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CLINICAL PEARL
Artificial Hydration in Pediatric End-of-Life Care
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As recently as 100 years ago, prior to the widespread use of life-extending medical technology, death occurred at home. The dying person gradually stopped eating and drinking, coma soon followed, and death occurred from the underlying illness.

This was an accepted practice at the time, but today there is some controversy about the withholding of medical nutrition and hydration at the end of life. While the dying person admitted to an acute care setting at the end of life is likely to receive medically provided fluids, the person in palliative care generally does not [1]. Health care professionals (including pediatric specialists), caregivers, and patients differ in their views about providing or withholding medical hydration at the end of life [1, 2]. Families and caregivers often want to hydrate patients, partly because of some commonly held assumptions about its medical benefits and harm prevention.

Dehydration is uncomfortable and withholding hydration increases suffering.
Palliative care professionals overwhelmingly report that dehydration at the end of life results in a peaceful, comfortable death. This seemingly counterintuitive phenomenon may be explained by the differences between the type of dehydration experienced by the person dying of an underlying illness and the other types of dehydration, as well as the beneficial physiologic sequelae of dehydration and the lack of caloric intake that often accompanies dehydration in this setting. Both hyponatremic dehydration—which can be caused when a person who has rapidly lost both sodium and water (e.g., from vomiting or endurance athletics) rehydrates only with water—and hypernatremic dehydration—which can be caused, among other things, by evaporative loss from large burn injuries—can lead to headache, abdominal cramps, nausea, and vomiting [3-7].

Most people are familiar with only with these types of dehydration. Isotonic dehydration (also called terminal dehydration), on the other hand, refers to the gradual, concomitant loss of sodium and water that occurs as the dying person decreases intake of food and fluid during the last days of life [4]. Thirst is generally mild. The most common complaint is dry mouth. Symptoms associated with the aforementioned other types of dehydration are generally not reported [8]. The patient eventually becomes dehydrated but is neither hyper- nor hyponatremic.

Isotonic dehydration actually appears to have some benefits. Patients entering terminal dehydration seem to require less pain control than those who receive hydration. Changes in metabolic state may contribute to decreased awareness.

Animal studies suggest that water deprivation results in higher levels of dynorphin, a potent opiate released by the hypothalamus [9]. At the same time, the shift from utilization of glycogen for energy to the breakdown of fatty acids as food intake diminishes results in ketone production. Rat studies suggest that an analgesic effect due to the former is experienced after 24 hours of food deprivation [10]. Observation of fasting humans suggests that ketosis provides an anorexic effect; furthermore, feelings of well-being and euphoria have also been reported by fasting adults [11, 12].

Dehydration causes biochemical abnormalities that cause discomfort. Abnormalities that develop appear to do so whether patients receive hydration or not. Patients terminally ill with abdominal cancer who did not receive hydration at the end of life rarely demonstrated hypernatremia or hyperkalemia [13]. BUN and creatinine increased as the end of life approached regardless of whether the patient received IV hydration [13].

Hydration is medically possible, so it should be provided. Medically provided hydration is viewed in law and ethics as a medical treatment, which means that, like other medical treatments, it can be withheld or withdrawn if it does not provide the desired benefit, or if the treatment creates a "disproportionate burden." Treatments considered to be palliative, on the other hand, cannot be withdrawn. There is no ethical or legal distinction between withholding artificially provided hydration and withdrawing it after it has begun [14].

Hydration may help with symptom relief. Expectations of hydration therapy's benefits are frequently exaggerated; though it does have some positive effects, they are very limited. Patients and caregivers (including professionals) often believe that dehydration will cause dry mouth and thirst and that hydration will prevent mental status changes. Prior personal experiences with dehydration reinforce this belief. Hydration, however, does not appear to affect fatigue [15], seems to have less effect on delirium as the end of life approaches, and has no effect on delirium resulting from organ dysfunction [16].

Dry mouth and thirst are the most common symptoms reported by dying patients who do not receive hydration, but dry mouth is not relieved with hydration [17]. Good mouth care is more beneficial in relieving dry mouth than hydration [18]. Thirst seems to be a nonspecific indicator of fluid status in the terminally ill and can be affected by other factors such as medications, sequelae of treatment, mouth breathing, and stomatitis [19].

That is not to say hydration therapy is without benefit. It was shown to reduce hallucinations, myoclonus, and sedation in a group of terminally ill cancer patients [15]. Opioid-induced neurotoxicity, a constellation of symptoms including sedation, mental status changes, and myoclonus caused by the accumulation of products of opioid metabolism, may be reversible with hydration, although data are not conclusive [20].

Burdens of Treatment

Not only is hydration often much less beneficial than assumed, but, in fact, it can bring about unwanted effects. Hydration may result in a variety of symptoms related to fluid retention, including peripheral edema, increased ascites, and pleural effusion [19]. Other reported symptoms and side effects include increased respiratory secretions, congestive heart failure, and increased gastric secretions resulting in nausea and vomiting [7, 8, 20]. Hypoalbuminemia from overhydration, which has been associated with IV hydration [13], disrupts oncotic pressure, which promotes peripheral edema. Other burdens of hydration therapy include lack of mobility, possible need for restraints, increased potential for bedwetting, need for changing or use of catheters, pain at insertion site, and barriers to physical closeness.

These unwanted effects of hydration may stem from the volume of fluid provided. Some studies have demonstrated that adequate hydration for terminally ill adult cancer patients can be achieved with lower fluid volumes than would be expected for medical or surgical patients [6]. Possible explanations include changes in body composition, weight loss, decreased insensible losses, and decreased renal function, factors which are also associated with aging and may not be applicable to children.

The Social Context

Though families may understand and respond to discussion of the benefits and drawbacks of hydration as a medical treatment, the emotional significance of withholding hydration is more difficult to overcome. The offering of food and beverages is universally experienced and recognized as a sign of love and caring. Feeding one's child is an essential part of parenthood. Ellyn Satter suggests that, in the ideal feeding relationship, the parent provides foods that are nutritious and easily managed by the child, and the child eats what he or she wants. When feeding does not go well, the parent's perception of his or her effectiveness as a parent suffers [21]. Refusal of food and fluids may be perceived as rejection of the caregiver and takes away a significant way for the caregiver to show love and support. For the parent of a dying child, this emotional distress is compounded as declining intake indicates that the disease is progressing to the end of life. Often caregivers will suggest that a child "would get better if he would just eat."

Determining Appropriate Treatment

Decision making for treatment must balance these understandable emotional responses and the child's and family's goals with the medical reality of the child's condition [22, 23]. The health care professional must weigh the risks and benefits of reasonable treatment with the comfort and interest of the child as the major consideration [23]. Consultation with the family's spiritual provider should also be sought, inasmuch as faiths differ greatly in their recommendations for the use of hydration at the end of life. But first and foremost, the child who can ask for fluids and who can safely consume them should have fluids offered. Often the small amount of fluid that is consumed by mouth is adequate to promote symptom relief.

The subjects of research regarding hydration status in the terminally ill are older cancer patients, and care must be taken when extrapolating these results to the pediatric patient. Children are at higher risk for fluid deficits due to increased total body water and insensible losses and generally have more intact renal function than older adults. The thirst mechanism in response to hydration status is more intact in the pediatric patient than in the older adult.

Current evidence suggests that hydration does not improve overall quality of life in patients within days to weeks of death, but may be some benefit for those patients with longer life expectancy [16]. Children and families should be informed that the gradual decrease in oral intake is a natural part of the dying process. If hydration is considered at the end of life, physical exam should focus on signs of fluid deficit, determination of etiology, and assessment of the effects of these symptoms on quality of life. Therapy decisions must be individualized, with patient comfort as the primary goal. Discussion with the child and family should center on realistic expectations for therapy. Health care professionals who are involved in the discussion of this topic and subsequent care of the child should come to a consensus as a team prior to presenting options to the family; open dissent among team members is distressing to patients and families.

Families should be informed that hydration may help to ameliorate some neurologic symptoms including delirium, mental status changes, and opioid-induced neurotoxicity [19]. Hydration is not likely to improve symptoms of dry mouth or thirst, however, but these symptoms can be easily managed with other measures, such as good mouth care and small sips of fluids. The burdens of hydration therapy should also be discussed.

A time-limited trial of intravenous hydration with clear definitions of the goals of treatment, length of trial including specific beginning and ending dates, and criteria for withdrawing treatment is useful to evaluate the potential benefit of initiating hydration therapy [22]. Lower volumes of hydration are associated with fewer deleterious effects; initiation at 50-75 percent of maintenance is an appropriate starting point with careful evaluation of subsequent fluid status and effect on distressing symptoms. Only if the goals of treatment have been met at the re-evaluation date should treatment continue [22].

Children and families should be informed that hydration can be withdrawn or withheld if desired, or if no benefit is observed, and be assured that the child will continue to receive appropriate care and management of symptoms whether hydration is continued or discontinued. Regardless of the decision made, families should receive support, including the suggestion of alternate ways for them to care for the child and assurance that all measures that could provide comfort have been attempted.

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