

End-of-Life Decisions and Advanced Old Age

ARTICLE (RÉVISION PAR LES PAIRS / PEER-REVIEWED)

Byron J. Stoyles¹

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Résumé

Malgré que la plupart des gens meurent à un âge avancé, peu d'attention est accordée aux cas impliquant des personnes âgées dans les débats sur les dimensions morales et juridiques de la prise de décision de fin de vie. Le but de cet article est de déterminer de quelle manière nos discussions devraient changer à mesure que nous prêtons attention aux facteurs importants influençant les décisions de fin de vie pour les personnes en âge avancé. Mettant l'accent sur la prévalence des comorbidités ainsi que la probabilité que les gens en âge avancé connaîtront une longue période de déclin de leurs fonctions avant de mourir, je soutiens que nos débats devraient être élargis pour inclure une plus grande considération à la façon dont nous voulons vivre dans les phases finales de la vie. Avec cela, je plaide contre la tendance à penser que la prise de décisions de « fin de vie » ne concerne que la prise de décisions concernant le moment et la façon dont il convient de mettre fin à la vie d'une personne. Je soutiens, en outre, que nous devrions sortir de la médicalisation de la mort.

Mots clés

euthanasie, suicide assisté, fin de vie, âge avancé, prise de décision, médicalisation

Abstract

Despite the fact that most people die in advanced old age, little attention is given to cases involving older people in debates about the moral and legal dimensions of end-of-life decision making. The purpose of this paper is to establish some of the ways our discussions should change as we pay attention to important factors influencing end-of-life decisions for people in advanced old age. Focusing on the prevalence of comorbidities and the likelihood that people in advanced old age will experience an extended period of declining function before death, I argue that our debates should be expanded to include greater consideration of how we want to live in the final stages of life. With this, I am arguing against the tendency to think that "end-of-life" decision making concerns only making decisions about when and how it is appropriate to terminate a person's life. I argue, further, that we should move away from the medicalization of dying.

Keywords

euthanasia, assisted suicide, end-of-life, advanced old age, decision making, medicalization

Affiliations des auteurs / Author Affiliations

¹ Department of Philosophy, Trent University, Peterborough, Canada

Correspondance / Correspondence

Byron J. Stoyles, byronstoyles@trentu.ca

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Conflicts of Interest

None to declare

Introduction

Debates about end-of-life decision making tend to focus on cases involving people we know about because of the highly public circumstances surrounding their deaths: Karen Ann Quinlan, Nancy Cruzan, Tracy Latimer, Sue Rodriguez, and Terri Schiavo. The notoriety of these cases is due largely to the fact that they are atypical. Each involves extraordinary circumstances including an elevated legal-political profile [1].¹ None of these landmark cases focuses on the conditions most of us will experience as we approach the end of our lives. Most people die without much media attention and fanfare. Most people do not die following an accident like Quinlan, Cruzan, or Schiavo, and most people's stories do not include the drama of a life ending in childhood like Latimer or at the age at which most people are healthy, able-bodied, adults like Quinlan, Cruzan, Rodriguez, and Schiavo.

Our fascination with famous cases distracts us from the reality that most people in North America die in old age. Demographic trends reflect an increasing number of people will live to, and die in, advanced old age – the 'baby-boomers' are now entering retirement and many in this generation are likely to live beyond their 85th birthdays [2]. Despite these facts, little attention is given to cases involving older people in either theoretical or practical discussions about end-of-life decision making. This is a problem for the reason that some of the salient factors influencing the decisions we make at the end of our lives tend to arise only when we are old. Thus, to the extent that we ignore cases involving older people, we stand to overlook important factors related to end-of-life decision making.

The purpose of this paper is to establish some of the ways in which our debates about end-of-life decision making will change if we give serious consideration to the many and complex factors influencing end-of-life decisions for people in advanced old age, i.e. people who are more than 85 years old. I start by establishing that people in advanced old age are more likely than other people, including other seniors over the age of 65, to experience comorbidities and an extended period of declining function before they die. Focusing on these factors, I argue that our discussions about end-of-life decision making should be refocused in two ways. First, we should pay more attention to questions about the quality of the lives people are living, questions that are difficult to answer in any context, but especially in the context of advanced old age. Second, we should resist the tendency toward the medicalization of dying and the related tendency to think about end-of-life decision making mostly in the medical context.

The Longer We Live...

Though most studies and published data classify any person who is over the age of 65 as elderly without distinction,² there are salient trends concerning the relation between the cause of death and age among seniors. These trends confirm that the longer a person lives, the more likely it is that the person will die after a prolonged period of declining function rather than of an acute event like a massive heart attack without any prior decline in health or of cancers that have a distinct terminal phase [4-12]. Consider, for instance, the relation between age and the two leading causes of death in North America: cancer and diseases of the heart (cancer in Canada, diseases of the heart in the United States) [3].³ The likelihood of dying of cancer is highest in individuals who are 65-70 years old

¹ I thank Stephen Katz for suggesting relevant literature to focus my thinking. He led me to consider the work by Sharon Kaufman [1] that informs the argument in the second part of this paper. Kaufman argues that what she calls the "cultural conversation" about end of life decisions emphasizes "discrete entities in opposition" that fail to capture the muddled nature of actual cases [1, p. 716].

² While I acknowledge that there are exceptions, in general, we see the lumping together of all people over the age of 65 even in reports that acknowledge both the need to consider the implications of an aging population on end-of-life decision making and the heterogeneity of health status in people of advanced age. One obvious offender is *The Royal Society of Canada Expert Panel: End-of-Life Decision Making* [3]. Even in the section of this report focussing on aging, only the group of seniors – i.e., the group of people over the age of 65 – is noted.

³ All statistical claims in this paper – even those for which specific statistics are not provided – are supported by the most recent data made available by [Statistics Canada](#) and the US [Centers for Disease Control and Prevention](#).

and it decreases as age increases afterwards. Conversely, the likelihood of dying of chronic diseases of the heart increases with age.

Among individuals aged 65-74, cancer is the leading cause of death in both Canada and the U.S. (45.2% in Canada and 35.2% in the U.S.). The percentage of deaths caused by cancer decreases in individuals aged 75 to 84; in this age group it is the cause of death in less than one third of cases (31.7% in Canada and 25.1% in the U.S.). For the group of individuals who are 85 and older, the percentage drops by half again (to 15.7% in Canada and 12.4% in the U.S.).⁴

Diseases of the heart are, taken together, the leading cause of death for people over the age of 85 (25.8% in Canada and 30.7% in the U.S.). Other chronic diseases that cause very few deaths in younger people also become increasingly prevalent in the group of people who are 85 years and older. Alzheimer's disease, for example, is the cause of death for approximately one percent of people who die between the ages of 65 and 74 whereas this increases to five percent or higher (5% in Canada and 7% in U.S.) in individuals reaching more advanced old age.

Comorbidity is also more prevalent in advanced old age [11,14]. It is estimated, for instance, that people in advanced old age are likely to have three or four chronic morbidities [15] and that 80% to 90% of elderly patients with infections also have other diseases including cancer, diabetes, Alzheimer's disease, chronic congestive heart failure and chronic obstructive pulmonary disease [16]. These conditions can be mutually exacerbating.

Given the fact that people in advanced old age become increasingly likely to die at the end of some chronic illness, along with the prevalence of comorbidity, it is easy to understand Joanne Lynn's observation that, though "'The Dying' are expected to do little but wrap up life and go...this dominant myth about dying does not fit many people. Many elderly people are inching toward oblivion with small losses every few weeks or months" [4, p. S14] in a way that makes sense of Jill Lepore's claim that "[t]he longer we live, the longer we die" [17, p. 159].⁵

Identifying just when a person has reached the stage that death would be a welcome alternative to continued living is a considerable challenge when the person's physical and mental health decline slowly and without any distinct terminal phase. Many of the cases upon which our public debates are focused involve people in permanent vegetative states and people facing predictably rapid trajectories of declining function owing to diseases such as Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease).⁶

In her highly publicized case in 1993, for example, Sue Rodriguez fought for (but was not granted) the legal right to assisted suicide after being diagnosed with ALS [19]. In 2012, another woman diagnosed with ALS, Gloria Taylor, was granted the right to assisted suicide by the Supreme Court of British Columbia [20]. (Though Taylor is now dead, the decision in her case has been appealed and will be considered by the Supreme Court of Canada.) Rodriguez, Taylor and others who fight for the right to assisted death share the assumption that there will be a time at which continued life would be bad for them. Because of the predictably rapid decline in function that results from ALS, people diagnosed with this disease are usually able to identify a specific stage in the process of decline after which they predict they will no longer want to be alive. Typically, this is the stage at which they are suffering too much to live even minimally well. (There is, of course, disagreement about how much a person should be willing or forced to suffer and what constitutes too much suffering.)

⁴ It is unfortunate that much of the scientific work done to help us better understand death and dying focuses on patients dying of cancer as these patients' experiences differ from the experiences of most people in advanced old age [13].

⁵ For the same language, see also [18].

⁶ Of the cases listed at the start of this article, Tracy Latimer's is the exception. Latimer was diagnosed with Cerebral Palsy and suffered both regular seizures and apparently constant pain until her father ended her life in 1993.

In contrast, and because they are inching toward oblivion, determining when people in advanced old age reach the stage at which their quality of life is so low that continued life is no longer desirable can be a real challenge. A person with Alzheimer's, for instance, is likely to suffer the most emotional stress in the early stages of this disease in so far as the person is still aware of, and frustrated by, her failing memory. As this disease progresses, the person is likely to experience a very long period of declining function. It is not clear at what point along this slow slide we might reasonably decide the person's life is no longer worth fighting to preserve. Even this, however, is easier than determining when all of the creaks and groans associated with growing old are simply too much to bear. Consider the following snippets from Roger Angell's account of life in his nineties:

Check me out. The top two knuckles of my left hand look as if I'd been worked over by the K.G.B. ... if I pointed that hand at you like a pistol and fired at your nose, the bullet would nail you in the left knee. Arthritis... I'm ninety-three, and I'm feeling great. Well, pretty great, unless I've forgotten to take a couple of Tylenols in the past four or five hours, in which case I've begun to feel some jagged little pains shooting down my left forearm and into the base of the thumb...

Like many men and women my age, I get around with a couple of arterial stents that keep my heart chunking. I also sport a minute plastic seashell that clamps shut a congenital hole in my heart, discovered in my early eighties... The lower-middle sector of my spine twists and jogs like a Connecticut county road. This has cost me two or three inches of height, transforming me from Gary Cooper to Geppetto...

I've endured a few knocks but missed worse. I know how lucky I am, and secretly tap wood, greet the day, and grab a sneaky pleasure from my survival at long odds. The pains and insults are bearable... [21]

For now, the pains are bearable. The question, though, is when will they be too much? Perhaps when something significant goes wrong, but more likely after inching along in successively tiny steps. Perhaps the fact that we inch along in this way will actually mean we never consider the pains and insults unbearable. As Angell goes on to note, "[r]ecent and not so recent surveys (including the six-decades-long Grant Study of the lives of some nineteen-forties Harvard graduates) confirm that a majority of us people over seventy-five keep surprising ourselves with happiness. Put me on that list" [21].

How we *live* matters

The manner in which Angell focuses on how older people are surprised by their continued happiness highlights that the important question does not concern how we die, but rather how we live. It is odd, then, that debates about the moral and legal dimensions of end-of-life decision making – debates intended to shape public opinion and policy – are really only debates about the permissibility of ending life [22]. The hyphenated term “end-of-life” has taken on a pseudo-technical meaning related to the termination of life in so far as the literature on end-of-life decision making focuses, almost exclusively, on the question of whether we should be allowed to determine when and how a person dies. The Royal Society of Canada's Expert Panel report on end-of-life decision making, for example, is focused on euthanasia and assisted suicide [3]. Empirical studies tend to focus on individual factors (such as the effective use of Do Not Resuscitate, or DNR, orders) that influence our decisions to continue or to discontinue life-sustaining treatment options. Even more comprehensive studies such as SUPPORT (the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment – a multimillion dollar and multi-site study of the process of dying in American hospitals) are focused on decisions related to dying.

One consequence of the manner in which our debates about end-of-life decision making are focused is that end-of-life discussions are often put off until a person is nearly dead. For example, discussions about advanced directives and DNRs frequently take place very late in the trajectory of illness [23], often within days of a person's death or discharge from a healthcare facility [24,25]. This is typically also the stage at which people enter palliative care. It is as though we believe that a person is not really dying until "he's... taking to bed, losing weight, and suffering from pain...when dying is all that he can do" [4, p. S14]. If we leave our end-of-life decision making until this point, however, any decisions we make will come well after the point at which they are relevant – well after palliative or hospice care could offer benefits to the elderly person, and perhaps even after the person would prefer to avoid aggressive treatment. At this point, we are too late to help the person in ways we could have been helping them all along.

The problem with the narrow focus of our debates is that we move away from the reason we are having these debates in the first place. We only consider whether or not euthanasia and assisted suicide should be allowed because we believe that some people's lives are no longer worth living or, worse, so full of pain that continued living would amount to too much suffering. The least controversial cases are those in which a person, such as Donald Low, is suffering as a result of an incurable condition that follows a predictable path of rapidly declining physical and mental function accompanied by intense pain and ending in death.⁷

It may be that "very little of the literature is based on the question of the worth of a life...because we have no calculus by which it can be defined."⁸ Yet, without considering the quality of life a person is living, the factors that play into our current, narrowly defined, debates are empty. Consider, for example, that there would be little sense in considering the likelihood that a specific course of treatment would, if pursued, keep one alive longer if continued life would constitute continued suffering.

Empirical evidence reflects that people in the final stages of life rank treatment options in relation to the likelihood that these treatment options will allow them to continue living with the capacity to maintain what is valuable in their lives. This is reflected in the judgments made by people like Sue Rodriguez and Gloria Taylor. As reported above, Rodriguez and Taylor fought for the right to die after predicting that ALS would reduce their ability to function to the extent that they would no longer be able to do any of the things that give their lives meaning.⁹ Similarly, and looking forward to old age, we might be tempted to embrace the *The Who's* infamous mantra "I hope to die before I get old" for the reason that we cannot imagine what will give our lives meaning when we start to experience declining health and function.

Here again, however, there is evidence that the decision making process is different for people in advanced old age than for younger people. Older people tend to think treatments are "desirable to the extent they could return the patient to his or her valued life activities" [26, p. 620]. People's decisions concerning whether or not they should pursue treatment options, including those that could prolong their lives, tend to hinge on the level of functionality they believe will be restored by the treatments being offered [27-29]. Many people in advanced old age opt for treatment whenever there is a good chance the treatment will restore their health to the same or better condition than they were experiencing before their condition necessitated intervention. And, most people would sacrifice quantity to preserve quality of life [27,28,30-33].

⁷ Donald Low was a microbiologist who became a recognized public figure during the SARS outbreak in 2003. Days before he died as a result of a brain tumour, Low produced a video making an informed and passionate plea for assisted suicide to be made legal in Canada. This [video](#) was published after his death.

⁸ This was suggested by Tom Koch in a helpfully critical review of an earlier version of this paper.

⁹ In this regard, the famous cosmologist Stephen Hawking is remarkable since he has both lived longer than most people with ALS and continues to live a life he thinks is a good life. In Hawking's case, it has proven possible to continue with the relationships and intellectual projects that give his life meaning.

As Angell reports, most people find themselves happy to continue living well beyond what they think of as the *prime* of life. In contrast to people diagnosed with ALS who have too little time to adjust to their rapid decline in function, people in advanced old age often experience declining function in such small increments that their valued life activities can change accordingly. Opting for treatment that would restore their health to the condition they were experiencing before the need for intervention amounts to opting to restore the functionality that allows for them resume their valued life activities.

While I would never deny that it is important to determine the moral and legal status of euthanasia and assisted suicide, I contend that we should expand the scope of what counts as an end-of-life decision to encompass decisions we make about the end of life in the broader sense of the final period of a person's life. In this broader sense and in the context of debates about end-of-life decision making, the end of a person's life should be taken to include any period of declined or declining physical and mental well-being before the person dies. For most of us who will live to advanced old age, this period can last decades as we experience comorbidities and the slow decline of function. And, in this context, there is an obvious sense in which deciding how we live in the final period of life is more important than the precise manner of how we die. To see this, consider the joke in which a teacher asks her students to introduce themselves on the first day of school by saying their names and then saying what their moms or dads do. When it is Luke's turn, he says, "My name is Luke and my dad is dead." After acknowledging the tragedy of the situation, the teacher asks Luke what his dad did before he died. In response, Luke grabs his throat and yells "*N'gungghhh!*"¹⁰ Perhaps the best way to put my point is that end-of-life decision making should not be restricted to the "*N'gungghhh!*" What comes before that is more important. Rather than focusing exclusively on the "end-of-life" understood in the narrow sense of the termination of life, our debates should take into account also how we live at the end of life – not in the minutes, hours, or days before we die, but in the months and years that constitute the last part of our lives.

I expect my argument for a shift in focus from the *end* of life to the end of *life* will seem somewhat banal to people working in the multidisciplinary field of gerontology.¹¹ These are people who are already studying how people live as they age. Moreover, palliative and hospice care specialists are already focused on helping people manage symptoms so they can live well.¹² So far, however, the work of gerontologists and palliative care specialists has done little to expand the focus of our debates about end-of-life decision making. In part, this might be for the reason that our debates tend to be contextualized in relation to medical decision making.

The Medicalization of Dying

Most people in North America die following a decision to withdraw or withhold treatment in healthcare institutions [36], despite the fact that most of us would likely choose to die elsewhere should the opportunity arise [37-46]. These facts reflect that dying has become a condition to be managed by medicine [1,47]. There is an odd tension that arises from this arrangement. Healthcare providers, who tend to see death as the enemy and allowing death as failure, are asked to administer care to help individuals die well. Despite the tension, palliative care centres and hospices are now established

¹⁰ This joke is an adaptation of the one presented by Angell [21].

¹¹ Indeed, Tom Koch, for one, has written more than one op-ed piece in which he pushes for discussions about the end-of-life to focus on compassion and care for old people [22,34]. Whereas Koch argues that we should be focusing on providing support for fragile people, my focus is on living well more generally.

¹² Unfortunately, palliative and hospice care realize an 'oncology model'. The care provided in palliative contexts typically is focused on managing the sort of symptoms experienced by patients with terminal cancer. These are patients who are often experiencing significant pain and anxiety. And, these are patients whose disease is likely to bring about death in a short timeframe once they enter into the terminal phase of their disease. Thus, palliative and hospice care is built on a model that does not apply to most people over the age of 85 [2]. That many palliative care groups are cancer-focused was cited as a limitation in reports concerning the use of palliative care for patients with heart failure and older patients [11,35].

contexts in which healthcare providers focus on managing symptoms rather than fighting underlying, morbid, conditions.

One consequence of the medicalization of dying is that end-of-life decisions become forced. Not choosing is not an option that is allowed in the clinical setting – even doing nothing becomes an option that must be chosen. There is a presumed *imperative of choice*, an imperative that, in the medical setting, someone *must* engage in the deliberative process that leads to a directive for treatment [1,47,48]. Despite this “dark side of patient autonomy” [48, p. 231],¹³ we now have many treatment options from which to choose.

Advances in medical research and technologies are making possible procedures that were recently impossible. With these advances come new ethical questions related to the end-of-life – new questions arising from our increasing ability to orchestrate the timing and manner of a person’s death [48-51]. For all practical concern, these were not questions demanding answers even 40 or 50 years ago when we lacked effective means to sustain life. (I suspect these facts explain why debates about end-of-life decision making arise mostly in the medical context.)

As research and technologies advance, the availability of treatments and procedures increases.¹⁴ Many courses of treatment that were novel in the recent past have become routine as a result. Heart transplants, for example, were rare and usually fatal in the late 1960s and throughout the 1970s. The success rates have since increased to the point that TIME magazine reported in 2009 that newest challenge concerning heart transplants is surplus demand [52]. Other surgical procedures that were once high risk and considered inappropriate for people in advanced old age are now routinely performed on elderly patients. And, as these treatments become routine, attitudes towards their use are adjusted and choice falls out of the equation [47]. Resources are typically put to use whenever, and to the extent that, they are available [53] and choice gives way to the “technological imperative”: we ought to do something whenever something is possible [54]. So strong is the bias toward intervention when intervention is possible that the technological imperative has become perceived as a moral imperative [47]. There is a moral pressure against denying a person any treatment that might keep the person alive.

Paradoxically, in the same context we find the presumed *imperative of choice*, choice is replaced by routine in so far as some courses of treatment have become so much a part of standard care that the possibility of withholding treatment is often not even considered. The use of antibiotics, for example, is now so routine that consent is not sought before treatment is started in most cases [16]. Antibiotics can make the difference between living and dying. And, though we should be wary of William Osler’s suggestion that “pneumonia may well be called the friend of the aged” [55], it is worth considering that dying of pneumonia or infection might not be so bad given the alternatives in some cases.

The bias toward intervention within hospital settings is reflected in the observation that, “while hospitals were once feared as ‘places to die’ because so little could be done to avert death, some people now fear hospitals as places to die because so *much* can be done.” [16, p. 10] There is a sense in which too much ‘care’ – meaning: too much intervention – can serve to detract from a dying patient’s well-being [53].

Conclusions

Taking seriously the idea that debates about end-of-life decision making are really debates about the decisions we want to be able to make, we need to avoid the medicalization of dying in so far as it moves us into a context in which decision making is either absent (as we blindly follow the

¹³ Loewy [49] argues that forcing someone to make a decision they do not want to make is a form of paternalism.

¹⁴ This is a consequence of decreasing costs, increasing success rates, the availability of caregivers trained to administer the treatments, the availability of equipment, the possibility of reimbursement, etc.

technological imperative) or forced (because refusing or withdrawing treatment becomes a choice that has to be articulated and, often, fought for). And, in any case, who wants to live in a medical context? Here we should remember the lesson from Aristotle that medicine is for the sake of health and health is for the sake of *living well*.

If one accepts my call to move the focus of our debates about end-of-life decision making from debates about *when and how life will end* to discussions about *the best way to live at the end of our lives*, then more work is needed to generate space in our debates for discussions about cases that better reflect the context in which people in advanced old age make end-of-life decisions. This is, after all, the context in which most of us will find ourselves at the end of our lives – a context that is different, in salient ways, from the context of those highly public cases that tend to be the focus of our discussions. Since most people will not die like Cruzan, Schiavo or Latimer, it is important that we also focus on normal cases.

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