Volume 48, Number 1 — 2003-2004

OMEGA

JOURNAL OF DEATH AND DYING

An Official Journal of the Association for Death Education and Counseling

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ISSN 0030-2228

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phone (631) 691-1270 ♦ fax (631) 691-1770 ♦ toll-free orderline (800) 638-7819
e-mail: baywood@baywood.com ♦ web site://baywood.com

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Printed in the United States of America on acid-free recycled paper

OMEGA, Vol. 48(1) 1-21, 2003-2004

ATTITUDES TOWARD AND DESIRE FOR ASSISTED SUICIDE AMONG PERSONS WITH AMYOTROPHIC LATERAL SCLEROSIS*

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ABSTRACT

This study aimed at investigating attitudes toward assisted suicide among individuals with amyotrophic lateral sclerosis, and the differences in health status (illness severity and functional disability) and psychosocial adjustment (depression, perceived stress, social support, and coping) between those in favor of and those against assisted suicide. This study also aimed at describing the characteristics of terminally-ill individuals who acknowledge contemplating assisted suicide. Forty-four individuals diagnosed with amyotrophic lateral sclerosis were surveyed about their attitudes and the circumstances that would make them contemplate assisted suicide and filled out standardized measures of mood, stress, social support, coping, and illness status. Seventy percent of the sample found assisted suicide morally acceptable and 60% thought it should be legalized. In addition, 60% of patients agreed they could foresee circumstances that would make them contemplate assisted suicide, but only three (7%) indicated they would have requested it already if it had been legal. Willingness to contemplate assisted suicide was associated with reports of elevated levels of depressive symptoms and reports of hopelessness. Results highlight the need to assess psychological status carefully when terminally ill individuals begin contemplating assisted suicide or voice a request for it.

*This article is based on the author's doctoral thesis at Simon Fraser University while under the supervision of Dr. James Ogloff. This research was made possible by the financial support of the Social Sciences and Humanities Research Council of Canada and of the British Columbia Health Research Foundation.

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Assisted suicide has commanded increasing attention in the media, legal and scholarly debates in the last 15 years, and remains at the center of much controversy. An air of liberalization marked the 1990s, with the Netherlands introducing guidelines to sanction physician-assisted suicide in 1993, Ballot Measure 16 in Oregon legalizing assisted suicide for the terminally ill in 1994, "voluntary euthanasia" becoming legal in the Northern Territories of Australia in 1995, and appellate courts in the second and ninth federal circuits in the United States deeming laws prohibiting assisted suicide unconstitutional in 1996. These legal changes paralleled the increasing support for assisted suicide among the general public documented by polls conducted across North America, Europe, and Australia over the last 40 years and suggesting that now over 60% of the public at large agrees that competent, terminally ill patients have a right to request aid-in-dying (Achille & Ogloff, 1997; Adams, Bueche, & Schvaneveldt, 1978; Blendon, Szalay, & Knox, 1992; Genuis, Genuis, & Chang, 1994; Jorgensen & Neubecker, 1981; Mullens, 1996).

Despite this trend of support for assisted suicide, strong opposition remains among those most religiously committed (Achille & Ogloff, 1997; Adams, Bueche, & Schvaneveldt, 1978; Anderson & Caddell, 1993; Cohen, Fihn, Boyko, Jonsen, & Wood, 1994; Jorgensen & Neubecker,1981; Shapiro, Derse, Gottlieb, Schiedermayer, & Olsen, 1994) and among those advocating for the rights of the handicapped, the terminally ill, and the elderly (Whitfield, 1987). In addition, courts and practitioners warn against the risk of creating a "slippery slope" of misuse and abuse of assisted suicide against vulnerable members of society (Chippeur & Marxwell, 1994; Hollander, 1989; Latimer, 1991; *Rodriguez v. British Columbia,* 1993).

While a review of existing laws and public opinion polls provide us with a window on attitudes toward assisted suicide in society today, these sources tell us little about the specific opinions of those most concerned by the issue, the terminally ill. If health care professionals (Anderson & Caddell, 1993; Cohen et al., 1994; Dickinson, Lancaster, Summer, & Cohen, 1998; Ganzini et al., 2000) and the general public (Achille & Ogloff, 1997; Adams et al., 1978; Blendon, Szalay, & Knox, 1992; Genuis, Genuis, & Chang, 1994; Jorgensen & Neubecker, 1981; Mullens, 1996) were often surveyed, relatively few studies have documented attitudes among the terminally ill. While the practical and emotional challenges of doing research among groups of terminally ill individuals are many, especially among those close to death, it is of crucial importance to gather as much data as we can from this segment of the population.

Early studies conducted among persons with HIV infection or AIDS found that 60% to 94% of this group were in favor of legalizing assisted suicide, that 55% to 90% wished to have the option available to them, and that 33% to 44% had considered it seriously or even made arrangements for it since being diagnosed (Breitbart, Rosenfeld, & Passik, 1996; Green, 1995; Ogden, 1994; Tindall, Forde, Carr, Barker, & Cooper, 1993). Studies done among cancer sufferers

highlight a possible link between terminal illness, depression, and a wish for an early death (Chochinov et al., 1995; Emmanuel, Fairclough, Daniels, & Clarridge, 1996). A review by Mishara (1999) suggests that among several diagnostic groups, chronic illness is a risk factor for suicide and that often the terminally ill will admit to having contemplated suicide or even wished for an early death at some point during their illness.

Even though the results of studies published thus far do seem to suggest that support for assisted suicide among the terminally ill is high, two issues remain particularly problematic. The first one is estimating the proportion of terminally ill individuals who personally request assisted suicide. The only available data regarding this come from the Netherlands, where statistics available for 1991 report 2,300 cases of assisted suicide by administration of a lethal injection, representing approximately 2% of all deaths in that country that year and 400 cases of assisted suicide by prescription of a lethal drug, representing less than 1% of all deaths that year (van der Maas, van Delden, Pijnenborg, & Looman, 1991). Some observers, however, believe that such numbers are conservative and that actual instances of assisted suicide may account for as many as 5% to 15% of all deaths (Huyse & van Tilburg, 1993).

The other problematic issue is understanding what motivates people to request assisted suicide. A careful review of the assisted suicide literature suggests that two perspectives prevail in that regard. The first one suggests that requests for assisted suicide are motivated by distress and are more likely to be made by those who are elderly, depressed, lonely, or frightened by their illness and who yearn for more comfortable living, better care, and increased support (Cain & Conwell, 1993; Hendin & Klerman, 1993; Quill, 1991). In such cases, a desire for hastened death is seen as remediable as long as medical, psychological, and palliative care are provided (Moulin et al., 1994). There is also a suggestion that, for many, fear of becoming a burden to others is an important motive behind contemplation of assisted suicide (Seale & Addington-Hall, 1994; Starace & Sherr, 1998; van den Boom, 1995; van der Maas et al., 1991), again suggesting that fear and distress may explain an expressed desire for assisted suicide. Inherent to this perspective is the assumption that a request for assisted suicide is reversible.

The other perspective suggests that a request for assisted suicide may be a rational and acceptable way of coping and of regaining a sense of control over an otherwise uncontrollable fate (Tindall et al., 1993; van den Boom, 1995). Proponents of this perspective suggest that the act of a competent terminally or incurably ill person that is performed to hasten death at the end of an enduring illness, that is not the result of an impulsive decision or of a decision clouded by mental illness, and that is performed for reasons that are understandable to the person's peers should be considered rational, whether suicide or assisted suicide (Starace & Sherr, 1998; Werth, 1996). Inherent to this second perspective is the assumption that a request for assisted suicide

can be deemed rational and can be granted in carefully assessed and carefully monitored cases.

THE PRESENT STUDY

The present study was designed specifically to survey a group of terminally ill patients to: 1) document their general attitude toward assisted suicide; 2) investigate how likely it is for them to contemplate assisted suicide personally; and 3) determine whether such contemplation or wish is associated with indices of distress, namely elevated depression and stress, poor support, and limited coping skills. To do so, this study looked at depression, perceived stress, social support, and coping as correlates of attitudes toward, and acknowledged desire for, assisted suicide.

Persons with ALS (PALS) were chosen for this study because they have an incurable, irreversible illness, which, in the end stages, forces them to live in a state of near complete paralysis and dependency. Contrary to AIDS or cancer, there is currently no hope for remission once the disease has been diagnosed. PALS have been vocal participants in the debate about assisted suicide (Hendin, 1997; *Rodriguez v. British Columbia,* 1993), both for and against, and along patients with cancer and chronic obstructive pulmonary disease, have been among the diagnostic groups most often represented in requests for assisted suicide (Sullivan, Hedberg, & Fleming, 2000). While the nature and severity of their illness may legitimize requests for assisted suicide in the eyes of observers, its incapacitating effects may make individuals who have ALS more vulnerable to abuse. It may also render them unable to self-administer a lethal dose of medication once they have reached a life expectancy of six months or less to qualify for assisted suicide according to guidelines currently in place in places such as Oregon (Oregon Death With Dignity Act, 1994).

METHOD

Participants

PALS (N = 44) had a mean age of 51.6 years (SD = 12.9, range 25 to 76), the majority were men (N = 33, 75%), lived with a spouse or common-law partner (N = 37, 84%), and had pursued professional training or obtained a university degree beyond high school (N = 31, 71%). Twenty-nine (66%) were no longer working due to ALS. Thirteen (30%) described themselves as Roman Catholic, 17 (39%) as Protestant, and five (18%) as atheist. The mean duration of their illness was 66.7 months (SD = 57.8) since onset of their symptoms and 54.0 months (SD = 52.0) since diagnosis. All PALS lived at home, 34 (77%) resided in the United States, seven (16%) in Canada, and three (7%) in the United Kingdom.

Instruments

Attitudes toward Assisted Suicide

Attitudes toward assisted suicide were assessed with a questionnaire developed for the purpose of the present study based on pilot interviews done individually with 12 PALS by the first author (Achille, 1999). In the questionnaire, assisted suicide was defined as an instance when "a medical doctor provides a lethal drug and advice to a terminally ill patient who wishes to end his or her life. The patient involved is usually in the last stages of a terminal illness and this is only done when the patient himself or herself requests it voluntarily."

To assess general attitudes toward assisted suicide, participants were asked to rate two statements on a scale from 1 "Strongly disagree" to 5 "Strongly agree." The first statement, which tapped general support for assisted suicide, was "I believe that if requested by a competent, terminally-ill patient, a physician is morally justified in helping this patient end his/her life by assisted suicide." The second statement, which tapped opinion toward the legalization of assisted suicide, was: "I would favor laws that would make physician-assisted suicide legal."

After general attitudes, participants were asked to rate two statements about personal wish for assisted suicide on a similar scale from 1 "Strongly disagree" to 5 "Strongly agree." The first statement was "I can foresee future circumstances that would make me consider asking for assisted suicide if it were legal" and the second was "If assisted suicide were already legal, I would have asked for it since being diagnosed with ALS."

Following these two statements, patients were asked to indicate to what degree each of five factors would influence their decision to contemplate assisted suicide. These five factors were: being completely dependent on others for self-care; feeling like I have no purpose in life; being on a ventilator; feeling like I am a burden to my family/close ones; feeling like I have lost my dignity. Each factor was rated on a scale from 1 "Not at all influential" to 3 "Very influential."

Patients were then asked to what degree, if any, it would bring them peace of mind if assisted suicide was legal and available, to what degree they feared that the legalization of assisted suicide may undermine trust in the medical profession, and to what degree they feared that assisted suicide might be used against them. Each question could be answered on a scale.

Finally, participants were asked to rate on a scale from 1 "Not at all" to 4 "A great deal" whether their attitude toward assisted suicide had changed since being diagnosed with ALS. They were also asked to check who they had discussed their views on assisted suicide with (spouse/partner, children, extended family, physician or other health care professional, religious leader, other).

Demographic Information

In the last section of the questionnaire, PALS were asked to provide information about age, gender, education, marital status, employment status, and religious denomination when applicable. They were also asked about their level of religiosity, which in the present study was defined as their degree of religious practice and assessed with a question about how frequently participants attended services (Never or almost never; A few times a year or on special occasions; Weekly or very often) and a question about how frequently they prayed (Never or almost never; Occasionally; Daily).

In this section, patients were also asked about their psychiatric history, namely whether they were consulting or had ever consulted a mental health professional, whether they were taking or had ever taken psychotropic medication, and whether they had thought about suicide at some point in their life.

Illness Status and Physical Functioning

In the section assessing illness status and physical functioning, participants were asked to indicate how long ago they remembered having started to experience illness symptoms and how long ago they had received a diagnosis of ALS. To assess their level of physical functioning, a self-report version of the ALS Severity Scale (ALSSS) (Hillel et al., 1989) was developed for the purpose of the present study. On this scale, participants are asked to describe four areas of their functioning, namely their ability to speak, to swallow, to move their arms, and to move their legs. For each area of functioning, they are given a series of four to five statements describing increasing levels of disability and are asked to choose the one that best describes their functioning in the stated area. For example, a question such as "How is your speech?" could be answered with choices including "Normal, no change noted," "Some difficulties, need to repeat on occasion," "Speech considerably more labored," and so on. Functioning in each category is summarized by a number corresponding to the statement chosen by the patient and overall level of functioning can be summarized by adding these four area scores into one overall score.

Depression

Symptoms of depression were assessed using the short version of the Beck Depression Inventory (BDI) (Beck & Beck, 1972). The short version retains 13 of the original 21 items and taps cognitive and affective symptoms, as they were found to discriminate best between depressed and non-depressed medical patients (Cavanaugh, Clark, & Gibbons, 1983; Plumb & Holland, 1977). For this form, as for the original, overall level of depression can be rated by a single number ranging from 0 to 39, and cut-off scores indicate whether each participant's score falls in the mildly, moderately, or severely depressed range.

Perceived Stress

How stressful each participant perceived his current situation to be was assessed using the Perceived Stress Scale (PSS) (Cohen, Karmarck, & Mermelstein, 1983), a 14-item self-report scale developed to measure the degree to which current events in a person's life are appraised as stressful. The PSS has been shown to have adequate reliability and scores on this scale have been found to be correlated with life-event scores and use of health resources, social anxiety, and avoidance coping (Cohen et al., 1983). Overall perceived stress is represented by a number ranging from 0 to 56.

Social Support

Social support was assessed using the six-item version of the Sarason Social Support Questionnaire (SSQ6) (Sarason, Sarason, Shearin, & Pierce, 1987). This short version of the original 27-item questionnaire (Sarason, Levine, Basham & Sarason, 1983) taps both network availability and perceived satisfaction with the support available, two main conceptual dimensions of social support (Barrera & Ainlay, 1983; O'Reilly, 1988). For each participant, a first score (SSQN) represents the number of people available to provide support and a second score (SSQS) ranging from 0 "Very dissatisfied" to 6 "Very satisfied" represents how satisfied the respondent is with the support he/she receives.

Coping

Coping was measured using the Coping Response Inventory-Adult Form (CRI) (Moos, 1993), which assesses eight types of coping responses, including approach and avoidance, emotion, and cognition-focused strategies. Its subscales include Logical Analysis, Positive Reappraisal, Seeking Guidance and Support, Problem Solving, Cognitive Avoidance, Acceptance or Resignation, Seeking Alternate Rewards, and Emotional Discharge. The CRI has been shown to have good psychometric properties, to be minimally correlated with social desirability, and to be appropriate for measuring coping with a diversity of experiences, including coping among medical patients and their families (Moos, 1993). For each participant, the CRI provides a description of how frequently he/she uses the various types of strategies to cope with an identified stress (in this case, having ALS.)

Procedure

Participants were recruited via three advertisements that were placed two months apart in the ALS Digest, an e-mail newsletter sent weekly to a reported readership of 3,000 worldwide. The ad described the study briefly and invited prospective participants to contact the principal investigator via e-mail to receive a copy of the survey. Participants had to have received a diagnosis of ALS.

Prospective participants contacted the principal investigator via e-mail in response to the advertisement in the ALS Digest. Each was sent a copy of the survey either as a hard copy, along with a self-addressed return envelope, or as an e-mail attachment, depending on their expressed preference. A letter of information describing the study was placed at the beginning of the questionnaire and stated that participants' willingness to complete the survey would be taken as an indication of their consent to participate. For each questionnaire that was not returned within one month of being sent to a prospective participant, an e-mail reminder was sent encouraging respondents to complete and return the questionnaire at their earliest convenience.

RESULTS

Response Rate

Altogether, 57 requests were made by PALS and 44 completed and returned the survey, representing a response rate of 77% among those who received the survey. All participants lived in a country or state where assisted suicide is currently illegal.

Missing Data

Missing data on standardized self-report measures were treated in conformity with each instrument's instructions for test administration. Altogether, less than 1% of the data from the self-report standardized measures were missing.

Attitudes toward and Desire for Assisted Suicide

Frequency counts were first performed to estimate the proportion of participants who were in favor of assisted suicide and the proportion of those who were in favor of its legalization. Seventy percent of PALS agreed or strongly agreed with the statement that if requested by a competent, terminally ill patient, a physician is morally justified in helping the patient end his or her life by assisted suicide, and 60% agreed or strongly agreed that the law should be changed to allow physician assisted suicide.

In response to the statement "I could foresee circumstances that would make me contemplate assisted suicide in the future if it were legal," 26 PALS (60%) agreed or strongly agreed that they could, 15 (33%) disagreed or strongly disagreed, and three (7%) said they were unsure.

Finally, when asked whether they would have asked for assisted suicide since being diagnosed with ALS if it had already been legal, three of the 44 PALS (7%) agreed that they would have. Despite this small number, it is the situation of these three individuals that informs us the most about circumstances that lead terminally ill patients to contemplate assisted suicide. We will return to them more in depth later.

Sociodemographic and Illness-Related Variables Influencing Attitudes toward Assisted Suicide

In order to investigate whether there were any sociodemographic or illness-related variables that explained differences between PALS who found assisted suicide morally acceptable and those who did not, these two groups were compared using *t*-tests for continuous variables (age, months since diagnosis, overall physical functioning) and chi-square analyses for categorial ones (education, marital status, religious denomination, frequency of attendance to religious services, frequency of prayer). Similar analyses were performed to compare PALS who favored the legalization of assisted suicide and those who did not.

For both sets of analyses (those who found assisted suicide morally acceptable versus those who did not, and those who were in favor of the legalization of assisted suicide versus those who were not), no differences in age, gender, level of education, marital status, or religious denomination were found (please refer to Table 1).

There were also no differences in the time since symptom onset, time since diagnosis, or level of physical and functional impairment between PALS who

Table 1. Demographic Differences between PALS Who Favor the Legalization of Assisted Suicide and Those Who Do Not[a]

Variable	In favor ($N = 26$)	Not in Favor ($N = 18$)	*P* value
Age (years)	52.9 ($SD = 13.7$)	49.6 ($SD = 11.8$)	.401
Gender split (% men)	85	61	.079
Education (% with a college or university education)	78	73	.732
Marital status (% married)	77	83	.448
Religious denomination (% Catholic, % Protestant)	23, 42	39, 33	.800
Attend services weekly (%)	19	56	.000
Pray daily (%)	30	56	.000

[a]Because results from comparisons between PALS who favored the legalization of assisted suicide and those who did not are very similar to the results comparing PALS who found assisted suicide morally acceptable and those who did not, only one set of results is presented here.

found assisted suicide morally acceptable and those who did not, and between PALS who believed that assisted suicide should be legalized and those who did not (please refer to Table 2).

However, differences were found based on religious practice. Those who were most likely to attend religious services (χ^2 (2, $N = 44$) = 15.38, $p < .001$) and who prayed on a regular basis (χ^2 (2, $N = 44$) = 6.65, $p < .05$) were significantly less likely to find assisted suicide morally acceptable or to support its legalization (attend services: χ^2 (2, $N = 44$) = 18.83, p < .001; pray: χ^2 (2, $N = 44$) = 13.78, $p < .001$) (please refer to Table 1).

Psychosocial Correlates of Contemplating Assisted Suicide

To investigate the psychosocial correlates of an acknowledged willingness to contemplate assisted suicide, the PALS sample was divided into two subgroups.

Table 2. Illness-Related and Psychosocial Differences between PALS Who Endorsed a Willingness to Contemplate Assisted Suicide ("Contemplate") and Those Who Did not ("Do Not Contemplate")[a]

Variable	Contemplate ($N = 26$)	Do Not Contemplate ($N = 18$)	*P* value
ALS severity[b]	10.5 (*SD* = 3.5)	11.0 (*SD* = 4.5)	.681
Months since onset of symptoms	66.3 (*SD* = 54.4)	69.1 (*SD* = 65.5)	.890
Months since diagnosis	56.0 (*SD* = 53.6)	66.5 (*SD* = 61.7)	.599
SSQN[c]	1.4 (*SD* = 0.8)	1.8 (*SD* = 0.9)	.108
SSQS[d]	4.8 (*SD* = 1.3)	5.4 (*SD* = 0.7)	.121
PSS[e]	20.8 (*SD* = 9.4)	17.5 (*SD* = 6.7)	.211
BDI—Short Form[f]	7.8 (*SD* = 4.5)	5.2 (*SD* = 3.3)	.044

[a]PALS who favored the legalization of assisted suicide were also those who acknowledged they could foresee circumstances that would make them contemplate assisted suicide. [b]Score on the modified ALS Severity Scale from 0 to 19, least to most disabled. [c]Number of people available to provide support as measured by the Social Support Questionnaire (six-item version). [d]Satisfaction with social support from 0 "very dissatisfied" to 6 "very satisfied" as measured by the Social Support Questionnaire (six-item version). [e]Score on the Perceived Stress Scale from 0 to 56, least to most perceived stress. [f]Score on the Beck Depression Inventory, short form, from 0 to 39, least to most severely distressed.

The first group comprised those who had agreed or strongly agreed that they could foresee circumstances that would make them contemplate assisted suicide and was labeled "contemplate." The second group comprised those who had disagreed, strongly disagreed, or indicated that they were not sure in response to the same statement; this group was labeled "do not contemplate." This breakdown was chosen because in actuality, it is those patients who indicate that they are contemplating assisted suicide who should be assessed to determine whether their contemplation is rational or whether it stems from distress. While some patients among those who were unsure and among those who disagreed may change their mind in the future, they would not undergo such evaluation until they openly expressed an interest in assisted suicide.

Those who could foresee circumstances that would make them contemplate assisted suicide were also those who favored its legalization and, as mentioned earlier, there were no differences in age, gender, or marital status between those who favored legalization and those who did not.

In terms of psychosocial variables, the "contemplate" group scored significantly higher than the "do not contemplate" group on the short version of the BDI ($F(1, 42) = 5.72$, $p = .021$) (please refer to Table 2). The "contemplate" group was also significantly more likely to endorse hopelessness on the second item of the BDI (χ^2 (2, 44) = 7.46, $p = .02$). In contrast, there were no differences between the two groups in their level of perceived stress, in the availability and quality of their social network, and in their use of coping strategies to deal with ALS (please refer to Table 2).

Among those who could foresee themselves contemplate assisted suicide, the most often cited motives for doing so were being completely dependent on others for everything and feeling like they were a burden to others. All but one patient (98%) agreed or strongly agreed that knowing that assisted suicide was available would bring them peace of mind and all but two (95%) disagreed or strongly disagreed that they would fear that assisted suicide might be used against them if it was legal.

Characteristics of Those Who Acknowledged They Would Have Requested Assisted Suicide Already

As mentioned earlier, three individuals (7% of the PALS sample) indicated they would have already asked for assisted suicide if it had already been legal. Because this number is too small to allow for statistical comparison between these three PALS and the rest of the patient sample, their psychosocial profile will be described in a qualitative way only. Two of the three individuals were men, they were in their 40s (two) and 60s (one), and all three were living with a spouse or common-law partner. None of them attended religious services regularly and only one prayed daily. They all had a college or university education and had worked prior to stopping due to ALS.

All three were strong advocates of self-determination and indicated that their contemplating assisted suicide was strongly influenced by the desire not to be completely dependent on others, the fear of becoming a burden to others, and the wish to preserve some sense of dignity. Interestingly, all three disagreed that assisted suicide should be reserved to those who have a life expectancy of less than six months. All of them indicated having discussed their wish with several others, including their spouse, doctor, and other family members or friends. Two reported having been treated by a mental health professional in the past, and two had had suicidal ideation since being diagnosed with ALS. Their level of physical disability varied: one was severely disabled by the illness, could no longer speak, and was almost completely paralyzed, while the other two had limited mobility and arm movement but could still communicate by voice.

In terms of psychological distress, two scored in the moderately depressed range and one scored in the severely depressed range on the short form of the BDI. On the second item of the BDI tapping hopelessness, all three indicated that they felt discouraged about the future. Two of the three were among the PALS who scored highest on the perceived stress scale and a half standard deviations below the patient mean on availability and satisfaction with their social network. The third did not fill out either measure. The one PALS among the three who scored highest on the short form of the BDI and on the Perceived Stress Scale and lowest on the Social Support Questionnaire was also the one who made the most use of avoidant coping strategies (scored Well Above to Considerably Above Average on three of the four avoidant coping strategies according to the CRI scoring categories).

Arguments Put Forth in Favor Of or Against Assisted Suicide

In terms of arguments used to advocate each position, PALS who found assisted suicide morally acceptable and favored its legalization indicated that their belief in self-determination had influenced their attitude significantly more strongly than those who did not find assisted suicide morally acceptable (χ^2 (2, $N = 44$) = 26.98, $p < .001$) or those who opposed its legalization (χ^2 (2, $N = 44$) = 19.8, $p < .001$). Those who did not find assisted suicide morally acceptable and those who opposed its legalization indicated that their belief had been significantly more strongly influenced by their belief in the importance of letting the dying process run its course (moral: χ^2 (2, $N = 44$) = 12.85, $p < .001$; legal: χ^2 (2, $N = 44$) = 9.39, $p < .001$), their fear that allowing physician-assisted suicide might open the door to involuntary euthanasia (moral: χ^2 (2, $N = 44$) = 14.39, $p < .001$; legal: χ^2 (2, $N = 44$) = 14.67, $p < .001$), and their concern that assisted suicide could be misused against disadvantaged groups (moral: χ^2 (2, $N = 44$) = 7.81, $p < .05$; legal: χ^2 (2, $N = 44$) = 9.93, $p < .01$). Those who opposed its legalization further indicated that their concern that physician-assisted suicide might result in

distrust of the medical profession had influenced their attitude significantly more strongly than those who favored it ($\chi^2(2, N = 44) = 11.10, p < .01$).

Relationship between Coping, Distress, and Contemplating Assisted Suicide

For each participant, eight scale scores were computed: one for each of the eight methods of coping assessed by the CRI. The mean scale scores for the eight coping methods were compared using *t*-tests with a Bonferroni correction. Strategies used most often by both groups included problem solving (e.g., taking things one day at a time, knowing what has to be done, and trying hard to make things work), seeking guidance (e.g., trying to find out more about the situation, talking with a spouse), and logical analysis (e.g., thinking of different ways to deal with the situation, trying to anticipate how things will turn out). Strategies least often used included emotional discharge (e.g., taking it out on people, doing something risky) and cognitive avoidance (e.g., trying to forget about the whole thing, denying how serious having ALS really is) (please refer to Table 3).

To further investigate the relationship between attitudes toward assisted suicide and physical and psychosocial status, Pearsons' correlations were run for the entire PALS sample. Variables included in this correlational analysis included age, level of impairment (ALSSS score), total scores on the PPS and BDI, scores on the availability and satisfaction with social support (SSQN, SSQS), raw scores on the eight coping strategies, and attitudes toward assisted suicide. For PALS, the

Table 3. Mean Raw Scores on the Coping Response Inventory Subscales

Type of coping: Subscale	PALS ($N = 44$)
Cognitive approach: Logical analysis	12.6 ($SD = 3.2$)
Cognitive approach: Positive reappraisal	10.7 ($SD = 3.8$)
Behavioral approach: Seeking guidance	12.5 ($SD = 3.4$)
Behavioral approach: Problem solving	13.3 ($SD = 3.9$)
Cognitive avoidance: Cognitive avoidance	6.6 ($SD = 3.4$)
Cognitive avoidance: Acceptance and resignation	9.4 ($SD = 3.6$)
Behavioral avoidance: Seeking alternate reward	10.1 ($SD = 4.4$)
Behavioral avoidance: Emotional discharge	5.8 ($SD = 3.2$)

attitude included in the analysis was how strongly they endorsed contemplating assisted suicide for themselves.

Among PALS, there was a significant negative relationship between scores on the short form of the BDI and the use of positive reappraisal ($r = -.30, p < .01$). The more they endorsed items in the direction of distress, the less likely they were to report using positive reappraisal as a method of coping with ALS. There was a significant negative relationship between the availability of social support and contemplating assisted suicide ($r = -.34, p < .05$). As expected, scores on the short form of the BDI and on the Perceived Stress Scale were significantly positively correlated ($r = .60$, $p < .01$). Finally, there was a significant positive correlation between the level of impairment reported and the use of acceptance and resignation ($r = .32, p < .05$).

DISCUSSION

As was found previously in published surveys of attitudes toward assisted suicide among other groups, the majority of PALS who participated to the present study found suicide morally acceptable (70%) and favored its legalization (60%). This parallels results from other studies reporting comparable rates of support among the general public (Achille & Ogloff, 1997; Blendon et al., 1992; Genuis et al., 1994), health care professionals (Bachman et al., 1996; Cohen et al., 1994; Fried et al., 1993; Lee et al., 1996), and terminally-ill patients (Breitbart et al., 1996; Ganzini, Johnston, McFarland, Tolle, & Lee, 1998; Owen, Tennant, Levi, & Jones, 1992; Tindall et al., 1993) PALS who were in favor of assisted suicide appeared to be strong advocates of an individual's right to self-determination and saw assisted suicide as a legitimate way for patients to preserve a sense of dignity and to avoid becoming completely dependent on, and possibly a burden to, others.

PALS who were most likely to be opposed to assisted suicide were those who were very involved in religious practice. Whether they described themselves as Catholics, Protestants, or followers of other religions, it is those who attended services and prayed regularly who were most strongly opposed to assisted suicide and who were least likely to favor its legalization. This is also consistent with findings from prior studies showing a strong and inverse relationship between support for assisted suicide and religious practice (Achille & Ogloff, 1997; Adams et al., 1978; Anderson & Caddell, 1993; Jorgensen & Neubecker, 1981; Wade & Anglin, 1987). For those against, they considered that assisted suicide was a violation of the notion that life is a gift from God and believed that nature should be left to run its course. Patients' comments during pilot interviews that were performed before the present study suggest that for many who are opposed to assisted suicide, the dying process could be reappraised as an opportunity for patients and their families to share precious moments together that should not be cut short. While many who favored assisted suicide also reappraised the dying

process in this way, they did not see this as incompatible with patients choosing their own timing to die.

In the present study, PALS who were strongly committed to their religion and practiced most consistently were also those most concerned that assisted suicide might be abused and that legalization might result in distrust of the medical profession.

In terms of how much the ALS experience influenced attitudes toward assisted suicide, all PALS, regardless of whether they were in favor of or against assisted suicide, indicated that having a terminal illness had polarized and strengthened, rather than changed, their attitude. Many PALS who found assisted suicide morally acceptable indicated that their attitudes had been longstanding and had predated their diagnosis, and many also indicated that it would bring them peace of mind if it became legally permissible. However, it is possible to assume that PALS, especially those in favor of assisted suicide, may have been biased toward affirming that their attitudes were longstanding.

In terms of assessing how many might request assisted suicide, 60% of PALS who participated in the study indicated that they could foresee circumstances that would make them contemplate this option. All of them most likely were aware of the deteriorating nature of their illness and therefore anticipated reaching a stage where they could do very little for themselves and where their quality of life may no longer seem acceptable to them. However, only three of the survey participants (7%) indicated that they would have already asked for it if it had been legal.

Among the group who admitted they could foresee circumstances that would make them contemplate assisted suicide, and especially amid the three who acknowledged they would have asked for it already since being diagnosed, findings, although limited in generalizability due to the sample size, suggest an association between depressive symptoms, hopelessness, low social support, and reliance on avoidant coping strategies. As a group, those who agreed they could foresee circumstances that would make them contemplate assisted suicide scored higher on a measure of depressive symptoms than those who reported they could not and were more likely to endorse feelings of hopelessness. Among the PALS sample as a group, levels of depressive symptoms also were correlated with poorer support (less availability) and less ability to use positive reappraisal as a coping strategy.

In the case of the three PALS who indicated that they would have asked for assisted suicide already, all three were among those who scored highest on the measure of depressive symptoms and all three endorsed some degree of hopelessness. Two reported having been treated by a mental health professional in the past and two had had suicidal ideation since being diagnosed with ALS. The case of one PALS specifically suggests that this individual not only scored highest both on the depression and perceived stress indices, but also scored lowest on social support and showed a high tendency to use avoidant coping. While it is the case of only one participant, this is one among 44 PALS surveyed

(2.7%), and one-third of those who clearly indicated they would have asked for assisted suicide already since being diagnosed with ALS.

Taken together, these findings concur with findings from prior studies that found an association between depression and contemplating assisted suicide or wishing for an early death among terminally-ill individuals (Breitbart et al., 1996; Brown, Henteleff, Barakat, & Rowe, 1993; Chochinov et al., 1995; Ganzini et al., 1998). This also lends support to the thesis that the wish to die and attitudes toward assisted suicide among the terminally ill are psychologically-rather than physically-mediated (Breitbart et al., 1996; Ganzini et al. 1998; Schneider, Taylor, Hammen, Kemeny, & Dudley, 1991), as physical status was not found to be related to attitudes toward or desire for assisted suicide.

Another way of interpreting the findings from the PALS sample is to look at them using the five criteria for rational suicide and assisted suicide elaborated by Werth (1996). The first criterion states that to be deemed rational, a request must be made by someone who is free of a mental illness or severe distress. The association found between markers of depression and hopelessness and the willingness to contemplate assisted suicide highlights the importance of assessing psychological distress very carefully. It is worth noting, however, that scores on a self-report measure of depressive symptoms cannot be equated to a formal diagnosis of depression.

The second criterion states that contemplating assisted suicide needs to be a non-impulsive consideration. The finding that a majority of PALS could foresee circumstances that would make them contemplate assisted suicide, but that a much smaller percentage would have asked for it since being diagnosed with ALS, despite having already experienced a significant decline in functioning, suggests that patients had already given this issue much thought and were not being impulsive in their consideration. Many PALS who were interviewed in the pilot phase reported that simply being alive, being able to spend time with loved ones, and being able to enjoy quieter activities had taken greater importance and provided them with a sense of having a good quality of life despite declining health and limited functioning (Achille, 1999). As suggested by others, when one's life is threatened, life itself might actually become more meaningful and precious (Feigenberg, 1980; Weisman, 1976).

The third criterion states that the request for assisted suicide must be congruent with an individual's personal beliefs and lifestyle. These patients were all strong advocates of autonomy and self-determination, and indicated that their attitudes toward assisted suicide had predated their ALS diagnosis. However, PALS' answers to this question may have been influenced by social desirability. Nonetheless, PALS' use of cognitive and behavioral approach strategies, such as seeking information about their illness, thinking of ways to deal with the illness, and trying to anticipate how things would turn out, to cope with ALS suggests that contemplating assisted suicide as an alternative may very well be consistent with their way of life.

The fourth criterion requires that patients be able to acknowledge the impact their decision might have on others, which was not assessed in the present study. The fifth requires patients to have had an in-depth discussion about assisted suicide with others, including professional and close ones. It is interesting to note that those who did agree they would have requested assisted suicide if it had already been legal indicated they had indeed discussed their view with at least four other people close to them. Still, in the more general case of PALS who indicated they could foresee circumstances that would make them contemplate assisted suicide even if they would not have asked for it already, a number indicated that they had not discussed their views on assisted suicide with close ones. Obstacles to such discussion may include not wanting to focus on unpleasant things, the timing being too early, or believing that there was unspoken congruence between their wish and the attitudes of those with whom they were close, as suggested by interviews done during the pilot study.

A unique aspect of this study was looking at the strategies they use to cope with ALS. Associations were found between the use of coping strategies and other markers of psychological and physical health. Among PALS, there was an inverse relationship between depressive symptomatology and reliance on positive reappraisal, suggesting that PALS least able to find a positive way of looking at ALS were most likely to be depressed, or that those most depressed were least likely to find ways of seeing their situation in a positive light. Among PALS, the greater their level of impairment, the more likely they were to rely on acceptance and resignation, suggesting that as the terminally ill go through different illness stages, they adjust their coping strategies accordingly.

The three main limitations of the study include the small sample size, that participants all had access to e-mail, and that the study looked at the specific case of ALS. However, it is worth noting that despite these shortcomings, the findings concur with those of a similar study done with a larger sample of ALS patients and caregivers that was published shortly after data collection for the present study was completed (Ganzini et al., 1998).

In summary, and in light of the above discussion of the rationality of contemplating assisted suicide, the results of this study suggest that the most pressing issues for clinicians involved in the care of the terminally ill and called upon to address requests for assisted suicide are as follows. First, we need to carefully assess the level of psychological distress experienced by patients who express a wish for assisted suicide and the extent to which their distress may impact their decision-making ability or may be treatable. It is important to stress that end-of-life decisions are very individual in nature and studies such as the present one are useful in pointing to factors that are implicated and need to be carefully assessed, namely depression and hopelessness.

Second, we need to be prepared to foster an open and supportive discussion between patients, professionals, and close ones who will be involved in and affected by requests for assisted suicide. We need to be especially prepared in

cases where opinions and desires might differ. There remains a certain paradox between statements put forth by patients that they should be free to choose assisted suicide, free from the pressure of others on the one hand, and that it is the fear of becoming a burden to others that might ultimately make them request it on the other. It is also worth noting that not all PALS in favor of assisted suicide or willing to admit they may contemplate it in the future had discussed their views with close ones.

Third, we need to gain a better understanding of the adaptation process that takes place over the course of the illness and that allows terminally ill patients to fend off depression and hopelessness even in the face of great physical and functional decline. An integral part of this process is to help both patients and their caregivers assess their use of coping strategies and educate them around ways to cope more effectively with the illness and its many challenges. Working on helping patients and their close ones find ways to reappraise their experience in a positive light and reach a sense of acceptance may be especially important, and goes along statements made by patients and close ones in the pilot phase of the study that in the face of advancing illness, patients and their close one need the make the most of their remaining time together.

ACKNOWLEDGMENTS

Many thanks to the dissertation committee, including James R. P. Ogloff, J.D., Ph.D. (supervisor), Steven D. Hart, Ph.D., Marilyn Bowman, Ph.D., and David N. Cox, Ph.D. Many thanks also to Bob Broedel of the ALS Digest for his help in recruiting participants and to Pier A. Achille, M.D. for his feedback on earlier drafts of this article.

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FIXIN' TO DIE

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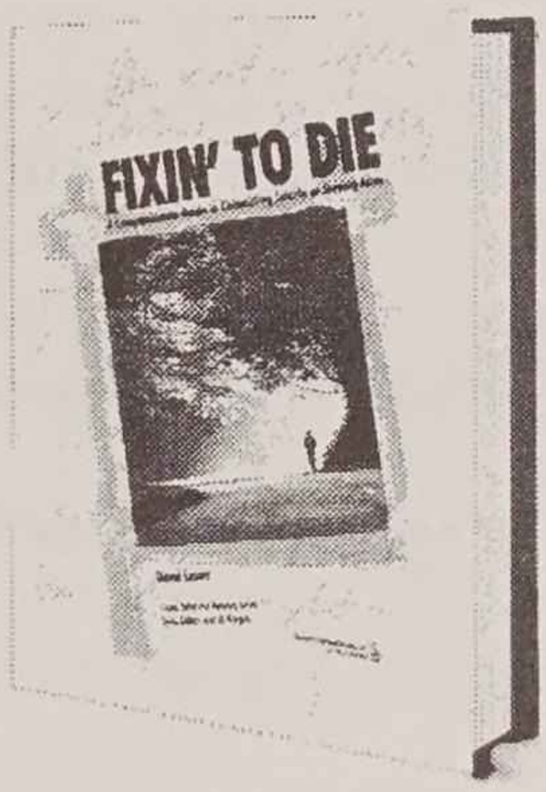

We all have to die. Most would prefer to die in their sleep, quickly and without pain. Many of us will not. In *Fixin' to Die*, author David Lester submits that a decision to commit suicide is highly personal and not to be enforced by others, whether psychiatrist, psychologist, law-maker, clergy, friend, or relative. He further contends that the choice of suicide can be both rational and morally sound. This book is a guide for those evaluating suicide as an option, for making the final decision and carrying it out, or resolving to continue living.

Fixin' to Die discusses the concept of death in an ideal world and what makes death "appropriate." Several definitions of an appropriate death are presented, and readers are encouraged to consider the matter for themselves. David Lester uses Harold Greenwald's *Direct Decision Therapy* to guide the reader through the decision-making process. Lester includes a case study of a family-involved decision and recommends that loved ones and significant others be included in the process. Further suggestions include how to plan the death ceremony and other tasks to be performed prior to death.

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OMEGA, Vol. 48(1) 23-44, 2003-2004

MICRO-SOCIOLOGICAL ANALYSIS OF SOCIAL SUPPORT FOLLOWING TRAUMATIC BEREAVEMENT: UNHELPFUL AND AVOIDANT RESPONSES FROM THE COMMUNITY*

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ABSTRACT

This article explores the reasons why parts of the social support to survivors of traumatic deaths fail. The data is based on in-depth interviews with 69 parents who lost their offspring due to suicide, SIDS, or accident between August 1, 1997 and December 31, 1998. Despite considerable positive support from their social network, the majority of the survivors also experienced some unhelpful encounters or lack of anticipated support. Network members often find it difficult to communicate support in a way that is helpful, and this is termed "social ineptitude." This ineptitude on the part of networks is explained by the lack of norms to guide this uncommon type of social encounter. The bereaved parents claim that "openness" and frankness about their situation is their best empowering strategy to meet this "social ineptitude." These concepts, as they are elaborated in survivors' accounts are discussed within a communicational and interactional perspective. A micro-sociological model of communication provides the frame of reference for the discussion.

INTRODUCTION

This article explores the communicative and interactional processes through which social support is solicited and conveyed in order to elucidate the failure of this form of support to survivors after sudden unexpected deaths. The research

*The author acknowledges The Norwegian Foundation for Health and Rehabilitation and the Norwegian Sudden Infant Death Society for financial support.

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upon which this article is based was part of the study "Support and care for bereaved after suicide, SIDS (Sudden Infant Death), and accident: Evaluation of recipients and providers of care" (Abbreviated: "The Support and care study") (Dyregrov, 2002; Dyregrov, Nordanger, & Dyregrov, 2003). An important finding from the study was that the survivors struggled with a diversity of problems, including difficulties in the encounters with members of their social network. Thus, the purpose of this article is threefold: 1) to present survivors' accounts of unhelpful/lacking social support; 2) to describe the best strategy for survivors in coping with unhelpful/lacking support; and 3) to discuss the process of conveying support by focusing on the micro-dynamics of the unhelpful/lacking support and the self-help strategy. Before the method and results are presented, the theoretical frame is outlined.

Bereaved Populations Benefit from Social Support—A Myth?

A considerable body of literature indicates that the sudden, traumatic loss of a child may have serious psychological after-effects, such as an existential crisis, complicated grief reactions, and difficulties with social functioning (Cleiren & Diekstra, 1995; Dijkstra, 2000; Dyregrov & Dyregrov, 1999; Dyregrov et al., 2003; Janoff-Bulman & Berge, 1998; Range, 1998). Numerous researchers have stressed the important role of social support in reducing grief symptomatology and facilitating psychological adaptation (Dunne, McIntosh, & Dunne-Maxim, 1987; Johnson, 1991; Reed, 1998; Rönnmark, 1999; Sherkat & Reed, 1992; Thuen, 1997a, 1997b). Social support usually refers to the emotional, economic, and practical help or information provided to the affected individual by significant others, such as family members, friends, neighbors, and co-workers (House & Kahn, 1985). Over the years, two main conclusions have emerged from this literature. First, social integration is directly and positively related to mental and physical health. Second, perceived emotional support is associated directly with better physical and mental health and usually acts as a buffer against the damaging impact of major life events and chronic strains on mental and physical health (Cohen, 1988; Cohen & Wills, 1985; Sarason, Sarason, & Pierce, 1990; Thoits, 1995). These conclusions imply that people with a good support network will not fall ill as easily and when they do, they will recover faster; in addition, the risk that they will die from their illness is reduced. This knowledge has provided the basis for social support programs for grieving populations (Gottlieb, 1992; Patton, 1996; Thuen, 1995).

Gradually, some less enthusiastic research reports began to emerge from researchers in more nuanced studies of social support. Thus, new directions in social support research included studies of the negative or unhelpful effects of social relationships, and the lack of support giving (Ingram, Betz, Mindes, Schmitt, & Smith, 2001; Rönnmark, 1999; Sarason et al., 1990; Thoits, 1995;

Wortman & Lehman, 1985). Researchers pointed out that social support might even be experienced as negative and thus have an effect contrary to its purpose. Findings reveal that victims of life crisis are deeply offended or upset by an emphasis on rapid recovery, displays of over-protectiveness, or insensitive statements (Harris, 1992; Sarason, Sarason, & Shearin, 1986; Thompson & Range, 1992). Dakof and Taylor (1990) pointed out that a typical problematic interaction with friends, involved social avoidance. Brabant, Forsyth, and McFarlain (1995) found that, in order to reduce the pain, anger, and social isolation resulting from lack of support, bereaved parents tried to teach family and friends how to give support. Several authors concluded that the form and consequences of any strain vary according to the nature of the relationship between the receiver and provider of potential support (Dakof & Taylor, 1990; Lehman, Ellard, & Wortman, 1986; Sarason et al., 1990). However, despite the huge amount of research carried out on social support and physical and mental health, there are still major gaps in our knowledge of the processes involved, particularly how, when, and *why* social relationships and support processes sometimes have unfavorable consequences.

A New Key to the Exploration of Unfavorable Social Support?

Although social support is conceptualized as a set of processes involving social interaction, it is often measured in quantitative terms, focusing on the presumed mediators of the processes (how many helpers, who do you have contact with, how often, how long, how personal, etc.). Hence, increased research attention should be directed towards the interactive processes between the providers and recipients of the social support essential for theory development (Albrecht & Adelman, 1987; Baxter & Montgomery, 1997; Sarason, Sarason, & Gurung, 1997).

To examine the nature of these processes, it seems necessary to explore in depth the elements of the communicative relationship between the receiver and provider of support. It is important to pursue the line of some researchers who propose that the concepts of social support and communicative competence have much in common (Hansson, Jones, & Carpenter, 1984; Sarason et al., 1986). This perspective highlights the understanding that meaning does not reside in the messages exchanged but in the perceptual processes of each participant (Sarason et al., 1990; Sarason et al., 1997). Thus, accepting the perspective that social support is fundamentally a relational communication process implies that social support must be explored as an interpersonal phenomenon. To achieve this, attention should be paid to the determinants of the microstructures influencing the communicative relationship relating to the loss.

A Relational Communicational Perspective

Some of the early researchers who have contributed to relational theory are Bateson (1972) and Watzlawick (Watzlawick, Beavin, & Jackson, 1967). Basic to the concept of relational communication is the notion that a message has "relational" and "content" components. While the latter refers to the content of a message, the former alludes to the relationship between the communicants (Millar & Rogers, 1976; Reusch & Bateson, 1951). Watzlawick and his co-workers (1967) hypothesized that the relationship aspects of communication are less evident in "healthy" relationships, while "sick" relationships ". . . are characterized by a constant struggle about the nature of the relationship, with the content aspect of communication becoming less and less important" (p. 232).

Especially important when it comes to the support and caring relationship is Watzlawick's assumption that: "If it is accepted that all behavior has message value, i.e., is communication, it follows that no matter how one may try, one cannot not communicate" (Watzlawick et al., 1967, pp. 48-49). Furthermore, this assumption implies that all encounters between social networks and survivors function as communication and, depending on the meaning created by the survivor, may be interpreted as supportive or as non-supportive.

"Meta-communication," i.e., communication about a communication," is another central and widely adopted concept within this tradition (Watzlawick et al., 1967). Whenever we communicate about how we communicate, we communicate at this level, and express the implicit or explicit rules of human interaction. The concepts elaborated by Watzlawick form the basis of Jacobsen/ Del Hymes' micro-sociological model of communication (Briggs, 1986), and have been employed in analyzing the interviewees' accounts in the present article. This model rests on a pragmatic perspective exploring the rules (or norms) which guide the formulation and interpretation of the messages that pass between human beings in a given socio-cultural context (Briggs, 1986).

As noted by Hymes (1971), the ability to communicate entails not only knowledge of syntax and semantics alone, but also communicative competence. Acquiring the latter involves knowing which expressions can be used in what circumstances to convey which meanings (Hymes, 1971). Being a relational concept, the term communicative competence also includes the ability to promote the communicative competence of others. The importance of the social roles, the social situation, and the type of communicative event pertaining to a given encounter are revealed in their joint role in defining the norms of interaction. In the encounter between the bereaved and the network, such norms will determine: Who is the helper supposed to support? What sort of support can/should be provided? How much can/should be said? What linguistic forms can/should be used? When and where is it expected or appropriate to give support? In a give situation, the network members, as well as the bereaved, will act according to their respective answers to these questions—if they have any clear answers.

METHOD

The following data is part of the larger quantitative and qualitative study entitled "the Support and Care study," which explores: a) the psychosocial situation of bereaved parents; b) the experiences of social network support, professional help, and self-care as reported by bereaved parents; c) the professional provisions for bereaved families as reported by local authorities; and d) the bereaved parents' experience of research participation. Mainly, the methodology underlying this article (one of the scopes of pt. b) is described in the following. For further details concerning methodology, see Dyregrov (2002) and Dyregrov et al. (2003).

Measurement

A qualitative research method was considered the most appropriate research method, and in-depth interviews the best technique to explore the inter-relational communicational processes that might facilitate or impede social network support (Kvale, 1996; Thoits, 1995). This method focuses on the generation or discovery of theory from systematically obtained and analyzed data. Ethnographic techniques were employed to explore recollections of the bereaved parents, tapping their "insiders' perspectives" through their descriptions rather than focusing on their explanations. Thus, it was important to allow the interviewees to generate their own stories, words, and images.

A theme guide was used, based on four themes, aimed at illuminating the survivors' experiences concerning: 1) quantitative dimensions of the support (sources of support, frequency, time perspective, etc.); 2) qualitative and relational dimensions of the support (particularly good or bad support, unhelpful support, lack of support, barriers for accepting support, etc.); 3) dimensions of ideal support (quantitatively and qualitatively); and 4) self-help strategies ("What has been the best self-help strategy to alleviate your situation?"). These themes were used as starting points for encouraging the survivors' narrative activity.

Participants

The sample comprised a total of 69 parents from 40 families, who had lost a child/young adult due to suicide (20), accident (10), or SIDS (10). The sample varied significantly with regard to the age of the survivors, the suicide group being the eldest ($M = 52.0$, $SD = 8.0$) followed by the accident group ($M = 40.0$, $SD = 8.5$); the SIDS parents ($M = 30.0$, $SD = 5.7$) were the youngest. The female/male ratio for the interview sample was 37/32. The families represented both rural (36) and urban (33) populations. With regard to the parents, their educational backgrounds ranged from secondary school (14), to college (35), and university (19). Sixty-six of the parents were married, while three were single. Fifty of the parents were employed (full or part time), while 19 were unemployed.

The parents had lived between 1 year and 55 years at their present place of residence ($M = 21$).

The parents psychosocial health was measured 6 and 23 months post loss (M = 14 months), and a majority revealed severe disturbances. Sixty-two percent of the interview sample scored above the cut-off score for a high level of psychosocial complaints (General Health Questionnaire), 59% experienced a high level of posttraumatic distress (Impact of Event Scale), and 72% scored above the cut-off level for complicated grief reactions (Inventory of Complicated Grief) (for more details, see Dyregrov et al., 2003). The mean age of the deceased in the interview sample was 21 years for suicide (range 11-28 years), 10 years (range 2-17 years) for accidents, and 2.2 months for SIDS (range 0-1 year).

Procedure

After a 1½ -year process of application, the Ministry of Law and Justice in Norway granted permission to undertake "the Support and Care study." They provided access to the names and addresses of bereaved families registered in the Norwegian police records (*Strasak*). The *Strasak* register contains all reported sudden deaths in Norway and is strictly confidential. Therefore, the Attorney General, the Council for Professional Secrecy and Research (UiO), the Medical Ethical Research Committee (UiB), and the Data Inspectorate of Norway all had to grant their permission for the study. This was the first time exemption had been granted to allow the use of this register for research.

The interviewees constitute a sub-sample selected from a larger sample of all the families bereaved due to suicide (162) and SIDS/child accidents (132) in Norway between August 1, 1997 and December 31, 1998. One hundred and fifty-five families (53%) participated in the first quantitative part of the study, and 95% of these families agreed to participate in in-depth interviews; 40 of these families were selected for in-depth interviews. The interview sample was defined as a theoretical sample; the criterion for selection was variety since the aim was to reveal the diversity of the survivors' experiences. After having sorted the families according to all available background variables in a matrix, four families were selected from each of the 10 postal regions in the country, thereby ensuring diversity (see participants).

The families participating in the larger study were contacted by letter in April 1999 and the interviews took place in the autumn of 1999. Trained researchers (a sociologist and a psychologist) conducted the interviews in the homes of the survivors between 9 and 27 months after the deaths (M = 19). Every interview was conducted in a relaxed, informal atmosphere, accompanied by a light meal prepared spontaneously by the bereaved families. The in-depth interviews lasted approximately 2.5 hours per person/couple (range = 1.5 - 4 hours). Twenty-nine interviews were conducted with both parents together, while eleven interviews were conducted with a single parent present.

Every stage of the research process was carried out in a very sensitive and careful manner, showing deep respect for the very difficult period the families had been through. The families were thoroughly informed by letter about the purpose of the project, as well as the principles of anonymity and confidentiality involved; they were offered telephone contact with the researcher, and were informed of their right to withdraw from the study at any time. They replied to this inquiry in a stamped addressed envelope, giving their written consent or informing the project group that they were unable to participate.

Analysis

The analysis followed the five-step phenomenologically-based meaning condensation procedure suggested by Giorgi (1975) and later by Kvale (1996). The first step required that, after the interviews had been conducted, tape-recorded, and transcribed by the researchers, the whole interview was read through to get a sense of the whole. Then, phrases or sentences ("meaning units") that directly pertained to the phenomenon under investigation were extracted from the transcribed interviews. Third, the themes that dominated the natural meaning units were stated as simply as possible, as these were understood by the researcher. The fourth step consisted of interrogating the meaning units in terms of the specific purpose of the study. Thus, the meanings expressed by the parents regarding their experiences with social network support were condensed into increasingly essential categories and meaningful themes. Repeated evidence of similar experiences across the interviews resulted in the identification of major concepts and themes. In the final step, the essential themes from all the interviews were linked together into descriptive statements of the core components of the phenomenon (Kvale, 1996). The condensed data was then analyzed employing meaning interpretation procedures in order to fulfill the third aim of this study. This allowed a deeper and more extensive interpretation of the data, in which the researcher sought the meanings behind or beneath what was said directly, in order to work out the structures and relations of meaning not immediately apparent in the text (Kvale, 1996).

Ecological Validity

In line with the notion that meaning is interactionally produced, this study has viewed the interviewee and the interviewer as being influenced by the same communicational components. Hence, some comments will be made on the ecological validity of the study, with regard to the effect of the researcher's presence and procedures on the narratives of the research subjects (Silverman, 1987). In order to reduce the influence of the researcher's way of thinking upon the interviewees, the decision was made to employ qualitative open interviews and the strategy of letting the interviewees direct the sequence of the

interview themes according to their own associations (Briggs, 1986). Being aware of the fact that the interview would constitute a significant channel through which the survivors could give meaning to their experiences, the researchers tried to develop an empathic listening mode which would catch the nuances and layers of meaning in what the interviewees told them (Kvale, 1996). The interview is a unique communicative event, involving negotiation between roles and frames of references. Efforts were therefore made to inform the survivors thoroughly about the type of interview, as well as about the researcher's role and background. The interviewees defined the social context themselves, by choosing to be interviewed in their own homes, while the interactional goal of the encounter was defined by both parties: a shared wish to throw light upon the situation of the survivors. A later study conducted in order to evaluate the interviews (Dyregrov, 2004) revealed that the survivors felt that they had benefited greatly from the experience, which they claimed had furthered their grief work. This feedback is valuable in the evaluation of the ecological validity of this study. Moreover, three survivors commented on the results and were strongly supportive of the conclusions that were drawn from the data.

RESULTS

The survivors appreciated most of the overwhelming support they received from their social networks, i.e., family, friends, acquaintances, work colleagues, and neighbors. Close friends and family came to comfort them at home; they brought food, wanted to help them with the housework, or took them out for a walk. Many survivors received warm letters, poems, or books. Most appreciated was the support provided by the network members who contacted them in their own homes. Here, the survivors felt freer to express whether they had the energy to see the visitors or not, and these encounters turned out better than when the survivors and network members met accidentally in public. It was noteworthy that the most appropriate and helpful responses were provided by network members who had themselves experienced a sudden unexpected death, or who had previously offered support to survivors.

However, despite all the positive experiences, they also had negative encounters with network members. Our findings were consistent with a study of Dakof and Taylor (1990) which indicated that what survivors defined as "ideal support" was a reiteration of what had been experienced as "helpful support," whereas "wished-for responses" were the mirror image of the "unhelpful/lacking support." Only the latter is focused in this article. The majority of the survivors in this study experienced what is termed "social ineptitude" from family, friends, neighbors, and co-workers. To cope with this social ineptitude, the survivors stressed the importance of what they called "openness."

Social Ineptitude

Social ineptitude refers to the difficulty a social network encounters in responding to and supporting those bereaved by sudden, traumatic deaths in a manner that is appreciated by the bereaved. A father expressed this as a bilateral problem after the suicide of his 14-year old son: "People learn to handle most situations in life, but when sudden and traumatic deaths occur, we ourselves, as well as the social networks, discover that we are completely inept at handling the situation."

The survivors gave numerous examples of the negative impact certain acts or utterances on the part of people in their social networks had had on them. Three dimensions of social ineptitude emerged: 1) anticipated support fails to appear (non-communication); 2) people suddenly withdraw from the bereaved (abrupt communication); and 3) unhelpful advice and support is offered (unsuccessful communication). Although there were some differences between the groups of bereaved as to how and to what degree they experienced this social ineptitude, the similarities were far greater than the differences. Thus, mainly the similarities will be focused in this article.

Anticipated support that fails to appear was exemplified by many stories in which family members or good friends were expected to support the survivors, but did not do so. When the survivors finally managed to contact these network members, they often heard: "We have been thinking so much of you," "We wanted so much to go and see you," etc. However, as remarked by the survivors themselves: "It does not help the grieving person at all if someone sympathize with them, so long as they are not aware of it." According to the survivors, it hurt even more when network members tried to excuse their absence by claiming to have been "so busy," "having had to work so much lately," etc. The absence of support from the workplace was noted by approximately one-third of the bereaved, as exemplified by a mother who lost her child in an accident: "None of the managers offered their condolences or mentioned the tragedy at all."

When *people withdrew from the bereaved,* it was both physically and in conversation. Nearly all the survivors told stories about members in their inner or outer networks who had changed direction, crossed the street, or looked another way when they had caught sight of the bereaved person. A mother who had lost her 15-year-old son due to suicide, exemplified this by saying: "The first time I met a close colleague after the death of my child he was sitting right across the table but turned away from me and conversed intensely with the guy next to him. Then he left the room without even saying goodbye to me—that had never happened before."

Another very common way for network members to withdraw social support was through conversational avoidance. Survivors gave a lot of examples in which network members had avoided talking about anything associated with death in

general or about that particular death, or they did not refer to the deceased by name in the conversation. One mother described this: "It really hurts my feelings when people seem to have burnt their lips and swallowed their tongue when they accidentally articulate his name." Some network members frenetically talked about anything but what had happened and the situation of the survivor. A father said: "It is so offensive when a person talks about everything except my dead boy, if I have expected to talk about him with that person. Such a conversation is completely meaningless to me." Survivors stressed that their wish to inform others about their present situation or to include the dead child in normal conversation did not imply that this was the only topic they were capable of talking about. However, they stated that a conversation about the tragedy seemed to them to be an important presupposition for the normalization of social interactions. A father said: "It is annoying to socialize with people who know what happened, and know that we know, without us being able to talk about it. By talking it over, we will establish a common basis, and then we can go on to everyday matters."

As reported by the survivors, this avoidance behavior on the part of network members was more frequent when the encounter took place outside the survivor's private home, e.g., in a shop, at a work place, at the funeral, or in a public place. They claimed that meeting network members at home facilitated closeness because there was more time and they themselves were in charge of the agenda.

There were numerous examples of *advice and support that was unhelpful* to the survivors, which had probably been thought helpful by network members. The survivors described a lot of "well-meant advice," thoughtless or even wicked remarks, and imprudent actions. A frequent comment made by the survivors regarding such well-intended advice from people, who had never experienced anything like this themselves, was: "They tried to help, but it went wrong." The advice offered was often not only poor, but also considered inappropriate, when given without any signs of empathy or respect. A mother, who had lost her 20-year-old son due to suicide, and who insisted on grieving in her own way and at her own pace, had the following comment to offer on the networks' tendency to give advice: "Immediately after his death I was at the graveyard every day, because it was important to me. Many people told me that I should not go there so often; it was not good for me. I think that advice mainly came up because it hurt them to see me there and they could not handle being confronted with their own death and grief." For this mother, the grave, the belongings, the mementos, and the memories of her son were important as a means to proceed with the grieving process. Parents stressed that nobody should give advice or proclaim themself to be an expert on the right or wrong ways of grieving. A mother who had lost her baby due to SIDS put this into words: "Nobody can ever get inside my mind and experience how dreadful this situation is. So, nobody can tell me what is right or wrong." A couple of survivors pointed out that it is important for the network to receive clear signals and messages from the bereaved in order to understand and respect that individual's way of grieving.

The survivors felt that although most network members wanted to be supportive, they often made thoughtless remarks such as: "Well, the grief will disappear after a while; There is a meaning in everything; As you had all the problems with your boy, this must also be a relief; Fortunately you have the other children left," etc. Some of the utterances gave rise to long-term frustrations and could never be forgotten. One such example is the mother who had lost her 19-year-old son due to suicide and her old aunt tried to comfort her by saying: "I believe that Sam is with God too, because God does not discriminate between people."

Inconsiderate and imprudent actions are the last form of unhelpful support included in the concept of social ineptitude. These were generally the actions of strangers who had experienced the loss of a child themselves and wanted to help. Although few survivors had actually had the privacy of their homes invaded by complete strangers, such episodes could be a great strain. Not all of those who have been bereaved managed the delicate balance between comforting and being comforted. One father who had lost his daughter in an accident described such an experience: "I was extremely angry. I felt that we were being burdened with her problems on top of our own." The strangers who appeared at the door of a non-religious family who had lost their son due to suicide and wanted to read from the Bible, exemplifies another form of imprudent action.

Taking the Supporters' Point of View

Despite the pain experienced as a result of the social ineptitude of network members as well as strangers, most of the survivors spontaneously commented that they sympathized with many of the dilemmas and difficulties facing their social networks. They understood perfectly that it was difficult for others to contact them and to know what to say. The survivors realized, either at the time or later, that helpers' painful remarks were the result of an inability to offer helpful support, rather than indifference. So, although they were hurt, they excused the providers to a large degree. One father expressed this sympathy when he said: "Although it hurts badly, I can very well understand those who are avoiding us. People cross the street. I might have done it myself because—what could we talk about?"

Even though many survivors stated that they would probably have reacted in the same helpless way before their own experience, they had now learned a lesson they would remember for life. They had learned the importance of receiving support and care from those in their surroundings, and they had experienced the pain when people avoided them. Second, they insisted that they felt better able to support others who experienced a crisis than before their own tragedy. A father claimed that this competence was lacking in his generation, basing his arguments on his upbringing: "I remember that we, the children, were given money to go to the cinema when my grandparents died. We were not supposed

to talk about it. Of course, such an upbringing has a lasting effect." This reflected the way of thinking at that time; that it was better to kill the problems by silence rather than let them grow by talking about them.

Finally, survivors stated that it seems as if network members have problems both with the form (how) and the content (what) when communicating with bereaved people. A father who had lost his son due to SIDS pointed out one way to reduce social ineptitude: "If they had simply said that they had not been able to face us in our difficult situation, I would have understood." A couple of parents suggested that the public should be trained in how to support and interact with people who have experienced serious life-crises.

Survivors' Openness

A lot of strategies were mentioned when the survivors answered the question "What has been the best self-help strategy to alleviate your situation?" Besides self-help strategies that fall into categories such as physical activity, good eating habits, reading, getting information, listening to music, working, etc., the number one category is "openness." This term covered spontaneous statements from most of the survivors (81%) from all over the country who claimed that openness was their most important resource in dealing with unhelpful/lacking social support, hopelessness, and isolation. The term includes many linguistic nuances, such as frankness, honesty, and directness in interaction with others.

Three categories of openness emerged from the interviews, obviously covering the different needs of the survivors. The first category is labeled *telling the story.* The survivors described that the opportunity to tell network members about what had happened and about their personal experiences related to the event had an important therapeutic value. A mother who had lost her daughter in an accident said: "I have to articulate what I am thinking of all the time. If I can do that I feel much better afterwards. I have to talk, or else I will go crazy."

The second category of openness is called *informing others.* The survivors stressed the importance of informing their social networks about the event, to signal to network members that they were allowed to talk to them about what had happened. Such behavior caused reactions of relief among many network members who, when facing the bereaved, did not have to pretend to be ignorant of what had happened.

Furthermore, the survivors had found that by speaking frankly about the loss, and by mentioning the deceased by name, they made it easier for the network who then felt that they were allowed to talk about the tragedy and would receive signals indicating how to behave. A mother who had lost her son due to SIDS confirmed this by saying: "It is important to talk about what happened. It is better if you start talking yourself, because most people do not know what to say or how to behave." Another survivor stated: "When I pronounced his name and talked about him, my friends knew that I would not be embarrassed by them doing

the same." In addition, the survivors strongly believed that this strategy helped them to avoid rumors, by informing larger groups of people at their schools, workplaces, etc. Three of the families bereaved due to suicide made the cause of death public through the obituary in the newspaper. One of the families announced: "He chose to end his life."

The third category is labeled *clarifying own needs* and refers to survivors who explicitly told their network how to provide support. Although not always possible because of lack of energy, half of the interviewed families stressed the importance of being explicit regarding needs for support. They described active strategies of making contact with network members, initiating conversations about their loss, seeking support from others, inviting people to their homes, etc. A young mother who had lost a son due to SIDS stated: "I think it is very important to thank people for contacting us in a direct way. If this is impossible, signal in some way or other, that support is good for you." When the survivors gave families, friends, co-workers, and neighbors direct and honest feedback on their support efforts, the network could then meet their demands for support. Thus, the openness helped the network members overcome their social ineptitude. Especially, the survivors following a suicide stressed this. Some very resourceful parents had gone straight up to people who avoided them. They told them that they wished to talk about their loss and explained what kind of support would be helpful. A mother who had lost her 21-year-old son due to suicide pointed out that this attitude was not easy: "It is not easy to take the initiative, because you may actually risk rejection and suffer another disappointment. Once I felt that a person was avoiding me out of fear and I decided that she had greater difficulties than me in dealing with the situation. Therefore, I made a detour just to meet her, and we were standing there talking for half an hour."

However, despite all the positive attitudes towards openness, there were also important indications that survivors might lack the energy or power to take the initiative or meet others with openness. As reported elsewhere in the study, this was the case among those who refused to participate (Dyregrov, 2002; Dyregrov et al., 2003). Other survivors encountered the problem that their network was not ready for the openness, and refused to address the topic despite the efforts of the survivor. Conflicts within networks or communication problems within the bereaved family were pointed to as barriers to openness.

Finally, survivors of suicide advocated openness even more strongly than the parents bereaved by SIDS and accidents, often linking the need for openness with the stigmatization of suicide. Many survivors of suicide experienced controversies related to the question of openness and honesty, and many disagreed about this within the same family. However, survivors who had been skeptical, but had given in to their spouses' belief in openness, were very positive when they realized the benefits of this strategy.

DISCUSSION

The data from the in-depth interviews confirms earlier research, which revealed that survivors felt that certain aspects of social network support was unhelpful or even harmful (Brabant et al., 1995; Dakof & Taylor, 1990; Lehman et al., 1986; Rönnmark, 1999; Thoits, 1995). According to the accounts of the traumatic bereaved, the networks seem to be very insecure about how to express their empathy when facing the bereaved. Few norms exist that can serve as a guide to the social network regarding how to support parents in this difficult situation. Thus, the survivors seem to be right when assuming that "the social ineptitude" of network members seems to be caused by an inability to offer helpful support, and not by indifference. Resourceful survivors have found that expressions of "openness" are the best ways to reduce the social ineptitude as well as their own feeling of insecurity in the encounters. In this way, the receivers and the providers of social support influence each other in reducing the uncertainty about the situation, each other, and the relationship (Albrecht & Adelman, 1987). Being able to talk about what happened, how they feel, and how they want to be helped, means that the bereaved receive more appropriate support and the social networks learn to deal with grief and support the bereaved after tragic events. This pinpoints the importance of seeing social support as a joint accomplishment.

The "openness" of the survivors obviously promotes communicative competence among social network members. As also noted by Brabant et al. (1995), the survivors "teach" their insecure social network how to offer support through communication and meta-communication. In this way, the survivors create a common frame of reference by actively informing network members about what has happened, and allowing or inviting them to provide support. This study also supports earlier findings which indicate that when survivors communicate their appreciation of a particular action either explicitly or implicitly, network members will increase the frequency of such actions. The opposite is also true, and when they communicate that an action is very unhelpful, this will minimize the likelihood of a repeat occurrence (Dakof & Taylor, 1990). Therefore, the "openness" through which the survivors communicate the basic "rules" for communication in order to gain better support, must be seen as an empowering self-help strategy. However, the success of the strategy will always be related to social, situational, and cultural factors and premises.

Micro Dynamics of the Unhelpful or Lacking Responses

To grasp the dynamics at work in encounters between network supporters and bereaved on a micro-level, concepts introduced by Del Hymes' (Briggs, 1986) have been adapted to a working model (see Figure 1).

Several of the basic components in the communication model play a dominant role in defining the major communicative function of these encounters. In the

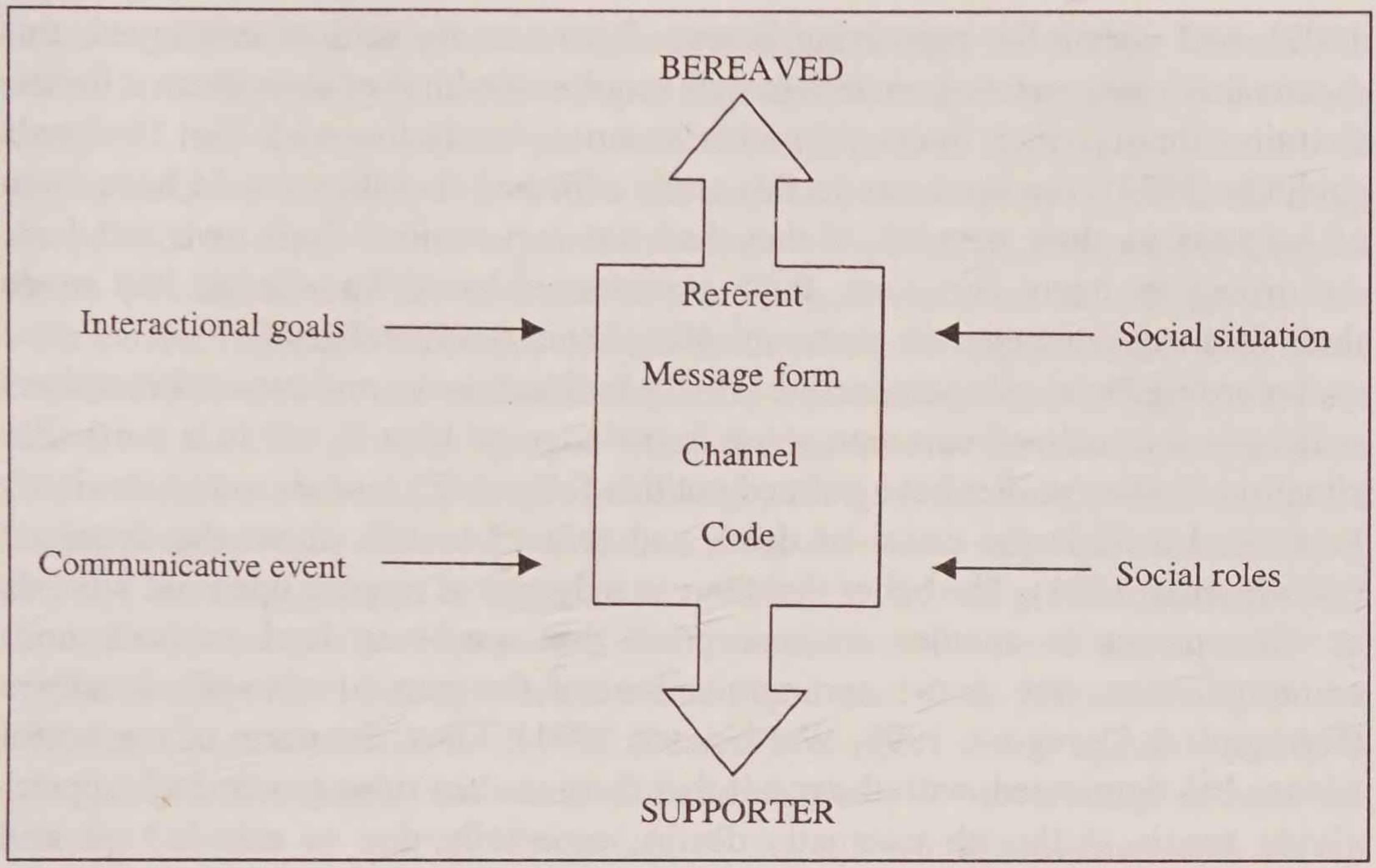

Figure 1. A micro-sociologic model of the communication of social support. (Social roles: assumed roles between the parts; Interactional goals: motivation for engaging in the encounter; Social situation: context for the encounter; Type of communicative event: category of social event; Message form: auditory and visual signals; Referent: semantic content; Channel: visual/acoustic or psychological circuits; Code: linguistic or nonverbal.)

following, each of the components is examined in terms of its role in shaping the meaning of what is said by both parties.

Supporting a bereaved person who has lost a child by traumatic death is an uncommon category of communicative events in any society. Since this kind of *communicative event* constitutes a critical, unusual, and uncertain situation for all parties concerned, common norms of interaction will be challenged. The parents' accounts indicate that network members and survivors often do not share a common interpretation of the "frame" for communicating following traumatic deaths. As pointed out by Bateson (1972), a frame constitutes the external conditions of the situation within which the context develops, and thus the frame will tell the interacting persons how to define the situation and thereby guide their production of meaning and actions. As also suggested by others, withdrawal and non-communication by the network members or the survivors is most likely due to the fact that they lack norms for interaction and canons for interpretation of that particular communicative event (Van Dongen, 1993). Since the child learns communicative forms within the socio-cultural contexts they live in (Bateson,

1972), and norms for supporting bereaved parents are seldom employed, this means that many network members will acquire this kind of competence for the first time through their interaction with the survivors. In line with Van Dongen's findings (1993), the survivors in this study affirmed that they would have been as helpless as their network if they had not experienced their own sad loss. According to many survivors, their experienced-based knowledge had made them far more competent in communicating about death and grief.

According Bateson's perspective (1972), both survivors and network members will have internalized common-sense knowledge of how to act in a particular situation. Earlier studies have pointed out that following a suicide many survivors have tried to hide the cause of death and refused to talk about the deceased (Wertheimer, 1991). The belief that there is a danger of ripping open old wounds as time passes is another misconception that seems to lead to both non-communication and abrupt communication on the part of network members (Dyregrov & Dyregrov, 1999; Wertheimer, 1991). Thus, the norm of respectful silence has dominated, with the result that there are not rules governing support-giving praxis. Although traumatic deaths, especially due to suicide, are still considered a highly private concern, there are signs that this is changing in Norway. As seen in other parts of this study, increased public knowledge of crisis psychology (Dyregrov, 2002) combined with trends towards openness about stigmatized topics, are gradually providing basic norms to regulate how to approach bereaved populations. At the same time as bereaved groups are increasingly turning to crisis psychology to fight their isolation and taking the initiative to change their adverse life-situations, there is also an official trend encouraging greater acceptance of psychological problems and diseases and placing these on the same footing as physical problems. These shifts are probably important steps in the redefinition of this particular communicative event.

The interactional goals, or the motivation of each of the participants for engaging in the encounter (Briggs, 1986), are evidently asymmetrical in this study. While most survivors express the need to talk about what has happened, many network members seem to want to flee the scene due to feelings of insecurity or fear of facing the grieving parents. The latter reaction is consistent with the findings of other studies, which show that social networks avoid confronting death in general and especially the death of a child (Lehman et al., 1986; Rönnmark, 1999).

Generally, when people are in familiar situations, they have clear implicit or explicit goals for the communication, and know what the encounter will lead to. This may explain why most of the network members who had experienced or supported others following a sudden unexpected death were more likely to offer support that matched the emotional and practical needs of the survivors (Thoits, 1995; Thuen, 1995; Van Dongen, 1993).

When the survivors made an effort to approach the network members, they were motivated by a strong wish to share and discuss their adverse life-situation with

their "significant others," i.e., those network members who they themselves defined as the closest. Studies have shown that active support by network members may be motivated by an interactional goal of expressing concern or giving information, whereas withdrawal may be a result of a fear of confronting the pain of others, a desire to minimize one's own anxiety, or a need to avoid a threat (Goldsmith, 1992; Lehman et al., 1986; Sarason et al., 1990). In line with earlier research, survivors of suicide in particular reported that they were concerned about the motives that caused some network members to approach them (Dunne et al., 1987; Van Dongen, 1993), and experienced more extreme responses from network members (Thompson & Range, 1992). Moreover, several survivors in the present study also express concern about how to approach the network. Finally, as social support is a joint accomplishment, it is of great importance that the interactional goals of the parties in the communicative event correspond.

The social roles that network members and survivors are assuming in the encounter have a profound effect on the sort of support that is signaled and how this is read. Consistent with earlier research, the role uncertainty of network members seems to account for much of the non-communication and abrupt communication seen in this study (Van Dongen, 1993; Wagner & Calhoun, 1991-1992). The survivors and the network members apparently defined their relationship in terms of different degrees of closeness. Thus, when the survivors in this study felt that they were not receiving support from a person they considered to be a close friend, the friend might define the relationship as less close, implying that the role would involve no obligations as a social supporter provider. The reason why close family members or friends also redefine the "rules" for providing support may reflect the fact that they are personally affected by the tragedy and the provision of support may threaten the survival of the system upon which their own social selves depends (Brabant et al., 1995; Lehman et al., 1986). This reveals the importance of seeing social roles as situational constructions and of bearing in mind that both survivors and network members are moving between a number of different social roles.

If the social roles of network members and bereaved have been characterized by an asymmetric (inferior-superior) relationship before the death, this may influence which partner takes the initiative following the loss. Thus, anticipated support that fails to appear, for example from employers, may sometimes be explained in terms of such mechanisms.

The social situation in which the interaction takes place may be crucial in determining how an encounter between survivors and network will proceed. As seen in the study, communication differs according to whether it takes place in a shop, in a work place, at the funeral, or in a public place, rather than in the survivor's private home. As reported by the survivors, when a lot of time is available, and fewer outsiders and distractions are present, the interaction between themselves and network members improves. These factors, which define the social situation, seem to be closely linked to a general fear people experience when

they feel that they lack control of the message form, code, and channels for expressing support in adverse life situations (Dakof & Taylor, 1990).

The message form consists of the auditory and visual communication signals that serve as sign vehicles in the communication between the survivor and network supporter (Briggs, 1986). Insofar as network members had tried to support the survivors, they had many problems in deciding what signs to convey to the bereaved. The tone or manner in which the support was provided was not always understood by the survivors, not least because the semantic content was often subtle and followed by nonverbal markers. Lehman and his co-workers (1986) found that many potential caregivers knew what they would *want* to say, but feared that it would not come out the right way. The interaction may be complicated still further by the fact that many survivors felt that their message was vague, because they did not want to demand too much from the network or be too disappointed if they were avoided. On the other hand, as noted by Dakof and Taylor (1990), when survivors communicated their appreciation in an explicit or implicit form, the network members increased the frequency of actions that were helpful.

Generally, all forms of communication have to be conveyed through visual or acoustic (physical or psychological) *channels* between participants. Whereas some messages can only be transmitted nonverbally, others may combine a minimally essential nonverbal component with verbal elaboration (Briggs, 1986). In this study, social support was communicated via many channels, such as face-to-face, by letter or telephone, through a poem, or by a dinner brought to the survivors' front door. The survivors stressed that network members should prioritize the nonverbal channels by just listening, instead of trying to give "good advice" that often turned out to be unhelpful or harmful. As such, the verbal components in the communication between survivor and network member showed distinct inadequacies.

Finally, both parties in an encounter must share the necessary *codes* in order to permit the encoding and interpretation of messages (Briggs, 1986; Hymes, 1971). The network members displayed a basic lack of certainty with respect to what code to use in this encounter in order to convey empathy to the survivors of traumatic deaths. While the survivors expressed a wish for shared feelings and closeness, many were met with cognitive and intellectual communication codes. All the inappropriate advice meant to be supportive may serve to support the assumption that it is even more difficult to express emotions and feelings than words (Briggs, 1986). When the body language of a network member showed less proximity than expected by the survivors, the latter felt they were being avoided and abandoned. Finally, the survivors' negative reaction to anticipated support that failed to appear, confirms Watzlawicks' (1967) notion that it is not possible *not* to communicate, because avoidance is also a code for communication.

Despite the relational perspective, the focus of this study has been more on the deficiencies of the social network than on those of the survivors. The argument for

this is that if supportive communication is to be a support, it must rest on the premises of the recipient and satisfy their needs. Moreover, we cannot discuss the experiences of the network members, since they have not been interviewed in the present study.

CONCLUSIONS

There seems to be few clear-cut norms guiding the social support-giving process between social networks and bereaved parents who have lost a child under tragic circumstances. Besides the norm of respectful silence (because some still believe that it is harmful to talk about death), there seem to be few rules governing the kinds of support to be given. Because suicide, accidents, and SIDS are fairly rare events, people are unsure of what to say and do to be supportive. Hence, it falls on the bereaved to tell their supporters what assistance they need and to signal that it is okay to talk about the deceased. This interplay has been analyzed through two main concepts, those of openness and social ineptitude, and micro-sociological communicational concepts have been employed in the discussion.

The concepts of "openness" and "social ineptitude" emerged from the bereaved parents' accounts of their encounters with their social networks. While social ineptitude refers to the networks' unhelpfulness or lack of support, openness relates to the survivors' efforts to inform their network about their situation and how they wish to be supported. As has been pointed out, many problems in this encounter are rooted in an apparently heterogeneous interpretation of the various components, which have been discussed under the headings social situation, social roles, interactional goals, communicative event, message form, etc. The way in which survivors and network members interpret these components is based on previous personal experience. Thus, heightened communicative competence in the widest sense is an important prerequisite for improved social support for bereaved populations. Overall, the survivors claim that communication about these communicative components will make it easier for the network to provide helpful support and thereby improve their situation. Hence, it is necessary to improve people's communicative competence in adverse life situations in order to improve social support for bereaved populations. Community based intervention programs for bereaved populations should include suggestions for improved network support. Future research could follow up on the accounts of the survivors in this study by approaching their social networks to obtain *their* accounts.

ACKNOWLEDGMENTS

The author acknowledges D. Nordanger for project participation and A. Dyregrov, P. Måseide, and O. Hellesøy for their comments on a draft of the manuscript.

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OMEGA, Vol. 48(1) 45-67, 2003-2004

GRIEVING, MOURNING, AND HEALING FOLLOWING YOUTH SUICIDE: A FOCUS ON HEALTH AND WELL BEING IN FAMILIES*

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ABSTRACT

Within the context of their grieving families, this grounded theory study explored survivors' experiences of healing following youth suicide. The major theme developed in this study, *Journeying Toward Wholeness*, is conceptualized as a process involving the inter-relationships among three sub-themes: *Grieving in Response to Youth Suicide*, *Mourning in Response to Youth Suicide*, and *Healing in Response to Youth Suicide*. Initially, grieving, mourning, and healing occur within individual and family realms. Theoretically congruent with systems theory, this mid-range grounded theory suggests that grieving, mourning, and healing are embedded within a broader social context. This theory purports that grieving, mourning, and healing are related, dynamic, and seamless processes influencing each person's journey toward wholeness following youth suicide. This theory supplements the basis of holistic practice, directs us to accept a broad range of survivors' expressions of movement towards wholeness and health, stresses the importance of working with survivors' stories, and encourages us in relational practice.

The increase in the incidence of youth suicide in recent years is a complex and disturbing fact of contemporary society. Despite an increase in the number of

*This research study was funded by The Alberta Association of Registered Nurses and The Regional Center for Health Promotion and Community Studies, University of Lethbridge, Lethbridge, Alberta.

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suicide prevention programs, youth suicide has been identified as a compelling global and national public and mental health problem of epidemic proportion (Leenaars et al., 1998). The short- and long-term health and human consequences associated with youth suicide are enormous, affecting each family survivor, the family as a unit, the community, and ultimately, society.

Youth suicide has its greatest impact on family members. The death of a youth due to suicide may represent many things to family survivors—the loss of a child, the loss of one's hopes and dreams, the loss of a shared future, and the loss of part of oneself. In the midst of tremendous upheaval, survivors of youth suicide (hereafter referred to as survivors) are often left on their own to cope. Indeed, survivors are challenged in terms of creating wholeness in their lives at a time when their realities have been shattered.

The grounded theory generated in this study, focused on family survivors' healing experiences following youth suicide, suggests that *Journeying Toward Wholeness* is facilitated by the inter-relationships among: *Grieving in Response to Youth Suicide*, *Mourning in Response to Youth Suicide*, and *Healing in Response to Youth Suicide*. The theory that was developed from the data illustrates that grieving, mourning, and healing are related, dynamic, and seamless processes influencing survivors' journeys toward wholeness. This article first locates this work in the related research, describes our conceptualization of survivors' experiences, and finally extrapolates applications for practice with families that are dealing with youth suicide.

RELEVANT LITERATURE

The scientific study of the *grieving* process spans more than three decades. According to Kagawa-Singer (1998), grief is the affective or emotional response caused by significant real or perceived loss, such as loss due to death. Early theorists, on the one hand, recognized the multi-dimensional and individualized nature of grieving. However, grieving was viewed as a linear process involving a series of stages or phases (Averill, 1968; Kübler-Ross, 1969; Martocchio, 1985; Parkes, 1970), characterized by a number of grieving-related tasks (Burnell & Burnell, 1989; Haig, 1990; Rando, 1995; Steen, 1998; Walsh & McGoldrick, 1991; Worden, 1982), often occurring over a prescribed time period. Contemporary theorists, on the other hand, argue that grieving is a dynamic rather than static phenomenon influenced by a number of contextual variables (Arnold, 1996; Copp, 1998; Cowles & Rodgers, 1991; Doyle, 1994; Stroebe, Van Den Bout, & Schut, 1994), and as such, is "inextricable from our sense of who we are" (Neimeyer, Keesee, & Fortner, 2000, p. 204). Anchored within the rich context of relationships, Noppe (2000) presents a developmental model that integrates attachment theory and cognitive development theory. A number of researchers and theorists now claim that during the course of their lives, survivors maintain healthy

and continuing bonds with deceased individuals (Attig, 1996; Klass, Silverman, & Nickman, 1996; Marwit & Klass, 1996; Rosenblatt, 1996).

Neimeyer (1998, 2000, 2001a, 2001b) contends that grieving is a process of reconstructing a world of meaning that has been challenged by loss. Neimeyer, Keesee, and Fortner (2000) recognize "the idiosyncratic nature of grief" (p. 197) and the highly individualized meanings that survivors attach to their grieving experiences. Moreover, these authors maintain that adjustment to loss can only be understood within the broader social context; they "envision 'grief work' as being done at the level of three interdependent and nested systems, corresponding to the self, family, and broader society, respectively" (p. 209). In fact, Neimeyer (2001a) argues that an expanded conception of meaning is necessary to provide a stronger basis for clinical intervention.

Mourning refers to the social customs and cultural preferences that are practiced following a death (Kagawa-Singer, 1998). While death itself is universal, the meaning of death and the way it is mourned varies among cultures. Persons in most cultural groups assert that grieving does not end. Mourning involves the ways in which we come to live with the loss, and how we search for, and integrate meaning related to, the loss within our lives (Marrone, 1997). Attig (1996) maintains that mourners have to relearn how to live in a world without the physical presence of the deceased person. As an adaptive measure, specific family and community rituals often serve to express grieving and mourning, thus easing the pain of loss.

According to Marrone (1999), the specific ways in which people discover meaning while mourning may be less important than the process of re-ascribing meaning. In uncomplicated mourning, this process typically involves: cognitive re-structuring, emotional expression, psychological reintegration, and psycho-spiritual transformation (Marrone 1997, 1999). Sabar (2000) offers a gestalt perspective specific to the tasks of mourning including: accepting the reality of the loss, experiencing the pain of grief, adjusting to the environment without the presence of the deceased person, and withdrawing emotional energy and reinvesting it in another relationship.

In recent years, theorists have begun to consider existential change, religious conversion, or psycho-spiritual transformation as important aspects of the mourning process for some persons (Marrone, 1999). Edwards (1997), for example, points out that the Zen Buddhist tradition is characterized by meditation and instructional practices that have strong connections to the grieving process. Interestingly, a connection between grieving, mourning, and healing has been documented in the literature. Grieving and mourning have been viewed as healing and adaptive processes integral to psychotherapy (Olders, 1989).

In contrast, the scientific study of *healing* has occurred only in recent years. This "healing consciousness" (Achterberg, 1990, p. 187) was born out of the perceived limitations of the biomedical model, and a recognition of current health promotion models that emphasize human potential, holism, and the triadic nature of humankind (i.e., body-mind-spirit) (Achterberg, 1990; Ferguson, 1980; Myss,

1996, 1997; Watson, 1999; Young, 2002). Although the scientific study of healing is a relatively recent phenomenon, healing has been studied with respect to adult male survivors of childhood sexual abuse (Burke Draucker & Petrovic, 1996), breast cancer survivors (Predeger, 1996), survivors of parent or sibling suicide (Demi & Howell, 1991), and survivors of suicide (Smolin & Guinan, 1993).

Dombeck (1995) defines healing as the process of re-establishing health and well being following some type of trauma. Healing, she maintains, is an active and internal process that includes investigating attitudes, memories, and beliefs with the desire to release oneself of all negative patterns that prevent full emotional and spiritual recovery. This internal review inevitably leads the person to recreate his or her life in ways that serves to activate the will—the will to see and accept life truths, and the will to begin to use energy for the creation of love, self-esteem, and health. According to Dombeck (1995), "Whatever the degree of trauma, the pathways to healing involve a symbolic awakening, a receptivity or hospitality to new learnings, and a commitment to intentionally tend to the practical activities of healing" (p. 60).

In *James's Will-To-Believe Doctrine* authored by Wernham in 1987, William James claims that humans are purposive in their actions and actively involved in the affairs of their lives. Further, he maintains that there are some life situations (e.g., youth suicide) that must be understood and addressed from a subjective standpoint. James argues that "there are occasions where it is more reasonable for a person to follow emotional or spiritual reasons for holding a belief—for the sake of fulfilling his hopes, desires, aims, needs, and the like than it is to believe on more narrowly 'rational' grounds" (Suckiel, 1982, p. 9). James maintains that even in situations where one is faced with inadequate evidence to support a particular belief, that it is not only prudent but it is necessary to believe in a certain way (Suckiel, 1982; Wernham, 1987). In such situations, the beneficial effects of believing contribute greatly to the believer's sense of health and well being. For instance, by believing that, despite great adversity, life is worth living, family members may be prompted to transcend their difficult circumstances and achieve their goals and dreams in life. In effect, believing can be justified solely on the basis of its practical consequences (Suckiel, 1982). Moreover, believing has the potential to become self-verifying (Suckiel, 1982; Wernham, 1987), supporting the view that "faith is necessary for the fact" (Suckiel, 1982, p. 78). Extending this thinking, believing, in fact, may play an important role in the process of healing; that is, holding a belief that healing is possible is a likely forerunner of experiencing healing.

Healing is synonymous with releasing inner pain, establishing new meaning, restoring integration, and emerging into a sense of renewed wholeness (Dombeck, 1995; Myss, 1996, 1997). Frankl (1984) extends this understanding, maintaining that healing involves finding meaning in suffering. Congruent with Aboriginal philosophy, healing, according to Katz and St. Denis (1991), is viewed as a "transition toward meaning, wholeness, connectedness, and balance"

(p. 24). Most of the aforementioned work focuses on individuals' reactions to and journeys of personal loss; rarely are family-level processes or applications addressed, or the roles of family relationships examined in terms of the mutual impact of individual grief, mourning and healing processes on those of the whole family.

Death by Suicide

Undoubtedly, death by suicide is a traumatic event; Judith Herman (1992) describes the impact of traumatic events this way:

> Traumatic events overwhelm the ordinary systems of care that give people a sense of control, connection, and meaning. Traumatic events are extraordinary, not because they occur rarely, but because they overwhelm the ordinary human adaptations to life. . . . They confront human beings with the extremities of helplessness and terror and evoke the responses of catastrophe (p. 33).

Catastrophic loss as a result of suicide poses specific problems for survivors (Jordan, 2001; Provini, Everett, & Pfeffer, 2000). Silverman, Range, and Overholster (1994-95) suggest that survivors experience unique grief responses and, in some cases, may be unable to fully deal with their grief. According to several authors, grieving following suicide is more intense than from other causes of death (e.g., homicide, accidental death, natural anticipated death) (Bailley, Kral, & Dunham, 1999; Watson & Lee, 1993). Survivors also face the difficulty of constantly feeling the need to explain the reason(s) for their loved one's tragic demise (Range & Calhoun, 1990). These survivors are more likely to assume responsibility for a loved one's death and they frequently experience an increased fear of their own self-destructive impulses (Worden, 1982). Suicidal death may even draw the entire family into distress (Provini et al., 2000). For instance, the joint experience of suffering may render family members unable to provide much needed support to one another, ultimately leading to breakdown within the family unit (Vachon & Stylianos, 1988). Advancing this idea, Bradach and Jordan (1995) document the negative intergenerational impact of traumatic loss on the family as a whole.

Sudden, unexpected, and premature death, such as death by suicide, has a dramatic effect on grieving in that "premature death disrupts the normal cycle of events" (Martocchio, 1985, p. 334). Lehman, Wortman, and Williams (1987) found that sudden and traumatic loss of a loved person is associated with long-term distress. In particular, Vargas (1991) found four prominent characteristics in family survivors of sudden and unexpected death, specifically: a) depressive symptoms (most common); b) preservation of the deceased person; c) suicidal ideation; and d) anger directed toward the deceased person.

In comparison to all other types of death, survivors of suicide receive the least amount of community support (Range & Calhoun, 1990; Thompson & Range, 1992-93). This lack of support is often compounded by the perceived stigma surrounding suicide (Bailley et al., 1999). Related perceptions of bereaved family members suggest that friends will not "be there" to the same degree and in the same ways that they would following other types of deaths (Thornton, Whittemore, & Robertson, 1989).

From a societal perspective, this ever-growing segment of the population is often left to grieve, mourn, and heal within health care and social systems that provides minimal support and assistance. Not only are survivors grieving, mourning, and healing in relation to suicidal loss, they are also struggling to attain some sense of being whole once again. Within the context of their families, this study investigated this struggle from the perspectives of those who had lost a youth relative to suicide.

METHODS

This grounded theory research study was exploratory and descriptive in nature, and constitutes in part a secondary analysis (Clarke & Lossette, 2000; Sandelowski, 1997; Thorne, 1994). Based on a health promotion philosophy that embraces the strengths and resilient nature of grieving individuals and families (Young, 2002), the research questions that guided this inquiry were: "How do family survivors heal following youth suicide?" and "What is the relationship between grieving and healing?"

Participants

Study participants consisted of family survivors who voluntarily identified themselves as having had experience with healing following the suicide of a family youth, aged 10-19 years. Recruitment strategies included a newspaper article and network sampling (Polit, Beck, & Hungler, 2001; Strauss & Corbin, 1998). Eleven families located in rural communities (n = 8) and small urban centers (n = 3) in three western Canadian provinces participated in the study. The families ranged in size from 3 to 12 individuals. Most families (n = 10) were of Canadian origin, mostly of European descent; one family (n = 1) was Aboriginal. A total of 41 family members participated in the study.

In total, 44 interviews were conducted, including 33 individual and 11 family interviews. A little more than half of the participants were female (n = 26). Participants ranged in age from 6 to 80 years with a mean age of 37.8 ± 1.4 (SE) years. The average length of time since the suicide was 3.1 ± 1.4 (SE) years, ranging from 6 months to 12 years. Most suicides (n = 9) occurred within the four years just prior to the time of data collection. Two survivors from

Table 1. Sample Population Data

Family	Number of persons in family (including deceased)	Individual interviews	Family interviews	Total interviews	Gender and Age of suicide victim	Length of time since suicide (years)
001	9	5	2	7	M-19	2.5
002	4	6	2	8	M-14	2
003	7	6	1	7	M-19	12
004	4	2	1	3	M-14	6
005	8	2	1	3	M-16	2
006	4	2	1	3	M-19	2.5
007	4	2	0	2	M-24	1
008	5	1	1	2	M-19	.5
009	5	2	1	3	M-17	.5
010	4	3	1	4	M-16	1.5
011	6	2	0	2	M-29	4

two different families had previous experience with the suicide of a significant other.

All 11 persons who ended their lives were male. They took their own lives by hanging ($n = 5$), shooting ($n = 5$), and drowning ($n = 1$). Six individuals left suicide notes. Nine youth ranging in age from 14 to 19 years ended their lives; two other individuals were older (i.e., 29 and 24 years of age) (see Table 1).

Data Collection and Analysis

The study was conducted in comfortable and natural settings—the homes of family members who provided written informed consent. The primary method of data collection involved a minimum of one two-hour interview, conducted by the Principal Investigator (RGK), with each individual family member and the family unit whenever possible. Interviews were tape-recorded and verbatim transcripts were prepared.

Forty-four informal, semi-structured, in-depth interviews (Fontana & Frey, 1994) were conducted during an 18-month period. Textual data included verbatim transcripts, field notes, non-technical information shared by participants (e.g., poetry, photographs, letters, newspaper clippings, art work), and analytical notes prepared by the researcher during the research process. The theory derived

for this article is technically a secondary analysis because we re-visited the data (initially collected in 1997) to re-conceptualize *Journeying Toward Wholeness* (Thorne, 1994).

Initially, data collection and analysis occurred simultaneously. First, extending the experience of being with the participants when they were talking about their experiences with losing a youth in their families, the researcher read and reread the textual data to ensure a full grasp of the participants' views. Data were then manually coded in a line-by-line fashion to reveal all potential ideas within the data (open coding) (Strauss & Corbin, 1998). Employing Frank's (1995) idea of "thinking with stories," textual data were coded by using "meaning units" composed of words, phrases, or paragraphs that represented some meaningful viewpoint expressed by participants about their experiences following youth suicide, with particular reference to the relationship between grieving and healing. During secondary analysis, these processes were repeated, except that no new data were collected; therefore, the "constant comparison" of grounded theory became a comparison of "data bits" with one another (Strauss & Corbin, 1998). We hold that this analytical approach honors the wisdom within each story, and at the same time preserves each participant's voice in representing the phenomena under study.

Based on a review of the literature and the researchers' felt sense about the data, grieving and mourning were initially viewed as related concepts that needed to be addressed separately. As analyses proceeded, however, we came to see the interrelationships and overlaps among grieving, mourning, and healing, and axial and theoretical coding developed accordingly (Strauss & Corbin, 1998). This is consistent with the notion that the grounded theorist works from "the bottom up," developing saturated theoretical constructs that build on, or emerge from, the data (Glaser, 1978, 1992).

Scientific Rigor

Trustworthiness of the study was established by the criteria (e.g., credibility, transferability, dependability, and confirmability) set forth by Lincoln and Guba (1985). Credibility was illustrated by triangulation of data collection methods (e.g., interviews, participant observation, and the researcher's reflexive journal), peer debriefing, and the use of ongoing member checking (Polit et al., 2001) with selected study participants. Transferability was achieved by the inclusion of two older participants near the end of the study. Dependability was attained by providing an "audit trail" (Lincoln & Guba, 1985, p. 319) documenting the decision making process used during the study. Finally, confirmability has been evident in affirmations received during and after presentations of the study findings at conferences attended by survivors and professionals working in the field.

Ethical approval for the study was obtained from Ethical Review Committees at two Canadian universities. In addition, during data collection, arrangements were in place for an appropriate referral for individuals and families in the event that such assistance was required.

DISCOVERED THEORY AND DISCUSSION: *JOURNEYING TOWARD WHOLENESS*

Youth suicide was the precipitating event that created a crisis for each of the 11 families that participated in this study. Without mercy, this single, irreversible event catapulted survivors toward a perilous and uncertain future. Drawing on inner strength and courage, survivors began the frequently scary and always demanding process of reconstructing their lives.

Journeying Toward Wholeness and Its Sub-Themes

In this study, survivors consistently described their experiences following youth suicide as "a journey." They also spoke repeatedly about being "fragmented" and feeling "torn apart inside by the tragedy." Moreover, survivors expressed a wish to regain some sense of "normalcy" and "wholeness" in their lives once again. Hence, we have called the overarching theme that is the subject of this article *Journeying Toward Wholeness*. This theme represents a synthesis of participants' articulated views about their experiences following youth suicide as well as the field noted observational data. *Journeying Toward Wholeness* is graphically depicted in Figure 1. The major theme occupies a central position in the diagram and was created by three over-lapping circles, representing the interrelationship among three sub-themes that were derived from participants' bereavement-related experiences. These sub-themes we have labeled: *Grieving in Response to Youth Suicide*; *Mourning in Response to Youth Suicide;* and *Healing in Response to Youth Suicide*. Broken lines denote the characteristic fluidity among these dynamic and seamless processes. Philosophically congruent with systems theory (McGoldrick, 1982; Wright & Leahey, 1984), the individual experiences of grieving, mourning, and healing simultaneously impact upon the family unit and the broader social context. The first sub-theme is addressed next.[1]

Grieving in Response to Youth Suicide

During their journeys, participants consistently spoke about their grief responses; hence, the first sub-theme was labeled *Grieving in Response to Youth*

[1] In the following description, quotation marks indicate words of participants, unless otherwise indicated. All names are pseudonyms.

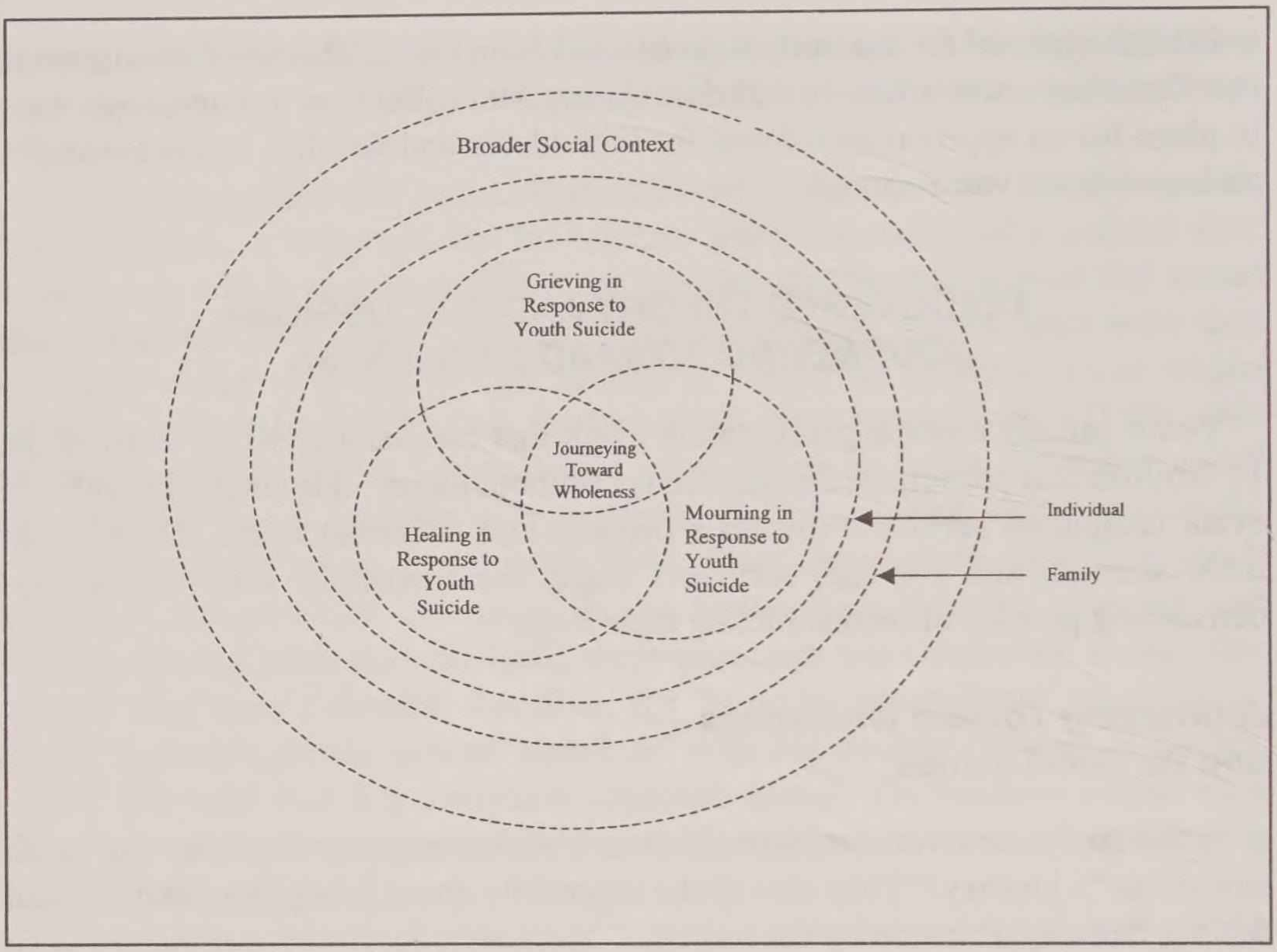

Figure 1. Grieving, mourning and healing following youth suicide: journeying toward wholeness.

Suicide. Grieving, for the purposes of this inquiry, refers to an individual's emotional response to the suicide of a family youth.

Soon after hearing the news, survivors experienced an intense period of grieving. During this transition time, survivors were forced to deal with the emotional impact of an unwanted change in their lives—the suicide of a family youth. In reference to grieving, survivors needed to process their own woundedness and address the confounding "why question."

Survivors repeatedly spoke about the "woundedness" they experienced, and "the sense of personal violation" and "trauma" they endured in relation to the suicide. Survivors sometimes felt "rejected" and "betrayed" as a result of a family youth's self-inflicted death. Marie, a mother, writes about her experience of being wounded in a letter to her deceased son:

> The screams that erupted from my body on this day were the beginning of many such screams over the next year and a half. They were screams that terrified your dog and he began to howl. I have never heard sounds like that before, and I too, was scared. I later came to compare that sound to the wailing of a pain filled animal. How true that I was wounded.

The pain and suffering that accompanied survivors' woundedness demanded their full attention. As a self-protective strategy, survivors characteristically engaged in "cocooning" (Grant Kalischuk & Davies, 2001, p. 174) as a way of processing the traumatizing impact of the suicide. Privately, using their own means, and on their own timelines, survivors needed to find ways of appropriately dealing with their anger, pain, and suffering. For example, in a letter to her deceased son, Sue, the mother of a 14-year-old youth who ended his life, wrote about her anger and its physical manifestation:

> There has been so much anger in me because of your decision to commit suicide. Some on it surfaced in ways that I didn't recognize. Six weeks after your death, I began to feel as if I had Parkinson's disease. I remember teaching and having to stand with my arms hugging myself as if I was cold. People looking at me would never have guessed the real reason that I held myself like that—it was to literally hold my body parts together.

These findings are supported by Bailley et al. (1999) who contend that survivors experience more frequent feelings of rejection and more total grief reactions than do survivors of other modes of death. This grounded theory study brings to light the traumatic nature of the grieving process following youth suicide; this finding is supported by Jordan (2001) who speculates that "traumatic grief is one likely sequelae of a suicide" (p. 97).

Integral to grieving, elusive attempts to find an answer to the pivotal "why question" consumed much of survivors' energy. Respondents in over half the families commented that a variety of factors may have influenced the youth's decision to end his life. These factors included: relationship difficulties, especially those involving romantic disappointment; mental illness; use of street drugs; infractions with the law; and undisclosed homosexuality. Despite speculating on these possible explanations, survivors continued to be haunted by the pivotal "why question." For some survivors, pursuing an answer to this perplexing question became their raison d'être. Jill, a sibling, commented, "When it is a suicide . . . it's a big question mark."

Uncomfortable with such uncertainty, most survivors needed to privately revisit the "why question" in their minds over and over again. In particular, they needed to relive again and again the time just prior to the suicide, looking for clues that might uncover some motive for the suicide. Despite the energy required, asking the "why question" was critical to survivors' grieving. Rae, an adult sibling, commented that it was only by asking this question that she was able to find out that there is no answer that would suffice. Arriving at this conclusion, she redirected her energy elsewhere. Several authors have identified similar themes of suicide bereavement, such as survivors struggling more with the mode of death and heightened feelings of rejection and abandonment following suicide (Jordan, 2001; Watson & Lee, 1993). In particular, Van Dongen (1990) noted that survivors experience "agonizing questioning" in response to suicide.

Mourning in Response to Youth Suicide

A prime focus for participants related to the ways in which they expressed and assimilated the experience of loss in their lives. Thus, the second sub-theme was labeled *Mourning in Response to Youth Suicide.* In this research, mourning refers to social customs and cultural practices implemented by survivors following youth suicide. Survivors mourned suicidal loss by: reviewing their lives; finding meaning and exploring spirituality; and implementing healing strategies.

Youth suicide prompted survivors to review their lives. For example, Liz, a significant other, described the review process this way:

> You need to get rid of the inhibitions that stop you from seeing the pain and the love. It involves allowing or letting yourself go into those corners of your life and those areas and regions that are unexplored . . . that are scary, that are totally new, and that you don't have any answers for at all. . . . The review process allows you to see things about yourself that you haven't seen before.

Mike, a father, further explained the complex nature of the review process:

> As you go through life, you pick up little packages of complexity that you carry with you. For boys, it's a little red wagon and for girls it's a little blue baby carriage. We all have our little packages wrapped up and the complexities go with you. You keep dragging the packages, and if you are the type of individual who has a complex life, you are dragging a pretty heavy load. All of these packages become a pretty heavy bundle by the time that you have a major crisis [i.e., youth suicide]. Then you have to go back and re-touch and re-claim every one of those complexities and work your way through them individually. It's almost like starting on a regressive basis and coming back to the reality of what is current.

In most instances, this awareness positioned survivors to begin acting more in alignment with their cherished beliefs and values. Joe, a father, commented:

> I always used to go for a few beers with the boys. Then, when all of this happened, I began to get my priorities right for the first time in my life. I started spending more time with my family.

Similar to this study's findings, Frantz, Farrell, and Trolley (2001) echo the notion that survivors may experience a positive outcome in relationship to the death of a loved one. As these authors point out, death sometimes brings families closer together. Their research found that following the death of a loved one, survivors were more likely to report feeling stronger, functioning more independently, and being more in tune with their life priorities (e.g., spending more time with family and friends).

Survivors consistently spoke about finding meaning in relation to their struggling and suffering. For instance, Rose, the mother of a deceased youth, pondered the meaning of her experience:

The themes that I saw in all of this were struggling and suffering. Life involves struggling and suffering, but that is what gives life meaning. Your never want everything resolved, because if everything is hunky-dory, then what's life all about? It's the bad and the good together that make you appreciate. You see, I never appreciated things as much as I do now before we lost Jason. Now there are little things that I appreciate, and I stop to relish the moment. It's almost like I stop to relish it for Jason too. It's like he's not here for this, but in another way he is here somewhere.

Approximately half of the survivors who participated in this study found meaning by believing that death occurs for a reason, including death due to suicide. Rae, a significant other, reflected on her experience: "It's an internal journey. . . . I have come to understand that it happened for a reason. . . . I still don't know why. One day I will . . . and I'll have to wait till then." Some survivors reached a point where they were comfortable despite not being able to comprehend everything about the suicide. They found meaning in their faith. Others found meaning in suffering. Sara, a mother, found meaning by ascribing new meaning to her experience:

> One of Rhy's [deceased youth] songs from the Crash Test Dummies came on [the radio]. All of a sudden, I could just feel the waves starting to come—I started with the real heavy crying. But now, when I am going into one of those real deep pains, I tell myself that those are the moments when Rhy is with me. That's when he is closest. So instead of only being in the pain and totally missing him, instead, I visualize Rhy being beside me in those moments.

Survivors frequently spoke about being on a "spiritual quest" or "pilgrimage." Many survivors expressed a renewed belief in a "Supreme Being," "Higher Power," or "God." Commonly, survivors felt "as if someone was watching over" them and they felt comforted by the presence of this Being. Rose, a mother, explained:

> I often think that he's like our guardian angel, he's around. . . . There is a spirituality that has come with the loss of our son. Like I wouldn't necessarily say that it's a religion, like I'd say that I'm searching for the religion that I can fit with the spirituality that has come to me. . . . Before I went to church and I believed in Christianity and I still do, but now it's broadened and I believe in a lot more things than just the restrictive part of Christianity. I've come to believe in reincarnation and in souls . . . extending beyond lives . . . soul mates . . . that kind of thing…maybe some kinds of messages perhaps from the grave.

In keeping with this view, Anne, an Aboriginal mother, talked about her deceased son's presence:

> I know that he's [deceased son] with me every day. He's a part of my existence. . . . Even now, he has a presence. There are messages that he has sent to us. I strongly believe that things happen for a reason, even in this case.

Jordan (2001) claims "Making sense of the suicide of their loved one is a major recovery task for survivors" (p. 99). In this study, making sense of the suicide often prompted survivors to explore the spiritual dimension of their experiences. Results of this study are also congruent with Neimeyer's (2000, 2001a, 2001b) important work in the area of meaning reconstruction following loss. In addition, this study's findings illuminate the spiritual aspect of survivors' experiences in keeping with the ideas shared by Marrone (1999) who maintains that "the ability to re-ascribe meaning in a changed world through spiritual transformation…may be more significant than the specific content by which that need is filled" (p. 495). Of significance, the findings of this research concur with William James's idea that believing can be extremely beneficial to the believer and, therefore, can be justified in terms of its practicality (Wernham, 1987).

The majority of survivors spoke about needing and wanting to find meaningful ways of continuing to love the deceased youth. Characteristically, survivors developed and employed a variety of culturally diverse healing strategies. The surviving members of the one Aboriginal family engaged in activities such as participating in healing sweat ceremonies and talking circles, prayer, speaking with elders, and story telling. Other strategies commonly implemented included: creating a healing environment, "living one breath at a time," performing rituals, treasuring mementos, reviewing photo albums, writing, composing poetry, creating art, using humor appropriately, playing music, reading, meditating, burning an eternity candle, seeking informal and professional help, and conducting and participating in suicide-related research. Writing was the most commonly used strategy. Marie, a mother, explained:

> For about six months I slept only three or four hours a night, and there were many times when I wished that I had a switch to the head because the mind wouldn't stop. So, this one particular night, about a month after Kevin's death, I sat down and started writing all of the thoughts that were in my head. For about the first six months, the journal entries are directed at Kevin—about the feelings that I was going through on those particular days, the kinds of fears, the anxieties, the claustrophobia, all of the things that the body and the mind were feeling and thinking. Since that day I have written well over 3,000 pages. What I realized was that the writing gave me an opportunity to talk to myself about my feelings. There were many times when I would write things down that my mind wasn't even ware of. I realized that it was a very healing thing to do.

Congruent with the findings of this study, using narrative to facilitate the re-authoring of the self in the wake of loss has been documented in the literature (Neimeyer, 2001a). Implementing healing strategies served as a way of validating the life of, and maintaining a healthy bond with, the deceased youth, and as a way of attaining a sense of inner peace. Kagawa-Singer (1998) underscores the importance of understanding cultural practices (e.g., rituals) surrounding death. Such understanding provides a meaningful context for grieving families and

friends. Honoring cultural practices provide survivors "with a sense of security and coherence as well as the emotional, social, and physical resources to navigate this final journey with integrity and peace of mind" (Kagawa-Singer, 1998, p. 1752).

Healing in Response to Youth Suicide

Eventually, most survivors increased their level of understanding about their experiences and their potential for healing. Hence, the third and final sub-theme of *Journeying Towards Wholeness* was labeled *Healing in Response to Youth Suicide*. Individual healing was described as both a solo and shared experience that was created and re-created during the course of each survivor's life. From this study's data, healing is defined as letting go of the negative impact of the suicide and achieving a sense of health and well being.

Even survivors who were unable to identify with healing in their lives ($n = 2$) during the interviews thought they had the potential to move in that direction at some point in the future. Survivors who became positively transformed by their experiences began connecting with others and with life again, albeit from a new vantage point. They transcended their unfortunate circumstances by reaching out to others and channeling their energy toward changeable aspects of their lives. They learned much about themselves from their experiences, and they used this knowledge to help others in similar circumstances, as well as to facilitate constructive change within society. *Healing in Response to Youth Suicide* was about deciding to heal and accepting social responsibility for communicating with others about youth suicide.

Most survivors decided to let go of the negative impact of the suicide by making three key decisions that launched them on their journeys toward wholeness. Specifically, survivors:

- Validated their own reality as separate from that of the deceased youth: "It was really interesting how I had to separate his actions and behaviors from my reality, and not even go there because there is no way that I could ever know what he felt or experienced." (Mike, father)
- Released themselves of the responsibility for the suicide:

  > On May 8, I gave Kevin the last gift that I could give him as his mother—I gave him permission to go. I had known that Kevin was okay when I received the rose at his funeral. For me, those two years since that day had been spent on healing me and I felt that the day had come to forgive my son, to tell him how loved he still was and to let him know that I was okay. It was a process that I sensed was necessary for me. In letting go of Kevin, I was also releasing me. (Marie, a mother)

- Decided to move toward healing:

> You survive or you die, and I am a survivor....There is too much goodness out there amidst all of the trauma, and it's just your attitude and how you face things. And you can find the ugliness if you look for it, but you can also find the goodness. . . . I've decided to invest my energy in healing. (Liz, a sibling)

Most often, the decision to move toward healing was initiated within each family by a survivor who was emotionally and spiritually close to the deceased youth prior to his death.

Survivors who experienced *Healing in Response to Youth Suicide* became socially responsible. They felt that the rejection associated with the sudden, violent, and self-inflicted death of a family youth brought negativity into their lives which caused them an enormous amount of pain and suffering. They perceived that a major portion of this negativity was related to the isolation they often felt, and the pervasive silence that surrounds suicide within society. Survivors often felt silenced in terms of speaking about their pain with others, especially with those external to the family unit. Approximately one third of the survivors began to accept social responsibility by talking openly about their traumatic experiences, especially within the public arena. These survivors realized the merit of using the lessons they learned as a result of their unfortunate circumstances to help others. For instance, Lynn, a mother, received direction for her life's work through a powerful dream:

> The night that Dean died, I had a dream about standing in the gymnasium talking to kids, and for 30 nights I had the same dream. And there was never a word that I could remember in the morning, just the recollection of me standing in the gymnasium talking to kids. And about three months after Dean's death, I knew that I wanted to become a speaker and to talk to adolescents about the impact that suicide has on the family.

These finding are supported by the extensive work of Myss (1996, 1997) and Dombeck (1995), both of whom maintain that healing occurs in response to a clear and conscious decision. Other researchers concur that accepting responsibility for social change is integral to healing (Burke Draucker & Petrovic, 1996; Demi & Howell, 1991; Predeger, 1996; Smolin & Guinan, 1993). In contrast to Provini et al.'s (2000) work addressing the distressing nature of suicide on the family unit, most participants in this study eventually were able to reach out and support both their own healing and that of other family members. Several of these survivors experienced post-traumatic growth (Tedeschi, Park, & Calhoun, 1998) and this greatly enhanced their sense of health and well being. In summary, this mid-range theory indicates that it is by moving through the inter-related processes of grieving, mourning, and healing that survivors eventually journey toward wholeness. Practice implications for facilitating the journey toward wholeness are addressed next.

IMPLICATIONS FOR PRACTICE

The findings of this study add to the literature on thanatology by providing a starting point for further examination of the interrelationships among grieving, mourning, and healing. This study is limited by its beginning nature and predominantly rural sample; the theory would benefit by being extended and tested by others, in different groups, cultures, and social contexts. Nonetheless, insights shared by these participants suggest that survivors have the capacity to tap into their innate strengths and coping capabilities, thus enabling them to journey toward wholeness.

Indeed, comprehending the far-reaching impact that youth suicide casts in its wake is one of the greatest challenges faced by survivors. Of critical importance, is survivors' need to address their woundedness—not only in relation to their losses, but also with respect to the sense of personal violation they endure as a result of the suicide. Professionals who work with survivors can expect to witness intense emotional responses from survivors and these reactions need to be viewed as appropriate and healthy responses to catastrophic loss. Survivors need to be supported and encouraged in expressing their pain in their own time and in their own unique ways. Professionals can also assist survivors by encouraging them to create quiet and comfortable healing environments that serve as sanctuaries for processing catastrophic loss.

In response to youth suicide, this study's participants undertook extensive life reviews. Subsequently, most survivors decided to align their actions more closely with their beliefs and values. For some survivors, this meant spending more time with loved ones, while for others it meant developing their potential as human beings and making a commitment to use their adverse circumstances to help others. Professionals working with families need to understand and support survivors during this review process because of its positive and empowering impact on each survivor's health and well being.

Survivors often felt compelled to assume an increased level of social responsibility. Most often this was accomplished by breaking the "no talk rule" within society. Storytelling served as a means for survivors to re-claim their voices. Professionals need to be cognizant of the emancipating effects of storytelling, especially for the storyteller. However, sharing stories of trauma is not easy because of what these stories evoke within the listener. Nonetheless, the very act of listening is powerful in that it assists survivors in beginning to reach out to others in similar circumstances. In turn, the use of narrative helps survivors in taking a proactive stance with regard to raising the level of collective consciousness about youth suicide and its impact on families and the broader community.

Professionals need to be mindful of how their own education influences the ways in which they practice. In the past, professionals have been educated to emotionally distance themselves from patients and families, to remain objective, and to base their decisions only on facts and scientific evidence. Even today,

professional education often fails to address the relationship between our personal and professional lives. For instance, professional education frequently emphasizes content based on logic and facts and subordinates the process with its focus on personal communication attributes such as empathy, compassion, and vulnerability. Consequently, professionals often tend to emphasize the science, rather than the art of their respective disciplines. To improve this situation, education needs to be shifted toward focusing on professionals as whole persons (i.e., personal and professional) and practice as always relational (Hartrick, 2002).

As professionals, we need to ask ourselves: Do we truly engage patients and families, or do we distance ourselves from them? As professionals, we need to enter into helping and caring relationships as "whole persons," as persons who have suffered, grieved, and mourned, and hence, as persons who have also experienced woundedness. Wells-Federman (1996) maintains that before one can be of assistance to others, one must awaken the healer within. As healers and as professionals, our gift to our clients lies in our capacity to remain open to our own vulnerability. By remaining open to our own suffering and vulnerabilities, we are well positioned to enter relationships as "whole persons," capable of responding in a caring and compassionate manner toward others as they engage in their own inner work. Conversely, when we distance ourselves from our own vulnerabilities, we become susceptible to limiting the growth of others. Hence, an important part of our education lies in being presented with opportunities to explore our own vulnerabilities, so that we can respond effectively to those entrusted to our care. Collaboratively created, ongoing educational sessions, implemented by an interdisciplinary group of health and social service professionals and survivors, could serve as a first step toward achieving this aim.

According to this study's participants, individual healing occurs as an act of volition. Professionals who work with this population need to be guided by the expressed wishes of survivors, trusting that each individual knows "when" and "how" to move toward wholeness. Moreover, professionals are in a key position to offer support to survivors as they sift and sort through the remains of their shattered lives. Survivors need to be supported in dealing with the chaos that colors their lives; it is from chaos that clarity and meaning eventually begin to emerge. As survivors find meaning in their experiences, they are then able to re-create their lives accordingly.

It is important that professionals be aware that, regardless of the mode of death, survivors continue to love the deceased person. As an expression of their continuing love, survivors developed personalized healing strategies that enabled them to maintain healthy and continuing bonds with the deceased youth. To assist survivors, professionals need to be aware of the vast array of culturally diverse healing strategies that have been successfully used by others in similar circumstances. Professionals can also assist survivors by assessing the loss history of each family member and, if possible, by identifying the family member who was emotionally and spiritually closest to the deceased youth prior to death. Not

only will this individual be most likely to begin the journey more readily than others, this person also may be able to play an active role in helping other family members do the same. Essentially, the role of the professional is to encourage and support family members in helping themselves and each other.

In conclusion, as one way of reconstructing meaning in relation to the loss experience, Neimeyer (2001a) underscores the importance of attending closely to the "language of loss" (p. 177). Such language may take a variety of forms including narrative and poetic expression. These creative language forms and self-expressions are sensitive to the nuances that characterize the loss experience (Neimeyer, 2001b). For one study participant, this venue was invaluable in that it helped her in finding meaning related to her experiences of grieving, mourning, and healing.

All is unfolding as it should.
I will know the whole story someday.
There is a reason for life: there is a reason for death.
I know beyond a shadow of a doubt that love goes beyond the grave.
I have developed a lot of gratitude:
For my relationships, both past and present, especially those that support my healing,
For the initiative I've exercised to sometimes step out of my comfort zone to help myself and others,
For the independence I've developed in creating personal space and distance when I've needed it for my own health and well being,
For humor and the healing salve it's been in transforming the blackness into color,
For the insight that has helped to sustain me and support others, as they have also sought to
Understand why?
For my faith in God and understanding the great resource of compassion.
(Jane, a sibling)

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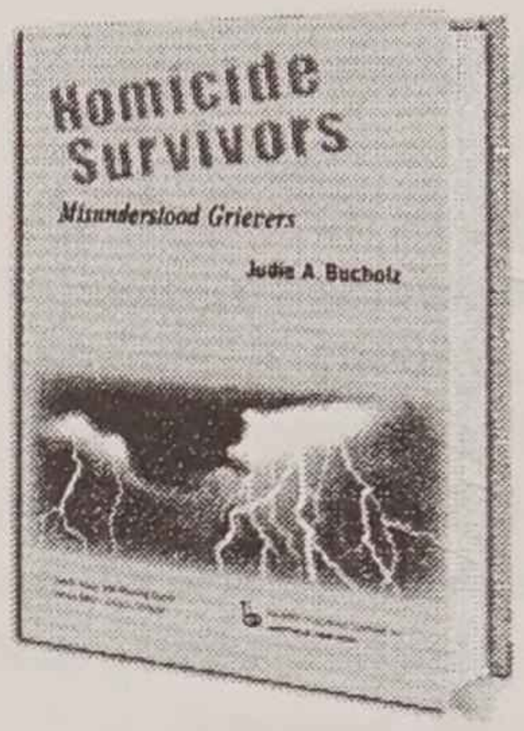

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Judie Bucholz

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OMEGA, Vol. 48(1) 69-84, 2003-2004

OMEGA: PRE-HISTORY OF A JOURNAL

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ABSTRACT

Omega, Journal of Death and Dying, evolved from a newsletter prepared and distributed through a research project based in a geriatric hospital. This article recalls the context within which the newsletter originated, offers selections from its contents, and provides glimpses of an early phase in the development of thanatology. The transition from newsletter to journal is also described. Many questions raised and suggestions offered by contributors to the *Omega Newsletter* during its 1966-1968 run are still relevant today.

History tends to slip away through the crevices of memory and the thinning of rank. This article takes the opportunity to put on record a few facts about the establishment of the first peer-reviewed journal in the field of thanatology.

Omega first appeared in 1970. At the same time, its sibling, *The International Journal of Aging and Human Development (IJAHD),* also made its debut. Both have been published regularly since that time, adding much to the scholarly and professional literature as well as evidencing the priorities, concerns, and methods of their changing times. The twin coming-forth of these journals could be regarded as an illustration of the resolute march of science, dumb luck, or a little of both. Readers are free to draw their own conclusions from the following chronological account.

THE STRAIGHT WAS TOO NARROW

Gerontology was well ahead of thanatology in the post World War II years. The general public, commercial interests, economists, care-providers, and researchers

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were waking to the challenges of an aging population. Gerontology was in urgent need of facts and significant journals already were in operation by the 1960s. The emerging multidisciplinary field was motivated to prove that it was as scientific as its more established peers. Studies that yielded numbers and emulated traditional journal reports were received with much more enthusiasm than ethnographic observations or attempts to address issues of meaning.

Death-related issues rarely surfaced in journals, conferences, or the classroom. Perhaps it was worry enough to take on aging without also confronting death, or, just perhaps, the new interest in long lives had the function of distracting from the fact that even the longest life comes to an end. Whatever the reasons, the pathway under construction by the pioneer gerontologists at mid-century was impressive, but, as it seemed to a few of us, rather narrow.

Social psychologist Richard A. Kalish and I were treated rather kindly by the academic and professional establishment as we explored both gerontology and thanatology, perhaps in part because we also were active in mainstream endeavors as well. Nevertheless, we brooded about the narrow boundaries that characterized gerontology at that time and the dearth of opportunities to share information on dying, death, grief, and related topics among the small and scattered band of proto-thanatologists. Needed was a journal devoted to death-related issues, and another that would encourage manuscripts exploring the sociocultural and humanistic dimensions of aging.

OMEGA BEFORE IT BECAME *OMEGA*

We could not will a journal into existence, but we did have access to a ditto machine (that temperamental and messy device that yielded a fuzzy blue printout . . . ask your grandmother about it). Kalish spent the summer of 1965 as a visiting research scholar with my new research and training project on death and dying in Cushing Hospital, a geriatric facility operated by the Commonwealth of Massachusetts. He had compiled a valuable annotated bibliography of articles and books on death. Perhaps we could put out some kind of newsletter to invite and share new references. We might also invite comments and reports from others around the world who had a professional or scholarly interest in death-related issues.

The first issue of this newsletter was churned out in March 1966. We called this newsletter, *Newsletter.* Consultant psychiatrist Avery D. Weisman soon offered *Omega* as the title. Actually, he added, it was the suggestion of his wife, Erma, who was more conversant with the Greek alphabet than the rest of us. From the second issue onward, *Omega* it was for the newsletter and eventually the journal. Copies of the first issue were dispatched to everybody we had on every address list. By this time, Kalish had returned to California State University at Los Angeles, leaving me to ruin a good shirt by carrying bundles of ink-shedding

newsletters to the post office. The first issue was a stapled sheaf of seven manuscript-sized pages.

VOLUME 1, NO. 1

Omega is the last letter, but can also be considered the last word if one is a little flexible about the Greek alphabet. Our first word was simply "Hello!" This was followed by a brief description of the purpose of the newsletter and a call for abstracts, announcements, requests for assistance, and so forth. We also asked:

> Will the NEWSLETTER eventually become an interdisciplinary journal? Is there need and support for such a periodical, considering the increasing proliferation of professional and scientific journals? These are matters for some vague future on which we have little perspective (p. 1).

The *Newsletter* then called attention to C. Murray Parke's ongoing study of young widows in Cambridge, Massachusetts (this would soon result in a landmark publication). Other news bits followed as samples of the material we hoped to receive from readers.

"Birth of the Death-People" was the feature attraction in this premier issue. The author had already introduced his concept of the "appropriate death," and published pioneering studies of the connection between personality and mortality risk. We offer here an abridged version of this keynote editorial.

> *Birth of the Death-People (by Avery D. Weisman, M.D.)*
>
> Only a few years ago, systematic studies of death and dying in psychological and psychiatric literature were limited to a few scattered and "classical" references. Today there are so many people investigating death and dying that we cannot keep up with each other's publications. We must establish a kind of house organ merely to let each other know of our presence!
>
> How can we account for the increased number of "death people?" It has been said that many physicians decide upon their choice of occupation after a close brush with death. But literature and art have accurately reflected the preoccupation with human morality in every age. Love and death are familiar companions, so we cannot claim that we have only now discovered death as a suitable topic for research.
>
> I believe that only in recent years has it become possible to study death with objectivity and freedom. It is perhaps the last area of human experience to resist exposure and liberation. We can now talk to people about death without being afraid of invading the preserve of religion or of offending the censorship of social custom. There is no inconsistency between religious practice and scientific study. Increasing our attention to social factors in illness has inevitably focused on the terminal phase of life.
>
> There are other reasons why death and dying have attracted so much of our current scientific interest. In earlier, isolated times, the bare knowledge that thousands died as a result of famine could scarcely retain more than a passing

thought, perhaps a twinge of compassion, and at the most a convenient contribution to the Red Cross. It is our generation that has become poignantly aware that each of us, at any moment, can become another statistic, another name buried in a casualty list, or an item on the obituary page. Although we are, as a rule, too intent upon establishing our own to worry about those who struggle for bread, the animal task of mere survival has become a common problem of mankind.

The curious paradox of science and technology allows millions of people to reach old age while at the same time threatens millions of people with sudden death by the decree of a dictator or by the blast of a thermonuclear explosion. The threat of unexpected death seems to have hastened the secularization of society. It is not only the proximity of death that emerges from censorship; we are also aware that each year there is an imposing number of people who decide to commit suicide. Because death looks at us from every direction, reality demands that we in turn look directly at death.

I believe that investigators and students of mind and society share a common interest in preventing meaningless death, whether from disease, disaster, or the inroads of senescence. As medicine seeks to circumvent and postpone death, so we "death-people" want to change our inner orientation from that of a passive, helpless onlooker to one of an active participant. All of us would like to improve the circumstances in which people sooner or later must die, and concomitantly to change the image of death. The concept of an *appropriate death* which Dr. Tom Hackett and I suggested several years ago was prompted by practical efforts to convert death from its image as an obscure and frightening fate into a condition which was both acceptable and compatible with choice.

None of us is so visionary as to expect that the fear of death will ever be wholly eliminated. Millennia of repeated injunctons and threats uttered in the name of death have guaranteed that death will always have the quality of disaster. But the common purpose of our work is a secular and dispassionate study of death.

Perhaps it is our task at this point in history to bring death back from the grave and integrate it with life. Even if we are surrounded with meaningless deaths and threatened with many more, it is our mutual intention to discover ways in which death may be accomplished with grace, dignity, and compassion.

THE BRIEF BUT LIVELY LIFE OF THE *OMEGA NEWSLETTER*

Weisman's seminal contribution placed the mission of the "death-people" within an historical, sociological, and philosophical context with urgent applications to individual lives. By implication, thanatologists were expected to have broad knowledge and perspective as well as skill and compassion in providing human services.

The second issue appeared in June 1966. It was now called: *Omega. A Newsletter Concerned with Time Perspective, Death, and Bereavement.* There was a major technological upgrade: we now had access to a spiffy mimeograph machine, resulting in a more effectively produced newsletter and a zone of safety for my shirts. Dozens of readers had responded to the first issue with encouraging comments, and additional people asked to be added to the mailing list. The first few pages were devoted to brief news items and comments. Particular attention was given to the marked increase in student interest in death-related topics. Kalish observed that this stirring among the students was "daring, anti-establishment, and consistent with the philosophic trends of the times. It shakes up the old folks . . . and becomes an excellent way of rebelling."

Attention was also given to another emerging phenomenon: "The Man or Woman from DEATH." We invited reports of personal experiences of readers who might have become seen in this role by their students and colleagues or others.

Among the first wave of comments was a letter from Andres Martiniz of Mexico City who called attention to the more conspicuous role of death in Mexican culture. We also noted a forthcoming issue of *Psychiatric Opinion* that was perhaps the first established journal to devote an entire issue to this topic. Interestingly, *Psychiatric Opinion* was edited at that time by Noah Gordon, author of *The Death Committee* and other best-selling novels.

Another auspicious event was described in some detail: a conference on "Terminal Illness and Impending Death among the Aged" sponsored by The Gerontology Branch of the Department of Health Education and Welfare. This seems to have been the first death-intensive conference developed under federal auspices. (Unfortunately, the bold, volatile, detailed, and occasionally bawdy proceedings were difficult to summarize and had very limited circulation.) Several recommendations were noted, though:

- Develop a continuing annotated bibliographic service;
- Improve training for the care of persons who are facing death; and
- Encourage or establish study group to design new environments for the end of life (note: this was several years before the establishment of modern hospice programs).

This same issue also reported on what might have been the first university lecture series on dying and death. It was a joint effort of the Psychology Department and the Rehabilitation, Research, and Training Center of Western Reserve University. Psychology professor Leonard Pearson was the guiding light for this series. Those of us who participated in the program were struck by the intensity as well as the size of the audience. (A leather-jacketed young woman, long blonde hair flowing, rode her Harley right up the steps of the building, and then seated herself on the floor because almost all the chairs were already occupied—thanatology, for the moment, had become hot.)

As early as its second issue, then, the *Omega Newsletter* was already reporting on groundbreaking events and developments. Its existence was at least provisionally justified.

Volume 1, issue 3 appeared in September 1966. It was duly noted that two dozen neurologists and neuroscientists had visited and been impressed by The Russian Institute for the Resuscitation of the Dead. Nothing was said about the awkward situation that might arise if the multitude of Stalinist purge victims were to manifest themselves again in their native land.

A psychologist (name withheld) who had once participated in a study of terminal cancer patients reflected:

> I can only say that I learned a good deal about death at that time. It was a topic that the medical men who dealt with it most intimately knew least about, talked the least about, and it produced a state of anxiety far greater in the professional people who dealt with these cases than it apparently did with the terminal cases themselves. . . . The hospital administrative staff told me in confidence that they are experiencing a good deal of difficulty in getting physicians to call on their patients, and that these physicians make visits in such institutions as brief as they possibly can.

Sociologist Thomas D. Elliot had written about bereavement in the 1930s to the general disinterest of other educators and researchers. We noted that he was now active in the Memorial Society movement and compiling an annotated bibliography on funerals. Not exactly forgotten because he had not been remembered in the first place, this pioneering thanatologist passed along a high-tech suggestion. Since cremation is a crude process, why not use laser beams as "a super-efficient and esthetic mode of cremation?" (Has this suggestion been taken up yet?)

The feature article, "Death and Mundanity," was provided by philosopher Maurice Natanson. He emphasized the "ordinariness" and "familiarity" in the character of death. Death is "a fundamental and thematic aspect of the reality of human existence. Most directly put, death . . . is the metaphysical condition for our being."

The December 1966 issue concluded the first year of publication. There were now more than 500 "subscribers" (not literally underwriters because the newsletter was as free as the breeze). Along with other developments in the field, we had the opportunity to report on a major breakthrough: a three-day program devoted to "The Care of Patients with Fatal Illness (February 15-17, 1967). The fact that this conference was organized by the New York Academy of Sciences suggested that thanatology was moving, if by fits and starts, to the main stage of scholarly and professional attention.

A sampling of topics at the New York Academy of Sciences conference can illustrate the variety of issues and approaches that were already operative, as well

as help us to remember some of the people who were marking significant contributions at that time:

Herman Feifel	Perception of Death
James A. Holland	Prediction of Time of Death in Patients with Advanced Cancer
Anselm Strauss	Dying in Hospitals: A Sociological View
Walter Kaufmann	Existential Philosophy and Death
Lawrence LeShan	A Psychotherapeutic Approach to the Patient with a Limited Life Span
Jacob Needleman	The Perception of Mortality
C. W. Wahl	The Management of the Dying Patient
William J. Curran	Legal Problems Associated with Death
Thomas P. Hackett & Avery D.Weisman	Denial as a Factor in Patients with Heart Disease and Cancer
Rev. Jack Mendelsohn	What a Piece of Work is Man
Laurens P. White	Re-Evaluation of the Role of the Physician in the Care of Dying Patients

Contributors included clergy, lawyers, philosophers, physicians, psychologists, and sociologists. The makings of a vital multidisciplinary field were beginning to emerge.

"The Humor of the Gallows" was Walter O'Connell's guest essay for this issue. O'Connell noted the dark humor abundantly demonstrated by Sir Thomas More "while imprisoned, awaiting the ghastly fate of being hanged, drawn, and quartered." He also noted that among More's many writings was the *Dialogue of Comfort,* "a forgotten classic of thanatology." O'Connell called for the development of post-Freudian personality theories that go "beyond the five year-old to [understand] aging and death."

Charles D. Aring, a distinguished physician, contributed another guest essay to this issue. "A Letter from the Clinical Clerk" was a moving and humane account of how his son, a clinical clerk on a medical ward, responded to the death of his first patient. Aring's son had observed closely and felt deeply as "a very good man of 83 without anyone at his bedside, nurse or friend," lay dying. This brief essay remains as poignant today as when it was written.

TWO MORE YEARS OF THE *OMEGA NEWSLETTER*

The newsletters were bulking up as we moved through the second and third years. There were more contributors to share more news, concerns, and suggestions. The Vietnam War evoked observations about dehumanization as numbers and military terminology glossed over the suffering and death of actual people. For example: "Word-magic to the rescue when number-magic falters: we kill 'VCs,' 'gooks,' and 'exterminate terrorists,' not men, women, and children."

Ohio State University professor Roland Fischer, a master of the complex literature on biological, physical, social, and symbolic time, contributed an impressive essay on "The Unity of Life and Time" to the first issue of volume 2. Surprisingly few probing analyses of time have subsequently entered the core thanatological literature despite the obvious and not so obvious resonances.

Psychiatrist Adriaan Verwoerdt, emerging as an expert in communication transactions between physicians and terminally ill patients, also called attention to the significance of time: "The knowledge about, or premonition of imminent death can interfere with the usual processes of anticipation and hope. This stress, combined with the impact of illness, can lead to a regression with a concomitant change in the patient's time scale. A regressive time scale is protective in the sense that day by day living again affords good prospect and hope."

The second issue launched a useful annotated bibliography section that continued throughout the newsletter's run. Several publications of enduring interest were acknowledged, as well as an error that has also perpetuated itself. The name of the author of the influential article, "Orientations toward death: A vital aspect of the study of lives" was given as Edwin S. Schneidman. The founder of the American Association of Suicidology spells his name without that "c," but many other people continue to like it better with. In the same issue Jeanne C. Quint (later Jean Quint Benoliel), shared personal experiences that led to *The Nurse and the Dying Patient* (1967). As both sociologist and nurse, this pioneering book was both preceded and followed by many other contributions Quint has made to the understanding and care of terminally ill people, as well as to the education of nurses.

A bit of speculation found its way into nearly every issue as a way of stimulating further observations and discussions. In this issue the subject was the possibility that "perhaps death does signal its approach to the dying person, often in ways that he does not recognize himself. This notion has a way of persisting although solid scientific evidence has yet to be made available to us." One of the incidents cited was that of an 80-year-old man who apparently had recovered his health after a stroke. In signing a letter to his physician son, he wrote, "Love, Mother and Dead." "Dad" had been intended, but "dead" was perhaps the subintended message as he died two months later sans a terminal diagnosis. This is an example of the numerous observations, questions, and hypotheses that were generated or disseminated throughout the brief run of the *Omega Newsletter*.

The third issue had several other significant new publications to welcome. The *Bulletin of Suicidology* was a crisp and stimulating publication sponsored by the Department of Health and Welfare. It would also have a relatively brief run, though, as Federal priorities shifted away from the evanescent but fertile fling with suicide prevention. John Hinton's *Dying* (1972 in its American edition) offered clinical research findings as well as personal observations. David Sudnow's *Passing On: The Social Organization of Dying* (1967) became an instant classic whose discoveries have been amply confirmed over the years.

Dick Kalish contributed a classic of his own in Volume 11, #3. "The Older Person and the Social Value of Life: A Brief History 1970 to the Present" was a revised version of a paper he had recently presented at a meeting of The Gerontological Society. He noted that historically the perceived diminished value of elderly adults carried over to support for prevention and management of illness. Avoidable suffering and premature death were more likely to befall elders because American society regarded them as, in general, having little "social utility." Now, however, this negative attitude was fading as a result of activism on behalf of the aged and the emerging finding that older workers are often highly productive and reliable. Kalish ventured that "the social value of life for the older person today is extremely high. . . . He is assumed to deserve this not because he is wealthy, honest, Anglo-Caucasian, or potentially productive, but because he has earned it by becoming old." Although this proposition was subject to controversy then as now, it did demonstrate the importance of studying age-differential societal attitudes as part of our understanding of the life course.

The final issue of Volume II described the mission announced by The Cryonics Society of Florida. The "freeze-wait-reanimate" movement was then in its early days and many an ambitious agenda was being designed and promulgated. The *Omega Newsletter* had been offering nonevaulative updates from time to time.

Psychologists Herbert Krauss and Rene Ruiz contributed a guest essay, "Explorations in Time Orientation: Future Time Avoidance." They suggested that at least some obsessions and compulsions could be thought of "as ways by which anxiety is bound by excluding futurity from the patient's self-awareness. Thus, while the rituals of the obsessive-compulsive might contain enormous symbolic content about the conflict he is trying to head off, this behavior also serves to ward off *future* threat. If one is continually washing his hands, he has no time for experiencing the natural flow of reality." Krauss and Ruiz reported that one of their recent studies (1967) found that in naturally stressful situation (a promotion board hearing), high anxiety participants tended to revert to the past in thought and language. In a limited sense, the Krauss-Ruiz studies could be regarded as objectified models of Kierkegaard's (1989) concept of dread. That death is part of the future prospect makes this line of research of interest to thanatologists but, like so many other early contributions, it has passed into scholars' oblivion.

Distinguished gerontologist Elias S. Cohen provided a prompt critique of Kalish's thesis on the social value of elderly people, agreeing with his conclusions but identifying dimensions that had not been addressed. What made this critique special was its provenance. It was presented under the auspices of the "Office of the Supreme Defender of the Primogenitary," which, of course, was a section of "Megaloptic Human Services Substation 4791, Mohole Governmental Control Center, Sublevel 134, Appalachia, Pennsylvania." The date of this critique, included in a 1967 newsletter, was March 31, 1997, and it was transmitted via "Videophone 1796-431-62-4976-35, Laser Channel 14913." Try pulling off a prank like this in today's journals!

This chockfull issue also included an appreciative review of another new book that was to have many years of readership and influence ahead: Earl A. Grollman's *Explaining Death to Children* (1967). It was one of the pleasures of this first active decade of the death awareness movement to welcome what were still rare contributions to knowledge and practice.

THE FINAL YEAR

What proved to be the final year of *Omega* as a newsletter opened with a concerned look at heart transplantation, then much in the news—along with inter-racial strife in South Africa. Would the demand for hearts lead to "pseudo-euthanasia" through which organs from non-whites and other oppressed populations might be harvested? "Would a 'white' heart ever be placed in the chest cavity of a critically ill Negro?" Concern was also expressed about the medical risks versus probability of successful outcome in this new technique. One of the editors added to the troubles with an abyssmal poem written from the standpoint of a recent multi-organ recipient. It begins:

> Me, not you, me!
> ---Wheee! Aint' that somethin'?
> Me, Old Nobody Me
> Shambling slum of a me
> Some of me buried alreaddeadedly
> Some of me patched
> Some of me matched
> Some of me new
> Some of me you
> New Man, me, hah!
> Heartficial art keep
> A smiling on me:
> First of what is sure to be
> Your customized refabricatee . . .

The poem continues, but we need not.

The assassination of President John F. Kennedy occurred days before Volume 3, #2 was ready for distribution. Kennedy's death was memorialized on the first page along with the question, "What does this mean to us?" The editor observed that "Death-by-violence seems to license and justify violent thoughts and language to those who have been struck by the news. . . . We have seldom heard so many people using violent, aggressive, and death words . . . as in the first few days after the assassination." One of the examples given were words "spoken by a highly educated adult who was livid with rage and sprinkling her conversation (unwittingly) with a weaponry of words." We were also concerned that "the sorrow and threat that surrounds our society after this latest assassination could, ironically, serve to distract us even more from attending to other forms of death. This remains to be seen."

In the wake of September 11, 2001, it would be seen that shock, sorrow, reflection, and compassion were quickly preempted by military rhetoric and activity, a national transition from victim to aggressor. "Ordinary deaths" were again shunted to the periphery.

The editors also had some apologizing to do:

> The lack of holes in this issue of OMEGA for your three-ringed, red-chested, swallow-tailed binder does not mean that we have simply goofed. It is just that the market for tiny round pieces of paper has dried up. Or would you believe that the small pieces we have been saving all these months have proven inadequate to plugging the holes in our own research and theory? . . . Yes, we goofed.

And where is such journalistic integrity today?

The feature attraction was psychologist Judith March Goldrich's guest essay, "Separation and the Sense of Time." One of her investigations (Goldrich, 1967) had distinguished between students with varying degrees of readiness to embark on their future careers. Perhaps not surprisingly, those who were itching to move from student to professional status were a deal more efficient in completing their dissertations. Goldrich speculates on the relationship between future time perspective, fear of separation, and death anxiety. She agrees with those who hold "that man's fear of the final separation of death has contributed heavily to the growth of religions and civilization," and that Christians are taught to live "with a view toward the next world which, it is said, will last for eternity." Human existence day by day seems precarious, however, and the universe limned by science does not seem especially supportive of human needs and aspirations. Today separation anxiety may be heightened by the emerging philosophy that "Not only is man separated from any possible higher order, but the *moments* of his lifetime are themselves separated from one another." Goldrich's wide-spanning thoughts include the influence of mother-child development at one extreme, and the place of humanity in the cosmos at the other (if, indeed, the cosmos admits of two neatly situated end-points).

Volume III, number 3 welcomed a new book by psychiatrist David M. Moriarity (1967), *The Loss of Loved Ones,* one of the first to examine family response to traumatic deaths. *The Psychological Autopsy: A Study of the Terminal Phase of Life* (Weisman & Kastenbaum, 1968, also was noted, this the result of field research at a Massachusetts geriatric hospital).

Sam Silverman, still a valuable contributor to the thanatological literature, offered a distinction between the concepts of denial and negation of death. One of his examples was drawn from the Neanderthal practice of burying the dead with flowers, a custom that, of course, is still widespread today. Silverman suggests that "flowers, the symbol of new life, and of the continuing cycle of birth, death and most importantly, rebirth, can be used in the sense not of a direct *denial* of death, but rather as a *negation* of death by the introduction of new birth." He also noted

that the cycle of the moon often has been interpreted as birth-death-rebirth, a possible model for the belief in mastery of death by negation rather than renewal.

Public health specialist James N. Colbert shared a previously unreported conversation that he and a friend had with a young man who died of cystic fibrosis while enclosed in an iron lung. Robert Nostri's awareness of his limited time on earth had been the subject of an article in *The Saturday Evening Post.* Colbert revealed that Nostri had an intense aversion to the prospect of dying in the hospital in an iron lung. "We even had an elaborate scheme. . . . As we had all been patients in the same hospital we knew a way to get him out the back entrance, and planned to have a rented truck waiting complete with oxygen equipment to transport him to the desert for his final hours. Bob told us that we would renege at the last minute, but we denied any such possibility." When the time came, the two friends "felt squeamish, as we remembered our promise." At the end, "I said, 'Bob, Bob I am with you all the way.' He kind of looked inside of me. It made me feel like there was too much pettiness in my own life. He said, 'Yeah, you're with me.'A few hours later Bob died."

The final issue of the *Omega Newsletter* (volume III, number 4) was prepared without sure knowledge that it would soon be replaced by a full-fledged journal. We did note, however, that there would be a delay before the next issue as we attempt to upgrade the production and, if at all possible, convert to a printed journal format. The guest essay was contributed by Murray Projector, an actuary practicing in Los Angeles. (Yes, an actuary named "Projector" is nonfictional; it was Los Angeles that we had our doubts about.) Projector had something to say about "The American Way of Looking at Accidental Death." He observed that Americans seemed to be obsessed with accidental deaths, an obsession further characterized as "this fetish for the fortuitous, this idolatory of the accidental." The media does a rousing job of reporting particular accident fatalities, but the media and the public's understanding of accidental death in general is disproportionate. "The significant statistic, the singular statistic, is that only 5% of all deaths in the United States are caused by accident. Put negatively or positively, 95% of all deaths are from natural causes."

Projector documents the steady decline in the rate of accidental deaths in America since the pre-automobile days. "The horse and carriage years were years of horse and carriage accidents, of railroad accidents, of steamboat sinkings, of conflagrations, of falling buildings. The railroad passengers then were greater daredevils than aircraft passengers today. . . ." Similar conditions existed in other parts of the world.

His conclusions were very much in keeping with the expose-and-banish-the-death-taboo mission adopted by this early wave of thanatologists. Obsession with the low-incident accidental deaths provided insulation against reflecting on the "natural death" that would end the great majority of lives. Furthermore, "there is another facet to our interest in the fatal accident. Perhaps it is the way we prefer to go, if the choice were ours. Modern medicine prolongs the terminal

illness, prolongs the suffering that generally accompanies a natural death. And who wants to suffer?"

This farewell issue welcomed another wave of new conferences and publications on death. It also reported "A Toe-Hold on the Ivory Tower." Several of the toes in question belonged to me as Wayne State University accepted my seminar on "The Psychology of Life and Death" as a formal course offering (it had actually had trial runs at a community college in Massachusetts). A few years later the course morphed into the interdisciplinary "Death, Society, and Human Experience" that continued to the fade-out of the 20th century. The other toes were property of Ed Shneidman who would in the coming semester challenge Harvard students with a one-time offering of "The Psychology of Death." Within a few years, "death education" took shape as a national movement, acquired and shed its novelty-fad status, and kept rolling.

FROM NEWSLETTER TO JOURNAL

The transition from newsletter to journal occurred rather suddenly and with its share of bumps and detours. Kalish and I had been exploring possibilities for some time though no strong prospects were on the immediate horizon. I then received an unexpected phone call with an invitation to launch a new journal dealing with aging and death. I suggested that two journals were more in order because aging people have more to do than die, and death does not have an exclusive contract with the aged. To my surprise, he agreed almost immediately and within a week we had a preliminary contract. Kalish, in turn, was surprised when informed of this windfall and had to be reassured that this was not a prank before agreeing to serve as editor of *Omega*. Either of us could have edited either journal, but Richard was perhaps more active in social thanatology at that time and I was embedded in a geriatric hospital clinical and research unit.

The first wobble in the process occurred when the acquisition editor told me he had parted ways with the publishing house he had represented. "But not to worry!" Events proved his optimism justified, although not entirely so. Within a month or so (I don't remember exactly), the editor had become associated with another established publisher, one that was eager to expand its journal program. We were in business with Greenwood Press, Inc. Editorial boards were quickly established for both journals, along with basic principles of operation which emphasized peer review and openness to a variety of approaches as long as the quality was there.

The next set of problems was encountered in the production process. Greenwood, primarily a book publisher, seemed to have underestimated both the depth of resources and the time pressure inherent in journal operations. As rookie editors with other full-time obligations, Kalish and I were sufficiently occupied in recruiting, evaluating, and preparing material for the first issues. Kinks in the production process seemed both mysterious and beyond our control. Nevertheless, both journals made their debut more or less on schedule in 1970

and somehow remained on a regular schedule thereafter. The production problems also continued and seemed to be most troublesome with *Omega.* Kalish made a valiant effort to resolve these problems but with limited success. Into his third year of creative leadership but gnawing frustration, Kalish resigned his editorship. I took over as temporary editor for the third issue of volume three (1972), and continued as the temp through volume 38, 1999 (by that time we had accelerated to an annual 8-issue, 2-volume format for both journals). I benefitted greatly from another bump in the road that occurred not long after Kalish's resignation. Greenwood sold much of its journal program to Baywood Publishing Company. At that time a relatively young and small operation, Baywood was also highly motivated and attentive to every facet of the process. There was a mutually supportive family-type atmosphere that would eventually lead to a larger and quite robust journal program. Fortunately, Kalish, who had remained affiliated as associate editor, became closely involved with Baywood and brought out a series of valuable edited books under their auspices. The history of the journal itself and its continuing relationship with the field of thanatology is perhaps a subject for another article and perhaps another author.

DISCUSSION

The prehistory of the *Omega Newsletter* as a journal and its rapid transition to journal status had much to do with its sociocultural time frame. Both aging and death were becoming more salient to the public and the professions for a variety of reasons and motivations (Kastenbaum, 1993). Perhaps the forces acting most directly on the emergence of the death awareness movement were consumerism and naturalism. The public became aware that it had the power of choice as consumer of products and, eventually, of services as well. If Joan and John Q. Public did not have to accept whatever vehicles Detroit felt like making, then why should they also have to accept a system of medical care that seemed to be increasingly impersonal and impervious to their needs and values? The naturalism movement was another facet of this re-evaluation of the relationship between individual and societal institution. "Natural birth," as represented to some extent by the Lamaze Method, became an appealing alternative. "Natural death" became, well, a natural development further down the line. Overall, there was a subtle but discernible shift in public attitude from accepting the "received socio-cultural life," to shaping one's own existence.

The *Omega Newsletter,* then, was not happening in a void. British reaction against the medicalization of death was occurring within the medical profession itself and St. Christopher's Hospice opened its doors a year after our first issue appeared, but Cecily Saunder's pioneering work in palliative care had been ongoing for some time. By 1968, the Living Will document had been introduced by an organization that had renamed itself Concern for Dying ("Euthanasia Educational Council" had led to some misunderstandings about it mission). Here

and there throughout the world there were a growing number of small projects, often informal and almost invariably underfunded, that explored many dimensions of dying, death, and grief. Furthermore, the suicide prevention movement was also moving ahead, as demonstrated by the establishment of the American Association of Suicidology in 1967. In the year between cessation of the newsletter and debut of the journal the public became much more aware of death-related issues with the publication of Elisabeth Kübler-Ross' first book (1969) and her numerous public appearances. "Thanatology" was still a word one seldom encountered unless burrowing into older and mostly neglected literature, but death was certainly in the air again.

Some publishers were catching on. There would be a steady increase in the number of scholarly journals devoted to aging issues. Special sections or issues on death were appearing occasionally in established journals. It was about time for an enterprising scholarly publisher to look into the possibility of a dying and death journal. The newsletter had found enough stimulating material to share that a publisher would not have to start quite from zero.

It was our impression that the newsletter both represented the nascent field at that point in time and contributed something to its continued development, if only an opportunity to communicate with scattered others who were also "somewhere out there trying to do something," and a slight touch of legitimization. In preparing for this article, however, I was also impressed by the quality of many of the guest editorials and brief reports. Some of the questions raised and suggestions offered are still very much in play. One could do worse than to read through the newsletters and the early years of the journal itself: here were soundings from "the birth of the death people," to borrow Avery Weisman's phrase.

An historian seeking to understand the emergence and development of the death awareness movement from the 1960s forward will find much of interest in the *Omega Newsletter* and the subsequent journal, as well as in the other valuable professional and scholarly periodicals and have now been serving the field for a number of years. What were the compelling issues? The marginal topics? The divisive issues? The implicit economic, political, and religious agendas? These questions can be addressed and other questions raised for readers who have a hunch that we might have a better understanding of where thanatology might be going if we had a better idea of where it is coming from.

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OMEGA, Vol. 48(1) 85-88, 2003-2004

STILLBIRTH: TO HOLD OR NOT TO HOLD . . .

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The prevailing clinical wisdom that for decades guided the psychosocial care of parents who have experienced stillbirth is aptly summarized by Klaus and Kennell (1982), "To help the mourning process, we encourage mothers to see and handle their infant after he has died. . . . The infant's identity can best be established if the bereaved parents are encouraged to look at, touch, and hold their child. . . .We have been impressed that the mourning process is particularly prolonged and difficult to resolve when the stillborn infant has not been seen or held by the parents" (pp. 286-287).

However, recent research reported in *Lancet* by Hughes et al. (2002) on the psychological effects of stillbirth found that "Behaviours that promote contact with the stillborn infant were associated with worse outcome. Women who had held their stillborn infant were more depressed than those who only saw the infant, while those who did not see the infant were least likely to be depressed. . . . Women who had seen their stillborn infant had greater anxiety and higher symptoms of PTSD than those who had not, and their next-born infants were more likely to show disorganised attachment behaviour. Having a funeral and keeping momentos were not associated with further adverse outcomes . . ." (p. 114). Their findings contradict good practice guidelines suggesting failure to see and hold the dead child could have negative effects on the parents mourning.

As though anticipating the *Lancet* findings, Kennell, et al. (1970) in a previous study noted that although mothers had "no unduly upsetting reactions at the time of physical contact or later pathologic grieving as defined by Parkes and Lindemann . . . *Because the interviews were conducted less than six months after the death of the infants and were designed to investigate the acute stages of the mourning process, it is not possible to state with assurance that later pathologic reactions . . . will not occur*" (p. 347, italics mine).

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When I shared the results of this study with colleagues, it became apparent how threatening research that does not support our own views or current practice is. The common reaction was to denigrate the study, even before reading it. One colleague suggested the work might have a cultural bias because it was conducted in England. I reminded her that much of our seminal research on loss has emanated from England, e.g., the work of John Bowlby and Collin Murray Parkes, the Tavistock studies and the creation of St. Christopher's, the first hospice, in London (Kastenbaum, 2001).

Why is the Hughes et al. study so surprising? The absence of rigorously designed research in the field has produced folklore around the practice of grief counseling. For decades we believed that individuals who did not do grief work would have a *pathological* reaction. Although we are more politically correct and replace pathological with complicated, most counselors still hold to this notion. They disregard recent studies (Kastenbaum, 2001; Martin & Doka, 2000) showing that many people, e.g., *instrumental grievers,* adjust well to loss without delving into a heavy affective laden exploration of their feelings. Sometimes grief counselors entangle themselves in contradictory clinical rhetoric: we espouse the protective and necessary benefits of denial as a natural psychological shock absorber while labeling a client who chooses to be silent as "resistant" or "in denial."

John Bowlby, "the pioneer and lead architect of attachment theory, taught that humans have an instinctive propensity to form strong and persistent affectional bonds" (Belitsky & Jacobs, 1986, p. 276). If depressive elements are embedded in the mourning process, why are we surprised to find that enhancing affectional bonds by holding a dead baby causes parents to mourn for longer periods? Or, a mother who holds her dead baby to have more symptoms of PTSD than a mother who does not. Noting the inherent psychodynamic complexity of pregnancy as a normative psychosocial crisis, Turrini (1980) states, "Critical to helping women in pregnancy is a proper diagnostic assessment. It must be appreciated that certain psychic developmental tasks of pregnancy are universal to all pregnant women. The major body changes in a short period of time and the challenge of attaching to, yet differentiation out from the developing baby are two of the critical tasks. It must be recognized that the women with well developed ego functions (the good enough mother) will be deeply challenged by these tasks. . . . Women with less structured egos, and less self-protective functions, particularly those without object constancy will experience severe stress and will need even greater support and help" (p. 147). Studies of infant-mother bonding underscore that touch is the most important behavioral system that binds mother and infant together (Klaus & Kennell, 1982). Furthermore, the infant's ability to initiate interactions and to respond to maternal stimulation is a powerful influence on the mother's early feelings of attachment (Kliot & Silverstein, 1980). However, what do we know about the psychiatric/psychosocial affects of mothers who touch (hold) a dead infant incapable of initiating contact or responding to maternal stimulation?

If the helping system induces depression then we must consider the depression iatrogenic and reexamine our practices. Indeed, to not take seriously research that challenges our current practice is a serious breach of our professional obligation to "first do no harm." Helping professionals such as Nichols (1989) advocated fiercely to give parents options in the care of their dead baby and to offer interventions that would promote adaptive coping, i.e., ". . . offering parents the opportunity to spend time with the child, by letting them know it is okay (*but not mandatory*) to be with the dying baby (p. 122, italics mine). However, at some point giving parents options has become usurped by prescription, i.e., "to begin the grief process for a stillborn baby, parents *must* face the reality of the loss " (Stack & Barnas, 1987, italics mine), and "parents *need to* see, and if possible to hold their dead infant" (Lewis, 1980, p. 312, italics mine). Could our overzealous desire to help, and a belief that we know what is best, cause us to lose sight that encouraging parents to hold their dead baby may deprive them of the needed mercy of denial? Are our attempts to help parents initiate the mourning process causing too much grief? Patients have the right to absorb or not absorb the full reality of their loss. I believe parents must face the reality of their loss on their own terms, not ours. Seeing, naming, keeping mementos, having a funeral and holding the dead baby, signify a gradient of confrontation with the reality of loss. To find that holding and seeing their dead baby may push some parents over a threshold seems reasonable as it may deprive them of the needed protection of denial. Helping professionals are quick to note that parents who hold their dead infant were glad they did (Klaus & Kennell, 1982). However, being glad they did does not negate that having done so might be detrimental.

If we believe our prevailing clinical acumen that everyone grieves differently in their own way and in their own time, then we cannot offer a one size fits all approach to psychosocial intervention following stillbirth. The most important question raised by the study of Hughes et al is whether it is time for those invoking psychosocial interventions to embrace the issue of *risks* and *benefits* discussions. Although the research is preliminary and should be viewed with caution, reasonable evidence now exists showing that mothers who hold their dead baby may experience disorganized attachment with a subsequent birth. We have to advise of this possible outcome.

Parents must be informed of the option to hold and see their dead infant. However, a helping professional's too rigid, overzealous adherence to perinatal bereavement protocols can deprive the patient of *individualized* intervention and care plan that is *assessment* driven. Indeed, perhaps the most serious deficit in the psychosocial management of stillbirth is the lack of a thorough psychosocial/psychiatric assessment *prior to* the introduction of postnatal care options for the stillborn.

We must be assertive to engage parents in more robust explanations of the risks as well as the possible benefits of their choices. Helping professionals advocated fiercely to give parents options in the care of their dead baby and to offer

interventions that would promote adaptive coping. However, blind adherence to practices that are not supported by current research subverts the very goal of our advocacy.

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OMEGA, Vol. 48(1) 89-99, 2003-2004

AN EXPLORATORY STUDY OF THE EMOTION-EXPRESSIVE BEHAVIORS OF "PEACE," "CONTENTMENT," AND "ANNOYED/IRRITATED": IMPLICATIONS FOR DEAD AND LIVING FACES

FRANK EYETSEMITAN, PH.D.
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ABSTRACT

This study initially set out to explore the facial features (and their descriptions) of the emotion-expressive behaviors of "peace" and "contentment" but ended up with a third one, "annoyed/irritated." The emotion-expressive behaviors of "peace" and "contentment" have been associated with the faces of deceased persons in a previous study. The pictures of two volunteers taken during a class on relaxation technique were given to 93 respondents made up of volunteer students from a small midwestern college and volunteer residents of a nursing home (see Appendix A and B). Participants were asked to choose from a list provided them the emotion-expressive behavior ("e.g., peace, content, hopeful, other") that closely described each of the facial pictures presented. They were also asked to both identify and describe the facial feature(s) that closely matched the emotion-expressive behavior they had chosen. Most of the respondents identified Picture #1 as "peaceful" and Picture 2 as "annoyed/irritated." The eyes and the mouth were more salient in describing both emotions. This study has implications for those who identify loved ones before viewing; for individuals who prepare deceased persons for viewing; for embalming educators; and for actors of these emotions.

Whereas Oatley and Jenkins (1992) contend that facial expression is by far the most extensive body of data in the field of human emotion, little or no studies has been done on the emotion-expressive behaviors of "peace" and "contentment," mostly associated with the faces of deceased persons. Therefore the aim of this

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exploratory study is to investigate the facial features that are associated with the emotions of "peace" and "contentment," since these emotions have implications for bereavement outcomes (see Eyetsemitan & Eggleston, 2002 for details).

The biological origin of emotion has been supported from cross-cultural studies with six emotions said to be universal (biologically wired). These are the emotions of happiness, surprise, sadness, fear, anger, and disgust (e.g., Ekman et al., 1987); also contempt, as different from disgust, appears to be universal (Ekman & Friesen, 1986; Ekman & Heider, 1988; Izard & Haynes, 1988). Emotions that are not biologically wired are learned. Since the emotion-expressive behaviors of "peace" and "contentment" are yet to be identified as biologically-wired, the assumption is that they are learned.

But in order to study emotion more precisely, emphasis has been placed on typical features (Ekman, 1992; Russell, 1991; Shaver, Schwartz, Kirson, & O'Connor, 1987), especially facial features that mark them. Using the Facial Action Coding System (FACS) of Ekman and Friesen (1978) the expressive signs of "embarrassment" has been identified (Keltner, 1995) while "happy" and "unhappy" smiles also have been differentiated (Frank, Ekman, & Friesen, 1993).

Different facial areas are considered important in emotion-expressive behaviors. For example, the appropriate display for the emotion-expressive behavior of "surprise" consists of curved eyebrows, wide-open eyes, a straight nose, and a rounded open mouth (see Ekman & Friesen, 1975 for details). For "fear," the eyebrows are raised almost meeting in the space just above the nose (Matsumoto, 1989).

There are conflicting reports, however, on which facial components are more salient in interpreting emotions. Whereas the eye region is said to be the most important (Young-Browne, Rosenfeld, & Horowitz, 1977), its saliency is said to be restricted only to the emotions of "anger" and "happiness" (Cunningham & Odom, 1986; Walden & Field, 1982). The mouth appears to provide more information for most emotions (Cunningham & Odom, 1986). However in the case of deceased persons who are embalmed and prepared for viewing, both the mouth and the eyes are shut. Thus viewers may have to rely on other facial features like the eyebrows, nose position, and even the closed eyes and mouth positions in making their interpretations.

Using Gross' (1998) consensual process model of emotion, the evaluation of emotional cues (e.g., facial features of a deceased person) occurs first before a coordinated set of emotional response tendencies (behavioral, experiential, and physiological) will occur; and these response tendencies may be modulated before an emotional response is finally made (or the ascription of an emotional discrete term like "peaceful" or "contentment" is made). Modulation could be influenced by alcohol and recreational drugs (e.g., Pervin, 1988); by socialization experiences (e.g., Martin & Doka, 1996, 1998); and by personality factors (e.g., Larsen & Ketelaar, 1991). In other words, two individuals may give the same facial features different interpretations.

METHOD

Participants

Participants were student volunteers from a small private college and resident volunteers from a nursing home in the midwestern part of the United States. The residents belonged to the high functioning unit of their nursing home, which had different units to which residents belonged, according to their functional status. The volunteers in this study were able to comprehend what the study was about. In addition, the research assistant, who worked at that time as a volunteer in this nursing home, attested to the functional status of the participants. All the participants totaled 93, and were made of up 25 males and 68 females with a mean age of 25 years (age range from 18 to 84).

Although a sample of convenience, the choice of college students and nursing home residents was to have a range of adults (both young and old) who typically make up the viewer-ship of deceased persons.

Instrument

There were two questionnaires; each had the same questions, but different pictures on them (see Appendices A and B). The pictures were the faces of two female volunteers taken during a relaxation exercise in a counseling class. Both pictures will be referred to as Pictures #1 and #2. Using what she described as a standard meditative relaxation technique the counseling professor asked the class to get into a comfortable position, close their eyes, and breathe deeply while counting from 10 backwards and visualizing descending a flight of steps. Next, the students were asked to tense and then relax their arms, hands, legs, and feet, while continuing to breathe deeply. All these continued for approximately five minutes. Picture #1 was shot during the relaxation phase while Picture #2 was taken during the tense phase.

This approach was adopted because of futile efforts to take facial pictures of dead persons. So while Pictures #1 and #2 provided the closest scenarios to the faces of deceased persons they also allowed for two different facial depictions, which may exemplify the possible range of facial depictions of deceased persons. In the previous study, Eyetsemitan and Eggleston (2002) used pictures of dead persons in a casket (photocopied from a book), but because the dead persons were in a laying down position it was difficult to tell if respondents' were prone as a result, in making attributions of the emotions of "peace" and "contentment" to the pictures shown them. Therefore, the approach adopted in this study allowed for the control of a likely position effect. Both pictures of volunteers in this study were taken in a sitting position.

In the questionnaire, respondents were instructed to select from a list one of the following emotion-expressive behaviors that closely described the face shown them: 1) "content"; 2) "peaceful"; 3) "hopeful"; and 4) "other" (they should

specify). Then they were asked to select a facial feature from among the following list: forehead, eyebrow, eyes, nose, mouth, cheeks, and chin, that was closely associated with the emotion-expressive behavior they had selected. Respondents were not restricted to the number of facial features they could select. In order words, they could select one or all of them. For each facial feature selected, a space was also provided for respondents to describe it.

Procedure

The two different questionnaires were handed to each respondent by the researcher or his research assistant in the classroom and respondents completed both questionnaires in no particular order. All the questionnaires handed out in the classroom were collected, so there was 100% return rate. A research assistant helped to conduct the same survey in a nursing home. But here, she helped the respondents to complete the questionnaires after reviewing the questionnaires with them. Again, there was 100% return rate.

RESULTS

The results show the number of respondents who associated the following emotion-expressive behaviors with Picture #1: "peaceful" (46), "content" (20), "bored/sleepy" (12), and "disturbed/irritated" (15). For Picture #2, a breakdown of the results shows the following: "peaceful" (17), "content" (20), "hopeful" (7), "concentrating/thinking" (13), and "disturbed/irritated" (35). More respondents identified Picture #1 as "peaceful" than they did Picture #2, and more respondents identified Picture #2 as "disturbed/irritated" than they did Picture #1. The combined totals of respondents who identified both pictures as "peaceful" was 63, as "content" was 40, and as "disturbed/irritated," was 50. Unlike the other emotions attributed to both faces, the numbers for "peaceful," "content," and "disturbed/irritated" were sizeable to analyze the facial features that described them.

Peaceful

The facial features closely related to "peaceful" in Picture #1 and the percentages of respondents who chose those facial features were the following: a) forehead (39%); b) eyebrow (35%); c) eyes (72%); d) nose (17%); e) mouth (72%); f) cheeks (24%); and g) chin (9%). Most of the respondents equally identified the eyes and the mouth as closely related to the emotion-expressive behavior of "peaceful." Ninety-one percent of those who identified the eyes described them as "closed gently/relaxed" and 85% of those who identified the mouth described it as "relaxed/not tensed up." For the forehead, 94% described it as "relaxed/no creases/no wrinkles." Eighty-eight percent described the eyebrows as "relaxed"; 73% described the cheeks as "relaxed"; 63% described the nose as

"relaxed"; and 100% of respondents who chose the chin described it as "relaxed." But the most salient facial features closely related to "peaceful" were the eyes and mouth.

In Picture #2 the eyes were mostly associated with "peaceful" (94%), followed by the mouth (76%), the eyebrows (41%), and by both the forehead and the cheeks (24% each). Eighty-two percent of those who chose the eyes described them as "closed gently/not tightly;" 85% of those who chose the mouth described it as "relaxed/slightly closed;" and 71% of respondents who chose the eyebrows described them as "relaxed/no wrinkles." One hundred percent of the respondents who chose the forehead and the cheeks described both as "relaxed." Again in Picture #2, the two outstanding features related to "peaceful" were the eyes and the mouth.

In both pictures, apart from the eyes and mouth, the eyebrow, forehead, and cheeks were other important facial features associated with the emotion-expressive behavior of "peaceful."

Content

In Picture #1, only six out of 20 respondents identified the forehead with "content." In all cases (100%), the forehead was described as "smooth/no strain/no wrinkles." Nine out of 20 respondents closely associated the eyebrows with "content" and 89% of them described the eyebrows as "relaxed/smooth." Fifteen out of 20 respondents chose the eyes and 93% of them described the eyes as "closed slightly and not scrunched." Eighteen out of 20 respondents (the highest number) identified the mouth as closely related to "content." Out of this number 78% generally described the mouth as "relaxed, with no expression." Both the cheeks and the chin were identified by only four respondents, but with no clear patterns of description.

In Picture #2, fifteen out of 20 respondents identified the eyes and the mouth; with only less than 50% (47% in both cases) describing the eyes and mouth as "closed lightly" and "closed with no expression," respectively. The cheeks were identified by only seven respondents; the forehead, nose, and chin by less than five respondents.

In both pictures, the eyes and mouth were more salient than the other facial features for the emotion of "content."

Annoyed/Irritated

This emotion-expressive behavior was not one of those being investigated, but turned out to be a response provided by a sizeable number of respondents. Fifteen respondents identified Picture #1 as "annoyed/irritated." Of this number, seven identified the eyes and all 15 identified the mouth with only three and under identifying the chin and the eyebrow. All the seven who identified the eyes described them as "closed/big/rolled back/dream-like." Ten of the 15 persons

(67%) who identified the mouth described it as "drooping/pulled downwards." The eyebrows and chin were identified by only two and three respondents, respectively.

However, more respondents (35 persons) identified Picture #2 as "Annoyed/ Irritated." Of this number 23 chose the eyes and they all (100%) described the eyes as "tightly shut," 30 chose the mouth and of this number, 50% of them described the mouth as "drawn down at the corners." All the 12 who chose the eyebrows, described them as "furrowed/higher than normal/drawn inwards." The forehead, cheeks, and chin were chosen by only five or less than five respondents. In both pictures, again, the eyes and mouth areas were more salient than the other facial features.

DISCUSSION/CONCLUSION

This study confirms previous findings that have identified the eyes and the mouth regions as salient parts for most facial emotions (cf. Cunningham & Odom, 1986; Young-Browne, Rosenfeld, & Horowitz, 1977). It also confirms Gross' (1998) model that recognizes the importance of modulating factors in emotion, exemplified by the respondents' ascriptions of different emotion-expressive behaviors to the same pictures, and the same emotion-expressive behaviors to different pictures—perhaps a reflection of respondents' different socialization experiences (cf. Martin & Doka, 1996, 1998) and different personalities (cf. Larsen & Ketelaar, 1991), which were not investigated in this study.

However most respondents described Picture #1 as "peaceful," and most of them described Picture #2 as "disturbed/irritated." So there is a pattern. Furthermore, there appears to be no positioning effect (sitting) in making facial attributions of the emotion-expressive behaviors of "peace" and "contentment" (cf. Eyetsemitan & Eggleston, 2002).

The facial features identified with the respective emotion-expressive behaviors have implications for persons who identify their loved ones before viewing and prepare the deceased for viewing; for embalming educators; and for actors of these emotions (in theater plays and movies).

In the future, the facial attributes of "bored/sleepy"; "thinking/concentrating"; and "hopeful" need to be explored with sizeable samples, as a large sample size is also needed for the emotion-expressive behaviors discussed in this article before definite conclusions can be made.

Furthermore, because the sample size was small it was not possible to compare subjects' perceptions, based on age and gender. Studies have found differences in the intensity of emotional expression between young and older adults. For example Levenson, Carstensen, Friesen, and Ekman (1991) studied older subjects' physiological responsivity to a directed facial task (moving muscles on the face to stimulate an emotional expression) in a relived emotion task and to relive past emotional experiences. They reported the magnitude of change found in

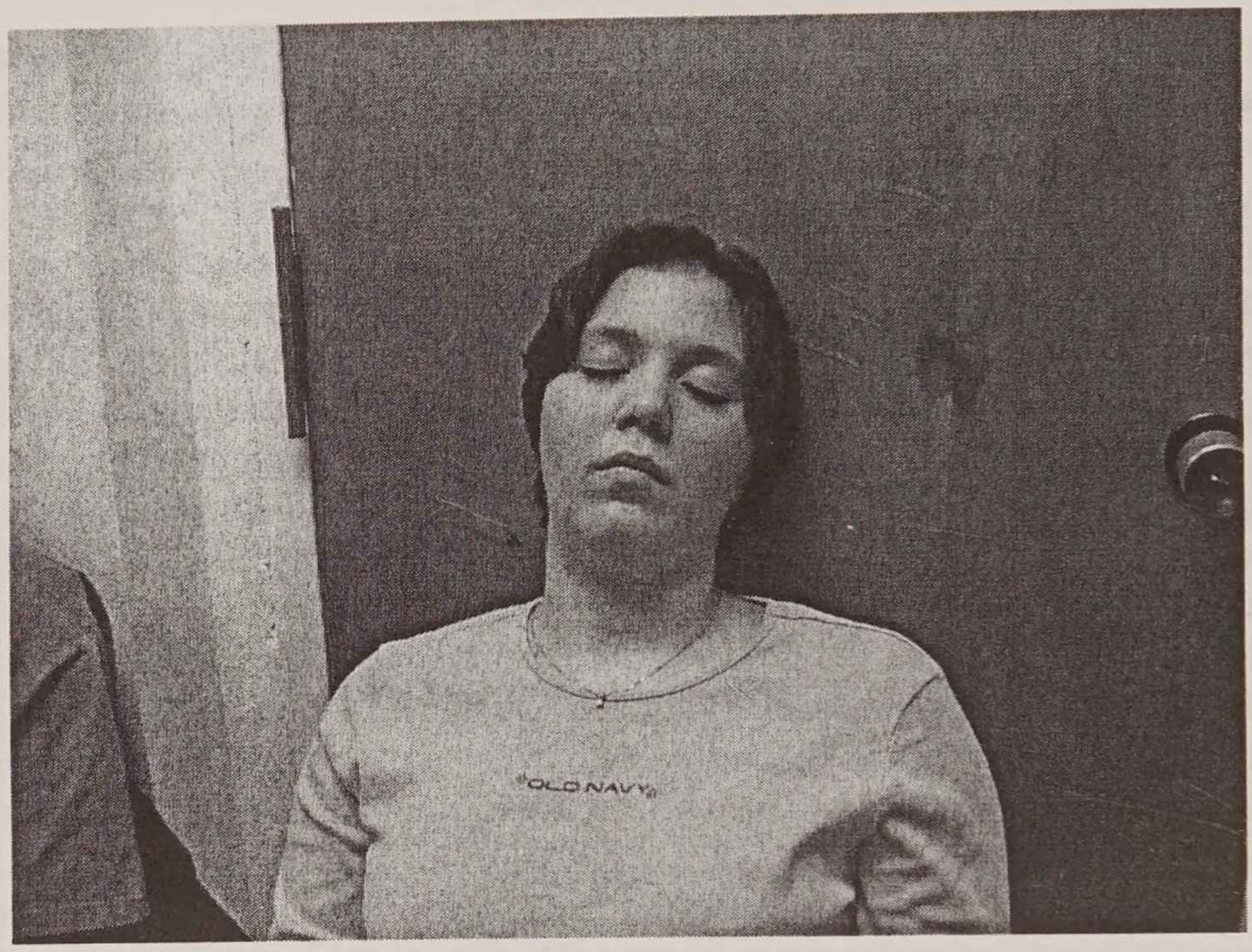
older subjects to be much less than that found in younger subjects, concluding that the autonomic reactivity expressed by older people was less intense than that expressed by young people. Gender difference was however reported with elderly women experiencing more intense emotions than elderly men when reliving emotional memories.

Lawton (1996) ascribes the reduced intensity in autonomic reactivity in older people to a physiological blunting or because older people find it difficult to deal with high levels of arousal and therefore evolve complex strategies for dealing with their emotions such as evaluating, deciding, delaying, and controlling.

Therefore, is the difference in physiological reactivity found between young and older persons likely to influence how both groups will perceive the facial emotions of others, and the facial features that describe the emotions? Future studies should investigate the influence of age and gender on the perception of the facial emotions reported in this study. Also important to investigate is whether people of different cultural backgrounds might have a convergence or not in identifying the emotion-expressive behaviors of "peace," "content," and "annoyed/irritated" (cf. Melzack, 1973; Turnbull, 1962).

Since this qualitative study has identified the emotion-expressive behaviors of "peace," "content," and "annoyed/irritated" with certain facial features, future studies might consider also using the Ekman and Friesen's (1978) Facial Action Coding System (FACS) to study these emotions.

Appendix A follows on next page



Picture 1

APPENDIX A
Survey on Facial Emotion

This is a survey on facial emotion. Please select **one** of the following emotion-expressive behaviors that closely describes the face presented to you:

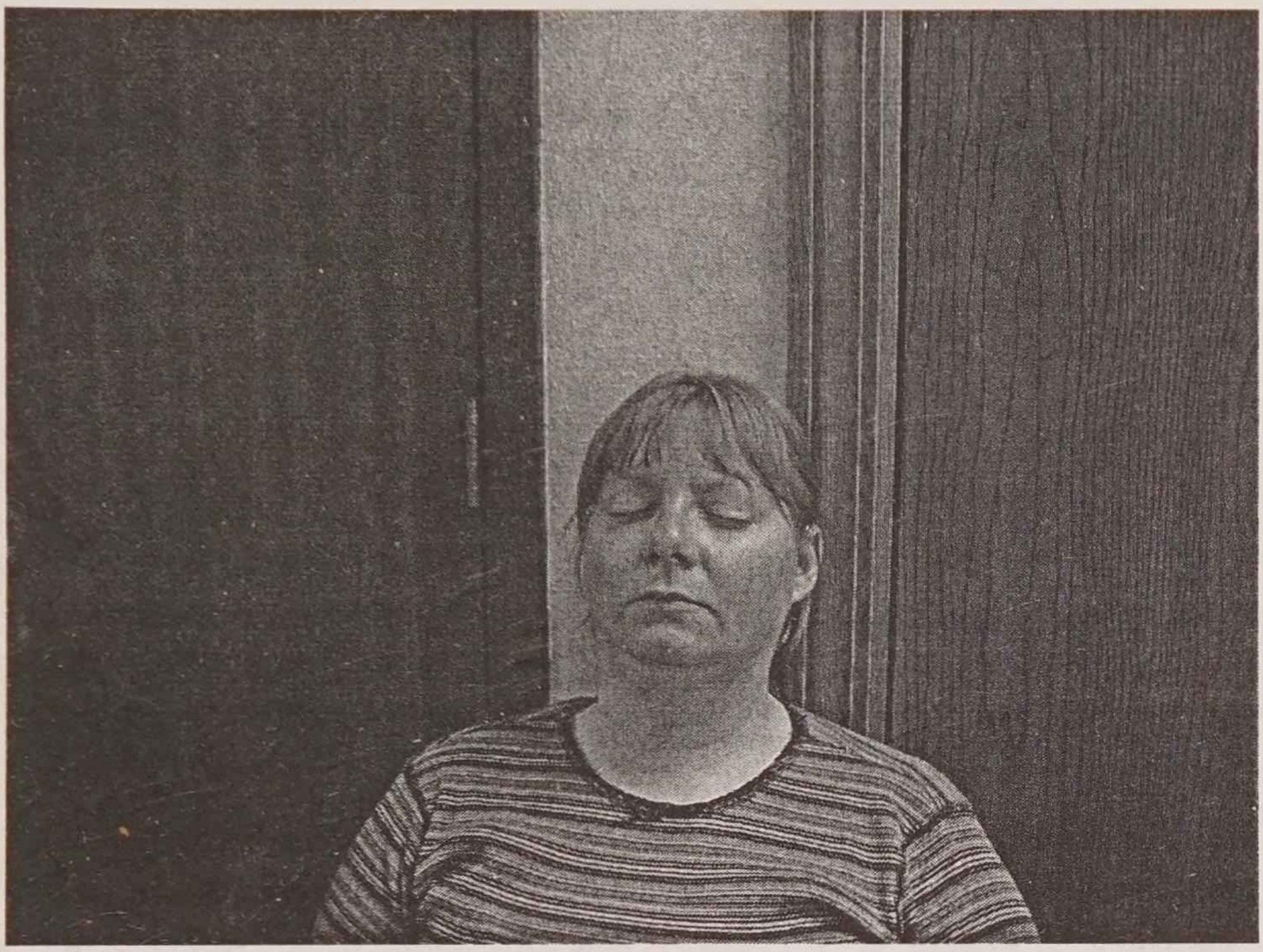
Content ___ Peaceful ___ Hopeful ___ Other (please specify) _____

Which of the following facial feature(s) is **closely** associated to the emotion-expressive behavior you have selected (you can select more than one)? Please briefly **describe** it in the space provided:

1. Forehead _____ *Description* _____
2. Eyebrow _____ *Description* _____
3. Eyes _____ *Description* _____
4. Nose _____ *Description* _____
5. Mouth _____ *Description* _____
6. Cheeks _____ *Description* _____
7. Chin _____ *Description* _____

Your Biographical Information:
Age: _____ Sex: Male _____/Female ____ Major _____
Comments: _____

Thank you!



Picture 2

APPENDIX B
Survey on Facial Emotion

This is a survey on facial emotion. Please select **one** of the following emotion-expressive behaviors that closely describes the face presented to you:

Content ___ Peaceful ___ Hopeful ___ Other (please specify) _____

Which of the following facial feature(s) is **closely** associated to the emotion-expressive behavior you have selected (you can select more than one)? Please briefly **describe** it in the space provided:

1. Forehead _____ *Description* _____
2. Eyebrow _____ *Description* _____
3. Eyes _____ *Description* _____
4. Nose _____ *Description* _____
5. Mouth _____ *Description* _____
6. Cheeks _____ *Description* _____
7. Chin _____ *Description* _____

Your Biographical Information:
Age: _____ Sex: Male _____/Female ____ Major _____
Comments: _____

Thank you!

ACKNOWLEDGMENTS

I wish to thankfully acknowledge Stacie Adams and Jessica Huff for their assistance with data collection; Renee Schilling and Kari Kelly, who as volunteers, allowed their pictures to be taken for this study; and Dr. Murella Bosse, the counseling instructor who gave the instructions on relaxation technique.

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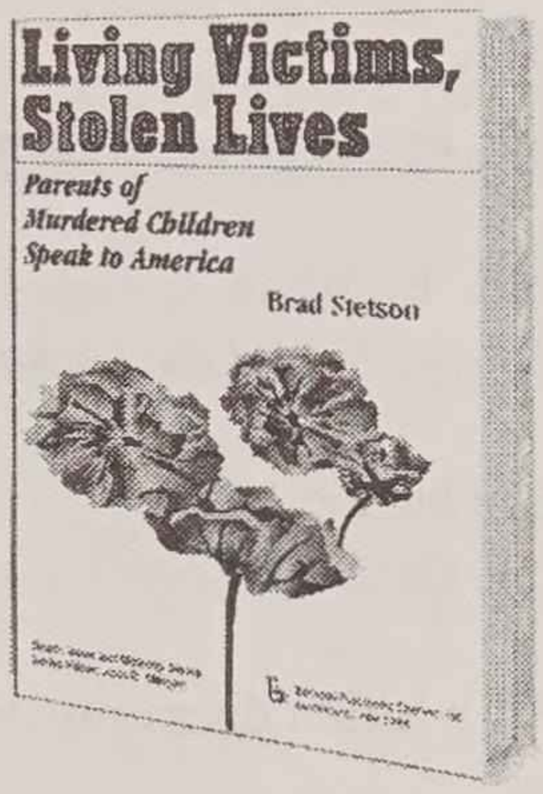

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Letters From A Friend
A Sibling's Guide for Coping and Grief

Erika R. Barber

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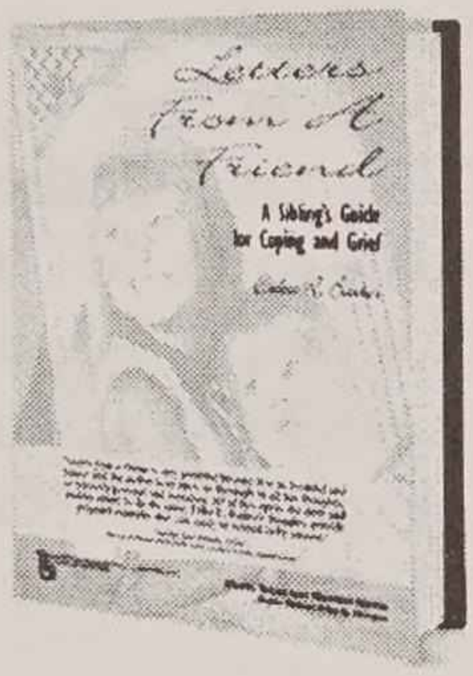

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Death Without Notice

Sandra Helene Straub

When someone you love dies, you wonder if you will survive. The death of a loved family member or friend brings a flood of feelings—sorrow, loneliness, abandonment, anger, and guilt. These feelings make the task of mourning one of our most painful human experiences.

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6″ × 9″, 184 pages, Cloth, ISBN: 0-89503-214-7, $39.00 plus $5.50 p/h

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ABC's of Grief

A Handbook for Survivors

Christine A. Adams

The *ABC's of Grief: A Handbook for Survivors* meets bereaved persons wherever they might be in the grieving process, providing snatches of meaning, hope, empathy, and understanding. The handbook is a product of the author's own passage and includes materials collected over a three-year period of the grieving process. Confronting her loss, Christine Adams found that it was all right to grieve at her own pace: one day at a time, one thought, word, and letter at a time, she grew and healed.

The handbook's alphabetical format allows readers or group leaders to focus on any aspect of grief that suits them. If a reader becomes absorbed in "anger" or "anxiety," he or she can go back to reread those parts of the handbook and with each visit will find some new realization and meaning. Every section contains appropriate quotations, stories, and poems, written by survivors who found solace in writing.

ABC's was written to be both a source of information and inspiration. The information is useful at a time of grief, the encouragement by the author is soothing, and the poems and stories remind the reader that others have visited the same places in their grief process. Counselors, therapists, social workers, and clergy will find the *ABC's of Grief* of tremendous value to their clients. In addition, every hospice would benefit by having a copy of the handbook in its library.

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