

## **Quality of life measures in palliative care**

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In health care Quality of Life (QoL) includes a range of components which are measurable and related to health, disease, illness and medical interventions. This concept is also named Health Related Quality of Life (HRQoL). HRQoL might be assessed by interviews or by questionnaires. Assessment by means of questionnaires has become the far most commonly approach. There is an enormous increase in publications indexed under the subject heading QoL in Medline, from 6 in 1966-70 to 12749 in 1996-2000.

The HR-QoL tools have been criticised within palliative care to be too restricted and not including specific goals of palliative care such as QoL before death, symptom control, family support, existensiell concerns etc.

It is a challenge to choose the right instrument that fit the specific aim of the project or the clinical problems in questions. HRQoL measures are generally divided into generic, disease specific and domain specific. Detailed understanding and knowledge of the content of the instrument is crucial in order to undertake a valid decision with regard to which instrument to choose in a given study.

The research on QoL for the dying patients is limited – probably related to several factors including methodological challenges on how to measure QoL. The complexity, length and content of the existing HRQoL instruments seem inappropriate for use during the dying process. Even with short simple methods, proxies may be the only alternative or complementary source of information.

Instruments that yield valid and reliable results with the smallest possible effort for the patients, and suitable for both patients and proxy ratings are needed.

The use of computer adapted testing methodology may allow for a more flexible way of administering the tool, including downloading from internet, administration by proxies and use of handheld devises. Scores can be computed immediately, presented in digital forms, and be available immediately for the decision making process.