



ADVERSE DRUG REACTIONS, INCLUDING SJS, TEN

## MAJOR PSYCHOLOGICAL COMPLICATIONS AND DECREASED HEALTH-RELATED QUALITY OF LIFE AMONG SURVIVORS OF STEVENS-JOHNSON SYNDROME AND TOXIC EPIDERMAL NECROLYSIS

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**Introduction:** Stevens-Johnson Syndrome (SJS) and toxic epidermal necrolysis (TEN) are life-threatening mucocutaneous reactions. No studies have been conducted on the psychological sequelae or general health-related quality of life (HRQOL) among SJS/TEN survivors.

**Objective:** We aimed to characterize the long-term psychological complications and HRQOL of SJS/TEN survivors.

**Materials and Methods:** The cohort includes survivors treated at Sunnybrook Health Sciences Centre, Toronto, Canada (1995–2015). Participants were assessed by psychological and HRQOL questionnaires. We chose psychometric, validated scales that would capture symptoms of depression and anxiety in a medical context (Hospital Anxiety and Depression Scale), overall psychological distress (General Health Questionnaire-12, GHQ-12) and evidence of PTSD (Impact of Events Scale-Revised). HRQOL was assessed by three validated questionnaires: Dermatology Life Quality Index, Skindex-29 and EQ-5D, and one specially designed for this study: SJS/TEN Survivors HRQOL. The participants were also assessed by a medical interview.

**Results:** Eleven of 17 (65%) participants were found to have symptoms of post-traumatic





stress and 5 (29%) had total scores in keeping with clinical signs of possible PTSD. Twelve (71%) had scores indicating clinically significant psychological distress, and 11 (65%) had symptoms of a psychiatric disorder. A moderate-extremely large effect on the lives of 9 (53%) participants was found. Fourteen (82%) participants reported that SJS/TEN decreased their quality of life. Despite most survivors having psychological distress and a psychiatric disorder (anxiety/depression), only four of them were assessed by a mental health professional during the period following SJS/TEN.

**Conclusions:** Survivors suffer from severe long-term psychological complications and decreased health-related quality of life. We advise that all patients should be offered psychological support during hospitalization, prior to discharge and throughout follow-up, and they should be offered contact with a support group. The GHQ-12 may be used to screen for psychological distress as it is a quick and valid instrument.

