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Age, Self-Reported Health, and End-of-Life Planning among Young and Middle-Aged American Couples

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Abstract

Objectives: We use the transtheoretical model of health behavior change to explain why rates of end-of-life planning remain low in the general population, and why surrogate decision-makers are often inaccurate about patients' end-of-life preferences.

Methods: We use quantitative data from an internet survey conducted between July and October 2010. This cross-sectional study included a sample of 2,150 participants between 18 and 64 years of age who belonged to one of 1,075 married or cohabiting heterosexual couples residing in the United States.

Results: Older age is associated with a greater likelihood of having executed a living will and/or appointed a durable power of attorney for health care. Older age and poorer health are associated with a greater likelihood of having discussed one's end-of-life health care treatment preferences with someone. Reasons for failing to plan differ by age and health status. The status of one's own end-of-life planning is unrelated to one's ability to accurately nominate one's partner's treatment preferences.

Discussion: A person's readiness to plan for end-of-life appears to differ across planning behaviors. Age and health are related to aspects of one's own end-of-life planning, but none of these factors are related to accuracy as a romantic partner's surrogate.

Keywords: advance care planning, death and dying, dyadic data, medical decision making

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People readily identify health states they consider to be “worse than death,” typically in situations where prognosis is poor and the duration of distress is extended (Sharma & Stano, 2010). However, terminally ill patients are not often able, either physically or mentally, to articulate their medical treatment preferences so as to avoid these states. There are legal mechanisms, called advance care plans, available to address this eventuality (Castillo et al., 2011). While healthy, a person may execute a document called a living will, and/or may appoint a representative known as a durable power of attorney for health care (DPAHC). Living wills detail the specific treatments a person would or would not want if in a certain health state. For instance, a person could stipulate that if he is brain-dead, he would not want cardiopulmonary resuscitation (CPR). A DPAHC is a person who is charged with making medical decisions on behalf of an incapacitated patient. Advance care plans are associated with use of hospice care and good medical team / family communication at end-of-life (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). In addition to completing formal advance care plans, individuals can also plan in informal ways: Discussion of preferences with family and physicians results in care that is more consistent with patients’ wishes than the care of persons who had no plans (Mack, Weeks, Wright, Block, & Prigerson, 2010).

Research shows that efforts to increase rates of discussion and advance care planning have been very successful among certain high-risk groups. Among nursing home residents, 70% have a living will and/or DPAHC (Resnick, Schuur, Heineman, Stone, & Weissman, 2009). Among decedents who resided in a health care system with a comprehensive end-of-life planning intervention program, 90% had advance care plans (Hammes, Rooney, & Gundrum, 2010). Yet rates of end-of-life planning remain low in the general population. In a 2007 survey of Maryland residents, 45% of adults aged 65 or older had advance care plans, but only a third of all adults aged 18 and older had them (Pollack, Morhaim, & Williams, 2010). Further, advance care plans may go awry if not accompanied by thoughtful discussions. Numerous studies that match participants’ preferences against their surrogates’ guesses of those preferences indicate that DPAHCs are no better than chance at identifying preferences (Shalowitz, Garrett-Meyer, & Wendler, 2006).

In the present study, we employ the transtheoretical model of health behavior change (TTM) to explain why rates of planning remain so low in the general population, and why surrogates are often inaccurate. We address these questions in a nationally representative sample of 1,075 heterosexual American couples aged 18 to 64. We focus on couples because a romantic partner is often a key individual in end-of-life planning: Among married older persons who have appointed a DPAHC, nearly three-quarters have appointed their spouse, and among married older persons who have not yet appointed a DPAHC, over three-quarters intend for their spouse to serve that role (Carr & Khodyakov, 2007; Moorman, 2011). We first explore how age and health status are related to (a) one’s own end-of-life planning, and (b) the reasons individuals without plans give for their choices. We then examine how one’s own planning status is associated with one’s knowledge of one’s partner’s treatment preferences. This information may help health care professionals to improve patients’ preparation for death and dying.

The Transtheoretical Model of Health Behavior Applied to Advance Care Planning

The TTM is an interdisciplinary framework that treats medical decision-making as a process that occurs over time, rather than an event that occurs at a point in time (Prochaska, 2008). It includes four stages of change, which describe how individuals move from having no intention to change their behavior (precontemplation), to considering a change (contemplation), committing to a change (preparation), and completing the change (action/maintenance). The four stages are marked by patients' shifting assessments of the ratio of the costs of change to the benefits of change (Prochaska, 2008).

Recently, health scholars have begun using the TTM to assess advance care planning (e.g., Finnell et al., 2011; Fried et al., 2010; Sudore et al., 2008). Individuals with no intention to plan are in the precontemplation stage. Those who intend to complete advance care plans within six months are in the contemplation stage; those who intend to complete plans within the next 30 days are in the preparation stage; and those who have completed plans are in the action / maintenance stage. Together, these studies conclude that beginning the process of end-of-life planning well in advance of health crises helps to ensure that by the time a patient requires end-of-life care, he or she has advanced beyond precontemplation.

Age, Health Status and Advancing Individuals Past Precontemplation

Despite health care professionals' encouragement to begin planning early, the positive association between age and advance care planning is well-documented: The older a person is, the more likely he or she is to have an advance care plan (Alano et al. 2010; Pollack, Morhaim, & Williams, 2010). Life expectancy at birth in the United States today is 75.7 years for men and 80.6 years for women (Kochanek, Xu, Murphy, Miniño, & Kung, 2011). The three leading causes of death – cancer, heart disease, and stroke – are chronic illnesses that manifest their symptoms over the course of many years and typically do not result in death until later life. These facts seem to have generated normative expectations; although few individuals possess detailed knowledge about mortality trends, subjective estimates of life expectancy are similar to actuarial estimates (Mirowsky, 1999). Therefore, young people may remain in the precontemplation stage, feeling that they have plenty of time ahead of them in which to plan.

But do young people remain “precontemplators” because they are young, or because they are healthy? Prior studies have conflated age and health status by limiting participants to older persons, recruiting participants from health care settings, and/or excluding measures of participants’ general health. However, Americans associate illness with advance care planning. In one study, the most frequent reason older adults visiting a general medical clinic gave for not having plans was that they were “too healthy” (Schickedanz et al., 2009). The most frequent reason Maryland residents gave for having an advanced care plan was a medical condition or diagnosis (Pollack, Morhaim, & Williams, 2010). The distinction between age and health is important: Campaigns to increase rates of advance care planning may well fail unless they use stage-appropriate methods to target the barriers to planning (Prochaska, Redding, & Evers, 2008). Thus, we ask the research questions:

> Research Question 1: Holding sociodemographic characteristics constant, what are the relationships among health status, age, and completion of end-of-life healthcare planning?
>
> Research Question 2: Do the reasons participants give for having no plans differ by age and health status?

Surrogate Accuracy and the Action Stage

The TTM has not yet been applied to research on surrogate accuracy, but it may serve as a helpful conceptual tool in this area of research. Thus far, researchers have been unable to identify many predictors of surrogate accuracy. One study indicates that DPAHCs do better when both surrogate and patient are African-American rather than white (Schmid, Allen, Haley,

& DeCoster, 2010). Another found that spouses are more accurate surrogates than are adult children (Parks et al., 2011). But men and women are equally poor surrogates, the surrogates of persons in poor health are no more likely to be accurate than the surrogates of persons in good health, and most disturbingly, discussions between patient and surrogate have no effect on surrogate accuracy (Ditto et al., 2001; Moorman, Hauser, & Carr, 2009). The strongest predictor of surrogate accuracy is the surrogate's preference for his or her own care (Moorman, Hauser, & Carr, 2009). That is, surrogates project their own preferences onto the patient for whom they are making decisions.

In this paper, we test a new factor: a surrogate's progress through the stages of change. Perhaps only surrogates who are in the action stage themselves are able to fully empathize with patients' preferences. Studying middle-aged members of a health insurance plan, Finnell and colleagues (2011) found that the stages of change were marked by participants' attitudes towards DPAHC appointment. Precontemplators were most opposed to thinking about end-of-life, contemplators and preparers perceived that advantages and disadvantages were balanced, and actors recognized the most benefits to preparing for end-of-life. If avoidant attitudes prevent a person from making his or her own plans, they may also prevent that person from understanding others' plans and performing accurately as a surrogate.

> Research Question 3: Holding sociodemographic characteristics constant, are a surrogate's own end-of-life plans related to his/her ability to correctly nominate his/her partner's treatment preference?

Method

Data

We used data from an internet survey conducted by Knowledge Networks, in conjunction with the National Center for Family and Marriage Research at Bowling Green State University, between July and October of 2010. This cross-sectional study included a sample of 2,150 participants between 18 and 64 years of age who belonged to one of 1,075 married or cohabiting heterosexual couples residing in the United States. Seventy percent of the couples were married and 30% were cohabiting.

In 1999, Knowledge Networks established the first online research panel (KnowledgePanel) that is a representative sample of the entire U.S. population, using probability-based sampling methodology that covers both the computer user and non-computer user populations. If the panel members did not have access to the Internet, the necessary equipment was provided. Recent research on survey methods indicated that a survey using the KnowledgePanel was comparably nationally-representative to a random-digit-dial (RDD) telephone survey (Chang & Krosnick, 2009). Additionally, data from KnowledgePanel internet participants were superior in reliability and validity to data from the RDD telephone survey.

The couples in this study were primarily recruited from the KnowledgePanel. Of the 70% of the sample comprised of married couples, all participants (i.e., both husbands and wives) were panelists. Of the 30% of the sample comprised of cohabiting couples, a third of participants (i.e., both partners) were panelists. An additional two sources were used to generate the remaining sample of cohabiting couples: Ten percent of cohabiting couples were comprised of a KnowledgePanel member and partner who was not on the panel, and 57% of cohabiting couples were comprised of two partners recruited through online advertisements (i.e., a non-probability sample).

Response rates varied by recruitment method. To be counted as a valid response, both partners in the couple had to complete a valid survey. Recruitment within the panel yielded a 50% response from married couples and a 41% response from cohabiting couples. Recruitment of panel members and their non-panel-member partners yielded only a 5% response rate. Response rates are not calculable for convenience samples, so response to the web advertisement is unknown.

End-of-Life Planning

Formal end-of-life care planning was assessed based on the following two questions: "Have you made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself? This is sometimes called a durable power of attorney for health care," and "Do you have a living will or advance directive? These are written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate." The formal end-of-life care planning variable has two mutually-exclusive categories: *has any formal plans (a living will and/or a DPAHC)*, and *has no formal plans (neither a living will nor a DPAHC)*. (A living will and a DPAHC have different effects on end-of-life care, such that there may be differences between persons who complete one but not the other. However, only 65 [3.1%] participants had a living will only, and 112 [5.3%] participants had a DPAHC only, making these two subgroups too small for statistical analysis.)

End-of-life discussion is a dichotomous variable that is based on the following question: "Have you discussed with anyone plans about the types of medical treatment you want or don't want if you become seriously ill in the future?" Those who had had a discussion were coded as 1 and those who had not were coded as 0.

Reasons for Having No Plans

Participants without a DPAHC, living will, or discussion were asked reasons why they had not completed formal planning. They were provided with eight closed-ended responses and asked to endorse as many reasons as applied. Reasons were aggregated into four codes. The category "Lacking information" included "I did not know this measure existed," "I do not know how to go about doing this," and "I do not believe this measure affects treatment." The category "Death avoidance" included "I have not thought about my treatment preferences," and "I do not want to think about dying and illness." The category "Other persons" included "My preferences are already known to others" and "I do not want to burden anyone with this responsibility." Finally, the category "Current good health" included "My health is currently good." Participants who had had no discussion were tallied in all categories in which they endorsed at least one reason. Participants who had neither a living will nor a DPAHC were tallied in all categories in which they endorsed at least one reason, regardless of whether it was a reason given for having no living will or a reason for having no DPAHC.

Knowledge of Partner's Preference

Participants were told "We have some questions about the kind of decisions you might make when considering your own health at the end of life. Suppose *you* had a serious illness today with very low chances of survival. What if you were mentally intact, but in severe and constant physical pain?" Participants answered using a scale ranging from 0 (*stop all life-prolonging treatment*) to 10 (*continue all treatment*). Then they were asked "Now please think about your spouse or partner. Suppose *your spouse/partner* had a serious illness today with very low chances of survival. What if s/he were mentally intact, but in severe and constant physical pain?" The participants then selected the number between 0 and 10 that they felt best represented the level of treatment their partner would like.

We constructed two outcome variables matching one partner's guess against the other partner's reported preference. One variable subtracted each male partner's actual preferences from his female partner's guess of his preference, and the other subtracted each female partner's actual preferences from her male partner's guess. Therefore, a score of 0 represented accuracy, while positive scores indicated an error of overtreatment – a partner believing that the other wanted more care than he or she indicated wanting – and negative scores indicated an error of undertreatment – a partner believing that the other wanted less care than he or she indicated wanting. These variables had few extreme values, and so we made them categorical as follows: under by 3 or more, under by 1-2, accurate, over by 1-2, over by 3 or more. The results are robust to alternate functional forms of these variables.

Age and Self-Reported Health

Our main independent variables of interest for the first research question are participants' age and their health status. *Age* is originally a continuous variable which ranges from 18 to 64 years of age. We recoded it into a three-category variable: *young* (18-34, born 1976-1992), *midlife* (35-49, born 1961-1975) (reference category), and *late midlife* (50-64, born 1946-1960). The results are robust to alternate functional forms of this variable.

For the third research question, on couple concordance, age was entered into regressions as a couple-level characteristic. In most couples, both partners were in the same age group (i.e., young, midlife, late midlife). In 192 couples, partners were in different age groups and were therefore coded as belonging to the age group of the oldest partner. (Even here, most age differences were small; for instance, a 51-year-old husband married to a 49-year-old wife.)

Perceived health status was derived from the following question: “In general, would you say your health is excellent, very good, good, fair, or poor?” The data showed skew; 88.0% of participants reported that their health was excellent, very good, or good. Therefore the variable was dichotomized such that *fair* and *poor* are coded as 1, and *good, very good* and *excellent* are coded as 0.

For the third research question, on couple concordance, health status was entered into regressions as a couple-level characteristic. The reference category was comprised of men in good, very good, or excellent health (i.e., healthy) partnered with women in good, very good, or excellent health. The remaining categories included men in fair or poor health (i.e., unhealthy) partnered with healthy women, unhealthy women partnered with healthy men, and couples in which both partners were unhealthy.

Individual Sociodemographic Characteristics

We also assessed participants’ socio-demographic characteristics, including education, race and gender. *Education* is a variable with three categories: *high school or less* (reference category), *some college education*, and *bachelor’s degree or higher*. *Race* has four categories: *white non-Hispanic* (reference category), *Black non-Hispanic*, *Hispanic*, and *other*. The “other” category included the 39 respondents who reported belonging to two or more racial categories. *Female* is a dichotomous variable where *women* are coded as 1 and *men* form the reference category.

Couple Sociodemographic Characteristics

Sociodemographic characteristics of the couple included relationship status and household income. *Cohabiting* refers to a couple's current relationship status; those who are *cohabiting* with a romantic partner are coded as 1, and those who are *married* comprise the reference category. *Annual household income* is an ordinal variable with 19 categories; the smallest category is "*less than $5,000*," and the largest category is *"$175,000 or more*."

Analytic Strategy

For the first research question, on health, age, and individual planning, the unit of analysis was the individual. Because married or cohabiting couples were the primary sampling units during data collection, the data violate the regression assumption that observations are independent. To adjust for the within-couple correlations, results were corrected for the clustering of 2,150 individuals in 1,075 couples. We tested the question through a sequence of binary logistic regression models, comparing (a) persons with any formal plans to persons with no formal plans, and (b) persons who reported discussions to persons who said they had not had discussions. For each outcome, the first model included age, health status, and sociodemographic characteristics as independent variables. The second model included age, health status, their interaction, and sociodemographic controls as independent variables.

The second hypothesis concerned age and health differences in the reasons given for having no plans. Chi-square tests were used to compare the proportion of persons in each age / health group who agreed with a reason. The third hypothesis, on couple concordance, was tested through multinomial logistic regression models. Independent variables included the planning status of both partners, the guessing partner's sociodemographic characteristics, and couple characteristics.

All analyses, both descriptive and multivariate, were weighted to adjust for differences in probability of selection. Use of the weights rendered the sample representative of the U.S. population. The statistical software package Stata 11 includes a set of commands for the analysis of complex survey data; these were used to apply the weight and correct for clustering. The majority of cases had complete data on the measures of interest. Income was the variable missing the most observations, at 44 (2%) cases. Therefore, listwise deletion was used.

Results

Descriptive Statistics

Similar to prior research, few of these young and middle-aged adults had planned for end-of-life. Only 28% had any formal advance care plans (i.e., a living will and/or DPAHC). Slightly over half (55%) reported having discussed their end-of-life treatment preferences with another person. The average participant's treatment preference was not extreme: On a scale ranging from 0 (*stop all life-prolonging treatment*) through 10 (*continue all treatment*), the mean score was 5.23 (*SD* = 3.60). Using the same scale, the average participant thought that their partner's treatment preference would be 5.51 (*SD* = 3.58). Please see Table 1 for descriptive statistics on all variables used in the analysis.

[Table 1 about here]

Health Status, Age, and Individual Planning

Age was associated with completion of a living will and/or DPAHC. Each age group was successively more likely to have formal plans: the youngest adults (aged 18-34) had 35% lower odds of having plans compared to adults in midlife (aged 35-49) ($p < .05$), while adults in late midlife (aged 50-64) had 88% higher odds of having plans compared to the adults in midlife ($p < .001$). Self-reported health status was not a significant predictor of formal planning. These results are presented in Table 2. Further, age and health status did not have a statistically significant interactive relationship to formal planning (not shown).

Both age and self-reported health were significantly associated with the odds of having held a discussion. Adults in late midlife had 79% higher odds of having had a discussion than adults in midlife ($p < .001$). Persons in fair or poor health had 85% higher odds of having had a discussion than persons in good, very good, or excellent health ($p < .01$). As with formal planning, the interaction of age and health was not significant for discussion (not shown).

[Table 2 about here]

Reasons for Having No Plans

The reasons participants in each age and health status category endorsed for having no plans can be found in Table 3. For formal plans, the proportion of each age/health group selecting the reason differed significantly for all four reasons. Of the six groups, both healthy and unhealthy young adults were the most likely to say that they lacked information about advance care planning, and that they preferred not to think about death. Persons in poor health in midlife and late midlife were the most likely to cite concerns related to other persons. The three groups in good health were much more likely than the three groups in poor health to say that health was a reason not to plan.

For discussion, the proportion of each age/health group selecting the reason differed significantly for two reasons. Persons in poor health in midlife and late midlife were the most likely to cite concerns related to other persons. Healthy persons of all ages were more likely than their unhealthy peers to say they were too well to need to discuss preferences.

[Table 3 about here]

Partner Accuracy

Contrary to expectations, one's own planning had little to do with one's ability to correctly nominate one's partner's preferences. Women who had any formal plans were more likely to be accurate than to make a small error of overtreatment; otherwise, no comparisons were statistically significant. Complete results for female surrogates are presented in Table 4. There were no statistically significant gender differences; that is, men's planning status was similarly unrelated to their accuracy in nominating women's preferences. Therefore, results for men are not shown, but are available from the first author upon request.

[Table 4 about here]

Discussion

This internet survey of 1,075 married or cohabiting couple dyads aged 18-64 revealed three new findings about end-of-life planning in the United States. First, age and health appear to have independent relationships to end-of-life planning, with age being the foremost of the two factors. Second, persons of different ages and health statuses give different reasons for not having plans. Third, one's own readiness to plan does not render one ready to perform as a surrogate for one's partner; individual end-of-life planning was unrelated to accuracy of proxy reports of partners' treatment preferences. These results indicate potential new directions for public health campaigns related to end-of-life health care preparation.

Age, Health, and Stages of Change

The findings in this study expand upon those of other recent research, using the framing principles of the TTM. In this study, 28% of adults 18-64 had reached the action stage with regard to formal end-of-life plans; this figure is close to the 34% reported in a representative sample of Maryland residents aged 18 and older (Pollack, Morhaim, & Williams, 2010). Over half (55%) had discussed their care preferences with someone.

As in prior studies, age was a strong predictor of planning status, with older adults more likely to have both formal and informal plans (Alano et al., 2010). TTM studies of a wide range of health behaviors, including cervical cancer screening, smoking, physical exercise, in populations including Taiwanese women, American smokers, Norwegian primary care patients, have found older age to be associated with the action stage and more successful behavior change (Sorensen & Gill, 2008; Tung, Lu, & Cook, 2010; Velicer, Redding, Sun, & Prochaska, 2007). Poorer health status was related to increased likelihood of informal planning only. Prior studies of end-of-life have had limited power to tease apart age and health status, but like the present study those studies indicate that a relationship between health and planning is only evident for certain measures of health, and certain end-of-life planning behaviors (e.g., Carr & Khodyakov, 2007; Fried et al., 2010). The present study is among the first to examine the interaction between age and health in end-of-life planning; we found no interactive association. Our research suggests that age is not a simple proxy for poorer health status. Future research might examine whether time-based factors such as birth cohort or duration of a negative health habit explain a general link between age and openness to health behavior change.

Processes of Change and Preparing for End-of-Life

Age and, for informal planning, health status were associated with one’s stage of change. These findings alone do not suggest fruitful directions for intervention work, because age and health are not readily alterable factors. However, there were also age and health differences in the reasons non-planners gave for lacking plans, which are alterable (Schickedanz et al., 2009). Therefore, a patient’s age and health status may tell a health care professional something about that person’s stage of change, allowing for quick and efficient targeting of information about end-of-life planning.

Prochaska and colleagues (2008) stress the importance of matching processes of change to an individual’s stage of change. Three of the four reasons for not planning offered in this study – lacking information about planning, wish to avoid thinking about death, and current good health – seem indicative of the precontemplation stage of change in which people do not even consider planning. Younger persons were most likely to name the first two as reasons they had no formal plans, and healthy persons of all ages were most likely to raise the third for both formal and informal plans. Reasons concerning other persons, including the belief that others already know one’s preferences and the desire to avoid burdening others, may be signs of the contemplation stage, wherein people consider planning but continue to focus on the reasons to refrain. Unhealthy persons in both midlife and late midlife were most likely to mention other persons. The processes of change most effective for moving persons beyond precontemplation include consciousness raising, dramatic relief, and environmental reevaluation, while self-reevaluation helps people to move from contemplation to preparation (Prochaska et al., 2008).

Therefore, practical factual information (i.e., consciousness-raising) about why end-of-life planning is important and how it is done is likely to appeal to young and healthy pre-contemplators. However, informational interventions may fail if they do not also include emotional material or raise empathy (i.e., dramatic relief and environmental reevaluation). Indeed, qualitative research indicates that adults identify concern for self or others and stories, experiences, and anecdotal evidence as the major influences on their planning behavior (Levi, Dellasega, Whitehead, & Green, 2010). Older or unhealthy persons may respond best to self-reevaluation, or clarification of values. Experts in end-of-life care recognize the difficulty of making decisions about specific treatments in advance, and instead stress the importance of value statements that can inform decision-making (Sudore & Fried, 2010).

Perspectives on Surrogate Decision-Making

Based on the TTM explication of stages of change and the associated attitudes towards health behaviors, we hypothesized that completion of plans might be associated with ability to understand one's partner's treatment preferences, whereas those who resisted planning for themselves might also resist a partner's attempts to plan. However, completion of one's own end-of-life plans was unrelated to accuracy at guessing one's partner's preferences. Although Sudore and colleagues (2008) found that communication appeared to be a precursor to the action stage of completing legally-recognized plans, Fried and colleagues (2010) found that end-of-life planning behaviors were independent. For example, one could have executed a living will but still have no intention to discuss it with family or physicians. Our results lend some support to Fried and colleagues' conclusion: Being in the action stage with regard to one's own plans appears unrelated to one's stage of preparation to serve as a surrogate decision-maker.

Limitations

This study is limited in several important respects. First, although the sample is a national one, design elements such as selection of heterosexual couples only prevent it from being truly nationally-representative. There is also debate about how representative an internet survey can possibly be, even when the sample is constructed using random digit dial (as large parts of this sample were), given that the internet-using population is (a) innumerable and (b) unlikely to have similar sociodemographic characteristics to the national population (Chang & Krosnick, 2009).

Second, self-reported health was our only measure of health. Self-reported health is a strong measure, independently predictive of mortality (DeSalvo, Bloser, Reynolds, He, &

Munter, 2006). Yet future research should examine the relationship of end-of-life planning to additional aspects of health, such as degree of functional limitation, number of hospitalizations, or disease diagnoses. Such research could help explain the circumstances under which health status is related to planning.

Finally, we provided closed-ended response options to questions about why individuals did not have end-of-life plans. Closed-ended responses might enable participants to choose socially-desirable answers, or to fail to report any additional reasons. In-depth interviews or focus groups may be better methods to elicit the reasons why people do not plan for end-of-life.

Conclusion

This study joins the recent wave of interest in applying the transtheoretical model of health behavior change as a framework for thinking about planning for end-of-life health care. Because end-of-life plans take shape over the course of time, we feel that the aspects of the TTM that treat change as a process are well-suited to the end-of-life context. Future use of the TTM may allow scholars and practitioners to design new methods of helping patients to prepare for their own death and dying, as well as that of close others.

References

Alano, G. J., Pekmezaris, R., Tai, J. Y., Hussain, M. J., Jeune, J., Louis, B., … Wolf-Klein, G. P. (2010). Factors influencing older adults to complete advance directives. *Palliative and Supportive Care*, *8*(3), 267-275. doi: 10.1017/S1478951510000064

Carr, D., & Khodyakov, D. (2007). End-of-life health care planning among young-old adults: An assessment of psychosocial influences. *Journal of Gerontology: Social Sciences, 62B*(2): 135-S141.

Castillo, L. S., Williams, B. A., Hooper, S. M., Sabatino, C. P., Weithorn, L. A., & Sudore, R. L. (2011). Lost in translation: The unintended consequences of advance directive law on clinical care. *Annals of Internal Medicine, 154*(2), 121-128.

Chang, L. & Krosnick, J. A. (2009). National surveys via RDD telephone interviewing versus the Internet. *Public Opinion Quarterly, 73*(4), 641-678. doi: 10.1093/poq/nfp075

DeSalvo, K. B., Bloser, N., Reynolds, K., He, J., & Munter, P. (2006). Mortality prediction with a single general self-rated health question: A meta-analysis. *Journal of General Internal Medicine, 21*(3), 267-275. doi: 10.1111/j.1525-1497.2005.00291.x

Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dresser, R., … Zyzanski, S. (2001). Advance directives as acts of communication: A randomized controlled trial. *Archives of Internal Medicine, 161*(3), 421-430.

Finnell, D. S., Wu, Y. B., Jezewski, M. A., Meeker, M. A., Sessanna, L., & Lee, J. (2011). Applying the transtheoretical model to health care proxy completion. *Medical Decision Making, 31*(2): 254-259. doi: 10.1177/0272989X10379917

Fried, T. R., Redding, C. A., Robbins, M. L., Paiva, A., O'Leary, J. R., & Iannone, L. (2010). Stages of change for the component behaviors of advance care planning. *Journal of the American Geriatrics Society, 58*(12), 2329-2336. doi: 10.1111/j.1532-5415.2010.03184.x

Hammes, B. J., Rooney, B. L., & Gundrum, J. D. (2010). A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *Journal of the American Geriatrics Society, 58*(7), 1249-1255. doi: 10.1111/j.1532-5415.2010.02956.x

Kochanek, K. D., Xu, J., Murphy, S. L., Miniño, A. M., & Kung, H. (2011). Deaths: Preliminary data for 2009. *National Vital Statistics Reports, 59*(4), 1-69.

Levi, B. H., Dellasega, C., Whitehead, M., & Green, M. J. (2010). What influences individuals to engage in advance care planning? *American Journal of Hospice and Palliative Medicine, 27*(5), 306-312. doi: 10.1177/1049909109355280

Mack, J. W., Weeks, J. C., Wright, A. A., Block, S. D., & Prigerson, H. G. (2010). End-of-life discussions, goal attainment, and distress at end-of-life: Predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology, 28*(7), 1203-8. doi: 10.1200/JCO.2009.25.4672

Mirowsky, J. (1999). Subjective life expectancy in the US: Correspondence to actuarial estimates by age, sex, and race. *Social Science and Medicine, 49*(7), 967-979. doi:10.1016/S0277-9536(99)00193-8

Moorman, S. M. (2011). The importance of feeling understood in marital conversations about end-of-life health care. *Journal of Social and Personal Relationships, 28*(1), 100-116. doi: 10.1177/0265407510386137

Moorman, S. M., Hauser, R. M., & Carr, D. (2009). Do older adults know their spouses' end-of-life treatment preferences? *Research on Aging, 31*(4), 463-491. doi: 10.1177/0164027509333683

Parks, S. M., Winter, L., Santana, A. J., Parker, B., Diamond, J. J., Rose, M., & Myers, R. E. (2011). Family factors in end-of-life decision-making: Family conflict and proxy relationship. *Journal of Palliative Medicine, 14*(2), 179-184. doi: 10.1089/jpm.2010.0353

Pollack, K. M., Morhaim, D., & Williams, M. A. (2010). The public's perspectives on advance directives: Implications for state legislative and regulatory policy. *Health Policy, 96*() 57-63. doi:10.1016/j.healthpol.2010.01.004

Prochaska, J. O. (2008). Decision making in the transtheoretical model of behavior change. *Medical Decision Making, 28,* 845-849. doi: 10.1177/0272989X08327068

Prochaska, J. O., Redding, C. A., & Evers, K. E. (2008). The transtheoretical model and stages of change. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice* (pp. x-c). San Francisco, CA: Jossey-Bass.

Resnick, H. E., Schuur, J. D., Heineman, J., Stone, R., & Weissman, J. S. (2009). Advance directives in nursing home residents ≥ 65 years: United States 2004. *American Journal of Hospice and Palliative Medicine, 25*(6), 476-482. doi: 10.1177/1049909108322295

Schickedanz, A. D., Schillinger, D., Landefeld, C. S., Knight, S. J., Williams, B. A., & Sudore, R. L. (2009). A clinical framework for improving the advance care planning process: Start with patients' self-identified barriers. *Journal of the American Geriatrics Society, 57*(1), 31-39. doi: 10.1111/j.1532-5415.2008.02093.x

Schmid, B., Allen, R. S., Haley, P. P., & DeCoster, J. (2010). Family matters: Dyadic agreement in end-of-life medical decision making. *The Gerontologist, 50*(2), 226-237. doi:10.1093/geront/gnp166

Shalowitz, D. I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine, 166*(5), 493-497.

Sharma, R., & Stano, M. (2010). Implications of an economic model of health states worse than dead. *Journal of Health Economics, 29*(4), 536-540. doi: 10.1016/j.jhealeco.2010.05.005

Sorensen, M., & Gill, D. L. (2008). Perceived barriers to physical activity across Norwegian adult age groups, gender, and stages of change. *Scandinavian Journal of Medicine & Science in Sports, 18*, 651-663. doi: 10.1111/j.1600-0838.2007.00686.x

Sudore, R. L., & Fried, T. R. (2010). Redefining the “planning” in advance care planning: Preparing for end-of-life decision making. *Annals of Internal Medicine, 153*(4), 256-261.

Sudore, R. L., Schickedanz, A. D., Landefeld, S., Williams, B. A., Lindquist, K., Pantilat, S. Z., & Schillinger, D. (2008). Engagement in multiple steps of the advance care planning process: A descriptive study of diverse older adults. *Journal of the American Geriatrics Society, 56*(6), 1006-1013. doi: 10.1111/j.1532-5415.2008.01701.x

Teno, J. M., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T. (2007). Association between advance directives and quality end-of-life care: A national study. *Journal of the American Geriatrics Society, 55*(2), 189-194. doi: 10.1111/j.1532-5415.2007.01045.x

Tung, W., Lu, M., & Cook, D. (2010). Cervical cancer screening among Taiwanese women: A transtheoretical approach. *Oncology Nursing Forum, 37*(4), E288-E294. doi: 10.1188/10.ONF.E288-E294

Velicer, W. F., Redding, C. A., Sun, X., & Prochaska, J. O. (2007). Demographic variables, smoking variables, and outcome across five studies. *Health Psychology*, *26*(3), 278-287. doi: 10.1037/0278-6133.26.3.278

Table 1 *Characteristics of Respondents to the National Center for Family and Marriage Research / Knowledge Networks Pilot Study 2010*

	Percent
End-of-Life Planning	
Any formal plans (living will and/or durable power of attorney-health care)	28.10
No formal plans	71.90
Discussion	55.03
No discussion	44.97
Treatment preference (0 = *stop life-prolonging treatment*; 10 = *continue all treatment*) [a]	5.23 (3.60)
Guess of partner's treatment preference (0 = *stop life-prolonging treatment*; 10 = *continue all treatment*) [a]	5.51 (3.58)
Individual Sociodemographic Characteristics	
18-34 (young)	29.32
35-49 (midlife)	36.16
50-64 (late midlife)	34.51
Good / very good / excellent health	87.98
Fair / poor health	12.02
High school or less	41.93
Some college	27.29
College degree or more	30.78
White	71.31
Black	7.28
Hispanic	14.55
Other race / ethnicity	6.86
Female	50.00
Male	50.00
Couple Sociodemographic Characteristics	
Cohabiting	17.85

Table 1, *cont'd*	Percent
Married	82.15
Annual household income (1 = *less than $5,000*; 19 = *$175,000 or more*) [a]	12.27 (3.90)
N	2,150

Note. Statistics are weighted to be representative of the U.S. population.

[a] Mean and standard deviation shown.

Table 2 *Binary Logistic Regressions, Odds of Having Completed End-of-Life Planning*

	Any Formal Plans	Discussion
	Odds Ratio (95% C.I.)	Odds Ratio (95% C.I.)
Age (vs. 35-49; midlife)		
18-34 (young)	0.65* (0.44-0.98)	0.88 (0.64-1.22)
50-64 (late midlife)	1.88*** (1.35-2.61)	1.79*** (1.32-2.44)
Self-Reported Health		
Fair/poor	1.64 (0.98-2.74)	1.85** (1.21-2.81)
Sociodemographic Characteristics		
Cohabiting (vs. married)	0.89 (0.61-1.31)	0.66* (0.47-0.92)
Annual household income (1 = *less than $5,000*; 19 = *$175,000 or more*)	1.07** (1.02-1.13)	1.05* (1.01-1.09)
Some college	1.11 (0.79-1.54)	1.17 (0.88-1.57)
College degree or more	1.54* (1.08-2.19)	1.20 (0.86-1.67)
Black	0.85 (0.41-1.75)	1.07 (0.58-1.99)
Hispanic	0.67 (0.40-1.13)	0.41*** (0.27-0.62)
Other race / ethnicity	1.21 (0.62-2.34)	0.52** (0.32-0.83)
Female	0.72** (0.59-0.88)	1.08 (0.89-1.32)
N	2,077	2,081
χ^2; *df*	88.5; 11	83.4; 11

Note. Standard errors are corrected for the clustering of 2,150 individuals in 1,075 couples. Statistics are weighted to be representative of the U.S. population.

$*p \leq .05$, $** p \leq .01$, $*** p \leq .001$

Table 3 *Reasons Given for Not Having Plans, by Age and Health Status*

	Young / Good Health	Young / Poor Health	Midlife / Good Health	Midlife / Poor Health	Late Midlife / Good Health	Late Midlife / Poor Health	χ^2 Statistic for Subgroup Differences
	Percent	Percent	Percent	Percent	Percent	Percent	
Formal Plans							
Lacking information	38.27	43.71	27.36	14.63	22.00	32.66	36.51**
Death avoidance	62.64	69.51	52.23	59.49	52.18	32.04	33.04**
Other persons	31.30	47.07	45.83	54.68	52.23	55.36	46.39***
Current good health	39.04	13.70	35.81	8.49	39.89	1.12	67.36***
Discussion							
Lacking information	14.73	8.89	16.70	16.99	19.04	17.95	2.50
Death avoidance	61.75	87.25	67.30	54.53	70.46	57.17	11.19
Other persons	14.41	3.67	15.00	34.44	24.68	42.53	31.16**
Current good health	36.43	2.45	34.63	5.66	29.59	0	a
N	551	43	738	58	627	123	

Notes. Chi-square tests were used to assess significant differences between the percentages for the six groups. For each type of planning, column totals exceed 100 because participants could choose multiple responses. Statistics are weighted to be representative of the U.S. population.

[a] In one category, no participants selected this reason (i.e., there is an “empty” cell). Statistical comparisons of percentages are therefore not possible.

Table 4 *Multinomial Logistic Regression, Odds that a Woman Knows her Male Partner's Treatment Preference*

	Under by 3 or more (N = 181)	Under by 1-2 (N = 153)	Over by 1-2 (N = 139)	Over by 3 or more (N = 238)
	vs. Perfect Match (N = 306)			
	Odds Ratio (95% C.I.)	Odds Ratio (95% C.I.)	Odds Ratio (95% C.I.)	Odds Ratio (95% C.I.)
Advance Care Planning				
Woman has any formal plans	0.82 (0.40-1.69)	1.15 (0.56-2.36)	0.39* (0.18-0.83)	1.16 (0.61-2.21)
Woman has held discussion	1.26 (0.72-2.23)	1.09 (0.61-1.93)	1.06 (0.58-1.93)	0.91 (0.53-1.57)
Man has any formal plans	1.32 (0.64-2.72)	0.60 (0.29-1.24)	1.81 (0.93-3.53)	0.82 (0.45-1.50)
Man has held discussion	0.58 (0.32-1.04)	0.97 (0.55-1.71)	0.76 (0.41-1.41)	0.91 (0.50-1.63)
Woman's Characteristics				
Treatment preference (0 = *stop life-prolonging treatment*; 10 = *continue all treatment*)	0.86*** (0.80-0.92)	0.97 (0.91-1.04)	1.09* (1.01-1.18)	1.18*** (1.08-1.29)
Some college	0.57 (0.31-1.07)	0.70 (0.36-1.34)	0.57 (0.29-1.10)	0.72 (0.42-1.23)
College degree or more	0.76 (0.39-1.49)	1.08 (0.55-2.12)	0.74 (0.36-1.52)	0.83 (0.45-1.52)
Black	0.29 (0.08-1.08)	1.09 (0.31-3.85)	0.22* (0.05-0.97)	0.58 (0.19-1.74)
Hispanic	0.49 (0.22-1.10)	0.52 (0.21-1.33)	0.87 (0.36-2.10)	0.58 (0.25-1.38)
Other race / ethnicity	0.32* (0.10-0.96)	1.41 (0.53-3.70)	0.65 (0.23-1.86)	1.68 (0.72-3.95)
Couple Characteristics				
Cohabiting (vs. married)	0.98 (0.51-1.86)	0.81 (0.41-1.59)	0.94 (0.48-1.86)	0.74 (0.40-1.36)
Woman unhealthy; man healthy	0.82 (0.32-2.05)	1.52 (0.59-3.89)	0.73 (0.26-2.07)	1.86 (0.84-4.10)
Man unhealthy; woman healthy	1.68 (0.67-4.22)	0.36 (0.11-1.15)	0.48 (0.16-1.50)	1.49 (0.59-3.77)
Both partners unhealthy	0.78 (0.23-2.61)	0.16 (0.02-1.17)	0.37 (0.08-1.75)	0.08** (0.02-0.38)
18-34 (young)	0.85 (0.44-1.64)	0.69 (0.35-1.38)	0.94 (0.46-1.93)	0.40** (0.21-0.76)
50-64 (late midlife)	0.49* (0.26-0.90)	1.12 (0.62-2.01)	0.70 (0.38-1.30)	1.34 (0.78-2.29)
Annual household income (1 = *less than $5,000*; 19 = *$175,000 or more*)	1.02 (0.95-1.11)	1.00 (0.94-1.06)	0.99 (0.91-1.09)	0.94 (0.88-1.01)

N	1,017
χ^2; *df*	196.08; 68

Note. Statistics are weighted to be representative of the U.S. population.

$^{*}p \leq .05$, $^{**}p \leq .01$, $^{***}p \leq .001$