

Refusing Cancer Medications to Avoid Delirium and Maintain Autonomy

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Shared decision-making within the patient-provider relationship is considered a cornerstone of the contemporary treatment of cancer here in Connecticut as well as nationally. It will be the focus of the 2017 Annual Meeting of the Connecticut Cancer Partnership. The relationship between patient and provider is critical and needs to develop and grow without diminishing the ultimate goals of cancer treatment: cure (whenever possible) and comfort (as much as possible). At the same time, the effective management of pain experienced by patients with cancer may limit one's mental capacities at a time when maximum autonomy and shared decision-making are needed most.

Sometimes the parallel emphasis on pain management and palliative care may conflict to the extent of resulting in delirium. An example of this tension occurs when the level of medication needed to control pain effectively results in diminished cognitive function, resulting in delirium. Another example is that of the "chemo brain" (i.e., post-chemotherapy cognitive impairment) that may occur due to chemotherapy.¹ (<https://www.cancer.org>).

Understanding how patients potentially avoid levels of medications that contribute to delirium to be able to participate fully in the shared decision-making process becomes an essential element in the care of individuals

diagnosed with cancer. For **certain** patients, being aware is more important than being free of pain; and maintaining autonomy is preferable to relief of discomfort and suffering that may occur with cancer.²

This perspective forms the basis of an emerging issue in the effective treatment of cancer: refusing medications to avoid delirium and maintain autonomy. In this brief, we explore the rationale for refusing medications during cancer treatment, especially when these medications are considered the 'gold standard' for cancer treatment and may contribute to acute confusion and decreased intellectual capacity via the development of delirium. We hope to provide insight into the potential ways in which the refusal of certain medications influences the patient-provider relationship and its inherent shared decision-making while also contributing to development of the 2018 revision of the Connecticut Cancer Plan.

Delirium is believed to be the most common sign of medical complications related to cancer treatment.³ Whereas the effects of delirium are known to contribute to adverse events in hospitalized older patients^{4,5} and taking specific medications has been identified as a risk factor for the development of delirium in patients with cancer,⁶ little is known or understood regarding the effects of delirium on autonomy, shared decision-making and the patient-provider relationship as these apply to adult patients diagnosed with cancer. Reasons for refusing medications and other forms of treatment for cancer are not well-researched, as evidenced by some of the 'most recent' information on this topic dating back more than a decade^{7,8}. Although

one study examined traits of older adult patients newly diagnosed with cancer and yet refused treatment,⁹ the body of literature on the refusal of cancer medications to avoid delirium and maintain autonomy is sparse at best.

Hindering one's ability to think clearly, delirium understandably is to be avoided by anyone undergoing treatment for cancer to allow for sound judgment in making necessary decisions throughout the course of chemotherapy, immunotherapy, narcotic-based pain management and other medication-related forms of cancer treatment.

Avoiding delirium and maintaining autonomy are priorities for individuals undergoing treatment for cancer and may be considered part of one's quality of life (QOL). This is in keeping with the Connecticut Cancer Plan, 2014-2017 and supports Goals 4 and 5 in their objectives to ensure that high-quality palliative care is accessible and available to all residents of Connecticut (Goal 4) and to provide the support necessary for all cancer survivors in Connecticut to enjoy a high QOL (Goal 5). Individuals undergoing cancer treatment may elect not to receive *all* forms of modern therapies from among the resources available, especially when a treatment modality (e.g., controlled or narcotic pain medications) contributes to acute confusion/delirium and subsequent impaired decision-making. Choosing against a treatment such as pain medication may be the case even if the treatment only has the *potential* to result in delirium, as an individual may refuse the treatment due to the chance of its contributing to impaired decision-making. Such choices on the part of the individual should be respected, while the goal of ensuring *both* effective pain control or treatment *and* maximum ability to be involved thoroughly in the process of shared decision-making is met as fully as possible. Effective pain management sometimes and unavoidably diminishes the full mental

capacities of the patient, thus blurring the lines between one's autonomy and the shared decision-making process that tend to characterize the patient-provider relationship. No one *wants* to be in pain; but, at the same time, no one wants to lose any more control – including one's decision-making abilities – while going through cancer treatment. Individuals requesting additional amounts of narcotic pain medication may become vulnerable to delirium, thereby treating cancer-associated pain while risking the presence of mind to make informed decisions related to QOL and the course of treatment.

As the Connecticut Cancer Partnership increases its focus on shared decision-making, this concern warrants further consideration in the 2018 revision of the Connecticut Cancer Plan.

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