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# Advance Care Planning for Older Homeless-Experienced Adults: Results from the Health Outcomes of People Experiencing Homelessness in Older Middle Age Study

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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 and older in Oakland, California. We assessed the prevalence of potential surrogate decision-makers, ACP contemplation, discussions, and ACP documentation (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 (range 52–82), 75.2% were male, and 82.1% were black. Sixty-one percent reported a potential surrogate, 21.5% had discussed ACP, and 19.0% reported ACP documentation. In multivariable models, having 1 to 5 confidants versus none (adjusted odds ratio (aOR)=5.8, 95% confidence interval (CI)=1.7–20.0), 3 or more chronic conditions versus none (aOR=2.3, 95% CI=0.9–5.6), and a recent primary care visit (aOR=2.1, 95% CI=1.0–4.4) were associated with higher odds of ACP discussions and each additional 5 years of homelessness (aOR=0.7, 95% CI=0.5–0.9) with lower odds. Having 1 to 5 confidants (aOR=5.0, 95% CI=1.4–17.5), being black (aOR=5.5, 95% CI=1.5–19.5), and having adequate versus limited literacy (aOR=7.0, 95% CI=1.5–32.4) were associated with higher odds of ACP documentation and illicit drug use (aOR=0.3, 95% CI=0.1–0.9) with lower odds. Although the majority of older homeless-experienced adults have a potential surrogate, few have

discussed or documented their ACP wishes; the odds of both were greater with larger social networks. Future interventions must be customized for individuals with limited social networks and address the instability of homelessness, health literacy, and the constraints of safety-net healthcare settings. *J Am Geriatr Soc* 66:1068–1074, 2018.

**Key words:** advance care planning; homelessness

In the United States, 2.5 million people experience homelessness each year;<sup>1</sup> the homeless population is aging, with a growing proportion of adults experiencing homelessness at age 50 and older.<sup>2</sup> Homeless adults experience early onset of geriatric conditions and premature mortality.<sup>3,4</sup> Thus, experts recommend that healthcare providers begin standard screening for geriatric syndromes by age 50 in people with a current or recent experience of homelessness (homeless experienced).<sup>4</sup> Advance care planning (ACP) is important given their high illness burden and frequent use of acute healthcare services. 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.<sup>5</sup> The low prevalence of established primary care for these individuals complicates efforts to have their wishes documented and honored.<sup>6,7</sup>

Effective ACP could help ensure that people experiencing homelessness receive end-of-life care that is consistent with their preferences. 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.<sup>8</sup> Although people experiencing homelessness share concerns of members of the general population,

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including having unfulfilled wishes and inadequate pain relief, they have additional concerns (e.g., fearing an anonymous, unmemorialized death; having inappropriate treatment of their body; not having a proper burial).<sup>9,10</sup> 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 their engagement in the full range of ACP behaviors, including discussions.<sup>11</sup>

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 directives.<sup>12</sup> To inform future interventions, we examined the prevalence of a full range of ACP engagement, including the availability of potential surrogates, contemplation of ACP, discussions with surrogates and clinicians about ACP wishes, and formal legal ACP documentation in 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.<sup>13</sup> 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.<sup>14</sup> 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 Survey, which asks 5 yes-or-no questions to assess engagement in the process of ACP.<sup>15</sup> 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 2 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 University of California, San Francisco institutional review board approved the study.

### Advance Care Planning

Based on pilot testing, we made minor language changes to the ACP Engagement Survey to increase readability for

older homeless populations.<sup>15</sup> This questionnaire was designed to assess several ACP behaviors and behavior change processes, including 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?”), ACP contemplation (“Have you ever thought about what kinds of treatment you would want in case you were seriously ill?”), ACP discussions (“Have you discussed your wishes with anybody?” (no one, healthcare worker (physician, nurse practitioner, physician assistant, nurse), social worker, family member, friend, other), 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?”), 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 2 outcomes: ACP discussions, defined as ever having discussed ACP wishes with anyone, and formal ACP documentation, defined as having formally designated a surrogate or completed an advance directive.

### Independent Variables

#### *Demographic Characteristics*

Participants self-reported their age, sex, race and ethnicity, and education. To assess health literacy, we used a validated 1-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, and categorized somewhat to extremely as adequate health literacy.<sup>16</sup> 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, and categorized these using validated categories (0, 1–5,  $\geq 6$ ).<sup>17</sup> 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 had spent homeless since age 18. We added 6 months of homelessness for each 6-month time period at follow-up that participants remained homeless to calculate years of lifetime adult homelessness. Because participants were currently homeless or recently had been, and in keeping with the transient nature of homelessness, we describe the sample as homeless-experienced.<sup>13</sup>

### 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 (WHO) Alcohol Use Disorders Identification Test (AUDIT) ( $\geq 8$  = moderate to

severe risk alcohol use). To assess illicit drug use, we administered the WHO Alcohol, Smoking, and Substance Involvement Screening Test using a lengthened timeframe of the previous 6 months for cocaine, opioids, and amphetamines ( $\geq 4$  for any illicit drug = moderate to severe risk illicit drug use). To assess the prevalence of depressive symptoms, we administered the Center for Epidemiologic Studies Depression Scale ( $\geq 16$  = depressive symptoms).<sup>18</sup>

### Health Status

Participants reported their health status (dichotomized as fair or poor vs good, very good, or excellent).<sup>13</sup> We asked participants to report whether a healthcare provider had ever told them they had coronary artery disease or myocardial infarction; chronic obstructive pulmonary disease, emphysema, chronic bronchitis, or asthma; cirrhosis or liver disease; congestive heart failure; stroke or transient ischemic attack; arthritis; diabetes; kidney disease; cancer (excluding nonmelanoma skin cancer); or human immunodeficiency virus or acquired immunodeficiency syndrome. We categorized participants as having 0, 1, 2, or 3 or more of these conditions.<sup>13</sup>

Participants reported whether they had difficulty performing activities of daily living (ADLs)<sup>19</sup> and instrumental activities of daily living (IADLs).<sup>20</sup> 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 7<sup>th</sup> percentile) indicated cognitive impairment.<sup>21</sup>

### Healthcare Use

We asked participants whether they had a regular healthcare location, other than the emergency department, defined as the place they usually went when sick or in need of health advice. We asked about healthcare use in the prior 6 months, asking whether participants had visited their regular healthcare location or the emergency department or had been hospitalized (categorized as any vs none for each type of use).

### Analysis

For time-constant, independent variables (sex, 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 preexisting hypotheses regarding factors associated with ACP and described participant characteristics and ACP engagement using percentages and means. We used logistic regression to determine bivariable associations between participant characteristics and ACP discussions and documentation. Using conservative estimates, we entered independent variables with bivariable associations with ACP of Type 3  $p < .20$  into multivariate models. We then performed backward elimination until only variables with Type 3  $p < .05$

remained. Nine percent of the interviews had missing data for the AUDIT instrument. We used iterative chained equations 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 (OR) for alcohol use problems presented in Table 3 using multiple imputation. We conducted all statistical analyses using SAS version 9.4 (SAS Institute, Inc., 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 Survey. The median age was 59 (range 52–82), 75.2% were male, 82.1% were black, 24.1% had completed less than a high school education, 31.4% had limited health literacy, and median years of homelessness was 4 (range < 1–43) (Table 1). One-tenth reported being married or partnered; 67.0% reported having 1 to 5 confidants, and 9.9% reported having 6 or more 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 alcohol and illicit drug use. The prevalence of depressive symptoms, fair to poor health, and ADL impairment were each approximately 50%. Seventy percent reported having a regular healthcare location; 58.8% had visited their (non-emergency department) regular place for health care, 29.3% had had an emergency department visit, and 18.3% had been hospitalized in the previous 6 months.

### ACP Engagement

Sixty-one percent of participants reported having a potential surrogate, and 35.8% had contemplated ACP (Table 2). More than one-fifth 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. Nineteen percent reported formal ACP documentation; 18.0% had designated a surrogate, and 8.8% had completed an advance directive.

### Factors Associated with ACP Discussions

After adjusting for variables associated with ACP discussions, each additional 5 years of lifetime homelessness was associated with 30% lower odds of having discussed wishes (adjusted OR (aOR)=0.7, 95% CI=0.5–0.9). Participants with 1 to 5 confidants (aOR=5.8, 95% CI=1.7–20.0) or 6 or more confidantes (vs 0 confidants) (aOR=5.1, 95% CI=1.4–23.2) and having had a primary care clinic visit in the prior 6 months (aOR=2.1, 95% CI=1.0–4.4) were more likely to report having ACP discussions. Those with 1 or 2 chronic conditions had lower odds than those with no chronic conditions of having held discussions (aOR=0.5, 95% CI=0.2–1.3) and those with

**Table 1. Participant Characteristics (N = 274)**

Characteristic	Value
<b>Demographic</b>	
Age, median (range)	59.0 (52–82)
Male, n (%)	206 (75.2)
Race and ethnicity, n (%)	
Black	225 (82.1)
White	23 (8.4)
Hispanic	13 (4.7)
Mixed	3 (1.1)
Other	10 (3.7)
Education < high school, n (%)	66 (24.1)
Health literacy, limited, n (%)	83 (31.4)
Housing status at time of interview, n (%)	
Homeless	116 (42.3)
Housed	145 (52.9)
Institutionalized	13 (4.7)
Years homeless, median (range)	4.0 (<1–43)
Marital status, n (%)	
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, n (%)	
0	63 (23.1)
1–5	183 (67.0)
≥6	27 (9.9)
Substance use, n (%)	
Moderate to severe risk alcohol use	61 (22.3)
Moderate to severe risk illicit drug use	60 (21.2)
Depressive symptomatology, n (%)	141 (51.5)
Self-rated health status, fair to poor, n (%)	140 (51.3)
Number of chronic conditions, n (%)	
0	52 (19.0)
1	88 (32.1)
2	68 (24.8)
≥3	66 (24.1)
Functional and cognitive status, n (%)	
Activity of daily living impairment	104 (38.1)
Instrumental activity of daily living impairment	135 (49.5)
Cognitive impairment	60 (21.9)
Healthcare use, n (%)	
Regular healthcare location	191 (70.2)
Primary care clinic visit in past 6 months	160 (58.8)
Emergency department visit in past 6 months	80 (29.3)
Hospitalized in 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 surrogate	49 (18.0)
Completed advance directive	24 (8.8)

3 or more chronic conditions had higher odds (aOR=2.3, 95% CI=0.9–5.6) (Table 3).

**Factors Associated with Formal ACP Documentation**

Participants who were black (aOR=5.5, 95% CI=1.5–19.5), had adequate (vs limited) health literacy (aOR=7.0, 95% CI=1.5–32.4), and had 1 to 5 (vs 0) confidants (aOR=5.0, 95% CI=1.4–17.5) were more likely to report formal ACP documentation. Participants at moderate to severe risk of illicit drug use were less likely to report ACP documentation than those at 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 and significant comorbidity, we found a low prevalence of engagement in a full range of ACP behaviors, including contemplation, discussions, and formal ACP documentation. More than half of our study population reported a potential surrogate, lower than that observed in similar safety-net populations, albeit still substantial,<sup>22</sup> but fewer than one-fifth had formally appointed a surrogate. One-third had thought about their ACP wishes, but fewer than one-tenth had completed an advance directive, a level of ACP engagement significantly lower than the general or safety-net populations.<sup>22–24</sup>

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. Although 70% of the cohort reported a regular place for healthcare, and more than half had visited their primary care provider in the prior 6 months, fewer than 5% had discussed ACP with providers. More years of homeless was associated with lower odds of having had ACP discussions but not documentation. This might be because prolonged homelessness increases social isolation, limiting opportunities for discussions with friends or family members. Prolonged homelessness could be a cause or a consequence of less-trusting and -durable engagement with confidants or the healthcare system, limiting the opportunity to have ACP discussions. Even if healthcare providers introduce ACP, people experiencing homelessness may choose not to engage in these discussions because of competing priorities (e.g., acute medical problems, obtaining food and shelter) or lack of trust.<sup>1</sup> In addition to well-known clinician barriers to ACP, (e.g., time constraints and lack of resources),<sup>7</sup> healthcare providers may also have misconceptions about people experiencing homelessness, such as believing that few have potential surrogates or are interested in discussing ACP.

Despite what may be assumed about social isolation of 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 low-income older adults to complete advance directives.<sup>25</sup> Those with more social support may have more experiences with advanced illness



**Table 3. Characteristics Associated with Advance Care Planning Discussions and Documentation**

Characteristic	Discussions		Documentation	
	Unadjusted	Adjusted	Unadjusted	Adjusted
	<b>Odds Ratio (95% Confidence Interval)</b>			
Female	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)	
Residence (reference homeless)				
Housed	1.9 (1.0–3.6) <sup>1</sup>		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) <sup>1</sup>	0.7 (0.5–0.9) <sup>3</sup>	0.8 (0.7–1.1)	
Black	2.2 (0.9–5.5)		4.3 (1.3–14.5) <sup>1</sup>	5.5 (1.5–19.5) <sup>2</sup>
Education, ≥high school or General Equivalency Development	1.3 (0.6–2.7)		2.0 (0.9–4.4)	
Health literacy, adequate	1.6 (0.8–3.3)		5.3 (1.2–22.8) <sup>1</sup>	7.0 (1.5–32.4) <sup>1</sup>
Married or living with partner	1.1 (0.4–2.8)		2.4 (1.0–5.7)	
Number of confidants (reference 0)				
1–5	5.1 (1.7–15.0) <sup>3</sup>	5.8 (1.7–20.0) <sup>2</sup>	5.8 (1.6–20.2)	5.0 (1.4–17.5) <sup>1</sup>
≥6	6.2 (1.7–23.3) <sup>3</sup>	5.1 (1.4–23.2) <sup>1</sup>	5.1 (1.1–23.5) <sup>1</sup>	3.0 (0.6–14.1)
Moderate to severe risk alcohol use	0.6 (0.3–1.1)		1.1 (0.5–2.2)	
Moderate to severe risk illicit drug use	0.7 (0.3–1.5)		0.32 (0.1–0.8) <sup>1</sup>	0.3 (0.1–0.9) <sup>1</sup>
Center for Epidemiologic Studies Depression Scale score ≥16	1.3 (0.7–2.3)		1.0 (0.6–1.9)	
Self-rated health, fair-to-poor	1.4 (0.7–2.5)		1.4 (0.7–2.6)	
Number of chronic conditions (reference 0)				
1–2	0.6 (0.3–1.4)	0.5 (0.2–1.3)	0.4 (0.2–0.9) <sup>1</sup>	0.5 (0.2–1.1)
≥3	2.3 (1.0–5.3)	2.3 (0.9–5.6)	1.0 (0.4–2.3)	1.4 (0.6–3.5)
Activity of daily living impairment	1.9 (1.0–3.4) <sup>1</sup>		1.0 (0.5–1.9)	
Instrumental activity of daily living 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)	
Regular healthcare location	2.4 (1.2–5.2) <sup>1</sup>		1.7 (0.8–3.6)	
Visit to regular healthcare location	2.5 (1.3–4.7) <sup>2</sup>	2.1 (1.0–4.4) <sup>3</sup>	1.7 (0.9–3.4)	
Emergency department visit	0.8 (0.4–1.5)		0.7 (0.3–1.4)	
Hospitalized	1.7 (0.9–3.5)		1.1 (0.5–2.3)	

p<<sup>1</sup>.05, <sup>2</sup>.01, <sup>3</sup>.001.

with loved ones; such experiences can increase motivation for, understanding of, and engagement with ACP.<sup>12</sup>

Black participants were more likely to complete formal ACP documentation than those from other racial and ethnic groups. Black Americans have a risk of homelessness that is 3 to 4 times as great as that of white Americans.<sup>26</sup> This is thought to be due to structural vulnerabilities (e.g., less family wealth, less access to rental housing, fewer employment and educational opportunities). Thus, black Americans who experience homelessness may have lower severity of, or be less likely to have, other factors associated with risk of homelessness, such as substance use and mental health problems.

Homeless-experienced adults, especially those with substance use disorders, are at greater risk of sudden morbidity or mortality,<sup>3</sup> heightening the need for ACP. Substance use was associated with 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 than longitudinal health care, creating a barrier to ACP documentation.<sup>1</sup>

There is a need for customized 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.<sup>11,27</sup>

Research studies of ACP interventions have been shown to increase rates of 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.<sup>28</sup> Our research suggests that clinicians can start the conversation by asking about potential surrogate decision-makers, because social support was strongly associated with 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 fifth-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](http://www.prepareforyourcare.org)).<sup>29,30</sup> Because 1-on-1 counseling may increase advance directive completion in homeless populations, use of peer counselors should be explored.<sup>28</sup>

Our study had several limitations. This was a cross-sectional study of 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 healthcare 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 overreporting. Our study included participants who had recently regained housing. Because 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, because we used participants' social contacts to locate participants. Because 12 participants died before the 18-month interview, our results may have been biased toward those with fewer health problems and with lower likelihood of completing ACP.

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

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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 study design, data analysis and interpretation, drafting of manuscript, and approval of final manuscript.

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