart failure.²⁷ For those with advanced heart failure, ventricular assist device therapies and heart transplantation offer potential for extended survival. However, 1/10 heart transplant recipients will die within a year of transplant.²⁸ For patients with implanted ventricular assist devices as a bridge to transplant or destination therapy (i.e., life-extending intervention for patients who do not meet criteria for transplantation), mortality and morbidity are significant with high rates of stroke, bleeding and sepsis.³³ In PI's study of medical decision making preferences among AYAs pre-heart transplant or post-transplant with serious complications, 6/16 eligible participants (38%) died before study enrollment/completion. Young people who die of heart failure overwhelmingly do so in intensive care settings.³⁰ Rates of hospital-based deaths accompanied by costly and invasive interventions near the end of life are exceedingly higher in pediatric heart failure populations when compared to other illness groups with similar disease severity. For example, more than 50% of youth with progressive cancer die at home. Of those with cancer who died in hospital settings, 45% received mechanical ventilation within the last 24 hours of life⁴⁰ compared to 86% of youth who died of heart disease.³⁰

Palliative and End of Life Care in Heart Failure. The 2014 Institute of Medicine (IOM) report, *Dying in America: Improving Quality and Honoring Individual Preferences Near End of Life*,²⁹ highlighted a critical need for “increased understanding of ways to improve participation in effective advance care planning and shared decision making among patients and families, including seriously ill children and adolescents, who may be able to participate actively in their health care decision making throughout their lives and as they approach death, and receive medical and related social services consistent with their values, goals and informed preferences.” Research on the end of life and palliative care needs of the growing AYA heart failure population is very limited.^{30–32} Youth with heart failure are also less likely to receive palliative care services when compared to other serious illness populations.³⁵ The lack of research and clinical attention to the palliative and end of life care needs of this young population is significant given high rates of mortality and symptom burden. In a randomized controlled trial of adults with heart failure, palliative care involvement was associated with patient improvements in quality of life and spiritual well-being and decreases in symptoms of anxiety and depression.⁴¹ Others have noted palliative care involvement to be associated with improved patient and family satisfaction, enhanced communication with medical providers, increased access to community and social supports, and reduced medical costs.⁴² As such, it has been recommended that interdisciplinary supportive care be provided throughout the heart failure course with early engagement in advance care planning (i.e., discussing one's wishes

and surrogate decision maker if unable to engage in medical decision making) due to challenges with prognostication and risk of sudden death in heart failure populations.⁴³

Communication in Heart Failure. Despite consensus statement⁴³ and other professional guidelines that recommend all adults with CHD participate in advance care planning,⁴⁴ minimal prognostic, advance care planning and end of life care focused communication occurs across heart failure populations. Among adults with CHD, only 1% recalled discussing advance care planning with their medical team even though 78% of the participants believed their healthcare providers should initiate end of life decision making discussions early in the disease course.⁴⁵ Only 37% of family members of adults who died of heart failure were aware of their loved one's poor prognosis. Few were informed of the imminent death of their family member; as such, over 1/3 of the patients died alone.⁴⁶ Communication about end of life care preferences occurs even less frequently among pediatric heart failure populations. Study PI recently conducted an international survey of multidisciplinary pediatric heart failure providers. Initial data analysis of 82 respondents suggests that providers rarely or never discuss death/dying, advance care planning or prognosis with pediatric patients with heart failure/heart transplant (ages 4-24 years). Respondents indicated a high level of discomfort in discussing these topics and noted that additional barriers include the patient/parent(s) being unaccepting of the prognosis, the patient/parent(s) having unrealistic expectations for treatment, and there being an unknown prognosis/disease trajectory. These barriers should not prevent us from addressing the end of life care needs of our AYA patients and families. Yet, the majority of AYAs with serious illnesses report feeling inadequately informed and insufficiently involved in their health care.^{47,48} Studies in other illness groups suggest that AYAs desire prognostic information early in their disease course. Many want to be made aware of their options and engage in shared decision making with caregivers.^{49,50} Although the degree to which youth desire active participation in discussions about death and dying varies, the majority of AYAs with life-threatening illnesses describe a preference to discuss their end of life care wishes – and to do so prior to becoming acutely unwell.⁵¹ In a randomized controlled trial of a family-centered advance care planning intervention among AYAs with cancer, intervention group family participants reported increased understanding and awareness of AYA end of life wishes.⁵² This is important given that others have documented discordant end of life care preferences among AYAs and their parents.⁵¹ In addition, AYAs in the intervention group were more likely than controls to object to invasive interventions at end of life.⁵² In a similar intervention trial among young people with HIV, engagement in advance care planning was associated with increased positive emotions following the discussion and reduced decisional burden.^{53,54} Others have suggested that youth engagement in advance care planning is associated with increased likelihood of home death and reductions in invasive interventions at end of life.⁵⁰ To the best of our knowledge, no studies outside our pilot work have sought to understand the palliative and end of life care needs of AYAs with heart failure.

STUDY AIMS

Based upon previous research by Dr. Cousino (PI) and her study team ([HUM00157016](#)), this study will pilot a physician-directed communication focused intervention, WE CHATT. The development of WE CHATT was informed by patients and their caregivers, with the ultimate goal of improving patient-centered communication for young people with advanced heart disease. The primary outcome of this pilot study is determining feasibility and acceptability, however, in the future, WE CHATT aims to (1) improve patient-centered communication with young people with advanced heart disease and (2) increase physician comfort in communicating with young people themselves regarding their communication needs and preferences.

METHODS

Recruitment and Sample

Physicians. A total of 20 physicians will be recruited. 10 will be randomized to participate in the intervention arm and 10 will be randomized to the control arm. Physician participants will be recruited from the Division of Pediatric Cardiology at the University of Michigan, which is currently comprised of 37 attending physicians and 16 fellows. All physicians with dedicated clinical effort will be eligible. Eligible physicians must anticipate remaining on staff ≥ 1 years. Study PI (Cousino) and Co-I (Schumacher) will co-lead recruitment efforts via presentation(s) of study objectives and procedures at faculty/fellow meetings. Cardiology faculty and fellows were informally surveyed regarding interest in participating in the study. Over 90% of faculty and fellows expressed openness to participating in the study. Thus, the recruitment goal of 20 physician participants is feasible.

Patient/Caregivers. Patients (12-24 years) with heart failure symptoms meeting criteria for New York Heart Association (NYHA) Class II - IV heart failure will be eligible (i.e., limitations in physical activity, fatigue, palpitations, dyspnea). One parent/caregiver of patient participants meeting inclusion criteria will also be eligible. This patient age range was selected in accordance with research in other illness groups,^{48,49,51} is consistent with the World Health Organization's definition of adolescent/young adult (AYA), and fulfills the Institute of Medicine's need for research on AYA end of life care preferences and decision making involvement.²⁹ This age range also captures the average age (17 years) of patients with congenital heart disease.³⁸ A *new patient* meeting the above criteria in any hospital setting (inpatient, outpatient cardiology clinic, emergency room) being cared for by a participating physician will be eligible for the study. Patients with significant cognitive/developmental delay with potential to impact study participation will be excluded from the study due to the focus on physician-youth communication. Parents and parent/caregivers who are non-English speaking will be excluded from this pilot study.

Compensation for Time. Intervention arm physician participants will receive a \$100 gift card for their time to complete surveys, attend intervention training, and engage in intervention with patient participants. Control arm physician participants will receive a \$25 gift card for their time completing surveys. All patient and parent/caregiver participants will receive a \$25 gift card for their time completing surveys.

Procedures

Intervention Arm. The WE CHATT communication-tool was developed based upon mixed-methods research and stakeholder engagement (patients, parents, physicians, nurses, hospital leadership) led by study PI, Dr. Cousino, over the past decade. It involves the collaborative completion of a 2-page communication preferences document between a primary physician and an adolescent/young adult patient. Intervention arm physicians will participate in a 1-hour training led by study PI, Dr. Cousino, featuring didactic, multimedia, and experiential-based learning to support their facilitation of the WE CHATT intervention with patients.

Control Arm. Physicians randomized to the control arm will not receive training in the WE CHATT communication intervention. Usual/standard care will be provided.

Descriptive Measures. All physician participants will be asked to complete a background/demographic questionnaire (e.g., age, years of practice, previous communication training). Baseline and post-intervention completion of a previously used/published measure of physician comfort in communicating with patients and families, particularly around difficult topics (i.e., prognosis), will also be completed. Medical chart review will be completed to gather patient demographics and basic medical history, which will be used to define the study sample.

Outcome Measures.

Physician Measures. Intervention-arm physician participants will complete an investigator-designed Likert-rating and open-ended question survey assessing intervention satisfaction, ease of intervention administration/completion, time to complete WE CHATT intervention with patient, barriers/feedback specific to WE CHATT, and knowledge gained/perceived impact on practice.

Patient/Caregiver Measures. Intervention-arm patient and caregiver dyads will complete an investigator-designed Likert-rating and open-ended question survey assessing intervention satisfaction, ease of intervention administration/completion, time to complete WE CHATT intervention with physician, barriers/feedback specific to WE CHATT, and knowledge gained/perceived impact on their medical care. All participating patients and parents will complete the self-administered 18-item Service Evaluation Questionnaire⁴⁹ as an assessment of healthcare satisfaction, which has been used in similarly aged samples.⁵⁰ Patient and caregiver versions of previously validated survey tools of trust in physician (PediTIPS) and perceived empathy (CARE measure) will also be completed.

Analysis Plan. Paired samples T-Test will be employed within the intervention arm to compare mean physician comfort, mean patient/family satisfaction, mean trust in physician, and mean perceived empathy. ANCOVA will be used to examine group differences in physician comfort, patient/family satisfaction, trust in physician, and perceived empathy. Frequencies, percentages and means will be calculated to describe physician, patient and family satisfaction with the WE CHATT intervention.

LIMITATIONS

Non-English speaking participants will be excluded from Study 1, limiting examination of cultural influences on end of life care preferences. Both physician fellows and attending physicians will be included as participants to ensure the recruitment goal of 20 is met for Study 2. We recognize that fellows are unlikely to have as much experience in patient communication as attending physicians, however, at our site, fellows often initiate difficult and advance care planning discussions given their primary roles in the cardiac intensive care unit. Others have included both fellows and attending physicians in their healthcare communication research.^{5,6}