

# RESEARCH REPORT

**“People kept dying ... a LOT.”**  
Assessing the end of life care needs of  
the homeless population in downtown  
Tucson, Arizona



Link to DRAFT copy of full study:  
[Click here](#)

“The reality of death is ever-present for the vast majority of the respondents in this study. 88% had faced the risk of death on the streets, many in multiple ways.”

CCHS Foundation





**Witness  
Jessica's story**

[Click here to view her  
video from the study](#)

# JESSICA: DYING ON THE STREETS FROM PULMONARY HYPERTENSION

"For many of those who had faced death on the streets, the danger of dying from a chronic disease was also an existential constant. 35.7% had faced the risk of death from respiratory disease (e.g. pneumonia, COPD), 35.7% had faced the risk of death from COVID-19, 32.1% had been threatened with death from heart disease, and 21.4% had experienced the risk of death from liver disease."

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88%

LIKE CATHERINE,  
HAS FACED THE RISK  
OF DEATH  
ON THE STREETS

## INTRODUCTION & CONTEXT



- SENIOR CITIZEN
- MULTIPLE CHRONIC ILLNESSES
- THREATENED WITH EXTREME VIOLENCE

The catalyst for our research can be summarized in two sentences:

- 1) In a dramatic demographic change, half of older homeless adults now become homeless for the first time AFTER the age of 50.
- 2) Because the homeless population is now so very much older, chronic illness and deaths among the unhoused are up by extreme margins.

In short, Catherine (seen in the photo to the left and on the previous page) is now the average woman on the streets. At the time of the photo, Catherine was a grandmother, she had multiple chronic conditions, she had been repeatedly exposed

to extreme violence, and she was systematically ignored when it came to her needs and wishes regarding end of life care. The focus for our research can be summarized in one short question:

**How can we bring effective end of life care planning to someone like Catherine?**



**WARNING: EXTREMELY VIOLENT VIDEO CONTENT**

Witness Catherine's story by [clicking here](#)

#### OUTSIDE SOURCES CITED:

• Brown, Rebecca T., Leah Goodman, David Guzman, Lina Tieu, Claudia Ponath, and Margot B. Kushel. "Pathways to Homelessness among Older Homeless Adults: Results from the HOPE HOME Study." PLOS ONE 11, no. 5 (May 10, 2016): e0155065. <https://doi.org/10.1371/journal.pone.0155065>.

• "Homeless Dying in Record Numbers on the Streets of Los Angeles." Accessed May 18, 2023. <https://www.usnews.com/news/healthiest-communities/articles/2019-04-23/homeless-dying-in-record-numbers-on-the-streets-of-los-angeles>.



# APPROACH

1

## Community discussions

As the marginalization of the homeless population informed our project, our very first steps were to include the homeless from the very beginning. To this end, we held informal discussions with over 50 homeless guests at the Sunday morning feeding project at The Z Mansion in downtown Tucson. The Z has been a trusted location for those on the streets in Tucson for over 20 years and the advice we received in those informal discussions was simple and direct: "Keep it real."

2

## Literature Review

In order to keep things "real," we developed our questionnaire using question pools many of the homeless have previously experienced. For example, the questions about their homeless situation were derived, in part, from the questions the homeless are asked when applying for housing with HMIS, the federal government's Homeless Management Information System. We used the same approach when developing questions about sexual orientation and gender identity (data collection best practices from Harvard), ethnicity and tribal affiliation (best practices developed by the federal Agency for Healthcare Research and Quality), and disability status and veteran status (also from HMIS). In short, the vast majority of our questions came from repeatedly validated sources to allow for apples to apples comparison of the data. We then held a three-person sample interview session (two men and one woman) to get an idea of the issues involved. At that preliminary session, it became obvious that the questions were of such a personal nature individual interviews would be the best way to get the most accurate data.

"KEEP IT REAL"

3

## Community interviews

From a pool of over 200 potential subjects from the Z Mansion, we randomly selected 32 guests to be interviewed. It is worth noting that all but one of the subjects showed up at the correct time and place for their individual interview. We conducted 32 one-hour-long interview sessions. Each subject agreed to be recorded on video and signed a release form based on a best-practices form developed by the Institutional Review Board (IRB) at Clemson University. Subjects were provided with water and Gatorade, a lunch to go, and were also given \$50 in cash for their participation.

4

## Statistical analysis & reporting

The lead researcher asked each question and then entered the answer into a digital online form. The data from each form was extracted and then analyzed in an industry-standard statistical analysis program. The results were then analyzed and presented in a written report.



Z Mansion Sunday Feeding Project

**The Z Mansion has been a trusted location for those on the streets in Tucson for over 20 years and the advice we received from the homeless guests was simple and direct: "Keep it real."**

# FINDINGS

With a constant threat of death and dying on the streets, the homeless population in downtown Tucson, Arizona evidenced a strong need and a strong interest in the creation of a text and image searchable online portal where the homeless could create and store ACP directives.

## Demographics

Among the 32 participants, 13 identified as female (40.6%), 18 identified as male (56.3%), and one identified as nonbinary (3.1%). The ages of those interviewed ranged from 35 to 68 with a mean age of 52 (9.5 SD). 28 identified as straight/heterosexual (87.5%), 3 identified as bisexual (9.4%), and one identified as gay or lesbian (3.1%). For those who selected an ethnicity, 4 selected "Hispanic or Latino" (12.9%) while 27 selected "Not Hispanic or Latino" (87.1%). Regarding race, 5 selected "American Indian" (15.6%) with 2 of those selecting Tohono O'odham Nation tribal affiliation, 2 selecting San Carlos Apache Tribe tribal affiliation, and 1 selecting "Lakota Sioux" tribal affiliation. Of the remaining 27 respondents, three indicated their race was "Black or African American" (9.4%), and 24 selected "White" (75.0%). Of those speaking a language other than English at home (n = 5), two spoke Spanish, two spoke San Carlos Apache, and one spoke Lakota Sioux.

## Disability status

One participant (3.1%) said they were deaf or had serious difficulty hearing, 3 (9.4%) indicated they had serious difficulty seeing even when wearing glasses, 7 (21.9%) said that because of a physical, mental, or emotional condition they have difficulty doing errands alone, 15 (46.9%) said that because of a physical, mental, or emotional condition they have serious difficulty concentrating, remembering, or making decisions, 16 (50.0%) said they had serious difficulty walking or climbing stairs, and 21 (65.6%) indicated they had a physical, mental, or emotional impairment, including an impairment caused by alcohol or drug abuse, post-traumatic stress disorder, or brain injury that is expected to be long continuing or of indefinite duration.



## Homeless situation

27 participants (84.4%) indicated they lived "outside" with 11 of those (40.7%) living in a park or desert area, 9 (33.3%) living on a street or in an alley, 4 (14.8%) living on private property with permission, 1 (3.7%) living on private property without permission, 1 (3.7%) living at a city bus station, and 1 (3.7%) living in their car. Of those who indicated they stayed outside or in a place not meant for habitation (n = 28), 75.0% (n = 21) had no tarp, sunshade, or rain cover, 53.6% (n = 15) had no sleeping bag, and 25.0% (n = 7) did not have a blanket. 28.6% (n = 8) of those living outside reported they did not have a reliable source of drinking water.

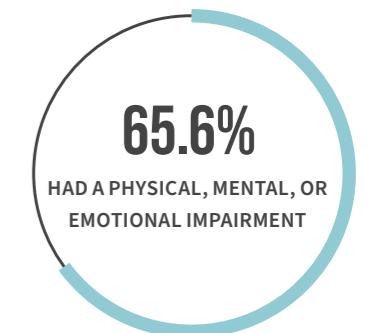
Of the 5 (15.6%) of the participants who reported living inside, 3 lived in transitional housing for homeless persons, 1 lived in a hotel or motel paid for with an emergency housing voucher from the government, and 1 lived in a temporary apartment paid for by their Social Security income.

The average time on the streets of all respondents was 10.2 years with a range of 3 months to 35 years. A significant majority (69%, n = 22) of those interviewed had completed high school, a GED, or some college. When asked about all possible sources of income with multiple choices possible, 5 respondents (15.6%) reported receiving no income of any kind, 18 (56%) reported regularly receiving income from odd jobs, day labor, or a part-time job. 5 (16%) reported income from the occasional or frequent selling of drugs, 3 (9%) reported income from occasional or frequent sex work, and 1 (3.1%) reported income from "flying a sign" or panhandling.

## End of Life Care Issues

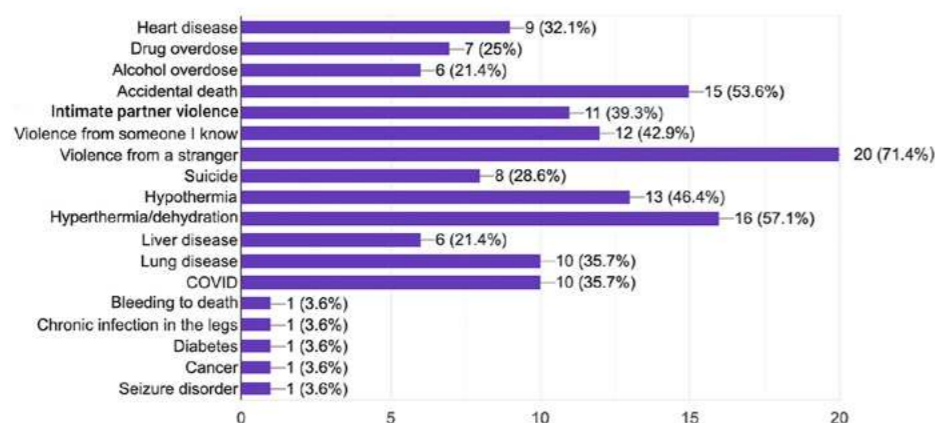
For many of those who had faced death on the streets, the danger of dying from a chronic disease was also an existential constant. 35.7% had faced the risk of death from respiratory disease (e.g. pneumonia, COPD), 35.7% had faced the risk of death from COVID-19, 32.1% had been threatened with death from heart disease, and 21.4% had experienced the risk of death from liver disease.

This exceptional risk of death on the streets extends to the family and friends of the homeless as well. When asked "How many of your family members have died on the streets?," one homeless member of the San Carlos Apache Tribe had lost 10 family members, one member of the Tohono O'odham Nation had also lost ten members, and one member of the Tohono O'odham Nation had lost 15 family members on the streets. When asked "How many of your friends and/or acquaintances have died on the streets?," homeless women had lost an average of 17.5 friends and/or acquaintances (SE ±4.007) and homeless men had lost an average of 12.6 friends and/or acquaintances on the streets (SE ±5.283). Given these results, it is not surprising that 69.2% of the homeless women surveyed were worried about dying on the streets, while 47.4% of the homeless men were also worried about dying.



Have you faced the possibility of death before while on the streets? If so, please describe what happened to you. Check all that apply:

28 responses



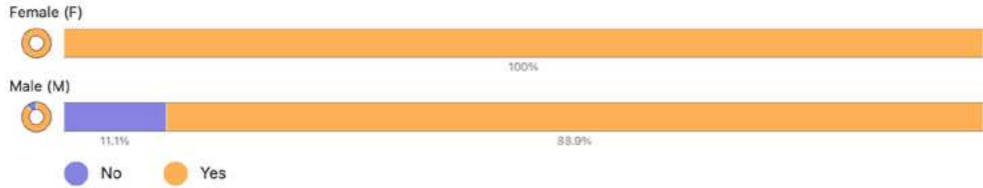


# FINDINGS

## Desire for Advanced Care Planning (ACP) Directives

Regarding specific ACP directives, 78.1% (n = 25) of those surveyed would be interested in completing a Health Care Power of Attorney if guided by a knowledgeable assistant with an additional 6.3% (n = 2) having already completed one. 65.6% (n = 21) would be interested in completing a Mental Health Care Power of Attorney if guided by a knowledgeable assistant with an additional 6.3% (n = 2) having already completed one. Also pointing to significant ACP acceptance by this population, 71.9% (n = 23) would be interested in completing a Living Will if guided by a knowledgeable assistant with an additional 3.1% (n = 1) having already completed one.

**GRAPH:**  
"If you were to create any of the forms above [ACP directives], would you be willing to have it/them stored with a current photo of yourself to allow your doctor to use an image search to find your records? (This would only be done if you were in a hospital and were unable to speak for yourself and had no form of identification.)" (N = 30)



**78.1%**  
WANT 1 OR MORE  
ADVANCED CARE  
DIRECTIVES

# NEXT STEPS

There is a strong need and a strong interest in the creation of a text and image searchable online portal where the homeless could create and store ACP directives. To this end, a feasibility study which would include the creation of a working and scalable portal is highly recommended.