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Advance Care Planning among Older Homeless-Experienced Adults: Results from the HOPE-HOME Study

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Abstract

Older homeless-experienced adults have low engagement in advance care planning (ACP) despite high morbidity and mortality. We conducted a cross-sectional analysis of a cohort of 350 homeless-experienced adults aged 50 in Oakland, California. We assessed the prevalence of potential surrogate decision makers, ACP contemplation, discussions, and ACP documentation (i.e., surrogate designation, advance directives). We used multivariable logistic regression to examine factors associated with ACP discussions and documentation. The median age of the cohort was 59 years (range 52–82), 75.2% were male, and 82.1% Black. Over half (61.0%) reported a potential surrogate. One-fifth (21.5%) had discussed ACP and 19.0% reported ACP documentation. In multivariable models, having 1–5 confidants vs. none (AOR 5.8; 95% CI 1.7–20.0) 3 chronic conditions vs none (AOR 2.3; CI 0.9–5.6) and a recent primary care visit (AOR 2.1; CI 1.0–4.4) were associated with higher odds of ACP discussions, and each additional five years of homelessness (AOR 0.7; CI 0.5 – 0.9) with lower odds. Having 1–5 confidants (AOR 5.0; CI 1.4–17.5), being Black (AOR 5.5; CI 1.5–19.5) and having adequate vs. limited literacy

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Conflict of Interest

The authors have no conflicts of interest.

Sponsor's Role

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Author Contributions

MK: Obtained funding, developed the study concept and design, and supervised data collection and sampling.

All authors: Contributed to the study design, analysis and interpretation of data, interpretation, drafting of manuscript, and approved the final manuscript.

(AOR 7.0;CI 1.5–32.4) were associated with higher odds of ACP documentation, and illicit drug use (AOR 0.3;CI 0.1–0.9) with lower odds. Although the majority of older homeless-experienced adults have a potential surrogate, few discussed or documented their ACP wishes; the odds of both increased with larger social networks. Future interventions must be tailored to individuals with limited social networks and address the instability of homelessness, culture and health literacy, as well as the constraints of safety-net healthcare settings.

Keywords

Advance care planning; homelessness

INTRODUCTION

In the United States, 2.5 million people experience homelessness each year;¹ the homeless population is aging, with a growing proportion of adults experiencing homelessness at ages 50 and over.² Homeless adults experience an early onset of geriatric conditions and premature mortality.^{3,4} Thus, experts recommend healthcare providers begin standard screening for geriatric syndromes by age 50 among people with a current or recent experience of homelessness (homeless-experienced).⁴ Advance care planning (ACP) is important for older homeless-experienced adults given their high illness burden and frequent contact with the health system. In a context of social isolation, homeless-experienced adults faced with decisional incapacity are more likely to die in an intensive care unit, a setting that they may not have chosen.⁵ The low prevalence of established primary care for these individuals complicates efforts to have their wishes documented and honored.^{6,7}

Effective ACP could help ensure people experiencing homelessness receive end-of-life care that is consistent with their preferences. Advance care planning (ACP) is defined as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care” with the goal of providing care consistent with individual values and preferences.⁸ While people experiencing homelessness share concerns expressed by members of the general population, including having unfulfilled wishes and inadequate pain relief, they report additional concerns (i.e. fearing an anonymous, un-memorialized death; having inappropriate treatment of their body; or not having a proper burial).^{9,10} There is emerging evidence that homeless-experienced adults are interested in discussing end-of-life care and are able to complete advance directives, but little is known about homeless-experienced adults’ engagement in the full range of ACP behaviors, including discussions.¹¹

The process of ACP includes a full range of behaviors including choosing a surrogate, discussing medical wishes with surrogates and clinicians, and documenting wishes in advance directive documents.¹² To inform future interventions, we examined the prevalence of a full range of ACP engagement including the prevalence of potential surrogates, contemplation of ACP, discussions with surrogates and clinicians about ACP wishes, and formal legal ACP documentation among a community-based sample of diverse, homeless-

experienced older adults. Using multivariable models, we analyzed factors associated with ACP discussions and formal ACP documentation.

METHODS

Recruitment and Sample

From July 2013 to June 2014, we enrolled a population-based sample of 350 homeless older adults from overnight shelters, homeless encampments, meal programs, and a recycling center in Oakland, California. We have described our recruitment process previously.¹³ Briefly, participants were eligible if they were English-speaking, aged 50 or older, and currently homeless or homeless-experienced based on the Homeless Emergency Assistance and Rapid Transition (HEARTH) Act definition.¹⁴ After determining eligibility, staff used a teach-back method to obtain informed consent.

Trained study staff administered a structured interview and clinical assessments at baseline and at 6-month intervals. Participants remained eligible for the study irrespective of their housing status at follow-up interviews. Starting at the 18-month follow-up interview, we surveyed participants about ACP, using a modified version of the validated ACP Engagement questionnaire, which asks five yes/no questions to assess engagement in the process of ACP.¹⁵ If participants missed the 18-month interview, we asked these questions at their next attended interview.

To maximize follow-up, at enrollment, we asked participants to report information about close social contacts. We asked participants to check in with study staff every month. If participants missed two or more check-ins, staff called their contacts and visited places they frequented. Participants received \$25 gift cards for the screening and enrollment interview, \$5 for each check-in, and \$15 for each follow-up interview. The study was approved by the University of California, San Francisco Institutional Review Board.

Advance Care Planning

Based on pilot testing, we made minor language changes to the ACP Engagement Survey to increase understanding in older homeless populations.¹⁵ This questionnaire was designed to assess several ACP behaviors and behavior change processes including, (1) a potential surrogate: "Is there someone you trust to make medical decisions for you in case you are too ill to make your own decisions?" (2) ACP contemplation: "Have you ever thought about what kinds of treatment you would want in case you were seriously ill?" (3) ACP discussions: "Have you discussed your wishes with anybody?" (No one; healthcare worker (physician, nurse practitioner, physician assistant, or nurse); social worker; family member; friend; other) (4) formal surrogate designation: "Have you made formal arrangements to name a person you trust to make medical decisions for you in case you are too ill to make your own decisions?" (5) advance directive completion: "Have you signed official papers about your wishes for medical care in case you are unable to speak for yourself because you are too ill?" To reduce participant burden, we skipped questions about formal surrogate or advance directive documentation if participants reported they did not have a potential surrogate or had not thought about ACP. Because ACP is a process we analyzed two outcomes: ACP

discussions, defined as ever having discussed ACP wishes with anyone, and formal ACP documentation, defined as either having formally designated a surrogate or completed an advance directive.

Independent Variables

Demographic Characteristics—Participants self-reported their age, gender, and race/ethnicity, and education. To assess health literacy, we used a validated one-item health literacy screen, “How confident are you filling out medical forms by yourself?” with response options of “not at all” to “extremely” on a 5-point Likert scale; we categorized “somewhat” to “extremely” as adequate health literacy.¹⁶ Participants self-reported their marital status. To assess social support, we asked participants to quantify the number of close confidants, defined as anyone in whom the participant could confide. We categorized these using validated categories (0, 1–5, or 6).¹⁷ At each interview, we determined whether participants still met HEARTH criteria for homelessness, categorizing participants’ current living situation as homeless, housed, or in an institution. At the baseline interview, we calculated the total number of years participants spent homeless since age 18. We added six months of homelessness for each six-month time period at follow-up that participants remained homeless to calculate years of lifetime adult homelessness. Because participants were either currently homeless, or recently had been, and in keeping with the transient nature of homelessness, we describe the sample as homeless-experienced.¹³

Substance Use and Mental Health—Using a shortened timeframe of the previous 6 months to correspond to study time intervals, we administered the World Health Organization’s (WHO) Alcohol Use Disorders Identification Test (AUDIT) (8 = moderate or greater risk alcohol use). To assess illicit drug use, we administered the WHO’s Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST) using a lengthened timeframe of the previous 6 months for the following substances: cocaine, opioids, and amphetamines (4 for any illicit drug = moderate or greater risk of illicit drug use). To assess the prevalence of depressive symptoms, we administered the Center for Epidemiologic Studies Depression Scale (CES-D) (16 = depressive symptoms).¹⁸

Health Status—Participants reported their health status, (dichotomized as fair or poor versus good, very good, or excellent).¹³ We asked participants to report if a healthcare provider had ever told them they had any of the following conditions: coronary artery disease or myocardial infarction; chronic obstructive pulmonary disease (COPD), emphysema, chronic bronchitis, or asthma; cirrhosis or liver disease; congestive heart failure; stroke or transient ischemic attack; arthritis; diabetes; kidney disease; cancer (excluding non-melanoma skin cancer); or HIV/AIDS. We categorized participants as having 0, 1, 2, or 3 or more of these conditions.¹³

Participants reported if they had difficulty performing activities of daily living (ADLs)¹⁹ and instrumental activities of daily living (IADLs).²⁰ We defined ADL and IADL impairment as difficulty performing at least 1 ADL or 1 IADL, respectively. To assess cognitive functioning, we administered the Modified Mini Mental State Examination (3MS); scores

1.5 standard deviations below an age- and education-adjusted reference mean (below the 7th percentile) indicated cognitive impairment.²¹

Healthcare Utilization—We asked participants if they had a regular healthcare location, other than the emergency department, defined as a place they usually went when sick or in need of health advice. We asked about healthcare utilization in the prior six months, asking whether participants had visited their regular healthcare location, the emergency department, or had been hospitalized (categorized as any versus none for each type of utilization).

Analysis—For time-constant, independent variables (gender, race, education) we analyzed responses from the baseline interview. For dependent ACP variables, we analyzed responses from the interview in which we administered the ACP module. We chose independent variables based on pre-existing hypotheses regarding factors associated with ACP, and described patient characteristics and ACP engagement with percentages and means. We used logistic regression to determine bivariable associations between patient characteristics and ACP discussions and documentation. Using conservative estimates, we entered independent variables with bivariable associations with ACP of Type 3 $p < 0.20$ into multivariate models. We then performed backward elimination until only variables with Type 3 $p < 0.05$ remained. Nine percent of the interviews had missing data for the AUDIT instrument. We used iterative chained equations (ICE) to impute values for each missing question. After creating 10 imputed datasets, we recalculated AUDIT scores using the imputed values. We derived the odds ratio for alcohol use problems presented in Table 3 using multiple imputation. We conducted all statistical analyses using SAS version 9.4 (Cary, NC).

RESULTS

Sample Characteristics

Of 350 participants who completed a baseline interview, 12 died and 18 dropped out before their 18-month follow-up. Of the 320 remaining participants, 274 (85.6%) completed the ACP Engagement questionnaire. The median age was 59 (range 52–82), a majority were men (75.2%), Black (82.1%), one-quarter had completed less than a high school education, 31.4% had limited health literacy and the median years homeless was 4 (range < 1 to 43) (Table 1). One-tenth reported being married/partnered, while 67.0% reported having 1–5 confidants and 9.9% reported having 6 confidants. At the time of the ACP interview, 42.3% met criteria for homelessness and 52.9% were housed; approximately one-fifth met criteria for moderate-to-severe risk of alcohol use and illicit drug use. The prevalence of depressive symptoms, fair-to-poor health, and ADL impairment were each approximately 50%. Approximately three-quarters (70.2%) reported having a regular healthcare location; 58.8% had visited their (non-emergency department) regular place for healthcare, 29.3% had an emergency department visit, and 18.3% had been hospitalized in the previous 6 months.

Advance Care Planning Engagement

The majority of the sample (61.0%) reported having a potential surrogate and 35.8% had contemplated ACP (Table 2). Over 21% of participants had discussed ACP wishes with someone: 15.7% with a family member, 3.3% with a friend, 4.0% with a healthcare provider,

and 1.1% with a social worker. One-fifth (19.0%) reported formal ACP documentation; 18.0% designated a surrogate and 8.8% completed an advance directive.

Factors Associated with ACP Discussions

After adjusting for variables associated with ACP discussions, we found that each additional five years of lifetime homelessness was associated with a 30% lower odds of having discussed wishes (AOR 0.7, 95% CI 0.5 – 0.9). Participants with 1–5 confidants (AOR 5.8, 95% CI 1.7–20.0) or 6 or more confidantes (compared to no confidants) (AOR 5.1, 95% CI 1.4–23.2) and having had a primary care clinic visit in the prior six months (AOR 2.1, 95% CI 1.0–4.4) were more likely to report having ACP discussions. Compared to those with no chronic conditions, those with 1–2 chronic conditions had a lower odds of having held discussions (AOR 0.5, 95% CI 0.2–1.3) and those with 3 or more chronic conditions had a higher odds (AOR 2.3, 95% CI 0.9–5.6). (Table 3)

Factors Associated with Formal ACP Documentation

Participants who were Black (versus non-Black) (AOR 5.5, 95% CI 1.5–19.5), had adequate health literacy (versus limited) (AOR 7.0, 95% CI 1.5–32.4) and had 1–5 confidants versus no confidants (AOR 5.0, 95% CI 1.4–17.5) were more likely to report formal ACP documentation. Participants with moderate-to-severe risk of illicit drug use were less likely to report ACP documentation than those with low risk (AOR 0.3, 95% CI 0.1–0.9).

DISCUSSION

In a population-based cohort of older homeless-experienced adults with a median age of 59 years and significant co-morbidity, we found a low prevalence of engagement in a full range of ACP behaviors, including contemplation, discussions, and formal ACP documentation. Over half of our study population reported a potential surrogate, a proportion lower than that observed in similar safety-net populations, but still substantial.²² However, less than one-fifth had formally appointed a surrogate. One-third had thought about their ACP wishes but less than one-tenth completed an advance directive, a level of ACP engagement significantly lower than the general or safety-net populations.^{22–24}

Although having a regular primary care visit in the past 6 months was associated with more ACP discussions, clinicians may be missing important opportunities to discuss ACP. While 70% of the cohort reported a regular place for healthcare, and over half had visited their primary care provider in the prior six months, fewer than five percent had discussed ACP with providers. Increasing years of homeless were associated with decreased odds of having ACP discussions, but not documentation. This might be due to prolonged homelessness increasing social isolation, thus limiting opportunities for discussions with friends or family members. Prolonged homelessness could either be a cause, or consequence, of less trusting and durable engagement with confidants or the healthcare system, impacting their ability to have ACP discussions. Even if healthcare providers introduce ACP, people experiencing homelessness may choose to not engage in these discussions due to competing priorities (e.g., acute medical issues and obtaining food and shelter) or a lack of trust.¹ In addition to well-known clinician barriers to ACP, (e.g., time constraints and lack of resources),⁷

healthcare providers may also have misconceptions about people experiencing homelessness, such as believing that few have potential surrogates or are not interested in discussing ACP.

Despite what may be assumed about social isolation among homeless populations, the majority of study participants reported potential surrogate decision-makers, and social support was strongly associated with ACP discussions and documentation. Social support and having a potential surrogate can increase willingness to complete advance directives among low-income older adults.²⁵ Those with more social support may have more experiences with advanced illness with loved ones; such experiences can increase motivation for, understanding of, and engagement with ACP.¹²

Black participants were more likely to complete formal ACP documentation than those from other racial and ethnic groups. Black Americans experience a three to four times increased risk of homelessness compared to white Americans.²⁶ This is thought to be due to structural vulnerabilities (i.e., less family wealth, less access to rental housing, and decreased employment and educational opportunities). Thus, Black Americans who experience homelessness may be less likely to have, or have lower severity of, other factors that are associated with the risk of homelessness, such as substance use and mental health problems

Homeless-experienced adults, especially those with substance use disorders are at increased risk of sudden death and mortality,³ heightening the need for ACP. However, substance use was associated with a lack of ACP documentation. Homeless-experienced adults with substance use problems have frequent contact with the healthcare system, but are more likely to receive episodic, rather than longitudinal healthcare, creating a barrier to ACP documentation.¹

There is a need for tailored interventions to help older homeless-experienced adults engage in a full range of ACP behaviors, including discussions and documentation. Prior research has found a low prevalence of advance directive completion in sheltered homeless populations.^{11,27} Research studies of ACP interventions have shown to increase completion of advance directives in populations recruited from homeless shelters or service agencies, but these studies have not focused on a full range of ACP activities.²⁸ Our research suggests clinicians may start the conversation by asking about potential surrogate decision makers, as social support was strongly associated with both discussions and documentation. Because literacy plays an important role, clinicians can use evidenced-based, easy-to-read ACP tools that have been shown to be beneficial in vulnerable populations, such as advance directives targeted to the 5th-grade reading level that include pictures to explain the text. These legal forms have recently been updated for all 50 states in English and Spanish (www.prepareforyourcare.org).^{29,30} Because one-on-one counseling may increase advance directive completion among homeless populations, the use of peer counselors should be explored.²⁸

Our study had several limitations. This was a cross-sectional study from a homeless cohort in Oakland, California where more residents identify as Black than the general population. Our results may not be generalizable to other populations of homeless-experienced older

adults. Oakland has a robust safety-net health care system; homeless-experienced adults in other regions may have less access to and use of primary care. We relied on self-report for ACP documentation, rather than chart review, which may have resulted in social desirability bias and over-reporting. Our study included participants who had recently regained housing. As we did not find an association between current housing status and ACP engagement, we do not believe this biased our results. Differential loss to follow-up may have increased our estimate of social support, as we used participants' social contacts to locate participants. As 12 participants died prior to the 18-month interview, our results may have been biased towards those with fewer health problems, and with lower likelihoods of completing ACP.

In conclusion, although the majority of homeless-experienced adults in our study have a potential surrogate, few had ACP discussions or completed ACP documentation, despite high morbidity and mortality. Homelessness is increasing in the U.S., particularly among older adults. Older homeless-experienced adults are at increased risk of dying without having their wishes honored, heightening the urgency to find effective ways to engage this population in a range of ACP behaviors that meets their needs.²⁸ Future interventions need to be tailored to individuals with limited social networks and address the concerns related to homelessness, cultural diversity, limited health literacy, lack of access to healthcare, mistrust in the healthcare system, as well as the constraints of safety-net healthcare settings.

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Table 1

Participant Characteristics

Variable	Total, n (%) n=274
Demographic characteristics	
Age, median (range)	59.0 (52 to 82)
Men	206 (75.2)
Race/Ethnicity	
Black	225 (82.1)
White	23 (8.4)
Hispanic/Latino	13 (4.7)
Mixed	3 (1.1)
Other	10 (3.7)
Education: Less than high school	66 (24.1)
Health Literacy: Limited	83 (31.4)
Housing status at time of interview	
Homeless	116 (42.3)
Housed	145 (52.9)
Institutionalized	13 (4.7)
Years homeless, median (range)	4.0 (<1 to 43)
Marital Status	
Married or living with partner	27 (9.9)
In relationship, not living together	11 (4.0)
Never Married	106 (38.8)
Separated or Divorced	98 (35.9)
Widowed	31 (11.4)
Number of confidants	
None	63 (23.1)
1–5	183 (67.0)
6 or more	27 (9.9)
Substance use	
Moderate or greater risk alcohol use	61 (22.3)
Moderate or greater risk illicit drug use	60 (21.2)
Depressive Symptomatology	141 (51.5)
Self-rated health status	
Fair-to-poor health	140 (51.3)
Number of chronic conditions	
None	52 (19.0)
1	88 (32.1)
2	68 (24.8)

Variable	Total, n (%) n=274
3 or more	66 (24.1)
Functional status and cognition	
ADL impairment	104 (38.1)
IADL impairment	135 (49.5)
Cognitive impairment	60 (21.9)
Healthcare utilization	
Regular healthcare location	191 (70.2)
Visit to primary care clinic, past 6 months	160 (58.8)
Emergency department visit, past 6 months	80 (29.3)
Hospitalized, past 6 months	50 (18.3)

Table 2

Advance Care Planning (ACP) Engagement

ACP Engagement	Total, n (%) n=274
Have potential surrogate	167 (61.0)
Contemplated ACP	98 (35.8)
Discussed wishes for medical care	59 (21.5)
With family member	43 (15.7)
With healthcare worker	11 (4.0)
With friend	9 (3.3)
With social worker	3 (1.1)
Formal ACP documentation	52 (19.0)
Formally designated a surrogate	49 (18.0)
Completed an advance directive	24 (8.8)

Table 3

Characteristics Associated with ACP Discussions and Documentation

	ACP Discussions		ACP Documentation	
	Unadjusted Odds Ratio	Adjusted Odds Ratio	Unadjusted Odds Ratio	Adjusted Odds Ratio
Men	Ref	-	Ref	-
Women	1.3 (0.7 – 2.5)	-	1.5 (0.7 – 2.9)	-
Age, 5 year increase	1.2 (0.9 – 1.6)	-	1.3 (1.0 – 1.7)	-
Homeless	Ref	-	Ref	-
Housed	1.9 (1.0–3.6) ^a	-	1.9 (1.0–3.7)	-
Institutionalized	1.6 (0.4–6.5)	-	1.1 (0.2–5.6)	-
Years homeless, 5 year increase	0.7 (0.5 – 0.9) ^a	0.7 (0.5 – 0.9) ^c	0.8 (0.7 – 1.1)	-
Non-Black	Ref	-	Ref	Ref
Black	2.2 (0.9 – 5.5)	-	4.3 (1.3 – 14.5) ^a	5.5 (1.5 – 19.5) ^b
Less than high school	Ref	-	-	-
High school/GED or higher	1.3 (0.6 – 2.7)	-	2.0 (0.9 – 4.4)	-
Limited health literacy	Ref	-	Ref	Ref
Adequate health literacy	1.6 (0.8 – 3.3)	-	5.3 (1.2 – 22.8) ^a	7.0 (1.5 – 32.4) ^a
Not living with a spouse/partner	Ref	-	Ref	-
Married or living with partner	1.1 (0.4 – 2.8)	-	2.4 (1.0 – 5.7)	-
No confidants	Ref	Ref	Ref	Ref
1 to 5 confidants	5.1 (1.7 – 15.0) ^c	5.8 (1.7 – 20.0) ^b	5.8 (1.6 – 20.2)	5.0 (1.4 – 17.5) ^a
6 or more confidants	6.2 (1.7 – 23.3) ^c	5.1 (1.4– 23.2) ^a	5.1 (1.1 – 23.5) ^a	3.0 (0.6 – 14.1)
Low-risk alcohol use	Ref	-	Ref	-
Moderate-to-severe risk alcohol use	0.6 (0.3 – 1.1)	-	1.1 (0.5 – 2.2)	-
Low-risk illicit drug use	Ref	-	Ref	Ref
Moderate-to-severe risk illicit drug use	0.7 (0.3 – 1.5)	-	0.32 (0.1 – 0.8) ^a	0.3 (0.1 – 0.9) ^a
CES-D Score<16	Ref	-	Ref	-
CES-D Score 16+	1.3 (0.7–2.3)	-	1.0 (0.6 – 1.9)	-
Good-to-excellent self-rated health status	Ref	-	Ref	-
Fair-to-poor health self-rated health status	1.4 (0.7 – 2.5)	-	1.4 (0.7 – 2.6)	-
No chronic conditions	Ref	-	Ref	-
1–2 chronic conditions	0.6 (0.3 – 1.4)	0.5 (0.2 – 1.3)	0.4 (0.2 – 0.9) ^a	0.5 (0.2 – 1.1)
3 chronic conditions	2.3 (1.0 – 5.3)	2.3 (0.9 – 5.6)	1.0 (0.4 – 2.3)	1.4 (0.6 – 3.5)
ADL impairment	1.9 (1.0–3.4) ^a	-	1.0 (0.5–1.9)	-
IADL impairment	0.9 (0.5–1.5)	-	0.8 (0.5–1.6)	-
Cognitive impairment	1.0 (0.5–2.0)	-	0.9 (0.5–2.0)	-

	ACP Discussions		ACP Documentation	
	Unadjusted Odds Ratio	Adjusted Odds Ratio	Unadjusted Odds Ratio	Adjusted Odds Ratio
No regular health care location	Ref	-	Ref	-
Regular health care location	2.4 (1.2 – 5.2) ^a		1.7 (0.8 – 3.6)	-
No visit to regular healthcare location	Ref	Ref	Ref	-
Visit to regular healthcare location	2.5 (1.3 – 4.7) ^b	2.1 (1.0 – 4.4) ^c	1.7 (0.9 – 3.4)	-
No emergency department visit	Ref	-	Ref	-
Emergency department visit	0.8 (0.4 – 1.5)	-	0.7 (0.3 – 1.4)	-
Not hospitalized	Ref	Ref	Ref	-
Hospitalized	1.7 (0.9 – 3.5)	-	1.1 (0.5 – 2.3)	-

^a p<.05;

^b p<.01;

^c p<.001