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Paediatric health related quality of life : a European perspective : instrument development, validation, and use in clinical practice

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**Paediatric
Health Related Quality of Life:
a European Perspective**

Instrument development, validation, and use in clinical practice

1. If health related quality of life (HRQoL) questionnaires are to be used routinely as an important part of clinical practice, the given obstacles need to be dealt with and HRQoL assessment needs to be promoted (this thesis).
2. No statistical technique will ever yield 'good' results from data of dubious quality. In turn, the quality of the collected data is very much tied to the skills of the researcher (M. Buyse, Cancer Clinical Trials. Methods and Practice. 1984; p102-23 and this thesis).
3. One needs to keep in mind that health related quality of life assessment will never address all issues that are important to the patient and that it can only supplement current clinical measures or communication and does not substitute them (this thesis).
4. Preferable above any new quality of life (QoL) questionnaire is the paediatrician's increased awareness of the patient's QoL, independently of how this is assessed (this thesis).
5. While health related quality of life may seem ill defined and its assessment unscientific, to the patient this subjective outcome may be more important than biomedical endpoints (C. Eiser and R. Morse, J.Dev.Behav.Pediatr. 2001; 22: p248-256 and this thesis).
6. The patient is the centre of the medical universe around which all our work revolves and towards which all our efforts tend (J.B. Murphy 1857-1916).
7. Quality of life, like "happiness" is a familiar yet elusive concept (R.B. Andelman, et al., The use of psychological testing for treatment planning and outcomes assessment. 1999; p1383-1413).
8. Health related quality of life is the gap between our expectations of health and our experience of it (A.J. Carr et al., BMJ. 2001; 322: p1240-1243).
9. Diving is meditation with a view.
10. Time is like a handful of sand, the tighter you grasp it, the faster it runs through your fingers.
11. The whole of life, from the moment you are born to the moment you die, is a process of learning (Jiddu Krishnamurti, 1895-1986).
12. He who does not research has nothing to teach.