
Living in the face of death: Interviews with 12 terminally ill women on home hospice care

MAREILE M. GRUMANN, PH.D. AND DAVID SPIEGEL, M.D.

The Psychosocial Treatment Laboratory, Department of Psychiatry & Behavioral Sciences, Stanford University School of Medicine, Stanford, California

(RECEIVED September 30, 2002; ACCEPTED December 20, 2002)

ABSTRACT

Objective: To determine how home hospice patients deal with their impending death and whether there is a need for greater involvement of mental health professionals in the care of patients dying at home.

Method: In a pilot study, 12 female home hospice patients with advanced cancer and a median survival time of 42 days were assessed using structured interviews and brief questionnaires. Topics of inquiry included facing death, fear of death, pain, fatigue, depression, and anxiety. Three key themes were extracted from the information reported by the women: (1) confronting the issue of death, (2) fear of dying and death and its correlates, and (3) spirituality/religious faith and its role in mitigating fear of death.

Results: First, all subjects reported thinking about their approaching death. For half of them, this thought was bothersome and these women were frequently troubled by unresolved issues and higher anxiety, pain, and fatigue. The majority of the subjects expressed a desire to actively discuss their impending death. Second, more than half of the patients reported being afraid of death and high death anxiety was associated with fear of dying in pain, high peak or usual pain, unresolved issues, and difficulty in parting with family in death. Third, most subjects experienced their religious faith as an important source of comfort and strength.

Significance of results: A substantial subgroup of home hospice patients expressed problems dealing with their approaching death. These problems are amenable to psychological treatment, such as fear of death, unresolved issues, parting with family, and pain. The findings, thus, highlight the need for close collaboration of mental health professionals with home hospice institutions.

KEYWORDS: Home hospice patients, Death anxiety, Unresolved issues, Parting with family, Religious faith

*It is so hard to live in the face of death.
People just don't understand what it is like.
They make inappropriate comments all the time.*

Linda, 47

INTRODUCTION

Over the past 20 years, the number of cancer patients dying at home has increased (Schachter &

Coyle, 1998). Hospice programs have been developed that deliver care to the terminally ill on an in- or out-patient basis but home care is the more popular choice (Schachter & Coyle, 1998). Competitiveness among hospice programs is strong, and lack of resources has been identified as one of the key stressors during the 1990s (Vachon, 2000), both

Corresponding author: Mareile Grumann, Ph.D., Blauenstrasse 2, D-79589 Binzen, Germany. E-mail: mgrumann@web.de

of which may explain why mental health professionals are usually not part of the core staff of home hospice. This, however, is disconcerting in the light of a high prevalence of death-related concerns in the terminally ill, between 50 and 80% (Cherny et al., 1994).

Few research studies inquiring about death-related worries and concerns have been conducted directly with hospice patients (Ita, 1995–1996), especially home hospice patients, so it is unclear at this point how this group experiences living with the imminence of death and whether mental health professionals are routinely needed to assist them in dealing with their approaching death. In the present study we identified three important death-related issues in a group of home hospice patients: (1) confronting the issue of death, (2) fear of dying and death and its correlates, (3) spirituality/religious faith and its role in mitigating fear of death.

Confronting the Issue of Death

It has been argued that an individual's confrontation with the death of self is an unthinkable thought in that it is impossible for a human being to imagine the nonexistence of one's consciousness (Gonda & Ruark, 1984). Facing death, thus, brings to the surface a basic human "conflict that flows from the individual's confrontation with the 'givens,' the 'ultimate concerns' of existence" (Yalom, 1980, p. 8), stirring feelings of unfamiliarity and separation from the world and experiences of loss of one's perceived identity (Yalom, 1980). Avoiding this confrontation, however, is at the cost of the perpetuation of suffering (see Attig, 1979). In the present study, we were interested in whether and how home hospice patients approach the inescapable reality of their imminent death.

Fear of Death and Dying

"The profundity of the fear of death consists of this: what is feared is the all-encompassing and irretrievable loss of existence itself which is the ground of all potential for the realization of value . . ." (Attig, 1979, p. 7). Few studies on fear of death so far have focused specifically on the population of terminally ill patients (Smith et al., 1983–1984) but, according to Dougherty et al. (1986), those that have done so show less psychopathology than commonly described in the clinical literature. For instance, Smith et al. (1983–1984) found fear of death in 20 terminally ill patients to be low both on the conscious and fantasy level. Fifteen of them were not afraid of death.

Spirituality and Religious Faith

It has been said that western psychology has long failed to recognize the relevance of spirituality and transcendental needs as intrinsic aspects of human nature (Walsh & Vaughan, 1982; Welwood, 1983), although recent studies indicate the fundamental importance of spirituality to the phase of dying (Smith et al., 1993). For example, strong spiritual awareness and a positive perspective on death, such as death being a natural process and part of life, were found to be associated with less psychological distress (Smith et al., 1983–1984). On the other hand, rigid religious belief systems can promote fear of death, if ideas of anticipated judgment and punishment are at the core of one's belief system (Gonda & Ruark, 1984). Studies on the role of religion in death anxiety have shown higher death anxiety in men with HIV and/or AIDS who reported greater church attendance, belonged to the religion of their childhood, referred to religion as "harmful," and did not have a spiritual belief system outside their formal religion (Franks et al., 1990–1991). It is unclear at this point how home hospice patients describe the role of spirituality or religion in their journey toward death.

In sum, the present investigation was a pilot study designed to help determine any areas of psychological distress that might require greater involvement of mental health professionals in the care of home hospice patients, such as becoming a regular part of the core home care team to assist patients in coming to terms with their approaching death.

METHOD

Procedure

Twelve women with advanced cancer were assessed. They lived within a radius of 30 miles from Stanford University and were under the care of one of three cooperating home hospice institutions. Recruitment of collaborating hospices was especially difficult because several hospices had been closed just prior to commencement of the project and one of the participating institutions was closed during recruitment. Some hospices felt reluctant to collaborate, as they did not want to incur additional stress for their staff or felt uncomfortable about burdening patients with research at this point in their lives. The study was approved by the panel on human subjects involvement in medical research at Stanford University.

Patients were eligible for participation if they were female, had a diagnosis of advanced cancer, had a prognosis of less than 6 months to live, were on home hospice care, and were physically and mentally able to be interviewed. Delirious, disori-

ented patients and those with debilitating brain involvement were excluded. Hospice nurses and social workers identified potential participants and informed them about the study by handing them a flyer. With assent from a potential participant, they forwarded her phone number to the interviewer who then contacted her to provide further information about the study and possibly schedule an interview at her home. It was emphasized that a participant could withdraw from the study at any time. All but one of the patients contacted agreed to participate and none withdrew.

To assure maximum privacy and keep intrusiveness to a minimum at a time when breaches of boundaries were common in other areas of patients' lives, such as dependence on others for intimate physical care, it was decided that no tape recording be done during the interview but notes were taken with agreement from patients. Interviews were arranged in a structured way. Questions from standardized questionnaires were used as a guideline for tapping specific areas of interest during the interview and questions on any relevant information were added, such as availability of a confidant. Subjects were allowed to elaborate on each question as much as they desired. Interviews were chosen over the questionnaire method as patients were too tired to read or write. They preferred talking and felt they needed time and an interactive person in order to elaborate more deeply on each question.

At a participant's request, the interview was divided into two or more sessions. Any person the participant wished to be present during the interview was welcome but their additional information was not used for the purposes of the study. Two husbands, a mother, a brother, and a nurse chose to be present. Follow-up visits outside the protocol were undertaken if a patient expressed a desire; however, any information collected during these visits was not used for the purposes of the study. Following the interview, the referring nurse or social worker was briefed about the interview, allowing for a participant's reactions to be monitored.

Materials

Data gathered from each subject included a patient's written informed consent, overall history of her cancer, current medications, and information from the interview. Interviews were based on questions from standardized questionnaires.

First, the Brief Pain Inventory (BPI; Cleeland, 1989) is a measure of the severity of pain and its impact on daily functioning. It consists of 12 items and is organized in two parts. The first part asks about the presence and severity of pain at its worst,

least, and usual levels (five items) and about the effectiveness of pain medication (one item). The second part asks about the extent to which pain interferes with daily activities, mood, enjoyment of life, social interactions, and sleep (six items). The tool is straightforward in its construction and has been extensively used in the United States, Europe, and Asia.

Second, the Brief Fatigue Inventory (BFI; Mendoza et al., 1999) was constructed in analogy to the BPI as a means of rapid assessment of self-reported fatigue severity. It consists of nine items assessing the level of fatigue and extent with which it interferes with daily activities. Its total internal consistency coefficient is .96 and individual Cronbach's alphas range from .95 to .96. Several measures have shown the validity of the scale, including construct, concurrent, and discriminant validities, a single-factor model fit, and a factor analysis with two other questionnaires.

Third, the Death Anxiety Scale (DA-S; Templer, 1970) measures an individual's attitude toward death-related experiences and attitudes. It is comprised of 15 items that are endorsed as either true or false and form one composite score. The scale possesses high face validity but other forms of validity have not been established. A test-retest correlation coefficient of .83 with a three week interval was demonstrated in a community college sample. Norms and standardized scores do not exist but a number of studies reported means and standard deviations for different samples. The DA-S is a very frequently used scale on death anxiety. In the present study, the scale was modified to fit the requirements of the present sample. Four items were omitted due to lack of applicability or appropriateness ("I dread to think about having an operation"; "I am not particularly afraid of getting cancer"; "I am not really afraid of having a heart attack"; "The sight of a dead body is horrifying to me"). To allow for a wider range of answers, the true-false answer format was modified to a 4-point answer format consistent with the other questionnaires. As the questions in this scale were intended to primarily stimulate verbal discussion of patients' personal perceptions and fear of death, the psychometric drawbacks of altering the scale were accepted.

Fourth, the Hospital Anxiety and Depression Scale (HAD-S; Zigmond & Snaith, 1983) is an extensively used psychometric instrument, specifically developed for a discriminant detection of depression and anxiety in hospital patients. Both constructs are covered in 7-item subscales and answers are rated on 4-point scales. Maximum subscale scores range from 0 to 21 for each scale and 0 to 42 for the total scale.

Table 1. Demographic characteristics of 12 women with advanced cancer

Sample size	$N = 12$
Age	Median: 63 (range: 41–91)
Ethnicity	Caucasian: $n = 10$ Asian: $n = 1$ Pacific Islander: $n = 1$
Marital status	Married: $n = 5$ Divorced/widowed: $n = 5$ Single: $n = 2$
Children ($n = 10$)	Median number: 2 (range: 1–4) $n = 7$ with adult children* $n = 3$ with teenage children**
Educational status ($n = 10$)	Some college: $n = 3$ College degree: $n = 4$ Master's, Ph.D., or higher education: $n = 3$
Religious affiliation	$n = 10$ Christian (2 Christian, 3 Catholic, 3 Methodist, 1 Baptist, 1 Episcopalean) $n = 1$ Jewish $n = 1$ None
Previous exposure to cancer-related deaths in family:	$n = 1$ Don't know $n = 3$ No $n = 8$ Yes, often multiple deaths

*Age 20 or above; **age 10–20.

According to the authors, internal consistency is good for both the anxiety (ranging from 0.71 to 0.41) and depression items (0.76). The clinical sensitivity of the scale was demonstrated in a correlation of the subscale scores with independent interviewer scores regarding the severity of mood disturbance. In consideration of the weakness of the patients in the present study, the interview included an abbreviated version of the scale for all patients ($n = 12$) and the full form for those that felt strong enough to do it ($n = 8$). The abbreviated version included the first eight items of the scale, four of which covered anxiety and the other four depression.

Analysis

Due to constraints in sample size, questionnaire data were analyzed conservatively, using nonparametric descriptive statistics. Interview data were analyzed by way of extracting common themes as relevant to participants. Furthermore, interview data were used to support and illustrate the questionnaire-based findings.

Sample

Socidemographic Information

Twelve women with a median age of 63 years participated. They were predominantly Caucasian, either married or divorced/widowed, and had children who were mostly adults themselves. All the women

were well educated, reporting at least some college training, and most of them belonged to one of the various Christian denominations (Table 1). To evaluate any effect of prior exposure to cancer-related deaths on a participant's coping with her own death, patients were asked about deaths due to cancer in their families. Most women reported at least one cancer-related death in their family (Table 1).

Medical Information

Patients in the sample were diagnosed with peritoneal, lung, cervical, colon, or breast cancer (Table 2).

Table 2. Medical information of 12 women with advanced cancer

Medical diagnosis ($n = 12$)	Breast cancer: $n = 5$ Colon cancer: $n = 3$ Cervical cancer: $n = 2$ Peritoneal cancer: $n = 1$ Lung cancer: $n = 1$
Time since first diagnosis: ($n = 12$)	Median: 5 (range: 2 months to 17 years)
Time since assignment to hospice: ($n = 12$)	Median: 14 days (range: 5 to 28 days)
Time from interview to death: ($n = 8$)*	42 days (range: 5 days to 14 weeks)

*Two participants were lost to follow-up, 1 is still alive (16 weeks past the interview), 1 was removed from this calculation, as she survived exceptionally long (11 months).

The distribution of the various cancers roughly corresponds to their prevalences in the general population, except for an underrepresentation of lung cancer. Median time since first diagnosis was 5 years, and all but two patients had been ill between 2 and 7 years. Subjects' median time on hospice at the time of study was 14 days and their median time from interview to death was 42 days ($n = 8$). Due to a sudden closing of one hospice, two patients were lost to follow-up, one is still alive (about 3 months post interview), and one survived exceptionally long (11 months). She was removed from the calculation of median survival time.

RESULTS

Most participants showed a notable interest in talking and, despite repeated reminders that a second interview could be scheduled if subjects were tired, none of the interview sessions was shorter than 60 min and some as long as 150 min (median time: 90 min). Two subjects asked that a second interview be scheduled. Participants generally expressed satisfaction with the interview, stating that it was "not too bad," "helpful," or "enjoyable." Five women asked for follow-up visits outside the study protocol and four were followed by phone outside the protocol. Below, we present results from themes that subjects spent the most time elaborating on: (1) confronting the issue of death, (2) fear of death and dying, and (3) religious faith.

Confronting the Issue of Death

Contemplating Death

Subjects were asked whether the thought of death entered their minds (DA-S: item 2). Eleven women

shared their thoughts on this question and all of them confirmed that they were thinking about death at least sometimes ($n = 4$) and most of them did so often or almost always ($n = 7$). They felt it was natural to think about death at this point in their lives, just as one woman put it "Sure, I think about death every so often but I do not ruminate about it." Asked whether the thought of death bothered them (DA-S: item 5), six women felt it was not (5/11) or only sometimes (1/11) a bothersome experience, but five reported feeling often or almost always bothered by the thought of death. While the importance of patients' religious faith did not differ between those for whom the thought of death was bothersome and those for whom it was not, there were trends toward higher fatigue and pain among those that felt troubled by the thought of death (Table 3). These patients also tended to report higher anxiety (median: 4) than those that did not feel bothered when thinking about death (median: 1.5), as reflected in the abbreviated version of the HAD-S. All of the five patients that felt uncomfortable thinking about death also reported having unresolved issues, while only one of the six women that did not feel bothered when thinking about death had unresolved issues.

When asked whether it made them nervous when people around them talked about death (DA-S: item 3), all but one woman (10/11) did *not* feel nervous when death was discussed in their presence or with them. One patient poignantly said, "It doesn't trouble me to talk about it because that is what is on my mind constantly." On the contrary, most patients expressed relief when having the opportunity to talk about death and felt disappointed or desperate when open communication was not possible, for instance, "I am desperately trying to talk to my husband about it but he is not coping and won't

Table 3. Raw scores and medians of fatigue, pain, and anxiety and the importance of religious faith for 11 women in relation to their feeling bothered by the thought of death or not

$N = 11$	Thought of death bothersome ($n = 5$)	Thought of death not bothersome ($n = 6$)
Fatigue*	Median: 8 Range: 5–9	Median: 5 Range: 0–10
Usual pain*	Median: 5 Range: 0–7	Median: 3 Range: 0–5
Anxiety**	Median: 4 Range: 2–12	Median: 1.5 Range: 1–11
Importance of religious faith	Faith important: $n = 4$ Faith not important: $n = 1$	Faith important: $n = 4$ Faith not important: $n = 2$

*Self-reported raw scores can range from 0 (no pain/no fatigue) to 10 (as bad as you can imagine).

**Shortened version of HAD-S. Raw scores can range from 0 (no anxiety) to 12 (very bad anxiety).

listen. I am longing for my sister in Virginia who is the only one who is understanding and accepting what is going on." In fact, the length of the interviews and subjects' eagerness to talk, especially about their thoughts on death, seemed to reflect their interest in sharing their feelings on this topic. Only one woman, despite discussing her thoughts about death, said she did not enjoy sharing her thoughts on this personal topic. Her nurses related that they were concerned about her never addressing the issue of her approaching death.

Hoping for a Miracle

The subjects in the present study were aware of their impending death. For an individual to be assigned to hospice, she has to acknowledge in writing that her estimated prognosis is 6 months or less. Despite this factual knowledge and its verbal affirmation during the interview, some women expressed hopes for cure, usually in the form of a miracle, such as "I am still hoping that Jesus would walk through the door and tell me I am cured." One subject insisted on the healing powers of herbal supplements, vitamins, and pomegranate juice, and inquired about treatment options at hospitals in Switzerland while acknowledging that neither her physical condition nor her poor financial situation would allow her to undertake the trip. Even subjects that did not hope for cure generally hoped for time. Six of the 12 women reported a personal guess about how much time they felt they had left but most often overestimated their actual survival times. For instance, 2 women who died within one week of the interview estimated their remaining life spans to be 3 and 6 months, respectively. Only 1 subject slightly underestimated her remaining time. Six subjects reported no personal feeling about the time left to them and felt that they did not want to know anyway.

Fear of Death and Dying

Fear of Death

Our sample of home hospice patients had been living with the diagnosis of a life-threatening illness for a median time of 5 years. We were interested in whether they would perceive death and dying as anxiety provoking, despite having lived with the threat to life throughout the time of their illness and choosing hospice care over continuation of treatment.

Subjects were asked if they were afraid to die (DA-S; items 4). Five of the 11 women answering this question felt that this fear was almost always

present, while the other half (6/11) reported feeling only sometimes (1/11) or almost never (5/11) any fear of dying. Women with cancer-related deaths in their families did not report substantially more or less death anxiety than those without previous exposure to cancer deaths in their families.

Fear of Death and Fear of Dying in Pain

Subjects were asked whether they were afraid of dying a painful death (DA-S: item 7). About half of the women (6/11) did not feel worried about a painful death but three worried sometimes (3/11) and two did so often or always. The relationship between fear of death and fear of dying a painful death seemed complex but clearly separate issues for most of the women. Some felt frightened of death but not of dying a painful death, while others were not afraid of death but feared dying a painful death. Some, despite being in pain, were neither afraid of death nor of dying a painful death and some feared both. Despite the complexity of this relationship, it appears that severity of pain is associated with subjects' fear of a painful death. The women that did not fear dying a painful death tended to report lower peak and usual pain than those in whom this fear was sometimes, often, or almost always present (Table 4). This is interesting because pain relief through medication was rated as rather effective by almost all patients (Table 4). It is unclear whether subjects' experiences of pain promoted their fear of dying in pain or whether fear of dying in pain sensitized women to experience more pain. Anecdotal information demonstrates the interdependence between the two factors. One subject felt anguished about her approaching death and referred to her life as a waiting game from which she could not escape. On the one hand, she felt intense fear of death and hoped that as many days as possible still separated her from death; on the other hand, she wished that her days of pain would pass faster and death bring relief of her suffering.

Fear of Death and Unresolved Issues

Half of the subjects in the present study (6/12) felt no pressure to resolve aspects of their lives before their deaths but the other half (6/12) did. Five of those that reported unresolved issues (5/6) also reported fear of death, while among those in whom fear of death was rare (6/12), only one patient reported unresolved issues. One woman explained "I feel there are things that are undone and I regret having pushed them away so long. Now there won't be enough time any more. I feel pressured by time: I am sleeping all the time but have not yet resolved

Table 4. Subjects' fear of dying in pain in relation to their usual and peak pain scores and self-reported effectiveness of pain control

	Fear of dying in pain (n = 5)	No fear of dying in pain (n = 6)
Worst pain*	Median: 6 Range: 0–10	Median: 5 Range: 0–8
Usual pain*	Median: 5 Range: 0–7	Median: 3 Range: 0–5
Self-reported effectiveness of pain control (%)**	Median: 100 Range: 50–100	Median: 100 Range: 90–100

*Self-reported pain can range from 0 (no pain) to 10 (pain as bad as you can imagine).

**Self-reported pain control can range from 0% (no pain control at all) to 100% (perfect pain control).

the things I wanted to resolve.” She still wanted to pick an urn and write cards to her grand-children and thank-you notes to her friends for their support, yet, felt too fatigued to organize these things. She feared death much but felt it was coming soon, which caused a state of urgency in her. Other women reported being ready to die but still recounted tasks they wished to accomplish, if there was enough time. As these things were optional, they were causing them little emotional strain. For instance, one woman felt that “although there are many things I would have liked to do, it is too late for that now and that is O.K.”

Two relationships were interesting. First, unresolved issues appeared to be associated with the experience of pain in that subjects reporting unresolved issues frequently described intense pain, while those without unresolved issues tended to report less intense pain (Table 5).

Second, there was a connection between unresolved issues and age. Women that reported unresolved issues tended to be younger than the median

age in the sample, whereas those without unresolved issues tended to be older than the median age (Table 6).

Fear of Death and Parting with Family

A predominant concern for almost every subject was the issue of parting with family in death. Nine women (9/12) explained, mostly visibly moved, that the hardest aspect about dying was having to leave their family. Of those that did not report this as being difficult (3/12), one had no family and one was married but had no children. Parting with loved ones was closely connected to the question of unresolved issues. In five of the six patients that reported unresolved issues, these issues involved leaving family behind, especially children. A single mother worried much about who would take best care of her young son after her death. Typical emotions that accompanied this issue included sadness, worry, guilt, and a sense of loss. *Sadness*, for instance, about not seeing one’s children’s lives un-

Table 5. Unresolved versus no unresolved issues in relation to high versus low pain

N = 12	Unresolved issues	No unresolved issues
Usual pain high*	n = 4	n = 1
Usual pain low**	n = 2***	n = 5

*Higher than median split of 3.5. Possible range: 4–10. Actual range: 4–7.

**Lower than median split of 3.5. Possible range: 0–3. Actual range: 0–3.

***One of the two subjects reported wanting to have the upholstery of her sofa done before dying but still felt ready to die any time.

Table 6. Unresolved versus no unresolved issues in relation to older and younger age

N = 12	Unresolved issues	No unresolved issues
Older age*	n = 1***	n = 5
Younger age**	n = 5	n = 1

*Older than median split of 63. Ages: 67, 68, 76, 79, 85, 91.

**Younger than median split of 63. Ages: 41, 42, 47, 50, 51, 59.

***Subject reported wanting to have the upholstery of her sofa done before dying but felt ready to die.

folding, was a frequently mentioned feeling as was *worry*, especially about the family's future and children's lives. One woman expressed great concern about how her husband would deal with her death. She was agonized by the fact that he would not allow her to talk to him about her impending death. Feelings of *guilt*, such as prematurely leaving one's family and the responsibilities once accepted were frequently recounted. A mother of two young children felt so much troubled by guilt that she often could not go to sleep. ". . . I have talked to them [children] about it [death] but still feel guilty. My mother died when I was 9 and pictures of this are now coming to my mind. I know what my children have ahead of themselves. I feel guilty about giving up treatment because my family may think I am giving up, although for me it felt wrong to continue treatment without seeing a real gain." *Loss* through death, especially in relation to separation from family, was a difficult issue for a number of subjects. One woman reported being extremely troubled by the anticipated separation that death would bring between her family and herself.

In sum, parting with loved ones ranged on a continuum from being a difficult, yet natural aspect of dying, to representing a pressing unresolved issue. Whether an issue was a difficult, yet natural aspect or an unresolved issue seemed to depend on its perceived significance and urgency.

Religious Faith

Religious Faith and Fear of Death

Subjects in the present study were highly interested in talking about their spiritual lives and expanded much on it. In light of the literature, it was interesting to examine any connection between their religious faith and death anxiety. Nine of the 12 women felt that their religious faith or spirituality played an important role in their present life situation, one subject (1/12) said she followed no religious faith and two (2/12) felt it was not important. All of those for whom religion or spirituality were important reported receiving inner strength from their religious or spiritual lives. One woman looked at her faith as ". . . my backbone in the illness and one of the two pillars that help me see it through to the end. I feel great inner peace that comes from daily prayer and studying scripture. The other pillar is my family." Some women mentioned external support by prayer groups through prayers said for them and community members actively visiting. When relating subjects' self-reported importance of religion to their death anxiety, death anxiety was not different for subjects that followed a religious

faith and nervousness talking about death was low among all subjects, irrespective of how strongly they felt about their religious faith (only one subject felt nervous when death was discussed).

Belief in an Afterlife and Fear of Death

Subjects expanded on a question as to whether the issue of life after death troubled them (DA-S: item 8). Most of them (8/11) felt the topic did not bother them, as death was not frightening but associated with images of comfort, paradise, and a better world. For instance, "Dying means transitioning into a new life that is worth looking forward to. There will be no pain and suffering over there and I will finally be coming to see Jesus Christ . . ." The single mother related that her belief in an afterlife comforted her: "I'll go to a better place and watch my son from above." Three subjects (3/11) found the issue of life after death sometimes troublesome. One of them reported following no faith and another one felt that her illness had caused a religious crisis for her, leaving her with feelings of ambivalence, especially toward the concept of heaven. "When the pain is very strong, then I doubt God's existence, although at other times I feel like a very religious person. I have been in this crisis for a long time but not resolved it yet." The women for whom religion and spirituality were important resources (9/12) preferred a wide variety of particular practices that gave them strength and comfort. Prescribed and free prayers, prayers said by a prayer group, Bible studies, and talking to a priest were mentioned as the most helpful means of religious practice. One subject explained that, while having been a devout Methodist throughout her life, her spiritual journey had produced a feeling of "inner smoothness" in her and the understanding that "it doesn't matter, if I am Buddhist or Christian or anything else. It is all about the same anyway."

SUMMARY AND CONCLUSION

In this pilot study, we interviewed 12 women with advanced cancer, all of whom were on home hospice care and had a median survival of 42 days from interview. We were interested in how patients on home hospice programs, which actively promote acceptance of terminal illness as a central part of their philosophy (Ita, 1995–1996), deal with their impending death and whether there are specific issues that call for provision of routine psychological care to these patients.

First, all subjects reported thinking about death, most of them did so often or almost always, thus, breaking through the common "unwillingness to

admit and come to grips with finitude and vulnerability” (Attig, 1979, p. 9). Half of them felt that the thought of death was bothersome to them and these women were also frequently troubled by unresolved issues and somewhat higher anxiety, fatigue, and pain. Most subjects expressed a desire to actively discuss the topic of death and reported feeling frustrated when having no opportunity to share their death-related thoughts and feelings with loved ones. Research has shown that discussion of existential issues, such as fear of death, results in lower mood disturbance, less maladaptive coping, and less phobic anxiety (Spiegel et al., 1981). Based on the finding that thinking about death was common and discussion of death-related thoughts desired by the women in the present study, expression of death-related thoughts and feelings in an open atmosphere should be encouraged by mental health care professionals in order for a dying patient to work through these thoughts and fears and attain higher emotional stability.

Second, about half of the subjects in the present study described being sometimes or always afraid of death. This is in contrast with the literature, reporting that fear of death in terminally ill cancer patients is low (Smith et al., 1983–1984), even lower than in healthy people or patients with a chronic, yet nonfatal illness (Dougherty et al., 1986). High fear of death in the present sample was associated with fear of dying in pain and intense usual or peak pain as well as the occurrence of unresolved issues and difficulty in parting with loved ones in death. Pain is multidimensional in nature, comprising not only physical aspects but other aspects as well, such as affect, cognition, and social relations, and these factors are interrelated (Breitbart & Payne, 2000). In regard to the present findings, diagnosing and treating pain must be a primary concern. It has been shown that pain control is less successful in patients on home hospice programs than those in hospital-based hospices, possibly due to less rigorous scheduling of pain medication at home (Morris et al., 1986). Adequate pain treatment in home hospice patients will also have to include a mental health professional’s diligent evaluation and treatment of possible psychological and spiritual factors, such as fear of death and unresolved issues. Little systematic research exists on the problem of unresolved issues, but it has been said that unresolved issues are related to anxiety (Cassem, 2000), and that for many patients in the final phase of their illness, the impetus toward seeking resolution of their unfinished business reaches a peak (Gonda & Ruark, 1984). Assisting a patient in working through and possibly resolving important unfinished business, such as parting with loved ones,

must, thus, constitute an important aspect of psychological care that will help a patient face death more comfortably and less fearfully.

Third, most women in the present study felt that their religious faith was an important aspect of their present lives and a source of comfort and strength. Their reports are in accordance with Reed’s (1987) notion that transcendental perspectives, as accrued over the life span, especially when death is drawing close, can assist an individual in maintaining a sense of well-being when faced with the dying process. One possible explanation is that it is the development of one’s personal spiritual awareness (cf. Smith et al., 1983–1984), as seen in the majority of the women in the present sample, rather than an uncritical compliance with an orthodox religious belief system (cf. Ita, 1995–1996; Franks et al., 1990–1991), that affords comfort and internal strength and elicits external support by spiritual companions. Spirituality and its role in alleviating suffering in cancer patients has gained increasing recognition over the past few years. It has been found to be negatively associated with anxiety, positively related to social support in terminally ill cancer patients (Ita, 1995–1996), and negatively associated with psychosocial distress (Smith et al., 1993). It represents the aspect that is the deepest and most genuine part of human nature (Kearney & Mount, 2000), thus, recognizing and treating spiritual distress and providing spiritual growth is a key area for mental health experts and pastoral care counsellors that must not be neglected.

These findings on (1) confronting the issue of death, (2) fear of death and dying, and (3) the role of religion/spirituality in terminally ill patients all highlight the need for improved collaboration of mental health professionals with home hospice institutions. Challenges, such as financial constraints and difficulty in implementing routine involvement of mental health professionals in the care of home hospice patients, will have to be faced if optimal holistic care for terminally ill patients close to death is to be ascertained.

LIMITATIONS

Sample size is a major limitation of this pilot study, which makes any interpretation and extrapolation of the findings difficult. Furthermore, all patients were female with advanced cancer and on home hospice care; thus, generalization to other groups of terminally ill patients, a male population, or those in hospitals is not possible. The study is cross-sectional in nature, relying on interview data collected at one point. It has been demonstrated that mental states in the dying, such as will to live

(Chochinov et al., 1999) or denial (Viederman, 2000), fluctuate rapidly and intensely. Thus, the findings in the present study must be viewed as tentative results.

While these limitations are acknowledged, it must be emphasized that the present study was designed to gather pilot information on psychological issues raised specifically by patients on home hospice care. According to Ita (1995–1996), few studies so far specifically target hospice patients. However, since 1980, there has been a steady increase in patients choosing to die at home or in a hospice (Schachter & Coyle, 1998), so this situation calls for studies specifically focusing on the concerns of this patient group. The present study was a first step in the development of a psychosocial care program for terminally ill cancer patients on home hospice care.

ACKNOWLEDGMENTS

The authors thank the 12 women who generously gave their time and thoughts for this study as well as Stanford Home Hospice, Hospice of the Valley, and Mission Hospice for their cooperation and support. Dr. Mareile Grumann was funded through a research fellowship by the German Research Association (Deutsche Forschungsgemeinschaft).

REFERENCES

- Attig, T. (1979). Death, respect and vulnerability. In *The Dying Human*, de Vries, A. & Carmi, A. (eds.), pp. 3–15. Tel Aviv: Turtledove Publishing.
- Breitbart, W. & Payne, D. (2000). Psychiatric aspects of pain management in patients with advanced cancer and AIDS. In *Handbook of Psychiatry in Palliative Medicine*, Chochinov, H.M. & Breitbart, W. (eds.), pp. 131–59. Oxford, New York: Oxford University Press.
- Cassem, E.D. (2000). Care and management of the patient at the end of life. In *Handbook of Psychiatry in Palliative Medicine*, Chochinov, H.M. & Breitbart, W. (eds.), pp. 13–23. Oxford, New York: Oxford University Press.
- Cherny, N.I., Coyle, N. & Foley, K.M. (1994). Suffering in the advanced cancer patient: A definition and taxonomy. *Journal of Palliative Care*, *10*, 57–70.
- Chochinov, H.M., Tataryn, D., Clinch, J.J., & Dudgeon, D. (1999). Will to live in the terminally ill. *The Lancet*, *354*, 816–19.
- Cleeland, C.S. (1989). Measurement of pain by subjective report. In *Advances in Pain Research and Therapy: Issues of Pain Measurement*, Chapman, C.R. & Loeser, J.D. (eds.), pp. 391–403. New York: Raven Press.
- Dougherty, K., Templer, D.I., & Brown, R. (1986). Psychological states in terminal cancer patients as measured over time. *Journal of Counseling Psychology*, *33*, 357–359.
- Franks, K., Templer, D.I., Cappelletty, G.G. & Kauffman, I. (1990–1991). Exploration of death anxiety as a function of religious variables in gay men with and without AIDS. *OMEGA*, *22*, 43–50.
- Gonda, T.A. & Ruark, J.E. (1984). *Dying Dignified. The Health Professional's Guide to Care*. Menlo Park, CA: Addison Wesley Publishing Company.
- Ita, D.J. (1995–1996). Testing of a causal model: Acceptance of death in hospice patients. *OMEGA*, *32*, 81–92.
- Kearney, M. & Mount, B. (2000). Spiritual care of the dying patient. In *Handbook of Psychiatry in Palliative Medicine*, Chochinov, H.M. & Breitbart, W. (eds.), pp. 357–373. Oxford, New York: Oxford University Press.
- Mendoza, T.R., Wang, X.S., & Cleeland, C.S. (1999). The rapid assessment of fatigue severity in cancer patients. Use of the Brief Fatigue Inventory. *Cancer*, *85*, 1186–1196.
- Morris, J.N., Mor, V., Goldberg, R.J., Sherwood, S., Greer, D.S., & Hiris, J. (1986). The effect of treatment setting and patient characteristics on pain in terminal cancer patients: A report from the national hospice study. *Journal of Chronic Diseases*, *39*, 27–35.
- Reed, P. (1987). Spirituality and well-being in terminally ill hospitalized adults. *Research in Nursing & Health*, *10*, 335–344.
- Schachter, S. & Coyle, N. (1998). Palliative home care—impact on families. In *Psycho-oncology*, Holland, J.C. (ed.), pp. 1004–1015. Oxford, New York: Oxford University Press.
- Smith, E.D., Stefanek, M.E., Joseph, M.V., Verdick, M.J., Zabory, J.R., & Fetting, J.H. (1993). Spiritual awareness, personal perspective on death, and psychosocial distress among cancer patients: An initial investigation. *Journal of Psychosocial Oncology*, *11*, 89–103.
- Smith, D.K., Nehemkis, A.M. & Charter, R.A. (1983–1984). Fear of death, death attitudes, and religious conviction in the terminally ill. *International Journal of Psychiatry in Medicine*, *13*, 221–232.
- Spiegel, D., Bloom, J.R., & Yalom, I. (1981). Group support for patients with metastatic cancer. A randomized prospective outcome study. *Archives of General Psychiatry*, *38*, 527–533.
- Templer, D.I. (1970). The construction and validation of a death anxiety scale. *Journal of General Psychology*, *82*, 165–177.
- Vachon, M.L.S. (2000). Burnout and symptoms of stress in staff working in palliative care. In *Handbook of Psychiatry in Palliative Medicine*, Chochinov, H.M. & Breitbart, W. (eds.), pp. 303–319. Oxford, New York: Oxford University Press.
- Viederman, M. (2000). The supportive relationship, the psychodynamic life narrative, and the dying patient. In *Handbook of Psychiatry in Palliative Medicine*, Chochinov, H.M. & Breitbart, W. (eds.), pp. 215–222. Oxford, New York: Oxford University Press.
- Walsh, R. & Vaughan, F. (1982). What is a person? *New Realities*, *4*, 48–52.
- Welwood, J. (1983). *Awakening the Heart*. Boulder, CO: Shambala Publications.
- Yalom, I.D. (1980). *Existential Psychotherapy*. New York: Basic Books.
- Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, *67*, 361–370.