One-Year Outcomes and Health Care Utilization in Survivors of Severe Acute Respiratory Syndrome

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Background: Severe Acute Respiratory Syndrome (SARS) became a global epidemic in 2003. Comprehensive information on 1-year outcomes and health care utilization is lacking. Research conducted during the SARS outbreak may help inform research planning for future public health emergencies. The objective of this study was to evaluate the 1-year outcomes in survivors of SARS and their family caregivers.

Method: The study was prospective and observational. We evaluated 117 SARS survivors from Toronto, Ontario. Patients were interviewed and underwent physical examination, pulmonary function testing, chest radiography, a 6-minute-walk test, quality-of-life measures, and self-report of health care utilization. At 1 year, informal caregivers were identified for a survey on caregiver burden.

Results: The enrolled survivors of SARS were young (median age, 42 years), and most were women (67%) and health care workers (65%). At 1 year after hospital discharge, pulmonary function measures were in the normal range, but 18% of patients had a significant reduction in distance walked in 6 minutes. The Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) domains were 0.3 to 1.0 SD below normal at 1 year. Of the patients, 17% had not returned to work by 1 year. Fifty-one patients required 668 visits to psychiatry or psychology practitioners. During the SARS epidemic, informal caregivers reported a decline of 1.6 SD below normal on the mental component score of the SF-36.

Conclusions: Most SARS survivors had good physical recovery from their illness, but some patients and their caregivers reported a significant reduction in mental health 1 year later. Strategies to ameliorate the psychological burden of an epidemic on the patient and family caregiver should be considered as part of future pandemic planning.

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SEVERE ACUTE RESPIRATORY syndrome (SARS) became a global epidemic in 2003. Most cases were in Asia, and the largest concentration of North American cases occurred in Toronto, Ontario.[1] Research efforts during and after the epidemic focused on the epidemiologic features of the illness,[1,2] the detailed characterization of the pathogen,[3,4] the clinical course,[5-10] and the short-term outcomes of the acute disease.[11]

The longer-term physical and psychological consequences of SARS were not reported until recently. Several investigations of these longer-term outcomes (>6 months) have focused on pulmonary function,[12-14] distance walked in 6 minutes,[12] and health-related quality of life (QOL).[12,13] To date, in patients with SARS, there is little information on the pattern of return to work, exercise tolerance, or health care utilization after the SARS episode. Also, there have been no reports to our knowledge on the impact of this acute illness on the family caregiver. The goals of this study were to conduct a comprehensive and family-centered evaluation of the 1-year outcomes in survivors of SARS and their family caregivers.

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METHODS

SETTING

The hospitals providing acute care to patients with SARS are located in the greater Toronto area, Ontario. This is an urban area of approximately 5.3 million people encompassing a geographic area of 7000 km^2,[15] the largest urban area in Canada, and the fifth largest in North America. The follow-up clinic was located at a quaternary care hospital in downtown Toronto.

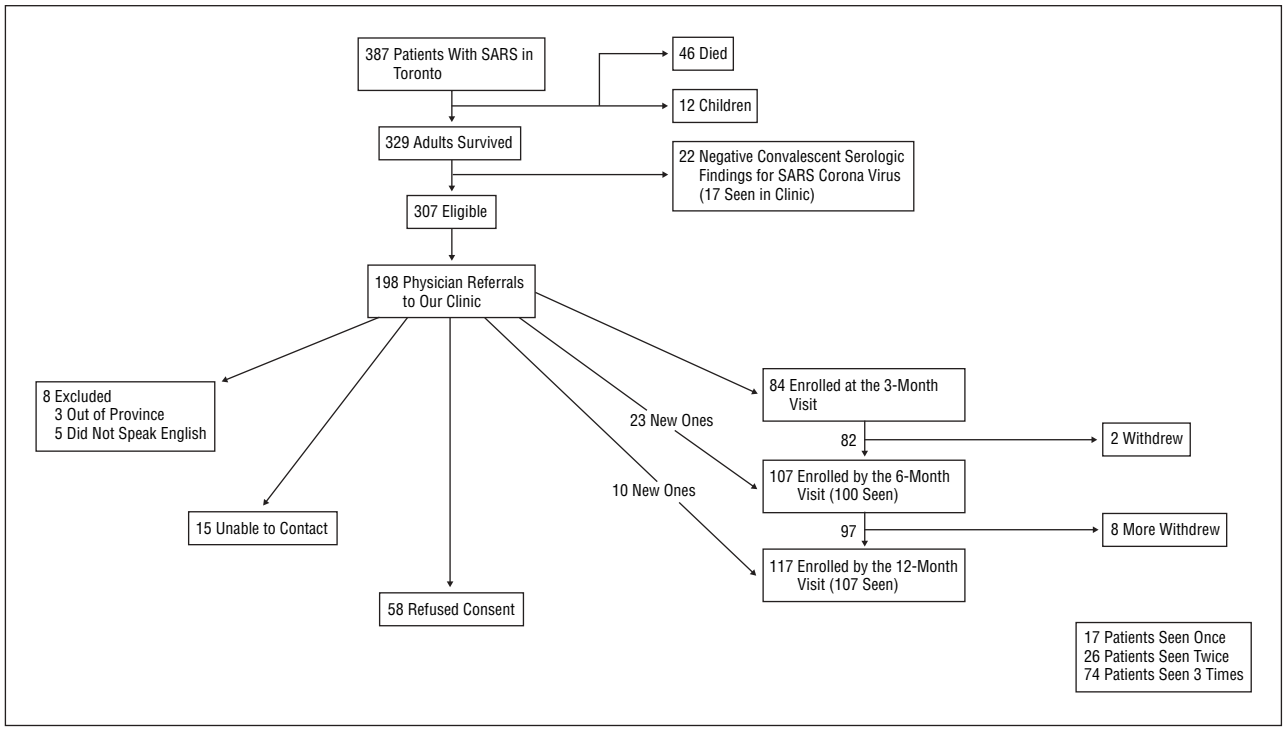

Figure 1. Enrollment of patients with severe acute respiratory syndrome (SARS) who were followed up for 12 months after hospital discharge.

STUDY DESIGN

Patients with SARS were referred to the longitudinal study by their acute care physicians. Discharge from hospital occurred between March 26, 2003, and August 22, 2003. Patient contact information was forwarded to the research site by the treating physician or hospital after their research ethics board had approved the protocol. Referred patients were eligible to participate if they were at least 16 years of age, had suspect or probable SARS according to Health Canada definitions,[16] and lived in Ontario. Patients were excluded if they had negative convalescent serologic findings for the SARS coronavirus (n=17)[17] or if they did not speak English (n=5). The research ethics boards at 20 participating institutions approved the protocol. All patients gave written informed consent (**Figure 1**).

BASELINE HOSPITAL INFORMATION

Baseline demographic data (described by Muller et al[18]) included clinical and treatment variables, length of hospital stay, and need for intensive care. Patients were also asked about their job status (health care worker or not), education, and history of lung disease.

FOLLOW-UP PROTOCOL

We evaluated patients 3, 6, and 12 months after hospital discharge. At each visit, SARS survivors were interviewed and underwent physical examination, a standardized 6-minute walk test,[19] pulmonary function testing, chest radiography, and convalescent SARS coronavirus serologic testing. They were systematically asked if they were experiencing cough, shortness of breath, alopecia, difficulty sleeping, myalgia, malaise, and fatigue. Two QOL instruments were administered. Participants were asked at each visit about health care utilization. At 1 year after discharge, survivors were offered a stage-1 cardiopulmonary exercise test.[19] They were also asked if they had a close family member or friend who assisted with their care in the early recovery period once their isolation was lifted. Informal caregivers were given questionnaires (**Table 1**) about how caring for a patient with SARS affected their lives.

QOL MEASURES

The Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) is a widely used and extensively validated generic QOL measure that consists of 8 multiple-item domains.[28] Scores are normalized to a mean±SD of 50±10, and 2 summary scores are calculated.[20]

The St George's Respiratory Questionnaire[29] is a pulmonary disease-specific QOL measure that captures symptoms, activity, and impacts scores as subscales. Scores range from 0 to 100, with higher numbers indicating poorer QOL. A difference of 4 points is clinically significant. The questionnaire has been validated in many lung disorders.[30-32]

HEALTH CARE UTILIZATION

At each appointment, patients were asked about visits to their general practitioner or specialists, tests performed, and hospitalizations. Referrals initiated by our team were included in the health care utilization numbers.

CAREGIVER QUESTIONNAIRES

An introductory letter, consent form, and questionnaires were sent to caregivers identified by the SARS survivors at 1 year after hospital discharge. The amount of care provided was assessed by the 17-item Caregiver Assistance Scale.[22] The 14-question Caregiving Impact Scale[22] measures the current level of lifestyle interference associated with providing care. Personal gain[24] (4 items) is a positive outcome of providing care and represents caregivers' inner growth, including gains in self-confidence or obtaining greater appreciation for their abili-

Table 1. Caregiver Questionnaire Characteristics

Instrument	Scoring	SARS Caregiver Scores	Comparison Scores
SF-36[20]	↑Score = better health-related quality of life (mean ± SD, 50 ± 10)	PCS = 52 MCS = 34	US "healthy" subjects,[21] mean ± SD PCS = 55 ± 27 US patients with angina,[21] PCS = 36 US "healthy" subjects,[21] MCS = 53 US clinically depressed patients,[21] MCS = 35
Caregiver Assistance Scale[22]	↑Score = more assistance performed (range, 0-102)	29	Caregivers for patients with stroke,[23] n = 47
Caregiving Impact Scale[22]	↑Score = more lifestyle interference (range, 0-84)	22	Caregivers for patients with stroke,[23] n = 29
Personal Gain Scale[24]	↑Score = inner growth, gains in self-confidence, and/or greater appreciation for one's own abilities (range, 4-16)	12	Caregiver for patients with ARDS,[25] n = 12
Pearlin and Schooler[26] 7-item measure	↑Mastery score = more individual sense of control over one's own life (range, 7-28)	18	Caregivers for patients with stroke,[23] n = 19
Social support survey[27]	↑Score = more social supports (range, 0-100)	67	Caregiver for patients with ARDS,[25] n = 73

Abbreviations: ARDS, acute respiratory distress syndrome; MCS, mental component summary score (calculated using the algorithm generated by Ware et al[21] and using the 4 mental domains of the SF-36: social function, role emotional, mental health, and vitality); PCS, physical component summary score (calculated using the algorithm generated by Ware et al[21] and using the 4 physical domains of the SF-36: physical function, role physical, bodily pain, and general health); SARS, severe acute respiratory syndrome; SF-36, Medical Outcomes Study 36-Item Short Form Health Survey.

ties. Mastery, an individual's sense of control over her or his life, was assessed by the 7-item measure from Pearlin and Schooler.[26] The amount of social support was evaluated using the Social Support Survey,[27] which contains 19 questions. A higher score indicates a higher level of the parameter measured.

STATISTICAL ANALYSIS

The primary outcome measure of the study was the 6-minute walk distance at 3, 6, and 12 months. Sample size and power calculations were not feasible owing to the lack of published data on long-term outcomes and survival for this new illness. We summarized continuous variables as medians and interquartile ranges and compared them between groups using the Wilcoxon rank-sum test. Categorical variables were summarized using proportions and 95% confidence intervals and compared between groups using Pearson χ^2 or Fisher exact test as appropriate. Multivariable regression analysis was not performed because of limited statistical power. The relationship between caregiver measures was analyzed using correlation coefficients.

RESULTS

CHARACTERISTICS OF THE PATIENTS

A total of 198 adults who were seropositive for the SARS coronavirus (at least 28 days after symptoms began) were referred to our clinic, and 117 patients were enrolled (Figure 1). It is not known why all eligible patients were not referred to us. Of those enrolled, 84 patients (72%) were seen at 3 months, 100 patients (88%) were evaluated at 6 months, and 107 patients (91%) were followed up to 1 year after hospital discharge. The atypical trend of increasing numbers was due to the unusual nature of an outbreak in which all patients fall ill in a very short time. Patient contact information became available to us about 3 to 8 months after acute illness. Median follow-up time for the 3-, 6-, and 12-month visits was 3.5, 7.1, and 12.5 months, respectively. No patient died during the year of follow-up. Home assessments were conducted for 2 patients at 6 months and for 8 patients at 1 year.

More patients in the study cohort were health care workers and had received systemic corticosteroids and fewer had at least 1 preexisting medical condition, but they were otherwise similar to the 307 adult survivors of SARS in Toronto (**Table 2**). The median age of our cohort was 42 years, 67% of the subjects were female, and 65% were health care workers. The cohort was highly educated. Two of the enrollees were not admitted to the hospital. The median length of hospital stay was 14 days. Of the patients, 16% required admission to the intensive care unit (ICU) for a median of 10 days, 9% of whom required mechanical ventilation. Of the 117 patients, 62% received systemic corticosteroids, 60% received ribavirin, 9% received interferon, and 11% of patients did not receive treatment with any of these agents.

GLOBAL ASSESSMENT

Patients self-reported a median loss of 9% of their body weight during acute care hospitalization. Of the patients, 67% reported alopecia; it resolved in most patients by 6 months and was not significantly associated with ribavirin administration in this limited sample (χ^2=0.59; P=.44). Chest radiographs were normal or had returned to pre-SARS baseline in all patients by 1 year, with the exception of 1 long-stay ICU survivor whose radiographs continued to show small lung volumes, fibrosis, and ground glass opacities beyond 1 year. Abnormalities on respiratory examination including wheezes, crackles, and tachypnea were found in 14%, 4%, and 2%, respectively, at the 3 visits. Fatigue (64%, 54%, and 60%) and difficulty sleeping (47%, 50%, and 44%) were commonly reported at the 3-, 6-, and 12-month time points, respectively. Patients also frequently mentioned shortness of breath (44%, 49%, and 45%) at the 3-, 6-, and 12-month follow-up visits, respectively. Only 12%, 18%, and 13% of patients stated that they were asymptomatic at the 3-, 6-, and 12-month visit. All SARS survivors who were mechanically ventilated reported muscle wasting and

Table 2. Characteristics of Enrolled and Nonenrolled Patients With SARS at Discharge From Hospital*

Characteristic	Enrolled Patients (n = 117)	Nonenrolled Patients (n = 187†)	*P* Value‡
Age, y	42 (33-51)	44 (34-57)	.13
Female sex	78 (67)	120 (64)	.66
Healthcare worker	76 (65)	58 (31)	<.001
Education			
≥University degree	90 (78)§	NA	NA
<University degree	26 (22)	NA	NA
≥1 Preexisting medical condition‖	11 (9)	34 (18)¶	.03
History of previous lung disease	20 (17)§	NA	NA
Ever smoked	20 (17)§	NA	NA
Hospital length of stay, d	14 (8-19)	11 (8-17)	.08
Need for ICU stay	19 (16)	29 (16)	.87
Length of ICU stay, d	10 (7-19)	14 (4-26)	.97
Need for mechanical ventilation	10 (9)	17 (9)	.87
Medication administered			
Systemic corticosteroid	72 (62)	84 (45)	.05
Ribavirin	70 (60)	102 (55)	.37
Interferon	11 (9)	9 (4)	.12
None of the above	13 (11)	40 (21)	.36
Weight loss, %	9 (5-11)#	NA	NA
Alopecia	78 (67)**	NA	NA

Abbreviations: ICU, intensive care unit; NA, not applicable; SARS, severe acute respiratory syndrome.

*Data are given as median (interquartile range) or number (percentage) of patients unless otherwise specified.

†Medical charts for 3 patients could not be retrieved.

‡Continuous variables were compared using Wilcoxon scores (Mann-Whitney test), and categorical variables were compared using the Mantel-Haenszel χ^2 test.

§Unknown in 1 patient.

‖Includes diabetes mellitus, chronic renal failure, hepatitis B, chronic obstructive pulmonary disease, coronary artery disease, congestive heart failure, active cancer, connective tissue disease, human immunodeficiency virus/AIDS, or transplantation.

¶Unknown in 2 patients.

#Unknown in 3 patients.

**Unknown in 5 patients.

Table 3. Ability to Exercise, Pulmonary Function, Return to Work, and QOL as Reported on the SGRQ in Patients With SARS During the 12 Months Following Discharge From Hospital*

Variable	Follow-up Visit		
	3 mo (n = 84)	6 mo (n = 100)	12 mo (n = 107)
Distance walked in 6 min	(n = 75)†	(n = 94)‡	(n = 98)†
Median (IQR), m	483 (396-552)	487 (447-553)	488 (448-555)
% of Predicted value§	81	81	83
Pulmonary function testing, % of predicted value	(n = 83)‖	(n = 97)¶	(n = 103)#
Forced vital capacity	98 (89-113)	103 (91-115)	103 (92-115)
Forced expiratory volume in 1 s	107 (94-120)	110 (100-122)	109 (96-122)
Total lung capacity	98 (88-111)	101 (93-112)	102 (92-112)
Residual volume**	101 (75-112)	98 (82-115)	96 (83-113)
Carbon monoxide diffusion capacity**††	87 (77-93)	86 (80-93)	85 (81-93)
Maximum inspiratory pressure**	68 (49-89)	74 (59-105)	78 (65-110)
Maximum expiratory pressure**	48 (40-61)	54 (43-67)	56 (45-73)
Return to work	(n = 84)	(n = 100)	(n = 107)
Full-time work	25 (30)	53 (53)	71 (66)
Pre-SARS level of work	35 (42)	63 (63)	79 (74)
Not returned to work	41 (49)	17 (17)	18 (17)
SGRQ‡‡	(n = 75)	(n = 83)	(n = 89)
Total score (normal = 6)	24 (8-36)	17 (6-34)	18 (5-34)
Symptoms score (normal = 12§§)	20 (8-35)	15 (4-36)	18 (5-40)
Activity score (normal = 9§§)	36 (12-60)	31 (6-60)	29 (3-54)
Impacts score (normal = 2§§)	14 (2-29)	9 (2-25)	10 (2-25)

Abbreviations: IQR, interquartile range; QOL, quality of life; SARS, severe acute respiratory syndrome; SGRQ, St George's Respiratory Questionnaire.

*Data are given as median (IQR) or number (percentage) of patients unless otherwise specified.

†Nine patients missed this test.

‡Six patients missed this test.

§Normal values were calculated in an age- and sex-matched population according to the method of Enright and Sherrill.[33]

‖One patient failed to present to the laboratory.

¶One patient failed to present to the laboratory, 1 felt ill and refused, and 1 became ill with testing and refused.

#One patient failed to present to the laboratory, 1 unable, 1 refused, and 1 became ill with testing and refused.

**These variables could not be assessed during home visits.

††Carbon monoxide diffusion capacity was not corrected for hemoglobin.

‡‡Lower scores indicate a better QOL; some patients did not return the questionnaire.

§§Normal values as per Jones et al.[29]

weakness at the time of hospital discharge. Three patients had new reactive airways disease. Two patients had entrapment neuropathies, 2 patients had hoarseness after prolonged intubation, and 1 patient had heterotopic ossification and discomfort at old chest tube sites.

SIX-MINUTE WALK DISTANCE AND PULMONARY FUNCTION

At 3 months, SARS survivors had a normal median 6-minute walk distance (81% of that predicted for an age- and sex-matched control population).[33] A reduced walking distance was present in 31% of patients at 3 months and in 18% at 1 year (**Table 3**). There was no relationship between 6-minute walk distance and exposure to steroids, burden of comorbid illness, preexisting pulmonary dysfunction, or degree of weight loss.

For most patients, spirometry, lung volume measures, and diffusion capacity were within normal limits at 3 months and remained normal for the duration of follow-up (Table 3). Patients admitted to the ICU had evidence of restrictive disease at 3 and 6 months after hospital discharge but had normal pulmonary function by 1 year. One long-stay ICU patient had moderate restrictive lung disease that persisted beyond the 1-year follow-up.

PATIENT QOL

All SF-36 domains were significantly reduced at 3 months with the exception of bodily pain. Role physical,

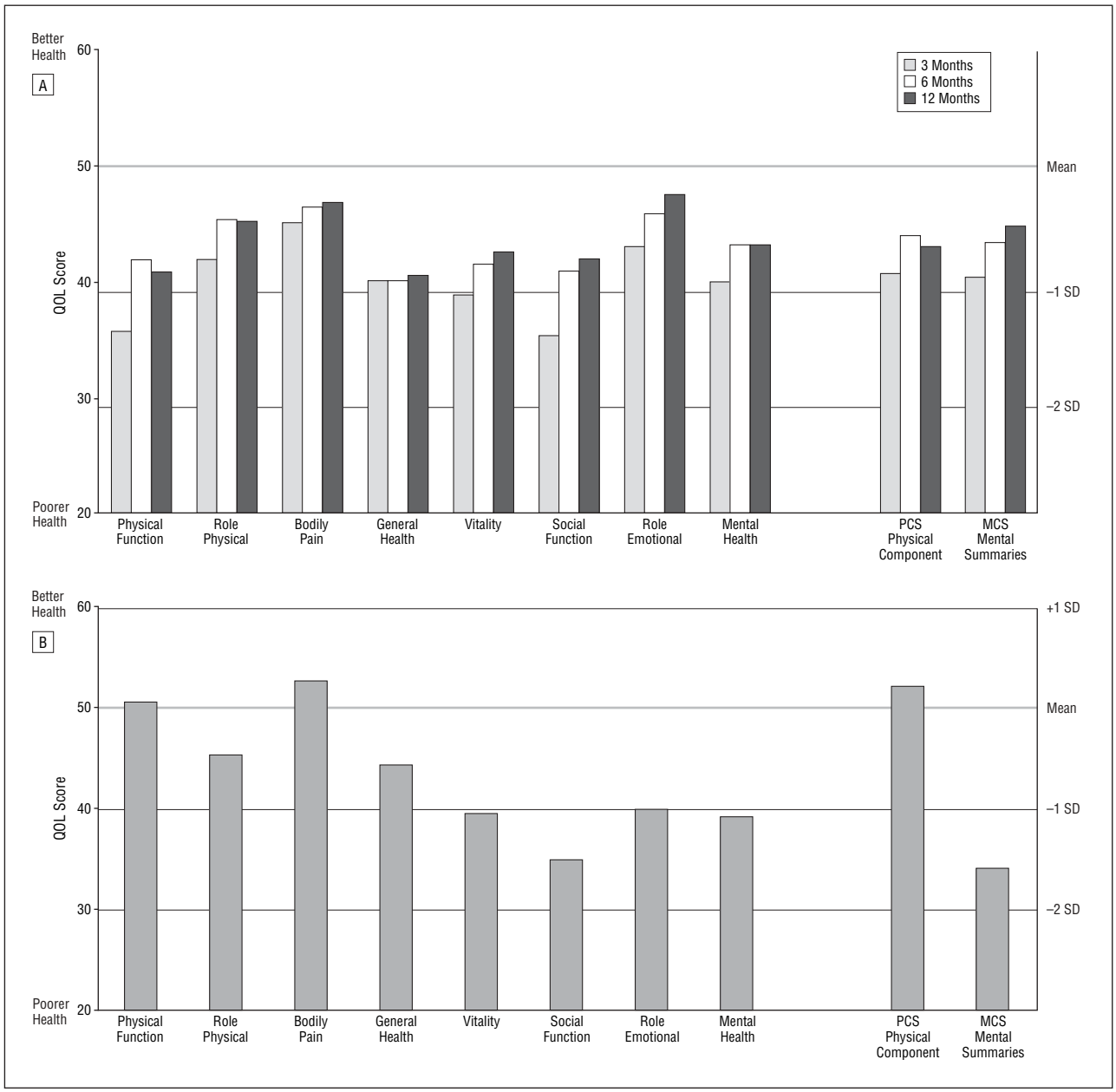

Figure 2. Mean health-related quality of life (QOL) scores among patients with severe acute respiratory syndrome (SARS) in the 12 months following hospital discharge (A) and their caregivers just after quarantine (B). MCS indicates mental component summary score; PCS, physical component summary score.

social function, and role emotional domains were improved at 1 year after hospital discharge but did not normalize. General health, vitality, and social functioning domains remained 1.0, 0.8, and 0.8 SDs below the normal range at 1 year after hospital discharge, respectively (**Figure 2**).

The St George's Respiratory Questionnaire total and domain scores indicated decreased QOL at 3 months that persisted at 1 year, despite some improvement from 3 to 6 months (Table 3).

RETURN TO WORK

Many patients initially returned to work part-time, gradually increasing their workload over 1 to 2 months. Only 23 patients returned to work full-time with no need for a modified schedule. Those who required a modified workload took a median of 94 days to return to any work. At 1 year, 17% of patients had not returned to work, and a further 9% had not returned to their pre-SARS level of work (Table 3).

HEALTH CARE UTILIZATION

Health care utilization of SARS survivors during the first year after hospital discharge was substantial (**Table 4**). Psychiatric evaluation accounted for the greatest number of visits. Of the patients, 74% saw their primary care physician a median of 5 times. Infectious disease specialists assessed 72% of patients, mostly in the first

Table 4. Health Care Utilization in Patients With Severe Acute Respiratory Syndrome in the Year Following Discharge From Acute Care Hospital

Utilization	Total No. of Visits	No. of Patients	Mean No. of Visits
Total Utilization			
Medical consultations			
Psychiatric	668	51	13.1
Psychiatrist	173	24	7.3
Support group	255	23	11.1
Psychologist	119	11	10.8
Social worker	60	10	6.0
Other*	61	10	6.1
Family practitioners	468	86	5.4
Infectious disease specialist†	196	84	2.3
Respirologist	25	11	2.3
Sleep studies	5	3	1.7
Physiatrist	16	9	1.8
Osteoporosis specialist	8	6	1.3
Neurologist	3	3	1.0
Other medical specialists‡	77	30	2.6
Rehabilitation services			
Intense specialized program§	N/A	9	
Hospital-sponsored program‖	229	20	11.5
Private occupational/ physiotherapy	571	20	28.6
Home Rehab service	12	2	6.0
Diagnostic tests¶	502	90	5.6
Homecare	91	5	18.2
Acute care admissions#	6	5	Mean days = 29.2
Emergency department	5	4	1.3
Surgical procedures**	4	4	1.0
Rehab center admissions††	3	3	Mean days = 49.3
Other miscellaneous services‡‡	12	6	2.0
Medical Consultations Initiated by Our Clinic Personnel			
Psychiatric	NA	17	NA
Respiratory/sleep assessment	NA	2	NA
Physiatrist	NA	5	NA
Osteoporosis assessment	NA	6	NA
Neurologic/neurocognitive testing	NA	3	NA
Referrals to other medical specialties§§	NA	11	NA
Referrals to other professionals/services‖‖	NA	11	NA

Abbreviations: NA, not applicable; Rehab, rehabilitation.
*Includes employee assistance program, occupational health counselor, and relaxation therapy.
†Most often within the first month after discharge.
‡Gastroenterology, internal medicine, asthma clinic, cardiology, dermatology, endocrinology, obstetrics/gynecology, kinesiology, oncology, ophthalmology, orthopedics, plastic surgery, nephrology, rheumatology, general surgery, urology, and vascular surgery.
§Program initiated by the workers compensation board consisting of assessment by a physiatrist, physiotherapist, occupational therapist, and psychiatrist. Treatment was 3 to 4 full days per week by whichever specialists were deemed required and for as many weeks as needed.
‖Program initiated by one hospital that had many health care workers affected; group met once a week for many months.
¶Most frequently used are chest radiographs and blood tests.
#Four of these were within 10 days of initial discharge.
**One hip fracture repair, 1 hip replacement for avascular necrosis, 1 cataract removal, and 1 repair of an old shoulder injury.
††Two were directly from the acute care hospitalization for severe acute respiratory syndrome; 1 was after hip fracture repair in a posttransplantation patient.
‡‡Includes immunizations, massage therapy, speech therapy, dietician, oxygen tank, arthroplasty knee, and nurse practitioner.
§§Otorhinolaryngology, general surgery, cardiology, nephrology, orthopaedics, rheumatology, thoracic surgery, and thrombosis clinic.
‖‖Diagnostic testing, pharmacy, wig specialist, and speech pathology.

Table 5. Characteristics of 46 Caregivers of Patients With SARS*

Characteristic	Value
Caregiver sex, female	26 (57)
Caregiver age, median (IQR), y	50 (37-58)
Relationship to patient	
Spouse (58% of these were male)	33 (72)
Sister	5 (11)
Mother	5 (11)
Other	3 (6)
Caregiver also had SARS	5 (11)
Caregiver SF-36 summary scores, mean ± SD	
Physical component	52 ± 11
Mental component	34 ± 16

Abbreviations: IQR, interquartile range; SARS, severe acute respiratory syndrome; SF-36, Medical Outcomes Study 36-Item Short Form Health Survey.
*Data are given as number (percentage) of caregivers unless otherwise specified.

3 months after discharge. Four patients were readmitted to acute care hospitalization within days of discharge, and 2 patients were admitted months later for non-SARS related issues. Three patients needed inpatient rehabilitation, and 4 had surgery over the course of the follow-up year.

CAREGIVER SURVEY

Seventy-two patients identified informal caregivers; 2 did not have adequate proficiency in English to complete the surveys. Forty-six surveys were returned for a participation rate of 66% (46/70). The caregivers were highly educated. The caregiver was usually the patient's spouse (72%), and was most often female (57%) (**Table 5**). Significantly fewer patients had returned to work in the responder group (P=.009); this is likely because people who recovered quickly and went back to work early had fewer needs, and so either these patients did not identify a caregiver or caregivers believed that they had not provided any care giving (**Table 6**).

The summary score of the physical components of the SF-36 for caregivers was normal compared with an age- and sex-matched Canadian[34] population. However, the mental component score was significantly below normal and was significantly correlated with the degree of lifestyle interference and loss of control reported by the caregiver (Pearson r=–0.6; P<.001 for both). The greatest decrements in caregiver SF-36 scores were in the mental health and social functioning domains (Figure 2). Caregivers reported a score of 29 of a possible 102 on the Caregiver Assistance Scale and 22 of 84 on the Caregiving Impact Scale. They reported a high level of personal gain (12/16) and a mid-range sense of control (18/28) over their own lives once quarantine and isolation were lifted. Social support was rated at 67 of a possible 100. Table 1 summarizes these results and presents scores obtained from caregiver studies with patients experiencing other illnesses for comparison.[21,23,25]

Table 6. Comparison of Patient Demographics of Enrolled Caregivers vs Total Cohort*

Demographic	Caregiver Sample (n = 46)	Not in Caregiver Sample†		P Value‡
		Declined (n = 26)	No Caregiver Identified (n = 28)	
Patient age at hospital discharge, y	45 (37-53)	39 (31-49)	41 (33-52)	.44
Patient sex, female	32 (70)	18 (69)	17 (61)	.88
Patient is health care worker	31 (67)	13 (50)	21 (75)	.21
Hospital length of stay, d	14 (8-19)	15 (10-18)	12 (7-21)	.56
Need for ICU stay	7 (15)	5 (19)	4 (14)	.69
Length of ICU stay	19 (10-56)	8 (7-17)	8 (5-9)	.05
≥1 Preexisting medical condition§	6 (13)	2 (8)	1 (7)	.42
Medication administered				
Systemic corticosteroid	25 (54)	18 (69)	20 (71)	.16
Ribavirin	26 (57)	13 (50)	17 (61)	.66
Interferon	7 (15)	2 (8)	1 (4)	.23
None of the above	5 (11)	3 (12)	5 (18)	.98
Patient returned to full-time work by 1 year	25 (54)	21 (81)	21 (75)	.009
Patient SF-36 score at 3 mo, mean ± SD	(n = 35)	(n = 16)	(n = 14)	
Physical component	40 ± 11	39 ± 12	48 ± 12	.02
Mental component	41 ± 14	37 ± 14	45 ± 13	.33

Abbreviations: ICU, intensive care unit; SF-36, Medical Outcomes Study 36-Item Short Form Health Survey.
*Data are given as median (interquartile range) or number (percentage) of patients unless otherwise specified.
†A total of 100 patients were approached to identify a caregiver.
‡Continuous variables were compared using Wilcoxon scores (Mann-Whitney test), and categorical variables were compared using the Mantel-Haenszel χ^2 test.
§Includes diabetes mellitus, chronic renal failure, hepatitis B, chronic obstructive pulmonary disease, coronary artery disease, congestive heart failure, active cancer, connective tissue disease, human immunodeficiency virus/AIDS, or transplantation.

COMMENT

To our knowledge, this is the largest prospective follow-up study of SARS survivors to 1 year. As with other SARS follow-up studies,[14,35,36] most patients had lung function that was within normal limits by 3 months after hospital discharge, and these normal results persisted to 1 year. The SARS ICU survivors had similar physical impairments to those described previously for acute respiratory distress syndrome (ARDS) survivors.[37] All ICU survivors had restrictive disease at 3 months, consistent with the findings of the Singapore[38] and Taiwanese[39] groups, and pulmonary function rose into the normal range by 1 year after hospitalization. Despite normal pulmonary function testing, normal exercise capacity, and a minority of patients (18%) with a clinically important reduction in distance walked in 6 minutes, many patients continued to report shortness of breath and fatigue as notable contributors to exercise limitation at 1 year.

The persistence of symptoms and perception of physical limitations were reflected in the QOL measures at 1 year. Of the survivors, 37% were still reporting an important reduction in their physical health (at least 1 SD below normal on the physical component summary score of the SF-36) at 1 year after acute care hospitalization. As reported by Ong et al[13] and our study, scores on the St George's Respiratory Questionnaire also confirmed a decreased QOL related to pulmonary symptoms. It is possible that the persistent symptoms of shortness of breath and fatigue may reflect a subtle degree of respiratory muscle weakness and a perceived increase in the work of breathing, but the exact pathophysiologic mechanism of these complaints remains unclear.

Of the patients with SARS, 33% reported a significant decrement in mental health at 1 year (at least 1 SD below normal on the mental component summary score) and the health care utilization data suggest an important need for psychological counseling and support after hospitalization. During the clinic visits, we had an opportunity to talk with patients and to understand the stressors that they experienced during this illness. Many patients experienced social stigmatization and loss of anonymity through the media, death of close family members and coworkers, and the inability to be present at the time of death or attend funeral services because of quarantine, isolation, or hospitalization. Several described the emotional strain of quarantine and isolation. Others described overwhelming fear for their physical health and a deep concern about the possibility of transmission to family or loved ones. Patients with SARS were subjected to extraordinary stressors during and after the outbreak and experienced significant emotional consequences as a result. Psychological trauma to patients and caregivers may have been reduced had their mutual support system remained intact through the outbreak, and this may have been achieved through video conferencing technology via the Internet. Telephone contact may also have helped but was not available in all circumstances because of the constraints of isolation rooms. Access to television and newspapers may also have helped those in hospital retain a sense of connectedness to the outside world. Early on in the SARS outbreak, the mode of transmission of the disease was unknown, and all person-to-person contact was minimized. However, some patients reported that health care workers insisted on spending time with and giving emotional support to them, and this helped to ameliorate their feelings of fear, anxiety, and isolation.

Acute illness affects the family as well as the patient. Caregivers told us that while their physical health remained at the level of the population average, the emotional impact of having a family member with an unknown illness was significant. Caregivers scored 1.6 SDs below the normal value expected for their age and sex on the mental component summary score of the SF-36 when asked to recall their feelings from the postisolation period. The caregivers of SARS survivors provided assistance after the isolation period to an extent similar to the caregivers of patients with ARDS at 2 years after ICU discharge.[25] Personal gain and perceived mastery of their situations were comparable in the SARS and ARDS cohorts, whereas ARDS caregivers believed that they had slightly more social support than did individuals caring for patients with SARS (Table 1).

Our study had several limitations. First, we enrolled only 38% of the entire Toronto population of adult survivors and 59% of those who were referred to us. Recruitment was challenging because many SARS survivors did not wish to be seen or discuss their experiences, and the members of our team were unknown to these patients. Our study sample contained an excess of health care workers, more patients who had at least 1 preexisting medical condition, and more who were treated with systemic corticosteroids. These facts, along with the high-education levels and the number of women in both the patient and caregiver groups, may limit generalizability. The number of health care workers in the sample may also skew the utilization of health care services used, since health care workers are very aware of their own health status and may use services more than other workers in the population.

Second, the premorbid health status of patients and their caregivers and the health care utilization of patients were not documented, and perhaps some of the functional limitation and decreased QOL that we observed was attributable to preexisting health conditions and not directly related to SARS. However, given the young age of both caregivers and patients and the fact that most were working prior to SARS, the likelihood of premorbid illness being a major contributor to the observed results seems minimal.

Third, the retrospective nature of the caregiver survey makes the caregiver information subject to recall bias. Finally, we were not able to include a control group in this study because of the unknown nature and outcome of this new infectious disease.

We have shown that most SARS survivors have pulmonary and functional recovery from their acute illness. However, 1 year after discharge from hospital, health-related QOL remained lower than in the general population, and patients reported important decrements in mental health. These findings are reflected in the notable utilization of psychiatric and psychological services in the 1-year follow-up period. We have also demonstrated that family caregivers experienced considerable emotional distress during the acute illness of their family member. These data may help to highlight the needs of patients and caregivers during and after an epidemic, the potential benefit of a family-centered approach to follow-up care, and the importance of exploring strategies to minimize the psychological burden of an epidemic illness as part of future pandemic planning initiatives.

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