

IMPACT OF SIGNIFICANT LIFE EVENTS ON HRQoL IN HAEMOPHILIA

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OBJECTIVES & METHODS

Our understanding of health-related quality of life (HRQoL) has focused primarily on the impact of clinical events. However, we have observed changes in HRQoL over time that are not fully explained by bleeding or medical events. (see poster # P-M-222) Thus it is important to explore the impact of other life events. This poster describes the non-medical life events experienced by boys and men with haemophilia during a key transition period. It also explores the distribution of these scores, and the relationship between SLE scores and HRQoL as measured by the SF36 Physical Component Summary (PCS) and Mental Component Summary (MCS) scores.

Recruitment: Males (14-29 years) with severe hemophilia A (HA) were recruited from 6 Canadian Haemophilia Treatment Centres.

Follow-Up: Prospectively followed for 2 to 3 years.

Outcomes: Key outcomes were assessed at baseline and every 6 months using the:

- ❖ SF-36: Physical Component Summary (PCS) and Mental Component Summary (MCS)
- ❖ SLE (Significant Life Event) Questionnaire
 - The SLE is a novel survey that required participants to rate the positive or negative impact of these events on their life events (-2 to +2).
 - SLE scores are computed as the sum of all events at each time period.

Table 1: Sample Questions from the SLE

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						

RESULTS

Sample: A total of 46 participants completed the study

- Mean Age = 21.4 (range of 13.0 to 28.7 years)
- 100% on prophylaxis
- Median Annualized Bleeding Rate in the 6 index joints (elbows, knees, ankles) ABRi = 0.7

Outcomes: Significant Life Events (SLE) were common:

- SLE scores ranged from -9 points to +16 points
- We observed more diversity among adults (mean of 2.5 events /6 months) than youth (mean of 1.9 events/6 months).

The most prevalent events, over 36 months, were related to work:

Q 13 My responsibilities at work changed significantly

- 101 reports in 36 months
- median impact of +1 [range of -2 to +2]

Q 14 I found a new job

- 78 reports, median impact of +1 [-2 to +2]

Q 12 I changed employment

- 66 reports, median impact of +1 [-2 to +2]

Q 5 I changed classes at school (e.g., new class or new grade)

- 60 reports, median impact of 0 [-2 to +2]

Q 17 There was another significant change in my romantic relationship

- 57 reports, median impact of 0 [-2 to +2]

There were also some less prevalent events that had substantial impact when they occurred. Examples include:

Q 20 I became a parent

- 5 reports, median impact of +2 [no range]

Q 18 My parents divorced or separated

- 4 reports, median impact of -1 [-2 to 0]

Figure 1: Distribution of SLE Scores Youth vs. Young Adults

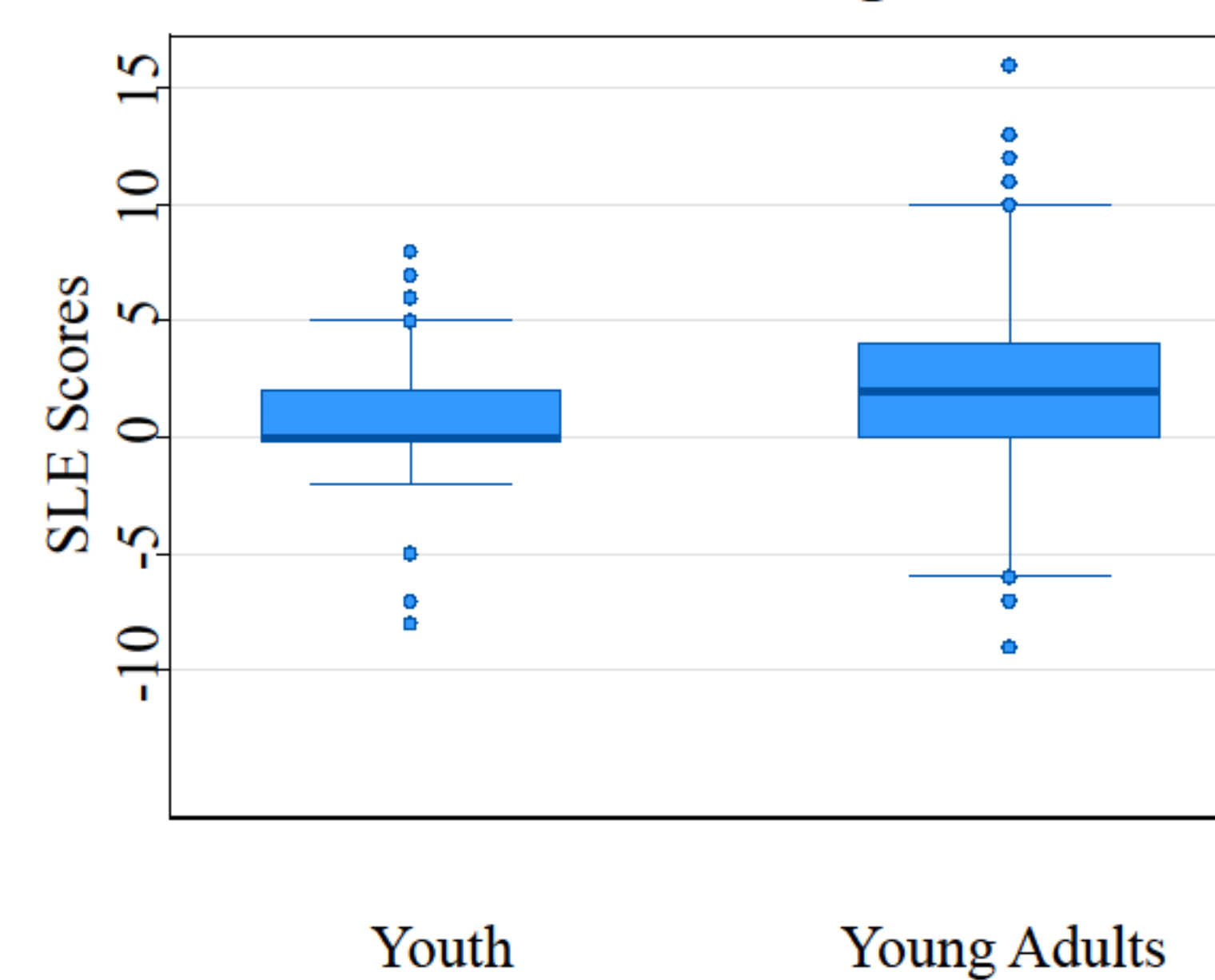
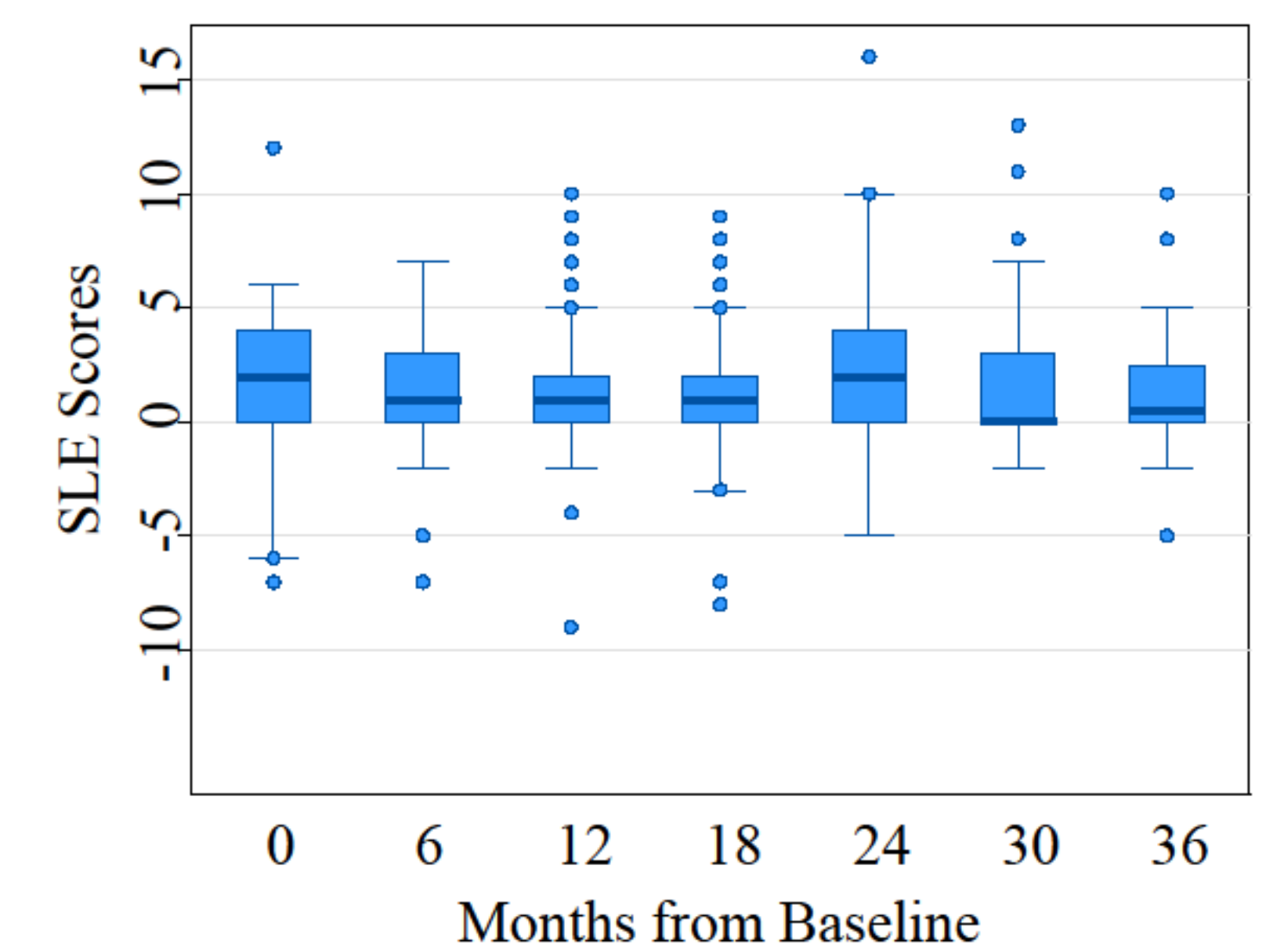


Figure 2: Distribution of SLE Score Over Time



Status Scores

SLE scores were not associated with PCS at 24 months ($r=-0.003$, $p=0.99$).

SLE scores were not associated with MCS at 24 months ($r=0.10$, $p=0.54$).

Change Scores from 12 to 24 months

SLE scores were not associated with change in PCS ($r=-0.02$, $p=0.90$).

SLE scores had a weak correlation with change in MCS ($r=0.25$, $p=0.10$).

Figure 3: Relationship between Change in PCS and SLE Scores

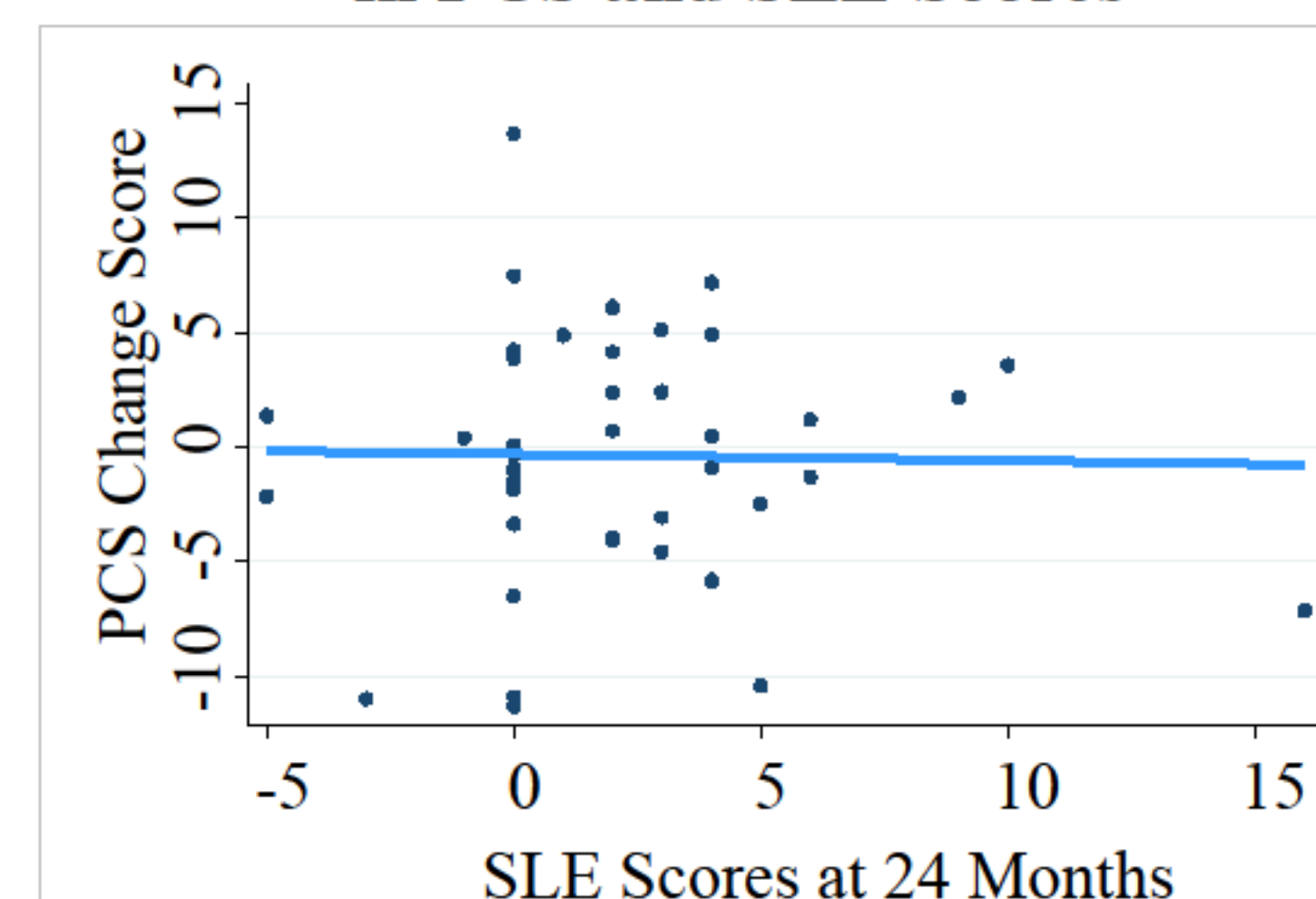
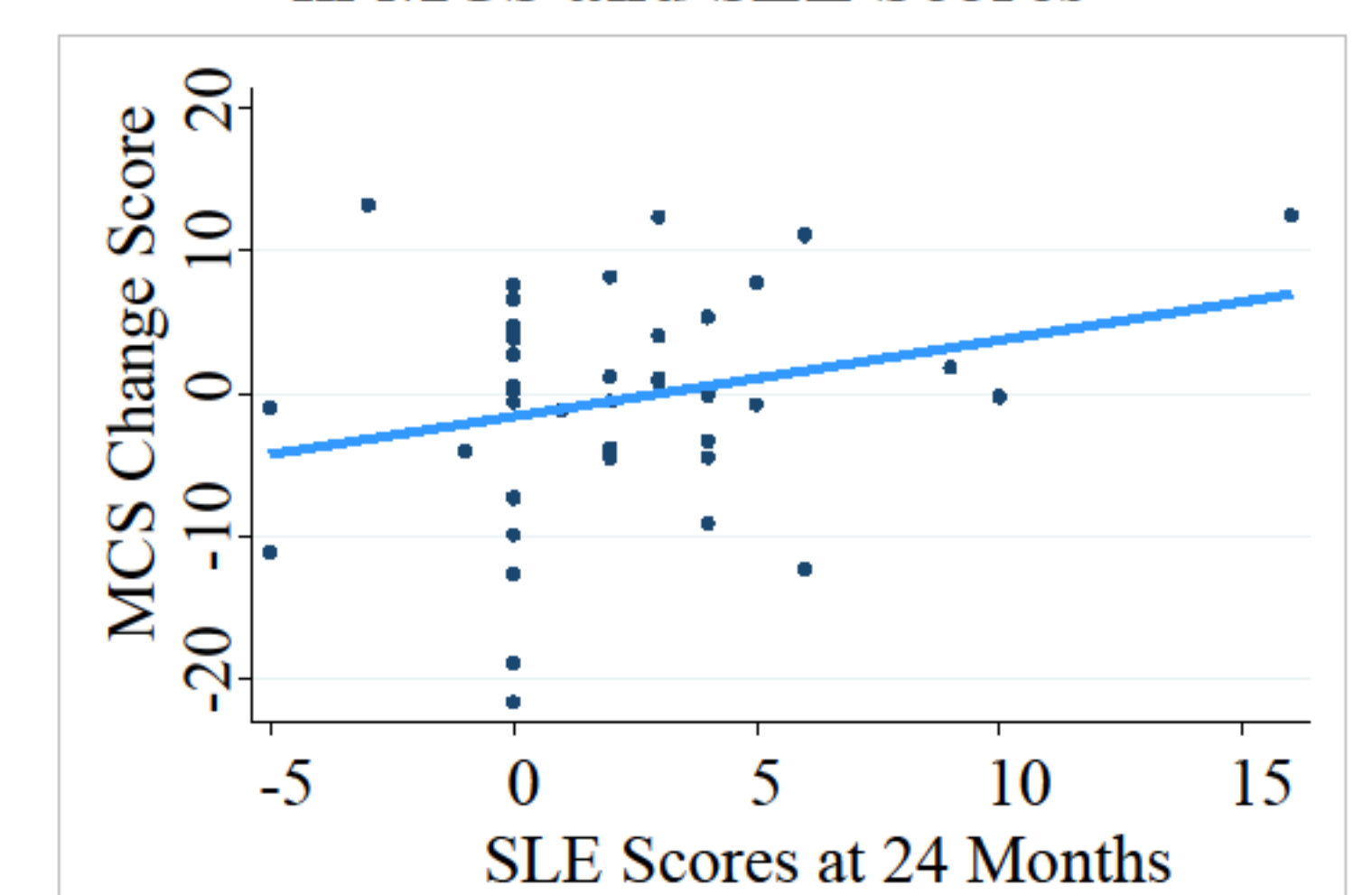


Figure 4: Relationship between Change in MCS and SLE Scores



CONCLUSION

The Significant Life Events questionnaire is a novel tool that attempts to catalogue and quantify the impact of personal and vocational life events. This study demonstrates that many life events did occur during a 36 month period, with a large range of cumulative impact. [Figure 1] The range was larger in young adults than in youth.

These scores did not predict HRQoL at any point in time (status scores) or the change in physical component of the SF36. However, the SLE scores had a weak effect on the change in mental component summary scores of the SF36.

More research needs to be done to better understand the value of the SLE and to examine variation in HRQoL.

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