



# HHS Public Access

Author manuscript

*J Pain Symptom Manage.* Author manuscript; available in PMC 2024 September 22.

Published in final edited form as:

*J Pain Symptom Manage.* 2023 March ; 65(3): e233–e236. doi:10.1016/j.jpainsymman.2022.11.015.

## US Immigrant Utilization and Perceptions of Palliative Care

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To the Editor:

U.S. immigrants are heterogeneous with diverse racial, cultural, and socioeconomic differences. Immigrants are far more likely than U.S.-born individuals to experience adverse social determinants of health and far less likely to access primary and secondary prevention, screening, and early interventions in primary care, leading to poorer health outcomes and higher rates of preventable illnesses.<sup>1,2</sup>

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Author Contributions

HLA, HKO, and KGS, made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data. All authors were involved in drafting the article or revising it critically for important intellectual content. All provided final approval of the manuscript and agree to be accountable for all aspects of the work. “\*” HKO and KGS made equal contributions to the study and manuscript.

Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.jpainsymman.2022.11.015](https://doi.org/10.1016/j.jpainsymman.2022.11.015).

The other authors have no conflicts to report.

In addition to facing onerous obstacles to accessing primary care, U.S. immigrants also face disparities in palliative and end-of-life (EOL) care. Previous studies have shown that race, ethnicity, and lower socioeconomic status are associated with lower satisfaction and perceptions of healthcare,<sup>3</sup> and this impact may translate to U.S. immigrants' perceptions of palliative care services. Although Barwise and colleagues showed that immigrant status was not associated with knowledge of palliative care,<sup>4</sup> studies that describe U.S. immigrants' perceptions of palliative care integration are limited.

Thus, to expand the existing literature on the drivers of disparities in palliative services among U.S. immigrants, we used data from a nationally representative population-based survey to characterize immigrants' perceptions of palliative care, which we hypothesized to be less favorable than US-born individuals.

## Methods

We examined data from the Health Information National Trends Survey (HINTS) 5 Cycle 2 (H5C2), conducted from January through May 2018 by the National Cancer Institute (NCI) via mailed questionnaires. HINTS 5 is a nationally representative survey in English administered to non-institutionalized civilian adults (aged ≥ 18 years) living in the U.S. to assess knowledge of, attitudes toward, and use of health information. The HINTS methodology details are available online.<sup>5</sup> H5C2 respondents provided written informed consent prior to completing the survey. We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.<sup>6</sup>

Our outcomes of interest were knowledge or awareness of palliative care, and respondents' perceptions of palliative care and corresponding survey items are outlined in e-supplemental Table 1.

Informed by prior work on sociodemographic and clinical factors that contribute to disparities in palliative care and EOL care utilization,<sup>7</sup> we accounted for the following covariates in our multivariable analyses: age (18–34, 35–49, 50–64, and 65+ years old), sex (male, female), race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and other), education level (less than college and some college or above), annual household income (less than \$20k, \$20k to less than 35k, \$35k to less than 50k, \$50k to less than 75k, \$75k or above), geographical residence (rural vs. urban), access to a regular healthcare provider (yes, no), previous diagnosis of cancer, and self-rated health status (poor/fair, good, very good/excellent).

We completed all statistical analyses using the “svy” command in the Stata 17.0 statistical software (StataCorp LP, College Station, TX). Final person weights and jack-knife replicate weights provided within the H5C2 dataset were used to estimate national-level values and standard errors of estimates, respectively.<sup>6</sup> Descriptive statistics were conducted by nativity status. Both unweighted frequencies and weighted percentages were also calculated. Differences in general knowledge, goals, and perceptions of palliative care between immigrant (foreign-born) and non-immigrant (native-born) individuals were assessed using chi-squared [ $\chi^2$ ] tests. We also performed binary logistic regression analyses controlling for

sociodemographic variables to examine the association between nativity/immigrant status and overall palliative care knowledge. To evaluate the relationships between immigrant status, goals, and perceptions of palliative care, we completed a multinomial logistic regression analysis that similarly adjusted for sociodemographic variables of age, gender, race, household income, access to a healthcare provider, education, geographical residence, self-rated health status, and previous diagnosis of cancer. Statistical significance was set at  $P < 0.05$ .

## Results

Of 3504 surveys, 3430 had complete data on immigration status (missing data 74/3504=2.1%) and were included in our analysis. Of the 3430 respondents, 499 (weighted %, 14.6) identified as foreign-born or immigrants of the U.S. Approximately half (50.3%) of the total weighted sample were aged between 18 and 49 years, 51.2% were female, 64.8% were non-Hispanic white, 60.1% had college or higher education, and 65.5% reported having access to a regular healthcare provider. Immigrants were more likely to be younger than age 65 years (12.5% vs. 20.5%;  $P=0.004$ ), live in urban areas (95.7% vs. 84.7%;  $P < 0.001$ ), report not having a regular healthcare provider (42.7% vs. 32.9%;  $P=0.015$ ) and have achieved lower than college-level education (48.2% vs. 38.3%;  $P=0.005$ ). [e-supplemental Table-1]

Notably, most (71.3%) of our cohort had never heard of palliative care. Overall, immigrants were more likely than US-born participants to 1) report that they have never heard of palliative care (77.4% vs. 70.0%;  $P=0.007$ ), 2) somewhat/strongly agree that accepting palliative care means giving up (22.3% vs. 14.2%;  $P=0.001$ ), and 3) somewhat/strongly agree that when they think of palliative care, they think of death (44.6% vs. 41.7%;  $P=0.017$ ). Additionally, they were less likely to somewhat/strongly agree that one of the goals of palliative care is to offer emotional and social support (79.5% vs. 93.8%;  $P=0.003$ ). [e-supplemental Table-2]

The results from the multinomial and binary logistic regression models evaluating the relationships between immigrant status, knowledge, goals, and perceptions of palliative care are in e-supplemental Table-1. After adjusting for sociodemographic and health-related variables, knowledge of palliative care was independent of immigrant status (OR 0.81 95% C.I 0.53, 1.23;  $P=0.321$ ). Similarly, in adjusted analysis, palliative care goals and perceptions remained largely independent of immigrant status. However, immigrants were still less likely to somewhat/strongly disagree (aOR 0.30 95% CI 0.10, 0.89;  $P=0.030$ ) that accepting palliative care means giving up and somewhat/strongly disagree (aOR 0.19 95% CI 0.04, 0.92;  $P=0.039$ ) that thinking of palliative care is associated with thoughts of death.

## Discussion

To our knowledge, this is the first study to examine perceptions of palliative care, specifically in the U.S. immigrant population. We found that immigrants were less likely than U.S.-born adults to somewhat/strongly disagree that accepting palliative care means giving up and to somewhat/strongly disagree that palliative care is associated with thoughts

of death. Our findings support our hypothesis that perceptions about palliative care differ between U.S. immigrants and U.S.-born adults even after controlling for different sociodemographic and clinical factors.

Immigrants were less likely to have a college education and have a lower household income than U.S.-born adults. Immigrants were also more likely to be younger and with lower rates of access to a regular healthcare compared to non-immigrants. Consistent with prior work,<sup>8</sup> these findings highlight the potential negative impact of socioeconomic factors on palliative care utilization and underscores the need to study the influence of sociodemographic and structural factors on U.S. immigrants' perceptions of palliative care and how they contribute to our observed differences between immigrants and U.S.-born individuals.

Palliative care has been associated with improved clinical outcomes (e.g., distress, physical symptoms, and mortality). We highlight negative perceptions (e.g., palliative care is for the terminally ill) about palliative care may be pervasive among U.S. immigrants. Gaps in knowledge about palliative care and its benefits are common outside the U.S., and these gaps may persist even after immigration to the U.S.<sup>9</sup> Globally, palliative care has been offered primarily to patients imminently approaching the end-of-life (EOL). Since most of the groundbreaking work on early palliative care integration has happened in the U.S.,<sup>10</sup> differences in perceptions about palliative care among U.S. immigrants compared to U.S.-born individuals may result from the global disparities in palliative care integration into mainstream healthcare. Hence, research that further examines the differences in palliative care uptake among diverse immigrants will inform the development of tailored educational resources for immigrants regarding palliative and EOL care.

Study limitations include cross-sectional nature of data, residual confounding due to unmeasured factors (country of origin, culture, religion, language, and acculturation), potential for recall and selection bias, and non-generalizability of our results to the entire U.S. immigrant population.

Table 1

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Disclosures and Acknowledgments

Time for study and manuscript preparation was supported by the National Cancer Institute through grant K08CA251654 to Dr. Amonoo.

Dr. Abrahm receives royalties from UptoDate and the Johns Hopkins University Press.

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**Table 1**  
Multinomial Logistic Regression Showing Odds of Perceptions of Palliative Care by Nativity Status

Outcomes Perception and Goals of Palliative care	Immigrant Versus Non-Immigrants		Immigrant Versus Non-Immigrants	
	OR (95% C.I)	P-value	aOR (95% C.I)	P-value
Accepting palliative care means giving up				
Reference (= Don't Know)	0.00	-	0.00	-
Somewhat or strongly disagree	0.23 (0.08, 0.61)	<b>0.004</b>	0.31 (0.10, 0.90)	<b>0.032</b>
Somewhat or strongly agree	0.46 (0.15, 1.43)	0.173	0.46 (0.15, 1.40)	0.164
If you accept palliative care, you must stop other treatments				
Reference (= Don't Know)	0.00	-	0.00	-
Somewhat or strongly disagree	0.65 (0.28, 1.49)	0.301	0.55 (0.18, 1.64)	0.277
Somewhat or strongly agree	1.03 (0.36, 2.89)	0.958	0.86 (0.24, 3.01)	0.807
Palliative care is the same as hospice care				
Reference (= Don't Know)	0.00	-	0.00	-
Somewhat or strongly disagree	0.59 (0.27, 1.30)	0.187	0.66 (0.23, 1.93)	0.438
Somewhat or strongly agree	0.80 (0.36, 1.80)	0.595	0.93 (0.28, 3.10)	0.901
When I think of 'palliative care, I automatically think of death				
Reference (= Don't Know)	-	-	0.00	-
Somewhat or strongly disagree	0.25 (0.08, 0.79)	<b>0.019</b>	0.19 (0.04, 0.93)	<b>0.040</b>
Somewhat or strongly agree	0.35 (0.10, 1.17)	0.088	0.39 (0.08, 2.00)	0.256
It is a doctor's obligation to inform all patients with cancer about the option of palliative care				
Reference (= Don't Know)	0.00	-	0.00	-
Somewhat or strongly disagree	0.63 (0.18, 2.18)	0.449	0.44 (0.10, 1.98)	0.279
Somewhat or strongly agree	0.42 (0.16, 1.13)	0.083	0.68 (0.23, 2.00)	0.477
Outcomes Goals of Palliative care are to . . .				
Help friends and family cope with a patient's illness				
Reference (= Don't Know)	0.00	-	0.00	-
Somewhat or strongly disagree	0.61 (0.09, 4.31)	0.623	0.65 (0.09, 4.98)	0.670
Somewhat or strongly agree	0.35 (0.07, 1.57)	0.166	0.37 (0.08, 1.63)	0.182
Offer social and emotional support				

Outcomes Perception and Goals of Palliative care	Immigrant Versus Non-Immigrants		Immigrant Versus Non-Immigrants	
	OR (95% C.I)	P-value	aOR (95% C.I)	P-value
Reference (= Don't Know)	0.00	-	0.00	-
Somewhat or strongly disagree	1.58 (0.29, 8.67)	0.586	0.70 (0.11, 4.30)	0.694
Somewhat or strongly agree	0.31 (0.07, 1.43)	0.132	0.39 (0.08, 1.89)	0.238
Manage pain and other physical symptoms				
Reference (= Don't Know)	-	-	0.00	-
Somewhat or strongly disagree	0.28 (0.02, 3.25)	0.298	0.10 (0.00, 3.10)	0.185
Somewhat or strongly agree	0.33 (0.07, 1.57)	0.159	0.23 (0.05, 1.16)	0.074
Give patients more time at the end of their life				
Reference (= Don't Know)	0.00	-	0.00	-
Somewhat or strongly disagree	0.63 (0.16, 2.46)	0.494	0.65 (0.11, 3.69)	0.619
Somewhat or strongly agree	0.81 (0.24, 2.77)	0.733	0.82 (0.15, 4.32)	0.812
OR: Odds ratio; aOR: Adjusted Odds Ratio. Models were adjusted for age, gender, race, household income, access to a health provider, education, geographical residence, self-rated health status and previous diagnosis of cancer				
Binary Logistic regression for the association between nativity status and knowledge of palliative care				
Outcomes	Immigrant versus Non-Immigrants		Immigrant versus Non-Immigrants	
Knowledge of palliative care	OR (95% C.I)	P-value	aOR (95% C.I)	P-value
Reference (=Never heard of it)	0.00	-	0.00	-
A little/very well	0.68 (0.52, 0.90)	<b>0.007</b>	0.82 (0.54, 1.25)	0.364
OR: Odds ratio; aOR: Adjusted Odds ratio. Models were adjusted for age, gender, race, household income, access to a health provider, education, geographical residence, self-rated health status and previous diagnosis of cancer				

Bolded values indicate *P*-values that were statistically significant at an alpha = 0.05 significance level.