The significance of the distinction between “having a life” vs. “being alive” in end-of-life care

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Abstract

In end-of-life care discussions, I contend that the distinction between “having a life” vs. “being alive” is an underutilized distinction. This distinction is significant in separating different states of existence conflated by patients, families, and clinicians. In the clinical setting, applying this distinction in end-of-life care discussions aids patients’ and family members’ decision-making by helping them understand that being alive can differ from having a life. Moreover, this distinction helps them decide which state may be the most important to them. After applying this distinction to three complex cases, I respond to the likely objection that “having a life” vs. “being alive” is less accurate and more controversial than other distinctions. I conclude by arguing that “having a life” vs. “being alive” is more accurate and less controversial than distinctions between medically indicated vs. medically inappropriate treatments, personhood, and quantity vs. quality of life.

Keywords End-of-life care · Communication · Decision-making · Ethical distinctions

In end-of-life care, there is often a time when patients, surrogates, and clinicians need to make difficult decisions. These decisions involve choices about goals of care, cardiopulmonary resuscitation measures, and life-sustaining treatments. In these situations, clinicians may rely on a range of clinical and ethical distinctions. These distinctions aim to facilitate the decision-making process by helping patients and loved ones identify their relevant considerations in deliberation. For example, is it more important for a particular plan of care to increase a patient’s “quantity” (life expectancy) or their defined “quality of life?” In addition, during end-of-life care discussions, a distinction can likewise serve as an explanation or justification for (or against) a specific plan of care or intervention. For example, stipulating the difference between interventions that “allow a patient die” vs. “intentionally cause death.”¹

In end-of-life care discussions, I contend that the distinction between “having a life” vs. “being alive” is an underutilized distinction. This distinction is significant in separating different states of existence conflated by patients, families, and clinicians. In the clinical setting, applying this

distinction in end-of-life care discussions aids patients’ and family members’ decision-making by helping them understand that being alive can differ from having a life. Understanding this difference helps them decide which state may be the most important to them.

Having a life vs. being alive

The distinction between having a life vs. being alive featured prominently in works by James Rachels and Thomasine Kushner. Rachels (1986) argued that it is a normative judgment and should replace the standard distinction between letting vs. causing a patient to die (Miller et al. 2010). Kushner (1984) applied this distinction to the ethical permissibility of abortions by arguing that the notion of “brain life” (the neurological capability of consciousness) is a relevant consideration. This paper narrowly applies this distinction to the domain of end-of-life healthcare and relies on Kushner’s articulation rather than Rachels.

The terms ‘being alive’ and ‘having a life’ are stipulated as follows. Being alive means that a person meets a biological criterion of functioning. (Kushner 1984). For humans,

¹ Rather than ‘killing,’ I use ‘causing death’ because, as argued by Miller and Truog (2012), this term is more normatively neutral with fewer implications concerning justification and authorization than ‘killing.’

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this means that one or more of the following conditions are met: (A) there is vital fluid flow (cardiopulmonary functioning), (B) there is homeostasis (self-maintenance of the organism), or (C) consciousness (Younger 2007; Veatch 2012). Being alive means a human meets conditions A, B, or C. Instead of being alive, I use *basic physical survival* for clarity and emphasis.

Basic physical survival contrasts with having a life. To have a life means a human is a subject of a life characterized by specific physiological and psychological experiences, patterns of thoughts, feelings, conduct, relationships to self and others, and a lived history (Kushner 1984). To be the subject of a life is characterized by specific properties and relationships. Moreover, as Kushner argues, possession of these properties and relationships entails “[being] capable of some degree of problem-solving, effecting relationships that give satisfaction, benefiting from past experiences to influence present situations as well as being capable of experiencing and expressing a range of emotions.” (Kushner 1984, p. 6). For clarity and to best encapsulate the aspects of having a life, I use the term the *capacity for living life*.

There is a close relationship between basic physical survival and the capacity for living life. First, both are states of existence. Basic physical survival and the capacity for living life require not being dead. Second, basic physical survival is an antecedent condition for the capacity for living life. One cannot experience living life if one is dead. Finally, there is difficulty in identifying the exact point at which one moves from basic physical survival to the capacity for living life (or visa-versa). So, while properties, relationships, and entailments characterize the capacity for living life, these should not be considered strictly necessary and sufficient conditions for living a life.

There are conceptual and practical differences despite the close relationship between these states of existence. Although both are states of existence, they are different *kinds of existing*. Consider that basic physical survival is only a necessary—not sufficient—condition for the capacity for living life. It does not follow that someone in the state of basic physical survival will also have the capacity for living life. These are different kinds of existing.

To illustrate, consider severely anencephalic newborns and adult patients in permanent vegetative states (PVS). Anencephalic newborns are in basic physical survival since they meet conditions A (vital fluid flow and B (homeostasis) but lack the capacity for life. Adult PVS patients meet requirements A (vital fluid flow), B (homeostasis), and even C (a level of consciousness activity but not awareness) for basic physical survival, but due to injury or illness, lack the capacity for living life.

Since basic physical survival and the capacity for living life are different kinds of existing, it is reasonable for a person to value them differently. To value something, a person accords significance to that thing, feature, or property, and it is a relevant factor in one’s deliberation, choices, and conduct. It is reasonable for one to value the capacity for living life more than basic physical survival. This valuing does not mean that basic physical survival lacks significance but only that the capacity for living life is more important. As Rachels points out,

Being alive, in the biological sense, is relatively unimportant. One’s *life*, by contrast, is immensely important; it is the sum of one’s aspirations, decisions, activities, projects, and human relationships (Rachels 1986, p. 5).

A patient or surrogate valuing a capacity for living life more than basic physical survival is consistent with the tenets of medical ethics.² Assuming conditions of reasonableness and decision-making capacity, patients not only have the moral right of self-determination in making their own healthcare decisions, but healthcare providers have professional responsibilities to support and respect these decisions. Moreover, while healthcare providers have a professional obligation of non-maleficence, the patient or surrogate ultimately determines the degree to which burdens and harms are intolerable (Beauchamp and Childress 2019; White et al. 2012).³

To summarize, basic physical survival means biological functioning; whereas, the capacity for living life means to be the subject of a life, possessing specific properties, relationships, and embedded social interactions. While both are states of existence, they are—conceptually and practically—different kinds of existing. Moreover, it is reasonable for one to regard the capacity for living life as being more valuable than basic physical survival. The following section applies this distinction to end-of-life care discussions and decisions occurring in the clinical setting.

² I use ‘surrogate’ to mean individual or group making decisions on behalf of a patient that lacks decision-making capacity.

³ Moreover, considering the capacity for living life as being more valuable than basic physical survival is consistent with many people’s affective responses to situations involving anencephalic newborns and PVS patients. Severely anencephalic newborns meet the criterion of basic physical survival but their parents grieve for their newborns’ loss of a capacity for living life. For adult PVS patients, they maintain basic physical survival, but these patients loved-one’s grieve for their loss of a capacity for living life.

The capacity for living life vs. basic physical survival in end-of-life care discussions

Before applying this distinction in the clinical setting, it is necessary to understand the process and complexity of end-of-life care decisions. Underwriting the decision-making process in healthcare is the patient-provider relationship (Enck 2014; Pellegrino 2006). In the patient-provider relationship, the goal is healing, and healing focuses on improving patient well-being (Pellegrino 2006; Cassell 2012). The best way to achieve healing requires the involvement of both patient and provider, which is the process of shared decision-making (Jonsen et al. 2010). Shared decision-making aims at patients and providers arriving at a mutually agreed-upon decision.⁴

Arriving at a mutually agreed-upon decision requires a balancing of two components. The first component is patients’ (or surrogates’) values, interests, preferences, and moral right to self-determination. The second is healthcare providers’ clinical expertise and ethical responsibilities of beneficence and non-maleficence (Beauchamp and Childress 2019; Jonsen et al. 2010). Communication between patient and provider balances these components in making decisions (Epstein et al. 2010).⁵

However, shared decision-making is often most challenging during end-of-life care. To illustrate, consider the following cases:

Case #1: Mr. H. is a 65-year-old man with gastric cancer and metastatic liver disease. His first round of chemotherapy treatment failed to slow the progression of his cancer. He has just started his second round of treatment, so it is too early to know whether it is working. If his second round of treatment does not work, Mr. H is considering another round of aggressive chemotherapy. Mr. H is married with two adult children, one of whom is married 1 year from now. He feels that aggressive chemotherapy is his only option for beating his cancer and living long enough to attend his daughter’s wedding.

Case #2: Mrs. A is an 85-year-old woman in the advanced stages of degenerative brain disease. Mrs. A has an advanced directive that stipulates she does not want any life-sustaining

treatments or interventions, specifically any artificial nutrition and hydration (ANH), once her condition has reached the point of being end-stage. However, Mrs. A’s husband and family are insistent that she receive artificial nutrition and hydration so that (i) she does not “starve to death” and (ii) to provide her comfort.

Case #3: James is a 5-year-old boy recently admitted with pneumonia. James suffered a severe anoxic brain injury from a near-drowning two years ago. Although on a ventilator, James’s parents had been caring for him at home. James’s parents are attentive and caring but concerned that his hospital admissions for pneumonia, which will likely continue to occur, will cause him suffering. James’s parents have questions about their son’s long-term plan of care.

These cases illustrate the complexity in end-of-life care and decision-making, requiring empathetic and patient-centered communication (Back et al. 2009). I contend the distinction between the capacity for living life vs. basic physical survival is a beneficial tool that helps patients or surrogates separate two states of existence and identify relevant values. To demonstrate, let’s apply this distinction to Mr. H, Mrs. A, and James’s case.

In case #1, Mr. H’s goal of care seems to be to extend his life span to be able to attend his daughter’s wedding in a year. However, if this second round of chemotherapy fails to treat Mr. H’s cancer, it is not evident that further chemotherapy would be beneficial. In this case, the physician could rely on the distinction between the capacity for living life vs. basic physical survival. First, the physician could specify the differences between the capacity for living life and basic physical survival. For Mr. H, the capacity for living life requires asking him to speak to the interests and values that are most important to him, such as spending time with his children. At this point, the physician can provide clinical expertise by advising Mr. H that further aggressive chemotherapy will likely not cure or benefit him but rather result in harm and burdens. For example, the side effects of the treatment might be severe enough to prevent him from attending his daughter’s wedding. At best, the third round of chemotherapy may allow Mr. H to be alive, but, at worst, it will not let him have the capacity to live life. Rather than focusing on basic physical survival, the physician could make a recommendation—consistent with Mr. H’s interests and values—to transition his goal of care from time-extension to symptom management and maximize the sort of life he values.

For case #1, distinguishing the capacity for living life from basic physical survival helps Mr. H identify the significant value of interacting with his daughter, facilitating his end-of-life care decision-making. In case #2, relying on the difference between the capacity for living life vs. basic physical survival is helpful not for the patient but Mrs. A’s husband and family.

⁴ Note that ‘mutually agreed’ simply means that the parties agree on a decision as at least being ethically and clinically permissible.

⁵ This shared decision-making process is an idealization, meaning that it may not be possible under certain non-ideal (real-world) conditions in certain situations. However, besides limited cases in which patients or surrogates cannot discuss their interests, values, or preferences, the shared decision-making model is ideal that providers should always strive towards following. It does not follow from something functioning under ideal conditions that make it any less relevant, practical, or essential to those in real-world or non-ideal situations (Simmons 2010; Annas 2011).

Mrs. A's husband and family struggle to understand the legally binding refusal of treatments stipulated in her advance care directive. The distinction of the capacity for living life vs. basic physical survival applies to Mrs. A's advance care directive as a way of illuminating her values to her husband and family. Mrs. A's advance care directive suggests that she values the capacity of living life with her aspirations, decisions, activities, projects, and relationships. Once Mrs. A's degenerative brain disease is end-stage, her basic physical survival is not valuable. Thus, Mrs. A's advance directive, understood regarding the distinction of the capacity for living life vs. basic physical survival, helps indicate the core values that underwrite her refusal of treatment to her husband and family.

By helping the surrogates understand not only Mrs. A's decision but the values that support it, a provider can then discuss the appropriate range of treatment options consistent with her values and preferences. The provider could suggest that all treatments and interventions alleviate Mrs. A's discomfort and suffering. Since ANH goes against Mrs. A's values and priorities, has no restorative or curative effects, causes pain, and prolongs the dying process for patients with degenerative brain diseases, it is not an appropriate treatment option for her (Finucane et al. 1999; Mitchell et al. 1998; Rabaneck et al. 1997). Relying on the distinction between the capacity for living life vs. basic physical survival helps to reframe the context of the situation from "starving Mrs. A to death" to removing treatments and interventions that cause suffering and are against her values and preferences.

In case #3, differentiating the capacity for living life from basic physical survival offers James' parents an opportunity for reflection on how they should live with his condition.⁶ For James' parents to know how they should live with his condition requires understanding his situation and medical condition and how they value James.⁷ To understand James's medical condition, specifically its permanence, a physician must explain to his parents that while in basic physical survival, he cannot live life. Because of vital fluid flow and homeostasis, he is in basic physical survival, but he will never have psychological experiences, patterns of thoughts, feelings, and conduct, and relationships to himself. By distinguishing the capacity for living life from basic physical survival, a physician helps James' parents understand the permanence of his condition.

Establishing the permanence of James' condition helps his parents understand his condition and offers an opportunity for them to reflect on the value James is for them.

Because James will never have the capacity to live life, his parents may conclude that basic physical survival is crucial. Alternatively, James' parents can also reasonably conclude that basic physical survival without the capacity for living life is an affront to their (and James') values. In this way, the distinction between the capacity for living life vs. basic physical survival helps James' parents better understand his medical condition, identify relevant values, and facilitate them to transition his care goals from chronic symptom management to comfort care.

However, transitioning the care goals is not the only decision entailed by applying the distinction between James' case. This distinction may help James' parents understand how they value him. What they love about James is not related to the capacity for living life. Instead, James's basic physical survival is the fundamental value for his parents. James' parents might conclude that they should live with him by caring for him at their house despite James's condition. Thus, regardless of how James' parents value him, the distinction between the capacity for living life vs. basic physical survival facilitates their decision-making about his care.

Objection

At this point, the objection to the distinction of the capacity for living life vs. basic physical survival might be that it is unnecessary. It is an unnecessary ethical and clinical distinction since clinicians already rely on more accurate and less controversial distinctions such as that between (1) medically indicated vs. medically inappropriate treatments, (2) patients having vs. lacking "personhood," (3) and patient's "quantity of life" vs. their defined "quality of life." In what follows, I elucidate this objection by explaining these three distinctions. I outline why one could regard them as being more accurate and less controversial than the capacity for living life vs. basic physical survival and apply them to the cases of Mr. H, Mrs. A, and James.

A fundamental issue is the clinical indication or appropriateness of medical treatments and interventions in end-of-life care situations. This issue concerns medical indication or clinical appropriateness, not a conflict of values. In these situations, the distinction between medically indicated and medically inappropriate treatments is more accurate and less controversial than a capacity for living life vs. basic physical survival. A clinician has neither a legal nor ethical responsibility to provide patients with medically inappropriate interventions. Medically inappropriate interventions have an exceedingly low chance of physiological effect or are futile (no physiological effect) (Bosslet et al. 2015).

Patient values are not fundamental in determining the clinical appropriateness of interventions in end-of-life care.

⁶ As Bernard Williams succinctly remarks, "It is not a trivial question, Socrates said: what we are talking about is how one should live" (Williams 1985, p. 1).

⁷ Not *whether* James's parents' value him.

For example, in Mr. H and Mrs. A’s case, the fundamental issue is that the proposed course of treatment and interventions for these patients are medically inappropriate—not whether these patients or surrogates prefer the capacity for living life vs. basic physical survival.

The second distinction concerns a difference between a patient having vs. lacking personhood. Personhood means possessing particular cognitive capacities, such as self-awareness, rationality, and sentience (Veatch 2012). The personhood distinction is accurate because it is evident when patients have (e.g., Mr. H) or lacks the cognitive capacities to be considered persons (e.g., Mrs. A and James). The personhood distinction is less controversial in end-of-life care decision-making situations since self-awareness, rationality, and sentience are often pertinent considerations or values for patients, surrogates, and clinicians. As a result, whether a patient is a person or values the cognitive capacities related to personhood is vital, not whether there is a difference between a capacity for living life vs. basic physical survival.

The last distinction asks patients and surrogates to identify and evaluate the differences and preferences between the amount of time a patient has before death vs. the degree of fulfillment of this patient’s values and interests during that amount of time. A patient or surrogate can compare time until death against their defined “quality of life.” It is a more accurate distinction since it helps identify two meaningful considerations or values for patients and surrogates: quantity vs. quality of time. Since prognostication is a necessary and accepted element of terminal conditions, this distinction is less controversial than distinguishing between a capacity for living life vs. basic physical survival. Comparatively, distinguishing between a capacity for living life vs. basic physical survival seems unnecessary and potentially more confusing for patients and surrogates.

Response

Despite the importance of these distinctions in clinical practice, the objection that they are more accurate and less controversial than a capacity for living life vs. basic physical survival is misguided for three reasons. First, this objection overstates the modesty of the argument. The argument contends that the distinction between the capacity for living life vs. basic physical survival facilitates patients and surrogates end-of-life care decision-making in some end-of-life circumstances. It does not follow from this that this distinction should replace all other ethical and clinical distinctions. Instead, distinguishing the capacity for living life vs. basic physical survival is one of many distinctions. It is a single conceptual tool among many to help patients, surrogates, families, and clinicians identify a relevant value or consideration.

Second, although there is overlap among these distinctions, conceptually, each focuses on something different, viz., patient’s preference regarding types of existing, medical indication of treatment, possession of requisite cognitive capacities, and choice between duration vs. satisfaction of time. Different focuses signify different concerns. Suppose the concern in a clinical situation is, for example, about identifying a patient’s preference between duration vs. satisfaction of time. In that case, the focus on distinguishing between quantity vs. quality of time makes it a better clinical distinction to use.

Since the aim is to use the distinctions to best address concerns, situations involving potentially medically inappropriate treatments under normal conditions require two distinctions. Distinguishing between medically indicated vs. medically inappropriate treatments address the concern of an intervention’s physiological efficacy. While crucial, this concern is narrow and does not account for a patient or surrogate’s values. Identifying a patient’s values often requires distinguishing between their values about a capacity for living life vs. basic physical survival. Using both distinctions is best for addressing concerns in this situation.

To illustrate further, consider the problems with addressing these concerns by using one distinction. While identifying an intervention as indicated or inappropriate is vital, concerns are left unaddressed. Consider that even if an intervention is medically appropriate, it does not follow that that it is consistent with a patient’s values or preferences to undergo this intervention. Conversely, while distinguishing between the capacity for living life vs. basic physical survival helps to identify values, it does not address concerns about whether an intervention is medically indicated or inappropriate for this patient.

In addition, clinical considerations of uncertainty, survival times if successful, and interventions on quality of life are often assumed, but not discussed, factors in determining medical appropriateness. Clarifying patients’ or surrogates’ values regarding kinds of existing requires communication between patient, surrogate, and providers. This communication is necessary as the basis for most patients’ or surrogates’ requests for potentially medically inappropriate treatment is a conflict of values. This conflict is often the result of a lack of communication between the patient or surrogate and provider about values—not simply because the requested interventions are medically inappropriate or futile (no physiological effect) (Bosslet et al. 2018; Kon, et al.. 2016; Lantos 2018).⁸

⁸ American Thoracic Society, American Association for Critical Care Nurses, American College of Chest Physicians, European Society for Intensive Care Medicine, and the Society of Critical Care’s policy statement contends that institutions and clinicians should move from referring to specific requests as being for “futile treatments” to “potentially inappropriate medical treatment.” The justification for the language change is that, in these situations, a clinician or health-

In these situations, clinicians are responsible for identifying and discussing the values in conflict with the patient or surrogate. Using the distinction between the capacity for living life vs. basic physical survival in conjunction with that of medically indicated vs. medically inappropriate treatments help best address concerns and values in a conflict that is often the impetus for requests of medically inappropriate treatment.

To illustrate, assess the cases of Mr. H and Mrs. A and consider applying both of these distinctions. In Mr. H's case, after establishing that the treatments are medically inappropriate, the difference between the capacity for living life vs. basic physical survival facilitates a discussion with Mr. H in identifying his values. In Mrs. A's case, these distinctions help his family understand that additional interventions not only will not work but violate what she valued most. Thus, both distinctions facilitate better decision-making in end-of-life care.

Finally, the objection is misguided because it is not evident that the distinction between capacity for living life vs. basic physical survival is less accurate or more controversial than these other distinctions. As already mentioned, the distinction between medically indicated vs. medically inappropriate treatments is most often a conflict of values, not physiologically efficacy, that requires more communication.

Regarding the personhood distinction, it is far from obvious that it is more accurate than the distinction between a capacity for living life vs. basic physical survival. Consider the situations in which the personhood distinction does not help patients or surrogates identify end-of-life care values and discussions. The concepts of self-awareness, rationality, and sentience lack determinate content to facilitating identification and discussion about patients' and surrogates' end-of-life care. However, the notion of a capacity to live life—possessing properties and being the nexus of relationships and social interactions—assists patients and surrogates in identifying specific values in lived-life experiences (Kushner 1984). Thus, it is far from obvious that the personhood distinction is more accurate than that of distinguishing between a capacity for living life vs. basic physical survival.

In terms of controversy, the personhood distinction is far more controversial. This distinction often conflates two senses of personhood. The non-moral sense of personhood defines a person as possessing particular cognitive capacities, but a moral sense of personhood establishes an entity with moral status (Veatch 2012; Beauchamp 1999). Conflation occurs when the non-moral sense of personhood is assumed to justify the moral sense of personhood. However,

this is an incorrect inference; it is the is/ought fallacy. Consider that possession or lack of cognitive capacities does not, by itself, indicate anything about an entity's moral status. Moving from a description of the state of affairs, an entity possessing or lacking cognitive capacities, to a normative claim that cognitive capacities affect an entity's moral status requires an additional premise. In the clinical setting, the conflation of these senses of personhood results in the controversial view that those without cognitive capacities have diminished moral standing.

Whether a patient is (or is not) a person in a non-moral sense does not affect clinicians' ethical responsibilities (or lack of) to this patient. The distinction between a capacity for living life vs. basic physical survival avoids the issue of moral status by holding that both kinds of existing have moral status. For example, although Mrs. A and James cannot live a life, they still have moral status. Clinicians still have ethical obligations to care for patients regardless of whether they lack non-moral personhood, like fetuses, neonates, PVS patients, or patients with advanced degenerative brain disease. In distinguishing between kinds of existing, this distinction helps patients or surrogates make their own evaluative judgment about which kind of existing they value. This judgment is not that the capacity for living life has moral status, but basic physical survival does not. Instead, this is a particular evaluative judgment made by a patient or surrogates about their value: a capacity for living life or basic physical survival.

The last distinction, "quantity vs. quality of life," is not more accurate or less controversial than the capacity for living life vs. basic physical survival. The former is contingent on clinicians' deeply flawed judgments about "quantity of life" and "quality of life." For "quantity of life," studies indicate not only physicians' prognoses for "quantity of life" terribly inaccurate—often optimistically overestimating survival by 530%—but also are frequently not given to patients with prognoses (Christakis and Lamont 2000; Dow et al. 2010; Kiely et al. 2011). Moreover, there are communication problems even in providing terminal diagnoses and prognoses to patients. Research indicates physicians' self-assessment of their skills for communicating terminal diagnoses and prognoses are inaccurate and often excessively self-flattering (Hilden et al. 2001; Ford et al. 1994). For "quality of life" judgments, evidence indicates that physicians incorrectly estimate their own patients' preferences for life-sustaining treatments (Schneiderman et al. 1993). For example, a study of homeless patients' preferences for resuscitation measures and life-sustaining treatments indicated that their desire for measures and treatments was more aggressive than physicians or patients with severe COPD (Norris, et al. 2005). As a result, because of these clinicians' flawed judgments and communication, the "quantity vs. quality of life" distinction is not more accurate or less

Footnote 8 (continued)

care team is responsible for identifying the values in conflict (Bosslet et al. 2015).

controversial than that of a capacity for living life vs. basic physical survival.

The advantage of the distinction between the capacity for living life vs. basic physical survival is it elucidates the values of a patient, surrogate, or family—not the clinician. As illustrated by Mrs. A’s case, a rational and reasonable patient has a moral right to self-determination, which includes refusal of life-sustaining treatments. A patient may refuse to undergo treatments because they do not value existing without the capacity to live life. Alternatively, as illustrated by James’ case, a patient or surrogate, not the clinician, determines which kind of existing is too burdensome or intolerable. For these reasons, the objection about the capacity for living life vs. basic physical survival in end-of-life care discussions is misguided.

Conclusion

I have argued that a physician’s use of the distinction between the capacity for living life (having a life) vs. basic physical survival (being alive) could play a significant role in end-of-life care. This distinction assists patients to have their decisions respected and supported with clinicians’ responsibilities of beneficence and non-maleficence. By separating these often-conflated but differing kinds of existing, patients and surrogates can better identify which they regard as more valuable. Facilitating conversations between patients and families in identifying values, interests, and preferences helps clinicians provide clinical expertise and information. As a result, the distinction between the capacity for living life vs. basic physical survival supports the shared decision-making process and end-of-life care decisions.

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References

Annas, J. 2011. *Intelligent virtues*. Oxford: Oxford University Press.

Back, A., R. Arnold, and J. Tulsky. 2009. *Mastering communication with seriously ill patients: Balancing honesty with empathy and hope*. Cambridge: Cambridge University Press.

Beauchamp, T. 1999. The failure of theories of personhood. *Kennedy Institute of Ethics Journal* 9 (4): 309–324.

Beauchamp, T., and J. Childress. 2019. *Principles of biomedical ethics*, 8th ed. Oxford: Oxford University Press.

Bosslet, G.T., T.M. Pope, G.D. Rubenfeld, B. Lo, R.D. Truog, C.H. Rushton, J.R. Curtis, D.W. Ford, M. Osborne, C. Misak, D.H. Au, E. Azoulay, B. Brody, B.G. Fahy, J.B. Hall, J. Kesecioglu,

A.A. Kon, K.O. Lindell, D.B. White, American Thoracic Society ad hoc Committee on Futile and Potentially Inappropriate Treatment, ... Society of Critical Care. 2015. An official ATS/AACN/ACCP/ESICM/SCCM policy statement: Responding to requests for potentially inappropriate treatments in intensive care units. *American Journal of Respiratory and Critical Care Medicine* 191 (11): 1318–1330.

Bosslet, G.T., B. Lo, and D.B. White. 2018. Resolving family-clinician disputes in the context of contested definitions of futility. *Perspectives in Biology and Medicine* 60 (3): 314–318.

Cassell, E. 2012. *The nature of healing: The modern practice of medicine*. Oxford: Oxford University Press.

Christakis, N., and E. Lamont. 2000. Extent and determinants of error in physicians’ prognoses in terminally ill patients: Prospective cohort study. *British Medical Journal* 320: 469–473.

Dow, L., J. Khatcheressian, L. Lyckholm, R. Matsuyama, T. Smith, and E. Virago. 2010. Giving Honest Information to patients with advanced cancer maintains hope. *Oncology* 24 (6): 251–254.

Enck, G. 2014. Pharmaceutical enhancement and medical professionals. *Medicine, Healthcare and Philosophy*, 17 (1): 23–28.

Epstein, R., D. Korones, and T. Quill. 2010. Withholding information from patients —When less is more. *New England Journal of Medicine* 365 (5): 380–381.

Finucane, T., O. Christmas, and K. Travis. 1999. Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA* 282 (14): 1365–1370.

Ford, S., L. Fallowfield, and S. Lewis. 1994. Can oncologists detect distress in their outpatients and how satisfied are they with their performance during bad news consultations? *British Journal of Cancer*. 70 (4): 767–770.

Hilden, J.M., E.J. Emanuel, D.L. Fairclough, et al. 2001. Attitudes and practices among pediatric oncologists regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology survey. *Journal of Clinical Oncology* 19 (1): 205–212.

Jonsen, A., M. Siegler, and W. Winslade. 2010. *Clinical ethics: A practical approach to ethical decisions in clinical medicine*, 7th ed. New York: McGraw-Hill Medical.

Kiely, B., M. Stockler, and M. Tattersail. 2011. Thinking and talking about life expectancy in incurable cancer. *Seminars in Oncology* 38 (3): 380–385.

Kon, A.A., E.K. Shepard, N.O. Sederstrom, S.M. Swoboda, M.F. Marshall, B. Birriel, and F. Rincon. 2016. Defining futile and potentially inappropriate interventions: A policy statement from the Society of Critical Care Medicine Ethics Committee. *Critical Care Medicine* 44 (9): 1769–1774. <https://doi.org/10.1097/CCM.0000000000001965>.

Kushner, T. 1984. Having a life versus being alive. *Journal of Medical Ethics* 1: 5–8.

Lantos, J. 2018. Tell parents the truth, but tell it slant. *Pediatrics* 142 (Suppl 3): S199–S204.

Miller, F., and R. Truog. 2012. *Death, dying, and organ transplantation*. Oxford: Oxford University Press.

Miller, F., R. Truog, and D. Brock. 2010. Moral fictions and medical ethics. *Bioethics* 24 (9): 453–460.

Mitchell, S., O. Kiely, and L. Lipsitz. 1998. Does artificial enteral nutrition prolong the survival of institutionalized elders with chewing and swallowing problems? *Gerontology* 53 (3): M207–M213.

Norris, Wendi, Elizabeth L. Nielson, Ruth Engelberg, and J. Randall Curtis. 2005. Treatment preferences for resuscitation and critical care among homeless persons. *Chest* 127: 2180–2187.

Pellegrino, E. 2006. Toward a reconstruction of medical morality. *The American Journal of Bioethics* 6 (2): 65–71.

Rabanceck, L., L. McCullough, and N. Wray. 1997. Ethically justified, clinically comprehensive guidelines for percutaneous endoscopic gastrostomy tube placement. *Lancet* 349 (9050): 496–498.

- Rachels, J. 1986. *The end of life: Euthanasia and morality*. Oxford: Oxford University.
- Schneiderman, L.J., R.M. Kaplan, R.A. Pearlman, et al. 1993. Do physicians' own preferences for life-sustaining treatment influence their perceptions of patients' preferences? *Journal of Clinical Ethics* 4: 28–32.
- Simmons, J. 2010. Ideal and nonideal theory. *Philosophy and Public Affairs* 38 (1): 5–36.
- Veatch, R. 2012. *The basics of bioethics*. Boston: Pearson.
- White, D., A. Jonsen, and B. Lo. 2012. Ethical challenge: When clinicians act as surrogates for unrepresented patients. *American Journal of Critical Care*. 21 (3): 202–207.
- Williams, B. 1985. *Ethics and the limits of philosophy*. Cambridge: Harvard University Press.
- Younger, S. 2007. The definition of death. In *The Oxford handbook of bioethics*, ed. B. Steinbock, 285–303. Oxford: Oxford University Press.

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