

Quality of Life Measurements in Spinal Cord Injury Patients

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Abstract

We recently developed *UceWeb*, an application for direct elicitation of utility coefficients (UCs), i.e. a measure of health states quality perceived by patients. *UceWeb* was used to interview a sample of patients affected by spinal cord injury (SCI). A standard questionnaire for measuring quality of life (QoL) and another one for the system evaluation were also administered to the same patients. The aims of this work are to (i) evaluate *UceWeb* usability; (ii) investigate relationships among QoL values elicited with different methods, (iii) create a reference set of UCs for the health states experienced by SCI patients. We show preliminary results obtained with the first 20 patients. Despite great variability found among QoL values elicited with the different methods, interesting correlations with patients' condition and profile have been found.

Keywords:

Quality of life, Utility Theory, Spinal Cord Injuries

Introduction

Measuring Quality of Life (QoL) of patients and correlating it with their clinical conditions may help to personalize treatments. Besides the individual level, specific QoL measures, namely the "utility coefficients" (UCs), are essential in cost-utility analysis, a technique used to evaluate interventions at a population level. *UceWeb* can be used by any physician, during face-to-face visits, to elicit UCs with the classical direct methods, i.e. rating scale (RS), time-trade-off (TTO), and standard gamble (SG) [1]. For each elicitation, a patient's (anonymous) profile is stored, so that, as the repository grows, it will be possible to retrieve UCs for target populations. Moreover, relationships among UCs elicited with different methods could be studied, which also is a research issue. In this poster, we illustrate our first application of *UceWeb*, related to patients with SCI; an insult to spinal cord usually causing permanent and often devastating neurologic deficits and disability. With SCI, the ultimate goal of rehabilitation is to enhance QoL.

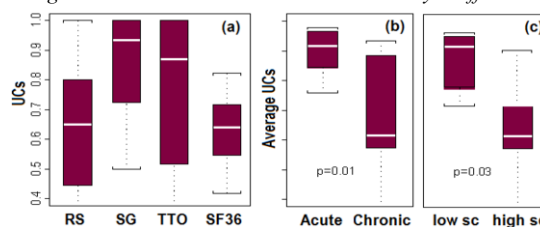
Materials and Methods

Twenty patients were consecutively recruited at the FSM Spinal Unit from October to December 2014. They were classified by the American Spinal Injury Association (ASIA) scale [2], from A (greatest impairment) to E (normal state). Using *UceWeb*, patients were firstly asked to rate their health state on a 0-100 scale (RS). Then they were asked to consider hypothetical scenarios: whether or not, and at which extent, they would give up part of their lifetime but living healthy (TTO); and which risk they would take, e.g. for a surgery, in order to be cured (SG). UCs were then calculated through known formulas. In addition, they answered the SF36

questionnaire, from which UCs were calculated using Brazier formula. A further Likert scaled questionnaire for evaluating the interaction with *UceWeb* was administered.

Results

Figure 1 – Some statistics on the elicited utility coefficients.



Boxplots show median and interquartile range (sc=scalarity)

All but 2 patients were very collaborative. Patients seem to understand RS and TTO methods slightly better than SG, for which two patients were not able to answer. While showing high variability, all scales are significantly correlated. According to past literature, RS values are significantly lower ($p < 0.01$) than TTO and SG, both of which incorporate the concept of risk in their definition (Fig.1a). RS and SF36 values are similar. Chronic phase implies lower UCs than acute (Fig.1b), probably due to burden of reintegration in daily life. Low scalarity patients had higher UCs (Fig.1c). Moreover, even without statistical significance (probably due to small sample size), ASIA C patients have higher UCs than A and B, and paraplegic patients have higher values than tetraplegic.

Conclusion

UceWeb is a usable application for collecting UCs in a homogeneous way. Results obtained in SCI can be the basis for further reasoning on the effect of SCI on the quality of life.

References

- [1] Parimbelli E, Sacchi L, Rubrichi S, Mazzanti A, Quaglini S. *UceWeb*: a web-based tool for Collecting and sharing quality of life data. *Methods Inf Med*. 2014 Nov 3; 53(6).
- [2] Kirshblum SC, Waring W, Biering-Sorensen F, Burns SP, Johansen M, Schmidt-Read M et al. Revision of the International Standards for Neurological Classification of Spinal Cord Injury. *J Spinal Cord Med*. 2011 Nov; 34(6):547-54.

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