

Effectively using communication to enhance the provision of pediatric palliative care in an acute care setting

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Abstract: The capability of effectively communicating is crucial when providing palliative care, especially when the patient is a child. Communication among healthcare professionals with the child and family members must be clear, concise, and consistent. Use of a communication tool provides documentation for conversations, treatment plans, and specific desires related to care. This paper describes communication theory, portrays the use of this theory to develop a communication tool, and illustrates the use of this tool by multidisciplinary members of a healthcare team to provide pediatric palliative care.

Keywords: palliative care, communication, pediatrics

Providing palliative care in a complex medical environment is challenging; providing this care to children requires specialized knowledge and training (Malloy et al 2007). Humanizing nursing communication theory, as described by Duldt-Batthey (2003), provides a foundation for assuring therapeutic communication happens among nurses and others, within healthcare situations. Solomon and colleagues (2002) have outlined goals for pediatric palliative care. These include enhancing the quality of life for the child and family, minimizing suffering, optimizing functioning and providing opportunities for personal growth. Each of these goals can be achieved by managing pain and other distressing symptoms as well as providing psychological and spiritual care throughout the course of the child's illness. In the United States, several pediatric healthcare facilities have initiated healthcare teams, which provide and coordinate palliative care, when appropriate, for pediatric patients (Carter and Levetown 2004; Children's Hospital and Regional Medical Center 2008). These experts agree that attaining palliative care goals within a complex medical system requires clear, accurate, and appropriate communication. The purpose of this article is to describe communication theory, portray the use of this theory to develop a communication tool, and illustrate the multidisciplinary use of this tool by when providing pediatric palliative care. The Comfort Care Communication Tool (CCCT) depicted in Table 1 was developed in response to the need to provide appropriate, timely, and appreciated care and provides effective communication among healthcare professionals (HCP), the child, and family members.

Communication theory

Previous research has identified ineffective communicating as a barrier which prevents the delivery of consistent, appropriate care (Browning and Solomon 2003; Carter and Levetown 2004). Effective, appropriate communication is particularly important when a child has a life-threatening or life-limiting illness and is at risk of dying. Effective

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Table 1 The comfort care communication tool

Comfort care communication tool (CCCT)		
Patient name:	Prepared by:	First visit:
Length of visit:	Present:	Update:
Primary physician:		
Other physicians:		
History of present illness:		
Medical indications:	Patient preferences:	
Neurological and pain:		
Cardiac:		
Respiratory		
Gastrointestinal:		
Genitourinary:		
Muscular/skeletal:		
Infection:		
Quality of life:	Contextual issues	
Discussion:		
Plan:	Who will do:	By what date:

communication allows the unique medical, psychological, spiritual, and social needs of the child to be known and included in the plan of care.

Clinical relationships within a complex healthcare system require multiple types of communication. Effective communication is dependent upon the ability to gather, assimilate, interpret, discriminate, and share information appropriately. Healthcare settings include many disciplines and hierarchies. Thus, proper communication requires skill, cognition, emotion, and value (Manning 1992). Research has demonstrated that communication skills increase when education is provided (Rosenzweig et al 2007). The skill of the HCP to communicate has been correlated to the capability of the patient to discuss end-of-life issues (Stuart and Knott 2008).

The humanizing nursing communication theory (Duldt-Bathey 2003) emphasizes the interpersonal relationships among nurses and others. These relationships aim to prevent ineffective communication and inappropriate outcomes. Humanizing attitudes, according to Duldt (1997), include feelings and facts. Evaluating interpersonal communication can be divided into feelings and facts, then determined them to be humanizing or dehumanizing. Humanistic communication begins with trust, praise, and eye contact. Information should be presented using clear statements, appropriate words in an authentic style, and maintaining an open posture. Time should be allotted for feedback and synthesis of the information. Dehumanizing communication occurs when demands or commands are given; questions are not answered or belittled.

Information provided in a dehumanizing manner is given in a monologue format, from a distance, with no touching, and without time to process the information or ask questions.

The Nursing Communication Observation Tool (NCOT) developed by Duldt (2000) is designed to evaluate interpersonal communication. Although this theory and tool was developed for nurses, we have found this theory to be applicable to any HCP during a clinical encounter. This tool may be used to provide feedback for the HCP; we have implemented the items within this tool when developing the CCCT. Thus, the link between theory and practice is clear, and the CCCT is theoretically based.

Communication patterns are variable and influenced by many factors. Several factors include style differences, gender, ethnicity, education, previous experiences, stress, fatigue, social structures, perspectives, cultural norms, and denial. Hospital settings are frequently hectic and noisy, with distractions from pagers and phones and interruptions caused by other people and care needs. Combining these personal and situational variables results in a multifaceted communication system, where it is not surprising that communication failures occur.

Sasou and Reason (1997) describes three categories of communication failure. These include: (1) system failure, in which the necessary channels of communication do not exist or are not functioning; (2) message failures in which the channels exist but the necessary information is not transmitted; and (3) reception failure, in which the channels exist, the right message is sent but it is misinterpreted by the recipient or arrives too late. The use of a communication tool, such as the CCCT, will minimize the occurrence of these situations, which carry dire consequences to these children and their families.

Comfort care communication tool

Each member of the PACCT multidisciplinary team must use excellent communication at all times. This is especially critical when information is being gathered to place in the CCCT. The CCCT document the outcome of conversations which are care goals. Completion of this tool follows the recommendations of Duldt (2000) by first communicating facts, in a trustful dialogue. Sharing health information prevents the need for children and family members to repeat information and minimizes chances that a HCP will be unaware of the desires of this child. Patient preferences are listed within the CCCT, minimizing the ability of any HCP to judge, disagree, or questions these preferences. The CCCT is initially presented at a patient care conference, in which

members of the healthcare team, family members and the child, when appropriate, are present. The goal of this meeting is to outline a plan that will provide (1) medical information, (2) what is quality of life for the child, (3) the contextual picture of the child's life, (4) care that is best for the child, (2) care that meets the needs of the family, and (3) care that is agreed upon by the healthcare providers.

The CCCT was modified from the Decision Making Tool (DMT) framework developed by the Pediatric Palliative Care Consulting Service at Children's Hospital and Regional Medical Center in Seattle, Washington (2008). This tool, used for guiding ethical decision making, is derived from the ethical "four box" method developed by Jonsen and colleagues (1998). Originally, the DMT was used by the PACCT, but feedback indicated that the title with the word "decision" in it was intimidating to the child and family members. Although it is recognized by the healthcare professionals that decisions may need to be made, the name was changed and the meeting is called a conversation.

The CCCT provides a format to document the wishes, hopes and desires of the child and his or her family members within four quadrants. The medical quadrant includes information about the disease, its expected trajectory, treatment and anticipated effects. This is generally completed by the primary care physician. The quality of life quadrant documents activities that make the child happy and what is important to the child. These may be toys, activities or visits from significant people. Information from the nurse and child life specialist is placed here. The contextual quadrant provides healthcare providers with information about the child and their family life when not hospitalized. This quadrant also describes their beliefs and values, insurance support and use of social services. The social worker and chaplain provide much of these data. The preference quadrant documents family choice with respect to the use of life support measures, preferred location if death is imminent and other specific requests. While each HCP provides input for this section, the PACCT nurse is responsible for assuring these topics are discussed.

The pediatric advanced comfort care team

The PACCT was developed and implemented at Children's Mercy Hospital and Clinics (CMH) in 2004. The goal of this team is to integrate palliative care services throughout the hospital (Ward-Smith et al 2007). PACCT services are not appropriate for children with a cancer diagnosis, for the oncology division has specific mechanisms in place.

This pediatric hospital is 260 bed tertiary healthcare facility located in a major Midwest metropolis in the United States. The PACCT model uses registered nurses to establish a multidisciplinary team from within the child's primary care team. A PACCT consult may be offered to any child with non-hematology/oncology life-threatening illness who is at risk of dying within five years. Once consulted, the PACCT nurse will follow the patient along with members of the multidisciplinary team throughout the child's illness.

Each member of the multidisciplinary team may provide data for the CCCT. In fact, the CCCT is most successful when many of the multidisciplinary team members, along with the primary physician, obtain data. Using humanistic communication and open ended questions, the knowledge, communication preferences, hopes, fears, joys, and desires are described. In general, this conversation begins by asking what is understood about the illness and how this impacts quality of life. Additional information may be gathered randomly, as appropriate, but it is the responsibility of the PACCT nurse to ensure that all areas of the CCCT are covered and to organize the information within the appropriate quadrant of the CCCT.

Multidisciplinary team

Each member of the PACCT nurse-directed multidisciplinary team uses humanizing concepts during conversations with the child and family. The use of these concepts acknowledges and validates the reality of the situation, yet allows the child and family to list their preferences. Thus, although the reality of a life-threatening illness and the possibility of the death cannot be altered, the focus is on the preferences related to life and the quality of that life. There is a need in healthcare to provide good communication which includes reflection and clarity of information, yet acknowledge feelings and preferences for decisions, without judgment. Each team member of PACCT brings their individual attitudes, skills, and patterns of interaction to each situation. However, each member also recognizes that communication is a human process and each person has her or his part to play within the central tripod of communing both with the child and family and within the interdisciplinary team. Focusing the communication by using humanistic language decreases personalization of any decision and keeps the communication targeted toward the care goals for the child.

The primary care physician remains in charge of the child's care and the child is not transferred to another hospital unit. A decision at CMH was to not implement a specific palliative care unit, but rather to allow the child to

remain receiving care from the unit and/or clinic they have been associated with. This eliminates the stigma attached to a palliative care unit, provides continuity of care and educates all HCP on palliative care principles. Thus, care is coordinated by the PACCT nurse, in consultation with the primary care physician.

Multidisciplinary team members

PACCT nurse

Once a referral is received, the PACCT nurse reviews the chart, initiates contact with the attending primary physician and identifies appropriate allied health professionals. Typically, the PACCT nurse is not known to the child or his or her family prior to this consult. It is the responsibility of the PACCT nurse to establish the multidisciplinary team that will coordinate and provide care. Each team will include a physician, PACCT nurse, social worker, and chaplain, with additional HCP added as indicated. If the child and family are known to any HCP, the aim is for that HCP be a member of the PACCT team for the child, as this provides continuity to care. During the PACCT nurse's initial conversation with the child and family, the PACCT program is presented, anxieties are addressed, the understanding of the child's medical condition are assessed and hopes and dreams are identified.

Humanizing conversation requires that the PACCT nurse be truthful when presenting palliative care as an option, allow the child and family time to process the information, be understanding about their situation and provide an environment where it is acceptable to grieve and cry. Personal agendas or opinions are not appropriate and the conversation needs to focus on the child as a person. Discussion about the burden and risk of treatment options should be discussed, for this concept often delineates 'whom' the intervention is 'for'. Separating interventions which are 'for' the child from those that are 'to' the child is the first step in making appropriate decisions. Written information about the PACCT program is provided for the child and his or her family members, along with contact information, should PACCT services be desired. The decision to use a palliative care approach is made by the child and family and assurance that whatever the decision is will be supported.

Social worker

At CMH, social workers are assigned to specific sections or units throughout the hospital. In many instances the social worker associated a PACCT multidisciplinary team will have had contact with the patient and family prior to PACCT involvement. This previous association usually surrounds

specific and often special needs for the child. This relationship provides an opportunity to develop a relationship with the child and family that is non-threatening and respectful. Once it becomes apparent that PACCT may be appropriate, the social worker may support the medical facts that result in palliative care becoming an option. Using humanizing behavior, the social worker may make suggestions, point out the fact that going home may not be feasible, and allow the child and family to make realistic choices. Once the PACCT becomes involved, the social worker has the unique challenge of balancing tasks necessary to provide appropriate care when the goals have been altered. The use of humanizing communication allows the child and family to grieve, vent and express concerns. Not responding with dehumanizing, judgmental, and negative feedback is most important. If the child or family outlines a discharge plan that is not feasible, coaching, supporting, and trustful dialogue will allow these plans to be altered which can lead to positive decision making.

Chaplains

At CMH, each full-time chaplain is assigned to specific hospital units, thus a chaplain may have a relationship with the child and family. At CMH, the role of the chaplain extends beyond particular religious practices and includes exploring a wide range of spiritual dimensions. Beyond religion, the chaplain can provide guidance as the child and his or her family members explore other spiritual dimensions. These may include thoughts about the divine, other or greater power, and the meaning of the child's illness. Using humanistic communication, the chaplain would ask "Where do you see God in all this?" or "Who are you able to talk about with these kinds of things?" rather than asking "what do you think about God?" Using open-ended questions which are neutral allows the conversation to be directed by the child or family, and avoids personal opinion. The chaplain helps the child and family identify their strengths, what gives them peace, their hopes, and their goals. Addressing quality-of-life concerns, the chaplain may describe life with continuous ventilator support, or the need for constant pain medication. Hospital-based chaplains are experts at combining medical decision-making with religious or spiritual goals. Understanding the context in which treatment decisions are made, and documenting these within the CCCT eliminates the need for the patient and family to amortize their decisions to each HCP.

Child life

As a member of the healthcare team, the child life specialist provides a positive experience within the hospital setting

for the patient and family. If the child has had repeated, or lengthy hospital stays, the child life specialist may be known. In nonpalliative care situations, the child life specialist uses therapeutic play to educate patients about their illness or injury at developmentally appropriate levels. One example of therapeutic play that is unique to child life specialists is the use of medical play. Medical play is child directed and utilizes blank cloth dolls which provide the patients to manipulate medical equipment and provide a self expressive activity. When a member of the PACCT team, the child life specialist may use therapeutic play to guide conversations between the child, their family, and any HCP. The use of medical play can identify misconceptions about illness, procedures and information. The child life specialist can offer parents, other caregivers and any HCP suggestions on how to communicate with the child using appropriate language and including individual needs for the child.

Providing care Ongoing visits

While a child is receiving inpatient care, PACCT services consist of daily visits from the PACCT nurse. These visits vary in length and content and are dependent upon the health condition of the child. The content of these visits may include answering healthcare-related questions, allowing the parent/guardian to talk about their child or just to vent their feelings and frustrations. The PACCT nurse actively listens to what is said and what is not said. Sitting silently as a family member expresses psychological suffering is one of the most powerful moments in humanistic communication. Intimacy is established in these moments, a concept which must be honored before a deeper trust can develop. Any conversation which involves sadness and suffering needs, if possible, to end on a note of hope. The other members of the multidisciplinary team will visit with the patient and family as needed.

Once the first three quadrants of the CCCT have been discussed, the PACCT nurse will approach the preference quadrant with a statement such as "I know you will want to minimize pain and suffering. Can you share with us some of the instances when this may apply?" The conversation for this quadrant defines preferences and outlines methods for reaching the child's potential. Finally, family members are asked if they understand what cardiopulmonary resuscitation (CPR) and other life support interventions are. These interventions are explained and questions are answered. A decision regarding what life support interventions the family might want may not be appropriate at this time. Many families have

thought about these issues, and may be capable of sharing preferences, such as not wanting a tracheostomy or desiring long-term ventilator support. The family is encouraged to share a story, hope or dream for the child as the conversation comes to an end. Each member of the multidisciplinary team provides support and acknowledges the difficulty of having to face life changing situations.

Once this conversation is concluded, the CCCT is completed and transferred into a word document by the PACCT nurse. A copy of this document is given to the child, when appropriate, and a family member. They are encouraged to review the document, make changes when necessary and give the form to the primary care physician. Once all revisions are made, the form is signed and distributed to the child and/or his or her parents, the primary care physician and placed in the medical record. The parents are encouraged to carry the CCCT with them, so it is available to an HCP within and outside of CMH. Thus, the CCCT describes the stated goals for the child. This minimizes miscommunication and eliminates communication errors as the result of message or recipient failure. The initial CCCT becomes the basis for ongoing discussion regarding the child's life and reflect the journey. It becomes a "snapshot" of whom the child is and a long term guide for providing appropriate care. The CCCT is updated as needed, especially when there are subsequent hospitalizations and/or changes in the child's medical conditions and/or preferences.

Clinical implementation

Providing pediatric palliative care which enhances quality of life and minimizes suffering requires effective communications among the child, family, and HCP. Recognizing that communication style differences exist, the CCCT bridges that gap and provides latitude for these differences. Use of the CCCT facilitates communication among all individuals affected when a child requires palliative care. Its use provides appropriate, timely, and valued care is delivered.

Disclosure

The authors report no conflicts of interest in this work.

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