Homelessness and End of Life Care: Methods to Study Health Disparities in Disadvantaged Populations

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1. Introduction

There is a high prevalence of homelessness in St. Paul and Minneapolis as well as the United States. Estimates of the number of homelessness in the United States range up to several million. According to the Wilder research Foundation, in the Twin Cities metro area over 4,000 youth and adults are in temporary housing programs and over 600 are unsheltered.

"Homeless" for this study is defined as having no regular place to live (i.e. having to stay in a shelter, a hotel paid for with a voucher, a friend's house, an abandoned building, outdoors or other places not intended for sleeping).

Among disadvantaged populations, homeless individuals experience the greatest risk of death, barriers to healthcare and lack of resources and close relationships deemed necessary for appropriate end of life (EOL) care.

Homeless individuals also utilize the healthcare system at a significantly higher rate than housed individuals. They are admitted to the emergency room and hospitalized at almost four times the rate of the general population of the United States. This is in a large part a consequence of their inability to access routine health care due to competing needs and lack of adequate health insurance.

Although homeless individuals experience such high rates of mortality and hospitalization, their attitudes, values and desires regarding EOL care had yet to be studied.

The major objective of this study was to test an advanced directive (AD) intervention in the homeless population of Minneapolis and St. Paul. Insights from this project will also be significant in the Following ways: they will address the EOL concerns of homeless people and provide the basis to test the needs of others who are separated from their loved ones and/or experience fragmented, episodic healthcare.

It is evident that homelessness research is particularly needed within the larger body of research on health disparities in disadvantaged populations. However, research on the health disparities of homelessness populations is scarce. This is in a large part due to the intimidating methodological challenges facing those who seek to study homeless populations.

The itinerant nature of the homeless population is the greatest challenge that effects the retention rate of studies of homeless individuals. Retention rates in studies of homeless populations range from 30 to 86 percent.

Previously used retention strategies included: outreach, phone tracking and gathering of anchoring points (information that will help locate an individual, such as an emergency contact).

In this investigation, we employed both traditional and innovative methods to increase retention. We found that the effectiveness of these strategies varied considerably among sites. These findings identify the challenges and innovative methods utilized to study homeless populations and pave the way for further research of disadvantaged populations in the United States.

2. Methods

Homeless adults in the Minneapolis and St. Paul area were asked to complete a self-report survey pertaining to issues of health, dying, personal relationships and EOL care. The participants were recruited from a wide variety of sites primarily serving the homeless. The sites included a 24-hour emergency shelter, a treatment program, overnight emergency shelters, a support group for street women, an intensive case management program, and a drop-in center. Participants were asked to meet our research team from the University of Minnesota in a common room to fill out the survey at a specific time. The participants received $20.00 for completing this initial survey. Exclusion criteria were: anyone under 18 years old, not homeless within the last six months, inability to speak and write English, and lack of decisional capacity to participate in the study as ascertained by a written screening tool. After completing the survey, the eligible adults were randomly assigned into two intervention arms, both of which offered them an opportunity to complete an AD. The two arms were a minimal intervention in filling out the AD (MI) and a guided intervention conducted by experienced health officials (GI).

A follow-up survey was completed three months after this initial intervention. A site-specific follow-up session was conducted at the same location in which the first intervention was held. All baseline participants were invited to this follow-up session via their contact information, posters at the sites and trusted community advocates. Similar to the first intervention, the participants were met by University of Minnesota researchers, asked to complete a survey and paid $20.00 for completing the survey. In addition to the site-specific follow-up sessions, further measures were taken to increase the retention of this study. Researchers conducted individual follow-up sessions and located individuals using both traditional and innovative methods. Retention strategies employed for individual follow-up included: outreach, word-of-mouth, a computer note, an e-mail, a cell phone call and through an advocate.

Currently, medical charts are being audited 18 months following the initial intervention to evaluate the effectiveness of the AD.

3. Results

Retention by Site and Follow-up

Site Description	Total Recruited	Site Specific Follow Up	Individual Follow Up	Percent Retained
24-hour Emergency Shelter	85	42	7	57.7
Emergency Night Shelter	101	29	29	57.4
Treatment Program	43	16	6	51.6
Drop-in Centers	22	8	8	72.7
Case Management Program	24	16	5	87
Street Women's Support Group	30	9	0	30
Total	306	120	55	57.0

Retention Strategies for Individual Follow-up

Method	Number	Percentage
Advocate	11	20
Computer Note/Cell Phone	16	29
Email	2	4
Outreach	18	33
Word of Mouth	8	15

4. Discussion

Of the 306 homeless individuals recruited for this study, 120 (39%) individuals were retained in the site specific follow-up session. However, as a result of the additional efforts of the researchers, another 55 (18%) individuals were retained in individual follow-up sessions. Therefore, the retention of homeless individuals in this study was approximately 57%. Thus, this study shows that it is plausible to conduct longitudinal research on individuals experiencing homelessness. In addition, individual outreach can greatly improve retention rates.

This study also showed that homeless individuals were connected to technology (27% of participants listed an e-mail address in the initial survey) and most participants had community cards and were therefore able to receive electronic messages at sites serving the homeless. An additional 18 individuals were reached via technology for individual follow-up sessions.

This study also showed that community connections, outreach and word-of-mouth are vital for both the recruitment and retention of homeless participants in research studies of homelessness. An additional 37 individuals were reached via personal contacts, outreach and word-of-mouth for individual follow-up sessions. Flexibility is also essential for researchers who seek to conduct longitudinal studies on homelessness.

Considering the larger aim of the study; individuals in the GI group were significantly more motivated to fill out an AD than individuals in the MI group. However, according to the 3 month follow-up survey the number of individuals concerned with EOL care issues almost doubled in both intervention arms.

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