

# Open Communication Between Caregivers and Terminally Ill Cancer Patients: The Role of Caregivers' Characteristics and Situational Variables

Yaacov G. Bachner and Sara Carmel

Department of Sociology of Health The Center for Multidisciplinary Research in Aging Ben-Gurion University of the Negev, Beer Sheva, Israel

This study assesses caregivers' perceived level of open communication about illness and death with their terminally ill relatives and examines the contribution of caregivers' characteristics and situational variables to the explanation of open communication. A total of 236 primary caregivers of terminal cancer patients participated in the study. Level of open communication was measured by 6 items clustered into 1 factor. Caregivers' characteristics were composed of demographic variables, personality traits, and negative emotional reactions to caregiving. The situational variables included the duration and intensity of caregiving, and perceived functioning and suffering of the patient. Caregivers experienced substantial difficulties in communicating with patients about illness and death. Level of open communication was explained by caregivers' emotional reactions (emotional exhaustion, depression) and self-efficacy, as well as by the duration of caregiving. Intervention programs for health professionals need to focus on prevention, identification, and treatment of caregivers at risk for negative reactions to caregiving.

The diagnosis of a life threatening disease such as cancer alters the relations among all family members. Interpersonal communication is an important and significant part of these relations. Studies show that higher levels of open communication between caregivers and patients at this moment of crisis may have a positive impact, whereas lower levels of open communication may have a negative impact on both parties.

Difficulty in discussing cancer openly often creates a void in the caregiver-patient relationship at a critical time when patients have a strong need to talk and share experiences (McGrath, 2004). Such situations not only harm the quality of caregiver-patient relations and family functioning (Edwards & Foster, 1999), but also often delay recognition and treatment of patients' pain or other symptoms that can be life threatening (Hinds, 1992). Furthermore, negative

feelings, uncertainty, lower sense of control, lower self esteem, and more psychological and physical problems are reported by patients in families who are not able to discuss cancer openly, in comparison to families who do not have such difficulties (Mesters et al., 1997). In contrast, honestly expressing concerns and feelings about cancer within the nuclear family enhances the abilities of family members and patients to cope with the disease (Gotcher, 1993). More specifically, open communication is associated with higher levels of empathy and intimacy among spouses and patients (Porter, Keefe, Hurwitz, & Faber, 2005), high levels of family members' support (Mesters et al., 1997), and lower levels of feelings of burden among caregivers (Fried, Bradley, O'Leary, & Byers, 2005). Talking openly and freely about cancer may facilitate the processing of cancer-related thoughts and feelings, which leads to meaningful interpretation of the experience and to emotional acceptance (Lepore & Helgeson, 1998). All of these studies emphasize the importance of open communication to patients' and caregivers' well-being and their ability to cope with the illness and its consequences.

Correspondence should be addressed to Yaacov G. Bachner, Department of Sociology of Health, Faculty of Health Sciences, Ben-Gurion University of the Negev, Beer-Sheva 84105, Israel. E-mail: bachner@bgu.ac.il

Despite the importance of open communication to both parties, and an expressed need for family members to communicate about the illness (Kilpatrick, Kristjanson, Tataryn, & Fraser, 1998), major barriers to open communication have been reported in the literature (Higginson & Constantini, 2002; Zhang & Siminoff, 2003). Difficulties in communication are reported in all stages of the terminal illness (Northouse & Northouse, 1987), but as the illness progresses, family communication becomes increasingly intermittent, and talking about death and dying is particularly difficult. Krant and Johnston (1977) reported that 92% of family members of American cancer patients had thoughts about the possibility of the patient's death, but only 22% discussed this possibility with the patient. A study that assessed communication at the end of life in three European countries revealed that in the last week of life 30% to 40% of patients experienced communication difficulties with their family members (Higginson & Constantini, 2002). Zhang and Siminoff (2003) reported that death and dying was the most difficult issue for family members and patients to discuss at late stages of lung cancer. Only 23% discussed issues of end-of-life care, and 12% talked about the possibility of institutionalization in a hospice.

Several explanations have been offered for the difficulties in communication encountered by cancer patients and their family members at the end of life. Vess, Moreland, Schwebel, and Knaut (1988) suggest that caregivers and patients commonly engage in mutual "protective buffering," that is, the avoidance of discussion of fears and concerns in order to protect each other. This avoidance may also stem from the unwillingness of both parties to acknowledge the patient's foreseen decline in health (Edwards & Foster, 1999). Many caregivers have the misconception that it is harmful for patients to discuss their illness or any negative aspects of the situation. These caregivers think that they always need to cheer up the patient and keep an optimistic atmosphere (Peters-Golden, 1982). Most of these explanations are in accord with Zhang and Siminoff's (2003) findings that the difficulties in interpersonal communication stem from three distinct cognitive processes: avoidance of psychological distress, desire for mutual protection, and belief in positive thinking. Another aspect is raised by Northouse and Northouse (1987), who claimed that many cancer patients' caregivers fear the disease themselves and therefore are reluctant to express feelings or to communicate about it.

There is a distinction in the literature between three groups of variables associated with caregiving outcomes: those pertaining to the caregiver, the patient, and the caregiving situation. Because this study evaluates the communication as perceived by the caregiver, we focus on characteristics and situational variables pertaining to caregivers, which were reported to correlate with caregivers' well-being. In each group of variables we examined well-established variables such as caregivers' personality characteristics, and new ones such as perceived level of patient's emotional and physical suffering. Contrary to most studies, we focus on the interpersonal communication regarding the last 3 months of the patient's life, when family communication becomes emotionally difficult. Our scale, therefore, includes reference to communication not only about the illness (as in previous studies) but also about the approaching death. Better understanding of the associations between these factors and communication difficulties experienced by caregivers at late stages of their loved one's illness will enable the development of intervention programs aimed at enhancing caregivers' level of open communication with their terminally ill loved ones.

The purpose of the study is twofold: (a) to assess caregivers' perceived level of open communication about illness and death with their terminally ill relatives, and (b) to examine the contribution of different caregiver characteristics and situational variables to the explanation of open communication.

#### METHOD

#### Participants and Procedure

Caregivers whose relative died of cancer at the age of 60 or over, and who did not receive payment for the care they provided, were recruited to participate in the study. Only primary caregivers—that is, those who provided the most hours per day of care for the patient during the terminal stage of the disease—were included in the study. In this sample, the mean hours of caregiving per day was high— 17.30 (range: 1–24, SD = 7.76).

A total of 491 potential participants was asked to take part in this study. Of this number, 54 caregivers could not be located, and 201 declined to participate. Most of the refusals were attributed to emotional difficulties caregivers continued to experience. Two hundred and thirty-six caregivers participated in the study, reflecting a response rate of 52%. This response rate is within the accepted limits for this type of research (Babbie & Benaquisto, 2002). No significant differences were found between the participants and nonresponders with regard to the sociodemographic variables such as age, sex, and place of birth. The sociodemographic characteristics of the participants are presented in Table 1.

The names of potential participants were obtained from the oncology department patient files of four general hospitals in the South and Central regions of Israel and home-care patient lists of the health insurance agencies in the corresponding hospital regions. These were obtained over a period of 18 months (June 2003–November 2004) and included patients who had died within the previous year. The study was approved by the Helsinki ethics committee of the local university medical center.

After obtaining the lists, a letter was sent to each prospective participant explaining the study and requesting his

TABLE 1
Description of Caregivers' Sociodemographic
Characteristics ( $N = 236$ )

Variable	N(%)	М	SD
Age (years)		55.37	13.69
Sex			
Men	53 (22.5)		
Women	183 (77.5)		
Marital status			
Single	16 (6.8)		
Married	95 (40.3)		
Divorced	16 (6.8)		
Widowed	109 (46.1)		
Number of children		2.58	1.54
Education level			
Elementary	25 (10.6)		
Some high school	33 (14.0)		
High school	62 (26.3)		
Beyond high school	39 (16.5)		
Some college	22 (9.3)		
College graduate	55 (23.3)		
Employment status			
Retired	116 (49.2)		
Part-time work	42 (17.8)		
Full-time work	78 (33.0)		
Duration of caregiving (months)		18.89	23.61
Relationship to the patient			
Spouse	106 (44.9)		
Son/daughter	113 (47.9)		
Son/daughter-in-law	10 (4.2)		
Other	7 (3.0)		

or her participation. A stub and phone number was attached, allowing the caregiver to decline participation and request no further contact. Roughly a week later, trained interviewers called prospective participants to explain the purpose of the study and to ask them to take part. A time and place for an interview was scheduled with those who agreed. Most interviews took place in the caregivers' homes and were conducted by experienced interviewers who were blind to the hypotheses of this study. The interviews included structured questionnaires only and lasted for an hour on average. The time between the death of care recipients and interviews was 283.4 days on average (range: 170-378 days, SD = 65.01).

#### Measures

#### Outcome Measure

Caregiver's perceived level of open communication with the patient about illness and death. This scale was developed based in part on the Openness to Discuss Cancer in the Nuclear Family Scale (Mesters et al., 1997) and on in-depth interviews with caregivers of cancer patients not included later in this study. Based mainly on these interviews a structured questionnaire was developed. The questionnaire retrospectively elicited the perceptions and feelings of caregivers regarding their interpersonal communication with patients about both the illness and the approaching death during the terminal stage (last 3 months of the patient's life). The questionnaire consists of six statements to which caregivers responded on a 5-point scale, ranging from 1 (not at all) to 5 (to a great extent) (e.g., "I hardly talked with the patient about his illness because I did not want to make him sad," "Conversation with the patient about his illness made me very uneasy," "I was afraid to talk with the patient about continuing my life without him," "I avoided talking with the patient about his feelings and fears," "I didn't know what to do or say to the patient in his suffering," "I avoided talking with the patient about his impending death"). An explanatory factor analysis with varimax rotation undertaken on all items yielded one factor with an eigenvalue of 4.4 and explained 39.5% of the variance. The least item loading was 0.560. Cronbach's  $\alpha = 0.80$ . The average of responses to all items comprised the index score. For adjustment to the other research variables, the direction of the scale was reversed, so that high scores represent high levels of perceived open communication.

#### Caregiver's Characteristics

Age and sex. These were obtained through self-report.

**Relationship to the patient.** Relationship was measured by the question "What is your relationship to the patient?" with four categories: (1) spouse, (2) son/daughter, (3) son/daughter-in-law, and other (4).

*Education.* Education was measured by the question "What is your highest education level?" with six categories: (1) elementary, (2) some high school, (3) high school, (4) beyond high school, (5) some college, and (6) college graduate.

**Religiosity.** Religiosity was measured by the question "I define myself as:" (1) secular, (2) conservative, (3) orthodox, or (4) ultra-orthodox. This variable was recoded into two categories, (1) secular (secular and conservative) and (2) orthodox (orthodox and ultra-orthodox).

*Employment status.* Employment status was measured by the question "What is your employment status?" with three categories: (1) retired, (2) part-time work, and (3) full-time work.

Sense of coherence. Caregivers' sense of coherence was measured by the abridged Sense of Coherence Scale (Antonovsky, 1993). The Sense of Coherence Scale aims to measure overall coping capacity. The scale consists of three dimensions: the extent to which an individual sees the world as comprehensible, manageable, and meaningful. The abridged form comprised of 13 items on a 7-point scale with two anchoring responses (e.g., "Do you feel that there isn't much meaning in the things you are involved in your daily life?", "Did it ever happen that people you trusted let you down?", "Do you have feelings you prefer not to feel?").

The scale has shown high validity and reliability in several languages and across populations. In this study Cronbach's  $\alpha = 0.77$ . The total score is the average of responses to all items. High scores represent a strong sense of coherence.

**Optimism.** Caregivers' optimism was measured by the Life Orientation Test (Scheier & Carver, 1985). The Life Orientation Test is a self-report measure that aims to assess the personality disposition of optimism versus pessimism. For this study we chose 12 items that assess generalized expectations for positive outcomes (e.g., "In uncertain times I usually expect the best," "I'm always optimistic about my future"). Responses were given on a 5-point scale ranging from 1 (*totally disagree*) to 5 (*totally agree*). Cronbach's  $\alpha = 0.78$ . The total score is the average of responses to all items. A high score represents a strong sense of optimism.

*Mastery.* Caregivers' mastery was measured by the Pearlin-Schooler Mastery Scale (Pearlin & Schooler, 1978). The scale is composed of 7 items that measure the extent to which one's life is considered to be under one's own control (e.g., "I can do almost everything I decide to do," "Sometimes I feel hopeless to cope with my problems in life"). Responses were given on a 5-point scale ranging from 1 (*totally disagree*) to 5 (*totally agree*). Cronbach's  $\alpha = 0.78$ . The total score is the average of responses to all items. A high score represents a strong sense of mastery.

Self-efficacy. Caregivers' self efficacy was measured by the General Self Efficacy Scale developed by Sherer et al. (1982). Self-efficacy refers to personal judgment of how well behavior can be implemented in situations that contain novel, unpredictable, or stressful elements (e.g., "I will always be able to solve difficult problems if I will make enough efforts," "I'm sure that I will be able to cope with unpredictable situations"). The 10-item version of the scale was used. Responses were given on a 4-point scale ranging from 1 (*does not describe me at all*) to 4 (*describes me to a great extent*). Cronbach's  $\alpha$  was high (0.90). The total score is the average of responses to all items. A high score represents a strong sense of self-efficacy.

Fear of death and dying. Caregivers' fear of death and dying was measured by the scale developed by Carmel and Mutran (1997). The scale consists of two factors, one for fear of death (6 items, e.g., "I'm very afraid of death," "I think a lot of my death") and the other for fear of dying (6 items, e.g., "I'm afraid of a long slow dying." "I'm afraid to lose my dignity in the end of my life"). Responses were given on a 5-point scale ranging from 1 (totally disagree) to 5 (totally agree). Cronbach's  $\alpha = 0.80$ . The total score is the average of responses to all items. A high score represents a strong fear of death and dying.

*Emotional exhaustion.* Caregivers' level of emotional exhaustion was measured by the 5 items from the Maslach Burnout Inventory (Maslach, 1978). The items were

adapted to informal caregiving and were phrased in the past tense (e.g., "I felt emotionally drained because of the care I gave the patient," "I felt tense because of the care I gave the patient."). Respondents rated each item on a 5-point scale ranging from 1 (*not at all true*) to 5 (*very true*). Cronbach's  $\alpha$  was high—0.92. The total score is the average of responses to all items. A high score represents a high sense of emotional exhaustion.

*Depression.* Caregivers' depression was measured by a modified version of the abridged Beck Depression Inventory (Beck & Steer, 1984). The original scale consists of 5 groups of questions, each composed of four statements, ranked according to severity, from which the respondent has to choose the statement that best reflects his or her feelings during the past week. The scale was adapted to informal caregiving by taking the most severe statement of each group of questions. Respondents were asked to rate each statement on a 5-point scale ranging from 1 (not at all true) to 5 (very true) (e.g., "When I cared for the patient in the terminal stage, I felt so sad that I couldn't bear it," "When I cared for the patient in the terminal stage, I felt that the future is hopeless and things will never change for the better," "When I cared for the patient in the terminal stage, I felt that as a man I'm a complete failure," "When I cared for the patient in the terminal stage, I felt dissatisfaction or boredom from everything," "When I cared for the patient in the terminal stage, I couldn't make decisions at all."). Cronbach's  $\alpha = 0.70$ . The total score is the average of responses to all items. High scores represent a strong sense of depression.

# Situational Variables

*Duration of caregiving.* Duration was measured by the question: "What was the total duration of caregiving (in months)?"

Average hours of caregiving per day. This was measured by the question "In the last three months of the patient's life, on average, how many hours per day were you engaged in caregiving?"

Level of perceived patient's physical suffering. This was measured by the question "Rate the level of the physical suffering of the patient in the last three months of his life." Responses were given on a 7-point scale ranging from 1 (*didn't suffer at all*) to 7 (*suffered very much*).

Level of perceived patient's emotional suffering. This was measured by the question "Rate the level of the emotional suffering of the patient in the last three months of his life." Responses were given on a 7-point scale ranging from 1 (*didn't suffer at all*) to 7 (*suffered very much*).

Level of perceived patient general functioning. This was measured by one item of the World Health Organization for assessing the general functioning level of

# 528 BACHNER AND CARMEL

patients: "Rate the general functioning level of the patient in the last three months of his life": (1) capable of doing all daily normal activities without limitations, (2) limited in strenuous physical activity but capable of doing light work, (3) not capable of doing any work but capable of taking care of himself, (4) capable of taking care of himself partially and bedridden most of the day, (5) not capable of taking care of himself at all, completely bedridden.

#### Statistical Analysis

The associations between caregivers' perceived level of open communication and the independent variables were examined with Pearson's or Spearman's correlation coefficients according to scale structures. Differences among mean values of continuous variables were tested using t tests and analysis of variance. The relative contribution of the different variables to the explanation of caregiver's level of open communication was examined by a hierarchical multivariate regression analysis. In the first block, the

caregiver's characteristics were entered. In the second block, the situational variables were entered. Only variables that correlated significantly with the dependent variable of open communication in univariate analyses were included as independent variables in this analysis. Internal reliability of the different scales was assessed using Cronbach's alpha coefficients. The data were analyzed with the statistical software SPSS, version 14.0. Significance level was set at p < 0.05.

# RESULTS

Descriptive statistics of all studied variables and the associations between the dependent variable of caregiver open communication and the independent variables are presented in Table 2. The level of open communication between caregivers and patients about illness and death was found to be low, indicating substantial communication difficulties between them. No significant differences in communication level

TABLE 2 Descriptive Statistics of all Studied Variables and the Associations Between Caregivers' Level of Open Communication and the Caregiver's and Situational Variables

Variable	No. of Items	Range	М	SD	Association With Caregive Open Communication
Caregiver open communication with the patient	6	1–5	2.04	0.99	
Caregiver's characteristics					
Sociodemographic variables					
Age	1	19–87	55.37	13.69	r = 0.03
Sex					
Male			2.24	0.93	t = 1.55
Female			1.99	1.01	
Relation to patient					
Spouse			2.15	1.13	
Son/daughter			1.93	0.87	F = 0.76
Son/daughter-in-law			2.16	1.03	
Other			2.20	0.61	
Religiosity					
Secular			2.16	1.01	$t = 2.25^*$
Orthodox			1.87	0.96	
Education level	1	1–6	3.71	1.65	$r = 0.19^{**}$
Personality traits					
Sense of coherence	13	1-7	4.66	0.96	r = 0.08
Optimism	12	1–5	3.82	0.66	$r = 0.14^*$
Mastery	7	1-5	2.39	0.89	r = 0.11
Self-efficacy	10	1-4	3.34	0.57	$r = 0.23^{**}$
Fear of death and dying	12	1–5	3.26	0.71	$r = -0.21^{**}$
Caregiving reactions					
Depression	5	1-5	2.81	0.97	$r = -0.28^{**}$
Emotional exhaustion	5	1-5	3.93	1.20	$r = -0.32^{**}$
Situational variables					
Duration of caregiving (months)	1	1-144	18.85	23.62	$r = 0.19^{**}$
Average no. of caregiving hours per day	1	0-24	17.30	7.76	r = 0.07
Level of perceived patient's physical suffering	1	1–7	6.29	1.45	$r = -0.17^*$
Level of perceived patient's emotional suffering	1	1–7	6.51	1.20	r = -0.10
Level of patient's general functioning	1	1–5	4.78	0.53	r = 0.07

\**p* < 0.05. \*\**p* < 0.01.

were found between relationship to the patient, caregiver sex, or age. Secular caregivers reported significantly higher levels of open communication with patients in comparison to orthodox caregivers. A significant positive correlation was found between caregivers' level of education and their level of communication. Three of the personality traits correlated significantly with level of communication. Positive correlations were found between optimism, self-efficacy, and level of open communication, whereas a negative correlation was found with fear of death and dying. The emotional reactions to caregiving-emotional exhaustion and depression-negatively correlated with level of open communication. With regard to the situational variables, a significant positive correlation was found between the duration of caregiving and open communication and a significant negative correlation was found with perceived patient's physical suffering.

A correlation matrix of all the independent variables that were found to be associated with open communication was calculated. The correlations among the different variables were found to be low to moderate, in a range between r = 0.01 to r = 0.46 (self-efficacy and optimism, respectively) in absolute value. Of note, most of the correlations were found to be lower than r = 0.30. These results imply that the variables are relatively independent and measure different constructs.

The significant independent variables were examined as possible predictors of caregiver's perceived level of open communication in a hierarchical multivariate regression analysis (Table 3). In the first block, the caregiver's characteristics were entered simultaneously into the equation. Self-efficacy, emotional exhaustion, and depression emerged as significant predictors of open communication. The model explained 22.4% of the observed variance and was found to be significant, F(7, 223) = 8.913, p < 0.001. The situational variables were entered simultaneously into the equation in the second block. This resulted in a significant change in  $R^2$  (with a modest  $\Delta R^2 = 3.7\%$ ). Together, the variables in the equation explained 26.1% of the observed variance, F(9, 223) = 8.409, p < 0.001. Four variables emerged as significant predictors of open communication: emotional exhaustion, r = -0.374, B = -0.227, p < 0.001; self-efficacy, r = 0.238, B = 0.306, p < 0.05; duration of caregiving, r = 0.181, B = 0.007, p < 0.01; and depression, r = -0.335, B = -0.138, p < 0.05. All of these variables (except duration of caregiving) are caregiver characteristics.

#### DISCUSSION

This study assessed caregivers' level of open communication with their terminally ill loved ones about their illness and the approaching death. It also examined the contribution of different caregiver characteristics and situational variables to the explanation of open communication.

TABLE 3 Caregiver's Characteristics and Situational Variables as Predictors of Caregivers' Level of Open Communication With Patients About Illness and Death

	_	~~~			-2	2
	В	SE	$\beta$	F	$R^2$	$\Delta R^2$
Caregiver charact	eristics					
Religiosity <sup>a</sup>	0.13	-0.10	-0.05	-0.78		
Education	0.04	0.02	0.04	0.62		
Optimism	0.11	-0.15	-0.10	-1.32		
Self-efficacy	0.13	0.33	0.20	2.57**		
Fear of death and dying	0.09	-0.15	-0.11	-1.67		
Emotional exhaustion	0.06	-0.22	-0.27	-3.99**		
Depression	0.07	-0.15	-0.15	-2.18*	0.224	
Situational variabl	es					
Religiosity <sup>a</sup>	0.13	-0.07	-0.03	-0.54		
Education	0.04	0.04	0.06	0.92		
Optimism	0.11	-0.15	-0.11	-1.37		
Self-efficacy	0.13	0.31	0.18	2.41*		
Fear of death and dying	0.09	-0.11	-0.08	-1.28		
Emotional exhaustion	0.05	-0.23	-0.28	-4.20**		
Depression	0.07	-0.14	-0.14	-1.99*		
Duration of caregiving	0.00	0.01	0.18	3.07**		
Patient's physical suffering	0.04	-0.05	-0.08	-1.29	0.261	0.037***

Note. Results of a hierarchical multivariate regression analysis.

 $a_1 = \text{secular}; 2 = \text{orthodox}.$ 

 ${}^*p < 0.05. \; {}^{**}p < 0.01. \; {}^{***}p < 0.0001.$ 

Caregivers rated their level of open communication with patients about illness and death as rather low. That is to say, caregivers experienced substantial difficulties in communicating with their loved ones about the illness and death, and avoided discussing these issues with them. No significant difference in communication level was found between caregiver sex and relationship to the patient. These findings imply that, regardless of the caregivers' sex or their relation to the terminally ill cancer patient, they experienced communication difficulties.

Caregivers' avoidance probably stems from their desire to protect the patient and to prevent any discomfort (protective buffering), as well as from their desire to protect themselves from their own fear of cancer and death. This type of behavior has been documented by numerous studies that report barriers and difficulties in the communication between caregivers and patients (Higginson & Constantini, 2002; Krant & Johnston, 1977; Vess et al., 1988; Zhang & Siminoff, 2003).

Results of the hierarchical regression analysis showed that most of the observed variance was explained by the caregivers' characteristics (22.4%). The situational variables added only a small percentage to the variance (3.7%). Caregivers' emotional exhaustion, depression, and self-efficacy, as well as the duration of caregiving, emerged as significant predictors of caregivers' level of open communication with patients. This finding suggests that the level of open communication is explained most by the caregivers' characteristics, especially their negative emotional reactions to the demands of caregiving.

The more emotionally exhausted and depressed caregivers were, the less they communicated with patients about illness and death. Emotional exhaustion and depression are two negative emotional reactions caused by the intensive demands of caregiving. Both reactions diminish the caregiver's ability to function effectively and provide the physical and mental care the patient needs (Bachner, 2005). Talking with the patient about his or her illness and impending death is a difficult task that requires substantial emotional strength. It is probable that caregivers who are exhausted and depressed tend to preserve their mental strength and therefore will avoid communicating with patients about matters that are emotionally draining. This is especially true for caregivers whose initial fear of cancer and death is high. These caregivers experience the greatest difficulties in communication with patients.

The higher caregivers rated their level of self-efficacy, the more they communicated with their relatives about the illness and death. Self-efficacy is considered a personality trait referring to self-perceived capabilities and therefore has an important impact on coping with various life stressors. Keefe et al. (2003) found that caregivers who rated their self-efficacy as high reported much lower levels of strain, as well as decreased negative mood and increased positive mood, in comparison to caregivers who rated their self-efficacy low. A negative association was also found between caregivers' level of self-efficacy and their physical and emotional reactions to the demands of caregiving (Schmall, 1995). Caregivers with high self-efficacy may have perceived the demands of caregiving, including open communication, as more manageable and therefore felt less emotionally exhausted and were able to communicate more with patients about the illness and death. Furthermore, these caregivers probably had lower levels of fear of death and dying, which enhanced their communication abilities.

Duration of caregiving was also found to be a significant predictor of open communication. The longer the duration of caregiving, the more open communication caregivers reported having with their terminally ill family member. Caregiving is a multidimensional task that involves much tension and requires energy and emotional resources, especially in the first phase of the illness, when the diagnosis is revealed to the patient and family. At this stage of the illness the patient and the caregivers are probably stunned and reluctant to communicate about the illness or death. They are full of hope for a full recovery and preparing for the healing process and the medical treatments the patient has to go through (Rait & Lederberg, 1990). As time passes and the health condition of the patient deteriorates, there is a cognitive and emotional adaptation of caregivers to the new situation and a recognition that the patient will not survive is gradually developed. It is possible that this adaptation and recognition enable caregivers to communicate more with the patient about his or her illness and impending death. Another explanation is that time may have increased caregivers' self-efficacy as they learned that they can cope with the difficult situation.

# Limitations

Several limitations of this study need be acknowledged. As with all retrospective studies, recall bias may have confounded participants' responses. This bias might be influenced particularly by the subsequent grief experiences, as well as the death trajectory of the illness and the nature of the cancer from which the patient died. Our moderate rate of caregiver participation reflects the challenge of recruiting participants for this type of research. This difficulty is a major one in the field of caregiving research and has been described by other researchers (Toseland, Blanchard, & McCallion, 1995). Although no significant differences were found between the participants and nonresponders with respect to the sociodemographic variables, the rate of nonparticipation may have affected our results in unforeseen ways. For instance, it is possible that the caregivers who participated in this study differ from those who declined to participate with regard to personality traits, coping ability, or psychological resilience. The lower number of men who participated in the study may be another limitation.

# Implications

Our findings have theoretical and practical implications. On the theoretical level, this study contributes to the growing body of knowledge in the field of interpersonal communication between primary caregivers and terminal patients about illness and death. Better understanding and further examination of the associations between caregivers' characteristics and their level of open communication with patients are needed. Special attention should be given to the caregiving reactions of emotional exhaustion and depression because these reactions can be prevented and treated. Deepening the understanding of the mechanisms behind these associations will have positive implications for the well-being of caregivers as well as patients. On the practical level, development of strategies and intervention programs for the health professionals is needed to identify caregivers at risk for such negative emotional reactions to caregiving. These programs should also offer guidance for preventing and lessening such negative reactions, as well as for strengthening caregivers' ability to cope with the various demands of caregiving.

#### ACKNOWLEDGMENTS

This study was supported by the Oncology Patient Memorial Fund, The Israeli National Institute for Health Policy and Health Services Research, and the Myers-JDC-Brookdale Institute.

#### REFERENCES

- Antonovsky, A. (1993). The structure and properties of the Sense of Coherence Scale. Social Science and Medicine, 36, 725–733.
- Babbie, E., & Benaquisto L. (2002). Fundamentals of social research (Canadian ed). Scarborough, ON, Canada: Thompson/Nelson.
- Bachner, Y. G. (2005). A model for explaining caregiving outcomes among informal caregivers of old cancer patients who died in two different settings of health services. Unpublished doctoral dissertation, Ben-Gurion University of the Negev.
- Beck, A. T., & Steer, R. A. (1984). Internal consistencies of the original and revised Beck Depression Inventory. *Journal of Clinical Psychology*, 40, 602–606.
- Carmel, S., & Mutran, E. (1997). Wishes regarding the use of life-sustaining treatments among elderly persons in Israel: An explanatory model. *Social Science and Medicine*, 45, 1715–1727.
- Edwards, H., & Foster, E. (1999). Avoidance of issues in family caregiving. *Contemporary Nursing*, *8*, 5–13.
- Fried, T. R., Bradley, E. H., O'Leary, J. R., & Byers, A. L. (2005). Unmet desire for caregiver–patient communication and increased caregiver burden. *Journal of the American Geriatrics Society*, 53, 59–65.
- Gotcher, J. M. (1993). The effects of family communication on psychosocial adjustment of cancer patients. *Journal of Applied Communication Research*, 21, 176–188.
- Higginson, I. G., & Constantini, M. (2002). Communication in end-of-life cancer care comparison of team assessments in three European countries. *Journal of Clinical Oncology*, 20, 3674–3682.
- Hinds, C. (1992). Suffering: A relatively unexplored phenomenon among family caregivers of non-institutionalized patients with cancer. *Journal* of Advanced Nursing, 17, 918–925.
- Keefe, F. J., Ahles, T. A., Porter, L. S., Sutton, L. M., McBride, C. M., Pope, M. S., et al. (2003). The self-efficacy of family caregivers for helping cancer patients manage pain at end-of-life. *Pain*, 103, 157–162.
- Kilpatrick, M. G., Kristjanson, L. J., Tataryn, D. J., & Fraser, V. H. (1998). Information needs of husbands of women with breast cancer. *Oncology Nursing Forum*, 25, 1595–1601.

- Krant, M. J., & Johnston, L. (1977). Family members' perceptions of communication in late stage cancer. *International Journal of Psychiatry in Medicine*, 8, 203–216.
- Lepore, S. J., & Helgeson, V. S. (1998). Social constraints, intrusive thoughts, and mental health after prostate cancer. *Journal of Social and Clinical Psychology*, 17, 89–106.
- Maslach, C. (1978). The client role in staff burnout. *Journal of Social Issues*, 34, 111-124.
- McGrath, P. (2004). Affirming the connection: Comparative findings on communication issues from hospice patients and hematology survivors. *Death Studies*, 28, 829–848.
- Mesters, I., Van Den Borne, H., McCormick, L., Pruyn, J., Boer, M., & Imbos, T. (1997). Openness to discuss cancer in the nuclear family: Scale, development, and validation. *Psychosomatic Medicine*, 59, 269–279.
- Northouse, P. G., & Northouse, L. (1987). Communication and cancer: Issues confronting patients, health professionals, and family members. *Journal of Psychosocial Oncology*, 5, 17–46.
- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behavior, 19, 2–21.
- Peters-Golden, H. (1982). Breast cancer: Varied perceptions of social support in the illness experience. *Social Science and Medicine*, 16, 483–491.
- Porter, L. S., Keefe, F. J., Hurwitz, H., & Faber, M. (2005). Disclosure between patients with gastrointestinal cancer and their spouses. *Psychooncology*, 14, 1030–1042.
- Rait, D., & Lederberg, M. (1990). The family of the cancer patient. In J. C. Holland & J. H. Rowland (Eds.), *Handbook of psycho-oncology* (pp. 585–606). New York: Oxford University Press.
- Scheier, M. F., & Carver, C. S. (1985). Optimism, coping and health: Assessment and implications of generalized outcome expectancies. *Health Psychology*, 4, 219–247.
- Schmall, V. L. (1995). Family caregiver education and training: Enhancing self-efficacy. *Journal of Case Management*, 4, 156–162.
- Sherer, M., Maddux, J. E., Mercadente, B., Prentice-Dunn, S., Jacobs, B., & Rogers, R. W. (1982). The Self-Efficacy Scale: Construction and validation. *Psychological Reports*, 51, 663–671.
- Toseland, R. W., Blanchard, C. G., & McCallion, P. (1995). A problem solving intervention for caregivers of cancer patients. *Social Science and Medicine*, 40, 517–528.
- Vess, J. D., Moreland, J. R., Schwebel, A. L., & Knaut, E. (1988). Psychosocial needs of cancer patients: Learning from patients and their spouses. *Journal of Psychosocial Oncology*, 6, 31–51.
- Zhang, A. Y., & Siminoff, L. A. (2003). Silence and cancer: Why do families and patients fail to communicate? *Health Communication*, 15, 415–429.