Study Overview

Objective. To determine whether homeless persons would engage in an end-of-life (EOL) advance care planning intervention to complete an advance directive, and to examine the EOL preferences of homeless adults who completed an advance directive.

Design. Prospective, single-blind, randomized controlled trial; SELPH (Study of End of Life Preferences for Homeless Persons).

Setting and participants. Participants were homeless adults recruited from 8 sites (emergency night shelters, 24-hour shelters, a day program, a treatment program, and a case-management program) in Minneapolis, MN, between November 2007 and August 2008. Participants were required to be at least 18 years of age, speak English, have decisional capacity, and have been homeless at any point in the past 6 months. After providing informed consent, participants completed a preintervention survey and were then randomized to either the self-guided or the counselor-guided EOL advance care planning intervention. 1:1 randomization was used for the first 200 participants in 6 out of the 8 sites, after which a 2:1 (counselor-guided vs. self-guided) randomization protocol was used for the remaining 2 sites to ensure completion of advance directives. The study used the SELPH advance directive (SELPH AD), a document that contained all elements of a legal advance directive in Minnesota, and was specifically designed to maintain the autonomy and dignity of marginalized persons. Participants in the self-guided intervention group were provided assistance with reading and writing and were given the option of forwarding their advance directive at a later point. Participants in the counselor-guided intervention group received an hour-long, one-on-one guidance session from a hospice or a social worker to enable advance care planning and completion of an advance directive. All participants were offered assistance in storing their documents at multiple sites including social service agencies, health care facilities, families, and a public website.

Main outcome measure. The main outcome measure was completion of the SELPH AD within 3 months of enrollment. Among those who completed an advance directive, the study examined preferences of EOL care and surrogate decision-making in response to 4 clinical scenarios. The Minnesota advance directive document presented 4 clinical scenarios in which EOL decisions by a proxy or surrogate may be needed: “If I had a reasonable chance of recovery,” “If I were permanently unconscious,” “If I were completely dependent on others,” and “If I were dying.”

Main results. There were 262 eligible participants who were randomly assigned to the self-guided (n = 117) and counselor-guided (n = 145) EOL advance care planning interventions. The majority of participants were men (73.7%) and black (53.8%). Of the 262 participants, 70 (26.7% [95% confidence interval [CI], 21.5%–32.5%]) completed the SELPH AD. The completion rate in the counselor-guided group (37.9%) was higher than that of the self-guided group (12.8%; P < 0.001) with an adjusted treatment difference of 26.4% (CI of adjusted difference, 15.3–34.3 percentage points). Within each randomization stratum and site, the completion rate for SELPH AD was higher in the counselor-guided group relative to the self-guided group. Within sites, the case-management site had the highest completion rate (55.6% [CI, 35.3%–74.5%]). Completion of an advance directive was higher for participants who were white, more than 50 years of age, or married. Participants who did not have trouble obtaining food, reported substance abuse, or had a regular source of health care were also more likely to complete an advance directive. Among the 70 people who completed an advance directive, 21% reported not wanting life-sustaining treatment if they were to become dependant on others, 37% if they were to become permanently unconscious, and 31% if dying. There were more white than black participants who opted to forego life-sustaining measures in response to the clinical scenarios. Of the 70 homeless persons, 87% named a family member as a surrogate decision-maker in their completed advance directives.

Conclusion. An EOL advance care planning intervention successfully engaged a diverse sample of homeless adults. The one-on-one counselor-guided intervention resulted in more completed advance directives than the self-guided
intervention. The majority of homeless persons were able to identify a surrogate decision maker and express specific preferences for their EOL care.

Commentary

Disparities exist in EOL advance care planning and delivery among adults of minority and lower socioeconomic status. Homeless persons are among the poorest in our society, face many chronic medical problems [1,2], significant barriers to health care [3,4], and increased premature mortality [5]. Because of their high morbidity and mortality from chronic illness, homeless persons are likely to encounter EOL situations without adequate preparedness. Previous studies have shown that homeless adults have personal views on death and dying [6,7], value advance directives, and will complete them under certain circumstances [8].

The current study builds on limited existing literature on EOL advance care planning in marginalized populations by showing that homeless adults successfully completed advance directives and expressed preferences for EOL care. The authors found that rates of advance directive completion among homeless persons (27.6%) were similar to those in the general population (15%–30%) [9], and were higher than those in socioeconomically similar patient populations such as African Americans, where rates are generally low (7%–11%) [10].

Homeless adults engaged in a one-on-one counselor-guided intervention were more likely to complete an advance directive than those in the self-guided group, suggesting that providing one-on-one counseling may be an efficacious strategy to facilitate engagement in EOL advance care planning among homeless adults. The majority of homeless persons identified a surrogate decision maker, most often a family member, suggesting that homeless persons are willing to entrust important health care decisions to a family member. Among the 70 participants who completed an advance directive, the proportion of adults willing to forego life-sustaining treatment in the setting of a coma or if dying was lower than that in the general population [10]. As seen in prior studies in the general population, black homeless persons were more likely to want life-sustaining treatments, perhaps reflecting a general mistrust of medical institutions in the homeless community [11]. While this study demonstrates that homeless persons can successful complete an advance directive, future work will have to examine its effects on EOL outcomes in homeless persons. In addition, future studies will have to determine if completing advance directives results in homeless persons receiving desired EOL care.

This study has a few limitations. Homeless persons were recruited from one U.S. city, and therefore the study may not be generalizable to homeless persons from other parts of the United States. In addition, only those homeless persons who accessed services were recruited, limiting generalizability.

There is the potential for selection bias if recruited participants were inherently more interested or knowledgeable about EOL advance care planning. The authors were unable to assess literacy of their participants, which could have affected completion rates of advance directives in the self-guided group. However, the study’s major strength was in demonstrating that homeless persons were engaged in their own EOL advance care planning and completed legal advance directives, which later became part of their medical records.

Applications for Clinical Practice

This study demonstrates that with adequate support, homeless persons can engage in EOL advance care planning, complete an advance directive, express preferences for EOL care, and name a surrogate decision maker. Given these findings, clinicians serving homeless adults should allocate time to discussing EOL preferences with all of their homeless patients, who are likely to encounter EOL situations given their high burden of chronic illness. These preferences should be well documented in their medical record, and patients should have easy access to these records and preferably have a copy on themselves. Given that homeless persons seek care in diverse settings, efforts should be made at communicating EOL preferences with new providers at other health care settings.

References