

Go Wish Together for Pediatric Solid Organ Transplant Families

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## Abstract

**Purpose statement:** The purpose of this quality improvement project was to improve the care of patients and families of the pediatric solid organ transplant team by focusing on patient and family- centered goals of care using primary palliative care skills and the Go Wish Together conversation tool.

**Background:** There is significant morbidity and mortality for solid organ transplant recipients. Referrals to palliative care (PC) in this adult and pediatric population are inconsistent and often late, near the patient's end of life. Improving quality of care through utilization of PC services can contribute to hospital savings through a reduction in LOS and reduced charges and can reduce nursing attrition. The post-transplant period can be complicated by significant symptom burden, however, referrals to palliative care in the adult and pediatric population are inconsistent and often late or at end of life.

**Practice change and Implementation strategies:** A convenience sample of families with pediatric patients admitted under the care of the SOT team at Nebraska Medicine was used. The process was introduced with written and verbal information by the provider to initiate the Go Wish Together Conversation Card game process. Caregivers were directed to divide the cards into categories of "very important", "somewhat important" and "not important". Category content was explored and discussed with the provider. A dot phrase was utilized to communicate participation in the project and family wish preferences were entered on a "sticky note" within the electronic medical record as a reference to be utilized during team rounds.

**Evaluation:** This project was implemented over a six-week period with eight parents of pediatric solid organ transplant patients in the pediatric and pediatric intensive care units at a large, urban academic health center in the Midwest. "For my child to be free from machines" and "To manage appetite changes and nutrition plans for my child" were the most frequently categorized in the very important category.

**Conclusions and implications for practice:** A focus on family-centered goals proved to be welcomed and beneficial in helping highlight family challenges and gaps in support that exist not only within the hospital environment, but within the larger context of these families' lives. Use of the conversation tool allowed an opportunity for caregivers to discuss their experiences and receive resources that otherwise would not have been addressed.

## **Background**

Palliative care (PC) is intervention and care that supports physical, psychological, spiritual, and psychosocial needs of the family and patient with a life-threatening illness, resulting in improved quality of life, through evaluation and relief of pain and other symptom management (World Health Organization, 2020). Care settings can include the patient's residence, hospitals, community-based health centers and specialized health facilities. (European World Health Organization, 2023). Pediatric palliative care utilizes a multidisciplinary team of medical professionals with specialized training in end-of-life care. The common disciplines are physicians, nurse practitioners, chaplains, social workers, registered nurses, and child life specialists (Linebarger et al., 2022). Palliative care has been most widely used for those with cancer, therefore most of the research has been extracted from this population. There is a large body of evidence on the positive effects that early use of palliative care services has on quality of life to include decreased depression and stress for the patient and caregivers as well as greater satisfaction with care (Wentlandt et al., 2017).

In the United States, about 10,000 children under the age of 15 will receive a diagnosis of cancer this year and greater than 1,000 of these children will not survive (American Cancer Society, 2023). Cheng et al., (2018) completed a multinational systematic review of pediatric cancer patients and utilization of palliative care between 1998 and 2017. They found almost half of these children and families received no palliative care support at all. In addition, review of the institutions that form the Children's Oncology Group revealed that 40% of these specialists fail to offer any PC services. This has great significance as only 10% of pediatric oncology patients in the United States are served outside of this organization (Cheng et al., 2018).

Nationally, there are 45,000 pediatric deaths a year, with the majority being in those less than one year of age, largely related to congenital disorders or prematurity. Greater than 95% of children worldwide with a palliative care need are in lower and middle-income countries, like Africa. Yearly, 56.8 million people world-wide would benefit from receiving palliative care. (World Health Organization, 2020). Unfortunately, only 14% of all those with a need are currently receiving services. This is in part due to a lack of palliative care education that exists among healthcare professionals as well as barriers to use of opioids and necessary controlled palliative medications (World Health Organization, 2020). Regional data from the European World Health Organization shows approximately 170,000 children die annually who have a palliative care need. They offer palliative care services in 20 countries and recognize successful palliative care support can be achieved even with limited resources (World Health Organization, Europe, 2023). Involvement of pediatric palliative care teams has shown improved outcomes and an increased opportunity for curative care and symptom management for patients with life-threatening illnesses (Friedrichsdorf & Bruera, 2018).

Over the past 10 years, the utilization of in-hospital palliative care has grown by 26%, resulting in more than 1/3 of all hospitals offering services. Of facilities with greater than 300 beds, 90% have available palliative care services and programs are more prevalent in nonprofit or public healthcare systems. (Schoenherr et al., 2019). A recent 5-year review of adult acute care-hospital palliative care use in the United States was reflective of developing data and guidelines that support use of early palliative medicine for those with serious illness. They found an increase in referrals for those with a non-cancer diagnosis. Approximately 1/3 of patients had a diagnosis of cancer and greater than 50% were located on a medical or surgical unit at the time of referral. Other common diagnoses were related to cardiac, pulmonary, and neurological

dysfunction (Schoenherr et al., 2019). There are racial and ethnic disparities in pediatric end of life care similar to those found in the adult population. These inequalities lead to lack of access to providers and facilities with specialized training and increased aggressive end of life interventions (Linebarger et al., 2022).

Evidence of palliative care use can be found involving patients with disease processes that may lead to lung, kidney, liver and cardiac transplantation. Because the disease progression of organ failure is not the same for everyone, uncertainty exists as to when to involve palliative medicine (Wentlandt et al., 2017). Despite the complex needs of these patients and families, palliative care has been shown to be underutilized, and end of life care frequently includes aggressive measures (Murakami et al., 2022). Delayed consultation until the end of life can be contributed to a patient's fear of being deserted by their primary transplant team, anticipated use of medications that are associated with dependence and respiratory compromise and scarcity of access to ancillary services. In addition, some transplant practitioners believe consultation to palliative care is identical to hospice care and would preclude ongoing or additional aggressive therapies (Scully et al., 2021).

Significant morbidity and mortality is experienced by recipients of solid organ transplantation during all phases of care. Annually, 10% of patients in need of a liver transplant in the United States will die prior to receiving an organ. Of those who receive a liver transplant, 10% will die prior to their first transplant anniversary (Vijeratnam et al., 2021). One-year patient survival rates are made publicly available by the Scientific Registry of Transplant Recipients and likely influence decisions made by transplant teams. While most transplant recipients (kidney, liver, heart, lung) have a 1-year survival of at least 80%, this time period can be complicated by significant symptom burden, infections, physical weakness and frailty, malignancies, allograft

dysfunction, central line associated complications and complex interpersonal and interprofessional relationships (Murakami et al., 2022). A study completed in 2014 focused on patients with non-curative chronic liver disease, showed 90% were without palliative care involvement. Of the small minority that did receive services, less than 30% had a documented “do not resuscitate” status. This is evidence of missed opportunities as palliative care teams have been proven to show decreased morbidity related to chronic illness and can advocate for discussions concerning advanced care planning (Wentlandt et al., 2017).

A review of pediatric patients without a cancer diagnosis who received home palliative care in 2014 showed a per patient hospital savings of \$275,000 which was contributed to decreased inpatient length of stay by almost 40 days, reduced hospital charges, and reduced resource utilization (Friedrichsdorf & Bruera, 2018). By establishing goals of care, there is a reduction in use of resources that are not reflective of patient and family priorities and needs. There is decreased use of intensive care units as well as a decreased 30-day readmission rate, contributing up to a 25% cost savings per in-hospital visit (Center to Advance Palliative Care, 2023).

Improving the quality of patient care through utilization of PC services can contribute to hospital savings and help reduce nursing attrition by decreasing the environment of emotional distress and improving job satisfaction. The average loss of a bedside nurse is greater than \$36,000 to almost \$60,000. This translates to a yearly hospital loss of \$4.9-\$7.6 million (Friderichsdorf & Bruera, 2018).

### **Significance**

Not only are there multiple professional organizations who support the use of early palliative care for those with serious, life-threatening illness, the practice is supported in the Healthy People 2020 and 2030 goals.

In 2000, the American Academy of Pediatrics (AAP) announced a policy statement

endorsing the use of palliative care. The AAP maintains their belief that children with life-threatening illness, or a terminal condition should receive palliative care consultation to assist the primary team in meeting the social and spiritual needs of the patient and to facilitate communication surrounding treatment decisions, goals of care, quality of life decisions and reduce the burden of illness (pain and other symptom management) (Linebarger et al., 2022).

The American Heart Institute advocates for early palliative care involvement recognizing the benefits of improved quality of life and symptom management for patients and families who have experienced heart failure or stroke or suffer from congenital anomalies and syndromes (American Heart Institute, 2022).

The American Medical Association *Code of Medical Ethics*' opinions and House of Delegates policies support utilization of palliative care to improve the quality of life for those with life threatening illness (Budhiraja, 2021).

The World Health Organization advocates for strong palliative care services accessible at all levels of care to help achieve universal health coverage. This is necessary in order to bring relief of health-related suffering which they see as a global ethical responsibility (World Health Organization, 2023).

Utilizing palliative care for patients with chronic illness contributes to the Healthy People 2020 goal to promote quality of life across all age stages with a focus on health-related quality of

life. This general concept remains an area of continued focus in the Healthy People 2030 objectives, defined as overall health and well-being (Centers for Disease Control and Prevention, 2020). In addition, because palliative care programs have been shown to be effective in improving patient and caregiver anxiety and stress, implementation can help us achieve two 2030 goals, EMC-D07 and EMC-DO4 (increase the number of children and adolescents who show resilience to challenges and stress as well as those who get appropriate treatment for anxiety or depression) Centers for Disease Control and Prevention, 2020).

### **Purpose Statement**

The purpose of this quality improvement project was to improve the complex care of patients and families of the pediatric solid organ transplant team by focusing on patient and family- centered goals of care using primary palliative care skills and the Go Wish Together conversation tool. Three aims were addressed.

1. Develop a process that supports effective use of the Go Wish Together tool for pediatric SOT team families.
2. Implement the process using a multi-disciplinary team of pediatric specialists who will provide education to bedside staff and serve as change agents. A dot phrase will be developed to document use of the tool and sticky notes will be entered into the electronic chart to provide communication to care staff.
3. Evaluate use of the conversation tool and its effect through review of the EPIC electronic medical record and focus group data collected from nursing and ancillary staff.

## **Review of Evidence**

For this project, the following search engines were utilized Bluejay, PubMed and Google Scholar. Key words utilized in this search included pediatric, solid organ transplant, perspectives of families, nurses, physicians, and providers, in conjunction with the words palliative care. Articles from the previous 5 years were included, using the timeframe of 2019 to current. All articles were written in English.

### **Provider Perspectives**

Although the benefits of PC services for patients and families in the solid organ transplant community are clear, significant provider specific barriers remain that prevent increased use. There continues to exist the misunderstanding that PC is specific to end-of-life care and the goals of therapy are in direct contradiction to goals of solid organ transplant (Cousino et al., 2019). Many providers associate PC as being synonymous with hospice. McDarby & Carpenter, (2019) conducted interviews with nineteen PC providers and 29 specialists within the same organization to explore perspectives that lead to barriers to effective inpatient collaboration.

Specialists included those in cardiology, intensive care, surgery, nephrology and oncology. Many stated the inability to separate PC from hospice is rooted in a misunderstanding that is embedded in their education and training on PC. Attitudes related to referrals for PC were found to be affected by professional relationships between teams, that were largely patient focused and reflected a lack of consistent opportunity for personal interactions or activities. This resulted in limited opportunities for more meaningful collaboration. They also found the common belief within the surgical team that consultation of the PC team means they are giving up on the patient, recognizing that this belief is rooted in bias. Others reported a lack of referrals due to their belief

that they themselves could provide adequate palliative care services (McDarby & Carpenter, 2019)

A study on PC collaboration for adult patients with end stage liver disease in the United States completed by Ufere et al., (2019) explored the perspectives of 396 practicing gastroenterologists and transplant and general hepatologists. Most of this group practiced in an academic hospital (79%) and greater than 50% had at least 10 years of experience. Ninety-five percent of these providers expressed the belief that PC should be available in centers who care for people with end stage liver disease and almost 90% believe it should be offered early in the course of illness (Ufere et al., 2019). However, almost half of these providers believed PC teams lack understanding on how to manage the physical symptoms that accompany end stage liver disease. As a result, almost all these physicians (97%) stated that hepatologists should have the expertise to manage the associated physical and psychological symptoms (Ufere et al., 2019). In addition, almost 90% felt end of life discussions and coordination of care at all levels should rest with the hepatologist. Despite these feelings of responsibility, most hepatologists expressed that they were not the optimal choice to provide PC services. No one in this group received more than 6 months of PC specific training and more than half had no training. These physicians also displayed reservations in seeking PC collaboration for actively listed transplant candidates with less than 50% stating they would refer. Almost one-third believe the goals of transplantation and PC are in conflict (Ufere et al., 2019).

Beltrand & Hamel (2021) discussed 33 articles from 21 journals published between 2009 and 2020 exploring perspectives and experiences of nurses and palliative care for infants and newborns. Greater than 90% of those surveyed advocated for formal PC team involvement to

support family and staff members (Beltrand & Hamel, 2021). In addition, they expressed frustration and emotional distress related to their inability to participate in decisions as their roles primarily involve education, patient advocacy, family support and making keepsakes prior to death (Beltrand & Hamel, 2021).

**Summary:** Providers continue to have a misunderstanding of PC that leads to barriers to timely referral. Many solid organ transplant providers see PC to be contradictory to their care goals, leading to referrals that primarily occur at end of life. In addition, there is a belief that families will feel deserted if PC is consulted. Gastroenterologists and hepatologists' views reflected a belief that PC should be offered early as a standard of care in centers who care for patients with end stage liver disease. However, they believed end of life discussions should be led by them over PC providers and that PC providers lack understanding of liver disease-related symptom management. Additionally, only half of these providers felt PC involvement was appropriate for those who are actively listed for transplantation. Other specialist providers either associate PC with hospice and end of life care or believe they themselves can provide adequate PC support. Nurses expressed support for early involvement of PC services and dissatisfaction with care situations that don't include their perspective when making decisions.

### **Family perspectives**

Sedig et al., (2019) explored end-of-life experiences through use of psychologist led focus groups with 12 bereaved parents of children who received cancer care from a large Midwest academic medical center between 2010 and 2017. Retrospective data was collected utilizing a written survey to evaluate end of life symptom management and opinions on specific services such as social work, child life, psychology and palliative care. Greater than 90% of these families were offered PC services (Sedig et al., 2019). Almost all families reported positive

feelings towards PC, noting it to be at least somewhat helpful and reported well controlled symptom management at the end of life (Sedig et al., 2019). The greatest reported benefit was centered around provider behavior and communication, described to be respectful, easy to understand and honest. However, some parents endorsed the desire for improved anticipatory guidance and a feeling of loss of control related to the hospital environment (Sedig et al., 2019).

McDarby & Carpenter (2019) completed interviews between 2017 and 2018 with 48 providers from four United States Midwest hospitals. Provider reports reflected families' confusion about the benefit of a PC team, believing their role to be solely focused on end-of-life care, in turn making them resistant to PC consultation and collaboration.

Bennardi et al., (2021) studied perspectives on PC collaboration through bereaved family members of cancer patients in Switzerland. Focus group and individual interviews were conducted with 10 individuals who experienced the death of a loved one 12-24 months prior to January or February 2020. Members reported positive feelings related to family conferences as they felt these helped to improve communication and afforded them the opportunity to express their needs. They witnessed barriers to effective collaboration as a result poor coordination of services and poor information sharing between teams (Bennardi et al., 2021).

Tagami et al., (2022) published findings from a nationwide survey conducted in Japan evaluating the introduction of specialized PC services from the retrospective perspective of bereaved family members who had a loved one with cancer. In 2018, five hundred and fifteen adult family members provided responses reflecting their experiences in a variety of adult PC settings including acute care hospitals, home-based hospice services and inpatient PC units. Participants were asked to provide a perspective from the patient as well as their own on whether they received referral to specialty PC services at an appropriate time. In addition, investigators

wanted to know what they felt was the greatest need to be addressed by specialty PC. A total of 315 of the 450 participants reported referral to services to be appropriate, defined as referral at diagnosis or during disease treatment (Tagami et al., 2022). These results are consistent with current literature that supports early referral to PC. The early PC referral process in Japan is supported by a 2007 National Cancer Control Act. Forty-five percent of participants expressed a need for assistance with physical distress, followed by end-of-life care (Tagami et al., 2022). Nearly 40% of individuals stated a need for guidance with making decisions (Tagami et al., 2022). This study also highlighted the correlation between the time of referral and quality of death. Those who rated the referral as appropriate, also expressed a higher score on the Good Death Inventory tool than those who thought the referral to be late.

Verbene et al., (2020) conducted at-home interviews between 2013 and 2016 with 42 parents of 24 children who were receiving PC services in a single institution in Amsterdam, Netherlands. The children had varied diagnosis and stages of illness, with 63% having a non-malignant disease and 63% having received initial PC around the time of loss of normality (Verbene et al., 2020). The investigators sought to evaluate how parents saw and experienced their family's and child's future within the context of PC. Families identified the importance of goal-directed discussions, anticipatory guidance and care that was consistent with a change in their child's needs. Families felt this care was supportive and allowed them to navigate the challenges of their child's course of disease. In addition, assistance with decisions about end-of-life care was noted to be helpful. This study not only highlights the importance of pediatric PC but the need to elicit family perspectives and values within the context of that care (Verbene et al., 2020).

Virdun et al., (2020) performed a qualitative study to evaluate adult patient perspectives on essential components of care that contribute to optimal hospital-based PC. Data was gathered from 21 phone interviews with adult patients identified to have PC needs, who were hospitalized in the previous 12 months in selected hospitals in New South Wales, Australia. Eleven patients had a non-malignant diagnosis while 10 had a malignant disease. Interviews occurred over a 12-month period from October 2018 and 2019. Consistent with previous findings, patients emphasized the need for effective, honest, and clear communication, collaboration between care teams that includes the patient and family, compassionate, considerate care delivery, and effective symptom management (Virdun et al., 2020). Additionally, cultural competency was highlighted as a needed communication skill. The need to address nutritional needs in relation to psychological health and have access to specialists were two new areas of focus that also emerged as important (Virdun et al., 2020).

**Summary:** Overall, families and patients believe PC involvement leads to an improved care experience. Within the PC experience, families expressed the need for health care providers to provide clear, honest and respectful communication, structured opportunities for information sharing, and culturally competent collaborative care that is reflective of family values and goals, while considering the current and anticipated disease course. Family barriers noted through provider interviews were related to a belief that PC is solely focused on end-of life care. An international study reflected the preference of early referral to PC not only for symptom and disease management but to shape a positive death experience. Parents of children and family members of adult patients had similar experiences and priorities of care.

### **Interventions to Increase Palliative Care Utilization**

Van Scoy et al., (2020) completed a mixed-methods cohort study in the United States on the effect of a conversation game focused on end of life, on attitudes regarding advanced care planning and completion of advanced directives in an African American Community. From 2018-2019 conversation events were held in 53 different community settings. Study data was extracted from 380 participants with 220 being included in the follow-up evaluation. Almost 50% of participants reported either completion of a new advanced directive or revision of an existing advanced directive (Van Scoy et al., 2020). In addition, 80% of participants had a conversation with a loved one about end-of-life. There were statistically significant differences in domains of readiness (0.98 compared to 0.33,  $P < .001$ ), self-efficacy (SD 0.98 compared to 0.54,  $P < .001$ ), knowledge (1.24 compared to 0.38,  $P < .001$ ) and an overall increase in the scores on the ACP Engagement Survey (Van Scoy et al., 2020). Research subjects reported this method to be informative, emotionally supportive and a non-threatening way to participate in advanced care planning discussion.

Kistler et al., (2020) completed a 20 article review of literature focused on triggered specialty PC consults involving 17,811 adult patients in emergency rooms and hospital inpatient environments, including intensive care units. Sixty percent of studies were quality improvement designs with the other 40% with a prospective cohort design. The emergency department and studies occurring in the oncology environment yielded the greatest PC consult trigger rates. A total of 85% of the tools screened patients at the time of admission and 50% included subsequent screening (Kistler et al., 2020). Only 10% of tools utilized were previously validated, and those utilized were not validated for the specific populations in these studies (Kistler et al., 2020). Most patients were identified through manual screening of records by staff. An electronic medical record was utilized by 15% of the projects to identify patients (Kistler et al., 2020).

Common trigger categories were advanced cancer, goals of care, readmission risk, neurological disease, organ failure, cardiac disease, functional status, and age with a median of 10 positive criteria resulting in a trigger. Trigger criteria were largely extracted from expert opinion and observation. Most triggers resulted in alerting the primary team. Once alerted, if approved by the team, the PC consult would occur. While 80% of studies captured patients with positive triggers, only 33% ultimately received a PC consult and only 25% of trigger tools led to an automatic PC consult (Kistler et al., 2020).

Bischoff, et al., (2023) completed a study using step-wedge design of an electronic screening tool meant to identify Medicare patients with PC needs in an outpatient setting in California between December 2020 and March 2022. The tool selected patients based upon ICD-10 codes and supplemental information to determine the degree of severity of illness. Over 2,000 patients were identified and 292 met criteria for serious illness. From this cohort, 145 patients went on to complete the study. Once identified by the screening tool, patients were randomly categorized into one of three cohorts and underwent a telephone survey conducted by a trained healthcare navigator. Through the interview process, 63.4% of participants reported significant physical symptoms and almost 30% of these noted symptoms to be severe (Bischoff, et al., 2023). Specialty PC services were offered to 47 patients and greater than 50% accepted (Bischoff, et al., 2023). Individual and group counseling was offered to patients who were found to have significant emotional distress. Of the 83 patients identified, 25 accepted individual counseling and 29 planned to participate in a group or class setting. End of life planning opportunities were discovered in approximately 56% of participants (Bischoff, et al., 2023). This program also allowed for assistance to be extended to care givers, of which 27 were contacted and 24 accepted assistance to help with ongoing emotional distress.

### **Prevalence of palliative care in solid organ transplant**

Gustafson & Song, (2020) summarized 20 studies based on the use of PC in solid organ transplantation published between 2002 and 2019. Study designs were variable with 60% observational design, 25% randomized controlled trials, and 15% quasi-experimental. Most studies were adult based with 10% of the articles having a pediatric provider or patient perspective. Overall, the review focused on pre and post-transplant patients and included candidates for liver, lung, heart, kidney and bone marrow. Four studies reported that providers recognized solid organ transplant patients could benefit from PC services and that those services are not contradictory to organ transplantation, Beck et al., (2016), Song et al., (2009), Colman et al., (2013) and Cousino et al, (2019). However, there was difficulty in determining the optimal time to involve PC with greater than 75% stating referral was appropriate when death is imminent. The recognition by providers for early primary palliative care can be hindered by the emotional toll of admitting a possible fatal outcome, resulting in delayed plans for symptom support (Friedrichsdort & Bruera, 2018). Twelve articles provided information on patients in the pretransplant phase, seven looked at use of PC to assist with patient management and decision making, and four articles evaluated use of PC post-transplant.

In a quasi-experimental study completed in 2015 by Bauman et al., early PC was provided as standard care during the evaluation process for liver transplant candidates. Data was collected from 30 participants. Half of these patients showed a clinically significant improvement in symptoms related to depression, likely secondary to improved management of disease-related symptoms (Bauman et al., 2015). This finding was duplicated in the observational study completed by Schwartz, et al., in 2012 in 20 pre-heart transplant patients.

These patients and families reported an increase in quality of life after improved management of symptom burden as a result of PC co-management (Schwartz et al., 2012).

Nolley et al., (2019) completed a retrospective cohort study of 597 adult lung transplant recipients from a single center in Pittsburgh evaluating their use of specialty PC services. Although current guidelines from The American Thoracic Society recommend that PC should be initiated when patients display symptoms of disease (Scully et al., 2022), almost two-thirds of initial specialty PC encounters occurred during the post-transplant phase with 45% occurring during the actual hospitalization for transplantation (Nolley et al., 2019). In the first two years following transplant, trends showed a significant increase in outpatient use from 2% to 16% and a noted increase of 23% to 42% in the inpatient environment (Nolley et al., 2019). Review of specialty PC in this population has shown most referrals occur near the end of life. Nolley et al., highlighted two previous studies of lung transplant centers based in the United States. One study reflected a referral rate of about 3%, and the other showed only 24 of 600 lung transplant recipients received PC services within their 16-month post-transplant period. Most referrals were completed in the patient's last 30 days of life (Nolley et al., 2019).

A pediatric study by Hollander et al. (2017) reviewed charts from 23 deceased heart transplant recipients. Patients ages ranged from two years to 20 with the median age at time of death of twelve. Approximately three children experienced an at-home death with the remaining 20 children dying in a hospital setting, most commonly an intensive care unit (Hollander et al., 2017). Most children experienced aggressive, life-sustaining care within their last day of life, including intubation, mechanical support or dialysis. Palliative care was only included in one-third of these cases and consultation occurred during the patient's last hospitalization (Hollander

et al., 2017). These findings are consistent with adult-based studies that reflect late and insufficient use of PC expertise in the solid organ transplant population.

Fisher et al., (2023) completed a prospective cohort study on the frequency of PC utilization in pre and post kidney adult transplant patients between 2008 and 2020. Investigators completed chart reviews for evidence of PC involvement in 2575 kidney transplant candidates and 1233 kidney transplant recipients. Greater than 70% of candidates and recipients were receiving dialysis and more than 50% had a diagnosis of physical or cognitive impairment (Fisher et al., 2023). Only 4.2% of candidates and 5.1% of recipients had evidence of PC involvement during their chart review (Fisher et al., 2023). Those transplant candidates with a higher mortality score influenced by comorbidities showed a higher probability of PC engagement.

**Summary:** There is evidence in the literature of the benefits of PC in the solid organ transplant population, both prior to and after transplant, with the largest body of evidence in the lung transplant community. PC utilization has shown a benefit to patients and families in relief of symptom burden and reported improved quality of life. Referrals to PC in this adult and pediatric population is inconsistent and often late, near the patient's end of life.

### **Problem Statement**

Despite mounting evidence that early involvement of palliative care can improve quality of life, increase patient satisfaction and reduce hospital costs, significant barriers continue to exist that prevent appropriate utilization. A Midwest academic health center lacks support for families of chronically ill pediatric patients with decision making including end-of-life care, specifically families of children receiving solid organ transplantation. This is due in part to lack of pediatric palliative care services as well as practice models and beliefs that undervalue

utilization of primary palliative care principles. There is an opportunity to improve utilization of primary palliative care skills in the pediatric solid organ transplant population to increase resources to facilitate decision making conversations with families and their care teams.

### **Theoretical Framework**

Kurt Lewin was a 20<sup>th</sup> century German psychologist who studied human behavior and is known for his Planned Change Theory. Lewin's Change theory recognizes change as a complex process that may involve conflict and complications but ultimately through effective group dynamics, can leave organizations to sustainable and successful change. Using a block of ice as a visual example of change, Lewin describes three stages, unfreezing, movement and refreezing (Juneja, 2022). In the first stage unfreezing, the focus is on recognition and understanding of the need for change through effective communication and a sense of urgency. Activities should promote evaluation of the current state and motivate individuals toward a desire for change. During movement, the transition begins, and changes are implemented. Consideration must be given for the uncertainty and fear that accompanies change, and support must include communication and encouragement (Juneja, 2022). The final stage is refreezing. Here, the change becomes normative, and a new state of equilibrium is established. This new state may be supported with policies and procedures and should include employee recognition through positive reinforcement. See appendix A for the three stages of change and planned action steps.

### **Methods**

#### **Design and Setting**

This quality improvement project was implemented over a six-week period with a convenience sample of families with pediatric patients who were admitted under the care of the

SOT team in the pediatric and pediatric intensive care units at a large, urban academic health center in the Midwest. Caregivers were given a letter of invitation explaining the quality improvement project and asking for their voluntary participation (Appendix B). Inclusion criteria included caregivers that were mothers or fathers, at least 19 years of age, and able to speak and read the English language. All patients remained hospitalized at least two days after initiation of the project.

### **Lewin's Movement**

Stakeholders and a core leadership group were identified to serve as change agents. This group included a pediatric nurse practitioner (PNP), a PC physician, the unit nurse manager, child life staff, the transplant social worker, bedside registered nurses, a physical therapist and a lead nurse. One of the bedside nurses changed roles within the institution but continued to participate in the core group as her new role was as a member of the pediatric leadership team. These members served as experts and references to staff and families during the process.

A PowerPoint presentation describing the implementation plan, gaps in PC support for SOT patients and families and national trend data was created and shared with the core leadership group. The Go Wish Together conversation tool was reviewed with team members and questions on implementation were answered. Additional conversations occurred during this meeting discussing pediatric end of life situations experienced at Nebraska Medicine which further highlighted the need for this project. After this initial meeting, the core group was given a list of the Go Wish Together cards via email. By vote, cards that were considered to be outside the scope of this project were omitted. This final version of the Go Wish Together tool was utilized for this quality improvement project. Information to additional staff was completed by word of mouth. The PowerPoint presentation was adapted and provided to the Solid Organ

Transplant Team (SOT) via email. An in-person discussion was completed with the service line chief in order to ensure his knowledge of the project.

### **Instrument**

The Go Wish Together conversation tool was adapted and piloted by Dr. Meghan Potthoff from the original adult-based Go Wish Game. This tool was developed in 2007 by Dr. Elizabeth Menkin and the Coda Alliance to increase discussions related to end-of-life care and support a more peaceful death (Potthoff, 2015). Because scales and ranking systems were determined to be too limiting and not reflective of needs, a card game was developed that included individual goals (Potthoff, 2015). After review of pediatric PC literature and evaluation of the tool by pediatric and pediatric PC experts, the 41-cards were modified to reflect recommended grammatical changes. There were no recommendations to delete or add concepts or subjects. The Go Wish Together tool was reviewed by the interprofessional team serving as change agents to identify cards most appropriate for the SOT team patients. Once the group agreed on a final modified version of the cards, the project lead reviewed these with the SOT team to ensure agreement for implementation. The original version of GO Wish Together tool with modifications as utilized for this project can be found in Appendix C.

### **Procedure**

The nurse practitioner (NP) approached qualifying families and introduced the project. They were given a copy of the invitation letter at that time and questions were answered. If interested, the NP scheduled a one-hour block of time that day to initiate the process. Meetings were held in the location preferred by the caregiver, whether that was at the child's bedside or in a private room away from the child. Each family received their own deck of cards to keep after the initiation process was completed. Sticky Notes with the words "very important", "somewhat

important” and “not important” were provided as category titles. The NP read each card out loud as it was being shown to the caregiver. No additional information or explanation was given concerning the card's content or meaning. Caregivers directed the NP to place the cards beneath the desired category titles. In the end, if the category “very important” contained more than three cards, caregivers were asked to prioritize their top three. Caregivers were notified that the priorities could be modified at any time at their request. Additionally, if priorities were believed by the NP or other staff to be met, a discussion was initiated with the caregiver in an effort to prioritize additional needs. A DOT phrase was developed in the electronic medical record (EMR) to document participation in the project and communicate family wish priorities. Once the top three priorities were identified, additional discussion occurred to ensure parents’ interpretation of the goal would be communicated. The participant’s exact language was utilized when possible. The top three wish priorities were placed on a “sticky note” within the EMR as a reference for all team members who cared for the patient. The EMR reflected participation in the project within two hours of implementation.

Because of the nature of SOT rounds, there was not a consistent opportunity to highlight family goal priorities with the large group. If there was no prior opportunity, discussions were initiated by the NP at a different time other than rounds with disciplines who had the greatest influence over a particular priority. If the caregiver was not present, a follow up conversation occurred with them in order to provide them with an updated plan. The core group met every 2 weeks during the implementation phase. Summaries of meetings were provided via e-mail to the group in order to keep everyone updated.

Data collected included patient age in months, whether the patient was pretransplant or post-transplant, role of caregiver and acuity of patient. A chart was created to record which cards

were placed in which categories and if the wild card was utilized. At the end of the six-week period, nursing and ancillary staff were invited to participate in two focus groups to explore perceived benefits from the Go Wish Together project and barriers experienced during the project. A script was utilized to ensure consistency with questions (Appendix D). The focus group meetings were recorded, transcribed verbatim, and a thematic analysis was completed. Wish priority data and focus group feedback was provided to nursing staff and the SOT.

### **Ethical Implications**

Documents were completed and submitted for IRB approval through Nebraska Medicine. Nebraska Medicine IRB deemed this project quality improvement. Following this, the documentation was provided to Creighton University for approval. Ethical standards were maintained throughout the project.

### **Results**

All caregivers who were approached agreed to participate and expressed appreciation for the opportunity to discuss their goals of care. Eight families participated in the project. Ages of children ranged from 11 to 204 months ( $M=116.9$  months,  $SD=77.9$ ). Seventy-five percent of the patients were in acute care status, 12.5% were progressive and 12.5% were critical. Most caregivers were mothers, 63% and 37% were fathers. A summary of demographics can be found in table 1.

Table 1: Demographics

Variable (N=8)	Frequency (%)
<b>Transplant Status</b>	
Pre	2 (25%)
Post	6 (75%)

Family Member	
Mother	5 (63%)
Father	3 (37%)
Acuity Level	
Acute	6 (75%)
Progressive	1 (12.5%)
Critical	1 (12.5%)

A total of 50% of caregivers used the wild card and 50% of these prioritized this subject as a top three option. Examples of topics that the wild card was used for included mobility and rehabilitation, consideration of the stress and trauma families have undergone, and that pain needs of the child be addressed from the mother's perspective. The patient of the caregiver who expressed a desire for care to be provided according to the mother's wishes was 17 years of age. Cards 21 (For my child to be free from machines) and 35 (To manage appetite changes and nutrition plans for my child) were the most frequently categorized in the very important category and were most frequently categorized in the top three. Families expressed a desire for their child to be "untethered" from cords and machines in order to participate in "normal childhood activities". Table 2 summarizes the cards frequently placed in "most important to me pile" and "not important to me pile". A summary of all card distribution can be found in Table 3.

Table 2: Top 3 cards by pile

MOST IMPORTANT TO ME		Frequency
Card 21	For my Child to be free of machines	6
Card 33	To identify and honor my child's wishes	4
Card 35	To manage appetite changes and nutrition plans	4
NOT IMPORTANT TO ME		
Card 2	Minimize arguments within our family r/t care decisions	6
Card 6	To have spiritual or faith based advisors available	6
Card 31	To identify who will manage my child's pain and symptoms	6
Card 38	To define my child's primary caregivers role	6

Table 3: Frequency by Card

Card Number	Card Topic	Frequency			
		Top 3	Most Important	Somewhat Important	Not Important
1	My relationship with my spouse or significant other To minimize arguments within our family related to care decisions	0	0	3	5
2	My fear of my child having an event when I am not there	0	3	2	3
3	To maintain memories of my child	0	1	3	4
4	To manage respiratory symptoms for my child	1	2	0	5
5	To have spiritual or faith based advisors available	0	1	1	6
6	To manage my child's mood and behavior changes	2	0	4	2
7	To involve my child in communication about their illness	0	3	1	4
8	To manage nausea, vomiting and/or constipation for my child	1	1	1	5
9	Wild card	2	2	0	4
10	To have decision making support	0	3	2	3
11	To define what my child can safely participate in	2	0	2	4
12	To communicate with my child about death and dying	0	2	1	5
13	My fear of talking about death	0	1	3	4
14	To address financial concerns	0	2	2	4
15	To talk about what scares me related to the care of my child	0	1	3	4
16	To prepare siblings for events ahead	1	2	1	4
17	To discuss my fear of leaving my child now	0	1	2	5
18	For my child to be free from machines	4	2	1	1
19	To discuss emotional support services available to me	0	1	2	5
20	Communication with my child about what to expect	1	2	1	4
21	To address my anxiety	0	2	3	3
22	To discuss my child's illness and the impact on my work	0	1	3	4
23	To provide support services for siblings	1	2	1	4
24	To manage my child's sleep/fatigue issues	2	0	4	2
25	To define my specialist's role in caring for my child and family	0	1	1	6
26	To identify who will manage my child's pain and symptoms	1	0	2	5
27	To write down my goals and wishes for my child	0	2	2	4
28	To identify and honor my child's wishes	0	4	3	1
29	My ability to provide care for my child	0	1	3	4
30	To manage appetite changes and nutrition plans for my child	4	0	3	1
31	To have an advocate who knows my values and priorities	0	3	3	2
32	To discuss options for bringing my child home	1	1	4	2
33	To define my child's primary caregiver's role	0	0	2	6
34	To discuss pain management options for my child	1	2	2	3
35	To maintain independence as a family	0	2	4	2

## Qualitative Results

In addition to completing quantitative analysis of the card distribution, focus groups were conducted with the interprofessional staff team to evaluate perceived benefits and barriers to utilizing the Go Wish together conversation tool with the PSOT team. During the analysis of the staff focus groups which was completed with Intellectus Software (2024), three themes emerged including Communication and Care Customization, Opportunities for improvement, and barriers to implementation.

*Communication and Care Customization*

The theme of Communication and Care Customization helps answer the research question by highlighting how Go Wish Together in a SOT unit facilitates meaningful communication between patients, families, and healthcare providers. Through the tool, individuals can discuss their values, preferences, and priorities regarding their end-of-life care, leading to more personalized and patient-centered care plans. This theme underscores the perceived benefits of enhancing communication and tailoring care to meet the unique needs and wishes of patients in the SOT unit.

Supporting excerpts for the theme are included below.

It was a really good avenue for communication just because it helped to introduce more things that the family might be uncomfortable bringing up on their own.

I think even just being there and seeing how different families prioritize things was helpful. I think it can help in relating to them a lot better and focusing your care on the things or bringing your attention to the things that they have said are a priority to them

I think that it is opening a holistic care dialogue that was not previously there.

It definitely started the conversation about priorities for the patient and for the family.

**Table 4 Communication & Care Customization Excerpts**

Code	<i>Number of Excerpts by Code</i>
Customizing Care to Patient and Family Priorities	5
Enhanced Communication and Holistic Care	3

*Opportunities for Improvement*

The theme "Opportunities for Improvement" within the perceived benefits of Go Wish Together in a SOT (Solid Organ Transplant) unit can help answer the research question by highlighting areas where participants believe the program can be enhanced to better meet their needs and preferences. These suggestions can provide valuable insights into specific aspects of the program that may not be as effective or engaging as intended, allowing for targeted improvements to be made based on participant feedback. By addressing these suggestions, the overall impact and effectiveness of Go Wish Together in a SOT unit can be enhanced, leading to a more positive experience for participants and potentially better outcomes in terms of communication, coping, and decision-making in the context of supportive transplant care.

Supporting excerpts for the theme are included below.

I think that maybe only having the nurse who sees it on the sticky note is a little bit of a barrier and we need to make it more visible to the team.

Staff awareness and education is necessary to ensure everyone knows what it is and that it is a priority for the team. Then everyone will be more likely to make it a priority.

There needs to be a way to bring it more to the surface with the whole multidisciplinary team; to help us all be on the same page and work together to meet those goals.

**Table 5 Opportunities for Improvement Excerpts**

Code	<i>Number of Excerpts by Code</i>
Ongoing Staff Education and Communication	2

### *Barriers to Implementation*

The theme of "Barriers to Implementation" helps answer the research question by identifying and examining the factors that hinder the successful implementation of the Go Wish Together program in a SOT unit. By exploring and understanding these barriers, such as lack of staff training, resistance to change, or logistical challenges, researchers can provide insights and recommendations to address these obstacles and improve the overall effectiveness of the program in the SOT unit.

Supporting excerpts for the theme are included below.

I would just think a barrier is just that it's just this initial group right now. I think that once this is spread to everybody it will be better implemented.

I know people are asking questions and they see it, but once it's really kind of explained to them and that these are this family's and patient's priorities then it will change that and make it a lot better. The fact that everyone has not been made aware of the project I would think is probably just the big barrier right now.

Not everyone is super aware.

**Table 6 Barriers to Implementation Excerpts**

Code	<i>Number of Excerpts by Code</i>
Lack of Awareness and Understanding Among Staff	3

### **Discussion**

Knowledge of family needs and priorities allows caregivers the opportunity to provide a more holistic care environment and family members the opportunity to have a greater impact on the care their family receives. It is important to note during this project, the variability of card selection as no card was considered to be a priority by all families and no card was considered to be "not important" by all families. This finding highlights the need for providers to engage in conversations that can uncover the unique needs and concerns of families and patients despite their common diagnosis. The conversations from this project were enlightening and provided

significant insight into each individual family. Most meetings occurred within an hour, however 30% took additional time. These meetings were more emotional and included longer more in-depth discussions about the child's illness and family experiences. While the cards had short phrases, they prompted deeper discussion and opportunities to open shared conversations. For example, one family who highlighted the need for assistance with siblings involved use of the educational staff. After meeting with the mother, they were able to develop a tailored plan and approach utilizing available community resources for a family member with a developmental disability. Additionally, they implemented use of a communication tool the team felt would be effective in helping the mother guide the sibling in appropriate interactions with the ill child. This example is consistent with results found by Sedig et al., (2020), highlighting the significance of parents' need for providers to assist with situations affecting quality of life of the child and other family members outside the hospital environment. Additionally, shared conversations improve communication related to patient care by providing insight into family perspectives that lead to improved decision-making abilities for clinicians and can help to shape health care policies (American Academy of Pediatrics, 2012).

Additional discussions included descriptions of near-death experiences as well as positive stories about home life. Consistent with findings from Van Scoy et al., (2020), use of a conversation tool such as the Go Wish Together card game can overcome negative barriers associated with death and dying discussions. These games can result in positive interactions that include laughter and learning and have the ability to create a safe non-threatening environment that facilitates difficult conversations. Feelings related to loss of control due to the hospital environment was apparent in the longer discussions. This was the most common parental experience noted in focus group discussions completed in 2020 by Sedig et al. Additionally, parents expressed a genuine appreciation for having the opportunity to express their goals and have these things considered by the medical team.

Although not in the top three, other issues were addressed if there were known resources for them. These were issues related to completion of paperwork for FMLA as well as providing resources to assist with financial needs, mental health and medical care for parents. Uncovering the need for assistance with employment paperwork was a surprising finding because there is a dedicated social worker as part of the team. This further highlights the importance of ongoing conversations about broad subject matters since we know family needs can change during the patient's hospitalization, especially if it is prolonged as is the case for many of our patients. Unmet parental medical and mental health needs are not entirely unexpected since the majority of our families do not live in Nebraska and as a result don't have a local primary care provider. This may be an opportunity for the SOT to develop a more robust list of resources or a collaborative relationship that can help meet these specific deficiencies.

To meet the priority "For my child to be free from machines," discussions occurred with nursing staff focusing on appropriate non-invasive monitoring of patients. This resulted in increased patient mobility and freedom from cords that can tether a child to their bed or crib. Additionally, plans were made with transplant team dieticians to provide time off total parenteral nutrition and enteral feeds when clinically appropriate. Modification of these diets provided interventions to address concerns related to freedom from machines by allowing freedom from tubing that can restrict mobility as well as the frequently seen priority "To manage appetite changes and nutrition plan". The need to address nutritional needs in relation to psychological health and have access to specialists were two new areas of focus that also emerged as important (Virdun et al., 2020).

The least prioritized cards were numbers 2 (To minimize arguments within our family related to care decisions), 6 (To have spiritual or faith-based advisors available) and 38 (to define my child's primary caregiver's role). Of the families surveyed, the participating parents expressed that care decisions primarily rested with them. Use of a sticky note within the EMR to

communicate family preferences was a well-received plan by families and served as a reference for staff caring for the patients. The importance of a standardized method of communication is supported in findings by Bennardi et al., (2021). Collaboration of care and in this case, support of parental priorities can be positively affected through the use of electronic communication.

During focus group discussions, staff reported use of the tool allowed families the opportunity to discuss broader care topics including uncomfortable subjects that likely would otherwise not be discussed and empowered them to participate in contributing to the health of their child. Although not all, some staff also expressed that knowledge of family priorities helped them tailor the care they provided. This is reinforced by findings from Moller et al., (2020) who reported the lack of such conversations removes the possibility of providing patient specific care, acknowledging the variability of patient and family needs. Additionally, staff expressed a belief that the tool had the ability to improve staff-parent relationships and decrease family feelings of powerlessness. Barriers to effective implementation reported in focus groups highlighted limitations related to use of the EMR as this was felt to lack visibility and prevented staff from keeping priorities as a focus, not achieving total staff orientation of the quality improvement project hindered opportunities by all staff to support family goals and absence of opportunities to embed family preferences into daily care discussions prevented collaborative care. There was also recognition that high patient volume and acuity negatively impacted recruitment of new members, raising the questions of by whom and when the tool should be introduced.

### **Limitations**

This project encountered several barriers throughout the implementation process as well as some limitations related to timing and scope of the implementation. The original timeline for implementation was altered due to delays from IRB approvals and staff training, this resulted in a shorter implementation window. There were no patient status changes so no re-evaluation of priorities occurred. Although communication was provided on the QI project to the SOT, there was a lack of feedback and involvement from leadership. The small sample size limits the possibility of applying broad generalization.

### **Future Implications and Sustainability Plan**

In discussing future use of the tool, acknowledgement of the limited use of palliative care by the solid organ transplant community was highlighted. This is a significant reality that has implications for continued use of this tool and will impact the ability to make a lasting change. The optimal time of introduction needs to be determined as well as methods to elevate communication around family priorities. Data will be reviewed and additional nurse practitioners within the SOT will be trained on use of the tool and the implementation process. Training will also be offered to PC staff at the direction of the physician champion. Total buy-in from the SOT will need to be secured since success of the process involves a change in rounding focus which includes embedding family centered goals into the discussion. Additionally, initiation of the tool may require utilization of SOT specific ancillary staff. There will need to be either monetary support to obtain a physical tool for every family or considerations for the creation of an electronic version. It will be important to incorporate use of this tool with staff members, possibly during the time of orientation. This will require support from the institution, possibly including policy creation and staff support for development of an electronic version. Financial support from a local foundation with a history of partnership in support of pediatric focused quality improvement projects may also be explored.

### **Conclusion**

Families of pediatric patients who receive care at Nebraska Medicine under the SOT need resources and support that can be attained through use of primary palliative care skills. A focus on family-centered goals proved to be welcomed and beneficial in helping highlight family challenges and gaps in support that exist not only within the hospital environment, but within the larger context of these families' lives. Use of the conversation tool allowed an opportunity for caregivers to discuss their experiences and receive resources that otherwise would not have been addressed. Many discussions were emotional and included tearful descriptions of their experiences. The most common priorities were to eliminate unnecessary monitoring and therapies that would result in freedom from cords, lines and machines. Positive feedback by families was provided to nursing and ancillary staff, noting an appreciation for a focus on caregiver goals. Staff expressed an

appreciation for the opportunity to have families express their priorities and include them in the focus of care. Mobility and rehabilitation are a significant issue in this population due to prolonged hospitalization. Having this as a suggestion would likely result in many families selecting this as a priority of focus. Continued use of this process should be supported by widespread, cyclical education of staff who care for these families. There should be careful consideration of who is best prepared to introduce the tool and when the tool should be introduced, acknowledging the use of inpatient clinical care staff has limitations related to prioritization of acute patient care needs. Utilization of ancillary staff such as social workers, child life staff, or nurse coordinators may be a solution to this challenge. Additionally, there should be time allowed, at least weekly, during rounds to highlight family-centered goals of care.

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## APPENDIX A

## LEWIN'S CHANGE MODEL

## UNFREEZE



- Attend staff meetings and provide PP presentation.
- Recruit and secure change agents.
- Present PP to SOT surgeons and explain plan for implementation.

## MOVEMENT



- Project leader or MD champion will initiate tool w/in 72 of admission for patients on the SOT service.
- Dot phrase will be developed and utilized to document occurrence and wish preferences in EPIC.
- Wish preferences will be placed on a "sticky note" to be seen by all who care for the patient.
- Wishes will be revisited as soon as possible with a significant change in patient status and upon family request.
- Core group will meet every 2 weeks for 3 months. Data will be collected summarizing wish priorities from families. Conduct focus groups at end of 3 months.
- Provide wish priority data to nursing staff at monthly staff meetings.
- Provide focus group results and wish priority data to SOT surgeons and nursing staff at end of 3-month period.
- Evaluate barriers to further implementation and modify process accordingly.
- Develop a plan to maintain supply of the tool.
- Provide training on use of tool to APRNs within the SOT team and PC staff under the direction of the physician champion.

## REFREEZE



- Initiate use of tool with every SOT patient admission.
- All SOT APRN members will be utilized to initiate tool.
- Continued use of dot phrase in EPIC to document occurrence.
- Evaluate process every 6 months for first year.
- Attend staff meetings monthly the first 3 months then every other month for the first year to receive feedback and track barriers.
- Provide updates on tool progress, effect on patient care, care environment and other notable measurable trends to SOT surgeons and staff monthly for the first 3 months then quarterly for the first year.

## Appendix B

Participant Recruitment Letter

IRB Protocol #2004831-01  
Pediatric Go Wish Together for Solid Organ Transplant

### **Invitation to Participate in Go Wish Together Quality Improvement Project**

To: Parents to children currently hospitalized at Nebraska Medicine under the care of the Solid Organ Transplant Team

My name is Trudie Owens. I am a Pediatric Nurse Practitioner and student working toward completing my Doctorate at Creighton University. The purpose of this quality improvement is to improve the complex care of patients and families of the pediatric solid organ transplant (SOT) team by focusing on patient and family- centered goals of care using primary palliative care skills and the Go Wish Together conversation tool. We know that good communication is essential to providing excellent care. The Pediatric Go Wish Together conversation tool will allow parents to set their priorities for their child and family while receiving specialized inpatient pediatric care.

I would like to extend an invitation for you to participate in this quality improvement project to explore the needs of parents receiving care under the Pediatric Solid Organ Transplant Team. If interested, please notify me so I can schedule a time to meet with you.

I thank you for your time and consideration.

Respectfully,

Trudie Owens, APRN, NP  
DNP Student, Creighton University  
Pediatric Nurse Practitioner, Nebraska Medicine  
402-559-5000

## Appendix C

Pediatric Go Wish Together Cards for QI project

- 1- My relationship with my spouse or significant other
- 2- To minimize arguments within our family related to care decisions
- 3- My fear of my child having an event when I am not there
- 4- To maintain memories of my child
- 5- To manage respiratory symptoms for my child
- 6- To have spiritual or faith based advisors available
- 7- To manage my child's mood and behavior changes
- 8- To involve my child in communication about their illness
- 9- To manage nausea, vomiting and/or constipation for my child
- 10- Wild card
- 11- Frequency of communication regarding palliative care-REMOVED**
- 12- To have decision making support
- 13- To define what my child can safely participate in
- 14- To communicate with my child about death and dying
- 15- My fear of talking about death
- 16- To address financial concerns
- 17- To define the palliative care team's role-REMOVED**
- 18- To talk about what scares me related to the care of my child
- 19- To prepare siblings for events ahead
- 20- To discuss my fear of leaving my child now
- 21- For my child to be free from machines
- 22- To discuss hospice services-REMOVED**
- 23- To discuss emotional support services available to me
- 24- To discuss an advance care planning document for my child-REMOVED**
- 25- Communication with my child about what to expect
- 26- To address my anxiety
- 27- To discuss my child's illness and the impact on my work
- 28- To provide support services for siblings
- 29- To manage my child's sleep/fatigue issues
- 30- To define my specialist's role in caring for my child and family
- 31- To identify who will manage my child's pain and symptoms
- 32- To write down my goals and wishes for my child
- 33- To identify and honor my child's wishes
- 34- My ability to provide care for my child
- 35- To manage appetite changes and nutrition plans for my child
- 36- To have an advocate who knows my values and priorities
- 37- To discuss options for bringing my child home
- 38- To define my child's primary caregiver's role
- 39- To have a written advance directive for my child-REMOVED**
- 40- To discuss pain management options for my child
- 41- To maintain independence as a family

## Appendix D

How did use of the Go Wish Together tool change the care provided to the patient/family?

Did this tool increase patient/family-centered communication?

If not, were there specific barriers to this?

If so, can you provide an example?

How did the Go Wish Together tool change the care/communication you specifically provided?

What barriers did you observe that prevented effective use of the tool?

What suggestions do you have that could improve the current process?

What barriers do you anticipate that could prevent continued use of this process?