

# IMPACT OF LIFE EVENTS AND TRANSITIONS ON HEALTH-RELATED QUALITY OF LIFE MEASUREMENTS IN YOUTH AND YOUNG ADULTS WITH HEMOPHILIA

Authors: J St-Louis<sup>1,2</sup>, V Blanchette<sup>3</sup>, T Burke<sup>4</sup>, F Ménard<sup>1</sup>, NL Young<sup>3,4</sup> and the Canadian Helixate Study Group\*

\* Members of the Canadian Helixate Study Group: S Cloutier, N Dower, R Klaassen, B Ritchie, GE Rivard, A Timmouth and M Warner.

Institutions: <sup>1</sup>CHU Sainte-Justine, <sup>2</sup>Hôpital Maisonneuve-Rosemont, <sup>3</sup>Hospital for Sick Children and <sup>4</sup>Laurentian University, Canada.

## BACKGROUND

Validated health-related quality of life (HRQoL) instruments are designed to measure the impact of disease on patients' perceptions of well-being. It is not known to what extent significant non-disease related life events or transitions may influence the results of HRQoL measurements. Youth and young adults with hemophilia A (HA) are likely to experience such life events or transitions.

## OBJECTIVES

- To introduce the Significant Life Events Questionnaire (SLEQ).
- To describe the frequency of significant life events and transitions experienced by youth and young men with HA, as part of a prospective longitudinal study.
- To assess the possible relationship of significant life events and HRQoL based on the baseline assessment of the study cohort using the SLEQ as well as generic and disease specific HRQoL questionnaires.

## METHODS

**Participants:** Males, 13 to 29 years of age, with moderate or severe HA treated with Helixate FS, were recruited from 6 treatment centres in Canada to participate in a longitudinal study of factors influencing HRQoL.

**Study Procedure:** Baseline assessment of study subjects included review of prior medical and hemophilia history, physical examination and joint assessment using the Hemophilia Joint Health Score<sup>1</sup>. Subjects reported their HRQoL using a generic tool, the SF-36<sup>2</sup> (all subjects), and 2 disease-specific tools, the CHO-KLAT<sup>3,4</sup> (for subjects age 13-17) and Haemo-QoL-A<sup>5</sup> (for subjects age 18-29). Subjects also reported their significant life events and transitions in the preceding 6 months using the SLEQ, which is a novel questionnaire listing changes in personal non-medical circumstances such as vocational or relational changes.

**SLEQ:** The questionnaire comprised 22 items consisting of possible life events applicable to this age group, as well as 3 open lines to add other events not covered by an item in the list. Subjects also rated the positive or negative impact of each of these events on their life using a 5 point scale (-2 to +2). The number of events and their weighed total score were computed.

**Analysis:** The relationship between the various HRQoL measures and the SLEQ was explored using linear regression.

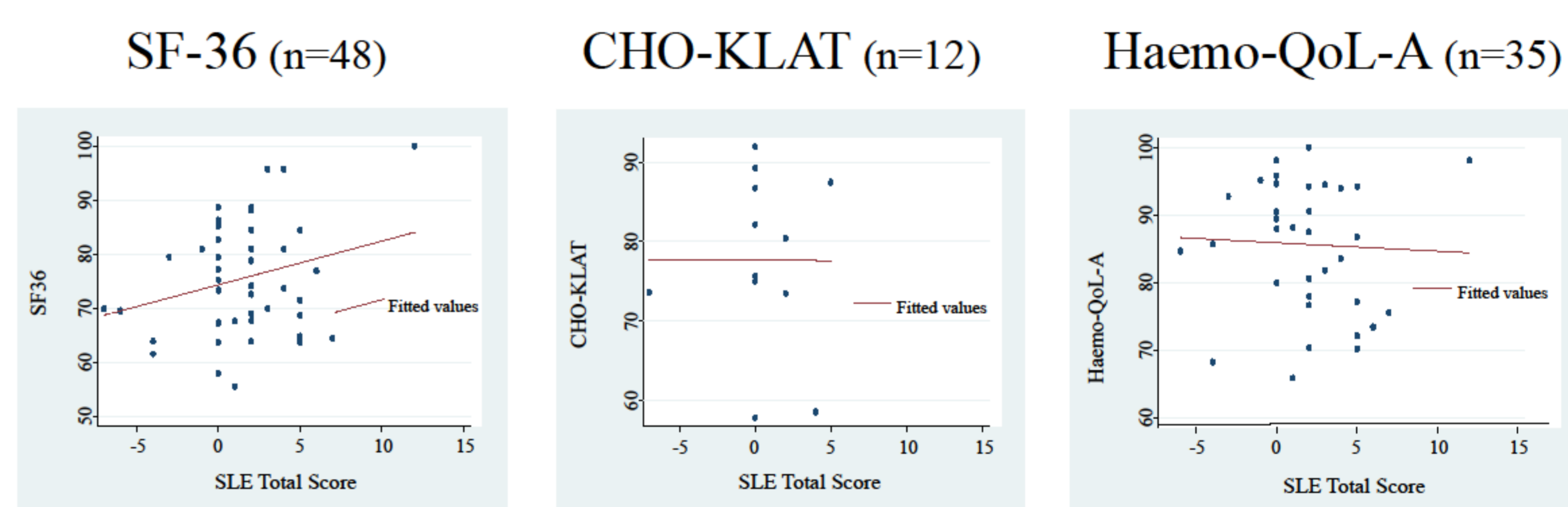
## RESULTS

- Sample: 13 youth (mean age=15.7 range=12.9 to 17.9 years); 35 young adults (mean age=23.5 range=18.4 to 28.7 years); 6% moderate and 94% severe hemophilia A; 47 were on prophylaxis and 1 was on demand.
- 62% of the youth and 94% of the young adults reported one or more significant life events in the preceding 6 months.
  - The aggregate impact of these events were varied
    - SLEQ scores in the youth ranged from -7 to 5
    - SLEQ scores in the adults ranged from -6 to 12
- The most consistently reported positive changes were: moving out of the house (17%) or change in job responsibility (25%). An example of event most often assigned a negative impact was: a significant change in romantic relationship (15%).
- There was no correlation between the SLEQ score and disease-specific HRQoL measures. However there was the suggestion of a weak correlation between the SLEQ and the generic HRQoL score SF-36.
  - Youth: CHO-KLAT vs. SLEQ  $r = -0.004$  ( $p=0.99$ )
  - Adults: Haemo-QoL-A vs. SLEQ  $r = -0.047$  ( $p=0.80$ )
  - All Ages: SF-36 vs. SLEQ  $r = +0.248$  ( $p= 0.09$ )
- The relationship between the SLEQ and SF-36 was strongest for the combined score, thus component scores were not reported.

### Sample items from the SLEQ

EVENT In the last 6 months...	Did not occur in the last 6 months	Impact of the event:				
		large negative impact	small negative impact	no effect	small positive impact	large positive impact
I moved out of my parents' home						
My parents divorced or separated						
I changed the school I was attending						
I entered University						
I entered the job market for the first time (full-time)						
There was a significant change in my romantic relationship						
I became a parent						

### Dot plot of QoL vs. Significant Life Events Total Score



## CONCLUSIONS

- Significant life events and transitions occur frequently in subjects with HA 13 to 29 years of age.
- These events appear to have some influence on the generic HRQoL scores as measured by the SF-36, but had no demonstrable effect on the disease-specific measures (CHO-KLAT and Haemo-QoL-A). Our hypothesis is that disease-specific measures, by focusing on issues more directly impacted by the disease and its treatment, are less sensitive to interference by non-medical events.
- The SLEQ may provide a tool to help elucidate the impact of other life events when using generic measures.

**Contribution:** These preliminary results form the foundation for a 3 year longitudinal study that will examine the effect of biological and life events on the HRQoL of youth and young adults with HA.

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