

Supplemental material

Quality of life is the individual's self-rated wellbeing originating from the interaction between physical health, psychological state, independence and social relationships^{1,2}. Diseases, such as the deformities of the spine, can affect quality of life by impacting on all these aspects.

As defined above, quality of life is multi-dimensional construct and items of questionnaires measuring quality of life investigate different facets of this variable. In the following table we report the number of items of the SRS22³ and ISYQOL⁴ questionnaires, grouped in the different domains according to their content.

SRS22		ISYQOL preliminary		ISYQOL final	
Domain	N of items	Domain	N of items	Domain	N of items
Function	5	Spine health	20	Spine health	13
Pain	5	Brace	23	Brace	7
Self image	5	Surgery	4		
Mental health	5	Physiotherapy	3		
Satisfaction with management	2				

ISYQOL was developed in different steps, starting from a content analysis of the posts published on an Italian internet forum (<http://www.scoliosi.org/?p=5>) where young people affected by a deformity of the spine can discuss their problems. This content analysis identified a number of quality of life problems in this patients' population, which were grouped into four domains (spine health, brace, surgery and physiotherapy). Items were developed on the basis of the results of the content analysis to eventually obtain the ISYQOL preliminary version (now dismissed).

The “spine health” domain included items asking for problems related to scoliosis or kyphosis (e.g. the fear that scoliosis will get worse) or to the back (e.g. the fear of suffering back pain during adulthood). Items of the “brace” domain asked for problems related to bracing (e.g. feeling not accepted by friends because of the brace). The “physiotherapy” and the “surgery” domains investigated problems such as the fear of undergoing spine surgery or the annoyance due to physiotherapy exercises.

The Rasch analysis of the ISYQOL preliminary version revealed that several items suffered poor measurement properties. The final version of ISYQOL was obtained after removing these items and improving the measuring characteristics of the remaining.

ISYQOL consists of items from the “spine health” and “brace” domains. The “spine health” domain investigates the impact of the disease and trunk deformity on the psychological wellbeing (*“Do you feel uncomfortable when you look at your back?”*), activity limitation (*“Despite your back problem, is your life normal?”*) and participation (*“Are you ashamed to show your body?”*). The items of the brace domain investigates the presence of different problems caused by the brace, such as the physical difficulties caused by the brace (*“Do you feel that your movements are restricted when you wear the brace?”*), the impact of the brace on the psychological wellbeing (*“Do you feel down because you can not do what you used to do before you wore the brace?”*) and the participation restriction caused by the brace (*“Because of the brace, you cannot dress as you would like to?”*).

Note that ISYQOL does not contain items from the “surgery” and “physiotherapy” domains, given that the majority of these items did not work well according to the Rasch analysis and were relatively under-represented according to the content

analysis. With this regard, it is important to stress that items about surgery or other treatments do not make ISYQOL unsuitable for measuring quality of life in patients who had or will have surgery. In the Rasch analysis framework, two items with a very different content can mark the very same level of quality of life. With that in mind, the quality of life level assessed by a surgery item can actually already be assessed by one of the ISYQOL items.

The SRS22 consists of 22 items, grouped into five domains. Items from the “self-image” and “mental health” domains evaluate the psychological impact of the spinal deformity, with the former quantifying the patients’ perception of their own body image and the latter quantifying anxiety and depression. The “pain” domain investigates the amount of pain suffered by the patient and the consumption of painkillers. The consequences of the spine disease in the activities of daily living are investigated in the “function” domain. Finally, the two items of the “Satisfaction with management” domain explore the patients’ satisfaction with the clinical management of their disease.

References

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