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Communication and Cultural Sensitivity for Families and Children With Life-Limiting Diseases

An Informed Decision-Making Ethical Case in Community-Based Palliative Care

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The health care decisions of families of children who have life-limiting genetic diseases are impacted by multiple factors including religious and ethical values, education and knowledge, emotional trauma, availability of support, and accessibility of care. Palliative care nurses must practice the highest standards by delivering nonbiased, nonjudgmental support to patients and families; however, nurses may experience moral distress if their personal values conflict with a family's decisions and needs. This case focuses on a family receiving community-based palliative care for a child with a genetic life-limiting disease. They had a family history of this disease, which had caused the deaths of previous children, and the mother had a current unplanned pregnancy. The care team overcame language barriers and cultural obstacles to establish a trusting relationship with the vulnerable pregnant mother. They were able to support her decision to terminate her pregnancy safely by helping her to navigate a complex health care system. Using 5 crucial pillars to assist health care members with the delivery of nonjudgmental family-centered palliative care is recommended: (1) identification of biases, (2) utilization of a culturally safe approach, (3) effective communication, (4) assessment and support, and (5) knowledge of community resources.

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Nurses may encounter ethical challenges while providing community-based palliative care. The present case is of a vulnerable family with a significant family history of a life-threatening disease and an unplanned pregnancy. This case study examines the means by which a team of community-based pediatric palliative care (CBPPC) nurses established trust and provided nonjudgmental communication in order to assist a family facing an ethical dilemma. Based on this study, guidelines were developed for providing nonbiased, family-centered palliative care.

The Case

The patient was a young child with a genetic life-limiting disease. Based on the child's health condition and the needs of the family, the pediatrician had placed a referral for CBPPC. Both parents were involved in the child's care; the mother was the primary caregiver, and the father worked outside the home. The mother could not speak or understand English and was illiterate in her native language; therefore, an interpreter service was utilized via telephone for each visit. The family had 2 prior infant deaths, and a toddler die of the same genetic disease; their one surviving child is the child in this case. The living child had minor developmental delays. The child was sick frequently, although like many children would still find time to play and bring joy to the parents. The family indicated that they were Muslim, and their Middle Eastern culture was an important factor. They conveyed to the nurse that important communications should be addressed to the father/husband because their cultural background designated him as the primary communicator and decision maker.

Community-based pediatric palliative care visits were provided in the family's home. The team was careful to respect

the family's cultural customs by removing shoes before entering the home, sitting on the floor, and accepting traditional offerings of tea or snacks. The palliative care team provided services such as medication reconciliation, and they managed symptoms including constipation, rash, seizures, urinary issues, and infections. The palliative care nurse coordinated specialists, obtained medical equipment, and helped to coordinate the child's school enrollment and therapy appointments. In addition, the nurse, social worker, and nurse practitioner offered emotional support to the family; the team spent considerable time listening to concerns and providing education regarding the disease, medications, and symptom management. During the home visits, the nurse, social worker, and nurse practitioner used open-ended questions to gather information and used reflective listening to ensure the parents' concerns were being heard and addressed. The CBPPC team used culturally sensitive, nonbiased methods of communication designed to encourage a trusting relationship with the child, as well as with the mother and father. After receiving several months of CBPPC visits, the mother confided in the palliative care nurse that she thought she might be pregnant. The nurse provided the mother with information regarding methods of determining pregnancy and the options available to the family. The family was faced with a difficult decision; having considered their circumstances and choices, they determined that termination was the best option for them, but they had limited financial resources and lacked the knowledge or experience to navigate the health care system. The CBPPC team assisted the family with obtaining medical services and provided support during their painful emotional recovery after experiencing another loss.

The CBPPC team formed an integral part of this family's health care constellation of providers, acting as a liaison between the family and various specialists. Because the team members had worked to establish a trusting relationship, the family felt able to confide their needs and decisions to the interprofessional team.[1] Their trust allowed the nurse to share an extensive knowledge of the health care system so that the family could pursue their health care goals safely.

Summary of the Literature

Palliative care tries to alleviate the suffering of children with serious illnesses and their families,[2] and it provides supportive services for caregivers.[3] Unbiased information from community-based, palliative care nurses plays a fundamental role in ensuring the well-being of families with children who have rare diseases, particularly those families with vulnerabilities.[4] Language barriers, limited education, poverty, and a lack of transportation are considered risks for family vulnerability.[5]

Location and availability of resources are important factors for families faced with difficult health choices. Community-based palliative care services for children and adults provide essential accessible health care. By assessing, planning, and delivering care in the home setting, palliative care providers can empower patients and families to regard themselves as equal members of a team in choosing the best interventions for themselves[4] and in determining their family's needs.[6]

There is research to suggest that a lack of clear, open communication between a palliative care team and a family can create conflicts,[5] but further research is needed to address communication regarding ethical decisions. Few articles are available involving palliative care and pregnancy termination for the parent of a child with a rare genetic disease. Nurses may have strong views or religious beliefs regarding pregnancy termination that can affect their ability to provide holistic care for a patient and their family or contribute to moral distress.[7-9] Moral distress has been documented when teams provide care for women who are pregnant and must make complicated, life-threatening decisions.[7] Implicit bias may occur when a person's opinions or beliefs inhibit the way they may treat or view another person based on a characteristic about the person. Implicit biases contribute to health disparities by potentially influencing how health professionals make decisions and communicate.[10]

Further education is necessary to train nurses, particularly those in palliative care, to combine motivational interviewing techniques with a nonbiased and nonjudgmental communication style during difficult ethical conversations. Research on giving nurses tools to maneuver through difficult conversations and patient interactions may be useful in decreasing moral distress and in reducing caregiver fatigue caused by moral distress.

Nursing Implications in Ethical Cases

Identified in this article are 5 pillars for implementing CBPPC care in cases involving ethical considerations: (1) identification of biases, (2) utilization of a culturally safe approach, (3) communication, (4) assessment and support, and (5) knowledge of community resources.

Identification of Biases

Nurses need to be aware of biases that could impact patient care. Unplanned pregnancy and pregnancy termination can be difficult topics to discuss because ethical views about pregnancy termination are often deeply held.[7] In this case, had the health care team members revealed any form of negativity concerning pregnancy termination, or had they withheld support for personal reasons, the family would not have been able to pursue their decision in a safe, timely, and knowledgeable way. Without the nurse's unbiased support, the family would have remained unconnected with appropriate medical specialists and community resources.

Community-based pediatric palliative care teams have a professional duty to implement legal, high-quality care and support. Patients and their families can be caused severe moral distress if they perceive that their ethical decisions are incompatible with a health care team member's personal beliefs.[7] For this reason, a member of a CBPPC team who is opposed to pregnancy termination and cannot offer unconditional support or manage that ethical dilemma with the support of the team should withdraw; this should be done without compromising unbiased family-centered care by revealing that the withdrawal is due to ethical opposition.

The American Nurses Association's Code of Ethics requires nurses to protect and care for patients without judgment, to not refuse care, and to advocate for patients in the manner necessary to ensure the successful achievement of desired goals.[11] Pregnancy termination is an ethical issue that nurses may not think they will encounter as professionals if they do not work in women's health care practice, but they may encounter this issue in many settings, including palliative care, as this case study has shown. It is therefore essential for palliative care providers to receive training designed to help them recognize and reflect on biases and perceptions that may affect their practice of nonjudgmental nursing care. This training can be incorporated into team meetings or be provided in external implicit bias training sessions.

Utilization of a Culturally Safe Approach

Culturally safe care is achieved when services are developed based on the uniqueness of each family.[5] Understanding that each family may possess unique religious and personal preferences is crucial for providing patient-centered, quality palliative and hospice care and practicing with cultural humility.[12] During the comprehensive intake process, palliative care nurses should discuss and document the family's religious, spiritual, cultural, and traditional preferences.[12]

The CBPPC team members removed their shoes at the door, sat on the floor, and shared tea at the beginning of visits. It was also important that male providers not be present in the home with the mother when the father was not present. In order to devise methods of delivering culturally competent and safe care, the CBPPC team employed open-ended questions with guided conversation, as indicated in the Table. This sensitivity to cultural preferences allowed for high-quality palliative care[13] that permitted the CBPPC team to address the family's traumatic past events and goals for the future.

It is essential that hospice and palliative care team members recognize any biases they may have toward vulnerable populations, as these biases can significantly impact the quality of care given.[14] Ethical biases could have affected the health care providers' perceptions of a family with inherited genetic diseases and limited resources desiring to have additional children. The family expressed that having children was part of their cultural norm and that they strongly desired to have more. Although 3 prior children had died and their remaining child was dying, the parents still wished to try to have healthy children. The CBPPC team respected their cultural values and developed a nonjudgmental supportive plan connecting the family with an obstetrician and a geneticist. Had the team suggested that further pregnancies should be avoided due to the genetic disease, the family's confidence in the CBPPC team would have been compromised.

Mitigating language barriers in palliative care is a necessity. Use of the telephone language translation line allowed the family to develop a strong and trusting relationship with the nurse[15]; without interpretation services, the outcome of the case could have been vastly different.

TABLE Motivational Interviewing (MI) Processes and Techniques Used in This Case

MI Process	OARS Techniques
• Engaging • Focusing • Evoking • Planning	• Open-ended questions • Reflective listening
Questions from the CBPPC team members	
• How would it be for you and your family if you continued to be pregnant?	
• How would it look if you did not carry this pregnancy to full term?	
• Help me understand how we can best support your family.	
• What do you think is the right choice for you?	
• Can we look at what options might be good for you?	
• Can I tell you about what some options might be for you?	
• Would it be okay with you if I talk with some doctors that specialize in genetics and pregnancy?	
• Would it be helpful if I contacted the specialists who can assist you in termination?	
• I hear you say you do not want to become pregnant again. Would you like me to provide you with some resources?	

Abbreviations: CBPPC, community-based pediatric palliative care; OARS, Open-ended questions, Affirming statements, Reflective listening, Summarizing.

Communication

Communication may be the single most important driver of high-quality palliative care[2,9]; together with coordination and advocacy, it is a link that binds the interprofessional

care team to the patient and family.[7,16] Motivational interviewing is a way to talk with and council patients to determine what their motivation is to discover health concerns or implement changes in their health. Motivational interviewing allows the patient to have control of his/her health and take part in shared decision making. In this case, the CBPPC providers used motivational interviewing methods of using open-ended questioning and reflective listening to identify the family's concerns and wishes (Table). These techniques helped the family to feel supported and enabled the CBPPC team to understand and support their preferences and goals.

Assessment and Support

The entire CBPPC team must assess for moral distress on a routine basis and should support each other through difficult ethical cases.[17] Assessment for moral or ethical stress can be incorporated into formal and/or informal team meetings.[18] Team members not involved in direct patient care can offer support to members who are. Although nurses may feel morally challenged by their cases, the American Nurses Association's Code of Ethics binds them to uniform standards of beneficence, autonomy, and justice.[11]

Community Resources

Familiarity with community resources is essential, particularly when CBPPC teams are working with vulnerable populations. In this case, the CBPPC nurse connected the family to accessible medical specialists and directed the mother to the local Planned Parenthood for affordable contraception and sex education. Communities may not have easily accessible clinics or Planned Parenthood branches, so nurses may need to build connections or create partnerships with other health care agencies to improve access to care. In this case, had the nurse expressed any negativity toward Planned Parenthood services, or refused to refer the mother to Planned Parenthood out of personal bias, the mother may not have obtained reliable sex education or had access to safe contraception. If the nurse had conscientious objection to termination of pregnancy they could be putting the parents and family at increased risk of cost and suffering. If the nurse had an objection to allowing the family to access their legal right for termination, the nurse should recognize this bias as having a negative impact on the health of the family and recuse herself/himself. Community-based pediatric palliative care members should maintain full and current knowledge of community resources and be able to set aside biases when directing families to available resources.

Outcome of the Case

The CBPPC team developed a trusting relationship with the vulnerable mother, father, and child through being dependable, nonjudgmental, and respectful of cultural preferences and choices. The mother discussed with the palliative care nurse her hope that her surviving child would live a long life, but she also expressed concern that the child had currently outlived their expectations. Over the course of many visits, the mother grew confident enough to speak about her other children, who had died of the same disease. The parents desired a healthy child, without the life-limiting illness, but were discouraged that this might not be possible for them. When the mother confided in the CBPPC nurse that she suspected she was pregnant, the nurse utilized internet images to show the mother what a pregnancy test looked like and where the family could purchase one. The mother and nurse coordinated so that the mother could take the pregnancy test during the next palliative care home visit, and the nurse could help the parents interpret the results and to understand their options.

Through the use of motivational interviewing techniques, the palliative care nurse was able to understand the importance of children in the family and that pregnancy termination was an extremely painful choice for them given their cultural and religious beliefs. Building on the trusting relationship they had established, the nurse was able to guide them through the complexity of the health care system, connect them to local obstetrics and genetics teams, and speak with specialists on the family's behalf, at their request. The CBPPC nurse assisted in scheduling and ensuring that the family had transportation to their appointments. With the assistance of the medical specialists and the palliative care nurse, the family was able to pursue their decision and safely terminate the pregnancy. The mother expressed appreciation to the nurse that she had been able to terminate before carrying to full term and that the parents would not have to watch another beloved child die.[19] She also expressed gratitude for the nurse's referral to Planned Parenthood; this proved to be a valuable resource for contraception and education as it was more affordable than a primary care provider's clinic. Although the family wished to have more children, they decided to use contraception to avoid the possibility of an unplanned pregnancy.

The implementation of home-based palliative care was a major step toward ensuring an enhanced quality of life for the child and family. Because of the ethical intricacy of the case, the interdisciplinary palliative care team routinely assessed for moral distress by conducting internal checkups and debriefings. Their support for one another allowed them to deliver truly comprehensive and unconditionally supportive family-centered care.

Future Practice

As the Hospice and Palliative Nurses Association indicated in August 2019, there are gaps in current research encompassing multiple facets of palliative care; some of those gaps are addressed in this article.[20] This case study addresses considerations regarding (*a*) care of children with

genetic illness, (*b*) cultural sensitivity, (*c*) language barriers and communication techniques, (*d*) team support for moral and ethical distress, (*e*) community-based care and resources for vulnerable populations, (*f*) goals discussions, (*g*) training for bias awareness, and (*h*) interprofessional collaboration. These issues should be considered critical to ensuring successful patient- and family-centered care, especially for vulnerable populations.[13]

Many communities do not have access to CBPPC; this is a serious obstacle to integrating palliative care into the home setting of a child with a life-limiting illness. To ameliorate this problem, educational programs can be created to train interdisciplinary teams to practice pediatric and family palliative care within the community; this may involve creating a partnership with larger institutions possessing established palliative care services. Moynihan et al[2] suggest establishing palliative care educational programs to encourage nurses to become advocates for palliative care services by becoming trained pediatric palliative care champions. Trained pediatric palliative care champions can offer critical support when communities do not have resources to establish independent CBPPC services.

Nursing programs should train students to engage in conversations regarding ethical dilemmas efficiently and with confidence. Motivational interviewing has been shown to be a helpful skill in palliative care.[21] Interprofessional simulations of patient care interactions can be utilized to practice communication skills. Recognition and adjustment of one's implicit bias can happen if difficult experiences are explored and discussed with a mentor, team, or self by various methods such as encouraging individuals to question deeply held beliefs and assumptions, take courses, listen to speakers who have experienced implicit bias, and review clinical encounters influenced by bias.[10] In order to assist nurses to identify care-impeding biases, nursing programs and orientations should consider requiring implicit bias training for both students and faculty and extend into practice.

CONCLUSION

By facilitating the communication of patient and family needs and goals and by connecting patients and families with community resources to improve quality of life, CBPPC and hospice nurses play an essential role in decreasing stressors and suffering. The implementation of palliative care improves patient outcomes, enhances interprofessional and family communication, and reduces end-of-life cost burdens both to families and to health care systems; however, the time it takes a nurse to develop trusting relationships, consider family-centered education needs, connect families with accessible specialists, and address their own needs and possible biases is not easily coded for compensation in the current health care system.

Without substantial CBPPC nurse involvement in this case, the outcome might have been far less satisfactory for the family. It is recommended that nurses and interprofessional teams implement the 5 crucial pillars discussed for providing ethical and safe palliative care.

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