Attitudes of the critically ill towards prolonging life: The role of social support

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Mutran, E. J., Danis, M., Bratton, K. A., Sudha, S. & Hanson L. (1997). Attitudes of the critically ill towards prolonging life: The role of social support. *The Gerontologist, 37*, 192-199.

is available online at: https://doi.org/10.1093/geront/37.2.192

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Abstract:

Desires to prolong life were investigated in a hospitalized sample of 212 persons over age 50 whose illnesses were severe and who had an average life expectancy of six to twelve months. The importance of social support was emphasized in defining the context in which the stressors of unfinished business and fear of death prompted desires to prolong life. Interactions existed in predicting desires for prolonging life based on ethnicity and whether respondents did or did not have sustained family contact. Family contact and salience increased the desire to live longer for African Americans, but not for Whites.

Keywords: ethnicity | family | death and dying

Article:

As medical technology continues to develop new strategies for dealing with life-threatening illnesses, researchers are beginning to focus attention on the attitudes of critically ill patients toward the extension of life, and on the factors that affect these attitudes. At this time, we have a very incomplete understanding of the views of the critically ill on prolonging life. Popular wisdom suggests that many people want to live as long as possible, with the proviso that some quality of life be maintained. However, little research has investigated the factors influencing attitudes that seek a balance between length of life and quality of life. This study seeks to gain insight into the way in which social networks, specifically with family members, contribute to a desire to extend life among the critically ill. We examine how individuals' interactions with family members modify the impact of explanatory factors on such desires.

Attitudes Toward Death and Dying

The literature on death and dying has so far paid little attention to examining the impact of social networks and roles on attitudes. What factors might influence attitudes toward death? Previous research focuses more on fear of death than on the desire to extend life; the two, while related,

are not identical. The literature suggests that some demographic factors may be associated with fear of death — namely, age, gender, and ethnicity. Older persons appear slightly less likely than younger ones to fear death, though the relationship is not very strong (Henderson, 1990; Lester & Templer, 1993; Thorson & Powell, 1990). Pollock's (1979) review of the literature indicated that women more often than men report a fear of death. Similar results were more recently noted by Dattel & Neimeyer, (1990), although it was not clear whether these findings reflect gender differences apart from differences in socialization and in emotional expressiveness. Others, however, found no gender differences in death anxiety or the willingness to undergo intensive care treatment (Conte, Weiner, & Plutchik, 1982; Danis, Patrick, Southerland & Green, 1988).

Some researchers report that African Americans have a greater fear of death than Whites, across diverse socioeconomic settings (Dodd & Mills, 1985; Sanders, Poole, & Rivero, 1980; Young & Daniels, 1980), and were correspondingly significantly more likely to desire life-sustaining treatment (Garret, Harris, Norburn, Patrick, & Danis, 1993).

Social Support: Networks, Stress, and Attitudes Toward Dying

In her seminal work on impending death, Elizabeth Kubler-Ross (1969) argued that there are five stages of attitude towards death experienced by terminally ill patients: denial, anger, bargaining, depression, and acceptance. Though the empirical usefulness and generalizability of these stages is debated, Corr (1993) argued that an important conclusion that could be drawn from this approach was that attitudes toward death, as the final stage of growth, can be understood in a larger context of attempts to cope with crisis situations. Kubler-Ross, herself a psychiatrist, emphasized the importance of social interaction to assist those who are coping with dying. Notwithstanding this, there has been little research on the potential effects of social networks on attitudes toward death. An exception is Wu's 1990 study of 26 terminally ill cancer patients in Hong Kong. She found that family support did indeed influence attitudes; patients with immediate family support expressed less depression, yet more fears, than those without such support.

The general lack of attention paid to the relationship between social networks and death-related attitudes is noteworthy given the extensive focus on the relationship between social support networks and health in general. Social support and networks have been linked to good health and longer life (Durkheim, 1951; Seeman, Kaplan, Knudsen, Cohen, & Curalnick, 1987; Steinbach, 1992), and to a variety of health practices such as compliance with hemodialysis (Christensen, 1992) and the use of physical therapy services (Coe, Wolinsky, Miller, & Prendergast, 1984; Minkler, 1986). Social networks and support appear to affect health outcomes such as immune response (Mclntosh, Kaplan, Kubena, & Landmann, 1993) and mortality due to heart disease and stroke (Gliksman, Lazarus, Wilson, & Leeder, 1995). In particular, social support has been found to buffer the effects of stress on depression (Christensen, Turner, Slaughter, & Holman, 1989; Kessler & McLeod, 1985; Thoits, 1987; Sherbourne & Hays, 1990).

Thoits (1982) argues that results that support this buffering hypothesis should be interpreted with caution, since most studies suffer from inadequate conceptualizations, which lead to problems in the selection of appropriate indicators. Confounding the additive effects of social support with its interactive effects is another serious problem (Wheaton, 1985); in fact, the interactive effects of

social support networks in buffering stress have been relatively under-researched (House & Kahn, 1985). Krause (1994), in a recent study, raises a further issue — whether stressors in more salient roles might have greater deleterious effects on outcome variables. It could be argued that social support is especially helpful if it comes from salient others. It is still not clear whether social support acts as a buffer only for particular stressors, or whether it is the quantity or the quality of social support that matters, most (Krause, 1994, 1995; Wilson, Calsyn, & Orlofsky, 1994).

As argued by House and Kahn (1985), the literature indicates the importance not only of the existence of contact with family and friends in predicting psychological and physical health outcomes, but also of the quantity or frequency of contact. In fact, Syme (1982) contends that the sheer quantity of social interaction might be more consequential for health rather than the structural organization or the functional content of networks, though the reasons why are not clear. Steinbach (1992) finds that among the elderly, contact with the wider family, rather than marital status, has important effects on the risks of institutionalization and death.

Social Support Networks Among the Elderly and Minority Groups

Social support may be essential near the end of life; however, substantial evidence indicates that it is less available for elders. Older people are more likely to live alone, to report fewer contacts with friends in the prior month, and to be less satisfied with their social support (Dean, Hoist, & Wagner, 1983). Advancing age and failing health can decrease the opportunity and motivation for social interactions later in life (Adams, 1987; Field & Minkler, 1988). Elderly people are more likely than others to experience a decrease in social support because more people in their network die and are not replaced (Antonucci & Akiyama, 1987). Silliman (1986) found that the elderly generally face a loss of roles and changes in the type and extent of social support available. The very elderly are particularly likely to suffer psychological distress from the loss of social support (Matt & Dean, 1993). Thus, social support and social networks are beneficial to health, but aging often brings both a loss of good health and a loss of social contacts. Family support has received much attention but, because family life involves both obligations and responsibilities, as well as affection, its effect on mental health outcomes has been complex. There are societal expectations of the family at the time of grave illness or death for family members to make an effort to visit the ailing member and/or to be present near the time of death.

The influence of social support and networks on health may also be mediated by ethnicity. Much research indicates that ethnicity interacts with a variety of factors in affecting health and well-being (Ferraro & Koch, 1994; Kessler & Neighbors, 1986; Mutchler & Burr, 1991). Mutran (1985) notes that researchers must consider that ethnicity can be an important moderating variable affecting the influence of an explanatory variable (such as social support) on a dependent variable (such as the desire to prolong life). The importance of family is one of the basic factors characterizing the lives of ethnic minorities. African Americans, in comparison to the general population, have larger household sizes, are more likely to live in intergenerational households, and seem to have closer and more frequent family contact (Becerra & Shaw, 1984). The importance of family bonds and allegiance across generations stand out as distinguishing characteristics of the African American family (Jackson, Antonucci, & Gibson, 1990). Elderly African Americans appear more likely to receive help from their families (Mitchell & Register,

1984; Lawton, Rajagopal, Brody, & Kleban, 1992). Yet, despite these ethnic differences, little research has been done on the role of social network and its relationship to stress among minority groups.

We address such gaps in the literature by examining the role of family relations in modifying the impact of background factors and stressors on attitudes toward prolonging life, which are conceptualized as reflecting the stress experienced by an individual approaching death. Those who wish to prolong life are viewed, in part, to have unfinished business and a fear of death and, consequently, as experiencing greater stress. We investigate how the existence of a family network eases or intensifies the stress surrounding death among elderly, critically ill persons. We also investigate how the nature of this network may differ between African Americans and Whites.

Conceptual Framework and Hypotheses

This study investigates both the potential mediating and moderating effects of social support on the desire to prolong life. We will test two possible models. One model would postulate that the desire to prolong life will be affected by a group of explanatory factors, as well as the feelings of having unfinished business and a fear of death (Figure 1). We consider that the existence of such feelings and fears mobilizes family support, expressed in frequency of contact with family members and mention of family as one of the most salient concerns of the person approaching death. Family salience and support in turn mediate the impact of the various background factors on attitudes to prolonging death (Figure 1).

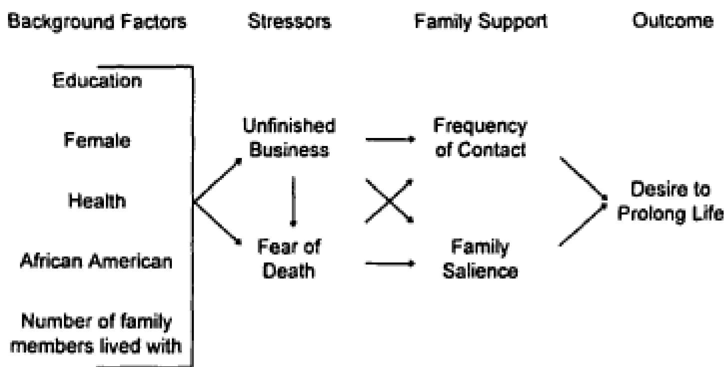

Figure 1. Model of the mediating influence of social support.

We expect that those who have feelings of unfinished business and those who fear death will wish to prolong their lives. Fear of death is itself affected by feelings of having unfinished business. Drawing from prior literature, we expect those who are older or more educated to be less likely to desire to prolong life. We have no a priori expectation regarding the impact of gender. However, in line with Garret et al. (1993), we expect African Americans to desire to prolong life more than Whites do. We examine these relationships controlling for perception of the subject's own health and the number of family members lived with.

An alternative view of family support is seen in Figure 2, where the existence and importance of a family network is seen as moderating the transition between life and death. The salience of the

family may be different between African Americans and Whites. In addition, if the family is not salient, it may not make a difference whether one sees family or not prior to death. We hypothesize that contact with family moderates between feeling that one has unfinished business or fear of death, and the desire to prolong life. Those who express a sense of having unfinished business and who are in contact with family members will be less likely to desire to prolong life than those who have similar attitudes, but who are not in contact with family members. We view fear of death as arising from the feeling of having unfinished business in addition to background factors, and investigate the modifying impact of family network on fear of death and the desire to prolong life.

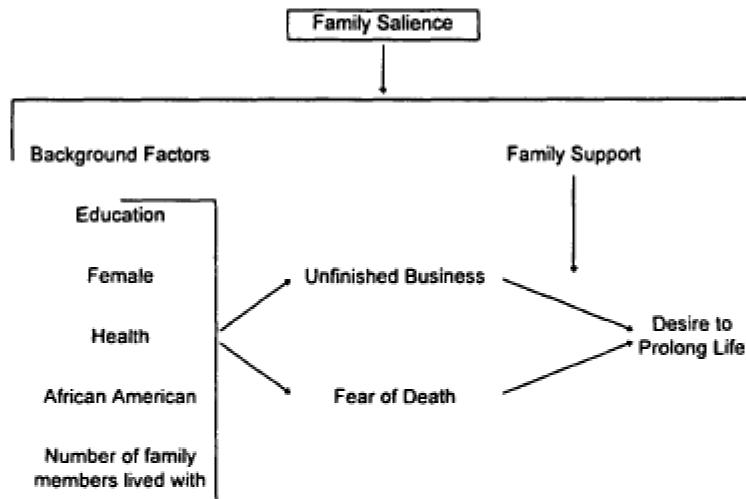

Figure 2. Model of the moderating influence of social support.

Methods

Subjects

All patients admitted to the Internal Medicine, Gynecology, and Family Practice Services of a university teaching hospital in North Carolina between October 1,1990 and July 31,1993 were screened for eligibility to participate in the study. Patients who were over age 50, living within a 60-mile radius of the hospital, with the diagnoses of chronic obstructive lung disease (COPD), congestive heart failure (CHF), cirrhosis, metastatic cancer, or stage IV lymphoma were included if they met medical criteria that identified patients with an average life expectancy of six to twelve months (for a more detailed description of these criteria, please refer to the Appendix).

To find eligible patients, a research nurse reviewed the hospital charts of patients admitted each day as identified by the hospital information system. Patients were ineligible if they had depressed consciousness, major psychiatric disease, dementia, severe communication difficulties prohibiting discussion of treatment preferences, or could not answer five of ten questions on the Short Portable Mental Status Questionnaire (Pfeiffer, 1975). Patients who went on to have organ transplantation were eliminated from the analysis. The cases included in the study thus numbered 253.

This project was approved by the Committee for the Protection of the Rights of Human Subjects. All participating patients signed a written consent form. After informed consent, trained interviewers conducted interviews during the hospital stay or at home immediately following discharge.

Measures

Our measures of social network focused first on family contact, which is a measure of family support, in accordance with the arguments of House and Kahn (1985), Syme (1992) and Steinbach (1992). Family contact was measured as a dichotomous variable, coded 1 if the patient saw family members other than those he or she lived with at least two or three times a month. Most patients lived with a spouse or child, thus incorporating these primary family members into the measure was not useful; therefore, a second measure controls for the number of family members lived with.

A third measure indicates family salience, given by the importance accorded to family by the patient at the time of the survey. The patient was asked, "What are the most important things to you at this time?" Those whose first mention was of family are given a value of 1, and the others are coded 0. A measure of quality of family interaction, namely, whether or not the patient had a family confidant at that time, was ascertained. Since the overwhelming majority of patients had a confidant, this measure could not be incorporated into the analysis.

The desire to prolong life was measured by summing responses to three items: "I would like to prolong my life as much as possible," "I would accept any medical treatment in order to prolong my life," and "I am willing to live without being able to get out of bed rather than not live at all." The reliability for this measure was .69.

Fear of death was assessed by combining the responses to two items: "I am afraid of death," and "Death seems like a time of peace to me" (recoded). Those who strongly felt that death was a time of peace and did not fear it were coded 1; those who did not feel death was a time of peace and feared it were coded 3. Those who feared death but felt it would be a time of peace, or those who did not fear death but felt it would be unpeaceful, were coded 2. Unfinished business was assessed by two items: "I worry that my family needs me" and " I am concerned that I have much unfinished business to attend to in life." The alpha coefficient for reliability was .62.

Control variables used in this analysis were assessed in the following manner: lives with family members coded from 0 to 3 persons (25% of the sample lived alone, 20% lived with 2 or 3 family members); gender, 1 = female; ethnicity, 1 = African American, 0 = White (all respondents were either White or African American); education = the number of completed years of schooling. Functional status was measured using the scale of health limitations from the Medical Outcome Survey Short Form (Stewart, Hayes, & Ware, 1988), alpha coefficient for reliability = .75. The short form asked about limitations to kinds or amounts of vigorous activities such as lifting heavy objects; running or participating in strenuous sports; walking uphill or climbing a few flights of stairs; bending, lifting, or stooping; walking one block; eating, dressing, bathing, or using the toilet; and limitations keeping one from working at a job, doing work around the house, or going to school.

Results

Descriptive Results

Table 1 includes descriptive information on all variables under study. The mean age was 63 years with a mean education of 10.5 years. This hospitalized sample had an over-representation of males (60% of respondents), and 75% lived with at least one other person. Thirty percent of the sample was African American, and 70% was White. Overall, the individuals in our study did not fear death. Approximately 43% of the sample strongly disagreed with the statement "I am afraid of death," and agreed with the statement that "Death seems like a time of peace." Thirty-one percent agreed that they were afraid of death and disagreed that it was a time of peace. Approximately 26% agreed or disagreed with both statements.

Table 1. Descriptive Statistics for Study Variables

Variable	Mean	*SD*	Range
Age	63.4	8.2	50–88
Education	10.50	4.12	0–22
Health	16.05	4.15	9–27
Number of family members in household (excluding self)	1.00	.76	0–3
Unfinished business	6.64	2.72	2–10
Desire to prolong life	11.48	3.34	3–15
	%	***n***	
Female	40.6	86	
African American	30.2	64	
Family contact at least 2 or 3 times a month	78.8	167	
Family important at this time	45.8	97	
Fear of death:			
1. Death is a time of peace and is not feared	42.9	91	
2. Death is not a time of peace, but it is not feared, or	6.6	14	
Death is a time of peace, but it is feared	19.8	42	
3. Death is feared and it is not a time of peace	30.7	65	

The study participants suffered from a number of limitations to their functional status. Only 2% had no limitations, 15% had been limited in some regard for three months or less, and well over half of the sample respondents had four or more limitations lasting longer than three months. The scale ranged from 9 to 26.5 with a mean of 16. Finally, despite these limitations, most respondents expressed a desire to prolong life. The scale of three items ranged from 3 to 15 with a mean of 11.57.

Model Results

Our first models predict the intensity of stressors toward the end of life (Table 2). Younger people, those who are African American, or those who live with a greater number of family members, expressed more feelings of having unfinished business. Education, sex, and health have no impact. With respect to the fear of death, as expected, having unfinished business heightens fear. Other factors have no impact.

Table 2. Variables Associated with Stressors Toward the End of Life: Unfinished Business and Fear of Death ($N = 212$)

Independent variables	Unfinished Business	Fear of Death
Education	–.066[a]	.070
	(–.043)[b]	(.014)
Female	–.046	–.016
	(–.254)	(–.028)
Poor health	.023	.045
	(.015)	(.009)
African American	.195**	.024
	(1.156)	(.044)
Age	–.260***	–.068
	(–.086)	(–.007)
Number of family members lived with	.152*	–.105
	(.546)	(–.117)
Unfinished business	—	.249***
	—	(.078)
Adjusted R^2	.15	.05

[a] Standardized coefficient (Beta).
[b] Metric unstandardized regression coefficient (b).
*p < .05; **p < .01; ***p < .001.

Table 3 presents results of models predicting the desire to prolong life. For comparison purposes, the first two models do not include interaction terms. In the first model, fear of death, having unfinished business, and education all significantly affect the desire to prolong life, in the expected directions. Neither ethnicity, gender, health, nor age appear to have a statistically significant influence on the desire to prolong life. The frequency of family contact and the salience of family also do not appear to significantly influence the desire to prolong life (Model 2). Thus, Figure 1 does not appear to accurately reflect the way social support influences stress and the desire to prolong life.

To specifically examine the moderating impact of social support networks, our third model incorporated interaction terms between family support and unfinished business, and between family support, family salience and ethnicity (Model 3). As in the second model, we find significant main effects on the desire to prolong life for fear of death, unfinished business, and education. As before, those fearful of death and those who feel they have unfinished business are more likely to wish to prolong their lives. The more educated are less likely to desire to prolong life. In addition, all three interaction terms have a significant impact on the desire to prolong life, indicating that Figure 2 more accurately reflects the relationship between social support and the stress surrounding the dying process.

However, interpreting the meaning of the interaction terms accurately requires further explication. Following Aiken and West (1991), Tables 4 and 5 present simple slopes of the regression equations for the interaction terms, which indicate the precise nature of the direction and significance of the impact of the interaction terms on the desire to prolong life, controlling for the other variables in the model. Table 4 shows simple slopes for the impact of ethnicity and unfinished business by frequency of contact with the wider family on the desire to prolong life.

Among those who have greater family contact, there is no relation between unfinished business and a desire to prolong life. However, if the subject has less frequent contact with family, there is a strong relationship between unfinished business and the desire to prolong life. African Americans who have more frequent contact with family members have a greater desire to prolong life. Those with less family contact have less desire to prolong their life.

Table 3. Predictors of Desire to Prolong Life: Background Variables, Stressors, Social Support, and Interaction Terms (*N* = 212)

	Model		
Independent variables	**1**	**2**	**3**
Education	–.242***[a]	–.226**	–.210**
	(–.197)[b]	(–.184)	(–.171)
Female	.068	.070	.040
	(.464)	(.479)	(.269)
Poor health	.070	.078	.053
	(.056)	(.063)	(.043)
African American	–.004	–.026	.035
	(–.029)	(–.192)	(.251)
Age	.004	.011	.035
	(.002)	(.004)	(.014)
Number of family members lived with	.034	.040	.072
	(.148)	(.178)	(.315)
Unfinished business	.162***	.258***	.238***
	(.636)	(.318)	(.292)
Fear of death	.255*	.153*	.146
	(.313)	(.602)	(.576)
Contact with family members greater than once a month	—	.044	.050
	—	.363	(.405)
Family salient	—	–.108	–.058
	—	(.363)	(–.436)
Family contact × unfinished business	—	—	–.186**
	—	—	(–.562)
Family contact × African American	—	—	.150*
	—	—	(2.842)
Family salience × African American	—	—	.164*
	—	—	(3.089)
Adjusted R^2	.16	.16	.21

[a] Standardized coefficient (Beta).
[b] Metric unstandardized regression coefficient (b).
*p < .05; **p < .01; ***p < .001.

Table 4. Simple Slopes for Unfinished Business and African American Race on Family Contact

	Contact Greater Than Once a Month	**Contact Less Than Once a Month**
Unfinished business	–.222	.610**
	(–.273)	(.750)
African American	.383*	–.329*
	(2.782)	(–2.390)

*p< .05; **p< .001.

Table 5. Simple Slopes for Family Contact and Family Salience for African Americans and Whites on Desire to Prolong Life

	African American	Whites
Family contact	.378*	.053
	(3.086)	(.453)
Family salience	.361†	–.061
	(2.714)	(–.461)

†p > .05 and < .10; *p < .05.

The interactive relationships between ethnicity, family contact, family salience and the desire to prolong life are further explored in the simple slopes presented in Table 5. Family contact, extending the notion indicated in Table 4, significantly increases the desire to prolong life only among African Americans, not among Whites. Similarly, family salience has no impact on the desire to prolong life among Whites, but increases desire among African Americans.

Discussion

Our findings shed new light on an under-researched topic: the factors influencing attitudes toward prolonging life among critically ill elderly persons, particularly family factors and ethnicity. What we found underscores the literature that emphasizes the importance of unfinished business near the end of life and concerns with the fear of death, and the combined effect of unfinished business and the fear of death on the desire to prolong life.

However, our study illustrates that these factors are moderated by family contact. For instance, family contact dampens the relationship between fear of death and unfinished business with a desire to prolong life. We speculate that those who are in contact with family members may have unfinished business, but the anxiety associated with the lack of resolution is less intense. On the other hand, those who have unfinished business and are cut off from their families, feel greater urgency in prolonging life. A potential higher-order interaction of unfinished business, fear of death, and family contact was investigated and found not significant.

Our findings in regard to ethnic differences are particularly important. Previous work has focused primarily on the main effect of ethnicity on attitudes toward death and life-sustaining treatment. It is important not only to investigate whether African Americans and Whites have differing attitudes toward death, but also to examine whether the effect of other explanatory variables are influenced by ethnicity. Given the differences between African American and White families, it is reasonable to expect that such variables as social support operate differently for the two ethnic groups (Garret et al., 1993; Mutran, 1985).

First, we see that there is a significant difference between African Americans and Whites in the salience of the family at this time, and its relationship to desires for prolonging life. For Whites, the relationship is near zero. For African Americans there is a positive, though marginally significant, relationship. But this relationship, combined with the relationship between family contact and desires to prolong life, emphasizes the close linkage of the individual with the family among African Americans. African Americans who do not have frequent contact with their family have less desire to prolong life.

Our initial arguments had suggested that the desire to prolong life was indicative of less acceptance of the death situation, and thus of greater stress experienced towards the end of life. Therefore, family contact at that time, if it reduced stress, would lessen the desire to prolong life. However, with respect to African American families, an alternative explanation might be considered. Many researchers have pointed out the importance of the family among the African American community at various stages of the life cycle, particularly of extended and fictive kin, when closer relatives are unavailable or not present (Dillworth-Anderson, 1993). These kin networks are an important source of various kinds of socioeconomic and psychological support throughout life. Therefore, toward the end of life, the fact that contact with and salience of extended kin among African Americans positively influences the desire to prolong life might be interpreted as the persistence of lifelong binding ties during the dying process among this group, and not necessarily of increased stress.

We thus find that family contact has a more important effect on the attitudes of African Americans than on those of Whites toward prolonging life. Of course, it is important as well to recognize that in our survey the vast majority of African Americans and Whites had family contact. In results not presented here, we conducted a logistic regression analysis predicting who was more likely to have family contact, which showed that education was the only important predictor; those with more schooling had less family contact.

We also see that those with more education have less desire to prolong life. We feel that the results emphasize the increased individuality that accompanies greater education, a greater reliance on self, yet also a greater rationality in dealing with the length versus the quality of life in extreme health conditions. The questions that measured the desire to prolong life included queries about accepting any medical treatment in order to live and living without being able to get out of bed. Thus, our findings indicate that more educated persons do not wish to lengthen life at the expense of quality of life.

More research needs to be done to examine in greater detail the effects of family contact on the desire to prolong life. This study is limited in its measures of social support. For instance, as we do not have a measure of quality of family contact, it is not clear whether it is quantity or quality that is more important. Moreover, we have not determined whether contact with friends, in addition to or instead of family, would have a similarly beneficial effect for the critically ill. Perhaps, for Whites, there may be associations with friends that act in a similar way to the family for African Americans. The content of feelings of unfinished business could also be further explored. In conclusion, more research is needed to clarify the relationship between social networks and attitudes toward death, and to develop interventions that have as their goal helping the critically ill come to grips with the end of life.

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Appendix

Patients with COPD were eligible if they met two of four of the following conditions: baseline PCO2 greater than or equal to 45; cor pulmonale; respiratory failure episode within the preceding year; or FEVI less than or equal to .5 liters. Patients with CHF were eligible with the following conditions: New York Heart Association class 4 symptoms or a left ventricular ejection fraction of 25% or less and use of two of four classes of medications, including diuretics, inotropes, angiotensin-converting enzyme inhibitors, and other vasodilators. Patients with cirrhosis were eligible if the diagnosis was confirmed by imaging or documentation of esophageal varices, and they had evidence of one of three conditions: hepatic coma, child's class C criteria, or child's class B criteria with an upper gastrointestinal bleed within the preceding six months. Patients with metastatic cancer or lymphoma were eligible if they had a biopsy-proven diagnosis and were aware of the diagnosis for at least one month.