

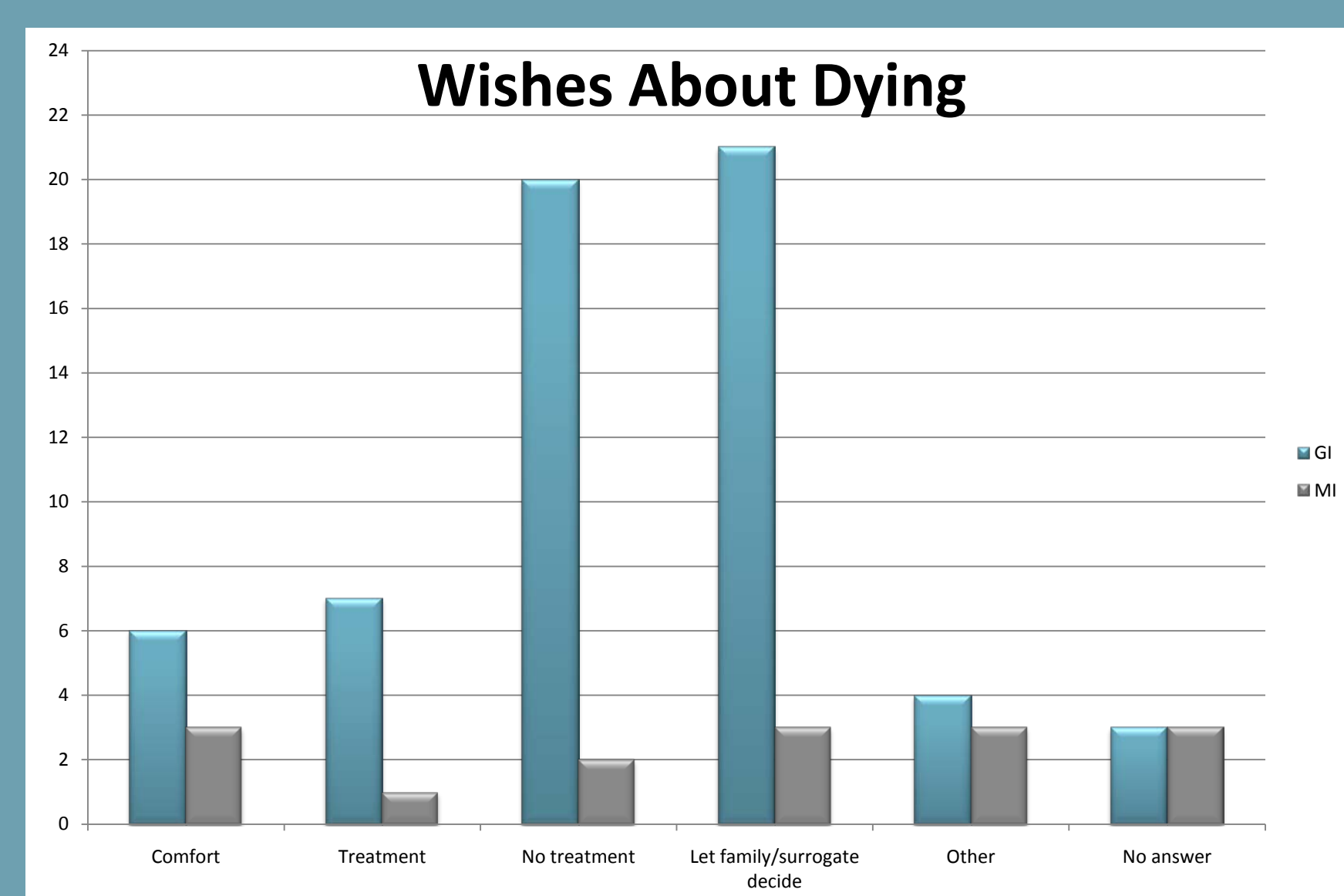
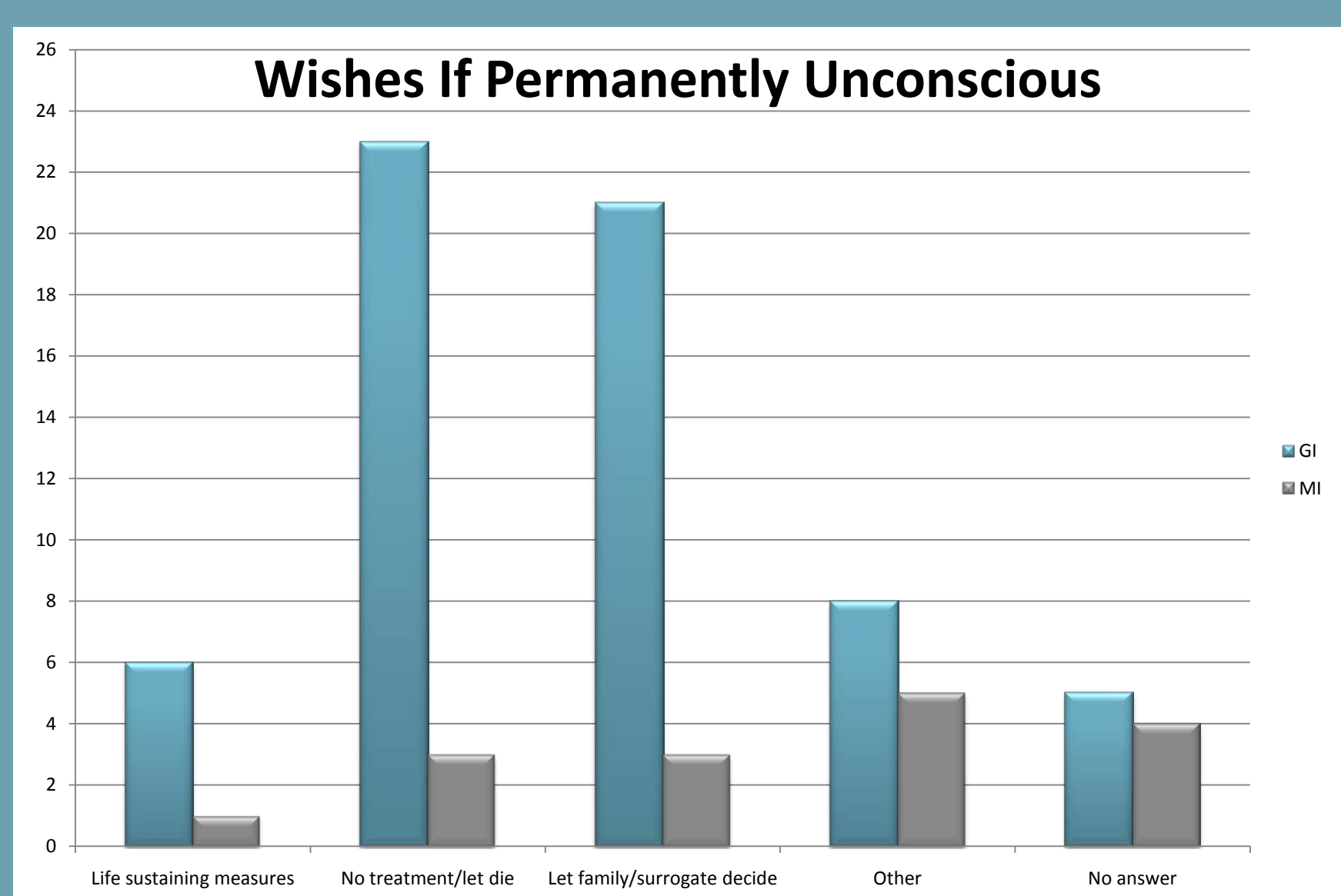
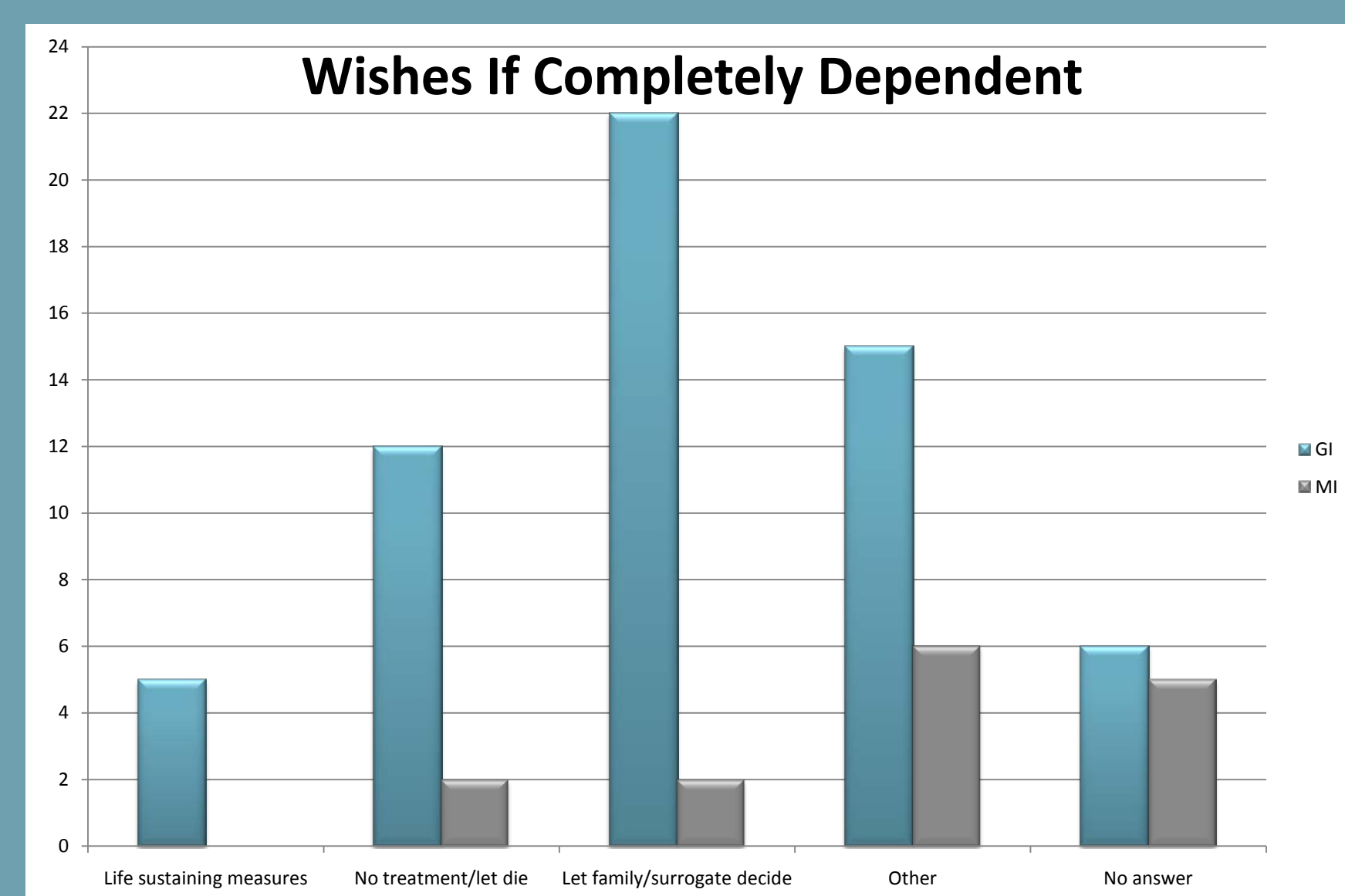
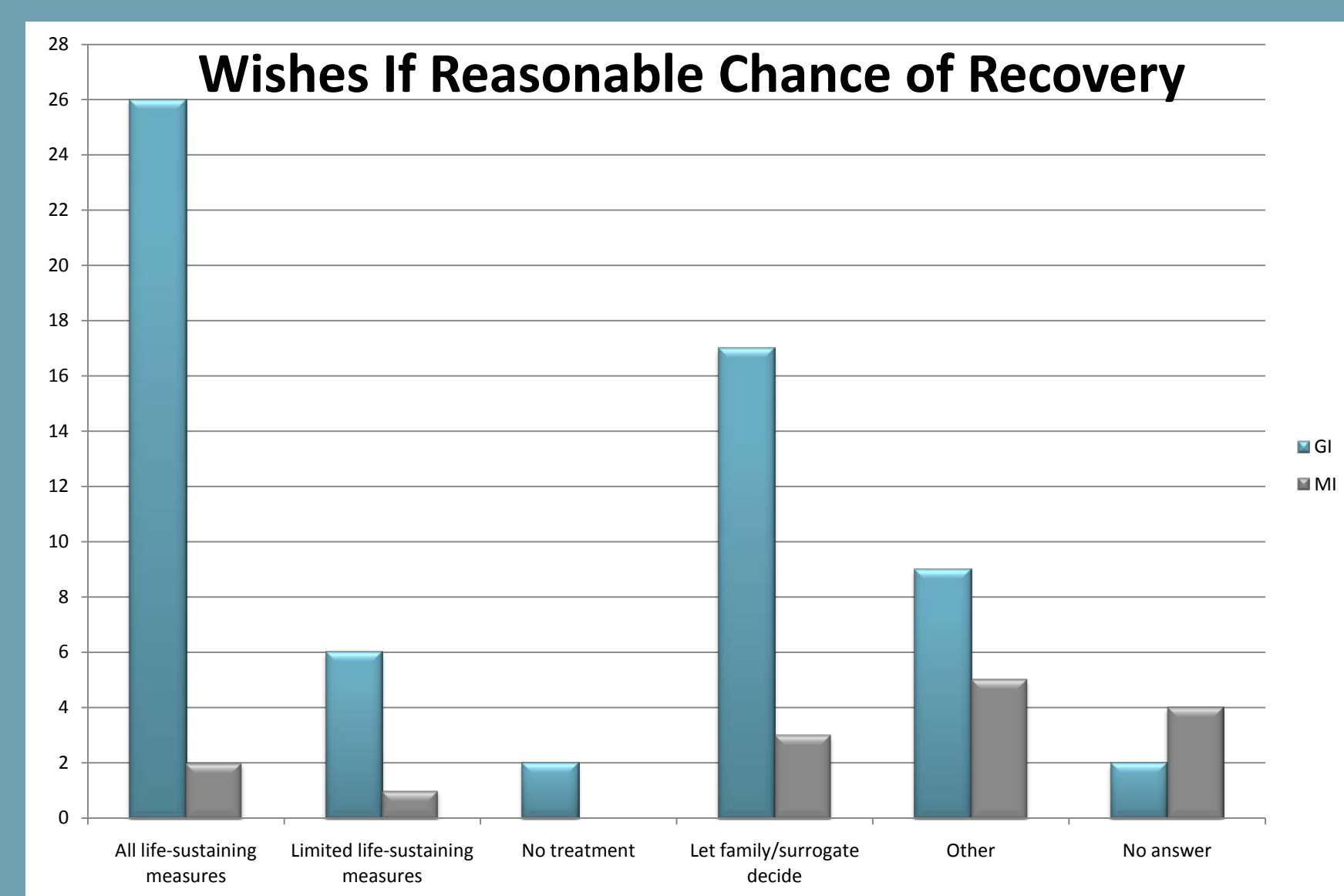
# Homelessness and End of Life Care: Analysis of the Living Wills of Homeless Individuals

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## Treatment data



## Introduction to homelessness and end of life care

Very little is known and few interventions have focused on improving end of life care for underserved populations

Several hundred thousand to several million people in the United States are homeless on a given night; about 7.5% of the US population will be homeless at some point in their lifetime

The number of homeless individuals in Minnesota in 2009 was estimated by the Wilder Research Foundation to be 9,452 youth and adults (46% of the homeless adults had a chronic health illness)

Homeless persons suffer from greater morbidity than any other impoverished population, face great barriers to health care and die at 3 – 10 times the rate than the general population

Advance directives or living wills are documents written by individuals that specify what actions should be taken for their health in the event they are no longer capable to make decisions for themselves

Advance care planning may be beneficial to homeless and other impoverished populations characterized by poor health and poor personal and health care relationships.

## Brief overview of study (methods)

**Recruitment:** 262 individuals were recruited from 8 different sites and programs that serve the homeless in Minneapolis, Minnesota (individuals were required to be at least 18 years old, speak English fluently, have decisional capacity and to have been homeless at any point during the previous 6 months)

**Intervention:** All participants were given the opportunity to complete an advance directive through one of two interventions:

**Minimal intervention (MI):** Individuals were given advance directive forms, educational information and the means to return the advance directive form to study staff

**Guided intervention (GI):** Participants were given the opportunity to return to the site on a subsequent day to receive one-on-one advance care planning counseling from social workers and study staff

**Outcome:** Advance directive completion was higher in the guided intervention group (37.9%) than in the minimal intervention group (12.8%)

**Retention:** To assess the effectiveness of the intervention a site specific follow-up was conducted three months after recruitment in which individuals filled out a survey identical to the one they completed at baseline (175 (57%) of individuals were retained in the study)

**Advance directive analysis:** Advance directives were coded by two investigators and subsequently audited by a single investor (all investigators met on a later date to discuss discrepancies that arose)

## Treatment Discussion

If they had a reasonable chance of recovery, most people (39%) indicated in their advance directives that they would want to receive all life-sustaining measures; many other individuals (28%) specified that they wanted a family member or other surrogate to decide.

If completely dependent, most people (34%) indicated that they wanted a surrogate (most often a family member) to make decisions for them. Discussion of family was a common and surprising occurrence throughout the advance directives, since it is usually thought that most homeless people are estranged from family. In fact, 82% of the individuals in the study appointed a family member as their designated health care agent in their advance directive.

If permanently unconscious, 37% of people wished to forgo treatment and if suffering from a terminal illness 31% of people wished to forgo treatment. These preferences are significantly lower than those expressed in other populations with results ranging from 78% - 94% of individuals wishing to forgo treatment when asked about similar scenarios. (This is most likely the result of mistrust between homeless people and health care professionals)

## Dignity Discussion

When asked "To respect my dignity, people who care for me could do the following:" many people (18%) responded that they simply wanted to be treated respectfully. For example, one person wrote "By not treating me as a child. To respect me as a human being."

When asked "Thinking back over my life, I am most proud of these things:" people gave many specific and poignant responses. 27% of people were proud of their children; 22% were proud of other members of their family; 13% were proud of personal traits and 21% mentioned specific accomplishments they were proud of. These accomplishments included "being able to cook for some very important people" and "worked with the homeless, involved in my community, served on boards."

When asked "I would want to be remembered as a person who:" 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 people said they wanted to be remembered as giving to others when they had nothing to give. One person wanted to be remembered as a person who "had a good heart, loved jazz, who liked to laugh, who gave to people when I did not have much to give, for loving my family."

A surprising result was that health maintenance activities are very important to the homeless. 19% said their goal is to stay healthy or improve their health; 30% listed specific healthcare maintenance activities as their goal. One person's goal was to "keep up with appointments and check medical records after test results."

## References

- Bartels D, Wall M, Ratner E, Ulvestad N, & Song J. Dignity matters: Advance care planning for homeless persons. *Journal of Clinical Ethics* 2008; 19: 214 – 2222
- Deganholtz H, Arnold R, Meisel A, & Lave J. Persistence in racial disparities in advance care plan documents among nursing home residents. *Journal of the American Geriatric Society* 2002; 50: 378 – 81
- Hauser J, Kleefeld S, & Brennan T. Minority populations and advance directives: Insights from a focus group methodology. *Camb Q Healthc Ethics* 1997; 12: 412 – 415
- Resnick B, & Andrews C. End of life treatment preferences among older adults: a nurse practitioner initiated intervention. *Journal of the American Academy of Nurse Practitioners* 2002; 14: 517 – 522
- Song J, Ratner E, & Bartels D. Dying while homeless: Is it a concern when life itself is such a struggle? *Journal of Clinical Ethics* 2005; 16: 251 – 261
- Song J, Wall M, Ratner E, Ulvestad N, Dee D, Gelberg L. Engaging homeless persons in end of life planning. *Journal of General Internal Medicine* 2008; 23: 2031 - 2045
- Tarzian A, Neil M, & O'Neil J. Attitudes, experiences and beliefs affecting end-of-life decision making among homeless individuals. *Journal of Palliative Medicine* 2005; 8: 36 – 48

## Dignity-based questions

