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# Expanded definitions of the “good death”? Race, ethnicity, and medical aid in dying

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## Abstract

The range of end of life options is expanding across North America. Specifically, medical aid in dying, or the process by which a patient with a terminal illness may request medical assistance with hastening death, has recently become legal in eight jurisdictions in the U.S. and all of Canada. Debates about aid in dying often rely on cultural constructions that define some deaths as “good” and others as “bad.” While research has found commonalities in how patients, family members, and health care providers define good and bad deaths, these constructions likely vary across social groups. Because of this, the extent to which aid in dying is seen as a route to the good death also likely varies across social groups. In this article, we analyse qualitative data from six focus groups (n=39) across three racial and ethnic groups: African American, Latino, and white Californians, just after a medical aid in dying law was passed. We find that definitions of the “good death” are nuanced within and between groups, suggesting that different groups evaluate medical aid in dying in part through complex ideas about dying. These findings further conversations about racial and ethnic differences in choices about end of life options.

### Keywords

End of life; aid in dying; focus groups; race; ethnicity; good death

## Introduction

Medical sociology has long sought to document how the institution of medicine shapes death and dying. For example, Glaser and Strauss (1966, 1980) revealed the process of dying within medical institutions, focusing on the organizational activities, interactional patterns, and temporal stages that shaped the inevitable experience of death (Baszanger, 1998, Strauss, 2000). More recently, Timmermans showed how medical professionals “broker” meanings about death, especially when ambiguity about the process or cause is present (Timmermans, 2005). These institutional contexts shape how providers and family members construct their sense that the death was “good” or “bad.” While many of these observations

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about medicine and dying continue to be relevant, recent changes to medicine require renewed reflection on the complex set of social and political conditions surrounding dying (Timmermans and Oh, 2010).

In this article, we examine one such change: the recent legalization of medical aid in dying (AID), which permits persons with terminal illnesses to request medical assistance to hasten death. Using data from focus groups with community members from a variety of racial/ethnic backgrounds, our analysis illustrates that constructions of the "good death" vary across social groups and that these constructions are part of how community members make sense of new end-of-life options, such as medical aid in dying. It also draws attention to tensions within discourse about medical aid in dying, highlighting how sociological perspectives challenge extant bio-ethics debates about the potential benefits and harms of AID.

## The "Good Death"

Cultural constructions about deaths as "good" or "bad" reflect larger societal expectations about what it means to live and die well. Several elements are common to Western ideals for the good death: pain relief, acceptance, mending of familial and other important relationships, and not being a burden to others (Zimmermann, 2012, Zimmermann, 2004, Broom and Cavenagh, 2010, Carr, 2003, Kellehear, 1990). These elements are prevalent in individual preferences and encoded into policy and law (Froggatt, 2007). Health care providers also have a role in defining the good death, "brokering" meanings about the dying process (Timmermans, 2005). From the perspective of health care providers, good deaths also refrain from unnecessary treatments that cause iatrogenic suffering, are timely, and do not involve conflict with family members (DelVecchio Good et al., 2004). The Western hospice and palliative care movement is largely based on these definitions of the good death (Hart et al., 2010). It is important to note, however, that these meanings about the good death are cultural constructions and do not reflect any inherently good or bad qualities of dying (Frith et al., 2013).

In fact, the ideals of the good death – while helpful for defining alternatives to medicalized, institutionalized deaths – can be a form of social control that seeks to discipline patients and their family members (Hart et al., 2010). Additionally, the dominant definition of the good death prioritizes a vision of dying that may not be achievable to all patients (Broom and Cavenagh, 2010). It de-individualizes the experience of death and disregards diversity within definitions of what is good (Long, 2004). For example, while a dominant message in palliative care academic literature is about acceptance of death (Zimmermann, 2012), some persons at the end of life see it as their moral responsibility to fight death to the end, especially as it is seen to benefit family members (Broom and Cavenagh, 2010).

Because the dominant definition of the "good death" is not preferable or achievable to everyone, we might expect that these messages do not resonate equally across society. The lack of resonance may explain some of the differences in rates of use of end-of-life care options, such as advance directives, hospice, and palliative care. It is likely that cultural resonance of good death ideals also affects individuals' interpretations of new options, such as medical aid in dying (AID), which allows a person with a terminal illness to request a prescription to hasten death. This new option has been widely contested and rhetoric on all sides often draws on constructions of the “good death” (Hillyard and Dombrink, 2001). Extant research is limited in its consideration of how these messages are received by the general public.

This article seeks to understand how community members from different racial and ethnic groups think about AID, which also reveals their acceptance and/or rejection of dominant good death definitions. While there is great diversity within racial and ethnic groups, our analysis reals some differences in how the good death is constructed and how well AID fits within that construction. These differences indicate that larger social inequalities shape how people from different racial and ethnic backgrounds think about death and dying.

## Medical Aid in Dying

As practiced in the U.S., medical aid in dying (AID) permits persons expected to live six months or less to request a prescription for medications intended to hasten death. Public support for AID has grown over time (Emanuel et al., 2016) with the Gallup poll reporting that in 2017 73% of Americans support doctors assisting someone with a terminal illness to end their life painlessly (Gallup, 2017). However, public opinion varies according to the framing of the issue (Magelssen et al., 2016, Rambotti, 2017). When medical action are seen as passive—or letting nature take its course, it is more widely accepted than when it is active—or causing the death (Sikora and Lewins, 2014). Public support for AID corresponds to recent legal changes in North America that make AID available in eight U.S. jurisdictions and all of Canada. This study pertains to California’s End of Life Option Act (EOLOA), which permits AID and went into effect in June 2016.

Despite the growth of AID, it is still considered controversial to many. Those in favour of AID claim that it epitomizes patient-centred care in that it leaves the decision about when, where, and how to die in the hands of the people with terminal illnesses (Coombs Lee, 2014, Coombs Lee and Grube, 2017, Karsoho et al., 2017). Some have even conceptualized these deaths as a form of “rational suicide” for older adults who have lived long enough to feel complete and want to end life on their own terms (Richards, 2017). Within this logic, the option should be implemented in a way that makes it equally available to all people, no matter their racial, ethnic, or social class backgrounds.

Those opposed often cite religious reasons. Studies find that both religious affiliation and behaviours associated with religion (attendance or identification) are associated with lower rates of approval of AID (Burdette et al., 2005, Jylhänkangas et al., 2014). Beyond religion, some have expressed concerns about how the option of AID might negatively affect society as a whole. Balch (2017) summarizes the argument against AID by asking if the choice to end one’s own life via AID might eventually be felt as an obligation, especially for people who are already vulnerable because of their age, lack of family resources, or marginalized social status. This obligation might be felt within interactions with health care providers who are asked to determine the value of life-saving interventions as well as within the family unit as dependent adults require more care (Richards, 2017).

Relatedly, some scholars argue that persons who are socially marginalized do not have full autonomy when making decisions about whether to continue living or not because of a moral devaluation of some lives (Sneddon, 2006, Drought and Koenig, 2002). But, other scholars object to framing AID in this way as it falls back on a paternalistic argument that is ultimately disempowering to those it is meant to protect (Scoccia, 2010). This debate is relevant for one of the most common concerns about AID, which is that it will disproportionately affect racial and ethnic minorities (Battin et al., 2007, Finlay and George, 2011, Golden and Zoanni, 2010, Ganzini, 2016). Opponents argue that racial and ethnic minorities might not receive high quality end of life care and instead will be encouraged to use AID—producing higher rates of utilization for persons of colour as compared to white people.

Taken together, the arguments against AID are concerned that AID will become the gold standard of the good death. As the gold standard, it would then exert disciplinary power, in the Foucauldian sense, over experiences of dying (Zimmermann, 2012). Specifically, Foucault's disciplinary power stems from knowledge and institutional practices that are used to classify, correct, and evaluate individual behaviours (Foucault, 2012[1979]). Through engagement with institutions and internalization of their standards, individuals come to discipline their own behaviour in line with institutional standards. In this way, if AID is the gold standard, both physicians and patients will orient their ideals about death toward it. This is especially a problem for vulnerable persons because the gap between reality and ideal is greatest for those who have poor care and therefore may be more enticed to use AID. Some think this will manifest in explicit discrimination and prompting to end lives early (Golden and Zoanni, 2010). But many think that it is more implicit or part of larger societal constructions about dying (Richards, 2017, Mann, 2015).

These concerns are part of how bioethicists think about AID, but sociological analyses can add depth to these conversations. Bioethics conversations often happen in the absence of systematic sociological data. In this article, we use focus group data to analyse how people from different racial and ethnic groups talk about AID, which also reflects their acceptance or rejection of dominant definitions of the good death. Understanding variation in the definition of the good death is important for making sense of reactions to the law as well as developing full explanations of existing racial and ethnic differences in use of a range of end-of-life care options.

## Race, Ethnicity, and End of Life

Despite some concerns that AID will be disproportionately used by those who are most socially vulnerable, data show that the rates of use for people of colour are much lower than that of people identifying as white. In fact, over almost twenty years, only three percent of people who died after receiving AID drugs in Oregon identify as any race other than white (OHPD, 2016). Although California is much more racially and ethnically diverse than Oregon, the numbers there still show that most people who use AID are white: 89.5% of the Californians using the End of Life Option Act (EOLOA) were identified as white (CDPH, 2017).

Explanations for racial and ethnic variability in use of AID fall into three broad areas: cultural, structural, and interactional explanations. The first explanation is that cultural and religious differences across racial and ethnic groups affect preferences for end of life care generally, and AID specifically. Numerous studies have documented racial and ethnic differences in attitudes about AID, with many concluding that religion or culture are the cause of these differences (MacDonald, 1998). In most studies, authors conclude that AID has more support from white people than from racial and ethnic minorities (Braun et al., 2001). However, deeper analyses show that the interplay between race, ethnicity, and decision-making about end of life are complex and that there is great variation within groups (Cain et al., 2018, Werth Jr. et al., 2002). For example, a recent study in California and Hawaii does not find statistically significant differences across racial and ethnic groups when assessing support for AID (Periyakoil et al., 2016). Given this, the literature is not settled on the extent to which attitudes are the root of differential rates of use of AID. It is possible, however, that cultural differences manifest in differing ideas about the definition of the good death, constructing AID as consistent with the good death for some, but not all, groups.

The second explanation is that people of colour lack are not given equal access to information and quality care across the life course. This means that as they face the end of life, they may not be aware of all options and that low rates of AID use are attributable to lack of knowledge or access (Kwak and Haley, 2005, Buchbinder, 2018). Additionally, many physicians do not discuss AID unless the patient brings it up first, which means that patients who do not know to ask will likely not learn that it is an option (Buchbinder, 2018). This explanation suggests that AID follows the same pattern as other types of end of life care services, such as hospice and palliative care (LoPresti et al., 2016, Cohen, 2008). In particular, racial and ethnic minorities are less likely to know about, make requests for, and receive hospice and palliative care than white people (Wicher and Meeker, 2012).

The third explanation focuses on patients' interactions with providers. Most AID laws in the U.S. give much discretion to physicians, who may opt-out of participating for any reason (Clodfelter and Adashi, 2016). This gatekeeper role of physicians likely affects which groups have access, regardless of their underlying desire (Buchbinder, 2017, Buchbinder, 2018). Physicians make judgements about when the request is “legitimate” and if/how they are willing to participate (Kimport et al., 2016). These physicians participate in the process as “death brokers,” constructing meaning about the process of dying and the cultural significance of various kinds of death (Timmermans, 2005). As they are constructing this meaning, it is possible that their own implicit understandings of persons from various social groups are implicated.

Likely, culture, structure, and doctor-patient interactions are all implicated in rates of AID use. The purpose of this article is to bring in the voices of the general public to enrich explanations, focusing specifically on how the good death is constructed in ways that are more or less consistent with AID. We ask: What do public opinions reveal about race, ethnicity, and end of life care? What do they reveal about constructions of the good death?

## Data and Methods

Because we were interested in public perceptions of AID, we conducted focus group interviews with community members from diverse racial and ethnic backgrounds in Los Angeles, California as the End of Life Option Act (EOLOA) went into effect. Focus groups are appropriate for capturing debates because they allow participants to speak to one another, building, contradicting, and adding nuance to the discussion (Kitzinger, 1994). Our approach sought to compare and contrast the themes of the debate across racial and ethnic groups, so we held six groups (n=39): two of the groups were composed of African American participants; two had Latino participants; and two groups were made up of white participants (See Table 1). The first author moderated all of the groups and the second author took notes.

We recruited focus group participants through two strategies. First, we identified community-based organizations serving populations of interest. We worked with those organizations to distribute recruitment materials and coordinate signups. Second, we advertised the focus groups on Craigslist, a popular online community board. In both types of recruitment, we used an informational flyer that invited participants to a conversation about the EOLOA. Interested parties emailed or called to be added to our list. For participants identified through both methods, we screened to determine that they were at least 18 and record their race/ethnicity. Potential participants were asked to self-identify their race and/or ethnicity, in an open-ended fashion. We recorded their verbatim self-identity and use their own racial/ethnic categories to name our analytic categories. So, for example, while there is a move in some scholarship to refer to people of Latin origin as Latinx, none of the participants in this study used that label, so we label our groups as Latino. We also gathered other demographic information, such as education, occupation, age, and gender. All interested participants at least 18 years of age were invited to participate in a focus group.

Groups were held in community centres and public areas convenient to participants. We performed the consent process individually, but answered any questions that emerged as a group. Focus group sessions lasted between 60–90 minutes. We compensated participants for their time with $20 gift cards to a local retailer. We advised participants that we wanted to hear their perspectives, but we did answer clarifying questions as they emerged. We asked how many participants had heard of the law, what they had heard, and what their reactions had been. We probed responses to get more information about how they learned about the law and the kinds of information and experiences they used to arrive at their position via the law.

All focus groups were audio recorded and transcribed verbatim. We used NVIVO 11 to manage the coding process. We first deductively coded discussions into arguments in favour of EOLOA, arguments in opposition to EOLOA, and questions or concerns. Within each of these deductive codes, we then generated a list of themes that emerged inductively (Boyatzis, 1998). These themes represented participants' sense-making about the law and definitions of the good death. Both authors then independently coded two transcripts and compared the results. We met in person to refine the coding scheme, modify definitions of the codes, and designate ideal examples of each theme. After finalizing the coding scheme, both authors coded each transcript at least once. We then met again to analyse how the codes were related to one another and helped answer our research questions. All aspects of the research were approved by our institutional review board.

## Reflexivity

We were reflexive about how our own demographic characteristics may influence the research. Both authors identify as white and speak English as our first language. Our own race/ethnicity and language positioned us as outsiders within the African American and Latino groups. This likely made race/ethnicity salient for these participants (Fryer et al., 2015). While outsider status can make it difficult to build rapport with participants, we used this status to present ourselves as naïve observers (Collins, 1986, DeVault, 1995). For some participants, this meant they felt a need to go into more detail to explain phenomena to us. For example, one participant in an African American group prefaced a statement about inequality by saying, “believe it or not…” and another began a story about choosing doctors who share their race/ethnicity by acknowledging that the interviewers were white and perhaps would not understand the challenge. We tried to minimize power differentials between researchers and participants by holding groups in community centres where participants felt comfortable and likely had attended other events.

Additionally, because end of life can be a sensitive topic, we started each focus group by setting ground rules about respect for others’ opinions and confidentiality. We reminded participants that there were no right and wrong answers and that we would be available after if any of the participants had additional questions. We brought along resources related to the law as well as grief groups and other supports for participants if the discussion raised residual feelings from their own experiences of loss.

## Limitations

Our approach has some limitations to note. The use of focus group data is appropriate for documenting community members’ reactions to the law, but we must be careful not to generalize to all members of the racial/ethnic groups. Our sample came from the Los Angeles metropolitan area, which undoubtedly differs from other parts of California and the United States. There is a great deal of heterogeneity within each of the racial/ethnic groups and we do not intend our analysis to speak to all members of these groups. Instead, we are interested in the extent to which dominant definitions of the good death are commonly held and/or challenged across social groups. Focus groups are an appropriate first step for this kind of analysis, but future research might include an effort to measure diversity within and across groups on a larger scale.

Our sample also includes adults of all ages. We aimed for a broad perspective on knowledge and reactions to the law, but as those reactions are likely conditioned on life experiences, we may have had different results if we had only selected older adults or those with serious illnesses. Our respondents self-selected into the study, which may indicate that they were more comfortable with talking about death than those who did not select into the study. Additionally, for respondents recruited from community groups, there was a strong likelihood that they had social relationships with at least one other focus group participant.

This dynamic meant that discussions were rich, but may not represent discussions between strangers. Finally, all focus groups were conducted in English, so the perspectives of those who did not speak English were not represented here.

## Findings

Knowledge about the EOLOA varied across the groups. For example, in both of the African American groups, most participants had heard of the law, even if they did not know details. In contrast, very few of the Latino or white participants had even heard of the law, though after a short introduction some noted seeing reports on television about the issue of AID. At this point, several participants in all groups noted that their existing knowledge came from news stories about Brittany Maynard, a young woman with brain cancer in California who had recently moved to Oregon to take advantage of the Death with Dignity Act (before the EOLOA was legal). Maynard's story was widely used by advocates and news media to illustrate questions of quality of life and individuals' ability to control the circumstances of impending death. These news stories often constructed Maynard's choices as consistent with the good death. One participant describes how seeing Maynard's story made her consider end of life issues:

> [Maynard's story] was on the news and then it was on Facebook, and I can see from what she looked like and then how progressively she was just changing her body through the medication. And how she was in such pain and because of the laws in California and her commitment was so sincere, she moved to Oregon… but I remember the tragedy
>
> (AA2).

Throughout the focus groups, many participants expressed compassion for Maynard's situation, but their individual positions toward AID varied.

In our groups, all of the white participants expressed support for the law and brought up very few concerns. The Latino participants were more divided: a minority of participants expressed support for the law, but even those who expressed opposition also discussed some of the reasons that one might consider AID. The African American participants expressed both strong support and strong opposition, but spent most of their time discussing their concerns about the law. As the discussions progressed, it was clear that one major difference between the African American groups and the other groups was that the African American participants had had a diverse range of end of life experiences and used these experiences to make sense of AID. Their range of experiences made the discussions especially nuanced and showed that they both accepted and rejected dominant constructions of the good death. The other groups had had more limited experiences with end of life or did not share their experiences with the group. While these findings should not be generalized to all members of these racial/ethnic groups, they are suggestive that broader social inequalities affect how participants think about death and dying.

Table 2 summarizes the major themes and provides illustrative examples. The remainder of this section will illustrate how participants across all groups constructed their own support or opposition to the EOLOA. These themes reveal diversity in the ways that participants thought about the good death.

## Support for the End of Life Option Act

Participants expressing support for EOLOA used similar language to discuss their support, regardless of race or ethnicity. For example, the most common theme was a desire to alleviate or prevent suffering that may accompany end of life. At least one person in each group discussed how that suffering may occur over a long period of time, which may also present a burden to family members. One participant in a Latino group expressed that he did not think he would use the EOLOA, but his experience with his mother's death made him unsure about if he supported the law or not:

> And I know that's easy to say that now, because I [have seen] what my mother went through and how she suffered. She would moan from the aches and pains. She was so sedated she didn't even know--so, it's horrible, it's horrible, it's horrible
>
> (L2).

Likewise, another participant described her father's experience with a stroke to illustrate that for some people, independence was more important than lengthening life:

> My father went in for surgery and he had a stroke. So when he came out after a week of being in a coma he wasn't the same. My father was a manly man, a strong man, and there were times when my sister and I were around him and we took personal care for him, you could see a moment where he's frustrated because his manhood was diminished to that point because he couldn't help himself [after] having that stroke
>
> (AA1).

All groups also used a discourse of individual choice to claim that even if they personally would not use AID, they believed that others should have the right. For example, after a lengthy discussion of religious opposition to AID, one African American participant said, "I wouldn't want to stand in the way of anybody else who would want to end their life, but I certainly would not." While many African American participants expressed that a higher power should decide when one dies, some also expressed that modern medical science kept people alive longer than they would like. Because of this, new choices like the EOLOA were necessary to protect against doctors "playing God."

> Your body could be in science 100 years from now, and they keep you in an incubator alive for as long as they want and keep testing. I would not want to be that person. So whether that's God or man or whatever, it could be a combination of all of the above. But I still think that at some point, I would want to have a choice
>
> (AA2).

Another said:

> I don't want to linger, but when is a doctor playing God? Is a doctor playing God by trying to keep them alive when they should have been dead because of that or be

> playing God by going ahead and hastening their death when they just may live another 20 years or something that they gave them
>
> (AA1).

In contrast, participants in the white groups were critical of doctors out of concern for barriers to participating in the EOLOA. The law allows for providers to choose not to participate. Several participants wondered if providers' ability to opt-out could make it more difficult for patients to make choices for themselves. Participants disagreed about the best way for doctors to discuss AID with their patients (i.e. doctor should bring it up vs. patient should bring it up), but participants in both white groups thought it should be widely available.

> I think it's kind of wrong for doctors or for hospitals to make a decision on what they are and aren't going to do. If you're a hospital then you should be there a hundred and ten percent for your patient. If you're a doctor you should be there a hundred and ten percent for your patient
>
> (W2).

Finally, when discussing possible reasons to support the law, some participants in the African American groups linked serious illness trajectories to a loss of self. One participant told a story of a time she faced a cancer diagnosis, noting that she could not face the person she imagined she would become:

> I was so afraid of that happening to me. My vanity, I didn't want to look at myself shrunken and throwing up, I didn't want to be a burden to my family, I didn't want to be a burden to my kids, I didn't want to look at myself this big [uses hands to gesture a weight gain], real dark and balding
>
> (AA1).

Participants used experiences of serious illness—their own and that of others close to them—to think through some of the reasons one might consider AID. This was even true among participants who expressed strong opposition to the law.

Across all groups, discussions about the EOLOA included references to participants' own ideas about the good death. Common elements included the desire to reduce suffering, avoid being a burden to others, and having choice. These common elements reflect dominant definitions of the good death. Other themes went beyond dominant definitions of the good death. For example, some participants in the African American groups also emphasized the importance of independence and not losing one's self as serious illness takes hold.

### Opposition to the End of Life Option Act

There are also some commonalities in how participants talked about their concerns about the law. Participants in all groups used the language of suicide stigma when discussing some of the reasons to oppose the EOLOA. Although proponents of the EOLOA have tried to rebrand the practice as 'aid in dying' and not suicide, many participants still referred to it as suicide and drew on their own experiences of a friend or family member ending their own lives as a way to make sense of the law. In those stories, most participants noted that suicide is very difficult for those left behind. This was even true for the white focus groups where participants expressed overwhelming support for the law, but empathized with the difficulty of losing a loved one to suicide. For the African American and Latino groups, however, the discussion of suicide was closely tied to religious beliefs:

> And so there were pejoratives attached to it if you were a Christian, and that is physician-assisted suicide, which is absolute suicide for Christians, okay? I mean, it’s a no-no; you go to the ninth circle of hell for it. So that’s the doctrine
>
> (AA1).

While Latino and African American groups all discussed religious opposition to AID, they also all discussed how a desire to avoid suffering and permit individual choice conflicted with religious doctrine. They noted this contradiction and discussed at length the tensions they faced when dealing with loss in their own lives.

Participants from all groups sometimes characterized this tension as resulting from a culture that wants the “easy way out” and is intolerant of difficult trials, like lengthy and painful deaths. One white participant described his family history, which included people living long lives, declining in their own homes, and slowly drifting toward death. He contrasts that with AID by saying:

> And I mean, in today’s society I don’t think people think as much that way, and it’s more like, “Well, let’s get it over with.” But I’m sorry to say that that’s it, but I think it’s almost that
>
> (W1).

Some participants judged the decision to hasten death harshly, calling it cowardly. For some African American and Latino participants, it was often characterized as brave to face the trials put forth by a higher power. Participants in the white groups did not discuss religious beliefs during the EOLOA groups. Even when we prompted them to talk about religion, they only talked about religious beliefs in the abstract; they did not link belief systems to their own perceptions of AID.

The Latino and African American groups also discussed how laws like this might disproportionately affect vulnerable people, especially racial and ethnic minorities and those without economic resources. Some participants framed their opposition as a larger problem with access to high-quality care:

> Participant 1: Like do[es] a poor person have as much shot at living as a person that’s affluent? Because believe it or not, the poor don’t get treated like the affluent, you know? They might tell you, ‘Well, you know what, take this. I got something for you, take it.’ They might encourage someone who’s not beneficial to them in terms of making money. They may encourage that person to take his own life.
>
> Participant 2: I don’t think they’re so much encouraging as I don’t think they give the poor the opportunity to better health care
>
> (AA1).

Some participants described other problems in the institution of medicine, especially in the process of determining prognosis. Several participants within the African American groups told stories about people who defied terminal diagnoses and lived much longer than expected:

> I guess the reason that I'm so convoluted by it all is because I've had two friends that were on life support and that I was told that neither one of them are going to live. And if they did live they would be vegetables; they wouldn't be able to talk, they wouldn't be able to move or nothing, their mind wouldn't be right. And both of them are okay
>
> (AA1).

Multiple participants nodded in agreement and we heard the same comment several times: "Physicians are just *practicing* medicine" as a way to say that doctors make mistakes.

Additionally, participants in some groups expressed that they did not know enough about end-of-life care to adequately advocate for their loved ones and make the right decisions:

> From what I know, from the little bit that I know, a lot of us are really not aware of the costs of treatment for cancer. Cancer, the treatment for it is very expensive, and I didn't realize that. I mean some of the pills, just the pills are extremely expensive
>
> (L1).

This lack of knowledge about health care was brought up most by Latino participants in our groups, who also discussed that they did not think their physicians gave them enough time to discuss end of life issues. The group discussed that ideally a doctor would give patients all information if they were considering AID, but several participants noted that they thought this was unlikely to be true.

> She mentioned about the doctor, talk to the doctor about that, but sometimes when you go to an appointment they are rushing you out because they have more people waiting
>
> (L1).

When participants discussed reasons to be wary of the EOLOA, their comments further enriched our understanding of the diversity of ways the good death is constructed. Participants across all groups saw AID as inconsistent with the good death when the discussion framed it as suicide, the easy way out, or against religion. For some participants, especially those in the African American and Latino groups, AID was also inconsistent with the good death when it was seen as an alternative to the best quality care or a solution to wider problems in the medical institution. Participants discussed inequality in access to care, providers who did not always know best, and how lack of knowledge and resources made it difficult for some members of these groups to advocate for the best care. These concerns indicate that larger racial and ethnic inequalities shape participants constructions of the good death.

## Discussion

The passing of California's End of Life Option Act (EOLOA) presents an opportunity to better understand how constructions of the good death vary across social groups and how those constructions inform support and opposition to AID. We analyse community members' reactions across racial/ethnic groups in order to understand similarities and differences in the extent to which AID is considered part of the good death. While our focus groups had some similarities in how participants made sense of AID, there were nuanced differences in these constructions of the good death, which led to differential levels of overall support for the EOLOA. On the whole, white participants constructed AID as more positive than participants in the African American and Latino groups, but participants from all groups expressed a complex set of opinions about what makes a good death.

Looking across groups, participants discussed AID as consistent with the good death when it was seen as alleviating suffering, avoiding burden to family members, and resulting from individual choice. Their use of the logic of choice and preventing suffering of self and family is consistent with wider discourses around AID as an option (Coombs Lee and Grube, 2017, Karsoho et al., 2016, McInerney, 2000). In some ways, this rhetoric aligns with middle and upper class, white values (Conway, 2014), which emphasize individual choice. While only a small number of people take advantage of the EOLOA, the discourse about individual rights, identity, and privacy (McInerney, 2000) appears to resonate widely and across the different groups we studied.

It was also clear in these focus groups that issues around caregiving and burden were part of individuals' sense-making about AID, but in contrast to many of the arguments against AID, most participants did not present themselves as subject to vulnerability or coercion. Instead, they expressed concerns about the effects of their dying process on their family members (MacArtney et al., 2016)—no matter the conditions of their dying (Seymour et al., 2007). In some cases, AID deaths were seen as preferable because they were more controlled. This emphasis on the family is not consistent with our current laws around end-of-life, which prioritize autonomy and are suspicious of family involvement in decision-making (Broom and Kirby, 2013, Wright, 2018).

Some also discussed wanting to remain independent with their sense of self still intact. This theme emerged only in the African American groups. While it is unlikely that this concern is isolated to some racial/ethnic groups and not others, it is noteworthy that only the African American participants discussed this issue. One potential explanation of this lies in recent research that African Americans are more likely to have experienced a variety of deaths through their life course than white people (Umberson, 2017). While our sample of participants is not meant to be representative, we do see evidence that participants in our African American groups drew upon a diversity of end of life experiences to make sense of AID. For example, several participants reported having familiarity with several serious conditions, including comas, drug overdoses, automobile accidents, AIDS, and strokes. These experiences prompted participants to reflect on the complex nature of suffering, including the loss of self, even if the body is still alive.

When participants discussed AID as inconsistent with the good death, they talked about it as a form of suicide or taking the easy way out. Some participants thought it was more honourable to fight for life rather than accept the impending death. AID was often constructed as against religious doctrine, which gives meaning to suffering. Although we did not probe around specific religious beliefs or practices, this sentiment was common within the African American and Latino focus groups. The white groups also used the rhetoric of avoiding the easy way out, but did not tie it to religion. Good death definitions of accepting death reflect larger middle-class values and definitions of respectability (Conway, 2014, Howarth, 2007). In contrast, willingness to fight for life may be seen in working class definitions of the good death (Conway, 2014, Frith et al., 2013). Participants in our groups had a wide range of educational and occupational backgrounds, but this working class commitment to fighting for life was strong, especially in the Latino and African American groups. It is possible that this is one way that definitions of the good death are classed and racialized.

Some participants were also concerned that AID was going to be used as an alternative to the best care, especially for those who already have poor access, knowledge, and treatment within the medical institution. Participants discussed issues within their interactions with providers. These interactional issues shaped the extent to which their wishes are voiced and followed (Gage-Bouchard, 2017). Participants discussed a range of ways that they have tried to advocate for themselves or loved ones in medical decision-making. For many, there was a sense that they must be protective against a health system that does not care about their best interest, which leads to two very different positions via AID. In one position, participants were critical of AID, which is controlled by the medical institution. Specifically, some African American and Latino participants were concerned that wider racial inequality would make them targets for hastened death. In the other position, participants expressed frustration that not all options are equally available to everyone at end of life. The simultaneity of these two positions likely makes it difficult for providers to know how to move forward with discussions about AID, especially for patients from racial and ethnic minority groups.

Implicit in many of the comments, across all of our racial/ethnic groups, was a critique of modern medicine’s role in dying processes. Participants expressed worry about health system processes that prolong poor quality of life and health care providers who are more focused on profit and technology than on patients. Arguments that medicine has gone too far are consistent with what Karsoho et al. (2016) find in the analysis of discourse around euthanasia laws in Canada. Within this discourse, medicine has failed by prolonging suffering, but by arguing that the remedy should be that patients can request euthanasia, this discourse actually further medicalizes dying (Karsoho et al., 2016). Within this critique of medicine, death via AID comes to seem more “natural” because it avoids the overuse of technological interventions and medicalized settings (Seymour, 1999). Given this, some opposition to AID is likely not about AID in particular, but about a concern with putting additional power within the medical institutions (Manning et al., 2017).

Undoubtedly, changes to medicine have extended life for many, but they have also brought up new ethical questions. Some scholars believe that giving individuals more control over their own dying process is the answer, but others are reluctant to consent to another medical technology that then shortens life (Sulmasy and Mueller, 2017). This is especially an issue when we consider that the care received across all domains of medicine is not equal. Sociology has a role in helping bioethicists think through these questions about vulnerability and AID (Weyers, 2006), using empirical data on meanings, attitudes, and practices. Simultaneously, medical sociology is enriched by integrating analyses of end of life options —especially those that are perceived as changing the field of medicine. Given that AID is still controversial to many and debates have not moved much in the last two decades (Hillyard and Dombrink, 2001), medical sociology has an opportunity to integrate systematic data to help understand how new options are received and made sense of within a moment where the organization of medicine is shifting (Timmermans and Oh, 2010).

Our findings inspire new questions about cultural constructions of the good death. While our findings should not be generalized to all members of these racial/ethnic groups, they do indicate that there is diversity within definitions of the good death. The dominant definition, upon which many interventions meant to improve end of life are built, does not resonate with all members of society equally. The diversity of good death definitions may require health care providers to seek out ways to better connect with all patient groups. One challenge of meeting multiple definitions of the good death may be that providers come to accept a “good enough” death, which prioritizes alleviation of physical suffering and marginalization of all other types of suffering (McNamara, 2004). More studies are needed to understand how to integrate multiple definitions of the good death into medical practice. Finding that constructions of the good death vary across groups is also important for understanding the concern that AID will become the “gold standard” of end-of-life care. We did not find that AID resonated equally across groups, suggesting that at least for these respondents, AID discourse did not exert a widespread normative pressure to hasten death.

Additionally, future studies are needed to capture axes of variation that we did not have in our study. For example, previous studies have shown that as patients face serious illnesses, their definitions of the good death reflect the unique trajectories of their particular illnesses, such as AIDS (Pierson et al., 2010) or heart failure (Gott et al., 2008). Because we recruited a wide group and asked them to think about end of life in general, their responses may have differed if they were considering more specific illness trajectories. Finally, this focus on cultural definitions of “good death” enriches cultural explanations for disparities in rates of use of AID, but our results also implicate a few structural and interactional factors that require further research. In particular, we need studies that systematically examine racial/ethnic differences in access to AID and other end-of-life options, as well as research on interactional patterns between patients and physicians that may make some options more available than others.

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## Table 1:

Demographics of Focus Group Participants

| | Gender | Age Range | Education Range | N |
|---|---|---|---|---|
| African American (Group 1) | 5 women 2 men | 30–79 | HS diploma - Prof degree | 7 |
| African American (Group 2) | 6 women 2 men | 40–79 | Some college - Prof degree | 8 |
| Latino (Group 1) | 6 women 3 men | 59–92 | Below HS - HS diploma | 9 |
| Latino (Group 2) | 1 woman 3 men | 25–50 | HS diploma | 4 |
| White (Group 1) | 3 women 2 men | 25–72 | Bachelors - Prof degree | 5 |
| White (Group 2) | 4 women 3 men | 19–59 | Some college - Bachelors | 6 |

## Table 2:

Themes Related to the End of Life Option Act, by Race/Ethnicity

| | AA | L | W | Example |
|---|---|---|---|---|
| **Support EOLOA** | | | | |
| Alleviate Suffering | X | X | X | "I am for it because if I had to suffer, I wouldn't want somebody to drag me on for five more years and there's no possibility for me, or a year from now or whatever, and I'm chronic pain and suffering. I would want to be able to choose my end" (AA2). |
| Avoiding Burden | X | X | X | "I just thought it would be a person really in pain, depressed, or doesn't really care about his life or tired of fighting for his life. So to give their family peace, I guess, that's my first thought" (L2). |
| Choice | X | X | X | "Personally, I would want to have the choice. I wouldn't necessarily take part in it, but I would want that option; so I'm for it" (W2). |
| Loss of Self | X | | | "And I mean I understood not being able to look at yourself and see what you're used to seeing, when your appearance begins to change and you start giving in or your body starts giving in to the effects of the disease. I kind of understood why she wanted to go" (AA1). |
| **Do Not Support EOLOA** | | | | |
| Stigma of Suicide | X | X | X | "So I don't think that something like this would go over as well where I grew up. Not to say that there wouldn't be people who would be thankful for it, but I think overall, as a culture, places like where I was raised, there would be a lot more resistance" (W1). |
| Religious Concerns | X | X | | "Everybody's faith is different. As far as the decision to take your life--because in my belief, too, I just believe that in God's time he's going to do what needs to be done… I don't think people should be cut short. You never know what's going to happen" (AA2). |
| Easy Way Out | X | X | X | "I always seen that they're willing to fight for their life and I think that's very courageous. And for a person to just want to take their life, then they're cowardly" (L2). |
| Vulnerable People | X | X | | "So I think we have to be concerned because of our history and the things that have happened to us as a people. We have to be conscious of: are we really going to have enough control mechanism that the wrong people don't become a part of this elimination situation?" (AA2). |
| Problems with Medicine | X | X | X | "And that's why they say they're practicing medicine because they're practicing sometimes. They're not really sure of what they're doing" (W1). |