CLINICAL PRACTICE

Palliative chemotherapy decision-making: A holistic perspective

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ABSTRACT

Palliative chemotherapy can be conceptually confusing to patients and their families. When presented as an option at end of life, the decision-making process can be particularly stressful as patients and their families struggle to understand the goals of palliative chemotherapy, and examine their own values, wishes, and expectations for care. Lacking a clear definition in the literature, palliative chemotherapy is highly individualized to patients. However, applying holistic strategies during the decision-making process can mitigate stress, protect patients and families from misinformation, and ensure that they do not miss the opportunity to evaluate their options. In this narrative review for clinical application, the authors highlight key issues in palliative chemotherapy and palliative chemotherapy decision-making, and present evidence-based strategies for supporting patients and families through the decision-making process from a holistic perspective.

Key Words: Cancer, Neoplasms, Palliative care, Holistic nursing, End of life

1. INTRODUCTION

1.1 Issues in defining palliative chemotherapy

Palliative chemotherapy has been defined variably in the literature, in part because clinicians have historically described the term palliative chemotherapy as puzzling[1,2] an oxymoron.[3] Inconsistent definitions of palliation in cancer have resulted in a lack of standardization across practices. The term is not standardized across practices, a phenomenon which may be attributed to inconsistent definitions of palliation in cancer. Palliation in cancer could indicate 1) a response to treatment; 2) a decrease in symptoms caused by the underlying cancer; or 3) increased quality of life.[1,2]

Though the word chemotherapy is widely recognized as the primary treatment for persons with cancer, chemotherapy has an ominous tone, is regarded as a mechanism for fighting for one's life and is strongly associated with resulting physical discomfort. Administration of palliative chemotherapy often results in unsavory side effects such as nausea, vomiting, alopecia, fatigue and pain.[4] In contrast, the word palliative, derived from the Latin word palliatus meaning to cloak or to shield,[5] conveys a distinctive sense of protection and safety. Not surprisingly, combining the two words results in a kind of paradoxical phrase; yet it is used habitually in oncology settings.[3] When introducing palliative chemotherapy as a treatment option, there is a high potential for patient/family confusion, which may result in distress and difficulty with decision-making The consequences of patient and family confusion may include communication barriers with their healthcare team and loss of trust, which then perpetuate miscommunication along the care trajectory. Worse, patient and family confusion about palliative chemotherapy may

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result in uninformed decisions and ultimately, unintended consequences.

Palliative chemotherapy is often presented to patients and families at the time of a major care milestone, such as when terminality becomes imminent or prognosis is poor. At these moments, patients and families can be especially vulnerable as they receive unfavorable news but are still expected to dictate their care. The palliative chemotherapy decision process is not only confusing and emotional but can also be quite profound. Patients and families navigate an intricate web of their own values, desires, cultural implications, wishes for end of life, and potential health sequelae while weighing their options, risks, benefits, and outcomes. The palliative chemotherapy decision-making process, wrought with complexities, is spiritual, intellectual, physical, and emotional—it is a holistic process. In this way, holistic strategies are well positioned to assist patients and families in reaching a decision that is right for them.

To combat adverse effects of the palliative chemotherapy decision-making process, healthcare teams should refer to the evidence. The literature illustrates issues surrounding palliative chemotherapy, difficult decision-making in healthcare settings, and evidence-based interventions for mitigating these. The aim of this paper is to present an overview of patient/family issues during palliative chemotherapy decision-making, and holistic nursing strategies for alleviating those issues.

The introduction of palliative chemotherapy to patients and families should not be done haphazardly. Nurses should apply evidence-based strategies to help mitigate potential distress and confusion. Because holistic nursing addresses the whole person, their needs, and their desires,[6] and because palliative chemotherapy is usually poised as an option during end of life, holistic strategies are suitable for application in palliative chemotherapy decision scenarios. The aim of this paper is to present an overview of patient/family issues during palliative chemotherapy decision-making, and holistic nursing strategies for prevent, mitigating, or alleviating those issues.

A lack of a clear definition of palliative chemotherapy is an inherent problem with the concept, and only propogates confusion among providers, nurses, and patients. However, despite having no standardized definition, many clinicians agree that a primary goal of palliative chemotherapy is increased quality of life.[7–9] Remaining goals of palliative chemotherapy are strictly circumstantial and specific to each patient's situation. Because of these varied goals, the purpose for using palliative chemotherapy is often misunderstood by patients and families. While a universal definition would be helpful, describing the intent of palliative chemotherapy, specifically the intent for the patient's unique situation, is key. Most importantly, as with all treatment decisions, it should be presented to patients/families as an option and a matter of choice. Unfortunately, an explicit standardized definition for palliative chemotherapy is still unlikely. Thus, the most concerning issue is the potential discord that occurs when a palliative chemotherapy option is presented to patients and their families, when providers do not recognize that patients and families do not understand what palliative chemotherapy is.

1.2 Issues in palliative chemotherapy decision-making

The crossroads at which patients and their families arrive when faced with a palliative chemotherapy option is emotionally exhausting. While trying to understand the paradoxical definition and individualized goals of palliative chemotherapy, patients and families must simultaneously address their values and wishes for end-of-life. The decision to pursue palliative chemotherapy can be particularly overwhelming when terminality may be freshly communicated to the patient/family. In various treatment settings, findings suggest that patients admit to defaulting to the recommendation of their providers, even when it means abandoning their own preferences.[10,11] Patients may be surrendering their input out of fear of taking up too much time, reverence for a physician, or due to a knowledge deficit. These phenomena may be more prevalent in certain cultures, age groups, or ethnic populations, introducing a potential for health disparity.[12] Patients and families with lower literacy levels and those with little-to-no prior experience with palliative care are more susceptible than their more-educated counterparts to withholding their input from their providers. Health care professionals, especially nurses, have an ethical obligation to afford each patient, regardless of background, the same opportunity to make informed decisions about their health.

Following conversations with providers that included both a palliative chemotherapy option and non-chemotherapy palliation option, some patients reported feeling that there is not a true choice before them; that they are choosing between palliative chemotherapy or "doing nothing".[13] Patients and families often misunderstand that there are no alternatives to palliative chemotherapy, or may falsely believe that the only alternative is passive, impending suffering as the body succumbs to the malignancy. The likely precursor of this misunderstanding is simply misinformation, but the consequence is quite poignant. If patients and families do not understand that they have options, then they have missed the opportunity to choose, and their healthcare team has thus failed to protect that right.

Sometimes, patients and their healthcare team establish excellent rapport over long periods of a caring relationship. Even in such cases, agreement between what patients with cancer want, and what physicians think they want, may be very poor.[9] If a decision is made on behalf of the patient (but without the patient actively participating) alternatives to palliative chemotherapy may not be revisited until it is too late. Without consideration of the whole person at the time of the decision, including background, psychosocial wellbeing, emotional stability, spiritual needs, insight, and family dynamics, the healthcare team risks leaving the patient and family's values out of the equation, completely. Decision-making includes providing adequate information at every opportunity during treatment and incorporating the patient's/family's values into treatment decisions.[14] Holistic strategies (as outlined below) have been shown to help alleviate these issues during difficult decision-making, and may be employed at any time during the palliative chemotherapy discussion.

For patients and their families, making the decision to choose or reject palliative chemotherapy can feel like the most important decision of their lives. Patients and families may need help working through the decision, if they are working to understand the goals of chemotherapy and alternative options, simultaneously. In end-of-life palliative care, nurses must consider the comprehensive, holistic needs of patients and their families, which encompass symptom burden, psychological and spiritual wellness, and management of the underlying disease.[15] In doing so, nurses can assist patients and families in making decisions that consider the whole person, where goals, wishes, and biopsychosocial wellness are incorporated at each step of the palliative chemotherapy decision process.

2. Narrative review method

The authors performed a narrative review of the literature for evidence-based interventions addressing palliative chemotherapy decision-making. The literature was searched using the subject headings and keywords "holistic nursing" and "decision-making" in PubMed and CINAHL databases. The initial search occurred in December 2018 and was updated in October 2019, applying no limits on pulication dates. Using the resulting articles' subject headings, the first author hand searched for additional relevant articles. The first author screened the articles for holistic or complementary interventions addressing difficult decisions or decision processes. Below, the authors discuss the applicability and implications of the holistic nursing strategies to palliative chemotherapy decision-making.

3. Search results

3.1 Make necessary preparations

Though seemingly simplistic, preparation is the first step to effective therapeutic decision-making.[16] At the center of holistic nursing is consideration of the whole person, which in the context of palliative chemotherapy decision-making, begins before the conversation ever occurs. Specifically, the nurse should be aware of the patient's medical, psychological, and social history before engaging with a patient regarding palliative chemotherapy and end-of-life wishes. Reviewing the patient's medical and social history can offer clues as to how the patient/family might be interpreting the options being presented. Also, reviewing the medical and social history improves the rapport between nurse and patient which gives the patient/family a sense of confidence in the nurse who demonstrates consideration of their personal situation.[15]

Additionally, the nurse must consider the physical environment in which a palliative chemotherapy discussion will occur, and ensure the environment is conducive to open communication.[15,17] A conducive environment is quiet, private, and has minimal opportunity for interruptions. The physical environment should be surveyed prior to the provider/patient/family discussion about palliative chemotherapy. If possible, the nurse may arrange for a private meeting space in a procedure room, conference room, or family room. This strategy is especially relevant if the patient's hospital room is a shared room, a room with curtain divisions, or a room without seating for the patients' family members. During the first provider discussion regarding the palliative chemotherapy option, the patient/family may be hearing the words "end of life" for the first time. The environment should be amenable to the possibility of a wide range of emotions, from anger to sadness to fear. If a physical environment is found to compromise privacy, dignity or communicative effort of the patient/family, the nurse must take an active role in amending the environment or locating a more suitable place.[15]

3.2 Perform a holistic assessment

Given that nurses spend the most time with the patient/family of any healthcare team member,[18] their input is essential in guiding the patient's care plan. To support the patient/family during the end-of-life period, and during the palliative chemotherapy decision-making process, the nurse may utilize a strategy called the holistic assessment. Holistic assessment is more comprehensive than a traditional assessment, and evaluates symptom burden, life experiences, spirituality, religiousness, coping behaviors, psychosocial wellness, family, social networks and physical health.[19,20] Holistic assessments are recommended at specific occasions

during a patients' care trajectories: 1) when the end-of-life phase is identified; 2) when death is immenent/diagnosed; 3) when patient or family request a revision; 4) any other time the healthcare professional feels appropriate.[20] Nurses can perform a holistic assessment simply by asking questions, but they may find holistic assessment instruments helpful in guiding the conversation. Following the holistic assessment, nurses should report findings to the team and refer to the assessment results when participating in care planning. The results from the holistic assessment may indicate the need for additional interdisciplinary services, such as help from chaplains, social workers, or pain specialists. Nurses can communicate these to the wider healthcare team.

3.3 Build rapport and leverage communication

Recognition of a patient's individuality is at the heart of effective therapeutic communication.[21] Using compassion when communicating with the patient/family means the nurse is demonstrating mindfulness and offering presence, which can encourage the patient/family to comfortably share feelings.[22] Offering one's presence is a fundamental part of spiritual care at end of life,[17] and the nurse's presence can independently bolster feelings of value and care in the patient.[23] Using active listening is another rapport-building strategy in which the nurse reflects what patients/families have communicated to him/her.[24] Building rapport reveals characteristics, traits, and cultural/familial beliefs that may otherwise be concealed, but could be significant factors of decisions and decision-related behaviors of patients and their families.

In the context of difficult decision-making, the most important consequence of increased rapport between nurse and patient/family is increased communication. Increased communication between the nurse and the patient/family improves the likelihood that any confusion, distress, or unmet needs of the patient/family surrounding palliative chemotherapy will surface. At the time of presentation, nurses should be prepared to address these issues—the true cornerstone of building rapport. Because insufficient information is associated with added patient anxiety and depression during cancer treatment courses[25] the nurse should take measures to provide more information (or find the team member who can).

Nurses should be present throughout palliative chemotherapy discussions and informed consent processes with the patient and family. As the provider initiates the palliative chemotherapy option, nurses may serve as an additional listener for the patient/family. Though seemingly redundant, repeating information that was shared during the initial palliative chemotherapy discussion may be beneficial for the patient/family later as they discuss the palliative chemotherapy conversation in private, revisit their goals, and begin to meet the effects of their decision. Repetition is an important tool, as patients/families may fixate on just one or two concepts during their initial palliative chemotherapy dialogue and miss other vital points/information being shared by their provider.

3.4 Assist the patient/family in prioritization

Assisting the patient/family to create a list that prioritizes their personal goals and wishes for the end of life/palliative treatment period can be a beneficial exercise.[26] Each patient's unique values should guide their decision to pursue palliative chemotherapy or not, and the final treatment selection should complement the patient's personal goals.[14,27] For example, a patient whose goals include living long enough to see his daughter get married may necessitate a different treatment than the patient whose primary goal is to die comfortably on his farm without frequent interruptions of clinic visits. Patients may need assistance articulating their goals/wishes. Empowering patients to take an active role in their care yields better patient outcomes,[28] and in clarifying goals/wishes, the nurse may strengthen the meaning-based foundation on which patients base their independent treatment decisions. Providing therapeutic communication and emotional support through this list-making exercise is well within the nurses scope. The exercise is a holistic strategy that promotes healing through self-awareness, bolsters confidence, and has a goal of offering peace with a final decision.

4. DISCUSSION

Holistic strategies are integral in assisting patients and families through their treatment decisions at all stages of the care trajectory, not only at end-of-life. However, special consideration and care should be taken during end-of-life decision-making, when patients and their families often experience heightened emotion, uncomfortable dialogue and difficulty coordinating care.[29] The strategies from the literature can assist the interprofessional team in realizing the patient's goals and wishes during palliative chemotherapy decision-making and may also protect team members from burnout.[30] The strategies may also assist the team in identifying situations that warrant further time with the patient, or a more detailed explanation of palliative chemotherapy in the context of the patient's world.

Though they spend the most time with the patient, staff nurses are challenged to meet the demands of daily tasks and may not realistically be afforded the time needed to apply the strategies outlined above. In addition, the typical model of hospital staff nursing supports rapid interchangeability in

nurses between shifts, thus interrupting process of building rapport and understanding the patient/family deeply. Thus, the recommendation following this review is to use an interdisciplinary team approach while supporting patients and families during palliative chemotherapy decision-making. Nurses should collaborate with their professional partners (social work, chaplains, advanced care providers) to select optimal strategies, then delegate these duties accordingly.

The focus of holism is treating the whole person.[6] In doing so, nurses integrate patients'/families' needs, wants, and values throughout the illness and decision-making process. The conceptualization of healing to include the mind, body, spirit, cultural, emotional, and relational domains, is paramount during end-of-life decision-making, especially when addressing a concept that is frequently misunderstood (palliative chemotherapy). Each of these domains (and their interconnectedness) must guide the approach of the interprofessional healthcare team as they propose palliative chemotherapy to patients and families. Careful consideration of the whole person via the above evidence-based strategies can help clarify understanding and wishes during end-of-life, which can then assist the patient/family to make the best decision which is conducive to those goals.

Despite the body of literature focused on palliative chemotherapy decision-making issues, the literature in the area of holistic interventions aimed at alleviating those issues is still underdeveloped. Future research should focus on developing holistic exercises/interventions that are tailored to varied populations of patients with cancer, such as individuals from diverse sexual/gender identifications, pediatrics, cultural minorities, and the families of patients who are no longer of decision-making capacity. Further work is needed to develop and disseminate holistic-interventions for clarifying goals, soothing patients and families, and protecting dignity/right to choose during difficult decision-making processes at end of life.

5. Conclusions

Possibly due to lack of a clear definition, palliative chemotherapy presents unique challenges for healthcare teams. The palliative chemotherapy decision is thus particularly challenging and begins with clarifying treatment goals while supporting patients' and families' personal wishes as they make their decision. If patients and families do not understand the goals of palliative chemotherapy, especially if the lack of understanding is not caught and promptly addressed, the healthcare team may create a loophole through which the patient and family's wishes fall. Holistic care requires attention to symptom burden, psychological and spiritual wellness, and applying holistic strategies throughout the palliative chemotherapy decision-making process protects the integrity of patient/family-driven care.Additionally, patients/families need to feel comfortable making their personal wishes known, and/or exploring treatment options with more detail. By utilizing the holistic strategies, the nurse assists the patient/family through the decision-making process and provides perspective to the interdisciplinary healthcare team. Nurses should lead by putting the patient and family in the center of care decisions and ensuring that treatment decisions at end-of-life are amenable to their whole person. Finally, additional research is needed to develop targeted strategies for use by interdisciplinary teams to support patients/their families during palliative chemotherapy decision-making. This review did not recover any studies which address palliative chemotherapy decision-making, specifically. This is an integral next step which will further support patients and families in oncology settings.

Conflicts of Interest Disclosure

The authors declare that there is no conflict of interest.

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