CALLiNGS Protocol: Care Across Locations Longitudinally of Goals and Symptoms

NCT : pending

June 23, 2018

Junior Faculty Career Development Award

CALLiNGS Protocol: Care Across Locations Longitudinally in Navigation of Goals and Symptoms **Interdisciplinary Pediatric Telepalliative Consultations for Hospice Teams**

Project Abstract

Despite 35+ pediatric hospice discharges to rural providers each year in Nebraska; primary care providers, hospice directors, and hospice nurses in Nebraska report they feel unprepared to manage pediatric hospice patients. In this pilot intervention study guided by the Theory of Unpleasant Symptoms, web conferencing services will connect an inpatient pediatric palliative care team with adult outpatient hospice providers to support local providers in assessing pediatric-specific care needs and implementing developmentally-appropriate pediatric treatment plans for 10-20 medically-complex children. The objective of this CALLiNGS (Care Across Locations Longitudinally in Navigation of Goals and Symptoms) mixed-methods study is to test feasibility, acceptability, and quality of life outcomes from using web-conferencing technology to connect a hospital-based interdisciplinary pediatric palliative care with statewide field-based hospice teams during interdisciplinary meetings at a minimum of every 15 calendar days. The reason for selection of every 15 days is because Medicaid requires that interdisciplinary hospice teams meet at a minimum of every 15 days to review patient symptom burden, medications, and plan of care. The study team hypothesizes that telepalliative care for children has the potential to improve the quality of care delivered to pediatric palliative care patients in a rural state by facilitating the confidence and comfort of local providers, enhancing goals of care conversations, improving symptom management for patients and therefore quality of life for family members, and creating a unified and cross-setting shared care model. The study intends to determine whether direct patient-specific pediatric mentorship or general pediatric palliative education is more helpful for hospice staff, for patient symptoms, and for family quality of life. If feasible this model could transform the pediatric palliative care delivery in the state of Nebraska with expanded opportunity for application in settings with similar subspecialty provider shortages.

Specific Aims The *Central Hypothesis* is that telepalliative care has the potential to improve the quality of care delivered to pediatric palliative care patients in a rural state by connecting local care providers with palliative care interdisciplinary subspecialists at an academic health center to facilitate improved symptom burden which translates into enhanced quality of life for the pediatric patient and family members, increased confidence and comfort of local providers, and ultimately the creation of a unified and cross-setting shared care model.

Aim 1. To investigate the symptom burden for pediatric patients and the quality of life impact for pediatric patients and their families through an interdisciplinary pediatric telepalliative consultation service partnered with local hospice providers with an interface at a minimum of every 15 day intervals.

Aim 2. To evaluate the self-efficacy, knowledge, and self-perceived adequacy of local hospice providers in caring for pediatric patients before and after interdisciplinary pediatric telepalliative consultation service partnership with these local hospice providers.

Aim 3. To explore the acceptability of teleconferencing services as a form of pediatric palliative care mentorship for local hospice teams caring for children and adolescents.

Expected Outcomes Based on geography and shortage of pediatric palliative subspecialists in Nebraska, the current model of hospice services is one in which pediatric patients are managed by local adult-based hospice teams after discharge from the pediatric hospital (34 such in the past 16 months). Sixty percent of academic pediatricians in Nebraska who served as primary providers for consecutive pediatric home discharge patients self-reported feeling "very deficient" to "deficient" when asked about competence after supporting terminal patients and families in care at home (n=12).[1] The knowledge gap and discomfort in managing children with complex symptom burden is magnified further for family practice or internal medicine teams serving in hospice roles for children in rural communities. Through a new telepalliative technology platform, this study fosters collaboration and communication to improve the quality of care for pediatric patients receiving hospice care in rural states. This model implements human interaction through technology to challenge the existing paradigm of silo-based care of pediatric palliative care patients. With roll-out of this intervention, we anticipate increase in pediatric hospice utilization (decreased in-hospital deaths). If feasible this model could transform the pediatric hospice care delivery in the state of Nebraska with expanded opportunity for application in settings with similar subspecialty provider shortages.

Table 1. Aims, Measures, and Time Points for this Exploratory Pilot Feasibility Study

Aim	Completed by	Measures and Designated Timepoints
Investigate symptom burden for pediatric patients and the quality of life impact for pediatric patients and their families	Patient Parent	PROMIS-37 – Every 15 days, as child is able Proxy-PROMIS-37 and PedsQL Family Impact completed by Proxy – Every 15 days
Evaluate the self-efficacy (comfort), knowledge, and self-perceived adequacy of local hospice providers	Hospice Nurse Team	Pediatric Palliative Care Questionnaire – Enrollment and end of study Qualitative Debriefing Survey (2 qualitiatve questions) – End of study
Explore the acceptability of teleconferencing services as a form of pediatric palliative care consultation	Hospice Nurse Team	Technology Acceptance Model (TAM) Tool – After telehealth encounters

Research Plan

Background and Significance

Based on rural geography and shortage of pediatric palliative subspecialists in Nebraska, the current model of hospice services is one in which pediatric patients are managed by local adult-based hospice teams after discharge from the pediatric hospital (34 such in the past 16 months). Sixty percent of academic pediatricians in Nebraska who consecutively served as primary providers for pediatric hospice patients self-reported feeling "very deficient" to "deficient" when asked about competence after supporting terminal patients and families in care at home (n=12).[2] Primary care providers, hospice directors, and hospice nurses in Nebraska report they feel unprepared and even "scared" about managing pediatric patients approaching natural end of life.[3] Children with complex medical conditions referred for palliative care experience multiple concurrent symptoms[4] with larger health related quality of life (QOL) score reductions based on symptom clustering.[5] An experience of multiple concurrent symptoms hinders accurate patient assessment, overall care management, and quality of life.[6,7,8,9] This symptom care is further complicated for adult-trained providers by the unique practicalities of caring for children such as: weight-based pharmaceuticals for children; developmental communication needs of children for patient-reported symptom status; psychosocial needs of caregiving parents, grandparents, and siblings; and hormonal and physical uniqueness in pediatric cohorts.

Access to pediatric-informed symptom management and developmentally-sensitive goals of care conversations should be considered a matter of justice and care equity for children receiving hospice services.[10] Advances in technology have made the use of telepalliative care a feasible option for palliative care subspecialty clinicians to provide clinical care and support.[11,12] In this longitudinal pilot intervention study guided by the Theory of Unpleasant Symptoms (TOUS), web conferencing services will connect the hospital interdisciplinary pediatric palliative care team with local hospice provider for interdisciplinary meetings to support local providers in implementing developmentally-appropriate pediatric treatment plans and addressing pediatric-specific care needs.

This research proposal is significant for five reasons: it responds to the top three pediatric palliative research needs recently identified by a large Delphi study (care coordination between health settings, symptom management, and quality innovation)[13] in addition to the Institute of Medicine Dying in America priorities[14] and the quality National Quality Form priorities;[15] it recognizes the role for collaboration in resource-limited settings; it incorporates technology in a humanistic way to foster transitions between care settings (makes "home" a reality for families not able to access pediatric trained hospice providers in rural settings);[16] it honors the perceived need shared by bereaved family members who have identified the immense need for symptom and psychosocial intervention for children at home at end of life;[17,18,19,20,21,22] and it identifies clinical outcomes not only through proxy opinions but also to include patient, family, and interdisciplinary team member perspectives.

The proposed children's hospital location averages approximately 30-40 additional in-hospital deaths (patients who would be hospice eligible) per year since 2013. This quantified number excludes any deaths that were from trauma or motor vehicle accident; includes hospital-location deaths related only to chronic illness. The general opinion from a chart review of those in-hospital mortality cases is that hospice was very likely not offered as a feasible option for these families due to current set-up of adult hospice services. The vast majority of referring pediatric providers simply don't refer to hospice as a realistic or compassionate transition for children. The study team anticipates being able to document increased referrals to pediatric hospice secondary to implementation of the telepalliative service pilot.

Innovation

This research proposal is innovative not only for the application of advanced technologies but also for the model of collaboration across care ages (continuum of care) and empowerment of medical homes.[23] The research proposal is innovative in relying not only on proxy report in the form of provider and parent perspective, but, in also eliciting direct child voice (an oft-silenced voice in the field)[24] for impact metrics. The research is innovative in inclusiveness by welcoming grandparent and sibling perspectives in family impact scales, a seemingly ignored and yet impacted population.[25,26,27] The research is innovative in recognizing opportunity for collaborative energy through consultation-based care for children (addresses silo-ed subspecialty care as a critical barrier to progress in caring well for children with palliative care needs). The research is grounded in the Theory of Unpleasant Symptoms (TOUS),[28,29,30,31] which theorizes that symptom intensity is illness and situation specific with variables that influence it but cannot be changed (such as the ill child's diagnosis, age, and gender) and that mood (depression, anxiety) can influence synergistic symptoms (fatigue, pain, nausea) which culminate in an influence on overall family function. Thus, the research is progressive in placing biological impact within context of whole-family psychosocial quality of life experience.

Conceptual Framework –

Theory - The theory which frames this study is the Theory of Unpleasant Symptoms (TOUS). This theory was developed to explore the understanding of relationships among multiple symptoms and how changes in symptoms translate into lived experience.[32] TOUS is thus recognized as a "middle-range" predictive theory.[33,34] TOUS has been used to develop preventive interventions to adjust influencing factors for improved symptom profile and thus improved quality of life with measured outcomes for adults.[35,36,37] Application of this theory for a pediatric population is highly-relevant and novel.

Concepts - The TOUS carries three major concepts as defined by the theory founder: **influencing factors, symptoms, and performance.**[38] *Influencing factors* are recognized as psychological, physiological, and situational factors which influence the intensity, timing, distress level, and quality of symptoms. For pediatrics, psychological factors are influenced by communication about feelings and honesty about diagnosis/prognosis in developmentally-relevant forms. Physiologic factors for pediatric patients are uniquely influenced by a child's ability to use his or her body to engage in normalized play and "good day" activities even during time of sickness. Situational factors for pediatric patients are influenced by family relationships and child trust in health care team and child sense of parental burden. "Unpleasant symptoms, in all their synergy, interaction, and complexity, are what the whole patient presents" and "the red flags of threat to health". [39] Interactions between symptoms are recognized by TOUS to be multiplicative and exponential rather than additive as symptoms "catalyze each other".[40] Performance in TOUS describes the outcome or effect of the symptom experience quality of life. A pediatric perspective on this concept would include play time, tolerance of cuddling or physical relatedness, storybook or music moments, and family/peer socialization (receiving engagement in addition to active engagement is relevant for child patients).

Model - The below-model depicts the relationships of the TOUS concepts with outcomes. The outcome of interest is pediatric symptom burden which then translates into a lived quality of life not only for the child but also for the family. By targeting the influencing factors (primarily the situational factor of direct communication with families and health care teams) and by targeting symptom burden, the telepalliative intervention is designed to impact quality of life as an outcome (Figure 1).

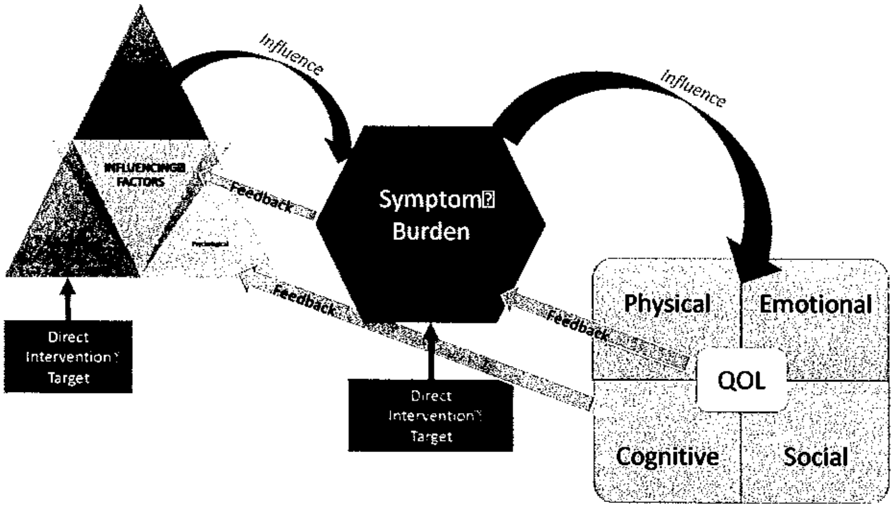


Figure 1. TOUS Model for Pediatric Telehealth Intervention
Note: This model was adapted from original imagery - Adapted from "The middle-range theory of unpleasant symptoms: an update" by Lenz et al. Abbreviation: TOUS = theory of unpleasant symptoms; QOL = quality of life.

Research Design and Methods
Description – This mixed-methods pilot feasibility study includes use of web-conferencing technology to connect a hospital-based interdisciplinary pediatric palliative care with statewide field-based adult hospice teams. The first collaborative meeting includes a comprehensive pediatric palliative care needs assessment completed with the patient, family, the pediatric palliative care team, and the local hospice team to include goals of care in symptom, relational, psychological, and spiritual domains as well as advance care planning content.[41] The ongoing intervention with the hospice team includes either pediatric educational modules OR shared visits during interdisciplinary meetings (with the invitation to the patient and family for inclusion via tele-presence) at a minimum of 60-min every 15 calendar days.
Team-Approach – The study is specifically an interdisciplinary team empowerment design. The telepalliative team "interacts with the goal of transferring knowledge from one discipline to another; which allows members to inform each other's work and compare findings"[42] toward shared, collective outcomes.
Sample and inclusion criteria – The study population includes all patients ages birth to 18 years referred to the inpatient pediatric palliative care team at Children's Hospital Omaha or the University of Nebraska Medical Center during hospitalization who are enrolling on home hospice services within the state of Nebraska at time of discharge from the hospital. Based on a chart review of three consecutive years (2013-2016), this situation includes an average of 30 pediatric patients per year. The mean age of this patient population based on three-year data is 7.4 years (range 3 days to 18 years); primary diagnosis included genetic (27%), oncology (23%), cardiac (18%), neurologic (18%), pulmonary (14%). Family distance from the hospital averaged 110 miles (range 7 to 320 miles). These children are noted to have a significant symptom burden to include pain, dyspnea, fatigue, nausea, and anxiety/depression.

Selection methods and sample size – Pediatric patients and their families will be informed of the CALLiNGS Protocol (**C**are **A**cross **L**ocations **L**ongitudinally **i**n **N**avigating **G**oals and **S**ymptoms) at time of home hospice enrollment to foster consecutive sampling enrollment. The local nurse team hospice will receive telehealth interdisciplinary team meetings specific to patient need for up to 60 minutes every 15 days. The pilot study size of 10-20 patients per hospice is grounded in evidence-base for feasibility study sample population size rather than power scales.[43] Note that study duration would be for a maximum of six months per enrollee (due to hospice enrollment being a six-month commitment as standard).

Hospice Intervention

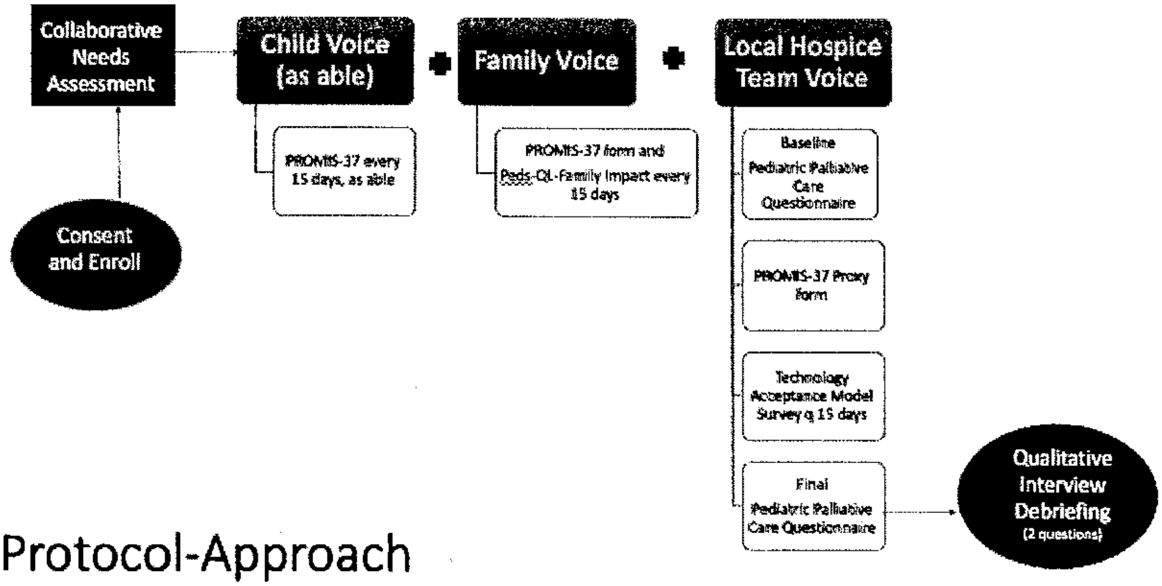
- Pediatric patient-specific case discussions for enrolled pediatric patients at hospice staff interdisciplinary team meeting every 15 days for 60 min sessions via telehealth

Study Variables and Measures – Although there is an increasing call for pediatric providers to foster patient voice, pediatric care teams often grade symptoms and report quality of life or the parent reports as proxy. The graded symptoms which lead to patient-interpretation of quality of life often include subjective symptoms such as nausea, dyspnea, fatigue, insomnia, anxiety, depression, mental clarity, and pain. This project thus commits to triangulate the lens on lived experience by eliciting child, parent, and family perspectives on symptoms and on quality of life. **Symptom and quality of life** outcomes will be obtained from a triad-view: from the child perspective (using the PROMIS-37™), from the guardian and hospice nurse perspective on the child's experience (using the PROMIS-37 Proxy Edition™), and from collective family perspective on family quality of life (using the PedsQL™ Family Impact Module).[44] Internal consistency reliability for the Total Scale Score (alpha = 0.88 child, 0.90 parent report).[45] Specific to pediatric illness, these scales have been utilized and validated.[46,47,48,49,50,51] **Technology Acceptance** will be measured by the Technology Acceptance Model (TAM) questionnaire as has been used in adult telehealth hospice settings,[52,53,54] consists of two six-item scales with reliabilities of 0.89 for usefulness and 0.87 for ease of use.[55] **Local hospice team sense of self-efficacy (comfort), knowledge, and self-perceived adequacy** of caring for pediatric patients will be measured using the Pediatric Palliative Care Questionnaire (known validity coefficients 0.88 and 0.92) and two qualitative interview questions asked pre- and post- intervention.[56]

Step-by-step outline of the CALLiNG protocol – With a letter of agreement between the pediatric palliative care team and the local hospice providers the teams will use the web-conferencing platform recommended by the American Telemedicine Association. The two teams can connect virtually, and even include the pediatric patient and family.

- *Baseline Needs Assessment to Guide Care is current standard of care* – Collaborative completion of baseline demographics and needs assessment form covering financial, psychosocial, demographic domains and goals of care to include advance care planning will be completed at first visit with patient, family, local hospice team to direct longitudinal care approach.[57] This is current standard of care (not new to hospice research project).
- *Consent/Enrollment* - Consent and enrollment procedures will follow strict Institutional Review Board expectations and ethical standard.
- *Stakeholder Survey* – Local hospice team will be asked about their perceived self-efficacy (comfort), knowledge, and perceived adequacy in caring for pediatric children in using quantified Pediatric Palliative Care Questionnaire scale pre- and post-child enrollment.

- *Symptom Burden and Quality of Life* – Child, guardian, and hospice team nurse will complete Pediatric PROMIS-37™ every 15 days to assess for symptom burden and translated quality of life.
- *Interdisciplinary (IDT) Telepalliative Care Meetings* –Technology Acceptance Model survey will occur every 15 days (in the pediatric palliative educational arm and in the patient-specific case discussion arm) as an automatic screen on the closing telepalliative screen to evaluate acceptability of technology interface. The reason for this frequency is that Medicaid requires that hospice interdisciplinary team interactions occur at a minimum of every 15 days.
- *Team Debriefing* – At enrollment and at the conclusion of the study period (six months per enrollee with total project duration 2 years) or within 3 days following a child's natural end of life; the local hospice team members will be invited to engage in a qualitative interview with two thematic topics: 1. Please describe your experience caring for a pediatric patient and 2. Please describe your experience with telepalliative use. This interview will be recorded and coded for content using Atlas.ti software.



Protocol-Approach

<u>*Data Plan*</u> – Descriptive statistics will be computed for each outcome variable at each time point. Repeated measures ANOVA and trend plots will be used to explore quantified symptom burden and quality of life trends over time. The association between individual and multiple symptoms will be explored via linear and multiple linear regression. Bland-Altman plots will be used to assess concordance between symptom and quality of life reporting. Crude (unadjusted) associations between demographics (such as family economics, diagnosis, level of technology, delay to initial palliative care) and symptoms / quality of life will be explored via ANOVA or linear regression, as appropriate. A similar analysis will be used to explore the association between how hospice team self-perceived confidence and knowledge of pediatric palliative care and child symptom and quality of life. In the event the assumptions of the parametric tests identified above are violated, the appropriate non-parametric test will be used. When a non-parametric test is used, the median and interquartile range for continuous outcomes will be reported. A significance level of 0.05 will be used to judge statistical significance. In addition to monitoring for statistical significance, the study team will follow minimally clinically important

difference (MCID) for symptom burden or quality of life values over time.[58] MCID has been defined as "the smallest difference in a score of a domain of interest that patients perceive to be beneficial and that would mandate, in the absence of troublesome side effects and excessive costs, a change in the patient's management."[59] Content of the two qualitative interview questions will be analyzed thematically using a qualitative coding methodology in Atlas.ti (Meaghann has completed graduate level qualitative coursework >9 credit hours and published >4 qualitative method manuscripts).[60]

Commitment to Share Findings – The research team supports public access to findings and has a plan to disseminate information through oral presentations and peer-reviewed manuscripts submitted across disciplines. Study participants will be provided with a summary document of collective findings at conclusion of the study to include publication copies. Symptom assessment/intervention and patient-centric care transitions between locations (inpatient to home hospice) are standards of pediatric palliative care.[61] The current state of the science is that: 1) There is a need for improved care for children at time of enrollment on home hospice; 2) Whether telehealth via case-specific pediatric mentorship during hospice interdisciplinary team meetings can improve that care is to be determined. Our intent is that this research would speak into that gap in the science! If feasible this model could transform the pediatric palliative care delivery in the state of Nebraska with expansion to other settings.

List of Preliminary Studies -

Weaver M. Growing symbiotic local partnerships to nurture quality pediatric hospice care in rural regions: Companion Planting. Accepted for publication in JAMA Pediatrics - 2017.

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Please see https://www.ncbi.nlm.nih.gov/pubmed/?term=weaver%2C+meaghann for full list.

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