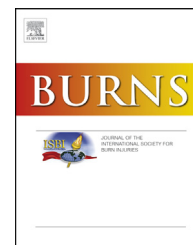


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Burn unit care of Stevens Johnson syndrome/toxic epidermal necrolysis: A survey

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ABSTRACT

Stevens-Johnson syndrome/toxic epidermal necrolysis (SJS/TEN) is a systemic disease that can be associated with debilitating acute and chronic complications across multiple organ systems. As patients with acute SJS/TEN are often treated in a burn intensive care unit (BICU), we surveyed burn centers across the United States to determine their approach to the care of these patients. The goal of our study was to identify best practices and possible variations in the care of patients with acute SJS/TEN. We demonstrate that the method of diagnosis, use of systemic therapies, and involvement of subspecialists varied significantly between burn centers. Beyond supportive care provided to every patient, our data highlights a lack of standardization in the acute care of patients with SJS/TEN. A comprehensive guideline for the care of patients with acute SJS/TEN is indicated.

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1. Introduction

Stevens-Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN) form a spectrum of immune mediated disease, typically triggered by medications [1] and characterized by cutaneous and mucous membrane sloughing during the acute phase [2]. SJS affects <10% of total body surface area (TBSA), while TEN involves ≥30% of TBSA [3] and is more often

associated with multi-organ failure [4,5]. SJS/TEN overlap is defined by involvement of 10–30% TBSA. The diagnosis of SJS/TEN is informed by clinical signs, and confirmed by skin biopsy demonstrating full thickness necrosis and separation of the epidermis [6,7]. The estimated annual incidence of SJS/TEN ranges from 2 to 7 cases per million [8–13] with a mortality of approximately 5% in SJS and 25–35% in TEN [14,15]. Affected individuals may develop severe inflammation of mucosal surfaces including the respiratory, gastrointestinal, and

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Abbreviations: SJS, Stevens-Johnson syndrome; TEN, toxic epidermal necrolysis; BICU, burn intensive care unit; IVIG, intravenous immunoglobulin.

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genitourinary tracts [16,17]. Metabolic imbalance, sepsis, pulmonary embolism, renal failure, hematologic abnormalities, and gastrointestinal hemorrhage can also occur [18–21]. Survivors may be left with severe, chronic, and often debilitating complications that can permanently impair activities of daily living and quality of life [22]. Ocular complications are recognized as the most significant sequelae of SJS/TEN [23–25]. However, other chronic complications that commonly affect patients include skin scarring and pigmentation; fingernail loss; respiratory dysfunction; vaginal, urethral, and/or anal stenosis; vulvar adenosis; penile phimosis; dental deformities; esophageal strictures; and dry mouth [22,26–29].

Despite the significant acute and chronic morbidity associated with this disease, recent advances in treatment have been limited and the optimal therapies for patients with SJS/TEN remain unclear. The basic approach to SJS/TEN is prompt termination of the offending agent and robust supportive care in a burn intensive care unit (BICU) [30]. Special attention is given to the airway, renal function, fluid and electrolyte balance, nutrition, skin and ocular surface, pain control, and mitigation of infection [16,31]. In addition to supportive therapy, various systemic interventions have been suggested in the acute management of SJS/TEN, particularly systemic corticosteroids [32], human intravenous immune globulin (IVIG) [33], and plasmapheresis [31]. Roles for granulocyte colony stimulating factor, cyclosporine, tumor necrosis factor inhibitors, and cyclophosphamide have also been proposed [26,34].

Perhaps because understanding of the immunopathogenesis of this disease remains elusive [6], the systemic treatment of patients with SJS/TEN has not been standardized [30]. The relative rarity of SJS/TEN makes randomized clinical trials prohibitive, resulting in a lack of evidence basis in treating the disease [35]. As patients with acute SJS/TEN are generally treated in a BICU [15], we conducted a survey of burn centers in the United States (US) to document their management of patients with SJS/TEN. Our goal was to capture any variation in current practices among burn centers and to identify opportunities for improvement in the management of patients with this complex disease.

2. Methods

This study received approval from the institutional review board of the Massachusetts Eye and Ear Infirmary. A survey was developed for phone interviews of nursing supervisors at all burn centers in the US. Most questions were binary in design. A list of all questions included in the survey can be found in Appendix A. A web-published database of all burn centers in the US (no. = 128) was downloaded from the American Burn Association (ABA) website (<http://www.ameriburn.org>, accessed on July 1, 2015). Heads of nursing were contacted either by telephone numbers listed in the database or as directed by hospital operators. All burn centers listed in the database were contacted. The telephone survey was conducted from July 6, 2015 to August 19, 2015.

Data were analyzed using Microsoft Excel. Summary data are presented as the percentage of number of responding burn centers that do admit patients with SJS/TEN ($n = 102$).

3. Results

3.1. Burn centers characteristics

One hundred and twenty-five of 128 burn centers listed in the database were operational during the study period (July 6–August 19, 2015). Clinical leadership at 111 burn centers participated in our survey, resulting in an 89% response rate. Most surveys were completed within the first five attempts. A few surveys were completed by email as requested by the respondents. On several occasions, nurse clinicians, clinical nurse educators, nurse practitioners, or charge nurses completed the survey. We could not complete phone interviews with 17 burn centers listed in the database. Three burn centers were closed, two opted not to participate, and heads of nursing at 12 burn centers could not be reached despite multiple attempts.

Among the participating burn centers, 92% confirmed that they admit patients with SJS/TEN. At institutions where burn centers do not admit SJS/TEN patients (9%), the patient is either admitted to another inpatient service (7%) or transferred to another hospital (2%). Among admitting burn centers, 52% were ABA verified and the majority were affiliated with an academic institution. The majority also reported accepting both pediatric and adult patients. Complete demographic and burn center characteristics are provided in Table 1.

3.2. Evaluation and diagnosis

Of the 102 burn centers that admit patients with SJS/TEN, 27% report having a written guideline, protocol, algorithm, or policy for the acute care of such patients. Twenty-five percent acknowledge using the SCORE of Toxic Epidermal Necrosis (SCORTEN) scale [36] in their evaluation of these patients, while 7% of respondents were uncertain if their burn team use this grading scheme. Most respondents reported that their burn team uses percentage of TBSA to guide their management. Skin biopsy is routinely performed at 77% of burn centers and 3% undergo a pathology report confirming SJS/TEN prior to admission to the BICU.

The involvement of subspecialty care in the BICU varied broadly. Ophthalmology (66%) was most commonly consulted as a routine, followed by dermatology (47%). Only a small percentage of burn centers routinely consulted gynecology for their female patients (13%). Routine consulting of other services such as urology, otolaryngology, pulmonology, and gastroenterology was rare (<5%) (Table 2). The routine involvement of infectious disease, internal medicine, and palliative care services was also volunteered by some respondents (no. = 8, 4, and 2, respectively).

3.3. Systemic treatment

Inquiries were made as to the use of systemic corticosteroids, IVIG, or plasmapheresis to treat patients with acute SJS/TEN. Systemic corticosteroids and IVIG were common treatment options (65% and 64%, respectively). However, systemic corticosteroids were not used routinely at any burn center,

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