The Myriad Strategies for Seeking Control in the Dying Process

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Purpose: This study explored the role control plays in the dying process of terminally ill elders by investigating the aspects of the dying process over which they seek to exercise control, the strategies they use, and whether they desire to exercise more control. Design and Methods: In-depth face-to-face interviews were conducted with 84 terminally ill elders receiving hospice care. Directed and conventional content analysis methods were used to identify main themes and patterns. Results: The results revealed that all 84 elders were using at least 1 primary control strategy in their dying process, 83 of whom did so in combination with another primary or compensatory secondary control strategy. Decision making, independence, mental attitude, instrumental activities of daily living, activities of daily living, and relationships were aspects of the dying process over which the respondents sought to exercise control. Over half of the respondents wanted more control; however, they felt their illness prevented it. Implications: The findings highlight the importance of terminally ill elders’ having opportunities to exercise control in their dying process. Practitioners need to ensure that these opportunities exist and to be aware that elders are adaptive and use multiple strategies in exercising control.

Key Words: Primary control, Secondary control, End-of-life care, Qualitative research methods, Quality of life

Research on end-of-life care has produced evidence that achieving a sense of control is viewed by terminally ill individuals (Singer, Martin, & Kelnar, 1999; Volker, Kahn, & Penticuff, 2004b; Wilson, et al., 2007) and those who care for them (Teno, Casey, Welch, & Edgman-Levitan, 2001) as playing an important role in the quality of their dying process. Terminally ill individuals have been found to consider the ability to exercise control as a desirable psychosocial outcome (Singer et al.) and a psychological comfort (Ganzini, Johnston, McFarland, Tolle, & Lee, 1998). Furthermore, the inability to achieve a sense of control has been associated with moderate to extreme suffering for some terminally ill individuals (Wilson et al., 2007) and a desire to hasten death for others (Back, Wallace, Starks, & Pearlman, 1996; Chin, Hedberg, Higginson, & Fleming, 1999; Coyle & Sculco, 2004; Oregon Department of Human Services [ODHS], 2000). Although sense of control evidently plays a key role in the psychological well-being of terminally ill individuals, less clear are the aspects of the dying process over which terminally ill individuals want to exercise control and the strategies they use for doing so.

In this article, we seek to advance our understanding of the role control plays in the dying process of terminally ill elders by investigating the aspects of the dying process over which terminally ill elders seek to exercise control, the strategies they use to do so, and whether they desire to exercise more control. By gaining a deeper understanding of the role control plays in the dying process of elders, health care and service providers and informal caregivers can work toward ensuring that elders exercise control in their dying process, thereby working toward the goal of improving the quality of end-of-life care.

Current Knowledge of Control’s Role in the Dying Process

The literature on the role of control in the dying process is continually expanding. Some information is available regarding the aspects of the dying...
process over which individuals, not necessarily elders, desire to exercise control, as well as the way in which they want to do so.

Aspects to Control

The factors motivating the consideration of a hastened death have been studied both retrospectively and prospectively. In retrospective studies, health care professionals or survivors of the deceased are asked to write case studies or respond to surveys concerning the factors cited by now deceased patients, who had considered or requested a hastened death. In prospective studies, individuals with a terminal illness (an illness likely to result in death), or who have been defined as terminally ill (less than 6 months to live), are directly asked about their consideration to hasten death and their reasons for doing so. Both retrospective and prospective studies provide insight into aspects of the dying process over which terminally ill individuals would like to exercise control.

Retrospective studies have found that loss of control over bodily functions (Back et al., 1996; Chin et al., 1999; ODHS, 2007) and physical symptoms (Volker, 2001) have served as factors motivating the consideration of a hastened death. A desire for control over the manner of death was found in both retrospective (Back et al.; Ganzini et al., 2002; ODHS, 2000; Volker) and prospective studies. In prospective studies, respondents who feared dying might become intolerable felt that having control over the manner of their death provided them with a sense of control (Ganzini et al., 1998; Schroepfer, 2006), as it did for those who feared a loss of control more generally (Chapple, Ziebland, McPherson, & Herxheimer, 2006). Respondents also noted that exercising control over the manner of death served to enhance their feelings of control over the disease itself (Albert et al., 2005), provided psychological comfort (Ganzini et al., 1998), and afforded a way to exercise control in an “untenable situation” (Coyle & Sculco, 2004, p. 703).

Other studies have sought to gain understanding about the aspects of dying over which terminally ill elders seek control by posing the question directly to bereaved caregivers, terminally ill individuals, and individuals living with a terminal illness. In one retrospective study, bereaved family members included in their definition of quality end-of-life care the ability for their deceased loved ones to have exercised control over their own health care decisions and daily routine (Teno et al., 2001). In another retrospective study (Volker, Kahn, & Penticuff, 2004a), advance practice nurses reported that patients sought control over decisions related to treatment, transitioning to dying, and end-of-life care, as well as over their comfort and dignity. In prospective studies, terminally ill individuals reported seeking to exercise control in end-of-life decisions (Singer et al., 1999; Volker et al., 2004b), over their dignity and physical comfort, the place of their death, and in preparing family for their pending death (Volker et al., 2004b). Although not all of the respondents in the aforementioned studies were elders, the information provides insight into aspects of the dying process over which terminally ill elders may desire to exercise control. To determine the control strategies used for doing so, an understanding must first be gained regarding the conceptualization of control.

Perceived Control Theories and Evidence

Numerous studies have been conducted on sense of control or, as it is often referred to in the literature, perceived control, which has to do with the expectation or perception of “engaging in actions” to either attain desirable outcomes or to evade those seen as undesirable (Rodin, 1986, p. 141). Perceived control is often presented as a “one-process construct,” but Rothbaum, Weisz, and Snyder (1982) have advanced the argument that it may actually be a “two-process construct” consisting of primary and secondary control (p. 8). These researchers define primary control as the perception that the individual has the ability to directly influence a desired outcome or avoid an undesirable one. Such beliefs develop when individuals endeavor to change directly the external environment to fit their own needs and are successful. Secondary control, in contrast, is the perception that the individual has the ability to influence more indirectly a desired outcome (Rothbaum et al.). This perception is formed when individuals endeavor to fit into their external environment and are able to do so. Thus, primary control attempts are focused on the external world and secondary control attempts on the individual’s internal self.

The life-span model of successful aging proposed by Schulz and Heckhausen (1996), which incorporates their life-span theory of control (Heckhausen & Schulz, 1995), builds on the notion of a two-process construct and argues that humans seek to exert control over the environment.
throughout their life span to attain goals. They propose three control strategies for doing so: selective primary control, compensatory primary control, and compensatory secondary control. Selective primary control involves individuals’ “investment of resources” such as their time, abilities, or efforts to attain a particular goal (Schulz & Heckhausen, 1996, p. 710). When individuals’ own resources are no longer sufficient to attain a particular goal, then compensatory primary control strategies become necessary, which require the assistance of others. Finally, compensatory secondary control involves the use of cognitive strategies on the part of individuals, which can include comparing their situation to someone whose situation is worse, disengaging from prior goals, augmenting the value of a new goal, or diminishing the value of an old goal (Heckhausen & Schulz). The use of compensatory secondary control strategies can work to maintain or lessen the losses that an individual is experiencing in his or her life.

Control Strategies Used

We are unaware of any research that has focused on control strategies used by elders in their dying process; however, evidence is available regarding the use of primary and secondary control strategies by elders with acute and chronic health conditions. In general, elders with chronic conditions have been found to use primary and secondary control strategies by elders with acute and chronic health conditions (Wrosch & Schulz, 2008). Due to age-related declines in late life, however, the tendency has been for elders to move toward using more compensatory secondary control strategies (Heckhausen, 1997). For elders experiencing a high number of health problems, Wrosch, Heckhausen, and Lachman (2000) found that the secondary control strategies of positive reappraisal and lowered aspirations were more strongly associated with their subjective well-being compared with elders who persisted in using primary control strategies.

Whether the findings regarding the control strategies used by elders with acute and chronic conditions hold true for terminally ill elders remains unclear at this time, as do the aspects over which terminally ill elders desire to exercise control. This study seeks to provide such insight by interviewing terminally ill elders about the aspects of their dying process over which they exercise control, the ways in which they exercise such control, and whether they would want more control.

Design and Methods

Participants

A purposive sample of 102 respondents was obtained at hospices throughout southern Wisconsin. Eligible respondents had to be at least 50 years of age, been told by a physician that they had 6 months or less to live, and deemed mentally competent by their nurse or social worker. Although age 50 would not normally be considered the lower age limit for elders, prior research experience with hospice populations (Schroepfer, 2006, 2007, 2008) has shown that to have enough male respondents, the age of inclusion needs to be lowered.

Procedure

A single-session face-to-face interview was conducted with each of 102 elders utilizing a mixed-method survey instrument. Interviews were audiotaped so that the qualitative portion could be captured verbatim, and the quantitative portion checked against what the interviewer recorded in the survey booklet. Interviews ranged in length from 23 to 178 min, with a mean of 63 min. Of the 102 respondents who completed the interview process, 18 respondents were dropped from the analysis because they declined to answer the control questions of interest. We have no way of knowing whether declining to answer these questions was systematically related to the level of control they exercised in their dying process. We do know, however, that a comparison between these 18 respondents and the 84 who completed the control questions revealed no differences in regard to age, gender, marital status, education, primary hospice diagnosis, or quality of life. Therefore, the final sample size used for analysis was 84.

Data Collection

Respondents were asked a series of questions regarding the control they were experiencing in their lives to determine the type of control strategies they were using. To learn about the aspects of the dying process over which they exercised control, respondents were asked if there were parts of their life over which they felt they had control. If respondents answered yes, they were asked to specify the parts. To determine the type of control strategy they used, they were next asked a series of questions regarding each part of their life over which they felt they had control. First, respondents were asked if they did things to directly control or
be in charge of that part of their life. If they said yes, they were asked to talk about what they did and how satisfied they were with it. Next, respondents were asked if there were other people whom they believed helped them control that part of their life. If yes, they were asked to talk about how these individuals helped them exert control. Finally, all respondents were asked if there were other parts of their life over which they would like to exercise control. If they said yes, they were asked to specify the parts and what they felt prevented them from having control. If they said no, they were asked why they did not want more control.

Quantitative data were gathered on respondents’ demographic information to explore whether the control strategies utilized by respondents differed based on their age, education, gender, marital status, or primary hospice diagnosis. Age was coded as a continuous variable, as was education, which was based on the number of years of schooling that respondents had completed. The respondents’ gender was coded as a dummy variable (0 = female and 1 = male), as was their marital status (0 = not married and 1 = married/partner). Respondents’ primary hospice diagnosis was grouped into four categories: cancer and, respiratory, heart, and muscular diseases.

To determine whether the use of control strategies was associated with respondents’ quality of life, quantitative data were gathered via a quality-of-life measure. Based on a previous study (Schroepfer, 2006) that sought to determine the factors that led terminally ill elders to consider or not consider a hastened death, nine factors were reported by elders as important to experiencing a quality dying process. These factors included having a reason for living, being able to maintain dignity, not feeling like a burden, living a life full of meaning and full of enjoyment, and feeling a sense of purpose, independent, useful, and hopeful. A thorough review of related literature produced several surveys containing one or more of the items but none that encompassed all nine items or that were designed for elders.

To address this problem, we used items from three survey instruments. The first is the Functional Assessment of Chronic Illness Therapy (FACIT)—spiritual well-being, a 12-item scale that has been designed to measure the spiritual domain of quality of life. Three items were borrowed from the eight-item subscale: a reason for living, a sense of purpose, and life has meaning. Tested in cancer populations (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002), this survey has been found to have internal consistency, high test–retest correlations, concurrent validity, discriminant validity, and a positive association with measures of quality of life. Four items were borrowed from the FACIT—palliative care: burden, dependence, usefulness, and hope. This scale is newer and currently undergoing psychometric testing. The third survey, the Structured Interview for Symptoms and Concerns (SISC), is a 13-item instrument designed specifically for patients receiving palliative care for advanced cancer. This instrument has been found to have high inter-rater reliability, good test–retest correlations, and concurrent validity. The two items taken from this survey measuring dignity and enjoyment of life were reworded, as was the response set. The reason for rewording the items is that they are worded as questions in the SISC, a format that does not fit with the statement format of the other items. Rewording of the response set occurred because it appears complicated and could prove burdensome to terminally ill elders. These items were measured on a 5-point ordinal scale ranging from 0 = not at all to 4 = very much. All nine items were summed, resulting in a possible score range of 0–36 wherein a higher score represented a higher quality of life.

Quantitative Analytic Approach

Bivariate analyses were conducted to determine if the control strategies used by respondents differed based on age, education, gender, marital status, and primary hospice diagnosis, as well as respondents’ quality-of-life scores. One-way analysis of variance (ANOVA) statistics were run to test the association between the control strategies used by respondents and their age, education, and quality-of-life scores. Cross-tabulations using the Pearson chi-square association test were conducted to test differences based on gender, marital status, and primary hospice diagnosis.

Qualitative Analytic Approaches

Using Schulz and Heckhausen’s (1996) theoretical framework, we conducted a directed content analysis (Hsieh & Shannon, 2005) of the information concerning what respondents or others did to control the various parts of their dying process over which they felt they exercised control. Directed content analysis uses theory to predetermine the categories that will be used in exploring the qualitative data. For this study, the first author read each interview transcript multiple times and grouped responses into the following control strategy categories: selective primary
control, compensatory primary control, and compensatory secondary control. Responses coded into selective primary control were those in which respondents described externally investing their efforts alone into attaining a particular goal. Respondents’ descriptions of exercising control externally with assistance from others were coded into compensatory primary control. Finally, responses that described the use of cognitive strategies to exercise control internally were coded into one of three types of compensatory secondary control strategies: adjustment of goals by lowering aspirations, self-protective positive reappraisal (Wrosch et al., 2000), and self-protective social comparisons (Chipperfield & Perry, 2006). As a reliability check, two members of the research team independently coded the responses based on the strategies identified. Initially, the team members were 76% in agreement and, after a discussion of the differing categorizations, arrived at a consensus on the remaining 24%.

Once the directed content analysis of the control strategies had been conducted, the two team members independently coded (a) the aspects of the dying process over which elders reported exercising control and (b) the aspects over which they desired to exercise control. This analysis did not employ a theoretical framework and so the team members utilized conventional content analysis (Hsieh & Shannon, 2005). Using an inductive method, themes were identified from repeated readings of the transcripts (Patton, 1990) and preliminary codes generated to represent the themes. Separately, the team members repeatedly read through and categorized the responses to the question regarding the parts of life over which respondents felt they had control. This same approach was used with responses to the questions regarding whether respondents felt there were other parts of their life they would like to control. If respondents answered yes, then team members categorized the parts that respondents wanted to control and what they felt prevented them from exercising that control. If respondents answered no, then responses regarding why they did not want more control were categorized. As with the directed content analysis, a reliability check was conducted between the two members of the research team, with an 82% initial agreement and full consensus reached upon discussion.

Results

The demographic characteristics of the 84 respondents were varied. Respondents ranged in age from 51 to 96 years, with a mean age of 76 years. The vast majority of respondents (n = 82; 98%) were White and 2 (2%) Black. Regarding gender and marital status, a little over half were female (55%; n = 46) and 42% (n = 35) married/partnered, 33% (n = 28) widowed, and 25% (n = 21) single/separated/divorced. Respondents were fairly well educated, with a range of 7–25 years of school completed and a mean of 13 years. The vast majority of respondents had some form of cancer (88%; n = 74), and others were diagnosed with respiratory (5%; n = 4), heart (4%; n = 3), neurological (2%; n = 2), and renal (1%; n = 1) diseases.

Control Strategies Exercised

All 84 respondents described the way in which they exercised control (see Table 1). Of these respondents, 83 reported using a primary control strategy in combination with another primary or compensatory secondary control strategy; only one reported exercising a single primary control strategy. This 84-year-old never-married woman described using selective primary control. Although she had cancer, her focus was not on the illness itself but on the goal of strengthening her legs so she could be more mobile. When asked if other people helped her exercise control, she said no. Thus, although it was likely that others were assisting because her mobility was limited, she did not feel their doing so helped in her exercise of control.

Nineteen (23%) of the 84 respondents reported they could no longer completely rely on their own resources to attain their goals and so asked for assistance (compensatory primary control). Respondents viewed asking others for assistance in a positive light noting that the assistance enabled them to maintain some control:

I feel like I’m probably . . . see, I’m not a quitter and I may have to ask for help but I do . . . and that way I can stay on a schedule and maintain a life that I feel that I’m still contributing something to my family. (62-year-old married woman)

Awareness of the need for assistance to exercise control did not necessarily mean that respondents would not like to exercise control on their own (selective primary control). For example, a 62-year-old married woman was used to having full control of her own home and stated, “Oh yeah, I would definitely like to go back to the way it was before all of this happened and be able to maintain my complete house and not have to ask for help in anything.”
Forty-two (50%) of the 84 respondents used a combination of selective and compensatory primary control. These respondents were able to use their own personal skills and resources to attain some goals but required assistance to attain others. For example, one 70-year-old divorced man exercised selective primary control in regard to attaining his goal of setting a daily schedule for eating, bedtime, and leisure activities; however, to attain his goal of bathing himself, he required assistance (compensatory primary control).

Compensatory secondary control was used in combination with compensatory primary control by 8 (9%) respondents and in combination with selective primary control, and compensatory primary and secondary control by 14 (17%) respondents. The eight respondents, who used a combination of compensatory primary and secondary control, used one of each type of control strategies. The 14 respondents who used a combination of selective primary control, and compensatory primary and secondary control, each reported one selective and one compensatory primary control strategy and one or two secondary control strategies. For those using compensatory secondary control, lowering aspirations was the most common strategy used: 16 (73%) of the 22 respondents spoke about adjusting their goals (lowering their aspirations) concerning exercising control. For example, an 88-year-old divorced woman sought to reframe her own inability to write checks any longer such that it was something her daughter needed to experience: “I think she [daughter] just offered [to write her checks] and I said sure . . . I said that’s fine. I felt it would be a good experience for her.”

Quantitative analyses were conducted to determine whether respondents’ demographic characteristics differed by these control strategy groups (CPC; SPC and CPC; CPC and CSC; and SPC, CPC, and CSC; Table 2). By necessity, the sole respondent who reported using only selective primary control was dropped from these analyses given the absence of variation. One-way ANOVA and chi-square tests revealed no significant differences in respondents’ age, gender, marital status, education, or primary hospice diagnosis by the control strategy grouping reported (see Table 2).

A one-way ANOVA test was also conducted on the control strategy groups and respondents’ quality-of-life score (see Table 2). The overall mean for quality of life was 22.6, with a range of 6–35: higher scores represent higher quality of life. Based on the finding of a significant $F$ ratio, $F(3, 79) = 5.15; p < .01$, Tukey’s honestly significant difference post hoc test was run to determine, through pairwise multiple comparisons, the control strategies that did and did not differ in regard to quality of life. The post hoc tests results revealed that respondents who used a combination of selective and compensatory primary control ($p < .05$) or a combination of selective primary control, compensatory primary control, and compensatory secondary control ($p < .05$) reported a significantly higher quality of life than respondents who used only compensatory primary control. No significant difference was found between respondents who used compensatory primary and compensatory secondary control and those who used only compensatory primary control. Although this group does not significantly differ, the result is likely due to the small sample size ($n = 8$). Thus, the overall finding from these tests suggests that exercising more than one control strategy was associated with higher quality of life than exercising only one control strategy.

<table>
<thead>
<tr>
<th>Theme</th>
<th>$n$ (%)</th>
</tr>
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<tbody>
<tr>
<td>Control strategies exercised</td>
<td></td>
</tr>
<tr>
<td>Selective primary control</td>
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<tr>
<td>Compensatory primary control</td>
<td>19 (23)</td>
</tr>
<tr>
<td>Selective and compensatory primary control</td>
<td>42 (50)</td>
</tr>
<tr>
<td>Compensatory primary and secondary control</td>
<td>8 (9)</td>
</tr>
<tr>
<td>Selective primary control, and compensatory primary and secondary control</td>
<td>14 (17)</td>
</tr>
<tr>
<td>Aspects of life over which control was exercised</td>
<td></td>
</tr>
<tr>
<td>Decision making</td>
<td>50 (59)</td>
</tr>
<tr>
<td>Independence</td>
<td>18 (21)</td>
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<tr>
<td>Mental attitude</td>
<td>18 (21)</td>
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<tr>
<td>Instrumental activities of daily living</td>
<td>18 (21)</td>
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<tr>
<td>Activities of daily living</td>
<td>14 (17)</td>
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<tr>
<td>Personal relationships</td>
<td>9 (11)</td>
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<tr>
<td>Desire for more control</td>
<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>Independence</td>
<td>14 (33)</td>
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<tr>
<td>Body functioning</td>
<td>13 (30)</td>
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<tr>
<td>Illness</td>
<td>10 (23)</td>
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<tr>
<td>Generativity</td>
<td>6 (14)</td>
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<tr>
<td>No ($n = 41; 49%$)</td>
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<tr>
<td>Satisfied with current level of control</td>
<td>31 (76)</td>
</tr>
<tr>
<td>Physical condition prevents exercising more control</td>
<td>7 (17)</td>
</tr>
<tr>
<td>God’s in control</td>
<td>1 (2)</td>
</tr>
<tr>
<td>No explanation provided by respondent</td>
<td>2 (5)</td>
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Aspects of Life Over Which Control Was Exercised

Respondents were asked to name and discuss the parts of their lives over which they exercised control, and they named anywhere from one (n = 27; 32%), to two (n = 34; 40%), to three (n = 14; 17%) to four parts (n = 9; 11%). Content analysis of these discussions revealed six thematic areas regarding the parts of their lives over which respondents felt they exercised control: decision making, independence, mental attitude, instrumental activities of daily living (IADLs), activities of daily living (ADLs), and personal relationships.

Decision Making.—Exercising control through decision making was reported by 50 (59%) of the 84 respondents, one of whom exercised control by herself and the others who did so with assistance. These respondents talked about making decisions or participating in the decision-making process with others regarding where to live, their finances, plans for death, how people provided their care, treatments they chose to receive, and their daily schedule and activities. Respondents noted that making a decision and having it supported by others provided them with a sense of control. A 72-year-old married woman stated, “I could tell her [daughter] this is what I want to do and we do it together. I feel like I’m a little bit more in control.” Several respondents noted that it was not the size of the decision or what was being decided; rather, it was having a decision to make that made them feel more in control. An 86-year-old widower made this point when he said, “It’s really small things like the choice of where you want to eat. It’s nice if somebody gives you a choice.”

Independence.—Eighteen (21%) of the 84 respondents reported that being independent was a part of their life over which they exercised control. Independence was expressed by respondents as the ability to “go where I want and do what I want,” “live my own life,” and “don’t have to ask for help from others.” These 18 respondents spoke in adamant tones when talking about having control over their independence, as illustrated by a 73-year-old married man’s, “I can do what I damn well please!” and a 79-year-old widow’s, “I don’t have to ask for help from others.” Control over independence was clearly very important.

Mental Attitude.—Exercising control internally over their own mental attitude was discussed by 18 (21%) of the 84 respondents. Using this compensatory secondary control strategy, a 77-year-old married man noted, “Well, I have control over my feelings; I have control over my mind.” . . . An 81-year-old married man reported, “Well, I can control my mental attitude toward the disease,
knowing that its terminal and I can’t do much about that.” . . . This ability to exercise control internally was viewed in a positive light, as expressed by one 72-year-old divorced woman who said, “Well, my viewpoint . . . is you cannot always control certain things you find yourself in but you (can) always choose your attitude.”

Instrumental Activities of Daily Living.—The ability to exercise control over one’s IADLs was reported by 18 (21%) respondents. Respondents spoke about being able to control their finances, order groceries over the telephone, and perform basic household chores. For example, a 67-year-old divorced woman reported exercising control over household chores: “Yesterday, my grandsons were here and they came to do the lawn and stuff like that, so I can still direct them and take care of the outdoors without being outdoors.”

Activities of Daily Living.—Fourteen (17%) respondents reported exercising control over ADLs. The importance of doing so is evident in the following statement by a 73-year-old married man:

. . . I uh, you know, I wash myself up every morning and uh, brush my teeth and all of those little tasks—don’t need any help other than my wife will—we usually do it in this room and she’ll bring in the equipment, you know. But if I had to, I could go into that bathroom next door and take care of it. It’s just a little simpler this way so, but I could do it, and I know I could.

Although still needing assistance with her bath, a 76-year-old divorced woman made a point to let the interviewer know that she still exercises some control over her bath: “Yeah, they [hospice certified nursing assistant] insist I should be helped with a bath, but I can still lift myself up out of the tub.” Concerning ADLs, the 14 respondents were all quick to point out that they exercised control, even if they were receiving assistance.

Personal Relationships.—Nine (11%) of 84 respondents talked about having control over how they relate with their family and friends. They talked about the value those relationships held for them and how they felt they had control over making sure they were positive relationships. An 81-year-old married man talked about how concerned he was by the impact his illness had on his loved ones and how he wanted to make certain the impact was positive.

I try to influence my family’s feelings toward my situation. I get the impression that . . . I’m concerned that they are also concerned about my situation—that it’s affecting them now. They’re calling everyday, they try to come everyday. So I’m sure it’s had a direct effect on their lives.

In addition to making sure their impact on loved ones was positive, respondents also talked about ensuring that those relationships were as normal as possible. One 86-year-old widower talked about how he made sure that he and his girlfriend “date just like anybody else.”

Desire for More Control

Although all 84 respondents reported experiencing a sense of control in their dying process, the question remained whether they felt it was enough. All 84 respondents were asked whether there were other parts of their life that they would like to control and 43 (51%) answered yes. When asked to identify those parts, four thematic areas surfaced: independence, body functioning, illness, and generativity. Having identified the part of their life they wanted to control, they were then asked to talk about what prevented them from doing so.

Fourteen (33%) respondents noted that they would like to exercise more control over their ability to be independent such as being able to stay in their house alone sometimes or being able to get in their car and drive wherever they wanted by themselves. It is interesting to note that when describing how they would exercise control in regard to their independence, all 14 respondents discussed the importance of being alone sometimes, a desire that may have resulted from the constant presence of caregivers. One 76-year-old divorced woman stated, “I would like to be independent again . . . do what I want and go where I want . . . navigate by myself.” When asked what prevented them from exercising such control, all 14 noted that it was their illness, which left them fatigued, nauseous, dizzy, or in pain.

Exercising control over their own bodies was the desire of 13 (30%) of the 43 respondents. The functions that respondents wanted more control over were incontinence, sexual performance, muscle and leg movement, appetite, physical strength, and memory. Lacking control over functions that people normally can control was very upsetting, as evidenced by one 90-year-old married man who was struggling with incontinence: “Well, accidents happen without any warning a lot of times.” Again,
when asked what prevented their exercising control, all 13 people stated that it was their illness.

The third most common theme to emerge was the desire to control their illness: 10 (23%) respondents spoke about wanting to control the impact their illness had on their ability to function physically in their daily lives. They also spoke of wanting to control their illness such that it would not be terminal. A 76-year-old divorced woman who was terminally ill with lung cancer said wistfully, “Just maybe—the only thing, oh, that’s more or less a desire . . . that they x-ray me once, and see that the spots are gone . . . controlling these spots on my lungs.” Although the desire was strong to exercise such control and fight their illness, respondents stated that what prevented them from doing so was that it was “not realistic.”

The fourth theme that arose was the desire expressed by six respondents (14%) to exercise control now and after their death on behalf of the next generation, a stage of development referred to by Erik Erikson as generativity (Erikson, Erikson, & Kivnick, 1986). Erikson’s seventh stage of his developmental theory, generativity versus stagnation, proposes that as part of their own development, adults assist the younger generation in leading meaningful lives. Although Erikson proposes this as a midlife stage of development, terminally ill elders who reported seeking to be instrumental in their children and grandchildren’s future lives ranged in age from 62 to 84 years. For example, a 62-year-old divorced woman longed to assist financially loved ones in difficult circumstances. A 73-year-old married man talked about his need for ensuring his grandchildren’s future education, and an 81-year-old married man who had lung cancer wanted to talk with young people about the dangers of smoking. Perhaps knowing that time was limited, these respondents felt the need to make a lasting impact on the next generation. When asked what prevented them from doing so, they talked about their children’s resentment and need for independence. One 71-year-old widow stated:

He’s a 21 year old man . . . I guess I would like him to have ways of being helped physically, medically, healthcare-wise. I can’t do any of that. . . . [I]f I were healthy, I couldn’t do those things. People have to do for themselves what they have to do. I’d like to make his life easier because there are things that I’ve seen because I’m older.”

For the 41 (49%) respondents who answered no to the question regarding whether there were other parts of their life that they would like to control, all but 2 (5%) provided an explanation. The vast majority (76%; n = 31) reported they were satisfied with their current level of control. Some of these individuals reported their satisfaction was due to their still exercising the same amount of control as before their illness: “I’m still kind of fully in charge of what I’ve done before.” Others spoke of feeling happy or peaceful with life in its current state: “I’m satisfied—life is where it should be.” The other eight respondents provided different explanations. Seven (17%) respondents stated that their physical condition left them unable to control other parts of their lives. An 84-year-old widow noted, “I’m not capable of doing the thing I would want to control.” The eighth respondent, a 55-year-old divorced woman, remarked she did not want control because “God’s in control.”

Discussion

The results from this study offer an understanding of the role control plays in the dying process of terminally ill elders and the potential association it has with quality of life in the dying process. The 84 elders interviewed provided information about the strategies they used to exercise control in their dying process, the aspects over which they exercised control, and whether they desired to exercise more control.

Control Strategies

Either on their own (selective primary control) or with the assistance of another (compensatory primary control), all 84 elders were exercising a form of primary control to attain a particular goal. The fact that these elders sought to exercise primary control, although they were very ill and their time was limited, is evidence of its importance.

Another important finding concerned the mix of control strategies that terminally ill elders used to exercise control. Although about a fifth of respondents exercised only one primary control strategy, the majority used two to four primary and secondary control strategies. Respondents had goals they wanted to attain and appeared to choose a control strategy that fit with the abilities they possessed related to that goal. It is also significant that although the exercise of primary control is visible to others, the exercise of secondary control may not be; yet, changing the internal self to fit with the external world did provide these respondents with a sense of control. For example, one 63-year-old married woman, who was chair bound
during the day, spent her days alone. A hospice worker came by each day and the woman always asked the worker to turn on the radio before she left. She loved to listen to the radio and felt that by asking the worker, she had control over being able to do so. One day, however, she forgot to have the worker turn on the radio. Unable to do so herself (selective primary control) or ask others to do it for her (compensatory secondary control), she turned to a compensatory secondary control strategy: “I didn’t have any of them to turn on my radio. My God, I thought, well all right, no sound but I could (still) hear the birds.” The use of multiple strategies is not only evidence of these elders’ desire to exercise control but their adaptability in doing so.

Findings from the study also reveal that the use of multiple strategies appears to be associated with quality of life in the dying process. Although the sole use of selective primary control could not be tested due to only one elder reporting its use, comparisons were made between the use of only compensatory primary control and the use of other combinations of control strategies. The one-way ANOVA test revealed that exercising more than one control strategy (compensatory primary control) was associated with a higher reported quality of life in the dying process, which has important implications for practitioners.

Aspects Controlled

The aspects respondents reported exercising control over provided insight into the world of terminally ill elders, which, due to being home or facility bound for the most part, was a smaller world than when they were healthy. As their world grew smaller, the areas in which they could exercise control became more limited. The six thematic areas that respondents spoke of concerning the exercise of control were decision making, independence, mental attitude, IADLs, ADLs, and personal relationships. Being able to make decisions that influenced their world and future death, to come and go and be alone, to choose their attitude, to perform IADLs or ADLs, and to ensure their relationships were positive, were the key aspects of the dying process over which respondents sought to exercise control. Realizing at some level that their world and often their ability to exercise control were constrained in ways they had not been before, respondents appeared to adapt by focusing on areas inside their world, being flexible in how they exercised control, as well as how much control they exercised.

More Control?

Study results revealed that over half of the respondents wanted to exercise more control in their dying process. Just as independence was an aspect of the dying process that many respondents reported exercising control over, 14 respondents who were not currently exercising such control desired to do so. The severity of their illness prevented exercising this control, just as it did in two other areas: their illness and bodily functions. Although they desired control in these areas, terminally ill elders were realistic regarding their inability to do so.

Perhaps the most surprising finding was that respondents wanted to exercise more control over the future success of their children and grandchildren. Erickson proposed generativity as a stage of development that takes place at midlife. Although these elders were not in midlife, perhaps in the final stage of life, the need to ensure the success of the next generation presented itself yet again. An alternative explanation may simply be that in providing for the next generation, these elders were able to leave behind a legacy of love.

Study Limitations and Future Implications

Although this qualitative study employed a large sample size, and new understandings were gained on the role of control in the dying process of terminally ill elders, limitations were present. First, 98% of the sample were Caucasian elders. Future research should be conducted with other racial/ethnic elders to determine the extent to which culture influences the role of control in an elder’s dying process. The role of the individual and the exercise of control tend to be Western values and so not all groups may view control in the same manner as the current study participants. Second, the lives of terminally ill elders are not stagnant; rather, they can shift very quickly due to advancing illness. The 84 respondents who volunteered to participate in the study may have done so because they were less ill than others who were not recruited. They may still have been at a point in their illness where they could exercise primary control more readily and rely less on secondary control strategies. The current study was cross-sectional in nature and so the results are based on one time point in the respondents’ dying process. A longitudinal study following elders throughout their dying process would provide
greater insight into whether they continue to be adaptive in the use of control strategies and what they seek to control changes. Third, the respondents participating in the current study were all receiving hospice care either at home or in a hospice inpatient facility. Future studies should look at elders who are dying in other environments and not receiving hospice care, such as a hospital or nursing home. It is not clear from the current study whether the environment itself and the type of end-of-life care being provided influenced respondents’ control strategies or the aspects of the dying process over which they desired control. Fourth, the respondents in this sample were terminally ill (less than 6 months to live), but it is feasible that elders with terminal or chronic conditions may experience similar physical limitations that impact their exercise of control. Certainly, the findings for this study’s terminally ill respondents bear similarities to the research findings discussed in the literature review on elders with chronic conditions in that they, too, have been shown to use a mix of primary and secondary control strategies (Wrosch & Schulz, 2008) and to use compensatory secondary control strategies, including positive reappraisal and lowering aspirations (Heckhausen, 1997). Future research should look more closely at the exercise of control for elders with acute, chronic, and terminal conditions to determine the similarities and differences in regard to how control is exercised and its relationship to quality of life. Fifth, in order for terminally ill elders to exercise control in their dying process, particularly when the control strategy is compensatory and necessitates the assistance of others, family members must be supportive of their doing so. A recent study (Schroepfer, 2008) found that the relational content of social relationships defined as the “functional nature or quality of social relationships” (House, Umberson, & Landis, 1988 p. 302) was related to the consideration of a hastened death. Quantitatively, poor or conflictual support was found to be a highly significant predictor of the consideration to hasten death, and, qualitatively, if an elder felt his or her own suffering or the suffering his or her care placed on loved ones was burdensome, he or she was likely to consider a hastened death. The current study did not include measures of the relational content of those who indirectly or directly supported the elders in their exercise of control in the dying process, or the impact of relational content on their quality of life. Future studies on exercising control in the dying process should quantitatively include relational content measures and qualitatively include questions on not only how others assist an elder in the exercise of control but also the elder’s experience with their doing so. Sixth, the finding regarding the association of control strategies with quality of life was limited to a bivariate analysis. Future research on this finding should employ the use of multivariate analyses to control for relevant control and predictor variables.

Practice Implications

The knowledge gained from these interviews has important implications for practitioners and family members providing care to elders during their dying process. Being cognizant of the life an elder had prior to his or her dying process and how that life has changed since the illness is important knowledge for family members to remember and practitioners to garner. As the health that once allowed an elder to be very much a part of the world outside his or her home or facility declines, so does the size of his or her world. Understanding this, family members and practitioner can seek to support the elder’s exercise of control within that smaller world, as well as the strategies he or she chooses to use. If family members and the practitioner are assisting the elder with a task, then supporting the elder’s need to exercise control as much as possible is key for the elder in exercising compensatory primary control. If an elder is physically limited to such a point that exercising primary control alone or with the assistance of another is not practical, then it is important that family members and the practitioner be aware that the elder may seek to exercise control internally over his or her mental attitude. Based on the expression of an elder’s attitude, it may appear that he or she is giving up; however, it may actually be that he or she is taking a realistic approach to the situation and using the compensatory secondary control strategy of lowering his or her aspirations. Based on the elder’s situation, the family and the practitioner must then determine whether the elder is lowering his or her aspirations unnecessarily or simply being realistic. Family members or the practitioner can then work with the elder to either reframe his or her situation in a way that allows for raising aspirations or, in the case of a realistic viewpoint, support the elder’s use of the control strategy. Because the exercise of more than one control strategy appears to be associated with a reportedly higher quality of life in an elder’s dying process, then family members and practitioners can
work to ensure that elders have the opportunity to do so whenever possible.

Decision-making, independence, mental attitude, IADLs, ADLs, and relationships were aspects of the dying process over which the respondents sought to exercise control. Providing the support and the opportunities for such control to be possible is an important role for family and the practitioner. For example, elders who talk about the importance of their always having been independent may necessitate their family members and practitioners locating such opportunities. The elders in the current study tended to equate independence with time alone; thus, family members and the practitioner can work to ensure that the elder has a period of privacy each day. Another example is the role decision making plays in the dying process. The study’s respondents were not focused on the size of a decision or the need to make one alone: They primarily wanted to be a part of the process and have the support of others in doing so. These interventions and others based on familial knowledge and a thorough assessment of an elder’s pre-and post-terminal illness life will assist family members and practitioners in ensuring that elders’ control preferences are supported in their final stage of life.

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