

Family matters: advance care planning for people experiencing homelessness

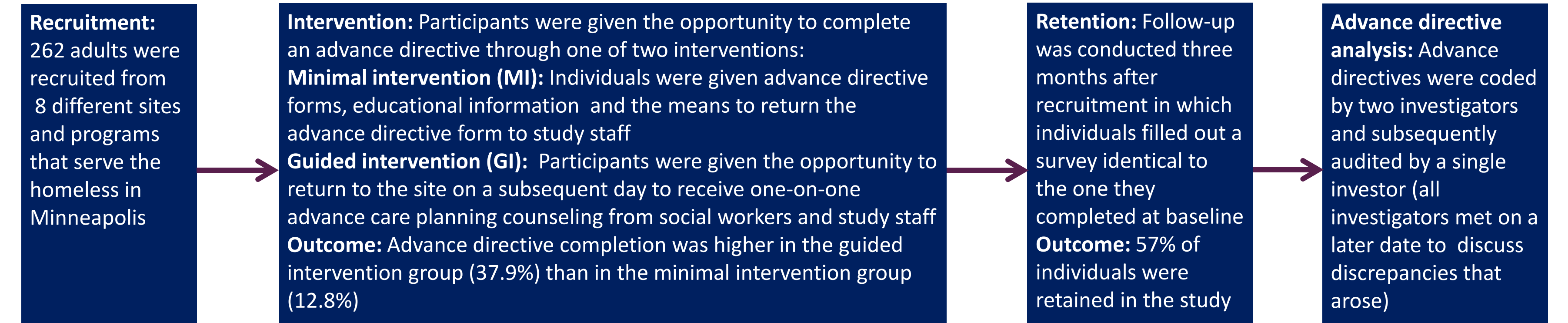
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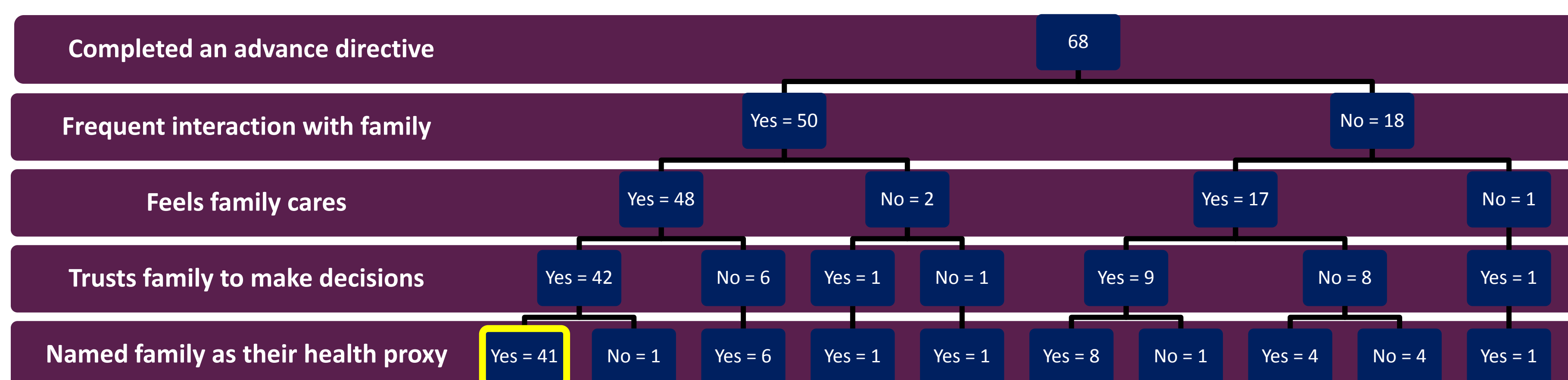
Homelessness and end of life care

- 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 of the general population
- Advance care planning may be beneficial to homeless and other impoverished populations characterized by poor health and poor personal and health care relationships
- Very little is known and few interventions have focused on improving end of life care for underserved populations
- 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
- Literature concerning the family relationships of single homeless adults is scarce (making the belief that homeless individuals are estranged from family a widely exploited assumption)

Study of End of Life Preferences among Homeless People



91 percent of individuals named a family member as a health proxy



Data extraction:

Data about interaction with family and family relationships (family cares and trusts family to make decisions) came from the baseline survey; data about advance directive completion and relationship to health care proxy came from the advance directives

Results:

- 60.3% percent of individuals (N = 41) saw their family regularly, felt that their family cared about them, trusted their family to make decisions concerning them *and* named a family member as a surrogate to make decisions concerning them in case of serious illness or death
- 72.5 percent of individuals (N = 50) reported seeing their family frequently
- Of the individuals that did not see their family regularly, 44.4 percent (N = 8) still felt as if their family cared about them, trusted their family to make decisions concerning them *and* named a family member as a surrogate to make decisions concerning them in case of serious illness or death
- 95.5 percent of individuals (N = 65) reported that they believed their family cared about them
- 77.9 percent of individuals (N = 53) reported that they would trust their family to make decisions for them in the case that they could not make decisions for themselves
- 91 percent of individuals (N = 62) named a family member whom they would like to make decisions for them in the case of serious illness or death

Conclusions:

These data negate the widely held assumption that homeless individuals are estranged from family and lack strong personal relationships

References regarding family appeared in ever question in the advance directive in six major themes

Theme: Evidence of strong family values and relationships (N = 73 responses):

- “Love my family and friends.”
- “Was a good father & brother & child.”
- “Loves his kids and their mothers very much.”
- “That my family has finally lifted themselves up by their bootstraps, from economic poverty.”
- “My kids & my parents. I’m proud of my family & proud to be in the family I was born in.”

Theme: Want family to make decisions in case of serious illness or death (N = 67 responses):

- “My parents know what to do.”
- “I would want it to be told to my mother, and allow her to make any decisions concerning me.”
- “Family and best friends visitations. Make sure my girls are okay, and help them in helping me, and them. My mother, and oldest daughter make any serious, life-threatening decisions, and if re-married, my spouse.”
- “The family to decide.”

Theme: After death family concerns (N = 58 responses):

- “I just want my family to carry on my respect when I’m gone.”
- “Do what you know I would expect for you. Help my beautiful daughters become the young, lovely ladies I know they can be.”
- “follows my wishes, continue you respect me and show my kids that there is a better way”
- “My children stay together, keep the family brother and well help each other.”

Theme: Evidence of strained or nonexistent family relationships (N = 25 responses):

- “Family not understanding my CD problems”
- “My sister she is still on the streets.”
- “They’ll just forget about me. Please don’t stress my kids out.”
- “Things with my family are not as good as I want them to be.”
- “My family needs to do what they have for their selves –Don’t worry about me!”

Theme: Do not want to burden or stress family (N = 21 responses):

- “No one will no who I am. Tragic circumstances that would obligate my family into ruin (financial consequences of medical costs), funeral/burial – who will pay for this?”
- “Refuse to be a burden to family, friends or others.”
- “My kids, I worry if they will be ok. My mom and my siblings because we’ve had so much loss recently.”

Theme: Want family to be there/be notified in case of serious illness or death (N = 19 responses):

- “Get of hold of my family and explain to them my situation on what going on.”
- “My mother to be notified.”
- “My family knows about my health conditions. I don’t want my family with no surprises. I want to know everything.”