

1 Introduction

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1.1 Background

Until recently, it was difficult to keep children with severe diseases alive. Therefore, mortality was most frequently used as an outcome of paediatric treatment.¹ As medical successes increased, morbidity, health status and the psychological and social consequences of a disease became more important.² Although the individual paediatrician already recognised that a certain disease or side effects of treatments can elicit quite different reactions in different children, a systematic outcome measure that could describe these individual differences was missing. This gap was filled by the introduction of the construct ‘Health related Quality of Life (HRQoL)’.³ This construct can be viewed as a method of translating a child’s experience of illness into a quantifiable outcome.⁴ Without this outcome measure, children’s well-being is estimated by researchers and paediatricians who use their own personal reference points and their own experience with similar patients as guidelines.^{5,6}

The definition of health provided in 1948 by The World Health Organisation⁷ as ‘a state of complete physical, mental, and social well being, and not merely the absence of disease or infirmity’ has been highly influential in defining the HRQoL construct. By now, there is a growing consensus on four aspects of HRQoL: it is multi-factorial (physical, psychological and social well-being), it is patient self-administered, it is subjective, and its value is variable over time.^{3,8} As a widespread definition or theoretical framework is missing, we propose a definition in which these four aspects are accounted for:

*HRQoL is the individual’s perception of problems in health status,
combined with the affective responses to such problems.*

In this thesis, the usefulness of this definition is explored in children up to 12 years of age. Furthermore, attention is given to the choice of a certain informant about HRQoL, measuring HRQoL in various age ranges and groups of children with disorders, and longitudinal changes in HRQoL.

1.2 Outline of this thesis

Chapters 2 to 6 concentrate on how to define and obtain HRQoL in children aged 6 to 11 and 1 to 5 years. To start with, *Chapter 2* deals with the construction of the TNO-AZL-Child Quality of Life (TACQOL) questionnaire. Psychometric performance of the TACQOL was studied in a large sample of children (age 6-12 years) from the Dutch open population. The chapter presents the definition of HRQoL that underlie this instrument as well as this thesis. The objective of *Chapter 3* is which informant to choose when studying the child's HRQoL: the child itself or his/her parent. The agreement between the TACQOL child form and parent form is tested in children between 8-11 years of age in the same sample as used in Chapter 2. In *Chapter 4*, agreement between children and parents is tested again, but this time in a sample of children with a chronic disorder. *Chapter 5* presents the psychometric performance of the TNO-AZL Pre-school Quality of Life (TAPQOL) questionnaire. The instrument was constructed according to the same principles as the TACQOL in order to assess HRQoL in children aged 1-5 year. The TAPQOL uses the parent as informant.

Chapter 6 discusses the HRQoL of pre-school children who were born prematurely. The relationship between the TAPQOL (as obtained from the parents), the parental feelings towards the child and the global HRQoL judgement of the neonatologist was studied.

Chapters 7 to 10 deal with HRQoL in a longitudinal perspective. *Chapter 7* consists of a systematic review on longitudinal studies in children between 0 to 12 years of age. The review explores the time variability of children's HRQoL in studies with at least two assessments of HRQoL. It focuses on underlying ideas about what exactly changes HRQoL. *Chapter 8* presents a strategy for dealing with the problem that measurement instruments used in a longitudinal study may differ at different time points. The strategy was applied to a set of longitudinal health status data, collected from preterm born children, but is thought to be very useful in HRQoL studies as well. In *Chapter 9*, the same sample as in Chapter 9 is presented, now with emphasis on the health status development between 5 and 10 years of age in the cohort of preterm children. *Chapter 10* describes a longitudinal study on the HRQoL, health status and self-perception of children with idiopathic short stature. These children participated in a randomised controlled study on the effect of growth

hormone treatment. In *Chapter 11*, the HRQoL results presented in this thesis are summarised and conclusions are drawn.

1.3 Reference List

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