



Self-reported preferences for patient and provider roles in cancer treatment decision-making in the United States

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Abstract

Objective: To describe differences in preferred roles in cancer treatment decision-making and identify associated sociodemographic and health-related factors among adults in the United States.

Methods: We conducted a cross-sectional analysis of nationally representative data from the 2014 Health Information National Trends Survey. Descriptive statistics were calculated and multi-variable logistic regression was conducted to examine associations.

Results: Half (48.3%) of respondents preferred a collaborative role in decision-making under the supposition of a moderate chance of survival; while 53.4% preferred a more active role when the chance of survival was low. Approximately 7%–8% indicated a preference for a passive role in decision-making, for both low and moderate chances of survival. Several predictors of role preference for cancer treatment decision-making emerged, including age, sex, education, race/ethnicity, and having a regular health care provider. At both low and moderate chances of survival, the college educated were less likely to prefer a passive role, whereas Hispanics were two to three times more likely than whites to indicate a preference for a passive role.

Conclusion: Adults' role preference for cancer treatment decision-making may be influenced by sociodemographic and health-related factors. Increased awareness of these factors, paired with enhanced patient–provider communication, may assist health care professionals in providing individualized and high-quality, patient-centered cancer care.

Keywords: Cancer; treatment decision-making; decision-making role preference

Introduction

In the rapidly advancing field of personalized medicine, there has been increased recognition of the pivotal role that patient-centered communication has in maximizing the benefits of current medical breakthroughs in cancer prevention, diagnosis, and treatment [1]. An essential attribute of achieving patient-centered, quality health care is the existence of effective and timely communication between patients and providers [1–3]. This open

and ongoing dialogue between providers, patients, and their families is key to building trust, a mutual understanding of patient health needs and values, and decision-making strategies that encompass approaches, goals, and expectations developed together [4–10]. In response to these and other observations, the United States has witnessed an evolution toward a more patient-centered and collaborative approach to cancer care [11, 12].

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Across the cancer care continuum, where medical decisions have significant implications for patient outcomes, patient involvement is especially important [1, 13]. Current definitions of patient-centered, quality health care not only advocate appropriate patient involvement in decision-making, but also support the need to assess and be responsive to patient preferences [2]. Patient involvement in medical decision-making has been commonly conceptualized as paternalistic (passive; provider controlled), shared (collaborative; patient and provider control), or informed (active; patient controlled with input from provider and other sources) [14–16]. Although patients' preferred role or level of involvement in decision-making can be somewhat variable, research indicates that most patients prefer to have a more shared or active role in their treatment decision-making, as opposed to a passive role [15–17]. Moreover, evidence suggests that when treatment decisions are made in concordance with patients' preferences and values, patients achieve greater satisfaction with care and have less decisional regret [14, 18].

Patient preferences for involvement in cancer treatment decision-making may be influenced by a number of factors, such as cancer type, severity of illness, access to care, and the health care system [1, 17]. In addition to the aforementioned extrinsic influences [1, 15], research also suggests that patients' role preferences are intrinsically moderated by individual patient-level factors, such as sociodemographic characteristics, which tend to be constant over time [15, 19]. Patient age, sex, race/ethnicity, and educational attainment have all been documented as influential in medical decision-making [15, 16]. For example, studies indicate that younger and more educated patients prefer active and collaborative roles, whereas older and less educated patients prefer more passive decision-making roles [20–22]. While sociodemographic characteristics alone do not predict one's decision-making role preference, they may serve as intrinsic moderators that either directly or indirectly influence decision-making via patients' affective and cognitive processes [1].

Much of the literature on role preferences for cancer treatment decision-making focuses on smaller homogeneous groups of cancer patients [16, 23–27], and to our knowledge, very few studies have been conducted among noncancer patients in the general patient population [21, 28, 29]. Although patients'

preferences may change in the trajectory from cancer diagnosis to treatment, research suggests that patients' cancer-related beliefs and medical decision-making preferences in a prediagnostic stage may be similar to those after diagnosis [28, 29]. In the present study, we aim to (1) describe differences in adults' preferred role in cancer treatment decision-making in the United States and (2) identify associated sociodemographic and health-related factors. This research adds to the existing literature by offering insight into a representative sample of the US general population's preferred role in decision-making. Further, given that providers are often unaware of patients' preferred level of involvement in medical decision-making [22, 30–32], these findings may impart an increased awareness of patients' role preferences, which may be useful in improving patient–provider communication and enhancing patient satisfaction with cancer treatment decision-making.

Methods

Study design, data source, and sample

Cross-sectional data from the 2014 Health Information National Trends Survey (HINTS) were analyzed. HINTS is a nationally representative survey that collects data on the use of general health and cancer-related information, and is administered biennially via mail questionnaires by the National Cancer Institute [33]. HINTS 4 Cycle 4 data ($N=3677$) were collected from US adults aged 18 years or older between August and November 2014. The response rate for the survey was 34.4%, comparable to that of previous HINTS iterations and other similar national surveys [34]. Information on the HINTS 4 two-stage stratified sampling design and other methodology details are described elsewhere [35].

For this analysis, we restricted the initial study population to respondents reporting at least one provider visit within the 12 months preceding the date of the survey ($n=2831$). Since the study investigates aspects of the patient–provider relationship, this restriction was made to ensure the sample was representative of adults with an established level of contact with at least one provider. Also, since the survey assesses treatment decision-making roles for a hypothetical cancer diagnosis, we excluded respondents with a current or previous cancer diagnosis, whose timing of diagnosis, gravity of treatment, and chance of survival could not be assessed ($n=448$). These



exclusions were also made to decrease response bias due to cancer patients' actual experiences with treatment. Thus the final sample size was 2383.

Measures

We included data from several survey items to describe respondents' self-reported characteristics. Sociodemographic variables included age, sex, education, race/ethnicity, marital status, employment status, and annual household income. Health-related variables encompassed measures of general health status, cancer history status, chronic disease burden, having a regular provider and health insurance status.

Cancer treatment decision-making role preferences were assessed with use of a two-item, modified version of the Control Preferences Scale (CPS) [21, 36]. Widely used, the CPS is a valid and reliable measure of role preferences in cancer treatment decision-making [16, 21, 36, 37]. Respondents were first asked to envision and indicate a preference for how much decision-making control they would like to have in treatment after receipt of a cancer diagnosis with a *moderate chance of survival and several treatment options* (i.e., *Suppose you have been diagnosed with cancer with a moderate chance of survival and several treatment options, what role would you prefer to take in deciding your cancer treatment?*). In separate survey item, respondents were then asked to indicate their decision-making role preference for an analogous hypothetical scenario with a *low chance of survival*. For analysis purposes, the original five-level CPS responses were collapsed into three previously established [21, 36] categories of role preferences. The first two responses (*prefer to make decision with little or no input from doctor and prefer to make the decision after seriously considering my doctor's opinion*) were categorized as *active*; the third response (*prefer that my doctor and I share the responsibility for the decision together*) was categorized as *collaborative*; and the final two responses (*prefer my doctor to make the decision after seriously considering my opinion and prefer to leave all decisions about my treatment to my doctor*) were categorized as *passive*.

Statistical analysis

All statistical analyses were conducted with SAS version 9.4 (SAS Institute, Cary, NC, USA). Multiple imputation [38, 39]

was used via IVEware to impute values of missing data for key variables through multivariable sequential regression [40, 41]. Estimation of the imputation model was improved by inclusion of study-related variables and supplementary HINTS variables (e.g., home ownership, English-speaking proficiency, birth country) known to have a strong association with the primary study outcomes and covariates [38]. The highest rates of missingness were among income level (9.25%) and race/ethnicity (8.48%); all other variables had missingness levels of less than 5.00%.

Descriptive statistics were calculated for all study variables. Multivariable logistic regression was used to estimate associations between patient-level characteristics (i.e., sociodemographic, health related) and cancer treatment decision-making role preference. Estimates for regression analyses are presented as adjusted odds ratios (OR) with 95% confidence intervals (CIs). All multivariable regression models were adjusted for key sociodemographic and health-related factors.

HINTS-supplied survey weights and SAS survey procedures integrating the jackknife variance estimation technique were incorporated to account for the HINTS sampling design and to calculate nationally representative estimates. All survey weights were previously calibrated for age, sex, educational attainment, marital status, race, ethnicity, and census region on the basis of the current US Census data [35]. HINTS-supplied survey weights were also calibrated for the variable measuring insurance status on the basis of the current National Health Information Survey data. Analyses from each multiply imputed dataset were then combined with use of the MIANALYZE procedure to generate final parameter and variance estimates [38, 42, 43]. Sensitivity analyses revealed no differences in the distribution of study variables on comparison of the observed versus imputed data. A type I error rate of 5% was assumed for all analyses and CIs. This study received an exempt status by the Baylor College of Medicine Institutional Review Board.

Results

Patient characteristics

Survey respondents' sociodemographic and health-related characteristics are provided in Table 1. Most respondents were younger than 50 years of age, female, college educated, non-Hispanic



Table 1. Sociodemographic and health-related characteristics of the study population (n=2831)

Characteristic	Unweighted number (weighted %) ^a
Overall	2831 (100.0%)
Age (years)	
18–34	344 (27.4%)
35–49	586 (26.5%)
50–64	1015 (26.9%)
≥65	885 (19.2%)
Sex	
Male	1055 (44.4%)
Female	1776 (55.6%)
Education	
Less than high school	223 (10.1%)
High school graduate	500 (16.8%)
College or higher	2108 (73.0%)
Race/ethnicity	
Non-Hispanic white	1679 (67.2%)
Hispanic	406 (12.5%)
Non-Hispanic black	461 (11.3%)
Non-Hispanic other ^b	285 (9.1%)
Marital status	
Married or living as married	1497 (58.3%)
Not married	1334 (41.7%)
Employment status	
Employed	1410 (58.9%)
Unemployed	1421 (41.1%)
Annual household income (US dollars)	
<35,000	1001 (29.8%)
35,000–74,999	922 (32.8%)
≥75,000	908 (37.4%)
General health	
Excellent or very good	1238 (47.3%)
Good	1093 (39.8%)
Fair or poor	500 (12.9%)
History of cancer	
No	2383 (90.4%)
Yes	448 (9.6%)
Chronic disease burden ^c	
0 diseases	806 (39.6%)
1 disease	793 (27.0%)
≥2 diseases	1231 (33.5%)
Regular provider	
No	638 (25.9%)
Yes	2193 (74.1%)

Table 1 (continued)

Characteristic	Unweighted number (weighted %) ^a
Health care coverage	
Uninsured	259 (9.1%)
Insured	2572 (90.9%)

^aAnalyses incorporated survey weights to calculate nationally representative estimates. Due to multiple implementation of missing data, the sum of all groups may not add up to the total number of participants and group percentages may not add to exactly 100%.

^bIncludes non-Hispanic individuals reporting American Indian or Alaska Native, Asian, Native Hawaiian/other Pacific Islander, or multiple races as their race.

^cRefers to a diagnosis of one or more of the following conditions: diabetes, hypertension, heart conditions (e.g., heart attack, angina), chronic lung disease, asthma, arthritis, depression, or anxiety disorder.

white, married, and employed and reported an annual household income of \$35,000 or greater. Most respondents had health insurance, had a regular health care provider, perceived themselves as being in excellent/very good or good health, and had one or more chronic diseases and no history of cancer.

Role preference in cancer treatment decision-making

Among all noncancer respondents in the study (n=2383), when presented with a hypothetical cancer diagnosis, nearly half (48.3%) indicated a preference for a collaborative decision-making role if given a moderate chance of survival; 53.4% indicated a preference for a more active decision-making role if the chance of survival was low. Regardless of the hypothesized severity of the cancer diagnosis, the proportion of respondents reporting a preference for a passive decision-making role was small, and did not differ significantly for different chances of survival (7.9% for moderate vs. 7.3% for low) (Fig. 1).

When stratified by level of education and race/ethnicity, we observed notable differences in the preferred role in cancer treatment decision-making (Fig. 2). Among those with a high school education or less, notwithstanding race/ethnicity, between 44.0% and 57.0% preferred a collaborative role if the chance of survival was moderate. Likewise, if given a moderate chance of survival, most college-educated

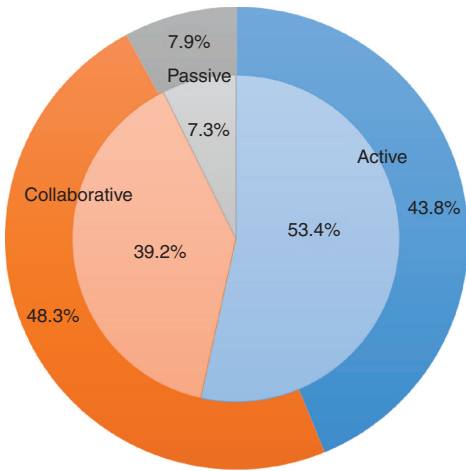


Fig. 1. Role preference in treatment decision-making among noncancer respondents given a hypothetical cancer diagnosis with a moderate or low chance of survival. The *outer ring* corresponds to a hypothetical scenario that involves a moderate chance of survival, and the *inner ring* corresponds to a hypothetical scenario that involves a low chance of survival. Due to multiple implementation of missing data, the sum of group percentages may not add to exactly 100%.

respondents preferred a similar collaborative decision-making role, with the exception of Hispanics, who indicated a preference for a more active decision-making role rather than a collaborative decision-making role (46.8% vs.

40.9%). In the case of a low chance of survival, the percentage of respondents within each racial/ethnic group preferring a collaborative decision-making role decreased with increased education, with the exception of the proportion of non-Hispanic blacks, which increased from 40.5% to 45.4%. Still, irrespective of race/ethnicity, level of education, or chance of survival, the least preferred decision-making role within each subgroup was passive – with the proportions ranging from 4.0% to 20.0%. However, among respondents with a high school education or less, the percentages of non-Hispanic blacks and Hispanics indicating a preference for a passive decision-making role was greater than that of their non-Hispanic white counterparts for both moderate and low chances of survival. In contrast, among the college educated, the proportion of non-Hispanic blacks preferring a passive role for a moderate chance of survival mirrored that of the non-Hispanic whites (4.5% vs. 4.5% respectively), whereas the proportion of college-educated Hispanics and non-Hispanic others indicating a preference for a passive role was comparable to that their own racial/ethnic counterparts with less education. We also observed a 5.5% increase in passive decision-making for Hispanics and a halving for non-Hispanic others when the chance of survival was low and on moving from high to low education levels within their own racial/ethnic group.

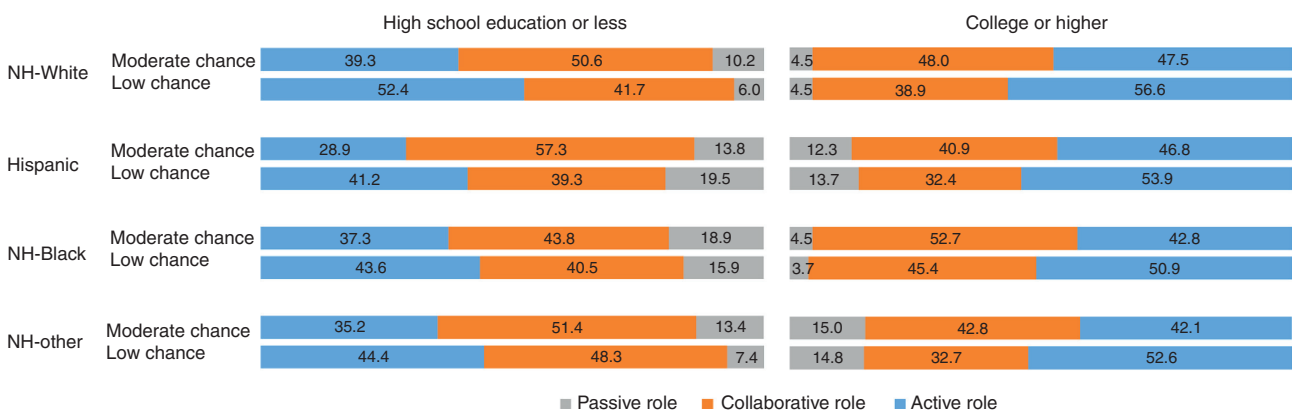


Fig. 2. Role preference in treatment decision-making among noncancer respondents given a hypothetical cancer diagnosis with a moderate or low chance of survival, stratified by level of education and race/ethnicity. Each of the 16 *horizontal bars* represents a specific stratum based on level of education, race/ethnicity, and the hypothetical chance of survival. The horizontal axis represents the proportion of respondents within a given stratum who preferred passive, collaborative, and active roles, respectively, in treatment decision-making. NH, non-Hispanic. Due to multiple implementation of missing data, the sum of group proportions may not add to exactly 100%.



Rates and predictors of passive role preference in cancer treatment decision-making

Despite representing only a small proportion of respondents, the highest percentages of a passive decision-making role if respondents were given a moderate chance of survival were observed among those with less than a high school education (17.6%), non-Hispanic others (14.6%), Hispanics (12.9%), the uninsured (11.4%), and older adults aged 65 years or older (11.0%) (Table 2). When instead faced with a low chance of survival, the population subgroups with the highest preferences for passive roles were similar: Hispanics (16.1%), the less educated (15.9%), non-Hispanic others (12.9%), and those without a regular provider (11.0%) (Table 3).

Several patient- and health-related characteristics were identified as predictors of a passive decision-making role preference in cancer treatment when respondents were faced with both moderate (Table 2) and low (Table 3) chances of survival. After adjustment for potential confounders, respondents' age, education level, race/ethnicity, and the presence of a regular provider were observed to be associated with a passive decision-making role preference. Among the college educated (OR 0.36, 95% CI 0.17–0.75) and those aged 35–49 years (OR 0.43, 95% CI 0.20–0.91), there was a decreased odds of a passive decision-making role preference if they were given a moderate chance of survival. Similarly, when the chance of survival was indicated as low, a decreased odds of a passive decision-making role preference was also observed among the college educated and those without a regular provider compared with the less educated and those with no regular provider respectively. In comparison with non-Hispanic whites, Hispanics were two to three times more likely to indicate a preference for a passive decision-making role for both moderate and low chances of survival.

Among the near 70.0% of respondents who had one or more chronic conditions (e.g., diabetes, hypertension, heart condition), both female and college-educated respondents were 44.0% and 57.0% less likely to prefer a passive decision-making role when there was a moderate chance of survival compared with males and the less educated respectively (Table 2). There were no statistically significant predictors of a passive decision-making role preference for a moderate chance of survival observed among those without a chronic condition

($n=745$). However, in the same group of respondents without chronic conditions, when they were faced a low chance of survival, there was an increased likelihood of a passive decision-making role preference among both Hispanics (OR 3.63, 95% CI 1.37–9.64) and non-Hispanic others (OR 5.08, 95% CI 1.36–19.02) compared with non-Hispanic whites, while there was a decreased odds of passive decision-making among the college educated (OR 0.21, 95% CI 0.05–0.85) compared with those with less than a high school education (Table 3).

Discussion

Cancer treatment decisions can be challenging and often reflect an individual's evaluation of the potential benefits and harms. More specifically, preferences for cancer treatment represent a subjective assessment of individuals weighing the potential treatment effects on their health-related quality of life and chance of survival [24, 44]. In this investigation, we examined nationally representative data to provide a comprehensive description of differences in adults' cancer treatment decision-making role preferences and the associated sociodemographic and health-related factors. Consistent with prior research [16, 17, 24, 27, 45–49], most respondents in this study preferred a collaborative role in cancer treatment decision-making with their providers. Significant variations in role preferences, however, were observed across respondents' sociodemographic and health-related characteristics. Marked differences in cancer treatment decision-making role preferences were also found when they were characterized according to the chance of survival (i.e., low or moderate). Together, these results yield unique insights into adults' decision-making role preference based on the supposition of a cancer diagnosis and further support the importance of patient-centeredness in cancer care.

In general, our findings indicate that adults prefer to take more active roles in deciding their cancer treatment, particularly when their perceived chance of survival is low compared with moderate (53.4% vs. 43.8% respectively). However, irrespective of the chance of survival, we found that respondents' cancer treatment decision-making role preferences differed by sociodemographic characteristics. In particular, racial/ethnic minorities in this study were more likely to indicate a preference for a passive role in treatment decision-making compared with non-Hispanic whites.



Table 2. Crude rates and adjusted odds of a passive role preference in treatment decision-making among respondents given a hypothetical cancer diagnosis with a moderate chance of survival

Characteristics	Overall ^a (n=2383)		Presence of chronic condition ^b			
			Yes (n=1638)		No (n=745)	
	Passive role preference (%) ^c	Adjusted OR ^d	Passive role preference (%) ^c	Adjusted OR ^d	Passive role preference (%) ^c	Adjusted OR ^d
Age (years)						
18–34	9.1	Reference	8.9	Reference	9.2	Reference
35–49	4.4	0.43 (0.20–0.91)	3.3	0.35 (0.08–1.51)	5.7	0.46 (0.14–1.53)
50–64	8.1	0.86 (0.47–1.55)	8.3	1.03 (0.24–4.37)	7.8	0.65 (0.22–1.88)
≥65	11.0	1.07 (0.51–2.23)	10.7	1.29 (0.32–5.15)	13.4	0.95 (0.25–3.60)
Sex						
Male	8.5	Reference	9.3	Reference	7.4	Reference
Female	7.4	0.75 (0.50–1.12)	6.5	0.56 (0.36–0.89)	8.6	0.94 (0.37–2.42)
Education						
Less than high school	17.6	Reference	15.3	Reference	27.9	Reference
High school graduate	9.3	0.55 (0.27–1.13)	10.2	0.77 (0.37–1.60)	7.9	0.21 (0.03–1.47)
College or higher	6.3	0.36 (0.17–0.75)	5.6	0.43 (0.19–0.97)	7.0	0.19 (0.02–1.79)
Race/ethnicity						
Non-Hispanic white	5.8	Reference	5.8	Reference	5.8	Reference
Hispanic	12.9	2.06 (1.00–4.24)	13.0	2.15 (0.92–5.07)	12.6	1.65 (0.43–6.35)
Non-Hispanic black	8.9	1.55 (0.85–2.82)	10.3	1.79 (0.80–4.00)	7.0	1.11 (0.26–4.73)
Non-Hispanic other ^e	14.6	2.47 (0.96–6.39)	11.4	1.83 (0.37–8.97)	18.5	3.35 (0.97–11.59)
Marital status						
Married or living as married	6.9	Reference	5.8	Reference	8.5	Reference
Not married	9.1	1.11 (0.74–1.66)	10.4	1.64 (0.92–2.94)	7.4	0.72 (0.28–1.85)
Employment status						
Employed	6.5	Reference	6.2	Reference	6.8	Reference
Unemployed	10.0	1.28 (0.78–2.09)	9.4	1.13 (0.66–1.93)	11.5	1.68 (0.66–4.30)
Annual household income (US dollars)						
<35,000	9.6	Reference	10.2	Reference	8.2	Reference
35,000–74,999	8.0	1.25 (0.72–2.15)	7.1	1.02 (0.47–2.24)	9.5	1.64 (0.49–5.52)
≥75,000	6.3	1.31 (0.69–2.49)	5.5	1.08 (0.47–2.50)	7.0	1.77 (0.45–7.00)
Regular provider						
No	10.2	Reference	10.9	Reference	9.7	Reference
Yes	7.0	0.72 (0.45–1.15)	6.9	0.67 (0.34–1.34)	7.2	0.79 (0.32–1.91)
Health care coverage						
Uninsured	11.4	Reference	9.1	Reference	13.8	Reference
Insured	7.5	0.75 (0.43–1.30)	7.6	1.01 (0.46–2.22)	7.3	0.50 (0.17–1.47)

All estimates were calculated with use of survey weights. Bold indicates statistical significance at $P < 0.05$.

NA, not applicable; OR, odds ratio.

^aRepresents all noncancer respondents in the study, excluding those reporting a history of cancer ($n=448$).

^bRefers to a diagnosis of one or more of the following conditions: diabetes, hypertension, heart conditions (e.g., heart attack, angina), chronic



Table 2 (continued)

lung disease, asthma, arthritis, depression, or anxiety disorder.

^cPercentage of respondents in each subgroup indicating a preference for a passive role in cancer treatment decision-making.

^dEstimated from a model with passive role preference as the outcome and all variables listed in the table as independent variables. The 95% confidence interval is given in parentheses.

^eIncludes individuals reporting non-Hispanic American Indian or Alaska Native, Asian, non-Hispanic Native Hawaiian/other Pacific Islander, or multiple races as their race/ethnicity.

Table 3. Crude rates and adjusted odds of a passive role preference in treatment decision-making among respondents given a hypothetical cancer diagnosis with a low chance of survival

Characteristics	Overall ^a (n=2383)		Presence of chronic condition ^b			
	Passive role preference (%) ^c	Adjusted OR ^d	Yes (n=1638)		No (n=745)	
			Passive role preference (%) ^c	Adjusted OR ^d	Passive role preference (%) ^c	Adjusted OR ^d
Age (years)						
18–34	9.4	Reference	10.3	Reference	8.9	Reference
35–49	6.6	0.68 (0.34–1.37)	7.5	0.82 (0.25–2.67)	5.5	0.55 (0.18–1.67)
50–64	5.3	0.58 (0.29–1.16)	4.7	0.56 (0.18–1.73)	6.7	0.69 (0.24–1.99)
≥65	8.0	0.79 (0.37–1.70)	8.3	0.98 (0.37–2.62)	5.5	0.35 (0.07–1.76)
Sex						
Male	8.1	Reference	8.4	Reference	7.6	Reference
Female	6.7	0.72 (0.44–1.19)	6.5	0.63 (0.34–1.19)	7.0	0.81 (0.32–2.01)
Education						
Less than high school	15.9	Reference	14.3	Reference	22.9	Reference
High school graduate	6.9	0.51 (0.25–1.03)	7.4	0.68 (0.29–1.56)	6.0	0.25 (0.05–1.19)
College or higher	6.3	0.41 (0.18–0.93)	6.0	0.55 (0.20–1.53)	6.7	0.21 (0.05–0.85)
Race/ethnicity						
Non-Hispanic white	4.8	Reference	5.4	Reference	4.1	Reference
Hispanic	16.1	3.06 (1.73–5.43)	16.6	2.58 (1.27–5.20)	15.3	3.63 (1.37–9.64)
Non-Hispanic black	7.5	1.51 (0.83–2.74)	8.6	1.57 (0.74–3.31)	5.9	1.47 (0.36–6.07)
Non-Hispanic other ^e	12.9	2.54 (0.92–6.97)	7.2	1.11 (0.14–8.56)	19.8	5.08 (1.36–19.02)
Marital status						
Married or living as married	6.0	Reference	5.4	Reference	7.0	Reference
Not married	9.0	1.22 (0.67–2.22)	10.1	1.55 (0.74–3.24)	7.6	0.94 (0.32–2.79)
Employment status						
Employed	6.5	Reference	6.3	Reference	6.6	Reference
Unemployed	8.7	1.21 (0.64–2.31)	8.5	1.16 (0.56–2.38)	9.1	1.39 (0.46–4.23)
Annual household income (US dollars)						
<35,000	9.3	Reference	9.9	Reference	7.9	Reference
35,000–74,999	6.7	0.96 (0.53–1.74)	6.3	0.86 (0.35–2.10)	7.3	1.18 (0.33–4.17)
≥75,000	6.2	1.17 (0.54–2.54)	5.4	0.99 (0.34–2.86)	6.9	1.54 (0.31–7.72)



Table 3 (continued)

Characteristics	Overall ^a (n=2383)		Presence of chronic condition ^b			
	Passive role preference (%) ^c	Adjusted OR ^d	Yes (n=1638)		No (n=745)	
Passive role preference (%) ^c			Adjusted OR ^d	Passive role preference (%) ^c	Adjusted OR ^d	
Regular provider						
No	11.0	Reference	13.4	Reference	8.9	Reference
Yes	6.0	0.60 (0.36–0.99)	5.7	0.48 (0.25–0.93)	6.4	0.78 (0.31–1.95)
Health care coverage						
Uninsured	8.1	Reference	10.0	Reference	6.0	Reference
Insured	7.2	1.15 (0.61–2.16)	7.1	0.94 (0.32–2.72)	7.4	1.51 (0.49–4.67)

All estimates were calculated using survey weights. Bold indicates statistical significance at $P < 0.05$.

NA, not applicable; OR, odds ratio.

^aRepresents all non-cancer respondents in the study, excluding those reporting a history of cancer ($n=448$).

^bRefers to a diagnosis of one or more of the following conditions: diabetes, hypertension, heart conditions (e.g., heart attack, angina), chronic lung disease, asthma, arthritis, depression, or anxiety disorder.

^cPercentage of respondents in each subgroup indicating a preference for a passive role in cancer treatment decision-making.

^dEstimated from a model with passive role preference as the outcome and all variables listed in the table as independent variables. The 95% confidence interval is given in parentheses.

^eIncludes individuals reporting non-Hispanic American Indian or Alaska Native, Asian, non-Hispanic Native Hawaiian/other Pacific Islander, or multiple races as their race/ethnicity.

These findings are in support of other studies that report that up to one-third of their Hispanic and non-Hispanic black patient populations reported experiencing a provider-based or passive role in cancer treatment decisions [50–55]. Although our study does not allow insight into the reasons for racial/ethnic differences in cancer treatment decision-making preferences, the literature suggests that such reasons are multifaceted and may be influenced by patients' cultural values, level of acculturation, family involvement, language barriers, spirituality, fatalism beliefs, health locus of control, socioeconomic status, and insurance coverage [1, 50–54]. While these factors offer conjectures for the observed differences in treatment decision-making preferences among racial/ethnic minorities and non-Hispanic whites, more research is needed to provide additional empirical evidence and theoretical explanations for minorities' decision-making role preferences. Further, given that a large share of the disparity in racial/ethnic minority patients' cancer survival

rates has been attributed to poorer quality of care, deficient patient–provider relationships, and dissatisfaction with cancer treatment plans [53, 56], incorporation of cultural and patient preferences into cancer treatment decision-making may improve patient–provider communication and yield optimal health outcomes [57].

Similar to other research findings, respondents with higher education levels reported an increased preference for having a more active role in decision-making [16, 58]. These results were expected given that the highly educated are typically more informed about their health conditions and more engaged in all aspects of their health care, including medical decision-making [59]. Higher educational attainment appeared to have a modifying effect on the influence of race/ethnicity, except among Hispanics. For example, non-college-educated non-Hispanic blacks and Hispanics had higher rates of a passive role preference than their non-Hispanic white counterparts. However, among college-educated



non-Hispanic blacks, the preference for a passive role was comparable to that of college-educated non-Hispanic whites, whereas the higher rate of a passive role preference among college-educated Hispanics was similar to that of Hispanics with lower levels of education. As alluded to earlier, the observed role preferences, particularly among Hispanics, could potentially be attributed to cultural factors or a greater disposition to avoiding questioning figures of authority (e.g., health care provider) [60]. Altogether, the aforementioned findings suggest the importance of delivering training and practice opportunities for providers that are not only structured to enhance the delivery of culturally appropriate care that but also aim to improve communication skills for eliciting patient preferences.

On consideration of the potential impact of respondents having at least one preexisting chronic disease, there were a few notable observations. Among respondents with chronic diseases, we observed a lower odds of a passive role preference among females and the college educated under the supposition of a moderate chance of survival. Similarly, decreased odds were also observed among respondents with chronic disease with a regular provider when the chance of survival was low. These results are in line with the general convention that female sex, higher education level, and a history of previous interactions with the health care system have been found to be associated with preferences for a more active role in health care decision-making [61, 62]. Conversely, research also suggests that those with several health issues, who are older, and who are less educated are more likely to have a more passive role in their medical decision-making [16, 25, 26, 63–65] because of limited medical knowledge, increased trust in the provider, or lower self-efficacy to have a more active role in decision-making [66, 67]. Future research should include more longitudinal studies that allow an in-depth examination of treatment decision-making and the extent to which role preferences change over the trajectory of the cancer and other chronic illnesses.

Limitations

There are limitations to this study that deserve consideration. First, the study data were derived from a cross-sectional survey and rely on self-reports. Therefore our results are subject

to selection and recall biases, and no causal inferences should be made. Second, HINTS has a low response rate; however, current methodological research suggests that bias due to low response rates may be minimal, considering the widespread comparability of national survey estimates with different response rates (e.g., low vs. high) [68–70]. Also, in comparison with previous research using complete case analyses, our use of multiple imputation for missing data may have aided in producing results that were less biased and more precise [38, 39]. Third, we were unable to account for respondents' self-efficacy in medical decision-making or level of trust in the provider to make such decisions, both of which have been noted as influential decision-making preferences among cancer patients and survivors [71].

Last, while there is research that suggests that prediagnostic and postdiagnostic cancer treatment decision-making role preferences have similarities [28, 29], our findings were based on the premise of a hypothetical cancer diagnosis, and thus should be interpreted cautiously. These results should not be viewed as estimates of role preferences among cancer patients. Instead, this study fills a literature gap by offering estimates of role preferences that have a high level of generalizability to the general US patient population. At minimum, our findings provide an initial purview of adults' cancer treatment decision-making role preferences and may assist in imparting an increased awareness of their variations by sociodemographic and health-related characteristics.

Conclusion

The findings from this nationally representative sample of the adult US population provide additional evidence that cancer treatment decision-making role preferences differ by individuals' sociodemographic and health characteristics. While these intrinsic characteristics are not modifiable during a single clinical encounter, our findings highlight the importance of providers' assessment, awareness, and discussion of patient preferences for their participation in their own care. For enhanced quality of cancer treatment decision-making and patient-centered care, these findings also identify opportunities to improve existing strategies and decision-making support tools so they are more responsive to the needs and preferences of the patient population.



Conflict of interest

The authors declare no conflict of interest.

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