

Well-being in informal caregivers of survivors of acute respiratory distress syndrome*

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Objective: With limited community services, the complex rehabilitation period after critical illness is often the responsibility of family members who, as a result, may experience negative health outcomes. The objectives of this research were to a) identify aspects of the caregiving situation that are associated with caregivers' experiences of emotional distress and psychological well-being; and b) compare health-related quality of life of informal caregivers to survivors of acute respiratory distress syndrome (ARDS) with age- and gender-matched population values.

Design: Cross-sectional survey of informal caregivers to ARDS survivors.

Setting: Toronto, Ontario, Canada.

Patients: Informal caregivers were individuals who were primarily responsible for providing and/or coordinating ARDS survivors' posthospital care and were not paid to do so.

Interventions: None.

Measurements and Main Results: The dependent variables were emotional distress, psychological well-being, and health-related quality of life. They were evaluated by the Center for Epidemiologic Studies Depression Scale, the Positive Affect Scale, and Medical Outcomes Study Short Form 36, respectively. Inde-

pendent variables included severity of illness indicators, patient depression (Beck Depression Inventory II), aspects of the caregiving experience (care provided, lifestyle interference, personal gain), and psychosocial resources (mastery and social support). Caregivers experienced more emotional distress when they experienced more lifestyle interference, had lower levels of mastery, and were caring for ARDS survivors with more depressive symptoms ($F_{3,42} = 15.69$, $p < .001$, adjusted $R^2 = .50$). In contrast, caregiver psychological well-being was associated with personal gains as a result of providing care and having more mastery and social support ($F_{4,41} = 9.40$, $p < .001$, adjusted $R^2 = .43$). Caregivers reported poorer health-related quality of life across all domains of the Medical Outcomes Study Short Form 36 compared with age- and gender-matched population values.

Conclusions: Informal caregivers experience negative health outcomes that persist almost 2 yrs after ARDS. New approaches, such as family-centered rehabilitation, caregiver education, improved respite, and home care, may benefit informal caregivers. (Crit Care Med 2006; 34:81–86)

KEY WORDS: caregivers; quality of life; mental health; respiratory distress syndrome; adult

Acute respiratory distress syndrome (ARDS) is characterized by bilateral lung infiltrates on frontal chest radiograph, a P_{aO_2}/F_{iO_2} ratio of ≤ 200 , and the absence of clinical evidence of left atrial hypertension (1). The incidence of ARDS ranges from 1.5 to 8.3 cases per 100,000 population per year (2, 3). ARDS survivors may experience muscle wasting and weakness

up to 1 (4) or 2 (5) years after discharge from the intensive care unit (ICU). Depression, anxiety, and cognitive changes including difficulty with memory and concentration may also be present (5–7). The current health care system encourages brief hospitalization and ambulatory treatment and offers limited community services (8). When survivors of critical illness are discharged from hospital, they

must rely on their informal caregivers for assistance and support. Few studies have examined caregiving issues in individuals who were admitted to an ICU (9), who received long-term ventilation (10), or who had a serious illness (11). None has focused on survivors of ARDS.

Informal care entails an individual, usually a female family member, providing unpaid assistance with a variety of everyday activities. These individuals can experience interrupted careers and lifestyles and uncertainty about the future, contributing to an overall experience of stress. Consistent with the stress theoretical perspective (12), caregivers can experience negative health outcomes, such as poor mental (13, 14) and physical (15, 16) health, as a result of primary stressors, for example, caring for individuals with physical and emotional disability (17–19), and secondary stressors, for example, lifestyle disruption due to providing care (20, 21). Psychosocial resources such as

***See also p. 243.**

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personal control or mastery (22–24) and social support (23, 25) can lessen the negative impact of caregiving. More recent research recognizes that not all caregiving is a negative or stressful experience, and some aspects can be beneficial (26). Personal growth (12), caregiving satisfaction (27), and positive feelings about caregiving (28) can have a beneficial impact on caregiver well-being.

To address the gaps in our knowledge about informal caregiving to survivors of ARDS, the objectives of this research were to a) identify aspects of the caregiving situation that are associated with caregivers' experiences of emotional distress and psychological well-being; and b) compare health-related quality of life of informal caregivers to survivors of ARDS with age- and gender-matched population values.

MATERIALS AND METHODS

Design and Procedure. This cross-sectional study of informal caregivers was part of a longitudinal cohort study of ARDS survivors from Toronto, Canada. A detailed description of this study has been published previously (4). Briefly, ARDS survivors were recruited between May 1998 and May 2001. Their physical functioning and quality of life were assessed 3, 5, and 12 months after discharge from the ICU. The caregiver study was conducted between October 2001 and December 2002. Participating ARDS survivors were mailed a letter introducing the informal care study and asking them to identify an individual who provided any necessary assistance with activities or instrumental activities of daily living or medical care during the first 3 months after hospital discharge. ARDS survivors asked this individual to complete and return a consent form and questionnaire in a self-addressed postage-paid return envelope. After 1 month, nonrespondents were contacted by telephone, new questionnaires were sent, and subsequent nonrespondents received three reminder telephone calls. The institutional ethics board approved this study.

Participants. We defined "informal caregiver" as the person who was primarily responsible for providing/coordinating any necessary assistance and was not paid to do so. Caregivers were included if they could read English and provide informed consent.

Measurement Instruments. The following ARDS patient information from the larger study (4) was used: a) sociodemographic characteristics; b) duration of mechanical ventilation and ICU and hospital length of stay; c) ICU severity of illness measures—Acute Physiology, Age, and Chronic Health Evaluation II (29), maximum Multiple Organ Dysfunction Score (30), and maximum Lung Injury Score (4); and d) distance walked in 6 mins (4). The

first three items were determined while the ARDS survivor was hospitalized. The distance walked in 6 mins was assessed every 6 months after the first year in the ARDS follow-up study. The 6-min walk distance obtained closest to the time at which the caregiver survey was completed was used in this study. Patients' depressive symptoms, measured by the Beck Depression Inventory II (31), were assessed at the same time as the caregiver study (32).

Informal caregivers provided sociodemographic information and completed standardized questionnaires. Sociodemographic characteristics included age, gender, relationship to the ARDS survivor, living arrangements (e.g., living with the ARDS survivor), previous caregiving experience, education, income levels, and employment status.

Emotional distress, specifically symptoms of depression, was assessed by the 20-item Center for Epidemiologic Studies Depression Scale (33). Items are rated on a 4-point scale ranging from 0 "rarely or none of the time" to 3 "most or all of the time" to reflect how they have been feeling over the past week. Four items are reverse scored and the items are summed to provide a total score. Higher scores reflect more depressive symptoms. Scores >15 reflect individuals at greater risk for clinical depression (34). Good internal consistency has been observed in the general population ($\alpha = .85$) (33) and in this sample ($\alpha = .89$).

Psychological well-being is the extent to which a person feels enthusiastic, active, and alert, and it was assessed by the Positive Affect Scale of the Positive and Negative Affect Schedule (35). Respondents rated the extent to which they had experienced each of ten emotions or feelings over the past week on a 5-point scale ranging from one 1 "very slightly or not at all" to 5 "extremely." The ten items are summed to give a total score ranging from 10 to 50 with higher scores indicating more psychological well-being. Internal consistency was good in an academic sample ($\alpha = .87$) (35) and in the current sample ($\alpha = .95$).

The amount of care provided during the past month with instrumental activities (e.g., finances) and activities of daily living (e.g., bathing) and medical care (e.g., medications) was assessed by the 17-item Caregiver Assistance Scale (20). Level of assistance for each item was rated on a scale from 0 "no assistance" to 6 "a lot." The items were summed to provide a total score ranging from 0 to 102, with higher scores indicating that more assistance was provided. Internal consistency was good in caregivers to advanced cancer patients ($\alpha = .87$) (20) and in the current study ($\alpha = .96$).

The 14-item Care-giving Impact Scale assessed current level of lifestyle interference due to providing care (20). Interference on each lifestyle domain (e.g., work, family relations, active recreation, etc.) was rated from 0 "not at all" to 6 "very much." Items were

summed to provide a total score ranging from zero to 84, and higher scores indicated more lifestyle interference. Good internal consistency was observed in caregivers to advanced cancer patients ($\alpha = .87$) (20) and in the current study ($\alpha = .96$).

Personal gain is a positive outcome of providing care and represents caregivers' inner growth, including gains in self-confidence or obtaining greater appreciation for their abilities, as a result of meeting the challenges of providing care (12). The measure contains four items rated on scales ranging from 1 "not at all" to 4 "very much." The items are summed to provide a total score with higher scores indicating more personal gain. Internal consistency was good in a sample of Alzheimer's family caregivers ($\alpha = .76$) and in our study ($\alpha = .90$).

The psychosocial resource mastery, an individual's sense of control over her or his life, was assessed by Pearlin's seven-item measure (36). Each item was rated from 1 "strongly disagree" to 4 "strongly agree." Five items are reverse scored, and the items are summed to provide a total score ranging from 7 to 28, with higher scores indicating more mastery. Internal consistency in the present study was good ($\alpha = .78$). The Social Support Survey was used to assess support in each of four domains: tangible, informational, emotional and affectionate, and positive social interactions (37). Nineteen items are rated from 1 "none of the time" to 5 "all of the time." Items are summed and rescaled to provide a total score ranging from 0 to 100, with higher scores indicating more social support. Internal consistency was good in this sample ($\alpha = .97$).

The Medical Outcomes Short Form-36 was used to evaluate caregivers' health-related quality of life in eight domains including physical functioning, role limitations (physical and emotional), emotional well-being, general health, pain, energy/fatigue, and social functioning (38, 39). All scales range from 0 to 100 with higher scores indicating better functioning in each domain. Internal consistency ranged from .82 to .93 across all subscales.

Statistical Analysis. We used *t*-tests, Mann-Whitney U test, and chi-square analyses to describe the caregivers and to compare patient characteristics for respondents with those for nonrespondents. With the available sample, all potential predictors could not be tested in a multivariable regression model without overfitting the model (40). With our sample size, the recommended number of predictor variables is five (40). We determined, by consensus, the five most important predictors for each regression model (40, 41). We removed predictors with *p* values >.20 to determine the simplest model and increase the variance explained (R^2) (4). Standardized β s allow comparison across variables measured on different scales. The assumptions of correlation and regression analyses were tested. To compare caregiver quality of life to the general

Table 1. Characteristics of informal caregivers

Characteristic (n = 47)	
Age ^a	52.9 (13.6)
Female ^b	32 (68.1)
Relationship to ARDS survivor	
Spouse ^b	31 (66.0)
Parent ^b	11 (23.4)
Other ^b	3 (6.4)
Months since hospital discharge ^a	23.1 (12.3)
Number of current care activities ^a	6.5 (5.8)
Mean level of care provided ^a	27.5 (28.7)
Live with care recipient full-time ^b	36 (76.6)
Previous caregiving experience ^b	12 (25.5)
Education	
College or less ^b	26 (55.3)
University or more ^b	17 (36.2)
Income ≥\$40,000	20 (42.6)
Primary daily activity	
Working for pay ^b	19 (40.4)
Caregiver/homemaker ^b	17 (36.2)
Other (retired, on disability) ^b	10 (21.3)
CES-D ^c	12 (4–23)
CES-D ^b >15	15 (31.9)

ARDS, acute respiratory distress syndrome; CES-D, Center for Epidemiological Scales—Depression Scale.

^aMean (SD); ^bnumber (percentage); ^cmedian (interquartile range). Not all percentages add to 100 because of missing data.

population, the following procedure was used. For each caregiver, we used the population value for the correct age and gender category as the normal value (42). We present the caregivers' median and interquartile range for each domain of quality of life as well as the age- and gender-matched population norm in Table 4. All analyses were conducted using SPSS version 11.0.1 (43).

RESULTS

One hundred and nine ARDS survivors participated in the longitudinal study (4), and a subset of patients were eligible for the caregiver study. Forty-two patients were not eligible for the following reasons: caregiver was non-English speaking (n = 4), patient died (n = 14), patient was self-care (n = 5), patient withdrew from the study (n = 17), and patient lived in a group home (n = 1) or long-term care facility (n = 1). Therefore, 67 ARDS survivors had caregivers who were eligible to participate. Seventeen surveys were not returned because they were not interested (n = 12), we were unable to contact some participants after repeated telephone calls (n = 4), and one survey was lost in the mail. Therefore, 50 caregivers returned their survey (50 of 67, 74.6%), and 47 (47 of 67, 70.1%) had complete data. Caregivers completed the survey on average 23 months (SD 12.3, range 6–53 months) after the ARDS sur-

vivor was discharged from hospital. Eighty percent reported that they were currently providing care consisting of at least one caregiving activity at the time of survey completion. Caregiver characteristics are summarized in Table 1.

ARDS survivors' sociodemographic characteristics, details about ICU stay, and illness severity are summarized in Table 2. At the time of the caregiver survey, the median distance walked in 6 mins for the ARDS cohort was 411 m (interquartile range 291–515), representing a median of 67.7% of their predicted values for age- and gender-matched values (44). These patients were compared with those ARDS survivors without a caregiver to understand how representative our study sample was of the original cohort (Table 2). ARDS survivors with caregivers enrolled in the study had a longer ICU length of stay compared with those ARDS survivors without a participating caregiver. No other differences were noted.

The research team selected, by consensus, the following variables for inclusion in the emotional distress regression model: caregiver lifestyle interference, mastery, and social support, and ARDS survivor depressive symptomatology and 6-min walk distance. Overall, caregivers reported more emotional distress when they were caring for ARDS survivors with

more depressive symptoms; they experienced more lifestyle interference and had lower levels of mastery ($F_{3,42} = 15.69$, $p < .001$, adjusted $R^2 = .50$, Table 3). Social support ($B = -.05$, $SE B = .09$, $p = .54$) and distance walked in 6 mins ($B = 1.79$, $SE B = 5.44$, $p = .74$) were not significantly related to emotional distress and were removed from the model.

Consensus from the research team selected personal gain, mastery, social support, lifestyle interference, and depressive symptoms in the ARDS survivor for inclusion in the regression model for psychological well-being in the caregiver. Overall, better psychological well-being was associated with caregivers gaining more personally as a result of their caregiving role and caregivers having more personal mastery and social support ($F_{4,41} = 9.40$, $p < .001$, adjusted $R^2 = .43$, Table 3). Lifestyle interference ($B = -.00$, $SE B = .06$, $p = .95$) was not related to psychological well-being so was removed from the model. This model had 13 influential cases (i.e., cases with extreme values for some of the variables that may influence the results of the regression), which were removed, and the model was re-run. These results were similar to the results using the full sample except mastery was no longer significantly related to psychological well-being ($p = .17$) and the adjusted R^2 was higher ($F_{2,31} = 35.43$, $p < .001$, adjusted $R^2 = .68$). The results of the model using the full sample are presented because we could not identify any characteristics of these individuals that would merit exclusion.

Overall, caregiver Medical Outcomes Short Form-36 domain scores were below those of age- and gender-matched population norms (42) (Table 4).

DISCUSSION

This study describes the experiences and health outcomes of informal caregivers to individuals who have survived a severe episode of ARDS and received assistance from an informal caregiver during at least the first 3 months after hospital discharge. Our caregivers' level of emotional distress (31.9% Center for Epidemiologic Studies Depression Scale >15) was higher than a national sample of American women (24%) (45) and lower than caregivers to recently institutionalized individuals with Alzheimer's disease (48.3%) (46). They reported a level similar to caregivers to ventilated ICU patients 2 months after hospital discharge

Table 2. Acute respiratory distress syndrome survivor characteristics for respondents and nonrespondents

Characteristic	Respondents (n = 50)	Nonrespondents (n = 59)	p Value
Age ^a	45.0 (14.4)	49.5 (17.5)	.15
Male ^b	27 (54)	36 (61)	.46
APACHE II ^a	22.0 (7.5)	22.9 (7.8)	.53
LIS ^a	3.6 (0.48)	3.4 (0.54)	.15
MODS ^a	11.5 (2.8)	11.1 (2.9)	.38
ICU days ^c	28.5 (17–51)	22.0 (14–41)	.07
Vent days ^c	27.5 (12–46)	17.0 (11–31)	.06
Hospital stay ^c	51.0 (26–84)	46.0 (28–64)	.43

APACHE, Acute Physiology and Chronic Health Evaluation; LIS, Aggregated Lung Injury Score; MODS, Multiple Organ Dysfunction Score; ICU, intensive care unit; ICU days, number of days spent in the ICU; vent days, number of days receiving mechanical ventilation; hospital stay, total number of days in hospital.

^aMean (SD) *t*-test; ^bnumber (percentage) chi-square test; ^cmedian (interquartile range) Mann-Whitney U test for nonparametric data.

(33.9%) (47). To the extent that caregiving adds to emotional distress, it is not surprising that our caregivers reported more distress than a national sample of American women (45) since other population-based research suggest that only a small percentage (e.g., 12%) (48) of these individuals were providing care. Caregiver emotional distress is a predictor of institutionalization, so it is not surprising that caregivers to recently institutionalized individuals with Alzheimer's disease (46) report higher levels of emotional distress (49, 50). It is interesting to note that our sample, obtained approximately 2 yrs after hospital discharge, had a level of distress similar to another sample of caregivers to recently (approximately 2 months previously) ventilated individuals (47). This suggests that ARDS survivors and their informal caregivers may still be experiencing the strain of the experience 2 yrs after hospital discharge.

Our caregivers reported high levels of emotional distress when ARDS survivors reported more depressive symptoms. These results are consistent with previous research with stroke caregivers who experienced more emotional distress if the stroke survivor also reported more depression (51). Our finding that disruption to caregivers' lifestyles (20) and personal mastery (22–24) was significantly associated with caregivers' experiences of emotional distress is also consistent with previous research. ARDS survivor functional status, expressed as the distance walked in 6 mins, was not associated with informal caregiver emotional distress. Similar findings were observed in informal caregivers to patients who had prolonged mechanical ventilation. Their research did not identify a significant relationship between physical functioning and caregiver depression (10).

Table 3. Multivariate regression analyses examining informal caregiver emotional distress and psychological well-being

	B	SE B	Beta	p Value
Emotional distress ^{a,b}				
Intercept	4.40	1.28		.001
Lifestyle interference	0.23	0.08	0.37	.005
Mastery	-0.13	0.06	-0.26	.026
Patient depression	0.41	0.02	0.30	.024
Psychological well-being ^c				
Intercept	-1.12	8.85		.900
Personal gain	0.98	0.33	0.34	.005
Mastery	0.74	0.40	0.25	.075
Social support	0.14	0.07	0.29	.052
Beck Depression	-0.16	0.10	-0.20	.121
Inventory				

B, beta; SE B, standard error of beta; beta, standardized beta.

^aEmotional distress was transformed using square root; ^bF_{3,42} = 15.69, *p* < .001, adjusted R² = .50; ^cF_{4,41} = 9.40, *p* < .001, adjusted R² = .43.

Table 4. Comparison of informal caregiver quality of life to population values

Quality of Life Domain	
Physical functioning	
Caregivers ^a	55 (28–80)
Population norm ^b	89
Role physical	
Caregivers ^a	67 (0–100)
Population norm ^b	84
Bodily pain	
Caregivers ^a	62 (32–100)
Population norm ^b	75
General health	
Caregivers ^a	52 (35–72)
Population norm ^b	77
Vitality	
Caregivers ^a	50 (30–70)
Population norm ^b	66
Social functioning	
Caregivers ^a	75 (38–100)
Population norm ^b	86
Role emotional	
Caregivers	67 (0–100)
Population norm ^b	84
Mental health	
Caregivers ^a	76 (47–88)
Population norm ^b	78

^aMedian (interquartile range); ^bpopulation norm median.

Psychological well-being or the experience of happiness was associated with caregivers becoming aware of their inner strengths as a result of their caregiving role. In addition, a greater sense of personal mastery and the availability of more social support were associated with better psychological well-being. These findings add to a comparatively new focus in the informal caregiving literature: the positive experiences of providing care (28). Our findings suggest that positive aspects of care, such as personal growth, contribute to psychological well-being. This may have important implications for the development of interventions, which usually focus on alleviating negative aspects. Future research may wish to explore how enhancing the positive elements of care may improve caregiver well-being as well as explore other aspects of the care situation that may influence caregiver well-being (e.g., leaving an unhappy work environment to provide care).

This study makes a unique contribution to the acute care and informal caregiving literature for a number of reasons. To our knowledge, this is the first study of informal caregivers to survivors of ARDS. Our caregiving sample was providing care to ARDS survivors representative of the larger ARDS cohort (4). These

ARDS survivors had longer periods of mechanical ventilation and longer ICU and hospital lengths of stay compared with other ICU survivors whose caregiver burden has been reported previously (9, 10, 47). As a result, our caregivers were still providing assistance approximately 2 yrs after hospitalization. In addition, our study contributes to the general caregiving literature by delineating the positive and negative aspects of providing care and identifying their distinct correlates. It also highlights some consistencies in caregiving experiences across patient populations. For example, lifestyle interference was also an important factor in caregivers to individuals with advanced cancer (20); mastery was important in caregivers to individuals with psychiatric diagnoses (24), individuals with dementia (22), and the disabled elderly (23); and patient depression was also an important factor in stroke (51). Overall, these findings suggest that there may be a common caregiving experience across diverse patient populations.

This study has several limitations. We captured a small, but representative, sample of informal caregivers and this limited our ability to construct more complex models of caregiver well-being. We also cannot conclude that the caregiving role caused emotional distress since we do not have information about their pre-caregiving mental health status. In addition, we surveyed these caregivers 6–53 months or, on average, almost 2 yrs after the ARDS survivor was discharged from hospital. It is possible that they experienced more emotional distress earlier in their caregiving than we may have captured by a longitudinal study. This study did not include, and, therefore, is not representative of, individuals who did not require care or who were institutionalized.

Future research should examine changes in informal caregiver experiences during the entire caregiving trajectory, starting with ICU and hospital care and following patients as they return to the community. Other issues not examined in this study, such as relationship quality between ARDS survivor and informal caregiver and a comparison of ARDS survivor and caregiver life before and after ARDS, may further our understanding of the magnitude of the impact of this illness. New interventions, such as family-centered approaches to facilitate recovery and adaptation of the patient and their informal caregiver, education specific to ARDS, clinical

New approaches, such as family-centered rehabilitation, caregiver education, improved respite, and home care, may benefit informal caregivers.

management of ARDS survivor depression, and increasing the availability of respite and home care for ARDS survivors and their caregivers, may be of benefit. Involving caregivers in the development of these new programs would increase the likelihood of meeting their needs. It is possible that the reverse may also be true; effective management of informal caregiver mental health may have the potential to decrease depression in ARDS survivors. Helping caregivers to understand that the caregiving role may reveal inner strengths and devising ways for informal caregivers to access social support may also contribute to psychological well-being. The development and evaluation of these strategies may identify the best ways to help ARDS survivors and their informal caregivers to effectively manage posthospital care, to achieve the best outcomes possible, and to help the family put the episode of critical illness behind them.

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REFERENCES

- Bernard GR, Artigas A, Brigham KL, et al: The American-European Consensus Conference on ARDS. Definitions, mechanisms, relevant outcomes, and clinical trial coordination. *Am J Respir Crit Care Med* 1994; 149: 818–824
- Villar J, Slutsky AS: The incidence of the adult respiratory distress syndrome. *Am Rev Respir Dis* 1989; 140:814–816

- Thomsen GE, Morris AH: Incidence of the adult respiratory distress syndrome in the state of Utah. *Am J Respir Crit Care Med* 1995; 152:965–971
- Herridge MS, Cheung AM, Tansey CM, et al: One-year outcomes in survivors of the acute respiratory distress syndrome. *N Engl J Med* 2003; 348:683–693
- Hopkins RO, Weaver LK, Collingridge D, et al: Two-year cognitive, emotional, and quality-of-life outcomes in acute respiratory distress syndrome. *Am J Respir Crit Care Med* 2005; 171:340–347
- Hopkins RO, Weaver LK, Pope D, et al: Neuropsychological sequelae and impaired health status in survivors of severe acute respiratory distress syndrome. *Am J Respir Crit Care Med* 1999; 160:50–56
- Rothenhausler HB, Ehrentraut S, Stoll C, et al: The relationship between cognitive performance and employment and health status in long-term survivors of the acute respiratory distress syndrome: Results of an exploratory study. *Gen Hosp Psychiatry* 2001; 23: 90–96
- Wilkins K, Park E: Home care in Canada. *Health Rep* 1998; 10:29–37
- Foster M, Chaboyer W: Family carers of ICU survivors: A survey of the burden they experience. *Scand J Caring Sci* 2003; 17:205–214
- Douglas SL, Daly BJ: Caregivers of long-term ventilator patients: Physical and psychological outcomes. *Chest* 2003; 123:1073
- Covinsky KE, Goldman L, Cook EF, et al: The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA* 1994; 272:1839–1844
- Pearlin LI, Mullan JT, Semple SJ, et al: Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist* 1990; 30:583–594
- Schulz R, Visintainer P, Williamson GM: Psychiatric and physical morbidity effects of caregiving. *J Gerontol* 1990; 45:181–191
- Schulz R, O'Brien AT, Bookwala J, et al: Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist* 1995; 35:771–791
- Schulz R, Beach SR: Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA* 1999; 282:2215–2219
- Lee S, Colditz GA, Berkman LF, et al: Caregiving and risk of coronary heart disease in U.S. women: A prospective study. *Am J Prev Med* 2003; 24:113–119
- House A, Knapp P, Bamford J, et al: Mortality at 12 and 24 months after stroke may be associated with depressive symptoms at 1 month. *Stroke* 2001; 32:696–701
- Majani G, Pierobon A, Giardini A, et al: Relationship between psychological profile and cardiologic variables in chronic heart failure. The role of patient subjectivity. *Eur Heart J* 1999; 20:1579–1586
- Ormel J, Kempen GI, Penninx BW, et al: Chronic medical conditions and mental

- health in older people: Disability and psychosocial resources mediate specific mental health effects. *Psychol Med* 1997; 27: 1065–1077
20. Cameron JI, Franche RL, Cheung AM, et al: Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer* 2002; 94:521–527
 21. Williamson GM, Shaffer DR, Schulz R: Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychol* 1998; 17:152–162
 22. Miller B, Campbell RT, Farran CJ, et al: Race, control, mastery, and caregiver distress. *J Gerontol B Psychol Sci Soc Sci* 1995; 50: S374–S382
 23. Yates ME, Tennstedt S, Chang BH: Contributors to and mediators of psychological well-being for informal caregivers. *J Gerontol B Psychol Sci Soc Sci* 1999; 54:12–22
 24. Noh S, Turner RJ: Living with psychiatric patients: Implications for the mental health of family members. *Soc Sci Med* 1987; 25: 263–702
 25. Miller B, Townsend A, Carpenter E, et al: Social support and caregiver distress: A replication analysis. *J Gerontol B Psychol Sci Soc Sci* 2001; 56:S249–S256
 26. Folkman S: Positive psychological states and coping with severe stress. *Soc Sci Med* 1997; 45:1207–1221
 27. Walker AJ, Acock AC, Bowman SR, et al: Amount of care given and caregiving satisfaction: A latent growth curve analysis. *J Gerontol B Psychol Sci Soc Sci* 1996; 51: 130–142
 28. Cohen CA, Colantonio A, Vernich L: Positive aspects of caregiving: Rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002; 17:184–188
 29. Knaus WA, Draper EA, Wagner DP, et al: APACHE II: A severity of disease classification system. *Crit Care Med* 1985; 13: 818–829
 30. Marshall JC, Cook DJ, Christou NV, et al: Multiple organ dysfunction score: A reliable descriptor of a complex clinical outcome. *Crit Care Med* 1995; 23:1638–1652
 31. Beck AT, Steer RA, Brown GK: Manual for the Beck Depression Inventory—II. San Antonio, TX, Psychological Corporation, 1996
 32. Al-Saidi F, Cheung AM, Tansey CM, et al: Neuropsychological sequelae in ARDS survivors. *Am J Respir Crit Care Med* 2003; 167: A737
 33. Radloff LS: The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement* 1977; 1:385–401
 34. Weissman MM, Sholomskas D, Pottenger M, et al: Assessing depressive symptoms in five psychiatric populations: A validation study. *Am J Epidemiol* 1977; 106:203–214
 35. Watson D, Clark LA, Tellegen A: Development and validation of brief measures of positive and negative affect: The PANAS scales. *J Pers Soc Psychol* 1988; 54:1063–1070
 36. Pearlin LI, Schooler C: The structure of coping. *J Health Soc Behav* 1978; 19:2–21
 37. Sherbourne CD, Stewart AL: The MOS Social Support Survey. *Soc Sci Med* 1991; 32: 705–714
 38. Ware JEJ, Sherbourne CD: The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992; 30:473–483
 39. McHorney CA, Ware JEJ, Lu JFR: The MOS 36-item Short-Form Health Survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Med Care* 1994; 32:40–66
 40. Babyak MA: What you see may not be what you get: A brief, nontechnical introduction to overfitting in regression-type models. *Psychosom Med* 2004; 66:411–421
 41. Steyerberg EW, Eijkemans MJ, Harrell FE, et al: Prognostic modeling with logistic regression analysis: In search of a sensible strategy in small data sets. *Med Decis Making* 2001; 21:45–56
 42. Hopman WM, Towheed T, Anastassiades T, et al: Canadian normative data for the SF-36 health survey. Canadian Multicentre Osteoporosis Study Research Group. *CMAJ* 2000; 163:265–271
 43. SPSS for Windows. Version 11.0.1. Chicago, IL, SPSS, 2001
 44. Enright PL, Sherrill DL: Reference equations for the six-minute walk in healthy adults. *Am J Respir Crit Care Med* 1998; 158: 1384–1387
 45. Bromberger JT, Harlow S, Avis N, et al: Racial/ethnic differences in the prevalence of depressive symptoms among middle-aged women: The Study of Women's Health Across the Nation (SWAN). *Am J Public Health* 2004; 94:1378–1385
 46. Schulz R, Belle SH, Czaja SJ, et al: Long-term care placement of dementia patients and caregiver health and well-being. *JAMA* 2004; 292:961–967
 47. Im K, Belle SH, Schulz R, et al: Prevalence and outcomes of caregiving after prolonged (> or =48 hours) mechanical ventilation in the ICU. *Chest* 2004; 125:597–606
 48. Cranswick K: Canada's caregivers. *Canadian Social Trends* 1997; Winter:2–6
 49. Arai Y, Sugiura M, Washio M, et al: Caregiver depression predicts early discontinuation of care for disabled elderly at home. *Psychiatry Clin Neurosci* 2001; 55:379–382
 50. Hebert R, Dubois MF, Wolfson C, et al: Factors associated with long-term institutionalization of older people with dementia: Data from the Canadian Study of Health and Aging. *J Gerontol A Biol Sci Med Sci* 2001; 56:M693–M699
 51. Dennis M, O'Rourke S, Lewis S, et al: A quantitative study of the emotional outcome of people caring for stroke survivors. *Stroke* 1998; 29:1867–1872