Ethical approach in nutrition and palliative care: A focus on caring for patients with advanced dementia

Perspectiva ética en la nutrición y los cuidados paliativos: un enfoque en la atención a los pacientes con demencia avanzada

Abordagem ética em nutrição e cuidados paliativos: um enfoque no cuidado de pacientes com demência avançada

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Summary

Palliative care (PC) is an aspect of healthcare that is receiving increasing attention. As with other areas of medicine, PC is influenced by what can be done technologically, what should be done ethically, and what must be done legally. I.e., the Troubling Trichotomy. This article deals primarily with the ethical perspectives of PC and nutrition. While two of the authors are from the U.S., a third provides a valuable international perspective. A brief introduction on ethics includes a discussion of the components of principalism, currently the most commonly used ethical approach across the world, including the Cartagena Declaration.

The success of interventions dealing with PC depend on accountability, communication and teamwork. The various roles of the different stakeholders, including the individual/family/surrogate decision-maker, treating healthcare team, PC team, and healthcare facilities, are discussed.

Patient-centered care requires effective communication. In complex cases, a number of specific recommendations by the treating PC team are required to reach this goal. A basic pre-requisite for a successful communication is differentiating PC from hospice care.

Resumen

El cuidado paliativo (CP) es un aspecto de la asistencia en salud que recibe cada vez más atención. Como ocurre con otras aplicaciones de la medicina, el CP está influenciado por lo que se puede hacer desde la perspectiva tecnológica, lo que se debe hacer desde la ética y lo que se debe hacer desde lo legal, es decir, la Triple Perspectiva (*Troubling Trichotomy)*. Este artículo trata principalmente de las perspectivas éticas del CP y la nutrición. Si bien dos de los autores son de Estados Unidos, un tercero ha proporcionado una valiosa visión internacional. Una breve introducción a la ética incluye una discusión de los elementos del Principialismo, enfoque ético más común que se utiliza en la actualidad en el mundo, incluida la Declaración de Cartagena.

El éxito de las intervenciones relacionadas con el CP depende de la responsabilidad, la comunicación y el trabajo en equipo (ACT, por sus siglas en inglés). Se discuten los diversos roles de las diferentes partes interesadas, incluido el tomador de decisiones en el plano individual / familiar / sustituto, el equipo médico tratante, el equipo de cuidado paliativo y los centros de atención médica.

Resumo

Os cuidados paliativos (CP) são um aspeto crescente da saúde. Tal como acontece com outras aplicações da medicina, é influenciado pelo que pode ser feito tecnologicamente, o que deve ser feito com ética e o que deve ser feito legalmente, ou seja, a Tricotomia complexa.

Este artigo trata principalmente das perspetivas éticas de CP e nutrição. Embora dois dos autores sejam dos EUA, um terceiro forneceu uma perspetiva internacional valiosa.

Uma breve introdução à ética inclui uma discussão dos componentes do principialismo, a abordagem ética mais comum usada hoje em todo o mundo, incluindo a Declaração de Cartagena.

As intervenções exitosas relacionadas com o CP dependem da responsabilidade, a comunicação e o trabalho em equipe (ACT). São discutidas as decisões tomadas pelos diferentes papéis das partes interessadas, incluindo o indivíduo / a família / e o tomador de decisões encarregado (SDM), o equipe de saúde tratante, o equipe de CP e as instalações de saúde.

O cuidado centrado no paciente requer comunicações eficazes. Para cumprir esse objetivo em casos complexos, é necessária uma série de considerações especi-

We review these concepts in detail for patients with advanced dementia, including the definition, signs, symptoms, nutritional needs, and interventions. Since most individuals with advanced dementia are elderly, it is important to note that aging is a process and not a disease, and that it often mimics the signs and symptoms of malnutrition. The responsibilities of the various PC, nutrition, and ethics stakeholders are outlined, followed by an illustrative case with follow-up questions and actions.

Keywords: Palliative Care; Patient-Centered Care; Ethics; Nutritional interventions; Dementia.

La atención centrada en el paciente requiere una comunicación efectiva. Alcanzar este objetivo en casos complejos exige que el equipo de CP tenga en cuenta una serie de consideraciones específicas. Un requisito previo básico de la comunicación efectiva es diferenciar el CP del cuidado para enfermos en estado terminal *(Hospice)*.

Estos conceptos se discuten en forma detallada en lo concerniente a pacientes con demencia avanzada (DA), incluidos el diagnóstico/definición, signos, síntomas, necesidades e intervenciones nutricionales. Dado que la mayoría de las personas con esta patología son de edad avanzada, es importante señalar que el envejecimiento es un proceso y no una enfermedad que a menudo reproduce los signos y síntomas de la malnutrición. Se describen las responsabilidades de las partes interesadas en CP, la nutrición y la ética, seguidas de un caso ilustrativo con preguntas y recomendaciones.

Palabras clave: cuidado paliativo, atención centrada en el paciente, ética, intervenciones nutricionales, demencia.

ficamente por parte da equipe de CP na realização de consultas.

Um pré-requisito básico das comunicações é diferenciar o CP dos cuidados ao paciente em estado terminal. Esses conceitos são discutidos mais especificamente quando se aplicam à demência avançada (DA), incluindo a definição, sinais, sintomas, necessidades nutricionais e intervenções. Como a maioria dos indivíduos com DA são idosos, é importante observar que o envelhecimento é um processo e não uma doença que muitas vezes pode mimetizar os sinais e sintomas da desnutrição. As obrigações das várias partes interessadas em CP, nutrição e ética são delineadas, seguidas de um caso ilustrativo com perguntas e recomendações.

Palavras-chave: equipe de cuidado paliativo, cuidado centrado no paciente, ética, intervenções nutricionais, demência.

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BACKGROUND

Throughout history advances in one arena have had the potential to present challenges in others. The emergence of PC is an example of an aspect of healthcare that has prompted the adaptation/application of ethical guidelines for its management. PC, as discussed in earlier sections of this journal, has evolved because of medical technological advances that have made it possible, particularly in the outpatient setting and in nutrition interventions(1). An additional area which has adapted is the legal realm, e.g., decision-making, informed consent.

Whether in nutrition interventions and/or PC or other aspects of medicine, the healthcare professional is often confronted with the dilemmas of what can be done technologically, what should be done ethically and what must be done legally. This concept, referred to as the troubling trichotomy has been discussed elsewhere(2). Dealing with the troubling trichotomy, particularly as it relates to PC and nutrition is depicted in Figure 1. In this section the focus is on the ethical perspective of nutrition and PC.

ETHICS - A PRIMER

What is meant by ethics and how does it differ from bioethics and morals?

Ethics has been defined in several ways. The Merriam-Webster Dictionary refers to ethics as "The discipline dealing with what is good and bad and with a moral duty and obligation"(4). Ethics can also reflect a group of moral principles and a system or theory of moral values(5). Ethics is part of philosophy and according to Childress and Beauchamp "Ethics is a generic term covering several different ways of examining and understanding moral life"(6). Bioethics is the subcategory of ethics that governs the ethical behavior of medicine and biological research(4, 7).

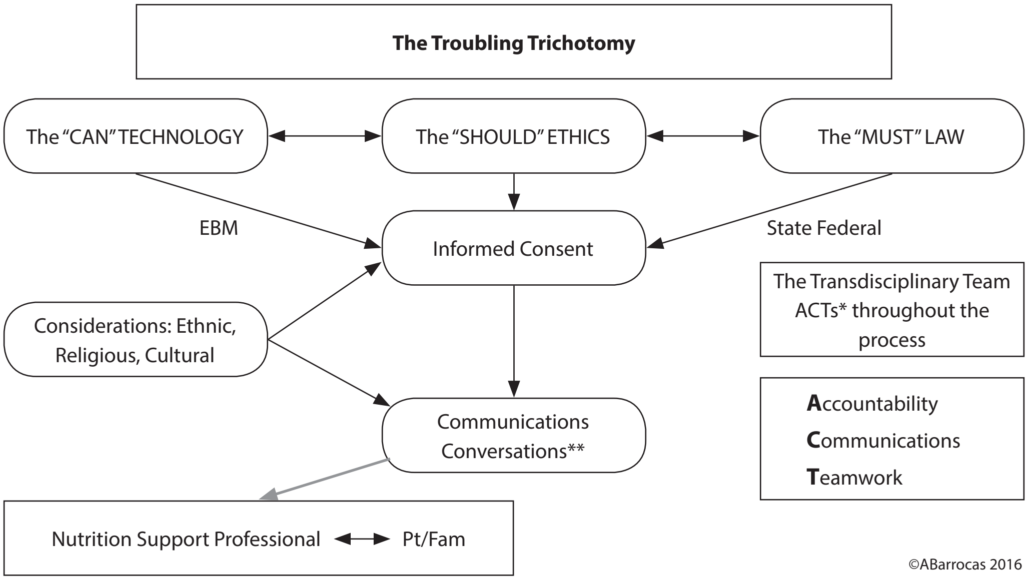

Figure 1. The troubling trichotomy (can/should/must) requires evidence-based medicine (EBM) in order for patients and/or surrogate decision-makers to provide an informed consent within state and federal statutory confines. Communications/conversations between the nutrition support professionals and the patients and families (Pt/Fam) include recognition of ethnic, religious, and cultural considerations. The transdisciplinary/cross-functional team ACTs using the acronym (accountability, communications, teamwork). Reprinted with permission and adapted from[3].

Clinical ethics

Basics of clinical ethics

Clinical ethics guides healthcare providers in the decision-making process during patient care, is grounded in medical science, law, policy, and demonstrates respect for the individual's autonomy(7). Clinical ethics application is best achieved by initially examining the process from the patient/family/SDM's perspective, rather than the healthcare clinician's perspective. The individuals who will be the most affected by the use of clinical ethics do not speak the medical-terminology language used in hospitals by healthcare clinicians, do not know what information the healthcare team needs and do not know the questions to ask the healthcare team. Previously, the healthcare team goal was to save *life and limb*. Currently, in addition to the two goals, the right goal, from the individual's perspective, is to provide healthcare based on the patient's wishes for their desired quality of life (QOL), within acceptable medical practices involving a shared decision-making process. Although morals and ethics are often used interchangeably, they are different. "Morals" refers to a value system which provides the limits of acceptable behavior by individuals and distinguishing between right and wrong conduct usually connoting an element of subjective preferences"(4). The differences between morals and ethics may be better understood by healthcare professionals if compared to more familiar terms and practices. On the one hand, morals are the policies (values) while on the other ethics (bioethics) are the procedures (behaviors) of how the policies are implemented in the context of appropriate (right) behavior.

What are moral (ethical) theories?

Moral, the most appropriate term, but sometimes referred to as ethical, theories are philosophical approaches serving as guides for how many ethical standards are implemented in specific situations through ethical reasoning. In essence they form our moral decisions(7). Ethics concerns with what we ought to do, not what we do. Ethical theories are formal, coherent, and justified statements about our behavior when faced with an ethical dilemma(8, 9). There are numerous ethical (moral) theories. The four commonly referred to are: Virtue (Socrates, Plato, Aristotle), deontology (Duties-Kant), utilitarianism (Consequentialism-Kant) and principlism (Beauchamp and Childress), the latter being an ethical approach rather than a true theory.

Virtue (innate character of the good person)

Virtue ethics is based on the right and wrong of an individual's character. It is anchored on the concept that the right action is the one a virtuous and good person would do in a particular situation. Aristotle, expanding on earlier teachings of Plato and Socrates, proposed "ethica" having to do with character. He believed that living in line with reason, an ability that is unique to human beings, can be "described as existing in a state of eudaimonia, the condition of human flourishing or living well," e.g. happiness, to further elucidate virtue ethics. A virtuous character is one that incorporates habits of courage, compassion, fidelity, honesty, and integrity(6-10). As an illustration of virtuous action, offering a time limited trial of artificial nutrition and hydration (ANH) for a permanent vegetative state (PVS) patient is a demonstration of respect and compassion.

Deontology (duties)

Immanuel Kant, one of the most significant philosophers in deontological ethics, described the categorical imperative as a philosophical formulation of the "golden rule". Decisions are based on the maxim of the motivation (means), not their results (ends). Deontology also affirms that ethical decisions must be universal as absolute judgements or duties. The intention of the agent, not the consequences determines the rightness or wrongness of decisions. An example of deontological practice would be proposing that all human beings, including those with PVS must be provided ANH, regardless of other considerations(6, 8, 10).

Utilitarianism (consequentialism)-The greatest good for the greatest numbers. Results rather than intentions

As opposed to deontology, utilitarianism affirms that the results (consequences), not our intentions (means) should direct our decisions and actions. This ethical theory, associated with John Stuart Mill, the English philosopher, supports the premise that the decisions that provide the greatest good for the largest numbers of individuals are the most ethical. Right and wrong is determined by the overall goodness of the consequences of action, thus the recognition of utilitarianism as a consequentialist moral theory(7, 11). Utilitarianism concepts are part of discussions regarding healthcare policies, economics, and allocation of resources as a recently observed during the COVID-19 pandemic(7, 12).

Principlism

Perhaps the most often ethical approach today is that of principlism *(autonomy, beneficence, nonmaleficence, justice)*, initially proposed by Beauchamp and Childress(6). The approach is based on four principles: autonomy, beneficence, nonmaleficence, and distributive justice detailed in Table 1.

Beauchamp and Childress indicate that the four principles embrace the cornerstones of our "common morality" referring to the central moral requirements essential to modern medicine(6, 7). Their approach provides, in a concise fashion, a way for healthcare professionals and other care givers to engage in deliberations more systemic and accessible(7). Dilemmas are resolved via the weighing the balance and specifications of the four basic principles. This approach is quite applicable in shared decision-making in a patient/family-centered healthcare environment in discussion and decisions regarding nutrition and other interventions in PC.

Regardless of the moral theory applied, as healthcare professionals approaching the issue of nutrition PC and ethics, we should always remember the admonition of an unknown anonymous source: "Cure sometimes, treat often, comfort always" (unknown author) (Figure 2).

Figure 2. Goals of healthcare professionals.

INTERNATIONAL PERSPECTIVE

Advances in medicine, the increase in life expectancy, the prevalence of chronic and progressive diseases with little possibility of response to therapy, and, multiple and changing conditions, have increased the number of patients requiring PC(13). Cardiovascular, respiratory, liver, neurological, autoimmune diseases, cancer, AIDS, kidney failure, multiple sclerosis, congenital anomalies,

Table 1. Principlism(6)

Principle	Characteristic
Autonomy	- Patients should be treated as autonomous agents. This means recognizing the individual's capacity for self-determination, their ability to make independent decisions and authentic choices about how they want to be fed/if they want to be fed or not, based on personal values and beliefs - Informed consent should be based on EBM, with prognosis and risks/burdens/benefits with and without nutritional interventions - Autonomy does not translate into an individual demanding a particular intervention that is not acceptable to the healthcare team, as it is not EBM, or if the burdens/risks outweighs the benefits - The concept of autonomy/self-determination parallels that of the US legal system
Beneficence	- In the best interest of the patient. Medical nutrition therapy should maximize potential benefits for their patients. Caregivers must follow professional obligations and standards. Caregivers must provide appropriate nutrition therapy following a medical indication and the consent of the patient - Supports patient-centered and shared decision-making care - Incorporates some of the older moral theories-virtues, duties, etc. - Treating the patient, family and SDM with respect and dignity assures them that the providers have the best interest of the patient as a central focus - Provides for confidential information to be protected promoting trust and well-being of the individual - Without honest communications the potential distrust and non-maleficence exist. Active listening is a major component of communications
Non-maleficence	- *Primum non nocere*-First do no harm- The prime directive is to prevent, minimize and relieve needless suffering and pain - The risks/burdens and potential complications of providing and forgoing interventions, e.g., ANH in PC must be thoroughly and honestly discussed with patients and/or family and surrogates
Distributive Justice	- Every individual is entitled to be treated fairly with an equitable process without regard to non-clinical factors, e.g. ability to pay for care - Treatment decisions should be based on clinical standards of care, EBM, patient and family preferences and institutional policies which should include resource allocation and triage policies

ANH: Artificial nutrition and hydration; EMB: evidence-based medicine; PC: palliative care.

and Alzheimer's among others, paint a real and alarming panorama. PC is a modality that helps to mitigate the emotional impact related to the anticipation of death and survival prognosis that these have on the patient, family and therapeutic team. The latter provides a support system to help patients lead an active and comfortable life, as much as possible, until their death(14).

The World Health Organization (WHO) estimates that each year 40 million people need PC, with the majority of them living in under-developed countries with limited or no access to PC(15). A study of 234 countries, territories and regions conducted by Lynch et al. found that PC services are only properly integrated in 20 countries, 32% had a limited service, and 42% lacked PC service(16).

The genesis of this unfortunate situation is made up of a wide variety of factors and nuances, such as: ignorance of the concept and benefits of PC among the different stakeholders of the health system, e.g., policy planners, health professionals, and society. Socio-cultural; spiritual aspects and religious beliefs about death and dying; misconceptions about the scope and target population of PC; and the fear of dependence on opioid analgesics with better access to them, are additional contributing factors to low acceptance of PC. A study comparing the consumption and availability of opioid analgesics showed that 83% of the world population lives in countries with very poor access to this type of analgesic(17) leading to the hypothesis that a vicious cycle would be delaying the expected progress of pain management as part of PC.

Human rights and palliative care

PC is recognized in the context of the human right to health which must be provided through integrated and person-centered health services. In Latin America, as in most regions worldwide, its implementation has required State legislation such as in the case of Chile, Colombia, Mexico, and Uruguay, among others. In most Latin American countries, there are national and institutional programs for pain clinics, cancer, chronic diseases, and PC in both public and private entities, Social Security, and non-profit non-governmental organizations. In those countries where there are solid PC associations, units, or services as part of the comprehensive care provided in the different specialties, the laws have been enacted and implemented more effectively(13-15).

The right to nutritional care

The right to nutritional care has been considered an emergent human right(18) related to the right to health and the right to food by the international scientific societies associated with the Federación Latino Americana de Terapia Nutricional, Nutrición Clínica y Metabolismo (FELANPE) in May 2019 as reflected in the Cartagena Declaration (CD), International Declaration on the Right to Nutritional Care and the Fight against Malnutrition(19).

The right to nutritional care must be exercised with an ethical foundation (values and principles) and with professionalism, incorporating the tenets of principlism as discussed earlier(18). The CD proposes 13 principles that promote nutritional care allowing sick individuals to receive nutritional therapy, recognizing the intrinsic value of each human being with respect for dignity, integrity, and the diversity of moral, social and cultural values. These 13 principles should be considered with decisions and actions regarding feeding patients. These actions should be supported by knowledge, benefits and burdens/risks, respect of autonomy and limited "futile"/"low yield" interventions(19). These principles highlight the deontological and principlism dimension of health professionals, especially physicians, in decision-making regarding PC, when facing the ethical dilemma of feeding the patient at the end of life (EOL).

PC must be provided in compliance with the principles of universal health coverage, regardless income, type of illness, age, social standing etc. This care is highly efficient when started early, since it improves the QOL of patients, reduces unnecessary hospitalizations and the use of other health services(13-17).

ETHICS AND PALLIATIVE CARE AT THE CROSSROADS

General considerations in clinical ethics and palliative care basics

Clinical ethics and PC basics involve a great deal of overlap; however, it is possible to determine what is distinctively in the clinical ethics domain, compared to PC application. These properties are identified in Figure 3 depicting clinical ethics and PC basics and PC application when a consult is ordered.

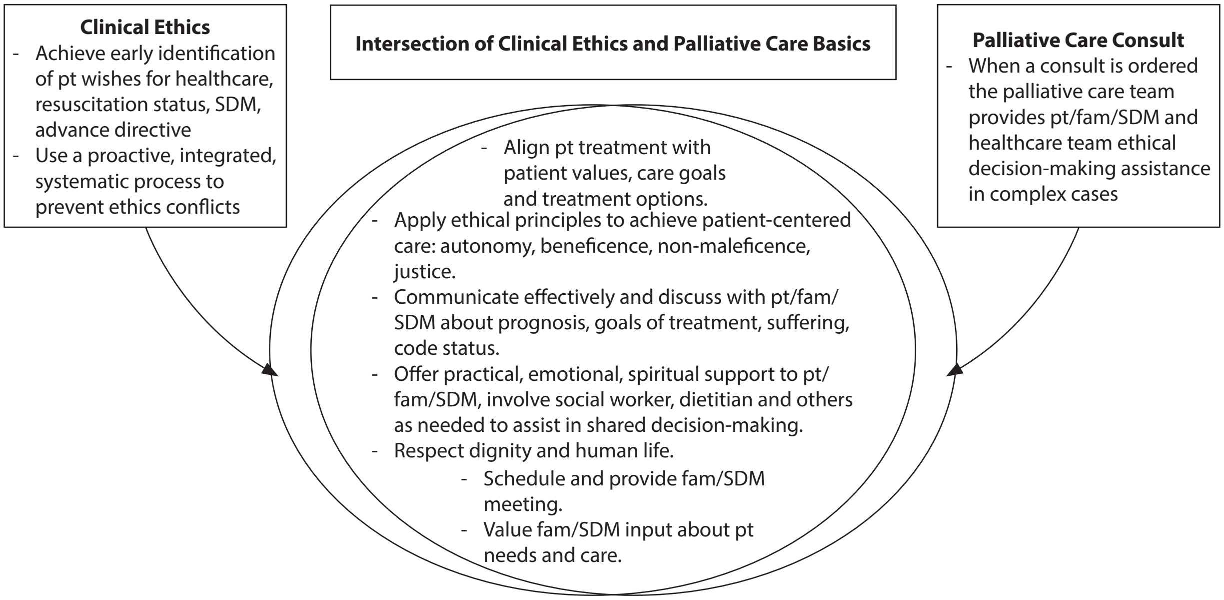

Figure 3. Clinical ethics and palliative care at the crossroads. Fam: family; pt: patient; SDM: surrogate decision maker.

Role of individual/family/SDM in clinical ethics

The first step in advance care planning ideally occurs before the individual's illness and/or hospitalization. Opening channels of communication for meaningful dialogue between individuals and their family members or SDM about EOL healthcare decisions is essential in order to prevent needless pain and suffering, and prevent the do everything directive in the hospital by the family members or SDM that is often not appropriate, based on an individual's wishes. The goal is to provide clarity for EOL decisions through advance care planning(20). The dilemma is how to get individuals early in their adult lives to begin this dialogue for themselves and older family members.

An advance directive is a legal document that gives individuals the ability and right to plan their own healthcare in the event they lose the capacity to effectively make decisions. Some advance directives can be vague and do not provide guidance in all healthcare decision-making scenarios in the hospital setting. Choices are not black and white in the intensive care unit (ICU); there are many shades of gray. The benefits versus burdens/risks of medical technologies are not easily grasped by a novice in a world where life and death decisions are common(20). Designating a durable power of attorney for health care (DPAHC) in an advance directive with discussion between the individual and the DPAHC about an individual's QOL goals and updating this information assists in optimum decision making during a healthcare crisis.

The family or SDM should be prepared to address questions that focus on long-term goals versus short-term goals for medical therapies. Does the individual not want any of these medical therapies at all, or is he/she willing to accept them for a certain period? What was the quality of the patient's life prior to the hospitalization? Was the patient living independently at home or in a convalescent hospital? What QOL may the individual anticipate after the acute hospitalization?(20). Informed consent should be "informed" detailing the prognosis with and without an intervention and complications associated with either alternative (Figure1)(3).

Role of treating healthcare team in clinical ethics

The role of the treating healthcare team in clinical ethics is to achieve early identification of the patient's wishes for healthcare treatments, resuscitation status, designated SDM, and presence of an advance directive. Obtaining this information requires a process to engage, educate and empower healthcare clinicians as to their role of incorporating basic PC concepts into their practice, as previously discussed in this article. There is a need to move the stigma from PC as a process only for the EOL phase of an individual's life. There is a difference between the treating healthcare team incorporating PC concepts/tools versus a PC consult. PC teams are resources for individuals handling a diagnosis that may negatively impact the person's QOL or healthcare situation requiring a treatment decision and are consulted when the treating healthcare team recognizes that the need for additional assistance for themselves and/or the patient/family/SDM(21).

Role of hospital in creating a proactive, integrated, systematic process to prevent ethics conflicts

The proactive, integrated, communications process could be applied throughout the hospital with all patients and completed within 24-48 hours of the patient's admission. Ideally, this information would be obtained immediately in the emergency room or on admission; however, that may not be possible. The goal would be to obtain essential information from the patient while still able to decide. Otherwise this process would be used with the family or SDM. A sample ICU Healthcare Communication Process presented in Table 2 would be completed by the patient's nurse, physician, or other designated healthcare clinician(20).

Intersection of clinical ethics and palliative care

Achieve patient-centered care

Incorporating the four ethical principles, as previously discussed (Table 1), into clinical practice is essential to achieve patient-centered care. Respect for autonomy involves determining the individual's wishes for their healthcare and clinicians incorporating those preferences in a shared decision-making process for treatment options. The application of beneficence, in doing good for patients and always acting in their best interest and non-maleficence, doing no harm would be represented by the healthcare team making recommendations to the patient/family/SDM about treatment options in conjunction with the patient's wishes. Distributive justice means that all patients should be treated equally

Table 2. Sample ICU healthcare communication process

Steps	Action components
1	Review the patient's information, including admit diagnosis, medical history, cultural diversity, preferred language, presence, and content of the individual's advance directive
2	Connect first with the patient/family/SDM before incorporating the communication process using cue-based discussion Provide a professional translator, if needed, rather than use a family member for translation
3	Sit down, listen more, speak slowly, and provide information in simple terms
4	Determine if there is an advance directive with a designated SDM and if the document has been recently revised/updated
5	Indicate patient/family/SDM are the center of healthcare team and other team members are available to assist them
6	Provide a written document, such as an ICU Healthcare Team Letter about the process in simple language and indicate contact name and phone number
7	Determine understanding of information by using the teach-back method of education
8	Communicate information obtained to appropriate healthcare team members, verbally if information is needed immediately, such as code status
9	Document in the patient's electronic medical record: - Healthcare Team Letter discussed with patient/family/SDM - Designated SDM name - Advance directive presence and content

ICU: intensive care unit; SDM: surrogate decision maker.

and/or fairly by the health care clinician with respect for dignity and human life, allowing for their differences in their clinical requirements(6).

Communicate Effectively

Effective communication involves not only the treating healthcare team discussion with the patient/family/SDM about prognosis, goals of treatment, suffering, code status, but also non-verbal aspects of communication that implies an openness and willingness for shared decision-making. Family members and/or SDM should be made to feel that their input about the patient's needs and care are valued. Scheduling early meetings and follow-up meetings with the family/SDM fosters open communication between the treating healthcare team and the family/SDM(22). The growing development of internet methods of communication, e.g., Zoom and Skype, has increased the ability to easily communicate regardless the location of the participant. Effective communications also imply active and effective listening.

The treating healthcare team member would incorporate cue-based discussion and the teach-back method of education with patient/family/SDM to promote effective communication(23). Cue-based discussion involves using terms that could cause the patient/family/SDM to grasp the concepts of patient-centered care: 1) patient-centered healthcare based on patient wishes; 2) family/SDM to express what patient would want; 3) family/SDM role is to represent the patient's wishes and not their own; 4) patient/family/SDM are the center of the healthcare team. The teach-back method of education involves the individual after being provided information is asked to repeat back what they understood the information to mean to them. If it is not correct, then the individual is provided the information differently and then once again asked to repeat back what they understood the information to mean to them. The focus is on health literacy, essentially to provide information in easily understood terms(23).

Offer needed support

The patient/family/SDM should be offered practical, emotional, spiritual support, which could include additional assistance from the social worker, dietitian nutritionist and others as needed from the treating healthcare team. Due to the impact that cultural values, religious beliefs, ethnic background, country, region, and geographical considerations can have on healthcare decision making, additional resources or individual assistance may be needed for the patient/family/SDM(23).

Palliative care teams and consults

PC teams are consulted to provide patient/family/SDM and the treating healthcare team members ethical decision-making assistance in complex cases. The transition from a clinical ethics focus approach to patient care, initially provided by the treating healthcare team during the hospitalization, to the PC team, ideally would appear to be a seamless collaborative continuum, from the patient/family/SDM perspective. PC team members, generally, have more time to spend with the patient/family/SDM dealing with the emotional and coping aspect of the illness, compared to the treating healthcare team members. Communication between the treating healthcare team members and the PC team members is essential.

PC teams, generally led by a physician, include members who are trained within their specialty, such as social workers, chaplains and other healthcare professionals to provide coping mechanisms for the patient/family/SDM to assist them in achieving clarity with healthcare shared decision-making. The treating healthcare team would continue to provide healthcare, which should be in sync with the coping mechanisms provided by the PC team, rather than mixed messages, essentially, delivering the same information to the patient/family/SDM on the individual's clinical status, illness trajectory and prognosis.

During the transferring process the patient/family/SDM would be informed of the various options for nutrition as part of PC if the individual is exhibiting swallowing difficulties:

- An oral diet with modified food and fluid consistency, as needed to prevent and/or limit the aspiration risk; although the oral intake may or may not be sufficient to provide nutrients to maintain the individual's nutrition status, but nutrient adequacy may not be required based on the goals of care
- Comfort feeding only includes careful hand feeding and stopping this process if the individual appears distressed; the focus is on interaction with the individual, incorporating meticulous mouthcare, socialization, and therapeutic touch(22)
- Short versus long-term enteral feeding with an enteral access device. The patient/family/SDM should be fully informed of the benefits versus burdens/risks of all options

Determination of understanding of the information and re-evaluation as needed of the decisions made are additional responsibilities of the palliative and healthcare teams. Although, the majority of PC is delivered during an acute hospitalization, PC is appropriate at any stage of serious illness to improve the patient's QOL and can be most beneficial when integrated early in the illness trajectory, including in the individual's home(24).

Many healthcare professionals, patients and families are reluctant to adopt PC since they equate it to hospice care. PC is different from hospice care. Although both offer compassionate care for individuals with a life-limiting illness, in contrast PC can be used while the patient is continuing to receive medical treatment. Hospice care is provided for terminally ill patients when treatment is no longer curative, and the expected survival is 9 months or less, but may vary from one country to another. PC can be used while the patient is continuing medical treatment through different phases of their life limiting illness(25).

Palliative care, nutrition and ethics regarding neurological/cognitive deficits considerations

There are efforts being made to clarify specific aspects of the diagnosis of coma, decreased consciousness, and dementia to assist healthcare clinicians in providing effective therapies and deal with treatment decisions(26). Practice Guidelines of the Dissemination and Implementation Subcommittees of the American Academy of Neurology, the America Congress of Rehabilitation Medicine and the National Institute on Disability, Independent Living, and Rehabilitation Research utilize the terms minimally conscious state (MCS) and disorders of consciousness (DoC)(27). The guidelines(27) recommend the replacement of the term PVS to chronic vegetative state (VS) or unresponsive wakefulness syndrome with the duration specified. The concern is that there is the possibility of misdiagnosis due to confusing neurologic deficits and subtle signs of consciousness. Dementias or DoCs may be primary neurodegenerative disorders, such as Alzheimer's disease, Parkinson's disease, chronic alcohol abuse, infectious causes. However, DoC may even be due to other conditions involving vascular disease or related to other factors such as traumatic injury or tumors.

DEMENTIA

What is dementia, types, signs, and symptoms?

The loss of cognition coupled with behavioral derangements to the degree that they hamper an individual's daily activities are the cornerstones of dementia. These changes are associated with personality alterations, short attention span and memory loss. In its most severe stage, the affected individual is completely dependent on others for achieving the activities of daily living, e.g., bathing, toileting, feedings, transferring, etc.(28). The various types of Dementia and some of the signs and symptoms are summarized in Table 3.

Table 3. Dementia types and symptom(29, 30)

Types	%	Signs and symptom
- Alzheimer's AD	53	- Loss of social skills
- AD vascular	10	- Disorientation
- Vascular	8	- Withdrawal from work or social activities
- Frontoparietal	8	- Trouble with comprehension
- Other	6	- Poor judgement
- Dementia with DLB	5	- Changes in mood and personality
- AD + DLB	10	- Agitation
		- Difficulty with familiar tasks
		- Difficulty communicating

AD: Advanced dementia; DLB: Dementia with Lewy bodies.

What is advanced dementia?

Advanced dementia (AD), also referred to as severe dementia or end-stage dementia, is defined as the stage of the disease where a person is totally dependent on others(31, 32). Since AD occurs mainly in older individuals it is prudent to remember that aging is "a process; not a disease". Many of the signs and symptoms often attributed to the aging process is like those of malnutrition, such as: loss of muscle mass, weight loss, inactivity, loss of appetite, apathy, failure to thrive, exhaustion, weakness, sarcopenia, fatigue. Particular attention to the nutritional status of the elderly patient with AD, because of its mimicry, is important since malnutrition impacts negatively on AD.

Feeding difficulties and dysphagia are common in AD and put the individual at risk of aspiration and subsequent pneumonia. For individuals with AD, loss of interest in food and the inability to swallow mark the final phases of the disease and are irreversible(33). Despite the presence of end-stage disease, family/SDM and healthcare clinicians often then deal with the question of use of ANH and the distinction between short-term with an acute situation versus use of a long-term enteral access device for nutrition. A strong evidence based of observational studies was found to show that the long-term enteral nutrition does not benefit individuals with AD and can cause harm(34, 35).

With a known illness trajectory of declining cognitive function in AD, early advance care planning becomes essential and selection of a SDM, if the individual wants to have a voice in their future healthcare, and re-evaluated over time as the illness evolves. The advance care planning takes the burden off the family in the eventual decision-making process about use of tubes for nutrition versus providing comfort foods for the individual, as their swallowing ability declines(35). Additionally, PC can improve the patient and caregiver satisfaction, QOL, and symptom burden at the EOL(33). The philosophy of PC in dysphagia management focuses on comfort, and the patient's wishes would always be part of care planning and working with family members and other stakeholders in developing plans of care using shared decision-making(36).

Alzheimer's disease

Alzheimer's disease is a terminal degenerative disease process that becomes worse over time and is ultimately fatal(37). Alzheimer's disease is the most common cause of dementia with specific brain changes. There are three phases of the Alzheimer's disease continuum: 1) preclinical Alzheimer's disease, 2) mild cognitive impairment, and 3) dementia. The Alzheimer's dementia phase is broken down into the stages of mild, moderate, and severe, reflecting the degree of impact everyday activities. Severe Alzheimer's dementia results in damage to areas of the brain that control swallowing. Individuals then start to exhibit difficulty with food and liquid intake, with potential subsequent aspiration and pneumonia(38).

Feeding tube use at the EOL was discussed in the Alzheimer's Association Report: 2020 Alzheimer's disease facts and figures(38). The report indicated the following concerns about tube feeding use in this population in the U.S.:

- Frequent transitions between health care settings resulted in more frequent use of tube feedings at the EOL, even though this medical therapy does not prolong life or improve outcomes
- Individuals with dementia were more likely to have a tube feeding if the person was managed by a subspecialist and a general practitioner, compared to being managed only by a general practitioner
- The use of feeding tubes in the last 90 days of life has decreased for individuals with Alzheimer's or other dementias with increased availability of hospice care
- Due to the lack of supporting evidence for use of feeding tubes for individuals with AD, the percentage of nursing home residents with tube feeding in the 12 months prior to death has decreased.

Vegetative state

The legal history related to the use and discontinuation of use of tube feedings in previously identified PVS patients spans several decades in the U.S. Three landmark court cases in the U.S., involving young women in their 20s in PVS from 1975-2005, have shaped current legal opinion. Legal positions on EOL care are continually evolving, resulting in variation in local and state laws and regulations and in various countries. Healthcare providers should seek appropriate legal counsel to guide their own practice(7, 24).

Care of patients in a VS or unresponsive wakefulness syndrome can result in ethical dilemmas for the family/SDM and healthcare clinicians, resulting in conflicts between the stakeholders. These conflicts may occur due to different visions, expectations, and hope for recovery; and opposing goals and contradictory feelings by family/SDM and healthcare clinicians. Key elements to prevent or resolve these ethical dilemmas involve an accurate diagnosis; clarity and uniformity in treatment goals and plans; an open and empathic communication by the healthcare clinicians; expertise and understanding the importance of contradictory thoughts and feelings by the individuals involved. Shared decision-making involving shared compassion for the patient may be a major factor in bridging the differences with the stakeholders(39). A PC consult would be extremely helpful in facilitating the process of compassion communication for all individuals involved in coming to a consensus on behalf of the patient.

OBLIGATIONS

Healthcare professionals dealing with patients with AD and other states of severely impaired conditions have unique ethical and professional obligations as described below.

Patient

It is estimated that by 2040, about 80 million people will suffer from some type of dementia, with significant costs of care per person, impacting direct costs of medical care. This situation has produced a worldwide alarm and has generated public policies, according to calculations by Alzheimer's Disease International(40).

About 60% to 80% of the elderly with chronic dementia suffer from AD, the majority having cerebrovascular disease. In Spain, the incidence of dementia is 10-15 cases/1000 people/year in the population over 65 years of age. If it is taken into account that age is one of the main non-modifiable risk factors (such as sex, and family history, among others), the increase in cases would be a consequence of the progressive aging of the population(41, 42).

The human being is unique deserving dignity, autonomy and freedom, with universal and individual characteristics determined by the cultural context in which they develop. Healthcare professionals should respect the patient's religious beliefs, socio-cultural environment, their capacity for self-determination, and their fears and anxieties. Patients receiving PC suffer and express a series of concerns, among them, fear of pain, the future, losing independence and consciousness. They are concerned about being a burden to the family, and life after death causes them anxiety.

The vulnerability of the patient with AD and clinical nutrition

Vulnerability implies recognizing that living beings are fragile and that they need others, which makes it appear as an essential dimension of human beings and therefore of social relationships(18). The notion of vulnerability is central to the component of clinical nutrition, in this regard the Declaration of Cartagena reads: "It is recognized that patients at risk or in a state of malnutrition are a group considered vulnerable from an ethical point of view. Malnourished patient implies recognizing that individuals may at some point lack the capacity and means to feed themselves and, therefore, this need must be addressed by professionals in clinical nutrition. Malnutrition implies physical, psychological, and social deterioration with the risk of losing one's life and the possibility of losing autonomy (18, 19).

Inadequate nutritional care, by omission or by prolongation beyond the medical indication, can violate human dignity. By recognizing nutritional therapy as a medical treatment, patients have the right and autonomy to reject it, and health personnel have the obligation to respect and abide by such decision and not to carry out actions considered futile(19). It is important to understand that the unlimited power of caregivers over the recipient of care contains potential risks and abuses described. It is indisputable to adopt ethics vulnerability with respect and support for the vulnerable person beyond the evaluation of their legal competence or cognitive abilities. The physical protection of the individual and informed consent; imply the commitment of responsibility and concern for others. Decision-making, as health personnel, family members or caregivers, should be made considering the risks and burdens/benefits of each activity, respecting the patient's preferences. In AD, as in other end-stage disease, nutritional therapy should be considered in the context of PC; bearing in mind that more than prolonging survival, the objective is to ensure the QOL and well-being of the patient(40).

Healthcare team

PC is recognized through key global mandates and strategies on universal health coverage, noncommunicable diseases, and integrated and people-centered health services(17). It has an interdisciplinary nature and is aimed at the patient, family/caregivers, and the community. PC consists of offering care, which means meeting the basic and individual needs of patients, whether at home, in a health institution or intermediate care. They provide care that affirms life and accepts death as a natural process. They do not intend to provoke or delay it through euthanasia or therapeutic obstinacy (also known as fierceness).

The following may be part of the interdisciplinary PC team: a doctor specializing in palliative/pain care, who generally coordinates the team; pharmacist, nurse, dietitian nutritionist, social worker, psychiatrist, psychologist, therapists, and chaplain or other type of spiritual advisor, each of them with specific functions related to their disciplinary competence and focused on providing comfort to the patient, respecting their beliefs, values, principles, feelings and experiences (Figure 2).

The nutritional therapy of patients receiving PC emotionally impacts the family who frequently request information and support(41). In the context of the patient with end-stage disease, two situations may arise that make communication and recommendations difficult regarding the patient's diet. One situation is the abstention (omission) and suspension of ANH, and the other is the voluntary and total cessation of oral or artificial feeding and hydration. These circumstances produce discrepancies and conflict, which can force the PC medical team to rely on family members who are more aware of the issue, and on other stakeholders (Tables 2, 4). Certain measures taken under family pressure can be reassessed and reconsidered over time after better communication and trust between the team and the family(42).

Just as the dietitian nutritionist will carry out a complete and individualized nutritional assessment, with emphasis on the presence of dysphagia, the nurse must establish the self-determination capacity of the patient/caregiver and the mechanisms used to adapt. This obligation is of special relevance in relation to the patient's nutrition to guide the educational process that they must provide as a team to the patient, family, and caregivers as part of nutritional care.

This process should include simple information on enteral nutrition, the absence of hunger and thirst in these patients; the potential complications and demonstrated futility of enteral nutrition in patients at the EOL. The healthcare team should explain the concept of nutrition and hydration as a measure of comfort and QOL and stress that the omission of artificial nutrition does not mean that the patient does not die of hunger or neglect of care(41). It is highly recommended to execute a document that expresses prior instructions or advance directives about the nutritional care preferred and appoint a legal representative who will enforce it. The decision must be shared and followed by the medical team. As the disease progresses, nutritional therapy will have various objectives, focused on well-being and QOL (Figure 4).

There is no "cookie-cutter" approach to the nutrition interventions in patients receiving PC. Each patient presents individual and unique circumstances which encompass their desires, severity of disease, demographics, and other characteristics. It behooves all the members of the healthcare team to be creative in the process to optimize nutritional care in this population. For instance, one of the authors had an interesting experience when his mother-in-law with AD refused eating or drinking except of small amounts of an oral calorically

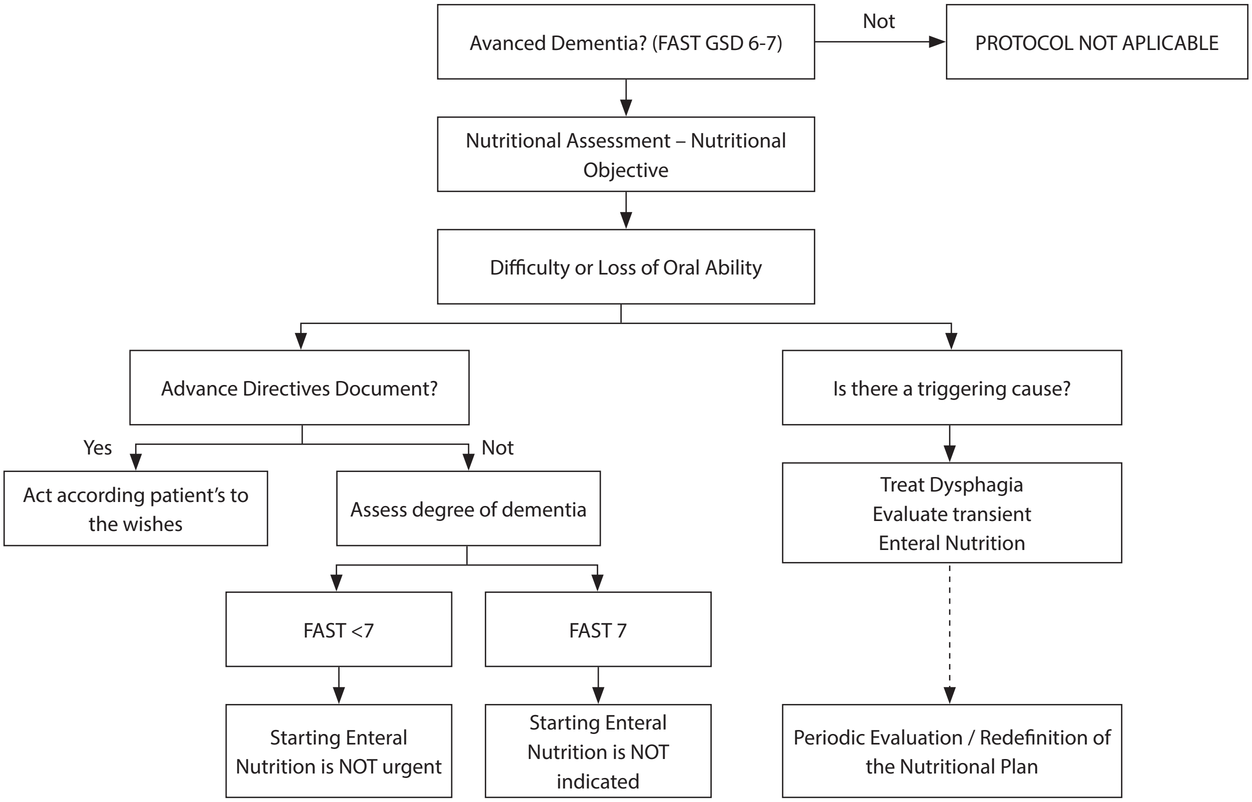

Figure 4. Algorithm for decision-making about the start of enteral nutrition in patients with AD. Modified from(42). FAST: Functional Assessment Staging in advanced dementia; GDS: Global Deterioration Scale.

dense supplement. A decision was made to only offer the patient half of the can of supplement, then return in 45 minutes to one hour and offer the second half with the thought that since exhibited short memory deficits the subsequent amount would be perceived as a first feeding. It worked! The patient never required tube feedings. She died several months later, in comfort.

Faced with dysphagia, a common entity in this type of patient, education to the patient/family and caregivers, provided by the PC team and reinforced individually by each professional who at the time follows the patient, should be oriented to:

- Provide indications for early detection of dysphagia to avoid related complications such as:
  - Malnutrition
  - Fluid and electrolyte imbalances
  - Bronchial aspiration, and others
- It is recommended to emphasize the sensory aspects of food:
  - Taste, smell, texture, presentation, environment, etc.
  - The use of thickeners generally based on gums.

In this regard, the *Sociedad Española de Nutrición Parenteral y Enteral* (SENPE) working group published the summary of recommendations for the nutritional management of AD(42).

Other caretakers

The patient with AD faces two inherent situations. On the one hand, a physiological reserve diminished by the aging process itself and chronic and incurable comorbidities. On the other a limited social support network, not only due to family losses but also due to sociodemographic structural changes that impact the need for care on the dimensions of health, nutrition, pain, anxiety and depression, among others.

The family or other caregivers fulfill the functions of accompaniment, affection and understanding of a patient with a chronic, progressive and incurable pathology associated with comorbidities. It is essential that they have certain knowledge about the disease, rights, skills and resources.

Health professionals who participate in the educational process of managing these patients have an ethical obligation to offer information about their rights, such as, not to continue suffering indefinitely, or use extreme and heroic measures deemed "futile", "low yield" or contraindicated. The family/caregiver needs that the health professionals fears of loved ones are taken into account before and after their death; die with dignity, comfortably and peacefully.

The patient receiving PC should be able to live to their maximum physical, emotional, spiritual, vocational and social potential, compatible with the state and progression of the disease. To achieve these goals the patient must be cared for by professionals who are sensitive, competent in their field and confident in what they do.

Patients who, supported by their relatives remain at home at the EOL, depend on the care and effort of family members. PC for patients with AD generates significant physical risks, exhaustion, emotional and economic burdens, and alterations of the family dynamics to family and other home care providers. Offering support to family caregivers should be included as part of the PC program. Table 4 summarizes common questions and answers family members and other caregivers with AD ask the PC team(42).

The objective of care for people with AD is comfort and not prolongation of life, and to improve the QOL. (Figure 2). Pain control is part of the comfort measures and that the relief of suffering of the QOL. Pain and suffering are not synonymous. Pain is common to all living beings, while suffering is a prerogative of the human person. Pain belongs to the order of the somatic, of the organic. Suffering is more related to the psychological sphere; it evokes deeper dimensions of the human being. You can suffer without physical pain(17, 43-45).

Interdisciplinary PC teams offer comprehensive patient care and accompaniment to the family/caregivers who require support and the tools to not only care but to accept the process of dying and develop the corresponding grief, avoiding therapeutic obstinacy or prolonging life ignoring the well-being of the patient and the family.(42-44, 46).

Table 4. Common questions and answers about ANH in advanced dementia. Modified from(42)

Questions	Answers
What is ANH?	ANH is the administration of nutrients and water through the gastrointestinal (enteral) or intravenous (parenteral) routes. If the gastrointestinal tract is used, nasogastric tubes are used (which are inserted through the nose and into the stomach) or gastrostomies (which are introduced directly through the skin into the stomach)
ANH would be helpful?	- ANH cannot, by itself, cure or reverse dementia and can have significant complications that can sometimes cause the patient requires hospitalization (hemorrhage, infection, etc.) and that, in some cases, can lead to death - There is no clinical evidence to show that ANH increase survival, decrease infections, prevent aspiration pneumonia, avoid or improve the evolution of pressure ulcers, increase weight, or improve functional status or quality of life of these patients
- Would it not feel better if the patient received ANH? - Will the patient not be hungry and thirsty if he/she do not get it?	- ANH does not make patients in this situation feel better. On the contrary, even simple hydration with IV fluids in patients in the final stages of life has been associated with an increased incidence of nausea and vomiting, increased secretions and lung problems, swelling of the body, etc., which sometimes forces the use of catheters and other treatments. Sometimes it is even necessary to restrain these patients to prevent them from removing the various tubes - The artificial hydration does not always resolve the feeling of dryness. Studies have shown that avoid the use of artificial nutrition the final stages of life is accompanied by comfort and a peaceful death - Furthermore, most patients in this situation do not perceive hunger or thirst, and when they do, they generally want to taste specific foods and respond to the administration of ice chips, sips of liquid, to which lips become moist, etc. If there is a decrease in the ability to swallow food and/or liquids, the healthcare team can provide guidance on how to act in this situation to meet the needs and maintain human contact with our loved one
So, if we do not provide food or drink, will that cause his death?	- No, the cause of death will be the evolution of the terminal illness itself - Furthermore, the fact that ANH is not administered does not mean that the necessary measures are not taken to provide maximum comfort

ANH: artificial nutrition and hydration; IV: Intravenous.

It is possible to improve the QOL patients with AD, if the interventions defined and indicated in PC are adequate and aimed at respecting human dignity, their wishes at the EOL, and manage to control physical pain but also relieve suffering and anguish(43).

ILLUSTRATIVE CASE STUDY

This was the third admission to the hospital within 6 months for the 63-year old mother of five children. On admission she presented with symptoms of pneumonia, because of her impaired swallowing ability along with her declining cognitive function. During the past 10 years following her husband's stroke and passing after a long hospitalization and extended time on home care with a feeding through a gastrostomy tube, she had started to mentally decline.

Her second oldest child was a nurse in the ICU at a local hospital. Being in the medical profession, she knew it was important to understand her mother's wishes for her future healthcare, when her mother might not be able to speak for herself. Over the years following her father's passing, she and her mother spoke about her wishes. Initially, her mother indicated she would never want anything done, compared to what happened with her husband–no pain, no pounding on the chest, no breathing machines, no feeding tubes. Ideally, it would have been helpful for her mother to have completed an advance directive at this point before she started her mental decline, indicating her healthcare wishes and selecting her daughter as the SDM. Unfortunately, in her family it was the oldest son, who would be making the decisions for the mother, if she could no longer express her wishes. The son did not want to even discuss with his mother what her wishes would be, he would determine what should be done at that time.

On this admission the daughter discussed with her mother's physician the need for a PC consult, due to the complexity of decision-making with the decision maker in conflict with the patient's wishes. Several family care meetings were held with the treating healthcare team, PC team, patient's oldest son and her daughter, who is an RN. The goal was to seek a consensus of the stakeholders in the best interest of the patient. The son ultimately concluded that he had been more focused on his wishes and not his mother's wishes for her healthcare. She was discharged home and offered comfort feeding, as tolerated, and informed that there could be an increased potential for aspiration despite appropriate precautions. Figure 5 illustrates the importance of early advance care planning and PC.

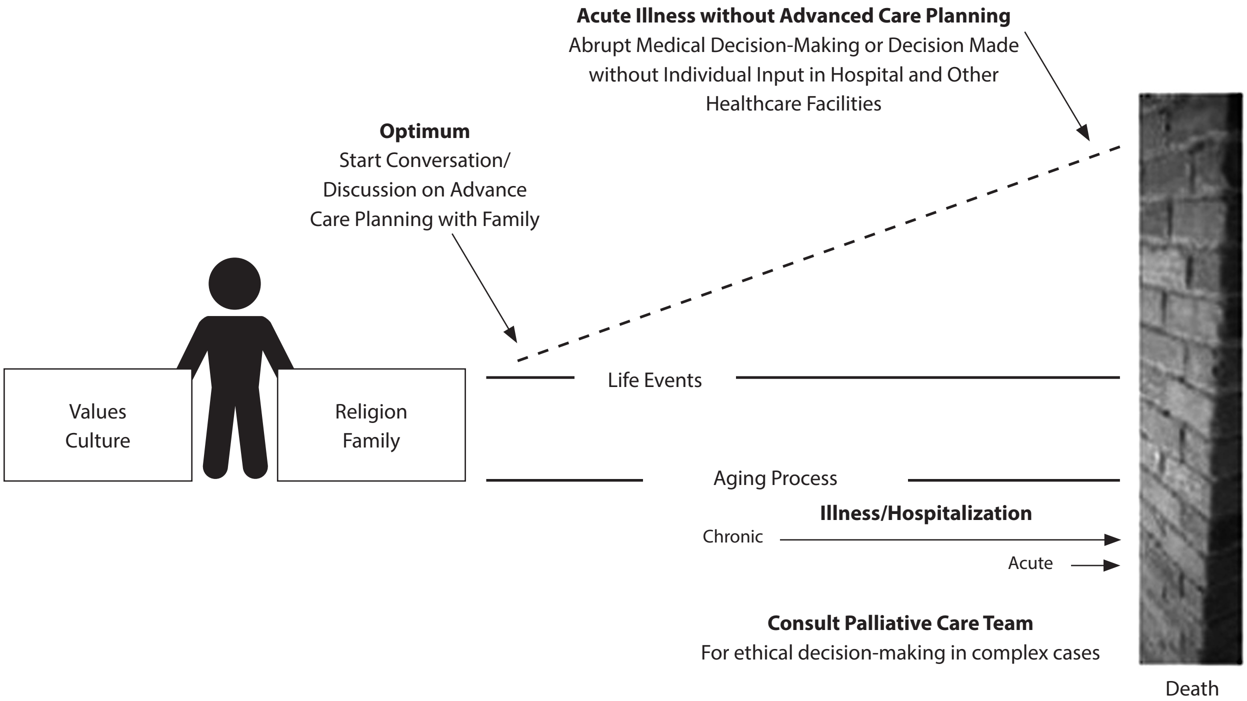

Figure 5. Sample advance care planning journey ending in hospital and other healthcare facilities. Reprinted with permission and adapted from Schwartz DB(47).

The following hypothetical questions and actions could be useful in the analysis and resolution of case studies.

- Her second oldest child is a nurse (medical profession). If the patient would not have a relative from the medical profession, what recourse would the patient have to assert her right to receive PC according to her desire?
- Both the daughter and the mother had spoken about her wishes. If not, what could she do to express her will?
- Her oldest son is who makes the decision for the mother. If he decides not to respect his mother´s will at the end of life, what would be the next step?
- She has not signed an advance directive. What is the ideal time to sign it?
- The daughter requested that her mother receive a PC consultation. In case the health team does not want to make the transfer to PC, what should she do?

Recommendation

The hospital ethics/bioethics services/committees can help resolve ethical dilemmas. Although it is true that they do not make decisions or formulate medical indications, they can guide, recommend and accompany conflict situations such as, move the patient from a medical treating team to PC, the suspension of artificial feeding, conscientious objection, among others.

CONCLUSION

While we have outlined and briefly discussed aspects of ethics and nutrition regarding PC care with a focus on AD, the reader is encouraged to further enhance their knowledge base by further reviews of the references and sources listed here and additional ones not included in this article. The greatest success in dealing with PC, nutrition and ethics can be achieved through application of the acronym ACT (accountability, communication and teamwork) while dealing with the troubling trichotomy (Figure 1).

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References

1. Palliative care: Learning then leading by example [Internet]. Smith A, American Association for Physician Leadership. 2020. (October 20, 2020). Available at: https://www.physicianleaders.org/news/palliative-care-learning-then-leading-by-example
2. Barrocas A. The troubling trichotomy 10 years later. Where are we now? Nutr Clin Pract. 2016;31(3):295-304. doi: https://doi.org/10.1177/0884533616629631.
3. Barrocas A, Cohen ML. Have the answers to common legal questions concerning nutrition support changed over the last decades? 10 questions in 10 years. Nutr Clin Pract. 2016;31(3):285-93. doi: https://doi.org/10.1177/0884533616644439.
4. Merriam-Webster Dictionary [Internet]. (November 2020). Available at: http://www.Merriam-Webster.com/dictionary/ethics
5. Hippocratic Corpus. En: Reiser SJ, Dyck AP, Curran WJ (editores). Ethics in Medicine: Historical, perspectives and contemporary concerns. Cambridge, Mass: MIOT Press. 1977.
6. Beauchamp TL, Childress JF. Principles of biomedical ethics. 6.th Edition. New York: Oxford University Press. 2009.
7. Schwartz DB, Barrocas A. Ethics and law. In: Mueller CM, Lord LM, Marian M, McClave SA, Miller S (editors). The ASPEN adult nutrition support core curriculum. 3.th Edition. Silver Spring, MD: American Society for Parenteral and Enteral Nutrition. 2017.
8. Moral theory [internet]. McMillan J, Royal College of Physicians and Surgeons of Canada. (October 2020). Available at: http://www.royalcollege.ca/rcsite/documents/bioethics/moral-theory-summary-e.pdf
9. Frederiksen CS, Nielsen MEJ. Ethical theories. In: Idowu SO, Capaldi N, Zu L, Das Gupta A (editors). Encyclopedia of corporate social responsibility. Berlin, Heidelberg: Springer. 2013.
10. The nature of morality and moral theories [Internet]. University of San Diego. (November 2020). Available at: https://home.sandiego.edu/~baber/gender/MoralTheories.html#:~:text=Morality%20is%20the%20system%20through,to%20good%20or%20right%20

conduct.&text=%C3%9D%20A%20moral%20theory%2C%20then,determine%20right%20and%20wrong%20conduct

11. The problem of moral knowledge. In: Sprague E, Taylor PW (editors). Knowledge and value: introductory readings in Philosophy. 1.st Edition. New York: Harcourt; Brace and Company. 1959. p. 483.
12. Barrocas A, Schwartz DB, Hasse JM, Seres DS, Mueller CM. Ethical framework for nutrition support allocation during shortages: lessons from COVID-9. 2020. Nutr Clin Pract. 2020:10.1002/ncp.10500. doi: https://doi.org/10.1002/ncp.10500.
13. Pinho-Reis C. Suporte nutricional em cuidados paliativos. Nutrícias. 2012;15:24-7.
14. Guía de cuidados paliativos [Internet]. Sociedad Española de Cuidados Paliativos. 2014. [Consultado el 5 de octubre de 2020]. Disponible en: http://www.secpal.com/biblioteca_guiacuidados-paliativos
15. Palliative care [internet]. World Health Organization. 2020. (October 2020). Available at: https://www.who.int/news-room/fact-sheets/detail/palliative-care
16. Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. J Pain Symptom Manage. 2013;45(6):1094-106. doi: https://doi.org/10.1016/j.jpainsymman.2012.05.011.
17. Seya MJ, Gelders SFAM, Achara OU, Milani B, Scholten WK. A first comparison between the consumption of and the need for opioid analgesics at country, regional and global levels. J Pain Palliat Care Pharmacother. 2011;25(1):6-18. doi: https://doi.org/10.3109/15360288.2010.536307.
18. Cardenas D, Pelluchon C. The ethical foundations of nutritional care: a viewpoint on the recent ESPEN guidelines. Clin Nutr. 2016;35(6):1587-1588. doi: https://doi.org/10.1016/j.clnu.2016.09.014.
19. Cardenas BD, Echeverri S. Aspectos éticos de la Declaración de Cartagena. Rev Nutr Clin Metab. 2019; 2(1):56-62. doi: https://doi.org/10.35454/rncm.v2supl1.032.
20. Bland A. Breathe: A true story of letting go of my parents gracefully for i will see them again. Bloomington. In: Xlibris Publishing Co. 2009.
21. Schwartz DB, Olfson K, Goldman B, Barrocas A, Wesley JR. Incorporating palliative care concepts into nutrition practice: Across the age spectrum. Nutr Clinc Prac. 2016;31(3):305-15. doi: https://doi.org/10.1177/0884533615621556.
22. Schwartz DB. Enteral nutrition and dementia integrating ethics. Nutr Clinc Prac. 2018;33(3):377-87. doi: https://doi.org/10.1002/ncp.10085.
23. Schwartz DB. Ethical decisions for withholding/withdrawing medically assisted nutrition and hydration. J Acad Nutr Diet. 2015;115(3):440-3. doi: https://doi.org/10.1016/j.jand.2015.01.002.
24. Kozlov E, Cai A, Sirey JA, Ghesquiere A, Reid MC. Identifying palliative care needs among older adults in nonclinical settings. Am J Hosp Palliat Care. 2018;35(12):1477-82. doi: https://doi.org/10.1177/1049909118777235.
25. Hospice and palliative care. Know the difference [Internet]. Center for Hospice Care. (Consultado el 2 de octubre de 2020). Disponible en: https://www.hospicesect.org/hospice-and-palliative-care
26. Provencio JJ, Hemphill JC, Claassen J, Edlow BL, Helbok R, Vespa PM, et al. The curing coma campaign: framing initial scientific challenges-proceedings of the first curing coma campaign scientific advisory council meeting. Neurocrit Care. 2020;33(1):1-12. doi: https://doi.org/10.1007/s12028-020-01028-9.
27. Giacino JT, Katz DI, Schiff ND, Whyte J, Ashman EJ, Ashwal S, et al. Practice guideline update recommendations summary: Disorders of consciousness: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology; the American Congress of Rehabilitation Medicine; and the National Institute on Disability, Independent Living, and Rehabilitation Research. Neurology. 2018;91(10):450-60. doi: https://doi.org/10.1212/WNL.0000000000005926.
28. What is dementia? symptoms, types, and diagnosis [Internet]. National Institute of Aging. 2017. (Consultado el 20 de octubre de 2020). Disponible en: https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis
29. 10 most common symptoms of dementia [Internet]. Vanta B, Facty Health. (Consultado el 25 de octubre de 2020). Disponible en: https://facty.com/conditions/dementia/10-most-common-symptoms-of-dementia/10/
30. Terminology heterogeneity. Advisory Council on Alzheimer's Research, Care, and Services. [Internet]. Petersen RC, Office of the Assistant Secretary for Planning and Evaluation. (November 2020). Available at: https://aspe.hhs.gov/advisory-council-april-2016-meeting-presentation-terminology-heterogeneity
31. Palliative care knowledge network: advanced dementia [Internet]. CARESEARCH palliative care knowledge network. 2020. (November 2020). Available at: https://www.caresearch.com.au/caresearch/tabid/2785/Default.aspx
32. Murphy E, Froggatt K, Connolly S, O'Shea E, Sampson EL, Casey D, et al. Palliative care interventions in advanced dementia. Cochrane Database Syst Rev. 2016;12(12):CD011513. doi: https://doi.org/10.1002/14651858.CD011513.pub2.
33. Our parents, ourselves: Health care for an aging population. A Report of the Dartmouth Atlas Project [Internet]. Bynum JPW, Meara E, Chang CH, Rhoads JM. The Dartmouth Institute for Health Policy & Clinical Practice; 2016. (November 2020). Available at: https://www.dartmouthatlas.org/downloads/reports/Our_Parents_Ourselves_021716.pdf
34. Thomas JL, Sanchez-Reilly S, Bernacki R, O`Neill L, Morrison LJ, Kapo J, et al. Advance care planning in cognitively impaired older adults. J Am Geriatr Soc. 2018;66(8):1469-74. doi: https://doi.org/10.1111/jgs.15471.

35. Schwartz DB, Barrocas A, Wesley JR, Kliger G, Pontes-Arruda A, Arenas Márquez H, et al. Gastrostomy tube placement in patients with advanced dementia or near end of life. Nutr Clin Pract. 2014;29(6):829-40. doi: https://doi.org/10.1177/0884533614546890.
36. Zahradnik EK, Grossman H. Palliative care as a primary therapeutic approach in advanced dementia: A narrative review. Clin Ther. 2014;36(11):1512-7. doi: http://dx.doi.org/10.1016/j.clinthera.2014.10.006.
37. Smith PA. Palliative care in dysphagia and dementia. Perspect ASHA Spec Interest Groups. 2020;506-10. doi: https://doi.org/10.1044/2020_PERSP-19-00038.
38. Alzheimer's Association. 2020 Alzheimer's disease facts and figures. Alzheimer's Dement. 2020;16:391-460. doi: https://doi.org/10.1002/alz.12068.
39. Span-Sluyter CAMFH, Lavrijsen JCM, Leeuwen EV, Koopmans RTCM. Moral dilemmas and conflicts concerning patients in a vegetative state/unresponsive wakefulness syndrome: shared or non-shared decision making? A qualitative study of the professional perspective in two moral case deliberations. BMC Med Ethics. 2018;19(1):10. doi: https://doi.org/10.1186/s12910-018-0247-8.
40. World Alzheimer Report 2019. Attitudes to dementia [Internet]. Alzheimer's Disease International. (November 2020). Available at: https://www.alz.co.uk/research/WorldAlzheimerReport2019.pdf
41. Estrategia en enfermedades neurodegenerativas del Sistema Nacional de Salud [Internet]. Ministerio de Sanidad, Servicios Sociales e Igualdad. 2016. (November 2020). Available at: https://www.mscbs.gob.es/organizacion/sns/planCalidadSNS/pdf/Est_Neurodegenerativas_APROBADA_C_INTERTERRITORIAL.pdf
42. Cantón BA, Lozano FFM, Olmo GMD, Casa NV, Wanden-Berghe C, Avilés V, et al. Manejo nutricional de la demencia avanzada: resumen de recomendaciones del Grupo de Trabajo de Ética de la SENPE. Nutr Hosp. 2019;36(4):988-95. doi: http://dx.doi.org/10.20960/nh.02723.
43. Slachevsky A, Abusleme LMT, Arenas MÁ. Cuidados paliativos en personas con demencia severa: reflexiones y desafíos. Rev Méd Chile. 2016;144(1):94-101. doi: http://dx.doi.org/10.4067/S0034-98872016000100012.
44. Echeverri SS. Unidad de cuidados paliativos. Una necesidad sentida. Actual Enferm. 2006;9(3):6-8.
45. Revilla HP. El dolor y la muerte. In: León CFJ, Pastor GLM (editores). Manual de ética y legislación en enfermería. España: Mosby/Doyma. 1997. p. 124-8.
46. Echeverri S. La Declaración de Cartagena desde la interdisciplinariedad. Rev Nutr Clin Metab. 2019;2(1):63-75. doi: https://doi.org/10.35454/rncm.v2supl1.03.
47. Schwartz DB. Integrating patient-centered care and clinical ethics into nutrition practice. Nutr Clin Prac. 2013;28(5):543-55. doi: https://doi.org/10.1177/0884533613500507.