UC San Diego

UC San Diego Previously Published Works

Title

Volunteer support, marital status, and the survival times of terminally ill patients

Permalink

https://escholarship.org/uc/item/55d951qx

Journal

Health Psychology, 24(2)

ISSN

0278-6133

Authors

Herbst-Damm, Kathryn L Kulik, James A

Publication Date

2005-03-01

Peer reviewed

Herbst-Damm & Kulik, 2005 proof

HERBST-DAMM AND KULIK

HEALTH PSYCHOLOGY

2005, 24, 2, 225-229

Volunteer Support, Marital Status, and the Survival Times of Terminally Ill Patients

Kathryn L. Herbst-Damm and James A. Kulik

University of California, San Diego

This study examines the possibility that volunteer support can influence how long terminally ill patients survive. Hospice patient files (N = 290) were coded for marital status and volunteer support condition, respectively, the latter on the basis of whether visits from volunteers were requested and received (n = 94), requested but not received (n = 28), or neither requested nor received (n = 168). Baseline health, disease type, and demographic dimensions were comparable across support conditions. Results indicated that when a baseline health status effect was controlled for (p < .0002), patients in the volunteer support condition survived significantly longer than did patients in either unvisited condition (p < .0001). Neither marital status nor gender independently predicted survival time.

Keywords: social support, marital status, terminal illness

Population studies have indicated that more extensive social relationship networks and social support are favorably associated with mortality (for reviews, see Cohen, 1988; House, Umberson, & Landis, 1988). Most such work has studied initially healthy individuals over an extended period of time. The relatively few studies that have examined whether support benefits longevity once a person has already contracted a disease have produced more mixed results. A study of cancer patients by Morgenstern, Gellert, Walter, Ostfeld, and Siegel (1984), for example, did not find that participation in weekly group meetings impacted mortality during 1- to 2-year follow-ups (see also Linn, Linn, & Harris, 1982), whereas Spiegel, Bloom, Kraemer, and Gottheil (1989) found that such a group intervention significantly increased the survival of metastatic breast cancer patients during the subsequent 10 years (but see Goodwin et al., 2001, for a failure to replicate this survival finding).

This study examines the relationship between support and mortality under even more extreme circumstances, namely when death is thought to be so imminent that support presumably can have little or no impact on longevity through effects on risk-taking behaviors (e.g., Umberson, 1987), health habits (e.g., Johnston, Foulkes, Johnston, Pollard, & Gudmundsdottir, 1999), or compliance with treatment (e.g., Richardson, Shelton, Krailo, & Levine, 1990). To examine this issue, we studied hospice patients who, by definition, were expected to live no more than 6 months and were receiving only palliative (as opposed to curative) medical treatment. Our primary index of support was whether patients received visits from hospice volunteers who had been trained to provide

emotional and instrumental support. Few studies have examined how volunteer support impacts recipients. Thoits, Hohmann, Harvey, and Fletcher (2000) found that hospital support visits from fellow (coronary bypass) patients were associated with lower subsequent mortality rates. Closer to the present context, Schulz (1976) found that institutionalized older people who were visited by student volunteers on a predictable or controllable schedule were happier and healthier than no-visit controls (see also MacNeill, 1995; Nagel, Cimbolic, & Newlin, 1988). Collectively, these studies suggest that supportive home visits by hospice volunteers may benefit the emotional well-being of terminally ill patients, although whether such visits might also extend survival time, our primary question, has never been examined.

Our second index of support, marital status, has been used commonly as an index of structural support (Umberson, 1987). In addition to being associated with mortality benefits in studies of initially healthy individuals (see Cohen, 1988; House et al., 1988), there is some evidence that the mortality benefits of marriage are stronger for men (Tucker, Schwartz, Clark, & Friedman, 1999; Wiklund et al., 1988). Whether someone faced with a terminal illness is apt to live longer if married and whether any such protective effect of marriage is gender dependent appear not to have been addressed previously.

In summary, extrapolating from work in other contexts, we hypothesized that receiving support from volunteers or having a spouse could increase how long terminally ill

patients live. A secondary hypothesis, based on epidemiological mortality studies, was that any such benefits of marital status would be stronger for male patients.

Method

Participants

Data were collected from the records of home-dwelling patients from San Diego Hospice & Palliative Care who died between January and December 2000. From the approximately 3,000 records, we initially randomly selected 320. Patients were excluded if they were living in skilled nursing facilities, were younger than 18 years old, were missing an index of disease severity, had been transferred from other hospice centers, or did not live at least 3 days. These exclusion criteria yielded an initial sample of 212 patients, only 16 of whom had requested and received volunteer support visits. To increase power and enable more meaningful comparisons, we therefore decided to code all available files from the original 3,000 patients who met the inclusion criteria and had received volunteer visits. This added an additional 78 patients, so that the final sample consisted of 290 patients, 94 of whom received volunteer visits. Occupations (classified according to Warner, 1960) did not differ by conditions (see Table 1 for additional background information).

We were interested in whether volunteer support and marital status predict longevity independent of a patient's baseline physical condition. Accordingly, each patient's

Karnofsky score, which nurses assigned on admission to hospice care, was used as a statistical control in all primary analyses. A Karnofsky score, which can range from 0 (death) to 100 (normal functioning with no evidence of disease), theoretically indicates the percentage of normal physical health and has been shown to be a reliable and valid index of disease severity (e.g., Grieco & Long, 1984).

Support Conditions

Volunteer support. Hospice volunteers are trained to listen and provide conversation, to meet grooming needs, and to read to the patient or family members. These services are offered to all patients at intake. Patients were divided into one of three categories, which analyses indicated did not differ by gender or marital status. Of primary interest, patients in the support condition (n = 94) requested and received volunteer visits at home, whereas those in the no support condition (n = 168) neither requested nor received volunteer visits. Patients in the support condition were visited an average of 5.67 hr (SD) = 22.8), most often with the indicated purpose of providing companionship or active listening. A third, smaller group (n = 28), referred to hereafter as the missed support condition, consisted of patients who requested volunteer services but were not visited for any of various reasons (typically scheduling conflicts). Although small in number, inclusion of the missed support patients allowed additional comparisons of interest, in that they were similar to the support group in wanting visits but were similar to the no support group in not receiving visits.

Marital status. Patients were classified as married if they were married (49.7%), had a gay or lesbian partner (1.3%), or had a significant long-term relationship (3.1%). Patients who were separated (1.0%), divorced (7.6%), widowed (30.3%), never married (4.1%), or otherwise single (2.7%) were coded as unmarried.

Longevity

³ Longevity was indexed objectively as the number of days from acceptance into hospice care to the time of death (M = 65.6 days, SD = 79.8, Mdn = 35.5).

Results

Preliminary Marital Status (married vs. unmarried) × Volunteer Support (support vs. no support vs. missed support) × Gender (male vs. female) chi-square analyses revealed no differences in terms of ethnicity, occupation, or primary diagnosis. Similar analyses of variance performed on patient age, Karnofsky scores, primary caregiver age, and number of people living with the patient likewise revealed no differences involving support conditions or gender, with the exception that men had somewhat higher Karnofsky scores than did women (Ms = 43.2 vs. 39.9, p = .03). Also, unmarried patients on average were older than married patients (Ms = 76.1 vs. 70.9, p = .01) and had younger primary caregivers (Ms = 52.0 vs. 64.7, p < .0001), the latter difference due to their greater likelihood of being cared for by one of their children rather than a spouse. There were no gender differences in the three support conditions (p > .38). Karnofsky scores were

related to longevity as expected (described below). Of the remaining background variables, only the number of people living with the patient was marginally (p = .07) related to longevity (all other ps > .23).

Longevity Analyses ⁴

We analyzed patient longevity first with Cox's proportional hazard modeling (Cox, 1972), which enables survival analyses with only minimal assumptions about underlying distributions⁴. As expected, the better the patient's physical status at program entry (higher Karnofsky score), the longer the patient lived, likelihood ratio $(LR) \chi^2(1, N = 290) = 13.9, p < .0002$. Controlling for this relationship, there were no differences in survival time for married and unmarried individuals (p > .41), but survival times in the support condition were longer than for those not visited (whether or not visits had been requested), $LR \chi^2(2, N = 290) = 77.68, p < .00001$ (see Figure 1). Specifically, the rate of death for patients not visited by volunteers was almost three times the rate of those who were visited (LR = 2.90), and there was no difference between the no support and missed support groups. There was no interaction between marital status and support condition (p > .13).

A parallel Marital Status × Volunteer Support Condition analysis of covariance produced similar conclusions. When we controlled for Karnofsky score (p < .01), patients who were visited by volunteers on average lived longer than those in the no volunteer support and missed support conditions (Ms = 119.00 vs. 41.08 vs. 31.17 days, respectively), F(2, -1.08 vs. 31.17 days, respectively)

(283) = 40.55, p < .0001, with no differences between the latter two groups (p = .50) or as a function of marital status (Fs < 1, ns).

Finally, to equate the support conditions as much as possible, we also matched each patient in the volunteer support condition with a patient in the no support condition in terms of Karnofsky score, age, gender, and diagnosis. This yielded 94 support—no support pairs that were virtually identical in Karnofsky scores (Ms = 41.6 vs. M = 41.8) and were highly equivalent in age (Ms = 73.8 vs. 75.2), gender (male: 40.4% vs. 53.2%), and diagnoses (cancer: 62.8% vs. 66.0%; heart disease: 18.1% vs. 17.0%; other: 19.1% vs. 17.0%). A matched-sample t test on this maximally equated subgroup revealed a similar survival advantage for those in the support compared with the no support conditions (Ms = 119.8 vs. 39.2 days), t(93) = 6.64, p < .0001.

Discussion

Before discussing the primary hypothesis, it should be noted that our secondary hypothesis—that marriage may confer significant mortality benefits, perhaps especially for men (Tucker et al., 1999; Wiklund et al., 1988)—was not supported. Although we had a reasonably large sample size, it remains possible that more statistical power would uncover a relationship between marital status and longevity. Note, however, that even if there is no such simple relationship in the larger population of terminally ill patients, this would not necessarily mean that marital support has no influence in a terminal-illness context. Marital status is an objective index of social integration that is often used as a

proxy for support, but it does not necessarily indicate the actual marital support given or perceived in a given context (Ritter, 1988). Some spouses who are generally supportive in healthier times may become ineffectively supportive when faced with the imminent loss of their partners (cf. Rook, 1992). Alternatively, even if spouses are being supportive and patients perceive and appreciate this support, the potential benefits may be neutralized if patients are also feeling guilty about the distress they are causing their partners. Thus, if future work can better determine the actual spouse–patient support dynamics, it may still be possible to find that subsets of married patients experience a survival advantage, even in an active dying context. We can only conclude that we found no evidence that being married itself, regardless of gender, prolongs the survival time of terminally ill individuals.

In sharp contrast, our primary hypothesis was confirmed, in that we did find differences in survival times, an average of about 80 days, between patients who received volunteer support visits and those who did not. Because randomly assigning volunteers to the dying patients was neither an option nor ethically justifiable, a major question is the degree to which support and no support groups were comparable in all ways except volunteer support. The respective groups did appear to be comparable across a broad array of background variables. The obtained volunteer effects were independent of the longevity that was predicted by baseline health, which was comparable across conditions. Thus, within the limits of measured baseline health, the results are not attributable to those in the support group being less ill at entry to hospice. Also noteworthy are the survival durations of the missed support condition, which were indistinguishable from the no

support condition and thus considerably shorter than those in the support condition. This pattern suggests that it was not something about the desire for volunteer support per se that was predictive of greater longevity.

Although our study design does not enable definitive causal inferences, it may still be of use to suggest several nonmutually exclusive pathways through which volunteer support may have influenced survival times. One interesting possibility is that volunteer support actually exerted indirect effects on patients by directly affecting patients' caregivers. Being relieved of the burden of caring for a dying loved one, even briefly, may have benefited caregivers' well-being (cf. Millan-Calenti et al., 2000), which in turn may have benefited longevity by improving the quality of care and support caregivers were able to provide.

Alternatively, volunteer support may have had a more direct effect on patients, for example, by affecting patients' feelings of control, which in turn may have increased longevity through enhanced immune functioning (cf. Kamen-Siegel, Rodin, Seligman, & Dwyer, 1991; Laudenslager, Ryan, Drugan, Hyson, & Maier, 1983; Sieber et al., 1992). Rodin and Langer (1977) found that instilling a sense of control in institutionalized older people reduced subsequent mortality, and Schulz (1976) found that institutionalized older people who were visited by student volunteers on a predictable or controllable schedule were judged happier and healthier than no-visit controls. We find it interesting that a follow-up study indicated that after these visits ended, the patients became marginally more likely to die during the subsequent 4 years than did those in comparison groups.

perhaps because they had lost a sense of control over the visits (Schulz & Hanusa, 1978). In contrast, in the present study patients in the support condition were able largely to control volunteer visitations right up until their deaths.

Another interesting possibility is suggested by a study by Bower, Kemeny, Taylor, and Fahey (1998), which found that *meaning finding*, defined as a greater appreciation for loved ones and a commitment to appreciating life more fully, was associated with positive immunological changes and a lower subsequent rate of AIDS-related mortality (see also Bower, Kemeny, Taylor, & Fahey, 2003). Perhaps volunteers also helped the dying patients with the process of gaining perspective on their situation, and this process played a role in extending patients' lives.

Separately or as a byproduct of these processes, volunteer support may also have benefited patients' emotional well-being, which itself can affect immune functioning (e.g., Herbert & Cohen, 1993). We were unable to obtain an adequate measure of patient affect³, so this remains a viable hypothesis for future study. We believe it will be important for future work to assess the effect of volunteer support on affect, whether or not it plays a role in longevity. Some might argue that extending life as long as possible is always warranted. We believe this is debatable, but most would agree that a relatively low-cost intervention that has the potential to extend and improve (or at least not diminish) the quality of the dying patient's life would be desirable. Support visits by volunteers to terminally ill individuals could prove to be just such an intervention.

References

Bower, J. E., Kemeny, M. E., Taylor, S. E., & Fahey, J. L. (1998). Cognitive processing, discovery of meaning, CD4 decline, and AIDS-related mortality among bereaved HIV-seropositive men. *Journal of Consulting and Clinical Psychology*, *66*, 979–986.

Bower, J. E., Kemeny, M. E., Taylor, S. E., & Fahey, J. L. (2003). Finding positive meaning and its association with natural killer cell cytotoxicity among participants in a bereavement-related disclosure intervention. *Annals of Behavioral Medicine*, *25*, 146–155.

Cohen, S. (1988). Psychosocial models of the role of social support in the etiology of physical disease. *Health Psychology*, 7, 269–297.

Cox, D. R. (1972). Regression models and life-tables. *Journal of the Royal Statistical Society. Series B (Methodological)*, *34*, 187–220.

Goodwin, P. J., Leszcz, M., Ennis, M., Koopman, J., Vincent, L., Guther, H., et al. (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *The New England Journal of Medicine*, *345*, 1719–1726.

Grieco, A., & Long, C. J. (1984). Investigation of the Karnofsky Performance Status as a measure of quality of life. *Health Psychology*, *3*, 129–142.

Herbert, T. B., & Cohen, S. (1993). Depression and immunity: A meta-analytic review. *Psychological Bulletin*, *113*, 472–486.

House, J. S., Umberson, D., & Landis, K. R. (1988). Structures and processes of social support. *Annual Review of Sociology, 14*, 293–318.

Johnston, M., Foulkes, J., Johnston, D. W., Pollard, B., & Gudmundsdottir, H. (1999). Impact on patients and partners of inpatient and extended cardiac counseling and rehabilitation: A controlled trial. *Psychosomatic Medicine*, *61*, 225–233.

Kamen-Siegel, L., Rodin, J., Seligman, M. E., & Dwyer, J. (1991). Explanatory style and cell-mediated immunity in elderly men and women. *Health Psychology*, *10*, 229–235.

Laudenslager, M. L., Ryan, S. M., Drugan, R. C., Hyson, R. L., & Maier, S. F. (1983, August 5). Coping and immunosuppression: Inescapable but not escapable shock suppresses lymphocyte proliferation. *Science*, *221*, 568–570.

Linn, M. W., Linn, B. S., & Harris, R. (1982). Effects of counseling for late stage cancer patients. *Cancer*, 49, 1048–1055.

MacNeill, S. E. (1995). Psychological factors associated with treatment seeking behavior for myocardial infarction. *Dissertation Abstracts International*, *56* (2-B), 1114.

Millan-Calenti, J. C., Gandoy-Crego, M., Antelo-Martelo, M., Lopez-Martinez, M., Riveiro-Lopez, M. P., & Mayan-Santos, J. M. (2000). Helping the family carers of Alzheimer's patients: From theory to practice. A preliminary study. *Archives of Gerontology & Geriatrics*, *30*, 131–138.

Morgenstern, H., Gellert, G. A., Walter, S. D., Ostfeld, A. M., & Siegel, B. S. (1984). The impact of a psychosocial support program on survival with breast cancer: The importance of selection bias in program evaluation. *Journal of Chronic Disease*, *37*, 273–282.

Nagel, J., Cimbolic, P., & Newlin, M. (1988). Efficacy of elderly and adolescent volunteer counselors in a nursing home setting. *Journal of Counseling Psychology*, *35*, 81–86.

Richardson, J. L., Shelton, D. R., Krailo, M., & Levine, A. M. (1990). The effect of compliance with treatment on survival among patients with hematologic malignancies. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 8, 356–364.

Ritter, C. (1988). Social supports, social networks, and health behaviors. In D. S. Gochman (Ed.), *Health behavior: Emerging research perspectives* (pp. 149–161). New York: Plenum Press.

Rodin, J., & Langer, E. J. (1977). Long-term effects of a control-relevant intervention with the institutionalized aged. *Journal of Personality and Social Psychology*, *35*, 897–902.

Rook, K. S. (1992). Detrimental aspects of social relationships: Taking stock of an emerging literature. In H. O. F. Veiel & U. Baumann (Eds.), *The meaning and measurement of social support. The series in clinical and community psychology* (pp. 157–169). Washington, DC: Hemisphere Publishing Corp.

Schulz, R. (1976). Effects of control and predictability on the physical and psychological well-being of the institutionalized aged. *Journal of Personality and Social Psychology*, *33*, 563–573.

Schulz, R., & Hanusa, B. H. (1978). Long-term effects of control and predictability-enhancing interventions: Findings and ethical issues. *Journal of Personality and Social Psychology*, *36*, 1194–1201.

Sieber, W. J., Rodin, J., Larson, L., Ortega, S., Cummings, N., Levy, S., et al. (1992). Modulation of human natural killer cell activity by exposure to uncontrollable stress. *Brain, Behavior, and Immunity, 6,* 141–156.

Spiegel, D., Bloom, J. R., Kraemer, H. C., & Gottheil, E. (1989, October 14). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *The Lancet*, *2*, 888–891.

Thoits, P. A., Hohmann, A. A., Harvey, M. R., & Fletcher, B. (2000). Similar-other support for men undergoing coronary artery bypass surgery. *Health Psychology*, *19*, 264–273.

Tucker, J. S., Schwartz, J. E., Clark, K. M., & Friedman, H. S. (1999). Age-related changes in the associations of social network ties with mortality risk. *Psychology and Aging*, *14*, 564–571.

Umberson, D. (1987). Family status and health behaviors: Social control as a dimension of social integration. *Journal of Health & Social Behavior*, *28*, 306–319.

Warner, W. L. (1960). Social class in America: A manual of procedure for the measurement of social status. New York: Harper & Row.

Herbst-Damm & Kulik, 2005 proof

Wiklund, I., Oden, A., Sanne, H., Ulvenstam, G., Wilhelmsson, C., & Wilhelmsen, L. (1988). Prognostic importance of somatic and psychosocial variables after a first myocardial infarction. *American Journal of Epidemiology*, *128*, 786–795.

Herbst-Damm & Kulik, 2005 proof

Kathryn L. Herbst-Damm and James A. Kulik, Department of Psychology, University of California, San Diego.

Correspondence concerning this article should be addressed to Kathryn L. Herbst-Damm,
Department of Psychology, 0109, University of California, San Diego, 9500 Gilman
Drive, La Jolla, CA 92093. E-mail: kherbst@psy.ucsd.edu

¹It typically took about 3 days for the initial volunteer visit to occur in the support condition. Because it would be misleading to include the 25 patients in the analyses that did not live at least this long, these patients are excluded from further analyses. Analyses that include these patients yield relationships between volunteer support and longevity that are even stronger than those reported.

²Longevity results based on the initial sample of 237 patients are virtually identical to those reported later for the final sample of 290 patients.

 3 We had hoped to assess patient affect on the basis of home visit ratings by hospice nurses (of patients being calm, pleasant, agitated, anxious, flat, withdrawn, tearful, and inappropriate). Unfortunately, an affect index at hospice entry, based on coding the initial 237 files, had unacceptably low internal consistency ($\alpha = .37$), as did the affect indices for the last several days of patients' lives (alphas < .50). Not surprising, further analyses revealed no differences as a function of volunteer support or marital status. Because these ratings are labor-intensive to abstract and lacked sufficient reliability for meaningful comparisons, we thereafter discontinued coding additional patient charts in terms of affect.

⁴Initial analyses revealed no significant relationships of patient gender with longevity. All analyses that follow therefore are collapsed across gender.

Herbst-Damm & Kulik, 2005 proof

⁵Hazard analyses that included the number of people living with the patient as an additional covariate indicated that this factor neither predicted longevity (p > .38) nor changed the results to follow. It therefore was dropped from the final analyses.

Herbst-Damm & Kulik, 2005 proof

Table 1
Baseline Demographics and Health Factors by Volunteer Group

Variable	No volunteer					
	Not requested $(n = 168)$		Requested $(n = 28)$		Volunteer $(n = 94)$	
	$M \pm SD$	n (%)	$M \pm SD$	n (%)	$M \pm SD$	n (%)
		Dem	ographics			
Age	73.8 ± 12.8		72.8 ± 13.4		73.8 ± 16.0	
Sex						
Male		82 (48.8)		14 (50.0)		38 (40.4)
Female		86 (51.2)		14 (50.0)		56 (59.6)
Ethnicity		-50 -60				
White		125 (74.4)		20 (71.4)		78 (83.0)
Black		11 (6.5)		2 (7.1)		2(2.1)
Asian		8 (4.8)		2(7.1)		1(1.1)
Hispanic		22 (13.1)		3 (10.7)		7 (7.4)
Other		1 (0.6)		1 (3.6)		1(1.1)
Missing		1(0.6)		0(0.0)		5 (5.3)
Marital status		tion of the second				
Married		93 (55.4)		18 (65.5)		46 (48.9)
Widowed		51 (30.4)		5 (17.2)		32 (34.0)
Umarried		24 (14.3)		5 (17.2)		16 (17.0)
No. of people living		50 00		20 20		3.5
with patient	1.5 ± 1.4		1.4 ± 0.9		1.2 ± 1.3	
		Heal	h factors			
Karnofsky	40.6 ± 8.8		42.7 ± 10.0		41.6 ± 8.2	
Diagnosis						
Cancer		124 (73.8)		18 (65.5)		59 (62.8
Heart illness		18 (10.7)		5 (17.2)		17 (18.1
Other		26 (15.5)		5 (17.2)		18 (19.1)

Note. Patients who did not request a volunteer, patients who requested but did not receive a volunteer, and those who received a volunteer did not differ on the above variables (ps > .11).

Herbst-Damm & Kulik, 2005 proof

Figure 1. Kaplan-Meier plot of probability of patient survival (y-axis) by longevity in days (x-axis) for three support groups.

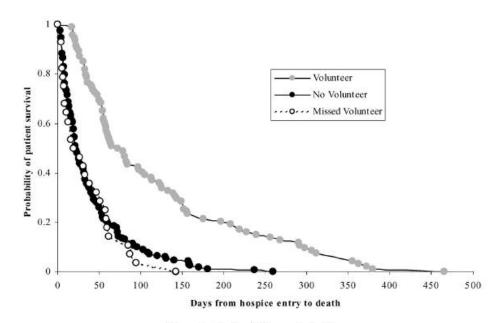


Figure 1. Kaplan-Meier survival plot.