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Goals of Care Conversation to Support Patient Empowerment in Managing Cancer Care

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Résumé de l'article

Les « objectifs de soins » désignent les valeurs, les objectifs et les préférences de traitement d'un patient atteint d'une maladie grave. Les conversations sur les objectifs de soins sont cruciales pour les soins des patients atteints de cancer et impliquent la prise de décision et l'autonomie du patient et de sa famille. L'étude de cas d'un homme atteint d'un cancer de la gorge lié au VPH illustre comment les facteurs émotionnels et la perte potentielle d'indépendance peuvent créer un conflit de valeurs entre les parties prenantes. Dans ce cas, le rôle de l'éthicien est de servir de médiateur et de protéger la relation de confiance entre le patient et le soignant. Lorsqu'elle intervient tôt dans la trajectoire de soins du cancer, une telle communication fondée sur l'éthique peut favoriser l'engagement du patient et de la famille, les progrès cliniques et l'amélioration de la qualité de vie.

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ÉTUDE DE CAS / CASE STUDY

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Gary Martinez[a]

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Abstract
"Goals of care" (GoC) refers to a patient's values, goals, and treatment preferences in severe illness. GoC conversations are crucial to the care of cancer patients and involve patient and family decision-making and autonomy. A case study of a man experiencing HPV-related throat cancer illustrates how emotional factors and potential loss of independence may create a GoC conflict of values. In this case, the ethicist's role is to mediate and protect the patient-provider trust relationship. When acted upon early in the cancer care trajectory, such ethics-based communication may promote patient-family commitment and clinical progress and improve quality of life.

Mots-clés
objectifs de soins, conversations, autonomie, valeur, cancer

Keywords
goals of care, conversations, autonomy, value, cancer

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INTRODUCTION

"Goals of care" (GoC) is an increasingly meaningful term used in medicine to refer to identifying a patient's personal values, goals, and treatment preferences in cases of severe illness (1). In this context, healthcare providers engage in GoC conversations that guide treatment plans and prioritize patient and family decision-making and empowerment. This communication is essential when managing the care of cancer patients.

CASE STUDY

Mr. F. is a 52-year-old man diagnosed with Stage II squamous cell throat cancer caused by the human papillomavirus (HPV). HPV-related throat cancer is a slow-growing virus that develops in the back of the throat (oropharynx) and frequently occurs in non-smoking, white, middle-aged (50-60 years) heterosexual men and typically presents with a noticeable lump and possible ear pain (2). Mr. F.'s presenting chief complaint was intermittent throat pain that radiated to the right tonsil area and right ear over a 5-6-month period. He reported no significant previous medical history or known contributing medical conditions. He reported occasionally smoking 1-cigarette weekly on and off for several years and "socially" drinks 4-5 glasses of alcohol per week. His initial diagnostic workup included a CT scan, an ultrasound test, which identified a 4.1 cm throat mass, and tissue biopsies to confirm a diagnosis of cancer. His treatment course included six weeks of chemotherapy, seven weeks of Proton therapy, and enrollment into a Phase II clinical trial. During this time, Mr. F. experienced 14 MRIs, 4 CT scans, and 3 PET scans. This treatment regime required Mr. F. to wear a special tight-fitting thermoplastic mesh mask for approximately 1.5 hours during treatment, which he reported as quite "challenging." His occupation is as a certified personal fitness trainer, and he participates in endurance cycling events. His partner, an experienced oncology healthcare professional, supports him.

ETHICAL ISSUE

Healthcare providers must recognize patients' unique goals early in the cancer care trajectory to preserve patient empowerment when developing clinical treatment plans (3). Although clinicians strive to include patients in treatment decisions, they often miss the opportunity to adequately empower patients by failing to communicate, ignoring emotional states, and making recommendations without understanding the patient's GoC concerns (4). These circumstances may result in patients feeling they have no choice but to comply with treatment, negatively affecting patient empowerment.

The case of Mr. F. illustrates such a loss of empowerment. Upon initial diagnostic testing, he expressed to the technician that his foremost GoC concern was being able to participate in an upcoming endurance cycling event. However, the primary care

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team was not aware of this GoC and scheduled immediate treatment plans for chemotherapy and Proton radiation. When notified of this plan, Mr. F. felt helpless and powerless to express his personal goals to his medical provider.

Mr. F.'s vulnerable emotional state is a common experience among newly diagnosed cancer patients. The emotional impact of a cancer diagnosis may range from feelings of anger, sadness, depression, loneliness, guilt, loss of independence, and inability to perform "normal" life activities (5). Mr. F.'s initial sense of helplessness grew into feelings of anger and hostility and led to his outright refusal to commit to further treatment. He abruptly stated that he would no longer be interested in continuing his recommended treatment plan. The healthcare team acknowledged Mr. F.s right to refuse treatment, but found it difficult to accept this position since Mr. F.'s cancer was highly curable with the given treatment plan (2). The radiology oncologist was reportedly incredulous and looked "strangely" at the patient, given the new diagnosis of throat cancer. When questioned, Mr. F. insistently refused to continue his treatment because he felt he had no alternative but to follow a prescribed treatment plan that did not prioritize his goals or wishes.

Accordingly, the medical team consulted the ethicist to address this conflict of values, provide more insight into the situation, and mobilize the aid of an outside party to facilitate the conversation. The ethicist's role in such cases is to mediate, protect the patient-provider trust relationship, and support patient empowerment (6). After the ethicist assessed Mr. F.'s understanding of his condition, he began his interview by asking, "What is important to you?" In time, with additional counseling, this simple statement empowered Mr. F. to feel less helpless, recognize his emotional state, and express his authentic feelings regarding his personal GoC in his cancer treatment plan. Upon conclusion, Mr. F. tearfully expressed his personal GoC desire to participate in a scheduled 150-mile endurance cycling event before beginning cancer treatment. When the physician realized how important this goal was to Mr. F., he decided to start treatment eleven days later to account for the duration of the race. In this way, the ethicist effectively mediated the conflict between the patient and provider while preserving that trust relationship and fulfilling the patient's GoC.

GOALS OF CARE CONVERSATION

Traditionally, GoC conversations occur late in the patient's disease trajectory, and under clinical circumstances when a cure is not possible, the interventional risk is too high, and suffering is present (1,3,7). This communication timeline is critically important when managing cancer patients. In such cases, healthcare professionals are encouraged to engage in "early" GoC conversations with the patient and family once the cancer diagnosis is confirmed (1,3,7). This proactive communication approach lays a foundation for patients to openly discuss personal goals and care preferences that reflect their values and to more fully engage in their medical treatment plans.

CONCLUSION

GoC conversations must incorporate a patient's values and care preferences to result in mutually acceptable and beneficial medical treatment plans. If done early in the cancer trajectory, such discussions may enhance patient commitment, engagement, and clinical progress, lessen potential depressive symptoms, and improve quality of life (1,3,5,7). Finally, ethicists may be pivotal in preserving the patient-provider relationship, encouraging authentic communication, and empowering patient decision-making.

DISCUSSION QUESTIONS

1. How can oncology healthcare practitioners better engage in "early" goals of care (GoC) conversations with patients and their families?
2. Is there evidence of best practice methods for oncology providers to discuss "early" GoC?
3. How can ethicists support patient empowerment regarding GoC decisions early in the cancer care trajectory?

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