Theory Connections

An emerging theory on parental end-of-life decision making as a stepping stone to new research

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Pediatric bone marrow transplant (BMT) is an aggressive medical treatment associated with high morbidity and mortality. Mortality rates for BMT vary from 37 to 77% depending on the underlying diagnosis and type of transplant performed (Pasquini & Wang, 2009). Parents are confronted with agonizing end-of-life (EOL) decisions for their child who is dying following BMT. As a pediatric BMT nurse, I accompanied many parents along the path of this decision making process. I had intimate knowledge that this process, whether a decision to agree to a do not resuscitate (DNR) order for their child or to withdraw life-sustaining therapy for their child who was dying following BMT, was both excruciatingly painful and courageous. But neither I nor the healthcare field in general had adequate knowledge of how this process occurred and what might be done to facilitate it for parents and their children. My dissertation provided an opportunity for initial study of this process.

The purpose of this article is to describe how a beginning middle-range theory, generated from my dissertation research, was used as a stepping stone to identify a focus for my next research project. During doctoral study, I was encouraged to look beyond my dissertation to consider a plan of continued scholarly inquiry. Developing that initial study after doctoral graduation may be more difficult than first imagined. A theoretical framework can facilitate this next step in research.

1. Background to initial research

The impetus for the initial research study came from my clinical experience as an inpatient pediatric BMT nurse. The experience of caring for this highly specialized population of patients and their families generated many unanswered questions for me. As is the case with many initial studies, these unanswered questions sparked curiosity and a desire to engage in exploration to discover the answers.

Of particular concern was the numerous treatment decisions parents were forced to make on a daily basis amidst the vast amount of medical information they received about their child’s condition. While the ability of parents to make decisions in this environment of uncertainty was impressive, there was a need for nurses and other healthcare providers to better understand and then facilitate this process for parents.

2. Developing the conceptual framework

One of the first steps in my research was to develop a conceptual framework using approaches of synthesis, derivation, and analysis (see Walker & Avant, 2011). A conceptual framework provides a global guide that is needed to begin any study, qualitative or quantitative. My experiential as well as science-based knowledge in the area of pediatric BMT nursing provided an important foundation for reviewing the literature relevant to my research focus. Databases used included Ovid, CINAHL, EBSCO, Medline, PsychINFO, and various sociology and theology databases. Key words used in the search were the following: pediatric cancer, parental grief, pediatric bone marrow transplantation, end-of-life decision making, parental decision...
3. Theory from research

I used the grounded theory methodology of Glaser (1978) to help me describe the process of end-of-life decision making as understood by the parents. In any research study it is essential that the researcher’s worldview be congruent with the methodology used. My worldview, which emphasizes the human–environment process as dynamic, ongoing, and self-constructing, was consistent with Glaserian grounded theory; this helped me make sense of what was going on in a given situation.

My research goal was not to predict the parental response in any given decision making situation. On the contrary, use of Glaser’s constant comparative method of data analysis helped me understand the process of end-of-life decision making as expressed by the parent through identifying and describing categories reflective of the process of parental end-of-life decision making. The basic social process (BSP), called a core category, is a central methodological idea in grounded theory and refers to the “fundamental patterns in the organization of social behavior as it occurs over time” (Glaser, 1978, p. 106). The core category emerges from the constant comparative analysis and links all the other identified categories together by explaining what was going on in the situation and accounting for any variations that were observed. The theory that emerged from my research was developed around a BSP, which was grounded in the parental participant data. As such, it was critically important to use the actual words of the parents in describing the emerging theory.

3.1. The realization of parental knowing

The basic social process identified in my initial research was called The Realization of Parental Knowing. It referred to the process of attaining an absolute certainty on the part of the parents that the time was “right” to let their child go (die). Parents sensed intuitively when something was wrong with their child but it took validation, both visual and scientifically based evidence of the child’s deteriorating physical condition to support the process of realization.

The grounded theory that emerged from my initial research was built around the BSP. The theory consisted of four key concepts, listed as the four key categories along with their supporting sub-categories in Table 1: developing trust (described as all-encompassing and something that had to occur if the parent was going to be able to make the end-of-life decision); committed to seeing it through (described how the parents approached, viewed, and navigated the journey that was pediatric BMT treatment); facing my worst fear (the unspoken traveler who accompanied the parents during this process); and acceptance of self (an important bridge to how parents felt about themselves and the decision they had made following the deaths of...
their children). These concepts elaborate on the process that parents used to navigate the human problem (the journey) of having to make the end-of-life decision for their children who were dying following blood and marrow transplantation.

The first two categories (developing trust, committed to seeing it through) were intertwined throughout the process such that neither category assumed importance over the other. As their children’s physical condition deteriorated, these categories began to merge with facing my worst fear. At some point following this merger parents were able to attain certainty that the time was “right” to let their children go (die) and were able to make the end-of-life decision.

All of the parents engaged in this process, albeit in their own unique way, in order to make the end-of-life decision. While the parents reported varying emotions (such as peace, emptiness, and anger) after the end-of-life decision was made, they all believed that they had made the correct decision for their child. They indicated that acceptance of self, as an outcome of the process, was a critical step that needed to occur if they were to move forward in the ongoing process of their own lives. The realization of parental knowing served to explain these categories and also provided a framework for linking them together in a meaningful way (Rishel, 2010b).

4. A new idea for research from theory

4.1. Background

The four key categories crucial to the development of the emerging theory in my initial dissertation research also had the potential to guide the development of the next study. Of particular interest, and one that warranted further study, was the category developing trust. The parents in the original study described developing trust in the health care team in the context of validating the information they received from providers regarding their child’s physical condition. This finding was consistent with that of other researchers who found that parents needed timely and accurate information about their child’s condition if they were to form a trusting relationship with the health care team (Thompson, Hupcey, & Clark, 2003).

The fact that parents in this study were given information throughout the entire course of treatment was not sufficient as the sole foundation for EOL decision making.

Each parent talked extensively about the need to develop trust in the physicians (primarily) and other health care team members in order to make treatment decisions for their children. Trust in physicians, as developed through validation of the information, appeared to be a critical component of the EOL decision making process for parents.

Several parents discussed use of the Internet as an important means of validating information that was being given to them. One parent described extensive use of the Internet as not only a validation tool, but also as a means of seeking additional treatment recommendations for their child. Other parents acknowledged that they had used the Internet at the beginning of the process to develop trust in the decision for BMT, but then abandoned the Internet as they believed they might encounter conflicting information.

4.2. Reciprocal trust

Previous researchers (Hinds et al., 2009; Nuss, Hinds, & LaFond, 2005) have written about parents developing a sense of competence in decision making and the development of trust among all parties involved in decision making. Reading the literature and working from my initial concept of developing trust, I identified a new concept I called reciprocal trust. Reciprocal trust extends beyond the idea of parents as competent decision makers for their dying children, to acknowledge the parents’ strong desire to be valued and subsequently trusted by themselves and others in their role as decision maker for their children. My dissertation findings indicated that 1) the establishment of reciprocal trust was crucial to parents as they developed confidence in their own ability to make the EOL decision and 2) the use of the Internet was a means of validating information regarding their child’s condition.

Parents often used the Internet to inform themselves and gain competence in their knowledge about their child’s health. The Internet was a potentially valuable tool that some parents used on the path to achieving reciprocal trust. It was abundantly clear that developing trust both in the health care team and in their own ability as sole decision maker for their dying child was a critical piece of the process, the realization of parental knowing, in order for the parents to make an EOL decision for their child (Rishel, 2010b).

4.3. Use of the Internet in establishing reciprocal trust

While it has been well established that parents rely heavily on facts and data about their child’s condition when they are faced with making treatment decisions (Rishel, 2010b) little is known about the use and influence of Internet information on the process of parent decision making. Data from my dissertation research supported these earlier findings. However, some parents described frequently accessing various sites on the Internet as an important means of validating information given to them regarding their child’s condition and as a source of seeking additional treatment recommendations.

Parents’ use of the Internet as an ongoing source of and validation tool for information shared by the healthcare team was a new finding that provided the impetus for a new research study. However, the concern expressed by parents was that Internet information was sometimes in conflict with information being given to them from members of their child’s healthcare team. A new study, then, will focus on developing a more valid account of the use and influence of information obtained from the Internet on parents who are faced with making an end-of-life decision for their child dying of cancer.

5. Conclusion

The purpose of this article was to describe how a beginning middle-range theory, generated from dissertation research, was used as a stepping stone to identify a specific focus for subsequent research. Overall, the process entailed movement back and forth, from research to theory, and theory to research, with practice providing foundational ideas.

The idea of Internet use as a key component in the process of parental EOL decision making was unanticipated during the original study. This idea occurred during data analysis as something potentially significant to the core category of developing trust.

Parents may seek guidance and/or assistance in validating information they have received from physicians and other healthcare providers. Providing support for parents as they establish their own empirical knowing in order to engage in treatment decision making has been shown to be a crucial factor for parents if they are ever to be expected to make an end-of-life decision for their children. Given the ease and accessibility of Internet information, parental use of the Internet seems like a significant area for further study of reciprocal trust and parental confidence in their knowledge for making EOL decisions about their child’s care.

While the findings of my dissertation study have contributed to nursing knowledge in EOL decision making in pediatric BMT, they have also opened the door to additional research and potential theory development. The realization of parental knowing theory is still emerging for continued testing and research into the complex area of parental EOL decision making.
References


