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Preparedness for Serious Illnesses: Impact of Ethnicity, Mistrust, Perceived Discrimination, and Health Communication

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Abstract

Background: Increasing severity of serious illness requires individuals to prepare and make decisions to mitigate adverse consequences of their illness. In a racial and ethnically diverse sample, the current study examined preparedness for serious illness among adults in California.

Methods: This cross-sectional study used data from the Survey of California Adults on Serious Illness and End-of-Life 2019. Participants included 542 non-Hispanic White (52%), non-Hispanic Black (28%), and Hispanic (20%) adults who reported at least one chronic medical condition that they perceived to be a serious illness. Race/ethnicity, socio-demographic factors, health status, discrimination, mistrust, and communication with provider were measured. To perform data analysis, we used logistic regression models.

Results: Our findings revealed that 19%, 24%, and 34% of non-Hispanic White, non-Hispanic Blacks, and Hispanic believed they were not prepared if their medical condition gets worse, respectively. Over 60% indicated that their healthcare providers never engaged them in discussions

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of their feelings of fear, stress, or sadness related to their illnesses. Results of bivariate analyses showed that race/ethnicity was associated with serious illness preparedness. However, multivariate analysis uncovered that serious illness preparedness was only lower in the presence of medical mistrust in healthcare providers, perceived discrimination, less communication with providers, and poorer quality of self-rated health.

Conclusion: This study draws attention to the need for healthcare systems and primary care providers to engage in effective discussions and education regarding serious illness preparedness with their patients, which can be beneficial for both individuals and family members and increase quality of care.

Keywords

serious illnesses; racial disparity; ethnicity; mistrust; perceived discrimination; health communication

Background

Managing a serious illness can be a frightening and difficult experience, especially for individuals who continually experience lower quality care and diminished access to care. When planning and selecting appropriate care and services for serious illnesses, an individual may face various emotional reactions, such as embarrassment and/or fear, and may avoid conversations with their provider regarding illness outcomes and treatment options.¹ However, it is now recommended by several agencies, including the Centers for Medicare and Medicaid (CMS), that individuals with serious illnesses learn about their rights and responsibilities of planning their health and personal affairs for when their serious illness worsens.² Furthermore, assessment and management of serious illness preparedness may be directly linked to the completion of advance directives and planning, use of palliative and hospice care, and acceptance of end-of-life and its changes. Additionally, preparing for serious illness can provide individuals with knowledge of their illness trajectory and increase their decision-making ability, leading to more effective plans and responses to their future health outcomes.

To ensure individuals with serious medical conditions are prepared for the trajectory of their illnesses, discussions with providers must be performed continually. Unlike advanced care planning, self-perceived serious illness preparation is a subjective assessment of a person's internal preparedness for future health conditions. In comparison, advance care planning is focused on the selection of a surrogate decision maker and documenting the directives and preferences for end-of-life medical care.^{3,4} Moreover, it encompasses communication and decisions about palliative care, hospice and other resources, which can be initiated by providers to start discussions surrounding the consequences of serious illness and death and dying. Despite advance care planning and serious illness preparedness being acknowledged as continual processes, serious illness preparedness is centered on the individualistic perception of the disease trajectory and future health outcomes if their health status deteriorates and serious illness worsens. For example, a patient with diabetes mellitus that is transitioning from oral antidiabetic medications to insulin management or end-stage renal disease patient preparing for dialysis and/or a kidney transplant. Even though these

concepts may be linked, serious illness preparedness focuses on planning response actions with regard to a specific illness or disease, as opposed to recording preferences for lifesustaining treatments when incapacitated. Even though there are similarities between the 2 concepts, serious illness management targets the subjective assessment of a individual's internal preparedness for future health conditions and worsening of current health issues.

Over the last 3 decades, issues related to serious illness preparedness for medical care have been extensively examined.^{5–11} A comprehensive review of the literature shows that targeted strategies have been tested and evaluated to promote the completion of these activities.¹² Numerous studies have shown that demographic characteristics, social and environmental disparities, such as low educational attainment and financial difficulties, have notable effects on the initiation and completion of planning and decision-making.^{13–24} Multiple systematic reviews conducted in recent years have documented multidimensional racial inequalities in health care utilization, medical treatment, and quality of care in minority populations in the United States.^{25–46} The racial disadvantage has also been documented throughout the literature for adults who receive specialized services, such as palliative care for people with serious illness or hospice services for people approaching the end of life.^{17,47–72} The racial disparities persist into end-of-life care, particularly regarding communication and family needs.⁷³

While a few studies have focused on advance care directives and planning among minority populations,^{15–24,74} to the best of our knowledge, no study has investigated serious illness preparedness among racial/ethnic groups. The objective of this study was to compare serious illness preparedness among non-Hispanic Blacks, Hispanics, and non-Hispanic Whites. We also examined perceived discrimination from the health care system, levels of mistrust toward their healthcare practitioners, communication with providers, and analyzed the impact of each of these factors on levels of serious illness preparedness with the 3 racial/ethnic groups. Using multivariate analysis, we adjusted for demographic and socio-economic variables while estimating the potential independent impact of perceived discrimination, mistrust, and communication on serious illness preparedness among individuals with serious medical conditions.

Methods

Design and Settings

This study used data from the Survey of California Adults on Serious Illness and End-of-Life 2019, which is a cross-sectional representative survey of California residents conducted on behalf of the California Health Care Foundation.⁷⁵ The sampling design and data collection methodology have been extensively described in previous literature.^{75–77} Data collection for the survey took place from June 2019 to July 2019. To ensure that racial comparative analysis could be performed, the survey oversampled the study population of non-Hispanic Black participants using supplemental non-probability sampling. The survey included a total of 2,588 California adults, aged 18 years and older. Out of the 2,588 respondents, a sub-sample (n = 585) reported at least one serious chronic condition. These participants were assessed on their preparedness if their chronic condition/s worsen. Almost 5% (n = 29) of participants of subsample were excluded from our data analysis due to self-

identification with other racial/ethnic groups not studied in our analyses or no identification of their racial/ethnic group. Therefore, our present study included 542 individuals with chronic condition/s who were 1) non-Hispanic Black, 2) Hispanic, or 3) non-Hispanic White. Overall, the survey targeted an equal number of participants with household incomes 1) under 150% federal poverty level (FPL), 2) between 150% and 399% FPL, and 3) at least 400% FPL and above.

Measurements

Independent Variable

Demographic and socio-economic characteristics included age, gender, educational attainment, marital status, ethnicity, and household income. Gender was a dichotomous measure (male = 1, female = 0 [reference group]). Age was a continuous variable. Educational attainment was operationalized as a continuous variable with a range between 0 and 14, with a higher score reflecting more years of schooling. Not married, widowed, separated participants were coded 0, while married or living with partners were coded 1. Income was measured as annual household income for previous years. Income was categorized by 3 levels: 1) under 150%, 2) 150–399%, and 3) 400% of the federal poverty level. Race/ethnicity was self-identified, and was dichotomized, with non-Hispanic Whites designated as the reference category.

Perceived Discrimination

Perceived discrimination was measured using a 10-item questionnaire. For all 10 items, participants indicated whether they agreed or disagreed with each statement. For example, participants were asked whether they had been the subject of discrimination by health care providers due to their ethnicity/race, language, income, or medical coverage. Principal component analysis was used to identify potential factors underlying the 10-item instrument that measures the type of discrimination. The Varimax rotation produced 2 distinct factors, explaining 58% of the variance. The first factor was associated with the 6 items that measure perceived discrimination associated with income, type of insurance, and being uninsured. The second factor produced by the Varimax rotation is associated with 4 items that measure perceived discrimination because of race/ethnicity and language.

Level of Mistrust

Mistrust was measured with a single item asking participants, "In general, how much do you trust your health care providers to act in your best interest?" Response options included "not at all," "not too much," "some," and "a lot." We use following coding: 1 = "not at all/not too much"; 2 = "some," and 3 = "a lot."

Communication With Providers Regarding Their Illnesses

Communication with providers regarding their chronic illnesses measured using following 5 items: "Have any of your health care providers talked to you about 1) how to make your life better as you live with your illnesses? 2) any fear, stress, or sadness you may be feeling? 3) what to expect if your illness gets worse? 4) both the good and bad things that could happen with your treatments? and 5) what is most important for you as you live your life

with your illnesses?" Cronbach's alpha coefficient for these 6 items was calculated to be 0.82. Furthermore, when items were deleted, the alpha scores ranged from 0.762 to 0.798, indicating that no single item decreased reliability appreciably. Therefore, we are convinced that a summative score of these 5 items is a reliable measure of communication with providers. This index for serious illness preparation includes the following tenets: 1) basic medical and illness history, 2) mental wellness, 3) expectations of illness/disease trajectory, 4) perceptions of treatment risks and benefits of treatments, and 5) personal short-term and long-term health goals. Therefore, these 5 items chosen to represent a proxy for serious illness preparedness.

Number of Chronic Conditions

The number of chronic conditions was measured based on self-report of being diagnosed with: 1) emphysema or chronic obstructive pulmonary disease, 2) heart disease, 3) cancer, 4) stroke, 5) HIV/AIDS, 6) cirrhosis or late-stage liver disease, 7) chronic or end-stage kidney disease, 8) hypertension, 9) diabetes, 10) depression, 11) an anxiety disorder, 12) bipolar disorder, and 13) any other serious illness.

Self-Rated Health (SRH) Status

Self-Rated Health (SRH) status was measured using a single item.^{78–81} Participants reported their overall health. Response options were coded as 1) excellent, 2) very good, 3) good, 4) fair, and 5) poor. The Institute of Medicine (IOM) recommends the use of Self-Rated Health Status for monitoring the health of the US general population.

Outcome Variable

Serious illness preparedness was measured with a single item asking participants, "*How prepared do you feel to deal with your illness(s) if it gets worse in the future*?" The response options were "very prepared," "somewhat prepared," "not too prepared," and "not at all prepared." In order to use multiple logistic regression, we used a binary code of 0 for not being prepared ("not too prepared," and "not at all prepared") and 1 for prepared ("very prepared," and "somewhat prepared").

Statistical Analysis

For descriptive statistics, we reported means and proportions (frequencies). For bivariate analysis, we used Chi Square or ANOVA tests. For multivariable models, we employed the multiple logistic regression technique. Adjusted Odds Ratios (ORs), 95% Confidence Intervals (9% CI), and p-values were reported. P-values equal or less than 0.05 were considered significant.

Results

Table 1 reports the characteristics of the study sample. This study included 542 individuals, of whom 154 identified as non-Hispanic Black, 106 as Hispanic, and 282 as non-Hispanic Whites, all aged 18 years and older (mean 57.7 ± 17.01). More than 28% of our sample reported having a high school diploma and 7% reported 0–11 years of education. Over 36% reported their household income in the range of 150% to 400% of the federal poverty

level, whereas almost 37% reported income under 150% of the federal poverty level. Only 4% of participants reported excellent health, whereas 34% described their health as poor (8%) or fair (26%). This cross-sectional survey shows that 19%, 24%, and 34% of non-Hispanic White, non-Hispanic Blacks, and Hispanic reported that they are not prepared if their chronic condition worsened, respectively. In addition, more than 60% of participants indicated that their health care providers never talked to them regarding their feelings of fear, stress, or sadness related to their serious illnesses. Similarly, only 45% of participants indicated that their health care providers talked with them about what to expect if their illness(es) gets worse.

Bivariate Correlations

Table 2 shows the bivariate correlation results between the independent variables and serious illness preparedness. At the bivariate level, all independent variables (except for the number of chronic conditions and perceived racial/language discrimination) were associated with serious illness preparedness. The following were all more likely to report higher levels of preparedness: i) men, ii) older adults, iii) higher education level, iv) married, v) higher income, vi) identification as a non-Hispanic White, vii) higher self-rated health, viii) lower levels of perceived discrimination, ix) frequent communication with their providers, and x) greater level of trust in their providers.

Multivariate Analysis

Table 3 reports result of the multiple logistic regression estimating independent association between serious illness preparedness and independent variables. The relationship between the independent variables that included in the logistic regression model was examined. We detected no harmful multi-collinearity among independent variables (the highest correlation was between variables that measured the self-rated health status and number of chronic condition; r = 0.314). Table 3 shows that adjusting for demographic, SES status, and other relevant variables, the index that measured perceived discrimination due to income or type or lack of health care coverage was associated with lower serious illness preparedness. This indicated that experiencing a higher level of discrimination because of income, type of insurance, and lack of insurance leads to a 65% (OR: 1.652; 95% CI: 1.299-2.101, p < 0.0001) increase in the odds of not being prepared for a serious deterioration in health condition. Similarly, those who indicated that they did not trust their health care providers were 0.379 times less likely to report serious illness preparedness (OR = 0.379; 95% CI: 0.176-0.816; P < .02), compared to those who have complete trust in their health care providers. Additionally, a lower level of self-rated health status decreased the odds of being among survey participants who indicated that they are prepared if their medical conditions get worse. Finally, racial and ethnic backgrounds did not remain significant when other relevant variables (particularly the variable that measures trust in providers) were held constant.

Discussion

This study documented that after adjusting for demographic, SES status, and other relevant variables, lower levels of serious illness preparedness was associated with 1) a higher

level of perceived enabling discrimination; 2) a higher level of mistrust with health care providers; 3) a lower level of communication with providers regarding their illnesses; and 4) a lower level of perceived health status. Additionally, racial/ethnic identity was correlated with serious illness preparedness at the bivariate levels, with non-Hispanic Blacks and Hispanics being less prepared for their serious illness than non-Hispanic Whites. However, at the multivariate level and controlling for other related variables, including level of trust with health care providers, perceived discrimination with health system, and level of communication with providers, racial/ethnic identity was no longer statistically significant with serious illness preparedness. Therefore, it is important to discuss the role of these 3 factors/variables on modifying the association between serious illness preparedness and racial/ethnic identity. Indeed, reviews of literature show that the level of communication with providers, ^{15,16,82,83} mistrust,^{84,85} and perceived discrimination^{86,87} are 3 strong predictors of advance care planning, palliative care as well as hospice care among minority populations. This is important for our findings as we uncovered these predictors to be significant for lower serious illness preparedness.

Evidence has shown that there are existing disparities in diversity, equity and inclusivity within healthcare and society.⁸⁸ Recent findings of other studies focused on race and income^{89,90} reveal that income and resources may indicate poorer health outcomes, as opposed to race. Viewing mistrust and lack of communication through lens of health disparities, attributed to lower resources and lack of adequate care can diminish notions that all inequality is due to race/ethnicity. Moreover, decisions regarding serious illness preparedness may be impacted by social status, personal responsibility of health, and structural pressures, all which may have a greater impact than race/ethnicity. Therefore, our significant factors from our multivariate analyses may be a result of economic, social, and personal factors, which can lead to other forms of discrimination, such as income, age, or disability. This may be more impactful than race/ethnicity, marking it a surprising finding. Despite this result, we still uncovered race/ethnicity to be significant in our bivariate analyses.

Numerous studies, including recent systematic reviews, show that ethnic/racial minority patients consistently experience poorer communication quality, information-giving, patient participation, and participatory decision-making than their non-Hispanic White counterparts.⁹¹. Community-based studies reveal that racial and ethnic minorities are less likely than non-Hispanic Whites to communicate their advance care preferences to their healthcare providers.^{15,16} Moreover, a recent systematic review of literature found that interventions promoting effective communication about aspects of serious illness preparedness improved concordance between preferences for care and delivered care.⁷ Elliott and colleagues (2016) suggest that excessive (compared to non-Hispanic Whites) mortality of non-Hispanic Black patients in the intensive care unit undergoing life-sustaining treatment is associated with differences in patient- and/or surrogateprovider communication.⁸³ Also, it is well-documented that non-Hispanic Blacks desire communication, information, respect, and a trusting doctor-patient relationship.⁹² Several studies have shown that minority groups desire initiatives that are sensitive to their religious values and cultural assumptions.^{17,18,22,93–96} Finally, knowing that communitybased interventions have been exceptionally successful among minority communities on a

variety of topics, additional investigational intervention are needed to focus on improving serious-illness planning.

Controlling for all other variables, our data show that mistrust in healthcare providers was associated with low serious illness preparedness. This finding is very similar to numerous studies that show low initiation of advance care planning and low completion of advance directives strongly are linked to mistrust in the health care system among various populations.^{85,97} A recent systematic review of 40 studies found that unwillingness to participate in advance care planning among adults is related to fear of the advance care planning process and to previous negative experiences with the health care system.⁹⁸ Medical mistrust is a major barrier to a strong patient-provider relationship and negatively influences health behavior and treatment outcomes.^{99–101} An extensive review of the literature shows linkage between patient mistrust, lack of commitment to treatment plans, negative health behaviors, and undesired health outcomes, particularly among minority groups.^{102–105} Indeed, there is an established body of literature indicating that minorities, particularly non-Hispanic Blacks, consistently report higher levels of mistrust in the health care system than Whites.^{97,104–107} Our study revealed that non-Hispanic Black and Hispanic participants are twice as likely as their White counterparts to admit that they do not trust their health care providers "at all." Hong and colleagues (2018) found in their systematic review of 26 studies, medical mistrust acted as a barrier to advanced care planning among non-Hispanic Blacks.⁸⁵ For racial/ethnic minorities, medical mistrust may be rooted in previous discriminatory experiences. 104,105,108-110

Our findings revealed that more than 56% of participant state that their health care providers never talked to them regarding their feelings of fear, stress, or sadness related to their serious illnesses. Moreover, at least half of our sample reported that their healthcare providers didn't discuss their illness trajectory and decision-making for future outcomes. Interestingly, almost 11% of participants indicated that they do not trust their providers at all and were likely to be unprepared if their health deteriorated. Cross-cultural studies commonly identify communication and the flow of information, perceptions of hospice and palliative care, and compatibility with beliefs (i.e. cultural, spiritual, social) as major barriers that profoundly impact services for serious illness preparedness.^{82,111,112}

Another important factor linked to serious illness preparedness in our multivariate analysis was the perception of enabling discrimination shown within the health care system and by providers. It is important to understand how specific factors, such as mistrust and discrimination, can impact serious illness preparedness and use of health care services. We documented that perceived discrimination due to enabling characteristics (income and type or lack of health care coverage) led to a 65% increase of not being prepared for carrying out effective management of serious illnesses.

Additionally, our data shows consistently strong association between perceived discrimination with medical care system and providers. For example, 38%, 27%, and 19% of non-Hispanic Blacks participated in this study indicated that they have been treated differently by health care providers because of their ethnicity, type of insurance, and lack of health care coverage, respectively. However, only 5%, 15%, and 9% of

non-Hispanic White participants, admitted that they were treated differently for the same reasons mentioned above, specifically ethnicity, type of insurance, and lack of health care coverage. Discrimination and mistrust are more common in minority populations with multi-morbidities who are managing multiple and complex illnesses.^{113,114} It is well-established that minority groups, such as non-Hispanic Blacks, have experienced decades of systemic and institutionalized racism and discrimination, in addition to unethical medical experimentation, which can result in lower levels of mistrust and various types of discrimination. In a comprehensive speculative essay, Rosenblatt (2009) paints a troubling picture of racism and its impact on preparedness for serious illness and end-of-life care in the United States. He argues that "*the racial system operates in ways that bruise some people and that make it difficult for those who are advantaged by the system to understand the system and their place in it; and so, ideally one way for end-of-life care facilities to deal with potential difficulties in black-white relationships is to provide contexts for dealing with bruises and obliviousness."⁸⁷*

Evidence shows that poor health status is a common facilitator for higher engagement in serious illness preparedness among many groups, including minority populations.⁸⁵ Interestingly, our data shows that participants who reported a higher level of self-rated health status were more likely to have higher levels of serious illness preparedness. Usually, individuals who are deemed to have a higher risk of dying due to illness may receive advance care planning counseling to ensure easier decision-making at the end of life, especially for those in poor health. However, these patients may not feel prepared, even after discussions with providers and family members and completion of advance directives. When their perceived health condition and quality of health worsens or is already poor, they may be less likely to admit that they are prepared for challenging situations. Instead, family members and healthcare providers should periodically assess patients' satisfaction with decisions for preparedness for serious illness management, followed by advance care planning.

Finally, it is important to despite our sample including all adults aged 18 and older, the average age was 58 (SD = 17), which reflects a wide range of individuals who perceived their chronic conditions as serious. Interestingly, at bivariate level, age was a significant predictor of the preparedness for serious illness, indicating that those who reported that they were not prepared, were 5 years younger than their counterparts who reported being prepared for serious illness. However, at the multivariate level, age was not significant, which is important to recognize as other variables, particularly gender and variables that measured mistrust were added to the model.

Implications

In our multivariate analysis, this study showed that serious illness preparedness was lower in the presence of medical mistrust in healthcare providers, perceived discrimination, less communication with providers, and poorer quality of self-rated health. While this finding has not been reported in this context previously, it is an indication of how impactful discrimination, mistrust, and communication with health system and providers shape the quality of care, patient behavior, and health outcomes that has been reported in

numerous studies.^{99–102,115–118} Planning for effective responses to serious illnesses requires ongoing engagement and dialogue with primary health care providers, family members, and thoughtful consideration of experiences and wishes.¹¹⁹

Consideration of various types of healthcare practitioners is integral as individuals residing in underresourced urban and rural areas may have greater access to nurse practitioners and physician assistants, as opposed to a physician, and should seek to maintain and regularly engage with a multidisciplinary healthcare team (i.e. nutritionist, occupational therapist, social worker). This may lead more positive perceptions of patients' self-assessment of their health and increase their preparedness to make decisions about their care. Therefore, healthcare providers (i.e. physicians, nurse practitioners, and physician assistants) should implement methods to initiate discussions regarding serious illness preparedness with patients at most visits with patients, which would also improve their communication skills and relationships with patients, especially under-served and minority groups.¹²⁰ Primary healthcare providers may find it difficult to discuss these topics with patients across the life cycle, such as goals of care or conversations about serious illness and its potential negative outcomes. The reluctance to discuss these topics with individuals across the life span may have to be integrated in the curriculum of their educational training, such as medical school.¹²¹ Discussing preparedness, if illnesses get worse, may be an interesting tactic to build relationships and rapport with patients to facilitate further discussion about advance care planning. Providers who have already had discussions with their patients about serious illness preparedness may find it easier to discuss end-of-life issues.

With regard to patient education and wellness, we acknowledge the need for innovative advance care planning models that integrate serious illness preparedness as one of the primary tenets, due to its focus on understanding the subjective assessment of an individual's illness preparedness, and their socio-psychological/cognitive status. Moreover, expectations of the illness trajectory should occur prior to advance care planning, and initiated at the time of diagnosis so that patients learn to adapt to their wellness change and planning of future health goals. This may eventually lead to reduction of chronic stress related to their illness and any future deterioration in physical and mental health status, especially for underresourced minority adults. The careful evaluation of patients' serious illness preparedness for dealing with serious illnesses may also help achieve a positive treatment outcome. However, it is quite possible that the self-perception of serious illness preparedness does not reliably capture the needs of patients. Therefore, future research should ideally include both objective and subjective (self-perceived) measures of patients' serious illness preparedness to. The variability in preparedness suggests that there is a great need for culturally sensitive, customized, stage-specific interventions based on individualized assessments of self-rated health, communication and experiences with health care system and providers to improve preparedness to carry out effective responses to serious illnesses. Finally, it is important for family members and providers to understand the patients' self-perception and preparedness of their future health condition and preferred method of treatment for the serious illness.

There were a few limitations with this study. First, this study utilized secondary data analysis. While secondary data analysis is flexible and can be utilized in several ways, it

can be limiting due to inability to capture other relevant variables/factors. For example, this dataset may have needed to add additional items/questions to describe the meaning of serious illness preparedness. Second, this was a cross-sectional study that prevented any determination of causal relationships. An additional limitation was the use of self-reported measures, which results in a degree of bias. Lastly, consecutive address-based sampling was utilized, which may limit generalizability. However, this study is unique as it included a more equal representation of non-Hispanic Blacks, Hispanics, and non-Hispanic Whites, which is not always represented in datasets. Despite these limitations, this is a novel study that contributes to the current knowledge on serious illness preparedness among these population of adults with serious medical illnesses.

Conclusion

This study shows that 3 factors—level of communication with providers, mistrust, and perceived discrimination—strongly predict the level of serious illness preparedness, which is similar to previous literature on end-of-life services and completion of directives. More importantly, our findings showed that non-Hispanic Blacks and Hispanics may be at a disadvantage due to lower levels of serious illness preparedness. However, knowing that perceived serious illness preparedness is based on self-perception, it is necessary that providers offer comprehensive and culturally competent knowledge to ensure that patients understand their health condition and illness trajectory, especially for minority populations. We strongly suggest that serious illness preparedness be further examined and its potential association with end-of-life and advance care planning. With greater knowledge and evidence, healthcare systems, communities, and families will greatly benefit from improved understanding of serious illness management, especially among underserved minority groups.

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References

- Greenlee K Making our own decisions about serious illness. Public Policy Aging Report. 2014;24(3):81–85.
- Warshany K, Sherrill CH, Cavanaugh J, Ives TJ, Shilliday BB. Medicare annual wellness visits conducted by a pharmacist in an internal medicine clinic. Am J Health Syst Pharm. 2014;71(1): 44–49. [PubMed: 24352181]
- Dingfield LE, Kayser JB. Integrating advance care planning into practice. Chest. 2017;151(6):1387– 1393. [PubMed: 28283409]
- Lunder U, erv B, Kodba- eh H. Impact of advance care planning on end-of-life management. Curr Opin Support Palliat Care. 2017;11(4):293–298. [PubMed: 28957882]
- Rao JK, Anderson LA, Lin FC, Laux JP. Completion of advance directives among US consumers. Am J Prevent Med. 2014;46(1): 65–70.
- Tamayo-Velazquez M-I, Simon-Lorda P, Villegas-Portero R, et al. Interventions to promote the use of advance directives: an overview of systematic reviews. Patient Educ Couns. 2010;80(1):10–20. [PubMed: 19879090]

- 7. Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of advance care planning: a systematic review and meta-analysis. J Am Med Dir Assoc. 2014;15(7):477–489. [PubMed: 24598477]
- 8. Patel RV, Sinuff T, Cook DJ. Influencing advance directive completion rates in non-terminally ill patients: a systematic review. J Crit Care. 2004;19(1):1–9. [PubMed: 15100999]
- Bravo G, Dubois M-F, Wagneur B. Assessing the effectiveness of interventions to promote advance directives among older adults: a systematic review and multi-level analysis. Soc Sci Med. 2008; 67(7):1122–1132. [PubMed: 18644667]
- Oulton J, Rhodes SM, Howe C, Fain MJ, Mohler MJ. Advance directives for older adults in the emergency department: a systematic review. J Palliat Med. 2015;18(6):500–505. [PubMed: 25763860]
- 11. Wilkinson A, Wenger N, Shugarman LR. Literature Review on Advance Directives. Department of Health and Human Services and RAND Corporation; 2007.
- Solis GR, Mancera BM, Shen MJ. Strategies used to facilitate the discussion of advance care planning with older adults in primary care settings: a literature review. J Am Assoc Nurse Pract. 2018; 30(5):270–279. [PubMed: 29757843]
- 13. Kwak J, Cho YI, Lee YS, Noh H, Roh S. Differences in advance care planning between American Indian and white older adults. Res Gerontol Nurs. 2019;12(1):34–43. [PubMed: 30653650]
- Koss CS, Baker TA. Where there's a will: the link between estate planning and disparities in advance care planning by white and black older adults. Res Aging. 2018;40(3):281–302. [PubMed: 29298597]
- Clark MA, Person SD, Gosline A, Gawande AA, Block SD. Racial and ethnic differences in advance care planning: results of a statewide population-based survey. J Palliat Med. 2018; 21(8):1078–1085. [PubMed: 29658817]
- Carr D. Racial and ethnic differences in advance care planning: identifying subgroup patterns and obstacles. J Aging Health. 2012;24(6):923–947. [PubMed: 22740168]
- Eneanya ND, Wenger JB, Waite K, et al. Racial disparities in end-of-life communication and preferences among chronic kidney disease patients. Am J Nephrol. 2016;44(1):46–53. [PubMed: 27351650]
- Garrido MM, Harrington ST, Prigerson HG. End-of-life treatment preferences: a key to reducing ethnic/racial disparities in advance care planning? Cancer. 2014;120(24):3981–3986. [PubMed: 25145489]
- Huang IA, Neuhaus JM, Chiong W. Racial and ethnic differences in advance directive possession: role of demographic factors, religious affiliation, and personal health values in a national survey of older adults. J Palliat Med. 2016;19(2):149–156. [PubMed: 26840850]
- Johnson J, Hayden T, True J, et al. The impact of faith beliefs on perceptions of end-of-life care and decision making among African American church members. J Palliat Med. 2016;19(2):143– 148. [PubMed: 26840849]
- 21. Koss CS. Does religiosity account for lower rates of advance care planning by older African Americans? J Gerontol Series B. 2018; 73(4):687–695.
- Portanova J, Ailshire J, Perez C, Rahman A, Enguidanos S. Ethnic differences in advance directive completion and care preferences: what has changed in a decade? J Am Geriatr Soc. 2017;65(6): 1352–1357. [PubMed: 28276051]
- 23. Rhodes RL, Ukoha NC, Williams KA, et al. Understanding under-use of advance care planning among a cohort of African American patients with advanced cancer: formative research that examines gaps in intent to discuss options for care. Am J Hosp Palliat Med. 2019;36(12):1057– 1062.
- Smith AK, McCarthy EP, Paulk E, et al. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. J Clin Oncol. 2008;26(25):4131. [PubMed: 18757326]
- Ahmed AT, Welch BT, Brinjikji W, et al. Racial disparities in screening mammography in the United States: a systematic review and meta-analysis. J Am Coll Radiol. 2017;14(2): 157– 165.e159. [PubMed: 27993485]

- 26. Salz T, Woo H, Starr TD, Jandorf LH, DuHamel KN. Ethnic disparities in colonoscopy use among colorectal cancer survivors: a systematic review. J Cancer Surv. 2012;6(4):372–378.
- 27. Green AK, Aviki EM, Matsoukas K, Patil S, Korenstein D, Blinder V. Racial disparities in chemotherapy administration for early-stage breast cancer: a systematic review and meta-analysis. Breast Cancer Res Treatment. 2018;172(2):247–263.
- Branson CO, Ferree A, Hohler AD, Saint-Hilarie M. Racial disparities in Parkinson disease: a systematic review of the literature. Adv Parkinsons Dis. 2016;5:87–96.
- 29. Cooper C, Tandy AR, Balamurali TB, Livingston G. A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. Am J Geriat Psych. 2010;18(3): 193–203.
- Saadi A, Himmelstein DU, Woolhandler S, Mejia NI. Racial disparities in neurologic health care access and utilization in the United States. Neurology. 2017;88(24):2268–2275. [PubMed: 28515272]
- LoPresti MA, Dement F, Gold HT. End-of-life care for people with cancer from ethnic minority groups: a systematic review. Am J Hosp Palliat Medic. 2016;33(3):291–305.
- 32. Washington KT, Bickel-Swenson D, Stephens N. Barriers to hospice use among African Americans: a systematic review. Health Social Work. 2008;33(4):267–274. [PubMed: 19070274]
- 33. Parajuli J, Tark A, Jao Y-L, Hupcey J. Barriers to palliative and hospice care utilization in older adults with cancer: a systematic review. J Geriat Oncol. 2020;11(1):8–16.
- 34. Narayan MC, Scafide KN. Systematic review of racial/ethnic outcome disparities in home health care. J Transcult Nurs. 2017;28(6):598–607. [PubMed: 28826334]
- Dong L, Fakeye OA, Graham G, Gaskin DJ. Racial/ethnic disparities in quality of care for cardiovascular disease in ambulatory settings: a review. Med Care Res Rev. 2018;75(3):263–291. [PubMed: 28882087]
- 36. Ugowe FE, Jackson LR II, Thomas KL. Racial and ethnic differences in the prevalence, management, and outcomes in patients with atrial fibrillation: a systematic review. Heart Rhythm. 2018; 15(9):1337–1345. [PubMed: 29803022]
- Goyal MK, Kuppermann N, Cleary SD, Teach SJ, Chamberlain JM. Racial disparities in pain management of children with appendicitis in emergency departments. JAMA Pediatr. 2015; 169(11):996–1002. [PubMed: 26366984]
- Meghani SH, Byun E, Gallagher RM. Time to take stock: a meta-analysis and systematic review of analgesic treatment disparities for pain in the United States. Pain Med. 2012;13(2):150–174. [PubMed: 22239747]
- Anderson AN, Higgins CM, Haardörfer R, Holstad MM, Nguyen MLT, Waldrop-Valverde D. Disparities in retention in care among adults living with HIV/AIDS: a systematic review. AIDS Behav. 2020;24(4):985–997. [PubMed: 31555931]
- Haider AH, Weygandt PL, Bentley JM, et al. Disparities in trauma care and outcomes in the United States: a systematic review and meta-analysis. J Trauma Acute Care Surg. 2013;74(5):1195. [PubMed: 23609267]
- 41. Schoenfeld AJ, Tipirneni R, Nelson JH, Carpenter JE, Iwashyna TJ. The influence of race and ethnicity on complications and mortality after orthopedic surgery: a systematic review of the literature. Med Care. 2014;52(9):842–851. [PubMed: 25100230]
- Driesman A, Fisher N, Konda SR, Pean CA, Leucht P, Egol KA. Racial disparities in outcomes of operatively treated lower extremity fractures. Arch Orthop Trauma Surg. 2017;137(10): 1335– 1340. [PubMed: 28748293]
- Sigurdson K, Mitchell B, Liu J, et al. Racial/ethnic disparities in neonatal intensive care: a systematic review. Pediatrics. 2019; 144(2):e20183114. [PubMed: 31358664]
- 44. Flores G. Racial and ethnic disparities in the health and health care of children. Pediatrics. 2010;125(4):e979–e1020. [PubMed: 20351000]
- 45. Bishop-Fitzpatrick L, Kind AJ. A scoping review of health disparities in autism spectrum disorder. J Autism Dev Dis. 2017; 47(11):3380–3391.
- Lewey J, Shrank WH, Bowry AD, Kilabuk E, Brennan TA, Choudhry NK. Gender and racial disparities in adherence to statin therapy: a meta-analysis. Am Heart J. 2013;165(5):665–678.e661. [PubMed: 23622903]

- 47. Gardner DS, Doherty M, Bates G, Koplow A, Johnson S. Racial and ethnic disparities in palliative care: a systematic scoping review. Fam Soc. 2018;99(4):301–316.
- Gramling R, Gajary-Coots E, Cimino J, et al. Palliative care clinician overestimation of survival in advanced cancer: disparities and association with end-of-life care. J Pain Symp Manage. 2019; 57(2):233–240.
- Hoerger M, Perry LM, Korotkin BD, et al. State-level differences in personality and geographic disparities in access to palliative care: findings on openness. Am Soc Clin Oncol. 2018;36(34):57.
- 50. Johnson KS. Racial and ethnic disparities in palliative care. J Palliat Med. 2013;16(11):1329–1334. [PubMed: 24073685]
- Mohammed KA, Osazuwa-Peters N, Sanfilippo KM. Sociodemographic and hospital level disparities in palliative care utilization among terminally ill patients with multiple myeloma. Blood. 2018;132(Supplement 1):3594–3594.
- 52. Paul S, Hester C, Wang SC, et al. Disparities associated with the receipt of palliative care in patients with metastatic gastric cancer. Am Soc Clin Oncol. 2019;37(4_Suppl):28.
- 53. Payne R Racially associated disparities in hospice and palliative care access: acknowledging the facts while addressing the opportunities to improve. J Palliat Med. 2016;19(2):131–133. [PubMed: 26840847]
- 54. Shreenivas AV. Racial Disparities in Palliative and Hospice Care Beliefs of Lung Cancer Patients. Icahn School of Medicine at Mount Sinai; 2018.
- Tella SH, Kommalapati A, Tandra PK. Disparities in the receipt of Palliative Care (PC) in metastatic renal cell carcinoma (mRCC). Am Soc Clin Oncol. 2019;37(15): Supple. e18108– e18108.
- Wen Y, Jiang C, Koncicki HM, et al. Trends and racial disparities of palliative care use among hospitalized patients with ESKD on dialysis. J Am Soc Nephrol. 2019;30(9):1687–1696. [PubMed: 31387926]
- Arenella C. Hospice and palliative care for African Americans: overcoming disparities. J Palliat Med. 2016;19(2):126–126. [PubMed: 26840844]
- 58. Cervantez SR, Tenner LL, Schmidt S, et al. Symptom burden and palliative referral disparities in an ambulatory South Texas cancer center. Front Oncol. 2018;8:443. [PubMed: 30374422]
- Ejem DB, Barrett N, Rhodes RL, et al. Reducing disparities in the quality of palliative care for older African Americans through improved advance care planning: study design and protocol. J Palliat Med. 2019;22(S1):S–90–S–100.
- Evans BC, Ume E. Psychosocial, cultural, and spiritual health disparities in end-of-life and palliative care: where we are and where we need to go. Nurs Outlook. 2012;60(6):370–375. [PubMed: 23141196]
- 61. Gardner DS, Doherty M. Exploring palliative care disparities in racially and ethnically diverse community-dwelling older adults. Innovat Aging. 2019;3(Suppl 1):S746.
- Dillon PJ, Basu A. African Americans and hospice care: a culture-centered exploration of enrollment disparities. Health Commun. 2016;31(11):1385–1394. [PubMed: 27007165]
- 63. Dillon PJ, Basu A. Toward eliminating hospice enrollment disparities among African Americans: a qualitative study. J Health Care Poor Underserved. 2016;27(1):219–237. [PubMed: 27763466]
- 64. Haines KL, Jung HS, Zens T, Turner S, Warner-Hillard C, Agarwal S. Barriers to hospice care in trauma patients: the disparities in end-of-life care. Am J Hosp Palliat Medic. 2018;35(8): 1081– 1084.
- Paredes AZ, Hyer JM, Palmer E, Lustberg MB, Pawlik TM. Racial/ethnic disparities in hospice utilization among Medicare beneficiaries dying from pancreatic cancer. J Gastrointest Surg. 2020;25(1):155–161. [PubMed: 32193849]
- 66. Rhodes RL, Teno JM, Connor SR. African American bereaved family members' perceptions of the quality of hospice care: lessened disparities, but opportunities to improve remain. J Pain Symp Manag. 2007;34(5):472–479.
- Rizzuto J, Aldridge MD. Racial disparities in hospice outcomes: a race or hospice-level effect? J Am Geriatr Soc. 2018;66(2): 407–413. [PubMed: 29250770]
- Turkman YE, Williams CP, Jackson BE, et al. Disparities in hospice utilization for older cancer patients living in the deep south. J Pain Sympt Manage. 2019;58(1):86–91.

- 69. Frahm KA, Brown LM, Hyer K. Racial disparities in end-of-life planning and services for deceased nursing home residents. J Am Med Dir Assoc. 2012;13(9):819.e817–819.e811.
- Karanth S, Rajan SS, Sharma G, Yamal J-M, Morgan RO. Racial-ethnic disparities in end-of-life care quality among lung cancer patients: a SEER-Medicare–based study. J Thorac Oncol. 2018; 13(8):1083–1093. [PubMed: 29753578]
- 71. Lyon ME, Squires L, D'Angelo LJ, et al. FAmily-CEntered (FACE) advance care planning among African-American and non-African-American adults living with HIV in Washington, DC: a randomized controlled trial to increase documentation and health equity. J Pain Symp Manage. 2019;57(3):607–616.
- 72. Zaide GB, Pekmezaris R, Nouryan CN, et al. Ethnicity, race, and advance directives in an inpatient palliative care consultation service. Palliat Support Care. 2013;11(1):5–11. [PubMed: 22874132]
- Welch LC, Teno JM, Mor V. End-of-life care in black and white: race matters for medical care of dying patients and their families. J Am Geriat Soc. 2005;53(7):1145–1153. [PubMed: 16108932]
- 74. Gerst K, Burr JA. Planning for end-of-life care: black-white differences in the completion of advance directives. Res Aging. 2008;30(4):428–449.
- 75. Foundation CHC. Help wanted: Californians' views and experiences of serious illness and endof-life care. 2019. Updated September 13, 2020. Accessed September 2020. https://www.chcforg/ publication/help-wanted-californians-views-serious-illness/
- Bazargan M, Cobb S, Assari S. Discrimination and medical mistrust in a racially and ethnically diverse sample of California adults. Ann Fam Med. 2021;19(1):4–15. [PubMed: 33431385]
- 77. PERRYUNDEM. Survey Methodology. Research Communication. 2019. Updated September 9, 2020. Accessed September 2020. https://www.chcforg/wp-content/uploads/2019/10/ SurveyAdultsSeriousIllnessEndLifeMethodologypdf
- Gunasekara FI, Carter K, Blakely T. Change in income and change in self-rated health: systematic review of studies using repeated measures to control for confounding bias. Soc Sci Med. 2011;72(2):193–201. [PubMed: 21146277]
- Idler EL, Benyamini Y. Self-rated health and mortality: a review of twenty-seven community studies. J Health Soc Behav. 1997; 38(1):21–37. [PubMed: 9097506]
- Mavaddat N, Parker RA, Sanderson S, Mant J, Kinmonth AL. Relationship of self-rated health with fatal and non-fatal outcomes in cardiovascular disease: a systematic review and metaanalysis. PLoS One. 2014;9(7):e103509. [PubMed: 25076041]
- Moor I, Spallek J, Richter M. Explaining socioeconomic inequalities in self-rated health: a systematic review of the relative contribution of material, psychosocial and behavioural factors. J Epidem Commun Health. 2017;71(6):565–575.
- Herbstsomer RA, Stahl ST. Cross-cultural experiences of hospice and palliative care services: a thematic analysis. Omega. 2020: 0030222820904205.
- 83. Elliott AM, Alexander SC, Mescher CA, Mohan D, Barnato AE. Differences in physicians' verbal and nonverbal communication with black and white patients at the end of life. J Pain Sympt Manag. 2016;51(1):1–8.
- 84. Bullock K Promoting advance directives among African Americans: a faith-based model. J Palliat Med. 2006;9(1): 183–195. [PubMed: 16430358]
- Hong M, Yi EH, Johnson KJ, Adamek ME. Facilitators and barriers for advance care planning among ethnic and racial minorities in the U.S.: a systematic review of the current literature. J Imm Minor Health. 2018;20(5):1277–1287.
- 86. Stein GL, Berkman C, O'Mahony S, Godfrey D, Javier NM, Maingi S. Experiences of lesbian, gay, bisexual, and transgender patients and families in hospice and palliative care: perspectives of the palliative care team. J Palliat Med. 2020;23(6):817–824. [PubMed: 31916901]
- 87. Rosenblatt PC. Racism and black-white relationships in end-of-life care in the United States: a speculative analysis. Illness Crisis Loss. 2009;17(2):113–124.
- Barnes C, Mueller K, Fawcett L, Wagner B. Living and dying in a disparate health care system: rationale and strategies for cultural humility in palliative and hospice care physical therapy. Rehabilitat Oncol. 2020;38(1):30–38.

- Rogers R, Eagle TF, Sheetz A, et al. The relationship between childhood obesity, low socioeconomic status, and race/ethnicity: lessons from Massachusetts. Child Obes. 2015;11(6):691–695. [PubMed: 26562758]
- 90. Iceland J. Racial and ethnic inequality in poverty and affluence, 1959–2015. Populat Res Poli Rev. 2019;38(5):615–654.
- 91. Shen MJ, Peterson EB, Costas-Muñiz R, et al. The effects of race and racial concordance on patient-physician communication: a systematic review of the literature. J Rac Ethn Health Dis. 2018;5(1):117–140.
- 92. Melhado L, Bushy A. Exploring uncertainty in advance care planning in African Americans: does low health literacy influence decision making preference at end of life. Am J Hosp Palliat Med. 2011;28(7):495–500.
- 93. Orlovic M, Smith K, Mossialos E. Racial and ethnic differences in end-of-life care in the United States: evidence from the Health and Retirement Study (HRS). SSM Populat Health. 2019;7: 100331.
- 94. Sanders JJ, Robinson MT, Block SD. Factors impacting advance care planning among African Americans: results of a systematic integrated review. J Palliat Med. 2016;19(2):202–227. [PubMed: 26840857]
- Fischer SM, Sauaia A, Min S-J, Kutner J. Advance directive discussions: lost in translation or lost opportunities? J Palliat Med. 2012;15(1):86–92. [PubMed: 22239609]
- 96. Waters CM. Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. Qual Health Res. 2001;11(3):385–398. [PubMed: 11339081]
- Kaplan LM, Sudore RL, Cuervo IA, Bainto D, Olsen P, Kushel M. Barriers and solutions to advance care planning among homeless-experienced older adults. J Palliat Med. 2020; 23(10):1300–1306. [PubMed: 32182155]
- 98. Johnson S, Butow P, Kerridge I, Tattersall M. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. Psychooncology. 2016;25(4):362–386. [PubMed: 26387480]
- 99. AlRuthia Y, Sales I, Almalag H, et al. The relationship between health-related quality of life and trust in primary care physicians among patients with diabetes. Clin Epidemiol. 2020;12:143. [PubMed: 32104098]
- 100. Alpers LM. Distrust and patients in intercultural healthcare: a qualitative interview study. Nurs Eth. 2018;25(3):313–323.
- 101. Berry LL, Parish JT, Janakiraman R, et al. Patients' commitment to their primary physician and why it matters. Ann Fam Med. 2008;6(1):6–13. [PubMed: 18195309]
- 102. Abel WM, Efird JT. The association between trust in health care providers and medication adherence among Black women with hypertension. Front Public Health. 2013;1:66. [PubMed: 24350234]
- 103. Cuffee YL, Hargraves JL, Rosal M, et al. Reported racial discrimination, trust in physicians, and medication adherence among inner-city African Americans with hypertension. Am J Publ Health. 2013;103(11):e55–e62.
- 104. Armstrong K, Putt M, Halbert CH, et al. Prior experiences of racial discrimination and racial differences in health care system distrust. Med Care. 2013;51(2):144. [PubMed: 23222499]
- Benkert R, Peters RM, Clark R, Keves-Foster K. Effects of perceived racism, cultural mistrust and trust in providers on satisfaction with care. J Natl Med Assoc. 2006;98(9):1532–1540. [PubMed: 17019925]
- 106. McLennan VEJ, Boddy JHM, Daly MG, Chenoweth LM. Relinquishing or taking control? Community perspectives on barriers and opportunities in advance care planning. Aust Health Rev. 2015;39(5):528–532. [PubMed: 26027685]
- 107. Sanders JJ, Johnson KS, Cannady K, et al. From barriers to assets: rethinking factors impacting advance care planning for African Americans. Pall Supp Care. 2019;17(3):306–313.
- 108. Greer TM, Brondolo E, Brown P. Systemic racism moderates effects of provider racial biases on adherence to hypertension treatment for African Americans. Health Psychol. 2014; 33(1):35. [PubMed: 23730720]

- 109. Peek ME, Nunez-Smith M, Drum M, Lewis TT. Adapting the everyday discrimination scale to medical settings: reliability and validity testing in a sample of African American patients. Ethnic Dis. 2011;21(4):502.
- 110. Shavers VL, Fagan P, Jones D, et al. The state of research on racial/ethnic discrimination in the receipt of health care. Am J Pub Health. 2012;102(5):953–966. [PubMed: 22494002]
- 111. Agom DA, Neill S, Allen S, et al. Construction of meanings during life-limiting illnesses and its impacts on palliative care: ethnographic study in an African context. Psycho Oncol. 2019; 28(11):2201–2209.
- 112. Dionne-Odom JN, Ejem D, Wells R, et al. How family care-givers of persons with advanced cancer assist with upstream healthcare decision-making: a qualitative study. PLoS One. 2019;14(3):e0212967. [PubMed: 30865681]
- 113. López-Cevallos DF, Harvey SM, Warren JT. Medical mistrust, perceived discrimination, and satisfaction with health care among young-adult rural Latinos. J Rural Health. 2014;30(4): 344– 351. [PubMed: 24576017]
- 114. Mattocks KM, Gibert C, Fiellin D, et al. Mistrust and endorsement of human immunodeficiency virus conspiracy theories among human immunodeficiency virus-infected African American veterans. Mil Med. 2017;182(11):e2073–e2079. [PubMed: 29087885]
- 115. Birkhäuer J, Gaab J, Kossowsky J, et al. Trust in the health care professional and health outcome: a meta-analysis. PLoS One. 2017;12(2):e0170988. [PubMed: 28170443]
- 116. Schoenthaler A, Montague E, Baier Manwell L, Brown R, Schwartz MD, Linzer M. Patient– physician racial/ethnic concordance and blood pressure control: the role of trust and medication adherence. Ethnic Health. 2014;19(5):565–578.
- 117. Haywood C, Lanzkron S, Bediako S, et al. Perceived discrimination, patient trust, and adherence to medical recommendations among persons with sickle cell disease. J Gener Int Med. 2014; 29(12):1657–1662.
- 118. AlRuthia Y, Almalag H, Sales I, et al. The relationship between trust in primary care physicians and medication knowledge among diabetic patients. Res Soc Administrat Phar. 2019; 15(6):656– 661.
- 119. Van Leuven K Advance care planning in healthy older adults. Californ J Health Promot. 2011;9(2):6–14.
- 120. Struck BD, Brown EA, Madison S. Advance care planning in the outpatient geriatric medicine setting. Prim Care. 2017;44(3): 511–518. [PubMed: 28797376]
- 121. de Caprariis PJ, Rucker B, Lyon C. Discussing advance care planning and directives in the general population. South Med J. 2017;110(9):563–568. [PubMed: 28863219]

Table 1.

Characteristics of Sample (n = 542).

	n	%
Gender		
Male	264	48.7
Female	278	51.3
Household income		
Under 150%	200	36.2
150%-399%	196	36.9
400%	146	26.9
Ethnicity/race		
White, non-Hispanic	282	52.0
Black, non-Hispanic	154	28.4
Hispanic	106	19.6
Marital status		
Not married	283	52.2
Married	259	47.8
Trusting health care providers		
No at all/not too much	58	10.8
Some	190	35.5
A lot	287	53.6
		Mean + SD
Age (Years: 18–93)		57.7 + 17.01
Education attainment (1-14)	10.62 + 1.86	
Self-rated health (1-5: excellent-poor)	3.08 ± 1.01	
Number of chronic conditions (1–13)	2.77 ± 1.70	
Communication with provider (0–5)	2.74 + 1.91	
Perceived enabling discrimination		-0.08 ± 1.05
Perceived racial and language related discrimination		-0.06 ± 1.11

Table 2.

Bi-Variate Correlates Between Independent Variables and Level of Preparedness for Worsening of Illness (n = 542).

	Preparedness	for serious illness	
Independent variables	Not prepared, N (%) ($X \pm SD$)	Prepared, N (%) ($X \pm SD$)	Sig.
Gender			0.000
Male	39 (15)	225 (85)	
Female	88 (32)	190 (68)	
Age	(53.8 ± 16.40)	(58.9 ± 17.03)	0.002
Education	(10.3 ± 1.83)	$(10.7\pm.1.86)$	0.034
Marital status			0.020
Not married	79 (28)	204 (72)	
Married	48 (19)	211 (81)	
Household income			0.000
Under 15%	67 (33)	133 (67))	
150%-399%	40 (20)	156 (80)	
400%	20 (14)	126 (86)	
Ethnicity/race			0.009
White, Non-Hispanic	54 (19)	228 (81)	
Black, Non-Hispanic	37 (24)	117 (76)	
Hispanic	36 (34)	70 (66)	
Trusting health care providers			0.000
No at all/not too much	29 (50)	29 (50)	
Some	52 (27)	138 (73)	
A lot	43 (15)	244 (85)	
Self-rated health status	(3.54 ± 0.99)	(2.94 ± 0.97)	0.000
Number of chronic conditions	(2.89 ± 1.56)	(2.72 ± 1.74)	0.297
Communication with provider	(1.73 ± 1.76)	(3.05 ± 1.85)	0.000
Perceived enabling discrimination	(-0.57 ± 1.17)	(0.69 ± 0.96)	0.000
Perceived racial and language related discrimination	(-0.03 ± 1.20)	(-0.07 ± 1.08)	0.726

Table 3.

Multivariate Logistic Regression Estimating the Correlation Between Independent Variables and Serious Illness Preparedness (n = 542).

Independent variable	OR	95% CI	Sig.
Gender			.001
Male	0.412	0.238-0.712	
Female	1.000	-	
Age	0.999	0.983-1.016	.910
Education	1.037	0.892-1.205	.635
Marital status			.371
Not married	1.276	0.749-2.174	
Married	1.000		
Household income			.645
Under 15%	1.000	-	.738
150%-399%	0.880	0.415-1.865	.683
400%	1.164	0.561-2.414	
Ethnicity			
White, non-Hispanic	1.000	-	.527
Black, non-Hispanic	1.498	0.744-3.016	.258
Hispanic	1.282	0.610-2.694	.512
Self-rated health	0.597	0.458-0.778	.000
Number of chronic conditions	1.029	0.877-1.209	.723
Communication with provider	1.451	1.263-1.667	.000
Perceived enabling discrimination	1.652	1.299–2.101	.000
Perceived racial/language discrimination	0.924	0.712-1.199	.553
Trust with health care providers			
Not at all/not too much	1.000	-	.037
Some	0.379	0.176-0.816	.013
A lot	0.919	0.522-1.620	.771
-2 log likelihood		405.787	
Nagelkerke		0.350	