Mind Frames Towards Dying and Factors Motivating Their Adoption by Terminally Ill Elders

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Objectives. This study was designed to advance the understanding of the physical and psychosocial factors that motivate terminally ill elders not only to consider a hastened death but also not to consider such a death.

Methods. I conducted face-to-face in-depth qualitative interviews with 96 terminally ill elders. An inductive approach was taken to locating themes and patterns regarding factors motivating terminally ill elders to consider or not to consider hastening death.

Results. Six mind frames towards dying emerged: (a) neither ready nor accepting; (b) not ready but accepting; (c) ready and accepting; (d) ready, accepting, and wishing death would come; (e) considering a hastened death but having no specific plan; and (f) considering a hastened death with a specific plan. From the data emerged approaches towards dying and accompanying emotions characterizing each mind frame, as well as factors motivating their adoption by elders. The results showed that psychosocial factors served more often than physical factors as motivators.

Discussion. The results demonstrate the importance of assessing the mind frame adopted by a terminally ill elder and his or her level of satisfaction with it. Terminally ill elders may experience a higher quality dying process when a traditional medical care approach is replaced by a holistic approach that addresses physical, spiritual, emotional, and social needs.

A NATIONAL mandate has been put forth to improve the comfort or palliative care provided to terminally ill individuals. This mandate is particularly relevant to Americans older than age 65, whose numbers have tripled in the 20th century and who have experienced a significant increase in their life expectancy (Hetzel & Smith, 2001). Elders now experience the greatest number of deaths in the United States (Arias, 2003), deaths that are often of poor quality. Research has shown that American elders experience severe pain in their dying process (Bernabei et al., 1998; SUPPORT Investigators, 1997), are undermedicated for their pain (Bernabei et al.; Cleeland et al., 1994), receive health care at odds with their end-of-life preferences (SUPPORT Investigators), experience psychosocial suffering (Chochinov et al., 2002; Pessin, Rosenfeld, & Breitbart, 2002), and experience existential suffering (Black & Rubinstein, 2004). These poor-quality dying experiences have contributed to the demand for the legalization of physician-assisted death, a demand that has raised ethical concerns and has led to research on the number of individuals requesting this option and the factors motivating them to do so. Knowledge of these factors serves to inform and guide health care practitioners in their quest to improve palliative care. It can also be argued, however, that knowledge of the factors that contribute to a quality dying process such that terminally ill individuals are motivated not to consider a hastened death is also essential to providing quality palliative care. This latter avenue of research has received little, if any, attention. The purpose of this article is to advance the understanding of physical and psychosocial factors that motivate terminally ill elders not only to consider a hastened death but also not to consider such a death.

Current Findings Regarding the Consideration to Hasten Death

Two types of studies emerge from a review of the literature on the consideration to hasten death: retrospective and prospective. Retrospective studies ask physicians, nurses, social workers, or survivors of the deceased to write case studies or answer surveys concerning the motivating factors cited by now-deceased patients who had considered or requested physician-assisted death prior to their death. Prospective studies interview a mix of individuals with a terminal illness (an illness likely to result in death) and people who have been defined as terminally ill (having fewer than six months to live) and ask whether they have considered hastening their death and, if so, their reasons for doing so.

Retrospective case study results have found that psychosocial factors play a more significant role than physical factors as motivators of a hastened death. Health care professionals have reported psychosocial factors that include a decreased ability to participate in activities that made life enjoyable (Chin, Hedberg, Higginson, & Fleming, 1999; Oregon Department of Human Services [ODHS], 2000, 2001, 2002, 2003), fear of future pain (Chin et al.; ODHS, 2000, 2001, 2002, 2003; Volker, 2001) or of uncontrollable symptoms, loss of meaning in life (Meier et al., 1998), the feeling that one is a burden (Back, Wallace, Starks, & Pearlman, 1996; Meier et al.; ODHS, 2001, 2002, 2003), loss of dignity (Back et al.; Meier et al.), loss of autonomy (Chin et al.; ODHS, 2000, 2001, 2002, 2003), loss of control over bodily functions (Back et al.; Chin et al.; ODHS, 2000, 2001, 2002, 2003) and over manner of death (ODHS, 2000; Volker), and loss of control in general (Back et al.). These studies reported neither depression nor religiosity, factors often discussed in relation to hastening death, as significant factors. Only two studies (Back et al.; Meier et al.) reported evidence of pain as a motivator.

Two retrospective studies that employed a quantitative approach also found that psychosocial factors were key motivators of the consideration to hasten death; they did not
find pain to be a significant factor (Ganzini et al., 2002; Jacobson et al., 1995). Hospice nurses and social workers reported that a desire to control the circumstances of death, the wish to die at home, the feeling that living was pointless, and a loss of dignity were most often discussed by patients desiring a hastened death (Ganzini et al.).

Quantitative prospective studies support the importance of psychosocial factors and provide evidence of the role physical factors play in the consideration to hasten death. These studies found that patients with a terminal illness or who were terminally ill were not likely to attend church (Breitbart et al., 1996) or to be religious (Breitbart et al.; Emanuel, Fairclough, Daniels, & Claridge, 1996), had few social supports (Breitbart et al.), experienced a low quality of social support (Arnold, 2004; Breitbart et al., 1996; Chochinov et al., 1995), and perceived their caregiving needs as high (Emanuel, Fairclough, & Emanuel, 2000). Emotionally, these patients reported a higher level of anxiety, a lower level of hope (Arnold) and a higher level of depression (Arnold; Breitbart et al.; Chochinov et al., 1995; Emanuel et al.) than did those individuals not considering a hastened death. Results regarding the role of pain were mixed. Three studies found that pain was not significantly related to the consideration to hasten death (Breitbart et al.; Chochinov et al., 1995; Emanuel et al., 1996), but two later studies found it to be a significant predictor (Arnold; Emanuel et al., 2000). These prospective studies did not measure loss of control.

The only qualitative study on the consideration to hasten death that could be located was conducted by Lavery, Boyle, Dickens, Maclean, and Singer (2001) on patients with HIV-1 or AIDS. According to this study, two major themes developed from discussions with participants considering a hastened death. The first theme involved a sense of disintegration, which resulted from the multiple symptoms and loss of bodily functions that eventually led participants to a dependency on others and a loss of dignity. The second theme, loss of community, reflected the lack of contact these individuals had with others. Participants also reported that the result of experiencing disintegration and loss of community was a perceived loss of self.

Much can be learned from these studies that can be used to guide health care practitioners in their quest to improve end-of-life care. Loss of self, dignity, and autonomy; loss of control over bodily functions and manner of death; lack of enjoyment and meaning in life; lower quantity and quality of social support; lack of hope; and higher levels of anxiety and depression are all key psychosocial factors that motivate some terminally ill individuals to consider hastening their death.

Although pain was a significant predictor of hastening death in only two studies, fear of future pain or uncontrollable suffering surfaced as a key factor in most studies. Clearly, some individuals who are not suffering in the present fear they will be suffering at some point in the future.

Addressing Current Limitations

Although current empirical evidence regarding the factors that motivate terminally ill individuals to consider hastening their death has provided insight into this issue, three major limitations exist that need to be addressed. First, the considerable research on hastening death described in the preceding section was conducted retrospectively (either with physicians or survivors) or prospectively (with patients who had a terminal illness). Studies conducted with physicians or survivors result in second-hand information that may not provide an accurate record of patients’ motivating factors. Although prospective studies do provide first-hand information, they too are problematic. Some patients with a terminal illness may be in the early stages of their illness and so are being asked to speculate about whether they would consider hastening death before death becomes imminent; in the later stages of their illness, their feelings may change. Prospective studies that include only terminally ill individuals are the most likely to provide the information necessary to understand the motivating factors for considering a hastened death.

Second, the main approach taken in research on considering a hastened death has been to measure quantitatively factors presumed to be key motivators, such as pain and depression. This approach has provided important information and should be continued. However, due to the current lack of information on the motivating factors for considering a hastened death, it may also be useful to step back and take a more open-ended approach to this research. The qualitative method is not constrained by what has been hypothesized; it allows for the exploration of the individual’s reasoning regarding his or her consideration to hasten or not to hasten death, and it allows one to discover the unknown. As evidenced in the literature review above, this method has rarely been used. Continuing to limit research in this manner may result in crucial factors remaining undetected, unaddressed, and not well understood.

Third, the lack of attention given to studying the factors that motivate terminally ill individuals not to consider hastening their death may limit the understanding of factors key to a quality dying experience. The current approach of focusing on the factors motivating the consideration to hasten death assumes that such information provides all the knowledge necessary for improving palliative care. Extending this approach to include asking individuals what it is about their dying process that keeps them from considering a hastened death can also serve to inform palliative care.

The current study addresses each of these three limitations. I used a prospective qualitative approach, sampled only elders who had fewer than six months to live, and examined the factors motivating the consideration not to hasten death in addition to factors motivating the consideration to hasten death.

Methods

Sample

The selection criteria for the study were threefold. Respondents had to (a) be 50 years of age or older; (b) be deemed mentally competent by their physician, nurse, or social worker; and (c) have been given a prognosis by a physician of 6 months or less to live. I initially set the age selection criterion at 60 years or older in order to coincide with typical age definitions of elders. Six months into the study, however, I lowered the criterion to 50 years or older in order to obtain a sufficient number of male participants so that I could examine gender differences.

I used purposive sampling. I contacted hospices, hospital-based inpatient palliative care programs, and hospital-based outpatient clinics caring for the terminally ill throughout Michigan in hopes of obtaining a population that varied with regard to race, education, and occupation. Of the 17 programs
contacted, 10 agreed to participate: 2 palliative care programs, 2 hospital outpatient clinics, and 6 hospices. Ninety-six terminally ill elders were approached by either a social worker or a nurse regarding the study, and all agreed to participate.

Participating elders ranged in age from 51 to 98 (M = 73.5). The majority of elders were White (84.4%), 15.6% were Black, and a little more than half were married (52.1%). Elders were quite varied in their religious preferences: Catholic (19.8%), Methodist (14.6%), Baptist (15.6%), other Protestant religions (35.4%), Jewish (2.1%), and no religious preference (12.5%). Most elders had some form of cancer (49.0%); others were diagnosed with end-stage renal disease (26.0%) or heart disease (15.6%). A small percentage (9.4%) of elders was dying of respiratory, neurological, or other diseases.

**Data Collection**

In face-to-face interviews, I asked respondents if they had given serious thought to hastening their death since finding out they had a serious illness that may shorten their life. If they answered no, I asked about their reasons for not considering a hastened death. If they answered yes, I asked how they were considering hastening their death and whether they were still thinking about doing so. If they were not longer considering doing so, I asked about their reasons for having once considered hastening their death, and their reasons for no longer thinking this way. If they were still considering a hastened death, I asked their reasons for thinking about doing so. All interviews were audiotaped and transcribed.

When answering these questions, respondents did not appear to construct their reality as they went along or to do so within the boundaries of hastening or not hastening death. Most respondents raised the topic on their own and began describing their mind frame towards dying prior to being asked questions regarding considering a hastened death. Although some respondents did not raise the topic and, when asked, dismissed any thought of hastening their death, their responses regarding why they would not do so were immediate and very indepth. I had the sense that they had already given the issue much thought and were simply sharing those thoughts with me.

**Data Analysis**

I analyzed the content of answers for themes regarding respondents’ reasons for considering or not considering a hastened death. Content analysis involved “identifying” and “categorizing” the main themes and patterns found in the data (Patton, 1990, p. 381). I took an inductive method in locating these themes and patterns. That is, I did not determine the themes and patterns prior to the analysis; rather, they emerged from repeated readings of the transcripts (Patton). I used this approach to identify respondents who were considering a hastened death and those who were not considering one, as well as the psychosocial and physical factors motivating their considerations. As a reliability check, a hospice social worker independently coded the thematic areas identified, and we reached complete agreement.

**RESULTS**

As was previously discussed, studies on the consideration to hasten death have traditionally assumed that terminally ill individuals face their dying in one of two ways: not considering a hastened death or considering a hastened death. I initially approached the present study operating under these same assumptions. Content analysis of the qualitative data revealed, however, that this dichotomous approach is an over-simplification of an elder’s potential mind frame towards dying. No label in the death and dying literature appeared adequate to describe what evolved in the qualitative analyses, and so I chose the term mind frame to refer to the overall attitude or orientation an elder had adopted towards his or her dying. Six distinct mind frames towards dying emerged: (a) neither ready nor accepting; (b) not ready but accepting; (c) ready and accepting; (d) ready, accepting, and wishing death would come; (e) considering a hastened death but having no specific plan and (f) considering a hastened death with a specific plan. Figure 1 illustrates how these six mind frames fall within the two traditional categories. Table 1 provides descriptive information regarding the elders who adopted each mind frame. I did not gather information regarding the approach or mind frame respondents had taken to previous life crises or whether past experiences influenced their current mind frame towards dying.

**Approach Towards Dying, Accompanying Emotions, and Motivating Factors**

Each mind frame towards dying that emerged from the interviews was distinguished by an approach towards dying, personal characteristics, accompanying emotions, and factors motivating the elder to adopt a particular mind frame. Motivating factors emerged from responses to the questions about the elders’ reasons for either not considering or considering a hastened death. The approaches, personal characteristics, emotions, and motivating factors characterizing each mind frame are summarized in the following sections.

It is important to note that respondents did not appear to shift from one mind frame to another during their interviews. Although 15 respondents spoke of having transitioned earlier in their dying process from another mind frame (this topic will be discussed in another article), neither they nor the other respondents appeared to shift from one mind frame to another during the interview. I did not determine the reasons for this consistency; however, one could speculate that the factors motivating their adoption of a mind frame did not change during the interview process and so neither did the mind frame itself.

**Mind Frame 1: Neither Ready Nor Accepting**

**Approach towards dying.**—Thirty-three elders (34%) spoke strongly about not being ready to die or willing to accept that death was imminent. Two approaches towards dying characterized this mind frame: fighting to live, and hoping or believing science would find a cure.

The predominant approach that emerged among these elders was that of fighting to live and not giving in to the disease. One 74-year-old divorced woman stated adamantly, “And I’m not ready, and I’ll tell you why. They can say four months; I’m going to live longer than that.” A 51-year-old man who stated emphatically, “I figure, I don’t really have to die if I don’t want to and I’m not going to,” talked about his wife’s determination and how he had adopted her attitude.

The second approach towards dying centered on the belief and hope that science would find a cure and that the elders...
would survive their illness. A 63-year-old elder said, “They’re going to find a cure for everything I’ve got, and I’m going to be able to live a lot longer.” This woman spoke with quiet resolve throughout the interview, as did the other respondents who spoke of a cure being found for their illness.

**Personal characteristics.**—Respondents adopting this mind frame towards dying had a mean age of 69 and had, on average, less than a high school education. They were predominantly women (52%), White (79%), married (67%), and of the Protestant faith (70%).

Table 1. Demographics of Elders Adopting One of Six Mind Frames Towards Dying (N = 96)

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Not Ready nor Accepting of Dying (%)</th>
<th>Not Ready but Accepting of Dying (%)</th>
<th>Ready and Accepting of Dying (%)</th>
<th>Wishing for Death (%)</th>
<th>Hasten Death, No Specific Plan (%)</th>
<th>Hasten Death, Specific Plan (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, in years (M)</td>
<td>69.3</td>
<td>71.9</td>
<td>81.3</td>
<td>83.2</td>
<td>73.8</td>
<td>74.0</td>
</tr>
<tr>
<td>Education, in years (M)</td>
<td>11.6</td>
<td>11.5</td>
<td>12.3</td>
<td>11.5</td>
<td>13.6</td>
<td>14.4</td>
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<tr>
<td>Gender (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Female (n = 54)</td>
<td>51.5</td>
<td>58.3</td>
<td>66.7</td>
<td>50.0</td>
<td>44.4</td>
<td>66.7</td>
</tr>
<tr>
<td>Male (n = 42)</td>
<td>48.5</td>
<td>41.7</td>
<td>33.3</td>
<td>50.0</td>
<td>55.6</td>
<td>33.3</td>
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<tr>
<td>Race (%)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Black (n = 15)</td>
<td>21.2</td>
<td>20.8</td>
<td>6.7</td>
<td>0.0</td>
<td>11.1</td>
<td>11.1</td>
</tr>
<tr>
<td>White (n = 81)</td>
<td>78.8</td>
<td>79.2</td>
<td>93.3</td>
<td>100.0</td>
<td>88.9</td>
<td>88.9</td>
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<tr>
<td>Marital status (%)</td>
<td></td>
<td></td>
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<tr>
<td>Married (n = 50)</td>
<td>66.7</td>
<td>45.8</td>
<td>26.7</td>
<td>50.0</td>
<td>44.4</td>
<td>66.7</td>
</tr>
<tr>
<td>Not married (n = 46)</td>
<td>33.3</td>
<td>54.2</td>
<td>73.3</td>
<td>50.0</td>
<td>55.6</td>
<td>33.3</td>
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<tr>
<td>Religion (%)</td>
<td></td>
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<td></td>
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<tr>
<td>None (n = 12)</td>
<td>15.2</td>
<td>12.5</td>
<td>13.3</td>
<td>16.7</td>
<td>0.0</td>
<td>11.1</td>
</tr>
<tr>
<td>Catholic (n = 19)</td>
<td>15.2</td>
<td>25.0</td>
<td>33.3</td>
<td>16.7</td>
<td>11.1</td>
<td>11.1</td>
</tr>
<tr>
<td>Protestant (n = 63)</td>
<td>69.7</td>
<td>62.5</td>
<td>53.3</td>
<td>66.7</td>
<td>88.9</td>
<td>55.6</td>
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<tr>
<td>Jewish (n = 2)</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>22.0</td>
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<tr>
<td>Primary diagnosis (%)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Cancer (n = 47)</td>
<td>54.5</td>
<td>54.2</td>
<td>46.7</td>
<td>16.7</td>
<td>55.6</td>
<td>33.3</td>
</tr>
<tr>
<td>End-stage renal disease (n = 25)</td>
<td>36.4</td>
<td>25.0</td>
<td>20.0</td>
<td>16.7</td>
<td>0.0</td>
<td>33.3</td>
</tr>
<tr>
<td>Heart disease (n = 15)</td>
<td>6.1</td>
<td>16.7</td>
<td>26.7</td>
<td>66.7</td>
<td>11.1</td>
<td>0.0</td>
</tr>
<tr>
<td>Other diseases (n = 9)</td>
<td>3.0</td>
<td>4.2</td>
<td>6.7</td>
<td>0.0</td>
<td>33.3</td>
<td>33.3</td>
</tr>
</tbody>
</table>
Elders discussed being with family, enjoying life, and having unfinished business as the factors motivating their lack of readiness regarding dying. They viewed death as a natural part of life and were matter-of-fact in their approach. A 73-year-old married woman stated, "Like I say, I don't want to die, but when that time comes, that’s it. I’ve got all the mourning to do and everything."

Several men and one woman spoke of fearing the unknown, being alone in the grave, and being afraid that loved ones would forget them after they die. An 81-year-old widower depicted these fears clearly: "There’s no future in dying. And, uh, you have to stay all alone in the grave and everything... If you die, uh, isn’t nobody going to care anyway. They’re going to forget you in less than two months."

The future pictured by these elders at the time of the interview did not include their death.

Factors motivating acceptance of dying.—Religious beliefs, which motivated elders who had adopted Mind Frame 1 not to be accepting of their dying, were a factor cited by elders who had adopted Mind Frame 2 regarding their acceptance of dying. The beliefs of both groups of elders centered on God’s will regarding their acceptance of dying, but the two groups differed in their view of what was God’s will. Elders who were neither ready nor accepting of their dying defined God’s will as for them to fight death. Elders who were not ready but who had accepted their dying reported that it was in God’s power to decide the time of death. Although they did not feel ready to die, they made the instrumental and emotional support received from family members served as a motivator not to hasten the time they had left. A 73-year-old married man stated, "They [family] care about me and will, will walk that extra mile for me."

Unfinished business, a factor reported by elders who had adopted Mind Frame 1, was also reported by elders who had adopted Mind Frame 2. The difference, however, was that unfinished business was discussed in terms of a sense of purpose or responsibility. As one 74-year-old never-married man noted, "I have taken it upon myself to decorate the graves on Memorial Day. And that’s quite a job, by the way. Somebody has to decorate the family graves, and I’ve sort of assumed that responsibility for myself."

Factors motivating lack of readiness regarding dying.—As with elders who had adopted Mind Frame 1, family and unfinished business were mentioned as motivators for lack of readiness on the part of elders who had adopted Mind Frame 2.

Most elders reported that they did not want to hasten their death because they were enjoying their life. This enjoyment of life included being with family and still having the ability to take an active role in their lives.

When elders who had adopted Mind Frame 2 spoke of families, the nature of the family ties differed from those of elders who had adopted Mind Frame 1. Only a few elders discussed how their loved ones still needed them. Instead, most spoke of how the instrumental and emotional support received from family members served as a motivator not to hasten the time they had left. A 73-year-old married man stated, "They [family] care about me and will, will walk that extra mile for me."

In addition, these elders were concerned about how emotionally difficult their death would be on their families. A 71-year-old married man stated, "I guess it’s going to be harder on them than on me because I won’t be here... They’ve got all the mourning to do and everything."

Unfinished business, a factor reported by elders who had adopted Mind Frame 1, was also reported by elders who had adopted Mind Frame 2. The difference, however, was that unfinished business was discussed in terms of a sense of purpose or responsibility. As one 74-year-old never-married man noted, "I have taken it upon myself to decorate the graves on Memorial Day. And that’s quite a job, by the way. Somebody has to decorate the family graves, and I’ve sort of assumed that responsibility for myself."

Elders who had adopted Mind Frames 1 and 2 viewed death differently regarding the non-acceptance or acceptance of dying. Elders who were not accepting of their dying espoused a negative view of death that included fear of the unknown. In comparison, elders who were accepting of their dying took a matter-of-fact approach towards dying. They viewed death as inevitable and either reported not being fearful or spoke of their fear in a matter-of-fact way:

Everybody’s scared of dying, I think. It’s the inescapable fact. We don’t... everybody wants to see the sun come up. There is a certain amount of fear attached, I think. You know, even though we know that death is inevitable and it’s going to happen to each and every one of us, we fear the unknown. Yeah. We fear the unknown.
Unlike elders who had adopted Mind Frame 1, the future these elders pictured did include their death.

**Mind Frame 3: Ready and Accepting**

**Approach towards dying.**—Fifteen elders (16%) indicated a readiness and acceptance regarding dying. Not only did these elders talk about not being afraid to die, many saw death as the avenue to a better place than they were in at the present. One 92-year-old widow said simply, “I’m not scared to die. I know there is a better place for me.” Others spoke of their belief in the goodness of God and of reunions with deceased loved ones.

The majority of these elders viewed death as a natural part of life. Some talked about how happy they would be when death finally arrived and that they were simply waiting: “I’m going to be happy when I leave this earth. I guess it’s kind of a selfish attitude, but I’ll be out of my misery . . . All I’m doing is just passing time. I’m just waiting for the day.”

**Personal characteristics.**—Respondents who had adopted this mind frame had a mean age of 81 and had, on average, a high school education. Two thirds of these respondents were women, three fourths were not married, 93% were White, and slightly more than half were Protestant.

**Accompanying emotions.**—Elders with this mind frame revealed two predominant emotions towards life and death. Some elders had found peace and were enjoying the time they had left. Others had not found peace, nor were they enjoying the time they had left. These individuals were simply waiting for death to come as they no longer felt they could justify their existence.

**Factors motivating readiness for dying.**—Enjoying life was reported by several elders when describing their readiness to die. Because it was measured in relation to the limited time the elders had remaining before dying, enjoyment of life differed between elders who had adopted Mind Frame 2 and those who had adopted Mind Frame 3. A 92-year-old widow who was ready and accepting of death stated with a smile, “Whatever God gives me, I’m willing to take.”

Several elders talked about no longer enjoying life; that their lives were full of sadness; and that they felt useless, dependent, and burdensome to others. These individuals were simply waiting for death to come, as evidenced by the following 75-year-old widow’s statement:

And, uh, so I’m ready to go any time. It’s hard on the family, and I’m really not living. Even here [her son’s house] with my family. I get up, and they’re wonderful to me, and I’m so thankful I have a place to be. But, uh, they’re trying too hard, and it’s putting them out . . . They say it isn’t, but you know it is. But like I say, I’m ready to cash in my chips.

A few elders discussed the openness they shared with family regarding their impending death and the loving manner in which their family responded to this openness. This openness appeared to allow them to ready themselves for death by being able to make plans and express feelings they needed to express before they died. For example, an 84-year-old widow stated, “Well, they [her sons] asked me . . . what kind of funeral do I want . . . We’ve always talked about death very openly, because we all know it’s going to happen some day to one of us. So you might as well . . . be ready.”

Other elders’ readiness for death was explained in terms of their age. They had lived what they felt was a long time and so were taking their impending death in stride. One widow stated, “I just figure I’m 70 years old, and you kind of expect you got to die sometime, and you got to have some kind of a disease. You know, so I just kind of put it in my stride.”

**Factors motivating acceptance of dying.**—Three motivating factors were discussed by elders who were accepting of their impending death: (a) the belief that one’s time of death was God’s decision and not their decision, (b) having no fear of death, and (c) the belief that dying may be better than living. The first two factors were also cited by elders who had adopted Mind Frame 2. In addition, elders who had adopted Mind Frame 3 reported being motivated by their belief that death would be better than their current state of living. One 80-year-old married woman said, “I feel, uh, that I’ve accepted it [dying], know what I’m saying? So, and there’s worse things, Oh, yeah. There’s worse things than dying. Sometimes it’s worse living.” Although her statement could be interpreted as a wish for death to come, when directly asked, she denied ever wishing for death.

**Mind Frame 4: Ready, Accepting, and Wishing for Death**

**Approach towards dying.**—When asked if they had seriously considered hastening death, six elders (6%) were adamant that they would not consider taking any action but that they did wish death would come soon. These individuals were similar to those who had adopted Mind Frame 3 except they explicitly spoke of wishing daily for death to come. Even though each talked about how difficult life was for them, all six elders were steadfast regarding not considering a hastened death. One 93-year-old widow stated, “I wish I could go to a better place, but I will not take my own life.”

**Personal characteristics.**—Respondents who had adopted this mind frame had a mean age of 83 and had, on average, less than a high school education. Fifty percent of these respondents were women, 50% were married, 100% were White, and two thirds were Protestant.

**Accompanying emotions.**—Elders who had adopted Mind Frame 4 demonstrated different emotions than elders who had adopted Mind Frame 3. Elders who were ready and accepting appeared peaceful or were simply waiting for death to come. Elders who were also wishing for death, however, displayed conflicting emotions regarding living and dying. At times, they laughed nervously about their situation, and at other times they spoke with great sadness, often crying. Elders who had adopted Mind Frames 3 and 4 did share feelings of uselessness and a sense that they could no longer justify their existence.

**Factors motivating wish for death.**—Half of these elders spoke only of psychosocial reasons for wishing death to come soon. Several elders were no longer enjoying life, and one 87-year-old woman reported feeling useless: “It’s just the way I...”
feel like it, you know, like I might as well go. What good am I anymore, you know."

Other elders also discussed physical motivators, including exhaustion and daily pain. A 90-year-old widow noted, “Sometimes I feel so rotten that I don’t care anymore.” Others, like this 93-year-old widow, expressed a fear of future suffering as a reason for wishing death to come: “My first husband, he suffered a long time. He had on those machines, and I used to say, ‘God,’ I said, ‘don’t let me go under those machines.’”

Factors motivating against the consideration to hasten death.—When these elders were asked why they had never moved beyond wishing for death to considering hastening it, two factors emerged. The first was the belief that the time of one’s death was God’s decision, as demonstrated by a married 84-year-old man’s statement: “I leave that [dying] up to the good Lord, and He’ll take you when He wants you.” The other factor was family. Elders talked about the love and support of their family and friends, as well as wanting to protect them from the pain that their suicide would bring.

Mind Frame 5: Considering a Hastened Death But Having No Specific Plan

Approach towards dying.—The approach nine elders (9%) took towards dying was to consider hastening their death. However, although they were considering hastening their death, they had not developed a specific plan to actually do so.

Personal characteristics.—Respondents who had adopted this mind frame had a mean age of 74 and had, on average, some college education. Men outnumbered women, a slightly higher percentage were not married (57%), 90% were White, and the majority was Protestant (89%).

Accompanying emotions.—These elders demonstrated conflicting emotions regarding their desire to hasten death and their taking the next step to develop a specific plan to carry out that desire. Their voices resonated with the emotional pain involved in considering hastening their death and taking the necessary actions to make it happen. As was the case with individuals who had adopted Mind Frames 3 and 4, individuals who had adopted Mind Frame 5 felt they could not justify their existence.

Factors motivating the serious consideration of a hastened death.—The factors motivating these elders to consider a hastened death were mostly psychosocial in nature, as they were for those elders who had adopted Mind Frame 4. Eight of the nine elders who had adopted Mind Frame 5 reported psychosocial factors that included loneliness, not enjoying life, lack of hope, boredom, uselessness, and being a burden. One 92-year-old man aptly expressed his lack of enjoyment in life: “I, if I could do away with myself, I would . . . I had to give up everything . . . golfing and bowling, sex life, riding my bike.”

Physical factors served as motivators for four of the nine elders. Two of these individuals were suffering pain at the time of the interview. One 53-year-old married woman reported despondently, “I’m tired. I’m tired of the struggle and the fighting and the pain and all of that.” A 75-year-old married man, who was one of two elders not currently experiencing pain but fearful of future suffering, stated sadly, “I, I fear some of the, uh, some of the physical stress that may come in the course of my dying. Nobody chooses to die little by little. At least, I can’t visualize that.”

Factors motivating the lack of a specific plan to hasten death.—All nine elders who had adopted this mind frame were suffering emotionally and/or physically such that death was preferable to living, yet they had not developed a specific plan for hastening death. Although only a few elders stated this preference specifically, others echoed this sentiment but used different words. For example, one 72-year-old widower stated in a voice full of despair, “I just want to get it over with . . . Tomorrow is the same thing, the same thing.” Discussions with these individuals revealed the physical limitations and psychosocial reasons preventing them from actually developing a plan to hasten their death.

Three elders were physically unable to hasten their death due to the limitations placed on them by their disease. For example, one man had multiple system atrophy and could only move his lips. These individuals would have required assistance to carry out any plan but either lacked family or friends who might have provided such assistance or, out of love and a sense of responsibility, would not ask them to do so.

The six elders who possessed the physical ability to carry out a plan without assistance had yet to develop one because of their family and friends. For example, two individuals were suffering from respiratory diseases that made breathing difficult, painful, and exhausting. One woman, who was presented at the interview, stated that she knew her terminally ill husband wanted to hasten his death but was vehemently opposed because she felt unable to cope without him. The other elder’s spouse, who was not present at the interview, was unaware of his wife’s desire to hasten death. The wife, however, knew that her husband was dependent on her emotionally and financially; this dependence kept her from developing a plan. Faced with the love and support they both gave to, and received from, others, these two elders could not make a plan.

Only one elder cited religious beliefs as her reason for not developing a specific plan. Although this 87-year-old widow felt that “there doesn’t seem to be any hope for anything,” and she refused to explain what her religious beliefs were, she felt strongly that these beliefs would not permit her to take the next step towards hastening her death.

Except for the respondent who felt that her religious beliefs would not allow her to make a specific plan to hasten her death, I felt the others would make a plan in the future should their circumstances change. The physical and psychosocial anguish expressed by these elders was very real. If someone had volunteered to assist them, or if their spouses had changed their mind regarding not wanting them to leave, I believe these elders would have sought the opportunity to develop a plan.

Mind Frame 6: Considering a Hastened Death With a Specific Plan

Approach towards dying.—The remaining nine elders (9%) were seriously considering hastening their death and had a specific plan of action. One 55-year-old married man had developed a suicide plan he could carry out on his own were his
suffering to intensify. Three elderly women (aged 65, 70, and 79), two of whom were married, all had end-stage renal disease and planned to go off dialysis. They had discussed with their physicians stopping their dialysis treatment and their physicians told them they would support their decision and provide the necessary assistance. A 75-year-old married woman had contacted the Hemlock Society and had received their support. Two elderly women and two elderly men (aged 75, 91, 69, and 76, respectively) were considering physician-assisted death and had received verbal support from their physician, with whom they had a close relationship. One of the women stated, “I have considered, I do like this physician-assisted suicide. With the assistance of a doctor, so you won’t have a, a, messy death . . . and they [doctors] have said that any time I'm going to want to, it’s up to me. That’s right. I’m very glad about it. Yeah.”

Personal characteristics.—Respondents who had adopted this mind frame had a mean age of 74 and had, on average, some college education. Two thirds were women, two thirds were married, and 90% were White. Although more than half of these respondents were Protestants, all respondents of Jewish faith (n = 2) were in this category.

Accompanying emotions.—Some of these individuals were very emotional when speaking of hastening their death, whereas others had a matter-of-fact approach to the topic. Elders who had family or friends felt conflicting feelings when they spoke of the impact their plan might have on loved ones. Elders who had adopted Mind Frames 3, 4, 5, and 6 all shared feelings of uselessness and the sense that their existence could no longer be justified.

Factors motivating the serious consideration of a hastened death.—All nine elders reported psychosocial factors as playing a crucial role in their desire for a hastened death. Eight of the nine elders expressed feeling useless. The frustration of feeling useless was evident in a 70-year-old widow’s inability to do the normal tasks of daily living: “I just can’t do what I used to. Um, I can’t go out, I can’t go to the store . . . I can’t write a check for nothing. I, it’s just a lot of things . . . Oh, I hate it.” A 91-year-old widow talked about how she no longer felt useful to others: “There’s not any good reason for me to go on living. Nobody really needs me . . . I’m really not serving any purpose. If you don’t, aren’t needed by anybody, you kind of have a different feeling about life.”

Six elders felt life no longer brought any enjoyment. Each day was filled with the limitations of their illness and the misery it wrought on their lives. One 76-year-old man had reached the point in his illness where he had lost the ability to move his body or speak. He had always loved to socialize, travel, and work—all things he was no longer able to do. Not being able to communicate with others or get around like he used to had a profound negative impact on him.

In addition expressing psychosocial factors as motivators, two elders who were currently only experiencing mild physical discomfort feared they would suffer terribly as death drew near. One elder had heard on television and read in the newspaper about how painful dying had been for other Americans and feared the same fate. The other elder had witnessed his mother’s suffering and was reminded daily of her terrible experiences.

The desire to hasten death was strong for the nine elders, and they all noted how having a plan provided a sense of control in case living became too unbearable. One 91-year-old widow was fueled by her desire for control over her body: “I just feel sometimes as though cancer is, uh, an opponent. And, it seems to me, it says to itself, ‘I am in control of this body. This is mine, I will do whatever I want to with it.’” She spoke with her long-time doctor about physician-assisted death, and he promised his support when she was ready. She felt that although the cancer now had the upper hand, she had the ultimate control through physician-assisted death.

Factors motivating against implementation of plan to hasten death.—Although all nine elders possessed a plan for hastening their death, they had not yet set an exact time for putting their plan into action. For some, physical limitations prevented them from carrying out their plan alone. For others, life was still bearable and they felt the need to protect their family from the taint and pain their suicide would bring. At that moment, the factors motivating elders not to move forward with their plan were proving stronger than the motivators for hastening death.

For some elders, physical limitations resulted in their not being able to carry out specific suicide plans. They had waited too long to put them into action and now were physically unable to do so. The anger and frustration felt by these individuals was expressed clearly by a 69-year-old married man who was suffering with amyotrophic lateral sclerosis: “… I can’t pull the trigger. Too weak. I’d have to make a fixture and fasten it and have a string and pull my arm.”

Although some elders had family who could assist and were supportive of their plan to hasten death, they could not bring themselves to accept their family’s assistance. They did not want to place loved ones in this position and were hoping to find others who would do so; they also did not feel comfortable about approaching their physician.

For the elders who were physically able to carry out their plan, family also played a role in their not yet having executed the plan. These individuals talked about the emotional pain a hastened death would bring their loved ones. Feelings of protecting family members from this emotional pain were uppermost in their minds. One 55-year-old married man, whose son had killed himself, his wife, and his children, was reluctant to put his wife through his own suicide if possible:

And basically for one reason. Yeah, I’ll tell you. We lost our son and his family back in ’91 . . . It was to do with drugs. And we don’t know . . . what happened, but supposedly he, he shot and killed his wife and the two-year-old son. And then himself, and they had a five-month-old baby that was suffocated . . . We found them, which made it ten times worse. And because of that, I would never do that to my wife. I wouldn’t do that.

For the other elders who also could go through with their plan without any assistance, life was still bearable. However, should the time come when they could no longer tolerate their lives, they indicated that their plan would be put into action.

All nine elders were experiencing critical junctures in their dying process. Either life had become unbearable due to their illness, or they feared it would be so in the future. The only solution they saw to address their physical and emotional pain
was to hasten their death, and they were strong in their conviction to do so, if it became necessary.

**DISCUSSION**

Prior studies on factors motivating terminally ill individuals to consider a hastened death assumed that they faced their dying by either considering or not considering a hastened death. This dichotomy was originally proposed for the present study; however, as the respondents’ stories unfolded, it quickly became clear that these 96 terminally ill elders had mind frames towards dying that were much more complex. Instead of the simple consideration to hasten or not to hasten death, six mind frames towards dying emerged. Furthermore, elders with differing mind frames were struggling with various issues related to their dying. Elders not considering a hastened death reported grappling with issues of readiness and acceptance, whereas elders wishing for or considering a hastened death reported grappling with whether to take action.

Researchers can draw no conclusion from the data regarding whether elders’ six mind frames fall along a continuum from neither ready nor accepting of dying to having a specific plan by which to hasten death. To consider these mind frames as a continuum implies that (a) these mind frames are stages terminally ill elders move through, and (b) one stage progresses to the next. The data support neither implication. Fifteen elders reported moving from one mind frame to another during their dying process, whereas others reported only having experienced one mind frame (this topic will be discussed in another article). Elders who reported changing their mind frame did not necessarily move sequentially consistent with the mind frames being a continuum or a series of stages. Although the cross-sectional data do not provide information on the issue of progression, they do provide insights into personal characteristics, approaches towards dying, and accompanying emotions that characterize each mind frame, as well as the factors that motivate its adoption by the elder.

**Personal Characteristics**

The elders who participated in this study did not enter into their dying process with a blank slate; rather, each brought with them values, beliefs, and experiences based on their age, education, gender, race, marital status, and religion (see Table 1). It was noted earlier that information was not gathered regarding the mind frame respondents had adopted in previous life crises, or whether past experiences influenced their current mind frame. Respondents’ personal characteristics, however, serve to provide some of this information.

Age and race showed some patterns in relation to respondents’ readiness for death. Respondents who were not ready to die, regardless of whether they did or did not accept death, were younger (71 and 69 years old, respectively), on average, than respondents who were ready and accepting (81 years old) or wishing for death (83 years old). It could be that age may reflect the timing of the death; that is, younger elders may feel that death is coming sooner than they had anticipated and so they are less ready for it. Race also revealed an important pattern, in that few Black respondents reported a readiness to die, and none wished for death. It is unclear why Black respondents might lack readiness, but it could be related to their spiritual beliefs.

Education, gender, marital status, and religion revealed some noteworthy patterns with regard to respondents who were considering a hastened death. Regardless of whether they did or did not have a specific plan, respondents who were considering a hastened death reported having at least some college education (14 and 13 years, respectively), whereas respondents who had adopted other mind frames reported having a high school education or less. Education may provide knowledge of end-of-life options as well as access to resources necessary to hasten one’s death. It is also important to note that a higher percentage of women than men reported having a specific plan to hasten their death, although the reason for this pattern is not clear. For the most part, respondents who were married and who were considering a hastened death had a specific plan, whereas unmarried respondents who were considering a hastened death did not. Having a partner to assist with hastening death may make it easier to develop a specific plan and act on it. Finally, although Catholics reported a high level of acceptance of dying regardless of their level of readiness, both Jewish respondents possessed a specific plan to hasten death. Again, it is difficult to speculate about the reasons for this difference.

The patterns noted above provide support for delving more deeply into the role that a respondent’s personal characteristics may play in the adoption of his or her mind frame. A mixed-method research approach would help gather information not only on which characteristics play a role in the adoption of mind frames but also on how they do so.

**Importance of the Psychosocial Aspects of Dying**

Family relationships; unfinished business; enjoying life; fear of dying; having lived a long time already; not enjoying life; feeling bored, lonely, useless, dependent, and burdensome to others; lack of hope; lack of control; religious beliefs; fear of future suffering; and physical suffering were all factors that motivated the elders interviewed for this study to adopt one of six mind frames. Many of these factors reflect what has been found in previous studies; however, the current study provides rich information on how the factors motivate the adoption of different mind frames towards dying. It is important to note that in the present study, as well as in the studies reviewed earlier in this article, psychosocial factors were mentioned as motivating factors more often than were physical factors. Physical suffering, however, is not a factor that can be ignored. In the current study, physical suffering was a motivating factor for 3 of the 6 respondents who were wishing for death to come and for 2 of the 9 respondents who were considering a hastened death but had no specific plan on how to bring it about. Although elders discussed psychosocial issues more often than physical ones, it may be that some of these issues were the result of physical limitations or problems brought on by their illness.

**Complexity of Motivating Factors**

The results of this study demonstrate that some motivating factors differed among elders with each of the six mind frames, and, even in the cases where some similarities existed, a closer look showed that these factors were not the same. Family is an excellent example of this. Family was a motivator for both elders who were neither ready nor accepting of dying (Mind Frame 1) and for elders who were not ready but who had accepted their dying (Mind Frame 2). Yet how family motivated
these elders’ lack of readiness differed. Elders who had adopted Mind Frame 1 cited the importance of providing emotional and instrumental support to their family. Elders who had adopted Mind Frame 2 spoke of receiving emotional and instrumental support from their family. Thus, it is not enough for health care practitioners to know that family is an important influence on readiness to die. It is also important to understand just how family ties affect the terminally ill elder’s readiness for and acceptance of their death.

Religious belief is another example of how a factor can appear to be the same across mind frames and yet can motivate elders to adopt different mind frames. Elders who were neither ready nor accepting of dying spoke of how God wanted them to fight to stay alive and did not want them just to accept their dying. God was important in a quite different way for some elders who explained their acceptance of death as based on their belief that time of death was God’s decision. The religious belief that God decides time of death also served to motivate some elders who wished for death but who were not seriously considering hastening it. These differences raise the issue of whether the respondent’s religious beliefs were of long standing and had led him or her to adopt the views towards death that had been described in the interviews, or whether the beliefs developed after the respondent’s diagnosis in order to support their mind frame the respondent needed to be in at that time. Either way, the religious beliefs held by some respondents gave them support for their mind frame.

These are only two examples of the complexity of the motivating factors that needs to be taken into consideration when health care professionals are working with terminally ill elders. For example, strong family ties or religious beliefs cannot always be assumed to operate in the same manner. Instead, professionals need to uncover the specific nature of such ties or beliefs.

Palliative Care Program and Practice Implications

The overarching implication to emerge from this study is the need to develop palliative care programs from a holistic rather than a primarily medical perspective. The elders participating in this study provided quite a bit of evidence as to the importance of addressing not only their physical needs, but their spiritual, emotional, and social needs as well. Developing a program that meets these needs has several underlying implications.

Once elders have been told they have fewer than six months to live, the main goal of palliative care programs becomes ensuring that they receive a quality dying process. The term quality dying process is ambiguous and so necessitates defining. The qualitative information provided by the 96 terminally ill elders interviewed for this study serves as a step towards such a definition.

For elders participating in the current study, a quality dying process meant recognizing that each had his or her own psychosocial, spiritual, and physical needs, and that whether or not these needs were met had an impact on the mind frame that elder adopted towards dying. If palliative care programs were to adopt the definition of a quality dying process as holistic and individualistic, it would be important to develop instruments that ensure a comprehensive assessment of each elder’s mind frame; the psychosocial, physical, and spiritual factors that led to its adoption; and the elder’s level of satisfaction with it. If the elder is satisfied, then such programs can emphasize to their practitioners the importance of respecting the elder’s wishes, even if the practitioner does not agree with them. However, if the elder is not happy with his or her current mind frame, then the elder and practitioner can address the factors that may allow for transitioning to another mind frame. It is crucial that palliative care programs acknowledge the fluidity of movement between mind frames (as evidenced by 15 of the 96 respondents who reported previous transitioning), such that elders’ psychosocial, spiritual, and physical needs are continually assessed as they move through the dying process.

In an attempt to ensure that each terminally ill elder has a quality dying process, I suggest the following guidelines for palliative care programs. First, the design of these programs may best be guided by the input of clergy, nurses, physicians, and social workers so that all aspects of care are considered. Second, once programs have been established, it may be beneficial for staff to work as a team in order to ensure that each terminally ill elder has all of his or her needs met. Third, in order to develop effective care plans, it may be helpful to develop evaluation instruments that assess the spiritual, emotional, social, and physical needs of the elder, as well as his or her current mind frame towards dying and the elder’s level of satisfaction with that mind frame. It is important, however, to honor the elder’s self-determination regarding his or her needs. This means that guidelines should be established that specify the need for practitioners to determine and honor what each elder feels are the most critical issues to be addressed. As was revealed in the current study, some terminally ill elders gave psychosocial issues higher priority than physical ones. Time is limited for these individuals, and it is important that elders be the ones to determine how their limited time is spent. Fourth, in the current study, sense of control served as a key motivating factor for not only considering a hastened death but also for developing a specific plan to carry it out. Although more research is necessary regarding the role sense of control plays in relation to a terminally ill elder’s dying process, palliative care programs should include the assessment and fulfillment of control needs in their care plans. Finally, palliative care health professionals need to attend training sessions that allow them to explore their own values and beliefs regarding death. An increased self-awareness and comfort with dying and death could result in practitioners being more receptive to allowing terminally ill elders to express their fears and concerns honestly throughout the dying process.

Study Limitations and Research Implications

Although this study advanced knowledge on hastening death and had an unusually large sample size for a qualitative study, there were also limitations. First, the sampling technique used in this study was purposive, so the findings cannot be considered representative of the population of terminally ill elders. Second, the research design used for this study was cross-sectional and only captured the elders’ mind frames at one point in time. I asked elders who were not currently considering a hastened death to recall whether they had ever considered hastening their death; in this way, I gained evidence regarding past mind frames. This evidence, however, was based on recall that could have been impacted by the elder’s medication or current situation. I did not ask elders who were considering a hastened death about prior views regarding hastening death.
Therefore, I do not know whether they had been considering a hastened death since they were diagnosed as terminally ill or whether, at one time, they had not been considering a hastened death. The current evidence that terminally ill elders transition between mind frames is an important finding and one that would be best followed up by using a longitudinal research design.

Additional research on this topic using a random sample and a longitudinal research design may add support and clarification to the program and practice implications suggested by the current data. Qualitative studies focused on race/ethnicity, gender, social class differences, and sites of care are necessary in order to obtain information that will improve the care of terminally ill elders. In addition, future research on this topic should aim to develop a multidimensional assessment tool that not only captures elders’ personal characteristics and their mind frames towards dying, but also assesses elders’ spiritual, emotional, social, and physical needs.

Acknowledgments
Support for this article was provided by the John A Hartford Foundation Geriatric Social Work Doctoral Fellowship Program.

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References
Received July 13, 2004
Accepted July 18, 2005
Decision Editor: Charles F. Longino, Jr., PhD