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International Association for Hospice and Palliative Care Response Regarding Voluntary Cessation of Food and Water

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Dear Editor:

We appreciate the comments sent by Dr. Vickie E. Baracos regarding the International Association for Hospice and Palliative Care (IAHPC) position statement on euthanasia and physician-assisted suicide (PAS)[1] and the opportunity to respond. IAHPC believes that no country or state should consider the legalization of euthanasia or PAS until it ensures universal access to palliative care services and to appropriate medications, including opioids for pain and dyspnea.

We believe that Dr. Baracos has misinterpreted our statement regarding voluntary cessation of food and water. IAHPC is not advocating that physicians and caregivers proactively stop providing food and water to patients who request euthanasia or PAS. We agree with Dr. Baracos' statement that patients may stop eating and drinking on their own volition and initiate the process when they are ready to die. Indeed, there is no ethical, moral, or legal reason to try to prevent people from ending their lives in that way.

However, we disagree that voluntary cessation of eating and drinking leads to agonizing and extended suffering, as Dr. Baracos implies repeatedly. The reports in the published literature and our clinical experience of caring for patients who voluntarily decided to stop eating and drinking show that these patients report not feeling hungry after the first 1 or 2 days and that good mouth care can relieve thirst.[2]

IAHPC maintains that it is part of standard palliative care to listen respectfully to patients wishing for hastened death (including requests for euthanasia and PAS). As we state in our article, these requests usually reflect lack of information about disease progression, existential distress, fear of the lack of control, and fear of becoming a burden to family members and caregivers. To alleviate these fears, we recommend active communication and identification of practical solutions to resolve specific issues.

As we also state in the IAHPC position statement, there are a few patients whose strong focus on self-sufficiency, self-determination, and unmet need to maintain control over the timing and method of their death causes distress. Voluntary cessation of fluid or nutrition with appropriate and adequate symptom control (palliative) measures may offer these patients relief. Even in such cases, with palliative care interventions, some patients may change their minds,[3] whereas others proceed with their decision to stop drinking and/or eating.

IAHPC recognizes that voluntary cessation of hydration and nutrition hastens death. Respecting the patient's wishes, as we recommend, means not providing artificial hydration and/or nutrition and providing appropriate control of symptoms that may occur under such circumstances. Without food, patients may live several weeks. Without fluids, death usually occurs within a week.

To fulfill ethical requirements, such a course of action means that the patient must clearly and consistently articulate the desire to stop eating and drinking. Patients and family members must also have full information, both about the process and the symptom control measures, and about other aspects of nutrition such as the social ties related to sharing food, or preparing food for a loved one. Provision of such information is part of a holistic approach delivered by a multidisciplinary team in constant communication with patient and family.

IAHPC is not, under any circumstances, recommending that healthcare providers withhold fluids and nutrition against a patient's will, or leave a palliative care patient with no alternative but to die of thirst or starvation against his or her will. Only after a patient has clearly expressed his or her wish for this course of action, voluntarily chooses to stop fluid and food intake, and only if such a patient is facing the end of life should a palliative care team respect and honor such a wish while continuing to provide appropriate care, including control of symptoms and distress.

Many symptoms such as anorexia, dysphagia, and delirium can impair oral intake. Coupled with refractory cachexia, such symptoms contribute to persistent weight loss and decreased quality of life. In addition, patients in the last days of life often have inflammatory response, hypermetabolism, and an overall catabolic state, resulting in persistent weight loss and functional decline, even when the starvation component can be addressed.[4] It is inhumane to force feed a patient who is terminal, and doing so does not result in any improvement in the survival or quality of life. On the contrary, such procedures are invasive and have negative effects.[5] Hydration

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may be considered on a case by case basis, taking into consideration the benefits and the patient's wishes.

Dr. Baracos is a renowned cachexia expert, and her arguments reveal her deep dedication to the care of vulnerable patients. They also demonstrate that this is a very emotionally charged topic, something that we also experience when we discuss this issue with patients' family members, palliative care teams, or other colleagues. Caring for patients who have decided to stop eating and drinking raises complex ethical problems that require a team approach and individualized discussions with each patient and family.

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