



Can I Give Food or Drink To My Terminally Ill Child?

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ARTICLE INFO

Received : 15/05/2015
Accepted : 30/05/2015
Published : 15/09/2015

KEYWORD

Withdrawal nutrition
End of life care
Palliative care
Ethical dilemma

ABSTRACT

Food is considered as a social responsibility of caregivers to their children. It has cultural connotation for all races notwithstanding their background and religious belief; that social responsibility should not be separated even in terminally ill patients. We recorded a case scenario of a terminally ill child who faced difficult end of life with inability to take oral fluids or food due to mechanical obstruction of duodenum by the pelvic rhabdomyosarcoma. From cultural context, the physical act of giving food and fluids to a sick person is considered "a display of one's affection". It is understandable that, once the dying phase has reached, and the body starts to shut down, administering fluids may not be useful despite it is deemed necessary from cultural point of view. This case illustrates an ethical dilemma in managing a child with end stage metastatic disease with multiple systemic complications, compounded with futility of medical care and complex social circumstances. It is quite challenging for physicians and relatives to provide good end of life care to patients in palliative care setting. Ensuring good quality of care, quality of life and quality of death are paramount to avoid suffering and distress among the patients and family members.

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Introduction

Artificial nutrition is a method used to bypass swallowing process by nasogastric tube, nasojejunal tube, gastrostomy tube or by total parenteral nutrition via a vein. Giving food or fluids is regarded as a symbol of continuing life. It is one of the basic needs that we provide to individuals that we cared for. Food and water play an important role in social and cultural rituals, and are associated with reward, punish, or demonstration of love. They represent form of care that can never be withheld or withdrawn,

especially from the children. In general, refusing to provide food and nutrition to a human or any other living being is considered as culturally unacceptable, uncompassionate and uncared action.

In palliative care setting, withdrawing or withholding nutrition poses a challenge. When a patient is at the terminal phase of life, food and fluids may no longer be required when medical treatment is futile and death is the ultimate outcome. In contrast, in a patient who is terminally ill and able to perform some physical

functions, withdrawing of nutrition can be rather contentious due to social duty and obligation. Mutual decision between the caregivers and physician should resolve matters such as abandonment or discontinuation of care, including withholding and withdrawing of nutrition or fluids.

Case Summary

A 4 year old girl with the background of relapsed pelvic embryonal rhabdomyosarcoma presented to our hospital. She had completed her chemotherapy and multiple attempts of curative and palliative surgeries in the other oncology centre. Her tumour became aggressive leading to multiple complications such as obstructive uropathy, proximal bowel obstruction, liver and nodal metastasis. In view of her advanced and incurable disease, she was planned for home death following discussion and consultation with the family members.

During her admission, she was found moody, and uncooperative for ambulation. She was not even engaged in conversation with her parents and staffs. Interaction was difficult mainly stemmed on multiple unsettled social and medical issues especially in term of pain relief. Graded increment of morphine dosage was given according her pain score response.

Her second problem was related to uncontrolled vomiting episodes following overgrowth of her tumour in the pelvis extending vertically leading to small bowel obstruction. This has drained her energy out and she became exhausted clinically. Complete obstruction was confirmed from the abdominal Computerized Tomography imaging. She wanted to drink, however, due to violent retching and vomiting, she was continued on intravenous fluids only. The paediatric surgical team opted for conservative approach, rather than aggressive surgical approach to bypass obstruction or venting colostomy, primarily due to her health frailty. Drugs such as octreotide, buscopan, granisetron, dexamethasone and pantoprazole were tried with minimal effect to her symptoms.

Her mother voiced concern on her eating and drinking capacity. At that stage, she was still alert, able to converse and request for drinks despite vomited back out shortly afterwards. The palliative care team decided to continue on intravenous fluids and total parenteral nutrition temporarily, and plan to get support in the community team should she be allowed to die at home .

She is the youngest out of 2 siblings and the parents have been divorced for last year. Since then, her mother has moved to stay up with her relative. The patient has voluntarily expressed her desire to stay in the hospital due to her illness and inadequate pain relief. Liaison with community palliative care team was done to provide continuous nursing care, family support and prevent negative family perception such as abandonment. Getting the family members together for counseling could be a daunting task due to some family members living separately in the other state.

Ethical Issue Discussion

Before we embark on the discussion, there are a few ethical issues that has to be clarified

- a) When do we decide to withdraw or withhold nutrition in terminally ill children?
- b) Is it permissible to withdraw or withhold fluids for dying children following consideration of cultural, moral, social and religious context?
- c) What is the primary goal of giving treatment such as fluids in a futile outcome scenario?

Palliative care in children differs from adult because of by proxy decision making. The complexity of the illness also includes whole family involvement, social influences, consideration on continuous emotional, cognitive and physical development. The objectives of care are focused at restoring health, maximizing benefit of care and minimizing potential harm from the planned care or treatment. If this is no longer possible and beneficial, then presumably the treatment given is not required. End objective

should be geared towards agreed goals, either curative or palliative mean.

Withholding or withdrawing treatment and care has long been debated in palliative care. Decision must be based on individual merit whether life prolonging treatment, including medical assisted nutrition or fluids, has potential beneficial outcome or not.

Why important

It is obvious that, the parents' role is in providing appropriate nutrition to sustain continual growth and health status for their children. The parents' duties also cover attending and fulfilling medical needs of their children should they become ill [1].

In Islam, children are valued and respected as individuals with inherent rights and they have the right to be treated with respect and without violence. The Islamic ethical rule stressed that harm should be prevented in Islam. The prevention of harm overrides a benefit of equal value, but if the benefit outweighs the harm, then priority is given to that objective. If a situation requires a choice between two possible harmful actions, the action that will cause the lesser harm is chosen to avoid the greater harm [2]. Hastening death from withdrawal of fluids or nutrition is forbidden. However, in circumstances where the treatment is futile, Islamic laws have allowed taking views after considering Islamic laws (Syariah), consensus of muslim jurist and analogical deduction. The purpose of these laws is to protect and preserve life, religion, progeny, wealth and intellect. If the guardian or patient refuses fluids or nutrition knowing deteriorating of the quality of life, the decision can be tricky because of patients and parental autonomy. Majority of muslim jurists insisted that once treatment has been intensified to save the life of a patient, life-saving equipment or medication cannot be turned off. Withholding or withdrawing treatment from any patient is therefore never easy and can never be generalized.

Despite the controversy, physicians come across situation where no oral alternative of fluids or nutrition in the palliative care management. One has to establish at that stage whether fluid or nutrition is considered as medication or daily requirement. There is no conclusive agreement for giving medical assisted nutrition or medical assisted hydration in the terminal phase of life. Extra fluids may cause over hydration in a dying phase, hence it causes unnecessarily fluid retention or increases respiratory secretion in the lung. This is contradicting the second ethical principle of non-maleficence. Giving fluids in a low metabolic state, such as terminal phase, may accelerate death. In addition, most terminally ill patients are unlikely to suffer from hunger or thirst and from the reduction of artificial nutrition or hydration [2].

Withdrawal's action was subjected to many factors - relieving of the suffering, financial constraint, faith, time, rejection, mistrust of the doctor and individual's intuition. Keeping dying patients dry at terminal phase of the illness may have good outcome and comfort. Although it is not surprising that these patients may have shorter life span, the burden of starving ill and young child can be a devastating task.

Literature reviews

Withdrawing and withdrawing treatment has been associated with many ethical issues such as professionalism and euthanasia. Children are unable to make autonomous decisions because of their immaturity and understanding according to their developmental milestone. In certain countries, Gillick competence [3] has been exercised, but this is not a universal factor in deciding the best interest of a child. Decision making in Malaysian children is mostly by-proxy. Parents have the ultimate say in the decision making based on the information given by the physicians. Gilliam et al argued that parental decisions do not have an absolute ethical weight. In circumstances where parental decisions cause significant harm to a child, appropriate intervention should be on the best interest of the child [4].

Feeding has been long considered to have emotive connection and has been part of basic element of the child's care. Children who cannot experience nurturing through feeding may have different type of needs. Medically provided fluids and nutrition are withheld or withdrawn under 2 conditions: (1) when a competent person has refused the intervention; or (2) in the case of persons who have never possessed decision-making capacity, this is done by a surrogate decision-maker in consultation with the physician [5]. In a child who is experiencing thirst or hunger, fluids and nutrition will be an essential element of palliative care. However, these actions may not be comforting for the child at terminal phase as this may serve to prolong the dying process without any purpose. The American Academy of Pediatrics supported the withdrawal of nutrition in limited circumstances. Decision usually falls within the authority of parents or guardians in consultation with the child's physician [6].

Withdrawal of artificially administered nutrition could also be viewed as "starving a patient to death". In paediatric populations, gastrostomy or nasogastric tube feedings or parenteral nutrition are the options available should oral feeding failed. The final goal and purpose of nutritional and fluids intervention must be clear whether it leads to a better quality of life, or slow death or much rapid growth of the cancer following aggressive nutritional intervention causing worsening of the symptoms.

Feedings is a necessity to sustain life. However, if it is done inappropriately, it may lead to a slow death process and 'bad death'. Providing measurable feeding action may be seen as first measure of comfort and care. This serves to satisfy hunger, quenching thirst, avoiding hunger "pains" that will allow for more interaction and communication between the patients and other healthcare workers. Moral values and prognostication play an important role in determining whether or not to withdraw or withhold the fluids. But if agreed decision is made, it is vital to withdrawing both nutrition and hydration together to avoid prolonging purposeless life of the patients.

'Good death' refers to spending final hours appropriately to improve the quality of life of a patient [7]. This includes adequate pain and symptom managements, avoiding a prolonged dying process, clear communication about decisions by patient, family and physician [8]. Among the factors which are considered as good death are 1) to be able to retain control of what happens 2) To be afforded dignity and privacy 3) To have control over pain and other symptoms. If these are the basis, would withdrawal of fluids or nutrition fit in the framework of 'good death' or does good death related to the whole process and experience rather than stated factors?

Actions

This case highlights fundamental difficulties when dealing with complex case as illustrated. Decision made should be tailored to Malaysian context in term of cultural, socio-demographic and religious requirement. We first decide the status of fluids or nutrition whether this has social influence or patient right or intervention is considered as part medical management. In our context, we believe it has both social and medical weight. A terminally ill child may be easier to withdraw by knowing trajectory of the disease. In a child who was not in the dying phase, withdrawing or withholding can be a difficult proposition. Prognostication in children is somewhat challenging. We faced dilemma between abandoning oral fluids requested which causing more stress and harm versus fulfilling her needs despite futility of our intervention. The hypothetical approach would be by creating venting gastrostomy to avoid mechanical obstruction of the duodenum, and allowing her to take orally and fluids easily drained through that. However, this was not possible due to her health frailty. We believed that harm outweigh the benefit if surgical intervention is performed.

At final phase of life and patients starts to die, putting fluids is detrimental to her health state. Administering fluids to terminally ill patients can accelerate death. A child who is at the terminal phase of life but still active, determination of when the fluids can cause harm is difficult. Appropriate time to withdraw fluids must be

recognized only when the child at dying phase. When the care is futile, communication with the family members and providing support is vital at that stage. Recognizing family's request and respecting their opinion can lead to mutual understanding to reduce the suffering of the patient. Best interest in this scenario is not for medical team to show abandonment. We have to consistently question our current goal of care – to balance the aim of giving fluids either to buy time or comforting effort. Parents have to be equipped with the sign of dying phase because it helps to decide on 'allowing natural death'. The patient has personally requested to be in the hospital knowing of her ill health status. We believe this has given psychological benefits to the patients and family to get support and multidisciplinary team involvement.

Risk-benefits - outcome concept is also an important help in deciding future outcome. The potential benefit from social point of view related to caregivers' fulfilling role towards their children. Quality of life of a patient is best viewed on how much symptoms can be relieved and what function can be achieved. In our scenario, there is possibility of withdrawing fluids to avoid violent vomiting episodes, but this was not performed considering cultural context and insisted request made by patient to taking on fluids.

Best interest is also a terminology which can have different operational definition. The best interest from the patient point of view may be different from the family or the physicians' point of view. Terminology to associate fluids and nutrition as medicine can be contentious. These two elements are essential component to sustain life. Goal of care with agreement on the family and patient wishes must be allowed to prevent unnecessarily prolongation of life, harmful effect of the treatment and potential complications following our decision. This has to be tallied according to emotional, religious, cultural factors as additional consideration.

The final verdict must be based on the palliative goals ie to give comfort and relieve suffering. Although the decision may tilt either way, either

to support or reject withdrawal fluids or food, careful resolution must be based on holistic implications in term of medical, cultural, religious and potential health impact of the patient in the near future.

Conclusion

Withdrawing and withholding fluids and food is a challenging task. Although many angles have been looked upon, however, many questions have been raised to ensure decision making is not manipulated. In children, parents need to be educated to choose what is appropriate according to their rights and best interest of their children.

Acknowledgment

I would like to thank the staffs at Hospital Universiti Sains Malaysia and the Kelantan Foundation for Disabled People (YOKUK) for directly or indirectly involved in the care of our palliative care patients.

Reference

1. Al-Azhar University. Children in Islam: Their Care, Development and Protection. International Islamic Center for Population Studies and Research. 2005. <<http://www.unicef.org/egypt/Egy-homepage-Childreninislamengsum28129.pdf>>
2. Alsolamy S. Islamic views on artificially nutrition and hydration in the terminally ill patients. *Bioethics*. 2012; 28: 96-99.
3. Hayhoe B. Decision making in children and Young People: Gillick competence? *InnovAiT*. 2008; 1: 764-770.
4. Gillam L, Sullivan J. Ethics at the end of life: Who should make decisions about treatment limitation for young children with life-threatening or life-limiting conditions? *Journal of Paediatrics and Child Health*. 2011; 47:594–598..
5. Diekema DS, Botkin JR. Clinical Report—Forgoing Medically Provided Nutrition and Hydration in Children. *Pediatrics*. 2009; 124:813–822.
6. American Academy of Pediatrics, Committee on Bioethics. Guidelines on forgoing life-sustaining medical treatment. *Pediatrics*. 1994; 93: 532–536.
7. Taib F. Is there a 'good death' among children with life limiting illnesses? *Malaysian Journal of Paediatrics and Child Health Online Early*. 2011.

8. Zahedi F, Larijani B, Bazzaz JT. End of Life Ethical Issues and Islamic Views. *Iran J Allergy Asthma Immunol.* 2007; 6: 5-15.
9. Jones BJM. Ethics and artificial nutrition towards the end of life. *Clinical Medicine.* 2010; 10(6):607-10.
10. Carter BS, Leuthner SR. The Ethics of Withholding/Withdrawing Nutrition in the Newborn. *Seminars in Perinatology.* 2003; 27(6):480-487.