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Correlates of patterns of health values of African Americans living with HIV/AIDS: Implications for advance care planning and HIV palliative care

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Abstract

Context & Objective—Advance care planning (ACP) rates remain low, especially among people who are HIV positive, disadvantaged, and African American. While ACP can be a sensitive topic for clinicians and patients to discuss, health values clarification can be an important initial step.

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Compliance with Ethical Standards:

All of the authors declare that they have no conflicts of interest.

Informed consent was obtained from all individual participants included in the study.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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Methods—Data were from the first 325 participants in the AFFIRM Care study, which enrolled adults living with HIV/AIDS in Baltimore, MD, who had histories of illicit drug use. Respondents were asked whether (yes/no) they thought any of six health states would be worse than death: severe unremitting pain, total dependency on others, irreversible coma, being on mechanical ventilation, nursing home residence, and severe dementia. Latent class analysis (LCA) was used to group individuals by their pattern of responses, interpretable as preference for aggressive (life-sustaining) or non-aggressive (palliative) end-of-life care. Latent class regression (LCR) analysis was used to examine associations between class membership and background, health status, and social variables.

Results—We found statistical support for a three-class LCA model: (1) the “Non-aggressive treatment” class, comprising 43% of cases, in which members perceived every state was worse than death; (2) the “Aggressive treatment” class, comprising 33% of cases, in which members perceived none of the states was worse than death; and (3) the “Mixed” class (24% of cases), in which members perceived only four of the six states were worse than death.

Conclusions—Three-quarters of participant response patterns had clear preferences for treatment decisions. Further research is needed to ensure inclusion of end-of-life scenarios relevant to this population.

Keywords

HIV/AIDS; African-American; advance care planning; health values clarification; life-sustaining or palliative care preferences; end-of-life scenarios

Introduction

Advanced care planning (ACP) focuses on helping individuals to clarify their personal health values in regards to planning for future medical care with the goal of enabling individuals to receive medical care that is consistent with their health values and goals.¹ ACP, which can include discussions regarding choosing a health proxy and completing an advance directive, is important to ensuring that end-of-life healthcare is consistent with patient and family values and to avoiding unwanted healthcare that may have no health benefits and adverse effects on quality of life at end-of-life.

Rates of advance directive completion remain low and have been slow to rise.^{2,3} Despite 20 years of emphasis, only one in three U S adults has any form of advance directive.⁴ While persons with serious conditions (e.g. cancer, HIV) have slightly higher rates of advance directive completion (30%–47%), they are usually completed in hospital settings near end-of-life, providing little opportunity for discussion and clarification of patients' health values.⁵

In a study of the health values of a critically ill patient sample, more than half of the study participants (68.9%) rated bladder or bowel incontinence and mechanical ventilation as health states worse than death.⁶ Being permanently bedridden, cognitively disoriented, requiring a gastrostomy feeding tube (G-tube), total dependency on others, and residing in a nursing home were perceived as states worse than death by 30%–50% of the respondents.⁶

These health scenario ratings may be interpretable as thresholds for patients' preference for life-sustaining, or aggressive healthcare.¹

Rates of advance directive completion are lower in patients with HIV/AIDS (8%–47%) than other serious conditions, especially among the 40% of HIV patients who are African American and the half of HIV patients with drug use disorders.⁷ Indeed, HIV patients are disproportionately disadvantaged persons, African American, and persons with behavioral (psychological and drug use) disorders that are associated with high rates of acute healthcare use and worse mortality rates, which provides more impetus for ACP.^{8, 9}

African Americans are less likely than whites to complete an advance directive; and they reveal different patterns of end-of-life healthcare preferences and have greater challenges communicating with healthcare providers.¹⁰ The little extant research suggests that social and cultural factors, such as religious attitudes or beliefs regarding what it means to be part of that faith, are formidable barriers to their advance directive completion, as well as to their attitudes toward life-sustaining treatment at end-of-life.^{11, 12} Even after adjusting for religious attitudes and socioeconomic status,³ African Americans are more likely than whites to report preference for life-sustaining end-of-life healthcare^{13–17} and tolerance of pain and discomfort.¹⁸ For people with low rates of ACP, especially under-researched populations including African Americans with HIV/AIDS and behavioral health disorders, it is important that the ACP process include health values clarification given their particular challenges with trust and communication in the healthcare system.^{16, 17}

Numerous factors could impact African American Persons Living with HIV/AIDS' (PLHIVs') wishes for medical treatments that could result in an outcome considered worse than death. Demographic characteristics, such as sex, spiritual beliefs, and perceptions of loneliness could shape their views of end-of-life care, as could experiencing chronic pain or suffering from depression, and social variables, such as the quantity and quality of support available from caregivers and social network members. However, not enough research exists that investigates the relationships between care preferences and demographic, health status, and social variables.

The purpose of the present study was to assess health values related to perceptions of health outcomes among PLHIV. Our study built upon the study by Rubin, Buehler, and Halpern,⁶ which examined attitudes toward health outcomes that the authors considered worse than death. Rather than investigate each health outcome individually as they had done, we used latent class analysis (LCA) to group participants into classes based on their patterns of responses. In addition, we explored correlates of individuals' class membership in each of the groups, in an effort to better describe a potentially heterogeneous population of African American PLHIV with current or former drug use disorders.

Methods

Procedure

The current analyses draw on baseline data from the AFFIRM Care study (2013–2018), which examines social environmental factors associated with palliative care interests and

quality of life among PLHIV and their informal caregivers. For the present study, we used data from the first 325 AFFIRM Care participants, who were recruited from previous similar studies and from the Johns Hopkins adult HIV clinic and community venues. The recruitment criteria included being an HIV seropositive adult who currently or formerly used illicit drugs (e.g., heroin, cocaine, stimulants) not including marijuana. Surveys were administered by computer assisted personal interview (CAPI), with sensitive information elicited by audio computer assisted self-interview (ACASI). The AFFIRM Care study has been approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Measures

This study used a values clarification approach to assess the outcome measure, “Which of the following health problems, if any, do you think are worse than death for a person?”¹⁹ Participants answered “Yes” or “No” to each of the following six response items: “Always having severe pain”, “Being totally dependent on others for care (like for eating, bathing, moving)”, “Being in a coma that he/she won’t come out of”, “Living in a nursing home for the rest of his/her life”, “Having a breathing tube down his/her throat for the rest of his/her life”, and “Having severe dementia, not being able to remember things or people”.

Three types of independent variables were included in the latent class regression: background, health status, and social variables. Background variables included sex, faith attitude toward life-sustaining care, loneliness, and current illicit drug use. Faith attitude was measured by the item, “Those who believe in God would want everything done to keep them alive in any condition they’re in”, with responses on a 5-point Likert scale from “Strongly agree” to “Strongly disagree”, which were subsequently dichotomized into 0 = “Strongly disagree, Disagree, and Neither agree nor disagree” vs. 1 = “Agree or Strongly agree”. Loneliness was measured by the item, “During the past week, I felt lonely,” with response options from 0 = “Rarely or none of the time” to 3 = “Most or all of the time,”^{20, 21} which was dichotomized into 0 = “None of the time” to “A little of the time” vs. 1 = “Occasionally/Moderate” to “All of the time”. Drug use was defined as having used heroin, cocaine, or stimulants in the previous 6 months.

Health status variables included chronic pain, memory, depression, and physical functioning. Chronic pain as measured by, “During the past 30 days, how much did pain interfere with your normal work or activities, including both work outside the home and housework?” with response options from 0 = “Not at all” to 4 = “Extremely”²² and was dichotomized into 0 = “Not at all to moderately” vs. 1 = “Quite a bit or extremely”. Memory was measured by, “In the past few weeks, how often have you gotten lost in a place you know well?” with responses ranging from 0 = “Never” to 3 = “Very often” and was dichotomized into 0 = “Never” vs. 1 = “Once in awhile, fairly often, or very often. Depression was measured by the 10-item version of the “Center for Epidemiological Studies – Depression”.^{20, 23} Depression was dichotomized such that 10 and above indicated probable depression, which is an established cutpoint for the scale.²³ Lastly, physical functioning was measured by two items, “How much does your health now limit your climbing several flights of stairs?” and “How much does your health now limit your moderate activities such as moving a table, pushing a

vacuum cleaner, or playing a sport?”, with response options for each ranging from 0 = “No, not limited at all” to 2 = “Yes, limited a lot”.²² The two physical functioning items were summed to create a total score, where higher scores represented more physical functioning limitations.

Social variables included reciprocity of support to caregivers, defined as “How much have you given things to [your most supportive person] in the past year,” which was dichotomized with 0 = “None or some” vs. 1 = “A lot.” Instrumental support was assessed with the item, “How much have you helped [your most supportive person] around the house in the past year?” with response options, 0 = none to 2 = a lot and dichotomized as 0 = “None” vs. 1 = “Some or a lot”.^{24, 25} Size of emotional support network was assessed by summing the number of persons who the respondent named as s/he could talk to about something personal or private.²⁶ Receiving personal care was measured by the item, “(In the last year), who has helped you with personal care, which includes eating, bathing, and dressing?” with answer choices 0 = nobody, 1 = friends or family, 2 = professionals (paid workers), and 3 = both. This item was dichotomized into 0 = nobody vs. 1 = friends, family, and/or professionals helped with personal care.

Data Analysis

Exploratory analysis, including generating frequencies and means, was performed using SPSS v.24. Latent class analysis (LCA) was performed in Mplus v. 7.4²⁷, with the six outcome variables measuring whether the participant considered each of the six health states as worse than death. LCA is a person-centered approach used to investigate the underlying, unobserved (latent) structure of the data. LCA uses categorical indicators to determine a small number of distinct groups, or classes, of study cases based on patterns of results.^{28, 29} Therefore, both the latent variable and indicator variables are categorical.²⁹

The main assumption of LCA is that the latent class structure, which is a categorical latent variable (i.e., class membership), accounts for the patterns of endorsed responses.³⁰ The questionnaire items, or indicator variables, are independent conditional on the class.^{28,31} Therefore, any associations between the endorsed beliefs are explained by class membership. This implies that within each class, measured indicator items are uncorrelated with each other, and the covariates do not influence the indicators given class membership.^{32,33} In the current analyses, individuals within each class are similar to each other based on their beliefs about states worse than death, but differ from members of other classes.²⁸

A series of LCA models were fit to the data. Beginning with the one-class model, we iteratively increased the number of classes per model (1 to 5 classes) until the best-fitting and most parsimonious model was reached. To determine the best-fitting model, several fit statistics were calculated, including the Bayesian Information Criteria,³⁴ sample size adjusted Bayesian information criterion (aBIC),³⁵ the Akaike Information Criteria (AIC),³⁶ and the parametric Bootstrap Likelihood Ratio Test (BLRT).³⁷ Models with lower aBICs indicated a better fit.²⁷ The BLRT gives a *p*-value that is used to determine if model fit is significantly better for the *k*-class model over the *k*-1 class model, where *k* equals number of classes.^{38,39} Per published recommendations, final decisions regarding model selection were based on statistical information and substantive theory.³⁹

Next, respondents were assigned to their most likely class based on their posterior probabilities only for the purpose of examining differences in frequencies of background variables among classes. Chi-square tests were calculated for categorical data, and one-way ANOVAs were calculated for continuous data. Where these tests were significant for the three classes, individual 2×2 tables were run using a chi-square statistic for categorical data, and individual t-tests were run with the continuous data.

Finally, a latent class regression (LCR) was performed by regressing the three classes generated by the LCA on the three types of independent variables (background, health status, and social).⁴⁰ An LCR is akin to a multinomial logistic regression; however the LCR does not assign respondents to classes. Instead, the LCR takes into account the uncertainty of class membership by using a latent variable. To investigate potential changes to class membership and item probabilities between the LCA and LCR, we checked these parameters and found that the differences in percentages and probabilities, respectively, were negligible. Simple regressions were performed with each independent variable and those significant at $p < .10$ or deemed theoretically important were retained. Finally, a step-wise regression approach was used to introduce the background, health status, and social variables. At each phase of testing, variables not significant at $p < .05$ were trimmed from the model. With all of the covariates in the model, the sample size was reduced from 325 to 317, indicating that 8 respondents or 2.5% of the sample was missing data on one or more of the covariates.

Results

Our sample was comprised primarily of African Americans (96.6%), the majority of whom were male (56.7) and earned less than \$1,000 per month (74.4%) (Table 1). Less than half indicated current drug use (38.0%) or had high depressive symptoms (36.2%). In their appraisal of the six health scenarios, between 46.3% and 70.2% of the respondents reported that a particular state would be worse than death (Table 1).

LCA models were run iteratively for models with 1–5 classes and fit statistics suggested that the 4-class model was the best-fitting model. However, one of the four classes contained only 7.1% of the sample, which was judged as too small to use in a LCR. Therefore, we chose the 3-class model.

The three classes were labeled based on the probabilities of endorsing each item regarding the health scenarios (Table 3 and Figure 1). One class (“Non-aggressive treatment”), comprising 43% of cases, reported values on health states worse than death that were suggestive of a preference for non-aggressive (i.e., palliative) care at end-of-life. Another class (“Aggressive treatment”), comprising 33% of cases, reported none of the states were worse than death, suggestive of a preference for aggressive, life-sustaining care at end-of-life. The last class (“Mixed”), which comprised 26% of cases, reported endorsements that were mixed: coma, breathing tube, dementia, and nursing home residence were considered worse than death, whereas severe constant pain and total dependence on others were not considered worse than death.

Participants were assigned to class only for the purposes of generating frequencies and means for variables within each class (Table 4). The “Mixed” class and the “Aggressive treatment” class had significantly more females (52.1% and 50.5%) than the “Non-aggressive treatment” class (34.7%). Age was marginally significantly higher in the “Aggressive treatment” class (53.7 years) compared to the “Mixed” class (51.3 years). There were no differences in the classes by education, drug use status, depressive symptoms or physical function.

The LCR revealed seven significant independent variables associated with class or group membership (Table 5). In terms of demographics, females had significantly lower odds of being in the “Non-aggressive treatment” class compared to the “Aggressive treatment” or “Mixed” classes (Adjusted Odds Ratio [AOR] = .39, $p < .01$, 95% Confidence Interval [CI] = [.21, .72] and AOR = .39, $p < .05$, CI = [.19, .82], respectively). Faith toward life-sustaining care was associated with higher odds of being in the aggressive treatment class than in the “Non-aggressive treatment” or “Mixed” classes (AOR = .39, $p < .01$, CI = [.21, .75] and AOR = .41, $p < .05$, CI = [.18, .90], respectively). Perceived loneliness had greater odds of being in the “Non-aggressive treatment” or “Mixed” classes than in the “Aggressive treatment” class (AOR = 6.57, $p < .001$, CI = [2.38, 18.10] and AOR = 8.42, $p < .001$, CI = [2.66, 26.62], respectively).

Results for the health status variables indicated that chronic pain was associated with higher odds of being in the “Mixed” class than in non-aggressive treatment class (AOR = 2.40, $p < .05$, CI = [1.05, 5.48] or in the aggressive treatment class (AOR = 3.03, $p < .05$, CI = [1.23, 7.14]). Having memory problems was associated with greater odds of being in the “Non-aggressive treatment” class than in the “Mixed” class (AOR = 3.07, $p < .01$, [1.32, 7.11]). Depression was marginally significant at the bivariate level but was excluded from the final model because it did not retain significance.

With regard to social variables, patients’ reciprocity of support to caregivers was associated with greater odds of being in the “Non-aggressive treatment” class than in the “Aggressive treatment” class (AOR = 2.50, $p < .01$, CI = [1.35, 4.62]), while greater size of emotional support network was associated with a greater odds of being in the “Mixed” class than the “Aggressive treatment” class (AOR = 1.46, $p < .05$, CI = [1.07, 1.99]) and in the “Non-aggressive treatment” class than in the “Aggressive treatment” class (AOR = 1.33, $p < .05$, CI = [1.03, 1.70]). Receiving help with personal care (activities of daily living), such as eating and bathing, was not statistically significant but retained in the model to adjust for informal care receipt.

Discussion

While prior studies suggest African Americans’ high preference for life-sustaining healthcare regardless of health state, our results indicate diversity in care preferences, and identified demographics, health, and social factors that distinguished patterns of care preferences. The largest LCA class comprised participants (43%) who reported that all six potentially negative outcomes of life-sustaining treatment would be worse than death, which is suggestive of a preference for palliative care at end-of-life. The smallest class (26% of

participants) comprised the “Mixed” class, in which respondents rated severe chronic pain and total dependence on others as not worse than death, but that being comatose, living in a nursing home, mechanical ventilation, or severe dementia were worse than death.

The middle-sized class (33%) comprised participants who rated none of the health scenarios as worse than death, which suggests a strong, and likely unwavering preference for life-sustaining care even in the setting of medically ineffective care. For those people and their caregivers, efforts to develop an ongoing trust relationship may be more appropriate than advocating for palliative care, which could increase resistance and ultimately undermine the relationship. Clinicians need to work at discerning whether a person is amenable to persuasion and when it is not possible because persisting may result in moral distress and may undermine the care the patient receives. Also, ACP research reflects values of the white middle class, which may not reflect the values of PLHIV who are largely African American and disadvantaged. Therefore, it is possible that a different paradigm is needed to engage them in decisions about their health and healthcare.

Overall, the diversity in care preferences may be due in part to sampling patients from outpatient clinics, who were less seriously ill as compared to inpatients sampled in most prior ACP research and whose preferences may change with illness progression. It is possible that the outpatient clinic patients, who are less seriously ill, may be the group where there is opportunity for engagement.

In adjusted analysis, female sex and endorsement that “Those who believe in God would want everything done to keep them alive in any condition they’re in” were associated with being in the “Aggressive treatment” versus “Non-aggressive treatment” class. While the finding on faith attitudes is consistent with the literature supporting African Americans’ normative perceptions that their religious doctrine upholds life-sustaining care at any state, females’ greater endorsement of life-sustaining care has not been consistently observed in the literature. It is plausible that women, as compared to men, prefer more life-sustaining care out of a stronger sense of social connectedness and obligation to close relationships, or that the quality and quantity of social support and caregiving that women have may help attenuate their perceptions of terminal health states.

Interestingly, perceived loneliness and greater reciprocity of support to caregivers were associated with being in the “Non-aggressive treatment” versus “Aggressive treatment” class, and greater number of emotional support network members was associated with being in the “Mixed” class over the “Aggressive treatment” class. In prior studies on a similar population, reciprocity of support to HIV caregivers was associated with stronger, higher functioning caregiving relationships as evidenced by its association with patients’ lower depressive symptoms, and better treatment adherence and HIV viral control.^{41, 42} Thus, our findings suggest that both a high degree of social integration as well as social alienation, as loneliness is found to be distinct from social isolation;⁴³ are associated with preferring (mostly) non-aggressive care at end-of-life. It is plausible that greater concerns of being a burden to loved ones among participants with stronger support and caregiving relationships may explain their preference for non-aggressive care. The findings indicated that loneliness, but not depressive symptoms, was significant. This suggests that perhaps negative

interactions with supportive ties (e.g., support that is inadequate or mismatched to expectation or incurs a sense of indebtedness)²⁵ may affect a sense of loneliness or alienation as well as preferences for non-aggressive care at end-of-life.

In regards to health status measures, participants with a high level of chronic pain symptoms as compared to those with low symptoms or none had greater odds of being in the “Mixed” class than in being in the “Non-aggressive treatment” class or the “Aggressive treatment” class. It is possible that study participants with chronic pain as compared to those without chronic pain symptoms had become habituated to pain and related disability, and thus viewed severe chronic pain and total dependency on others as tolerable states. This supports previous findings that patient perceptions of hypothetical health scenarios as worse than death may well alter their perceptions once they experience the health state themselves.⁴⁴ Therefore, ACP is likely a fluid process and once people decide on their preferences, they may revise their decisions later based on their experience with health symptoms.

Having memory problems was associated with being in the “Non-aggressive treatment” class rather than the “Mixed” class. It is possible that memory problems are indicative of the burden of (uncontrolled) chronic conditions or other neurocognitive disorders, which along with related dependency on others, is often well established as stressful for caregiving dynamics. Therefore, engaging in advance care planning/completing an advance directive is particularly important in the context of cognitive impairment and has a more profound effect on end-of-life care utilization than for older persons without cognitive impairment. However, ACP/advance directive completion occurs less often in the context of cognitive impairment.^{45, 46}

Limitations

Our survey of adverse health outcomes was not comprehensive but does include most of the conditions assessed in a prior study by Rubin and colleagues⁶ regarding ratings of health scenarios as worse than death. However, there are no standard ways of assessing health values. While it may be useful for broaching the topic of ACP, the answers themselves are useful to clinicians to the extent to which responses align with actual end-of-life health scenarios. Additionally, the data are cross-sectional, which precludes any conclusions regarding temporality in the findings. Finally, because our sample was recruited from an outpatient HIV clinic located in an academic hospital, generalizability may be limited.

Implications

Few studies have examined health values, although clarification of these values can help patients and their healthcare providers elucidate patients’ values and preferences for aggressive treatment or palliative care at end-of-life. Eliciting such information may be helpful in initiating ACP discussions among clinicians and patients and their family as a step toward collaborative end-of-life healthcare decision making and ensuring their mutual understanding and that patients’ end-of-life care is aligned with their values. It may also be helpful to know when to advocate for DNR status versus simply establishing a longitudinal trust relationship, especially with people who distrust the health care system.

This study highlights the associations between personal characteristics and preference patterns for care in the case of six conditions or situations. The lack of understanding of these scenarios should prompt further discussion among providers and patients. Different treatment options in different contexts should be offered by providers, who seek to understand patient preferences. Providers should strive to make educated decisions rather than assumptions about patient preferences. Caregivers, who should also be involved in this discussion process, need to ascertain care recipient preferences, which might be ever-changing based on varying prognoses given the uncertainty of the progression of HIV. Patients have a need to feel autonomous and live independently, which is of high importance to their sense of dignity and to their health values.

To our knowledge, this is the first examination of correlates of end-of-life healthcare preference patterns in a vulnerable, under-studied population of PLHIV comprised predominantly of African Americans. Our findings demonstrate how health values and patient background and social correlates can be operationalized. Further research is needed to explore participants' intended meanings of responses, specifically whether responses to health states worse than death can indeed be assumed to correspond to interests in palliative versus life-sustaining care. Nonetheless, that findings support the study population's amenability to discussing health values and suggest it may be a useful approach to clinicians' initiating the process of advance care planning.

Conclusions

We found that in addition to the expected "Non-aggressive treatment" class and an "Aggressive treatment" class, representing the extremes of perceptions regarding states worse than death, a quarter of participants were classified as having "Mixed" preferences for end-of-life care. We posit that members of the "Mixed" class experience or have experienced chronic pain and therefore, rated pain and dependence on others as not worse than death, while they rated the other four states as worse than death.

Several background variables, health status indicators, and social factors were associated with class membership, which helped to explain differences between members of each class and how that might contribute to their valuations of quality of life and death. Including background, health status, and social variables in our model helped to illustrate the dynamic interplay between physical, emotional, social, and spiritual determinants of health care decision making, especially for this population, for which clinicians need a broader framework for assessing ACP that includes all of these elements.

Future research should further explore the interpretation and replicability of study results. For example, further examination of quantity and qualities of supportive relationships and of faith attitudes regarding life-sustaining care is important to understanding the extent to which health factors, current caregiving relationship dynamics and religious faith may explain patterns of healthcare preferences.

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Table 1

Frequencies and means of background variables and study variables used in the latent class analyses and latent regression analyses (AFFIRM Care study; N = 325).

Variables	N (%) or Mean (SD) ^a	Range
Sex (Female)	141 (43.7)	
Age (Mean (SD))	52.7(6.5)	24–67
Race/Ethnicity (African American)	315 (96.6)	
Education (High School or higher)	169 (52.5)	
Income (\$999 or less)	242 (74.4)	
Current drug use (Heroin, cocaine, stimulants)	124 (38.0)	
Depression (10+ on CES-D)	118 (36.2)	
Viral suppression	273 (84.4)	
Belief in God to stay alive (Agree/strongly agree)	207 (63.5)	
Loneliness (Occasionally to all of the time)	51 (15.6)	
Chronic pain (Quite a bit/extremely)	72 (22.1)	
Memory problems (Once in a while to very often)	63 (19.3)	
Give things to caregiver (A lot)	153 (51.7)	
Helped caregiver around the house (Some or a lot)	212 (71.6)	
Received help with personal care (yes)	245 (66.4)	
Emotional support (No. of supporters) (Mean(SD))	1.9 (1.2)	0–8
Physical functioning limitations (Mean(SD))	1.7 (1.3)	0–4
States Worse than Death		
Chronic severe pain	151 (46.3)	
Totally dependent on others	156 (47.9)	
Being in a coma	229 (70.2)	
Living in a nursing home	174 (53.4)	
Having a breathing tube	217 (66.6)	
Having severe dementia	201 (61.7)	

Table 2

Latent class analysis fit statistics indicating a 3-class model best fit the data (AFFIRM Care study; N = 325).

No. of Classes	AIC ^a	BIC ^b	aBIC ^c	LMR ^d	BLRT ^e	Entropy	Class Proportions
1	2610.38	2633.10	2614.07	NA ^f	NA	NA	100.0
2	1992.39	2041.62	2000.38	<.001	<.001	.90	63.8, 36.2
3	1905.61	1981.35	1917.91	<.001	<.001	.87	43.6, 23.0, 33.4
4	1860.61	1877.21	1877.21	<.01	<.001	.88	40.8, 28.3, 23.9, 7.1
5	1858.03	1986.79	1878.94	.12	<.05	.88	42.2, 26.5, 15.4, 10.7, 5.2

^aAIC = Akaike Information Criterion

^bBIC = Bayesian Information Criterion

^caBIC = sample size adjusted Bayesian Information Criterion

^dLMR = Lo-Mendell-Rubin Likelihood Ratio Test

^eBLRT = Bootstrapped Likelihood Ratio Test

^fNA = Not Applicable

Table 3

Probabilities of endorsing each health scenario, ascertained in the survey as states worse than death (AFFIRM Care study; N = 325).

Health scenario	Non-Aggressive Treatment Class	Mixed Class	Aggressive Treatment Class
Constant Pain	0.82	0.15	0.21
Dependence	0.92	0.06	0.19
Coma	0.98	0.88	0.22
Nursing Home	0.91	0.56	0.02
Breathing Tube	0.95	1.00	0.06
Dementia	0.96	0.72	0.10

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Table 4

Frequencies and means of demographic and background variables of participants assigned to most likely class based on posterior probabilities (AFFIRM Care study; N = 325).

	Non-aggressive Treatment Class	Mixed Class	Aggressive Treatment Class
Characteristic	% or Mean	% or Mean	% or Mean
Education (High school or more)	53.7	58.3	46.7
Sex (Female) *	34.7 ^a	52.1 ^b	50.5 ^b
Current drug use	40.1	36.6	36.2
Depressive symptoms, high	38.1	35.2	33.3
Age (Mean) †	52.6 ^{ab}	51.3 ^a	53.7 ^b
Physical limitations (Mean)	1.6	1.8	1.8

* 2 × 3 chi-square analysis significant at p<.05.

† One-way ANOVA significant at p<.10.

The same alphabetical superscript denotes estimates that are not significantly different, while different alphabetical superscripts denote estimates that are significantly different at p<.05.

Unadjusted and adjusted latent class regression analysis results of predictors (background variables, health status, and social variables) of class membership (Non-aggressive treatment, aggressive treatment, and mixed) (AFFIRM Care; n = 317).

Table 5

	Non-Aggressive Treatment Class vs. Aggressive Treatment Class		Mixed Class vs. Aggressive Treatment Class		Non-Aggressive Treatment Class vs. Mixed Class	
	AOR	CI	AOR	CI	AOR	CI
Sex (female)	.39 ^c	.21, .72	.99	.47, 2.09	.39 ^b	.19, .82
Belief in God to stay alive	.39 ^b	.21, .75	.41 ^b	.18, .90	.97	.43, 2.19
Lonely	6.57 ^d	2.38, 18.10	8.42 ^d	2.66, 26.62	.78	.31, 1.95
Drug use	--	--	--	--	--	--
Chronic Pain	.80	.36, 1.78	2.40 ^b	1.05, 5.48	.33 ^b	.14, .81
Lost in place know well	1.50 ^a	.96, 2.34	.49	.20, 1.17	3.07 ^c	1.32, 7.11
Depression	--	--	--	--	--	--
Physical Functioning	--	--	--	--	--	--
Reciprocity	2.50 ^c	1.35, 4.62	1.91	.86, 4.22	1.31	.60, 2.87
Emotional support	1.33 ^b	1.03, 1.70	1.46 ^b	1.07, 1.99	.91	.69, 1.20
Do Chores	--	--	--	--	--	--
Receive help with personal care	1.03	.56, 1.91	.94	.42, 2.07	1.10	.48, 2.54

OR = Odds Ratio

AOR = Adjusted Odds Ratio

CI = Confidence Interval

^a p<.10,

^b p<.05,

^c p<.01,

^d p<.001.