

THE 2004 CARL A. MOYER AWARD

Late Outcomes in Adult Survivors of Toxic Epidermal Necrolysis After Treatment in a Burn Center

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Despite improved survival after burn center treatment for patients with toxic epidermal necrolysis (TEN), little is known about the overall long-term outcomes in these patients. In this work we sought to analyze late outcomes in survivors of TEN who were treated in our burn center. Subjects completed a questionnaire that included the RAND 36-Item Health Survey (SF-36) and the Dermatology Life Quality Index. Subjects were examined, when possible, and completed the Functional Independence Measure. Scores on the SF-36 were compared with age- and sex-matched National normative data. All results are presented as the mean \pm SD. Of 35 adults admitted with TEN between January 1, 1995, and January 6, 2003, 10 have died in hospital, 4 have died since discharge, and 8 have been lost to follow-up, leaving a study population of 13 subjects (age 45 ± 18 years with initial %TBSA involvement 65 ± 29). Follow-up occurred at 38 ± 27 months after discharge. The most common ophthalmic problems were chronic photosensitivity (54%) and dry eyes (31%). The Dermatology Life Quality Index (maximum-worst score = 30) was 9 ± 10 . SF-36 scores were significantly lower than in the age- and sex-matched normal population across all domains except mental health. The Functional Independence Measure score (maximum-best score = 126) was 123 ± 4 . Survivors of TEN demonstrate a high level of independent function in activities of daily living, but numerous complications of TEN significantly impair their overall quality of life, emphasizing the need for long-term follow-up. (*J Burn Care Rehabil* 2005;26:33-41)

In the past decade, increasing numbers of patients with toxic epidermal necrolysis (TEN) and Stevens-Johnson syndrome/toxic epidermal necrolysis (SJS-TEN) overlap have been treated in burn centers.¹⁻⁸ Although survival rates appear to be improved with earlier referral to a burn center,^{6,8} little is known about the long-term outcomes in these patients after their discharge from the burn center. Although many

individual late complications of TEN and SJS-TEN overlap have been described, including chronic pulmonary disease,⁹ ocular and cutaneous sequelae,¹⁰⁻¹³ and vulvovaginal disorders,¹⁴ these reports have mostly involved patients who were not treated in burn centers. This issue is relevant because burn centers typically treat patients with the most severe forms of the disease. These patients have lengthy and complex hospital stays with significant morbidity.⁸ However, data on long-term outcomes in this group of patients are unavailable. Furthermore, no studies have assessed the effects of TEN, its treatment, and its complications on "global" or "overall" health-related quality of life. Although one report on the long-term consequences of TEN in children who were treated in a burn center has been published,¹⁵ no studies have looked at late outcomes in adults.

The purpose of this study was to identify not only individual long-term complications but also the over-

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0733-8481/2005

DOI: 10.1097/01.BCR.0000150215.79228.79

all effect of these complications on health-related quality of life among patients with TEN or SJS-TEN overlap who were treated in our burn center. One of the main limitations in assessing long-term outcomes of patients with TEN is the rarity of the disease and the relatively small number of patients that are treated in any one burn center each year. When these issues are compounded by the typical problems associated with maintaining long-term follow-up, only small numbers of patients are eventually available for study. Although our primary intention was to assess late outcomes in our own patients, this was performed within the context of eventually wishing to apply our assessment strategy to a larger number of patients in a multicenter study.

METHODS

Patient Selection

This study was approved by the Research Ethics Board of our institution. Patients who were admitted and treated for TEN or SJS-TEN overlap at our adult regional burn center between January 1, 1995, and June 1, 2003, were identified using the burn center's computerized database. Clinical criteria¹⁶ and skin biopsies were used to define SJS-TEN overlap and TEN. The records of these patients were reviewed to gather demographic and disease severity information, comorbidities, suspected causative drugs, methods of treatment, length of stay, length of mechanical ventilation, complications, and mortality.

Subject Recruitment

Eligible former patients were contacted by telephone to request their participation in the study. Former patients who consented were mailed both a form explaining the study as well as the study questionnaire. Patients whose addresses were available, but who could not be reached by phone, were sent the same package with a more detailed explanation of the study.

Study Questionnaire

The questionnaire was a composite instrument, made up of two validated scales, (the RAND 36 Item Health Survey 1.0 and the Dermatology Life Quality Index), and several other sections that pertained to the recovery process, return to work or school, and dermatologic, ophthalmologic, gynecologic, and respiratory complications.

The RAND 36-Item Health Survey 1.0 or Short Form 36 (SF-36)¹⁷ is a validated questionnaire designed to assess eight health dimensions, including

physical and mental health and function. This instrument was used to assess overall health-related quality of life. The SF-36 is divided into eight domains: physical functioning, role limitations caused by physical health, role limitations caused by emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health. The domain scores each range from 0 to 100, with a higher number indicating a more favorable health status. The SF-36 was scored according to the method outlined by Medical Outcomes Trust's SF-36 Health Survey Manual and Interpretation Guide.^{17,18} Age- and sex-adjusted normative data for the SF-36 were derived from published National normative data¹⁹ on the basis of sex and age at the time of follow-up. Because no baseline SF-36 scores at the time of the onset of illness could be obtained, an extrapolated score based on age, sex, and comorbid illness was determined from the National normative data, as an estimate of health related quality of life before hospitalization for TEN.^{17,18}

The Dermatology Life Quality Index (DLQI) is a validated instrument designed to assess quality of life as it relates to dermatologic conditions.²⁰ The DLQI was analyzed according to the scoring instructions outlined by Finlay and Khan.²⁰

Questions regarding recovery and long-term complications were developed by the authors on the basis of a review of the literature with respect to the known late sequelae of TEN. Study participants answered questions either by circling the most appropriate answer or filling in the blank where indicated. Patients were assigned a study number, and no identifying information was included directly on the questionnaire. Approximately 15 to 30 minutes were required to complete the entire questionnaire. Study participants then mailed back the questionnaire.

Follow-up Examination

Participants were then contacted to ask whether they were willing to come to clinic for a follow-up assessment with the Senior Investigator. The focus of the visit was the assessment of the appearance of the skin and nails. After patients had been examined in clinic, the burn center physiotherapist administered the Functional Independence Measure (FIM),²¹ an 18-item instrument designed to assess progress during rehabilitation and ability to perform activities of daily living independently.

Statistical Analysis

Data are presented as mean \pm SD. Descriptive statistics were generated for all variables. Two-tailed Student's *t*-tests were used to compare scores of the TEN

sample to the age- and sex-adjusted normative data. Data were analyzed with the Statistical Package for the Social Sciences (SPSS version 11.0.1) for Windows (SPSS Institute, Chicago, IL).

RESULTS

Study Population

Thirty-five patients were treated for TEN or SJS-TEN overlap between January 1, 1996, and June 1, 2003. Of these patients, 20 were female (57%) and 15 were male (43%), with a mean age of 51 ± 19 years. The mean % TBSA involved with rash was $65 \pm 28\%$, with epidermal detachment involving $38 \pm 28\%$ TBSA. Ten patients (29%) died while in hospital, leaving 25 patients who survived and were discharged home. Four patients were found to have subsequently died since their discharge from hospital. This left 21 former patients; 15 were contacted by telephone and agreed to participate and were mailed the survey package, whereas 6 could not be contacted by phone (disconnected or wrong number). These six former patients were mailed the survey using their most recently available contact addresses. Responses were received from 13 of the

15 former patients that had been reached by phone (87% response rate), but there were no responses from the six former patients who could not be reached by phone. Therefore, 13 patients, representing an overall response rate of 62%, were available for inclusion in this study. Six of the 13 patients (46%) agreed to present for a follow up examination and completion of the FIM.

At the time of their burn center admission, the group's mean age was 43 ± 17 years, and the total % TBSA involved with rash at presentation was 66 ± 29 , with $34 \pm 25\%$ TBSA as epidermal detachment. The duration of mechanical ventilation, defined as the time from intubation to the time during which the patient tolerated 24 or more consecutive hours without mechanical support (ie, oxygen face mask or tracheostomy mask only), was 13 ± 12 days. The length of stay, defined as the duration of burn center and/or acute care hospital stay, was 37 ± 35 days. The individual characteristics of the 13 patients at the time of their burn center admission are summarized in Table 1. The mean time between hospital discharge and completion of the questionnaire was 38 ± 27 months. The age of the participants at the time of completion of the survey was 45 ± 13 years.

Table 1. Characteristics of study participants at the time of burn center admission, including age, sex, significant preinjury medical conditions, the extent of skin involvement at presentation expressed as total percent TBSA involved and percent TBSA with epidermal detachment, days of mechanical ventilation, dose of intravenous immunoglobulin (IVIg) received, and the length of stay at the burn center

Case	Age, yrs	Sex	Premorbid Conditions	Drug	%TBSA Involved Total/Detach	Days of Mechanical Ventilation	IVIg, gm/kg	Length of Stay, Days
1	47	F		Septin	90/60	4	0	13
2	71	M	Hypertension	Amoxicillin	60/60	31	0	123
3	33	F	Epilepsy	Dilantin	30/15	8	3.0	11
4	26	F	Bipolar A.D.	Carbamazepine	60/10	10	2.0	13
5	69	M	Hypothyroid hypertension	Amoxicillin	80/40	8	2.0	14
6	23	F	HIV	Ibuprofen	50/40	25	1.8	48
7	46	F	Hypertension, uric acid uric acid	Septin	80/10	0	2.7	4
8	46	M	Diabetes, CAD	Carbamazepine	100/30	2	2.7	69
9	34	F		Ibuprofen	60/41	30	2.5	68
10	68	F	Lymphoma	Allopurinol	100/25	23	2.0	54
11	63	M		Allopurinol	100/90	27	1.9	43
12	39	M	Psoasitic arthritis	Mobicin	15/10	0	2.7	12
13	19	F	Epilepsy	Dilantin	30/10	7	2.7	14
Mean \pm SD	43 ± 17				66 ± 29 34 ± 25	13 ± 12		37 ± 35

Recovery Process

At discharge from the burn center, eight patients went directly home and five patients were transferred to a rehabilitation/convalescence facility before eventually returning home. Only one patient (8%) required a homecare nurse, whereas the remainder indicated that they had at least one primary caregiver who was either a spouse (46%), parent (39%), or other family member (31%).

All patients had a lengthy recovery period before they returned to work or school. One patient had been retired at the time of his illness whereas 12 had been employed. Of these, six (50%) indicated that they had not yet been able to return to work. In four cases, this was because their job had been terminated because of their lengthy absence during illness and recovery. In two cases the respondents indicated that they remained unwell and were physically or mentally unprepared to return to work. Six patients had returned to work at 5 ± 1 months after hospital discharge (range, 3 to 7 months). Two of these patients were able to return to their previous job duties, but four required modification of their previous work duties for the following reasons: exhaustion; development of epilepsy after encephalitis; tearing of the eyes, causing difficulties with reading and writing; and complaints, including foot pain and exhaustion. One patient who worked and attended university lost credit for one semester.

Ophthalmic Complications

Late ophthalmic complications were observed predominantly in the patients who had conjunctival in-

volvement during their acute illness. These complications are summarized in Table 2. The most common complications were chronic photophobia (54%), and dry eyes (31%). Entropion with trichiasis was the next most frequently documented complication (Figure 1)A, causing corneal abrasions in one case. One patient (case 9), who had severe acute eye involvement, went on to develop extensive, debilitating ophthalmic problems, with significant deterioration in visual acuity after discharge. These complications included keratoconjunctivitis sicca, bilateral lid margin squamous metaplasia with corneal ulcerations, and bilateral ectropion. The patient presently is undergoing bilateral resurfacing of the tarsal conjunctiva with buccal mucosal grafts and will ultimately require corneal transplantation.

Skin and Nail Changes

This section of the questionnaire was answered by 12 of the 13 respondents, with 1 patient choosing not to answer any of the questions. Fifty percent of respondents (6/12) indicated that they had persistent nail deformities, including dystrophic nails, ridging, streaky pigmentation of the nail bed, and nongrowing nails (Figure 1)B. Both fingernails and toenails were affected. Nine of the patients had persistent skin pigmentation abnormalities; of these, three patients reported areas of hypopigmentation only, one patient stated that areas of skin were hyperpigmented, and five patients indicated that they had both hyperpigmentation and hypopigmentation (Figure 1)C. All but one of these patients indicated that their pigmentation abnormalities had partially faded over time. The patients with pigmentation abnor-

Table 2. Summary of the ophthalmologic complications that occurred (+) or did not occur (-) after hospitalization for GEN

Case No.	Acute Involvement?	Dry Eyes	Photophobia	Entropion	Entropion			Lid Adhesions, Symblepharons	Loss of Visual Acuity
					With Trichiasis	Corneal Abrasions	Corneal Ulcers		
2	Yes	-	-	-	-	-	-	-	
4	Yes	-	-	-	-	-	-	-	
5	Yes	+	+	-	-	+	-	-	
6	Yes	-	+	-	-	-	-	-	
8	Yes	-	+	-	-	-	-	-	
9	Yes	+	+	+	-	+	+	+	
10	Yes	-	-	-	-	-	-	-	
11	Yes	+	+	-	-	-	-	-	
12	Yes	-	+	-	-	-	-	-	
1	No	+	+	-	-	-	-	-	
3	No	-	-	-	-	-	-	-	
7	No	-	-	-	-	-	-	-	
13	No	-	-	-	-	-	-	-	

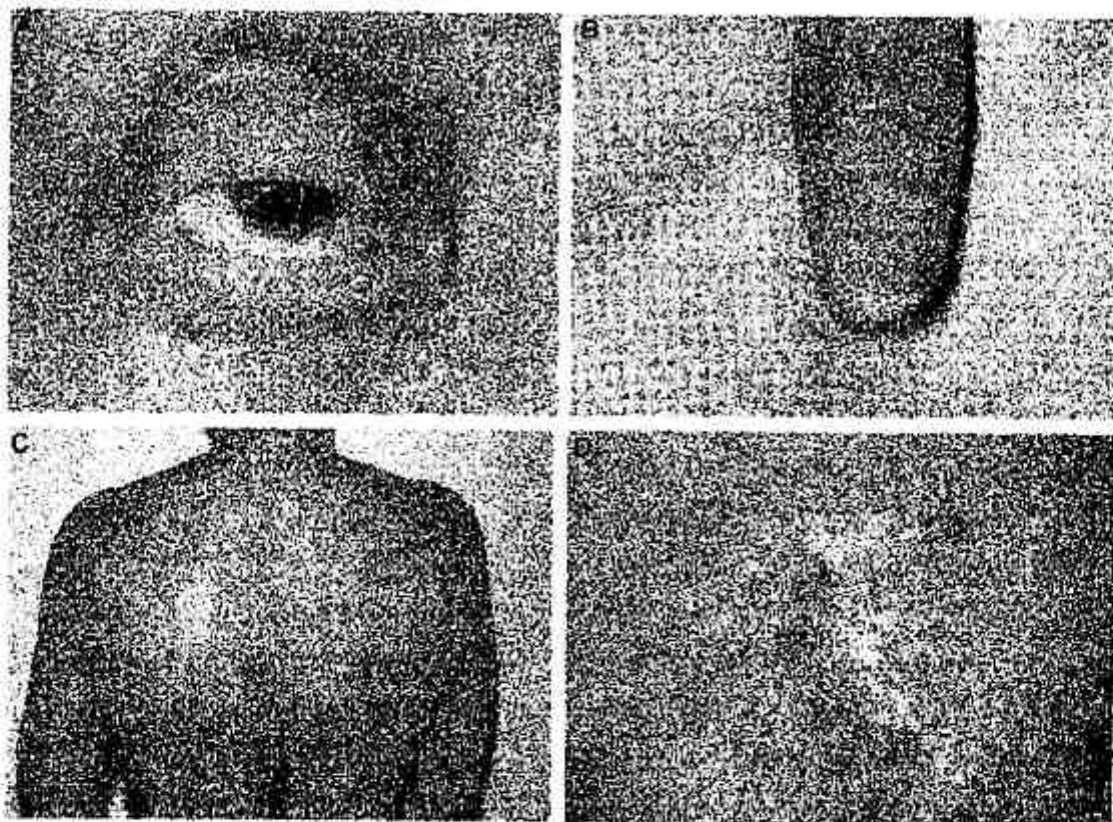


Figure 1. Examples of late toxic epidermal necrolysis (TEN) manifestations, including eyelid adhesions with entropion and trichiasis (A), dystrophic nail growth (B), spotty hyperpigmentation (C), and punctate keloid scars at staple insertion sites (D).

malities were of the following ethnic backgrounds: 33% African American, 33% Southeast Asian, 22% Caucasian, and 11% Asian. Four patients (33%) reported chronic pruritus since discharge from hospital.

Six patients were examined in clinic. Two of the six patients presented with multiple, punctate keloid scars corresponding exactly to the skin staple sites on which skin substitutes had been applied at the time of their acute illness in the burn center (Figure 1)D. One patient was African American, the other was East Indian, and both were dark skinned.

Eleven patients completed the DLQI. The maximum score for this instrument is 30, with a higher score indicating a decreased quality of life. The mean score for the respondents was 9 ± 11 . Five patients (45%) scored the minimum score of zero; the remaining six scored between 5 and 27. The score of those who reported persistent skin pigmentation changes was 13 ± 11 , which differed significantly from the patients who did not have lasting pigmentation

changes (mean score of 0, $P = .05$, Mann-Whitney *U* test). Three patients indicated that they suffered from another dermatologic condition (one eczema, one psoriasis, one not stated). The scores of the patients with concomitant dermatologic conditions were not significantly different from those of patients who did not have any comorbid dermatologic conditions.

Vulvovaginal Complications

Eight women completed the section of the questionnaire pertaining to vaginal complications. Of these, six had vaginal mucosal involvement during their acute illness. One woman had undergone menopause and was on hormone replacement therapy since her discharge from hospital. One woman reported vaginal dryness, itching, pain, burning, and abnormal discharge. Her records indicated moderate-to-severe vaginal desquamation and sloughing during hospitalization for TEN. This patient also reported genital adhesions (unspecified vaginal, vulvar, or both) and

had undergone surgery for this complication. This patient did not answer any of the questions regarding pain or bleeding during intercourse. Four of the women reported attempting sexual intercourse after TEN, and all four were successful in their attempts. Only one of these patients reported pain and bleeding during sexual intercourse.

Overall Health-Related Quality of Life

The estimated SF-36 score of the subjects before hospitalization (extrapolated from normative age, sex, and premorbid-illness matched data), their measured SF-36 scores at follow-up, and the National normative SF-36 scores are shown in Figure 2. In the study group there was a decline in the SF-36 score from before hospitalization to the time of follow-up in every domain. The study group's scores at follow-up were significantly lower than in the normal population in all domains with the exception of scores for the mental health domain.

Functional Independence Measure

This instrument was used for the six patients who agreed to present for a follow-up visit. All six of the patients obtained high scores on the FIM, with a mean score of 123 ± 4 , of a maximum of 126 (range, 117–126).

DISCUSSION

Adult survivors of TEN and SJS-TEN overlap who were treated in our burn center had significantly lower overall health-related quality of life compared with the normal population as a whole when assessed at a mean of approximately 3 years after

discharge from the burn center. Half of these adults had not yet returned to work because of their illness and, of those who could return to work, resumption of their original job duties was the exception rather than the rule. A broad spectrum of ophthalmic, skin, nail, and vulvovaginal complications were identified among this group of survivors. The main relevance of these findings is that they identify the need for regular, long-term, and multidisciplinary follow-up of these patients.

The SF-36 measures general health status through assessment of eight domains that encompass both physical and mental well-being. Because it was impossible to have a patient complete the SF-36 before experiencing TEN, the "baseline" scores used as a comparison to the measured scores of patients after TEN were extrapolated from age-, sex-, and disease-matched controls from the normative population.¹⁹ Although all of the post-TEN scores were numerically lower than the "baseline" scores, it is impossible to tell whether the differences were statistically significant, given the small sample size and the fact that the "baseline" scores were extrapolated and not directly measured. However, all of the measured post-TEN domain scores of our patients, with the exception of mental health, were significantly lower than the age- and sex-matched national normative domain scores for the population as a whole. The lack of significant difference in the mental health domain may simply reflect the capacity of these patients to develop coping skills in response to their illness and the subsequent complications. This characteristic of mental health suggests that people tend to adapt to whatever happens. The high scores on the FIM indicate that these patients did not have any major functional limitations that impaired activities of daily living. This result is in sharp contrast to patients with burn injuries with comparable % TBSA burns and lengths of stay, who had substantially lower FIM scores.²² Presumably, the burden of critical illness, lengthy hospitalization, and the complications of TEN contributed to an overall loss of vitality, chronic pain, and emotional lability. This explanation, rather than specific functional limitations, was the likely basis for the delayed and inconsistent return to employment that was observed among these former patients. We recognize that the patients who were evaluated using the FIM were self-selected (ie: those who agreed to come to clinic) and may have been more independently functional than those patients who declined to come for follow-up, thus biasing the results. However, it is likely that patients who recover from TEN are able to resume most activities of daily living because of the absence of skin and joint contractures (which typi-

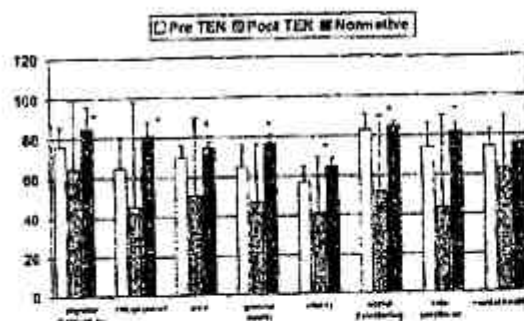


Figure 2. Short Form 36 (SF-36; \pm SD) scores extrapolated at baseline before onset of toxic epidermal necrolysis (TEN; Pre TEN), measured at follow-up after discharge (Post TEN), and age- and sex-matched national normative scores for the population. * $P < .05$ between Post TEN and normative scores.

cally complicate the recovery of a burn patient, for example).

Late ophthalmic complications develop in 20%¹² to 75%²³ of patients with TEN and appear to be the most common problem faced by survivors of TEN. The incidence of late ocular complaints in our study population was 77%. It is not known whether the development of late ocular complications is related to the severity of eye involvement during the acute phase of the disease. One study of eight patients with TEN with longitudinal follow-up between 0.5 and 8 years found that there was no relationship between initial severity of ocular involvement and the development of late ophthalmic complications.²³ Our data, in contrast, suggest that late ophthalmologic sequelae are uncommon in patients who did not have eye involvement during the acute phase of TEN. The hallmark of acute ocular involvement during TEN is intense conjunctival inflammation with the formation of pseudomembranous and membranous conjunctivitis. Ultimately, this leads to the formation of cicatrices (scars) of the eyelids, between the eyelids, or between the tarsal conjunctiva (inner aspect of the eyelid) and the bulbar conjunctiva (conjunctiva over the globe).¹² The manifestations of these scars can range from ectropion with exposure keratitis^{12,24-26} to symblepharon (scarring between tarsal and bulbar conjunctiva causing incomplete blink and exposure keratitis),^{17,23} to entropion with trichiasis (inward turning of the eyelashes which abrade the cornea).^{11,23} Three of our patients had the latter complication, and one had to regularly trim his eyelashes with scissors to prevent corneal abrasions.

Another common late ocular complication of TEN is keratinization of the conjunctiva of the eyelid margin (tarsal conjunctiva). This abnormal epithelialization can lead to mechanical trauma to the cornea and can produce manifestations such as foreign body sensation, excessive lacrimation, eye pain, photophobia, and corneal erosion or ulceration.¹⁷ Indeed, the most severe ocular complication in our series of patients (case 9) resulted from this process and has resulted in the need for bilateral lid margin resurfacing with buccal mucosal grafts in that patient. Finally, a common and bothersome late ocular complication of TEN is the development of dry eyes. This may result from cicatricial occlusion of the lacrimal and accessory lacrimal gland orifices causing a defective aqueous layer of the tear film or, more commonly, results from deficient mucin in the tear film caused by the destruction of the conjunctival goblet cells.¹² One third of the patients in this survey experienced this problem and required either short- and/or long-term tear replacement drops.

Perhaps the most socially disabling long-term complication in survivors of TEN are the changes in the skin and nails. The skin may become hypopigmented, hyperpigmented, or present with mixed pigmentation disturbances.^{15,27,28} Hypertrophic scars, although rare, have been reported.^{13,18} Nine of the 13 subjects in our series (69%) had persistent changes in skin pigmentation. Although none of our patients developed hypertrophic scarring, interestingly, punctate keloids occurred in two cases at sites onto which surgical staples had been inserted to secure skin substitutes. This complication of treatment has not been previously noted in the literature. Thus is an important reminder to use staples sparingly, especially in cases in which the individual is a potential keloid former. The nail changes reported by six (46%) of our patients included variable pigmentation of the nailbed with mainly hyperpigmentation, along with ridging of the nails and abnormal nail shape. Abnormal pigmentation and nail growth dystrophy are recognized complications of TEN and appear to be permanent. Chronic pruritus occurred in 33% of our patients, which was slightly less frequent than that which was reported in Sheridan's report on late TEN complications in children.

The DLQI is a validated, system-specific quality of life measure that was designed to assess the effect of cutaneous disease on work, leisure, daily activities, personal relationships, and treatment during the week before answering the questionnaire.^{20,29} The DLQI previously has been used to study quality of life as related to dermatology in patients with acne, psoriasis, and atopic dermatitis but has never been used in the setting of TEN. The DLQI score of our patients was comparable to the scores of 100 normal controls, reported by Finlay and Khan.²⁰ However, the score of those who reported persistent skin pigmentation changes differed significantly from the patients who did not have lasting pigmentation changes. This might indicate that persistent hypopigmentation or hyperpigmentation of the skin has a detrimental effect on quality of life, from a dermatologic perspective.

Gynecologic care is vital for women during the acute phase of TEN. Vulvar involvement during hospitalization can include erosions, ulcerations, and bullous lesions, whereas vaginal involvement may consist of erosions and vaginitis.¹⁴ Long-term complications can include vulvovaginal synechiae and vaginal stenosis. In our study, six of the eight women who responded to the questionnaire had experienced vaginal mucosal involvement in the acute phase of TEN, but only one of these women suffered from genital adhesions in the long-term, for which she required corrective surgery. This same woman was the

only respondent who had late vaginal symptoms. Meuneux et al¹⁴ also used a questionnaire to identify long-term genital complications in a series of 18 women who had recovered from TEN. Of the nine respondents that had suffered genital mucosal involvement acutely, five (56%) developed late vaginal symptoms. Fourteen of their patients had attempted sexual intercourse, compared with four of our eight patients. Intercourse was painful in four of the cases reported by Meuneux et al and, of these, bleeding resulted in two cases. Only one of our patients reported pain and bleeding during sexual intercourse. The small number of questionnaire respondents in our study makes it difficult to estimate the frequency of long-term vulvovaginal complications in female survivors of TEN. However, our results indicate that long-term vaginal complications do occur and need to be addressed during follow-up of these patients.

We felt that evaluation of respiratory complications by questionnaire would prove to be less useful than for ophthalmologic, skin, or vaginal complications. Furthermore, pulmonary function tests would be the most accurate way to assess the respiratory status of this group of patients. Hence, we did not explore the potential late respiratory effects of TEN in this study. McIvor et al⁹ performed serial pulmonary function tests, at 12 to 17 months after discharge from burn center, on four survivors of TEN, three of whom had undergone a mean of 18 days of mechanical ventilatory support during their illness, and one patient who had not been intubated during the acute phase. Three of these patients, including the one who had never been intubated, showed persistent and significant reductions in their diffusion capacity for carbon monoxide, at less than 75% of predicted. Lung volumes and flow rates were within predicted ranges in all cases. Notwithstanding the small sample size in that study, the results suggest that there may be permanent impairment in gas exchange in patients who survive TEN. However, whether this is clinically important is unknown.

The main limitation in our study was the small sample size. However, we believe that our recruitment of former patients is typical and representative of what could be expected from most burn centers that regularly treat TEN cases. One of our interests was to assess the suitability of our survey, with the intention of eventually applying it to larger numbers of patients in a multicenter study. The questionnaire was easily completed by the participants within 15 to 30 minutes and has provided useful information on the late health status of our TEN survivors. Therefore, we believe that our questionnaire would be well suited for wider distribution by several burn centers,

in an effort to more accurately assess the late outcomes after TEN care in a burn center. Data of this nature would potentially be important in supporting the continued role of burn centers in the treatment of this disease. Our findings also emphasize the need for ongoing multidisciplinary follow-up care of these patients, well past discharge from the burn center. The burn clinician and burn team are clearly the most appropriate coordinators of this follow-up, rather than the patient's primary care physician.

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