

Homelessness and End of Life Care:



A Qualitative Analysis of the Living Wills of Underprivileged Individuals

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Introduction

The major objective of this study is to test an advance directive (AD) intervention in the homeless population of Minneapolis and St. Paul.

This project will address the end of life (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 episodic healthcare.

Estimates of the number of homeless people in the United States range up to several million.

In the Twin Cities metro area over 4,000 youth and adults are in temporary housing programs and over 600 are unsheltered.

“Homeless” 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 or outdoors).

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

Homeless individuals are admitted to the emergency room and hospitalized at almost four times the rate of the general population of the United States.

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

Their concerns have generally been ignored, since most EOL care has focused on the concerns of the white middle class.

In general, homeless people have been found to be very willing to describe their preferences and concerns and eager to have a voice in what the future may bring in the event of serious illness or death.

Homeless people have been found to have very unique concerns regarding healthcare and EOL care, since they frequently witness sudden and violent death on the streets.

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.

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 and received \$20.00 for completing this initial survey.

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 MI and GI.

Minimal intervention (MI): Individuals in the MI group were not invited to return to a subsequent meeting, but were given the means to return their AD to the investigators by mail.

Guided intervention (GI): Individuals in the GI group were invited to return on a subsequent day to meet with an investigator to complete the AD. During this subsequent meeting, the individuals met privately with an investigator who could answer questions about EOL care. The form was witnessed by two people (an investigator or shelter staff).

(The AD expanded upon the recommended language for legal sufficiency of ADs in the Minnesota state statutes. Questions were added to capture the unique concerns of homeless individuals.)

A follow-up survey was completed three months after the initial intervention. The site-specific follow-up session was conducted at the same location as the first intervention.

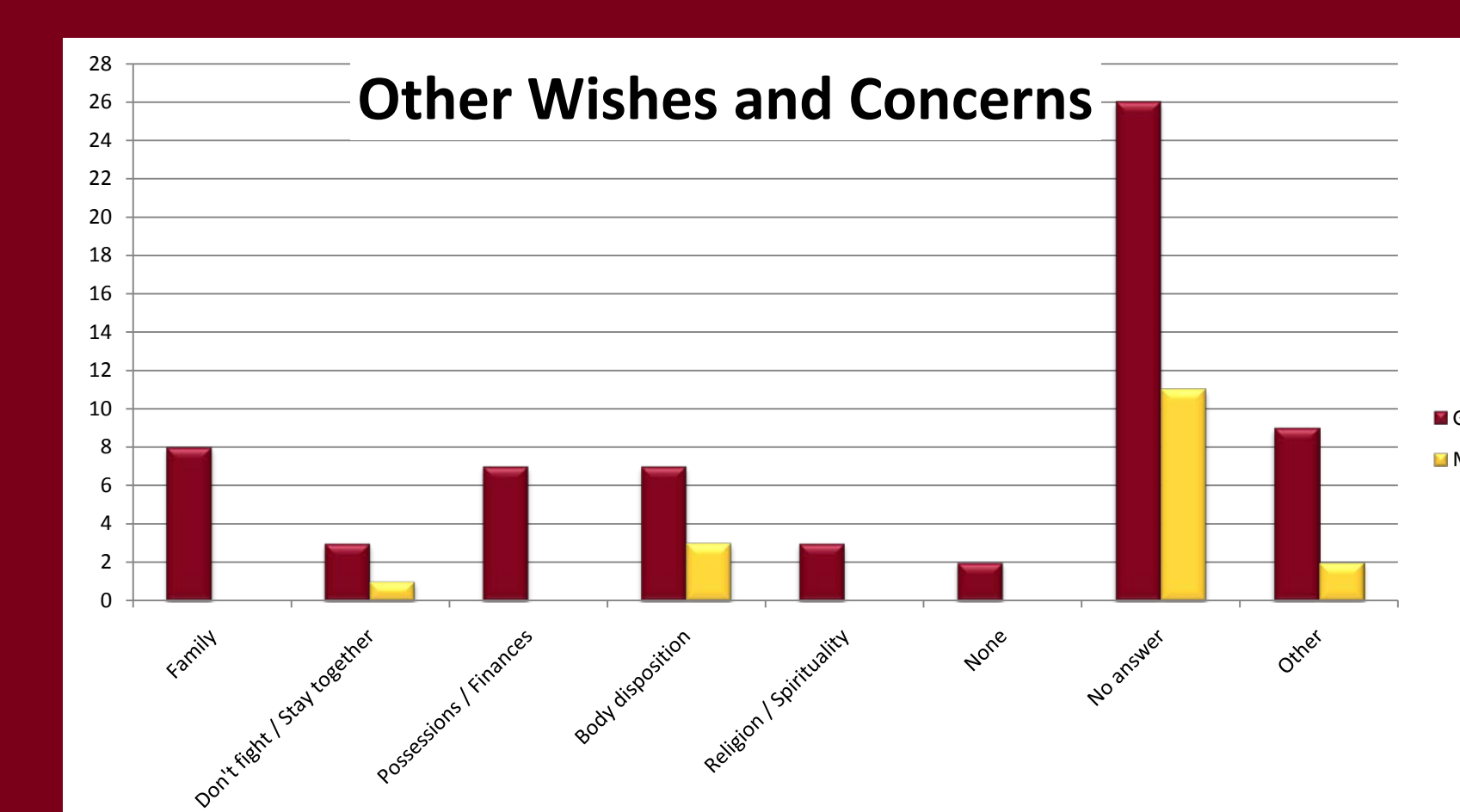
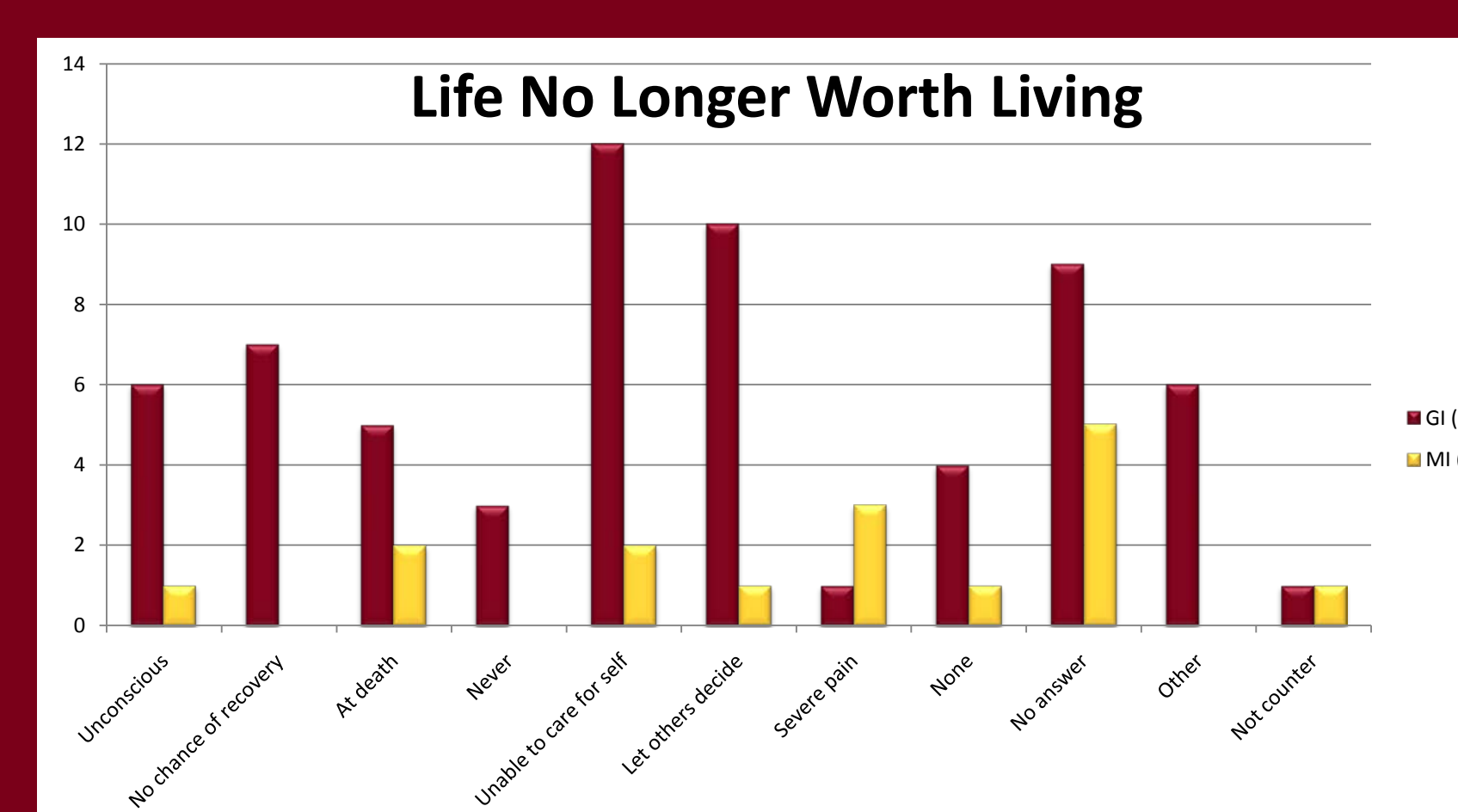
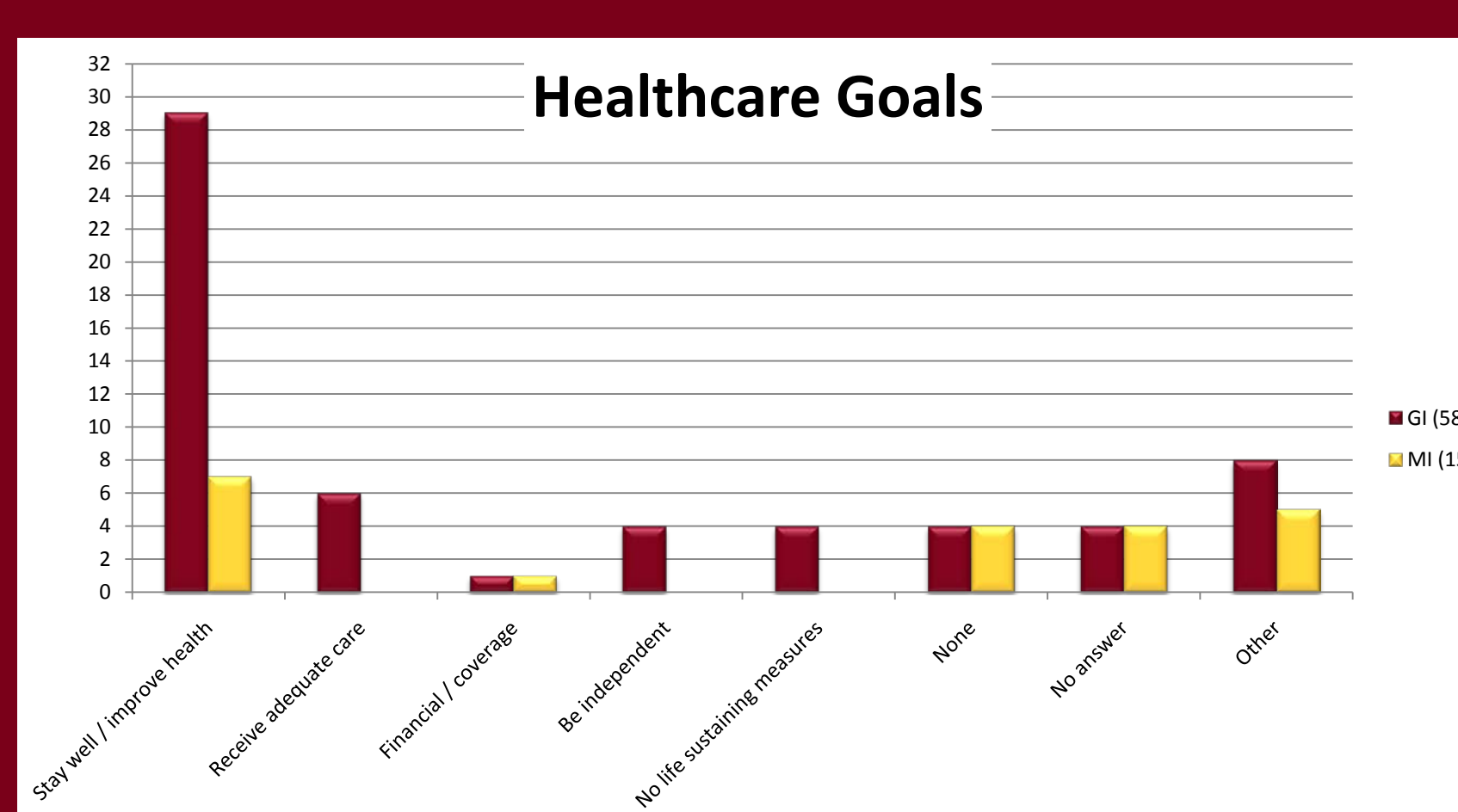
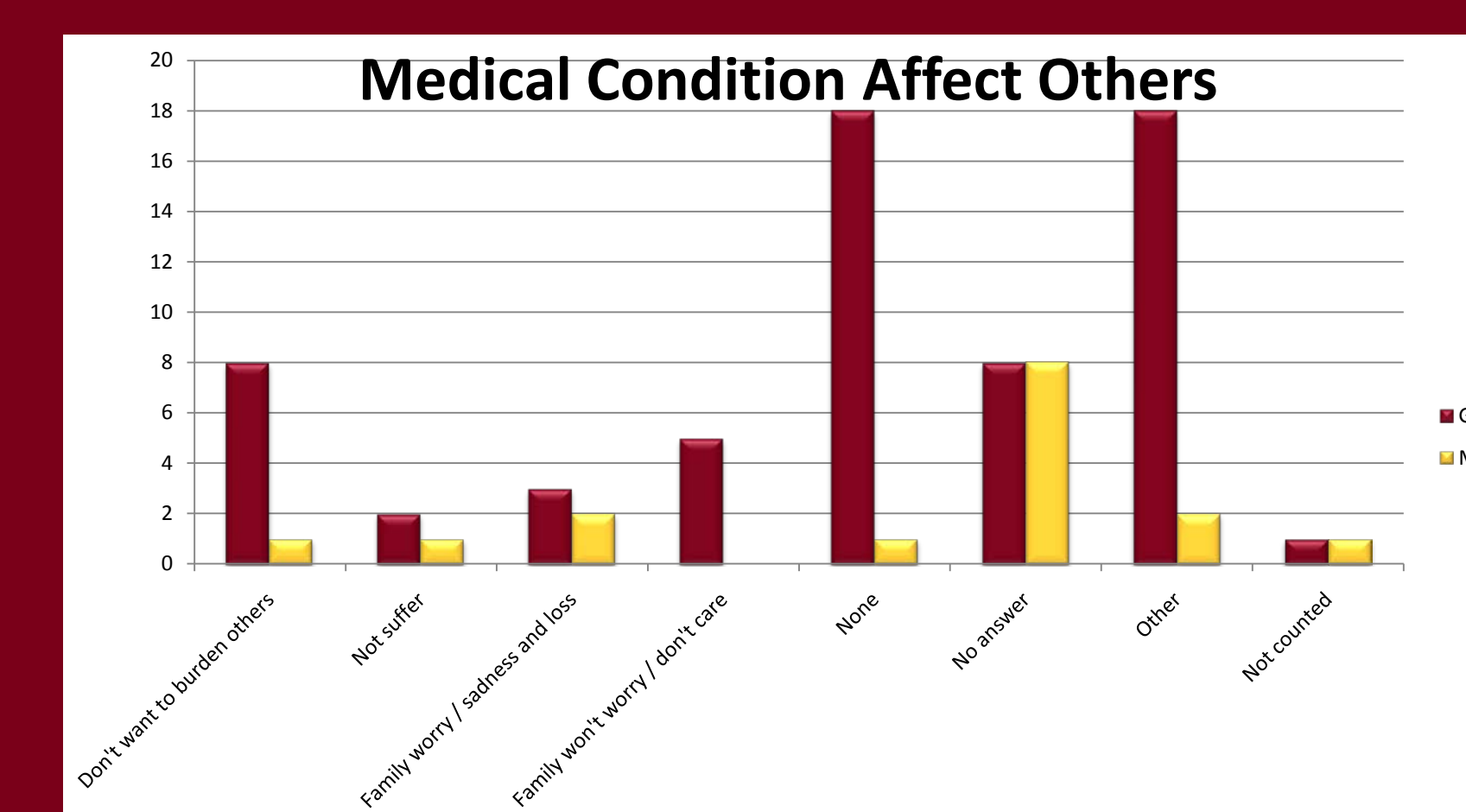
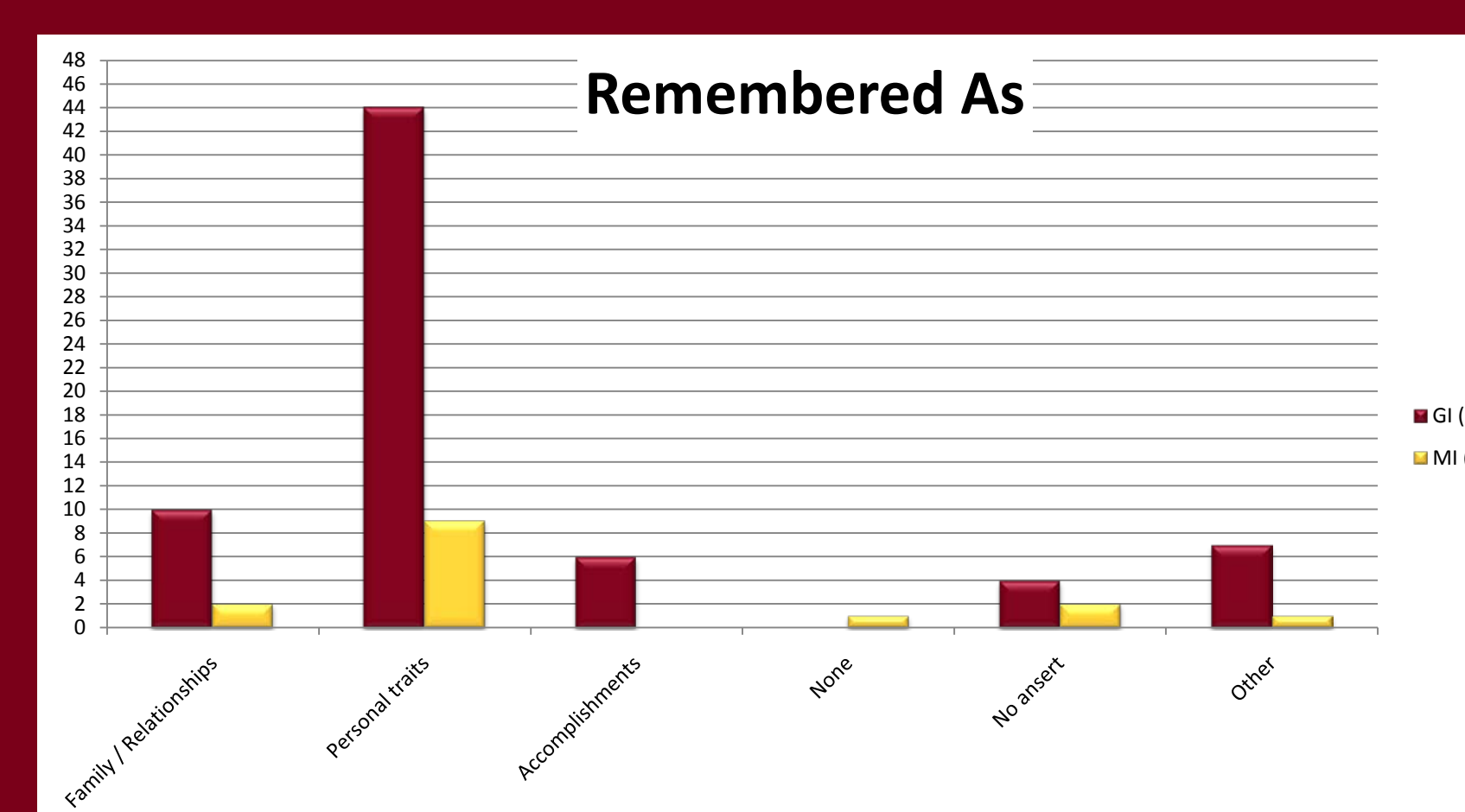
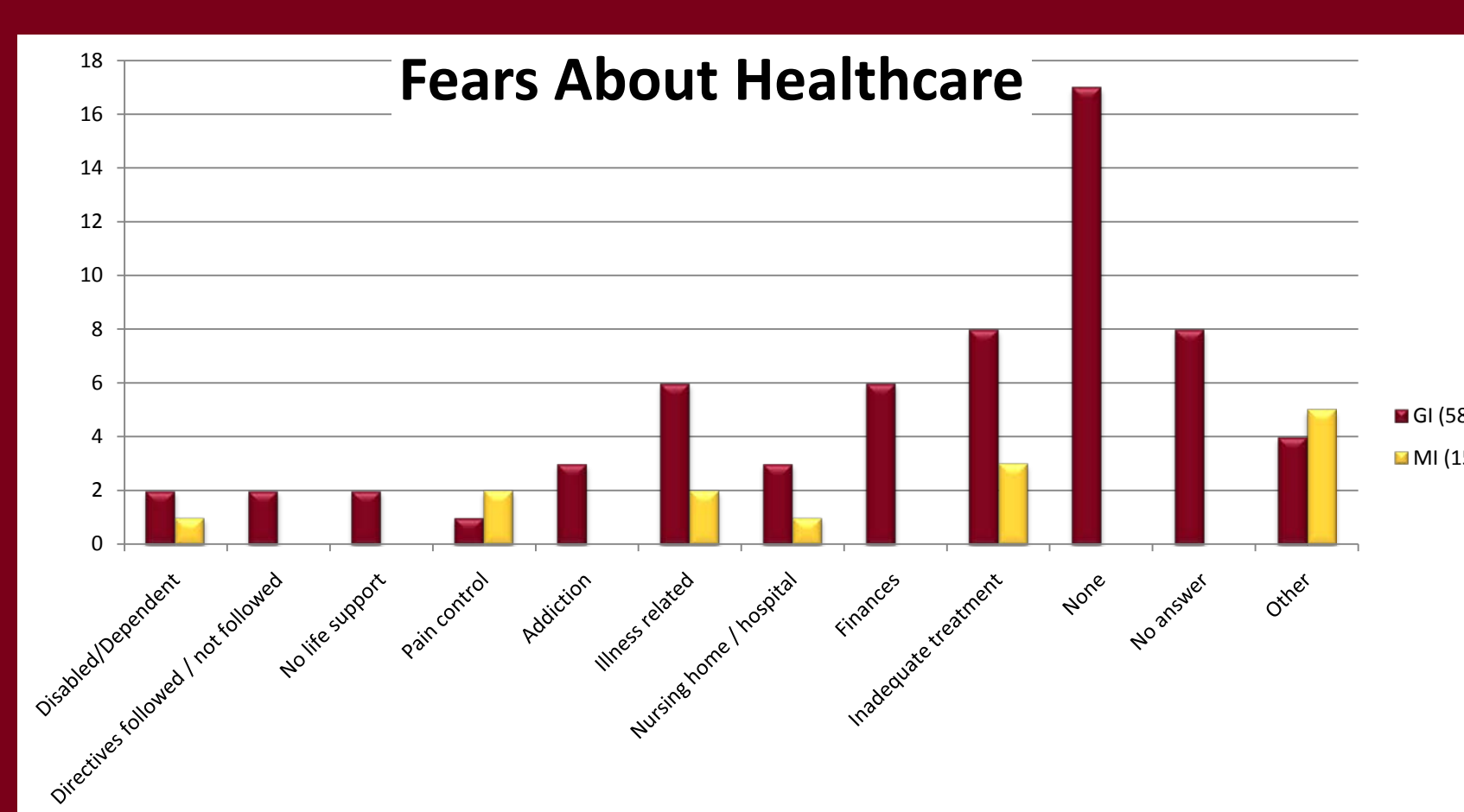
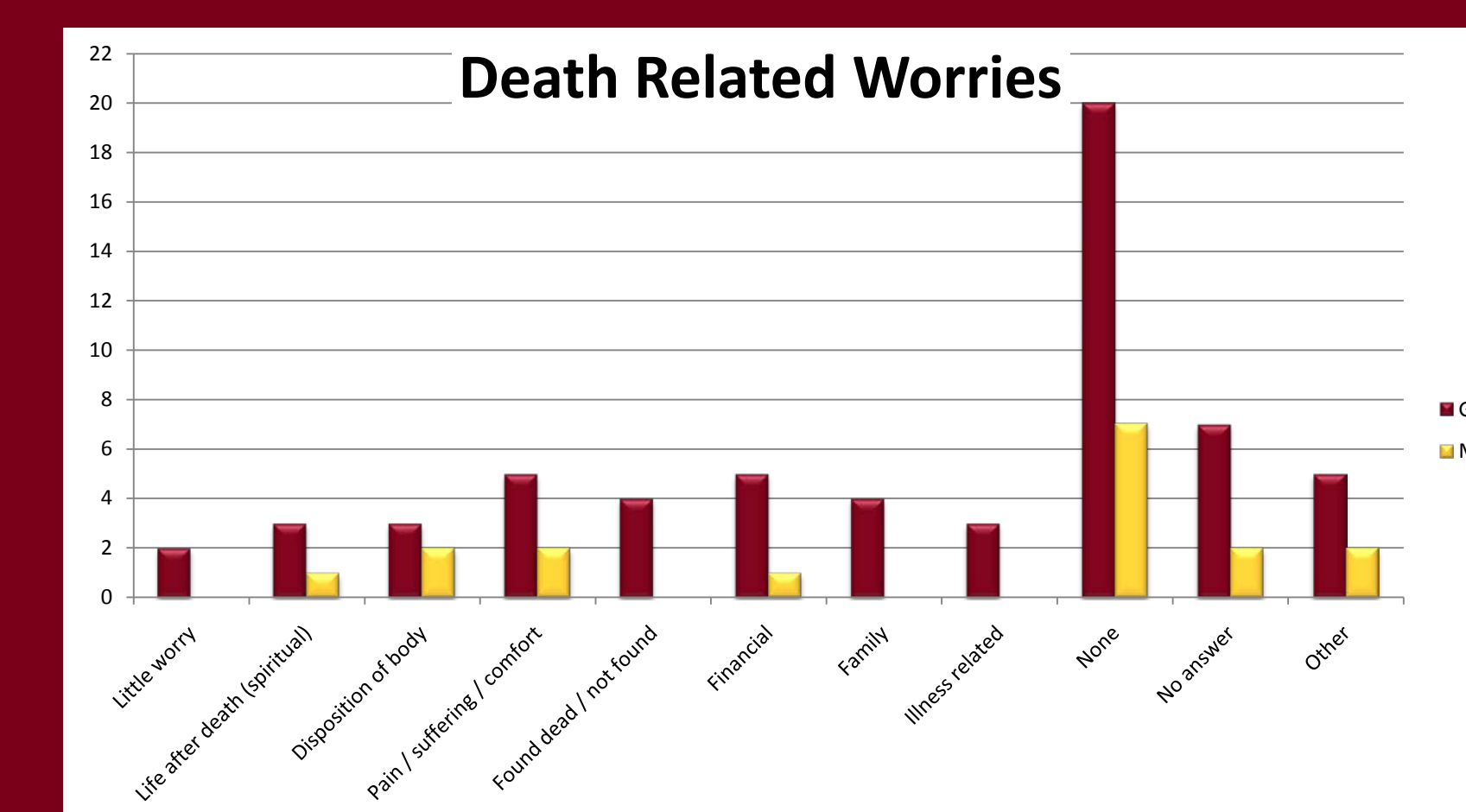
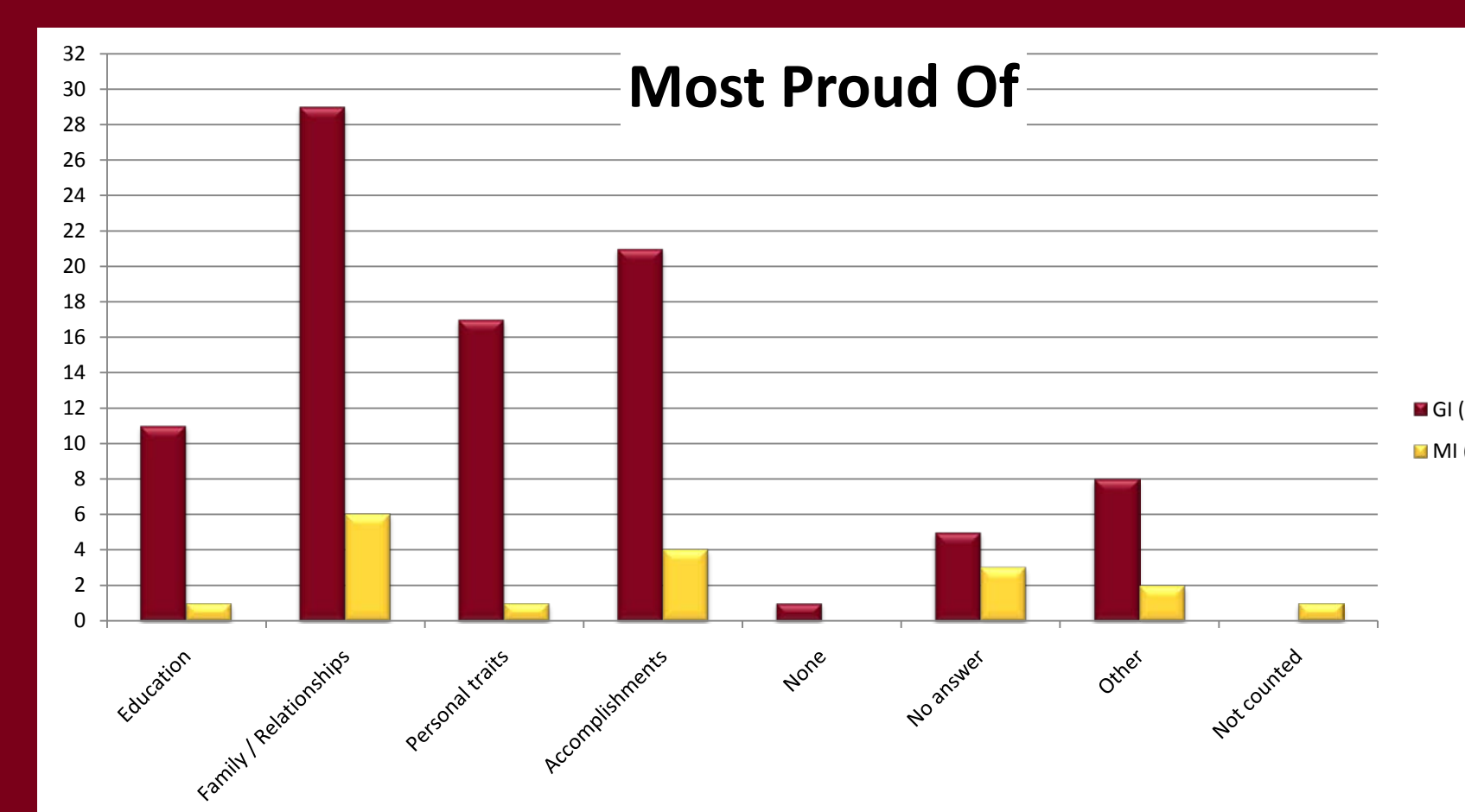
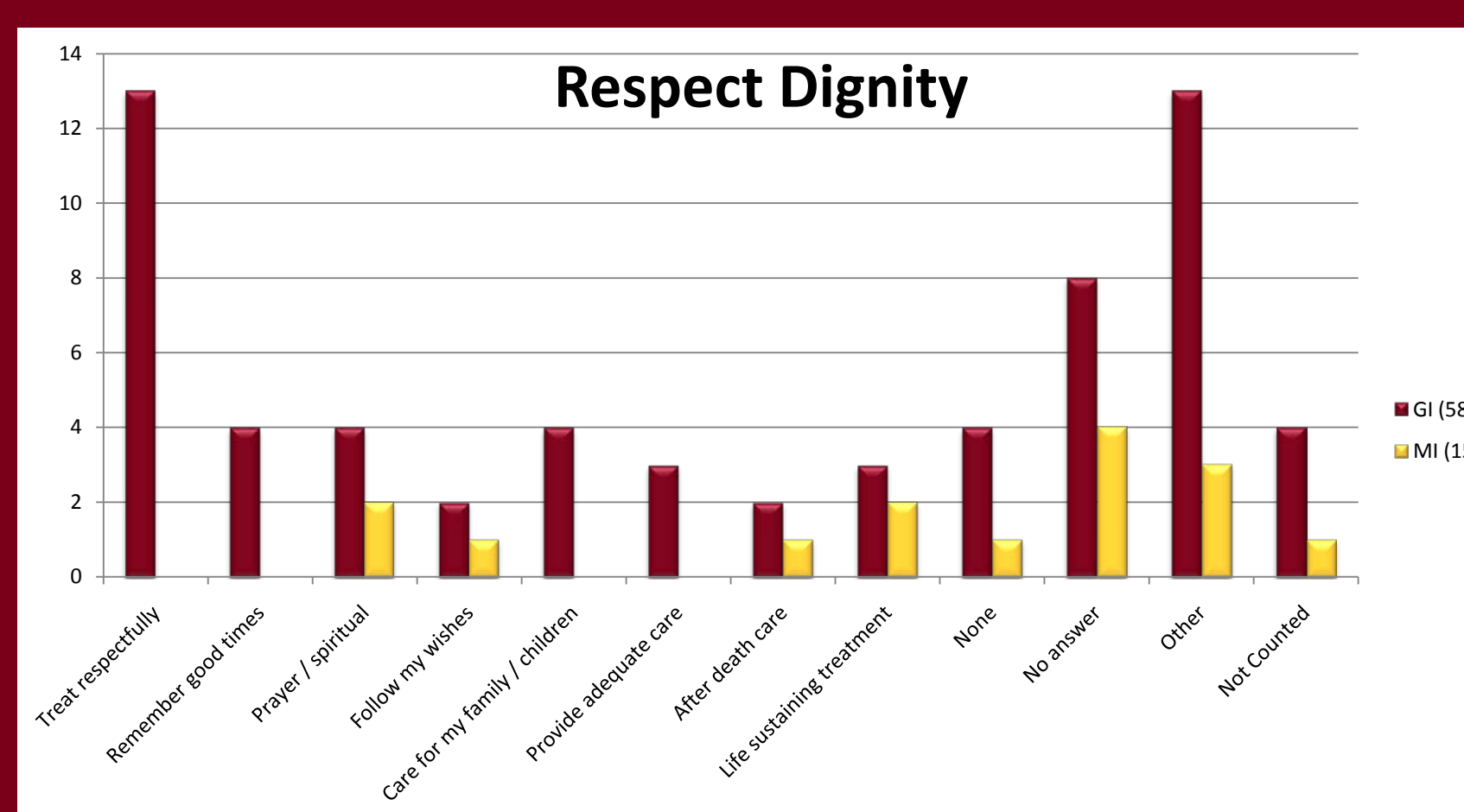
Currently, medical charts are being audited 18 months following the initial intervention to evaluate the effectiveness of the ADs.

Out of the 306 homeless individuals recruited for the study, 73 individuals filled out an AD.

Of the 73 people, 15 were assigned to the MI group and 58 were assigned to the GI group.

A qualitative content analysis was conducted in which multiple investigators individually coded responses from the ADs. This data was audited and a final consensus was reached after discussion by three investigators.

Data



Discussion

A large number of people (36%) had no fears concerning healthcare. Of those with fears most feared inadequate care. Responses included “Sooner or later there won’t be any healthcare for the homeless” and “Best care is reserved for the people with the most money.”

A Surprising result was that healthy care and health maintenance activities are very important to the homeless. 14 people (19%) said their goal was to stay well or improve their health. 22 people (30%) indicated specific health maintenance activities as their goal. One person’s goal was to “Keep up with appointment and check on medical records after test results.”

Homeless people are proud of a lot of things. 20 people (27%) were proud of their children and 16 people (22%) were proud of other members in their family. Of the people who were proud of their children most said they were proud of “having children” not raising them or their relationship with them. 10 people (13%) listed personal traits they were proud of and 15 people (21%) mentioned specific accomplishments they were proud of. One of these was “Being able to cook for some very important people.”

An astounding number of people (81%) wanted to be remembered by a personal trait. Many (40%) wanted to be remembered as good, kind or helpful. A lot of the people said they wanted to be remembered for giving to others when they barely had anything to give. One person wanted to be remembered as “Had a good heart, loved jazz, who liked to laugh, who gave people all I had when I didn’t have much to give, for loving my family.”

An unexpected trend of each answer was the connectedness the homeless people had to their families. One of the reasons we conducted this study was because it is assumed that homeless people lack the personal relationships needed for proper EOL care. From personally speaking to the people, the best explanation is the location of our study. It may be family connections that keep homeless people in Minnesota despite harsh winters on the streets.

References

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