Introduction

Do-not-resuscitate (DNR) order has been reinforced legally in end of life, but there is no definite evidence when to stop artificial nutrition and hydration. The role of artificial nutrition and hydration in the last days or weeks of life is discussed with patients and family. There is no right or wrong in this issue, but giving best quality of life is what we care. One study revealed 71% of patient’s family survivors felt distress and grief about voluntary stopping of eating and drinking. Giving well known information in advance becomes very important. We hope all patients could preserve autonomy and control at the end of life.

Cultural differences and background knowledge will affect the decision making. Health practitioners have the responsibilities to provide clear, easy-to-access information and advice which will improve doctor-patient communication. Over the past decade, there have been more and more tools supporting patients and family to involve in medical issues. Shared decision making (SDM) is a process in which doctors, patients and family work together with the best available evidence when facing highly uncertain medical questions. The model of SDM has three steps: a) introducing choice, b) describing options, and c) helping patients know preferences and make decisions.

We establish one patient decision aid about providing artificial nutrition and hydration in end of life. This model rests on supporting a process of deliberation, and on understanding that decisions should be influenced by exploring and respecting “what matters most” to patients as individuals, and that this exploration in turn depends on them developing informed preferences.

Materials and Methods

Hospice-and-palliative-care team found that patients within terminal stage and families often raised questions about fluid and nutrition supplement. There was only 51% in correct rate of cognitive accuracy in these patients from one study since February 2017, so the team promote SDM in corporation with the government policy. In March 2017, we based upon Ottawa Decision Support Framework to design the interactive assessment in these patients by “Living within terminal stage of cancer, should I receive nutrition or fluid supplement?”. During April and June in 2017, for the patients within cancer terminal stage having questions about nutrition or fluid supplement questioned we provided assist tools in SDM, so that patients and their families could fully understand the pros and cons of nutrition or fluid supplement and the effectiveness of the treatment from view of evidence based medicine to help them make their final decision. So that the care team could better understand the patient and family’s decisions, stay with the patient to the last stage of their life.

Results

Evaluation of the patient and family members for the help of nutrition or fluid supplement in decision-making process, the patient and family satisfaction all improved, this tool could help the medical team members in more clearly explaining the decision-making content to the patient and family, in more easily reading the information to obtain more detailed empirical results, in more easily analyzing the nutrition or fluid supplement linked with different dimensions. Besides, the medical team through the decision-making process can also understand different minds among patients and their families and respect for the family members in the decision-making process. In the near future, results of this study can also be extended to the diseases full of medical uncertainties, complex and multiple choices, medical treatments lack of evidence and life-threatening risks... etc.

Conclusions

Shared Decision Making (SDM) is a process by which the clinician, patient, and family contribute to the medical process. The goal of SDM is to facilitate the doctor-patient communication and make treatment decisions that are consistent with the Patients’ and Family Members’ goals, and preferences. The implementation of SDM is the use of aids, including a written, video or interactive electronic tool designed to inform patients and their families about the choice of care, each of the benefits, side effects, and even cost. Not only to increase patients’ and family members’ knowledge, compliance and , but also reduce patients’ anxiety, unnecessary care or extra cost. We designed a patient decision aid (PDA) focusing on the role of the artificial nutrition and hydration in end-of-life cancer patients who are in the last days or weeks. There have been a few evidences in such issues which have no right or wrong answers. The PDA discuss knowledge, comparison with treatment or not treated, and then lead the patients and family to choose an option. The medical team could understand the patients’ and family members’ decisions and then achieve a win-win situation.